

SCRAMBLING FOR CARE: AUTISM IN RURAL AMERICA

BY

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ABSTRACT

The path to autism diagnosis and intervention has always been arduous, but families in small towns with limited access to healthcare services are at a much greater disadvantage. Amid the Covid-19 pandemic, the surge in virtual services for autism has offered clinicians and researchers a unique opportunity to bring care to the home of geographically underserved communities. Through interviews with autism researchers, health experts, and family members of autistic individuals, this two-part project takes a look at the barriers to autism care in rural America, and the potential and limitations of telehealth to expand access to services.

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## ***Part 1***

On a cold February morning, snow is drifting down in the small-town of Ruthven, Iowa. Atreyu Franks, 6, sits on red plastic chair against the brightly adorned walls of a classroom at Ruthven-Ayrshire Elementary School. His gaze is transfixed on the moving images playing out on the laptop screen, but his body appears restless. Every so often, he bites his thumb and flaps his arms in the air.

A teacher's assistant holds Atreyu's hand and walks him over to a different table to trace alphabets on an iPad. He screams, running in circles around the classroom, and plops back into the red chair to continue watching cartoons.

24 February 2017 is a big day for everyone. Teachers at this small public school in Ruthven, Iowa, are receiving training on how to stave off Atreyu's tantrums and support his learning in the classroom.

Atreyu's mother, April Franks, sits in one corner of the room, silently recording the interaction on her phone for researchers tuning in from hundreds of miles away.

Atreyu was diagnosed with autism at age 4. Until early 2016, he was enrolled at a different public school outside the county. "He got sent there because of the level of care he needed that Ruthven-Ayrshire wasn't able to provide," said April.

Things began to change when he turned five. First were the occasional complaints about aggression towards teachers and peers. Then he bit his own arm so hard, there was "a gaping hole" left behind, April recalls. One day, April was called in and the teachers informed her they wanted the family to look into enrolling him at a different school. Atreyu had been expelled.

The same problems had bled into Atreyu's life at home. He often hit his younger sisters, two of whom are non-verbal and use a wheel-chair to move around. And when he got upset, he repeatedly banged his head against the walls of his bedroom.

In a bigger town, the Franks might've been able to find a therapist who offered Applied Behavior Analysis (ABA), an intensive one-on-one therapy for autistic children with severe behavioral problems. But Ruthven is a small community of less than 800 people. On Google maps, it appears as a tiny square surrounded by lush green cornfields on all sides. If you Zoom in, two gas stations, a church, and a few scattered houses pop up. The closest grocery store is out of town, a half-hour away. And there are no autism specialists. The closest therapist practices two hours away at the Children's Autism Center in Clear Lake, Iowa.

There is a shortage of trained therapists for ABA across the country, said Jennifer Hamrick, behavioral analyst and co-director of an autism research center at Texas Tech University in Lubbock, Texas . But these disparities are felt more acutely the further you get into smaller rural communities, where "it takes a full day of driving to receive any kind of specialty care."

Research has shown that states need, on average, 3 to 4 ABA therapists for every 100 autistic children. In Iowa, there are 8,000 children with autism but less than 200 trained ABA therapists, dozens fewer than the state needs.

These experts mostly operate in cities, while families of autistic children, much like 43% of the state's total population, live in rural communities like Ruthven.

So, in the fall of 2016, when April heard of a clinical study at the University of Iowa that would teach parents to do ABA therapy at home, she connected with the researchers right away. "Luckily, the cut-off age was six years and nine months, and we had just gotten in," she said.

The researchers used an online video-conferencing software, Vidyio, to meet with April and Atreyu in the family's home every week for the next six months. Within a couple of weeks, Atreyu's self-injurious behaviors, like biting and banging his head, began subsiding and he was learning quicker than ever before.

Atreyu's teachers at Ruthven-Ayrshire were still struggling. He had already been expelled from his last school, so when April asked the researchers to coach his teachers that February morning, they agreed.

