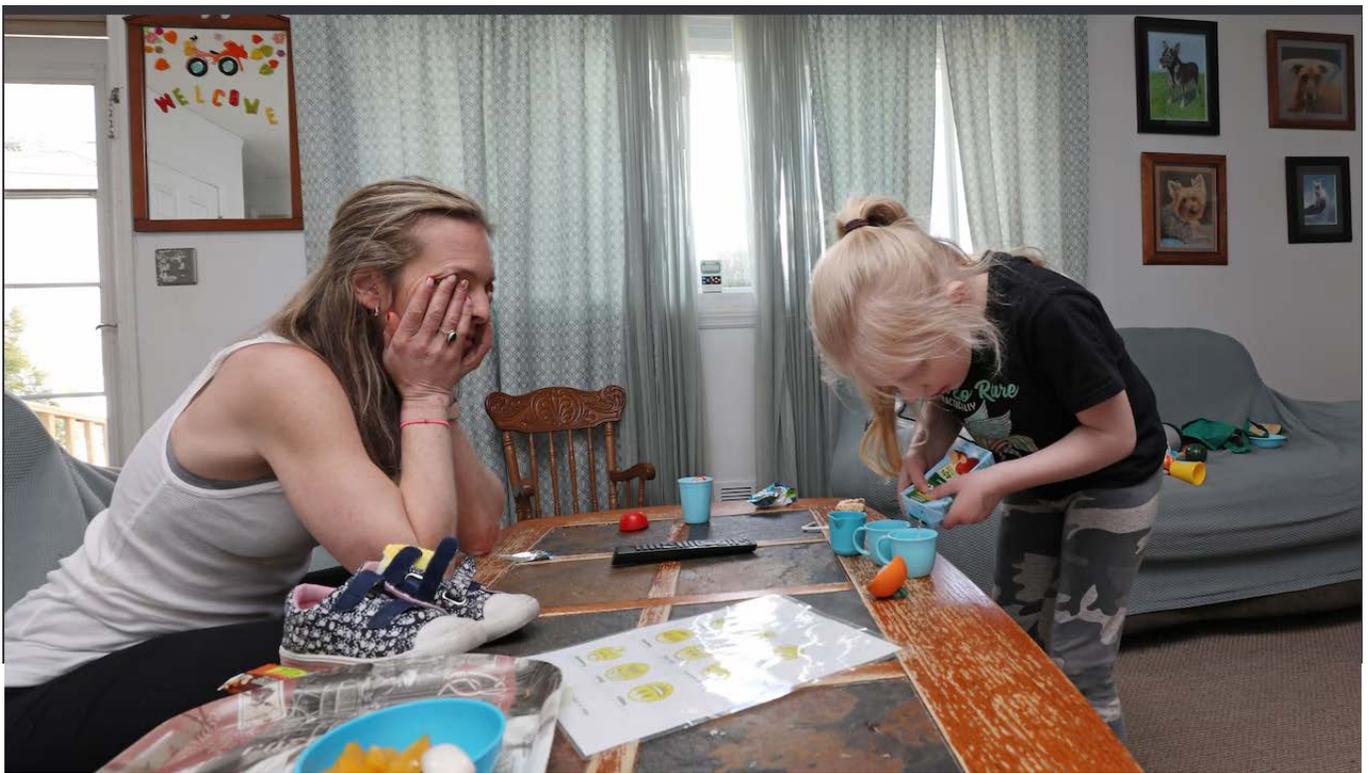


Severe autism, frantic families

N.J. is too slow to help children with severe autism. Inside a mother's desperate plea.

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Chelsea Cella, left, watches her daughter Gianna Joachim pour juice in a cup. Gianna loves to pour liquids.
Amanda Brown | For NJ Advance Media

By [Susan K. Livio](#) | NJ Advance Media for NJ.com

Gianna Joachim is a hurricane, a twister of giggles and screeches, a steel blue-eyed, ivory-skinned 7-year-old whose internal motor is always revving at top speed.

