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ALZHEIMER'S AWARENESS: BARRIERS TO DIAGNOSIS, TREATMENT, AND CARE COORDINATION

HEARING

BEFORE THE

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OF THE

COMMITTEE ON FINANCE

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ALZHEIMER'S AWARENESS: BARRIERS TO DIAGNOSIS, TREATMENT, AND CARE COORDINATION

WEDNESDAY, NOVEMBER 20, 2019

U.S. SENATE,
SUBCOMMITTEE ON HEALTH CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 2 p.m., in room SD–215, Dirksen Senate Office Building, Hon. Patrick J. Toomey (chairman of the subcommittee) presiding.

Present: Senators Roberts, Thune, Cassidy, Lankford, Daines, Young, Portman, Stabenow, Cantwell, Menendez, Carper, Cardin, Brown, Casey, Whitehouse, Hassan, and Cortez Masto.

Also present: Republican staff: Alyssa Palisi, Staff Director for Senator Toomey. Democratic staff: Alex Graf, Staff Director for Senator Stabenow.

OPENING STATEMENT OF HON. PATRICK J. TOOMEY, A U.S. SENATOR FROM PENNSYLVANIA, CHAIRMAN, SUBCOMMITTEE ON HEALTH CARE, COMMITTEE ON FINANCE

Senator TOOMEY. The subcommittee will come to order. Welcome to the Senate Finance Subcommittee on Health Care hearing "Alzheimer's Awareness: Barriers to Diagnosis, Treatment, and Care Coordination." It is my pleasure to welcome four witnesses today for an important conversation on challenges with treating and caring for Alzheimer's patients and the emotional toll this disease takes on caregivers.

Alzheimer's disease is really in a category of its own. One in ten seniors has Alzheimer's disease. According to the Alzheimer's Association, in 2019 alone this disease and other related memory disorders are estimated to cost $290 billion in health care, long-term care, and hospice services. The majority of these costs, about two-thirds, are borne by the Medicare and Medicaid programs and, worst of all by far, there is no cure.

With November being National Alzheimer's Disease Awareness Month, I want to briefly share a story about an individual with Alzheimer's who candidly shared his experience with thousands of Pennsylvanians. Bill Lyon, a beloved sports writer at *The Philadelphia Inquirer,* passed away on Sunday at the age of 81 after a hard-fought battle with Alzheimer's disease.

Bill wrote many columns detailing his 6-year battle with the disease. In one column he described it as "an insidious, relentless, and a gutless coward who will not come out and fight. Instead, he lies in ambush in my brain, and the only way I can put a face on him is to look in the mirror."

I would like to ask unanimous consent to enter a couple of articles detailing his battle into the record, without objection.

[The articles appear in the appendix beginning on page 77.]

Senator TOOMEY. Like Bill and his family, there are millions of Alzheimer's patients and their loved ones who know this disease all too well. I know firsthand just how devastating it is to families. My own father and grandmother passed away after years of struggling with Alzheimer's. Finding a cure for this disease must remain a top priority. And I am optimistic that a cure will be discovered in my lifetime.

That said, progress has been very slow. Despite billions of dollars in public and private investment, Alzheimer's patients have very limited options. Just a handful of medicines are available, and they only slightly reduce the symptoms of the disease. For this reason alone, Congress must not undermine future investment by the private or public sector in their efforts to find cures by upending drug research and development. And, while finding a cure is one challenge, access to necessary long-term care services is another.

Medicare offers very limited coverage for long-term care needs. If you are very wealthy, these services are easily affordable. And for very low-income individuals, these services are available through Medicaid at little or no cost. But the average American approaching retirement is not at all likely to have nearly enough cash savings to cover the average cost of a typical long-term care event, such as the need for nursing home, or in-home care due to the onset of a chronic illness.

A large number of middle-class families face financial ruin at the hands of Alzheimer's. To guard against extraordinarily high costs, long-term care insurance can be a viable option. Yet only 17 percent of adults actually own such a policy. Many families without long-term care insurance find premiums to be unaffordable, but insurers have had to charge higher prices due in large part to longer than expected life expectancy of beneficiaries with Alzheimer's disease.

One way to address high premiums is to expand the risk pool by attracting healthier or younger enrollees. Congress ought to consider legislation that makes it easier for families who are planning ahead to buy long-term care policies.

Toward that end, today I released the discussion draft of legislation that would empower individuals to use their retirement plans to buy long-term care policies on a tax-free basis. Today, some individuals can use their 401(k)s to buy life insurance. Similar treatment ought to be given to long-term care insurance.

I hope to gather additional feedback on this idea and to introduce formal legislation soon. I look forward to hearing from our witnesses and hope to work on a bipartisan basis to reduce the barriers that we discussed today.

I now yield to the ranking member, Senator Stabenow, for the purposes of her opening statement.

[The prepared statement of Senator Toomey appears in the appendix.]

OPENING STATEMENT OF HON. DEBBIE STABENOW, A U.S. SENATOR FROM MICHIGAN

Senator STABENOW. Well, thank you very much, Mr. Chairman. It has been a pleasure to work with you on this hearing. I know we share a passion for this issue, as all of us who are here today do. Welcome to all our witnesses, particularly my friend from Michigan. We are looking forward to hearing from you as well.

Everyone in this room really knows the numbers, and the chairman has spoken about the numbers. We have 5.8 million Americans living with Alzheimer's today, including one out of 10 people over the age of 65, and that includes 190,000 people in my home State of Michigan. But this is not about the numbers. This is about people's lives. It is about individuals. It is about families. This really is a family disease. And we are here today to talk about the families who watch this horrific disease steal their loved ones away, one memory at a time.

We need better treatment. Families need more support. Most of all, we need a cure. The good news is, we are making some progress. But as the chairman indicated, it is not as fast as we all want it to be. For decades, research on the brain, which is the most complex organ in the body, was funded as if it was one of the least important. That has changed. Since 2011, Federal funding for Alzheimer's has more than quadrupled. New researchers are entering the field and moving the science of Alzheimer's forward.

We need to keep that up. We need to make it faster, because telling a smart scientist with a great idea that there simply is not enough money to fund their research could mean a cure passes us by.

I have also been focused with my colleagues on efforts to provide more support for patients and their families. After a successful bipartisan push, the Centers for Medicare and Medicaid Services implemented our HOPE for Alzheimer's Act. This means that Medicare is now reimbursing for a doctor's visit to create an individual care plan for a patient and their family for newly diagnosed Alzheimer's patients. The benefit ensures doctors give a clear diagnosis to patients, including information about what treatment options there are, what medical and community services also are available. This is good for patients. It is good for families. It is good for the Medicare program.

Unfortunately, the Centers for Medicare and Medicaid Services have not been doing aggressive outreach and education to healthcare providers and patients, as called for in our legislation. And so, in fact, we talked yesterday with leadership from CMS about moving much more aggressively for doctors to know about this benefit—for patients and families to know.

But we have also introduced the Improving HOPE for Alzheimer's Act, which I have been joined in by 46 bipartisan Senators, including, on this committee, Senators Menendez, Scott, Carper, Cassidy, Cardin, Daines, Brown, Lankford, Whitehouse, and Cortez Masto. And so this is a strong bipartisan effort. We will move forward to pass the bill, but this can be done administratively, and we hope that it will.

Our bill requires HHS to conduct a nationwide campaign to increase awareness and usage of the care planning visit. Building on the care planning benefit, I have also introduced legislation with Senators Capito, Menendez, and 15 others called the CHANGE Act, which will encourage timely and accurate detection and diagnosis using evidence-based tools. Only 16 percent of seniors receive regular cognitive assessments during health-care checkups. Our bill will fix that. We made a lot of progress, but we have so much more to do. And that is why we are here today.

And again, I am looking forward to our discussion and how we can work together to move forward to support families, support patients, and find a cure.

Thank you, Mr. Chairman.

[The prepared statement of Senator Stabenow appears in the appendix.]

Senator TOOMEY. Thank you, Senator Stabenow. Without objection, any other member's opening statements will be made part of the record. And now we will hear from our witnesses.

First we will hear from Dr. Jason Karlawish, a professor of medicine, medical ethics and health policy, and neurology at the University of Pennsylvania, as well as the co-director of the Penn Memory Center. I am proud to say the Commonwealth is home to one of the top academic research centers in the country, in fact in the world, and Dr. Karlawish will discuss barriers to diagnosis and treatment of Alzheimer's disease.

Next we will hear from Ms. Janet Tomcavage, chief nursing executive at Geisinger. I am glad to have you with us today. It is great to have one of the Nation's largest integrated health service organizations here to offer insights into how we can improve care coordination activities in the Medicare and Medicaid programs.

We will then hear from Mr. Marc Cohen, a professor of gerontology and co-director of the LeadingAge LTSS Center at the University of Massachusetts Boston. He also serves as research director at the Community Catalyst Center for Consumer Engagement in Health Innovation. Dr. Cohen will discuss improvements that can be made to increase the availability of affordable long-term care insurance.

And last but not least, I will yield to the ranking member for the introduction of her constituent.

Senator STABENOW. Thank you very much, Mr. Chairman. It is really my honor to introduce my friend Lauren Kovach, who is a board member of the Alzheimer's Association, Michigan-Great Lakes Chapter. She has been a fierce advocate for Alzheimer's since her beloved grandmother Helen was diagnosed with the disease.

Lauren, along with her mom Pat, cared for Helen, whom Lauren called "Chupe," for more than 15 years. Each year, Lauren is a top fund-raiser for her local chapter's Walk to End Alzheimer's, which raises awareness and funds for Alzheimer's care, support, and research. Her story was also featured in the spring 2019 edition of *ALZ* magazine. Frankly, Alzheimer's is a top priority in my office in part because Lauren makes sure that it is. And so I am so glad that you are here. Thank you for traveling from Michigan to join us.

Senator TOOMEY. Thank you, Senator Stabenow.

As a reminder, each witness will have 5 minutes to present their oral testimony. We will begin now with our first witness, Dr. Jason Karlawish.

STATEMENT OF JASON KARLAWISH, M.D., PROFESSOR OF MEDICINE, MEDICAL ETHICS AND HEALTH POLICY, AND NEUROLOGY; AND CO-DIRECTOR, PENN MEMORY CENTER, UNIVERSITY OF PENNSYLVANIA, PHILADELPHIA, PA

Dr. KARLAWISH. Thank you, Senator Toomey and Senator Stabenow, for your invitation. I greatly appreciate it.

So on Tuesday, July 15, 1980, the people of the United States met Alzheimer's for the first time. The occasion was a joint House and Senate hearing on "The Impact of Alzheimer's Disease on the Nation's Elderly."

There was, by the way, one and only one Congressperson present at that hearing, Senator Eagleton. The first witness, the first American to speak to her fellow Americans about living with Alzheimer's disease, was Mrs. Bobbie Glaze, one of the founding members of the Alzheimer's Association. She told the story of her husband's dementia. The neurologist delivered his diagnosis in the waiting room. Ignorance and indifference were the norm. She said, "I was given no explanation of what Alzheimer's disease is, what to expect, how I might learn to cope, nor was I directed to someone who might be able to direct me in the monumental problems that lay ahead."

So I am a physician. I trained in geriatric medicine. I am a researcher at the University of Pennsylvania. I co-direct the Memory Center dedicated to the diagnosis, care, and research for persons living with Alzheimer's and their family members. Had the Glazes been cared for at a memory center such as where I practice, they would not have suffered as they did. Unfortunately, there are still too many persons with Alzheimer's disease and their families who are telling the same story as Bobbie Glaze told some 40 years ago.

The typical new patient visit at the Penn Memory Center begins with a family recounting a despairing narrative of frustrated months, even years, searching for answers and struggling to get care. To make a diagnosis and to care for a person living with Alzheimer's disease, I need about 60 minutes to discover that the person has cognitive impairment, that this impairment causes her to be less efficient in performing her day-to-day tasks, or that she needs someone else to actually assist her with those tasks.

By "day-to-day tasks," I mean activities of daily living like managing a checkbook and using the computer. "Less efficient" means the person struggles but can still carry on. That is what we call "mild cognitive impairment." If you need someone else to help, what I am describing is "dementia." In a word, the person is disabled.

I interview not one but two people. I interview the patient, like any adult doctor with adult patients, but I also interview someone else who knows the person well, like a partner or an adult child. And that person typically goes on to become their caregiver. I see them later for a diagnostic follow-up visit to explain the diagnosis. They then meet with a social worker to address the patient's functional needs and caregiver strain. We may, for example, recommend a driver's evaluation, or a review-only access to the patient's bank account.

The plan is ongoing. We train the caregiver how to talk to the patient about attending an adult day program and how to help the caregiver locate one—and how to figure out how to pay for it.

There are tremendous benefits to this standard of care. It has been shown to lead to shorter time to the diagnosis, and it lowers Medicare costs in the year after receiving that diagnosis. We are able to do this at the Penn Memory Center because we benefit from cross-subsidies from research and philanthropy. This is standard of care, but it unfortunately is not the routine. There is a scarcity of physicians skilled in diagnosing and discussing a treatment plan with a person living with Alzheimer's disease and their caregiver.

There is a shortage of geriatricians, geriatric psychiatrists, and neurologists, as detailed in my written testimony. Physicians who do have the skills lack the resources to practice them. The most important intervention you can provide to your constituents in your States is to give American medicine a business model to diagnose and care for patients with Alzheimer's disease.

The code that has been mentioned earlier by Senator Stabenow, the Cognitive Assessment and Care Plan, is a tremendous step forward to achieve this. It recognizes the complexity of a workup and the need to include a caregiver in the workup, and to create a care plan. This is exactly what Bobbie Glaze was searching for 40 years ago. Unfortunately, as you know, only about 1 percent of those eligible to get that code receive it. So here is your charge. Here is America's charge.

We have to study who is using this code, who is not, why are they using it, why are they not, and how is it working? And we should do that study with the same urgency as we study the Alzheimer's biomarkers to discover a cure and better treatments.

Some preliminary results from my own work to figure out why: I have found out that some Medicare Advantage plans are not paying for it. Primary care practitioners are confused about how to implement it across visits. We at the Memory Center do not use the code, actually, because social workers do the bulk of our work around care planning, and they are not allowed to be covered under the code. The code needs to reimburse not just for that one-time care planning, but it needs to reimburse for the ongoing management and care of the patients, because this is a chronic disease.

And finally, I would ask CMS to look very closely at how this code is integrated into or can be better integrated into its extremely ambitious and very important Comprehensive Primary Care Plus initiative, otherwise known as CPC-plus.

Thank you. I greatly appreciate your interest and look forward to the Q&A, and my colleagues' presentations as well.

[The prepared statement of Dr. Karlawish appears in the appendix.]

Senator TOOMEY. Thank you, Dr. Karlawish. Ms. Tomcavage, you are recognized for 5 minutes.

STATEMENT OF JANET TOMCAVAGE, R.N., MSN, CHIEF NURSING EXECUTIVE, GEISINGER, WINFIELD, PA

Ms. TOMCAVAGE. Thank you, Mr. Chairman and members of this subcommittee. I would like to outline a few challenges and opportunities that we believe are needed to improve the care of individuals with Alzheimer's, and take a few minutes to describe some of the innovative programs that we are doing at Geisinger, and identify barriers that we think should be removed.

One of the biggest barriers that we see is really a lack of understanding and education on what I would call how to take action by both individuals who are affected and their families, as well as the physicians who are caring for the elderly.

Often people will say, "Oh, I am just getting older," thereby minimizing the subtle signs of memory loss or confusion, and really not drawing it to physicians' attention. There is also a fair amount of complacency in the medical community around treating common conditions such as hypertension, which contributes significantly to the physiologic changes that are occurring in the aging brain.

We need a community awareness campaign, much like we have done for heart disease, breast cancer, or the opioid crisis. We have not addressed Alzheimer's in that way. In most cases, memory and thinking challenges are identified too late, as we have heard. Better education, more time with seniors, and reliable assessment tools are needed in the primary care setting.

We need to include memory and cognition as part of Medicare's annual wellness visit and complete formal memory assessments on seniors as a standard of care. In addition, we need to push out care to patients in their homes, telehealth services that will allow us to remotely leverage clinical experts such as neurologists who are in short demand, particularly in rural areas, to appropriately assess, treat, and monitor patients whom we know are starting to demonstrate mental decline. In addition, we need home services to evaluate the safety and social supports of the home, which are critical components of a comprehensive plan of care.

The health-care system has really a relatively weak infrastructure to support patients and their caregivers. Services such as adult day care, respite, and home assistance, and better advanced care planning lack adequate funding. These services can keep people safe and in their own homes. Payment for unlicensed caregiver support will be critical in the long-term success for keeping individuals with Alzheimer's in their homes and in their communities and out of custodial care. Even hospice has a gap. When we go in hospice, we give up many services that are needed to keep patients and individuals safe in their home.

I would like to turn to a little bit about what we at Geisinger are trying to do to identify and deliver an integrated approach to senior care. Geisinger opened its first Memory and Cognition Center last year, led by a behavioral neurologist and a multidisciplinary team. We have a physical location open full-time and consultation outreach, but we are limited. The waiting time to get patients into that center is significant.

We also implemented Geisinger at Home last year, where we send a team of health-care clinicians directly into high-risk patients' homes. We provide an array of services, including clinical and social assessments to optimize the treatment plan, and we can provide acute treatment center services directly in the home that avoid unnecessary emergency department and hospital utilization.

We work closely with patients' goals of care, particularly around advanced illness and end of life. We have seen almost 5,500 patients in Geisinger at Home, and we have seen incredible results. Admissions to the hospital have reduced by 35 percent. ER is down by 20 percent. And we have saved about $500 PMPM, or per member per month, in our Medicare Advantage Plan.

And then finally, 65Forward is a new primary care model that we just implemented in August of this year. 65Forward is only for seniors. It is a primary care office that is only open for individuals who are over 65. We have reduced panel size for physicians to about 400, compared to the 2,000 that normal primary care providers take. We do annual wellness visits and comprehensive memory and cognition testing, all in an effort to develop individual plans of care. We have on-site pharmacy, nutrition, et cetera.

In summary, I think that there is much that can be done. I believe the most urgent need and the biggest opportunity is funding to ease the burden for families caring for loved ones with Alzheimer's. New payment models are needed to support care giving services. Second, we need to support a more comprehensive education for our primary care providers. Early detection, screening, and intervention will make a difference.

Thank you.

Senator TOOMEY. Thank you very much, Ms. Tomcavage.

[The prepared statement of Ms. Tomcavage appears in the appendix.]

Senator TOOMEY. Dr. Cohen, it is your turn for 5 minutes.

STATEMENT OF MARC A. COHEN, Ph.D., CLINICAL PROFESSOR OF GERONTOLOGY, McCORMACK GRADUATE SCHOOL, AND CO-DIRECTOR, LEADINGAGE LTSS CENTER, UNIVERSITY OF MASSACHUSETTS BOSTON; AND RESEARCH DIRECTOR, CENTER FOR CONSUMER ENGAGEMENT IN HEALTH INNOVATION, COMMUNITY CATALYST, NEWTON, MA

Dr. COHEN. Thank you, Chairman Toomey, Ranking Member Stabenow, and members of the subcommittee, for the opportunity to testify. I will draw upon my more than 30 years of research on how the private long-term care insurance market could help middle-class Americans pay for care, including Alzheimer's care. I say "help" because this challenge is far too big for either the public or the private sector alone to handle.

I would like to focus on a few broad points about current problems and how to improve the affordability and accessibility of private long-term care insurance. First, because the long-term care risk is perfectly suitable for risk pooling through insurance, we have an opportunity to move our financing system for middle-class Americans away from a private-pay, safety net-based impoverishment model toward an insurance-based approach. Private insurance can play its part in helping move toward this goal. Second, making private insurance more accessible means making it more affordable and attractive to consumers, which will require a multipronged strategy. Finally, even in the context of market improvements, voluntary private long-term care insurance is likely to play, at best, a modest role in meeting our challenge. Paradoxically, public insurance models could very well spur significant growth in the private market as sectoral roles become better defined and citizens can plan appropriately.

Most middle-income Americans are not poor enough to immediately qualify for Medicaid until they spend down much of their savings to obtain program eligibility. And penetration of private long-term care insurance is relatively small. In addition to consumer confusion about the risk, the product, and the roles of the public and the private sectors, the costs of traditional and combination products remain out of the financial reach of many middle-class Americans. And this is a shame, because those who have purchased policies and need care receive significant value from their policies. Research shows that they are very satisfied, and their coverage is enabling their needs to be met while at the same time reducing burdens on family caregivers. So what can be done?

To increase accessibility, efforts should be focused on reducing selling costs and making changes to product design to make products less costly. Efforts could also include targeted tax incentives. And we also have to enhance the value proposition to consumers so products are perceived as a good deal and attractive.

Currently, for example, products are level-funded, but they could be priced on a term basis, much like life insurance, and then become level-funded at a later age. Additionally, premiums and benefits could be indexed to costs which lower initial premiums.

Should policymakers decide on tax incentives for the purchase of private policies, one approach would be to provide targeted middle-class benefits, including a reshaping of benefits, like inclusion of long-term care coverage in cafeteria plans and FSAs, and treating premiums as qualified 401(k) expenses with no early withdrawal penalties. To be effective, such tax benefits need to be targeted to individuals with savings plans who could otherwise not afford policies, and the benefit would have to be high enough to induce purchase. To reduce selling costs, insurance could be made available as part of other health-care offerings.

To enhance consumer confidence, the new policy offered by the Federal Long-Term Care Insurance Program, for example, includes a premium stabilization feature. And long-term care offerings could be sold on the exchanges and as enrollments in Medicare and Medicare Advantage, or employers could be required to offer education and policies that have people, on an opt-out basis, make their choice.

Without the development of some level of public insurance, however, we will not be able to insure the vast majority of middle-class Americans. Washington State passed the Nation's first public insurance program, which leaves a great deal of room for private insurance to supplement the public coverage. Also gaining interest is a public approach covering catastrophic or back-end costs, along with steps to encourage private insurance take-up rates to protect against up-front costs. Again, private policies could be positioned as supplements, not unlike Medigap insurance.

In closing, the solutions put forward to improve the affordability and accessibility of private insurance in my written testimony, even if they are incremental, need to be part of a comprehensive enough approach to reflect the magnitude of the problem that we are facing. A joint public-private approach could make a big difference for families with significant long-term care needs like those who suffer from Alzheimer's and related dementias.

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

[The prepared statement of Dr. Cohen appears in the appendix.]

Senator TOOMEY. Thank you, Dr. Cohen.

Ms. Kovach, you are recognized for 5 minutes.

STATEMENT OF LAUREN KOVACH, ALZHEIMER'S ADVOCATE, BRIGHTON, MI

Ms. KOVACH. Good afternoon, Chairman Toomey, Ranking Member Stabenow, distinguished members of the subcommittee. Thank you very much for the opportunity to share my personal story on the impact Alzheimer's has had on my family. My name is Lauren Kovach, and I am here today to share my story as a caregiver and an advocate with the Alzheimer's Association and Alzheimer's Impact Movement.

About 20 years ago, my life took an unexpected turn when my grandmother, Helen Tannas, was diagnosed with Alzheimer's at the age of 82. 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. My grandmother lived to take care of her family. We are Macedonian. That is what we do. Growing up, my mom, brother, and I lived four houses down the street from my grandmother, and since my mom was a single working mom, we were always over at Grandma's.

As a child, my grandmother was a daily part of my life. I never imagined life without her down the street. I was 21 years old and in my third year at college when my grandmother was admitted to the hospital. I was terrified at the thought of losing her. She spent 10 days in intensive care undergoing a battery of tests which resulted in several diagnoses. All of the conditions were treatable, except one: early stage Alzheimer's disease.

When I was growing up, my grandmother had a pet name for me. She called me "moe chupe, moe chupe." That is Macedonian for "my girl, my girl." So 1 day after her diagnosis, I turned to my grandma and said, "You are my chupe. You are my girl." The nickname she had given me so many years ago had come full circle. It was now our turn to give back the love and sacrifice she had always given us.

And so my mom and I made a pact that we would do whatever it took to keep my grandmother home, and we prepared for the longest good-bye of our lives. After the diagnosis, we adjusted our lives to become full-time caregivers. I withdrew from college, and eventually my mom had to retire early from her teaching career. We knew we needed to take steps to care for the woman who spent most of her life caring for us, but we did not know what those steps were or how to make a plan.

We did not even really know what deciding to be a full-time caregiver meant. There was a long and very bumpy road ahead for all of us. When we were discharged from the hospital, that was it. They gave us our discharge papers and wished us the best of luck; no pamphlets, no explanations, no support. There we were, facing this life-changing news and having to immediately make one major decision after the other with no time or guidance to make a long-term plan. We were not aware of resources that could have helped my mom and me manage the stress of caregiving, like adult day services, or possibly respite care.

Unfortunately, we learned about those too late, after my grandmother had passed away. Fortunately, families now facing an Alzheimer's diagnosis have new options that were not available to my family. In 2017, Medicare began covering comprehensive care planning services to people with cognitive impairment, a critical step in improving the quality of care and quality of life for those with Alzheimer's and their caregivers.

Having a care plan would have helped us answer those first questions of "How do we take care of her, and what do we do now?" Everyone should have access to this lifeline. However, fewer than 1 percent of seniors living with Alzheimer's actually received care planning in 2017. That is why I am so thankful to Ranking Member Stabenow for introducing the bipartisan Improving HOPE for Alzheimer's Act, which is already co-sponsored by 46 Senators, including many of you on the subcommittee.

This important bill would help increase access to care planning services that would have significantly improved the quality of life for my grandma, my mom, and me. Full-time caregiving while navigating the health-care system is both physically and emotionally draining. I cannot describe the level of exhaustion and desperation that we felt.

I learned to live in the moment, figuring out what to do as I went along, because I did not know how much time I had left with her. We kept on fighting. It was not always easy, but my mom and I were able to keep my grandmother home for her entire journey. From the time she was diagnosed, my grandmother never spent a single night by herself.

In 2017, my grandmother declined into the late stage of the disease. My chupe started dying on a Saturday. She had lived with Alzheimer's for 15 years and passed away on June 3, 2017, at age 97. I crawled in bed and laid my head on her chest as she was taking her final breaths. I told her, through tears, that it was okay to go, and I promised her that I would never stop fighting for her, for the three of us, and the immeasurable bond that we shared.

I am determined to fulfill that promise. It is why I continue to volunteer hundreds of hours each year as an advocate.

Thank you for holding this hearing today, and I respectfully request that you continue to make Alzheimer's research a priority and work together to pass critical legislation like the Improving HOPE for Alzheimer's Act. We must do all we can to ensure the best quality of life and care for those living with Alzheimer's and the people who are for them.

Again, thank you for the opportunity to share my story. I look forward to answering any questions you may have.

[The prepared statement of Ms. Kovach appears in the appendix.]

Senator TOOMEY. Thank you very much, Ms. Kovach, for a very compelling and powerful story. I appreciate it. I appreciate all of our witnesses today.

Let me begin with an observation here. I expect every one of us is frustrated by the fact that, after all these years, we still do not have a cure for Alzheimer's. Yet it strikes me as odd that we sometimes seem unwilling to declare victory in other areas where we have had great success. I am thinking of the incredible success we have had in fighting HIV/AIDS, which no longer is a death sentence. In fact, today the number of Americans who die from Alzheimer's runs at least seven times greater than the number who die from HIV/AIDS, and the HIV/AIDS death number is declining.

The number of Americans living with Alzheimer's today is five times higher than the number with HIV/AIDS. Overall cost to taxpayers to treat Alzheimer's patients is nearly 10 times the cost of treating and preventing HIV/AIDS. And maybe most importantly, HIV/AIDS now is a chronic illness that is very well managed and, with the proper medication, victims live normal lives for decades. It is a fantastic victory, while Alzheimer's is still a death sentence.

And yet, despite those facts, the NIH spends more money on research for HIV/AIDS than it does for Alzheimer's. I think it is time to reconsider how we allocate these resources.

But let me move on to the draft that I released earlier today. This legislation—well, it is not legislation yet, but I hope to introduce it as such soon. And it is meant to deal with access and affordability of long-term care insurance. The proposal, the idea, is to move the needle on affordability by allowing families to use retirement dollars to buy long-term care insurance on a tax-free basis. Dr. Cohen alluded to this idea in his comments.

And it would do so by making the following simple changes. It would allow individuals to withdraw funds from their 401(k)s and IRAs for the purchase of long-term care insurance without facing what they would face today, which is a 10-percent early withdrawal penalty. And it would exclude the withdrawal from income tax to the extent that it is used to pay for long-term care insurance, with some cap, let's say $2,000 annually.

So, Dr. Cohen, the data from the Joint Committee on Taxation shows about a quarter of middle-class taxpayers under the age of 65 actively contribute to retirement accounts, and therefore they would be presumably eligible to benefit from this proposal. That adds up to over 24 million households. And for this population, the middle-class family that is saving for retirement, I would just like to ask you for your comments.

Do you think that this change in our tax law would help these folks to make long-term care more accessible and more affordable?

Dr. COHEN. Sure. Thanks. Yes, I mean it will, for those people who have those savings accounts, for two reasons. One, of course because, in a sense, you are making the cost of the insurance cheaper, and so that of course is an incentive.

But I think even more important, having that available there is a clear signal being sent to people at a young age that this is a risk that they need to start considering even in their working years, their 40s and their 50s. And for that reason, people who would otherwise not even have knowledge that this is coming down the road would have to make an asset decision.

Senator TOOMEY. I would like to ask whether there is a possible additional benefit to this. And that is, presumably by making it more affordable, you would have a higher participation rate in the purchase of long-term care, including by younger and healthier people. In your view, is that likely to expand the risk pool in a way that would itself tend to lower premiums so that we create almost a virtuous cycle of driving down the cost of long-term care?

Dr. COHEN. That is a good point. If a policy like this indeed brings in a wider risk pool, then that can lead to a number of things. Number one, the need for underwriting. The strain on underwriting diminishes because you have a wider base in the risk pool. That can then indeed lower premiums. I think that is the key point, and I think you hit that really.

Senator TOOMEY. And also just the sheer scale. If, as you say, it does in fact induce people to participate, the scale of that participation allows whatever fixed costs to be distributed over a larger pool and thereby also further tends, all else being equal, to drive down the cost.

Dr. COHEN. Yes. And one of the components of that, of course, is the marketing cost, which is a driver of insurance.

Senator TOOMEY. Right.

Dr. COHEN. And so you end up needing to spend less on the education and so on to elicit purchase.

Senator TOOMEY. Thanks, Dr. Cohen. And I recognize Ranking Member Stabenow.

Senator STABENOW. Thank you, Mr. Chairman. Thanks to all of you. And, Lauren Kovach, thank you for sharing your personal story. I know your grandma is very proud of you right now. So we are so glad that you are here.

You mentioned the Improving HOPE for Alzheimer's Act and the fact that we need to make sure that people are sent home with more than what you got, discharge papers and the best of luck, which happens to too many people. And I appreciate your support and help with this as we are moving this forward.

But could you talk more about what care planning with your grandma's doctors would have meant to you as a caregiver?

Ms. KOVACH. Sure. So the things I know now—and down the road we were denied for Medicaid, like you talked about, and you know, you have to spend it down, and really Medicare did not cover any services that we knew of at that time.

So essentially we had zero help—zero. It was just my mom and me. And so all these years, looking back, if someone had said to us, "Hey, here, even reach out to the Alzheimer's Association," I would have said, "Oh, my gosh, there is a whole association for this?" Or if they were to say, "You know, we can have somebody help you do a care planning session." If I would have learned back then about things like possibly getting an elder care attorney, or the ins and outs of Medicaid and Medicare and all this, we might have had a better idea of how to plan for the future.

And we talk about long-term care planning, but we did not know that was a thing. A lot of people do not think about that until it is too late. So if we had all those resources back then, I feel like maybe our 15 years could have been quite a bit easier on both my mom and me.

Senator STABENOW. So you really did walk out not knowing any of these things and had to try to just figure it out as you went along?

Ms. KOVACH. Well, luckily we have the University of Michigan and the Alzheimer's Disease Center right by us, so eventually we said, "Okay, you know, maybe we should kind of look into this Alzheimer's Center," and we took her there and got her tested and met a wonderful physician there. But, no, we kind of just navigated this through ourselves.

Senator STABENOW. Well, I know you did a great job, but we need to make sure that that is not happening to family members and patients as they go into the doctor's office and hear about this diagnosis.

Dr. Karlawish, I appreciate your testimony and appreciate the great work that is being done through your UPenn Memory Center. And you talked about—well, I should say the CHANGE Act, which Senator Capito and Senator Menendez and a group of us have introduced, is really working to address several of the issues that you talked about in your opening statement: increasing the use of evidence-based detection tools, making sure physicians appropriately document a diagnosis in the medical record, ensuring referral to appropriate services and specialists.

I know that you are doing that. We have some Centers of Excellence in Michigan that are doing that. But not everybody is doing that. In fact, my guess would be that the majority are not, and not everyone is having access to this. So when we look at this, does what we are doing through the CHANGE Act make sense to you? And what else do we need to do to make high-quality care the norm not the exception in terms of public policy-making?

Dr. KARLAWISH. Yes. If someone is diagnosed in America today with diabetes, it is expected that they are going to have the opportunity to meet with a dietician and get an education about how to live with diabetes. It certainly is not expected that they are told they have diabetes, here is your prescription, see you in 6 months. And that is just expected. Similarly with heart disease. The expectation, for example, after a heart attack is access to cardiac rehab and education. So I think two very common prevalent diseases where we of course—well, why does that exist in those diseases? Because there is a business model to support and sustain that.

I have used that phrase, and I know it may sound awkward to hear from a physician about the, quote, "need for a business model," but simply put, physicians need time to take care of patients, and time is money. And they need to be reimbursed appropriately. The problem in the case of the diagnosis of cognitive impairment and the diagnosis of Alzheimer's disease is that physicians right now do not have the adequate reimbursement to cover the time that they would need to do that.

That is why I think CPT code 99483 offers that opportunity. But as I pointed out, the uptake is so low. So I think that the challenge is how to find out why they are not using it, what are the barriers to using it? And as I said in my remarks, I think that that is as important a research project as research to discover better treatments.

I would suggest we think about creation of comprehensive Alzheimer's centers in regional areas where the difficult cases, the complicated cases, can be referred. They can also be centers of training for physicians out in the community as well, to do workups. We have that for cancer centers, for example.

Senator STABENOW. That is a great idea. You talk about the fact that you need about 60 minutes, which of course is a longer period than a regular visit that a physician would have, and that you talk to someone other than the patient and develop a plan, which is terrific.

I wonder if you could just talk about the downstream effects of investing in such a high level of care, and how do outcomes compare to patients who actually leave the office with what happened with Lauren—just "good luck"?

Dr. KARLAWISH. Right.

Senator STABENOW. I mean, there is a case to be made, I assume, for doing it the way you are doing.

Dr. KARLAWISH. Yes, there is. You cannot—right now, you cannot diagnose Alzheimer's disease if you do not talk to someone else, because you need that collateral history to understand the clinical significance of whatever cognitive problems you have picked up on testing. This is not just the fancy stuff we do at Penn because I am an academic. That is the standard of care. I was part of a group writing diagnostic guidelines for physicians in America that the Alzheimer's Association organized.

And one of our standard recommendations is to get collateral information from an informant. That is standard. That person also generally becomes the caregiver as well. So what physicians need is, they need to be able to have that additional time to talk to that other person, the spouse, the daughter typically, sometimes the son, to find out what is going on and make sense of whatever they picked up on cognitive testing.

When I talk to my colleagues who do not have the sort of hour that I have, what they tell me about is how they try to break it into a series of visits, two, three 20-minute visits. I have talked to colleagues in other countries, and that is what they do as well.

So you know, my message to CMS would be: let's educate the physician workforce about how to restructure a visit to both interview the patient and interview an informant. And that probably is going to take more than 20 minutes. It probably will take more than one visit. What the physician wants to know is, can I do this in a way that I can document it, get compensated, and not fall behind and not be told at the end of the month, "You are way down on your RVUs"? And that is the challenge.

Senator STABENOW. Thank you. Thank you very much.

Senator TOOMEY. Thank you. Let me just inform everyone, a vote is underway, and I am going to recognize Senator Cassidy.

And, Senator Cassidy, I would like to suggest that if neither Senator Stabenow nor I are back, but Senator Roberts is here, then if you would recognize him when you finish. And, Senator Roberts, if you would proceed to take the gavel until such time as I am able to return, I would be grateful.

Senator Cassidy?

Senator CASSIDY. First, let me associate my remarks with Senator Toomey. I did my residency when the AIDS epidemic broke out. Society responded, spending hundreds of billions of dollars to find treatments. And a disease which was not diagnosable and was fatal is now something you live with, and you might be more likely to die with Alzheimer's if you have HIV than from HIV.

So it does seem like we need to redirect. HIV still gets 10 percent of NIH's budget, roughly. Why don't we take 10 percent and give it to Alzheimer's? That is the one which is most pressing, and most pressing on the fisc.

So, related to that, one of the arguments—and I do not expect any of you to weigh in on that—but I do expect you to weigh in on this, Dr. Karlawish. One of the arguments against investing more in basic research for Alzheimer's is that the science is not mature, that it is a barren field, if you will, and even if you put more money there, it would be like rain on a concrete sidewalk—it would just roll off.

Is that true, or, no, really there is basic research opportunity that if better funded would develop more?

Dr. COHEN. It is not true.

Senator CASSIDY. So more dollars would be helpful on the basic research aspect of it?

Dr. COHEN. Absolutely. I——

Senator CASSIDY. And I do not mean to cut you off, I just have lots of questions.

Next, you mentioned the business model—and this will be to you and Ms. Tomcavage. There is a Medicare Advantage Special Needs Plan which theoretically is a business model for caring for those with dementia. I will take your point. It is not for the initial diagnosis. But it would be after diagnosis. Is that MASNP not an adequate business model for the care of the patient?

Ms. TOMCAVAGE. So I would say that, if you are in a value-based payment model, that is the way we need to go. So a lot——

Senator CASSIDY. So the MASNP would be the way to go?

Ms. TOMCAVAGE. Yes, because you have a premium dollar that is at risk, right? And you work with providers to minimize dollars that are spent on non-necessary things.

Senator CASSIDY. So, Dr. Karlawish again—I only have 5 minutes now that Senator Roberts showed. Before I had a lot more time.

Dr. Karlawish, you mentioned that the social worker does not get paid, even though the social worker is doing that which is within our scope of license, et cetera, et cetera. But under the MASNP, Ms. Tomcavage, it really seemed like the social worker could be reimbursed regardless.

Ms. TOMCAVAGE. So the social worker is not reimbursed, but if the social worker is provided as a resource from a value payment perspective versus the fee-for-service——

Senator CASSIDY. Yes, I get that. I get that. And if the effect is the same, you can still pay for it.

Ms. TOMCAVAGE. Exactly.

Senator CASSIDY. So, if you will, there is a—we may need to tweak it for the initial diagnosis. The other thing we have been working on, for example, is the direct primary care model to be used by Medicare. And a direct primary care I think would also—because you mentioned the rate-limiting step is, you need an hour.

But if you have a direct primary care physician who will spend as much time as necessary, then all of a sudden that would take care of that initial diagnosis. I will make a plug for that.

Dr. KARLAWISH. I do not know what a "direct primary care"——

Senator CASSIDY. That is kind of like a blue-collar concierge where you pay $50 to $75 a month for a physician who then is at your beck and call, so to speak. And they have to bring value, or else you terminate the contract. And so they are there to make sure that you do not have to come back for 15-minute aliquots of time. You come back for the time you need, and otherwise you cancel the contract. It really is a very market-based approach. The family practitioners love it.

Dr. Cohen, you mentioned tax incentives to purchase, or tax-preferred—but health savings accounts can now be used to purchase long-term care insurance. Do we need something more than the HSA, which is currently available? Why do we need more than the HSA's ability to pay for long-term care insurance, I guess is my question.

Dr. COHEN. I think the proof is in the pudding. You know, the take-up rate and the use of the HSAs for those purposes is very small.

Senator CASSIDY. I get that, but I think that is almost a lack of awareness of the need. I mean my dad, the day my children were born, bought a policy for $1,000 which gives him like a million dollars of coverage for the rest of their life. So if he bought everybody long-term care insurance the day they were born, that would make a difference, right?

Dr. COHEN. Awareness is definitely part of the issue. But the other part of the issue is that—I think the sweet spot is the people who, in the absence of insurance, would have to spend down to Medicaid. So it also depends on——

Senator CASSIDY. Yes, but it still takes a kind of "I am not going to think about that because I have more pressing needs now."

Dr. COHEN. Absolutely.

Senator CASSIDY. It almost seems like it would have to be mandatory. Let me ask one more quick question on telehealth, digital health. It seems like you could do a lot in this space, particularly for a rural person.

Dr. Karlawish, it seems like you could actually do much of your exam via a well-done telehealth visit, and certainly if you combined it with some digital health. Any thoughts?

