

## A PARENT’S CRISIS

### Early intervention services cut across NY

#### Justin Murphy

Rochester Democrat and Chronicle USA TODAY NETWORK

Gamze Venable knew that *something* was the matter with her daughter, Adriana. She was still in diapers and non-verbal at age 3, banging her head on the walls and being hospitalized for dehydration after refusing to eat. But it wasn’t until the day she visited Mary Cariola Children’s Center in September 2017 that she accepted how much help Adriana really needed.

“I thought maybe she had some issues here and there, but I didn’t really realize until we walked into the school and Adriana was on the floor (refusing to move),” Venable said. “I said: ‘I really need a place.’ ... We couldn’t function as a family.”

It took more than a year for Adriana to get services, and only then because of a fortuitous opening at Mary Cariola. A year later she has a few words in her vocabulary and even sings from time to time. She



**Adriana Venable, 4, pats therapy dog Baily during a program at the Mary Cariola Children’s Center.**  
CARLOS ORTIZ/ROCHESTER DEMOCRAT AND CHRONICLE



interacts with her younger sister, who is well ahead of her developmentally.

That progress has been slowed, though, by inconsistent supplemental services. It took months to get an autism specialist and occupational therapist making home visits, then a change in school districts meant both were abruptly removed.

The Venables can't usually attend family functions because they know Adriana will cause a commotion. They have no lives of their own. It fatigues and frustrates them, hurts their marriage and their work lives.

It is a familiar feeling for many local parents of young children with developmental delays or other special education needs.

In 2017, parents, school districts and service providers all said the same thing: Monroe County and every other community in New York face a crisis in the shortage of special education services available for the youngest children.

A year later, they're all saying an already critical situation has gotten much worse.

One prominent prekindergarten program at Hillside will soon close, joining several other organizations that could no longer afford to operate at a deficit. Others have reduced the number of evaluations they provide, even as the need increases. Families seeking speech, physical or occupational therapy for their pre-school age children are more likely to find the news that none are available.

Things have deteriorated to the point that the Children's Institute is exploring a class-action lawsuit against New York state.

"It's dire," Children's Institute Director Dirk Hightower said. "We are not meeting benchmarks to evaluate children and provide services that the state requires we provide. If that happens repeatedly, it's an issue ... and it doesn't appear anything is being done."

Such a lawsuit would be unexpected for Gov. Andrew Cuomo, who said Oct. 31 in a meeting with the *Democrat*

RCSD tracks the number of preschoolers who spent time in the neonatal intensive care unit. It rose from about 15 percent in the early 2000s to nearly 20 percent in 2016-17, and a greater proportion of them stayed for more than three days.

Now 17 percent of preschoolers use prescription medication, compared to about 10 percent in the early 2000s.

"The need is getting more severe," said Karen Spawton, Rochester's coordinator for pre-K special education. "The educational system has not kept up with the medical community."

### **No state action**

The report from The Children's Agenda also recommended equalizing rates for Early Intervention (ages 0-3) and preschool services; consolidating much of the administrative work at the state level rather than making families sort through a maze of county, school district and non-profit entities; and establishing a statewide rate-setting methodology.

None of those items are any closer now to reality.

"I've talked with some legislators and they're sympathetic to the situation but I haven't heard of anything that's actually being done," Tracy said.

When asked about the funding shortfall Oct. 31, Cuomo responded that he hadn't heard about it. His budget director, Robert Mujica, said: "It's not a statewide issue. We're paying a lot of money to these providers. ... If there's an issue specific to here, we'll look at it."

That is contradicted by numerous providers and experts in Rochester and elsewhere, including the statewide early learning coalition Winning Beginning NY. In 2017 it reported a one-third decrease in Early Intervention funding since 2010 and warned that "experienced, high quality EI providers have shut their doors or stopped taking EI cases, making it difficult for children to access their mandated services in a timely manner in certain areas," including the North Country and New York City.

and *Chronicle* editorial board, that he hadn't heard of the problem at all.

Adriana Venable's story is typical: a delay of many months to receive an evaluation, then many more months to receive services that Gamze Venable said are now being rolled back under the direction of the Webster Central School District.

Webster spokeswoman Krista Grose did not comment on Venable's case but said the district is following students' individual education plans (IEPs) in all cases and "encourages open and ongoing communication with parents of all students regarding their IEPs and other educational matters."

