

DEEP DIVE

The promise of telehealth in autism diagnoses

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Photography by Hannah Yoon

On a snowy day in December 2022, Coraline Vazquez spent the morning playing with her parents, Dani and Gabe. In pajamas and sweatpants, the trio snuggled together on the floor in Coraline's cozy bedroom in the family home in Kutztown, Pennsylvania, a town of about 4,000 people an hour and a half northwest of Philadelphia. On a small table, a cellphone was propped up, its camera aimed at Coraline as the 2-year-old turned her attention to a pile of large plastic blocks spilled across the rug. One by one, she picked them up and placed them next to each other in a line.

"You don't want to stack them?" Dani, 22, asked.

Gabe, 24, demonstrated by picking up a block and putting it on top of another. When he held a block out to her, Coraline added it to the tower they were building. Then she took another one from him.

"Thank you," Coraline said.

"Thank you," Dani echoed.

For about half an hour, they vroomed toy cars across a play mat and played tickle monster and catch.

Kaitlin McHenry's voice came through the phone. "Do you have bubbles?" she asked.

Dani produced a green plastic jar.

"One, two ... blow!" cried Gabe, blowing a string of pearly bubbles into the air.

A bubble floated toward the window, and Coraline raced after it. "Bubbles!" she yelled.

In many ways, it was typical family hangout time. But not entirely. McHenry is a nurse practitioner at the Children’s Hospital of Philadelphia (CHOP), and she was trying to determine if Coraline has autism, something the Vazquezes had been worried about for months. To help with this, Dani occasionally picked up the phone and followed Coraline as the little girl darted into the corner to look for a toy or climbed into the pile of pillows on her bed — whatever angle might help McHenry, who had asked to see Coraline’s face and eyes as much as possible, even when Dani and Gabe were answering questions about Coraline’s medical and developmental history.

At one point, McHenry heard a happy little scream and asked about it. She also asked about behavior and language skills, eye contact, gestures, play habits and interactions with other children.

“You said following directions is hard,” she said. “If you said, ‘Coraline, go get your shoes,’ would she do it?”

“No.”

“What if you pointed?”

“Not really.”

When Gabe and Coraline were stacking blocks, McHenry asked Gabe to delay handing over a block so that Coraline would have to ask for it. Block in hand, he pretended to look the other way. Instead of asking, Coraline grabbed his hand and pulled it toward her. And when Gabe started blowing bubbles, McHenry wanted to see if Coraline would ask her father to blow more. Coraline did ask, sort of — “I love you! Bubbles!” she cried. But first, she tried touching her father’s hand.

Picking up a parent’s hand and moving it to a car, a block, or the wand from the bubble jar is not typical of children her age. “We call it using the hand as a tool,” McHenry says.

McHenry was also watching to see if Coraline engaged in **restricted interests and repetitive behaviors** such as hand-flapping, toe-walking or lining up toys. The Vazquezes reported several of those, and McHenry saw Coraline flap her hands briefly and line up some toys during the observation. She also saw Coraline exhibit what the Vazquezes called her “power up.” The little girl shut her eyes and squeezed her fists for a few seconds.

“Would you describe that as a body tensing?” McHenry asked.

“Yes.”

After they had been on the Zoom call for about 90 minutes and were wrapping up the play session, McHenry asked, “Do you think I got a pretty decent picture of a day in the life?” She wanted to be sure that Dani and Gabe felt that their child had been truly seen.

The evaluation was conducted under the auspices of the **Autism Diagnostic Clinic** of Easterseals Eastern Pennsylvania, which offers autism assessments to children younger than 3 years who have been referred through early-intervention programs. But none of those evaluations take place at the clinic’s home base in Reading, a small city about 50 miles west of Philadelphia. Instead, Easterseals collaborates with clinicians from CHOP and St. Christopher’s Hospital for Children in Philadelphia to offer remote evaluations in families’ homes with parents in the critical role of “play partners.” Parents or caregivers must lead their children through a set of guided activities designed to elicit certain kinds of social behavior and communication, and capture it all for the video camera, too.

