AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

S. HRG. 117–103

21ST CENTURY CAREGIVING: SUPPORTING WORKERS, FAMILY CAREGIVERS, SENIORS AND PEOPLE WITH DISABILITIES

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

ONE HUNDRED SEVENTEENTH CONGRESS

FIRST SESSION

WASHINGTON, DC

JUNE 17, 2021

Serial No. 117–04

Printed for the use of the Special Committee on Aging

Available via the World Wide Web: http://www.govinfo.gov

U.S. GOVERNMENT PUBLISHING OFFICE
46–223 PDF WASHINGTON : 2021

SPECIAL COMMITTEE ON AGING

ROBERT P. CASEY, JR., Pennsylvania, *Chairman*

KIRSTEN E. GILLIBRAND, New York
RICHARD BLUMENTHAL, Connecticut
ELIZABETH WARREN, Massachusetts
JACKY ROSEN, Nevada
MARK KELLY, Arizona
RAPHAEL WARNOCK, Georgia

TIM SCOTT, South Carolina
SUSAN M. COLLINS, Maine
RICHARD BURR, North Carolina
MARCO RUBIO, Florida
MIKE BRAUN, Indiana
RICK SCOTT, Florida
MIKE LEE, Utah

STACY SANDERS, *Majority Staff Director*
NERI MARTINEZ, *Minority Staff Director*

C O N T E N T S

Page

Opening Statement of Senator Robert P. Casey, Jr., Chairman 1
Opening Statement of Senator Tim Scott, Ranking Member 2

PANEL OF WITNESSES

Ai-Jen Poo, Executive Director, National Domestic Workers Alliance, Chicago, Illinois 5
Stephanie Blunt, Executive Director, Trident Area Agency on Aging, North Charleston, South Carolina 6
Brittany Williams, Homecare Worker, SEIU 775 Member, Seattle, Washington 8
Theo Braddy, Consultant and Former CEO, Center for Independent Living of Central Pennsylvania, Harrisburg 9

APPENDIX

PREPARED WITNESS STATEMENTS

Ai-Jen Poo, Executive Director, National Domestic Workers Alliance, Chicago, Illinois 35
Stephanie Blunt, Executive Director, Trident Area Agency on Aging, North Charleston, South Carolina 41
Brittany Williams, Homecare Worker, SEIU 775 Member, Seattle, Washington 45
Theo Braddy, Consultant and Former CEO, Center for Independent Living of Central Pennsylvania, Harrisburg 50

21ST CENTURY CAREGIVING: SUPPORTING WORKERS, FAMILY CAREGIVERS, SENIORS AND PEOPLE WITH DISABILITIES

THURSDAY, JUNE 17, 2021

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

The Committee met, pursuant to notice, at 9:34 a.m., via Webex, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senators Casey, Gillibrand, Blumenthal, Rosen, Kelly, Warnock, Tim Scott and Rick Scott

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

The CHAIRMAN. The Senate Special Committee on Aging will come to order.

Today's hearing takes place as COVID–19 vaccination rates continue to climb and states across the country are opening up their economies. We can finally see the light at the end of this dark tunnel. Now we must learn from the devastation brought on by COVID–19.

We know that the pandemic exposed long-standing challenges that American families confront each and every day. The pandemic highlighted the essential value of care, both that supported by a professional workforce and that of unpaid family caregivers.

At today's hearing, our witnesses will speak about the caregiving economy, both paid and unpaid, and what is needed to ensure that seniors and people with disabilities have access to the supports that they need. Medicaid Home and Community-Based Services enable more than three-and-a-half million people to remain in their homes, to stay active in their communities and to lead independent lives. This assistance often includes help with activities of daily living, such as eating, bathing and managing medications.

Too many Americans, likely millions more, are not able to access these services, placing significant financial and emotional strains on families. We know that almost 820,000 Americans languish on wait lists for Medicaid Home and Community-Based Services, sometimes waiting for these services for years. That is one reason why President Biden proposed a historic $400 billion investment over 8 years in these essential services as part of the American Jobs Plan.

Congress is currently debating the contours of legislation to invest in our infrastructure and fix our nation's long-neglected road-

ways and bridges, just by way of example. Obviously, other parts to that bill as well. For millions of families across the country, but especially for women, their bridge to work might be a physical bridge, but it may also be the bridge of care, caregiving bridge, whether it is Home and Community-Based Services or whether it is childcare or other supports for the family.

The President's proposed investment will make it possible for more Americans to receive high-quality services and supports. This investment will allow them to live in their own homes, participate in their communities, go to school and hold a job. It will help family members who are often the unrecognized and unpaid caregivers providing support every day.

This investment is also about services, but it is definitively about jobs. We must turn these jobs into good quality family sustaining jobs. In Pennsylvania, for example, the median wage for a direct care worker is just $11.99 per hour, and many have fewer or no benefits, those in this workforce. As we will hear today, the majority of these workers are women and from communities of color. Among homecare workers, 62 percent are people of color. An investment in these essential workers is long overdue.

A little over a month ago I spoke to Lisa Savage from Philadelphia. Lisa left her career of more than 20 years to be a homecare worker in order to support her son, Brandon, who was shot and left paralyzed while at home on a break from college. Lisa Savage said the following to me, "as a homecare worker, we are essential. We are essential because we care for the elderly and we care for people with disabilities at home," Lisa is right. An investment in her, in her essential work, is critical. An investment in homecare workers across the country is long overdue.

I look forward to hearing from our witnesses today about these important issues, but before we begin, I want to remind Committee members and witnesses to please keep your remarks and questions to 5 minutes. We have a countdown timer that can be viewed alongside the other participants' windows on Webex. Following opening remarks, Senators will ask their questions based on seniority, and I ask that members have their cameras turned on a few minutes prior to their questions.

With these logistical notes, I turn to our Ranking Member, Senator Scott.

OPENING STATEMENT OF SENATOR TIM SCOTT, RANKING MEMBER

Senator TIM SCOTT. Thank you, Mr. Chairman, for holding another really important hearing for those of us who are all very concerned about our aging community and the way in which they age, the care that they receive.

I had the good fortune, and still have the good fortune in many ways, to be raised by a single mom who was a caregiver. She spent 40-plus years as a nurse's assistant in hospitals caring for our elderly patients. Having an appreciation for the hard work, the struggle of caregivers is something that I grew up watching and experiencing.

The truth is, Mr. Chairman, I think you and I will both agree that caregivers need to be celebrated today coming out of a pan-

demic in a way that we have never, ever celebrated them. Too often too many of them are working for too few dollars in their paychecks. Having been raised with my brother in that household, I will say that the one thing that I would never, ever change is the compassion and the sensitivity that my mom learned through being a caregiver.

Made me a very different person and made my brother a better person, and frankly, it is that important part of caregiving that you cannot buy. You just cannot buy people who love and care for the patients as my mother did and so many others do today.

We think about people that we know first, and I think about Claudia Bentley in my Charleston office and Kathy Crawford in my Charleston office who both are caregivers.

Claudia's husband, Ed, suffers from Alzheimer's and she basically has at least two full-time jobs at the exact same time. Kathy has cared for two elderly aunts into their nineties in their home and then her mother-in-law, who passed away unfortunately just last week at 91 years old.

Kathy and her husband moved the mother-in-law into the house so that they could provide high-level, high-quality care for the ones that they love the most. I think it is one of the best things we can do is take care of those that took care of us when we could not take care of ourselves.

From 2008 to 2018, the population over 65 years of age grew from 39 million to 52 million. By 2060, that population will be 95 million people. That is a lot of folks that will need a high level of care. My concern with the president's approach to this issue is just throwing money at the issue will not solve the problem of quality control. It will not solve the problem of family members being able to take care of their family members. We cannot use a one-size-fits-all plan.

It is one of the reasons why I will release today a white paper, a discussion on a better way forward, a way that allows for us to look at the unique opportunities within family systems and our other apparatus to provide the type of unique programs and care provision that our seniors want and deserve.

The truth is that having our seniors spend all their assets down to be eligible for Medicaid makes it very difficult for us to have intergenerational wealth created, especially in those communities where their net wealth is eight times lower than the rest of our country. We have to make sure that we focus our attention on programs that do not require us to see the resources depleted before you are even eligible for assistance. I think there is a better way, and our focus on that better way is going to be the focus of our attention on providing a flexible tailored program that allows for caregivers to be appreciated, celebrated and allows the family members who need the help the most to have access to resources that allow for their lives to be the best. I am a big believer that the latter range should be better than the former range, as we have learned in the Good Book.

With that, Mr. Chairman, I look forward to hearing from our witnesses. I thank each and every one of you for being here today and I look forward to having a robust discussion on ways for us to improve the quality of the outcome of those we love the most.

The CHAIRMAN. Ranking Member Scott, thank you for our opening. I will now turn to our witness introductions, and I will start and I will have the first, then I will turn to Ranking Member Scott for the second.

Our first witness is Ai-jen Poo. Ai-jen is the cofounder and executive director of the National Domestic Workers Alliance. She is also the cofounder and director of Caring Across Generations, a coalition of organizations working to strengthen the caregiving infrastructure for America's families. She is a recognized expert in family and elder care and has been chosen by Time magazine as one of the 100 most influential people in the world and was a recipient of a MacArthur Genius Foundation—I am sorry, MacArthur Genius Award in 2014.

Ranking Member Scott, I will turn to you for our second introductions.

Senator TIM SCOTT. Thank you, Mr. Chairman. It is my pleasure to introduce today an individual who has, I will say—I will stray briefly from my prepared remarks, but let me just say this first. Stephanie Blunt is a champion of people who need a little help, people who want to be independent, people who have passion for life, people who are still in the prime of time—in the prime of their lives.

Stephanie, for the last 20 years, has literally dedicated so much of her life to helping seniors throughout the metropolitan Charleston area, as well as the State as a whole. She is the executive director of the Trident Area Agency on Aging, where she has worked, as I just said, for more than 20 years. In her capacity, she provides oversight for Federal, State and private funds used for serving seniors and family caregivers.

She also leads development of strategic and operational plans in support of the agency's mission. Stephanie's testimony today is based on her experience working with older Americans and their caregivers. We will hear about the pivotal work she has done to support our most valuable citizens.

Stephanie, we appreciate your hard work, your dedication to the seniors in our State, in our low country. She has been in the nonprofit world from my days in the nonprofit world back in the early 2000's, so God bless your efforts and may you continue to have strength and good health.

The CHAIRMAN. Thank you, Ranking Member Scott. I will now turn to our third witness, Brittany Williams.

Brittany Williams, I want to say first of all, thank you to Brittany for being with us today, but also for being so patient as we navigated some technology challenges. I am glad you were able to be here by phone and we will be able to post your picture with the audio when it is your turn to testify, so we are grateful.

Brittany is a professional homecare worker in Burien, Washington. She is a third-generation caregiver who began work as a homecare worker after watching her mother and her grandmother do the same work. She is also a member of Service Employees International Union, Local 775.

Then finally, our fourth witness is Theo Braddy.

Theo is someone I met a couple of months ago when we were talking about these issues in the midst of the pandemic. Theo is

also a Pennsylvanian. I do not mind mentioning that. He is currently a consultant working in the area of disability and nonprofit management. For 31 years Theo was the CEO of the Center for Independent Living of Central Pennsylvania and also helped people with disabilities live where and how they wished. Theo is a person who has lived with a disability since he was 15 years and has used Home and Community-Based Services for more than four decades. Theo, we are grateful that you are with us today.

Before I start with our witness statements, I wanted to acknowledge Senator Rosen is with us. As I often mention during our hearings, we are going to have senators who will be in and out going to different hearings, but just we will wait for some to get back to do questions. I want to acknowledge those who are here early and then we will go from there, but let us turn to our first witness, Aijen Poo, for our first statement.

STATEMENT OF AI–JEN POO,
EXECUTIVE DIRECTOR, NATIONAL DOMESTIC WORKERS ALLIANCE, CHICAGO, ILLINOIS

Ms. POO. Chairman Casey, Ranking Member Scott and distinguished members of the Committee, thank you for the opportunity to testify today. At Caring Across Generations and the National Domestic Workers Alliance, we have worked for over a decade to bring attention to the urgency of state and Medicaid Home and Community-Based Services for older adults and people with disabilities. We now have a once in a generation opportunity to invest, to build the 21st Century care infrastructure we need.

Caregiving is personal to me. My own grandfather, who helped raise me, taking me to and from school, teaching me the values of hard work and respect for my elders, values that shaped who I am today, had to be placed in a nursing home against his wishes when he lost his vision and we could not find homecare assistance. He shared a room with six others, many who were crying in misery. He could not eat the food or sleep.

The staff was overwhelmed with too many people to care for and he passed away after just a few months, fearful and a shell of himself. While this is my own story, it is certainly not unique. Eighty-eight percent of aging adults prefer to receive long-term services and supports in the home and community-based setting. These services are out of reach for too many.