Gianna hurls herself on the floor and cries when her mother lingers for more than a minute on the telephone. She has slammed her own face into floors and walls, loosening her teeth and causing nosebleeds. A bookstore and a department store had to be locked down and searched after she stealthily hid from her parents.

Gianna is among the nearly 17,000 children with "profound" or "severe" autism in New Jersey, representing slightly more than one-quarter of the children on the autism spectrum. Medical experts say they need steady, intensive behavioral therapy and medication to lead anything approaching a peaceful, fulfilling life.

But the Joachim family of Howell in Monmouth County, like so many others raising children with severe autism, spend most of their waking hours bargaining and battling for the services a physician has prescribed for their daughter.

Gianna is supposed to be getting 15 hours a week of behavioral therapy after school to learn basic life and social skills, like dressing herself, riding in a car and playing with other children. But since November, those hours have been cut to three hours, then to 90 minutes, said her mother Chelsea Cella. In the last few weeks, Gianna is not getting any behavioral therapy as the mother and company disagree over the type and terms of treatment the child should receive

When she pressed the state-licensed therapeutic company for an explanation, Cella said she was told the problem was "staffing issues." Instead of treatment, Gianna gets a growing number of medications to control her behavior. It's an awful tradeoff and no way for a child to live, Cella said.

"A doctor has prescribed 15 hours a week. If she needed dialysis, they wouldn't say, 'Sorry we don't have enough machines for you today.' This ought to be illegal." .

The struggles of Gianna's family are all too familiar in New Jersey, home to the third-highest child autism rate in the nation. Many families say it is difficult if not impossible to get the help they need for their children, forcing them to spend hours each week cobbling together networks of public and private services. This is especially true for kids with severe autism

Part of the problem is that there is a shortage of skilled therapists able to meet the demands of working with a child with severe autism and willing to accept the meager wages compared to jobs in schools. Many times, parents also have to fight with insurance companies who may question the necessity of frequent, long-term treatment.

And for years no state government agency has been responsible for ensuring these children get the therapies prescribed for them. Promises to attack the problem with a 2020 law that would require skilled therapists to be licensed and get more of them into the pipeline have progressed very slowly, and it may take years for the impact to be felt.

That is no solace to parents who are afraid the window is closing on the time Gianna and other children like her need to learn crucial coping skills.



Cella, 43, who holds a master's degree in special education and has worked with disabled children prior to becoming a mom, admits she is overwhelmed trying to meet Gianna's needs while also trying to give her 4-year-old son the attention he deserves.

"The medicine she takes only works for 4 hours. Then I have to give her something else. I feel so guilty giving it to her," she said. "Gianna was done a huge disservice, causing a gigantic regression and medication issues."

Is New Jersey a leader?

People with profound autism have a low IQ, possess limited or no verbal skills, require lifelong care and are prone to severe behavior that can hurt themselves and others and damage property. At least 10,000 children with profound autism in New Jersey engage in severe harmful behavior, according to Autism New Jersey.

When the Rutgers University Center for Autism Research| Education and Services was founded four years ago, Robert Wood Johnson Medical School Pediatrics professor Wayne Fisher said the first order of business was to focus on children with profound and severe autism. Like in New Jersey, more than one in four children with autism across the nation have profound autism.

"The biggest need that we saw from the start was the need for individuals with severe problem behaviors," Fisher said. "But if we can get them in and analyze their behavior and train parents, we often are successful in keeping them in their home environment."

The lack of support and reliable services for people of all ages with severe autism has been one of the most frequent complaints brought to the attention of Paul Aronsohn since he took a job as Ombudsman for Individuals with Developmental Disabilities and Their Families in 2018.

"It was a crisis pre-pandemic. But since then, the crisis has become more pronounced and more severe," Aronsohn said.



Gianna Joachim rides in the car to go get her little brother from daycare. Amanda Brown/
For NJ Advance Media

Out of options, some parents dial 911 or take their children to the emergency room, "where they stay for several hours or several weeks before being discharged on an unhealthy (and often, unhelpful) mix of psychotropic medications and frequently get turned away," according to the Ombudsman's latest annual report, released in August.

