

RI EDUCATION

Infants, toddlers face long wait for crucial Early Intervention services in R.I.

“The child gets on the waitlist and by the time you’re able to get them, they’re within a year of aging out,” a provider told the Globe. “And we know how critical it is to get to them in those early years.”

By **Steph Machado** Globe Staff, Updated September 24, 2023, 7:31 p.m.



Olivia Ippolito blows bubbles with her 2 1/2-year-old son, Levi, as his occupational therapist, Kayla, looks on. Federal law requires an initial meeting take place within 45 days. But it took more than nine months for Levi to get off the waitlist and be evaluated, forcing him to lose time for crucial interventions. MICHAEL FRANK/RHODE ISLAND PBS

This story was produced in collaboration with Rhode Island PBS Weekly. [Watch the episode here.](#)

PROVIDENCE — Olivia Ippolito has long been worried about her son Levi's development.

Levi, who was born in April 2021, was late to walk and struggles with speech. He's hard of hearing, has several medical problems, and an overall diagnosis of global development delay. At 2-and-a-half, Levi is currently closer developmentally to an 18-month-old.

"He can say a lot of things, but they don't make sense together," Ippolito explained in a recent interview with the Globe, while Levi played nearby.

Ippolito said Levi's pediatrician referred him to Early Intervention last September. The federally mandated program is run through the state of Rhode Island, providing children who have developmental disabilities from birth until age 3 with key services — at no cost to families — that can help them catch up to their peers. The program, experts say, can prevent children from needing further special education as they grow.

But Levi couldn't get in.

"Sorry, we have a waitlist," Ippolito recounted being told last fall. In the meantime, she got pamphlets in the mail detailing developmental milestones Levi should have been achieving. (He wasn't.)



RHODE ISLAND PBS WEEKLY

The Long Wait

Clip: Season 4 Episode 39 | 8m 26s

“I was really mad about it,” she said. “But what am I going to do, report them to the government? They are the government.”



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Federal law requires an initial meeting take place within 45 days. But it took more than nine months for Levi to get off the waitlist in late June of this year, when he was finally evaluated and determined to be eligible for the program.

Levi is just one of hundreds of children 3 years old and younger waiting far longer than the legal amount of time allowed for Early Intervention in the past two years in Rhode Island, prompting concerns about long-term implications for children who do not get help at an early age. The crisis began in 2021, and the state still has not been able to eliminate the waitlist.

As of Sept. 15, there were 862 infants and toddlers waiting for an initial evaluation meeting, according to Kerri White, the spokesperson for the R.I. Executive Office of Health and Human Services, where the Early Intervention program is housed. (The number of children on the waitlist fluctuates; there were 691 on June 30, then the number rose to 912 in mid-August after a spike in referrals.)

I here are children on the wait list f Early Intervention.

Source: R.I. Executive Office of Health and Human Services • As of Sept. 15

 Interactive content by Flourish

Roughly half of those children have been waiting longer than the 45 days required by law, White said. And there may be even more children waiting — the number does not include those who have had their initial meeting to create a plan but are not yet receiving the services they need.

Levi finally started receiving occupational therapy at home this summer, and is slated to start speech therapy through the Early Intervention program soon.

“I didn’t realize it would take that long and I would have to hound people for that long,” Ippolito said. But after waiting all that time, Levi will become ineligible for Early Intervention in April, when he turns 3. (Public school districts are required to provide special education services starting at age 3.)

Before 2021, according to state officials, there were no children waiting longer than 45 days. Advocates say there shouldn’t be a waiting list at all.

“The number should be zero,” said Leanne Barrett, the senior policy analyst at Rhode Island Kids Count. “I don’t think we should have any waitlist. There should be no children waiting longer than 45 days.”

‘If you think it’s that important, pay for it’

Rhode Island uses nine private providers to deliver Early Intervention services to infants and toddlers. The largest one is Meeting Street, a nonprofit organization in South Providence that is known for its special education programs that serve children from birth until adulthood.

“They’re waiting a really long time,” said John Kelly, the president of Meeting Street, in an interview with Globe. “It’s criminal. It’s really awful.”

