

Testimony to the Senate Special Committee on Aging
“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”
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Thank you, Chairman Casey, Ranking Member Braun and members of the Senate Special Committee on Aging for inviting me to speak to you today. My name is Jacinta Burgess, and I am a home care worker from Harrisburg, PA.

I care for my mother, Stephanie, in our home full-time. I have been doing so for roughly three years, with help from my older brother. We believe that is the best way for her to receive care — no one knows a mother like her children. Not only does a parent watch their child grow and change, the child does the same in regard to their parents.

My mother's health began to decline in 2016 while we were living in Washington, D.C., and I worked full time in Arlington. When my mother's issues became life threatening, the decision was made for her to move back to our home state of Pennsylvania, because I couldn't care for her in our home in D.C., due to my work schedule. I followed a few years later, excited about a job offer that would provide better pay and more freedom, and bring me closer to my mother again.

But when I lost my job and income in 2020, I was no longer able to assist my mother with her bills. In November of 2020, my mother had a medical crisis, was hospitalized, and I made the decision it was best for her to live with me. Since then I have been my mother's aide full time with assistance from my older brother William. Without income, I looked into programs that would assist me with caring for her as well as provide income.

I care for my mother because it is the right thing to do, and I would do so even if I weren't getting paid. But love can't pay the bills, so we depend on the wages I earn for this work. But it's not nearly enough to make ends meet. So many home care workers take on second or third jobs to earn more income, but I'm unable to work outside my home due to the care my mother requires. It's not safe for her to be on her own for too long.

Have you ever heard of the Riddle of The Sphinx? The stages referenced in this riddle are how I view life. At the beginning of the day we are crawling on all fours;

by noon we are walking upright on two feet; and when evening comes, we are still upright if we're lucky, but we'll probably need to rely on a cane to stay that way. My mother got me through the morning and noon, so I feel it's only right that I help her through the evening.

Now, I am my mother's eyes, ears, mouth, hands and feet. As her caregiver, my days are spent making sure that she is living a happy, comfortable, full life, while doing everything she needs to manage her illnesses. When my mom wakes up, I'm there to ask her what she needs for that morning. Some days, she needs help bathing and getting dressed. I help her with other day to day duties that most healthy people take for granted including opening doors, pouring a glass of water, getting into cars or turning a knob on our stoves. My mother also experiences chronic pain so I spend a lot of time giving her massages.

I am here today to tell you that home care workers like me are struggling, and care consumers like my mother are going without the quality care they deserve. Low wages, a lack of benefits, inadequate training, and insufficient funding for home- and community-based services has created a care crisis in our country. Caregivers can't afford to stay in these jobs, causing turnover rates as high as 60 percent in some markets¹, and consumers can't afford or access care. Congress has the power to improve care jobs for the 2.6 million² home care workers across the country, and the nearly 10 million seniors and people with disabilities whose lives depend on access to quality, affordable care.

When I officially became my mother's caregiver, I was paid around \$12.39 an hour, but was only paid for 15 hours a week, despite caring for my mother 24/7. Over the past three years, my wages have increased by just 99 cents, to \$13.38.

But my hours have recently increased to 65 hours per week. Home care jobs are full-time work, but the hours we're paid for can go up and down without warning. Changes in funding, policy, or decision making can decrease the hours home care workers are paid for — and hours that consumers receive care. Home care jobs need to be treated as full-time jobs, with reliable consistent schedules and wages that reflect the true value of our work. I live in fear of those hours being cut at any time for any reason, which would hit us hard financially.

In 2023, while the cost of living is skyrocketing and inflation is forcing people to make impossible financial decisions, \$13.38 is not enough for me — or any

¹ Understanding the Direct Care Workforce, PHI, 2023 available at <https://phinational.org/policy-research/key-facts-faq/>.

² *Id.*

working person — to pay all of my bills and live comfortably. I can't pay all my utilities and other bills in full, while still having money left over for food. My income is low enough to qualify for Medicaid, but I make too much to qualify for food assistance or other federal programs.

My mother has to help pay the rent and utilities out of the money she receives monthly from Social Security. But her benefits are just high enough that she has to pay for her own insurance, and her food stamp allowance has been cut. If my mother didn't live with me, she'd be homeless. And if I didn't live with my mother, I'd be struggling to survive if not homeless myself. I'd be a home care worker without a home of my own.

