

'So rudderless': A couple's quest for autism treatment for their son hits repeated obstacles

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When Sebastian Rios was a toddler, he hardly talked. "Don't worry," his pediatrician told Amparo and Victor Rios, Sebastian's parents. Kids who grow up in households in which both Spanish and English are spoken are sometimes slower to develop language skills, she said.

Plus, Sebastian was developing well in other ways: When he was just 18 months old, for example, he could identify the magnetized letters of the alphabet on the refrigerator at their home in Bronxville, a short train ride north of New York City.

But by the time Sebastian was a little over 2 years old, his skills weren't keeping up with those of other kids his age: He spoke only simple words, like "mama" and "dada," and had problems interacting with people, Amparo Rios said. He didn't know how to play with other kids and didn't care about showing people his toys or sharing them. He made eye contact less and less.

The Rioses worried their son might have autism but didn't know how to get a [definitive diagnosis](#) for his lagging skills or how to get him help.

One in 44 children have been diagnosed with autism spectrum disorder by age 8, according to federal estimates. It is a [developmental disability](#) that affects people's social and communication skills and their behavior to varying degrees. About a third of children with autism have intellectual disabilities as well, according to the federal Centers for Disease Control and Prevention.

As awareness of the autism spectrum has grown, new diagnostic criteria that cover milder forms of the disability have helped draw attention to the needs of children, like Sebastian, who may benefit from ongoing treatment and need significant support to go to school and participate in activities like sports.

Autism can't be diagnosed with a [blood test](#) or scan. Instead, professionals generally rely on in-depth interviews with parents or caregivers about a child's development, as well as evaluations of a child's behavior during one-on-one sessions. Those may require out-of-pocket payments as insurance companies impose stricter coverage standards. Parents can wait months for appointments with a developmental pediatrician or other specialists.

"There are significant provider shortages, especially with the number of children who are diagnosed or suspected to have autism these days," said Kelly Headrick, senior director of state government affairs and grassroots advocacy at Autism Speaks, a research and advocacy organization.

As a result, the Rioses discovered, getting a diagnosis and any subsequent help can be a long, winding, nerve-wracking, and sometimes costly road.

Although parents may notice developmental problems during a child's first 18 to 24 months, children aren't diagnosed with autism, on average, until they are more than 4 years old, studies show. That means missed opportunities for intervention: Research shows that early treatment of autism leads to better outcomes.

Eager to get help for Sebastian, the Rioses asked their pediatrician for help when their son was 2. The doctor referred them to their school district, so Sebastian could be assessed for special education services.

But he was too young for the district to help.

The Rioses learned that children under age 3 need to connect with services through the federally mandated early intervention program that requires states to provide services to children with developmental delays or disabilities.

The family waited more than three months for the battery of tests and appointments to be completed, and the gap between Sebastian's development and that of other kids his age continued to widen. In addition to his language and social developmental delays, he struggled with imaginative play and was intensely self-directed, focused completely on what he wanted to do when he wanted to do it.

Although the staff members of the early intervention program didn't have the specialized skills necessary to provide a [medical diagnosis](#), they recommended Sebastian begin [occupational therapy](#), speech therapy, and applied behavior analysis, a widely used technique in which therapists work intensively with [children](#) who have autism using positive reinforcement to achieve goals related to communication, learning, motor, and other skills. For example, a therapist might encourage a child to play a game the therapist has chosen before playing the game the child prefers. If the child does that, he might be praised by the therapist or get something else he values, like a toy or playground time.

The early intervention program paid for someone to go to the Rioses' home six hours a week to do ABA therapy. But Amparo Rios said the therapist didn't focus on Sebastian's problem areas, such as transitioning from one activity to another without having a meltdown, so she wanted a different ABA therapist.

The Rioses had [health coverage](#) through a plan administered by Trustmark, which set coverage policies in consultation with Amparo

Rios' employer, a local college. But Sebastian needed a medical diagnosis of autism from a provider the plan considered a qualified clinician before it would pay for ABA therapy—a diagnosis Sebastian still didn't have at age 3. At about this time, the Rioses noticed their son was "stimming," shorthand for self-stimulating behavior, often repetitive movements or sounds that help calm or comfort people with autism. In Sebastian's case, he made grunting noises.

Since there is no single standardized test required to diagnose the condition, providers use different tools—some of which specific insurers will not accept.

The family took Sebastian to a neurologist for an exam, but she said she wasn't sure he had autism. "We felt so rudderless," Amparo said. "We didn't know who to turn to to diagnose him or figure out what was wrong with him."

Six months later, in September 2020, the family found a clinical psychologist who specialized in autism spectrum disorders and was in their provider network. She tested Sebastian over three months, evaluating his cognitive abilities and his capacity to attend to tasks, follow directions, and pay attention, among other things. The pandemic slowed medical care to a crawl, and in May 2021 she finally diagnosed Sebastian, then 4, with Level 1 [autism spectrum disorder](#), the least limiting form, and recommended he again begin ABA therapy.

The delay cost Sebastian. His stimming behaviors got worse, and he made eye contact with others less frequently. "We had very mixed feelings about the diagnosis," said Amparo. "It was a relief that we had a diagnosis we could rely on for medical care. But it was mixed because as parents we didn't know what he would grow up to be."

Two years after the Rioses noticed their son's atypical behaviors, they

enrolled him in individual ABA therapy for 15 hours a week at a center near their home. It felt like the pieces were finally falling into place. Sebastian's [language skills](#) were getting better because of speech therapy, but he was very self-directed and still not good at making eye contact. He sometimes wandered off on his own, a terrible safety risk, and couldn't use the bathroom by himself.

Amparo's health plan administrator, Trustmark, confirmed that ABA therapy was covered, with a copayment of \$25 per session.

It was tough for Sebastian at first, Amparo said, as he worked with a therapist to learn how to be less rigid and less focused on doing only what he wanted to do. But he gradually got better at skills like making eye contact and using the bathroom on his own.

The relief was short-lived.

In September, the Rioses started getting notices from the health plan administrator saying it wouldn't pay for the therapy because it wasn't medically necessary. Unfortunately, the therapist who had provided the diagnosis hadn't screened Sebastian using the Autism Diagnostic Observation Schedule (ADOS-2), a highly regarded test.

Sebastian's developmental pediatrician sent a letter to the health plan explaining the need, and the ABA therapy provider sent clinical notes from Sebastian's sessions.

It didn't work. Trustmark refused to pay for the ABA therapy, and in February the Rioses discontinued it. Now they're facing more than \$11,000 in bills for the sessions. Without the therapy, their son's progress is slipping, Amparo said. He's stimming more and has been distracted and disruptive in his kindergarten class, needing constant reminders to stay focused.

Trustmark declined to comment for this article.

"It's just really frustrating" for parents, Amparo said, "but ultimately it's very sad for my son."

The Rioses appealed the denial but lost. An independent reviewer found in May that the ABA services weren't medically necessary and questioned whether Sebastian had autism. He noted that Sebastian hadn't been screened using the ADOS-2 test and said he needed it.

It was the last straw. Amparo quit her job, and the family switched their health coverage to her husband's plan. They began a new assessment process for Sebastian, now 5. They paid \$500 to a provider to administer the ADOS-2 test, which confirmed his [autism](#) diagnosis in June. Now, three years after starting the search for help, they're trying to enroll Sebastian in ABA therapy again using the new health plan's coverage.

"You want your child to be assessed as early as possible to get as much help as possible," Amparo said. "This is a critical time in his development, and I just feel beaten down."

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