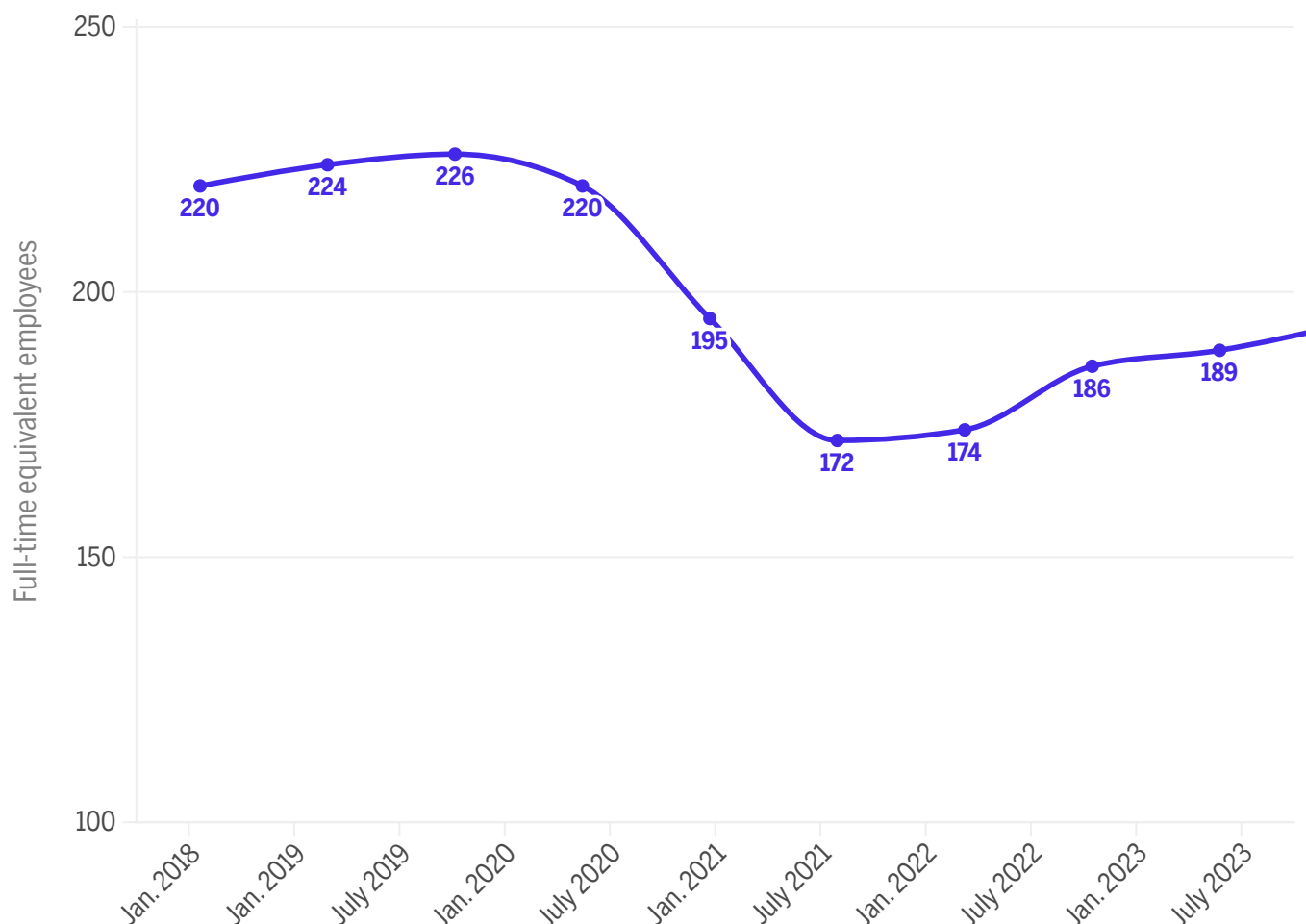
Kelly said Meeting Street currently has 470 children on its waiting list for Early Intervention, and is not in compliance with the 45-day rule in federal law. He says the nonprofit simply does not have the staff to serve all the children who are waiting.

