

# Ava's Law

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## AND THE EARLY AUTISM PROJECT

This mother leads the fight to get the help her daughter so desperately needed which has become a platform for all of Georgia's children who are handed the blow of an Autism diagnosis

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photos by **DAWN MCDANIEL OWENS** and provided by Anna Bullard



**SHOWN** Ava with Senator John Albers, Republican District 56 (2014 Sponsor of Ava's Law)

We didn't raise our children around a table of political debate. Family meals were filled with simple stories about life in the south often spiced up and stretched as far as possible for extra flavor. Until November 6, 2006, we might have been able to keep right on saying politics wasn't our thing. But the day my granddaughter Ava was diagnosed with autism, politics came to the table. Like getting a draft notice in the mail, we'd been called to the front lines. Autism was our battle now.

2006 was also the year the Center for Disease Control (CDC) reported that 1 in 110 children were being diagnosed with autism. As shocking as that seemed at the time, today that number is 1 in 68. As a family, we all dealt with Ava's diagnosis differently. My prayers switched between pitiful pleadings to outright anger sometimes in the same breath.





ANNA LEARNED HOW TO BE AN ADVOCATE FOR HER DAUGHTER. BEFORE LONG, ABA SERVICES WERE MADE AVAILABLE FOR OTHER CHILDREN WITH AUTISM IN OUR LOCAL SCHOOL SYSTEM. BUT ANNA KNEW IT WASN'T ENOUGH.

By the time a child with autism entered school critical time had been lost. Early intervention is crucial. And yet without insurance coverage, intensive early intervention therapies such as ABA are simply not affordable for most families.



As Ava's father, Noah, struggled with denial, Anna, the oldest of our four children, struggled with misplaced guilt as her mother. And yet, she knew such thoughts were only a waste of time. Regardless of how or why, her task now was to find help for her daughter.

And in fact, Anna discovered, there was help for children with autism. The U.S. Surgeon General, American Academy of Pediatrics, and the American Medical Association had already endorsed a therapy called ABA (Applied Behavior Analysis) about which Autism Speaks states on their website:

[S]tudies have demonstrated that many children with autism experience significant improvements in learning, reasoning, communication and adaptability when they participate in high-quality ABA programs. Some preschoolers who participate in early intensive ABA for two or more years acquire sufficient skills to participate in regular classrooms with little or no additional support.

But when Anna asked Ava's Developmental Pediatrician about ABA, she was told that it was the "Cadillac version" of therapy, and Anna couldn't afford it. And even if she could somehow come up with the money, it wasn't available

**RIGHT** Anna and husband, Noah, with their three girls Ellie, Ava, and Lily. "As a family, they all dealt with Ava's diagnosis differently. Prayers were switched between pitiful pleadings to outright anger sometimes in the same breath. As Ava's father, Noah, struggled with denial, Anna, the oldest of our four children, struggled with misplaced guilt as her mother. And yet, she knew such thoughts were only a waste of time. Regardless of how or why, her task now was to find help for her daughter."

in small towns like Lyons, Georgia, where Anna's family lived. While we were still trying to deal with the knowledge of Ava's diagnosis, the doctors' words felt as if we had now been tossed into the ocean and told we couldn't have a life jacket because we weren't from Atlanta or some other larger city. In fact, the doctor went on to say, Anna needed to just accept that Ava would most likely never say more than a few words or live on her own. But telling Anna to sit back and do nothing for her daughter was like telling a lion not to roar.

A short time after Ava was diagnosed with autism, the insurance company sent them a letter stating that her speech therapy would no longer be covered. In fact, nothing that might possibly be connected to autism would be covered. We couldn't understand how an insurance company could simply refuse to cover anything that might benefit a child with autism. If a child had cancer, could they refuse to pay for chemotherapy if it was needed? If they had asthma, could they be dropped from coverage?

