

Paid Family Caregivers

The heart behind the truth

COMMONWEALTH COUNCIL ON
**DEVELOPMENTAL
DISABILITIES**

My son is 15, weighs 160 pounds and has Cerebral Palsy. He is wheelchair dependent and dependent on others for almost all daily living activities. He can become combative without warning. Having someone other than family assist in the home can be a safety hazard to them, just for doing their job. Just because he's wheelchair dependent doesn't mean he's not able to cause harm. It's also not behavioral related. It's something else out of his control. It is brain injury related. He hates it just as much as I do. He is super remorseful when he comes to after an episode. But the damage is done. Not everyone is as forgiving as family.

Sending him to school has also been a hazard to others. He's on a public-school homebound program. His treatment would decline dramatically if it wasn't for Participant Directed Services which include paid parent caregivers. This is important as I have found myself in situations discovering poor treatment when left to trust others with his care.

I have never paid myself with the waiver to be a SAHM as I am the representative, but when I needed my husband's support at home a few years ago, he was able to leave his job to help at home. I'm forever thankful for that with the Michelle P waiver.

I am a disabled Army veteran from Maine and my first born was delivered here in Kentucky. Due to medical negligence during his birth, he sustained a brain injury. His settlement reflected, and a special needs trust was set up around such programs they said my child would be entitled to.

We have continued to remain residents here in Kentucky because we realize as he becomes an adult his need for caregivers will remain and such a waiver doesn't exist in my home state.

I've often said we need a federal program that allows families to move states and still receive the bare minimum for their disabled loved ones versus being trapped in a state due to available services that wouldn't be available if they moved. Or a move can place their child on a decade long waitlist. We are moving backward even remaining on programs in our state of residency that are long established.

~Anonymous to protect their son