

**AN ECONOMY THAT CARES:  
THE IMPORTANCE OF  
HOME-BASED SERVICES**

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

SECOND SESSION

WASHINGTON, DC

MARCH 23, 2022

**Serial No. 117-14**

Printed for the use of the Special Committee on Aging



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# **AN ECONOMY THAT CARES: THE IMPORTANCE OF HOME-BASED SERVICES**

**WEDNESDAY, MARCH 23, 2022**

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

The Committee met, pursuant to notice, at 10:30 a.m., via Webex, Hon. Robert P. Casey, Chairman of the Committee, presiding.

Present: Senators Casey, Gillibrand, Blumenthal, Warren, Rosen, Warnock, Tim Scott, Braun, and Rick Scott.

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

The CHAIRMAN. We will get started.

The hearing will come to order. We are gathered today in the Aging Committee to discuss the critical need to lower costs for families, to get Americans back to work, and to strengthen our economy. For too long, our Nation has viewed caregiving as a personal problem or limited to one family, and expecting those families to figure it out on their own. American families are silently struggling to find and afford reliable, high-quality care that enables their loved ones to live independently.

Today our witnesses will speak about the importance of home and community-based services for seniors and people with disabilities and the investment American families across our Nation desperately need. Brandon Kingsmore and Alene Shaheed will testify about how these services have changed their lives. They will talk about how home-based services make it possible not only for them to live but to thrive.

Brandon and Alene are not alone. More than 3 million Americans are able to remain in their homes and stay active in their communities because of home-based care, but at the same time, almost 820,000 Americans are languishing on wait lists for these services, sometimes waiting not just weeks, not just months, but years waiting for these services. This limited access to care hurts more than just those in need of services. An underinvestment in caregiving affects all of us, it even hurts our economy. Without access to this care, many people, usually women, are forced to leave the workforce to care for a loved one.

An investment in home-based care is an investment in families and our Nation. It will help people get back to work. It gives fami-

lies, something that I believe that is immeasurable, peace of mind, the peace of mind in knowing that their loved ones are cared for.

This kind of investment will also give home care workers, the majority of whom are women from communities of color, a much-needed and long overdue raise. These workers provide essential care. An investment in home and community-based services would give these hard-working women, or I should say mostly women, the opportunity to better support their own families and their communities.

Last June, 40 Senators introduced the Better Care Better Jobs Act, Senate bill S. 2210. I am proud to lead that legislation in the Senate, which has earned the support of over 800 national and state organizations. This bill is an investment in better jobs for home care workers, better care for seniors and people with disabilities, and better support for those family caregivers I talked about earlier. This investment is about services and jobs.

Over 100 top economists and public policy experts have said that investing in home care will help the United States maintain a competitive workforce. The leading economic analysis firm, Moody's, found that, "long term, the economy receives a lift from this policy, as it supports higher labor force growth."

This investment is what makes sense for families, what makes sense for workers and what makes sense for our Nation, so it is an investment that is needed now, not 10, 20 years from now. We need this investment now.

The Committee has received over 335 statements for the record that support the need for an immediate investment in home and community-based services, so I look forward to hearing from our witnesses about this important issue.

Ranking Member Scott, I will turn to you for your opening remarks.

#### **OPENING STATEMENT OF SENATOR TIM SCOTT, RANKING MEMBER**

Senator TIM SCOTT. Thank you, Chairman Casey, and thank you to the witnesses for being with us today. This is such an important topic and I am so thankful that Chairman Casey has decided to make this one of our priorities for this day.

Without any question, you think about the fact that we have 46 million Americans today over the age of 65 living in the U.S., and just a few years from now, by the year 2050, that number will go from 46 million to around 90 million Americans. That is astounding growth that we should anticipate.

By 2030, 1 in 5 Americans is projected to be 65 years or older. Nearly 90 percent of our seniors want to stay in their own homes as they age. To do this, seniors often turn to the support of their family members, and when I say that I am going to talk about how 44 million Americans provide, every year, around 37 billion hours—B as in boy—billion hours of assistance to family members. That, to me, is astounding, and it is a number for us to digest, but it is really hard to understand how important staying in your own home is and the cost, maybe not just financial cost but the human cost of providing that care, 37 billion hours a year.

Family caregivers provide over 75 percent of caregiving here in the United States. That is a significant investment into our loved ones, and it is an important investment and one that we should take a look at and find ways to make that support better.

The Build Back Better proposal relies almost exclusively on funding long-term care through Medicaid, and that path, of course, is going to be quite challenging for so many families. The qualifications for Medicaid is significantly a hard threshold to cross over, which requires you to eliminate most of your resources, so that means that we need to look for other solutions. A better path forward would invest significant funding in a push for a self-directed care approach. This would give caregivers and recipients the means to make informed decisions about the services they need while providing resources to do so.

Last June, I released a report, "Expanding Opportunities for Older Americans: Self-Directed Home and Community Based Services." We looked for solutions in the report so that we could understand and appreciate what actually would help, what would be beneficial for families providing those 37 billion hours on an annual basis, and some of the solutions that we talked about was encouraging State Medicaid programs to establish self-directed care options.

In addition to that, growing the long-term care insurance market, this is a critical piece. The earlier you purchase this insurance coverage the cheaper it is and the longer it will last for most American families, empowering the Nation's volunteer army of 53 million family caregivers through sustainable funding that will improve conditions for caregivers while enhancing service quality.

I have been around amazing caregivers all of my life, frankly. My mother is a nurse's assistant. She is in her 49th year of full-time employment, providing care. She loves what she does so much so that it is, in fact, her mission, and so understanding and appreciating first-hand the struggles, the challenges, and the rewards of caregiving are undeniable in the household that I grew up in, and frankly, as I see my mother on the weekends when I am back in town she talks about how important it is for us to address this issue. It is one of the reasons why, Chairman Casey, I am so thankful that we are having the hearing that we are today.

The CHAIRMAN. Ranking Member Scott, thanks very much for your opening statement. Now we will introduce our witnesses. The order we had it in, Ranking Member Scott, is you would do the first introduction. Is that correct?

Senator TIM SCOTT. Yes, sir.

The CHAIRMAN. Okay.

Senator TIM SCOTT. Thank you, Mr. Chairman.

Last month we held a hearing on how to improve care experience for people enrolled both in Medicare and Medicaid. We call this the dual eligibles, and this is such an important part of the folks that we are talking about today, are those folks who are dual eligible for both Medicaid and Medicare.

We heard from a witness representing South Carolina's Department of Health and Human Services. She described consolidating 10 Medicaid home and community-based services over 5 years. Too many waivers create confusion and administrative burden for both

patients and providers. Our witness today has witnessed an important report describing how Congress can help states avoid this unnecessary complexity.

Lisa—I am going to butcher your last name—Lisa Harootunian is an Associate Director for the Bipartisan Policy Center Health Program. She is an expert on Medicaid policy issues, including long-term care and home and community-based services. Lisa is responsible for managing BPC's portfolio of work on long-term care, chronic care, integrating care for dual-eligible beneficiaries and other issues impacting individuals with complex needs.

Lisa has been with BPC for almost 3 years. She previously worked for Virginia State's Medicare agency where she researched and analyzed issues impacting the Medicaid program.

Lisa holds a juris doctor, a masters of social work degree, and is a member of the Virginia State Bar. In her testimony, we will hear Lisa explain the Bipartisan Policy Center's proposal to make it easier for states to streamline and simplify these home and community-based service authorities.

We look forward to hearing your testimony, and I apologize for mispronouncing your last name.

The CHAIRMAN. Ranking Member Scott, thank you. My notes say you got it right. I hope I am right about that, but thank you, Ranking Member Scott.

Our second witness is Anne Tumlinson. Anne is a national expert on health and aging, assisting states and providers on policies involving health and eldercare systems. She is the Founder and CEO of ATI Advisory, a leading national research firm.

I will move next to our third witness, Brandon Kingsmore, from Allentown, Pennsylvania. Brandon is currently a recipient of home and community-based services. His care worker, Lynn Weidner, has also joined us today.

Brandon receives home care assistance from Lynn, which enables him to live independently. After trying other careers, Lynn found her true passion in health care working as a full-time caregiver.

Both Lynn and Brandon have been strong advocates for the importance of these services, and they have worked along with me and our office and others to make the case about funding these services, and recently, I guess back in October now, both Lynn and Brandon were in Scranton, Pennsylvania, my hometown, during a visit of the President of the United States, and Brandon and Lynn were able to spend some time talking to President Biden about how Lynn's care helps Brandon every day, and that was a revealing moment for so many of us who were there on that day.

We want to thank both Brandon Kingsmore and Weidner for joining us today.

Then finally, our fourth witness—because I am including Lynn and Brandon as one witness; I think Brandon might do most of the talking here, but we will hear from both—but our fourth witness is Alene Shaheed. Alene is from Jacksonville, Florida. After working 30 years in retail she retired but returned to work in her 60's as a security guard. As a result of a spinal cord injury, Ms. Shaheed lost the ability to walk. She now receives 20 hours of home care, allowing her to live safely and independently in her



own apartment, cut back from the 35 hours a week before the pandemic.

Ms. Shaheed, we are also grateful for your testimony today and grateful you are with us at this hearing.

Now we will turn to our witnesses. We will begin with Lisa Harootunian, and you may begin your testimony, and please correct us if we mispronounced your last name.

**STATEMENT OF LISA HAROOTUNIAN,  
ASSOCIATE DIRECTOR, HEALTH PROGRAM,  
BIPARTISAN POLICY CENTER, WASHINGTON, D.C.**

Ms. HAROOTUNIAN. Thank you. Good morning, Chairman Casey, Ranking Member Scott, and distinguished members of the Committee. Thank you for inviting me to testify today about a bipartisan pathway to improve the availability of Medicaid home and community-based services. I commend the Committee for considering this critical issue through a bipartisan lens.

My name is Lisa Harootunian and I am Associate Director of the Health Program at the Bipartisan Policy Center, a nonprofit organization that combines the best ideas from both parties to promote health, security, and opportunity for all Americans. Today I will cover the importance of improving access to Medicare home and community-based services, key challenges created by the current patchwork of HCBS authorities that states use, and BPC recommendation to address those challenges.

Expanding access to home and community-based services has historically received bipartisan support, and Congress has made meaningful progress toward improving the availability of those services since the program began. However, the need for these services persists, and it will continue to grow as the population ages rapidly.

In addition, the high rates of COVID-19 infection and mortality in congregate care settings have exacerbated the need for home and community-based care options, and for individuals with functional limitations or cognitive impairment, HCBS has long played a critical role in allowing Medicaid beneficiaries to live independently and to work. Together, these factors have brought national attention to the need for better access to home and community-based services.

Before I discuss BPC's recommendation to improve access to HCBS, I would like to first highlight some of the challenges in the current system that we sought to address.

Historically, states have predominantly relied on 1915(c) waivers to provide HCBS because they allow states to target services to certain subpopulations and to certain regions. States may also cap enrollment, and together this all allows some budget predictability for services.

States also use multiple 1915(c) waivers, with each State using an average of 5 waivers and some states relying on up to 11 waivers at once. In addition, states also provide HCBS through 1115 waivers in State plan options, including 1915(I), (j), and (k) State plan amendments.

This patchwork of HCBS waivers and State plan amendments that states use have led to three key barriers to the availability of these services, including, first, a system that is extremely complex

and burdensome for states to administer; second, HCBS programs that are challenging for beneficiaries to navigate; and third, inequities in access to HCBS, both within and between states.

What can we do? To address the growing number of Americans who need assistance with daily activities but who prefer to receive care in their home or community, continued bipartisan collaboration is necessary. As described in BPC's report, "Streamlining and Simplifying Medicaid HCBS Authorities," Congress should consider a bipartisan pathway forward that would improve the administratively complex and piecemeal structure for HCBS authorities.

To this end, BPC recommends streamlining and simplifying Medicaid HCBS waiver and State plan authorities into a single State plan amendment that retains much of the flexibilities of existing authorities. This would reduce complexity in the system while still providing states with budget predictability for HCBS. Ultimately, this change should improve access to services for Medicaid beneficiaries by reducing administrative burden for states managing HCBS programs, making it easier for beneficiaries to navigate the system, and helping to make services more uniform from State to State and across subpopulations in a State.

While BPC's recommendation to simplify and streamline Medicaid HCBS waivers and State plan amendments would address several important challenges to HCBS access, we recognize that it would not solve all of the challenges to service access and delivery, but streamlining and simplifying these authorities could be addressed independently or as part of other efforts to reform the HCBS system.

The enormously complex system remains a challenge to the availability of home and community-based services but with your continued leadership and bipartisan collaboration we can help more Americans access the critical services that they need to live independently and to work.

Thank you once again to the Committee for convening this important hearing, and I look forward to your questions.

The CHAIRMAN. Thanks very much, Ms. Harootunian. We are grateful for your testimony.

I usually mention at the beginning of the hearing about Senators being in and out of this hearing and other hearings and commitments they have. I know so far Senator Warren has appeared at the hearing as well as Senator Rick Scott, and I know others will be moving in and out as we move forward.

Our second witness is Ms. Tumlinson. You may begin.

**STATEMENT OF ANNE TUMLINSON, CEO,  
ATI ADVISORY AND FOUNDER, DAUGHTERHOOD,  
WASHINGTON, D.C.**

Ms. TUMLINSON. Chairman Casey, Ranking Member Scott, members of the Committee, thank you for the opportunity to testify on the importance of home-based services to family caregivers. In addition to being the CEO of the research advisory firm, ATI Advisory, I am also the founder of a grassroots community of family caregivers called Daughterhood.

Home and community-based services make it possible for many individuals with long-term service and support needs to remain

where they want to be, which is in their homes, but unfortunately our home care system and its infrastructure are vastly underdeveloped and under-resourced to meet the growing need for service, and if we do not invest in them American families are going to face very serious economic challenges, possibly even more than they are today.

What few people is that most older adults with high levels of need still live in the community, and many of those who do rely almost exclusively on family caregivers. Fully a third of high-need Medicare beneficiaries who are living in the community today with that high level of need are below 200 percent of the Federal poverty level and they are not on Medicaid, which means they cannot access home-based care.

As a reminder, unlike nursing home, Federal Medicaid law does not require states to offer home and community-based benefits, and for older adults and people with physical disabilities, Medicaid still spends more on institutional care than on home and community-based services, and even among individuals with resources, finding and deploying even privately financed home-based services and supports is very challenging. These families report not knowing where to go and not being able to find what they need.

The good news is that states received a temporary infusion of Federal funds for home and community-based services in the American Rescue Plan Act, but to stop here would be like bringing an umbrella to a hurricane. The number of individuals in our country who are 85 years and older will double by the year 2035, and that population is the 85 years and older who are much more likely to have high needs, and at the same time, caregivers available to take care of them are declining.

Much more Federal investment is needed to galvanize and support states and communities in developing the infrastructure and systems along with a variety of publicly and privately funded HCBS, home and community-based services, can travel. If we fail to make a sustained Federal investment in home and community-based services we will continue to rely heavily on unpaid family caregivers, and when they give out, nursing homes.

What I can tell you from my own experience, as well as being part of community of unpaid family caregivers, this is simply not a sustainable path. Caring for a person who needs assistance performing daily activities is hard, full-time work. Family caregivers tell me all the time about how they quit their jobs or cut back, they spend less time with their children, they get sick, they spend their own resources, and often their only choice, aside from quitting, is a nursing home, because they cannot find adequate support in the community.

As the growth in the size of this very old population starts to accelerate, our families, employers, communities, states will feel these strains in a really profoundly, pronounced way. Investing in home and community-based services is one of the most impactful actions that we can take today to support individuals in need and their families in the future.

Thank you again, and I look forward to your questions.

The CHAIRMAN. Ms. Tumlinson, thanks for your testimony. We will now turn next to Brandon Kingsmore and Lynn Weidner.

**BRANDON KINGSMORE, DISABILITY ADVOCATE, PUBLIC  
SPEAKER, (ACCOMPANIED BY LYNN WEIDNER,  
HOME CARE WORKER) ALLENTOWN, PENNSYLVANIA**

Mr. KINGSMORE. Thank you for inviting me and my caregiver, Lynn, here to speak to today. My name is Brandon Kingsmore. I live in Allentown, Pennsylvania.

I have relied on home care my whole life. People do not know what that is like so I will share my story, but how many times will I have to tell the same story over and over before I am taken seriously?

I was born with cerebral palsy. Growing up we did not qualify for Medicaid but we also could not afford to pay for home care out of pocket. Money was already too tight. My mom had to be a full-time caregiver on top of her full-time job. My sister shared the responsibility of taking care of me, and she also gave up a lot of her teenage years to do that. It was hard to think about what we would do if anything happened to my mom.

On days when no one could be home with me I spent 8 hours a day. I felt alone, glued to my home. It was all I could do to just sit in one place, play video games, or watch movies. If something happened to me I had no choice but to wait for someone to get home to help. For example, if I had to go to the bathroom there would not be anyone there to help me. It was dehumanizing.

Qualifying for Medicaid made a big difference. Home care opened my world and allowed me to do more. Home care is everything to me. My ability to live depends on it. Without care, people like me wonder, will I get out of bed today? Will I eat today? Will I be able to go to the bathroom today? Being in a wheelchair is hard enough. The world is not built for people like me. Why do I have to fight for what should already be a basic human right?

My life changed when Lynn became my caregiver. Lynn gives me the freedom to live my life the way I want, where I want, but not everyone is as fortunate as me. Many of the people cannot afford or access care now, or they are on a waiting list. We become isolated, depressed, and removed from society against our will.

All we want is to be participate in our economy and communities, but the choice is often made for us. The way things are going now, we are seen as numbers, but we are not.

I am nobody special. I am just a normal guy looking for a fair shot and a better life, but that shot hangs in the balance as you debate dollars and cents. This is not dollars and cents. This is life and death.

Please do not make me tell the same story again. Home care workers give so much of themselves to give people like me a good life. I want caregivers like Lynn to have a good life as well. We have the opportunity to make history in this legislation. This could be a time for everyone to remember. This contains everybody—people like me as well.

Please, invest and pass Better Care Better Jobs Act now. Thank you.

Ms. WEIDNER. Good morning. Thank you for inviting me and Brandon to speak today. My name is Lynn Weidner. I have been Brandon's full-time caregiver for 11 years. Recently my mother fell ill so I am her caregiver as well.

I have worked in long-term care for more than 20 years, as a CNA in nursing homes and groups homes and in home care, so I can say, with a great deal of expertise, our country's long-term care system is crumbling, especially after COVID-19. It is like the game of Jenga, where you make one wrong move and the whole thing starts falling apart.

Without the support of Congress there is no money to expand and improve care services or to pay, train, and sustain the home care workforce, and if you do not have a home care workforce then there is no care, and without care there is no life. The demand for care is skyrocketing but there is low pay and lack of benefits. They force home care workers to leave the industry.

Policies like the Better Care Better Jobs Act will make sure that every care consumer has their needs met by a strong care workforce. I am fortunate to have something that many care workers do not, which is the right to join together in a union, and across the country, caregivers in our unions are demanding the changes that we need to provide the care that our consumers deserve. For all the victories that we have won over the years there is a long list of injustices that we need to keep fighting for.

Brandon was actually born before the Americans With Disabilities Act was passed, and that was a great start. We still live in an ableist, ageist, racist, sexist world where people in need are being excluded and forgotten, and our country's leaders need to take a good look in the mirror and reevaluate how seniors and people with disabilities are treated, how home care workers are treated, how women of color, who do the majority of this work, are treated.

March is Women's History Month. What better time to turn collective appreciation for women into meaningful action that lifts us out of poverty and finally gives us the respect, protection, and pay that we deserve?

Without the support of the entire Senate we will be back to square one. Caregivers will suffer because they cannot afford food, shelter, health care, and there will be no one left to help keep people like Brandon alive. You know, we need better care. We need better jobs. We really need it now. Thank you.

The CHAIRMAN. Lynn, thank you. I want to thank you and Brandon for your testimony. Finally, our final witness for today is Ms. Shaheed. You may begin your statement.

**STATEMENT OF ALENE SHAHEED, HOME CARE  
RECIPIENT AND FORMER FLORIDA HEALTH JUSTICE  
PROJECT CLIENT, JACKSONVILLE, FLORIDA**

Ms. SHAHEED. Thank you, Chairman Casey, Ranking Member Scott, and the Members of the Committee. Thank you for the opportunity to share my experience with you today as someone who is enrolled in Medicaid home and community-based services. My name is Alene Shaheed. I am 76 years old and I live in Jacksonville, Florida. I live alone and have no relatives that live in this area.

In 2005, I retired after 30 years. I started enjoying my retirement traveling, visiting friends, and doing some of the things I was not able to do while I was working. I was also taking care of my

nephew, who was with me until 2010, when he graduated high school.

In 2013, needing more money, I went back to work and worked as a security guard in a private community. In 2016, I started to experience mobility issues. I went to the doctor and learned that I had a growth on my spine. It took two surgeries to remove the growth, one in February 2017 and the second surgery in July of the same year. After the second surgery, I was unable to walk and now need a wheelchair for mobility. I also require assistance bathing, dressing, housekeeping, some toileting, and meal preparation.

I am enrolled in Florida's Medicaid long-term waiver and I am approved for 35 hours of care per week. The assistance of the home health aide allows me to remain living at home, independent, and on my own, with assistance. When given the option, I chose to receive services at home and not go into a restrictive nursing home where you are told what to eat, when to eat, when to sleep, when to get up, and if you can have visitors. I chose to live at home and not going to a nursing home because I value my independence.

I am approved for help for 7 days a week for 5 hours each day. Right now I can only find an aide for 20 of those hours. Since January 2022, I have not been able to find an aide to come on Saturdays, Sundays, and Mondays, so I do not have any help for 3 days until the aide comes.

This means I am unable to shower for 3 days. I cannot take out the trash because I cannot get my wheelchair in and out of the trash room. I am only able make easy-to-prepare food on my own. A couple weeks ago when I was fixing myself ramen noodles, tipped over the cup, and accidentally poured boiling water onto my leg and sustained a second-degree burn. Thankfully it did not get infected, but the burn is on my leg which I use to transfer and making it difficult to do it by myself.

Not having the help affects every aspect of my life because the aides are my lifeline to remaining independent. I absolutely do not want to go into a nursing home.

Why is this happening to me and thousands of others? It is due to the underfunding of Medicaid and the wages of home care workers are too low. The average pay for aides is \$10 to \$13 an hour. Since the pandemic, the aides are unwilling to come and risk their health and their families' health for just \$10 an hour, so they went into private-pay insurers who pay more and to jobs that pay more. The workers are hurt by how little they are paid and I am hurt by how little they are paid. Valuing me means valuing them, and valuing them means valuing me, and we all deserve to be valued.

I know that many people are in the same situation as I am that need these services but they must be adequately funded. Thank you for allowing me to share my story with you today.

The CHAIRMAN. Ms. Shaheed, thank you very much for your testimony, and thanks for sharing your own personal story. We are grateful for that.

We will turn to our questions now, and folks know how we alternate between both sides of the aisle. I will start and then we will go next to Senator Braun, and then Senator Gillibrand, and we will go from there as Senator appear.

Let me just start. On this round I will just ask one question. I want to start with Brandon Kingsmore. Brandon, I want to ask you about your story, a lot of which you shared with us today. You shared how home-based services has enabled you to live a life that is a substantial life. In fact, I heard you say that in Scranton back in October when you were talking to the President. I understand that without that care that Lynn provides you that this kind of a life would not be possible for you.

Many people across the Nation are not able to receive the same kind of care that you are receiving. In your written testimony, you note that you did not qualify for Medicaid until you were 18 years of age because of how limited home and community-based services were where you lived.

My question is how important is it that we invest in home and community-based services across the nation?

Mr. KINGSMORE. Well, if you think about the growth of home care, it is growing at such a fast pace. I think home care right now is the fastest-growing industries, and one day we are all going to need help, whether we want it or not.

This is something that should be address. We should not be fighting for it in the 21st century. My only goal is that people will understand that it is not about dollars and cents. This is about life and death.

Without these home care services; my life would not be what it is and I would not be the man I am today.

The CHAIRMAN. Well, Brandon, thanks. The story you told about the concern you had about your mom, who was working full-time and providing care full-time, I think is instructive for all of us, that so many families are making those sacrifices, and the difference that Medicaid made in your life, as you said, made a big difference.

We will turn now to Senator Braun for his questions. Senator Braun.

Okay. Why don't we move to Senator Gillibrand.

Senator GILLIBRAND. Thank you, Mr. Chairman. I appreciate it, and thank you for holding this essentially important hearing. I really appreciate the topic.

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. Today, more than 1 in 5 Americans are family caregivers, having provided care to an adult or to a child with a disability at some time in the last 12 months.

It is clear that we need to ramp up our investment and improve the availability of home and community-based services and our care infrastructure for many more Americans. That is why I am a champion of—sorry, that is Maple—that is why I am a champion of Senator Bob Casey's Better Care Better Jobs Act and its commitment to a massive care infrastructure investment as well as my proposal for a national paid leave program.

Ms. Tumlinson, how do the diverse needs of older adults and people with disabilities inform the need for improving availability of a wide range of home and community-based services? Does our care infrastructure and workforce meet all the needs from all people with disabilities? Are people falling through the cracks?

Ms. TUMLINSON. Thank you, Senator. That is a great question. It is almost a hallmark, I would say, of our patchwork, undeveloped system, the extreme inconsistencies in access across nearly every facet that you can imagine, so across states, within states, rural versus urban, racial disparities, age disparities. Accessing home and community-based services often can just be a question of are you living in the right neighborhood, in the right State, with the right set of needs.

The averages that we see in the national data, they mask really big differences, and overall just obscure the fact that certain populations are very much being left behind. Rural areas, in particular, struggle with supply of agencies and providers due to drive time. We see Black individuals using nursing homes that are lower quality a lot more frequently than white nursing home residents, and we see them lacking access to more private pay options such as assisted living.

It is very much a hallmark of our system, the unevenness of the access to services.

Senator GILLIBRAND. Yes, that is what we have seen in New York as well. We know that, again, for Ms. Tumlinson, we know that paid family medical leave, a crucial necessity for workers facing their own or their families' health issues, positively boosts the economy. We know that workers spend the wage replacement income they earn, which leads to further job creation and labor income for workers in various sectors. The widespread lack of paid leave disproportionately affects women, people of color, and low-income workers.

Would you please describe how national paid family and medical leave might help address these overwhelming, growing demands for caring support and long-term care?

Ms. TUMLINSON. Sure. I will just start first by saying that I have personally been away from work for an estimated month out of the last three, very recently, helping my 81-year-old mother take care of my father at the end of his life, and fortunately for me I have access to paid leave—I am the owner of the business so I have a lot of control. I have wonderful coworkers who have covered my work while I have been out, but I am so far from the norm, and we are essentially on the precipice of essentially having to build what I call a caregiving society, and I love what Lynn said earlier, “Without care there is no life.” I am going to use that and quote her often going forward.

This is what we will all be doing soon, whether we are paid or unpaid. We will be delivering care and receiving care, and even if we, and when we, succeed in making these new investments in infrastructure through the Medicaid program, families will still experience crises and other needs that require their attention, and paid leave must be the norm and not the exception or we are just going to see even more sort of extreme economic insecurity as a result of having to make very, very difficult choices between work and taking care of family members.

Senator GILLIBRAND. Thank you, and just one question for Mr. Kingsmore. Thank you for sharing your experience. Could you describe how investments in care work and Medicaid home and community-based services translates to improved health outcomes?



Mr. KINGSMORE. Yes. It would be great for both parties, both for the caregiver and the client as far as money to pay for gas, better training, more opportunities. It would be better for the workforce because a lot of people quit their jobs because of lack of funding or they do not make enough money.

If they had the proper things that they need I do believe that the workforce would be better off and both parties would be benefit.

Senator GILLIBRAND. Thank you very much and Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Gillibrand. Before turning to Senator Braun I just wanted to make sure that we acknowledge some folks. We are obviously acknowledging folks that have appeared at the hearing and have their camera on, and then some may have to leave and come back in a different order, but I know that we were joined earlier, and maybe still, by Senator Rosen and Senator Blumenthal, but we will turn to Senator Braun and then we will see where we are with the next Senator.

Thank you, Senator Braun.

Senator BRAUN. Thank you, Mr. Chairman. My question is going to be for Ms. Harootunian, and it is going to be related to, in 2020, Federal Government increased funding for Medicare and Medicaid spending, over \$1.5 trillion on health care services. CMS has also issued waivers of Federal requirements to expand beneficiary care access at this time. As a result, the GAO identified several risks to program integrity, due to the suspension of these safeguards, increasing chances of fraud, waste, and other abuse.

In your opinion, the drivers of health care spending and poor clinical outcomes for older and disabled Americans, has increased spending actually addressed, in measurable ways, improving the outcomes, and has the usage of waivers complicated matters as well? I would like you to focus on the amount of money we are spending, are we getting better outcomes since we are borrowing so much of it each year, and then weigh in on waivers as well.

Ms. HAROOTUNIAN. Thank you, Senator. Increased spending does not always equal better outcomes. It is important that spending be targeted in the right ways to promote quality outcomes, you know, a lot of times ensuring that care is integrated, it is easy for beneficiaries to navigate and access, and ensuring that the delivery of those services is efficient and optimized and that there is less complexity in the system can help make sure that those services are accessible and delivered in the best way possible.

Senator BRAUN. What about the waivers? What has that done to the complexity of trying to get everything to work as well? Would you comment on that?

Ms. HAROOTUNIAN. Yes, so right now, as I mentioned, some states can rely on up to 11 1915(c) waivers, and that is just the 1915(c) waivers. On top of that you have got the 1115 waivers and then the variety of State plan amendments that states are relying on. This creates lots of complexity for states using multiple waivers and State plan amendments. They have to administer multiple programs and benefit packages with different eligibility, reporting, and other requirements, and each waiver is only for a limited time, and states have to periodically submit renewal requests to CMS.

Given this variation in length of each waiver, those renewal processes can require significant staff bandwidth at the State Medicaid level, and it is burdensome for states, so adding to the complexity of that, states also need to oversee multiple contracts and contractors, manage several waiting lists, and oversee different sets of quality metrics for each of these waivers.

Senator BRAUN. One final question. I have been a proponent, since I have been in the Senate, of reforming health care from the bottom up. Hospitals, insurance companies, practitioners, pharma, all of that amounts to about 18 to 20 percent of our GDP, depending on how you actually measure it. Most other countries are more in the neighborhood of 10 to 12 percent.

In your observation, what are the most critical things you could do, generally, to make health care more affordable, whether the government pays for it or private insurers do, through employers? What would be a couple three things that would bring the cost down for everyone?

Ms. HAROOTUNIAN. One thing that we are focused on is, again, reducing complexity in the system. To the extent that you can simplify and streamline those existing authorities that states are using and make those processes more efficient and less burdensome, have them require less staff time and less bandwidth to accomplish that, you know, you can get greater outcomes and promote some better results there.

Senator BRAUN. Very good, and I would add to that that I think the whole industry needs to embrace full transparency in competition. That would especially be helpful to fully insured plans in the private side of how we pay for health care, and I think it would address maybe some of the imbalances I see out there in terms of some providers saying they do not get enough from Medicare and Medicaid, and then through the private side of insurance as it weighs into health care, prices are exorbitant.

We will not solve it today. Thanks for weighing in on this component of it.

The CHAIRMAN. Senator Braun, thanks very much.

I know we are waiting for a number of Senators to either get back to the hearing or to get ready for questions, so I will move to what is only my second question. I am reclaiming some of my time from earlier so we can keep the hearing moving.

I wanted to turn to Ms. Shaheed. Your personal story is a great American story of hard work and sacrifice and overcoming so many challenges, and I just wanted to commend you for telling your story, because when you tell your own story you not only inform us but you inspire others to tell theirs and to move the ball forward on public policy.

You talked about how home-based services keep you in your apartment and living an independent life, which you said is most important to you. You also noted, and I am quoting you, "I am approved for help for 35 hours of work right now. I can only find an aide for 20 hours a week. Since January of this year I have not been able to find an aide to come on Saturdays, Sundays, and Mondays," unquote.

That is obviously a significant decrease, and as you stated, has led to you going days without receiving care.

You also shared that as a result, “This means I am unable to shower for 3 days.” There is no excuse in the United States of America for someone living in our country going that long without basic care, and the tragedy here is that Washington has not responded, most recently, but over many, many years, and that is why we are advocating in such a determined fashion to finally—finally—as a matter of national policy, to fund home and community-based services so that people have a chance to receive these services at home.

You know, a lot of people may not realize but we already made a decision decades ago to use the Medicaid program as a way to provide long-term care to families, right? That is not limited to families that are low income. A lot of middle-class families benefit from Medicaid. They get their nursing home care. Middle-class families get their nursing home through Medicaid. I cannot say that enough. I might say it again later in the hearing, because people in Washington do not seem to hear it.

It is not a question of whether Medicaid is going to provide funding for care, for long-term care. It is a question of whether Americans are going to have a choice to get the care in the setting that they want, the setting that is preferred by many—not all, but many—which is home-based care, so that is what we are talking about here. We are either going to validated that choice or we are not. Washington has not done that so far.

Ms. Shaheed, sorry for that long prelude but how would raising wages for workers impact the availability of home care workers that provide the type of care you receive?

Ms. SHAHEED. Yes, Senator Casey. Thank you so much for having this hearing and for bringing these issues to the forefront. Having the wages increased of the home care workers would give me a greater quality of life. My dignity suffers, and my health suffers, when I am unable to shower for 3 days. I am isolated. I am not able to participate with a lot of community here in my apartment complex because I am not comfortable going in a setting with my friends and I have not had a bath in 2 days.

The increase in the wages is the key. That is the key component as to why I do not have the help that I need. The wages that are being paid by Medicaid are too low, and the reason I have not had an aide to come on those days, the case manager called 12 different agencies. She called 12 agencies and was unable to find help to come on any of those days. She called 12, and then she called 5 more, but no one was available because no one is willing to work for those wages that are being paid, so the increase would increase my quality of life greatly. Thank you, Senator Casey.

The CHAIRMAN. Thanks for making that point and for being willing to share your own personal story. Wages matter, and if we really care about older Americans, if we really care about people with disabilities, we are not just going to have some policy. We are going to have a policy that lifts up the wages of those workers to accord them the status that we claim to accord them as Americans.

Everybody says we care about caring for older Americans. Everybody says we care about caring for children and people with disabilities, and yet the people who are doing the hard work every day

are not paid a hell of a lot—\$12 an hour is the average across the country. That is unacceptable in America.

I will turn next to Senator Rosen.

Senator ROSEN. Chairman Casey, I cannot see if Ranking Member Scott is there, thank you as well for holding this important hearing, for the witnesses for being here today, for being willing to share your stories and do the work that you do.

You know, I am a former caregiver for both my parents and in-laws, and so I understand the important role caregivers play in helping their loved ones continue to live independently in their own homes and even be able to thrive if they are in nursing home or assisted living or memory care, as my mother-in-law was.

I have heard from constituents across Nevada, including caregivers represented by SEIU, about the many struggles of being a caregiver, a full-time, physically and emotionally demanding job. That is why I was so proud to stand with Chairman Casey in co-sponsoring the Better Care Better Jobs Act, which, among other important things, would support the HCBS workforce, including by significantly strengthening worker protections. I also co-sponsored the Credit for Caring Act, which would provide caregivers with a Federal tax credit of up to \$5,000 to cover expenses associated with caregiving. If you are caring for a loved one—parents and in-laws, like I was—that could make quite a difference for families.

Building on what all of my colleagues have mentioned here, Ms. Weidner, as a home care worker represented by SEIU, can you tell me how you feel about having those worker protections, union representation that supports you on a day-to-day basis, and what else do you think that we can do here, in Congress, or all of us can do to prioritize to work on both the economic and mental and emotional support to caregivers like you who are going in to so lovingly help others live a productive life? It is just invaluable what you do.

Ms. Weidner?

Ms. WEIDNER. Thank you. The first thing I would like to say is that sometimes home care can be extremely isolating. We work by ourselves. You know, we disappear into the background sometimes because we are in people's homes. We are not in the facility. There is no people touring.

One of the things that I noticed specifically, for myself, is I worked in two different states in home care, in North Carolina and then we moved here to Pennsylvania. In North Carolina I did not know any other care workers. I was completely alone.

When I moved to Pennsylvania I found out that there was a home care workers' union, and in joining the union I found a community. My union siblings are my friends and my support. Honestly, I do not know how I would have survived the pandemic and all these anxieties and lack of resources without them. We were mailing gloves across the State to each other. We were sharing masks, if somebody knew how to sew, because those resources were really hard to find.

In Pennsylvania, we were able to start a training program. We were able to help home care workers learn skills we need to keep ourselves and clients safe. This is because of the advocacy of the home care workers' union. It did not exist before we had to start fighting for it.

Congress needs to prioritize passing this funding because we cannot think of this as like just individual elements. We need to tackle everything all at once. It will direct more funding to programs that are directly supporting us, like wages and training and accessible care. In our union were able to win, this year, 8 percent raises for home care workers, and that is something, you know, I really appreciate, but I am not bumped to \$13.50 an hour. It is still not enough. I can walk to Taco Bell and make \$15 an hour, but if I have a human life in my hands and if I am providing them care, you know, it is \$13.50. Does that mean that my labor is less important? I do not think it does. I think that we are important. I think that we need to increase funding so that we can make sure that not only the workers are taken care of but also our consumers. Thank you.

Senator ROSEN. You know, I think you hit it right on the head there. You are important. The work you do is important. You talked about community and having a network of people that you work with so that you can learn from each other and grow. Community matters. It matters for the people you care for and it matters for all of you workers.

I know I just have a few seconds so I will take my answer off the record, but what I was going to ask Ms. Shaheed is about lack of standardized workplace protections for people who work in home care center, like Ms. Weidner. It is, unfortunately, a transient field with high turnover, and there is really a burden in finding new caregivers and making sure they have the protections when they go into someone's home to care for them.

I will submit these for the record. I appreciate you all being here, and I will support you every way I can. I know what it feels like, and I know what it means. I know what it meant to my family, and you always will have my support. Thank you.

The CHAIRMAN. Senator Rosen, thanks very much for your questions. I know we are going to be turning to other Senators as they appear. In the interim, I wanted to pose a question to Ms. Tumlinson.

In your testimony you talked about your work with Daughterhood and gaps in services for family caregivers. You noted how that compelled you to develop a platform to connect family caregivers with one another and to connect them to other resources.

As we noted earlier, over 53 million family caregivers across the country are taking care of their loved ones, including 1.6 million in my home State of Pennsylvania. While many Americans gladly take on these responsibilities, it is really an act of love that they take on these responsibilities over and over again.

Family caregivers often shoulder many, many burdens. I cannot even imagine. I never had to do it myself, but so many have, so these burdens can include enormous financial costs, lost wages when they leave the job that they are in to care for a family member or a loved one. They can also forego, and often do forego, promotions at work because they are not there. They are home or they are in a family member's home taking care of them. Some are forced to leave the workforce altogether.

Ms. Tumlinson, how would an investment in home and community-based services fill some of the gaps in care and enable family caregivers to return to work?

Ms. TUMLINSON. Thank you. Thank you for that question. I always say, when I am talking to people about what it is like to be a family caregiver, it is really like all across the country right now every single family is essentially building and creating an entire system of care delivery, from scratch, all alone. That is what everyone is doing right now. It like we are homesteading long-term care, essentially, in this country.

This investment—an investment, and I love that word, because it implies that we are preparing strategically for the future, not just throwing another Band-aid on the problem. We are thinking strategically, as the Federal Government, as a State, as the private sector, about what we need to do to prepare.

When I talk to family caregivers, essentially what they need, and what we would invest in, I think, as a country, is kind of the four cornerstones of the infrastructure, which is an increase in the services that are available to individuals who qualify, but more importantly, reforming the eligibility system so that we do a better job of identifying people who have financial and functional needs, so that we can qualify them for services in the first place.

Obviously, and we have talked about this, many others have talked about this, the importance of workforce and compensation of wages and training in order to prepare the workforce. That is a huge gap that the families are dealing with, and then for everybody, not just Medicaid beneficiaries but for everyone in the country we have to build a strong infrastructure so that there is a place to go in your community, where you could be supported and helped along this journey, regardless of how you are paying for the services.

The CHAIRMAN. I appreciate that. Thank you.

Senator Warnock—we are joined by Senator Warnock. Thank you.

Senator WARNOCK. Thank you so very much, Chairman Casey. I am glad to be here to address the issues facing the caregiving economy in our country. Home and community-based services, HCBS, helps older Americans and people with disabilities live independently and to live lives with dignity.

This has been especially important during the pandemic, or at least the pandemic has pulled these issues into sharper focus, when older and vulnerable folks were able to stay at home with their caregivers instead of being crowded, for example, in a nursing home, and nursing home are an important part, obviously, of the ecosystem of care, but in the pandemic, home and community-based services allowed people to be at home, and therefore, to mitigate risks around COVID-19.

There are tens of thousands of Americans who likely qualify for this service but are not able to get it because the program does not have enough money. For example, in Georgia, we have about 8,000 older folks and people with disabilities waiting to receive this at-home care. For me that is unacceptable.

Ms. Tumlinson, I want to ask you about waiting or planning lists for HCBS. As you know, nearly every State offers at least one kind

of HCBS waiver that allows folks to get care at home rather than in a nursing home. How can Congress get those 8,000 Georgians, folks I represent, off the waiting list and into care and services?

Ms. TUMLINSON. Thank you. Thank you for that question. These waiting lists represent real need and desperation among many families. Those numbers are really concerning, and the truth is unfortunately even worse news is that there are lots more people in need than are on even the waiting lists, so depending on the State, you know, we may or may not really be measuring the true effect of unmet need in that State.

What states tell me is that the most important thing, from their perspective, in building up their systems and services so that they can serve everybody who has need and qualifies for services is having financial predictability and having sort of the certainty about the funding, so I think from my perspective the best thing that Congress can do to help Georgia and other states with meeting that unmet need that is represented, in part, by these waiting lists, is to increase the Federal match rate, to give them essentially the money that they need. You know, not just for funding the services but also for doing the planning and the infrastructure development that they need to do to make sure that the delivery system is there to actually serve people when they come off the waiting list, so we have to have that kind of ready to go, so those two things are important and states really need it. It is very, very hard for them to prioritize this from a staffing perspective or even from a budgetary perspective if they do not have that support from the Federal Government.

Senator WARNOCK. Thank you so much, and I agree, and it is the reason why I am so focused on this issue and engaged trying to co-sponsor the Better Jobs Better Care Act, a piece of legislation that would be helpful.

Medicaid is 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 this spending goes toward the home and community-based services program, which typically involves assistance with activities of daily living, like cooking, bathing, housework, essential things, and this is obviously limited to folks eligible for Medicaid, meaning there are many in Georgia who are not able to receive this support because Georgia continues to refuse to expand Medicaid, leaving hundreds of thousands of Georgians unable to receive these benefits.

Mr. KINGSMORE, you are currently a recipient of Medicaid HCBS. What would happen if you lived in Georgia and were not eligible for these services?

Mr. KINGSMORE. I would be in a home. I would be trapped in a system that did not care. People get shoved in the corner and are unable to live the way they want or how they want. I am glad that I live in Pennsylvania, but we are supposed to be the greatest country on the face of the earth. Something needs to be done, especially the older generation, because—we are important too. We are not supposed to be stuck in a home or trapped in a system that does not care about us. We are supposed to be the greatest country in the world, being prepared for something like this. It has been going on for far too long and it needs to change.

Senator WARNOCK. Thank you so very much, and what you describe as what would be your situation if you lived in Georgia is a situation of a number of Georgians, so thank you for your voice and courage on this. It is the reason why we have got to continue to try to find and fix it. Ten years after the Affordable Care Act was passed, Congress has to close the loop and make sure that people have access to Medicaid, including folks who could benefit from home-based care.

Thank you so much.

The CHAIRMAN. Thank you, Senator Warnock. I appreciate you being here, and thanks for your advocacy.

We will turn next to Senator Warren.

Senator WARREN. Thank you, Mr. Chairman, and thank you for holding this hearing and for your steadfast advocacy on this.

We know that the majority of adults and people with disabilities want to live at home. We also know that chronic underfunding of home-based services has taken this option off the table for many, and it has left hundreds of thousands of people on waitlists all across this country.

The failure to invest in home-based services not only harms people who need care, it also harms the workers who deliver it. Home care workers who are more likely to be women and people of color earn a median wage of just \$12 an hour, and they are three times as likely to be in poverty compared to other workers, and they are less likely to have employer-sponsored benefits, like health care and paid leave.

The COVID-19 pandemic has made these challenges even worse, as caregivers have delivered essential services in jobs where social distancing was nearly impossible and personal protective equipment was alarming scarce.

Ms. Weidner, you have shared that as recently as last year you were earning \$12 an hour as a home care worker. Can I ask you to say a word about how that has affected your financial security?

Ms. WEIDNER. Yes. Thank you. The low wages in home care have been really difficult. It usually means I need to work more than one job to make ends meet. I am working more than 80 hours a week. I do not have days off. I get paid 8 hours a day but I really provide 24-hour care, and a lot of that means that I end up in a lot of debt. A lot of it is medical debt, but there is others as well, and it is nearly impossible to climb out of that debt when you are living paycheck to paycheck. It is emotionally and physically taxing, and then having that financial stress looming over you just makes it that much harder to get into the correct headspace to complete my job the way I want to.

Senator WARREN. Wow. Well, I very much appreciate you sharing that.

You know, under these conditions it is no surprise that states are reporting a shortage of dedicated home care workers, and despite the growing demand for home-based care, the turnover rate in direct care jobs is as high as 60 percent.

Ms. Shaheed, you have spoken about the shortage of home care workers where you live. How has this affected your ability to get the care that you need?



Ms. SHAHEED. Senator Warren, thank you. You are asking how has the shortage affected me?

Senator WARREN. Yes.

Ms. SHAHEED. The shortage, greatly, because I am unable to access—without the home health aide coming into my home and assisting me with my daily living, my world slows down to where I am not able to access outside of my front door, because I am totally dependent on them to do things for me that I am now unable to do for myself.

The shortage—my quality of life goes downhill when I do not have the home health aide coming into the home to assist me with those things that I need to do in order to be living independent. The shortages are just—things are not well because of the shortage of workers, and there is a shortage of workers because there is low pay, and until that is resolved, it just continues.

Senator WARREN. Yes. I appreciate your underscoring this, and I think Mr. Kingsmore said earlier that if he could not get access to home-based care then he would be forced to live in a nursing home or he would be back home without the quality of life that he has now.

You know, I worry about the fact that too many people are forced into nursing homes or other congregate care facilities because they cannot access the care they need at home, and the pandemic has just made clear how devastating the consequences of those decisions can be.

As of January, 23 percent of all COVID-19 deaths in the United States happened in long-term care facilities, so right now Congress is considering legislation that would make an historic investment in home and community-based care to ensure that more people can access these services, and that starts with training home care workers like the essential workers that they are, by paying home care workers a living wage, by providing them with good benefits, by ensuring that they have the right to join a union.

Ms. Weidner, I know we are running out of time here, but can I just ask you just to say a word about what those investments would mean for you and for the people around you.

Ms. WEIDNER. Yes, absolutely. I mean, an increase in funding for home care would change absolutely everything, honestly. I mean, having access to a living wage and benefits—I do not know what a day off is. Health insurance is incredibly expensive for me on the marketplace right now, and most home care workers cannot even afford it, so we are health care workers that go without health care.

It would mean turning home care jobs into a professional health care career. That means that we would increase the workforce. People would be able to stay in their jobs, and that means that people would be receiving care, the care that they need and the care that they want. Families need this investment and care workers need this investment as well.

Senator WARREN. Well, you have put it very well, and thank you very much for that summation of what is going on here.

Home-based care is essential infrastructure for families. These investments provide necessary financial security for home care workers. They ensure that more adults and people with disabilities

live in dignity, in the setting of their choice, and they would allow unpaid caregivers who have taken leave from their jobs to care for a loved one to be compensated for their work or to return to the workplace if that is what they wanted.

As our population ages, demand for home-based care is only going to increase, so the time for us to act is now. I am ready to join you, Mr. Chairman, in getting this done.

Thank you.

The CHAIRMAN. Senator Warren, thanks very much for being with us today and thanks for your questions and your advocacy. We have work ahead, and this hearing helps us light the path forward for that work, but thanks for working with us on this.

I do not think we have other Senators who are waiting to ask questions, so in the interest of keeping everyone's time in a more efficient fashion I think what I will do is close and note for the record that we will have the hearing record open.

I wanted to start by thanking each of our witnesses for their testimony today and also for their willingness to appear, and to tell their own stories. It is not always easy to tell people about your own life, your own challenges, your own struggles, and we hope in some cases your own opportunities that you can be very positive about, but too many families are not provided the opportunity for these kinds of services, for home and community-based services, whether they are a senior or a person with a disability.

I wanted to thank our witnesses for being with us today and sharing not only their stories but also their expertise, whether that expertise is gained personally, through your own life, or the expertise of long years of study of these important policy issues.

Before closing I wanted to highlight a new report from the Community Living Policy Center at Brandeis University. This report is entitled "Reducing Costs for Families and States By Increasing Access to Home and Community-Based Services."

This particular report cites AARP data that indicates that 6 in 10 family members have had to reduce or quit their employment to care for a loved one—6 in 10 family members who have had to reduce or quit their employment to care for a loved one, so those numbers are not just significant when you enunciate the number. You can see the impact it is having all across America.

This means that these family members have had to reduce their family income to care for a member of their family. As I said earlier, it is an act of love, and they are happy to do it, but we should not continue to put them in the position of having to reduce their income or having to leave their job. Lack of available care in America means these families that have this challenge will have less income and greater expenses, so increasing the investment in home and community-based services can send family members back to work.

I believe, in the U.S. Senate, we have some basic obligations, year in and year out, and among those obligations, I believe, are the following. We have an obligation to lower costs for families, Senators have an obligation to create jobs that will sustain families, and, of course, we have an obligation to help Americans get back to work. All three of those obligations can be met for Senators

supporting a policy that will increase our investment in home and community-based services.

Many people remember the American Rescue Plan passed a little more than a year ago, March 2021, which included a new investment in a great American idea—home and community-based services. That was kind of the first new funding we had for these services in a generation, and that was just the start, but we need a much greater investment to make this a reality for so many families. As we have heard today, we have got to build on this initial investment in the Rescue Plan, and we need to do it now, this year, to bring relief to American families.

In the end this is about all of what we talked about. It is about better care for seniors and people with disabilities. It is about better jobs for those who are doing that noble, essential, and heroic work, caring for folks in their homes or in the community, and it is also about providing a measure of relief to those tens and tens of millions of Americans who are providing care for a loved one every day, leaving their jobs, increasing their costs to do that. They should be the beneficiaries of the work of the U.S. Senate.

We are grateful today for our witnesses and for the Senators who attended and for those who are lifting up these policies to have us, as Americans, not just meet the obligations that public officials have but to create the America that we hope to have.

We all say we care about seniors. We all say we care about people with disabilities. Then should we not, at least, provide a measure of funding so that these Americans, who in many cases have worked their whole lives, and all they are asking for is an opportunity to choose the setting within which they receive their care, in the home or in the community. Some may choose to have their care in a nursing home or a long-term care facility of another kind. That is their choice, but that should not be the only choice, and in America, unfortunately, for too many Americans that is the only choice.

We have a long way to go. We have more work to do, but this hearing helped us lift up seniors and people with disabilities and their needs and helped us lift up those workers who are doing this work and those families who are struggling every day.

Thanks very much for your time, and our hearing is adjourned.  
[Whereupon, at 11:33 a.m., the Committee was adjourned.]



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## **APPENDIX**

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## **Prepared Witness Statements**

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**Written Testimony of Lisa Harootunian  
Before the U.S. Senate Special Committee on Aging Hearing:  
*An Economy That Cares: The Importance of Home-Based Services*  
March 23, 2022**

Good morning, Chairman Casey, Ranking Member Scott, and distinguished members of the committee. Thank you for inviting me to testify today about a bipartisan pathway to improve the availability of Medicaid home and community-based services (HCBS). I commend the committee for considering this critical issue through a bipartisan lens.

My name is Lisa Harootunian, and I am an associate director of the Health Program at the Bipartisan Policy Center, a non-profit organization that combines the best ideas from both parties to promote health, security, and opportunity for all Americans.<sup>1</sup> BPC drives principled and politically viable policy solutions through the power of rigorous analysis, painstaking negotiation, and aggressive advocacy.

Democrats and Republicans have historically supported efforts to expand Medicaid HCBS,<sup>1</sup> and Congress has made meaningful progress toward improving the availability of those services since the inception of the program; however, the need for these services persists and will continue to grow as 10,000 baby boomers turn age 65 each day until 2030, at which point the youngest of the generation will reach that age. In recent years, COVID-19 has exacerbated the need for home and community-based care options as an alternative to congregate care settings, which experienced high rates of infection and mortality. Additionally, for individuals with functional limitations or cognitive impairment, HCBS have long played a critical role in allowing Medicaid beneficiaries to live independently and to work.

To address the growing number of Americans who need assistance with daily activities, but who prefer to receive care in their home or community, continued bipartisan collaboration is necessary.

As described in BPC's report, [\*Streamlining and Simplifying Medicaid HCBS Authorities\*](#) (October 2021), Congress should consider a bipartisan pathway forward that would improve the administratively complex and piecemeal structure for HCBS authorities. To this end, **BPC**

<sup>1</sup> The Deficit Reduction Act of 2005 (DRA), for example, included provisions to create the 1915(i) state option to offer HCBS. The language was based on bipartisan legislation, S. 1602, the Long-Term Care Choices Act, sponsored by Sen. Chuck Grassley (R-IA) and co-sponsored by Sens. Evan Bayh (D-IN) and Hillary Rodham Clinton (D-NY). The Money Follows the Person Demonstration was also enacted as part of the DRA and was based on legislation introduced by Sen. Tom Harkin (D-IA), and was cosponsored by Republican Sens. Gordon Smith of Oregon and Mike DeWine of Ohio. The Balanced Budget Act of 1997 (BBA) included the PACE Coverage Act, which permanently established the PACE model under both Medicare and Medicaid. The PACE Coverage Act was introduced in the Senate by Sen. Chuck Grassley (R-IA), and originally co-sponsored by Sens. Bill Frist (R-TN), Daniel Inouye (D-HI), and Bob Graham (D-FL).

**recommends streamlining and simplifying Medicaid HCBS waiver and state plan authorities into a single state plan amendment (SPA), with the goal of reducing complexity for states administering the programs and for beneficiaries navigating the system.** This reform would also help to make services more uniform from state to state and across populations within a state. Ultimately, this change should improve access to services for Medicaid beneficiaries.

Historically, states have relied on 1915(c) waivers to provide HCBS, as these waivers allow states to target services to certain subpopulations and provide states with budget predictability. States often use multiple 1915(c) waivers—with each state using an average of five waivers and some states relying on up to 11 waivers at once—to target different populations or provide different services.<sup>11</sup> States also provide HCBS through 1115 waivers and state plan options, including 1915(i), (j), and (k) state plan amendments.

The patchwork of HCBS waivers and state plan amendments that states use have led to three key barriers to the availability of Medicaid HCBS, including:

1. A system that is extremely complex and burdensome for states to administer;
2. HCBS programs that are challenging for beneficiaries to navigate; and
3. Inequities in access to HCBS both within and between states.

The use of multiple waivers or a combination of waivers and state plan amendments creates an enormously complex system for states to manage, because they must administer multiple programs and benefits packages with different eligibility and other requirements.

When beneficiaries seek HCBS, they must navigate the different sets of requirements to determine which program will provide the benefit package that best meets their needs. Beneficiaries often have several options to choose from, and some waivers may have waiting lists. Additionally, because of the targeting of services allowed under 1915(c), not all waivers provide the same benefits across the state or to all subpopulations. Multiple waivers and SPAs operating simultaneously create a challenging system for beneficiaries to navigate and in some cases could make it impossible for them to receive all necessary services through a single program.

The current structure of HCBS authorities encourages states to rely heavily on multiple waivers, which can lead to inequitable access to services within and between states. For example, two residents of a state may have similar diagnoses and HCBS needs but may not be eligible to receive the same services due to the geographic targeting allowed under 1915(c) waivers. Although all states offer HCBS, the services covered, access to those services, and spending varies significantly across states.

Simplifying and streamlining states' HCBS authorities by creating a single SPA would improve the availability of HCBS by reducing administrative complexity in the current system. This would reduce administrative burden for states administering HCBS programs, make it easier for beneficiaries to navigate the system, and help to address inequities in access to HCBS within and

between states. States could better design and administer their HCBS programs around the needs of the beneficiary, while also improving the beneficiary experience.

Streamlining and simplifying HCBS waivers and state plan options could be addressed independently, or as part of other efforts to reform the system.

**Policy Recommendation: Simplify and Streamline Medicaid HCBS Authorities**

*Congress should establish a new consolidated SPA, combining existing state plan options and waivers. Current enrollees should be grandfathered to prevent a disruption in services.*

The administrative complexity and inequities in the current system could be addressed by replacing the complex patchwork of state plan amendments and waivers with a single, consolidated state plan amendment that draws from authorities that exist under current law. Ideally, the SPA would provide necessary services to those in need and retain much of the flexibility of existing HCBS waiver and SPA authorities to give states budget predictability for HCBS. Transitioning waivers to an improved state plan option would promote administrative efficiency, make programs more accessible to beneficiaries, and improve equity in access to services.

**Key Provisions**

Congress should establish a new consolidated SPA that would combine existing authority from Medicaid state plan options, including 1915(i), (j), and (k), and Medicaid waivers, including 1915(c) and Section 1115 (except in limited circumstances). Congress should phase out existing authorities and require states to deliver HCBS through the new SPA within five years of enactment. Existing enrollees served under current HCBS authorities should be grandfathered to prevent a disruption in services. Under this approach, the HHS secretary would develop a template for the consolidated SPA that states would use to address eligibility, benefits, and projected enrollment.

**Eligibility:** The new consolidated SPA would maintain current income eligibility rules and flexibilities. Similar to rules governing section 1915(i) SPAs, states could cover individuals with incomes up to 300% of SSI, or about 221% of the federal poverty level (FPL). States would provide an estimate of the number of eligible individuals based on state-established criteria, and could modify the needs-based criteria if enrollment exceeds projections. States could provide HCBS to beneficiaries before their conditions meet an institutional level of care standard, and that earlier access could delay or avoid more costly care.

**Benefits:** The new consolidated SPA would allow states to cover the full range of HCBS currently authorized under state plan benefits and sections 1915 and 1115 of the SSA.

**Individualized Care Plan:** Under the consolidated SPA, states should conduct independent assessments; develop individualized care plans in consultation with providers, caregivers, family, or representatives; and identify services to be provided. States must allow individuals to choose self-directed services. States would not be required to meet Medicaid requirements for

comparability or amount, scope, and duration of services standards; however, states must continue to comply with federal nondiscrimination rules and the HHS secretary should establish and enforce protections against discrimination.

**Maintenance of Effort:** As discussed in more detail below, to receive an enhanced administrative match under the consolidated SPA, states must comply with a maintenance-of-effort requirement for HCBS eligibility and benefit standards.

**Spousal Impoverishment Protections:** When simplifying and streamlining HCBS authorities into a single SPA, Congress should permanently authorize the state option to extend protection against impoverishment for spouses of individuals receiving Medicaid HCBS.

#### *Enhanced Match and Payment for Services*

**Enhanced Administrative Match:** States that comply with a maintenance-of-effort requirement for HCBS eligibility and benefit standards would be eligible for an enhanced administrative match for activities related to streamlined eligibility and enrollment functions, such as those typically performed by states’ “No Wrong Door” system, as well as for ombudsman activities and infrastructure development.

**Additional Enhanced Administrative Match for HCBS Quality Reporting:** Congress should direct the secretary of HHS to develop recommended core and supplemental sets to measure HCBS quality.<sup>2</sup> States that choose to measure and report on an approved set of HCBS quality measures would be eligible to receive an additional 1% Federal Medical Assistance Percentage (FMAP) increase beyond the enhanced administrative match.

**Maintaining Existing Initiatives:** The 6% enhanced FMAP for 1915(k) and the enhanced FMAP available for the Money Follows the Person (MFP) demonstration would extend to the consolidated SPA. The MFP demonstration would be permanently reauthorized. Under current law, states can also receive a 90% enhanced FMAP for integration and coordination of services for eight quarters through the Medicaid Health Homes model. This should continue under the consolidated SPA.

#### **The Need for Bipartisan Action**

The growing need for HCBS, coupled with the impact of COVID-19 on congregate settings and individuals’ preferences to receive care in the home or community, has brought national attention to the need for HCBS reform. BPC’s recommendation to simplify and streamline Medicaid HCBS waivers and SPAs offers a bipartisan pathway toward improving the availability of Medicaid HCBS. BPC believes streamlining HCBS into a single state plan option strikes a balance between simplifying administrative complexity and providing states with budget

<sup>2</sup> CMS is considering establishing a nationally available set of recommended Medicaid HCBS quality measures; in September 2020, CMS sought [public feedback](#) on a draft for a voluntary set of HCBS quality measures. Congressional action would ensure continued progress toward a nationally available set of quality measures for HCBS care delivery.

predictability, while helping to advance the goal of expanding access to services and improving the beneficiary experience.

Critical to the success of this effort will be ensuring that states receive comprehensive guidance and technical assistance from CMS to support transition to a consolidated SPA, and to ensure clarity around the flexibilities and characteristics of the new authority. This should be implemented in close coordination with states and other stakeholders.

Thank you once again to the Committee for convening this hearing. The enormously complex HCBS system remains a challenge to the availability of home and community-based services, but with your continued leadership and bipartisan collaboration, we can help more Americans access the critical services they need to live independently and to work. I look forward to your questions.

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<sup>i</sup> [www.bipartisanpolicy.org](http://www.bipartisanpolicy.org).

<sup>ii</sup> MaryBeth Musumeci, Molly O'Malley Watts, and Priya Chidambaram, "Issue Brief: Key State Policy Choices About Medicaid Home and Community-Based Services," Kaiser Family Foundation, February 2020, 37. Available at: <http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services>.

**Statement of Anne Tumlinson  
CEO, ATI Advisory and Founder, Daughterhood  
March 23, 2022 Hearing before the U.S. Senate Special Committee on Aging  
“An Economy That Cares: The Importance of Home-Based Services”**

Chairman Casey, Ranking Member Scott, and Members of the Committee, thank you for the opportunity to testify on the importance of investments in Medicaid home and community-based services.

My name is Anne Tumlinson, and I am the CEO of the research and consulting firm, ATI Advisory, which employs over 20 experts working with business and government to improve care delivery and financing for complex care populations. I am also the Founder of a grassroots community of family caregivers, called Daughterhood. Daughterhood operates local groups across the country that provide informal support and resources to family caregivers.

Home and community-based services (HCBS) are a critical part of the continuum of care for people with long-term services and supports (LTSS) needs. Whether funded by Medicaid or through private dollars, we know that these services make it possible for many individuals with high needs to remain safely in their homes, which is the preferred care setting for most individuals. A 2021 study replicating the CAPABLE program, an integrated home visit and home modifications program, found substantial improvements in function among participants who were able to remain in their own homes with targeted home care supports and modifications.<sup>1</sup> Home care can provide a family the key support it needs to delay or avoid a long-term institutional placement. Research shows that a person’s risk for nursing home

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<sup>1</sup> [Sarah L. Szanton et al., “CAPABLE program improves disability in multiple randomized trials,” Journal of the American Geriatrics Society 69, no. 12: 3631–40.](#)

placement is significantly lower for each five-hour increment in personal care the person received.<sup>2</sup>

Unfortunately, our home and community-based system and its infrastructure are vastly underdeveloped to meet the needs of the growing population that will need long-term services and supports at some point in their lives.

- Even now, Medicaid spends more (54%) on institutional care than on home and community-based services for older adults and individuals with physical disabilities.<sup>3</sup>
- Of the approximate 3 million Medicare beneficiaries living in the community who need support with two or more activities of daily living, one third live below 200% of the federal poverty level but are not on Medicaid, and therefore cannot access HCBS.<sup>4</sup>
- Three-quarters of the direct care workforce supplying the labor for LTSS doesn't earn a living wage.<sup>5</sup> More than half of home care workers are on public assistance, and more than half are paid less than \$13 per hour.<sup>6</sup>
- Even among individuals with resources, finding and deploying privately financed home-based services and supports is challenging. These individuals often report not knowing where to go, and not being able to find what they need.

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<sup>2</sup> Sands LP, Xu H, Thomas J 3rd, et al. Volume of home- and community-based services and time to nursing-home placement. *Medicare Medicaid Res Rev.* 2012;2(3):mmrr.002.03.a03. Published 2012 Aug 6. doi:10.5600/mmrr.002.03.a03. For additional data on the value of HCBS, see ATI Advisory and Arnold Ventures compendium of research.

<sup>3</sup> Steve Eiken et al., "Medicaid Expenditures for Long-Term Services and Supports in FY 2016." Calendar year 2016 was chosen because more recent reports do not include all states, which affects the national average.

<sup>4</sup> ATI Advisory analysis of the Medicare Current Beneficiary Survey, 2019.

<sup>5</sup> LeadingAge, "Making Care Work Pay."

<sup>6</sup> PHI, "Direct Care Workers in the United States: Key Facts."

As a result, the majority of high need older adults living in the community are receiving assistance from family caregivers alone. Mounting evidence shows that family caregiving has a significant impact on the economy: 40% of family caregivers reported having to go from full-time to part-time employment to care for a loved one and almost 20% left their paid jobs altogether.<sup>7</sup> To say those family caregivers are stretched thin is euphemistic. What I hear from our Daughtershood community over and over is that every single family operates like it is on its own island. There is nowhere to turn for services and supports. When we can't do it anymore, and the money runs out, often a nursing home is the only option.

The good news is that some efforts are underway to address system inadequacies. States received an infusion of federal funds in the historic American Rescue Plan Act (ARPA). This is important to respond to the added HCBS needs and costs associated with the pandemic. And it will help jumpstart HCBS capacity building. But it's just a start. And importantly, it is temporary. States tell me that they need a reliable and sustained federal commitment of resources in order to commit to long-term changes.<sup>8</sup> There have been some limited private sector initiatives as well, including technology developments and health plan offerings.

But these small, incremental, or temporary solutions are not enough. It's like we are bringing an umbrella to a hurricane.

The population shift the U.S. is experiencing right now is nothing short of seismic. The number of individuals in our country who are 85 years and older will double by 2035 and triple by 2060, up to 19 million people.<sup>9</sup> At the same time, the number of caregivers available to provide support

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<sup>7</sup> [Rosalynn Carter Institute for Caregivers, "How "Working While Caring" Impacts Our Caregivers and Our Nation's Economy."](#)

<sup>8</sup> [ATI Advisory, "A Blueprint for Reforming Medicaid Long-Term Services and Supports and Creating Good Caregiving Jobs."](#)

<sup>9</sup> [Census.gov, "Demographic Turning Points for the United States: Population Projections for 2020 to 2060."](#)



is declining. Much more federal investment is needed to galvanize and support states and local communities in developing the infrastructure and systems along which a variety of publicly and privately funded HCBS can travel.

There are significant consequences if we fail to make a sustained federal investment in Medicaid HCBS. Without investment, we will continue to rely heavily on nursing homes. Today they are the primary infrastructure we have, and the only guaranteed source of long-term services and supports for people with high needs. And we will also continue to over-rely on unpaid family caregivers.

And what I can tell you from my own experience as well as being part of a community of unpaid family caregivers is that families face very tough choices today. Caring for a person who needs assistance performing daily activities is work, whether it's paid or not. It requires not only the hands-on support but also the management of care needs that cross-cut long-term services and supports AND medical care. I often say that families end up being the ultimate case coordinators. Over and over, they tell me about quitting jobs to provide this care and the threat this creates to their economic security. In addition, they severely compromise their own health and well-being. They compromise relationships with their children and spouses.

As growth in the size of the very old population starts to accelerate, our families, employers, communities, and states will feel these strains in a much more pronounced way. To prepare, we must invest in HCBS. This is the number one, most impactful federal outlay we can make right now to support individuals in need and their families. Without it, I fear the current state HCBS infrastructure will collapse leading to more and more families facing financial and emotional devastation, and an even greater reliance on institutional care.

**Testimony to the Senate Special Committee on Aging Hearing  
“An Economy That Cares: The Importance of Home-Based Services”  
March 23, 2022**

**Brandon Kingsmore, Home Care Consumer  
accompanied by Ms. Lynn Weidner, Home Care Worker, United Homecare Workers of  
Pennsylvania & SEIU Healthcare PA**

Thank you Chairman Casey, Ranking Member Scott, and members of the Senate Special Committee on Aging for inviting me and my caregiver, Lynn, to speak today. My name is Brandon Kingsmore, and Lynn and I live in Allentown, PA.

I've relied on some form of home care my whole life, a reality so many people never experience, so it is very important to me that I share my story openly and honestly. Especially because at some point, as we all get older, every one of us will need this type of care. I want people to understand that quality, affordable, accessible home care is so much more than just a social service or numbers on a spreadsheet — it is a lifeline for the 61 million people with disabilities and 54 million people aged 65 and older who call this country home.<sup>1</sup> I hope that what I share with you today will make clear why we, the people, need you, our country's leaders and decision-makers, to support and pass President Biden's life-changing investment in care.

To be clear: we need this funding. It's the only way to raise wages for workers and lower costs for families. We are facing a large-scale crisis and COVID has made clear that when you just fix around the edges, lives are lost. It is why Congress must pass the Better Care Better Jobs Act — now.

Before I tell you my story, I want to speak on behalf of everyone whose lives depend on quality, affordable home care, and whose lives depend on the decisions made on Capitol Hill. For too long, our elected leaders have allowed our healthcare system to fail us. COVID-19 certainly made clear that access to care is a matter of life or death, and too many working families have suffered the devastating consequences of our country's under-funded, under-resourced, under-prioritized home- and community-based services.

Please make the right decision. Please do what's right. Please come together and pass this investment in better care, better jobs and a better future for all.

I was born with cerebral palsy and I use a wheelchair to get around, which means I sometimes need a little help doing things throughout the day. Growing up, my mother did everything for me. I grew up in North Carolina, and I didn't qualify for Medicaid until I was 18 because of how limited home- and community-based services are there. My mother's insurance wouldn't cover home care, and we couldn't afford to pay out of pocket, so she had to be my full-time caregiver on top of her other full-time job.

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<sup>1</sup> <https://www.aging.senate.gov/imo/media/doc/How%20American%20Families%20Benefit.pdf>

I felt so guilty. I felt like a burden. I still do, sometimes.

When I finally qualified for Medicaid, finding a reliable, consistent, well-trained home care worker proved almost impossible. There was a period of time when my mother couldn't be there to provide the care I needed, so I spent my days sitting, playing video games, watching movies, just waiting for her to get home to help me go to the bathroom, prepare a meal, or go out. I felt trapped in my home, and I prayed for the better, more active and fulfilling life I knew I could live if I was able to afford quality, consistent, reliable home care.

This is a situation so many care consumers face, but so often goes unseen. There aren't enough home care workers to meet the demand, so care consumers become isolated or forced to leave their homes and live in a facility. We become removed from society against our will. We want to participate in our economy and communities, but the choice is made for us when lawmakers refuse to acknowledge and take action to change a system designed to hold us back.

Today, nearly 350,000 Pennsylvanians need help with daily activities, such as bathing and dressing.<sup>2</sup> But data show there are fewer than 198,000 home care workers to fill these roles.<sup>3</sup> Something doesn't add up. With the demand for care skyrocketing, especially as the long-term impacts of COVID come to light, the commonwealth will need to fill more than 292,000 home care jobs by 2028.<sup>4</sup> Investing in HCBS will ensure the needs of every care consumer are met by attracting and sustaining our home care workforce. Policies like the Better Care Better Jobs Act will put the country on the right path to building a sustainable and durable home- and community-based care system and build an economy that works for all working people.

With the way things are now, people like me wake up each morning, not knowing if a home care worker will be there that day. If our home care worker is sick or needs to take time off, which is likely unpaid because most don't have paid sick time or paid leave, there's no guarantee that another caregiver will be available to cover their shift. If someone is available, they're often not prepared or trained in advance to provide the specialized care each individual consumer needs. Oftentimes, they're working one or two other jobs because the pay for care jobs is so poor, so they only have an hour or two to provide care for someone who needs help 24/7.

It is humiliating and dehumanizing to be 32 years old and have someone put you in a diaper, because they don't have the training or the time to help you go to the bathroom.

But this isn't the fault of the home care workers. The people who do this work love helping others and care about people in need. They want to do this work, and so often put their needs

<sup>2</sup> Paul, Rafal, & Houtenville. 2020. Annual Disability Statistics Compendium: 2020 (Table 1.8). University of New Hampshire, Institute on Disability. [https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2021\\_release\\_year/Final%20Accessibility%20Compendium%202020%20PDF\\_2.1.2020reduced.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2021_release_year/Final%20Accessibility%20Compendium%202020%20PDF_2.1.2020reduced.pdf)

<sup>3</sup> PHI. "Workforce Data Center." Last modified September 2, 2021. <https://phinational.org/policy-research/workforce-data-center/>.

<sup>4</sup> Home care job openings include new jobs created and jobs that need to be filled due to workers leaving the field or the labor force. PHI, 2020. <https://phinational.org/policy-research/workforce-data-center/#tab=State+Data&nav=Employment+Projections&states=42>

aside to meet the needs of others. But the system elected leaders have built isn't designed to set them up for success.

March is Women's History Month, a time to celebrate, honor and reflect on the women who keep our communities running and our economy strong. The home care workforce is a workforce of 90 percent women, and more than 60 percent people of color. But our country has a track record of choosing not to invest in these jobs, therefore choosing not to invest in the Black, brown, immigrant and indigenous women who do this essential work, despite the system working so hard against them. Why is that? Is this work not important? Are these women not important? Instead of tweeting about it, why not turn collective appreciation for women into meaningful action that lifts women and women of color out of poverty and finally gives them the respect, protection and pay they deserve?

Shamefully low pay and a lack of benefits force home care workers to leave the industry in search of work they need to pay their bills, support their families and build a life on. Training isn't prioritized for home care workers, despite their role as essential healthcare workers. Instead, employers put home care workers in situations that put their health and safety — and their consumers' health and safety — at risk. Affordable healthcare isn't offered to many home care workers, so if they get hurt or sick, going to the doctor isn't an option without facing financial ruin. And as I said, without paid sick days, taking time off means they don't get paid.

People who want to do this work can't afford to, the people who already do this work are treated as expendable, and the people who depend on this work are left without options.

If Lynn gets hurt or sick and is unable to provide care, I'd have no one. There wouldn't be another home care worker to fill in for her. It's incredibly isolating. Without a home care worker, I don't have a life. I can't go anywhere or do anything. I have a life. I have a voice. I have feelings. I have goals and ambitions.

Being in a wheelchair is hard enough. Not all buildings or transportation options are accessible — not even my apartment. My apartment was built long before power chairs existed. The hallway is too narrow, the doorways are too tight, and the counter tops are too high. I can't access the bathroom with my wheelchair to get in the shower, so my caregiver has to physically lift my 120-pound frame onto a countertop and carry me several feet to the bathtub to get cleaned up. I can't brush my teeth at the bathroom sink, so I use a cup at the dining room table.

And the looks I get on the street, the way I'm spoken to like I'm a toddler, and when people act as though they're scared of me is the reality I face every time I leave the house. Why is it that I have to fight for everything I need? Why should people like me, older Americans, and our families have to bankrupt themselves because they can't afford care that helps them with the simple basics of life like bathing and toileting?

When Lynn became my full-time caregiver 11 years ago, everything changed. Suddenly, the life I always dreamed of was in reach. Without Lynn, I would be in a nursing home at the age of 32,

or home alone for hours a day, with no hope or freedom. Having a disability shouldn't mean your life is over. Home care workers give us a substantial life, and allow us to stay in our communities.

But for all the work home care workers do caring for others, they can barely care for themselves. Data show the median wage for home care workers nationally is \$12.98 an hour, and Lynn now makes \$13.50 an hour as a home care worker in Pennsylvania, after her union won eight percent raises for home care workers in our county.<sup>5</sup> Home care is an emotionally and physically demanding job. But with the rising cost of living, inflation, and other economic stressors, wages this low make it impossible for home care workers to meet their basic needs, take care of themselves and their families, and live comfortably.

Home care is one of the fastest growing industries and jobs in the country due to exploding demand that will only get worse as times go on and more people get older. But because of the poor quality of these jobs, we cannot recruit enough workers, and turnover in the field is through the roof. Again I ask: why is this the reality we accept? For me and so many others, care work is a matter of life and death. If there are no care workers, then there is no care.

Our saving grace has been Lynn's union, SEIU Healthcare Pennsylvania and the United Home Care Workers of Pennsylvania. Uniting home care workers across the Commonwealth, Lynn's union has spent decades fighting for the dignity and respect that caregivers and consumers deserve. As part of her union, Lynn fights alongside other workers and their consumers for what every home care worker deserves: a living wage, access to training, affordable health insurance, and collective bargaining rights.

Around the country, at the bargaining table, in the streets, in the halls of state houses and Congress, caregivers and their unions are leading by example and demanding structural changes to the long term care system. When workers come together, the state listens in the way it would never listen to just one worker alone. But for all the victories, there is a long list of injustices to keep fighting.

We live in the wealthiest country in the world, yet the unaffordable cost of home care, the lack of comprehensive paid leave, and a severe shortage of home care workers forces many working families to choose between caring for a loved one and a paycheck. This is an impossible choice, and many people end up leaving their jobs to care for family and friends who can't afford or access home- and community-based services — without pay.

In Pennsylvania, there are 1.59 million family caregivers providing 1.33 billion hours of care to loved ones 18 and older.<sup>6</sup> Investing in better care and better jobs would make it possible for family members who left their careers to assume caregiving responsibilities to return to the

<sup>5</sup> All wage data comes from PHI. "Workforce Data Center." Last modified Sept. 2, 2021. <https://phinational.org/policy-research/workforce-data-center/>.

<sup>6</sup> Reinhard et al. 2019. Valuing the Invaluable: 2019 Update. AARP. <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>

workforce, knowing a skilled, dedicated, consistent home care worker is caring for their loved ones.

Our country's leaders need to take a good look in the mirror and reevaluate the way seniors and people with disabilities are treated. We need to reevaluate how home care workers are treated. We need to reevaluate how the women, women of color, and immigrants who do the majority of this work are treated.

I was born in 1989 — before people with disabilities had any rights. The Americans with Disabilities Act was passed in 1990, and that was a start, but we still live in an ableist, ageist, racist, sexist world where people in need are excluded and forgotten.

A better future means life, liberty, and the pursuit of happiness for all. Isn't that what this country is all about? I dream of a future where all people, of all races, of all genders, of all ages, of all backgrounds can wake up each morning knowing they're healthy, safe and able to provide the best lives for themselves and their families.

That's why Lynn and I are here today. We can't make a better future if we don't address these deeply rooted issues now.

I'm nobody special — I'm just a guy from Pennsylvania looking for a fair shot at a good life. But I feel a responsibility to speak up for the millions of people who are just like me. Chairman Casey has given Lynn and I the chance to spread our message further than we thought possible. Last year, we even had the honor of meeting President Biden. It is an honor and a privilege being able to speak to members of this committee and other lawmakers face to face about what it's like to be me, what it's like to be Lynn, and what it's like to know our lives hang in the balance as you debate dollars and cents. This isn't just dollars and cents. The choices you make dictate the way I can live my life, the way all of us can live with dignity when the day comes that we or a loved one needs this care.

But I can't help but think to myself... I've told my story so many times. How many more times will I have to say this before lawmakers take meaningful action? Honestly, when I share my story with people who are fortunate enough to have the financial resources to access and afford care, I wonder whether or not they're really taking in my words. Unless you live this life — having a disability or providing care — you can't possibly understand how hard it is and just how much we rely on home- and community-based services.

This is a human rights issue. It is unacceptable that in 21st century America, the freedom to live is 100% based on money and the priorities of other people — particularly of some elected officials on Capitol Hill. With the way things are now, Medicaid only sees us as numbers. But we're not. We're humans that deserve to live life. We're people with feelings and emotions.

