

DEEP DIVE

Moving for autism care

BY MARTA ZARASKA

4 AUGUST 2021

Photography by Kristian Thacker

After their son Jett was diagnosed with autism, Sarah Harris and James Shilling found the local care wanting in West Virginia, where they live. They faced long waitlists for the standard autism therapy, **applied behavior analysis** (ABA), and local schools were either too expensive or lacked programs appropriate for their son. Harris and Shilling envied the options they found in the neighboring state of Ohio, such as ABA-centered curricula designed for children with learning and sensory differences. “I got really frustrated that we couldn’t do something like that,” Harris says. They wanted to move — but felt they could not afford to do so. Shilling’s unionized job as a truck driver was not easily transferable, and the family feared losing their health insurance.

David and Michelle Lane, who live in Kentucky, were also eyeing better care across state lines. When their son Aaron, who has autism, became aggressive as a pre-teenager, nothing they tried seemed to help. Appropriate therapy and schooling seemed elusive where they lived, Michelle recalls. So by the time Aaron was 17, the family felt they had exhausted all local options, and they decided to move. “We looked all over the whole country,” David says. In the end, they decided on Boston, Massachusetts, after friends with a daughter on the spectrum raved about the great schools there.

No one knows exactly how many families move, or want to move, for better autism services in the United States, but some evidence suggests that the desire to do so is common. Unpublished findings from a 2004 survey of 969 caregivers of people with autism suggest that about 1 in 5 moved to get higher quality services, according to **David Mandell**, associate professor of psychiatry and pediatrics at the University of Pennsylvania in Philadelphia. Local U.S. autism organizations, including the Autism Society of Colorado and AutismUp in Rochester, New York, say that just about every week they hear from a family wanting to move to another state in search of superior care. And autism forums on sites such as BabyCenter, Facebook and Reddit are rife with questions from parents about autism-friendly states.

“It breaks my heart and makes me angry that we as a society have decided that these are not services that we value enough.” David Mandell

That so many autism families are willing to uproot themselves reflects an endemic problem in the U.S.: large disparities between states in access to diagnostic services and treatments for autism, schooling and the cost of care, according to several reports documenting these issues. These disparities lead to inequities between people who can afford to move for better options and those who cannot, says **Dennis Wall**, a biomedical data scientist at Stanford University in California. But even for the more fortunate families, the differences create a ‘Sophie’s choice’: Move in search of better options for their children but lose the stability of home, or stay put and keep some supports but relinquish the possibility of others.

Moving often has serious downsides, including cost, distance from family support systems, and life disruptions of the type autistic people find especially difficult. “I can only imagine that for a child for whom routines are comforting and helpful, which is all children but maybe especially children with autism, that moves can be incredibly psychologically disruptive,” Mandell says. In addition, relocation is not necessarily a panacea. No state is perfect; there are gaps in care everywhere, and places that are great for young children may not be optimal for older ones.

Experts say that the situation for these families would be vastly improved if autism diagnostic services and treatments were easily accessible across states and counties and were reimbursed equally. “It breaks my heart and makes me angry that we as a society have decided that these are not services that we value enough, and that these are not people we value enough, to make autism services available where people are,” Mandell says.

Trial and error:

Obtaining an autism diagnosis is one hurdle that families find more or less of a challenge depending on where they live. For the Lanes, getting a diagnosis for Aaron was straightforward. When Aaron was 18 months old, he was assessed at the University of Kentucky. “We were fortunate,” David says. For Jett’s family, finding diagnostic expertise was far more difficult. Although Jett started showing some atypical behaviors at age 3, it took five years to figure out why. Troubles at daycare, and then at school, led Jett’s parents to shuffle him from one doctor to another. At the age of 3 and a half, Jett was diagnosed with **attention deficit hyperactivity disorder**, for which he took stimulants; he was also prescribed antidepressants and antipsychotics. No one mentioned autism.

An online database of autism resources called **GapMap** shows how far the average person would need to travel to get a diagnosis in a given state. In New Jersey, that distance is about two miles; in Nevada, it is more than 30 miles. Such disparities may be due to a multitude of factors, such as a state's economic health, population density and the strength of lobbying efforts by local autism communities. More than 83 percent of all U.S. counties lack any diagnostic services whatsoever, GapMap suggests. This hole in care is important because early diagnosis "should help accelerate access to therapy, which can have bigger benefits if delivered early and consistently," says Wall, who led the GapMap project.

