

Hearing on Caring for Aging Americans

HEARING
BEFORE THE
COMMITTEE ON WAYS AND MEANS
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HOUSE COMMITTEE ON WAYS & MEANS
CHAIRMAN RICHARD E. NEAL

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

FOR IMMEDIATE RELEASE
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CONTACT: (202) 225-3625

Chairman Neal Announces a Hearing on Caring for Aging Americans

House Ways and Means Chairman Richard E. Neal announced today that the Committee will hold a hearing entitled “Caring for Aging Americans” on Thursday, November 14, 2019 at 10:00 AM in room 1100 Longworth House Office Building.

In view of the limited time available to hear witnesses, oral testimony at this hearing will be from invited witnesses only. However, any individual or organization not scheduled for an oral appearance may submit a written statement for consideration by the Committee and for inclusion in the printed record of the hearing.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Please Note: Any person(s) and/or organization(s) wishing to submit written comments for the hearing record must follow the appropriate link on the hearing page of the Committee website and complete the informational forms. From the Committee homepage, <http://waysandmeans.house.gov>, select “Hearings.” Select the hearing for which you would like to make a submission, and click on the link entitled, “Click here to provide a submission for the record.” Once you have followed the online instructions, submit all requested information. ATTACH your submission as a Word document, in compliance with the formatting requirements listed below, **by the close of business on Friday, November 29, 2019**. For questions, or if you encounter technical problems, please call (202) 225-3625.

FORMATTING REQUIREMENTS:

The Committee relies on electronic submissions for printing the official hearing record. As always, submissions will be included in the record according to the discretion of the Committee. The Committee will not alter the content of your submission but reserves the right to format it according to guidelines. Any submission provided to the Committee by a witness, any materials submitted for the printed record, and any written comments in response to a request for written comments must conform to the guidelines listed below. Any submission not in compliance with these guidelines will not be printed but will be maintained in the Committee files for review and use by the Committee.

All submissions and supplementary materials must be submitted in a single document via email, provided in Word format, and must not exceed a total of 10 pages. Witnesses and submitters are advised that the Committee relies on electronic submissions for printing the official hearing record.

All submissions must include a list of all clients, persons and/or organizations on whose behalf the witness appears. The name, company, address, telephone, and fax numbers of each witness must be included in the body of the email. Please exclude any personal identifiable information in the attached submission.

Failure to follow the formatting requirements may result in the exclusion of a submission. All submissions for the record are final.

ACCOMMODATIONS:

The Committee seeks to make its facilities and events accessible to persons with disabilities. If you require accommodations, please call (202) 225-3625 or submit a request via email to WMDem.Submission@mail.house.gov in advance of the event (four business days' notice is requested). Questions regarding accommodation needs in general (including availability of Committee materials in alternative formats) may be directed to the Committee as noted above.

Note: All Committee advisories and news releases are available at <http://www.waysandmeans.house.gov/>

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WITNESSES**Kristina Brown**

Caregiver, Medical Student

[Witness Statement](#)**Robert Egge**

Chief Public Policy Officer, Alzheimer's Association

[Witness Statement](#)**Joanne Lynn, MA, MD**

Health & Aging Policy Fellow, Program to Improve Eldercare, Altarum

[Witness Statement](#)**Robert Blancato**

National Coordinator, Elder Justice Coalition

[Witness Statement](#)**Richard J. Mollot**

Executive Director, The Long Term Care Community Coalition

[Witness Statement](#)**Edo Banach**

President & CEO, National Hospice and Palliative Care Organization

[Witness Statement](#)

Hearing on Caring for Aging Americans

U.S. House of Representatives
Committee on Ways and Means,
Washington, D.C

The Committee met, pursuant to notice, at 10:04 a.m., in Room 1100, Longworth House Office Building, Hon. Richard Neal, [Chairman of the Committee] presiding.

*Chairman Neal. The Ways and Means Committee will come to order.

Good morning and welcome. We are here to discuss a difficult issue that confronts nearly every family in our Nation, and that is how to care for our loved one as they age.

It is certainly appropriate that we work to address this matter in November, which is Alzheimer's Awareness Month and U.S. National Family Caregivers Month.

This is a deeply personal issue for many of us in the room, and for those who have not personally struggled to ensure an older relative receives the care they need, you most certainly know someone in your life who has.

Navigating a fragmented and insufficient long-term care system can be not only confusing and emotionally taxing, but also enormously expensive, indeed, even unaffordable. Around the clock in-home care costs about \$180,000 per year. It costs over \$80,000 a year to live in a nursing home, and assisted living costs \$43,000 a year.

These high prices certainly weigh heavily on aging Americans and their families as

they try to plan for future long-term care needs. Most Americans want to age in their homes, but they need help to stay there, relying heavily on family members and friends for day-to-day assistance.

Uncompensated caregivers, like our witness, Kristina Brown, are the unsung heroes in many of these cases. Often their own health, finances, and family relationships become strained as they take on caregiving roles. Exacerbating these challenges is our Nation's failure to guarantee paid family and medical leave compared to other industrialized nations.

So we want to thank Kristina and all of our witnesses for being here today who courageously will tell their personal stories and share their expertise.

At this time I want to do something that is a bit unusual, and that is I want to yield my time to Congresswoman Linda Sanchez, who has recently told me of her family's moving story of caring for loved ones experiencing dementia as they have aged.

Now let me yield to her so she can share her experience with the committee, a reminder this is neither a Democratic nor Republican issue.

Ms. Sanchez.

*Ms. Sanchez. Thank you, Mr. Chairman. I am incredibly grateful for your leadership on this issue, and I am so pleased that you called a full committee hearing so that all committee members have the chance to address this incredibly important area of health care.

And finally, I want to thank all of our witnesses for joining us here today and to give us ideas and their stories on what they confront.

For millions of American families, much like my own, the heartbreak of watching a loved one struggle with Alzheimer's disease or related dementias is a pain that we know all too well, and this devastating disease disproportionately affects certain groups, especially women and the Latino community.

Indeed, Latinos are one and a half times more likely than non-Latinos to develop Alzheimer's disease.

By the year 2030, nearly 40 percent of all Americans living with dementia will be Latino and African American, but it is not a disease that is singular to minority communities. It affects every community.

These statistics should scare all of us. I understand the pain that this disease brings to families because my father Ignacio recently passed from Alzheimer's. We saw him struggle with the disease for more than 15 years, and it was a long, slow, painful decline. It was frustrating to watch a once vibrant man who had sacrificed and done so much for my family slowly lose his independence.

And it was equally hard knowing that there was nothing that I could do to stop the disease's progression. As if that was not cruel enough, two years ago my mother Maria was diagnosed with the same disease.

Alzheimer's is relentless, and it is cruel. And it does not progress at a constant speed. There are good days and there are bad ones, and there are times when the scale and magnitude of the disease seems pretty overwhelming.

But I am one of the fortunate ones. I have a large family. I come from a family of seven brothers and sisters, and we share the financial and caregiving burden for my mother as we did for my father. We are fortunate because we all live within 30 minutes of her home and within 30 minutes of each other, and fortunately for now, my mom is still living in her home.

But not everybody is fortunate to have the large support network that we have. Many people are only children, having to care for aging loved ones. Many are in the sandwich generation, having to raise children and care for aging parents. Many do not live in the same States as their aging parents.

So we rely on caregivers, and the statistics on caregiving in America is astounding. Over 40 million Americans currently deliver unpaid care to an aging relative or friend. The CDC reports that more than 16 million Americans, nearly half of all caregivers, provide more than 17 billion hours of unpaid care for family and friends living with Alzheimer's.

About two-thirds of these caregivers are women. Thus, they are disproportionately impacted, and another quarter care for an aging parent and for children under the age of 18. Hispanics and African American caregivers experience higher burdens from caregiving than their counterparts.

We have to address successful strategies for dealing with our aging population, and we must help caregivers and ease their financial and caregiving burdens.

Our only option for now, because we do not have a cure for Alzheimer's and dementia, is to promote and enact policies that improve the lives of the patients and the caregivers.

I look forward to discussing these topics with our witnesses later in the hearing. I encourage my colleagues to take advantage of the wisdom of our panel of witnesses, and again, I want to thank you, Mr. Chairman, for calling this hearing.

And I yield back.

*Chairman Neal. Thank you, Congresswoman.

And I want to acknowledge that your candor and your openness to bringing topic forward.

And let me now recognize the ranking member, Mr. Brady, for an opening statement.

*Mr. Brady. Thank you, Chairman Neal.

Republicans have a long history of supporting American seniors, working across aisle to make meaningful strides and improve the health and social services they rely on.

With 10,000 Baby Boomers retiring each day, Republicans have been leaders in helping America's aging population. In 2003, under the leadership of President Bush and a Republican Congress, I was proud to help create for the first time an affordable lifesaving prescription drug plan for seniors.

Today 43 million Americans are enrolled in this lifesaving program, which came in 50 percent under budget, and still delivers affordable premiums.

Additionally, serving as chairman of the Health Subcommittee, I was proud to champion a bipartisan IMPACT Act. We know that how Medicare takes care of patients after they leave the hospital is equally as important as the care they receive while hospitalized.

But the status quo often is not working for aging Medicare beneficiaries getting care in post-acute care settings. The IMPACT Act enables Medicare to collect data to achieve three goals: to compare quality among various post-acute care settings; to improve the way hospitals and needs providers plan for patient discharge; and to use this new information to make improvements to how Medicare pays these facilities while ensuring that our patients are receiving the best in correct settings for care.

Over 5 years later, this law is working. CMS is collecting data in the nonpartisan Medicare Payment Advisory Commission is way ahead of the curve, taking steps to determine how Congress can create a transition to a unified post-acute payment system that is focused for seniors on quality and accountability.

Though there is still more to do, this work means America's seniors and Medicare are in a better place today.

Also serving as committee chairman, I was proud to join our Social Security Subcommittee leader, Sam Johnson, and John Larson to pass the Strengthening Protections for Social Security Beneficiaries Act. Social Security, as you know, appoints a

representative payee when a person is unable to manage or direct the management of their Social Security benefits.

Representative payees play an important role in how we care for our aging Americans. However, there were serious concerns about representative payees that Congress, frankly, needed to address.

Together Republicans and Democrats who worked to strengthen oversight of representative payees, also reducing the burden on family members, gave Americans a greater say in selecting their payee if they should need one in the future and ensuring this was the person they could trust.

These were not small actions, but made substantial changes to our entitlement programs to help those receiving Social Security and Medicare benefits.

Republicans remain eager to continue working with their Democrat colleagues to continuing strengthening these important programs for American seniors.

I do admit part of our work in Congress is to stop what we believe are dangerous ideas from being signed into law. We are very concerned that Speaker Pelosi's Fewer Cures for Patients Act would stop new cures and medicines from being developed for our seniors. That partisan legislation, which passed out of this committee, would tell our seniors who are struggling with ALS and Alzheimer's and those who care for them that hope for a cure is at risk.

H.R. 3 is the first step in what we worry is a very extreme health care agenda, including Medicare for All. The effects that this radical health care approach would have on our seniors, I think, is unfathomable.

The private plan seniors enjoy, gone. The private plans of American workers, including caregivers for seniors, eliminated. In their place, long wait lines and not being able to go to the doctor of their choice.

That is a life-threatening change, especially for our seniors, many of whom fought for us, raised us as children and grandchildren so we could, too, work toward living the American Dream.

We owe it to our seniors and those who care for them to continue improving these programs. We owe it to future generations to ensure our safety net can continue to deliver on its promises.

Today we are going to hear from a panel of expert witnesses about serious programs plaguing the Medicare program today especially for the sickest patients. Some of these quality issues are so severe they jeopardize the lives of our seniors.

We have to find a way to work together to strengthen these programs for current and seniors in the future. We need to work diligently together to protect our vulnerable members of seniors today, but we also need to empower future seniors by guaranteeing them choice in the health care and retirement that they want, not the one that Washington thinks will work best for them.

And as I close, I want to recognize one of our staffers, Carla DiBlasio, as she departs for a new adventure in her home State of Ohio. Carla's exemplary work has been critical to advancing real bipartisan solutions to the problems Americans face each and every day.

Her departure is bittersweet. We will miss her and wish her the best of luck.

Thank you, Chairman.

*Chairman Neal. Thank you.

And let me speak for the majority here. We want to take time to acknowledge Carla DiBlasio's really fine work as a member of the staff of the Ways and Means Committee. We know she is going to return to her hometown in Cleveland, but one of the things that we have all been fortunate to have here in the Ways and Means Committee is a terrific

staff.

So Carla has provided dedicated service to this committee, both as counsel to Representative Price when he served as a member, and as professional staff advisor to Ranking Member Brady.

We are grateful for the work that she has done on opiate measure, in particular, and we wish her well and thank her for her service as she embarks on a new journey in life.

[Applause.]

*Chairman Neal. I want to thank Mr. Brady.

And without objection, all members' opening statements will be made part of the record.

So I want to thank our distinguished witnesses for taking the time to appear before us today to discuss these very important issues.

First, we want to welcome Kristina Brown, a caregiver and current medical student.

Robert Egge is the Chief Public Policy Officer of the Alzheimer's Association.

Then we have Joanne Lynn, a Healthy and Aging Policy Fellow for the Program to Improve Eldercare at Altarum.

Next, we have Robert Blancato, who is the National Coordinator for Elder Justice Coalition.

Richard Mollot is the Executive director of Long Term Care Community Coalition.

And finally we have Edo Banach, the President and CEO of the National Hospice and Palliative Care Organization.

Each of you will have your statements made part of the record. I want to ask you to summarize your testimony in 5 minutes or less, and to help you with that time, there is a timing light at your table. When you have 1 minute left, the light will switch from green to yellow and then finally to red when the 5 minutes are up.

Ms. Brown, would you please proceed?

STATEMENT OF KRISTINA BROWN, CAREGIVER, MEDICAL STUDENT

*Ms. Brown. Good morning, Chairman Neal, Ranking Member Brady, and distinguished members of the committee. Thank you for the opportunity to share my thoughts this morning.

My name is Kristina Brown. I am a caregiver and medical student.

When I was 16, my life suddenly shifted. My mother at 43 years old lost the ability to walk due to multiple sclerosis. Soon she could no longer stand, eat, or bathe without assistance.

I became her primary caregiver and for 6 years provided 10 hours of care each day.

Despite what many may think, having a disability does not guarantee access to resources. Because my mother has an income of \$36,000 from her divorce settlement, is younger than 65, and lacks a 10-year employment history, she has been denied Medicare, Social Security disability insurance, and Medicaid, despite its expansion.

Her private insurance company, like most, does not cover home care for daily needs. So I filled in the gap. In high school, I would wake up at 5:30 each day to help with the bed bath and lift my mother into her wheelchair. Despite being a straight A student, I almost did not graduate from high school because I had so many absences from taking care of my mother.

I routinely missed meals and sleep and strove to hide my exhaustion, weight loss, and social isolation from the people around me. I lost my adolescence.

I declined full-ride merit scholarships from out-of-State universities I longed to explore, and during college my sister and I moved back home since we could not afford extra help.

We had few alternatives. Most nursing facilities serve only seniors, and even if we

found one for younger adults like my mother, the cost of that care could exceed \$10,000 a month.

Home care is only slightly more affordable at 6 or \$7,000 per month. Like many families, we could not afford full-time coverage. Like many caregivers, I was made to feel invisible, that my health and my future did not matter.

From afar in medical school, I had taken out loans to pay my mother's mortgage. I worked a weekend job on top of being a full-time medical student. Combined with my sister's meager salary, this barely ensures our mother's survival. We are running out of options.

We could sell our home to qualify for State assistance or I could leave medical school to become a full-time caregiver for my mother.

But even these extreme temporizing measures would only drive us further into a vicious cycle of financial instability. Caregiving fuels generational poverty with an even greater impact on millennials and women who take on that role. When women become caregivers, they become two and a half times more likely to live in poverty.

This past September, our situation took another turn. My sister who had been caring for my mother while I have been away in medical school was moving to start a new job. I canceled my board exams and dropped everything so I could fly home.

Since we could not afford a home care agency, I recruited and trained caregivers that I found online. I filled out reams of applications and made a flurry of phone calls to my mother's social worker, the Health and Human Services Department, and the Regional Disability Resource Center seeking financial support. So far none has arrived.

Though I returned to campus, this arrangement is tenuous and all-consuming. Already home health aides have quit unexpectedly leaving my mother to forego regular meals and bathing while 1,000 miles away I scramble to find replacements.

From week to week I still do not know whether my mother will receive the care she needs. As this committee meets to discuss caring for aging Americans, I ask that you take steps to ensure that families like mine do not continue to fall through the cracks.

First, we must eliminate age gaps and income gaps so that middle aged, middle income adults with disabilities can qualify for long-term care through Medicaid, especially when their home care expenses far exceed their income.

The Medicaid cutoff should not be based on income alone, but rather on income adjusted by care costs.

Second, the Family and Medical Leave Act should provide paid leave to caregivers, and universities should offer support stipends to help ease the burden on student caregivers like me.

Third, we must aim for universal long-term care to ensure that every adult with disabilities has affordable access to sustainable care.

This will be costly, but doing nothing will only serve a silent punishment to individuals with disabilities and their caregivers. No family or young caregiver should have to sacrifice their health, education, and financial stability just to meet basic human needs.

Numbers cannot capture the cost my family has incurred over the past decade, from sleepless nights to the sting of dreams deferred. Sometimes my mother calls me to apologize for being sick.

Despite the uncertainty of the situation, I focus on carving out a new future for my family and others like ours.

Thank you for listening.

*Chairman Neal. Thank you, Ms. Brown.

Mr. Egge, would you please proceed?

STATEMENT OF ROBERT EGGE, CHIEF PUBLIC POLICY OFFICER,
ALZHEIMER'S ASSOCIATION

*Mr. Egge. Chairman Neal, Ranking Member Brady, and members of the committee, thank you for holding this important hearing today and for the opportunity to testify on how America is caring for its aging population, including those with Alzheimer's and related dementias and their caregivers.

Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other brain functions. Ultimately, Alzheimer's is fatal.

We have yet to celebrate the first survivor of this devastating disease. More than 5 million Americans are currently living with Alzheimer's, and many more are living with other diseases that cause dementia.

Without significant action, as many as 14 million will have Alzheimer's by 2050.

In addition to the suffering caused by the disease, Alzheimer's is also creating an enormous strain on family finances, the health care system, and Federal and State budgets. Alzheimer's is the most expensive condition in America, with costs set to skyrocket at unprecedented rates.

In just this year alone, Medicare and Medicaid will cover the cost of more than two-thirds of the cost of the care of persons with Alzheimer's, an estimated \$195 billion.

Fortunately, new options are now available to individuals and families affected by Alzheimer's. Beginning in 2017, Medicare now reimburses physicians and other health care professionals who are providing comprehensive care planning to individuals with cognitive impairment.

This is a critical step towards improving the quality of care and quality of life for

those with Alzheimer's and their caregivers. Analyses show that dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. It allows diagnosed individuals and their caregivers to access medical and non-medical treatments, clinical trials, and support services available in the community.

However, upon analysis of CMS data, the Alzheimer's Association has determined that fewer than 1 percent of those living with Alzheimer's and other dementias received this much needed care planning in 2017, fewer than 1 percent.

For the benefits of care planning to reach more Americans affected by Alzheimer's, more clinicians must use this care planning benefit. The bipartisan Improving Hope for Alzheimer's Act would help achieve that goal by requiring the Department of Health and Human Services to, first, educate clinicians on the existence and importance of Medicare care planning benefit; and, second, report to Congress on the barriers to individuals receiving this care planning service and how to increase its use.

This bill has garnered significant bipartisan support in both chambers, and we urge the Committee on Ways and Means to hold a markup.

We look forward to working with the bill's sponsors and committee leadership to ensure its movement in the full House and Senate.

Robust care planning is the first step to learning about long-term care options and to selecting the preferred and most appropriate services for persons with dementia, their families, and their caregivers. These individuals need access to a wide variety of services, such as Adult Day, home health, respite, skilled therapy, residential facilities, and nursing home care.

Because those with dementia and their caregivers have unique needs that change over the course of the disease, they typically use long-term care services differently as their

condition progresses.

At each stage of the disease, caring for a person with Alzheimer's and other dementia poses special challenges. For example, family caregivers help individuals managing escalating difficulties with communication and behaviors, as well as increasing needs for supervision and personal care. As symptoms worsen, family caregivers often experience increased emotional stress and depression, health problems, and depleted incomes.