Walk a day in my shoes. Walk a day in Lynn's shoes. Walk a day in the shoes of someone who suddenly fell ill or got in an accident that leaves them totally reliant on someone else to help

them live. It could happen to anyone, at any time, no matter who they are. But our current long term care system cannot guarantee home care for all who need it. Our current long term care system does not have the funding and resources necessary for recruiting, training and sustaining a home care workforce. The system is crumbling — especially after COVID-19. And that's why we need action now.

The needs of people with disabilities, seniors, working families, and children cannot be ignored any longer. If this legislation dies, caregivers will suffer because they cannot afford food, shelter, or healthcare, and clients will perish because no one will be there to keep them alive.

Senators, please invest in care workers like Lynn by granting HCBS the funding it needs to make home care jobs good union jobs with pay and benefits that reflect the true value and impact of their essential work.

Senators, please invest in care consumers like me by investing in HCBS, providing funding so we can get the care we deserve from the compassionate, well-trained, dedicated home care workers we depend on to live.

We are the closest we have ever been to finally beginning to address the long term care crisis in this country. We — people with disabilities, older Americans, our families, and the workers who support us — matter. Don't leave us behind again. Congress must act now.

Written Testimony of Alene Shaheed  
 United States Senate, Special Committee on Aging  
 An Economy That Cares: The Importance of Home-Based Services  
 March 23, 2022

Chairman Casey, Ranking Member Scott, and the Members of the Committee,

Thank you for the opportunity to share my experience with you today as someone who is enrolled in Medicaid home and community-based services. My name is Alene Shaheed. I am 76 years old and I live in Jacksonville, Florida.

In 2005, I retired after 30 years of doing customer service and started enjoying my retirement traveling, visiting friends, and doing the things I wasn't able to do while I was working. I was also taking care of my nephew during this time up until 2010. In 2013, to have more money, I went back to work as a security guard in a private community. In 2016, I started to experience some mobility issues. I went to the doctor and learned that I had a growth on my spine. It took two surgeries one in February and one in July to ultimately remove the growth. After the second surgery, I was unable to walk and now I use a wheel chair for mobility. I also need assistance with bathing, dressing, housekeeping, some toileting, and meal preparation.

I am enrolled in Florida's Medicaid long-term care waiver and I am approved for 35 hours of help per week. My home health aide allows me to continue to remain living at home and helps me be independent. When given the option, I chose to receive services at home and not go into a restrictive nursing home where they tell you when you can eat, when you have to get up in the morning and go to sleep, or even when you can have visitors. I value my independence and I am capable of living at home with assistance.

I'm very fortunate that I am in the long-term care program in Florida since thousands of people in my situation are on waiting lists because there isn't enough funding for the program. Even being enrolled in the program, I have always experienced gaps in my services when a home care aide didn't show up for various reasons. But there were always workers available. Now and since the pandemic started, the services have been in decline and so has the quality of my life. I am now experiencing lapses in services. While I am approved for help seven days a week for five hours a day, right now I can only find an aide for 20 hours a week. Since January of this year, I have not been able to find an aide to come on Saturdays, Sundays, and Mondays. So I don't have any help for three days until my other aide comes on Tuesday.

This means I am unable to shower for three days. I cannot take out the trash since I can't get in and out of trash room with my wheel chair, which is important for cleanliness. I can only make easy-to-prepare food on my own. A couple weeks ago when I was fixing myself ramen noodles I accidentally tipped over the cup of boiling water on my leg and now have a large burn. Thankfully it did not get infected, but the burn is on my left leg which I use to transfer in and out of bed making it harder for me to do that on my own. I'm also spending more time in my wheelchair because I do not have help, which puts me at risk for pressure sores. I also feel very socially isolated. I live in an apartment complex for seniors. Last weekend, they had a St. Patrick's day pot luck, but I was unable to go because no one was able to help



me get bathed and dressed. Not having the help affects every aspect of my life because the aides are my lifeline to independence. I absolutely do not want to go into a nursing home.

Why is this happening to me and so many thousands of others? It's due to the underfunding of Medicaid and the wages of home care workers are too low. The average pay for aides is \$10 - \$13 an hour. Even before the pandemic, my aides told me they worked two jobs. They would help me during the day and then go work at nursing home at night to take care of themselves and their families. When the pandemic came about, I started to see a decline in the program because the aides were unwilling to put themselves and their families at risk for just \$10 an hour. So now they are going to work for a private agency or they find another job that pays better. The workers are hurt by how little they are paid and I am hurt by how little they are paid. Valuing me means valuing them and valuing them means valuing me. And we all deserve to be valued.

I know that many people are in the same situation as me. These services are our lifeline to remain independent and live with dignity. They must be adequately funded. Thank you again for letting me share my story with you and for having this hearing.



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## **Questions for the Record**

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U.S. Senate Special Committee on Aging  
**“An Economy That Cares: The Importance of Home-Based Services”**  
 March 23, 2022  
 Questions for the Record  
**Ms. Lisa Harootunian**

**Senator Tim Scott**

**Question:**

Ms. Harootunian, when I introduced you, I referred to Eunice Medina of South Carolina’s Medicaid agency who had spent 5 years consolidating 10 waivers. I’ve heard from other state Medicaid offices they spend way too much time negotiating waivers with the Centers for Medicare and Medicaid Services. You and your team at the Bipartisan Policy Center recommend simplifying and streamlining the patchwork of existing Home and Community Based Services Waivers and State Plan Amendments into a single option. Would you please describe the challenges in the current system and how a transition to a consolidated State Plan Amendment would address those challenges while ensuring that states retain the flexibility to design programs that best fit their needs?

**Response:**

States rely on a patchwork of Medicaid home and community-based services (HCBS) waivers and state plan amendments (SPAs) to provide HCBS. In fact, the number of 1915(c) HCBS waivers averages five per state and ranges from one to 11. Additionally, states also cover HCBS through 1115 waivers and state plan options such as the 1915(i), 1915(k) Community First Choice, or 1915(j) option for self-directed personal assistance services. This patchwork of HCBS authorities has created an extremely complex and burdensome system for states to administer and for beneficiaries to navigate.

The use of multiple waivers or a combination of waivers and state plan amendments creates an incredibly complex system for states to manage, because the state must keep track of different eligibility rules, benefit packages, and reporting requirements for each waiver. Also, each waiver is for only a limited time and states must periodically submit renewal requests to the Centers for Medicare & Medicaid Services (CMS). Given the variation in length of each waiver, the renewal process requires significant staff time and is burdensome on states. Adding to the complexity, states may also need to oversee multiple contracts and contractors, manage several waiting lists, and oversee different sets of quality metrics.

As described in greater detail in the Bipartisan Policy Center’s report, [\*Streamlining and Simplifying Medicaid HCBS Authorities\*](#) (October 2021), many states rely on waivers to control costs and cite this reliance as a challenge to effective administration of their programs.

Moreover, the U.S. Government Accountability Office (GAO) released a report, [\*MEDICAID: State Views on Program Administration Challenges\*](#) (April 2020) acknowledging that many state officials GAO interviewed suggested allowing states to limit HCBS enrollment through their state plans and allowing more flexibility in their ability to target long-term services and supports to certain beneficiaries.

The Bipartisan Policy Center's recommendation for a consolidated SPA would address these challenges for states by increasing flexibility under state plan authority while preserving budget predictability for HCBS. The consolidated SPA would also eliminate the burdensome waiver process for HCBS, the other administrative responsibilities that states must manage for each waiver, and the uncertainty—for states, plans, providers, and beneficiaries—that arises from relying on time-limited waivers.

The current system is also challenging for beneficiaries seeking HCBS, because they must navigate the different sets of requirements to determine which program will provide the benefit package that best meets their needs. Beneficiaries often have several options to choose from, and some waivers may have waiting lists. Additionally, because of the targeting of services allowed under 1915(c), not all waivers provide the same benefits across the state or to all subpopulations. Multiple waivers and SPAs operating simultaneously create a challenging system for beneficiaries to navigate and in some cases could make it impossible for them to receive all necessary services through a single program.

The Bipartisan Policy Center's proposal for a consolidated SPA would address these challenges for beneficiaries by reducing complexity in the current system and making it easier for beneficiaries to navigate the system. Under a consolidated SPA, states could better design and administer their HCBS programs around the needs of the beneficiary while also improving the beneficiary experience.

Simplifying and streamlining states' HCBS authorities by creating a single SPA would thus reduce administrative burden for states administering HCBS programs and make it easier for beneficiaries to navigate the system. This reform could be addressed independently, or as part of other efforts to reform the system.

**Question:**

Ms. Harootunian, one of the challenges we are trying to address across our whole health system is equity. This hearing is concerned with the most vulnerable people with complex health needs. They do not have equitable access to care. How would the consolidated State Plan Amendment you propose address current inequities in access to Home and Community Based Services?

**Response:**

The patchwork of waivers and state plan amendments (SPAs) that states use to provide home and community-based services (HCBS) has resulted in divergent levels of access to HCBS both within and between states. The Bipartisan Policy Center's proposal would address that barrier to the availability of Medicaid HCBS by establishing a consolidated SPA that would improve equity in HCBS access both within and between states.

The current structure of HCBS authorities encourages states to rely heavily on multiple waivers, which can lead to inequitable access to services within a state. For example, two residents of a state may have similar diagnoses and HCBS needs but may not be eligible to receive the same services due to the geographic targeting allowed under 1915(c) waivers. A consolidated SPA would allow states to phase in enrollment, but they must provide coverage statewide within five years from the time the SPA is approved. Improving access to HCBS statewide would improve equitable access to HCBS within states.

The patchwork of HCBS authorities also contributes to inequities in the availability of HCBS between states. More uniformity across states would be achieved through the statewide coverage requirement of the consolidated SPA, the requirement to allow individuals to choose self-directed services, and the requirement for individualized care plans that would promote person-centered care across states. Simplifying and streamlining authorities would also improve inequity in access to HCBS across states by eliminating the burden that states experience in administering multiple waiver programs and by creating less complex systems for beneficiaries to navigate and access services.

Finally, the new state plan option would improve uniformity across states by helping to clear wait lists for services.

**Question:**

Ms. Harootunian, while it is important to simplify and streamline these Home and Community Based Services authorities, we also have to make sure we spend these dollars wisely. It is easy to say “just spend more money to solve the problem,” without addressing any root cause of the problems. What mechanisms exist under BPC’s proposal to help states control costs?

**Response:**

The Bipartisan Policy Center’s proposal to simplify and streamline Medicaid home and community-based services (HCBS) authorities into a consolidated state plan amendment (SPA) would improve access to HCBS by reducing complexity in the current system while preserving certain flexibilities to help states control costs.

Currently, many states provide HCBS through 1915(c) waivers because the waivers allow states to target services—to specific populations and geographic locations—and to cap enrollment, thus providing budget predictability for HCBS.

The Bipartisan Policy Center recommends drawing from existing authorities to create the new SPA in a way that preserves budget predictability for HCBS. Under the consolidated SPA, states could control costs through population targeting (as currently allowed under 1915(c) waivers) and through the amount, duration, and scope of services offered. Also, as currently allowed under the 1915(i) state plan option, states could limit participation by estimating the number of individuals they expect to enroll, then modifying the needs-based eligibility requirements and ending enrollment once they reach that number.

Another way that our proposal could reduce costs over the long-term is by allowing states to offer HCBS to individuals before their conditions worsen and require more costly care.

Moreover, HCBS authorities such as 1915(c) waivers and the 1915(k) state plan option currently require individuals to meet criteria for an institutional level of care standard; meaning, individuals often cannot access HCBS until their conditions require significant and more costly interventions. Under the consolidated SPA, as under the current 1915(i) state plan option, individuals would not have to meet criteria for an institutional level of care. This would allow states to offer HCBS to individuals earlier, which could delay or avoid more costly institutional care.

To ensure successful transition from current authorities to the new consolidated SPA and to help states understand the utilization controls and other flexibilities available to them, states will need comprehensive technical assistance and guidance from CMS.



U.S. Senate Special Committee on Aging  
**“An Economy That Cares: The Importance of Home-Based Services”**  
March 23, 2022  
Questions for the Record  
**Ms. Anne Tumlinson**

**Chairman Robert P. Casey, Jr.**

**Question:**

Throughout your testimony, you noted that most individuals would prefer to receive care in the home rather than in a facility, if possible. You also discussed the importance of access to high quality care in the home in order to avoid or delay care in a facility-based setting. I believe this to be true, not only for individuals eligible for Medicaid home and community-based services, but also for people with Medicare, who may prefer to receive care in their home. That is why I am a supporter of the Choose Home Care Act, or S. 2562, which would provide people with Medicare additional options to recover at home following a hospitalization.

How would an extended home health benefit like the one outlined in the Choose Home Care Act increase options for care and impact quality of life for people with Medicare and their families?

**Response:**

Many family caregivers tell me that they would prefer post-acute care services at home, but the Medicare home health benefit and payment design simply will not support their need for daily skilled nursing and home health aide services. In its March 2021 report, the Medicare Payment and Advisory Commission’s (MedPAC) reported that the number of home health aide visits per episode declined from 13.4 in 1998 to 1.3 in 2019. Skilled nursing visits declined from 14.1 to 8.1 and therapy visits increased from 3.8 to 8.1 over that same time period. Over the ensuing decades, family caregivers have been forced to compensate for the infrequent and low intensity supply of nurses and home health aides in the home. And when they can’t, they are desperate for high quality skilled nursing facility care.

Now is a good time to be providing beneficiaries and their families more options to receive post-acute care at home. Home-based medical care is an increasingly accepted site of care within the larger healthcare delivery and payment system. For example, home-based primary care practices are growing, as are home-based palliative care services. More hospitals are adding hospital-at-home programs. Telehealth technology and its rapid adoption during COVID is accelerating and supporting healthcare at home. In-home dialysis and Hospice care are additional examples of home-based medical care. These models are especially effective in a value-based care context, where payment is dependent on outcomes and costs.

The Choose Home Care Act addresses many of the shortcomings in the current Medicare home health benefit. For individuals who need daily skilled care – that is, individuals who would

otherwise qualify for a skilled nursing facility benefit – the legislation allows for daily skilled care, recognizes the importance of home health aides in meeting functional needs in post-acute care, and sets a 30- day episode length over which a wide range of services would be available for agencies to deliver. Of note, the legislative language includes, in this list of services, training and respite for family caregivers and care coordination services. These are especially valuable services for family caregivers juggling many demands following a hospitalization.

A home-based extended care services benefit, like in the Choose Home Care Act, must include strong certification criteria for agencies delivering this new benefit. With so many more services in the extended benefit, agencies must be able to demonstrate the requisite technological, clinical, and operational sophistication to serve a more complex patient population. Competency in delivering care coordination will be especially important to avoid over-burdening family caregivers with complex scheduling tasks.

If enacted, this legislation will further divert patients from Medicare skilled nursing facility (SNF) stays. At the start of the pandemic, hospitals began sending a [higher share of Medicare fee-for-service](#) discharges to home health compared to SNFs. This trend has continued, depriving SNFs of Medicare fee-for-service revenue they need to subsidize Medicaid long stay residents. The erosion of Medicare fee-for-service volume could have consequences for access to, and quality of, Medicaid long-stay beds in the future, particularly in rural and under-served areas.

While we will hopefully see increased investment in Medicaid home and community-based services and a continued shift to aging at home, the fact remains that nursing homes are the only long-term care benefit that federal law requires state Medicaid programs to cover. And for families whose loved ones have extremely high needs (e.g., Alzheimer's), a nursing facility is often the best option for their family. As we move more post-acute care home, we should be aware of the consequences of shifting Medicare dollars out of nursing homes and consider how to create a long-term care system with sufficient financing and infrastructure to support individuals with high levels of need in the setting that is best for them.

#### **Senator Mark Kelly**

##### **Question:**

Thank you for testifying. Your testimony referenced your professional experience within the community of family caregivers your organization works to support. In Arizona, we have about 870,000 family caregivers who provide billions of dollars' worth of unpaid care every year. During the pandemic, folks were providing nearly eight additional hours of care each week on top of everything else. As you said, caregiving is work. It's not easy. I think we need to do a better job of showing caregivers' value to our communities.

This is why I'm a cosponsor of the Credit for Caring Act, which would provide family caregivers a tax credit of up to \$5,000 to help with out of pocket caregiving costs. It would place a value on this unpaid work.

This is not the only thing we can do to improve quality of life for both caregivers and those they care for, but do you agree that this would be a helpful way to offset costs for folks that aren't paid for their family caregiving work?

**Response:**

I agree that a tax credit for out-of-pocket caregiving costs would help relieve some of the significant financial strain and burden that family caregivers face. Family caregivers often lose income as they cut back at work or leave their job altogether. They also face unreimbursed expenses for healthcare, housing, and long-term care. This strain, reduced income, and higher expenses damages their long-term health and financial security.

The Bipartisan Policy Center (BPC) cites important research on this topic in its September 2021 report, [Bipartisan Solutions to Improve the Availability of Long-Term Care](#), which recommends a caregiver tax credit, "...one in five family caregivers reports high financial strain, and 23% take on more debt. In addition, they incur roughly more than \$7,400 in nonreimbursed out-of-pocket costs each year on paid care and related expenses.<sup>1</sup> Researchers estimate that the economic value of unpaid caregiving was \$470 billion in 2017."<sup>2</sup> The BPC further points out that, "unpaid care and financial assistance that family caregivers provide can help to keep frail and functionally or cognitively limited individuals in their homes. This assistance can delay the need for expensive LTSS, such as nursing facility costs."

<sup>1</sup> AARP, "Surprising Out-of-Pocket Costs for Caregivers," October 1, 2019. Available at: <https://www.aarp.org/caregiving/financial-legal/info-2019/out-of-pocket-costs.html>. See also: Chuck Rainville, Laura Skufca, and Laura Mehegan, "Family Caregiving and Out-of-Pocket Costs: 2016 Report," AARP Research, November 2016. Available at: [http://www.aarp.org/content/dam/aarp/research/surveys\\_statistics/ltc/2016/familycaregiving-cost-surveyreslrc.pdf](http://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/familycaregiving-cost-surveyreslrc.pdf).

<sup>2</sup> Susan C. Reinhard, Lynn Friss Feinberg, et al., "Valuing the Invaluable: 2019 Update, Charting a Path Forward," AARP Public Policy Institute, November 2019. Available at: <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-pathforward.doi.10.26419-2Fppi.00082.001.pdf>.

U.S. Senate Special Committee on Aging  
“An Economy That Cares: The Importance of Home-Based Services”  
March 23, 2022  
Questions for the Record  
Mr. Brandon Kingsmore and Ms. Lynn Weidner

Senator Tim Scott

**Question:**

Mr. Kingsmore, thank you and Ms. Weidner for taking the time to share your experience with the Committee. You spoke about the rising costs of rent, groceries, gas and how they impact your lives. I am also concerned about the impact inflation, the highest in 40 years, is having on the everyday lives of all Americans, especially individuals who have the hardest time making ends meet. Can you tell us what high inflation would mean in your everyday lives, especially in light of the Treasury Secretary’s recent comment that inflation will remain “uncomfortably high” for another year?

**Response:**

It’s easy to say we’ll plan for something financially and budget expenses. But nobody plans to get hurt, have a child with a disability, have a family member that suddenly needs care, or expect inflation.

Plans fall apart. You have to adapt — but not everyone has unlimited resources to depend on, and unexpected expenses means having to make sacrifices. With wages under \$15 an hour, and no paid time off or affordable healthcare, adapting could mean facing financial ruin for caregivers and their families. That means that we have to invest in Medicaid Home and Community Based Services (HCBS) so that workers, consumers, and their families are able to survive even in the face of an uncertain economy. For us, in some cases, it is life and death. For home care consumers, affording quality, accessible care is enough of a financial stressor. When you factor in rising costs of food, gas and other basic needs, getting the care we need becomes that much harder. But for people like me, access to quality affordable care is a basic need. Medicaid HCBS is the largest payer for these services. I am lucky that I am eligible, but unless we value it and invest in it, too many people will continue to suffer and not have the ability to choose community-based care.

Unless you live this life — having a disability or providing care — you can’t possibly understand how hard it is and just how much we struggle to get what we need. As prices for basic needs rise, home care workers are going to leave the industry to find higher-paying jobs that allow them to be a little more comfortable in an already impossible situation. And that has huge repercussions for those who need services and their families. If there are no providers and no workers, there is no access to care in the community.

**Senator Mark Kelly****Question:**

Mr. Kingsmore, thank you for sharing your personal experience. It really does make a difference. You mentioned that differences among state thresholds and requirements for Medicaid meant you didn't qualify for home and community-based services until you turned 18. But even then, you didn't have an easy time finding a caregiver. What would you want this committee to know about your experience as you searched for a full-time caregiver? In addition to strengthening caregiving as a profession—which we know the need for, given the average hourly rate in Arizona and the shortages in the caregiving workforce we're seeing for a rapidly aging population—what policies does Congress need to look at?

**Response:**

I consider my direct care workers my angels. To me that is truthfully what they are. They watch over their clients, making sure they give us the best care possible to keep us healthy and independent, while at the same time not caring about their own wellbeing. But because caregivers aren't paid a wage that reflects the value of their job, there aren't enough home care workers to meet the growing demand. I've had a lot of trouble even finding a worker that can give Lynn a break from time to time, and if anything happened to her, my life would take a dramatic turn for the worse.

Before I found Lynn, I had a series of care workers that came in and out. The turnover rates were terrible, and every single time I got a new caregiver, I had to retrain them all over again. Many times a caregiver would come in and they were not physically capable of caring for me. I even had a caregiver refuse to put me on the toilet and made me use diapers, even though I'm continent. When we don't value home care as a real profession, we can't hire well-trained professional workers, because people who do this work are overworked and underpaid. Making home care a professional job, with benefits and a union is essential for people like me who depend on these workers.

Lynn's union, SEIU Healthcare Pennsylvania / United Home Care Workers of Pennsylvania has made all the difference. United in their union, Pennsylvania home care workers have been able to advocate for and win critically needed improvements to the long-term care system — improvements that benefit both workers and consumers. But too many home care workers across the country don't have the right to a union. Without a united voice, these caregivers are robbed of the community they need for support. They're unable to speak out and call for change, and that's not right. Without a union, home care workers become trapped in a system that's designed to hold them, and the people they care for back. It's time Congress build a pathway for unions for all care workers. When home care workers unite together, they have the power to make a difference in all our lives. It just makes sense.

Care consumers like me should be able to choose the services that work for us, without fear of cost or whether it's even available where we live, so that we can live with dignity and independence. A robust federal investment in Medicaid home and community-based services (HCBS) would make it possible for millions to afford the home care services they need — because home care is more cost effective than institutional settings.

More funding to HCBS is the only way we're going to get to where we need to be. It's the only way we're going to give hard working women the respect, protection and pay home care workers deserve, so they can give their clients the quality, reliable care we depend on to live. We also need a Caregivers Bill of Rights.

Domestic workers must be included in common workplace protections like paid overtime, paid sick days, safe and healthy working conditions, meal & rest breaks, and freedom from sexual harassment.

We need to create new protections to address the unique challenges of domestic work: written agreements, fair scheduling, a standards board and support for survivors of sexual harassment. We need to ensure that rights aren't just on paper, but that they can be enforced and implemented, including know-your-rights information and mechanisms against retaliation.

**Question:**

Ms. Weidner: What would you like this committee to know about your experience as a caregiver?

**Response:**

Caregivers allow people like Brandon to stay in their own homes and be active in their communities for as long as possible. Living at home reduces healthcare spending and improves mental health for consumers, but because of the low quality of care jobs, caregivers find themselves struggling to survive and stay healthy themselves.

I love what I do. I've dedicated my life to this work. Caregiving is incredibly rewarding, but it's incredibly demanding and exhausting, too. I've struggled with the deep emotional and physical toll it takes. Because of the low quality of home care jobs, I've experienced burnout, anxiety and depression throughout my career.

I started my career in North Carolina, where homecare workers are often overlooked, and I felt very isolated. When I moved to Pennsylvania I was thrilled to find that there was a homecare workers union. In my union I have been able to speak up for essential services. I have been able to fight for, and win, the biggest raise I've ever received: 8 percent! Yet, even that 8% doesn't bring me to the amount that fast food workers in my city earn. Healthcare is an essential service, and throughout the pandemic we have been called heroes. We have been praised for our sacrifices to our health and safety to care for others, and yet praise isn't enough for a workforce of people who give everything of themselves.

We need health insurance, we need paid time off, we need a true livable wage. Until we have those things, your praise means nothing. Words can't feed us, clothe us, or house us. We need real change. Too many homecare workers are living in poverty and can barely take care of themselves. We give everything of ourselves in sacrifice to others. I love my job, and I wouldn't do anything else. But I'm done being the silent, hidden backbone of the healthcare system in this country. We are saving the government billions in Medicaid spending by keeping our clients healthy and out of hospitals and nursing homes. It's time that we are recognized. I will continue to fight with my union to make sure that care workers are valued in this country.

U.S. Senate Special Committee on Aging  
“An Economy That Cares: The Importance of Home-Based Services”  
March 23, 2022  
Questions for the Record  
**Ms. Shaheed**

**Senator Tim Scott**

**Question:**

Ms. Shaheed, thank you for sharing your personal experience. Home and Community-Based Services help individuals like you stay at home instead of being forced to move into an institution. States offer these services through waivers negotiated with the federal government. The problem is the process has become so bureaucratic that there are more than 300 waivers currently active across the country. Ms. Shaheed, can you share the impact all of this bureaucracy has had on your care?

**Response:**

Thank you, Senator Scott, for the question. I cannot speak to the 300 waivers across the country, Florida has two Medicaid waivers and I am able to speak about my enrollment and experience in Florida's Medicaid long term care waiver specifically. I am fortunate to be enrolled in the waiver and receiving services. Over 60,000 older adults and people with disabilities like me are currently on the waitlist for the waiver because there is not enough funding to provide slots for all those who are eligible.

My experience in the waiver has included my hours of care being improperly reduced because I needed to switch health plans to obtain better medical supplies. I had to appeal that decision, it took several months to resolve the issue. Today, despite being in the waiver and allotted 35 hours of at-home care per week. I currently have an aide for 26 of those hours. Prior to, 03/28/22, I had only 20 of those hours filled.

I do not receive care on weekends because my health plan cannot find anyone to come and provide assistance. I believe that is due to the very low wages home care workers are paid. Thank you again for the question.

Respectfully,

Alene Shaheed





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## **Statements for the Record**

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Closing Statement of  
Senator Tim Scott, Ranking Member  
March 23, 2022

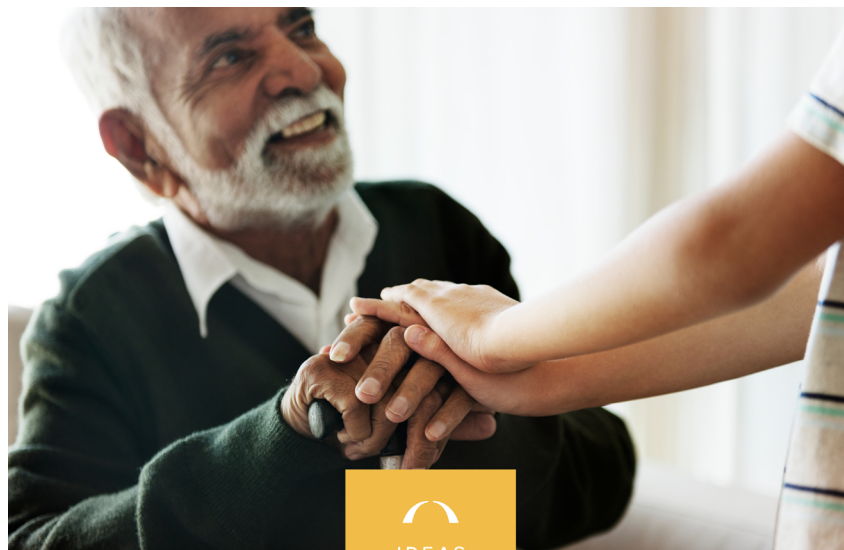
**An Economy That Cares: The Importance of Home-Based Services**

Thank you, Chairman Casey. The Chairman and I agree that family caregivers are an inspiration and require our support. Mary from South Carolina became a full-time caregiver for her mom when she became ill with Alzheimer's in 2011. Mary and her husband cared for Mary's mom until she passed in 2017.

Despite personal setbacks, Mary had no regrets on how she spent the six years with her mom when she had Alzheimer's. Mary's mother worked two jobs to give her and her siblings the best life she could, and Mary wanted to do everything she could to ensure her mom was happy and comfortable in the twilight of her life.

Build Back Better does not address the long-term issues with caregiving and can lead to new concerns. Relying on Medicaid will require families to spend down almost the entirety of their assets, making care conditional on eliminating wealth. This will disproportionately impact Black families, whose wealth is eight times lower than white families. It is also a substantial increase in funding for a program rife with fraud and devoid of quality measures.

I know we can try to find a more bipartisan approach to help both paid and unpaid family caregivers. Thank you, Mr. Chairman, I yield back.



# Streamlining and Simplifying Medicaid HCBS Authorities

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OCTOBER 2021

Bipartisan Policy Center

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## HEALTH PROJECT

Under the leadership of former Senate Majority Leaders Tom Daschle and Bill Frist, M.D., the Bipartisan Policy Center's Health Project develops bipartisan policy recommendations that will improve health care quality, lower costs, and enhance coverage and delivery. The project focuses on coverage and access to care, delivery system reform, cost containment, chronic and long-term care, and rural and behavioral health.

## ADVISORS

The Bipartisan Policy Center staff produced this report in collaboration with a distinguished group of senior advisors and experts, including Sheila Burke, Jim Capretta, and Chris Jennings. BPC would also like to thank experts Henry Claypool and Sara Rosenbaum for their contributions to this report.

## ACKNOWLEDGMENTS

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## DISCLAIMER

The findings and recommendations expressed herein do not necessarily represent the views or opinions of BPC's founders or its board of directors.

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## Glossary

<b>ACA</b>	AFFORDABLE CARE ACT
<b>ADLs</b>	ACTIVITIES OF DAILY LIVING
<b>CMS</b>	CENTERS FOR MEDICARE & MEDICAID SERVICES
<b>EPSDT</b>	EARLY AND PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT
<b>FMAP</b>	FEDERAL MEDICAL ASSISTANCE PERCENTAGES
<b>FPL</b>	FEDERAL POVERTY LEVEL
<b>HCBS</b>	HOME AND COMMUNITY-BASED SERVICES
<b>IADLs</b>	INSTRUMENTAL ACTIVITIES OF DAILY LIVING
<b>IDD</b>	INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
<b>LTSS</b>	LONG-TERM SERVICES AND SUPPORTS
<b>MFP</b>	MONEY FOLLOWS THE PERSON
<b>PACE</b>	PROGRAM OF ALL-INCLUSIVE CARE FOR THE ELDERLY
<b>SPAs</b>	STATE PLAN AMENDMENTS

## Executive Summary

Congress is considering legislation to expand the availability of Medicaid home and community-based services (HCBS) by making additional resources available to states as part of a larger reconciliation bill. Although the reconciliation bill does not have bipartisan support, Democrats and Republicans have historically supported efforts to expand HCBS.<sup>a</sup> Policymakers support expansion for several reasons, including a recognition that individuals prefer to receive services at home and in the community. Regardless of the outcome of the pending reconciliation legislation, Congress should consider additional steps beyond funding that would improve the administratively complex and piecemeal structure for HCBS authorities.

This report focuses on streamlining and simplifying states' HCBS waiver and state plan authorities into a single state plan amendment (SPA), with the goal of reducing complexity for states administering the programs and for beneficiaries navigating the system. Streamlining and simplifying the program would make services more uniform from state to state and across populations within a state. Ultimately, this change should improve access to services.

The patchwork of waivers and SPAs that states use to deliver HCBS has created challenges for states and beneficiaries alike and has resulted in divergent levels of access to services both within and between states. Historically, states have relied on 1915(c) waivers to provide HCBS, as these waivers allow states to target services to certain subpopulations and provide states with budget certainty. In 2020, of the 254 active 1915(c) waivers, most targeted individuals with intellectual disabilities (91 waivers), those with physical disabilities (86 waivers), and seniors ages 65 and older (64 waivers).<sup>1</sup> Multiple 1915(c) waivers have enabled states to target different populations or provide different services, with some states relying on up to 11 waivers at once.<sup>2</sup>

The use of multiple waivers or a combination of waivers and state plan amendments creates an enormously complex system for states to manage and beneficiaries to navigate. States often have to administer multiple programs and benefit packages with different eligibility requirements. Beneficiaries must navigate the different sets of requirements to identify the pathway most likely to meet their needs. Additionally, the current structure encourages states to rely

<sup>a</sup> The Deficit Reduction Act of 2005 (DRA), for example, included provisions to create the state option to offer HCBS. The language was based on bipartisan legislation, S. 1602, the Long-Term Care Choices Act, sponsored by Sen. Chuck Grassley (R-IA) and co-sponsored by Sens. Evan Bayh (D-IN) and Hillary Rodham Clinton (D-NY). The Money Follows the Person Demonstration was also enacted as part of the DRA and was based on legislation introduced by Sen. Tom Harkin (D-IA), and was cosponsored by Republican Sens. Gordon Smith of Oregon and Mike DeWine of Ohio.



heavily on multiple waivers, which can lead to inequitable access to services within a state. For example, two residents of a state may have similar diagnoses and HCBS needs but may not be eligible to receive the same services due to targeting allowed under 1915(c) waivers.

Although most of the national conversation around HCBS expansion is focused on increasing the number of people served and strengthening the infrastructure and workforce that care for them, simplifying and streamlining states' HCBS authorities by creating a single SPA would reduce complexity in the current system. This streamlining would enable states to better design and administer their HCBS programs around the needs of the beneficiary, while also improving the beneficiary experience.

## Summary of Recommendations

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### Streamlining and Simplifying Medicaid HCBS Authorities

- A. Congress should streamline and simplify Medicaid HCBS waiver and SPA authorities by creating a single, consolidated SPA that retains much of the flexibility of the existing HCBS waiver authorities and state plan options. Congress should phase out existing HCBS waivers and SPAs and require states to deliver HCBS through the new SPA within five years of enactment.**
- B. The Centers for Medicare & Medicaid Services (CMS) should provide clarification on the 1915(i) option to phase-in coverage and extend that option to the new consolidated SPA.**
- C. CMS should provide comprehensive technical assistance to states during the transition to the new state plan authority. During this transition, CMS should collaborate with the Administration of Community Living, and Congress should provide additional resources to CMS for providing technical assistance.**

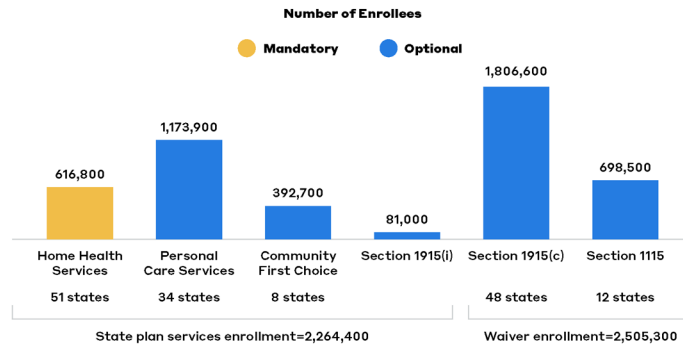
**Note:** See below for detailed recommendations.

## Background

In 2018, an estimated 14 million adults in the United States reported a need for long-term services and supports (LTSS).<sup>3</sup> LTSS refers to a broad range of paid and unpaid medical and personal care assistance that individuals may need when they have difficulty completing self-care tasks due to age, chronic illness, or disability.<sup>4</sup> LTSS includes assistance with activities of daily living (ADLs), such as eating, bathing, and dressing, as well as with instrumental activities of daily living (IADLs), such as medication management and meal preparation.<sup>5</sup> People who need LTSS typically have physical, cognitive, developmental, mental, or chronic health conditions.<sup>6</sup>

The majority of paid LTSS is financed jointly by the federal government and states through the Medicaid program.<sup>7</sup> Medicaid spent \$182.9 billion (combined federal and state) on LTSS in calendar year (CY) 2019, the most recent year with data available, accounting for about 43% of the \$426.1 billion spent by all payers.<sup>8</sup> LTSS includes institutional care – provided in skilled nursing facilities or other congregate care settings – and services provided at home or in other community-based settings, typically referred to as HCBS.<sup>9</sup> Calculating total HCBS enrollment is difficult, because individuals may receive services under more than one authority. But roughly up to 2.5 million individuals were enrolled in waivers and up to 2.3 million were enrolled in state plan services in fiscal year (FY) 2018 (Figure 1).<sup>10</sup> In FY2016, the last year for which complete state and federal data are available,<sup>b</sup> Medicaid programs (federal and state combined) spent approximately \$94 billion on HCBS, which was slightly more than half of total LTSS expenditures.<sup>11</sup>

b CMS released an updated [report](#) on Medicaid LTSS expenditures in January 2021, but the report lacks data on managed long-term services and supports (MLTSS) spending in five states. In almost all those states, MLTSS programs account for a large share of overall LTSS expenditures. As a result, we use data from the next most recent report, which includes MLTSS expenditure data in almost all applicable states except California and South Carolina.

**Figure 1: Enrollment in Medicaid HCBS by Program Authority, FY2018**

Sources: Kaiser Family Foundation, [Medicaid Home and Community-Based Services Enrollment and Spending](#)

Note: Adding figures across these authorities does not equal total HCBS enrollment, as individuals may receive services under more than one authority.

## A Brief History of Medicaid LTSS Coverage

### 1960s

Since enactment of the Medicaid program in 1965, states have been required to provide LTSS to individuals ages 21 and older in an institutional setting – i.e., nursing homes.

### 1970s

Home health care services – which are primarily medical services provided by a physician or nurse but which also include home health aide services<sup>12</sup> – were optional under the program until 1970, when Congress required states to cover home health services for those entitled to skilled nursing facility care. Physical and occupational therapy, however, remained optional.<sup>13</sup> Rehabilitation services have been an optional state plan benefit since the start of Medicaid. Additional institutional service options became available to states in the early 1970s; these included intermediate care nursing facilities, intermediate care facilities for individuals with intellectual disabilities, and psychiatric hospitals for adolescents and children under age 21.<sup>14</sup> The secretary of the U.S. Department of Health and Human Services (HHS) established personal care services as an option in the mid-1970s.<sup>15</sup>

### 1980s

In 1981, Congress expanded states' ability to provide HCBS through section 1915(c) waivers. It provided federal matching dollars for a broad range of HCBS, if the federal spending did not exceed what the federal government would have spent on institutional care for those receiving home and community-based services.<sup>16</sup> Congress also authorized targeted case management as an optional service in 1986.

### 1990s

Congress established personal care services as an optional state plan benefit in the early 1990s. In 1999, the Supreme Court ruled in *Olmstead v. L.C.*<sup>c</sup> that medically unjustifiable institutionalization of individuals violates the Americans with Disabilities Act. The court said states must administer services in the setting that is most integrated in the community and that is appropriate to meet the needs of the individual.<sup>17</sup> The court also held that states could establish waiting lists if they are cleared at a “reasonable pace,”<sup>18</sup> a standard that was not defined and has not been enforced.

### 2000s

In 2005, Congress sought to further expand HCBS through state plan options, rather than the use of federal waivers. The Deficit Reduction Act authorized the first HCBS state plan option under section 1915(i); this option provided services to those who do not require an institutional level of care. The act also authorized an option under section 1915(j), which added self-directed care to Medicaid HCBS under the Money Follows the Person demonstration program (MFP).<sup>19</sup> The Affordable Care Act (ACA) included an additional state plan option under section 1915(k), known as the Community First Choice Option.<sup>20</sup> The ACA also established Medicaid Health Homes— an optional state plan benefit to coordinate care for individuals with chronic conditions— and the Balancing Incentive Program.<sup>21,d</sup> For more detailed information on each of the waivers, state plan options, and demonstration programs, see Appendix 1 and BPC’s June 2021 white paper, *Streamlining and Simplifying Medicaid HCBS Part I*.

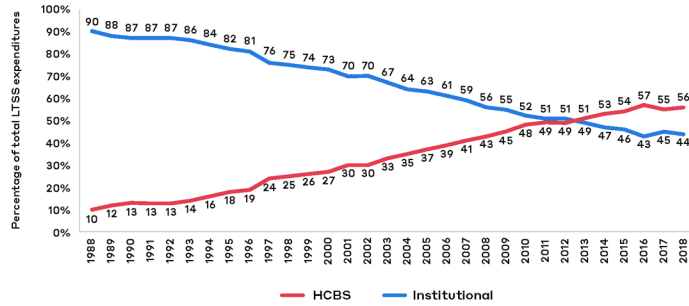
Although not specific to HCBS, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) has become a critical source of HCBS for children with disabilities. EPSDT requires states to offer comprehensive services to children, and to furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions.<sup>22</sup> HCBS covered by the EPSDT benefit may include private duty nursing, personal care services, home health and medical equipment and supplies, and rehabilitative services.<sup>23</sup>

Collectively, the *Olmstead* decision and federal statutory and policy changes resulted in a significant increase in HCBS costs. From FY1999 to FY2018, Medicaid LTSS spending on institutional care decreased from 74% to 44% of total Medicaid LTSS expenditures, while spending on HCBS grew from 26% to 56% (Figure 2).<sup>24</sup> These numbers are averages and do not provide a full picture of access to services in each state. As outlined below, state spending on HCBS as a percentage of LTSS spending varies significantly, contributing to inequitable access to HCBS between states.

HCBS advocates have long viewed the distinction between mandatory and optional services as evidence of a bias toward providing LTSS in institutions, such as nursing homes, versus in the home or community. For many advocates, as long as institutional care is mandatory and HCBS are optional, the state, rather than the individual, ultimately controls where beneficiaries live. Regardless of this distinction, the historically piecemeal approach to expanding HCBS has produced a patchwork of waivers and state plan amendments that is complex for states to administer, encourages inequities in access to services, and confuses beneficiaries needing services.

c *Olmstead v. L.C.*, 527 U.S. 581 (1999). In this 1999 opinion written by Justice Ruth Bader Ginsburg, the court held that states must provide community-based services to those with mental illness, when: 1) state professionals have determined that community placement is appropriate; 2) the individual prefers a community-based setting; and 3) community-based care can be reasonably accommodated, considering the state resources and the needs of others with mental disabilities.

d The Balancing Incentive Program was enacted under the ACA and made enhanced matching dollars available to participating states to increase the share of LTSS dollars spent on HCBS, and to improve the LTSS infrastructure to create a more consumer-friendly, consistent, and equitable system.

**Figure 2: Changes in Federal Spending on LTSS, FY1988 to 2018**

Source: CMS, [Long-Term Services and Supports Rebalancing Toolkit](#), November 2020

## HCBS Benefits and Eligibility under Current Law

### HCBS Covered Services

Home and community-based services include a wide range of medical and non-medical services designed to support individuals in the community. States often combine mandatory medical services, such as home health, and optional services, such as rehabilitation services, with non-medical services, primarily specified under section 1915(c) of the Social Security Act. HCBS generally may include:

- Home health care services<sup>e</sup> (mandatory for those entitled to skilled nursing facility care);
- Personal care services;
- Private duty nursing services;
- Targeted case management services;
- Program of All-Inclusive Care for the Elderly (PACE) services, which include all Medicare-covered, Medicaid-covered, and other services determined necessary by the interdisciplinary care team to improve or maintain the participant's health;<sup>25</sup>
- Case management services;
- Rehabilitation services, including those related to behavioral health;

<sup>e</sup> Required home health services that states must cover under the benefit include nursing services; home health aide services; and health care related medical supplies, equipment, and appliances that are primarily and customarily used to serve a medical purpose. Additional services that states may cover under the home health benefit include physical therapy, occupational therapy, or speech pathology and audiology services. 42 CFR § 440.70.

- Services authorized under 1915 (b), (c), (i), (j), or (k); 1115; or 1937 of the Social Security Act.<sup>f</sup> 1915(c) waivers, the most common HCBS waiver, allow states to cover case management services, homemaker/home health aide services and personal care services, adult day health services, habilitation services, respite care, and other services requested by the state and approved by the secretary of HHS.<sup>26</sup> States may also cover day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not provided in a facility) for individuals with chronic mental illness;<sup>27</sup>
- HCBS covered through EPSDT.

All states offer HCBS, either through benefits, waivers, HCBS-specific state plan amendments, or a combination of benefits, waivers, and amendments.<sup>28</sup> Often, states combine waiver authorities and state plan amendments to design and administer multiple programs with different sets of services, eligibility rules, federal renewal periods, and other features.

### Eligibility for HCBS

States generally define eligibility for mandatory and optional HCBS through financial, categorical, and functional eligibility criteria. Therefore, individuals' ability to receive HCBS depends on their income and assets, their place in one of the categories of covered subpopulations, and their level of functional and clinical need for services.

**Financial and Categorical Eligibility:** Individuals must have low incomes to be financially eligible for Medicaid services, including HCBS. States set income and resource limits for various categories of mandatory and optional eligibility groups, in accordance with federal requirements. Most HCBS programs target older adults and individuals with disabilities. Those populations may qualify for Medicaid through either mandatory or optional eligibility pathways.

For example, federal rules require states to provide Medicaid coverage to individuals ages 65 and over, and to individuals who are blind or have disabilities who receive cash assistance through the Supplemental Security Income (SSI) program.<sup>29</sup> In 2021, the income limit for SSI for an individual is \$794 per month and the resource limit is \$2,000.<sup>30</sup> States may rely on the SSI financial eligibility criteria, or they may set more restrictive criteria for individuals who qualify based on SSI.<sup>31</sup> States may also cover other low-income individuals ages 65+ or those with disabilities who are not receiving SSI cash assistance.<sup>32</sup> States may use more generous financial limits for that optional eligibility group.

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<sup>f</sup> See Appendix I for a table describing these authorities.

In placing HCBS participants, subpopulation categories include:

- I/DD (intellectual/developmental disabilities);
- SMI (serious mental illness);
- Individuals ages 65+;
- Individuals under 65 with physical disabilities.<sup>33</sup>

A large majority of HCBS users (63.9%) and almost all users who tend to incur the highest cost (86.6%) were eligible for Medicaid HCBS due to disability in 2012, the most recent year data are available.<sup>34</sup> The most common diagnoses for those with high costs were intellectual disorders and related conditions, mobility impairments, and epilepsy.<sup>35</sup> Those who tend to incur high costs were less likely than all HCBS users (11.4% versus 29.8%) to be eligible due to age.<sup>36</sup>

**Functional Eligibility Criteria:** In addition to financial and categorical eligibility requirements, individuals generally must meet functional eligibility criteria for HCBS. Functional eligibility criteria for most Medicaid LTSS services, including HCBS, generally mandate that individuals require care that would otherwise be provided in an institutional setting, such as a nursing home. No federal definition for functional eligibility criteria exists. Most states define the need for HCBS through a mix of factors, such as an individual's ability to perform activities of daily living and clinical criteria related to the diagnosis of an injury, illness, or disability.<sup>37</sup>

## Recent Action

Although this report focuses on simplifying and streamlining the structure for HCBS authorities, it is important to understand the broader political landscape surrounding HCBS. Policymakers have sought to expand the availability of Medicaid HCBS for more than 40 years to address the growing number of Americans who need assistance with daily activities but who prefer to receive care in their home or community. Notably, home and community-based care is usually less expensive on a per person basis than institutional care.<sup>38</sup> More recently, in the wake of the high mortality rates in nursing homes and other congregate settings during the COVID-19 pandemic, advocates are urging expanded access to HCBS.

### Legislation in Response to COVID-19

The American Rescue Plan Act of 2021 contained a 10% increase in the federal share of Medicaid expenditures (FMAP) for certain activities that enhance, expand, or strengthen Medicaid HCBS.<sup>39</sup> In May 2021, CMS released [guidance](#) on implementing the enhanced FMAP and detailed the activities eligible for the increased federal match. Examples of the eligible activities include:

- New or additional HCBS;
- HCBS provider payment rate and benefit enhancements;
- Supplies and equipment;
- Caregiver support;
- Support to improve the functional capabilities of persons with disabilities;
- Transition support;
- Mental health and substance use disorder services;
- Outreach; and
- Access to COVID-19 vaccines.<sup>40</sup>

With limited exceptions, the additional federal funding is available to states from April 1, 2021, to March 31, 2022.<sup>41</sup> States must use the money to increase HCBS spending above current levels.<sup>42</sup> Detailed data on how states have used the additional funds to date are not yet available. But according to one preliminary survey, states most often reported plans to increase HCBS provider payment rates and to use the funds for workforce recruitment.<sup>43</sup> The Congressional Budget Office estimates this funding will cost the federal government \$12.7 billion over the 12 months it is in effect.<sup>44</sup> Additionally, President Biden has proposed longer-term investments in HCBS through the [American Jobs Plan](#). Specifically, the plan calls for a \$400 billion investment in



HCBS over ten years to expand access to services, extend the Money Follows the Person program, and increase wages for caregivers.<sup>45</sup>

### Better Care Better Jobs Act

Members of Congress have introduced numerous bills to expand the availability of Medicaid home and community-based services, but these measures have little bipartisan support. In June 2021, Sen. Bob Casey (D-PA) and Rep. Debbie Dingell (D-MI-12) introduced the [Better Care Better Jobs Act](#), which builds on the HCBS funding included in the American Rescue Plan Act. The legislation expands HCBS by making permanent the 10% increase in the federal Medicaid match to states for delivering HCBS and provides a temporary 80% federal match, through 2031, for administrative activities related to improving HCBS.<sup>46</sup> States would have to meet several requirements to receive the increased federal match.

The legislation would provide \$100 million to states for HCBS infrastructure improvement planning grants.<sup>47</sup> In line with a [previous BPC recommendation](#), the MFP demonstration program would be made permanent. The program would also receive \$450 million in funding each fiscal year. Finally, the state option for impoverishment protections for the spouses of those receiving HCBS waiver services would be made permanent.<sup>48</sup> Under current law, spousal impoverishment protections are permanent for the spouse of those receiving institutional care. However, spousal impoverishment protections for HCBS expire in 2023. Although the Congressional Budget Office has not provided a public estimate of the proposal, proponents want to keep the cost under \$400 billion.

### Reconciliation

Although the Better Care Better Jobs Act substantially invests in HCBS, the legislation lacks bipartisan support. Given this reality, Democratic members of Congress want to use the upcoming reconciliation bill, where a simple majority is needed to pass legislation, as a vehicle to enact the Better Care Better Jobs Act. However, due to Republican opposition, it is unlikely that all the proposed legislation would be included in the final reconciliation bill. Currently, the Better Care Better Jobs Act has 37 Democratic and two independent Senate co-sponsors.<sup>49</sup>

The House Energy and Commerce mark-up includes a \$190 billion investment in HCBS, about half of the \$400 billion the president proposed. As of late September, the text includes several provisions from the Better Care Better Jobs Act, such as making MFP and the option for spousal protections for HCBS permanent, while other provisions, such as a permanent 7% enhanced FMAP for HCBS, differ slightly (the Better Care Better Jobs Act calls for a 10% increase).

## Challenges under Current Law and Opportunities under a Consolidated SPA

Despite the greater investment in resources, the patchwork of waivers and state plan amendments that states use has created various challenges in meeting the need for HCBS and has led to inequitable access to services both within and between states. The disjointed approach has also led to an administratively complex system for states to manage and beneficiaries to navigate.

### Administratively Complex System for States

In determining what authority to use to expand HCBS, states look closely at cost. As outlined above, states that choose to cover optional Medicaid HCBS may deliver these services through a variety of waivers or state plan options. Most often, states rely on 1915(c) waiver authority to deliver these services because of the financial predictability they provide. States may target waiver services to specific populations or regions and cap enrollment for these services. In FY2018, expenditures for Section 1915(c) waiver programs reached approximately \$35.7 billion,<sup>9</sup> and accounted for more than half of Medicaid HCBS expenditures.<sup>50</sup> Only a small percentage of HCBS expenditures were for services provided through the 1915(k), 1915(i), or 1915(j) state plan options.<sup>51</sup>

States may rely on multiple 1915(c) waivers simultaneously to target different populations or provide different services, with some states using up to 11 waivers at once.<sup>52</sup> In 2020, of the 254 active 1915(c) waivers, most targeted individuals with intellectual disabilities (91 waivers), those with physical disabilities (86 waivers), and seniors ages 65 and older (64 waivers).<sup>53</sup>

State officials have acknowledged they rely on waivers to control costs and cite this reliance as a challenge to effective administration of their programs. An April 2020 [report](#) from the Government Accountability Office found that many state officials reported difficulty meeting the requirement to enroll all eligible individuals when their state opts to cover HCBS under their state plan; the enrollment requirement complicates states' cost control efforts and increases their use of waivers and demonstrations, which allow capping enrollment.<sup>54</sup> To address this problem, the officials suggested allowing states to limit HCBS enrollment through their state plans.<sup>55</sup>

<sup>9</sup> Due to data limitations, CMS excluded FY2017 and FY2018 data for California, Illinois, New York, and Virginia in reporting expenditures by service category. Excluding those states, total HCBS expenditures were approximately \$70.4 billion, and Section 1915(c) waiver program expenditures were approximately \$35.7 billion in FY2018. Including those states, total section 1915(c) waiver program expenditures were approximately \$49.7 billion.

States also reported that limitations in their ability to tailor LTSS to certain populations lead to similar challenges. For example, establishing different eligibility criteria for nursing facility services and HCBS, or differentiating services between urban and rural areas, leads to increased use of waivers and demonstrations, which increases complexity.<sup>56</sup> To address this problem, state officials suggested more flexibility in their ability to target LTSS to certain beneficiaries under state plan authority.<sup>57</sup>

The use of multiple waivers or a combination of waivers and SPAs creates an incredibly complex system for states to manage, because the state must keep track of different eligibility rules, benefit packages, and reporting requirements for each waiver. Additionally, each waiver is for only a limited time. If states wish to continue providing HCBS through waivers, states must periodically submit renewal requests to CMS. State officials have noted these waiver application and renewal submissions require significant resources, and the variation in length of each waiver and their renewal processes adds to the burden of administering HCBS through waivers.<sup>58</sup> States may also need to oversee multiple contracts and contractors, manage several waiting lists, and oversee different sets of quality metrics, among other responsibilities that contribute to the complexity of administering multiple HCBS authorities.

A consolidated SPA would provide flexibility to states to customize HCBS programs, while preserving the budget predictability for HCBS that the state plan makes possible. The consolidated SPA would also eliminate the burdensome waiver process for HCBS and other administrative responsibilities that states must manage for each waiver.

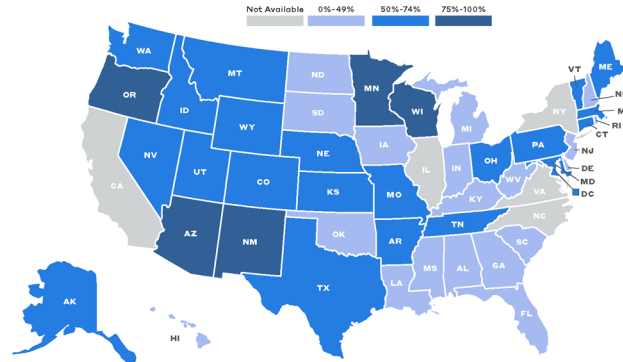
## Inequity in Service Availability and Beneficiary Access

### Variation in State Spending

Although all states offer HCBS, the services covered, access to those services, and spending varies significantly across states and within states. In 2018, HCBS as a portion of state LTSS expenditures ranged from 30% in Rhode Island to 83.4% in Oregon (Figure 3).<sup>59h</sup> In 27 states where spending data was available, HCBS accounted for 50% or more of total LTSS expenditures.<sup>60</sup> Generally, spending on HCBS made up a larger portion of total LTSS expenditures in states that provide these services through an MLTSS program.<sup>61</sup>

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<sup>h</sup> CMS excluded California, Illinois, New York, North Carolina, and Virginia from this ranking because of the lack of data.

**Figure 3: Percentage of Medicaid LTSS Spending for HCBS by State, FY2018**Source: [MACPAC](#), April 2021

The availability of waiver slots in Michigan is one example of unequal access to HCBS within a state; certain counties have only one waiver slot for every 58 eligible individuals, compared with one slot for every 20 eligible individuals in the rest of the state.<sup>62</sup> When states administer HCBS through a patchwork of waiver programs with separate benefit packages targeted to certain populations based on, for example, diagnosis or geographic location, beneficiaries with similar needs in the same state may not be able to access the same services in the community.

In addition to certain target groups receiving more or different services within a state, federal cost neutrality formula requirements for waivers can contribute to imbalances in total HCBS spending across populations. In FY2017 and FY2018, states spent almost three-quarters of total 1915(c) waiver program expenditures on individuals with intellectual or developmental disabilities (IDD) or autism spectrum disorder.<sup>63</sup> During that same period, older adults and individuals with physical or other disabilities accounted for the remaining 22% of 1915(c) waiver program expenditures.<sup>64</sup> Since Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) have historically had higher payment rates than nursing homes, the cost neutrality formula generally allows higher HCBS expenditures for waiver programs that target individuals with developmental disabilities.<sup>65</sup> Inequities in allowable HCBS spending between populations could contribute to unmet needs for certain populations.

Unlike waivers, SPAs can provide more equitable access to HCBS both between states and between different populations within a state. Although states would still retain many of the flexibilities that exist under the current HCBS authorities, a single, consolidated SPA would end the practice of states targeting services to specific geographic areas (except in limited circumstances, described below). In addition to reducing inequities in access within a state, a single SPA would not

have to meet federal cost neutrality requirements. Equity in spending on HCBS between different diagnostic groups would therefore likely improve as well.

The consolidated SPA could also help improve equity in access to HCBS across states by reducing administrative complexities that may deter states from modifying or expanding their waiver programs.

### **Waiting Lists and a Complex System for Beneficiaries to Navigate**

Today, about half of 65-year-olds will need LTSS at some point in their life.<sup>66</sup> As the U.S. population ages and the need for LTSS continues to grow, states and the federal government are concerned about the cost of expansion because of the perceived unmet need for services, often referred to as the “woodwork effect.” This is the belief that when services become widely available, qualified individuals will come out of the woodwork to seek care.

A report by the Kaiser Family Foundation found that in 2018, nearly 820,000 individuals were on waiting lists across 41 states.<sup>67</sup> However, Kaiser and the Medicaid and CHIP Payment and Access Commission note that the accuracy of waiting lists varies significantly by state, and the estimate should not be considered a precise measure of unmet need for HCBS.<sup>68</sup> For example, some states do not complete eligibility screening before an individual is placed on the state’s waiting list.<sup>69</sup> Additionally, while data show that wait times vary greatly based on the state, waiver, and target population, ranging from 1 to 14 years, stakeholders have reported that some of those on waiting lists may be receiving state plan services through Medicaid or from family caregivers.<sup>70</sup> Notably, the IDD population accounts for 72% of those on waiting lists in 2018.<sup>71</sup>

When individuals seek HCBS, they must determine which program will provide the benefit package that best meets their needs. Beneficiaries have several options to choose from, and some waivers may have waiting lists, creating a complex decision for the individual. As mentioned above, some states rely on as many as 11 HCBS waivers at once. Additionally, because of the targeting of services allowed under 1915(c), not all waivers provide the same benefits across the state or to all subpopulations. According to a 2016 policy brief by Kaiser, “If different services are offered through different programs, people with multiple needs may have to choose which services to pursue and which to forgo.”<sup>72</sup> Multiple waivers and SPAs operating simultaneously create a complex system for beneficiaries to navigate and in some cases makes it impossible for them to receive all services to meet their needs through a single program.

Consolidating HCBS authorities into a single SPA could help to clear waiting lists, as 1915(i) SPAs – which could provide the foundation for the new consolidated SPA – do not allow for waiting lists or the same targeting of services that occurs under 1915(c) waivers. Additionally, beneficiaries would no longer have to navigate and apply to multiple waiver programs with different eligibility requirements and benefit packages.

## Policy Recommendations

Although most of the national conversation surrounding HCBS is focused on strengthening infrastructure and the workforce, simplifying and streamlining the authorities that states use to provide HCBS can also advance the expansion of services and reduce administrative complexity.

The following policy options seek to increase the availability of HCBS in Medicaid and to advance equity in access by streamlining and simplifying administrative requirements. This goal could be achieved by replacing the complex patchwork of state plan amendments and waivers with a single, consolidated state plan amendment that draws from authorities that exist under current law. Streamlining and simplifying HCBS waivers and state plan options could be addressed independently, or as part of other efforts to reform the system. Ideally, the SPA would provide necessary services to those in need and give states budget predictability.

### Streamlining and Simplifying Medicaid HCBS Authorities

#### A. Consolidated State Plan Amendment

Congress should create a single, consolidated SPA that retains much of the flexibility of the existing HCBS waiver authorities and state plan options. (See Appendix II.) Congress should phase out existing authorities and require states to deliver HCBS through the new SPA within five years of enactment.

Transitioning waivers to an improved state plan option would incentivize infrastructure development for HCBS, promote administrative efficiency and access, and support person-centered care for beneficiaries while providing states with the desired budget predictability. A consolidated state plan option should include requirements or incentives for uniform assessments and person-centered care plans; incentives for states to help individuals transition from institutional to community settings; incentives for streamlined enrollment; and a single entry point to access HCBS.

#### Key Provisions

Congress should establish a new consolidated SPA that would combine existing authority from Medicaid state plan options, including 1915(i), (j), and (k), and Medicaid waivers, including 1915(c) and Section 1115 (except in limited circumstances). Existing enrollees in each of these options should be grandfathered to prevent a disruption in services. Under this approach, the HHS secretary would develop a template that includes the following information to be provided by the states:

- Eligibility, including income and resource standards, and functional status criteria;
- Benefits covered;
- An estimate of the number of individuals the state projects will be eligible.

#### Eligibility

**Income and resources:** Under the consolidated SPA, states should be permitted to cover individuals with incomes up to 300% of SSI, or about 221% of the federal poverty level (FPL). This recommendation does not broaden current income eligibility limits, and it would preserve current eligibility. Under the 1915(i) SPA, states may cover individuals with incomes up to 300% of SSI, who are eligible for HCBS under an approved 1915(c), 1915(d), 1915(e), or 1115 waiver.<sup>73</sup>

Under current law, states have flexibility on income eligibility and resource standards. Examples include the option, under the Katie Beckett provision of the Tax Equity and Fiscal Responsibility Act (TEFRA), to waive the counting of parental income and resources for children under 18 years old who live at home, but would otherwise be eligible for Medicaid-funded institutional care; the option under the Ticket to Work and Work Incentives Act to create a buy-in program for individuals with disabilities; the option to raise the income eligibility level up to 100% of FPL for individuals over age 65 or those under age 65 with disabilities; the option to cover certain individuals with incomes above financial eligibility limits through the medically needy pathway; and the option to cover individuals with incomes up to 300% of SSI who are in an institution or receive HCBS under a waiver. Under this recommendation, states could continue to enjoy these flexibilities.

**Functional status:** Under the new SPA, states would have to establish functional status criteria that requires an assessment of an individual's support needs and capabilities. This would involve considering the inability of the individual to perform two or more ADLs or the need for significant assistance to perform such activities. Other factors to assess include the need for substantial supervision to protect an individual from threats to health and safety due to severe cognitive impairment, as well as need related to a serious mental illness.

States could modify the criteria without obtaining prior approval by the secretary of HHS if enrollment exceeds projections. However, to ensure transparency when adopting the consolidated state plan, states should be required to describe the process they will use to modify eligibility criteria once the enrollment projection is met. States could also consult their consumer and stakeholder advisory boards when setting enrollment targets and determining eligibility criteria modifications. Although states already can modify criteria to limit enrollment under 1915(i) SPAs, states have not used this authority. They have instead relied on multiple waivers guaranteeing budget predictability by capping enrollment and targeting services. Accordingly, BPC

includes a recommendation below for CMS to work closely with states and provide technical assistance on implementing the consolidated SPA, to ensure maximum flexibility.

Under the consolidated SPA, as under 1915(i), individuals would not need to meet criteria for an institutional level of care. This would permit states to offer services to individuals before their conditions require significant and more costly interventions. To assure equity in the provision of services, states would be required to establish a more stringent needs-based criteria for individuals requiring an institutional level of care.

**Individualized Care Plan:** Under the consolidated SPA, states would have to conduct independent assessments; develop individualized care plans in consultation with providers, caregivers, family, or representatives; and identify services to be provided. States must allow individuals to choose self-directed services. But states would not be required to meet Medicaid comparability, or amount, scope, and duration of services standards.

**Maintenance of Effort:** As discussed in more detail below, to receive an enhanced administrative match under the consolidated SPA, states must comply with a maintenance of effort requirement for HCBS eligibility and benefit standards. This would ensure that federal funding supplements, not supplants, existing state funds expended for Medicaid HCBS, as of the date Congress passes legislation establishing the consolidated SPA.

**Spousal Impoverishment Protections:** Congress should permanently authorize the state option to extend protection against impoverishment for spouses of individuals receiving Medicaid HCBS.

#### Covered Benefits

The new consolidated SPA would allow states to cover the full range of HCBS currently authorized under state plan benefits and sections 1915 and 1115 of the SSA. Examples of services that states could cover include:

- Home health care;
- State plan personal care services;
- Rehabilitation services, including those related to behavioral health;
- Case management;
- Homemaker/home health aide and personal care;
- Adult day health care;
- Habilitation;
- Respite;
- Day treatment or other partial hospitalization services, psychosocial rehabilitation, and clinic services (whether or not furnished in a facility) for



individuals with chronic mental illness;

- HCBS covered through EPSDT;
- Other services approved by the secretary of HHS.

#### Enhanced Match and Payment for Services

**Enhanced Administrative Match:** States would be eligible for an enhanced administrative match for activities related to streamlined eligibility and enrollment functions, such as those typically performed by states' No Wrong Door system, as well as for ombudsman activities. An enhanced match would allow states to establish administrative structures that ensure individuals know how to access Medicaid HCBS, furthering efforts to rebalance the LTSS system and promote person-centered care in the community. To help states transition to the consolidated SPA, BPC recommends an enhanced match rate for the administrative services related to streamlined eligibility and enrollment functions, including infrastructure development. To receive the enhanced match, states must comply with a maintenance of effort requirement for HCBS eligibility and benefit standards to ensure federal funding supplements, not supplants, existing state funds expended on Medicaid HCBS, as of the date Congress passes legislation establishing the consolidated SPA.

#### Additional Enhanced Administrative Match for HCBS Quality Reporting:

States that choose to measure and report on an approved set of HCBS quality measures would be eligible to receive an additional 1% FMAP increase beyond the enhanced administrative match. Congress should direct the secretary of HHS to develop recommended core and supplemental sets of HCBS quality measures. In developing these quality measures, HHS should collaborate with the administrator of CMS, the administrator of the Administration for Community Living, the director of the Agency for Healthcare Research and Quality, and the administrator of the Substance Abuse and Mental Health Services Administration. HHS should also solicit feedback from stakeholders and incorporate their suggestions into their recommendations. States would have the option of adopting the core set of HCBS quality measures or another set of HCBS quality measures approved by the HHS secretary.

**Maintaining Existing Initiatives:** The 6% enhanced FMAP for 1915(k) and the enhanced FMAP available for the Money Follows the Person demonstration would extend to the consolidated SPA. The MFP demonstration would be permanently reauthorized.

States may also receive a 90% enhanced FMAP for integration and coordination of services, as permitted under current law for eight quarters through the Medicaid Health Homes model.

States may develop payment rates for services in accordance with applicable state plan requirements.

**B. CMS should provide clarification on the 1915(i) option to phase-in coverage and extend that option to the new consolidated SPA.**

As discussed above, many states provide HCBS through 1915(c) waivers because the waivers give them the ability to target services to specific populations and geographic locations, and to cap enrollment, thus providing budget certainty. Although states may not place caps on enrollment under 1915(i), they can limit participation by estimating the number of individuals they expect to enroll, then modifying eligibility requirements and ending enrollment once they reach that number.

Under current law for 1915(i) SPAs, states do have an additional option to target services to specific populations during the first five-year period the SPA is approved. States can phase in enrollment of eligible individuals or the provision of services under this option.<sup>74</sup> The phase-in can be dependent on the needs of a population, the availability of infrastructure to provide services, or both.<sup>75</sup> In this case, infrastructure is defined as “the availability of qualified providers or of physical structures and information technology necessary to provide any service or set of services.”<sup>76</sup> To use this option, the state must submit a plan to CMS for approval that outlines the criteria used for phasing in the benefit. By the end of the period, all eligible individuals must be able to receive services statewide.<sup>77</sup>

The Office of the Assistant Secretary for Planning and Evaluation within HHS previously recommended that CMS clarify that a state can use the phase-in option to test new HCBS approaches in a specific geographic location before it makes these approaches available statewide.<sup>78</sup> This option means the state can study the impact of the policy change, determine whether current infrastructure is adequate to support the policy changes, and potentially modify the policy before implementing it statewide.<sup>79</sup> As states continue to develop their HCBS programs, flexibilities such as these can help them make changes to their programs to best serve beneficiaries. A phase-in approach can be useful as states implement the consolidated state plan option. The ability to phase in enrollment and the provision of services should apply to the new consolidated SPA as well.

**C. CMS should provide comprehensive technical assistance to states as they transition to the new consolidated HCBS state plan authority.**

Transitioning from waivers to a state plan option would require both technical assistance and guidance from CMS, specifically the Disabled and Elderly Health Programs Group. CMS should work closely with states as they implement the new streamlined SPA and help states prepare to transition from current authorities to the new SPA. During this transition, CMS should also collaborate with the Administration for Community Living under HHS.

In addition to providing direct technical assistance, CMS could implement an HCBS technical assistance initiative similar to the Integrated Care Resource Center, which helps states develop integrated care programs for dual eligible Medicare-Medicaid beneficiaries. CMS could also provide states with planning grants and create a learning collaborative, so states can learn best practices from each other.

## Longer-Term Pathway to a More Comprehensive HCBS Reform

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Although consolidating HCBS authorities into a single SPA will likely reduce administrative burdens and increase equity in access to services, more comprehensive reforms are necessary to meet the growing need for LTSS in the United States. In September 2021, BPC released a report, [Bipartisan Solutions to Improve the Availability of Long-Term Care](#). The report included recommendations for Congress on establishing a refundable tax credit for caregivers to help with out-of-pocket costs for paid LTSS-related care and on expanding access to HCBS for middle-income individuals who are ineligible for Medicaid. Specifically, BPC recommended that Congress establish a buy-in to HCBS for Medicare-only beneficiaries. BPC also recommended that Congress create a transitional program to support the expansion of integrated delivery models and build caregiver capacity until the new HCBS buy-in is fully implemented.

The buy-in would be made available to Medicare beneficiaries with LTSS needs who do not qualify for Medicaid. Services would be offered through a fully integrated care model, such as a Medicare Advantage Dual Eligible Special Needs Plan or the PACE program. The services would be fully subsidized for those who are under 221% of FPL (about \$2,372 per month for an individual in 2021),<sup>80</sup> and sliding scale subsidies would be available for those between 221-400% FPL. Those who are ineligible for subsidies would still be able to access the services by paying for them.

The proposal included one of three service packages for beneficiaries to choose from:

- A set of services with a fixed dollar amount to be used by beneficiaries to address their individual needs (similar to the CAPABLE program);<sup>i</sup>
- Up to 10 hours per week of personal care assistance services; or
- Services covered under Section 1915(c) of the Medicaid program.<sup>j</sup>

BPC intends to further refine this proposal through future study. BPC would focus on developing a model of administration within Medicare that permits income-based targeting of services and builds on existing state-level expertise in the delivery of HCBS.

## Conclusion

The growing need for LTSS, coupled with the impact of COVID-19 on congregate settings and individuals' preferences to receive care in the home or community, has brought national attention to the need for HCBS reform. However, many of the congressional proposals to expand HCBS lack bipartisan support. BPC believes streamlining HCBS into a single state plan option strikes a balance between simplifying administrative complexity and providing states with budget predictability, while helping to advance the goal of expanding access to services.

<sup>i</sup> The Community Aging in Place—Advancing Better Living for Elders (CAPABLE) program was developed at the Johns Hopkins School of Nursing. The time-limited program aims to help participants decrease the risk of falling, improve functional status and independence, and age safely at home. Key components of the program include home-based, one-on-one care from a registered nurse (who provides four visits to each participant), an occupational therapist (who provides six visits to each participant), and a handyperson (who provides up to \$1,200 in services, including home modification). See Johns Hopkins School of Nursing, "Community Aging in Place – Advancing Better Living for Elders (CAPABLE)," Available at: [https://nursing.jhu.edu/faculty\\_research/research/projects/capable/index.html](https://nursing.jhu.edu/faculty_research/research/projects/capable/index.html).

<sup>j</sup> 1915(c) HCBS include "case management services, homemaker/home health aide services and personal care services, adult day health services, habilitation services, respite care, and such other services requested by the State as the Secretary may approve and for day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness." § 1915(c)(4)(B) of the Social Security Act.

## Appendix I

### HCBS Waivers and State Plan Amendments

HCBS Authorities	Eligibility	Limits and Flexibilities	Population Targeting (Comparability)	Geographic Targeting (Statewide)	Self-Direction
<b>Section 1915(c)</b>	Individuals who meet the state's institutional level of care (meaning individuals could be admitted to a nursing facility, hospital, ICF/IID); the need for services must be based on an assessed need and identified in a state-approved service plan.	States may cap enrollment. In the aggregate, program services must not cost more than what would have been incurred to care for participants in an institution, referred to as "cost neutrality."	States may target based on age or diagnosis, including children, adults with physical disabilities, individuals with intellectual or developmental disabilities, individuals with traumatic brain injuries, individuals with MH/SUD, and older adults, among others.	States may limit a program geographically.	States can choose to offer self-directed HCBS under this benefit.
<b>Section 1915(l)</b>	Individuals who are eligible for medical assistance under the state plan, meet state-defined needs-based criteria, and reside in the community.	No cost neutrality requirement. States may not cap enrollment or maintain waiting lists. States may limit participation through needs-based eligibility criteria.	Option to target the benefit to a specific population based on age, disability, diagnosis, and/or Medicaid eligibility group. The lower threshold of needs-based criteria must be "less stringent" than institutional and HCBS waiver program level of care.	Benefit must be offered statewide.	States can choose to offer self-directed HCBS under this benefit.
<b>Section 1915(k) Community First Choice Optional State Plan Benefit</b>	Individuals who meet the state's institutional level of care (meaning individuals could be admitted to a nursing facility, hospital, ICF/IID, an institution providing psychiatric services for individuals under age 21, or an institution for mental diseases for individuals age 65 or over, if the cost could be reimbursed under the state plan) can qualify for services under section 1915(k).	States cannot limit the number of eligible individuals served.	States cannot target the benefit to a particular population.	Benefit must be offered statewide.	States can choose to offer self-directed HCBS under this benefit.

HCBS Authorities	Eligibility	Limits and Flexibilities	Population Targeting (Comparability)	Geographic Targeting (Statewide)	Self-Direction
<b>Section 1915(j) Optional Self-Directed Personal Assistance Services (PAS)</b>	Individuals must be eligible for state plan personal care services or a section 1915(c) waiver program to qualify for services under section 1915(j)	States may limit the number of people who will self-direct their PAS.	States can target people already getting section 1915(c) waiver services.	PAS may be offered in certain areas of the state or statewide.	PAS is self-directed.

### Research and Demonstration Programs

Research & Demonstration Programs	Eligibility	Limits and Flexibilities	Population Targeting	Geographic Targeting	Self-Direction
<b>Section 1115 Demonstration Authority</b>	States may waive certain statutory provisions such as "comparability" to define target populations for demonstration services/activities, which should be available based on individual assessments of need as defined by the state.	Demonstrations must be budget neutral, meaning that the federal costs associated with the proposed demonstrations cannot exceed the federal Medicaid costs absent the demonstration.	States can target section 1115 demonstration services to particular populations meeting defined characteristics.	States can waive "statewide" to target demonstration services at particular geographic areas.	States can choose to offer self-directed HCBS under this authority.
<b>Money Follows the Person Demonstration</b>	Participants must be Medicaid beneficiaries residing in an institution for 90 days or more, not counting short-term rehabilitation days. In addition, participants must move to a qualified residence in the community	States project annual transition benchmarks to determine enrollment based on an annual grant-funded budget.	States can target demonstration services to particular populations meeting a state's institutional level of care and MFP eligibility criteria.	States can target MFP demonstration services at particular geographic areas.	States can choose to offer self-directed HCBS under this project.

