

Kids with complex conditions often lack adequate in-network care

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Children with complex medical conditions, especially those who require behavioral health treatment, often have to go outside of their insurance plans' provider networks for care, a new study has found.

Almost one in five [children](#) with complex, chronic [medical conditions](#) such as [cystic fibrosis](#) and Type 1 diabetes, who also need behavioral health care, are seen by specialists who are out of network, found the new study, led by researchers at The Ohio State University. It appears in the journal *Medical Care*.

The need for out-of-network care means more out-of-pocket costs to families, and can compound the stress of caring for a child with lasting medical needs, said lead author Wendy Xu, an associate professor of health services management and policy at Ohio State.

"In the U.S., the reality is that the more health care needs you have, especially from specialists, the greater chance you will find your needs won't be met, even if you have private insurance coverage," Xu said.

"Inadequate provider networks can really constrain their access to care and it's an ongoing struggle. These are conditions that will never go away and are pretty severe, and these patients very often face additional care needs because of mental health conditions."

Using a national medical claims database that included almost 8.7 million people up to 18 years old, Xu and her colleagues examined groups of patients by level of medical complexity and compared their [health care use](#), costs of care and the amount of money their families paid in out-of-pocket costs.

About 24% of children with complex, [chronic conditions](#) received out-of-network care, compared to 14% of those with noncomplex chronic conditions and 7% of those without chronic health problems.

Out-of-network cost sharing averaged \$930 a year for [pediatric patients](#) with complex, chronic conditions (7% of those in the study) compared to \$634 for those with noncomplex chronic conditions and \$332 for the

majority of children.

Researchers and policy experts have previously explored the hardships of out-of-network care for adults, but little is known about pediatric coverage—largely because most children are generally healthy and don't often require specialty care, Xu said.

"Only a small fraction of kids tend to rely on specialty care providers, but that doesn't mean they should be forgotten. For children with complex chronic conditions, and for their families, this can present significant hardship," she said, adding that the study doesn't account for those cases where families didn't seek needed care because it was too expensive or inconvenient.

Many children with complex conditions also need to be seen by non-physician therapists and psychologists for behavioral conditions associated with their diagnosis, and that's when in-network access to care gets even more challenging.

"One of the saddest findings was that among those with behavioral health needs, their rates of having to see a provider out of network were surprisingly high, and that was true even for those kids who didn't have complex, chronic conditions," Xu said.

Rates of out-of-network care were high across the board (in excess of 14%), but highest for those with complex medical needs, at more than 19%.

"This leads to excessive burdens to families, especially those with children who have complex conditions. Navigating different providers and the scheduling system and multiple specialties is hard enough, and when they have behavioral [health care](#) needs, there's another level of work," Xu said, adding that COVID-19 has exacerbated the challenges

on the behavioral health front.

"There's been a huge increase in the behavioral health needs as a result of interrupted school schedules, sickness and all kinds of other issues—making this issue even more concerning," she said.

Policy solutions could include minimum numbers of providers in specialties based on plan enrollment, she said, and in those states that already have such regulations, the states could consider closer scrutiny of network adequacy. Improved [workforce development](#) for behavioral [health](#) providers, subsidies to encourage providers to join networks and increased payments for the care they provide could also help, she said.

Other Ohio State researchers who worked on the study are Yiting Li, Chi Song, Seuli Bose-Brill and Sheldon Retchin.

More information: Wendy Y. Xu et al, Out-of-Network Care in Commercially Insured Pediatric Patients According to Medical Complexity, *Medical Care* (2022). [DOI: 10.1097/MLR.0000000000001705](#)

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