Across the United States nearly 820,000 older adults and people with disabilities are on waiting lists for Medicaid HCBS. People wait years, sometimes decades, for access to services. There are homecare deserts across the country, especially in rural communities, and we are facing an elder boom. By the year 2050, the population of people 65 and older will nearly double. With 10,000 people aging into retirement per day and living longer, there is an overwhelming demand for care in the home and in the community.

To age at home, we need infrastructure, including a strong direct care workforce. From 2018 to 2028, the U.S. will need to fill over 4.4 million homecare job openings, making homecare one of the fastest growing occupations in our economy. The average annual income for a homecare worker is $17,200 per year. The median hourly wage only increased by a total of 91 cents between 2009 and

2019. One in eight direct care workers lives in poverty and three—quarters earn less than a living wage in their states. This essential workforce of women, majority women of color workers who we are counting on to care for us, cannot care for their own families doing this work.

The proposed investment of $400 billion for HCBS and the American Jobs Plan will jumpstart economic recovery in a number of ways. First, according to one estimate, the $400 billion would create nearly 800,000 new care jobs and over 1.1 million new jobs overall each year over 10 years, adding an estimated $40 billion in new income to American families every year.

Second, it will raise wages and offer real economic security for the direct care workforce so they can sustain in the profession, work that cannot be outsourced or automated, and one that has faced legal exclusion from basic protections for generations because of the devaluing of caregiving and largely due to racism and sexism. This is a powerful way to directly create good jobs for women and women of color to be a part of our economic recovery.

Third, by expanding access to services, the plan will allow for people with disabilities to live independently, to work and live full lives in the community.

It will enable quality of life and better healthcare outcomes for older people, including people with chronic illnesses like Alzheimer's who want to live at home connected to friends and family. Expanding access to services and a strong workforce are interdependent goals that go hand and hand.

Finally, it will support the 48 million family caregivers who are also majority women who have long struggled to manage work and caregiving. The pandemic pushed nearly four million women out of the workforce due to caregiving challenges. Our recovery must enable them to have the real choice to go back to work.

The care economy is the foundation of the entire economy, from childcare to paid leave to HCBS. When we invest in care, we invest in opportunity for all. An investment of $400 billion in the American Jobs Plan and Home and Community-Based Services is an investment that cannot be shortchanged. Thank you so much.

The CHAIRMAN. Thank you, Ms. Poo, for that testimony. Before we move to our second witness, I wanted to acknowledge as well Senator Blumenthal and Senator Rick Scott.

Next we will have Stephanie Blunt. You may begin.

STATEMENT OF STEPHANIE BLUNT, EXECUTIVE DIRECTOR, TRIDENT AREA AGENCY ON AGING, NORTH CHARLESTON, SOUTH CAROLINA

Ms. BLUNT. Chairman Casey, Ranking Member Scott, members of the Senate Special Committee on Aging, it has been an honor to serve in the South Carolina aging network for the past 20-plus years, both at the local service provider level and at the Area Agency on Aging level.

Trident Area Agency on Aging is one of 10 area agencies on aging in the State of South Carolina designated by the South Carolina Department on Aging. Since our organization was formed in 1991, we have worked with both the public and private sectors to develop a cost-effective approach to long-term care services. We

serve as the resource connection for seniors, adults with disabilities, family caregivers and professionals.

I lead a staff of over 15 who have daily contact with seniors and their families. Annually, our staff and volunteers serve over 12,000 seniors and 1,500 family caregivers. It is my responsibility to work within budgets, adhere to regulations, follow policies and procedures, but at the end of the day, it is about making all of those factors connect with the people who need our assistance on a daily basis.

Since 1965, the Older Americans Act has been a solid foundation for aging services throughout our country, and my years of experience have taught me how to cobble together Federal, State and local resources to meet the needs of a very growing and diverse aging population. States, regions and counties are all different, and it is a waste of resources to collect needs assessment data year after year and not be able to really offer the services and supports that will prevent seniors from going into the hospital or seeking long-term care placement.

While the Older Americans Act is designed with some local flexibility, there are still restrictions on which sets of funds we can use to fund which services, and that presents a challenge, so Area Agencies on Aging, we need flexibility at the local level so that we can determine how those funds are to be spent, and spend those funds how seniors need them.

Since 2001, our Area Agency on Aging has offered through the Older Americans Act the National Family Caregivers Support Program Services. We have seen first-hand the challenges that many caregivers are facing, particularly the working family caregiver. Our staff receive calls from stressed out family caregivers on a daily basis who are trying to juggle their full-time employment, as well as their families and their caregiving responsibilities.

Through the Family Caregiver Support Program, we are able to provide information, connect caregivers to resources, offer education, like dementia education, and also respite services. The respite that we do provide is helpful to so many caregivers, as it gives them a break. In South Carolina, the average respite assistance is valued at about $2,000 annually. We are providing about 90 hours of assistance per year. While this is very beneficial to so many caregivers, it does not meet the ongoing needs of the working family caregiver.

Our country's affordable healthcare options, you know, they are difficult—you know, our long-term care assistance is fragmented and so families are seeking affordable care options. In addition, we need more investment in more fiscally responsible home and community-based service options.

The lack of workforce in the homecare industry continues to be a barrier in providing respite services and homecare services. You know, we rely heavily on these direct homecare workers to perform light housekeeping, help with personal care and also provide their meal preparation, because we want to have these services in place because we want to keep seniors out of long-term care placement. Unfortunately, hiring these direct care workers is a challenge.

In my region, I surveyed some of our providers and the pay is anywhere from 10 to 17 dollars an hour, but that $17 an hour is

not the norm, because that is based on the years of experience in the field, the certifications they have and the level of care that they are providing. We really need to increase compensation for these direct care workers—they are so essential to our system—and enhance the rates for community-based service providers who are funding—who are employing these individuals.

I just again want to thank you for the opportunity to speak with you this morning and just allowing me to share my experience on serving older adults, people with disabilities and also our most important family caregivers.

Thank you.

The CHAIRMAN. Ms. Blunt, thanks for your statement. We will turn next to our third statement from Brittany Williams. Ms. Williams, you may begin.

STATEMENT OF BRITTANY WILLIAMS, HOMECARE WORKER, SEIU 775 MEMBER, SEATTLE WASHINGTON

Ms. WILLIAMS. Good morning, and thank you, Chairman Casey, Ranking Member Scott, and members of the Aging Committee. My name is Brittany Williams. I live in Burien, Washington. I am a homecare worker and proud member of SEIU 775. We represent over 45,000 in-home caregivers in Washington and Montana.

Homecare workers have helped seniors and people with disabilities live with dignity and independently in their homes. I currently take care of three clients, providing essential life-sustaining care, such as bathing, cooking meals, cleaning, helping them go to the bathroom, running errands, and anything else they may need throughout the day.

Caregivers is not just a job for me. It is in my genes. I grew up watching my grandmother and my mom doing the same work. While I was in school learning my ABCs from my teachers, I also learned an invaluable lesson of compassion and care from my mom and grandma. Even as a child I could see that care is essential and it is giving life work that I am blessed and proud to do.

This job is hard. I always say that homecare workers are the maintainers of life, but we can barely survive ourselves. That is the way it has always been for homecare workers. Black women like me have been caring for this nation for centuries, but due to the long history of racism and sexism, our work has been labeled as unskilled women's work, and that narrative has been used to devalue us and hold us back.

Homecare is one of the lowest paying jobs in the country and where many lack access to benefits. I am a single mom of two amazing children, but I worry about letting them down. My family has to budget every penny and save wherever we can for an emergency. I struggle to meet our basic needs like paying our bills, putting food on the table. I simply cannot afford to give my children some of the opportunities their peers have.

If things were not bad enough already, the COVID–19 pandemic ran us into the ground. Everything that I thought was secure the pandemic took away. It took away the security of having a safe place for my children to learn.

It took away the security of working in the hours to earn what I need to provide for my family, and it took away the security of

having a roof over my head. I became exhausted and angry at the injustice of it all. A global pandemic, economic turmoil, and on top of all of that, the racial violence.

I stayed strong and I did what I had to, but I would be lying if I said I was not scared for my life and the lives of my family and clients each and every day. Thank God for my union, SEIU 775. Together we have won higher wages, better benefits. Now Washington homecare jobs are among the best in the Nation. The victories are bittersweet because not every homecare worker is in my position. Like my mom down in Arkansas, she does not have a union and she earns just $11 an hour.

We need to fill nearly five million homecare jobs by 2028. The low quality of these jobs force people out of the industry and leave shifts unfulfilled and clients without caregivers. Our country needs a care wakeup call and that is why we support the American Jobs Plan. This investment in care will be lifechanging. It could transform homecare jobs into family sustained union careers so we can build the workforce we need to meet the growing demand for care.

This investment will help build back a more inclusive recovery, lifting millions of women, black women, women of color, immigrants out of poverty and at the same point in our lives. We all will need this kind of care at some time. It is not fun to think about, but everyone deserves the comfort of knowing a skilled and dedicated caregiver will be there when the time comes. If you or your family member suddenly needs homecare tomorrow, are you confident you will be able to get the resources and services you need? Are you confident that your constituents could do the same?

I suggest you do not wait to find out. Care cannot wait and neither should Congress. Thank you.

The CHAIRMAN. Ms. Williams, thank you for your statement.

Now we will turn to our fourth witness, Theo Braddy.

STATEMENT OF THEO BRADDY, CONSULTANT AND FORMER CEO, CENTER FOR INDEPENDENT LIVING OF CENTRAL PENNSYLVANIA, HARRISBURG, PENNSYLVANIA

Mr. BRADDY. Again, first of all, I would like to thank you, Chairman Casey and Ranking Member Scott and members of the Special Committee on Aging, for inviting me to share.

I would also like to thank all the panelists, but I certainly would like to thank the young lady that just spoke, the homecare worker. I feel your pain.

My name is Theo Braddy and I became a person with a disability at the age of 15 after breaking my neck playing high school football in Wadley, Georgia. I am originally from Georgia and I am 61 years old. I retired early in 2019 after working 31 years as the CEO of the Center for Independent Living of Central Pennsylvania. Our mission is to eliminate and prevent barriers that are faced by people with disabilities on a day-to-day basis.

I am married. I have a 28-year-old daughter and a 23—year-old son. I now work part time as a consultant. Most importantly and assuredly, for this hearing I am a user of Home and Community-Based Services. That is very important. I have used Home and Community-Based Services for over three decades. As I share my story, Senators, please understand that this is not only my story,

but it is a story that has lived out for millions of people cross this country, including the young lady who just spoke, the homecare worker.

Disability, what we do not know is when it can happen. It happened to me playing high school football, a game I. It happened to Christopher Reeve riding a horse. What we do know for sure, that life will change when it does. You will be faced by all types of new barriers in life, and that turning point was at age 15, 46 years ago. At age 15, my life changed. I became paralyzed from the neck down and I could not do anything for myself.

Now, I usually do not talk about this, but for the purpose of this virtual meeting, I need to really describe to you that my disability is significant. I am paralyzed from the neck down. I virtually cannot do anything for myself. I have spent 46 years in a wheelchair, and if I could spin around and pull myself through these earphones I would show you, because you need to know my situation.

I cannot move my fingers. I do not have any dexterity. I do not have any triceps and muscles. I have biceps, but I have very little movement. I cannot get in and out of bed. I cannot dress myself. I cannot undress myself. I cannot even bathe myself.

Life changed for me. It became what I refer to as a maze of confusion. I ended up in a nursing home. The young lady that said something about the crying and misery, I remember when I was 15 years old not being able to sleep because people were just crying all night long. The weight of all of this came on my family because I spent that time, a year in a nursing home. When I came home from rehab, we were dirt poor. My mom could not help me with anything, so the only option was for me to go into a nursing home, and I spent a year in a nursing home. That crying and that misery, it haunted me.

Fortunately, like most people with disabilities, my family came in and my brothers and sisters, they brought me to Pennsylvania. I ended up on the third floor in an apartment building, looking out a window for weeks at a time waiting for my brothers to come over and carry me down three flights of stairs and getting back up again. That went on for a long, long time.

I have no way of explaining how it feels not to be able to do anything for yourself anymore, having to depend on family members, of the kindness of strangers. Sometimes strangers are not kind. I remember one time when I was trying to put money into a parking meter and a stranger came by. I was waiting on someone to come by to help me put the money in and he looked at me as I asked him to help, and he said, I did not have time for that, and he kept on walking.

We cannot always depend on the kindness of strangers. Home and Community-Based Services changed all of that. It started when I received attendant care services. I said this many times before. People with disabilities do not want to be taken care of. They want—they do not want to be seen as objects of charity. We want to contribute.

