

Senate Special Committee on Aging
Summary: “An Economy That Cares: The Importance of Home-Based Services”
March 23, 2022

The Senate Special Committee on Aging [held a hearing](#) on home and community-based services (HCBS) and the importance of home health care. Topics discussed included investment in the home-based care workforce and infrastructure, financing of HCBS through Medicaid, and the Better Care Better Jobs Act ([S. 2110](#)).

Members attending the hearing included: **Committee Chair Bob Casey (D-PA)**, **Ranking Member Tim Scott (R-SC)**, **Sens. Kirsten Gillibrand (D-NY)**, **Elizabeth Warren (D-MA)**, **Rick Scott (R-FL)**, **Jacky Rosen (D-NV)**, **Mike Braun (R-IN)**, and **Raphael Warnock (D-GA)**.

Witnesses:

- [Lisa Harootunian](#), Associate Director, Health Program, Bipartisan Policy Center
- [Anne Tumlinson](#), CEO, ATI Advisory and Founder, Daughterhood
- [Brandon Kingsmore](#), Disability Advocate
- [Lynn Weidner](#), Home Care Worker, United Homecare Workers of Pennsylvania
- [Alene Shaheed](#), Home Care Recipient and Former Client, Florida Health Justice Project

Key Takeaways from Opening Remarks from Committee Members:

[Committee Chair Bob Casey \(D-PA\)](#)

- HCBS allow more than three million Americans to remain in their homes and be active in their communities. However, almost 820,000 Americans are on waitlists for these services. This limited access to care hurts more than just those in need of services; it hurts all of us and our economy as people are forced to leave the workforce to care for their loved ones. The Better Care Better Jobs Act is an investment for better care for seniors and those with disabilities, home care workers, and family caregivers. This investment also gives home care workers a much needed and long overdue raise. These workers provide essential care, and this investment would give home-based care workers the ability to support themselves and their families. This investment is needed now.

[Ranking Member Tim Scott \(R-SC\)](#)

- There are 46 million Americans over the age of 65 in the US, and this number will skyrocket to 90 million Americans in 2050. By 2030, one in five Americans will be 65 years or older. Nearly 95 percent of seniors want to remain in their own homes as they age, and seniors often turn to their family members for assistance. Family caregivers provide over 75 percent of caregiving services in the US, and we need to find ways to make that support better. A better path forward would give caregivers and recipients information about the services they need while providing resources to do so. Last June, I released a report ([Expanding Opportunities for Older Americans: Self Directed Home and Community Based Services](#)) where we looked for solutions to understand what would be helpful for family caregivers. The solutions discussed in the report include helping state Medicaid programs to establish self-directed care options, as well as growing the long-term care insurance market.

Key Takeaways from Opening Remarks from Witnesses:

Lisa Harootunian, Associate Director, Health Program, Bipartisan Policy Center

- *State HCBS Waivers:* Congress has made meaningful progress towards improving access to these services, but additional work still needs to be done particularly as COVID-19 and the aging population has exacerbated the need for HCBS services. For individuals with functional or cognitive impairment, HCBS has allowed these individuals to live and work independently. However, some of the challenges in the current system include the reliance on 1915(c) and 1115 waivers, resulting in a patchwork system that is extremely complex and burdensome for states to administer, HCBS programs that are challenging for beneficiaries to navigate, and inequities in access to HCBS both within and between states.
- *Recommendations:* To address these challenges, we need continued bipartisan collaboration. As described in our report ([Streamlining and Simplifying Medicaid HCBS Authorities](#)), Congress should pursue a bipartisan path forward to improve the administratively complex and piecemeal HCBS structure by coalescing these waivers into a single state plan amendment that retains the flexibilities of existing authorities. This would reduce complexity in the system while still providing budgetary authority to states. This would make it easier for beneficiaries to navigate the system and easier for the state to administer. While this would not solve all access issues, this would support efforts to improve availability of HCBS services.

