United States Senate Special Committee on Aging

From Infancy to Aging: The Effects of Caregiving Across the Lifespan

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Testimony of Linda Orndoff

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Hello Chairman Casey. My name is Linda Orndoff. I am a home care worker from Coal Center, Pennsylvania. I take care of my elderly mother and my oldest grandson who has autism.

I am a participant-directed home care worker. This means I work directly for my participants, my mother, and my grandson, rather than through an agency. This type of care allows the participant to direct their own care and to choose who works for them. A lot of times, like in our situation, this means family members. They choose people who they know and are comfortable with, rather than whomever an agency sends.

Nevertheless, whether you are participant-directed or an agency worker, doing home care work is a big sacrifice. When I was asked to come here today to speak to you, I was told to just tell my story. I want to share what it is like to be a home care worker. But to make you understand what a home care worker goes through you need to know why the situation is like it is. Because of poverty wages and no benefits, we have a huge crisis in the home care industry. Tens of thousands of home care workers must depend on state and federal assistance programs, like food stamps, Medicaid & sometimes cash assistance just to live.

In our country, there is only 1 caregiver for every 6 people who need and want care and to make it possible for them to be able to remain in their homes. Without enough home care workers, many people are being forced into nursing homes and assisted living facilities as they cannot find caregivers to keep them at home. In 2021 the annual turnover in the care workforce was 64% and it is only getting worse. It is getting worse because most potential caregivers are unable to do this work when it pays so little and offers no benefits or security.

In my case when my mother and grandson began needing my care full time, I had a big choice to make, put them in a home or quit my job. I chose them. After that, everything about my life changed. When I had to quit my job, I took a huge pay cut and suddenly I had to figure out how to live on poverty wages. I am currently making $13.52, the same hourly wage I made back in the late 80's - early 90's. I could barely live on those wages then, and I certainly can't live on these poverty wages now. When I chose to take care of my family and stop working, I no longer had health insurance, paid sick time, paid vacations, or any retirement benefits.

My mother and grandson depend on my care 10 hours a day, 7 days a week. My mother has polycythemia vera which is a rare blood disorder that makes your blood too thick and can lead to strokes and organ damage. She also has chronic kidney disease. She is also senile and has some dementia. She gets angry a lot and is very defiant, mostly towards me. We live in the country, on 4 acres, and she likes to wander away a lot (mostly tracking her cat). Two summers ago, she disappeared from me, and I couldn't find her anywhere. I was about to call 911 when I heard a noise at the top end of the property. I found her in weeds up to her waist, in bedroom slippers, trying to pull old lumber with rusty nails in it that my brother-in-law had stacked there to burn. So now I have video cameras set up everywhere to track her. Last summer she fell in the front yard about 100 yards from the house, looking for the cat, and she couldn't get up, so she was crawling up through the yard. She lets the cat out the front door and immediately goes to the back door and starts calling her to come in.

My mother likes to get up in the middle of the night and rearrange all the cupboards in the house. Last year when the overflow on the bathroom sink rusted out and started leaking, I told her I was going to have to replace the sink. But she decided it was the drainpipes instead, so she took a hammer and fixed them. Boy did she ever. On top of all of that, she is totally deaf, even with her hearing aids in. This makes communication with her incredibly difficult. I have tried several voice-to-text programs, but they screw up more than they work, so I have to write lots and lots of notes. I could tell you a lot more stories but suffice it to say she keeps me very busy.

In 2014, shortly after I took guardianship of my oldest grandson, he was diagnosed with Asperger syndrome. Asperger syndrome is a previously used diagnosis that is on the autism spectrum. He also suffers from chronic depression and obesity. In 2019 he and I started a walking program, and he lost over 60 pounds in 3 months. I was very proud of him. Unfortunately, my mother's mobile home that they lived in caught fire. It was a total loss. I was able to get them a newer, manufactured home to replace it. But everything was reliant on me and by the time I got everything up to the newer codes and got the house set up and them back home he had put almost all the weight back on. Since then, with my mother’s further decline, it has been very difficult for me to be able to leave the house. My grandson's weight has continued to escalate, and I worry every day about his health, which is starting to decline.

I am very active with my union SEIU / United Home Care Workers of PA. In recent years we fought for and won paid training classes for home care workers. These classes teach home care workers CPR and safety training, which I have completed. They also offer classes in working with dementia and autism patients, that I would love to take. I feel they would help me in dealing with the day-to-day tasks of taking care of my mother and grandson. However, these are both 8-hour courses and while they are paid training, when you have no one to cover for you it is very difficult to get them done.

As a participant-directed worker, I do not have the same collective bargaining in PA like other workers. This needs to change so we can fully advocate for ourselves. In states where home care workers have collective bargaining, they have won important victories like healthcare and living wages.

Because of the workforce crisis in our industry, it is nearly impossible to get backup care. So, if I get sick there is no one there to take care of them. A couple of years ago when I caught COVID I was completely down for 5 days. My older sister who can sometimes help me was in Florida on vacation and there was no one to feed my mother or grandson. This year in May I was bit on the neck by a spider. I got very sick for almost a week, but I managed to keep working. I don't have health insurance, so I didn't go to the doctor. After a week I started to get better and then I got sick again. I had a rash on my neck that was spreading that I had attributed to the spider bite. Then the pain started, and it got so bad I went from wondering if I was going to die to hoping that I would. I finally went to a doctor even though I couldn't afford it. I was eventually diagnosed with stage 3 Lyme disease. But if we had health insurance this never would have progressed to that point.

I would like to be able to tell you, other than the fact that bugs seem to like me, that my story is a unique one, but it is not. In my time in the union, I have spoken to a lot of workers who work 90 and even 100 hours a week. I have listened to the story of a young woman from Philadelphia who after working a full day taking care of her elderly diabetic mother, she then loads her in a car, even in the dead of winter with her blankets and medicines and drives for door dash all night to keep a roof over their heads. I have heard stories from workers who have contemplated suicide from depression over facing eviction from their homes.

We all know home care workers save the system, and taxpayers, tens of thousands of dollars per year caring for folks in their homes over putting them in nursing homes or assisted living facilities. And that these folks have better overall health outcomes. But we need to come up with a plan for how to get caregivers out of poverty. Otherwise, there is no way that we can build a sustainable home-care system. Because we can't take care of them if we can't take care of ourselves.