HCB Services, especially attendant care services, did that for me. I call it the great equalizer. There are many times throughout my 31 years of work when I had to depend on attendants to drive me

back and forth to my many meetings because they were just too far or just too painful for me.

Being provided with attendant care gave me back my independence and my ability to live life fully again. Once I started receiving Home and Community-Based Services, I enrolled in Edinboro University and received my earned bachelor's degree, then I moved to Philadelphia, Temple University, and received my master's degree in social work, with Honors. This was done based on one time a OVR counselor telling me I was not college material when I told him I wanted to go to college. In undergraduate school for the first time in my life I was able to move off campus and live by myself and use attendant care services. That is something all students want to do.

Shortly after finishing my MSW, I worked with a small group of Central Pennsylvanians, people who wanted to apply for a grant to establish what was a major thing at the time, Center for Independent Living. Once that grant was approved, I became the director for 31 years, like I said.

I have taught as adjunct professor at Millersville University, at Temple University as well, and lectured all over the country. I have been appointed to serve on boards by three different Governors, and as a result, I have impacted many lives for the better. All along the way, my different attendants helped me get in and out of bed, went with me as I needed, not 24/7, but just as I needed.

This is what attendant care is all about. This is what Home and Community-Based Services is all about. This is what I want you to take away, Senators. Do not miss this. All the time.

The CHAIRMAN. Sorry, I am just going to—just want to jump in. We are over time by more than 2 minutes.

Mr. BRADDY. Oh, I am so sorry. I am so sorry.

The CHAIRMAN. I just wanted to make sure we can get to our questions. I hate to cut you off.

Mr. BRADDY. No, that is fine. That is fine.

The CHAIRMAN. We might be able to develop more of it during questions.

The CHAIRMAN. I know that we are juggling senators who are in and out, so I am going to concede my question time to Senator Blumenthal.

Senator BLUMENTHAL. Thank you so much, Senator Casey. I am so grateful to you for having this hearing and for your championing this cause of home and community-based care. You have been just such a steadfast advocate.

I really want to thank this panel. You know, we hear from a lot of witnesses. I have four hearings and meetings this morning. A lot of it happens at the same time, but sometimes a panel really cuts through to your heart, and this panel, Mr. Braddy, thank you so much for that really eloquent testimony. Thank you to Ms. Williams.

You know, SEIU, we owe that union so much because they really help protect the homecare workers in a way that Congress has failed to do.

You are right, and I am quoting you, "Care cannot wait," and neither should Congress, and that is why many of us feel like Sen-

ator Casey, that this kind of Home and Community-Based Service should be part of our infrastructure and it has to be a part of what we do.

In Connecticut, we have 500,000 family caregivers. Let me repeat, 500,000 family caregivers in a State with a population of about three a half million people. That is a sizable part of our whole population. They are people who are families taking care of members of their families. They are people like Ms. Williams working professionally. They are people like the attendant who is taking care of Mr. Braddy. They have been going through unprecedented stress, anxiety, hardship, physical labor, so this kind of lost wages, missed opportunities, unparalleled stress, cries out for action for the sake of the people who they care for, as well as themselves.

Let me ask Ms. Poo, you have spoken a bit about the impact of unpaid caregiving on families, mentally, physically, financially, and Mr. Braddy, you have shared your experience receiving care from family members before HCBS.

Maybe I can ask you, how important is the unpaid—the support that we provide unpaid caregivers, the tools, the training, the support they need? I just want to mention that I have introduced today the Alzheimer's Research and Caregiver Trust Fund Act, which Americans would be able to donate to through their annual tax returns. The donation would then be directed toward NIH and the Administration of Community Living to support and train caregivers. I think we have coming together different ideas.

Let me ask you, Ms. Poo, how important are the tools and training to the caregiver, the family caregivers?

Ms. POO. Thank you for the question, Senator. It is absolutely essential that we support our family caregivers. Frankly, care in America is an all-hands on deck situation. We need to support our family caregivers.

We need to support our professional caregivers. Frankly, there will be a lot of family friends and neighbor care that we will rely on as well. It is often posited as an either/or, and in fact, we need to support all, a strong workforce and families.

We know that almost 20 percent of family caregivers have quit their jobs because of caregiving, and 70 percent of family caregivers are forced to make work adjustments, like cutting back on hours or turning down a promotion. All of this can result in lost wages, diminished Social Security earnings, jeopardizing the overall economic stability of families and communities, so we do need to support family caregivers.

I also want to highlight the sandwich generation, those who are both raising young children and managing care for aging loved ones or loved one with disabilities. They are in a particularly difficult position. Really do need support.

Senator BLUMENTHAL. What percentage have been forced to leave their jobs?

Ms. POO. Twenty percent, sir.

Senator BLUMENTHAL. Twenty percent and 70 percent adjusting their work schedules. You know, my time has expired. I really would thank you, Senator Casey. You have been very, very gracious. Again, thank you for having this hearing.

The CHAIRMAN. Thank you, Senator Blumenthal. I know we are joined as well by Senator Kelly. I will turn to Ranking Member Scott, but I do want to make reference to the fact that we have had some technical issues, so we are trying to work them out, but I want to turn to Ranking Member Scott for his questions.

Senator TIM SCOTT. Thank you, Mr. Chairman. You seem to be handling the technical issues seamlessly. Most of us cannot tell, so thank you for your hard work behind the scenes.

Ms. Blunt, once again, just thank you for your dedication to caregiving throughout South Carolina, and specifically in the low country. I know that you recognize that by the year 2030, our small State will have 1.8 million South Carolinians who are probably going to need a higher level of care than they currently do right now.

Can you tell us how your partnerships with local businesses and community leaders benefit seniors? One of the challenges that we have is that sometimes this one-size—fits-all says that the government is the only solution. Certainly, has to play a significant role, but it cannot be the only way forward. We are going to have to have community leaders and partnerships that provide some bridge to our seniors.

Can you talk just for a few minutes about—however long you want on that topic.

Ms. BLUNT. Thank you, Senator Scott. Sure. I tell you, partnerships are vital and essential to the Area Agency on Aging services, and the Old Americans Act provides that framework for us to engage in those partnerships, and that is so critical. For instance, let me just give you an example. You know, we receive on a daily basis intakes and provide assessments for seniors who are reaching out to us for services, like home-delivered meals. Well, it does no good to end a call knowing that a senior is hungry and saying, okay, I will put you on a waiting list for services.

We are able to operate a food pantry here, and that is because we have local partnerships in our community with private businesses and our Lowcountry Food Bank. We can provide seniors with basic food to get them through until we are able to connect them with SNAP resources or give them additive services.

Another partnership I just want to highlight, you know, even with the city of Charleston, the Mayor's Office on Aging, you know, I cannot—you know, this past Tuesday was World Elder Abuse Awareness Day and, you know, we highlighted elder abuse awareness because that is a huge issue in our communities. You know, we want to make sure that we are training. You know, through our partnership it was a grant that we received, and we were able to train police officers on how to investigate elder abuse.

Those partnerships are so, so, so very, very critical. I can talk about them all day long. Again, you know, it is us pulling together. No one entity can do it by themselves, and it really takes all of us working together to meet the needs of a growing and diverse aging population.

Senator TIM SCOTT. Well, Ms. Blunt, you bring up another question for me. In your testimony you talk about the frustration of trying to manage multiple funding streams and programs that all focus on caregiving for senior Americans. How can Congress play

a role in fixing this convoluted system, as well intended as it is, is really inefficient in its delivery system in meeting the needs at the user level?

Ms. BLUNT. Sure. The Older Americans Act, while it does provide some flexibility, you know, we do find that it is—you know, we have fragmented services, you know. Like in South Carolina, we try to partner—we work with our Medicaid agency. You know, the Area Agencies manage the Older Americans Act services and, of course, the Department of Health and Human Services manages the Medicaid waiver program.

You know, we want to avoid duplication, so it is so important that we are working together to make sure that we are maximizing all of our resources in our community. With regards to the Older Americans Act, for instance, with home delivered meals, as I discussed, you know, we have a growing waiting list for home delivered meals in our region. Sometimes the money is given to us in, you know, two parts, two subparts of the Older Americans Act.

Being able to maximum—you know, transfer—you know, to increase transfer capacity rather than having people sit on a waiting list, you know, we should be able to provide services if the money is there. We should be able to help people and get them off the waiting list. Like I said, no senior should be hungry in our community.

Senator TIM SCOTT. Yes, ma'am. Well, I know I am about out of time, so I will make a statement as opposed to asking a question and you can just shake your head if you agree or disagree. In South Carolina, and I think around the country, the truth of the matter is that as you wrestle with the streams of resources that may or may not be available, that is one convoluted system itself. According to a survey, 77 percent of respondents in South Carolina were unaware of GetCareSC website, which would allow for a site that aggregates the information that can help caregivers and the folks that they care for understand what is available.

Ms. BLUNT.

Senator TIM SCOTT. Knowledge is power. We simply need to also make sure that we have a strong marketing network to help people understand what is even available in some instances.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Ranking Member Scott. I will have a round of question—or I will take my round of questions now. I wanted to go back to Theo Braddy.

Theo, I did not want to cut you off earlier, but yours, like so many stories we are hearing today, is a compelling story about the benefits of Home and Community-Based Services as a leader in this field. In your testimony you talk about how [audio disruption] about your reference in both the written and the statement you made earlier about when you were on that third floor in an apartment building looking out a window for weeks at a time waiting for your brothers to come over and physically carry you down three flights of stairs—so you have seen it up close.

Mr. BRADDY. Senator, you are cutting out. I missed that question.

The CHAIRMAN. Can you hear me now?

Mr. BRADDY. I can hear you now.

The CHAIRMAN. Okay. I was saying you are both an expert in the area, but also a consumer of the services. My question is, do we need to expand Home and Community-Based Services, and do homecare workers need better wages and benefits, in your opinion?

Mr. BRADDY. Yes. Yes, sir. Yes, sir. Again, I apologize for extending my time there. I got a little carried away, so I definitely apologize for that. Yes, it is really about time. We have talked about this for a while. It is about time for us to recognize that homecare workers, attendant care workers, personal care workers, whatever you want to call them, are valued in this community here for families. We definitely need to increase their rate so we can make it more available.

Even more so, Senator, and Committee members, in this COVID–19 period, where we are already seeing a shortage of homecare workers who are not vaccinated and sometimes choose to be not vaccinated. I have already experiencedb people not being able to get services because of that. Yes, we need to increase that hourly rate immediately.

The CHAIRMAN. Thanks very much for your insights. I wanted to turn to Ms. Williams. We know that homecare workers are essential. We have all said that today in one way or another. We also know, and you know personally, that it is demanding work. Too often workers like you who have provided this kind of care do not see their work valued the way it should be. In many parts of the country, the homecare workforce is characterized by, unfortunately, low wages, limited access to benefits and very, very high turnover, and that is not good for anybody.

This occupation is among the fastest growing in the United States as the aging population is steadily increasing demands for services. In order to meet the demand for services, we need to ensure that the workforce exists to provide that care and that these are good jobs that pay middle-class wages.

Ms. Williams, how important is it that we turn care work into a stabile middle-class career for homecare workers across the country?

Ms. WILLIAMS. Thank you for that question. I really want to say like, you know, investing in caregiving is an investment in our community. When we have those strong and stabile homecare careers, we are literally making a way for those family members who would have not been able to work, whether they are your doctors, your lawyers, your garbage workers, your teachers, your firefighters, police officers.

We are allowing them the ability to go out and work. At the same time, we are allowing those consumers, our clients, the ability to still have dignity throughout their lives.

We want to make sure that we are making it a career instead of a job, so that the future people that will come into this field will have something to look forward to. It also causes an interest into what would be a door opening toward the medical field. Once you feel that compassion and that love and you see that smile on a person's face after a day of work, that might have been draining on the caregiver, but it was fulfilling for the client. It becomes an awe moment of, okay.

To look at your paycheck at the end of the 2-week period and see that my family is taken care of, I was able to put back into my community because I was able to buy a home, I was able to put back into my community because I was able to go to the grocer, or I was able to pay my bills, that is why it is essential to make it a career, middle—class field.

The CHAIRMAN. Thanks very much for bringing your personal experience to this. I know my time period is over by way of the clock, but I know we are juggling both senators coming in and out and also some senators trying to connect and they are having some technical difficulties. I can turn to Ranking Member Scott again or I can --

Senator TIM SCOTT. Yes, sir.

The CHAIRMAN [continuing]. ask a couple more questions.

Senator TIM SCOTT. Happy to ask a question.

The CHAIRMAN. Okay.

Senator TIM SCOTT. Mr. Chairman. I did not give Ms. Blunt an opportunity to talk about the GetCareSC and the importance of having a portal where people can go and get information in one site.

