

Autism: "Don't Ignore My Son!"

Bill Davis and his wife have had to fight every step of the way to get their autistic son, Chris, the help he needs -- and they won't take no for an answer. Meet this determined family, then get our exclusive guide to top resources on autism. By

Abigail Pogrebin from [Parents Magazine](#)

Meet the Davis Family

In a cramped row house in Lancaster, Pennsylvania, amid cluttered furniture, shoes stacked on the staircase, and laundry hanging in odd places, there are piles and piles of doughnuts. On the kitchen table and countertops and in the fridge: fat, powdery, supermarket doughnuts. They lead a visitor to wonder about the nutritional habits of the family that lives there. But doughnuts are often the only food that 8-year-old Chris Davis, who is autistic, will eat. Considering the fact that he used to refuse solid food altogether, shovel handfuls of mud in his mouth, chew the wall plaster and the table wood, and gag at almost every smell, eating fried dough is a massive improvement.

The doughnuts are just one sign that the home is centered around Chris. There's also the video equipment in the living room that monitors his bedroom so his parents can watch his therapy sessions and make sure he's playing safely; the hundreds of unreturnable rented movies that Chris has removed the labels from and organized by bar code; and the tiny pictures of food -- watermelon, raisins, Twizzlers, Froot Loops, and of course, doughnuts -- that Chris pulls off of a Velcro strip to let his parents know what he wants.

Unlikely Crusaders

If a casting director were looking for a couple to play parents who have devoted every waking second to helping their son cope with a baffling affliction, Bill and Jae Davis -- a former Harley rider and manicurist -- wouldn't get the part. The couple, who also have a 13-year-old daughter, Jessica, have subsisted on Bill's bartender salary and a gritty resolve to give their son the best possible chance at a rich life. Self-schooled experts, they know more about cutting-edge autism treatment than most pediatricians.

Bill, stocky and unshaven, comes to the door dressed in a black T-shirt emblazoned with a yellow road sign: "Caution: Empowered Parent." Despite the circles under his eyes, he is exuberant about his son. "He is such a great friend, I can't begin to tell you."

Chris is round-faced and neatly dressed, with a crew cut like his dad's. When he bounds down the stairs and leaps into Bill's arms, he shatters the stereotype of a distant, antisocial autistic

child. Five years ago, however, Chris would sit by himself in the corner, transfixed by floating dust particles, flapping his hands, or throwing tantrums that often broke the furniture.

Bill had "autism" tattooed on his chest three years ago, hoping it would spur people to ask him about the disorder. "I am putting it in their faces, telling them, 'Open your eyes. There are kids out there like my son, and they deserve your attention.' "

A Growing Concern

The news spotlight is finally shining on autism, a lifelong developmental disorder caused by an abnormality of the brain. The number of children with the condition seems to be skyrocketing: Fifteen years ago, as few as 1 in 2,500 were thought to be autistic, but the National Institutes of Health now estimates that the incidence is 1 in 500. Many doctors attribute the dramatic rise to a greater awareness in the medical community, but researchers are desperately searching for genetic or environmental causes of the increase.

Like most autistic children, Chris developed normally at first. At age 2 1/2, however, his behavior changed dramatically -- he stopped speaking and eating, lost interest in toys, went limp or screamed whenever he was touched, wouldn't look at anyone, and stared at the ceiling fan for hours. At his worst, when he was 3, he would head-butt his father and sister and fling his feces from his crib.

Although Jae and Bill had read about autism and thought Chris had many of the symptoms, their pediatrician cautioned them against jumping to conclusions. Refusing to wait, the couple consulted psychiatrists, neurologists, and audiologists -- paying out of pocket because they had no insurance. They were stunned to learn there was no medical test for autism, only a checklist of warning signs. "Nobody would tell us what was wrong with our son," Bill recalls. Finally, when he was 3 1/2, Chris was diagnosed at Children's Hospital of Philadelphia.

Many parents are devastated to discover that their child has autism, but the Davises were energized. They finally had a name for Chris's behavior -- and a cause to take on. "I don't think it ever occurred to us that we couldn't handle it," Jae recalls. Adds Bill, "Jae just said, 'Let's get to work.' "

No Time to Lose

The Davises knew in their hearts that it was crucial to get Chris into a treatment program immediately. Although Pennsylvania provides special education for children under 5, the Davises were initially told it would take three months to get an evaluation, two months more to get results, and even longer to find the proper placement. Infuriated, Bill called his state representative to complain. Two days later, evaluators came to his house to observe Chris.

There were no classes specifically for autistic children, so Chris was placed in an early-intervention classroom with many children. But after all the effort to get him there, school was a tremendous disappointment, and his parents pulled him out after only a few weeks. "The teachers didn't know what to do with him -- he'd just sit in the corner and flap his arms," Bill says. "We tried four special-ed classrooms before we came to the conclusion that Chris would

be better off at home," Jae says.