Effective, evidence-based interventions can reduce depression among dementia caregivers, help them cope with their often overwhelming responsibilities, and can help to keep the person living with Alzheimer's in the home longer.

Other needs of persons living with dementia and their caregivers also extend well beyond the health care system. Upon diagnosis, affected persons not only need help managing other chronic conditions, but they often need community-based supports like safety assessments, legal and financial services, transportation, and help managing dementia-related behaviors.

The health care and the long-term service and support systems as they exist today all too often fail those who are living with dementia and their caregivers. We must do all we can to ensure the best quality of care and quality of life for those living with Alzheimer's and for those who are for them.

We look forward to working with the committee to advance bipartisan solutions that will have a meaningful impact on America's seniors, including passage of the Improving Help for Alzheimer's Act.

Again, thank you for the opportunity to testify, and I look forward to answering any questions you may have.

*Chairman Neal. Thank you, Mr. Egge.

Dr. Lynn, would you proceed, please?

STATEMENT OF JOANNE LYNN, M.A., M.D., HEALTH & AGING POLICY
FELLOW PROGRAM TO IMPROVE ELDERCARE, ALTARUM

*Dr. Lynn. Good morning, Chairman Neal, Ranking Member --

*Chairman Neal. Would you turn on your microphone?

*Dr. Lynn. Good morning, again, Chairman Neal, Ranking Member Brady, and other members of the committee.

Thank you for holding this hearing aiming to focus attention on the challenges that face us within just 15 years as we double the number of elderly persons living with progressive disabilities.

I commend the committee for your attention to retirement security and Medicare coverage for hearing, vision, and dental care, and I am especially heartened that you are willing to address the challenges of long-term disability.

Most Americans, including most of us in this room, will live with serious disabilities in old age. For an average of 2 years, we should be able to count on living comfortably and meaningfully in those years with costs and burdens that we all can bear whether as elders, family members, caregivers, or taxpayers.

I have been a physician for 45 years, mostly serving people living with serious chronic conditions and old age. I have worked in research, education, public health, and improvement implementation.

I have come to realize that our beloved United States faces a serious challenge with the oncoming number of elderly persons who arrive at old age with inadequate finances and who eventually will live with serious disabilities.

Without changes within a decade, most people who live their working years in the middle class will be unable to afford housing in retirement. Stop to think about that.

Will we really tolerate millions of elderly people on the streets, living in cars and tents?

Will we still pay for expensive hospitalizations and drugs for people who cannot get lunch?

Will it be okay for me to write a prescription for a \$1,000 drug for an elderly person living in a car without food?

Families will often try hard to help. You have already heard one story of that, which is the very definition of "family." But that means that we will be spreading impoverishment across later generations.

Already many cities have half-year waits for home-delivered food for people who are acknowledged to need home-delivered food.

The wait for disability adapted senior housing in most areas usually ends with nursing home placement or death, not a house.

Perhaps family caregivers and their adult family members living with disabilities will generate a strong voting bloc to push for change. We surely should.

Half of retirees now have less than \$25,000 in savings beyond Social Security before they are ill. For many reasons we will not be able to support one another in old age using contemporaneous taxes alone. There will be just too many frail and impoverished elders.

We need to engineer strategies that would get more of the costs covered by savings.

One appealing proposal would be to have government at some level pick up the cost of the long tail of long-term care and leave the front end to the elders, their families, and local arrangements.

The waiting time before the government picks up the cost would depend upon the elder's earnings. So well off people might have to cover 5 years, while low wage earners

might only have to cover one.

This makes it cost much less than 1 percent added to the Medicare tax, and it would open the market for a variety of savings arrangements, including tailored insurance products. If we could get a substantial proportion of elderly people paying their own way through the period of disability at the end of life, we would be in a much better position to provide supports for all of us.

There are probably other ways to get this done, but we need to be developing and testing them now. There is a long lead time to have effective savings plans for old age.

We also need attention to both family and paid caregiving and to housing, workforce, transportation, and food. We need to rediscover neighborliness. We need bold innovation. We need to learn our way into a set of social arrangements that will serve all of us well.

We can do this. This is a brewing calamity that could be averted. We all have a stake in it. Everyone here will be touched either directly or through family and friends.

Will we be a Nation that learns to ignore elders dying without homes and food or will we learn to arrange things so that most of us have lives that are as comfortable and meaningful as possible despite disabilities and the shadow of death?

You have a large voice in the course we take, and I hope you will take up the leadership on these issues. If you do not and the Nation continues to slide into abandoning us in our last phase of life, we will get what we deserve: misery.

We can do better, and you can help.

*Chairman Neal. Thank you.

Mr. Blancato.

STATEMENT OF ROBERT BLANCATO, NATIONAL COORDINATOR, ELDER
JUSTICE COALITION

*Mr. Blancato. Chairman Neal, Ranking Member Brady, distinguished members of the committee, as the National Coordinator of the nonpartisan Elder Justice Coalition, I am proud to participate today.

Chairman Neal, thank you also for your strong advocacy for nursing home and hospice residents.

Caring for aging Americans is a challenge whether they live in facilities or independently. Achieving quality care is the goal. Affording it is often the main obstacle.

The Genworth's "Cost of Care" report says that the median national cost of a nursing home is about \$90,000 a year, home health about \$50,000 a year, and assisted living about \$48,000 a year.

Savings are being tapped. A Gallup and West Health poll showed that seniors withdrew an estimated \$22 billion from long-term savings just in the last 12 months to pay for health expenses.

And Health Affairs says that more than half of middle-income seniors over 75 will not be able to afford medical expenses or assisted living in 10 years.

How to make care affordable? First, we must preserve Medicare. Do not block grant or put caps on care. Continue to have it cover more home and community-based care and raise reimbursement rates for nursing home staff.

Let us consider a long-term care benefit under Medicare. The tax code could help more with a tax credit for family caregivers or a deduction for purchase of long-term care insurance that provides choices and has strong consumer protection.

Let's look at emerging State models like the Washington Long-term Care Trust Act,

which provides lifetime benefits for long-term care financed in part by premiums paid.

Cost is one issue. Quality of care is also important, especially in nursing homes. Less than 5 percent of older adults live in these homes.

But the GAO says that while abuse deficiencies make up less than 1 percent of the total, they noted a doubling in cited abuse deficiencies from 2013 to 2017.

There was Senate testimony from a daughter whose mother died from dehydration in a nursing home that was given a five-star rating by CMS.

And this recent headline: "Police charge three nursing home workers with running a fight club of patients with dementia."

Please note there are many fine nursing homes in this country. I know because my mother lived in one, but where problems exist we must act.

Recently there has been a pattern of abdication of responsibility by certain Federal agencies in protecting nursing home and hospice residents.

We need to revisit conditions of participation for any nursing home or hospice receiving Medicaid or Medicare funds. Problems like failure to report abuse and neglect, failure to remedy why it happens, failure to recruit and retain qualified staff, there must be consequences tied to conditions of participation.

On the hospice front, I commend the introduction of the bipartisan Hospice Care Improvement Act. We must do more.

State serving agencies must also report cases of abuse. Laws mandating prompt reporting of crimes in nursing homes must be enforced.

We need better coordination between all levels of government on emergency response plans for nursing homes.

And for the 95 percent of older adults who live in the community, we must reauthorize the Elder Justice Act.

Moving to rural older adults, more than 25 percent of older Americans living in rural America, their challenges are real: transportation, high housing cost, opioid crisis, and the lack of economic development.

But the real crisis is in health care. Rural elders have higher rates of chronic disease and disability and lower prevalence of healthy behaviors and rising rates of suicide.

Access to health care is a genuine issue. In addition to a pronounced shortage of primary health care personnel, we have a doubling in rural hospital closing from 2013 to 2017 compared to 5 years ago.

For a solution, let's continue to expand Telehealth while closing the digital divide.

Dedicated funds for the opioid crisis must go to rural.

Before a rural hospital closes, declare a public health emergency and maybe avert it, and expand the PACE Provider Grant Program.

Also today more than 1.1 million older adults are LGBTQ. Many have endured years of discrimination in employment and housing and endured it in silence.

Now as they age, they encounter discrimination in long-term care facilities, which led to the long-term care equality index to promote equitable and inclusive care for LGBTQ older adults and facilities, including having trained staff. More facilities should adopt this.

We also need to designate LGBTQ as an underserved population to get accurate data on elder abuse.

Moving to food insecurity, whether people can obtain enough food to lead a healthy life, feeding America's 5.5 million older adults who were food insecure in 2007, doubling the rate from 2001, factors that contribute to food being low income, living in a food desert, and inadequate transportation.

Food insecurity poses a threat to health. One serious consequence is malnutrition,

which one in two older adults is at risk.

Congress can help this year. Maintain the House-passed funding levels for fiscal year 2020 for key nutrition programs.

Get the Senate to pass the House Older Americans Act reauthorization, which has first-time malnutrition screening.

Expand outreach for more older adults to get SNAP.

Do a national inventory on food deserts, and then a strategy to reduce them.

And have CMS at long last approve malnutrition quality measures and acute care.

In less than 10 years, those 65 and older will go to 20 percent of our population, up from 13 percent. We enjoy a greater quantity of life.

Our present and future public policies now need to focus on improving the quality of life.

Thank you, Mr. Chairman.

*Chairman Neal. Thank you.

Mr. Mollot, would you proceed?

STATEMENT OF RICHARD J. MOLLOT, EXECUTIVE DIRECTOR, THE LONG
TERM CARE COMMUNITY COALITION

*Mr. Mollot. Chairman Neal, Ranking Member Brady, and distinguished members of the committee, thank you for holding this important hearing and inviting me to testify.

My name is Richard Mollot. I am the Executive Director of the Long Term Care Community Coalition, a nonprofit, nonpartisan organization dedicated to improving care and dignity for residents in nursing homes and assisted living.

We conduct substantive research on long-term care policies and the extent to which basic standards of care are realized in the lives of residents who are typically elderly and frail.

Half of all people who reach their late 50s will spend some time in a nursing home making nursing home quality and safety a matter of concern to virtually every family in the United States.

Additionally, as this is Alzheimer's Awareness Month, it is important to note that more than 50 percent of residents in assisted living and nursing homes have some form of dementia or cognitive impairment, and two-thirds of dementia-related deaths occur in nursing homes.

Nursing home and assisted living safety is of the utmost importance to those living with this disease and to their families.

Thanks to the 1987 Nursing Home Reform Act, every family who turns to a nursing home for care, whether short-term rehab or long-term care, is promised that they will be safe, receive needed care and services, and be treated with dignity.

Unfortunately, far too often in communities in every State in our country, those promises are broken.

Though the reform law and existing standards are strong, the persistent failure to ensure basic compliance with these standards by both the States and the Centers for Medicare and Medicaid Services, CMS, has resulted in a situation where a sophisticated, profit-driven industry essentially operates as its owners see fit.

In the absence of effective enforcement, there is little to stop nursing home companies from maximizing profits at the expense of resident care.

Some nursing homes honor their promises to residents and families, but far too many do not.

Most, though not all, nursing homes have insufficient staffing to meet residents' basic clinical and hygiene needs.

Over 40 percent of U.S. nursing homes have what we call chronic deficiencies: repeated violations of the same regulatory requirement year after year after year.

Abuse, neglect, even crimes against residents are persistent and pervasive. Approximately 20 percent of residents are administered antipsychotic drugs every day, despite the FDA's black box warning not to use these drugs on elderly people due to substantial risk of harm and even death.

Basic infection control and prevention are inexplicably ongoing challenges. According to the CDC, quote, "one to three million serious infections occur every year in these facilities. Infections are a major cause of hospitalization and death. As many as 380,000 people die of the infections in long-term care facilities every year," unquote.

These are not abstract problems. Avoidable pain, degrading conditions, and substandard care are a part of hundreds of thousands of nursing home residents' lives every day.

This now includes Holocaust survivors, veterans who have fought for our country, our mothers, and our fathers.

We frequently hear about seniors with dementia who are drugged into oblivion rather than provided essential care services or even rudimentary activities to meet their needs.

Basic palliative care, freedom from pain, and hospice care, the chance to die in comfort with dignity are increasingly out of reach for too many of our seniors because they are facilities for profits first.

It does not have to be this way. Enforcement of minimum standards is needed. We must address the disconnect between the promise of the nursing home reform law and the reality for families. Neither the State agencies nor CMS are fulfilling their mission to protect residents and the integrity of the Medicare and Medicaid program.

We must hold the line against current efforts to undermine regulatory minimum standards and reduce the already low frequency of nursing home inspections. Residents' lives and families' peace of mind depend on it.

We must codify safe staffing standards. The widespread failure to provide sufficient care staff universally recognized for decades is a national disgrace.

We must establish a medical loss ratio for nursing homes. American families and taxpayers have a right to know that a reasonable percent of the public funds that nursing homes receive to provide care to vulnerable seniors is actually going towards that care and not be siphoned off into uncapped profits, unrestricted administrative expenses, or, as frequently happens, unlimited and unaudited related party transactions.

And, lastly, alternative options to nursing homes must be safe, accessible, and affordable. Seniors and families want and deserve options to nursing homes that provide safety in a more home-like setting.

While most States now are rightfully opening up assisted living to Medicaid beneficiaries, the utter lack of Federal standards in this sector has unsurprisingly led to

increasing reports of abuse and neglect. Our seniors and their families deserve better.

Thank you again for your time and for holding this important hearing.

*Chairman Neal. Thank you.

Mr. Banach, would you proceed please?

STATEMENT OF EDO BANACH, PRESIDENT AND CEO, NATIONAL HOSPICE
AND PALLIATIVE CARE ORGANIZATION

*Mr. Banach. Chairman Neal, Ranking Member Brady, and members of the committee, thank you so much for the opportunity to testify at this important hearing focusing on caring for aging Americans.

I also want to single out Congressman Reed, a hospice volunteer, and Representatives Panetta, Kind, Walorski, and Buchanan and others for their strong leadership of hospice and palliative care.

My name is Edo Banach. I am President and CEO of the National Hospice and Palliative Care Organization, founded in 1978, and HPCO is the Nation's largest membership organizations for providers and professionals, for people who are affected by serious and life limiting illness.

And HPCO's members include over 2,000 hospice providers and palliative care providers and account for nearly two-thirds of those who get hospice care in this country; employ over 60,000 professionals and hundreds of thousands of volunteers.

Hospice is a national treasure. It is not, has never been, and should not be a partisan issue. We all get sick at some point in our lives, and we all die.

From the beginning, the hospice benefit has been bipartisan. In fact, former Senator Dole and former Congressman Leon Panetta, father of Mr. Panetta on this committee, Jimmy Panetta, were two of the bipartisan bicameral leaders of the fledgling hospice movement on Capitol Hill almost 40 years ago.

In 1982, this very committee held a hearing on the legislation that would create the Medicare hospice benefit. It was introduced and supported by over 200 folks, including Representative Bill Gradison.

Without their early leadership in advancing hospice, the benefit would not be here today, and without your leadership, the benefit is not going to be where it needs to be tomorrow.

For many people, hospice provides the right level of Care at the right time for patients at the end of life. At its best, hospice is everything we want the health care system to be. It is interdisciplinary. It is person-centered. It is compassionate.

Most people assume that hospice is a place. In fact, it is not a place. It is a type of service usually delivered to people in their home.

Hospice also cares for people as people. We meet people where they are. One of the things we are very proud of is the We Honor Veterans Program. You will see the pin here. I urge all of you to support We Honor Veterans and attend a pinning ceremony for folks in your district.

We offer much more than just hospice care for people. We also support whole communities through disaster relief and assistance in the wake of 9/11, shootings in Las Vegas and Orlando, national disasters like Hurricane Katrina and Maria, floods and wildfires.

We care for families. We care for communities, and we do much more than providing care for individuals.

There are challenges in hospice. Half of people never get hospice. Of those who get hospice, most get it for only a few days or a few weeks.

We have challenges in the workforce. Ten thousand people are turning 65 every day.

We have challenges in rural and underserved communities. Accessing hospice can be incredibly difficult. I visited a hospice in Miles City, Montana, this past summer that serves 11 counties.

We are so thankful for Representatives Kind and Walorski for their support of the Rural Hospice Act, which also provides support for federally-qualified health centers.

Above all else, we have to ensure that patients and families that get hospice care get the best possible quality of hospice care possible.

We take seriously the set of OIG reports that outlined issues with CMS oversight of hospice and described poor examples of care. We are excited about working with Senators Portman and Cardin on the Hospice Care Improvement Act and look forward to working with Representatives Panetta and Reed on the House version.

I want to be very clear. Any provider that is not fully committed to providing the best quality care should be in another line of business.

Speaking of gaps, I want to spend the rest of my time echoing words that Congresswoman Sanchez talked about, and this is very personal for me. I have two great aunts. One is Great Aunt Ruby, who lives in Richmond. One was Great Aunt Grace. They are an example of the failure of our health care system.

Great Aunt Grace was 95. She fell down her stairs. She went in and out of the hospital, ended up dying on hospice care for a few days. She is an example of a health care system that requires you to be broken in order to fix you.

Great Aunt Ruby is still at home. She has COPD. She is dying, but she will not accept hospice care, which is my failure as well as the failure of this health care system. So as a result 911 is her default health care system.

We can do better to get people more interdisciplinary, person-centered care before they decline. What if we provided person-centered, interdisciplinary care for people before they fall down stairs or cried out for help? And what if we did it without people having to give up?

We offer a vision for some changes that we can see in our health care system and in

hospice itself, and we look forward to discussing that with you during the questions and answers.

Thank you for your time.

*Chairman Neal. Thank you.

We will now proceed to questioning under the 5-minute rule, and consistent with committee practice, I will recognize those members present at the time that the gavel came down and in order of seniority.

Let me begin by recognizing myself.

Dr. Lynn, Dr. Blancato, you both have highlighted that we as Americans are wholly unprepared for aging on a myriad of fronts, financial, long-term care needs and beneficiary protections, amongst others.

Dr. Lynn, you know I have been a long-time champion of financial security in retirement. You testified that half of all Americans from 65 to 74 have no retirement savings at all, and that caregivers lose hundreds of thousands of dollars from retirement by caregiving.

What suggestions would you have for those of us on the committee to address that issue?

Would you please all speak into the microphones?

*Dr. Lynn. There is clearly going to need to be governmental action. That could be a Federal backstop on the cost of long-term care.

If we had a Federal backstop on the cost of long-term care, that means that the front end, the first part of long-term care would be up to others, but the Federal Government or even a State government would pick up the long tail. Then I think that there would be possible for there to be savings plans and insurance schemes that would allow people to come into old age with much more preparation.

I dropped my own long-term care insurance this year when the premium doubled. I think that in the present market, it is not a viable product, but it could be.

I am sure there are other ways. Washington State has started a front-end insurance

scheme where if a worker pays in for 10 years, they are guaranteed up to \$36,500 in front end coverage.

Minnesota is considering adding the same sort of thing to Medicaap and MA plans.

I think there probably are a number of ways to get more financing into the long-term care system beyond Medicaid. I am very worried about Medicaid being the main way to pay for long-term care.

It is very difficult to administer it at the boundary. We have many, many more people in the income gap just above Medicaid who cannot afford to pay for what they need, but who cannot get into Medicaid because they have too much income. We had an example of that earlier.

That number will grow, and the State budgets that have to be balanced will probably have to restrict eligibility for Medicaid over time or at least not grow it at the rate that the population needs.

So we really need a vigorous comprehensive approach. I think the government is going to have to be involved, but I think we also are going to have to develop strategies that end up making it possible for ordinary people to go into retirement with adequate retirement savings and with security against the cost of long-term care.

*Chairman Neal. Thank you.

And, Mr. Blancato, there are a number of organizations in Massachusetts that are attempting to address food security, such as the Boston medical Center. Your testimony has discussed malnutrition in older adults, and in this day and age, sad to acknowledge that there are older Americans who do not have food on their tables.

What do you think we could be doing in terms of health care and Medicare to ensure that our seniors have enough to eat?

*Mr. Blancato. Mr. Chairman, you are right. Massachusetts is a leader. They have

a great network of nutrition service providers across the State. Massachusetts is one of only two States that create by law a Malnutrition Commission, which issued a report in 2018, and their work is continuing, and I hope I can add a summary to my statement in the record.

In addition, the Boston Medical, I am proud to serve on the National Advisory Board of the Human Nutrition Resource Center at Tufts University, which has done also important research work and practice work in food security.