“The child gets on the waitlist and by the time you’re able to get them, they’re within a year of aging out,” Kelly said, briefly getting choked up. “And we know how critical it is to get to them in those early years. That’s painful.”

Data from the agency that runs the program shows the number of employees working in Early Intervention programs dropped during the pandemic, going from a high of 226 full-time equivalent employees in July 2019 to 172 by January 2021.

The staffing numbers have been recovering, but are still below 200 employees across the nine providers, even as the number of children being referred to the program continues to grow.

Rhode Island Early Intervention Staffing Levels



Source: R.I. Executive Office of Health and Human Services • STEPH MACHADO/GLOBE STAFF

 A Flourish chart

“We’re short staffed,” Kelly said. “Everyone’s short staffed. And not everyone wants to hear it, but that comes down to money.”

Physical, occupational and speech therapists can often get higher-paying jobs in hospital and school settings, which are competing for the same talent as Early Intervention providers, Kelly said. He said the nonprofit pays therapists between \$63,000 and \$80,000 per year, and candidates are turning down job offers for better pay elsewhere.

Since parents do not pay anything for their children to access the program, Meeting Street and other providers are paid through the child's health insurance, either Medicaid or private insurers.

Rhode Island raised its Medicaid reimbursement rates by 45 percent in 2022 — the first increase in two decades — after the crisis in the program emerged in 2021. Kelly said the money has helped raise wages, but still isn't enough to cover costs.

“So the federal government and the state have said this is a mandated entitlement, we're just not going to pay for it all,” Kelly said. “I think it's outrageous. ... If you think it's that important, pay for it.” Meeting Street solicits private donations to supplement the money it gets from the government and health insurers.

Governor Dan McKee's administration repeatedly declined to provide anyone to be interviewed about how they are addressing the crisis in the state's early intervention system. Via email, spokesperson Kerri White pointed to several actions that have already been taken, including directing more than \$15 million in COVID relief funds to early intervention providers, raising the Medicaid rates in 2022, and leading a workforce campaign to recruit more staff.

McKee did not include the Medicaid rate increase in his budget proposal in January 2022, however, despite a request to do so from his health and human services agency. The rate increase was added in by the General Assembly before passage.

Kelly said Meeting Street used their allocation from the American Rescue Plan Act to give retention bonuses to staff and additional salary bumps beyond the annual cost-of-living increase.

Barrett said the Right from the Start Campaign, a coalition of eight organizations including Kids Count, is asking the McKee administration for another 30 percent Medicaid rate increase in next year's budget, along with an annual cost-of-living adjustment to the rate.

The group sent its formal request to the Executive Office of Health and Human Services earlier this month. Barrett said raising the Medicaid rate has the additional benefit of requiring private insurers to pay more, because of a state law requiring health insurance plans pay at least the Medicaid rate for early intervention services.

The advocates are also asking for early intervention workers to be added to an existing state pilot program that provides free child care to child care workers, helping parents of young children stay in the workforce.

White said EOHHS has not yet determined whether it will include another Medicaid rate increase in its annual budget request, which is due to McKee on Sept. 30.

House Speaker Joseph Shekarchi said in a statement to the Globe he would be reviewing the recent report on provider rates from the Office of the Health Insurance Commissioner before weighing in on any additional rate increases.

R.I. and Mass. not in compliance with federal law

While Rhode Island is not alone in struggling to attract and retain staff for early intervention, plenty of states are managing to comply with federal law.

According to the U.S. Department of Education, 24 states plus Puerto Rico are currently in compliance with the section of the Individuals with Disabilities Education Act that governs early intervention.

In New England, it's a mixed bag. New Hampshire and Connecticut are both meeting the requirements of the law, while Massachusetts and Maine are listed under "needs assistance for one year," according to the federal agency's determinations issued in June 2023.

Rhode Island and Vermont are listed under "needs assistance for two or more consecutive years."

Only two states received a determination worse than Rhode Island's this year: Indiana and Mississippi, which are both listed under "needs intervention."

