

# **Access to Home and Community-Based Services: *Recent Progress and Opportunities for the Future***



**CHAIRMAN BOB CASEY (D-PA)  
U.S. SENATE SPECIAL COMMITTEE ON AGING**



## A Note from the Chairman

*“We, as a Nation, must come together to address the needs of the workforce that will help us care for those needing support.”*

*Aging Committee Hearing on HCBS, March 2023*



Throughout my time in the Senate and as Chairman of the U.S. Senate Special Committee on Aging, I have led numerous efforts to ensure long-term, sustained investment in HCBS. All people deserve access to quality care, without having to leave their homes and communities to move to institutional settings. The professionals providing that care deserve fair wages and working conditions, access to paid leave, and opportunities to grow in their careers. In the last several years, we have increased pay for HCBS professionals, introduced legislation to eliminate waitlists, and highlighted why access to HCBS is so vital, but so much more work needs to be done. As Americans, we assume that care will be there when we need it; care will not be there for many unless Congress takes action. I urge families, advocates, and my Senate colleagues to continue working on these issues. As the advocacy community has often said: “Care can’t wait!”

# Introduction

As Chairman of the Aging Committee, Senator Casey's top priority has been keeping the Nation's promises to older Americans and people with disabilities. Chairman Casey believes we owe it to every older adult, every person with disabilities, and their families to have the resources and ability to decide when, where, and how to receive care as they age and as they need it.

## Background

In 2022, there were 57.8 million people over the age of 65 and 70 million adults with disabilities.<sup>1</sup> The country's aging demographic has and will continue to shift significantly, with adults over the age of 65 outnumbering children under the age of 18 by 2034.<sup>2</sup> The vast majority of older adults and people with disabilities want to and are able to live at home and remain in their communities, but to do so they need some assistance with health services like skilled nursing, physical therapy, occupational therapy, and medication management; or help with activities of daily living (ADLs) such as eating, bathing, toileting, and dressing.

Assistance with ADLs at home are often provided by family caregivers and Home and Community-Based Services (HCBS) professional caregivers. These services enable older adults and people with disabilities to lead independent lives at home instead of moving to institutional settings, like nursing homes, where unsafe staffing levels remain an intractable issue.<sup>3</sup> Inadequate staffing levels result in lower quality of care and increase mortality for nursing home residents.<sup>4</sup>

Older adults and people with disabilities want to remain in their homes and communities—88 percent of older Americans believe that it is important to age in place and people with disabilities have long fought for the right to live in the community, not in institutions.<sup>5</sup> Between our Nation's growing population of older adults and the preference of older adults and people with disabilities to live at home, greater investment in HCBS is needed, including expanding the professional workforce that provides long-term care at home.



In 2024, over 700,000 people were on HCBS waitlists not receiving the critical services needed to live in the way they desire.<sup>6</sup> Over the next 10 years, the need for home care workers is expected to grow by 21 percent, with nearly 719,000 job vacancies projected each year.<sup>7</sup> Without future investments in HCBS, additional individuals will have to join waiting lists, prolonging them from receiving needed care and services or forcing them to live in overly restrictive and more costly institutional settings.

## **Heather Tomko** **Whitehall Borough, Pennsylvania**



“I’m Heather – a 36-year-old woman and a lifelong Pittsburgher. 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 an electric wheelchair since I was about two years old. Having SMA means that I rely on caregivers to do the things that most people take for granted. I rely on a mix of my parents as unpaid caregivers and paid caregiving through HCBS. I have been able to cobble together a patchwork of care

that just barely works, but does not work well. While I’m incredibly grateful for my parents’ willingness to help, they are aging, and I know that there is a point in the future when they will no longer be able to provide care. That thought terrifies me. I would not be able to receive the care I so desperately need solely relying on HCBS. Every day, I worry that my only option will be to move into a nursing home, leaving my incredibly full and vibrant life behind – an incredibly sobering thought for someone in their mid-30s. If HCBS do not receive priority support and funding in the next Congress, this fear could very well become my reality.”