Ms. Blunt, as opposed to asking you to nod because I was running out of time—I apologize—now we have more time.

I will go back to you with the really important question about the dissemination of information that is critical for our seniors and their healthcare providers to have access to. I think that survey is right that 77 percent of respondents were unaware of the fact that there was a place that they could go to get more information. That seems to be a really important part of this puzzle.

Would you speak about the importance of having that one-stop shopping for this really important issue?

Ms. BLUNT. Absolutely, yes. Thank you for the question. You know, first of all, sometimes family caregivers do not even know they can ask for help, so it is important to have a resource for them that they can access very easily at their leisure. Again, like I said, they are juggling so much. They are juggling their family and their full-time employment and the caregiving responsibilities, so we need to kind of meet them where they are.

I know we have also worked outreach, I will tell you, is so important, and we have been working on an educational platform. Thanks to—you know, we have our national Association of Area Agency on Aging that, you know, promotes best practices throughout the country. We are connected and trying to get together an educational platform for our family caregivers, so again, they can access that portal and get quality training, accurate training. It is so important that they give accurate information so that they can provide better care for their loved ones and access and connect with the resources in the community.

Again, we are trying to think differently, think of new ways and innovative ways to serve our seniors, partnering with organizations to do even more outreach and since the pandemic. We were able to master this virtual platform, but I will tell you, I think the challenge in that has been connectivity, because in our rural areas not all of our seniors and family caregivers have access, you know, to broadband. That kind of makes it a challenge for us.

Again, we are happy to start to get back out in our communities now, partner with our faith-based organizations and to continue promoting GetCareSC and all of the services that are provided at the Area Agency on Aging level.

Senator TIM SCOTT. Ms. Blunt, you just raised another really important point that I was not going to ask about, but it seems like this is a really important part of the conversation, innovation and technology. There is no doubt that a Harris poll suggests that 8 out of 10 Americans really like, love telemedicine, virtual medicine.

I am thinking back to a different day when my mom, as I have already said, spent 40-plus years—she is still working, but no longer the nurse's assistant that she was. Forty-plus years as a nurse's assistant providing care, and then her aging parents needed care and so my mother and my aunt both had to take care of my grandmother in her home and then later my grandfather in his home.

Truth be told, getting the loved one to the doctor, in fact, it is getting off work, doing split shifts at work so you can work 4 hours in the day, take 3 hours in the afternoon, you go to doctor's appointment, you come in later, telemedicine really could provide a higher quality of experience for the caregiver and the patient. Any thoughts on that from an innovative standpoint?

I will say that I visited Salley, South Carolina, my grandfather's hometown. Broadband, high-speed broadband is an issue, so certainly connection issues is something we need to work on as well. Telemedicine seems to reduce the burden on the caregiver and increases the quality for the patient.

Ms. BLUNT. It sure can and, you know, like you said, brings in the family caregiver, because sometimes you have family caregivers in multiple states who want to be involved in what is going on with mom and dad. Yes, absolutely bringing families together so they can help to coordinate care and coordinate not only the services, but of course, their healthcare. It is so, so very important. We just need to make sure whatever platform we are using is user friendly.

Senator TIM SCOTT. Yes, ma'am.

Ms. BLUNT. Senior priority, that they are able to again access it and just making sure—you know, specifically transportation, that is a whole other topic. Again, it would be important because some of these seniors lack transportation.

Senator TIM SCOTT. Yes, ma'am.

Ms. BLUNT. No one wants to go down that rabbit hole, but--

Senator TIM SCOTT. Mr. Chairman, I am just going to propose that Ms. Blunt identified you, sir. That is a rabbit hole that we need to go down at some point. I served on the United Way Board of Directors for the Tri-County area and I will say that we spent a lot of time working on programs and projects to help seniors make it to their doctor's appointments, but also getting your hair done. I mean, there are a lot of things. The quality of life experience itself is limited by transportation.

There are some fairly creative ways to help seniors be able to afford and have access to ride-sharing services and/or make the whole process easier for seniors. It is something that we do not always think about, especially in cities in the south where transit is not an option, honestly, for most seniors. You have to have a cre-

ative, innovative way of providing that resource and the time to do it, to get to and from.

Thank you, Mr. Chairman. I went over by a minute or so.

The CHAIRMAN. That is quite all right. We are doing a lot of juggling. Ranking Member Scott, thanks very much.

I will start with more questions. I might be interrupted if we have a senator that is connected. We have had some senators having difficulty connecting, but if they are-if they do get connected, I will interrupt my questions.

I wanted to turn to Ai-jen Poo for a question regarding the workforce. Again, we keep coming back to this issue of who is doing this work because it is so important to highlight. We know that the workforce that provides these services, Home and Community-Based Services, are majority women. That does not surprise anyone, but also a majority of women of color, or workers of color, more broadly.

This has been the case for far too long. We know that family caregiving responsibilities have more frequently fallen to women, often pulling them out of the labor force more often than men. Can you speak about the importance of investing in these services from a different perspective here for the purposes of this question, from the perspective of gender equity, but also racial equity?

Ms. POO. Yes, Mr. Chairman. Thank you for the question. Raising the pay for homecare workers would disproportionately benefit women, who make up 9 of 10 workers in the homecare workforce. It would also benefit the 63 percent of homecare workers that are black, Latinx, Asian American and Native American. According to the Groundwork collective, 68 percent of black and Latinx caregivers said that family caregiving responsibilities impacted their ability to work, 10 percentage points higher than white caregivers.

Women of color already face obstacles in accessing higher paying jobs and quality jobs, including occupational segregation and discrimination. Also, investing in HCBS would increase women's labor market participation, which is a key factor in a healthy economy. Millions of women, as I mentioned earlier, were forced out of the labor market in 2020, in large part due to family caregiving responsibilities, and as a result, we have the lowest female labor participation rates since 1988. These investments would really support black women and other women of color who were among those hardest hit through the pandemic.

The CHAIRMAN. Ms. Poo, thank you for your response to that. I am going to turn back to Theo Braddy. Theo, in your testimony, you talked about how when you first became paralyzed in that football injury that you had, all of the caregiving responsibilities fell to your family, which is, I think, a reality for many American families. They go through similar experiences when a loved one develops a disability or an older relative needs more assistance.

While some family members are able to provide these services, others cannot and it often places significant financial burdens on families as individuals to give up their job or work reduced hours to provide care. I have heard just in the last couple of months folks in Pennsylvania and throughout the country where that is the reality. They have had to give up a career, as many of you have experienced yourselves.

Can you say more about how expanding these services can benefit family caregivers, which is in the—as we heard testimony earlier today, is in the tens of millions? How can these services benefit the family caregiver but also all family members general?

Mr. BRADDY. Yes, a couple things, Senator. One is the need for respite care, right? Often family members are just completely overburdened and need someone to come in and provide that service. Another thing I have seen, especially in the rural areas, there is a need for family members to become paid attendants, and because there is no other service available in that area in regard to agency attendant care, whatever. It is important for those family members to be recognized as legitimate homecare attendants and get paid for their services, and I have seen that quite often because it is unavailable.

It is very important into how essential is family members to provide attendant care services to their members who are disabled, and we do not always recognize the importance of that.

The CHAIRMAN. Theo, thank you very much for that response. I know we are still juggling a little bit. I know that Senator Warnock was, I think, connected, Senator Rick Scott as well. I will ask another question.

Senator TIM SCOTT. Mr. Chairman, I have a question, sir, if you want me to go with a question.

The CHAIRMAN. Yes. Yes.

Senator TIM SCOTT. Thank you, Mr. Chairman.

The CHAIRMAN. Ranking Member Scott, thank you.

Senator TIM SCOTT. Yes, sir. I know you have your hands full, and I am happy to try to lighten a little bit of that load, because Ms. Blunt has not answered enough questions for me yet, so I have questions for her. I see Mr. Braddy over there laughing like he is talking like a South Carolinian. She is gifted and I am blessed to have her as our witness.

You served on a task force for South Carolina on long—term care. Now, I will say that this issue is talked about a lot because she is my American hero. I have spent several years in the industry selling long-term care policies, so this issue for me is something that I have personally thought about for 20-plus years, maybe 25 years or so, having been in the industry as a pup. I was only two years old when I started, by the way, and literally have spent some time thinking about what can make aging gracefully better.

You served on that 2014 State task force on long—term care. What has changed? What recommendations would you suggest that we as a committee, as a Congress and as a nation embrace or at least consider?

Ms. BLUNT. It was a privilege working on that long—term care task force, and we still, you know, are meeting today, because that process was like a strategic planning process around long-term care in the State of South Carolina. The first step was actually getting all the stakeholders, getting us all to the table and actually just talking, and getting us to work together with regards to policy and program development.

At the end of the day, we do cross—we do cross, so it is important that we come together. The right hand should know what the

left hand is doing so that we can work together and at the end of the day provide a seamless transition of services for our seniors.

What came out of that, as you alluded to, with SC or—earlier, prior to it being GetCareSC, we had South Carolina Access, and that is because people were looking for that one-stop shop that you referred to. As a result of that task force coming together, that is how we eventually got to having GetCareSC and, you know, started to put together marketing behind it and educating our community about long—term care services—many other things have come out of it, partnerships.

You know, we at the Area Agency, we are working with our Alzheimer's Association. We are working with AARP. We are just working with a lot of organizations who are our stakeholders, who we rely on to help us think differently. You know, oftentimes, you know, we have been thinking one way for so long, but that may not work right now. We need to—we need to change our thinking, again, bring us together, having us talk and having us collaborate.

The workforce issue, you know, that has been—you know, especially with the homecare we have been talking about, our paid professional direct care workers, that has been an issue that we are trying to tackle. You know, like I said, we came up with 30 recommendations. I will tell you, the real work came when you had to prioritize those recommendations, even of great consensus. Again, just bringing down those barriers and us talking and working through this complex homecare system in our State.

Senator TIM SCOTT. Thank you, Ms. Blunt. I will say that when I was selling the long-term care policies—and I do think we should spend some time at some point talking about the importance of helping those who can afford the long-term care policies and things that they can do that hopefully prevent the Medicaid depletion of your resources is an important part of the consideration, making it easier to digest, whether it is using the 125 platforms that allows for these policies to be tax deductible or something that actually encourages people to make a decision about long—term care assistance when they are in their forties, when it is pennies on the dollar, versus their sixties, when the expense is exorbitant.

I did not sell any policies in people, of course, in their sixties because it is just too expensive. In your forties, early fifties, this is the affordable alternative that keeps you at home or makes you the decisionmaker and not someone else, so that is a really important part of the equation, that we should find a way to encourage a public/private partnership.

I will say that when you think about those days, the activities of daily living, the five to seven activities of daily living that trigger your care is really important for us to assess how we deliver on the promise of high-quality care assistance in any form or fashion, and I think that is the important part of the formula that we still have to work through.

Mr. Chairman, I know that my time is down to zero-plus three, so I will turn it back over to you, sir, and happy to ask another question if we have members that are waiting.

The CHAIRMAN. I have to tell you, Ranking Member Scott has been on the button in his timing today. I was going to give him another minute or two or five, but now one thing I have learned—

and I see Senator Warnock, if he is ready for questions, we can turn to him.

One thing I have been informed about is these technological challenges today are not only the Aging community. This is a Senate-wide internet issue, so we are going to have—we might have some Senators that can connect by way of audio only, but if Senator Warnock is able to connect by audio, I will turn to him next, if we can see him.

Senator WARNOCK. Well, thank you very much, Mr. Chairman. I am glad to be here and glad I could get on the internet to address the issues facing our caregiving economy. I have long been a big supporter of Medicaid, Medicaid expansion, Medicaid as the primary source of coverage for long-term services and supports in the United States, accounting for 52 percent of all spending on long—term care nationwide.

The majority of the spending goes toward the Home and Community-Based Services program, HCBS, which typically involves assistance with activities of daily living like cooking, bathing, other types of housework. These critical services enable aging individuals and people with disabilities to remain in their own homes, to stay active in their communities, to lead independent lives instead of moving to institutional settings, as most Americans would prefer to receive service and supports at home.

Ms. Poo, as you know, unlike nursing homecare, state Medicaid programs are not required to cover HCBS care at home, which means the kind of at-home care Medicaid recipients can get from this program varies from State to State. Can you speak to how this patchwork leads to gaps in coverage across the states?

Ms. POO. Yes. Thank you for the question, Senator. The fact that Home and Community-Based Services, unlike facility-based care, is optional and not mandatory, it means that states can cap how many people they serve and limit the types of services offered, and this leads to some states having long waiting lists and families not being able to get the full array of supports and services that they need.

Even if they get pulled off the wait list, they may still not get the services that they need, and that, in addition to variation in pay and protections for workers that provide Home and Community-Based Services, leads to a system that is complicated to navigate, leaves many waiting with nothing, and some without what they need. In Georgia, for example, there are 8,000 people on waiting lists for this very reason, Senator.

