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# TAKING AIM AT ALZHEIMER'S: FRONTLINE PERSPECTIVES AND CAREGIVER CHALLENGES

## HEARING

BEFORE THE

## SPECIAL COMMITTEE ON AGING

## UNITED STATES SENATE

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**THURSDAY, MAY 20, 2021**

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

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

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

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

The CHAIRMAN. Good morning, everyone. The Senate Special Committee on Aging will come to order. First and foremost, I want to welcome all of the advocates from the Alzheimer's Association who are watching from home. This Committee is privileged to host this hearing every year in partnership with the association. I especially remember Senator Collins working so hard to make sure this hearing happened every year when she was Chair.

Today's hearing takes place as families across the Nation continue on a long journey to heal from the horrors of this pandemic. We cannot forget the dreadful impact of COVID–19. No community, no family was spared, and more than 587,000 lives have been lost in the United States.

Through the American Rescue Plan, working families have more money in their pockets, our children are returning to school safely, and everyone who wants to can be vaccinated. Just last week, the Biden Administration announced guidance to carry forward new funding for home and community-based services. This funding can bring a measure of relief to millions of families, including those with Alzheimer's disease and other dementias. President Biden's Jobs Plan includes policies to help Americans who have dementia, to help their families and the workers who care for them.

We know that Alzheimer's disease is an unforgiving and cruel condition. That might be an understatement. This affects over six million Americans, including in my home State of Pennsylvania 280,000 people. At today's hearing, our witnesses will testify about the hardships of Alzheimer's disease and other dementias. We will hear about the debilitating and progressive nature of this awful disease and the terrible toll it takes on family caregivers.

I am pleased to lead the effort here in the Senate every year to advocate for more research funding at the National Institutes Of Health. we have a long way to go to focus on this issue.

We will also hear today about, as I mentioned, home and community-based services, which provide, of course, a lifeline for millions of American families. More than 3.5 million Americans, including adults with dementia, rely on services like help with groceries and shopping or bathing or household work in order to stay healthy, to stay safe and independent for as long as possible. I have heard from Pennsylvanians across our Commonwealth, including dementia caregivers, about how important home and community-based services are to families.

We are blessed today to have a great panel of witnesses, and from my home State of Pennsylvania, from Lancaster County, Katelyn Montanez, who will share her powerful story. Katelyn's story and those like hers compel us—compel us—to invest in these services. The President's plan will help bring long overdue help to families who struggle day in and day out to care for their family members, their friends, and their neighbors.

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

To Ranking Member Scott, I am pleased to turn it over to you for your opening remarks.

## OPENING STATEMENT OF SENATOR TIM SCOTT, RANKING MEMBER

Senator TIM SCOTT. Thank you, Chairman Casey, and thank you for your commitment to such an important issue. To those of you joining us today, we are so thankful that you are here, and we are so thankful that you have led the fight for all of us on this really important issue.

There is no doubt that the COVID impact on Alzheimer's and the caregivers was devastating. Frankly, I think about folks in my home State of South Carolina, Karen Sheppard of Monck's Corner, who takes care of her mother. Her mother was diagnosed eight years ago. Before COVID, she used to have a private sitter that was able to come and help out some so that she could go to her own doctor's appointments. When businesses started shutting down, she lost her respite care. During the first wave of COVID, we saw Alzheimer's and dementia deaths increase by 18 percent nationwide. Far, far too many people.

Last month, I along with 23 Senators sent a bipartisan letter to Secretary Becerra asking him to target the remaining $23 billion of COVID relief to people with Alzheimer's. Under the previous administration and two years prior, funding for Alzheimer's increased by 420 percent, from $595 million in 2015 to $3.1 billion in 2021. Linda Talbert, from Greenville, South Carolina, who lost her husband to this disease at the age of 56, pointed out, "This is not"—

and I love this comment, and Chairman Casey will love it as well: “This is not a red issue or a blue issue. This is truly a purple issue.” It is the color of the tie that I am wearing today and, frankly, it is what we both know is one of the reasons why this hearing is perhaps one of the more important hearings we will have all year. We are bringing not a partisan coalition together. We are bringing an American coalition together. The American family is focused on an issue that we know is devastating families throughout this country. By doing so, we believe that by bringing more attention to this important topic, we will be able to help bring more resources and more expertise to the table. We are so thankful that we have the host of panelists, the experts that we have to talk about an issue that they are personally impacted by and that they continue to strive for solutions to help the next wave of caregivers, the next wave of folks impacted by that. For that we are eternally grateful for the experts that we have.

I will say that when you think about it, Mr. Chairman, as you noted in our last hearing, nearly half of all the people with Down Syndrome will develop Alzheimer’s, and nearly one-third will be by the age of 50. Seventy percent of women with a prenatal diagnosis of Down Syndrome have abortions. I thank you for recognizing our shared commitment to improving the lives of people with Down Syndrome and Alzheimer’s.

When it comes to doing the best with what we have, South Carolina is truly a trailblazer. In 1988, South Carolina launched the Nation’s first Alzheimer’s disease registry, which informs clinical research and planning for medical and social services. While we are leading the fight, we are also in the trenches. South Carolina has the sixth highest death rate for Alzheimer’s in our Nation. Sixth. Patty Younts of Pawleys Island, in 2012 Patty’s husband, Howard, was diagnosed with a rare type of Alzheimer’s disease that causes severe visual impairment. He sees the world as if he is looking through a broken mirror. Patty is an advocate and a caregiver, and she and Howard just celebrated their 35th anniversary. Happy anniversary, Patty.

People like Karen, Linda, Patty, our witnesses today, and all of you joining virtually, give us hope. You give me hope. The Alzheimer’s Association says the first survivor of Alzheimer’s is still out there, and I know they are right, and I believe that today’s hearing will help us hit the accelerator in that direction.

I look forward to hearing from our witnesses today and working with them to find that first survivor and so many more.

Thank you, Chairman.

The CHAIRMAN. Ranking Member Scott, thanks very much.

We are going to turn to our witness introductions in a moment, but I want to acknowledge the Senators who are already here. We know that this is a day when Committee members have a number of hearings at the same time. Some have three at the same time; some have four. I know that Senator Collins is with us, Senator Blumenthal, and I will turn to Senator Lee, who will do our first witness introduction. Senator Lee?

Senator LEE. Thanks so much, Mr. Chairman, and thank you, Ranking Member Scott. It is a real honor to introduce Dr. Mark Supiano who hails from our great State of Utah. Dr. Supiano is a respected geriatrician and a professor at the University of Utah School of Medicine. He is someone who has spent 30 years providing primary care for older adults. He is the chief of geriatrics and the executive director at the University of Utah Center on Aging.

Dr. Supiano's interests stem really from his passion to care for a complex and vulnerable population. He has been regularly cited as among the best doctors in America. As a geriatrician, Dr. Supiano is on the front lines in caring for people with Alzheimer's disease and related dementias.

His research focuses on the age-related increase in blood pressure which has emerged as a key link to developing Alzheimer's. He is also a member of the prestigious Alzheimer's Association Research Roundtable, supported by the BOLD Infrastructure for Alzheimer's Act, enacted into law in 2018.

Thank you, Dr. Supiano, for all of your great work and for being here with us today. We look forward to your testimony.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Lee, thanks very much.

