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How the autism bill passed in Alabama: An oral history

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In a lengthy, months-long battle in 2017, a group of parents and families – with the help of politicians and lobbyists – managed to pass HB 284, a bill that mandated coverage of behavioral therapies for children with autism. The passage was a rare example in the Alabama Legislature of a bill passing despite significant opposition from two major interest groups. As legislators gather for the start of the 2018 session, here is the story of the passage of the autism bill, in the words of some of those who helped get it through.



Standing-room only during committee discussion on the autism insurance bill at the Alabama Statehouse in Montgomery, Ala., on Thursday May 4, 2017. (Photo: Mickey Welsh / Advertiser)

The therapy

Applied Behavior Analysis has existed since the 1960s, and has widely proven benefits for children with autism.

Lisa Whitson Riley, parent and advocate (son George was diagnosed with autism at age 4): I was having such a hard time potty training him. I knew something wasn't right. I went to the pediatrician a couple of times. One older male pediatrician said, "Moms over 40, you make mountains out of molehills. I got a doctor who said, "OK, if you think there's something wrong, let's do physical tests."

Sen. Cam Ward, R-Alabaster: Autism's not like any other developmental disability. It doesn't start at 3 and end at 10. It goes on the rest of your life.

David Bicard, Great Leaps Learning Center, Montgomery: Behavior analysis is a branch of psychology. It is a branch of psychology in which we look at how the environment influences or affects behavior. Part of what we do is do an initial behavioral assessment to

determine what sorts of behaviors the child needs to more of and what they need to do less of. Part of that assessment is identifying aggressively behavior or self-injurious behavior. The theory is if we can change the environment, we can change the person's behavior.

Catey Hall, parent and advocate: They had to implement examples for him to understand. So they had to physically show him every single command, such as "William, sit in your chair." So they would have to physically move him into the chair so he would understand how to sit.

Ward: My daughter was unable to speak for a long time. Originally she learned sign language, and then she was able to communicate in social settings. They basically force you to learn what it's like to speak with others, and socially adapt. It's very intense and very one-on-one.

Riley: One of the big things is to help them communicate effectively. It helps them to recognize their processing is a little different. One thing done is understanding facial expressions and body language. A lot of them don't understand that. One of the big things for my son was learning to respect people's personal space. If you were standing in line, he might be breathing down your neck.

Bicard: It takes hours and hours of therapy in order for the skills to begin to emerge. But once those skills emerge, then that learning takes off.

Riley: The doctor prescribed 40 hours. When they're small, they prescribe the most hours, because that's when it's the most effective.

Hall: It's more effective and very critical when they're younger. (William) couldn't speak when he was 2, up until he was 3. They would show him objects and try to tell him what those words were.

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While proven effective, the intense nature of the therapies are expensive, and because coverage of the therapies was not mandated in Alabama, families often find themselves with large bills.

Riley: The first year, we paid something like \$28,000.

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Ward: We had a family that supported us. 85 percent of people in Alabama couldn't afford to do that for their kids.

Riley: We sold our big house. Our \$300,000 plus house. We bought a smaller house. We liquidated our 401K. And we changed our investment structure so we contribute what our employers would match.

The push for coverage

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People take part in the Walk for Autism at Ida Bell Young Park in Montgomery, Ala. on Saturday April 5, 2014. (Photo: Mickey Welsh / Advertiser)

and ensuring that parents and advocates were as present as much as possible during the legislative session.

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Hall: A small group of parents and the Autism Society had done this for years. What they did not have was a strong presence of advocates and parents self-advocating, asking legislators to support them. We decided we're going to do that this year.

Riley: The Autism Society sent out newsletters. I set up a Facebook page to hang around that we all then started tapping into and using. We would use the Facebook page to reach people who weren't on the Facebook page. I posted everything. I did Facebook, Twitter and LinkedIn. And there was another parent who did Instagram and Snapchat. We flooded social media.

Hall: We would say 'We need people here.' And people came. It was hard for those families. The ones who couldn't secure child care, they would bring their children with autism there.

Ward: Catey was in the balcony videotaping the debates and streaming it live on Facebook. We didn't have it on Facebook in 2012.

