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Battling Insurers Over Autism Treatment

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It took Beverly Chase 14 months of fighting with her health plan, Cigna Behavioral Health, to get payment for autism treatments for her 4-year-old son, Jake. This, despite considerable leverage on her side: a state law in Indiana, where she lives, requires insurers to pay for the behavioral therapies that parents say can produce striking improvement in autistic children.

Cigna did not respond to her request for months, and later argued that her son's therapist was not properly accredited. Even after the plan agreed to contribute to the costs, Mrs. Chase, who lives in Avon, Ind., said she still had to make \$500 a month in co-payments.

"In Indiana the law is on your side," Mrs. Chase said, "if you have the tenacity, the mental health and the stability" to insist on the benefits, adding, "It is not an easy road."

With an estimated 425,000 autistic children in the United States, parents are increasingly demanding that insurers pay the bills for treatment. But most insurers say that such treatment has not been proved effective by scientific tests and that therapists often do not have sound credentials.

Even in the 17 states where autism coverage is required by law, insurers often drag their feet on payment or avoid it in individual cases by questioning the qualifications of the therapist or even a doctor's affirmation that treatment is medically necessary.

Autism is a poorly understood brain disorder that impairs the ability to communicate, form relationships and tolerate change.

The kind of intensive therapy that Mrs. Chase has arranged for her son was first developed in the 1970's. The approach, called applied behavioral analysis, breaks learning into tiny components and uses elaborately prescribed behavioral teaching techniques, initially with one teacher for each child. Toddlers begin by learning to imitate a simple action and eventually go on to more complex things like having a conversation or engaging in pretend-play activity.

For the parents of these children, winning the insurance

battle is crucial because therapy can easily run into tens of thousands of dollars a year over many years. And the window of opportunity for treatment may be small: most experts say that the younger the child, the greater the response to therapy.

Several states, among them California, Texas, New Jersey and Connecticut, require health plans to cover treatment. Many of these state mandates, typically enacted despite stiff opposition from insurers and employers' groups, are rooted in state laws passed since the late 90's that required mental health coverage comparable to benefits for physical ailments. Employers and insurers have said that they plan to lobby legislatures in Indiana and other states to repeal the requirements for autism coverage next year.

Yet state mandates do not necessarily translate into coverage.

Insurers have long raised objections about the very nature of autism treatment. Edward Jones, a senior official of PacifiCare Behavioral Health and chairman of the American Managed Behavioral Health Association, an insurance industry group, asked, "Is this really an educational service or a therapeutic service?"

A diagnosis for autism is included in the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association. Treatment of some kind for most disorders in the manual is covered by health plans.

According to Mr. Jones, though, "most people feel it is a biological, neurological disorder, but that cannot be proven." He added that "we don't seem to have any biological treatment for autism."

Mr. Jones also said that some autistic children may have depression or attention deficit disorder, as well, and can be covered for the cost of drugs for those conditions.

Years ago, as many as 90 percent of children identified as autistic were institutionalized as adults. Beginning in the 1970's, researchers started reporting striking progress made by autistic children who had received intensive behavioral therapy.

A small study involving 19 children and 40 more in control groups published in 1987 found that half of a group of autistic children who received up to 40 hours a week of intensive behavioral therapy were classified as functioning normally after three years of treatment. Only 2 percent of the children in the control group reached that level.

Other studies of that treatment approach have also reported positive results for many children, but researchers have had difficulty setting up studies of statistically

comparable groups, including some willing to forgo the intensive therapy.

"We couldn't leave the house when Anthony was 2," said Beth T. Sigall, who lives in northern Virginia. "If it were not for the therapy, there was simply no way we could have had a respite from caring for him. Now he is 5, in kindergarten and can function like a 5-year-old."

The one-on-one applied behavioral therapy part of Anthony's treatment has been completed. Now he receives speech and occupational therapy and help at home with reading and handwriting. But Mrs. Sigall said her Blue Cross plan still owed her \$12,767 for therapy from February 2003 to January 2004.

Cases like that of Anthony Sigall are not enough to convince most insurers that autism treatments - even if a doctor says they are necessary - should be covered. Also, officials at most health plans are unwilling to talk about their coverage for fear of attracting families with expensive needs. A spokeswoman for Cigna said that under federal privacy rules, the company could not discuss the specifics of Mrs. Chase's fight to obtain coverage.

Parents say treatment costs often exceed \$25,000 a year, forcing some families to drain college and retirement savings and take on second mortgages.

For insurers, the problem is that while "behavioral therapy may be helpful for kids in certain ways," Mr. Jones said, "there really isn't evidence at this point to support that it is effective for autistic kids in general."