But going to the issue of what can we do more, let's begin by monitoring closely Medicare Advantage as it starts to move into the more non-medical supplemental services that are especially for the chronically ill.

Nutrition is a key Medicare Advantage program that can cover expanded home delivered meals as well as meals in a congregate setting and programs providing food and produce. The key will be what will they do in plan year 2021.

It is very important for local connections to be made between nutrition service providers and these Medicare Advantage plans because if it is done correctly, it could be a new funding stream for more meals and more food.

And also, we should be thinking about extending this to fee-for-service Medicare if the Medicare Advantage experiment works well.

I also think we should think about expanding medical nutrition therapy as a nutrition care service, and as we talked about earlier, let's move forward on a dental benefit for Medicare. Poor oral health really contributes to malnutrition, and this would continue if you do this to the positive Medicare trend of covering more preventative services than ever before.

And then I would also say let's determine through data collection how much programs like the Older Americans Act nutrition programs and home delivered meal

programs save Medicare and Medicaid each year and plow back some of those savings into those community-based programs which are providing meals on a regular basis.

I have additional thoughts. I will submit them for the record, Mr. Chairman.

*Chairman Neal. Please do.

And, Mr. Mollot, you have raised concerns about the quality of care that some patients are facing, and while most nursing homes are providing good care, you have described disturbing instances of substandard care for many patients and their families.

I have been working with HHS to address the issue of overprescribing antipsychotics to nursing home residents.

And what suggestions would you have along those lines for Congress as we begin to talk about a long-term care initiative?

*Mr. Mollot. Well, thank you for asking that.

The overuse and inappropriate use of antipsychotic drugs on residents and nursing homes and in assisted living and in other settings is really disgraceful, frankly, and it harms hundreds of thousands of people every day.

I would say, first of all, a lot of families that we talk to, they do not even know that their loved one is receiving these drugs or they are explicitly told by caregivers not to look up the drug online.

It is really important that we have informed consent, and as part of that, what Congress could do is to pass an informed consent bill that included written informed consent and that provided for the resident and the family to periodically review and, again, give informed consent as necessary if those drugs are to continue because really there are very, very, very limited circumstances under which someone should be receiving an antipsychotic drug for any extended period of time unless they have a condition of schizophrenia or another specific illness.

Secondly, we really need to require minimum staffing. As I mentioned in my testimony earlier, the lack of staffing in the majority of nursing homes results in people not getting the care that they need and it results in too many residents being given these drugs as a sedative to make them easier to care for essentially for simply the convenience of staff who are not there.

So we really need to have to make sure that there are at least enough staff to meet the clinical needs of residents.

We desperately need a new OIG study related to movement, and I think the recognition nationally on the astounding overuse of antipsychotic drugs in this country begun in 2011 as a result of a couple of reports by the OIG at the time, who said that Americans, families, residents should be outraged and seek solutions. That was 8 years ago.

And then lastly, I would say enforcement. I track enforcement very carefully around the country as well as the drugging rates, and CMS, when it launched its so-called Partnership to Improve Dementia Care and Reduce Drugging, promised, promised that there was going to be enforcement of longstanding requirements in regard to not giving unnecessary drugs, and that enforcement has never happened.

Thank you.

*Chairman Neal. I thank the gentleman.

Let me recognize the ranking member, Mr. Brady, to inquire.

*Mr. Brady. Chairman Neal, thank you for calling this important hearing.

This is an area I think we can, Republicans and Democrats, can work together on.

Mr. Banach, in your testimony you talked about hospice care and how reforms have developed in a bipartisan way, much like the hospice benefit was originally created, would bring hospice into the 21st century to address the growing needs.

Chairman Neal and I, in the wake of two disturbing reports detailing deficiencies in the quality care delivered to some Medicare hospice folks, we joined together to send a letter to Senators, to CMS requesting information regarding the agency's efforts to address certain hospice failings.

We also agree with you that drug pricing has to come down in all of these areas. We have got to find a way to lower drug prices for patients and encourage more lifesaving cures as we do it.

You know, we had been working together as a committee on lowering those prices and accelerating those cures. That work has been set aside for H.R. 3, the Speaker's drug bill, which we are, as Republicans, very concerned that it will actually preclude cures, especially for the most stubborn diseases we have.

And I, like many of you, have a neighbor who died of glioblastoma, another dear friend who is struggling with it, two friends who died of ALS, and a neighbor, once vibrant, struggling with Parkinson's.

We are all hoping and praying and working for cures in these areas, and our genuine worry is that H.R. 3, which is not going to go much past the House, you know, would damage those cures and the hope for them.

So I was in the Alzheimer's Walk the other day. I try to go there every year in Montgomery County. It is really inspiring, 2,000 walkers. They raise a ton of money. In Texas we have 300,000 people dealing with dementia and over a million caregivers.

So it is really, really just a great morning all around, and, Mr. Egge, and I so appreciate being part of that, and I always talk about how effective you are in both advocacy, research, support services. All that the association does is just terrific.

My question is: given the current political landscape, which is a little rough around here, do you think us finding a bipartisan solution to drug pricing, long-term care, finding

that balance between lower prices and encouraging more cures, how important do you think that is for the Alzheimer's community?

*Mr. Egge. Thank you for that question.

I think everybody agrees that you can make this point for many diseases, but certainly you can from Alzheimer's. As I mentioned we are longing to recognize our first survivor of this disease and have effective treatments; that we certainly need to have that innovation.

I think it is absolutely important that we make sure that when those treatments are available, that the millions who need them have access to those treatments.

So it is fundamentally important that Congress continues to focus on this set of issues and they necessarily interrelate to find the solution that we need in the Alzheimer's community and in so many others.

*Mr. Brady. Thank you, Mr. Egge.

Mr. Banach, you talked about hospice care. So my mom, you would have enjoyed her. She raised five of us by herself after my dad was killed when we were young, really remarkable.

But she, like your aunt, struggled with COPD. So even though living with my sister, the last couple of years was pretty tough, and the last few weeks were especially so.

Hospice was great, you know, was a great comfort for her, was a huge help to us as a family. We got great care there, which is why it is always regrettable to learn that many hospices had a deficiency in 2016, that 20 percent of hospices, according to the OIG, had serious deficiencies.

And CMS does not always have the tools in its toolbox to enforce quality of care, other than simply shutting them down, which we do not want to do for seniors.

Would it be helpful for Congress to provide CMS with additional statutory

authority to provide remedies for that poor performance short of shutting them down to ensure that seniors get that high-quality care that you are seeking for them to have?

And if so, are there any intermediate remedies that would be helpful to increase that quality, eliminate those deficiencies?

*Mr. Banach. Thank you so much for the question, Congressman Brady.

You know, as I said before, I think one of the problems with hospice is that most folks do not know about it until it is too late. So one issue we have is not enough people getting hospice care.

Then we have the second question and issue that you talked about, which is poor performing hospices. We fully support giving CMS additional tools to provide better oversight of hospices, and we are really focused in a couple of areas:

One, CMS oversight;

Two, education of the hospices themselves. That is part of the work that an HBCO does;

And three is information for consumers.

So we want consumers to be making informed decisions, to be using Hospice Compare, which is up there but not great and needs to be improved.

So better tools for consumers; additional oversight for CMS; and additional education, which is something we can all do together I think is something we can all agree to.

*Mr. Brady. Great. Thank you, sir.

*Mr. Banach. Thank you.

*Mr. Brady. Chairman.

*Chairman Neal. Thank you, Mr. Brady.

Let me recognize the gentleman from Georgia, Mr. Lewis, to inquire.

*Mr. Lewis. Thank you very much, Mr. Chairman, for holding today's hearing.

I would like to welcome and thank each and every one of you for being here today. In particular, I want to thank Ms. Brown for telling us about your family. Your story is a very moving one.

It is unbelievable to me what you have been through. I know many people across America experience struggles similar to yours, and I thank you for sharing your personal story. It is not easy. It is not easy to do, a story of caring for a loved one, for your mother.

Ms. Brown, we know that 60 percent of all caregivers are women, and we know that for low income women caregiving is associated with an increased risk of poverty. Ms. Brown, as a black woman studying to be a doctor, taking out loans to care for your mother, maybe share more about the challenges you face.

*Ms. Brown. I thank you for that wonderful introduction to your question.

And, yes, in terms of the challenges that I face, in addition to the financial strain, there is also the challenge of being concerned about my future and having my future put at risk multiple times over the course of my lifetime because of the gaps in health care.

Another big challenge has just been with my family. All of us have had to make sacrifices, and all of us are very concerned that we do not have a way forward.

Does that help answer your question?

*Mr. Lewis. Well, if you care to elaborate more.

*Ms. Brown. Sure. Okay. I mean, as I had mentioned in my statement, most recently I have had to consider withdrawing from medical school. I think that consideration should not be anything that anyone should have to work through, especially since I worked hard my entire life to pursue this goal and hopefully to make a change.

So I do ask for everyone to at least think about your own children or the young people in your life whom you want to see succeed, and I think we need to do more for

young caregivers like me.

*Mr. Lewis. Well, thank you.

Dr. Lynn, how could Congress ease the burden for others who are in similar circumstances? What can Congress do? What can we do?

*Dr. Lynn. Congress has authorized the first year of developing a community care corps that would organize neighborhoods to help out. We only have the funding for the first year. So you could appropriate and authorize funding for the National Community Care Corps, which would provide infrastructure and instruction and so forth, not much money, but much more local innovation.

We also could start supporting caregivers. The Federal requirements for certification of electronic medical records does not yet even require a slot for identifying the caregiver when the person is in a medical situation.

Can you imagine having an electronic record that did not identify the parents for a child? And yet a dementia patient or a person with severe disability could be in a hospital and the caregiver's name and identity is not even in the record? How blind can we be?

We have caregivers who have no income who are impoverishing themselves. We have an example of impoverishment that goes does generations. It used to be that people burned their mortgage before they retired. They had a pension and Social Security, and their kids got their legacy.

Legacies are evaporating in long-term care. So we need to have ways to protect the caregiver. Many countries give a caregiver credit for their Social Security. Many countries give at least poorer families a stipend for doing caregiving.

We do none of that. It is as if we plot to make it difficult to be a family caregiver.

Very few employers give flexibility to family caregivers. They end up losing their jobs because they had to suddenly go home when an aide got sick.

So we need to really acknowledge where we are in having a very large number of people who need that sort of support, and the changes are in a number of ways. Many of them are not terribly expensive. They are confronting what it is we need to do, what would help Ms. Brown's situation.

Obviously, there ought to be a way in which she did not have to give up her future and her education in order to take care of her mother.

*Mr. Lewis. Thank you, Dr. Lynn.

My time has expired.

Thank you, Mr. Chairman. I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Florida, Mr. Buchanan, to inquire.

*Mr. Buchanan. Thank you, Mr. Chairman.

As he mentioned, this is not a Democrat or Republican issue. This is very much a bipartisan issue that we all understand the significance of it.

And I also want to thank the panel of witnesses. We have got a great panel here today.

But as you mentioned, 10,000 people a day turn 65. I am in a district in Sarasota-Tampa Bay region, 225,000 seniors. So all of this, the things we are talking about are very personal.

I want to also just mention what Ms. Sanchez brought up. I was not going to say anything, but I thought it was appropriate she shared her story.

You know, I was one of six kids, the oldest. At 33, my dad, 58 years old, worked in the factory, never spent a night in the hospital, perfect health, a big, strong, strappy guy, and we found out he had Alzheimer's.

And it came out of nowhere. You know, as a family we were in denial, frankly, for

a couple of years, but we addressed it, and I was fortunate because I do not know what we would have done otherwise, but I was fortunate as financially I took my dad in for 12 years. He lived with us, my wife and myself.

But it was tough to see something like that happen. I was not even sure what Alzheimer's was at that time, but again, it was something that was devastating.

That is why my heart goes out to Ms. Brown. I cannot imagine. We were more fortunate because we could provide some nursing and other capability, but I cannot imagine someone that is in your shoes, and we need to do more to help you.

Let me mention. Mr. Egge, you being involved and key with the Alzheimer's Association, is there anything from a prevention standpoint?

I know there are a lot of things you are probably looking at, but as it relates to diet and exercise, or I know there is not a magic pill, but are you spending much time in looking at that?

Because some people say with Type 2 diabetics, a lot of that is sometimes lifestyle, not all of it, but some of it, but I was just curious from your standpoint.

*Mr. Egge. Thank you.

It is a great question, and we certainly are seeing emerging evidence that that is, in fact, the case. A recent study called SPRINT MIND was very suggestive of controlling your blood pressure can help in this regard.

And also the Alzheimer's Association appreciates Congress' support for medical research running for Alzheimer's because it is allowing this research to move forward and has received bipartisan support.

Trials that are looking at just those kinds of interventions so that we have an evidence-base that can competently --

*Mr. Buchanan. The reason I am asking as a kid I ate a lot of spam and Cola.

*Mr. Egge. Well, I am sorry. That is --

*Mr. Buchanan. Well, let's not go on there.

But let me move forward. Yeah, you know what it is. I am in trouble.

Mr. Banach, let me ask you just quickly. I was at a roundtable the other day in our area in Sarasota. We have a hospice there. I am sure you are familiar with Tidewell. They also provide over \$1 million in their budget where they finance it themselves for tragedies locally, whether it is national tragedies, shootings. Opioid deaths are big in our area, but they weigh in in a big way in terms of providing families and others support.

Is that the case with other hospices around the country or are just lucky to have Tidewell in our area?

*Mr. Banach. Well, you are lucky to have Tidewell, Congressman Buchanan. They are a fantastic program, and thank you for your support of theirs.

But there are a number of other hospices around the country that not only provide sort of the bare minimum conditions of participation that provides support for folks in hospice and then for a year after hospice, provide bereavement support to their families, but go way above and beyond that.

Hospices in New York got involved during and after 9/11. Hospices in Orlando and Los Vegas got involved during those shootings, and every time there is a flood or a wildfire, any national disaster, what ends up happening is that the first responders and also the folks who are impacted by that disaster have a certain amount of grief that follows it after the news cameras move on, and they are the ones who actually provide a lot of that support.

This is support that they all provide.

*Mr. Buchanan. Let me interrupt because of my time.

The other thing I just want to say locally they provide a lot in terms of opioid in our

region. It has been a big issue.

But I did want to touch on the 55 percent of people that have Medicare but use hospice and other things. What can we do to educate and help them, encourage them to get involved?

And I say that because both of my parents passed away and my wife's parents, and if it was not for them, it would have been a lot more difficult process to get through.

*Mr. Banach. Thank you.

Two things. One is in terms of education. Hospice is not about giving up. So to my Great Aunt Ruby, hospice is not about giving up. You are going to receive additional supports and services.

The second thing is actually changing some of the rules. It is true that when people are eligible, they have to make this hard choice: do I continue to receive curative care or do I choose palliative care instead?

You should be able to get both services. It does not cost more money. It keeps you out of the hospital, and that is a reform we would love to work on.

*Mr. Buchanan. Thank you.

And I yield back.

*Mr. Banach. Thank you.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Texas, Mr. Doggett, to inquire.

*Mr. Doggett. Thank you, Mr. Chairman.

And thanks to each of you for truly insightful testimony this morning. I think this National Family Caregiver Month is an appropriate time to have this hearing and to honor the millions of people like Ms. Brown who are out there providing caregiving at great personal cost.

I have seen estimates in my home State of Texas of as many as 3.4 million family caregivers who provided over 3 billion hours of unpaid care each year to secure the health and care of their loved ones.

Through the highs of new life and the lows of loss, caregiving clearly can put a life on hold. Family caregivers are less likely to accelerate in their careers, often missing workdays or leaving the workforce altogether.

We know this burden is overwhelmingly on women. Some economists estimate that it is such a burden that it has affected the level of participation by women in the workforce.

I know that from the range of legislation you mentioned this morning, that there is no panacea for this problem, but I think one answer that is important is legislation that I have joined with our colleague, Rosa DeLauro, in sponsoring to provide paid family leave through the Family Act.

For those who receive long-term care outside the home, there are also obstacles within the Medicare system on access to the skilled nursing benefit. It is contingent upon a 3-day in-patient hospital stay.

Back in 2015, I authored a bill that became law, the Notice Act, to provide notice so that patients would be aware they had been placed in this status, but we very much need to move beyond that because of the great financial burden when a patient is placed in observation.

Our colleague, Congressman Joe Courtney, has an important Improving Access to Medicare Coverage Act that would address this problem, and I hope we can adopt it.

A more modest measure related is one that I have filed with our colleague, Jason Smith, the Medicare Home Health Flexibility Act. It is designed to provide access for occupational therapists to conduct the initial home health assessment and open therapy.

As Ms. Brown's testimony indicates, there is more of a problem here than just the impact on seniors near the end of their life. I think particularly of those individuals who struggle with total and permanent disability. There are shortcomings in our Social Security and our Medicare system in this regard.

A person who maybe has to go all the way through the appeal process to acquire Social Security disability benefits, then is required to wait 5 months before they get a dollar of those disability benefits, and an amazing and inexplicable additional 2 years before they access any AmeriCare coverage. We need to correct that. There is no justification for that giant gap.

And of course, assuring health care, one of the most important steps this Congress has taken, is the Affordable Care Act itself.

I believe that with regard to nursing homes, which Mr. Blacato and Mr. Mollot addressed, I recently saw a front page story in the San Antonio Express about identifying a number of area nursing homes with major deficiencies, questionable care. One of the things we have seen in emergency care is the increasing involvement of private equity, which sometimes raises costs and is a major obstacle to our action on surprise billing.

What impact has it had in the nursing home area, Mr. Blacato?

*Mr. Blacato. Congressman Doggett, I am not completely sure on that answer. I am happy to look into it for the record.

I think the other issue that relates to that is to examine the transparency of ownership of nursing homes because there seems to be a growing issue about chains opening and there being a lot of accountability issues that we need to address.

*Mr. Doggett. Okay. Mr. Mollot or Dr. Lynn?

*Mr. Mollot. Sure. Thanks.

Well, the investment by real estate investment trusts and other entities that have

nothing to do with health care into the nursing home world has essentially savaged the industry and, I think, care across the country. We are seeing that more and more with entities that buy up nursing homes. They have no experience in the business. They sell out the underlying property.

There was a case a couple of years ago of one of the largest chains in the country that sold to a real estate investment trust. I forget the figures exactly, but it was something like \$7.4 billion, and then it turned around and sold the underlying properties for \$7.2 billion, leaving about 99 percent of the assets gone.

And as a result, some of those nursing homes went on to other providers that were not capable of handling them. This was a multi-State issue, but we see that that is just one case that was a multi-State issue.

But we are seeing it over and over and over again that monies are being syphoned away from nursing homes and from care, and that they are just being devalued and then sometimes even closing.

*Mr. Doggett. Thank you very much.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Nebraska, Mr. Smith, to inquire.

*Mr. Smith of Nebraska. Thank you, Mr. Chairman.

And certainly thank you to all of our witnesses here today.

I think we are discussing very relevant issues, and in caring for our seniors, I know that we want a lot of options. I do want to reflect briefly on hospice care and a salute to every single hospice worker in America for walking alongside families during difficult journeys, but celebrating life along the way, and I really salute and respect all of the hospice care providers for all that they do.

As we examine various issues and options for seniors, I appreciate that we can share

our ideas here, legislation that we are working on. I think a lot of common sense solutions are out there with proposed legislation.

Let me just cover a little bit here. One example, Home Care for Seniors Act, H.R. 2878, which I am co-leading, would include qualified home care services in the expenses eligible to be covered by health savings accounts. I think that would be a good approach.

Also the Rural Health Clinic Modernization Act, H.R. 2788, which I introduced earlier this year, would help keep rural health clinics open and serving the primary care needs of our rural seniors.

Another bill I have cosponsored, H.R. 2693, would increase access to osteoporosis prevention and treatment by correcting an under-reimbursement issue, which makes it more difficult for seniors to access the necessary screening.

While these are common sense solutions and they could bring about some immediate positive impact, I think it is also necessary for us to think a little bit outside the box, as it is said, to come up with innovative solutions that can both improve outcomes for our seniors and also help to lower actual health care costs at the same time.

One bill I have been working on this year and hope to reintroduce soon is the Reducing Unnecessary Hospitalizations for Seniors Act, or as we call it the RUSH Act. This bill would utilize telemedicine to reduce unnecessary transfers of patients from a skilled nursing facility to the emergency room.

