

background

Report # 96

Autism Emerges As A Public Concern

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Autism Exposed: A Growing Public Concern

Autism Gains The Spotlight

Advocacy, spike in prevalence help raise awareness

In the span of a few decades, autism spectrum disorders has moved from an issue on the fringes of public awareness to one that is attracting widespread news coverage and political support for research to broaden what is known about this group of disorders and to develop interventions to help those afflicted and their families.

This heightened awareness has been driven by aggressive, well-organized advocacy groups, including parents of children with autism, as well as other factors – not the least of which are estimates that suggest autism is much more prevalent than doctors, researchers and policymakers believed it to be as recently as a decade ago.

The Centers for Disease Control (CDC) estimates that as many as 1 in 150 American children have an autism spectrum disorder. This group of developmental disabilities that has no known cure include autistic disorder, pervasive developmental disorder and Asperger Syndrome. The symptoms of these disorders vary. However, they are defined by significant impairments in social interaction and communication and are often accompanied by extreme behavioral challenges.

“There certainly has been an increase in awareness. Parents worry a lot more about autism now than they ever did before,” said Nancy J. Minshew, M.D., director of the Center for Excellence in Autism Research at the University of Pittsburgh. The center is one of a network of Collaborative Programs of Excellence in Autism established in 1997 with funding from the National Institutes of Health.

The higher public profile has translated into considerable gains in the field of autism. At a time when legislation authorizing funds to address a single disease is uncommon, autism has been the exception. For example:

- In Washington, President George W. Bush last year signed the Combating Autism Act, authorizing nearly \$1 billion over five years for research, early intervention and other autism services.
- This year, Pennsylvania lawmakers introduced a bill that, if passed, would require private insurers to cover a portion of early intervention services and therapies for those with autism spectrum disorders.
- In a major reorganization of the Pennsylvania Department of Public Welfare, a Bureau of Autism Services was created to offer expertise and support for state agencies that serve Pennsylvanians with autism.

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Heightened awareness and a recent surge in cases of autism spectrum disorders have been accompanied by rising demand throughout the nation for services to help the children afflicted and their families.

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“On the service side, there has been a huge gain in the expenditures and resources that families with autism are getting that they did not get 10 years ago,” said Ray Firth, director of the University of Pittsburgh Office of Child Development’s Division of Policy Initiatives.

“The question is, what effect is it having? It’s not curative. In some cases, it is increasing functioning level. To a fair extent, it helps to relieve the strain on the family. And there is more training on effective invention. Are families better off today than 10 years ago? Absolutely. Was their coming together and organizing effective? Absolutely.”

For all of the strides made in raising awareness of autism spectrum disorders, much about these disabilities is still a mystery. A cure remains elusive. What causes autism is unknown. Even the reason why autism is more prevalent today than a decade ago is a topic of debate.

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Many More Cases

Estimates of the number of children with autism spectrum disorders have risen significantly in recent years. The most recent government survey reported by the CDC found that an average of as many as 1 in 150 children have an autism spectrum disorder diagnosis. More than a decade earlier, prevalence estimates had autism diagnosed in as few as 1 in 2,500 children.

However, even with the recent increase in cases, the prevalence of autism remains significantly lower than the average rate of mental retardation in the United States. An estimated 1 in 103 children are diagnosed as having mental retardation, according to the CDC.

The recent CDC study was based on 2002 health and school records in communities across 14 states. It reported that the prevalence of autism among 8-year olds varied by state, ranging from 1 in 94 children in New Jersey to 1 in 303 children in Alabama. In Pennsylvania, 1 in 189 children in the communities surveyed had an autism spectrum disorder diagnosis.

The Question Is, Why?

Reasons for the surge in documented cases remain a matter of debate, leaving important questions without definitive answers.

One possibility is that more children have an autism spectrum disorder than in previous decades. However, other factors may also play a role, including increased public awareness of the disorders, the introduction in 1992 of a separate autism diagnostic classification, as well as subsequent revisions to that classification.

It is also likely that steadily improving diagnostic techniques are contributing to the higher number of documented cases being reported today. Re-

cent research has led to a better understanding of the disorders, which, in turn, has led to a broader range of children being diagnosed. There is, for example, a recognition that autism spectrum disorder is a continuum that occurs across the IQ spectrum and in varying degrees of severity that was not appreciated before.

“We are diagnosing better,” said Marilyn Hoyson, Ph.D., chief operating officer of The Watson Institute, in Sewickley, PA, which provides a range of services for children with autism, as well as education and consultation services for school personnel and others who work with the children.

“We know more about this disability, so we are clearer about the diagnosis. We are able to diagnose early. We are able to diagnose milder cases, which we call high-functioning autism or Asperger Syndrome. Those people are now getting diagnosed, as are more adults and teenagers. We weren’t doing that before.”

What causes autism has not been determined with scientific certainty. However, one theory – the use of the mercury-containing preservative, thimerosal, in some childhood vaccines – has been cited widely in the news media as a possible cause of autism and a reason for the rise in prevalence rates.

The most recent position of the CDC is that the weight of available scientific evidence does not support the hypothesis that vaccines cause autism. However, the American Academy of Pediatrics, vaccine manufacturers and others agreed in 1999 that thimerosal should be reduced or eliminated in vaccines as a precautionary measure.

Today, with the exception of some influenza vaccines, none of the vaccines received by American preschool children to protect them against 12 infectious diseases contain thimerosal.



for more information

Below are links to federal and Pennsylvania government sites related to autism.

Pennsylvania Department of Public Welfare:
www.dpw.state.pa.us/ServicesPrograms/Autism/

Centers for Disease Control (CDC):
www.cdc.gov/ncbddd/autism/index.htm

National Institute of Mental Health:
www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml

Additional information can be found on the Internet using a keyword search to locate the websites of nonprofit organizations dedicated to autism education and advocacy.

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