Anne Tumlinson, CEO, ATI Advisory

- *Background on HCBS:* HCBS make it possible for individuals with long-term care needs to remain within their homes, but our home care structure is vastly under resourced to meet the growing need for services. Most older adults with higher-level needs still live in the community and rely on family members for caregiving services. A third of these individuals are also at or below 200 percent of the federal poverty level and are not on Medicaid, making them ineligible for home-based care under Medicaid. Additionally, federal law does not require Medicaid programs to offer coverage for HCBS yet finding and deploying privately financed HCBS is challenging. States do receive federal funds for HCBS under American Rescue Plan Act, but it is insufficient for our rapidly aging population.
- *Recommendations:* Much more federal investment is needed to help communities develop a HCBS infrastructure which works together with private HCBS. Without doing this, we will continue to rely heavily on unpaid family caregivers, and when they give out, nursing facilities. Caring for family members is hard, full-time work, and these caregivers have to choose between quitting their jobs to care for family members full time or putting their family members in a nursing home. Investing in HCBS is one of the most impactful actions we can take to support families and their futures.

Brandon Kingsmore, Disability Advocate

- I've been on home care my whole life. I was born with cerebral palsy; growing up, I didn't qualify for Medicaid but couldn't afford to pay for home care out of pocket. My mom had to be a full-time caregiver on top of her full-time job, with my sister sharing the responsibility. It was hard to think about what we would do if anything happened to my mom. Some days, I spent eight hours

per day alone in my home, in one place; if something happened to me, I would have had to wait for someone to get home and help. If I had to go to the bathroom, I would not have had anyone to help me. Qualifying for Medicaid made a huge difference; without care, people like me have to wonder if they can eat, get up, or go to the bathroom that day. Why should I have to fight for something that should be a basic human right? My current caregiver gives me the freedom to live my life the way I want, where I want. What people like me want are to participate in our economy and community, but the choice is often made for us. Home care workers give so much of themselves for people like me to have a better life. We have the opportunity to make history with this legislation. Please invest and pass the Better Care, Better Jobs Act now.

Lynn Weidner, Brandon's full-time caregiver

- I have worked in long-term care for more than 20 years, and I can say with expertise that our country's long term care system is crumbling. Without the support of Congress, there is no funding to train and sustain our workforce. The demand for care is skyrocketing, but the low pay forces home care workers to leave their jobs. Policies like the Better Care, Better Jobs Act would help to bolster the home care workforce. Caregivers in our unions are demanding change to allow us to provide the care our clients deserve. We live in an ableist world where people are being excluded and forgotten. Without the support of the entire Senate, we will be back to square one. Caregivers will suffer due to insufficient pay, and people like Brandon will suffer due to a lack of caregiving support.

Alene Shaheed, Home Care Recipient and Former Client, Florida Health Justice Project

- I started to experience mobility issues in 2016 due to a growth on my spine which took two surgeries to remove. After the second surgery, I was unable to walk and now need a wheelchair. I now require assistance in bathing, housekeeping, toileting, and meal preparation. I am enrolled in Florida's Medicaid Long-Term Care waiver and am approved for 35 hours of home care per week, which allows me to remain independent and at home. Right now, I can only find an aide for 20 of those hours. I have not been able to find an aide to come on Saturdays, Sundays, or Mondays, leaving me unable to shower, take out the trash, make meals, and more. Not having the help, I need affects every aspect of my life, as my home care aide allows me to remain independent. The average pay for home care workers is \$10-13 per hour. During the pandemic, aides are unwilling to come and risk their and their families' health for ten dollars per hour. Valuing me means valuing them, and we all deserve to be valued. Home care workers must have adequate funding.

Key Takeaways from Discussion:

Importance of and Investment in HCBS

- **Sen. Bob Casey (D-PA):** Brandon, you shared how HCBS has enabled you to live a "substantial life"; and without that care that Lynn provides you, this kind of life would not be possible for you. So many people across the nation are not able to receive the care that you are receiving. How important is it that we invest in HCBS across the nation?

