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United for Quality Care

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Taftville

SEIU District 1199 New England
Before the Appropriations Committee

Good afternoon Senator Osten, Representative Walker, and members of the Committee. My name is Pamela Hunt and I am a Personal Care Attendant (PCA) in Taftville. I have been taking care of my son for the 10 years. My son was born with a condition called Trisomy 13, otherwise known as Patau Syndrome, in which the individuals cells have three copies of the Chromosome 13 instead of the usual two. He has a lot of anomalies as a result. He was deaf, blind, and non-verbal, and he has cognitive disabilities. My son was born without a heartbeat. The hospital was willing to let my son die. They asked why I keep bringing him back there, and I had to go to the ethics committee of the hospital and fight for his right to live.

As a mother I had to fight for him then just as I fight for him now. Caring for him isn't easy. Much of the work is grimy: He is incontinent and requires cleaning. He has a g-tube that sometimes gets backed up and comes out of his gut. Sometimes he needs suction. Moreover, since I am his only caretaker, I don't get to experience the world outside. I don't get to socialize with people in the streets or go out for coffee and donuts. Staying at home during the pandemic made no difference to me since I rarely get to leave my house anyway.

Normally I don't even get to sleep more than four hours a night. Being deaf and blind, my son doesn't experience the audio-visual cues that signals his body that it's time to sleep. He doesn't produce melatonin. So we have to medicate him to regulate his sleep patterns. But the medicine only works for three or four hours at a time before he wakes up and has to be medicated again. He cannot be ignored when he wakes up because he self-stimulates by hitting himself. He has a high tolerance for pain, so he risks injuring himself. He could burst a blood vessel or even fracture his bones.

My son requires 24 hour care, yet I only get paid 8 hours a day. And if that isn't challenging enough, we get barely over \$15 per hour. It takes \$73,000 for a family of four to live: To have a roof over your head, to put food on the table, to put gas in your car, to buy clothes for your children, and so on. Most of us would be lucky to make \$30,000. How can we live on \$15 per hour? It is barely enough to survive. It's not a living wage. It's starvation wages! They should be ashamed of themselves!

Yet it is too much to qualify for Husky. I found out that I no longer qualify for insurance when I went to a medical appointment in January and was asked to provide a new insurance card. PCAs don't get health insurance through their jobs, private insurance

is too expensive, and I make too much to qualify for Husky. This would be challenging for anybody. But as a cancer survivor this puts me in an especially precarious position. I have since had to cancel medical appointments and forgo mammograms, biopsies, and other essential tests that I can no longer afford. I have to remain healthy, yet the stress and fear of getting sick is having an adverse impact on my wellbeing. The government is willing to let us die. Who is going to take care of my son should anything happen to me?

Why are having to fight for what should be a basic human right? Why are having to fight for health insurance and living wages? Please support funding for home care services. We deserve better. Thank you for your time.