

My name is Nicolas Brown. I am 22 years old and was born with myotubular myopathy. This means that I have low muscle tone. I have always been raised by a single mom. I have also required nurse/caregiver hours since I was 5 years old.

Getting adequate caregivers is always a challenge. Since I have moved to Oregon my mom and I have been through the process of finding, hiring and training caregivers through DHS to find qualified caregivers. Many of these people turned out to be drug addicts, alcoholics, or people who do not think of me as their boss and say things like “don't tell me how to do my job” or just ask my mom everything instead of me. I even had a caregiver pass out on my bathroom floor due to a drug overdose. My mom has had to fire several nurses who were asleep on the job, not suctioning me, not repositioning me and could not be woken up. Many of them took night shift jobs so they could sleep and go to their day shift job.

I have contacted every single homecare worker on the registry, and the majority only want 10 hours a week to keep their state benefits or they are scared to work with me because I have a high level of medical needs.

If I do not have a caregiver, my mom has to have to cover, which happens a lot! When she has to fill in for someone without notice its stressful. Working outside the home to support our family can be impossible because of all of these people calling out of work. My mom has to use her PTO to cover open shifts which means she doesn't get vacation days. She has to cancel business and personal opportunities to cover for my caregivers.

In 2013 my mom was forced to admit me to a medical facility to give her time to find caregivers for me. It was supposed to be for a month, but turned into 6. I had lost all my caregivers and my mom had to be sole caregiver 24/7. Because I am vent dependent, incontinent, oxygen dependent and need to be suctioned and repositioned all night, I require 24 hour care.. After 19 days of caring for me around the clock she was forced to put me into a facility due to pure exhaustion and a lack of being able to go out and make money to support us. California only paid her 6 hours to be my caregiver even when she was covering 24 hours a day. I won't go into details about my time at this facility but it broke me. I had no autonomy, no self determination and I couldn't share my opinions or act of my own accord. I was treated as if I was intellectually delayed, which I am not. The facility did not know how to deal with a child who could speak and advocate for himself. If I broke a rule, I would get my phone taken away, locked in my room, etc. By the end of this horrible stay I had lost my sense of worth and sank into a deep depression.

Today I have a great team of caregivers, but I never know what might happen. We have to adapt and prepare for their illnesses, personal reasons when they need to take off, vacations and other things. My mom has to cover all the gaps. When my mom is my caregiver I have never felt a lack of self-determination. When she is my caregiver on Sundays, I have more fun, more autonomy, and feel better than with any one of my other caregivers. I completely agree with parents being paid to care for their minor children, as i've experienced this policy when we lived in California

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If my mom had not been paid to be my caregiver during the times that there were no caregivers or nurses available, I don't know what would have happened to me. I would probably be living in a facility and I feel like I would have just given up. The six months I did have to spend in a facility broke me as a human being. I still experience PTSD because of the time I spend there. My mom being paid as my caregiver never took away my ability to make my own decisions. Her being paid actually made our lives easier. Wondering how you will pay the rent and buy groceries while caring for your child is stress on top of stress. No family should have to go through that because their child is born with a disability.

Throughout having my mom as a paid caregiver, regardless of whether I was a minor or not, my mom and my relationship has NEVER changed. It is as strong as it has ever been, and that's my lived experience.