Senator WARNOCK. It is an issue I have been working on for a while and continue to work on. Can you speak about what Medicaid expansion in Georgia and in the other 11 states that have yet to expand Medicaid, what would Medicaid expansion mean to providers and how would that benefit homecare workers?

Ms. POO. It is incredibly essential. It is so well documented that Medicaid expansion will improve access to healthcare, health outcomes, increased financial security due to the reduction and share of health costs that will improve economic mobility because it is easier to go to work or to look for work.

For example, adults in Ohio and Michigan recorded that the coverage by Medicaid expansion made it easier for them look for work

or go to work. Sixteen percent of homecare workers lack health insurance. Forty-three percent rely on public healthcare coverage, most commonly through Medicaid and Medicaid expansion. Medicaid expansion under the Affordable Care Act would benefit more homecare workers, providers who rely on Medicaid for their health insurance.

Senator WARNOCK. Providing care would actually enable people to work, which is an interesting observation, where we can have folks putting the work requirements as a basis for getting the care, and you are saying getting the care actually enables people to work; is that correct?

Ms. POO. Absolutely. That is right, Senator.

Senator WARNOCK. Thank you so much.

The CHAIRMAN. Thank you, Senator Warnock. I want to give people a sense of where we are headed next. We are going—we are alternating, obviously, from one side to the other. I am told that Senator Braun might be available, at least by audio. If he is not, I will turn to Senator Rick Scott and then Senator Gillibrand.

Senator Braun, are you connected or not? Okay, does not sound like it. Senator Rick Scott will be next.

Senator RICK SCOTT. Thank you. Thank you, Chairman.

First, I want to thank Ranking Member Tim Scott for his report on Home and Community-Based Services reform with a focus on self-directed care models. We have that in Florida, but we call it the participant directed option.

When I was the Governor of Florida, I finished about two and a half years ago, we made a series of reforms to our Medicaid program and provided more Home and Community-Based services and benefits to our Medicaid enrollees.

We went statewide with our Medicaid managed care plans.

As part of what we—that we were able to add additional benefits, such as home delivery of meals, housing assistance, which may include rent, utilities, grocery assistance and cellular service. We were able to help people maintain their health and safety before they got sick to go to the hospital without the constraints of what is or is not traditional covered services, and we were able to empower our enrollee members to receive care from an approved home health agency or from a friend, neighbor, family member or other trusted caregiver. I look forward to working with the Committee and I want to thank again, Ranking Member Scott and this Committee on replicating this across the country.

My first question is for Ms. Blunt. How can we work to make government more efficient? Beneficiaries receiving homecare are typically dual eligible with Medicare and Medicaid. My experience is these programs do not talk to each other. For example, a neglectful attendant might a cost beneficiary to go to the hospital. These Medicaid costs are absorbed by Medicare. The Medicare program does not necessarily share this information with the Medicaid program and we lose part of the feedback loop on care and measuring quality, or in this case, substandard quality.

How can we better integrate these services so we can detect substandard care? How can we better measure service quality and outcomes? How do you make sure we get a good return on our tax dollars? Would you consider inadequate coordination of care to be a

big problem and perhaps maybe the biggest problem in effective management for Medicare, Medicaid and other Americans Act programs?

Ms. BLUNT. Thank you so much, Senator Scott, for that question. You know, it is one of the frustrating things that we see on the local level is, you know, we do not have the ability—it all starts with our data systems, being able to track data, systems being able to talk to each other.

If we have the ability to—you know, when we do intakes and we are doing initial client assessments, you know, if we have the ability to collect that baseline data and then be able to report on the progress, report on what we are doing, identify and show the changes that we are making, then I think we will have a better system in place overall. You alluded to, yes, the system. The long-term care system is fragmented, and that presents a challenge, because, you know, we are not able to talk to each other.

We want to make sure that we are utilizing our resources as efficiently as possible and not double serving someone or duplicating services and efforts. We want to utilize our tax dollars as efficiently as possible, but it all starts with our data systems.

I know that is a challenge for us here in our state because we can show outputs all day long. We can show the number of meals we provided and the amount of transportation we provided, but we really need to be able to show what difference our services are making and how we are keeping people out of hospitals and how we are delaying long-term care placement.

Senator RICK SCOTT. Thank you. Ms. Blunt, one of the challenges of caring for our seniors and any vulnerable population is the potential of abuse and neglect by caregivers, our personal attendants, and the fear of the patient, of speaking up. Abuse can have physical signs, but neglect could be an attendant who shows up and does subminimal effort, which may be, as you know, harder to detect, but it has the potential to put the beneficiary into eventually a health crisis, or a new wheelchair ramp that looks usable, but not—you know, might not be up to code.

Can you speak to how we can protect our seniors from any particular harm and building accountability and how you handle these challenges in your area?

Ms. BLUNT. Certainly. You know, it is about training and educating the community, making this issue making—raising awareness to this issue. Again, we just celebrated World Elder Abuse Awareness Day on June 15th, and we partnered with the city of Charleston and the Medical University of South Carolina Center on Aging to really promote elder abuse awareness. Again, it comes down to the training. We were able to partner with the city of Charleston and train police officers on investigating allegations of abuse. It is so important that we all come together, because it is such a huge and complex issue.

Senator RICK SCOTT. Thank you. My last question, Ms. Blunt, is with Medicaid homecare being a single-payer government-dominated market, ensuring the buyer is getting a good value for the money can be pretty challenging. In Florida we have worked to address this by tying choice to the patient, by allowing them to direct

where their Medicaid dollars go and give them the ability to hire and fire their personal caregiver if they wish.

What are some of the ways you think a State can evaluate the quality of homecare services, and what are you doing in your state?

Ms. BLUNT. What we are doing—okay, so what we are doing in our State is we are—you know, it is about talking to the individual, you know, making sure we are doing the monitoring, that ongoing monitoring, and speaking with the senior, making sure that they are getting the care. You know, it is about quality assurance monitoring and making sure that everything lines up. We do not reimburse—and then with Older Americans Act funds, we do not reimburse if we do not have all of the documentation in place. We do not reimburse if we cannot confirm that the services were received by the senior, so that is just briefly, you know, kind of what we are doing here in our office.

Senator RICK SCOTT. Thank you. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Scott. Senator Gillibrand.

Senator GILLIBRAND. Thank you, Mr. Chairman. Ai-jen, thank you so much for your testimony and for your leadership. I am extremely grateful for all the work that you have been doing for communities in New York and across the country. We know that paid leave, paid family medical leave, is a crucial necessity for workers and for families, especially when a family member has a health issue.

We know that a national paid leave plan would positively boost the economy, as workers spend their wage replacement income that they earned, leading to further job creation and labor income for workers in various goods and service sectors. Widespread and active paid leave disproportionally affects women of color and lower income workers who are less likely than other workers to receive paid leave benefits from their employer.

Do you agree that national paid family and medical leave plans, such as the one proposed by President Biden, is America's Family Plan and My Family Act, helps address the overwhelming growing demand for caregiving support and long—term care?

Ms. POO. I absolutely do agree, Senator, and thank you for your leadership on this issue. It is so essential for the 48 million working family caregivers who work full time and spend more than 20 hours a week caring for aging loved ones or loved ones with disabilities. They need the ability to have time and take leave to care for the people that they love when they need to, for the care workforce, the essential workers who have been keeping us all safe taking care of the people that we love. As homecare workers, as domestic workers, they need paid leave in order to take care of their families so that our caregivers can care for those that they love too. That is absolutely essential, essential, and a structure.

Senator GILLIBRAND. Thank you. Thank you very much.

When it comes to family caregiving, how else can we provide the financial support that they need? I co-sponsored the Social Security Caregivers Act, which would create a credit that could be used, added to an individual's earnings to calculate their future Social Security benefits. I also have the idea of making full-time caregivers eligible for their own Social Security payments and checks.

Are these two ideas that you support? Do you have other ideas that we could consider and perhaps legislate?

Ms. POO. Absolutely. I support both of those ideas, and I also want to note that investing $400 billion in Medicaid Home and Community-Based Services is also supportive of family caregivers who need respite care and who need support. Oftentimes, care for the aging and people with disabilities is an all-hands-on deck situation and requires both family members and homecare workers, and I certainly support expanding access to respite care of all sorts, additional cash assistance to cover the cost of caregiving and more assistance in navigating all of these programs and services.

Senator GILLIBRAND. Thank you. That is extremely helpful. For Mr. Braddy, how do the diverse needs of the population that depend on Home and Community-Based Services, including older adults and people with disabilities, impact the need for availability of a wide range of home and community-based services, and does our care infrastructure workforce meet all the needs of all the people with disabilities? Are people falling through the cracks?

Mr. BRADDY. Yes, Senator, so many people are falling through the cracks. I think it is important for us to also look at some of the most difficult things in regard to support services, such as transportation that is affordable, accessible transportation. That is very key.

All thing—only thing, assisted technology and technology is lacking. People with disabilities benefit strongly with assisted technology. Often durable medical equipment is not provided. There is often caps to that by insurance, Medicaid and often insurance companies. They practice the thing of not medically necessary. Example is twice my insurance company denied me and said my power wheelchair was not medically a necessity, and obviously it is, right? I had to protest just to get my motorized wheelchair.

Those are the kinds of things that often fall through the crack that unfortunately people are not aware, and a family member would go in their own pocket to provide durable medical equipment for their child because that is what they do. They take care of their children with disabilities. Any parent would do that. They just do not know how to fight insurance companies.

Senator GILLIBRAND. Well, thank you so much. Thank you all for your testimony today. I am very grateful for your leadership. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Gillibrand. We will turn next to Senator Rosen.

Senator ROSEN. Thank you, Chair Casey and Ranking Member Scott for holding what I consider such an important hearing, so heartfelt. All the witnesses, thank you for your work and everything that you do.

As many of my colleagues know, I stepped away from my career as a computer programmer to take care of my aging parents and my in-laws. I was lucky enough to have them live nearby and they all got old and ill and began their journeys on that road about the same time. This issue is very personal to me, because I lived through it, in just the same way that so many Americans, they just take on that responsibility for caring for a loved one when they have to.

It is not always something that you can plan for. It sometimes just happens and you have to deal with it and do the best you can. I recently had the opportunity to meet with SEIU homecare workers in Las Vegas, of course, hear directly about the work they do and the challenges they face. In Nevada and across the country our homecare workers, of course, are overworked, underpaid and under appreciated for the critical work they do. I want to tell you, in my experience so many of those workers, those folks who were there for me in assisted living, in nursing homes and hospitals and homecare, all of it, they were angels to my loved ones and to me and to my family, and I appreciated what they do. Given these challenges, the right to organize, it is so important for healthcare workers. I am grateful to SEIU for all the work you are doing in Nevada.

Ms. Williams, can you tell me about your experience as an SEIU homecare worker, about the importance of your union benefits and the protections you have in a profession that is unfortunately undervalued. I thank you, for the families that you are taking care of.

Ms. WILLIAMS. Thank you. First, I just want to thank Ranking Member Scott for bringing attention to the different portals that different states do have where the clients and the caregivers can connect directly.

I am blessed with a union, and a lot of times we overlook the simple things. As I was listening to you all, that I have come to, you know, expect, because I receive this from my union, I receive and have won, you know, retirement and health benefits and wage increases, and the list goes on and on. When you are having amazing people like Senator Scott's mom in other states doing the same job, or my mom in Arkansas doing the same job but they are not being valued, it is heartbreaking. It is heartbreaking because we are the maintainers of life.

When we are maintaining that life—like I said earlier, we were giving the ability for the rest of society to continue forward. For a lot of our clients, some of them are able to work or continue forward what they were doing because now they have that extra balance to rebalance them from where they were, normal people given an unexpected new norm, and that caregivers, that missing fourth wheel of their car that comes in and basically rebalancing everything. When you are giving that fourth wheel enough air to do his job properly, a union, it makes the ride for all of us even smoother.

Senator ROSEN. Thank you. Speaking of smooth rides, I want to talk about incorporating palliative care into a healthcare—into caregiving plans, because I dealt with this with my mother, who had terminal cancer, lung cancer, and she needed palliative care. It would not be curative, but it would remove some of her pain. The challenges I had I launched a bipartisan comprehensive care caucus to raise the benefits of palliative care overall. Ms. Blunt, as an executive director of an Area Agency on Aging, are any of your caregivers trained in palliative care and how do you collaborate in that space?

Ms. BLUNT. Sure. Thank you for that question, Senator. Yes, our caregivers are trained in palliative care. We work—in South Carolina, we work with DHEC—licensed agencies, and so they have to

ensure that training requirements are met. At the Area Agency on Aging level, we do collaborate with hospice organizations, because we have several in our community that are doing really, really good work. They have partnered with us and provide that training and conducting that outreach and just making sure that these services and the caregivers even know that that is an option, a service that they may be accessing.