Unfortunately, especially during nights and weekends, seniors in these skilled nursing facilities are often transferred to the emergency room due to relatively minor illnesses or accidents simply because there is no qualified medical practitioner on site to diagnose or treat the patient. This bill would reduce those transfers by using telemedicine to connect the skilled nursing facility staff with the remotely located medical practitioner who can guide the staff through diagnosis and treatment for minor issues or make the

determination to transport the patient to an emergency room in more complicated or urgent scenarios.

Reducing these unnecessary transfers both saves money by preventing expensive emergency room visits and improves patient outcomes by preventing the unnecessary stress and trauma of a transfer to an already vulnerable patient.

I certainly look forward to working with my colleagues to work on these issues.

I know that it has been referenced already with the aging populations in many of our districts, especially a district like mine where out of 93 Nebraska counties, so much of the population is concentrated in three counties out of the 93.

I have so many counties in my district. Some are I would call rural. Others I would call remote, where some are lucky to have access to a hospital with one doctor, for example.

So we need to look at flexibility where and when we can, and certainly telemedicine, I think, play an important role in that.

Would any of you care to reflect on telemedicine and the role you see it playing in these topics that we are discussing?

Dr. Lynn?

*Dr. Lynn. Yes, I think that telemedicine offers a tremendous opportunity both in the ways that you are talking about in emergency care and also in access to specialists and the kinds of things that have happened in Project ECHO out of New Mexico where specialists are networked in to support local doctors.

But I think we also in many areas could have in-nursing home and even in-home direct services. Consider the model of PACE, the Program of All-inclusive Care of the Elderly, and the dramatic reductions that they have the use of ERs and hospitals because they have 24-7 care around the clock, all the time, with a comprehensive care plan.

So they know if this person would really resist going to the hospital and would prefer to have the diagnosis at home. Most of the U.S. population, not necessarily the land mass, is urban or suburban, and it would be relatively easy to mobilize that kind of service.

But it requires continuity in care planning, which we do not value in our care system at the present time. You have to know right off is this a person who is getting close to the end of life and should be treated at home rather than undergoing the travail of going to an emergency room and being frightened and left alone and so on, or is this a person who just had a fall and needs to have an X-ray? They can get the X-ray at home.

*Mr. Smith of Nebraska. Right.

*Dr. Lynn. There is a lot of opportunity there that we have not used.

*Mr. Smith of Nebraska. Thank you.

*Chairman Neal. I thank the gentleman.

Let me call upon the gentleman from California, Mr. Thompson, to inquire.

*Mr. Thompson. Mr. Chairman, thank you. Thank you for having this hearing today.

And, Ms. Sanchez, thank you for the role you played in bringing this important matter to the forefront.

And thanks to all of the witnesses who are here. You all have done an outstanding job, and in particular, Ms. Brown, thank you. What a courageous story of dedication and love and commitment, sadly a story that you should not have to tell because you should not have to have done that. But you are a very impressive young woman for the role that you took.

I would like to talk a little bit about hospice, and I have heard from hospice in my district a lot, but the one problem that keeps coming up is workforce shortages.

You know, the labor shortages are a challenge to all of health care, as we know,

provider shortages, nursing shortages, caregiver shortages, and hospice is far from immune.

The problem is particularly acute in the rural parts of my district, and I am assuming that is the same across the country.

So, Mr. Banach, I would like to ask you. Could you talk a little bit about those workforce shortages and the effect both to access to hospice care and the quality of care?

*Mr. Banach. Thank you for the question, Congressman Thompson.

Indeed, I think access is strained when the number of caregivers and folks that are available to care for the population is shrinking and the population is growing. Hospice is an interdisciplinary model.

So with hospice it is even worse because you are not only talking about the shortage of physicians and nurses and social workers and therapists and aides. You are talking about the shortage of all of them.

There are a couple of things that we can do. One involves training. PCHETA is a bill that actually was passed by the House that would provide better training on hospice and palliative care.

And the other thing is really taking a look at the pay that we provide to some of these folks. It is difficult for a hospice and many care providers to compete with a packaging plant where you can earn \$20 an hour putting books in boxes, when the fare more arduous work of being a hospice aide is stacked up against it.

So I think we have to make some priorities in this society, and I think prioritize caregivers, prioritize home health aides and other aides that provide those services, as well as providing more training to physicians and nurses and social workers.

*Mr. Thompson. Thank you.

I also hear the impact the cost of living has, and it speaks directly to the issue of pay. You know, I have some people who are driving 90 minutes both ways just to be able

to provide hospice care and afford to live. So I think you are spot-on here.

*Mr. Banach. And that is especially acute in California and places like that. Absolutely.

*Mr. Thompson. Mr. Mollot, do you have the same problems in the skilled nursing facilities that we have in hospice?

*Mr. Mollot. Well, I think that especially when the economy is good, we see that there is more pressure on health care. We see that in nursing homes because nursing homes are historically a really poor place to work. The most dangerous profession now is being a nurse aide. It is often a thankless job. We have seen studies over the years that looked at working conditions.

I mean, salary is important. When someone can make the same amount of money working at McDonald's or working in a packaging plant than they can carrying for a resident and they are not allowed to care for that resident because there is so little staffing and there is so much pressure and it is such a bad environment, that they will choose the other or -- and there is the turnover again -- that they will leave.

So it is a huge issue.

*Mr. Thompson. Thank you.

And I would like to talk about something else, another problem. My district has recently been devastated by fires over the course of the last four years, and as a result, we have had constituents who have had their power shut off for days on end.

And I just heard from a hospice in my district where the power had been shut off for 8 days in 30 degree weather. It was so bad that they had clients who had to go sometimes with medical equipment attached to them and sit in their cars just to get warm.

It is not just a California problem. I know Florida had similar problems in their hurricanes.

Mr. Banach, what sort of things can Congress do to make hospice and any elder care facilities more resilient or more prepared for natural disasters?

*Mr. Banach. Thank you for the question.

The National Hospice and Palliative Care Organization has a foundation that actually provides support for some of these hospices when the disaster sort of hits, but I think it is clearly insufficient.

When you look at disaster relief funds that are released, they do not help hospices. They do not help these health care providers actually deal with the consequences of a shutdown. They do not buy the supplies that they need to supply power during a shutdown.

And I think one thing we do need to look at is prioritizing support as we see disasters seemingly every month. We a different disaster of a different sort. I think we need to prioritize the flow of disaster relief funds to help health care providers really keep going.

*Mr. Thompson. Thank you.

I would like to talk to you offline.

*Mr. Banach. I would love that. Thank you.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Texas, Mr. Marchant.

*Mr. Marchant. Thank you, Mr. Chairman. Thank you for having this hearing today.

This issue is beginning to affect all of us. I have an 89-year-old mother, and she is very appreciative of the home health care that she gets, and I hear about this subject every Sunday afternoon when I go and visit her.

Over the last couple of years, several of the post-acute care sectors have experienced a transition to a new payment system. CMS has mostly chosen to wait for data

to become available from the new models before instituting behavioral assumptions into their payment methodology.

I believe home health providers are being treated differently. CMS is instituting behavioral assumption rate cuts to the detriment of home health providers and seniors. Elderly Medicare beneficiaries want to receive medically necessary health care in their homes, but may no longer have the ability to do so with such a payment reduction.

Mr. Chairman, with that I ask that we look to consider H.R. 2573, the Home Health Payment Innovation Act. Ms. Sewell has worked tirelessly on this bill to address the patient driven groupings model, behavioral assumptions, and the bill would require Medicare to institute rate adjustments only after home health behavioral changes actually occur and ensure Medicare budget neutrality to limit the risk of the disruption by a new payment system.

Lastly, I would like to once again ask the committee to consider H.R. 2073, a bill I cosponsored with Congresswoman Katie Porter to permanently extend the seven and a half percent threshold for medical expense deduction.

The medical expense deduction provides relief to families, especially older Americans and seniors, to offset the cost of their health care expenses, and giving the certainty to those families is something that this committee should take up as soon as possible.

Thank you, Mr. Chairman, and I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Hartford, Connecticut, Mr. Larson, to inquire.

*Mr. Larson. Thank you, Mr. Chairman.

And I want to thank all of the panelists for their expert testimony. This is extraordinarily important, and I commend the chairman for bringing these issues to the

forefront.

I also would like to thank Ranking Member Brady who mentioned in his opening comments that if a senior is no longer able to manage their own Social Security benefits, the Social Security Administration will appoint a representative payee to help them.

This program is an important part of our Nation's care system, and in 2018 this committee worked bipartisanship to strengthen it. I commend the ranking member and it is work that I am proud to have participated in.

Most payees are family members. However, if there is no family or friend available, then the Social Security Administration will consider creditors, such as nursing homes and assisted living facilities.

Because of the conflict of interest, this is supposed to be a last resort. Unfortunately, we have heard testimony at prior hearings that some nursing homes require that they be made a resident payee, even when relatives are available to serve as the payee.

We have asked the Social Security Administration to review how it selects payees, including these facilities.

I thank Ranking Member Brady for raising the issue of Social Security representative payees. I look forward to continuing to work together to protect vulnerable beneficiaries, including when creditors, such as nursing homes, are the payees.

And with that, Mr. Chairman, I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from New York, Mr. Reed, to inquire.

*Mr. Reed. Well, thank you, Mr. Chairman, and thank you for holding this hearing today, as well as hearing my comments from my colleague from California about her personal experience, and thank you for being a champion in this area in your work.

You know, as we have talked numerous times, and I am so glad to see Mr. Banach

here to discuss the issue of hospice and palliative care in America and how that fits into the delivery of health care for our seniors and for folks as we face those years of advanced aging.

But you know, what I wanted to focus on as a hospice and palliative care advocate and also a volunteer myself, certified volunteer who spends time volunteering in hospice facilities and sitting and standing with families and patients of hospice care.

Maybe we could touch on I think something that gets lost in regards to hospice and palliative care, and that is, one, the failure to embrace it in regards to the honest conversation I think we need to have in America about end of life and facing those issues of death and dying in our community in not a negative way but in a positive way.

And I will tell you firsthand, given the experience I had from the day my mom was diagnosed with lymphoma to the day she passed in my arm, it was hospice and palliative caregivers that provided that care and comfort of allowing her to enjoy those days in a very positive fashion in her own home and in her own bed.

And so maybe if you could, Mr. Banach, talk a little bit about how hospice and palliative care should not be viewed in sometimes a negative light, but the positive impacts it has on the quality of life of patients receiving that care and how their lives are improved by having the ability to control how they are going to exit this world, but also how they are going to enjoy family, loved ones, how they are going to spend time in a quality fashion as opposed to maybe a lack of quality fashion.

Could you offer any insights to us as to why hospice and palliative care should be viewed in a very positive light as to the care that it provides?

*Mr. Banach. Thank you, Congressman Reed, and thank you for your leadership around this and your leadership around PCHETA and other legislation.

I think there are really two issues that we are talking about here. One is structural

and one is educational. The structural issue is that, you know, when we talk to people, we say, "Look. We have got this great benefit for you. It provides all of these services and supports that the rest of Medicare does not. You can get a nurse. You can get a social worker. You can get a chaplain."

What is the catch? Well, the catch is you have to give up curative care in order to get it, and when people hear that, they say, "You know what? I am not ready for it." My Great Aunt Ruby is in that situation.

I think we should remove that barrier in order to sort of remove the stigma, but the other part is that we end up having these conversations about what people's wishes are way too late. We need to have them much earlier.

This is about choice. This is about what kind of care folks want to get, and so the right time to educate folks around hospice and advanced illness care is before they are in the position where in advanced illness or require hospice.

I think people are more open to having the conversation at that point, and I think so removing the stigma and then removing some of the barriers that exist because of the legislation I think would both help people get into hospice earlier.

I think we should actually create a serious illness benefit that precedes hospice so that folks get some version of interdisciplinary person-centered care and say, "You know what? I want that. I want more of that." And that is what hospice will be.

*Mr. Reed. Because I looked at some legislation I am interested in pursuing. There were some studies out that when you qualify for Medicare, just having a conversation as you enroll in Medicare about end of life, hospice, palliative care, and what is out there.

One, I think it would go a long way, in my humble opinion, to raise that awareness, but also it would save something like \$2 billion a year to America's health care system just having that requirement in Medicare enrollment to have a discussion.

What do you want to do? You are sitting here healthy. You are sitting here vibrant. What do you want to do in regard to that situation that we are all going to face one way or the other?

Is that assessment accurate?

And could you touch upon the savings to the system that this represents?

*Mr. Banach. Yes. And I cannot speak to the savings, but I can say that they would be considerable.

But I think you are absolutely right. Morally, the right thing to do if you want people to have some choice and some agency over the kind of care that they are going to get is everybody who gets onto Medicare should have a welcome to Medicare physical. A part of that conversation should be, "What are your wishes? You never know what is going to happen tomorrow. What kind of care do you want to get?"

And, again, if you have that conversation when people are healthy and when they are getting onto Medicare, it sort of normalizes that conversation so it does not happen during a crisis later, absolutely.

*Mr. Reed. I really appreciate that. My time has expired, and I look forward to expanding that awareness and education across America.

*Mr. Banach. Thank you, sir.

*Chairman Neal. Thank you, Mr. Reed.

Let me recognize the gentleman from Oregon, Mr. Blumenauer, to inquire.

*Mr. Blumenauer. Thank you, Mr. Chairman.

This has been, I think, one of our more moving and encouraging hearings that we have had.

Linda, I appreciate your putting a very human face on this, your leadership and being able to, I think, help us move this along. It is long overdue, and I appreciate it.

Ms. Brown, you are proof of what Dr. Lynn said, that if we do not get this right, we are evaporating or as you said it, this legacy evaporates because of long-term care mismanagement.

I am encouraged by hearing so many of my colleagues here on both sides of the dais talking about simple, common sense steps that can be taken. Some of you are aware of the struggle we had for the Federal Government to put a value on talking to patients and their families about what their needs were. We have made some progress, but we have got a long, long way to go.

I am hopeful that we will be able to boil down some of these specifics and continue that bipartisan dialogue, but be able to not worry about solving everything at once, but deal with specific steps that will make a difference for families, for caregivers, for patients, and candidly, that will help us in the long run save taxpayer dollars.

We pay so much on failure in terms of wasted money and wasted lives.

Dr. Lynn, you have discussed the program for all-inclusive care for the elderly, PACE Program. It has been exciting for me to watch in my community, and it is one of those simple, common sense approaches that really enables people to have a higher quality of life and be able to get more out of the resources.

But I must say, Congresswoman Walorski and I have been focusing on one area of the PACE Program that we think there is, in fact, a problem because for middle and low income Medicaid only beneficiaries, the expensive Part D premium costs for PACE can make it unaffordable, \$800 a month or more.

I support allowing just Medicare only beneficiaries to have the choice of either using their PACE Program's Part D or stand-alone marketplace for Part D.

Mr. Chairman, Congresswoman Walorski and I have legislation focused on this to try and help this little, tiny adjustment that would make such a difference in people's lives.

I understand, Dr. Lynn, that last year and this year the PACE Program submitted a waiver request to CMS on the Medicare only PACE Part D issue.

I also understand that they appear to have denied those waiver requests, and this letter's denial pointed to a statutory prohibition.

Would you care to elaborate on that?

*Dr. Lynn. Yes. We have actually submitted the wavier twice. The first time CMS said that it was within their statutory authority. The second time they said it was not.

The issue is that the Part D statute came into place after the PACE statute. The PACE statute requires there being no copays or deductibles. The Part D statute turns on there being copays and deductibles.

So we proposed that the PACE Program be able to buy the market-based plan and do all the wraparound services, and in the PACE Program that applied for the waiver, the premium would be \$1,200 a month versus \$50 a month for the beneficiary in the market-based plan, and then the wraparound services would add a couple hundred dollars more to pay the copays and deductibles.

It seems to us that it is within their statutory authority, but we would be perfectly happy to have a statute to fix this because at the present time effectively Medicare only beneficiaries cannot access PACE because of Part D.

*Mr. Blumenauer. Thank you.

My time is expiring. Mr. Chairman, I would hope that we could zero in on this to clear up the ambiguity if CMS does not act. I tend to agree with her. I think they could, but we ought to take the steps to make sure that we remove this unnecessary burden.

*Chairman Neal. It sounds very sensible, Mr. Blumenauer.

*Mr. Blumenauer. Thank you, Mr. Chairman.

*Chairman Neal. Let me recognize the gentleman from Pennsylvania, Mr. Kelly, to

inquire.

*Mr. Kelly. I thank the chairman, and thanks for holding this today.

And thank you all for being here.

I think that all of us at some point in our life look at what is going on especially with our seniors and trying to come to grips with how we are going to handle this.

I know my mother, as she was getting older, she used to make this comment all the time. She said, "One thing we do not want to be, your father and me. I do not want to be a burden to you and your brothers and your sister."

And I thought that was kind of unusual that somebody who had given up their whole life to raise us was more worried now at this point in her life of being a burden.

And so the hearing today is really good. It is good to hear from you.

I am trying to look at it though from a sustainable business model because as much as we get involved in the feelings of all this, then the question is: okay, so how do you sustain it? How do you fund it? And where do you get the revenues?

And then who are we trying to serve? Is it a government program or is it a patient? And I think we get wrapped around the axle on these issues sometimes trying to figure out who is it exactly that we have to please.

And I think that Chairman Brady was talking about the deficiencies, and as we go through the binder, all of the different things we look at is where is it coming up short.

I have got to tell you I have got a couple of constituents back in Erie, Pennsylvania, Mark and Amy Gusek. Their whole life has been working in these facilities. They have five facilities in Erie, Pennsylvania, Sharon, Pennsylvania, and Meadville, Pennsylvania.

And so when I talk to Mark, and I have been to the homes, and I think it is really good for all of us to visit these homes and see what is going on in these homes and how the people that we are most concerned about are really handling it.

And one thing I liked about the Guseks, in their homes, they have a really robust procedure where the patient, the actual people get a chance to interact and discuss where it is that they think it is coming up short. So it is a customer satisfaction index that they are looking for, not so much pleasing a government program, but making sure they are taking care of the people that are there.

All of you do this, and you have a great deal of background and depth of how we should handle it, Ms. Brown, especially you, listening to what you have to say.

I used to after mass go and have breakfast, and there was a bunch of older guys around up at the Gideons, and one gentleman one day, I looked at him and I said, "You do not seem like you are okay today."

And he started crying, and he said, "Well, I am 86 now. My wife has Alzheimer's. I am her chief caregiver. I went to the store the other day and when I came home, she was not there, and I was frantic trying to find out where she had gone, and finally one of the neighbors came up and said, you know, she was out walking down the street. We got here. We brought her home and she is here."

I said, "I am really sorry to hear that."

He goes, "Do you know what? I get so upset about this stuff."

And I could see that I said to him.

And he said, "But you know what? People know that my wife is going through something, but they have no idea what I am going through."

And I think that is what we come down to. How do we help those who are helping others?

Can any of you give us any ideas?

Because we keep looking to the government to come up with an answer instead of the people to come up with the answer, the people that we serve.

So if you know, each of you, I know they have very limited time to discuss these things, and so we have so much legislation that is out there and ideas of how to fund it, but this has got to be a sustainable business model that people can rely on.

So just some ideas that you can go through, Dr. Lynn.

*Dr. Lynn. Yes. We have done an analysis of how much could be pulled from the medical care system and the various proven approaches that work. We need, I think, an era of substantial innovation. We need to free Erie, Pennsylvania to figure out how to provide really excellent care, and they would do things that are quite striking, I believe.

They would do things like having home care entities work in a geographic area. So one aide moves along.

They would do things like work on culture change in nursing homes like the ones you have described, but we need some examples that really pull us back.

We have a tremendous amount of money going into this population. It is just going into the population in all the wrong ways. I can get a \$100,000 drug with the sweep of my pen, and I cannot get supper, and that is wrong.

And the fact that we develop a system that does not allow people to make savings for their own future or that create barriers like her mother did not work 40 quarters. Well, that does not mean the family has to sink into poverty.

We built a care system in 1965 around the idea that people died abruptly with heart attacks and strokes. The average age of death was 68. It was very uncommon to make it to the 80s and 90s that you are all telling stories about, and now that is the common place.

We need to redesign, and in order to redesign we need a few years of substantial innovation, which we are stultifying by having trivial little things being done here, and they are important that we do them, but also do the more fundamental stuff that will get us into the end of the 21st century without bankrupting and without watching a whole lot of people

die without food and housing.

