

**UPLIFTING FAMILIES, WORKERS,  
AND OLDER ADULTS: SUPPORTING  
COMMUNITIES OF CARE**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
**ONE HUNDRED EIGHTEENTH CONGRESS**

FIRST SESSION

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WASHINGTON, DC

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**Thursday, March 9, 2023**

U.S. SENATE  
SPECIAL COMMITTEE ON AGING  
*Washington, DC.*

The Committee met, pursuant to notice, at 10:33 a.m., Room 106, Dirksen Senate Office Building, Hon. Robert P. Casey Jr., Chairman of the Committee, presiding.

Present: Senators Casey, Gillibrand, Blumenthal, Kelly, Warnock, Braun, Scott of Florida, Vance, and Ricketts.

**OPENING STATEMENT OF SENATOR  
ROBERT P. CASEY, JR., CHAIRMAN**

The CHAIRMAN. The hearing will come to order.

I want to thank everyone for being here for the first Aging Committee hearing of this new Congress, and we are grateful that we could start in such a big room. We usually don't have the big room, so we are grateful for that.

I do want to welcome everyone today and to thank you for being here, those who are in the audience and those who are providing testimony. I am delighted that Senator Mike Braun of Indiana will serve as the new ranking member of the Committee. He has been not only a member of the Committee, but a very diligent member. He has been to a lot of hearings, and we are grateful for that and grateful for his work as ranking member.

I wanted to start as well by welcoming new members of the Committee, and as many of you know, at these Committee hearings, especially on a Thursday, where we often have our hearings, people are in and out. Members are going to multiple hearings. I was almost much later for this hearing because I had to testify briefly at a hearing on the derailment in Ohio that affected Pennsylvania as well, so you will see Senators that will come in and out, but we have three new members of the Committee who are also new members of the Senate—Senator J.D. Vance of Ohio, Senator Pete Ricketts of Nebraska, and Senator John Fetterman of Pennsylvania, so we are grateful for their membership of the Committee and look forward to working with them and their contributions over the next two years.

As many of you know, the Aging Committee has historically been a Committee that fosters both bipartisanship and collaboration, as we examine difficult issues facing so many older Americans, and as

I continue as chairman, I hope to continue the same spirit of bipartisanship and advance an agenda to build both health and economic security for seniors, people with disabilities, and their families.

Today's hearing will discuss the caregiving workforce, both paid and unpaid, and those who are providing so-called, as the acronym—like everything in Washington has an acronym—HCBS, home and community-based services, and so important to focus on that.

The United States is in the midst right now of a caregiving crisis. There is no other way to describe it, and home and community-based services are not only important, but they are not readily available for those who need them, and we have got to change that. We have a lot of work to do to accomplish that.

In a new report just released last week, ANCOR and United Cerebral Palsy found that 63 percent of home care providers have discontinued services or programs because of staffing shortages. Eighty-three percent of service providers reported turning away families because they don't have the staff to provide the services. The report also found that ninety-two percent of service providers are struggling to meet quality standards because of lack of staffing. Ninety-two percent of service providers having a staffing problem.

When it comes to the staff who are providing this critical, back-breaking work, home care workers often struggle to support their own families because they are paid an average of just \$19,000 per year. This workforce, the majority of whom are women of color, are more likely to live in poverty than the general public. Many work only for their wages and have few or no benefits, including paid leave or even sick leave.

It is time we make the smart economic choice for the country—to help our families, to invest in our families, to invest in caregivers—and strengthen this workforce by making a generational investment in home care services. That is why in January, I reintroduced, with 39 co-sponsors, the Better Care Better Jobs Act. It is Senate Bill 100. It should be easy to remember that.

This Bill focuses on home and community-based services, and I want to describe what those are. Some people have a general sense of it. Here is what we are talking about when we talk about so-called HCBS. A variety of medical and human services that enable older adults and people with disabilities who need assistance to live in their own homes or in a home-like setting and remain part of their communities instead of living in an institutional setting.

Now most institutional settings do a really good job, and people can get really good care there, but Americans should have another option, and most Americans do not, do not have that other option.

Home and community-based services can include the following—assistance with the activities of daily living; home healthcare, of course; physical and occupational therapy; skilled nursing care, like you receive in an institutional setting like a nursing home; home meal deliveries can be part of this; transportation; and so much more.

This Bill, the Better Care Better Jobs Bill, is an investment in better jobs for home care workers, better care for seniors and people with disabilities, and better support for family caregivers. More

than 50 million Americans provide help for their families every day of the week.

This investment is about services. It is also about turning poverty jobs into family supporting jobs. It is about creating a workforce that is paid a living wage so that home care workers do not need to work 60 hours a week, 70 hours a week, 80 hours a week just to feed their families. It is about creating a workforce that is professionalized and respected so that we can recruit and retain the workers to provide more of these critical services.

This investment is how we begin to address the healthcare workforce shortages that we have spoken about to support American families. It is also about supporting family caregivers, as I mentioned before, who are often unrecognized and unpaid caregivers, providing support every day to their loved ones.

As we know, the overwhelming majority of people with disabilities and older adults want to live and remain in their own homes. We need to ensure that families have a real choice when it comes to the supports and services that their loved ones need, so that is why I will also be introducing today the HCBS Access Act, so that everyone eligible for Medicaid long-term care services and supports will have the ability to choose home care and remain in their communities without fear of being put on a long waiting list.

The Better Care Better Jobs Act and the HCBS Access Act are complementary. The first one is an investment to create a robust HCBS provider infrastructure for the recruitment and the retention of workers. The second bill establishes a permanent funding stream to keep the infrastructure strong and make sure that we are able to continue to pay direct care professionals at a rate that ensures qualified, reliable services and a qualified, reliable workforce into the future. The HCBS Access Act also creates real choice for individuals and families to be able to choose between home care supports and institutional care.

Taken together, these bills will revitalize the caregiving workforce and create sustained changes for home and community-based services. We should pass these common sense bills so families don't have to face difficult decisions about how to care for a loved one. We, as a Nation, must come together to address the needs of the workforce that will help us care for those who need support.

I look forward to hearing from our witnesses about the need to create and sustain a strong home care workforce, and now I turn to Ranking Member Braun for his opening remarks.

#### **STATEMENT OF SENATOR MIKE BRAUN, RANKING MEMBER**

Senator BRAUN. Thank you, Chairman Casey.

He is correct. This is a Committee that in the time I have been here, we have covered more terrain—we really can't legislate through it, but we can talk about a lot of issues, and it is one where I think especially as it relates to all of us that will be there some day in that aging category, and so many things that we do as a Federal Government—Social Security, Medicare, Medicaid—take a much broader discussion than what we have here today. It needs to be fixed. It needs to be saved.

I come from the world of where I have run stuff before I got to the Senate for 37 years, and no other place quite works like this

place, and I have never seen so many—a place where so many people look to it and depend upon it, so that is always a factor as we look at what we are going to do, try to do it more efficiently, more cost effectively.

On the Committee, as a business owner, my priority was to have healthy employees. I took on healthcare in general many years ago and did some things entrepreneurially, like turning my employees into healthcare consumers. Asking them to own their own well-being, so when they get in that elderly category they can enjoy life and not be riddled with having to fight healthcare issues. The old “ounce of prevention being worth a pound of cure” goes a long way.

When it comes to like reforming Medicaid to support, Senator Casey was talking about it, home-based care, that is important. It is probably a way that if you get that right, you get the workforce training kind of orienting in that direction, you can save money and maybe do it more efficiently.

Community-based services I think are going to gain stride and become more important each year we get down the trail. Not only for Hoosiers, but for folks across the country. That dynamic I think is going to be in play, and we need to make sure we get it right.

Now, one in five Americans, one in five, is a family caregiver. I mean, that is a big number. When you take 20 percent of 330 million, that is a lot of people that probably are not going to be really ready to go when that time comes, and we got to get better at it to make that work.

I got one example, Cornerstone Lutheran Church in Carmel, Indiana. Decades ago, members of this church recognized the need to support family caregivers, so they established what they called a “Friendship Group.” Now Friendship Groups have grown across the State, helping family caregivers know where to turn for support. I think that is important.

Whenever we can do it from the grassroots up, it is probably going to be done a little better, and it is probably going to be more cost effective, too.

Federal policies should support family caregivers. The Administration’s proposed Independent Contractor Rule will hurt caregivers, in my opinion, by restricting the independent work and the flexibility it offers. Seventy-four percent of independent workers say they prefer the arrangement because it gives them flexibility to be one of those one in five of all Americans that are going to be caregivers eventually.

Women, who make up the majority of caregivers, will be disproportionately harmed by restricting independent contracting. That is a whole other issue we have to deal with to make sure that dovetails into what we are trying to accomplish here.

Inflation is still high and widespread. It is not going to go away anytime soon. It impacts all of us as we try to recruit and retain new employees, including caregiver employers. The Better Care Better Jobs Act, which was talked about earlier, I think is going to maybe add to inflation, so sometimes we do things here, even though well intended, might be counterproductive.

The Federal Government wants to rebalance spending on long-term services and supports from institutional care to home-based services. Rebalancing means shifting weight from one side to the



other. It doesn't mean putting more weight or more burden on trying to do it, so we have to be careful there.

I introduced the bipartisan JOBS Act with Senator Kaine to expand Pell Grant eligibility to shorter-term job training programs. I think that is going to be a win-win. I hope Senator Casey joins us on that, and I think that has got a good chance of making it through this Congress.

I also reintroduced the Prioritizing Evidence for Workforce Development Act to fund education and workforce programs with proven outcomes. I think that is important. This Bill would help scale successful programs like the Goodwill Excel Center, which helps adults earn their high-school diplomas and provides training so they can enter the high-demand, high-wage fields.

In our State of Indiana, 135,000 jobs need a better high school education. We export four-year degrees in our State. Our guidance counselors at many schools do not even tell kids about jobs like will be needed for caregiving in the home.

We also need to make sure that the wages are there, so it is attractive for people to get into fields. This needs to all be guided. It needs to be promoted, and kids coming out of high school, regardless of what your trajectory is—doctor, astronaut, plumber, electrician, anything in between—need the skills that we seem to not be delivering, and it would really come into play when it comes to what we are talking about here today, so as long as I am here, I am going to push that from this level. Don't dismiss what can be done in your own States, a lot of times where the laboratory of finding things that work and you can pay for actually occur.

I yield back.

The CHAIRMAN. Thank you, Senator Braun, for your opening remarks and grateful for the work you are doing as Ranking Member.

I want to start with our witnesses. What I will do is introduce each of you, and then we will start with testimony, but I will introduce each of you first, and I apologize in advance for the brevity of our introduction because that doesn't, of course, capture all the work that each of you does.

I want to start with our first witness, Dr. Kezia Scales. Dr. Scales is Vice President of Research and Evaluation at the Paraprofessional Healthcare Institute, or PHI. For nearly fifteen years, Dr. Scales has been studying person-centered, high-quality, long-term care with a focus on direct care workers.

Thank you, Dr. Scales.

I am going to now turn next to Ranking Member Braun to introduce our second witness.

Senator BRAUN. My pleasure to introduce Dr. Hannah Maxey, Associate Professor of Family Medicine and Director of the Bowen Center for Health Workforce Research and Policy at Indiana University School of Medicine. She is a nationally recognized expert in health workforce policy, with a specific focus on State solutions for recruitment, retention, and regulation.

Dr. Maxey has been a licensed dental hygienist in Indiana for over twenty years. She spent nearly a decade practicing in public health clinics operated by the Marion County Public Health Department, prior to pursuing both a Master of Public Health and a

Doctorate of Philosophy in Health Policy and Management, both at Indiana University.

Her experience as a practicing healthcare professional in public health clinics provides perspective on the critical role of health workforce. She serves as an expert consultant to the National Governors Association and has worked on issues ranging from family—from health workforce data collection to policy design and implementation. Most recently, she has provided expertise for Indiana’s Direct Service Workforce Plan.

She is honored here today to be joined by her 15-year-old, Sebastian, in the row behind. Welcome to both of you to the hearing today.

The CHAIRMAN. Thank you, Senator Braun.

Our third witness is Pam Lowy. Pam is the Executive Director of Great Bay Services. Great Bay Services is an organization dedicated to providing support for adults with intellectual and developmental disabilities. We thank her for her testimony.

Our fourth and final witness is Jacinta Burgess from Harrisburg, Pennsylvania, which is right in the southcentral part of our State in Dauphin County. Jacinta is a caregiver for her mother and a strong advocate for her mother’s needs. She will share her experience as a caregiver.

I want to thank Jacinta for being here today, and I also want to thank your mother, Stephanie, whom I met earlier, and your brother William, who are in the audience. We are grateful for all of you being here today.

Before I turn to our first witness, I wanted to mention that some of our Senators will be here asking questions and appearing virtually, not in person, and that is something that we provide an opportunity for, and I know that Senator Gillibrand is appearing at the hearing today in that fashion.

We will start with our first witness and then proceed one after the other. We will start with Dr. Scales.

**STATEMENT OF KEZIA SCALES, PH.D., VICE PRESIDENT  
OF RESEARCH AND EVALUATION, PARAPROFESSIONAL  
HEALTH INSTITUTE (PHI), DURHAM, NORTH CAROLINA**

Dr. SCALES. Good morning. Thank you, Chairman Casey, Ranking Member Braun, and members of the Committee, for the opportunity to testify on the importance of investing in the home care workforce and supporting our communities of care. It is an honor and a privilege to be here today.

As noted, I am Vice President of Research and Evaluation at PHI, a national New York-based nonprofit organization that works to transform elder care and disability services by promoting quality direct care jobs, including home care jobs, as the foundation of quality care.

More than 2.6 million home care workers, primarily women, people of color, and immigrants, assist older adults and people with disabilities across our country every day, because the population is rapidly aging and because most of us wish to age in place, nearly a million more new home care workers will be required by 2030. That is more new jobs in home care than in any other occupation in the United States.

Yet, as Chairman Casey spoke about, we are facing a workforce shortage right now because home care worker wages are too low, employment benefits are inadequate, training and career development opportunities are limited, and these jobs are insufficiently recognized, respected, supported, and valued. Existing and potential home care workers are being forced to choose more viable employment opportunities in other industries, leaving home care providers struggling to maintain services, and individuals and families without the support they desperately need.

Investing in home care jobs is a critically needed strategy to strengthen and stabilize this workforce to meet ever-growing needs, and I use the word “investing” because it will pay off.

First of all, raising wages for home care workers will lift these essential workers out of poverty and enable their economic independence. Currently, 53 percent of home care workers rely on public assistance like Medicaid and SNAP just to meet their basic needs. If we raise wages, we will substantively reduce expenditure through these and other public programs, and what is more, these jobs will become more attractive and sustainable, thus reducing costs associated with recruitment, turnover, and contract staffing.

Second, by investing in a more stable, sufficient, and well-prepared workforce, we can better ensure home care continuity and quality, which, in turn, can prevent or delay more costly outcomes. In other words, if individuals receive the support and services they need when they need them, their experiences and outcomes will improve, and the total costs of care, particularly to Medicaid and Medicare, will decrease.

Third, family caregivers will benefit financially. We know that family caregivers, the bedrock of our long-term care system, experience significant employment challenges, often having to reduce their hours, forgo promotions, or leave their jobs entirely. With more paid care available, family caregivers will continue to support their loved ones, but without having to compromise their economic productivity, financial security, and overall well-being.

Finally, investment in the home care workforce—again, one of the largest, but lowest-paid occupations in our country—will stimulate consumer spending and support economic growth overall. A living wage will provide millions of workers with more income to spend on food, housing, healthcare, transportation, and other basic necessities, generating new jobs and building wealth in local communities across America.

The Better Care Better Jobs Act exemplifies the potential for Federal leadership on this important issue. Through this legislation, States would be eligible for a permanent increase in the Federal match for their Medicaid home and community-based services, or HCBS. This legislation is so important in recognizing the indivisibility of job quality, workforce stability, and service delivery.

To receive the funds, States will have to regularly assess and update their reimbursement rates to fully cover labor costs and ensure that increases actually benefit workers. They will need to strengthen training and credentialing opportunities for both paid and unpaid family caregivers, and they could receive additional funds to build their consumer direction programs and related workforce, and they will be expected to evaluate and report on their suc-

cess, thus ensuring accountability and helping build the evidence base on high-quality, cost-effective home and community-based services.

The Better Care Better Jobs Act would be transformational, and it is not the only solution. We also need to enhance equity, as Chairman Casey was speaking about, by putting HCBS on equal footing with other long-term care options across States, as promoted by the HCBS Access Act.

We need to test new approaches to workforce recruitment, retention, training, and advancement and scale up those that achieve the best value. We need to ensure that home care workers and family caregivers have access to paid leave so that they can afford to take time off without sacrificing their employment, and more.

Now is the time to embrace these solutions for the benefit of everyone who has a stake in strong communities of care, which is every single one of us.

Thank you very much. I look forward to questions.

The CHAIRMAN. Dr. Scales, thanks very much.

Dr. Maxey.

**STATEMENT OF HANNAH MAXEY, PH.D., MPH, ASSOCIATE  
PROFESSOR OF FAMILY MEDICINE AND DIRECTOR OF  
THE BOWEN CENTER FOR HEALTH WORKFORCE RESEARCH  
AND POLICY, INDIANA UNIVERSITY SCHOOL OF  
MEDICINE, FISHERS, INDIANA**

Dr. MAXEY. Thank you.

Good morning. Thank you for your time, Chairman Casey, Senator Braun, distinguished members of the Committee.

Time waits for no man. The issues of the aging are the issues of us all. I applaud the Committee's commitment to supporting the communities of care for our honored aging citizens.

As Ranking Member Braun mentioned, my experience as a healthcare professional and a workforce researcher are broad and have extended more than two decades. I am here today as a health workforce policy expert to speak to the solutions that States are developing and implementing to build and strengthen their home and community-based services workforce, or HCBS workforce.

I am delighted to be joined by my son, Sebastian, who is currently working on his Eagle Scout project back in Fishers, Indiana, and is deeply interested in American government.

In the balance of power between the Federal and State governments, States oversee policy and programming related to workforce development, occupational regulation and public protection, and social services. All of these have a direct impact on the HCBS workforce. Keeping a finger on the pulse of related State efforts is critical to understand the national landscape and ensure policy alignment from the halls of Congress to our State general assemblies and, ultimately, within the homes of our seniors.

I am delighted to have provided research support to my home State on the Indiana Direct Service Workforce Plan. This initiative is a foundational part of LTSS reform in Indiana, seeking to enhance access to HCBS services. Indiana is one of numerous States that have engaged in planning to develop and strengthen this workforce. Many of the strategies I will discuss today are a part of Indiana's plan.

Also I would like to note that although these strategies may be beneficial for the private sector, my research and expertise on these matters is focused on State solutions.

HCBS quality metrics recently released by CMS are appropriately focused on member experience. What is not in writing is that achieving many of these metrics hinges upon the availability and dependability of a competently trained workforce. HCBS workers require certain skills to care for our honored aging. Regardless of whether that worker is employed by a provider or a self-directed consumer, training standards support a minimum level of quality.

Some States have developed portable credentials for individuals that have met training standards. Frequently, these are implemented through registries for qualified workers. Portable credentials empower workers by demonstrating their training achievements and facilitating their pursuit of economic opportunity among new employers, in new settings, or through additional academic training and stackable credentials. Empowered workers power our economy.

Training registries can also empower employers and self-directed consumers by enabling them to verify that a worker has achieved training standards prior to entering into arrangements. When coupled with incident reporting and high-fidelity investigation processes, State registries can also protect the public from bad actors. Self-directed consumers and employers alike can query these registries to ensure that a worker does not have any substantiated abuse, neglect, or exploitation claims against them.

In addition to consumer protection, registries offer States an opportunity to collect supplemental information on their workforce. Such information is useful for workforce assessments, targeting development initiatives, and evaluating the impact of these initiatives. Indiana is a leading State in this space, recently having leveraged such information to identify and strengthen career pathways for the facility-based direct care workforce.

Wage is commonly cited as the greatest challenge to the HCBS workforce recruitment and retention. State Medicaid programs are the single largest payer for LTSS services in the United States, but the true costs associated with our public LTS services are even greater when we account for the many HCBS workers who qualify for and receive public assistance, such as Medicaid, SNAP, or TANF, based on their income.

Recognizing Medicaid's influence over HCBS workforce markets and wages, many States, including Indiana, have developed targeted initiatives to enhance wages and benefits. Such strategies include competitive rate setting, wage passthroughs, and value-based incentives. A conundrum within these discussions is the impact that wage enhancements can have on worker benefits.

As I just mentioned, many HCBS workers receive public assistance. Strategies which increase wages to just over public assistance qualification can negatively impact overall income. This is commonly referred to as the benefits cliff. States are exploring where these cliffs exist to ensure their solutions are data driven and have a net positive impact.

I would like to thank you for this opportunity to brief you on the great work going on in Indiana and States across our Nation to uplift older Americans and the workforce that is supporting them.

Thank you also for your leadership on this topic and your commitment to supporting and advancing State solutions.

The CHAIRMAN. Dr. Maxey, thanks for your testimony.

Ms. Lowy, you may begin.

**STATEMENT OF PAM LOWY, EXECUTIVE DIRECTOR, GREAT BAY SERVICES, DOVER, NEW HAMPSHIRE**

Ms. LOWY. Thank you, Chairman Casey, Ranking Member Braun, and members of the Committee, for the opportunity to testify on the importance of investing in the home care workforce.

In particular, I want to recognize my home State Senators, Senators Shaheen and Hassan, for their support of Senate Bill 100, and Senator Hassan for her co-authorship of Senate Bill 1437, who are watching this remotely.

My name is Pam Lowy, Executive Director of Great Bay Services, a provider of home and community-based services along the northern coast of New England. Our organization was founded in 1954. We started the first New Hampshire school for children with disabilities, opened a training center to provide employment for adults with disabilities, and helped close down the last New Hampshire institution for disabled citizens.

We serve adults with intellectual and developmental disabilities, such as those with Down syndrome, autism, and cerebral palsy. This population is low-income, most with co-occurring mental health diagnoses—most commonly depression and anxiety—and 60 percent of whom live with caregivers over the age of 60. My own brother David is a Great Bay Services client who lives at home with our 89-year-old father.

We facilitate the independence and personal fulfillment of the people we serve, putting a lot of time, thought, conversation, and effort into what each person considers to be a meaningful day. For some, this includes working, in which we support them. For others, this includes volunteerism.

My brother David, after volunteering at a soup kitchen, at the ASPCA, or greeting returning servicepeople at Pease Air Base, always tells me “I helped today. I am proud of myself.”

Caregiving is essential work, and that work is only accomplished with skilled caregivers. However, we are experiencing a significant shortage. One reason is the wages for a caregiver. The Massachusetts Institute of Technology living wage calculator estimates the living wage for an adult with one child in our region is approximately \$35 per hour, working 40 hours per week. The current wage we are offering direct support professionals, or DSPs, is \$16 an hour, and the majority of the supports we offer are contracted by Medicaid for a maximum of 30 hours per week.

DSPs live paycheck to paycheck. When their vehicle needs repairs or they have out-of-pocket medical expenses, they have to make some very difficult decisions, because our supports and workforce are such an integral part of our clients’ daily lives, going fully remote, even for a short time at the start of the COVID-19 pandemic, significantly affected their well-being. One program partici-

pant's mental health suffered so greatly that he was hospitalized. Others needed emergency one-on-one supports to ensure they wouldn't experience a similar breakdown.

As Executive Director, I have found myself repeatedly in situations where I have had to make the ethical choice—raising wages and mileage reimbursement despite Medicaid not covering the increase, temporarily closing programs after COVID exposures—and pray that it wouldn't bankrupt us.

The average wage for DSPs in our region is \$13 to \$15 an hour. Even with a starting wage of \$16, it is not enough at Great Bay Services. We continue to lose potential workers to other employers, and I am regularly forced to advise interviewees who State they cannot afford to accept my job offer that they would earn more working elsewhere.

Staff in our field are financially struggling, barely making ends meet, but constantly agonizing over what would happen to the people we support if they don't come to work. DSPs in general tend to be older workers. Our average staff age is 46, with over 10 percent of our staff being 65 or older. Our longest-serving staff came to us straight out of college in the early 1970's and 1980's. They have decades of experience in the field and decades-long relationships with our clients.

The average wage for DSPs across the U.S. is not a living wage. One of our staff members confided in me that they had been homeless for their first few years in the field, struggling to raise a child on what was then barely above minimum wage.

The ARPA funding Congress provided enabled us to pay tenure-based bonuses to our staff who stayed with us through COVID. One staff member cried in my office in gratitude that they could pay their oil bill as a result of that bonus. We were able to offer new hires bonuses, as well as more robust trainings to all staff because of that increased funding.

This has had an important impact on our hiring and retention, but it will not be a lasting impact. External financial stressors regularly impact the individuals we employ and can spill over into their work and their interactions with our clients in obvious ways, such as a vehicle breakdown, and less obvious ones. A stressed human support worker is less able to provide the empathetic, compassionate support our clients deserve.

These DSPs are individuals from whom we expect a similar, if not higher, level of skill compared to other positions, which, unlike DSPs, have standard occupational classifications, such as certified nursing assistants, home health aides, and personal care assistants. DSP work is complex and goes well beyond caregiving, requiring skills including behavioral assessment and prevention, medication administration, and many personal and intimate caregiving tasks.

I ask Congress to provide adequate funding for HCBS to keep Great Bay Services and organizations like ours from going bankrupt and to keep our staff able to provide the necessary daily supports for Americans with disabilities. We make it possible to keep older adults and people with disabilities safe, stable, and in their homes, workplaces, and out in their own communities in which they play a vital role and where they prefer to be.

Thank you for the opportunity to share my story, which is similar to that of thousands of providers across the country. I look forward to answering your questions.

The CHAIRMAN. Ms. Lowy, thanks very much for your testimony. We will conclude our testimony with Ms. Burgess.