- **Brandon Kingsmore:** Home care is one of the fastest growing industries in the nation. One day, we're all going to need help whether we want it or not. It's not about dollars, it's about life and death. Without these services, my life would not be what it is, and I would not be the man I am today.
- **Sen. Gillibrand (D-NY):** Some 20 million Americans already require long-term care, and we will need to fill an estimated 4.7 million home care jobs by 2028. More than one in five Americans are family caregivers. It's clear that we need to ramp up our investment and improve access to HCBS and that's why I'm a champion for Sen. Bob Casey's Better Care, Better Jobs Act. I also have a proposal for a national paid leave program, which would allow people to be more available to care for family members. How do the diverse needs of older adults and people with disabilities inform the need for improving availability for a wide range of HCBS? Does our infrastructure and home care workforce meet our needs, or are people falling through the cracks?
- **Anne Tumlinson:** There are extreme inequities and inconsistencies in access across states. Accessing services is a question of if you're living in the right neighborhood, in the right state, with the right set of needs. Rural areas in particular struggle with a supply of agencies and providers due to drive time. We also see Black Americans using nursing homes that are lower quality more frequently than white Americans.
- **Sen. Casey (D-PA):** Ms. Tumlinson, you developed a platform for family caregivers to connect with one another and share resources. 1.6 million Americans take on these burdens which can include enormous financial costs. How would an investment in HCBS allow family care workers to return to work?
- **Anne Tumlinson:** Across the country, every single family is building and creating an entire system of care delivery from scratch, all alone. It's like we're homesteading long-term care. An investment in home-based care would increase the services available. Investment is also needed to reform the eligibility system to identify people with financial and functional needs, adequately compensate and train the home-based care workforce, and build a strong infrastructure so that there is a place to go in every community where families can go to be supported regardless of how they're paying for services.
- **Sen Warren (D-MA):** As our population ages, demand for home-based care is only going to increase. The time to act is now: I am ready to join the Chairman to get this done. Ms. Widener, could you speak on what investments in home-based care would mean for you and the people around you?
- **Lynn Weidner:** It would change everything. Access to a living wage and benefits would change the lives of health care workers who go without health care. Families need this investment, and care workers need this investment as well.

Medicaid Coverage of HCBS

- **Sen. Braun (R-IN):** In 2020, the federal government increased funding for Medicaid and Medicare, spending over \$1.5 trillion on health care services. The Centers for Medicare and Medicaid Services (CMS) has also issued waivers to federal requirements to improve access to beneficiary caregiving. As a result, the Government Accountability Office (GAO) has identified several risks to program integrity due to the suspension of these safeguards increasing chances of fraud and other

abuse. Has increased spending actually improved outcomes, and have the uses of waivers complicated matters?

- **Lisa Harootunian:** Increased spending doesn't always equal better outcomes, spending needs to be targeted to improve quality outcomes. Some states rely on up to eleven 1915(c) waivers, which creates complexity for states administering multiple programs and benefit packages. States have to periodically submit renewal requests, and these renewal processes require significant staff bandwidth. States need to oversee multiple contractors and multiple quality metrics for each waiver.
- **Sen. Warnock (D-GA):** Medicaid is the primary source of coverage for long-term services and support. The majority of this spending goes towards the HCBS programs involving assistance for daily living activities. There are many in Georgia who are unable to receive this support as the state refuses to expand Medicaid. Mr. Kingsmore, you are currently a recipient of Medicaid HCBS. What would happen if you lived in Georgia and were unable to receive these services?
- **Brandon Kingsmore:** I would be trapped in a nursing facility, shoved in a corner and unable to live the way I want and how I want. We're supposed to be the greatest country on Earth; we're not supposed to be trapped in a system that doesn't care about us.