The Franks had hoped these therapy skills would allow them, and Atreyu's teachers, to help him for the coming years, after the study ended. They are one in a growing number of families who have turned, in recent years, to a kind of do-it-yourself ABA therapy, performed by the caregivers themselves with the coaching and support of professional therapists. Enabled by video conferencing and other digital technologies, this new model of ABA therapy has promise to increase access for rural communities but it isn't a "one size fits all" solution.

For families like the Franks, it's given them hope, but it has also put them in what amounts to a race against time: It's uncertain whether access to ABA therapy – either in-person or over video conferencing – will expand quickly enough to solve their problems.

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The use of ABA therapy in autism started in the 1960s when Ole Ivar Lovaas, a clinical psychologist and professor at the University of California, Los Angeles, became interested in how complex human behaviors could be shaped through positive or negative reinforcement.

Today, ABA therapy is the most widely used intervention for autism. The sessions are used to deliver a highly structured regimen that teaches autistic children one "desirable" behavior at a time; this can vary, depending on the child's needs, from how to use the bathroom and respond to greetings to tying shoelaces.

Up until 2009, autism researchers had only looked at the effectiveness of ABA therapy when done face-to-face by a therapist. When a family lived further away, they would send the therapist to their home or set up a makeshift clinic closer to them.

"We'd drive about three and a half hours, and they [families] would drive around 2 hours," said Hamrick, who also runs a mobile autism clinic for families residing in rural areas of West Texas.

But driving for hours isn't ideal for the therapists or families. Long drive times mean that therapists are able to meet with fewer families. And if parents cancel an appointment on short notice, the session time goes to waste. So, as the bitter reality of geography goes, small towns remain the most underserved communities for autism services in America.

In 2009, researchers at the University of Iowa set out to change that with a series of studies that would look at whether parents and caregivers could be coached over a video call to do ABA therapy with their children.

"There was a fiber optic network in Iowa that had just connected hospitals, government buildings, schools and libraries," said David Wacker, a now retired special education professor at the University of Iowa, who led these research projects. "If we could do assessment and treatment in 90 minutes in an outpatient clinic, why couldn't we do it over the optic cable?"

Between 2009 to 2014, the researchers assessed 94 autistic children. These children were divided into three groups to compare the cost and effectiveness of ABA therapy over telehealth with in-person therapy at home.

Children in the first group received ABA therapy from a specialist face-to-face in their home. The second group consisted of families who had to drive to a nearby clinic to meet with an ABA therapist over telehealth. And the last group stayed in their home and met with the therapist over telehealth.

The results of this study were "promising", according to Wacker. It suggested that ABA therapy over telehealth is just as effective as in-person visits with a therapist; they both reduced "problem behavior" – aggression, self-injury, defiance – in autistic children by over 90%.

To contrast the cost of therapy across different delivery methods, Wacker and his team also calculated staff,

facility, and family expenses. These included everything from salaries, the cost of purchasing a computer, paying for internet and gas, to the maintenance fee for a clinic.

They found that the expense of sending a therapist to a family's home for three months came at about \$6000, while doing the same therapy over telehealth, in a family's home, only cost around \$2200.

A year later, in 2015, these researchers teamed up with other autism specialists at the University of Houston-Clear Lake and Emory University to run the first large trial of this new approach to delivering ABA therapy at home, over telehealth. They wanted to see whether this approach, which had previously been tested with children with mild behavioral issues, could also be effective for young autistic children, who experience severe behavioral problems. A total of thirty families, across Iowa, Georgia, and Texas, participated in this study. The Franks were one of them.

As part of this study, O'Brien coached April once a week to handle Atreyu's tantrums and reward him for completing small tasks. One evening, April wanted to work on Atreyu's frequent meltdowns, during which he'd hit himself repeatedly to escape completing unpleasant chores.

She began by asking him to put colorful magnetic alphabets in a box, while O'Brien continued to watch their interactions closely over Vidyo. Atreyu remained huddled on the floor, shouting and hitting his head with his hands, while April tried to gently coax him into following her directions.

As the minutes ticked on, Atreyu watched his mother play with the alphabet letters and slowly calmed down. He then began to put letters in the box himself. One. Two. Three. Four. Five. The shouting started back up again. This is all they were going to achieve today.

