

Good morning, Chairman Neal, Ranking Member Brady, and distinguished members of the Committee. Thank you very much for the opportunity to share my thoughts this morning. My name is Kristina Brown. I am a caregiver and fourth-year medical student at Yale.

My final year at medical school began this fall with an unexpected flight home to Colorado. My mother has multiple sclerosis, and my sister, her caregiver for the past three years while I attended school in New Haven, was moving away to start a new job she'd suddenly gotten. There was no one else but me. I postponed my hospital rotation and canceled my board exam. I notified the school registrar, saying I was uncertain of when I could return and resume my studies.

Many people assume that having a disability guarantees access to a network of resources. Not so. Because my mother has an income of \$36,000 from her divorce settlement, is younger than 65 and lacks a 10-year employment history, she is disqualified from receiving Medicaid (despite its expansion), Medicare and Social Security Disability Insurance. Her private insurance company, like many others, does not cover home care for daily needs. The [median cost](#) of this service, for help seven days a week, is more than \$80,000 per year. Like many families, we could not afford full-time coverage. This posed a life-altering dilemma: One of us had to stay home to care for her.

With my sister away at college, I went first: At age 16, when our 43-year-old mother lost the ability to walk, my life shifted to sleepless nights and baby monitors. Her disease progressed swiftly; soon she could no longer stand, eat or bathe without assistance. For six years, I provided 10 hours of care every day.

I woke up at 5:30 each morning. After helping my mom with a bed bath, brushing her teeth and lifting her into her wheelchair, I would arrive late to school, breathless and racking my brain for an excuse to tell my English teacher. I accumulated enough pink tardy slips that, despite being a straight-A student, I received a letter threatening my graduation. I dedicated weekends to caring for my mother and missed class to make it to her doctors' appointments. I quit the cross-country team after finally making varsity. I skipped prom. I turned down the chance to give the graduation speech. I lost my adolescence, and still my mother needed more support than I could give.

Even though I told no one about my home life, it permeated every decision I made. When I received my high SAT score in the mail, I cried tears of disbelief: I soon received a flood of invitations to apply to Ivy League schools and full-ride scholarship offers from out-of-state universities I longed to explore. I declined them all, knowing I had to stay nearby for college. To save money on home health-care costs, my sister and I spent weekends with our mother; that way, we wouldn't have to hire extra help for the physical tasks that required two people. Midway through my sophomore year, we both moved off campus and back in with her.

I knew that even if I reached out for assistance, few resources were available: Most nursing facilities serve only seniors. And even if we found a facility for younger adults with disabilities like my mother's, the cost of that care could exceed \$10,000 a month. Home care is only slightly more affordable, at \$6,000 or \$7,000 a month. My mother is on a first-name basis with all the local paramedics — not because of medical crises, but because of the many nights when we needed another set of hands just to help her get out of her wheelchair and go to bed.

These strains can take a toll on caregivers' health. Sixty percent of people caring for adult relatives or friends also have [full- or part-time jobs](#), according to the AARP's Public Policy Institute. More than half of caregivers report [a decline in exercise](#), poor diet and not seeing their doctor as needed. Chronic stress in caregivers has been shown to increase the risk of [high blood pressure](#) and [heart disease](#). Compared with their peers, elderly individuals who serve as overburdened caregivers are [1.6 times more likely to die](#) within four years. [Only 13 percent of caregivers](#) are between the ages of 18 and 29, according to Gallup-Healthways, so fewer studies exist on the effects on younger people. From my own experience, I can say that I routinely missed meals and sleep during my adolescence, and that I strove to hide my exhaustion, weight loss and social isolation from the people around me.

In recent years, I've taken out loans to keep up with mortgage payments on our family's home in Colorado, and, for additional income, worked shifts in the radiology department at the university's hospital. Combined with my sister's meager salary, this barely ensures our mother's survival. We are starting to run out of options: We could sell our home to qualify for state assistance; I could leave medical school to become a full-time caregiver for my mother. But taking these extreme, temporizing measures would only drive us further into a vicious cycle of financial instability.

Caregiving fuels generational poverty, disproportionately affecting millennials and women who take on that role in their families. People like my sister and me, who begin caregiving as first-time job-seekers or students, may face significant [employment challenges](#): Millennial caregivers are more likely than previous generations to be passed over for promotions, forced to reduce their job responsibilities or fired, according to the TransAmerica Institute. Just a few years of caregiving early in life creates cumulative financial setbacks for women, making them less likely to have [retirement savings](#) and more likely to require government assistance. A 50-year-old woman earning \$40,000 a year who leaves the workforce to care for a family member for five years [loses 11 percent of her potential lifetime earnings](#) (\$256,753), according to the Center for American Progress. If she does the same at 25, she loses 20 percent of her lifetime earnings (\$679,000). When women become caregivers, they also become 2.5 times [more likely to live in poverty](#).

