

My name is Aranka Matolcsy. I am from South Paris, Maine and I am here to be a voice for thousands of Maine families who are struggling with realities of being caregivers of children with significant needs. I am here to implore for your support of parents as paid caregivers of minors with disabilities in support of LD 346 - An Act to Clarify the Requirements for Family Caregivers

Let it be very clear that minors with disabilities and their caregivers are the most marginalized, impoverished and desperate people in our nation. And, we represent all colors, genders, religions and cultures.

My son was born with a serious genetic condition that has crippled my ability to work, isolated us socially pushed us into food insecurity, being cold in our home, not having gas to travel outside of basic necessities, and so many of the emotional and traumatic experiences that are the reality of poverty.

My son was born after I had paid into the "system" for over 20 years. I was an NPO executive implementing capacity-building programming for my communities. Colby has Down syndrome, Autism Spectrum Disorder, ADHD and more. Necessarily, because of his needs and the rampant systemic brokenness that leaves him and me without basic needs being met, our lives have spiraled into desperation.

My son and I now live under the federal poverty line. My ability to work and be hired with any regularity has ended due to the tremendous amount of medical and special needs of my child. Our lives have been driven into food insecurity, fear of foreclosure, isolation and hopelessness. Those systems I paid into for almost three decades are letting us down at EVERY turn: public school, specialized services, Social Security.

We are languishing; I can't find regular work that is flexible enough to bend around 35+ missed days between September and June, with little to no day care options because Colby is required to have one-on-one support in order to be safe to attend. Furthermore, public education cannot provide reliable or safe transportation or instruction so his needs must be met out of district on a regular basis.

I have repeatedly attempted to submit documentation to Social Security and other agencies to prove that the numbers of hours I spend directly supporting my son's needs is preventing me from working enough to make ends meet but none of it matters due to the mandatory child support offset, Social Security says my son's is not eligible for his full benefit.

So I work 2 jobs in 2 counties every minute I can possibly work outside of providing direct one-on-one to a 12-year old child that requires "Eyes On AT ALL TIMES" due to choking and sharps hazards and unsafe and violent behavior with animals, himself and others. In fact in this moment, he is crazily chewing on legos trying to eat them to get my attention, because he can hear me tying which triggers him to obsessively seek negative attention.

This stress may likely be killing me. I have multiple stress-related health conditions that are getting worse. I am going for another endoscopy tomorrow. A major health crisis would cause me to lose our home. I literally work on my smartphone in the bathroom, in parking lots, while Colby is sleeping, and every possible moment. My level of exhaustion and poor health is not sustainable. Our situation is a house of cards than can fall anytime. Then how much money are the taxpayers going to pay for us?

Paying parents of disabled children as caregivers is critical lifeline. PLEASE HELP US. My friend can't be here, she is a single mom of a child who is wheelchair bound nonverbal, but because he is not intellectually disabled, they do not qualify for in home support. Her hernia is so bad she can barely function but she can't get surgery because she has no support for her son. That is why she is not here. I can't wait to testify so I have to submit it. My child could elope under my in attention to wait for a chance for you to hear me begging in person.

I could be earning income for the tremendous work I do with my son and buying my own food, but instead I am relegated to SNAP benefits for which I have been publically humiliated by people in line behind me as yet another cashier makes a big deal out of a problem with my card. Yes, openly shamed by strangers for having a SNAP card which came with becoming a single parent of a child with severe needs.

At every turn, we are suffering and falling through the cracks. My child is being robbed of me, as our lives spiral farther down into despair. Paying parents as caregivers of disabled children is a chance at a better life for everyone involved in the equation around disabled minors!

I should not face losing the home I spent my entire adult life working toward because I have a child whose disabilities prevent me from working with any regularity. The life I live with my child is devastatingly difficult and hopeless. I grapple daily with crippling fear about not having enough food and gas, as well as hopelessness for my child's future after I am gone and am no longer able to protect him and advocate for him.

As a hard-working and community contributing citizen, I should have the opportunity to stay in my home and provide the care my child needs to be a healthy, contributing member of our society, especially after paying into the system faithfully my entire adult life. Enabling parents of children with severe needs to be paid as caregivers would be a tremendous step forward in building a brighter future for my child and others in our same situation.

I implore you to support this critical proposal. Thank you.

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