Dr. KARLAWISH. I think the follow-up care, particularly once there is a diagnosis and a care plan and an identified carrier in place, I think a lot of follow-up care can be done by telephone.

Senator CASSIDY. I am not speaking telephone, but——

Dr. KARLAWISH. Yes, sorry; I am very 1970s on that one. It can be done by very sexy digital things and whatnot. But I do think that the initial visit really does require a face-to-face engagement. But subsequent care, particularly talking with the caregiver to help solve problems, manage behavior problems, manage other functions, can very well be delivered by remote methods. And oftentimes, actually, that is what we do at the Memory Center, particularly when people have problems with behaviors and it is very difficult to get them to come in. Hence, the need for engagement via electronic media.

Senator CASSIDY. I found, though—and I will finish with this—I have found that many of those who are poor and rural will never get to a neurologist.

Dr. KARLAWISH. Access for individuals in rural areas to medicine in general is a challenge, absolutely.

Senator CASSIDY. I yield back. Thank you all. And, Ms. Kovach, very moving.

Senator ROBERTS [presiding]. Thank you to all the witnesses. I have a full speech that I am not going to read into the record because it is very duplicative of all of us who care very much about this disease, this threat.

I am particularly struck, Lauren, with your testimony about your grandmother. Maybe it is Macedonia, but there is a Macedonian diet, by the way, and that is supposed to be helpful. I do not know if that was the case or not. But the thing that struck me was, as you said, when you were first discharged from the hospital, that was it, bingo, just, "You are out of here."

And I think that is one of the things that unfortunately still happens to a lot of us, or a lot of people who are simply not aware of treatment facilities, long-term care, et cetera, et cetera, et cetera.

How many read the article in *The Wall Street Journal,* "What Science Tells Us About Preventing Dementia"? Did anybody read that? Well, we can make copies. How about that. But this caught my eye because it was the first time I had really seen anything for the individual who may be worried about themselves, and I think that is a real concern.

We just lost a brother-in-law not too long ago. He was very good at masking what he thought was ongoing, and he would not ask for help. He was in Arkansas and felt very embarrassed about even asking about it with his colleagues.

And so the only thing I recognized was that he would be very quiet for a longer period of time. But he always had this impish grin, anyway, and so I just thought he thought something was terribly funny that I said. So, you know, I let it go. That was unfortunate. For several years, I think, I can think back that that was the case.

Here is what they say, if I can get to number one. Number one is low blood pressure. I guess that is up to the individual, and you do what you have to do.

Number two is exercise. Everybody pretty well understands that—you know, back to blood pressure.

Number three is cognitive training, that education increases a cognitive reserve, a term for the brain's ability to compensate for the neurological damage. The Framingham study, for example, found that participants with at least a high rate really found some progress with this.

Four is diet. And there is a Mediterranean diet, and there is something here that I do not recognize. The Mediterranean diet, the MIND diet—and it is the MIND diet that comes way ahead. Does anybody know what the MIND diet is? It does not go ahead and explain that. I would have to Google it to find out what on earth you do with a MIND diet. But the Mediterranean diet maybe would be the same as in Macedonia.

And number five is sleep. Then there are a lot of things about what you are doing every day. And it says if you do five or six things a month, you are okay. We do five or six things every day here, so I guess that protects us to some degree.

I want to know about the caregiver. I want to know what each of you thinks is the best way that we can be of help to the caregiver, given Lauren's testimony. And I am assuming that was some time ago, Lauren. That really worries me, because of personal situations that I have gone through with family of mine and other relatives and otherwise, and I think we need a lot of help with the caregiver almost as much as we do with the patient.

Would any of you like to comment? Yes, sir.

Dr. KARLAWISH. I agree. I want to pick up from Ms. Kovach's remarks. She talked about how she, quote, "became a full-time caregiver." Essentially what she was describing was "I took on a job," and your mother took on a job. And in our remarks before, our conversation before the hearing, you told me that your mother actually left the workforce as a teacher to do this, which meant she left making money. She was no longer contributing to Social Security. If she was under 65, maybe she had to struggle to get health insurance, because we tie health insurance to a job oftentimes. It was a job, but of course she did not think of it as a job. She was taking care of someone she loves. But yet that is what she was doing, losing wages.

And I think we have to respect the fact that we want families to care for these patients because they best understand the individual. They best can make them feel at home and give them the dignity they want. That is what we want.

But we have to understand that when we ask daughters, and sometimes sons, and partners to care for individuals with cognitive impairment, we are asking them to take on a job that they are not getting paid to do and that, as a result, they are losing wages. Some of them do not have health insurance because they are not yet 65, unless they can buy into the exchanges, for example. And they are not contributing to the economy anymore.

And so they are not contributing to a productive America anymore. She was not teaching students anymore. I have daughters in my clinic who reduce and/or leave work to care for their families. So they are not contributing to the American economy anymore, and they are working as unpaid workers to take care of their relative because they love them. And they are the ones who should do it.

So that is what we have to address for our caregivers, the economic burden. One-third to one-half of the cost of Alzheimer's disease to America is the cost of you and your mother taking care of your grandmother. That is the economic crisis.

Senator ROBERTS. I thank you for that answer. I apologize to my colleagues for going over time. I just want to emphasize, I think that we could do a lot better job in somehow unifying a response effort across the country. We were talking about telemedicine before, and that is a big thing out in my part of the world. I am from

Dodge City, KS, way out there. And that does not mean that we do not have hospitals, et cetera, et cetera, et cetera. But the telemedicine part of it is really outstanding.

It would be wonderful if a person going through this could hook up almost immediately with it.

I recognize the distinguished Senator Menendez.

Senator MENENDEZ. Thank you, Mr. Chairman. Thank you to the witnesses for sharing your insights and expertise.

Alzheimer's disease not only presents our Nation with an enormous health-care and fiscal challenge but also takes a tremendous toll on every family that is forced to confront it.

I know this at a deeply personal level, as my mother suffered with Alzheimer's for 18 years before it claimed her life. And during the early years of her diagnosis, there were many days that mom seemed just fine. But year after year, those good days became fewer and farther between. It was a long and heart-breaking goodbye to the strongest woman I have ever known. [Pause.]

And I know the pain that my family felt is the same pain felt by families of more than 180,000 New Jerseyans battling Alzheimer's today, and millions more Americans nationwide.

I know about the inter-generational challenges that confront people caring for their ailing parents and grandparents, as Dr. Karlawish was talking about. My sister was a legal secretary, and I was down here in Washington, so our choice, because of cultural preferences, was to keep mom at home. And so that meant her having to largely give up her job and me trying to supplement the income at the same time she was getting her son through medical school and I was getting my two kids through college—these intergenerational challenges of taking care of a loved one in the twilight of their life and being able to have the resources to prepare for your children.

I know the extraordinary physical and emotional demands placed on caregivers and the vital role that Federal programs like Medicare and Medicaid play in patients' lives.

So whether it is investing in life-saving medical research, or protecting the rights of patients diagnosed with early-onset Alzheimer's, or defending the Medicaid coverage relied on by one in four seniors with dementia, I believe we have to pursue every strategy we can to improve the lives of patients with Alzheimer's and help their families cope with the demands of their care.

To that end, I would like to ask you, Dr. Karlawish, do you believe that we have the clinical workforce needed to ensure the treatment of the growing number of Americans—that they will receive the best care with the most recent advances regardless of where they live?

Dr. KARLAWISH. I do not.

Senator MENENDEZ. That is what I thought the answer is. And that is just one of the dimensions of this challenge that we need to address.

Let me ask you also—Latinos are more than one and a half times more likely to develop Alzheimer's as their white counterparts. African Americans are twice as likely to develop the disease as their non-Hispanic white counterparts are. Are there any current schools of thought why these groups have higher rates than others?

Dr. KARLAWISH. Yes. There are two, at least. One is in America, particularly, race tracks social and economic access. And individuals who have a life of struggle, socioeconomic struggle, even poverty, until they reach the social insurance program of Medicare, they have had patchy health care up until then.

So, for example, undiagnosed or only partially treated heart disease. And so as a result, they are at greater risk of developing dementia later on in life because of having less healthy brains, which was outlined by your colleague—the many things you can do to maintain your brain. So, for example, blood pressure control that requires diagnosis and treatment, oftentimes from about the age of 40 or 50 on.

So people of color in America, to the extent that poverty often tracks race in America, have not enjoyed access to health care so consistently.

And the second is called access to quality education. As your colleague mentioned, there is good data that quality education reduces the risk of developing Alzheimer's disease. That probably relates to two things.

Number one is creation of brain reserve. There is a neuroscience theory behind that that I think is robust. But also, education gives you access to social and economic stability. And so I think that the legacy of race in America in socioeconomic impact on individuals is one reason why Latino individuals and people of color face great risks of developing Alzheimer's.

Senator MENENDEZ. That is why it is important to increase our minority participation in clinical trials——

Dr. KARLAWISH. Absolutely.

Senator MENENDEZ [continuing]. So we can get a better sense. Finally, if I may, I was sitting with Senator Romney who—he and his wife fund a neurological center in Harvard which has like 400 scientists. He told me that you can get a brain scan, and the doctors can look at your brain scan and tell you whether 10 years hence you may very well possibly be subject to Alzheimer's. And the reason that that is important is because there are some trials going on where there is some type of spray or other inoculation that would act as somewhat of an immunization.

Are you familiar with that work?

Dr. KARLAWISH. Very much so. I have been part of it as a researcher, and the Penn Memory Center participates in several of those studies.

In brief, we have made tremendous advances in our understanding of Alzheimer's disease since 1976 when Dr. Katzman said, "It is time to stop referring to senility as senility and recognize it for what it is, which is Alzheimer's disease."

In just 40 years—at the same time that cancer and cardiovascular disease were very well recognized in 1976, think about that, this disease was essentially unrecognized. In just 40 years, we have made tremendous progress transforming the way we understand this disease.

When I started practice at the Penn Memory Center in 1997, you had to be demented in order to be diagnosed with Alzheimer's disease. It was a Gothic horror story, because you had to die to get a brain autopsy to then show that in fact what caused your dementia was Alzheimer's disease.

Now we can visualize the pathologies of Alzheimer's disease using neuroimaging, the scans that Senator Romney was talking about, in a living person. It can visualize amyloid protein, the pathologic protein, in a living person's brain using imaging. And we have developed techniques to visualize tau protein as well.

The vision we have in the field—imagine getting tests that show the presence of these proteins, and other tests as well that show evidence of neural degeneration, and therefore, before you are disabled, starting treatment to slow down the process of neural degeneration leading to the kinds of problems that your family dealt with, for example.

That is the vision that we have, similar to the vision of, you turn 50 and you get a cholesterol test, and based on that result, you start a therapy. Or you get a bone marrow density test, and based on that result, you start a therapy. That is a vision. And I have to say again, in 1997 that was unknown to us, and now in less than about 20 years, look at the progress we have made.

And I want to thank you all, because that is because of the funding that you all began to do. When you doubled the NIH budget, and then when you passed the Alzheimer's Accountability Act and increased the funding available for Alzheimer's disease, that is an incredibly short period of time for the progress that we have made, an incredibly short period of time.

Senator TOOMEY. Senator Casey?

Senator CASEY. Thanks, Mr. Chairman. Thanks for the hearing.

I want to thank the panel. I know we were all in and out for your testimony, so we missed some of it, but I will start with Dr. Cohen.

In your testimony, you testified about how expensive long-term care insurance is, and that it is out of reach for many middle-class families. Obviously, that means Medicaid for a lot of families.

A 2019 report by the Alzheimer's Association says, quote, "Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illnesses," unquote. The same report estimates that Medicaid pays over $49 billion to care for people with Alzheimer's disease and other dementias. Medicaid funds care that includes both nursing home and home- and community-based services. It is a critical support to so many families.

There is a big debate here about what to do next. One side wants to go in one direction, and the other side in a different direction. There have been proposals to block-grant or to put a cap on the program.

We know the value of Medicaid, and I guess I wanted to ask you about the impact of either cuts or caps to Medicaid funding and the impact that would have for people living with Alzheimer's disease and their families.

Do you have an opinion about that?

Dr. COHEN. First, you are absolutely right about the centrality of Medicaid, especially for people with Alzheimer's and related dementias, because they have this extended use. And I think the issue here is—I will get to the per capita caps—but I think one of the reasons that there is a concern with the middle class having to spend down their income and assets and then quality for Medicaid is that there may be available alternatives for them like private insurance so that those people who do not have any private alternatives have a strong social safety net. And that is a significant problem today.

With respect to per capita caps, I mean, frankly, that would shift the financial risk to States and to individuals. One of the issues is that they do not take into account the determinants of need.

So if you are just looking at a population basis, for example, it does not account for changes in the morbidity, the health status. It does not account for very different distributions, even among the elderly population.

You take a State like Alaska that has some of the fastest-growing population over age 85, a per capita cap—and those are the folks, by the way, who have the highest incidents of needing care for Alzheimer's and related dementia and functional impairments. So you have this issue, then, that you are going to end up underfunding because it is not related to need.

And the final issue, I think, on that is that right now we have had a rebalancing in the Medicaid system where there is a tremendous amount of money going to home- and community-based care. Nursing home care is a mandatory benefit under Federal law. Home- and community-based care is optional. And so you run the risk actually of having States that face additional pressures having to cut home- and community-based care. And I think a number of people have spoken about the importance and the desire of wanting people to be able to age in place.

So I mean, it would be a serious concern.

Senator CASEY. Thanks, Doctor. I appreciate that.

Dr. Karlawish, I want to turn to you. I want to join my colleague, Senator Toomey, in welcoming you here and recognizing the good work the Penn Memory Center does. In the interests of time, I will just pose the question briefly.

The connection between hearing loss and dementia—if you could speak to that. I have legislation that I will make sure you are aware of, and I will send you a broader question in writing, but just if you could talk about that connection.

Dr. KARLAWISH. Yes. There are several identified risk factors for dementia. I mentioned a few of them already: poor cardiovascular health, poor quality education. And another is hearing loss; that is well recognized in the literature now.

There are randomized trials, studies going on now, that test whether correcting hearing loss can slow the rate of cognitive decline. Having said that, hearing loss in and of itself is a disability and limits quality of life. So I think it only adds to correcting what I think is a bizarre aspect of our Medicare statute, which is that access to hearing aids, like glasses and dental care, is oddly not provided. And the statute was written in 1965. I mean, we did not have the Internet and whatnot, et cetera.

So correction of hearing loss is not just about improving your ability to hear. There is good data suggesting it may well be about also maintaining one's cognitive abilities as well.

Senator CASEY. Thanks, Doctor.

Senator TOOMEY. Senator Whitehouse?

Senator WHITEHOUSE. Thank you very much, Mr. Chairman. Let me say how happy I am to have a meeting of the Health Subcommittee of the Finance Committee. I hope we have many more. There was a long drought before we got started, and I appreciate it. This is terrific. So, well done.

First of all, let me thank Ms. Tomcavage for being here, for being you, for being Geisinger. I am a delivery system reform maven. All the way back to "To Err Is Human" and "Crossing the Quality Chasm," I have been watching Geisinger and what you have been doing on that front, and it is really fabulous. So a big congratulations to you.

The Alzheimer's population can overlap with the, what goes by different names, end-of-life population, advanced-care population—now the latest nomenclature out of the Innovation Center is the "Seriously Ill Persons" population. And there is a new Innovation Center program for seriously ill persons that has been just proposed there in the, what do they call it, request for proposals, I think, phase.

And I would be interested if any of you have taken a look at that. We probably do not have time to discuss it right now, but I did a lot of work with that in trying to get that off the ground. If you have any thoughts on that program and how it could be improved, or what you think its prospects are for doing good in this area, I would love to hear that.

If you could take that as a question for the record, and if you have something to say, just send in a note on that subject. I think it is potentially exciting, and it breaks up some of what I consider to be the really dumb rules as they pertain to this population, like 3 days and 2 nights in the hospital before you can get to a nursing home. For this population, that makes no damn sense at all. Or not being able to have access to home care until you are truly homebound, that makes no sense to this population either.

So there are a couple of, I think very good ideas, and I would just like to hear your thoughts on those.

Last, this illness has been such a plague on so many families, and it is such a huge, looming cloud over the finances of our health-care systems, I am looking for what you think are the bright spots. What are the exciting new openings? What are the things that you think we should be most reassured about? What is the good news in this rather grim illness?

Dr. KARLAWISH. A couple of things. Number one, we are here talking about it. As I mentioned to you, at the first Senate hearing on this topic, there was one Senator present: Senator Eagleton. That is the first thing: we are talking about it.

The second thing is——

Senator WHITEHOUSE. I had family members who probably had this illness, but nobody had even a name for it.

Dr. KARLAWISH. Correct. Because it was considered——

Senator WHITEHOUSE. They are a little bit nutty, yes.

Dr. KARLAWISH. It was considered an extreme stage of normal aging, and therefore not something that medicine should care about, and a private family problem that would be dealt with by families.

Senator WHITEHOUSE. Yes.

Dr. KARLAWISH. Since then, autonomy has become a sacred value, thankfully, such that anything that takes away our ability to exercise our right to live the lives we want to live is something we do not want, and Alzheimer's does that right away and early on. So that is what made it a disease.

In that sense, it is a disease of autonomy. It is, in that way, if you will, a very American disease because it gets right to the heart of what we care most about: the ability to live our lives the way we want to live them.

Since 1976, as I pointed out earlier, we have made tremendous progress in understanding the biology of the disease. And now, being able to visualize that biology in life, not having to wait until you die to be told that it was Alzheimer's, not having to wait for that Gothic horror story, that means that we are able now, in the last just about 12 years, to test drugs that target the pathology to see if we can change the rate of decline.

And so, I think we should have hope that, in a reasonable period of time, we will be diagnosing this disease potentially before you are disabled and beginning treatment before you are even disabled, to slow down that decline, to slow down that time before someone is having memory problems that interfere with their daily life.

I would also point out that, again courtesy of NIH funding, multiple studies have validated ways to help families like Ms. Kovach's.

The one challenge, though, from all those wonderful studies—all those excellent studies like the REACH program—is the failure to translate them into our health-care system, like say Geisinger, and make them just part of the standard of care.

And a lot of it has to do with the fact that the Medicare statute was written to reimburse doctors to practice medicine. It was not written to reimburse America to provide health care to its seniors.

And so, if there is one plea I would make, it would be to think about how, not just care planning, but then care delivery can be better integrated into our health-care system.

Senator WHITEHOUSE. Well, thank you. My clock has run out, so other witnesses who have thoughts are more than welcome to communicate them to me in an answer as a question for the record, as well as about the SIP program. Thank you.

Thanks, Mr. Chairman, and thank you to the ranking member for organizing this. I think this is terrific. Keep doing it.

Senator TOOMEY. Senator Cardin?

Senator CARDIN. Thank you, Mr. Chairman. I thank both you and Senator Stabenow for not only conducting this hearing, but for your leadership on these issues with the legislation that you have filed.

We have all been very much impacted by Alzheimer's. I want to thank all the panelists. Ms. Kovach, your story puts a face on what we know is in our community, but when you hear the gross numbers, each one is a family. And we thank you for your courage to come here and tell about your circumstance.

Clearly we have to continue the research and be more aggressive, because there are still a lot of questions that are unanswered, many questions unanswered about this disease.

We have to deal with third-party reimbursements for the continuum of care, including early detection, and the issues we have talked about. We have to have a more aggressive plan to deal with caregivers and caregiving, including how we deal with respite care for those who are taking care of their family members at their home, and long-term care insurance—all of that.

But, Dr. Karlawish, I want to go to the point that you really got me interested in: being able to go to my doctor, get some tests done, and find out if I have a problem. So I am wondering, if we are not at that point yet during our primary care visits, our wellness visits, where we can have pretty good indicators as to whether it is called for to do further investigations and perhaps scans, how close are we to that point?

And as I understand it, reimbursement is not clear as to whether that would be fully reimbursable at this particular moment.

So are we at the point where the proper protocols in primary care should be more aggressive in helping to identify earlier those who have vulnerabilities?

Dr. KARLAWISH. Right now we need to provide a good, solid business model to American medicine to identify people with disabling cognitive impairments; in other words, people with dementia, because they are sick and they need help.

A vision for the future would be a vision where you do not have to be cognitively impaired and disabled to be diagnosed with the disease. We are not at that point yet with our science.

The bride is waiting for a groom. The bride is the biomarkers that we have discovered that can pick up evidence of the disease even before you are ill. The groom, if you will, that we are waiting for is the drug that goes after that biomarker and changes the rate of cognitive decline.

In other words, imagine that we were in a world where we could measure elevated cholesterol and predict that it is going to cause, down the road, a heart attack, or diminished bone mineral density and predict, down the road, that the person could develop a fracture, but lacked the HMG-CoA reductase inhibitor drug to give the person with the elevated cholesterol, or the bisphosphonate to give the person with the reduced bone mineral density. We do not have that drug yet.

And I do think that, once we have that drug, then we marry those two together and that recreates a new way of diagnosing the disease.

Senator CARDIN. So are you saying we have to have an effective way to deal with those who are early detected before we can implement protocols to determine whether someone has a vulnerability?

Dr. KARLAWISH. Correct. I am not an attorney, but I will play one in this hearing room. I want to really emphasize, when we speak about early detection, what I am talking about is labeling someone independent of how they are doing—before any evidence of cognitive impairment.

Senator CARDIN. Right. Right. It would just——

Dr. KARLAWISH. We are not ready to do that because we have not—and now I am going to speak like a scientist—we have not validated those methods of detection. In other words, they do not stand up.

Senator CARDIN. That is what I thought. I gotcha. And of course the analogies—we could go through so many different types of tests we take today for all types of things, from early detection of cancer to high blood pressure.

Dr. KARLAWISH. Those are validated tests. Exactly.

Senator CARDIN. So what do we need to do to be able to get to those types of validated tests? Is it additional resources on research? What is the major—or is it just going to take time?

Dr. KARLAWISH. Two things. Of course it will take time. Research is number one. And I thank you on behalf of my colleagues for the funds that you have allocated to the NIH to support that research. Studies like the anti-amyloid and asymptomatic Alzheimer's study, the Generation Project, the DIAN program, are just a few of the studies that are attempting to do just the kind of validation studies that we need to do.

You funded them, NIH has funded them, and we need to continue to fund them and fund more. That is one thing.

The second thing, though, is to begin to anticipate a health system with this new model of diagnosis and treatment——

Senator CARDIN. Okay.

Dr. KARLAWISH [continuing]. And what it will take to implement this new model of the disease. But again let me emphasize, right now in America there are people with dementia who are not being diagnosed, who are not getting care, and families who are suffering. And they have to come first. And they are asking right now for your help.

Senator CARDIN. I have just one last question. You mentioned a brain scan can determine whether there is a deficiency in the brain. That technology is here today, is it not?

Dr. KARLAWISH. That is right. FDA has approved PET radio tracers that measure amyloid in the brain, and amyloid is one of two pathologic hallmarks of Alzheimer's disease.

There are also tracers being developed to measure tau protein, which is the other pathologic hallmark of the disease. Those are being studied, et cetera. And one is FDA-approved; the other is still under study.

Senator CARDIN. Thank you, Mr. Chairman.

Senator TOOMEY. Senator Carper?

Senator CARPER. Thanks so much for being here. My mother had dementia. Her mother had dementia. Her grandmother had dementia. So this is something we have a lot of familiarity with in my family, especially on my mother's side of my family. The last thing I do at night, usually before I go to bed, I have a picture of my mom in the prime of her years, probably just right out of high school, sitting on my desk and I turn out the light on my desk and say goodnight to her. So this is something that is near and dear to my heart, as I am sure it is to others.

This question may have already been asked, and if it has been, excuse me, but I read an interesting book over the August recess called "Grain Brain," G-R-A-I-N Brain. We have the name of the physician who wrote it. But one of his contentions in his book is that there are things we can do with respect to our diet, with respect to exercise, with respect to things that stimulate our brain, and that they will not stop Alzheimer's altogether or the progress of dementia entirely, but they can slow it down—but they can slow it down.

And I want to just go down the line here, starting with you, ma'am, if I could. Do you put any credence in any of that, please? And if you do not know, just say "I don't know," and we will let somebody else take a shot at it.

Ms. KOVACH. I don't know, but I do have a comment. So I look at my grandmother, and she walked a mile every day. She did crosswords every day. She was married for 52 years to the love of her life. She was happy as can be. And she got Alzheimer's. So sometimes I think we don't know. If you have a brain, you are at risk.

Senator CARPER. Thank you. Please?

Dr. COHEN. I am not an expert. The evidence seems to suggest that cardiovascular exercise, a good amount of sleep——

Senator CARPER. Oh, yes, sleep was another point that was mentioned.

Dr. COHEN. Right.

Senator CARPER. Also the quality of the sleep; not just how long, but the quality of sleep.

Ms. TOMCAVAGE. So I think there is a whole host of medications, anticholinergics, for example, that really do mimic or increase the risk of Alzheimer's. So I think those are things that we need to get very aggressive with—warning labels and education with providers. So that is another area, not nutrition or exercise, but something we can do.

Senator CARPER. Okay then, Dr. Karlawish?

Dr. KARLAWISH. The AARP's Global Council on Brain Health, of which I am a member, has developed a series of evidence-based reports which identify many of the things you have identified already, as well as others, for the maintenance of brain health.

The Centers for Disease Control had a healthy brain research network that is currently not active, one of whose missions was to promote these brain-healthy activities.

There is a lot that we know about what can maintain a healthy brain. You have listed out several of them here. I think what is needed is to get the message out to the American public and to think about how we can create brain-healthy societies.

Senator CARPER. All right; thanks. I want to follow that with a question. I think, Dr. Karlawish, you noted in your testimony that our health-care workforce is probably too small and insufficiently trained to diagnose and treat patients with Alzheimer's disease.

The Rand Corporation group has made similar conclusions, finding that workforce shortage has produced ultimate wait lists of, I think, about a year and a half for dementia screening and treatment.

And I wondered if you might have some recommendations for us for increasing the supply of geriatricians, for psychiatrists, for neurologists, and others to ensure that we can meet the needs of our seniors with dementia.

Dr. KARLAWISH. Yes; I mean, doctors are economic actors. Give them an incentive to pursue this. Make it worth their time, number one.

Number two, exercise some of the ability, some of the influence that Medicare has on America's training programs, residency slots that are supported by Medicare. Think about how those might be incentivized to train people in those fields.

Going into college and then med school, and then the low wage of a residency fellowship, is an economic challenge. Think about ways that we could minimize the cost to an individual training to become a physician. I mean, I have colleagues who say, "I would like to go into X, but I am getting so far into debt that I am not going to go into internal medicine; instead, I am pursuing a field where I can recover some of that debt."

So think about using the strings of the purse, if you will, to incentivize people to pursue what right now are not as lucrative areas, or as remunerative areas of medicine at the training level, both as individuals as well as in residency programs in terms of the slots that are offered.

Senator CARPER. Just a quick follow-up, if I could, Mr. Chairman. Do you think we could train primary care providers, including nurses and physician assistants, to provide some of the screenings and care planning services that might be needed?

Dr. KARLAWISH. I do.

Senator CARPER. Thank you. Could you be more succinct? [Laughter.]

Dr. KARLAWISH. Yes. [Laughter.]

Senator CARPER. Thank you.

Dr. KARLAWISH. No; I mean again, analogies of the diseases here are very helpful. I mean not every case of congestive heart failure needs a CHF board-certified congestive heart failure-certified cardiologist. Many internists can handle many cases of heart failure.

The discerning internist knows, she knows when it is time to refer. And we can do the same thing with cognitive disorders. And so, no, this is not simply the work of physicians.

Moreover, the work of other very skilled professions is needed here for their expertise, such as social work, which is critical to this disease and needs to be part of the care plan.

Senator CARPER. Thanks so much. Thanks very much to all of you.

Senator TOOMEY. Senator Lankford?

Senator LANKFORD. Thank you, Mr. Chairman. Thank you all for being here and the dialogue about Alzheimer's. This is important to my family, as well as just about everybody on this dais, as talked about—how Alzheimer's has affected their family directly. And thanks for your story, Ms. Kovach, and to be able to walk through that.

Let me ask a question about a worldwide look. We are spending billions of dollars, Federal tax dollars, working on brain mapping, research, all kinds of diagnosis, treatments, and everything else. Who else is doing this worldwide? Where else is there significant research going on? And what do you see?

Dr. KARLAWISH. Europe has also made a substantial investment in this space in their research, the European Union. There is an investigative group there called EPAD, European Prevention of Alzheimer's Disease initiative.

And Japan has made tremendous investments in the delivery of care, particularly robotics, for example.

Senator LANKFORD. Do we have enough coordination?

Dr. KARLAWISH. Yes. NIH funded a grant called “The Alzheimer’s Disease Neural Imaging Initiative.” We all call it ADNII. And it is ongoing, and it has been validating the biological markers of Alzheimer’s disease. It is almost like sort of writing the encyclopedia, or the dictionary, of Alzheimer’s.

And ADNII became a model for ADNIIs throughout the world. And so if you look across other countries like Australia, Korea, Japan, and Europe, there are similarly modeled ADNII studies doing similar kinds of measures, et cetera, so you can begin to compare across countries, across databases, how these cognitive measures, biomarker measures, functional measures, compare.

That was our innovation that we then exported.

Senator LANKFORD. As it should be, for us to be able to work together on this. There will be individuals in Japan who will take on this issue differently than those who are in Europe, different than those who are in the United States. And as we each do our individual research, I just want to make sure there is enough cooperation and there are no barriers to coordination on working towards a solution.

Dr. KARLAWISH. Yes; I mean the annual meeting of Alzheimer’s researchers, AAIC, is a truly international meeting. This year, in fact 2020 I should say, is the next meeting; it will be in Amsterdam. The meeting before that was in Los Angeles. So this is a we-are-all-in-this-together disease.

Senator LANKFORD. I would assure you that is true for us, at least for all the families that have been affected as well.

Let me talk a little bit about care coordination and the barriers around care coordination. Family members are trying to get answers while they are trying to also take care of family members as they walk through the process of trying to be able to work through a physician or through a nurse or through a facility that may provide housing. There are lots of questions there.

What are you finding, as far as ways that can be improved? What are the barriers to care coordination and getting answers?

Ms. TOMCAVAGE. Yes; so I think there are a significant number of barriers. One, there is a fair amount of difference in funding at the local level. And we are here at the Federal level, but the reality is that much of the funding also comes through at the State level. And so, you know, helping to kind of look at that, I think, is important.

We talked earlier about the fact that people just do not know what resources are out there. And I think we need to continue to kind of educate on that. We have approached it from a perspective of a non-physician role. So I think there really are non-physician roles that are important.

We actually have a, what we call a “non-licensed community health worker.” Many folks have used community health workers over the years, but we have really used them to be really the connector to the community. They work in their community. They hit the streets in their community, so to speak, so that they know all of the resources that are in their community.

I think it is about connecting the families to those resources sooner rather than later, so that they can understand what they are going to need.

The other kind of last point I will make is anticipating the decline. So a lot of times we wait until the family gets exhausted, and then we are kind of running around trying to put a plan in place. We talked about a plan of care earlier. And so I think really thinking much more aggressively about advancing illness that we talked about earlier, and helping the family understand the changes that are likely going to come, I think is important—to get up front so that the families have the respite that they need.

Senator LANKFORD. And obviously, the reasonable person to be able to answer those questions initially, to be able to connect to them, is a physician or a nurse or someone who is there around diagnosis to then try to figure out how we help provide a connection to services. Is there a barrier to getting that information to physicians and nurses, to get them the information to be able to help them to know where to go next?

Ms. TOMCAVAGE. No, I don't think so, if you work in a team environment—so organizations that have a team approach where you have aligned either social workers or community health workers who really know the community, and then can link it to the physician through to the team. I think it really comes down to primary care and specialty care teams that really leverage non-physician workers.

Dr. KARLAWISH. At the Memory Center, very quickly, when I have a diagnostic follow-up visit, it is myself, the patient, the family member, and one of our social worker team in the room. I deliver the diagnosis, answer their questions, et cetera, and then they go off with the social worker to continue the discussion around the care plan.

So that means we have to have four chairs in the room, at least.

Senator TOOMEY. Senator Daines?

Senator DAINES. Thank you, Mr. Chairman, and thank you for holding this hearing today.

Sadly, Alzheimer's and dementia affect the lives of thousands of Montanans. My wife and I were part of an Alzheimer's walk in Bozeman, my home town, when the weather was a little bit warmer, a few months ago. And not only do they affect those living with the disease, but also, as has been discussed here in this hearing, family members, caretakers, community members who are helping them fight every day and every night.

It was in September in fact that Cindy and I had the honor of walking in the Walk to End Alzheimer's in Bozeman. That is my home town since 1964. It was great to see such a large response from the community that got out to walk that day.

Walking side by side with those folks gave me the opportunity to hear first-hand—you have a lot of time just to chat and hear everybody's story about those who have personally been impacted by just a devastating disease.

Like Chris in Bozeman, MT, whose family received a tough early-onset diagnosis and struggled to navigate the dementia care planning maze until they actually reached out to our office. Or Lynn in Billings who endured 3 years of uncertainty and saw seven—

seven specialists before getting a definitive dementia diagnosis for her husband.

These are the stories that I bring with me to Congress that help serve as an important reminder for how critical our efforts are to help combat Alzheimer's.

We have made some good progress over the years to tackle this devastating disease, but there is so much work to be done. So, still a long road to go. And that is why we are here today.

For the more than 21,000 Montanans currently living with Alzheimer's, and the 27,000 expected to develop this disease by 2025, early detection, diagnosis, and access to care planning services are absolutely critical.

Unfortunately, we know that Alzheimer's can be difficult to diagnose. And once a family finally receives a diagnosis, patients and families can face this complex maze of treatment and support options they must navigate through. And that is why I am working on the bipartisan Improving HOPE for Alzheimer's Act that will help patients and families living with dementia by enhancing access to care planning.

It is stories like those from Chris and from Lynn across Montana that help highlight why this bill is so important for those who are on their journey with this terrible disease.

Dr. Karlawish, can you speak to your experience with care planning and the types of services Alzheimer's patients and their families can benefit from receiving when planning for the future?

Dr. KARLAWISH. Sure. So after labeling the person's cognitive problems as a dementia caused by Alzheimer's, what is the stage? You need to think about what the stage is, by which you mean, what are the disabilities the person has? Problems with finances? Transportation? Cooking? How then are we going to take care of those disabilities? Who will manage transportation? How will a meal be provided? How will medications be managed? How will finances be assisted?

And so the care plan involves, for that individual who is disabled, coming up with who the people are who are going to help with those things. Sometimes it is a family member. Oftentimes it is family, but other people as well.

A core question we ask is: what is a typical day? Is it safe? Is it social and engaged? And what resources do you need to keep it safe, social, and engaged?

As the disease gets worse, patients start to need more supervision. And an adult day program becomes often very important. So, finding an adult day program, training the caregiver for how to talk to their relative about the need to go to it, getting transportation to it, paying for it, are all things that we help coordinate for them as well.

So you have to think of this disease like a disability. Instead of needing things like wheelchairs and ramps and doors that open automatically, et cetera, what you need is someone who is going to help that person self-determine their life. That is to say, manage their medications, manage their money, manage transportation, manage cooking.

And so, care planning involves sitting down with a family and going through that typical day, going through those activities of daily living and making sure that they are covered, making sure they are taken care of.

Senator DAINES. Dr. Karlawish, I want to follow up with another question before my time runs down. And that is, there is a common misperception that Alzheimer's is a disease that affects only older people. The truth is that an estimated 200,000 people in the country are living with early-onset Alzheimer's, and many with early-onset are in their 40s and 50s, often in their prime earning years, which just makes what you just described that much more challenging.

They have families. They have careers. They are even caregivers themselves when Alzheimer's disease strikes.

You describe in your testimony, Dr. Karlawish, that research has helped to transform the way Alzheimer's is diagnosed. I am a little over time here. It is my last question. But could you explain why this is important and what efforts are being undertaken to help diagnose this disease early on?

Dr. KARLAWISH. A disease is best diagnosed before that disease is causing disability and treated, obviously, before disability. There is a substantial research effort underway to do just that.

What are the markers that we can measure? And then, based on those who have evidence of the disease, then give a treatment. There are several NIH studies working in this space. It is an enormously promising area of research for both people with early onset and late onset of the disease.

I will stop there.

Senator DAINES. Okay; thanks, Dr. Karlawish.

Mr. Chairman. Thank you.

Senator TOOMEY. Senator Brown?

Senator BROWN. Thank you, Mr. Chairman. And thank you for calling this hearing.

When I talk at home, and I live in Cleveland, about—and first, Ms. Kovach, I have unfortunately been in and out of this hearing because of other things, and we all have those conflicts, but your testimony was some of the best I have heard here, over the years, so thank you. Thanks so much.

When I talk about this at home, I often talk about how Governor Kasich, a Republican, and I, a Democrat, worked to implement the Affordable Care Act over time in Ohio, and he did Medicaid expansion. Nine hundred thousand Ohioans have insurance who did not have it prior to the Affordable Care Act; 600,000 through Medicaid expansion, and a number similar in your State. And those of you from Pennsylvania and Michigan had similar numbers, plus tax credits to help insurance become more affordable; 23- and 24-year-olds staying on their parent's plans, consumer protections for those who have preexisting conditions.

A report just came out that 2 million Ohioans have a preexisting condition in a State of 12 million—not much different from the national average.

Another benefit included in the ACA is the guarantee of a no-cost annual wellness visit for Medicare beneficiaries. This visit includes testing for cognitive impairment. You know how important that is.

Dr. Karlawish, in 2016 you authored an opinion piece in *Forbes,* commenting on how important the ACA has been in our collective fight against Alzheimer's. Briefly elaborate on provisions in the ACA that have advanced the prevention and the diagnosis and the early care of Alzheimer's patients, including the individuals you treat at your practice, if you would.

Dr. KARLAWISH. Yes, for me it was sort of a moment of revelation, which is, you think most people with Alzheimer's disease are over 65. They have the social insurance program of Medicare, so why would the ACA matter? Because the ACA was about expanding coverage for health insurance, people who do not yet have Medicare.

And then I had the realization, as I was looking at people coming into my practice, that many of them, they are caregivers as an adult child who is not yet qualified for Medicare. And many of them were telling me stories about how they were reducing their work or leaving the workforce in order to care for their relative.

And it occurred to me that, to the extent that, for whatever odd reason, in America health insurance is tied to having a job, that they were sort of taking a risk of under-insuring themselves for health care. So it suddenly occurred to me, oh my God, the ACA is insuring my caregivers, giving them the ability to get health insurance while they are trying to care for their relative. Which is what I think your mother went through when she left the workforce to take care of your grandmother.

So that was one. And then a lot of the innovations we have been talking about around care coordination, around improving diagnosis, have been made possible by the Center for Medicare and Medicaid Innovation, or CMMI. And CMMI was created by the Affordable Care Act.

And so when I hear about, you know, removing the Affordable Care Act, every word and whatnot, I am like, I do not want to see CMMI go because it has been sort of an engine for innovation in development and delivery of Medicare services.

And then finally, as you point out, the Medicare annual wellness visit kind of put on the map for medicine the need to pay attention to and take seriously cognitive impairment, just as you take seriously hearing impairment, weight loss, visual loss, et cetera.

And so again, while it was sort of an act to give health insurance to people who were not yet qualified for Medicare, it suddenly occurred to me that this act is actually incredibly important for taking care of patients with Alzheimer's disease.

Senator BROWN. Thank you for that. In my State, 200,000 people are battling this disease, roughly 200,000 or more than that. And there are still efforts—as you know, the President tried and Congress failed by one vote to repeal the Affordable Care Act. And now he is in court in Texas, and it will get to the Supreme Court, to wipe those benefits away. And you know what that would mean.

Ms. Kovach, in the last minute or so—thanks for being here. I wanted to share a note from Ellen Gerber of Cincinnati. She wrote me about her mom diagnosed with dementia 6 years ago. She said, "I've been supporting my mom's care for almost 6 years. I had to quit a career long before I would have left the workforce. I was not ready to retire. My mom now is 95. There is nothing else wrong with her other than her dementia. She will be needing my support and care for many more years. My greatest fear is she will get to the stage where she does not recognize us."

You talked about the long good-bye. She does too. Alzheimer's and dementia is called "the long good-bye." So as a Baby Boomer, my fear is that this is my future.

How can Congress better support families like yours and Ms. Gerber's?

Ms. KOVACH. So my mom definitely did not want to retire; she had to retire. And the first year after my chupe got out of the hospital, that year mom did continue working and we took 12-hour shifts every single day for a year. And mom just looked at me and said, "Don't work. We'll figure it out, but don't work. Let's get her back on track."

There were situations where, because I am the granddaughter, even though I had shared the same legal address as her for probably about 5 years and I was one of her two full-time caregivers, I could not get FMLA because I was not a spouse, I was not a parent, I was not a child.

So I know other States are starting to work on it. If we had a family paid leave, that greatly would have benefited my mom and me because we both wanted to work, but we had to deal with this.

And if there would have been kind of a middle balance, it probably could have relieved a lot of our stress too.