Over the next few weeks, April stuck to this regimen in and outside of sessions with O'Brien. If Atreyu hit himself, he'd have to put the magnetic alphabets in a box. And after the task was completed, he would get to watch his favorite music video.

In just a month, Atreyu went from putting five alphabets in the box, without needing a break, to adding 40. His tantrums became less frequent and April gained confidence that she could carry out ABA principles at home.

"I was nervous when we started," she said. "I knew going in people are skeptical of ABA and I had my own reservations with it."

In the last several years, ABA therapy has garnered negative attention in the autism community for disregarding the emotions of autistic children. For example, to learn what triggers "problem behavior" in a child, therapists often ask parents to withhold a favorite activity. If this sparks a tantrum, they later use this favored activity to reward the child for completing tasks.

When O'Brien walked April through these principles of ABA therapy, she felt uncomfortable and "didn't understand why they'd want to intentionally cause a meltdown in Atreyu."

"It makes sense now," she said. "I had to be a part of this process and do it *myself* to see how it goes. To realize it will be okay."

By the end of this clinical trial, Atreyu's parents knew the drill. They could trust his tantrums to pass if they stuck to the routine and replaced the interaction with a positive reinforcement.

This home-based approach is also valuable for other reasons. When parents travel to a clinic, they are often tired, stressed, and worried about adapting the therapy techniques to the child's home environment, according to Sally Rogers, Program Director of Early Start Denver Model (ESDM), an intervention that uses ABA techniques.

"Over telehealth, you see the whole picture faster, sooner," she said. "It's a natural, less formal situation, so families feel less under the microscope."

ABA therapy can be intense and therapists try to guide parents in many different ways. Sometimes it means describing techniques during a session, or sending a step-by-step guide to an activity. Occasionally, O'Brien would even send short videos to walk families through a therapy technique.

But often, parents of non-verbal children with severe behavioral issues feel unequipped to deal with instances where tantrums escalate to complete meltdowns. When the parents of Kylie Matthews, a non-verbal 14-year-old on the spectrum, suddenly lost access to ABA services during Covid-19 lockdowns, they felt like they couldn't learn the necessary ABA skills quickly enough to help stave off her tantrum spirals.

"As much as we don't have the bandwidth to really become professionals, we had no choice," said Kylie's father Jerney Matthews, who couldn't give up trying.

"It's a big issue because it's a completely different situation than face-to-face coaching" said Leslie Neely, a professor of psychology at the University of Texas in San Antonio, who supervises therapists in training.

Coaching parents to do ABA therapy requires extensive training even for therapists. And, in a public health emergency, like the Covid-19 pandemic, where there isn't time for any, parents and therapists can end up feeling lost.

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After the study ended, April Franks considered taking her son Atreyu to the Children's Autism Center in Clear Lake, Iowa, for ABA therapy. The specialists wanted to start at 40 hours of therapy every week and reduce the time depending on how well Atreyu responded to the intervention.

But childcare options in Ruthven are limited and April didn't trust anyone to not "lose their mind" taking care of her two younger daughters, while she drove Atreyu to and from the clinic every day.

"Three out of four [of my] children have disabilities. I don't get to have the option to go to appointments that are hours away," she said.

It's been a little over five years since Atreyu's participation in the study ended. Most of the behaviors the researchers tried to reduce have returned in full force and he has learned many new ones. He's much stronger and bigger now, and the tantrums are "much scarier" than they used to be.

This past January, the Franks placed Atreyu into a residential home, an experience that turned out to be traumatizing. The staff had told April she couldn't see or speak with Atreyu during his first month in the facility. "They said it would give him time to get used to his new surroundings," she said.

When the staff contacted April to update the family on Atreyu's difficult adjustment, she gave them advice to handle this tantrums, but the facility manger told her they will "do it their way."

"The first time I saw him after that 30 days was the day that I pulled him out," said April. "The severity of his bruises - both of his arms were ripped open again - oh my god. He had bruising all over the back of his hands, his head, his cheek."

The Franks believe these bruises were self-inflicted. Over the years, Atreyu's behavioral problems have progressively gotten worse and the family's optimism to find the right services for him is quickly diminishing.