## **Coverage of HCBS**

Medicaid is the main payer of long-term care services in the United States, with HCBS accounting for almost 59 percent of all Medicaid long-term care spending.<sup>8</sup> States can choose to provide HCBS as a state plan benefit or through HCBS waivers.<sup>9</sup> In general, state plan benefits are provided to all Medicaid beneficiaries for whom they are medically necessary. Individual states determine what is “medically necessary,” so eligibility for home and community-based care varies from state to state.<sup>10</sup>

States can also offer HCBS through waivers, which are often targeted to specific populations such as people with autism, traumatic brain injuries, or mental health needs.<sup>11</sup> However, states are able to cap the number of people they serve on HCBS waivers, resulting in long HCBS waitlists in many states.<sup>12</sup> The average person on an HCBS waitlist waits 40 months to receive full services.<sup>13</sup> In 2024, 40 states had waiting lists for Medicaid HCBS, and between 2023 and 2024 waitlist enrollment increased by 2.6 percent.<sup>14</sup>

While on waitlists, individuals still need care. This often results in the pressure for family members to provide unpaid caregiving. Families and individuals who are not eligible for Medicaid or are stuck on waitlists also may pay out-of-pocket for professional home care services. The costs of out-of-pocket care can place significant financial pressure on families, often costing tens of thousands of dollars a year depending on the level of care an individual requires.

## **The HCBS Workforce**

The United States is in the midst of a caregiving crisis. The country does not have sufficient numbers of direct care workers to meet the care of Americans needing home and community-based services. As HCBS waitlists continue to grow, long-term care workers face challenges. A recent survey of HCBS providers showed all 50 states experiencing home care worker shortages, and 43 states reported that some HCBS providers no longer provide services due to worker shortages.<sup>15</sup>

Without direct care workers, it is impossible to provide HCBS. However, many issues directly affect the challenges of recruiting and retaining long-term care workers.

Staff who provide critical support to others often struggle to support their own families. In 2022, the median hourly wage for all direct care professionals was \$15.43, with home care workers earning \$14.50.<sup>16</sup> One in eight direct care professionals live in poverty and 46 percent rely on public assistance, such as Medicaid, food assistance, or supplemental benefits.<sup>17</sup> In addition to low wages, direct care workers report high levels of burnout and professional fatigue due to the daily physical and emotional demands of their jobs, lack of respect for the care that they provide, and health and emotional effects from battling the COVID-19 pandemic.<sup>18</sup> Most direct care professionals are women and people of color, further perpetuating racial, gender, and economic inequalities.<sup>19</sup>

Low wages, few or no benefits, and a lack of respect for the essential work they do is no way to treat our direct care workers. The result often means they are unable to fully support those in need of care. Insufficient staffing and high turnover rates result in workers who are on the job and must work longer hours with more strenuous workloads, resulting in increased rates of burnout. Home care agencies are battling extremely high staff turnover rates and higher costs as a result of needing to use temporary staffing services, which can be twice as expensive as a permanent fulltime worker.

The annual turnover rate for direct care workers is estimated to be anywhere from 40 to 60 percent annually.<sup>20</sup> From 2019 to 2022, hospital discharges to home health agencies were delayed by nearly 13 percent due to HCBS staffing shortages.<sup>21</sup> In 2022, 44 states reported permanent closure of at least one Medicaid HCBS provider.<sup>22</sup> Over 83 percent of surveyed home health care providers said they turned away or stopped accepting referrals because of staffing shortages and 63 percent discontinued services for the same reason.<sup>23</sup> For long-term care professionals working to take care of people with intellectual and developmental disabilities, 83 percent turned away new referrals due to staffing shortages.<sup>24</sup>

## ***Importance of Addressing HCBS Shortages***

When it comes to long-term care services, we need to ensure that families have a real choice about where and how their loved ones will be cared for and where they will live. Providing a true choice to older adults and people with disabilities to live in their own homes respects their autonomy and freedom to make decisions about their lives.

