disabilityscoop

How Rural Communities Can Fill Care Gaps For Children With Special Health Care Needs

by Lauren DeLaunay Miller, California Health Report | December 17, 2024

A sign just south of Bishop, Calif. along Highway 395 shows the distance to Los Angeles, where many residents must travel for specialized health care. (Lauren DeLaunay Miller/California Health Report)

Katrina Otten was nearly seven months pregnant with twins when she started struggling to breathe. It was March of 2020. Afraid she might have COVID-19, she went to the hospital near her home in Bishop, Calif. There, they found something worse: She was bleeding internally, and the doctors told her that she needed an emergency C-section. Soon, Otten was loaded onto a fixed-wing plane and flown to a larger hospital in Loma Linda, Calif., more than 250 miles south. It took her 10 days to recover, but it took her twins even longer.

Two months passed before her newborns were strong enough to go home and join Otten, her husband, and their three older sons in Bishop. Otten and her family were ready to put that scary episode behind them, but in September of 2020, she started suspecting that something wasn't quite right with Hudson, one of the twins. He wasn't responding as quickly, and compared to his brother, Grayson, he seemed different.

The Ottens had already traveled back to Loma Linda three times that summer so their specialists could check up on the twins' development, and at their September appointment, they learned that Hudson had cerebral palsy. By this time, Otten had realized there was a price to pay for living in such a rural area — limited access to specialty care. Knowing that Hudson would continue to need specialized medical attention as he grew, she and her husband, Adam, felt they had only one choice. "We started gathering boxes," said Otten.

Amidst a nationwide shortage of pediatric subspecialty physicians, families caring for children with special health care needs in rural areas are often forced to travel long distances for care. For those in California's remote Eastern Sierra, including the Otten family, that means hundreds of miles of driving, often at their own expense. Navigating the complicated network of specialists, insurance companies, and state and county agencies can take a large toll on families.

For some families, the burden is too great to bear, and moving to be closer to care feels like the only option. For others, the burden is shouldered by parents for whom managing the bureaucracy while advocating for their families feels like a full-time job. Physicians and parents agree that on top of bringing more specialists to rural areas, increasing the flow of information between agencies and making travel reimbursements easier to attain would ease some of this burden on families.

Pediatric specialists often earn less than general pediatricians, even though they have undergone three years of additional training, leading fewer future physicians to seek out this line of work. General pediatricians are among the lowest-paid doctors in the country, largely because of low federal reimbursements for care. The result is a physician shortage, with children in rural areas suffering disproportionately.

Children with special health care needs, according to the Centers for Disease Control and Prevention, include those with physical, intellectual and developmental disabilities, in addition to those with medical conditions like asthma, diabetes and blood disorders. Nearly 1 in 5 American children have a special health care need, and while they are distributed equally in urban and rural areas, children in rural areas face increased barriers to care.

Dr. Lindsey Ricci is currently the only full-time pediatrician at Northern Inyo Hospital in Bishop. Northern Inyo's other full-time pediatrician is currently on maternity leave, and another pediatrician travels to the area occasionally. She said that while this small team, plus the family medicine providers at the nearby rural health clinic, has typically been able to manage the community's routine pediatric needs, they do not have the resources to manage the complex requirements of treating children with special health care needs. But, "because we're the only pediatric clinic in town, we do see a lot of the medically complex kids," Ricci said.

Mammoth Hospital, 45 miles north of where Ricci works, employs three full-time pediatricians, but they, too, are in short supply of specialists. Ricci believes that the reason for this mostly comes down to numbers. Inyo and Mono are two of the least densely populated counties in the state, and compounding factors like a lack of reliable public transportation make the distance even more difficult to manage. Northern Inyo does occasionally receive visits from out-of-town specialists who can see patients, and she believes that making these visits more frequent and reliable would help ease the burden of travel on families. Telehealth appointments with specialists can also help reduce families' need to travel, she said.

A change in plans

After Hudson's cerebral palsy diagnosis, the Ottens assumed they'd need to move to a more urban area. But as they considered where to relocate, they also began to discover travel reimbursement options that made staying put more viable. Four years after the birth of their twins, the Otten family still travels to Loma Linda regularly for care, but they've decided to put away the moving boxes — for now.