I know that we are going to have some other introductions by Committee members, but I might jump out of order here and turn to Ranking Member Scott for the next introduction.

Senator TIM SCOTT. Thank you, Chairman Casey.

I am pleased to introduce someone who is truly a godsend to Alzheimer's patients and caregivers in the Palmetto State: Peg Lahmeyer. Peg is a civic leader in the metropolitan Charleston area and throughout the State of South Carolina as well as the Nation. She is co-founder of the ARK of South Carolina where she has been the executive director for 25 years. That is awesome. We love that type of longevity and support.

In 1996, she first developed the ARK as a community outreach program at St. Luke's Lutheran Church in Summerville. She offered respite once a week to families living with Alzheimer's disease or related dementia. Over the years, the ARK has expanded by both adding programs, including training police officers and other first responders, and extending its services to underserved areas in both rural and urban South Carolina.

Last year, Peg was named Trailblazer of the Year by the Greater Summerville/Dorchester County Chamber of Commerce. Before founding the ARK, Peg and her husband, Jim, were caregivers for her mother who had Alzheimer's and moved from Alabama after Peg's father passed away back in 1990.

Thank you, Peg, for your important work and for being here with us today. We look forward to your testimony.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Ranking Member Scott.

I will do the next two introductions, but before I do that, I want to acknowledge that Senator Rosen is joining us, and we will be acknowledging Senators as they appear.

I wanted to introduce Dr. Jennifer Manly. She is a professor of neuropsychology at Columbia University in New York City. Her research aims to improve the diagnostic accuracy of neuropsychological tests for detecting cognitive impairment and Alzheimer's disease among African American and Hispanic elders. Dr. Manly will speak about the nature and progression of Alzheimer's disease and the populations at highest risk for acquiring the disease.

Our final witness that I will introduce is a Pennsylvanian, Katelyn Montanez. Katelyn is a resident of Lancaster County, in particular, Ephrata, Pennsylvania. She is a social worker and caregiver to her father, who was diagnosed with younger-onset Alzheimer's in 2015. Katelyn will share her father's journey of receiving his diagnosis and accessing much needed supports, including home and community-based services. She is a strong advocate for people living with Alzheimer's disease across the country.

Katelyn, thanks for being with us, and we are looking forward to your testimony.

We will now turn to our witnesses for their statements. We will begin with Dr. Supiano. Dr. Supiano, you may begin your testimony.

## STATEMENT OF MARK A. SUPIANO, M.D., PROFESSOR AND CHIEF, DIVISION OF GERIATRICS, UNIVERSITY OF UTAH SCHOOL OF MEDICINE, EXECUTIVE DIRECTOR, UNIVERSITY OF UTAH CENTER ON AGING, SALT LAKE CITY, UTAH

Dr. SUPIANO. Well, thank you, and good morning, everyone. Chairman Casey, Ranking Member Scott, and members of the Special Committee on Aging, thank you for providing me this opportunity to present my perspective on the exciting approaches that are available today supporting the goal to take aim at Alzheimer's Disease and Related Dementias, or ADRD. In addition to the kind introduction that Senator Lee provided for me in my roles at the University of Utah, I also want to point out that I am a member of the American Geriatric Society Board of Directors.

In my primary care geriatrics medical home clinic, with the support of an interprofessional team of providers, I evaluate patients who present with cognitive concerns, diagnose and treat ADRD, and provide ongoing longitudinal care for these patients and their caregivers. I am an investigator on two NIH-funded clinical trials that are evaluating vascular risk factors for ADRD, and, finally, as Senator Lee mentioned, I am involved with the Building Our Largest Dementia, or BOLD, Public Health Center of Excellence on dementia risk reduction.

Recent advances in strategies to prevent cognitive impairment and to provide effective dementia management services that incorporate caregivers lead me to offer the following recommendations that take aim at ADRD.

First, promote prevention strategies. Promoting cognitive screening is an important prerequisite to implementing prevention strategies. Creating a dementia—aware society where cognitive screening is normalized will help to reduce the stigma that often accompanies a dementia diagnosis. Requiring validated, objective, screening tests of memory and cognition in the Medicare Annual Wellness visit is one strategy to accomplish this.

Implementing public health strategies that target modifiable dementia risk factors that are the focus of the CDC BOLD Infrastructure programs will be critically important. Vascular aging and hypertension have emerged as key actors in the ADRD story, particularly with the good news that the development of cognitive impairment can be prevented with better control of high blood pressure.

Since many of the modifiable risk factors disproportionately impact underserved populations who have adverse social determinants of health, approaches to mitigate the impact of these health disparities are urgently needed.

Second, develop a dementia-competent work force. Most dementia care is provided by primary care health professionals. All members of the health care team will require education and training to competently evaluate and manage patients with cognitive impairment. In parallel, there is a need to expand the number of geriatrics health care professionals, including geriatricians and cognitive specialists, to meet the demands for appropriate diagnosis of patients with dementia.

There is a special need to support hands-on caregivers and the direct care work force in both home and long-term—care settings to equip them to care for persons with dementia. This support should include ensuring living wages, benefits, and paid family leave.

Third, support dementia care management programs and family caregivers. There is a pressing need to provide options so persons with dementia can access the right care, in the right setting, at the right time. Efforts to expand home and community-based services, as Senator Casey was mentioning in the introduction, and making these evidence—based programs such as the Care Ecosystem and the Community Aging in Place Advancing Better Living for Elders more broadly available will help decrease excess health care system utilization and avoid premature placements in skilled nursing facilities. The recently introduced bipartisan Comprehensive Care for Alzheimer's Act is designed to support the development and evaluation of dementia care management programs like these.

Fourth and finally, to continue to invest in ADRD research. The recent infusion of ADRD research support has already begun to yield important results, identifying effective strategies to prevent and manage ADRD, in parallel with efforts to develop and provide disease modifying treatments for AD, the importance of implementing existing preventive strategies cannot be overstated. Just a 2-year delay in dementia onset would translate to 2.2 million fewer Americans developing dementia by the year 2040, a 20-percent reduction.

Finally, additional research is needed to identify mechanisms for cognitive resilience, promoting cultural awareness, and addressing the disproportionate impact of health disparities in developing cognitive impairment.

Thank you for giving me this opportunity to share my perspective this morning and these recommendations with you. I look forward to addressing your questions and comments.

The CHAIRMAN. Dr. Supiano, thanks for your statement.

We will now move to Dr. Manly. You may begin.

## STATEMENT OF JENNIFER MANLY, Ph.D., PROFESSOR OF NEUROPSYCHOLOGY, DEPARTMENT OF NEUROLOGY AND THE TAUB INSTITUTE FOR RESEARCH ON ALZHEIMER'S DISEASE AND THE AGING BRAIN, COLUMBIA UNIVERSITY IRVING MEDICAL CENTER, NEW YORK, NEW YORK

Dr. MANLY. Thank you. Chairman Casey, Ranking Member Scott, and distinguished members of the Committee, thanks for the opportunity to speak to you today.

Over the last decade we have seen a tremendous increase in the federal investment for research on Alzheimer's disease, or AD. Thank you. This investment has accelerated our understanding of the heterogeneity of AD and has allowed us to engage a more diverse group of Americans in Alzheimer's research, but little progress has been made in decreasing racial and ethnic disparities or equitable care for those living with AD.