Anna began to educate herself on the politics of insurance. As a public schoolteacher, Noah's family insurance was a state health benefit plan. Anna learned that of the three types of insurance, state, private, and self-funded, changes to state insurance could only be made by the Governor with the agreement of the General Assembly. The Insurance Commissioner, on the other hand, regulated private insurance. Basically, she learned that legislators would have to pass a bill to affect change in the private market. "And businesses who choose self-funded insurance," said Anna, "could choose to add an autism benefit, which is exactly what companies like Home Depot, Turner South, Chase, and Southern Company have done for their employees."

According to the Child & Adolescent Health Measurement Initiative, autism will affect "more children than are affected by diabetes, AIDS, cancer, cerebral palsy, cystic fibrosis, muscular dystrophy or Down syndrome – combined." If insurance companies refused to cover treatment, why weren't Georgia's legislators doing what they could for those in the private sector? In the 2007-2008 legislative session



nine other states had passed legislation that would require insurance companies cover various treatments for autism. Seven more states followed with similar legislation in 2009. Why hadn't Georgia been first in line when it came to providing treatment for our children with autism?

Although these questions needed to be asked, our immediate concern was Ava. She had never said mama or daddy. She couldn't tell us if she was hurt or hungry or afraid. It was becoming impossible to take her to church or out to eat with her family. Anna and Noah also had two other children, Ellie and Lily, who needed them.

When Anna heard about the Early Autism Project (EAP), Inc., a company in South Carolina that "offers the highest quality of intensive, research-based behavioral treatment for children and young adults



**SHOWN** A map of the states where EAP currently services families.

**EAP provides ABA therapy to children and young adults in homes, clinics, school and on or near military bases throughout the country. They are always adding new service areas.**

between the ages of 20 months and 21 years with autism spectrum and related disorders,” she immediately gave them a call and asked if they would come to Georgia and help Ava. Ann Eldridge, a BCBA (Board Certified Behavior Analyst), drove from South Carolina to Johnson Corner, a small rural community on the outskirts of Lyons, to meet with us, and I mean all of us: Ava, her parents, two sisters, three aunts, an uncle, her grandparents, and her great-grandmother.

Ann took us through a workshop, and then wrote an individualized program for Ava. Since therapy wasn’t covered by insurance in Georgia, therapists were not available in our area. But Ann trained college students (looking for extra work) how to implement Ava’s daily program of ABA therapy. We pulled together as a family and covered the cost for the forty plus hours of therapy Ava needed to receive each week.

After only two weeks of ABA therapy, Ava was following directions for the first time. I cried as I watched her sit at a table and play with toys, something she’d never done before. To this day we consider EAP and Ann Eldridge to have been a divine gift



**ABOVE** Ava being interviewed by a Macon news reporter at the Capital in Atlanta. When Ava's Law failed to pass in 2014, Ava wanted to know why. Anna knew her daughter wanted the truth, but how could she look her in the eye and tell her that the decision was driven by money and politics? Instead, Anna broke down and cried.

from God to our family. When it was time for Ava to start pre-k in 2009, she was able to be in a regular educational classroom. Soon she was reading circles around many of her peers.

Anna learned how to be an advocate for her daughter. Before long, ABA services were available for other children with autism in our local school system. But Anna knew it wasn't enough. By the time a child with autism entered school critical time had been lost. Early intervention is vital. And yet, without insurance coverage intensive early intervention therapies such as ABA are simply not affordable for most families.

2009 was also the year the autism community in Georgia began to draft a bill that would require insurance in the private market to "cover medically necessary services for the evaluation, assessment, testing, screening, diagnosing and treatment of autism spectrum disorder." When Anna was asked if the bill could be named after Ava, she knew that saying yes would change her life forever. She also knew that this was the torch she was called to carry.

"It wasn't going to be easy. Republicans are philosophically opposed to mandates, and the senate was a Republican majority," said Anna. "A mandate is basically the government telling the private sector what they have to do. Nobody likes that. But when it comes to treatment for autism, it's just the right thing to do."