Sadly, my situation is not unique. Forty-three percent of home care workers live below 200 percent of the poverty level, and more than 50 percent rely on some form of public assistance. Thirty-six percent of home care workers do not have affordable housing.³

Everything in my household branches out from me. I am the head of household with my head on a swivel, and I'm stuck between a rock and a hard place. I have nowhere to turn because every direction brings me face to face with a new obstacle or an old one that I've been putting off.

What things keep you up at night? I have too many to count. At night, I toss and turn worrying about whether I forgot to pay a bill, or if an auto-payment is going to overdraft my account. I worry about the condition of our apartment, and what kind of legal assistance I can obtain when it comes to the issues we're facing with building management. In my head, I fight with a number of voices and issues — including my own — over things I want to change so badly, but can't because of how little money I make and resources I have.

If you are constantly worrying about pay, bills, doctor appointments, hours being cut, how to stretch this and cut that and adjust those to make it all work on someone else's timeline... Do you have time to be happy?

I am fighting to survive a system that seems like it was created for me to fail. Do you know how to breathe without air? I don't. This line of work can feel suffocating. I watch as my friends, family and fellow home care workers are stretched to their limits.

³ Direct Care Workers in the United States: Key Facts, PHI, Sept. 6, 2022 available at <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

My cousin Venetia is also a home care consumer. She requires care 24 hours a day, and has cycled through a number of home care workers over the years. When Venetia finally found an aide she loved and could rely on, that aide left the homecare field for better pay and benefits elsewhere. Home care workers develop very close bonds with our consumers, and we sometimes get to know them better than anyone else. We have firsthand knowledge of their routines, unique needs, and personality preferences. When people like my cousin aren't able to receive consistent care, their quality of life is deeply impacted.

It's hard to attract and retain home care workers because for so many of us, the pay is not something you can live on, there are no paid days off, there's barely any training and there are no medical benefits. People want to do this work, but when they see how disrespected, unprotected and shamefully underpaid we are, they turn the other way. From 2020 to 2030, the home care workforce will have 4.7 million total job openings.⁴ How are we supposed to fill those jobs and meet the skyrocketing demand for care when home care workers are treated the way we are?

If I had a liveable wage, I could possibly own a home instead of paying into a rental system that disrespects me and takes advantage of me with poor quality and bug-infested housing. I could take driving lessons and eventually purchase a car so I wouldn't be at the mercy of Uber or Lyft. I could take my pets to the vet for treatment without having to max out my credit cards or put off treatment for them. I could stop putting off treatments for myself and mother. I could actually save money for a rainy day or a vacation.

Our current apartment has had roach infestations, ventilation issues and other maintenance and logistics issues that make it hard to maintain a basic sense of comfort. It's not the standard of living I want for myself or my mother, but it's all we're able to afford right now.

We were recently told we have to move out of our current apartment once our lease is up. But it's not that easy. We need to find accessible housing that we can actually afford, and where we won't have to uproot and leave every year or so.

Consistency is so important in home care — but despite all my efforts to build a stable household and life for my mother, our options are limited because I don't make enough money

⁴ *Id.*

I am a caregiver through and through. I love caring for people and animals, and that's always been part of who I am. This is work I love and want to do. But home care is an emotionally and physically demanding job.

Some mornings I wake up, and I don't want to get out of bed. I want to just lay face down on the floor. I'm devastated that life is so hard for my mother and I. She worked so hard to take care of me growing up, and I want to give her that same care in return. I can't afford the mental health care I need to stay strong for my mother.

It may sound silly to you, but our cats are sometimes our only sources of support and comfort. They soothe us and show us love when it seems like the entire world has turned its back on us. I love our cats, but people should have a stronger support system than just their pets.

How is anyone supposed to enjoy their life if all they have to look forward to every morning are the struggles they face?

A severe shortage of home care workers forces many working families to choose between caring for a loved one and a paycheck. Just like me, working people are too often forced to leave their jobs or stop working entirely when the need for care arises in their family. Oftentimes, it's because they can't afford the cost of care, or in some communities, there aren't enough caregivers or resources to meet their needs.

My friend and union buddy Genale cares for her mother who has dementia and her father who has various ailments. Genale has a spouse who supports her and helps her care for her parents, but he has a full-time job as well. They give all their love and energy to Genale's parents, so that the time they have left is as peaceful as possible. Some would say why not put her mother in a nursing home?