Evaluations such as Coraline’s were practically unheard of before the COVID-19 pandemic. When much of the world shut down in the spring of 2020, it presented a daunting challenge: The gold-standard instrument for autism diagnosis — the second edition of the Autism Diagnostic Observation Schedule (ADOS-2) — had to be conducted in person by a trained professional and wasn’t valid if the participants wore masks. But the pandemic was also an opportunity. By redefining best practices and expanding how children are evaluated, autism clinicians realized they might be able to help solve a persistent problem: the long wait families endure to get a diagnosis in the United States.

“There are many children that you can very confidently diagnose with a high degree of accuracy without the ADOS.” Kaitlin McHenry

“We’ve been referring kids and families to one type of process in all circumstances,” says psychologist **Zachary Warren**, director of autism research at Vanderbilt University Medical Center in Nashville, Tennessee. Yet there are “huge percentages of kids that have to wait tremendous periods of time before they’re offered answers and services that are meaningful to them.” Waits of more than a year are common.

Waits are especially long for families who live in rural areas and must travel sizable distances — taking time off work and sometimes staying overnight — to see providers, all at considerable

expense. Families who face financial or language-related barriers are also often at a disadvantage — some don't own a car, have limited paid time off or can't afford child care for their other children. Some studies have shown that children in rural settings and those who are at or below the poverty line receive diagnoses **six months to a year later** than their peers in better-served communities. Older children also usually wait far longer to be evaluated, both because of a push to prioritize younger children and because not all clinicians see children older than 3.

Put simply, in rural and urban locations, there are too many children who need to be evaluated and too few clinicians qualified to do it. As a result, a child with autism in the U.S. is diagnosed, on average, around the age of 4. Yet most parents report concerns before their child turns 2, and in some cases it is possible to accurately diagnose autism as early as 18 months. Earlier diagnosis allows for quicker access to services that help children thrive.

The pandemic forced a reckoning, says **Kristin Sohl**, a pediatrician and professor at the University of Missouri in Columbia. "It caused a lot of us to think more about the system and the inefficiencies in the system — the bottlenecks, the disparities."

Though the preliminary evidence is promising, it is still too soon to say whether telehealth and other new strategies can make a meaningful dent in the wait time for autism evaluations. No one claims remote diagnosis should be used for every child; it seems to work best as a form of triage, allowing clinicians to diagnose some children more quickly, and opening space at autism centers for those with traits that are harder to capture on camera. But because the pandemic led to a surge in the use of telehealth, large studies are now underway that will confirm — or not — the efficacy of this approach. "I think now we can take some time to evaluate what's working," says **Lonnie Zwaigenbaum**, professor of pediatrics at the University of Alberta in Edmonton, Canada.

Yet there is no going back entirely to the way things used to be. After leaping from 0 to 100 percent early in the pandemic, virtual evaluations still make up a substantial number of visits at several large clinics. And virtual clinics such as Easterseals are becoming more common. For instance, a fully virtual diagnostic practice called **As You Are** launched in 2022 and now operates in 10 states.

"I've been for a long time wanting my clinicians to think outside the box about ways to conduct diagnostics," says clinical psychologist **Jessica Greenson**, who directs the autism center at the University of Washington in Seattle. "The pandemic enabled me to just say, 'We've got to do it.' I think everybody, after having tried it, sees the benefits."

Like many other parents of autistic children, Dani Vazquez first worried about her daughter's development around the time Coraline was turning 2. At the same age, a friend's child was speaking in full sentences, eating a variety of foods and putting on her own shoes. Coraline was doing none of those things. Although she had some words, the little girl didn't seem to use them in a meaningful way. She refused anything but macaroni and cheese, mashed potatoes and milk — "the white diet," Vazquez called it. Although Coraline liked to have her parents nearby, she didn't engage much with other children her age and rarely played with toys the way they were designed to be used — she lined up toy cars rather than driving them, for instance.

As Coraline neared age 3, her behavior also became harder to manage — in the supermarket, she started lying down in the aisle in front of the cart, crying and flailing her arms and legs. Vazquez had grown up with a cousin who has autism and was familiar with some of its traits; it wasn't clear if Coraline was having a typical toddler meltdown or showing signs of sensory overload. She noticed that Coraline sometimes flapped her hands, walked on her toes, and spun in a circle without seeming to get dizzy — all movements that can signal autism.