Of course, insurance companies sent their lobbyists to fight the bill. Some purported to legislators that the cost to individuals and small businesses in Georgia would be astronomical. They fought as if they were defending a great cause, and yet the only great cause for which they fought was the pockets of insurance companies. What would be astronomical was the cost to taxpayers





It's up to us to see it, believe in it,  
and give them the help they need  
so they can *shine.*



for lifelong care for those with autism who did not receive intensive early intervention with therapies such as ABA.

One recent Harvard study has estimated the cost to U.S. society for care for a person with autism to be about “\$3.2 million over his or her lifetime.” That cost, according to the Autism Society website, “can be reduced by 2/3 with early diagnosis and intervention.”

Another person who was greatly impacted by Ava’s transformation was her great-uncle, Senator Tommie Williams. At the time he was also Pro Tempore in the state Senate. As a co-sponsor of the bill, he felt certain that if legislators could just meet Ava, they would understand the need for the bill. The day Anna brought Ava to the capital she stood beside her great-uncle and led the Senate in the Pledge of Allegiance. Later, Ava met with Governor Sonny Perdue. After the Governor talked with her, he was so amazed that he asked Senator Williams if he was sure Ava’s autism diagnosis had been correct.

Senator Williams had witnessed life with Ava before and after therapy.

“Quite sure,” he answered the Governor.

Even in such a challenging climate the bill passed in the Senate, “But it never made it out of the House Insurance and Labor Committee for a vote,” said Anna. On the last day of the 2009 legislative session, Senator Williams asked that the Senate send Ava’s Law into a study committee in order to keep the bill alive. It would also give the autism community more time to prepare data for the following year. Only, Ava’s Law was kept in study committee through 2010 and 2011. All the while, six more states passed autism bills in 2011, and three more in 2012.

But during this time the autism community in Georgia was also growing stronger and more unified. In the fall of 2012, Thomas Torrey, a professional videographer from Charlotte, North Carolina, created an amazing short video about Ava and the autism bill called Ava’s Law. Ava was in the 4th grade at the time and at the top of her class. (She tied with two of her classmates that year for the highest score in Math on the CRCT.) The video was posted on YouTube just after the 2013 legislative session began.

Anna’s work for families with autism also took a new turn in 2013. After five years as Director of Family Connections in Toombs County, Anna took the position with EAP as Director of Community Outreach and Advocacy. Including Georgia, EAP serves families in nine states.

With a redrafted bill and the renewed support of Autism Speaks, everyone was hopeful. As more and more people viewed the video, news of Ava’s Law increased. Anna was flooded with calls for interviews by many news networks including CNN, Atlanta’s 11Alive, and Savannah’s WTOG. *The Atlanta Journal Constitution*, *The Macon Telegraph*, and other news outlets also continued to follow Ava’s Law closely.

“I didn’t think it would be easy, but I honestly thought that after all that time in study committee it was going to be different,” said Anna. Only 2013 was no different for Ava’s Law than 2009. “We had the support of Lieutenant Governor Casey Cagle, who has always had a heart for children with disabilities in the state of Georgia. And we had real data and real numbers from other states where autism legislation had already passed. The projected cost would be an average increase of only about 35¢ per month in insurance premiums for consumers. But even though Ava’s Law had been in study committee since 2009, we were told it had to go through the Governor’s new mandate study committee.”

In 2014 Anna once again pressed forward. With the Lieutenant Governor’s support, Ava’s Law continued to gain support in both the Senate and the House. The bill also gained strong support from Senator Renee Untermann. “The autism bill not only passed through the Senate Insurance Committee for the third time, it passed with a 51-0 unanimous vote in a Republican majority senate,” said Anna. “It was a historical moment for autism in Georgia. But this time it was not sent to the House for a vote because we were told there were concerns about ObamaCare even though we had lawyers present with actual research that proved it would not affect this bill nor bring about additional cost to taxpayers in any way,” said Anna.