Hager: The grassroots support for the Alabama Autism Insurance Law was so tremendous that lawmakers soon became interested in learning more about the absence of insurance coverage for children who have autism. Parents, self-advocates living with autism, grandparents, aunts, uncles, teachers, neighbors and friends were advocating ferociously for this bill for their loved ones.

Trotter: There were generally a couple of advocates in the State House on session days. We made sure they touched their members and their senator that represents them and whoever they could get in front of.

Riley: I had coffee parties. What I did was I posted on Facebook, 'Hey, come meet me at the coffee house.' We would pass out the list and call senators and members of the House and ask them to support this bill. We personalized it. Not just calling and saying 'Support this because I want you to,' but 'I know someone.'

Gunnells: We saw this through the process with members. It's one thing for a member to get 100 phone calls from individuals all over the state, but what they're really interested in is that one phone call from their constituent. If an individual is passionate about any issue, they have elected officials in the state Legislature they need to talk to.

The opposition

The major opposition to the bill came Blue Cross Blue Shield of Alabama and the Business Council of Alabama, both of which cited concerns over costs — particularly the lack of age caps in early versions of the legislation — and broader, philosophical opposition to mandates. Requests for comment from BCBS and BCA President and CEO Bill Canary were not answered Friday. BCA went as far in its opposition to compare HB 284 to the Affordable Care Act, and not in a flattering way.

Billy Canary (March 2017 Op-Ed): It is an unenviable position as the business community's stance against health mandates is misconstrued as opposition to treatments or diseases. That is simply not true. But it certainly is easy and convenient to transform the business community's opposition to open-ended government mandates with a broad brush of being against autistic children receiving therapy.

Gunnells: We talked to Blue Cross early on and talked to BCA early on. We just had a fundamental disagreement.

Blue Cross Blue Shield (statement on HB 284, March 2017): The bill would require additional benefits for the coverage of autism across Alabama, affecting individual and family plans, small and large employer plans, and large publicly funded plans such as the State Employees' Health Insurance Plan (SEIB) and the Public Education Employees' Health Insurance Plan (PEEHIP), and more than 500 plans covering county and city governments. The bill imposes autism benefits requirements that are completely open-ended with no

limitation on annual benefits or restrictions on age.

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The State Employees Insurance Board later ran cost estimates on coverage for state employees, and found the expense of covering ABA therapies amounts to less than 1 percent of their total revenues (<http://www.montgomeryadvertiser.com/story/news/politics/southunionstreet/2017/08/29/state-workers-could-see-improved-vision-benefits-next-year/612720014/>). Riley emailed Canary to express her opposition to his stance.

Riley: I have to say Bill Canary emailed me back. By far, it was one of the best emails I have ever gotten. It was respectful. It was detailed. He explained why BCA had its position. Of course, I didn't agree with it. But I appreciated it. He felt like for small business, they can't support any kind of mandate.

Hall: They tried to kill it at every step. At the insurance committee level. Everybody knew that when this bill got a vote on the floor, it was going to go. Nobody's going to be a jerk and vote against kids with autism. So they tried to keep it away from the floor.

Ward: There was a lot of opposition. Philosophically, the concept of government-mandated insurance was very unpopular, and I think Obamacare drove a big part of that.

Into the Senate



Sen. Trip Pittman, left, and Sen. Cam Ward, right, listen during committee discussion on the autism insurance bill at the Alabama Statehouse in Montgomery, Ala., on Thursday May 4, 2017. (Photo: Mickey Welsh / Advertiser)

The bill passed the Alabama House in April and then went up to the Senate, where it languished 'in the basket' – in other words, waiting assignment to a committee to begin the process in that chamber. It was eventually assigned to Sen. Trip Pittman's Senate Finance and Taxation General Fund committee.

Riley: I had been through the fight. Because I had been through the fight, I wasn't trusting of the process at all. I was going to go for the fight, because it was something my kid needed. I just didn't go in thinking 'Yeah, we're going to get it done.' Every time I went in I just thought "I'm going to fight as hard as I can and do everything I can to do it."

Hall: I was ecstatic it passed (the House) 100 to 0 (<http://www.montgomeryadvertiser.com/story/news/politics/southunionstreet/2017/04/20/house-approves-autism-therapy-coverage-requirement/100689976/>). And then immediately it was 'OK, we've got to tackle the Senate.' It was encouraging because of the number on that board at the end of that vote.