Senator BROWN. Thank you for sharing how much you love your mom and your grandmother. I was in Laconia, NH about a year or several months ago, and a woman said to me, a long-time child care worker who had probably done it for 40 years, she said child care in this country should be a public good, similar to parks and public education. And she was extending that generally to caregiving, what many, many, many countries, almost every rich country in the world does in terms of children, in terms of family leave for any host of reasons. And that just speaks to that.

So thank you so much to all of you.

Senator TOOMEY. I want to thank all of our witnesses. This was very, very informative and very helpful. I should point out for those of you who may not be aware, but a subcommittee hearing very seldom gets as many members of the Senate as this one did today, which I think speaks to the interest and the concern that members have about this topic, and also to the real value of the testimony that you were all able to provide.

So I really, really thank you for that. I do think there is a lot that we can do that could very well be bipartisan that would help deal with this incredible challenge that we face. And we will need your help and guidance along the way.

Members will have 2 weeks to submit written questions that can be answered later in writing. Those questions and your answers will be made part of the formal hearing.

And with that, this subcommittee hearing stands adjourned.

[Whereupon, at 3:58 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF MARC A. COHEN, PH.D., CLINICAL PROFESSOR OF GERONTOLOGY, MCCORMACK GRADUATE SCHOOL, AND CO-DIRECTOR, LEADINGAGE LTSS CENTER, UNIVERSITY OF MASSACHUSETTS BOSTON; AND RESEARCH DIRECTOR, CENTER FOR CONSUMER ENGAGEMENT IN HEALTH INNOVATION, COMMUNITY CATALYST

INTRODUCTION

Thank you, Chairman Toomey, Ranking Member Stabenow, and members of the subcommittee. I am Marc Cohen, a clinical professor at the McCormack Graduate School at UMass Boston, the co-director of the LeadingAge LTSS Center at UMass Boston, and the research director at the Center for Consumer Engagement in Health Innovation at Community Catalyst, in Boston. I am also a former founder and president of LifePlans, Inc., a Boston-based long-term care research, consulting, and risk management company.

I appreciate the opportunity to testify on this panel. While Alzheimer's and related dementias represent among the most costly long-term care liabilities—costing the Nation over $290 billion,[1] of which out-of-pocket costs will total $62 billion or 22 percent of the total—individuals with functional impairments also face significant financial exposure.[2] In fact, the total cost of providing long-term care services and supports (LTSS) to the current cohort of individuals age 65 and over—including a valuation of care provided by family members—will exceed $6.3 trillion. Slightly less than half of these costs will be incurred over the next decade alone.

These staggering national costs are driven by a large and rapidly growing population in need, extended life expectancies (even among those with impairments) and high costs of care. With median annual nursing home costs totaling $92,000[3] and home care costing as much as $46,000 per year, long-term care represents the single largest financial risk faced by older adults and their families. The share of the population that will have to purchase care and pay out-of-pocket can expect to spend up to $140,000 (2015 dollars); public payers like Medicaid will have to pick up another roughly $120,000. Thus, the total average public and private costs for those who need and have to purchase care exceeds $250,000[4] per person.

In my testimony today, I will draw upon my more than 30 years of research on how the growth, development, and revitalization of the private long-term care insurance market could help in this effort. I say "help" because my own view is that this challenge is far too great for any one sector—public or private—to handle on its own. Both sectors will have an important role to play. My research over the years has been supported by the Department of Health and Human Services, the SCAN Foundation, America's Health Insurance Plans, the Robert Wood Johnson Foundation, AARP, and the National Council on Aging (NCOA).

I would like to make a number of broad points today about the current market context and how to improve the affordability and accessibility of private long-term care insurance.

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[1] *https://www.alz.org/media/Documents/alzheimers-facts-and-figures-infographic-2019.pdf.*

[2] *https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf.*

[3] *https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/131168_050516.pdf.*

[4] *https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.*

First, the challenge of LTC financing will only grow in the years ahead and the nature of the LTC risk—which is unpredictable, highly skewed, and potentially catastrophic—makes this liability perfectly suitable for risk pooling through insurance. We have an opportunity to move our financing system for middle class Americans away from a "private-pay safety-net based impoverishment model" toward an insurance-based approach. Private insurance can play its part in helping us move toward this goal.

Second, making private insurance more accessible is not only a question of its affordability, but also of its overall attractiveness and appeal to consumers. There are many reasons[5] why the private market has underperformed. A multi-pronged approach designed to lower the costs of the insurance and increase its attractiveness is needed. More specifically, a combination of actions designed to influence both demand and supply problems can lead to further growth in the market and help assure that private insurance plays a more meaningful role in financing care.

Finally, even in the context of market improvements, voluntary private LTC insurance is likely to represent only a modest piece of the solution to the financing challenge facing the country. Indeed, while my focus today is on the private market, I want to point out that there are efforts across the States aimed at developing public insurance approaches that provide interesting and unique opportunities to test new models for private and public insurance to work together. As I will explain below, public insurance models could very well spur growth in the private market, as sectoral roles become better defined and enable citizens to plan appropriately.

BACKGROUND MARKET CHALLENGE

Let me begin by making the observation that Americans are unprepared to absorb potential LTSS costs and roughly 70 percent of people retiring at age 65 will have some level of LTSS need. As well, 50 percent[6] will have a significant need requiring help with more than two functional limitations or with dementia-related issues and nearly one in six[7] need care for more than 5 years and incur more than $250,000 in expenses. Many of these individuals will have Alzheimer's or related dementias and thus face a particularly large financial challenge as well as family challenge. This is because they tend to require care for many years and most LTSS support is provided or supplemented by family[8] and friends. This is a greater problem today due to smaller family size, the increasing employment of both spouses, the mobility of adult children, and strains faced by "sandwich generation"[9] caregivers. These are all trends that portend less available family care in the future, even as the demand for care grows. Between 2015 and 2050, the ratio of potential caregivers to the population age 80 and over will decline from seven to one to only three to one.[10] And, this does not even account for the additional demand for care presented by the roughly 40 percent[11] of those who have LTSS needs that are under age 65.

Most middle-income Americans are not poor enough to immediately qualify for Medicaid-financed care, which makes them completely exposed to high out of pocket costs. It is important to note that roughly half of Americans age 65 to 74 have no retirement[12] savings at all to deal with this risk. Medicaid[13] covers care in nursing homes and pays for home and community-based care, but requires individuals to first "spend down" much of their savings in order to be deemed eligible to receive these benefits. Thus, while it ensures *access* to a level of care after paying an *"infinite deductible,"* it does not insure against high or catastrophic costs. Moreover, due to budget constraints, even eligible individuals cannot always access[14] needed care

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[5] *https://aspe.hhs.gov/system/files/pdf/177866/MrktExit.pdf.*

[6] *https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.*

[7] *https://www.thescanfoundation.org/sites/default/files/financing_long-term_care_chartpack_092016_final.pptx.*

[8] *https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html.*

[9] *https://www.pewsocialtrends.org/2013/01/30/the-sandwich-generation/.*

[10] *https://www.aarp.org/content/dam/aarp/ppi/2018/08/across-the-states-profiles-of-long-term-services-and-supports-full-report.pdf.*

[11] *https://www.aarp.org/content/dam/aarp/ppi/2017-01/Fact%20Sheet%20Long-Term%20Support%20and%20Services.pdf.*

[12] *https://www.gao.gov/assets/680/670153.pdf.*

[13] *https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/.*

[14] *https://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2012-data-update/.*

when they need it, but instead are placed on waiting lists.[15] Finally LTSS is approaching 30 percent to 45 percent of State Medicaid budgets[16] and growing rapidly, putting pressure on States and in some cases, crowding out other critical policy priorities.

Because of limited market penetration, stand-alone private long-term care insurance—which typically provides access to a “pool of dollars” which can be spent in a variety of institutional, home and community-based care settings—has played only a modest role in paying for care. It pays well less than 10 percent[17] of the Nation’s LTSS bill. Today roughly seven million Americans have policies, which are paying benefits to roughly 300,000 individuals.[18] And the cost of policies has been rising. A 60 year old purchasing a policy in 2015 spent roughly $2,700 in annual premiums for a policy—an increase of 42 percent[19] over the prior decade. Thus, such premium levels are now out of the financial reach of most middle-class Americans; less than one-third[20] of new buyers are drawn from the broad middle class, that is, those drawn from the middle third of the income distribution.

But, affordability is not the only challenge. Confusion[21] about public and private roles in paying for costs, myopia, mistrust of the insurance industry, adverse selection and high selling costs have all contributed to declining sales of private policies. In 2018, fewer than 60,000 individual policies were sold in the United States compared to an average annual sales of roughly 500,000 policies at the turn of the century. A positive trend, however, is that the decline in the sale of individual policies has also been accompanied by growth in combination or “hybrid policies”[22] that add long-term care coverage to other forms of insurance or financial product like riders to life insurance or additional LTSS coverage on annuity products. These policies have the attractive feature of paying out benefits to policy-holders even if they never need to access the long-term care benefit. Currently there are roughly 750,000[23] such policies in-force and the market has shown significant growth over the last 8 years. Like stand-alone policies, however, these products also appear to be attracting primarily upper income individuals so that here too, there are affordability challenges for most middle-class Americans. Thus, those who cannot rely on the social safety net when they face significant LTSS costs, nor have enough income or assets to purchase care, also do not have an accessible insurance option available to them. They therefore face the risk of severe financial stress, often have to rely extensively on family members to provide care, or their care needs are not met.

While cost is the largest barrier to purchase, I want to draw your attention to other challenges associated with expanding the market that have resulted in “too little” insurance. On the demand side, consumers misperceive[24] their own risks of needing LTSS, they underestimate the costs of those services and they do not understand the degree to which existing programs do or do not offer coverage against those risks.[25] Additionally, some may prefer to rely on Medicaid-financed care. For people who tend not to perceive there is a problem, private insurance does not seem like a reasonable option, even if they had the money to pay for it.

Second, decision-making around private long-term care insurance can be complicated. People have difficulty considering the future implications of today’s choices—especially when they are uncertain and unpleasant. When considering current products, consumers need to make decisions about future levels of daily cov-

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[15] *https://aspe.hhs.gov/basic-report/impacts-waiting-periods-home-and-community-based-services-consumers-and-medicaid-long-term-care-costs-iowa.*

[16] *https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpenditures2016.pdf.*

[17] *https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.1226#B4.*

[18] *https://naic.org/prod_serv/LTC-LR-18.pdf.*

[19] *https://www.ahip.org/wp-content/uploads/2017/01/LifePlans_LTC_2016_1.5.17.pdf.*

[20] *https://www.treasury.gov/initiatives/fio/Documents/FACIFebruary2018_UMass.pdf.*

[21] *https://www.thescanfoundation.org/publications/making-progress-expanding-risk-protection-for-long-term-services-and-supports-through-private-long-term-care-insurance/.*

[22] *https://www.limra.com/en/newsroom/news-releases/2019/individual-life-insurance-combination-product-premium-falls-2-in-2018/.*

[23] *https://naic.org/prod_serv/LTC-LR-18.pdf.*

[24] *https://www.ahip.org/wp-content/uploads/2017/01/LifePlans_LTC_2016_1.5.17.pdf.*

[25] In a national survey conducted in the summer of 2019 with adults ages 18+, over 70 percent of respondents felt it was not very likely or not at all likely they would ever need long-term care in a facility (nursing home or assisted living) and two-thirds felt they would not likely need care at home. In the same survey, one-third of adults admit they do not know how LTC costs are paid for, while 42 percent believe that their health insurance, Medicare, or Medicare supplemental coverage pays for long-term care. “Directive Analytics Omnibus Study,” conducted for ET Consulting, summer 2019.

erage, how long such coverage should last, the amount of inflation protection, the size of the deductible and so on. Confusion about the product as well as overall cost has also contributed to lack of demand. As well, voluntary private insurance requires underwriting, which excludes[26] many individuals from coverage. Moreover, large and unexpected premium increases for products has made some consumers mistrustful of insurers and wary of making purchase decision that are costly to reverse.

Finally, people who believe that they can pay for some care, but are afraid of the catastrophic risk, can no longer purchase policies that cover the “tail risk” because almost all policies now place limits on the duration of coverage and companies do not sell unlimited coverage[27] policies. Insurance companies have been unsuccessful at pricing products to insure this “tail risk” or uncapped liability, in part due to concerns about adverse selection.

On the supply side, given the lack of knowledge and understanding among the general public, it is not surprising that selling costs are typically high. Second, insurers face a variety of unpredictable phenomena that affect the pricing of policies such as risks associated with inflation rates, interest rates, people’s behavior regarding their desire to maintain the insurance, and changes in mortality and disability. These are not easy parameters to predict 30 years into the future. Many of these risks are hard to spread because they are common to the whole population—insurers have had to deal with this by de-risking the product and also charging larger risk premiums.

Because of the fact that all major determinants of pricing and profitability have gone in the wrong direction over the past two decades, there has been a major exodus of companies from the market, as returns on the product have been significantly below expectations. In the year 2000, a more than 100 companies were selling LTC insurance to consumers; currently, less than 20 companies are selling a meaningful number of stand-alone policies. Put simply, the market is shrinking rather than growing, and this at a time when more Americans are facing long-term care risks and costs.

This is occurring even as a growing number of people are benefiting from their policies as claimants. In 2017, nearly 81,000[28] new claims opened and the claim reserves that have been set aside for each claim to cover expected liabilities is over $100,000. Research[29] suggests that people who receive benefits from their policies are very satisfied, with half saying that in the absence of their policy they would receive less care, 60 percent saying they would have to rely more on their families for help, and upwards of 90 percent indicating that the insurance benefits are helping them meet their current care needs.

The underdevelopment and growing unaffordability of private insurance, and the absence of public insurance presents a fundamental problem: people have no way to plan effectively for what is actually a perfectly insurable risk. Their current options are inefficient, unattractive or both. If people rely on savings, they will likely save too little or too much, since they cannot easily predict whether they will face catastrophic LTSS burdens. If they rely on Medicaid, they must first expend significant personal resources, and only then qualify for coverage that in many places still limits the availability of in-home care. Even when people have budgeted carefully through their working lives, they can still end up impoverished, because they receive little or no help if they need significant amounts of care.

ENHANCING AFFORDABILITY AND DEMAND

Since current strategies have not worked well in assuring broad consumer appeal and insurer enthusiasm, what can be done? To increase accessibility, efforts could be focused on lowering the net cost of the product through targeted subsidization, reducing selling costs and considering changes to product pricing approaches to make them less costly, and enhancing the value proposition to consumers so that peoples’ “tastes” for insurance change and products are more attractive. A benefit of accomplishing these goals would be to induce companies to reconsider the market and potentially reenter and provide more affordable products.

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[26] *https://www.healthaffairs.org/doi/10.1377/hlthaff.2015.1133.*

[27] *https://www.ahip.org/who-buys-long-term-care-insurance/.*

[28] *https://naic.org/prod_serv/LTC-LR-18.pdf.*

[29] *https://www.ahip.org/experience-satisfaction-levels-of-ltc-customers/.*

Premium Cost Reduction

Affordability of policies has been viewed as one of the biggest barriers to greater penetration among middle income individuals. Changes to the underlying funding structure of products could lead to lower cost policies. Currently, products are level-funded, but they could be priced on a "term-basis,"[30] much like life insurance, and as part of the structure, gradually add in a pre-funded amount to become level-funded at say, age 65 or 70. This would necessitate clear consumer disclosures and protections, but this approach does have the virtue of making policies more affordable at younger ages when competing demands on resources are greatest. Having the premium become level when people are done working and more likely to be on fixed incomes also helps assure that policies will remain affordable at the time that they are needed most.

A related approach involves indexing both premiums and benefits to account for increases in the cost of services. Such an approach could be tied to actual changes in the cost of long-term care. This method has the virtue of reducing the uncertainty around the inflation risk, as well as lowering initial premiums, and makes the product more affordable for consumers. It also reduces the level of initial reserves that must be set up by the company, which in turn eases the amount of capital required to support the product. In addition, there is evidence that requiring a 5 percent annual benefit increase (such as had been done for early Partnership Policies) leads to over-insurance; that is, benefits in these policies are growing much more quickly than the costs of care. For that reason, providing greater flexibility regarding the level of indexing to be offered could lead to lower priced products that still protect consumers by assuring benefits keep pace with inflation in long-term care costs.

Should policymakers decide to invest resources to subsidize the purchase of private policies, an approach that could increase sales would be to provide targeted middle-class tax benefits to people who would otherwise not be able to purchase policies. Strategies could include direct targeted tax subsidies or also a reshaping of benefits like inclusion of LTC insurance in cafeteria plans and FSAs, treating premiums as qualified 401(k) expenses, that is, no early withdrawal penalties and no income tax on withdrawn monies spent on LTC insurance premiums. Given the change in the nature of the products on the market, the premium associated with the long-term care coverage on combination products would also need to be subject to such treatment.

The reshaping of benefits must also recognize that many people do not participate in such savings plans—roughly 55 percent[31] of employees have a workforce retirement plan—and this is also evidenced by the fact that median value of household liquid assets for 80 percent of the household population age 50 and over is less than $100,000.[32] Thus, for tax benefits to be effective, they need be targeted correctly to the sub-set of individuals with such savings plans who could not otherwise afford policies and the benefit would have to be high enough to induce purchase. Prior studies[33] of State-based tax incentives showed very little impact, in large part because the value of the tax benefit was so small.

As well, current Federal tax incentives have little to no effect on insurance rate take-up among the middle class because of changes brought about by the Tax Cuts and Jobs Act,[34] which dramatically increased the standard deduction. The main way taxpayers receive Federal tax benefits for long-term care insurance is by taking an itemized deduction for medical expenses, which can include private long-term care insurance premiums. The Joint Committee on Taxation estimated that the number of filers who itemize will fall from 46.5 million in 2017 to just over 18 million[35] in 2018, meaning that about 88 percent of the 150 million households that file taxes will take the increased standard deduction.

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[30] *https://www.soa.org/globalassets/assets/Library/Newsletters/Long-Term-Care/2013/january/ltc-2013-iss33.pdf.*

[31] *https://www.pensioninsights.org/publications/statistics.*

[32] Author's analysis of the 2016 Health and Retirement Survey. Financial assets consist of retirement plans (IRA, Keogh accounts), stocks, mutual funds, investment trusts, checking, savings, money market accounts, government savings bonds, T-bills, bonds, bond fund other savings.

[33] *https://pubmed.ncbi.nlm.nih.gov/19938726/.*

[34] *https://www.congress.gov/115/bills/hr1/BILLS-115hr1enr.pdf.*

[35] *https://taxfoundation.org/90-percent-taxpayers-projected-tcja-expanded-standard-deduction/.*

Reducing Selling Costs

The high selling costs of policies is often cited an important cost challenge so finding new ways to distribute the product is important. For example, the insurance could be made available as part of other health-care [36] offerings. Moreover, in addition to the special supplemental benefits available to the chronically ill allowed under the Chronic Care Act,[37] greater coverage for LTSS could be permitted to become part of a Medicare Advantage (MA) offering. As well a "forced choice" of a modest option at the time of enrollment to either traditional Medicare or to an MA plan would increase exposure to the insurance. It could also be offered with one or more of the approved Medigap insurance plans currently selling on the market. These options would assist individuals who have put off making their planning choices before retirement, and would help support lower marketing cost policies.

The insurance exchanges could also provide individuals with the opportunity to examine and purchase private LTC insurance. Finally, it is worthwhile to consider requiring employers to offer coverage as an optional benefit to employees; the plans could be set up so that employees must opt out and the expenses associated with setting up such a plan would be recognized as expenses. Alternatively, employers could be required to provide education and information on private LTC insurance as part of the standard employee benefits package.

Enhancing Consumer Confidence, Knowledge, and Changing the Value Proposition

One of the issues that has led consumers to lose confidence in the industry, has been the significant rate increases that have occurred over the last decade. These increases [38] have resulted due to a variety of factors—some of them within the control of the insurance company and some of them outside that control. Either way, it is clear that for consumers to feel comfortable with the product, they need to have a sense that they know what they will be paying for it over the long-term. This presents a difficult challenge to insurers, yet some of the recommendations regarding product structure discussed above can be helpful.

An additional and innovative approach taken by LTC Partners—the administrator of the Federal Long-Term Care Insurance Program (FLTCIP)—is to build in rate stability through product design. Their new plan includes a "premium stabilization feature" [39] (PSF). The feature is designed to reduce the need for future premium increases by building into the base premium some additional protection. This protection can be used to offset an enrollee's future premium payments under specific conditions or it will provide a refund of a premium death benefit. In some sense, like the life-LTC or life-annuity combination products, this assures that individuals are likely to receive some financial benefit from their policy or have complete rate stability during the life of the policy. It does, however, cost more than policies that do not have this feature. The company is betting on the fact that consumers are willing to trade off a somewhat higher premium for the premium stability and/or death benefit.

There is a need for a major targeted public education campaign to eliminate confusion about risk, who pays for services, misunderstandings about product coverages, and others. The campaign could target people beginning at age 40 and could accompany communications about social security benefits with warnings regarding the consequences of ignoring the LTSS risk and the availability of products to cover risks. To date, efforts at education have fallen short, as witnessed by the continued misunderstandings about what the public sector does and does not pay for and about the potential liability facing individuals as they age.

Even with the actions that I have discussed thus far, it is clear to me that without an expanded Federal and/or State role—specifically, the development of some level of public insurance—the needle is still not likely to move enough to protect the majority of middle-class Americans. Because Medicaid is the largest LTSS public payer and States pay roughly half the costs, they feel the pain most acutely. It is therefore not surprising that a number of States are actively exploring and/or developing

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[36] *https://www.thescanfoundation.org/publications/making-progress-expanding-risk-protection-for-long-term-services-and-supports-through-private-long-term-care-insurance/.*

[37] *https://www.cms.gov/Medicare/Health-Plans/HealthPlansGenInfo/Downloads/Supplemental_Benefits_Chronically_Ill_HPMS_042419.pdf.*

[38] *https://naic.org/documents/cipr_current_study_160519_ltc_insurance.pdf.*

[39] *https://federalnewsnetwork.com/benefits/2019/10/opm-announces-new-long-term-care-insurance-plan-option/.*

State-based[40] social insurance initiatives or other strategies for addressing the problem. They have concluded that the costs of waiting are becoming higher than the costs of taking action.

For example, Washington State[41] passed the Nation's first long-term care social insurance program—the Long-Term Care Trust Act—which provides a benefit that pays up to $100 a day for about one year ($36,000) for a qualifying individual. Given the total risk faced by individuals, this public program leaves a great deal of room for the private insurance market to expand by supplementing or wrapping around the States coverage. Private policies could top off the public benefits and/or pay additional benefits when the public insurance benefits are used up. This would have the effect of making private policies far more affordable—as they would be covering less risk—and it could also make it easier to sell private insurance in the context of the public program. An important requirement would be to assure that eligibility criteria for the public and private insurance coverage is in sync so that consumers can be assured of continuity in coverage.

As well, one program design gaining some traction among researchers,[42] policymakers,[43] and stakeholders[44] is the establishment of a public program to cover catastrophic or "back-end" LTSS costs alongside steps to encourage private insurance take-up rates to protect against "up-front" risks. The intent with this design is twofold: first, to target publicly-financed benefits to expenses that exceed amounts that middle-income (along with higher-income) people can reasonably be expected to manage—either with private insurance or personal resources; and second, to enhance the attractiveness and purchase of the limited coverage private insurance products that insurers prefer, by positioning them as gap fillers that, in combination with public insurance, facilitate relatively comprehensive protection against LTSS costs. Again, this will likely have the effect of reducing selling costs for private insurance, as the lines between public and private responsibility will be clearly delineated. The Society of Actuaries is currently funding a study of how a catastrophic State-based plan might impact both the private market and Medicaid savings using the State of Minnesota as the trial case for study.

The hope is that in the context of a public program that pays for catastrophic costs, private insurance will become more affordable, people's "tastes" for insurance will change, the confusion that is in part encumbering market growth will diminish, and more companies will enter the market to provide new products to cover front-end risk. An analogous situation arose after the Federal government began insuring acute care costs through the Medicare program. In 2016, 30 percent[45] of Medicare beneficiaries, about 9 million people, had Medicare Supplement policies sold by private insurance companies that fully or partially cover Part A and Part B cost-sharing requirements, including deductibles, copayments, and coinsurance.

Experience from other industrialized countries[46] suggest that private insurance products almost always fill important coverage gaps in the presence of publicly funded programs, the latter[47] almost never insuring 100 percent of the risk. Most importantly, there would be a clear delineation of public and private sector roles. This should enable consumers to make informed decisions about the risk they are responsible for and it should also make the market environment attractive enough to encourage greater carrier participation. Such a market would be characterized by more affordable and accessible insurance, greater consumer knowledge and understanding, and a shared role for covering this major uncovered risk.

In closing, there are many ways that we can make private insurance more accessible and affordable and the solutions that are put forward need to reflect the magnitude of the problem that we face. While all of the specific steps that I have discussed are helpful, and worthy of consideration, a joint public-private approach is

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[40] *https://www.questia.com/library/journal/1P4-2235646795/the-states-can-t-wait-the-long-term-care-financing.*

[41] *https://www.agingwashington.org/files/2019/02/2019-Long-Term-Care-Trust-Act-Fact-sheet.pdf.*

[42] *https://bipartisanpolicy.org/wp-content/uploads/2018/01/Public-Catastrophic-Insurance-Paper-for-Bipartisan-Policy-Center-1-25-2018.pdf.*

[43] *https://pallone.house.gov/media/press-releases/pallone-unveils-proposal-medicare-long-term-care-benefit.*

[44] *https://www.convergencepolicy.org/wp-content/uploads/2016/02/LTCFC-FINAL-REPORT-Feb-2016.pdf.*

[45] *https://www.kff.org/medicare/issue-brief/sources-of-supplemental-coverage-among-medicare-beneficiaries-in-2016/.*

[46] *http://www.oecd.org/els/health-systems/47884985.pdf.*

[47] *https://www.milbank.org/quarterly/articles/long-term-care-financing-lessons-from-france/.*

most likely to move the needle and make a difference for middle class people. Clearly, those families who will face the difficult issue of paying for Alzheimer's or related dementias would benefit the most from being insured when such an event happens, and we should keep them in mind when we consider steps to improve the market.

I appreciate the opportunity to testify about these important issues and I would be happy to answer any questions that the committee might have.

QUESTIONS SUBMITTED FOR THE RECORD TO MARC A. COHEN, PH.D.

QUESTIONS SUBMITTED BY HON. TIM SCOTT

Question. There are currently 92,000 South Carolinians living with Alzheimer's disease, and by 2025, there may be as many as 120,000. Alzheimer's ranks as the sixth leading cause of death in our State and imposes substantial and burdensome costs on many of South Carolina's seniors, along with their families and other caregivers. As our population continues to age, long-term care will become all the more important in meeting the needs of those living with Alzheimer's or other dementias. Roughly 70 percent of Americans aged 65 and older will need long-term care at some point in their lives, and more than two and every five seniors aged 85 and older have Alzheimer's. Dr. Cohen, as you note in your testimony, "[T]he challenge of LTC financing will only grow in the years ahead." You also point out that the nature of LTC risk "makes this liability perfectly suitable for risk pooling through insurance." I agree with your conclusion that private insurance should "[play] a more meaningful role in financing care."

As you mentioned in your testimony, and as Senator Toomey has proposed, I see allowing for tax-and penalty-free distributions from 401(k)s to fund LTCI or hybrid product premiums as a wise step forward in making coverage more affordable and accessible. What other concrete and targeted steps could Federal policymakers take to enhance the private LTCI market and the growing hybrid product market?

Answer. Indeed, allowing for tax- and penalty-free distributions from 401(k)s to fund LTCI or hybrid product premiums would make coverage more affordable and accessible for those who have such savings vehicles. There are a number of additional strategies that could be taken to make the insurance—whether the stand-alone or hybrid products—more affordable and accessible. In line with tax advantaged 401(k)s, the creation of LTC savings accounts similar to Health Savings Accounts (HSAs) along with making current HSAs flexible to enable long-term care premiums and expenses to be treated as allowable expenses would lower the net cost of insurance for those who have such accounts. This could encourage individuals to participate in such accounts, especially as knowledge among the working population regarding the long-term care risk becomes better understand. For these to work, the requirement that they be conditioned on having a high deductible health plan would need to be waived since such plans do not cover long-term care expenses. Second, current tax incentives that are conditioned on individuals itemizing deductions and having to pay in excess of 7.5 percent to 10 percent of adjusted gross income each year are ineffectual. Targeted tax-subsidies to lower and middle class individuals who in the absence of such subsidies would not be able to afford insurance is another way to lower the net cost of insurance and increase take-up rates.

Such income-based subsidies could target the population most exposed to impoverishing themselves and spending down to Medicaid eligibility should they have a significant long-term care need. To that end, the Federal government may consider a full Federal tax deduction for long-term care insurance premiums for such individuals. As well, allowing the purchase of this insurance within the context of a cafeteria plan or from an FSA would also likely encourage take-up rates among the working age population, which typically face lower premiums than individuals who are looking to buy the insurance in their late 50s or 60s.

Question. Are there regulatory barriers at the Federal level that constrain or inhibit private LTCI or hybrid product market growth? What steps could be taken to mitigate or eliminate these barriers?

Answer. There are a number of barriers that if removed could have a positive effect on the market. The requirement that insurers offer 5-percent compound inflation protection with stand-alone LTC insurance policies and the requirement that purchasers of Partnership policies who are under age 75 must accept inflation protection for the policy to be tax-qualified, is not as consumer-friendly as it might seem. First, there is ample evidence given the increase in long-term care costs over the last 20 years that this is an excessive amount of benefit indexing. Long-term care costs have not generally risen at 5 percent per year and insuring for this amount of protection is quite costly and in fact leads to over-insurance for those who buy it. Insurers are only required to "offer" the inflation protection, and consumers have the right to refuse it. However, offering this level of protection does change the choice architecture for consumers and can lead people to believe that unless they purchase this amount, the policy does not hold value. As well, given the variability of long-term care costs across the States, as well as the local underlying factors leading to changes in costs, it makes more sense for States to determine the percentage of inflation protection that should be offered to consumers. The requirement that insurers offer inflation to consumers should remain, but there should be greater flexibility regarding the level of the offer and the structure of the mechanism designed to assure that benefits keep pace with changes in costs. It should be noted that most individuals purchasing long-term care insurance do not expect their policy to pay for all costs, and therefore, some level of co-insurance is expected among buyers (AHIP, 2010). The implication is that greater flexibility regarding inflation protection is in line with consumer preferences.

Second, for the most part long-term care insurance is regulated by the States and the National Association of Insurance Commissioners (NAIC) has developed and updated model regulations for long-term care insurance. In some cases there is not alignment between Federal law and NAIC models like the Health Insurance Portability and Accountability Act (HIPAA) and the Deficit Reduction Act (DRA). The reason is because the language in these two acts is not in sync with updated versions of the NAIC model and they refer to older models that are outdated. To avoid this, Federal law should reference and require compliance with the most current version of the NAIC model for new policies that are being sold on the market.

Finally, there are a variety of new product designs that are being considered and others that are being marketed to consumers that are constrained by Federal requirements unrelated to consumer protection. For example carriers are looking to develop and market flexible premium structures (*e.g.,* term premium pricing up to a maximum age) and adding cash value to policies in forms other than return of premium. Currently, HIPAA prohibits tax qualified stand-alone policies from containing a cash value feature. This means that individuals with stand-alone policies either receive benefits if and when they have a long-term care need, or they pay premiums and do not receive benefits because they do not need them. Given that roughly 50 percent of individuals over age 65 are not expected to have a significant long-term care need, many people who would consider the insurance may be reluctant to buy it if they perceive that they will not receive any financial benefit from doing so. If some level of cash value in stand-alone policies was allowed in the context of HIPAA and DRA, this could make policies much more attractive to individuals and lead to greater market penetration.

As well, making legislative changes that would allow "lifespan" products to emerge could also help boost the market. For example, insurance products like life, disability, and others are typically most relevant during one's working years. However, if these products could then convert into long-term care coverage at older ages, when these other coverages are less needed, that would change the "choice-architecture" in an important way. Rather than having to purchase a policy as one nears retirement, one could "opt out" of a policy that was converting to long-term care coverage. Research suggests that an opt-out approach, where one is already conditioned to paying premiums over a long period of time, could lead to meaningful market expansions. Legislative changes related to Federal tax treatment that would specifically allow such products would be needed to encourage growth in such plans.

Question. What impact would a broader private LTC and combination product market have on Medicaid's long-term fiscal outlook?

Answer. The key to assuring that broader stand-alone long-term care insurance and combination products improve Medicaid's fiscal outlook is that market expansion occur among the lower and middle class population. These are the people who either spend-down to Medicaid when they have a significant need or are immediately eligible for Medicaid. To the extent that policies are designed to be both attractive and accessible (*i.e.,* affordable) to such individuals, the impacts on Medicaid long-term care expenditures can be significant. If, however, market expansion occurs among individuals who are unlikely to spend down to Medicaid even in the presence of significant long-term care need, then the impacts of Medicaid will be negligible. In short, market expansion to the broad middle class could have a major impact on slowing the growth in Medicaid LTSS expenditures and the social safety-net would be left to serve primarily those who have no private alternatives under almost any condition due to their low wealth status.

Question. In outlining one of the barriers to more robust private-sector participation, you cite affordability challenges, asserting that current premium levels are "now out of the financial reach of most middle-class Americans," offering as an example the average annual premium for a 60-year-old purchasing a policy in 2015. It is worth noting, however, that purchasing age significantly impacts LTCI premiums.

Given that a 45-year-old who purchases an LTCI policy will likely pay around half of what a 60-year-old purchaser of such a policy might pay, what steps can Federal and State governmental entities, as well as private-sector stakeholders, take to educate Americans about the impact of purchasing age on premium costs and to encourage the public to purchase these products at an earlier age to avoid exposure to higher premiums?

Answer. This is a critically important issue and must be addressed in the context of other actions designed to make the insurance more affordable. There is ample evidence that people (1) underestimate their future risk for needing care; (2) underestimate the costs of long-term care; and (3) believe that they are already covered for care—through Medicare or their private health insurance—should the need arise. Thus, it is no surprise that few people insure against this risk since they grossly underestimate it and the perceived value of the insurance compared to its cost, is very low. In short, the value proposition needs to change in order for younger individuals to even consider purchase, especially when there are so many competing demands on their resources (*e.g.,* housing, day care, saving for children's college, and retirement savings accumulation.) Part of what will change the value proposition is a very robust education campaign with variable messaging to account for the heterogeneity in the population, concrete signaling form the Federal and State governments that the insurance is worthy of consideration (*e.g.,* incentives for purchase including targeted tax benefits) and the proliferation of mechanisms that make it easier for people to put aside money to pay for premiums (*e.g.,* tax advantaged savings plans).

Question. Given the substantial variation in premium costs based on purchasing age, why, in your view, do so many Americans forgo purchasing LTCI policies for so long, if they purchase private policies at all?

Answer. Greater education, needs to occur and it must begin with outlining for people the actual risk that they face. As stated above few people insure against this risk since they grossly underestimate it, believe the exposure is covered by other programs and thus the perceived value of the insurance compared to its cost, is very low. For younger individuals to even consider purchase, especially when there are so many competing demands on their resources, the value proposition needs to change. More specifically, we must find ways to make the insurance more affordable and accessible and we must change "tastes" for the insurance. The latter can be accomplished through serious public education.

It must also be recognized that many people do not save adequately for their own retirement and that income replacement during retirement is viewed as a necessity, whereas saving for long-term care may be viewed as a somewhat discretionary expenditure. Thus, in light of other pressing current and future financial needs, forgoing purchase of long-term care insurance until these other items are addressed may be a perfectly rational decision. Even so, there is significant under-penetration among individuals who today could afford to purchase policies and there is much work to be done with this segment of the population to get them insured.

Question. As you explain in your testimony, some Americans "misperceive their own risks of needing LTSS" or "do not understand the degree to which existing programs do or do not offer coverage against those risks." You also highlight that "some may prefer to rely on Medicaid-financed care."

In your testimony, you mention that "[t]o date, efforts at education have fallen short." To your knowledge, what efforts have Federal and State agencies taken in recent years to attempt to address the misperceptions that you reference and to better inform the public as to what level of coverage various programs provide with regards to LTCC? In what ways have such efforts been successful, and where have they fallen short?

Answer. The Federal Government's "Own Your Future" campaign was certainly a step in the right direction. The "Own Your Future" Long-Term Care Insurance campaign was a joint awareness program between the Federal Government and individual States that was developed in January 2005. It was specifically designed to raise awareness to individuals about the need for planning for long-term care. Roughly 25 States have participated in this campaign to raise awareness among residents between the ages of 45–70. In the participating States, a letter from the Governor was mailed to all residents talking about the importance of planning for long-term care. An individual who responded to the letter would receive a free Long-Term Care Planning Kit.

While this campaign did raise some level of awareness in the States in which it was operating, results indicated that the impact of the campaign was limited, both with respect to awareness of the campaign itself and to initiation of planning behaviors around long-term care. More specifically, across the various campaign States, slightly less than 8 percent of the individual households that received letters from their governor requested the Planning Kit. The response rate was highest in Virginia (9.1 percent), and the average of 7.7 percent across all the States did exceed the campaign's baseline estimate of 5 percent which was considered an appropriate response rate for a social marketing campaign. These response rates are also significantly higher than comparable private sector direct mail campaigns on this topic (which might see responses of 0.1 percent to 2.0 percent) *(https://aspe.hhs.gov/basic-report/final-report-own-your-future-consumer-survey)*.

As well, there have been successful education and marketing campaigns at the employer level. Relatively high take-up rates for LTCI in a number of settings suggests that there is potential to increase LTCI coverage, even in the presence of relatively generous Medicaid programs, which some have posited reduce the demand for LTCI. More than a decade ago, six States and the District of Columbia that offered group long-term care insurance plans had take-up rates for people over age 45 that were double the national average—over 10 percent compared to 5 percent (LIMRA, 2010). Private employer-sponsored LTCI that is coupled with little to modest underwriting requirements, active outreach and education campaigns, and reduced selling costs realized penetration rates of 9.4 percent in CalPers and 20.4 percent for the Minnesota Public Employees LTC program (Minnesota Management and Budget 2010).[1] Thus, we do have concrete examples of increased insurance take-up rates and there is an opportunity to learn from such experiences.

Question. You discuss the need "for a major targeted public education campaign" and go on to briefly describe the key components of such a campaign. What role should Congress play in authorizing or encouraging such a campaign? If we were to codify such a campaign in legislation, what components and features should we include, and what do you see as potential pitfalls? What tools might we leverage to ensure that the campaign reaches key target populations?

Answer. Congress would need to authorize the appropriate Federal agency (*e.g.,* Department of Health and Human Services, Education Department, etc.) to work directly with individual States to develop campaigns that take account the unique population demographics of the State and the long-term care service, insurance, and Medicaid program infrastructure so that an effective and targeted campaign is implemented. Clearly, the necessary funds to support such an effort would need to be appropriated. The biggest potential pitfall would be presuming that a single national message would move the needle. This needs to be a highly nuanced and targeted campaign that relies on both traditional and social media outreach and messaging. Moreover, the message would be different across the age distribution.

Question. Why, from your perspective, might some consumers "prefer to rely on Medicaid-financed care"?

Answer. Consumers may prefer to rely on Medicaid-financed care when they do not have family supports available to help them compensate for functional or cognitive limitations nor have adequate resources to purchase care on their own. That is, they have few resources available to purchase care. More pressing demands on what little resources they have make Medicaid the safety net program on which they can rely should they have a significant long-term care need.

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[1] The CalPers program relies on a moderate level of underwriting, known as a short form. The Minnesota program is a guaranteed issue program and therefore does not use underwriting methods. The Minnesota program also includes non-forfeiture provisions to the coverage.

Question. What limitations or particular challenges might relying on Medicaid-financed LTSS pose for consumers (*i.e.,* in terms of optionality and flexibility)?

Answer. There are a number of challenges associated with relying on Medicaid-financed care. First, obtaining eligibility through spend-down is a threat to many individuals' financial security. Second, many States have waiting lists and access limits for home and community-based care. Third, programs often have less flexibility in requirements around the way that services must be provided. Fourth, reimbursement rates often do not support development of a high quality workforce and service infrastructure. This can lead to sub-optimal care provision for our most vulnerable citizens. Finally, States are struggling with budget pressures because long-term care expenditures are approaching 30 percent to 45 percent of State Medicaid budgets and growing rapidly. This means that additional pressure is likely to lead to cutbacks in coverage, diminished reimbursement to providers, and the potential underinvestment in other policy priorities.

Question. What challenges might our current level of reliance on Medicaid for LTSS pose, in the coming years, for State governments, taxpayers, and providers (*i.e.,* nursing homes, considering payer mix and reimbursement policies)?