A porous patchwork of insurance policies for telehealth ABA therapy does not make things easy for them. Under a 2019 mandate, all 50 states and Washington, D.C. are required to provide some insurance coverage for autism services. In Tennessee, for example, the state covers "any [autism] treatment that is medically necessary and appropriate, and is not experimental."

This includes ABA therapy, which has been around for decades. But the use of video-conferencing software

to deliver it is still considered new. As a result, many insurance providers consider ABA therapy over telehealth to be experimental and do not cover it, leaving families of young autistic children in rural America scrambling for care.

A little over a year ago, the Franks packed up their life and moved down south to Huntsville, Alabama. April grew up in Georgia and had been wanting to be closer to family for a couple years. When Atreyu's stepfather got his plumbing license in the state of Alabama, the family finally decided to make the move.

The rapidly growing city of Huntsville is 500 times the size of Ruthven. It is completely new territory. In their small town, everyone knew the Franks. Once, Atreyu bolted and almost made his way to the highway. A neighbor brought him back. "It's so much more dangerous living in a bigger city where you don't know anyone and he can take off running," said April.

With their move to Huntsville, April had hoped they would get more options for ABA therapists. The closest one is only a half-hour away, but in metropolitan areas waiting lists for ABA therapy are much longer – between 6 months to a year. "It's so sad to me that services are still not available to us," she said.

Atreyu is 12 years old now — too old now for his parents to do ABA therapy at home. With the exception of supporting families during Covid-19, researchers and clinicians only work over telehealth with families of autistic children that are seven years old or younger. It wouldn't be safe to do it with older, stronger children, said O'Brien.

The Franks are considering placing him in residential housing for autistic teenagers and adults. But the memory of their previous residential-facility experience is still painful and fresh.

## *Part 2*

It's a Wednesday morning in late March, and Obadiah has a busy day ahead of him. The five-year-old sits alone in one corner of the preschool classroom while his friends run around, yelling at each other. A teacher's assistant tries to quieten the group, but within a matter of seconds the classroom erupts into a cacophony of screams, as other kids join the chaos.

Overwhelming situations, like this one, typically trigger an intense meltdown in Obadiah that sometimes lasts for hours, said his mother, Liz Talton. These meltdowns were so frequent up until a month ago that the family avoided leaving their house altogether.

Obadiah was diagnosed with autism at age 3. In March 2020, when most clinics were shut down amid the growing coronavirus outbreak, Liz met with an autism specialist over Zoom after six months of waiting for an appointment. "We got lucky compared to some other families," she said. "Somebody canceled their appointment, so they squeezed us in early."

This diagnosis unlocked much-needed resources for the family: insurance coverage of private speech and occupational therapy once a week, and an individualized education program at the public preschool.

Now every Wednesday afternoon, Liz picks Obadiah up from school and drives 40 minutes to the only autism clinic with a speech and occupational therapist within 50 miles of the family's rural hometown. There, Obadiah learns how to use the toilet, write his name, and speak in small sentences.

For the past month, the occupational therapist has also been coaching him on how to manage his emotions in loud, intense situations at school. Like many other autistic kids, he experiences sensory overload when the sounds around him are too overpowering for his brain to process all at once. "He starts crying and yelling. He'll cover his ears, too, because it's too much for him with everything going on," said Liz.

After weeks of practice, Obadiah is ready to handle the noise this morning. He puts his headphones on and walks over to a small plastic bin lying on the classroom floor. This seemingly ordinary storage container is his safety net, filled with some of his favorite sensory toys – a blue fidget spinner, some sand, and a weighted silver ball – to distract him from the mayhem.

When Liz arrives at the preschool at noon, the teacher rushes over to share Obadiah's progress with her. "He was in his little world, ignoring them and just being good," she recalled the teacher saying. "It's leaps and bounds from what it was."

For Liz, this "lucky day" is the culmination of the family's relentless struggle that started three years ago, when she first grew worried about his lack of eye contact and delayed speech. For months, the pediatrician dismissed her concerns, slowly chipping away at Obadiah's valuable developmental time when he could benefit from a diagnosis that would allow the family to access therapy sooner.