## Appendix II

### Consolidated State Plan Amendment

*Note: The policy recommendation for a consolidated SPA is explained in the left column of the table below. References to existing statutory authority are in the center column as a point of reference, and how BPC's proposal would affect current law is in the right column.*

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<p><b>Key Provisions:</b></p> <ul style="list-style-type: none"> <li>Establish new consolidated SPA, combining existing authority from Medicaid state plan options, including 1915(i), (j), and (k), and Medicaid waivers, including 1915(c) and Section 1115 (except in limited circumstances).</li> <li>Existing enrollees in each of these options should be grandfathered to prevent a disruption in services.</li> <li>Under this approach, the HHS secretary would develop a template that includes the following information to be provided by the states: <ul style="list-style-type: none"> <li>» Eligibility, including income and resource standards, and functional status criteria.</li> <li>» Benefits covered.</li> <li>» An estimate of the number of individuals the state projects will be eligible.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>The following sections of the SSA: <ul style="list-style-type: none"> <li>» 1915 (i) – HCBS SPA.</li> <li>» 1915 (j) – Self-directed personal assistance services for individuals who would otherwise require personal care services or are covered under 1915(c) waiver.</li> <li>» 1915 (k) – Community First Choice – Personal attendant services and supports for those who need an institutional level of care.</li> <li>» 1915(c) – Medicaid HCBS waiver.</li> <li>» 1115 – Demonstration Authority.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Requires legislation to combine existing waiver and SPA authorities into a single SPA, and to ensure existing enrollees are grandfathered into the new SPA.</li> <li>Requires legislation to replace existing state plan options and waivers; to require states to transition to the new consolidated SPA within five years of enactment; and to direct the HHS secretary to develop the template for states.</li> </ul>



Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<p><b>Eligibility:</b></p> <ul style="list-style-type: none"> <li>• <b>Income and resources:</b> States may cover individuals with incomes up to 300% of SSI, or 221% of FPL. States could continue to adopt flexibilities related to income eligibility and resource standards, such as options under the Katie Beckett provision of TEFRA, TWWIA, etc.</li> <li>• <b>Functional status:</b> States must establish functional status criteria that requires an assessment of an individual's support needs and capabilities. States must take into account the inability of the individual to perform two or more activities of daily living or the need for significant assistance to perform such activities, or the need for substantial supervision to protect an individual from threats to health and safety due to severe cognitive impairment, and such other risk factors as the state determines to be appropriate.</li> <li>• States may modify the functional criteria without obtaining prior approval by the secretary of HHS if enrollment exceeds projections. However, when adopting the consolidated state plan, states are required to describe the process they will use to modify eligibility criteria once the enrollment projection is met, to ensure transparency. States may engage their consumer and stakeholder advisory boards when setting enrollment targets and determining eligibility criteria modifications.</li> <li>• Individuals do not need to meet criteria for an institutional level of care, and the state must establish a more stringent needs-based criteria for individuals requiring an institutional level of care.</li> </ul>	<ul style="list-style-type: none"> <li>• The 300 percent option (parity).</li> <li>• The following sections of the SSA: <ul style="list-style-type: none"> <li>» 1915 (k).</li> <li>» 1915 (i) – including the option for states to limit participation by modifying the needs-based criteria once actual enrollment exceeds the state's projected enrollment. This effectively limits enrollment growth to those in greater need of services, while allowing the state to continue to serve those who enrolled at the less stringent level of care.</li> <li>» 1915 (j).</li> </ul> </li> <li>• States have an obligation under <i>Olmstead</i> to make services available in the most integrated setting appropriate to the Medicaid beneficiary's need.</li> <li>• Section 2404 of the ACA modified the definition of "institutionalized spouse" in Section 1924 of the SSA, which provides impoverishment protections for spouses of individuals in institutional settings, to include individuals receiving services through 1915 (c), (i), or (k) and 1115 waivers providing HCBS. <ul style="list-style-type: none"> <li>» Originally set to expire in 2018, Congress has extended these protections through 2023 from subsequent legislation.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Current law. <i>Note: BPC addressed HCBS expansion in our September 2021 report, <a href="#">Bipartisan Solutions to Improve the Availability of Long-Term Care</a>.</i></li> <li>• Clarify that states set an enrollment target under 1915(i). When that enrollment target is reached, the state may modify the needs-based criteria for LTSS by using more stringent criteria. Extend this to the new consolidated SPA.</li> <li>• Legislation establishing the consolidated SPA should require states to conduct independent assessments and develop individualized care plans; require states to allow individuals to choose self-directed HCBS; allow states to waive comparability, amount, duration, and scope standards; and should include a maintenance of effort requirement.</li> <li>• Requires legislation to make permanent the existing state option, which will sunset in 2023, to extend protection against impoverishment for spouses of individuals receiving Medicaid HCBS.</li> </ul>

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<ul style="list-style-type: none"> <li>• <b>Individualized Care Plan:</b> States must conduct independent assessments; develop individualized care plans in consultation with providers, caregivers, family, or representatives; and identify services to be furnished.</li> <li>• <b>Self-Directed Services:</b> States must allow individuals to choose self-directed services.</li> <li>• <b>Comparability, amount, duration, and scope:</b> States are not required to meet Medicaid comparability, or amount, scope, and duration of services standards.</li> <li>• <b>Maintenance of Effort:</b> To receive an enhanced administrative match under the consolidated SPA, states must comply with a maintenance of effort requirement for HCBS eligibility and benefit standards to ensure federal funding supplements, not supplants, existing state funds expended for Medicaid HCBS, as of the date Congress enacts legislation establishing the consolidated SPA.</li> <li>• <b>Spousal Impoverishment Protections:</b> Congress should permanently authorize the state option to extend protection against impoverishment for spouses of individuals receiving Medicaid HCBS</li> </ul>		

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<b>Optional Covered Services:</b> <ul style="list-style-type: none"> <li>• Home health care (remains mandatory as under current law).</li> <li>• State plan personal care services.</li> <li>• Rehabilitation services, including those related to behavioral health.</li> <li>• Case management.</li> <li>• Homemaker/home health aide and personal care.</li> <li>• Adult day health care.</li> <li>• Habilitation.</li> <li>• Respite.</li> <li>• Day treatment or other partial hospitalization services, psychosocial rehabilitation, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.</li> <li>• HCBS covered through EPSDT.</li> <li>• Other services approved by the HHS secretary.</li> </ul>	<ul style="list-style-type: none"> <li>• Sections 1915 (i) cross-referencing 1915 (c)(4)(B); 1915(j); 1905(a) of the SSA.</li> </ul>	<ul style="list-style-type: none"> <li>• Current law.</li> </ul>
<ul style="list-style-type: none"> <li>• SPA does not require cost neutrality as do waivers.</li> </ul>	<ul style="list-style-type: none"> <li>• Sections 1915 (i) and 1915 (k) of the SSA.</li> </ul>	<ul style="list-style-type: none"> <li>• Current law.</li> </ul>

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<p><b>Enhanced Match and Payment for Services:</b></p> <ul style="list-style-type: none"> <li>• <b>Enhanced Administrative Match:</b> States are eligible for an enhanced administrative match for activities related to streamlined eligibility and enrollment functions, such as those typically performed by states' No Wrong Door system, as well as for ombudsman activities, and infrastructure development. To receive the enhanced match, states must comply with a maintenance of effort requirement for HCBS eligibility and benefit standards to ensure federal funding supplements, not supplants, existing state funds expended for Medicaid HCBS, as of the date Congress enacts legislation establishing the consolidated SPA.</li> <li>• <b>Additional Enhanced Administrative Match for HCBS Quality Reporting:</b> States that choose to measure and report on an approved set of HCBS quality measures would be eligible to receive an additional 1% FMAP increase beyond the enhanced administrative match.</li> </ul>	<ul style="list-style-type: none"> <li>• Section 1943 of the SSA.</li> <li>• <b>No Wrong Door:</b> The ACA allowed individuals to apply for Medicaid through any means, whether through state or federal marketplaces, state Medicaid agencies, by phone, or by fax. The No Wrong Door single entry point system builds on collaborative efforts of CMS, the Administration for Community Living, and the Veterans Health Administration to support states' efforts to streamline access to LTSS options for all eligible populations. The program promotes: <ul style="list-style-type: none"> <li>» Public outreach and coordination with key referral sources.</li> <li>» Person-centered counseling.</li> <li>» Streamlining access to public LTSS programs.</li> <li>» State governance and administration.</li> </ul> <p>States may receive administrative match for administrative activities performed through No Wrong Door systems, including Medicaid outreach; referral, coordination, and monitoring of Medicaid services; facilitating Medicaid eligibility; and other Medicaid administrative functions such as training, program planning, quality improvement, and information technology.<sup>81</sup></p> </li> <li>• <b>Balancing Incentive Program (BIP):</b> Section 10202 of the ACA established the BIP. The program authorized grants to states to increase access to noninstitutional LTSS. Total funding over the four-year program (October 2011 – September 2015) was \$2.4 billion in federal enhanced matching payments.</li> </ul>	<ul style="list-style-type: none"> <li>• Requires new legislation to: <ul style="list-style-type: none"> <li>» Establish the enhanced administrative match for activities related to streamlined eligibility and enrollment functions;</li> <li>» Direct the secretary of HHS to develop a recommended core set and supplemental set of HCBS quality measures; and</li> <li>» Establish an additional 1% FMAP increase for states that choose to measure and report on an approved set of HCBS quality measures.</li> </ul> </li> </ul>

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
	<ul style="list-style-type: none"> <li>• States with HCBS spending that accounted for less than half of total LTSS expenditures were eligible to participate in the program.<sup>82</sup> Participating states received an enhanced FMAP for HCBS, and were required to meet certain HCBS spending and infrastructure goals, including creating a No Wrong Door single-entry point for those seeking LTSS.<sup>83</sup> Eighteen of 21 participating states continued the program from 2011 to 2015, and most states received extensions through 2017 to complete the work.<sup>84</sup></li> <li>• The enhanced FMAP was tied to the percentage of a state's LTSS spending, with lower FMAP increases going to states that needed to make fewer reforms. States spending less than 25% of LTSS dollars on HCBS at baseline received a 5% enhanced FMAP, and were required to increase HCBS spending to at least 25% of total LTSS spending. States spending between 25% to 50% of LTSS on HCBS at baseline received a 2% enhanced FMAP, and were required to spend at least 50% of LTSS dollars on HCBS.</li> <li>• States were required to use the enhanced FMAP to provide new or expanded HCBS, and were also subject to a maintenance of effort provision prohibiting them from decreasing eligibility below December 31, 2010 levels.</li> <li>• Sections 1139A and 1139B of the SSA— related to core measurement sets for adults and children in Medicaid and CHIP.</li> </ul>	

Consolidated SPA Defined	Drawing from Existing Authorities	Proposed Change from Current Law
<p><b>Maintaining Existing Initiatives:</b></p> <ul style="list-style-type: none"> <li>• The 6% enhanced FMAP for 1915(k) and the enhanced FMAP available for the Money Follows the Person (MFP) demonstration extend to the consolidated SPA.</li> <li>• Permanently reauthorizes the MFP demonstration.</li> <li>• Through the Medicaid Health Homes model, states may receive a 90% enhanced FMAP for integration and coordination of services, as permitted under current law for eight quarters.</li> <li>• States may develop payment rates for services in accordance with applicable state plan requirements.</li> </ul>	<ul style="list-style-type: none"> <li>• Section 1915(k) of the SSA.</li> <li>• <b>The Money Follows the Person (MFP) Demonstration:</b> Section 6071 of the Deficit Reduction Act of 2005, as amended by subsequent legislation. Extended through September 30, 2023, by Section 204 of the Consolidated Appropriations Act, 2021 (P.L. 116-260), which also appropriated \$450 million for FY2021 - FY2023.</li> <li>• The program provides incentives to states to move individuals from institutional settings to HCBS. Grant awards are available to states for the fiscal year they got the award and four additional fiscal years after. Eligible individuals include people who live in an institution for more than 90 consecutive days. States receive an enhanced FMAP for covered demonstration and HCBS for the first year the individual receives services in the community after leaving an institution. (Exception: Days that a person was living in the institution for the sole purpose of receiving short-term rehabilitation services reimbursed by Medicare do not count toward this 90-day period.)</li> <li>• <b>Medicaid Health Homes:</b> Section 1945 of the SSA; Section 2703 of the ACA.</li> <li>• Under this state plan option, states receive a 90% enhanced FMAP for Health Home services. The enhanced FMAP is available for the first eight quarters that the program is effective. Required Health Home services include: <ul style="list-style-type: none"> <li>» Comprehensive care management;</li> <li>» Care coordination;</li> <li>» Health promotion;</li> <li>» Comprehensive transitional care/follow-up;</li> <li>» Patient and family support; and</li> <li>» Referral to community and social support services.</li> </ul> </li> <li>• Use of health information technology to link services where appropriate is strongly encouraged.</li> </ul>	

## Endnotes

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**IDEAS. ACTION. RESULTS.**

March 22, 2022

Chairman Bob Casey  
Special Committee on Aging  
United States Senate

Ranking Member Tim Scott  
Special Committee on Aging  
United States Senate

Members  
Special Committee on Aging  
United States Senate

Re: Hearing March 23, 2022 - "An Economy That Cares: The Importance of Home-Based Services"

Dear Chairman Casey, Ranking Member Scott, and Members of the Committee,

The Special Committee on Aging is scheduled to hear testimony tomorrow regarding the importance of home-based services for persons who require close care. I am not familiar with the witnesses who are listed on the committee's website. I am, however, very familiar with the subject matter because of my firsthand experiences with our son, now age 53, who is non-verbal, mobile, and unaware of danger and with my husband who, before his death on March 11, 2020, suffered from the devastating effects of Alzheimer's Disease.

I am concerned that the committee include testimony from a wide range of persons who are affected by federal policies related to long-term care, including those of us whose lives have been both upended and informed by loved ones who require eyes-on/twenty-four-hour care and our firsthand experiences with congregate care facilities.

*The nation needs a range of treatment care options including the option of licensed congregate care facilities to meet the diverse conditions of persons with disabilities and their families. Persons with profound cognitive and other developmental disabilities and persons disabled by age and ravaged by Alzheimer's Disease receive life-saving services in congregate care settings. Defenseless individuals benefit from close centralized systems of care; the safeguards found in licensed congregate care services are essential as care options for persons unable to speak and unable to care for themselves.*

*Please make clear the committee's support for the option of licensed facility-based care for individuals unable to care for themselves.*

*I and others would welcome the opportunity to testify about our firsthand experiences before your committee.*



Thank you for your attention.

Thank you for your public service.

Carole L. Sherman

Mother and Guardian of John, age 53, who functions on the level of a young toddler  
President, Families & Friends Association, Arkadelphia HDC, Arkadelphia, Arkansas

(501) 680-5893

Cc: HON John Bozeman  
HON Tom Cotton  
Board of Directors, Families & Friends of Care Facility Residents  
(Arkansas' statewide parent-guardian association)

## PUTNAM COUNTY LEGISLATIVE FORUM 11/18/21

## Home and Community Based Services

- Allow elderly and disabled individuals to receive services in the least restrictive environment
- To improve function
- To minimize progression of disability
- To maintain the best quality of life

## Shortage of available qualified home health aides due to:

- Low wages
- Limited benefit packages
- Inadequate public transportation
- No mileage reimbursement
- Not seen as a respected profession

## Average salary for home health aides by county

- |               |           |            |            |
|---------------|-----------|------------|------------|
| • Westchester | \$16.00hr | \$640.00wk | \$2,752.mo |
| • Putnam      | \$13.00hr | \$520.00wk | \$2,236.mo |
| • Dutchess    | \$12.00hr | \$480.00wk | \$2,064.mo |

## Living wage by county

- |               |         |          |            |
|---------------|---------|----------|------------|
| • Westchester | \$20.hr | \$800.wk | \$3,440.mo |
| • Putnam      | \$22.hr | \$880.wk | \$3,784.mo |
| • Dutchess    | \$17.hr | \$680wk  | \$2,924.mo |

Average Rent by county for a 1-bedroom apartment without utilities

- Westchester \$2,055.
- Putnam \$1,847.
- Dutchess \$1,148.

Percentage of gross income paid by workers earning a living wage for rent by county

- Westchester 60%
- Putnam 49%
- Dutchess 39%

Percentage of gross income paid for rent by home health aides by county

- Westchester 75.6%
- Putnam 82.6%
- Dutchess 71.8%

Conclusion

- Rent subsidy programs tell us that our housing cost should not be more than 30 – 40% of our gross monthly income
- For home health aides the percentage is higher than 70% in Dutchess, 75% in Westchester, and 82% in Putnam Counties
- How then can we provide home and community-based services to the elderly and disabled population
- in the least restrictive environment

- To improve function
- To minimize progression of disability and
- To maintain the best quality of life

With these woefully inadequate wages for home health aides?

**Medicaid Payments Should Go to Caregivers, Not to Unions**

Stephen Delie, Director of Labor Policy, Mackinac Center for Public Policy

The Mackinac Center for Public Policy is a nonprofit research and educational institute that advances the principles of free markets and limited government. Through our research and educational programs, we challenge government overreach and advocate for free-market approaches to public policy that allow people to realize their potential and their dreams.

The Mackinac Center strongly opposes the expansion of Medicaid payments to labor organizations acting as a putative employer for home-based health care services. Such payments would continue a system through which payments to home health care providers are diverted away from the vulnerable families who need it the most. Such diversions do not benefit individual providers or those in their care, but rather empower public sector unions to engage in inherently political activity. *Janus v American Federation of State, County, and Mun. Employees, Council 31*, 138 S. Ct. 2448, 2480 (2018). Congress should not allow unnecessary outside interference between caregivers and their patients.

**Background:**

In 2011, the Mackinac Center was the first organization to discover the redirection of Medicaid payments to labor organizations, commonly referred to as “dues skim.” In Michigan, the Service Employees International Union’s local affiliate recognized it could obtain “dues” from home health care providers and worked to unionize them. First, the SEIU lobbied the state to create an agency known as the Michigan Quality Community Care Council that would serve as the putative employer of home health care providers in Michigan.<sup>1</sup> The SEIU then bargained with that “employer” to unionize these workers. This all happened even though fewer than 20% of the affected home health care providers voted in the certification election.<sup>2</sup> Many were not even aware that a unionization election had occurred.

As a result, a portion of the federal money meant to pay these home health care providers to care for others — often their seriously ill or disabled family members — was redirected to the SEIU as dues.<sup>3</sup> By 2012, the SEIU had successfully redirected over \$34 million in Michigan alone.<sup>4</sup>

After the Mackinac Center discovered this arrangement and brought it to the public’s attention, the Michigan Legislature exempted home health care providers from Michigan’s public sector bargaining law.<sup>5</sup> There were also lawsuits throughout the states, ultimately resulting in the United States Supreme Court’s 2014 ruling in *Harris v. Quinn*, which forbade states from requiring home health care providers in right-to-work states to pay agency fees to keep their jobs.<sup>6</sup>

<sup>1</sup> <https://perma.cc/LJ79-EZK7>.

<sup>2</sup> <https://perma.cc/L9SY-KB2T>.

<sup>3</sup> <https://perma.cc/D6CA-M3JA>.

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

<sup>5</sup> 2012 MI PA 1018.

<sup>6</sup> <https://perma.cc/PF69-6WBY>.

In Michigan, after reforms were passed (and later reaffirmed in a ballot proposal),<sup>7</sup> home health care providers overwhelmingly demonstrated they did not wish to be unionized. In less than a year, SEIU Health Care Michigan's membership fell from 55,265 to 10,918.<sup>8</sup> That number has only continued to fall, with 2020 membership listed as only 7,181.<sup>9</sup> In other words, when given the choice about whether to become a member of a union, only 13% of providers decided it was worthwhile.

### **Comments on the Departments Proposed Rule**

Any legislation which would permit the deduction of union dues from the Medicaid payments of home-based caregivers is of questionable benefit to providers, at best. This is particularly true in the case of those caregivers who serve as home health care providers for sick and disabled family members.

#### **1. Objections to Dues Skim Generally**

Past experience demonstrates that dues skim would authorize a system that drains federal funds from the pockets of those who need it most, namely, home caregivers. Given that it was common for most caregivers to not even be aware of their unionized status, it is wildly inappropriate to implement a system in which payments of Medicaid funds can be directed to third parties without significant additional protections.<sup>10</sup>

The practical consequences of permitting dues skimming cannot be understated. The providers from whom payments would be diverted are often the family members of those with serious illnesses or disabilities, who would be otherwise unable to care for themselves. These family members sacrifice their time and energy, compensated primarily through Medicaid payments. Despite this, the caregiver and patient see little, if any, tangible benefits from unionization. Home health care providers are not employed by an outside agency, but rather by their patients, and work from either their own homes, or the homes of their ill and disabled relatives. They manage their own working conditions and hours, based on the needs of their patients. Unions play no representational role in these areas, the traditional core of collective bargaining.

Likewise, it is unnecessary to permit diversion of Medicaid payments for purposes of training. It would be difficult, if not impossible, to track whether each labor organization paid directly through

<sup>7</sup> <https://perma.cc/9KTL-BJ96>.

<sup>8</sup> Available through LM-2 reports for SEIU Health care Michigan. The fall in membership can be seen by comparing the 2012 and 2013 LM2 reports, available at file number 543-857. <https://olmsapps.dol.gov/query/getOrgOrv.do>.

<sup>9</sup> Available through LM-2 reports for SEIU Health care Michigan for the year 2020. <https://olmsapps.dol.gov/query/getOrgOrv.do>.

<sup>10</sup> As previously stated, only 20% of the affected caregivers in Michigan voted in the unionization election. <https://perma.cc/L9SY-KB2T>. In a study measuring election participation in fourteen states and three California counties, that number averaged only 27%. <https://perma.cc/D6CA-M3JA>. For Washington and Oregon, the percent participating was 31% and 42% respectively. <https://perma.cc/VE6U-JF97>. In some states, such as Illinois and Iowa, no election was even held. *Id.*

Medicaid actually provides training. It would be similarly difficult to quantify the value of that training, or to track whether home caregivers participate in it. There has also been little, if any, evidence that demonstrates how diverting payments has benefitted providers in the past.

To the extent legislation is aimed at providing better resources for providers, a far better proposition would be to continue the status quo and allow providers to choose whether they wish to pay for additional training. Such trainings could be offered by any third parties, including unions, and priced at a level selected by those organizations. It would then be up to the providers, who regularly make decisions about what is best for their patients, to decide whether a particular training provides enough value to justify the cost.

History teaches us that allowing diversion of Medicaid payments to unions does not benefit providers. In our state, there has been an 87% reduction in SEIU Health Care Michigan's membership once caregivers were no longer required to maintain membership to keep their jobs.<sup>11</sup> If the alleged benefits of unionization of home caregivers are as significant as claimed, this membership drop would be unexpected. Congress should not consider legislation that is contrary to the free choice of a vast majority of providers.

Caregivers should not find their Medicaid payments reduced to pay for membership dues in a labor organization. This is doubly true for those who are most vulnerable, caring for family and loved ones in a home health care capacity. The consequences of the proposed legislation are serious and would hurt families, as demonstrated by a recent documentary film "The Big Skim," in which providers tell how they were affected by the previous dues skim efforts.<sup>12</sup> If nothing else, these stories should give Congress pause about the wisdom of proceeding with this proposed rule.

## **2. If Legislation is to Advance, it Must Adequately Protect Caregivers' Constitutional Rights**

The Mackinac Center maintains that dues skim is inherently unethical and must be reformed. Permitting dues skim doubles down on a policy that hurts home health care providers, and which is overwhelming unpopular with caregivers. To the extent legislation endorsing this system moves forward, however, it should at minimum include meaningful protections designed to ensure caregivers have full knowledge of their rights.

Any legislation permitting dues skim should contain a requirement that providers voluntarily consent to having their Medicaid payments diverted. This requirement cannot be illusory and must ensure voluntariness. To do so, legislation must account for two key opinions of the United States Supreme Court that have provided greater protections to home health care providers.

In 2014, the Court decided *Harris v. Quinn*, 134 S. Ct. 2618 (2014), which held that independent in-home caregivers in Illinois could not be forced to pay agency fees as a condition of employment. That decision was later expanded upon in the landmark *Janus v. Am. Fedn' of State, Cnty., and Mun. Emps., Council 31*, 138 S. Ct. 2448 (2018), in which the Court ruled that public sector

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<sup>11</sup> *Supra*, notes 11 and 12.

<sup>12</sup> <https://perma.cc/7X2J-RX7K>.

employees, including home-based health care workers, could not be required to financially support a union in order to keep their jobs.

*Janus* examined whether public employees had a First Amendment right to refuse to financially support a public sector union. The Court answered affirmatively, noting that all actions of a public sector union, even traditional representational activities, were “inherently political.”<sup>13</sup> Since payments to these unions necessarily, therefore, supported an act of political speech, such payments could not be compelled under the First Amendment.<sup>14</sup> Instead, the Court ruled, public sector workers must first waive their First Amendment rights before any dues or fees could be withdrawn from their paychecks.<sup>15</sup>

The Court continued by elaborating on precisely what was required. It held that a worker’s First Amendment “waiver cannot be presumed. Rather, to be effective, the waiver must be freely given and shown by ‘clear and compelling evidence.’”<sup>16</sup> To satisfy that standard, “employees [must] clearly and affirmatively consent before any money is taken from them....”<sup>17</sup>

Other Supreme Court precedent highlights the standards that should be applied when evaluating whether a waiver is the result of clear and affirmative consent, as required by *Janus*. First, a waiver must be a “knowing, intelligent act ... done with sufficient awareness of the relevant circumstances and likely consequences.”<sup>18</sup> “An effective waiver must ... be one of a ‘known privilege or right.’”<sup>19</sup> It must also be done with “a full awareness of both the nature of the right being abandoned and the consequences of the decision to abandon it.”<sup>20</sup> Therefore, for any truly voluntary waiver to occur, employees must know both what their rights are, and the consequences of waiving those rights.

It is not enough for proposed legislation to contain a term requiring a provider “voluntarily consents” to diversion of Medicaid payments to a third party. That addition fails to meet the requirements highlighted above if it carried no further protections.

This is particularly true in light of union-supported state laws limiting the ability of outside organizations to communicate with public sector and home health care employees regarding their rights.<sup>21</sup> In Washington, a union-supported ballot initiative, approved by voters, prevents anyone from obtaining the contact information for home health care providers, with an exception for a

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<sup>13</sup> *Id.* at 2480 (citation and internal quotations omitted).

<sup>14</sup> *Id.* at 2486.

<sup>15</sup> *Id.*

<sup>16</sup> *Id.*

<sup>17</sup> *Id.*

<sup>18</sup> *Brady v. United States*, 397 U.S. 742, 748 (1970).

<sup>19</sup> *Curtis Pub Co v. Butts*, 388 U.S. 130, 143 (1967) (citation omitted).

<sup>20</sup> *Moran v. Burbine*, 475 U.S. 412, 421 (1986).

<sup>21</sup> These laws, and their effects on the workers’ rights, are discussed extensively in the Goldwater Institute and Cato Institute’s joint *amicus curiae* brief in *Troesch v. Chicago Teachers Union*. This comment will highlight a number of these laws, but wishes to draw Congress’ attention to this additional resource, available at: <https://perma.cc/DC6S-N7CM>.



union that serves as their exclusive representative.<sup>22</sup> And Washington is not the only state to adopt such a law. Indeed, at least 10 states have some law restricting access to the contact information of public sector employees or care providers.<sup>23</sup> This is in addition to other laws giving unions preferential access to newly hired employees, in order to convince them to join a union.<sup>24</sup> Unions have no incentive to inform these employees of the full extent of their First Amendment rights to either join or refuse to join a union; in fact, they have every incentive to not do so.

Without significant protections designed to demonstrate a caregiver's consent is truly voluntary (as described above), providers are at risk of being forced to pay dues to a labor organization they often don't know they are even members of. Worse still, since these dues would pay public sector labor organizations, they would be funding inherently political activity, often without meaningful knowledge or consent on the part of the provider.

Therefore, to the extent Congress chooses to move forward with legislation, despite the well-grounded opposition thereto, it should at the very least clarify that "voluntary" payments to third parties be truly voluntary. This would require that providers be fully informed about their rights before agreeing to divert funds, including their rights not to be forced to financially support a union to continue to receive Medicaid payments or otherwise keep their jobs. Absent such information, a provider's consent cannot be said to be a "knowing, intelligent act" as required by *Janus*.

Some states, such as Alaska, Texas, Indiana, and Michigan, have already identified the need for employees' First Amendment rights to be further protected.<sup>25</sup> If this legislation advances, we urge Congress to follow the example of these states by requiring specific waiver language designed to protect caregiver rights. Such language should be made part of a waiver form and contain language that is substantially similar to the following:

"The Department of Health and Human Services wishes to make you aware that you have a First Amendment right, as recognized by the United States Supreme

<sup>22</sup> See *Boardman v. Inslee*, 978 F.3d 1092, 1123–24 (9th Cir. 2020) (Bress, J., dissenting) (citing Wash. Rev. Code §§ 42.56.640(2), 42.56.645(1)(d), 43.17.410(1)), *petition for cert. filed*, No. 20-1334 (Mar. 24, 2021).

<sup>23</sup> *Id.* See also, Cal. Gov't Code §§ 3558, 6254.3; Haw. Rev. Stat. § 89-16.6(a), (d); 5 Ill. Comp. Stat. 140/7.5(oo), (pp), 315/6(c), (c-5); 26 Me. Rev. Stat. Ann. § 975(2); Md. Code, State Pers. & Pens. §§ 3-208, 3-2A-08; Md. Code, Educ. § 6-407; Md. Code, General Provisions §§ 4-311(b)(3), 4331; N.J. Stat. Ann. 34:13A-5.13(c), (d); N.Y. E.O. 183 (June 27, 2018); N.Y. Civ. Serv. Law §§ 208(4)(a), 209-a(1)(h); 3 Vt. Stat. Ann. §§ 909(c), 910, 1022(c), 1023; 16 Vt. Stat. Ann. §§ 1984(c), 1985; 21 Vt. Stat. Ann. §§ 1646, 1738(c), 1739; 33 Vt. Stat. Ann. § 3619; see also Or. Rev. Stat. §§ 192.355(3), 192.363, 192.365, 243.804(4)(a).

<sup>24</sup> See, e.g., Cal. Gov't Code § 3556; 5 Ill. Comp. Stat. 315/6(c-10)(1)(C) (enacted December 2019); 26 Me. Rev. Stat. Ann. § 975(1)(c); Md. Code Ann., State Pers. & Pens. § 3-307(b)(3), (5); Md. Code, Educ. §§ 6-407.1, 6-509.1(a)(1); Mass. Gen. Laws Ann. ch. 150E, § 5A(b)(iii); N.J. Stat. Ann. 34:13A-5.13(b)(3); N.Y. Civ. Serv. Law § 208(b), (c); Or. Rev. Stat. § 243.804(1)(b)(B); Wash. Rev. Code § 41.56.037.

<sup>25</sup> Texas Attorney General Opinion No. KP-0310; 2019 Op. Alaska Att'y Gen. (August 27)(Opinion); Indiana Attorney General Opinion 2020-5 (June 17, 2020); <https://perma.cc/9UCK-NUBM>.

Court, to either join, or refrain from joining and paying dues to a union or labor organization. Your membership and payment of dues are voluntary and you may not be discriminated against or terminated for your refusal to join or financially support a union. By signing this form, you are agreeing to authorize dues from any payments to you by the Department in the amounts specified in accordance with your union's bylaws. You may revoke this authorization at any time."<sup>26</sup>

In addition, the legislation should require the department to verify that any payments to third parties are, in fact, authorized by each caregiver. Evidence of voluntariness should have to be provided directly to the department by the individual caregiver, rather than any third party, including their purported union. And the department should confirm with the individual caregiver that any payment to a third party is consistent with his or her wishes before diverting any payments. This is especially important given a number of cases in which labor organizations forged dues authorizations, and it helps to avoid that problem going forward.<sup>27</sup>

While these additions do not alleviate the fact that the proposed rule is a policy that hurts caregivers, it at least ensures that providers will be given a free and truly voluntary choice about where their Medicaid payments should be directed.

### **Conclusion**

The Mackinac Center strongly opposes legislation that would permit the diversion of Medicaid funds to third parties. Such a change would harm caregivers, provide no meaningful benefit to their patients, and directly lead to the federal funding of the inherently political activity of public-sector unions. Funds paid to caregivers should be used to support their efforts to care for the sick and disabled. But, to the extent Congress does authorize dues skim legislatively, it should also include specialized procedural protections to adequately protect providers' First Amendment Rights under *Janus* and *Harris*.

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<sup>26</sup> This language is a variant of the language proposed by Chase Martin in his piece "Ending the Skimming of Union Dues from Federal Child Care Funds." <https://perma.cc/8LBS-WBY6>. In discussing similar diversionary payments, Mr. Martin proposes language to protect child care providers, as well as providing the justification for taking protective action. Much of this publication is equally applicable to home health care providers and is therefore useful in evaluating potential legislative language.

<sup>27</sup> See, e.g., *Quezambra v. United Domestic Workers of America, AFSCME Local 3930*, 445 F. Supp. 3d 695 (C.D. Cal., 2020) (under appeal); <https://perma.cc/Z7X2-HVPH>.

01/20/22

Catherine Ivy Kennedy  
 \*\*\*\*\*  
 \*\*\*\*\*  
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To whom it may concern,

I have been using Consumer Directed (CD) Personal Care Attendant services for over two decades. I'm writing this letter about the lack of equity between CD in home pay rates and group home pay rates. You can see who I mailed a copy of this letter on page 3.

COVID19 has exacerbated systems such as CD Personal Care Attendant services that were already broken. A Medicaid Consumer Directed Attendant paycheck has never been close to a living wage pay rate. What that translated to during COVID19 is I could not find attendants to assist me with activities of daily living in my home. Inequitable attendant pay rates created a barrier to me to access Home and Community Based Services (HCBS).

The Department of Justice investigated Virginia's compliance with both The Americans with Disabilities Act (ADA) and the U.S. Supreme Court's ruling, the Olmstead decision. On January 26, 2012, the DOJ and Virginia reached a settlement agreement. The result was institutions (known as training centers) closed, and group homes were opened. The choice to answer the DOJ settlement agreement was to downsize Virginia's institutions to group homes. It's apparent Virginia is continuing its institutional bias.

Currently, group home attendants are paid more than in home attendants. Stop incentivizing (paying more, sign on bonuses, etc.) for serving people with disabilities in institutional type settings, such as group homes. The setting of where an individual receives attendant services should not dictate pay rates. End institutional bias by paying Consumer Directed (CD) in home attendants a living wage. Support policy that shows equity in accessing Home and Community Based Services (HCBS).

Due to the institutional bias that is shown in inequitable attendant pay rates, people with disabilities died of COVID19 in nursing homes and group homes. Disabled lives are so devalued that there are no statics on how many people died of COVID19 in nursing homes. Caring for people in their home would've lowered the death rate in nursing homes.

On January 7, 2022, the Centers for Disease Control and Prevention (CDC) Director Dr. Rochelle Walensky spoke on ABC's Good Morning America. Her comment could be viewed as Ableist when referring to groups of people with disabilities or have chronic illnesses as "unwell to begin with". Systemic Ableism negatively impacts in home attendant pay rates during state and federal budgeting time.

Payment goes directly to group home and agency owners making it impossible to know what they pay their attendants. Group home and agency owners are not regulated on what amount they pay their attendants. In most cases, the attendant's pay rate is lowered and the difference goes to "the office". From the lack of data that office could be the size of a coat closet. I can tell you from my experience the admins in the office miscommunicate, are unprofessional, disorganized and have no leadership skills to properly train and manage attendants. I've also seen them mistreat attendants to the point that attendants quit.

Take that in and then consider my side. I can have my DD Wavier revoked if I supplement attendant pay to compete with group home and agency pay rates. The agencies are easy to start up (due to lack regulations) that there are so many of them and they are drawing attendants in at such speed that it depletes my CD hiring choices. My CD hours are permanently split for the duration I'm with an agency. If the agency attendant does not come to work, my CD attendant can't claim those hours even though they are doing the work of the attendant who no showed. "The office" is paid those hours that their attendant did not come to work, (Isn't that Medicaid fraud)?

This is not equity in using Home and Community Based Services (HCBS).

Not knowing what agencies and group homes are paying their attendants further accentuates the the existence of institutional bias. Because group home and agency owners are not regulated on what amount they pay, you can't see their attendant's pay rate in charted data. Their rate is shown as a lump sum, of admin cost, etc. I want realtime public transparency of attendant pay rates of all operating providers, group homes, agency and Consumer Directed in a per hour format. Profiteering from caring for disabilities in this way is a slippery downward slope.

Data/feedback/surveys from people who use Consumer Directed (CD) attendant services are not collected by Department of Behavioral Health and Developmental Services (DBHDS) because a person who uses CD services is not a provider. I want a seat at the table as an individual who uses Consumer Directed attendant services.

How can my voice (and others) be heard when the focus is on providers? Failure to collect data from Consumer Directed users also leads to failure to disseminate valuable tools to empower attendants and people with disabilities. MySupport was a website much like Match.com that connected people on specific shared individual characteristics. Attendants could find work and people could search for attendants. Managed Care Organizations (MCOs) stopped funding MySupport because not enough people were using the site. I would like to know how much money Virginia spent advertising MySupport? I'd say MySupport failed in Virginia because there's no list of individuals who use Consumer Directed services.

I want nursing students to spend 2 months as a Consumer Directed Personal Care Attendant in their community before Nursing Schools issues LPN licenses. With all schools on board it would greatly help the CD attendant situation while providing an hands on experience for students. I have used online job boards at my local college with no results. I need the Virginia Board of Nursing to put my idea into action for it to be a success.

On a personal note, my husband can't return to the workforce because how bad it's gotten with Personal Care Attendants. Factors that contributed to my decision to resign from my job were the problematic situations I've described in this letter. Systematic Ableism has a impact on the economy. I'm asking for equity in Personal Care Attendants pay rates to end the institutional bias.

Best regards,



CC:

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To add to 2023 letter

When there is one time payments like during COVID, the agency is in charge of getting payments (\$1000) to their eligible attendants. Attendants may have no knowledge of and/or may not receive these payments. It is left up to the agency to report which of their attendants receive these one time payments. That's a huge level of trust to the agencies bolstered with institutional bias. CD attendants receive one time payments from time they have already summited.

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The Washington Post

The state budget hearing (in Jan)

Iris Lundy  
Director - Health Equity at Sentara Healthcare

Senator Bob Casey  
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Why do Medicaid transportation brokers get paid a per-member monthly rate, regardless of how many rides, if any, a Medicaid user takes?

Where aren't the pay rates in a hourly format for attendants Consumer Directed, in home agency, group home?

How much money does a Service Facilitator make from one person using Consumer Directed personal care services? Can a person not use a Service Facilitator and their CD Personal Care Attendant still receive payment from a fiscal agent? With the absence of a Service Facilitator can a CD attendant receive payment from a fiscal agent and earn a living wage? (Money saved from not having a SF can go to CD attendant)

Why are there penalties for supplementing a CD attendants pay so waiver pay plus supplemental pay would equal a living wage for CD Personal Care Attendants?

Change wording to extreme profiting

On a side note I rarely get sick. In my perspective what is “unwell to begin with “ are the broken systems I cope with such as Medicaid transportation brokers who get paid regardless if they pick me up or not, as well as ableism in the response I hear in “the fax is lost” repeatedly to point I unnecessarily have to get an added provider involved in which insurance is billed twice for one issue, etc.

Medicaid transportation info, tie it to extreme profiting of agencies:

“It's a lucrative business, with transportation management contracts that can be worth tens of millions of dollars for companies. The two companies that have contracts in Georgia have given extensively to political campaigns of elected officials in the state. ... They (Medicaid transportation brokers) are paid a per-member monthly rate that averages \$5.60 (in 2022), regardless of how many rides, if any, a Medicaid user takes.”

What I repeatedly see is policy that allows extreme profiting from disability and inequitable delivery / utilization of Home and Community Based Services.

To counter act the false perception that disability is less than or less worthy (shown in low attendant pay rate) infuse serving people with disabilities into school curriculum. ... nursing schools.

Examples of intersectionality of Systemic Ableism and Systemic Racism:

In 1974, Congress extended FLSA wage and hour standards to long-excluded private household workers. A year later, however, the U.S. Department of Labor (DOL) interpreted the new amendment to exempt home-care workers, even employees of for-profit entities, by misclassifying them as elder companions, akin to babysitters.

On January 7, 2022, the Centers for Disease Control and Prevention (CDC) Director Dr. Rochelle Walensky spoke on ABC's Good Morning America. Her comment could be viewed as Ableist when referring to groups of people with disabilities or have chronic illnesses as “unwell to begin with”. Systemic Ableism negatively impacts in home attendant pay rates during state and federal budgeting time. I'm asking for equity in Personal Care Attendants pay rates to end the institutional bias.

Solutions:

Remove DD Waiver restrictions on supplementing pay so attendants can earn a living wage.  
Add requirement to LPN license that before graduating nursing school, students will serve as a Consumer Directed attendant for three months.

Collect data on money that's not being used as intended and redirected it to pay consumer directed in home care attendants a living wage.

Two funding sources:

1. Medicaid transportation brokers paid for EACH person on Medicaid rather if they use their transportation or not
2. Redirect money to pay consumer directed in home attendants a living wage from the agencies charging Medicaid on days when no attendant came into work in the home

Put in after how they treat each other

There's a level of generational trauma that can prevent a person from taking in information during training. I'm a survivor of parental Narcissistic Abuse and I can spot trauma/abuse in the behavior of the majority of the agency office staff and in the attendants they hire. Personal Care Attendants are in my home to care for me. It is draining for me when I end up at times handling their trauma. One might perceive the trauma they have rooted in the past of slavery. Slavery is responsible for the undervaluation of care work.

The rising need for care services can not be solved by the market. Supply and demand alone is not going to solve the problem. The 1974 FLSA wage and hour standards must be reversed.

it's a business. getting people with disabilities into places where they can charge insurance more .... it's profit and institutional bias. Compounded with Ableism at the U.S. Government level .... in 1974, Congress extended FLSA wage and hour standards to long-excluded private household workers. A year later, however, the U.S. Department of Labor (DOL) interpreted the new amendment to exempt home-care workers, even employees of for-profit entities, by misclassifying them as elder companions, akin to babysitters.

for next years online meetings:

End institutional bias by paying Consumer Directed in home attendants a living wage. Support policy that shows equity in access to Home and Community Based Services (HCBS). Stop incentivizing (paying more, sign on bonuses, etc.) for serving people with disabilities in institutional type settings, such as group homes. The setting of where an individual receives attendant services should NOT dictate pay rates. Currently, group home attendants are paid more than Consumer Directed in home attendants. Payment goes directly to group home and agency owners making it impossible to know what they pay their attendants. Not knowing what agencies and group homes are paying their attendants further accentuates the the existence of Virginia's institutional bias. I ask for realtime public transparency of attendant pay rates of all operating providers, group homes, agency and Consumer Directed in a per hour format. I ask for a seat be added at the table for individuals who use Consumer Directed. In Virginia only Providers are considered in feedback/surveys, etc. A solution to be put into action are nursing students spend 2 months as a Consumer Directed Personal Care Attendant in their community before Nursing Schools issues LPN licenses. I'm asking for equity in Personal Care Attendants pay rates to end the institutional bias.

End institutional bias by paying Consumer Directed in home attendants a living wage. Support the Better Care Better Jobs Act to ensure living wages in Home and Community Based Services. Currently, group home attendants are paid more than Consumer Directed in home attendants which is an example of Virginia's institutional bias. I'm asking for equity in Personal Care Attendants pay rates to end the institutional bias.

Here are four solutions:



1. Remove DD Waiver restrictions on supplementing pay so attendants can earn a living wage.
2. Add requirement to LPN licenses that before graduating nursing school, students will serve as a Consumer Directed attendant for three months. Collect data on money that's not being used as intended and redirected it to pay Consumer Directed in home care attendants a living wage,  
I can think of two funding sources:
3. Medicaid transportation brokers paid for EACH person on Medicaid rather if they use their transportation or not. Put a stop to that and use that money for living wages.
4. Redirect money to living wages, from the agencies charging Medicaid on days when no attendant comes into work.

As of February 2022 a report from Kaiser Family Foundation, states over 200,000 people with disabilities died of COVID19 in nursing homes. "Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died From COVID-19"  
<https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/>

As of March 22, 2022 there is no report on how many people with disabilities died of COVID19 in congregate setting such as nursing homes, group homes, etc. The reports I've seen combine staff and people with disabilities in their numbers.

"Medicare is going to set higher standards for nursing homes and make sure your loved ones get the care they deserve and expect." said at the State of the Union Address on March 1, 2022.  
and then

There was a Senate Committee on Aging hearing "An Economy That Cares: The Importance of Home-Based Services" on Wednesday, March 23 2022 at 10 a.m. Eastern Time (9 CT / 8 MT / 7 PT).

Stop gaslighting people with disabilities by claiming to value HCBS though budgets show extreme profiting from nursing homes, group homes, etc. Simultaneously the death rate of people with disabilities is unknown from COVID19 in congregate settings. End the institutional bias.



**American Association of Service Coordinators**  
659 High Street, Worthington, OH, 43085  
614-848-5958 | [servicecoordinator.org](http://servicecoordinator.org)

**Written Testimony of Michelle Missler**  
**President and CEO, American Association of Service Coordinators**  
**Senate Special Committee on Aging**  
**“An Economy that Cares: The Importance of Home-Based Services”**  
**March 23, 2022**

Chairman Casey, Ranking Member Scott and Members of the Committee:

Thank you for the opportunity to submit written testimony. We appreciate this hearing and your attention to the pressing issue of how to serve a growing aging population so that older adults can live well in their communities for as long as possible.

The American Association of Service Coordinators (AASC) represents more than 3,900 service coordinators across the country who are working in affordable housing for older adults. They serve a vital purpose in connecting low-income residents in these communities to essential home and community based services, resources and supports. In doing so, service coordinators play a pivotal role in nationwide efforts to assist older adults to age in place with the support they need.

Ninety-three percent of residents living in federally assisted affordable housing properties with service coordinators (e.g. HUD Section 202) continued living independently instead of moving to facilities with higher care levels in 2021. This is significant because surveys show up to 90% of older adults want to continue living in their communities and it saves them from paying the high cost of moving to an institutional setting. The majority of those living in federally assisted housing do not have the financial means to pay for long-term services and supports if needed and must rely on Medicaid to afford long-term care, including nursing homes and assisted living.

To promote aging in place, service coordinators directly and individually support each resident they serve an average of 35 times throughout the year. The majority of supports address social determinants of health, including helping older adults to access meals, transportation, health care and positive social interactions. Service coordinators also regularly help residents understand health plans and billing, access translation services, and adhere to care plans once they return to the property from hospital, rehab or long-term care stays.

Service coordinators also collaborate with community providers to host regular programs that inform residents on managing chronic health conditions. Preventive programs are even more common, with service coordinators organizing falls prevention instructors and mobile podiatrists and dentists, as examples. They also partner with nursing schools to host blood pressure checks and vaccine clinics.

It's imperative that service coordinators be able to connect the older adults they serve to home health providers who can assist them with daily tasks and health management as part of a holistic aging in place strategy. However, as the demand for these types of supports surpasses availability, service

coordinators are increasingly adding residents to waiting lists instead of arranging the services they need now.

AASC strongly supports efforts to increase availability of home and community based services and the workforce that makes these services possible. Safe, secure, and affordable housing with service coordination can serve as a platform for service connection and delivery. However, adequate resources must be accessible to fully realize the potential of supportive housing.

Conversely, home-based care is not possible when an older adult can't afford a home or a home that is reasonably habitable. Sadly, for far too many older adults and people with disabilities, this is out-of-reach unless they have access to affordable housing. The need for adequate affordable housing is huge with two thirds of older adults who are currently eligible for assistance going unserved because of a lack of units. We are pleased the President's Fiscal Year 2023 budget provides for badly needed new HUD Section 202 housing and encourage Congress to make ongoing investments in this area.

Thank you for the opportunity to share how service coordinators are making a difference in health and wellbeing and to bring attention to the challenges they face in connecting older adults to home and community based services, particularly home-based health care.

We encourage you to learn more about the service coordination programs in your states as you consider ways to improve how our nation is supporting our most vulnerable. AASC stands ready to support the Committee as it works to strengthen home and community based services and the coordination of them to ensure older adults have opportunities to age well and thrive in their communities.

March 22,, 2022

Senator Bob Casey  
Chairman  
U.S. Senate Special Committee on Aging

Senator Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging

*Via email:* [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

**RE: March 23, 2022 Hearing on “An Economy That Cares: The Importance of Home-Based Services”**

This statement is submitted on behalf of the signors on the attached letter, with over 225 organizations signed on ranging from AARP, Caring Across Generations, SEIU to the American Association of Pediatrics, Little Lobbyists and MomsRising supporting the \$150 billion investment in HCBS.

As the letter states:

The undersigned organizations...

“support the \$150 billion investment in HCBS. As you know, a large investment is essential for building a sustainable HCBS infrastructure that can begin to address the magnitude of need in our communities. This investment will both increase access to Medicaid HCBS and help address the direct care workforce crisis--creating more direct care jobs to support people with disabilities and aging adults, and making those jobs better.

To address the long-standing inequities the pandemic exposed and exacerbated, this investment is critical to fortify a workforce that must continue to expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers--who are primarily women of color--have been devalued and underpaid for decades, leading to severe staff shortages that result in crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to

achieving a high quality of life for workers and recipients alike.

When older adults who want to age in place and people with disabilities who need support to work, live independently, and be a part of their communities are left waiting, the responsibility for care and support often falls on unpaid family caregivers, who also need financial assistance. The costs of this inadequate system fall disproportionately on people of color with limited income and wealth. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented. Home and community-based services are also more cost effective and what people want, so it is a win/win for families and state and federal governments.

We once again thank you for your leadership and urge that you continue to include and prioritize the large investment in Medicaid HCBS, and the workforce that provides them, as you negotiate any package moving forward. We stand ready to assist you in any way we can. To that end, the undersigned advocacy organizations representing millions of constituents across the country, thank you again and stand ready to work to ensure these HCBS investments become law.”

Thank you again for holding this hearing and for the opportunity to provide input. Should any questions arise, feel free to contact Nicole Jorwic, Chief of Advocacy and Campaigns at Caring Across Generations, [nicole@caringacross.org](mailto:nicole@caringacross.org)

Most Sincerely,

A handwritten signature in black ink, appearing to read "Nicole Jorwic". The signature is fluid and cursive, with a long horizontal stroke at the end.

Attachment

President Joe Biden  
1600 Pennsylvania Avenue, N.W.  
Washington, DC 20500

March 22, 2022

Dear President Biden:

We deeply appreciate all you are doing to lift the need to invest in Medicaid Home and Community-Based Services (HCBS), including expressing your support in your State of the Union Address for investing in Home and Community-Based Services and reforming Long-Term Services and Supports.

We are so grateful to your continued support for the \$150 billion investment in HCBS. As you know, a large investment is essential for building a sustainable HCBS infrastructure that can begin to address the magnitude of need in our communities. This investment will both increase access to Medicaid HCBS and help address the direct care workforce crisis--creating more direct care jobs to support people with disabilities, including children, and aging adults, and making those jobs better.

To address the long-standing inequities the pandemic exposed and exacerbated, this investment is critical to fortify a workforce that must continue to expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers--who are primarily women of color--have been devalued and underpaid for decades, leading to severe staff shortages that result in crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to achieving a high quality of life for workers and recipients alike.

When older adults who want to age in place and people with disabilities who need support to work, live independently, and be a part of their communities are left waiting, the responsibility for care and support often falls on unpaid family caregivers, who also need financial assistance. The costs of this inadequate system fall disproportionately on people of color with limited income and wealth. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented. Home and community-based services are also more cost effective and what people want, so it is a win/win for families and state and federal governments.

We once again thank you for your leadership and urge that you continue to include and prioritize the large investment in Medicaid HCBS, and the workforce that provides them, as you negotiate any package moving forward. We stand ready to assist you in any way we can. To that end, the undersigned advocacy organizations representing millions of constituents across the country, thank you again and stand ready to work to ensure these HCBS investments become law. If you have any questions feel free to contact Nicole Jorwic, [nicole@caringacross.org](mailto:nicole@caringacross.org)

Sincerely,

AARP

Access Ready

Aging Life Care Association

Alabama Disabilities Advocacy Program

Alzheimer's Association

Alzheimer's Impact Movement (AIM)

American Academy of Pediatrics

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union

American Council of the Blind

American Federation of Teachers

American Geriatrics Society

American Muslim Health Professionals (AMHP)

American Network of Community Options and Resources (ANCOR)

American Society on Aging

American Therapeutic Recreation Association

Amputee Coalition

Arizona Center for Disability Law

Arkansas Governor's Council on Developmental Disabilities

Asset Building Strategies

Association of People Supporting Employment First (APSE)

Association of University Centers on Disabilities

Autism Speaks

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Be a Hero

California Advocates for Nursing Home Reform  
 California Alliance for Retired Americans  
 California Down Syndrome Advocacy Coalition  
 California Foundation for Independent Living Centers (CFILC)  
 California State Independent Living Council (SILC)  
 Caring Across Generations  
 Carolina Institute for Developmental Disabilities  
 Center for Advocacy for the Rights and Interests of the Elderly (CARIE)  
 Center for Public Representation  
 Chamorro-Carolinian Language Policy Commission  
 Child & Family Service  
 Christopher & Dana Reeve Foundation  
 Coalition of Texans with Disabilities  
 Coalition of Health Services- Uniting Parents  
 Coalition on Human Needs  
 CommunicationFIRST  
 Community Access Center  
 Community Catalyst  
 Community Legal Aid Society, Disabilities Law Program  
 Community Options  
 CRIL  
 Designer Genes of North Dakota, Inc  
 Disability Rights Iowa  
 Disability Law Center of Alaska  
 Disability Law Center of Massachusetts  
 Disability Law Center of Utah  
 Disability Rights Arkansas  
 Disability Rights Center - NH  
 Disability Rights Center of Kansas  
 Disability Rights Education and Defense Fund (DREDF)  
 Disability Rights Louisiana  
 Disability Rights Maine  
 Disability Rights Nebraska  
 Disability Rights New Jersey  
 Disability Rights Oregon  
 Disability Rights Rhode Island  
 Disability Rights Texas  
 Disability Rights South Carolina  
 Disability Rights Mississippi  
 Down Syndrome Alabama



Down Syndrome Connection of the Bay Area  
Down Syndrome Innovations  
DSAW  
Easterseals  
Epilepsy Foundation  
Faith in Public Life  
Florida Health Justice Project  
Foundation Plus  
FSL  
Georgia Council on Developmental Disabilities  
Grand Rapids Home for Veterans  
Hand in Hand: The Domestic Employers Network  
Health Care Voices  
Idaho Council on Developmental Disabilities  
Indiana Disability Rights  
Iowa Developmental Disabilities Council  
Jewish Family and Children's Service of Greater Philadelphia  
Jewish Family Service of Greater Dallas  
Jewish Family Service St. Paul  
Jewish Federation of Chicago  
Justice in Aging  
JVS+Kadima  
Kentucky Protection and Advocacy  
Lakeshore Foundation  
LeadingAge  
LIFE ElderCare  
LifeLong Medical Care  
Little Lobbyists  
Little Lobbyists  
Long Beach Gray Panthers  
ltcop  
Lutheran Services in America-Disability Network  
Main Street Alliance  
Maine Developmental Disabilities Council  
Make It Work Nevada  
Marin Center for Independent Living  
Maryland Developmental Disabilities Council  
Maryland Down Syndrome Advocacy Coalition  
Massachusetts Down Syndrome Congress  
Massachusetts Senior Action Council

Michigan Developmental Disabilities Council  
 Minnesota Governor's Council on Developmental Disabilities  
 MomsRising  
 Montgomery County Down Syndrome Interest Group (MCDSIG)  
 Muscular Dystrophy Association  
 National Academy of Elder Law Attorneys  
 National Association for Home care & Hospice  
 National Association of Councils on Developmental Disabilities  
 National Association of Social Workers (NASW)  
 National Association of State Long Term Care Ombudsman Programs (NASOP)  
 National Consumer Voice for Quality Long-Term Care  
 National Council of Jewish Women  
 National Council on Aging  
 National Council on Independent Living  
 National Disability Rights Network (NDRN)  
 National Down Syndrome Congress  
 National Employment Law Project  
 National Health Council  
 National Health Law Program  
 National Partnership for Women & Families  
 National Resource Center on Domestic Violence  
 National Respite Coalition  
 National Women's Law Center  
 NC Equal Justice Alliance  
 NDSC  
 Network of Jewish Human Service Agencies  
 Nevada Governor's Council on Developmental Disabilities  
 NH Alliance for Healthy Aging  
 North Dakota Protection & Advocacy Project  
 NTG  
 Our Mother's Voice  
 Parent  
 Parent Advocate  
 Parent of a child with special needs  
 Partnership for Inclusive Disaster Strategies  
 patient/parent of caretaker (daughter)  
 People Inc  
 Protect TX Fragile Kids  
 RespectAbility  
 RESULTS

## RESULTS DC/MD

Rolling Start, Inc. Center for Independent Living

San Francisco Senior & Disability Action

Schenectady ARC

Senior Services Coalition of Alameda County

Service Employees International Union

Silicon Valley Independent Living Center

St. Barnabas Senior Services

TASH

Texas Parent to Parent

The AIDS Institute

The Arc Michigan

The Arc Minnesota

The Arc New York

The Arc of Alabama

The Arc of Anchorage

The Arc of Buffalo County

The Arc of Central Alabama

The Arc of Central Nebraska

The Arc of Colorado

The Arc of Connecticut, Inc.

The Arc of Illinois

The Arc of Kentucky, Inc.

The Arc of Lincoln

The Arc of Nebraska

The Arc of New Mexico

The Arc of Nevada

The Arc of NJ

The Arc of Norfolk

The Arc of Ohio

The Arc of Oklahoma

The Arc of Pennsylvania

The Arc of Platte County

The Arc of South Carolina

The Arc of Texas

The Arc of the Mid Ohio Valley

The Arc of the United States

The Arc of Virginia

The Arc of Washington State

The Arc of West Virginia

The Gerontological Society of America  
The Jewish Federations of North America  
The Kelsey  
TheCIL, Inc. (Center for Independent Living-Berkeley)  
TN Council on Developmental Disabilities  
UMass Boston, Gerontology Institute  
Union for Reform Judaism  
United Spinal Association  
United State of Women  
Utah Developmental Disabilities Council  
VI Developmental Disabilities Council  
Well Spouse Association  
World Institute on Disability  
WWAARC  
Your Supports Your Way



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

**United States Senate Committee on Aging Hearing on "An Economy That Cares: The Importance of Home-Based Services"**

**March 23, 2022**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Committee on Aging hearing "*An Economy That Cares: The Importance of Home-Based Services*." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. Among other issues, this statement highlights the importance of home- and community- based (HCBS) services.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. It is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. AIM is the advocacy affiliate of the Alzheimer's Association, working in strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

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

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

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

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

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

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

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

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

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

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

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

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers much needed support. These services empower caregivers to

provide quality care for their loved ones while giving them an opportunity to manage and improve their own health.

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

#### **Conclusion**

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



***An Economy That Cares: The Importance of Home-Based Services***  
**Questions for the Record**  
**Questions for Lisa Harootunian, Associate Director, Health Program, Bipartisan Policy Center**

Ms. Harootunian, during the hearing Senator Braun asked you a question about whether increased spending leads to improved outcomes. Your response was that increased spending does not always lead to better outcomes and that spending must "be targeted in the right ways to promote quality outcomes." Your response focused on beneficiaries' ease in access and "ensuring that care is integrated and easy for beneficiaries to navigate and access, and ensuring that the delivery of those services is efficient and optimized." I agree that programs must be accessible for beneficiaries. However, you did not touch on the need for spending to be targeted toward building and sustaining the direct care workforce, without which beneficiaries would have no access to home and community-based services.

The direct care workforce is in the midst of a long-standing and worsening crisis due to decades of underinvestment and the COVID-19 pandemic. Nationwide, the average hourly wage for DSPs is \$13.36 with turnover rates ranging as high as 79.5%.<sup>1</sup> Disability service providers are struggling to compete for staff with more lucrative positions in entry-level industries, including convenience stores, retail, and fast food, but these community providers are exclusively reliant on stagnant Medicaid reimbursement rates and lack the resources to be competitive. The exodus of direct care professionals from the field has left individuals with I/DD without consistent access to critical support and at a higher risk for hospitalization and institutionalization.

In 2021, the American Network of Community Options and Resources conducted a provider survey<sup>2</sup> which revealed that the COVID-19 pandemic has made an ongoing workforce crisis much worse. Among the findings of that survey are that 77% of providers have been forced to turn away new referrals, 58% of providers have discontinued programs and services, and 92% of provider continue to grapple with the impact of the pandemic on recruitment and retention.

**Questions:**

- Do you agree that the sustainability of the direct care workforce is critical in ensuring people with disabilities have access to home- and community-based services?
- Can you provide more information about how an investment in the direct care workforce could promote quality outcomes?

<sup>1</sup> Nat'l Assoc. of State Directors of Developmental Disabilities Services & Human Svcs Research Inst., *National Core Indicators Intellectual and Developmental Disabilities 2020 Staff Stability Survey*, available at [https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport\\_FINAL.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport_FINAL.pdf)

<sup>2</sup> Am. Network of Cmty. Options & Res., *The State of America's Direct Support Workforce 2021*, available at [https://www.ancor.org/sites/default/files/the\\_state\\_of\\_americas\\_direct\\_support\\_workforce\\_crisis\\_2021.pdf](https://www.ancor.org/sites/default/files/the_state_of_americas_direct_support_workforce_crisis_2021.pdf)





U.S. SENATE SPECIAL COMMITTEE ON AGING  
 "AN ECONOMY THAT CARES: THE IMPORTANCE OF HOME-BASED SERVICES"  
 HEARING TESTIMONY  
 Wednesday, March 23, 2022

Dear Chair Casey and Ranking Member Scott:

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to provide testimony on the importance of the Medicaid Home and Community Based Services (HCBS) program.

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

*The Direct Care Workforce Crisis Endangers Access to HCBS*

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

However, the DSP workforce is in the midst of a long-standing crisis due to decades of underinvestment, which is now being amplified significantly by the COVID-19 pandemic.

Nationwide, the average hourly wage for DSPs is \$13.36, with turnover rates ranging as high as 79.5%.<sup>1</sup> The most recent National Core Indicators Staff Stability Survey reveals that in 2020, full-time vacancy rates increased by 45%.<sup>2</sup> Disability service providers are struggling to compete for labor against industries that have traditionally paid entry-level wages, such as convenience stores, retail, and fast food. While many businesses in those industries adapted to the pandemic economy by offering increased wages and hazard pay, community providers have not had these options, as they are primarily reliant on stagnant Medicaid reimbursement rates.

The resulting exodus of DSPs from the field has left individuals with I/DD without consistent access to critical support and at a higher risk for hospitalization and institutionalization. A 2021 survey conducted by ANCOR confirms the negative impacts of high turnover on

<sup>1</sup> Nat'l Assoc. of State Dirs. of Developmental Disabilities Servs. & Human Servs. Research Inst., *National Core Indicators Intellectual and Developmental Disabilities 2020 Staff Stability Survey*, available at [https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport\\_FINAL.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport_FINAL.pdf)

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

access to services.<sup>3</sup> That survey finds that 77% of providers have been forced to turn away new referrals, 58% of providers have discontinued programs and services, 81% of providers are struggling to achieve quality standards, and nearly three in 10 providers report spending at least \$500,000 annually on costs associated with high turnover and vacancy rates. In addition, 92% of providers report that the COVID-19 pandemic continues to complicate their ability to recruit and retain qualified DSPs.

#### *Congress Must Invest in the HCBS Program*

These relentless challenges illustrate why support for HCBS is essential. In November, the U.S. House of Representatives passed legislation to provide a nearly \$150 billion investment in the HCBS program. This level of funding is the minimum investment necessary for states to begin building a sustainable HCBS infrastructure that can start to address the magnitude of unmet need in our communities. This funding would not only strengthen the ability of people with disabilities and our aging neighbors to live a life with dignity in their homes and communities, but it would create countless jobs and boost local economies.

In analyzing the nearly \$150 billion investment included in the House-passed legislation, the Congressional Budget Office (CBO) concluded that the investment would lead to an increase in both HCBS services and employment of direct care workers. The CBO analysis stated:<sup>4</sup>

The total amount of HCBS that people used would increase, and the employment of direct care workers who provide HCBS funded by Medicaid would increase to cover additional services and enrollees. CBO expects that wage increases would be sufficient to increase the supply of workers to cover those hours once the policy was fully implemented. (Wages would also increase in other sectors of the economy employing workers with similar skills.) The total labor supply—including HCBS and other sectors—would increase.

#### *Temporary Investments Are Not Sufficient to Solve the Crisis*

We appreciate the investment Congress has already made in the Medicaid HCBS program through the American Rescue Plan Act, which has been critical in supporting access to HCBS and enabling providers to invest in their direct care workforces. However, more than a year later, nineteen states have yet to receive the conditional approval needed from CMS to access full funding.<sup>5</sup> And, even for those states where plans have been approved, limited one-time funding is insufficient to address the gravity of the workforce crisis. Providers and DSPs will face a devastating fiscal cliff when that funding expires on April 1. The investment of nearly \$150 billion for the HCBS program would empower providers to continue retaining existing workers and recruit new ones, ensuring sustainable services for individuals with I/DD and their families.

<sup>3</sup> Am. Network of Cmty. Options & Res., *The State of America's Direct Support Workforce 2021*, available at [https://www.ancor.org/sites/default/files/the\\_state\\_of\\_americas\\_direct\\_support\\_workforce\\_crisis\\_2021.pdf](https://www.ancor.org/sites/default/files/the_state_of_americas_direct_support_workforce_crisis_2021.pdf).

<sup>4</sup> Cong. Budget Office, *Economic Effects of Expanding Home- and Community-Based Services in Medicaid* (2021), available at <https://www.cbo.gov/system/files/2021-11/57632-Medicaid.pdf>.

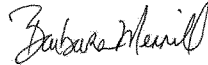
<sup>5</sup> See Lauren Weber & Andy Miller, *Why Billions in Medicaid Funds for People with Disabilities are Being Held Up*, NPR (Mar. 2, 2022), available at <https://www.npr.org/sections/health-shots/2022/03/02/1083792436/why-billions-in-medicaid-funds-for-people-with-disabilities-are-being-held-up>.

HCBS has grown exponentially since its inception 40 years ago and plays a critical role in ensuring people can be supported in their homes and communities. However, absent the necessary infrastructure investments to sustain the DSP workforce, Medicaid HCBS programs will continue falling far short of reaching everyone in need.

*Conclusion*

We urge you to prioritize the needs of people with I/DD by supporting legislation to invest \$150 billion to strengthen and expand the Medicaid HCBS program. If you have questions or would like to discuss further, please feel free to contact Shannon McCracken, ANCOR's Vice President for Government Affairs, at [SMcCracken@ancor.org](mailto:SMcCracken@ancor.org).

Sincerely,

A handwritten signature in cursive script that reads "Barbara Merrill".

Barbara Merrill  
Chief Executive Officer  
ANCOR



March 22, 2022

The Honorable Robert Casey  
Chairman  
U.S. Senate Special Committee on Aging  
Washington, DC 20510

The Honorable Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging  
Washington, DC 20510

Dear Chairman Casey and Ranking Member Scott:

On behalf of the American Seniors Housing Association (ASHA), I thank you for your leadership in holding this hearing today: “An Economy That Cares: The Importance of Home-Based Services”.

ASHA is a national organization of over 500 companies involved in the operation, development, investment, and financing of the entire spectrum of seniors housing – independent living, assisted living, memory care, and Continuing Care Retirement Communities (CCRCs). Our members’ communities serve a wide range of seniors, from those who require assistance with activities of daily living (ADL) such as eating, bathing, and dressing, to those with significant needs associated with Alzheimer’s disease and age-related dementia. Our members are on the front lines when it comes to serving frail seniors by providing 24/7 expert care, supportive services, dining, housekeeping and myriad activities that promote wellbeing and social interaction. Senior living offers a valuable and much-needed option for aging seniors and their families in need of care that is community-based. As Congress considers policies and programs to address the long-term care needs of aging seniors, we ask that you not overlook the benefits of senior living, especially as an HCBS setting in any expansion of the Medicaid waiver program. The demand for this setting is significant, the benefits are many, and the average national costs are among the lowest of Long Term Care Services (LTCSS) options and therefore beneficial to taxpayers.

#### **The Demand for Long Term Care Services and Supports**

The demographics of our aging society makes the work of policymakers who serve on this Committee critically important. Simply put, people are living longer -- and there are more of them. The size of the 65 and older population will almost double from 54 million today to 98 million in 2060. (Population Reference Bureau’s Population Bulletin/U.S. Census Bureau). The number of people 85 and older will nearly triple to 18 million. Recent projections estimate that about one-half of Americans reaching age 65 will need long-term care services and will incur, on average, \$138,000 in long-term care costs. These projections are especially concerning for those seniors who are unprepared financially. Nearly 4 in 10 mistakenly expect to rely on Medicare to pay for their long-term care needs and 1 in 3 have done little to no planning for their own care needs.

As you explore the issues relative to Home Based Community Services today, we ask that you also keep in mind the vital role that senior living plays in the delivery of care to aging seniors who are challenged by physical, as well as cognitive decline. Senior living IS community-based, and almost 2 million people live in senior living communities. While largely a private pay model of residential care, 10 percent of dual eligible seniors live in assisted living communities. These communities meet the criteria set by CMS under the Medicaid Home and Community Based Services (HCBS) program thus allowing the use of a

Medicaid waiver to partially pay for the costs of assisted living communities. This critical program gives eligible seniors and their families another option for the care and services they need, but only in the states that have a waiver program for assisted living. Unfortunately, eligibility for and access to assisted living varies by state. Congress should take whatever action is appropriate to promote the value proposition senior living brings to the Medicaid program and encourage adoption by more states.

#### **Benefits of Senior Living:**

Senior living offers significant benefits to residents that are not always available to an older adult living in a traditional single-family home or apartment. Policy goals that are singularly focused on keeping seniors in need of care in their traditional home, to the exclusion of other residential care settings overlook these benefits. For example, the community living environment in assisted living combats prolonged social isolation, lack of engagement and loneliness that can contribute to functional and cognitive decline, as well as depression and anxiety in older adults. Eating well by maintaining a nutrient-rich diet every day can improve overall energy and reduce the risks of heart disease and other illness. Older adults suffering from Alzheimer's or other dementia have special needs that cannot be addressed by a family caregiver or home health aide. These benefits should factor heavily in policy initiatives to improve options and choice. Coupled with the demand for aging services described above, it is important for policymakers to foster an "all the above" policy strategy that meets the needs of our seniors today and in the future. "Aging in place" is not limited to living out your final years in a person's traditional home. Senior living communities not only offer their residents the ability to "age in place" but to do so in an environment that creates opportunities for social and intellectual engagement, promotes wellbeing and makes them feel like they are "home".

#### **Cost of Care:**

In addition to the many benefits to the seniors who live in an assisted living community, the cost of this setting remains the lowest among the various options for care. According to the 2021 Genworth Annual Cost of Care Report, the median monthly and annual costs for the selected settings are as follows:

<b>Provider</b>	<b>Setting</b>	<b>Monthly Cost</b>	<b>Yearly Cost</b>
Home Health Care (44 hours per week/52 weeks)	Homemaker Health Aide	\$ 5,148	\$ 61,776
Assisted Living Community (12 months of care/housing)	Private, One Bedroom	\$ 4,500	\$ 54,000
Nursing Home Care (365 days of care)	Semi- Private Room	\$ 7,908	\$ 94,896
	Private Room	\$ 9,034	\$ 108,408
Adult Day Health Care (5 days per week/52 weeks)	Day Program	\$ 1,690	\$ 20,280

While the median cost for Assisted Living is clearly lower than the median costs of home health care, it is also important to note that is not a fair comparison. The cost of assisted living is inclusive of meals, care, private apartment, activities, transportation, and other services. The median cost for a home health aide is limited to services provided 44 hours per week. It does not include meals and activities and the ongoing costs of maintaining a home, i.e. mortgage or rent, repairs, utilities etc. will remain the responsibility of the client. In addition to the lower costs of assisted living to the private paying public,

when accessed under a government program such as Medicaid the savings to the federal and state government is significant. It can further be argued that when a senior lives in an assisted living community, emergency room visits and hospitalizations are fewer as compared to someone living at home, resulting in savings to the Medicare budget.

**Assisted Living is part of HCBS Infrastructure**

As you continue to focus on rebalancing LTSS into home and community-based settings, assisted living should be part of that conversation. Assisted living is an often-unrecognized part of the HCBS infrastructure for frail seniors. In addition to being “home”, these communities offer much-needed socialization opportunities and critical functional supports to help prevent an individual from declining into a more complex institutional level of need.

Thank you for your attention to these important issues and taking the views of ASHA into consideration as you move forward. Please reach out with questions to Jeanne McGlynn Delgado, ASHA’s VP of Government Affairs at [jeanne@ashaliving.org](mailto:jeanne@ashaliving.org) or call 202-885-5561. We look forward to working with you and your staff

Sincerely,

A handwritten signature in blue ink, appearing to read "David Schless".

David Schless

President



The Arc of Northern Virginia  
2755 Hartland Rd., Suite 200  
Falls Church, VA 22043

T 703-208-1119  
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Statement for the Record

Hearing: An Economy That Cares: The Importance of Home-Based Services

United States Senate Special Committee on Aging

Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott:

The Arc of Northern Virginia is celebrating our 60<sup>th</sup> anniversary this month as a non-profit working to promote and protect human and civil rights for people with developmental disabilities, and ensure they have fulfilling lives in their communities of choice. We answer thousands of inquiries each year from people seeking resources to work, live, and recreate in Northern Virginia.

Over the course of the pandemic, we have seen the tremendous impact ARPA funding had in keeping programs open and helping to ensure people with disabilities could get the staff support they need to be safe and included in their communities. The Better Care Better Jobs Act would help ensure funding like this continues. The number one concern and frustration we hear from people with disabilities and their loved ones are the challenges finding and keeping staff. Permanent funding support, as outlined in the BCBJ Act, would alleviate a great deal of that stress. Now, Direct Support Professionals (DSPs) see a less-than-living wage, a job with no career path, and hard work. We need legislation, including the Better Care Better Jobs Act, to ensure those vital jobs are attractive to the right kind of employees and support them in staying in and growing in those positions for years.

Thank you for your time and work on this lifechanging legislation. We strongly urge you to pass the Better Care Better Jobs Act to move us toward a country where people with developmental disabilities and their staff are valued, supported, and included.

Sincerely,

Lucy Beadnell  
Director of Advocacy  
[Lucy.Beadnell@TheArcofNOVA.org](mailto:Lucy.Beadnell@TheArcofNOVA.org)

**Lydia Nunez Landry,**  
Disability rights advocate

Submitted for the United States Senate Committee on Aging on:  
**An Economy That Cares: The Importance of Home-Based Services**  
Wednesday, March 24, 2022

Chairman Casey, Ranking Member Scott, and distinguished Members of the Committee,

I am a disabled woman and former certified long-term care ombudsman. I write to you today to stress the need for the passage of the Better Care for Better Jobs Act and specifically the dire need to adequately fund Home and Community Based Supports and Services (HCBS). First, I am grateful for this hearing; it acknowledges the humanity of disabled people and the decades of sacrifice made by disability activists striving to create an equitable society for disabled people; a society where we can lead interdependent, self-directed lives within our communities. Second, I appreciate the opportunity to contribute to the dialogue. I—and other disabled people—have not been lavished the same platforms to speak given to the long-term care industry, health care professionals, and providers. As a result of this, the voices of disabled people, including those at imminent risk of institutionalization, have been squelched by dominant social narratives, narratives that judge our struggle for self-determination as unrealistic, reduces our humanity to cost-effectiveness and cost-benefit analyses, and persists through professionals' mistaken belief that they know what is best for us.

Most people think nursing homes and similar institutions the “natural” place for many older and disabled people—we routinely encounter the rhetorical question, “what else are we going to do with them?” I want to impress upon you today the repugnance that such hand-waving resignation tacitly accepts, and why, therefore, HCBS is not only a viable alternative, but a moral imperative.

Generally speaking, when *any* group of people is marked as suspect or inferior in some manner, when its members are segregated and denied the resources and liberties that others enjoy, their [flourishing will indeed be impeded](#), and they will be at a greater risk of neglect, abuse, and contracting infections or disease. This is evidenced throughout history, from the decaying and dank [tenement houses of the early 19<sup>th</sup> century](#), the horrific conditions of the [Warsaw ghetto](#), to the [abuses that occurred in state institutions](#) for people with disabilities. Given a deadly pandemic *combined* with deplorable (or at best unsafe) conditions, where people are [segregated and treated as fungible objects from which to extract government benefits](#) (or cheap labor) it is time that we honor the humanity of disabled people and prioritize HCBS over a dangerous and irreparable institutional model—a model that, with every institutional death, deficiency, and failure, demands increased funding despite decades of abysmal outcomes. This would fulfill our obligations to disabled people set forth in the Americans with Disabilities Act; what use, after all, are legally enshrined rights when social facts prevent certain groups from exercising them. We all have the legal freedom of speech, but the quality of that freedom hangs on privilege and position—some social groups have unfettered access to platforms, soapboxes, and network news shows, while others suffer a systemic silencing that exposes the pretences of proclaimed universal freedoms. State interventions can work to rehabilitate unjust conditions that produce



counterfeit rights, and the provisions for HCBS in Better Care for Better Jobs Act has just that potential.

On occasion, circumstances force us to confront the ugliness and brutality that inevitably festers where we sequester vulnerable people; [stories of abject cruelty](#) rip away the veil of inattention we cultivate to block from our view the relentless mill of everyday abuse, neglect, and hopelessness. In these moments of outrage, we perceive the true nature of institutionalization and perhaps even what we must do, but those flashes of insights quickly fade. Soon those with vested interests haul out the timeworn reform narratives and “bad apple” scapegoats that persuade us to look away again, to participate in systemic neglect from afar.

As a long-term care advocate, I could not simply look away from the toll of daily abuse and neglect residents experience or ignore their justified feelings of abandonment and the despair it begets. My advocacy work bears out what ought to have long been obvious to any attentive person, namely, that segregating people in institutions can never foster or indeed ever permit equal treatment. Nor—as over a hundred years of disability history attests—can this model be fixed through reform. We cannot fix that which, by its nature, leads to systemic human rights violations. Severing people (like older and disabled people) from their homes and communities necessarily devalues them as persons and citizens. The diminishment is felt immediately. The freedoms they enjoyed vanish as institutional regiments constrict the courses of their lives. These utilitarian routines deprive them of their privacy and autonomy for the sake of efficiency and cost-effectiveness. Confined in these facilities without the projects and relationships that endowed their lives with meaning and shaped their social identities, they experience a kind of social death. And so too their former communities, continuing on without them, lose the connection to them as full persons still deserving of the moral consideration and respect we are obliged to confer on those people in the community. Isolated, powerless, and dehumanized, people institutionalized inevitably suffer grave harms, not only from abuse and neglect, but from the very act of banishing them from the moral communities that granted the rights and benefits they are now denied.

To be sure, congregate institutions try to simulate community to hide these realities, but such ersatz contrivances are no substitute for genuine social inclusion and belongingness; the simulations are parodies. Such a model cannot produce “person-centered care” no matter how many CMS regulations we enact *and* enforce. Nor can quarterly [congressional hearings](#) and [regulatory tweaks](#)—informed by the [usual actors](#) they serve to benefit—amount to anything more than theater, political performances that strike those [people who must endure the injustice](#) as thoughtless cruelty.

Only a transformative shift in public policy can end these injustices. This shift will require scrutinizing narratives widely considered axiomatic. [These include the beliefs that institutionalization is an unavoidable consequence of aging](#) and disability, that [institutions provide safer](#) environments (a claim long used to rationalize the barbarity of social removal despite [evidence demonstrating the contrary](#)), that uprooting people from the homes, communities, and personal identities they spent lifetimes nurturing is compatible with our most revered social ideals, and finally that we can outsource our humanity—that is, our moral and social obligations to one another, including our disabled parents and children—as a revenue source for corporations and the [workers they exploit](#) and expect humane results.

By now, we *know* these outcomes of the institutional model; it is a model that objectifies deeply human concerns and favors economic values and imperatives such as competitiveness, efficiency, and profit margins, values that tend to [attract predatory actors](#). And yet we persist with it, and one must ask why. *Why* do we continue to allow neglect, abuse, and dehumanization to go unchecked? Why do we allow those same predatory [actors to manufacture and control the narratives](#) that frame these issues, and indeed provide them [platforms](#) in the halls of Congress and in the media to influence unwitting advocates? Why do we persist with this cultivated naivety in the face of so much everyday suffering? The poor human rights records of congregate care facilities long predate [the COVID-19 crisis, but the crisis has laid bare](#) the preexisting conditions that led to deaths of [over 181,000 disabled people in these institutions](#).

Cultural change is impossible within the institutional habitus, particularly so when professional and agency advancement, [corporate profit](#), race, age, and [ableism](#) are added to the brew. From the institutional point of view, the dehumanizing model is working as intended. Hence, pumping in ever more money to fund the same solutions and reforms will not bring about different results. As we have seen during the COVID-19 pandemic, nursing homes made [record profits](#) from taxpayer funded [COVID subsidies](#), yet COVID cases and deaths, along with [non COVID deaths resulting from inadequate infection control practices and severe understaffing](#), continued to rise.

There will be no substantive change until we end the [Medicaid institutional bias](#) by diverting taxpayer funds away from institutions and to programs that maintain or reestablish community integration. As I often explain, nursing homes are the most [subsidized](#) industry in the United States and [increased monetary rewards](#) serve only to entrench [industry malfeasance](#). Diverting Medicaid dollars to fund [Home and Community Based Services](#) not only reaffirms our commitments to the ADA, the U.S. Supreme Court's *Olmstead* decision, and our professed democratic principles, it will also do more to soften the resolve of a recalcitrant industry than years of congressional hearings. In the long run, we will waste fewer resources on researching deficient industry practices and developing complex strategies to instigate change (only to be undone by lobbyists), on the [Office of Inspector General](#) (OIG) and the U.S. [General Accounting Office \(GAO\) investigations](#), on Ombudsman programs, on regulatory agencies to maintain the illusion of oversight, on healthcare costs resulting from the industry's negligence, and on subsidizing the industry's cost of doing business. Lastly, from my own perspective, after what I have witnessed in institutions during my years of service as a certified volunteer long-term care ombudsman,<sup>1</sup> the prospect of being socially removed to a setting that by its nature engenders abuse and neglect, keeps me up at night in terror.

Sincerely,

Lydia Nunez Landry

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<sup>1</sup> I recently resigned after years of observing relentless neglect and abuse that our broken system perpetuates.



**Statement for the Record  
Hearing: An Economy That Cares: The Importance of Home-Based Services  
United States Senate Special Committee on Aging**

Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott,

I am the President/CEO of the St. Louis Arc, a nonprofit organization that provides services and supports to over 4,500 individuals with intellectual and developmental disabilities throughout the greater St. Louis metropolitan region. For over 40 years, I have worked with and been an advocate for individuals with IDD. Never in my career have I experienced the crisis we are seeing today and you have an opportunity to help all Home and Community Based Services (HCBS) providers across the United States.

The Better Care Better Jobs Act is critical to the survival and success for all HCBS providers. Throughout the pandemic, we were able to retain much of our existing workforce through the tremendous assistance provided by the American Rescue Plan Act (ARPA) funding. With this funding, we were able to offer our essential workers, Direct Support Professionals (DSP) premium pay to help recruit and retain good staff to provide high quality supports and continuity to some of our most vulnerable citizens. The Better Care Better Jobs Act would ensure those funds would continue and our services will be uninterrupted.

