

Submitter: Nickole Cheron
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB576

My name is Nickole Cheron I am speaking to you now representing myself, though you will see other testimony I was a part of from the city of Portland.

I have been working at the city of Portland for 17 years. My contribution at the city has included fighting regulation to make us one of the only cities that require Uber and Lyft to provide wheelchair accessible transportation. Being amongst the few cities nationwide that have an adaptable bike program that is an alternative to bike share programs geared toward able-bodied people. Developing an emergency preparedness training geared specifically towards people with disabilities. Sitting at the table to ensure that safe rest villages and alternative campsites for houseless members are also accessible... because we know in Portland 71% of houseless folks have a disability. I have slowly work my way up from a program coordinator I to an analyst III where I now manage an office with four staff and yet every year it becomes harder and harder for me to accept a merit increase or promotion because doing so would take away my ability to have care. I have limited my hours to 36 for the last 10 years to keep myself in the income cap yet I still often work 40 or even 50 hours on any given week. And I do that because I believe in being a civil servant and I am petrified of losing my caregivers.

I have done social justice work for the majority of my adult life. When I first learned about red lining and how it prevented black GIs from buying homes in areas of town that would have, when sold decades later, create generational wealth for their families I was appalled. It never occurred to me that as a person with a neuromuscular disease from birth that I too would experience systematic oppression. As a kid growing up federal laws mandated I got to go to public school, and Voc rehab help me go to school and get a degree. But no one prepared me for all of the oppression and systematic ableism I will encounter trying to become an independent adult. I was so glad Oregon had the employed persons with disabilities program and for the first decade of my career my salary didn't even come close to meeting the income cap. But now at the age of 51 my disease is progressing and I know down the road I will need more than just the six hours of care I use today. And so a few years ago I started to think about purchasing a two bedroom condo where I could essentially offer someone room and board to have the safety and support of someone overnight and emergency care. And the truth is I can't afford to buy a two bedroom condominium, pay mortgage, HOA's, and property tax in the city of Portland unless I make more money, but I can't make more money or I lose my care... And I can't afford both my care and rent.

Having income and asset caps for severely disabled people who work is institutional ableism. We work and we contribute, but because we can't afford both to pay for a high level of caregiving we need and save money to buy a house we are stuck in a cycle of poverty. And yes the state does provide ample funds for hiring caregivers six hours a day but I don't know if you're aware how much work I have to do recruiting those caregivers, training those caregivers, doing timesheets for those caregivers. Managing my care is a part-time job but I do it because like most of you I want to contribute, have a purpose and be an independent adult. Removing the income caps is not going to make me a rich person. Removing the asset caps won't see me buying a yacht. It may allow me to buy a home of my own, with an extra room for live in... where in my days on my own terms and not in assisted living at a cost to the state well above what I receive now for care.