When Liz finally managed to receive a referral to meet an autism specialist, she started searching for experts in her small town, Soap Lake, only to find that the closest one practices an hour away, in Wenatchee, Washington. The months-long waiting list at this doctor's clinic kept the family anxious and up at nights. Their days, in the meantime, were filled with calls and emails to their insurance company which declined to cover the cost of the autism assessment.

Then, the Covid-19 pandemic hit and autism centers in the state began to shut down. "What am I going to do if he has autism?" Liz recalled asking herself. "And how am I going to help him without a diagnosis? It was really hard. And lonely, too."

To help families in this predicament, experts started conducting virtual autism assessments using video-conferencing software, like Zoom. Meanwhile, some researchers also began to develop new tools to replace traditional screening and diagnostic assessments, which are only meant to work for in-person visits.

"There's great appeal to that standardized approach [of diagnosing autism]," said Jeffrey Baker, a



pediatrician and medical historian at Duke University. “But we’ve always struggled with it. Making parents come from vast distances [to get a diagnosis] just was never going to be a practical thing. At some point, we had to start thinking more creatively.”

For the Taltons, this approach of virtually transporting the clinician to the family’s home for an autism assessment has been a success. With the diagnosis, Obadiah is now able to go to therapy, where he is blossoming, and family has more clarity and direction, which is hard to come by without a clear answer.

Whether virtual autism assessment will become the norm is unclear. But some researchers argue telehealth may be the way forward in overcoming problems with autism screening and diagnostic tools, a lack of training for pediatricians, limited access to specialists, and the consequent long delays that make an already fraught process more taxing for families in rural America.

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Nestled at the edge of Eastern Washington’s Coulee Country, the two-mile-long Soap Lake is known for its “healing waters”. Local Native American tribes would gather around ‘Smokiam’, pronounced *smoke-eye-um*, to trade, soak in its water, and race horses.

Today, the rural town of Soap Lake extends along the shoreline of its namesake and is home to boarded up health resorts, a small grocery store, and plenty of mom-and-pop shops. Like Liz, many people who live here today also grew up in the town and never left.

“It’s a beautiful place to escape city life and connect with nature, especially if you live further out on a farm. You don’t have to worry about people always passing by your house, or the traffic,” said Liz.

To get to the closest shopping mall, it takes an hour of driving. Growing up here, Liz and her cousins “made their own fun” by playing in the lake and sitting on the beach. She had envisioned the same for her kids: a childhood of peace, stability, and normalcy. But when she got married in 2014, she didn’t know what the future held — the new, unexpected ways in which she, and her family, would struggle with rural life.

The Taltons underwent two and a half years of infertility treatment before they got pregnant with Obadiah. Every month, Liz and her husband drove three hours to the closest fertility clinic in Seattle for an intrauterine insemination. Travelling for hours was hectic and emotionally draining, and it quickly became apparent to them what it entails to seek specialty care while living in a small, rural community.

“Almost every day I was thinking, Oh my gosh, I’m facing the possibility of never having children,” said Liz. “So, of course, I did everything I could. And when I was able to conceive, it was both shocking and magical.”

Things went well for the first year or so. Obadiah hit all the developmental milestones on time— he made eye contact, responded to his name, and spoke a few small words. And then, it all slowed down as soon as he turned two.

In April 2019, Liz took her concerns to the pediatrician, who asked her to fill out a brief questionnaire called M-CHAT, which stands for the Modified Checklist for Autism in Toddlers that is used to screen children for the disorder at 18 and 24 months. This test asks parents “yes” or “no” questions about their child’s social behavior and language skills to determine whether a child is at risk of developing autism.

When the doctor went over Liz’s answers, she reassured her that Obadiah seemed to be doing just fine, but Liz was not satisfied.

“My concerns were completely dismissed because when you go in for an appointment, you’re only there for 20 minutes. So they’re really not seeing the behavior, the speech or, you know, the whole big picture,” she said.

