

Preschoolers caught in special ed crisis

Crisis

WATCHDOG

“WE’VE DONE A *serious disservice* TO KIDS WITH DISABILITIES IN THIS STATE ... AND YOU *see the impact* WHEN THEY GET TO KINDERGARTEN.”

DAN WHITE, MONROE 1 SUPERINTENDENT

Delays in early interventions put hundreds at disadvantage

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Everything Leilani Mohamed says, her mother writes down in the margins of a notebook. “I’m OK.” “Watch this.” “Look Mom, sky so pretty.”

Leilani is 5 years old; her collected speeches fit along the edges of notebook pages because she was diagnosed three years ago on the autism spectrum. In between the things Leilani has said, Geanna Mohamed writes down the services her daughter is supposed to get.

Speech services, physical therapy, occupational therapy. When Leilani gets them, she blossoms, her mother said, “like a flower in its natural state.” She greets people by name, sings songs and walks like a crab.

When Leilani doesn’t get the help she needs, though, she wilts.

Leilani’s story encapsulates a crisis in early education in New York that has been brewing for years, leaving young children foundering when simple interventions could prepare them for success.

Hundreds of young children in Monroe County, and more across the state, are facing delays in receiving the early medical and educational interventions to which they’re entitled, putting them at a developmental disadvantage and greatly increasing the chances they’ll need more, costlier help later in life.

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Geanna Mohamed has found it hard to get needed services for her daughter, Leilani, 5, diagnosed three years ago on the autism spectrum. Leilani's story encapsulates a crisis in early education in New York that has been brewing for years, leaving young children foundering when simple interventions could prepare them for success.

OLIVIA LOPEZ/@OLOPEZ4/STAFF PHOTOGRAPHER



Schuyler Peck, 5, exercises to strengthen his core muscles. His mother, Sharon, noticed he struggled to sit up or walk. His pediatrician recommended a gross motor evaluation, but it took eight months before the Rochester City School District found a specialist to see him.

JAMIE GERMANO/@JGERMANO1/STAFF PHOTOGRAPHER

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In the 2016-17 school year alone, nearly 400 3- and 4-yearolds in Monroe County were not evaluated for developmental delays within 60 days of their referral as required by law, according to local school district records.

That is more than a quarter of all children who were referred and that number is almost certainly underreported.

Those who are evaluated often struggle to get the services they're prescribed. This, even as the Rochester community has unanimously embraced early education as key to eradicating poverty, based on the findings of innumerable researchers.

The simplest explanation is that there are not enough special education teachers, speech pathologists and physical therapists to meet the demand. According to local providers and schools, though, that problem has been driven in large part by an inadequate, tardy and convoluted reimbursement process at the state level.

Simply put, they say, there isn't enough money for special education and interventions for children from birth to age 5. Indeed, a number of local organizations that evaluate or serve children have left the field in the last several years because they can't break even.

One of them is Monroe 1 BOCES, which was serving between 100 and 140 children a year until 2013-14, when annual operating deficits between \$10,000 and \$100,000 became too much to swallow.

"Even the (providers) that are still open will tell you — they're limping by, at best," Monroe 1 Superintendent Dan White said. "We've done a serious disservice to kids with disabilities in this state ... and you see the impact when they get to kindergarten."

In prekindergarten, Leilani Mohamed's speech therapy sessions were canceled regularly because no specialist was available. She switched to Stepping Stones, the program for students with disabilities, and made wonderful progress until her regular speech therapist left and was not replaced for months.

Then Stepping Stones closed for good in late June, unable to continue financially. On the same day, Geanna lost her job. She'd missed too much time trying to arrange care for Leilani, who after a months-long gap in services had regressed to spitting and kicking.

"The little bit of language that Leilani had was gone," Geanna said. "My child wasn't even calling me 'Mom.'"

'Getting worse and worse'

Even in the acronym-laden world of education policy, special education for children under the age of 5 is devilishly complex.

For children younger than age 3, it is called Early Intervention (EI) and administered by the local county government. For children ages 3 and 4, services are coordinated through the local school district, though the school generally does not provide them.

Reimbursement comes, in different proportions, from the county and the state.

Whether for EI or preschool special education, the actual work — evaluating children for speech or physical delays and working one-on-one to correct them — is mostly done by a number of local independent organizations who contract with the county or school district.

It is those contractors, including Mary Cariola Children’s Center, Rochester Speech and Hearing Center and Bright Start Pediatrics, that have raised the most urgent alarm over the funding shortage.

Mary Cariola stopped doing EI because of funding, but nonetheless lost about \$300,000 last year on evaluations and prekindergarten services, including self-contained special education classrooms, its superintendent, Christine Sheffer, said.

