

## Families of special needs children wait for therapy

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CHICAGO – Alexander watches “Paw Patrol” with fervor, bowls his baby brother over with hugs and does everything with gusto.

What the 3-year-old West Chicago toddler can’t do yet is speak more than a few words. His balance is wobbly, and he isn’t able to let his preschool teachers know when he’s hurt or scared.

When his mother, Hilda Garcia, had him tested, the youngster qualified for five therapies through a U.S. program dedicated to treating developmental delays in babies and toddlers – treatment designed to help Alexander develop the tools he needs to thrive.

The relief she felt in identifying what he needed was short-lived.

The federally mandated Early Intervention program is plagued by chronic staffing shortages nationwide, leaving thousands of desperate parents frustrated: They know their children need support, they’re aware of proven therapies that could make a difference, but they have to wait for months to get the help they need.

After 14 months of phone calls, hours of research and pushing herself to the limit with work and child care, Garcia finally landed an in-person Early Intervention appointment, but even then she couldn’t get Alexander all the therapies he needed. She tears up as she recounts how overwhelming the fight to secure

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access has been.

“I didn’t have any support,” she said.

### ‘The earlier, the better’

Early Intervention was created in 1986 to address developmental delays in children like Alexander as soon as possible. About one in six children in the U.S. has at least one developmental disability or other developmental delay, according to the U.S. Centers for Disease Control and Prevention.

Since all U.S. states and territories accept federal funding for Early Intervention, they are obligated to provide services to kids who qualify under the Individuals with Disabilities Education Act.

But providers are scarce in almost all states. Some children wait months or years for the care they need, and many age out of the program before they access any services at all.

The COVID-19 pandemic worsened chronic staffing shortages, in part because many providers didn’t want to risk infection by entering families’ homes, even when restrictions on in-person visits were lifted, according to Maureen Greer, the executive director of the Infant and Toddler Coordinators Association, which supports the Early Intervention system nationwide.

For similar reasons, families were also less likely to request in-person help during the pandemic. But now the number of children seeking services has rebounded, and states are struggling to find the staff to meet the

needs of families with young children with disabilities, according to Katy Neas of the U.S. Department of Education.

Service delays in Illinois, where Alexander lives, nearly doubled in 2022, according to Chicago-based early childhood advocacy organization Start Early. Waitlists – technically not allowed since all eligible kids are entitled to Early Intervention – have increased dramatically, and thousands of providers have left the field, according to the Illinois Department of Human Services.

When children turn 3, the responsibility for providing special education services shifts from Early Intervention to school districts. But those systems are understaffed and booked up, too, according to speechlanguage pathologist Sarah Ziemba, an Early Intervention provider in Peoria, Illinois.

Waiting means skipping precious months of development, while acting early saves money on special education and other services later in life.

“Research really supports that the earlier, the better. And so when we miss those opportunities to help them at those younger ages, sometimes we are limiting their potential into adulthood,” said Ziemba.

Families with private insurance can opt to pay for therapy appointments outside the Early Intervention program, but those without the means can be left behind, according to Ziemba.

“In a way, Early Intervention is contributing to some social inequity,” she explained.

Research supports her assessment. A report published this year by the National Institute for Early Education Research found that Asian, Hispanic and Black children are less likely to receive Early Intervention and Early Childhood Special Education services than white non-Hispanic children.

“For Black children, the disparities in access to services are especially large and cannot plausibly be explained by differences in need,” the report says.

Income also plays a role, said lead researcher Allison Friedman-Krauss.

“Poorer states are serving a lower percentage of children, so really suggesting that there is a problem there,” Friedman-Krauss said.

But there is no way to attract more providers without better wages, Ziemba explained. Early Intervention providers in Illinois are government contractors, meaning they get no health benefits or paid time off, and they can effectively double their salaries by working in other settings such as hospitals, schools or nursing homes.

“People are just done with it, and it has gotten worse even in the last two months,” Ziemba said in late July. “I really feel like we’re kind of seeing the implosion of the whole program.”

As families lose access to the free or reduced-cost therapies, pressure builds on schools to pick up the slack, but they’re short on special education teachers, too.

“In the long term, we’re seeing kids fall farther and farther behind,” said Ziemba, who has done this work for nearly 25 years.

Illinois Gov. J.B. Pritzker signed a budget in June giving Early Intervention providers a 10% raise. That helps, Ziemba said, but likely won’t make up for the impact of inflation and may not be enough to slow the steady exodus of workers. She and another provider say wages were stagnant for years.

In July, the administration announced a retention program designed to reward tenured Early Intervention providers, interpreters and service coordinators with payments of up to \$1,300 to stay in the field.