HCBS Workforce Reform

- **Sen. Casey (D-PA):** It's not a question of whether or not Medicaid will provide funding for long-term care; it's a question of whether or not Americans can get their care in the setting they want, which is home-based care. How would raising wages for workers impact the availability of home-care workers that provide the type of care you receive?
- **Alene Shaheed:** My dignity and health suffer when I am unable to shower for three days. I am isolated and not able to participate in my community. An increase in the wages of home-based care is the key component to improving my quality of life. My case manager called 17 different home-based care agencies, but no one is willing to work for \$10 per hour.
- **Sen. Rosen (D-NV):** I'm a former caregiver for both of my parents and in-laws. I've heard from constituents across Nevada on the hardships of being a full-time caregiver; that's why I was proud to be a cosponsor of the Better Care, Better Jobs Act which would significantly strengthen HCBS workforce protections. I also cosponsored the Credit for Caring Act ([S. 1670](#)) which would provide caregivers with a federal tax credit of up to \$5000 to cover expenses associated with caregiving. Ms. Widener, can you tell me about how having union workforce protections supports you on a day-to-day basis?
- **Lynn Weidner:** Home care can be extremely isolating. In joining the home care workers union, I found a community. In the beginning of the public health emergency (PHE), we were sending personal protective equipment (PPE) to each other; and we started a training program to keep ourselves and our clients safe. Congress needs to prioritize passing this funding because we need to tackle all elements of home-based care at once. This year, our union was able to win an eight percent raise for home care workers, but \$13.50 per hour is still not enough. Does this mean that my labor is less important? No. We need to make sure that not only the workers are important, but the consumers are as well.
- **Sen. Warren (D-MA):** The majority of older adults and people with disabilities want to live at home. The failure to invest in home-based services harms both beneficiaries and workers. Home care

workers, which are more likely to be women and people of color, are three times more likely to be in poverty compared to other workers. Caregivers deliver essential services in jobs where social distancing is nearly impossible. Ms. Widener, you shared that as recently as last year you were earning \$12 per hour as a home care worker. How has this effected your financial security?

- **Lynn Weidner:** I have to work more than one job, amounting to about 80 hours per week. I'm in a lot of debt, which is nearly impossible to climb out of when I'm living paycheck to paycheck.

Miscellaneous

- **Sen. Gillibrand (D-NY):** We know that paid family and medical leave is a crucial necessity for workers facing their own or family's health issues. A widespread lack of paid leave disproportionately impacts people of color, women, and low-income workers. Will you please describe how a national paid leave program could help address these overwhelming, growing demands for long-term care?
- **Anne Tumlinson:** We are on the precipice of having to build a care-giving society: without care, there is no life. Whether paid or unpaid, we will all be either giving care or receiving care. Families will still experience crises that require our attention, and paid leave needs to be the norm unless we want to see extreme economic insecurity.
- **Sen. Braun (R-IN):** America's health care spending far exceeds the spending of other countries. What are three things that would bring the costs down for everyone?
- **Lisa Harootunian:** One thing that we're focused on is reducing complexity in the system, which would streamline processes and authorities that states are using. This would result in less staff time and bandwidth needed to accomplish outcomes.
- **Sen. Warnock (D-GA):** HCBS helps older Americans and people with disabilities to live independently. This has been especially important during the pandemic, and HCBS has allowed people to be at home so as to mitigate risk regarding COVID-19 transmission. There are many Americans who qualify for these services but are unable to receive it. Ms. Tumlinson, I want to ask you about waiting for HCBS services. How do we get people off the waiting list to receive these services?
- **Anne Tumlinson:** Depending on the state, we may not be able to fully measure the unmet need. The most important need for states is financial predictability, and a certainty about where the funding is coming from. The best way to meet unmet need is to increase the federal match rate to give states the money they need to fund services and planning for the infrastructure development needed to serve people when they come off the waiting list.
- **Sen. Casey (D-PA):** I would like to thank our witnesses for being here today and sharing their expertise. I want to highlight a new report from the Community Living Policy Center at Brandeis University, entitled "[Reducing Costs for Families and States by Increasing Access to Home and Community Based Services.](#)" This report cites American Association of Retired Persons (AARP) data which shows that six in ten family members have had to reduce or quit their employment to care for a loved one. These family members have had to reduce their family income to care for a member of their family, and we shouldn't continue to put them in this position. Lack of available care in America means these families will have less income and greater expenses. Among our obligations in the U.S. Senate is to lower costs for families, create jobs that will sustain families, and help Americans get back to work. All three of these obligations will be met by Senators

supporting legislation which will increase our investment in HCBS. The American Rescue Plan included investments in HCBS—the first new funding for these services in a generation. We need a much greater investment to make this a reality for so many families. In the end, this is about better care for seniors and people with disabilities, better jobs for the home care workforce, and providing a measure of relief to tens of millions of Americans who provide care for a loved one every day.