Answer. As mentioned above, there are significant challenges associated with current reliance on Medicaid for financing care, especially as the baby-boom generation retires. At a high level, unless funding is significantly enhanced and/or greater numbers of individuals are able to avail themselves of public (*e.g.,* Washington State) or private insurance alternatives, growth in Medicaid financed long-term care services threatens to crowd out other budget priorities, lead to gross under-investment in our service infrastructure and lead to even greater shortages of service providers. All of this at a time when a growing number of individuals will need to rely on the paid (formal) system of care as family caregiving capacity continues to diminish.

Question. In a 2017 Mercatus Center Working Paper, Mark J. Warshawsky and Ross A. Marchand argue that "private LTCI is crowded out by the current Medicaid provision," noting that, despite "widespread and significant holdings of housing and retirement assets" among retired households, these holdings tend to fall into "precisely the asset classes that Medicaid rules and State administrations either always or sometimes exempt from consideration in determining eligibility." Lax programmatic eligibility rules along these lines have, the paper asserts, "led middle- and upper-income older Americans to seek Medicaid enrollment" and have weakened incentives for proactive consumer participation in the private long-term care insurance marketplace.

Putting aside other challenges facing the private market, do you agree with Warshawsky, Marchand, and others that Medicaid, as currently administered, "crowd[s] out" private long-term care insurance?

Answer. I think that this argument is more theoretical than empirical, and it tends to be somewhat exaggerated. While some have argued that the Medicaid program, which represents the largest public payer of LTSS, "crowds out" or suppresses demand for private insurance, evidence suggests that the impact is likely modest in light of other issues affecting demand and that effects are at the lower end of the income scale. Even proponents of the theoretical argument for crowd-out point to problems with the product as an empirical explanation of the market's failure to thrive and suggest that even eliminating the issue of "crowd-out" may not be enough in and of itself to move the needle on insurance take-up rates (J. Brown, testimony to the Commission on Long-Term Care, August 20, 2013).

Having been part of a team researching this issue (Unruh, et al., 2016) we found that individuals with lower asset levels would be more likely to decline the option to purchase private insurance coverage which could be viewed as quite rational in the presence of Medicaid. However, while previous research has suggested that crowd-out extends high into the asset distribution, our results suggest crowd-out is focused instead at lower levels of the asset distribution. Specifically, estimates suggest that moving from the asset category <$50,000 to the $50,000–$100,000 category leads to a 7-percent increase in the likelihood of purchasing a policy. Crowd-out is less rationale at upper-middle and upper asset levels, which is why sales are concentrated at these levels even as penetration remains low. Finally, there is very little current evidence of a relationship between the attractiveness of a particular State Medicaid program and long-term care insurance take-up rates. That is, we do not currently see States with very generous Medicaid programs also exhibiting low private insurance take-up rates.

Question. On the Medicaid policy front, what steps can we take to reduce middle- and upper-class reliance on Medicaid for LTSS? Do you share the authors' generalized sense that eligibility rules can be too "lax," and, if so, are there areas that are particularly ripe for reform?

Answer. The way to reduce *middle income* reliance on Medicaid is to expand insurance options, both public and private, for these individuals. The fundamental financing problem is the absence of an effective insurance mechanism. The distribution of risk makes long-term care perfectly suited to an insurance solution because (1) many people will have no need and a small number will be have catastrophic expenses; (2) it is difficult to predict where you might fall in the distribution of risk, and; (3) even for the few who have the resources, savings does not make sense and it unreasonable. All of this argues for moving the current financing system away from a *welfare-basis* toward an *insurance-basis*—whether primarily public (as in the recently passed Long-Term Care Trust Act in Washington State), private (combination products and stand-alone insurance) or more likely, a combination of both.

As mentioned above, there is no empirical evidence that making Medicaid rules more stringent leads to greater private long-term care insurance take-up rates. Even in States that have increased "look-back" periods and in States that have made a greater effort at estate recovery among individuals who have accessed the Medicaid system, the effects on long-term care insurance sales have been negligible. A study conducted more than a decade ago found that even if every State in the country moved from their current Medicaid asset eligibility requirements to the most stringent Medicaid eligibility requirements allowed by Federal law demand for private long-term care insurance would rise by only 2.7 percentage points (Brown, Coe, and Finkelstein, 2007).

The question is whether taking such an approach in order to increase insurance sales at the margin is worth the costs, which would be significant to millions of Americans. In fact, making Medicaid eligibility rules more stringent would only harm those individuals and their families for whom private alternatives do not represent a reasonable choice. The evidence is overwhelming that individuals currently receiving benefits under the Medicaid program are disproportionately older age, female gender, minority race/ethnicity, less educated, tend to be unmarried, have very low net wealth, are living below the Federal Poverty Level (FPL), have poor self-rated health, higher chronic conditions, and they are much more likely to have depression. For this group of highly exposed Americans, Medicaid represents more than a social safety net, it offers a literal lifeline of essential support to them. Making it more difficult for such people to access the social safety net is at odds with the purpose for which such a safety net exists—namely, to protect our most vulnerable citizens who lack the means to do so on their own.

Question. Beyond consumer financing, LTSS providers also face hurdles that will likely increase as our population continues to age. With regards to growing nursing home workforce needs, the statutory CNA training lockout stands, in my view, as a key impediment. Under current law, nursing homes that receive a fine above a certain level, regardless of cause, automatically lose their ability to train staff to attain State certification as CNAs through so-called Nurse Aide Training and Competency Evaluation Programs (NATCEPs). This lock-out lasts for 2 years, even if the home in question acts quickly and proactively to address deficiencies and become compliant. I have collaborated with my colleague, Senator Warner, to draft bipartisan legislation aimed at better targeting this penalty to encourage nursing home quality without needlessly restricting training programs that could otherwise help to meet workforce needs. If, for instance, the deficiency that triggers a CMP does not harm patients and is promptly addressed, then the facility should have its approval restored. Our bill would also promote workforce integrity by allowing providers participating in Medicare and Medicaid to access the National Practitioner Data Bank to conduct employee background checks.

Outside of increased Federal subsidies or grants, what steps can Federal policymakers take to better address nursing home workforce needs without increasing the regulatory burden for facilities?

Answer. The CNA training lockout is indeed a significant challenge for nursing homes. Even if a nursing home corrects the deficiency and comes into compliance, it is forbidden to run a training program for a full 2 years, which is a counterintuitive (and counter-productive) policy response. Impeding a nursing home's ability to train nurse aides runs counter to the goal of assuring the best quality resident care. That is why it is so important to move S. 2993 (the Ensuring Seniors' Access to Quality Care Act) through the legislative process to successful passage.

Another step the Congress can take to address nursing home workforce needs is to direct and fund the National Academies of Science, Engineering, and Medicine to undertake a consensus study of the evidence base for nursing home quality and then map the evidence to the participation requirements that all Medicare and Medicaid supported nursing homes must comply with. While certain regulatory provisions may not directly affect the quality of care one way or the other, such a review of current regulatory enforcement approaches could lead to more collaborative and less punitive methods of nursing home regulation that better align with the ultimate goal of improving care. For example, inclusion of staff into the problem-solving process could encourage greater staff engagement and lower turnover, both significant problems facing the industry right now. The fact is, the regulatory approach we use today was designed a generation ago. It could benefit greatly from an overhaul that takes into account all that we have learned over the past 32 years about quality and that also recognizes staffing realities.

There are additional steps to consider to address the overall current and growing nursing workforce shortage. The Geriatric Workforce Enhancement Program (GWEP), under title VII and title VIII of the Public Health Service Act, is the only Federal program that trains health-care professionals at every level in the special health-care needs of older people. As our population ages, this program will become more critical than ever and requires greater resource support to keep up with increasing need. The program currently is funded at $40.7 million and an $11 million increase in funding, to $51 million, would allow eight more training sites to become operational. Several educational institutions have developed training programs and applied for GWEP money to put them into operation, but the program's funding limitations have prevented approval of their applications. Moreover, an increase in resources for the program would also be important for the Geriatrics Academic Career Awards which support skilled clinicians in researching and training other health-care professionals to care for older people.

LeadingAge, representing thousands of non-profit LTSS providers serving millions of seniors across the LTSS spectrum—from subsidized senior housing and home care to assisted living, nursing homes and hospice—has advocated for approaches to help foreign-born workers come to the United States to work in the aging services system. For example, the LeadingAge IMAGINE Initiative puts forward concrete steps that could be taken to assure that there are enough people to fill the jobs that will grow and are associated with the rapid aging of the US population. These include such things as: (1) enacting an "H2Age" temporary guest worker program for certified nurse aides (CNA) and home care aides; (2) expanding the EB–3 visa program to allow more foreign-born direct care workers to enter the U.S.; (3) modifying the EB–3 visa to increase the number of visas available specifically to address LTSS needs; (4) modifying the R–1 visa program to provide religious visas to temporary workers in faith-based organizations; (5) Enacting "Carer Pairer," a new authority under the J–1 visa program, to include aging services workers in addition to child care workers; (6) amending the North American Free Trade Agreement (NAFTA) to include aging services workers, and; (7) increasing the number of refugees permitted to enter the U.S. accompanied with concrete steps to employ those refugees in the LTSS sector.

In my testimony to the committee, I made the point that relatively few Americans have private insurance that covers long-term nursing home care. This therefore leaves Medicaid as the primary source of funding for nursing home care; on average 62 percent of nursing home revenues come from Medicaid. Nursing homes depend on Medicaid not only to cover the cost of day-to-day care and operations but also to pay for staff training. Yet, due in part to low reimbursement rates, this funding source has created significant challenges for nursing homes. In fact, median operating margins for facilities have now dipped below zero (CliftonLarsenAllen, 2019, *34th Skilled Nursing Facility Costs Comparison and Industry Trends Report*). Moreover, many nursing homes are struggling to generate enough cash flow to cover operations. It is therefore not surprising that many are no longer in a position to reinvest in their organizations. Moreover, this can handicap them in recruiting and retaining the staff they need to care for residents, and underscores the critical need I discussed in my testimony for moving the system toward an insurance-basis—public and private—to provide financial protection to Americans and support the development of a high quality service infrastructure.

In the meantime, and while we work to move toward a public and private system that insures greater numbers of Americans against the potentially catastrophic costs of long-term care, Congress and the Centers for Medicare and Medicaid Services should help to assure that Medicaid funding levels match the growing needs of an aging population; that reimbursement for services is closely linked to current cost data in the State; that rates are updated annually, and; that individual nursing homes do not face financial exposure from untimely processing of Medicaid applications. Clearly, Congress needs to work with CMS, with States, with providers, with consumers, and with the research community to address the myriad of questions facing the direct care work force and in particularly, those serving our most vulnerable citizens in nursing homes. This must be done with a full recognition that given population aging, effective reform will require tradeoffs among all interests and it will require more financial resources for the system to provide the level of care required.

QUESTION SUBMITTED BY HON. MAGGIE HASSAN

Question. According to a 2019 National Academy of Social Insurance report that you coauthored, as many as one in six working adults act as a caregiver for a senior in their family.

Many of these individuals are ultimately left with the impossible choice between earning a paycheck and taking care of a loved one in need. That's why it is critical to ensure access to paid family and medical leave programs that provide wage replacement to workers who need to care for a sick family member.

Based on your research, can you please explain the socio-economic impact that a federal paid family and medical leave policy could have on individuals with Alzheimer's and family caregivers?

Answer. The Federal paid family and medical leave policy can have a major and positive impact on individuals with Alzheimer's and family caregivers. As was pointed out in the report, ". . . there is a wealth of research showing that access to paid leave increases maternal workforce attachment after giving birth, reduces poverty for households with children, and may also be associated with increased earnings for mothers. Access to paid parental leave for new fathers hasbeen demonstrated to increase women's employment and future earnings. Paid medical leave can help workers with disabilities avoid income loss, separation from the workforce, or unwanted reductions in hours. Workers who experience a serious medical incident are also more likely to return to work when paid leave is available. Additionally, as the Baby Boomer generation ages, the demand for family caregivers who can provide support to their parents and other aging loved ones will grow, especially for those suffering from Alzheimer's disease. As the challenges of balancing work and caregiving responsibilities mount, many workers—particularly women, people of color, and low-wage workers, who may have more care responsibilities and less access to paid family leave—risk negative economic outcomes, such as lost earnings, undesired shifts from full- to part-time work, or being pushed out of the workplace altogether. One study found that women over the age of 50 who left the labor force early to care for an elder suffered forgone wages averaging $142,693 and reductions in lifetime Social Security benefits averaging $131,351; for men, forgone wages and Social Security benefits averaged $89,107 and $144,609, respectively (MetLife Mature Market Institute, 2011).

In addition to the financial benefits for workers and their families, access to paid parental leave has been associated with positive health outcomes for both children and parents. Regarding parents, and more specifically, new mothers, they benefit from the time to recover and bond with their infants; women with more generous leave benefits showed decreased depressive symptoms and higher overall health status after childbirth compared to those who took shorter leaves. Additionally, paid leave is correlated with higher participation in preventive health screenings and care, both for workers themselves and for their dependent children. The available literature does suggest that health outcomes for sick older children and aging individuals alike are improved with support from family members. One recent study on paid family leave in California found that the program is correlated with an 11 percent relative decline in nursing home utilization among seniors (Kanika and Wolf, 2017). In short, such a policy should increase the capacity of family caregivers to provide support to those suffering from Alzheimer's and help to reduce the negative effects on their financial well-being.

PREPARED STATEMENT OF JASON KARLAWISH, M.D., PROFESSOR OF MEDICINE, MEDICAL ETHICS AND HEALTH POLICY, AND NEUROLOGY; AND CO-DIRECTOR, PENN MEMORY CENTER, UNIVERSITY OF PENNSYLVANIA

Thank you, Senators Toomey and Stabenow, for you and your colleagues' invitation to talk to the Senate Committee on Finance, Subcommittee on Health Care, about the state of research and care for persons living with Alzheimer's disease. I am a physician trained in geriatric medicine and researcher at the University of Pennsylvania. I am the co-director of the Penn Memory Center, a center dedicated to the diagnosis, care and research for persons living with Alzheimer's disease and their family members.[1]

My overall message is this: America has made remarkable, even spectacular, progress with research to develop better treatments, and to understand the natural history and costs of the disease.

America has not made the same progress with diagnosis, treatment, and care coordination, or, in a word, care.

America has made tremendous progress in research to understand the natural history and costs of Alzheimer's disease and therefore to improve diagnosis and treatment.

In 1981, the physician and National Book Award-winning essayist Lewis Thomas published "The Problem of Dementia" in the popular science magazine *Discover*.[2] The esteemed and accomplished former dean of New York University's and Yale University's medical schools and, at time of this essay, President of Memorial Sloan-Kettering Cancer Center, pushed Congress to give special consideration and high priority for one particular disease: Alzheimer's disease. He called it "the disease-of-the-century" and "the worst of all diseases." He urged Congress to use its budgetary powers to exercise a target and frontal assault on the disease. It took Congress some years to listen to his admonition, but you did. Below, I highlight three of your accomplishments:

- In April 1990, at the joint senate-house hearing "Alzheimer's—the Unmet Challenge for Research and Care" Senator Mark Hatfield, Republican of Oregon, brought room 2322 of the Rayburn House Office Building to a hushed, plaintive silence as he opened the hearing. "My father was a third generation in our family of blacksmithing. . . ." He told his colleagues about a man of extraordinary physical strength who became so forgetful that he lived his last years in a nursing home, "a powerful man reduced to practically nothing—as almost a vegetable." You listened to your colleague. Senator Hatfield's CARE Act increased funding to NIH by $100 million, a doubling in research funds.
- On January 4, 2011, President Obama signed the National Alzheimer's Project into law. This created and maintains an integrated National Alzheimer's Plan to address the disease.[3] All Federal agencies and departments whose charge affects the lives of persons with Alzheimer's disease participate in providing information and coordinating research and services. Advisory Council members are drawn from across multiple Federal departments and agencies as well as 12 members from outside the Federal government including caregivers, patient representatives, researchers, and "voluntary health association representatives." The plan is accelerating the development of treatment to prevent, halt, or reverse the disease, improve diagnosis, and coordinate care and treatment.
- In December 2014, Congress passed the "Alzheimer's Accountability Act."[4] The Act authorized the director of the National Institutes of Health to prepare an annual budget to meet the benchmarks and goals of the National Alzheimer's Plan. This budget is unique. It bypasses the usual process that begins with congressional review and revisions, but instead goes directly to the

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[1] The services and research performed at the Penn Memory Center are described at *www.pennmemorycenter.org.*

[2] Lewis Thomas. "On the Problem of Dementia." *Discover.* August 1981, pp. 34–36. Reprinted in: *Late Night Thoughts on Listening to Mahler's Ninth Symphony.* The Viking Press, New York: 1983, page 121.

[3] U.S. Code, Title 42. The Public Health and Welfare. Chapter 118. Alzheimer's Disease and Related Dementias Research. Subchapter III–A. National Alzheimer's Project. Section 11225. The National Alzheimer's Project. 42 U.S. Code § 11225. The National Alzheimer's Project.

[4] *https://www.congress.gov/113/plaws/publ235/PLAW-113publ235.pdf.*

> president. Simply put, NIH had been granted the power to ask Congress for exactly how much money is needed to address the Alzheimer's crisis.

These efforts have created and sustained a research infrastructure. Highlights, but by no means exclusive parts, of this infrastructure include Alzheimer's Disease Research Centers, the Alzheimer's Disease Neuroimaging Initiative, the Alzheimer's Disease Cooperative Study (now the Alzheimer's Clinical Trials Consortium), the Resources for Enhancing Alzheimer's Caregiver Health, and the Health and Retirement Study's Aging Dementia and Memory Study.

This infrastructure has revolutionized the ways we understand the costs of Alzheimer's disease and how we treat it. The Health and Retirement Study's Aging Dementia and Memory Study has shown the disease's total yearly costs to the U.S. in 2010 were as much as $215 billion.[5] As much as one-third to one-half of this arresting total is the cost of a family caregiver's time and effort providing care.

Resources for Enhancing Alzheimer's Caregiver Health has shown that caregiver education, problem-solving strategies, care navigation support, support after discharge from a hospital or nursing home, and decision-making support reduce caregiver distress, costs of care and improve patient quality of life.[6] These interventions might also reduce the costs.

This infrastructure has revolutionized the ways we understand what is Alzheimer's disease. When I began my practice in 1997, a person had to have disabling cognitive impairments to be diagnosed with Alzheimer's disease. In other words, a person had to be diagnosed with dementia in order for me to diagnose whether she had Alzheimer's disease or some other disease that caused her dementia. A definitive diagnosis was only possible after death, when a neuropathologist performed a brain autopsy. In 20 quick years, researchers transformed this.

We made discoveries that allow my colleagues and me at the Penn Memory Center to diagnose the disease when a person has only mild cognitive impairment, commonly called "MCI."[7] We are able to detect biological markers of Alzheimer's pathologies (that is, biomarkers) in the brain of a living person. These markers have led to a revision of the diagnostic criteria for Alzheimer's disease.[8]

The gothic horror story—the need to die to get an accurate diagnosis—is ending.

We are also studying drugs that target the disease. Most provocatively, as part of the NIA-funded Alzheimer's Clinical Trials Consortium, we are testing these drugs in persons who have either biomarkers of the disease or genes that increase the risk of developing dementia, but have no signs and symptoms.[9] At the Penn Memory Center, we have study subjects taking the morning off from work or delaying their departure for a turkey-hunting trip to come in for study visits testing a drug that we hope will delay the time before they have to stop working or hunting because of mild cognitive impairment or dementia.

This research has taught us that Alzheimer's disease is a complex disease. Among the most important recent discoveries is that biomarker patterns in patients with "early onset Alzheimer's disease," meaning before the age of 65, differed from those with "late onset Alzheimer's disease." We have also discovered that dementia in persons over 80 is commonly caused not by the classic Alzheimer's pathologies of amyloid and tau but by those two pathologies and a third and not well understood pathology called "pathologic TDP–43."

These findings are of substantial importance to America. Persons over 80, sometimes called "the oldest old," are the largest proportion of persons with dementia. The aging of the "baby boom" generation assures they're the fastest growing proportion as well.

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[5] Hurd M.D., Martorell P., Delavande A., Mullen K.J., Langa K.M. Monetary Costs of Dementia in the United States. *New England Journal of Medicine.* 2013;368(14):1326–1334. doi:10.1056/NEJMsa1204629.

[6] For an overview of the results of the REACH studies, *see* Richard Schulz, ed. "Handbook on Dementia Caregiving: Evidence-based Interventions for Family Caregiver." Springer Publishing Company, 2000. ISBN–13: 978–0826113122.

[7] For an overview of MCI, *see* Ronald Petersen. "Mild Cognitive Impairment." *New England Journal of Medicine.* 2011; 364:2227–2234. Petersen led the team of Mayo Clinic researchers who discovered the concept.

[8] Jack C.R., Knopman D.S., Jagust W.J., et al. "Tracking pathophysiological processes in Alzheimer's disease: an updated hypothetical model of dynamic biomarkers." *The Lancet Neurology.* 2013;12(2):207–216. doi:10.1016/S1474–4422(12)70291–0.

[9] *See* for example the A4 Study, *www.a4study.org.*

These findings, therefore, suggest that for persons who are 80-plus, treatment for any one pathology alone, such as amyloid, may not be sufficient to slow the disease. They suggest that a person who started treatment at, say, 70 and lives to 80 may develop a new cause of cognitive impairment.

The unifying word that summarizes these findings is "heterogeneity." Alzheimer's disease is not like polio, a disease caused by a single virus that will be tractable to a single treatment. A reasonable expectation is a cure for some, a chronic disease for many.

Let me close this summary of the progress in our research with an assessment by George Vradenburg, chairman of USAgainstAlzheimer's:

> I think we're going to be in a world in which we have some successful drugs but the drugs are only going to be partially effective and where we're going to need high-quality care institutions for a very, very long time.[10]

Simply put, we're not going to drug out way out of this complicated problem. We are going to need to care for each other.

Care for persons living with Alzheimer's disease needs to improve.

On Tuesday, July 15, 1980, at a few minutes before half past 10 in the morning, in room 4232 of the Dirksen Senate Office Building, the people of the United States of America met Alzheimer's disease for the first time. The occasion was "Impact of Alzheimers disease on the Nation's elderly," a joint hearing before the Subcommittee on Aging of the U.S. Senate's Committee on Labor and Human Resources and the Subcommittee on Labor, Health, Education, and Welfare of the House Committee on Appropriations. The host, and the only Congress person present at the hearing, was the chair of the subcommittee on aging, Senator Robert Eagleton of Missouri.

The first witness, the first American to speak to her fellow Americans about living with Alzheimer's disease, was Mrs. Bobbie Glaze, one of the founding members of the organization that would come to be called the Alzheimer's Association.

Glaze told the story of her husband's dementia. Life with the disease was "a funeral that never ends." Her husband was once "a handsome, vital, athletic man, a civic leader, a public speaker, a highly respected businessman." Now, she explained, he was "a statistic." It had been 4 years since he spoke or recognized her. She too felt stripped of identity.

She narrated their years long decline. It was their decline because, as he became more and more disabled, agitated and withdrawn, they became impoverished and she, isolated.

Along the way were unremitting indignities. The neurologist delivered his diagnosis in the waiting room. Ignorance and indifference were the norm. "I was given no explanation of what Alzheimer's disease is, what to expect, how I might learn to cope, nor was I directed to someone who might be able to direct me in the monumental problems ahead."

I am confident that had the Glazes been cared for at a memory center such as where I practice, they would not have suffered as they did. I am sad however that there are still too many persons living with dementia and their families who are telling the same stories Bobbie Glaze told some 40 years ago.

The typical new patient visit at the Penn Memory Center begins with a family recounting a despairing narrative of frustrating months, even years, searching for answers and struggling to get care.

To make a diagnosis and care for a person living with Alzheimer's disease I need about 60 minutes to discover that the person has cognitive impairment and that this impairment causes her to be either less efficient performing day to day tasks, or needs someone else to assist her with tasks. "Day-to-day tasks" means activities of daily living such as managing a check book, using the computer, cooking a dinner, traveling from one place to another. "Less efficient" means the person struggles and takes longer but still can carry on.

A person with cognitive impairment who is less efficient in their day-to-day tasks has what we call "mild cognitive impairment," or MCI. A person with cognitive impairment who "needs someone else to help" has dementia. The person is disabled.

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[10] Cynthis Helzel. "Making a Difference." Argentum. 25 August 2017.

To gather this information, I interview not one, but two people—the patient with the memory problem and someone else who knows him well, such as a partner or adult child. That person typically becomes the caregiver. I obtain about 25 minutes of cognitive testing and, in most cases, I order tests, most commonly an MRI of the brain.

Later, I see the patient and caregiver for a 30-minute diagnostic follow up visit. At that visit, I explain the diagnosis, stage and care, answer questions and then they meet with a social worker to develop a plan to address the functional inefficiencies and impairments.

This care plan educates the patient and caregiver about the diagnosis, stage and what to expect in the future. It addresses the patient's functional impairments and the sources of caregiver strain. For example, we may recommend the patient undergo a driver's evaluation or the caregiver gain view only access to the patient's bank and credit accounts. This care planning is ongoing. In time, we train the caregiver how to talk to the patient about attending an adult day program and help the caregiver locate and figure out how to pay for the program.

We are able to do this at the Penn Memory Center because we benefit from cross subsidies from research and philanthropy. Our entire social work team is made possible by a generous donation the caregiver of one of our patients.

Some key points.

- We do not have a "test" for dementia or MCI. There is, therefore, no "test for Alzheimer's disease."
- An MRI is very helpful to show neurodegeneration, but it does not explain what caused neurons to die.
- Amyloid and tau tests, such as measured using a PET scan, are very important to show why neurons are dying. When both are present, they show that Alzheimer's disease is the cause of a person's MCI or dementia. Amyloid and tau however are seen in other diseases. These scans are, at present, most valuable when they are negative. A negative result removes Alzheimer's disease as the cause of the person's cognitive impairment. Of course, in the event a drug is discovered that targets tau or amyloid and, as a result, slows the death of neurons, then these tests will be valuable as a means to guide treatment decision making.
- Cognitive testing is a *very important* part of the assessment, but cognitive testing is just one part, and it needs context. This context includes the quality of the person's education and the nature of their occupation. At Penn, we see college graduates who are accomplished executives with nearly normal testing but have MCI or even mild stage dementia caused by Alzheimer's disease. Quality of education is a notable issue for America's older adults, particularly persons of color who were raised and educated in schools that were segregated. Cognitive testing done without context is simply hard to interpret. Context explains why there is not "one test for all." This explains, at least in part, why the Medicare annual wellness visit's requirement for "the detection of the presence of any cognitive impairment" has been difficult to implement.

There are tremendous benefits to this approach to diagnosis and care. Individuals with cognitive decline who sought care from a specialist (that is, a neurologist, psychiatrist or geriatrician) had a shorter time to diagnosis of Alzheimer's disease[11] and had lower Medicare costs in the year after receiving a diagnosis of Alzheimer's dementia than those diagnosed by a non-specialist.[12]

Why is what we do at a memory center not routine?

Reason #1: There is a scarcity of physicians skilled in making and disclosing a diagnosis and discussing a treatment plan with a person living with dementia or MCI and their caregiver.

1. There is a shortage of geriatricians.[13]

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[11] Kirson, Noam Y., et al. "Assessing the economic burden of Alzheimer's disease patients first diagnosed by specialists." *BMC Geriatrics* vol. 16 138. 11 Jul. 2016, doi:10.1186/s12877–016–0303–5.

[12] Alzheimer's Association. "2019 Alzheimer's Disease Facts and Figures." *Alzheimer's and Dementia* 2019;15(3):321–87.

[13] Fried, L.P. and Hall, W.J., (2008). "Leading on Behalf of an Aging Society." *The Journal of the American Geriatrics Society,* 56(10), 1791–1795. doi: 10.1111/j.1532–5415.2008.01939, and

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The American Geriatrics Society estimates 30 percent of the 65-plus patient population will need a geriatrician. One geriatrician can care for ~700 patients. This means "30,000 geriatricians will be needed by 2030 to care for about 21 million older Americans." In 2016, there were 7,293 certified geriatricians in the U.S. or 1 geriatrician for every 1,924 Americans age 65 or older in need of care. The United States has approximately half the number of certified geriatricians that it currently needs.

2. There is a shortage of geriatric psychiatrists.[14, 15]

The American Association of Geriatric Psychiatry has about 2,000 active members. The 2003 President's Commission on Mental Health Subcommittee on Older Adults (2003), concluded that "at the current rate of graduating approximately 80 new geriatric psychiatrists each year and an estimated 3 percent attrition, there will be approximately 2,640 geriatric psychiatrists by the year 2030 or one per 5,682 older adults with a psychiatric disorder."

3. There is a shortage of neurologists.[16]

A report by the National Center for Health Workforce Analysis estimates that while the supply of US neurologists may have grown by 11 percent between 2013 and 2025, demand will have grown by 16 percent.[17] The current national and geographic shortfalls of neurologists are likely to worsen, exacerbating long wait times and reducing access to care for Medicaid beneficiaries.[18] A large number of neurologists do not accept new Medicaid patients and most do not pursue cognitive disorders. Most pursue more lucrative fields such as stroke, MS, epilepsy and neurocritical care.

4. Primary care physicians struggle to diagnose and treat patients with MCI and dementia.

Documented barriers are: time constraints, inadequate knowledge, an inadequate skill set, fear of making an incorrect diagnosis, lack of remuneration, and lack of coordination between physicians and community services.[19]

Reason #2. Physicians who have the skills to detect and work up cognitive impairment lack the resources to practice them. In my research on the Alzheimer's crisis in America, I found only one center that is like the Penn Memory Center and is not affiliated with an academic medical center or a clinical trial center. Memory Care in Asheville, NC, run by Margaret (Peggy) Noel, M.D. is supported some by Medicare billing but as well depends on donated space, a fee charged to the caregiver for their counselling, and annual fundraising.

What needs to be done?

1. Expand the physician workforce.

- Medicare should consider how its influence over reimbursements to teaching hospitals can incentivize the numbers of persons pursuing residency and fellowship training in geriatrics, geriatric psychiatry and cognitive neurology.
- Persons pursuing geriatrics, geriatric psychiatry and cognitive neurology ought to be able to apply for grants to cover the salary of the trainee.

2. Create a better business model for the diagnosis and care of persons with Alzheimer's disease. The majority of persons with Alzheimer's disease are over 65 and so covered under Medicare. Medicare therefore has a key role in shaping the business model for the care of persons with Alzheimer's disease.

The American Geriatrics Society. "Current Geriatrician Shortfall." Available at: *https://www.americangeriatrics.org/sites/default/files/inline-files/Current-Geriatrician-Shortfall_0.pdf.*

[14] Membership Directory, American Association for Geriatric Psychiatry [cited November 13, 2019].

[15] IOM Study on Mental Health Workforce of Older Adults Fact Sheet.

[16] Burton, Adrian. "How do we fix the shortage of neurologists?". *The Lancet Neurology* 17.6 (2018): 502–503.

[17] *https://bhw.hrsa.gov/sites/default/files/bhw/health-workforce-analysis/research/projections/BHW_FACTSHEET_Neurology.pdf.*

[18] Timothy M. Dall, Michael V. Storm, Ritashree Chakrabarti, Oksana Drogan, Christopher M. Keran, Peter D. Donofrio, Victor W. Henderson, Henry J. Kaminski, James C. Stevens, Thomas R. Vidic. *Neurology* Jul 2013, 81 (5) 470–478; DOI: 10.1212/WNL.0b013e318294b1cf

[19] Hinton, Ladson, et al. "Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives." *Journal of General Internal Medicine* 22.11 (2007): 1487–1492.

In January 2017 CMS introduced the G0505 Medicare procedure code.[20] Its purpose is to pay clinicians to assess patients with cognitive impairment, including dementia, and the creation of a care plan. One year later, the G0505 code was superseded with CPT code 99483, "Cognitive Assessment and Care Plan Services." These billing codes are tremendous steps forward. Their key innovations are they recognize the complexity of a workup; explicitly include caregivers; require a written, shared care plan.[21]

This is what Bobbie Glaze was looking for.

I applaud the effort of several Senators who just 1 month ago, wrote to Seema Verma at CMS that in 2017 *less than one percent* of seniors eligible to receive this benefit actually accessed it in 2017. The senators were right to urge Administrator Verma to educate clinicians to use the codes and discover the barriers to implementing it.[22]

We must study who is using this code and who is not, why, and how well it works. We should do this with the same urgency as our studies of Alzheimer's biomarkers.

I close with the results of some preliminary studies to begin to answer these questions.

1. I have learned that some Medicare advantage plans were not paying for it.

2. Primary care physicians need to be instructed on how to spread this work out over several visits.

3. Medicare should study how to integrate this code into its Comprehensive Primary Care Plus initiative.

4. The code should recognize that many of the services for dementia care are effectively and efficiently delivered by nurses, social workers, and community health workers. We at the Penn Memory Center are not using it. Why? The code allows "Any practitioner eligible to report E/M services can provide this service. Eligible providers include physicians (MD and DO), nurse practitioners, clinical nurse specialists, and physician assistants." Social workers perform our care planning.

5. The code does not reimburse for ongoing care management services.[23]

The code ought to cover interventions that can prevent or reduce patient's symptoms and caregiver stress training. These include support to enhance the caregiver's skills, case management and coordination of services and supports among providers and community resources such as an adult day program.

QUESTIONS SUBMITTED FOR THE RECORD TO JASON KARLAWISH, M.D.

QUESTIONS SUBMITTED BY HON. TODD YOUNG

DEVELOPMENT OF AN ALZHEIMER'S TEST

Question. You mention in your testimony that we currently do not have a "test" for dementia or MCI.

Where are we in terms of research and development for this type of test?

Answer. When the topic is Alzheimer's disease, nuance reigns.

We in fact don't have "a test" for either mild cognitive impairment (MCI) or dementia. We do have a number of tools that can assist a clinician to detect these conditions. Both MCI and dementia describe the severity of a person's cognitive and functional problems. Alzheimer's disease is one cause of MCI and dementia. Other

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[20] Perry, William et al. "Population Health Solutions for Assessing Cognitive Impairment in Geriatric Patients." *Innovation in Aging* vol. 2,2 igy025. 12 Oct. 2018, doi:10.1093/geroni/igy025.

[21] "Advisory Council on Alzheimer's Research, Care, and Services." *Measuring Progress, Recommendations, and Moonshot Updates.* Washington: Department of Health and Human Services (U.S.) (2019), *https://aspe.hhs.gov/system/files/pdf/261851/Mtg32Sum.pdf.*

[22] *https://www.mcsally.senate.gov/mcsally-bipartisan-group-senators-urge-expanded-access-families-alzheimers.*

[23] Boustani, Malaz, et al. "An alternative payment model to support widespread use of collaborative dementia care models." *Health Affairs* 38.1 (2019): 54–59. *https://doi.org/10.1377/HLTHAFF.2018.05154.*

diseases cause MCI and dementia, such as, for example, Lewy Body Disease (this disease caused Robin Williams dementia).[1]

"Cognitive problems" means changes in a person's memory, word finding, problem solving, attention and spatial abilities. We typically assess these using pencil and paper tests. There are many different kinds of tests and some of the more well-known ones include the Montreal Cognitive Assessment, or MOCA.[2]

Unlike, say blood pressure or weight, there is no single and widely accepted test. Test scores need to be interpreted in light of the person's background, particularly their educational and occupational attainment. This need for interpretation is why it is possible for a person to have a "normal score" on a common test used as part of an assessment for cognitive impairment and yet be diagnosed with MCI or even mild stage dementia, or alternatively have an "abnormal score" and yet not have cognitive impairment (the problems of false negative and false positive assessments, respectively).

"Functional problems" means changes in a person's ability to perform day-to-day tasks, such as traveling from home to the store, shopping, managing money, cooking a meal, and using the computer. We typically assess these by talking to someone who knows the person well, such as a spouse, friend or adult child.

MCI describes a person who has cognitive problems and is less efficient doing functional tasks. They take longer to shop or pay the bills. They may make a few mistakes but they catch them, usually.

Dementia describes a person has cognitive problems and, as a result, is unable to perform at least come functional tasks. Someone else has to help the person shop or manage money or drive. Beginning in about the mid-1980s, we began to label this person "a caregiver."

Clinicians have many, many tools to assist them to determine whether a person has MCI or dementia. There is, however, no one test that can do this without the work of a clinician. That clinician needs to talk to someone else such as a spouse or family member to determine if there has been functional decline. The clinician, or someone she designates such as a nursing assistant, needs to perform cognitive testing.

All of the above points are leading up to two points:

1. Testing cognition alone does not detect cognitive impairment. In other words, testing cognition alone does not detect either MCI or dementia, particularly mild stage dementia. Yes, of course, in a person who have moderate to severe stage dementia, a cognitive test alone could detect that. Why? Because the person performs so poorly on the test. The problem with detecting MCI and dementia, particularly mild stage dementia, is the overlap between "normal scores" and "abnormal scores." Hence the need for the functional assessment.

2. An "Alzheimer's test" is a test that detects the pathologies that cause MCI and dementia. We are able to detect these pathologies. We can measure amyloid protein in spinal fluid or with PET scan of the brain. We can detect tau protein in spinal fluid and soon with a PET scan.

An Alzheimer's test does not detect dementia or MCI.

The Medicare annual wellness visit requirement for the detection of the presence of "any cognitive impairment" is a well-intentioned effort to make American medicine attend to their patients' brain health. It was an idea written by Congress. Not medicine.

All of the above is leading up to a policy change. A smart revision to the requirement would be to assess cognition and function in order to detect the presence of cognitive impairment. This would align with the intentions of CPT code 99483, designed to support "Cognitive Assessment and Care Plan Services."

Question. What more could be done at the Federal level to encourage research into the development of an Alzheimer's test?

Should we be encouraging prize competitions, like that of EUREKA?

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[1] Susan Schneider Williams, Robin Williams' widow, recounts her husband's diagnosis in this essay in *Neurology. https://n.neurology.org/content/87/13/1308.*

[2] *See https://www.mocatest.org/*—President Trump's clinician used the MOCA in his 2018 annual physical.

Answer. What is a vision for a future for the development of tests to detect cognitive impairment and Alzheimer's disease? Two things.

First, unobtrusive monitoring that shows how a person is functioning in her day-to-day life. The term "unobtrusive monitoring" describes sensors of common everyday activities such as traveling about, driving, banking, managing medications, and using technology like the stove and computer. Think of a "smart phone" or even a "smart home" that monitors day to day activities. Imagine a future when financial transactions are monitored for signs of cognitive decline. There is tremendous opportunity to use real-world financial data to identify persons who are having problems with financial capacity or are victims of fraud and abuse.

Second, a blood test that detects biomarkers of amyloid and tau, and, someday as well the other diseases that cause MCI and dementia. Imagine for example a blood test for Lewy Body Disease.

We should encourage the development of these biomarker and monitoring technologies. Much research is under way.

Would a prize help to speed research along? With a clear goal and flexibility in the timeline, a prize is a great motivator. The biggest challenge, and so the biggest prize, is translating these discoveries into routine clinical practice.

Right now, in America, what would most help would be to create a health-care system that allows a clinician to administer cognitive tests, talk to an informant about function, and if these assessments raise concerns, perform a workup. The Medicare CPT code 99483 could facilitate this, but it is notably underutilized. If we figure out why that will be a eureka moment.

ASSESSMENT TOOLS

Question. You talk a lot about cognitive testing and its importance in assessing whether a patient could have dementia.

Should we be encouraging the Centers for Medicare and Medicaid Services to utilize the existing Welcome to Medicare initial exam and Medicare annual wellness visits to try to screen, detect, and diagnose Alzheimer's and related dementias in their earliest stages?

Answer. We should encourage the detection of dementia. This will require cognitive testing *and* functional assessment. In the Welcome to Medicare exam and the annual wellness visit the clinician can obtain cognitive testing. The challenge is obtaining a functional assessment. This is best done by talking to someone who knows the person well, such as a spouse, adult child, neighbor or friend.

We ought to create a health-care system that allows a clinician to administer cognitive tests, talk to an informant about function, and if these assessments raise concerns, perform a workup. As referenced above, the Medicare CPT code 99483 could facilitate this, but it is notably underutilized.

QUESTIONS SUBMITTED BY HON. BENJAMIN L. CARDIN

CARING FOR PERSONS LIVING WITH ALZHEIMER'S DISEASE

Question. While efforts to find a cure for Alzheimer's disease are critical, we must ensure that patients who are diagnosed have the care coordination that meets their personal, medical, and financial needs.

Ms. Kovach's selfless act to care for her grandmother is tragically common, as many people with Alzheimer's disease come to rely on a partner or a child as a caregiver. The Alzheimer's Association estimates that there were 293,000 caregivers in Maryland last year that provided 334 million hours of unpaid care at a value of $4.2 billion.

Since 2013, I have been proud to annually introduce a resolution with Senator Collins recognizing the work of Direct Support Professionals (DSPs). DSPs are integral to the system of providing long-term support and services for Alzheimer's patients.