Rates of Alzheimer's are higher among African Americans and Hispanics than non-Hispanic whites, and this means that at the same age, a higher proportion of Black and Hispanic older adults live with AD than among whites. More women are affected by AD than men because women live longer, and age is the primary risk factor. Women represent about two—thirds of the dementia caregivers in the United States. It is now well established that people who had fewer opportunities to receive education when they were children are at higher risk for Alzheimer's disease later in life. There is evidence that early life residence in a "Stroke Belt" state, including states that Committee members represent, such as Georgia, North Carolina, and South Carolina, leads to higher risk for AD, even if you move out of the Stroke Belt.

Overall, Alzheimer's disease is underdiagnosed. Only about half of the people who have Alzheimer's disease ever receive a formal diagnosis by a doctor, and these missed diagnoses are more common among Black and Hispanic older adults than among whites.

For the past 23 years, I have been an investigator for a community-based longitudinal study of aging and dementia, where I partnered with the African American and Caribbean Hispanic older adults of Washington Heights, Hamilton Heights, Inwood, and Harlem in northern Manhattan. My work focuses on understanding why disparities in AD and dementia are maintained and how to narrow or eliminate them. Our research points to historical and contemporary policies that have created unequal access to resources and may increase exposure to stressors throughout life. These conditions get "under the skin" early in life and account for disparities in AD as people get older.

For example, before Brown v. Board of Education and continuing today, racist policies and residential segregation forced Black children to attend underfunded schools that had large student/teacher ratios, lower teacher salaries, and discriminatory disciplinary policies. Many older Americans who live in Washington Heights immigrated from the Dominican Republic, where, especially in the rural areas, there was little governmental investment in education and fewer opportunities for children to go to school or to learn to read or write. My research team found a connection between these early life school policies and later-life risk or dementia. People who went to school in counties, States, or countries that invested more resources in schools are at lower risk for cognitive impairment and dementia when they get older. Our research in Washington Heights suggests that investment in schools that serve Black and Hispanic children would narrow inequalities in dementia in those groups.

One of the biggest challenges for families in Washington Heights is that most of the doctors who provide specialized dementia care do not speak Spanish. Specialists that are bilingual in Spanish and English have long waiting lists of people who need an assessment. Using an interpreter for any medical visit has limitations, but this is even more of a barrier to quality care when the patient has cognitive deficits.

Lack of culturally appropriate resources for dementia diagnoses and care is a key reason why African Americans and Hispanics with dementia are less likely than whites to have a formal diagnosis.

Expansion of paid family leave is an equity issue for dementia care and services, because people from minoritized backgrounds are more likely to rely on informal and unpaid family caregiving. This has a disproportionate effect on wealth and well-being because people from minoritized backgrounds are less likely to hold a job with paid family leave benefits. Many women of color must leave the workforce to take care of loved ones with dementia.

The home health care or direct care work force largely consists of women of color, many of whom have less than a high school education and were born outside the U.S. Direct care workers earn low wages and experience high turnover. It is time to raise wages and facilitate career advancement opportunities for direct care workers to be consistent with the essential role that these paid caregivers play in the well-being of our society.

Thank you.

The CHAIRMAN. Dr. Manly, thank you for your testimony.

Now we will turn to Ms. Lahmeyer.

## STATEMENT OF PEG LAHMEYER, EXECUTIVE DIRECTOR AND CO-FOUNDER, THE ARK OF SOUTH CAROLINA, SUMMERVILLE, SOUTH CAROLINA

Ms. LAHMEYER. Good morning. Thank you to the Senate Special Committee on Aging, Chairman Senator Casey, and Ranking Member Senator Scott. Thank you for this opportunity to testify.

Growing up in rural Alabama with older parents and much older siblings, I witnessed how our family and extended family cared for each other and nurtured each other through good times and tough times. These impactful life experiences shaped my life.

My family expanded to Summerville, South Carolina, with a wonderful husband, six children, including stepchildren and an adopted at-risk teenager.

My mother was diagnosed at age 76 with Alzheimer's. Multiple visits to Alabama showed the continual decline of both of my parents. My father, age 80, was my mother's caregiver for eight years when he called and said that he needed help. We moved her to a facility in Montgomery, which was 45 miles from my dad. It was devastating to both of them.

My father died in 1990 at the age of 90. We moved mother to live with us, and I was granted conservatorship. Working full time, I resigned to become her full-time caregiver. I worked part time at night delivering newspapers so I could be home during the day.

After discussing the plight and the needs for caregivers to "have a break" and support, I was asked to start a group social respite program at our church. In January 1996 the ARK opened its doors.

Needing skilled care, my mother moved into an Alzheimer's long-term care in 1995 before the ARK actually opened. She died in 1997 at the age of 93. Her legacy lives on through the ARK.

I sought every opportunity to speak to anyone—church, civic, businesses, governmental groups, clubs, and anywhere I could find an audience. The Alzheimer's Association in Charleston was just starting, and I became involved in many of their educational committees, fundraising, and eventually as a board member.

As a previous business person, I believe in the power of the Chamber of Commerce. Becoming a member has opened many doors for support and growth for the ARK. Nonprofits are essential to the community, and building relationships is vital.

The ARK provides so much more than respite to five counties in the low country of South Carolina. They include: four respite half days a week in Summerville; bus service since 2000; a satellite respite center in Harleyville weekly; four support groups in Berkeley and Dorchester counties, one for wives only; and also we have an early memory loss program that meets weekly.

Our outreach program, the NOAH Project—Neighborhood Outreach Alzheimer's Help—provides educational classes, memory screenings, health and resource events; also law enforcement and first responder training, which is evidence—based and certified through the South Carolina Criminal Justice Academy; caregiver workshops and train-the-trainer programs, both in person and virtual; and include powerful tools for caregivers, which is a 6-week evidenced-based class, and also the train-the-trainer program for professionals. These versions also come in Spanish and Korean.

All of these services are provided by five full-time and four part-time staff. They are devoted, passionate, fun loving, supportive, and caring. In 2018, we acquired a home to move our services from the church and to be able to enable expansion.

Through the shutdown and pandemic, our social program closed for seven months. The staff immediately started calling and emailing caregivers, creating fun activity baskets that were delivered to their homes. Zoom was our salvation for our educational workshops, memory screenings, and support groups. Caregivers and families felt less isolated and connected. The train-the-trainer classes reached as far as Alaska and beyond.

When we returned to full-time programming, we saw the decline in our ARK families because of the isolation and lack of socialization. Now we know that our programs are so vital for their well-being, and now we are seeing the effects of dementia to include not only the Baby Boomers but also the Millennials are experiencing caregiving and in some cases early onset dementia.

Funding for grassroots organizations is paramount. Additional state funding for aging services is critical especially for Alzheimer's support programs. Families need to afford in-home care as well.

With the support of South Carolina's Office on Aging, we have been able to build our education program. More funding for aging services is needed as the numbers continue to increase and every day and every minute.

Senators, caregiving families need your help, and thank you so much for the help you have given, and, Senators thank you very much for your time.

The CHAIRMAN. Ms. Lahmeyer, thanks so much for your testimony.