Sen. Dick Brewbaker, R-Pike Road: I walked in the chamber one day and I spoke with Rep. Patterson. I've got a kid with disabilities, not autism, but I asked him what committee is it in up here. And I thought there was a decent chance I would get it. He said it's still in the basket. This is at least a week or 10 days after the House passed it. I found (Sen. Tom) Whatley, R-Auburn, who was the Senate sponsor. And he said "it's in the basket."

Hall: We had our heads up on that. This concentration of the grassroots went to (Senate President Pro Tem) Del M. Hunter, and he really wanted to say "Please, get this bill out of your basket."

Trotter: Sen. Marsh, as he does with every bill, took a measured approach, looked at all sides from the start. At the end of the day, after listening to everyone, he promised to put the bill on the floor. And at the end of the day, he did that.

The bill going to Pittman at first dampened hopes for the legislation, and it lingered in his committee for some time.

Trotter: Sen. Pittman had deep-rooted concerns about the bill, and I don't doubt those for a second. On the other hand, you're talking about people's children, and this is their No. 1 issue.

Sen. Trip Pittman, R-Montrose: My concern was philosophical. It's been totally mischaracterized. I'm probably the most independent person in Montgomery. I just don't believe in mandates.

Hall: The whole time we were arguing with Sen. Pittman. He said 'Oh, this budget, it's going to blow it out of the water.' We were saying the number given by Blue Cross Blue Shield of Alabama are totally inflated. The state employee board finally looked at those numbers and said "This is not a big deal."

With no action taking place in early May, a group of senators – including Brewbaker; Ward; Bill Holtzclaw, R-Madison and Quinton Ross, D-Montgomery – took to the podium one day. Brewbaker said he had read "outright crap" about the costs of the legislation. He later gathered signatures from 26 of 35 senators demanding a vote, and threatened to slow down the session if it didn't occur.



Sen. Dick Brewbaker on the senate floor at the Alabama Statehouse in Montgomery, Ala., on Thursday May 4, 2017. (Photo: Mickey Welsh / Advertiser)

Brewbaker: I will admit to being intentionally irritated when I read the first set of cost estimates put out by people trying to kill the bill. The projections were pulled out of thin air.

Ward: It was probably about two hours before. We had been mingling on the floor. (Brewbaker) was very adamant. He said "Cam, this is wrong."

Brewbaker: I decided, "To hell with that." We all started going to the mike.

Hall: I was in the State House and I got a text message from the lobbyist: "You're missing Brewbaker."

Brewbaker (May 2, 2017) (/story/news/politics/southunionstreet/2017/05/02/brewbaker-demands-vote-autism-insurance-bill/101215638/): There are more people like me who will get increasingly uncooperative if this bill continues to be blocked. I would urge leadership to get the bill in front of a committee this week. We can do better than this.

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Riley: I was so thankful. We just hugged him.

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Brewbaker: None of that would have gotten off the ground if Holtzclaw, Ward and Ross

weren't willing to go to the mike that day. It had to be more than just me.

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The bill did eventually come up for a vote in Pittman's committee, where Pittman offered numerous amendments (/story/news/politics/southunionstreet/2017/05/10/autism-bill-passes-senate-committee-after-large-changes/101514376/) that were mostly rejected. Some ones stuck, though. One excluded businesses with 50 employees or less from the mandate. Another imposed an age cap, cutting off mandate for children at age 16 (later, it was raised to 18).

Hall: I was in tears in that meeting. When he threw down the 16-year limit, that's when I started crying.

Bicard: In a medical model, you give some medicine, and the patient is cured of the symptoms. So if someone has the flu, they'll give the medicine and the patient gets better, and the symptoms are alleviated. The medical model doesn't really fit very well with a chronic condition like autism. You can't give a child some medicine and they're cured of autism.

Ward: The concern was, "I get all this therapy until age of 18 and I do better, and then all of sudden, this therapy, it's pulled out from under me."

Pittman: The parents are extremely concerned about their children and want their children to have normal lives. But like anything in government, who's going to pay for it? There's no free lunch.

The committee did approve the measure. Then, in an unusual move, Pittman delayed reporting it out to the full Senate for a vote.

Pittman: That's why you're a senator. One senator has a lot of influence. If you know something is going to be costly, and you're opposed to something, you want it to be further modified. I felt small businesses didn't need to be mandated.