Our DSP's are required to play many roles each day in their jobs. They must act as medical professionals, counselors, dietitians, physical therapists, life coaches, chauffeurs, personal care assistants, and more. For all their work and responsibilities, DSP's barely make above minimum wage. We cannot compete with for profit businesses that are offering \$15-24 per hour for much less strenuous work. For too long, DSP's have been undervalued and underpaid for the vital services they provide. The Better Care Better Jobs Act can rectify this matter.

Today, the St. Louis Arc has over 45 jobs open. We cannot recruit and retain the quality of staff we once did. This staffing crisis has never been more critical. In 2020 and 2021, the St. Louis Arc hired 219 individuals. Today, only 78 (36%) of those hired remain. The vast majority of those who left us indicated they left for higher wages. This is not a sustainable model. We need your support.

People with IDD deserve the best possible care and the staff who provide those supports deserve much better compensation. I urge you to pass the Better Care Better Jobs Act to ensure people with IDD get the services and supports they need to lead their best possible lives. Thank you for your consideration of this matter.

Sincerely,



Mark A. Keeley, MSW, LCSW  
President/CEO



1177 N. Warson Road • St. Louis, MO 63132 • (314) 569-2211 • (314) 569-0778 fax • [www.slarc.org](http://www.slarc.org)

## THE Arc OF WALKER COUNTY

ADVOCATING AND PROVIDING SERVICES FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
AND PROVIDING SUPPORT TO FAMILY AND FRIENDS OF THOSE INDIVIDUALS SINCE 1975



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### Statement for the Record

Hearing: An Economy That Cares: The Importance of Home-Based Services

United States Senate Special Committee on Aging

Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott:

The Arc of Walker County provides services and supports to adults who have intellectual disabilities in Jasper, Alabama and surrounding communities. Services include 24/7 residential supports, community day, supported employment and early intervention. We appreciate you both for having this hearing.

The Better Care Better Jobs Acts would improve the lives of so many of the people we serve. Without ARPA funding, we wouldn't have been able to continue services during the pandemic. When that funding is gone, we will look at which programs may be cut or discontinued. However with the Better Care Better Jobs Act this funding would continue and we could continue to provide these desperately needed services in the community. Even a lapse in funding would be detrimental to our programs, so I ask you both to pass the act now.

The Better Care Better Jobs Act would allow us to address wages and benefits for our staff permanently instead of intermittently – our full-time direct care employees make \$10/hour – below the poverty line for a family and inadequate in today's economy. Funding for services is so low at this point in time, we are unable to raise wages any more to compete even with fast food restaurants or retail establishments. Putting a dollar on the type of services we provide is very difficult and services have been underfunded for more than 20 years. We need to pay our staff a live-able wage. With live-able wages, we could reduce turnover and recruit more staff, thus serving more people.

We are so appreciative to get the attention to wages as it seems for years to have been "left up to the community providers" that are severely underfunded. The Arc of Walker County is hurting and many other agencies like ours have closed.

Thank you again for your attention to the Better Care Better Job Act and we will certainly appreciate the passing of this act.

Sincerely,

Joanna Brand,

CEO/President

Statement for the Record  
March 24, 2022  
Caring Across Generations

Senator Bob Casey  
Chairman  
U.S. Senate Special Committee on Aging

Senator Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging

RE: March 23, 2022 Hearing on "An Economy That Cares: The Importance of Home-Based Services"

Chairman Casey and Ranking Member Scott:

Thank you for holding this timely hearing to underscore the critical role of the care economy and how investments in Home and Community-Based Services will support care workers, care recipients, and the economy as a whole.

The COVID-19 pandemic has underscored the critical role of care in our economy. Home and Community-Based Services (HCBS) are crucial to enabling seniors and people with disabilities to lead independent lives and receive the care they need. We must invest in HCBS if we are to meet the ever-rising demand for home services and ensure that millions of Americans can access care and receive quality services. The Better Care Better Jobs Act does just this, by expanding eligibility and strengthening pay and workplace protections for direct care providers. Direct care providers, predominantly women of color, have long been overlooked and undervalued, and it is past time that we correct this historic injustice. The \$150 billion for HCBS proposed by the Biden Administration and passed by the House would enable serious investments that expand access by helping states slash waitlists and creating more well-paying direct care jobs. Investing in care work is a boon to our economy as a whole, as it will alleviate the burden felt by so many family caregivers who have had to balance their jobs along with caring for loved ones. Congress must act on these vital provisions to uplift all Americans, and we are glad that the Senate Special Committee on Aging is working to address these issues.

Should you have any questions, please feel free to contact David Kimelman, Legislative Manager, at [davidkimelman@caringacross.org](mailto:davidkimelman@caringacross.org).

Sincerely,

A handwritten signature in black ink, appearing to read "David J. Kimelman".

David J. Kimelman





March 30, 2022

Senator Bob Casey  
Chairman  
U.S. Senate Special Committee on Aging

Senator Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging

*Via email:* [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

**RE: March 23, 2022 Hearing on “An Economy That Cares: The Importance of Home-Based Services”**

Dear Senators Casey and Scott;

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. The undersigned co-chairs of CCD’s Long Term Services and Supports (LTSS) Task Force submit the following statement in response to last week’s hearing on “An Economy That Cares: The Importance of Home-Based Services.”

As has been clear since the beginning of the pandemic and has unfortunately been demonstrated over the last two years, people with disabilities are, and will continue to be, particularly at risk of COVID-19 infection, facing a high risk of complications and death if exposed to the virus, and needing to isolate themselves for protection.

As was discussed by several witnesses, it is imperative that Congress take steps to provide states with the resources they need in order to meet their obligation to ensure that, during and beyond this crisis, people with disabilities have the services and supports they need to live in the community. With federal support, states can take steps now to rebuild their workforce and expand the number of people with disabilities who are supported in their homes and communities, rather than being forced into congregate settings in violation of their rights and at risk to their health. Over the past two years, we have sent numerous letters from national and state organizations highlighting the urgent needs of the disability community and service systems, and specifically highlighting the need for dedicated funding for HCBS.

State HCBS programs face staff shortages due to sickness, self-isolation, childcare needs, low wages, and the fact that HCBS service workers have long been underpaid. These real challenges do not change states' obligations under the law, the rights of people with disabilities to live in the community, or the dangers posed by congregate settings. It is imperative that Congress pass a significant investment of dedicated HCBS funding --lives hang in the balance.

Several other programs support access to HCBS and limit the risk of unnecessary institutionalization, including the Money Follows the Person (MFP) program and HCBS Spousal Impoverishment Protections. We urge that these programs be included and made permanent in any package that seeks to address HCBS funding. The MFP program provides enhanced funding to states to help transition individuals who want to move out of institutional care and back to the community. This enhanced funding assists with the costs of transitioning people back to the community, including identifying and coordinating affordable and accessible housing and providing additional services and supports to make successful transitions. MFP has consistently led to positive outcomes for people with disabilities and older adults and shown cost-savings to states since it was passed with strong bi-partisan support in 2005. The Centers for Medicare & Medicaid Services (CMS) found an average cost savings of \$22,080 in the first year per older adult participant, \$21,396 for people with physical disabilities, and \$48,156 for people with intellectual disabilities.<sup>1</sup>

Additionally, Medicaid's "spousal impoverishment protections" make it possible for an individual who needs a nursing home level of care to qualify for Medicaid while allowing their spouse to retain a modest amount of income and resources. Since 1988, federal Medicaid law has required states to apply these protections to spouses of individuals receiving institutional long term services and supports (LTSS). This has helped ensure that the spouse who is not receiving LTSS can continue to pay for rent, food, and medication while the other spouse receives their needed care in a facility. Congress extended this protection to eligibility for HCBS in all states beginning in 2014, so that married couples have the same financial protections whether care is provided in a facility or in the community.

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<sup>1</sup> <https://www.medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf> (Page 11-12)

We once again thank you for your leadership and urge that you continue to include and prioritize the large investment in Medicaid HCBS, and the workforce that provides them, as you negotiate any package moving forward. We stand ready to assist you in any way we can. If you have any questions feel free to contact Nicole Jorwic, [nicole@caringacross.org](mailto:nicole@caringacross.org)

Julia Bascom,  
Autistic Self Advocacy Network

Dan Berland  
National Association of State Directors  
of Developmental Disabilities Services

Nicole Jorwic  
Caring Across Generations

Jennifer Lav  
National Health Law Program

Gelila Selassie  
Justice in Aging



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Hane A. Mogal

March 29, 2022



Senator Bob Casey  
Chairman  
U.S. Senate Special Committee on Aging

Senator Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging

Via email: [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

**RE: U.S. Senate Special Committee on Aging Hearing on "An Economy That Cares: The Importance of Home-Based Service" (March 23, 2022)**

I am writing this statement on behalf of the Older Adult Advocacy Taskforce in Miami-Dade County, Florida. The taskforce is a collaboration of more than twenty experts, providers, funders, and advocates working on issues of aging and older adults in Miami-Dade County. Since 2015, as a part of our convening role in Miami-Dade County, United Way Miami has facilitated the taskforce partnership. Partners have joined forces to identify and promote policy opportunities to address the growing level of unmet need among older adults (age sixty and older) in Miami-Dade County.

People are living longer, but traditional public investments in HCBS for older adults have not kept pace. As a result, older adults in our community are becoming increasingly marginalized. Because we are a community that values diversity and fairness, we know we can do better. When the taskforce began, the number of older adults left unserved on the waiting list for Medicaid Home and Community-Based Services (HCBS) in Miami-Dade County was several thousand, and already alarming at that level. Today, that waiting list has grown closer to 16,000 unserved older adults.

This trend is a grave concern of the taskforce – and not only because of what it means for the safety and well-being of older adults who live alone, or for the families struggling to continue working and making ends meet while simultaneously caring for children and an older adult. The taskforce is concerned because, in spite of the demographic data and projections available, we have not seen more policy initiatives on a scale to match the size and scope of unmet need and the realities of our shifting population.

From this context, I am extending the gratitude of our taskforce to you and to the U.S. Senate Special Committee on Aging ("the Committee") for hosting the March 23<sup>rd</sup> hearing. I am emphasizing our thanks to our Senators Rubio and Scott who are members of the Committee, and I have copied both on this letter. The testimony that was shared (including that from a HCBS recipient in Florida) highlighted the ongoing concerns of our taskforce. Among these are the need to: 1) increase resources for Medicaid HCBS in order to serve more people; 2) support family caregivers as an important part of community aging solutions; and 3) focus on addressing HCBS workforce issues. Note that even prior to the COVID-19 pandemic, local providers of HCBS shared that they could not find and retain staff; they could not compete with other industries where employers offered higher wages for jobs that came with far less responsibility, stress, and training required (e.g. jobs in the food industry and retail). Workforce issues intensified during the pandemic.

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The Committee's hearing was an admirable opportunity to raise visibility of critical issues, and it mirrored recent efforts of our taskforce. In July 2021, the taskforce and United Way Miami signed onto a [letter](#) (along with more than 400 other organizations, groups, and advocates in Florida). The letter was shared with Senators Rubio and Scott and other members of Florida's Congressional Delegation. It urged them to see the importance of supporting funding for Medicaid HCBS, and it emphasized HCBS programs as a much less expensive approach, compared to nursing facility care, for assisting low-income people that require assistance with basic activities of daily living.

Also in 2021, the taskforce began meeting with our congressional delegates and/or their staff in order to share how aging issues are playing out among their constituents in Miami-Dade County. We alerted them to three possibilities for 2021-2022 where the taskforce felt they had opportunities to press highly impactful policy advancements including: 1) the Better Care Better Jobs Act (BCBJA), 2) the Credit for Caring Act (CFCA), and 3) reauthorization of the Older Americans Act (OAA). We emphasized the BCBJA as a major opportunity to incentivize serious and lasting changes at the state level that would benefit current older adults and give Florida a leg-up on meeting the needs of future generations of older adults too.

The taskforce is committed to continuing to share with our elected leaders the aging experiences and issues bubbling up from our community. We are grateful that the March 23<sup>rd</sup> hearing has given us more information and understanding to be able to do so. We hope you will continue these invaluable endeavors of the Committee. At any time, feel free to reach me for more information.

Sincerely,

A handwritten signature in black ink, appearing to read "Linda Schotthoefer".

Linda Schotthoefer  
 Vice President of Community Initiatives  
 United Way Miami  
[SchotthoeferL@unitedwaymiami.org](mailto:SchotthoeferL@unitedwaymiami.org)  
 305-646-7081

Cc: Senator Marco Rubio, c/o Varela, Jaime (Rubio) [Jaime\\_Valera@rubio.senate.gov](mailto:Jaime_Valera@rubio.senate.gov)  
 Senator Rick Scott, c/o Honts, Jared (Scott) [jared\\_honts@rickscott.senate.gov](mailto:jared_honts@rickscott.senate.gov)

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Teresa McKeegan  
Teresa McKeegan

To the U.S. Senate Special Committee on Aging (from Suzanne Gracewski),

Please support this bill to simplify care giving for adults with disabilities.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Suzanne Gracewski

Without the supports of the HCBS, my two sons who are 30 & 34, would not be working, contributing to our community and to society as a whole. It is the supports through HCBS that have provided the tools that we as a family can not, for them to have a successful and meaning life. We are the lucky ones, so many are in need of these supports and there is currently not enough funding to meet the need.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!  
Darla Helt

I've worked with young adults (as a special education teacher) who are cognitively impaired. Some can enter the job market with support and many of them need a lot more services. I agree that there's a great need for health care, training opportunities and group housing subsidized by the gov. Everyone needs a chance for a fulfilling life. The young adult's parents are aging and some have health concerns of their own that make it unfeasible for them to care for and provide a safe home for them.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,  
Sue Bockelman

My name is Sarah & I have a 13 year old son who is autistic. I am unable to work because I have to care for him. We frequently go months at a time without respite care. It's difficult to find quality caregivers for the low rate they are paid. I worry for my son's future when I am no longer able to care for him. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!  
Sincerely,  
Sarah Howard

Thank you for taking the time to read my comments.

HCBS services is an integral part of my son's life. It allows him to live an incredibly different life than otherwise possible. Supported employment not only gives him a sense of purpose, self confidence and growth it provides him with an interactive experience of/with community and allows him to contribute to society in positive, productive ways. At the same time, equally important, it helps provide opportunities for others in the general population to interact with him and gain a broader understanding of persons in the IDD community.

Being paid as his parent/caregiver allows me to stay home and provide him with the best care and understanding that he needs twenty four hours a day.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Pamela van Marle

My daughter is 34 and lives on her own in her community where she friends, attends community events, volunteers, hosts her church bible study and looks for work. These services are critical for her to be able to continue to live the life she has forged for herself. Despite living with Cerebral Palsy and a cortical vision impairment she is an active and giving community member. Let's be sure she gets to continue doing that!

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely, Jennifer Newhouse

My 26 year old son, Tyler desperately wants to be in a Community based home but with the funding available now it's just not possible. It is critical to improve the funding for the HCBS so our children can live the lives they were meant to live. Thanks for your consideration.  
Liz Mckinnon

We are worried about how our non-verbal autistic son will live after he is done with school in the immediate future and in the long term after my husband and I are dead. Who will be there to help him? He is not able to do the typical daily tasks without supervision.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!  
Sonjia Henson

My 51yr old son lives in his own apt. with brief oversight for safety, health etc from caregivers, he is considered high functioning. These caregivers work an often unsafe, dirty (from human waste etc) long hours, thankless job for a very low wage. They are doing vital work and deserve great recognition and a living wage. Most caregivers in the Seattle area live far away from their clients and have long, undesirable commutes. Let's treat them with respect by giving them a suitable wage and benefits etc.  
Angela Dews

My adult daughter has intractable epilepsy and behavioral issues. She wanted to live on her own but can't because of her seizures. Without home and community-based services, she would be home-bound and would not be able to live independently but with help. She was fortunate to be able to get services and has caregivers to dispense her medication and that allow her to have access to her community. But these caregivers are underpaid and staffing shortages can impact her care. Without these critical services for people with disabilities, impacts how they can live, work, and access their community. Please adequately fund these vital services for all people with disabilities so they can live without barriers and realize their potential.  
Sandra Olson

My daughters age 18, my age 62, she's done with all the school supports....Now what? She need supports all through out her life....Now what? Community based services is what will keep her going- Please remember these services are needed for her daily life care, such as bathing, eating, taking medication, getting around to community functions, and daily life tasks, for those who are not challenge take for granted, such as daily bathroom skills/needs such as wiping and flushing and washing hands after. These are daily life skills, ones that always get forgotten about , that are essential for our children and adults who are challenged. Please do not forget about our children, even when the school bus stops coming to our home, most kids get forgotten, but we as aging parents still need to care for the adult children, that no longer go to school. Please vote to keep these essential services alive for those who are less fortunate. Thank you!  
Laurene Rusing

I am an elderly woman who depends on help to keep the independence that I do have of living in my own Apartment. Without the help I do receive I could face living in a nursing home, and that is something that I don't even wan to think about! With the help of a caregiver I can stay in my own place and be happy. I ask you to PLEASE see this issue through my eyes and how IMPORTANT it is to me and many, many, more like me.  
I do Thank you, ahead of time, for your supporting of people like me with disabilities.  
estrillita nelson

I am my adult daughter's care provider, she has DD & mental health issues, she relies on me for everything, from Sun-up to bedtime & I'm available around the clock if she needs care-doesn't feel well, nightmares, yet her allocated hours keep her & I below poverty level existence. As a senior myself, I do not know that treed will be adequate/appropriate services or placements for "out of home", when I can't do this anymore. She needs with all skills of ADL. You need to realize how demanding this is & with aging parents, what is to happen to them with out better HCBS NOW!! Help my daughter & others like her.  
People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,  
Donna Godfrey

My adult daughter has Autism and relies on her community based services to live independently in the community. Without these supports I don't think she would be alive today and she is only 42. I don't believe we should call the US a civilized country if we can't take care of those in need and less fortunate than the rest of us. Please support these life preserving services for those who need them!

Peggy Cobb

My daughter is 26 years old and has cerebral palsy. She is unable to dress, feed, or get herself out of bed without help. She graduated Summa Cum Laude from NC State University in 2017 with degrees in Political Science and Nonprofit Management and Accounting. She has lived interdependently utilizing a combination of roommates and direct support professionals since she went to college. Without home and community based supports she would either still be living at home with her parents or in an institution. Not only is having her live in her own home cheaper but it also allows her as typical a life as she can achieve. There is a direct support professional crisis right now that has made getting workers to fill this important role in society almost impossible. There are also as many people on the waitlist for waiver services in North Carolina than are currently receiving it...over 10,000! I know that my family would have imploded had we not received a CAP slot when my daughter was young. Please do everything to increase access and the quality of home and community based supports.

Sincerely,  
Sandy McMillan,

Dear Committee Members,

I am a 70-year-old quadriplegic (52 years post injury). Along with aging comes more problems with basic health needs such as skincare, breathing, and energy. All of these problems are byproducts of aging but many of these byproducts can be ameliorated with the assistance of good Personal Care Assistant. Massachusetts has a generous (compared to other states) reimbursement rate of \$17.71. However, at that rate I've had ads running for months without a capable person responding. In order to keep people with disabilities in their homes living independently and healthy a solid set of home care based services (HCBS) has to be developed. It's impossible to get good help as we pay little more than what an adolescent can earn working at Burger King. There's no incentive for anyone to become a Personal Care Assistant.

The path we are currently following will certainly lead to many of us being housed in nursing homes or long-term care facilities. We know from our personal experiences and anecdotal evidence this is a death sentence. We will be refusing people with disabilities the right to remain in their home, lived with their families, and participate in community life. It's against the law and is an immoral as we travel. That's not living-- that's just existing. We could say the same about a houseplant. Please don't turn us into Spider Plants.

Sincerely,  
Joeseeph Tringali



Thank you for reading my story. My son is 33yrs old. He had a liver transplant 30 yrs. ago. He also lives with Smith-Magenis Syndrome, a difficult behavioral syndrome.

He has lived in an AFH, and Residential Supportive Supports in years past, but needed to move home after he became ill in 2020. He needed to recover from pneumonia, it took a good month.

So, he moved home with his dad and me. We both are retired, and living on SS. My son has been needing more medical care as he ages, liver and heart mostly now. He will need more nursing care, or really, really good staff that can know how to support him.

I am resigned to finding an assisted living support for his needs. That is what he is assessed for, and because we have had the past experience with AFH, and RES, and with staff that were remarkable, but with other issues pertaining to training. My son did have to go to the ER a few times due to illness and medication issues. Because he cannot communicate his needs, it takes time and nursing training to see the underlying issues that he presents with.

Because of needs, and because of the nursing care he will need eventually, how can AFH be able to care for higher need residence? I hope that someday, the senior living business will provide care for those with IDD. Most of them don't. Why does the Senior and Disability not include a Developmental Disability office under their oversight? Most of the nursing facilities mention that they need specific licensing for that support- and then others don't. It's confusing for me because I've been there. I now need senior services for my 33 yr. old. One idea I have is to contract with assisted living more, provide training on their site, which allow more beds to be for Medicaid, and with DDA funding too. There has to be a better way. I am grateful that I can share my story. I would like to learn more about what the possibilities are as we move forward!

Mary Monroe

My name is Steve Grammer from Roanoke, VA. I was born with Cerebral Palsy, and I was forced to live in a nursing home at the age of twenty-two when my mother became ill and could no longer take care of me. There were no other options available to me. I lived on the Alzheimers unit at the nursing home for 9 long years until I was finally able to get a DD Waiver. Now I live on my own, in the community with supports, however the supports I have do not cover all of my needs. That is why fully funding HCBS is so important for me and other just like me. I struggle daily finding and keeping Caregivers. Not having Caregivers would force me back into an institution, which is a violation of my ADA right. Caregivers are paid very low by the state and are not offered benefits by the state. They should be paid within the 75th percentile and offered full medical benefits.

Again, I'm asking to fully support HCBS to allow people with disabilities to live in the least restrictive environment possible and have a life like yours!

Thank you for your time and consideration!

Steve Grammar

Dear President Biden,

The reason I want this bill to pass because community-based services with mean people living in their own homes instead of living in institutions I hope you can pass this bill some more people can have a choice where they could live in the community and please reduce the waiting list I am a person is totally blind I'm advocating so I could be able to live at home with my family instead of going to the facility or nursing home or a Groupon I have been on the lesson taxes since 2008 and I've been waiting for 14

years for services what services would mean to me is having a personal care attendant and the service is getting better and please pass this bill so the staff can get paid in the right amount and so the staff won't have any more high turnover this is a big crisis this is really important to me and other people in the disability community I really want this to pass because that way people could have freedom to live wherever they want instead of a nursing home group home or a big institution I think it's time to add funding for a community-based care very important to pass this bill thanks for reading my story I hope this will make an impact on your decisions that you make in Congress

Sincerely Linda Trongone

Dear Committee,

People are being placed in institutions if they pay more for community care it will be more freedom and people able to choose where they live i'm hoping this will all pass that was I could get rid of the waiting list I've been on the bus since 2008 I've been waiting for 14 years in Texas if you pass this! I'd be very important that way more people with this build is common in the community choice really big impact of the pastors though that I have a live at home with my family and friends instead of an institution and pay the direct care staff more money that way they could stay and help the clients better and that's really important to me thanks for reading my story hopefully we'll make a impact on the way home thanks

Sincerely Linda Trongone from San Antonio Texas

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I have 3 adults with autism who use this services and the workers are never trained proper and often do. It understand the disability due to low wages and no benefits they level of people who apply for these jobs are unskilled and often uneducated. Funds to increase the training of workers is necessary to help possibly get these disabled adults into some kind of work but if the workers are unable to teacher them to bath or cook or do chores then a job is likely not gonna happen.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Wendy Swartz

Dear Committee,

My daughter, Sydney (aged 22) has autism and a rare genetic syndrome called Coffin Siris Syndrome. She relies on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. After high school, it is even more important that she received these vital supports. Individuals with disabilities took a HUGE hit with COVID because of lack of services and lack of staff.

There isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. My daughter waited almost 14 years to get services. My daughter, like many other individuals with disabilities rely on staff that they have built relationships with to assist them.

Direct care workers are severely underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. Because of this, I, along with other family members, have had to fill in the gap to provide supports to my daughter. It definitely takes a village with her and my village is disappearing.

Please invest in this funding so that people like my daughter can get the support she needs, but can also learn to be a part of the community by working, volunteering, and doing community service. She has a great support system at home and will never live in an institution, but HCBS support is critical to her and our family.

I would be happy to introduce you to a group of individuals and their parents in Columbus, IN who have been severely impacted by lack of supports - so much so that we started our own day program for adults with disabilities. Or if you wish, come and meet our sweet Sydney!

Regards,  
Heather Baker

Dear Committee,  
My 24-year-old daughter has been on waiting lists for HCBS since 2001. I pray that I live to see her will find placement in an HCS group home. Please provide funding for more HCBS for people like her.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Regards,  
Karen Scheinbaum

Dear Committee,

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

One of the US' most vulnerable populations should not be without these basic supports. High turnover in direct support providers can be dehumanizing to people receiving services. Reasonable pay for DSPs would create stability in the system and people's lives.

Regards,  
Alexis Reed

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

We want programs to reopen and stay open so that disabled people have place to go to  
But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Nancy Esparza

Dear Committee,

My son Morgan Dooley has lived a HCS group home. We live in Texas and for the last 3 sessions in Texas we have cut money from HCS services. During the Pandemic it has been very hard to get people to work. I do know some staff that has not gotten a day off since Christmas. I'm getting older and I do not feel safe with what we have in place. Please understand what we need to help people in the community. There needs to be more accountability and understanding how to make this better. Please understand we love our children but we won't live forever. Mom of a very sweet young man Morgan

Regards,  
Michelle Dooley

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Their agent committed the reason why I want to pass the services bill because it would be better for people with disabilities to live at home instead of an institution I think it's about time they find community care because it gives people more choices and freedom and they can live in our homes are their families

And also so it would be less expensive than living in an institution I think it would be a good thing to pass community care so people can live where they want to live and I enjoy living with my family and friends I feel like I get more freedom when I'm at home for us as an institution please pass this bill and get rid of all the waiting list some more people to get services in their communities I'm a person with a disability from Texas I've been waiting 14 years get on a Medicaid waiver in Texas I've been on the list since 2008 for me having services on me more freedom and independence and that way I could stay in my home with my family

Thanks for hearing my story! Please pass this bill some more people with disabilities can live at home

Regards,  
Linda trongone

Dear Committee,

The reason why I want to pass this bill because it's better for people disabilities to live in that community instead of institutions! i'm a person with a disability home and community based services with me living in my home with my family and friends instead of getting placed in an institution please pass this bill so we can get rid of the waiting list and that direct care staff can get paid more money this pillow is very important because that with people could live in dependent lives and I get our freedom instead of being segregated and institutions  
Thanks for hearing my story hopefully this can make an impact on your decision on passing this bill!

Sincerely Linda Trongone

Dear Committee,

My son is one of many people with disabilities who rely on home and community-based services (HCBS). He moved to a group home this fall after a delay due to staffing shortage and is thriving.

There isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Mindy Kruckenberg

Dear Committee,

As a parent/legal guardian of an adult in Resource Community, I wish to share that this system is very broken and needs your urgent help! Our daughter is desirous of independent living but there aren't enough resources, even through private pay if we were able, for her to live her very best life.

We use Link/Sycamore services to help w transportation for her job but they are not overly reliable & we too often have to rush and get her to her job. She has worked 6.5 yrs and has never missed a day of work unless it was prearranged. My experience w Resource Community is that they WANT to work and they WANT to be at work EVERY day! Options for full-time employment w benefits should be available which would allow MANY of them to come off of the government system and free up funds for those who need it!

This community of folks desire and actually deserve to be able to live independently and have reliable services/providers to care for them just as seniors and folks afflicted w dementia/Alzheimers! Many folks like our daughter need some oversight for their own protection. Not everyone afflicted needs full-on physical or medical assistance. The CIH and FSW waivers are way too far apart; meaning FSW waiver doesn't offer enough for full independence and CIH waiver requires too many unfortunate & desperate circumstances.

We have been and will continue to seek fully independent residence with proper supports for our daughter! But things must change! We will likely pass away before her (God willing) and the very best thing would be for her to have already been living independently which would allow for the least disruption to her routine and likely her grieving. If she lives w us until we die, she will not only lose her FT care-givers but also have to be uprooted from very important routines in her life! Our daughter presents much like Dustin Hoffman's character in the movie, Rainman. We want to do all of the very best things for her including minimizing her distress at the times of our passing!! We also wish to assist her in living her very best life while we are alive in allowing her to have a place of her own like her non-afflicted peers! It is completely disheartening to say the least, especially since we are 100% willing to help her achieve this goal!

Housing and transportation options along w proper funding assistance and wages for proper/QUALIFIED caretakers must be addressed as well as incentives for employers to WANT to hire them and make proper arrangements for the needed guidance for these very willing folks! They want to 'belong' and be accepted just like everyone else!

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
April Elmore

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

I have worked in this field for over 15 years. Trust me, I am not in it for the money. I am all in for the people we support and them living meaningful and fulfilled lives. It is heartbreaking to know that there are people out there that are on waiting lists for living quality lifestyles. Everyone deserves the opportunity to have support when needed. Everyone deserves to be treated with dignity and respect. Everyone deserves an opportunity to live a dignifying life like yours.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to

high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Amber Thompson

Dear Committee,

People with disabilities, like my son Brian, rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

Brian, who has autism, will be 28 next week. He's a determined young man. Despite his challenges, he wants to graduate with his degree from a 4-year college and is now in his senior year. He only has one hour of support each week (due to a lack of staff), but he needs assistance with transportation, medication management, groceries, apartment cleaning, and socialization. HCBS can help adults like Brian be more independent so they'll eventually need fewer supports. That's Brian's goal, and he's getting there with what is really a patchwork of supports--including that one hour from an agency near his university.

As his parents (aging parents at that), we're hopeful that he'll be able to live and work in a community with some support to live his best life. To make that happen and ensure his success, we need you to recognize how invaluable and even cost-effective HCBS can be. It's also important that Congress make HCBS portable, so that individuals with disabilities don't need to start over again at the bottom of a waiting list if they need to move from one state to another to be closer to family.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means people with disabilities are staying at home, missing opportunities to live, work, and participate in their chance communities. Often, it means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Anne Higley



Dear Committee,

My daughter is now 54 years old. She is autistic, and cognitively disabled, has almost no speech, has very poor balance, must have food ground, and is prone to pneumonia. After living at home, in a short time facility, a traditional facility, she began placement in community waiver homes of varying conditions until she arrived at her present residence, a facility that has worked hard to find a way to not only communicate with her and get her opinions but to help her find ways to help them. She feels she has friends and a life to look forward to. However, I was notified today that another residence in this agency was forced to close. Lack of staffing along with increasing costs have shrunk the population sharply. Cathy now has a new roommate and probably a high percentage of new staff. The few original staff have done an amazing job in acclimating new employees to her needs and understanding how to become trusted by her. But the place is shrinking and I worry that they may not be able to care for her much longer. We have waiting lists of people who need these services and instead these homes are closing. I feel guilty and grateful that so far she is being served. I am in my late eighties and must find a home without stairs and I must stay as close as I can to her.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community.

Regards,  
Darla Chafin

Dear Committee,  
Many people with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. My 40 year old disabled (from birth) daughter is one of them.  
We have been richly blessed by these services for help that we can't provide. My daughter would need more help if she did not have me and family members who are able to help her.

There isn't enough money in the HCBS program to support everyone. Because my daughter has family who are able to help she gets by well. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions where quality of life is poor.

Regards,  
Stevi Carlson

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I am disabled and I need my workers to help me every day Please don't stop my help God love

Regards,  
Molly VanNorman

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My adult son with autism has been living in the community for years. He has been thriving. He rents a small house and has learned to handle the upkeep both inside and outside of the house. He has learned how to be a good neighbor and made friends in the neighborhood.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Maria Krause

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. Our adult daughter, age 37, was living in the community with a roommate for 10 before we brought her home when Covid started. Now we are hoping to get her back on her own in a nearby apartment with direct care staff so that she can continue to feel she is building her own life with dignity.

Direct care workers are dramatically underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. We are blessed to have staff who have worked with our daughter for many years. They are devoted, but its inconceivable that they can't have a decent standard of living for the heartfelt and critically-important work they do for vulnerable people.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Donna Raphael

Dear Committee,

Why I do what I do.

I have the honor of caring for and working with autistic fraternal twin brothers. They do not talk. I have to admit I had no idea how I would communicate with them when I first started. The one thing I did know is they enjoy eating. They have a bin of sensory items that one in particular bears down on. One day while one of the brothers was sitting at the kitchen table, like he usually does, I placed a cow and pig figurine in front of him. I said "John, would you like beef or pork for dinner?" He put the pig in his mouth. This one simple step led to my understanding of how much they understand. I have worked with them going on four years. The things they have taught me are priceless. Patience. Tolerance. Humility. Love. The roles we play are priceless. Parent. Teacher. Nurse. Why are we not compensated fairly? Please consider raising the wage so we do not have to struggle to care for those who struggle.

Thank you, Jennifer Fahey

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to

high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

People of all abilities are making my community a nicer place. It is time to offer enough support for all people with disabilities to live in communities with good accessible housing and employment opportunities. Thank you for listening.

Regards,  
Marci Whiteman

Dear Committee,

People with autism and other disabilities are individuals who rely on home and community-based services (HCBS) for everyday supports, getting around in their community, safety support, dressing, bathing, taking medication, grocery shopping, meal preparation and so much more.

Direct care providers are grossly underpaid with expectations to possess and provide high levels of quality care. This incongruent expectation quickly leads to high turnover rates, critical staffing shortages, and ultimately compromised care for many people with disabilities — often placing these individuals at severe risk. All too often, this means unpaid and exhausted family caregivers are filling gaps in care.

It is our social responsibility to properly care for our most vulnerable citizens.

Please support a historic investment in disability funding, so everyone can get the support they require to live in their chosen community - instead of segregated in institutions.

Please take a moment to deeply reflect on the social and moral obligations we owe to those less fortunate than others. And remember, they are members of loving families who have devoted endless support, care, and many sleepless nights in anguish and worry. Do the right thing, take a stand, and raise the bar for social and moral integrity. Thank you.

Regards,  
Pam Pendleton

Dear Committee,

I am a mother to an inspiring young man with disabilities. My son needs the nursing care that he receives through HCBS services. If it wasn't for nurses that help care for Luke in our home, he would be spending alot more time in the hospital! The help I get to care for my son allows me to get things done around the house, it allows me to have time to breathe and recharge so that I can be the best mother I can be for him. 24 hour a day care is exhausting and I can't tell you how very grateful I am to have the

help for my son so that he does not have to stay in a facility, he can be at home where he belongs. People with disabilities, like my son, rely on home and community-based services (HCBS) for everything from personal care to giving medications and doing lung assessments or performing suctioning to keep his lungs clear. Many times he does not get enough hours covered due to the provider crisis we are experiencing.

My plea to you is to ensure there is enough money in the HCBS program to improve the MASSIVE provider shortage going on in our country. Home care nurses and Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means family caregivers, like me, are not able to find nurses to fill the shifts that my son has been approved for. This leads to exhaustion for caregivers like myself and many of my friends.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Thank you for listening!

Regards,  
Kim Musgrave

Dear Committee,

My friend is helping me with daily tasks while I work on getting a home health aide. My ability to safely stay in my own home without burdening my friend depends on whether Congress fully funds community based services.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Nicholas Faby

Dear Committee,

Thousands of Individuals with disabilities rely on home and community-based services (HCBS) for everyday living.

HOWEVER, ENORMOUS AMOUNTS OF FEDERAL FUNDS ARE SIPHONED OFF ANNUALLY TO PROVIDER AND COMMUNITY ADVOCACY ORGANIZATION'S SIX FIGURE INCOME SALARIES. AS A RESULT OF THIS SIPHONING, thousands of DD individuals are stuck on waiting lists, not receiving services critical for their care.

Direct care workers HAVE BEEN UNDERPAID FOR DECADES, yet largely IGNORED BY DD advocacy groups - leading to high turnover, critical staffing shortages, and compromised care for many people with disabilities. The Arc organization is one of many well funded entities who access millions of dollars annually, while unpaid family caregivers continue to shoulder 24-7 caregiving. Comprehensive legislative audits are critical in uncovering the alarming and blatant misuse of FEDERALLY ALLOCATED HCBS funds.

Submit your message  
Send Email

Regards,  
Leon Kelley

Dear Committee,

We cannot imagine raising our son with Down Syndrome (and significant congenital defects) without the help of the various waivers that have supported his care and us in caring for him up till now (he's 26). We would have had a very bleak couple of decades & counting financially and otherwise, on top of emotional exhaustion. We will be caring for our son till death do us part. Please fund HCBS generously enough so that no families raising loved ones with significant disabilities are left unsupported. This is one of the many measures of a civilized country.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Julie Hauf

Dear Committee,

Until I had a few accidents riding public transit, I didn't realize how much I might need such services. They do great work and deserve more funding.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Kim Osborn

Dear Committee,

This is a personal appeal from someone who ESCAPED to Home & Community-Based Services from an institutional setting.

I have lived independently with supports for twenty years, but without those supports I might not even be here. The facility where I had been living before made multiple attempts to trick doctors into drugging me into a more pliable state -- because I was 'difficult' due to my 'grandiose' requests such as being allowed to pour milk in my own cereal rather than having it sit getting soggy for 5-10 minutes before residents were allowed into the facility's dining room. I had life, but neither liberty nor the pursuit of happiness.

Many thousands more Americans who could live independently are, as you read this, being stopped solely by the lack of HCBS and/or appropriate housing. I urge you to increase funding for these life-altering, and often life-SAVING, programs.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community -- instead of in institutions.

Regards,  
Jaccorbeau Terrone

Dear Committee,

My son is only able to live in his community and enjoy community activities because he lives in a group home that supports his high level of basic daily needs. It is the only model in our state that works for him. Because waitlists are so long and the funding stream does not cross state borders. If he were to lose access to the group home model, he couldn't just move to another state. I don't know what we would do to support his daily life.

Many people do not realize how much the HCBS waiver is the often the only resource allowing people with intellectual/developmental disabilities to lead full lives.

The HCBS is underfunded leaving almost 2,000 people on one of the waiting lists in our state. The workforce shortage and low pay rate has caused 30 group homes to close in our state in the last few years.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. It will keep my son in his community. I can't imagine it any other way. - Thank you

Regards,  
Kim Humphrey

Dear Committee,

I am a minister, and many of my congregation members are elderly and/or disabled. They rely on on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. With home and community services, they can live independently or with their families. Without it, they end up in institutions. Institutions cost more to them and to society, and they are also not as good to live in as your own home. Why are we accepting a situation that is worse for disabled people and costs everyone more? It is cruel and wasteful. We need better home and community-based services.

Currently, there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the help they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. I know so many family members of elderly and disabled people who are worn out and at their wits end. It is not sustainable,



they need help. We need better (and better-funded) HCBS.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Anna Haugen

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My 30 year old son has significant disabilities and lives at home, but goes to a Dayhab program through Home and Community Based Services. This program has always had staff shortages, but it is critical now. This is caused because direct care staff are very underpaid and overworked. My husband is 72 & I am 69, so my son will need to go to a group home some day to live, but I could not trust them to properly care for him with the staffing problems now. He was on a waiting list for 8 years to get services. Please appropriate funds for this much needed program!

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Donna Landry

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My daughter is participating in the home and community based services program. Her continued participation is threatened by the crisis of a lack of qualified direct care workers. Finding and keeping direct care workers has always been a challenge but since the pandemic it has been impossible. There is

not only constant turnover in staff but a significant lack of training among those who are working in this capacity. We live in Michigan which offered a \$2.35 increase in pay since the pandemic in a effort to increase the workforce that increased hourly rates to \$12.35 - \$13.85. But four years ago our experience was trained direct care workers were refusing to even interview for a position that paid less than \$15.00 an hour. Now there are fast food and retail businesses offering starting pay of \$18 - \$20 an hour. It is impossible to compete. My daughter again has to rely on her parents for assistance and is watching her dreams of independence and a career that she spent years preparing for disappear. Without support for the services needed it will be impossible to participate in the home and community based programs. The promise of independence, employment and community participation will become empty promises.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Carole Vennema

Dear Committee,

My adult disabled child has been stuck on a waiting list since 2001. Please help get her services.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Karen Scheinbaum

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All

too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Rural areas, in particular, lack even more access to HCBS and when they are available, they are extremely limited in terms of accessibility, they lack the necessary resources and workforce to support individuals with disabilities in their communities, and often lack the cultural responsiveness to appropriately and effectively support individuals in their homes and communities.

My family's experience is no different. I have provided supports for family members the last 13+ years and have not been able to work, or start and foster my own career despite having a masters degree in Forensic Psychology and years worth of advocacy and government relations experience as a result of navigating multiple systems at the local, state and federal level.

I am concerned that once our youth becomes an adult I will still have to provide most of the supports for him, because of the lack of supports, resources and services the movement for deinstitutionalization promised and also envisioned by President Kennedy's Community Mental Health Act of 1963 would provide.

While I see consistent movement towards and willingness to provide accessible and culturally responsive home and community-based services for individuals with disabilities, I also see a lot of despair and exhaustion on behalf of those providing these services as they are overworked, tired, and lack the appropriate level of resources to provide these services.

The consensus usually is:

"We would love to support every individual with disabilities and provide them with the level and types of services necessary and are culturally responsive for them to live and function independently within our community, BUT we don't have the money, the people, or overall resources to do this"

I ask you, as a parent and community advocate, please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Regards,  
Alisha Overstreet

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My 28 year old daughter with autism has been on the Texas waiting list for HCS services for 13 years. She requires assistance with all aspects of daily living, which makes it a challenge for me to work. I am her only caregiver. Please do what you can to help this vulnerable population of citizens. It is the right thing to do for them.

Regards,  
Caroline Deisze

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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While we need this, we also need accountability for where this funding goes. My daughter is in a very much needed DD system. The caregiver when you consider that it is tax free, makes more money than I do as a teacher of many, many years. Yet, I still do a lot of the caregiving instead of the Host Home provider. It is becoming a racket because there is no accountability in place to ensure that these people are actually doing their job. We need these homes we with the Host Home is very badly. It would be nice if they had to be licensed like daycare providers and there was some way for guardians and parents to ensure that their family members were getting the care they need and as agreed-upon in their plan.

We are going through Dora because a lot of people have even died in these homes. Dora wants proof and yet my daughters last home was deemed abusive by APS and I get nothing to show that so how do I prove this to get this to happen in an already broken and messy system. I am a teacher and I'm out there doing my job yet the people that are behind this money or still using Covid to not be in the homes at all. Even then they're not in very much and nobody has any teeth to ensure that people do what they are saying they are doing or that they say are supposed to be doing. All too often when the person using these services complain they are basically called a liar and forced to live in poor conditions. The other alternative is up in the streets. People do not understand how many of the homeless are in need of these services but can I get them.

It is a good and much-needed thing that is missing two important pieces - funding and accountability for the huge amount of money being put out for these services.

It would be also nice if it wasn't looked at so much as a business but as a service. If I want to become a positive take care of the needs of my daughter, it is unreal paperwork and the constant stuff I need to go through that actually doesn't do anything as to the actual care of my daughter. The premise is that I must become a small business I maintain all of those regulations when is actually the care of my own child that needs to be in a Host Home for reasons that I would be very happy to explain (long story).

I won't be around forever to be able to ensure her care and I'm really hoping the system improves before that happens.

Thank you for your consideration in this matter.

(FYI) my title is Ms. but it wasn't working right to give me choices and I couldn't send without something. Mrs. Showed up and I took it since o couldn't get a drop down or a way to type in the spot. How many are not able to send this in because of this error. I do hope you read this and fix it.)  
Carrie

Regards,  
Carrie Gagnon

Dear Congress,

The life of a parent to a disabled child/adult is filled with anxiety, instability, financial issues, inability to work full-time, constant research and moving to find a better place that offers supports. My son turns 22 on May 11th and on that date he will no longer have anywhere to go during the day. He went into a summer day program last year that lasted maybe 6 weeks, then they shutdown. Now he is on a waitlist. Just a quick background, he has low functioning Autism, nonverbal and has experienced a life in/out of group homes since age 9. 3/4 of the homes were not, to say the least, staffed with caring, loving individuals. I pulled him from his last group home in July 2019, due to an assault from another resident, while staff slept.

To my point, our country needs funding for quality HCBS; when our children with disabilities get older, parents are getting even older. In most of our states, parents are not able to work full-time jobs while managing their adult child 24/7. Some states offer parents to be the "Host Home Provider" and receive financial support, as long as they do not remain the legal guardian; which makes no sense to me at all, why can't I be my son's Guardian and receive financial compensation; yet, states will pay strangers to care for someone else's child? Where's the logic in this? We will be moving, yet again, back to the East Coast in order to find more support for my son; he will likely have to go back into a group home as my husband and I are getting older and there are more day programs available back east. The biggest problem with moving from state to state is starting over and going back on a waitlist for medwaiver. Medwaiver, I believe should transfer from state to state and not make individual's with disabilities have to start all over again. But our other children are east and we will have to rely on them as well until he can get into a group home that we trust and a day program, which could take several years. I am my son's host home provider in Nevada, which has been a huge support; he's on medwaiver, and fortunately I am in a career that is always in high demand (special ed teacher), so my district was able to keep me on as a contracted part time teacher. But the bottom line, is families to profoundly autistic children are constantly asking, what next? what now for my child? How do I make a living? How can I get a break? It's constant change for families like mine. It's constant anxiety. My son is 6' tall and 195 lbs

now and although he has come a LONG LONG way since his tantrumming days and headbanging in public, he still squawks and screams and hits his head with his wrist and so my anxiety level goes up when I'm with him 1:1 in public. There is so much wrong in the system from funding needed for individuals like my son for day programming and group homes; he enjoys getting out of the house and going in the car, being with other individuals, and needs a purpose even if it's going to a recreational/social day program because this gives meaning to his life. When he's home full-time (on school breaks), his anxiety levels go up, his old self-injurious behaviors increase and that's not a good situation for either of us, which sometimes make me feel like he needs to be in a group home again where staff can take turns with him. Here, it's basically just me who cares for him 24/7. Group home staff need to be treated as professionals; better trained/quality staff members and the pay needs to improve a great deal in order to keep good staff.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Leanne Ingram

Dear Committee,  
I would like to start with not everyone that needs this service is registered. Therefore, the money you think you may need to support this is only for the people that have been able to complete applications and/or have faith in a system that will protect their child. There is work to be done and part of that is increasing funding. That is just part, the other part is reviewing options and creating additional supportive choices that reflect the needs of the community. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Regards,  
Sarah Worthington

Dear Committee,

“THE TRUE VALUE OF ANY SOCIETY IS MEASURED BY HOW IT TREATS ITS MOST VULNERABLE MEMBERS.”

Why is this such a problem in the United States, the richest country on earth? This should be a done deal, non-partisan and why are we even talking about funding when it's a human right in the United States? This should be funded in full, with an automatic inflation clause.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Regards,  
Helen Cunningham

Dear Committee,  
I take care of my 30 year old son, who suffered a brain injury, at home. I need a lot more help and am aging quickly. What will happen to my son when I'm gone?

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Cristy Laier

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I have worked in this field for almost 20 years. While finding qualified staff has been difficult for a number of years, I have never seen a staffing crisis like we are in now (and I worry that it could get worse). I oversee a day program for people with developmental disabilities and we are greatly understaffed, to the point that we are only able to support a small fraction of the people who want services and less often than they want. My staff are also covering at a residence due to short staffing which further spreads our resources. The level of difficulty in finding staff has increased tremendously, applications come in few and far between and often people want higher salaries than we are able to offer and they end up finding a job somewhere else. Without staffing, we cannot give the people the services that they need. Please help support HCBS services and living wages for the people who do this important job.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Sue-Anne Cocks

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. My loved one is schizophrenic. He's been waiting for housing for 2 years. Any kind of housing! I work less to care for him. My state would pay me to care for him....if he were elderly. It is emotionally draining to care for a loved



one with schizophrenia. He doesn't have the mental stability to be a real friend to me. If he wasn't ill, I'd have kicked him out long ago. But his illness is why he's like this, so I continue protecting him from homelessness.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions or worse, prison.

Regards,  
Heather Turnage

Dear Committee,

I have two sons with autism. Age 26 and 30. One is able to work and live on his own. The other one will always need to live with assistance. We have a dire need for housing for people who want independence and only need supervision. Not group home settings. Independent living settings for people with Autism. I worry every day of what will happen to my son when I die? Will he live on the street will someone be kind enough to help him out for free? Will someone abuse him or take advantage of him?

HELP

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Michelle MacAfee

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. My daughter is one such individual who lives in a 24-hour supported home. Staffing her home with direct care workers is the biggest challenge.

The current pay rate for direct care workers is so low that it is hard to find competent people. Also, once someone is hired they rarely stay long because they do not make a living wage. There have been days and weeks when the staffing agency had no staff and my daughter was disappointed to be forced to

leave her residence and move home. She is part of a most vulnerable population that needs consistent, stable, quality care.

Funding must be increased to pay direct care workers more. They also need specialized training in disabilities and behaviors to understand the population better. Providing direct care is an important job and deserves appropriate compensation.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community.

Regards,  
Karen Hasler

Dear Committee,

People with disabilities, like my adult son Zachary, rely on home and community-based services (HCBS) for everyday things like behavioral and vocational supports, getting around the community, having an advocate who can communicate their needs in a variety of settings and ensure their safety, dressing, bathing, taking medication, being able to enjoy recreational experiences, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are woefully underpaid, which leads to high turnover, critical staffing shortages, and unstable and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care, often risking their own jobs and the family's financial stability.

Please support a historic investment in disability funding, so everyone can get the support they need to enjoy the best possible quality of life and fulfill their potential in their own community - instead of in institutions.

Regards,  
Tracy Bodnar

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. My son was in an institution for a few years. He only stayed 4 nights a week, and I picked if up and he came home. He was home for 4 months in the summer. It was a very heartbreaking time for my family. He could not go to a school in town and he needed the help to learn. This was my only option doing what was best for him not us. I do not to go that route again after 61 years of fighting for him. He his very involved in the community and was given the honor of Assistant Fire Chief of our local Fire Department. Thank you for your consideration in this matter.

Regards,  
Kay Pullen

Dear Committee,

People with disabilities rely on home and community-based services (HCBS)  
My daughter Daisy is living on her own and saving the government a ton of money by not being placed in a group home. Without HCSB she would not be able to continue and would be forced to use much high cost services. Additionally, these services allow her to participate in community activities and join the work force ( and pay taxes ).. which I believe is a critical long term goal of people with disabilities. But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Marian Desimone

Dear Committee,  
Home and Community Based Services (HCBS) allow people with disabilities to fully participate in their communities - to live, to go to school, to work, to shop, to worship - at a much lower cost than living in an institutional setting.

But there isn't enough money in the HCBS program to support everyone. Too many people are not getting the services they need. People with disabilities do not have needed access to personal care attendants, ramps and home modifications, assistive technologies, access to health care, income supports or opportunities to work.

Please support a historic investment in disability funding, so everyone can get the support they need to live and work in their community, and unnecessary institutional spending is reduced.

Regards,  
Brenda Foreman

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My son has Williams Syndrome, and our family relies on help from our local community programs for him. With out these great programs our son wouldn't be receiving the caring support he requires to live life to his fullest potential.

Regards,  
Leah Dusing

Dear Committee,

I implore to you include home and community based services in any budget, regardless.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Philip Aydinian

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, links to safe people that can be trusted, getting around the community, dressing, bathing, taking medication, help organizing personal papers, and much more.

More advocates connected in a group living setting could help SO many. This setting was needed for my grandmother. My 80 year old mother, myself being disabled, and even my 19 year old nephew who lives with SBB could benefit from this. I was excited to see this was a topic up for discussion.

Let's create something new moving forward. Consider nonprofits or foundations to help with funding. 1 large home in 1 town at a time is a great starting point. Perhaps a new position for Social Worker in Home Operations could be created.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community.

Regards,  
Dawn Liljenberg

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. my daughter is one of these people she is bed ridden there are weeks she does not get to bath or change her bedding. She cannot cook so she is limited on her diet and even with her skills on the computer, she creates book covers and album covers she is not able because she cannot afford the means. Someone that could earn, but need help with food, cleaning her home and helping her stay clean as well as better equipment but non seems available for her so she lives in squaller.

Regards,  
Kindra Gillis

Dear Committee,

People with disabilities need there to be funds to support home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

Those who provide home and community services are so grossly underpaid that there is a shortage of workers. My own son's staff are too few and those who work with him put in many more hours to care for others who like my son would have no support if they didn't take on more clients. These workers Often have run down cars lack health insurance etc. while the Adminstration staff enjoy great salaries and benefits but never help out when their clients face dangers due to being short staffed. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please invest in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Michelle Ajamian

Dear Committee,

People with intellectual and developmental disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, inclusiveness within the community, life-sustaining activity of daily living skills (ADLS) (e.g. dressing, bathing, food preparation, feeding, transferring from bed to adaptive equipment, transportation to and from events/appointments, taking medication, and much more).

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are VASTLY underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means AGING and unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Joseph Mangio

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.\*\*\*\*\*

I am a senior, almost 70 years young.

My cerebral palsy was not diagnosed until my later teen years. I had many needs for medical and speech, and occupational therapy (that I did not receive) throughout my childhood. A new family doctor was the first to actually notice and direct me see to a neurologist. That office was far from home, so there was no continued follow-up.

My poor coordination, difficult speech, messy handwriting, and shaky limbs were impairments that the neurologist claimed would get better as I aged. During my twenties, my handwriting began to be fairly neat with much practice and slowness.

No one told me that my spastic cerebral palsy (although not further affecting the brain as I age), would be debilitating as I age.

My current neurologist is very helpful.

I have had occupational, physical, and vocal therapy. My voice-talking is sometimes difficult.

My husband and I are looking for a ground level place to live, as our condo has stairs.

We moved to an apartment that was managed so terribly that we moved back to our condo.

Thank You !

Regards,  
Rebecca Lyons

Dear Committee,

People with disabilities and their families rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

My husband is a disabled Viet Nam Veteran and we depend on the support of AHRC's residential program for our multiple handicapped daughter.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Patricia Hines

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

My husband and I are in our 70's & 60's respectively, and we are still supporting our adult son with disabilities. We need help as we are about to be fully on our own pensions and Social Security. We should be able to get help for our son, so he does not have to depend on us so much.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Denise Berry

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My son has severe autism, and will require the care of direct care workers for the rest of his life. These are amazing people who do the most difficult jobs, without commensurate compensation. They are hardworking, caring, and creative, and help my son live a life with dignity. Seems to me a society can be measured by the way it takes care of it's young, elderly, infirm, and disabled-the most vulnerable.



In order for this population to be cared for properly, their caregivers need to be compensated fairly. That is needed so they can live, not a life of luxury, just a life. Fair pay also encourages retention of good workers.

Ask any parent how grateful they are for their child's caregivers. They are like gold to us.

Living in an institution is not living, and it is a dreadful option. Please support our direct service providers, so they can support my son, and he can live a life with dignity.  
Thanks for listening.

Regards,  
Linda Mancuso

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. We need programs reopened so the disabled people have a place to go instead of staying home.

Regards,  
Nancy Esparza

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

My granddaughter would greatly benefit from living in a group home. She has a job and loves to interact with people, but she has cognitive delays that prohibit her from living alone.  
I totally support HCBS.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Diane Elmore

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. I know this to be true because I am the mother of two men with intellectual disabilities. One receives services at a group home and the other lives in an apartment. Neither would be able to thrive without this support.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. Many families worry about whether there will be care for their loved ones when they are gone. Without additional funding for this program, those worries remain.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Micki Coppel

Dear Committee,

I have a 14 year old son who will need Home and Community Services as an adult. My son, like other people with disabilities, relies on these services for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But, politicians have been coming for my son and other disabled people year after year with budget cuts, so much so that the percentage of homeless people with disabilities is growing. Disabled people are people, with all the rights of any other citizen. They deserve the care and respect of being citizens of this country, including support.

I am terrified about what will happen to my son, as do so many others, when I die or am disabled and can no longer care for him myself. The options are not what any parent would want for their child, and the waiting lists could leave him without necessary care for extended periods of time.

There simply isn't enough money in the HCBS program to support everyone. Too many people are stuck

on waiting lists and not getting the services they need. Direct care workers are grossly underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. As a mother, of course I will care for my child. However, in doing so, that means I have to give up my previous full-time professional employment. That results in another challenge for families with disabled children. That makes it near impossible for me to put away money for my child's future needs. Every way we turn, someone, some agency, some budget is taking money and services away from our kids who need it to simply survive.

WE ARE BETTER THAN THIS!!!!!!

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community.

Regards,  
Jennifer Johnson

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My son has had to go to a large institution for respite care. 170+ miles from where we live. He has a life in our community and should be able to live here and receive the care he needs

Regards,  
Sue Buchholz

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on

waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I have 2 children with high functioning autism. They may never be able to live on their own. They will need employment support, transportation and help with daily living.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Victoria Roeslein

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Having caregivers that take care of my son allows him to experience a level of independence similar to what young adults with no disabilities enjoy. Without that funding the alternative is institutional living - where there is little if no independence.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Paula Renfro

Dear Committee,

We have an adult son (age 53) with autism and related intellectual disabilities. He lives at home with us, his parents. For many years, he has received home and community-based services (HCBS) for employment support, and transportation to /from his work site. He is proud of his supported employment position (recycling crew at George Mason University) and to be a productive contributing member of the community.

We, his parents, are well into our retirement years, and are planning residential relocation to another state, to be near our son's sister and family who will assume oversight of his care and well being when

we no longer will be able to fulfill his care.

We are aware there isn't enough money in the HCBS program to support everyone. Too many individuals with special needs are stuck on waiting lists and not getting the services they need. We do not know whether our son will be eligible for residential housing should that become necessary in the next several years. This will become a critical need for all families who have a special needs family member who will need a residential placement that will provide a safe, stable, continuing quality of life.

Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to continue to live in their community, with assurance that residential service options will be available when it becomes a critical need.

Regards,  
Richard Schneider

Dear Committee,

People like my son are unable to live independently and parents like me worry everyday what will happen to their adult children when they die. Who will take care of them, who will keep them safe, and where will they live? Despite our best efforts to plan and save, the majority of us are in no position (financial or otherwise) to have an adequate and truly comprehensive "action plan" in place. Having a child with a disability, amongst it's many challenges. Is also incredibly expensive and makes saving for any kind of care after our death extremely difficult and, in all too many cases, virtually impossible. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Greg Masucci

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

The Olmstead Decision by the Supreme Court states the people with disabilities have the right to live in the community NOT institutions. More than 21 years later Congress and the states have yet to fully fund HCBS ordered by the Supreme Court.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Angela Gardner

Dear Committee,

Our daughter is ID/DD and autistic. For 20 years, she participated in a sheltered workshop. As you know the sheltered workshops were closed down by government orders. She was better off at a subminimum paying job than she is now: No paying job, trouble getting respite care which is so important to her and her 24/7-365 parents. She does get 2 hours a week of SCL which does get her out into the public sector - and that is because the staff is very good and knows her really well and can get her to do anything. Please support any possible help for the disabled. They have no means to fight the beauracy on their own.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Sharon Coffin

Dear Committee,

As a Person with a disability, I depend on in-home care. in-home and community-based services (HCBS) are vital for users to achieve Independence and physical autonomy, by offering everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

What it all means is people with disabilities are given a real chance to fully participate in society, the economy and real quality of life.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

The lack of respect shown to care workers through their wages also shows a lack of respect for the people needing the services care workers provide. People with disabilities WANT to participate in society, work, pay taxes, have LIVES. But when services are under funded, you show you DON'T want those things for them.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Janice Wallace

Dear Committee,

In the revealing light of COVID and the pre-existing caregiver crisis, I am writing to propose what I believe to be a better way to provide our most vulnerable citizens with the quality care they so desperately need.

My husband and I have been caring for our adult daughter, Mary Addison, for 28 years. She has had an active seizure disorder from birth. In the early years it was hundreds of seizures per day. After two brain surgeries, she got down to less than 20 grand mal seizures per day. She currently has four to six grand mal seizures per day. Not only have the seizures and surgeries given her lasting cognitive and physical deficits, but also, they have caused her many, many trips to the ER and lengthy hospital stays. Having a child (now adult) that requires that level of attention, it is nearly impossible to find affordable, reliable, skilled care. Waiver funds don't pay enough for skilled care (\$20+ per hour) and we are not allowed to pay waiver workers more than paid by Medicaid or we lose our benefits. So, the care provided by Medicaid is inadequate (for direct care service workers and families) for many reasons, but here are the most critical:

1. Low pay for direct care service workers means high turnover.
2. High turnover means a constant stream of strangers alone in my home with my daughter. We have been robbed numerous times and unskilled, non-dedicated workers have allowed accidents and unsafe situations.
3. High turnover means that I am only as reliable on my job as the service worker. If she doesn't show up

to her job, I can't show up to mine.

I was not able to fulfill my obligations at work and was asked to leave my job. I was never again able to work a full-time job that would pay enough to cover private pay quality care yet allow me the flexibility required to care for our daughter (to have to not go to work because my caregiver didn't show or quit, to race home for injuries, to stay with her in the hospital, etc. )

We were on waiting lists for years before we were able to get any funding/services through CLTC or ID/RD. Because of the very high level of her medical needs, the services for which we qualified still could not provide the reliable staff required to handle the challenges and allow me to go back to work.

So, I found myself:

- Out of work, dramatically reducing our income.
- Unable to find (and keep) work that would allow me to take time for the emergency and hospital care for our daughter
- Unable to find and afford skilled, reliable care so I could take (and keep) a job
- Unable to be paid to care for our daughter myself
- Unable to file for unemployment
- Unable to file for disability
- Yet being limited in my ability to earn a living by someone else's disabilities.
- When she became an adult, we had to pay to get guardianship of her so that we could make medical decisions on her behalf. Now, because we are her guardians, we are still not allowed to be paid to care for her.

As you can see, we have been caught in an impossible trap for 28 years.

Care for some (not all) aging Americans is different as there is usually some kind of retirement funds to pay for private care and the care does not often go on for more than 3-5 years.

With Appendix K (COVID In-Home Supports), I am finally able to be paid a small amount to provide the care for our daughter that I have provided nearly 24/7 for 28 years. However, this relief will end when the COVID crisis ends.

The COVID crisis may end, but my unemployment crisis will not. The COVID crisis may end, but the caregiver crisis within the direct care service industry will not end. So, here are some of my proposed solutions:

1. Currently, care agencies in SC are paid \$17-20 per hour to administer care for Mary Addison. The agencies then pay care workers \$10-12.50 gross per hour. It would be less expensive to pay me the \$12.50 (or more) per hour directly to provide the 24/7 skilled care she needs. Why force us to have underqualified strangers in our home when I could earn the income we so desperately need by providing the skilled care. When we need a break, SC Respite Coalition and other agencies can help us with additional funding to pay temporary (and expensive) high quality, skilled care.
  2. If there is a shortage of qualified care workers (the caregiver crisis), would it not make sense to pay more family members who choose or need to do the caring instead of forcing family members to try and keep outside jobs while dealing with unreliable, underpaid, inadequate staffing? This would greatly reduce caregiver burnout and stress and improve quality of care while immediately increasing the number of "direct care service workers" who are currently called "parents." (I understand, there are many families whose children with disabilities or other family members do not require the level of attention and care our daughter does. Of course, it would make more sense for such a caregiver to receive services instead of DDSN pay so she can return to his/her higher paying job.)
- I am grateful for Appendix K. Our family needs all the help we can get, but it is so important that this funding continue to be available.

It is not mandatory legislation that guardians NOT be paid. I understand it is simply something South



Carolina has chosen. I am hopeful that you will give this situation careful consideration and realize that you have a simple solution available that could be an important choice for families under "self-directed funds."

I am willing to come to Columbia to meet with you and others, if necessary.

I hope you and your family are well and I am grateful for your service to our families.

My best,

Mary Tutterow

Dear Committee,

I am writing from the Tennessee Council on Developmental Disabilities, a state agency that works for long-term, positive change for people with developmental disabilities of all ages and their families.

I'd like to share this 2-minute video featuring Bryshawn Jemison, a young man with I/DD. Bryshawn lives a life anyone would envy, with support through Tennessee's HCBS program. View the video here: <https://youtu.be/CLgJkLsRzzA>.

The Council has seen the many ways Home and Community-Based Services (HCBS) support greater inclusion, independence, and self-determination for people with disabilities, including those with the greatest support needs. People who receive services can think about their goals and plan for the life they want for themselves. Services can take weight off the shoulders of family caregivers, who may have been serving as full-time supports for a loved one with a disability.

Tennessee's Medicaid agency has this year added 2,000 slots to our state's HCBS program, focusing on people who have been on the waiting list the longest. We are proud to see this progress but know that most people who are eligible are still not receiving services. (Administration on Community Living data say only 17% of people with I/DD nationally are getting paid supports. See this report: <https://acl.gov/30years>.)

The Tennessee Council has been working to educate our statewide disability community about accessing HCBS and to support our HCBS program in reaching people with clear information about services and program updates. We know that expanded federal support for these services would have a hugely positive impact on the ability of people with I/DD in our state to live good lives in their communities.

Thank you for your support for the disability community in Tennessee and beyond.

Regards,

Jolene Sharp

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. My family and I are fortunate. My 102 year old mother and 33 year old daughter have this care. I am one of those family members filling the gap at age 72. Many others do not have this advantage and languish on waiting lists.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Linda Storm

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. We do this because we don't want to see our loved ones isolated or warehoused.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. To live in situations that add to their quality of life and keeps them safe.

Regards,  
Hilda Kapeles

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

The turnover rate in this industry is historically high. We need funds, and permanent funds to fix this issue. My job, and I believe people who do my job and other places and where I work would say that they love their job, and we do. This type of care is so important. We need to fix this pay/wage issue. A general manager at a Dunkin or Panda Express earns more than us. That's an issue, a very concerning one.

Regards,  
Eric Noepel

Dear Committee,

I have an adult 35 year old son who can live a full life with home based services. He requires assistance with everyday living activities: 1.Organizational skills to prepare for the day

2.Transportation to/from his job

3.Meal preparation and planning

4.Laundry and house cleaning skills

5.Personal hygiene skills

6.Money Management

7.Interaction with community

8.Medication Management

ALL this assistance is provided in the home setting where he is HAPPY and still a PRODUCTIVE CITIZEN!!!

What more could a parent want????

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
DEBRA WOOD

Dear Committee,

Hello!

My 21 year old daughter is someone who needs support every hour of every day. She has been in the Developmental Delays Waiver Waiting list for 18 years. She can function with assistance and guidance, and is still learning skills every day. Unfortunately she has been let down by the Department of

Education, Piedmont Community Services and now the Department of Aging and Rehabilitation. We have no help except what I have fought for and or provided for myself. In her 21 years, there has been a lack of trained professionals and a desire to actually help our children. While I live in Franklin Country because of its beauty and community, our taxes don't seem to come back to our county to help our own children. Please support more funding for our children and the disabled.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Robin Mays

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

Many of them, like our son, are unable to live at home. As parents, we are constantly worried that another staff member will quit or that some staff is required to put in double shifts because there is no one available to cover that shift. These people are not being paid enough!!

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability.

Regards,  
Katherine Mosbaugh

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My grandson, Travis Whetstone, 27 lives at home, with single mom, has multiple systems in wheelchair. On Medicaid, but unable to find RN to stay with him. His aunt who has no experience has agreed to learn to stay with him so Mom can keep their home. Mom was denied caregiver pay due to the fact she is not RN or LPN. Neither is his aunt.

Please do something to help, Mom will not allow him to be institutionalized.

Regards,  
Judy Bowles

Dear Committee,

This has become a nightmare for my family. Because my family is considered middle class we did not qualify for any services and had to wait for the HCBS list. In Texas, that list is over 15 years long, I'm still waiting. My son is going to be 21.

I had to quit my teaching job to stay home to care for him in 2011. I lost income. My family lost income and still we did not qualify for services. We owned a home.

My son has Down syndrome so he suffers from speech problems and has problems being understood so he suffers from anxiety. His IDD is low so he was never trained for a job. But I think there could have been more if I had found the right help.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Why do families have to suffer? All we did was have a child that maybe no one wanted.

People tell me they are surprised that I don't get money for my son. I don't know why they think that.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My son is never going there he belongs home with his family.

Regards,  
Mary Ramos

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

As aging parents of a 22-year-old daughter who requires total care, we need the supports of HCBS. Without those supports, our daughter will be unable to contribute to our society. Without those supports, she will end up in a more expensive state-run institution.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Karin Coppernoll

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

Too much money for Medicare and Medicaid goes to funding Nursing Homes and care for services there which could be provided from home at a LOWER PRICE, and more comfort, dignity, and safety of the person in need of the services.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Remember, 1 in 4 people in the US have a disability, and disabilities are acquired everyday. Would you like to end up in a nursing home at 45 or 50? Or would you like the dignity of being able to stay in your own home?

A vote in favor of funding HCBS is a vote for quality of life.

Regards,  
Shannon Tarkowski

Dear Committee,

My son at 17 was in a motor vehicle accident where he acquired a Traumatic Brain Injury. He came home from rehabilitation hospitals after 4 years and it is evident that home is where he belongs. He needs assistance from personal care attendants for his every day needs but mentally he is aware, knows what is going on and can communicate. He just physically can't do everyday tasks as his TBI has left him in a state of hardship with his physical abilities. We are struggling to find those personal care attendants because the pay is lower than what folks can get paid at a fast food restaurant and the work as a personal care attendant is more involved. As a parent I am often having to take care of my son because I can't find help to cover all the hours he is allotted. Please consider adding funds to the home and community based services so we can offer higher wages than \$11.69/hr for the work that his care attendants perform. Thank you kindly for reading my concerns.

Regards,  
Tammy Harris

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Day programs are very important to us so that the people with disability can go to instead of staying they need to get out do things like going to a day program and doing on the go youth program so they see their friends we would like to see community based reopen again so that we can go back instead of staying home I want congress to read my story and get back to me

Regards,  
Nancy Esparza

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. My son has not received services for over a year because of the lack of monies paid to support professionals. These services are critical to him because my husband & I are elderly. What will happen to him when we can no longer care for him or die?

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Debbie Fabio

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My daughter is severely disabled and receives HCS funding. This makes it possible for her to live in a small group home near us, which she loves, and not to live far away in an institution.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Georgia Couch

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on



waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Joseph Joseph

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like working, shopping, exercise, volunteering and socialization.

But there isn't enough money in the HCBS program to keep community-based programs running. Too many programs are short-staffed, and too many long-term employees are leaving due to low pay.

Please support a historic investment in disability funding, so everyone can get the support they need to work and volunteer in their community.

Regards,  
Sid Franks

Committee members:

Dues skimming schemes are harmful to home care workers. In 2015, Pennsylvania Governor Tom Wolf issued an executive order allowing United Home Care Workers to dictate the terms and conditions of employment for home care workers in Pennsylvania. Prior to this, the union donated nearly \$4 million to the Governor's campaign. The executive order enabled the union to deduct two percent of workers' pay for union dues. Wolf then received an additional \$45,000 from the union for his reelection campaign in 2018. The executive order was wildly unpopular among home care workers, with only 13 percent of eligible workers voting in favor of representation. Home care workers were so strongly against unionization that they sued Governor Wolf over his executive order. Dave Smith and his friend/home care worker Don Lambrecht filed a lawsuit that stayed the executive order for three years. Home care workers in Pennsylvania are against unionization and deserve to have control of their money.

For more information on dues skimming in Pennsylvania, see:

<https://www.commonwealthfoundation.org/2019/05/03/union-medicaid-dues-skimming-scheme-finally-ends/>

<https://www.commonwealthfoundation.org/2018/08/22/pa-supreme-court-allows-stealth-unionization-of-home-care-workers/>

Thank you for your time,

Andrew Holman  
Policy Analyst, Commonwealth Foundation  
Andrew Holman

Hello Senate Special Committee on Aging,

I am a geriatric physician providing house calls to patients in the Santa Clarita Valley (northern Los Angeles County) for 35 years.  
 My practice has been devoted to home bound seniors and those who are disabled.  
 It is incredibly important we fund in-home services so citizens can "age in place." Not one of my patients has ever said, "Please Dr. Dorio, send me to a nursing home!"  
 Providing well-educated caregivers are necessary, but I also feel we must have a larger regiment of health care professionals providing home care, including more doctors and nurses.  
 Technology as well cannot be ignored, and having robots, communication devices, transferring equipment, automatic medication dispensers, worthy mobility devices, and much more would aid in keeping people in their home.  
 As a medical professional seeing the growth in this effort, I hope Congress will specifically focus on this need, and not approach this tangentially so we can achieve the worthy goal of "aging in place."  
 Financially supporting this effort is critically important, but the basis of success will be the creative ideas we develop in implementation.  
 Please contact me should you want suggestions in this effort.  
 Sincerely,  
 Gene Dorio, M.D.

Dear Committee,

During your deliberations, please understand how important HCBS funding is to the individuals and families served by the many voluntary agencies throughout NYS. Lives have been changed so much for the better as a result of these funds and it would be wrong and hurtful to our most vulnerable people to decrease or limit these funds.

Please continue to make a difference for individuals and families. IOT is the right way forward. Thank you.

David Borge

To the U.S. Senate Special Committee on Aging,

I have been working with the disabled for 35 years. My son is disabled and learning and working with him encouraged me to go to college for my Bachelor's degree in Human Services and I have made working with the disabled a career. I now own a Supported Living Agency supporting disabled adults. Through my experiences the more Government agencies feel our job is important the better the employees we get coming through the door. Paying a living wage is a huge need as well as proper support to the clients being served in the form of crisis stabilization, proper mental and medical health care. Please this field will not survive if things are not fixed.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

JEAN Linghor-Pittsenbarger

To the U.S. Senate Special Committee on Aging,

The state of home and community based services in this country is simply deplorable. Americans should be allowed to choose how and where they live their lives, and not forced to live in institutions because those are the only places that can serve them. An investment in HCBS would massively improve the quality of life of millions of Americans who have a disability.

One thing this country does very well is take care of the aging. The similarities in services required in aging that are also required for the IDD community is staggering. Yet we can somehow have no problem providing these services in home to the aging population, but for those with IDD we are unable to? The models to do this are already in place, we just need the funding. Imagine forcing the elderly to live somewhere they do not want to live in order to receive their services. This is something that seems unfathomable to happen, yet we do it every day to IDD community. End this discriminatory practice and invest in HCBS for this community so that they can all live their lives the way they want to. Thank you.

Sincerely,

Jake Murray

To the U.S. Senate Special Committee on Aging (from Tina Conforti),

Hello ! I have a daughtier age 53 not verbal Autistic I don't understand why the state those not fund for a ASL sign language we are in need of this services my doughtier and others like her the are unable to exspress there needs ,Please sponsor a bill for ASL Communication sign language . I also like to bring to your attention to get a better quality services for adults living in Supporting living services ,the quality of care those not meet the individuals there served ,thank you Tina

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Sincerely,

Tina Conforti

To the U.S. Senate Special Committee on Aging (from SUSAN ADELMAN),

Thank you for working on Home and Community Based Services. People not connected to someone with a disability think there are programs that provide care. They do not understand that the services are so underfunded and inequitable. Our family has been struggling with the systems since our daughter was born with Down syndrome in 1996. We have benefitted from 0-3 programs, struggled with underfunded school systems, fought for access to community and have yet to take on housing and long term security for her. Please take this opportunity to include Disability in the movement to celebrate Diversity and Equity. Disability is the one marginalized group that Everyone has the opportunity to join.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Sincerely,

SUSAN ADELMAN

To the U.S. Senate Special Committee on Aging (from Mary Rief),

Michael - age 37 with Down Syndrome. Lives independently in a shared home with housemates. Caregiver comes daily to help him with meals, laundry, shopping, personal hygiene reminders, medication reminders, directions on cleaning, co-ordinates ride and meal schedules and so much more. Michael has a part time job that he walks to and from. He is capable of working about 12 -20 hours per week efficiently. He attends the local special needs adult support groups when they are meeting, attends church, a young adult group and attends family gatherings regularly. Michael has a very full, productive and active life. All of this is possible with the funding from Home and community based services and supplemented by us, his parents. As Michael ages, his needs will increase as almost 100% of older adults with Down Syndrome will suffer from Alzheimer's. We are advocating now so that he will be able to stay in his loving community even if we are no longer alive to take care of him. Thank you for your time - Michael thanks you too!!

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But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Sincerely,

Mary Rief

Good morning. I'm writing to you regarding the critical importance of community based services. I'm physically disabled and I rely on services provided through Virginia's Medicaid waiver program. Services are unavailable because Medicaid reimbursement rates are extremely low. I receive attendant services through the FIS Waiver, a crucial service which allows me to work, attend appointments and engage with my community. Attendant pay in southwest Virginia is currently \$11.81 per hour. To put this in perspective, high school students with zero work experience are earning \$14 per hour working in local restaurants. It is impossible to find dependable aides willing to work for \$11.81 per hour which has a direct impact on my ability to live my life. I'm also eligible to receive private duty nursing through the FIS Waiver. I'm still fighting to be able to access those services, but that is a story for another day. Reimbursement rates for private duty nursing in southwest Virginia are \$38.50 per hour for RN and \$28.66 per hour for LPN. RNs are typically case managers in the home health, private duty settings with very minimal interaction with patients. The vast majority of nurses performing care in private duty settings are LPNs. The state requires nursing services to be accessed through nursing agencies which take about \$4 from nurses' hourly pay. After the agency takes their cut, an LPN would only make \$24.66 per hour which is significantly low. Dramatically improving reimbursement rates is critical to supporting individuals with developmental disabilities. We desperately need dependable care and support. Virginia

and the United States have been putting people with disabilities on the back burner forever and that must end.

I'm happy to provide you with additional information or answer any questions you may have. I'm also happy to come to D.C. and explain how critical this issue is. Thank you for your time and thank you for fighting for people with disabilities.

Sincerely,  
Jessica Swanson M.B.A.

To the Senators of the United States:

My name is Barbara Pritchard, and I am honored to have this opportunity. I am a 66-year-old woman with significant disabilities, living in my own home in Urbana, Illinois. I have Cerebral Palsy, significant vision issues, and have been a wheelchair user throughout my life – as was my late husband.

I live in my own home, designed and built in 2005 by my late husband and myself, to make our lives more independent. Six years ago, I had a procedure that went terribly wrong, leaving me unable to independently transfer from my motorized wheelchair to the commode, shower, or bed. I rely on individuals to assist me on a daily basis with personal care, reading, driving, shopping, and most household tasks. I employ 6-8 people at any given time, to help me with these daily tasks – and many others.

I have both a Bachelor's degree and an MBA in business. I worked for more than 16 years in the field of social service, with and for people with disabilities. In retirement, I am \*very\* active on the local, state, and federal levels, volunteering on at least 20 different boards, commissions, and groups relating to disability rights and healthcare equity.

I consider myself to be extremely fortunate, because both my parents and my in-laws had means, and this enabled my late husband and I to live a life like any other – as all people deserve. Being able to pay out-of-pocket for the care and supports I need is costly, but I can have who I want in my house, when I need them. This gives me more choices and flexibility in the care and supports I receive.

In the disability community, I am in the minority – since the majority of individuals with disabilities do not have the opportunity for enough employment to pay for what they need. As a result, they may depend on federal and state resources, including affordable/accessible housing, rent, food, medical care, and individuals to help them accomplish daily tasks and self-care.

Home and community-based services (HCBS) \*must\* provide individualized supports, to meet each person's needs and wants. It is my belief that having choices in where you live, who surrounds you in your life, and what supports you need and want can enable you to be happy, fulfilled, and an active member of the community you choose. A life like mine or yours is no more costly than institutionalizing people – and is certainly more fulfilling.

A life like any other is a life that is part of the community. Being in the community needs to be the first choice in receiving supports and services -- benefitting both the individual and their community. Nursing homes should not be the first choice.