**STATEMENT OF JACINTA BURGESS, HOME CAREGIVER/  
DIRECT CARE WORKER, HARRISBURG, PENNSYLVANIA**

Ms. BURGESS. Good morning, and thank you, Committee Chairman Casey, Ranking Member Braun, and members of the Committee, for inviting me to speak today.

My name is Jacinta Burgess. I am a home care worker from Harrisburg, Pennsylvania.

I have cared for my mother, Stephanie, full time for roughly three years. My brother is her part-time caregiver as well. I am honored that they are here with me today.

We believe that the best way for our mother to receive care is at home with the people and things she loves. I care for my mother because she did her best to raise me. It is my duty to do my best to care for her now, but love can't pay the bills.

My mother suffers from a number of neurological conditions, including essential tremors, which cause her body to involuntarily and painfully shake, sometimes for hours. Her condition also leads her to become confused. One time, she accidentally turned the stove's gas on, and it leaked for hours, and before she stopped driving, she almost hit a group of children crossing the street. These experiences led me to start caring for her full time.

I am my mother's eyes, ears, voice, and hands. As her caregiver, I make sure that she is living a happy, comfortable, full life, while managing her illnesses and chronic pain. When my mom wakes up, I am there to ask her what she needs to start her day. She might need help bathing and getting dressed or a massage to relieve her pain. I help her with day-to-day duties that most healthy people take for granted, including opening doors, walking, getting into a car, cooking, or even pouring a glass of water.

I am here to tell you that home care workers like me are struggling. The pay is not something you can live on. There are no paid days off. There is barely any training, and there are no medical benefits.

When I officially became my mother's caregiver, I was paid around \$12.39. Over the past three years, my wages have increased by just 99 cents.

In 2023, with the cost of living skyrocketing, \$13.38 is not enough for me or any working person to pay all their bills and live comfortably. My mother has to help me pay the rent and utilities out of her monthly Social Security benefits. If we didn't have each other, my mother and I would be homeless and struggling even more than we are now.

Everything branches out from me. I am the head of the household with my head on a swivel. I am a queer black woman living in America, and I also have to worry about caring for a parent. Most mornings I don't want to get out of bed. I struggle with deep depression and anxiety but can't afford the mental healthcare I need to stay strong for myself and my mother.



How is anyone supposed to enjoy their life if all they have to look forward to are the struggles they face? It may sound silly, but our cats are sometimes our only source of comfort. My mom massages my cat Chaka to calm herself frequently. I love our cats, but they should not be our support system.

If I had a livable wage, I could live, not just survive. I could afford to buy a car so that we wouldn't be dependent on rideshares. I could purchase a home so I can afford the standard of living and stability I want for my family. Our current apartment has roaches and ventilation issues that make it hard for my mother to breathe.

What keeps you up at night? I toss and turn worrying about whether I forgot to pay a bill, an autopayment overdrafting my account, and the condition of my apartment. I fight with a number of things I want to change so badly but can't because of my lack of money and resources.

There are so many care stories I could tell. Like my cousin Venetia, who requires 24-hour care but doesn't have a consistent caregiver, and they generally don't last for longer than a few weeks. There is a severe shortage of home care workers, or my friend and union buddy Genale, who cares for her mother and struggles to find time to care for herself, but without Genale, there is no guarantee her mother would be safe or cared for.

For decades, home care workers have organized, advocated, and rallied for justice. My union, SEIU Healthcare Pennsylvania, has made a huge difference in my life. My union is a community of support and inspiration.

I have a vision of America where long-term care is accessible, affordable, and consistent for all. We need our elected officials to champion efforts to make home care jobs full-time, respected union careers and raise standards of care for consumers.

I am important. My mother is important. My cousin Venetia is important. Genale is important, and every care worker and care consumer is important.

Thank you.

The CHAIRMAN. Ms. Burgess, thanks very much for bringing your personal story to this hearing.

I will start my questions, my first question directly to you. Before I do that, though, I wanted to mention as well. We have—as I mentioned earlier, with Senator Gillibrand appearing virtually, we also have Senators who appear as part of this hearing. Senator Warnock and Senator Scott—Senator Rick Scott of Florida, and we will have other, as I also mentioned, other Senators coming in to ask questions as we go.

Ms. Burgess, let me start with you. As you know, in many parts of the country, this workforce that we have been talking about, the home care workforce that you are part of, is characterized by low wages, limited to no benefits, and high turnover, and that is just a brief summary.

The need for more Americans to do this work has never been, I think, more apparent. You heard Dr. Scales mention, what is it, a million, we will need a million people between now and 2030, not even a decade away. A million more people to do this work.

Ms. Burgess, you mentioned in your testimony that you make \$13.38 an hour, and I believe you said that that had only increased by, what was it, 90—

Ms. BURGESS. Ninety-nine cents.

The CHAIRMAN [continuing]. Ninety-nine cents since—

Ms. BURGESS. I started in 2021, so it only increased at the beginning of last year.

The CHAIRMAN. About a year?

Ms. BURGESS. Yes.

The CHAIRMAN. Going into your third year, I guess. The Better Care Better Jobs Act would improve the compensation for workers such as you, and I think that is critically important. Paying home care workers a living wage is not just the right thing to do for that individual, it is the right thing to do for all of us because you can't have good care if you have consistently low wages over time.

It is also important for our economy. If we are going to call ourselves the greatest country in the world with the strongest economy, we got to have the best caregiving in the world, and we have work to do to achieve that.

Ms. Burgess, what would a living wage mean for you? What would it mean for your family? What do you believe it would mean for other care workers?

Ms. BURGESS. As I previously stated before, a livable wage would mean that I could own my own home instead of paying into a system that I feel disrespects me and takes advantage of me. I could own a car, pay car insurance, save money for a rainy day. Take my pets to the vet instead of putting off their care.

I could also assist my mother in her medical bills, and I could also pay my own medical bills and my own debts. It would make things so much better for not just my family, but other families in the care system.

Home care workers wouldn't have to struggle so much, and they wouldn't have to stretch their money as far and wide as possible. They would no longer have to be living paycheck to paycheck without this cloud over their head.

The CHAIRMAN. And your work, what comes with your work is a lot of stress, I imagine.

Ms. BURGESS. Yes.

The CHAIRMAN. Is that true?

Ms. BURGESS. Yes, a lot.

The CHAIRMAN. I think we have to ask ourselves as Americans, would we want the person who is caring for us or caring for our mother or our father or loved ones, would we want that person to be someone who is paid a very low wage and has a lot of stress in their life? Think about that for a moment. Is that the kind of healthcare that we want for our country? I think most people would say the answer is a resounding no to that question.

Dr. Scales, I want to keep to my time because I will be telling my colleagues to stay within their time, so I don't want to go over, but, Dr. Scales, the legislation I have introduced would make a substantial investment in home and community-based services. This investment would directly improve the lives of older Americans and people with disabilities and help the workforce.

Can you speak to how these investments would benefit the workers, also benefit American families more broadly and our economy?

Dr. SCALES. Absolutely. Thank you, Chairman Casey.

For home care workers, I feel like Ms. Burgess has spoken to this truth so compellingly already, but these investments would mean the ability to really make a living while supporting the lives of others, ideally without having to rely on public assistance programs to make ends meet. That means the ability for job seekers across the board to be able to choose to do this work, for home care workers to be able to continue to do it over time, and to be respected and valued for that commitment.

With regards to families, these investments would make a meaningful difference in the availability of paid respite care and ongoing assistance, and that, in turn, would support family members' abilities to manage their caregiving responsibilities without undermining their own jobs and careers.

It is important to say also that more paid support would also allow family caregivers to safeguard their own health and well-being, which would have positive implications for their ability to show up for their family members and in their jobs.

At the systems level, in terms of our country's economy, I will say again that I think that we can achieve net economic benefits from investing in HCBS and the workforce, because by spending more money upstream on these jobs and these services, we will see downstream savings in terms of reduced spending on public assistance, reduced spending through Medicare and Medicaid on more costly settings of care, and more contributions to the economy from these millions of workers that we are talking about.

I think the challenge really is here to just follow the money to see, to be able to demonstrate the systems-level return on investment and strengthen coordination and integration where possible so that we do really realize that goal.

The CHAIRMAN. Dr. Scales, thanks very much.

Before turning to Ranking Member Braun, we are joined by Senator Ricketts. I mentioned the new member of the Committee and new member of the Senate. Welcome, Senator.

Senator Braun.

Senator BRAUN. Thank you, Chairman Casey.

Back in Indiana, I know that we have got some institutions like Ivy Tech that has got a program to kind of upskill. I am interested in getting your comments on that, and it looks like in our State we are going to need about 14,000 more caregivers over the next 10 years. That is a lot.

Whenever you can have skills upgraded—and I know career and technical education is an important thing. We are the biggest manufacturing State per capita, and we have got lots of jobs that are begging because we don't have those basic skills coming out of high school where you need to kind of upgrade them a little bit in some cases, so I have got a bill out there, the JOBS Act, with Senator Kaine that would allow Pell grants to be used for this type of training and certification.

I would like you to weigh in on how big a deal that would be to get these skills kind of upgraded, and then in our own State, we have heard the wage level, which does not seem to be a living

wage, what is that stratification in Indiana for home caregivers? By upgrading your skills, will the market pay a better wage if you are doing that?

Dr. MAXEY. Thank you so much for your question, Senator Braun.

With regards to support for training programs, cost can be a major barrier to individuals pursuing training and pursuing career pathways. As States are considering, including Indiana, developing and formalizing training programs, there will likely be costs associated with those, so any types of programs that can defray or reduce the barrier to cost to training that can qualify an individual for jobs I think will hopefully go far to advancing and addressing our workforce shortages.

Regarding wages in Indiana, I would love to get you the formal information on where we stand today and kind of where we have been, and I would be happy to followup with that. I do believe that as we move toward an Indiana—and I know other States are doing the same—toward having some type of training standards, that those training standards, once an individual has them, they will be empowered to negotiate with their employers, also to seek out new employment opportunities.

Ideally, we want people to be retained in their positions and roles, but we also want to empower people to find the best job situations for themselves, so I do think that we will see some advancement of wage through training.

Senator BRAUN. How long have we had Ivy Tech devoting special training toward caregivers in the home? How long has that been in our own State?

Dr. MAXEY. To my understanding, more recent that Ivy Tech has been working specifically with the direct support professional training program with the State of Indiana, and we are really looking forward to see how that might be expanded to help support home and community-based workers in other settings, including with the aging.

Senator BRAUN. Well, not only whatever you need in terms of the extra skill enhancement, this is something, too, that I believe we need to take all the way back into secondary education to where you are trying to do some of these things, because when it looks to be so many people working in a given arena, why wait until after high school to get with it.

This is going to become a bigger issue rather than a smaller one, so I think it makes a lot of sense that across this array of career and technical education that we start giving it its due in high school, that we don't guide against it, stigmatize some of these pathways because they are needed.

As Ms. Burgess said, you can't make a living on the wages that we are currently devoting to it, so, to me, to solve this and really do it, it has got to occur way back in even middle school and high school to where you start pointing out where the need is, and then if you need extra training after high school, fine, but try to get started back there.

I Yield back.

The CHAIRMAN. Thank you, Senator Braun.

Now next we will turn to one of our new Senators, and I know Senator Ricketts was here just a little bit before Senator Vance, but technically, technically, Senator Vance has seniority.

Senator RICKETTS. He was here first.

The CHAIRMAN. Senator Vance, you are recognized.

Senator VANCE. Thank you, Mr. Chairman.

Pete, I guess you should get out of my chair then. I should sit a little closer to the member there.

Well, let me just—let me start here by offering a few thoughts. One of the things I worry about, of course, is that we have a really weird demographic situation in our country—and I apologize for coming late. I am sure that we have discussed that issue a little bit, and I am sure it is something all of you are very aware of.

We have an aging society. Most American families are having fewer children, and if you play that experiment out long enough, what you end up with is a lot of people who are a little on the older side who need more care and fewer and fewer people on the worker side who can provide that care. That is true whether you are talking about in-family care. That is true whether you are talking about nursing homes and so forth.

I guess where I would start here is the job of caregiver is almost a saintly calling here. If you think about this, it includes a number of unglamorous duties. I am sure I am not telling you guys anything that you don't know there.

It is a tough job in a lot of ways, and what my staff has found, that some of the initial, entry-level postings for these caregiving roles are something like \$15 an hour, which is hard for a lot of people, even those who want to do healthcare, to swallow, so they often don't appeal to Americans in the middle of their lives, and I don't doubt that these jobs are richly rewarding for devoted caregivers, but caregiver work can, of course, include duties such as bathing elderly wards, some of whom are suffering from dementia and may not remember who the caregiver is by the end of it. In short, this is very hard and often thankless work.

I guess the first question that I would ask, given how stressed the industry is, and I sort of direct this to everybody, but is how are the caregivers doing psychologically? We talk a lot about the economics and the statistics, but do you feel like the caregivers you guys are seeing, are they doing well? Are they happy? Are they feeling the stress? I would love to hear your feedback on that.

Ms. BURGESS. As a home care worker myself and as part of SEIU Healthcare Pennsylvania surrounded by home care workers all the time, I, myself, am not doing well. I struggle with depression and anxiety. My friends often are struggling. My friend—actually, Genale, she takes care of her mother. Her mother has dementia. She is often, you know, emotional.

Many people in this field are overwhelmed and often overworked because we don't have any other person really to rely on besides our family, and sometimes it is hard to get other home care workers to come in, depending on what area you live in, to relieve you of duty, so it is very hard.

Senator VANCE. Well, I appreciate that, Ms. Burgess, and thank you for what you do, and I am sorry to hear that, but we certainly admire what you do.

I guess maybe sort of one followup question then—again, to whoever on the panel would like this—is what do we do about this, right? I mean, if you have overstressed caregivers, you have a demographic situation that seems to be going in the wrong direction, it is going to get worse, it seems like, before it gets better just because of the aforementioned issue.

Let me just ask a very direct question. Do you think the starting wages of caregivers are too low?

[Witnesses nodding.] That is a yes. Okay. What do you think, if I am right that it is about \$15 an hour—and if I am wrong, please correct me, but what do you think the right number is here for entry-level caregivers to entice younger workers into this profession to begin with?

Ms. BURGESS. I can say for me I only get paid \$13.38. I don't make \$15, and most of my union members do not either. Now the starting wage would preferably be probably in the \$20 range. I will let someone else speak.

Senator VANCE. Sure. Thank you.

Dr. SCALES. Can I add—oh, go ahead.

Ms. LOWY. It feels a little bit like Price is Right. We all want to jump in with this question.

I do wonder whether or not a lot of us have the same number in mind. I do appreciate the question, and as Jacinta pointed out that where we are at right now is absolutely too low. I would say we are about \$5 an hour behind where we should be for the skill level we are expecting.

I have a beautiful graphic that was put together by the National Association for DSPs that shows the crossover between DSPs, LNAs, home healthcare aides, and these other positions. Generally speaking, their entry-level wage is about \$20 an hour, so the fact that we are paying \$16, really trying to push it, trying to be staffed.

I am sorry, Doctor.

Dr. SCALES. Am I allowed to respond?

Senator VANCE. Please. Please do, yes.

Dr. SCALES. Okay. I would just add that the median wage for home care workers across the Nation is \$14.09 an hour, and really where we need to get to are wages that are livable, and there are calculations for that, which allow people to pay their bills, achieve economic independence, reduce reliance on public assistance, but also that are competitive to wages in other industries that are pulling from the same labor pool, because to your point about the changing population, our changing population structure, we need absolutely more people to be choosing these jobs, and right now, we are losing them to jobs that require the similar level of training and experience or even less, and what we see across the board in every single State, the median wage for home care is less than the median wage across these other industries that are offering sort of reasonably competitive jobs.

Senator VANCE. Thank you. I realize I am at the end of my time here, but I fear that we are in a bit of a spiral here, and we need to get out of it, because as I said earlier, the problem is going to get worse before it gets better.

Thank you all for being here, and thank you, Mr. Chairman.

The CHAIRMAN. Senator Vance, thanks very much.

Senator Ricketts, you are rewarded for your patience.

Senator RICKETTS. Thank you very much, Mr. Chairman.

This obviously is a difficult situation. As Governor of Nebraska, this was something that we faced as well. I think just generally in the country between 2008 and 2018, we saw the number of people who were 65 or older go from something like 39 million to 52 million, and by 2060, I think that number is supposed to be 95 million.

In Nebraska, in the last Census, something like 16.4 percent of our population was above 65, and we have got about 200 skilled nursing facilities and assisted living facilities and about 100 hospitals that also are providing different levels of care. The hospital is providing different level of care to seniors.

The workforce shortage is one of the things that we hear from this industry, as well as other industries. I also think there might be some analogies here to the childcare industry as well, but it is certainly a big challenge.

We have had a number of our nursing facilities close in Nebraska. Certainly workforce is part of the challenge, but also one of the things I have seen is census, too. A lot of times when we are looking at these, particularly in rural areas when they close, they are at 50 percent census. They would have capacity to take on more people, so that is one of the other challenges we have.

When we are talking about licensures and things like that, that also kind of plays into this and the qualifications. Dr. Maxey, based on your research on how to better support caregivers, do you believe industry standards for training and credentials will remove employment barriers?

Dr. MAXEY. Thank you for your question, Senator Ricketts.

I would like to be clear that I am not necessarily stating licensing for HCBS or direct care workers, but rather some training standards that States can implement and then potentially coupled with training registries. I do feel as though training standards will empower those workers. They will have set skills. They will be able to demonstrate those skills to their employers, and I do believe that that will help to retain people in these jobs as well as help put them, those that would like, on a trajectory for career pathways, whether they are in healthcare or some other related field.

Senator RICKETTS. Also, Dr. Maxey, I think there is about 30 States right now that require agencies to obtain a personal care license, and licensure across States vary. Is there a State that you believe should serve as a model for others to follow?

Again, you are talking about training versus licensure. Is there, again, somebody you point to and say, hey, this is a State that has done it well? Maybe it is not licensure, but maybe it is training. Just talk to me about kind of what has your research shown as far as like who is doing a good job of this?

Dr. MAXEY. You know, States are all very unique, and so I would say that their strategies range, and I would like to clarify agencies—licensing of agencies would be different than licensing of the specific worker, so there are numerous States that license these agencies, and then the agency is responsible for training the workers and maintaining their own training activities.

There are other States that actually have the training provisions in statute and implement those in varying ways. I would be happy to get back with you with some very specific information on the States that take those different approaches and what it looks like within them.

Senator RICKETTS. Is there a State, though, that you can point to and say, hey, this is a State that seems to be addressing the issue better than other States with regard to workforce and how to provide care and that sort of thing?

Dr. MAXEY. I would say that based on my work right now, there are States across the Nation and pretty much every State is looking for solutions, and again, they really truly vary based on what a specific State's environment is and how their home and community-based services are structured. I would hesitate to say one leading State in these spaces. I would rather provide you with a list of those that are taking these different approaches.

Senator RICKETTS. Just out of curiosity, just again Nebraska, we have urban areas. We have rural areas. Typically, where we have had problems with nursing homes closing has been in our rural areas. Is that similar for Indiana as well?

Dr. MAXEY. Yes. Rural areas definitely are having more extreme workforce challenges. I can't necessarily speak to agencies and facilities because I work more on the workforce side, but I can definitively tell you that rural communities in Indiana and rural communities in many States are grappling with these same issues.

Senator RICKETTS. Great. Thank you very much.

I yield back, Mr. Chairman, and I note that I actually made it in on time.

The CHAIRMAN. You did.

Senator RICKETTS. Unlike my colleague here.

The CHAIRMAN. There will be—you get free Pennsylvania candy for that.

Thank you, Senator Ricketts. Senator Kelly?

Senator KELLY. Thank you, Mr. Chairman.

As a kid, one of my favorite trips was going to Hershey, Pennsylvania, so I remember it well.

Thank you to all our witnesses for being here today.

Dr. Scales, I hear from employers across Arizona how challenging it is to find direct care workers, and I know this is not unique to our State, but the need is serious. Nearly a fifth of Arizona's population is over the age of 65. The University of Arizona in our hometown of Tucson projects that our State is going to need about 55,000 more direct care workers by 2030. Not too far away.

We have seen our providers come up with some pretty creative solutions to try to get by and continue providing high-quality care for Arizonans. In Tucson, high school students are getting engaged in career and technical education programs in the caregiving space, and our public university system is working to build out online curricula to provide frontline workers with a base level of geriatrics training that they can translate into their everyday work, and we are trying a variety of different things in the State.

One idea I would like to focus on is viewing direct care as an opportunity for long-term career growth. That is what might get the high schooler excited about becoming a certified nursing assistant,



and it is not only to work as a CNA in your high school program, it is getting the opportunity to grow in a field where you can make a difference in somebody's life and see your income increase as you advance professionally and build a meaningful role in our healthcare team.

Now you have done some research on this on career advancement models in direct care, so what does your research tell us about the most effective ways to grow direct care as a career path?

Dr. SCALES. Thank you for the question, Senator Kelly, and thank you for all of the exciting work that is happening in Arizona around training and career development for this workforce.

I think what is really important is that, for the most part, when we think about career advancement for direct care workers, we often think about it as moving up the nursing ladder, so moving from a direct care role to a licensed practical nurse or a vocational nurse and to registered nurse, and that is a really important pathway.

The step from being a personal care aide or home health aide or even CNA to that next step on the career ladder, that can be a really big step in terms of the time it takes, the financial resources required, educational experience, and more, especially for workers who are juggling multiple jobs and family caregiving responsibilities as well.

I think we need to think about how to bridge that significant gap and also create advancement opportunities within direct care as ends in themselves, so that is what we really are looking at, at PHI, is how to build out these different advanced roles that can be stepping stones or can be really richly rewarding career steps in themselves.

We are looking at senior aide roles, condition specialist roles, peer mentor roles, and transition specialist. All different kinds of roles that take the core competencies of direct care and elevate them with additional training and responsibilities and earning potential as well.

Just to give you one quick example. We pilot tested an advanced role called the Care Connections Senior Aide role in New York City with home care agencies and a managed care plan, and through this program, home health aides were elevated to a salaried position, and in that role, they coached the full home care workforce team. They helped manage sort of more acute caregiving challenges, and they served as a recognized role on the interdisciplinary care team.

What we saw through our demonstration project was that that made a meaningful difference in terms of clients, patient outcome, as well as job satisfaction for those involved, and reduced caregiver burden, so it is really—I think our challenge is to—there are these innovations happening in the field, and our challenge is really to invest in them, evaluate them robustly so we can look at replication and scale up.

Senator KELLY. Are you going to scale that pilot program?

Dr. SCALES. It has a lot of potential, yes.

Senator KELLY. What can the Federal Government do to help?

Dr. SCALES. Well, that is where the Federal Government could really take a role in identifying and supporting some of these inno-

vation efforts, innovative efforts. Really looking kind of across the types of models, geographies, conditions involved and so forth so that we can really do a cross-section of robust testing in order to build the evidence base for what we really should invest in going forward through a sort of more structural means like payment streams and so forth.

Senator KELLY. Thank you, Dr. Scales.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Kelly. Senator Blumenthal.

Senator BLUMENTHAL. Thanks, Mr. Chairman.

I want to thank our chairman. As I am sure everybody here and everybody listening knows, he has been a steadfast champion of home healthcare. I have been proud to support many of his efforts, including the American Rescue Plan Act, which was hopefully transformative in making the kind of significant investments that he has led and others of us have supported, because one of the most important investments we made was in the Medicaid home and community-based services section, providing States with a 10 percent increase, as you know, in Federal home and community-based service dollars if they expand and strengthen and enhance these services.

I think these kinds of investments and incentives have enormous payback. They are truly an investment with tremendous dividends, and I hope that we will continue funding these kinds of services.

Last month, I was honored to join SEIU 1199 in Connecticut to help kick off their Support Long-Term Care Workers campaign, and I want to mention this union because I think, in fact, organized labor and unions are so important in representing home healthcare workers and urging us to do better by them so that they can do more and better for the people they serve. That union proudly represents 26,000 workers.

Think of it for a moment, 26,000 workers in Connecticut, including home care workers who fight for the people they care for. Not just themselves, but people they care for. It seems clear to me that an investment in healthcare workers, especially at a time when there are shortages, lack of training, and burnout, that is an investment in the people that they serve.

I know that Senator Casey has asked Ms. Burgess about a true living wage and how it would impact you, and your story is powerful and heartbreaking. I wonder if the panel could speak to the importance of training, as well as proper compensation?

Dr. MAXEY. Thank you, Senator Blumenthal.

My name is Hannah Maxey. I would be happy to take that.

I am sure you are aware that CMS has finalized a set of competencies for HCBS workers, but those serve more as a guidepost to States, whereas in other occupations or facility-based settings, there are stronger guidelines or regulations regarding that. Training standards are critically important for these workers and can help support a consistent level of quality and service across the different consumers that they might work with and the different settings that they are in.

Ms. BURGESS. I wanted to say thank you for that question.

In Pennsylvania, we just recently won funding for paid training programs, first of their kind in the State, which just rolled out ear-

lier this year. Caregivers who have never received any healthcare training are now getting certified in everything from CPR to dementia capability care, nonviolent crisis intervention. It is very important like to have that training so that we know what we are doing on the spot.

Even when I think of the care that I give my mother, her care is going to progress. She is going to need more, and my knowledge needs to grow, so the training that we would be provided would be lifesaving.

Senator BLUMENTHAL. Very important comment. Thank you.

Thank you all for your service.

The CHAIRMAN. Thank you, Senator Blumenthal.

I know we are going to have to wrap up soon. I might have one more question. Senator Braun.

Senator BRAUN. One more.

The CHAIRMAN. One more? Okay.