Senator ROSEN. Well, I just—again, my time is up, Mr. Chairman. I just want to really thank you and Ranking Member for having this hearing, for recognizing that this is an issue that touches every family at some time in their life and the people that they love, and we just need to be sure that we support everyone the best we can. Thank you.

The CHAIRMAN. I want to thank Senator TIM SCOTT. Thank you.

The CHAIRMAN. I want to thank Senator Rosen. Ranking Member Scott, I know I was going to try to connect—I was going to try to connect, or see if we could connect with Senator Braun. I know he has been trying to connect Senator TIM SCOTT. He has.

The CHAIRMAN [continuing]. in terms of audio. Is that *what do we know about that*?

Senator TIM SCOTT. No, not so far. I know that my staff has been reaching out to his and we have not had any success so far. Mary, I do not know that we have Senator Braun available at this point technology.

[Pause.]

Senator TIM SCOTT. He is unable to connect, sir.

The CHAIRMAN. Well, Ranking Member Scott, I think I will turn to closing.

Senator TIM SCOTT. Okay.

The CHAIRMAN. If it is okay.

Senator TIM SCOTT. Yes, sir.

The CHAIRMAN. Well, thanks very much. I just have a couple of comments and then I will turn to the Ranking Member for his closing comments. Coming out of the devastation of this pandemic, we have had a lot of challenges, obviously, for families. I think one thing that is in my judgment an obligation for those of us in the House and the Senate is to do everything we can to bring about not just change in light of this pandemic, but transformative change, both for families facing these challenges that we have talked about today, as well as the workforce.

The American Jobs Plan includes, as I mentioned earlier, a historic investment in what I think is a Great American idea, Home and Community-Based Services, which a lot of Americans receive already, but a lot more do not, unless we make this investment. This investment will ensure that older adults and people with disabilities are able to receive the services they need to remain independent and to be active members of their communities. We must make this investment to strengthen and fairly compensate a critical workforce that has been neglected for far too long. I think the pandemic, as it did on a number of fronts, highlighted that lack of investment and highlighted the essential nature of the work done by those caregivers.

I look forward to working with all of our colleagues to advance the policies we have talked about today. I do want to thank in par-

ticular our witnesses, Ai-jen Poo, Stephanie Blunt, Brittany Williams and Theo Braddy.

Now I will turn to Ranking Member Scott for his closing comments.

Senator TIM SCOTT. Thank you, Mr. Chairman, and thank you for handling with grace the challenges from a technological standpoint that the Committee was faced with today. For most of us it seemed to be a very small, recognizing your hard work behind the scenes. I realize it was infinitely more than a small challenge, but you handled it quite well.

Thank you to each of the witnesses who invested their time, and frankly, to those who have had really challenging yet inspirational stories. Thank you, sir, for your amazing testimony, and frankly, your life's journey that tells us that all things are still possible, no matter the challenges. Whether it is a football accident at 15 years old, it is just a powerful story that we all benefit from hearing.

Ms. Williams, thank you so much for recognizing my mom and her sacrificial service to other. One of the reasons why I think I am a United States Senator today is because I had such a wonderful model that I was able to follow from a very early age.

I will say this, that Chairman Casey and I probably disagree on a lot of issues, but the way that he handles himself makes me so proud to be the Ranking Member on this Committee. While we may not see the same solution, we typically see the same problem. The beauty of America is that we can take different paths to the same problem and hopefully open eyes that we are all in this together.

I would say that the American Jobs Plan is a Federal Government-centric approach to solving needs that I consistently disagree with. I see the same need, but I think that the community and the local solutions are consistently better for the patient and the caregiver. While we will disagree on some of the solutions, I do think the importance of agreeing on the problem should not be overlooked or understated.

Patients and families want flexibility for patient—centered, self-directed care, not government-directed bureaucracy. That is really the most important point for me. In fact, we believe that the Federal Government spending more in this area is an important consideration, and frankly, an important resource. We would want it to be directed to local organizations to provide the highest level of care.

There is a reason why the things that we care about most are not in Washington. They are in our own houses, our families. To the extent that we can provide more resources, more information, more collaboration from the local level up and not from the Federal Government down, we believe will provide the highest continuum of life and care.

Mr. Chairman, I thank you for this hearing. I think each panelist for your expertise in providing what we needed to hear. I do think that we will find better solutions when we are working together for those solutions, even though we may disagree on how to get there. Mr. Chairman, I yield back the balance of my time.

The CHAIRMAN. Ranking Member Scott, thanks for your statement and thanks for working with us on this hearing. I think we can both commend and salute our staff on my side, represented by

Stacy Sanders, who had to do the really hard work on the, not just the hearing, but on the technological issues. We are grateful for their work and others who helped us get through the challenge we had.

I also want to thank the Ranking Member for sharing not only his thoughts and his views on these issues, but sharing his mom's story. It just shows that so many Americans have had these experiences, and we need to benefit and learn from all of those stories.

Again, we want to thank our witnesses for contributing both their time and their expertise. If any senators have additional questions for the witnesses or statements to be added to the record, the hearing record will be kept open for 7 days until next Thursday, June 24th.

Thanks, everyone, for participating today. This concludes our hearing.

[Whereupon, at 11:18 a.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

Statement of Ai-jen Poo, Executive Director, National Domestic Workers Alliance

June 17, 2021 Hearing before the U.S. Senate Special Committee on Aging

"21st Century Caregiving: Supporting Workers, Family Caregivers, Seniors and People with Disabilities"

Introduction

Chairman Casey, Ranking Member Scott, and Members of the Committee, thank you for the opportunity to testify on the importance of investments in Medicaid's Home and Community-based Services as central to our economic recovery.

My name is Ai-jen Poo, and I am the Executive Director of the National Domestic Workers Alliance (NDWA) and Caring Across Generations (CAG). Founded in 2007, the National Domestic Workers Alliance is the nation's leading voice for 2.2 million domestic workers who work as nannies, home care workers, and house cleaners in private homes. NDWA works to improve the quality of jobs in the care economy, and to achieve fairness and dignity for this workforce that provides essential care and cleaning services in our homes. Many domestic workers are also older women, and family caregivers. NDWA's community includes over 250,000 domestic workers in all 50 states, and 74 local affiliate organizations and chapters in 36 cities and 19 states.

Caring Across Generations was founded in 2011 to bring together family caregivers, care workers, people with disabilities and older Americans to advocate for a strong care infrastructure that would support us all to live, work, care and age with dignity. Caring Across Generations is working to create a culture that values care and caregiving, and policies that support universal access to long-term services and supports (LTSS), childcare, paid family and medical leave (PFML) benefits and a strong care workforce. We work with a diverse network of over 100 national, state and local advocacy organizations and unions, including caregiver, aging, disability rights and justice, disease-based groups, women's organizations and more.

Together, NDWA and Caring Across Generations have worked for a decade to bring attention to the growing need for care, and the urgency of investing in Medicaid Home and Community Based Services for older adults and people with disabilities. I believe we have a once in a generation opportunity to do precisely that -- to build the 21st century care infrastructure we need.

Caregiving is personal to me. My grandfather, Liang Shao Pu, played a critical role in raising me. He lived a long and full life. He was a student and teacher of tai chi, a die-hard Wheel of

Fortune fan, and an avid reader. He spent a lifetime working and caring for his family, including his wife of more than 40 years after she suffered a stroke. Towards the end of his 93 years, he lost his eyesight, and needed more support than my family was able to provide him at home. We could not find appropriate home care support, so my grandfather was placed in a nursing home against his wishes.

I visited him there and I will not forget it. He was in bed in a dark room with six other people, including several who cried out in misery. The lights didn't work. My grandfather was distressed, he had not eaten or slept in some time, he was frightened, and depressed. A shell of himself. The staff was overworked and struggling to manage all the people in their care. After just three months in the facility, my grandfather passed away. I will always regret that these were the conditions of my grandfather's final days.

The Case for Robust Investments in Home and Community Based Services

While this story is my own, it is hardly unique. Eighty eight percent of aging adults prefer to receive long-term supports and services (LTTS) in home and community-based settings. But these services are out of reach for too many. Across the United States nearly 820,000 aging individuals and people with a disabilities are on waiting lists for Medicaid HCBS[1]. People on waiting lists for Medicaid HCBS often wait years, sometimes decades to access these vital services. And we are facing an elder boom: by 2050, the population of people 65 and older will nearly double[2]. With 10,000 people aging into retirement per day, and living longer, there's overwhelming demand for care in the home[3].

For older Americans to live and age at home, we need infrastructure -- including a robust workforce that can meet the demand. From 2018 to 2028, the U.S. will need to fill over 4.4 million home care job openings -- making home care one of the fastest growing occupations in our economy. But because of low-wages and poor job quality, workers must struggle to survive in this profession. According to PHI, home care workers earn on average $17, 200 annually.[4] The median hourly wage for home care workers only increased by a total of 91 cents between 2009 and 2019[5]. In the same time period, the number of jobs in this industry saw growth of over

[1] MaryBeth Masumeci, Molly O'Malley Watts, and Priya Chidambraram. Key State and Policy Choices about Medicaid Home and Community-Based Services (February 4, 2020) available at https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/

[2] U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, What is the lifetime risk of needing and receiving long-term services and supports (April 4, 2019) available at https://aspe.hhs.gov/basic-report/what-lifetime-risk-needing-and-receiving-long-term-services-and-supports

[3] Emily Swanson and Ricardo Alonso-Zaldivar, The Christian Science Monitor "Most Americans would rather age at home, says poll" (May 3, 2021) available at https://www.csmonitor.com/USA/Society/2021/0503/Most-Americans-would-rather-age-at-home-says-poll

[4] PHI, High Demand Yet Low Wages for Direct Care Workers available at https://phinational.org/news/new-research-high-demand-yet-low-wages-for-direct-care-workers/

[5] PHI, Direct Care Worker Median Hourly Wages Adjusted for Inflation, 2009 to 2019 available at http://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends

1,400,000 jobs or approximately 145%[6]. The wages have not kept pace with increases in cost of living over the last 10 years.[7] As a result, one in eight direct care workers[8] lives in poverty, and three-quarters earn less than the living wage in their states[9].

Care work is also emotionally taxing and physically punishing -- involving heavy lifting, long hours, and exposure to potentially hazardous materials[10]. Low pay, combined with difficult and poor working conditions, has led to chronic staffing shortages in the home care sector, and instability for care workers and the families that they serve.[11] Turnover rates are high[12]. Even home care workers who love their jobs often leave the profession for other low-wage service jobs because they can't make ends meet on the wages they earn. For example, PHI found that in all 50 states and the District of Columbia, wages of direct care workers are lower than the median wage for other occupations with similar entry-level requirements, such as janitors, retail workers, and customer service representatives.[13] This also means there are many parts of the country with home care deserts, where people simply cannot get access to these services because there's no workforce, especially in rural communities.

---

[6] PHI, Direct Care Worker Employment, 2009 to 2019, available at http://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Employment+Trends

[7] Bureau of Labor Statistics, Consumer Price Index Historical Tables for U.S. City Average, available at https://www.bls.gov/regions/mid-atlantic/data/consumerpriceindexhistorical_us_table.htm.
See also Irene Jiang, Business Insider, How much American grocery staples like bread, bacon, and coffee cost now versus 10 years ago (Dec. 18, 2019) available at https://www.businessinsider.com/grocery-price-change-bread-bacon-cost-10-years-ago-now-2019-12#tomatoes-11.
See also Aimee Picchi, CBS News, It's been a record 11 years since the last increase in U.S. minimum wage (Jul. 24, 2020) available at https://www.cbsnews.com/news/minimum-wage-no-increases-11-years/

[8] Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone. Leading Age. "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities" (September 2020) available at https://www.ltsscenter.org/wp-content/uploads/2020/09/Making-Care-Work-Pay-Report-FINAL.pdf

[9] Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone. Health Affairs. "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities" (December 7, 2020) available at https://www.healthaffairs.org/do/10.1377/hblog20201202.443239/full/

[10] Linda Burnham and Nik Theodore, Home
Economics: The Invisible and Unregulated World of Domestic Work, National Domestic Workers Alliance, pp. 28-32 (2012) https://domesticworkers.org/sites/default/files/HomeEconomicsReport.pdf

[11] Chris Farrell, Forbes, The Shortage Of Home Care Workers: Worse Than You Think (April 18, 2019), available at https://www.forbes.com/sites/nextavenue/2018/04/18/the-shortage-of-home-care-workers-worse-than-you-think/?sh=6f1ed6f83ddd

[12] Margaret Barthiel, NPR, Many Health Workers Earned Low Wages, Suffered Losses During The Pandemic (March 10, 2021) available at https://www.npr.org/local/305/2021/03/10/975626535/many-health-workers-earned-low-wages-suffered-losses-during-the-pandemic

[13] Robert Espinoza, PHI, Competitive Disadvantage: Direct Care Wages Are Lagging Behind (Oct. 13. 2020) available at https://phinational.org/resource/competitive-disadvantage-direct-care-wages-are-lagging-behind/

The President's proposed $400 billion investment in Medicaid's Home and Community-based Services (HCBS) would expand access to these essential services and care for the older adults and people with disabilities. Medicaid eligible older adults and people with disabilities will finally have the services and supports they need to live independently and in their chosen community. And it will raise wages and improve conditions for the direct care workforce, an essential workforce in need of investment. These two goals are interdependent and we must invest boldly if we are to achieve these dual goals.