In the spring of 2022, not long after her second birthday, Coraline was evaluated by local early-intervention providers and qualified for speech and occupational therapy. Around the same time, Vazquez raised her concerns about autism with her family doctor. The doctor wasn't worried but searched for a developmental pediatrician, a common first step when there are concerns about autism. But as of 2021, there were only 728 certified developmental and behavioral pediatricians in the U.S.

Vazquez's doctor told her she would need to find a qualified clinician on her own. Her advice, as Vazquez remembers it, essentially was, "Google it."

Meanwhile, the therapists working with Coraline told Vazquez that other children they worked with who were similar to Coraline had already been diagnosed with autism.

Vazquez did find a doctor more than an hour away, but they couldn't see Coraline until after she was 3. Eventually, at a check-in with her early-intervention coordinator, Vazquez mentioned the difficulty she was having getting a diagnosis and was referred to Easterseals. She got lucky and was given an appointment for a little over a month later (the usual wait time is more than six months).

The current bottleneck in autism diagnosis grew out of good intentions. When the ADOS was

introduced in 1989 by autism researchers **Catherine Lord** and **Sir Michael Rutter**, it provided a much-needed standardization of the autism evaluation process. Revised a few times since then, it comprises 30 to 60 minutes of tasks that assess communication, social interaction, play, restricted interests and repetitive behaviors. A trained examiner scores each task and totals the scores at the end.

“I’ve been for a long time wanting my clinicians to think outside the box about ways to conduct diagnostics.” Jessica Greenson

As the ADOS became the preferred form of assessment, families were sent to specialized autism centers, where children also underwent cognitive testing, parents gave complete histories, and clinicians — usually psychologists or developmental pediatricians — provided extended feedback sessions. Such multi-faceted evaluations were thorough and professional, but also time consuming, sometimes requiring multiple visits. And the number of trained clinicians did not increase as fast as the number of children who needed to be seen. That limited number of developmental pediatricians, for instance, results in a national average of more than 100,000 children per provider. That figure falls to almost 25,000 in Washington, D.C., and leaps to more than 900,000 in Utah.

Fortunately, psychologists, nurse practitioners and others also perform autism evaluations, and several programs are underway to expand the pool of credentialed providers [see **Alternative approaches**]. But for the moment, the bottleneck still exists.

So even before the tumult of the pandemic, many clinicians were searching for something better. Although diagnosing autism requires expertise, it does not require one specific evaluation instrument. “There are many children that you can very confidently diagnose with a high degree of accuracy” without the ADOS-2, McHenry says. Still, there was resistance in the field from clinicians who doubted the validity of shorter, remote evaluations, and payors created a roadblock by rarely reimbursing for telehealth, even as a handful of studies suggested that the approach had promise. Warren and his colleagues at Vanderbilt were among those testing the possibilities. They were using telehealth in the far corners of Tennessee to reach families who had a hard time making it to the clinic in Nashville. Working with the state’s early-intervention program, they conducted clinic-to-clinic assessments in which a local therapist or health-care provider was trained to run children through an assessment tool, and the autism experts at Vanderbilt observed virtually to make a diagnosis.

Rural road: A residential road slopes into the distance in Kutztown, Pennsylvania. Easterseals collaborates with the Children's Hospital of Philadelphia to offer remote autism evaluations in families' homes.

Lap lean: Coraline, milk in hand, leans on her father, Gabe.

In picture: Kaitlin McHenry observes the Vazquez family via video screen as part of a remote autism diagnosis.

Finger puppets: Coraline plays with her father at their home in Kutztown. Some clinicians find at-home assessments easier because the child is in a familiar environment.

Tip toes: Coraline walks across the porch of her family home. Toe-walking is one of many things clinicians look for during remote assessments.

All stripes: Coraline and her father play an educational game in the family's living room.

Green balloon: Dani and Gabe help entertain Coraline with a ballon in the living room.

It worked well, but the process was cumbersome, requiring a clinician at each end. And Warren saw a need for a tool specifically designed for telehealth: one that would cut the time for the behavioral observation, make use of widely available materials and provide understandable instructions. Using machine learning, Warren's team first worked out which skills and behaviors were most predictive of autism and then used those features to design a set of eight assessment activities and seven scoring elements. They called the new instrument **TELE-ASD-PEDS** (TAP) and started a small clinical trial to test its efficacy.

That was just before the pandemic hit.