In 1999, the Supreme Court gave people with disabilities the right to live in the community. We can't fully live in the community without individually-designed supports. My needs are different than any other person. Without individualized supports, I would be unable to live the life I choose -- and deserve, under the ADA and Olmstead.

Barb Pritchard

My husband and I have chosen to provide in home care for our adult daughter with quadriplegia CP, who is legally blind and non verbal. She requires 24/7 care with nurse delegated duties. Over the years I have found that the state has served us well, when Anna turned 18 I was able to quit my part time job by becoming paid care provider. Employment outside the home was difficult due to her medical issues. When she turned 21 and wasn't able to attend school during the day we wouldn't have financially made it without my income watching Anna at home.

It is with joy that we have Anna at home with us. I can't thank the state enough for providing the opportunity. There are great gaps in our State for placement of severely disabled adults. We are honored to be paid for keeping her home, but we couldn't afford to do it without.

In home care giving life brings me peace of mind, I don't worry about her being neglected or abused. We were grateful not to be locked out from seeing her during the pandemic because we could be locked in with her.

There are challenges, most having to do with paperwork, managing her care with agencies and the union, SEIU is pursuing our membership even though we have opted out (numerous times). SEIU has mailed us new member packets because we are now transitioned into CDWA, they are making generalized statements that we are a part of the union now.

As parents the union doesn't benefit us, we are not being "fought for" as the union proclaims.

I have to work over 40 hours a week.  
I must work holidays, weekends and nights,  
I must cancel plans and be the substitute when scheduled care givers aren't able to come in to work.  
My home isn't a private place to live and enjoy life because care providers come in to provide care.  
I don't get to have a career.  
I don't get to retire from care giving.

These are just a few of the many items other care givers pay 3% of their income to protect. I hope opting out of union dues remains an option.

I have had a wonderful experience with social workers, DSHS, DDA, DVR and the "system" as a whole. OPRS has been a game changer for our family! I love the opportunity to have a real time off.

If I could make one change it would be to free up the distinction between Personal Care hours and Respite hours. Because community activity groups can use respite hours Anna is able to attend Bridge of Promise (a life line to her emotional well being). Sometimes I wish I could trade some PC hours turning them into Respite hours to allow for more community integration. If there is ever a committee to look into this I'd love to share more.

Thank you for all you do,

Melissa Santiago

Good morning

I am a parent provider of 2 adult sons and wanted to Take a moment to let you know my perspective I do feel as a parent provider that to make it mandatory for us to log in hours daily under the CDWA new guideline as well as any training requirements along with any SEIU 775 membership dues that we used to be able to opt out of apparently might be coming back in and let me say I do not appreciate being forced to pay any Union dues to a Union that I don't agree with.

THESE RESTRICTIONS ARE UNNECESSARY AND INVASIVE..

in summary:

I feel the best way to help support providers particularly Live in ones is to loosen the reigns of mandatory daily log in of hours, don't allow seiu and their political agenda to force mandatory dues , raise the minimum wage for those of us with more years experience and allow caregivers the right to use their reitement accts whenever they want regardless of the amount put in

Thank you

Crystal barrett

U.S. Senate Special Committee on Aging,

On behalf of the Freedom Foundation, a nonprofit state policy organization based in Olympia, Wash., with offices around the country, I'd like to pass along our research into the often deleterious role labor unions like SEIU have had on Medicaid-funded home and community based services programs, and how the Build Back Better Act would make matters worse by incentivizing state adoption of the kinds of harmful policies SEIU has advocated for and implemented in Washington.

The information may be relevant to the committee's upcoming March 23 [hearing](#), "An Economy That Cares: The Importance of Home-Based Services."

While the importance of home-based services is indisputable, states like Washington have permitted SEIU to dominate their home and community based services programs. Our research shows that, when these programs are structured in a way that benefits unions, caregivers, clients and taxpayers all suffer. A copy of our research paper, "Stop the Spread: How the BBBA Seeks to Replicate Washington State's Union-Dominated HCBS Model Nationwide," is attached and available online at:

<https://www.freedomfoundation.com/wp-content/uploads/2021/11/Stop-the-Spread-BBBA-HCBS-Report.pdf>



An op-ed length summary of our paper was published by *RealClearHealth* and is available online at:  
[https://www.realclearhealth.com/articles/2021/11/16/build\\_back\\_better\\_act\\_steers\\_billions\\_of\\_medicaid\\_dollars\\_to\\_labor\\_unions\\_111268.html](https://www.realclearhealth.com/articles/2021/11/16/build_back_better_act_steers_billions_of_medicaid_dollars_to_labor_unions_111268.html)

Please do not hesitate to contact me with questions or for additional information.

Respectfully,

Maxford Nelsen

Director of Labor Policy | Freedom Foundation

This action was wholly unnecessary. It was and is an unnecessary burden to caregivers. Caregivers are now going to be required to pay L & I taxes/fees. No other job in the state of Washington requires the employee to pay the entirety of L & I taxes/fees. This has always been a cost the employer pays.

None of the links provided by DSHS and/or ALTSA have worked. No one answers the phones when you have questions. I was on hold from 2 PM to 7 PM when they closed. Never did get ANY assistance with the troublesome, confusing CDWA website. Many caregivers in rural areas do not have access to reliable internet services, yet now we will be required to do everything 'online.'

Caregivers already once went through a grinder mess when they were transitioned to IPOne. Now here we go again, messing up our medical insurance, our time off and there are absolutely no guarantees that we will be paid on time when we can no longer use IPOne. No one at DSHS or CDWA cares one bit whether or not I am paid on time and can pay my own bills.

Shannon Hensley, Caregiver

Hello,

I would like to make a comment on The U.S. Senate's Special Committee on Aging hearing to discuss "The Importance of Home-Based Services." This hearing is to take place on Wednesday, 3/23/2022 at 10:00 AM EDT.

I work as a Caregiver in Washington State, and I am also an Assistive Technology Specialist for the ALS Association. I represent many caregivers and clients with severe disabilities.

In Washington State, "The Training Partnership", run by the Union SEIU 775 has been entrusted to handle all training for home-based caregiving.

To say that they have dropped the ball is an understatement. SEIU has unilaterally ceased providing Advanced Training, required by Washington State Law RCW 74.39A.351 for years now. No Executive Order, or legislative action suspended this law. This training would provide access to higher wages for caregivers.

SEIU also has been unable to consistently deliver Continuing Education Training, required under Washington State Law RCW 74.39A.341. Again, no Executive Order, and no legislative action suspended

this law. Not only is this Continuing Education supposed to provide a higher quality of care to clients, caregivers are also supposed to be paid for this training.

The Training Partnership is still being paid millions of dollars to provide services they refuse to deliver on. The Training Partner Executives are still enjoying exorbitant salaries.

It is not possible for caregivers to file grievances about these violations of the Collective Bargaining Agreement, and Washington State law, because of the conflict of interest between the Union, and the Training Partnership.

It is heartbreaking, that SEIU has fought so hard for burdensome training requirements, which mostly serve to only disincentivize people from becoming caregivers, only to fail to provide the services that they claimed so vital to the industry.

Thank you,

Ken Finlayson

Greetings,

I am a home Healthcare provider and take care of my adult son with Down Syndrome and autism in my home. He requires full-time care, special diet and medical care and monitoring. I am grateful to help him be safe and healthy and to provide him with a loving and beautiful life with his family and opportunities in the community. His quality of care here at home far exceeds what he would receive in a care facility or group home.

I have not been a fan of SEIU, they took dues for months out of my check without my permission at the beginning of my employment- they lied and cheated. Thankfully this was reversed after it was taken to court, but I am very hopeful that Seiu does not attempt to make caregivers go against their personal beliefs to stuff their own pockets with money.

Thank you,

Monica Ingalls

Hello.

It's my understanding that the Senate's Special Committee on Aging has undertaken a conversation regarding the importance of home-based services for people with disabilities. It's my further understanding that the current committee majority wants to use the hearing as a cheerleading opportunity for SEIU.

I am long-time caregiver for a family member. My wife's sister is developmentally disabled and has lived with us for over 22 years; long enough for me to well remember how perfectly fine we were all doing *before* the SEIU magically appeared in our work lives and put their oar deeply in.

The committee can cheer SEIU as much as they like, but the *fact* of the matter will still be that this private organization is as corrupt as they come. Their sole purpose for existence is to skim untold

millions of dollars from the paychecks of caregivers and other folks like myself under the guise of “representing” us in the workplace. Any thinking adult can see with ease that the lion’s share of the money they *steal* (that’s correct: *take without permission*) from us either lines the pockets of union fat cat leaders or pours directly into left leaning political causes, notwithstanding the beliefs, values and protestations of those *robbed*. Read *Harris v. Quinn* (2014); *Janus v. AFSCME* (2018).

And don’t even get me started on their mandatory “training” scam.

Warmly,

Brad Boardman

I wanted to register my concerns about the problems we, as individual providers are having in the state of Washington. We are facing increased pressures to provide care for free. Instead of objective assessments of need, the state sees annual assessments as tools for improving the state budget. SEIU 775 refuses to advocate on behalf of providers who, due to the high acuity of their clients, must live with the client - and who must provide all necessary care. Required unpaid care has hit our family with burdens not faced in other labor situations - and no one cares! Once placed in our homes, there is no available escape from the system's wage theft. Our state operates all federal wage and hour laws by MOU with the federal Dept. of Labor. The state is both the thief and the police. The voice that we pay dues to - SEIU 775 is, at best, an enabling participant in the ongoing wage theft. The federal administration is asleep. Only the Congress can save us. Thank you.

To the U.S. Senate Special Committee on Aging (from Cathy Muffly),

Taking care of people who cannot take care of themselves is one of the most important things we can do, it is one of the hardest, challenging, and most rewarding things to do, and most people can't do it, but it is the right thing to do. Just think if it were one of your loved ones, or even yourself, wouldn't you want someone to take care of you in your home and community? It is also so difficult to find caregivers willing to do this job, and it should be acknowledged how difficult this job is and be paid well to get the job done. We need to take care of these people who cannot take care of themselves, it is the right thing to do. Please help, and take care of these people who cannot take care of themselves and help to keep them in their homes and community. Thank you!

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

CATHY MUFFLY

To the U.S. Senate Special Committee on Aging (from Enza Moore),

My Son is 30 with DS—he is enjoying entitled To same things that most Americans have. But, that not the case. There not enough Caregivers due to wages. I have a job That allows me to work from home . Most parents have to choose Work or their Child this is overdue and the HCBS be passed immediately

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Sincerely,

Enza Moore

To the U.S. Senate Special Committee on Aging (from Mary Monroe),

Thank you for reading my story. My son is 33yrs old. He had a liver transplant 30 yrs. ago. He also lives with Smith-Magenis Syndrome, a difficult behavioral syndrome.

He has lived in an AFH, and Residential Supportive Supports in years past, but needed to move home after he became ill in 2020. He needed to recover from pneumonia, it took a good month.

So, he moved home with his dad and me. We both are retired, and living on SS. My son has been needing more medical care as he ages, liver and heart mostly now. He will need more nursing care, or really, really good staff that can know how to support him.

I am resigned to finding an assisted living support for his needs. That is what he is assessed for, and because we have had the past experience with AFH, and RES, and with staff that were remarkable, but with other issues pertaining to training. My son did have to go to the ER a few times due to illness and medication issues. Because he cannot communicate his needs, it takes time and nursing training to see the underlying issues that he presents with.

Because of needs, and because of the nursing care he will need eventually, how can AFH be able to care for higher need residence? I hope that someday, the senior living business will provide care for those with IDD. Most of them don't. Why does the Senior and Disability not include a Developmental Disability office under their oversight? Most of the nursing facilities mention that they need specific licensing for that support- and then others don't. It's confusing for me because I've been there. I now need senior services for my 33 yr. old. One idea I have is to contract with assisted living more, provide training on their site, which allow more beds to be for Medicaid, and with DDA funding too. There has to be a better way. I am grateful that I can share my story. I would like to learn more about what the possibilities are as we move forward!

Mary Maureen Monroe  
Bellingham, WA

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Sincerely,  
Mary Monroe

To the U.S. Senate Special Committee on Aging (from Peggy Cobb),

My adult daughter has Autism and relies on her community based services to live independently in the community. Without these supports I don't think she would be alive today and she is only 42. I don't believe we should call the US a civilized country if we can't take care of those in need and less fortunate than the rest of us. Please support these life preserving services for those who need them!

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Sincerely,  
Peggy Cobb

To the U.S. Senate Special Committee on Aging (from Estrillita Nelson),

I am an elderly woman who depends on help to keep the independence that I do have of living in my own Apartment. Without the help I do receive I could face living in a nursing home, and that is something that I don't even want to think about! With the help of a caregiver I can stay in my own place and be happy. I ask you to PLEASE see this issue through my eyes and how IMPORTANT it is to me and many, many, more like me.

I do Thank you, ahead of time, for your supporting of people like me with disabilities.

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Sincerely,  
estrillita nelson

To the U.S. Senate Special Committee on Aging (from Laurene Rusing),

My daughters age 18, my age 62, she's done with all the school supports....Now what? She need supports all through out her life....Now what? Community based services is what will keep her going- Please remember these services are needed for her daily life care, such as bathing, eating, taking medication, getting around to community functions, and daily life tasks, for those who are not challenge take for granted, such as daily bathroom skills/needs such as wiping and flushing and washing hands after. These are daily life skills, ones that always get forgotten about , that are essential for our children and adults who are challenged. Please do not forget about our children, even when the school bus stops coming to our home, most kids get forgotten, but we as aging parents still need to care for the adult children, that no longer go to school. Please vote to keep these essential services alive for those who are less fortunate. Thank you!

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Sincerely,

Laurene Rusing

To the U.S. Senate Special Committee on Aging (from Sandra Olson),

My adult daughter has intractable epilepsy and behavioral issues. She wanted to live on her own but can't because of her seizures. Without home and community-based services, she would be home-bound and would not be able to live independently but with help. She was fortunate to be able to get services and has caregivers to dispense her medication and that allow her to have access to her community. But these caregivers are underpaid and staffing shortages can impact her care. Without these critical services for people with disabilities, impacts how they can live, work, and access their community. Please adequately fund these vital services for all people with disabilities so they can live without barriers and realize their potential.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Sandra Olson

To the U.S. Senate Special Committee on Aging (from Angela Dews),

My 51yr old son lives in his own apt. with brief oversight for safety, health etc from caregivers, he is considered high functioning. These caregivers work an often unsafe, dirty (from human waste etc) long hours, thankless job for a very low wage. They are doing vital work and deserve great recognition and a

living wage. Most caregivers in the Seattle area live far away from their clients and have long, undesirable commutes. Let's treat them with respect by giving them a suitable wage and benefits etc.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Angela Dews

I have heard the Senate is planning some discussion of home health care providers, and any providers who are critical of SEIU are not allowed to speak at this hearing. Is the truth something that should be hidden? SEIU sent people to our door pretending to provide me with information about SEIU. They asked me to sign their IPAD (signature line only) to verify they provided me this information. That signature was used to put me BACK in the Union after I fought for a year to get out of it.

EVERY SINGLE ACTION TAKEN BY SEIU claims to protect the handicapped, BY SUPPRESSING ANYONE WHO SPEAKS OUT AGAINST THEM.

THIS UNION IS NOTHING BUT ORGANIZED CRIME to support their lavish conventions,,,,,, and anyone who supports them and suppresses their criminal and unethical behavior is as criminal and unethical as them.

Robin McKay

To the U.S. Senate Special Committee on Aging (from Liz Mckinnon),

My 26 year old son, Tyler desperately wants to be in a Community based home but with the funding available now it's just not possible. It is critical to improve the funding for the HCBS so our children can live the lives they were meant to live. Thanks for your consideration.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to



high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Sincerely,

Liz McKinnon

To the U.S. Senate Special Committee on Aging (from Shannon Andersson),

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Sincerely,

Shannon Andersson

To: The U.S. Senate's Special Committee,

Since 2018 when SEIU took over my family has felt huge repercussions which have negatively impacted our lives and support for the success of our family raising a child with severe disabilities at home in Wa. and his success to thrive. Prior we always had an quality Agency in Wa. that sent out loving, responsible, well trained care which helped our child and family thrive. It is SEIU that put these Agency's out of business after 2018, forced us to pay fees and given us "Corina Care" which is the opposite of care we had provided by Agency's. Now we have no oversight of our care providers or accountability except ourselves, we have no person of contact. We now have huge gaps of no care for 6-12 mo at a time because there is no good help to hire. They hire anyone with two feet who pass a slim background check, list them on a site, do a little general training and that's it. Disabilities matter...our son is non verbal so he cannot understand broken English, it disables him even more. Out of the very few IPs we at times can choose from, most can not speak clear English. This has hindered the success of our family, marriage, health and long term ability to keep caring for him. It has worsened his disability and added behavior problems out of his own frustrations. Our children can not prosper and are hindered by the very system that is supposed to help them.

From: A loving parent who has given it all and just needs a little quality support living in Wa.

Thank you.  
Tammy McIntosh

To whom it may concern,

I am an IP in WA state and I love my job. It's not an easy job and often times an unpleasant one but good care providers are desperately needed and poorly paid for the vital services we provide in order to keep people out of care facilities.

It upsets me greatly when I receive deceptive emails from SEIU trying to trick IPs into joining the union under the guise of "updating my contact information". That needs to stop!! IPs should have a clear choice to join or to decline and not be tricked into it.

Over the past 12 months, we've had to struggle unnecessarily to get continuing education completed. While we have been granted time extensions, it causes undue stress, especially for those of us that work full time. And the course choices need to include more topics that we can use to better serve those we care for. Basic information for common illnesses must be included!

Please listen to our concerns! You need us!

Very sincerely,  
Shawn Garrison

Dear Committee Members,

I am a 70-year-old quadriplegic (52 years post injury). Along with aging comes more problems with basic health needs such as skincare, breathing, and energy. All of these problems are byproducts of aging but many of these byproducts can be ameliorated with the assistance of good Personal Care Assistant. Massachusetts has a generous (compared to other states) reimbursement rate of \$17.71. However, at that rate I've had ads running for months without a capable person responding.

In order to keep people with disabilities in their homes living independently and healthy a solid set of home care based services (HCBS) has to be developed. It's impossible to get good help as we pay little more than what an adolescent can earn working at Burger King. There's no incentive for anyone to become a Personal Care Assistant.

The path we are currently following will certainly lead to many of us being housed in nursing homes or long-term care facilities. We know from our personal experiences and anecdotal evidence this is a death sentence. We will be refusing people with disabilities the right to remain in their home, lived with their families, and participate in community life. It's against the law and is an immoral as we travel.

That's not living- that's just existing. We could say the same about a houseplant. Please don't turn us into Spider Plants.

Sincerely,  
Joseph Tringali

My daughter is 26 years old and has cerebral palsy. She is unable to dress, feed, or get herself out of bed without help. She graduated Summa Cum Laude from NC State University in 2017 with degrees in Political Science and Nonprofit Management and Accounting. She has lived interdependently utilizing a combination of roommates and direct support professionals since she went to college. Without home and community based supports she would either still be living at home with her parents or in an institution. Not only is having her live in her own home cheaper but it also allows her as typical a life as she can achieve. There is a direct support professional crisis right now that has made getting workers to fill this important role in society almost impossible. There are also as many people on the waitlist for waiver services in North Carolina than are currently receiving it...over 10,000! I know that my family would have imploded had we not received a CAP slot when my daughter was young.

Please do everything to increase access and the quality of home and community based supports.

Sincerely,  
Sandy McMillan,

Hello,  
I'm writing to ask for you full support of HCBS. Fully funding this will help keep people with disabilities out of institutions and living in the community with the supports they need and being able to live in the least restrictive environment possible, which is our ADA right.

My name is Steve Grammer from Roanoke, VA. I was born with Cerebral Palsy, and I was forced to live in a nursing home at the age of twenty-two when my mother became ill and could no longer take care of me. There were no other options available to me. I lived on the Alzheimer's unit at the nursing home for 9 long years until I was finally able to get a DD Waiver. Now I live on my own, in the community with supports, however the supports I have do not cover all of my needs. That is why fully funding HCBS is so important for me and others just like me. I struggle daily finding and keeping Caregivers. Not having Caregivers would force me back into an institution, which is a violation of my ADA right. Caregivers are paid very low by the state and are not offered benefits by the state. They should be paid within the 75th percentile and offered full medical benefits.

Again, I'm asking to fully support HCBS to allow people with disabilities to live in the least restrictive environment possible and have a life like yours!

Thank you for your time and consideration!

Sincerely,  
Steve Grammer- Graduate of Partners in Policymaking 2013, Advocate for people with disabilities.

I've been fortunate to receive Home and Community Based services for 18 years. I could write a book, but I'll keep it short and sweet.

The absolute most important thing is the inexcusable wages the caregivers make an hour. It is a slap in the face to me and the caregiver. For caregivers not to get paid more than anywhere else, anywhere, it's disgraceful, disrespectful, and degrading. They are working with human beings not food or boxes.

I need Home healthcare agencies and caregivers who are trustworthy, responsible and care about us who depend on them. I don't need Agencies and caregivers who leave me bed-ridden, nothing to eat or drink, and can't go to the bathroom. I've found that 80% of caregivers are horrible because Agencies do not pay competitive wages to hire descent people.

I am an adult who was born with a disability, I worked 20 years. I can't really do anything for myself, like, dress, cook, bathe. I'm a happy person with a disability, I'm in no pain, I have a lot of friends, I love my home and dogs, The thought of living in a nursing home has never crossed my mind. Caregivers deserve competitive wages and I deserve better trustworthy, responsible people who care.

Christina Trimnell

I am an IP for 4 men with developmental delays. I have been working for the same men since 2003. Two of them are my sons and the other two are sons of personal friends who have since passed. I have taken training all these years and most times the trainings were on care that these guys don't need nor will they. I have no desire to take on any new clients. Cut the costs. Look at Care Givers. Look at how many years and how much training they have already had and see if they are going to make care giving a career.

And don't get me started on mandatory union dues. I never contact the union nor will I. Why would anyone want to pay this greedy union for working for the state and not the individuals. They are too political. I might support them if they stayed in their own lane of supporting the people that pay them.

Cheryl Metcalf

We were also pleased to hear President Biden reaffirm his commitment to continuing his push for HCBS in his [State of the Union Address](#). The President's continued commitment to HCBS is critical, and we have appreciated his efforts to prioritize a significant investment in HCBS as a key policy priority since he took office. We were especially pleased in light of [last month's fact sheet from the Biden Administration](#) announcing several reforms to improve quality and accountability in nursing facilities.

While it is imperative to protect our people trapped in nursing facilities – and all institutions – these investments were framed as part of the President's commitment to ensuring that older Americans and people with disabilities can live in an accessible, inclusive, and equitable society. Institutions restrict people's freedom – by their very nature – and cause immense harm. No amount of reform will lead to an accessible, inclusive, and equitable society. We are grateful for the President's commitment to HCBS, which will truly lead to access, inclusion, and equity.

A significant investment in HCBS is urgently needed to expand access to services and support the workforce that provides them. We are pleased that the Administration and Congress are continuing to

prioritize this. While this investment was urgently needed even before the COVID-19 pandemic, the pandemic made it even more critical.

Thank you for your consideration,

Cynde Soto  
Systems Change Coordinator

Carrie Madden  
Systems Change Advocate

Communities Actively Living Independent and Free  
634 South Spring St 2<sup>nd</sup> Floor  
Los Angeles, CA 90014

Hello,

In regards to the committee hearing on Home Based Services, I am submitting my experience as a parent provider for my adult daughter with a permanent disability.

I have been providing home based care for my daughter for the last 8 years. SEIU has made this experience more challenging and burdensome with the deduction of dues (initially taken from my pay for her care without my permission) and with time-consuming and frankly, unnecessary trainings foisted on caregiving parents that have no real benefit except to the people the trainings employ. The adoption of the new "system" to employ caregivers with Consumer Directed Employment spends even more taxpayer money to operate and is beyond frustrating for many parents and other home caregivers in its complicated and flawed software launch. It seems millions of dollars were spent to create giant new complicated computer program with the ultimate goal of capturing dues revenue. Such a waste.

Please consider how the siphoning of union dues, required union trainings and onerous computer tasks affects home based caregivers who are just getting by day to day doing the actual work of caregiving and getting paid very little for their effort.

Thank you,

Miranda Thorpe

To the U.S. Senate Special Committee on Aging (from Suzanne Gracewski),

Please support this bill to simplify care giving for adults with disabilities.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Suzanne Gracewski

To the U.S. Senate Special Committee on Aging (from Sonjia Henson),

We are worried about how our non-verbal autistic son will live after he is done with school in the immediate future and in the long term after my husband and I are dead. Who will be there to help him? He is not able to do the typical daily tasks without supervision.

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Sincerely,

Sonjia Henson

To the U.S. Senate Special Committee on Aging (from Martha Maier),

The whole point of waiver services is to allow people to live in their communities instead of institutions. However, so many people with I/DD don't have the support they need to live in the community since HCBS services aren't fully funded. Please fund these to the extent needed to provide those with I/DD full and meaningful lives in their communities.

Sincerely, Martha Maier

To the U.S. Senate Special Committee on Aging (from Sarah Rogers),

We think about our daughter's future after our deaths. She has Down Syndrome. She will never live independently. She doesn't want to be a burden on the lives of her siblings. She can use your continued help to keep the quality of her life.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Sincerely,

Sarah Rogers

To the U.S. Senate Special Committee on Aging (from LeAnn Lasco),

My disabled adult daughter

Her language communication is American Sign Language and is missing from her future.

Beside her being deaf and mute, is challenged with less than 5 percentile in weight, height, and mental development, plus ADHD.

She is 29 and been with DDA for years...

She has been involved with an abundance of services both wonderful and some failing ... The need she has yet to acquire is supported living with American Sign Language supports for the rest of her life.

American Sign Language should be a part of the system so supported living (specifically in Clark county/ cowlitz county Washington) available for ADLs and 24 hour support

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

LeAnn Lasco

To the U.S. Senate Special Committee on Aging,

My son needs services and he is not receiving anything.

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But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Sincerely,

Donna Barber

To the U.S. Senate Special Committee on Aging,

I am one of the lucky ones as my son gets HCBS waiver services, which are critical to him being able to live in the community. Thousands are waiting for these services though because there is not enough funding for everyone. Finding direct support professionals is a real struggle! They can work at a fast food restaurant and make more money with less work. We need to pay caregivers what they are worth! Many families care for their adult sons or daughters with disabilities, many of them aging parents. In Washington State, we have parents in their 90s still caring for their adult children in their 60s and 70s. Although they save the state a lot of money, they can't continue forever. Please make sure home and community based services are well funded for people with developmental disabilities.

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Sincerely,

Diana Stadden

To the U.S. Senate Special Committee on Aging (from Jennifer Newhouse),

My daughter is 34 and lives on her own in her community where she friends, attends community events, volunteers, hosts her church bible study and looks for work. These services are critical for her to be able to continue to live the life she has forged for herself. Despite living with Cerebral Palsy and a cortical vision impairment she is an active and giving community member. Let's be sure she gets to continue doing that!

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Sincerely,

Jennifer Newhouse

To the U.S. Senate Special Committee on Aging (from Pamela van Marle),

Thank you for taking the time to read my comments.

HCBS services is an integral part of my son's life. It allows him to live an incredibly different life than otherwise possible. Supported employment not only gives him a sense of purpose, self confidence and growth it provides him with an interactive experience of/with community and allows him to contribute to society in positive, productive ways. At the same time, equally important, it helps provide

opportunities for others in the general population to interact with him and gain a broader understanding of persons in the IDD community.

Being paid as his parent/caregiver allows me to stay home and provide him with the best care and understanding that he needs twenty four hours a day.

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Sincerely,

Pamela van Marle

To the U.S. Senate Special Committee on Aging (from Darla Helt),

Without the supports of the HCBS, my two sons who are 30 & 34, would not be working, contributing to our community and to society as a whole. It is the supports through HCBS that have provided the tools that we as a family can not, for them to have a successful and meaning life. We are the lucky ones, so many are in need of these supports and there is currently not enough funding to meet the need.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Sincerely,

DARLA HELT

Hello everyone, I understand that there is a committee meeting where there were invites to testify regarding home care and SEIU.

We have found SEIU to be difficult in their recruiting tactics. We prefer not to belong to SEIU because we are individual providers and see little benefit to paying hard earned Medicaid money to the union. Initially we were told that Washington state was a union state and we had to pay the union dues even though we did not sign up or request we be SEIU members. We had NO choice.

When we finally had a choice, a union rep was sent to our house and waited an extended time on our private property until I came home. When I came home, the rep persisted to require that I sign a document joining the union before they would leave our property. I was unloading groceries and caring for our disabled child. And they would not leave. Later I found I had a choice and I wrote a letter requesting I withdraw the membership. This letter was sent during the time that the union says members can withdraw BUT the union would not answer or acknowledge my certified letter request. I had to get an attorney to write SEIU a letter to get them to follow their stated guidelines.

We need choices. The Medicaid money paid to us as individual providers for home care is not significant and taking out dues for a union we do not wish to join takes needed money from our pocket which is used to take care of our child at our home. I believe I would not be asked to testify because I am not a SEIU cheerleader.

Thank you for listening.

Jacalyn Holsted

I am a parent caregiver who for years as a non union member had union dues (\$50 per month) deducted from my pay. I was not in agreement that I was underpaid as a caregiver. I was urged to agree to union membership and politely declined. There is no justification in my mind to having union dues deducted from my pay.  
Respectfully,  
Julie Stiles

I am a caregiver for my twin grandsons who have cerebral palsy. They are young adults now but require full care. I have been helping care for them long before I was paid to do it. Then the SEIU somehow got involved and all caregivers, family or not, were required to join the union. I don't have anything against unions. In fact I have been a member of the Teamsters and the IAM. Both of those unions charged a set amount of dues per month, regardless of how much I earned. The SEIU charges 3.2 % percent of wages per client so if I work more hours I pay more dues. The dues should be a set reasonable amount. For this reason, I opted out of the SEIU when given the opportunity and I hope membership does not become mandatory again.

Sincerely,  
Barbara Ray  
Family Caregiver

U.S. Senate's Special Committee on Aging:

Regrettably, I just received word SEIU is gunning for another mandatory collection of dues from Medicaid paid home health care providers. Must we really go through this again?

The last time SEIU tried this, care providers across WA state were unaware the SEIU was succeeding at collecting dues—that is, until we received our paystubs. Only a small percentage of the few providers who did know about this event approved unionizing Home Health Care Providers (HHC), which was a far cry from a majority. Thankfully, we had the choice of opting out—which I did; however, before doing so, the union deducted dues based on a percentage of my wage. In other words, the more hours we put in, the more the union took.

Like any other Medicaid HHC, the number of Medicaid paid HHC hours a client is allotted a month is determined by his level of care at his annual ISP. Should we be coerced into paying union dues again, Medicaid funds—the taxpayer's money—will be redirected to support a union. For what? Certainly not to benefit of the elderly or disabled.

As a parent provider of an adult TBI child, who has been a recipient of Medicaid in home care assistance since his tragic accident nearly thirty-three years ago, I am here to tell you that the union's accolades that these dues provide funding for "better training and education" has not been beneficial for the client or the care providers. In fact, if anything, the quality of care has significantly declined since the union's presence. Furthermore, what "training" is the union provides comes at a significant fee to be paid by the care provider. So, again, Medicaid funds earned by the care providers goes back to the union.

As a parent provider of an adult child that requires 24/7 care, I take offense at any organization who wants to take the tax payer's dollars for personal gain, particularly when it has proven to be detrimental to the support of my son and those in his position. The minimal compensation HHC's, and parent providers in particular, receive should not be cut even shorter with union dues that serve no purpose. As a single parent provider caring for my adult disabled child in my home saves the taxpayer's more than \$7000 month. However, the availability of care providers—let alone, quality providers—is in critical short supply. Should the union be allowed to take dues and cut HHC provider's wages even more will only decrease our HHC supply.

Let Medicaid funds should supplement much needed client hours and HHC's wages, not contribute to a union's billion plus dollar coffers. Medicaid funds be directed to what they are intended for—supporting the client and the care providers who support and care for them. The quality and quantity of care should be a priority—not an agenda for union's profits.

Do not increase the already critical shortage of Home Health Care Provider by allowing unions to collect unwarranted dues.

Please stop the theft of Medicaid client's care.

Thank you for listening,

Celinda G. Matthews

Parent Provider, Legal Guardian of adult child

I am an individual provider and I am not a member of SEIU and I do not want to be a member.  
SEIU does nothing but take money from those of us that can least afford it. I know they have spend a lot of union dues buying Democrat politicians and that is wrong.  
Any action on your part to force people into the SEIU is going to be met with protests at the next election.  
I urge you to not force the corrupt union on us.

Elizabeth Dodd

I once worked for UFCW where we no choice about joining the union, we had to.  
So when SEIU started taking union dues out I thought it was mandatory. I use to joke that if they ever got my name right I might consider it, when they first started.  
Years down the road I learned we had a choice and we had to sign up for it.  
Than I noticed that they were not only taking dues out but voluntary dues as well, which I learned was for political things. Like I had asked them to take extra money from me. Believe me, I am poor. Work pay check to pay check and spent many nights not eating and many holidays with no presents for me kids.  
So I requested my signed documents from seiu proving I joined the union and requested extra money out. I thought it was a joke what they sent back to me. A BLANK form. Nothing checked, nothing filled out and nothing signed. SEIU STOLE SEVERAL THOUSANDS of Dollars from me for years.  
To top it off at that time the only thing I was allowed to do as a union member was attend meetings and vote. They couldnt help me if I had a issue at work with sexual harassment or abusive boss.  
All I want the SEIU to for me is PAY me back the money they stole and be held accountable for it.

Attached is the blank form they sent me that I so called signed back when the first went union.

Heather O'Neal (Home Health Care Provider/IP for about 22yrs)

I just wanted to share a few thoughts with you regarding SEIU and our upcoming change to a new IP program.

I'm sorry but I have nothing positive to say about SEIU. From the getgo they have wanted to impose horrific union dues on individual providers. I chose to opt out of the dues requirement. If a mandatory dues requirement is reinstated I will quit my job. I have worked as a caregiver for about 12 years and I love my job.

SEIU has kept us from taking our continuing education classes for the past year and they have offered no new classes. It's almost impossible to sign up for classes or get credit for classes that we've taken. There is no communication between SEIU and individual providers.

I can see no benefit that SEIU does for individual providers.

Caroline Harding

I have a daughter with a Developmental Disability that I care for at home and use respite caregivers to get an occasional break. In the past I have had several respite providers that may only provide 2 or 3 hours a month care. If they were to be forced to join the union, the minimum union dues are \$35 a month. This would take their whole salary away. I have lost a caregiver due to the SEIU backed CDWA starting up in our state (excessive rules, complicated rollout, unending technical issues, etc.) and would hate to lose more due to them being forced to join a union. If they were required to join a union, it would make them effectively have to work for free. The union is driving away caregivers and we are not in a position to be losing more caregivers. Please do all you can to prevent the unions from forcing caregivers to join.

Kayleen Glenn

To Whom It May Concern:

I am writing in regards to the hearing of the U.S. Senate's Special Committee on Aging (Wednesday at 10 a.m. EDT) to discuss "The Importance of Home-Based Services."

I am a paid giver for my adult disabled twin daughters, Mary and Madeline. I am strictly a caregiver for them. I have very strong feelings against being a member of the union SEIU. Initially I was a member because membership was presented during caregiver orientation as an unofficial requirement and an SEIU representative was there to ensure we filled out our paperwork. When I realized I could opt out of SEIU, I did so. I then received repeated phone calls, letters and even 2 home visits from SEIU representatives questioning my choice to opt out.

Two main purposes for opting out was excessive required training for parents who have been caregivers since their child was born and also the exorbitant cost of dues. I was not charged a flat fixed monthly rate but rather a percentage of the hours that I work for each daughter, per pay period. My daughters have high needs and one has paraplegia. They require 24 hour care so the more hours I work, the more dues I pay to SEIU. I do not receive more benefits than those who work less but I pay much more in dues. SEIU collects 3.2% of our wages. The caregiver hourly wage is not a reasonable living wage in Seattle, where we live. Every bit of income I earn is precious, valued and necessary. We are families trying to work and care for our disabled children and respectfully request your consideration in allowing freedom of choice in regards to becoming a member of SEIU.

Please allow caregivers the right to choose whether or not they join SEIU. Please do not make it mandatory.

Kind Regards  
Jodi Hoopes  
Seattle, WA  
Parent of Adult Twin Disabled Daughters

Dear Reader:

This email is in regard to the U.S. Senate's Special Committee on Aging is having a hearing on Wednesday at 10 a.m. EDT to discuss "The Importance of Home-Based Services."

I am a paid caregiver for my disabled adult twin sons, and I chose *not to be a member of the SEIU*.

When I began being a paid provider for my sons, I went to my parent orientation, I told the SEIU representative I was declining not to join the union. I did not sign anything but was automatically enrolled. Why must I become a union member to provide care for my adult twin sons? I do not plan on being a caregiver for anyone other than them.

My main reason for not joining was of cost of the union dues. The hourly pay is not a living wage, and then they collect 3.2% of our wages. I am a caregiver for my two sons, and they take a percentage of the hours that I work for each of my sons each pay period. It should be a fixed, flat amount and reasonable for caregivers to make a living wage. I live in Seattle and the cost of living is very high. I cannot afford to pay dues that are the *highest in the nation!!*

*The SEIU has harmed caregivers. There is a lack of caregivers, low pay and high union dues. Please do not make it mandatory to become a member of the SEIU it should be a choice!*

Thank you,  
Kristina Ray  
Parent Provider of adult twin sons

To the members of the Senate Special Committee on Aging,

My name is Rebecca Japko and I represent my sister, Linda Jimenez who now lives at a Texas residential facility. After my sister was asked to leave a nursing home for developmentally disabled individuals, she was admitted to the ER and an order of protective custody was issued. The Local Intellectual Developmental Disability Authority (LIDDA) was unable to find a group home provider that would admit her with challenging behaviors and a multitude of medical issues. What that LIDDA failed to tell me was that they are HCBS providers themselves with 24-25 group homes.

Thankfully, my sister has thrived at her Intermediate Care Facility (ICF) and is alive almost 10 years after our mother's death from Alzheimer's disease and two trauma-filled years of psychiatric hospitalization. My sister has received excellent care and treatment at her residential facility. She was near death at the psychiatric facility and her placement at her ICF has provided lifesaving care.

While I support community services for those who are able to avail themselves of these resources, there is a small population of the intellectually and developmentally disabled that require intense support and 24/7/365 care and supervision by professionals. Many of these individuals have been asked to leave home and community based settings when their medical needs increase or if their behaviors become unmanageable in the home. If the option of an ICF is eliminated it would undermine a family's ability to choose the setting that best meets the needs of their loved one. It seems a governmental overreach that those with the ideology of "community for all" could know the residents' needs as intimately as the guardians. Guardians who are not paid but simply are guardians out of love.

I am pleading with you not to forget that the MOST vulnerable and severely disabled individuals who live in ICFs.

Sincerely,

--

Rebecca Japko, PART President  
512-585-2478  
Parents and Allies for Remarkable Texans  
Living at Texas State Supported Living Centers  
PO BOX 40096  
AUSTIN TX 78704-0002  
[ourparttexas.com](http://ourparttexas.com)

Speak up for those who cannot speak for themselves, for the rights of all who are destitute.

Speak up and judge fairly; defend the rights of the poor and needy.

Proverbs 31:8-9 (NIV)

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I think the people should have a choice,

Whether or they want to join the Union.

Or not . And whether they want dues taken out of their earnings. Also I believe that they should not.

Have to work 80 hrs in order to

get medical and proper vacation time. I also believe that training should be voluntary. And the Senate and Union shouldn't. Have that much power over

the people. This bill should be voted on.

and lessen the strings they have.

Angela Jensen

Hello,

I understand there are a few more days to submit comments and wanted to add an important issue for in-home caregivers that the legislators should consider changing.

EVV (Electronic Visit Verification) was mandated by the Federal government to insure caregivers are "clocking in" and "clocking out" when caring for their clients. Live-in caregivers are able to opt out of this burdensome requirement if they are Individual Providers (IPs), however, *live-in caregivers who must work through a home health agency to bill their hours through Medicaid are not exempt*. My daughter now lives in a private group home and her live-in caregiver who works through an agency must clock in and out everyday despite the fact *that she lives there*. Home Health agencies tried to get an exemption from EVV for their live-in caregivers but were unsuccessful. This process becomes even more complicated when multiple people live in the group home (can you imagine clocking in and out every



day for three separate clients?) This amounts to wasted and distracting time on a phone app when the caregiver should be focused on caring for the clients. As well, when the clients go home to their parents on a weekend or for a vacation, the parent must then use EVV to get paid for providing care to their loved one because the client does not live with them full-time. This policy is truly inane and more appropriate for agency shift workers, not live-ins.

Please bring this issue to light and let these legislators know that ALL live-in caregivers, whether IPs or home health agency employees, should be EXEMPT from EVV.

Thank you,

Miranda Thorpe (parent caregiver)  
Redmond, WA

To the Senate Special Committee on Aging,

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my friends and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when we have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help us get out of bed, take care of our hygiene needs, and help us get started with our day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or forced to call 911 because they are left in an emergency health situation with no support or help.

The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country.

As a Center for Independent Living, we see first hand the effects such limits and increases can have on an individual and their family.

Thank you for your time-

Shannon Monyak

To the U.S. Senate Special Committee on Aging,

I have worked with young adults (as a special education teacher) who are cognitively impaired. Some can enter the job market with support and many of them need a lot more services. I agree that there's a great need for health care training opportunities and group housing subsidized by the gov. Everyone needs a chance for a fulfilling life. The young adult's parents are aging and some have health concerns of their own that make it unfeasible for them to care for and provide a safe home for them.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Sue Bockelman

To the U.S. Senate Special Committee on Aging (from Sarah Howard),

My name is Sarah & I have a 13 year old son who is autistic. I am unable to work because I have to care for him. We frequently go months at a time without respite care. It's difficult to find quality caregivers for the low rate they are paid. I worry for my son's future when I am no longer able to care for him.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Sarah Howard

To the U.S. Senate Special Committee on Aging (from Donna Godfrey),

I am my adult daughter's care provider, she has DD & mental health issues, she relies on me for everything, from Sun-up to bedtime & I'm available around the clock if she needs care-doesn't feel well, nightmares, yet her allocated hours keep her & I below poverty level existence. As a senior myself, I do not know that there will be adequate/appropriate services or placements for "out of home", when I can't do this anymore. She needs with all skills of ADL. You need to realize how demanding this is & with aging parents, what is to happen to them with out better HCBS NOW!! Help my daughter & others like her.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Donna Godfrey

To the U.S. Senate Special Committee on Aging (from Pamela Wilson),

My son has always contributed positively to our community, and has a good quality of life and richness of experience because he has had home and community-based services (HCBS).

Home and community-based services are extremely cost-effective and provide a safety net for those who become disabled through accident or disease, as well as those who are born with a disability and thrive in their own neighborhoods.

Too many hard-working family members have been taken out of the workforce to provide care when services are unavailable or inadequate and where waiting lists are prohibitively long. In many places, direct care workers cannot afford to live on wages offered, and must seek employment elsewhere, increasing the risk to those who require support to have access to caregivers who are trained and experienced.

Disability affects individuals of all political beliefs, all ages and income groups.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to

high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Pamela Wilson  
14211 SE 177th St Apt B201  
Renton, WA 98058  
[pmwilson@aol.com](mailto:pmwilson@aol.com)

To the U.S. Senate Special Committee on Aging (from Callie Wilson),

Those of us among the temporarily able-bodied need to think about this.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Callie Wilson  
3043 Central St SE  
Olympia, WA 98501  
[hellocallie@comcast.net](mailto:hellocallie@comcast.net)

To the U.S. Senate Special Committee on Aging,

My son needs services and he is not receiving anything.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

Donna Barber  
77 Desparado Rd  
Oroville, WA 98844  
[dlb0909@yahoo.com](mailto:dlb0909@yahoo.com)

To the U.S. Senate Special Committee on Aging,

My sister has heavily relied on Community Based services to lead a fully productive and active life. This has taken much of the tremendous challenge off our family after my mom died and is invaluable to her, us and our nation.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community!

Sincerely,

John Kersting  
2404 Olympia Ave NE  
Olympia, WA 98506  
[johnkersting@yahoo.com](mailto:johnkersting@yahoo.com)

To the Senate Special Committee on Aging,

My name is Maria Matzik, and I am a consumer of the Ohio Home Care Waiver program, a Medicaid funded program. I have Spinal Muscular Atrophy Type II; I use the assistance of a ventilator and I have a

tracheostomy. I use a reclining motorized wheelchair for mobility. I chose the option of Home and Community Based Services instead of the state's segregated, abusive, and expensive entitlement to institutionalization.

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my friends and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when we have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help us get out of bed, take care of our hygiene needs, and help us get started with our day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or be forced to call 911 because they are left in an emergency health situation with no support or help.

I have experienced these problems firsthand, and this is my story.

My partner of 27 years, and I have been involved with State and National advocacy since 1995. We worked on the rules for the Ohio Independent Provider program the entire time (from 1995 until implementation in 1998). We worked with many other states, CMS and advocates to get the best program that Ohio would allow. It was a fight, and definitely not everything that we wanted or hoped for, but it was a better option for most of us than home care agencies.

The Ohio Department of Medicaid (ODM) - at the time Ohio Department of Health and Human Services threatened us by saying that if we did not accept their proposed rules that we would not get any program. Many of us were outraged! During the Ohio Joint Committee on Agency Rule Review (JCARR) Hearings the room was packed – standing room only. I testified in disgrace of their proposed rules, and threat, and I presented to them with a LARGE jar of Vaseline served on top of a copy of their rules! That took everyone back to the table to come up with something that everyone could agree on.

We also advocated for, and participated in, the process to write and pass the statute for the Ohio Medicaid Waiver Home Care Attendant Provider Type. I was the only individual who testified for this.

I have used ONLY Independent Providers since 1999 and I have had very little issues – by far less problems than my years with home care agencies. Unfortunately, Independent Providers are becoming scarce and home care agencies will not cover my level of skilled needs. Most agencies will not even do shifts.

I was one of the individuals who advocated for this option back in the mid-90s after going to Washington DC and speaking with many senators and representatives. This was a result of Ohio's Job and Family Services threatening to throw me in a nursing home on the day of my graduation because the State did not offer the coverage that I needed to "assure my health and safety".

I had just completed a 4-year college degree at Wright State University in 1995 where I juggled a full class schedule, student attendants (who were non-licensed individuals and were phenomenal) and agency nurses (the agencies were my nightmare, but 90% of the nurses were incredible). I was looking forward to graduation and beginning a new life here (I am from Pennsylvania and came here for school). Ohio decided that since I did not have 24 hours a day covered that I was not safe and the best place for me, if I decided to stay and not return to Pennsylvania, was a nursing home.

One agency, so I thought, was my savior. This agency agreed to cover me and “eat” the 2 hours. I later found out that 2 nurses working for me through this agency agreed to take a significant pay cut and that is why the agency agreed to “save me”.

I have been my own advocate, as well as an advocate for individuals with disabilities across the nation, my entire life. If these programs were not in place individuals with disabilities would be forced into institutions with no chance of ever leading a fulfilling life.

Though the old stereotypes still exist I am here to tell you that people with disabilities can be productive citizens, taxpayers, parents, spouses, and even your employer given the options of appropriate services to achieve our maximum independence. In addition, I have a job, a wonderful partner, beautiful kitties, great friends, own an accessible home, own a wheelchair accessible vehicle, *and pay taxes*.

*Medicaid Home and Community-Based Services (HCBS) waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation. The HCBS waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.*

I am writing this to not only share my story, but to inform you about a population that is almost always overlooked, individuals with disabilities who are aged 21 to 64. In most cases these individuals do not have any family or spousal support. This is the population that I am in and who I diligently fight for to ensure that they have equal opportunity to live a full and productive life. This is the population who desperately need Medicaid and Medicaid Waiver services.

Many years ago, a large group of consumers, parents and advocates began a long battle with the state of Ohio to create a home care program that not only provided the services that an individual needed to remain in the community, but one that offered consumer choice as well as, the most important thing, consumer control. We had come a long way in the past two decades and have gained many positive changes that should be recognized, but we have also faced some recent setbacks and have far to go to achieve the “choice” and “control” that we advocated for over 20 years ago.

When we started this advocacy effort the progress was slow and frustrating because the Bureaucrats could not grasp what it was that we were asking for. It was next to impossible to engage in any form of dialogue even though we were the population who would be impacted the most by their decisions. We were lucky if they even took the time to return one of our phone calls. The sense was very clear that they believed that they knew what was best for us and did not feel the need to include us in creating this new program. Finally, a statewide effort was made to involve representatives from our regional The Health Care Finance Administration (HCFA office), which is now the Centers for Medicare and Medicaid Services (CMS). The tide began to turn when the requests that we had made for things like “choice” and “control” were validated by HCFA. Focus groups were created and plans were set into motion. Then, time moves on and Waivers are born.

Many years passed once the Waivers were put into place and there were not many dealings with the Bureau. Then a new administration brings changes to the Budget and proposed changes to, guess who, the disability population once again. We made attempts to speak with our legislators (just like we do today), to no avail.

Most people view “disability” as an “illness” or a “condition”. It is just a natural part of life for most of us. I don’t have to think about what my needs are – I know my needs just like you know yours. The difference is that you perform your own tasks, and I cannot. I have to think about who will perform my tasks and how. I have always trained all of my providers, both licensed and non-licensed. I have trained all my providers to do everything from moving me correctly to changing my tracheostomy. I have been hospitalized once in 1993 for respiratory failure caused by inappropriate ventilator settings by my doctor.

For many years, because of the nursing shortage, I have not been able to find enough nursing coverage. That means that when I get up in my wheelchair on Friday morning I do not go back to bed again until Sunday night. That means that I can only get washed up, but not take a complete bath. That means that I stay in the same clothes. That means that I do not have tracheostomy care to clean my trach. That means that I remain on my left side because I cannot roll in my wheelchair. That means that if I need to go to work on the weekend I still go. That means that I get little to no sleep. Ask yourself, “Can I do this”? Most of you will answer “no”.

I have had the choice – either go through what I have just described or go to bed on Friday night and still not be able to do several things mentioned above, like trach care, not be able to go anywhere, do anything and get depressed because I am not taking part in life. For me, this is a choice that I am willing to make because it is a “choice”. If we lose our Medicaid coverage or continue to have issues with hiring reliable and responsible home care providers “we” will have “no choice”! We will have “no life”!

People with disabilities are resilient individuals with a passion for life and a drive to succeed. Most non-disabled individuals will never, and could never, endure the oppression, segregation, discrimination, humiliation, ignorance, and pain that individuals with disabilities face throughout their entire lives. We are constantly having to prove our worth and value to a society that only values wealth, beauty and success. It is time that society, and even some of our best intended advocates, stop trying to paint a picture by using our inabilities and our financial drain on society and the budget. It is time to fight like our life is in danger because it is!

The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years.

Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country!

Remember: The Disability Culture is the only culture that anyone can enter at any time!



Thank you for working with us to ensure that “Civil Rights” are provided to all individuals. We strive to be part of a community that works together to demand equal rights for *ALL* citizens.

Respectfully Submitted,

Maria A. Matzik  
267 Royal Oaks Drive  
Fairborn, Ohio 45324  
(937) 623-9351 cell

I depend on disability services to services to live independently at home on my own rather than an institution please support disability services thank you  
Randy Schlecht

To the Senate Special Committee on Aging,

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my friends and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when we have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help us get out of bed, take care of our hygiene needs, and help us get started with our day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or are forced to call 911 because they are left in an emergency health situation with no support or help. The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide. I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country. Thank you. Sincerely,

Denise D. Ackerman  
5135 Galley Hill Road  
Milford, OH 45150

To the Senate Special Committee on Aging,

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my friends and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when we have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help us get out of bed, take care of our hygiene needs, and help us get started with our day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or forced to call 911 because they are left in an emergency health situation with no support or help.

I work for a disability-focused nonprofit in Ohio, the Center for Independent Living Options, and many of my colleagues and the people we serve are able to live in their homes and apartments, and are able to work and have vibrant social lives because they receive support from direct care staff for daily and weekly living activities. Without those staff, many of them would be forced to live in nursing homes or care facilities, or be unable to keep full-time job because they would not be able to get themselves out of bed and get ready for their day on their own. Direct care staff don't just care for people – they provide people with disabilities the opportunity to live their best lives and contribute to our workforce and communities.

The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country. Thank you.

Sincerely,  
Patrick Ober

To the Senate Special Committee on Aging,

Because I am one of thousands of people with disabilities that would be forced into a nursing home if I lost my home & community based care (HCBS) that enables me to be a productive and important member of my community, I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Ohio, is in a crisis. Our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or forced to call 911 because they are left in an emergency health situation with no support or help.

My friend was in the hospital for months after 3 days without help, and has never fully recovered!

The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make

a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

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Sincerely,  
Heather Sturgill

To whom this may concern,

My mother was only 56 when she started showing symptoms of dementia. She progressed very quickly which is sad because she was still taking care of my 13 year old brother. She had to sell her house of 25 years and lost several properties. As we continued to wait for social security disability to go through, she would get out of the townhome she was renting and wonder the streets. No one was able to take care of her. My brother had school, my other brother had to work and I lived 40 minutes away taking care of my children. We didn't have enough money to pay for a 24-hour caregiver. If we had the funds my brother could have quit his job to take care of her full time. This policy is so important to our disability community. We all struggle every day trying to take care of our loved one's and we really need the support from our government. Thank you.

Amber Bristow

Dear Senators,

I am writing to you today as a 50 year old woman that is the primary caregiver for my parents, both of whom are 89 years old.

My grandparents were Italian immigrants that worked hard and barely made ends meet. Because of that, my parents were never really taught how to manage money. While they never made a lot of money, they always seemed to spend every bit they had and never saved for the future.

My husband and I have done the opposite and we have quite a bit of money saved for our retirement. We will need it, as we are childless by choice and will need to use our wealth to pay for the care we need as we age.

I tell you this background because I want you to understand why I have the perspective I have. My husband and I each worked hard, have master's degrees, and each earned over 6 figures per year. Because we feel that social safety nets are important, we are fine with the rate of taxation we pay,

and wouldn't mind paying more to ensure that everyone has access to health care and the assistance they need as they age.

Because my parents never saved for their future, and my husband and I have been financially successful, I had been financially supporting my parents since they turned 80 and started spending more and more money on prescriptions and their medigap policy premiums were unaffordable on their social security income. Four years ago, my mother fell and my father was showing signs of dementia, so they really could no longer live independently.

I had to quit working so that I could move my parents in with me and care for them. Four years later, they are still here. I hate that my life has become that of a caretaker. I enjoy working. I am not a caretaker by nature. I have an MBA and was a senior level manager at a Fortune 500 company before starting my own business. I owned my own real estate company for 10 years and was netting about \$115 K per year. I had to give all of that up to become a caretaker - a job I never wanted and do not enjoy.

I do have a senior helper that I bring in every morning M-F, so that I can get out of the house. Originally, I was hoping that I could get a part-time job in the mornings so that I could improve MY life, seeing as being a full-time caretaker is making me miserable and actually, ill. However, I haven't been able to do so because the senior helper is sometimes late, sometimes absent, and sometimes off. Much of the lateness, unscheduled absences and scheduled absences are due to child care issues. In the 9 months that we have had this helper, she has experienced more lateness, and unscheduled/scheduled absences due to child care than I racked up in my entire working career. It has validated my decision to be childless by choice because if I had to live with the constant stress of missing work because of child care issues, well....I wouldn't. But so many of these home health workers don't have a choice!

We do have her through an agency, so they always offer to send someone in her place. But if you know anything about Alzheimer's patients, you know that they need routine and they need familiarity. So sending a random stranger over for a couple of hours on a random day is not very helpful to me - it is only going to cause my father to have a meltdown and that is just adding stress to my life.

I mentioned that being a full-time caretaker is actually making me ill. I have had auto-immune disorders the majority of my life. However, until I became my parents' caretaker, you never would have known it. My rheumatologist always remarked that she loved seeing me for my quarterly visits, as I was always laughing, smiling, working hard and doing well. I exercised, ate healthy foods, took my meds, got my check-ups, worked a lot, but also spent a lot of time with my best friends on the weekends. My rheumatologist now describes me as "full of existential dread" when she sees me. My friends rarely see me. I still exercise, eat healthy foods, take my meds and get my check-ups, but because I am miserable being a caretaker, I am stressed. Stress causes inflammation, which then aggravates my auto-immune disorders and then I get ill.

SO now that you understand where I'm coming from, here are my constructive thoughts around what government can do to improve the whole senior care system:

1) Make senior care providers an actual profession - there should be a training program that teaches required skills and certifies people to be a senior care provider/helper. Most of the people that agencies send do not have any special training other than some company specific training, which seems inadequate. There are special skills needed for this job - there should be a certification program at our

nation's community colleges to help train people to provide the type of care seniors need and family members can trust.

2) Once you create a certification program, a living salary will probably be an outcome of it - I personally believe there should be a national minimum wage that pays people enough to afford a safe place to live. I know that is not an idea that can make it through Congress, though. But if there was a certification program to become a senior helper, I do believe that higher salaries would follow. If you treat this job like a profession by making it well-regulated and routinely inspected, companies will hire workers with better skill sets, which in turn will require higher salaries.

3) Provide some sort of national child care program. This is something that will help all parents in this country, not just senior helpers. Many women (and a disproportionate amount of BIPOC women) are forced out of the workforce or forced into underemployment because of the challenge of finding decent, affordable child care.

4) Create a federal nursing home withholding tax. This would be similar to social security and medicare, but would be used to assist people with paying for nursing home care if they need it at some point.

Here's the paradox that I want to leave with you as I wrap up: these seem like programs that require a lot of tax dollars to enact, but they really aren't. If more people are in the workforce (like me and other family caregivers that have to either leave or be underemployed in order to provide care), there are more salaries to tax. If senior helpers are a true profession requiring certification and earning higher salaries, the raw dollars being collected in taxes is higher even if the tax rate isn't. People never like withholding taxes and they will always grumble about paying more when they don't perceive a benefit. However, Medicaid is picking up the tab for America's nursing home care today, and it is not getting any money into the coffers to offset that expense. If we at least created a trust fund to invest withholding amounts to do so, it would cost taxpayers collectively less by offsetting more.

And by the way, why is Social Security withholding shut off after about \$80 k in earnings? My husband earns \$140 k per year. We can well afford the withholding tax on every single dollar of it. And we would prefer that we paid it, so that we can be certain that Social Security will be there for us when we are old enough to claim it!

The problems our society is facing are huge, and getting bigger by the day as more and more baby boomers hit full retirement age, and Gen Xers like me decide to retire early. But it would be so easy to mitigate those problems if we just did it as a society. Every family trying to solve these problems on their own is creating a patchwork of care that is costing the government more money than it needs to, and is resulting in more stress and illness in family members than it should.

Thank you for taking the time to listen to my thoughts on this topic.

Sincerely,  
Joanne Mazzaferro

To whom it may concern:

Both myself and my husband are on disability as well as my mother. My husband is bedridden with extensive health issues, even with both my condition and my mom's we provide care for my husband, we have equipment for lifting and transferring him but our insurance doesn't provide any respite care and pays only a percentage for most of his needs leaving me in debt without resources to pay these debts. More complete coverage in areas of respite care and basic needs would be a wonderful addition. Also my son who has many many health issues cannot get insurance because he can't work so he doesn't qualify for Medicaid or insurance tax credit because he has no income therefore we are watching him die because doctors are refusing to see him because of his and our inability to pay and he can't get disability because of lack of recent medical care. This is an issue that definitely needs addressed. These are things of immediate concern to our family and many others in like situations, it seems our government has forgotten those of us who have medical problems and need help to stay home, the help is very little and for those who are working in the field of home health (which I used to do) the pay is low and the work is not only physically challenging but mentally and emotionally challenging as well. I think all those on disability living at home should receive medically necessary equipment and supplies like briefs, wipes, bedpads, nutritional supplements, colostomy, feeding tube, breathing accessories and other absolute necessities through insurance routes that pay 100% or 100% subsidy programs and the necessities need to be the ones that work for the individual not one product fits all.

Sincerely,  
Sheila McGhee

My name is Loretta Hall and I am the caregiver for my husband. He has Parkinson's and dementia and in wheelchair. I clean him toilet bathe him dress him give him his meds transport him to appointments. He has had this horrible disease for 16 years. We are both 72. I am a retired nurse I used to teach nursing students at a university but he needs constant assistance now so for 3 years I've become almost as much home bound as him. Other than grocery store. I'm not getting any younger and with his meds diapers equipment etc we are having a hard time with bills etc. I would continue to teach but can't afford a sitter for him and I've looked at caregiver pay but he isn't on Medicaid and we have a little in savings that I have begun pulling from it to pay bills. We could really use some help. We live in Indiana. Thanks for your support

Loretta Hall

Homecare saves lives from deprivation of the soul a slow suicide process due to loss of hope. As a State Tested Nurse Aide I've seen this effect on various disabled adults throughout my 24yrs of serving in different capacities. Home Community Base Services gives life to the despondent soul by keeping an Independence that most people take for granted the power to choose from day to day the course of their lives from when to take showers to what's for dinner. The simplest forms of independence truly makes all the difference to an individual who battles with the reality of their body possibly giving out on them permanently.

We as a nation that strives for freedom of choice in our world need to remember that charity does start at home with those individuals that are homebound due to disabilities that are a matter of life & death.

Lets keep this priceless gift through services that reflect the heart of our nation support Home Community Base Services (HCBS)!!

Sincerely  
Marisol Companioni-Johnson

To the Senate Special Committee on Aging,

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, we are in a crisis. Ohio has roughly 117,000 people on home care waivers through multiple state agencies funded by Medicaid. We are in a state where there are more people over 60 then in their 20's. The growing need for caregivers will increase as the baby boomer generation ages and/or more people become disabled.

Ohio has many systemic problems that challenge our ability to recruit and hire workers. Some of our issues with recruiting workers include but are not limited to low wages, managed care contracting issues, an inaccessible provider enrollment process, lack of oversight to make sure state agencies follow the Americans with Disabilities Act, provider pay issues and training challenges. Investing in a healthcare workforce is important to make sure people have equal access to supports and services in their communities. It costs 1/6 the cost to live in the community then in an institution . It is our Olmsted right to live in the community with the right supports possible.

We appreciate the Covid relief funds but those funds did not provide any sustainable platform to help recruit or hire workers. In fact, many providers can't even access those funds. It is heartbreaking as many providers are in desperate distress with exasperated costs of PPE and/or Covid related challenges and no support from the state of Ohio. We need funds that will raise the wages— the reality is our providers need a living wage.

Ohio needs funds for a long term investment in home and community based services. We are asking you to provide funds to raise the wages of our home care workers so that these jobs can qualify for funding under the workforce investment act (WIA) so that states can bring training opportunities to people who want to go into in the healthcare workforce. We believe that a living wage will help bring people out of poverty and allow more self sufficiency for families across our state.

I am artist and person with a disability. While going through my own awful struggle to access care, I decided to make a visual representation of our struggles to recruit workers in Ohio. In 2021, I interviewed people across the state of Ohio and asked them if I could paint them into art. People shared their struggles to access home and community based supports. Many people shared on how there is no staffing, low wages and the fact people can work in fast food and get paid more money then in home care. These art pieces are a visual representation of what it is like in Ohio and also on the National end of home care.

In my own personal story, my biggest challenges to recruit and hire workers are a reflection of lack of oversight with state agencies following the federal laws like the Americans with Disabilities Act , managed care contracting issues and low wages. I also have Limitations around the electronic visit

verification laws under 21st Century Cures Act and the Ohio Safe at Home laws. At \$12.96 an hour with no benefits it is hard to recruit anyone for this job. In my particular situation when it takes managed care medicaid organizations 17 months to contract an established medicaid provider and there is no oversight it produces additional hardships because people cannot wait 17 months for a job people don't want to stick around for long haul to begin work—would you? It surely is a CMS oversight issue that really needs addressed as well.

HCBS workers need a living wage- inflation has made the cost of everything go up and some workers cannot even afford gas in their car to come work a 3-4 hour shift. I am on day 271 of my back up plan for home care because Ohioans like myself cannot recruit workers. I am authorized 58 hours of home care a week. Most weeks I see maybe 7 of those hours if I am lucky. It is usually only one day a week that I get a hot meal and shower. I am not alone this is the case for thousands of Ohioans with disabilities and seniors. Those authorized care cannot get that care.

We all know #CareCantWait .... This could be you... everyone is one Caregiver away from the forced incarceration into a nursing home or even death.

The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide. I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country. Thank you.

Sincerely,  
[Alicia Hopkins Columbus, Ohio]

#### Image description #1

People with disabilities, family members of people with disabilities, caregivers and others around Ohio with word cloud bubbles speaking up about the caregiver crisis in home care, nursing homes and developmental centers. Many people talk about paying a living wage, low wages overall, ADA access issues, challenges with provider enrollment, finding workers. The piece has a flamingo red road with green and yellow grass in some parts and solid green grassy area in other parts. There is a human heart in the center and hands multi colored in middle reaching down in a city. These issues effect people of all races, genders and cultural backgrounds.

#### Image description #2

Yellow and apricot background people with disabilities and caregivers all around with a mixture of families. This piece highlights the Ohio HB 110 hearing so there is a number of speakers at podiums in one panel sharing some statistical information about the direct support crisis. There are also hcbs care managers sharing about struggle to find workers in our states out of date provider directories. There are caregivers sharing about the low wages. Each piece a word cloud bubble that is in the center. One bubble says "Ohio needs an Immediate action plan equipped with hiring initiatives, systematic overhaul to provider enrollment and contracting issues." Another bubble says "There are thousands of people with disabilities and seniors without the authorized care on home and community based waivers through the Ohio Department of Medicaid, Aging and Developmental Disabilities." Another bubble has



an eye in it and says "All eyes are on legislators to do the right thing." Lastly just Ohio must invest in healthcare workforce.

#### Image description #3

This is an art piece featuring a candle in the middle that gives us a moment of silence for lives lost due to the lack of caregivers across the United States. So there is a big map of the United States. There is also a magnifying glass that has state of Ohio in it. This piece is National overview... letting people know ,ore than an Ohio issue. There is flamingo red background with black tan and khaki colored letters say one caregiver away from... it goes over into right canvas is painted grassy green with gray tombstones. In white letters it says without care more people will die! Also there are people on a gray sidewalk have word cloud bubbles say "Thousands are without care..." #WeAreEssential "We need an immediate action plan." "One more day without a plan could mean one more life." There is also a plane in this piece flying overhead says #CareCantWait

#### Image description #4

One Caregiver Away From..in purple text.

There is a multi color hand goes into piece from an angle it hands a heartbeat long through the hand . There are people all around some with disabilities, some families, caregivers and every day people. There are people of different races, genders and cultural backgrounds. There is a gray line goes through top with white letters that say low wages, plain language, credentialing, EVV, systemic medicaid issues. Blue sky with some green lines in it with yellow and green grass. Some of word cloud bubbles include things like ADA, one of says "who will step up to help " people standing speaking of low wages.

To the Senate Special Committee on Aging,

A child dying before a parent. A child left with no other option than a nursing home when a parent dies. Both horrifying. This is the nightmare that keeps me awake at night. Kevin is 38 years old; I am 70. He was diagnosed with spinal muscular atrophy at the age of 9 months—the No.1 genetic killer of children under the age of 2. The fact he has lived this long is with the help of nurses through the Medicaid Waiver Program. He was in the first group of people to be signed up for the waiver program in 1992.

Today Kevin's specific care include the following:

- Tracheostomy tube
- Part-time ventilator (nights and when ill)
- G-button – nights and when ill
- Wheelchair
- Shower chair
- Bedside commode
- Multiple respiratory treatments (morning and evening)
- Total help with all personal care needs
- Molded wheelchair to accommodate his scoliosis
- Hospital bed
- Ceiling Lift

In spite of this all, he is a very smart, well-spoken, polite young man, having graduated from college magna cum laude with nurses accompanying to classes.

The shortage of healthcare workers is at a crisis right now. In thirty years, I have never seen it so inadequate. It threatens the health (both physical and mental) of client and family. There are many reasons why this has happened, some with resolutions; some not.

In 1992, when Kevin started, there were many more nurses than clients; now there are many more clients. Waiver programs are now open to many more people. Because of our wonderful technology, people with complex medical needs are living longer.

In Ohio, our Medicaid Waiver system is administered through two separate areas: Department of Health and Department of Developmental Disabilities(DODD). Kevin is on the MyCareOhio Waiver through the Department of Health with care management through the Western Reserve Area Agency on Aging. Families can seek out nurses through agencies or independent providers. It has been my experience and well documented through the Ohio Independent Providers Sites that many nurses/providers prefer going through DODD because it pays better. This has hurt many of us in terms of getting appropriate staff. I don't really understand how one department can pay more than the other if they are both Medicaid dollars. I only know it is hurting my family.

Of course, the pandemic, has added to this shortage. People took a closer look at their jobs and what they liked and did not like. Many decided they valued jobs that valued their experience and paid more in line with that experience.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years.

So back to us, Kevin has a nurse only one day a week, we are approved for six. He also is approve for seven nights a week. This is a hit/miss type of thing. We have become prisoners in our own home. If I get sick or go into the hospital, he would also probably have to go into a hospital since we have only a fraction of the care he needs.

I will take care of my son until I know longer can. However, with the lack of homecare, I fear it may well be sooner than later and will be forced into a nursing home that cannot adequately address his medical or physical needs.

He deserves better. PLEASE HELP.

In appreciation of your time,

Carolyn Anderson

I am 62 years old and have been a quadriplegic 37 years and I want to express my support of HCBS as being able to live in the community is of utmost importance to me.

Also wanted to state, I feel the age cap (through the age of 64 years) should be lifted for MBIWD as many disabled individuals continue to work past age 65.

Thanks for your attention in this matter. Please email me if further information is needed.

Sincerely

Connie Fraley

To the Senate Special Committee on Aging and Staff

I am writing to request that the federal government expand access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my friends and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when we have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help us get out of bed, take care of our hygiene needs, and help us get started with our day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or forced to call 911 because they are left in an emergency health situation with no support or help.

*I have experienced these problems firsthand. Due to the low pay for providers along with the attendant shortage in California, it has taken me over a year to find a caregiver to work for me on weekends. The caregiver has failed to show up to work at least three times with no notification. Would you still have a job if you didn't notify your boss on three occasions? Why do people have to suffer in such situations? California and other states have no backup attendant services so I was left to fend on my own until the early evening when I could finally get another attendant to help me. I wish to fire my current weekend attendant but, I realize that it will probably take me another year before I find a replacement. So, I am still having to deal with my current subpar attendant.*

The issues are apparent and obvious to all of us that use direct care staff. Direct care providers make a median hourly wage in California of \$16.00 an hour or \$30,720 each year and that is not enough for a single person, let alone a mother with a family. It is very common to have attendants applying for food stamps and Medicaid.

The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Californians with disabilities and people nationwide.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Please pass this critical legislation so

that people with disabilities know that their independence, health, and safety matter to our country.  
Thank you.

Sincerely,  
Marissa Shaw  
Richmond, California

to the Senate Special Committee on aging

Please expand access to home and community based revenue and invest in funding and resources to directly support the workforce caring for our elderly Americans.  
there are staffing shortages that make caring for loved ones a very hard, meager job. citizens in nursing homes receive less than adequate care-my mom was in a nursing home and did not get a shower the whole 20 days she was there. for an example.

the caring people who chose to keep their loved ones at home need some adequate affordable help. If you are poor, you get medicaid-if you are rich, the cost doesn't matter, but if you are just above poverty or low middle income, you get no help. The proposed tax credit may help some folks but i don't expect it to help me at all. There needs to be some sort of respite care available for those of us who take care of our loved ones 24/7/365. it's a grueling, thankless job.

Please help the caregivers.  
Thank you.

Debora Webber

Dear Senate Special Committee on Aging:

We are writing to you to submit a statement for the record about the critical nature of home and community-based services to our lives as individuals with disabilities. Currently, there is a dire workforce shortage of care providers across the nation, including, but not limited to, California residents with disabilities who are subject to going without care, having to accept minimal or subpar care, or who face a constant crisis in trying to find elusive caregivers to provide us daily personal care services in our own homes.

We are at a Katrina level of crisis in trying to find anyone, even minimal care services, to assist us with bathing, grooming, dressing, bowel and bladder care, getting in and out of bed, and assisting with our paramedical service needs to sustain independent living over being forced into institutional placements. Because the shortage of care workers is magnified we are having to face sub minimal care to keep workers who otherwise we would replace because of their inadequate ability to do the job. Wages are so low and benefits are poor in this field that individuals with disabilities cannot find competent reliable direct care workers for our jobs. Government programs must improve the pay and benefits for our ability to attract and retain competent workers to provide persons with disabilities and

seniors the dependable long-term care that such individuals with disabilities and seniors desperately need.

State HCBS programs are duplicative leading to unnecessary provider training, enrollment processes, and an approach based on different care models that must be simplified, consolidated, and uniform with changes made to the nurse practice act.

The entire home and community-based services system is completely broken and needs to be overhauled with major improvements that the Better Care Better Jobs Act can hopefully begin to address.

The following reforms are critical going forwards to ensure access to care for persons with disabilities and seniors:

- 1) A national uniform assessment system for recipients of care;
- 2) Delink the HCBS system from the medical model into a social and human rights model of care with emphasis on self-directed and independent provider care where the state has liability for insuring recipients have meaningful access to care and not some hollow words on paper;
- 3) HCBS services must be transferable and portable for the end user to be able to get services across state lines without limitations and changes to an individuals' whole person plan;
- 4) The transferability and portability of HCBS services must be paid by a home state and should not cause a reduction in services to the individual with a disability in being served by the state they migrate to on a temporary or permanent basis. However, if the individual recipient moves permanently to the new state, the cost of care should be transferred permanently to the new state with portability provisions that keep the individual's plan of care intact and not subject to arbitrary reductions;
- 5) States must be required to provide seniors and persons with disabilities the right to access 24/7 backup emergency HCBS services during care provider absences. Such backup contracted HCBS services must be available to:
  - the recipient of record who does not have a care provider (because they cannot find competent, stable, dependable employees with ability and skills to perform needed tasks);
  - to recipients who require paramedical services (i.e. bowel and bladder care, catheter care, colostomy care, wound care, injections, feeding tube assistance, ventilator care, oxygen assistance, etc.); and
  - to recipients who have been exposed to or test positive for COVID-19 and any variants following provision of all safety protocols and regular testing.
- 6) Weekend and holiday pay differential for direct support worker availability for these HCBS jobs so that the recipient can find workers and not be abandoned on holidays and weekends like tends to happen regularly especially on holidays to individuals without family member care providers;
- 7) Local care provider referrals that identify the skills of the provider, days and times of availability, providers who can communicate in your chosen language, insures their knowledge about abuse and neglect requirements to help insure non-victimization of seniors and disabled recipients including instituting a recipient complaint process that doesn't induce fear of institutionalization and requires the

immediate disbaring of care providers who are found to have inflicted emotional or physical abuse and neglect on recipients needing care or who've abandoned recipients without substitute care availability and/or not performed duties as part of care assessments resulting in harm to HCBS recipients, insures provider referrals are near the recipients' location, and requires referring agencies to uphold their responsibilities to perform ongoing outreach and provider recruitment with state and county oversight and discipline;

8) Lift overtime providers' hours caps across states that inhibit the ability of HCBS recipient employers to enjoy an individualized independent normal life of self-determination which is person-centered with supportive services with emphasis that direct care providers are there to assist the individual in achieving their own goals, dreams, and desires so the person can thrive and reach a positive lifetime outcome. These arbitrary state imposed HCBS provider hours caps inhibit the ability of recipient-employers to take a vacation, travel, access employment and career advancement opportunities, access medical treatments because provider hours caps limit freedoms most Americans take for granted by requiring recipients to hire a different care provider in the middle of pursuits or bring two providers at their expense. These arbitrary caps disproportionately impact persons with the most severe impairments like Ady Barkan, lawyer and activist, or those persons similarly situated;

9) Insure access to programs, services, and activities that are best suited to the individual's needs, choice, and desired outcomes for all persons with disabilities regardless of type of disability whether physical, mobility, hearing, visual, mental, learning, and/or behavioral health without unnecessary appeals to achieve access to ones' care needs;

10) Insure access to competent and dependable supportive services that is provided by direct support workers with life skills and ability to perform tasks and exercise judgement in the case of immediate emergencies to which a provider must have the capability to respond in a reasonable and timely manner;

11) Meaningful access to programs, services, and activities must prioritize the right of the individual with a disability to access supportive services outside of the family home if they wish to live independently in the community. Recipients should not be held captive to their family home to receive needed care based on a family's need for income. Likewise, HCBS recipients should not be denied access to care based on the lack of a care provider workforce shortage that states could have addressed over the past three decades as part of state and county reports on meeting care needs of recipients living in the community. State HCBS programs could impose a county cost sharing provision for recipients with disabilities and seniors who become institutionalized simply because they could not access care to live in the community based on county failed care provider recruitment to incentivize counties to be interested in keeping recipients living independently in the community;

12) Access to care workforce should not prioritize family providers in a manner that maintains low state wages for all providers, but wages should be set at a living wage level across all states and counties which differs by state;

13) Offer differential pay to providers willing to work for HCBS recipients with severe impairments and disabilities who are predominantly reliant on non-relative community care providers including individuals with multiple providers where at least one provider is a non-relative provider, where a recipient cannot find a provider or in cases where adults and seniors need extraordinary care.

Specifically, differential pay for recipients with severe impairments' providers must be as follows:

#### INNOVATING DIFFERENTIAL PROVIDER PAY

Provider wages raised across the board will not help those with severe impairments as wages must be differentiated for providers willing to work for recipient employers with severe impairments who:

- 1) have no relative providers and/or live-in providers;
- 2) recipients with severe impairments with two or more providers where at least one is a non-relative community care provider; or
- 3) extraordinary cases for recipients with a severe disability who have a relative provider and/or live-in provider,
  - and where other providers would be hard to locate to serve such extremely disabled recipient employers with
  - high complex care needs over the age of 18, or for where the difficulties exist to serve such recipients in
  - finding outside reliable competent community care providers, an exemption should be granted allowing
  - differential higher payment for a relative and/or live-in provider. *However, the adult child who is over the age of 18, has every right to a person-centered plan to be free of parental control (or outside control) to allow independent living and not be used by parents and a relative and/or live-in provider as their source of family income if the adult child freely chooses to move out of a family home setting and live independently in the community on their own with services and supports.*

Without differentiating provider wages in light of a county cost of living and a local city minimum wage, it WILL NOT uplift those IHSS/WPCS/HCBS recipient employers either out of the dire inability to locate competent non-relative and/or live-in providers to work for those of us with a significant disability. This is especially true since service competition with home health agencies and hospitals are driving up care costs under a medical model and competitors are chasing federal HCBS funding dollars for their health care programs and managed care systems, sometimes collecting funding while denying access to care because of conflicts of interests and profiteering (see Iowa State Auditor's report on their managed care issues). See <https://www.usnews.com/news/health-news/articles/2021-10-20/auditor-iowas-privatized-medicaid-illegally-denies-care> and <https://www.weareiowa.com/article/news/local/iowa-medicaid-survey-report-state-auditor-rob-sand-managed-care-organizations-mcos/524-8b88f9a2-7fd2-451b-8249-fa12580e8fed> and <https://www.legis.iowa.gov/docs/publications/ADRPT/1139698.pdf>

The pandemic has exposed the critical nature of supportive services that is absent, but are needed in this country. Many persons with disabilities and seniors in care facilities have died. Many persons with disabilities and seniors are living in their own homes and are socially isolated, absent a circle of support, and are going without the care that they need which is not adequately captured by HCBS payment or statistical data. California and other states are denying access to care on a regular basis through regulatory loopholes. For instance, under California's In-Home Supportive Services (IHSS) program and Medicaid Waiver Personal Care Services (WPCS) programs that declare recipients as the employer, under direct knowledge of the dire direct care worker shortage, state agency public officials claim to CMS to be compliant on paper with federal COVID orders to access federal Medicaid funding. They do

this by issuing California Department of Public Health (CDPH) or California Department of Social Services (CDSS) state vaccine orders holding recipient employers responsible for implementation of insuring compliance with that order for their IHSS/WPCS care providers. Of course, California state agencies have no intention of asking HCBS recipient populations for proof that care providers are actually vaccinated or for insuring recipient-employer providers are following weekly testing protocols to verify federal order compliance. Asking HCBS recipient-employers would risk driving care availability lower than the dismal level it is already and asking would jeopardize state HCBS Medicaid funding.