“We remain committed to giving our service providers the support and resources they deserve for caring for our state’s children,” said Alex Gough, a spokesperson for the governor’s office.

The impact therapy can have is palpable. Lindsey Faulkner, a mother of four living in Peoria, got in-person speech therapy sessions for her 2-year-old daughter, Aria, within a month of her referral. She raves about the difference she has seen in her child after a year of working with therapist Megan Sanders.

“She was an entirely different kid a year ago,” Faulkner said.

Early on in their sessions, Aria zoomed around the room. Now, Aria can sit and engage with Sanders for most of the session. She looks Sanders in the eye more often, responds to her gentle guidance and is starting to use sign language.

“We’ve come a long way,” Sanders said. “My goal throughout is just to make her more able to express herself.”

When Aria was about a year old, Faulkner noticed that words the toddler had been using started to disappear. “She began screeching for everything that she wanted rather than asking us for help or gesturing.”

Aria qualified for speech, developmental and occupational therapy, and was diagnosed with autism when Faulkner was finally able to secure an appointment with a developmental pediatrician, 2 1 / hours away in St. Louis. Although Aria started speech therapy

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promptly, she has been on the waitlist for developmental therapy for more than a year.

Faulkner was “floored” when she learned about the wait times.

“You need to get answers for your child,” she said. “But here, now you have to sit and wait.”

Early Intervention providers and service coordinators, who connect families with therapists, are woefully underpaid, according to Darcy Armbruster, a physical therapist who serves DuPage County near Chicago and has worked in the Early Intervention program for 11 years.

Armbruster said it would make more financial sense for her to quit Early Intervention, but she stays because she loves the relationships she builds with families. Still, she has a child of her own to care for, and a mortgage to pay. Passion and job fulfillment don’t pay the bills.

“Every month I have to sit down and reevaluate where I am and if I can keep going and doing this,” she said.

### **For parents, getting help can feel ‘like another job’**

Hilda Garcia’s son, Alexander, qualified for five Early Intervention therapies in 2021 – physical, occupational, developmental, behavioral and speech. But the family waited more than a year before he received any of those services in person.

While they waited, Garcia signed Alexander up for virtual therapy, which didn’t start for more than six months. But virtual appointments weren’t effective, especially for physical therapy.

Garcia tried to do the exercises with her toddler herself, but it never seemed to work. Finally, they were able

to secure an in-person appointment through a private provider. They never made it off the Early Intervention waitlist. The therapist could tell much more by interacting with her son in their home.

“His lips were not able to move the way they should so that speech can come out,” Garcia said.

Garcia, meanwhile, was juggling child care, work and the almost full-time advocacy needed to get Alexander what he needed. “It feels like another job,” she said.

Garcia, who speaks English, is part of a primarily Spanish-speaking community in West Chicago, and she knows many parents can’t advocate for their kids in a second language.

“I can’t imagine somebody else going through what I went through without speaking English,” she said.

Translators are available, but that adds another layer of complexity to an already onerous process. Communication cuts into hourlong therapy sessions, leaving less time for actual therapy, she explained.

Garcia worries about Alexander. She knows he’s missing vital tools. She is concerned about his safety because he struggles to communicate and has issues with balance.

Just this summer, she said, another child pushed him off a playground set. A report from the school described his injuries as a scratch, Garcia said, but he continued to cry out “Mama, mama” and point to his back.

She gave him Tylenol and asked about “pain” or “hurt,” but he didn’t understand. She called his pediatrician, who recommended a trip to the emergency room, where they took X-rays and tested Alexander’s urine for blood.

When the results came back, they told her he’d had “a significant fall.”

Garcia gently rocks Alexander’s baby brother in her arms as she tells the story. There’s a heaviness in her voice. If he had undergone speech and physical therapy sooner, would Alexander have been able to tell the other child to stop? Could he have kept his balance, preventing the fall?

“I wonder if we would have had the Early Intervention in-person session earlier, if things would have been better by now,” Garcia said.

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**Hilda Garcia holds her infant son at her West Chicago, Ill., home as she talks about her other son, 3-year-old Alexander, who is being treated for developmental delays. Even after a wait of over a year, Alexander wasn't able to get all the therapies he needed. CHARLES REX ARBOGAST/AP**



**Alexander, 3, who is being treated for developmental delays, qualified for five Early Intervention therapies in summer 2021, but his West Chicago, Ill., family waited more than a year to get any of those services in person. CHARLES REX ARBOGAST/AP**



**Hilda Garcia works with her 3-year-old son, Alexander, on his speech at their West Chicago, Ill., home. Recounting how she has juggled child care, work and the almost full-time advocacy needed to get Alexander needed therapy, Garcia says: "It feels like another job." CHARLES REX ARBOGAST/AP**

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