Quantity of resources does not always coincide with quality of care, however. In West Virginia, the average distance to obtain an autism evaluation is only about 11 miles, but Jett's parents bounced from one specialist to another for years before Harris herself noticed similarities between Jett's experiences and those of an autistic friend. She called the friend, and he helped her find a psychologist who finally diagnosed Jett with autism at age 8. "I felt relief at first. Then I felt upset that it took that long," she says.

In a 2017 study, researchers compared the odds of being diagnosed with autism among children of nurses in 48 states. They found that the children living **in the Southeast** at age 6 were about half as likely to receive an autism diagnosis as was typical for the 6-year-olds overall, after controlling for the mother's age, the child's sex and community income, among other factors.

```
!function(){"use strict";window.addEventListener("message",(function(a){if(void 0!==a.data["datawrapper-height"])for(var e in a.data["datawrapper-height"]){var t=document.getElementById("datawrapper-chart-"+e)||document.querySelector("iframe[src*='"+e+"']");t&&(t.style.height=a.data["datawrapper-height"][e]+"px"))}})}();
```

Treatment options also vary widely by state. In West Virginia, Jett's mother faced a shortage of the professionals, called board-certified behavioral analysts (BCBAs), qualified to deliver ABA. This therapy can boost learning, social skills and daily function in people with autism, data show. But a **lack of BCBAs** means that it is often left in the hands of less qualified technicians, who may deliver substandard care. States need a minimum of **three BCBAs per 100 autistic** children to provide adequate care, according to a 2020 report.

But in West Virginia, there is just slightly more than one BCBA per 100 children with autism. Although Jett received 11 hours a week of one-on-one therapy before the pandemic, that has since drastically declined. "We get an hour and a half a week, and that's a group, so he basically hangs out with a few other kids and plays board games," Harris says. BCBAs are particularly scarce in Idaho, Oklahoma and Mississippi; these states and a number of others have fewer than one BCBA per 100 autistic children. By contrast, in Massachusetts, Vermont and New Hampshire there are, respectively, about nine, six and five BCBAs per 100 children with autism. More than half of U.S. counties have **no BCBAs whatsoever**.

In Kentucky, where there is only slightly more than one BCBA per 100 children with autism, Aaron had good care until he was 12. He was getting up to 30 hours per week of one-on-one ABA, which is enough for optimal progress, research shows. He became increasingly aggressive in middle school, however. “This was a very difficult time. We were just looking for any solutions,” David says. Aaron was put on behavioral medications, which at first worked, and then didn’t. Finding a good school and therapy for him was an uphill battle. “We couldn’t find any good options in Kentucky,” David says.

Other clinicians important for autism care, such as speech therapists, pediatricians and physical therapists, are also in short supply in some states. In the Northeast, more than half of children with autism see **multiple specialists**, according to a 2019 study. But in the South, which includes Kentucky and West Virginia, only about one in three autistic children receives this kind of help.

Paying for care is another consideration. All states and Washington, D.C. have autism mandates — laws requiring health insurers to cover autism treatments — but these mandates differ considerably in how much coverage they provide. For instance, Massachusetts has no age caps on coverage, but Mississippi ends benefits once the child is 8 years old, and many others end coverage between the ages of 18 and 21, according to a **comparison of state mandates** published last year. Oklahoma and a few other states set a limit on the number of service hours, usually 25 hours per week, and 23 states have an annual benefit limit ranging from \$20,000 to \$72,000.

The number of people with autism who qualify for **services through Medicaid** also varies by state, according to a study published in July. In most states, eligibility criteria have loosened over the past decade or so, however, fueling a fivefold increase in the number of Medicaid programs that provide care specifically for autistic individuals.

```
!function(){"use strict";window.addEventListener("message",(function(e){if(void 0!==e.data["datawrapper-height"]){var t=document.querySelectorAll("iframe");for(var a in e.data["datawrapper-height"])for(var r=0;r
```