In addition to respect for one’s autonomy and freedom, there are financial benefits to HCBS compared to care in institutional settings. HCBS are more cost effective than institutional care. In 2023, HCBS averaged \$75,500 a year, whereas a semi-private room in a nursing home cost \$104,000 annually.<sup>25</sup>

Expanding access to HCBS will also support family caregivers. Over 53 million Americans are family caregivers.<sup>26</sup> Family caregiving can place significant strain on the financial, physical, and mental wellbeing of caregivers. For example, caregivers report difficulty paying bills and poor mental health as a result of caregiving.<sup>27</sup> For respite care, family caregivers often look to HCBS professional workers to help with caregiving responsibilities. However, the significant HCBS worker shortage means that family caregivers struggle to find workers to help them when they need it most.

## **Shona Eakin** **Erie, Pennsylvania**



“I am a person with disabilities who has worked as the executive director of a Center for Independent Living and home care agency for the past 24 years. In addition to managing a home care agency, I am also a user of HCBS. Every day, my HCBS professional worker comes to my house at 4:00 in the morning and helps me get dressed so that I can go to work and do my job to make sure that other people also have the help they need to live independently. The work that HCBS workers do is invaluable, but we need to

be treating our HCBS workers better. HCBS workers need health insurance, livable wages, and good benefits—this meaningful work should not be just a job but a career.

I believe that we have the power to make a difference in the lives of millions of people receiving and providing HCBS—it can be done if it’s the will of the people. I want the people to understand why HCBS is so important.”



# Recent Effort to Increase Access to HCBS

## ***Executive Orders and Regulatory Actions***

The White House and federal agencies issued policies to improve the availability of home care services. In an Executive Order issued in April 2023, President Biden called for increasing compensation and improving job quality for long-term care workers.<sup>28</sup> A final report from the Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services from January 2024 issued a number of suggestions for improving wages for direct care workers, including implementing wage pass-through policies.<sup>29</sup> The Centers for Medicare and Medicaid Services (CMS) went on to codify a Medicaid HCBS wage pass-through requirement in April 2024.<sup>30</sup> The rule requires that at least 80 percent of Medicaid payments go to HCBS professionals instead of administrative overhead or profit.<sup>31</sup> Policies such as wage pass-through requirements are vital to guaranteeing that federal dollars are being spent to ensure individuals have access to services and workers are paid fair and competitive wages.

## ***Enacted Legislation***

The *American Rescue Plan Act (ARPA)*, which was signed into law in March 2021, played a role in increasing wages for HCBS professionals in recent years. The average hourly wage for an HCBS direct service provider has risen from just below \$13.00 an hour at the start of the pandemic to approximately \$14.50.<sup>32</sup> ARPA funds are available through March 2025, but without additional resources, the hourly rate for HCBS workers may decrease after those funds are expended.

## ***Senate Hearings***

Several Congressional Committees have examined HCBS issues over the years, exemplifying the need to address ongoing HCBS unmet need and challenges.

In September 2023, the Senate Finance Committee held a subcommittee hearing titled, *Aging in Place: The Vital Role of Home Health in Access to Care*. The hearing focused on the costs and Medicare and Medicaid benefits for home health services, as well as the health benefits of aging in place.<sup>33</sup>

Under Chairman Casey's leadership, the U.S. Senate Special Committee on Aging has held multiple hearings addressing the need for HCBS supports. Most recently, in August 2024, the Committee held a field hearing entitled, *From Infancy to Aging: The Effects of Caregiving Across the Lifespan*, that examined caregiving challenges such as cost, quality, and availability of care, that families face.<sup>34</sup>