In your testimony, you describe some of the steps of the care planning benefit that the Penn Memory Center employs, including discussing optional caregiver programs like adult day health programs. We want to ensure that Alzheimer's patients and their families have the full array of caregiver services available and provided as options.

Can you discuss how Penn Memory Center works to ensure that the care planning benefit for Alzheimer's patients includes all available caregiver service options?

Answer. We have social workers with the knowledge of the programs available in our region and the skills to help a patient and family member decide what services they need, how to access them and how to pay for them. A social worker or other health-care or social-service professional is an essential part of the care team. The general term for such a person is a "care manager."

At the diagnostic follow up visit, the patient and family routinely meet with a care manager to review and create a care plan. The policy message here is that clinicians need to have easy and unencumbered access to persons who can help a family assemble a care plan.

Question. Are there best practices around this that you would recommend to Medicare?

Answer. A critical need is for care managers to assist a patient or family member to access care services and support. One examples of this in practice is at UCLA.[3] I refer you as well to this review of how to design systems of care for older adults with dementia.[4]

QUESTIONS SUBMITTED BY HON. SHERROD BROWN

SOCIAL DETERMINANTS AND ALZHEIMER'S DIAGNOSIS

Question. Several presenters at the 2017 Alzheimer's Association International Conference presented data that indicate a link between social determinants and the development and prognosis of Alzheimer's disease. Specifically, these studies found that stressful life events such as interactions with the criminal justice system, poverty, lack of access to preventive healthcare, lack of education, and food insecurity were associated with an increased development of Alzheimer's disease and a worse disease prognosis.

In the course of your practice, have you observed a link between social determinants like poverty, education, and nutrition with Alzheimer's risk and prognosis?

It has been well established that preventive health care is a key to a long and healthy life. In your opinion, does this same paradigm apply to preventive efforts towards poverty, poor education, and malnutrition?

In 2017, Alzheimer's cost the U.S. health system an estimated $259 billion, which includes $175 billion in Medicare and Medicaid payments. Do you believe that additional investment in addressing the social determinants of health may help reduce future health-care costs associated with Alzheimer's disease?

Answer. The three questions are thematically linked, and so I'll answer them together.

In the past 30 years, the risk of developing dementia has been declining. There still are millions of people with dementia. There just aren't as many as we expected, and, if we take action, there may be fewer than the 13 million projected in 2050.

The NIH funded Framingham study found that from 1970 to 2008, the risk of getting dementia has been steadily declining. A twenty percent drop per decade.[5]

This seems ironic. In that same time period, researchers haven't discovered drugs targeting the pathologies that we think cause Alzheimer's disease and so prevent dementia caused by those pathologies, but something must be working.

What has been working? What interventions are preventing dementia and keeping the brain healthy despite Alzheimer's pathology? A dive into the data shows the answers.

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[3] *See* the UCLA dementia management program. *https://www.uclahealth.org/dementia/*.

[4] Callahan et al. *Health Affairs.* "Redesigning Systems of Care for Older Adults With Alzheimer's Disease." *https://www.healthaffairs.org/doi/10.1377/hlthaff.2013.1260*.

[5] Claudia L. Satizabal, Alexa S. Beiser, Vincent Chouraki, Geneviève Chêne, Carole Dufouil, and Sudha Seshadri. "Incidence of Dementia Over Three Decades in the Framingham Heart Study." *The New England Journal of Medicine* 374;6: 523–32.

Over 30 years, the residents of Framingham who had access to health care took more and more treatments and interventions to prevent heart disease, such as antihypertensive medications and a heart-healthy lifestyle, and if they developed heart disease, such as a heart attack or stroke, they received care. The more care they got, the healthier were their brains. Their risk of dementia was lower. Drugs to lower blood pressure and cholesterol were one intervention. The residents of Framingham also benefited from reductions in rates of tobacco smoking and other heart-healthy lifestyles.

Framingham's results aren't unique. Similar large studies from Sweden and the United Kingdom showed the same results.[6]

A 2017 report in the *Lancet* summarized the evidence about what increases the risk of dementia and so how we can prevent dementia. As much as 35 percent of the lifetime risk of developing dementia is caused by things people can do something about.[7] These risk factors are: less than a high school education; hypertension; obesity; hearing loss; tobacco smoking; depression; physical inactivity; social isolation; and diabetes.

Each of these can be intervened on (see for example, my answer to Senator Casey's question about the benefits of correcting hearing loss).

ACCESS TO PROPER NUTRITION AND THE RISK OF DEVELOPING ALZHEIMER'S

Question. There is a growing body of evidence linking diet to the risk of developing Alzheimer's disease and other forms of dementia. Diets rich in healthy fats, whole grains, fresh fruits, and fresh vegetables have been linked to a decreased risk of developing various forms of dementia. Research studies also indicate that children who partake in a nutritious diet at a young age are more likely to continue eating healthy as they mature into adulthood.

Earlier today, the Trump administration finalized changes to the Supplemental Nutrition Assistance Program (SNAP), which could strip hundreds of thousands of people of their SNAP benefits, causing an estimated 61,000 households in Ohio to lose access to this important program. A study by the Urban Institute found that these changes (imposing stricter work requirements, capping allowance deductions, and altering the way participants are enrolled in the program) would result in 3.7 million fewer people per month receiving SNAP benefits along with 982,000 students loosing access to free or reduced lunches.

Does maintaining a proper diet play a role in reducing the risk of developing a cognitive impairment like Alzheimer's disease?

Answer. Yes. See answer above for why. To reiterate, a diet that is heart-healthy, limits obesity, and prevents or treats diabetes is a brain-healthy diet. Put another way, SNAP is part of our Nation's effort to prevent dementia.

Question. Can people take preventative measures in childhood, adolescence, and adulthood to reduce the risk of developing a cognitive impairment like Alzheimer's disease?

Answer. Yes. Again, see above for why. Several of the risk factors are events that occur in early life—hypertension, obesity, tobacco habits, inactivity, and, of course, education.

Question. When treating a patient with a disease like Alzheimer's, do you recommend that the patient improve or maintain a healthy diet?

Answer. I recommend a heart-healthy life. This includes exercise, no smoking, and a heart-healthy diet. I encourage social engagement such as at a senior center or an adult care program.

Question. Would a reduction in access to healthy foods impact the prognosis for a patient diagnosed with a cognitive impairment like Alzheimer's disease?

Answer. A heart-unhealthy diet will harm a vulnerable brain.

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[6] Matthews F.E., Arthur A., Barnes L.E., et al. "A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the Cognitive Function and Ageing Study I and II." *Lancet* 2013; 382: 1405–12.

Qiu C., von Strauss E., Beckman L., Winblad B., Fratiglioni L. "Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden." *Neurology* 2013; 80: 888–94.

[7] *See* Livingston et al. "Dementia prevention, intervention and care." *Lancet.* 390;2017: 2673–2734. *https://doi.org/10.1016/S0140-6736(17)31363-6.*

REDUCED RATES OF COGNITIVE ASSESSMENT

Question. During the hearing, we discussed the many benefits included in the Affordable Care Act (ACA) that both help individuals with Alzheimer's as well as their family members and caretakers. One benefit of the ACA that you mentioned was the creation of an Annual Wellness Visit (AWV) in the Medicare program, which includes a screening for cognitive impairment.

In general, does early detection of a cognitive impairment such as Alzheimer's disease lead to improved prognosis?

Answer. The key term here is "detection" and to recognize that detection is distinct from "screening." "Detection" means efforts that are in part individualized to a person. "Screening" describes a uniform approach for all persons.

The "detection of cognitive impairment" requires testing the person's cognition and also talking with someone close to the person to assess whether the person is having any inefficiencies or problems doing day-to-day tasks. My answer to Senator Todd Young's question details this.

Detection is a sensible thing to do. The longer a person suffers cognitive impairment, the more the person experiences unaddressed disabilities. As a result, the person suffers from errors taking medications, missed doctors' appointments, social isolation, financial errors, financial abuse or exploitation, and poor nutrition.

Question. In your professional opinion, does the ACA benefit of an AWV screening help identify patients with early signs of cognitive impairment, who otherwise might slip through the cracks?

Answer. See answer to previous question.

Question. Would the elimination of this benefit (and the resulting decrease in the number of individuals undergoing this screening) hurt our Nation's effort to combat disease like Alzheimer's and care for patients with cognitive impairments?

Answer. Yes, of course. The smart next step in our Nation's effort to transform Alzheimer's disease and related disorders from a crisis to a manageable problem to align the vision of the Annual Wellness Visit with the CPT code 99483, designed to support "Cognitive Assessment and Care Plan Services."

QUESTIONS SUBMITTED BY HON. ROBERT P. CASEY, JR.

Question. Thank you for your testimony at the hearing. I would like to follow up with you about my question related to hearing loss and dementia. In your response to my question, you referenced research that draws a link between hearing loss and an increased risk for dementia. My legislation, the Medicare and Medicaid Dental, Vision, and Hearing Benefit Act of 2019 (S. 1423) would ensure that dental, vision, and hearing services are guaranteed benefits for all Medicare beneficiaries. I know you have extensively researched Alzheimer's disease and related dementias, as well as provided care to many people living with Alzheimer's disease. Would you provide a more detailed explanation of the impact hearing loss can have on a person's cognitive function? Do you think that increasing access to hearing services could help maintain and improve healthy brain activity, especially for aging adults?

Answer. Hearing loss is common. Among persons over 55, 32 percent experience it. Many studies show hearing loss is associated with an increased risk of developing dementia. For a thorough review of these data, please see the work of the Lancet Commission.[8]

The key points are that hearing loss is one of the largest of the modifiable risk factors for dementia. Preventing or treating hearing loss could reduce the population risk of developing dementia by as much as nine percent. In America, this translates into millions and millions of older adults.

Multiple mechanisms explain this association. Hearing loss causes social isolation which, in turn leads to cognitive impairment. The less aural input the brain receives, the harder it is for a person to learn and remember facts. The harder a person has to work to learn and remember, the more the person work to perform other cognitive tasks. As hearing loss worsens without correction, the many brain regions

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[8] Livingston et al. "Dementia prevention, intervention and care." *Lancet.* 390;2017: 2673–2734. *https://doi.org/10.1016/S0140-6736(17)31363-6.*

that process auditory information are not sufficiently stimulated, leading to loss of function.

Increasing access to hearing services could therefore help maintain the cognitive health of aging Americans.

QUESTIONS SUBMITTED BY HON. SHELDON WHITEHOUSE

Question. In 2020, the Center for Medicare and Medicaid Innovation (CMMI) will implement a care model for beneficiaries with significant chronic illness(es), who have high utilization rates and fragmented care. Through the Seriously Ill Population (SIP) model, CMS will temporarily raise provider payment rates for beneficiaries in the program while providers coordinate care and stabilize patients.

What is your assessment of the SIP model?

In what ways could SIP improve care delivery for beneficiaries with chronic illnesses?

Do you see any areas for improvement to the CMMI proposal?

Answer. Among the many causes of disability and death, as well as caregiver burden and loss of income, is the health care system. Fragmented and uncoordinated care is a particular problem for older adults who have multiple illnesses, especially if one of those illnesses is dementia. Unlike a disease, this cause of morbidity and mortality is fixable, even curable.

The Seriously Ill Population model is an example of the kinds of interventions that can achieve this. It will improve care because it will eliminate unnecessary medication and test prescribing, educate the patients and especially the family on how to care for the person, identify flares of illness before they require hospitalization, and minimize unnecessary days in hospital.

Question. Many families feel frustrated with the apparent lack of progress on finding a cure or treatment for Alzheimer's. However, you all commented on the increase in knowledge and resources available to families of Alzheimer's patients in recent years.

Please describe any recent advances in our understanding of Alzheimer's and dementia and any progress towards medical treatment.

What avenues of current research appear to be most promising?

Answer. Twenty years ago, a definitive diagnosis of Alzheimer's disease could only be made after the person with dementia had died, from the results of a brain autopsy. Now, we can visualize the pathologies in the living person. We call these "biomarkers." These biomarker discoveries are a tremendous advance. They not only allow for greater diagnostic understanding, they are the route to discovering treatments that target those pathologies.

We have as well an increasing understanding of the complexity of the causes of dementia. Again, this is very useful for guiding the design and testing of drugs.

We have a greater understanding on the kinds of lifelong habits and behaviors that are associated with harming brain health.

All of this knowledge came from research. Much of it funded by NIH.

The avenues of current research that are promising are studies designed to: understand the biomarkers of disease and how they relate to disease progression and clinical problems; intervene on biomarkers and so slow disease; discover the social, clinical, and ethical implications of using these biomarkers in clinical practice; discover how best to deliver life course interventions to reduce the risk of dementia; and improve the delivery of diagnostic and care services.

Question. In what ways have resources available to families and caretakers improved?

Answer. The first studies of family caregiving began in the 1980s. They described the challenges of care for a person with dementia. Soon thereafter, studies developed and tested interventions to address those challenges and, in doing so, improve caregiver and patient well-being and quality of life. For a summary of this research and its results, I commend the National Academy of Medicine report “Families Caring for an Aging America.”[9]

Question. How can Congress best support advancements in Alzheimer’s research and care?

Answer. Support research that will discover better ways to diagnose and treat the disease (the biomarker based work), identify cognitive impairment (the detection of cognitive impairment work) and deliver care to caregivers and patients (the translation of these discoveries into clinical practice).

QUESTIONS SUBMITTED BY HON. CATHERINE CORTEZ MASTO

Question. In 2018, Senator Susan Collins and I introduced the BOLD Infrastructure for Alzheimer’s Act, which Congress passed. The bill treats Alzheimer’s as the public health crisis that it is, taking advantage of the role that local public health departments can play in implementing disease interventions like early detection and diagnosis. How is the disease progression different in a patient who has had the benefit of an early diagnosis?

Answer. An early diagnosis, meaning at the stages of MCI or mild stage dementia, allow the person with the disease and their family to identify functional inefficiencies and problems, address them, and plan for how to identify and manage future inefficiencies and problems. This in turn reduces the harms from the failure to address these matters, such as errors in the management of medications, problems caring for a chronic disease like diabetes, financial errors or fraud and abuse, depression and anxiety. Of particular value are interventions that focus on a caregiver’s skills and training. Studies show that these interventions can delay the time before a person is admitted to a long term care facility, which is a marker of disease progression.

The National Academy of Medicine report, “Families Caring for An Aging America,” provides a well-organized and thorough summary of the studies testing caregiver interventions.[10] The report also makes recommendations that Congress can enact. Many of these recommendations are ensconced within the BOLD Act.

Question. BOLD will support the development of care planning services for people living with Alzheimer’s; Medicare covers those services, and we have to ensure people can take advantage of them. Can you speak to the difference in health outcomes between those who have a clear care plan, versus families who do not have access to that type of assistance?

Answer. See above.

Question. BOLD requires CDC to increase the analysis and timely public reporting of data on Alzheimer’s, cognitive decline, caregiving, and health disparities. What kind of difference will additional surveillance information have on your research? What are the areas of greatest need when it comes to population health data that would help in Alzheimer’s research?

Answer. America needs data that describe and track America’s patients and caregivers. These data will greatly inform the impact of dementia on our Nation’s economy and families. It will also aid in documenting the effectiveness of interventions. Public health data are especially valuable to show how all Americans are experiencing dementia.

These data will allow America to identify and so address disparities in detection and outcomes. This is especially important in settings such as rural and suburban regions (cognitive impairment hinders a person’s ability to travel about to get help), poverty (much of long-term care services and supports are paid “out of pocket”), and ethnic and racial diversity (the experience of cognitive impairment is often influences by how people understand cognition and aging).

Someday America will have an effective treatment for Alzheimer’s disease (a drug that slows the disease). Someday America will effectively deliver health care to patients and their caregivers.

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[9] *See* “Families Caring for an Aging America” at *https://nam.edu/families-caring-for-an-aging-america/*.

[10] The report, a report in brief, and recommendations are all available at *https://nam.edu/families-caring-for-an-aging-america/*.

Surveillance data will be *tremendously important* to inform how well these treatments are being prescribed throughout America (*i.e.,* access) and their outcomes on the persons with dementia and their family members.

Question. One of the recommendations in the National Plan to address Alzheimer's is to explore the effectiveness of new models of care for people with Alzheimer's disease. Have you seen models that are promising in addressing the needs of Alzheimer's patients? Does Congress need to push CMMI to develop Alzheimer's specific models? Caregivers are critical to a patient's outcomes—do you have thoughts on how we account for that in payment models?

Answer. CMMI efforts such as comprehensive primary care (CPC) and Medicare's CPT code 99483 are impressive steps in the right direction so that Medicare supports the care of older adults with chronic diseases, especially older adults with dementia (caused by Alzheimer's disease, and other diseases as well). Congress ought to continue this move in the right direction.

Caregivers are critical to a patient's outcomes. Payment models should account for the time that a clinician needs in order to talk to the patient and the caregiver. These models should account for the fact that these conversations may occur face-to-face in the office or via e-communication in the electronic medical record, or the telephone.

Americans need a health-care system that can do the following:

- Diagnose a person with dementia or MCI: this means provide adequate compensation to the provider to take the time to interview and examine the patient and to identify and interview the caregiver.
- Identify the caregiver and document them in the patient's medical record.
- Provide caregivers access to the patient's medical record.
- Expect that at the time of discharge from hospital the patient is asked to identify a caregiver (and, if the patient is unable to do to so, the clinicians seek one out). This caregiver should then receive education about the patient's diagnoses and post hospital plan of care.
- Provide the person with dementia and MCI, and their caregiver education and training.
- Provide access to care and support for care services and supports, especially transportation, adult day activity programs, and respite care.

PREPARED STATEMENT OF LAUREN KOVACH, ALZHEIMER'S ADVOCATE

Good afternoon, Chairman Toomey, Ranking Member Stabenow, and distinguished members of the committee. Thank you very much for the opportunity to share my personal story on the impact Alzheimer's has had on my family. My name is Lauren Kovach, and I'm here today to share my story as a caregiver and an advocate with the Alzheimer's Association and Alzheimer's Impact Movement. Twenty years ago, my life took an unexpected turn when my grandmother, Helen Tannas, was diagnosed with Alzheimer's at the age of 82.

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.

My grandmother lived to take care of her family—we're Macedonian, that's what we do. Growing up, my mom, brother, and I lived four houses down the street from my grandmother and since my mom was a single, working mom, we were always over at grandma's. My grandmother helped my brother and me with our homework, she cooked dinner for us, and was the center of countless family celebrations. As a child, my grandmother was a daily part of my life. I never imagined life without her down the street.

I was 21 years old and in my third year at college when my grandmother was admitted to the hospital. I was terrified at the thought of losing her. My grandmother spent 10 days in intensive care undergoing a battery of tests, which resulted in several diagnoses. All of the conditions were treatable except one—early-stage Alzheimer's disease.

When I was growing up, my grandmother had a pet name for me. She called me "moe chupe, moe chupe," Macedonian for "my girl, my girl." One day after the diagnosis, I turned to my grandmother and said, "You're my chupe; you're my girl." The nickname she had given me so many years ago had come full circle. It was now our turn to give back the love and sacrifice my grandmother had always given us. And so my mom, my brother, and I made a pact that we would do whatever it took to keep my grandmother at home. We prepared for the longest good-bye of our lives.

After her diagnosis, we adjusted our lives to become full-time caregivers. I withdrew from school and eventually my mom had to retire early from her teaching career. We knew we needed to take steps to care for the woman who spent most of her life caring for us, but we didn't know what those steps were or how to make a plan. We didn't even really know what deciding to be a full-time caregiver meant—there was a long and bumpy road ahead for all of us.

When we were discharged from the hospital, that was it. They gave us our discharge papers and wished us the best of luck. No pamphlets, no explanations, no support. We were fortunate to be near the University of Michigan, which has an Alzheimer's Disease Center, and a neurologist who confirmed the Alzheimer's diagnosis. That neurologist was great, but again, she didn't provide us with any resources or information on what to expect from this diagnosis or what we were supposed to do next.

There we were facing this life-changing news and having to immediately make one major decision after the other, with no time or guidance to make a long-term plan. We weren't aware of resources that could have helped my mom and me manage the stress of caregiving, like adult day services and respite care. Unfortunately we learned about those too late—after she had passed away.

Fortunately, families now facing an Alzheimer's diagnosis have new options that were not available to my family back then. In 2017, Medicare began reimbursing physicians and other health-care professionals for providing comprehensive care planning services to individuals with cognitive impairment—a critical step in improving the quality of care and quality of life for those with Alzheimer's and their caregivers.

Comprehensive care planning is crucial to helping those living with Alzheimer's and their families answer those important first questions after a diagnosis of "how do I take care of my loved one?" and "what do I do now?" A care planning visit includes an evaluation of cognition and function, measuring neuropsychiatric symptoms, a safety evaluation, identifying and assessing a primary caregiver, development of advance care directives, and referrals to community services. 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. Everyone should have access to this lifeline.

However, analysis has shown that fewer than one percent of those living with Alzheimer's and other dementias eligible to receive these services, actually received care planning in 2017. In order for more Americans affected by Alzheimer's to receive these critical care planning services, more clinicians must use the care planning benefit.

That is why I am so thankful to Ranking Member Stabenow for introducing the bipartisan Improving HOPE for Alzheimer's Act (S. 880), which is already cosponsored by 46 Senators—including many of you on this subcommittee. This important bill 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's care planning benefit, and second, report to Congress on the barriers to individuals receiving care planning services and how to increase their use.

If this care planning code had existed 15 years ago, it would have significantly improved the quality of life for my grandma, my mom, and me. Full-time caregiving while navigating the health-care system is both physically and emotionally draining. I can't describe the level of exhaustion and desperation we felt.

It wasn't always easy, but my mom and I were able to keep my grandmother at home for her entire journey—from the time she was diagnosed, my grandmother never spent a single night by herself. If my mom wanted the night off, I would stay home with her. If we went to visit family in Chicago, grandma would come with us.

During the day, when we left for work, we'd leave post-its around the house. Simple things like "remember to brush your teeth," "coffee is made," and "lunch is in the fridge." And that worked for a while. But as the disease progressed, we had to move past the "post-it phase." My mom would call her during the day to ask how lunch was and my grandma would say it was great—but we would get home and her sandwich would still be in the fridge.

I learned to live in the moment, figuring out what to do as I went along, because I didn't know how much time I had left with her. We kept on fighting. We held on tightly as the disease stole her from us. I felt like I was living the same day over again for years, struggling to keep her alive and healthy. But even as she forgot who we were, there was no question that my grandmother loved us. We loved each other until the very end.

It wasn't until 7 years after her diagnosis that I found my purpose in life, thanks to the Alzheimer's Association. As my grandmother's cognition and memory declined, I wanted to learn more about the disease. I set out looking for information. Somehow I knew that purple was the color of Alzheimer's awareness. I Googled "purple Alzheimer's shirts" and the Alzheimer's Association was the top hit.

Poring over the Association's website, I learned about the Association's Walk to End Alzheimer's and reached out to my local chapter. I educated myself, spoke with families going through the same hardships, and fully committed myself to spreading awareness of the disease. I've been a volunteer, fundraiser, and advocate ever since. I'm proud to have led the planning committee for the annual Walk to End Alzheimer's in my hometown of Brighton, MI, which raises awareness and funds for Alzheimer's care, support, and research. I eventually became involved with the Alzheimer's Association Advocacy Forum, where I've made huge strides in advocacy.

Even as I watched the person who meant the most to me slip away for 15 long and brutal years, I knew that I had found my niche, my purple tribe, to help me through the hardest years of my life. Though there is no cure, treatment, or prevention for Alzheimer's, that didn't mean I would go down without a fight.

In 2017, my grandmother declined into the late stage of the disease. My mom and I had handled the day-to-day care of my grandmother together for 15 years, but we had reached the point where we decided we needed the help of hospice care. By definition, hospice provides comfort to both the person dying and to the family, but our family had a terrible experience with it.

I had a bad feeling right off the bat. The social worker talked to us for about an hour but not once sat with or visited my chupe.

The next day there was another knock at the door. This time it was Adult Protective Services, responding to an abuse and neglect complaint filed against my mom and me by the hospice care company. We were stunned. We spoke with the agent at length before he turned his attention to my grandmother. The pair was soon singing and clapping.

We knew we needed Medicaid coverage to help cover the cost of her care, but there was a 6- to 12-month wait. The agent told me to keep this horrible, false abuse and neglect complaint on file, because as embarrassing as it was for us, it meant she would get bumped to the top of the list.

The agent offered reassurance on his way out. "If only everyone could be as loved as her," he said. "Keep doing what you're doing."

We also applied for help through our local Area Agency on Aging. A caregiver who was contracted through one of the authorized companies called my mom to set up a time for our first home consult. But, she never showed up for the visit and when my mom called to check on where she was, she told us she had taken another job. That meant we went back on the wait list and my grandmother died before we got any help. I wish we had had the lifeline that Senator Stabenow's Improving HOPE for Alzheimer's Act would provide for families. Having a caregiving plan rather than muddling through day by day would have been such a relief.

My chupe started dying on a Saturday. She had lived with Alzheimer's for 15 years and passed away on June 3, 2017 at age 97. I crawled in bed and laid my head on her chest as she was taking her final breaths. I told her through tears that it was okay to go. And I promised her that I would never stop fighting for her, for the three of us, and the immeasurable bond we shared.

I am determined to fulfill that promise. It is why I continue to volunteer hundreds of hours each year as an advocate.

Today, more than 5 million Americans are living with Alzheimer's. The number of Americans living with Alzheimer's is growing—and growing fast. With the aging of the baby boom generation, the number of Americans aged 65 and older with Alzheimer's is expected to dramatically escalate. By 2050, nearly 14 million Americans may be living with Alzheimer's.

That is why it is so critically important to prepare now. To increase awareness of and access to important services like the Medicare care planning code. Robust care planning is the first step to learning about and selecting appropriate, patient-centered supports and services for persons with dementia, families, and caregivers. It was overwhelming when my grandmother was diagnosed. It can be difficult for families to juggle the stress of a diagnosis with the immediate care needs of their loved one living with Alzheimer's while also trying to research services such as adult day, home health, respite, skilled therapy, residential facilities, and nursing home care.

Thank you for holding this hearing today and I respectfully request that you continue to make Alzheimer's research a priority and work together to pass critical legislation like the Improving HOPE for Alzheimer's Act. We must do all we can to ensure the best quality of care and quality of life for those living with Alzheimer's and the people who care for them. Again, thank you for the opportunity to share my story. I look forward to answering any questions you may have.

QUESTIONS SUBMITTED FOR THE RECORD TO LAUREN KOVACH

QUESTIONS SUBMITTED BY HON. SHERROD BROWN

THE ECONOMIC STRAIN OF CAREGIVING

Question. When an individual is diagnosed with a disease like Alzheimer's, generally speaking, unpaid caregivers provide the majority of daily care. These caregivers can be family members, friends, or other community members, but regardless of who they are, the vast majority of unpaid caregivers shoulder a significant economic burden as a result of taking on these duties.

Experts have estimated that unpaid caregivers contribute as much as 18.5 billion hours of care, which is valued at approximately $234 billion. A recent study showed that 18 percent of unpaid caregivers went from working full time to only part-time, and 9 percent left the work force completely, with 6 percent retiring early. With reduced work, loss of work, or retirement comes increased financial burden, decreased income, and possibly loss of retirement benefits.

As you and I discussed during the hearing, current Federal law does not allow for unpaid caregivers to take paid or unpaid leave from their jobs if the person they are caring for is not a spouse or a child. These factors leave unpaid caregivers with a mountain of life altering decisions and too few tools to handle them. Recent efforts by the Trump administration could entirely eliminate the small set of tools that remain at the disposal of caregivers, things like SNAP and the ACA.

Ms. Kovach, you were an unpaid caregiver for many years, and now you are an advocate within that community. In your experience, are the financial challenges that you experienced while caring for your grandmother the norm for other unpaid caregivers?

Answer. The financial challenges my family faced are absolutely the norm for other unpaid caregivers, not just throughout Michigan but across the entire country. The number one thing I hear from other unpaid caregivers, especially those taking care of an elder parent or their spouse, is that they have no choice but to unexpectedly spend down their retirement savings. These hard working people responsibly save money in their 401(k)s for their entire careers and it seems that in this current caregiving era, their retirement accounts will instead be used to pay for loved ones' long-term care.

Question. Do you believe that reduced access to benefits such as SNAP and health-care subsidies would hurt not only unpaid caregivers, but also the vulnerable people that they care for?

Answer. Access to resources and financial assistance is so important to people living with Alzheimer's and also to their caregivers. Our country needs to expand the amount of available resources in order to help the millions of families struggling to provide unpaid care to their loved ones.

Question. Would expanded access to paid and unpaid leave have helped you and/or your family while you were caring for your grandmother? Do you believe they it would help other families who are currently serving as unpaid caregivers for a family member?

Answer. I did not qualify for FMLA, because my loved one was not a spouse, child, or parent. That was incredibly frustrating to me because I shared the same legal address as my grandmother and I was one of her two primary, and only, caregivers. I was caregiving throughout my entire twenties, when I should have been working full time, contributing to my 401(k) and investing money for my future. Instead, I had to figure out a way to be in two places at one time. Paid, or even unpaid, family leave would have helped me manage work and my job as a caregiver.

Paid family leave would have certainly helped my mom, who was forced into early retirement way before she was ready for it. If she had paid family leave, she could have continued working and caring for her Mom, not forced to make the agonizing decision between the two. It's all or nothing the way the current system is set up, there is no room for a healthy balance between work and home life when someone needs 24/7 care. You will hear that caregivers often pass away before the person living with the disease and I truly believe this is due to stress, exhaustion and caregiver burnout. My perfectly healthy Mom who had never been on a single medication her entire life, was almost a prime example of that. She had four stents put in after Chupe died, and the cardiologist said she was close to having a widowmaker heart attack. In all those years, she never once noticed the symptoms because she was too busy taking care of Chupe.

PREPARED STATEMENT OF HON. DEBBIE STABENOW, A U.S. SENATOR FROM MICHIGAN

Thank you, Mr. Chairman, for holding this important hearing today. Welcome to our witnesses, and thank you for being here.

Everyone in this room knows the numbers: 5.8 million Americans are living with Alzheimer's today, including one in 10 people over age 65 and 190,000 people in my home State of Michigan. By 2050, it's estimated that as many as 14 million people nationwide will have the disease. And Alzheimer's cost the United States $290 billion this year, and at the current rate, costs will rise to $1.1 trillion by 2050.

But we're not here to talk about numbers. We're here to talk about people's lives. And we're here to talk about the families who watch this horrific disease steal their loved ones away, one memory at a time. We need better treatments. Families need more support. Most of all, we need a cure.

The good news is that we have made some progress on both fronts. For decades, research on the brain, which is the most complex organ in the body, was funded as if it was one of the least important. That has changed.

Since 2011, Federal funding for Alzheimer's has more than quadrupled. New researchers are entering the field and moving the science of Alzheimer's forward. We need to keep up that momentum—because telling a smart scientist with a great idea today that there simply isn't the money to fund her research could mean a cure passes us by.

I've also led the effort to provide more supports to patients and their families. After a successful bipartisan push, the Centers for Medicare and Medicaid Services implemented my HOPE for Alzheimer's Act. This means that Medicare is now providing a doctor's visit to create an individual care plan for newly diagnosed Alzheimer's patients. The benefit ensures doctors give a clear diagnosis to patients, including information about what treatment options and what medical and community services are available. This is good for patients, families, and the Medicare program.

Unfortunately, the Centers for Medicare and Medicaid Services did not conduct an outreach and education campaign to health-care providers and patients, as called for in my original legislation, so uptake of the code has been too slow. That's why I have introduced the Improving HOPE for Alzheimer's Act, cosponsored by 46 bipartisan Senators including Senators Menendez, Scott, Carper, Cassidy, Cardin, Daines, Brown, Lankford, Whitehouse, and Cortez Masto on this subcommittee.

Our bill requires HHS to conduct a nationwide campaign to increase awareness and usage of the care planning visit. HHS could do this right now, even before we pass the legislation, and we've asked them to do so.

Building on the care planning benefit, I've also introduced legislation with Senators Capito, Menendez, and 15 others called the CHANGE Act, which will encourage timely and accurate detection and diagnosis using evidence-based tools. Only 16 percent of seniors receive regular cognitive assessments during health-care check-ups. Our bill will fix this.

We've made a lot of progress, but we all know there's a lot more to do. I look forward to our discussion today about how we can work together to combat Alzheimer's disease.

PREPARED STATEMENT OF JANET TOMCAVAGE, R.N., MSN, CHIEF NURSING EXECUTIVE, GEISINGER

Good afternoon, Mr. Chairman and members of the Senate Committee on Finance Subcommittee on Health Care. My name is Janet Tomcavage, and I am Geisinger's chief nursing executive. I want to thank the subcommittee for holding this hearing on an important health-care issue facing our country—one that Geisinger is invested in: providing the best possible care for our patients and health plan members while testing new innovative care models for the future.

Today, I speak to you as a nurse and health-care executive who has worked at Geisinger in a variety of roles for more than 30 years. I began my current position as chief nursing executive in August of this year. Before assuming this role, I was chief population health officer and have had the honor and privilege to work with seniors for much of my career. Consequently, this has afforded me the ability to look critically at how we deliver health care to our most vulnerable individuals and work together with health care teams to redesign care for those populations who have multimorbid and debilitating chronic health conditions.

Geisinger is one of the Nation's largest integrated health services organizations serving a population of more than 3 million residents throughout central, south-central, and northeast Pennsylvania, and in southern New Jersey at AtlantiCare, a member of Geisinger. Our physician-led system includes approximately 32,000 employees, nearly 1,800 employed physicians, 13 hospital campuses, two research centers, a school of medicine, and a 580,000-member health plan. The integration of hospitals, clinics, providers, and a health plan has allowed Geisinger to test innovative care delivery models, integration, quality, and service while driving our mission to make health easier for the patients and communities we serve.

CURRENT STATE

Alzheimer's disease is increasing in incidence, and recent estimates now indicate that it may be as high as the third leading cause of death behind only heart disease and cancer. One in 10 Americans over the age of 65 has Alzheimer's. In 2016, over 40 percent of residential care community residents had Alzheimer's and almost 48 percent of nursing home residents have the diagnosis.

Alzheimer's is the most common form of dementia and identifies the loss of cognitive functioning as well as behavioral abilities which leads to challenges with thinking and remembering, agitation, wandering, and aggression as well as difficulties with simple activities of daily living including meal preparation, grocery shopping, driving, or personal hygiene. While medical treatment is an important component, managing the behavioral symptoms is often a more complex scope and one of the biggest barriers to care for individuals with dementia.

I'd like to outline the challenges and opportunities we see that are needed to improve care of the aging brain including Alzheimer's, describe some of the innovative programs we've launched at Geisinger and identify how CMS can remove the barriers to caring for patients and families dealing with dementia.

First, we know there are several modifiable risk factors for developing Alzheimer's. If given appropriate time and support, primary care providers and their teams could more aggressively address those risks with their older patients and, we believe, reduce the rate of future memory loss and dementia.

One of the biggest barriers to reduce the risk of developing dementia is a lack of understanding and education on how to take action—by the individuals affected and their families as well as physicians caring for the elderly. Often people will say, "Oh well, I'm just getting older," thereby minimizing the subtle signs of memory loss or confusion and not drawing it to a physician's attention. There is also a fair amount of complacency in the medical community around treating common conditions such as hypertension, which we know contributes to physiologic changes that occur in the aging brain.

"Brain-impairing" medications are another critical area to address. Older individuals are often more susceptible to the side effects of medications that are used to treat medical conditions such as overactive bladder, sleep issues, allergies, mood disorders, COPD, and Parkinson's disease. And those side effects can often cause dementia-like symptoms.

Medicines such as anticholinergics actually increase the risk of developing dementia because of the action of the drug. We need better education for families and physicians around those risks, and stronger warning labels. We need better, safer options and drug formulary management.

In most cases, "memory and thinking" challenges are identified too late. Better education, more time with seniors and reliable assessment tools are needed in the primary care setting. We need to include memory and cognition as part of an annual wellness examination and complete formal memory assessments on our seniors. A focused assessment that leads to a high-quality diagnosis of memory issues in the older population needs to become the standard of care.

We need to develop a new series of health-care services that can "push out" care to patients and their families where they need it—in their home. For instance, resources for telehealth services would allow us to leverage clinical experts, particularly in rural areas, to appropriately assess, treat and monitor patients who we know are starting to demonstrate mental decline. In addition, home services can evaluate the safety and social supports in the home which are critical components of a comprehensive treatment plan for individuals with Alzheimer's.

A separate issue from the above clinical improvements, is the support and reimbursement for caregiving. The health-care system has a very weak infrastructure to support patients with Alzheimer's and their caregivers. Services such as transportation, adult daycare, respite care, in-home assistance, and better advanced care planning lack funding. These services can keep people safe and in their own homes and are also needed for respite for the families but are not adequately reimbursed by Medicare or Medicaid. Payment for unlicensed caregiver support will be critical to the long-term success of keeping individuals with dementia in their homes and communities. And in cases where funding from Medicare does support home aide services, if families were to choose hospice, the support for caregiver assistance is no longer available and often the reason that families do not enroll their loved ones in hospice in the last months of their lives.

Finally, we need funding for research on how to stop these diseases. Alzheimer's, Parkinson's, and dementia have not had the investment needed to find treatment options, although they are prevalent and drive the utilization of costly health resources. The focus and funding level should be similar to cancer and other conditions. We need clinical trials that test novel preventative, symptomatic and curative treatments for memory disorders.

NEW CLINICAL MODELS AT GEISINGER

I'd like to turn now to what we are doing at Geisinger to address these risk factors and gaps in caring for patients with the aging brain. At Geisinger, we are developing a more comprehensive and integrated approach to senior care. We're testing new delivery models, including several that were recently implemented over the last year.

Geisinger opened its first Memory and Cognition center led by a behavioral neurologist surrounded by a team of individuals with a mixed skill set that complements the needs of the patients served. Pennsylvania has the second oldest population in the United States—Florida is number one. In addition, 80 percent of Geisinger's inpatient hospital volumes are over age 65 and the senior segment of our population is the only segment growing in our clinical footprint. The business case is relevant—but not yet self-sustaining. The team is a multidisciplinary alliance with primary care leveraging neurologists, pharmacists, case management, nutrition, speech therapy, occupational therapy and physical therapy. Consultation outreach clinics are also available in two other locations across our network one day per month. However, the wait times to get into the center are significant. Expansion is limited due to inadequate funding for the non-reimbursed but important services such as care management, exercise therapy, etc. Anecdotal outcomes are very evident and clinical trials are underway to test the Center's impact, but no current impact outcomes are yet available.

Another newly implemented care model is Geisinger at Home. For our highest-risk patients, those with multiple and complex conditions often including dementia, we send a team of health-care clinicians into targeted patients' homes. Physicians, advanced practitioners, nurses, pharmacists, nutritionists and mobile health paramedics provide a full complement of care and service right in their home as needed. These services provide thorough clinical and social assessments, optimized treatment plans, and acute care services directly in the home in an effort to avoid unnecessary emergency department and hospital utilization. In addition, the team works closely with the patient and family to understand the patient's goals of care specifically around advanced illness and end of life care.

We have seen almost 5,400 patients in Geisinger at Home, and the results have been incredible. Families who have been overwhelmed by managing their loved one's complex care are extremely thankful for the program. We've seen a decrease in hospital admissions for patients in this program by 35 percent. And emergency department utilization is also down about 20 percent. The longer patients are in the program, the more significant impact we're seeing. For our Medicare Advantage members, we have realized about a $500 PMPM improvement in the first year of the program.

And finally, our most recent implementation is a new approach to primary care called 65Forward—a new primary care model implemented in August of this year. 65Forward is primary care practice that is dedicated only to the care of seniors—individuals over the age of 65. This program was developed in conjunction with our health plan for Medicare Advantage members.

In addition to regular primary care visits, these locations will focus on coordinated annual wellness visits, comprehensive memory and cognition testing, functional status and mental health assessments and other services to meet the individual needs and maintain their health and wellness. The practices include nursing support, nutrition resources, and an on-site pharmacist and wellness coach. They also support activities that are proven to contribute to health and wellness, including exercise classes and equipment, cooking classes and social activities such as knitting, crafts and book clubs.

Since the physicians in Geisinger 65Forward see only Medicare patients, we have decreased the number of patients that a primary care provider would normally see in his/her panel to 450 (as opposed to 2,000) to ensure they have the time needed for these seniors. Because the practices just opened in late summer, we don't yet have outcomes to share from this delivery model. We will be evaluating these services by looking at total cost of care, and quality outcomes including both preventative and chronic care measures.

Caring for those with these progressive neurological conditions and finding better answers is a burden and responsibility shared by our healthcare system, government and private funders, and American families. I believe the most urgent need and the biggest opportunity is funding to ease the burden of families caring for their loved one with declining health and Alzheimer's. New payment models are needed to support caregiving services to help keep people safe and in their homes for as long as possible.