Hall: Nobody had done that, ever.

Ward: It's structured in the House. In the Senate, it moves between all kinds of rules processes. Our issue was special order. If you're opposed to it, there's a whole lot more ways to kill it.

Hall: We started calling, emailing Sen. Marsh and (Senate Rules Committee chair) Jabo Waggoner (R-Vestavia Hills). I know after tremendous pressure from our community – Del Marsh is on a radio show and I can't remember which one, but he basically said "you're going to get your vote."

Passage



Rep. Jim Patterson presents the autism insurance bill on the house floor at the Alabama Statehouse in

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When it got to the floor of the Senate on May 16, the measure passed 33-1 ([/story](#)

[/news/politics/southunionstreet/2017/05/16/alabama-senate-approves-autism-insurance-bill/101766710/](#)) despite a last-minute push from BCA calling the measure "an Obamacare-style tax hike." Pittman cast the only vote against the bill.

Pittman: People voted on it for various reasons. I'm certainly very sympathetic to a child and family who has to deal with it. But it was a question of where the money comes from.

Riley: I thought "We're not done yet. But we got past that." And then it hit me: "Oh shoot, we've got a different governor. Has anyone talked to the governor?"

Trotter: We felt like the odds were in favor that she was going to sign.

Two days later – after midnight — the House approved the final bill 103-0 ([/story/news/politics/southunionstreet/2017/05/18/autism-insurance-bill-gets-final-legislative-passage/101821304/](#)), sending it to Gov. Kay Ivey. The vote came somewhat early, and several advocates weren't present.

Hall: I just happened to be there. I was not planning to be there until the next day. That's when we were told it was going to be on the floor.

Riley: Katie was there that night, and had it on Facebook Live. I was watching it that night. I never felt like it was over.

Patterson (May 18, 2017): It ought to show the public their lobbying counts a lot. What I'm hearing from my district is this is a popular thing. You can have an effect.

Hager: Like many in Alabama, my son is still not covered for autism therapy by his health insurance. There are many families covered after HB 284, but there are many left uncovered and future work to be done.

Hall: My initial reaction was I was happy for the people covered, and I was sad for the ones that weren't covered. But after the dust settled, this was a good law. Compared to the states that went before us, we passed a good law out of the gate. Georgia's age cap was like 9 in the initial passage of its law.

Both Riley and Hall attended Gov. Kay Ivey's signing ceremony for the legislation ([/picture-gallery/news/2017/05/19/autism-bill-signed-into-law/101878340/](#)).

Hall: I can't say what it meant to see that pen get to that paper. We had fought so hard to get that pen to that paper. I was proud of our state and I was proud of our legislators that organized, and I was proud of those families to who sacrificed their home and children.

Riley: I sat there and trembled and cried. I took George with me. I literally, I sat on the edge of my chair . . . I wasn't going to believe it until I saw (Ivey sign). Once I saw that, I bawled.

The lessons

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Gov. Kay Ivey and autism advocates after Ivey signed the autism insurance bill into law May 19, 2017. (Photo: Andrew Yawn / Advertiser)

Advocates are still watching how the law will be implemented, and want to see it expanded to include those not covered in the initial bill. But for all involved, there were lessons to be drawn from the experience.

Trotter: For those covered by the law, it's a life changer for those kids. If they can get intervention early on, it has a significant chance of mainstreaming the child. I would say for me it's at times overwhelming to work on something that has that much of a positive impact on those folks' lives.

Bicard: The success of the bill was solely on the families. It was the families that made the difference.

Pittman: I opposed the mandate and unknown costs. I did bring the bill up for a vote and signed it out of committee. It will help a lot of children, and that is good.

Gunnells: Don't underestimate your own advocacy. We saw this through the process with members.

Hall: The biggest lesson is you can have an impact if you show up and make your voice heard. These legislators are mostly down there doing their things. When you show up and say "hey, I need you to vote favorably on this bill," you'd be surprised on how many people want to vote for their constituents.

Riley: There are no shoo-ins. I don't care how important it is. There are no shoo-ins. I don't care how simple it should be. When you say 'supporting children with autism,' no one in their right mind would say 'no, we're not going to do that.' Every single thing you get that comes out of the State House, you are going to have to fight for it.

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