

NEWS

# Despite federal directive, Texas denies Medicaid coverage for autism therapy

BY KATE HARRINGTON, KAISER HEALTH NEWS

8 JULY 2016

Like many parents of children with autism, Braulio De La Cruz sought an expensive therapy called applied behavioral analysis — or ABA — when his son Noah Leonardo was diagnosed last year.

Noah, now 3 years old, qualifies for Medicaid coverage because he had been approved for **Social Security's Supplemental Security Income (SSI) program**, and his neurologist sent paperwork to get the state to cover the therapy. But Medicaid officials rejected the request. De La Cruz appealed the decision, but that effort hit a major roadblock last fall when the state suddenly said the Medicaid program would not cover behavioral therapy.

Now De La Cruz, of Houston, and other parents — who say their children with autism are legally entitled to such treatment — are butting heads with Texas officials. And without Medicaid coverage, they must either forgo the therapy or find a way to pay for individual insurance plans that help pick up the costs.

De La Cruz has turned to an individual Humana plan to cover his son's therapy. But it costs him \$198 a month, a small fortune when he is watching expenses closely while preparing to go back to school to study nursing. And the cost goes beyond just the premium.

"The most difficult part is the deductible," he says. "It's \$6,500 — it's pretty outrageous that you have to pay that before anything is covered."

In addition, the effects of the Texas rejection of ABA coverage were compounded for many families by a controversial state decision to **cut back on Medicaid payments for other home-based therapy services** for children, including many that youngsters with autism might use.

Texas Health and Human Services Commission representatives declined to comment for this story, except to say that Texas, like other states, is reviewing guidance from the federal Centers for Medicare & Medicaid Services (CMS) on this issue. Texas legislative leaders also declined to comment.

Dan Unumb, executive director of the Legal Resource Center at Autism Speaks, a national advocacy group for families, says if federal officials don't weigh in, Texas families may have to turn to litigation to convince the state not to resist covering behavioral analysis. De La Cruz says he is considering a suit if the state doesn't change its course.

"I don't know if they'll continue to draw a line in the sand, and I don't know what steps CMS may be taking," Unumb says. "My sense is that there's many layers to things in Texas."

### A federal directive:

In 2014, CMS **advised states** that they must cover all medically necessary care for Medicaid-eligible children with autism up to age 21. Advocates say that includes therapies a doctor deems necessary for a child, including behavioral analysis, which uses positive reinforcement to encourage behavioral modification and can run from \$60 to \$150 an hour.

Some states — California, Virginia and Maine, for example — needed very little prodding to put policies in place. Others, including Ohio and Florida, did so only after being hit with court suits.

But Texas responded slowly. One of the advocates at the center of the debate is Shylo Bundy. When her daughter, Zuri Horsley-Bundy, who qualified for Medicaid also through the SSI program, was diagnosed with autism at 15 months of age, the toddler's doctor prescribed 30 to 40 hours a week of behavioral therapy. Medicaid officials denied the coverage. Bundy, an attorney who lives outside Dallas, immediately put her law skills to work, spending months appealing, making phone calls and contacting legislators until she eventually got the state to reverse the decision. (Bundy and her husband have traded off not working so that someone can be home to take care of their daughter.)

After her success, Bundy began a pro bono effort to help a handful of other families get Medicaid coverage, too.

Zuri Horsley-Bundy was diagnosed with autism at 15 months old.