Second, we need funding to support more comprehensive education and tools for primary care providers as well as for the support of in-home therapies. Early detection, screening, and intervention can make a difference. We must address the lack of research into the causes and treatment of dementia with the goal to avoid and delay the effects of the aging brain.

With the right focus and attention we can make a difference in the trajectory of these devastating neurologic conditions and the toll they are taking on our loved ones and communities across the country.

I will leave you with a simple example that is reflective of what can be easily done. Patricia is an older woman who came to the Memory and Cognition center for the first time with a diagnosis from her primary care provider of Alzheimer's disease. On her screening with the commonly used Mini Mental State Examination (MMSE) she was 23 out of 30, consistent with a mild dementia level of impairment. On the initial review, there was one medication she was taking that caused concern—a low-dose benzodiazepine that she took at bedtime every night for sleep. The family indicated that she had been on that medication for years and it couldn't possibly be the cause of her problems. Her neurologist shared that he couldn't cure Alzheimer's disease, but likely could get her a good night's sleep without the use of this medication. Though skeptical, they took the Memory and Cognition program's advice on establishing good sleep habits and use of melatonin. When the patient came back for follow-up, she reported that she was sleeping better than she had in years, and that she felt more like her normal self. When rescreened with the MMSE she now scored a 29 out of 30, consistent with a more normal level of performance. Our lead neurologist has shared that Geisinger's Memory and Cognition unit, simply by transitioning people from high risk medications to better targeted therapies, has "cured" more people's memory and thinking problems than anything else he has seen in his career.

Geisinger is committed to being a resource and an engaged partner in the work supporting physical and mental wellness in seniors. Thank you again for the opportunity to provide you with our thoughts on this critical health issue. I am happy to answer any questions you may have.

QUESTIONS SUBMITTED FOR THE RECORD TO JANET TOMCAVAGE, R.N., MSN

QUESTIONS SUBMITTED BY HON. JOHN THUNE

Question. Thanks for your testimony about how we need to get care out to patients where they need it. South Dakota has led the way in advancing telehealth and remote monitoring to help seniors stay in their homes and out of more costly settings of care. We're also using it to connect rural providers with support in providing specialty care.

The inclusion of telehealth as a supplemental benefit in the CHRONIC Care Act was an important step in promoting access to care through telehealth. How are health plans and health systems taking advantage of telehealth as a new benefit for MA patients with Alzheimer's? Are there still any barriers to uptake policymakers should be aware of?

Answer. I think that many MA plans are ready to reimburse but health-care systems are still working to leverage this technology in a reliable way. Many health-care systems are implementing telehealth services from hospital to hospital or from a primary care provider office to a specialist office but what remains needed is to leverage technology directly from patient homes into specialty providers offices. Health-care systems are still "figuring out" how to most effectively deliver those services as the availability on in-home technology is often too complicated for patients to do on their own. At Geisinger we are using community health workers to facilitate the use of in-home telehealth services.

Question. Along the same lines, I have long supported the principles of value-based insurance design to help plans meet the needs of chronically ill patients, like those with Alzheimer's.

I recognize the CHRONIC Care Act's provisions on supplemental benefits for items that are not primarily health related (transportation, home care, home modifications) have only been in effect for a short time, but is there anything policymakers should consider to further promote plan uptake of this flexibility that could help Alzheimer's patients?

Answer. The challenge that many families face is the need for ongoing services such as in-home aide services. Unlike home modifications or even transportation, in home care services are generally needed daily and often for a long period of time. This service can be costly and often not affordable for most families. MA plans are beginning to provide services, but the amount of support needed is still not affordable for families and we have a long way to go to improve this level of support that is clearly the biggest need.

QUESTIONS SUBMITTED BY HON. BENJAMIN L. CARDIN

USING PRIMARY CARE TO REDUCE THE RISK OF DEMENTIA

Question. According to the Alzheimer's Association, Americans living with Alzheimer's disease is projected to more than double by 2050—from 5.8 million Americans living with Alzheimer's to nearly 14 million Americans. Furthermore, by 2050 the number of baby boomers is projected to rise to 88 million Americans.

Since those affected by Alzheimer's disease is expected to grow, we must expand and prepare our health-care workforce to take care of these patients as well as support families and caregivers.

I am very interested in your comments about how to engage primary care physicians with their patients to reduce the risk of developing dementia. You mentioned in your testimony that if given appropriate time and support, primary care providers and their teams could more aggressively address risk factors for developing Alzheimer's.

What are your recommendations for improving how providers reduce risk of dementia in primary care settings?

Answer. Adding an assessment process to the annual wellness visit is one way to help prioritize this assessment for PCPs. I also think a patient awareness campaign—where we educate the public much like we have done with heart disease or stroke or drug abuse. Put knowledge in the hands of the consumer and they will "force" providers to address management of things like hypertension or assessing early in our seniors.

Question. What are the current barriers you face in implementing these changes? How can Congress be helpful?

Answer. I would suggest again adding in a short assessment requirement as part of the annual wellness visit.

QUESTIONS SUBMITTED BY HON. SHELDON WHITEHOUSE

Question. In 2020, the Center for Medicare and Medicaid Innovation (CMMI) will implement a care model for beneficiaries with significant chronic illness(es), who have high utilization rates and fragmented care. Through the Seriously Ill Population (SIP) model, CMS will temporarily raise provider payment rates for beneficiaries in the program while providers coordinate care and stabilize patients.

What is your assessment of the SIP model?

Answer. I think the potential for the model is exciting. The key will be where the care coordination investment is made. Naturally, dollars typically go to primary care but for some subsets of the population with extremely advanced illness—the PCP is not always the lead. For example, for patients with advanced heart failure, connecting services to the cardiologist might make sense or in patients with chronic lung disease the role of pulmonary specialists is critical. Same would go for end stage renal disease. So, allowing a model that encompasses home based services that connect to primary and specialty care might be a better solution for these very complex patients who in many cases are declining, increasing in frailty and the need for home-based services.

Question. In what ways could SIP improve care delivery for beneficiaries with chronic illnesses?

Answer. If the services truly allow for care management/care coordination services that support patients across both primary and specialty care in different delivery models, then this will be helpful. The other remaining gap that poses significant gaps in the ability to help individuals stay in their home is the lack of support for in-home, but non-medical services. Aide services for bathing, food preparation, lifting, mobility, night time oversight etc. are very much needed to help keep individuals in their homes and out of hospitals and skilled nursing facilities. Much of the acute utilization is not driven by medical exacerbations but rather by caregiver exhaustion or poor support to manage their condition in the home. This is very evident in the hospice benefit. Many individuals turn down the hospice benefit because it does not help with daily support that many patients and families need as the patient declines.

Question. Do you see any areas for improvement to the CMMI proposal?

Answer. As above.

QUESTIONS SUBMITTED BY HON. MAGGIE HASSAN

Question. The Office of Disease Prevention and Health Promotion at HHS has stated that Alzheimer's disease and other forms of dementia are more frequently undiagnosed among patients living in rural communities.

As we already know, even those who receive a diagnosis face significant hurdles when it comes to accessing care.

How can Congress work to ensure that those living with dementia in rural communities are able to receive a more timely diagnoses?

Answer. I believe adding the assessment for dementia in the annual wellness visit is one way to support earlier diagnosis. I also believe that we need to develop a community awareness campaign much like has been done around heart disease, breast cancer and other common conditions. Using public service avenues to educate families about the symptoms to bring to their loved one's primary care providers.

Question. How can we then ensure that these patients have adequate access to follow-up care and support services?

Answer. Many of the new care models that CMS is supporting, and testing should help improve this work. Telehealth is another avenue that needs to be expanded as it is a cost-effective way to monitor directly in patient's homes to provide ongoing assessment of the individual's progress.

QUESTIONS SUBMITTED BY HON. CATHERINE CORTEZ MASTO

Question. BOLD will support the development of care planning services for people living with Alzheimer's; Medicare covers those services, and we have to ensure people can take advantage of them. Now that Medicare reimburses providers for care planning, what are the barriers that families run into in accessing those services?

Answer. The biggest gap that I see is that CMS has brought forward so many new billable services and I believe that many providers are not aware of these opportunities. Secondly, access to Alzheimer's COEs is limited and wait times are extremely long.

Question. One of the recommendations in the National Plan to address Alzheimer's is to explore the effectiveness of new models of care for people with Alzheimer's disease. Have you seen models that are promising in addressing the needs of Alzheimer's patients? Does Congress need to push CMMI to develop Alzheimer's specific models? Caregivers are critical to a patient's outcomes; how can we account for that in payment models?

Answer. Geisinger has been testing new models of care that support more comprehensive care of individuals with serious chronic illnesses including Alzheimer's. Memory Centers are key services, but the number of such services are not enough. Developing models such as focused senior centers like Geisinger's 65Forward that will support a comprehensive primary care model only for seniors is one such model. We are early in the delivery of this model so outcomes are as of yet unknown. Geisinger at Home supports a comprehensive in-home care delivery model that has demonstrated an almost 38-percent reduction in admissions and 20-percent reduction in ED utilization. Both models need to continue to be studied and tested. And finally, caregivers are at the foundation of a successful model. None of our payment models really support this need. The recent changes that allows Medicare Advantage plans to offer non-medical services will only skim the service. Some families simply do not have the resources to provide in-home care and supervision for individuals with Alzheimer's. Home support services (non-licensed caregivers) are in my opinion the most important need in providing support to individuals with Alzheimer's. Most of these patients need supervision and help with activities of daily living—we need to assure their safety. They do not need nursing or licensed care. And for families who do provide the direct care—having respite care periodically or even on a regular basis to help them continue to manage their loved one's needs but also allow the family to "get away" is important. Recognizing the need for non-licensed "care" support is an vital component of what CMS and Congress needs to continue to address.

PREPARED STATEMENT OF HON. PATRICK J. TOOMEY, A U.S. SENATOR FROM PENNSYLVANIA

Welcome to the Senate Finance Subcommittee on Health Care hearing: "Alzheimer's Awareness: Barriers to Diagnosis, Treatment, and Care Coordination."

It is my pleasure to welcome four witnesses today for an important conversation on challenges with treating and caring for Alzheimer's patients and the emotional toll this disease takes on caregivers.

Alzheimer's disease is really in a category of its own:

- One in 10 senior citizens has Alzheimer's disease;
- According to the Alzheimer's Association, in 2019 alone this disease and other related memory disorders are estimated to cost $290 billion in health care, long-term care, and hospice services;
- The majority of these costs—about two thirds—are borne by the Medicare and Medicaid programs; and
- Worst of all by far, there is no cure.

With November being National Alzheimer's Disease Awareness Month, I want to briefly share a story about an individual with Alzheimer's who candidly shared his experience with thousands of Pennsylvanians. Bill Lyon, a beloved sports writer at *The Philadelphia Inquirer,* passed away on Sunday at the age of 81, after a hard-fought battle with Alzheimer's disease.

Bill wrote many columns detailing his 6-year battle with the disease. In one column, he described it as an insidious, relentless and, "a gutless coward who won't come out and fight. Instead, he lies in ambush in my brain, and the only way I can put a face on him is to look in the mirror." I'd like to ask unanimous consent to enter a couple of articles detailing his battle into the record without objection.

Like Bill and his family, there are millions of Alzheimer's patients and their loved ones who know this disease all too well. I know first-hand just how devastating it is to families. My own father and grandmother passed away after years of struggling with Alzheimer's.

Finding a cure for this disease must remain a top priority, and I am optimistic that a cure will be discovered in my lifetime. That said, progress has been very slow. Despite billions of dollars in public and private investment, Alzheimer's patients have very limited options. Just a handful of medicines are available, and they only slightly reduce the symptoms of the disease. For this reason alone, Congress must not undermine future investment by the private or public sector in their efforts to find cures by upending drug research and development.

While finding a cure is one challenge, access to necessary long-term care services is another. Medicare offers very limited coverage for long-term care needs. Now if you're very wealthy, these services are easily affordable, and for very low-income individuals, these services are available through Medicaid at little or no cost. But the average American approaching retirement is not at all likely to have nearly enough cash savings to cover the average cost of a typical long-term care event, such as the need for nursing home care or in-home care due to the onset of a chronic illness. A large number of middle-class families face financial ruin at the hands of Alzheimer's.

To guard against extraordinarily high costs, long-term care insurance can be a viable option. Yet only 17 percent of adults actually own such a policy. Many families without long-term care insurance find premiums to be unaffordable, but insurers have had to charge higher prices due in large part to the longer-than-expected life expectancy of beneficiaries with Alzheimer's disease.

One way to address high premiums is to expand the risk pool by attracting healthier or younger enrollees. Congress ought to consider legislation that makes it easier for families who are planning ahead to buy long-term care policies. Toward that end, today I released a discussion draft of legislation that would empower individuals to use their retirement plans to buy long-term care policies on a tax-free basis. Today, some individuals can use their 401(k)s to buy life insurance; similar treatment ought to be given to long-term care insurance. I hope to gather additional feedback on this idea and to introduce formal legislation soon.

I look forward to hearing from our witnesses and hope to work on a bipartisan basis to reduce the barriers that we discussed today.

From *The Philadelphia Inquirer,* November 17, 2019

BILL LYON'S FIGHT WITH ALZHEIMER'S: HE NEVER, EVER QUIT—PERSPECTIVE

Jessica Griffin/Staff

Legendary Inquirer sports writer Bill Lyon died at age 81 on Sunday.

In 2016, Lyon stunned readers by revealing his Alzheimer's diagnosis. Over the next two years, Bill wrote candidly about his illness, nicknaming it Al—or in feistier moments, That Rat Bastard. He chronicled what it was like to move out of his multistory home and into a place with no steps, a necessary adjustment as he got sicker. He shared anecdotes about using a cane and working with therapy dogs.

"My intent is to write columns about my dementia," Lyon wrote in 2016. "My hope is that the columns will be cathartic and perhaps be of some help to anyone else who's going down this same long and winding road. . . . My intent is to write until . . . well, until I can't."

Eventually that day came and Lyon shared his struggles with writing—both the mental challenges from increased writer's block, and the physical impediments like tremors that shook his hands so much he couldn't type. But even after that, Lyon continued to share stories, dictating columns to Inquirer editors who visited him.

What stuck with readers most about Lyon's story was his fighting spirit. In his inaugural Alzheimer's piece, he wrote, "You wake up one morning and something is missing and you're not sure how or what. So what do we do? Resist. And persist. And never, ever, ever give in." Lyon didn't give up, even after the tragic loss of his beloved wife and "best pal" Ethel in 2018.

In his last column for the Inquirer, Lyon wrote of his sincere hope that a cure for Alzheimer's would be found so that others who had been diagnosed with the disease could eventually say, "Up yours, Al!"

My Alzheimer's fight: Never, ever quit

Al is an insidious and relentless little bastard, a gutless coward who won't come out and fight. Instead, he lies in ambush in my brain, and the only way I can put a face on him is to look in the mirror.

"So what do you want to do?" the man in the white lab coat asked.

"I should very much like to kick Al's ass," I said.

My Alzheimer's fight: Adjust, adapt, push on

With your tremors tap-tap-tapping at warp speed, try to tie your shoelaces. Thank you, whoever invented Velcro.

Of course that still leaves the socks. And the assumption that you have the right foot where the right foot goes. And the left foot—look, I'm happy if I can average three for 10. That gets you in the Hall of Fame, right?

My battle with Alzheimer's: Mind, body, meds

I awaken each morning—thank you for that—and gingerly swing my legs over the side and down to the floor. It sounds like the Gunfight at the OK Corral. Slowly I stand upright, and this sound is like milk being poured on cereal . . . snap . . . crackle . . . pop. . . .

And so another day is launched and it sure does beat the alternative.

What, I inquire of my body, new surprises do you have in store for us today?

My Alzheimer's fight: Shaping other minds

How come I can remember the lyrics from a long-forgotten ballad, but I, for the life of me, can't remember what I had for lunch?

There's long-term memory and medium-term memory and the ultimate indignity, the dreaded short-term memory, which involves the marching from room to room, fuming and venting, and where-oh-where are my &*#@ glasses, and the answer, of course, is on top of your head, you poor pathetic wretch.

Thanks, and what's your name again?

My battle with Alzheimer's: Finding my way back

I walked on, panic-stricken, past banks and funeral parlors and schools, and looked up to find myself standing in the middle of a median strip on West Chester Pike with traffic roaring past on both sides. I had no idea how I got there. It was as though I had been sleepwalking.

Bill Lyon: In battle against Alzheimer's, giving ground only grudgingly

All in all, I have good days and some not-so-good days. Sometimes I can dress myself and sometimes I can't. Sometimes I can read one paragraph all the way through and sometimes I can't. Sometimes I get discouraged and sometimes I—no, I won't give in.

I do not delude myself. Al is a killer, but I try at every turn to cut him off and stomp on his mangy butt. I'll go kicking and screaming all the way, hoping this journal will be of some comfort and inspiration to those who have been diagnosed and to those who care for them.

Bill Lyon: Secret weapon against Alzheimer's

Of all the meds and all the walking and all the therapy, what keeps me going, always so hard and so fast, what makes me want to stick around for more, stands at the top of a hill and calls to me: "Come on, Pop-Pop . . . Come on. . . ."

Packing up a house full of memories while battling Alzheimer's

The place in which we have lived the last 42 years . . . the place in which we have raised three generations . . . the place into which we have stuffed a basement and a garage and an attic and a backyard storage shed with . . . with, well, good grief, and did we ever throw anything away?

But we will be now, because we're leaving it.

For ever.

Each day the pile of discards grows higher.

Coming home, to the land of no steps

One step . . . one lousy little step . . . one %&#%$!!!! step, and I ended up ingloriously sprawled on a surface of unforgiving linoleum that had been laid over concrete that you could build an interstate on.

I noticed I was leaking blood from my left knee, which was swelling into a rainbow of colors and was sending a rather urgent message to my brain, to wit: "Damn but this hurts."

I couldn't move.

I tried to yell, but all that I could coax out was a pathetic squeak. How humbling. How unmanly. I was living a TV commercial. I was also hearing that familiar mocking of the rat bastard Al, my Alzheimer's nemesis: "What's wrong, Candy Ass? Can't get up?"

Bill Lyon: Time to shine a light on Alzheimer's

What we don't know we fear and we lock up and throw away the keys. So for many of my generation there has been a stigma attached to whatever that is in the basement . . . and never dare speak.

It's time to shine a light on Al. So now we mobilize, starting with public awareness. There are more than five million of us out there, and the toll is rising, just as our population rate rises. Remember that Alzheimer's is called the Family Disease because in virtually any household there are apt to be patients and those who care for them.

Bill Lyon: Still lessons to learn while fighting Alzheimer's

A confession: The cane cast an ominous shadow of dread over me—I saw it as a symbol of impending doom, a fate hopelessly sealed.

There is, after all, a progression of descent, isn't there? Isn't this the cycle of decline?

First a cane.

Then a walker.

Then a wheelchair.

Then. . . .

But not me. No sir, no damn way. I had made a silent vow when the Alzheimer's first hit, a vow of defiance. You'll not be getting me off my legs. I'll stand 'til the very end.

Ghostly visits and the power of hugs

Can't say for sure when I softened. But I think it was around the arrival of Al. Alzheimer's brings with it sorrow and misery and before I knew it I was offering solace and comfort to those whose lives he touched.

We all, every one of us, has a load to carry, and while a hug may seem a trifle, it has remarkable recuperative powers.

And isn't it deliciously ironic how this show of affection just fries Al?

Bill Lyon: Alzheimer's chips away at your ability to communicate

I taught myself how to type as a sophomore in high school in 1955. You know, two fingers, hunt and peck. I got to be pretty good, and pretty fast, which pleased me greatly. I used to be able to make a typewriter sound like a machine gun.

But some months ago I found it was taking me longer to write. Then pretty soon I could barely put pen to paper. First, the paragraphs took a lot longer, and then the sentences. I couldn't get it back. It's writer's block, and we all know what that is. But this was different because it was not only mental but physical. Literally physical. I couldn't lift my hand up off the desk.

Life after Ethel, and why I'll never, ever give in to Alzheimer's

My wife is gone now, and I struggle with what I am supposed to do. Everyone grieves in their own way. There is no manual for grief. What you should do, I am told, is to go ahead and mourn. Then celebrate the good times, and we had a lot of those.

So I'm going to resume my crusade against Alzheimer's in her memory, and remember the mantra we shared: resist, persist and never, ever give in.

How two Bernese mountain dogs are helping me battle Alzheimer's

When Darla and Harvey make their rounds, Darla instinctively goes to the walkers and wheelchairs, while Harvey poses for pictures. Meanwhile, Al mutters and stews. For all the meds that are forced on us, for all the surgeries and rehab, none are quite as soothing as a dog's nuzzle.

We are tethered to each other, man and dog. They reach the deepest part of us.

Fighting to the finish for an Alzheimer's cure

Give us time, the researchers say. Funny thing is, that's all we've got.

You know the drill by now: Resist. Persist. Never, ever give up.

In my mind, I play games with the Cure. I envision a lab technician drops a beaker of some exotic drug, the glass shattering on the floor, splashing behind a desk, there to merge with another drug. Eureka!

If only it were so easy.

Additional articles by Bill Lyon on his fight with Alzheimer's disease can be found at the following link: *https://www.inquirer.com/news/bill-lyon-alzheimers-philadelphia-inquirer-sports-writer-20191117.html*.

COMMUNICATIONS

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Chairman Toomey, Ranking Member Stabenow, and Members of the Senate Finance Subcommittee on Health:

On behalf of the Alzheimer's Foundation of America (AFA), a nonprofit organization whose mission is to provide support, services and education to individuals, families and caregivers affected by Alzheimer' disease and related dementias nationwide, and fund research for better treatment and a cure, we commend the Subcommittee for honoring National Alzheimer's Awareness Month by holding this hearing on Alzheimer's disease to raise awareness and highlight obstacles in diagnosis, treatment and care that impacts the quality of life for the millions of American families who live with dementia.

Alzheimer's Disease and Its Impact

Alzheimer's disease is the sixth leading cause of death in the U.S.[1] and the only cause of death in the top 10 with no cure or treatment to reverse or slow its progression. It is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. As our population ages, incidences of the number of persons affected by this insidious brain disorder are expected to double by 2060 according to the Centers for Disease Control and Prevention (CDC).[2]

Individuals with Alzheimer's disease use a disproportionate amount of health care resources; for instance, they are hospitalized two to three times as often as people the same age who do not have the disease.[3] Similarly, nearly half of all nursing home residents have Alzheimer's disease.[4]

Overall, health costs for persons with dementia are substantially larger than those for other diseases, and many of the expenses are not covered by private or public health insurance programs.[5] This places a large financial burden on families, and

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[1] While the Centers for Disease Control and Prevention (CDC) lists Alzheimer's disease as the sixth leading cause of death in the U.S. *(see www.cdc.gov/nchs/fastats/leading-causes-of-death.htm),* recent studies cite that over 500,000 Americans a year die as a result of dementia, making Alzheimer's disease the third leading cause of death in the U.S. *See* "Contribution of Alzheimer disease to mortality in the United States," James, Bryan Ph.D. et al., *Neurology* (March 5, 2014) *(www.neurology.org/content/early/2014/03/05/WNL.0000000000000240).*

[2] Matthews, Kevin A. et al., "Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged ±65 years," *Alzheimer's and Dementia: The Journal of the Alzheimer's Association,* Volume 15, Issue 1, 17–24 (2018).

[3] "Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient," National Alliance for Caregiving, November 2011 *(www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).*

[4] *See* "Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia," AHRQ Publication No. 12(13)–EHC127–EF *(www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050127/)* (approximately 45–67% of all nursing home residents have dementia).

[5] Kelley A.S., McGarry K., Gorges R., et al. "The Burden of Health Care Costs for Patients with Dementia in the Last 5 Years of Life." *Ann Intern Med.* 2015;163:729–736 (October 27, 2015) *(https://doi.org/10.7326/M15-0381).*

these burdens are particularly pronounced among the demographic groups that are least prepared for financial risk.[6]

In addition to costs of care, there's an additional human toll. For each person with Alzheimer's disease, there are multiple caregivers who respond to 24/7 needs related to activities of daily living. Caregiving duties often fall on family members who are overwhelmed both emotionally and physically, and whose health and well-being often suffer as they fulfill this role.[7] There is a higher incidence of sickness and mortality among Alzheimer's disease caregivers, compared to other caregivers.[8] In 2011, family caregivers provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over $210 billion.[9]

Finally, there is no drug or modifying treatment to stop or slow the progression of dementia. Four decades of intense research efforts have failed to yield any effective pharmaceutical interventions for Alzheimer's disease with a clinical trial failure rate of nearly 99.6% (compared to a 20% success rate for cancer drugs).[10]

Barriers to Diagnosis

Several barriers remain in place that make it difficult for physicians to diagnose dementia. A study examining the literature around these obstacles identified six common themes[11] including lack of support for patients, caregivers, and physicians, time and financial constraints, stigma, diagnostic uncertainty, and concerns around disclosure of the diagnosis.[12] Further, a 2006 editorial in the *Journal of the American Geriatric Society* estimated that missed diagnoses are greater than 25 percent of the dementia cases and may be as high as 90 percent.

Accurate and timely diagnosis can provide greater opportunities for people with Alzheimer's disease to participate in clinical trials. New drug therapies currently being tested focus on stopping progression in the early stages of the disease, requiring trial participants to have low to mild cognitive impairment. Cognitive screening can help identify this pre-symptomatic population who will be essential to accelerate promising drug development.

Early detection will allow individuals to adopt prevention strategies that help slow or plateau progression of dementia.[13] Lifestyle activities like increasing aerobic exercise, maintaining a "Mediterranean" diet, controlling hypertension and engaging in cognitive "brain" games have been shown to decrease cognitive decline and dementia by increasing an individual's cognitive reserves.[14]

Given the obstacles to early detection, a simple, inexpensive and non-invasive cognitive screening should be promoted and encouraged. AFA recommends that Congress expand memory screening efforts and promote the benefits of memory screening and early detection of Alzheimer's disease. To accomplish this, we urge Congress to:

- Fund the BOLD Act initiatives at CDC which will go to increasing education of public health officials, health care professionals and the public on Alzheimer's, brain health and cognitive health disparities.

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[6] *See* Kelley A.S., *Ibid.* "Average total cost per decedent with dementia ($287,038) was significantly greater than that of those who died of heart disease ($175,136), cancer ($173,383), or other causes ($197,286) ($P < 0.001$). Although Medicare expenditures were similar across groups, average out-of-pocket spending for patients with dementia ($61,522) was 81% higher than that for patients without dementia ($34,068); a similar pattern held for informal care."

[7] "Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient," National Alliance for Caregiving, November 2011.

[8] *Ibid.*

[9] A. Stevens, Ph.D., "Next Steps in Family Caregiving Research: Interventions Designed for Impact" *(www.nia.nih.gov/sites/default/files/alan_stevens_0.pdf).*

[10] Z.S. Khachaturian, Ph.D., "40 Years of Alzheimer's Research Failure: Now What?". *MedPage Today* (September 13, 2018) *(https://www.medpagetoday.com/neurology/alzheimersdisease/75075).*

[11] D. Judge, J. Roberts, R. Khandker (et al.), "Physician Perceptions about the Barriers to Prompt Diagnosis of Mild Cognitive Impairment and Alzheimer's Disease," *International Journal of Alzheimer's Disease,* vol. 2019, Article ID 3637954, 6 pages, 2019, *https://doi.org/10.1155/2019/3637954.*

[12] *Id.*

[13] Crous-Bou M., Minguillón C., Gramunt N., Molinuevo J.L. "Alzheimer's disease prevention: from risk factors to early intervention." *Alzheimer's Res Ther.* 2017;9(1):71. Published September 12, 2017. doi:10.1186/s13195–017–0297–z.

[14] Stern Y. "Cognitive reserve in ageing and Alzheimer's disease." *Lancet Neurol.* 2012;11(11):1006–12.

- Increase physician and public awareness of Medicare's annual wellness visit and its cognitive screen component, as well as its reimbursement.
- Incentivize private insurers to reimburse health professionals for conducting cognitive screens of older Americans or those who have a genetic link—or other predisposition (*i.e.,* play contact sports)—for dementia.

Barriers to Treatment

In 2012, Congress approved the National Plan to Address Alzheimer's Disease which sets a goal for preventing and effectively treating Alzheimer's disease by 2025. AFA is grateful that Congress, in the past several budget cycles, has honored this commitment by approving historic increases in federal funding for clinical research into a cure for Alzheimer's disease. Appropriations for the National Institute on Aging (NIA), the nation's leading federal funder of Alzheimer's disease research, has increased from just over a billion dollars in 2012, to over three billion in fiscal year 2019.

This influx in funding has allowed NIA to fund new and innovative targets in the hopes of finding a cure. These new targets include inflammation, tau proteins, neurotransmitters, genetics, hypertension and growth hormones to name a few. Failure to provide such an investment will leave promising research unfunded and further increase the timeline to get us to a cure or modifying treatment.

In addition to funding, the lack of an Alzheimer's disease infrastructure will pose as a barrier to treatment should one or more therapies become available. A substantial number of existing cases with mild cognitive impairment (MCI) would have to be screened, diagnosed, and then potentially treated as quickly as possible when a therapy first comes to market, in order to prevent progression to Alzheimer's.

A 2018 study found the infrastructure for Alzheimer's disease to be lacking and that the US health system was unprepared and currently insufficient to handle the expected caseload if there was a cure.[15] According to the study, the most pressing constraint is limited capacity of specialists to evaluate and diagnose patients, but access to imaging to confirm Alzheimer's disease and to infusion centers to deliver the treatment would also contribute to waiting times.[16]

To alleviate these barriers to treatment, AFA recommends that Congress:

- Continue robust investment into research of dementia at the National Institute of Aging (NIA) and other federal health agencies.
- Invest in Alzheimer's disease infrastructure which includes promotion and expansion of a geriatric workforce, increased awareness of brain health and access to imaging and other tools to aid in diagnosis and treatment.

Barriers to Care Coordination

Caring for a loved one with Alzheimer's disease or a related dementia poses enormous and life-changing challenges for families and caregivers. Person-centered, coordinated care delivery models and smart investments in supports and training will extend limited resources by lowering overall costs of care for a person with Alzheimer's disease. Coordinated care delivery that avoids unnecessary hospitalizations and provides tools to care partners that can delay nursing home placement are necessary policy changes that will allow Americans to provide quality care until such time as clinical research discovers a cure or effective treatment for this fatal brain disorder.

According to an AARP study, despite a growing evidence that person-based coordinated care models coupled with dementia caregiver supportive services are effective, few of these care models have been implemented into everyday practice.[17]

AFA urges Congress to call on federal health programs to fully adopt person centered care coordination models and caregiver support programs, including:

- Medical homes for persons living with dementia—Medical homes deliver care that is coordinated, comprehensive, efficient and personalized. Practitioners

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[15] Liu, Jodi L., Jakub P. et. al., "Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment," RAND Corporation, 2017 *(www.rand.org/pubs/research_reports/RR2272.html).*

[16] *Ibid.*

[17] AARP Public Policy Institute, "From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia" (September 2017) *(www.aarp.org/ppi/info-2017/from-research-to-standard-practice.html).*

manage all aspects of care, not just treatment.[18] Coordinated care prevents unnecessary services and reduces overall health care costs by targeting the precise needs of the person.

- Independence at Home (IAH)—The IAH model uses primary care teams led by physicians or nurse practitioners to deliver timely, in-home primary care to Medicare beneficiaries with multiple chronic illnesses and functional impairments, including those living with dementia.
- Program of All-Inclusive Care for the Elderly (PACE)—PACE focuses only on seniors, who are frail enough to meet their State's standards for nursing home care. PACE features medical and social services that can be provided at an adult day health center, home, or inpatient facility. For most people, the service package allows them to continue living at home while receiving services.
- The REACH VA Program—is designed to assist caregivers with challenges such as self-care; problem solving; mood management; asking for help; and stress management. Caregivers are matched with a trained and certified REACH VA Program Coach who provides individual sessions where the caregiver receives support, training and best practices.

AFA appreciates the opportunity to provide some recommendations that could help overcome the current barriers to the diagnosis, treatment and care coordination of Alzheimer's disease. AFA stands ready to assist 'you and the Committee in any way to advance these and other proposals that will provide optimal care, while creating efficiencies that lower costs of care without compromising access or quality. Feel free to contact Eric Sokol, AFA's senior vice president of public policy at: esokol@alzfdn.org if you have any questions or need further information.

AMERICAN COUNCIL OF LIFE INSURERS AND NATIONAL ASSOCIATION OF INSURANCE AND FINANCIAL ADVISORS

Statement for the Record of Susan K. Neely, President and Chief Executive Officer (ACLI), and Kevin M. Mayeux, CAE, Chief Executive Officer (NAIFA)

The American Council of Life Insurers (ACLI) and the National Association of Insurance and Financial Advisors (NAIFA) appreciate the opportunity to submit this statement for the record on "Alzheimer's Awareness: Barriers to Diagnosis, Treatment and Care Coordination." We thank Chairman Pat Toomey (R–PA) and Ranking Member Debbie Stabenow (D–MI) for holding this important hearing, and applaud Chairman Toomey's leadership in advocating solutions. Chairman Toomey's proposal would help families by allowing them limited access to their retirement savings to help pay for long term care insurance. By providing this flexibility, more families will have protection against spending down their hard-earned savings to pay for long-term care.

ACLI advocates on behalf of 280 member companies dedicated to providing products and services that promote consumers' financial and retirement security. Ninety million American families depend on our members for Long-Term Care Insurance (LTCI), life insurance, annuities, retirement plans, disability income insurance, reinsurance, and dental, vision and other supplemental benefits. ACLI represents member companies in state, federal, and international public policy forums that support the insurance marketplace and the families that rely on life insurers' products for peace of mind. ACLI members represent 95 percent of industry assets in the United States.

Founded in 1890, NAIFA is the oldest, largest and most prestigious association representing the interests of insurance professionals from every congressional district in the United States. NAIFA members assist consumers by focusing their practices on one or more of the following: life insurance and annuities, health insurance and employee benefits, retirement planning, multiline, and financial advising and investments. NAIFA's mission is to advocate for a positive legislative and regulatory environment, enhance business and professional skills, and promote the ethical conduct of its members.

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[18] The Patient-Centered Primary Care Collaborative, Joint Principles of the Patient-Centered Medical Home (February 2007).

Long-Term Care Financing

By 2030, those 65 years of age and older will represent 21 percent of the population, and 70 percent of individuals living past age 65 will need some long-term care.[1, 2] On average, women need 3.7 years and men 2.2 years of care. Twenty percent of these people will need long-term care services for more than five years. During the next 20 years, the share of the U.S. population that is 85 years or older will more than double.[3] Currently, about 42 percent of those 85 and older have severe long-term care needs, but only 26 percent use paid long-term care.[4] As the elderly population grows, demand for long-term care will increase. By 2050, up to 14 million seniors will require some form of long-term care.

The cost of long-term care is high and increasing. According to a recent survey, adult day care costs approximately $19,500 per year. An assisted living facility costs approximately $48,612 per year. A private room in a nursing home costs approximately $102,200 per year. Costs are rising approximately 3 percent per year.[5] Long-term care ranks as the second greatest financial concern for Americans, behind only retirement savings.[6]

According to the AARP, in 2017 spending for Long-Term Services and Supports (LTSS) totaled $235 billion. Medicaid accounted for 57 percent of that cost, out-of-pocket expenditures made up 23 percent, private long-term care insurance comprised four percent, and the remaining 16 percent was for other products. These numbers show that more can be done to help alleviate the pressure on Medicaid by allowing the private marketplace to take on more of the cost. This current path is not sustainable for either individuals, their families, or the public treasury.

Given the strong possibility that the typical senior will require long-term care, and given its high and escalating cost, whether seniors enjoy a comfortable retirement or suffer economic hardship may depend largely on their ability to afford long-term care. Most Americans have not planned for this and face the prospect of paying large sums "out-of-pocket" or relying on Medicaid, which in its current form requires one to "spend down" virtually all assets and retirement income in order to be Medicaid-eligible. Neither option is appealing and may leave seniors and their spouses impoverished, with few choices other than reliance on federal and state safety nets.

The private long-term care insurance marketplace offers meaningful solutions. Private long-term care insurance currently pays for only 4 percent of total nursing home expenditures for seniors.[7] There is clearly a large gap in the market which private long-term care insurance can fill.

Long-Term Care and Alzheimer's

As the American population ages, the prevalence of Alzheimer's disease increases. Currently an estimated 5.8 million Americans are living with Alzheimer's disease and that number is projected to increase to nearly 14 million by 2050.[8] Alzheimer's disease is the leading cause of long-term care insurance claims,[9] and the impact of a growing population afflicted with the disease will increase the need for long-term services and supports. Additionally, almost two-thirds of Americans with Alzheimer's disease are women. Women are nearly twice as likely to develop the condition as men.[10] This highlights the growing financial risk that Alzheimer's disease poses to women who are not protected by long-term care insurance coverage.

Long-Term Care Insurance

Millions of Americans' financial and retirement security are at risk from exposure to unfunded long term care needs. Access to expanded options to meet and finance

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[1] U.S. Census Bureau, 2019 Statistical Abstract of the United States, Table 8.

[2] U.S. Department of Health and Human Services (extracted on November 15, 2019); and Genworth, 2019 Cost of Care Survey.

[3] U.S. Census Bureau, 2019 Statistical Abstract of the United States, Table 8.

[4] U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, "What is the Lifetime Risk of Needing and Receiving Long-Term Support Services," April 2019. Based on 2014 data.

[5] Genworth, 2019 Cost of Care Survey.

[6] 2019 Insurance Barometer Report, LIMRA.

[7] ACLI calculations of Centers for Medicare and Medicaid Services. Health Expenditure Survey (extracted on November 14, 2019).

[8] 2019 Alzheimer's Disease Facts and Figures Report p. 22.

[9] The American Association for Long Term Care Insurance (quoting Society of Actuaries LTC Experience, extracted on November 15, 2019).

[10] 2019 Alzheimer's disease Facts and Figures Report p. 18.

the need for long-term services and supports will enable consumers to address those needs without eroding other assets or burdening family and friends.

Long-term care insurance covers services that assist individuals with cognitive difficulties and to those who are unable to perform activities of daily living, such as eating, bathing, or getting dressed. There is a misconception among many Americans that Medicare will cover their long-term care expenses. In fact, most of those costs are not covered. Long-term care insurance provides financial assistance for necessary care separate from "medical treatment." Since most care is not treatment, it is not typically covered by medical expense coverage or Medicare.

Long-term care insurance is a relatively new product. It was introduced in the 1970s to meet a growing need of American families with loved ones requiring care for long-term services and supports. The first generation of these products suffered pricing challenges due to actual experience and generous benefits. Insurers have stabilized more traditional products, and concurrently have developed next-generation hybrid and combination products that provide both life insurance or annuity payments and long-term care benefits. These developments enable consumers to protect against long-term care events, with far less price volatility than the first generation of products.

Approximately 7.4 million people have purchased long-term care insurance to help manage their future care needs. The number of Americans needing long-term care is expected to rise to 27 million by 2050.[11] In 2018 alone, consumers received nearly $12 billion in long-term care insurance claims payments.[12] By covering long-term care costs, insurers will save Medicaid approximately $50 billion in the coming years, benefitting the solvency of federal and state Medicaid programs.[13]

Building Awareness and Facilitating Purchase of Long-Term Care Insurance

ACLI and NAIFA applaud Chairman Toomey's leadership in putting forth a proposal that would assist families to prepare for their long-term care needs by allowing them to have limited access to their retirement savings to help pay for long-term care insurance. With this sort of flexibility, more families would have protection of retirement savings and be far better positioned to meet long-term care expenses.

ACLI and NAIFA also continue to work with the recently organized U.S. Treasury interagency task force on long-term care insurance. We understand that the task force has been reviewing various proposals to reform federal laws and regulations concerning long-term care insurance, including, among other options, federal policy options presented by the NAIC to Congress for its consideration in April 2017.

Alongside the NAIC options, ACLI and NAIFA offer recommendations we believe are achievable and would substantially improve consumer access to private long-term care insurance coverage. These recommendations specifically identify potential reforms to federal laws, regulations, and policies that would complement regulatory reforms at the state level related to long-term care insurance.

There may be additional and more comprehensive reforms warranted that will require systemic changes to the way we view long-term care funding with the ultimate goal of creating a comprehensive long-term services and support financing system. One such approach that warrants discussion is to have private insurance plans cover initial costs and the government serve as "catastrophic backstop." However, we believe the task force's current consideration of the achievable near-term changes described below would lead to measurable improvements for American consumers seeking to access long-term care coverage. Included in this statement is the NAIFA letter to the task force and the joint ACLI and American's Health Insurance Plans (AHIP) letter to the task force regarding such recommendations, they are summarized here:

- Launch a national educational campaign to help consumers understand both the need for and benefits of long-term care insurance coverage.
- Provide tax incentives to expand consumer access to long-term care insurance coverage through workplace and retirement plans:

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[11] H. Stephen Kaye, Charlene Harrington, Mitchell P. LaPlante, "Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?", *Health Affairs,* January 2010.