The agency has set ambitious goals it must achieve to break even on evaluations this year, but Sheffer did not sound optimistic about meeting them.

“We really believe we have an obligation to do evaluations, but the reimbursement rate doesn’t support the amount of work they take,” she said.

The state reimburses providers a baseline of \$376 for every child they evaluate, but operators say that doesn’t cover their costs, and the number hasn’t increased for years. Each evaluation usually includes a consultation with at least three or four highly trained specialists, including a speech pathologist, physical and occupational therapist and a special education teacher.

“Evaluations are complex, and you can’t just push them through the pipeline, because they’re kids,” Sheffer said.

The true cost of service is difficult to quantify; most providers could more easily say how much money they lose each year overall. Advocacy organization The Children’s Agenda plans to analyze the question this fall, hoping its findings will make it easier to lobby for more money.

With relatively few local evaluators, Monroe County and local school districts are in a bind.

The state has regulations about how soon a child must be evaluated after being referred — 60 days for preschoolers, 30 days for EI — but it is sometimes impossible to find an evaluator within that time frame.

More than half of Monroe County school districts were in less-than-complete compliance with the 60-day timeline in 201617, sometimes by an alarming margin.

Rush-Henrietta was on time with just 42 percent of its 111 referrals; East Rochester and West Irondequoit were both at 63 percent.

The Rochester City School District met the deadline on 51 percent of its 488 referrals, by far the most of any local school district.

In response, it has begun doing evaluations in-house, a service it expects will require a \$500,000 annual subsidy.

“It was getting worse and worse, and there were no other options,” the district’s early education director, Robin Hooper, said. “You can’t just come to a stand still and do no evaluations.”

That change in policy came too late for 4-year-old Schuyler Peck, whose mother had noticed he struggled to sit up or walk. His pediatrician recommended a gross motor evaluation, but it took eight months before RCSD could find a specialist to see him.

The specialist determined that Schuyler had weak core muscles. That explained why he always wanted to be held rather than sitting on his own.

“I didn’t realize that sitting up for him was so difficult,” his mother, Sharon Peck, said. “He wants to lean on you and have you provide the stability.”

By the time Schuyler was connected with a therapist, there were only three weeks left in the school year. His mother did what she could over the summer, but resuming those services will be crucial as he begins school this fall.

“He’s a smart kid and I didn’t want him to be discouraged in school if he doesn’t have the stamina to stay seated on the rug,” Sharon Peck said. “I don’t want his physical needs to turn him off to learning.”

To make matters worse, in an anonymous 2015 statewide survey by ROC the Future, more than a third of the 247 responding school districts said they purposefully delay obtaining parental consent for an evaluation to keep the 60-day clock from starting, thereby decreasing the chances of being caught out of compliance. That delay also distorts the data on the extent of delays in service and is one reason why the extent of the issue is likely underreported.

For Early Intervention, the Monroe County Department of Health reported a 92 percent compliance rate for 2015 on about 180 referrals and said it was lower than that in 2016 due to evaluator capacity issues.

“In the current state, it’s impossible to get them all done,” said Sue-Ellen Stacey, who coordinates pre-K special education in Greece. “We’re at the mercy of the providers.”

Solution? Raise reimbursement rates

When providers, school administrators and advocacy groups are asked the best way to solve the problem, their answer is unanimous: Raise the reimbursement rates.

That was the message of a 2007 report by a governor's statewide task force; of a 2009 study by Monroe 1 BOCES; of a lobbying excursion that local advocates, including the Rochester City School District, took to Albany this spring; and of a recently completed study of early education workforce issues by ROC the Future.

"That is the 800-pound gorilla that we've got to deal with, is getting realistic reimbursement rates that reflect the true cost of service," said Rick Costanza, a Monroe Community College education professor who led that ROC the Future study.

A survey of local lawmakers showed uneven support for increased spending on early special education to raise reimbursement rates. State Sen. Joe Robach, R-Greece, who sits on the education committee, said in a statement only that he would "(look) to find a way in which the state can work with providers and municipalities to ensure that these services are available to the children who need them."

There have been a number of abortive attempts at legislative fixes, including a vetoed bill by state Assemblywoman Ellen Jaffee, D-Suffern, Rockland County, to further study the Early Intervention reimbursement process.

"Legislators are well aware of the problem, but nothing's happening in Albany," RCSD's Karen Spawton said.

Besides additional funding, some other partial solutions exist. To address the shortage of speech pathologists, several people said New York should create the licensed position of speech pathologist assistant, which exists in many other states and can help alleviate the crushing workload without requiring people to go through as rigorous an academic program.

