

**Testimony to the Senate Special Committee on Aging Hearing  
“An Economy That Cares: The Importance of Home-Based Services”  
March 23, 2022**

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Thank you Chairman Casey, Ranking Member Scott, and members of the Senate Special Committee on Aging for inviting me and my caregiver, Lynn, to speak today. My name is Brandon Kingsmore, and Lynn and I live in Allentown, PA.

I’ve relied on some form of home care my whole life, a reality so many people never experience, so it is very important to me that I share my story openly and honestly. Especially because at some point, as we all get older, every one of us will need this type of care. I want people to understand that quality, affordable, accessible home care is so much more than just a social service or numbers on a spreadsheet — it is a lifeline for the 61 million people with disabilities and 54 million people aged 65 and older who call this country home.<sup>1</sup> I hope that what I share with you today will make clear why we, the people, need you, our country’s leaders and decision-makers, to support and pass President Biden’s life-changing investment in care.

To be clear: we need this funding. It’s the only way to raise wages for workers and lower costs for families. We are facing a large-scale crisis and COVID has made clear that when you just fix around the edges, lives are lost. It is why Congress must pass the Better Care Better Jobs Act — now.

Before I tell you my story, I want to speak on behalf of everyone whose lives depend on quality, affordable home care, and whose lives depend on the decisions made on Capitol Hill. For too long, our elected leaders have allowed our healthcare system to fail us. COVID-19 certainly made clear that access to care is a matter of life or death, and too many working families have suffered the devastating consequences of our country’s under-funded, under-resourced, under-prioritized home- and community-based services.

Please make the right decision. Please do what’s right. Please come together and pass this investment in better care, better jobs and a better future for all.

I was born with cerebral palsy and I use a wheelchair to get around, which means I sometimes need a little help doing things throughout the day. Growing up, my mother did everything for me. I grew up in North Carolina, and I didn’t qualify for Medicaid until I was 18 because of how limited home- and community-based services are there. My mother’s insurance wouldn’t cover home care, and we couldn’t afford to pay out of pocket, so she had to be my full-time caregiver on top of her other full-time job.

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<sup>1</sup> <https://www.aging.senate.gov/imo/media/doc/How%20American%20Families%20Benefit.pdf>

I felt so guilty. I felt like a burden. I still do, sometimes.

When I finally qualified for Medicaid, finding a reliable, consistent, well-trained home care worker proved almost impossible. There was a period of time when my mother couldn't be there to provide the care I needed, so I spent my days sitting, playing video games, watching movies, just waiting for her to get home to help me go to the bathroom, prepare a meal, or go out. I felt trapped in my home, and I prayed for the better, more active and fulfilling life I knew I could live if I was able to afford quality, consistent, reliable home care.

This is a situation so many care consumers face, but so often goes unseen. There aren't enough home care workers to meet the demand, so care consumers become isolated or forced to leave their homes and live in a facility. We become removed from society against our will. We want to participate in our economy and communities, but the choice is made for us when lawmakers refuse to acknowledge and take action to change a system designed to hold us back.

Today, nearly 350,000 Pennsylvanians need help with daily activities, such as bathing and dressing.<sup>2</sup> But data show there are fewer than 198,000 home care workers to fill these roles.<sup>3</sup> Something doesn't add up. With the demand for care skyrocketing, especially as the long-term impacts of COVID come to light, the commonwealth will need to fill more than 292,000 home care jobs by 2028.<sup>4</sup> Investing in HCBS will ensure the needs of every care consumer are met by attracting and sustaining our home care workforce. Policies like the Better Care Better Jobs Act will put the country on the right path to building a sustainable and durable home- and community-based care system and build an economy that works for all working people.

With the way things are now, people like me wake up each morning, not knowing if a home care worker will be there that day. If our home care worker is sick or needs to take time off, which is likely unpaid because most don't have paid sick time or paid leave, there's no guarantee that another caregiver will be available to cover their shift. If someone is available, they're often not prepared or trained in advance to provide the specialized care each individual consumer needs. Oftentimes, they're working one or two other jobs because the pay for care jobs is so poor, so they only have an hour or two to provide care for someone who needs help 24/7.

It is humiliating and dehumanizing to be 32 years old and have someone put you in a diaper, because they don't have the training or the time to help you go to the bathroom.