Dementia is a devastating, terrifying disease, and there are so many different factors at play when determining the best course of care. Genale's mother knows her daughter. She loves and trusts her daughter. In her family's situation, putting her mother in a facility was not the best option. This is why it's important to build a long-term care system that gives working families like mine and Genale's the option of quality, affordable home care.

Investing in home and community-based services and the workers who do this job must be a national priority, because home care workers are an essential part of America's family healthcare system. The work we do makes all other work possible. When families know their loved ones are safe and cared for, they can go to their own jobs and continue working.

I can't work outside of my home because I am scared to death that my mother would not be able to get the exact care she needs otherwise. I haven't taken more than a day away from her in at least three years, because without me or my brother, there is no one else to care for her in the way she needs.

When you think of our own loved ones, how do you want them to be cared for? I'm sure you, like all families, want your parents, grandparents, and loved ones with special needs to be able to stay at home if they can and to receive the highest quality of care, delivered by skilled, experienced caregivers who you know are able to care for themselves without worrying about how they're going to pay their bills or put food on their table.

That is why home care workers must be respected, protected and paid. When our work is undervalued, when we must work long hours with no time off, no sick days, and struggle to get by, it's impossible to attract and retain the workforce all American families are counting on.

We are in a care crisis, and transforming these low-wage jobs into liveable-wage union jobs will bring the transformative change we need to move our country forward.

For decades, home care workers have organized, advocated and rallied for justice in the long-term care industry. We keep getting pushed down, but we know that so long as we can see the sky, the only way to go is up.

To further strengthen these jobs, we must guarantee all home care workers the right to join together in a union. I'm fortunate enough to have that right, and my union, SEIU Healthcare Pennsylvania, has made all the difference. Last year my fellow union members and I successfully pushed PA's Department of Human Services to increase reimbursement rates for home care by 8 percent statewide, leading to a \$1 an hour increase in all participant-directed caregivers' wages. Because we're a union, we had a seat at the table when administrators were deliberating over that decision. And we were able to take collective action— in meetings, on petitions, and at rallies—to advocate for our position.

We've also won funding for paid training programs—the first of their kind in Pennsylvania—which rolled out earlier this year. Caregivers who had never received any substantive healthcare training are now getting certified in everything from CPR to dementia capable care and nonviolent crisis intervention. We're professionalizing our

workforce to deliver higher quality care to our clients and demonstrate to decision-makers that they can no longer deny real workers the wages and benefits we deserve.

But my union represents more than just advocacy and worker power. My union is a community of support and inspiration.

Home care workers are so isolated in our work. We don't see other caregivers or consumers throughout the day. It's not easy to have a social life when you are giving or depending on care every hour of every day. My union helps me and my mother stay connected with other caregivers and consumers who understand exactly what we're going through. I know I'm not alone in this fight for higher wages and better standards of care

But for workers without a union, the median wage for unionized home care workers nationally is \$13.00, compared to \$11.66 for non-unionized home care workers. Unionized home care workers are much more likely to have health insurance through their employment than non-unionized home care workers — more than half of unionized home care workers have employment-related insurance, compared to 31 percent of non-unionized home care workers.⁵

Unfortunately, home care workers are currently denied a clear path to a union. Rules are rigged against workers who try to unionize, and employers can block workers who try to organize all too easily. Many home care workers — the majority of whom are women and women of color — are excluded from laws governing union rights. This must change.

The more than 740,000 home care workers united in SEIU and the two million still fighting for a union share a vision of America where long-term care is accessible, affordable and sustainable for all. We must transform home care jobs into family-sustaining careers for the generations of workers and consumers to come. This transformation would not only help those that do this work get the respect, protection and pay we deserve, but it is necessary if we are going to build a durable long-term care system.

We will all age into this system eventually, if not sooner due to unforeseen medical conditions or accidents. When that time comes, don't you want the comfort in knowing a skilled, dedicated caregiver will be by your side? Everyone deserves that peace of mind,

⁵ Caring for the Future: The Power and Potential of America's Direct Care Workforce, p. 41, PHI, Jan. 12, 2021 available at <https://phinational.org/resource/caring-for-the-future-the-power-and-potential-of-americas-direct-care-workforce/>.

but for real, working families across the country, the stability of tomorrow is not guaranteed.

Our nation can't go on the same way when it comes to care. The system was broken long before the COVID-19 pandemic, and the pandemic has only made the issues worse. We need our elected officials to champion higher standards for care and care jobs across the country.

I am important. My mother is important. My cousin is important. Every care worker and care consumer is important.