We need Erie or whoever to step forward and say, "Yes, we will take this on, and we need to evaluate that. We need to support it. We need to free them from a whole bunch of regulations."

Why in the heck can a Medicare person not get into PACE? We put a rule in place in the way.

Why can a mother not get Medicaid? We put a rule into place.

Everybody here tells their story, and they say, "Were we not lucky that X?" You just were not lucky.

And the point is to not have to be lucky to get a fair deal in this country.

*Mr. Kelly. But there is no one size fits all is basically what you are saying. So when we actually allow the people who we are serving to have the input, then we get a positive answer to it.

Ms. Brown, I want to thank you really for what you have done for your mom. You are a great example of what family means. So thank you so much.

Mr. Chairman, I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Wisconsin, Mr. Kind, to inquire.

*Mr. Kind. Thank you, Mr. Chairman.

I want to thank all of the witnesses for your testimony today.

Mr. Chairman, thanks for teeing up this hearing. We are just scratching the surface on such an overwhelmingly important issue right now.

And I also want to thank Ms. Sanchez, too, for her point of focus on this and sharing her own personal testimony. It shows how this impacts millions and millions of families in America every day, and with 10,000 Baby Boomers retiring and getting old and

having to access this type of care, time has run out. It is at our doorstep right now.

Another issue that we really have not talked about much, but we also need to be promoting, I think, to a much greater extent is the use of advanced directives. I have seen firsthand how well this works with my own health care provider, Gunderson Health System in La Crosse and the Respecting Choices Program where they are getting people signing up with their own advanced directives, having these conversations within the family.

I know my whole family has ADs on record. My young children have ADs even, talking to them at an early age, and just knowing what people are expecting with their own long-term health care needs could go a long ways, too, to finding a lot of the solution.

And, Mr. Banach, I want to thank you for your organization's endorsement and support of the Rural Access to Hospice Act. It is legislation I have introduced with Mrs. Walorski. We are trying to move this forward in a bipartisan fashion right now, trying to fix an anomaly in the Medicare reimbursement system.

The legislation, very simply, would allow the federally qualified health centers to receive payment for serving as the hospice attending physician and have an impact on over 24 million Americans using these federally qualified health centers every year.

So hopefully, with the support of the committee, we are going to be able to advance that and look forward to working with you as we do.

And, Dr. Lynn, I want to thank you for the passion that you brought with your testimony here today. You talked in your opening statement about the cost of long-term care, and that is a problem.

I am living this with my own parents who are 90 years old right now. My dad was paying into a long-term health policy for over 30 years and checking all of the right boxes. Now that he is in care placement facility to make sure that he qualifies for it and even having gone through that process, it is only a fraction of the overall cost.

I want to ask you the state of the marketplace right now when it comes to long-term care policies because it seems like it is failing. It is a challenge to sign people up early enough, but to sustain it because of ever-rising premiums, and then as they get older, the premiums go up and they are making these difficult decisions. Do I still write that monthly check or do I just let the policy lapse?

And it is hard to predict what type of long-term care is even going to look like 15, 20, 25 years from now. So how do you make this actuarially sound?

Do you have any thoughts with the long-term care marketplace out there right now?

*Dr. Lynn. Well, the long-term care marketplace is effectively dead outside of a very few arenas. So Federal employees still have a fairly decent shake, but almost no one else does.

It is the only huge risk that we do not insure for, and you cannot tell today whether you are going to have 20 years of long-term care or none. It still happens, although it is pretty rare, that people have none.

You know, we forget that if we cure all of the named illnesses, you still get frailty and die, and frailty still takes a few years of self-care disability before you die.

So we really need to create the possibility of having insurance products that work, and those could be governmentally sponsored as the one in Washington State does or they could be attached to something we are willing to buy like Medicaid policies or they could be free-standing long-term care insurance policies.

But then the huge risk has to be borne somewhere else. You cannot create a market where the risk could be three days or could be 30 years.

*Mr. Kind. Yes.

*Dr. Lynn. When I first started working in a nursing home, I picked up a person whose stroke was before I was born. No one can save for that.

So we need to get that kind of risk into a pool so that the up-front risks that most of us will face are savable.

*Mr. Kind. I think you put your finger on it. I mean, right now the risk is mainly on the individual or the family, and they bear the entire downside risk to all of this. So how we establish that pool so there is a spreading of that risk is the only way insurance ultimately is going to work.

And, Mr. Blacato, you mentioned in your opening statement. You talked about the tax credit program that the State of Washington has moved forward on. We are going to watch that with intense interest, but you also talked about the failure of Medicare in filling this gap.

But gap you know well, we took a run at it under the Affordable Care Act, and we could not get the numbers to work. Actuarially we could not get it to work.

But you still think there is some hope or some way within Medicare that we could try to work on this?

*Mr. Banach. I would like to think so. And I would also like to think that one of the approaches that may be worth thinking about with long-term care insurance is to begin with home and community-based coverage first. You know, get people in the door.

Because if it is about a market not thriving because people are concerned about the larger questions down the road, if you are going to need community-based care, things of that nature, maybe the way to start is slowly.

And the other thing, too, is that there has to be much more consumer input into the development of long-term care insurance plans, and I would hope we would do that.

*Mr. Kind. Okay. Thank you.

Thank you, Mr. Chairman.

*Chairman Neal. I thank the gentleman.

Let me call upon the gentleman from Missouri, Mr. Smith, to inquire.

*Mr. Smith of Missouri. Thank you, Mr. Chairman.

I want to thank all of the witnesses for being here.

There is nothing I take more seriously than helping my constituents navigate the problems that they may have with working with the Federal Government, working with their health care.

As I have told the members of this committee before, the number one problem I hear from folks back home is access to health care. Just last week we received a call from a hospital about a veteran who was dying. The hospital had been attempting to get him into hospice care. It was about 3:30 p.m. on a Friday afternoon, and we called a number of VA contacts in trying to help this gentleman.

The hospital permitted him to stay over the weekend, but unfortunately Monday morning he died, never receiving his hospice care.

Mr. Banach, as you noted in your testimony, the average length of stay in hospice care is 18 days. With the timelines this short, it is crucial providers in hospice facilities are fully staffed and able to treat every single patient. Otherwise patients like the gentleman I just mentioned will continue to die before they get access to hospice care.

While problems with the VA health system are outside the scope of this committee's jurisdiction, in this case, there are root causes of a widespread problem for an entire Nation.

Rural communities in Missouri and across our country are facing a crippling shortage of health care providers. As of September, there were nearly 1.1 million health care and social service job openings. If we do not do something, this problem is only going to grow.

Members of the majority have put forward some solutions to the workforce

shortage, but these misguided proposals, in my opinion, will cost our country billions of dollars and, sadly, will have no impact on filling the gap or meeting the unmet market need for more professional caregivers in rural America.

In the hospice industry alone, the current rates of educating and training medical professionals in palliative care will not be enough to ensure aging Americans have quality of care. Current estimates show there will be no more than 1 percent growth in the palliative care and hospice physician workforce in the next 20 years, while the number of people eligible for palliative care will increase by over 20 percent.

Our population is getting older. The Baby Boomers, my parents' generation, will all reach the age of 65 by 2030. Ten thousand Boomers turn 65 every day. We must address shortages in the health care workforce because the demand for high quality care is only going to increase.

Mr. Banach, what are you seeing in workforce needs?

How would you characterize the gap between trained professionals and the needs of the elderly with serious and chronic illnesses?

And how is the problem specific to hospice?

*Mr. Banach. Thank you, Congressman Smith, for your question.

A start is the PCHETA law that the House passed, and we thank you for that. That provides better education and training, but as you said, it is a drop in the bucket. It is not enough.

We do need a bit of a change in terms of what our priorities are. There are plenty of investments that are going into in-patient settings. There are plenty of investments that go into hospitals and graduate medical education and everything else that goes with it.

There is very little investment in community workers, in training there as well. So I think part of it is to sort of take a look at where our priorities are and shift some of the

resources from in-patient settings where people do not want to be and do not want to die to the community where people want to be and want to die.

In hospice, it is incredibly acute. I think not being able to get hospice care is partially about not having enough folks to care for them. It is also partially about the rules.

When a hospice does not want to take a patient, it is sometimes the product of we are not sure if they are ready. We do not want to get audited if we take them and then the government comes in later and says, "You should have taken them." We need to change that as well.

The other piece is we need to actually provide a glide path for folks who are not ready for hospice but want to get some of that care, an earlier benefit.

The pin that I have here on my lapel is the We Honor Veterans Program. I think it is something that we are very proud of and something that obviously could have helped more in this particular situation, but the idea that someone served their country and then cannot get access to hospice care is appalling, and it is something I think we definitely want to improve and work on.

Thank you for your question.

*Chairman Neal. I thank the gentleman.

We will now proceed based upon practice to recognize two Democrats and then one Republican.

Mr. Pascrell is recognized.

*Mr. Pascrell. Thank you, Mr. Chairman.

Our witnesses have been terrific, all of them, and specifically Ms. Brown. Thank you for telling us your life story, real story.

And thank you, Congresswoman Sanchez, for your compelling story as well.

And, Mr. Panetta, thank you for helping us at getting this in front of us today.

So the aging population is growing tremendously. You all agree to that. The number of Americans aged 65 and older is projected to nearly double from 52 million in 2018, as it was, and to 95 million by 2060.

And that 65 and older age group share of the total population will rise from 16 percent to 23 percent. So we have heard a lot of data today. I think that is important and critical to where we are going, a sustainable program.

The gentleman from Missouri I think has hit on a very important issue. I think we should address it, as to the priority of funds.

But our aging population, the cost of care and the cost of care settings are extraordinarily expensive. You know how much it costs per month. You know what it costs when it is in home. They are almost beginning to match each other.

These costs can be even higher depending on the level of care needed.

Mr. Blancato, and thank you for the work you do as National Coordinator of Elder Justice. That is what we are looking for. We are looking for justice here, are we not, Mr. Blancato?

*Mr. Blancato. Yes, Congressman.

*Mr. Pascrell. So you highlighted in your testimony and what I read before that that accurate data is key to informing consumers of the quality of nursing homes through CMS' nursing home compare Website.

How can CMS improve data audits and enforcement measures so consumers can make an educated decision on long-term care options?

Families are thrown into the o go zone. They do not know where to go and who to call on. How can we be sure that a five-star rating for quality is really accurate also?

*Mr. Blancato. Thank you, Congressman Pascrell, for the question.

I think in response to that story that was given in testimony in the Senate about the

woman whose mother died in the five-star facility, CMS very recently took a step to now place an icon on their Website next to any facility that had any record of abuse and neglect so that you could see that as a consumer before you went the route of making the decision to place someone in that facility.

And that was seen as an important first step, but until you reach the point where you are doing regular audits of the data you submitted to get the rating, you are missing the boat.

*Mr. Pascrell. Are we doing daily audits?

*Mr. Blencato. I am not even sure we are doing quarterly.

*Mr. Pascrell. When we send our kids to school, to college, we want a report. Now, you have to give a report on fire safety. Can they get out of their buildings? Can they get out of their dorms? Does the college check this X amount of times?

We have Federal legislation to that effect, bipartisan legislation at that.

How about the legislation to deal with this problem?

*Mr. Blencato. And I believe that in the course of the next few weeks there has been legislation evolving, the Elder Justice Act reauthorization that is going to originate in the Senate and come to this committee for review, and there are proposals on that very topic about nursing homes compared, how to improve it, how to deal with issues around auditing.

And I look forward to working with the committee to see if we can get the strongest possible language in there on behalf of consumers.

*Mr. Pascrell. In 2016, and I will conclude on this point, the 30-day hospital readmission rate was a little over 17 percent for Medicare patients, which is nearly twice as high as the rate for those with private insurance.

Taken together, elder abuse costs \$2.8 billion per year in Medicare hospital costs

alone. So we not only have to have a sustainable system regardless of which part of the system you look at. We must have a sustainable review of whether it is working, how it is working because I know of the abuse in many of these residences that we are talking about here.

*Ms. Sanchez. [Presiding.] The time of the gentleman has expired.

*Mr. Pascrell. Thank you.

*Ms. Sanchez. Thank you, Mr. Pascrell.

We now move to the gentleman from Illinois, Mr. Davis, for questions.

*Mr. Davis. Thank you very much, Madam Chairman, and I want to commend you and Representative Panetta for the role that both of you played in causing this hearing to take place.

I want to thank the chairman for calling it and all of the witnesses for participating with us today, and I seriously believe that you can measure the greatness of a society by how well it treats its old, how well it treats its young, and how well it treats those who have difficulty caring for themselves.

We have heard a great deal about the personal sacrifices of individuals like Ms. Brown in caring for her mother, but you know, unfortunately, many people are unprepared to become the caregivers that we need due to their own circumstances or the inability to have resources to help.

Of course, caregivers may be family members, friends, health professionals, social workers, members of the clergy that provide care at home or in institutional settings.

When it comes to unpaid assistance and support for people who cannot care for themselves, it is estimated that 44 million people ages 18 and older are providing care to people with all kind of health issues right in their own communities.

According to the Family Caregiver Alliance, they reported that the value of this

unpaid labor force is estimated to be at least \$306 billion annually, nearly double the combined cost of home health care, \$43 billion, and nursing home care, \$115 billion.

Many analysts have reported that family members and loved ones who provide care to individuals with chronic or disabling conditions are themselves at risk of physical and mental health disorders.

Of course, one way to help aging Americans is to ensure workers that they have access to paid leave for caregiving. Too often hardworking Americans are forced to make a false choice between family and work, but we all know that taking care of a loved one facing a serious health condition is not a choice. It is a responsibility. You do what you have to do.

My congressional district has one of the highest percentages of children being cared for by their grandparents, followed closely by two other Chicago area districts.

Further, within the African American community extended family like aunts and cousins, as well as friends, are often kinship caregivers in addition to grandparents. That is why we have hearings on the need for paid family and medical leave both in my subcommittee, the Subcommittee on Worker and Family Support, and then in the full committee.

Dr. Lynn, when you talked about the lack of flexibility employers give to family caregivers and the way that causes them to take unpaid leave and often retire early, I was reminded of one of my constituents who testified at our subcommittee hearing.

She is caring for her grandson while working, and she had to give up a good job that paid better because it did not provide enough flexibility to accommodate caregiving, and she worries every day about her own health and how her family would get by if she could not work.

Dr. Lynn, how does this kind of access help relieve some of the problems with

leave?

*Dr. Lynn. Well, we certainly move to find ways to provide leave for caregivers. We need to provide ways to provide them with things like medical care insurance and Social Security while they are working full time taking care of somebody.

Caregivers get a really short shrift here, and the kinds of things that you are talking about are things that ought to be on the table. We ought to put together a package that makes it work, and we have not.

Caregivers are invisible in our system. They vanish from work. They go into poverty themselves, and nobody notices or cares. We need a caregiver union to speak up on behalf of all of us who will be, have been, or are now caregivers.

*Mr. Davis. Thank you very much.

And I yield back.

*Chairman Neal. [Presiding.] I thank the gentleman.

Let me call upon the gentleman from Illinois, Mr. LaHood, to inquire.

*Mr. LaHood. Well, thank you, Mr. Chairman.

And I want to also thank the witnesses today for your valuable testimony and sharing your stories, and it is a great opportunity to raise awareness.

As most of us know, the month of November is Alzheimer's Awareness Month, and last week when I was back in my district, I got together in Bloomington, Illinois with a group from the Illinois chapter of the Illinois Alzheimer's Association.

And so around the table we had a really robust discussion with caregivers and doctors and family members on this issue, and one of the issues that was highlighted for me in that discussion was the hard work and dedication and the sacrifice it takes to be a caregiver.

When we got to the specifics in the round table discussion, one of the overarching

issues that came up was the lack of a uniform diagnosis tool and the lack of patient education on tools we currently have in Medicare to help craft a comprehensive and coordinated treatment plan for both the patient and the caregiver.

One tool we already have in Medicare, as many of us know, is the annual wellness visit. As the percentage of the Medicare population with Alzheimer's and dementia continues to increase, the annual wellness visit allows for a physician to work with a Medicare beneficiary to develop a personalized prevention plan for future medical issues, including Alzheimer's or dementia.

One aspect of the annual wellness visit is the assessment of cognitive impairment. Assessing cognitive impairment early is especially critical, and that is why I was proud to cosponsor the CHANGE Act with Rep. Linda Sanchez earlier this Congress.

Obviously, the CHANGE Act will help maximize the value of the Medicare annual wellness visit to catch cognitive impairment and signs of Alzheimer's early.

Among other provisions, our bill requires testing for cognitive impairment during the wellness visit and its progression at future visits to ensure follow-up with more advanced Alzheimer's and dementia screening if impairment worsens.

Mr. Egge, thank you for your testimony, and as you likely know, Medicare began reimbursing providers for comprehensive care, planning appointments for individuals with cognitive impairment back 2017. This allows newly diagnosed individuals and their caregivers to learn about medical and non-medical treatments, clinical trials, and support services available in their community.

Unfortunately, the utilization rate remains low, and we heard that last week. Like the care planning benefit, the annual wellness visit is also underutilized among Medicare beneficiaries.

The question for you: how do you think we can increase the public's awareness of

these services?

And how can they be enhanced to provide the most value to the Medicare population?

And I will also add in a district like mine, I have 19 counties, and it is a rural district. We also heard a lot about how do we get the word out, how do we communicate and advocate in our rural areas.

Thank you.

*Mr. Egge. Yes, thank you for that question and for everything you said.

I could not agree more. The importance of early detection and diagnosis is critical. One thing that we have often heard is that there is a misunderstanding about how important that is and what can be done once that diagnosis takes place, which is all too often lacking.

And that is why we have focused so much of our attention on making sure that this care planning benefit that you referenced, that people are aware of it, especially clinicians, and that they make the connections that we know can be made to evidence-based, very effective intervention, such as training for caregivers and connection to community resources that already exist.

We see this as a linchpin moment in the care of everybody with dementia and their caregivers, and that is why I emphasize so much the Improving Hope for Alzheimer's Act because it makes that linkage, as you pointed out, between early detection and diagnosis in that conversation with the health care provider to the services that do exist today that should be further strengthened, but are there.

*Mr. LaHood. Thank you for your comments.

Those are all my questions, Mr. Chairman.

*Chairman Neal. I thank the gentleman.

Before I recognize Ms. Sanchez, I want to take a moment to recognize myself.

Elder care is an issue that I have long been passionate about. I have been working over the past number of months with the Department of Health and Human Services to address patient safety issues in long-term care.

Ranking Member Brady and I wrote a letter regarding the hospice failures identified in a recent Inspector General report. Separately, I have written a number of letters asking the Centers for Medicare and Medicaid Services to take a more aggressive action in examining overprescribing of antipsychotics to people with dementia. These drugs have a black box warning against the use in the population. Yet we know they are still being prescribed excessively.

Without objection, I intend to submit these to the record.

[The information follows:]

[Rep. Neal Letter to CMS Administrator Seema Verma on Antipsychotic Misuse in Nursing Homes \(July 25, 2018\)](#)

[Rep. Neal Letter to CMS Administrator Seema Verma on Continued Concern with Overuse of Antipsychotics in Nursing Homes \(January 22, 2019\)](#)

[Rep. Neal and Rep. Brady Letter to CMS Administrator Seema Verma on Concern over OIG Report on Medicare hospice deficiencies \(July 30, 2019\)](#)

[Rep. Neal Letter to CMS Administrator Seema Verma on Concern over OIG Report Results \(August 27, 2019\)](#)

*Chairman Neal. With that, let me recognize the gentlelady from California, Ms. Sanchez, to inquire.

*Ms. Sanchez. Thank you, Mr. Chairman.

And, again, to our witnesses, thank you so much for your wonderful testimony today.

Earlier in my remarks I mentioned the need for policies that would improve the lives of patients and caregivers, and that is why, as Mr. LaHood mentioned, I am proud to have introduced along with him the Concentrating on High Value Alzheimer's Needs to Get an End, or more commonly referred to as the CHANGE Act. We like our acronyms here.

This bill is a bicameral bill. So there is a companion bill in the Senate, and it would give providers the tools that they need to detect and diagnose Alzheimer's at its earliest stages.

We know that Alzheimer's often goes under-detected for many years, and it is typically not detected until very late in the disease cycle.

And, again, we also know that communities of color and women face higher risk for the disease and barriers to treatment and research.