"We know the earlier we can provide treatment, we know that the individual will be better off," Aronsohn said in an interview.

"No one is held to account for missed sessions and the regression" that happens when behavioral therapy slacks off, he said.

Behavioral therapy, delivered through state Department of Children and Families' approved providers, must be delivered early and consistently, he added. "A day in the life of a child is like a year. You can't get that back we need to get those interventions as soon as possible," Aronsohn said

Autism spectrum disorder is a neurological condition that affects how people learn, communicate and behave and has no scientifically confirmed cause or cure. One in 35 children in New Jersey have been diagnosed with autism, the third-highest rate in the country, behind Minnesota and California.

So it's no surprise that with such an outsized demand for answers and services, New Jersey has cultivated a reputation for having some of the most respected autism researchers and special education programs in the nation.

The mostly widely accepted and research-tested therapy for autistic children is Applied Behavior Analysis, better known as ABA, according to experts in the field. The therapy involves intensively repeating a task - from tying a shoe, playing with another child or any behavior a child needs to learn - and rewarding with praise or something tangible when the child complies.

Such progress can't happen without highly skilled professionals directing the therapy on a consistent basis. They must show parents how to reinforce the behaviors at home.

But even in New Jersey, with its good reputation for treating autistic children, there's a crisis-level shortage of these therapists.

Gianna Joachim receives speech and other therapies at school in her special education classroom. But she was also prescribed home and after-school treatment, and early on it showed tremendous promise, - until it was interrupted and gradually reduced starting 10 months ago, her mother said.

Sunny Days, Gianna's behavioral therapy provider located in Monmouth and Ocean counties, declined to discuss Gianna's care, even if her parents signed a privacy waiver.

"Every client and family are protected under HIP AA, and while we can't discuss individual circumstances, we can assure you that every child's needs are different and we work very hard to cater to all children and families in our care," Lindsay Hilsen, Sunny Days' chief clinical officer and program director for New Jersey, wrote in an email to NJ Advance Media.

Hilsen did acknowledge there is a burgeoning and unmet demand for these services in general.

"We can confirm that there is currently a nationwide shortage of Board Certified Behavior Analysts and Behavior Technicians. At this time, there is a huge deficit in the field. We also struggle between the recommendations of what the physician prescribes versus what the insurance company will approve," Hilsen wrote.



Chelsea Cella (left) brings her daughter, Gianna Joachim back to the car after the youngster tried to run away. Amanda Brown/For NJ Advance Media

Coping and hanging on

ABA therapy relies on parents understanding and following the treatment plan and carrying it out when the therapist goes home.

But what if the therapist isn't trained on how to approach a child with severe autism? Cella said more than one therapist burst into tears and fled. Another refused to return because, her supervisor said, because she did not like Cella's questions or her tone.

What happens if a child is at risk of hurting herself, she can't sleep through the night? Gianna's doctor recommended the family buy a \$16,000 "cubby bed," a soft, plushy capsule with the use of lights and music that distract the child from trying to flee while zipping her safely inside. The problem: the insurance company rejected the purchase for almost a year because, "it does not cure Autism," according to the letter denying coverage.

"I want to mention Gianna has smashed her head on the walls and floors causing 3 teeth to loosen, bloody nose multiple times, smashing her face on rails bruising her face, jumped out of crib while heavily medicated, thank goodness only causing slight injury," Cella wrote in response to the denial.

"Although she is video monitored and we are close by it is IMPOSSIBLE to stay up 24 hrs a day, 7 days a week to monitor her while she is sleeping, and be able to function in order to take care of her and my 4-year-old son."

She won the appeal. The bed arrived in April, saving bedtime for the Joachim family.

For lower-income families, Medicaid pays the tab for therapies and equipment. One-third of New Jersey residents with private insurance are covered by state-regulated insured plans that by law must cover such therapy. But most New Jersey families are covered by insurers that have more room to reject paying, said Kim Mack Rosenberg, an attorney in Princeton who represents clients on the autism spectrum and the agencies that provide them therapy.