I wanted to turn to Ms. Lowy. I know that you shared your organization's experience providing care during the COVID-19 pandemic. As we heard, direct support workers went above and beyond to provide essential care during that crisis, often at great risk to their own health and their own safety, and too often that wasn't recognized. We didn't highlight that.

We do know that in the American Rescue Plan, we allocated \$12.7 billion in dedicated home and community-based services funding for States to address the urgent needs caused by the pandemic, including supporting the workforce, and we know this was kind of a short-term investment.

We have also noticed that a lot of States have used those dollars to begin to build more of a foundation for home and community-based services, so tell us, what would it mean to recruiting and retaining HCBS workers when those Rescue Plan dollars are expended?

Ms. LOWY. Thank you, Senator Casey.

Sustained Federal investment in HCBS would enable us to raise wages. With the ARPA funding that we received, we were able to give bonuses because it was a short-term investment, but we weren't able to have a sustained investment in raising wages. That obviously is the foremost challenge in recruiting and retaining staff.

We also would like to offer a career path for DSPs with skill and responsibility-linked raises. Obviously, as both of the doctors have talked about, it is so important to have these additional skill sets fostered and that training funded, but at present, because we don't have any titular or financial recompense available to staff members who are interested in these additional training avenues, it is difficult even if we have the funding for the training in order to encourage folks to pursue that.

I also wanted to mention that there are—we need to be able to provide these career paths for young workers, and our industry at present is not able to offer it, and in addition, these specialized training avenues that we could offer people, DSPs could specialize in things such as memory care. A lot of people don't realize that 50 percent of adults with Down syndrome develop dementia by the age of 50, and so that is an area we would love to be able to train

staff in, but the motivation isn't there if we are not able to give them a career path in that direction.

Obviously, also program development is very important. Just as for teachers or social workers, one size does not fit all for the folks that we support, so being able to develop challenging programming.

Then, finally, I wanted to mention that transportation and transition services are two areas that vary greatly from State to State, from underfunded to nonexistent, so those would be two areas I would love to be able to invest more in.

Thank you.

The CHAIRMAN. Thanks very much. Senator Braun.

Senator BRAUN. Thank you.

My final question is going to deal with something I did in my own company roughly 15 years ago, when I was sick and tired of hearing how lucky I was premiums are only going up five to ten percent each year. I took the entire system, kind of turned it on its head. We were able to self-insure, but that made a big difference once we became the insurance company, when I found out how much profit they were making on our plan back then.

A cornerstone was to really emphasize prevention and wellness, giving all the tools to my employees to become engaged healthcare consumers owning their own well-being. I would like Dr. Scales and Dr. Maxey to weigh in on can we weave prevention and wellness into whatever the model is to keep the elderly more healthy, to where you lighten the load for the caregivers that are already overburdened?

Can that work even as you are already old? I know it works when you can catch all this early on, and it has kept us—you won't believe the results. We have not had a premium increase in 15 years, so we fixed it by taking a different approach. Wellness, an ounce of prevention worth a pound of cures.

Go ahead, Dr. Scales.

Dr. SCALES. Thank you.

I absolutely agree that the more that we can provide opportunities for individuals to safeguard their health and wellness throughout their lives will make all the difference as we get older. I absolutely think we need the structural conditions in place to enable people to do that, and that means having health insurance, being able to seek preventive care, or address issues earlier rather than later in their trajectory.

What I would add is that that question, to me, brings up the importance of the home care workforce, because so much of what home care workers do is enable people to maintain their optimum health and well-being, to maintain their functionality, to stay active, to stay engaged in their communities. All things that actually will keep them on a better healthcare track for longer rather than having to go without those needs being met and ending up sooner in the hospital, in the emergency department, in a nursing home before it is really necessary for them to be there, and so forth.

Senator BRAUN. Dr. Maxey.

Dr. MAXEY. Yes, thank you.

I am going to bring it back training, but maybe instead of formalized training, home and community-based workers or even informal family caregivers need to be equipped with the information to help

support the individual they either serve or their loved ones in what prevention is.

That might look like a registered nurse that cares for that individual at their medical appointment providing some health education to the caregiver. I think there are many ways that that can happen, but I absolutely think that the caregiving workforce, either the formal employed or the informal, can absolutely be a part of supporting prevention and wellness for individuals that are receiving home and community-based services.

Senator BRAUN. Thank you.

The CHAIRMAN. Thank you, Senator Braun.

We will now turn to our closing statements, and we want to again thank the witnesses for their testimony.

As we heard today, investing in the direct care workforce will have major economic benefits for many Americans. Studies have repeatedly demonstrated that paying home care workers will improve the financial security of those families, both the care recipients as well as the workers, and an investment in this workforce will boost the economy in communities across the country.

It is not a surprise that every State, every single State, participated in the American Rescue Plan Act HCBS program to provide more funds to bolster home-based services. The rescue legislation had about \$12.7 billion, and every State took advantage of that.

We must build on the investment now and certainly in the future and fortify a workforce that helps millions of Americans live better lives, safer lives, and more independent lives.

Ms. Burgess and all the care workers are long overdue for a raise, and I noted in your testimony, Ms. Burgess, you said, "It was my duty to care for my mother," and I think you summed up pretty well in your written testimony what this means for the worker. You said, "I care for my mother because it is the right thing to do, and I would do so even if I weren't getting paid, but love can't pay the bills, so we depend on the wages I earn for this work, but it is not nearly enough to make ends meet."

I think that says it all in terms of the challenge our country faces, so one of the bills that we should consider is the Better Care Better Jobs Act, as well as the new HCBS Access Act, to improve the recruitment and retention of direct care workers and provide the home care supports that older adults need and people with disabilities need.

The Committee has received 10 statements for the record that support the need for an investment in these services, so be assured that every single American will either require long-term care services and supports or need to support a loved one at some point in their lives.

I look forward to working with my colleagues to address the needs of millions of Americans and their families in need of supports and services.

I now turn to Ranking Member Braun for his closing remarks.

Senator BRAUN. Thank you, Mr. Chairman.

Enjoyed the conversation. We always learn a lot, always having great witnesses that live it in the field each day.

We are transitioning everywhere across America, where we obviously got an underpaid workforce. We are trying to find that right

solution. The problem obviously is going to grow. Nearly all countries are dealing with the same issue. For us, I think we are just at the cusp of it, just due to population growth and the whole dynamic of where our country is headed.

I think it is going to be necessary to look to what we can do here to make it easy. A lot of times folks look to the Federal Government, and I think we should be leading and set the general context.

However, we don't mind our own house very well. For all the places that depend on this place, we are currently running nearly \$1.5 trillion in deficits each year, and that is roughly 30 percent of our budget. That is a bad business plan for all the folks that look to the Federal Government. Where, in the past, you know, we have been there, but we have not done it by borrowing from future generations.

I think it is even more important for these solutions to probably be crafted in the States where the rubber meets the road, where all the action is happening, where most of the workforce training is going to occur, and make sure we find best practices there. I am going to keep promoting legislation that is doable, that can get across the finish line.

The JOBS Act that Senator Kaine and I are promoting, just to put more money into Pell grants—or not more money into Pell grants, but being able to use it for job training, stuff like that, and then I am hoping that the entrepreneurs, the caregivers, all of you that do the work and the heavy lifting on the ground keep weighing in on what you need, where you need more help, and hope this place gets its house in order to where it can do a better job and make sure you push hard at the State level as well.

Thank you.

The CHAIRMAN. Thank you, Ranking Member Braun.

I want to again thank all of our witnesses—Dr. Scales, Dr. Maxey, and Ms. Lowy and Ms. Burgess—for your testimony, for being here today in person and providing us the benefit of your experience, both personally and professionally.

If any Senators have additional questions for the record or statements to be added to the record, the hearing record will be kept open for another seven days until next Thursday, March 16.

We want to thank you all for participating in today's hearing, and we are adjourned.

[Whereupon, at 12:01 p.m., the hearing was adjourned.]

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## **APPENDIX**

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**Prepared Witness Statements**

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**Statement of Kezia Scales, PhD**  
**Vice President of Research and Evaluation, PHI**

**March 9, 2023 Hearing Before the U.S. Senate Special Committee on Aging**  
**“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”**

Thank you, Chairman Casey, Ranking Member Braun, and Members of the Committee, for the opportunity to testify on the importance of investing in the home care workforce and supporting communities of care.

My name is Kezia Scales, and I am the Vice President of Research and Evaluation at PHI, a New York-based national nonprofit organization that works to transform eldercare and disability services by promoting quality direct care jobs—including home care jobs—as the foundation of quality care.

For more than three decades, PHI has been the nation’s leading expert on the direct care workforce through our research, policy analysis, and direct consultation with policymakers, payers, providers, and workers—providing a unique 360-degree perspective on the long-term services and supports (LTSS) system and its workforce in the United States. Over the years, we have also designed a broad range of groundbreaking workforce interventions that optimize and elevate the role of direct care workers through training, advanced roles, enhanced supervision, and more. Throughout our history, PHI has worked successfully at the state and federal levels to promote bipartisan policy initiatives that improve job quality and build this workforce.

My own research and advocacy on this workforce began about 15 years ago when, as a new researcher, I was hired to conduct an ethnographic study of direct care. Through months of participant observation, I experienced firsthand the complex skills that this work requires, and I witnessed its immeasurable impact on individuals’ health, wellbeing, and quality of life. I also saw how difficult it was, and is, for direct care workers to make a living even as they support the lives of others. Improving the recognition of and investment in this essential workforce has become my life’s work.

I will begin my testimony by describing the direct care workforce, focusing on the home care workers who are the priority for this hearing. From there, I will attest to the systems-level benefits of greater investment in this workforce, lifting up the Better Care Better Jobs Act as a model for driving the transformative changes that are needed.

### **An Essential and Expanding Workforce**

According to PHI's analysis of employment data from the Bureau of Labor Statistics, more than 2.6 million home care workers (primarily home health and personal care aides) assist millions of older adults and people with disabilities across our country every day.<sup>1</sup> Home care workers comprise more than half of the total direct care workforce, which also includes those who are employed in residential care communities, skilled nursing homes, and other settings. Altogether, the direct care workforce is larger than any other single occupation in the United States.

Home care workers enable members of our families and communities to live and age in place. They provide support with necessary daily activities, such as bathing, dressing, using the toilet, and eating. They assist with meal preparation, housework, and grocery shopping. They help their clients schedule and attend appointments, manage medications, monitor chronic conditions, and identify changes of status or circumstance that may need intervention. They promote independence, help overcome social isolation, facilitate paid employment, and serve as a key link among individuals, family members, and health care and social service providers. In many cases—as seen in sharp relief during the COVID-19 pandemic—they serve as a lifeline for their clients.

Given our aging population and the overwhelming preference for receiving LTSS at home,<sup>2</sup> the home care workforce more than doubled in the previous decade—adding nearly 1.5 million new jobs from 2011 to 2021.<sup>3</sup> Looking ahead, this workforce is expected to require nearly a million more new workers (from 2020 to 2030), which is more absolute growth than in any other occupation in the country. When also accounting for home care positions that will become vacant as existing workers leave this workforce or exit the labor force altogether, 4.7 million total job openings will need to be filled in home care during the same decade.

### **Poor Job Quality is Driving a Workforce Crisis**

Notwithstanding these workforce projections, home care agency providers and individual consumers are *already* struggling to recruit and retain home care workers.<sup>4</sup> Annual turnover in this workforce is consistently high, estimated at 64 percent in 2021.<sup>5</sup> National data on the workforce shortage are not available, but one analysis found significant differences in the supply of personal care aides relative to potential need across the country, particularly in rural areas and in the South.<sup>6</sup> And in a recent Harris Poll survey

commissioned by CVS Health, nearly 7 in 10 family caregivers of older adults reported a shortage of paid caregivers.<sup>7</sup>

The problem is partly demographic. From 2016 to 2060, the population of adults over the age of 65—more than half of whom are projected to need LTSS<sup>8</sup>—is expected to nearly double from 49.2 million to 94.7 million.<sup>9</sup> At the same time, the population of adults age 18 to 64 is expected to remain relatively static, which means that the ratio of potential caregivers to those who might need care is steadily decreasing.

But the problem is also structural—and that part is fixable. Home care jobs—fulfilled primarily by women, people of color, and immigrants—are consistently poor-quality jobs. The median hourly wage for home care workers was just \$14.09 in 2021 and, due to low wages and high part-time employment rates, median annual personal earnings were estimated at just \$19,100 in 2020 (the most recent year of data available in each case).<sup>10</sup> Because of low wages, 43 percent of this workforce live below 200 percent of the federal poverty level, 36 percent are housing cost-burdened (i.e., spend more than a third of their total household income on housing-related costs), and more than half (53 percent) access some form of public assistance, like Medicaid, food and nutrition assistance, and/or cash assistance. Less than 2 in 5 home care workers hold employer- or union-sponsored health insurance.

Home care wages are not living wages, nor are they competitive. According to PHI's analysis, the median wage for direct care workers (including home care workers, the lowest-paid segment of this full workforce) in every state falls short of the median wage for all other occupations with similar or even lower-entry level requirements.<sup>11</sup> The difference ranges from about \$1.50 to as much as \$5.00, depending on the state.

Home care jobs are also characterized by insufficient training, few career development opportunities, limited supervision and support, and an overall lack of respect and recognition.<sup>12</sup> Taken together, these challenges drive existing and potential home care workers into more viable employment options and career pathways in other industries—leaving home care employers struggling to maintain services, and consumers and families without the support they desperately need.

### **The Net Benefits of Investing in Home Care Jobs**

Investing in home care jobs—including in wages, benefits, training, and other job quality elements—is a critical strategy for stabilizing and strengthening this workforce to meet the ever-growing need for home care services.

A living wage for home care workers could lift existing workers out of poverty and financial precarity—while also helping address the structural, intergenerational inequities that impact the women and people of color comprising this workforce.<sup>13</sup> Beyond the beneficial impact for workers and their families, this investment would also yield a reduction in public assistance expenditure. A recent report from LeadingAge, a national association representing nonprofit aging services providers and other mission-driven organizations, estimated that raising direct care wages to a living wage in 2022 would reduce the use of public assistance programs among these workers by nearly 17 percent, equating to public savings of \$1.6 billion.<sup>14</sup>

Higher wages and better benefits would also make home care jobs more attractive to new job seekers, which is a necessary step toward building the pipeline into these jobs and filling workforce gaps. Home care agencies would see a reduction in the high costs of recruiting new workers, managing turnover, and paying contract staff—enabling them to spend more on job quality and care quality.

A more stable and sufficient home care workforce would also help overcome service gaps and ensure continuity and quality of care for consumers. This outcome would be invaluable for those who require paid support to live their daily lives with independence, dignity, comfort, and safety—but there is enormous potential value for our health and LTSS system as well. On balance, the evidence indicates that home care can help maintain optimal levels of health and function while preventing or delaying more costly outcomes such as emergency department visits, hospitalizations, and early nursing home admissions.<sup>15</sup> Because home care workers have historically been overlooked by researchers as well as policymakers (with key exceptions), their specific role in achieving these quality outcomes and cost savings still requires research. Nonetheless, it is clear that they perform a wide range of health-relevant tasks and, especially with targeted training and better integration into the care team, can make a measurable difference.<sup>16</sup>

Family caregivers will also benefit from investments in the home care workforce, which in turn will benefit our economy overall. Nationally, more than 53 million family

members (and neighbors, friends, and other individuals)<sup>17</sup> contribute an estimated \$470 billion annually in unpaid care.<sup>18</sup> Among these unpaid caregivers, the majority report having experienced at least one change in their own employment situation due to caregiving, such as reducing hours, taking time off, foregoing a promotion, or giving up paid work entirely. Approximately half report negative financial outcomes such as increased debt, loss of savings, late or unpaid bills, and more. With more paid care available for respite and ongoing assistance, unpaid caregivers could continue supporting their loved ones without reducing their own economic productivity or financial security.

Finally, investment in the home care workforce—one of the largest but lowest-paid occupations in our country—could stimulate consumer spending and support economic growth overall. The LeadingAge analysis cited above also estimated that paying direct care workers at least a living wage would add \$17 to \$22 billion to local economies from 2022 to 2030 as these workers spend their additional income on food, housing, health care, transportation, personal items, and other necessities—generating up to 86,000 new jobs in other sectors of local economies. This potential benefit holds true in the current economic context, as economists have shown that while minimum wage increases have a nominal impact on inflation,<sup>19</sup> low-income households themselves are particularly vulnerable to inflation, given the focus of their spending on household necessities.<sup>20</sup>

#### **The Promise of the Better Care Better Jobs Act**

Because Medicaid is the largest payer for LTSS, including home and community-based services (HCBS),<sup>21</sup> Medicaid is the best vehicle for making immediate and industry-wide improvements in home care access and job quality.

The Better Care Better Jobs Act exemplifies the potential for federal leadership to compel transformational change through Medicaid.<sup>22</sup> Through this legislation, states would be eligible for a permanent 10-percentage point increase in the federal match for Medicaid HCBS, plus enhanced administrative funds. This investment would help sustain the progress that states have already made with enhanced HCBS funding through the American Rescue Plan Act.<sup>23</sup>

Three elements of this robust legislation deserve highlighting. First, the Better Care Better Jobs Act includes a funded obligation for states to develop “HCBS infrastructure improvement plans” that outline how they will invest the additional funds. This provision creates a historic opportunity for states to strategically develop their HCBS programs and

workforces—with meaningful public input—rather than (by necessity) responding in ad hoc ways to growing and evolving population needs.

Second, the Act recognizes the indivisibility of job quality and service delivery—prioritizing the workforce investments that are needed to actualize all other HCBS improvement goals. To receive the enhanced federal funds, states will have to regularly assess and update their HCBS reimbursement rates to cover workforce recruitment and retention costs, as well as ensure that rate increases benefit workers directly. They will also be required to strengthen training and credentialing opportunities for both paid and unpaid caregivers, and will be eligible to receive additional funds to establish or strengthen their self-direction programs and related supply of “independent providers” (i.e., workers directly employed by consumers through these programs).

Finally, by requiring states to evaluate and report their successes in increasing the availability of HCBS, reducing disparities in access, and reaching competitive wage and benefit levels for home care workers, the Act will also ensure accountability in the use of public funds *and* help build the critically needed evidence base on effective HCBS policymaking. All of these elements would be strengthened by the passage of the HCBS Access Act, which—by making HCBS a mandatory benefit, among other provisions—would put HCBS on equal footing with other LTSS settings, such as nursing homes.

### **Conclusion**

Investment through Medicaid is not the only solution to the home care workforce crisis. Home care workers and working family caregivers alike urgently need access to paid sick leave and paid family and medical leave, so that they can afford to take time off without sacrificing their employment opportunities. Immigration reform is needed to strengthen the pipeline into home care jobs and to protect the rights and safety of immigrants within the existing workforce. Targeted funding is needed to develop new approaches to workforce recruitment, retention, training, and advancement—and test their impact on service access, quality, and cost. But the Better Care Better Jobs Act is momentous in providing the leadership, funding, and technical assistance that states need to strengthen home care services and to improve home care workers’ job quality and economic security. For these reasons, we urge Congress to pass and fully fund this legislation, for the benefit of everyone who has a stake in a strong, sustainable home care system—which is every single one of us.



## Notes

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- <sup>3</sup> PHI, 2022.
- <sup>4</sup> Kerr, Natalie. 2022. "A Shortage of Health Aides is Forcing out Those Who Wish to Get Care at Home." *Shots: Health News from NPR*, May 5, 2022. <https://www.npr.org/sections/health-shots/2022/05/05/1095050780/a-shortage-of-health-aides-is-forcing-out-those-who-wish-to-get-care-at-home> <https://www.npr.org/sections/health-shots/2021/06/30/1010328071/with-workers-in-short-supply-seniors-often-wait-months-for-home-health-care>.
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- <sup>11</sup> U.S. Bureau of Labor Statistics (BLS), Division of Occupational Employment and Wage Statistics (OEWS). 2022. *May 2011 to May 2021 State Occupational Employment and Wage Estimates*. <https://www.bls.gov/oes/home.htm>; O\*NET. 2022. O\*NET 27.0 Database; analysis by PHI, 2022.
- <sup>12</sup> Scales, Kezia. 2022. "Transforming Direct Care Jobs, Reimagining Long-Term Services and Supports." *Journal of the American Medical Directors Association*, 23(2): 207-213.
- <sup>13</sup> Dill, Janette, and Mignon Duffy. 2022. "Structural Racism and Black Women's Employment in the US Health Care Sector." *Health Affairs*, 41(22): 265-272; Iezzoni, Lisa I., Naomi Gallopyn, and Kezia Scales. 2019. "Historical Mismatch Between Home-Based Care Policies and Laws Governing Home Care Workers." *Health Affairs*, 38(6): 973-980.
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<sup>17</sup> National Alliance for Caregiving and AARP. 2020. *Caregiving in the US 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-inthe-united-states-01-21.pdf>.

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<sup>19</sup> Bivens, Josh. 2022. “Inflation, Minimum Wages, and Profits.” *Working Economics Blog*, September 22, 2022. <https://www.epi.org/blog/inflation-minimum-wages-and-profits-protecting-low-wage-workers-from-inflation-means-raising-the-minimum-wage/>.

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<sup>22</sup> Senate Bill 100. 2023. *Better Care Better Jobs Act*, 118<sup>th</sup> Congress. <https://www.congress.gov/bill/118th-congress/senate-bill/100>.

<sup>23</sup> Medicaid.gov. “Strengthening and Investing in Home and Community Based Services for Medicaid Beneficiaries: American Rescue Plan Act of 2021 Section 9817.” Accessed February 28, 2023. <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817/index.html>.



**SCHOOL OF MEDICINE**  
BOWEN CENTER FOR HEALTH  
WORKFORCE RESEARCH & POLICY

**Written Testimony of Hannah Maxey,  
Associate Professor of Family Medicine &  
Director, Bowen Center for Health Workforce Research and Policy  
Indiana University School of Medicine**

**Uplifting Families, Workers, and Older Adults:  
Supporting Communities of Care**

**United States Senate Special Committee on Aging  
March 9, 2023**

Good morning and thank you for your time, Chairman Casey, Ranking Member Braun, and distinguished members of the Committee.

Time waits for no man. The issues of the aging are the issues of us all. I applaud the Committee's commitment to supporting communities of care for our honored aging citizens.

As Ranking Member Braun mentioned, my experiences as a health professional and workforce researcher are broad and have extended more than two decades. I am here as a state health workforce policy expert to speak to the solutions that states are developing and implementing to build and strengthen their direct care workforces.

States have a critical role in reinforcing the front line of our nation's communities of care and, importantly, home and community-based services (HCBS). In the balance of power between the federal and state governments, states oversee policy and programs related to workforce development, occupational regulation, and social services. All of these have a direct impact on the HCBS workforce. Keeping a "finger on the pulse" of related state efforts is critical to understanding the national landscape and ensuring policy alignment between the halls of congress and state general assemblies, and ultimately results in effective care within the homes of our seniors.

I am delighted to have provided expert research support to my home state on the development of the Indiana Direct Service Workforce Plan.<sup>1</sup> This initiative is a foundational part of long-term services and support (LTSS) reform in Indiana<sup>2</sup> seeking to expand access to home and community-based services (HCBS). Indiana is one of numerous states that have engaged in planning to develop and strengthen this workforce. Many of the strategies I review were examined by or are a part of Indiana's plan. Also, I would like to note that although these strategies may be beneficial for the private sector, my research and expertise in these matters is focused on state solutions.

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<sup>1</sup> Indiana Direct Service Workforce Plan. 2022. Available at: [https://www.in.gov/fssa/ompp/files/2022DSWRReport\\_FINAL.pdf](https://www.in.gov/fssa/ompp/files/2022DSWRReport_FINAL.pdf)

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### Home and Community Based Services Workforce

HCBS quality metrics recently released by CMS<sup>3</sup> are appropriately focused on the member experience, including consumer choice in service provider, reliability of caregivers and the perception of safety and support. Although not explicitly stated, the achievement of many of the HCBS metrics hinges upon the availability and dependability of a competently trained workforce.

The HCBS workforce is comprised of formal, paid caregivers who provide personal care and supportive services for people, enabling them to live in their homes and communities. It is important to note that informal caregivers (family members and friends, many of whom are unpaid) are critically important partners in supporting the dignity and care of their loved ones. While critical, these roles are outside the scope of this current discussion.

Whereas common titles and training standards exist for many health occupations, this is not the case with the HCBS workforce. A 50-state analysis, published in 2019, identified 25 different titles used by states for HCBS workers.<sup>4</sup> Even within a single state, HCBS worker titles can vary based on the specific services they are hired to provide for each individual they serve. HCBS workers may care for more than one individual. One HCBS worker caring for two clients with different service needs and covered under different programs may work under two different titles. Lack of a common title may lead to confusion among workers and consumers. Additionally, lack of common titles hinders coordination of state policy and planning activities related to the HCBS workforce. Finally, at a time when states are seeking strategies to recruit and retain workers, lack of a common title threatens public understanding of this important workforce. To streamline state planning and eliminate confusion for workers, providers, and consumers, some states have developed standardized HCBS worker definitions and titles. Other states, including Indiana, are currently exploring such strategies as part of their broader initiatives.

### Training Standards

HCBS consumers have a wide variety of support needs. Some consumers need hands-on assistance with activities of daily living (ADLs) such as personal hygiene or eating while others require higher-level support of instrumental activities of daily living (IADLs), with tasks such as managing personal finances or medication reminders. Some consumers have conditions associated with aging, such as dementia, or experience disabilities, both physical and developmental. In any instance, HCBS workers must be armed with both “soft skills” such as compassion and respectful communication, as well as hands-on skills which allow fellow Americans to continue to live as independently and with as much dignity as possible. Regardless of whether the worker is employed by a provider or a self-directed consumer, training standards support a minimum level of quality.