But this isn't the fault of the home care workers. The people who do this work love helping others and care about people in need. They want to do this work, and so often put their needs

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<sup>2</sup> Paul, Rafal, & Houtenville. 2020. Annual Disability Statistics Compendium: 2020 (Table 1.8). University of New Hampshire, Institute on Disability. [https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2021\\_release\\_year/Final%20Accessibility%20Compendium%202020%20PDF\\_2.1.2020reduced.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2021_release_year/Final%20Accessibility%20Compendium%202020%20PDF_2.1.2020reduced.pdf)

<sup>3</sup> PHI. "Workforce Data Center." Last modified September 2, 2021. <https://phinational.org/policy-research/workforce-data-center/>.

<sup>4</sup> Home care job openings include new jobs created and jobs that need to be filled due to workers leaving the field or the labor force. PHI, 2020. <https://phinational.org/policy-research/workforce-data-center/#tab=State+Data&natvar=Employment+Projections&states=42>

aside to meet the needs of others. But the system elected leaders have built isn't designed to set them up for success.

March is Women's History Month, a time to celebrate, honor and reflect on the women who keep our communities running and our economy strong. The home care workforce is a workforce of 90 percent women, and more than 60 percent people of color. But our country has a track record of choosing not to invest in these jobs, therefore choosing not to invest in the Black, brown, immigrant and indigenous women who do this essential work, despite the system working so hard against them. Why is that? Is this work not important? Are these women not important? Instead of tweeting about it, why not turn collective appreciation for women into meaningful action that lifts women and women of color out of poverty and finally gives them the respect, protection and pay they deserve?

Shamefully low pay and a lack of benefits force home care workers to leave the industry in search of work they need to pay their bills, support their families and build a life on. Training isn't prioritized for home care workers, despite their role as essential healthcare workers. Instead, employers put home care workers in situations that put their health and safety — and their consumers' health and safety — at risk. Affordable healthcare isn't offered to many home care workers, so if they get hurt or sick, going to the doctor isn't an option without facing financial ruin. And as I said, without paid sick days, taking time off means they don't get paid.

People who want to do this work can't afford to, the people who already do this work are treated as expendable, and the people who depend on this work are left without options.

If Lynn gets hurt or sick and is unable to provide care, I'd have no one. There wouldn't be another home care worker to fill in for her. It's incredibly isolating. Without a home care worker, I don't have a life. I can't go anywhere or do anything. I have a life. I have a voice. I have feelings. I have goals and ambitions.

Being in a wheelchair is hard enough. Not all buildings or transportation options are accessible — not even my apartment. My apartment was built long before power chairs existed. The hallway is too narrow, the doorways are too tight, and the counter tops are too high. I can't access the bathroom with my wheelchair to get in the shower, so my caregiver has to physically lift my 120-pound frame onto a countertop and carry me several feet to the bathtub to get cleaned up. I can't brush my teeth at the bathroom sink, so I use a cup at the dining room table.

And the looks I get on the street, the way I'm spoken to like I'm a toddler, and when people act as though they're scared of me is the reality I face every time I leave the house. Why is it that I have to fight for everything I need? Why should people like me, older Americans, and our families have to bankrupt themselves because they can't afford care that helps them with the simple basics of life like bathing and toileting?

When Lynn became my full-time caregiver 11 years ago, everything changed. Suddenly, the life I always dreamed of was in reach. Without Lynn, I would be in a nursing home at the age of 32,

or home alone for hours a day, with no hope or freedom. Having a disability shouldn't mean your life is over. Home care workers give us a substantial life, and allow us to stay in our communities.

But for all the work home care workers do caring for others, they can barely care for themselves. Data show the median wage for home care workers nationally is \$12.98 an hour, and Lynn now makes \$13.50 an hour as a home care worker in Pennsylvania, after her union won eight percent raises for home care workers in our county.<sup>5</sup> Home care is an emotionally and physically demanding job. But with the rising cost of living, inflation, and other economic stressors, wages this low make it impossible for home care workers to meet their basic needs, take care of themselves and their families, and live comfortably.

Home care is one of the fastest growing industries and jobs in the country due to exploding demand that will only get worse as times go on and more people get older. But because of the poor quality of these jobs, we cannot recruit enough workers, and turnover in the field is through the roof. Again I ask: why is this the reality we accept? For me and so many others, care work is a matter of life and death. If there are no care workers, then there is no care.

Our saving grace has been Lynn's union, SEIU Healthcare Pennsylvania and the United Home Care Workers of Pennsylvania. Uniting home care workers across the Commonwealth, Lynn's union has spent decades fighting for the dignity and respect that caregivers and consumers deserve. As part of her union, Lynn fights alongside other workers and their consumers for what every home care worker deserves: a living wage, access to training, affordable health insurance, and collective bargaining rights.

