United States Senate Special Committee on Aging

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

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Testimony of Heather Tomko

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Good morning, Chairman Casey. Thank you so much for allowing me to share my testimony today. My name is Heather Tomko - I'm a 35-year-old woman and a lifelong Pittsburgher, a graduate of both Carnegie Mellon University and the University of Pittsburgh, and a current employee of Pitt as well. I'm also disabled - I have a progressive, genetic neuromuscular disease called Spinal Muscular Atrophy (SMA). I've never been able to walk, and I've used a wheelchair since I was about two years old.

Growing up with a disability like SMA means that my life looks a bit different than most people's. I need help doing most of the things people tend to take for granted - getting in and out of bed, using the bathroom, taking a shower, getting dressed, and even brushing my hair. That help has come in various forms over the years. Up until college, my parents were my sole caregivers, and I relied completely on them. When I was accepted to Carnegie Mellon and decided to live in the dorms on campus, my family and I had to figure out how I would get the help I need while living away from home, and that was my first experience with paid personal care attendants (PCAs). Since graduating from college, I've moved back home with my parents and my sister, who shares my disability, and have a mix of unpaid care from my parents and paid care through PCAs.

I learned quickly while at college how much of an adjustment relying on PCAs was going to be for me. Not only in terms of having to explain and be comfortable with strangers doing my care (though that was also new to me), but in terms of the management of my PCAs schedules. I got my PCAs through an agency, who coordinated the hiring and scheduling of my PCAs to fill the hours I'd been allotted through my Medicaid waiver.

But I realized that while the agency was in charge of my schedule, I was ultimately responsible. If a PCA called off for one of my shifts, which happened not infrequently, I was the one without care if the agency couldn't find a replacement in time. I was the one making frantic phone calls to the agency every few hours checking in with them, and I was the one who had to call my parents and ask my mom to spend the night with me in the dorm when the agency wasn’t able to find anyone in time. All while also trying to adjust to college life, make new friends, finish my homework assignments on time, and study for exams. Nothing adds to your stress level quite like knowing you have a midterm the next day, and not being sure if you will have a way to get out of bed beforehand to actually go take the exam.

This lack of stability with PCAs during my time at Carnegie Mellon was a large part of my decision to move back home after college. At least at home, I would have my parents as backups already in the same place, and I wouldn’t need to make any 11 PM phone calls after another last-minute call off. Over the years, I have cobbled together a patchwork of care, luckily finding a handful of consistent PCAs (though never enough to actually fill all the hours allotted to me) with my parents filling in the rest of the gaps.

Finding consistent care is an important distinction, and a detail that is often overlooked. My care, while not overly difficult, does require explanation, and training, and a little bit of getting used to. When someone is putting me into my wheelchair where I’ll spend the next 5 hours in the same position, it’s important that I’m comfortable and supported correctly while I’m there. And if I have a revolving door of PCAs, rather than a handful of consistent people, it becomes near impossible for me to have my needs actually met properly, because by the time a PCA and I have settled into a comfortable routine, they’re already moving on.

And while I have a patchwork system that is manageable for now, I worry every single day about what my future could look like. I’m 35 right now, and my parents are in their 60s. I’m incredibly grateful that they’re still able to lift me, and to help me with the more physical aspects of my care. But I know that this won’t be the case forever – they’re aging, and at some point in the not-so-distant future, they’re not going to be able to care for me (and my sister) like they do now. And I’m terrified what that will mean for me. If I can’t find consistent care, my only option would be to move into an assisted living facility, and leave my full and vibrant life behind.

And while these are only my own personal experiences, I also see them mirrored every day in my professional life. I’m the Outreach Coordinator at the University of Pittsburgh’s National Rehabilitation Research and Training Center on Family Support. In this role, I serve as the liaison between academia and the larger family caregiving community. In my interactions with both caregivers and people receiving care, I found that the most common comments and questions I got were about how they, as family caregivers, were shouldering the majority of care for their loved ones, and how they were struggling to find and keep PCAs. Because while we often look at “paid caregivers” and “unpaid caregivers” as two different silos, both actually exist intersectionally along the care continuum. Many family caregivers are looking for PCAs for their loved ones as well – not necessarily to replace their unpaid care, but to supplement it – to allow family caregivers the time and space to care for themselves, as well.

While this has been a challenge for years, I've found that it's gotten exponentially worse following the pandemic – it's gotten to a crisis level that I've never experienced before. And I know that the problem is multifaceted, but it's clear that one major issue is the stagnant wages for PCAs. I've mentioned how pivotal getting this care is to me and my life – without it, I could quite literally be stuck in bed all day – but the wages PCAs receive do not reflect how critical their services are. Someone can actually make more and have a higher chance of growth and promotion by working at Target than they can by working as a PCA. We've seen companies raising their wages to entice people back into the workforce following the pandemic, but I haven't seen that happening for PCAs. So, I'm seeing what has been a long-standing issue now brewing into a perfect storm of losses in the workforce with stagnant, non-competitive wages, with no changes in sight.

Increasing wages to a competitive level for PCAs is long overdue. I urge you to act on this before it's too late for me and the thousands of others who rely on care to live our daily lives. Thank you so much for allowing me the chance to speak with you today, and to share my experiences and submit my testimony.