HCBS workers require certain skills to care for our honored aging. Developing these important skill sets requires education and training. CMS has finalized a set of competencies for these workers,<sup>5</sup> which is intended to support states in developing standardized approaches to HCBS worker training. Unlike other healthcare support occupations such as nursing assistants<sup>6</sup> and

<sup>3</sup>CMS Home and Community-Based Services Quality Measure Set Measure Summaries. 2023. Available at:

<https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measure-set-summaries.pdf?t=1678120836>

<sup>4</sup>PHI - Personal Care Aide Training Requirements. 2019. Available at: <https://www.phinational.org/advocacy/personal-care-aide-training-requirements/>

<sup>5</sup>CMS Direct Service Workforce Core Competencies. Centers for Medicare & Medicaid Services. 2014. Available at:

<https://www.medicaid.gov/sites/default/files/2019-12/dsw-core-competencies-final-set-2014.pdf>

<sup>6</sup>42 CFR 483.138. Available at: <https://www.govinfo.gov/content/pkg/CFR-2020-title42-vol5/pdf/CFR-2020-title42-vol5-part483-subpartD.pdf>

home health aides,<sup>7</sup> these competencies serve as more of a guidepost and are not required within federal rules.

Across the nation, state approaches to training for HCBS workers are as varied as the needs of the consumers being served. Some states, give employing agencies broad autonomy in crafting their own competencies, training, and curriculum.<sup>8</sup> Under this schema, pursuing employment opportunities at another agency would require that the HCBS worker undergo retraining and evaluation. Other states opt for a standardized approach for both competencies and training, which assures consumers that they are getting a consistently skilled level of care and provides workers with a portable, centralized learning credential they can bring with them from one employment opportunity to the next. Still other states have pursued a hybrid approach, in which competency standards are outlined by the state but agencies have the flexibility to develop their own training. Indiana's Direct Service Workforce Plan outlines a plan to identify a state minimum training and competency standard that promotes a high quality of care and supports the reduction of financial and administration burdens to providers.<sup>9</sup>

### **Portable Credentials**

Portable credentials empower workers by demonstrating their training and experience and facilitating their pursuit of economic opportunities with new employers, in new settings, or through additional academic pursuits and stackable credentials. These credentials may be implemented as a state recognized certificate of training completion or through a state training/credentialing registry.<sup>10</sup> Portable credentials allow employers and self-directed consumers to verify that an HCBS worker has achieved training standards prior to entering any arrangements. In the instance that a state maintains a training/credential registry, such registries may also serve to facilitate connections between qualified HCBS workers and consumers.

Recognizing that empowered workers power our economy, several states have developed portable credentials for individuals that have met HCBS training standards.<sup>11, 12</sup> Other states are exploring opportunities in this space. Indiana's Direct Service Workforce Plan recognizes the value of portable credentials as a way to enfranchise workers and reduce administrative and fiscal burdens on the employer.

### **Incident Reporting**

Incident reporting (IR) registries and high-fidelity investigation processes can protect the public from bad actors. Incident reporting generally refers to the process of reporting, investigating, and adjudicating reportable incidents. Results of IR processes may be made available on state registries, as deemed appropriate, to support public protection. This may be implemented as either standalone IR registries (commonly referred to as bad apple registries) or integrated into

<sup>7</sup> 42 CFR 484.30. Available at <https://www.govinfo.gov/content/pkg/CFR-2011-title42-vol5/pdf/CFR-2011-title42-vol5-sec484-36.pdf>

<sup>8</sup> IC 16-27-4-16 - Evaluation and Training. Available at: <https://iga.in.gov/legislative/laws/2021/ic/titles/016#16-27-4-16>

<sup>9</sup> Indiana Direct Service Workforce Plan. 2022. Available at: [https://www.in.gov/fssa/ompp/files/2022DSWReport\\_FINAL.pdf](https://www.in.gov/fssa/ompp/files/2022DSWReport_FINAL.pdf)

<sup>10</sup> PHI - Personal Care Aide Training Requirements. 2019. Available at: <https://www.phinational.org/advocacy/personal-care-aide-training-requirements/>

<sup>11</sup> Arizona Direct Care Curriculum Project. 2011. Available at

[https://www.azahcccs.gov/PlansProviders/Downloads/DCW/Manual\\_%20Level%20I%20Fundamentals\\_English.pdf](https://www.azahcccs.gov/PlansProviders/Downloads/DCW/Manual_%20Level%20I%20Fundamentals_English.pdf)

<sup>12</sup> The QuILTSS Institute - Career and Education Pathway. 2019. <https://quiltss.org/wp-content/uploads/2019/01/QuILTSS-Career-Education-Pathway.pdf>

training/credentialing registries which is common among healthcare professions, including nurse aides.<sup>13</sup>

The U.S. Department of Health and Human Services reported that over 5 million older adults experience abuse every year.<sup>14</sup> In the case of HCBS workers, reportable incidences may include actions such as abuse, neglect, and misappropriation of funds. A recent report found that IR registries can increase transparency and prevent bad actors from transitioning to new positions thereby protecting vulnerable adults.<sup>15</sup> This protection is primarily realized through informed hiring decisions among provider employers and self-directed consumers. It is difficult to assess the effectiveness of IR registries, as a prevented incident is much harder to quantify than an actual incident. States engaged in broader HCBS workforce planning initiatives have the opportunity to consider IR strategies and strengthen protections for our honored aging.

### Social Services Programs

State Medicaid programs are the single largest payer of LTSS in the United States.<sup>16</sup> As such, HCBS service rates are a primary source of wage support for workers. Notably, low wages are commonly cited as one of the greatest challenges to HCBS workforce recruitment and retention.<sup>17</sup> It is important to note that the true costs associated with public LTSS services are even greater when accounting for the many HCBS workers who qualify for and receive public assistance, such as Medicaid, SNAP and TANF.<sup>18</sup> States are examining HCBS reimbursement strategies to enhance wages and benefits to bolster their workforce.

Recognizing their influence over the HCBS worker labor markets and wages, many states, including Indiana, have developed targeted initiatives to enhance wages and benefits, including competitive rate setting, wage-pass throughs, and value-based incentives. Some states have implemented rate setting methodologies that incorporate a competitive wage factor to account for competing employment sectors. Several state legislatures have set wage floors or a minimum wage for their direct care workforces.<sup>19,20</sup> Wage pass-throughs are another common approach whereby state appropriations may be directed to worker wages or benefits. Dozens of states have wage pass-through requirements for HCBS. These strategies typically involve earmarking a specified percentage of rate increase for HCBS to go directly toward payroll tax liabilities, wage, or benefits. Many of these wage pass-through strategies also involve attestation, auditing, and reporting to ensure compliance. In some instances, pass-throughs are tied to value-based incentives intended to enhance service quality. Value-based strategies link

<sup>13</sup> 42 CFR 483.156. Available at: <https://www.ecfr.gov/current/title-42/chapter-IV/subchapter-G/part-483/subpart-D/section-483.156>

<sup>14</sup> Department of Health and Human Services Elder Justice Report. 2017. Available at:

<https://acl.gov/sites/default/files/programs/2017-11/2017%20EJCC%20Report.pdf>

<sup>15</sup> National Adult Protective Services Abuse Registry National Report. 2018. Available at: <http://www.napsa-now.org/wp-content/uploads/2018/05/APS-Abuse-Registry-Report.pdf>

<sup>16</sup> Who Pays for Long-Term Services and Supports? Congressional Research Service. 2022. Available at:

<https://crsreports.congress.gov/product/pdf/IF/IF10343#:~:text=Medicaid%20is%20the%20largest%20single,42.1%25%20of%20all%20LTSS%20expenditures>.

<sup>17</sup> Direct Care Worker Disparities: Key Trends and Challenges. 2022. Available at: <https://www.phinational.org/wp-content/uploads/2022/02/Direct-Care-Worker-Disparities-2022-PHI.pdf>

<sup>18</sup> State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages. MACPAC. 2022. Available at:

<https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief-on-HCBS-workforce.pdf>

<sup>19</sup> Addressing Wages Of The Direct Care Workforce Through Medicaid Policies. 2022. Available at:

<https://www.nga.org/publications/addressing-wages-of-the-direct-care-workforce-through-medicaid-policies/>

<sup>20</sup> Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences. 2020. Available at:

<https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf>

increased payments to enhanced training, level or type of care provided, or achievement of beneficiary goals.<sup>21,22</sup>

### Benefits Cliff

A conundrum within these discussions is the impact enhanced wages can have on HCBS workers benefits. Many LTSS workers receive public assistance, such as Medicaid, SNAP and TANF.<sup>23</sup> Strategies which increase wages to just over public assistance program qualification can negatively impact overall income, commonly referred to as the benefits cliff. Recently, the Atlanta Federal Reserve examined this issue and developed a “Cliff Dashboard”.<sup>24,25</sup> Their dashboard is customizable and can be used by states to identify at what wage level LTSS workers may lose certain safety-net services (generally public assistance programs) and at what level they achieve financial sustainability. States, including Indiana, are exploring where these “cliffs” exist to ensure their solutions are data-driven and have a net positive impact.<sup>26</sup>

### Workforce Data to Inform Planning

States require data on the HCBS workforce to understand the current state, identify gaps, and prioritize strategies. Unfortunately, high-quality data on this workforce is elusive. States may leverage registries or other reporting mechanisms such as provider reporting, provider surveys (such as those captured through National Core Indicator Staff Stability Surveys),<sup>27</sup> member quality measures, or administrative processes to gather the workforce information that is needed to inform planning and evaluation. Each of these strategies have associated benefits and limitations.

It is worth noting that states with training/credentialing registries have the unique opportunity to collect supplemental information on their workforces. Supplemental workforce information, such as demographics, education, and employment characteristics, can be strategically gathered through questions integrated into registry application and renewal.<sup>28,29</sup> The workforce information collected through this approach is extremely useful to states for workforce assessments, targeting development initiatives, and evaluating the impact of such initiatives. Indiana is a leading state in collecting timely health workforce data and utilizing this information to inform relevant policy and programming.<sup>30, 31, 32</sup> Recently, the state leveraged such information

<sup>21</sup> Addressing Wages Of The Direct Care Workforce Through Medicaid Policies. 2022. Available at:

<https://www.nga.org/publications/addressing-wages-of-the-direct-care-workforce-through-medicaid-policies/>

<sup>22</sup> Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences. 2020. Available at: <https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf>

<sup>23</sup> State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages. MACPAC. 2022. Available at: <https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief-on-HCBS-workforce.pdf>

<sup>24</sup> What Are Benefits Cliffs? Atlanta Federal Reserve. Available at: <https://www.atlantafed.org/economic-mobility-and-resilience/advancing-careers-for-low-income-families/what-are-benefits-cliffs>

<sup>25</sup> Atlanta Federal Reserve Cliff Dashboard. Available at: [https://emar-data-tools.shinyapps.io/cliff\\_dashboard\\_demo/](https://emar-data-tools.shinyapps.io/cliff_dashboard_demo/)

<sup>26</sup> Indiana Direct Service Workforce Plan. 2022. Available at: [https://www.in.gov/fssa/ompp/files/2022DSWRReport\\_FINAL.pdf](https://www.in.gov/fssa/ompp/files/2022DSWRReport_FINAL.pdf)

<sup>27</sup> NCI Staff Stability Survey. Available at: <https://legacy.nationalcoreindicators.org/staff-stability-survey/>

<sup>28</sup> Informing Health Care Workforce Policy by Leveraging Data: A Toolkit for States. 2020. Available at: [https://www.nga.org/wp-content/uploads/2020/11/NGA\\_informing\\_health\\_care\\_workforce\\_policy\\_by\\_leveraging\\_data.pdf](https://www.nga.org/wp-content/uploads/2020/11/NGA_informing_health_care_workforce_policy_by_leveraging_data.pdf)

<sup>29</sup> Life Cycle of Health Workforce Data in Indiana. 2021. Available at: <https://scholarworks.iupui.edu/bitstream/handle/1805/26292/Lifecycle%20of%20Data.pdf?sequence=1&isAllowed=y>

<sup>30</sup> Bowen Health Workforce – Information Portal. Available at: <https://bowenportal.org/>

<sup>31</sup> Indiana Governor’s Health Workforce Council: <https://www.in.gov/dwd/about-dwd/ghwc/>

<sup>32</sup> State of Indiana’s Health Workforce, 2022. Available at: <https://www.in.gov/pla/files/Annual-Report-of-the-State-of-Indianas-Health-Workforce-November-1.-2022.pdf>

to identify and strengthen career pathways for Certified Nurse Aides.<sup>33</sup> The state is currently working on strategies to enhance information on the HCBS workforce.<sup>34</sup>

Data is the foundation of informed workforce policy. As it stands today, states are piecing together information and, at best, have a patchwork picture of the HCBS workforce. Recognizing this gap, many states are working on solutions to ensure they have the data they need to inform HCBS workforce planning and evaluate policy.

### **Conclusion**

The HCBS workforce underpins the Communities of Care that many of our seniors rely on to live their best and fullest lives. At some point in our lives, many of us will rely on this workforce, for a loved one or even for ourselves.

States, including Indiana, are actively pursuing strategies to strengthen this workforce and shore up HCBS. Strategies such as training standards and portable credentials can empower workers and advance consumer choice and safety. Other strategies focus on enhancing wages to support recruitment and retention. Regardless of their approach on specific workforce issues, all states require information to support informed decision making and many states are exploring strategies to ensure they have the data they need.

Thank you for this opportunity to brief you on the great work that is going on in Indiana and in states across our nation to enhance the HCBS workforce. Thank you for your leadership on this topic and your commitment to supporting state solutions.

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<sup>33</sup> Certified Nurse Aide as an Occupational Pathway to Licensed and Professional Nursing in Indiana. 2017. Available at: [https://scholarworks.iupui.edu/bitstream/handle/1805/14015/2017\\_CNA\\_%20Report\\_Fact\\_Sheet.pdf?sequence=1&isAllowed=y](https://scholarworks.iupui.edu/bitstream/handle/1805/14015/2017_CNA_%20Report_Fact_Sheet.pdf?sequence=1&isAllowed=y)

<sup>34</sup> Indiana Direct Service Workforce Plan. 2022. Available at: [https://www.in.gov/fssa/ompp/files/2022DSWRReport\\_FINAL.pdf](https://www.in.gov/fssa/ompp/files/2022DSWRReport_FINAL.pdf).





Written Testimony of Pam Lowy,  
Uplifting Families, Workers, and Older Adults:  
Supporting Communities of Care

March 9, 2023

Thank you, Chairman Casey, Ranking Member Braun, and Members of the Committee, for the opportunity to testify on the importance of investing in the home care workforce. My name is Pam Lowy, Executive Director of Great Bay Services, a provider of Home & Community Based Services along the northern coast of New England. Our organization was founded in 1954. We started the first NH school for children with disabilities, opened a training center to provide employment for adults with disabilities, and helped close down the last NH institution for disabled citizens.

We serve adults with intellectual and developmental disabilities such as those with Down Syndrome, Autism, and Cerebral Palsy. This population is low income, most with co-occurring mental health diagnoses (most commonly depression and anxiety), and 60% of whom live with caregivers over the age of 60. My own brother, David, is a Great Bay Services client who lives at home with our 89-year-old father.

We facilitate the independence and personal fulfillment of the people we serve, putting a lot of time, thought, conversation, and effort into what each person considers to be a meaningful day. For some, this includes working, in which we support them. For others, this includes volunteerism – my brother David, after volunteering at a soup kitchen, at the ASPCA, or greeting returning servicepeople at Pease Air Base, always tells me: “I helped today. I’m proud of myself.”

Caregiving is essential work and that work is only accomplished with skilled caregivers. However, we are experiencing a significant shortage. One reason is the wages for a caregiver. The Massachusetts Institute of Technology Living Wage calculator estimates the living wage for an adult with one child in our region is approximately \$35 per hour, working 40 hours per week. The current wage we are offering Direct Service Professionals (DSPs) is \$16/hour and the majority of the supports we offer are contracted by Medicaid for a maximum of 30 hours/week. DSPs live paycheck to paycheck. When their vehicle needs repairs, or they have out of pocket medical expenses they have to make very difficult decisions.

Because our supports and workforce are such an integral part of our clients’ daily lives, going fully remote – even for a short time – at the start of the COVID-19 pandemic significantly affected their wellbeing.

One program participant's mental health suffered so greatly that he was hospitalized. Others needed emergency one-on-one supports to ensure they wouldn't experience a similar breakdown.

As Executive Director I have found myself repeatedly in situations where I've had to make the ethical choice – raising wages and mileage reimbursement despite Medicaid not covering the increase, temporarily closing programs after COVID exposures – and pray that it wouldn't bankrupt us. The average wage for DSPs in our region is \$13-15/hour. We have a starting wage of \$16 and it's still not enough. We continue to lose potential workers to other employers. I regularly am forced to advise interviewees who state they cannot afford to accept my job offer that they would earn more working elsewhere.

Staff in our field are financially struggling, barely making ends meet, but constantly agonizing over what would happen to the people we support if they don't come to work. DSPs in general tend to be older workers. Our average staff age is 46, with over 10% of our staff being 65 or older. Our longest-serving staff came to us straight out of college in the early 1970s & 80s. They have decades of experience in the field and decades-long relationships with our clients.

The average wage for DSPs across the US is not a living wage. One of our staff members confided in me that they had been homeless for their first few years in the field, struggling to raise a child on what was then barely above minimum wage. The ARPA funding Congress provided enabled us to pay tenure-based bonuses to our staff who stayed with us through COVID. One staff member cried in my office in gratitude that they could pay their oil bill as a result of that bonus. We were able to offer new hires bonuses as well as more robust trainings to all staff because of the increased funding. This has had an important impact on our hiring & retention, but it will not be a lasting impact.

External financial stressors regularly impact the individuals we employ and can spill over into their work and their interactions with our clients in obvious ways (such as vehicle breakdowns) and less obvious ones (a stressed human support worker is less able to provide the empathetic, compassionate support our clients deserve). These DSPs are individuals from whom we expect a similar if not higher level of skill compared to other positions which (unlike DSPs) have Standard Occupational Classifications such as Certified Nursing Assistants, Home Health Aides, and Personal Care Assistants. DSP work is complex and goes well beyond caregiving, requiring skills including behavioral assessment and prevention, medication administration, and many personal and intimate caregiving tasks.

I ask Congress to provide adequate funding for HCBS to keep Great Bay Services and organizations like ours from going bankrupt and to keep our staff able to provide the necessary daily supports for Americans with disabilities. We make it possible to keep older adults and people with disabilities safe, stable, and in their homes, workplaces, and out in their own communities in which they play a vital role and where they prefer to be.

Thank you for the opportunity to share my story, which is similar to that of thousands of providers across the country. I look forward to answering your questions.

**Testimony to the Senate Special Committee on Aging  
“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”  
March 9, 2023**

**Jacinta Burgess, Home Care Worker  
SEIU Healthcare Pennsylvania, Harrisburg, PA**

Thank you, Chairman Casey, Ranking Member Braun and members of the Senate Special Committee on Aging for inviting me to speak to you today. My name is Jacinta Burgess, and I am a home care worker from Harrisburg, PA.

I care for my mother, Stephanie, in our home full-time. I have been doing so for roughly three years, with help from my older brother. We believe that is the best way for her to receive care — no one knows a mother like her children. Not only does a parent watch their child grow and change, the child does the same in regard to their parents.

My mother's health began to decline in 2016 while we were living in Washington, D.C., and I worked full time in Arlington. When my mother's issues became life threatening, the decision was made for her to move back to our home state of Pennsylvania, because I couldn't care for her in our home in D.C., due to my work schedule. I followed a few years later, excited about a job offer that would provide better pay and more freedom, and bring me closer to my mother again.

But when I lost my job and income in 2020, I was no longer able to assist my mother with her bills. In November of 2020, my mother had a medical crisis, was hospitalized, and I made the decision it was best for her to live with me. Since then I have been my mother's aide full time with assistance from my older brother William. Without income, I looked into programs that would assist me with caring for her as well as provide income.

I care for my mother because it is the right thing to do, and I would do so even if I weren't getting paid. But love can't pay the bills, so we depend on the wages I earn for this work. But it's not nearly enough to make ends meet. So many home care workers take on second or third jobs to earn more income, but I'm unable to work outside my home due to the care my mother requires. It's not safe for her to be on her own for too long.

Have you ever heard of the Riddle of The Sphinx? The stages referenced in this riddle are how I view life. At the beginning of the day we are crawling on all fours;

by noon we are walking upright on two feet; and when evening comes, we are still upright if we're lucky, but we'll probably need to rely on a cane to stay that way. My mother got me through the morning and noon, so I feel it's only right that I help her through the evening.

Now, I am my mother's eyes, ears, mouth, hands and feet. As her caregiver, my days are spent making sure that she is living a happy, comfortable, full life, while doing everything she needs to manage her illnesses. When my mom wakes up, I'm there to ask her what she needs for that morning. Some days, she needs help bathing and getting dressed. I help her with other day to day duties that most healthy people take for granted including opening doors, pouring a glass of water, getting into cars or turning a knob on our stoves. My mother also experiences chronic pain so I spend a lot of time giving her massages.

I am here today to tell you that home care workers like me are struggling, and care consumers like my mother are going without the quality care they deserve. Low wages, a lack of benefits, inadequate training, and insufficient funding for home- and community-based services has created a care crisis in our country. Caregivers can't afford to stay in these jobs, causing turnover rates as high as 60 percent in some markets<sup>1</sup>, and consumers can't afford or access care. Congress has the power to improve care jobs for the 2.6 million<sup>2</sup> home care workers across the country, and the nearly 10 million seniors and people with disabilities whose lives depend on access to quality, affordable care.

When I officially became my mother's caregiver, I was paid around \$12.39 an hour, but was only paid for 15 hours a week, despite caring for my mother 24/7. Over the past three years, my wages have increased by just 99 cents, to \$13.38.

But my hours have recently increased to 65 hours per week. Home care jobs are full-time work, but the hours we're paid for can go up and down without warning. Changes in funding, policy, or decision making can decrease the hours home care workers are paid for — and hours that consumers receive care. Home care jobs need to be treated as full-time jobs, with reliable consistent schedules and wages that reflect the true value of our work. I live in fear of those hours being cut at any time for any reason, which would hit us hard financially.

In 2023, while the cost of living is skyrocketing and inflation is forcing people to make impossible financial decisions, \$13.38 is not enough for me — or any

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<sup>1</sup> Understanding the Direct Care Workforce, PHI, 2023 available at <https://phinational.org/policy-research/key-facts-faq/>.

<sup>2</sup> *Id.*

working person — to pay all of my bills and live comfortably. I can't pay all my utilities and other bills in full, while still having money left over for food. My income is low enough to qualify for Medicaid, but I make too much to qualify for food assistance or other federal programs.

My mother has to help pay the rent and utilities out of the money she receives monthly from Social Security. But her benefits are just high enough that she has to pay for her own insurance, and her food stamp allowance has been cut. If my mother didn't live with me, she'd be homeless. And if I didn't live with my mother, I'd be struggling to survive if not homeless myself. I'd be a home care worker without a home of my own.

Sadly, my situation is not unique. Forty-three percent of home care workers live below 200 percent of the poverty level, and more than 50 percent rely on some form of public assistance. Thirty-six percent of home care workers do not have affordable housing.<sup>3</sup>

Everything in my household branches out from me. I am the head of household with my head on a swivel, and I'm stuck between a rock and a hard place. I have nowhere to turn because every direction brings me face to face with a new obstacle or an old one that I've been putting off.

What things keep you up at night? I have too many to count. At night, I toss and turn worrying about whether I forgot to pay a bill, or if an auto-payment is going to overdraft my account. I worry about the condition of our apartment, and what kind of legal assistance I can obtain when it comes to the issues we're facing with building management. In my head, I fight with a number of voices and issues — including my own — over things I want to change so badly, but can't because of how little money I make and resources I have.

If you are constantly worrying about pay, bills, doctor appointments, hours being cut, how to stretch this and cut that and adjust those to make it all work on someone else's timeline... Do you have time to be happy?

I am fighting to survive a system that seems like it was created for me to fail. Do you know how to breathe without air? I don't. This line of work can feel suffocating. I watch as my friends, family and fellow home care workers are stretched to their limits.

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<sup>3</sup> Direct Care Workers in the United States: Key Facts, PHI, Sept. 6, 2022 available at <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

My cousin Venetia is also a home care consumer. She requires care 24 hours a day, and has cycled through a number of home care workers over the years. When Venetia finally found an aide she loved and could rely on, that aide left the homecare field for better pay and benefits elsewhere. Home care workers develop very close bonds with our consumers, and we sometimes get to know them better than anyone else. We have firsthand knowledge of their routines, unique needs, and personality preferences. When people like my cousin aren't able to receive consistent care, their quality of life is deeply impacted.

It's hard to attract and retain home care workers because for so many of us, the pay is not something you can live on, there are no paid days off, there's barely any training and there are no medical benefits. People want to do this work, but when they see how disrespected, unprotected and shamefully underpaid we are, they turn the other way. From 2020 to 2030, the home care workforce will have 4.7 million total job openings.<sup>4</sup> How are we supposed to fill those jobs and meet the skyrocketing demand for care when home care workers are treated the way we are?

If I had a liveable wage, I could possibly own a home instead of paying into a rental system that disrespects me and takes advantage of me with poor quality and bug-infested housing. I could take driving lessons and eventually purchase a car so I wouldn't be at the mercy of Uber or Lyft. I could take my pets to the vet for treatment without having to max out my credit cards or put off treatment for them. I could stop putting off treatments for myself and mother. I could actually save money for a rainy day or a vacation.

Our current apartment has had roach infestations, ventilation issues and other maintenance and logistics issues that make it hard to maintain a basic sense of comfort. It's not the standard of living I want for myself or my mother, but it's all we're able to afford right now.

We were recently told we have to move out of our current apartment once our lease is up. But it's not that easy. We need to find accessible housing that we can actually afford, and where we won't have to uproot and leave every year or so.