Before I introduce our last witness, I wanted to acknowledge Senators, as I said, as they appear. Senator Warnock has been on for a little while, and I missed him earlier, so I want to acknowledge his presence at the hearing.

Finally, our fourth witness and final witness is
Katelyn Montanez. Katelyn?

## STATEMENT OF KATELYN MONTANEZ, FAMILY CAREGIVER, EPHRATA, PENNSYLVANIA

Ms. MONTANEZ. Chairman Casey, Ranking Member Scott, and members of this Committee, thank you for the opportunity to testify before the Committee about my experiences as a caregiver for my father.

I am a full-time mother, I have a full-time job, and I am a full-time caregiver. Each of these responsibilities are important. Taken all together, it can be overwhelming. My hope is that, in sharing my story, others who are impacted by this disease that have similar stories will feel less alone. I am a social worker and an advocate for my father and for the millions of Americans who have family or loved ones living with Alzheimer's and other dementia. My father, Luis, was diagnosed with younger-onset Alzheimer's at age 54. I was only 22 years old. This year, he turned 61, just one year younger than my grandmother who passed away of the same disease.

More than six million Americans are living with Alzheimer's. My father's story represents only one set of unique challenges which individuals and caregivers live with every day. I want to underscore the importance of what this hearing is based around: expanding the support of daily and long-term-care needs for people with dementia, which includes the support of caregivers.

My father began showing symptoms of Alzheimer's in his early 50's, but he was not formally diagnosed until years later in 2015. After he began displaying symptoms my family was familiar with, my parents visited a few providers to see if they could figure out his neurological and other health issues. It took meeting with several doctors before one of them recognized the signs of younger-onset Alzheimer's.

Prior to his diagnosis, my mother made it her mission to attempt to understand how to navigate the resources that could help my family. My dad was unable to earn a living for his family and just stayed home, confused and disoriented. He had been a custodian at a local school, and now we were faced with a difficult new reality. My mom and I were both working full time, and we were unable to provide the 24-hour supervision he needed. The delay in diagnosis and fragmented care he received left us feeling frustrated, alone, and unable to access much needed supports and services. It was an incredibly challenging time for us. At first, when he was assessed for home and community-based services, he was not eligible because he could still do many things on his own. He actually was denied twice. Since he was not able to receive services, my family was constantly concerned about his safety. There have been numerous instances when my father was confused, and as a result, ended up wandering and becoming lost.

Last fall, we were fortunate enough to finally get him Medicaid home and community-based services through the waiver program in Pennsylvania. A medical social worker helped us through the application process and with the numerous assessments and paperwork that had to be done. It was a game changer for us, but it should not be that hard for people to receive the services they need.

My father has been receiving home and community-based services now for about seven months. I know this Committee's hearing today is focused on the importance of these services, and I cannot tell you how thankful I am that we were able to have access to them. We recently had to move my dad to my sister's house because my mom was no longer able to care for him. The services he is receiving give him an aide for about three hours a day and Meals on Wheels. When he was living with my mom, the aides would help clean the house, help my dad with breakfast, and even take him on short rides. Now that he is living with my sister, the aides take him on walks and sometimes even bring her dogs along. The aides also come in the evening to give my sister a chance to run errands and just have a break. We have also run into some issues as well. Right now my sister has not been able to find an aide for my dad because of the high burnout and turnover rates.

With someone living with Alzheimer's or dementia, consistency of care, including who is providing the care, is essential. Being an aide is hard work with little pay. Aides should be paid more for the work they do and have better access to dementia education and training for their workers. If aides received proper training to work with individuals living with Alzheimer's and dementia, they would have the tools they need to help redirect, would understand common behavioral issues, and it could lead to more successful interactions. People living with Alzheimer's have good days and they also have bad days, but better trained aides who get paid higher wages would bring consistency for my dad and a better quality of life for him and my family.

Congress has continued to keep Alzheimer's and dementia top of mind when working on important issues like home and community-based services. Chairman Casey, I am grateful for your leadership on this important and deeply personal issue. I am a passionate advocate for my dad and for those living with Alzheimer's and other dementia. It is important to me that people living with Alzheimer's, including those who are younger than 60, are able to receive the care and support they need.

I will continue to be the voice for people who have lost theirs. Congress must ensure all communities have access to high-quality, culturally appropriate services and supports. Additionally, I respectfully ask you to increase access to home and community-based services for individuals living with Alzheimer's and dementia, including individuals living with younger-onset Alzheimer's. Please continue to make Alzheimer's research a priority and to work together to pass critical legislation like the Comprehensive Care for Alzheimer's Act and the Equity in Neuroscience and Alzheimer's Clinical Trials Act. These are the bipartisan priorities I am advocating for, along with the over 2,000 other advocates that are participating in the Alzheimer's Association and Alzheimer's Impact Movement Advocacy Forum this week. These policies will help other families like mine receive the support and services we all need and deserve to lead to improved research outcomes.

Thank you for inviting me to speak, for listening to my story, and for all that you have done. I look forward to answering any questions.

The CHAIRMAN. Well, Katelyn, thanks very much for your statement, and we will now move to questions. I will start, and then we will go to Ranking Member Scott.

I wanted to start, I guess, with a question both for Ms. Lahmeyer as well as Katelyn regarding the challenge of this kind of caregiving. As your testimony indicates and as so many people as part of this hearing understand, this is hard work. I have never done it myself, but I can get some sense of it listening to your testimony. It is also deeply personal, in many cases individuals taking care of a close family member, a parent or someone very close to them.

We know that long-term-care services can ease the burden on the caregiver. We also know that most people want to receive those kinds of services, and they need those services and supports in their homes for as long as they possibly can. It is hard, hard work.

I wanted to ask both of you, and we will start with Ms. Lahmeyer, do you believe that families need more support at home? I know that is kind of a broad question, but can you speak to that?

I think you are muted.

Ms. LAHMEYER. I thought I had——

The CHAIRMAN. There you go.

Ms. LAHMEYER. I apologize. Definitely. Listening to Katelyn's story and seeing how their family has worked together to make that happen, but also, you know, the caregiver's burnout is just unbelievable if they do not have help. You know, the Committee did long-term-care services, the Area Agencies on Aging have the ability to provide vouchers for in-home services, but they are very limited. They can also provide vouchers for caregivers to be able to access respite programs like the ARK. Again, they are very limited ways—vouchers, I should say, limited vouchers available to the families, so they may only get a voucher for 12 visits. Well, that is only once a month, and the caregiver needs more than that in respite.

Also, looking at our Medicaid system, the higher reimbursement for providing care in the home to help these families, if they do have to make that long-term-care decision. I know when my mother was admitted to the Life Care Center, they did have an Alzheimer's unit. At that time they were accepting Medicaid. Since the numbers are growing with Alzheimer's and such, and more people are aging, they finally pulled their Medicaid reimbursement contracts and [inaudible]. I was fortunate to get in under that wire, but there are so many facilities that are needed to be able to accept Medicaid for the care of Alzheimer's patients, and I would encourage a look at that possible scenario to determine more help for families that have to make that long-term-care decision, ways to be able to have them in a quality facility that understands ADRD. Thank you.

The CHAIRMAN. Thank you so much.

Katelyn?