On the last day, Anna stood in front of a TV screen in the hallway of the Capital with other lobbyists, and watched a live feed of the final moments of the 2014 session. As the clock neared midnight, “Several lobbyists came and offered condolences to us as it became clear that Ava’s Law was not going to get a vote.”

Even so, 2014 session did have a great victory for

## SPEAK OUT AWARD

In November 2014 Anna received the Speak Out Award from Autism Speaks at the National Autism Law Summit in Nashville, Tennessee. “The impact of your advocacy efforts and creativity of your video demonstrate a true commitment to spreading autism awareness and understanding to others.”



some. “Governor Nathan Deal added an Autism benefit to the state health benefit plan,” said Anna, “which was a great victory. It was also bittersweet for our family. Ava was still excluded from coverage because the benefit has an age cap of ten. We started this when Ava was four years old; she turned ten this year. But whether it benefits my child or not, it was the right thing to do. If it affects one child, it’s the right thing to do.”

But it’s simply not enough. Not when the number of Georgians covered by private health insurance is almost 2 million. “If your child has autism and you are in that group, it’s very likely that you don’t have coverage,” said Anna.

There are 38 states to date that have passed legislation requiring insurance coverage for autism, and Georgia is still not among them. “Although I’d heard it said many times, I’ve never seen one document with actual data that proves adding an autism benefit would cost this astronomical amount of money to small businesses and private insurance holders. Not one real document. But we do have proof. We have real data that proves otherwise.”

In November 2014 Anna received the Speak Out Award from Autism Speaks at the National Autism Law Summit in Nashville, Tennessee. Along with the award were these words by co-founders Bob and Suzanne Wright: “The impact of your advocacy efforts and creativity of your video demonstrate a true commitment to spreading autism awareness and understanding to others.”

At present, **EAP is in the process of opening a clinic in Pooler. Almost every week Anna receives a call from another family in Chatham County.** “They tell me that they found EAP online and want to know about our services. I explain that we employ BCBA’s who can provide in-home

intensive services with ABA within a natural environment so that kids will be able to participate in their schools and communities. Then I ask them what kind of insurance they have, and if they know if they have autism benefits. It’s the next call I get when they tell me that their insurance does not cover therapy for autism that will break your heart,” said Anna.

Her work also involves helping families through the process of appeal. “We can provide information to the insurance company and let them know other plans in which autism is covered. But when you tell a family that’s just received an autism diagnosis that in the best case this is going to be about a six-month process, it’s devastating. Their child is crying uncontrollably, and they have nothing. I also have quite a few families with Medicaid who call, and I have to tell them that currently Medicaid offers no benefits for ABA in Georgia.”

When Ava’s Law failed to pass in 2014, Ava wanted to know why. Anna knew her daughter wanted the truth, but how could she look her in the eye and tell her that the decision was driven by money and politics? Instead, Anna broke down and cried. The following Sunday during a time of prayer at church, Ava stood up and prayed:

Dear Jesus, I just thank you for all these people here today. I just thank you that you’ll show my mama how to do Ava’s Law, and how to do it in the Capital. Show her what direction to go in and light up the path that you want her to go in.

On the second day of the 2015 legislative session, Anna announced: “Ava’s Law is now Senate Bill 1. Senator Charlie Bethel is our sponsor. We are honored that he will lead our charge to guarantee treatment

for Autism in Georgia to those with insurance in the private market. Thank you to all the families for continuing to fight and have hope.”

I’ve no doubt that the light Ava prayed for will not fail to appear. It is the torch my daughter carries of love for Ava, her family, and for the families of Georgia with autism. We really cannot afford to miss what each one of these “1 in 68” children” have to give. It’s up to us to see it, believe in it, and give them the help they need so they can shine. Perhaps theirs will be the light the world will one day need most of all. † **CCL**

**For more information about EAP or Ava’s Law contact Anna Bullard at 912-293-5217 or email her at [annawb3@gmail.com](mailto:annawb3@gmail.com). You can also follow Anna at [avaslaw.net](http://avaslaw.net).**

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