Consistency is so important in home care — but despite all my efforts to build a stable household and life for my mother, our options are limited because I don't make enough money

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<sup>4</sup> *Id.*

I am a caregiver through and through. I love caring for people and animals, and that's always been part of who I am. This is work I love and want to do. But home care is an emotionally and physically demanding job.

Some mornings I wake up, and I don't want to get out of bed. I want to just lay face down on the floor. I'm devastated that life is so hard for my mother and I. She worked so hard to take care of me growing up, and I want to give her that same care in return. I can't afford the mental health care I need to stay strong for my mother.

It may sound silly to you, but our cats are sometimes our only sources of support and comfort. They soothe us and show us love when it seems like the entire world has turned its back on us. I love our cats, but people should have a stronger support system than just their pets.

How is anyone supposed to enjoy their life if all they have to look forward to every morning are the struggles they face?

A severe shortage of home care workers forces many working families to choose between caring for a loved one and a paycheck. Just like me, working people are too often forced to leave their jobs or stop working entirely when the need for care arises in their family. Oftentimes, it's because they can't afford the cost of care, or in some communities, there aren't enough caregivers or resources to meet their needs.

My friend and union buddy Genale cares for her mother who has dementia and her father who has various ailments. Genale has a spouse who supports her and helps her care for her parents, but he has a full-time job as well. They give all their love and energy to Genale's parents, so that the time they have left is as peaceful as possible. Some would say why not put her mother in a nursing home?

Dementia is a devastating, terrifying disease, and there are so many different factors at play when determining the best course of care. Genale's mother knows her daughter. She loves and trusts her daughter. In her family's situation, putting her mother in a facility was not the best option. This is why it's important to build a long-term care system that gives working families like mine and Genale's the option of quality, affordable home care.

Investing in home and community-based services and the workers who do this job must be a national priority, because home care workers are an essential part of America's family healthcare system. The work we do makes all other work possible. When families know their loved ones are safe and cared for, they can go to their own jobs and continue working.

I can't work outside of my home because I am scared to death that my mother would not be able to get the exact care she needs otherwise. I haven't taken more than a day away from her in at least three years, because without me or my brother, there is no one else to care for her in the way she needs.

When you think of our own loved ones, how do you want them to be cared for? I'm sure you, like all families, want your parents, grandparents, and loved ones with special needs to be able to stay at home if they can and to receive the highest quality of care, delivered by skilled, experienced caregivers who you know are able to care for themselves without worrying about how they're going to pay their bills or put food on their table.

That is why home care workers must be respected, protected and paid. When our work is undervalued, when we must work long hours with no time off, no sick days, and struggle to get by, it's impossible to attract and retain the workforce all American families are counting on.

We are in a care crisis, and transforming these low-wage jobs into liveable-wage union jobs will bring the transformative change we need to move our country forward.

For decades, home care workers have organized, advocated and rallied for justice in the long-term care industry. We keep getting pushed down, but we know that so long as we can see the sky, the only way to go is up.

To further strengthen these jobs, we must guarantee all home care workers the right to join together in a union. I'm fortunate enough to have that right, and my union, SEIU Healthcare Pennsylvania, has made all the difference. Last year my fellow union members and I successfully pushed PA's Department of Human Services to increase reimbursement rates for home care by 8 percent statewide, leading to a \$1 an hour increase in all participant-directed caregivers' wages. Because we're a union, we had a seat at the table when administrators were deliberating over that decision. And we were able to take collective action— in meetings, on petitions, and at rallies—to advocate for our position.

We've also won funding for paid training programs—the first of their kind in Pennsylvania—which rolled out earlier this year. Caregivers who had never received any substantive healthcare training are now getting certified in everything from CPR to dementia capable care and nonviolent crisis intervention. We're professionalizing our



workforce to deliver higher quality care to our clients and demonstrate to decision-makers that they can no longer deny real workers the wages and benefits we deserve.

But my union represents more than just advocacy and worker power. My union is a community of support and inspiration.

Home care workers are so isolated in our work. We don't see other caregivers or consumers throughout the day. It's not easy to have a social life when you are giving or depending on care every hour of every day. My union helps me and my mother stay connected with other caregivers and consumers who understand exactly what we're going through. I know I'm not alone in this fight for higher wages and better standards of care.

But for workers without a union, the median wage for unionized home care workers nationally is \$13.00, compared to \$11.66 for non-unionized home care workers. Unionized home care workers are much more likely to have health insurance through their employment than non-unionized home care workers — more than half of unionized home care workers have employment-related insurance, compared to 31 percent of non-unionized home care workers.<sup>5</sup>

Unfortunately, home care workers are currently denied a clear path to a union. Rules are rigged against workers who try to unionize, and employers can block workers who try to organize all too easily. Many home care workers — the majority of whom are women and women of color — are excluded from laws governing union rights. This must change.

The more than 740,000 home care workers united in SEIU and the two million still fighting for a union share a vision of America where long-term care is accessible, affordable and sustainable for all. We must transform home care jobs into family-sustaining careers for the generations of workers and consumers to come. This transformation would not only help those that do this work get the respect, protection and pay we deserve, but it is necessary if we are going to build a durable long-term care system.

We will all age into this system eventually, if not sooner due to unforeseen medical conditions or accidents. When that time comes, don't you want the comfort in knowing a skilled, dedicated caregiver will be by your side? Everyone deserves that peace of mind,

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<sup>5</sup> Caring for the Future: The Power and Potential of America's Direct Care Workforce, p. 41, PHI, Jan. 12, 2021 available at <https://phinational.org/resource/caring-for-the-future-the-power-and-potential-of-americas-direct-care-workforce/>.

but for real, working families across the country, the stability of tomorrow is not guaranteed.

Our nation can't go on the same way when it comes to care. The system was broken long before the COVID-19 pandemic, and the pandemic has only made the issues worse. We need our elected officials to champion higher standards for care and care jobs across the country.

I am important. My mother is important. My cousin is important. Every care worker and care consumer is important.

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**Questions for the Record**

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**SENATE SPECIAL COMMITTEE ON AGING**  
“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”  
March 9, 2023  
Questions for the Record  
Dr. Hannah Maxey

**Senator Raphael Warnock**

**Question:**

Georgia is one of ten states that has not adopted Medicaid expansion. Caregivers, including those who provide home and community-based services (HCBS), make wages low enough to qualify for public assistance, including Medicaid. However, since Georgia continues to refuse to expand Medicaid, there are fewer people in this labor market that can qualify for Medicaid. This increases the burden on an already overstressed workforce.

**Dr. Maxey**, can you describe how caregivers in Georgia, where the health care gap still exists and over 600,000 people don't have access to free and affordable health care, are disproportionately harmed?

**Response:**

Thank you for your question on affordable health care for home care workers. As you are likely aware, these workers tend to be low-income women, people of color and immigrants, groups that traditionally experience challenges in areas such as education, housing and healthcare.<sup>1</sup> Georgia has approximately 36,000 home health aides (HHA) and personal care aides (PCA) earning an average hourly rate of \$12.10 and an annual income of \$25,160.<sup>2</sup> This income falls below 200% of the federal poverty line for individuals. For the estimated one third of home care workers in Georgia who have dependent children,<sup>3</sup> this income places their households close to the federal poverty line.<sup>4</sup>

According to PHI, just 36% of home care workers are offered health insurance through an employer in Georgia,<sup>5</sup> leaving nearly two-thirds without employer-sponsored healthcare benefits. Medicaid is not likely an option for Georgian home care workers that lack employer-sponsored benefits. Adults under the age of 65 without a disability or other qualifying condition are not eligible for Medicaid in Georgia.<sup>6</sup> Purchasing an individual health insurance policy on the open

<sup>1</sup> Direct Care Workers in the United States – Key Facts, 2021. Available at: <https://www.phinational.org/wp-content/uploads/2021/09/Direct-Care-Workers-in-the-US-2021-PHI.pdf>

<sup>2</sup> US Bureau of Labor Statistics – Occupational Employment and Wage Statistics – 31-1120 Home Health and Personal Care Aides, 2021. Available at: <https://www.bls.gov/oes/current/oes311120.htm#st>

<sup>3</sup> PHI Workforce Data Center – Direct Care Workers by Parental Status, 2020. Available at: <https://www.phinational.org/policy-research/workforce-data-center/#states=13&var=Parental+Status>

<sup>4</sup> Healthcare.org – Federal Poverty Level, 2023. Available at: <https://www.healthcare.gov/glossary/federal-poverty-level-fpl/>

<sup>5</sup> PHI Workforce Data Center – Direct Care Workers by Health Insurance Status, 2020. Available at:

<https://www.phinational.org/policy-research/workforce-data-center/#states=13&var=Health+Insurance>

<sup>6</sup> Georgia Medicaid, 2023. Available at: <https://medicaid.georgia.gov/how-apply/basic-eligibility>

market is likely cost prohibitive for Georgia's home care workers. The average annual cost of an individual plan in the open market was \$7,911<sup>7</sup> in 2022, one third of the estimate annual income of Georgian home care workers. Expansion of Georgia Medicaid which offers health insurance coverage options for low-income adults would provide qualifying home care workers with benefits.

I hope this information is helpful. If you have additional questions, please do not hesitate to reach out to me at [hmaxey@iupui.edu](mailto:hmaxey@iupui.edu).

Hannah Maxey, PhD, MPH, RDH  
Associate Professor and Director  
Bowen Center for Health Workforce Research & Policy  
Indiana University School of Medicine Department of Family Medicine

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<sup>7</sup> Kaiser Family Foundation – 2022 Employer Health Benefits Survey, 2022. Available at: <https://www.kff.org/report-section/ehbs-2022-section-1-cost-of-health-insurance/>

**SENATE SPECIAL COMMITTEE ON AGING**

“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”

March 9, 2023

Questions for the Record

Ms. Pam Lowy

**Senator Raphael Warnock**

**Question:**

HCBS encompass a wide set of services ranging from physical therapy and home health services to assistance with activities of daily living. Despite the importance of the care they provide, professional caregivers are paid extremely low wages.

**Ms. Lowy**, how would investments in HCBS through legislation like the *Better Care Better Jobs Act*, which I have cosponsored, improve wages for professional caregivers? How would increasing wages for caregivers reduce external financial stress and improve the quality of care that your staff is able to provide for older adults and people with disabilities?

**Response:**

Thank you, **Senator Warnock**, for your question and for your co-sponsorship of the *Better Care Better Jobs (BCBJ) Act*.

Investments in Home & Community Based Services (HCBS) through legislation like the BCBJ Act would increase wages for caregivers by continuing the American Rescue Plan Act-increased Federal Medical Assistance Percentage (ARPA-increased FMAP), which enabled my organization, Great Bay Services (GBS), to pay our long-serving staff tenure bonuses and our incoming staff hiring bonuses. For an organization like GBS, continuing this increased FMAP would enable us to give each of our staff a \$1/hour cost of living raise, plus tenure increases of \$0.25/hour for each year of employment – all effective immediately. Our entry level wage would rise to \$17/hour and our average Direct Support Professional (DSP) wage would rise to almost \$19/hour. Having expressed to the Committee earlier this month that we as an industry aim to raise entry level DSP wages to \$20/hour in the near future, Great Bay Services raising entry level wages to \$17/hour would close the gap for new hires to 18% below target and for the average tenured staff to 5% below target.

**This would be beyond life-changing – it has the potential to be industry-changing.**

The Massachusetts Institute of Technology Living Wage calculator estimates the living wage for an adult with one child in our region is approximately \$35 per hour, working 40 hours per

week. Our industry average wage is \$12.50/hour – barely above one third of that amount. Aiming to pay DSPs – individuals from whom we expect a similar if not higher level of skill compared to other positions such as Certified Nursing Assistants, Home Health Aides, and Personal Care Assistants - \$20/hour is a base level goal. A living wage is our longer-term goal. The *Better Care Better Jobs Act* would represent significant progress on this front.

Increasing wages for caregivers would improve the quality of care that my staff – and staff like them across the country – provide to older adults and people with disabilities in the following ways:

- Our staff are currently living paycheck to paycheck and have no “rainy day” fund if their personal vehicle, used for work due to transportation underfunding, breaks down or if they have out of pocket medical expenses. Higher wages would mean less sick time and less time off work in general.
- Elevated time off work for our DSPs leads to dropped support hours for the vulnerable Americans who depend upon us daily for everything from community engagement to in-home services to supports in their own workplaces.
- Elevated time off for our DSPs has a domino effect on the natural supports of the people we support: if we cannot provide supports, an unpaid family or community member is forced to take time off at their own workplace in order to provide emergency supports.
- Beyond loss of service hours, financially strapped (and under-supported) DSPs are less able to provide the empathetic, compassionate support our clients need and deserve, and under-maintained vehicles can pose a safety or comfort issue for the people we support when a staff member puts off vehicle servicing due to lack of available funds.
- The open positions we have are not attractive to qualified candidates who could easily earn more money working elsewhere – in retail, in fast food, in warehouses, etc.

I greatly appreciate your interest in and advocacy for better quality care to two of America’s most vulnerable populations: older adults and people with disabilities. We in the HCBS DSP community thank you.



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**Statements for the Record**

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U.S. SENATE SPECIAL COMMITTEE ON AGING  
 Uplifting Families, Workers, and Older Adults: Supporting Communities of Care  
 Hearing Testimony  
 Thursday, March 9, 2023

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to provide testimony on the importance of the Medicaid Home and Community Based Services (HCBS) program and the crisis among the direct support workforce that endangers access to these services.

Founded more than 50 years ago, ANCOR is a national, nonprofit association representing 2,000 private community providers of long-term supports and services to people with intellectual and developmental disabilities (I/DD), as well as 56 state provider associations. Combined, our members support more than one million individuals with I/DD across their lifespan, and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

*The Direct Support Workforce Crisis Endangers Access to HCBS*

Through the Medicaid HCBS program, our members offer a broad range of supports to help people with I/DD live full and independent lives in the community. The backbone of these services are direct support professionals (DSPs), who not only provide essential caregiving services to people with I/DD, but also provide an array of supports ranging from assistance in grocery shopping to job training and employment supports.

This direct support workforce that enables the supports and services provided through the HCBS program is in crisis. This workforce crisis predates the COVID-19 pandemic, stemming from decades of underinvestment in the program and stagnant reimbursement rates that leave providers unable to offer wages that are competitive with those of hourly-wage industries, such as fast food, retail, and convenience stores. But the COVID-19 pandemic has exacerbated the existing crisis to levels that threaten the very infrastructure of HCBS.

In 2022, ANCOR surveyed its community-based provider network to measure the impact the workforce crisis has had on their ability to provide services. Data from the *State of America's Direct Support Workforce Crisis 2022*<sup>1</sup> indicates:

- **83%** of providers are turning away new referrals due to insufficient staffing—a 25.8% increase since the beginning of the pandemic.
- **63%** of providers have been forced to discontinue programs and services—a staggering 85.3% increase since the beginning of the pandemic.
- **55%** of providers are considering additional service discontinuations if the current high turnover and vacancy rates persist, with only 8% indicating they would not.

<sup>1</sup> American Network of Community Options and Resources, [The State of America's Direct Support Workforce Crisis 2022](#) (Oct. 2022).  
 1101 King Street, Suite 380, Alexandria, VA 22314-2944 P: 703.535.7850 F: 703.535.7860 E: [ancor@ancor.org](mailto:ancor@ancor.org) [www.ancor.org](http://www.ancor.org)

- **92%** of providers indicated that they had experienced difficulties in achieving quality standards due to insufficient staffing, representing a 33.3% increase since the beginning of the pandemic and a 13.6% increase in the last year alone.
- **71%** of case managers are struggling to connect families with services due to lack of available providers.

As providers continue to grapple with the loss of staff and inability to continue the provision of many programs and services, people with I/DD are experiencing diminishing access to community-based services and increased risk of hospitalization or institutionalization.

*The Expiration of Temporary Funding and Key Flexibilities Are Exacerbating the Crisis*

The COVID-19 pandemic necessitated the declaration of a public health emergency (PHE) in 2020. With that PHE declaration came important investments in the Medicaid program and the authorization of regulatory flexibilities for states to ensure the continuation of programs and services. While responding to the unique circumstances of the COVID-19 pandemic, these investments and regulatory flexibilities also provided temporary support toward stabilizing the increasing exodus of direct support professionals from the field.

However, the upcoming termination of the PHE means that many of these flexibilities are ending. Providers are concerned that the roll-back of additional funding and flexibilities, like expanded service settings and the ability to provide temporary direct support wage increases, will decrease access to services. In fact, ANCOR's survey found that 66% of providers are concerned that staff vacancy and turnover rates will increase when COVID-19 relief funding and regulatory flexibilities related to the COVID-19 public health emergency are terminated.

Additionally, many states are facing the termination of temporary funding authorized by the American Rescue Plan Act (ARPA), which provided increased federal funding to support access to HCBS. An analysis by the National Association of State Directors of Developmental Disabilities Services reported that 44 of the 49 state ARPA spending plans reviewed included one-time and time-limited initiatives aimed at addressing ongoing workforce issues. Now, providers who relied on these initiatives to stem the flood of workers from the field are facing an increased workforce crisis and fiscal cliff when the funding expires.

Further exacerbating the loss of increased federal funding is the impending compliance deadline for the Home and Community Based Services Settings Rule. The deadline comes at the same time as the wind down of critical funding and expiration of key flexibilities meant to help temper the impact of the workforce shortage. States and providers seeking to comply with the criteria established under the Settings Rule to ensure people accepting Medicaid-funded HCBS receive those services in the most integrated settings possible, face additional challenges.

*Congressional Action Is Necessary to Sustain the HCBS Program*

Given the mounting challenges providers face in ensuring people with I/DD can continue to access critical home and community-based services, it is time for Congress to take action to strengthen the direct support workforce.

We are grateful to the leadership from Chair Casey on the introduction of the Better Care Better Jobs Act and the HCBS Access Act to strengthen and expand the Medicaid HCBS program. In

particular, we appreciate the emphasis on investing in the direct support workforce and the requirement for states to regularly review payment rates as a mechanism of ensuring adequacy reimbursement rates, and in turn, improve direct support wages. We ask members of this committee to support both bills.

We also urge support for the creation of a standard occupational classification for direct support professionals. The creation of a discrete classification for direct support professionals will create a mechanism for collecting consistent national data on the direct support workforce and help in stabilizing wages<sup>2</sup> for direct support professionals.

Absent additional investments in the Medicaid HCBS program, it is likely that many more providers will be forced to turn away individuals seeking services and close their doors altogether. Congress has the ability to take the initiative to begin to stabilize the direct support workforce and in turn, deliver on the access and inclusion promises of the Americans with Disabilities Act by ensuring the Medicaid HCBS program remains sustainable.

*Conclusion*

We thank you for shining a light on the importance in investing in the Medicaid HCBS program and addressing the ongoing workforce crisis. We urge you to support legislation to strengthen and expand the Medicaid HCBS program through investing in the direct support workforce. If you have questions or would like to discuss further, please feel free to contact Elise Aguilar, ANCOR's Director of Federal Relations, at [eaguilar@ancor.org](mailto:eaguilar@ancor.org).

Sincerely,



Barbara Merrill  
Chief Executive Officer  
ANCOR

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<sup>2</sup> See Health Management Associates, [Review of States' Approaches to Establishing Wage Assumptions for Direct Support Professionals When Setting I/DD Provider Rates](#) (July 2022). The report found that of the states surveyed, the vast majority relied on federal data from the U.S. Bureau of Labor Statistics to establish wage assumptions, and that without a classification for direct support professionals, states' wage assumptions varied widely.



My name is Angela King and I am the CEO for Volunteers of America (VOA) Texas. I appreciate the opportunity to submit testimony regarding the dire state of the workforce for community-based services for people with intellectual and developmental disabilities (IDD).

Volunteers of America operates Home and Community Based Services (HCBS) in 14 states across the country, and never has our organization faced the challenges in recruitment and retention that we are facing today. I know this industry well. I began my own career 40 years ago as a Direct Support Professional (DSP) on the night shift, while I was in grad school, at the state institution in Fort Worth, Texas. I later worked as a weekend "house parent" at a small group home which was an emerging service at that time. Now, of course, we all strive to insure that supports for people with disabilities are community-based, person-centered, and choice-driven. All these goals are impossible to reach without a stable workforce.

I have seen many changes over the years, but the situation now is more dire than ever. Over the past two years at VOA Texas, our turnover rates have more than tripled. Our most recent quarter's rate was 44%. Due to the workforce shortage, we have been forced to close and consolidate group homes to maximize our staffing coverage. In some cases, we have had to tell families that we can only provide supports if they can help us locate staff members to work with their family member.

In the past few months, the Austin American Statesman newspaper has run an investigative series on the dire state of services for people with IDD in Texas. This reporting has highlighted the increase in abuse and neglect reports, service closures, and recruitment barriers. The articles stressed the importance of the DSP work, while highlighting that many are working 70 hours a week or more to try to cover shifts abandoned by other staff months ago.

Our current rate structure in Texas is based on DSP wages at \$8.50 an hour and has not been updated in a decade. Of course, it is impossible to hire qualified people at this wage, so VOA is finding a way to pay our employees more, but we are severely limited by the wage structure due to the fact that our services are 100% Medicaid funded.

As a result, services are closing, and individuals are being turned away because we cannot find people to take these important jobs. Even more troubling, it is becoming increasingly difficult to provide the same quality of care because the remaining staff members are exhausted, poorly trained, and overwhelmed. When we say that services are at the breaking point, it is not an exaggeration.

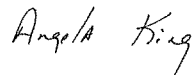
The reality is that in many situations, a DSP may be responsible for every drink of water for an individual will receive, day after day, year after year. But that same DSP is trying to support

their own family, being asked to work 4 shifts in 2 days, exhausted, and being paid less than their friends who work in fast food or retail. No matter how dedicated that individual DSP is, no matter how much they love their job, they simply must make enough money to survive themselves, so they leave the job they love and the individuals who are relying on their supports. So, who gives that person their next drink of water? This is no longer a rhetorical question; it is a daily dilemma for providers all over the country. When my colleagues ask me “what keeps me up at night?”, I do not struggle for an answer.

We must increase the wages, benefits, and respect for our DSP workforce. There needs to be a consistent expectation across the country that rates in the Medicaid system are based on living wages and capable of sustaining a qualified workforce. There is no doubt that this will take an investment of resources into the Medicaid system and a requirement at the federal level that rates are structured based on wage scales that are current. The need is urgent; our clients literally need a drink today, tomorrow, and in the years to come, and without immediate action, the care system that we have so proudly built over the past 40 years is going to soon collapse.

Thank you for the opportunity to provide my input on this crisis and I appreciate the efforts you are making to address this workforce crisis.

Sincerely,

A handwritten signature in cursive script that reads "Angela King".

Angela King  
CEO  
VOA Texas



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March 7, 2023

Dear Chair Casey and Ranking Member Braun:

Thank you for the opportunity to provide testimony for the hearing, Uplifting Families, Workers, and Older Adults: Supporting Communities of Care.

My name is Dahlian Porter, and I am the Senior Vice President of Program Services at ADAPT Community Network. The ADAPT Community Network has been helping children and adults with intellectual and developmental disabilities for over 75 years. We offer a range of services, including health care services, supported employment, adult learning and day services, and community habilitation programs. Our goal is to create a more inclusive world.

I have worked in the Intellectual Developmental Disabilities field since 1987, beginning with my first job in the field as a direct care worker. I know this field well and the challenges faced by both providers and direct care workers themselves.

But now, more than ever, the industry is in crisis. In New York, we began to see the crisis take hold even before the onset of the COVID-19 pandemic, when we began to see a decline in attracting workers to the field. Providers' ability to pay workers a living wage is severely hindered by the stagnant Medicaid reimbursement rates, meaning that employers simply cannot remain competitive with other private sector employers like restaurants and retail. Even when we can recruit employees, wages are so low that staff are often forced to work two to three jobs in order to sustain themselves and their families—a reality for many of our staff, the majority of whom are single mothers.

Providers must be able to pay staff a living wage. We also want to be able to provide adequate health care benefits and transportation assistance to staff to help absorb expenses incurred when traveling to and from jobs. But without an investment in the Medicaid program, we cannot effectively raise wages or support our direct care workforce.

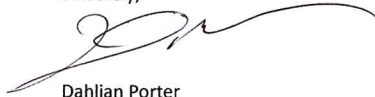
The result is a constant turnover among direct care staff. Without enough staff, people seeking services face a dire future. Because of the workforce shortage, the waiting list for services are growing as programs are unable to resume services at full capacity. People are sitting at home waiting for services for which they may never be given access. Residential programs have and will continue to consolidate their homes to ensure they have required staffing levels, further decreasing the availability of services.



I am asking Congress to act now and invest in our Medicaid-funded services. Our staff deserve a living wage and the individuals they support deserve access to services that will enable them to live full, independent lives in their communities. Please support legislation to bolster the Medicaid home and community-based services program and invest in the workforce, such as the HCBS Access Act and the Better Care Better Jobs Act.

Thank you for your consideration of this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read 'Dahlian Porter', with a long, sweeping flourish extending to the right.

Dahlian Porter  
Senior Vice President of Program Services  
ADAPT Community Network



**Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record**

**United States Senate Special Committee on Aging Hearing on "Uplifting Families, Workers, and Older Adults: Supporting Communities of Care"**

**March 9, 2023**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing "Uplifting Families, Workers, and Older Adults: Supporting Communities of Care." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. Among other issues, this statement highlights the value of long-term care settings as well as home- and community-based services (HCBS) for individuals living with Alzheimer's and other dementia.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Alzheimer's Impact Movement is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

An estimated 6.5 million Americans age 65 and older are living with Alzheimer's dementia in 2022. In addition, total payments for all individuals with Alzheimer's or other dementias are estimated at \$321 billion (not including unpaid caregiving) in 2022. Medicare and Medicaid are expected to cover \$206 billion or 64% of the total health care and long-term care payments for people with Alzheimer's or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer's and other dementias are projected to increase to more than \$1.1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

We encourage the Committee to consider the following recommendations to improve the support of the growing number of families affected by Alzheimer's, especially given the unique challenges the dementia care community faces in HCBS and long-term care settings.

