

NEWS

# Research raises questions about impact of state autism insurance mandates

BY SHEFALI LUTHRA, KAISER HEALTH NEWS

11 MAY 2016

A total of 44 states and the District of Columbia have laws on the books requiring health insurers to cover autism treatments. But new research evaluating the so-called 'insurance mandates' suggests these efforts are failing in key ways to help people — especially children — get needed therapy.

These findings, which were to be presented Wednesday at a major **conference on autism spectrum disorder** and will appear this summer in *JAMA Pediatrics*, highlight the consequences of this shortfall.

There's been a push for health insurers to better cover often-pricey autism treatments, especially **applied behavioral analysis**, a type of behavioral modification therapy.

Those efforts come as autism rates have ballooned. In 2014, the most recent year for which data are available, the Centers for Disease Control and Prevention (CDC) estimated that **1 in 45 children** are on the autism spectrum, with features ranging from communication difficulties to repetitive or obsessive behaviors. In 2000, the rate was **1 in 150**.

Researchers found that the **state mandates** — which apply to coverage available on the individual market and some group and employer plans — led to about 12 percent more children getting some kind of treatment for autism. But when compared with the number believed to have the condition, it's not nearly enough, they say.

“These numbers are orders of magnitude below” the CDC’s autism estimates, says David Mandell, one of the researchers and director of the University of Pennsylvania’s Center for Mental Health Policy and Services Research. “It suggests that a lot of commercially insured kids with autism are not being treated through their insurance.”

The shortfall may have significant health consequences, says Daniele Fallin, who chairs the Johns Hopkins University department of mental health and directs Hopkins' Wendy Klag Center for Autism and Developmental Disabilities. For children, it's important to get treatment as soon as possible. If that doesn't happen, the condition will become more complicated — and more costly — to treat in the long run.

"It's a big concern any time you see this kind of treatment gap," says Fallin, who wasn't affiliated with the study.

The researchers used insurance claims data from 2008 to 2012 compiled by the Health Care Cost Institute, a nonprofit organization that focuses on price transparency. They divided the case files of 154,000 children into four groups. First, they took states with insurance mandates and split the files between children whose coverage was affected and those whose was exempt. Then, in states without insurance mandates, they divided children with commercial insurance — that is, insurance that would have been hit by a mandate if one existed — and those whose policies still wouldn't have been affected. The study did not include Medicaid plans, and the claims data was pulled from three large insurance companies in all 50 states plus the District of Columbia.

The researchers then analyzed how many autism-related treatments those individuals billed to their insurance, controlling for factors such as age, sex, health plan type and calendar month. They found that having a mandate in place increased the level of treatments billed by an average of about 12.2 percent — 9.9 percent during the mandate's first year, 16.6 percent the second year and 17.2 percent in subsequent years.

But questions persist beyond whether children with autism got some form of care. The researchers are still teasing out what kinds of treatments children who used their insurance actually received. And, Mandell says, it leaves open how good that care actually was.

The takeaway is that insurance mandates are "necessary but not sufficient" for helping people get needed therapies, he says.

That makes sense, says Alycia Halladay, chief science officer at the Autism Science Foundation, which helps fund research. Requiring health plans to cover autism therapies was important as a first step, she argues. But more needs to be done.

"You can't rely on these mandates alone. You can't say, 'OK now, everything's hunky dory, and everyone's being served the right way,'" she says.

There are a few possible reasons the coverage requirements aren't always translating to people getting treatment.

Even if insurers have to cover care, there's wide variation in how generous the coverage is. Plans

can argue that certain services — such as speech and occupational **therapy**, as well as applied behavioral therapy — aren't necessary, or they can require higher cost-sharing from beneficiaries, or reimburse at a low enough rate that doctors don't participate. Also, not all mandates are equal — some states **cap how much spending** a plan has to guarantee, allow ceilings to the number of doctors' visits or limit the **age range** of beneficiaries.

Even when a mandate is in place, it's often unclear what insurance plans are actually required to pay for, says Halladay. Plus, parents of children with autism may not realize what services are covered, she says.

Then there's also the fact that, compared with the need, not enough doctors are familiar with autism treatments, notes Mandell, who coauthored a **qualitative study** published last November in the journal *Autism*.

"There are long waiting lists for people to get medical referrals for their autism-related problems. There are wait-lists all over the place. And that's because there aren't enough people trained," Halladay says. "It's not an easy problem to solve."

That could have cost implications, too. Insurance plans have argued that mandates could drive up premiums. So far, they've resulted in increases of about 1 percent, according to the **National Conference of State Legislatures**, but those could grow if plans cover more services or autism rates keep climbing. That could also color whether other companies not covered by the mandates choose to cover these services. For instance, the laws don't affect large companies that are self-insured, though some, such as Home Depot and Microsoft, provide autism treatment coverage.

*This story originally appeared on Kaiser Health News. It has been slightly modified to reflect Spectrum's style.*

*For more reports from the 2016 International Meeting for Autism Research, please [click here](#).*