

[Listen Live \(https://player.streamguys.com/gpb/sgplayer3/index.php\)](https://player.streamguys.com/gpb/sgplayer3/index.php)

[LIVE AT 4:30 P.M. Kemp, DPH, GEMA, and Georgia Guard to Give COVID-19 Update \(https://www.gpb.org/coronavirus\)](https://www.gpb.org/coronavirus)

Fight Or Flight Mode: How A Mother Fights For Her Son With Autism

By [JADE ABDUL-MALIK \(/PEOPLE/JADE-ABDUL-MALIK\)](/PEOPLE/JADE-ABDUL-MALIK) • APR 24, 2020

 [Share \(http://facebook.com/sharer.php?\)](http://facebook.com/sharer.php?)

[u=http%3A%2F%2Ftinyurl.com%2Fybgtkxc5&t=Fight%20Or%20Flight%20Mode%3A%20How%20A%20Mother%20Fights%20](http%3A%2F%2Ftinyurl.com%2Fybgtkxc5&t=Fight%20Or%20Flight%20Mode%3A%20How%20A%20Mother%20Fights%20)



(//www.gpbnews.org/sites/wjsp/files/styles/x_large/public/202004/DSC09663.JPG)

Elizabeth Sherwood watches her son Johnathan play outside with his therapist Marco Perez.

JADE ABDUL-MALIK / GPB NEWS

Ever since Gov. Brian Kemp mandated shelter-in-place orders and moved classes to online learning to slow the spread of COVID-19, several families have been coping with their new day-to-day — making a clear routine, establishing boundaries and trying to make the most of their new normal for a while.

Mother of two Elizabeth Sherwood is particularly exhausted.

“The kids are not in a routine at all,” she said. “Forget having special needs on top of it.”

I wanted him to say Mama.

Johnathan’s beginnings

Sherwood had inklings of suspicion that her oldest child Johnathan had autism. At 6 months old, he wasn’t hitting milestones (https://www.cdc.gov/ncbddd/actearly/pdf/checklists/checklists_6mo.pdf) such as showing curiosity or responding to emotions. He was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (<https://www.ncbi.nlm.nih.gov/books/NBK519712/table/ch3.t1/>) when he was 2 years old; autism wasn’t an official diagnosis in 2006.

Johnathan’s diagnosis prompted her into flight or fight mode. She chose to fight.

“My attitude at that time was autism was curable,” Sherwood said.

Before Johnathan was born, Sherwood worked in Smith Barney’s operations department. She was on an optimistic track to become a manager. As soon as her son was diagnosed, she volunteered to go part-time, but as his condition got worse, she chose to leave when her company was sold.

Instead of working full-time, Sherwood took Johnathan back and forth to the Marcus Autism Center (<http://marcus.org>) in Atlanta for early intervention protocols.

“I worked for 12 years and then once he got his diagnosis, I took that hat off and I was in mommy mode,” she said.



(<https://mediad.publicbroadcasting.net/p/wjsp/files/s>

Sherwood tried it all to improve Johnathan's quality of life — several types of therapies, gluten-free and casein-free diets, B12 shots, fish oil and even hyperbaric oxygen chambers (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3472266/>).

Elizabeth Sherwood and her son Johnathan.

CREDIT COURTESY OF ELIZABETH SHERWOOD

“All of my salary went to those interventions because all I cared about at that time was my son talking,” Sherwood said. “I wanted him to say ‘Mama.’ That's what I lived for.”

Eventually, Johnathan's diagnosis became more complex. He was later diagnosed with a complex partial seizure disorder and a sleep disorder. He also has the mental development of a 15-month-old child.

“My son is ... one of the most severe cases that a lot of doctors have seen,” Sherwood said.

The divorce rate is between 80 to 90% among special needs parents and I'm about to become one of those; I never thought after 22 years of marriage I would be there, but I am.

Asking for Georgia's help

The Sherwood family resides in a quiet cul-de-sac. A “Caution Autistic Child” sign is screwed underneath their street sign, and a blue light flickers outside their front door for autism awareness.

Sherwood's father made paintings of her children and they hang high in the entryway. They're the only art on the walls that Johnathan can't reach.

Johnathan is now 15 years old. He's nonverbal. His sleep disorder keeps him up for hours almost every day of the week and he's incontinent. When he wants attention, he'll pat his mother on the back of her head several times, try to make himself vomit or scream.

Johnathan is also going through puberty, quickly outgrowing his mother and 7-year-old sister.



(<https://mediad.publicbroadcasting.net/p/wjsp/files/s>)

Elizabeth Sherwood asked the Acworth Police Department to put up signage on her son's behalf.

holes in walls. Sherwood hired a contractor to install an 80-pound door for her bedroom because Johnathan destroyed the previous one. There are special door knobs and padlocks on every door and cabinet in the house. Johnathan's room, once adorned with a swing and bookshelves, is vacant with the exception of two mattresses on the hardwood floor and a hole in the wall near the window.