In response, Warren made TAP freely available and created a webinar to teach other clinicians how to use it. Results from a study comparing TAP to in-person diagnoses were still forthcoming, but in **Vanderbilt's early study** of 204 remote evaluations, the nine ADOS-2-trained clinical psychologists who participated reported they were comfortable using the tool and confident in their diagnoses (71 percent of the children were found to have autism).

Easterseals Eastern Pennsylvania already provided early-intervention services such as speech and occupational therapy, and, like Warren's group, started its Autism Diagnostic Clinic using clinic-to-clinic assessments. In 2018, with funding from the state's Department of Health, Easterseals launched a pilot hybrid telehealth program for families in the immediate county. Families came to the clinic in Reading, where experts from CHOP observed virtually as an occupational therapist ran through the ADOS-2 with a child on site.

The clinic was already evaluating a few children a month that way before COVID-19 arose. As devastating as the pandemic was, it was also "a bit of serendipity," says Jill Glose, who created the Easterseals autism clinic. By using Vanderbilt's TAP, the clinic could see families who lived farther away, and they could conduct evaluations in just about any setting. "We've done them at homeless shelters, at hotels," McHenry says. Over the next two years, Easterseals added clinicians from St. Christopher's, some of whom can conduct evaluations in Spanish. Though limited by funds and the availability of clinicians, Easterseals expanded the number of evaluations to 10 to 12 children per month and the number of counties served to six, including the rural Pocono Mountains in Northeastern Pennsylvania.

When Dani Vazquez was told Coraline's evaluation would be virtual, she was nervous about not being seen in person. "At first, I can't lie, I was a little skeptical," she says.

Vazquez wasn't the only one who saw challenges ahead. When McHenry started doing remote

evaluations with Easterseals, she worried about what she would be able to physically see. “Where are the cameras? Can I see eye contact?” she wondered. Her biggest concern was how the assessment would feel on the other side of the camera. “Would families feel like we were providing the support they needed emotionally in giving a life-changing diagnosis?”

But McHenry and the other clinicians soon found that the process worked well. It helped that the children at Easterseals come through the early-intervention system, which means developmental concerns have been identified and children have already had cognitive testing. In addition, Gloria Alvarez, the autism program manager at Easterseals, works with families ahead of time. She emails instructions listing toys and other items to have on hand, such as bubbles and small containers of a child’s favorite snack, although Alvarez urges parents not to go out and buy anything they don’t already have, because the clinicians have gotten good at using the toys on hand.

Two or three days before an evaluation, Alvarez troubleshoots any technology issues — another major concern — in a short prep call with the parents or caregivers. Cellphones and tablets, which nearly every parent has, work better than computers for filming because they make it easier to follow a child around or change the camera angle. Alvarez suggests turning the phone on its side to get a wider picture and having another adult on hand so one person can play and one can film, as the Vazquezes did. Out of more than 200 evaluations over the past two years, there has rarely been a time when a parent’s home didn’t have adequate reception. On one occasion, Alvarez figured that out ahead of time and sent them to a relative’s house. Still, cellphone calls disrupt the signal. Dogs bark in the background. Siblings pop in front of the camera wanting to know who’s there. Parents log in from the car if they’re not home at the start time.

Flexibility is the name of the game, and McHenry took everything in stride during the call with the Vazquez family — Coraline crying when her nose was wiped, Coraline jumping on and off the bed in her pajamas, Coraline throwing a tantrum when the bubbles were put away. McHenry told the Vazquezes that if Coraline was losing patience and needed to simply play, that was OK.

“I mean, this is her world,” McHenry said. “We’re just living in it.”

At Easterseals and other virtual clinics, providers report that seeing children in their natural environment has turned out to be a boon. Children are more themselves when they “don’t have to go into this office with bright lights, noises, strangers, wait in a waiting room for 30 minutes and just get dysregulated so much,” says Alvarez, who occasionally used to accompany families to evaluations when she worked as an early-intervention coordinator. “Instead, they’re in their house with their favorite play partner, their mom or dad or Grammy, and they’re cozy. It’s warm and super familiar.”

Even so, there are a small number of children who do need to be seen again, either via telehealth or in person. Some children have other neurological concerns or challenging behavior that make them hard to assess. In other cases, the traits are subtle and take time to see. Sometimes, social difficulties don't appear until children get older and social expectations increase. TAP doesn't help in those cases, because it is designed for children younger than 3. (The Vanderbilt team has also created a version for preschool-aged children, which they are testing.)