Ms. MONTANEZ. I agree as well. I believe we do need more resources within the home and services. I think the challenges and the different uncertainties that my family and I experienced were very troublesome and very difficult to work through. Like I stated in my testimony, the countless paperwork, the countless calls just to get my father services, especially since he is so young with Alzheimer's, was just very difficult. My hope is to see changes especially for the younger people who are diagnosed with Alzheimer's, to be able to have that prevention implemented immediately once the diagnosis—once the person is diagnosed. I think it will help family members just ease the burden, just to have that extra support. Like I said in my testimony, those three hours a day for my sister have been a blessing. Could we, you know, use more and need more? Of course. I guess we have to start somewhere, and, yes, thank you.

The CHAIRMAN. Thank you so much.

Ranking Member Scott?

Senator TIM SCOTT. Thank you, Mr. Chairman. I think it would be appropriate for me to perhaps yield my time to former Chairwoman Collins who is actually the founder of the Senate Alzheimer's Task Force. Senator Collins, if you would be willing to take the first question since you have earned the right to do so, I would really appreciate hearing from you first.

Senator COLLINS. Senator Scott, thank you so much for your typical graciousness. In just a few minutes, the HELP Subcommittee, of which I am the Ranking Member, is holding a hearing on health care worker shortages, so it is very relevant to a lot of the issues that we are talking about.

I am the founder and co-Chair of the Senate Alzheimer's Task Force, and for many, many years, I chaired this annual hearing, and it feels so strange to not be chairing it now. I know that with Senator Scott and Senator Casey, the Committee is in great hands. Thank you for your graciousness.

Alzheimer's is our most costly disease, and it also exacts such a tremendous human toll, not just on the victims but on the entire family. Katelyn, I was really moved by your testimony and what you are doing to take care of your dad while you take care of your children, you are working, and how difficult that is.

In my own family, Alzheimer's has claimed my father, two of my uncles, my grandfather, cousins. It is unfortunately very widespread, and I watched my mother heroically take care of my father at home for eight years before he went into the veterans' home. It was just so difficult, even with a little help from family members. It was really hard to access care.

There is an issue that Katelyn raised that I want to ask Dr. Supiano about. She mentioned the delayed diagnosis for her father, and according to a survey by the Alzheimer's Association, 22 percent of primary care doctors said that they had no residency training in dementia diagnosis and care, and of those who did undergo training, 65 percent said that it was very little.

Legislation that I offered to reauthorize the Geriatrics Workforce Enhancement Program and reinstate the Geriatrics Academic Career Award Program was signed into law as part of the CARES Act. Doctor, I would like to hear from you your thoughts on how medical education programs can be improved to better prepare our health care work force to serve Alzheimer's patients.

Dr. SUPIANO. Well, Senator Collins, first, thank you for your leadership on this very important matter and supporting the work that the Senate has done related to Alzheimer's disease and also with the Health Care Act and particularly with your support of the Geriatric Workforce Enhancement Program and the Geriatric Academic Career Award Program. Full disclosure, I am funded through the Utah Geriatric Education Center, and I am presenting to our group, who is holding their retreat later today, so we thank you very much for that ongoing support.

To respond to your question specifically about how we can further address the education deficit in dementia care and, for that matter, to extent it further to really geriatric care, I have been invested in medical education throughout the 30 years of my career in academic geriatrics, and we continue to pursue efforts in really two prongs: first, to certainly promote the growth and development of more geriatric health care professionals. That is what the GWEP and the GACA programs are designed to do, and expansion of those programs would certainly address that component.

The second prong is to increase geriatrics and dementia education for all trainees across all health professions, and to that end, aligning the funding for graduate medical education, which, as you know, comes from Medicare, comes from CMS. Aligning the education dollars that support graduate medical education with competencies in geriatrics and dementia care would be a really important step in that direction.

There are specific targets that we would love to see to enhance the training for all health care professionals.

The final point I would make is educating all primary care providers who are currently in practice as well as society, as I mentioned in my opening statement, creating a dementia-aware society and normalizing cognitive screening for everyone, and to that end requiring an objective assessment of cognitive function as part of the Medicare annual wellness visit would be another approach to address the need that you have so appropriately identified.

Senator COLLINS. Thank you very much, Doctor, and thank you, Mr. Chairman, and thank you, Senator Scott, for allowing me to go early so that I can race off to my other hearing. This is such an important issue and near and dear to my heart, and, Ms. Montanez, I know that you too are a caregiver, and my heart goes out to you as you try to balance everything also. I want to thank all four of the excellent witnesses that are here today, and please be assured that I am going to continue to work hard until one day we have a means of prevention, effective treatments, and ultimately a cure for this devastating disease. It is just so important.

Thank you all. Thanks so much.

The CHAIRMAN. Senator Collins, thanks very much, and we well remember those hearing rooms packed with people for this hearing every year. This year it is virtual, of course, but we know a lot of people are connecting.

Just to give you a sense of order, we will go to Senator Gillibrand next, and then I will turn to Ranking Member Scott. Senator Gillibrand, welcome.

Senator GILLIBRAND. Thank you, Mr. Chairman, and I am sorry to not have been present for my introduction. I was unaware of the timing, so I apologize. I want to thank everyone for the countless hours, dedication, and work that we have done to lift up the voices of our Alzheimer's community. I also want to thank the caregivers for their countless hours, dedication, and mental and physical toll that they have given, because as caregivers they give so much.

According to the Alzheimer's Association, nearly 83 percent of the help provided to older adults in the United States comes from family members, friends, and unpaid caregivers. While caring for a loved one with Alzheimer's is rewarding in its own right, it can also be stressful, bringing physical and mental challenges and health challenges for caregivers who are often overlooked, and they are not addressed.

Ms. Montanez, thank you for sharing your story. As a caregiver, what has been your biggest challenge in addressing and facilitating care for your loved one? Are there support services or resources that you wish you had known about or had access to earlier in the process?

Ms. MONTANEZ. Thank you for your question. I would say the most challenging experience that we walk through would be just not having access to services immediately. Like I said in my testimony, my dad was very, very young. I can just remember the countless calls that I made to Office of Aging and being told, "Call back when he turns 60. When he turns 60, he would be guaranteed services." Unfortunately, we could not wait until he was 60 years old. When my mom went into the hospital, that is when he got services because he was considered abandoned, an abandoned person.

I would just wish that he received services, whether it was like Meals on Wheels or even an aide years ago, just to have interactions and have those social interactions that he desperately needed, because within those first few years, he was just home alone a lot of the time, and myself, I was in graduate school, and then my mom was working full time.

Senator GILLIBRAND. Thank you.

Dr. Manly, welcome. I am so glad you were able to be one of our expert witnesses today. What resources do you think are needed most to ensure caregivers of people with Alzheimer's are in the best position to provide support and care for their loved ones while also ensuring their own well-being?

Dr. MANLY. Thank you for that question, Senator Gillibrand. I think that our research actually suggests that investment in neighborhoods, in housing, and in health care in racial and ethnic communities that are underserved and advancing racial equity in institutions which have a positive impact on some of the issues that you raised, essentially we need to focus on the neighborhood or local level, increasing options for families that are seeking dementia services in places that they live. This means potentially getting the best minds together to innovate and broaden dementia care options in neighborhoods where there is a higher impact of dementia, and also incentivizing dementia specialists to practice in these communities. This will help us narrow dementia care inequalities.