Because behavioral therapy requires a long-term commitment, Mack Rosenberg said she represents many families in negotiations with insurance companies that question the medical necessity of these costly expenses. The Joachim family has had battles with their insurance company over therapy but those issues have been resolved, Cella said.

How a child with profound autism may experience the world

Children with profound autism may not be able to speak. They may hurt themselves or others by biting or hitting and damage or destroy property. They may run into a busy street.

All of these behaviors are a form of communication, said Fisher from the Robert Wood Johnson Medical School. Sometimes the child finds harmful behavior the quickest way to get their needs met.

When people with severe autism hit themselves, they don't necessarily experience pain the same way others do, Fisher said. There is evidence a person with severe autism may experience something akin to a "runner's high," producing an endorphin rush, he said.

People in this special needs community often say: "When you've met one person with autism, you've met one person with autism." Everyone is so different - the way they experience fun, pain, fear and pleasure.

This is true for Gianna, who in addition to autism, has a rare form of the genetic disease, lysosomal storage disorder, that has interfered with her development.

With all of her diagnoses, Gianna, or "G" as her family calls her, would seem to be fragile. It's quite the opposite.

"Gianna needs sensory input, the rougher the better," Cella said.

As a baby, Gianna barely cried, Cella said. "I had to keep a chart to remind me when she slept or ate."

"She would never go to sleep in a quiet environment so we could take her anywhere. We began to notice the louder the environment, the calmer she got and would fall asleep," Cella said.

"However, she never really smiled either. Gianna always had this kind of stary, but blank look in her eyes. We even asked the pediatrician, 'could she have clogged tear ducts?' and 'why does she like to be played so rough?' We were dismissed and told to be thankful we have such a good baby and a lot of babies like rough play. Not like this, I thought."

Gianna was diagnosed with autism at age 3.

Cella said she is reluctant to ask relatives or friends for help watching Gianna because her behavior is too volatile and her energy level too intense to try to keep up with. For five years, the family relied on the same respite worker for weekly visits. But she recently took another job. She's available for date nights once a month.



The Joachim family keeps a collection of PECS (Picture Exchange Communication System) cards to help Gianna communicate. Amanda Brown/For NJ Advance Media

Around every corner, there is potential danger for Gianna to hurt herself or her little brother (the family requested his name be withheld to protect his privacy). There are cameras in every room, connected to a control center in a pantry-closet near the kitchen. There are locks on every cabinet and appliance and gates separating the kitchen and the living room.

Sunny Days has not maintained a steady schedule in nearly a year, and she has regressed, Cella said. The management promises to discuss their goals for Gianna and the milestones they've reached in therapy, according to emails correspondence with the family. But according to Cella, they are still withholding information and limiting Gianna's access to treatment and socialization activities.

"It feels like an abusive relationship," Cella said.

Until they get answers, the family has halted behavioral therapy and limited Gianna's involvement at Sunny Days to speech and occupational therapy, said Cella, who described these therapists as "wonderful."

With her son in daycare, Cella spent the summer keeping her tireless daughter busy. With *The Price is Right* on a TV loop, they played games and with puzzles. But one of Gianna's favorite activities is pouring water, sand or dried beans from one container to another. The repetition and the sensations captivate her.

"My daughter is 100% on the go - she can't stop moving," Cella said.

"She tosses and smooshes her body on 'comfort nuggets,' square blue pillow-like mats that can be made into a fort or an obstacle course, or even a human sandwich," her mother said.

"I also have a gym trampoline in my living room for her. She loves deep pressure on her feet. She is constantly jumping."

She loves listening to heavy-metal music and having dance parties with her dad. Lincoln Park and Pantera are her favorite, the louder the better. Cella said she is not allowed to join the dance parties; they are a moment just for her and her daddy. Screeching will ensue if she tries.

"She has violent tantrums and then snaps out of it laughing," Cella said.

The Joachim family does get some blessed moments of peace.

They are often on Sundays with Nancy Forsyth, a certified equine therapist at the Allaire Community Farm in Howell. Forsyth, who has a special needs son, has been working with people with autism, traumatic brain injuries and post-traumatic stress disorder for three decades. Cella was once her volunteer before she became a mom.



