Why insurance denies your claim, but pays your neighbor's

September 8 2016, by Tom Murphy

In this Thursday, Sept. 1, 2016, photo, Caiti Riley, who lost her left leg when she was 4-years-old, poses for a photo near her home in San Antonio. Riley's insurance plan is paying most of the cost for a new running leg to complement the one she uses every day. (AP Photo/Eric Gay)

Tracey Stahl lost part of a leg to bone cancer last fall, and she has to wince through bouts of crippling pain from an ill-fitting artificial limb because of a strange health insurance limit: Her plan covers just one

limb per lifetime.

She now has to weigh whether to dump the nearly $9,000 cost of a new leg on her credit card as she fights her insurance company over the restriction. "I feel—it's embarrassing to say—paralyzed about what to do," said Stahl, from her home in Penfield, New York.

Caiti Riley's left leg was amputated below the knee at age 4 due to a rare birth defect. The San Antonio resident is 31 now and covered by the best insurance she's ever had. Her plan is paying most of the roughly $5,000 bill for a new running leg to complement the one she uses every day.

"I work out every day, there's nothing really that I can't do now," she said.

Glaring differences in insurance coverage persist for amputees, children with autism and others in need of certain expensive treatments even after the Affordable Care Act set new standards as part of its push to expand and improve coverage, and despite efforts by states to mandate coverage for some treatments.

These differences don't develop simply because some people pay more for better coverage. Instead, they stem from random factors like what state someone lives in or who happens to provide their coverage—and often people can do nothing about it. The federal health care law largely leaves decisions on what actually gets covered up to states or employers who provide insurance for their workers.

These gaps can bury patients in debt or force them to skip care. And they may become more common as health care costs continue to rise and insurers and employers look for ways to control that expense.

Researcher Sabrina Corlette thinks nothing short of federal action can

close these coverage gaps, and she doesn't see that happening anytime soon.

"I think you would need to see Congress say, 'Ok, we need more uniformity here,'" said Corlette, a Georgetown Health Policy Institute professor. "And I just don't see this Congress or any near-term Congress stepping in and wanting to do that."

States have passed about 1,800 mandates requiring the coverage of various treatments or conditions, according to the National Conference of State Legislatures. But those mandates don't extend beyond state borders, and they don't apply to the self-funded coverage offered by nearly all large employers.

North Carolina, for example, recently became one of 44 states to require coverage of autism treatments—and it won't help Iris Castillo one bit.

The Raleigh, North Carolina, resident said it felt like a cold bucket of water had been tossed on her when she learned that insurance from her new job won't cover applied behavior analysis therapy for her 9-year-old son, Alex.

Hours of this daily therapy, which is a standard treatment for autistic children, have helped Alex learn simple tasks like how to brush his teeth or say hi to another kid. Castillo worries that her son will regress if treatment stops. But it can cost more than $40,000 a year, far beyond what Castillo's family can afford.

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"You don't feel like you're in control," she said.

Her employer's coverage is self-funded, which means it pays its own health care bills instead of buying coverage from an insurer. That also means it doesn't have to comply with most state coverage mandates.

Employers have been slowly switching to this type of coverage for several years to help control what has become one of their largest expenses and to avoid some of the requirements imposed by the ACA, said Robert Laszewski, a health care consultant and former insurance executive. He expects gaps or differences in coverage to become more common as health expenses grow.

Insurers and employers routinely cover organ transplants, heart procedures and other expensive surgeries. But coverage still varies widely for a range of patients that also includes people recovering from eating disorders like anorexia and women who need breast reduction surgery to ease back pain.

The cost of a particular treatment, the need for it in a covered population and lingering disagreements over necessity help explain some coverage differences.

Bariatric surgery, which can improve the health of obese patients by limiting food intake, can cost $7,000 to $30,000. Coverage is improving, and Dr. John Morton estimates that about 75 percent of patients who need the surgery have some insurance for it.

But the quality of that coverage varies widely, according to the Stanford School of Medicine surgeon. Some plans only cover the procedure for severely obese patients, while others may charge deductibles of around $10,000, which can dissuade many from having surgery.

An annual survey of large employers by the benefits firm Mercer found that 40 percent offered no coverage for infertility treatment last year. Some companies don't view it as essential to a person's health, while others with an eye toward attracting and keeping good workers, have started offering the coverage to help LGBT patients conceive.

"We see a lot of variation between employers, and it's extremely confusing to the consumer," said Dr. David Kaplan, a senior partner at Mercer.

Tracey Stahl, who lost her leg to cancer, got a prosthesis in January, but her leg shrank so the artificial limb no longer fits. This forces her to use crutches or a wheelchair when she has to walk more than a short distance. If the pain grows too intense, she retreats to bed and keeps her leg elevated.

She bought her coverage on New York's public insurance exchange. Her insurer, Excellus BlueCross BlueShield, said the coverage it sells there follows a model set by the state. The insurer rejected Stahl's claim for a new limb in May and then rejected her appeal in July.

In Texas, Caiti Riley said her previous insurance capped limb coverage at $2,500 every four years, which she likened to "a smack in the face." Now her coverage is so good she says she almost feels bad about it.

"I know what the challenges are," she said. "If you go out and get in a car accident and lose your leg, you're not going to be prepared for something like this."