We found in our research that telehealth was the way for us to get a hold of people in these communities, and this would also help people get the care in the home where they need it. Underserved communities need the devices and they need the connectivity that is required for this tool to work. This is because early and accurate diagnosis of dementia is at the core of provision of dementia services, but in underserved communities, there are fewer resources to refer patients to dementia care professionals.

I think we talked about earlier investment in training programs that graduate qualified, culturally competent behavioral health professionals with specialty training in dementia would have helped to narrow some of these gaps. Thank you.

Senator GILLIBRAND. Thank you so much, Dr. Manly, and thank you so much, Mr. Chairman, for this excellent hearing.

The CHAIRMAN. Thank you, Senator Gillibrand.

I will turn now to Ranking Member Scott.

Senator TIM SCOTT. Thank you, Mr. Chairman, for this hearing, again, because I will tell you I am learning a lot from the witnesses.

Ms. Lahmeyer, thank you for your 25 years of work and dedication and, frankly, your passion that is seen through the ARK. A couple questions for you. Some of the comments that you have made that I find very interesting is the importance of nonprofits like yours working with other organizations within the community. I found it heartening to see that you were really helping to educate law enforcement and train law enforcement because I know so often the calls that go out when someone is lost or missing is going to be responded to by a law enforcement officer. Making sure that our first responders have that really important training so that the person who is being approached gets a little more sensitivity, gets a different approach because it is really not a law enforcement matter, but someone has to have that sense of responsibility and urgency to go find that person.

Tell me how you worked to build those community ties that led to the type of cooperation that you are seeing in our low country community in South Carolina.

Ms. LAHMEYER. Thank you, Senator Scott, for that question. Part of our NOAH Project is that outreach help, and we have worked with about 20 different communities across the state within the last 15 years or so to build programs within—support programs within the communities, whether it be a support group or a respite center or just training and inviting us back and back and back to do more education in the community. We feel education is really the key to being able to access caregivers and educate them about what there are about resources and services that we can bring into the communities that they are not even aware of. The way we do that is we normally will go to talk to the community leaders, the mayor, the bank president, you know, the ladies' guild at the churches or whoever we can get together and sit down at a table with them, and oftentimes we have been requested to come to a community to do that. I know the mayor of St. George had done that many years ago, and so we sat down at the table with all the bank leaders and civic clubs and business leaders and said—you know, we do not go in with a cookie-cutter approach. We go in and we sit down at the table and say, "What do you feel like your families that are living with dementia, what are the needs as caregivers"—regardless of whether it is dementia or not. "What do you feel that your community needs?" Then sometimes they do say, "Well, we would like to have a support group." Oftentimes that is how it all begins, is to—excuse me?

Senator TIM SCOTT. I said, "Yes, ma'am."

Ms. LAHMEYER. Then that grows into a respite program where they can come to a day program, socialize, and the caregiver can get a break. Then we have the health fairs with all types of trainings, improving memory loss, memory screenings, and so we will work with that community as long as they need us, and go forward with that. That is the key, is finding those people in that community that make things happen, and then we go from there.

Senator TIM SCOTT. Thank you very much.

Dr. Supiano, let me hop to you in my last minute or so.

One of the things you talked about is the importance of the co-morbidities, the fact that I live in what they call the "Stroke Belt," and the second leading cause of death in South Carolina is heart disease. I will say this: You have brought or at least illuminated the importance of the issue of these co-morbidities that really work against the patient who then develops Alzheimer's.

In your research, hypertension and Alzheimer's, how can we help inform, educate patients to seek the diagnosis and/or get more information about the Alzheimer's component, whereas the hypertension, you might be driven to the doctor, but Alzheimer's sometimes we just ignore some of the symptoms? It seems to me that that is a really important intersection for patients, especially in communities like South Carolina and the minority communities that have a higher incidence of hypertension or diabetes, too.

Dr. SUPIANO. Senator Scott, you are exactly right. We have a lot of work to do, frankly, to improve those risk factors across the country, but particularly in parts of the country that are affected by these health disparities and have very high cardiovascular risk factors, as you point out, of high blood pressure and diabetes.

I think part of that messaging for us is that we now have evidence that what is good for the heart is good for the brain. If we can get the message across that addressing your blood pressure level or your diabetes or your level of cholesterol can be important to protect your brain health down the road, not only prevent the heart attack or stroke, I think that is part of the messaging that we need to communicate to the health care system as well as to society to help really address the epidemic of those risk factors, the epidemic of obesity for similar reasons. What is good for the heart is good for the brain.

Senator TIM SCOTT. Chairman Casey, I know I am over time, so let me just say this very quickly. I do think that I would love to have another hearing on the marketing, the strategies necessary to make sure that our communities have more information about the important information being shared with the panelists. Thank you so much.

The CHAIRMAN. Ranking Member Scott, thank you very much.

Now we will turn next to Senator Warren.

Senator WARREN. Thank you, Mr. Chairman. Thank you for all the work that this Committee has done over the years to bring attention to Alzheimer's.

I also want to say thank you to the families who are impacted by this devastating disease who have come to be with us today to advocate for progress. You know, here in Congress it is our responsibility to do everything we can to find a cure. In 30 years, experts estimate that spending on Alzheimer's will increase to more than $1 trillion to pay for doctor's visits, medications, emergency departments, hospital admissions, skilled nursing facility care. Even today, Americans spend an estimated $305 billion a year caring for people with Alzheimer's, but the National Institute of Health spends just one percent of that amount on Alzheimer's research. Providing continued enhanced funding is a critical weapon in our fight against this disease.

Let me start with you. Dr. Supiano, we spend far too little on Alzheimer's research, but I would like to understand more about the impact that even that small amount of funding has had. What scientific advances and improvements have been made as a result of the federal research dollars that we have spent?

Dr. SUPIANO. Yes, thank you, Senator Warren, for that question, and thank you for your advocacy for enhancing Alzheimer's disease research and research in biomedical science in general. Your point is well taken, but the investment that has been made, as I said in my testimony, the infusion of support over the last several years has resulted in dramatic advances. We now are aware that there are effective strategies to prevent the development of cognitive impairment. We also know—and related to the focus today on caregiving—that there are effective dementia care management programs that incorporate caregivers that have been shown to decrease health care utilization and prevent early nursing home placements. If these investments are important, you are also aware—and I know last year this Committee heard testimony from Dr. Richard Hodes, the Director of the National Institute on Aging, and the investment that has been made in the basic biology of Alzheimer's disease and the genetics of Alzheimer's disease is also bearing fruit. We are on the cusp, hopefully, of being able to offer the first disease-modifying drug for Alzheimer's disease. We have a lot more work to do, but thanks to the infusion of support that has been made to date, these advances are now available, and they are ready to be implemented. I think now is our chance to provide the support to now implement these particular strategies now that we know that they are effective.

Senator WARREN. Well, that is powerfully important. Federal funding helps drive innovation, and it helps move us that much closer to a cure.

In the last 10 years, the Federal Government has increased funding for Alzheimer's and dementia research, but it is still not enough. Meanwhile, the coronavirus pandemic upended biomedical research across the country, which has led to delays in critical studies.