There are resources supporting caregivers, but families like mine fall through the cracks. The Family and Medical Leave Act allows for 12 weeks of leave each year so that people may tend to

loved ones, but this time off is unpaid. While many workplaces have paid parental leave, and educational institutions offer stipends for students with children, such policies exclude other kinds of caregivers. Programs such as [respite care](#) and [adult day care](#) often have limited funds, or come with out-of-pocket costs or age requirements.

Last spring, Washington became the first state to [pass a publicly funded long-term-care benefit](#). It provides individuals \$100 a day, with a lifetime cap of \$36,500, to pay for services including caregiving, meal delivery and nursing home fees; lawmakers estimate that the measure will ultimately save the state billions in Medicaid costs. Widely adopting such programs would be expensive, but without help, families like mine will be crushed by needs we cannot meet.

Somehow, after a few weeks, my family pieced together a patchwork of caregivers who could help my mother with bed, baths, meals and overnights. Since we couldn't afford aides from certified agencies, I recruited people through online ads and trained them in her needs and routines. I filled out reams of applications and made a flurry of phone calls to my mother's social worker, the state's health and human services department, and the regional disability resource center, seeking financial support. (So far, none has arrived.) This arrangement has allowed me to return to campus for now. But it's also haphazard, and could collapse at any moment. Home health aides have quit unexpectedly, leaving my mother to forgo regular meals and bathing while, thousands of miles away, I scrambled to find replacements, calling the police department to ask them to perform welfare checks. From week to week, I don't know whether my mother will have the care she needs.

Numbers alone cannot capture the costs we've incurred: every sleepless night, every missed opportunity, every surge of shame and guilt. Some nights, when I'm away at medical school, my mother calls me to apologize for being sick: She always dreamed of being able to take care of me and my sister, and instead our youth has been devoted to taking care of her. It took me years to feel worthy of pursuing a separate identity for myself. In the face of insurmountable health-care expenses, my family had become numb to the sting of dreams deferred. Yet with each day more uncertain than the last, I focus on carving out a new future for us amid this fragile present.

As this committee meets to discuss Caring for Aging Americans, I ask that you take steps to ensure that families like mine do not continue to fall through the cracks. As a long term goal, we must aim for universal long term care to ensure that every adult with disabilities has affordable access to sustainable care. And there should be a greater investment in home and community based services, so that younger adults with disabilities like my mother can stay in their homes, live with their families, and participate in their communities.

In the short term, we must eliminate age gaps and income gaps so that middle-aged, middle income adults with disabilities and home care expenses that far exceed their income can qualify for long term care services through Medicaid. We must change the Medicaid cutoff such that the

threshold is not based on income alone, but rather on income adjusted by care costs. No family should have to spend the entirety of their income, go into debt, and forgo their future just to meet basic human needs. By addressing these gaps, the system would not require young caregivers like me to sacrifice health, education, employment, and financial stability. To further support caregivers, the Family Medical Leave Act should offer paid leave. And universities should offer support stipends to help ease the burden on student caregivers who, like me, may be working part-time jobs and taking out significant loans in order to help support their loved ones. We need respite care that is affordable and accessible to caregivers and care recipients of all ages.

There are multiple paths to better supporting caregivers. We can start small. We can start by giving voice and visibility to caregivers. Thank you for listening, for seeing me, and for your commitment to improving the lives of families and caregivers.

Addendum:

Additional Suggestions to Better Support Individuals with Disabilities and their Family Caregivers:

- The industry of home healthcare agencies should be regulated to ensure that hired caregivers are fairly compensated and home healthcare is more affordable
- Approve continual, long term rehabilitative services such as physical therapy and occupational therapy for those who need it most. Many insurance companies only cover a portion of a limited number of physical therapy visits (my mother's private insurance covers about 20 visits per year). But for people like my mother, who have a chronic physical disability, strengthening exercises are key to maintaining health and independence in completing activities of daily living such as eating and bathing. For many with physical disabilities, it is impossible to do regular strengthening exercises independently. Adults with significant physical disabilities need licensed physical and occupational therapists to assist long term. Otherwise, when the service caps out, people like my mother are left to spend the rest of the year losing muscle tone and becoming weaker, less independent, and in greater need of assistance. Investing in long term physical and occupational therapy would allow adults with disabilities to maintain independence in certain daily tasks and ultimately require fewer services.
- Drive down the cost of durable medical equipment and allow more frequent renewals. For example, most insurance companies only allow adults with disabilities to qualify for a new wheelchair every 5 years, a stipulation that can put many people at risk for pressure sores and back problems if their chair is poorly fitting or loses support with time. The cost of a private pay wheelchair is around \$12,000 or more depending on needs. No one should have to pay that much or wait five years to have equipment that is necessary for daily life and wellbeing.