These investments would be historic and impactful for our recovery in several ways.
First, according to a recent analysis, investing $400 billion in the HCBS sector will create over 1.1 million new jobs each year over 10 years, nearly 800,000 of which are home and community-based care jobs. This investment would add an estimated $40 billion additional income for workers and their families each year[14]. These figures include over 58,000 new jobs in Pennsylvania, over 18,000 in Arizona, and more than 14,000 jobs in Georgia to name a few. This proposed investment would generate $40 billion per year in additional income for American families and the economy.

An investment in HCBS prioritizes a workforce that -- because of racism -- has faced exclusion from labor rights and protections since the New Deal[15]. To this day, 63% of home care workers are Black, Hispanic, Asian American/Pacific Islander or Native American.[16] Placing this workforce, at the forefront of this jobs and infrastructure plan is not only good policy, it reflects a true commitment to equity. This investment will have compounded impacts for women, older women, and women of color -- seeding an economic recovery for women that is sorely needed. These are jobs that won't be automated, and can't be outsourced, so they will be here to stay, and we must make them good jobs. Just like we transformed manufacturing jobs in the 1920s and 1930s from dangerous, poverty wage jobs, to jobs with real economic mobility, we can and must do the same for care jobs. And we will all benefit.

Second, more than 50 million unpaid family caregivers are stepping in and juggling care for their loved ones while also managing full-time work outside the home. We know that 60 percent of family caregivers are women. The majority of working family caregivers report having to make changes to their work status due to caregiving responsibilities, like reducing work hours,

---

[14] Lenore Pallodino, Chirag Lala. Political Economy Research Institute. "The Economic Effects of Investing in Quality Care Jobs and Paid Family and Medical Leave" (June 14, 2021) available at

https://www.peri.umass.edu/component/k2/item/1465-the-economic-effects-of-investing-in-quality-care-jobs-and-paid-family-and-medical-leave

[15] Economic Policy Institute, Domestic workers are underpaid and unprotected by labor law during the coronavirus pandemic (May 14, 2020) available at https://www.epi.org/press/domestic-workers-are-underpaid-and-under-protected-by-labor-law-during-the-coronavirus-pandemic/

[16] Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone, Leading Age, Making Care Work Pay, p. 13 (Sept. 2020) available at https://leadingage.org/sites/default/files/Making%20Care%20Work%20Pay%20Report.pdf

changing jobs, or leaving the workforce altogether[17]. The burden is especially acute for sandwich generation family caregivers, the 11 million Americans providing care for an aging or disabled loved one while also raising and managing caring for children.[18] This is particularly important in light of the nearly 3 million women who've been pushed out of the workforce in the pandemic because of caregiving challenges, also disproportionately women of color. Women's overall participation in the workforce dropped to 57% -- the lowest level since 1988[19]. When family caregivers are forced out of the labor market, there are both short term and long-term consequences for their financial well-being, including diminished Social Security benefits.

Third, the benefit to consumers cannot be overstated. Quality of life and independence for older people and people with disabilities should be a top priority for an aging nation. Consistent, dependable assistance allows people to live full lives, with dignity, connected to their families and communities. Atul Gawande writes in his bestselling book, *Being Mortal*, about the importance of "being the author of your own story." These services allow people to live life on their own terms, even as they become more frail, they allow people with disabilities to work and be full participants in our recovery and so much more.

Finally, there are benefits to our public health and our health care system overall. The direct care workforce provides critical support with activities of daily living such as bathing, dressing, and some also provide medical care, such as managing medications or performing tracheostomy care. Improving and expanding these services in the home and community will result in downstream savings in our healthcare system, reducing the need for institutional care, which can be more expensive, and preventing expensive, unnecessary emergency room visits and rehospitalizations.

Conclusion and Recommendations

The care economy is the foundation of the entire economy. When we invest in it, we invest in jobs and prosperity for all. That is why Medicaid Home and Community Based Services are widely popular across the political spectrum, across the country. Voters and families agree -- we need a strong care infrastructure. And these services, and this workforce, are simply essential.

We have a once in a generation opportunity to strengthen our economy for the next era, an opportunity that is also a responsibility we have to our nation's older people, people with disabilities, our families and the caregiving workforce.

---

[17] National Alliance for Caregiving. "Caregiving in the U.S. 2020" (2020) available at https://www.caregiving.org/caregiving-in-the-us-2020/

[18] Lisa Weber Raley, MA. Burning the Candle at Both Ends: Sandwich Generation Caregiving. In the U.S. (November 2019) available at https://caringacross.org/wp-content/uploads/2019/11/NAC_SandwichCaregiving_Report_digital112019.pdf

[19] National Women's Law Center, The Pandemic, The Economy, & The Value of Women's Work p. 3 (March 2021) available at https://nwlc.org/wp-content/uploads/2021/03/Final_NWLC_Press_CovidStats.pdf

Former First Lady Rosalynn Carter once said, “There are only four kinds of people in the world. People who are caregivers or will be caregivers. People who need care or will need care.” We will all be in a position of providing or needing care, sometimes simultaneously, particularly because our nation is aging.

The proposed investment of $400 billion in the American Jobs Plan is an investment in all of us, one that cannot be shortchanged. The additional investments in child care and paid family and medical leave in the American Families Plan, these are investments in us -- in our ability to live, work and care, with dignity, even as we age.

Testimony before the United States Senate Special Committee on Aging

Stephanie Blunt

June 17, 2021

Senator Scott, Senator Casey, Members of the Senate Special Committee on Aging:

Thank you for the opportunity to speak with you this morning. It has been a pleasure serving in the South Carolina Aging Network for the past twenty-five years at the local service provider level and at the Area Agency on Aging level. Trident Area Agency on Aging (TAAA) is a private, Nonprofit Corporation designated by the South Carolina Department on Aging as one of ten Area Agencies on Aging (AAAs) in the State.

Since the organization was formed in 1991, we have worked within the public and private sectors to develop a cost-effective approach to long-term care services. We serve as the resource connection for seniors, adults with disabilities, family caregivers, and professionals. I lead fifteen (15) staff who have daily contact with seniors and their families. Our office directly provides Assessment, Family Caregiver Support, Information and Referral Assistance, Long Term Care Ombudsman, Insurance Counseling and Senior Medicare Patrol. It is my responsibility to work within budgets, adhere to regulations, and to develop and implement Policies and Procedures; but at the end of the day, it's about making all of those factors connect with the lives of real people who need our assistance. Annually, our staff and volunteers serve over 12,000 seniors and 1,500 family caregivers.

Since 1965, the Older Americans Act (OAA) has been the solid foundation for aging services throughout the country. My years of experience in the field have taught me how to cobble together funding from federal, state, and private

resources to meet the needs of a growing and diverse aging population. It is not an easy task to make regulations and criteria match the needs of people in the community. States, regions and counties all have different needs. It is a waste of resources to collect needs assessment data and not be able to make real changes or offer other services that will keep seniors out of hospitals and delay long-term care placement. While the OAA is designed with some local flexibility in mind, there are still restrictions on which services we can provide with which set of funds. AAAs need to have more flexibility to determine how the funding is spent locally.

Since 2001, our AAA has offered caregiving support services through the OAA National Family Caregiver Support Program. We have seen first-hand the many challenges that family caregivers face, particularly the working family caregiver. On a daily basis, our staff receive calls from stressed out family caregivers who are balancing fulltime employment, their family, and their caregiving responsibilities for aging parents and grandparents. Through the Family Caregiver Support Program, we are able to provide information to family caregivers, connect them to services, provide Dementia education and offer respite.

The respite that we provide gives caregivers a temporary break from caregiving responsibilities. In South Carolina, the average respite assistance is valued at approximately $2,000 annually, thus providing a break of around ninety (90) hours per year per family caregiver. This respite break is helpful to many caregivers; however, it does not meet the ongoing needs of working family caregivers. Finding affordable eldercare options is a difficult task for nearly every family, given our country's fragmented long-term care system, the lack of investment in the more fiscally responsible home and community-based options, and the workforce challenges.

The lack of workforce in the home care industry continues to be a barrier in providing respite for family caregivers and home care services. We rely heavily on trained, professional direct care workers to perform personal care, light housekeeping and meal preparation for seniors who are at risk for long-term care placement. Unfortunately, hiring and retaining direct care workers has become a tremendously difficult task given the low wages this work pays despite the demands of the job. In our region, the pay for a direct worker ranges from $10 to $17 per hour, depending on years of experience, certifications and the level of care they provide. We need to increase compensation for direct care workers and enhance the reimbursement rates for home and community-based service providers who employ these workers if we are able to meet the rising and complicated service needs of our aging population.

In 2014, I served on the Steering Committee of the South Carolina Institute of Medicine and Public Health (IMPH) Long-Term Care Taskforce. The Taskforce released a report in June 2015 that became a statewide tool used to raise awareness about various components of the long-term care system in South Carolina. The Steering Committee was comprised of governmental agencies, as well as stakeholders representing the long-term care industry, such as the Alzheimer's Association and AARP. We worked in four sub-committees and developed thirty (30) recommendations. The real work began when we had to prioritize those recommendations and begin working on solutions to improve long-term care in South Carolina. We need to require agencies that provide long-term care services on the federal, state and local levels to better collaborate in planning and in program development.

TAAA would not be able to meet the needs of seniors and family caregivers without our community partners, such as the Alzheimer's Association, the Medical University of South Carolina Center on Aging, the City of Charleston Mayor's Office on Aging, and the Lowcountry Food Bank. These are just a few of the many organizations that partner with us to strengthen the long-term care system in our region and throughout Palmetto State. Thank you for the opportunity to testify before this committee and allowing me to share my experience in serving older Americans and family caregivers.

Testimony to the Senate Special Committee in Aging
"21st Century Caregiving: Supporting Workers, Family Caregivers, Seniors and People with Disabilities"
June 17, 2021

Brittany Williams, Home Care Worker
SEIU Local 775, Seattle, WA

Thank you, Chairman Casey, Ranking Member Scott and members of the Senate Special Committee on Aging for inviting me to speak to you today. My name is Brittany Williams, and I'm a single mom, a home care worker and a proud member of SEIU 775 from Seattle, WA.

As a home care worker, I help seniors and people with disabilities in my community live with dignity and independence at home. Home care workers like me provide essential, life-saving care, such as bathing, cooking meals, cleaning, helping clients go to the bathroom or move around their homes, driving to and from appointments, running errands and anything else someone may need throughout the day.

Caregiving isn't just a job for me — it's in my genes. I grew up in Arkansas, watching my grandmother and mother care for seniors and people with disabilities in our community. While I was in school learning my ABCs and 123s from my teachers, I was also learning from my mother and grandmother invaluable lessons in compassion and what it means to care for someone in need. They were the best role models a young girl could ask for. It became clear to me at a very young age that care is essential, and that care work makes all other work possible. I felt a strong calling to carry on the legacy of the generations of women before me and become a home care worker.

I currently take care of three different clients. When I start with each client, I do the baseline check I learned in training. This helps me ensure that each client is in a good place and there have not been drastic changes from the last time we met. After my baseline check, I do a variety of care plan directed activities, such as making sure they have the medications they need, picking up groceries and preparing food for them, and making sure their homes are safe and clean. It's life-giving work I am proud to do.

In addition, I am occasionally asked to fill in for another caregiver. When these opportunities arise, I'm not always given complete information about my temporary clients' conditions. For one such client, I knew they were agitated from the moment I stepped in the door. Relying on my deescalation training, I was able to help the client feel comfortable and safe. Throughout the week I relied on this training daily. By the end, when I met the client's representative, I learned the client suffered from dementia. I was thankful for my training — without it, that week could have taken a very different turn.

Because of the care home care workers provide, people in need of long term care can stay in their homes, surrounded by the people and things that they love. Home care workers help our clients live longer, fuller lives. It's a blessing to work with my clients, and the trust and love we share with one another is unlike any other.