Ann Scales, a spokesperson for the Massachusetts Department of Health, said the commonwealth "does not permit waitlists," and more than 99 percent of children receive early intervention services within 30 days.

The reason for its latest federal determination, Scales said, is that Massachusetts did not evaluate enough children when they exited early intervention and transitioned to preschool. She said the issue is being rectified with providers.

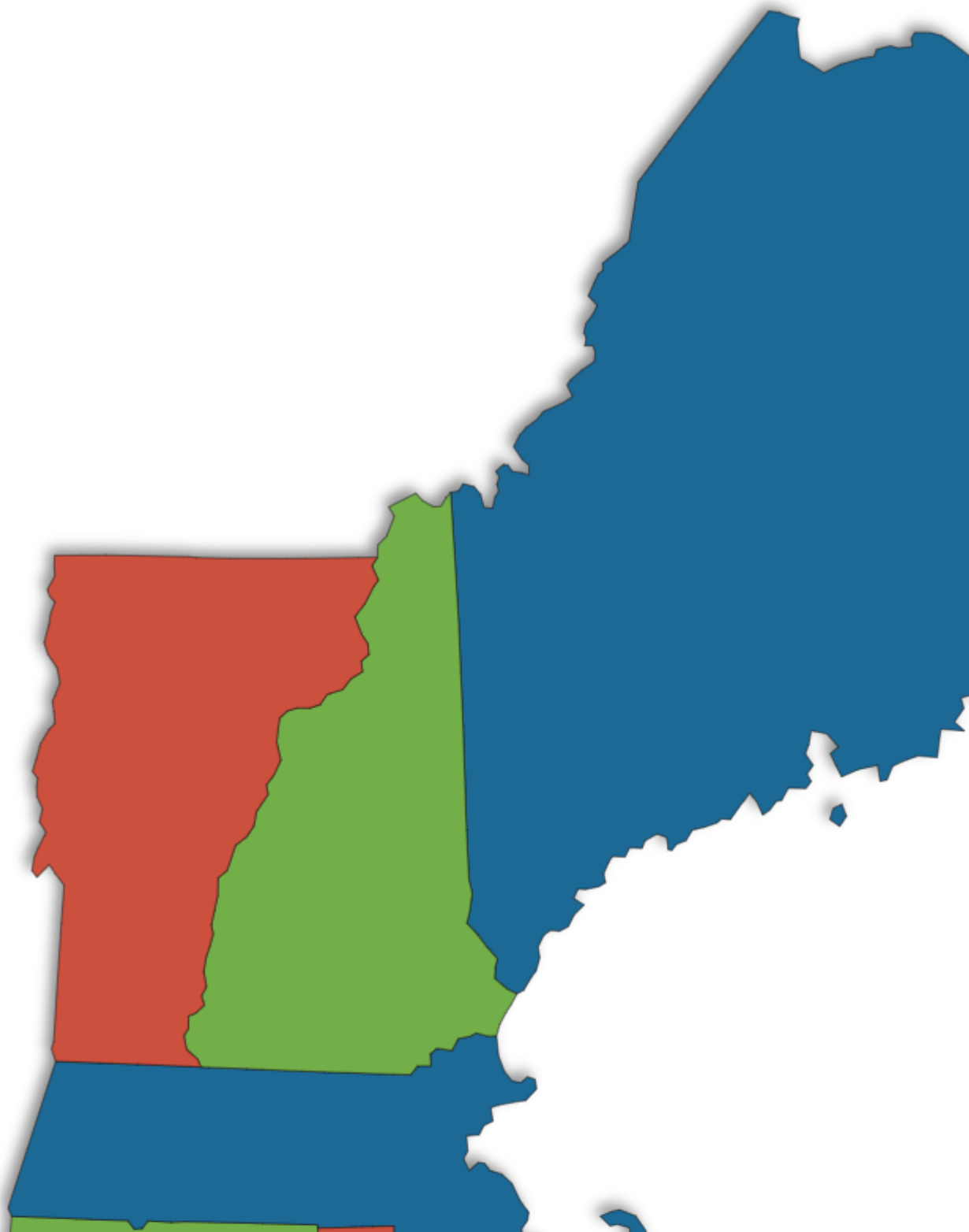
Two New England states are meeting federal early intervention program requirements

