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State Insurance Mandates For Autism Treatment Fall Short

By SHEFALI LUTHRA • 23 HOURS AGO

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Early treatment for autism is key to making the most of the intervention, researchers say.

MARC ROMANELLI / BLEND IMAGES RM/GETTY IMAGES

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Forty-four states and the District of Columbia have laws on the books requiring health insurers to cover autism treatments. But research evaluating these insurance mandates suggests the efforts are failing to help many children get needed therapy.

The state requirements have increased the number of children by about 12 percent, according to the research presented Wednesday at a major conference on autism spectrum disorder (<http://www.autism-insar.org/imfar-annual-meeting/imfar-2016>).

There's been a push for health insurers to better cover often-pricey autism treatments, especially applied behavioral analysis (<http://khn.org/news/narrow-marketplace-plans-in-texas-pose-problems-for-autistic-children/>), a type of behavioral modification therapy.

Those efforts come as autism rates have ballooned. In 2014, the most recent year for which data is available, the Centers for Disease Control and Prevention estimated that 1 in 45 children (<http://www.cdc.gov/nchs/data/nhsr/nhsr087.pdf>) are on the autism spectrum, with symptoms ranging from communication difficulties to repetitive or obsessive behaviors. In 2000, the rate was 1 in 150 (<http://www.cdc.gov/ncbddd/autism/data.html>).

Researchers found that the state mandates (<https://www.autismspeaks.org/state-initiatives>), 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 that's not nearly enough when compared with the number believed to have the condition, they say.

"These numbers are orders of magnitude below" the CDC's autism estimates, said David Mandell, one of the researchers and the 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, said Daniele Fallin (<http://www.jhsph.edu/faculty/directory/profile/967/margaret-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," said 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 who would have been affected had there been a state mandate, and those who would not.

The study did not include Medicaid plans. 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 were billed to insurance, controlling for factors like 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 patients got some form of care. The researchers are still teasing out what kinds of treatments children who used their insurance actually received. And, Mandell said, 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 said.

That makes sense, said 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 argued. 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 said.

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 is wide variation in how generous the coverage is. Plans can argue that certain services like speech and occupational therapy (<http://khn.org/news/michelle-andrews-health-law-provides-coverage-for-special-needs-people/>) as well as applied behavioral therapy aren't necessary. Or insurers can require higher cost-sharing, or reimburse at a low enough rate that providers don't participate. Also, not all mandates are equal – some states cap coverage (<http://khn.org/news/michelle-andrews-on-autism-coverage-and-changes-in-connecticut/>), allow ceilings to the number of visits or limit the age range (<http://khn.org/news/michelle-andrews-autism-adult-treatment-options/>) of beneficiaries.

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

Then there's also the fact that, compared to the need, not enough doctors are familiar with autism treatments, noted Mandell, who co-authored a qualitative study (<http://aut.sagepub.com/content/early/2015/11/26/1362361315605972.abstract>) published last

November in the journal *Autism*. The research presented Wednesday will appear this summer in *JAMA Pediatrics*.

"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 said. "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 (<http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>), but those could grow if plans cover more services or autism rates keep climbing. That could also color whether other companies not included in the mandates choose to cover these services. For instance, the laws don't affect large companies that are self-insured, though some, like Home Depot and Microsoft, provide autism treatment coverage.

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