

Report # 97

Trends In Autism Intervention And Research

December 2007

Autism Exposed: A Growing Public Concern

Demand For Services Rising

Awareness also contributing to advances in research

Greater awareness of autism spectrum disorder and improved diagnostic methods have led to an increase in diagnosed cases and has helped doctors identify children with autism earlier in their lives. These developments have contributed to a historically high demand for services to help the children afflicted and their families.

The group of disorders has no known cure, and neither the understanding of autism or the development of therapies has reached maturity. Experts generally agree, however, that chances of a child enjoying a fuller life tend to improve the earlier interventions are started.

The increase in diagnosed cases of autism spectrum disorder has had a dramatic impact on many of the organizations that serve children with autism, such as The Watson Institute in Sewickley, PA. There, the number of children with autism receiving services has risen in the past seven years from fewer than 100 to nearly 900. The greater caseload has resulted in a increase in staff from a half dozen employees to more than 75.

The Watson Institute, which specializes in children who have special needs, offers autism services that include diagnostic evaluation, outpatient learning and development, and a LEAP program that supplements a preschool curriculum with strategies that concentrate on developing functional skills, independent play, work skills, language, social interaction and adaptive behavior.

Autism defies a one-size-fits-all approach to invention. The thinking and learning abilities of people with autism

can vary, for example, from gifted to severely challenged. Autism spectrum disorder can be discerned before the age of 3 and lasts throughout a person's life.

"The earlier you start, the better the outcomes," said Joseph R. McAllister, Jr., director of psychological services at The Watson Institute. "The outcomes are still diverse. On an individual basis, we are still not very good at predicting who is going to respond dramatically and who is going to have a limited response. But, across the population, early intervention makes a tremendous difference."

Another trend is that children are being diagnosed earlier than ever before. "When I started at Children's Hospital [of Pittsburgh] in the Child Development Unit in 1990, the average age a child got a diagnosis in the Pittsburgh region was about four-and-a-half years," Dr. McAllister said. "When I left in 1999, it was down to about three-

and-a-half. Now we are substantially below that. We are occasionally seeing kids under 18 months of age. Probably the youngest we've diagnosed is 12 months."

Early intervention focuses mostly on improving engagement. For example, getting children to play, interact and engage with others; getting them look at a book with another person and comment and react to it; and helping them learn to express what they want or need.

"If these kids are left alone, they wouldn't naturally do those things. They would just let things happen to them," said Marilyn Hoyson, Ph.D., chief operating officer of The Watson Institute. "But early intervention can show them, teach them that they can control things in their environment – they can tell people what to do; they can get things for themselves."

The Watson Institute has also seen greater demand for training for those who work with children with autism and for

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consultation, particularly teachers and others employed in area school districts. "More and more districts are learning that they have these children in their schools who they might not have known about," said Dr. Hoyson. "And more and more districts are opening classes [to higher-functioning children with autism]."

Government Responds

A well-organized campaign has been waged in recent years to move autism into the policy spotlight by national autism advocacy groups, such as Autism Speaks, Cure Autism Now and the Autism Society of America.

One indication of their effectiveness is the federal Combating Autism Act, signed into law last year. Not only was it one of the few single-disease laws ever enacted, it got its start in the Senate as a bill co-sponsored by members on the opposite ends of the political spectrum who rarely found themselves occupying common ground – then-U.S. Sen. Rick Santorum, R-PA, and Sen. Christopher Dodd, D-CT.

The law authorizes Congress to spend about \$950 million over a period of five years, but they must vote each year to appropriate the funds. The bulk of the money – more than \$600 million – is earmarked for National Institutes of Health research, including the autism Centers for Excellence.

Another bill, introduced in Congress earlier this year, would authorize about \$80 million in fiscal 2008 to increase the access of children and families to interventions and services.

Advances In Research

Considerable ground has been gained in the laboratory in recent years.

Research that showed autism to be a disorder of brain and cognitive development as well as a family genetic dis-

order, demonstrated to the broader scientific community the important role autism plays in understanding human function, brain development and genetic regulation of brain development. An understanding of these processes is key to developing effective interventions for autism and other disorders.

"We are light years ahead of where we were 20 years ago and 10 years ago," said Nancy J. Minshew, M.D., director of the Center for Excellence in Autism Research at the University of Pittsburgh, who has spent 22 years studying autism. "When I started, everybody thought that autism was going to be caused by another disorder – that there would be no autism in its own right. Now we know that only 5 to 10 percent of cases are due to some other disorder, like Fragile X or chromosome abnormality."

Advances in understanding autism spectrum disorder include evidence of accelerated brain growth beginning around 12 months of age that could lead

to the disorganization of brain connections and development of neural systems. Scientists better understand how the brain thinks and how neural systems are put together that affect abilities such as social abilities, motion processing and face processing. Recent studies also suggest that autism disrupts the mirror neuron system that is important to the execution and observation of movement, and higher cognitive processes, such as language, being able to imitate and learn from others' actions or empathize with their pain.

Autism, said Dr. Minshew, "is an enormous public health problem and the next era of cognitive neuroscience research. Who does not want to know about higher-order abilities, like social function, using language to communicate, how you reason and problem solve, and how the brain is wired to support those things?"

**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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Children, Youth & Families **background** is published by the University of Pittsburgh Office of Child Development (OCD), a program of the University of Pittsburgh School of Education. These reports are based on available research and are provided as overviews of topics related to children and families.

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