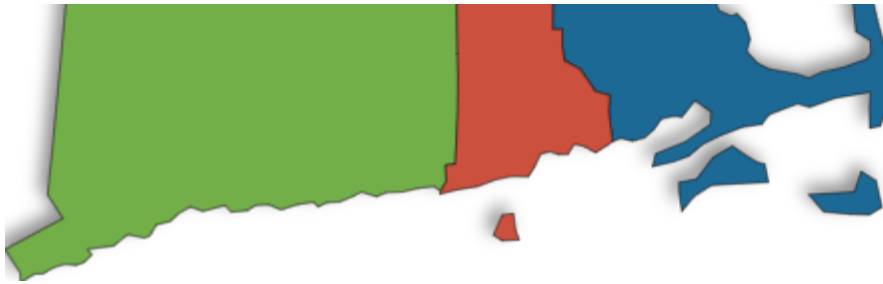
Early intervention programs are designed to support children under 3 with developmental delays and disabilities.

Meets Requirements

Needs Assistance

Needs Assistance (two or more consecutive years)





Source: IDEA Individuals with Disabilities Education Act, US Department of Education
ALEXA GAGOSZ/ GLOBE STAFF

✿ A Flourish map

In a letter to acting health and human services secretary Ana Novais in June, the U.S. director of the office of special education programs Valerie Williams said Rhode Island was required to announce the enforcement action to the public, including in a notice to media outlets. (No such notice has been sent out, but White said the state has until mid-October to do so.)

Federal law also requires states provide public updates about their Early Intervention program through a public body called the Interagency Coordinating Council. The meetings are not easy to find if you don't already know where to look. In the state's open meeting portal on the R.I. Secretary of State's website, the most recent meeting listed under Interagency Coordinating Council was posted in 2011.

The actual recent meetings, including one held last week, are listed under "Health and Human Services, Rhode Island Executive Office of," but not under the name of the actual public body.

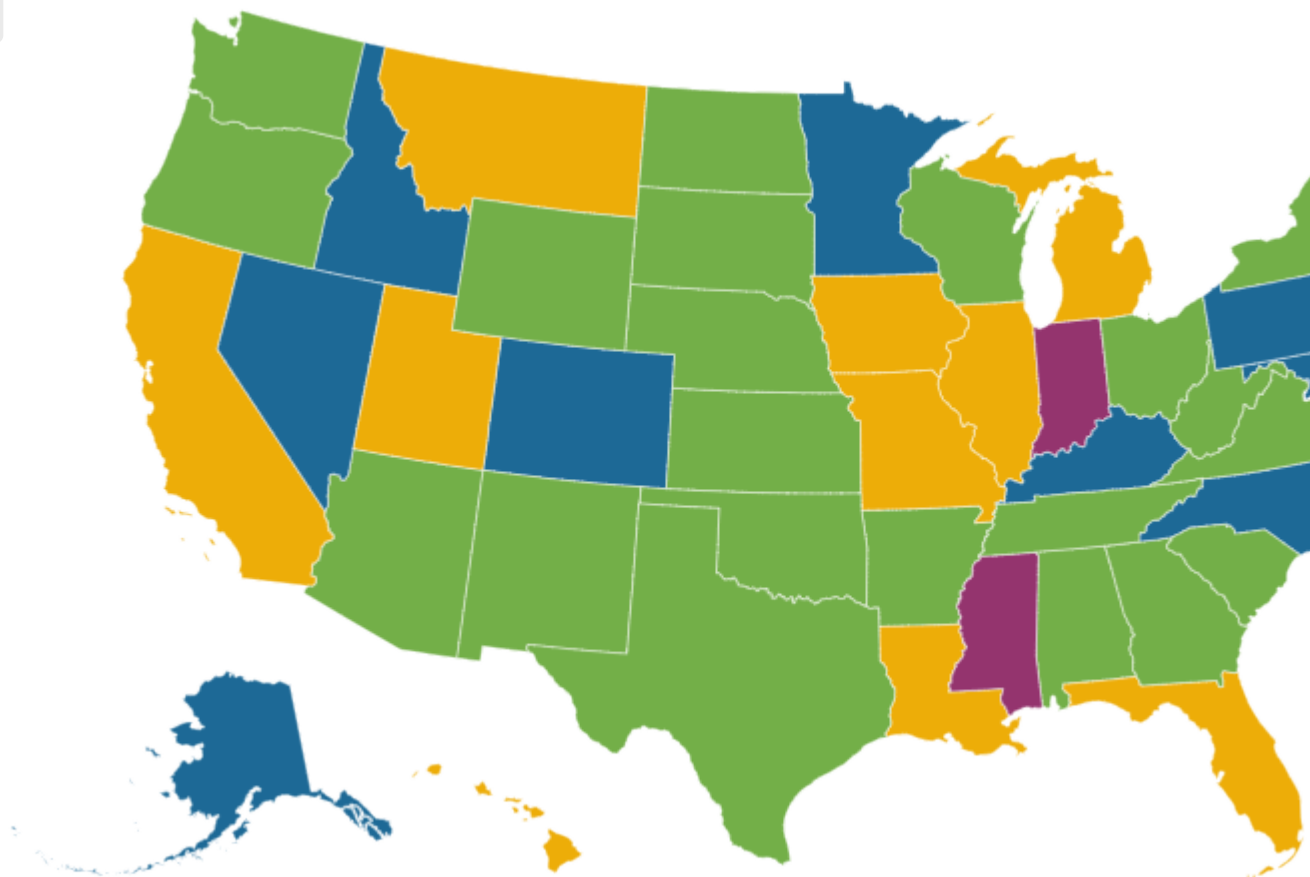
Asked about the meeting notices, White said state officials would work with RIPIN, the nonprofit that manages the meetings, and the secretary of state's office to make the postings more clear moving forward.