Meanwhile, Sherwood and her husband of over 20 years have been separated since 2019 and are now filing for divorce. Once the divorce is finalized, she says she expects to have primary custody of her two children and work full-time.

"The divorce rate is between 80 to 90% among special needs parents and I'm about to become one of those," Sherwood said. "I never thought after 22 years of marriage I would be there, but I am."

She works 10 hours at nonprofit respite organization, but lately she's had to work less because her children are home throughout the day due to COVID-19.

Sherwood applied for government assistance on Johnathan's behalf. He's eligible for skilled nursing care and personal care support 40 hours a week under the Georgia Pediatric Program (<https://medicaid.georgia.gov/document/publication/georgia-pediatric-program-gapp/download>) — a Medicaid program that provides services to medically fragile children under the age of 21 — but she said the agency hasn't reached out to her since they were approved in November 2019.

"My best friend [is in the] same exact situation, but she gets 14 hours a week and had no issues finding care, but it's unskilled nursing (<https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-CustodialCarevsSkilledCare-%5BMarch-2016%5D.pdf>)," Sherwood said. "And I wanted unskilled nursing because we don't need nurse care (<https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-CustodialCarevsSkilledCare-%5BMarch-2016%5D.pdf>)." "

She has also applied every year for the Katie Beckett Waiver — a need-based Medicaid program for children under 18 — to no avail. For now, Johnathan has an RBT, or Rational Behavior Therapy, therapist who cares for him for several days of the week.

Sherwood said he needs around-the-clock care and she's been fighting for it for nearly 10 years.

"My job has been taking care of my son — which I'm okay about," Sherwood said. "But the thing is, it's a 24/7 job [with] the amount of paperwork and phone calls that I have to make on his behalf. It's ridiculous."

You feel like you are failing your kid.



"It's like he's forgotten"

Georgia's Medicaid offers two waiver programs for families like Sherwood's. The New Options Now (NOW) Waiver

https://mediad.publicbroadcasting.net/p/wjisp/files/styles/x_large/public/202004/DSC09659.JPG

Marco Perez is Johnathan's therapist who uses ABA, or Assisted Behavioral Analysis, to help him.

CREDIT JADE ABDUL-MALIK / GPB NEWS

<https://medicaid.georgia.gov/media/3751/download>) is a support package of services for individuals with developmental disabilities while the Comprehensive (COMP) Waiver (<https://medicaid.georgia.gov/media/3751/download>) program is state-supported care for individuals with more severe needs.

Though these waiver programs stem from Medicaid, the federal government allows states to cap their funding. Georgia Council on Developmental Disabilities (<http://gcdd.org>) Executive Director Eric Jacobson said states are also allowed to create waiting lists.

"They can say, 'We're only going to serve so many people. We're only going to spend so much money,'" he said. "[States are allowed to say,] 'It can't be more expensive than what it would've cost to serve you in a nursing facility or an institution.'"

Annually, The NOW waiver is estimated to cover approximately \$25,000 worth of services and the COMP waiver is estimated to cover \$50,000 to \$75,000 worth of services, Jacobson said. This could include care from skilled professionals, respite care or other demands.

"If things go the way they're supposed to go, those dollars should cover an individual's needs," Jacobson said.

However, funding that helps families with special needs are becoming more unstable.

"The problem with any of those state funded [programs] — which is what we're seeing right now — is that when cuts happen to the budget, those are generally the first things that are cut because of the fact that there [are] no federal matching dollars," Jacobson said.

He said there's also a shortage of direct support professionals (<https://thearc.org/policy-advocacy/direct-support-professionals/>), people who work closely with people with special needs and support them during the day.

“Right now, there is a huge shortage of direct support professionals, not only in Georgia but across the country,” Jacobson said. “In general, we pay these folks in Georgia \$7 to \$10 an hour, which is not enough to support their families.”

Sherwood is scared of what the budget cuts could mean for her son.

“I feel that's all I've seen in the news lately, is that they're trying to cut resources everywhere and especially with special needs,” she said. “I'm eventually going to have to look into residential [housing] for my son and that will absolutely kill me if I have to do that.”



(<https://mediad.publicbroadcasting.net/p/wjsp/files/s>

Toys, drawers and bookshelves used to be in Johnathan's room, but his room had to be stripped bare because of his physically destructive behaviors.

CREDIT JADE ABDUL-MALIK / GPB NEWS



(<https://mediad.publicbroadcasting.net/p/wjsp/files/s>~~https://mediad.publicbroadcasting.net/p/wjsp/files/s~~ *It's like he's forgotten, 202004, DSC0136.JPG*)

Johnathan sometimes sits at the front door when waiting for his therapist to arrive.

CREDIT JADE ABDUL-MALIK / GPB NEWS

I'm bawling my eyes out; I'm exhausted and yet it does not really seem to matter

that we're used to kind of dealing with families that really don't know what they're doing and you really do know what you're doing,” Sherwood said.

There are at least 6,000 families on the NOW/COMP Waiver waiting list. Sherwood was on it for nearly 10 years. After almost 10 years of waiting, Sherwood received an email from the Georgia Department of Behavioral Health and Developmental Disabilities in March stating that Johnathan is not moving toward waiver services.

