

Delays for autism diagnosis and treatment grew even longer during the pandemic

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Wylie James Prescott, 3, had to wait more than a year after his autism diagnosis to begin behavioral therapy, even though research shows early treatment of autism can be crucial for children's long-term development.

His mother, Brandie Kurtz, said his therapy wasn't approved through Georgia's Medicaid program until recently, despite her continued requests. "I know insurance, so it's even more frustrating," said Kurtz, who works in a doctor's office near her home in rural Wrens, Georgia.

Those frustrations are all too familiar to parents who have a child with autism, a complex lifelong disorder. And the pandemic has exacerbated the already difficult process of getting services.

This comes as public awareness of autism and research on it have grown and [insurance coverage](#) for treatment is more widespread. In February, Texas became the last state to cover a widely used autism therapy through Medicaid. And all states now have laws requiring private health plans to cover the therapy, applied behavior analysis.

Yet children from Georgia to California often wait months—and in many cases more than a year—to get a diagnosis and then receive specialized treatment services. Therapies that can cost \$40,000 or more a year are especially out of reach for families who don't have insurance or have high-deductible health plans. Children from [minority communities](#) and those who live in [rural areas](#) may face additional barriers to getting help.

"You would never allow a kid with cancer to experience these waits," said Dr. Kristin Sohl, a pediatrician at University of Missouri Health Care and chair of the American Academy of Pediatrics' Council on Children With Disabilities Autism Subcommittee.

During the early months of the COVID-19 pandemic, many families canceled in-home services, fearing infection. Virtual therapy often didn't seem to work, especially for nonverbal and younger children. With fewer clients, some providers laid off staff or shut down entirely.

And treatment services always face high turnover rates among the low-wage workers who do direct, in-home care for autism. But COVID-19 made the staffing problem worse. Companies now struggle to compete with rising wages in other sectors.

The Centers for Disease Control and Prevention estimates that autism affects 1 in 44 U.S. children, a higher prevalence rate than ever before. Autism symptoms can include communication difficulties and repetitive behaviors and can be accompanied by a range of developmental and psychiatric health conditions.

Early diagnosis of autism can make a difference, Sohl said. Symptoms of some kids who begin their therapy by age 2 or 3 can be greatly reduced.

Diagnoses are typically done by developmental-behavioral pediatricians, psychologists, psychiatrists and neurologists, all of whom are in short supply. The shortage of developmental pediatricians is especially acute. Even though they do three more years of fellowship training than a general pediatrician does, developmental pediatricians typically earn less.

General pediatricians with training can also do assessments, but insurers often require a specialist's diagnosis before paying for services, creating a bottleneck for families.

"If we solely rely on specialists, we're setting ourselves up for failure because there aren't enough of us. We need the [insurance companies](#) on board," said Dr. Sharief Taraman, a pediatric neurologist and president of the Orange County, California, chapter of the American Academy of Pediatrics.

Even in a metro area, getting a child an appointment can take months.

"We cannot get these families in fast enough," said Dr. Alan Weintraub, a developmental pediatrician in suburban Atlanta. "It's heartbreaking."

Some parents pay cash for an evaluation with a private specialist, worsening disparities between kids whose parents can afford to skip the wait and those whose parents cannot.

Once a child has been diagnosed, many face an equal—or longer—wait to get autism therapies, including applied behavior analysis, a process that aims to improve social, communication, and learning skills. These sessions can take more than 20 hours a week and last more than a year. ABA techniques have some critics, but the American Academy of Pediatrics says that most evidence-based autism treatment models are based on ABA principles.

Accessing such treatment largely depends on insurance coverage—and for many families how well Medicaid pays. The Georgia Medicaid program reimburses well for ABA, Georgia doctors said, while Missouri's pay is low, leading to a scarcity of options there, Sohl said.

In California, Medicaid reimbursement rates vary by county, and wait times for ABA range from about three to 12 months. In the rural northern reaches of the state, where few providers work, some families wait years.

During the first year of the pandemic, Claire Hise of Orange County was thrilled with the ABA therapist who worked with her son. But in January 2021, the therapist quit to go back to school. The company she was working with sent others. Hise had to train each new therapist to work with her son, a difficult process that always took more than a month. "It's a special relationship, and each kid with autism is an individual," Hise said. "It takes time."

By then, they were out the door, replaced by another after no more than four to six weeks. Sometimes the family waited weeks for a replacement.

Hise tried switching to another company, but they all had a six-month waitlist. "He's already so far behind," Hise said. "It's really a year I feel we've lost."

The average age of diagnosis in the U.S. is about 4 years old, but Black and Latino children on average are evaluated later than white kids.

"The impact on families having to wait for diagnosis or treatment can be devastating," said Kristin Jacobson, founder of the Autism Deserves Equal Coverage Foundation, an [advocacy group](#) in California. "They know in their gut something is seriously not right and that there is help out there, and yet they are helpless to do anything about it."

Araceli Barrientos helps run an autism support group in Atlanta for immigrant families, for whom language barriers can cause additional snags. It took her more than a year to get her daughter, Lesly, diagnosed and two more years to secure further treatment.

Sabrina Oxford of Dawson, in rural southwestern Georgia, had to take her daughter Jamelyn more than 150 miles to the Marcus Autism Center in Atlanta to get her diagnosed. "You don't have any resources around here," Oxford said.

Dr. Michelle Zeanah, a behavioral pediatrician, draws families from 60 mostly rural counties to her clinic in Statesboro, Georgia. "There's a massive shortage of people willing and able to do an [autism diagnosis](#)," she said.

Getting insurance to pay for autism treatment can be another frustrating

process for families. Therapy denials can be triggered by clerical errors or missed paperwork. Insurer approvals can be especially difficult for [older children](#), who can be less likely to get treatment services than younger ones, said Dr. Donna Londino, a child and adolescent psychiatrist at Augusta University in Georgia.

Many children with autism also need speech, occupational, and physical therapy, all of which are generally easier to secure than [behavioral therapy](#). But even then, Weintraub said, the insurers push back: "They really dictate how many services you can have. These families, literally, meet obstacles at every turn."

David Allen, a spokesperson for AHIP, an insurance industry trade group formerly known as America's Health Insurance Plans, said insurers often require prior authorization to ensure that autism services are "medically necessary and evidence-based" and that patients are treated by "providers with appropriate education and training in treating [autism](#)."

Tracy-Ann Samuels of New York said she paid out-of-pocket for speech and occupational therapy for her son, Trey, now 15. Two years ago, after 18 months on a waiting list, he finally got ABA services covered by insurance.

"He's doing so great," she said. "My son was nonverbal. Now he's talking my ear off."

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