**Home- and Community-Based Services: Needs of the Alzheimer's and Dementia Community**

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, an estimated 65 percent of people with Alzheimer's live in the community, and states are driving much of the development of and better access to HCBS. State governments can reduce long-term costs and increase access to person-centered care in the home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

Several states are implementing innovative solutions to address Alzheimer's in the Medicaid and non-Medicaid spaces by developing critical, cost-effective, dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and support that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and enjoy a greater quality of life. Medicaid should adopt a core set of home- and community-based services that are specifically designed for people with dementia. A core set of HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible

People living with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and nursing home care. Additionally, 32 percent of individuals using home health services have Alzheimer's or other dementias. Persons affected by dementia use a wide range of long-term supports and services, for example:

*Adult day services.* Twenty-eight percent of individuals using adult day services have Alzheimer's or other dementias. Ten percent of adult day services specialize in caring for individuals with Alzheimer's disease or other dementias. The median cost of adult day services is \$75 per day, and the cost of adult day services has increased by 1.5 percent annually over the past five years.

*Residential care facilities.* Thirty-four percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias. Fifty-eight percent of residential care facilities offer programs for residents with dementia. The median cost of care in an assisted living facility is \$4,429 per month or \$53,148 per year, and the cost of assisted living has increased by 3.6 percent annually over the past five years.

*Nursing home care.* Forty-eight percent of nursing home residents have Alzheimer's or other dementias. Nursing home admission by age 80 is expected for 75 percent of people with dementia compared with only four percent of the general population. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions. The average cost for a private room in a nursing home is \$299 per day (\$109,135 per year) and the average cost of a semi-private room is \$263 per day (\$95,995 per year). The cost of nursing home care has increased three percent annually over the past five years for both private and semi-private rooms.

*Respite.* Given the demands and responsibilities placed on caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. The use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. This is consistent with the growing demand the Alzheimer's Association hears from our constituents. Yet the availability of respite programs in the community is limited. We applaud Congress's passage of the Lifespan Respite Care Reauthorization Act (S. 995/H.R. 2035) to meet this demand.

**Home- and Community-Based Services: The Impact on Family Caregivers**

While 83 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of all caregivers who help older adults do so for someone with Alzheimer's or another dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2021, more than 11 million unpaid caregivers provided an estimated 16 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economical value of over \$271.6 billion. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. Approximately one-fourth of Alzheimer's and dementia caregivers are "sandwich generation" caregivers — caring for both someone with the disease and a child or grandchild.

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while giving them an opportunity to manage and improve their own health.

Important provisions within recent legislation would add much-needed funds to home- and community-based services, permanently authorize protections against spousal impoverishment, and make permanent the Money Follows the Person program. Medicaid pays for long-term care services and nursing homes for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias are 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias. These important programs will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid.

One way the Association is helping caregivers of individuals with Alzheimer's is by providing a 24/7 Helpline (800.272.3900) available around the clock, 365 days a year. Through this free

service, specialists and master's-level clinicians offer confidential support and information to people living with dementia, caregivers, families, and the public. The Fiscal Year 2023 Consolidated Appropriations Act (P.L. 117-328) allocated \$2 million for the Alzheimer's Call Center, and we look forward to working with the Committee to continue funding this vital resource to individuals living with the disease as well as their caretakers.

#### **Direct Care Workforce in Long-Term Care Settings**

People living with Alzheimer's and other dementia make up a significant portion of all long-term care residents, comprising 48 percent of residents in nursing homes and 34 percent of all residents in assisted living communities and other residential care facilities. Twenty-four percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with one percent of Medicare beneficiaries without these conditions. Approximately 75 percent of individuals with Alzheimer's disease diagnosed at age 70 will reside in a nursing home by age 80, compared with only four percent of the general population surviving to age 80. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance.

As the prevalence of Alzheimer's disease increases, so does the need for members of the paid dementia care workforce. Shortages in direct care workers will place an even bigger burden on family and friends who provide unpaid care — already an effort equivalent to nearly \$257 billion per year. The United States will have to nearly triple the number of geriatricians to effectively care for the number of people projected to have Alzheimer's in 2050, while efforts to increase recruitment and retention remain slow. In 48 U.S. states, double-digit percentage increases in home health and personal care aides will be needed by 2028 to meet demand. From 2016 to 2026, the demand for direct care workers is projected to grow by more than 40 percent, while their availability is expected to decline.

The [Alzheimer's Association's Dementia Care Practice Recommendations](#) include the following recommendations specific to workforce: (1) staffing levels should be adequate to allow for proper care at all times — day and night; (2) staff should be sufficiently trained in all aspects of care, including dementia care; (3) staff should be adequately compensated for their valuable work; (4) staff should work in a supportive atmosphere that appreciates their contributions to overall quality care because improved working environments will result in reduced turnover in all care settings; (5) staff should have the opportunity for career growth; and (6) staff should work with families in both residential care settings and home health agencies. Additionally, we know that consistent assignment is an important component of quality care for staff working with residents with dementia.

While much of the training for long-term care staff is regulated at the state level, we encourage the Committee to consider proposals that support states in implementing and improving dementia training for direct care workers, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on a thorough knowledge of the care recipient and their

needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

We also urge the Committee to support states in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that has hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

The Alzheimer's Association and AIM look forward to working with the Committee to shape specific proposals to better train and support the direct care workforce to provide the highest-quality support for individuals living with dementia. In the meantime, we encourage you to keep residents living with dementia top-of-mind as you continue this important work.

**Conclusion**

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of families affected by Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to address the challenges facing the dementia community.



## THE PHOENIX RESIDENCE, INC.

U.S. SENATE SPECIAL COMMITTEE ON AGING

Uplifting Families, Workers, and Older Adults: Supporting Communities of Care

HEARING TESTIMONY

Thursday, March 9, 2023

Dear Chair Casey and Ranking Member Braun:

I am Darlene Scott, President and CEO of The Phoenix Residence, Inc. a nonprofit organization in St. Paul Minnesota and a member of the American Network of Community Options and Resources. It is an honor to present testimony to the U.S. Senate Special Committee on Aging regarding the importance of the Medicaid Home and Community Based Services (HCBS) program and the impact of the workforce crisis on individuals with disabilities, their families, Direct Support Professionals, and providers who support individuals in living their best life.

Phoenix Residence Inc. for over 40 years has provided (HCBS) for more than 100 individuals helping them to live in homes and communities of their choice. We work closely with a sister nonprofit who serves over 400 individuals providing similar services to help individuals maintain community living and employment. We are a proud member of our local and national trade associations representing 2000 or more providers in disability services.

We appreciate the U.S. Senate Aging Committee's efforts and attention to the workforce crisis. It is the single most important issue that threatens the livelihoods of the aging and disability services community. Nationally, the turnover rate is 45- 50% within our industry. We are literally screaming at the top of our voices about the condition of our industry and the fear of what will happen to vulnerable people if we don't make the necessary investments in the system. We need legislation to expand access to home and community- based services for older adults and people with disabilities, and injured workers, while improving benefits and wages of the direct care professionals who provide necessary supports to this community. We ask that members of this Committee support legislation to strengthen HCBS.

In Minnesota it is reported that individuals with disabilities face a worrisome future as a wave of group home closures hit the state last fall and home care providers report no staff to support individuals seeking care in their private homes. The staff shortages and low wages for direct support professionals is devastating our industry.

More than 170 group homes across the state of Minnesota have closed since fall of 2021, that is about 4% of the state's group homes closing in less than one year. Phoenix Residence Inc. also closed group home services and in-home support during this period due to the workforce shortage and reimbursement rates for these services not keeping pace with the demand. Closing homes and services that individuals have come to rely on causes fear, anxiety and disrupts the lives of people who must move away from their home, friends, and providers that they trust.

Given the stagnant Medicaid reimbursement rates, resulting in low wages for direct care professionals, employees working within long-term-care services typically work 2-3 jobs to make ends meet or work significant overtime within a single job. The current direct care workforce is overextended resulting in reduced quality of care and negative outcomes for all.



Phoenix Residence Inc. is not able to take on additional services and to be honest we are struggling to maintain the services that we currently provide. We are operating with a reduced capacity of about 50 full-time positions as we are unable to fill them. The regulations and requirements that we operate under are not changing; they are increasing and without the necessary funding to support these services I am not sure how we or any provider within this system can survive.

In addition, to all the above, the announcement of the ending of the Public Health Emergency and with it; the emergency flexibilities and funding provided to states to help during the pandemic--will create more problems within our fragile industry.

We need congressional action to invest in the HCBS system. The system was designed to promote more efficient and cost-effective services providing an alternative to more costly institutional services. The current environment will set us back and will prove more costly if we are not proactive at making the investment needed to get the program back on track to doing what it was designed to do.

Senator Casey, thank you for your on- going support and for your unwavering commitment to the aging and disability services community. We appreciate the introduction of the Better Care Better Jobs Act and HCBS Access Act to shore up the Medicaid HCBS program.

Again, thank you for the opportunity to provide testimony to the U.S. Special Committee on Aging. Please reach out to me if you have any questions or I can be of help to you or the committee.

Sincerely,

THE PHOENIX RESIDENCE INC.

Darlene Scott  
President & CEO





March 9, 2023

The Honorable Bob Casey  
Chairman  
United States Senate Special Committee on Aging  
G16 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Mike Braun  
Ranking Member  
United States Senate Special Committee on Aging  
G16 Dirksen Senate Office Building  
Washington, DC 20510

Dear Chairman Casey and Ranking Member Braun

On behalf of Argentum, the leading national association representing senior living communities and the older adults and families they serve, I want to commend you for holding this important hearing today on workforce shortages facing the American health care system as a whole and share with you how this shortage is impacting senior care.

The members of Argentum operate senior living communities offering assisted living, independent living, continuing care, and memory care services. Along with its state partners, Argentum's membership represents approximately 75 percent of the professionally managed communities in the senior living industry—an industry with a national economic impact of nearly a quarter of a trillion dollars and responsible for providing more than 1.6 million jobs. These communities are home to nearly two million vulnerable seniors, offering choice, dignity, security, and comfort in the final years of life.

It is our view that policymakers have focused almost exclusively on nurse and physician shortages, but not enough on the shortages in long-term care. While both sectors are facing staffing challenges, the workforce shortages in the long-term care industry will eclipse those in all other health care sectors. Currently, there is a shortage of roughly 400,000 senior caregivers, and that number will only continue to grow. In fact, by 2040, the United States will need to fill more than 20 million jobs to care for our nation's seniors.

Within the long-term care sector, shortages in the "senior living" workforce (assisted living, memory care and independent living) are objectively the most acute. The senior living industry lost more than 100,000 positions between February 2020 and November 2021, leaving the industry far below pre-pandemic employment levels. While the hospital and home health care sectors are closer to returning to pre-pandemic employment, the senior living workforce is still facing unprecedented shortages of caregivers. Today, 96 percent of senior communities are facing staff shortages, with 70% experiencing "significant or severe" shortages.

The U.S. population is aging at the fastest rate in our nation's history. Today, 17 percent of Americans—or 55.7 million people—are 65 and older, a 38 percent increase since 2010. By 2040, 22 percent—or 80.8 million Americans—are projected to be 65 and older, more than twice as many as in 2000.



The most rapidly aging segment of the population are seniors aged 85 and older, and it is these individuals who will need the greatest and most direct care. By 2060, the 85 and older population will nearly triple to 19 million people and the number of centenarians will grow from 92,000 in 2020 to roughly 590,000.

Since most older Americans have at least one chronic condition, an estimated 70 percent will need some form of long-term care in their lifetime, and more than 50 percent will need a high level of care. Put simply, they will need a caregiver. But will they be able to find one? We are deeply concerned that if we do not act now, there will not be enough caregivers to meet the needs of the tens of millions of seniors who will need help in the coming decades.

Argentum and its members have long supported a number of legislative and regulatory solutions to resolve this workforce shortage crisis. Much of the federal infrastructure is already in place, and simply retooling current workforce development programs to better meet this workforce could have an immediate effect. Efforts such as the bipartisan SENIOR Act, introduced in the House by Representatives last year to address the senior care crisis, would build upon existing workforce programs. Specifically, it would bolster workforce development programs within the Health Resources & Services Administration (HRSA) by emphasizing geriatric care and the needs of this vulnerable population. Expanding the caregiving workforce and increasing the number of individuals eager to serve our nation's seniors is one step to address systemic workforce shortages. Argentum strongly supports this bill and urges the Senate to take it up and pass it in the 118<sup>th</sup> Congress.

Expanding the caregiving workforce will also have a positive economic impact. The nonprofit Family Caregiver Alliance reports that more than 1 in 6 Americans working full-time or part-time assist with the care of an elderly or disabled family member, relative, or friend, and 70 percent suffer work-related difficulties due to their dual roles. The survey estimates that 61 percent of caregivers who work outside the home experience at least one employment change due to their caregiving responsibilities, such as cutting back work hours, taking a leave of absence, or receiving a disciplinary warning about performance or attendance.

Recent findings estimate that family care giving led to the loss of 656,000 jobs, with an additional 791,000 family caregivers suffering from absenteeism at work. These job losses and absenteeism among family members and informal caregivers have a direct annual economic impact of \$43.9 billion, and indirect costs of \$221 billion in lost productivity.

The 10 million caregivers aged 50 and above who care for loved ones lose an estimated \$3 trillion in wages, pensions, retirement funds, and benefits. The total costs are higher for women, who lose an estimated \$324,044 due to caregiving, compared to men at \$283,716. Importantly, these calculations do not account for the emotional and logistical stresses experienced by family caregivers, the disruption of daily lives and relationships, and frequency of caregiver burnout. By easing these burdens, assisted living can increase productivity and the economic well-being of families, and more importantly, let them enjoy being a spouse, child or partner again without the strain of being the primary caregiver.



Argentum has consistently supported Medicaid Home & Community-Based Services (HCBS) Programs and efforts to strengthen their workforce. HCBS programs ensure that the most vulnerable of our nation's seniors have opportunities for care in settings such as assisted living, where greater independence and quality of life can be maintained at a fraction of the cost to taxpayers, as compared to nursing homes and other like settings as appropriate.

However, 44 states reported a permanent closure of at least one HCBS provider in 2022, up from 30 states in 2021 and nearly two-thirds of HCBS providers have discontinued services and cut back programs in response to the current workforce crisis. Waitlists currently number roughly 700,000 people nationwide, and more than 80 percent of providers are already turning away new referrals because of limited staff capacity, a 26 percent increase from 2020. We urge the committee to act quickly to preserve these critical programs.

In conclusion, I want to thank you for holding this important hearing. Given the scope of the workforce shortage in every segment of our health care system, it is my hope that the committee will hold additional hearings to further examine the crisis and policies to expand and retain our caregiving workforce so that all Americans can continue to access care. Argentum and its members look forward to working with you and your colleagues to pursue cost-effective solutions to meet the challenges of our rapidly changing population.

Please contact my office with any questions or requests for additional information.

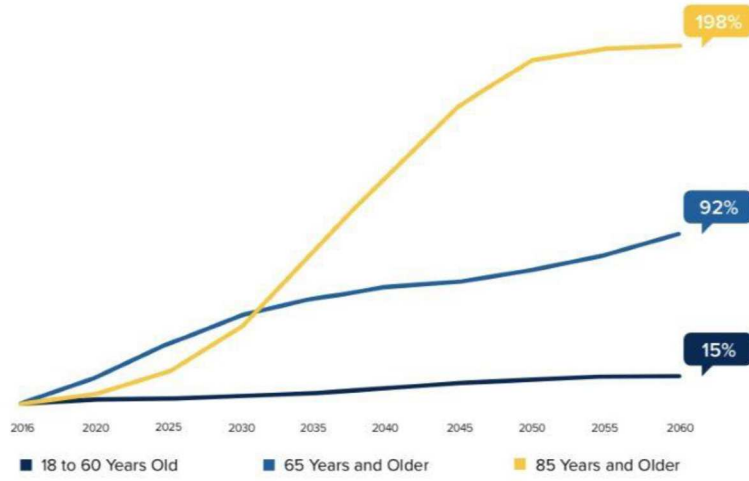
Sincerely,



James Balda  
President & CEO  
Argentum



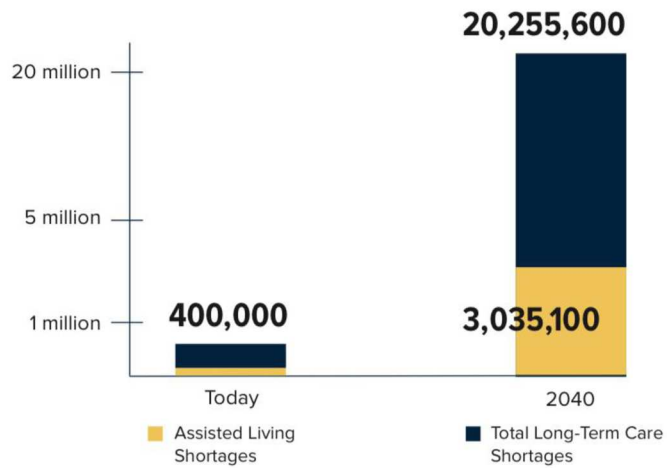
Projected Population Growth by Age Group, 2016 to 2060





## LONG-TERM CARE WORKFORCE CRISIS THROUGH 2040

Severe job shortages will grow exponentially





## Senior Living Industry Workforce Projections: 2021 to 2030

State	2021 Jobs	2030 Jobs	Net Job Growth	Occupational Replacement Needs*	Total Employees Needed
Alabama	7,400	8,000	600	9,700	10,300
Alaska	1,300	1,500	200	1,800	2,000
Arizona	21,900	26,900	5,000	30,800	35,800
Arkansas	4,300	4,600	300	5,600	5,900
California	93,500	107,900	14,400	127,000	141,400
Colorado	16,900	20,200	3,300	23,400	26,700
Connecticut	10,000	11,300	1,300	13,400	14,700
Delaware	3,300	4,000	700	4,600	5,300
District of Columbia	1,100	1,200	100	1,400	1,500
Florida	62,300	75,100	12,800	86,800	99,400
Georgia	19,400	22,800	3,400	26,600	30,000
Hawaii	2,900	3,300	400	3,900	4,300
Idaho	6,700	8,200	1,500	9,400	10,900
Illinois	34,900	38,400	3,500	46,200	49,700
Indiana	17,600	19,400	1,800	23,300	25,100
Iowa	13,800	15,400	1,600	18,400	20,000
Kansas	14,200	15,900	1,700	19,000	20,700
Kentucky	5,900	6,400	500	7,700	8,200
Louisiana	6,100	6,700	600	8,100	8,700
Maine	5,400	6,000	600	7,200	7,800
Maryland	21,700	24,400	2,700	29,100	31,800
Massachusetts	21,800	25,900	3,300	29,600	32,900
Michigan	31,000	33,800	2,800	40,800	43,600
Minnesota	24,900	28,900	4,000	33,900	37,900
Mississippi	3,700	4,000	300	4,900	5,200
Missouri	13,300	14,500	1,200	17,500	18,700
Montana	3,000	3,400	400	4,000	4,400
Nebraska	8,500	9,700	1,200	11,500	12,700
Nevada	4,000	5,000	1,000	5,700	6,700
New Hampshire	4,500	5,300	600	6,000	6,600
New Jersey	21,000	23,900	2,900	28,300	31,200
New Mexico	3,700	4,300	600	5,000	5,600
New York	28,800	32,900	4,100	38,900	43,000
North Carolina	31,300	36,600	5,300	42,800	48,100
North Dakota	2,700	3,000	300	3,600	3,900
Ohio	33,100	35,800	2,700	43,400	46,100
Oklahoma	6,300	6,700	400	8,200	8,600
Oregon	25,000	28,500	3,500	33,700	37,200
Pennsylvania	62,000	68,500	6,500	82,300	88,800
Rhode Island	2,800	3,200	400	3,800	4,200
South Carolina	13,600	16,000	2,400	18,700	21,100
South Dakota	3,300	3,800	500	4,500	5,000
Tennessee	14,100	15,600	1,500	18,700	20,200
Texas	49,700	59,000	9,300	68,500	77,800
Utah	7,800	9,600	1,800	11,000	12,800
Vermont	2,400	2,700	300	3,200	3,500
Virginia	29,200	33,800	4,600	39,700	44,300
Washington	30,400	35,600	5,200	41,600	46,800
West Virginia	3,000	3,200	200	3,900	4,100
Wisconsin	32,100	36,300	4,200	43,100	47,300
Wyoming	900	1,100	200	1,300	1,500

Source: Argentum analysis of data from the Bureau of Labor Statistics

\* In addition to the net job growth in the senior living sector, the industry will need to fill job openings that result when employees permanently leave their occupations, either through exiting the labor force or transferring to a different occupation. These are referred to as 'occupational replacement needs.'



Senior Living Industry Workforce Projections: 2021 to 2040

State	2021 Jobs	2040 Jobs	Net Job Growth	Occupational Replacement Needs*	Total Employees Needed
Alabama	7,400	8,800	1,400	21,500	22,900
Alaska	1,300	1,800	500	4,100	4,600
Arizona	21,900	33,700	11,800	73,300	85,100
Arkansas	4,300	5,000	700	12,300	13,000
California	93,500	125,600	32,100	290,700	322,800
Colorado	16,900	24,500	7,600	54,700	62,300
Connecticut	10,000	13,000	3,000	30,400	33,400
Delaware	3,300	4,900	1,600	10,800	12,400
District of Columbia	1,100	1,300	200	3,200	3,400
Florida	62,300	91,600	29,300	203,500	232,800
Georgia	19,400	27,200	7,800	61,700	69,500
Hawaii	2,900	3,800	900	8,900	9,800
Idaho	6,700	10,200	3,500	22,300	25,800
Illinois	34,900	42,700	7,800	103,100	110,900
Indiana	17,600	21,600	4,000	52,000	56,000
Iowa	13,800	17,400	3,600	41,400	45,000
Kansas	14,200	18,000	3,800	42,800	46,600
Kentucky	5,900	7,000	1,100	17,100	18,200
Louisiana	6,100	7,500	1,400	18,100	19,500
Maine	5,400	6,700	1,300	16,100	17,400
Maryland	21,700	27,800	6,100	65,700	71,800
Massachusetts	21,800	29,300	7,500	67,700	75,200
Michigan	31,000	37,100	6,100	90,500	96,600
Minnesota	24,900	34,100	9,200	78,100	87,300
Mississippi	3,700	4,400	700	10,800	11,500
Missouri	13,300	15,900	2,600	38,800	41,400
Montana	3,000	4,000	1,000	9,200	10,200
Nebraska	8,500	11,200	2,700	26,200	28,900
Nevada	4,000	6,300	2,300	13,600	15,900
New Hampshire	4,500	5,900	1,400	13,700	15,100
New Jersey	21,000	27,600	6,600	64,400	71,000
New Mexico	3,700	5,100	1,400	11,600	13,000
New York	28,800	38,100	9,300	88,700	98,000
North Carolina	31,300	43,500	12,200	99,000	111,200
North Dakota	2,700	3,400	700	8,100	8,800
Ohio	33,100	39,100	6,000	95,900	101,900
Oklahoma	6,300	7,200	900	17,900	18,800
Oregon	25,000	33,000	8,000	76,800	84,800
Pennsylvania	62,000	76,500	14,500	184,000	198,500
Rhode Island	2,800	3,600	800	8,600	9,400
South Carolina	13,600	19,100	5,500	43,300	48,800
South Dakota	3,300	4,400	1,100	10,200	11,300
Tennessee	14,300	17,500	3,400	41,900	45,300
Texas	49,700	71,200	21,500	159,800	181,300
Utah	7,800	12,000	4,200	26,100	30,300
Vermont	2,400	3,100	700	7,300	8,000
Virginia	29,200	39,700	10,500	91,200	101,700
Washington	30,400	42,400	12,000	96,300	108,300
West Virginia	3,000	3,400	400	8,500	8,900
Wisconsin	32,100	41,500	9,400	97,700	107,100
Wyoming	900	1,300	400	3,000	3,400

Source: Argentum analysis of data from the Bureau of Labor Statistics  
 \* In addition to the net job growth in the senior living sector, the industry will need to fill job openings that result when employees permanently leave their occupations, either through exiting the labor force or transferring to a different occupation. These are referred to as 'occupational replacement needs.'