Nearly half of US states meet federal requirements in providing early intervention programs

Meets Requirements
Needs Intervention

Needs Assistance (one year)

Needs Assistance (two or more consecutive years)



Source: [IDEA Individuals with Disabilities Education Act](#), US Department of Education
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‘It’s very demoralizing.’

Barrett said failing to intervene at an early age, before a child starts school, is like trying to start a basketball game already 20 points behind.

“It’s very demoralizing,” Barrett said. “It’s very hard for the kids, or the basketball team, to have the ability to close that gap.”

The early intervention crisis is already bleeding into the special education system, Barrett noted, including in Providence where [hundreds of preschool-aged children](#) are waiting to be evaluated for special education.

Public school districts are required to serve children with special needs starting at age 3, a task that's becoming more difficult in light of both the staffing shortage and the early intervention delays.

A class-action lawsuit filed in response to Providence's failure to provide pre-K special education [was recently settled](#). The backlog of children waiting to be evaluated has not yet cleared.

Ippolito says she fears the effects Levi's long wait will have on his future development. "It's a very tight window," she said.

Their situation has already had practical effects. While waiting for early intervention services earlier this year, Levi was told he had to leave his daycare center, which said it couldn't provide for his needs with its current staff-to-student ratio.

As a single mom, Ippolito couldn't go to her job without childcare for Levi. She works as a licensed practical nurse, helping other families whose children have complex medical needs.

"There's a whole family that's going to suffer because I don't have anywhere to send him to daycare," Ippolito said in August. "Because I can't work."

Ippolito recently got Levi into a private daycare, where his new early intervention providers can visit to work with him directly. And while the center is costing her a large chunk of her income, she can at least go back to work.

She proudly noted that while Levi still isn't regularly using two-word combinations, he recently mastered the phrase: "love you."

Asked what she would say to state leaders who are responsible for fixing this system, Ippolito did not mince words: "Why do you think that my kids aren't worth it?"



Levi Ippolito, 2 1/2, looks at a tablet at his home in Providence. Federal law requires an initial meeting take place within 45 days to determine if a child needs early intervention services. But it took more than nine months for Levi to get off the waitlist and be evaluated, forcing him to lose time for crucial interventions. MICHAEL FRANK/RHODE ISLAND PBS

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