Determined to design a home-therapy program, Jae set out to learn everything she could -- doing research online, making phone calls, and going to conferences. Meanwhile, Bill spent entire days beside Chris -- reading and talking to him, kissing and hugging him, and stroking his back. "I was desperate to keep him in our world," he says.

The couple started sleeping on a futon in the living room so they could turn their room into a classroom and bedroom for Chris, who'd been sharing a room with Jessica. Jae had heard about a behavioral technique called Discrete Trial Instruction, in which kids learn skills by breaking them down into small steps and receiving rewards. She hired psychology students from two nearby colleges and trained them to work as therapists six to eight hours a day, seven days a week. At first, the biggest challenge was getting Chris to sit still and pay attention. Jae stays up late each night preparing his lessons for the next day and has kept precise data on his surprisingly rapid progress.

Their next challenge was getting the state to pay for Chris's treatment, which the couple could never have afforded on their own. The Individuals with Disabilities Education Act guarantees free, appropriate education for all children ages 3 and older, but the Davises had to prove that their home program was the only option that was appropriate for Chris's needs. They did exhaustive homework, reading law books and cases from other states, and refused to back down from their demands.

Finally, the state agreed to pay \$15,000 to \$20,000 annually, about what it would cost if Chris were in public school. Bill and Jae hold fund-raisers and borrow money to help pay the additional \$20,000 each year for speech therapy, occupational therapy, gym classes, and other expenses. "Any parent who's been through this knows that you do what you have to do," says Pennsylvania Congressman Jim Greenwood, an autism advocate whom Bill invited to come meet Chris. "In case after case, I've seen that the system will always try to save money unless it's made too uncomfortable by the parents."

The Best for Chris

The experts who regularly squeeze up the stairs to observe Chris's therapy have been astounded by what the Davises have been able to accomplish on a shoestring budget. His room is jam-packed with more materials than you'd find in an average school classroom. Shoe bags are overflowing with beads and marbles, which Chris uses to learn math concepts and colors. There's a cabinet filled with 500 homemade flash cards, plus charts of body parts and Chris's height and weight. Musical instruments hang on the back of his door. Lining the shelves are plastic bowls filled with Legos, pom-poms, fake money, and Chris's collection of plastic Honkers, his favorite Sesame Street monsters. His daily agenda is on the wall, and his therapist crosses off each subject -- geography, math, science, and reading -- as he finishes. On a math worksheet, for instance, he'll circle three shapes out of ten or measure with a ruler. For science, he'll assemble a rock collection. He knows all the states and can match up presidents' faces with their names.

However, Chris didn't talk at all until age 6. "I honestly don't think he understood what language was for," Bill says. Jae read about a technique called PECS (Picture Exchange Communication System) and made a series of laminated pictures -- of foods, household objects, places, actions -- that Chris could point to. He also communicates by spelling words with Scrabble tiles. When he finally started to speak, his words were unclear, but his parents never gave up until they figured out what he was saying. Now he can speak in one- to three-word sentences and even says "please" and "excuse me."

Despite Chris's steady improvement, Bill and Jae don't hold out hope that he'll ever have a high-paying job or live alone. They dread the thought that Chris will have to get by without them someday, but the family has already discussed the fact that he'll ultimately live with his sister. "I'm prepared to take care of him," says Jessica, who seems much more mature than the average 13-year-old. She has always treated him "like a normal kid" and defended him when he's been teased by other children.

Helping Others

The Davises know how difficult it is for parents of autistic children to figure out what's best for their kids. Bill has written two books, *Breaking Autism's Barriers* (Jessica Kingsley) and *Dangerous Encounters: Avoiding Perilous Situations With Autism* (Jessica Kingsley). He gives speeches for autism organizations and parent groups around the country and teaches police officers and firefighters how to help autistic people in emergency situations.

Bill also lobbied hard for a federal bill sponsored by Rep. Greenwood. Passed in 2000, the law called for the creation of five autism resource centers, which are now being established across the nation. Parents will finally know where to go to find top experts and programs, instead of having to track them down on their own. Jae spends at least ten hours each week on the phone with parents and has helped more than 75 families set up their own home programs, creating PECS pictures for them and assisting with paperwork for the state. Bill insists that his wife can find a way to teach Chris -- and other autistic children -- anything. "We're a good team because she sees what Chris sees, and I feel what he feels."

Indeed, Bill and Jae's intense devotion is a magnetic force that has pulled Chris into the real world. On a recent afternoon at the local Prestige Gymnastics, Bill watched his son bounce on a long, black trampoline. Chris seemed utterly delighted -- almost giddy. "I love you!" Bill shouted, despite the girls' gymnastics class close by. "Look at him," Bill marveled. "We're truly blessed."