Gianna Joachim rides a horse named Kodiak during therapy at Allaire Community Farm in Wall Twp. The team of (standing, left to right) Nancy Forsyth, Joan Fiumefreddo, Karen Martin and Barbara Silverman work with her during a session. Gianna is happiest here, her mother says. Amanda Brown/For NJ Advance Media

One Sunday, it looks as if Gianna is simply following directions and guiding the horse. But Forsyth is guiding her through an entire mind and body workout. Forsyth and her volunteers are building eye-hand coordination, posture, and verbal skills. Gianna's speech skills, growing since the summer, showed their first signs of progress here, Cella said.

Gianna doesn't like to be touched, so Forsyth tailors the instructions to help her relax and succeed in their tasks of leading the horse or tossing rings on cones.

"As she walked for a few steps, she didn't want to stop, her whole demeanor changed," Forsyth said.

A riding therapy lesson sets up Gianna, and her family, for a relatively quiet day, Cella said.

"It's her happy place," Forsyth said. "This is what I love."



Chelsea Cella and Brian Joachim watch their daughter Gianna Joachim during equine therapy at Allaire Community Farm in Wall Twp. Amanda Brown/For NJ Advance Media

These services and the family's insurance copays are covered by grants from foundations and local charities. PerformCare, the state's outside administrator for children's mental health services, has provided the family with a liaison to advocate for Gianna but so far hasn't helped deliver the services she needs, her mother said.

Cella cannot work, but she has a binder full of letters and leads, and when Gianna and her son are at school, she fills her time making calls and writing letters, asking for help. Her next goal: a therapy dog.

The isolation of being the parent of a child with severe autism creates toxic thoughts, Cella said. Can any behavioral therapist help Gianna? Do the therapists hate Cella? One email she shared with NJ Advance Media said a therapist refused to return to the home.

Why does Gianna kick and smack her, but not Brian? Does her daughter hate her?

Girl Storm

Peg Kerswell understands the isolation.

A 54-year-old musician from New Milford, Kerswell wrote a book last year, "Girl Storm, that frankly describes the shock, exhaustion and fear she and her husband, Jim, experienced raising Ellie, a child with severe autism.

This is how Kerswell described their bedtime ritual with Ellie, then 12.

"God bless Ellie," I say. Deep exhale of exhaustion. "And God help Mommy and Daddy." Another deep exhale. "Amen."

She giggles and so do I. I look at Ellie with her clasped praying hands, her eyes gleaming with excitement and mischief and my heart soars. How I love this little girl. Especially right now at this moment because she's in bed and I will finally get a break from her. I kiss her on the bridge of her tiny nose, my favorite spot, while holding down her arms so she won't hit me.

Kerswell said there were ample opportunities for behavioral therapy in Bergen County, but the treatment just didn't help Ellie.

It also grew increasingly harder to keep Ellie safe, she said. They bought floor and wall padding, wrestling mats "to cushion the blows when she dropped her body onto the floor and banged her head," according to the book.

What the family desperately sought and seldom found was respite providers - professionals educated and trained to work with profoundly disabled children for a few hours a week or month to give parents a break.

"I was desperately trying to find more respite and that is when we realized we had exhausted everything," she said. "The only solution - is to place her in a home."

Bancroft, located in south Jersey and one of the largest providers of housing and services for people with developmental disabilities, has been home for Ellie, now 20, since she was 14.

For families, "It's a minute-by-minute existence," she said.



Gianna Joachim, right, got a new bed designed to keep her safe and prevent her from eloping at night. She, her mom Chelsea and her dad, Brian, play in her room in the family's Howell Twp. home. Amanda Brown/ For NJ Advance Media

What now for Gianna and other kids like her?

Left untreated, 8-in-10 kids with autism who hurt themselves or others will continue to do so 20 years later, according to research cited by Autism NJ.

The shortage of programs for this population is "an urgent, mounting crisis ... due to its rapid increase in prevalence and the severity," according to The National Council on Severe Autism.