Total Senior Care Workforce Projections: 2021 to 2030

State	2021 Jobs	2030 Jobs	Net Job Growth	Occupational Replacement Needs*	Total Employees Needed
Alabama	52,300	54,900	2,600	62,700	65,300
Alaska	6,300	7,800	1,500	8,600	10,100
Arizona	92,800	119,300	26,500	128,200	154,700
Arkansas	46,200	48,400	2,200	56,300	58,500
California	964,300	1,209,000	244,700	1,357,600	1,602,300
Colorado	85,700	106,200	20,500	115,600	136,100
Connecticut	80,400	91,900	11,500	103,600	115,100
Delaware	17,300	21,500	4,200	23,300	27,500
District of Columbia	13,200	14,600	1,400	16,500	17,900
Florida	251,500	296,400	44,900	321,200	366,100
Georgia	95,000	111,100	16,100	121,200	137,300
Hawaii	17,200	20,300	3,100	22,500	25,600
Idaho	28,200	35,600	7,400	38,100	45,500
Illinois	204,300	223,300	19,200	254,200	273,400
Indiana	101,100	108,800	7,700	123,300	131,000
Iowa	57,600	62,300	4,700	71,100	75,800
Kansas	57,000	64,100	7,100	73,300	80,400
Kentucky	56,200	59,900	3,700	68,800	72,500
Louisiana	73,100	80,900	7,800	91,500	99,300
Maine	26,200	29,300	3,100	33,700	36,800
Maryland	82,300	92,000	9,700	102,900	112,600
Massachusetts	179,600	215,700	36,100	239,600	275,700
Michigan	127,700	137,900	10,200	157,200	167,400
Minnesota	144,300	171,800	27,700	191,400	219,100
Mississippi	36,800	40,200	3,400	45,600	49,000
Missouri	128,100	140,300	12,200	162,600	174,800
Montana	14,200	16,300	2,100	18,200	20,300
Nebraska	31,700	35,100	3,400	39,500	42,900
Nevada	28,700	38,200	9,500	40,500	50,000
New Hampshire	19,900	22,600	2,700	25,400	28,100
New Jersey	137,200	156,700	19,500	173,300	192,600
New Mexico	45,700	56,800	11,100	62,100	73,200
New York	591,500	700,400	108,900	762,500	871,400
North Carolina	132,800	155,500	22,700	170,400	193,100
North Dakota	14,800	15,700	900	17,900	18,800
Ohio	212,900	225,000	12,100	256,100	268,200
Oklahoma	47,400	49,000	1,600	56,300	57,900
Oregon	76,700	91,900	15,200	104,800	120,000
Pennsylvania	320,000	364,200	44,200	416,800	461,000
Rhode Island	19,100	20,900	1,800	23,300	25,100
South Carolina	65,100	78,300	13,200	85,500	98,700
South Dakota	12,600	13,700	1,100	15,400	16,500
Tennessee	85,500	93,900	8,400	106,100	114,500
Texas	498,400	608,200	109,800	644,700	754,500
Utah	33,600	42,100	8,500	45,300	53,800
Vermont	14,400	16,800	2,400	19,100	21,500
Virginia	124,300	147,100	22,800	162,600	185,400
Washington	136,600	173,200	36,600	193,900	230,500
West Virginia	29,300	30,700	1,400	36,000	37,400
Wisconsin	116,100	134,500	18,400	153,800	172,200
Wyoming	6,700	8,300	1,600	9,200	10,800

Source: Argentum analysis of data from the Bureau of Labor Statistics  
 \* In addition to the net job growth in the senior living sector, the industry will need to fill job openings that result when employees permanently leave their occupations, either through exiting the labor force or transferring to a different occupation. These are referred to as 'occupational replacement needs.'







**Total Senior Care Workforce Projections: 2021 to 2040**

State	2021 Jobs	2040 Jobs	Net Job Growth	Occupational Replacement Needs*	Total Employees Needed
Alabama	52,300	58,600	6,300	136,800	143,100
Alaska	6,300	9,900	3,600	20,700	24,300
Arizona	92,800	160,800	68,000	317,400	385,400
Arkansas	46,200	51,600	5,400	122,800	128,200
California	964,300	1,558,400	594,100	3,285,900	3,880,000
Colorado	85,700	136,100	50,400	278,700	329,100
Connecticut	80,400	108,100	27,700	238,100	265,800
Delaware	17,300	27,900	10,600	56,400	67,000
District of Columbia	13,200	16,400	3,200	37,000	40,200
Florida	251,500	360,200	108,700	750,900	859,600
Georgia	95,000	133,500	38,500	281,800	320,300
Hawaii	17,200	24,700	7,500	52,700	60,200
Idaho	28,200	46,800	18,600	93,000	111,600
Illinois	204,100	249,000	44,900	567,600	612,500
Indiana	101,100	119,200	18,100	272,600	290,700
Iowa	57,600	68,900	11,300	157,900	169,200
Kansas	57,000	73,700	16,700	166,600	183,300
Kentucky	56,200	65,000	8,800	151,500	160,300
Louisiana	73,100	91,400	18,300	205,700	224,000
Maine	26,200	33,400	7,200	76,000	83,200
Maryland	82,300	105,000	22,700	232,600	255,300
Massachusetts	179,600	266,100	86,500	566,000	652,500
Michigan	127,700	151,100	23,400	347,700	371,100
Minnesota	144,100	212,100	68,000	451,500	519,500
Mississippi	36,800	44,400	7,600	101,500	109,100
Missouri	128,100	156,700	28,600	363,700	392,300
Montana	14,200	19,300	5,100	42,000	47,100
Nebraska	31,700	39,600	7,900	89,000	96,900
Nevada	28,700	53,200	24,500	102,500	127,000
New Hampshire	19,900	26,500	6,600	58,200	64,800
New Jersey	137,200	183,300	46,100	396,700	442,800
New Mexico	45,700	73,100	27,400	150,000	177,400
New York	591,500	849,700	258,200	1,783,300	2,041,500
North Carolina	132,800	187,500	54,700	396,700	451,400
North Dakota	14,800	17,000	2,200	39,400	41,600
Ohio	212,900	241,300	28,400	560,100	588,500
Oklahoma	47,400	51,200	3,800	121,500	125,300
Oregon	76,700	113,000	36,300	246,900	283,200
Pennsylvania	320,000	422,000	102,000	951,000	1,053,000
Rhode Island	19,100	23,400	4,300	52,200	56,500
South Carolina	65,100	97,000	31,900	202,200	234,100
South Dakota	12,600	15,100	2,500	34,100	36,600
Tennessee	85,500	105,300	19,800	237,600	257,400
Texas	498,400	766,000	267,600	1,537,700	1,805,300
Utah	33,600	55,100	21,500	110,400	131,900
Vermont	14,400	20,100	5,700	44,300	50,000
Virginia	124,300	179,100	54,800	380,700	435,500
Washington	136,600	226,500	89,900	473,900	563,000
West Virginia	29,300	32,500	3,200	78,200	81,400
Wisconsin	116,100	160,000	43,900	355,800	399,700
Wyoming	6,700	10,500	3,800	22,100	25,900

Source: Argentum analysis of data from the Bureau of Labor Statistics  
 \* In addition to the net job growth in the senior living sector, the industry will need to fill job openings that result when employees permanently leave their occupations, either through exiting the labor force or transferring to a different occupation. These are referred to as "occupational replacement needs."





March 8, 2023

The Honorable Bob Casey  
Chair  
Special Committee on Aging  
United States Senate

The Honorable Mike Braun  
Ranking Member  
Special Committee on Aging  
United States Senate

Dear Chair Casey and Ranking Member Braun,

The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy organization committed to improving the lives of women and families by achieving equity for all women. We promote fairness in the workplace, reproductive health and rights, access to quality, affordable health care, and policies that help all people, especially women, meet the dual demands of work and family. Over the last five decades, we have focused specifically on tackling gender-based barriers, often rooted in longstanding stereotypes and biases, used to limit the opportunities available to women, men, gender minorities, and all those deemed to be out of step with assumptions about so-called proper gender norms or roles. We believe that it is essential to prioritize equity – in health care and health care systems, in our economy, in our workplaces – to create environments fully capable of responding to the diverse needs of patients, workers, and indeed all people regardless of their background or resources. Our goal is to create a society that is free, fair and just, where nobody has to experience discrimination, all workplaces are family friendly, and every family has access to quality, affordable health care and real economic security. We thank you for the opportunity to submit a statement on “Uplifting Families, Workers, and Older Adults: Supporting Communities of Care.”

**The Impact of Racial and Gender Inequities on Aging Women and the Direct Care Workforce**

For aging women and their families, a lifetime of gender and racial inequities severely impedes their ability to retire and pay for the care services they need. Overall, women are paid an estimated 77 cents for every dollar paid to a man.<sup>1</sup> This pay gap is especially stark for women of color: Latinx women are paid about 54 cents, Black women are paid about 64 cents, and Native women are paid about 51 cents for every dollar a white, non-Hispanic man was paid in 2021.<sup>2</sup>

Occupational segregation is the biggest driver of these wage gaps.<sup>3</sup> Occupational segregation happens when one demographic is overrepresented in a certain type of

job. These jobs have different wages, benefits and working conditions. Occupational segregation is a direct result of systemic and policy choices driven and informed by sexism, racism, ableism, and other forms of discrimination. As a result, women, and particularly women of color, are more likely to work in devalued roles with lower wages.<sup>4</sup>

Finally, women are more likely to experience economic hardship, including loss of income, when their employer does not offer paid family or medical or paid sick leave.<sup>5</sup> The economic impact is particularly significant for women with lower incomes and women of color.<sup>6</sup> Women may also experience harassment and discrimination upon returning to the workforce. The lack of a national paid family and medical leave or paid sick leave program continues to disproportionately affect women's economic security and career advancement, as well as contributing to the current care crisis. Direct care workers, who are disproportionately women of color, are expected to work *without* the guarantee of making a living wage or proper supports to ensure a safe environment for workers and those in need of care.

The combined effect of these lifelong inequities has devastating effects for the retirement security and care of aging women and their families. To truly support aging women, we must address the problem early on by dismantling the barriers they face at every stage in their lives.

#### **The United States Urgently Needs to Invest in Care Work**

The need for caregiving and caregivers is essential and universal. Every person and family at some point will likely face a caregiving challenge or need caregiving support, whether to care for an ill parent or spouse, bond with a new child, or recover from a personal medical challenge. Yet, our nation has consistently fallen short in adopting the policies necessary to support workers and families when these needs arise. Instead, women have been expected to shoulder the bulk of caregiving responsibilities, stemming in part from longstanding stereotypes and attitudes about women's roles and duties.

When care is treated as a private responsibility, individual women and families are left to fend for themselves and solve care problems on their own. In lower-income families, disproportionately families of color, this often means impossible strains between jobs and family, patchwork systems of care from extended family or neighbors, and deep financial insecurity. Higher income families – more often white – have the resources to outsource their care dilemmas. They often rely on an underpaid care workforce with few job protections and largely comprised of women of color. Without national paid family and medical leave, and without leave policies that include extended and chosen family, this disparity will continue to be a reality.

The United States' ongoing lack of caregiving infrastructure is connected to the devaluation of caregiving and care workers that has been entrenched in our society for decades. Our unwillingness to invest in care is due, in part, to our unwillingness to treat care work as “real work” and to treat care workers as “real workers” deserving of strong protections and supports. This is rooted in a history of racism and sexism harkening back to the nation's earliest days, during which enslaved Black women were forced to work as caregivers for many white families, while being denied any legal right to care for their own loved ones. All of these factors have contributed to the occupational segregation within the direct care workforce.

These systemic failures have led to direct care worker shortages, exacerbated by the COVID-19 pandemic. And voters are taking note: Over one third (35%) of voters nationwide say that after the COVID-19 pandemic, the government has done too little for women, caregivers and those responsible for balancing work and home life.<sup>7</sup> This care crisis has left aging adults without the care they need and deserve to be able to age in place and with dignity. Women in particular have a higher average life expectancy than men,<sup>8</sup> meaning they are more likely to require care as they age.

The Better Care Better Jobs Act and HCBS Access Act would make critical investments in our care workforce. The Better Care Better Jobs Act would increase payment rates for direct workers providing care through Medicaid Home and Community Based Service (HCBS) waivers. The HCBS Access Act would establish grants to recruit and train direct care workers and family caregivers. Investing in HCBS and direct care work is imperative for ensuring we can provide reliable and quality care to aging Americans.

### **Older Adults Have the Right to Age in Their Homes and Communities**

Increasing HCBS funding is vital for aging Americans. While Medicaid covers long term services and supports in institutional settings, it is the HCBS waiver that allows Medicaid recipients to receive supports in their homes and communities. Aging in one's home and community not only improves health outcomes—it is also less expensive.<sup>9</sup> When aging Americans are placed in nursing facilities, family caregivers are often left responsible for hefty bills for a substandard quality of care.

In 2021, 37 states had wait lists for HCBS waivers, with an average wait of 45 months.<sup>10</sup> During the COVID-19 pandemic especially, those living in institutions have been at greater risk of infection and death. In 2020, nursing home and assisted living facilities made up 38 percent of COVID-19 fatalities.<sup>11</sup> Nursing home COVID-19 cases and deaths continue to place more vulnerable residents at risk.<sup>12</sup> The option to age at home and in the community should be guaranteed and readily achievable. Investments in HCBS through the Better Care Better Jobs Act and the HCBS Access Act would make this possible. The HCBS Access Act would establish

HCBS as a mandatory benefit, ensuring the only option for aging Americans is not a nursing facility or institution.

### **Social Security Must Address Lifelong Inequities**

While addressing HCBS and caregiving structures is an important step, there is more that we must do to ensure aging people in the United States can achieve economic security. Over a lifetime, employment inequities and our lack of support for caregivers lead to large gender and racial gaps in retirement savings and other financial assets, as well as other forms of wealth such as housing equity. Common topline statistics such as average retirement savings can be deeply misleading because assets are increasingly concentrated among the wealthiest households and can conceal deep and intersecting inequities related to race, gender and class. The wealthiest ten percent of households – which are nearly 90 percent white – hold more than three-quarters of all wealth in the United States, with a median net worth of more than \$1.9 million. Among the bottom 20 percent, median net worth is just \$9,300.<sup>13</sup> Among households headed by mid-career and older workers, between the ages of 39 and 54, half have less than \$32,000 in financial assets. Among Black households, half hold less than about \$9,000; among Hispanic households, half hold less than \$4,600.<sup>14</sup> Forty-two percent of households headed by someone between the ages of 45 and 54 do not even have a retirement account.<sup>15</sup>

Social Security remains the foundation of retirement security for these and all workers. But the structure of Social Security retirement benefits also echoes inequities that women and workers of color experience in their working years. Gender and racial wage gaps mean that these workers tend to receive lower Social Security benefits, and time spent out of the workforce for caregiving undermines the ability of many workers, especially women, to earn credits toward retirement. And the growing problem of worker misclassification, including the advent of platform-based employment in driving, delivery and even health care, threatens to leave many workers – again, disproportionately workers of color<sup>16</sup> – outside the protection of this bedrock system.

### **Conclusion**

A national paid family and medical leave program, increased funding in HCBS, investments in higher wages and improved working conditions for caregivers, and reforms to how Social Security retirement benefits are calculated are critical for the economic and physical health and well-being of aging Americans and their loved ones.

- Enacting a comprehensive national paid family and medical leave program will improve gender and racial equity in caregiving and in workplaces, and

will support the health and caregiving needs of all working people across their lifespans – including older women workers who are family caregivers.

- Adequate funding for home- and community-based services will improve care quality and support dignity and self-determination for older adults and people with disabilities, as well as improving job quality for our largely female care workforce and reducing costs for families.
- Redefining the number of years of work to include caregiving will allow for credits to be accumulated for Social Security retirement while acting as a caregiver for aging family members.

The National Partnership for Women & Families will continue to be on the forefront as a leader in supporting policies that benefit and empower aging and disabled people—in particular, aging and disabled women of color—along with their families and direct care workers.

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<sup>1</sup> National Partnership for Women & Families. (2022, October). *America's Women and the Wage Gap*. Retrieved 8 March 2023, from <https://www.nationalpartnership.org/our-work/resources/economic-justice/fair-pay/americas-women-and-the-wage-gap.pdf>.

<sup>2</sup> National Partnership for Women & Families. (2022, October). *Quantifying America's Gender Wage Gap by*

*Race/Ethnicity*. Retrieved 8 March 2023, from <https://www.nationalpartnership.org/our-work/resources/economic-justice/fair-pay/quantifying-americas-gender-wage-gap.pdf>.

<sup>3</sup> Blau, F. D., & Kahn, L. M. (2017). *The Gender Wage Gap: Extent, Trends, and Explanations*. *Journal of Economic Literature*, 55(3), 789-865. doi: 10.1257/jel.20160995. Retrieved 8 March 2023, from <https://www.aeaweb.org/articles?id=10.1257/jel.20160995>.

<sup>4</sup> U. S. Department of Labor. (2022, March). *Bearing the Cost: How Overrepresentation in Undervalued Jobs Disadvantaged Women During the Pandemic*. Retrieved 6 March 2023, from <https://www.dol.gov/sites/dolgov/files/AWB/media/BearingTheCostReport.pdf>; Hegeswich, A., & Mefford, E. (2021, March). *The Gender Wage Gap by Occupation, Race, and Ethnicity 2020*. Retrieved 6 March, 2023 from Institute for Women's Policy Research website: <https://iwpr.org/iwpr-issues/esme/the-gender-wage-gap-by-occupation-race-and-ethnicity-2020>.

<sup>5</sup> Richards, Mikhaila. (2022, November 16). *Fewer than Half of Employed Women Say Their Employer Offers a Paid Parental Leave or Family and Medical Leave Benefit*, Kaiser Family Foundation. Retrieved 8 March 2023, from <https://www.kff.org/womens-health-policy/press-release/fewer-than-half-of-employed-women-say-their-employer-offers-a-paid-parental-leave-or-family-and-medical-leave-benefit/>.

<sup>6</sup> Ibid.; Frye, Jocelyn et al. (2022, March 4). *Black Women Need Access to Paid Family and Medical Leave*, Center for American Progress. Retrieved 8 March 2023, from <https://www.americanprogress.org/article/black-women-need-access-to-paid-family-and-medical-leave/>.

<sup>7</sup> Lake Research Partners. (2022, November). *Election Omnibus Survey*. Unpublished.

<sup>8</sup> National Center for Health Statistics, Centers for Disease Control & Prevention. (2022, August 31). *Life Expectancy in the U.S. Dropped for the Second Year in a Row in 2021*. Retrieved 8 March 2023, from [https://www.cdc.gov/nchs/pressroom/nchs\\_press\\_releases/2022/20220831.htm](https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220831.htm).

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- <sup>9</sup> Caldwell, Joseph. (2022, March). *Reducing Costs for Families and States by Increasing Access to Home and Community-Based Services 2*. Retrieved 8 March 2023, from <https://heller.brandeis.edu/community-living-policy/images/reducing-cost-hcbs.pdf>; Reaves, Erica L. et al. (2015, December 15). *Medicaid and Long-Term Services and Supports: A Primer*. Kaiser Family Foundation. Retrieved 8 March 2023, from <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer>.
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- <sup>16</sup> Anderson, Monica Anderson et al., (2021, December 8). *The State of Gig Work in 2021*, Pew Research Center. Retrieved 8 March 2023, from <https://www.pewresearch.org/internet/2021/12/08/the-state-of-gig-work-in-2021/>.



March 15, 2023

The Honorable Bob Casey  
 Chairman  
 Special Committee on Aging  
 U.S. Senate  
 G31 Dirksen Senate Office Building  
 Washington, DC 20510

The Honorable Mike Braun  
 Ranking Member  
 Special Committee on Aging  
 U.S. Senate  
 G31 Dirksen Senate Office Building  
 Washington, DC 20510

Dear Chairman Casey and Ranking Member Braun:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, appreciates the opportunity to submit a written statement for the hearing on “Uplifting Families, Workers, and Older Adults: Supporting Communities of Care.”

Families in search of long-term care services, including care at home, now enter a world that is confusing, costly, under-regulated, and lacking in transparency. Too often, those families feel forced into institutional settings, while individuals who end up in nursing homes often yearn to stay in their homes near family and friends. Finding care at home is extremely challenging: families often must desperately cobble together a patchwork of care and services they need. This system is failing American families and it is failing American taxpayers.

The problems we are seeing today are only the tip of the iceberg. These challenges only get worse as our population ages. Long-term care is a growing and critical need that can define the quality of life for any one of us and will be increasingly sought after in the coming years.

We must provide greater support for family caregivers who are often the first line of assistance for their loved ones, make important investments and policy changes to give more people more affordable options to get care at home, and secure a strong, sufficient, and stable 21<sup>st</sup> century paid workforce to assist older adults and people with disabilities. We need solutions that meet people where they are and meet the everyday needs of individuals and families nationwide.

#### **Supporting Family Caregivers**

Family caregivers providing care to loved ones are the backbone of the long-term care system in this country. They help make it possible for older adults, people with disabilities, and veterans to live independently in their homes and communities. These caregivers are of all ages, races, and ethnicities and cut across all segments of our population. They perform physically, emotionally, and financially challenging work, often without pay. A [new AARP report](#) finds that millions of family caregivers are providing a staggering, estimated \$600 billion annually in unpaid care to their loved ones, more than all out-of-pocket spending on health care in the U.S. in 2021. In



addition, a 2021 AARP [report](#) found that family caregivers are spending, on average, 26 percent of their income on caregiving expenses, or \$7,242 annually. If families were not shouldering these caregiving responsibilities, taxpayers would be on the hook for much more costly nursing home care and unnecessary hospital stays. Six in ten family caregivers also work full- and part-time jobs.

A growing number of family caregivers – [nearly 60 percent](#) -- are also increasingly performing complex medical/nursing tasks that nurses normally perform, such as wound care, injections, tube feedings, medication management, and many other complex care tasks. This is in addition to assisting with daily activities such as eating, bathing, dressing, meal preparation, finding and coordinating care, transportation to medical and other appointments, supporting their loved one through care transitions such as from hospital to home, managing finances, and so much more.

There is a significant cost to caregiving – opportunity, financial, health, and well-being. Family caregivers bear it all. The demands on family caregivers are not just a family issue and family caregivers need support. That is why supporting family caregivers is a top priority for AARP. In September, 2022, the Department of Health and Human Services released the [2022 National Strategy to Support Family Caregivers](#), as required under the RAISE Family Caregivers Act (P.L. 115-119), championed by AARP. It includes about 500 actions to support family caregivers, including nearly 350 actions federal agencies have committed to taking over the next few years and over 150 actions that states, communities, and other stakeholders can take, as well as policy changes requiring legislation. AARP is focused on turning this National Strategy into action that provides meaningful, tangible outcomes and support for our nation's family caregivers.

AARP is focusing our attention on these family caregiver priorities and we urge Congress to:

- Make providing care easier, including through expansion of resource navigation tools, examination of policy changes to improve the navigability of resources, caregiver training, education, and inclusion in care, as well as through increased access to paid care at home and other supports.
- Alleviate the financial and other challenges faced by many family caregivers that can undermine their own well-being, including better access to respite care, paid leave, and financial relief such as through family caregiver tax credits, like the bipartisan Credit for Caring Act, and reimbursement programs.
- Improve the health and well-being of family caregivers, many of whom have seen their own personal situations worsen, including through family caregiver needs assessments to help target and tailor needed supports to family caregivers efficiently and effectively.

Congress has the opportunity to make a real difference in supporting family caregivers and showing them they are valued. This issue has enormous relevance to voters everywhere.

**Home Care**

After a lifetime of hard work and contributing to our society, America's seniors deserve to live with independence, security, and dignity. AARP supports older adults having high-quality, affordable options when it comes to long-term care—especially care at home. In a [2021 AARP survey](#), three-fourths of adults age 50-plus told us they wish to remain in their current homes and communities for as long as possible.

Older adults need more options for getting care at home. It is past time for Congress to put home care (home and community-based services (HCBS)) on a level playing field with nursing homes or institutional care in Medicaid. Congress should increase access to, options, and eligibility for care at home, including by providing permanent financial protections for the spouses of individuals receiving Medicaid HCBS, making permanent the Money Follows the Person Demonstration that helps individuals move from nursing homes to the community, eliminating or reducing waiting lists, expanding presumptive eligibility, incentivizing HCBS expansion, and more. Care at home is also generally more cost-effective. On average, Medicaid can serve about three people in their homes and communities for the cost of one person in a nursing home.

Investing in home care will help get individuals the services and supports they need, where, when, and how they need them. Providing necessary home care can also reduce the challenges facing some family caregivers and enable them to return to the paid workforce and improve their financial security. We note there is great variation in Medicaid across and even within states in terms of eligibility, benefits, and access.

We must also ensure that individuals and families who do not rely on Medicaid can access the supports and services they need to live and get care at home. We need to make home care options more affordable—and available—so nursing homes are not seniors' only choice.

**Paid Direct Care Workforce**

Direct care workers provide the bulk of paid long-term care. These workers hold a variety of job titles, including personal care assistants, home care aides, and certified nursing assistants (CNAs). They work in diverse settings, including private homes, adult day centers, nursing homes, assisted living residences, and other residential care settings. Older adults and people with disabilities rely on the vital support provided by this workforce to enable them to live in their homes and assist with tasks such as eating, bathing, and dressing.

We need more direct care workers, as there is already a real shortage that will only grow as the population ages. When family caregivers are unavailable or are providing all the care they can, a shortage of skilled workers makes life difficult for individuals and families searching for quality care, and there is a strong need to develop an adequate workforce to care for older adults and provide long-term care. Direct care workers play a critical role in the success of states' long-term care systems, but low wages, few benefits, poor working conditions, and few advancement opportunities have led to dangerous staffing shortages. Many workers are forced to work

multiple jobs in multiple homes or facilities just to make ends meet. Unfortunately, many of these direct care workers also lack basic benefits such as paid sick or family leave.

The workforce challenges in long-term care are a serious threat to the lives and safety of older Americans who receive that care. AARP encourages Congress to take action to help attract and retain direct care workers through increased pay and benefits, paid leave, improved training, career pathways, and other job improvement initiatives. Investing in Medicaid home care would also support the workforce that provides these critical services. We also appreciate the Administration's commitment to establishing minimum staffing standards – a key component of quality care -- in our nation's nursing homes that participate in Medicare and Medicaid.

AARP urges Congress to support family caregivers, give people more options for care at home, and address direct care workforce development and retention. Both family caregivers and direct care workers are critical members of individuals' care teams. AARP looks forward to working with you and the Administration to address these important issues. If you have any questions, please feel free to contact me at [r-richards@aarp.org](mailto:r-richards@aarp.org).

Sincerely,

A handwritten signature in blue ink that reads "Rhonda Richards". The signature is fluid and cursive, with the first name being more prominent.

Rhonda Richards  
Government Affairs Director  
Government Affairs

**Testimony for the Record to the Senate Special Committee on Aging**  
**“Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”**  
**March 9, 2023**

**Suzanne Ott, Home Care Worker**  
**SEIU Healthcare Pennsylvania, Venango County, PA**

My name is Suzanne Ott and I am a caregiver in Venango County, Pennsylvania. I am also a member of my union, SEIU Healthcare Pennsylvania.

