

# Overwhelmed by Autism

**A dramatic increase in diagnoses has lawmakers debating the state's role.**

BY JENNIFER B. SAUNDERS

**L**earning your child has been diagnosed with autism is difficult for any parent. But for many, diagnosis is only the beginning of coping with a frustrating patchwork system to find information, resources and services for their child.

States often lack a coordinated system or a centralized agency to provide autism services, leaving a complicated maze of services for parents to navigate. In addition, the cost of caring for a child with autism can be crippling.

For state policymakers, the growing number of children with autism and their wide-ranging health, social services and special education needs pose a challenge. Although many states have provided care for and education to autistic children, some lawmakers worry that overstressed state budgets can't currently afford such assistance.

Autism—a neurodevelopmental disorder that leads to behavioral challenges and problems with social interaction and communication—was first described in the 1940s, but diagnostic criteria were not developed until the 1980s. Since then, the number of diagnosed children has risen drastically.

Autism now is more common than juvenile diabetes and childhood cancer. More than 250,000 children ages 6 to 21 with autism received public special education services in 2007, compared to roughly 54,000 children in 1998.

Last year, the Centers for Disease Control

*Jennifer Saunders tracks maternal and child health issues for NCSL.*

## WHAT IS AUTISM?

Autism generally refers to a group of disorders that cause developmental disabilities and numerous social, behavioral and physical challenges.

People with autism often display atypical behaviors and interests, unusual ways of learning and paying attention, and impaired verbal and nonverbal communication skills. They also often have physical ailments such as asthma, digestive disorders, persistent viral infections and epilepsy.

Symptoms often appear before age 3 and last throughout life. Autism occurs in all racial, ethnic and socioeconomic groups, but is four times more likely to occur in boys than girls. Currently there is no cure, but early detection and treatment can greatly improve symptoms and development.

and Prevention released data from 2006 estimating that one in 110 children in the United States have autism, or about 730,000 children, up from one in 150 in 2002.

The number of people served by California's Department of Developmental Services, for example, increased twelvefold between 1987 and 2007. Texas experienced a fourfold spike in diagnoses of autism over the past decade.

This dramatic rise has caused researchers at the Centers for Disease Control to elevate autism to an urgent public health concern, and parents and others to wonder what's causing this growth. It's not clear how much

*"It's important to understand the emotional, physical and financial strain that autism puts on a family."*

LOUISIANA REPRESENTATIVE PATRICK WILLIAMS

is a result of heightened awareness and better diagnoses and how much is a true increase in prevalence.

## THE COST OF A LIFETIME

A Harvard School of Public Health study estimates it costs \$3.2 million to care for an autistic person over a lifetime. Families may spend more than \$67,000 a year to cover direct medical and nonmedical expenses, not counting the emotional toll of such a condition.

"Hearing from families who are literally going broke because their insurance companies won't cover autism treatments" is what compelled New York Senator Charles J. Fuschillo Jr. to sponsor legislation requiring insurance companies to cover autism treatment. The legislation passed both chambers, but as of press time had not yet been signed



**SENATOR**  
**CHARLES FUSCHILLO JR.**  
**NEW YORK**





**REPRESENTATIVE**  
**PATRICK WILLIAMS**  
**LOUISIANA**

by the governor.

Generally, states with insurance mandates require coverage for applied behavior analysis; physical, occupational and speech therapy; and pharmaceutical, psychiatric, psychological or other care.

Louisiana Representative Patrick Williams says it's also "important to understand the emotional, physical and financial strain that autism puts on a family."

At the same time, however, some policy-makers fear requiring coverage for autism will increase the cost of premiums for many other families already struggling to pay for health care. In 2007, South Carolina Governor Mark Sanford vetoed legislation requiring autism coverage. He said that, while the bill would raise the quality of insurance for families of autistic children, it would "correspondingly increase the cost, and consequently lower the access to health insurance for many other families across our state," citing an estimate that premiums would increase the cost of insurance policies by \$48 a year. The legislature overrode the veto.

**STATE PAIN, TOO**

The cost of providing autism services can be significant.

