

# Few Options for Treating Autism

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HOUSTON

**R**ecent news of a steep rise in childhood autism cases in California came as no surprise to parents of children who struggle with the disorder. In the eight years since my husband and I enrolled our son, now 11 years old, in a private school for children with autistic-spectrum disorders, we have seen the number of students triple — mirroring the three-fold increase, over about a decade, in autism cases reported in California.

Scientists now agree that aspects of the disabling syndrome occur in one of 500 births. And yet this scary statistic has spurred no large-scale, national response. For most parents, finding effective treatment remains a do-it-yourself project. A daunting one, to be sure. Here in Texas, government-sponsored programs for children with autism and other developmental disabilities have waiting lists up to nine years long.

But autism is a window-of-opportunity disorder, which means the earlier in a child's life you intervene to adjust the faulty neural wiring that causes it, the better the outcome. So most families swallow their grief and get down to work. They devour the latest research, dose their children with nutritional supplements they read about on the Internet, and flock to autism conferences to absorb wisdom from the experts. As new, experimental treatments emerge — sometimes invasive, invariably expensive — some do-it-yourselfers try them all, even if they must empty savings accounts and assume second mortgages in the process.

According to many experts, the most effective treatment for autism in very young children is intensive

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education — one-on-one teaching of language and skills. The cost? An average of \$33,000 a year, for one child.

By law, of course, parents of all children with disabilities can turn for help to the public schools. According to the provisions of the Federal Individuals with Disabilities Education Act, schools must identify disabled children and provide them with "free and appropriate" educations, beginning at age 3.

However, there are several catches. Courts have ruled that the law does not oblige teachers to follow so-called best practices with disabled children or to help them reach their full potential. School personnel often protest that the law requires

## Disabled students can't rely solely on public schools.

them only to help the child make measurable progress — which can be interpreted as making eye contact with the teacher or holding a pencil correctly in seven out of 10 attempts. While some families have won court battles to gain early intervention for their children, the victories are not widespread. Across the country, less than 10 percent of children with autism receive the amount of therapy that a national panel of experts recommended last year.

But the bigger problem is that autism has not yet been accepted as a medical condition. There is no blood test for the disorder, no obvious physical marker. But despite mounting research showing that autism is a genetically based brain disorder, some health insurance providers refuse to cover such core needs of autistic children as speech

and occupational therapy, on the grounds they are educational rather than medical services.

Which brings some of us back to where we started. Faced with finding a decent middle school for our son to enter next year, my husband and I have joined with parents in the same fix to start one ourselves. But some parents are too poor, or too exhausted from raising children who may have challenging behaviors, to do everything themselves. For these families better remedies are needed.

First, public schools should not be acting as emergency rooms for autistic children. While schools must play a substantive role, they need partners in the challenge of helping students with the disorder. As an initial step, federal government should reimburse schools for the additional costs of educating disabled children. Currently, Congress covers 17 percent of these expenses, rather than the 40 percent required by law. Federal policy makers are holding out for a complete overhaul of special education, charging that the current system creates nightmarish paperwork for schools.

Fortunately, Congress has taken a step toward bringing autism into the medical mainstream. As part of the Child Health Act of 2000, it authorized funding for research to study autism. This could be the start of a broad initiative to address what one California researcher called an autism epidemic.

Until the system changes, parents of autistic children will be on their own, left open to experiences like the one I had with a public school speech therapist at the start of my family's autism journey. She explained she could not help my son reach the goals the school district found appropriate for him because she was too busy. Granted, she did have a heavy caseload and other administrative duties. But if the public schools cannot meet their obligations, somebody else — the federal government, health insurers — needs to share this responsibility. □