“It's like he's forgotten, 202004, DSC0136.JPG) said. “And then you feel forgotten and you feel like you're failing your kid.”

Sherwood heard that she could escalate her son's case by calling the Georgia Crisis and Access Line (<https://namiga.org/georgia-crisis-and-access-line/>) whenever she needed immediate assistance. When a mobile unit would come to her house to help, she said they could only offer in-community services.

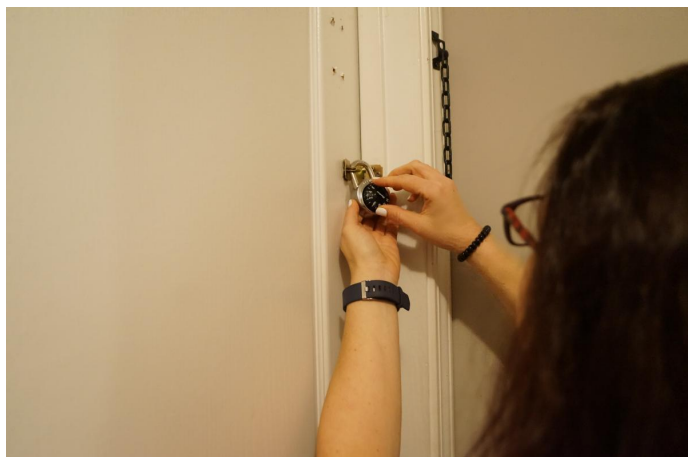
“They said, ‘Mom, I gotta be honest with you that we're used to kind of dealing with families that really don't know what they're doing and you really do know what you're doing,’” Sherwood said.

When she would get in touch with her NOW/COMP waiver case navigator, she would explain details of the damage Johnathan would inflict on their home, specifically the window he'd shattered, in hopes to receive more help.

"If you hear my story and the fact that my son is literally destroying my house, and then the shattering of the window and then you've got a cut because you stepped on some of the glass that's shattered," she said, "I'm bawling my eyes out; I'm exhausted and yet it does not really seem to matter."

Because of the stress, Sherwood is mentally struggling.

Her and her soon to be ex-husband's marriage slowly became about their children, family outings are rare and she used to overeat to cope with her stress.



"You wind up excluding yourself in your house like you're a prisoner in your own house and I feel like my son is like the main guy, the ward," Sherwood said.

I am just a mom who loves her kids.

(https://mediad.publicbroadcasting.net/p/wjsp/files/styles/x_large/public/202004/DSC09597.JPG)

Elizabeth Sherwood has to put locks every door, including Johnathan's bedroom door.

CREDIT JADE ABDUL-MALIK / GPB NEWS

A mother's love

Despite Sherwood's family receiving little government assistance, community support surrounds them. Local churches check on them, their neighbors are an extra set of eyes when Johnathan is outside and Sherwood has a network of friends that relate to her journey of advocating for her son.

Sherwood said she found out about state aid, nonprofit grants and other funding for families with special needs through other mothers.

"We have to take care of each other because nobody is taking care of us," she said.

During the shelter-in-place orders, someone from a local church called Sherwood to check on her and the family. She updated them on her family and they called her Superwoman. Sherwood rejected that title.

"I'm just a mom who loves her kids," she said.

TAGS: [SPECIAL NEEDS \(/TERM/SPECIAL-NEEDS\)](#)

[MACON \(/TERM/MACON\)](#)

[GEORGIA \(/TERM/GEORGIA\)](#)

[SAVANNAH \(/TERM/SAVANNAH\)](#)

[ATLANTA \(/TERM/ATLANTA\)](#)

[CORONAVIRUS \(/TERM/CORONAVIRUS\)](#)



<https://mediad.publicbroadcasting.net/p/wjsp/files/s>

Paintings of Elizabeth Sherwood's two children as babies hang above the front door.

CREDIT JADE ABDUL-MALIK / GPB NEWS

f [Share \(http://facebook.com/sharer.php?](http://facebook.com/sharer.php?)

[u=http%3A%2F%2Ftinyurl.com%2Fybgtkxc5&t=Fight%20Or%20Flight%20Mode%3A%20How%20A%20Mother%20Fights%20](http://facebook.com/sharer.php?u=http%3A%2F%2Ftinyurl.com%2Fybgtkxc5&t=Fight%20Or%20Flight%20Mode%3A%20How%20A%20Mother%20Fights%20)

Comments **Community** **Privacy Policy** **1 Login** ▾

Recommend **Tweet** **Share** **Sort by Best** ▾

Start the discussion...

LOG IN WITH

OR SIGN UP WITH DISQUS **?**

Name

Be the first to comment.

Subscribe **Add Disqus to your site** Add Disqus Add

RELATED CONTENT

[\(/post/why-these-moms-decided-show-solidarity-woman-who-left-son-atlanta-hospital\)](/post/why-these-moms-decided-show-solidarity-woman-who-left-son-atlanta-hospital)