



---

Portfolio Media, Inc. | 230 Park Avenue, 7th Floor | New York, NY 10169 | www.law360.com  
Phone: +1 646 783 7100 | Fax: +1 646 783 7161 | customerservice@law360.com

---

## A Mother's Fight To Secure Insurance Benefits For Autism

By **Jennifer Mandato**

Law360 (May 9, 2024, 2:30 PM EDT) -- Lorri Unumb's son Ryan was 18 months old when she and her husband felt he wasn't developing typically. As first-time parents, the Unumbs were adapting to the learning curve of assessing childhood development when Ryan's doctor recommended him for additional evaluation; specialists at Johns Hopkins Hospital diagnosed him with autism months before his second birthday.



Lorri Unumb

As it was the early 2000s, autism wasn't the household word it is today, Unumb told Law360.

Ryan's doctors recommended he take part in applied behavior analysis, or ABA, therapy, which focuses on utilizing the principles of human behavior such as repetition and positive reinforcement to try to achieve a change in behavior.

The therapy, however, is "extensive and expensive," and with Ryan being recommended to partake in a 40-hour-per-week program based on his severe impairment, the cost would be roughly \$70,000 a year, Unumb said.

"I remember turning to my husband and saying, 'Oh my gosh, thank goodness we have health insurance,'" she shared. "I had no idea that at that time, health insurance would not pay one penny of it."

With Mother's Day approaching on May 12, Law360 spoke with Unumb about her decade-plus journey advocating for her son and other autistic people to have coverage options for their medically necessary treatments.

## Coverage Starts in the Home

Unumb recognized the privilege her family held; they were able to downsize their home, move from Washington, D.C., back to her home state of South Carolina and live off of her husband's attorney salary while dedicating her salary as a law school professor to Ryan's care. Knowing, however, that other families who were not as well off couldn't afford the same level of care kept Unumb up at night, she told Law360.

"This is so unfair to those families and to those children because through no fault of their own, they're not going to have the ability to access a nice ABA program of however many hours those particular children would need," Unumb said.

The realization that coverage was unavailable despite a lifetime of paying premiums for healthcare coverage was shocking to Unumb, but it was then that it dawned on her that maybe she was fated to correct this injustice through her law school education and becoming Ryan's mother.

"I couldn't understand why [ABA therapy] wasn't covered, but I couldn't figure out any other way to get it covered other than to have the legislature mandate it," Unumb said.

And so, Unumb sat down at her kitchen table and wrote a two-paragraph bill stating that South Carolina health insurance providers must provide coverage for medically necessary, evidence-based care as recommended by a physician.

Unumb said she was careful not to overreach in her request, focusing on the standard of care for autism.

At the end of 2004, Unumb contacted a South Carolina legislator and asked him to introduce the bill, setting off a three-year-long journey of lobbyist opposition and modification to the proposal. In 2007, Ryan's Law was passed, mandating coverage for behavioral therapy in the state.

## Nationwide Changes

Following Unumb's success in South Carolina, the national nonprofit Autism Speaks caught wind of her advocacy and asked her to run the organization's government affairs department, a role that would see her traveling the country and working to replicate Ryan's Law in all 50 states. At the time, Indiana was the only state aside from South Carolina to have meaningful autism insurance reform, enacted in 2001, according to the National Institutes of Health.

Unumb conceded that prior to her work with Autism Speaks, she wasn't "an expert in any way" in insurance.

"When I first was sitting down to write the legislation, I remember the first thing I was trying to research was, 'can a legislature even tell an insurance company what it must cover?'" she said.

Unumb dedicated her time to learning the ins and outs of the insurance industry, utilizing her resources with Autism Speaks to go beyond creating the legislative mandates and encourage self-funded companies and the Centers for Medicare & Medicaid Services to implement autism insurance benefits.

"One of the main things I learned is that, even as hard as it is to pass a bill to get legislation through in a state, and definitely as hard as it is to do that 50 times over, you still have a ton of work to do to make sure everybody has access to care," Unumb said.

She said she learned "how to speak the language" to self-funded benefit managers and explained to them that if autism benefits are mandated in the state where a company is headquartered, self-funded companies should add the benefits to their coverage or risk losing employees to companies offering those benefits under fully funded plans.