I take care of my children's father, Andre Dixon, who had a stroke on Oct. 18, 2018. After his stroke, he went to the hospital, and then to a nursing home for rehab. Our family wanted him to eventually come back home, so I volunteered to be his caregiver.

Since Andre's stroke, he can't speak as well as he used to, he can't walk, and he has trouble with his vision, among other health issues. I help Andre bathe, get dressed, go to the bathroom, empty his urinal, brush his teeth, cut his hair, cook and serve his food, and more. I make sure he's sitting up so he won't choke. I'm careful that he's eating healthy foods, because he is at high risk for pre-diabetes. I also give him his medicine, make sure he uses his CPAP machine, keep up with all his appointments, take him to doctors appointments, advocate to his doctors for him the best I can, and counsel him through hard times. I teach him speech and I teach him balance, trying to get him to take a step or two and do basic tasks that we all take for granted.

In other words, throughout one day I'm a nurse, a cook, a barber, a physical therapist, a speech therapist, and the list goes on. Home care workers need to be prepared for anything, which means we need special training and expertise, just like any other healthcare worker. Because we are so isolated in our workplaces — unlike hospitals or nursing homes, where help is a call button away — it's on us alone to manage all day-to-day tasks, as well as any unexpected issues or emergencies. It's a lot of pressure for one person, but we know it's just part of the job.

However, home care workers very quickly become burned out, physically and mentally. But while we care for others, we often don't have the resources to care for ourselves. Forty-three percent of home care workers are below 200 percent of the poverty level and 53 percent rely on some form of public assistance.<sup>1</sup> How is this okay? We need to be our best selves possible for our clients, but without affordable healthcare, paid time off, or other benefits we cannot stay healthy and well rested. Many of us keep going to work when we're sick, injured or exhausted — because taking time off means missing a day's pay, or going to the doctor means we'll be getting a bill we can't possibly afford.

Our children are also a big part of our lives. Andre and I share two children— Andrea, who is six, and Suzanne, who is three. My oldest daughter, Jayonaa, is 16 and was born with sickle cell

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<sup>1</sup> PHI. (2022). "Direct Care Workers in the United States: Key Facts." Retrieved from: <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

disease. There are many times when Andre and I have to pack up and travel over an hour to Pittsburgh to go to the hospital with Jayonna. Our two youngest stay in a crisis center on those nights. These trips impact his care in many ways. We sleep on pullout couches in the hospital and he's not able to use his CPAP machine. Also, because the hospital is so short staffed, I have to do a lot of Jayonna's care as well, which cuts into the care I can give Andre. It's a lot, but we make it work because it's so important to us to keep our family together.

Our case worker just put in a request for home modification so that our house can be more accessible for Andre. We rent from family, and there's a big lack of accessible housing in our county. Currently, his wheelchair is so wide that it can't fit through any of our doors. All of our bedrooms are upstairs, so he has to crawl on his hands and knees, just to go into his room while I stand behind him to help prevent him from falling. There are six stairs, then a curve, then another six stairs, and he does that all on his hands and knees. He always takes a three minute break once he does the first six at the curve. When he makes it up the stairs, he's breathing hard and heavy so he has to take another break for five minutes before crawling six feet into his room. If he ever falls, he has to immediately go to the ER and get tests. Our goal is to never let him fall so I'm right beside him whenever he moves from one place to another.

He crawls so much on his hands and knees that he has hard spots all over his knees that filled with water. They're painful so now he uses knee pads, though those get uncomfortable eventually and he ends up going back to crawling on his bruised knees.

How is this any way for a person to live?

Six months ago, Andre was going to therapy for walking. But when his blood pressure went up, he was taken out of PT because they didn't want him to have another stroke with this increased physical demand. He also had a severe sleep disorder which resulted in him getting a CPAP machine.

I share this with the Committee because it's so important that you know all of the issues that caregivers are dealing with on a daily basis. When I first started this job two years ago I didn't have any training. I didn't know anything about caregiving; all I knew was I wanted to keep my family together and I was pregnant. I knew that my children deserve to have their father in their lives. When Andre first had his stroke, I visited him in his nursing home and I learned from his nurse how to feed him (he couldn't swallow well), dress him, and do occupational therapy with him. Most caregivers don't have a chance to learn from other healthcare professionals like I did, and instead they have to figure it out on the job.

The good news is that my union, SEIU Healthcare Pennsylvania, has been fighting for paid training programs for PA homecare workers, and just won the first we've ever had here. As of last month, caregivers can get trained on CPR, dementia care, mental health, first aid, body systems, and more.

I am very grateful for the opportunity to do the work that I do, but there are so many things that make it really difficult to live as a full time caregiver. First and foremost, we caregivers aren't paid enough. I am only paid \$12.69 an hour, and get paid for 49 hours when I actually work over 60 hours each week, and that is common for many caregivers in this field. We work seven days a week, and go over our allotted hours because we care about our clients. We don't get any paid holidays, breaks, sick time or overtime. Because I live with my client I am on call 24/7. It never stops.

Home care workers don't get healthcare benefits with the job, so I get my insurance through Medicaid. Being paid so little, there is no money left for childcare. This means I need to care for Andre and our two young children, all of whom are completely dependent on me. It's extremely difficult to hold a baby and maneuver a wheelchair, so I had to teach Andre how to hold the baby in his condition so I can move all of us around.

We've tried to find another caregiver so that I can have backup when I can't be home, but we haven't found anyone yet. A lot of people come over to meet us and learn about the work, but are intimidated by how much care Andre needs and won't do it for such a low wage. And so I keep doing it all, even though it's more than one person can really handle.

Home care is the backbone of the healthcare field. When a person leaves a hospital or clinic, and they return home, they'll likely still need care — especially after a health emergency like a stroke, like Andre. Home care workers are there to continue their care plan. We are an essential part of the recovery process, and we allow our clients to live full lives.

Everyone deserves to be treated with dignity and respect, and everyone deserves care. That is why I decided to join my union – United Home care Workers of Pennsylvania, SEIU Healthcare PA. We caregivers deserve a seat at the table, and there are so many of us that together we can make these changes. I am a union activist because I want change. Since we formed our union in PA a few years ago, we've won two pay raises, COVID bonuses, and a paid training program. None of this was happening before caregivers spoke up to change things.

We need the federal funding so that we can expand home- and community-based services and improve care jobs, including higher pay and basic benefits like healthcare insurance. If this happens, then sky's the limit to what we can do to expand home care for those who need it.



Mosaic National Supports | 402.896.3884 | 877.366.7242 | mosaicinfo.org

4980 South 118th Street, Omaha, NE 68137

**U.S. SENATE SPECIAL COMMITTEE ON AGING**

*UPLIFTING FAMILIES, WORKERS, AND OLDER ADULTS: SUPPORTING COMMUNITIES OF CARE*

*HEARING TESTIMONY  
Thursday, March 9, 2023*

Dear Chair Casey and Ranking Member Braun:

Thank you for the opportunity to provide testimony regarding the current crisis impacting home and community based services.

Mosaic is a nonprofit healthcare organization serving nearly 5,000 people across 13 states in more than 700 communities. We help empower people with disabilities, mental and behavioral health needs and autism, as well as aging adults to live their best life. We primarily serve people in home and community services. Mosaic is funded primarily by Medicaid which is approximately 97% of our funding.

As the President and Chief Executive Officer of Mosaic, the Direct Support Professional (DSP) workforce crisis is real. In my nearly 37 years at Mosaic, we have not experienced turnover and concerns about consistent quality of services than we are now. We traditionally have had a 45% turnover and now we are experiencing turnover of over 70%. Additionally, with the high turnover and lack of continuity of care, this impacts quality of service. We struggle, just as similar Medicaid funded programs, with recruiting and retaining our DSPs. For example:

- Thanks to the one-time pandemic relief funding of the PPP loans, we increased our DSP wages by nearly 25%. Yet, we are experiencing a DSP vacancy rate across the network that is averaging 20% - 24%. Unfortunately, the additional funding is not applicable to administrative costs and has created a wage compression between DSPs and Supervisors.
- We have expanded the scope of how we recruit for DSPs through engaging with new vendors and technology (i.e. DSP applicants can submit an application and schedule an interview within 3 minutes) along with an enhanced presence on social media platforms.
- We have provided sign-on bonuses and additional pay for hard to fill shifts, in addition to offering enhanced scheduling options to promote better balance for the DSP (i.e. 3 – 10 hour shifts or 3 – 12 hour shifts) and that helps but bottom line, we are working very, very hard to find staff that are willing to work as a DSP in both rural and urban locations.
- We have been forced to exit services in one state (Texas) because wages were so low we could not attract staff - the Medicaid rates were rarely increased and in urban areas, like Dallas and San Antonio, it was impossible to recruit DSPs for what was in late 2019 an \$8.50 hour wage.
- We have been faced with significant program issues making tough decisions like stopping day program services for people who do not receive residential services because we did not have the staff.
- In some states, where we provide intermittent in-home services people do not receive the services they are eligible for because Mosaic, like other providers, does not have staff to cover the hours.

And it's still not enough.

We are grateful for the America Rescue Plan Act (ARPA) which provided much needed additional funding to states, yet with the expiration of this funding and the unwinding of the public health emergency, critical federal aid that has been a lifeline for states will be dissolving soon, and we are still in a crisis.

Given Mosaic's primary funding source as Medicaid, it has been over 20 years since a major investment has occurred in this system. As you can imagine, the lack of an investment over the years is resulting in our system becoming archaic. For example:

- Medicaid reimbursement rates are not current with inflation. We need a major investment to increase rates and then a system to link rate reimbursements to cost of living adjustments.
- Accessing services is complex and confusing. We need a streamlined system where access to Home and Community Based Services (HCBS) and eligibility for services is clear and uniform amongst states.
- Need a better system that helps prevent market disparity.
- Thresholds for people supported with Medicaid need to increase so that people do not have to choose between community employment and being able to have support for healthcare appointments and grocery shopping.
- Need to eliminate institutional bias so that states will offer HCBS services as a permanent support versus listed as an optional service for Medicaid recipients.

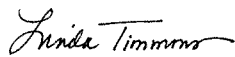
As we look to the future of services, the above recommendations to the Medicaid system are in addition to a much-needed investment in our DSP workforce. Additionally, we need more flexible service delivery models that are personalized, such as self-directed and paid family caregiver. Through exploring personalized services, it will help alleviate the DSP workforce crisis, increase continuity and consistency of care and decrease safety concerns. It will also assist with positively impacting the waitlist for services for people with intellectual and developmental disabilities (IDD). For example:

- Mosaic's data for personal outcomes demonstrates that a shared living model and supported living have the highest outcomes for people such as, understanding their rights, feeling safe, free from abuse and neglect, continuity of care.
  - People with challenging behaviors was 87% lower when organizations provided each person with continuous and consistent services.
  - The number of emergency department visits for people was 90% lower when people participated in the life of the community.
  - The number of injuries for people was 60% higher when people had direct support staff turnover within 2 years.

Thank you for the Committee's review and consideration of investments which would positively impact our workforce challenges and the Medicaid system as a whole.

I am available to answer any questions the Committee may have.

Sincerely,



Linda Timmons  
President and Chief Executive Officer  
Mosaic





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Hartford, CT 06112  
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***Testimony Submitted to the U.S. Senate Special Committee on Aging:***

**HEARING TESTIMONY**

**Submitted By: Barry M. Simon, President & CEO**

**Thursday, March 9, 2023**

Dear Chair Casey and Ranking Member Braun:

My name is Barry Simon, and I am the President and CEO of Oak Hill and Easterseals of Oak Hill located in Connecticut. I appreciate the opportunity to provide testimony on the importance of the Medicaid Home and Community Based Services (HCBS) program and the crisis among the direct support workforce.

Founded more than 130 years ago, Oak Hill is a leader in providing the highest quality community-based programs through over 20 distinct programs and 152 program sites, classrooms, and homes located in 73 towns throughout Connecticut. Oak Hill normally employs over 1,700 (1,500 with current vacancies) professionals to successfully help meet the changing needs of close to 30,000 people with disabilities each year. We are among the 300+ member agencies of the Connecticut Alliance, the voice of Community Nonprofits, and a proud member of our national trade association ANCOR. I am submitting this testimony on behalf of those we serve, our incredible staff (a large part of which are SEIU-1199 union members) and hundreds of thousands of individuals served by the community provider system. As an agency we are funded by the Connecticut Department of Developmental Services, Department of Social Services, Department of Mental Health and Addiction Services, Department of Children and Families, the Department of Education, and several other state Agencies. Medicare & Medicaid long term services and supports are our primary specialty healthcare service along with special education. Our mission is to partner with people with disabilities, to provide services and solutions promoting independence, education, health, and dignity.

I want to share with you, as Connecticut's largest provider of services for people with disabilities, it is very difficult to do business given the long-standing underfunding of rates for the services we provide in CT. It is hard to offer fair and equitable pay and benefits, and it is hard to accept people into services that are stuck on wait lists (while we have vacant beds, 6 empty homes and 40 children on our referral list) due to the staffing crisis.

As you know, we have been ravaged by COVID-19, and even while our employees have gone above and beyond, we facing unprecedented challenges recruiting and retaining staff of all skill levels and salaries. The issues created stagnant reimbursement rates, including going 17 years of no rate increases for administrative and general costs for things such as gas, oil, electricity, business insurances, human resources requirements, facilities maintenance, Electronic Health Records, etc., has continued to exacerbate our challenges to run our agencies. The CT Governor's budget proposes two more years of zero increases to our rates, how is this just,

***Our Mission: Oak Hill sets the standard, partnering with people with disabilities, to provide services and solutions promoting independence, education, health and dignity.***

The Connecticut Institute for the Blind, Inc. (dba Oak Hill) is a 501(c)(3) not-for-profit corporation

equitable, or inclusive for our employees and how could this possibly be seen as acceptable to help promote access to services for the people we serve?

Please remember, we are not able to raise taxes or raise our rates to cover costs; we are rate takers. Our staff, homes, and equipment are tired. We do not expect hospitals to give inadequate raises to staff and ask them to do procedures with 17-year-old equipment. Yet our critical services continue to be under-resourced and overlooked. Doing more with less, we have been doing that, and it is not a sustainable option. I am asking that you pass legislation to fund us appropriately. The reality of equality and change is in your hands. In the political process you often ask for our votes; in this process we are asking for your vote to make equality and inclusion for our staff and clients we serve an imperative in the budget process and not evade the long-term issue at hand.

I am grateful to the leadership from Chair Casey on legislation to strengthen and expand the Medicaid HCBS program. I also urge support for the creation of a standard occupational classification for direct support professionals. The creation of a discrete classification for direct support professionals will create a mechanism for collecting consistent national data on the direct support workforce and help in stabilizing wages for direct support professionals.

Without additional investments in the Medicaid Home and Community Based Services (HCBS) program, providers like Oak Hill will be forced to turn away even more individuals seeking services and close programs. Congress has the ability to take the initiative to begin to stabilize our workforce and in turn, deliver on the access and inclusion promises of the Americans with Disabilities Act.

I thank you for today's hearing and elevating the importance of addressing the ongoing workforce crisis. We urge you to support legislation to strengthen and expand the Medicaid HCBS program. If you have questions or would like to discuss further, please feel free to contact me.

Sincerely,

A handwritten signature in blue ink, appearing to be "B. Casey", is written over a light blue rectangular background.

**Uplifting Families, Workers, and Older Adults: Supporting Communities of Care**

March 9, 2023

Senator Case, Chairman of the Special Committee on Aging, and committee members.

I would like to begin by thanking you for precious time to discuss the importance of uplifting families, workers, and older adults and for your efforts to strengthen home and community-based services.

My name is Tatia Cooper, I am President and CEO of Home Care Associates (HCA) of Philadelphia, A Worker Owned Company. In 1993, HCA was established in Philadelphia, Pennsylvania as a replication project of a larger worker-owned Home Care Agency, located in the Bronx, NY. As a worker-owned company, HCA recognizes the connection between quality jobs and quality care. Ownership not only provides caregivers an opportunity to gain from a financially stable company but also allows workers to have a voice in how decisions are made. Ultimately, HCA believes when Direct Care Workers feel valued, are heard, and recognized for their contributions to the industry, earn a living wage, are appropriately trained, have opportunities for growth, and feel they are a legitimate part of the healthcare team; care delivery and is positively impacted.

HCA' consumers often share how critical their Direct Care Workers are to their ability to remain safely at home, maintaining independence and accessing supportive services. At the height of the COVID-19 pandemic and post covid, we heard a great deal of concern, from our consumers, regarding the use of technology their inability to access social supports. We received an extraordinary number of requests for technical assistance from Direct Care Workers. Although telehealth served to fill gaps in the system at the onset of and post COVID, Consumers often lacked the technology and knowledge to virtually attend doctors' appointments and access other community services. ARPA funds

provided the resources needed to purchase devices that would enable our workers to assist consumers in understanding and navigating telehealth, as well as the ability to access additional services and supports. By training our employees on the use and benefits of technology to support in-home care, we were able to transfer that knowledge to our consumers, relieving them of the stress and anxiety associated with navigating health care systems post COVID. Without these funds, HCA would not have been able to address the concerns we heard.

At its inception, HCA committed to providing quality, skilled, training that continues to exceed state requirements. HCA training curriculum includes but is not limited to topics such as Diversity and Inclusion, Problem Solving, accessing community resources, Effective Communication, Understanding the health care team, Diseases of the Elderly, Behavioral and Cognitive Health, Physical Disabilities, Nutrition, Aging and Accident and illness prevention.

Prior to the COVID-19 Pandemic, we began to see a decrease in interested candidates wishing to work as Direct Care Workers. We believe much of the decrease is related to low wages and a lack of training and formal certification. Since the onset of COVID-19, recruitment and retention has suffered. Attaining, retaining, and paying workers to train and employ has just about come to a complete stop. To pay a living wage, in 2018, the city of Philadelphia signed a law requiring an increase in minimum wage to \$15.00 per hour. This law impacts city workers, contractors, and subcontractors. Effective January 31, 2022, although the state minimum wage remains at \$7.25, PA. state employees earn a minimum of \$15.00 per hour. These changes, that do not positively impact our workers, sends a strong message, and discourages growth in the industry. Most of the clients we serve are Medicaid and/or Medicare eligible. We rely on reimbursement from the State to cover all cost associated with providing care including wages, benefits, purchasing PPE, training, software, hardware, cost of maintaining credentials, cost of licensing, and the cost of compliance such as software and staff needed to comply with state and federal mandates like Electronic Visit Verification.

HCA is reimbursed an average of \$19.92 per hour. Although we fully support paying a living wage, it is just not impossible for us. As demand for our services increases, retention and recruitment suffer. Wait list for services are getting longer as consumer are at increased risk for injury and accidents. There is not one quality Home Care Provider who would disagree. The need is urgent. Short term and long-term support are critical to providing quality care and meeting the demand. Workers must receive hazard pay and incentives for remaining in the field. A more robust training increases quality and formal certification creates standards of professionalism. Paying a living wage helps to break the cycle of poverty by ensuring that our workers can provide for their own families. The stress and anxiety associated with not being able to feed your own children, pay your rent/mortgage, and/or keeping the lights on is exaggerated when your job is to care for others who are also poor and struggling. Our workers think of their consumers as family. Many of our workers will tell you that in addition to providing for themselves, on at least one occasion, they felt the need to purchase food or household supplies for their consumers as well.

At the height of the pandemic, one of our workers shared concern about the potential spread of COVID-19 in consumers homes. She stated that her consumer could not afford cleaning products to properly sanitize her home. At the time finding a can of Lysol or other sanitizing products was impossible. When you could find products, the cost was multiplied numerous times. As an agency, we were concerned about our ability to afford and provide PPE for our workers, while our workers were concerned about PPE for their consumers. One worker asked if we could create a universal precaution solution to leave in our consumers homes. This would provide relief to consumers and reduce stress and anxiety for our workers. HCA purchased water, bleach, alcohol, and aloe. Approx 20 of our staff came together every Saturday to create a universal cleaning solution and hand sanitizer. We distributed the spray bottles with cleaning solution and sanitizer to all our employees. We instructed them to teach consumers how to use the products and requested they leave products in each of their consumer's home. The positive responses we received from consumers was overwhelming and provided us with a great deal of motivation to continue our work.

Recently I spoke with a worker who has been employed with us for more than 15 years. He stated that he sincerely loved the company and appreciated the training but didn't think he could afford to continue working in the industry. There was nothing I could say to him, I understood. I explained that although we are fighting for increased wages our hands are tied. I asked him to hang in there, to please give us more time. Burnout among workers is high. Because of recruitment struggles, overtime is high and costly. Workers are tired and feeling unappreciated. Deterred from the work they love. Low wages, high risks, feeling ignored, neglected and unappreciated all contribute to the decrease in workforce.

Direct Care Workers are needed just as other members of the care delivery team are needed, Nurses, Doctors, Physical Therapist, Dieticians, etc.

Instead of encouraging employees to leave the industry in pursuit of higher paying jobs, Career ladders within the Direct Care Worker field are necessary. Behavioral, cognitive, disability, and disease management are all areas Direct Care Workers can work as part of the team to reduce illness and prevent hospitalizations and readmittances. Supporting and investing in communities of care, including workers, families and older adults is long overdue. HCA fully supports The Better Jobs Better Care Act. Without support to promote recruitment and retention of Direct Care Workers, increased wages, and opportunities to develop skills and access training; waitlist for services will get longer and longer, consumers will be forced into long term care facilities, we will see increased hospitalizations, injuries and accidents.

Ms. Yvette Beatty  
5818 Cedarhurst Street  
Philadelphia, PA. 19143

March 2, 2023

The Honorable Bob Casey.  
United States Senate. Washington, DC 20510.

Dear Senator Casey:

My name is Yvette Beatty and I reside in Philadelphia, Pa. I am currently employed with Home Care Associates, a worker owned home care company located in Philadelphia. I have worked at Home Care Associates for more than 28 years and am a worker-owner and member of the Board of Directors.

I am writing you to submit my statement for the record regarding my experience as a home care worker. My experience as a home care worker has been both rewarding and challenging at the same time.

My experience caring for others began at age 10. I helped a couple in my neighborhood, who were both legally blind. For about a quarter a day, I would run to the store, help carry bags, and help them at home. They wanted their independence, and that was special to me. Even though they were blind, remaining independent was important to them and I really admired that. As a young adult, I volunteered at a hospital as a candy striper and won candy striper of the year. I was very proud of the work I contributed. I also had different jobs caring for people in their homes and was almost always paid under the table. Later, I went to school to become a nursing assistant and was hired to work with children with disabilities. I did that for five years, until the organization closed. Following that, I had my first child. I needed to make money to provide for my family but struggled to find work. I was told that either I didn't have enough experience, education or was just not a fit. I had to rely on welfare, but I knew I didn't want this permanently for myself and my children's life.

A neighbor told me about Home Care Associates (HCA), a worker owned home care agency. I walked in one day; they interviewed me on the spot and hired me the same day. I needed to complete the required Home Health Aide training course prior to providing care. The training provided a lot more than I expected, I learned a lot and was treated like a professional. Me, a single mom on welfare, they didn't shut the door on me. They gave me training and gave me a voice, I felt like I mattered. Today, I am a home health aide, worker owner, mentor, policy

action group member and community Ambassador. When I applied for other jobs, free or paid training wasn't offered. I believe all direct care workers should be trained. I have family members who are battling cancer and have caregivers who were hired without proper training or no training at all.

In my opinion, Home Health Aides deserve better pay. Although our jobs may not look like other professional health care workers. The work we do is extremely important, we are professionals. We are all on the same team. Home Care Workers are the frontline workers, preventing accidents, repeat visits to hospitals, and we work to keep people safe and independent at home. I feel we are forgotten and continue to be let down. We do this job from the heart, with love, compassion, and skill. But there is little appreciation and recognition for the work we do. Most of us struggle to provide for our own families, we are the working poor. We deserve better: to be paid a living wage and recognized for the important work we do and positive contributions we make to the healthcare industry. Many of us are living paycheck to paycheck. While going to work every day to care for others, I struggle to care for myself. I can barely keep food on my table, pay for my own medications and my medical care co-pays. I am not able to afford healthy foods to properly care for myself and my family. At times, I have fallen behind on my housing expenses and have had to borrow money to make ends meet.

I also worry about continuing to work through this coronavirus. I cared for my patients at the peak of the pandemic, this just added stress to my existing stressful life. I just cannot abandon my clients. If we are not there to take care of them, they lose their independence, desire to age at home and are more likely to get sicker. During the virus, my company provided supplies but struggled to find them. When I would see a box of masks, I'm buying it. Even though that \$5 I spent could make a difference in feeding my family or paying my bills. I continue to struggle today.

When I leave my home to work as a home care worker, it is like a battlefield. I go through many obstacles to get to work. I must travel through some un-safe neighborhoods on busses and trolleys which increase my exposure to COVID, through all different weather conditions including rain, snow, sleet, and extreme temperatures. For some of us, we must also get our kids to day care and help our own parents and family members before we go to work. All of this happens before I arrive on the job to provide the quality care.

Home Care Workers need better pay, a living wage and respect for the necessary work we do. Home Care Agencies need support from Federal and State funders and legislators to support their home care workers, provide training and provide better pay.

Today, I own a house and I'm no longer on welfare. Home Care Associates connected me to programs that allowed me to purchase my house. My daughter went to college, I was able to get loans and she was eligible for some grants. I'm getting ready to retire but am fearful that I might not make it financially. Even though I am afraid about how I will survive, after so many years of service to others, I am proud of my success in my life and the care I delivered. I know



my contributions helped my patients and I'm so glad to have spent all these years at Home Care Associates.

Thank you for the work you are doing to support Direct Care Workers and for your understanding that better jobs equal better care.

Sincerely,

Yvette Beatty