Gamze Venable once had to quit her job after Adriana was kicked out of day care; now she is director at Generations Child Care in Fairport and welcomes Adriana there every day after the Mary Cariola program ends.

"It's a disaster 90 percent of the time," she said.

"My whole goal is to help this child so at the age of 40 she's not still living with us, not able to handle things. ... What do I do as a parent?"

### **Funding is insufficient**

The issue is complicated but far from new. It boils down to this: state reimbursement levels for special education services for children ages 0-4 have remained essentially flat, or even decreased, for more than 20 years.

Organizations that offer those services must do so at a loss or quit, leaving the schools and families that depend upon them in an increasingly tight bind.

In the Greece Central School District, Committee on Preschool Special Education chairwoman Sue-Ellen Tracy said that within weeks of the start of the school year she had already run out of slots to provide special education classroom services to 3- and 4-year-olds, whether at home or in a center.

"Each year, we're hitting a wall in terms of finding available services sooner," she said. "This is the soonest I've ever seen. ... It's a really frustrating situation and there's not a whole lot we can do about it."

Rochester-area providers have taken the lead statewide in addressing the issue. Part of that effort was a study earlier

A 2017 statewide survey of providers and school district coordinators showed that 22 percent of young children were not receiving the services they needed.

In a written statement, state Sen. Rich Funke said the Cuomo administration deserves the lion's share of the blame for being "AWOL on this topic." He supports additional funding, he said, but wants to ensure that more money in the budget equates to higher rates and is not just swallowed up in administrative costs at the state level.

State Assemblyman Mark Johns said he favors increased investment in early education through the budget as a way to stave off greater costs later in people's lives.

State Sen. Joe Robach, Assemblymembers Harry Bronson and David Gantt and Congressman Joe Morelle did not respond to requests for comment.

One thing that has changed is a new regulation allowing school districts to evaluate children with their own staff. That's not necessarily an appealing prospect, however, for schools where specialists are already stretched thin.

RCSD has already expanded its evaluation teams but faces the same workforce shortage as every other provider in the community.

"If I start another eval team, I'll just be hiring out of those same agencies and more of them will close," Early Education Director Robin Hooper said. "I don't think that helps us a lot."

The situation is hardly better elsewhere in the country, though some states, including Massachusetts, do have a more streamlined process. Stacy, from Greece, said parents who arrive here from the South marvel at how much better the access to services is.

Even from district to district in New York, access to resources can differ. That is why The Children's Agenda recommended more centralized control, and why the Venable family has found Adriana's path so discouraging.

They found the East Rochester school district competent, if slow; Fairport, excellent; and Webster, "the worst decision we ever made," in Gamze Venable's words.

"We moved five miles and all our services were taken away — it's a joke," she said. "We were already getting

this year by The Children’s Agenda seeking to determine the true cost of providing services to young children. It found, for instance, that physical therapy for children ages 0-3 should be reimbursed at \$147 an hour rather than the current \$86.

The Children’s Agenda collected more than 1,100 letters from 50 congregations in support of greater funding during its Children’s Interfaith Weekend in October and is partnering with several other organizations on statewide advocacy efforts. In the meantime, independent providers are trying to squeeze evaluations and service provision into their budget, and ultimately dropping out when it becomes too difficult. The latest casualty is Hillside Family of Agencies’ Crestwood campus, which will stop providing prekindergarten day services after June.

Catholic Family Center also announced in October that it would stop providing coordination services — helping families to navigate the complicated system — in January. It served about 200 families in 2018.

“Right now, the rate they reimburse is much less than what it actually takes to do the job,” Director of Children, Youth and Family Services Jennifer Berenson said. “We hung in there as long as we could, really. ... No one’s in this looking to make money, but you have to pay the people to do the work that needs to be done.”

Some of the increased need is a result of world-class neonatal care. Simply put, the premature infants whose lives are saved at birth often need intricate care when they reach school age.

the help we needed. ... I’m afraid all our progress will be a waste.”

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**Special education teacher Tracy Webster conducts a class with four-year-olds at the Mary Cariola Children’s Center.** CARLOS ORTIZ/ROCHESTER DEMOCRAT AND CHRONICLE

**Najir Jones, 4, tries on a hat during a program at the Mary Cariola Children’s Center.** CARLOS ORTIZ/ROCHESTER DEMOCRAT AND CHRONICLE

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**Karen Spawton**

*Rochester’s coordinator for pre-K special education*