

Alabama

After autism diagnosis, Alabama families face steep bills for therapies not covered by insurance



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It was a bad morning. After months of work, Ashley Sparks had finally gotten her 5-year-old daughter Brinley to a point where she could put her pajamas into the laundry basket every morning before getting dressed.

It sounds like a simple thing. For Brinley, though, even simple jobs can be frustrating to the point of tears. It's hard for her to control her behavior when she can't communicate what she needs or feels.

This morning she started what the family calls a "meltdown" – flailing, kicking, yelling, crying. Ashley tried calmly showing Brinley what she was supposed to do.

"She lost it, kicking and screaming," said Ashley, later, recounting the story. While Brinley was flailing, she kicked Ashley hard in the base of the throat "and out of reaction," said Ashley, "I popped her hard on the butt. And you can't do that to an autistic child."

Brinley started crying, "Mommy!"

"And I picked her up and I'm sobbing into her shoulder, and she grabbed my face," here her voice breaks, "and she said, 'It's OK, Mommy.'"

It was a bad morning. And even as she held her daughter and cried, Ashley was grateful that Brinley had exhibited empathy, something that can be hard for a little girl with autism.

Brinley was diagnosed with moderate-to-severe autism when she was 2 – Ashley remembers the exact day, Jan. 30, 2013.

"I never grieved it until now," said Ashley, "now the truth about her limitations is becoming very apparent. It's difficult because I want the best for her. I want her to have independence and pride.

"Every little thing that you do throughout your day is a massive struggle for her. Watching that and knowing that there is something that can be done..." Ashley trails off; she can't finish the sentence.

The Sparks are one of about 50,000 families in Alabama affected by autism, a developmental disorder that impairs a person's ability to communicate and interact.

When Brinley was diagnosed by a clinical psychologist at Vanderbilt University Medical Center, her doctor recommended she undergo Applied Behavioral Analysis, or ABA. It's the gold standard for autism therapy, and **there has been a dramatic increase in its use** over the past decade, according to Autism Speaks, an advocacy organization. In people with autism, ABA fosters skills like looking, listening and imitating, as well as basic life skills like reading and interacting appropriately with others.

But ABA is expensive. Sessions are highly specialized and run anywhere from \$50 to \$100 or more an hour. Most doctors recommend 10-40 hours per week, depending on the severity of the disorder.

For families in most states, ABA therapy is covered by insurance to some degree.

But Alabama is one of only seven states nationwide that does not mandate insurance coverage for autism treatment for all children.

"If our children had diabetes or asthma, they would receive therapy for those disorders," said Bama Hager, policy director at the Autism Society of Alabama. "But our children have autism and can't receive therapy that's covered by insurance.

"This is a big issue. If a child gets services and therapy at a young age, they can be incredibly productive and successful students and citizens."

Falling in the gap

The Sparks family lives in Huntsville, where Ashley works as a hospice nurse and her husband is a public school teacher. They have three daughters, ages 3, 5 and 8 – Brinley is the only one with autism.

They have health insurance through the state-administered Public Education Employees' Health Insurance Plan (PEEHIP). It does not cover Brinley's autism-related treatment. Sparks was told by PEEHIP representatives more than once that although a limited amount of speech therapy is covered by PEEHIP for other diagnoses, autism was excluded.

If Brinley were to receive her psychologist's recommendation of 20-40 hours per week of ABA, speech and occupational therapies, her family would have to pay more than \$30,000 per year out of pocket.

"We fall in that gap," said Ashley, "where we can't afford (the recommended therapies) but we don't qualify for assistance, either."

They do what they can, paying out of pocket for speech and occupational therapy for Brinley at a local therapy center.

"It's \$116 a week. That's manageable," said Ashley. "\$700 a week is not."

No guarantees

The state has made strides toward insurance coverage for autism therapies, but to date there's still nothing on the books that guarantees coverage for all children with autism.

In 2012, the Alabama Legislature passed the Riley Ward Insurance Reform Act, which said private insurers in Alabama would offer employers the opportunity to include coverage for autism therapies in their employee health care coverage. The act makes that offering available only for children 9 years old and younger. It does not guarantee insurance coverage for autism therapies.

In practical terms, "the Riley Ward Act led to expansion of speech and occupational therapy coverage for some families living with autism," said Hager. "Most of the expansion was due to an increase in dialogue about autism therapies."

It's difficult to feel like everywhere you go your child is a nuisance to society.

