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Parents sue the state for unlawfully denying medically fragile children in-home nursing

ALBUQUERQUE—Families struggling to care for kids who require round-the-clock care filed a class action lawsuit in U.S. District Court late last week against the New Mexico Human Services Department for failing to provide medically necessary in-home nursing hours as required by federal law. The families are also suing Western Sky Community Care Inc., Blue Cross Blue Shield of New Mexico, and Presbyterian Health Plan Inc. for failing to deliver required nursing services for medically fragile children despite being paid by the state for these services.

“All parents want their children to be safe and healthy, learning and progressing. The difference for parents like us is that we also lose sleep over the complicated logistics necessary to keep our three-year-old Caleb alive,” said Jeremy Vaughan, a plaintiff in the lawsuit and a law enforcement officer. “Our many difficulties have just been exacerbated by Covid and then made worse when I was shot in the line of duty and left unable to lift more than five pounds.”

Like other medically fragile children, Caleb Vaughan has a chronic and life threatening medical condition. He was born with Down Syndrome and at nine-months old developed a rare seizure disorder that causes dozens of seizures a day. He requires a wheelchair, is visually impaired and nonverbal, severely cognitively delayed, requires oxygen at night, and is primarily fed through a gastrostomy tube.

Caleb was approved for 173 hours a month of in-home professional medical care based on his medical conditions, but he only receives 76. Federal law requires states and insurance

companies contracted with the state to provide these hours of care to qualifying children like Caleb.

A University of New Mexico Center for Development & Disability survey of children on the Medically Fragile Waiver—a large portion of the 400 medically fragile children in the state—found that only about half of those children were receiving the full amount of nursing hours they qualified for.

Disability Rights New Mexico discussed the lack of required in-home nursing for medically fragile children with HSD in October 2021. Despite HSD’s knowledge of these long-standing systemic problems, there has been no apparent progress in ensuring medically fragile children get the care they need and are entitled to.

“In-home nursing has an incalculable impact on our son’s development and interaction with others. It greatly improves his and our family’s quality of life and makes it possible for him to enter the wider community,” said Victoria Vaughan, Caleb’s mother, who also works for law enforcement. “He brings so much joy to us, to Tommy—his six-year-old brother, and to the community. You should’ve seen his response to the encouragement and cheers when we took him to Walmart so he could practice walking on his own in a public space with a gait trainer. That experience would have been impossible without his nurse.”

Vaughan continued, “There are, unfortunately, frequent more serious occasions where we need a professional nurse. On our seven minute drive home from physical therapy this week, Caleb started to sputter and choke. Our nurse told me to pull the car over immediately. She attended to him and ensured his airway was clear until we got home and she could check his oxygen levels. I cannot attend to Caleb and drive at the same time. Without nursing care, parents don’t have many options in situations like that and are faced with difficult decisions.”

“Children are healthier and happier when they are with their families and community, not relegated to institutional care,” said Jesse Clifton, an attorney at Disability Rights New Mexico. “The state is obligated under federal law to ensure that every medically fragile child in New Mexico has access to medically necessary in-home nursing. It is legally bound to hold the managed care organizations named as defendants accountable to their contractual obligations. Instead, the state continues to pay care organizations under contract to provide Medicaid services despite their failure to do so, and already burdened families suffer the consequences.”

“Unfortunately, we just don’t receive enough of the hours of in-home nursing that Caleb qualifies for. It impacts our jobs, our marriage, friends, finances, other family members, and our son Tommy. We are in a state of chronic, all encompassing stress,” said Jeremy Vaughan. “Caleb goes to a school that serves the blind and visually impaired. If he is sick, which is very often, we have to figure out a plan. Who’s leaving their job that day? Who doesn’t have court that day? And we can never plan for the long term because we never know if we have a nurse in six months. In-home nursing alleviates some of the stress, but only if we actually get it.”

A nursing shortage exists in other medical fields but other medical service providers have hired traveling nurses from other states or countries to fill vacancies. The defendants have not attempted a similar strategy to increase obligatory medical care for New Mexico's most vulnerable children.

"In-home nurses provide an invaluable service to our loved ones who need professional medical care at home, but they continue to be underpaid," said Stephanie Welch, New Mexico Center on Law and Poverty Workers' Rights Director. "Everyone deserves to be compensated fairly for their work. Caring for children with special needs in their homes appeals to many nurses, but they must also make important financial decisions. To increase the number of nurses necessary to meet legal obligations to medically fragile children, the managed care companies should consider increasing pay."

[The M.G v. Scrase complaint can be found here.](#)

Photos courtesy of the Vaughan family.

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Disability Rights New Mexico is a private, non-profit organization whose mission is to protect, promote and expand the rights of persons with disabilities. We are the designated protection and advocacy program for New Mexico, and as such we have authority under federal law to pursue legal, administrative and other remedies on behalf of persons with disabilities. We protect, promote, and expand the rights of persons with disabilities.

The New Mexico Center on Law and Poverty is dedicated to advancing economic and social justice through education, advocacy, and litigation. We work with low-income New Mexicans to improve living conditions, increase opportunities, and protect the rights of people living in poverty.