

Cerebral Palsy Research Foundation of Kansas Posture Seating Support Initiative

March 5, 2025

To: Senate Committee on Ways & Means

From: John Cuffe, VP of Technical Services at CPRF

Chairman Billinger, Vice Chair Claeys, and Members of the Senate Committee on Ways & Means, my name is John Cuffe and I oversee the Cerebral Palsy Research Foundation of Kansas (CPRFK) Wheelchair & Posture Seating Program. Thank you for allowing me to provide testimony on behalf of this valuable program which has been partially funded through the Department of Health and Environment, Services for Children with Special Health Care Needs (SCSHCN) for decades.

I would like to give you brief history of CPRFK's Wheelchair & Posture Seating Program. CPRFK recognized the short-term and long-term benefits of posture seating for children and adults with severe disabilities and their families through our affiliation with Rehabilitation Engineering Centers across the country, promoted by the Federal Department of Education in the late 1970s. We began providing this service to Kansans with disabilities in the early 1980s, and the demand and costs for these services have grown significantly. We have had an increase in client participation of our services by 45% over the last 10 years.

Posture seating is critical for those children and adults with severe disabilities who utilize a wheelchair. The three primary purposes of a posture seating system are to facilitate mobility; to provide optimal positioning for work, classroom learning, daily functional activities; and to prevent secondary medical conditions such as pressure wounds, scoliosis, and pneumonia. The average medical cost to treat a pressure sore is \$43,000 for the first hospitalization (CMS study in 2007).

I have spent the past 14 years working as an occupational therapist in healthcare and joined the team at the Cerebral Palsy Research Foundation of Kansas (CPRFK) over a year ago. We are an outpatient rehabilitation clinic in Wichita, Kansas and the only Certified Kansas Medicaid Seating Clinic south of the Kansas City area. Though based in Wichita, we serve clients across the state, focusing on those in the bottom two-thirds of the state.

We pride ourselves on serving those with physical and intellectual disabilities and being a voice to advocate for them in supplying necessary wheelchairs and equipment. We are distinctly positioned to carry out this mission as we have a full metal and wood fabrication shop and the largest spare parts inventory in the state to serve clients who depend on wheelchairs for mobility. Since the late 1970s, CPRF has been dedicated to fitting wheelchairs and serving those with disabilities, making us the only clinic of our kind in the state with these fabrication capabilities and, as far as we know, the only one in the Midwest.

CPRF had been fitting wheelchairs long before I joined the organization. Still, as a student doing a rotation, I saw the benefit that the clinic offers those who use wheelchairs as their primary means of mobility. Over the past year, I have had a steep learning curve and have seen what our DME suppliers and my cohorts are reporting as some of the largest number of denials by the MCOs that they have seen. These denials are prolonging wait times for new wheelchairs, repairing parts for wheelchairs, and essentially putting their health at risk due to not having optimal positioning in their means of mobility. In the past year, I have seen denials for clients who have been in molded seating for the previous 7 years, a client who could drive a wheelchair with an eye gaze system being stuck in a manual chair as she is unable to drive herself, a client with muscular dystrophy denied a power chair, and a client with cerebral palsy being denied anterior tilt despite recommendations by a

speech therapist that to prevent the client from choking or having food/fluids go into his lungs, he would need such equipment.

We served 843 clients last year and due to our expertise and ability to serve this client population, the need for our services and advocacy has only grown over time. Few organizations in Kansas, particularly nonprofits, provide wheelchair fittings for those with disabilities and have the expertise in wheelchair fitting and the capacity to carry out the mission in a timely and efficient manner. At CPRFK, we serve as a watchdog as a nonprofit organization. We allow vendors to come into our shop as we advocate for our clients and their medical needs. This collaborative approach helps us ensure that our clients receive the best possible care and support.

Timeliness and Efficiency:

On average, it takes three months or more for clients to receive parts for their wheelchairs while they wait for insurance approvals. This process is neither timely nor efficient. Our therapists spend significant time writing letters of medical necessity for 15-20% of the clients we see. After researching and writing up a letter to address the denial, which can take anywhere from 30 minutes to 2 hours, it is then returned to the vendor for resubmission and appeal for medically necessary equipment. It is often denied multiple times before finally approval is given. It is estimated that the wait time for a new chair could be reduced by 2 months if the Medicaid MCO denials were eliminated.

Importance of Posture Seating Repairs:

Imagine this scenario: Your car breaks down unexpectedly. While it's certainly inconvenient, you know that within a short distance, there's a mechanic on nearly every street corner. You have a plan in place—call a tow truck, get your car to the shop, and within a matter of days, your car is repaired and back on the road. During this time, you might have to adjust your schedule or find alternate transportation, but you have options and a clear path to resolution.

Now, consider the experience of someone who relies on a wheelchair for mobility. When their wheelchair has an issue, it's not just an inconvenience—it's a loss of their legs, their independence, and their ability to move. Unlike car repair shops, there isn't a wheelchair repair shop on every street corner. If a suitable backup wheelchair is available, it must fit them adequately, which is often not the case. The timeframe to get their wheelchair looked at and repaired can be lengthy, involving multiple steps just to determine the extent of the issue and create a repair plan. If insurance is involved and there are any denials for necessary parts, the delay extends even further. Each step adds more time, and the person is left waiting, unable to regain their mobility swiftly. Unlike a car repair, getting a wheelchair back in working order can take months, leaving the individual confined, dependent, and often frustrated. Their wheelchair isn't just a convenience; it's their lifeline, their means to interact with the world, and to live their life to the fullest. When delays happen, it's as if their legs have been taken away, and getting them back depends on a complex and often slow-moving system.

Conclusion:

Ladies and Gentlemen, the time for change is now. We must ensure that our system prioritizes timely access to medical devices for those who need them most. We must establish processes that hold the MCOs accountable for excessive and unwarranted denials. By taking these steps, we can create a situation where every individual, regardless of their abilities, has the opportunity to live with independence, dignity, and equal access to essential medical devices.

Thank you for your time and consideration. I urge you to act swiftly and decisively to ensure that no one else has to endure the prolonged and unjust wait for devices vital to their well-being.