Unfortunately, it isn't unusual for pediatricians to lack training in recognizing autism, according to Nicole Ginn Dreiling, clinical director of the Raleigh TEACCH Autism Center at the University of North Carolina. Most of them don't learn about it in medical school and rely on screening tools like M-CHAT to evaluate if a child should be referred to an autism specialist for an assessment.

But studies have shown that M-CHAT is not finely tuned to accurately identify risk of autism because the condition is a broad spectrum that affects individuals very differently. Parents often have limited knowledge of autism as well, which affects their answers to questions about autism-like behaviors, such as rocking, avoiding eye contact, and difficulty in understanding reactions, in their child. And restricting these answers to a simple "yes" or "no" on the questionnaire makes it more challenging for the pediatricians to get a reliable reading.

"It's important for screening tools to see if these behaviors look atypical as opposed to present or absent," said Josephine Barbaro, associate professor in the Olga Tennison Autism Research Centre (OTARC) at La Trobe University in Australia. She has developed a more accurate screening questionnaire for autism, which, unlike M-CHAT, asks about infrequent and inconsistent use of common behaviors, like eye contact and engagement with others, to monitor the risk of autism in young children.

Barbaro's research with this early detection screen has shown that signs of autism are evident in children as young as 12 months old. However, the average age of diagnosis in the U.S. is 4 years.. This is because autism screening and diagnostic tools have always been infamously unreliable for doctors to identify behavioral problems stemming from the disorder.

For a very long time, there wasn't even a clear diagnosis for autism. Children who exhibited behavioral problems that are now identified as autism-like were lumped into a broad category of schizophrenia. In 1980, for the first time, third edition of the psychiatric handbook used by clinicians in the U.S. listed autism as a distinct disorder and laid out the criteria for its diagnosis.

It was also around this time when researchers developed the current "gold standard" tools for autism diagnosis, called the ADOS and ADI, but they came with their own flaws: it cost families over \$2,000 for a single assessment and, for the results to be reliable, the observations had to be interpreted by a specialist who is trained in identifying autism, unlike most pediatricians.

But in small, rural towns, like Soap Lake, there is a dire shortage of such specialists. In fact, a recent study led by researchers at the University of Louisville in Kentucky revealed that in more than half of all U.S. counties, there are no autism experts, despite the need for their services.

As a result of limited access, families suffer from the bottleneck in autism diagnosis. Waiting lists are long and it can take up to a year for a family to receive a clinical evaluation of autism for their child, said Alacia Stainbrook, autism specialist and associate director of an early intervention program, TRIAD, at Vanderbilt University in Nashville, Tennessee.

Liz had heard of these long delays from a friend in Soap Lake whose child "was on the waiting list of an autism center in Seattle for two years". She urged Liz to act fast and book an appointment with a specialist immediately. In October 2019, six months after their last meeting with the pediatrician, Obadiah had "reverted back to babbling". It was then that the Taltons knew they shouldn't wait any longer.

"I had spent months scouring the internet for answers because anybody that I ever saw for him never informed me about autism," said Liz. "And then once we started, you know, putting the pieces together and looking at all the other symptoms, it became evident very quickly [that Obadiah could have autism]."

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On a Tuesday morning in late-March 2020, Liz logged onto Zoom for the family's long awaited appointment with an autism expert. The clinician started by asking her in-depth questions about Obadiah's social behavior: does he have a fixation with specific objects? Does he play with his toys differently? How does he interact when you ask him a question?

After 30 minutes of interviewing Liz, she then moved onto the behavioral observation component of the diagnosis process. Liz was instructed to sit down and carry out a set of activities with Obadiah, allowing the expert to gauge his communication and problem solving skills.

With the doctor's coaching, Liz took a small spoon and placed it in front of Obadiah. She then asked him to pretend feed the toy in front of him, but he looked puzzled and swiftly knocked the spoon off the table.

"I just couldn't get him to focus," said Liz. "And then she [autism specialist] told me, it does very much seem like he has autism because he's checking all the boxes."

After over a year of doubt and uncertainty, within an hour of meeting the specialist, Liz had an answer. But for some families this day doesn't come until much later or sometimes at all, according to Cece Wolfner, the sister of an autistic 29-year-old man, Brooks Wolfner, who was misdiagnosed with a different behavioral disorder until he was six.