So early detection, it seems to me, is one of the areas where we can focus to allow patients to be referred for additional testing, allow them to be referred for community-based support services, and potential clinical trials as well.

Mr. Egge, I am going to shift a little bit and talk a little bit more about caregivers because caregivers do an incredible job under very trying circumstances.

But can you tell us what are some of the unique needs that are faced by caregivers of individuals who live with Alzheimer's and dementia-related diseases?

And what more needs to be done to try to help the population of caregivers?

*Mr. Egge. Thank you for that question.

I think some of the unique needs center around the evolving nature of the disease. It may feel at the beginning for somebody who is dealing with this disease that they, in a sense, have it down. They can handle what is going on, how the disease is unfolding.

And you may know intellectually that the disease will change presenting to live through it, and that is why it is so important to have training for caregivers in particular, that they can identify what is likely to happen, how that will necessitate changes in how they provide care, and they know what services are available.

Perhaps the thing I hear the most often about the challenges of caring for somebody with dementia is interpreting behaviors, especially as communication becomes more and more difficult. It is unsettling. It is difficult, and it leads to often placement in nursing homes before it would otherwise be necessary if you had that person-centered approach to understand what might be driving those behaviors and how they can be best dealt with in non-medical ways.

*Ms. Sanchez. Thank you.

Another piece of legislation that I am proud to cosponsor, again, with a colleague on this committee, Mr. Reed, is the Credit for Caring Act, which would provide much needed tax credit for family caregivers.

Caregivers face many missed opportunities because of the responsibility of providing support, and our bill tries to relieve just a little bit of that burden, of that financial burden.

Ms. Brown, I really cannot thank you enough for sharing your very powerful story, and while today's hearing is focused on older Americans, caregivers definitely deserve our attention and our support.

I am interested in hearing from you. You talked a little bit about possibly having to

leave the study of medicine because of the responsibility of your caregiving burden. I want you to focus a little bit on what are some of the missed opportunities that you have experienced as a result of the responsibility of being a caregiver for your mother.

*Ms. Brown. I thank you for that question.

So, yes, some of missed opportunities include educational goals. For instance in high school just worrying that I was not going to graduate, despite working very hard.

Also the opportunity of being a young person, I quit the cross-country team. I skipped prom. I did not spend time with friends very much growing up, and I do think that has a long-lasting impact, and it is unfair for young adult caregivers, and even child and teen caregivers, to have to sacrifice being adolescent.

So that in addition to the educational opportunities are the most striking sacrifices that I have made.

*Ms. Sanchez. And with those missed educational opportunities, would you say that that has impacted your future financial opportunities as well?

*Ms. Brown. In some ways. So I had to take out student loans to pay my mother's mortgage. I have taken out more than I need to, and I do have concerns about my future financial stability as a result.

I am hopeful that I will complete medical school this year and become a doctor and be able to carve out a financial path for myself, but that is a huge barrier and something that I constantly worry about.

*Ms. Sanchez. Again, thank you so much for coming to share your story with us. And I yield back to the Chairman.

*Chairman Neal. I thank the gentlelady.

Let me recognize the gentlelady from Washington State, Ms. DelBene, to inquire.

*Ms. DelBene. Thank you, Mr. Chairman.

And I want to thank all of our witnesses for joining us today, and in particular, Ms. Brown, thank you so much for sharing your story.

In my State of Washington, we passed a new public benefit for long-term services and supports. It is called the Long-term Care Trust Act. I believe we are the first State in the country to do so.

So Washington residents will contribute to a new payroll tax, and in return by 2025, Washington residents will receive support services. Actuaries estimate the new Washington State benefit will save the State's Medicare program \$4 billion by 2052.

And I know States like Hawaii and California are also in planning stages to create a similar benefit.

Dr. Lynn, can you talk about how the Federal Government could build on these State efforts to provide much needed long-term services and supports to Medicare beneficiaries?

*Dr. Lynn. Yes, the States are clearly under the gun, the cost of Medicaid is eating their budgets, and some are doing very creative things. Washington State has not only done what you have said, but also has a very vibrant data analytic capability growing that most States do not yet have.

There are innovations going on in Minnesota to try to put some costs into Medigap and Medicare Advantage plans. Hawaii has a proposal or has an implemented endeavor to support caregivers.

We need to encourage the States to do these things, but then we also need to harvest and grow them so that there ought to be a way to interface with these sorts of things at the Federal level.

As we get more Federal involvement, not every State can do what Washington State has done or may be inclined to, but some will, and some will do very creative things.

I think that it would be very good if the CMMI, for example, offered to recruit some States that are willing to have some communities in their States will build the care system of the future that would meet the business requirements that you are speaking of, and then we would have the really vibrant laboratory that would teach us, and we would be able to say, "Here is where we should go to."

People ask me, "Well, where in the country is this being done right?"

You say nowhere. There are places in other countries, but no one believes those other countries.

So we need to build our own models and then celebrate them. And Washington State, I take off my hat to you that you have done this much.

But we need, you know, to really know a group in HHS that has the responsibility to harvest the insights and to generate the energy to try much more aggressive things. We really only have a short time before we have so many people in need.

*Ms. DelBene. Mr. Blancato, you brought up the legislation, our Washington legislation, in your opening testimony. Do you have any feedback on that?

*Mr. Blancato. Well, again, I offer congratulations as well for the work. I know it took three legislative sessions and a lot of work on the part of different people. And I was in Washington State recently speaking to their Area Agency Association who will have a role going forward in this program as well.

I think the key thing is, you know, there was a poll that was done by AARP in conjunction with the work on this legislation, and they polled voters 18 to 34, and 83 percent of them supported the concept behind a Long Term Care Trust Act, which demonstrates the intergenerational attractiveness, if you will, of a viable long-term care plan, whether it is at the State level or beyond.

And I think the other part that is important about what you are doing is you already

have some estimates of savings that will accumulate to Medicaid. That is the kind of data that the country needs to get because if we can accomplish savings through long-term services and support against the Medicare and Medicaid program and started realizing those savings and investing more in those long-term services and support, I think we would be better off.

*Ms. DelBene. And you kind of alluded to the next question I was going to ask, is: if States do programs like this, what is the impact on Medicare, if we have non-medical services and supports that are potentially being covered through a program like Washington State?

*Dr. Lynn. It has been lunatic to have long-term care separated from Medicare, and Medicare is going to benefit from this sort of thing. If people get approved, they will not be in emergency rooms so often, if they get bed baths and the kind of support that is essential to people doing well.

So, yes, Medicare will benefit, and we need to estimate those benefits. When Medicare says they are doing total cost of care, it is absolutely maddening because they never count long-term care costs on Medicaid or to the family, and the family is taking it on the chin.

So we need to start really accounting for the total costs and figuring out how to make it be a viable arrangement for the whole society.

*Ms. DelBene. Thank you.

I yield back, Mr. Chairman.

*Chairman Neal. I thank the gentlelady.

With that, let me recognize the gentleman from Arizona, Mr. Schweikert, to inquire.

*Mr. Schweikert. Thank you, Mr. Chairman.

You know this is one of my personal fixations, the number of times I get teased by

the chairman because it is one of my few times to speak without a chart.

Why do you laugh at my charts?

But this is actually -- and thank you for being here -- but this is a big deal, but it is even bigger. This is also retirement security, what happens near the end of life, you know, everything from States like Arizona that have tried very hard on what we like to refer to as living wills, advanced directives, those things. How do they fit into it, to the conversation, is MMMI dual-eligible populations?

But I want to go first on something and see if there is some optimism because we know the fact we have 74 million Baby Boomers. We are about halfway through them turning 65, and when we talk about national debt, it is uncomfortable politically for us to tell the truth, but it is substantially driven by our demographics.

You know, there are some numbers. Three-quarters of what we look at as our national debt growth over the next 30 years is substantially the benefits that are earned, promised from Baby Boomers.

But we are also not the only country to be going through something like this, and this is where I am going to ask for, first, some bit of optimism and creativity.

I have a series of articles here that we have been collecting for this hearing:

One in the Wall Street Journal recently that Baby Boomers would prefer to stay home.

Technology that Japan is adopting to be able to provide services to seniors to be able to stay at home.

Some concepts of creativity with certain types of ride-sharing where Meals on Wheels is coming to house; that they should also be dropping off the update of your oxygen tank; that they could also take someone to their medical visit; the concept of some consolidation of the data that is used for outreach to our seniors that do choose to stay at

home.

Do I have anyone on the panel that actually sees some adoption of whether it be technology or consolidation of these community resources that provide you optimism?

Doctor.

*Mr. Blancato. Yes, Congressman. Yes, there is a lot of reason for optimism because there are many, many technology entities, many start-ups that are coming into the business and want to go into the aging market and make a difference.

And going to the point about the business case and the business model, that is really where the excitement rests because once they understand the market piece of what is involved in aging services, aging programs, and what you can do in the private sector, technology level, there is tremendous cause for optimism.

There are organizations out there doing this on a regular basis. So that is one place for optimism.

*Mr. Schweikert. Can you be really more specific?

Let's go to Dr. Lynn. Do you see anything specific in your optimism?

*Dr. Lynn. Yes. The start is this hearing. I mean, people are beginning to take notice and maybe in time.

The kinds of things that you were talking about, and, yes, we need to develop the robots that Japan is developing, and we need to develop the modes of service delivery that are much more efficient.

But we need the focus to be on getting that done so that we do it in time.

*Mr. Schweikert. We are working on it.

Mr. Banach.

*Mr. Banach. Yes, I am happy to weigh in. You know, I think that the demographics in some ways are going to drive us to be more creative and more innovative.

We have less money to go around, and we have to be smarter about how we spend it.

I mean, the fact is we are spending a lot of money on get sick, get broken care, and we have to shift some of that to helping caregivers and providing support in the community.

I am encouraged by, you know, Amazon getting into the space of providing services and supports to their employees. So it is not only going to be the government that provides some of this support. It is also going to be private industry that says, "You know what? Our employees are spending way too much time away from their desks dealing with these issues. We have to provide them some support so that they can be more productive."

*Mr. Schweikert. That is fair.

Mr. Chairman and committee members, do you remember a couple of weeks ago when I showed a board of a pill dispenser that was to make sure that someone who may be at home, may have some forgetful issues is taking the right combinations at the right time?

We actually found an additional study of the billions and billions and billions and the number of deaths that were stunning because individuals do not take or take improperly pharmaceuticals.

That simple machine is just a pill dispenser that at certain times if you did not take it, it provides the family warning and notification.

I only hold that out as one tiny little cog in the wheel of this is incredibly human. You saw the stories of what is happening in States like Maine where they cannot find enough workers in their nursing facilities and they are shutting down these facilities because they do not have enough labor. That is just our demographics.

Could we ever as a committee be willing to let some of us bring in some examples of some of this technology?

It is only a small part of the solution, but it might be a fascinating conversation of

how do we promote this.

*Chairman Neal. I would be happy to entertain the gentleman's thoughts on this.

*Mr. Schweikert. And with that, Mr. Chairman, I yield back. Thank you for your tolerance.

*Chairman Neal. I thank the gentleman.

Let me call upon the gentlelady from California, Ms. Chu to inquire.

*Ms. Chu. Yes. This topic is so important to me. My mother-in-law was once a vibrant person who was so happy to see us. When she got into her late 80s though, she developed dementia.

At first, she would ask questions repeatedly, not remembering that we had answered it only moments before. Then she stopped smiling as we came as her mind became a fog. And finally she stopped recognizing us, her children.

She has since passed away, but I say that even if your parents do not recognize you, they deserve quality care, and that is why paid family leave is so important.

And so I would like to address this to Ms. Brown and Dr. Lynn.

We are one of the only developed countries in the world without paid family leave. We do have family leave in the U.S., but it is not paid, meaning that most people cannot afford to take off time from work.

Now, my State of California does have paid family leave and has had it for the last 15 years, and it has worked well, but without paid family leave, so many are left in the lurch.

And paid family leave can help women stay in the workforce, can lead to more economic stability for older women in retirement, can lead to better health outcomes for children, ill and injured adults and older individuals who require caregiving supports.

And so we do have this bill called the FAMILY Act, which was introduced by

Congressmember Rosa DeLauro, which has 199 cosponsors and more than 650 groups that support this bill and would provide up to 12 weeks of partial income when you have to take time off for helping those with serious health conditions, like your own or the birth or adoption of a child or for caring for a family member.

So my question, Ms. Brown and Dr. Lynn. Do you think the FAMILY Act would be a useful tool in helping family caregivers provide care to their loved ones with conditions like dementia, Alzheimer's, or MS?

Ms. Brown.

*Ms. Brown. Yes, absolutely. Thank you for the question.

And I am happy to hear about this act. I do think that especially for young women who are at risk of losing up to 20 percent of their lifetime earnings by leaving the workforce to care for a family member, this act would be instrumental in helping these caregivers stay in their jobs and continue to have lifetime earnings.

I do think that no one can predict a love one's course, and caregiving is lifelong. So I do think it is very important that at every stage in life employees, and especially women, are supported in being caregivers for their loved ones.

*Dr. Lynn. As Mr. Schweikert said, it is a small piece of what we need to do, and yes, of course, we need to do this.

And it is amazing how difficult it has been. I would point out that it does not help lots of people. It would not have helped you because you were not a worker at the time you were drawn into it.

It does not help employees that are self-employed or in small businesses, and it is only partial pay for 12 weeks, and you know, your caregiving goes on for years.

But it is helpful and at the very least gives a nod that the community cares, you know, and that we are beginning to take notice of what is going on. So, yes, let's do that,

but as a springboard for bigger things.

*Ms. Chu. Absolutely. Dr. Mollot, I was so dismayed to see the numerous violations at nursing homes. There is a database, and I found that one facility in my district failed to use clean kitchen items to serve patients. Another failed to follow physician directions when giving patients their medication. Of course, that is a threat to the patient's wellbeing.

And yet another facility failed to refer a patient to the dentist. So he was unable to get his dentures fitted. As a result, the patient was not able to eat his food and began rapidly losing weight.

What can Congress and CMS do to strengthen minimum standards to keep these patients healthy and safe?

*Mr. Mollot. Well, thank you for that question because there is so much that could be done, and this affects people who are in a nursing home for long-term care, as well as for short-term rehab. It really does impact everyone.

Most importantly, as I mentioned in my testimony, we have really strong standards based upon the reform at least for now, and the problem is that those standards are not in force. So the States essentially are contractees of CMS in terms of enforcement, but CMS does no quality assurance pretty much at all to make sure that the States are doing a good job.

So what we could do, Congress and certainly CMS, is to make the States do a better job. There are actually regional offices of CMS around the country whose pretty much sole role is to make sure the States are doing what we pay them to do, which is protect our residents, and they just do not do it.

Thank you.

*Ms. Chu. Thank you.

*Chairman Neal. Thank you.

Let me recognize the gentlelady from Indiana, Ms. Walorski.

*Ms. Walorski. Thank you, Mr. Chairman.

Thank you to our panel here today.

You know, if it was possible and I could give a Congressional Medal of Honor, I would honor every hospice worker, every PACE facility, every federally qualified health clinic that serves the people of this country. I cannot say enough about those services in my district.

Unsung heroes for sure, you know, workforce issues, lack of pools of people to hire and train and those kinds of things, but I just want to thank all of you for being here and for representing those groups.

I do believe that preserving Medicare is a priority. I do believe that we have to honor our promises to the American people and ensure that those who have worked their entire lives to earn their Social Security and Medicare benefits are able to utilize those programs during their retirement years.

It is also important that we strengthen those programs so they remain available to future generations.

I have been working with my colleagues on bipartisan solutions as well to support older Americans in communities across this country and help them lead healthy and independent lives.

Some of these common sense bills that I have worked on we have already talked about and heard about, but the Rural Access to Hospice Act, which would ensure patients in rural communities can receive hospice care from their local primary care provider.

The Home Care for Seniors Act, which would help seniors access the care they need, allowing them to use HSAs for home health care.

The Beneficiary Enrollment Notification and Eligibility Simplification Act, which would simplify the Medicare Part B enrollment process and help prevent lifetime late enrollment penalties.

The Improving Hope for Alzheimer's Act, which builds on the hope for Alzheimer's by requiring the Department of Health and Human services to inform health care providers about care planning benefits available through Medicare.

And H.R. 2693, a bill that will help Medicare beneficiaries with osteoporosis by updating reimbursements for DX exams that are used in identifying and treating osteoporosis in at risk seniors.

I also worked with Congressman Blumenauer, as he mentioned, and CMS Administrator Verma on finalizing the rule for the Programs for All-inclusive Care for the Elderly, or the PACE Program, which gives more flexibility for PACE organizations' interdisciplinary teams and allows certain non-physician primary care providers to offer services in the place of primary care physicians.

And I do look forward to continuing to work with my colleagues on initiatives to lower costs and to improve access to care and services so more seniors can enjoy quality of life.

Mr. Banach, thanks for joining us here. I have appreciated listening to your testimony. I mentioned the Rural Access to Hospice Act, which I helped to introduce with my colleague, Mr. Kind.

Can you explain to the committee the statutory barrier that currently prevents hospice patients from seeing their attending physician that is with a federally qualified health care center, and how that hinders a patient's quality of life while at hospice?

*Mr. Banach. Thank you, Congresswoman for your leadership on this.

Folks who get their primary care through a rural health clinic or a federally

qualified health center are forced to make a really difficult decision. Keep your doctor and stay with the rural health clinic and stay with the federally qualified health center or choose hospice, but you cannot keep both your doctor and hospice at the same time, which is insane.

It is a bit like the choice folks go through in choosing hospice to begin with. Do I want hospice or do I want curative care also?

What this bill would do is it would remove that barrier. You can keep your doctor, and that doctor can be your attending physician in hospice, which is a great step forward.

Thank you for your leadership.

*Ms. Walorski. I appreciate it.

Dr. Lynn, I just wanted to thank you for your work. Like you, I am a huge fan of the PACE Program, especially after visiting a facility in my district last year, realizing though that not a lot of my colleagues actually have the PACE Program in their districts.

So can you explain to them the innovative way they provide services and care to seniors with complex health care needs, number one?

And do you have any recommendation on how we can expand this kind of care across the country?

*Dr. Lynn. PACE is marvelous. For a set price, they provide everything except housing that a person may need for people who are sick enough and disabled enough to be in nursing homes.

So it is a very disabled population, and the record in keeping people at home and supported and safe is remarkable. Almost no one leaves PACE once they are in PACE.

But PACE is effectively barred to Medicare only people, for reasons we talked about before. Part D has a bizarre regulation requiring that you buy the PACE Part D plan, which a Medicare only person sees as going from roughly \$50 to over \$1,000 a month. So

nobody will do that.

We need to fix that. We need to probably allow there to be some PACE services ahead of nursing home eligibility. There is an eligibility, of course, that varies by State, but many people need that kind of comprehensive service for maybe 6 weeks after a hospitalization.

*Ms. Walorski. I have got to cut you off right there. Thank you so much. I appreciate it.

And I yield back my time.

Thank you, Mr. Chairman.

*Chairman Neal. I thank the gentlelady.

And without objection, I wish to include Terri Sewell's statement and have it entered into the record.

[The statement of Ms. Sewell follows:]

[Terri Sewell Statement for the Record](#)

*Chairman Neal. I note that Representative Sewell has questions for the witnesses that she will submit in writing.

And with that, let me recognize the gentlelady from Wisconsin, Ms. Moore, to inquire.

*Ms. Moore. Thank you so much, Mr. Chairman.

And I want to thank all of the witnesses for their patience. This has been a very long morning.

I just want to say to Ms. Brown please do not drop out of medical school. I mean, I am almost prepared to contribute to your Go Fund Me page. I am almost ready to volunteer one of our colleagues, a couple of them from Colorado to try to figure out. We can call the Lutherans, call the Catholics, call the Jews, call all of them, the NAACP, everybody to find people to help you do it.

Your mom would not be pleased if you dropped out of medical school. I am sure that as a grandmother and great-grandmother that I am speaking for her as well.

I thank all of you all professionals for being here today, and I guess I really think you have all really pointed out that there is no way that the people can afford long-term care at this point, and the uptake of long-term care insurance has been something that the majority of the population has taken on to the extent that it is going to ameliorate the social problem that this creates.

I hail from Wisconsin, and for long periods of time, Wisconsin have the largest number of people who were institutionalized and not being able to stay at home.