In 1999, California chaptered legislation known as AB1682 to create county IHSS Public Authority or county consortium agencies to be the employer of record for collective bargaining on county wages for IHSS care providers. As part of that legislation, a useless caregiver referral system was established at county IHSS Public Authorities as well as an alleged backup provider emergency services system which is basically only on paper and is pre-disposed to deny backup services to care recipient employers, is unpublicized to recipient employers, is not available 24/7, and fails to serve recipient employers with disabilities and seniors trying to remain living independently in the community against all odds especially those with severe impairments and disabilities most at-risk of institutionalization. Alleged county backup service contracts are for simple liability protection for the IHSS Public Authority agency director and staff as IHSS care providers are considered the agency personnel. Simultaneously, HCBS recipients are deemed the employers and care gaps are alleged to be addressed (on paper) to claim that the IHSS recipient employer allegedly has access to backup care, but no state or county agencies audit these contracts. No state or county agency insures the individual IHSS/WPCS/HCBS recipient-employers can actually access the supportive services that the individual with a disability and senior has been assessed for and services authorized.

The California State Auditor issued a report on the state IHSS program dated February 25, 2021 which stated 40,000 recipient employers were going without care and approved In-Home Supportive Services (IHSS) program services each month in 2019. Parts of the audit were disputed by the state California Department of Social Services (CDSS) upper level staff (some retired December 2021), but the California Auditor refuted the CDSS agency denial by saying that the state agency was using the provision claiming that the recipient of care was the employer to deny its responsibility and liability to insure access to care for alleged recipient-employers who are undergoing a severe IHSS/WPCS provider shortage that has left individuals with severe impairments struggling to find anyone to work to access care that has been authorized and approved on paper.

California State Auditor's Reports on IHSS (there are 10 reports, recent most relevant):

February 25, 2021 Report 2020-109:

Fact Sheet: <https://www.auditor.ca.gov/pdfs/factsheets/2020-109.pdf>

Summary: <https://www.auditor.ca.gov/reports/2020-109/summary.html>

Full Report HTML: [Report 2020-109](#)

Full Report PDF: <https://www.auditor.ca.gov/pdfs/reports/2020-109.pdf>

Recommendations: <https://www.auditor.ca.gov/reports/recommendations/2020-109>

State Auditor Rebuttal Response Comments # 4 to CDSS on IHSS: [Report 2020-109](#) and see other reference "as we note here" in # 4 comments by Auditor.

See Appendices B sections: [https://www.auditor.ca.gov/reports/2020-109/responses.html#AUDITEE1\\_rebuttal](https://www.auditor.ca.gov/reports/2020-109/responses.html#AUDITEE1_rebuttal)



Conclusion

Please take these points into consideration to make any necessary changes to the proposed Better Care Better Jobs Act. These critical improvements to home and community-based services for persons with disabilities and seniors reliant on long-term services and supports to live independently and safely in the community in their own homes out of expensive institution care settings.

It is vital to the civil rights of persons with disabilities living in the community to be able to find care based on an Independent Provider and social and human rights model where individual recipient-employers of direct support workers can have a robust workforce of care providers to select from to deliver care to meet the individuals' personal care needs based on their disability, including those who need paramedical services in California and across all states.

Respectfully,

Connie Arnold, M.S., Health Services and Public Administration Policy, Disability Rights Advocate 30+ Years

Marissa Shaw, MPA; Policy Consultant on Rights of Persons with Disabilities & Seniors

To whom it may concern,

I believe it is obvious the the "Workers Union" SEIU-775 is a pure profit consuming union that relies on making their profit by force. My personal experience dealing with them has been a most unprofessional one. Their letters, emails, speakers, consistently wine and complain about whatever issue or opposition they face. They cannot dare even be questioned, have pushed for a forced joining of their union. I still have not received a refund for dues I payed that I later found I did not have to. When I was hired as an IP I was told it was mandatory and later found out it was a complete lie.

In conclusion:

A union who's foundation is built on dishonesty and no choice must go. Unions need to be established purely for the benefits of the workers who choose to be a part of it and need to have 0 political ties and any donations need to be to neutral parties with no agenda. This philosophy is far from SEIU-775 and not only should they not be welcomed into this transition, but should be removed completely.

Thank you for taking the time to review my experience,

Scott Damico

Hello,

My name is Breanda Taylor.

I was blessed with 2 amazing parents.

It's my honor to care for my dad them now they are elderly and need me as I once needed them.

I should not have to leave my career, eat my savings I grew as a single mom, and stress about how to eat and pay bills, put my daughter through college while providing the care my parents need and deserve.

They make “too much” for Medicaid services but not enough to “pay” for care to live.  
My dad was in The Army National Guard for 9 years and deployed by Governor during hurricane Donna, and yet is. It religions for any benefits!

This HAS to change!!

Please make the necessary adjustments to allow family caregivers to be paid in order to survive while honoring our elderly.

I'd love to advocate, speak and assist in anyway I can.  
Please feel free to reach out.

From a concerned Lewy Body Dementia Daughter.

Thank you,  
Breanda Taylor

Dear Committee,

My 13 year old has developmental disability. Despite his disabilities, he is a very social person and always has a big smile on his face when he interacts with other people. He enjoys living with family and participating community activities.

I am worried about the huge waiting list for people like him to get home and community-based services (HCBS). Direct care workers are deeply underpaid. The perfect HCBS programs and services only exist in the government booklets and websites. In reality, it is hard to hire direct care workers to run the programs because of the low wages offered. And the quality is suffered because of the high turnover rate.

I am also worried whether or not I can still keep my job (even with my earned advanced degree), if I have to fill the gaps due to the shortage and unreliability of HCBS.

Please support a historic investment in HCBS, so developmental disabled people can get the support they need to live in community - instead of in institutions. Families like ours really need to get a peace of mind.

Regards,  
Xiaopeng Li

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. In our family, we have been supporting our 31-year-old son at home in the afternoons because his provider is so short staff that they've shortened hours and staffing is so tight that we aren't able to hire a PCA because the rates are too low.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Win Evarts

Dear Committee,

I am a constituent and a father of a developmentally disabled son who relies on HCBS services. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
William Robinson

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

As the mother of a special needs individual on a PFDS waiver my family is personally impacted by this situation. As a result I am weighing in to ask that this request for support of a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Sincerely,  
Amara Geffen

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

We have 2 sons age 25 and 22 who both need to have places to go, friends, support and a place to become as independent as possible..

My husband and are are getting older and will not be here for ever, family is not an option so we need help

Please help pass this,  
Julie O'Rear

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

My 47 year-old son, who now lives with us, relies on the support he needs for all aspects of daily living. Untrained and inexperienced staff require us to provide on-the-job training and emergency support even as we age and start to need assistance ourselves. We fear for the future, and his.

There isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Stephen Young

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I am extremely worried about the adequacy of care for my 45-year-old developmentally disabled daughter now that I am 70 y/o and my eyesight and general health are in sharp decline. Since she has no siblings or close relatives, I have to hope that our government will take care of her. God bless you for your efforts to ensure my daughter's safety and health.

Regards,  
Dianne Moffat

Dear Committee,

My adult son is affected by autism. He has been approved for 11 hours of community habilitation for years. We have NEVER received more than 4 hours a week due to staffing shortages.

My son graduated high school. He CAN be eventually fully integrated into a social & employment environments. But HE needs your help! Each day he becomes more isolated and depressed. He is now in counseling. PLEASE help us!

People with disabilities rely on home and community-based services (HCBS) for everyday things like

employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Renee McAfee

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My son lives in a group home. The staff is wonderful to him, caring and compassionate. They are the front line workers. Their pay scale is so low, and turnover is extremely high. We lose valuable staff over and over. The direct care workers endured over the past two years working with Covid all around them. They stayed and held down the fort. We are all so afraid there will be no group home staff in the future, and houses will close. Parents are getting too old to care for their loved ones. What will happen we ask every day. This is a 24/7 worry. Please pass a pay raise, and keep community based services in place. Our most vulnerable populations needs you.

Thanks,  
Cynthia Perrone

Dear Committee,

My 37 year old son has autism and lives in a group home as his father and I can no longer care for him at home and other living options are not available. His needs are significant and funding to support his care givers who provide his daily living needs is crucial. These folks are under paid and homes are understaffed as a result of staff turnover. Good dedicated people can't afford to stay when other much easier jobs pay so much more!

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Jaclyn Merens

Dear Committee,

I am a 67 year old parent of a 30 year old son with autism and co-occurring mental health challenges. My son will probably not be able to ever live independently and will always need some level of support. My ability to continue to take care of my son is diminishing due to my own age. He has no siblings and I worry every single day about what will happen to him when I am no longer alive. Although he is lucky enough to have home and community based services in Pennsylvania, that is becoming meaningless in an environment where providers are no longer able to hire direct care and other professional staff because they are so vastly underpaid.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Carol Bowen

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like

employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I know first hand about the staff shortages which have caused a lot of issues with getting proper support for my 21 year old grandson with severe Autism and I DD. He is such a sweet innocent boy but he is a runner which puts him in constant danger. my biggest fear is that he will be able to get out and run into the street and be hit. This is a real possibility because the HCS Provider can not find staff due to low wages for this kind of work. Please, please pass this bill to provide needed assistance so my grandson can get the care he needs.

Thank you for looking out for the most vulnerable of our population.

Regards,  
Charlene Weigel

Dear Committee,

Hello, I am your constituent and the mother of a 24 year old man who is autistic and has a cognitive disability. I'm writing to urge you to increase investment in home and community-based services. My son has the potential to be employed, which both would be good for him and would save the government money in the long run. However, employment services for him and his peers is woefully underfunded. Because he would need more time than average to learn job skills and be supported by a job coach, he can't access the necessarily more intensive training that would help him contribute to society.

There isn't nearly enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Carole Slipowitz



Dear Committee,

I have a 31 year old son with autism who receives help through home and community based services. He is very impacted by his autism and has very minimum language. But he attends a special program for adults with autism during the day held at the University of Cincinnati and paid for by a HCBS waiver. He has HCBS providers that allow him to spend time in the community doing lots of activities such as horseback riding, skiing, eating out, art classes, etc. Our son got on the list for these services when he was around 5 years old and finally got to the top of the list when he was 18 years old.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Judy Newport

Dear Committee,

Home- and Community-Based Services (HCBS) are the gateway to integration for many individuals with disability. For many of the people I know and work with, it is an opportunity to fully engage in integrated settings and discover oneself, their personality, hobbies, interests, talents, and much more. For some, it was the escape from an unpleasant group home setting; for others, it was the chance to explore the city and find work. These opportunities are made possible by the Medicaid waivers and HCBS. Because happiness is not found simply in the quantity of life, but the quality.

The Medicaid Waivers provide opportunity for self-discovery, the pursuit of passion, and finding value in those who have spent their lives believing that they have none. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
James Murphy

Dear Committee,

People with disabilities and their parents/guardians rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, working on life skill goals and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Robin Lopez

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I manage a supported living program in Oregon, my office supports upwards of 35 to 40 individuals whom experience a variety of Intellectual and developmental disabilities. The supports that our company offer to these people runs from support around medication, hygiene, home upkeep, cooking, shopping, money management, Pretty much the entirety of their lives to allow them to live as independently as they are able. They work in the general community, they have friends, they enjoy going out to dinner, movies, or walking the park. They love meeting people, and being part of the world as a whole. They deserve to have people see them for more than just their disabilities, and they deserve to have help when they need help.

Please, Please, help us help people who have every right, and every need to be a part of the world and to thrive. They can not do that without our help.

Regards, Amie Goar

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Personally, my daughter is 24 years old with Down Syndrome. We are much older parents. She is incredibly capable and has the ability to learn new things. Her dream is to be able to continue the very full life she has now, because of what we are willing to provide, which is mainly in the community, after we pass. Having access to a wide variety of HCBS is crucial to the possibility of this coming to be. This support is what every person should get to have a meaningful day to day existence.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Jacqueline Stroh-Tillman

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I am the grandmother of a wonderful young lady with autism. She will be 21 in May and I will be 73 this summer. We are a very small family unit and I worry what will happen to her once I am gone. She will need help with employment, housing, and getting around. I hope she can count on you to make these supports possible. There are many other Tennesseans looking to you for support too. I ask you to consider appropriately funding home and community-based services to make these resources available to them and help give them the tools for independence in their lives.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Thank you for your consideration.

Regards,  
Denise OBriant

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

As the parent of an adult daughter with multiple disabilities we realize how important access to community support is. This is a community that is often pushed aside for those who can more easily speak up for themselves. As one of the most vulnerable populations, we must make it a priority to invest in services (ie., community housing, transportation, activities, etc.) that allow these individuals to live as a productive member of society.

Regards,  
Betsy Cousins-Coleman

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

While waiting years for a spot in an HCS Group Home my Intellectually and Developmentally Disabled daughter had hundreds of mental health crisis In turn the mental health of the whole family suffered. We placed over 40 calls to 911 for assistance in containing her safely. E.

What a trauma for her, her siblings and us, her parents. Our family savings were heavily taxed as we tried all sorts of care and paid extra for in-home help. We are fortunate to be well-resourced, and it still brought us to our knees and kept us there so long we still get PTSD.

There is no way for a family to maintain 24/7 care without breaking down. In addition to attending the complex needs of my daughter, we had other children to consider. On top of that we were expected to:

- recruit, train and supervise in-home help. -
- attend the numerous medical/behavioral health appointments.
- Compete with other special needs families for specialized health services that are affordable and decent quality.
- Manage a team of psychiatrist, therapist, physical therapist, speech therapist, School District team, local DHS team, doctors, special recreation providers (hard to find!), recalcitrant insurance and medicaid providers, AND advocate for disability rights.
- Don't even get me started on the horrors of medication management.
- Repair relationships after property damage and attacks on family members and school employees,
- Help every family member deal with the trauma.
- And all without breaking down.

Impossible. The school district and our family were overburdened by needing to "backfill" much of the void not filled by HCS.

And my poor Andrea, she was in crisis so much that it was normalized for her. Which of course worsened her condition, prolonged her need for intensive interventions, and cost more.

UNDERFUNDING NECESSARY DISABILITY SERVICES INCREASES THE NEEDS FOR FUNDING AND DECREASES THE WELLBEING OF THE INDIVIDUAL, THEIR FAMILY, AND THEIR COMMUNITY.

Finally after assaulting an in-home therapist from Texas DHS she was given an emergency spot at the front of the HCS waiting list. It still took months to find a placement, during which time therapy was suspended as too dangerous.

After years in an HCS Group Home with 24/7 line-of-sight care Andrea is doing much better. She still requires a lot of help. But the frequency, intensity, and duration of her mental health crisis has dropped significantly. She participates in community activities, is training for the local Special Olympics swim team, and attends a Day Habitation.

There are tens of thousands more IDD children and adults on waiting lists across the country. Their own mental health slowly eroding as their communities, schools, emergency services, and family falter under their care. For many of them they face a future where homelessness, jail, or death is as likely as placement in a safe Group Home.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions, on the streets, or in the grave.

Regards,  
Gloria Krein

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. We want to provide care for our own daughter for as long as we can, but we need professionals to complete the "circle of support" before we are gone. Support services already in place help us to "stay in the game" longer to reduce the overall burden of care on society at large.

Regards,  
Sheila Bengtson

Dear Committee,

Our son, Jon Herzog, is 41 years old, and lives with cerebral palsy, cognitive disabilities and Crohn's Disease. He relies on his group home-based staff and visiting nurses to live every day. PLEASE INCREASE SUPPORT FOR THESE CRITICAL CAREGIVERS WHO MAKE OUR SON'S LIFE POSSIBLE.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Jennifer Rathbun

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

My developmentally disabled, 18 year old son needs care 24/7. I have MS and am unable to care for him. He needs to be in a group home and we need congress to support community living.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Joanne Wilson

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I've had to rely on my 70 year old mother to provide for my total care needs for the past 3 years; first, because of Covid restrictions, as I am at high risk for a fatal outcome and could not have an aide in the house, and now because of the work force crisis for home care workers due to low pay and minimal, if any benefits. States do not have enough money in their budgets to solve this crisis without federal help. The lack of adequate funding has severely impacted my ability to get out in the community and to pursue work.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Katrina Jirik

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

For the last 24 years since August of 1998 I have lived in my own apartment with the care that I require due to a disability of C.P. With the support of both family friends and my care staff I have completed two years of college, served on the a D.D.C Council etc. With the finding for the support that I need I would be in a nursing home.

Regards,  
David Schlegel

Dear Committee,

I have two adult sons with ASD and other disabilities. My older son relies on the HCBS system through Medicaid and Community Mental Health to relieve the caregiving burden on me and my husband, who of course do not get paid. The pandemic has caused a lot of the providers to go out of business or become severely short-staffed. My son is also aging out of all special education services, so he will need even more support through HCBS. We need to improve and expand these services, so my son does not "fall off" a cliff when he ages out of school and can have a productive life, and also because we parents are aging and will not be able to provide all this unpaid support forever!

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Thank you for your attention to this important matter, our loved ones lives depend on it!

Regards,  
Barbara Byers



Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. My brother who was born with Down Syndrome thrived in a CBRF with the help of his staff and the services that were provided. But Direct Support Staff are not paid adequately for the work that they do.

Also, there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Frances Hoffman

Dear Committee,

Hi, I am the Mom and guardian of 22 year old twin young adults with ASD. They would not be able to attend community college and get an education without this support. They do not drive, and rely on me for many supports. But they are doing well in school and will be graduating soon with AA degrees and are looking for employment. They are awesome and capable young men who deserve a chance and a better life. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Tammy Sadoff

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone, MY FAMILY INCLUDED. My 30 year old son with autism is now in a group home in MA (after we relocated for work) because he was stuck on a waiting list with NO services in MD. He was found eligible in MD, but no money was available to keep him home with us, as he needed 1:1 support & my own health issues impacted his caregiving. Too many people are stuck on waiting lists and not getting the services they need.

PLEASE support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Kathleen Hamelin

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

As an aging parent of a young adult with disabilities who is on the waiting list, serious action needs to be taken to fund the HCBS program. I provide 24/7 care that includes every aspect of daily living, transportation, care needs, medical assistance to name of few areas, that without those supports, life would not exist.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Stacy Irons

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on

waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Please also invest some of that money for a raise to DSPs in a way that allows them to assist with parenting tasks when working with parents with disabilities.

Thank you!

Regards,  
Julia Simko

Dear Committee,

I am writing to urge increased investment in home and community based services (HCBS). Apologies for the length of this message, but this issue is a critical one and I wanted to share my story so you can see the real world effect of the funding you are considering. My family is at their breaking point, and we are very typical for our population.

My son, Jack Ellis, is a 21 year old boy with very severe autism. People like my son rely on HCBS for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. Jack can't be left alone, can't get out into the community without supervision, and needs help navigating almost every aspect of everyday life that most people take for granted.

There isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

This is EXACTLY what has happened to our family over the past year. My husband and I are aging. Jack was supposed to transition to a group home with full time staff. That home cannot find and keep staff to meet the needs of the young men already living there, let alone my son and the other boy due to move in. No other homes can find support staff either, so Jack remains at home. Adult day programs are also unable to find staff, and our local appropriate program has a SEVEN YEAR waiting list.

We currently have no respite workers to help with Jack, or behavioral therapists, although he qualifies for both services. There simply isn't staff at the agencies. I quit my job to take care of Jack, because he can't be left alone. My husband and I haven't even had a meal alone together in years due to the lack of qualified respite workers.

When people can make more money working at McDonalds than caring for a disabled person, how are we ever to meet Jacks staffing needs? We have no other family. What will happen to Jack when we are

gone, or too old to physically care for him anymore? I can't begin to describe the desperation we feel right now.

People like Jack are the most vulnerable people in our population. How we address their needs says everything about us as a society. Jack can't vote, but his family and our friends do. We have to speak for him and others like him. We need help, now more than ever.

Please support a historic investment in disability funding, so Jack and others like him can get the support they need.

Thank you.

Regards,  
Kristin Cihak

Dear Committee,

Home based services (HCBS) provide the services that allow people with disabilities to live a normal, engaged lifestyle where they can contribute to their community. These funds also save the government \$140,000 per individual per year when compared to the cost of housing people with disabilities in institutions. In 2009 (the most recent year for which data are available), the average annual expenditure for state institutions was \$188,318, compared to an average of \$42,486 for Medicaid-funded home and community-based services.

In an institution near me where people with disabilities are housed 8 individuals died from COVID-19 due to the close accommodations whereas my daughter, who lives in the community and was able to isolate as needed, never contracted COVID-19. My daughter has a part time job bagging groceries at a food store, volunteers at a food pantry and is learning to care for herself with the support of family and service providers paid by home based funding (HCBS).

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. Unpaid family caregivers are fill in the gaps of care and then are unable to work and provide for the financial needs of the rest of the family

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Sally Mydill

Dear Committee,

One of my adult sons is one of the many autistic aging out of all school programs this year. His dad and I are divorced but both care for him—he needs 24/7 care. I'm not sure how to care for him all day and still be able to work to pay my

mortgage and provide for my other son and myself.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the UHCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Cathy Asimakopoulos

Dear Committee,

My Brother and other People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Sara Davis

Dear Committee,

Home and Community Based Services (HCBS) allow people with disabilities to fully participate in their communities - to live, to go to school, to work, to shop, to worship - at a much lower cost than living in an institutional setting.

But there isn't enough money in the HCBS program to support everyone. Too many people are not getting the services they need. People with disabilities do not have needed access to personal care attendants, ramps and home modifications, assistive technologies, access to health care, income supports or opportunities to work.

Please support a historic investment in disability funding, so everyone can get the support they need to live and work in their community, and unnecessary institutional spending is reduced.

Regards,  
Melanie Hogan

Dear Committee,

I am writing on behalf of an adult family member with Intellectual and Development Disabilities who requires 24/7 care for multiple disabilities. We urge your full support of HCBS services.

People with disabilities rely on home and community-based services (HCBS) for safety, health, and well-being -- including employment supports, navigating and participating in their community, dressing, bathing, taking medication, and other daily living activities.

The lack of adequate HCBS funding results in people stuck on waiting lists and not getting the services they need. Direct care workers are underpaid and undervalued, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care. Individuals with no safety net are at great risk for requiring emergency care.

The pandemic highlighted longstanding vulnerabilities in the care of people with disabilities. We need to ensure that funding and flexibilities continue so that these members of our community receive the care and support they need to survive and thrive. Supported living in communities, and not in institutions, should be everyone's right.

We hope we can count on you to support a historic investment in disability funding, so everyone can get the services that they require - and deserve - to live safely in their community.

Regards,  
Anna Perrone

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

My granddaughter, who has Down syndrome, is graduating high school this spring and will be needing transportation, even if she stays at home. Better would be a community home where she can have friendships and people her age to be with. Please consider funding better lives for a growing proportion of the population, people with disabilities.

Regards,  
Deborah Schoenholz

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My son Austin has Down syndrome. He's ten and has been on the waiting lists his whole life. We're still way down on the lists, and he will need the support to live in the community rather than in an institution, which costs the government much more money.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Kelley Mindrup

Dear Committee,

My adult son with disabilities relies on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, protection and prevention of challenging behaviors, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Carol Meredith

Dear Committee,

In the past, my son was institutionalised due to health issues in my family. We needed support to take care of him. Today he is at home with family being supported by services in his community. We rely on home and community-based services (HCBS) for getting around the community, dressing, bathing, taking medication etc.

Lack of adequate funding for the program has many people

Regards,  
C. Morris

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My wife Anastasia and I have been trying to recruit staff to support our son, Jess, during the day unsuccessfully for 9 months now. At the allowed hourly wage rate of \$16.50 we have not been able to find anyone. We need a significantly increased federal HCBS investment so that we can offer wages that will attract and retain support staff.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Robert Lawhead

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.



But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My daughter is 23 and she suffers from autism, Tuberous Sclerosis Complex and epilepsy. She functions at about a three year old level and needs 24/7 assistance for all activities - dressing, bathing, toileting, meal prep, eating and seizure management and medication administration. My husband and I are 61 and 72 and we have our own health issues. She fell down the stairs in our home and broke her arm. We were barely able to get her up or turned to assess her injuries. We are becoming physically unable to manage our daughter in our home and need her to be in an independent living arrangement in our community with direct support and care BEFORE we are too old to manage the transition or one of us dies. And she deserves to live independently in our community where she can access all that our community has to offer. But there are few options available for her based on limited housing and funding and the inability to find people to care for her. We are scared for our future and for hers.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Julie Blum

Dear Committee,

I have an adult son with Down's Syndrome and people with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more. Children with disabilities need continued care throughout their lives, they do not just age out of the system. They need care workers who are compassionate and patient. The people who care for our loved ones need to be recognized for the work they do. We are losing caring staff due to low wages and this compromises the care received by people with disabilities. This puts the burden on families.

Please protect one of our most vulnerable population. People with disabilities cannot advocate for themselves please be responsible when making decisions that affect them and their families.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Bobbie Maitoglou

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like

employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Here in California there aren't even any institutions that can serve my adult disabled daughter, and it is very hard for the agency that provides home care workers for her to find and hire workers when so many entry level jobs pay higher starting wages. We really need increased funding to pay higher wages for home care workers - these are important jobs and should be paid as such. My daughter is lucky to have a home, but needs in home care to be able to stay there. Please approve new and urgent funding for HCBS.

Regards,  
Michelle Donaldson

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Our daughter Leah is almost 27 years old and has Down syndrome. She works 8 hours a week at a local grocery store and at TJ Maxx. She attends a day program 2 days a week. She needs supports at be independent in our community. Her goal is to increase the number of hours she works and live in her own apartment. She needs to practice the skills to live independently with qualified support providers. It is so very, very, very, very difficult to find people who can and will support her. Providing support requires skills and personality — it's hard work that is very individualized to each person's needs. Support individuals need to be trained and paid fairly to provide the services Leah needs. Right now we don't have enough support for Leah and she spends far too much time at home in front of a screen which is not good for her.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Susan Toronto

Dear Committee,

My daughter is 24 and we won't be able to care for her at home forever. Without HCBS she will eventually be homeless.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Marietta Shirk

Dear Committee,

I have worked in the developmental disabilities field for over 30 years. I have witnessed the much needed closure of state institutions funded by Medicaid with state and federal funds. The savings from the closure of institutions is huge - but those funds have never been fully reinvested in home and community based services. I urge you to support a historic investment in disability funding, so everyone can get the support they need to live in their community - families and people with IDD are desperate for this help. People serving people with IDD are desperate for high wages and benefits to continue working in this field. The time is now for this historic change.

Regards,  
Sally Morris

Dear Committee,

My son David resides in a 4 person supervised IRA in an apartment in a small apartment building in Brooklyn, NY. He is part of his community and he and his roommates participate in the community garden. Prior to the pandemic, he participated in volunteer community work activities with his day program. While the DSP workforce crisis has limited his return to full community integration, the potential remains.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Rachelle Kivanoski

Dear Committee,

Many Senators have met my son Rob Stone in his role as a Little Lobbyist. Rob relies on HCBS in order to remain in his community after high school graduation. Without this funding, due to his high medical needs, he would be receiving care in an institution. Rob is a lively, funny and talented 25-year-old, who is an artist (with his own art website), an advocate, and a writer. Institutional funding is more expensive than HCBS waivers. Please fund community living in order to save families money and save our government money.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Jeneva Stone

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on

waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

There are thousands of people with disabilities in Illinois who can greatly benefit their communities if they have support I know because my daughter is one who works to make her community better but even her supports are VERY fragile!

Regards,  
JAMES STAHL

Dear Committee,

As Executive Director of the Williams Syndrome Association, I support more than 6000 individuals with WS and their families - including my own adult son.

People with Williams syndrome and ALL disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Terry Monkaba

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

There also needs to have help for the recipients of Medicare who are above the poverty line. We can't always depend on our significant other to always be there to help!

Regards,  
Barry Glaberman

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

I am the grandmother of a child with Autism and epilepsy. His mother passed away 3 years ago. I am his only support. At home service is the only way I can take care of him. Also, I worry what will happen if I get ill or. Will there be room in a group home for him? Only you have the power to say yes to that. I sincerely hope you will.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Valerie Martin

Dear Committee,

My 34-year-old daughter has Down syndrome and relies on her home and community-based services (HCBS) waiver for everyday things like a job coach for her job at one of the Microsoft Cafes, getting around the community, her everyday health needs like, taking medication, going to the doctor and making sure she is safe and healthy, and much more. She lives with me because there are not enough supports on her waiver to move out on her own, so we are waiting for a different waiver.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Cathy Murahashi

Dear Committee,

As someone who cares deeply about people with developmental disabilities and believes in community-based services and inclusion, I must emphasize the critical importance of home and community-based services (HCBS) and ask that you invest in HCBS to ensure people with disabilities live independent lives.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Regards,  
Robin Tatsuda

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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We have adopted 8 special needs children from Foster care. There just isn't enough support in the subsidy nor home care afterwards.

Regards,  
Tracy Kottenbrook

Dear Committee,

WE NEED to INVEST in our most precious population of persons that don't have a voice. They are the marginalized in our society and it has to stop. They deserve a place to live within a community that is safe. My daughter with disabilities will rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more when my husband and I are no longer able to provide. This future scares us to think we will not be here to protect and provide but neither will the support for these deserving individuals be available. It must be provided.

We are on a waitlist for over 15 years and until then it is our financial and emotional commitment that will continue but what if something happens to us? We are older parents and can we really wait until we're in our 70's to then received and establish services for our daughter.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please SUPPORT a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Mary Cockrell

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I have noted your willingness to fund agencies that provide research and training (UCEDDs, Protection and Advocacy, and Councils for Developmental Disabilities) if funding is a concern please consider the direct redistribution to provide direct care.

Regards,  
Melanie Tyner-Wilson



Dear Committee,

I am the President/CEO of the St. Louis Arc, an agency that provides services and supports to over 4,500 individuals with intellectual and developmental disabilities. I have worked with this population for over 40 years.

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Mark Keeley

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Please help disabled people to thrive and be useful members of society!

Regards,  
Kathy Goings

Dear Committee,

People with disabilities rely on home-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions. Hello, please know our family is in need of help for an aging disabled son and brother. He is needing to live in his own home (which I keep up). I am 83 and in poor health. My disabled son should stay in his own home with assistance in the keeping up of the home,,,,,,,,right now a new roof, new ceiling as rains brought it down.....and general upkeep .....services in the community needs to address my son living where he has for his lifetime. Please, please help the elderly disabled keep the standard of life he has been living in.....thank you for you assistance in this important matter. stop

Regards,  
Carol Milao

Dear Committee,

I am a young women who has two graduate degrees from The University of Texas, owns a condo in downtown Austin, and is currently working in DC for a large non-profit organization. I also have a physical disability that requires a moderate amount of personal care to go about my busy days.

I am sure I would not have made it this far without my personal care team (all of them are family). Unfortunately, not every family is in the position to offer support.

This is why I am writing to you today. Every individuals with disabilities and their caregivers should have access to these personal care services, regardless of ability to pay. And for that to happen, we need more funding.

Here is a little more about these vital services: People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so more "Taylors" can live their dreams in the community of their choice.

Regards,  
Taylor Woodard

Dear Committee,

Do you remember Matthew? He came on the Waiver in FL through APD crisis and is now in another crisis. He had to move to a local group home due to the extreme night time Care and parent unable to meet the needs. Then the staff at group home all quit. Praying for home operations and APD to agree to extensive level 2 rehabilitation funding to hire medically trained individuals to keep watch over oxygen needs at night. Please help our most vulnerable individuals. I received my Governor's appointment to Family Care Council Area 15 in late 2011. I met then Gov. Scott in 2014 at the Family Cafe and Governor Summit of Disabilities with a joint press conference with Governor Scott, APD and Family Care Council Florida. I still serve on that Council as co chair to educate and empower individuals with intellectual and developmental disabilities and families while partnering with the Agency for Persons with Disabilities-APD, to bring quality services to individuals with dignity and choice. [www.fccflorida.org](http://www.fccflorida.org)

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Melody Hearn

Dear Committee,

Families with disabilities deeply rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, respite care, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid (less than the minimal living wage), which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of

care, or parents with children with disabilities often lose jobs or cannot work because of lack of proper support in the home and community.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Rachel Dreher

Dear Committee,

My son Jason, who was born with Down Syndrome, is 36 and enjoys a productive life as a farmer, baker and member of a lifesharing community on a farm. He is only able to do this because of the HCBS funding he has been fortunate enough to receive. People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Stephanie Lynch

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. My daughter has been on the waiting list for 17 years. My husband and I are in our sixties and have trouble meeting her needs.

Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care and as we age it is overwhelming.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards, Julie Lewis

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

My son is on a waiting list in Nebraska for individuals with developmental disabilities. We have been waiting 5 to 6 years. My son has limited speech and is an alternate curriculum placement at school. We have been forced by our situation to keep one parent out of the workforce to care for our son and take him to therapies. Several therapies that would be beneficial to him such as social skill programs are not covered by insurance and thus we do not enroll him in them because they are too costly. We have spent thousands of dollars out of pocket every year for the last 8 years in therapy, and gotten no assistance from the state or federal government. We are lucky to be one family that has good private insurance and lucky to be a two parent family that can afford to keep one parent home. Many others don't have these options.

Even when we are eventually provided with a spot on a medicaid waiver, we continually hear about how there are no providers because the pay is too low. So even when we do get a spot, we wonder if we will have to continue in the same 'holding pattern' of not being able to have both parents employed because we won't be able to find qualified caregivers for our child. As a parent, having your children safe and well cared for after you are gone is always a concern, but when that individual cannot advocate for or care for themselves that fear is so amplified. Please pass legislation to provide more support for individuals and families that need these programs.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Angela Gleason

Dear Committee,

My son is 27 year old with Autism. There is NO Housing, NO Transportation, NO social support for his profile. WE NEED HELP. We won't be here forever and he cannot live on his own. HELP People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

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Regards,  
Sharon Riddle

Dear Committee,

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Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

I am the Executive Director of The Arc of Northern Virginia. There are more than 14,000 people with intellectual and developmental disabilities on the Virginia Medicaid Waiver waiting list who need critical services and supports. It is time to act now!

Regards,  
Rikki Epstein

Dear Committee,

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My previous husband died of cancer, and he lost his balance and ability to communicate the last six months of his life. He was 58; too young for Medicare, not quite poor enough for Medicaid, and it takes months for those services anyway. I had to lift him every time he needed to use the commode, and he was tall and over 200 lbs. It ruined valves in my legs. Why couldn't I have help then? Policy. And that's the truth. Home health aides also need to be paid enough so that they won't quit. Please pass the bill!

Regards,  
Elizabeth Horn

Dear Committee,

I am concerned people with intellectual and developmental disabilities that could otherwise live in the community with supports will have to go into institutions.

In Florida our wait list is very long and those who are on the HCBS have to also wait because they don't pay enough to hire direct support professionals.

Thanks for your consideration.

Regards,  
Alan Abramowitz  
2898 Mahan Dr  
Tallahassee, FL 32308

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

I am a direct care worker and former teacher. As a teacher I worked with students ages 18-22 and we worked on job skills along with home/community independent skills. It saddens me that in Florida students leave school at 22 and then sit on the HCBS waiting list for at least seven years unless there is a crisis in their life. During this time they have lost most of the skills that I spent so much time working on while in school due to a lack of consistent work with them.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Regards,  
Shelbea Houston

Dear Committee,

ATTENTION, THIS IS NOT ANOTHER FORM EMAIL! THIS IS A CRISIS PLEA FOR INTERVENTION FROM A 71 YR. OLD WHO IS BEING SYSTEMATICALLY Retaliated AGAINST BECAUSE I DARED TO ATTEMPT TO REPORT A 5 AGENCY MEDICAID SCAM...SENT PROOF TO THE GOVERNOR AND ATTORNEY GENERAL SO MY PUNISHMENT FROM HHSC IN AUSTIN HAS BEEN TO LIMIT ME TO A SINGLE STATE SERVICE, LEAVING ME ENDANGERED IN MY HOME.

Regards,  
Judy Brady-Sertich

My name is Asia Sprewell Systems Change Advocate here at Rolling Start Inc.  
I'm in support of the Air Carrier Access Amendment Act. Will be retweeting.

Asia Sprewell

TO: GOV. DeWine and the Senate of Congress

RE: FRANK MEEKER – WRONGFUL DEATH  
NEW DAWN AND OAKHILL NURSING HOMES

Ohio Revised Code 2905.03: Unlawful restraint is a serious criminal offense.  
Ohio Revised Code 2921.11 giving false testimony in a court of law by Yvette Schupbach, administrator and SW of New Dawn, and Christine Menegay from APS in Canton, Ohio.

Frank had a previous stroke years ago and had an ostomy bag. He was driving, shopping, eating out with his wife, going to Amish Country and enjoying life. He had a seizure, they found a UTI and he should have gone home. Due to another fault of a social worker she wanted him to have rehab that he never received. He wound up with a long list of complications from nursing homes by being abused and neglected.

COMPLAINTS AGAINST NEW DAWN AND OAKHILL NURSING HOMES IN THE STATE OF OHIO FROM JULY 3, 2020 TO MARCH 28, 2021.

Frank Meeker suffered severe emotional abuse and neglect resulting in an unstageable bedsore in New Dawn and Oakhill Nursing Homes infected with Pseudomonas green pus and Mersa leading to wrongful death. Unlawful restraint section 2905.03 Ohio Code resulting in prison and fines.



1. Frank was supposedly being rehabbed in Woodlawn Aultcare NH. Due to drug overdoses they once found nothing wrong and he just woke up from the drug. The other was low blood gases from the drugs. He was hospitalized and contracted covid from either of these locations. He was treated and released later but still positive. To recover from covid, he was in good health. if a person is still positive but showing no signs for 10 days, he was not contagious. Still at the time, there were only two NH's accepting positive patients. Again it was for rehab. He was not ill and could walk with a walker and talked normal when he entered New Dawn.

2. He wanted to go home and the Dr. said he'd be better off at home. his POA did not have time so she told the SW at new dawn that I was taking the POA to get him home. I had the papers drawn up. Evette

s Schupbach illegally and unlawfully blocked, intercepted and obstructed my POA. She did this knowingly and intentionally w/o legal justification; thus hindering his wellbeing and taking away his civil rights. She told me that no papers were allowed in the building and he's not signing anything. This was before she had him illegally deemed incompetent. She held him in unlawful imprisonment. She confined him holding him hostage which is abuse of power. She wanted her attorney who ran a Guardianship Mill to have power so no one could make decisions but them. Thus New Dawn and Karen Dummermuth (very poor reviews) could make money. Together they prevented him from leaving and detained him against his will. False imprisonment is a criminal offense leading to a kidnapping charge. It's unlawful detention to "keep their beds filled for payment" as the administration told Dr. Perkowski. The following statements are from Dr. Perkowski about New Dawn Nursing Home in Dover, Ohio.

1. He has "patients that need to go home." The administration told him that "they need to keep their beds for payments!" He "flipped" in anger but doesn't want to quit because he feels an obligation to his patients.

2. "They have no rehabilitation at this facility. They have no tools to rehab."

3. He "revealed his frustration to the manager but they will not discharge patients. He is unhappy with New Dawn's administration. "There's a business side and a clinic side."

4. "Frank is not getting the best possible care."

5. "They are not aggressive in their treatment to help patients become independent."

6. "He's in a Covid unit but has been Covid clean for several weeks." I asked him and the management to move him out of there. His response was that "we are discharging him soon so we won't change his current environment."

7. "He's eating well and the PEG tube can be removed after starting a bolus feeding instead of the drip."

8. "Frank should not be here!" he said.

9. "The Covid motives for the Covid Unit is financial."

10. "The head nurse, Donna, was recently fired. The last few weeks there have been lots of problems there. It's not good for the patient's care."

11. He said he's "angry and questions the motives of the administration."

12 "The patients are getting substandard care!"

13. NEW DAWN is "shady."

14." They wanted me to do things, I would not do."

He is willing to testify in court.

He wanted them to remove patients from Covid units that shouldn't have been there. They would not do it so he quit!

3. YEVETTE drugged FRANK MEEKER and ask the Dr. to ask him questions on the SLUM's Test and declared him incompetent to keep him. (needed to keep the beds filled for payment.) My brother would want me to be his POA not her attorney to make his decisions. I have this statement recorded by him. They showed no compassion for Frank. It was an opportunity for financial gain as the Dr. said.

4. Evette called her attorney Karen Dummermuth who runs a Guardian Mill to call for emergency guardianship to own him, refusing my POA. Yevette was notified by Frank's POA, his daughter, that I would be taking over POA. This was before he had her SLUM's Test.

5. The social worker, Yevette, hindered an investigation and provided false testimony. She defamed, slandered me and purged herself in court which is obstruction of justice. I have all the CD's of the court hearings and the records from New Dawn.

1. She testified that Frank wants to stay there.
2. That he's not safe at home because his sister and wife will kill him.
3. That he was in poor health, LONG TERM and conspired to keep him lying in bed 24/7. Enclosed are photos of the bed sore.
4. That the sister wants to take him home against medical advice. DR. PERKOWSKI SAID HE WAS READY TO GO HOME AND THAT HE WOULD BE BETTER OFF IN HIS OWN HOME WITH HIS FAMILY.
5. When the sister calls, he gets agitated with the staff (because he wanted me to get him out). They told him he's long term and had no home to go to. The records will tell you how the staff agitated him. New Dawn records reveal how he pounded on the walls for help all night and they ignored him. Evette testified that I was responsible so a restraining order was put against me not to call or see Frank. This upset him more because his family was his only way out.
6. New Dawn's attorney was given Guardianship which upset him even more. Some stranger now able to keep him against his will in that bed.
7. I went to court 6 times to get him out. Karen Quinlin, Magistrate, and Karen Dummermuth, New Dawn's attorney with a Guardian Mill conspired with the false testimony of Evette Schupbach to hold Frank hostage and unlawfully take away his civil rights. The Magistrate cut me off several times and when I told her about Dr. Perkowski She said that she "didn't care".
8. When a Notary observed Frank signing my POA papers through the window, Yevette said the curtains were closed. They were not closed!!
9. She violated my civil rights as her false testimony to the Magistrate who believed her lies and put an unlawful restraint against me. I have recordings of my brother begging, pleading and crying to get him home. I promised him I would. No one showed any compassion to Frank. It was all about the money!

I recorded conversations with Frank that prove these false statements. He cried and begged us to get him out of there. When nurses approached in the hospital, he said, "don't hit me!" They sat on him and knocked his head against the wall at ND. He fought them because he wanted out. When he fought to get out, he was drugged with Ativan and antipsychotics. Even Haldol which should not be given with seizures. I promised him that I would get him home! He tried to crawl out. An EMT, Nick Abrams who worked for Regency Ambulance, was a friend of Frank's. He found him on the cold floor in a diaper yelling for help. The nurse told Nick to leave Frank there on the floor.

The following statements are made by the nurses in the records that I obtained:

1. Frank pounded on the walls yelling for help constantly.

2. He tried to fight his way out and swore at them for keeping him confined on his back and "keeping his bed filled for payment."
  3. The BEDSORE became unstageable infected to the bone with osteomyelitis with *Pseudomonas* (bacillus of green pus) and Mersa which is spread by CONTACT. He was becoming septic.
  4. That Frank had many bouts of *C. Difficile* causing diarrhea which is contracted in nursing homes. He was given a plethora of antibiotics which kills the microbiome in the gut.
  5. That Frank kept telling us he was cold and started a cough. We took warm clothes and requested blankets. I saw them put them in the closet from the window. He was hospitalized for pneumonia the next day.
  6. That Frank suffered severe emotional and physical harm. There was no TV. He was alone, isolated, left looking at the ceiling 24/7. These were his remarks. Depression, anxiety, and confinement became mentally stressful.
  7. That he suffered severe muscle atrophy and bone loss from lying in one position with no physical therapy.
  8. That his right knee was swollen from falling out of bed. An MRI was not done.
  9. That Frank was found unresponsive, taken to Union Hospital and found to be overdosed on drugs. A family member yelling in his ear woke him up.
  10. That he was having constant seizures, taken to the hospital and found to have a low amount of his antiseizure meds, Valproic Acid, in his blood. He was not getting his meds.
  11. He yelled "help, help me" of which the records stated that they ignored his pleas for help. They also state the plethora of times that he told them he wanted to go home. They pumped the Ativan to control him. He wasn't going to just lay there. He wanted his home and his family wanted him home. Why were they making us all miserable and unhappy? Money!!! The longer they kept him, the more complications set in. You can't just force a person to lie in a bed for months when he could walk when he was admitted. They told the Dr. they needed to "keep the beds filled for payment."
6. Evette's attorney wanted to add Frank to her guardianship mill. Karen Dummermuth was an accessory to kidnapping by aiding and abetting the SW. They were preventing him from going home and detained him against his will.
7. He cried and begged us to take him home. There was no reasons for him to be there as we had home health care and nursing visits ready to set up. He was not incompetent. I taped my conversations as he told me how he was being treated and begged us to come and get him.
8. The several times that he went to Union Hospital, he was getting cachexic and septic confirmed by Aultman Hospital.
9. In the beginning at New Dawn, Donna Cobedesh, the Director of Nursing, told us that Frank was not eating. He was always knocked out when we looked through the window from over drugged. We requested A PEG tube for nourishment. Donna was fired later. Not sure why. Was she against the way ND was treating their patients?
10. He finally got out of New Dawn because they fed him on his back and suffered from aspiration pneumonia. First to Union then to Akron General who cultured *E. Coli* from the gut in his lungs. He was there 22 days.
1. When our father was in the hospital in his late 70's, Frank and I rode in the elevator with his Dr. Asking for a prognosis. The Dr. replied "when people get that old, sometimes it's better to just to let

them go, especially those in nursing homes.” Astonished at that remark, Frank said “they better never treat me like that and better never put me in a nursing home because I’ll fight my way out.” True to his words he was fighting. And we were fighting to get him out. There was no need to keep him at that time. All his complications were obtained from lying on his back with no physical therapy. Yvette told the court that I was trying to take home against medical advice. Dr. Perkowski said “he’d be better off at home. He was getting substandard care.” He said he’d testify in court. The Magistrate said that she didn’t care!

2. Frank could have and should have gone home. He fought to get out of there and we fought in vain to get him out to no avail.

There are many more stories to tell here that will be revealed in my documentary. WE NEED TO CHANGE LAWS THAT RUN OHIO NURSING HOMES, ESPECIALLY RULES ABOUT GUARDIANS AND POA’S. THE FAMILY HAS TO BE INTERVIEWED AT THE SAME TIME WITH THE NURSING HOME TO SEE WHO IS LYING AND DETAINING PATIENTS UNLAWFULLY FOR THOSE MEDICARE PAYMENTS. The public must know the pain and suffering that my brother, Frank Meeker was forced to unlawfully endure. The Dr. said their motives were financial. I witnessed it. They fought so hard to keep him depriving him of his home, his happiness, his family, and his safety.

He was forced to go to a NH for rehab which he never got and contracted a long list of complications from being there. May 16, 2020 he was fine and walking well. He was coping well with a previous stroke and an ostomy. He was driving and enjoying life with his family. May 17, 2020 he had a seizure and was taken to Aultman. He should have gone home after a short stay. The SW’s there said he’s got to have rehab which he never got. What he got was complications and drugs because he didn’t want to be there. There really was no reason for him to stay there. Ohio needs to regulate this abuse not the ODH. I’ve contacted them 6 times and each time they’ve found nothing! They have no idea what’s going on. They even called me Mildred King on the envelope. Mildred must be complaining also.

About Oakhill:

Another long story. Call me and I will tell you. Frank’s bedsore by this time was huge. I must send you the photos. If I can’t with an email, how can I get these photos to you. He had an appointment at Aultman Wound Care on a Wednesday with Dr. Amed. I called Oakhill the day before and left a message to not miss that appointment warning them of sepsis. They didn’t answer their phone. I called Kathy at the Wound Center and she said they didn’t show up. I called the administrator, Toni, and she called Frank’s daughter to tell me not to call there anymore! I called all day for an ambulance to get him there the next morning. It appeared they had to make the appointment for transportation for insurance purposes. They made his appointment for 4 days later. He had sepsis from the bedsore infected with Pseudomonas and Mersa. His birthday was May 29 and he passed from septic shock the day before. HE SHOULD HAVE GONE HOME 9 MONTHS AGO AND HE’D STILL BE ALIVE.

I’D LIKE TO KNOW WHAT YOU’RE GOING TO DO ABOUT NURSING HOMES AND MONEY, ABUSE OF POWER WITH POA’S AND GUARDIANSHIP. WHEN I COME TO CANTON, I WOULD LIKE TO INTERVIEW YOU FOR MY DOCUMENTARY. I WITNESSED THE PAIN AND SUFFERING AND SOMETHING HAS TO BE DONE.

WHAT ARE WE GOING TO DO? I am obligated to continue his fight for Justice. Our mother died from sepsis in a nursing home. Mother was from an untreated urinary tract infection and father was from aspiration pneumonia. WAS THE DR. IN THE ELEVATOR CORRECT?? When people get old, just let them

go! Maybe they don't have families to care for them, but Frank did. He and we were denied his life. False imprisonment is a criminal offense.

I have proof of all my statements..

Also I can prove the following Ohio Codes were violated:

Section 2905.03 New Dawn Nursing Home

and 2921.11 Administrator Yvette Schupbach - false testimony in a court of law. And the Magistrate who did not hear my testimony. I was cut off several times.

The Probate Court in Tuscarawas Co and Stark County have been given false testimony which I can prove in a court of law. False testimony from Christine Menegay from APS will be proven in my documentary also. There is much more to this story than is written here.

In the month of July, 2020, I repeatedly told Yvette Schupbach that we are making arrangements to take Frank home. She was always very arrogant and said that he cannot leave. It's against medical advice. The Dr. told me he was ready to go home.

August 8, 2020, I arrived to get Frank home.

August 15, 2020, Frank's daughter called and told her that I, Frank's sister, was taking over POA because Yvette Schupbach was giving her a difficult time also about his discharge.

August 17, 2020 daughter sent papers to give up her POA.

August 18, 2020 I had an my POA papers.

August 18 to 20, Yvette said that no papers allowed in the building and he's not signing anything. No Notary is allowed.

August 21, she had the Dr. ask questions on the SLUM'S Test.

(In the records, he was repeatedly drugged with Ativan. He told me "they're not keeping me here. I want out!")

August 24, she had her attorney Karen Dummermuth file for emergency guardianship on the grounds that I wanted him released against Dr.'s orders. I told you what he said about New Dawn Nursing Home. He quite his position due to their negligence. Dummermuth has a Guardianship Mill and has 18 negative reviews. She also seems to have too close of a relationship with Karen Quinlan. Quinlan treated her with respect and cut me off several times. She also regarded Schupbach's testimony and not mine.

I'm seeking to expose New Dawn and Oakhill Nursing Homes for the suffering and pain they caused Frank and our family. There has to be consequences for abuse and neglect. The administration actually admitted they didn't want any patients released because they "needed to keep their beds filled for payment." I'm trying to contact the head nurse that was fired and the administrator who quit. Also the staff needs to be held responsible. I told Chasity that Frank was sick. She said, "he's not sick." He was admitted to the hospital the next day with pneumonia. She wouldn't even put the clothes we brought because he complained for a week that he was cold and started a cough. This is only one of many, many examples of neglect.

I'm seeking justice for my brother, Frank Meeker. They fought to keep him for the money. They have to be exposed and reprimanded. Enclosed is a picture of his unstageable bedsore infected to the bone.

RESPECTFULLY, DR. MARILYN MEEKER BERNSTEIN



Make today a breakthrough.

## Written Testimony for the Record

**Maynard Friesz, Vice President of Policy and Advocacy, Cure SMA**

**U.S. Senate Special Committee on Aging  
March 23, 2022 Hearing on**

### **An Economy That Cares: The Importance of Home-Based Services**

Chairman Casey, Ranking Member Scott, and Members of the Committee,

Thank you for holding a hearing to examine the importance of home-based services that allow people with spinal muscular atrophy (SMA) and others to maintain their health and independence. As the leading national organization that advocates for children and adults with SMA, a rare degenerative neuromuscular disease that robs individuals of physical strength, Cure SMA is pleased to share the perspective of individuals with SMA and their families on the critical nature of home-based services and their ongoing challenges in finding personal care attendants (PCAs) and other paid caregivers.

Many individuals with SMA require assistance with daily activities, such as personal hygiene, getting dressed, eating, and transferring out of bed and into a motorized wheelchair. These Medicaid-funded caregiving services are essential for individuals with SMA, of all ages, to attend school, go to work, live on their own, and contribute to their communities. A **3rd grade teacher with SMA from Texas** receives essential assistance from PCAs at three intervals during the day, in the morning to help her get dressed and transport her to work, in the middle of the day, for restroom breaks, errands and medical appointments, and in the evening, to assist with end-of-day tasks, such as showering and getting ready for bed. Without this assistance, she would not be able to live independently or earn a living. A **Maryland family with a son with SMA** relies on licensed registered nurses (RNs) or licensed practical nurses (LPNs) for in-home care and services, such as g-tube feeding and airway clearance, and to support their son as he attends school. *"Professional caregivers are so vital for all people and a healthy community, society and world,"* **an adult with SMA** said about access to Medicaid home and community-based services, a key priority in Cure SMA's *Greater Independence* legislative agenda.

**Regardless of the state they live in, individuals with SMA and their families face regular challenges in finding and retaining caregivers and in accessing the caregiver hours they need to remain independent.**

#### **CHALLENGES IN FINDING AND RETAINING CAREGIVERS**

Individuals with SMA, on average, utilize 2.5 caregivers to assist with their daily activities, according to Cure SMA's 2021 Community Survey. However, finding paid caregivers, such as PCAs, nurses, and home health aides, is increasingly difficult for adults with SMA (45%



of whom identified it as a top unmet need) and for families of children with SMA (29% said it was a top unmet need). A **Massachusetts man with SMA** who requires paid caregivers for his independence has been unable to fill open caregiving jobs. *"Not long ago, 1 part-time opening drew about 20 applicants. Now, I have received 0 applicants for jobs over the past couple of years."* Finding caregivers is a problem in urban and rural areas across the country. A **woman with SMA who lives in one of the 50 largest U.S. cities** said, *"finding and retaining a solid crew of caregivers that are reliable, understand the job, and are compatible with me"* was her biggest challenge in maintaining her independence. A **woman with SMA from Maine** worries what will happen if her current caregivers leave for other jobs. *"I live in a rural place and can't even get caregiving services here even though I need them."* Low pay and a lack of benefits, training, and career mobility contribute to challenges in finding and retaining caregivers. *"It has been an incredibly difficult journey to find anyone who is willing to work due to the level of assistance required to help me get through an average day,"* said a **woman with SMA from Ohio**.

#### **CHALLENGES IN RECEIVING ADEQUATE CAREGIVING HOURS**

Nearly half (47%) of all adults with SMA and families of children with SMA that utilize home care services require 40 or more caregiving hours a week, including 19% who need 100 hours or more of weekly caregiving support. However, many individuals with SMA report a significant gap in the caregiving services they need and the caregiving hours they are approved for through their Medicaid agency. A **28-year-old North Carolina working adult with SMA** lives with his parents because he lacks the caregiving hours to live on his own. *"My caregiving need is at least 50-60 hours a week, but Medicaid only pays for 40 hours, which is not a lot when you need SMA level of care."* He noted that his caregiving hours were cut when he turned 21. *"They think you are more independent and need less care. The opposite is true. I am more independent, and I need more hours to keep my independence and to continue to work."* A **Florida woman with SMA** also faces a lack of approved caregiving hours. *"I'm well under the hours I need to have all my necessary shifts filled."* Given the nature of the disease, caregiving needs may increase for a person with SMA as they age. A **52-year-old working adult with SMA from Wisconsin** said the changes in his SMA has required increasingly more personal care assistance to stay employed and get through the day. *"It has progressed to the point where I need assistance with all daily living activities, such as dressing, bathing, eating and toileting. My insurance does not cover the cost of my personal care workers, and I continue to be in a situation where I cannot afford the care that I need."*

#### **CHALLENGES FOR FAMILY CAREGIVERS**

Due to the lack of caregiving support through Medicaid, many individuals with SMA must turn to unpaid family caregivers to assist with unmet needs. Cure SMA's 2021 *Understanding the Caregiver Experience* survey found that family caregivers of children and/or adults with SMA provide, on average, 45 hours per week in unpaid caregiving services, which is significantly higher than the 23.7 hours per week of all caregivers, reported in the 2020 [Caregiving in the U.S. report](#). Family caregivers of individuals with SMA reported financial strain, work limitations, and poorer health due to their caregiving responsibilities. Many adults with SMA who rely on a parent or spouse when they lack



Medicaid caregiving hours face an additional threat to their independence due to the age of their caregiver. About 65% of family caregivers of adults with SMA are 50 years old or older, according to Cure SMA's caregiving survey. *"My mother helps me when I don't have a PCA but as she is in her sixties, I worry about the toll it takes on her health."* said a **Mississippi adult with SMA**. An **Indiana woman with SMA** fears her independence if something happened to her family caregiver. *"If I didn't have my mom, I would no longer be able to be independent and potentially would have to move into a long-term nursing facility."*

#### **CONCLUSION**

Cure SMA and the SMA community wholeheartedly agree that home-based services, which we highlighted in our recent [Caregiving Needs of the SMA Community: In Their Own Words](#) report, are important and essential and deserve our country's attention and investment. We appreciated that Congress increased the federal funding match that states receive for Medicaid home and community-based services in the American Rescue Plan (ARP). The extra ARP funds have helped states begin to address the caregiving shortage in their states. For example, a **Tennessee woman with SMA** was able to recruit for a caregiver position at a higher wage through her consumer-directed program because of the ARP funding increase. However, this federal funding match was temporary. The caregiver challenges are ongoing.

Cure SMA asks Congress to act on the information and testimony from this Special Committee on Aging hearing to increase caregiving hours and to address the workforce shortages that exist across the care economy. Thank you for considering the views and experiences of individuals with SMA and their families.





**Tracie Sharp, President and CEO**  
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March 21, 2022

The Honorable Bob Casey  
 Chairman  
 Senate Select Committee on Aging  
 U.S. Senate  
 G41 Dirksen Senate Office Building  
 Washington, D.C. 20510

The Honorable Tim Scott  
 Ranking Member  
 Senate Select Committee on Aging  
 U.S. Senate  
 G41 Dirksen Senate Office Building  
 Washington, D.C. 20510

Re: Medicaid Home and Community Based Services Dues Skim

Dear Chairman Casey, Ranking Member Scott:

On behalf of the State Policy Network (SPN), in preparation for the Committee's March 23 hearing on "The Importance of Home-Based Services" we write to educate members about an on-going scheme that has siphoned over \$1 billion from the Medicaid Home and Community Based Services program and the paychecks of hardworking care providers into public-sector unions coffers. SPN is the national nonprofit organization that works daily to strengthen and defend the rights of working families by promoting policies that safeguard personal freedom, economic liberty, the rule of law, and property rights, and foster limited government. Our network includes 64 independent state think tank affiliates.

In several states,<sup>1</sup> governments automatically deduct a portion of Medicaid or other government aid from home healthcare providers' assistance checks and give that money to

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<sup>1</sup> Eleven state governments have the infrastructure that allows them to skim money from home caregivers' Medicaid checks and give it to unions. They are: California, Connecticut, Illinois, Maryland, Massachusetts, Minnesota, Missouri, New Jersey, Oregon, Vermont, and Washington. While unions in some of these states may not currently be active, dues skimming is still allowed to occur.

government unions, before the aid ever reaches providers. Many providers are unaware this money is even being taken; others are aware but struggle to stop their state and union from skimming money from their checks; and some caregivers allege the unions and governments are fraudulently skimming the money. SPN opposes this practice on legal, policy, and moral grounds.

At the core of this issue is [clear and established law](#) that Medicaid funds should go only towards services that help the truly needy individuals the program supports. Unfortunately, the practice of dues skimming is in direct conflict with the intent of that law. The Obama administration flouted the Social Security Act by adding an exception via regulation in 2014<sup>2</sup> to permit third parties to receive Medicaid funds, a change that was clearly intended to help a particular group financially. But it wasn't Medicaid recipients the administration sought to support, it was the Obama administration's political allies, labor unions, who were meant to benefit from the dubious regulatory add-on. As a result, hundreds of millions of dollars were scraped, often without consent, from the paychecks of hardworking Medicaid providers to cushion the coffers of the unions. Because funds were directed away from Medicaid providers to unions, it was likely in violation of the Social Security Act. The Supreme court also ruled later in *Janus v. AFSCME* that when this is done without consent, it is illegal. The Trump administration attempted to roll back the Obama-era rule, but this effort was entangled in court proceedings. The current administration is considering another rule change to bring back that language while giving a nod to *Janus* rights.

Allowing this diversion of Medicaid funds is bad policy for several reasons, not the least of which is that it converts Medicaid funds meant for caregivers and providers in local

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<sup>2</sup> <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

communities into cash for state and national campaigns and politics. While the rule repeatedly states that it will allow funds to go to a third party for *health insurance, skills training and other benefits customary for employees,*” data from past practice irrefutably reveals<sup>3</sup> that much of the money will be channeled to political candidates. At the heart of *Janus* was the fact that funds were going from unwilling providers to unions, which in turn used significant portions of those funds to advocate for political causes and campaigns.

Finally, we oppose this practice because it is morally wrong. It has a direct and negative impact on some of the most dependent and needy citizens in our communities, including the loved ones who care for them. In recent years, SPN has collected many personal stories<sup>4</sup> of families impacted by dues skim, including the Coomer family that lives outside Seattle in Washington State. Sally Coomer provides in-home care for her adult daughter, Becky, who experienced a brain injury at birth that left her with developmental disabilities, cerebral palsy, and blindness. Sally receives a monthly Medicaid stipend that was cut short when her state government skimmed money from it without her consent and gave it to a union. Thankfully, because of the result of *Janus*, even the Biden administration’s current attempt to reinstate this practice cannot force her to give up some of her much-needed Medicaid payment. But many others like Sally have been confused or coerced into handing these funds over to the state unions. Sally, like countless others, doesn’t want to be coerced or deceived into paying a union just so she can look after her daughter. Sally said it best: “Caring for my daughter is not a job that needs union intervention. This is my daughter, and this is our life circumstance.”

Unfortunately, the Coomer family’s story isn’t unique. Miranda Thorpe, a mother in Washington who provides in-home care to her adult daughter, Sarena, has been working to

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<sup>3</sup> <https://www.unionfacts.com/cuf/>

<sup>4</sup> <https://spn.org/blog/spn-releases-the-big-skim/>

educate other caregivers about their rights not to pay a union. Sadly, many states and the unions they work with have imposed hurdles that make it difficult, if not impossible, for busy relatives of sick and disabled adults to leave a union and protect their Medicaid stipends in full. Mothers like Kris Greene, in Minnesota, know how crucial this needed support is to keep their patients, in this case, her daughter Meredie, at home and comfortable. Every dollar state governments are allowed to skim from Medicaid checks and give to unions is a dollar not spent on people like Becky, Sarena, and Meredie. These vulnerable citizens are why the integrity of this Medicaid program must be protected and why this scheme is morally wrong.

This practice also hurts the care providers. Of the \$170 billion per year Medicaid spends on long-term services and supports (LTSS), nearly 60 percent is used for home and community-based services.<sup>5</sup> The majority of these funds are expended to allow Medicaid recipients to continue to reside at home or in the community, rather than in expensive long-term care facilities.

The efforts of independent in-home health care providers are central to keeping elderly and disabled Medicaid beneficiaries, like those mentioned above, at home and out of nursing homes. These caregivers help beneficiaries with a variety of personal care activities and chores like bathing, dressing, grooming, housecleaning, preparing meals and eating, laundry, grocery shopping, and traveling to doctor appointments. Kris Greene explained: “(The Medicaid program has) been able to keep (my daughter) Meredie at home instead of having to be in a group home or state-funded place. It’s helped maintain her stability ... It’s been really good for her. I can only imagine where she’d be without it.” Many, perhaps most independent in-home health care providers are relatives or friends of the individuals they assist.<sup>6</sup>

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<sup>5</sup> Steve Eiken, et. al. (2018) “Medicaid Innovation Accelerator Program, Medicaid Expenditures for Long-Term Services and Supports in FY 2016”

<sup>6</sup> *Protect Providers Homepage* (SPN <https://www.protectproviders.com/>); J. L. Wolff, K. Davis, M. Leeds et al. (2016) *Family Caregivers as Paid Personal Care Attendants in Medicaid*, Roger C. Lipitz Center for Integrated Health Care, Johns Hopkins University (<https://www.jhsph.edu/research/centers-and-institutes/roger-c-lipitz-center-for-integrated-health-care/issue-brief-family-caregivers.html>)

Because independent in-home health care providers who rely on Medicaid as their primary source of revenue are engaged in single-worker, single-employer relationships that often involve family members or friends, there is no obvious role for unionization of these individuals. Nevertheless, union officials have colluded with government administrators in some states in order to make independent in-home health care providers another source of dues income. In a significant number of states, they have been successful at forcibly unionizing these caregivers and arranging for automatic dues deductions from their Medicaid payments.

Prior to the United States Supreme Court's decision in *Harris v. Quinn*, 134 S. Ct. 2618 (2014), which held that independent in-home caregivers in Illinois could not be forced to pay union fees, there is a good chance that withdrawals from a home health provider's paycheck for union fees were mandatory. There was no way for most workers to opt out of paying union fees. Although voluntary unionization of independent in-home caregivers may not be objectionable, the coercive tactics unions have used to recruit and retain members are disturbing.

Union officials and their allies in state governments typically attempt to designate independent in-home caregivers as state employees for the purposes of collective bargaining. Workers are denied all other benefits of employment such as access to state retirement plans, state health insurance plans, state employee workers' compensation insurance, and even indemnity in the event of lawsuits, but through this vehicle unions become their exclusive representatives. States then serve as organized labor's "dues collectors," automatically deducting funds from workers' Medicaid payments on the unions' behalf.

Some states have deducted as much as \$1,000 a year from independent in-home health providers' modest pay for years, often without workers' knowledge or consent. In this way, unions have colluded with friends in state governments to siphon an estimated \$1.4

billion from Medicaid, including \$150 million in 2017 alone.<sup>7</sup>

Although the Biden administration's current proposed rule bends to Janus and requires that Medicaid funds are diverted from their original purpose to unions only with "voluntary consent," those organizations have taken extreme steps to continue the flow of Medicaid dollars. They have tried to prevent independent in-home health providers from learning their rights, mandated or pressured them into attending coercive, union recruitment meetings that were labeled as informational sessions, and placed enormous obstacles in the way of caregivers who want to stop states from deducting union dues from their paychecks. Labor officials have used state resources to promote union membership, and encouraged providers to join unions electronically, via hand signed cards, or by telephone, while making it extremely difficult to resign from them.<sup>8</sup>

It is often unclear what, if any, benefits unions offer caregivers and Medicaid beneficiaries for the substantial fees they charge. The loophole that permits this scheme needs to be closed to safeguard Medicaid funds for those who truly need them, and ensure full compliance with the law. It will also give government and union officials clear guidance that they must follow in substance as well as form the Supreme Court's rulings in *Harris and Janus v. Am. Fed'n of State, Cnty., and Mun. Emps., Council 31*, No. 16-1466 (2018), which held that state-employed workers cannot be required to support unions as a condition of employment. The Biden administration rule change will undo the many benefits that the previous administration's reversal of Obama's rule provided to critical Medicaid providers,

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<sup>7</sup> Maxford Nelsen (2018) "Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity"

<https://www.freedomfoundation.com/wpcontent/uploads/2018/07/Getting-Organized-at-Home.pdf>

Dues Skimming FAQ's, State Policy Network, <https://spn.org/dues-skimming-faqs/>

<sup>8</sup> Maxford Nelsen (2016) "Six Ways SEIU 775 Is Getting Around Harris v. Quinn,"

(<https://www.freedomfoundation.com/labor/six-ways-seiu-775-is-getting-around-harris-v-quinn/>)

Maxford Nelsen (2016) "Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity.")

who will once again be subject to confusing rules, coercive union tactics, and cuts to their paychecks.

It is also important to remember that this practice is not needed if providers want to join a union. Those who wish to belong to a union are still free to join, even if dues skimming is prohibited. Ending the dues skim would mean the government can no longer take money from caregivers' support checks and give it to unions; to belong to a union, providers would simply need to send their dues payment to the union themselves. If providers and patients agree with and want to financially support unions' partisan political lobbying, they are still free to do so. But, the government should not be collecting money on behalf of unions, and certainly not without caregivers' express consent.

As the Committee hears testimony about the importance of home-based services and the need for more funding, we urge members to address dues skim. This deceptive practice hurts independent in-home health care providers, and the truly needy people they serve, by having their Medicaid funds siphoned off by organized labor. It also fleeces American taxpayers at a time when the country can least afford it. The end results are pay cuts providers cannot afford, the erosion of a critical workforce, and ultimately direct harm to the truly needy people the Medicaid program was meant to serve.

We welcome the opportunity to work with you and your staff on this issue. Please contact SPN Senior Advisor Jennifer Butler ((561) 352-0011, [butler@spn.org](mailto:butler@spn.org)) with any questions. Thank you.

Regards,



Tracie Sharp  
President & CEO  
State Policy Network



March 29, 2022

Re: Urgent need for expansion of HCBS

To the Senate Special Committee on Aging,

I am writing to request that the federal government **expand access to quality home and community-based services (HCBS) and invest more funding and resources to the direct support workforce**. I am both a researcher and a disabled person who is observing and living out this crisis in multiple ways. Our University of Cincinnati Center for Excellence in Developmental Disabilities works to improve outcomes for people with disabilities. We do this in several ways, including gathering information and increasing knowledge about the current state of Ohioans with disabilities. In Ohio, we have more than 68,000 people on a waiting list for HCBS<sup>i</sup>. Unfortunately, our state also maintains the 2<sup>nd</sup> largest number of institutions that severely restrict the community integration of Ohioans with disabilities<sup>ii</sup>—more than 30 years after the Americans with Disabilities Act and more than 20 years after the Olmstead Supreme Court Decision<sup>iii</sup>.

Thank-you for facilitating last week's hearing on our country's urgent need and long-overdue investment in HCBS, including bolstering our direct support provider workforce. I appreciated the DSP perspectives shared during the hearing. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

The Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Recent analyses indicate a minimum \$150 billion and ideally a \$400 billion investment would fund





progress to matching our HCBS system's capacity with the increasing and under met needs of aging Americans and Americans with disabilities<sup>ii</sup>.

In addition to increased federal investment in HCBS, Congress should compel the US Bureau of Labor Statistics to establish a Standard Occupational Classification for Direct Support professionals. The absence of this classification status has allowed states to underpay DSPs and it forgoes a path for people to make this important profession a career.

Much of my work in the last two years has studied the tragic cost of what our system lacks. More than 200,000 Americans-most with disabilities-have died in congregate settings<sup>iv</sup>. Many died waiting for the lives in their communities that our laws and values uphold. People with disabilities have shown immense resilience despite disproportionate losses during the Covid-19 pandemic. Hope for these critical improvements in the system is waning but remains. We must act now in improving our HCBS infrastructure.

Thank you for your consideration and service.

Sincerely,

Kara Ayers  
Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)  
Director of the Center for Dignity on Healthcare for People with Disabilities  
Assistant Professor, Division of Developmental and Behavioral Pediatrics and the University of Cincinnati College of Medicine  
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937-305-8254

<sup>i</sup> "IDD Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers as of 2018," State Health Facts. Washington, DC: Kaiser Family Foundation, accessed March 28, 2022.

<sup>ii</sup> "The Case for Inclusion 2022: Blazing Trails for Sustainability for Community Disability Services," ANCOR Foundation and United Cerebral Palsy, accessed March 28, 2022.

<sup>iii</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1998).

<sup>iv</sup> "Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died from Covid-19". Washington, DC: Kaiser Family Foundation, accessed March 28, 2022.



*Achieve with us.*

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March 21, 2022

**Statement for the Record**  
**Hearing: An Economy That Cares: The Importance of Home-Based Services**  
**United States Senate Special Committee on Aging**  
**Wednesday, March 23, 2022**

Dear Chairman Casey and Ranking Member Scott:

The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities (IDD) and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities and their families through advocacy, empowerment, and education. We thank you for having today's hearing and for focusing on the importance of Home and Community Based Services. Because of HCBS, individuals with IDD are able to live full lives in the community as opposed to living in a segregated institutional setting.

With this in mind, The Arc of New Jersey is eager to see passage of the Better Care Better Jobs Act which will make a monumental investment in HCBS and will subsequently help people with IDD and their families access the services and supports they need. With funding from the American Rescue Plan Act, New Jersey was able to temporarily increase funding to community provider agencies that support people with IDD to ensure these individuals continued to receive the services and supports they depended on, despite the incredible challenges brought about by the COVID-19 pandemic. These funds kept programs afloat, and temporarily increased wages for the Direct Support Professional workforce. The Better Care Better Jobs Act would help to solidify the service delivery system for people with IDD. Instead of just giving one-time, temporary bumps in wage, the Better Care Better Jobs Act would lead to substantial and permanent wage increases to the workforce. This would reduce turnover of workers and provide the continuity of care that people with IDD require. Chapters of The Arc, who deliver the hands-on services, report crisis-level staff vacancies. This makes it incredibly difficult to offer high-quality and robust services and makes it difficult for individuals with IDD who rely on their DSPs for assistance with personal and intimate tasks. It also proves very challenging for families who need DSPs to support their loved one.

That is why we urge you to pass the Better Care Better Jobs Act as soon as possible. This will ensure that the systematic issues facing the service delivery system are addressed with a more permanent solution, instead of temporary band aids. Furthermore, individuals and their families can be confident that the pool of Direct Support Professionals will be dependable and available to meet their needs. Thank you again for today's hearing and for the change to provide comment on this important matter.

*For people with intellectual and developmental disabilities*

Dear Honorable Senators,

My name is Grace Tsao, I am a 44-year-old disabled Asian American woman and I live in a suburb right outside of Chicago, Illinois. Thank you for the opportunity to offer testimony on Home and Community Based Services (HCBS). As a person with a disability who needs care in order to live in my home and community, HCBS is vitally important to me.

I was diagnosed with muscular dystrophy at age six or seven and have lived with a lifelong disability. I have used a power wheelchair since I was 11. Muscular dystrophy is a progressive disability and over the years I have lost the ability to do many things I used to be able to do but have adapted and made changes so that I can keep moving forward. I have low lung function and rely on the use of a BiPAP machine to breathe for half of the day. I have significant chronic pain and have limited use of my muscles and need help for most things. These days I need help with almost all activities of daily living from transferring in and out of bed into my wheelchair, showering, dressing, going to the bathroom, household chores, cooking, help with eating, laundry, cleaning, etc., the list goes on and on.

But I am also a wife, daughter, sister, and friend. I am important to the lives of many people. I have a bachelor's degree, two graduate degrees, and many certificates. I have worked in state government, non-profit, and higher education and have volunteered for many organizations. Having access to HCBS is a significant reason why I was able to

thrive in the community. After high school I went away to college and graduate school because my state, Illinois, was able to offer me HCBS so that I could have personal care assistants to help with my activities of daily living. Having access to HCBS changed the trajectory of my life. It allowed me to have experiences that most people without disabilities often take for granted. It allowed me to have freedom and independence that all of us deserve. My first job out of college over two decades ago was working at the Illinois Department of Human Services (IDHS) on Illinois' response to the 1999 US Supreme Court decision *Olmstead v. L.C.* that unjustified institutionalization of people with disabilities violated Title II of the Americans with Disabilities Act. Unfortunately, more than 20 years later Illinois and the United States have barely made a dent, and there is still so much to be done to integrate disabled people into the community, we have a long way to go, and the fight continues. All people should be afforded the option to live in the community if they choose to. We need to eliminate housing seniors and people with disabilities in institutional settings. We all have the right to live and thrive in the community.

There was also a large period of my adult life that I did not have access to HCBS. During those years I relied on family and friends for help. Having sporadic help was an incredibly difficult way to live. Your time is not your own and you must rely on the schedule of others to live and survive. I was constantly late to things, missed appointments, had limited showers, had the indignity of having toileting accidents, missed meals, and had falls and injuries.

I often think of aging with a disability. At my age, as my muscular dystrophy continues to progress and my needs increase as the years go by, having access to HCBS and being a client of the Home Services Program (HSP) in Illinois is everything to me. It allows me to live in my own home in my community. For now, I can rely on my husband to fill in the gaps of care. But he has back issues and one day when he may no longer be able to help me or if something happens to him, I will be at extreme risk of going to a nursing home because Illinois does not provide enough hours for the level of care I need. I'm also constantly reminded of the fact that one bad lung infection could possibly alter the course of my life. I have seen friends and people I know with muscular dystrophy and other disabilities end up in nursing homes at a young age as their disabilities progress because they do not have enough hours of care provided by their HCBS program. I often worry that as I age, I will always be a step away from a nursing home. That is not the life I want to live. This is not the life that any one of us should be forced to live, imprisoned without independence, often living in inhumane conditions, simply because we need additional care to live.

The federal government needs to increase HCBS funding so that states across the country can provide enough hours of care to fit the needs of their clients. As we can see from living in a pandemic for over two years, good health is not a given. Any one of you here can become disabled at any given point in your life or by the sheer process of aging. Wouldn't you want it to be your choice to live in your own home rather than be forced into an institution out of necessity? For those of you that envision things from a purely fiscal perspective, it also makes more financial sense to allow people to have

whatever care they need to live in the community, it is far less expensive than to house them in nursing homes. It is as simple as that.

There should also be more funding options for people who do not qualify for Medicaid to receive HCBS services. There is often an expectation in our society that families should give up everything to support their disabled relatives. But often this is not feasible, nor should it be the answer. Family members of people with disabilities must make a living and have their own lives and responsibilities and people with disabilities have the right to live independently. We should provide more HCBS service options for people who are married. Often those who are married are denied funding or do not receive enough funding for HCBS services because they count spousal income or there is an expectation that spouses should be the sole caregiver. Spouses should be allowed to be paid personal care assistants in all states, not just in some. There should be additional help for families of children with disabilities if they need it. Families should not go bankrupt or be stretched to the limit just because one or more of their members need care.

People who do care work should also be paid a living wage and be given benefits.

There has been an incredible number of care workers that have left the industry during the pandemic. Almost everyone I know who rely on personal care assistants across all states have had an incredibly difficult time hiring care workers during the pandemic and most of us have a shortage in care. Things were already difficult before the pandemic with care workers struggling to make ends meet and fighting for a living wage. The

pandemic exacerbated the problems. Care workers provide intricate, lifesaving, and life changing care and it is a difficult job with little pay and benefits. The pandemic also makes the job a high risk for infection for workers and clients alike. Improvements in HCBS programs also need to include pay increases and benefits for care workers. This will in turn benefit people with disabilities and seniors as well by having access to quality workers with less turnover.

HCBS waiting lists should be eliminated, too many people end up in nursing homes or even die while waiting to be approved for services and this is unacceptable. More funding should also be directed at helping people coming out of institutions and nursing homes so that they can live in the community. More assistance is needed to help them find affordable and accessible housing and HCBS as they transition out of nursing homes.

If the coronavirus pandemic has taught us one thing is that our lives are all intertwined. Everyone has been touched by the pandemic, but vulnerable groups like people with disabilities, seniors, and members of Black and Brown communities have been disproportionately affected by COVID-19. I hope that the disparities that have been highlighted and that have always existed will continue to be at the face of our country's consciousness. We should all care about the collective good of everyone in the community. When we do, we are all the better for it. Nursing home residents have had more disproportionate numbers of infections and deaths than the rest of our society. The devastating effects the coronavirus pandemic has had on the nursing home

population also illustrates the importance of providing home health and personal assistant services so that people can live in the community. I hope that we can move toward this goal.