In June 2024, the U.S. Senate Special Committee on Aging held a joint hearing with the U.S. Senate Committee on Veterans' Affairs entitled, *Heroes at Home: Improving Services for Veterans and their Caregivers*. The hearing explored ways the Veterans Health Administration (VHA) provides caregiving support as well as home and community-based services to help veterans age in their place of choice.<sup>35</sup>

In April 2024, the Committee held a hearing entitled, *The Long-Term Care Workforce: Addressing Shortages and Improving the Profession*.<sup>36</sup> This hearing looked at the broader long-term care workforce, including the HCBS workforce. During the hearing, Chairman Casey offered several policy solutions to the long-term care workforce shortage, including increasing pay, expanding long-term care professionals' benefits, and instituting stronger worker protections.

Additionally, on March 9, 2023, the Committee held a hearing entitled, *Uplifting Families, Workers, and Older Adults: Supporting Communities of Care*.<sup>37</sup> The hearing examined the caregiving workforce in the United States, including the work of both paid and unpaid caregivers, and the economic benefits of ensuring the availability of services and the economic cost of under or unpaid caregiving.

## **Chairman Casey's Efforts**

Investment in HCBS is critical for older adults, people with disabilities, and their families. We all hope that when we or our family members need care, it will be there. Without action, the already strained service delivery system will not be able to accommodate the growing need. Our Nation must do better for Americans who need care and the professionals who provide that care. Chairman Casey has long championed addressing this crisis by improving access to HCBS and has introduced several pieces of legislation in the 118<sup>th</sup> Congress to do so, including:

- The *Long-term Care Workforce Support Act* (S. 4120), introduced in April 2024, would address the need for a strong long-term care workforce across all service delivery models, including nursing homes and home care settings.<sup>38</sup> The legislation will increase the number of direct care professionals; create pathways for women, people of color, and people with disabilities to enter and be supported in the workforce; improve wages and benefits; provide safe working environments, protect workers from exploitation, and identify effective recruitment and training strategies.
- The *Better Care Better Jobs Act* (S. 100), introduced in January 2023, would make states eligible for a permanent increase in the federal Medicaid match for HCBS, help states to establish workforce registries, and enhance funding for administrative activities associated with improvement efforts.<sup>39</sup> To be eligible for the funding, states would have to expand access to services, strengthen and expand the workforce and demonstrate how rate increases would translate to higher compensation for workers.
- The *HCBS Access Act* (S. 762), introduced in March 2023, would make HCBS a required benefit for Medicaid recipients, along with increasing Medicaid funding for HCBS.<sup>40</sup> The bill would provide people with disabilities and older adults who need long-term services and supports a real choice between receiving services in home and community settings or in nursing homes or other facility care settings.
- The *HCBS Relief Act of 2023* (S. 3118), introduced in October 2023, would continue the 10-point Federal Medical Assistance Percentage (FMAP) increase for state Medicaid HCBS programs for an additional two years, through March 2027.<sup>41</sup> This dedicated funding stream would help states further stabilize their HCBS service delivery networks, recruit and retain HCBS direct care workers, and meet the long-term care needs of people eligible for Medicaid HCBS.

## **U.S. Senate Special Committee on Aging Fact Sheets**

Under Chairman Casey's leadership, the U.S. Senate Special Committee on Aging has created several educational and advocacy products related to HCBS, including:

- A fact sheet produced in collaboration with the U.S. Senate Committee on Finance examining the importance of investing in and expanding HCBS, including state-by-state data on Medicaid enrollment, ARPA funding, HCBS waitlists, and median home health worker wages.<sup>42</sup>
- Four national and fifty-one state fact sheets that illustrate the impact that the *Better Care Better Jobs Act* would have had for people with disabilities and older adults if it had passed, including the number of new home care jobs the bill would create, the number of individuals who would receive services due to its passage, and the cost savings of providing care at home instead of in congregate care settings.<sup>43</sup>
- Fifty state fact sheets entitled, *How Democrats' Agenda Benefits Older Adults and People with Disabilities*. These fact sheets detail how the ARPA dollars were invested in each state to expand access to HCBS, provide access to COVID-19 vaccinations, support older adults and family caregivers, and help protect nursing home residents from COVID-19.<sup>44</sup>