For years, Brooks' family felt rudderless in their quest to help him because the pediatrician didn't find him to be at risk for autism, said Cece. The clinician's misjudgment had a domino effect: years of delay in Brooks' autism diagnosis, support, and self-acceptance journey.

For this reason, researchers like Dreiling argue that training pediatricians to identify autism should be the very first step towards ensuring that all autistic children who need services are able to receive them.

In 2017, when Dreiling heard about the Echo Autism Project that connects autism experts with pediatricians for free online training, she felt that it was the perfect partnership for the research center to make an impact. "We decided to give it a shot with the goal of saying, how can we really start building capacity right in their [families] community, so they're not having to go elsewhere," she said.

Now Dreiling and her team of autism experts at the University of North Carolina meet with pediatricians twice a month for an hour-long online training session that addresses different aspects of working with families of autistic children. The focus of these sessions ranges from how to identify autism and conduct a screening to referring families for an autism assessment.

"We've received feedback from pediatricians that they're screening and can now manage autism better in their home clinics," said Dreiling. "But families are still having to wait for testing."

Unfortunately, the process of getting an autism diagnosis is like solving a puzzle: families can't get a clear answer unless all the pieces come together perfectly. Pediatricians are a necessary part of the process, but their ability to help families is limited when there's a backlog of children waiting to see a specialist for an official diagnosis.

It boils down to supply and demand: there's far more families who need an autism assessment for their child than specialists who can perform the assessment. Training more doctors to become highly specialized in autism will take time, so some researchers have begun to develop tools that will take autism assessments from a very limited group of experts into the hands of parents and primary care doctors.

"We have this really long wait with children to come in and to be evaluated for autism," said Liliana Wagner, a psychologist and autism researcher at Vanderbilt who is involved in the creation of one such tool. "There's a potential that from first concern to diagnosis, you can really close that gap by using a tool over telehealth so that the family can get the answer more quickly."

Alongside a team of experts, Wagner has developed a video screening assessment for autism called TELE-ASD-PEDS, or TAP. This remote autism assessment uses a set of activities that hone in on the child's speech, body movements, and social behavior. Through simple techniques like playing peek-a-Boo with the child to see if they react, or observing if they throw the ball on "ready, set, go!", families can have an autism diagnosis within 20 minutes.

Though the researchers are still collecting data on how effective TAP is in accurately identifying children

who have autism, “there’s an extremely high level of agreement between the use [results] of TAP over telehealth and then in-person autism evaluations,” according to Wagner.

In February, a review of studies on tools for virtual autism diagnosis also offered favorable evidence regarding the potential of this new approach; when compared with an in-person autism evaluation, the accuracy of these tele-assessments ranged from 80% – 91%.

But there are big drawbacks for researchers to consider as well. Though families have clarity after an autism diagnosis, many parents also experience grief and a profound sense of loss.

“I was a wreck,” said Liz. “It’s not like someone died, but you’re realizing that your child has like a lifelong condition that you have to manage. It’s just all new and it’s a lot.”

During this time, having a positive interaction with the clinician can change parents’ outlook and offer them comfort. But with telehealth, forging a connection with the doctor becomes even more challenging; for Liz, the experience of receiving a telehealth diagnosis for Obadiah resulted in feelings of isolation and helplessness that she’s still working hard to overcome.

And for some families, this new approach doesn’t work at all. In cases where it’s a little more ambiguous if a child has autism, parents are referred for an in-person assessment, said Stainbrook.

Having embarked on this difficult journey as a parent, if there’s anything that Liz has learnt, it’s the importance of having support. Today she writes about her experience with Obadiah’s telehealth diagnosis to “start a conversation about the needs of families in rural areas” and build a resilient community of mums like her.

Meanwhile, Obadiah is learning new words in therapy every week. It’s helping him forge friendships at school and strengthening the bond he has with his younger brother.

“There’s this common misconception that people with autism just don’t have the same level of care,” said Liz. “But I can see them coming together. It’s all about communication.”

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