So a couple of things I guess I would love to see you address. First of all, just to talk a little bit more about the proposed cut in Medicaid that this administration is proposing in my State. It would mean \$21 per day per person cutting in care, the extent to which that would complicated the shortage of workers, the lack of pay for workers, and

what we ought to do with regard to that.

And I guess the next thing I would love for you guys to weigh in, I have an earned income tax credit proposal that would actually provide the earned income tax credit to caregivers to sort of meet some of the expenses of people who actually can keep their loved ones at home.

So that, would you please lean in?

Thank you.

*Dr. Lynn. Medicaid payment in most States is so marginal that any reduction means that you are just not going to have the workers that you need.

I was recently in a city in Ohio that has 250 people already assessed to need in-home care, and they cannot fill that need because they cannot hire the people. The workforce is just not there at \$11.80 an hour.

And the Medicaid reimbursement rate makes it impossible for an agency to provide more than \$11.80 an hour. So they are just sort of between a rock and a hard place. Those 250 people are just waiting till a calamity which will get them in the hospital, which will then get them into a nursing home under Medicaid rather than at home, which is a disastrous way to proceed. It is sort of designed by the devil.

And so, yes, we really must watch for the cuts in Medicaid. We have to look for ways in which people who are working as front-line aides get a living wage.

Your issue on the tax credits for caregivers, again, is a small step in the right direction. It is sort of like the previous question, you know, about having something of a family leave payment. It is a small step in the right direction.

It at least acknowledges the importance, but it also will not really help long-term situations like Ms. Brown's situation, which is what is becoming standard.

Remember the average person now -- just look around the room -- the average

person will have 2 years of self-care disability requiring someone else's help all the time every day. If you do not happen to have six or seven brothers or sisters or spouse that is still able to take care of you, you are in a tough spot.

So we need these small steps. We need to do those, and we need to do them quickly.

We also need to address the longer term issues.

*Ms. Brown. If I may just add to that, I just want to speak to the idea of having that tax credit for caregivers. I think that is a step in the right direction, but I do think that it does not solve the greater issue because that only puts more burden on caregivers to do an already impossible task.

So I think it would be helpful down the line. I think what we need is more support and more services to be able to hire trained professionals to care for our loved ones so that caregivers can have freedom and financial stability going forward.

Thank you.

*Ms. Moore. Thank you.

*Chairman Neal. I thank the gentlelady.

With that let me recognize the gentleman from Pennsylvania, Mr. Evans, to inquire.

*Mr. Evans. Thank you, Mr. Chairman.

Mr. Chairman, I, too, would like to join my great colleague from the State of Wisconsin and join her effort with Ms. Brown in any way from the City of Philadelphia, Brotherly Love and Sisterly Affection. So I join in any way I can be of help.

But while I am asking a question, Ms. Brown, what would you like to see Congress do to address this issue?

You have your chance to tell us what would you like to see us do to address this issue.

*Ms. Brown. Yes, thank you for that question.

So as I mentioned in my testimony, I think that we need to take a few steps going forward. The first is we need to address these gaps. There are many families like mine that are falling through the cracks because they are middle aged and middle income and not qualifying for Medicaid, Medicare or Social Security disability insurance.

I think we can start by expanding Medicaid such that individuals with disabilities are receiving the care they need. We can do that by changing the cutoffs that we have so that it reflects the cost of care because no one should have to spend more than their income, have their children go into debt, and miss school and not have a future just to meet these basic needs.

I also do think that we need to have a greater investment in home and community-based services. Families like mine and many seniors as well deserve to live in their homes and have a happy and healthy life there.

I do think that given the cost of home and community services, specifically home care through agencies, that is less than a nursing home. So I do think that it could be a very safe and more affordable option going forward.

And of course, I think that greater support for caregivers overall so the Family and Medical Leave Act giving paid time off, as well as perhaps having universities and workplaces give additional stipends to caregivers who might still be sacrificing a lot of their financial stability and their earnings to help their family members.

Thank you.

*Mr. Evans. Dr. Lynn, one of the most pressing issues I can think of when it comes to health care is the issue of inequality in terms of access and treatment. My district in Philadelphia has a poverty rate of 20.4 percent. Poverty is something that tends to affect people throughout the course of their lifetime often because of a lack of opportunity and

resources, like healthy food, good schools, affordable housing, well-paying jobs.

We live in a world where unfortunately your zip code can be a strong factor in determining your life expectancy. This is especially true when we look at the aging population.

They face difficulties finding care, affordable housing, and home delivery food. They depend on limited retirement savings and possibly cannot physically or mentally or financially afford to live by themselves as they get older.

Dr. Lynn, how can we work to make sure all older adults regardless of their background or zip codes can access the quality they need?

*Dr. Lynn. This really goes to the huge and growing gap in income for all disadvantaged groups, which adds up over a lifetime.

You know, Ms. Brown will have to pay off all those debts, and so she will start way behind somebody who comes out without the debts.

And the average black head of household at retirement has one-seventh of what the average white head of household has at retirement because disadvantage has accumulated over a lifetime.

As you say, we really need to be attentive to this inequity. At the present time on medical care and long-term care, the very poor at least have their safety net of Medicaid. It is the people just above Medicaid that are really put in a bad spot.

Some States have developed ways in which home and community-based services can be provided with a partial payment by the person. So if your income is a little too high, as your mother's is, she might have been asked to pay half of that income and then the rest be picked up by Medicaid.

Most States just have a cliff. If you make one dollar more than whatever the Medicaid eligibility level is, the only way Medicaid will help you is to move into a nursing

home whereby all of your income is confiscated except for maybe \$50 a month.

That is a really cruel choice to go into a nursing home at 30 or 40 years old and have no income beyond a little bit of pin money from there forward until you die. So people try very hard to resist that.

We need to have these sorts of sliding scale kinds of approaches. We also need to have fair equity in their lifetimes. In fact, we have to have a vibrant economy to support an aging population.

So the fact that we do not invest in children actually ends up crippling our ability to support the people in your community. We need to be not incarcerating nearly half of black young men. We need to really be investing in children.

*Chairman Neal. I thank the gentleman.

I recognize the gentleman from Texas, Mr. Arrington, to inquire.

*Mr. Arrington. Thank you, Mr. Chairman. Thanks for holding the hearing, very, very important to everybody up here, I can assure you.

And thank you to the panelists for your insights and your commitment to our aging population, our fellow senior Americans.

I have got a tremendous number of seniors in my district in West Texas, and we have some unique challenges being in a majority rule region of Texas. I am listening and learning. I have got a lot to learn, quite frankly, on this subject, in all candor.

But I just returned from my last work week, and I spent some time at a nursing facility called Silver Spring, and I am reminded of what a treasure our seniors are, and I feel like often we push them out of sight, out of mind. They are part of the forgotten community in this country, and they have so much to offer.

I mean, I left that place happier and in a better state of mind just having been around them. I mean, there was a lady who was holding a hymnal with one hand because

she had to bring it so close to read it and was playing the piano with the other, and she could play any song in that hymnal, and we sang together and we prayed together, and there is just a special something about our seniors.

And we need to honor them. I mean, that is the bottom line for me, is I want to honor them, and this is squarely in the mission of the Federal Government in the sense that we need to provide for the general welfare of the public.

This is a public good and it is the right thing to do.

Now, the question is: how do we do it right? Because these programs are not sustainable. We talk about Medicare Trust Fund, Social Security Trust fund. We look at the total ecosystem of safety nets for seniors. They are not sustainable. We all know that.

But at the same time, neither is our fiscal condition for this great country, \$23 trillion in debt, and I know you guys care about the next generation of seniors and Americans, not just our seniors, right?

So we have got to figure out how to solve this problem while not breaking the back of this country and putting more deferred taxes, because that is what the \$23 trillion is; it is a deferred tax. Someone is going to pay it. We may not, but our children are.

And I have not been to one hearing where we just had children and grandchildren out there where you are saying, "Please, please leave me the same freedoms and opportunities that you guys had, please."

It is just so easy to fix problems. It is easy to find the ways to fix problems without consideration for the means for how to do it, and I know that is our challenge and not necessarily something we have asked you to consider, but I want to put that out there because we do not talk about it enough.

And that is the biggest challenge, is what tradeoffs. And, yes, Mr. Banach. How do

you say your name?

*Mr. Banach. Banach.

*Mr. Arrington. Banach.

*Mr. Banach. I would love to address that.

*Mr. Arrington. Please, please. I am tired of preaching up here.

*Mr. Banach. Thank you.

First of all, hospice is one of those places that actually sort of provides some of that support and provides dignity. It provides chaplaincy services, and I think that is one of the things, but the problem is it is at the very end, and you have to give something up in order to get it.

Two examples from my own life in terms of, you know, folks that I have experienced care with that I mentioned in my testimony. My Great Aunt Ruby who is still alive and is just about 90 uses 911 as her primary care system, right?

So when we talk about what we can pay for and what we cannot pay for, the problem is the status quo, is someone like Ruby every week calls 911, ends up in the hospital every week, and Medicare pays for that.

But if Ruby needs a touch, if Ruby needs a conversation or support, forget it. She does not get it.

The other thing is the other woman I mentioned, my Great Aunt Grace, who died at 95. She declined, declined, declined, shut in, fifth floor walk-up for years and years and years, and so there is really nothing in this country that helps us to prevent those declines.

But when she fell down those stairs and ended up in the hospital and ended up in a nursing home, all of that is covered.

*Mr. Arrington. That is right.

*Mr. Banach. So, again, it is about the priorities we make as a country in being

reactive when something goes wrong and we put people together once they are broken, and we do not actually make those investments much earlier than that.

*Mr. Arrington. I agree with you. I think we could argue the same with respect to leveraging technology on the front end.

But I do not have any more time. I look forward to working with you individually to learn more and to help create a more sustainable safety net for our seniors.

Thank you, Mr. Chairman.

*Chairman Neal. I thank the gentleman.

With that, let me recognize the gentleman from Virginia, Mr. Beyer, to inquire.

*Mr. Beyer. Mr. Chairman, thank you very much.

And thank all of you for just for what you do every day, not just being here.

I mentioned earlier while we were meeting in the back that my sister developed early dementia, and the expense on the family was extraordinary. We were able to afford it, but I just could not imagine if you did not have a successful family business how you would ever be able to afford it.

I also was thrilled this morning to learn that for the first time ever the World Economic Forum in 2020 is going to have a focus on Alzheimer's, which is a major step forward when you get the leaders of the world who will have 60-some president of countries there for that.

And, Mr. Banach, I want to thank you because my mother, my father, and my sister all died while under hospice care, which made an enormous difference for us. So thank you.

And then the other thing I was fascinated to learn, you know, we struggle as Democrats and Republicans on the issue of our Federal debt, and we all know that you cannot make any progress on it by just looking at the defense budget or non-defense

discretionary, that it is Social Security, Medicare, and Medicaid.

John Larson has the eminently thoughtful Social Security 2100 bill, which I hope we will pass this year or next, which will solve one-third of that Medicare, Medicaid, Social Security leg.

But the notion that if we can successfully address dementia and long-term care, that could make a real dent in both the Medicare and Medicaid spending is pretty exciting for us. So thank you.

I want to look specifically at the issue of long-term care insurance. I am a Federal employee. So I get to sign up. So my rate only went to about \$5,000 a year. I understand from my wonderful staff it is about \$2,700 overall, but a lot of Federal employees saw their things go up to 226 percent of what they were before.

And now there is this new kick-in on the premium stabilization feature, that 3.0 plan, to try to hold these things down.

But, Mr. Blancato, Bob, with all of your experience with aging, we talk not just about how you fund it, but what are the other creative ways to try to hold the cost themselves down?

And is keeping people in their homes at least a subset of that?

*Mr. Blancato. Well, on the second part, absolutely, Congressman. Home and community-based services will end up being a much more cost effective way to do business.

I think the issue is there has got to be more of an inducement on the part of the contributors to long-term care, in other words, the working people contributing to the program so that it is not all about the claims that come later that bankrupt the individual plan.

So the more attractive a long-term care insurance policy is to a consumer, the more

likely they are to take it up, and then if enough people come into the program, you know, theoretically -- again, you cannot project all of these things because like Joanne say, there is a long tail involved with long-term care insurance -- but it has to do with more people recognizing the need to purchase long-term care insurance.

But also it is the responsibility of the industry to make the product more responsive to what consumers want. We have moved away from it being only nursing home insurance, which is a good thing.

And in the Federal plan I have some familiarity with it. It covers a lot of other things, including assisted living and in-home and care coordination, but that has got to be the way the market looks, too. The market has got to think in terms of what really is important to an individual to make them want to make that investment.

And I think that is where we have to go forward.

*Mr. Beyer. Dr. Lynn?

*Dr. Lynn. And you add that the what are called the IADOs, the instrumental activities of daily living, really should be able to be done in a neighborly way and not have to be paid for.

So there is a period of time in the decline of most people where they need help getting the groceries in or repairing their handrail or repairing a light bulb. Those things right now often fall to having to pay someone to do that.

We are working on a -- I have a pin right here -- the National Volunteer Care Core that is a very small, thin reed that Congress allowed last year that really should be worked up.

We should have villages and Care Cores in most communities. They are doing that part of the work so that the personal care is all that has to be paid for.

*Mr. Beyer. Great. Let me make one last point. Thank you, Dr. Lynn.

In July of this year, the Trump administration reversed Obama era protection for aging seniors and allowed forced arbitration back in nursing home agreements. You know, they are surreptitiously baked into the fine print.

And it is almost impossible for these residents or the decision-makers to be fully informed of voluntary consent to arbitration before dispute resolution.

So CMS, Center for Medicare and Medicaid Services, said, quote, "Significant evidence that pre-dispute arbitration agreements have a deleterious impact on the quality of care for patients."

I am out of time, but I just want to make that clear point that this is public policy moving in the wrong direction.

Mr. Chairman, I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Illinois, Mr. Schneider, to inquire.

*Mr. Schneider. Thank you, Mr. Chairman.

I want to thank the witnesses for joining us today, for sharing your perspectives, your experience, your expertise. In particular, I want to thank you, Ms. Brown, for the bravery in sharing your story, for the perseverance and courage your story reflects and demonstrates.

You have poignantly described how taxing and time-consuming caring for a family member can be. I will say this on a personal level as a proud Cherry Creek graduate, also from Denver, that your Colorado roots but your aspirations are inspiring, and I will join with my other colleagues. Whatever it takes, do not quit and let us know how we can help.

Now, as your personal story is distinct to you, the impact of your story is not unique. So many people share that circumstance. It is often too common where children and grandchildren of parents who are going through difficult circumstances are left to

ensure that their loved ones get the care that they need and deserve.

And this is a looming crisis. We are at a point where an entire generation is just beginning to hit the peak of their demand as patients in the need for care with, as we have talked about today, not enough caregivers to provide that care.

What it means is that the situation as you described is increasingly going to become the norm, not the exception, unless we establish the supports and resources necessary as you talked about, Dr. Lynn.

Some of that may come from the community, but much of it needs to come through, as you pointed out, Ms. Brown, allowing people to access care without having to give up their lives.

Compounding the crisis, as you testified Mr. Egge, is a growing share of seniors with Alzheimer's and dementia, and that number continues to go up each and every year. Over the past decade, Congress has rightfully increased funding for Alzheimer's research, but we are still a very, very long way, hopefully getting closer, but still a way from early diagnosis and much less a treatment and a cure.

And we are anxiously waiting for that very first survivor. Continuing investment in research is vital, but we also have to invest in those caregivers.

For seniors suffering from Alzheimer's and dementia right now, we have to find new and innovative ways to treat them, but we also have to take care of those around them.

Mr. Egge, are there any early demonstration projects or services you believe have been particularly effective at caring for our seniors with Alzheimer's, either at the State or Federal level?

And how can we expand on those to ensure more patients get the care they need?

*Mr. Egge. Thank you.

Yes, we know a great deal as the good news about what does work and what we can

do, what we can build on, and one of our major challenges is to connect those who need these services, given the awareness for how to make those connections and take advantage of what is available and what we have shown can work.

Programs like Reach VA, which is an intervention in the VA system to train caregivers to how to provide more effective care would be one of many examples.

We have also mentioned that we have tools on early detection and diagnosis, and we have to make sure our clinicians are using it to do just that, and then make those connections.

We have a lot more to learn as well, and that is one reason why, for instance, the increase in research at the NIH also focuses on developing health care system solutions for those with dementia because that is an important part of what we need to get better at.

So I appreciate the look all across the system at the things that we can do. We will have to make sure they happen, but there is much more that we need to learn as we have heard from all of the panelists today.

*Mr. Schneider. Great. Thank you. I appreciate that.

In my minute left, I want to turn back to you, Ms. Brown, and maybe take it from a different angle. You described your situation in high school when your mother was diagnosed with MS, and you talked about keeping it from your teachers, from other people you were at school with.

As you look back, are there ideas for programs we might do for, in particular, young people, people who are still in their studies, whether it is high school or university, to help them reach out, ask for help, but continue with their studies and continue to pursue their dreams?

*Ms. Brown. Yes, thank you for that question.

So you are absolutely right. In high school, I did not have people to reach out to.

Mostly it felt that we had gone down a whole list of options and there was no alternative.

I do think that for other young caregivers who might be in my shoes, I think we can help support them by first adding visibility and awareness of this issue. I think that many teachers, many adults simply are not aware that there are young caregivers out there. So having them knowledgeable about this issue and willing to lend a listening ear.

And as I mentioned also being able to have financial support for young adult caregivers, whether that is through supporting their loved ones themselves, I think that is very important because that would allow people like me to just be a teenager and young people and not have the social isolation and all those things that I experienced.

*Mr. Schneider. Great. Well, thank you, and I am out of time. I yield back.

*Chairman Neal. Thank you.

With that, let me recognize the gentleman from Ohio, Dr. Wenstrup.

*Mr. Wenstrup. Thank you, Mr. Chairman.

Thank you all for being here.

Ms. Brown, I want to start with you. I do not know how you are doing it. I do not know how you are doing it. I know when I was in school, I worked, but I did not have a sick parent, and I could be 500 miles away or so, and so I recognize what you are going through. You are going to be a great caregiver.

I think about when I was a resident and we were going through oncology rotations. You know, it was more about this patient has this and here is what we do for it, but I did not see the big picture.

I did not see the big picture until my sister got leukemia, and then you realize that this is a family event. This is not just that patient. This is everybody involved.

So you already got that heads up. You know, it took me until residency to figure out that these health issues are more than just the person there.

But I do want to say, too, I do not want you to quit because we can talk about all of these things. We have a caregiver shortage. We have a physician shortage and a shortage of residencies. And all the talk that we have in here about whether it is Medicare for All or whatever the case may be, if we do not have people like you continuing on your course, we are in big trouble.

And it is upon us to try and make sure that we can increase the number of providers and residency programs available. I hope you get your first pick when the time comes. Good luck to you.

But also, you know, Dr. Lynn, you talked about long-term plans. You know, I am in a situation as a doctor to put money away and develop a long-term plan. I got married late. I have got young kids. My wife and I are like I do not want to leave this all on them, and so we bought into a long-term plan.

Not everyone has that wherewithal or can think that far ahead, and we need to go in that way.

And you talked about neighborliness. You know, there is a lot of that that is missing. As you know, care for your next door neighbor sometimes. I even remember, you know, my great-grandmother would spend 4 months with my grandparents, then 4 months with my great aunt and uncle, then 4 months with my great aunt, and move around.

People do not have that like we had in the past, but I do recognize especially from my patients that had Alzheimer's what it did to the rest of the family, especially to a spouse, and I would have conversations with them and say, you know, "You are going to have to get help," and fortunately, a lot of patients I knew had the wherewithal to get help because it was taking your health down, too, because of the hours you put in and the challenges it comes with.

So these are real issues that I am so grateful you are all addressing, bringing to our

attention and knowing that it is something that is important.

Look. We have more seniors than we have ever had before. I hope that as we go forward we will find ways to maybe make recommendations to prevent Alzheimer's and to treat Alzheimer's.

You know, it took the 1960s to say smoking caused lung cancer. You know, maybe we will find some things that we are doing that we should not be doing that are leading to the problems besides just getting old.

And, Mr. Banach, thank you very much. My father diagnosed in January with pancreatic cancer, gone three months later, and hospice was wonderful. No doubt about it. Helpful, respectful, caring, able to pass away at home with his family all around him. That is as good as it is going to get in those situations. So I do appreciate it.