In Alberta, Canada, Zwaigenbaum does outreach to a northern area of the province where some of the children he assesses are already in school and used to screens. For some youth with autism, online interactions are "kind of the center of their social world," and they can manage themselves "a bit differently" there, he says. But remote visits with these children can still be challenging. Sometimes they just shut down or walk away from the screen. For these reasons, Zwaigenbaum says, telehealth is "not a fix for all the challenges of the system."

Still, according to Alvarez, about 85 percent of children they evaluate are ultimately diagnosed with autism. "That's great because that means our referral people did their job," she says. And a significant majority of the time, McHenry and the other clinicians say they are quite confident in the diagnoses they make through the program.

That was the case with Coraline.

"I agree with you guys," McHenry told the Vazquezes. "I think she has autism. I also think she's going to do well."

"You have no idea how much I needed to hear that," Dani said. She was the one who had spotted the autism traits when others around her couldn't see them.

"We're also still looking to help her take it to the next level," McHenry said.

Then she spent some time describing what autism is. Alvarez and the service coordinator, who had observed the evaluation with their cameras off, joined in at this point to discuss recommendations. Those included an inclusive preschool classroom and **applied behavior analysis** (ABA) therapy. Alvarez also told the Vazquezes about a six-week ABA parent coaching program that Easterseals offers, which gives parents something to do right away as they wait to get services for their child, because the wait for ABA therapy can rival the wait for an initial diagnosis. (Here, too, there aren't enough providers to fill demand.)

A few weeks after the evaluation, Dani Vazquez was relieved. "I like knowing that there's a name for it, there's a community and there's help," she said. As a young mother, she found it comforting to know her parental instincts had been right, and that McHenry was so optimistic about Coraline's future. She had already heard from an ABA therapist and planned to take McHenry's diagnosis to the family's upcoming meeting with the county about preschool for Coraline, who would soon be

3. “It’s making everything easier,” Vazquez said.

She was so happy with the virtual evaluation that she had already recommended Easterseals to a friend seeking an evaluation for her own child.

Thinking back on that morning in Coraline’s bedroom, Vazquez remembered something else: the snow outside. Some evaluations at CHOP were canceled that day. If they had been planning to see McHenry in person, Coraline and her parents might still be waiting.

Alternative Approaches

Virtual diagnosis is not the only strategy that autism centers are using to reduce long wait times for evaluations, and TAP is not the only new evaluation instrument being used either in person or via telehealth.

The Brief Observation of Symptoms of Autism (BOSA), developed by a team that includes **Catherine Lord** (co-creator of the ADOS), consists of less than 15 minutes of guided interaction between a child and a clinician or caregiver, which can be observed live or video-recorded by a clinician trained in scoring the ADOS-2. The BOSA offers four versions, aimed at children with different profiles, such as a test for minimally verbal children and a test for verbally fluent children aged 6 through 10 years. Evidence that it works is preliminary but promising.

Telementoring, which trains pediatricians and other community providers in autism diagnosis to expand the pool of qualified clinicians, has shown promise, too. One such program is ECHO Autism, which was founded by Sohl in Missouri in 2015. Her original goal was to organize “hub teams” of experts to advise pediatricians caring for children who were waiting to be seen at an autism center. “Doctors were asking, ‘What should I do while we wait?’” Sohl says. Rather quickly, however, she recognized that some cases were clear. “We all know this kid has autism,” Sohl remembers thinking. “Are we honestly OK with saying, ‘Send them to this center and it’s going to be a year?’”

They decided to add community-based diagnosis and usually work with an evaluation instrument called the Screening Tool for Autism in Toddlers and Young Children. In the ECHO Autism model, which has established partnerships in more than 15 states and five countries, pediatricians spend six months to a year getting trained in autism diagnosis and then have virtual case discussions with the experts. “We call it guided practice,” Sohl says. A pilot study in Missouri reported that ECHO Autism reduced wait times for diagnosis by an estimated two to six months and reduced families’ round-trip travel by an average of 173 miles. “My mission is to try to figure out how to get to no waitlists,” Sohl says. An inadvertent consequence, however, is that there are waitlists of

pediatricians who want to be trained.

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