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HEALTH / AUTISM

Parents press states for autism insurance laws

By CARLA K. JOHNSON
Associated Press
Monday, October 20, 2008

In Washington state, Reza and Arzu Forough pay more than \$1,000 a week for behavior therapy for their 12-year-old autistic son.

In Indiana, Sean and Michele Trivedi get the same type of therapy for their 11-year-old daughter. But they pay \$3,000 a year and their health insurance covers the rest.

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Michael Conroy/AP
Sean and Michele Trivedi laugh as they play with their 11-year-old daughter Ellie, outside their home in Carmel, Ind., Thursday, Oct. 2, 2008. Ellie, who has autism, receives behavior therapy that is covered under the family's health insurance.

Two families. Two states. Big difference in out-of-pocket costs.

If autism advocates get their way, more states will follow Indiana's lead by requiring health insurers to cover intensive and costly behavior therapy for autism.

In the past two years, six states — Texas, Pennsylvania, Arizona, Florida, South Carolina, Louisiana — passed laws requiring such coverage, costing in some cases up to \$50,000 a year per child.

The powerful advocacy group Autism Speaks has endorsed bills in New Jersey, Virginia and Michigan and is targeting at least 10 more states in 2009, including New York, California and Ohio.

Other states, including Illinois, have similar bills in the works but aren't working directly with Autism Speaks.

"This is the hottest trend in mandates we've seen in a long time," said J.P. Wieske, a lobbyist for an insurance coalition that argues that these state requirements drive up insurance costs for everyone. "It is hard to fight them."

For lawmakers, voting against these measures means voting against parents who are struggling to do the best for their children.

Parents tell moving stories about how behavior therapy works better than anything they've tried. In two states, bills got nicknames like "Steven's Law" and "Ryan's Law," so voting against them was tough.

Arzu Forough of Kirkland, Wash., who is pushing a bill in her state, credits behavior therapy for teaching her son Shayan, at age 3, to make a sound to ask for a drink of water. Now 12, he is learning to converse about his favorite food and music, and to talk about his frustrations rather than throw tantrums.

Trained therapists, using principles of applied behavior analysis (ABA), created a system of rewards to teach Shayan these skills. As a preschooler, he got a piece of cheese when he said "bubba" for water. Now a therapist rewards him with tokens when he responds in conversation. He uses the tokens to "buy" privileges like going for a car ride.

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Elaine Thompson/AP
Shayan Forough, right, gets a kiss on the forehead from his mother, Arzu Forough, during a brief break in a session of Applied Behavior Analysis therapy at their home Monday, Oct. 6, 2008, in Kirkland, Wash. Shayan's parents pay more than \$1,000 a week for the therapy for their 12-year-old autistic son.

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Shayan's improvements are a welcome relief to his mother, who once called for police help with her out-of-control son while she was driving.

"I pulled over to the side of the road," she said. "I had to call the police to drive behind me so I could drive safely home."

The Foroughs have health insurance, but it doesn't cover Shayan's therapy. Although they both work full time, they must live rent-free with her elderly mother to be able to afford his treatment.

Meanwhile, the Trivedi family of the Indianapolis suburb of Carmel, get 25 hours a week of behavior therapy for 11-year-old Ellie. They contribute co-pays and a deductible, totaling about \$3,000. Insurance pays the rest, about \$47,000 a year.

Michele Trivedi is an autism activist. She fought for years after a vaguely worded 2001 Indiana law required coverage but insurers still refused to pay for ABA. Finally in 2006, she helped convince the state's insurance commissioner to issue a bulletin spelling out what was expected of insurers.

"It's no longer acceptable that blatant discrimination against people with autism occur," Trivedi said.

Autism is a range of disorders that hinder the ability to communicate and interact. Most doctors believe there is no cure. An estimated 1 in 150 American children are diagnosed with it.

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Supporters say behavior therapy has decades of research behind it and can save money in the long run by keeping people out of institutions. Researchers agree, but say much remains unknown about which therapy works best for autistic kids, whether long-term gains can be claimed, and whether it works with older children.

Some states require behavior therapy coverage up to age 18 or 21. But the scientific evidence for ABA is strongest for the youngest, ages 2 to 5. Some researchers have reported on individual children with autism who no longer appeared disabled when they reached school age.

The most rigorous studies, though, show mixed results. A study published in 2000 showed that preschoolers who got intensive behavior therapy had greater gains in IQ than children who didn't get the therapy. But there was little difference in the two group's language development or the intensity of behavior problems. And the children most severely affected by autism showed no comparative gain.

Another study in preschoolers, published in 2005, showed little difference between an intensive ABA-based program run by therapists and less-intensive therapy from parents; children in both groups improved.

When it comes to older children, the research is sparse, said Tristram Smith of the University of Rochester Medical Center in New York, who co-authored the 2000 autism study.

"You could make a decent case for the little kids up to 6 or 7 that (insurance mandates) would be appropriate," Smith said. "I think it would be hard to make that case for older kids."

Another autism researcher, Laura Schreiber of the University of California at San Diego, said "fly-by-night" behavior therapists could defraud insurers with ineffective therapy.

"I would like to see insurance cover this kind of intervention because it's documented to be effective," she said. "But insurance companies have every right to monitor whether it's working. If it's been two years and there are no gains, an insurance company should be saying, 'What are we paying for here?'"

The Council for Affordable Health Insurance, the industry lobbying arm, estimates autism mandates increase the cost of insurance by less than 1 percent by themselves, but when combined with other requirements make insurance less affordable.

Susan Pisano, a spokeswoman for America's Health Insurance Plans, said the industry has been wary of laws ordering a specific treatment because when new scientific evidence emerges, the mandate remains frozen. And she questions whether behavior therapy is medical or educational.

The American Academy of Pediatrics includes ABA therapy in its clinical report on autism, but describes it as an "educational intervention."

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"There has been an effort to transfer the response to autism from school systems to the health care system," Pisano said.

Nevertheless, some big companies and the U.S. military are providing ABA-based autism therapy as a benefit.

The U.S. military's Tricare health insurance program not only covers up to \$2,500 a month for the therapy, but also recently expanded the definition of who can provide it to make it more accessible. And some self-insured companies, including Microsoft and Home Depot, pay for autism behavior therapy.

Gaining insurance coverage state by state is the top lobbying priority for Autism Speaks.

"It's the No. 1 thing we hear from parents," said Elizabeth Emken, the group's vice president of government relations. "What's more difficult than knowing there's an effective treatment for your children, but you can't afford to offer it to them because it's not covered by insurance?"

A new federal law requiring insurers to make coverage for mental health conditions equitable with other health coverage was tacked onto the recent financial industry bailout package.

Autism Speaks applauds the law, but says autism is not a psychological condition and that the insurance industry has refused to cover autism treatments in states with mental health parity laws on the books.

"We hope it sets the stage for the Congress and the next president to continue this effort to end discrimination in the health insurance marketplace," Emken said. "Whichever party is elected, autism will be on the table and be a major point of discussion. There may have to be a federal mandate."

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