I also want to mention something, too, that was mentioned. Was it Dr. Lynn? Somebody said, you know, you have to get broken to be fixed, and you know, I have been saying for some time that as a health system, we are great at innovation and treatment and things like that, but we need to prioritize keeping people healthier longer.

And the more we can do, you know, you talk about falling, you know. How many does somebody fall, break their hip, and they are elderly, and that is the beginning of the end?

And I see things at home, groups like people working cooperatively. They will come in and fix your home so even your toilet paper holder is a grab bar. There are all of these things that we can try to do to prevent calamities that lead to a bad outcome.

And I think we need to keep thinking in that direction, and we should focus on the health span of people, not just their lifespan, but how do we keep people healthier longer?

So I am doing a lot of talking, but I do want you to comment if you could quickly on the challenges of rural hospice because my district is both urban and rural.

*Mr. Banach. Well, thank you. Thank you so much for your comments, Congressman.

In rural America the challenge is often just to get someone to come out and provide you with help, and so clearly it is an area where technology can help.

I think that we also see the challenges in rural America of social isolation, of depression, of addiction, and what you really need there is someone to come and provide you with some support.

Unfortunately, hospice is only there at the tail end, and you know, as you said, you should not need to get broken. You should not need to be at the very end in order to get some supportive services.

The volunteerism of hospice is, I think, something that the rest of the health care system can get, and I think we are seeing signs of that, and I think there is support for the family with hospice as well. So thank you for your question.

*Mr. Wenstrup. Thank you, Mr. Chairman.

*Chairman Neal. Thank you, Doctor.

With that, let me recognize the gentleman from New York, Mr. Suozzi, to inquire.

*Mr. Suozzi. Thank you, Mr. Chairman.

This is such an important issue that you have called this hearing about today. We hear all of these personal stories from everybody. It affects us all personally. It affects me personally.

I want to thank the witnesses, certainly you, Ms. Brown, as everybody has pointed out. It is such a wonderful story, and to all of the witnesses for you devoting your lives to this issue. We appreciate your expertise, and we appreciate you waiting here all of this time for the hearing. We have been in and out, and you have been sitting there the whole time.

I see Dr. Lynn is getting more and more cold when her sweater comes on because it is so cold in here.

But we really appreciate everybody's expertise, and we need your help.

I am just going to tell you quickly my personal story. I grew up in a house. All four of my grandparents lived in the house growing up. Three were very sick.

I really look back it now. My mother was so remarkable in the way she helped to take care of them. She was a registered nurse, but she was a full-time caregiver for everyone.

My parents recently passed away. My father was 95, had dementia issues at the end of life. My mother was 93. They both had long-term health care insurance, and we had home health caregivers. My sister came to live at the house for the last 3 months of my mother's life.

I was the mayor of my hometown where I had three nursing homes, and when I was the mayor back in the 1990s, we helped build three assisted living facilities, a big model that started to grow in the 1990s.

And then I was the county executive of a big county in New York State where we had this unusual model with the local governments, the City of New York and the local counties have to pay towards our Medicaid. We had hundreds of millions of dollars of Medicaid expense, most of which is for nursing homes.

And looking at it, I learned so much about this cottage industry that exists, encouraging families of elderly people to get rid of their assets, give it to their kids or give it to their spouse, and then have spousal refusal or the kids refuse to take care of them, and then it is legalized. It is fraud, quite frankly, but it is legal. It is legal. I do not want to mischaracterize it, where people get rid of their assets, and then the government pays for Medicaid, and it is a huge expense.

And there is a storm coming. As all of you have testified, there are so many more people that are going to be in this situation as the years go on, senior citizens especially growing in enormous numbers, and if they have to be cared for in nursing homes, which is not the best way to end life I would argue, and we have to pay for it through Medicaid, it is going to break the bank and it is going to be a bad system that people's lives have no quality of life.

So what do we have to do? We have to talk about this more than we are, and we have to talk about people's end of life issues. We have to talk about what it means to become frail and what are you going to do and talk about your death decisions you have to make.

And we have to get people to plan for the future, and we need people to buy long-term health care insurance, but it is unaffordable right now. There is no good model that exists out there right now for long-term health care insurance.

So we have to figure out how to create an affordable long-term care program for people, and I would suggest, but I am not going to be wedded to it, that it be a public-private partnership of some type.

So I want to offer right now, especially to you, Dr. Lynn, but to anybody else who is willing to work on this. Let's try and figure out what would be the model. Let's work with industry. Let's get the insurance companies that used to do long-term health care insurance that do not and find out what the problems are.

Let's look at your suggestion, Dr. Lynn, of figuring out the public piece of the government subsidizing the long tail and working with industry for them to create what it would take for the public-private partnership, where the government helps, industry helps, expertise of yourselves.

I will work on that with you, and I will ask my Republican colleagues if someone

wants to work with me on this, that we develop a bipartisan proposal to finally start addressing long-term health care insurance because the storm is coming. It is right around the corner, and it may be here already.

And for some families it is here already, like Ms. Brown's, where people just cannot live with this.

So, Dr. Lynn, you talked about a pilot program. Would you be interested in trying to explore either working with industry or doing a pilot program?

*Dr. Lynn. Absolutely. That is what we need. Mr. Schweikert was saying, you know, "Where is the voice of optimism?" This is the voice of optimism.

*Mr. Suozzi. That is me. I am a very optimistic person.

No, so I want to meet with you. I want to talk about this. I want to actually develop a model, and maybe we could do it with a pilot program in my home country, for example, or some other place and maybe find a Republican who wants to do it in their county, but let's do a pilot program or let's go right to industry and set up a model.

*Dr. Lynn. Do both.

*Mr. Suozzi. Okay. Thank you.

Would anybody else be interested in participating in that effort?

*Mr. Blacato. Yes, absolutely.

*Mr. Suozzi. Mr. Blacato.

*Mr. Blacato. Absolutely. A lot of New York insurance companies would be interested up there, too.

*Mr. Suozzi. Yes. You heard all of the stories from all of the members here. This touches every single family. This is so real. This is something people care about a lot more than a lot of things they see on television these days.

How do we address long-term health care? This really will resonate as a political

matter, and it will actually make people's lives better, and we just need to get together and do the hard work necessary to figure out the answer.

So I thank you so much for your testimony here today.

We are so grateful.

And thank you, again, Mr. Chairman.

*Chairman Neal. I thank the gentleman.

We do have votes on the floor, but we would like, if possible, to finish up here.

The chair will recognize the gentleman from California, Mr. Panetta, to inquire.

*Mr. Panetta. Outstanding. Thank you, Mr. Chairman.

And thank you to the witnesses for your preparation and for your experience and for being here today and sitting here this amount of time but, more importantly, what you have to say.

Obviously, this can be a tough topic to talk about, but fortunately, you are here to provide the testimony, but also you have been here, and I appreciate that, and other members have responded to you as well, not just members on this dais that you see here, especially Congresswoman Sanchez, but also members before us who have picked up the torch and basically put forward legislation like the bipartisan effort that, Mr. Banach, you mentioned 37 years ago in talking about the Medicare hospice program.

That provided a great comfort to beneficiaries, their families and obviously to caregivers and allows people to live out their final days of their lives with dignity.

But over the last decade as you know, that program has grown in popularity and has led to new challenges ensuring a high quality of care.

In July the HHS, Health and Human Services, Office of Inspector General put out a couple of reports, as well as the GAO put out a report, one titled "Caring for Aging Americans," the other one by the GAO talking about nursing homes, better oversight

needed to protect residents from abuse.

And I would ask for unanimous consent to introduce these into the record, Mr. Chairman.

*Chairman Neal. So ordered.

[The information follows:]

[HHS Statement for the Record](#)

[GAO Statement for the Record](#)

*Mr. Panetta. Thank you.

Fortunately, we have the reports, but unfortunately, they highlighted several cases of extreme neglect and patient abuse and facility deficiencies. Now, these reports make it clear that we do need to strengthen oversight in our hospice program in order to better protect the integrity of this program and for those that seek comfort at the end of their lives.

Now, obviously, I want to thank you and thank the Ways and Means Committee, as well as industry stakeholders and the NHPCO for working with me on legislation to improve the programs and to ensure that the most vulnerable patients are provided the services that they need in a setting that they can trust.

Now, Mr. Banach, if I could, as you know, the only remedy for hospice providers that was cited with significant deficiencies is removal from the Medicare program, correct?

*Mr. Banach. That is correct.

*Mr. Panetta. And the OIG recommended that CMS adopt alternative sanctions for hospice, which are included in the hospice program integrity bill introduced by Senators Portman and Cardin.

How will hospice providers adapt to those types of alternative sanctions?

*Mr. Banach. Congressman Panetta, thank you for your leadership around this.

We are fully supportive of the idea that we really have to do three things around program integrity. One is better education. The other is between transparency for consumers, and the third, which you were just talking about, is better oversight.

Hospice providers are going to have to adapt. The fact is that the ones that are following the rules and are doing things the right way actually welcome additional intermediate sanctions that are somewhere in between. You can be a program till you cannot be a program and efforts really to sort of improve their ability to provide care.

So I think that we are a partner in that and NHPCO is in terms of providing

education, and the government is a partner in that.

One size does not and should not fit all. So in terms of government oversight, a program that has been in existence for one year and one that has been in existence for 40 years may have different levels, yet they are surveyed the same exact way. They are overseen the same exact way.

So the ability of the government to have more tools at their disposal is something that we support, and we thank you for your work on this.

*Mr. Panetta. Yes. No, well, thank you for your help.

Like I said, and I think as all of us know up here on this dais, we cannot do this without the support from all of you. So thank you very much.

Also, are you continuing to work with CMS on implementation and providing guidance to hospices?

*Mr. Banach. Absolutely, both with CMS and with OIG. We actually recently had a town hall meeting with the OIG where they took questions and provided input to our members, and we have had significant discussions with CMS as well.

I think that, you know, for better or worse, we have learned from the way that other industries have sort of often pretended that there are no problems. There are problems, and it is our responsibility to make sure that we enhance the services that are provided to folks.

Our North Star is the consumer that is on the receiving end of care, and we want them to get the best care possible.

*Mr. Panetta. Thank you, and I look forward to accepting that responsibility with you.

*Mr. Banach. Thank you.

*Mr. Panetta. Thank you. I yield back.

*Chairman Neal. I thank the gentleman.

Let me recognize the gentleman from Kansas, Mr. Estes, to inquire.

*Mr. Estes. Thank you, Mr. Chairman.

And thank you to all of the witnesses for joining us today. I know you have had a long day and helping us go through this effort.

You know, with 10,000 Baby Boomers retiring every day it is important that we make sure that our current health care and long-term care systems have the capacity to help support our aging Americans. However, the capacity right now is about half of what it needs to be, and we need to make sure that that process is improved.

We need to improve the quality of care delivered to seniors at certain facilities as well, as we have talked about in the OIG report.

Shortcomings in capacity and quality of care, however, are due in part under Medicare the Federal Government is the customer, not the patient.

To address some of these issues facing Americans, there are some specific areas I would like to address. First talks about nursing home care. One way to improve nursing home care is make sure that we do a thorough overhaul of the system.

We also need to make sure that there are simple process improvements, that we streamline the administrative burdens to put the focus back on patient care and not on paperwork and bureaucracy.

That is one of the reasons I was proud to introduce, along with my colleague, Representative Evans, H.R. 4468, the Nursing Home Workforce Quality Act. Not only this legislation introduced some common sense process improvements, but it also helps ensure that the quality standards of nursing homes are upheld, allows for additional oversight of nursing homes with systemic problems, and addresses critical shortage in certified nurse assistants.

Specifically, the legislation allows nursing homes that have triggered a 2-year ban

on the in-house CNA training to immediately resume such programs after the Secretary has certified that all quality concerns cited and fined have been addressed and resolved.

This ensures that nursing homes continue to meet high quality standards without losing staffing levels which we know are critical to the quality of care that the patient receives.

That is one of the issues that I see running through my district with folks talking about not having enough of a skilled workforce ready to help provide the needs that they need.

While I am looking forward to continuing to work on this effort, I want to make sure that abuse, neglect, and other systemic problems that cause patients harm or to receive low quality of care cannot and will not be tolerated.

I have got a question here, Mr. Mollot. It is my understanding that hospitals, skilled nursing facilities, home health agencies, and in-patient rehab facilities have regulations that include the patient's right to be free from abuse and neglect. However, only skilled nursing facilities have regulations that define such terms as abuse and neglect.

Are the definitions of abuse and neglect defined adequately in your opinion?

*Mr. Mollot. For nursing homes specifically?

*Mr. Estes. Yes.

*Mr. Mollot. I think that they are good definitions. I think the fact that they are not well enforced, of course, implies that there is a disconnect.

It is hard to say because, again, I think that the definitions are really good. I think that the outlines are there. We have worked with CMS for years on developing the guidance around that as well as, of course, the initial regulations, and so the language is there. The bones are there.

The fact of the matter is that as I mentioned before, they are just not implemented

by CMS or by the States.

*Mr. Estes. Should we have similar definitions across some of the other facilities as well?

*Mr. Mollot. Well, I think in terms of abuse and neglect, abuse and neglect is abuse and neglect anywhere because like good dementia care is good dementia care anywhere. So I am not an expert at all by any means on hospitals or other settings besides nursing homes and other residential care.

But I would say, yes, it makes sense to me.

*Mr. Estes. Yes, thank you. I appreciate that.

In addition to talking about nursing home care, I will also make a quick comment about Alzheimer's and our fight against that.

We all know Alzheimer's is one of those most costly diseases for the elderly population, specifically long-term care costs, but thankfully, we live at a time with medical innovation, and just last month Biogen submitted approval from the FDA for a new drug to treat Alzheimer's.

This is news I am sure to give a lot of hope to so many doctors, patients, and caregivers touched by this devastating disease. I hope that in my lifetime we will be able to find new treatments for Alzheimer's that improve the quality of life for these patients and ultimately reduce the cost associated with this tragic disease.

With that I yield back my time, Mr. Chairman.

*Chairman Neal. I thank the gentleman.

The pending vote on the floor just gives us very little time. So I would like to recognize the gentleman from Nevada, Mr. Horsford, to inquire.

*Mr. Horsford. Thank you very much, Mr. Chairman, and to the ranking member for holding this hearing.

Like so many others in this room, providing quality care to our loved ones who are seniors is deeply personal, and I want to thank my colleague, Congresswoman Sanchez and Mr. Panetta, as well as the entire panel for your expertise and your personal perspective and, Ms. Brown, again, for bringing a young perspective to the challenges that so many people face.

When I was just 9 weeks old my grandmother suffered a debilitating stroke and went into coma for 6 months, and when she came out, she was paralyzed on the left side of her body and ended up needing around-the-clock nursing care in order to provide the quality of life that she had for 27 years until she passed away.

I visited my grandmother virtually every week in a nursing home until she passed, and so I know what good nursing home care look like and what bad care looks like. You can literally smell it when you walk into a facility and whether they care for their patients properly or not.

I also want to share another Nevadan story, Mr. Billy Ellison from North Las Vegas. Billy is 81 years old and recently spent time in a short-term post-acute hospital. His wife Sylvia reached out to my office recently seeking help for Billy and shared her horrific experience, an experience which is all too common for seniors in some facilities throughout the country.

Billy's care providers, the individuals that are responsible for his health and safety, stopped caring for him appropriately, especially when it came to cleaning his ailing body. They stopped bathing him properly, and they would not rotate him on his sides frequently, which led to painful bed sores.

He has since left the facility and is healing in his home, but when he was released, Sylvia was worried about who was going to help her take care of Billy, a challenge which we have discussed in this hearing impacts one in seven American women who become the

primary caregivers for loved ones in their lifetimes.

According to the AARP, caregiving is particularly time intensive for those caring for a spouse. Most spouses provide nearly 44.6 hours of care a week, truly a full-time job.

Luckily, my office was able to work with the Ellison family and help them secure a home health nurse. Since we communicated with them last, Billy and Sylvia have reported that they are happy with the nurse who comes to their home and supports their family's caregiving and medical needs.

So I am glad that my office was able to assist Billy and Sylvia, but it should not take congressional assistance for America's seniors or their loved ones to live their lives with dignity and respect by our health care system.

So, Mr. Mollot, I want to ask. You specialize in the long-term care on which my grandmother depended. Can you speak to how Congress can help work to provide seniors with alternatives to traditional nursing homes and how these alternatives may improve a patient's quality of life?

*Mr. Mollot. Yes, thank you for that question.

I would just like to say, first of all, because we talked a lot or touched a lot upon nursing homes that nursing homes are supposed to provide a home-like setting and care with dignity, resident choice, resident direction, et cetera, and the fact that it does not, that so many of them you know right away and I do, too, when I visit one if it smells bad that there is something wrong here, but sometimes even when it smells good, there is something wrong there because those requirements are ignored.

And we just hope and pray that there are family members as advocates to avoid pressure ulcers, to avoid being drugged to death.

That being said, there are alternatives, of course, and more and more people are looking for those alternatives, assisted living, home care that has come up a number of

times today.

The problem and issue from our perspective is that we are seeing a population, as people have noted, who have needs that are considerable, and if they are getting care in their homes, if they are getting care in assisted living, a more residential setting, that is great, but there has to be some kind of quality and some kind of monitoring that is meaningful and consistent.

And that is what we are really missing.

*Mr. Estes. Throughout the entire system.

*Mr. Mollot. So I think going towards assisted living, as I mentioned in my statement, more and more States -- I think 48 States now -- have Medicaid assisted living. It is a good deal for the assisted living provider as well. There is a high reimbursement rate.

But we have facilities that are taking people with dementia, taking people who have high physical and clinical needs without even having a nurse there, without even professional staff.

*Chairman Neal. I thank the gentleman.

*Mr. Mollot. Thank you.

*Mr. Estes. Thank you.

*Chairman Neal. With that let me recognize the gentlelady from Florida, Ms. Murphy.

*Ms. Murphy. Thank you, Mr. Chairman. And thank you for holding this hearing. As next to lowering the cost of prescription drugs, the ability to afford to age with dignity and at times age in place is one of the issues I hear the most about.

But given the limits of time, I would like to submit my statement and questions for the record.

*Chairman Neal. So ordered.

[The information follows:]

[Rep. Stephanie Murphy Statement and Questions](#)

*Ms. Murphy. Thank you, and I yield the remainder of my time.

*Chairman Neal. I thank the gentlelady for that courtesy that she has extended.

And let me thank our witnesses for their testimony.

Please be advised that members have two weeks to submit written questions to be answered later in writing. The questions and your answers will be made part of the formal hearing record.

And with that the Ways and Means Committee stands adjourned.

[Whereupon, at 1:38 p.m., the Committee was adjourned.]

Submissions for the Record follow:

[American Association of Retired Persons](#)

[American Association of Service Coordinators](#)

[AMDA](#)

[America's Health Insurance Plans](#)

[American Physical Therapy Association](#)

[American Speech-Language-Hearing Association](#)

[Center for Elder Law & Justice](#)

[Center for Aging Americans](#)

[Center for Medicare Advocacy](#)

[Dean Lerner](#)

[Leading Age](#)

[Human Rights Watch](#)

[Justice in Aging](#)

[Fracture Prevention Coalition](#)

[National Consumer Voice for Quality Long-Term Care](#)

[National Hospice and Palliative Care Organization](#)

[National PACE Association](#)

[Service Employees International Union](#)

[Private Care Association](#)

[Rep. Brian Higgins](#)

[Rep. Stephanie Murphy](#)

[Rep. Terri Sewell](#)

[Texas Association for Home Care & Hospice](#)

[United States Department of Justice Office of the Deputy Attorney General](#)

[West Health](#)

Questions for the Record follow:

[Questions for the Record from Rep. Gomez](#)

[Joanne Lynn Response to Questions for the Record from Rep. Gomez](#)

[Questions for the Record from Rep. Holding](#)

[Edo Banach Response to Questions for the Record from Rep. Holding](#)

[Edo Banach Response to Questions for the Record from Rep. Kelly](#)

[Questions for the Record from Rep. Larsen](#)

[Joanne Lynn Response to Questions for the Record from Rep. Larsen](#)

[Questions for the Record from Rep. Suozzi](#)

[Robert Mollot Response to Questions for the Record from Rep. Suozzi](#)

[Questions for the Record from Rep. Murphy](#)

[Bob Blancato Response to Questions for the Record form Rep. Murphy](#)

[Richard Mollot Response to Questions for the Record form Rep. Murphy](#)