My life and the lives of millions of seniors and people with disabilities are every bit as valuable as everyone else simply in the fact that we are human. There are thousands and millions of stories like mine all over this country.

Thank you again for the opportunity to share my story and perspectives on HCBS.

Sincerely,

Grace Tsao



March 20<sup>th</sup>, 2022

RE: U.S. Senate Special Committee Hearing on Aging  
March 23<sup>rd</sup> 10:00 am "The importance of Home-Based services".

To whom it may concern,

My name is Sally Coomer and I have an adult daughter that receives community based In-home personal care services through DDA. My daughter requires around the clock care, and I am her paid parent provider along with my oldest daughter and her husband. Without these services Becky would surely have to resort to institutional care. These services are what has allowed her to remain living at home and in her own community. They are critical to her quality of life. The biggest threat to our community-based services that we face as providers is the control and power that SEIU has over the Medicaid home care services. Over the last 15 years I have seen the increasingly negative impacts of SEIU affecting both the individual provider as well as the agency provider. As an example, In 2009 SEIU fought to remove any related family providers from working as an agency employee and required them to quit their job and become an individual provider. These agency employees caring for a family member had to quit their agency job, lose their agency benefits, take reduced wages, lose overtime, and once moved from agency provider to an Individual provider, parents were then prohibited from paying into the social security system, (IRS Notice 2014-7 law). This was extortion, we were given the choice to either move over to become an IP and continue caring for our loved one, or we could not provide the job of caring for our own child in their home. This decision impacted up to 40,000 family providers for the purpose of the SEIU 775 gaining millions of dollars in union dues from these new family caregivers forced to move over to the individual provider system. This same union continues to legislate for such stringent and overly burdensome training requirements, that it makes recruiting of new caregivers nearly impossible. This has contributed greatly to the caregiver shortage we all face today. It is again extortion, when the union requires dues of 3.2% from a caregiver's wages, even when they have not consented to being a union member. They are charging the highest percentage of union dues of any union in the nation.....(for us that is over \$269 monthly) It is appalling when you think those funds could otherwise be used for additional care to the vulnerable client. I have experienced their coercive dues collection practices and endured continual political propaganda which gets exhausting for caregivers and families. SEIU claims to offer medical/dental benefits to the provider which is actually paid for through Medicaid dollars and would be offered regardless. I do not need a union to represent me, while I am caring for my own daughter in our home. There continues to be a huge need for home and community-based services. The biggest burden for families, caregivers and clients is navigating the system and trying to manage the stringent and overwhelming training requirements and always battling the SEIU 775 union.

Thank you for your consideration,

Sally Coomer



March 30, 2022

The Honorable Bob Casey  
Chair, Senate Special Committee on Aging  
G41 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Tim Scott  
Ranking Member, Senate Special Committee on Aging  
628 Hart Senate Office Building  
Washington, DC 20510

**Re: Comments for the Record of March 23, 2022, Hearing, "An Economy That Cares: The Importance of Home-Based Care"**

Dear Chairman Casey and Ranking Member Scott:

As President and CEO of Lutheran Services in America, I write to you on behalf of the Lutheran Services in America-Disability Network (LSA-DN) that is dedicated to ensuring that people with disabilities have the opportunity to be full participants in their community and live with dignity, respect and independence in the home and community of their choice. LSA-DN is part of Lutheran Services in America which is a national network of 300 Lutheran health and human services organizations that reaches one in 50 people living in America and has combined revenue of over \$23 billion. Lutheran social ministry organizations are deeply embedded in over 1,400 communities in 45 states across the country and have provided services for over 150 years.

As providers of home and community-based services (HCBS), our members know first-hand the importance of these services to millions of people with disabilities and older adults, and that a long-term investment is required to expand access. However, without an equal investment in the workforce that provides these services, our nation will lack the qualified workers needed to provide them to those who need them. The years long HCBS waitlists that plague many states will not be eliminated unless there are enough direct care workers to provide services.

Currently, providers are experiencing the worst workforce shortage we have seen for direct care staff—either prior to or during the height of the pandemic. Many organizations are reducing the number of people they serve or are unable to meet the demand for services because of workforce



shortages. This is particularly a problem in rural communities where some rural programs or providers are closing due to insufficient staffing, exacerbating an already limited set of services in rural areas.

Most older adults and people with disabilities want to live at home, yet many face barriers to accessing the support they need to do so. The HCBS workforce provides vital services, and yet these workers—who are primarily women of color—have been underpaid for decades given the low Medicaid reimbursement rates for these services. Long-standing staffing shortages, which the pandemic exacerbated, have created gaps in service availability, lengthy waiting lists, and additional obstacles to achieving a high quality of life for workers and people with disabilities and their families.

LSA-DN applauds the Senate Aging Committee for holding a hearing to examine the importance of HCBS and for focusing on the needs of the workforce that makes these services possible. However, much more needs to be done. The workforce crisis is impacting every state: it is a national crisis, and thus requires a national solution. That is why LSA-DN calls on every member of the Senate Special Aging Committee to support a significant, long-term, federal investment in HCBS and direct care workforce development.

States have had to rely on relatively small and short-term funding increases to help them address decades long HCBS and workforce issues. But our nation needs an investment of at least **\$250 billion for HCBS and workforce development** if we want to expand these services. An investment in HCBS and the direct care workforce on this level would be transformational and would directly improve the lives of millions of older adults and people with disabilities and the people who care for them.

Fully funding this investment would enable providers to expand services and eliminate the nationwide waitlist of 850,000 older adults and people with disabilities so they can receive needed services in their homes and communities. This would also help address the workforce shortage, for example, through increased wages and benefits for direct care workers. It would provide relief for families and allow millions of family caregivers to return to the paid workforce. It would also enable people to live in their homes and communities and avoid more expensive hospitalization and institutionalization. Finally, it would allow expansion of the Money Follows the Person program and for older adults transitioning from acute care settings to



their homes to receive the services needed to prevent rehospitalization, such as transportation, nutrition, and more.

While the COVID-19 pandemic has presented our nation a multitude of challenges, it has also presented the opportunity to make an unprecedented investment in the direct care workers who have been the frontline heroes during the pandemic. This essential workforce helps ensure that older adults and people with disabilities can thrive and live with dignity and respect. We urge every member of the Aging Committee and Congress to show their commitment to HCBS and the direct care workforce by providing at least \$250 billion in funding.

Thank you for your consideration. If LSA-DN can be of assistance, please do not hesitate to contact Josh Dubensky at [jdubensky@lutheranservices.org](mailto:jdubensky@lutheranservices.org).

Respectfully,

A handwritten signature in black ink that reads "Charlotte Haberaecker".

Charlotte Haberaecker  
President and CEO

March 22, 2022

Chairman Bob Casey  
Special Committee on Aging  
United States Senate

Ranking Member Tim Scott  
Special Committee on Aging  
United States Senate

Members  
Special Committee on Aging  
United States Senate

Re: Hearing March 23, 2022 - "An Economy That Cares: The Importance of Home-Based Services"

Dear Chairman Casey, Ranking Member Scott, and Members of the Committee,

The Special Committee on Aging is scheduled to hear testimony tomorrow regarding the importance of home-based services for persons who require close care.

I am writing as the parent of a severely autistic adult with behavioral challenges who suffered great trauma in the HCBS disability service system, including a broken eye socket, toxic overmedication and sexual abuse but who found appropriate and safe services in a public congregate intermediate care facility that had the on-site treatment team, levels of professional watchful eyes, campus amenities and professionally trained, supervised staff that were necessary for his survival.

I am concerned that the needs and the services along the continuum of care for the most disabled are being marginalized and ignored by policymakers in favor of the agenda of interest groups who stand to profit by eliminating the "competition", ie. public Intermediate Care Facilities. Privatized HCBS services can and do reject providing services for the most disabled because they cannot manage these clients in their system. This leaves nowhere to go for people like my son but retro-fitted hospital emergency rooms, jails and psychiatric "boarding" at great cost to society and trauma, injury and death to the most vulnerable.

The Supreme Court recognized in *Olmstead* that not everyone can benefit from the "Community" but "*As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. . .*

*Some individuals . . . may need institutional care from time to time 'to stabilize acute psychiatric symptoms'.*

*For other individuals, no placement outside the institution may ever be appropriate...for these persons, **institutional settings are needed and must remain available.**"*

- *Olmstead v. L. C.*, 527 U.S. 581, at 604-605

“In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, *States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.*”

•Olmstead v. L. C., 527 U.S. 581, at 610

Please demonstrate your support for facility-based congregate care and the vast number of families who rely upon this lifeline for their severely disabled loved ones.

Many of us would gladly volunteer to testify as to our needs and experiences if given an opportunity.

Sincerely,

Susan H. Jennings

Mother / Co-guardian of Joey, age 3, severe autism, White Haven Center  
ICF Advocates for Choice – President

<https://my-icf.org>

570-447-6330



Testimony of The Michael J. Fox Foundation for Parkinson's Research

United States Senate Special Committee on Aging  
 "An Economy that Cares: The Importance of Home-Based Services"

March 29, 2022

The Honorable Bob Casey  
 Chairman, U.S. Senate Special Committee on Aging

The Honorable Tim Scott  
 Ranking Member, U.S. Senate Special Committee on Aging

Chairman Casey and Ranking Member Scott:

On behalf of The Michael J. Fox Foundation for Parkinson's Research (MJFF), I write to express my appreciation to you and the members of the committee for hosting the hearing, "An Economy that Cares: The Importance of Home-Based Services." People with Parkinson's disease (PD) depend on access to home health services to lead healthy, fulfilling, and independent lives.

About 62 percent of people living with Parkinson's receive care from a family care partner. For many family and friend caregivers of people with Parkinson's disease, providing care is a full-time job. MJFF supports robust federal investment in the home health care worker economy to provide relief for the burden placed on family and friend caregivers.

Parkinson's disease is a chronic, progressive neurological disorder affecting over one million people in the United States. There is no treatment to reverse, slow, or stop the progression of Parkinson's and symptoms include mobility, movement, and swallowing problems as well as dementia. There also is no cure.

Parkinson's costs Americans at least \$52 billion each year – roughly half of which is covered by Medicare and Social Security in caring for people living with the disease. By 2037 – just 15 years from now – that cost is estimated to balloon to nearly \$80 billion when more than 1.6 million Americans are projected to be living with Parkinson's. Estimates indicate that one in six Americans suffers from a neurological condition. Parkinson's is the fastest growing neurological disease in the world and is the second most common condition after Alzheimer's disease.

Unpaid family caregivers provide an estimated \$470 billion in care every year when they assist loved ones with providing medication, activities of daily living, preparing meals, and transporting them to medical appointments. As the population ages and scientific advancements continue to improve health outcomes and lifespans for people with Parkinson's, the need for home health care, and the financial burden of this care, will only increase. Informal caregivers provide invaluable support for the physical, mental, and emotional needs of patients, too often at the expense of their own participation in the workforce, given the shortage of affordable home health care options.

Caregivers for people with Parkinson's also provide meaningful social contact to provide relief from the social isolation and loneliness many experience while living with PD. Due to the prominence of symptoms that inhibit mobility and interfere with daily activities, people with Parkinson's are especially prone to social isolation and loneliness if they are home bound. Studies have shown that that people with Parkinson's who report higher levels of social isolation and loneliness are more likely to experience a decreased quality of life. There is even a direct correlation between greater social isolation and greater symptom severity. Home-based caregivers therefore provide a vital lifeline to people with Parkinson's

Ensuring that home health care workers have access to a living wage will create greater access to care for people with Parkinson's. MJFF believes that increasing the accessibility of home health care will decrease the financial and emotional burden on family caregivers and provide better outcomes for people with Parkinson's. Thank you for giving time and attention to this important matter and for providing this opportunity to share essential information with the committee on the importance of home health care to people with Parkinson's disease. Please contact Nora Eigenbrodt at [neigenbrodt@michaeljfox.org](mailto:neigenbrodt@michaeljfox.org) should you have any questions or require further information.

Sincerely,



Ted Thompson, JD  
Senior Vice President, Public Policy



To the Senate Special Committee on Aging,

I am writing to request that the federal government expands access to home and community-based services (HCBS) and invest more funding and resources to the direct support workforce. Here in Ohio, my loved ones, friends, clients and I are currently in a crisis. Thousands of people with disabilities are forced into institutions and nursing homes when they have no need to be there, simply because it is more and more difficult to find and keep direct care staff to help them get out of bed, take care of their hygiene needs, and help them get started with their day as productive and important members of our communities. The problems with our HCBS systems are causing people to starve, injure themselves trying to move around on their own, or forced to call 911 because they are left in an emergency health situation with no support or help.

I have experienced these problems firsthand. My son in law became bedridden and has a TBI all from a bleeding ulcer. We spent 16 hours a day with him while he was in a Nursing Home trying to recover in Columbus, Ohio. We got him home and he receives 56 hours of care a week. He needs 24/7 care 365 days a year. We tried agencies but at \$11 an hour the aides do not care. I closed my business and became his aid at \$11 an hour through an Agency. I was never paid overtime for the 16 hours worked over the 40. My daughter has to fight to get him things he needs and is still waiting on some of those things. I came close to losing my home because \$11 an hour is not enough to cover daily and household bills.

The issues are apparent and obvious to all of us that use direct care staff or are direct care staff. I became an Independent Provider through the State of Ohio Department of Medicaid. As an Independent provider I make a median hourly wage of \$12.96 an hour or \$41,900 each year. My 40 hours of pay is \$26,956.80 plus my overtime pay of \$14,903.20. If I worked at McDonald's I would NOT be responsible for someone's life! I also would be making \$15 an hour, \$31,200 base pay plus my 16 hours of overtime at a rate of \$22.50 an hour times 16 hours a week for overtime yearly pay of \$18,720 bringing my yearly income to \$49,920. That difference of \$8,000 a year would keep me as a productive home owner in my community.

I also am an Independent Provider for the Ohio Department of Aging through the Ohio Passport Choices program. According to Ohio Administrative Code 5160-1-06.1 my client is to work out a pay rate for me that cannot be more than \$25 an hour. No more than 60% of the cost of them being in a Nursing Home. My client tried to get me the \$6.25 every 15 minutes (\$25 an hour) but his case worker stated than pay was the maximum amount to cover everything for him including meals. Yet on the same OAC it says my other Medicaid/Medicare client the maximum I can bill is \$3.24 every 15 minutes which is what I billed. She stated she would try to get me \$15 an hour. If I used her logic I would be billing my other client at 60% too of what the State of Ohio allows which would be \$1.94 every 15 minutes which would pay me \$7.77 an hour under the Passport HCBS waiver of Participant- directed individual provider. I was approved for this in January 2022, my 2<sup>nd</sup> client was approved in February and we both are still waiting to start his services. The first client I applied for still is waiting for Molina to approve him for the Choices program.

I also am an Independent Provider for Ohio Department of Developmental Disabilities. My pay there is \$21.36 an hour. My client does NOT need any assistance with bathing, dressing or feeding, unlike my other 2 clients (1 on Medicaid and 1 on ODA Passport) who need help with those activities of daily living. I keep track of her (DODD client) daily calories and drive her around.

The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide. As you can see there is a great difference in my pay as an Independent Provider through all 3 State of Ohio Departments. I have written Governor DeWine because even the process to become an Independent Provider is a mess and takes forever as you can see from my experiences. As long as there's such a BIG gap in pay and no benefits for the Independent Providers between the 3 Departments there will always be a shortage in help.

I strongly support the Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so

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many years. Please pass this critical legislation so that people with disabilities know that their independence, health, and safety matter to our country. Thank you.

Sincerely,

Marilyn K. Curtis

14399 Cleveland Rd. SW

Pataskala, Ohio 43062

614-515-9011



**MAX RICHMAN  
PRESIDENT AND CEO  
NATIONAL COMMITTEE TO PRESERVE SOCIAL SECURITY AND MEDICARE  
STATEMENT FOR THE MARCH 23, 2022 HEARING RECORD ON  
“AN ECONOMY THAT CARES: THE IMPORTANCE OF HOME-BASED SERVICES”  
THE SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE**

On behalf of millions of our members and supporters, I commend the Senate Special Committee on Aging’s important work related to improving access to home and community-based services (HCBS) for seniors and people with disabilities.

The COVID-19 pandemic has dramatically underscored what decades of research on infection control and beneficiary preference already made clear: nursing homes are often dangerous for residents and staff. According to the Government Accountability Office, 82 percent of surveyed nursing homes had an infection prevention and control deficiency between 2013 and 2017. As of February, [200,000](#) nursing home residents or staff died of COVID which is nearly one quarter of all COVID-related deaths in the United States. It is abundantly clear that seniors are safer in their homes where [approximately 75 percent](#) of seniors wish to live as they age.

Despite all that we know about nursing home deficiencies, 820,000 Americans are on wait lists for Medicaid home and community-based services. Without access to Medicaid HCBS the only option for people who can’t afford to pay for long term care out of pocket is a nursing home.

Given that seniors continue to be vulnerable to COVID even with vaccination, there is an urgent need to extend and enhance funding for home and community-based services created by the American Rescue Plan Act (ARPA), including wage and benefit increases for home care workers to help recruit and retain them. State Medicaid programs have used these COVID-19 public health emergency (PHE) authorities and funding to:

- Expand eligibility criteria for seniors and people with disabilities
- Streamline enrollment processes
- Reduce premium and cost sharing requirements
- Improve provider payment rates

These emergency funds, which are currently bolstering home care services for seniors, will run out when the public health emergency ends. The National Committee is concerned that without

resources for home-based long-term services and supports, seniors will be forced back into the same institutional settings that proved so deadly over the course of the pandemic.

Moreover, there is evidence that shifting people out of nursing homes and back into their homes can save money. One [study](#) found that a gradual shift away from institutional care to home based services could reduce long term care spending by 15 percent.

For this reason, the National Committee strongly supports Chairman Bob Casey’s legislation, S. 2210, the Better Care Better Jobs Act, which would provide a permanent enhanced funding stream for Medicaid HCBS and make the “Money Follows the Person” rebalancing demonstration program and spousal impoverishment protections for Medicaid HCBS permanent.

The National Committee continues to support improving access to Medicare’s home care benefit and creating a long-term care benefit that beneficiaries who are not Medicaid eligible can access. It is a shame that so many of our seniors must impoverish themselves to access long term care benefits when they outlive their savings. We look forward to working with members of the Senate Special Committee on Aging to improve long term services and supports for seniors so that they can more safely age with dignity in their homes.

Thank you again for holding this timely and important hearing.



Elizabeth G. Taylor  
Executive Director

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**Statement for the Record  
March 22, 2022  
National Health Law Program  
to the  
Senate Special Committee on Aging**

**Committee Hearing: "An Economy That Cares: The  
Importance of Home-Based Services."**

On behalf of the National Health Law Program (NHeLP), we submit this statement for the record for the U.S. Special Committee on Aging hearing entitled "An Economy That Cares: The Importance of Home-Based Services."

NHeLP is a public interest law firm working to protect and advance the health rights of low income and underserved individuals. Founded in 1969, NHeLP advocates, litigates, and educates at the federal and state levels. Consistent with its mission, NHeLP works to ensure that all people in the United States have access to affordable, quality health care, including home and community based services (HCBS) for people with disabilities.

HCBS allows people with disabilities and older adults to remain at home and active in their communities, while improving their health and quality of life outcomes. Additionally, HCBS typically costs less per-person than institutional services. HCBS is a key component of Medicaid, which is the nation's primary payor of HCBS services such as personal assistance, supported employment, peer support, and other services older adults and people with disabilities need to remain at home. While all State Medicaid programs can cover these critical services, the extent to which they do often depends on geography or political context – not need. Some states choose to cover expansive HCBS, but others do not. This means that two people with the exact same needs living in different states may get vastly

different services. Worse yet, because states can “cap” the number of enrollees or the costs associated with these services, many people end up waiting years, even decades, for Medicaid HCBS services.<sup>1</sup> These same barriers do not exist for mandatory nursing facility care services. It is often easier for someone who needs assistance to enter institutional care than to receive HCBS in their communities. Those who do access HCBS often have to forgo basic life opportunities that others take for granted, like being able to move states for school or a job, or marry and form a family. Those actions can endanger their access to HCBS.

Additionally, the currently underfunded HCBS system is unsustainable. People with disabilities and older adults languish on waiting lists, experience gaps in coverage, or are forced into institutional settings when they are unable to access care due to inadequate coverage. People approved to receive HCBS often struggle to find staff to support them, largely because low Medicaid rates lead to systemic staffing shortages, high turnover rates, and inadequate training.<sup>2</sup> The essential workers who provide HCBS services—primarily women and people of color—are among the lowest paid health care workers in the United States, which perpetuates more racial and economic injustices.<sup>3</sup> Quite simply, we cannot improve access to Medicaid-funded HCBS without also raising the rates for these services, and ensuring those rate increases go to increased wages and benefits for HCBS direct care workers.

As Congress moves forward, legislators must prioritize expanding access to HCBS services by addressing structural barriers, by providing robust funding, and by increasing support for caregivers and direct service providers to ensure these services remain available.

Medicaid has always been the primary driver of innovation in HCBS, and much progress has been made over the past two decades to improve access to HCBS for older adults and people with disabilities. For example, the Money Follows the Person (MFP) demonstration program

<sup>1</sup> See MaryBeth Musumeci, Priya Chidambaram & Molly O'Malley Watts, Kaiser Family Foundation, *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists* (April 4, 2019), <https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/>.

<sup>2</sup> See National Association of State Directors of Developmental Disabilities Services & Human Services Resource Institute, *2019 National Core Indicators Staff Stability Survey Report* (January 6, 2021), [https://www.nationalcoreindicators.org/upload/core-indicators/2019StaffStabilitySurveyReport\\_FINAL\\_1\\_6\\_21.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2019StaffStabilitySurveyReport_FINAL_1_6_21.pdf).

<sup>3</sup> See, The ANCOR Foundation & United Cerebral Palsy, *The Case for Inclusion 2022 Blazing Trails to Sustainability for Community Disability Services* (2022), [https://caseforinclusion.org/application/files/1716/4658/7147/Case\\_for\\_Inclusion\\_2022\\_Blazing\\_Trails\\_to\\_Sustainability\\_for\\_Community\\_Disability\\_Services.pdf](https://caseforinclusion.org/application/files/1716/4658/7147/Case_for_Inclusion_2022_Blazing_Trails_to_Sustainability_for_Community_Disability_Services.pdf).



has helped over 150,000 people transition from institutional settings, to receive care and services in their own homes. Additional funding via the American Rescue Plan Act helped states fund HCBS has been critical in helping states provide HCBS through the worst of the pandemic, but the funding is temporary.

Congress now has the opportunity to take another huge step forward towards improving the lives of people with disabilities and older adults. The Better Care Better Jobs Act would give states a much-needed infusion of federal funds for HCBS via a permanent increase in states' federal medical assistance percentage (FMAP) for these services, and would turn current short-term investments in HCBS into more meaningful, long-term opportunities to build and sustain a responsive, comprehensive HCBS system. The Act would also Invest in the direct care workforce by addressing insufficient payment rates and requiring that rate increases are passed on to direct care workers. We call on Congress to build a sustainable HCBS infrastructure and fix structural biases that make it easier to access institutional care than community-based services by passing the Better Care Better Jobs Act.

Thank you for your consideration of our comments. If you have questions about these comments, please contact Dania Douglas ([douglas@healthlaw.org](mailto:douglas@healthlaw.org))







March 30, 2022

The Honorable Bob Casey  
Chairman  
Special Committee on Aging  
United States Senate  
393 Russell Bldg.  
Washington DC 20510-3804

The Honorable Tim Scott  
Ranking Member  
Special Committee on Aging  
United States Senate  
104 Hart Bldg.  
Washington DC 20510-4002

Dear Chairman Casey and Ranking Member Scott:

On behalf of the National Multiple Sclerosis Society (Society), thank you for holding the hearing "*An Economy That Cares: The Importance of Home-Based Services*". The Society believes that expanded access and robust investment in home-based care will improve outcomes and provide financial relief for those living with multiple sclerosis (MS), their care partners and their families.

Nearly one million people in the United States live with MS, an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness, and paralysis. The total estimated cost to the U.S. economy, including government, industry, and individuals, is \$85.4 billion per year<sup>1</sup>. Most people are diagnosed between the ages of 20 and 50, when they are in their prime working years. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted but advances in research and treatment are leading to better understanding and increasingly effective treatments for the disease.

Many people with relapsing forms of MS experience a progression of symptoms throughout their disease course that result in loss of function and increasing disability over a time span of many years. Others with progressive forms of the disease experience progression more rapidly. While most people with MS do not become severely disabled, accumulation of disability is a known factor in their declining participation in the workforce over time.<sup>2</sup> The Society serves as a resource for people with MS and their families, care partners and health care professionals for information and referrals for a wide range of needs related to home and community-based services (HCBS) and assistance for activities of daily living. Collectively, these requests consistently rank in the top five reasons that individuals contact the Society or our MS Navigators. Additionally, requests for financial assistance from the Society are connected to the costs that people incur to remain safe and stable in their homes. MS Navigators consistently hear from those on HCBS waiting lists, those who struggle to keep home care workers, and are often helping to find temporary solutions to these issues, when that's even possible. They also approve Society financial assistance funds to fill gaps in these supports including covering short-term home care and respite care, chore services, and other needed supports to help individuals with MS remain in their home.

When people with MS are left without this assistance or waiting on waitlists, sometimes for years, the responsibility for care and support often falls on unpaid family caregivers and care partners. A new study of the economic burden of MS in the United States calculated that care partners pay an average of \$4,333 each year to provide care to someone living with MS<sup>iii</sup>. Access to HCBS is more cost effective for families and in line with what people who live with these chronic conditions want and need to live their best lives.

As stated repeatedly throughout the hearing, Medicaid HCBS have long played a critical role in allowing Medicaid beneficiaries to live independently and to work. The growing need for HCBS, documented racial disparities in HCBS utilization, and the impact of COVID-19 on congregate care settings and individuals' preferences to receive care in the home or community, has brought us to a breaking point where immediate action on HCBS reform must be a priority. The Society has long supported this Committee's and the Administration's focus on expanding access to and sufficiently funding investments in HCBS. We believe that the Committee should focus on:

- **Simplifying and stream-lining Medicaid HCBS waivers and state plan amendments (SPAs).** We believe that this approach to standardizing the Medicaid HCBS waivers and SPAs offers a bipartisan pathway toward improving the availability of Medicaid HCBS. We agree with the Bipartisan Policy Center that this action strikes the right balance between simplifying administrative complexity and aligning these benefits in a consistent fashion and providing states with budget predictability, while helping to advance the goal of expanding access to services and improving the beneficiary experience<sup>iv</sup>. We also agree that current beneficiaries should be grandfathered in to prevent interruptions in care.
- **Ensuring robust funding for HCBS to build a sustainable infrastructure.** Funding for HCBS must be a priority so that we can begin to address the magnitude of need for people who need access to these services. We believe that the investment that President Biden called for in the State of the Union of \$150 billion is essential to meeting this goal. This investment will both increase access to Medicaid HCBS and aid in addressing the challenges of the direct care workforce by allowing for job creation to support people with disabilities.
- **Investing in the HCBS workforce.** A focused commitment to equipping the HCBS workforce is critical to addressing the long-standing inequities the COVID-19 pandemic has exposed and exacerbated. Sustained funding is critical to fortify a workforce that must continue to expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers have been devalued and underpaid for decades, leading to severe staff shortages that result in crucial gaps in service availability, lengthy waiting lists, and service line closures. Increasing the salaries and ensuring benefits such as paid sick and family leave for these individuals will ensure the workforce remains ready and capable to address this growing need of the US population.
- **Safeguarding equitable access to HCBS.** We agree that the use of non-Medicaid providers of HCBS will help address current gaps in the system and alleviate the burden on an already taxed system. We believe private HCBS providers should be complimentary to those services provided and paid for through Medicaid but shouldn't replace state funded HCBS providers and services. Our MS Navigators are currently working with people with MS who are seeking HCBS from private providers who stop accepting new Medicaid enrollees when Medicaid funds run out, and

we are worried that this trend will continue and worsen if private providers are seen as a replacement for state-funded providers. Additionally, we are concerned that a reliance on private service providers will exacerbate health equity discrepancies between what individuals who could afford the private companies receive and what people who rely on Medicaid funded providers receive.

- **Ensuring access to HCBS during natural disasters.** The Society believes that seamless access to care and HCBS should be maintained for any Medicaid recipient forced to cross state lines before, during and after a natural disaster. We would urge the Committee to prioritize passage of S.2646, the Disaster Relief Medicaid Act which would ensure Medicaid assistance to individuals and families affected by a disaster or emergency.

We once again thank you for your leadership and urge that you continue to include and prioritize the large investment in Medicaid HCBS, and the workforce that provides them. As you negotiate any package moving forward that will improve access to and funding for HCBS, we hope that you will keep our recommendations top of mind. If you have any questions, please contact Leslie Ritter, AVP of Federal Government Relations at [Leslie.Ritter@nmss.org](mailto:Leslie.Ritter@nmss.org).

Sincerely,



Bari Talente, Esq.  
Executive Vice President, Advocacy and Healthcare Access  
National MS Society

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<sup>i i</sup> “B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021.

[https://ectrims2021.abstractserver.com/program/#/details/presentations/557.](https://ectrims2021.abstractserver.com/program/#/details/presentations/557)”

<sup>ii</sup> Strober LB, Callanan RM. Unemployment in multiple sclerosis across the ages: How factors of unemployment differ among the decades of life. J Health Psychol. 2019 Sep 14;1359105319876340. doi: 10.1177/1359105319876340. Epub. ahead of print. PMID: 31522567.

<sup>iii</sup> “B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October 2021.

[https://ectrims2021.abstractserver.com/program/#/details/presentations/557.](https://ectrims2021.abstractserver.com/program/#/details/presentations/557)”

<sup>iv</sup> Hayes, Katherine et al. Streamlining and Simplifying Medicaid HCBS Authorities. 26. October 2021. <https://bipartisanpolicy.org/report/streamlining-and-simplifying-state-hcbs-authorities/> (accessed March 25, 2022).



March 29, 2022

Senator Bob Casey  
Chairman  
U.S. Senate Special Committee on Aging

Senator Tim Scott  
Ranking Member  
U.S. Senate Special Committee on Aging

Via email: [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

**RE: U.S. Senate Special Committee on Aging (“the Committee”) March 23, 2022  
Hearing on “An Economy That Cares: The Importance of Home-Based Service”**

This statement is submitted by the [Florida Health Justice Project](#) (FHJP), a nonprofit health advocacy organization whose mission is expanding access to healthcare with a focus on Florida’s most vulnerable populations. Accordingly, we prioritize work on behalf of low-income frail and disabled seniors who require Medicaid home and community-based services (HCBS) in order to remain safely at home and out of an institution. Among other things, FHJP has published an [advocate’s guide](#) and a [consumer video](#) that explain this complex and critical program for vulnerable Floridians and their families. We also work with clients on individual appeals and with those who wish to [share their stories](#) underscoring the lack of resources in this critically underfunded program.

On behalf of our clients, storytellers and the other marginalized Floridians who need Medicaid HCBS, we extend heartfelt thanks to you and your staff members. We understand that you are all incredibly busy, and we are extremely grateful to the Committee for holding this hearing. We are especially grateful that you invited Alene Shaheed to testify. FHJP has worked with Alene for several years—both on resolving her [individual appeal](#) when her managed care plan cut her services and on the [systemic issue of enrollees suffering ongoing gaps in services](#). Alene’s testimony eloquently described what it’s like to go days at a time without any home health aide coming to help with the basic activities of daily living. She was also profoundly clear about the fact that Medicaid home health workers must be paid more in order to resolve the problem.

The suffering caused by untenably low worker pay is obviously a national problem, and any meaningful effort to improve the situation will require Congressional action. Given the import of the program and the urgent need for increased resources, FHJP and two of our state partners shared this [letter](#) with Senators Rubio and Scott, as well as all of

our Florida representatives on July 13, 2021. The letter, which was signed by over 400 Florida organizations and individuals, noted that most people who need Medicaid HCBS end up on a waiting list, currently over 60,000 Floridians. It also described how the severe underfunding of home health workers is hurting those who, like Alene, managed to get off the waitlist and enroll in one of the state's HCBS programs, but who still cannot get the care they need. As Alene testified, this results in dire situations as profoundly vulnerable program enrollees, including those who are incontinent and need assistance to change, bathe etc., are left without any help for days. Another former FHJP client, [Shirley](#), who was bed-bound following a stroke, relies entirely on home-health aides to operate the special lift to get her out of bed. Like Alene, her Medicaid managed care plan is unable to find aides to take care of her on the weekends, forcing her to stay in bed for the entire weekend and increasing her risks for bed sores and skin infections.

We also appreciated the Committee's focus on the need to adequately compensate family care caregivers, and/or provide sufficient funding for home care workers so that family members can rejoin the workforce. Another former FHJP client, Thelma, illustrates this need. [Thelma](#) quit a good job to care for her elderly mother who requires 24/7 care. Especially in light of all the nursing home deaths due to COVID-19, Thelma adamantly refused to put her mother in a nursing home and there was no alternative other than to quit her job. Although Thelma was promised 41 hours of pay, the managed care plan continued to cut her hours as her mother's Alzheimer's progressed and her health worsened. Although FHJP successfully represented Thelma in an appeal, most enrollees whose services are denied, terminated or reduced, do not receive free legal assistance, and the vast majority either do not file an appeal or they lose their pro se appeals.

We are grateful that both Florida senators (copied on this letter) are on the Committee, and we are hopeful that they will play a role in helping to secure needed additional resources. Senator Casey, we are also grateful that you underscored the fact that most seniors who need HCBS were once middle class, and that most long term care in this country is provided through state Medicaid programs. We also want to underscore that home-based services provide a much less expensive alternative to nursing facility care.

The March 23 hearing did a wonderful job in documenting the national need for increased Medicaid HCBS resources. The Better Care Better Jobs Act (BCBJA) will help provide states with funding to build the necessary HCBS infrastructure and support front line workers and family caregivers.

We urge the Committee to keep educating other members of the Senate on the need to pass this investment as soon as possible.

Thank you again for all your time and all that you do. Please do not hesitate to contact me if you have any questions.

Sincerely,

s/Miriam Harmatz

Miriam Harmatz  
[harmatz@floridahealthjustice.org](mailto:harmatz@floridahealthjustice.org)  
786-853-9385  
Florida Health Justice Project  
Advocacy Director & Founder

Cc: Senator Marco Rubio, c/o Varela, Jaime (Rubio) <[Jaime\\_Varela@rubio.senate.gov](mailto:Jaime_Varela@rubio.senate.gov)>  
Senator Rick Scott, % (Scott) [jared\\_honts@rickscott.senate.gov](mailto:jared_honts@rickscott.senate.gov)



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**S.2210**

**Proponent Testimony**

**United States Senate Special Committee on Aging**

**Brittanie Maddox**

**Disability Rights Advocate, The Ability Center of Greater Toledo**

**March 29, 2022**

Chairman Casey, Ranking Member Tim Scott, and members of the Senate Special Committee on Aging, thank you for the opportunity to provide proponent testimony on S.2210 Better Care Better Jobs Act. My name is Brittanie Maddox, and I am a Disability Rights Advocate with The Ability Center of Greater Toledo, a Center for Independent Living serving seven counties in Northwest Ohio. The mission of The Ability Center is to advocate, educate, partner, and provide services that support people with disabilities to thrive within their communities. We are in support of S.2210 and believe that this legislation will positively impact people with disabilities.

On behalf of The Ability Center of Greater Toledo, I urge Congress to support S.2210 to increase supports to Home and Community Based Services (HCBS) as well as increase funding and resources for the direct support workforce. If enacted, S.2210 will make significant changes that would support people with disabilities to live and thrive within their communities.

In Ohio, people with disabilities who rely on in-home care are experiencing devastating crises. Many of those individuals are forced into institutions and nursing homes due to provider shortages. It is difficult to find and retain a direct support professional due to low wages, high-turnover rate, difficult certification processes, and the increasing costs of goods and services. Without in-home care, people with disabilities may be unable to get out of bed, perform daily life activities, and forced to isolate from their community. Direct support professionals are a vital part of the workforce that assist people with disabilities and their families to live independently.

According to a PHI report, "Direct Care Workers in The United States: Key Facts," in-home care workers are significantly under paid, majority comprised of women and women of color<sup>1</sup>. In 2020, the average national

<sup>1</sup> PHI. (2021, September 7). *Direct Care Workers in the United States: Key Facts*. <https://phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2/>



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median income was \$13.56 an hour and 45 percent of direct care workers rely on a form of public assistance like Medicaid, food assistance, as well as others. In Ohio, direct support professionals on average make \$12.10 which does not cover their basic needs. Without benefits, equitable wages, and resource supports for this growing workforce, many individuals are forced to leave their positions thus putting their clients at risk for institutional living. Expanding funding and resources to HCBS will not only assist those whom they support but will improve the lives of these professionals. All workers in The United States deserve to be equitably compensated for their work and provided opportunities to grow within their field of choice.

We strongly urge Congress to enact the Better Care Better Jobs Act, which will provide more money and resources to supporting direct support professionals that reflects their value in the communities and to people with disabilities.

Thank you for reviewing my submission of Proponent Testimony. My contact information is provided below and please do not hesitate to contact me if you have any additional questions.

Sincerely,

Brittanie Maddox, Disability Rights Advocate  
 The Ability Center of Greater Toledo  
[bmaddox@abilitycenter.org](mailto:bmaddox@abilitycenter.org)  
 (419) 885-5733 x120





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March 30, 2022

Senator Bob Casey  
Chairman  
US Special Committee on Aging

Senator Tim Scott  
Ranking Member  
US Special Committee on Aging

Sent via email: [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

### Re: March 23, 2022, Hearing: An Economy That Cares: The Importance of Home-Based Services

I submit this statement to you today on behalf of the National Council on Independent Living (NCIL). NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of individuals with disabilities and organizations including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the US.

The Independent Living Movement was founded on the principles of independence, equality, and consumer control, and with the imperative for people with disabilities to live free and independent lives. NCIL was established as a national representative of the Independent Living movement, Centers for Independent Living, and people with disabilities across the country. NCIL has long advocated that people of all ages and with all types of disabilities must have the option to obtain the services and supports they need in their homes and communities. We are grateful to you for holding this important and very timely hearing and for the opportunity to submit this statement for the record.

As you know, the COVID-19 pandemic has had a disproportionate impact on disabled people and older adults. In particular, disabled people, older adults, and workers in congregate settings have accounted for a disproportionate share of COVID-19 infections and deaths. The issue of increasing access to home and community based services, including improving wages and

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benefits for our direct support workers – most of whom are women of color – predated the pandemic but is more urgent than ever before.

[Over one in four adults has a disability. Over one in three adults ages 65 and older have a disability.](#) All of these people have the right to live and receive services in their communities, according to the Americans with Disabilities Act and the United States Supreme Court holding in the 1999 *Olmstead v. L.C.* case. Yet far too many people with disabilities are forced to live in institutions to get the essential services they need. Millions more remain in the community without the crucial services they need – hundreds of thousands of those on years-long waiting lists. Some of these people are relying on family members or others to fill these gaps, resulting in short- and long-term financial instability for millions of people and families; an investment in HCBS will allow many of these family members who have been serving as unpaid caregivers to return to the workforce. And while much progress has been made to expand access to these critical services and reverse the institutional bias, community-based services remain out of reach for far too many.

Medicaid is the largest payer for long term services and supports (LTSS), and [Medicaid funds the majority \(57%\) of HCBS](#). Medicaid is also the only program that covers the full range of HCBS disabled people and older adults need to live independent lives in their communities. However, because of the optional nature of Medicaid HCBS, there is significant variation across states, with resources and access to HCBS varying widely. While most states are improving, the recent Medicaid data (pre-pandemic) found that [18 states still spend as much or more on institutional care as on HCBS](#). As a result, in some states, hundreds of thousands of disabled people and older adults are on waiting lists for HCBS; many of these people will wait years before becoming eligible for services if something does not change.

NCIL envisions a world where people with disabilities are valued equally and participate fully. The opportunity to live in our communities, integrated into society, is the gateway to equality and full participation. Our country's long-standing underinvestment in HCBS continues to prevent that from happening.

Disabled people and older adults urgently need a transformative investment in home and community based services. The Better Care Better Jobs Act (BCBJA) would provide states with support to significantly expand access to HCBS while investing in the direct support workforce. Importantly, it would also address the institutional bias by making the Money Follows the Person program – a critical Medicaid program that supports people to transition from institutions to the community – and HCBS spousal impoverishment protections permanent. Both of these policies are critical for helping disabled people and older adults transition out of institutions and avoid them in the first place.

The significant unmet need for HCBS preceded COVID-19. The pandemic urgently intensified this need. States have been able to do some important work with American

Rescue Plan Act funds, but it is critical the Senate pass the Better Care Better Jobs Act so this work can continue. We urge the Senate to do this as soon as possible.

We thank you again for holding this important hearing. If you have any questions, please do not hesitate to contact our Policy Director, Lindsay Baran, at [Lindsay@ncil.org](mailto:Lindsay@ncil.org) or (202) 207-0334.

Sincerely,

Darrel Lynn Jones  
Executive Director



Statement for the Record  
 Hearing: An Economy That Cares: The Importance of Home-Based Services  
 United States Senate Special Committee on Aging  
 Wednesday, March 23, 2022

Via email: [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

Dear Chairman Casey and Ranking Member Scott,

This statement is submitted on behalf of Be a Hero, a health care justice advocacy organization. We promote health justice in America and the idea that health care should be a human right. Be a Hero was formed after Ady Barkan — already an activist for social, economic, and racial justice — was diagnosed with A.L.S. in 2016. Ady is also a full-time home- and community-based services (HCBS) user, and his team of caregivers work around the clock to ensure that he is safe, that his ventilator functions at all times, and that he is able to live his beautiful life with his wife and two young children in their own home. In our efforts to achieve health justice, Be a Hero advocates for improvements to the United States' long-term care system, particularly regarding access to Medicaid HCBS.

We appreciate you holding this hearing on the importance of home-based services. In the two years since the beginning of the COVID-19 pandemic, official counts show more than one million COVID-19 infections occurred among nursing home residents and that at least 150,000 nursing home residents died of COVID-19<sup>1</sup>, which does not include cases nor deaths in congregate care facilities that are not nursing homes. In these two years, more than 2,200 nursing home staff also died from COVID-19. The pandemic has shown the urgent need for expanded access to HCBS, in addition to a well-paid and safe workforce.

While the vast majority of Americans would prefer to receive care at home when it is needed<sup>2</sup>, more than 820,000 disabled and older Americans are currently on Medicaid HCBS waiting lists with an average wait time of 39 months<sup>3</sup>. Even for those who qualify for Medicaid HCBS, many are unable to receive the care they desperately need because of worker shortages and the permanent closure of HCBS providers in two-thirds of states since the onset of the pandemic<sup>4</sup>.

<sup>1</sup> <https://data.cms.gov/covid-19/covid-19-nursing-home-data>

<sup>2</sup> [https://www.aarp.org/content/dam/aarp/research/surveys\\_statistics/lrc/2021/caregiving-tax-credit-in-home-care-bipartisan-support-report.doi.10.26419-2Fres.00486.001.pdf](https://www.aarp.org/content/dam/aarp/research/surveys_statistics/lrc/2021/caregiving-tax-credit-in-home-care-bipartisan-support-report.doi.10.26419-2Fres.00486.001.pdf)

<sup>3</sup> <https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicare-home-and-community-based-services/>

<sup>4</sup> <https://www.kff.org/coronavirus-covid-19/issue-brief/state-medicare-home-community-based-services-hcbs-programs-respond-to-covid-19-early-findings-from-a-50-state-survey/>

Despite the closures of HCBS providers, home care is the fourth largest occupation by volume of employed people nationally and the most common occupation in Pennsylvania, California, Massachusetts, Minnesota, Missouri, New Mexico, and New York<sup>5</sup>. The professional home care workforce, primarily made up of women of color<sup>6</sup>, is severely underpaid and devalued, and workers often receive no benefits<sup>7</sup>. Workers make only \$12 per hour on average and more than 40% of direct care workers require some form of public assistance to make ends meet. More than 15% of direct care workers live in poverty and 44% live in low-income households<sup>8</sup>. While the workforce grew by half in the last decade and is expected to continue rapidly growing with the US's aging population<sup>9</sup>, direct support roles have turnover rates of 44%<sup>10</sup>, still leaving many disabled people and seniors in need. The severe staff shortages in the home and community based care workforce leads to crucial gaps in service availability, lengthy waiting lists, service closures, and additional obstacles.

Without adequate funding and a robust and well-compensated workforce, home care and support falls disproportionately on unpaid family caregivers. More than 1 in 5 Americans are unpaid family caregivers, who are disproportionately women of color with limited income and wealth. Unpaid family caregivers experience significant workforce and earning losses. The grand majority of unpaid family caregivers have no paid help for their loved one<sup>11</sup>.

To address the care crisis faced by disabled children, adults, and seniors who need HCBS and the needs of caregivers, we need a robust investment in Medicaid HCBS. Without a robust investment, disabled and older Americans will continue to wait on years-long waiting lists or be forced into dangerous institutions to receive the care they require to survive, the care workforce crisis will continue to deepen, and caregivers will continue to receive substandard wages. The Better Care Better Jobs Act would offer the necessary solutions to transforming Medicaid HCBS, which would give disabled and older Americans the ability to choose where they receive life-saving care and increase the caregiving workforce.

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5

<https://www.americanprogress.org/article/investing-home-care-early-childhood-educators-outsize-impacts-employment/>

6 <http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf>

7

<https://www.epi.org/publication/domestic-workers-chartbook-a-comprehensive-look-at-the-demographics-wages-benefits-and-poverty-rates-of-the-professionals-who-care-for-our-family-members-and-clean-our-homes/?chartshare=194272-194214#17>

8 <http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf>

9 <http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf>

10

[https://caseforinclusion.org/application/files/5015/8179/5128/Case\\_for\\_Inclusion\\_2020\\_Key\\_Findings\\_021420web.pdf](https://caseforinclusion.org/application/files/5015/8179/5128/Case_for_Inclusion_2020_Key_Findings_021420web.pdf)

11

<https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

Be a Hero urges the Senate to pass the Better Care Better Jobs Act and to invest in Medicaid HCBS to ensure that disabled and older Americans can receive the life-saving care they need, when they need it, and with dignity, and to ensure the care workforce is well-compensated.

Thank you for holding this hearing and for the opportunity to provide this statement for the record. Please reach out to Victoria Cross, Senior Policy & Legislative Lead, at [victoria@beaherofund.com](mailto:victoria@beaherofund.com) if Be a Hero can be of any assistance or answer any questions.

Sincerely,  
Be a Hero



**The Kelsey**

Disability-forward housing  
solutions that open doors to homes  
and opportunities for everyone

Re: HCBS Statement of Record

*Sent via email to [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)*

Wednesday, March 29, 2022

United States Senate Special Committee on Aging  
G41 Dirksen Senate Office Building  
Washington, D.C. 20510-6050

Dear Chairman Casey, Ranking Member Scott, and Distinguished Members of the Senate Special Committee on Aging,

Thank you for the opportunity to submit a statement of record to support the March 23, 2022 hearing "An Economy That Cares: The Importance of Home-Based Services". As a disability-forward housing organization, The Kelsey is submitting this statement to highlight the critical need for the "H" in "HCBS" - the assurance that all HCBS users have access to a home where they can receive the services needed. At The Kelsey, we pioneer disability-forward housing solutions that open doors to more affordable homes and opportunities for everyone. We have 240 affordable, accessible, integrated, and inclusive homes in our pipeline and lead organizing and advocacy initiatives to support market conditions to make inclusive housing the norm.

Firstly, The Kelsey supports the robust recommendations to improve HCBS that are laid out in the version of Build Back Better passed by the House and the recommendations mapped out in the draft version of the HCBS Access Act. The Kelsey also supports the intention of the HCBS Settings Rule, the disabled leaders that advocated for its creation, to support truly integrated, community-based, inclusive housing options for people with disabilities that support choice and the realization of Olmstead and the ADA.

As a housing developer and social impact organization led by people with and without disabilities, we witness firsthand the extreme shortage of housing and services that people with disabilities need in order to thrive in their own homes and communities. We also know that the ability to successfully access home and community-based services is contingent on the ability to

[thekelsey.org](http://thekelsey.org)



The Kelsey

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solutions that open doors to homes  
and opportunities for everyone

live in accessible, affordable, and integrated housing. Therefore, it is critical that Congress pursue a continued commitment to invest in the infrastructure of HCBS, which must include affordable, accessible, integrated, and serve-linked housing.

To be clear, The Kelsey asserts the necessity for housing and supportive services to come from separate systems (i.e. Department of Housing & Urban Development, other local and state housing programs, and Medicaid), yet both systems need to be more strategically coordinated, significantly more funded, and have greater implementation disability-forward policies. All of which must uphold and make the promise of the ADA and the Olmstead ruling a reality: that all people with disabilities, including those who need supportive services and particularly those who are multiply marginalized, can live and thrive in their own homes and communities of choice.

We strongly believe that the following policy interventions must be considered when exploring how HCBS can be bolstered, including how to ensure all people can transition out of congregate settings into housing and communities of their choice:

- In addition to eliminating the Medicaid institutional bias, there should be robust increased investment in Money Follows the Person and HCBS Medicaid Waivers, including housing-related services.
  - Within Medicaid HCBS, there should be specific bolstering of housing-related services, which increase people's ability to transition out of congregate care facilities into community-based housing. We also recommend exploring ways that the housing-related services dollars can be more impactful and support housing stability and retention; for example, having the funds cover 1-3 months' rent instead of just the initial transition to housing costs.
  - As state programs decrease investment in institutional, licensed, and congregate housing models, a commensurate investment in the housing and service costs of those programs should be allocated towards the in community-based models. Closure of institutional models is essential and federal and state governments must ensure that the land and funding previously and currently dedicated to those models is allocated toward the present and future housing needs of people with disabilities in inclusive, integrated models.
- Increase investment in affordable, accessible, and integrated existing and new housing stock, including in the following ways:
  - As the Low-Income Housing Tax Credit (Housing Credit) is the main tool to fund affordable housing, at minimum the private activity bond cap must be lowered from 50% to 25% and there must be an increase in allocations by 50 percent over

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current levels to help meet the vast and growing need for affordable housing. These Housing Credit investments are baseline and should be paired with innovative solutions for Housing Credit can better serve hard-to-reach communities, including people with disabilities who are extremely low and low income who need HCBS.

- Significantly increase funding for the Housing Choice Voucher program, including the Mainstream Voucher Program and Non-Elderly Disabled vouchers.
- Significantly increase funding for HUD Multifamily housing, specifically Section 202 and Section 811 project-based and tenant-based assistance.
- Significantly increase funding for Housing Trust Fund and other funding pools that explicitly produce and preserve deeply affordable housing.
- Increase alignment and coordination across HUD & HHS, in the following ways:
  - Releasing joint guidance on how Public Housing Authorities (PHAs) can better partner with disability serving organizations, to ensure that people with disabilities, particularly those who are currently in or at risk of institutionalization, can get easier access to Housing Choice Vouchers.
  - Building off of [The Medicaid Innovation Accelerator Program \(IAP\)](#), effective from 2016-2019, when CMS worked with state Medicaid agencies and their state housing partners to develop public and private partnerships between the Medicaid and housing systems and when states were supported to in the creation of detailed action plans that foster additional community living opportunities for Medicaid beneficiaries.
  - As the COVID19 crisis continues, we are concerned that in a rush to expand permanent supportive housing (PSH), including turning hotels and other non-congregate shelters into PSH, “mini-institutions” will be developed. As HUD leads in financing diverse housing options, housing options that do not meet CMS’s “[HCBS settings rule](#)” should not be eligible for Medicaid funding for these services. HUD, CMS, ACL, and DOJ must create an internal understanding of what constitutes qualities of community-based settings that distinguish them from institutional settings and issue guidance to all of its recipients and grantees.
- Pilots to explore can include:
  - A pilot mechanism for housing costs that can follow a person from an institutional setting into a community-based integrated setting. Medicaid funds support individual services—including those related to housing—but corresponding housing infrastructure is also essential in the form of HUD housing development subsidies and other federal housing incentives that support more noninstitutional, affordable, and accessible housing stock. In the long term, this federal investment would both be cost-effective and ensure that the right to community living for people with disabilities can be fully realized.

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- Pilot program to match HCBS users who match income eligibility with a housing voucher. A voucher for all individuals who utilize HCBS services or a capital subsidy for projects who designate affordable, accessible homes for people with disabilities ensures the housing right of people with disabilities, especially those who use supportive services, becomes a reality.

In conclusion, thank you again for the opportunity to comment. As a disability forward housing organization, we welcome follow-up discussion and collaboration on how to ensure that the "H" in HCBS is strong enough to ensure that all Disabled people who need services have affordable, accessible, and inclusive housing in the communities of their choice.

Sincerely,

Allie Cannington  
Manager, Advocacy & Organizing  
[allie@thekelsey.org](mailto:allie@thekelsey.org)  
(415) 413-7059  
The Kelsey

Micaela Connery  
CEO  
[micaela@thekelsey.org](mailto:micaela@thekelsey.org)  
The Kelsey

March 28, 2022

Senator Bob Casey

Chairman

US Senate Special Committee on Aging

Senator Tim Scott

Ranking Member

US Senate Special Committee on Aging

VIA Email: [SFR@aging.senate.gov](mailto:SFR@aging.senate.gov)

RE: March 23, 2022, Hearing on "An Economy that Cares: The Importance of Home-Based Services"

I would like to submit this written testimony for Denise Myler, a Disabled Advocate and I live in Ammon, Idaho.

Home and Community Based Services (HCBS) is critical to the independence for Idahoans with Disabilities. In Idaho, HCBS funding for Direct Care Workers (DCW) has been sorely lacking. 27 Assisted Living Facilities (ALF) have voluntarily surrendered their license, due to the lack Certified Nursing Assistants or DCW. Between 2020-2022 5 Developmental Disabilities Providers closed due to staffing issues, additionally 81 HCBS Providers closed. In 2021, 15,500 Idahoans used HCBS Services. The problem is based on Center for Medicare and Medicaid Services (CMS) low state reimbursement rate increase for HCBS Services. Congress needs to increase HCBS Services rates and then require the state to monthly report that HCBS-DCW rate reimbursement when to the Direct Care Workforce and not to Owners of HCBS Providers. This monthly report will allow CMS to see problems ahead of time for HCBS-Direct Care Workforce. CMS can then send quarterly reports to this Committee and the Senate Health, Education, Labor and Pension Committee.

Senator Casey

March 28, 2022

Page 2

Senator Casey and Senator Scott in doing a quick Google Search, I could not find a GAO Study specifically focusing on the HCBS-Direct Care Workforce National Rates.

Let me get personal and tell you about some friends. First, my force DCW quit in July 2021 because she could make more money as a NEMT Driver. Second, a friend in Northern Idaho has resultantly moved into an ALF because his family members trying to fill in for no DCW were at risk of losing their jobs. This friend now lives in an institution which costs more than if this friend lived in the community. Third, I have another friend who lives at-risk of losing their independence and either being forced to move to a sibling's home or an institution due to not having enough money in their Self-Directed budget to pay higher wages. Idahoans with Disabilities who want to get out of their institution cannot because they face a dual connected problem of not enough affordable/accessible housing and HCBS-Direct Care Workforce.

Senator Casey and Senator Scott thank you for the Committee's March 23<sup>rd</sup> hearing and allowing my submission of testimony until March 29<sup>th</sup>.

Sincerely,

Denise Myler

Disabled Advocate

3698 Heartland Circle

Ammon, Idaho 83406

[Dmyler5@gmail.com](mailto:Dmyler5@gmail.com)

208-523-4164

Dear Committee,

People with disabilities rely on home and community-based services (HCBS) for everyday things like employment supports, getting around the community, dressing, bathing, taking medication, and much more.

But there isn't enough money in the HCBS program to support everyone. Too many people are stuck on waiting lists and not getting the services they need. Direct care workers are underpaid, which leads to high turnover, critical staffing shortages, and compromised care for many people with disabilities. All too often, this means unpaid family caregivers are filling in the gaps of care.

Please support a historic investment in disability funding, so everyone can get the support they need to live in their community - instead of in institutions.

Signed,

Jennifer Mynard, Linda Trongone, Wendy Swartz, Melissa Barkes, Paula Vanier, Joyce Dickson, Deanna Bruno, Kendra Garcia, Tracy Perry, Maureen Rankin, Nicole Perry, Donna Greenwell, Cindy Curtis, Phyllis Priest, Natasha Pelczynski, Tristen Hunsinger, Adam When, April Elmore, Stephen Jones, Marcia King, Lonnie Polok, Grant Kaylor, Teresa Juehring, Kim Hurley, Kristin Vohs, Joseph Mangio, Audrey Jones, April Brewer, Pamela Krinsky, Graham Rowe, Darla Chafin, Debbie Walderbach, Loretta Hurley, Mary Butler, Lisa Vittitow, Tammy Dawson, David Cole, Jennifer Wilson, Caelan Thorne, Claire Cameron, Nina Fiore, Cynthia Curtis, Eileen Therrien, Karen Therrien, Karen Mayer, Rosemary Schultz, Pat Jurann, Judy Volkman, , Christy Courtney, Colleen Tapia, Randy Dalton, Jordanna Cox, Jennifer Fahey, Alberta Borneo, Mary Cohagan, Donna Palombo, Adrienne Fee, Veronica Barney, Dori Babcock, Jane Veno, Danilynn Walters, Carole Rosen, Charlene Boydston, Jenny Reinke, Darla Helt, Sarah Howard, Pamela van Marle, Suzanne Gracewski, Leyte Jefferson, Laura Waterstripe, Lydia Nunez Landry, Brennan Kannapell, Donna Landry, Dianne Erder, Debra Casey, Carole Vennema, Lori Schalow, Virginia Horne, Elizabeth Muir, Nanette Klokowski, Alex Wight, Monica Yandura, Gregg Holder, Allyson Bennett, Melanie Roy, Eileen Jefferson, Krystn Faller, Janet Atkinson, Sonjia Henson, Angela Dews, Sandra Olson, Laurene Rusing, Estrillita Nelson, Diana Stadden, Stacey Hall, Molly Bisson, Jackie Goldberg, Cooper Christina, Monty Garrett, Barbara Burns, Sandy Reynolds, Cynthia Wood, Renee Reif, Sisson Peggy, Maryanne Bunting, Esther Maclin, Jacqueline Curtis, Paul Collins, Tina Carter, Julia Petecki, Janis Hemmesch, Ashley McReynolds, Tani Shimmin, Bruce Cratty, Cristy Laier, Heather Turnage, Robin Windsor, Steven Goldin, Lori St Peter, Laurita Kelly, Jody Mack, Summer Martin, Denise Summers, Tj Malone, Judy Meters, Lisa Smith, Barbara Dempsey-West, Wesley Ford, Jenna Marsh, Wendy Sharp, Terri Grasso, Desiree Walkowski, Karen Barrett, Melinda Ketchum, Linda Mitchell, Louise Circelli, Heather Misner, Hope Martinson, Elizabeth Goulart, Regina Ashby, Meghan Pierri, Candice Kelsch, Angie Maniaci, Dale Cooper, Donna Barney, Abigail Houghton, Barbara Berry, Marianne Barbera, Ryan Hunter, Alicia Wilemon, Theresa Meiners, Cristina Duran, Ree Edozie, Jacqueline Wuebbeling, Tania Malven, Andrea Cruise, Jerri Woods, Millicent Leow, Allison Pereira, Judy Gabler, Patti Miller, Alejandra Rivera, Martha Ashley, Betty Wilson, Lobsang Dhondup, Deborah Earle, Ellen Franzen, James Greek, Mark Koritz, Charlie Schmidt, Allison Fradkin, Rev. Jones, Lana Schmitt, James Fentress, Beverly Garcia, Shontae Johnson, Richard Gallo, Phillip Garner, Kathryn Walek, Lauren Wade, Nancy Dealy, Sandra Williamson, Ruth Boice, Kathy Burton, Mary Belyea, Kathleen Lonergan, Katherine Wright, Keith Kiernan, Antonio Pousa, Brenda Pritchard, Beth Darlington, Benjamin Stone, Marlene Cooper, Kathy Starling, Vicki Hensley, Denise

Torres, Kristine Gravell, Katherine Hunt, Gary Overby, Tammy Beauchemin, Terri Beers, Kyle Sinett, Rebecca Lander, Cyndi Bosze, Jeannette Baechle, Shari Schmitt, Paul Collins, Patricia Derrough, Mark Escario, Tracy Turner, Stacey Stingley, Frank Oberc, Ava Gibson, Katherine Heinman, Tina Stanton, Mary Brawner, Paul Ridikas, Michele Logsdon, Corynne Romine, Sherrie Henderson, Tristan Henderson, Marilyn Schamber, Mark Grenard Sandra Walters, Anthony Green, Leo Finnegan, FEsmeralda Winchell, Caryle Cox, Kristen Bertrus, Jake Thorn, Theodore Mussano, Brigid O'Brien Tabitha Weaver, Beverly Maniscalco, Tammy Koerner, Pamela Ingram, John Ingram, Alexa Brill, Rhonda Netzhimer, George Marsik, Jan Menear, Kathy O'Brien, Victoria Roselein, Nancy Wilson-Soga, Elizabeth Rosenthal, Hallie Long, Jeaneane Miller, Kim Halischak, Donna Davis, Mary McQueen, Mara Mayer, Sandra Cobb, Gregg Masucci, Mary Brett, Deanna Doran, Kari Norton, Beverly Radford, Jessica Rollins, Diane Sjolander, Barbara Davis, Marlene Leone, Shannon Smith, Perceve Frauline, Heurys Ramirez, Christopher Schwenk, Brittani Burt, Jon Frieswick, James Arruda, Garland Burkett, Karolyn Bryan, Kay Cardona, James Klein, Joy Carmack, Christopher Lawrence, Brenda Lehrman, Joshua Strainix, Joyce Shiffrin, Sheryl Vernon, Kimberly Santore, Molly Wang, Kathleen Besterman, Jeffrey Haagenson, JoAnn Rienzie, Kathleen Black, Amber Robles, Claire Manning, Geri Coppernoll, Patrick Curran, Matt Fico, Karen Larson, Rebecca Barrick, SarahJane Mills, Beth Townsend, Linda Mclean, Vinson Burch, Mikki Chalker, Carol Gentry, Victoria Antley, Linda Woods, Randolph Streng, Missy Martin, Marilyn Ewing, Nancy Esparza, Justin Bernard, Cynthia Ziegler, Helen Trepanier, Heather Romanek, Sherry Cruz, Jill Blaske, Domingo Mendoza, Vickie Mendoza, Sheilah Garry, Beverly Tuthill, Taylor Sinett, Essence Scott, Nora Handler, Evelyn Walker, Donald DeCann, Sheri Najera, Wendy Sinett, Kim Weinmaster, Sean Connor, Liz Kogel, Mary Pagels, Claudia Vargas, Katherine Long, Jeffrey Hurwitz, Elise Carlson, Diana Sweeney, Daniella Graziano, Thomas Taranto, Janet Williams, Marcia Podsiadlo, Roberta Gallant, Deborah Owens, Brian Colfer, Alexander Walker, Jodi Daniels, Alaina Millard, Marilyn Morgan, Patricia Kuhn, Rosanna Lichtenthaler, Gimbels Pon, Brian Liston, Donna Arthur, Kristin Grauman, Robin Turin, Anthony DeSalis, Kristi Desimone, Douglas Elmore, Ellen Metzger, Brian Long, Ashley Klejna, Alison Zukowski, Michael Botticelli, James Zukowski, Sarah Hankins, Janice Retz, Linda Johnson, Sandra Butts, Doreen Chamberlain, Leanne Roe, Julia Wilson, Aicka Godinez, Wendy Forkas, Catherine Andert, Russ Ziegler, Shannon Allsop, Phil Samuelson, Cheryl Miliello, Carl Schultz, Joanne Buccellato, Timothy Roche, Cindy Jordan, Ken Lundgreen, Gail Yeatman, John Gillespie, Denise Von Moore, Tracy Wilson, Dennis Fox, Anna George, Sandra Fuller, Kirsten Hansen, Jocelyn Gallant, Moheni Gaji, Donald Hunt, Rania Kelly, Joychine Eaglin, Patricia Hollinger, Kristian Burch, Anne Autry, Christine Jawish, Kevin Ryan, Barbara Van Camp, Dennis Vogel, Debra Santamaria, Patricia Allgor, Debra Gleason, Dario Morell, Crystal Mitchell, Victoria Foti, Tom Whalen, Sari Miller, Marilyn Rolfe, Andrea Cerros, Christine Rivera, Jason Hopper, Dawn Albanese, Patricia Cachur, Katie Kroes, Rhonda Partride, Richard Stern, Karen Clayton, Diane Dearborn, Patricia DeLuca, Imelda Reno, Colleen Tapia, Eileen Stuart, Kim White, Pam Heavens, Chris Parker, Helen Stanley, Bryan Miranda, Julio Ramirez, Jennifer DiBello, Lawrence Emark, Sunita Persaud-Garib, Linda Irby, Paul Azevedo, Liz Rusnak, Jerri Woods, Sandra Walsh, Catherine Borger, Patricia Vance, LaVerne McGregor, Jonathan Spiller, Marilyn Loos, Karen Barr, Elizabeth Chesebro, Angela Edwards, Cathy Morenus, Jennifer Caffery-Healey, Monica Karavanic, Michelle Kearnan, Elizabeth Spratley, Daniel O'Connor, Mehrdokht O'Connor, Jennifer Cusack, Cheek Tia, Edward Spain, Jennifer Sinistore, Robert Hergueter, Sandy VanEck, Kelly Hull, Melanie Tyner-Wilson, Chloe Rothschild, Sharan Rosen, Melissa Mitchell, Nahed Zayed, Linda Gones, jannett Lovett, Cathy Kohlun, Jenkins Dawn, Sharon Conrad, Stephen Grammar, Curtis Harris, Sara Breaux, Lauren Loughlin, James Gould, Revonda Luttrell, Tim Burden, Gail Yeatman, Mary Fillyaw, Sarah Karbowiak, Julie Martin, Maryellen Halloran, Adrienne Pfaff, Mary Janzen, Brian Easley, Christine Easley, Cheryl Etheredge, Lay Mary, Valencia Tate, Ava Gurba, Deb Lambright, Amy Sanderson, Carrie Weiler, Rosalie Austin, Jen McCulloch, Cindi Paschall, Tanya Schoonveld, Heather Sobczak, Leslie Wilton, Coble Shari, Jessica Rivera, Simone Mitchell, Jennifer Townsley, Joanne Hawkins, Nohemi Frisbie, Nancy Ferrarini, Arlene Abreu, Tamsin Wotton, Victoria

Moffett, Ileana Lamberts, Julie Svalbe, Tanya Cruz, Angelia Krikke, Amanda Santos, Brent Libasci, Courtney Stinson, Donna Greenwell, Jerri Woods, Katy Held, Sue Papajesk, Krystal Jones, Dana Ocampo, Tracy Carreola, Seneca Rodriguez, Jeanne Cella, David Lau, Torrey Androski, Christina Cahmbers, Micki Coppel, Nancy Camajani, David Mack, Linda Forgave, Amanda Rogers, Marianne Barbera, Jane Majewski, Kathleen Rohwedder, Lisa Romeo, Steve Johnson, Allison Gerkensmeyer, Fonda Davis, Mitchell Angela, Heidi Wedige, Beth Dolan, George Rogers, MaryAnn Spitale, Michelle Hicks, Suzanne Aaron, Claire Manning, Matthew Boguske, Christi Cooper, Shannon Andersson, Teresa McKeethan, Jason Foltz

March 22, 2022

Chairman Bob Casey  
Special Committee on Aging  
United States Senate

Ranking Member Tim Scott  
Special Committee on Aging  
United States Senate

Members  
Special Committee on Aging  
United States Senate

Re: Hearing March 23, 2022 - "An Economy That Cares: The Importance of Home-Based Services"

Dear Chairman Casey, Ranking Member Scott, and Members of the Committee,

The Special Committee on Aging will hear testimony on March 23, 2022, on the importance of home-based care services.

If the Committee is to understand the care needs of the diverse population of disabled and elderly Americans, it certainly must also consider the care needs of persons who require and choose care in congregate settings, such as intermediate care facilities for individuals with intellectual disability (ICF).

My children are non-verbal, tube-fed, epileptic, quadriplegic, and profoundly intellectually disabled. They are totally dependent upon others for all of their life needs. They are also immensely happy, well-adjusted young adults who have an active social life in their ICF home and in the daily outings their ICF makes possible for them. I could never provide the kind of care they receive and the type of social engagement they enjoy at their ICF in our family home. They lead full lives thanks to this Medicaid certified program.

To give you an understanding of the fullness of the care they receive, they have access to 24-hour nursing care, personal care, physical and occupational therapy, a nutritionist, a wheelchair technician, orthotics support, a dental clinic, the oversight of a medical director, social activities, and transportation to their day program, and other community outings. They each have a detailed habilitation plan which their care team carefully implements and documents.

Furthermore, the cost of their care in their ICF with its shared resources is far less costly than receiving care in a home setting. Many of the daily care services that their conditions require just would not be available practically or economically in a home setting.

While home care works well for many, it is not the solution in all circumstances. I encourage you to hear from a wide variety of Americans when formulating policy, including from experienced and loving families of individuals with intellectual disability who rely upon intermediate care facilities.



I would welcome the opportunity to testify before your committee and share our families' experience with this excellent Medicaid program.

Thank you for your consideration and your service.

Caroline Lahrman

Mother and guardian of Henry Lahrman and Elizabeth Lahrman, age 22, residents of  
Heinzerling Community

614-359-9323



The Arc of East Central Iowa  
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 Cedar Rapids, IA 52401  
 T 319 365-0487  
 F 319 365-9938  
 www.arceci.org

Statement for the Record

Hearing: An Economy That Cares: The Importance of Home-Based Services

United States Senate Special Committee on Aging

Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott:

My name is Kristen Krambeer and I am the Advocacy Program Coordinator for The Arc of East Central Iowa. We serve individuals diagnosed with disabilities and mental health over 6 counties in Iowa. I have been affiliated with The Arc for 14 years as a family member to one of our individuals and as a staff member. I know the struggles of Home and Community Based Services because I have lived them. Our individuals and their families are in desperate need of support from lawmakers to get the necessary funding to survive and we greatly appreciate your willingness to have the hearing this week.

I could go into every finite detail of where we are sitting at in the social services field, but the reality is you have limited time to make decisions and hearing the reality from someone who has lived the struggles tends to put things into perspective of what is happening for those of us in this field and the individuals we serve.

These are our realities:

- We don't have enough staff. We are quickly reaching a point of no return for those needing disability services. In Iowa we have 17,000+ people without the needed assistance to live their lives in their homes. That is 17,000 people who are in desperate need of help and each day who feel the constant strain of not being recognized as valuable enough to receive the services they need to survive. For those families fortunate enough to have the financial ability, they are attempting to fill the void by providing their own services for their loved ones or are footing astronomical bills to cover the discrepancies of our systematic issues.
- Many of our participants are going without. We have individuals who can't get staff consistently which results in them going without things like bathing more than once a week. It's such an odd thing to say in a country which prides itself in being one of the greatest in the world, we have Americans who believe bathing to be a luxury because they are unable to have someone come in and help.

***Achieve with us.***

- Our staff are struggling to stay afloat even after working full time for us. While others across the U.S. are getting 7% to 20% raises, staff in the social services field are not. Many people have made the difficult choice to sell their homes to find cheaper housing, go without bare necessities, or have made the difficult choice to leave the social work field for more money. As providers our hands are tied because we can't increase pay and those willing to offer us grants do not want their gifts going to staff payroll. Our staff are visiting food pantries during their working hours to take our individuals and are then returning to those same food pantries after working hours to gather food for their own pantry. Imagine if you couldn't afford to visit the grocery store or having to decide if you would rather have your power or water turned off.
- The work we do and the people we serve are often seen as less than. It can be forgotten by those who haven't experienced disabilities on how quickly it can reach their doorstep. Anyone can become disabled and may need Home and Community Based Services. We have served teachers, nurses, doctors, lawyers, business owners, etc. These were all people who never dreamed a disability would impact their daily lives, but disability has no prejudice, no rhyme, no reason. It reaches people in ways they have no control of from conception to death. At any moment while driving a car, getting off a train, changing a lightbulb, playing with their children, sitting down for dinner, and so many more ways. If we are all fortunate one day, we will reach the age of elderly status and will need the same assistance we in the disability services field are providing currently for all ages. If heaven forbid you woke up tomorrow with a disability, do you think you would have access to the services you needed? Do you think someone living in middle America or in poverty would receive your same level of care? Currently, we have a 3-to-5-year waitlist for waiver services in Iowa and many states waits are longer than ours. If someone is diagnosed today, they will wait years to get the things they need. Our individuals, their families, and our communities are feeling a much larger burden than what many are aware of due to the lack of support and services.

The Better Care Better Jobs Act is needed and the only people who can make the decision are lawmakers. Please pass this bill, please help not only the Iowans I see each day, but all the people in the U.S. struggling to make it to their next bath, their next meal, and hopefully to their next birthday.

Thank you,

Kristen Krambeer  
 Advocacy Program Coordinator  
 The Arc of East Central Iowa  
 680 Second Street SE  
 Cedar Rapids, Iowa 52401

Phone: 319-365-0487, x1028  
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*Achieve with us.*

**“An Economy That Cares: The Importance of Home-Based Services”  
Statement for the record from Cathy Ludlum**

Members of the Senate Special Committee on Aging,

My name is Cathy Ludlum, and I am living proof that with the right supports, anyone can live and participate in the community. I have only the use of three fingers, my five senses, my speech, and my brain. I drive a power wheelchair, and operate my computer using my voice. But that is basically all I can do for myself. I need complete assistance with every activity of daily living, including eating, toileting, showering, and dressing. I also need assistance with some medical tasks.

For 30 years, I have lived on my own with the help of personal care attendants (also known as PCAs or personal assistants). These dedicated and hard-working people have made it possible for me to work, engage socially, and have a great life.

In recent years, however, it has been increasingly hard to find qualified staff. By qualified, I do not mean medically trained. I do all my own training, and I am told that I do it well. By qualified, I mean reliable, flexible, hard-working, patient, and kind individuals who are willing to live my life along with me.

The long history of underpayment and devaluation of the people providing these services has taken its toll. Combined with our increasingly fragmented societal structure, people are less interested in supporting others in what can be a challenging field.

We need to energize people to take on this work, and to make it worth their while. Support professionals should not have to sacrifice their own well-being or that of their families in order to provide critical support services to a growing population of disabled and elderly people.

My independence is at stake. I am constantly struggling to patch together enough supports to keep me healthy and productive. I deeply appreciate the Senate taking a hard look at home and community-based services. Please act NOW because thousands of us are teetering at the edge of survival.

Thank you for your time and attention.

Sincerely,  
Cathy Ludlum  
Manchester, CT  
860-649-7110  
[cathyludlum@cox.net](mailto:cathyludlum@cox.net)



## STOP THE SPREAD:

HOW THE **BUILD BACK BETTER ACT** SEEKS TO REPLICATE  
WASHINGTON STATE'S UNION-DOMINATED HOME AND  
COMMUNITY BASED SERVICES MODEL NATIONWIDE

*Maxford Nelsen, Director of Labor Policy*  
*November 2021*

### EXECUTIVE SUMMARY

One of the most expensive elements of President Joe Biden's "Build Back Better" agenda, which congressional Democrats are seeking to pass unilaterally via the budget reconciliation process, is a vast expansion of Medicaid funding for home and community-based services (HCBS) that provide in-home care to, and prevent the institutionalization of, adults with functional disabilities. Such services are provided via state-designed-and-operated programs operating within federal parameters.

While the precise increase in funding in the Build Back Better Act (BBBA), H.R. 5376, has yet to be determined amid fast-moving negotiations in Congress, the proposals released so far all offer states hundreds of billions of dollars in additional federal funds to expand their HCBS programs.

The White House has claimed the additional spending is necessary to "permanently improve Medicaid coverage for home care services for seniors and people with disabilities... The framework will improve the quality of caregiving jobs, which will, in turn, help to improve the quality of care provided to beneficiaries."<sup>1</sup>

While additional funding for HCBS may or may not be justified, the federal funds come with conditions designed to steer potentially billions of dollars in Medicaid funds to unions representing home care aides, like the Service Employees International Union (SEIU) and American Federation of State, County and Municipal Employees (AFSCME).

As a condition of receiving the additional funding, states must implement changes to their HCBS programs designed to encourage the unionization of home care aides and are incentivized to use a historically disfavored model that would allow unions to force caregivers to pay dues as a condition of employment in states lacking right-to-work protections. Further, federal grant funds are made available to go directly to union-operated training programs for home care aides.

Certain congressional supporters of the BBBA have made it clear that boosting home care unions is a goal of the bill. In a recent op-ed, Rep. Robin Kelly (D-IL), brazenly argued that the BBBA would allow "organizations like SEIU" to "advocate" for home care workers."<sup>2</sup> SEIU endorsed Kelly in 2020<sup>3</sup> and contributed thousands of dollars to her campaign.<sup>4</sup>

For its part, the SEIU has claimed the BBBA will mean, "Hundreds of thousands of union jobs for home care workers."<sup>5</sup>

<sup>1</sup> The White House, "President Biden Announces the Build Back Better Framework," October 28, 2021.

<https://www.whitehouse.gov/briefing-room/statements-releases/2021/10/28/president-biden-announces-the-build-back-better-framework/>

<sup>2</sup> Rep. Robin Kelly, "Congresswoman Robin Kelly: Investing in home care is investing in Black women," *The Grio*, October 1, 2021.

<https://thegrio.com/2021/10/01/rep-robin-kelly-investing-in-home-care-black-women/>

<sup>3</sup> SEIU Healthcare Illinois-Indiana, "2020 Election Center," <https://seiuhealth.org/resources/election-information/#endorse>

<sup>4</sup> See Schedule B of the Forms 3X filed with the Federal Elections Commission by the SEIU Committee on Political Education in 2020.

Available online at:

<https://docquery.fec.gov/cgi-bin/fecimg/?202004209224113436>

<https://docquery.fec.gov/cgi-bin/fecimg/?202010209312995189>

<sup>5</sup> Thomasine Wilson, "LIVE: Join our final push to win investment in home care!" Service Employees International Union, November 16, 2021. [https://www.freedomfoundation.com/wp-content/uploads/2021/11/LIVE\\_join-our-final-push-to-win-investment-in-home-care.pdf](https://www.freedomfoundation.com/wp-content/uploads/2021/11/LIVE_join-our-final-push-to-win-investment-in-home-care.pdf)



The structure of the legislation suggests that the architects of the BBBA look to replicate SEIU's dominance of the home care system in Washington state nationwide, and union-sympathetic coverage of the BBBA's HCBS provisions by prominent newspapers has repeatedly held up Washington state as an example to be emulated.<sup>6</sup>

In Washington, home care aides for Medicaid clients are unionized, with dues deducted from their Medicaid payments by the state. Additionally, the state requires robust training, of questionable utility, for caregivers and pays SEIU to provide it. Finally, the state uses Medicaid funds to pay trust funds affiliated with SEIU to provide health insurance, retirement and other benefits to caregivers. These entities face little meaningful accountability and typically operate with relatively high operating costs, often paying the union for administration. Overall, nearly three percent of the payroll expenses the state incurs on behalf of HCBS caregivers wind up in union coffers.

Expanding similar arrangements nationwide could potentially increase union revenue by billions of dollars, much of which, if history is any guide, will be spent by SEIU and AFSCME on furthering their wide-ranging political and electoral goals.

Given the degree to which they stand to benefit, it comes as no surprise that unions like SEIU are spending millions of dollars on advertisements and lobbying urging passage of the BBBA.<sup>7</sup>

If Congress believes additional HCBS funding is warranted, it should simply provide the funds to states with the flexibility to expand and improve such programs as they see fit. Structuring the program in such a way as to divert potentially billions of dollars in Medicaid funds to a politically influential special interest group with a track record of exploitative practices simply cannot be justified.