Private insurance plans across the state cover varying amounts of occupational and speech therapy per year. A few larger companies – one or two out of thousands statewide, said Hager – choose to cover ABA.

Blue Cross and Blue Shield of Alabama, the state's largest private insurer, typically covers 30 visits each of occupational therapy and speech therapy per year per child (up to age 9), but does have some plans that cover more, and some that cover an unlimited number of visits. A representative of BCBS of Alabama

said ABA is covered for some of its benefit plans.

Hager said most private policies she's seen for Alabama families with autism have covered 30 sessions of speech or occupational therapy per year.

"But the typical recommended number of sessions for a child with autism would be in the hundreds per year – a few times a week – for speech therapy and for occupational therapy," she said. "(Coverage) doesn't even come close to what the recommended approach for autism would be."

According to the Autism Society of Alabama, none of the state-regulated health plans in Alabama cover ABA therapy.

Currently there aren't any plans to include ABA as a covered benefit for PEEHIP members, said Donna Joyner, PEEHIP director. She said PEEHIP does cover up to 30 sessions of speech therapy and limited occupational therapy.

"I know that (ABA) services are quite expensive and the last time we inquired with Blue Cross Blue Shield (which processes PEEHIP's medical claims), the cost associated with (ABA) was not within PEEHIP's reach," she said.

"We would like to cover everything," said Don Yancey, deputy director of the Retirement Systems of Alabama, which administers PEEHIP. "But the funding we get from the legislature is limited. There's not been money available to provide what funds are necessary to do a lot of the things we'd like to do."

"It's a balancing act we engage in every year, trying to have enough money to pay the claims we incur for all 330,000 of the lives we cover."

For people with Medicaid, coverage for ABA therapy may be required under a Medicaid benefit called Early and Periodic Screening, Diagnostic and Treatment (EPSDT). But because the EPSDT language is open to interpretation, some states have chosen to include ABA as a covered benefit; some states, like Alabama, have not.

Organizations like the Autism Society of Alabama and Autism Speaks are focusing efforts this year on insurance reform, holding an Autism Legislative Day on March 15. The ASA launched a social media campaign, #AutismMatters, to highlight absence of insurance coverage for autism therapies.

Most Alabama residents with health insurance are covered by Medicaid or through their employers' self-funded plans, which aren't subject to state law.

If the Alabama Legislature passed a state law mandating insurance coverage for autism therapies, the only policies that would be required to cover them are the fully-funded insurance policies subject to state regulation – and those make up less than half the insurance coverage in the state.

Would it be expensive?

The ASA maintains that cost to insurers to cover autism therapies like ABA would be low if it was spread across a large pool of participants. As an example, Hager points to Missouri.

In 2010, the Missouri Legislature passed a law that required health insurance coverage for autism treatment, and specifically required coverage of ABA for children up to age 18. According to a recent report to the Missouri Legislature, premiums for all insurance plan members rose about 50 cents per month that year as a result of the plans covering autism therapies including ABA.

"It does not appear to be a drastic increase in premiums," said Hager, "for businesses that choose to include autism coverage in their employee health insurance plans."

She said the costs on the front end are balanced by savings to taxpayers for extra services and support that adults with untreated or undertreated autism need later in life.

A 2007 study estimated **it costs a state \$3.2 million per person** in special education, services and loss of productivity for people who have not received appropriate treatment for their autism spectrum disorder.

"Autism is a lifelong disability, but you can improve the trajectory so they can need fewer services and less support, have a better quality of life and a higher likelihood that they will be employed," said Anna McConnell, state autism coordinator at the Alabama Department of Mental Health.

Its own animal

Brinley Sparks has been making strides in speech and communication, but her family has seen a "huge regression" in her behavior, said Ashley Sparks.

When something triggers a meltdown in Brinley, "you can see it in her face – she's scared when she gets out of control. And because she's scared her tantrum gets worse," said Sparks.

"It's incredibly overwhelming how much she needs. Autism is its own animal. It's the most emotionally and mentally draining thing that I've ever encountered."

Brinley and her family are headed to Le Bonheur Children's Hospital in Memphis this month to see a pediatric neurologist about suspected seizures. They've also started a GoFundMe campaign to **raise money for a service dog**, which they hope will help Brinley better cope when she feels overwhelmed or frustrated.

They also hope ABA might be available to Brinley in the future.

"It's difficult to feel like everywhere you go your child is a nuisance to society – that your child is not worth paying for," said Sparks.

"We shouldn't have to worry about this. At the end of the day, this should be a covered, medical issue."

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