But this job is hard. It's physically and emotionally demanding, and you have to have unlimited patience, compassion and energy to do this job well. But it's not just the job itself that's taxing. It's also what's happening behind the scenes.

I always say home care workers are the maintainers of life — but we can barely survive ourselves.

Home care is one of the lowest paid jobs in the country. The median hourly wage for home care workers nationally is just over $12 an hour. Of the more than 2.4 million home care workers in this country, 47 percent live below 200 percent of the poverty level, and more than 50 percent rely on some form of public assistance. Many of us don't have affordable healthcare, and because we can't afford to see a doctor, we sometimes have to push through an injury or illness and go to work. Many home care workers don't have paid sick time either, so if we take a day off, we don't get paid. And without that paycheck, we might not be able to afford groceries, that month's rent, or our children's school supplies.

I first started home care work in Arkansas, and was paid minimum wage. I couldn't afford to take a sick day and struggled to support myself. When I moved to Washington, I joined SEIU Local 775, the state's caregivers union. Being able to join with other home care workers changed my world and created a new sense of possibility. When I started, I took 70 hours of training to make sure I can do the work I need to do to keep my client safe.

My mom says that home care work in this country is like diving into the deep end of a swimming pool when you can't swim. And that's the way it's always been for home care workers — long before my mom or my grandma started doing this job. Today, nearly 90 percent of home care workers are women, more than half are women of color, and three in ten are immigrants. Black women like me have been the caregivers of the nation for centuries, but due to a long history of racism and sexism, our work has been falsely labelled as unskilled women's work, and that narrative has been used to exclude home care workers from labor laws and deny us the protections afforded to other workers.

And if things weren't bad enough already, the COVID-19 pandemic ran home care workers into the ground. Everything I thought was secure, the pandemic took away. It took away my security of having someplace safe for my son to learn when the schools closed down. It took away my security of being able to work the hours I need to work in order to provide for my family. And that resulted in losing the security of having a roof over my head in the city that I love. Even though eviction moratoriums were in place, when my lease came up for renewal I was forced with the choice to pay back thousands of dollars of missed rent or move. I was lucky to have a

community around me to support me and help with my move, but the pandemic caused a whole lot of stress.

Over the past year, healthcare workers have been celebrated as heroes. We've all seen the videos of people clapping, banging pots and pans, and honking their horns for healthcare workers starting their shifts. It's a beautiful thing. But who has clapped for the home care workers, who worked tirelessly to keep people safe in their homes and out of nursing homes during a global pandemic?

Each day, home care workers like me are forced to make impossible decisions, and the daily anxiety of feeling that I could potentially put my client at risk when we faced PPE shortages was crippling. How do I make these decisions in the midst of everything that's happening around me? Pandemic, economic turmoil, fighting for hazard pay and PPE, and then add on top of that, racial violence. That's asking people to do too much by themselves. I stayed strong and I did what I had to do for myself, my family and my clients — but I'd be lying if I said I wasn't scared for my life each and every day I walked out the door.

I ended the year exhausted and angry. I'm angry at the injustice of it all.

Home care is one of the most important jobs in our communities, and home care workers deserve to be respected, protected and paid a living wage for the essential work we do. Some 20 million Americans already require long term care. With roughly 10,000 people turning 65 every day, we will need to fill an estimated 4.7 million home care jobs by 2028. In Washington State alone, estimates find that by 2030, Washington will need an additional 400,000 home care workers to meet the demand for care services. But the low quality of these jobs forces people out of the industry, leading to turnover rates as high as 60 percent in some markets.

Without a strong, well-supported home care workforce, our country is in the midst of a care crisis. Long term care is often inaccessible and unaffordable for working families. With no other options, people must quit their job to serve as full-time, unpaid caregivers. And sometimes, those in need are forced to go without care altogether.

No one should be forced to leave their jobs to stay at home and care for a loved one, just because there is no other option. And no one should ever have to forego the life-saving care they need.

To solve this crisis, we need to build a strong home care workforce that can answer the call for care. When families are in need, we need a system where affordable care is accessible to everyone — no matter who they are or where they live— and gives families the piece of mind so that they can continue going to work knowing their loved one is safe and cared for.

In addition to being a third generation home care worker, I am also a third-generation union member. My grandma was part of the bus union in Arkansas — she was the first woman to drive a city bus in Little Rock. My dad was a member of the police union. My mother has been a

caregiver for over 32 years, and when she lived in Washington, she was a proud member of SEIU 775, too.

And thank God for my union.

When I first started in home care I made just $9.45 an hour — a wage I couldn't afford to live off of. But united in our union, home care workers were able to win the raises and benefits we needed. Caregivers now start at $16.72 an hour, we have paid time off, mileage reimbursement and guaranteed raises every six months, with increases based on experience and training. We have paid sick leave, paid administrative leave, access to free slip resistant shoes to minimize on the job injuries, and PPE at no cost. We won healthcare benefits. We have solid retirement plans. Just before the pandemic, we celebrated the passage of the HADit bill — a law to make care environments safer for everyone by eradicating harassment, abuse, and discrimination of caregivers.

But even that isn't enough. With the cost of housing and food and everything else, $17 an hour isn't a living wage. Thanks to the temporary increases in federal funds through the Families First and American Rescue Plan laws, we have won hazard pay of roughly $2.50 an hour through the pandemic. That has been a lifesaver, helping caregivers pay the bills, stay in our homes and continue working. But we need a living wage all the time, not just during the pandemic. When this temporary federal funding ends, we're back to the status quo for home care.

The national long term care system isn't working, and healthcare disparities have created a reality where a person's zip code determines access to essential health services and the standard of care they receive, as well as the quality of home care jobs. My mom is still a home care worker in Arkansas, and although we do the exact same work, her situation is worlds different from mine. She makes just over $11 an hour caring for my grandmother — with all of the experience she has, she would be making around $20 an hour doing the same work in Washington.

My union sisters and brothers have been able to make Washington State home care jobs among the best in the nation. I'm grateful for my union and the work we've done together and am so blessed to be part of this community, but the victories are bittersweet because I know not every home care worker is in my same position. Every home care worker who provides essential services to seniors and people with disabilities should have that same kind of union support to back them up.

As home care workers, we work tirelessly to help support quality of life and feel a moral responsibility to do so. I don't fight for just myself, my coworkers and clients, but for the younger generations too. If my children choose to follow in my footsteps and become caregivers, I don't want them to struggle to make ends meet and provide quality care like I had to. I don't want what we've won to become a thing of the past.

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're to 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.

Our country needs a wakeup call, especially in the wake of a devastating global pandemic where care was center stage. The American Jobs Plan's $400 billion investment would be life-changing for home care providers and consumers alike. We need access to quality, affordable health services, clean air and water, and opportunities that allow our children to grow and thrive no matter where we live. New funding is needed to raise wages to attract the workforce we need to meet the demand for care and return quality of life for millions of seniors and people with disabilities who are reliant on our services. We need policies that make it easier for workers to join unions and advocate for their profession and those that they serve, so people have an actual choice of where they want to receive care and age without bankrupting themselves. And this investment will provide an opportunity to address the impact of systemic racism and sexism on home care workers and women of color to lift millions of Black, Latina, Asian, indigenous and immigrant women out of poverty and provide a much-needed economic boost to communities of color — those hit hardest by COVID-19.

Take it from me: the need for care can change in the blink of an eye. When that time comes, don't you want the comfort in knowing a skilled, dedicated caregiver will be by your side? If you or a family member suddenly needed home care tomorrow, are you confident that you'd be able to get the resources and services you need?

I suggest you not wait and find out. Care can't wait.

We can't go back to the way things were before the pandemic and that is why we are supporting the American Jobs Plan. Care work is infrastructure because it's what makes all other work possible. Care work gets seniors and people with disabilities the support they need to live with dignity and independence at home and in their communities. It's the foundation of our economy — no one can do their job if they or their loved ones aren't cared for. I want to thank you in advance for standing up for caregivers, standing up for essential workers, and making sure the world we are building is one we can all be proud of. Caregivers need to be seen as the professionals we are. We are the maintainers of life, and for that, we must be respected, protected and paid.

REFERENCES

PHI. "Direct Care Workers in the United States: Key Facts." (2020)
Retrieved from: https://phinational.org/resource/direct-care-workers-in-the-united-states-key-facts/

Banijamali, S., Hagopian, A., Jacoby, D. "Why They Leave: Turnover Among Washington's Home Care Workers" (2012) Retrieved from: https://fliphtml5.com/yyhu/tbcb/basic

Theo Braddy
Testimony before the
United States Senate Special Committee on Aging
June 17, 2021

I would first like to thank you Chairman Casey, Ranking Member Scott and the members of the Special Committee on Aging, for inviting me to share my story.

My name is Theo Braddy. I became a person with a disability at age 15 after breaking my neck playing high school football in Wadley, Georgia.

I am originally from Georgia. I am 61 years old. I retired early in 2019 after working 31 years as CEO of the Center for Independent Living of Central Pennsylvania (CILCP). The mission of CILCP is to eliminate and prevent barriers faced by people with diverse disabilities on a day-to-day basis.

I am married with a 28-year-old daughter and a 23-year-old son. I now work part-time as President of Theo Braddy Consulting.

Most importantly for this hearing, I am a user of Home and Community-Based Services (HCBS) and have been for almost three decades.

As I share my story, please understand that it is not only my story, but a story that is lived out by millions of people across the country!

Disability - What we don't know is when it can happen, but what we do know for sure is when it happens, life will change!

You will be faced with all types of new barriers in life. The turning point in my life happened when I broke my neck that April 46 years ago, at age 15 and my life changed.

I became paralyzed from the neck down and I couldn't do anything for myself!

Life changed for me. It became what I refer to now as a "maze of confusion".

I ended up in a nursing home at age 15, and like most people becoming disabled, the full weight of caring for someone newly disabled falls solely on the family. For me, that responsibility fell to my brothers and sisters.

You see, they got me out of the nursing home and moved me to Pennsylvania where I ended up on the 3rd floor of an apartment building looking out of a window for weeks at a time, waiting for my brothers to come over and physically carry me down 3 flights of stairs and eventually back up again. That waiting on others went on for a long time.

I have no way to explain how it feels not to be able to do anything for yourself anymore. I left rehab not even being able to feed myself or able to push my manual wheelchair.

Home and Community-Based Services changed all of that. It started when I received attendant care services.

I have said this many times in my career, people with disabilities do not want to be taken care of. We do not want to be objects of charity. We want to contribute and give back!

HCBS attendant care services did that for me. I call it the great equalizer!

Breaking my neck paralyzed me. It took away my ability to do things for myself independently. I couldn't dress or bathe myself, feed myself, get in or out of bed. I couldn't go anywhere without help from others.

There were many times throughout my 31 years at works when I had to depend on attendants to drive me back and forth to my many meetings, because it was just too far or too painful for me to do it myself.

Being provided with attendants gave me back my independence and my ability to live life fully again.

Once my I started to receive HCBS I enrolled in Edinboro University in Erie, earned my degree, and graduated with honors. I then went on to graduate school at Temple University in Philadelphia and received my master's in social work (MSW).

In undergraduate school, for the first time, as all college students want, I was able to move off-campus and live in an apartment by myself.

Shortly after finishing my MSW, I worked with a group in central Pennsylvania to apply for a grant to establish what became the Center for Independent Living of Central PA.

Once the grant was approved, I applied for the director position, and I ended up leading the organization for 31 years.

I have taught as an adjunct professor at Millersville and Temple Universities and have visited quite a few colleges as a guest lecturer.

I have been appointed to serve on boards and commissions by 3 different Governors. These include the Pennsylvania Human Relations Commission; The Pennsylvania State Independent Living Council; and the Pennsylvania State Board of the Office of Vocational Rehabilitation, which I current serve on.

As a result, I have impacted many lives for the better!

All along the way, my different attendants helped me get up in the morning, travel with me as needed, and assisted me in getting back in bed at night. Not 24/7 but when I needed them. They made it possible to live a full life.

This is what I want to be your takeaway - don't miss this!

All the time I was going to school, leading a non-profit agency, and helping to form state and federal policy, I was still paralyzed from the neck down. My physical disability didn't change. So what did?

My access to HCBS!

Some might say I've received a lot of support and resources for one person. But this is the thing — I have paid more taxes and put so much more money back into the economy than what has ever been spent on me as I was being supported through HCBS.

This is one reason why HCBS is so essential. It is an investment in the potential of people, people who, so often, society wants to write off.

Believing in the potential of people with disabilities will yield a return on that investment.

What it did for me, it can do for so many others: for people with disabilities; for older adults, for their families, and for the workers who provide the services, if we make the investment in HCBS.

HCBS is not only a great equalizer, it is a game changer!

This is why the $400 billion proposed by President Biden's Infrastructure Bill for HCBS is so essential.

Please don't forget this! Thank you!

○