Otten believes that travel reimbursement, whether it's through a local transit agency, insurance companies, or private funding should be easier to get for families like hers. For two years, her family was able to get some travel expenses reimbursed through the Eastern Sierra Transit Authority, but now the agency's website says that "the funds for this program have been exhausted." Otten hopes the program might resume, but the agency hasn't been able to give her any estimates of when that might be.

The Ottens have also obtained some travel reimbursement through California Children Services (CCS). CCS is a statewide program that helps arrange and pay for medical care, equipment and rehabilitation for children with certain conditions. The Ottens have insurance through their employers, and it did not originally occur to them that

their son might have more resources as a Medi-Cal patient than he would on their Anthem Blue Cross plan. But Otten said that enrolling Hudson in Medi-Cal made navigating CCS reimbursements significantly easier, though she has also received a large number of claim rejections.

A 2017 California law requires Medi-Cal managed-care health plans to include reimbursement for travel arrangements, but data on how many patients have made use of this benefit are sparse. Medi-Cal typically requires that patients use public transportation or ride-share services before being reimbursed for their private vehicles, putting the burden of proving that a private vehicle is their only option on rural families who often live in areas without public transportation.

Besides connecting its patients with CCS, Northern Inyo Hospital does not have any reimbursement programs of its own, but Mammoth Hospital does. Rhiannon's Kids is a program administered by the Mammoth Hospital Foundation that helps its patients get reimbursed for travel funds. The foundation said that last year, they helped 18 families; the year before, 23. Their funding is only available to Mammoth Hospital patients, however, which makes the Ottens ineligible.

Navigating all this bureaucracy, from private insurance companies to Medi-Cal, CCS to Kern Regional Center, Northern Inyo Hospital to Inyo County Health and Human Services, has forced Otten to become an expert advocate. She says that the many offices that help her family do not often communicate well with one another, and it's up to her to file a constant stream of paperwork. "It was like another job," Otten said. Now, she helps other families in her community navigate these agencies, but she wishes that there was a professional to do that.

And, Otten said, it's not just the financial cost of routine travel that adds up for families — it's also the time. Otten has spent innumerable hours traveling back and forth to Los Angeles, and she's not the only one. For V. and her family, the frequency of their travel to Children's Hospital Los Angeles made staying in the Eastern Sierra even more complicated. V., whose full name is being withheld at her request to protect her family's privacy, has two children with special health care needs. Her son, born in 2009, has a heart condition, and her daughter, born in 2015, has a seizure disorder. Both have spent significant time in the hospital and, in 2017, V. and her husband contemplated the same big decision that the Ottens once did. The 250 miles that separated them from their children's specialists became too much to bear, and they moved to Los Angeles.

A few years later, V's children's health conditions had stabilized and they didn't require as much medical help. So in 2020, when her work offered her a chance to move back to the Eastern Sierra, the family decided it was time to go home. They missed the quiet, calm environment of Bishop, and thought that getting away from the hustle and bustle of the city would be good for them all. They packed up, again, and moved back to Bishop.

And yet, the medical hurdles kept coming. In the summer of 2022, two years after moving back to Bishop, V.'s daughter needed two surgeries that resulted in her being flown to Los Angeles. And while she has since stabilized, next year, V.'s son will face a difficult heart surgery, one that was too complicated for their doctors in Los Angeles to perform. Instead, the family will use their summer break to stay temporarily in Palo Alto, Calif. while their son undergoes care at Stanford Medical Center.

Meanwhile, many other families of children with special health care needs choose to leave the area permanently once they realize the enormity of the struggle ahead of them, said Ricci, Northern Inyo's pediatrician. That makes the number of these children in the Eastern Sierra seem disproportionately low compared to more urban locations, she said.

For the V's and the Ottens, the decision to stay in Bishop is one they make daily. They love the community and want to stay as long as they can. Their hope is that the state and local agencies take steps to increase access to doctors in rural areas, including Bishop, and step up reimbursements for travel costs. That would make it easier for them to remain.

"This is where we want to be," Otten said.