As the number of kids diagnosed with autism grows, families commonly endure months-long waits for workers who plan and deliver this therapy, according to experts in the field.

The number of trained therapists focused on ABA therapy is growing, but "the number of individuals diagnosed with autism also has grown and their need for services can be tremendous," said Kim Mack Rosenberg.

In addition, those workers who come to the home to carry out the therapy plans - registered behavioral technicians, who won't be licensed - aren't paid well for very difficult jobs, getting about \$20 to \$25 an hour. And in many cases, they are not adequately trained.

"There is a high turnover in the field," Christina Simmons, an assistant professor at Rowan University's Center for Behavior Analysis, Research, & Services, which admits about 40 undergraduate and graduate students a year in an effort to address the shortage of workers. "Competitiveness of salaries is certainly a consideration for our students."

But so is the challenge of the work itself, she said.

Before students even go into the field, the center provides virtual reality training through a state Health Department grant that allows their avatars to test out strategies on a virtual child. Then in the real world, the center sends students out in teams.

"It is a demanding job. It is certainly not easy work, especially as you increase the level intensity of the behaviors that you are working with," Simmons said.

Many school districts have behavioral therapists on staff, but as the child gets older and the behaviors worsen, intense interventions are needed right away, said Patricia Miller, the mother of a 23-year-old son with profound autism who leads the New Jersey chapter of the National Council on Severe Autism.

"From diagnosis to age 8 there are potentially some good services, like ABA-driven clinics. Once they hit 8 they get lost in the system," Miller said. When this individualized care tapers off, "those with profound needs begin to flounder and really suffer."

There are 3,143 professionals with advanced college degrees in New Jersey who are certified by a national accrediting board to practice applied behavior analysis - assessing children's needs, setting treatment plans and overseeing those who come to the home. They are stretched thin. There are approximately 66,000 children with autism in New Jersey, with varying degrees of need.

"Precious few behavior analysts have this highly specialized training," said Suzanne Buchanan, the executive director for Autism NJ who chairs the State Board of Applied Behavior Analyst Examiners.

The Murphy administration says it is aware of the shortage of therapists and is trying to address it.

In June, the state departments of Human Services and Children and Families launched a program to give 100 graduates \$50,000 breaks on student loans if they work as behavioral therapists for at least a year, according to Jason Butkowski, spokesman for the Department of Children and Families.

New behavioral therapy centers are opening, including one each in Morris and Burlington counties, he added. These additions "will make it easier for families to connect to the therapeutic resources their children need."

Under a law championed by Autism NJ and signed by Gov. Phil Murphy in 2020, behavior analysts will have to be licensed by the state in order to continue working in the field.

But the seven-member board only finalized the online licensing applications in July, according to a recap of that month's meeting. The state had licensed three applied behavior analysts as of Oct. 1, according to the state Division of Consumer Affairs.

The board also will update its website's FAQ section announcing that the public may file complaints against therapists on the state Division of Consumer Affairs **website**, Buchanan said during the meeting.

The framework for a regulated system of treatment for children with severe autism is on the horizon. However, time is running short for children who cannot wait.

Gianna's parents feel there is still time to keep her from winding up in a group home. She is only 7. And she's making progress with speech, using more words all the time.

But what hasn't changed is her lightning-fast mood swings and her outbursts of aggression with her mom and her 4-year-old brother, who is frightened of her at times. At night, after Gianna is zipped up in the Cubby bed, he will climb into bed with his parents and cling to them. He is a sweet but very nervous child, she said.

"I feel completely lied to. I feel outraged because we are the best state to deliver these services to children. Without behavior therapy I don't know what is going to happen to my daughter." Her greatest fear is Gianna will "wind up probably going into a hospital or a facility because she's only getting bigger and stronger."

Gianna "needs the help now. My daughter is an example of how we're just wasting time."

"What parents like us have been and go through on a daily basis is mind blowing. Our voices need to be heard."



Chelsea Cella waits for her daughter Gianna Joachim in the family's Howell Twp. home. Amanda Brown/For NJ Advance Media