Around the country, at the bargaining table, in the streets, in the halls of state houses and Congress, caregivers and their unions are leading by example and demanding structural changes to the long term care system. When workers come together, the state listens in the way it would never listen to just one worker alone. But for all the victories, there is a long list of injustices to keep fighting.

We live in the wealthiest country in the world, yet the unaffordable cost of home care, the lack of comprehensive paid leave, and a severe shortage of home care workers forces many working families to choose between caring for a loved one and a paycheck. This is an impossible choice, and many people end up leaving their jobs to care for family and friends who can't afford or access home- and community-based services — without pay.

In Pennsylvania, there are 1.59 million family caregivers providing 1.33 billion hours of care to loved ones 18 and older.<sup>6</sup> Investing in better care and better jobs would make it possible for family members who left their careers to assume caregiving responsibilities to return to the

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<sup>5</sup> All wage data comes from PHI. "Workforce Data Center." Last modified Sept. 2, 2021. <https://phinational.org/policy-research/workforce-data-center/>.

<sup>6</sup> Reinhard et al. 2019. Valuing the Invaluable: 2019 Update. AARP. <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>

workforce, knowing a skilled, dedicated, consistent home care worker is caring for their loved ones.

Our country's leaders need to take a good look in the mirror and reevaluate the way seniors and people with disabilities are treated. We need to reevaluate how home care workers are treated. We need to reevaluate how the women, women of color, and immigrants who do the majority of this work are treated.

I was born in 1989 — before people with disabilities had any rights. The Americans with Disabilities Act was passed in 1990, and that was a start, but we still live in an ableist, ageist, racist, sexist world where people in need are excluded and forgotten.

A better future means life, liberty, and the pursuit of happiness for all. Isn't that what this country is all about? I dream of a future where all people, of all races, of all genders, of all ages, of all backgrounds can wake up each morning knowing they're healthy, safe and able to provide the best lives for themselves and their families.

That's why Lynn and I are here today. We can't make a better future if we don't address these deeply rooted issues now.

I'm nobody special — I'm just a guy from Pennsylvania looking for a fair shot at a good life. But I feel a responsibility to speak up for the millions of people who are just like me. Chairman Casey has given Lynn and I the chance to spread our message further than we thought possible. Last year, we even had the honor of meeting President Biden. It is an honor and a privilege being able to speak to members of this committee and other lawmakers face to face about what it's like to be me, what it's like to be Lynn, and what it's like to know our lives hang in the balance as you debate dollars and cents. This isn't just dollars and cents. The choices you make dictate the way I can live my life, the way all of us can live with dignity when the day comes that we or a loved one needs this care.

But I can't help but think to myself... I've told my story so many times. How many more times will I have to say this before lawmakers take meaningful action? Honestly, when I share my story with people who are fortunate enough to have the financial resources to access and afford care, I wonder whether or not they're really taking in my words. Unless you live this life — having a disability or providing care — you can't possibly understand how hard it is and just how much we rely on home- and community-based services.

This is a human rights issue. It is unacceptable that in 21st century America, the freedom to live is 100% based on money and the priorities of other people — particularly of some elected officials on Capitol Hill. With the way things are now, Medicaid only sees us as numbers. But we're not. We're humans that deserve to live life. We're people with feelings and emotions.

Walk a day in my shoes. Walk a day in Lynn's shoes. Walk a day in the shoes of someone who suddenly fell ill or got in an accident that leaves them totally reliant on someone else to help

them live. It could happen to anyone, at any time, no matter who they are. But our current long term care system cannot guarantee home care for all who need it. Our current long term care system does not have the funding and resources necessary for recruiting, training and sustaining a home care workforce. The system is crumbling — especially after COVID-19. And that's why we need action now.

The needs of people with disabilities, seniors, working families, and children cannot be ignored any longer. If this legislation dies, caregivers will suffer because they cannot afford food, shelter, or healthcare, and clients will perish because no one will be there to keep them alive.

Senators, please invest in care workers like Lynn by granting HCBS the funding it needs to make home care jobs good union jobs with pay and benefits that reflect the true value and impact of their essential work.

Senators, please invest in care consumers like me by investing in HCBS, providing funding so we can get the care we deserve from the compassionate, well-trained, dedicated home care workers we depend on to live.

We are the closest we have ever been to finally beginning to address the long term care crisis in this country. We — people with disabilities, older Americans, our families, and the workers who support us — matter. Don't leave us behind again. Congress must act now.