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Autism help, and challenges along the way

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As the number of children with autism grew in the 1990s and 2000s, Florida parents pressured the state Legislature to require employer-funded insurance policies to pay for behavioral treatments and loosen the requirements for Medicaid coverage.

For parents of children with autism, applied behavior analysis (ABA) is considered the gold standard for helping their children learn to fit into the world.

The treatment is marked by intensive work that, in essence, rewards good behavior and ignores bad.

In 2008, Florida became the fourth state to mandate coverage.

But there's a problem: While ABA therapists can be found in some larger Florida cities, large swaths of the state have no one with the proper training.

"How tremendously frustrating it is to finally get the coverage, and then not find anyone who could do the therapy," says Sharon Boyd of Port Charlotte, whose son Austin, 13, was found to be autistic a decade ago.

"It's like they decided to cover it, but didn't put a system in place to provide it."

Although the Centers for Disease Control and Prevention reports that 1 in 88 children in the country has an autism spectrum disorder, no one knows for sure how many of them live in Florida.

Data on prevalence was last reported by the CDC in 2008, with an estimate of 1.5 million people with autism nationwide, and included only a handful of states.

Early on, before coverage was mandated, Boyd quit her job as a registered nurse to qualify for Medicaid to help Austin. She lived on \$20,000 a year with five children, an income low enough for Medicaid waivers to pay for her son to receive ABA for nine crucial years.

The difference it made was "huge," she says.

"I think someday he will be a great employee for someone," Boyd says.

For the two years she was unable to find anyone to work with Austin, she trained three of her daughters' 20-year-old friends from high school to take over the treatment.

She knows of other parents who mortgaged their homes to pay for treatment out of pocket or divorced solely to qualify for Medicaid.

"Because for years it was supply and demand, only the rich people were getting treatment," Boyd says.

Even with coverage, therapists only had two hours a week to devote to her son, which she feels isn't enough for the treatment to work properly. She studied ABA herself and works with her home-bound son.

Boyd was among those who pushed the Legislature for coverage as an advocate with Autism Speaks, a nationwide organization begun by parents.

Under the Florida autism legislation that began in 2010, a Medicaid waiver can be sought from the federal government to cover treatment for up to \$36,000 annually and up to \$108,000 for total lifetime benefits. The numbers are adjusted for inflation.

Treatments covered include ABA, as well as occupational, speech and physical therapies.

However, Medicaid, which considers requests for treatment on a case-by-case basis, can deny

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ABA treatment if it is determined that it is not medically necessary.

The state's Agency for Health Care Administration has stated that ABA is an experimental treatment.

Parents are forced to sue the state if they are denied coverage. In a recent case in Miami, reported by the Miami Herald, a U.S. district judge struck down the state's decision to refuse to pay for ABA, calling it "arbitrary, capricious and unreasonable."

The state is appealing the order.

The expense of paying for treatment is increasingly at issue following Gov. Rick Scott's recent announcement that he supports the expansion of Medicaid coverage to more Floridians under the Affordable Care Act.

In 2005, the latest year for which CDC data is available, the average annual Medicaid cost per child with autism was \$10,709.

Because the numbers of eligible children with autism aren't yet known, no one can predict with certainty how many would be added to Medicaid rolls if the program is expanded in Florida.

Tim Weil, professor of applied behavior analysis in the department of child and family studies at the University of South Florida, says he is not surprised that families are finding it difficult to get Medicaid to cover treatment.

"Regardless of the situation, regardless of the agency, there will always be pushback," he says.

Because the goals in ABA are so tangible, it is easier to measure success than it is with talk therapy or other treatments.

But it can be expensive.

"Most of the time, ABA takes place in the home, and it takes a lot of time and can be costly," Weil said. "People with autism need a lot of hours of remedial work. You can't come in and in five hours a week get the child to learn whole repertoires of behavior."

The ABA program at USF is small, but this fall it will enroll doctoral students for the first time.

The Combating Autism Reauthorization Act of 2011 has provided \$106.5 million to support graduate-level training for professionals to diagnose and treat autism.

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