Dr. Supiano, has the coronavirus pandemic impacted the work of scientists and researchers who are studying Alzheimer's?

Dr. SUPIANO. Yes, thank you, Senator Warren, and to a certain extent, the scientific community is not immune from the effects of the pandemic and the way that it has altered the way that we go about our business, in this case biomedical investigation, yes, and some delays are apparent in clinical trials for Alzheimer's disease, and the impact of the pandemic on recruitment into those trials and being able to conduct those trials safely has certainly had a delay. To that end, getting even more support now to make up for that lost time and accelerate advances going forward will be even more important as we now emerge from the pandemic, thankfully. As you pointed out, medical scientists are innovators, and we have learned a lot through the pandemic. To be able to conduct pragmatic trials that can be done remotely, applying virtual telehealth technologies to medical research is another opportunity and another advancement that has been made. There are some benefits from what we have been living with in the last year that, while there have been delays, we have still been able to make progress in this fight against Alzheimer's disease and related dementias.

Senator WARREN. Well, I know that biomedical researchers have made valiant efforts to innovate and to keep these studies going during the pandemic. This just underscores the need for more federal support. That is why I will soon be introducing the National Biomedical Research Act, a bill that would invest $100 billion over 10 years in research at NIH and FDA. This is the funding that could be used to fund breakthrough treatments for Alzheimer's or to find ways to slow the progression of the disease.

I appreciate the work that you have been doing. I know that no amount of research funding can make up for the heartbreak of losing a loved one to Alzheimer's. Research funding can help prevent the heartbreak for many other families down the line. I am very hopeful that my colleagues in the Senate will join me in supporting the National Biomedical Research Act. Let us get this one done.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Warren.

We will turn next to Senator Braun.

Senator BRAUN. Thank you, Mr. Chairman.

I have two questions, both for Dr. Supiano. I had a bill out there called the "Promising Pathways Act," and it is for diseases just like Alzheimer's, ALS, and we spent so much money over the years, I think sevenfold over recent times, on Alzheimer's. It has had one of the highest failure rates of any ailment and attempts to try to get something to work. I think you talked about earlier there is a lot of stuff in the pipeline that looks promising.

Does it make sense on ALS, Alzheimer's, that we try to pick up the pace for the folks that are in the clinical trials, especially where there are signs of promise that you are making some headway, and do it a little differently than what you would do on something that has effective therapies out there, looking for new or refining? Do you think that would make sense with Alzheimer's specifically to try to have a different paradigm for getting some of these promising therapies to the marketplace to help folks that have no other options?

Dr. SUPIANO. Yes, thank you, Senator Braun. I agree with you that given the devastating effects of Alzheimer's disease in particular, anything we can do to speed the development and implementation of the disease-modifying therapies will pay dividends. In addition to that, as you pointed out, I believe that the timing is right, given the investment that has been made in the last several years in these basic understandings of Alzheimer's disease and, as you point out, ALS, investigators here, my colleague in the Department of Neurology, the Chair of the department, Dr. Stefan Pulst, has just recently identified a very promising therapy for ALS that you may be familiar with.

Yes, based on these medical advances, I think the time is now right to be able to move this forward.

Senator BRAUN. Would you and others in the field be willing to have a discussion with the FDA who would have to be behind that idea? In my attempts to do so, you generally get interest in it, and then it goes back to the paradigm of, you know, that normal format and sequence. I am OK with that other than in places where you have no other options. Is that something you would be willing to engage with them on?

Dr. SUPIANO. Yes, Senator Braun, and many of us in the geriatric research community have been closely working with the FDA, not only in this area but in others, and the regulatory aspects of therapies like this as it relates to older individuals are really important. It is all the more important to make sure that older adults are included in the trials that are being done so that we can generalize the results. This communication with the FDA is important, and, yes, we would want to partner with you to advance that area.

Senator BRAUN. Very good. My second question would be on any disease, rather than treating it, ideally we would love to prevent it. I know that there are kind of related discussions on cardiovascular issues, even depression, on the mental health side of things. Do you think eventually we are going to find a way to prevent it? Or do you think resources should be put into therapies to treat it? Obviously, I think we probably want to do both. I would love your opinion on what you think might be the best placement of our resources currently when it has been so elusive on either one of them.

Dr. SUPIANO. You are correct, Senator Braun, we need both. The disease-modifying therapy advances, as we just discussed, are critical. I will point out, though, that we do now have evidence bases that much of Alzheimer's disease and related dementias can be effectively prevented. The old initiative that I mentioned, the public health initiative on dementia risk reduction, is reviewing what have been identified as 12 potentially modifiable risk factors. Most of these are lifestyle effects. We have already talked about some of them: obesity, high blood pressure, diabetes, poor nutrition, limited education, and down the list. We know that those are effective strategies. The Lancet Commission in their report from last year suggested that attending to those 12 modifiable risk factors would prevent 30 percent of Alzheimer's disease and related dementias.

My point would be that we know what these strategies are. We need to better implement them. We need to make sure that they are being addressed across health disparities, as I responded to Senator Scott's question earlier, the need to address the cardiovascular risk factors in areas of the country where these are extremely high. We do know what is effective. We just need to invest in public health measures now that will help us do better to modify those risk factors. Prevention, I think, is—an ounce of prevention is a pound of cure, I gather.

Senator BRAUN. Yes. Very good. Thank you so much.

Dr. SUPIANO. My pleasure.

The CHAIRMAN. Thank you, Senator Braun.

We will turn next to Senator Lee.

Senator LEE. Thanks so much, Mr. Chairman.

You know, most of us have a loved one or we at least know someone whose loved one has experienced the difficulties of Alzheimer's. In Utah, there are more than 300,000 people age 65 and older and as many as one in ten of them have Alzheimer's disease, a higher rate than most other states. The number of Utahns with Alzheimer's who are 65 and older is expected to increase by as much as 40 percent over the next five years. Thankfully, Utah is taking proactive steps to address Alzheimer's disease and related dementias.

Dr. Supiano, can you tell me about some of the ways in which Utah is leading the country in Alzheimer's research and tell us a little bit about how Utah's State Plan for Alzheimer's Disease and Related Dementias is contributing to this effort?

Dr. SUPIANO. Yes, thank you, Senator Lee. As you pointed out, Utah does have a very high rate of Alzheimer's disease in our state. It is a byproduct of the good longevity that we have, so the strongest risk factor for Alzheimer's disease and related dementias is advancing age. With the great life expectancy in our state, we can expect to have more cases of Alzheimer's as time goes on, all the more reason to focus on these preventative strategies, as I was discussing.

You are correct that we are very fortunate that our state legislature has supported the implementation of the Utah State Plan for Alzheimer's Disease and Related Dementias. There is now, I believe, $1 million as a line item coming every year to the Department of Health to implement this strategy. It calls, for example, for enhancing screening for cognitive impairment across the state, so a dementia-aware state. It calls for some of the workforce need that we have been discussing this morning. It calls for further investment in Alzheimer's research, and it also calls for supporting community organizations. As we heard from Ms. Lahmeyer in South Carolina, working hand in hand with community organizations and AAAs is another part of the state plan.

