

Hello. My name is Rae Sunshine Lee. I live in Ohio. I am a social worker with a Bachelors in Human Services, and I have several disabilities. Severe visual impairment, traumatic brain injury, along with fibro myalgia, which has me in a wheel chair a lot of the time. The limitations were enough to cause me to advocate for myself to find help, and I did that through the Passport program in Ohio. In so doing, I found myself advocating for others as well, here in Ohio.

Originally, my husband and I lived in California, where I received services from a community-based program known as In Home Support Services. This program allows spouses to care for their loved ones who have a disability, and be paid by the state to do it. My husband and I successfully participated in that program for about 10 years, and then we moved to Ohio in 2020. I contacted the Ohio Area for Aging and they told me about the Passport program. They also informed me that, because of the pandemic, spouses were now allowed to be personal care givers to their spouses, but that this may end at the end of the pandemic. I researched that and found that 35 states were already allowing spouse participation, even before the pandemic, and 15 were not. Sadly, Ohio was in the latter.

My husband and I did qualify for the passport program, which was great, but the hours that they allow independent care-givers who are spouses are a lot less than someone who is my related. I was only given 72 hours per month. The pay was also quite small in comparison to others in the same field, who do the same thing. Many of these care-givers are paid as much as 20 to 25 dollars per hour. The Passport program budgeted about 14.00 per hour. Wouldn't it be nice if all care-givers in the state were paid the same rate, i.e., 25.00 per hour, since they are all doing the same job? It is not livable to support a family on such a limited income, so my husband also had to seek employment elsewhere. Not that I like to complain, I do not. I do however like to see things in the order of fair and equal treatment. After all, according to God, *"a workman is worth of his hire"*. 1 Timothy 5:18

When all my daily needs are met, I can go about doing things that are fulfilling, which makes me happy. Some of these things are, going out to Open Mic night at the local theater and singing for people, perform in productions such as Last Evangelist and other films, advocate for others on the phone by seeking out other organizations that help persons with disabilities (PWDs), and having church services in my home. You see, my husband is a Bible teacher, and I am a licensed Pastor. When he teaches the Bible at home, I video record his teaching and put it on his website, which is www.pickupgodsword.com. It is something we started a few months ago and he now has 8 videos up there. I also am in process of recording 2 music cds through technology provided by a grant I received from the Ohio Arts Council. And these are just some of the things I do.

Without the help of my independent care-giver, my husband, I could not do these things. His daily help to meet my needs is irreplaceable. Some of the things he does for me are, bathing and help with personal hygiene, dressing, cooking, doing house chores that I used to do, like sweeping, mopping, dishes, laundry, grocery shopping, taking out trash, etc. In that same category, my husband now takes me to my monthly writer's class where I participate in reading articles that I have written and published. My husband, Gregg, reads the article out loud to the class, who then critique it. My husband does all my driving, which includes doctors'

appointments and local activities. I could not do this without Gregg's assistance. All these things combined, along with others I may not have mentioned, help to make me a very happy person and I am able to be a help to my community, as well as those around me.

I have heard from others for whom I advocate about the struggles they face when seeking out professional care-givers as the care-giver crisis in Ohio is staggering. One example of a client I have helped in the past is the treatment she gets from her allegedly 'trained' care-giver. Her care-giver is supposed to cook her meals. The care-giver takes in upon himself/herself to tell the patient that the care-giver does not want to cook for her, and suggests they go to a fast food restaurant. As the patient is bullied into making the unhealthy decision, her diet suffers terribly. She has gained over 50 pounds because of this one problem. Problem is, LACK OF TRAINING. 2 hours of training is not enough to send someone out to be a care-giver to a special needs person. And, yes, this is happening today, in Ohio.

Don't get me wrong here. Believe me, I am thankful that, at least in my case, my husband is allowed to be my care-giver, for as long as it lasts. But the wages they budget for this program is poverty-driven, and it saddens me. Not only does he have to help me with all my needs, he then must go outside to work another job, just to pay the bills. To be perfectly clear, I believe the wages paid to independent care-givers should be increased to meet the standard of living we all face.

I think that a bottom-line reminder is necessary here, to culminate my request.

1. According to Appendix K, 'allowed parents of minors and spouses of consumers on Ohio Department of Medicaid, Ohio Department of Aging and Developmental Disabilities to provide care for a loved one during the Federal Pandemic Emergency'. The pandemic may be nearing its' end, but the need for independent care-giving from qualified relatives is not. This program needs to continue past the culmination of the pandemic because, today, people are not always as comfortable allowing strangers in their homes, as they once were. Mental health is as important as physical health, and the emotional impact of forcing an unknown person into a person's household can be devastating.
2. Consider allocating funding to encompass a raise for all care-givers so that they may keep their focus on their patient's 100 percent on the time, instead of having to split their time between care-giving and a job outside the field.

Thank you so much for your time and consideration.

Pastor Rae Sunshine Lee, BSW

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