Paid Family Caregivers

The heart behind the truth

COMMONWEALTH COUNCIL ON
DEVELOPMENTAL
DISABILITIES

My name is Tiffany Owsley, and I am not only a mother, I am also a full-time caregiver to my children who survived devastating brain injuries. I became a paid caregiver through the Kentucky Traumatic Brain Injury Trust Fund, but long before any title or funding existed, I was already living this life every single day.

Our family's story is one that most people could never imagine until they live it themselves.

I am raising multiple children with severe disabilities and complex medical needs. My sons are nonverbal, require constant supervision, and depend on me for nearly every aspect of daily life. One of my children has a traumatic brain injury and a tracheostomy. Another lives with cerebral palsy, autism, and an anoxic brain injury. Both require around-the-clock care, therapies, medical equipment, safety monitoring, transportation to appointments, medication management, and emotional support. At the same time, I am also raising a young neurotypical toddler who deserves the same love, attention, and experiences any child deserves.

People often hear "paid caregiver" and assume that means help arrived. The truth is, being a paid caregiver as a mother often means carrying the same overwhelming responsibilities with very little relief — except now your love, exhaustion, grief, advocacy, and survival are also tied to systems, paperwork, shortages, approvals, and constant fights for resources your child medically needs.

There have been moments where I spent entire days calling Medicaid, medical supply companies, insurance representatives, doctors, and caseworkers trying to secure basic supplies my child cannot safely live without. I have sat awake through nights monitoring breathing, suctioning secretions, repositioning bodies, calming meltdowns, preventing elopement, cleaning medical equipment, and preparing medications — only to wake up and do it all again with no real break.

This life is isolating. It is physically exhausting. It is emotionally devastating at times.

But it is also filled with love that is impossible to explain unless you've lived it.

Our good days may look different than most families', but they matter just as much. A smile, a new sound, eye contact, laughter between brothers, a calm day without medical emergencies, hearing my children enjoy something others take for granted — those moments become everything. We celebrate victories that many people would never even notice because we understand how hard they were earned.

Being a mother caregiver means learning how to survive while grieving the life you thought your children would have, while still fighting every day to give them the best life possible. It means advocating constantly, even when you are exhausted. It means becoming nurse, therapist, teacher, scheduler, protector, transporter, comfort person, and safe place all at once.

I do this because they are my children. I do this because they deserve dignity, safety, joy, opportunities, and love. But families like mine need support that goes beyond words. Paid caregiver programs matter because they allow medically complex and disabled individuals to remain with the people who know and love them best. They acknowledge the reality that caregiving is work — skilled, demanding, nonstop work — even when it is done by a parent.

I am proud of my children. I am proud of the strength our family has found through unimaginable circumstances. But I also want people to understand the reality behind these roles. Behind every “caregiver” is a human being carrying enormous emotional, physical, and financial weight while trying to preserve some sense of normalcy and joy for their family.

This life has changed me forever. It has broken me in places, strengthened me in others, and taught me that survival itself can become an act of love.

And despite everything, we keep going.