Regarding Medicaid coverage, Unumb said she would never forget the bulletin CMS issued on July 7, 2014, clarifying that all states should be covering autism benefits and ABA. The moment was bittersweet, Unumb said. She recognized that for kids diagnosed in 2007, when Ryan's Law was passed, the time span between then and Medicaid coverage becoming available was their entire early childhood.

Autism Speaks is not without controversy, as autistic individuals and their families have criticized the organization's representation of autism and distribution of funds in the past. According to the organization's website, Autism Speaks is working to adapt its operations, aiming to be more inclusive of autistic people and their loved ones.

Unumb shared that while she did have occasional brushes with people who disliked Autism Speaks, her work running the government affairs department was "laser-focused" on getting people access to care.

In some instances, Unumb experienced autistic individuals expressing that they didn't want care "forced on them." In response, Unumb said that the only objective was to make care accessible for those who choose to access it.

For herself, she was grateful to Autism Speaks for dedicating resources to the mission of expanding autism insurance benefits and giving her the opportunity to travel the country and accomplish that mission.

## Seeing All Sides to Autism Insurance Benefits

In 2019, Tennessee became the 50th and final state to mandate insurance benefits for autism therapy.

That same year, the Council of Autism Services Providers, the trade association that represents autism provider organizations, approached Unumb with an offer to serve as its top executive.

Unumb shared that while she initially rejected the offer as she was content with her role at Autism Speaks, her children encouraged her to reconsider.

"I decided, having spearheaded this whole effort to create insurance coverage for autism, now the focus shifts," Unumb said. "Now, my interest as a parent is making sure that the funding stream

doesn't get abused."

The ABA provider market exploded after insurance coverage came onto the scene and consistent funding became available, allowing entrants to run a good business and make a good living as an ABA provider, Unumb told Law360.

"Some people who had never known anything about autism or ABA before suddenly were opening up ABA businesses," she said.

Crossing over to CASP, the provider association, would allow Unumb the opportunity to ensure that people weren't entering the market "just because they see a dollar to be made."

Unumb conceded that finding herself as CEO of CASP is "a little bit strange," as she's not a provider or clinician and doesn't have training in the clinical work, but she said she believes CASP welcomed her because it knew her only interest is in making sure autistic individuals get the services they need.

"It's an odd set up, but it's pure," Unumb told Law360, "I don't care how much money your company makes; I just care that you're providing high-quality services to kids and adults with autism."

She has called upon the skills she learned while advocating for legislative insurance mandates, as a lot of the issues providers face are insurance-related.

At least 95% of the ABA providers in the association are purely insurance-funded, and Unumb's previous experience has been a major advantage in helping providers negotiate with insurance carriers and navigate the "relatively adolescent" healthcare field of applied behavior analysis, she said.

## Going Global

While ABA therapy and insurance benefits along with it have made significant strides since Ryan was first diagnosed in the early 2000s, Unumb said she wakes up every day thinking about what still needs to be accomplished.

A large portion of the disdain for Autism Speaks was among higher-functioning individuals who can advocate on behalf of themselves, prompting a shift in focus to those individuals. However, that has led to some attention being pulled from some of the individuals who need 24/7 care, she said.

Ryan, now 23, has limited speech and will never live independently because he is a more severely impaired individual, she said.

For Unumb, Ryan's entry into adulthood is a reminder that housing opportunities and employment programs to serve people who are more severely impaired are seriously lacking.

That realization sparked Unumb's latest project: building a campus for autistic adults in her hometown, set to welcome its first resident by the end of this year.

Unumb's hard-earned advocacy success has marked her as a resource in the industry.

Unumb has been called on by other moms and organizations to help teach how she and her team were able to secure insurance coverage for autism. In recent years, she's shared strategies and

lessons with RESOLVE, the national infertility association, along with organizations advocating for dyslexic people and individuals with other developmental disabilities.

Her heart, however, primarily remains in autism care, and she now meets with families and policymakers in other countries where there is inadequate access to autism intervention and "very little in the way of meaningful insurance coverage."

Thus far, Unumb has met with autism communities across Asia, Europe and the U.K. and said that the families' needs are very much the same no matter the location.

"It's an honor to provide a little hope to them based on what we accomplished in the United States," she said.

---

All Content © 2003-2024, Portfolio Media, Inc.