## **Future Steps to Safeguard and Bolster Access to HCBS**

To fulfill the promises the country has made to Americans with disabilities and older adults, HCBS must be enhanced, the workforce that provides services must be stabilized and professionalized, and family caregivers must be provided with the supports to be able to see their loved ones provided with the services necessary to live full, independent lives. To accomplish those goals, Congress must:



- Protect Medicaid. As Medicaid is the primary payer of HCBS, protecting the program is of the utmost importance. Republicans have proposed multiple changes to the Medicaid program, including adding work requirements for recipients and capping federal Medicaid spending by making the program a block grant or instituting per capita caps. All of these policy proposals have the ability to decrease access to HCBS and increase waitlists, resulting in higher rates of institutionalization, greater burdens on family caregivers, and the loss of autonomy for older adults and people with disabilities.
- Extend the *American Rescue Plan Act's* (ARPA) Federal Medical Assistance Percentage (FMAP) increases. In 2021, Chairman Casey fought to have an FMAP increase for HCBS included in ARPA. This increase has resulted in more than \$37 billion in investment in HCBS, but the funds will be expended by March 2025.<sup>45</sup> Without an extension, states will have less funding for HCBS, forcing them to decrease pay for HCBS professionals or make cuts to the number of individuals who access HCBS. Congress should extend this funding by reintroducing and passing Chairman Casey's *HCBS Relief Act*, which provides a two-year extension or Chairman Casey's *Better Care Better Jobs Act*, which includes a 10-year extension. To create a more sustainable program, Congress should pass the *HCBS Access Act* or the *Long-Term Care Workforce Support Act*, which both include permanent FMAP increases for HCBS.
- Make HCBS a required Medicaid benefit. Currently, states are not required to offer HCBS but many offer HCBS through waiver programs, meaning states can limit the number of people they provide HCBS to. This has resulted in egregious wait times for HCBS, where people who want and are able to live in their own homes must make a choice—pay out of pocket, find a caregiver, or live in a nursing home. Chairman Casey's *HCBS Access Act* would require all Medicaid programs to cover HCBS, ensuring that people who need and want HCBS are able to receive them.
- Strengthen the HCBS workforce. To meet the large gap in unmet HCBS needs, we need to strengthen the HCBS professional workforce. For too long, we have treated the HCBS workers who work emotionally and physically demanding jobs caring for our loved ones poorly. We need to support HCBS and other long-term care workers through ensuring livable wages, better benefits, stronger workforce and labor protections, and career advancement opportunities.

- Increase support for family caregivers. The invaluable caregiving contributions of family caregivers are often overlooked.<sup>46</sup> Chairman Casey has long-championed bipartisan efforts to support family caregivers. Increasing funding for respite care and support programs (e.g., The National Family Caregiver Support Program under the *Older Americans Act*), incorporating family caregivers into care teams, and expanding self-direction programs—where care recipients can hire family caregivers to provide long-term support services—will help to support caregivers as they continue to care for their loved ones living at home and in the community.<sup>47</sup>
- Expand access to home modifications and technology that enable older adults and people with disabilities to live independently at home. Accessible housing modifications (e.g., grab bars and wheelchair ramps) and assistive technology devices (e.g., screen readers) can significantly increase the independence of older adults and people with disabilities, enabling them to live and work in their homes and communities. Support for efforts to provide home modifications, accessible technology, and accessible housing, such as Chairman Casey's *Visitable Inclusive Tax Credits for Accessible Living (VITAL) Act*, would ensure that people who can live at home with some accessibility accommodations are able to do so instead of in institutions due to a lack of accessible housing.<sup>48</sup>

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