[12] ACLI calculations based on 2018 NAJC Annual Statement data.

[13] Life Plans, Inc. for AHIP "'The Benefits of Long Term Care Insurance and What They Mean for Long Term Care Financing," November 2014.

  - Making long-term care insurance coverage available through Internal Revenue Code Section 125 cafeteria plans and Flexible Spending Arrangements;
  - Allowing tax-free premium payments for long-term care insurance policies from 401(k)s, 403(b)s, IRAs, and other retirement plans; and
  - Permitting employees to make additional contributions to Health Savings Accounts to pay for long-term care insurance premiums.
- Support legislation or regulatory guidance that would confirm and allow the payment of long term care insurance incidental benefits from policies that enhance care options for policyholders and provide access to benefits including those intended to support healthy, independent living and aging in place, prior to satisfying the current eligibility requirements of a severe cognitive impairment or substantial assistance with the requisite activities of daily living. This allowance should not cause the policy to forfeit its tax qualified status.
- Revise current federal requirements surrounding inflation protection for long-term care insurance policies to encourage policy design innovations that would meet the needs of consumers more effectively.

We believe these recommendations align with our mutual goals to expand consumer choice and access to quality long-term care insurance coverage, reduce out-of-pocket long-term care costs faced by consumers and protect retirement savings, manage long-term care insurance premiums, and improve health outcomes for long-term care insurance policyholders in the most cost-efficient manner possible.

Again, thank you for the opportunity to comment on this vitally important issue. The life insurance industry looks forward to working with you as your work and consideration of policy solutions continues.

AMERICA'S HEALTH INSURANCE PLANS AND AMERICAN COUNCIL OF LIFE INSURERS

August 30, 2019

The Honorable Michael Faulkender
Assistant Secretary for Economic Policy and
Chair of the Federal Interagency Task Force on Long-Term Care Insurance
Department of the Treasury
1500 Pennsylvania Avenue, NW, Room 3454 MT
Washington, DC 20220

RE: AHIP–ACLI Comments on Potential Federal LTC Reforms to Improve Financial Security of Americans

Dear Mr. Faulkender:

America's Health Insurance Plans (AHIP) and the American Council of Life Insurers (ACLI), on behalf of their member insurers, appreciate the opportunity to respond to the Federal Interagency Task Force on Long-Term Care Insurance's (Task Force) invitation for comments on potential reforms to federal laws, regulations, and policies that complement reforms at the state level relating to the regulation of long-term care insurance (LTCI). We commend the Task Force for considering the challenges of long-term care (LTC) financing that American consumers face as a matter of national interest, requiring a coordinated response from the federal government.

Millions of Americans' financial and retirement security are at risk from exposure to unfunded LTC events. Access to additional options to meet and finance the need for long term services and supports (LTSS) will enable consumers to address those needs without eroding other assets or imposing on family and friends. We welcome the opportunity to work with the Task Force to develop policies that would improve the private financing of LTSS.

AHIP is the national association whose members provide coverage for health care and related services to millions of Americans every day. Through these offerings, we improve and protect the health and financial security of consumers, families, businesses, communities and the nation. We are committed to market-based solutions and public-private partnerships that improve affordability, value, access and well-being for consumers. Our members provide a range of products to millions of consumers, including major medical coverage, disability income insurance, dental insurance, LTCI, reinsurance, pharmacy benefits, and administrative services for self-funded health plans.

ACLI advocates on behalf of 280 member companies dedicated to providing products and services that promote consumers' financial and retirement security. Ninety (90) million American families depend on our members for LTCI, life insurance, annuities, retirement plans, disability income insurance, reinsurance, dental and vision and other supplemental benefits. ACLI represents member companies in state, federal, and international public policy forums that support the insurance marketplace and the families that rely on life insurers' products for peace of mind. ACLI members represent 95 percent of industry assets in the United States.

We understand that the Task Force has been reviewing various proposals to reform federal laws and regulations concerning LTCI, including, among other options, the federal policy options presented by the NAIC to Congress for its consideration in April 2017. Having also reviewed the NAIC options, we offer recommendations that we believe are achievable and would meaningfully improve consumers' access to private LTCI coverage. Further, as the Task Force requested, our recommendations specifically outline potential reforms to federal laws, regulations, and policies that would complement regulatory reforms at the state level related to LTCI. There may be additional and more comprehensive reforms warranted that will require systemic changes to the way we view LTC funding with the ultimate goal of creating a comprehensive LTSS financing system. One such approach that warrants discussion is the government serving as "catastrophic backdrop" and private insurance plans covering initial costs. However, we believe the Task Force's current consideration of the more achievable near-term changes described below would lead to meaningful improvements for American consumers seeking to access LTC coverage.

Below we summarize our recommendations regarding the Task Force's consideration of proposed options to expand consumer access to LTCI coverage:

- Launch a national educational campaign to help consumers understand both the need for and benefits of LTC coverage.
- Provide tax incentives to expand consumer access to LTC coverage through workplace and retirement plan options:
    - Making LTC coverage available through Internal Revenue Code (IRC) Section 125 cafeteria plans and Flexible Spending Arrangements (FSA);
    - Allowing tax-free premium payments for LTCI policies either from or within their 40 l (k)s, 403(b)s, IRAs, and other retirement plans; and
    - Permitting employees to make additional contributions to their Health Savings Accounts (HSA) to pay for LTCI premiums.
- Support legislation or regulatory guidance that would confirm and allow the payment of LTCI incidental benefits from LTCI policies that enhance care options for policyholders and provide access to benefits, including those intended to support healthy, independent living and aging in place, prior to satisfying the current eligibility requirements of a severe cognitive impairment or substantial assistance with the requisite activities of daily living. This allowance should not cause the policy to forfeit its tax qualified status.
- Revise current federal requirements surrounding inflation protection for LTCI policies to encourage policy design innovations that would meet the needs of consumers more effectively.

Our detailed recommendations are outlined in the enclosed attachment. We believe these recommendations align with our mutual goals to expand consumer choice and access to quality LTCI coverage, reduce LTC costs faced by consumers, manage LTCI premiums, and improve health outcomes for LTCI policyholders in the most cost-efficient manner possible.

We appreciate Treasury's efforts to seek detailed input on how to expand and improve private LTCI coverage to help achieve these mutual goals. We look forward to working with the Task Force throughout this process as a resource to provide further clarification on any of these comments and to offer additional perspectives on the issues that impact our members.

Sincerely,

Susan Coronel Executive Director for LTC AHIP	Charles Piacentini Vice President, Insurance Regulation & Associate General Counsel ACLI

Enclosures: AHIP-ACLI Recommendations

AHIP-ACLI RECOMMENDATIONS

TO FEDERAL INTERAGENCY TASK FORCE ON LONG-TERM CARE INSURANCE
IN RESPONSE TO REQUEST FOR PUBLIC COMMENTS ON
PUBLIC POLICY AND REFORM PROPOSALS THAT WOULD HAVE THE MOST IMPACT ON
IMPROVING THE LONG-TERM CARE INSURANCE MARKET

The public and private sectors must partner to improve access to long-term care insurance (LTCI) coverage, enabling individuals to preserve their health and protect their ability to remain financially secure as they age. Initiatives that (1) promote consumer awareness, (2) increase access to coverage, and (3) encourage innovation, both to address the diverse care needs of individuals and families and to respond to changes in the care delivery landscape, will enhance consumer choice and improve access to quality LTCI coverage. In addition, these initiatives will serve to reduce LTC costs, manage premiums, and improve health outcomes for LTCI policyholders. By expanding LTCI coverage among middle class Americans, the social safety net will be preserved for those who need it most.

I. LAUNCH A NATIONAL AWARENESS CAMPAIGN TO HELP CONSUMERS UNDERSTAND THE IMPORTANCE OF PLANNING FOR A LONG-TERM CARE (LTC) EVENT

Recognizing that consumers must appreciate the risks associated with a potential LTC event, implementing a comprehensive awareness campaign is a key component of efforts to expand access to LTCI, especially among the middle class. Educational programs must effectively explain, among other things, (1) the risks of potentially needing long-term supports and services (LTSS) later in life, (2) why planning for LTSS is a necessary part of a comprehensive retirement security strategy, and (3) the meaningful options available to assist consumers in covering their LTC needs, including the purchase of LTCI. A targeted education program will help consumers understand the importance of planning and may encourage the middle class to purchase LTCI.

A well-researched education and awareness effort is critical to encouraging and enabling consumers to take personal responsibility for their future LTC needs. Based on their past effectiveness, the “Own Your Future” Awareness Campaign and the National Clearinghouse for LTC Information website should be re-launched. Notably, consumer interest in purchasing insurance to address potential LTC needs increased as a result of “Own Your Future.”

LTCI carriers are committed to working with federal and state government leaders to support education and awareness efforts to inform consumers about the valuable protection LTCI coverage provides.

II. PROVIDE TAX INCENTIVES TO EXPAND CONSUMER ACCESS TO LTC COVERAGE THROUGH WORKPLACE AND RETIREMENT PLAN OPTIONS

Nearly 180 million Americans obtain health care coverage in the workplace, which suggests that employers are well-positioned to help individuals understand the value of Qualified Long-Term Care Insurance (QLTCI) and expand investment in this coverage. Workers should be permitted to leverage workplace channels and retirement plan options to save for their LTC needs. Approaches that should be considered include:

a. ***Cafeteria Plans (IRC 125) and other Flexible Spending Arrangements (FSA):*** Cafeteria plans (often incorporating an FSA) provide employees an opportunity to receive certain qualified benefits on a pre-tax basis. Under current law, qualified benefits include most accident and health benefits, adoption assistance, dependent care assistance, group term life insurance, and health savings accounts.

Permitting LTC coverage to be included in a cafeteria plan would make it more affordable. This solution would have limited impact on the tax dollars received from employees, because most employees would simply shift their cafeteria plan/ FSA dollars from other pre-tax benefits to LTCI coverage. Adding QLTCI as a qualified benefit gives employers a new way to add value for their employees—and provides additional opportunities for Americans to become more educated on why QLTCI is important to their financial stability and peace of mind.

b. ***Distributions from Retirement Plans:*** An uninsured LTC event significantly threatens the financial and retirement security of most Americans. Expanding consumer access to pre-tax funds to purchase LTCI will protect retirement savings from erosion resulting from funding costly LTSS.

Enabling individuals to make LTCI premium payments from their 401(k)s, 403(b)s, IRAs, and other retirement plan options, income tax free (or with a lesser tax burden imposed) and subject to limits, would permit the purchase of meaningful LTCI coverage. Consumers would be able to use these pre-tax assets to fund either a traditional LTCI policy or a "hybrid" (LTC benefits in conjunction with a life insurance policy or an annuity contract), which would reduce the cost of this coverage, making it accessible to more Americans. By utilizing a limited amount of their retirement assets to fund LTCI, consumers can protect themselves against LTC events as these assets accumulate while enhancing overall retirement security.

c. ***"Within Plan" Investments:*** Individuals currently saving for retirement through 401(k)s, 403(b)s, IRAs, and other retirement plans would be permitted to make premium payments for LTCI coverage that will be considered a retirement plan investment ("Within Plan").

Individuals would be allowed to leverage their retirement savings through the "Within Plan" approach to invest directly in QLTCI coverage. Premium payments would be treated as a movement of monies from one plan investment to another, so they would not be taxable distributions. Should the policyholder become chronically ill or otherwise entitled to QLTCI policy benefits, the benefits would be paid to the retirement plan which would then pay them to the participant as a plan distribution.

The benefits would be treated in the same manner as income on any other plan investment and, therefore, considered taxable income when distributed under existing tax rules governing retirement plan distributions. This approach would have only a modest tax revenue loss since pre-existing retirement savings used to pay premiums are already in a tax-favored format.

d. ***Health Savings Accounts (HSA):*** Under current law, individuals with high deductible health plans can choose to make tax-deductible contributions to an HSA. In addition to helping to pay for out-of-pocket health costs, these tax-deductible dollars can be used to pay premiums for QLTCI.

We support changes to the contribution limits for HSAs that would allow individuals to make additional contributions to their HSAs equal to what they would pay in premiums for qualified LTC plans. In addition, individuals should be allowed to contribute to their spouse's HSA if the spouse is covered by QLTCI.

Under current law, if an individual has an HSA but no longer has high deductible health plan coverage, he or she cannot contribute additional amounts to the HSA. However, under this proposal, if the individual has QLTCI coverage during a taxable year, he or she would be allowed to make additional contributions in that year, pursuant to this special rule, equal to their QLTCI premiums as long as they already have an HSA. This approach provides more flexibility and choice, allowing employees to save more pre-tax dollars to buy LTCI coverage for themselves or their spouse.

III. ALLOW PAYMENT OF LTC INCIDENTAL BENEFITS THAT WOULD ENHANCE CARE OPTIONS FOR LTCI POLICYHOLDERS

Older adults will need assistance as their levels of dependence begin to increase. Waiting until the onset of chronic illness or severe cognitive impairment is too late. LTCI policies can help policyholders and their families delay the need for more substantial levels of facility care and keep them in their homes. Since facilities tend to be more expensive, this would be a benefit to care recipients, their families, and ultimately to private and public payers.

Federal legislation or regulatory guidance should confirm that tax qualified LTCI policies may provide incidental benefits prior to the onset of an insured's chronic illness where such benefits are (a) incidental to a policy' s overall benefits (*e.g.,* less than 10% of the policy' s lifetime benefit limit), and (b) expected to delay the onset of an insured's chronic illness or the severity of the insured's future chronic illness. Examples would include the provision of home assessments to identify risks which could lead to chronic illness (such as tripping hazards), installation of ramps and railings, caregiver training for family members, and sharing information regarding local LTC providers to those who need (or anticipate needing) assistance.

This allowance should not cause a LTCI policy to, forfeit its tax qualified status. Providing these benefits would allow insurers to provide personalized services to their policyholders and permit consumers to stay in their homes and communities, which is what they generally prefer.

IV. AMEND CURRENT FEDERAL INFLATION PROTECTION REQUIREMENTS

Inflation protection is an important LTCI feature. However, existing laws governing this benefit option often discourage consumers from seeking LTC protection altogether. Eliminating or revamping inflation protection requirements could encourage policy design innovations that would meet the diverse needs of consumers. Given that "one-size-fits-all" solutions do not work for everyone, it is important for consumers to have a variety of products and options from which to choose when evaluating their LTC protection needs.

Below are specific recommendations to revise current inflation protection requirements contained in Health Insurance Portability and Accountability Act (HIPAA) and the Deficit Reduction Act of 2005 (DRA):

a. ***HIPAA—Remove the requirement that 5% inflation coverage be offered to all applicants and replace it with a requirement to offer some form of inflation protection.*** A carrier may offer the applicant inflation coverage (compound, simple, or a guaranteed purchase offer) that best meets their needs without requiring an expensive 5% compound offer that may not even be appropriate. This change would simplify the sales/disclosure process. An LTCI policy should still retain its tax-qualified status with this change so long as some offer of inflation coverage is made that is approved by the applicable state regulatory authority.

b. ***DRA—Remove the inflation coverage age tier requirements.*** As long as an LTCI policy meets all tax qualification requirements under HIPAA (*i.e.,* the inflation requirement as described above), the DRA Medicaid Partnership requirements should be fulfilled as well. Thus, a tax qualified policy would satisfy the DRA Partnership requirements.

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August 27, 2019

Federal Interagency Task Force on Long-Term Care Insurance
Department of the Treasury
1500 Pennsylvania Avenue, NW, Room 3454 MT
Washington, DC 20220

RE: Federal reforms to complement state level long-term care insurance reforms

Dear Chairman Faulkender and Task Force members:

The National Association of Insurance and Financial Advisors ("NAIFA") appreciates this opportunity to comment on potential reforms to federal laws, regulations, and policies to complement reforms at the state level relating to the regulation of long-term care insurance (LTCI).

Founded in 1890 as The National Association of Life Underwriters (NALU), NAIFA is the oldest, largest and most prestigious association representing the interests of insurance professionals from every Congressional district in the United States. NAIFA members assist consumers by focusing their practices on one or more of the following: life insurance and annuities, health insurance and employee benefits, retirement planning, multiline, and financial advising and investments. NAIFA's mission is to advocate for a positive legislative and regulatory environment, enhance business and professional skills, and promote the ethical conduct of its members.

NAIFA supports proposals at the federal and state level to increase consumer conversations and awareness of the social need for long-term care supports and services. The NAIFA Limited and Extended Care Planning Center is a community with a common purpose to maximize professional and consumer awareness and the distribution of limited and extended care solutions.

LTCI can be vital in addressing our nation's long-term care needs, particularly with an aging "boomer" generation that could eventually overwhelm our nation's already financially strained government programs. LTCI is sold to individuals or through a group plan offered by an employer. It is imperative that LTCI play a significant role in the financing of long-term care services. LTCI can ensure that significant personal care expenses are met without burdening one's family or depleting other financial assets, while lowering Medicaid and Medicare costs for taxpayers.

NAIFA supports a broad array of solutions to increase coverage opportunities that fit individual and family needs as well as provide affordable meaningful benefits to a wider consumer market including the following:

Establish a Federal Retirement and LTC Education Campaign
While Americans recognize the need to save for retirement, few are aware of the need to protect their savings against the steadily growing costs of long-term care services. Unfortunately, far too many individuals mistakenly believe health insurance, Medicare or Medicaid will cover their long-term care services. Others believe they can self-finance only to learn that their assets will not pay for care unless they are sold. These misconceptions stop or delay planning for long- term care expenses. A robust education campaign to increase the public's knowledge of LTCI, promote the need for LTCI planning, and educate consumers on the options for LTCI coverage—both private and public plans—and the benefits and limitations of those options.

NAIFA was a strong supporter of the previous Own Your Future Awareness Campaign and the National Clearinghouse for LTC Information Website. A relaunch of these initiatives, especially with the vast array of social media opportunities now available, can increase awareness and planning to meet care needs.

Permit LTCI Purchase Through Sec. 125 Cafeteria Plans and Flexible Spending Arrangements
Helping people plan for their long-term care needs by allowing them to purchase LTCI coverage at their place of employment should be part of our nation's answer to the long-term care financing challenge. Nearly 180 million Americans get health care coverage through their place of employment. Federal legislation could facilitate access to LTCI coverage, such as amending federal law to permit workers to buy LTCI with contributions to their employer-sponsored cafeteria plans or flexible spending arrangements (FSAs). We believe workplace offerings will raise workers' awareness of the risk, increase their understanding of coverage options, and enable them to plan for long-term care expenses in an affordable manner.

Permit Penalty-free Distribution from Retirement Plans to Purchase LTCI
For well over a century, NAIFA members have helped individuals, families and businesses reduce risks and protect asset s, fund major expenses like college, long-term care and retirement, plan their estates, provide employee benefits and group insurance, and reach their financial goals. Public policy should support initiatives to encourage comprehensive planning and flexibility to address evolving financial needs. Allowing retirement plan participants to make tax-free distributions from 401(k), 403(b) or an Individual Retirement Account (IRA) to purchase LTCI—both traditional and hybrid policies—will allow workers to customize and comprehensively address their financial protection needs to include long-term care .

Enhance Use of HSAs for LTC Expenses and Premiums
Permitting workers to make additional contributions to their Health Savings Accounts (HSA) to pay for LTC plans. Under current law, individuals who have a high deductible health plan can choose to make tax deductible contributions to an HSA. In addition to helping to pay for their out-of-pocket costs immediately, these tax-deductible dollars can be used to pay premiums for Qualified Long-Term Care Insurance (QLTCI). The tax-preferred treatment of HSAs, combined with higher deductibles, offer an incentive for people to make informed health care choices often leading to the greatest cost value. The same benefit can be recognized in QLTCI by adding flexibility for consumers. NAIFA supports changes to HSA contribution limits allowing individuals to make additional contributions to their HSAs equal to what they would pay in QLTCI premiums. Account holders should also be allowed to contribute to their spouse's HSA if the spouse is covered by QLTCI.

Revamp Inflation Protection Requirements
Current inflation protection requirements substantially increase LTCI premiums and often discourage consumers from seeking LTC protection. Inflation protection is an important LTCI insurance feature. However, flexibility in feature design, including inflation protection, would encourage policy design that would better meet

the needs of consumers and broaden protection coverage. Recommended revisions follow:

- ***Health Insurance Portability and Accountability Act (HIPAA)***—Remove the requirement that 5% inflation coverage be offered to all applicants; and replace it with a requirement to offer some form of inflation protection. The carrier may offer the applicant inflation coverage (compound, simple or a guaranteed purchase offer) that best meets their needs without requiring an expensive 5% compound offer that may not even be appropriate for the applicant and his or her needs. This would simplify the sales/disclosure process. A LTCI policy should still retain its tax-qualified status with this change so long as some offer of inflation coverage is made that is approved by the applicable state regulatory authority.
- ***Deficit Reduction Act (DRA)***—Remove the DRA inflation coverage age tier requirements. If an LTCI policy meets all tax qualification requirements under HIPAA (*i.e.,* the inflation requirement as described above), the DRA Medicaid Partnership requirements should be treated as met, too. Essentially, this simplifies DRA Partnership requirements so that if it is a tax-qualified policy, DRA requirements are satisfied.

We appreciate this opportunity to provide comments and your consideration of our views. Should you have any questions, please contact NAIFA staff Diane Boyle dboyle@naifa.org or Steve Kline skline@naifa.org.

Sincerely,

Jill M. Judd, LUTCF, FSS
NAIFA President

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Alzheimer's Disease is the most common form of dementia.[1] As of 2019, 5.8 million Americans are living with Alzheimer's Disease, with this number projected to increase to 14 million by 2050.[2] Alzheimer's Disease and other dementias cost the United States more than $290 billion, with more than 16 million Americans providing unpaid care for this population.[3] With the increasing number of people and their families affected by Alzheimer's Disease and the high costs associated with caring for this population, it is essential that we work to improve care by ensuring stable funding for patient care and maintaining an appropriate workforce. America's Health Insurance Plans (AHIP)[4] and our member health insurance providers are committed to finding solutions to these issues, and we support the Committee's focus on addressing Alzheimer's awareness and their commitment to caring for the people living with this disease and their caregivers.

Funding Care for Those With Alzheimer's Disease

People struggling with Alzheimer's Disease deserve high-quality care. The care they need can often be expensive and be required for several years. In fact, the total cost of care for someone with Alzheimer's or other forms of dementia is estimated to be $341,850.[5] America needs real solutions to provide for these patients' needs from diagnosis and treatment to long-term care, including funding for the long-term care services they require. Expanding access to long-term care insurance can provide this financial security and peace of mind. Solutions to make long-term care insurance coverage more available include:

- Launching a national educational campaign to help consumers understand both the need for and benefits of long-term care coverage.

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[1] *https://www.cdc.gov/aging/aginginfo/alzheimers.htm.*

[2] *https://www.alz.org/alzheimers-dementia/facts-figures.*

[3] *https://www.alz.org/alzheimers-dementia/facts-figures.*

[4] AHIP is the national association whose members provide coverage for health care and related services to millions of Americans every day. Through these offerings, we improve and protect the health and financial security of consumers, families, businesses, communities, and the nation. We are committed to market-based solutions and public-private partnerships that improve affordability, value, access, and well-being for consumers.

[5] *https://www.alz.org/media/Documents/2015FactsAndFigures.pdf.*

- Providing tax incentives for employers to offer long-term care coverage to employees. Incentives may include:
    - Making long-term care coverage available through Internal Revenue Code (IRC) Section 125 cafeteria plans and Flexible Spending Arrangements (FSA);
    - Allowing tax-free premium payments for long-term care policies either from or within their 401(k)s, 403(b)s, IRAs, and other retirement plans; and
    - Permitting employees to make additional contributions to their Health Savings Accounts (HSA) to pay for long-term care premiums.
- Allowing patients to access long-term care insurance benefits that support healthy, independent living and aging in place before they are technically eligible.[6]
- Allowing for different types of financial protections against inflation for long-term care policies; this would encourage more innovation among long-term care insurers as they design new types of policies for consumers.[7]

Enacting these policies will offer individuals with Alzheimer and other forms of dementia, as well as others with long term care needs, a new pathway to independence and financial security, while ensuring the best use of taxpayer dollars that are spent on care.

The Role of Federal Programs in Funding Alzheimer's Care

Medicare. Medicare covers eligible services for individuals with Alzheimer's Disease or other dementias. Those services include cognitive assessments, home safety evaluations, planning for care, and hospital stays.[8] Medicare Part D also covers many prescription drugs for beneficiaries with Alzheimer's Disease and other dementias.[9]

Starting with plan year 2019, CMS expanded the definition for primarily health-related supplemental benefits, permitting MA plans to offer benefits such as adult day care services, in-home support services, respite care, and home and bathroom safety devices and modifications.[10] Via these new flexibilities, MA plans are able to offer additional benefits to address unmet medical and social needs for these individuals.

The Bipartisan Budget Act of 2018 (Public Law No. 115–123) also included a provision that expanded the types of supplemental benefits that MA plans can offer to eligible chronically ill enrollees. These benefits are referred to as Special Supplemental Benefits for the Chronically Ill (SSBCI). The SSBCI do not have to be primarily health-related, but the item or service offered must have a "reasonable expectation of improving or maintaining the health or overall function of the chronically ill enrollee."[11] Examples of benefits covered under the SSBCI criteria include food and produce deliveries, transportation for non-medical needs, social needs benefits, and general supports for living. These recent benefit flexibilities allow MA plans to offer important, valuable services.

As a result, health insurance providers are offering services specifically tailored to those with Alzheimer's Disease. For example, Tufts Health Plan in Massachusetts is working with the local chapter of the Alzheimer's Association to help those with Alzheimer's Disease and their caregivers.[12] Within the program, a Tufts Dementia

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[6] Currently, providing these types of benefits may cause an LTC insurance policy to forfeit its tax qualified status. Issuance of legislation or regulatory guidance that allows for these benefits would help consumers remain healthy and independent longer.

[7] HIPAA and many states require LTCI policies to offer a benefit that automatically increases a policyholder's benefit at an annual compounded rate of 5 percent. This inflation protection offer is expensive and discourages consumers from seeking protection altogether. Eliminating or revamping inflation protection would meet the diverse needs of consumers. Given that "one-size-fits-all" solutions do not work for everyone, it is important for consumers to have a variety of products and options from which to choose when evaluating their LTC protection needs.

[8] *https://www.ems.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/Downloads/Medicare-and-Medicaid-Benefits-for-People-with-Dementia.pdf.*

[9] *https://www.ems.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/Downloads/Medicare-and-Medicaid-Benefits-for-People-with-Dementia.pdf.*

[10] CMS HPMS Memo. Medicare Advantage Organizations and Section 1876 Cost Contract Plans. April 27, 2018.

[11] CMS HPMS Memo. Implementing Supplemental Benefits for Chronically Ill Enrollees. April 24, 2018.

[12] *https://www.ahip.org/board-spotlight-tom-croswell-president-ceo-of-tufts-health-plan/.*

Care Consultant directly connects patients to resources at the Alzheimer's Association. Resources include: referrals to community resources, care planning, educational materials, answers to disease-related questions, information on support groups, and more.[13] This model has seen success and is now being replicated in other parts of the country.

Aetna's Resources for Living Program also aims to fill the gaps in caring for those with Alzheimer's Disease by providing access to at-home services such as cleaning and cooking, caregiver support services such as help with childcare and respite care, and social activities such as transportation and classes for skills and interests.[14]

Medicaid. In addition to Medicare, Medicaid covers a broad range of services for people with Alzheimer's Disease and other dementias. In fact, 27% of people with Alzheimer's Disease or other dementias who have Medicare also have Medicaid.[15] For people with both Medicare and Medicaid, Medicaid coverage wraps around their Medicare benefits, covering Medicare cost sharing and long-term services and support (LTSS) like nursing facility and home- and community-based services. For people covered only by Medicaid, Medicaid covers important services like assessments, physician and diagnostic services, LTSS, care management, hospital stays, and prescription drugs.

Services health insurance providers serving Medicaid eligible members with Alzheimer's Disease include: community-based services such as therapeutic care, personal care, meals, speech therapy, and occupational therapy.[16] In some cases, Medicaid also covers respite care and supportive services for family members who provide unpaid care for relatives with Alzheimer's Disease who are enrolled in Medicaid. Respite care allows family caregivers time to attend to their own lives and personal affairs, helping to reduce caregiver "burn-out."

One example of the kinds of supports provided by Medicaid health insurance providers to members and their caregivers is Centene's Caregiving Collaborations Program which provides tools for informal caregivers such as: information on balancing needs; a Caregiver Journal to stay organized and track daily routines; a Caregiver Portal for authorized caregivers to view the member's care plan and other information; resources on early symptoms and managing illnesses; and other resources to increase collaboration between caregivers and Centene's medical teams.[17]

Commonwealth Care Alliance (CCA) is another example; CCA provides members of their Senior Care Options plan personalized care designed to expand as the member's needs increase over the course of their disease. Members receive ongoing health and functional assessments, assistance with health care appointments and personalized comprehensive care plans which include individualized goals identified by the member and their caregivers.

CCA is able to wrap long-term services and supports around the member and their family consistent with the member's needs and goals; examples of those services include home making, tech enabled supports such as a "medication box" for medication management, home delivered meals, personal care services, Adult Family Care, Adult Day Health and home based health care delivered by a CCA Nurse Practitioner who collaborates with the member's primary care provider and other health care providers. These services that health plans provide their members are crucial to ensuring coordinated, effective care for those with Alzheimer's Disease and other dementias.

Addressing the Caregiver Shortage

Research finds that 83% of help provided to older adults in the U.S. comes from family members, friends, and other unpaid caregivers.[18] In 2017, unpaid caregivers contributed 18.4 billion hours—valued at $232 billion—in care to those with Alzheimer's Disease and other dementias.[19] As our population ages, the age of the individuals willing and able to provide uncompensated care is also increasing—putting this important part of the safety net at risk. A 2015 study found that the average

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[13] *https://www.tuftsmedicarepreferred.org/members/caring-loved-one/alzheimer%E2%80%99s-association-partnership-tufts-health-plan-members.*

[14] *https://www.aetnamedicare.com/en/live-well/resources-for-living.html.*

[15] *https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf.*

[16] *https://www.molinahealthcare.com/members/ca/en-US/mem/medicaid/medical/coverd/lts/Pages/cbas.aspx.*

[17] *https://www.pahealthwellness.com/members/ltss/caregiver-resources/organizational-tools.html.*

[18] *https://www.alzheimers.net/5-09-16-dementia-financial-costs-take-toll-on-families/.*

[19] *https://www.alzheimers.net/5-09-16-dementia-financial-costs-take-toll-on-families/.*

age of unpaid caregivers was 49.2, and among them 34% were over the age of 65.[20] A 2013 study by AARP found that the nation would see a dramatic decline over the next 20 years in the caregiver support ratio: from 7 potential caregivers for every person in the high-risk years of 80-plus in 2010, to 4 for every person 80-plus in 2030.[21]

The United States must take steps to ensure a robust paid workforce to provide care for seniors. According to the Bureau of Labor and Statistics, approximately 4.5 million people are part of the direct care workforce, including personal care attendants, home health aides, and nursing assistants. The direct care workforce is expected to grow by 41% between 2016 and 2026.[22] Individuals who take on the job of direct care are tasked with providing some of the most important care needed by patients with complex medical needs. Direct caregivers assist patients with bathing, toileting, meal preparation, eating, and a variety of other services that are highly personal and essential to a patient's well-being.

Despite the importance of the work, compensation for these workers is low. From 2008 to 2018, these workers experienced little to no pay increases.[23] Caregivers often receive few of the benefits that other employers offer, such as paid leave. This combination of low pay and few or no benefits leads to low job satisfaction, high rates of caregiver burnout, and, consequently, high rates of turnover.

Understanding the physical and emotional toll caregiving can take, health plans are giving caregivers access to free nurse help-lines; comprehensive educational programs including information on enrollment timelines, plan benefits, differences between plan types, etc.; caregiving overviews; incentives for preventive care services, and access to mental health services.[24] Health plans are committed to reducing the burden on caregivers and ensuring caregivers get the information and support they need.

In the coming years, aging Americans who require assistance, including those with Alzheimer's Disease and other forms of dementia, will continue to face even more significant challenges in identifying and retaining caregivers. The decline in the availability of family caregivers coupled with the challenges of the paid workforce will place a significant burden on private financial resources, and stress publicly financed programs.

Conclusion

AHIP thanks the Committee for focusing on the important issue of caring for Americans with Alzheimer's Disease. As our population continues to age rapidly, we must urgently address funding for long-term services and supports and ensuring an adequate caregiver workforce. We look forward to working with the Committee on solutions to ensure efficient and effective care for this population moving forward.

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Statement of Michael G. Bindner

Chairman Toomey and Ranking Member Stabenow, thank you for the opportunity to submit these comments for the record to the Committee on Finance.

Alzheimer's is a very sexy topic. It demands dollars for research and drug development. There is a better way to approach the topic. In her book, *Dementia Reimagined,* Dr. Tia Powell shows that curing Alzheimer's should not be our goal, as current and future treatments are unlikely to produce significant rewards for patients. Managing dementia, which is low tech but not inexpensive, is a better and more

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[20] *https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf.*

[21] *http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf.*

[22] *https://www.americanprogress.org/issues/healthcare/reports/2019/04/10/468290/state-options-making-wise-investments-direct-care-workforce/.*

[23] *https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends.*

[24] "Let's Recognize the Importance of Family Caregivers." AHIP Blog Post. Published: November 11, 2019.

necessary course. We are already spending money to do it and there is value in doing it better. She should be scheduled as a future witness.

Her book is available on Amazon at *https://www.amazon.com/dp/073521090X/ref=cm_sw_r_cp_apa_i_jcAZDbVW4198M.*

She gave a talk on C-SPAN book TV that can be viewed at *https://www.c-span.org/video/?460544-1/dementia-reimagined.*

As I stated in the recent full committee hearing on Drug Misuse, employers who hire their own doctors and pharmacists, whether as part of a cooperative purchase program or as an offset to a single-payer program (whether it is Single Payer Catastrophic or Medicare for All) will provide better treatment for dementia patients at lower cost. Including franchise and 1099 employees in the employee pool would also be advantageous to employees, companies, and society. Please see Attachment One for more on Employee Ownership.

Thank you for the opportunity to address the committee. We are, of course, available for direct testimony or to answer questions by members and staff.

Attachment One

A. Employee Ownership, March 7, 2019

Employee ownership is the ultimate protection for worker wages. Our proposal for expanding it involves diverting an ever-increasing portion of the employer contribution to the Old-Age and Survivors fund to a combination of employer voting stock and an insurance fund holding the stock of all similar companies. At some point, these companies will be run democratically, including CEO pay, and workers will be safe from predatory management practices. Increasing the number of employee-owned firms also decreases the incentive to lower tax rates and bid up asset markets with the proceeds.

Establishing personal retirement accounts holding index funds for Wall Street to play with will not help. Accounts holding voting and preferred stock in the employer and an insurance fund holding the stocks of all such firms will, in time, reduce inequality and provide local constituencies for infrastructure improvements and the funds to carry them out.

ESOP loans and distribution of a portion of the Social Security Trust Fund could also speed the adoption of such accounts. Our Income and Inheritance Surtax (where cash from estates and the sale of estate assets are normal income) would fund reimbursements to the Fund.

At some point, these companies will be run democratically, including CEO pay, and workers will be safe from predatory management practices. This is only possible if the Majority quits using fighting it as a partisan cudgel and embraces it to empower the professional and working classes.

The dignity of ownership is much more than the dignity of work as a cog in a machine.

B. Hearing on the 2016 Social Security Trustees Report

In the January 2003 issue of *Labor and Corporate Governance,* we proposed that Congress should equalize the employer contribution based on average income rather than personal income. It should also increase or eliminate the capon contributions. The higher the income cap is raised, the more likely it is that personal retirement accounts are necessary. A major strength of Social Security is its income redistribution function. We suspect that much of the support for personal accounts is to subvert that function—so any proposal for such accounts must move redistribution to account accumulation by equalizing the employer contribution.

We propose directing personal account investments to employer voting stock, rather than an index funds or any fund managed by outside brokers. There are no Index Fund billionaires (except those who operate them). People become rich by owning and controlling their own companies. Additionally, keeping funds in-house is the cheapest option administratively. I suspect it is even cheaper than the Social Security system—which operates at a much lower administrative cost than any defined contribution plan in existence.

If employer voting stock is used, the Net Business Receipts Tax/Subtraction VAT would fund it. If there are no personal accounts, then the employer contribution would be VAT funded.

Safety is, of course, a concern with personal accounts. Rather than diversifying through investment, however, we propose diversifying through insurance. A portion of the employer stock purchased would be traded to an insurance fund holding shares from all such employers. Additionally, any personal retirement accounts shifted from employee payroll taxes or from payroll taxes from non-corporate employers would go to this fund.

The insurance fund will save as a safeguard against bad management. If a third of shares were held by the insurance fund than dissident employees holding 25.1% of the employee-held shares (16.7% of the total) could combine with the insurance fund held shares to fire management if the insurance fund agreed there was cause to do so. Such a fund would make sure no one loses money should their employer fail and would serve as a sword of Damocles' to keep management in line. This is in contrast to the Cato/PCSSS approach, which would continue the trend of management accountable to no one. The other part of my proposal that does so is representative voting by occupation on corporate boards, with either professional or union personnel providing such representation.

The suggestions made here are much less complicated than the current mix of proposals to change bend points and make OASI more of a needs-based program. If the personal account provisions are adopted, there is no need to address the question of the retirement age. Workers will retire when their dividend income is adequate to meet their retirement income needs, with or even without a separate Social Security program.

No other proposal for personal retirement accounts is appropriate. Personal accounts should not be used to develop a new income stream for investment advisors and stock traders. It should certainly not result in more "trust fund socialism" with management that is accountable to no cause but short-term gain. Such management often ignores the long-term interests of American workers and leaves CEOs both over-paid and unaccountable to anyone but themselves.

If funding comes through a Subtraction VAT, there need not be any income cap on employer contributions, which can be set high enough to fund current retirees and the establishing of personal accounts. Again, these contributions should be credited to employees regardless of their salary level.

Conceivably a firm could reduce their S-VAT liability if they made all former workers and retirees whole with the equity they would have otherwise received if they had started their careers under are formed system. Using Employee Stock Ownership Programs can further accelerate that transition. This would be welcome if ESOPs became more democratic than they are currently, with open auction for management and executive positions and an expansion of cooperative consumption arrangements to meet the needs of the new owners.

STATEMENT SUBMITTED BY MICHELLE COX

I am a CPA who was looking for information on the tax extenders recently passed when I stumbled onto the topic of "Alzheimer's Awareness: Barriers to Diagnosis, Treatment, and Care Coordination" which is a subject very near and dear to my heart as I lost my husband on May 3th of 2019 to a variation on the Alzheimer's spectrum called Frontotemporal Lobe Degeneration. The last 10 years of his life was a nightmare scenario unfolding in slow motion as his bosses started to notice he was not operating at full capacity and took the budget downturn of 2008 as an opportunity to put his position up for deletion in a request for budget cuts. He was a Botanist who worked for the City of San Antonio at the Botanical Garden for 32 years after he had been recruited straight out of college and was a very well-respected source of plant knowledge for the region. He was sought out to identify unknown plants regularly and won every contest for plant and weed identification that he ever entered. In lieu of being transferred out he took early retirement to be a full-time dad to our four kids and he kept working leading tours and giving talks but it was getting harder for him to remember the plant names and he was getting lost driving the kids to routine places like school. At that point he was going to the doctor by himself but he was kind of a problem patient because he missed appointments and didn't take prescriptions regularly so he kept getting moved around among doctors and clinics. One doctor declared he had diabetes at his first visit, another said he had high blood pressure, another put him on medication for thyroid issues and soon he was taking a multitude of various pills where he had previously been healthy. I started to suspect it was all of the prescriptions causing his dementia-type issues so we decided to switch him to a doctor of a family friend whom the friend assured us would not over-medicate him and I started going to the appointments with him. I quickly came to realize why all of other doctor's offices ran him off because he had big problems with being on time, filling out paperwork, going to the bathroom when the doctor was ready to see him, making sexually inappropriate comments to the nursing staff and doctors, etc. This doctor agreed to run her own tests and adjust his medicine deciding he did not have diabetes but basically keeping him on everything else and wanted to add in an anti-depressant which he refused to take because he had known several friends who either killed themselves or had suicidal thoughts while on the drugs. I mentioned to her about his dementia-type issues and she said depression would cause all of those issues and that needed to be ruled out first by taking the drugs. He continued to refuse until things got so bad that he finally agreed to give it a try and they did stabilize his moods but the confusion was getting much worse. She said the dose was too low to fix that and doubled it and sent us back home again for months to see if the new level would help. When we went back and I reported no improvement she finally agreed to order neurological testing and gave us the permission slip to see the neurologist that we needed for the insurance company. It took many months to get the referral to the neurologist with a preliminary appointment where he then referred my husband to a neuro-psychologist, blood testing and an MRI. He was receiving his pension of 3k per month and I was working as much as I could part-time for my father's CPA firm but it took us a while to save up the $800 co-pay for the MRI test so that caused another delay. After many months of getting the referrals and tests performed and results back to the Neurologist he basically said "get your paperwork in order" and asked if we had all of the Power of Attorneys, etc. in place and sent us away saying he would send the full report to the primary care doctor who would brief us. When we went in (months later) she said she hadn't received the report just to keep on with the status quo and come back in 3 months which we did and she still didn't have the Neurologist report but seemed completely unfazed by it and assured us she would have it when we came back in 3 more months.