One key reason why there aren't more speech pathologists locally is that there is only one local college program to train them.

It is at Nazareth College; the State University College at Geneseo had one until 2013-14, but canceled it due to high costs and difficulty recruiting faculty, among other things.

Some people also mentioned increased tuition assistance or loan forgiveness programs for people going into early education intervention services as part of the solution. One problem is that physical and occupational therapists often leave early education for sports medicine or nursing homes, where they can earn significantly more money.

"If you're going to take out loans to go to college for six years, you'll graduate with an expectation of a certain salary to pay those loans back," RCSD's Robin Hooper said. "The odds you go into pre-K special interventions services are pretty low."

Massachusetts is considered an exemplar for the way it operates Early Intervention. As in many other states, it does not have a separate pre-K tier; instead, children go directly from Early Intervention to getting services at school.

There is also a requirement in state law that the Legislature review statewide reimbursement rates every two years.

Even there, though, advocates say there isn't necessarily enough funding available to adequately intervene with all children who require it.

“I think early childhood services across the board are challenging to fund,” said Kelly Brennan, a regional representative on the Massachusetts Early Intervention Consortium. “There’s just not a recognition of their value among the people setting the rates.”

For parents whose children need help, that value couldn’t be clearer.

Max Paolini of Greece still wasn’t talking by age 2. At day care he threw toys and refused to interact with the other children; his teachers grew exasperated and called his mother, Lisa Paolini, nearly every day asking her to come get her son. Eventually, she was told he couldn’t return.

The pediatrician told Lisa to get Max evaluated for a speech delay, and she managed to get an appointment quickly. He was diagnosed with a speech delay and switched to Stepping Stones, where he got regular therapy.

“We were crying with happiness the first day,” Paolini said. “They were so patient with him and so caring and so genuine. ... We didn’t know there were special schools like that.”

Since the closure of Stepping Stones, Max’s family has pieced together services through home visits from other providers.

Hooper and Karen Spawton from RCSD have been two leading local advocates on the issue, in part because they see what happens when the system fails a child.

“The part that’s extremely frustrating is, we know the impact this can have on kids’ longrange trajectory,” Hooper said. “Every politician at the federal, state and local levels says the highest importance is for kids to succeed at the highest level, with Common Core tests and STEM and whatnot — why are we not providing needed interventions when kids are born until they’re 5 years old?”

“If we want a kid to reach a goal, but we let them languish until they’re 5, they’re not going to get there.”

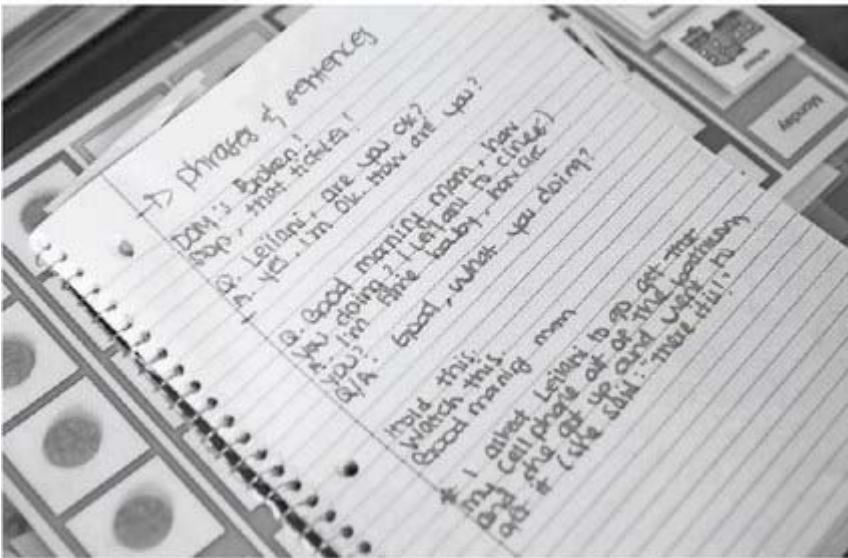
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Schuyler Peck, 5, right, and his twin brother, Asa, race along the sidewalk to help him strengthen his core muscles. Schuyler has been diagnosed with core muscle weakness — it explained why he always wanted to be held rather than sitting on his own — and his mother fears that he will fall behind in school.

JAMIE GERMANO/@JGERMANO1/STAFF PHOTOGRAPHER



Leilani Mohamed is 5, but just started talking last summer. Her mother uses a notebook to keep track of new phrases and things she says. When Leilani gets therapy, she blossoms, her mom says. When she doesn't, she wilts.

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