Still, he acknowledged that "we know there are ways that kids can benefit from early interventions, school-based intervention, combinations of speech therapies, occupational therapies."

To help resolve the debate, Mr. Jones said the industry association is now "looking for two well-controlled studies by two independent research teams to validate that it is effective."

The first results from a randomized study - overseen by researchers from the University of Rochester Medical Center involving intensive therapy for 150 children, 3 1/2 or younger at the start, at 11 private and university-affiliated autism centers - have been accepted for publication in a professional journal.

A separate randomized clinical trial with 48 children, 18 months to 24 months old at the start, is under way at the University of Washington, with funds from the National Institute of Mental Health, said Geraldine Dawson, director of the university's autism center in Seattle. "We have reason to believe, based on the research, that early

intensive behavioral intervention is quite effective for many kids with autism," she said.

Not every child responds to the program, Ms. Dawson said, but some children who receive early intensive behavioral therapy make significant progress and are then able to go into a regular classroom.

Insurers say that even if the treatments are effective, there are too few people trained in the field. Autism therapists, Mr. Jones said, "often are not licensed professionals."

"It may be somebody with a bachelor's degree," he added, though that may be changing as autism treatment becomes more common. The University of Washington's autism center, for example, is training people with graduate degrees to design programs for individual children and to train and supervise certified paraprofessionals who provide the therapy in a child's home, Ms. Dawson said.

There are similar training programs at other schools, including the University of Rochester, U.C.L.A., Rutgers and universities in Kansas, Texas and Michigan.

Across the country, a handful of self-insured employers including Microsoft, Eli Lilly, the Arnold & Porter law firm in Washington and Agere Systems, are paying for applied behavioral therapy.

Microsoft provides services with a somewhat flexible three-year cost limit of \$70,000 for every family that has an autistic child, a company spokeswoman said. The three-year coverage includes 85 percent of costs up to 180 visits with a program manager and 1,350 visits with a therapy assistant, she said.

"I never see a bill, it all goes straight to our insurance plan," a Microsoft employee, Erin Brewer, said. Her daughter Morgan, 4 1/2, goes to a free preschool where half the children are autistic or have other special needs. Ms. Brewer said she felt lucky. "I feel like I'm working for the benefits," she said.

Richard Fade, a senior vice president at Microsoft who has an autistic child, persuaded the company to cover such treatments. Mr. Fade and his wife, Susan, also gave \$5 million, matched by the Bill and Melinda Gates Foundation, to the University of Washington to help finance Ms. Dawson's work.

Traditional health plans, by contrast, have very limited or no coverage, said Kenneth Sperling, a health care specialist at Hewitt Associates, the big benefits consulting firm based near Chicago. Visits may be limited to 60 a year.

Blue Cross officials in Maryland and Indiana, for example, said they covered autism therapy in those states, where the legislatures have required it. But they said they did not pay for behavioral therapy in states where it is not required. Similarly, Cigna said it covers treatment for autism "in states where it is mandated" and for employers that request the coverage. In Minnesota, which requires the coverage under a mental health law, some insurers have paid in varying degrees for autism therapy.

While waiting for the outcome of clinical trials, some private insurers have pushed parents to seek care through special-education classes in schools and reimbursement from state Medicaid programs, both of which vary widely across the country.

The Maryland education department, for example, pays for as much as 30 hours a week, including time at school, of one-on-one therapy for 900 children with varying degrees of autism, as long as they meet annual eligibility criteria. But the Maryland program does not have enough money to cover 3,184 other students with autism. Louisiana, with less money, could not even find psychologists willing to accept the state's low payments, said Nell Hahn, a disabilities lawyer in Lafayette, La.

The federal government has come down on both sides of the debate over payments. Tricare, the health system for the military, requires coverage for behavioral therapy for the children of parents on active duty. But the Federal Employees Health Benefits Program is resisting efforts by a group of families in northern Virginia to add autism therapy to the list of required benefits.

The group of families said the surgeon general's Web site indicated that 30 years of research had demonstrated the effectiveness of applied behavioral methods, and studies in the last 10 years showed positive outcomes with very young children with autism.

But the Office of Personnel Management, which runs the federal employees' benefits program, dismissed the treatment as inadequately proved. In a letter in October to Representative James P. Moran, Democrat of Virginia, John C. Gartland, an official at the personnel office, said an unnamed consultant had indicated that behavioral therapy "has not been proven in randomized experimental trials as beneficial."

The argument over coverage is so fierce because 90 percent of private insurance is still aimed at serving healthy people, said Jeffrey Crowley, a health policy researcher at Georgetown University. And autism, like certain other conditions, said Sara Rosenbaum, a professor of health law at George Washington University, "is on the outer limits of what the commercial insurance market will handle."