At this point things were getting seriously bad like I would ask him to bring me a fork and he would pick up a box of Kleenex. I started talking to my clients whom I knew were dealing with similar issues and got a referral to a gerontologist at the UT Health System which was like a dream come true for me. I had started attending a support group for FTD and when I asked for doctor referrals I could never get one because San Antonio is a big military city and all of the others seemed to be patients at the VA. I was envious of them because the VA seemed to take care of everything where I was on my own trying to go to different places for tests and getting the results back to the doctors then trying to get them to follow up with anything. The UT Health System has a multi-story building called the Medical Arts and Research Center that houses all of the testing my husband ever needed once he started being seen over there and the doctor immediately had the results and followed up with us. The doctors were never in a hurry and even started making home visits when it became too difficult for me to transport my husband which is not something that I think anyone is aware of unless they live through the experience. In all of the support groups I went to the spouses really bear the burden of care and it is 24 hours a day, 7 days a week mentally, physically and emotionally challenging that I can go into details about but you have probably already heard those stories. What I would like to share is how much I needed help with his care that I was unable to get with him having a Medicare advantage plan and I don't understand if I was not given proper directions or if it was really true (my husband was 67 when he died).

My husband had colitis all of his adult life that he managed between diarrhea and constipation with a careful collection of prescription and over the counter medications that only he could navigate. In the end it was his colitis coming out of remission in September of 2018 with 8 months of non-stop diarrhea that cost him his life. When his colitis first came back and he lost 20 lbs. over a series of weeks we took him to the hospital and they admitted him and they were tracking his bowel movements at 23 times in 24 hours. He was a wanderer with poor cognitive skills at this point and they couldn't get enough medication in him to keep him in bed so they got the insurance company to agree to a 24 hour assistant to sit with him day and night for the 5 days he was there. They also decided it was too harsh on the skin of his bottom to keep up with the diarrhea so they put a tube into him while the skin healed. At the end of the 5 days (which is when I believe the medicare benefits must have expired) they told me he was a hopeless case and we needed to move him to hospice. I didn't understand but the long and short of it was that I had to take him home or take the transfer to their hospice facility which I agreed to do and invoked hospice paperwork. When we got to the hospice facility and he sat up and started walking around the nurses quickly told us we would have to keep someone with him 24/7 because they weren't staffed for that and he couldn't be walking around as most people in the facility were days or hours from death and he couldn't be disturbing them. I agreed and we revoked the hospice paperwork and they put him into an ambulance and sent him to University Hospital where they left us mostly unattended in the ER for 13 hours then told me at 3 am that his condition was untreatable and they were releasing him to me. While we were at the ER the tube came out and they cleaned him up and informed me that it wasn't safe to keep one in any longer, we would just need to use diaper ointment and change him regularly. So here I was at 3 am being released with my husband who had previously needed 24/7 assistant and a rectal tube at a hospital who said he was terminally ill and ready for hospice then suddenly he has "no treatable conditions" and I was all alone taking him back to our house. I called his wonderful doctor the next day in great distress who did come to see Paul and offered me some different prescriptions to try to control the diarrhea and told me there was no prescription benefit for the adult diapers. I was soon spending upwards of $50 per week on diapers and paying $12 per hour for nursing assistants on a private basis because I had some help from friends and family members with watching him prior to the colitis problems but everyone drew the line there. When tax season started I had to juggle what I could afford to pay for the CNA and try to work from home which was actually a bit easier at this point because he had gotten so weak and slept most of the time. I don't understand why there are/were no benefits with his Aetna Advantage Medicare plan to help me with caring for someone who clearly was not able to take care of himself and had no control over his body functions. He always had a great appetite and ate continuously which kept him alive for the 8 months. I had a client who is college aged son was injured in a motor cycle accident and he lost his vision. He never had a job or paid benefits into any system yet he was accepted onto Medicaid and she was able to quit her job and get paid to take care of him since he can't take care of himself. How and why was my husband who worked from age 15 to 56 and paid into the system all of those years not qualified for help when he couldn't take care of himself and I had to pay out of pocket for help so I could leave the house to work and raise a family? Why aren't adult diapers covered by insurance? How can incontinence caused by a brain that isn't working correctly not be a medical issue whereas a bandage to cover a wound is? Is this really correct or did I get bad information from the doctors and insurance company because I wouldn't begin to know where I was supposed to look to research this for myself especially not at that time when I had so much on my plate. There seems to be a lot of resistance with the insurance companies to accept that a brain that used to work perfectly and now doesn't work causing an individual to require assistance to stay alive is a medical necessity. At a minimum I should have been given 40 hours per week of paid assistance to allow me to work—how can a person just stop working to take care of a terminally ill family member for free? I am a CPA and I can tell you the numbers don't work—you will lose everything if you don't keep generating enough income to pay your bills.

I read an article this morning about a disabled college student who has a paid assistant through Medicare in her state and she was informed that if she took a $14 per hour internship her income would be too high to continue to qualify for these benefits but obviously not high enough to pay the expenses on her own. This is all wrong and having a disability or having a family member with a disability should not mean financial devastation. I hope that you will do something to help the others who are just starting down the path that I just got off of the hard way. I loved my husband dearly and did the best I could to take care of him but we really could have used a lot more help. I almost feel like I should have been assigned a social worker or given a packet of information when he got the diagnosis because living with someone who has Alzheimer's is a full time job in addition to what you already had on your plate before the diagnosis so caregivers really need to have all available resources made readily available to them as it overwhelming to try to figure it out on the fly, trust me I know.

What I think could have happened better:

1. I wish I could have bypassed the whole primary care physician system and taken my husband straight to an Alzheimer's Center for Testing as soon as I knew something was wrong—spouses know these things.
2. I wish I had been handed a packet of information and a social worker type contact to help me on a daily basis get through what I had ahead of me and help to understand insurance and benefits and respite care and my own care. I

saved the government tens of thousands of dollars by keeping my husband at home and taking care of the majority of his care or paying for what I couldn't do—I should have had some help. I know the information is out there but expecting me to find it on my own was too much.

3. I wish there was something in between taking the burden on yourself or turning your loved one over to an institution. I went to many support groups and the hardest part seemed to be deciding when you were just before your breaking point with keeping him/her at home and finding a facility to take over. Why can't there be more help with keeping the Alzheimer's patient at home where we are all more comfortable and able to spend time together and certainly more cost effective than institutional settings which range from 5k per month to 12k per month for memory care in San Antonio.
4. I wish the cost of the MRI had not been so financially prohibitive all at once. We hadn't met our deductible so I had that entire $800 cost all at once and the testing centers don't send you a bill that you might not pay—they didn't even take him back until I had paid with a credit card. Families of a person living with a neurological disorder don't have big savings accounts I can assure you.
5. I wish there was more help for the working-class in dealing with this situation. We have 4 years left on our mortgage with lots of equity in our home and a pension that disqualified us from any Medicaid type benefit. I was told that everything I needed help with wasn't covered by his Medicare Advantage plan, only "Medical" issues like testing and prescription drugs were covered which is meaning less when there are no medications or treatments or cures why test or seek medical interventions. How is it not a "Medical" issue when someone goes from having a fully-functioning brain and body to one that doesn't work well enough to know how to take care of himself? If I hadn't been there to cook for him and remind him to eat and buy food to bring into the house and he starved to death what would the cause of death had been? Does this happen? What happens to single people who develop Alzheimer's and don't qualify for Medicaid or have enough income to pay ongoing bills and hire assistance? I am in that group now so I hope that this issue will be addressed.

GENWORTH FINANCIAL

INTRODUCTION

For forty-five (45) years, Genworth has played a significant role in addressing the long term care (LTC) needs of Americans by providing insurance protection to more than two million (2M) people. Decades of experience in the LTC insurance market has given the company unique insights into the challenges the country faces in providing LTC services to the aging population.

The need for long term care is growing in the United States, driven primarily by cognitive disorders. These impairments—including Alzheimer's disease and other forms of dementia—account for fifty-one percent (51%) of Genworth's claim dollars and thirty-five percent (35%) of the company's total claims.

Meanwhile, our current public financing system is confronting a significant challenge as our society faces a tsunami of future long term care needs. Millions of families are stretched thin as retirees exhaust their savings rapidly, only to become destitute and reliant on state Medicaid programs, which already are over-burdened.

Genworth appreciates the work of the Senate Committee on Finance and specifically the Health Care Subcommittee's heightened focus on Alzheimer's disease and other long term care issues. We also applaud Senator Stabenow for her "Improving HOPE for Alzheimer's Act," and Senator Toomey for developing a new proposal that will empower Americans with options to use some of their employer-based retirement savings in a tax-advantaged way to plan for potential long term care events through the purchase of private long term care insurance. Incentives like this will help make financial planning more feasible by expanding access to products and services to allow individuals to achieve that goal.

We offer the Committee the following comments and information about Genworth's experience in the long term care arena for your consideration. We hope this information serves as a helpful resource. Should you have any questions or request additional information, please contact Lynn White, Senior Vice President and Chief of Staff at Lynn.White@genworth.com.

About Genworth Financial

Genworth is a leading insurance holding company committed to helping families become more financially secure, self-reliant, and prepared for the future. The company holds leadership positions in mortgage insurance and long term care insurance. Headquartered in Richmond, Virginia, Genworth traces its roots back to 1871 and became a public company in 2004.

Genworth has been in the long term care insurance market since its inception in 1974—forty-five (45) years. The Company has played a significant role in addressing the long term care needs of Americans by providing insurance protection to more than two million (2M) people.

Genworth has the most extensive experience in the long term care insurance industry, with nearly two hundred eighty thousand (280,000) claims processed and more than eighteen billion dollars ($188) in benefits paid to date. Each day, Genworth pays more than seven million dollars ($7M) in claims to cover the cost of care for its policyholders.

Aging in America, Alzheimer's Disease and the Demand for Long Term Care

Understanding the Need

The need for long term care services is compelling and growing. Despite the fact that the number of Americans who will require long term care services is expected to increase significantly, and seventy percent (70%) of people turning sixty-five (65) can expect to require long term care in their lifetime,[1] most have not planned for potential long term care financing needs. Meanwhile, according to consumer research commissioned by Genworth, two-thirds (66%) of Americans incorrectly believe that Medicaid or Medicare will cover all or part of their long term care needs.[2] Unfortunately, most Americans do not fully appreciate the grave financial risks they face from a long term care event, and how these considerable costs can deplete their retirement savings. With more than ten thousand (10,000) Baby Boomers turning sixty-five (65) every day, preparing for a long term care event is a critical part of retirement planning.[3]

Rising Cost of Care

Additionally, the cost of long term care services has increased steadily over the last several decades. According to the most recent Genworth Cost of Care survey, the 2019 national average annual cost for long term care in a private nursing home room is over one hundred two thousand dollars ($102,000)—and has increased by more than three percent (3%) per year over the past five (5) years.[4]

The Drivers of Long Term Care

As the largest long term care insurance provider in the country, Genworth has the most extensive claims database in the industry with nearly two hundred and eighty thousand (280K) claims processed and more than eighteen billion dollars ($188) in benefits paid through December 2018. On average, the company pays over seven million dollars ($7M) in benefits each business day. This extensive claims-paying experience has given us a deep understanding of both market and benefit utilization trends—what causes people to claim, where they claim, claim costs, and much more.

Alzheimer's Disease and Its Impact on Long Term Care

Dementia, Alzheimer's, and other cognitive conditions account for **thirty-five percent (35%)** of Genworth's opened claims and **fifty-one percent (51%) of all benefit dollars paid** by the company (primarily driven by claim duration). Yet, the impact of Alzheimer's disease, along with other forms of dementia and cognitive conditions, is not exclusive to Genworth policyholders. With more than five and a half million (5.5M) Americans age 65 and older living with Alzheimer's today, this single disease creates more demand for long term care services than any other ailment by a large margin.[5] Consider also that women, for whom Genworth has made the majority of benefit payments, make up almost two-thirds (nearly 63%) of the people in

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[1] Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, "Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief," July 2015.

[2] LTC Consumer Sentiment Study, J&K Solutions, September 2017 (commissioned by Genworth).

[3] U.S. Census Bureau, "An Aging Nation: The Older Population in the United States," May 2014.

[4] Genworth 2019 Cost of Care survey.

[5] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."

the United States with Alzheimer's[6] and account for approximately two-thirds of the unpaid caregivers for people with the disease as well.[7]

It is estimated that more than sixteen million (16M) Americans provide unpaid caregiving for those afflicted with Alzheimer's disease or other dementia.[8] Payments for care are estimated to be two hundred and ninety billion ($290B) in 2019, including one hundred and ninety-five billion ($195B) in costs incurred by Medicare and Medicaid.[9] By 2050, the total cost of Alzheimer's and other dementias is expected to exceed one trillion dollars ($1T) annually.[10] Although the National Institutes of Health (NIH) projects that it will spend slightly more than two billion dollars ($2B) in 2019 on Alzheimer's research,[11] that amount is a fraction of the disease's financial impact and less than half of the amount allocated to the search for cancer cures this year ($5.74B).[12]

Investments in Alzheimer's research have led to treatments that may help delay the onset of symptoms and have helped to reduce the need for care. Further reducing the incidence of Alzheimer's and dementia, by either delaying the onset of symptoms or preventing them altogether, would have a profound impact on the nation's long term care challenges. Therefore, Genworth supports additional funding allocated by Congress for Alzheimer's research, which can ultimately lead to more meaningful advances in the treatment of these devastating diseases.

The Cost of Long Term Care

Unfortunately, as the number of Americans who need long term care has increased, so has the cost of the services they require. Since 2004, Genworth has published an annual Cost of Care survey to track and catalogue the costs of care received in homes, adult day care centers, assisted living facilities, and nursing homes. The Genworth Cost of Care survey is the most comprehensive of its kind, covering four hundred forty-one (441) regions across the United States. The results are derived from data collected from more than fifteen thousand (15,000) survey responses submitted by nursing homes, assisted living facilities, adult day health facilities, and home health providers.

Like the surveys before it, the 2019 Cost of Care results indicate that expenses for care, no matter where received, continue to rise. Nationwide median annual costs of care for 2019 are provided below:

- Homemaker Services—$51,480 (an increase of 7.14% from the previous year)
- Home Health Aide—$52,624 (an increase of 4.55% from the previous year)
- Assisted Living Facility—$48,612 (an increase of 1.28% from the previous year)
- Nursing Home, Private Room—$102,200 (an increase of 1.82% from the previous year)

The full interactive survey includes access to cost information by individual states and metropolitan area.[13]

To put these numbers in perspective, the estimated median household income for the United States was $61,937 in 2018, less than a one percent (1%) increase from 2017.[14] The current federal statutory minimum wage is seven dollars and twenty-five cents ($7.25) per hour—which has held steady for the last ten (10) years.[15] In short, while income has remained relatively stable, the cost of long-term care has increased, as has the number of individuals needing care.

The story of the impact of long term care on the U.S. economy does not end there. Often, as a result of these growing costs, family members voluntarily reduce their compensated time at work or leave the workforce altogether. According to a 2015 study by AARP, approximately forty million ($40M) Americans serve as unpaid fam-

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[6] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."
[7] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."
[8] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."
[9] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."
[10] Alzheimer's Association, "2019 Alzheimer's Facts and Figures."
[11] Alzheimer's Association, "Fiscal Year 2020 Alzheimer's Research Funding."
[12] National Cancer Institute, "Plans for NCI's Fiscal Year 2019 Budget."
[13] Genworth Financial, "Cost of Care 2019."
[14] U.S. Census, "Household Income: 2018."
[15] U.S. Department of Labor, "Minimum Wage."

ily caregivers, with the economic value of this care estimated at four hundred seventy billion dollars ($470B).[16]

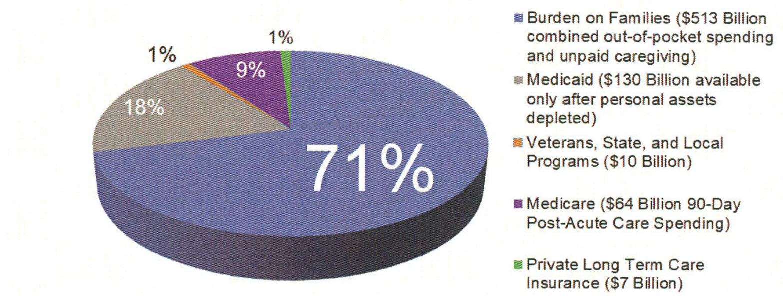
Beyond Dollars—The Toll of Long Term Care on Families and Caregivers

While the financial impact on caregivers often is significant, the emotional impact should not be underestimated or overlooked. Genworth conducts a regular comprehensive research study, Beyond Dollars, to understand the experiences and perspectives beyond those of the care recipient.[17] The 2018 study surveyed more than twelve hundred (1,200) people with personal involvement in a long term care event lasting more than thirty (30) days—as caregivers, as care recipients, or as family members of someone experiencing a long term care event.

The 2018 Beyond Dollars survey provided insights into the many ways that family caregivers are impacted by a care event.[18] Among the findings, half (50%) of respondents reported having less time for their spouse/partner, children, and themselves, and forty-six percent (46%) reported that the long term care event negatively affected their own health and well-being. Caregivers estimated spending ten thousand four hundred dollars ($10,400) of their own funds on out-of-pocket expenses in support of a care recipient. Additionally, half (50%) reported negative effects on their careers, and of those, sixty-two percent (62%) believed they lost income as a result of caregiving, with thirty percent (30%) reporting missed career opportunities. Notably, fifty-two percent (52%) of caregivers said they did not feel qualified to provide physical care.

Paying for Long Term Care

Unlike acute health care, long term services and supports ("LTSS") are almost never covered by health insurance policies, HMO plans, or Medicare supplemental insurance. Medicare only covers limited acute care for ninety (90) days, although those who have a Medicare Advantage plan may have access to select long term services and supports if provided by their particular plan. Most financing of long term care is provided by families who often pay out of pocket, followed by the default public payer—state Medicaid programs (which are intended to be the public safety net for lower income individuals). The chart below illustrates the distribution of LTSS costs among common payors.[19]



Without advanced planning, ailing seniors can very quickly drain their personal and their family's financial resources as long term care costs continue to rise. These costs often increase the financial burden on the younger generation providing long-term care—which ultimately could threaten their own financial security. Consider, in 2016, among households headed by someone age 65 to 74, median net worth was just above two hundred twenty-four thousand dollars ($224K), according to Federal Reserve data—a six percent (6%) decrease from 2013.[20] However, if home equity is excluded, the median senior-citizen household has a much smaller net worth (although long term care expenses often are covered by the sale of a home).[21]

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[16] AARP, "Valuing the Invaluable: 2015 Update."

[17] Genworth Financial, "Beyond Dollars 2018."

[18] Genworth Financial, "Beyond Dollars 2018."

[19] The SCAN Foundation, "The State of Long-Term Care Financing—Long-Term Care Spending in the United States," March 17, 2014.

[20] Federal Reserve, "Changes in U.S. Family Finances from 2013 to 2016."

[21] "Retiree Net Work Declines," *U.S. News and World Report,* July 2013.

Education and Planning

Before reaching retirement age, it is critical that all Americans become better informed about the realities surrounding the incidence and cost of long term care events and plan for possible future needs. As previously noted, seventy percent (70%) of Americans turning sixty-five (65) will require some form of long term care in their lifetime—yet most Americans have not planned for this need.[22]

In the past, the Department of Health and Human Services launched the "Own Your Future" campaign in an effort to increase awareness among the American public about the importance of planning for future long term care needs. Operational from 2005 to 2012, twenty-four (24) states and the District of Columbia participated in the initiative's core activities. The campaign was supported by the governor of each participating state and utilized direct mail to target households with family members between the ages of forty-five (45) and seventy (70).[23]

The campaign still is active in some states, including Minnesota and has been viewed as largely successful, having educated Americans about the need to plan.[24] However, it no longer is operational in other states, leaving an ever-increasing knowledge gap among the middle class. State awareness campaigns did effectively drive both interest in and the purchase of long term care insurance and enabled individuals to take responsibility for their long term care needs.

Additionally, in 2005, the National Long Term Care Clearing House was created. The Clearing House website, which is still operational today, was developed by the U.S. Department of Health and Human Services to provide information and resources to help individuals and families plan for long term care needs.[25]

The Role of the Private Market: Long Term Care Insurance

A comprehensive, national long term care solution must include private long term care insurance coverage. Given current state and federal government challenges to pay for entitlements as Americans age, the public sector simply cannot afford to cover all long term care costs.

While the costs of LTC policies vary, the average annual premium for a long term care policy is roughly $2,700.[26] As the Cost of Care survey indicates, the annual cost of a nursing home potentially could be *nearly thirty-eight (38) times that amount,* and often self-funded savings are not sufficient to cover this expense.[27]

Approximately seven million (7M) Americans—only eight percent (8%) of the population—have a long term care insurance policy.[28] The private insurance market can and should play an even more significant role going forward. However, to do so, change is required. Given appropriate changes in the regulatory and legislative environments, the LTC insurance industry can work with the public sector to expand access to private long term care insurance and identify ways to make it more affordable for Americans.

There is no doubt that private long term care insurance helps to shoulder a huge financial burden for policyholders, their network of caregivers, and reduces some exposure to which state Medicaid programs are subject. Medicaid is the payer of last resort but has become, by default, the nation's largest payer.

Long term care insurance policies offer tremendous value to policyholders. Genworth's policyholders generally have access to LTC benefits that are many multiples of the premiums they have paid, and will pay, in the future. With the cost of a private nursing home room now averaging approximately two hundred eighty dollars ($280) per day across America,[29] it is fair to say the cost of care almost always will greatly outweigh the cost of insurance many times over.

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[22] Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, "Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief," July 2015.

[23] The SCAN Foundation, "The Own Your Future Long-Term Care Awareness Campaign: Implications for CLASS."

[24] Minnesota Department of Human Services, "Own Your Future."

[25] National Long Term Care Clearing House website.

[26] AARP, "5 Things You SHOULD Know About Long-Term Care Insurance," March 1, 2018.

[27] Genworth 2019 Cost of Care Survey.

[28] National Association of Insurance Commissioners and Center for Insurance Policy and Research, "The State of Long Term Care Insurance: The Market. Challenges and Future Innovations," May 2016.

[29] Genworth Financial, "Cost of Care 2019."

For private long term care insurance to play a more meaningful role in the system, we recognize the need for greater market penetration. Put simply, we believe more workers should consider and ultimately purchase LTC insurance in the context of their retirement planning. Through a combination of (1) changes to the regulatory framework which are currently being advanced at the state level, (2) new products designed to be both more accessible and affordable (therefore more appealing to the middle income market), and (3) tax incentives, such as those included in Senator Toomey's new proposal, the private market can grow- both in terms of the number of policyholders and the number of carriers designing and offering products.

The Path Forward—Public Policy Considerations

America needs to pursue a more rigorous public policy platform to address long term care needs. Looking beyond the financing imperative, the multi-dimensional challenges of caregiving, healthy aging, chronic disease impact, and retirement security planning all must be addressed as part of comprehensive long term care reform. This is a discussion the nation and its policymakers need to have, and we appreciate the attention being afforded to this important issue by the Senate Finance Committee's Health Care Subcommittee.

Public policy that promotes responsible retirement savings, including access to meaningful private long-term care insurance options, especially for the middle class, will encourage accountability, appropriate planning, and informed decision-making, while addressing potential long-term care needs.

We believe several changes to public policy are required, including:

- Adequate funding of research for Alzheimer's and other chronic diseases, which make up the majority of long term care expenses;
- Increasing public education and awareness of the need to prepare for long term care costs as part of a comprehensive retirement security plan;
- Making retirement savings and long term care protection an *objective* of future tax reform;
- Building and maintaining an adequate, skilled, and diverse workforce to provide care for the growing population of older Americans and people with disabilities;
- Advancing programs that increase awareness of and support for caregiving—paid and unpaid; and
- Expanding support for family caregivers, including funding initiatives to provide training and other information about available services such as respite care.

Importance of Long Term Care as an Integral Part of Retirement Planning

As we previously have suggested, the greatest unmet retirement income security threat for most Americans is the potential cost of long-term care. For married Baby Boomers, average long term care costs represent over eighty percent (80%) of a typical couple's total retirement savings shortfall.[30] Without insurance to cover those long term care costs, retirement savings can easily be depleted within a very short period, often leaving the chronically-ill individual (and later, the surviving spouse) with little or no retirement income. As a result, any plan to deal with unmet long term care financing needs should include changes that make long term care costs and insurance a vital part of the retirement security conversation.

Today, many working Americans have most, if not all, of their retirement nest eggs in IRAs, 401(k) plans, or other qualified retirement savings plans. However, the current tax treatment of distributions from those retirement plans imposes unnecessary and inappropriate impediments on the use of those savings to protect against long term care risks in retirement. In effect, the current tax treatment traps financial resources in the retirement plan when it could be in the individual's best interest to use some of those funds to protect themselves and their families.

Individuals who need to use retirement plan savings to cover long term care insurance premiums will be taxed immediately, at ordinary income tax rates, on the amount withdrawn from the plan. In some cases, where an individual is still working, access to savings in certain types of qualified retirement plans is prohibited entirely by what is commonly known as "in-service distribution restrictions" of existing law. Even where retirement plan assets are available for distribution, a ten percent

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[30] For married Baby Boomers, the average LTC costs represent over 80 percent of an average couple's total retirement savings shortfall (EBRI, February 2015).

(10%) excise tax (on top of the ordinary income tax) will apply if the distribution is made before age fifty-nine and a half (59½).

Senator Toomey's proposal addresses some of these concerns. Genworth strongly supports his efforts in this regard and commends the Senator for all that he has done on this critical issue. It is imperative that the retirement plan rules are amended to unlock retirement savings and permit Americans to protect themselves and their families against potentially catastrophic long term costs in the future.

Tax-free distributions from qualified defined contribution retirement plans, 403(b) arrangements, and IRAs can fill the long term care gap that currently exists for many middle class Americans in their planning for retirement security. Moreover, a change to tax rules could expand employer engagement, through their human resources functions, in educating workers on these issues.

Unlocking retirement plan assets could be especially beneficial for the millions of working Americans who have made sacrifices to save for retirement. Many of those individuals and couples are now experiencing (and are often sharing) the LTC financing and caregiving burdens of their parents, but they also have already tied up most of their savings in their homes and their retirement plans. Removing the barriers to retirement plan distributions may be the most realistic way for them to protect themselves (and their children) from the financial devastation that unforeseen long term care expenses can cause.

We urge the members of this Subcommittee to continue work on this critical issue for all Americans.

Conclusion

The need is clear. While the challenge is complex, the realities of the future require thoughtful deliberation and meaningful action. Genworth believes that there are effective public policy solutions to address the long term care financing challenge, and that the private market is an integral component of a comprehensive, national response. We welcome the opportunity to participate in the discussion.

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Chairman Toomey and Ranking Member Stabenow, LeadingAge appreciates the opportunity to submit this statement for the hearing record. Our members have a long history of service to older people and we greatly appreciate the committee's focus on the impact of Alzheimer's on caregiving and the concomitant need for an adequate financing model for long term services and supports (LTSS). We think it is highly significant that this committee, and the House Ways and Means Committee have elevated the issue of LTSS and its impact on caregiving and as we stated to the House Committee, we reiterate here—we would be pleased to work with the committee to address the issues raised.

We represent more than 5,000 aging-focused organizations that touch millions of lives every day. Alongside our members and 38 state partners, we address critical issues by blending applied research, advocacy, education, and community-building. We bring together the most inventive minds in our field to support older adults as they age wherever they call home. We make America a better place to grow old.

All LeadingAge members are not-for-profit. About 75% of our members had their origins in faith-based communities; others were established by fraternal or cultural organizations. Some have served their communities for over 100 years. Our members work every day with persons affected by Alzheimer's—patients, their family, professional caregivers

The Issues:

People come to need a wide variety of services as they age. We appreciated the range of issues committee members and witnesses addressed at the November 20th hearing. As witnesses testified, determining causation of Alzheimer's and related dementias has been frustratingly elusive. More promising has been the development of diagnosis, care and treatment modalities, as the testimony from Jason Karlawish and Janet Tomcavage indicated.

Regardless of geography or provider type, LeadingAge members are striving to improve the lived experience of individuals with dementia, and their care partners. People with dementia live in every setting throughout the constellation of housing, services and supports. While the current numbers are staggering, as a provider organization we strive to be guided by the expertise of the lived experience of the people we serve and focus on helping people live well with dementia. We are part of the advocates and providers across the country who are exploring critical questions about serving people with dementia. Should we segregate people based on a diagnosis? What is meaningful engagement (vs. entertainment) for people with dementia? How can people with dementia be involved in decision-making and planning? How do we build actual and metaphorical ramps so people living with dementia can continue to thrive long after diagnosis? How we respond to these questions will help drive both professional and unpaid caregiving for the foreseeable future.

As Chairman Grassley stated for the record, the consequences of caring for persons with Alzheimer's falls hardest on unpaid caregivers. "According to the Alzheimer's Association, more than 16 million Americans are providing unpaid care for people with dementia, such as Alzheimer's disease, amounting to 18.5 billion hours annually. The brunt of this work is done by family members." *https://www.finance.senate.gov/chairmans-news/grassley-on-alzheimers-awareness-barriers-to-diagnosis-treatment-and-care-coordination.*

The consequences of this model will last for generations, as was noted by the caregiver witness at the hearing on Caring for Aging Americans held by the House Ways and Means Committee on November 14th. Said Kristina Brown, describing the impact of caring for her mother on herself and her sister, 'Caregiving fuels generational poverty, disproportionately affecting millennials and women who take on that role in their families." *https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/Kristina%20Brown_Testimony.pdf.*

Family caregivers work out of love, and often out of necessity, but the lack of systemic social and economic supports has significant negative economic and social outcomes that are just not fair and certainly not necessary.

This hearing addressed legislation that can alleviate some of the most serious weaknesses in our care system. The Improving HOPE for Alzheimer's Act, S. 880, improves comprehensive care planning, and The CHOICE Act, S. 1126, supports utilizing evidence-based tools to detect cognitive impairment and provide appropriate referrals. In addition, potential legislation to encourage purchasing private long-term care insurance was discussed, reflecting the lack of adequate personal financial resources available to pay for needed services.

We strongly support efforts to improve care coordination and services, but with this statement wish to stress the critical importance of addressing public and private long-term care financing.

Recognizing the inadequacy of the current patchwork of long-term services and supports financing, heavily dependent as it is on Medicaid and unpaid informal caregiving, LeadingAge began working in 2004 to develop proposals for a better system.

By 2030 more than one in five Americans will be over the age of 65, with a 50% possibility of needing paid long-term services and supports before they die and few options to pay for it through either public programs or private savings. And we cannot forget that the need for LTSS is not limited to older persons; research indicates that approximately 40% of persons with LTSS needs are under 65. Favreau It and Johns on, Microsimulation Analysis of Financing Options for Long Term Services and Supports, (Urban Institute, November 2015, page 4). *https://www.thescanfoundation.org/media/2019/10/nov_20_revised_final_microsimulation_analysis_of_ltss_report.pdf.*

As Dr. Cohen noted in his testimony before this committee, the need for long term services and supports is a risk that is appropriate for insurance to cover. LeadingAge recommends a dignity driven and universal long-term services and supports insurance program grounded in the principles of shared risk and consumer flexibility. We are encouraged that witnesses addressed the importance of a public insurance program at this hearing and at the November 14 Ways and Means Committee hearing, "Caring for Aging Americans."

For persons with Alzheimer's or other conditions that lead to functional limitations, a public insurance-based financing system can provide independence, choice and autonomy now missing, when the only alternatives are impoverishment (either to pay for services or to qualify for Medicaid) or dependence on others. These values are quintessentially American.

For unpaid caregivers, financing alternatives can alleviate the economic and social consequences described in the testimony of Kristina Brown at the Ways and Means Committee hearing cited above. While both Senate and House hearings are targeted at aging Americans, it is instructive to recall that the need for LTSS is not limited to persons over 65, and younger persons like Ms. Brown's mother can have disabling conditions that affect them for decades as well.

Challenges:

We strongly believe that Congress must take up the challenge of developing a public program. Much work has already been done to identify potential models and address critical questions like cost. Final reports from the Bipartisan Policy Center, LeadingAge Pathways, and Convergence were issued in 2015 and are still relevant. *https://www.thescanfoundation.org/publications/side-by-side-review-of-long-term-care-financing-policy-recommendations/.*

What that public program should look like, how it should be paid for, and who it should cover are critical questions that must be grappled with if we are to provide the services needed by persons with Alzheimer's and other chronic disabilities, support in formal, unpaid caregivers and ensure the economic viability of the paid workforce.

States are also recognizing that they can play a role in developing publicly financed long-term care insurance, as states are deeply affected by the fact that the Medicaid program pays for well over 50% of all LTSS costs. We were pleased to hear comments at the hearing on Washington State's new long-term care financing program, which will finance a capped amount of long-term services and supports with a dedicated payroll tax. States can serve as a laboratory to develop insurance and care models supported by taxpayers and determine pain-points for payment by their citizens.

The second challenge is what should be the role for private long-term care insurance? As has been well documented, private, voluntary long-term care insurance has not proved feasible for financing LTSS. Dr. Cohen's testimony points to many of the reasons private insurance simply has not and cannot work under our current system. We strongly support his conclusion that we need a public insurance program as the predicate model, with private insurance serving in effect as a wrap around for non-covered services, analogous to the role that Medi-gap policies play in the Medicare program. The public program makes private program feasible and allows the private market to develop new products that might be more attractive and certainly less expensive. We would just note however, that accessibility must also be addressed, specifically, the exclusion of persons with pre-existing conditions from coverage and/or the prohibitive policy costs. These negative characteristics of private long-term care insurance must at some point be addressed directly if private insurance is to provide effective coverage.

Conclusion:

We firmly believe that the nation' s current methods for financing long-term services and supports are unsustainable, irrational, and unfair for individuals and families. We commend all of those addressing this critical issue and we will continue to work with them to frame and support workable solutions.

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Statement of George Vradenburg, Chairman and Co-Founder

Chairman Toomey, Ranking Member Stabenow, and other Members of the Subcommittee,

Thank you for holding this hearing today on "Alzheimer's Awareness: Barriers to Diagnosis, Treatment, and Care Coordination." This topic is immensely important to the work of UsAgainstAlzheimer's, a disruptive non-profit organization that is laser-focused on accelerating our nation towards a cure for Alzheimer's and dementia.

Alzheimer's disease and dementia constitute the top public health crisis of our time, according to four former U.S. surgeons general who made this point in an editorial last month. Currently, about 5.8 million Americans are living with this disease—5.6 million of whom are over the age of 65—at a 2019 cost to our healthcare system of $290 billion. It is the only top-10 cause of death in America without an effective treatment or cure.

Age remains the No. 1 risk factor for this disease, and neither the disease pathology nor the demographics are in our favor. The rate of incidence for Alzheimer's doubles every five years after age 65, and we know that between 2010 and 2030, the number of Americans age 65 and older is expected to grow 81 percent. By comparison, the growth rate is 16 percent for the next fastest-growing demographic, 35–44, over the same time period.

This disease disproportionately affects women and people of color. Two-thirds of Americans living with Alzheimer's are women, and 60 percent of those caring for someone with the disease are women. Further, research from UsAgainstAlzheimer's, Johns Hopkins, and the USC Edward R. Roybal Institute on Aging projects that by 2030, nearly 40 percent of Americans living with Alzheimer's will be Latino or African American. This is an urgent health equity issue.

These trends are only going to continue, and our nation is fast approaching a tipping point from which it will have immense difficulty recovering.

This disease is expensive, disproportionately hurts women and minorities, and is growing as our population ages. Those are all at the population level. As patient advocates, we know that it is devastating for each individual person living with the disease and for their families.

One of the reasons dementia is so devastating is that it is often diagnosed when it is too late. Studies tell us that doctors miss the diagnosis about half of the time until patients have serious symptoms. We would not accept a system that only diagnoses cancer at Stage 4, but that is more or less where we are with Alzheimer's and related dementias.

Further, we know that communities of color face acute challenges with accessing an accurate and timely diagnosis. African Americans are three times more likely to develop Alzheimer's than non-Hispanic whites, and Latinos are one and a half times more likely to develop Alzheimer's than non-Hispanic whites. Despite this higher risk, African Americans and Latinos living with dementia are, on average, less likely than non-Hispanic whites to have actually been given a diagnosis by a provider.

Senators Shelley Moore Capito and Debbie Stabenow, along with Senators Bob Menendez and Roger Wicker, have introduced S. 1126, also known as the CHANGE Act, which would drive early detection and diagnosis for a vulnerable population. The bill now has 17 cosponsors. It is a groundbreaking bill that fights Alzheimer's disease on multiple fronts, and I urge every Member of the Subcommittee to support it.

The CHANGE Act would incentivize and equip providers with tools they need to accurately detect and diagnose Alzheimer's at its earliest stages—the stages where something can be done. It requires testing for cognitive impairment or progression of cognitive impairment in both the "Welcome to Medicare" initial exam and annual Medicare wellness visits using assessments identified by the National Institutes of Health. If cognitive impairment or progression of cognitive impairment is detected, patients would be referred for additional diagnostic services to specialists trained in diagnosis or treatment of Alzheimer's disease and related dementias, community-based support services and appropriate clinical trials. We now know that there is much we can do for people who are in the early stages of dementia, and it is time for Medicare to make that possible for more people.

We urge the Senate Finance Committee to pass the CHANGE Act and, as part of this effort, obtain a Congressional Budget Office score and the necessary technical assistance from CMS to enact the measure.

Our focus is—and should be—on those living with the disease. But because of the way this disease works, it also creates turmoil for families and other caregivers.

Thanks to modern medicine and technology, people are living longer than ever before. Our nation benefits from these advancements, but it must also respond to what they mean for a rapidly aging—and even more rapidly growing—segment of the population.

For example, in 2017, 16.1 million family—that is, unpaid—caregivers in our country provided an estimated 18.4 billion hours of care. That is an extraordinary economic cost—but I want to make another point very clearly.

Alzheimer's is not like other diseases. It is not like cancer. It is not like heart disease. It is not like diabetes. While millions of Americans and their families grapple with these conditions, they are supported with treatments and even cures that ultimately allow many people to be able to live "normal" lives. They are living with or surviving their disease, even years after initial diagnosis.

That is simply not the case with Alzheimer's—there is no remission from this disease once it reaches a certain stage. The longer the disease has to take hold, the more insidious its symptoms become. The emotional and economic toll this levies on families and caregivers is, in actuality, unquantifiable. This is a good enough reason, in my mind, to support the CHANGE Act, comprehensive paid family leave and other legislation that promotes innovative approaches to supporting family care partners.

This disease affects patients, their families, and caregivers, and there is an immense fiscal cost to our nation as well. Much of the $290 billion in 2019 economic costs that I referenced earlier is in Medicare and Medicaid payments. Medicaid payments are on average 23 times higher for those with Alzheimer's compared to those without, and Medicare payments are three times greater on average. By 2050, estimates show that direct costs alone will increase to $1.1 trillion over a projected 14 million people living with the disease—unless there is a treatment or cure for Alzheimer's.

This brings me to the U.S. Preventive Services Task Force, which has issued draft guidance that the latest scientific evidence is "insufficient" to justify screening for mild cognitive impairment in older Americans. Frankly, this couldn't be further from the truth. UsAgainstAlzheimer's fiercely rebutted that draft guidance with our own public comments. I mention it here to you today as yet another example of an under appreciation of the magnitude of the crisis we are facing in Alzheimer's and dementia and the progress we have made to understanding what can be done if it is caught early enough. The task force should understand the importance of cognitive screening for a highly vulnerable segment of the population—especially when there is a growing body of mainstream scientific evidence which states that we can, potentially, do something to slow or even stop the progression of cognitive decline. The American Academy of Neurology joined with us and more than 150 dementia-patient-serving organizations in calling for early detection and screening.

The Committee has gathered today to talk about Alzheimer's awareness and barriers to diagnosis, treatment and care coordination. This is an important and timely hearing as November is Alzheimer's Awareness Month, and at a time when Alzheimer's is the top public health crisis of our time.

UsAgainstAlzheimer's and others throughout our movement are seeking a national and global response to Alzheimer's equal to the attention and urgency given to AIDS, cancer and climate change. I hope it leads to the day when we finally eliminate the risk of Alzheimer's and dementia. For patients, for caregivers, for families and for our nation, the stakes are too high to accept anything less than complete victory over this disease.

Thank you.

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