Last year, the Virginia Joint Legislative Audit and Review Commission estimated that more than 11,000 people with autism received assistance—including services in schools under the Individuals with Disabilities Education Act, Medicaid waivers and vocational rehabilitation programs—at a cost of more than \$84 million.

Some states have had difficulty keeping pace with the need for special education, especially in rural areas. States that do provide those special education services spend about \$12,000 more per student per year, according to the U.S. Government Accountability Office.

Ultimately, lawmakers must decide how much responsibility state government has to pay for the care for people with autism and

Vaccines are often acknowledged as one of the greatest public health advancements in history. They've saved millions of lives and are credited with increasing people's life spans significantly.

In recent years, however, an increasing number of parents have chosen to stop vaccinating their children because of concerns that vaccines cause autism or other conditions. Concerns include the use of the mercury-containing preservative thimerosal; the number of vaccines given at one time; and the spacing of vaccines within the first years of life.

In July 1999, as a precaution, the federal government asked vaccine manufacturers to reduce or eliminate use of the preservative. Since 2001, with the exception of some flu vaccines, thimerosal has not been used in routinely recommended childhood vaccines. And in 2004, the Institute of Medicine concluded there is no association between thimerosal-containing vaccines and autism.

Nonetheless, some parents and advocates continue to cite a 1998 study published in the British journal *The Lancet* as evidence of their concerns. The study suggested a link between autism and the measles, mumps and rubella, or MMR, vaccine. The study, led by Dr. Andrew Wakefield, was recently retracted by the journal, and Wakefield was found guilty of serious professional misconduct by the General Medical Council of the United Kingdom.

Concerns regarding vaccine safety continue to receive media attention, and some parents continue not to vaccinate their children. Public health officials are concerned that as pockets of unvaccinated children increase, a greater risk exists for outbreaks of certain diseases among these children and individuals who cannot be vaccinated due to other health complications. Officials point to extensive vaccine safety procedures, including testing and production standards, and the CDC and the federal Food and Drug Administration continue to monitor any reported problems from vaccines to ensure the highest standard of safety.

---

how much lies with families, schools, health insurance providers and others. Legislators also must determine which programs and resources offer the best use of limited state funds.



**REPRESENTATIVE**  
**KATHY ANGERER**  
**MICHIGAN**

Court decisions could require states to provide certain services, such as Medicaid’s requirements to cover “medically necessary” treatment for children or federal special education requirements.

Delaying services, however, can also cost. That’s why some lawmakers back early intervention that can lessen the needs—and costs—down the road, both for parents and the state.

“We need resources in place now, not 10 years from now,” says Williams. “Our medical community, educational community and local-state-federal governments need to understand the effect this is having on our community. We have to work together to combat this disorder.”

Early treatment will reduce the need for school-funded special education services and long-term support such as job training, Medicaid and adult day care.

“With treatment, 47 percent [of children with autism] will recover typical function and another 40 percent will achieve significant improvement,” says Representative Kathy Angerer of Michigan.

But “without early diagnosis and treatment, the average cost to the state over the life of a child with autism is more than \$2 million,” she says.

#### **AUTISM LEGISLATION**

Over the last few years, legislation related to autism has increased significantly. Between 2006 and 2007, states passed nearly 50 bills. This year, 44 states and the District of Columbia considered more than 400 bills.

The more than 60 autism-related bills enacted this year range from increasing awareness to appropriating funds for services. This year, eight states passed laws to require insurance companies to cover diagnosis and treatment.

Virginia lawmakers passed a bill directing the Department of Behavioral Health and Developmental Services, in coordination with other agencies, to develop ways to help people with autism to find and keep jobs. Lawmakers in Arizona, Massachusetts and New Hampshire created task forces, councils or commissions to study autism or the coordination of services provided by state agencies, schools and other organizations.

“As the numbers of children with autism climb, more people will need help,” says New York’s Fuschillo. “We need to do whatever we can to make their lives better.”

And as this growing group of children ages, states may face a set of new challenges. Investments in coordinating services and intervening early may reduce the demand for expensive services down the road.

“Regardless of the cause” of the increase in cases, says Angerer, “it is imperative that states take immediate action to ensure that families affected by autism can get the help they need.”