### ANALYSIS OF THE BUILD BACK BETTER ACT'S HOME CARE PROVISIONS

The BBBA, H.R. 5376, contains a number of provisions aimed at increasing funding for Medicaid HCBS funding, encouraging state expansion of HCBS, and shaping the way in which states provide such services. Many of these provisions are specifically designed to promote the unionization of home care workers and steer Medicaid funds into union coffers.

However, the haste with which the legislation is being written and rewritten has made tracking the precise details difficult. An ostensibly \$3.5 trillion draft of the BBBA was introduced on Sept. 27 and clocked in at 2,468 pages.<sup>8</sup> However, on Oct. 28, the House Rules Committee released a smaller, purportedly less expensive version of the bill running 1,684 pages.<sup>9</sup> This draft of the BBBA contained two generally similar, but not identical, versions of the same text pertaining to HCBS funding, one prepared by the Committee on Energy and Commerce<sup>10</sup> and one prepared by the Committee on Ways and Means.<sup>11</sup> The two committees' language differed both from each other and from the original text of the BBBA, but no mechanism was provided to determine which is the "real" version.

<sup>6</sup> Brigid Schulte and Cassandra Robertson. "Mother and Daughter Do the Same Job. Why Does One Make \$9 More an Hour?" *New York Times*. May 10, 2021. <https://www.nytimes.com/2021/05/10/opinion/home-health-wages.html>

Eric D. Lawrence. "Unionization could help home health care workers with wages, experts say." *Detroit Free Press*. October 19, 2021. <https://www.freep.com/story/news/local/michigan/2021/10/19/biden-caregivers-unions/586853001/>

<sup>7</sup> Tian Weinberg. "New Poll: 81% of U.S. Voters Support Transformative 'Build Back Better' Home Care Investment." SEIU. September 21, 2021. <https://www.seiu.org/2021/09/new-poll-81-of-u-s-voters-support-transformative-build-back-better-home-care-investment>

<sup>8</sup> The text of H.R. 5376 is available online at: <https://www.congress.gov/bills/117/7th-congress/house-bill/5376>

<sup>9</sup> Available online at: <https://rules.house.gov/sites/democrats.rules.house.gov/files/BILLS-117HR5376RH-RCP117-17.pdf>

<sup>10</sup> See Title III, Subtitle F.

<sup>11</sup> See Title XIII, Subtitle E.

Still another draft was released by the Rules Committee on Nov. 3 totaling 2,135 pages.<sup>12</sup> The following analysis is based on the latest version.

### **TRAINING GRANTS**

Sec. 22302 of the BBBA appropriates \$1 billion in grant funds to be allocated over 10 years to “eligible entities,” which include labor unions and affiliated funds, as well as state governments, Indian tribes and certain nonprofits. Grant funds must be used to develop and implement a strategy to recruit direct support workers, to retain direct support workers, and/or to develop or implement a paid training program for direct support workers focused on, among other things, workers’ rights under federal, state or local employment laws, including “forming, joining, or assisting a labor organization.” The training must also seek to help increase the “skills and competencies” of participating direct support workers with the goal of helping them attain “any associated recognized postsecondary credentials.”

In developing the grant proposal, applicants must “assure” HHS that they will “consult” with “direct support workers, *their representatives* [labor unions], and recipients of direct care services and their families.” (Emphasis added).

Grantees must also,

“...provide competitive wages, benefits, and other supportive services, including transportation, child care, dependent care, workplace accommodations, and workplace health and safety protections, to the direct support workers served by the grant that are necessary to enable such workers to participate in the activities supported by the grant.”

In short, grant funds can go directly to unions, and even non-union recipients may need to promote the unionization of direct support workers.

### **HCBS IMPROVEMENT PLANNING GRANTS**

Sec. 30711 of the BBBA appropriates \$130 million, “to remain available until expended,” for “HCBS improvement planning grants” to states.

States’ HCBS improvement plans must document the “existing Medicaid HCBS landscape” and include a description of how the state will increase the use of HCBS and ensure compensation for direct support workers is “sufficient” to support “recruitment and retention” and ensure “the availability of home and community-based services.”

In developing such plans, states must allow for,

“...a public notice and comment process that includes consultation with Medicaid eligible individuals who are recipients of home and community-based services, family caregivers of such recipients, providers, health plans, direct care workers, *chosen representatives of direct care workers* [labor unions], and aging, disability, and workforce advocates.”

(Emphasis added).

States must implement their HCBS improvement plan if it is approved by the Department of Health and Human Services (HHS).

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<sup>12</sup> Available online at: <https://rules.house.gov/sites/democrats.rules.house.gov/files/BILLS-117HR5376RH-RCPI17-18.pdf>

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### **ADDITIONAL FEDERAL FUNDING FOR HCBS IMPROVEMENT STATES**

If a state's HCBS improvement plan is approved by HHS and the state remains in compliance with various requirements, Sec. 30712 provides that the state becomes eligible for a six-point increase in its federal medical assistance percentage (FMAP), or the share of the state's Medicaid expenditures covered by federal funds.<sup>13</sup>

To receive the added federal funds, states must "update qualification standards" and provide "training opportunities" for HCBS caregivers.

States must also "...update and, as appropriate, increase payment rates" for HCBS services to "support recruitment and retention of the direct care workforce" by completing, "at least every 3 years," a "transparent process involving meaningful input from nongovernmental stakeholders." The process is designed to increase wages to direct support workers in a manner bearing a striking — and likely not coincidental — resemblance to collective bargaining.

### **PROMOTION OF THE AGENCY WITH CHOICE MODEL**

Sec. 30712 further provides that HCBS improvement states may receive an additional, one-and-a-half-year, two-point increase in their FMAP (for a cumulative eight-point increase) if they establish, on their own or via contracting with one or more "entities," an "agency with choice or a similar service delivery model" to perform the functions of, among other things:

- "Registering qualified direct care workers and assisting beneficiaries in finding direct care workers";
- "Undertaking activities to recruit and train independent providers to enable beneficiaries to direct their own care, including by providing or coordinating training for beneficiaries on self-directed care";
- "Ensuring the safety of, and supporting the quality of, care provided to beneficiaries";
- "Supporting beneficiary hiring, if selected by the beneficiary, of independent providers of home and community-based services, including by processing applicable tax information, collecting and processing timesheets, submitting claims and processing payments to such providers"; and,
- Ensuring such programs do not "promote or prevent the ability of workers to form a labor organization or discriminate against workers who may join or decline to join such an organization."

The agency with choice model is one method by which states have historically been permitted to structure HCBS delivery. It is also the model unions representing home care workers have come to prefer as it provides the legal structure needed to require caregivers to pay union dues as a condition of employment.

Medicaid does not generally pay beneficiaries directly, but rather reimburses providers for services rendered to beneficiaries. At the same time, a consensus has developed in recent decades regarding the importance and benefits of maximizing beneficiaries' ability to self-direct their care. To accommodate these two realities,

<sup>13</sup> Medicaid and CHIP Payment and Access Commission. "Matching Rates." Accessed October 28, 2021.

<https://www.macpac.gov/subtopic/matching-rates/>

U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health and Evaluation. "Federal Medical Assistance Percentages or Federal Financial Participation in State Assistance Expenditures (FMAP)." Accessed October 28, 2021.

<https://aspe.hhs.gov/federal-medical-assistance-percentages-or-federal-financial-participation-state-assistance>

"Medicaid provides for financial management services (FMS) entities (sometimes also referred to as fiscal intermediaries) to pay self-directing program participants' workers... States may arrange for FMS through a 'fiscal/employer agent' (F/EA) in which the FMS is strictly a payroll agent and self-directing program participants are their workers' sole legal employers under tax law. Alternatively, states may arrange for FMS via an 'Agency with Choice' (AwC). Although, for tax purposes, the AwC is the sole legal employer of self-directing program participants' workers; AwCs do not assume all of the other employer responsibilities of a typical home care agency."<sup>14</sup>

While both methods are permissible, HHS during both the Obama and Trump administrations promoted the fiscal/employer agent model over agency with choice, as the former best permits clients to take charge of and direct their own care.

In 2010, HHS explained that, "Fiscal/Employer Agents are most effective for implementing participant direction programs" because:

"First, using an F/EA provides participants a high degree of choice and control over their workers as their common law employers, while reducing their employer-related burden by managing the payroll and bill payment tasks. Second, using an F/EA provides safeguards for participants by ensuring that all required taxes are paid and all Department of Labor and workers compensation insurance requirements are met. Third, using an F/EA can provide fiscal accountability for states."<sup>15</sup>

In 2016, the Center for Medicaid Services (CMS) within HHS released an informational bulletin to states in which it explained;

"There are generally two models of PCS [personal care] service delivery that states can choose to make available: agency-directed or self-directed. Agency-directed is the traditional delivery model for PCS. Under this approach, a qualified PCS agency hires, fires, pays and trains PCAs to provide services to eligible individuals. A variation of the agency model is the agency with choice', in which an agency is co-employer with the beneficiary of PCS attendants. Self-directed PCS is an alternative to the traditional delivery model. Under self-directed models, beneficiaries or their representatives have decision-making authority over PCS and take direct responsibility to manage their services with the assistance of a system of available supports... Beneficiary decision-making and autonomy are hallmarks of self-directed models of service provision, and CMS strongly encourages use of self-directed models with necessary supports using a person-centered planning process."<sup>16</sup>

(Emphasis added).

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<sup>14</sup> Pamela J. Doty, Marie R. Squillace, and Edward Kako. "Analysis of State Efforts to Comply with Fair Labor Standards Act Protections to Home Care Workers." U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. January 7, 2020. <https://aspe.hhs.gov/reports/analysis-state-efforts-comply-fair-labor-standards-act-protections-home-care-workers-0>

<sup>15</sup> Janet O'Keeffe, Paul Saucier, Beth Jackson, Robin Cooper, Ernest McKenney, Suzanne Crisp and Charles Moseley. "Understanding Medicaid Home and Community Services: A Primer, 2010 Edition." U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. October 28, 2010. <https://aspe.hhs.gov/reports/understanding-medicaid-home-community-services-primer-2010-edition-0>

<sup>16</sup> Vikki Wachino and Shantanu Agrawal. "Strengthening Program Integrity in Medicaid Personal Care Services." Centers for Medicare & Medicaid Services. December 13, 2016. [https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/cib121316\\_1.pdf](https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/cib121316_1.pdf)

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And in 2019, a CMS guidance document stated that, “The Fiscal/Employer Agent model provides Medicaid program participants with the greatest level of flexibility and empowerment” and observed that, “Many states... use this model to allow Medicaid program participants and their families to self-direct.”<sup>17</sup>

### CIRCUMVENTING THE SUPREME COURT

Most likely, the BBBA incentivizes states to adopt an agency with choice model not because it is best for clients, but because unions believe this structure provides them with the legal authority necessary to compel home care aides to pay union dues as a condition of employment.

In June 2014, the U.S. Supreme Court ruled in *Harris v. Quinn* that the First Amendment does not permit states and unions to compel “quasi-public employees,” like the Illinois personal assistants for Medicaid clients who brought the lawsuit, to pay union dues or fees as a condition of employment.<sup>18</sup>

Ever since unions began organizing home care workers in California in the early 1990s, the challenge has been to establish a common employer against which to bargain. In self-directed HCBS programs, individual workers contract with the state or a fiscal/employer agent to serve individual clients, who are the employers of record, making traditional unionization under the National Labor Relations Act effectively impossible.

Rather than attempt to get Congress to amend the NLRA, however, unions turned to the states, which have the authority to permit or regulate the unionization of public employees via state collective bargaining laws. To solve the problem of no common employer, unions lobbied state officials to declare home care workers public employees solely for the purpose of placing them under the state’s collective bargaining laws for government workers and to designate a single government agency or official as their putative “employer.” As these state laws generally allowed unions to force public employees, such as teachers, to pay union dues/fees as a condition of employment, caregivers found themselves in the same position. This was the approach adopted in Illinois and, to varying degrees and for various times, at least 14 other states.<sup>19</sup>

In *Harris*, however, the Supreme Court recognized that these unions typically provided minimal representational benefits to caregivers while spending the collected dues on political advocacy. Consequently, the Supreme Court struck down the forced payment “scheme” as compelled speech in violation of the First Amendment.

As a result of the ruling, unions could no longer collect dues from the tens of thousands of unionized home care aides who never signed up for or resigned their union membership.

Upset with the loss in revenue, SEIU 775 — which represents the 45,000 individual provider home care aides (IPs) serving Medicaid clients in Washington state — concocted a scheme to reimpose mandatory dues.

As far back as June 2014, SEIU 775 had asked Gov. Jay Inslee to help the union respond to the anticipated loss in *Harris* by “contract[ing] with an outside entity to run the home care system, making IPs private-

<sup>17</sup> Centers for Medicare & Medicaid Services. “Application for a §1915(c) Home and Community-Based Waiver, Instructions, Technical Guide and Review Criteria, Resource Attachments.” Version 3.6, January 2019. <https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/resourceattachmentsjan2019.pdf>

<sup>18</sup> *Harris v. Quinn*, 573 US 616 (2014). [https://www.supremecourt.gov/opinions/13pdf/11-681\\_j426.PDF](https://www.supremecourt.gov/opinions/13pdf/11-681_j426.PDF)

<sup>19</sup> Maxford Nelsen. “Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity.” The Freedom Foundation. July 2018. <https://www.freedomfoundation.com/wp-content/uploads/2018/07/Getting-Organized-at-Home.pdf>

sector employees.”<sup>20</sup> However, this change required legislative action and the union lacked the political support in Olympia to implement it until after Democrats recaptured the state Senate majority via a 2017 special election.<sup>21</sup>

In 2018, at the urging of SEIU 775, the Washington State Legislature passed and Gov. Inslee signed SB 6199, directing the state to contract with a “consumer directed employer” (CDE) to manage the workforce of home care aides serving Medicaid clients.<sup>22</sup>

Regulations subsequently adopted by the Washington State Department of Social and Health Services (DSHS) define the CDE as:

“...a private entity that contracts with the department to be the legal employer of individual providers for purposes of performing administrative functions. *The consumer directed employer is patterned after the agency with choice model*, recognized by the federal centers for medicare and medicaid services for financial management in consumer directed programs.”<sup>23</sup>

(Emphasis added).

As an agency with choice, the CDE will:

“...[operate] under a co-employment arrangement whereby employer status is shared by the participant and an agency. For IRS purposes and other considerations, the agency is the primary or legal employer and officially hires the worker(s), processes human resource forms, and manages the payroll tasks. They also monitor the participant’s health and welfare, ensure that intended services are provided, and may provide guidance on recruiting, training, managing, and discharging workers. The participant or his/her representative is the secondary or managing employer. In this role, the participant or representative recruits, interviews, and selects workers, and then refers them to an agency for the completion of employment/payroll paperwork. In addition, the participant or representative trains, manages, and discharges workers (to the extent they wish to).”<sup>24</sup>

Union and state officials made no secret of their reasoning for the change. As “employees” of a private company in a state without right-to-work protections, caregivers could again be forced to pay 3.2 percent of their paychecks to SEIU 775 as a condition of caring for, in most cases, loved ones and close friends.<sup>25</sup>

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<sup>20</sup> Diane Lutz and Roslyn Marcus. “Governor briefing: Update on Harris v. Quinn Union Requests.” Washington State Office of Financial Management. June 3, 2014. <https://www.freedomfoundation.com/wp-content/uploads/2018/05/OFM-Gov-Briefing-6-3-14.pdf>

<sup>21</sup> Natalie Brand. “Dhingra wins Legislative District 45, Democrats control both legislative chambers.” *King 5*. November 8, 2017. <https://www.king5.com/article/news/politics/dhingra-wins-legislative-district-45-democrats-control-both-legislative-chambers/281-490007926>

<sup>22</sup> The Washington State Legislature’s official bill page for SB 6199, including text and history, is available online at: <https://app.leg.wa.gov/billsummary?BillNumber=6199&Year=2017&Initiative=false>

<sup>23</sup> See WAC 388-115-0503.

<sup>24</sup> Janet O’Keeffe, Paul Saucier, Beth Jackson, Robin Cooper, Ernest McKenney, Suzanne Crisp and Charles Moseley. “Understanding Medicaid Home and Community Services: A Primer, 2010 Edition.” U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. October 28, 2010. <https://aspe.hhs.gov/reports/understanding-medicaid-home-community-services-primer-2010-edition-0>

<sup>25</sup> Maxford Nelsen. “Forcing union membership is no way to run government-funded home health care. *The Seattle Times*. March 25, 2018. <https://www.seattletimes.com/opinion/forcing-union-membership-is-no-way-to-run-government-funded-home-health-care/>

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The secretary of the Washington State Department of Social and Health Services (DSHS) acknowledged to legislators that contracting with a CDE/agency with choice would allow the union to reimpose “a closed shop” in which dues payment is mandatory.<sup>26</sup>

When asked by *The Seattle Times* whether SB 6199 was about requiring caregivers to support his union, SEIU 775's president simply replied, “Anything that allows for stronger unions... is obviously good in and of itself.”<sup>27</sup> The union's secretary-treasurer made similar comments in an interview with *The News Tribune*:

“...[Adam] Glickman said the possibility of a union in which workers can't opt out of collective bargaining costs without religious objection would be 'a good thing' that would make SEIU a 'stronger union.' Glickman said sidestepping a Supreme Court decision, within legal bounds, to reach that goal is not unethical as some Republicans have claimed. 'I don't think there's anything wrong with states legislating their values even if those values conflict with Supreme Court decisions,' he said.”<sup>28</sup>

The state has since hired a vendor to serve as the CDE/agency with choice and is in the early stages of transitioning caregivers over to the new vendor. According to DSHS, the first pilot group of about 200 caregivers began logging hours for the vendor on October 1, 2021. About 16,000 more will transition over on Feb. 1, 2022, and the remaining 30,000 will transition on April 1, 2022.<sup>29</sup> By the summer, caregivers will likely find themselves back where they were before *Harris*, with nearly \$1,000 per year being diverted from their paychecks to SEIU 775 and nothing they can do about it.<sup>30</sup>

Nationally, unions and allied organizations have not publicly endorsed the agency with choice model as a workaround to *Harris*. But they've definitely hinted at attaching federal funds to Medicaid dollars to promote unionization of home care workers.

Earlier this year, the SEIU-supported<sup>31</sup> Paraprofessional Healthcare Institute (PHI) wrote that Washington's decision to contract with a single CDE/agency with choice “could serve as a model for other states to replicate in their own consumer-directed programs.”<sup>32</sup>

In the context of the BBBA specifically, *Bloomberg Law* reported in May that, according to congressional sources, SEIU was pressing for the legislation to promote the creation of “new entities [that would] assume the role of employers,” thus allowing for the unionization of caregivers as employees. Unsurprisingly, the SEIU itself refused to comment.<sup>33</sup>

<sup>26</sup> Bill Moss. Letter to the Washington State Senate Health and Long Term Care Committee. January 26, 2018. <https://www.freedomfoundation.com/wp-content/uploads/2018/02/Senate-Health-and-Long-Term-Care-Hearing-1-25-18-Response-to-question-...-002.pdf>

<sup>27</sup> David Rolf. Interviewed by Jim Brunner of *The Seattle Times* on “The Overcast” podcast. February 16, 2018. <https://soundcloud.com/seattletimesovercast/ep-69-seiu-leader-david-rolf-on-labors-wa-agenda-and-reshaping-the-union-movement>

<sup>28</sup> Walker Orenstein. “Inslee signs controversial union bill despite calls for a veto.” *The News Tribune*. March 27, 2018. <https://www.thenewstribune.com/news/politics-government/article206839864.html>

<sup>29</sup> Washington State Department of Social and Health Services. “Pilot and Hiring Phases.” Accessed October 28, 2021. <https://www.dshs.wa.gov/sites/default/files/ALISA/stakeholders/documents/CDE/CDWA%20Overlay%20-%20Hiring%20Phases%20by%20County.pdf>

<sup>30</sup> Joseph O'Sullivan. “How unions are racking up new wins in Democratic-controlled Washington state.” *The Seattle Times*. August 2, 2021. <https://www.seattletimes.com/seattle-news/politics/how-unions-are-racking-up-new-wins-in-democratic-controlled-washington-state/>

<sup>31</sup> According to union LM-2 reports to the U.S. Department of Labor, SEIU affiliates contributed \$418,878 to PHI between 2006 and 2016. A summary of the contributions is available online at: <https://www.freedomfoundation.com/wp-content/uploads/2021/11/SEIU-contributions-to-PHI.pdf>

<sup>32</sup> Stephen Campbell, Angelina Del Rio Drake, Robert Espinoza, and Kezia Scales. “Caring for the Future: The Power and Potential of America's Direct Care Workforce.” Paraprofessional Healthcare Institute. January 2021. <http://phinational.org/wp-content/uploads/2021/01/Caring-for-the-Future-2021-PHI.pdf>

<sup>33</sup> Alex Ruoff, Ben Penn, and Katia Dmitrieva. “Biden \$400 Billion Care Plan Would Have a Caveat: States Opt In.” *Bloomberg Law*. May 7, 2021. <https://news.bloomberglaw.com/health-law-and-business/biden-400-billion-care-plan-would-have-a-caveat-states-opt-in>

And for years, labor groups have called for, “Policies that attach quality workplace requirements to public funds,” such as requiring states to “create a central decision-making body with whom workers can collectively bargain over wages and job standards” as a condition of receiving federal Medicaid funds.<sup>34</sup> Washington’s experience, combined with the fact that the BBBA is using the promise of federal funding to incentivize states to adopt an agency with choice model — which HHS has not historically recommended — strongly suggests the goal is to deprive caregivers of their constitutional right to refrain from union dues payments on a technicality.

### THE SEIU MODEL IN WASHINGTON STATE

The BBBA’s endorsement of the agency with choice model is just one of the many ways the legislation seeks to transform the nation’s HCBS into Washington’s likeness. Since 2001, SEIU has dominated and shaped the state’s home care system, ensuring that a healthy portion of the Medicaid funds intended for client care end up in the union’s treasury, where they are used to subsidize the union’s wide-ranging political agenda.

While large and increasing amounts of Medicaid funds are expended on HCBS in Washington state, many of the union-operated training and employee benefits programs — the kind the BBBA seeks to expand around the country — suffer from a lack of accountability, high administrative costs, and apparent cronyism, and fail to produce the intended results.

### TRAINING

In 2011, Washington voters approved Initiative 1163,<sup>35</sup> a union-backed ballot measure that created the most robust training requirements for home care aides in the country, with most providers required to obtain and maintain a home care aide certificate by completing 75 hours of initial training and 12 hours of annual continuing education.<sup>36</sup> Washington state’s experience with mandated training requirements for home care workers serving Medicaid clients has produced, at best, mixed results.

As a result of the initiative, all training for IPs must be provided by a single “training partnership” selected by the IPs’ union, SEIU 775.<sup>37</sup> Unsurprisingly, the entity selected by SEIU 775 — the SEIU Healthcare NW Training Partnership (TP) — was one that it created and that it claims is now the largest such training operation for home caregivers in the country.

Under Article 15.4 of the 2021-23 collective bargaining agreement (CBA) currently in effect between the state of Washington and SEIU 775, the state pays \$0.435 for every hour worked by an IP to the TP.<sup>38</sup> The Partnership reported total revenue of \$42.3 million on its tax return for FY 2020, and its executive director was paid \$245,379.<sup>39</sup> SEIU 775 and the Training Partnership share officers, office space and a call center.

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<sup>34</sup> Sarah Leberstein, Irene Tung, and Caitlin Connolly, “Upholding Labor Standards in Home Care: How to Build Employer Accountability Into America’s Fastest-Growing Jobs,” National Employment Law Project, December 2015. <http://stage.nelp.org/wp-content/uploads/Report-Upholding-Labor-Standards-Home-Care-Employer-Accountability.pdf>

<sup>35</sup> Bailey Ludlam, “Washington Long-Term Care, Initiative 1163 (2011),” Ballotpedia. Accessed October 28, 2021. [https://ballotpedia.org/Washington\\_Long-Term\\_Care\\_Initiative\\_1163\\_\(2011\)](https://ballotpedia.org/Washington_Long-Term_Care_Initiative_1163_(2011))

<sup>36</sup> Washington State Department of Health and Human Services, “Individual providers.” Accessed October 28, 2021. <https://www.dshs.wa.gov/altsa/home-and-community-services/individual-providers>

<sup>37</sup> RCW 74.39A.360.

<sup>38</sup> Article 15 of the 2021-23 collective bargaining agreement currently in effect between the State of Washington and SEIU Local 775.

Available online at: [https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse\\_homecare.pdf](https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse_homecare.pdf)

<sup>39</sup> The most recent Form 990 filed by the Training Partnership with the Internal Revenue Service is available online at: [https://apps.irs.gov/pub/epostcard/cor/510673005\\_202006\\_990\\_2021052618210524.pdf](https://apps.irs.gov/pub/epostcard/cor/510673005_202006_990_2021052618210524.pdf)

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And the state's financial obligation towards the Training Partnership has proven lucrative for SEIU 775 as well. In FY 2020, the TP paid \$3.4 million — 8.1 percent of its total revenue that year — to SEIU 775.<sup>40</sup>

Further, the TP consistently collects more in revenue than it expends on training, leading to steadily increasing net assets and cash holdings. From FY 2012 to 2020, the TP's expenses increased by 352 percent, while its net assets increased by 668 percent. The TP also pays steadily increasing amounts to SEIU 775, totaling \$17.8 million from 2013-20.

SEIU Training Partnership Revenue and Expenses				
Year	Revenue	Expenses	Net Assets	Paid to SEIU 775
FY 2020	\$42,334,393	\$38,345,728	\$17,775,913	\$3,428,305
FY 2019	\$32,885,504	\$32,059,904	\$13,787,248	\$2,627,071
FY 2018	\$31,644,127	\$29,533,784	\$12,961,648	\$2,570,763
FY 2017	\$27,223,994	\$24,558,564	\$10,851,305	\$2,077,623
FY 2016	\$25,102,293	\$20,782,659	\$8,185,875	\$2,024,206
FY 2015	\$18,632,059	\$18,609,068	\$3,866,241	\$1,921,508
FY 2014	\$21,137,787	\$20,312,161	\$3,843,250	\$1,852,089
FY 2013	\$13,022,417	\$12,664,658	\$3,017,624	\$1,286,194
FY 2012	\$11,105,663	\$10,886,695	\$2,659,865	Unknown
<b>Total</b>	<b>\$223,088,237</b>	<b>\$207,753,221</b>	<b>\$76,948,969</b>	<b>\$17,787,759</b>

Source: Form 990 tax returns submitted by the TP to the IRS.

The state's statutorily required financial obligation to the TP as the monopoly provider of mandated training to IPs has, predictably, limited providers' choices, resulted in poor customer service, and has made it difficult for some rural providers to access required training. After all, the TP's revenue is completely untethered from its performance.

And alternatives are available. In fact, more than 50 other entities are certified by DSHS to offer the same 75-hour, long-term care training provided by the TP — they just can't serve the IPs SEIU 775 represents. Most would also likely be ineligible to receive training grant funds under Sec. 22302 of the BBBA.<sup>41</sup>

Despite the hundreds of millions of Medicaid dollars paid to the TP since passage of I-1163 in 2011, recruitment and retention challenges continue to plague the state, and a series of audits conducted by the Washington State Auditor suggests the stringent training requirements bear at least some of the blame.

A 2014 audit found that, despite efforts in prior years to improve the completion rate, only one-third of persons seeking a home care aide certificate completed the training and were certified within required deadlines. The auditor noted that, "Program managers told us they believe that the failure of workers to complete the certification has resulted in a higher turnover rate, which can affect continuity of care for clients."<sup>42</sup>

<sup>40</sup> *Ibid.*

<sup>41</sup> Washington State Department of Social and Health Services. "Find a Training Class." Accessed October 28, 2021. <https://fortress.wa.gov/dshs/adsaapps/Professional/training/training.aspx>

<sup>42</sup> Washington State Auditor's Office. "Initiative 1163: Long-Term Care Worker Certification Requirements." December 18, 2014. <https://portal.sao.wa.gov/ReportSearch/Home/ViewReportFile?arn=1012952&isFinding=false&sp=false>



The audit further reported that,

“Program managers recognize that both completion rates and timeliness need to be improved, but point out that some factors are outside their control. For example, some people caring for a family member might decide not to pursue the 75 hours of required training needed to gain the certificate. Agency officials suggested that some workers leave the home care aide certificate program to pursue other types of certifications. For example, becoming a certified nursing assistant requires about 10 additional training hours but may lead to greater employment opportunities. Some people simply change their minds about working in the field, and others fail background checks. All these reasons affect home care aide certificate completion rates.”<sup>43</sup>

In other words, the training requirements themselves were problematic.

A subsequent audit in 2016 found that the home care aide “certification completion rates have remained flat” despite efforts to increase passage, including lowering exam passing scores.<sup>44</sup> Of course, the TP gets paid the same regardless of the success or failure of its trainees in passing the state home care aide certification exam, and may even benefit from being paid to train students a second time who were unable to earn their certificate the first time.

Finally, the most recent state audit from 2019 examined reducing training requirements for certain caregivers as a way to boost recruitment:

- “Broad demographic trends and various studies suggest a growing need for long-term care, though it is difficult to quantify. Those trends and studies also suggest there will be an insufficient number of caregivers to meet that need.”
- “The expected shortages in long-term care workers mean that families of people with disabilities, including those who are eligible for Medicaid, will likely face challenges in finding qualified caregivers. One possible way to address future unmet need is to expand training and certification exemptions beyond those currently afforded to parents and adult children.”
- “By reducing the training requirements and offering the flexibility of online training, extended family members may be more inclined to become individual providers and be paid for their services.”

Overall, however, the auditor’s report concluded without making any formal recommendations given the lack of hard data about the effectiveness of the training.<sup>45</sup>

Despite repeated studies by the auditor, no empirical evidence to date suggests Washington state’s training requirements have measurably improved client care. Instead, the primary purpose of the training, in addition to serving as another revenue source for SEIU 775 via the TP, appears to be allowing the union to argue for higher wages and benefits at the bargaining table on the unproven assumption that time spent in a TP classroom increases the value of caregivers’ labor.

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<sup>43</sup> *Ibid.*

<sup>44</sup> Washington State Auditor’s Office. “I-1163: Long-term Care Worker Certification Requirements 2016.” August 4, 2016.

<https://portal.sao.wa.gov/ReportSearch/Home/ViewReportFile?am=1017262&isFinding=false&sp=false>

<sup>45</sup> Washington State Auditor’s Office. “Assessing Extended Family Exemptions for Individual Providers.” February 21, 2019.

[https://sao.wa.gov/wp-content/uploads/Tabs/PerformanceAudit/PA\\_I-1163-Extending\\_Family\\_Exemptions\\_ar1023358.pdf](https://sao.wa.gov/wp-content/uploads/Tabs/PerformanceAudit/PA_I-1163-Extending_Family_Exemptions_ar1023358.pdf)

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## HEALTH INSURANCE

Pursuant to Article 9.2 of the current CBA between SEIU 775 and the State of Washington, the state pays \$3.79 for every hour worked by an IP to the SEIU Healthcare NW Health Benefits Trust (HBT) for the purposes of offering health insurance benefits to certain IPs.<sup>46</sup>

Though paid for by Medicaid, eligibility for benefits and benefit amounts are both determined by the HBT. To qualify for benefits at present, an IP must work at least 80 hours per month and pay a nominal premium of \$25 per month.<sup>47</sup>

As part of the SEIU 775 constellation, housed in the union's downtown Seattle office, the HBT pays both the TP and SEIU 775 for various administrative services. From FY 2010-19, the HBT paid nearly \$24.5 million to the TP and a further \$2.4 million to the union.

SEIU Health Benefits Trust Revenue and Expenses							
Year	Revenue	Benefits paid	Admin. Expenses	Paid to SEIU TP	Paid to SEIU 775	Total expenses	Net Assets
FY 2019	\$258,351,358	\$185,625,028	\$25,642,234	\$6,238,379	\$408,025	\$211,267,262	\$241,327,232
FY 2018	\$239,391,455	\$167,558,616	\$23,480,649	\$6,318,960	\$289,510	\$191,039,265	\$186,867,423
FY 2017	\$203,533,519	\$143,743,328	\$18,587,123	\$3,228,773	\$215,483	\$162,330,451	\$141,741,573
FY 2016	\$190,079,616	\$124,180,837	\$7,128,097	\$3,563,183	\$255,370	\$131,308,934	\$100,540,754
FY 2015	\$168,660,785	\$148,524,734	\$4,834,052	\$2,275,922	\$173,843	\$153,358,786	\$41,770,072
FY 2014	\$149,889,337	\$145,671,055	\$4,072,234	\$1,565,043	Unknown	\$149,743,289	\$26,468,073
FY 2013	\$125,875,145	\$129,225,279	\$2,722,813	\$595,073	\$265,576	\$131,948,092	\$26,322,025
FY 2012	\$124,576,251	\$116,158,847	\$2,358,374	\$413,886	\$355,999	\$118,517,221	\$32,394,972
FY 2011	\$113,703,712	\$103,572,725	\$1,972,905	\$233,802	\$343,533	\$105,545,630	\$9,881,942
FY 2010	\$102,781,675	\$105,398,688	\$1,391,848	\$33,693	\$80,453	\$106,790,536	\$1,723,860
<b>Total</b>	<b>\$1,676,842,853</b>	<b>\$1,369,659,137</b>	<b>\$92,190,329</b>	<b>\$24,466,714</b>	<b>\$2,387,792</b>	<b>\$1,461,849,466</b>	<b>\$809,037,926</b>

Source: Form 990 tax returns submitted by the HBT to the IRS.

Like the TP, the HBT pays high, and rapidly growing, amounts towards administrative expenses. Since FY 2010, the HBT's revenue has increased 250 percent, but benefits paid have increased by only 176 percent. Meanwhile, the HBT's administrative expenses have increased by 1,842 percent and its net assets by 14,000 percent. In FY 2019, only 71.2 percent of the HBT's revenue went towards paying out benefits to IPs.<sup>48</sup>

Part of the HBT's asset accumulation can be explained by its transition from a fully insured plan to a self-funded plan in August of 2016. Instead of paying premiums, as a self-funded plan, the HBT needs enough reserves to manage unexpectedly high claims. An employee benefits consultant for the HBT testified before the Washington State Legislature in 2017 that self-funded plans are recommended to have at least

<sup>46</sup> See Article 9 of the 2021-23 collective bargaining agreement currently in effect between the State of Washington and SEIU Local 775. Available online at: [https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse\\_homecare.pdf](https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse_homecare.pdf)

<sup>47</sup> SEIU 775 Benefits Group. "Get Covered." Accessed October 28, 2021. <https://www.myseiubenefits.org/health/get-covered/>

<sup>48</sup> The most recent Form 990 tax return submitted by the SEIU Healthcare NW Health Benefits Trust to the IRS is available online at: [https://apps.irs.gov/pub/epostcard/cor/201842198\\_201906\\_9900\\_2020100817359412.pdf](https://apps.irs.gov/pub/epostcard/cor/201842198_201906_9900_2020100817359412.pdf)

16 weeks of reserves available.<sup>49</sup> As of June 2019, the HBT had cash and investment assets sufficient to cover nearly 67 weeks of benefits.<sup>50</sup>

This should come as no surprise, given the HBT's structure. In the private-sector, employers have financial incentives to limit health insurance costs. There is no such dynamic with the HBT. As currently structured, SEIU is able to determine (1) through bargaining, the amount that a third-party, the state, will pay for IPs' health benefits, (2) worker eligibility for health benefits, and (3) the amount to spend on benefits. This structure creates incentives to overcharge and under-deliver for benefits, and to steer funds towards SEIU affiliates. Finally, the HBT has never been — and, as an ERISA-governed trust, probably cannot be — audited by the state, and the lack of public disclosure or financial transparency requirements from the HBT further decreases its accountability.

## RETIREMENT

As required by Article 21.2 of the CBA between SEIU 775 and the State of Washington, the state pays the SEIU 775 Secure Retirement Trust (SRT) \$0.80 for every hour an IP works in order to provide retirement benefits for eligible IPs.

As with the HBT, the SRT unilaterally determines benefit eligibility requirements, vesting standards and benefit amounts. Also like the HBT, it faces minimal financial transparency obligations and lacks any incentives to control costs or maximize benefits for IPs, leaving it largely unaccountable. The SRT is a relatively new benefit though, like the other funds operated by SEIU 775, it has begun finding ways to pay the union for various services.

SEIU Secure Retirement Trust Revenue and Expenses						
Year	Revenue	Benefits paid	Admin. Expenses	Paid to SEIU 775	Total expenses	Net Assets
FY 2020	\$44,644,639	\$533,393	\$4,148,825	\$28,457	\$4,682,218	\$110,883,823
FY 2019	\$27,179,610	\$0	\$3,529,176	N/A	\$3,529,176	\$59,039,680
FY 2018	\$16,030,748	\$0	\$2,246,448	N/A	\$2,246,448	\$35,389,246
FY 2017	\$21,861,841	\$0	\$256,895	N/A	\$256,895	\$21,604,946
<b>Total</b>	<b>\$109,716,838</b>	<b>\$533,393</b>	<b>\$10,181,344</b>	<b>\$28,457</b>	<b>\$10,714,737</b>	<b>\$226,917,695</b>

Source: Form 5500 annual returns submitted by the TP to the U.S. Dept. of Labor

Despite collecting nearly \$110 million in the first years of its existence, the SRT has paid only 0.5 percent of this in benefits to IPs.<sup>51</sup> Though the SRT's net assets are growing rapidly, it has spent 19 times as much on administrative expenses as it has on benefits to IPs.

The experience of the SRT suggests that, at least in the early years, states that use additional federal Medicaid funds to stand up new benefit programs for home care aides may find themselves spending most of the money on administrative costs, with little to no benefit provided to caregivers.

<sup>49</sup> Galen Li. Testimony before the Washington State Senate Ways and Means Committee, February 14, 2017.

<https://www.tvw.org/watch/?clientID=9375922947&eventID=2017021247&startStreamAt=6088&stopStreamAt=6172&autoStartStream=true>

<sup>50</sup> According to Part X of the HBT's most recent Form 990 tax return filed with the IRS for the period ending June 30, 2019, the HBT had \$808,772 in non-interest-bearing cash, \$34,504,959 in savings, and \$202,775,264 invested in publicly traded securities, for a total of \$238,088,995, or 128 percent of the \$185,625,028 in benefits the HBT paid out during the 52 weeks FY 2019. 52 weeks multiplied by 128 percent equals 67 weeks.

<sup>51</sup> See the most recent Form 5500 annual return submitted by the SEIU 775 Secure Retirement Trust to the U.S. Department of Labor. Available online at: <https://efast2-filings-public.s3.amazonaws.com/prd/2021/04/14/20210414220900NAL0008190289002.pdf>



## REFERRAL REGISTRY

The newest benefit for IPs to be included in the CBA between SEIU 775 and the state of Washington funds a duplicative, third-party referral registry. Article 14.5 of the CBA obligates the state to contribute \$0.03 for every hour worked by an IP to “a third-party vendor jointly selected by the State and the Union” for the purposes of offering “an online and telephone based registry referral service” to connect IPs seeking work with Medicaid clients seeking caregivers.<sup>52</sup>

Unsurprisingly, the selected vendor — Carina<sup>53</sup> — was created and is managed by SEIU 775. Its executive director received \$222,490 in compensation in FY 2019.<sup>54</sup>

As a newer and less expensive benefit than training or health insurance, Carina has yet to collect the eye-popping revenue of other SEIU 775-operated trust funds.

Nevertheless, the fact that the state agreed to pay for Carina’s creation and management is noteworthy if only because DSHS *already* operated, and continues to operate, its own taxpayer-funded referral registry.<sup>55</sup>

Carina Revenue and Expenses			
Year	Revenue	Expenses	Net Assets
FY 2019	\$1,782,155	\$1,979,088	\$1,867,978
FY 2018	\$1,587,974	\$588,584	\$2,064,912
<b>Total</b>	<b>\$3,370,129</b>	<b>\$2,567,672</b>	<b>\$3,932,890</b>

Source: Form 990 tax returns submitted by Carina to the IRS.

As another example of how Medicaid-funded and union-selected/affiliated benefit trusts face no accountability for performance, the state and union have faced (and dismissed) an IPs’ grievance pointing out that Carina has yet to offer any “telephone based” referral services, despite the obligatory language to that effect in the CBA.<sup>56</sup>

## THE BBBA’S FINANCIAL BENEFIT TO UNIONS

While it is impossible to measure the extent to which the BBBA, if adopted, would steer Medicaid funds into union treasuries, it could amount to hundreds of millions — if not billions — of dollars.

The exact cost of the HCBS components of the BBBA is not presently known. Press reports commonly suggested the original version of the bill would direct \$400 billion to HCBS, as President Biden called for in March 2021 as part of his “American Jobs Plan.”<sup>57</sup> However, a more recent September analysis by the union-aligned Economic Policy Institute estimated the original bill would have directed \$344 billion to “long term care.”<sup>58</sup>

<sup>52</sup> See Article 14 of the 2021-23 collective bargaining agreement currently in effect between the State of Washington and SEIU Local 775. Available online at: [https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse\\_homecare.pdf](https://ofm.wa.gov/sites/default/files/public/labor/agreements/21-23/nse_homecare.pdf)

<sup>53</sup> See <https://www.carinacare.com/>

<sup>54</sup> The most recent Form 990 filed by Carina with the Internal Revenue Service is available online at: [https://apps.irs.gov/pub/epostcard/cor/320530631\\_201906\\_990\\_2021012117625095.pdf](https://apps.irs.gov/pub/epostcard/cor/320530631_201906_990_2021012117625095.pdf)

<sup>55</sup> See <http://www.hcr.wa.gov/>

<sup>56</sup> Ann Green. Letter to Kenneth J. Finlayson, Jr. August 18, 2021. [https://www.freedomfoundation.com/wp-content/uploads/2021/10/G21-085\\_GrievanceResponse.pdf](https://www.freedomfoundation.com/wp-content/uploads/2021/10/G21-085_GrievanceResponse.pdf)

<sup>57</sup> The White House. “FACT SHEET: The American Jobs Plan.” March 31, 2021. <https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/>

<sup>58</sup> Adam S. Hersh. “‘Build Back Better’ agenda will ensure strong, stable recovery in coming years.” Economic Policy Institute. September 16, 2021. <https://www.epi.org/publication/ijja-budget-reconciliation-jobs/>

**Stop the Spread: How the BBBA Seeks to Replicate Washington State's Union-Dominated HCBS Model Nationwide**

While the Congressional Budget Office has yet to complete its analysis of the most recent version of the bill,<sup>59</sup> congressional Democrats estimate it will add \$150 billion in HCBS funding.<sup>60</sup>

The Kaiser Family Foundation estimates Medicaid spent \$114 billion on HCBS in FY 2021 and that, if another \$400 billion was evenly spent over the next 10 years, it would amount to “at least” a 33 percent/\$40 billion annual increase over the baseline, and “even more if state spending also increases.”<sup>61</sup>

A Freedom Foundation research paper documented that, in 2017, unions like SEIU and AFSCME collected \$147 million in dues deducted from Medicaid payments to 358,000 home care aides in eight states, including Washington, Oregon, California, Minnesota, Illinois, Connecticut, Massachusetts and Vermont.<sup>62</sup> That amount has almost certainly increased since. In California, for instance — home to the bulk of currently unionized caregivers nationwide — the two unions representing caregivers in the state's In-Home Supportive Services (IHSS) program saw their dues revenue cumulatively increase 11 percent, from \$104.6 million in 2017 to \$115.6 million in 2020.<sup>63</sup>

Year	SEIU 2015			
	Total Dues	Total members	IHSS Members	Average member dues
2017	\$78,814,307	192,376	179,729	\$409.69
2020	\$89,089,900	188,778	180,048	\$471.93
Year	UDW			
	Total Dues	Total members	IHSS Members	Average member dues
2017	\$25,780,529	81,448	81,050	\$316.53
2020	\$26,554,910	72,149	72,149	\$368.06
Year	Combined			
	Total Dues	Total members	IHSS Members	Average member dues
2017	\$104,594,836	273,824	260,779	\$381.98
2020	\$115,644,810	260,927	252,197	\$443.21

Source: Forms LM-2 submitted by SEIU 2015 and UDW to the U.S. Dept. of Labor.

<sup>59</sup> Phillip L. Swagel. “CBO’s Schedule for Releasing a Cost Estimate for H.R. 5376, the Build Back Better Act.” Congressional Budget Office. November 9, 2021. <https://www.cbo.gov/publication/57601>

<sup>60</sup> House Committee on the Budget, Chairman John Yarmouth. “The Build Back Better Act: Transformative Investments in America’s Families & Economy.” November 5, 2021. <https://budget.house.gov/publications/report/build-back-better-act-transformative-investments-america-s-families-economy>

<sup>61</sup> MaryBeth Musumeci. “How Could \$400 Billion New Federal Dollars Change Medicaid Home and Community-Based Services?” Kaiser Family Foundation. July 16, 2021. <https://www.kff.org/medicaid/issue-brief/how-could-400-billion-new-federal-dollars-change-medicaid-home-and-community-based-services/>

<sup>62</sup> Maxford Nelsen. “Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity.” The Freedom Foundation. July 2018. <https://www.freedomfoundation.com/wp-content/uploads/2018/07/Getting-Organized-at-Home.pdf>

<sup>63</sup> According to Statement B, Item 36 of the Form LM-2 submitted by SEIU 2015 to the U.S. Department of Labor for calendar year 2017, the union collected \$78,814,307 in dues that year. SEIU 2015’s LM-2 for 2017 is available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=668930&rptForm=LM2Form>

Further, Statement B, Item 36 of the union’s LM-2 for 2020 indicated the union collected \$89,089,900 in dues. SEIU 2015’s LM-2 for 2020 is available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=750539&rptForm=LM2Form>

Similarly, the United Domestic Workers of America/AFSCME Local 3930 reported collecting \$25,780,529 in dues on Statement B, Item 36 of its 2017 LM-2, and \$26,554,910 on its 2020 LM-2. UDW’s 2017 LM-2 is available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=670792&rptForm=LM2Form> The union’s 2020 LM-2 is available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=752424&rptForm=LM2Form>



Assuming the same held true for other unions, current baseline practices resulted in unions collecting about \$163 million in 2020.

If all else remained equal, simply increasing HCBS funding by 33 percent annually over 10 years, as the Sept. 27 version of the BBBA would do, would presumably increase union dues revenue in the states in which caregivers for Medicaid clients are already unionized by an equivalent amount, translating to an extra \$54 million in dues annually for unions, or \$540 million over 10 years.

Adding \$150 billion in HCBS funding over 10 years, as the current version of the BBBA proposes to do, would represent roughly a 13 percent annual increase in funding, translating to an additional \$21 million in dues revenue per year, or \$212 million over 10 years.

However, the BBBA is engineered specifically to *increase* the unionization of home caregivers, though the extent to which it would do so is impossible to predict.

If states without right-to-work protections for private-sector employees in which home care aides are currently unionized and working under a fiscal/employer agent model switch to an agency with choice model in the same way Washington did, hundreds of thousands of caregivers could be forced to pay union dues.

For instance, in Washington state, 26 percent of Medicaid-paid IPs — almost 12,200 caregivers — were not paying dues as of July 2021.<sup>64</sup> On average, SEIU 775 members pay about \$920 in dues per year, so again requiring all IPs to pay dues as a condition of employment next year, via the transition to the agency with choice model, should increase the union's annual revenue by about \$11.2 million.

The boost to unions from mandated dues payment would be even more dramatic in states like California, where only half of IHSS providers are currently union members. The California Department of Social Services reports there are about 520,000 caregivers in the IHSS program,<sup>65</sup> but between them, SEIU 2015 and UDW claim only 261,000 members.<sup>66</sup> Forcing the other 259,000 to pay union dues would increase the unions' annual revenue by about \$115 million.

Combined, mandating union membership for HCBS caregivers in Washington and California alone — where about 80 percent of currently unionized HCBS caregivers work — would increase union dues collection by at least \$1.26 billion over 10 years. Factor in 13 percent more Medicaid spending on HCBS services — meaning more and/or better compensated caregivers — and this amount rises to \$1.42 billion.

Further, HCBS caregivers in some or all of the other 42 states will likely end up being unionized because of the BBBA's promotion of union membership, generating still more, but indeterminate, dues revenue for unions, though the right-to-work laws presently on the books in 27 of these states would at least prevent caregivers from being forced to pay dues even under an agency with choice model.<sup>67</sup>

<sup>64</sup> According to payroll data obtained by the author from the Washington State Department of Social and Health Services via a request submitted via Chapter 42.56 RCW, the Public Records Act.

<sup>65</sup> California Department of Social Services. "In Home Supportive Services (IHSS) Program." Accessed October 28, 2021. <https://www.cdss.ca.gov/inforesources/ihs>

<sup>66</sup> Schedule 13 of SEIU 2015's LM-2 Form for 2020 indicates the union had 180,048 public homecare worker members. The LM-2 is available online at: <https://olmsapps.dol.gov/query/orgReport.do?ptfid=750539&rptForm=LM2Form>

Schedule 13 of UDW's LM-2 Form for 2020 indicates the union had 72,149 members that year.

<sup>67</sup> National Conference of State Legislatures. "Right-To-Work Resources." Accessed October 28, 2021. <https://www.ncsl.org/research/labor-and-employment/right-to-work-laws-and-bills.aspx>

Lastly, unions will almost certainly be funneled additional, non-dues revenue through employer-funded and union-administered benefits trusts and collect additional deductions from HCBS caregivers' Medicaid payments as political contributions.

At the high end of the spectrum, consider what would happen if every state HCBS model ended up looking like Washington's as a result of the BBBA, complete with unionization under an agency with choice model and an array of union-operated training programs and benefits trusts.

At present, every hour an IP works costs the state of Washington between \$21.91 and \$24.71.

Between dues deducted from IPs' wages and payments by union-affiliated trusts to the union itself, about 2.7 percent of these hourly rates find their way to SEIU 775.

If (1) the BBBA increases annual HCBS spending from \$114 billion to \$123 billion, (2) 75 percent of HCBS funds go towards caregiver payroll and benefits, and (3) Washington state's model spreads nationwide, meaning 2.7 percent of all HCBS worker payroll and benefits payments went to unions, it would amount to annual revenue for unions of \$2.5 billion, or \$25 billion over 10 years.

Reducing this amount by about 25 percent based on (1) the fact that half the nation's population lives in right-to-work states and cannot be required to pay union dues and (2) the assumption that only about half of unionized caregivers in such states would join a union, puts the annual revenue for unions from HCBS funds at about \$1.9 billion, or \$18.8 billion over 10 years, under the BBBA.

Of course, states will diverge in their approaches, with some being more union-friendly than others, caregivers in some states may opt not to unionize at all, and the exact amount of additional funding for HCBS under the BBBA has yet to be determined.

Whatever the exact amount, it is clear that unions stand to gain significantly from the ability to capture massive amounts of Medicaid funds under the BBBA.

### **THE LEGALITY OF DEDUCTING UNION DUES FROM MEDICAID PAYMENTS**

Another factor with the potential to dramatically affect the ability of unions to access HCBS funds involves the interpretation of a longstanding federal Medicaid statute.<sup>68</sup> Specifically, 42 U.S.C. § 1396a(a)(32) provides that, with certain enumerated exceptions, "no payment" for Medicaid services be made to "anyone other than... the person or institution providing such care or service."

<sup>68</sup> For more detailed discussions of this issue, see:

Maxford Nelsen. "As HHS Secretary, Becerra Would Back Labor Unions over Home-Care Workers." *National Review*, March 3, 2021.

<https://www.nationalreview.com/2021/03/as-hhs-secretary-becerra-would-back-labor-unions-over-home-care-workers/>

Maxford Nelsen. Comments on Notice of Proposed Rulemaking, File Code CMS-2444-P, RIN 0938-AU73, September 28, 2021.

<https://www.regulations.gov/comment/CMS-2021-0130-0033>

Maxford Nelsen. "Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity." The Freedom Foundation, July 2018. <https://www.freedomfoundation.com/wp-content/uploads/2018/07/Getting-Organized-at-Home.pdf>



Nevertheless, since SEIU unionized California's IHSS caregivers in the 1990s, states that have allowed for the unionization of their workforce of HCBS caregivers have also deducted union dues directly from the Medicaid payments made to these caregivers and forwarded the funds to the applicable unions. Effectively, these states are making Medicaid payments to third parties who provide no services to Medicaid beneficiaries in direct violation of federal law.

While *Harris v. Quinn* at least gave home care aides the right to refrain from authorizing such deductions, unions and sympathetic state officials have implemented a variety of coercive practices and policies designed to make it easy for unions to sign people up for dues payments and very difficult for caregivers to opt out.

For instance, all eight states deducting union dues from Medicaid payments to caregivers allow for some union access to employee orientation or training programs for the purposes of soliciting membership. In Washington, caregivers must participate in two captive-audience sessions as part of their onboarding process and once a year thereafter as part of their continuing education.

While dues deductions can be authorized via multiple means — in writing, electronically, telephonically, etc. — and at any time, unions often insist that dues cancellations be submitted in writing during arbitrary annual escape periods as short as a few days.

Worst of all, unions in Washington, California and Minnesota have all faced legal actions by a growing number of caregivers whose signatures were forged by union organizers on membership forms.<sup>69</sup>

All of these coercive practices are enabled by states' role as the dues-collector for unions. If dues were not collected via payroll deduction, home care aides could still pay union dues if they wish but would have to make their own payment arrangements with the union, giving them far greater control over their membership in the process.

Unfortunately, the federal law requiring caregivers to be paid directly and in full for their services has yet to be meaningfully enforced.

During the Obama administration, HHS chastised Washington state for withholding dues from caregivers' Medicaid payments but did nothing to enforce the law. Instead, despite admitting that federal law does not provide for "exceptions to the direct payment principle," it tried to give the practice legal cover via adoption of an administrative regulation in 2014 allowing states to make deductions from Medicaid payments for "benefits customary for employees," arguably including union dues.

The Trump administration, recognizing the regulation contradicted the statutory direct payment requirement, repealed it but was unable to take any enforcement action to bring states into compliance before President Biden's inauguration. Under Biden's secretary Xavier Becerra, HHS recently proposed to reinstate the Obama-era regulation purporting to authorize the deductions.

If the statute is ultimately interpreted to prohibit such deductions, it would help ensure that both currently unionized caregivers and any unionized as a result of the BBBA have a meaningful choice about whether to sign up for union membership and pay union dues. If, however, states and unions are allowed to continue coercively seizing dues from caregivers' Medicaid payments, many thousands will find themselves paying dues to this private special interest against their will.

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<sup>69</sup> The Freedom Foundation. "SEIU Hit with Second RICO Suit." September 30, 2021. <https://www.freedomfoundation.com/litigation/seiu-hit-with-second-rico-suit/>



### POLITICAL INFLUENCE OF UNIONS REPRESENTING HCBS CAREGIVERS

The unions that currently represent HCBS caregivers in eight states tend to be exceptionally active politically, a result of exploitative practices and limited representational obligations.<sup>70</sup>

In the context of HCBS, there are no workplaces in the traditional sense. Caregivers work in their clients' homes which, often, are also their own. Consequently, there are no workplace issues for a union to mediate or resolve. For example, there is simply no mechanism for a caregiver serving their adult child to file a grievance against that child for the conditions in the caregivers' home. Further, the topics subject to bargaining are typically far more limited than in the private sector or even in the case of traditional public employees like teachers. In *Harris*, the U.S. Supreme Court recognized that HCBS caregivers occupy an "unusual status" and that, as a result, the "powers and duties" of the unions representing them are "sharply circumscribed."<sup>71</sup>

Finally, the number of contracts the union must negotiate is typically limited. In Washington state, SEIU 775 negotiates a single collective bargaining agreement with the state once every two years on behalf of the state's roughly 45,000 caregivers, an on-and-off process that generally lasts a few months. For this limited service, the union collects \$44 million in revenue per year.<sup>72</sup>

By way of comparison, the Washington Education Association — the state's largest union — represents nearly 100,000 teachers and public-school employees, negotiates hundreds of collective bargaining agreements with school districts around the state, and provides traditional workplace representation services. Its annual revenue is about the same as SEIU 775's.<sup>73</sup>

The union generates its revenue via an exceptionally high dues rate — 3.2 percent of caregivers' gross wages.<sup>74</sup> The average caregiver pays nearly \$900 per year in dues.<sup>75</sup> State employees, by contrast, are generally employed full-time, amply compensated, and receive a higher level of traditional workplace representation, but pay only 1.5 percent of their gross wages in dues, averaging \$850 per member per year.<sup>76</sup>

What SEIU 775 doesn't spend representing caregivers, it spends on politics. For years, the union has estimated that 40 percent or more of the dues members pay — which are divided among SEIU 775, the SEIU Washington State Council and the SEIU headquarters in Washington, D.C. — goes to support

<sup>70</sup> See generally, Maxford Nelsen. "Getting Organized at Home: Why Allowing States to Siphon Medicaid Funds to Unions Harms Caregivers and Compromises Program Integrity." The Freedom Foundation. July 2018. <https://www.freedomfoundation.com/wp-content/uploads/2018/07/Getting-Organized-at-Home.pdf>

<sup>71</sup> *Harris v. Quinn*, 573 US 616 (2014). [https://www.supremecourt.gov/opinions/13pdf/11-681\\_j426.PDF](https://www.supremecourt.gov/opinions/13pdf/11-681_j426.PDF)

<sup>72</sup> See Statement B, Item 49 of SEIU 775's LM-2 report for 2020. Available online at:

<https://olmsapps.dol.gov/query/orgReport.do?rptId=747518&rptForm=LM2Form>

<sup>73</sup> See Part I, Line 12 of the Washington Education Association's Form 990 tax return filed with the Internal Revenue Service for FY 2019. Available online at: [https://apps.irs.gov/pub/epostcard/cor/910460645\\_201908\\_9900\\_2020120217462374.pdf](https://apps.irs.gov/pub/epostcard/cor/910460645_201908_9900_2020120217462374.pdf)

<sup>74</sup> See Item 21 of SEIU 775's Form LM-2 for 2020. Available online at:

<https://olmsapps.dol.gov/query/orgReport.do?rptId=747518&rptForm=LM2Form>

<sup>75</sup> *Ibid.* Divide Statement B, Line 36 of SEIU 775's Form LM-2 for 2020 ("Dues and Agency Fees") by Schedule 13 ("Total Members/Fee Payers").

<sup>76</sup> Divide Statement B, Line 35 of AFSCME Council 28's Form LM-2 for FY 2021 ("Dues and Agency Fees") by Schedule 13 ("Total Members/Fee Payers"). Available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=782993&rptForm=LM2Form>





activities unrelated to workplace representation.<sup>77</sup> In 2020, SEIU 775 reported spending \$2.8 million on “political activities and lobbying.”<sup>78</sup>

Indeed, HCBS Medicaid funds have made SEIU 775 arguably the preeminent political force in Washington state<sup>79</sup> — surpassing even the teachers’ union, which has twice as many members.

### CONCLUSION

Caregivers who serve Medicaid-eligible adults with functional disabilities work difficult jobs and provide an important service. Further, the demand for in-home care is growing as the population ages. However, even if Congress determines that additional funding for HCBS is warranted in principle and can develop a fiscally responsible method to pay for the added cost without harming the nation’s fragile and slowing economy, there is simply no excuse for sending billions of dollars in Medicaid funds to one of the nation’s largest and most politically aggressive special interest groups.

Congress should not let labor unions hide behind the elderly and persons with disabilities while rigging Medicaid for their own enrichment. To prevent this from happening, any additional HCBS funding made available to states should come without strings attached and leave states free to experiment and develop programs that make sense, instead of using federal funds to incentivize a union-centric model that harms caregivers and Medicaid clients and wastes taxpayer dollars.

<sup>77</sup> See the statement of chargeable and nonchargeable expenses the union prepared in accordance with *Chicago Teachers Union v. Hudson*, 475 U.S. 292 (1986) and includes in its new member solicitation packets. Available online at: <https://www.freedomfoundation.com/wp-content/uploads/2018/07/SEIU-775-membership-solicitation-packetmembership-formHudson-notice-May-2018.pdf>

<sup>78</sup> See Statement B, Item 51 of SEIU 775’s Form LM-2 for 2020. Available online at: <https://olmsapps.dol.gov/query/orgReport.do?rptId=747518&rptForm=LM2Form>

<sup>79</sup> Austin Jenkins. “Unions in Washington state secure wins under Democratic one-party rule in Olympia.” *KUOW*. August 2, 2021. <https://www.kuow.org/stories/unions-in-washington-state-secure-wins-under-democratic-one-party-rule-in-olympia>

Joseph O’Sullivan. “How unions are racking up new wins in Democratic-controlled Washington state.” *The Seattle Times*. August 2, 2021. <https://www.seattletimes.com/seattle-news/politics/how-unions-are-racking-up-new-wins-in-democratic-controlled-washington-state/>



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## Statement for the Record

Hearing: An Economy That Cares: The Importance of Home-Based Services

United States Senate Special Committee on Aging

Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott:

Founded by parents of children with intellectual and developmental disabilities (IDD) in 1946, The Arc Minnesota is a statewide nonprofit advocacy organization that promotes and protects the human rights of people with IDD, supporting them and their families in a lifetime of inclusion and participation in their communities. We believe people with disabilities are inherently strong, powerful, capable, and resilient.

We are writing to express support for the *Better Care Better Jobs Act* because it would support the ability of persons with disabilities to live in their chosen community, select the supports they need and hire the staff that best supports their individual needs.

The *Better Care Better Jobs Act* would build on the benefits to Minnesota from \$2.833 billion American Rescue Plan Act (ARPA) funds <sup>1</sup>that provided many supports to the disability community and others that included<sup>2</sup>:

	Fiscal Year 2021-2023	Fiscal Year 2024-2025
<b>E-12:</b>	\$525 Million	\$675 Million
<b>Higher Education</b>	\$100 Million	\$100 Million
<b>Health Human Services</b>	\$100 Million	\$100 Million
<b>Agriculture/Broadband</b>	\$ 10 Million	\$ 10 Million
<b>Housing</b>	\$ 10 Million	\$ 12 Million
<b>Transportation</b>	\$200 Million	\$ 15 Million
<b>Labor/Workforce</b>	\$125 Million	\$ 17 Million
<b>State Government</b>	\$ 67 Million	\$ 63 Million

E-12 funding from the ARPA and state funds helped address the setbacks in education for students with disabilities caused by remote learning during the pandemic. It freed up funding to pay for a *Recovery Education* bill that The Arc Minnesota helped pass, which provided funding for identified needs and services denied during the pandemic.

Higher Education investments from ARPA and state funds can ensure that young adults with intellectual and developmental disabilities have real opportunities for post-secondary education and the experience that other peers get by going to a campus environment. This is a critical investment in the future

<sup>1</sup> *State Fiscal Recovery Funds*, Minnesota Management & Budget (MMB) <https://mn.gov/mmb/arp/state/>

<sup>2</sup> *Minnesota Global Agreement & Working Group Framework*, 5/17/2021: [House/Senate/Governor Agreement](#)



opportunities for employment and advancement of young people with disabilities. It is also a critical way to address workforce shortage issues, by fostering less reliance on paid, formal supports as people with disabilities move into adulthood.

Health & Human Services ARPA funding and state funds helped supplement disability programs impacted by COVID including paying for Personal Protective Equipment (PPE) for Direct Support Professionals (DSPs), COVID testing and tracking, and COVID vaccines and treatments. Many providers used a tele-health model for delivering services during the pandemic and there necessary investments in technology that needed to be paid for through state and federal funding.

ARPA funding and state funds helped providers of disability services to weather the storm from a loss in revenue when programs could not operate because of COVID and the shortage of staff who became sick with COVID and were unable to work.

ARPA funding was allocated to address the lack of broadband internet access in many communities in rural Minnesota. This lack of broadband access impacts the delivery of health care services, support services, employment opportunities, and the ability to communicate with the broader community. Black, Indigenous and other people of color (BIPOC) communities may also have a lack of broadband access and this can negatively affect providing remote special education services.

ARPA funding and state funds for housing continues to address the lack of affordable housing for low-income people and people with disabilities. The Arc Minnesota has a Housing Stabilization Services (HSS) contract with the Minnesota Department of Human Services that allows persons with disabilities to receive one-to-one assistance in finding affordable accessible housing. We need much more affordable accessible housing to provide for people with disabilities to leave institutional settings and live in the most appropriate integrated setting of their choice. Individualized community based housing also helps to address the workforce shortage issues, as those models foster community interdependence and less reliance on paid staff.

ARPA funding and state funds helped strained public transportation systems in Minnesota survive the loss of users when public transportation shut down or few chose to use it because of the COVID risk. Minnesota public transportation agencies also lost drivers who got sick with COVID or chose to resign to pursue other occupations. Slowly there is a return to people using public transportation, but agencies still have operating budget deficits and need support to continue these vital services.

ARPA funding and state funds for employment programs was critical to continue programs that people with disabilities needed in order to maintain employment or return to the workforce after being laid off. The unemployment rate of persons with disabilities remains high and individualized supports are necessary for many people to find employment and stay employed. Again, this also supports workforce shortage issues, by allowing people to contribute to their own cost of care via earned income.



ARPA funding and state funds for State Government helped the Council on Disability coordinate a disability response to the COVID-19 crisis and ensure that people's rights were respected. There was specialized outreach to ensure that the disability community participated in opportunities to be vaccinated.

In addition to the Global Agreement, the Governor and Legislature agreed to use \$75 million in the *COVID Flexible Fund* for Summer Learning. This helped address disparities in educational opportunities for students with disabilities caused by the pandemic.<sup>3</sup>

*The Better Care Better Jobs Act* would ensure that all of these wonderful "down payments" on our human infrastructure needs that began under ARPA would continue over the next decade. These supports are needed and long overdue for the disability community and the American people.

There is a documented Direct Support Professional (DSP) workforce shortage in Minnesota and other states.<sup>4</sup> This staffing crisis affects licensed providers and people who choose to use self-directed options under Medicaid disability waiver programs in Minnesota. Solving this problem will require many different approaches that provide maximum choice for people with disabilities to choose the type of supports that work best for them especially self-directed options. The Arc Minnesota has published a list of recommendations for addressing the DSP workforce shortage.<sup>5</sup> There has been research of options for addressing the DSP workforce crisis by the Minnesota Olmstead Subcabinet that potentially could be funded using the Better Care Better Jobs Act.<sup>6</sup>

In conclusion, The Arc Minnesota fully supports *The Better Care Better Jobs Act* because the disability community and the American people need these investments in our human infrastructure. The time for action is now, and we support actions the committee can take to enact this legislation!

Sincerely,

Andrea Zuber  
Chief Executive Officer

<sup>3</sup> *Recovery Education Bill*, The Arc Minnesota, August 20, 2021: <https://arcminnesota.org/back-to-school-recovery-education/>

<sup>4</sup> *The Direct Care Workforce Shortage*, Minnesota Department of Human Services: <https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/workforce/>

<sup>5</sup> *Position Statement – Direct Support Professional Workforce Shortage in Minnesota*: <https://arcminnesota.org/resource/position-statement-direct-support-professional-workforce-shortage-in-minnesota/>

<sup>6</sup> *Recommendations to Expand, Diversify, and Improve Minnesota's Direct Care and Support Workforce (2018)*; Minnesota Olmstead Subcabinet Cross-Agency Direct Care and Support Workforce Shortage Working Group: [https://www.house.leg.state.mn.us/comm/docs/8RX\\_eZVFs0qOLynIOZCDTw.pdf](https://www.house.leg.state.mn.us/comm/docs/8RX_eZVFs0qOLynIOZCDTw.pdf)



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***Achieve with us.***

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President

Leo V. Sarkissian  
Executive Director

March 23, 2022

United States Senate Special Committee on Aging  
G41 Dirksen Senate Office Building  
Washington, D.C. 20510-6050

Statement for the Record  
Hearing: An Economy That Cares: The Importance of Home-Based Services

Dear Chairman Casey and Ranking Member Scott:

On behalf of The Arc of Massachusetts, I am writing to thank you for holding this critical hearing on the importance of home and community-based services (HCBS). The mission of our organization is to enhance the lives of people with intellectual and/or developmental disabilities (IDD), including autism, and their families. We fulfill this through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society. The Arc of Massachusetts represents the interests of more than 200,000 children and adults with IDD and autism. Our outreach to individuals is largely served through 17 chapters throughout the state. We provide information, education and consultation to community agencies, legislators, and municipalities. We are a chapter of The Arc of the United States, the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

We urge Congress to pass the Better Care Better Jobs Act (BCBJ Act). As Massachusetts and the country continue to recover from the pandemic, the bold investment in Medicaid Home and Community-Based Services (HCBS) outlined in the BCBJ Act is critical to our state to support people with disabilities, aging adults and both paid and unpaid direct support workers and caregivers. The bill will bring vital funding to strengthen and expand the Medicaid HCBS infrastructure and workforce. During the pandemic, the entire Massachusetts Medicaid program (MassHealth), Department of Developmental Services (DDS), and the Massachusetts Rehabilitation Commission (MRC) which cover most of the long term supports and services (LTSS) available for people with IDD and autism, were under unprecedented strain. This is especially true for our HCBS system as even more aging adults and people with disabilities needed support at home to avoid nursing facilities and other institutions, where the risk of death was exceedingly high.

The American Rescue Plan Act (ARPA), passed by the federal government in March 2021, provides crucial federal aid to Massachusetts to respond to the public health and economic impacts created by the COVID-19 pandemic. But it is *temporary* relief. Massachusetts state and local officials have until 2024 to allocate the funds and until 2026 to spend it. The ARPA funding affects all the DDS community programs and MassHealth Office of Long-Term Supports and Services, including HCBS as well as behavioral health programs. These programs like DDS Day and Employment and Family Support Services and MassHealth Day Habilitation, Personal Care Attendant (PCA) and Adult Foster Care (AFC) programs were given an additional 10% staff rate increase, and some programs received even higher rate enhancements for periods of time. The 10% increase and other short-term increases have been significant for these programs receiving it to stay afloat. However, the temporary funding is

simply not enough due to the direct support workforce shortage, transportation staff shortage and the continued strain of COVID on our communities. The inability to recruit, hire and retain staff long-term continues to negatively impact the support and services for families and individuals with IDD and autism, especially those individuals turning-22 and others who have behavioral health or medically complex conditions. There are 5-7,000 individuals with intellectual and developmental disabilities on waitlists to receive DDS and MassHealth day program services, placing a strain on families and the residential support system. The workforce crisis means that the responsibility of care, support, and transportation still falls on unpaid family caregivers.

The BCBJ Act is a necessary, long-term investment to expand access to services for people with disabilities and address the direct support workforce crisis, including raising wages and creating more jobs, as well as other vital provisions that would improve the quality of life for people with disabilities and their families. The BCBJ Act would make sure the ARPA funding continues and ensures there is no lapse in funding. This bill would create sustainability in the service system so states can plan to address the systemic problems by raising wages to make direct support professionals (DSP) jobs better and ensure less turnover - rather than just giving short-term bonuses.

In Massachusetts, our Medicaid (or MassHealth) HCBS waivers allow individuals with disabilities and elderly persons to get needed support and services at home rather than in an institution. We have approximately 160,000 people in Massachusetts who may qualify for HCBS waivers. Unfortunately, these HCBS waivers do not always adequately serve everyone in need and unless our state properly funds and supports the direct support professional (DSP) workforce, these HCBS programs will not thrive. For example, some families choose residential placement for their young adult children because they lack sufficient in-home supports and cannot wait for those supports to arrive.

As the population ages, the need for HCBS will increase for both people with disabilities and their family caregivers. Each year, about 1,300 individuals with IDD turn 22, aging out of the school system and into adult services in Massachusetts. The work that the direct support workforce does is invaluable to the IDD community, serving as the linchpin to successfully live the independent life that they choose in their communities. This workforce includes home care workers, PCAs, and DSPs, who provide these vital services yet have been devalued and underpaid for decades. They require skills and professional training, and presently their compensation does not reflect their responsibilities and importance. The low wages make it difficult to provide continuity in services, provide a family sustaining wage, and threatening the quality of care for people with disabilities.

Further, the disproportionate burden of the gaps in our HCBS system also fall on women and people of color with limited income and wealth who have the responsibility of providing care—both unpaid and underpaid. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented. Investment in HCBS would help address inequities and strengthen our economy by providing for good jobs for direct care workers and allowing family caregivers to rejoin the workforce.

This is a critical opportunity to build the HCBS system to support all people who need home and community-based supports and services. We urge our lawmakers and leadership to support the Better Care Better Jobs Act's investment in the Medicaid HCBS infrastructure and the workforce that provides these essential services.

Thank you for your past support and commitment to people with IDD, including autism, and their families in Massachusetts.

If you have any questions, please contact Ellen Taverna, The Arc of Massachusetts Director of Public Policy at [taverna@arcmass.org](mailto:taverna@arcmass.org).

Sincerely,

*Ellen Taverna*

Ellen Taverna  
Director of Public Policy  
The Arc of Massachusetts





*Achieve with us.®*

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March 22, 2022

**Statement for the Record**

Hearing: An Economy That Cares: The Importance of Home-Based Services  
United States Senate Special Committee on Aging  
Wednesday, March 23, 2022

Dear Chairman Casey and Ranking Member Scott:

Thank you for holding this hearing to discuss the need and importance of home and community-based services (HCBS). It is without a doubt one of the most pressing topics among your colleagues and constituents.

The Arc New York is a family-led organization that advocates and provides supports and services for New Yorkers with disabilities in our mission to "provide people with intellectual, developmental, and other disabilities the ordinary and extraordinary opportunities of life." With 36 operating Chapters across New York state, our organization supports more than 60,000 individuals and families and employs more than 30,000 people statewide.

The parents who created our organization were among the earliest advocates for quality services and opportunities for people with intellectual and developmental disabilities (I/DD). In the more than 70 years since our founding, we have witnessed – and at many times driven – massive transformation and progress in our field. Over those seven decades, New York has developed a robust system of exceptional, comprehensive individualized services and programs that aid independence, support families, and emphasize inclusion in communities.

The United States and the State of New York have a legal and ethical obligation to provide and uphold essential services, quality care, and

integration for people with I/DD. The federal government and the states equally share this responsibility for the people we support.

Families all over the country are facing difficult decisions about supporting family members with disabilities or who are aging. HCBS services include day habilitation services, residential, respite care, service coordination, and adaptive technologies. In New York, over 326,000 people with disabilities and aging adults receive HCBS through Medicaid. These numbers have been further exacerbated by the COVID-19 pandemic. Today, the need for these critical services has far surpassed the limits of our current system.<sup>1</sup> HCBS provides opportunities for people with I/DD to receive supports in their own home or community, rather than institutions or other isolated settings.

HCBS is the primary funding mechanism for supporting individuals in the community, and includes a variety of services and supports uniquely tailored and individualized to meet each person's needs and goals. Over 80% of these services are provided by voluntary nonprofits like The Arc New York. New York state receives only the minimum federal match of 50% for HCBS. This is not a sustainable model for waiver services. Having a permanent and dedicated 10 percentage point increase in the Federal Medical Assistance Percentage (FMAP) for delivering HCBS, in addition to funding for improvements and innovation, would be life changing for individuals receiving services.

Expanding HCBS would help address long waiting lists for services and pave the way for desperately needed and well-deserved Direct Support Professional (DSP) compensation increases and career paths. We cannot stress enough the importance of investing in our care infrastructure and your support of the Better Care Better Jobs Act. Not only will these funds go directly into our local economy, but it will vastly improve the quality of life for DSPs and the people they support.

DSPs are essential workers who provide daily care, services and supports to people with intellectual and developmental disabilities from dawn to dusk every single day. These workers – the majority of whom are women and people of color – have been underpaid and undervalued for too long. Caring for people with complex needs is a rewarding yet challenging job, which requires ongoing training, high-level of responsibility, and skill.

However, we are facing a workforce crisis unlike we have ever seen. This escalating crisis will continue to force interruptions in essential services, program closures, and

<sup>1</sup> Eiken. 2017. Medicaid Long-Term Services and Supports Beneficiaries in 2013 (Table 1). Truven Health Analytics. <https://www.medicaid.gov/sites/default/files/2019-12/ltsa-beneficiaries-2013.pdf>.

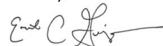
loss of care throughout the New York state and beyond. We find ourselves in a dangerous position of facing safety concerns for our overly-extended workforce and the people they support. Not only is this unsustainable, but it is also untenable that after years of progress and that we would allow the system to crumble.

DSP responsibilities far exceed those of entry-level minimum-wage employees. We need to face reality that they are not receiving equal pay for equal work. The average statewide starting salary for a DSP is currently \$14.47 – 3.45% lower than the \$15 fast-food minimum wage. In some regions of the state, DSPs start at less than \$14. Our recruitment efforts are not competitive, and many of our most skilled and experienced DSPs are leaving for higher-paying, entry-level jobs. Their contributions and dedication are invaluable, and continuity of care is essential in promoting positive outcomes for the people we support. The proposed investments in HCBS and our workforce in this legislation are a result of years of advocacy. There is strong data to support the need. Now is the time to invest in our workforce, our loved ones, and our communities.

The BCBJA is a once-in-a-generation opportunity to create the care economy infrastructure that New Yorkers and the nation need, while providing increased wages, career ladders, and opportunities for DSPs, who are the backbone of the system of supports and services that people with I/DD and their families depend on. We ask that you diligently focus on funding HCBS and consider it a necessity rather than an option.

Once again, we thank you for this opportunity to comment on this important topic, and for your determined support.

Sincerely,



Erik C. Geizer  
Chief Executive Officer

**JOAN KELLEY**

Vice-President, Kansas Neurological Institute (KNI) Parent Guardian Group

March 22, 2022

**TO: SFR@aging.senate.gov** - *sent electronically*

Chairman Bob Casey  
Special Committee on Aging  
United States Senate

Ranking Member Tim Scott  
Special Committee on Aging  
United States Senate

Members  
Special Committee on Aging  
United States Senate

Re: Hearing March 23, 2022 - "An Economy That Cares: The Importance of Home-Based Services"

Dear Chairman Casey, Ranking Member Scott, and Members of the Committee,

Thank you for your public service to represent all Americans, including profoundly affected individuals requiring the 24-7 continuum of care in Medicaid approved Intermediate Care Facilities. (often maligned as "isolating" institutions).

The Special Committee on Aging is scheduled to hear testimony tomorrow, March, 23, 2022, covering the importance of home-based services for persons who require close care.

While unfamiliar with the witnesses listed, I am however, keenly aware of this subject matter, related to my 30 years of firsthand experience caring for a profoundly affected grandson, who functions cognitively at the toddler level. For a number of years Aidan was adversely affected in the fragmented HCBS system - a system which has become increasingly impossible to navigate.

HCBS system providers can and do reject providing services for highest risk individuals as they cannot manage these clients cost-effectively within their system. This often leaves no recourse for profoundly disabled individuals like my grandson, unless ICF placement remains a viable option in states across the nation. I'm sure you would agree

that retro-fitted hospital emergency rooms, jails and psychiatric “boarding” are poor substitutes for proper care of our most fragile citizens.

Majority and concurring opinions in the 1999 landmark Olmstead Decision clarified the need for a range of treatment care options, including licensed, centralized care facilities. Our most vulnerable Americans benefit from the ICF environment, where economies of scale provide the safeguards and essential staff for persons who are unable to speak, advocate or to care for themselves. From Olmstead:

*“Some individuals . . . may need institutional care from time to time 'to stabilize acute psychiatric symptoms' . . . . For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available.” • Olmstead v. L. C., 527 U.S. 581, at 604-605*

Please make clear the committee’s support for the option of Medicaid licensed facility-based care for individuals unable to care for themselves.

I and many others would welcome the opportunity to testify before your committee regarding our firsthand experience providing 24-7 care for profoundly affected I/DD individuals.

Thank you for your time and attention.

Respectfully,

Joan Kelley, Legal Guardian for Aidan, age 31  
Vice-President, KNI Parent Guardian Group  
Secretary, ICF Advocates for Choice <https://my-icf.org>

Gardner, Kansas  
785-218-7195

Cc: Honorable Jerry Moran  
Honorable Roger Marshall