With that, and also with the support that we have through the Utah Governor's Commission on Aging, we are really poised to advance these programs that address Alzheimer's disease and related dementias across the state. The final aspect of this that I am really excited about and relevant to today's hearing is the focus on caregiving. As part of the Center on Aging that I direct at the University of Utah, we have made an investment, and thanks to funding from the National Institute on Aging to our College of Nursing and to Dr. Lee Ellington, we have support for a caregiving coalition that will focus on supporting the research and implementation we need to help better support family caregivers, particularly those with dementia.

We are really well poised in Utah, Senator Lee, with the support that we have from the state legislature, the Department of Health, and with the research support from the University of Utah and the support that we have from NIH, we are poised to make these advances.

Senator LEE. Thank you so much, Dr. Supiano.

Ms. Lahmeyer, in your testimony you speak about the personal experiences and sacrifices you made in caring for both your mother and your father and how that led you to found ARK of South Carolina. My own mother-in-law, Carole Burr, passed away just about a year ago after a long and heroic battle with Alzheimer's disease, so I know firsthand some of the difficulties this disease brings both to the patient and to the loved ones of a patient.

The services that you and your colleagues provide really exemplify the value of everyday individuals stepping up to serve those in need. As you put it in your testimony, the nonprofits are essential to the community, and I could not agree more.

Ms. Lahmeyer, given your experience at the ARK of South Carolina, what can individuals across the country do to better serve and provide relief to those in their communities who are struggling with Alzheimer's dementia or the possibility of being a better caregiver?

Ms. LAHMEYER. Thank you, Senator Lee, for that question. As you say, nonprofits are essential because we can provide some of the services much more economical and affordable for families because we are nonprofit; we rely on donations and grants and state funding coming down from the Area Agency on Aging and South Carolina Aging. I would just encourage families to reach out, as I did, to church or reach out to an organization and ask if they can help build a program similar to the ARK. For 25-plus years, I have spoken to a lot of states and communities across the Nation at different conferences and things that I have been to and attended as a presenter, and there is a network of respite care centers across the Nation funded through Brookdale National Group Respite Foundation, and I would encourage communities to reach out to that organization and find out about starting a respite center or other type of caregiver services, you know, getting together with support groups and things like that, and then just building from there, because there is going to be someone in that community that will be a leader and will step up to the plate. The support needs to be there to help you do that, and I have found that the Chamber of Commerce and some of our other health care partners that provide care and support to families are more than willing to join us.

I hope that answers your question. Thank you.

Senator LEE. Thank you very much. Thank you, Mr. Chairman. I see my time has expired.

The CHAIRMAN. Senator Lee, thank you very much.

We will now turn to Senator Rick Scott.

Senator RICK SCOTT. Thank you, Chairman.

First off, I want to thank everybody for being here today, and I want to thank the Chairman for putting this important hearing together to discuss a pretty big issue from my home State of Florida. As you all know, Florida has a significant aging population, and so many of our residents and families have been affected by this heartbreaking, life—altering disease.

During my time as Governor—I finished in the end of 2018, and I was Governor from 2011 to 2018—we were able to invest record funding in the Alzheimer's Disease Initiative. In my last year, actually, we did $26 million just in state funding for education and support services for patients and their caregivers. We established the Ed and Ethel Moore Alzheimer's Disease Research Program which supports research for better prevention, diagnosis, treatments, and cures for Alzheimer's disease, and provides grant support of researchers, which is important. Our state is also the proud home of the Byrd Alzheimer's Center and Research Institute, which is the world's largest free-standing research institution dedicated to Alzheimer's. They are actually launching a new podcast series this week to provide information for caregivers.

We also have the Florida Alzheimer's Disease Research Center, which coordinates efforts from several universities. We tried to do that with a variety of things, including cancer and Alzheimer's, to get our universities that are doing research and hospitals to coordinate their research. Right now this group is doing a long-term study with hundreds of members of our Hispanic population, many of them that Spanish is their primary language, to see how we can better address the issues for the minority population. We have been able to do a lot, but as we all know, there is a lot left to do.

Dr. Manly, I understand that Medicare has a yearly wellness visit benefit, which includes a cognitive impairment assessment. Do you think that is sufficient? Do you think it is doing a good job of catching signs of Alzheimer's? Or does it need to be modified?

Dr. MANLY. Thank you for that question, Senator, and I am very familiar with the researchers and research facilities that you mentioned that are doing very good work in the state of Florida. I think that the annual wellness exam is one important step to incentivizing primary care physicians to do cognitive screening. I think that one major challenge that we have is that this kind of work, early diagnosis and screening for cognitive impairment, takes time. It takes time and it takes training.

Some of the instruments that we have available take time to administer, and I think one limitation that we have faced is that the health care professionals that are administering this annual wellness exam, many of them do not speak the languages of the patients. In your State of Florida, in my State of New York, there is a greater burden with cognitive impairment among people who are Hispanic. This is because of—when Dr. Supiano mentioned the 12 modifiable risk factors that drive risk for Alzheimer's disease, these risk factors are socially determined. They have their roots in life course inequalities, and that is why minoritized populations bear a greater burden of Alzheimer's disease.

As I mentioned earlier in my testimony, we have got to, I think incentivize training programs that are based in communities where people speak the language of the folks who are disproportionately burdened this disease in order to—and incentivize them to practice in the neighborhoods where these patients live. That means that the annual wellness exam gives us this structure for assessing and screening, but we need the cultural competency of the practitioners, and we need to do a better job of having our health care system earn the trust of the communities that they serve. Thank you.

Senator RICK SCOTT. Thank you. To anybody who would like to answer this, elder abuse is a serious problem for seniors, from physical abuse to financial abuse, and both of those things clearly happen in each of our states. What do you all recommend is a better way to protect our seniors with Alzheimer's who may not even remember the abusive actions or who it was, from strangers, family, and caregivers?

Dr. SUPIANO. Well, Senator Scott, this is Mark Supiano. I am happy to jump into that. You have raised a very important concern for protecting all older adults, but particularly those who have cognitive impairment, from both physical and financial abuse.

From the financial fraud perspective, one of the key education components for patients and their families who are presenting with cognitive impairment is to be proactive about identifying financial protections for that patient to put firewalls around their financial assets so that they are protected from people that might take advantage of their limited cognitive abilities. Being proactive as part of a dementia care team, professionals who can—it would often include a social worker that can help patients and their families set up those appropriate protections for their financial assets, would be a huge step in the right direction for preventing the financial abuse.

Senator RICK SCOTT. Thank you. Chairman, thanks again for holding this hearing.

Ms. LAHMEYER. Senator Scott, may I add something to that?

Senator RICK SCOTT. Absolutely.

The CHAIRMAN. Sure.

Ms. LAHMEYER. I am sorry. We are over. I see that.

I find that courts here in South Carolina are wonderful with counseling with families and helping families get at conservatorship or guardianship in case there is a family member trying to take advantage of a care receiver. I always recommend elder law attorneys and especially our probate court is phenomenal with helping families protect the individual.

Senator RICK SCOTT. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Scott, thanks very much.

I just want to let everyone know where we are and what we will do now. I will turn to a second round of questions that I have and Ranking Member Scott may have. We may go back to the first round for a Senator who is likely to return, but let me go back to Dr. Manly. I was noting in the materials for your testimony some of your background, just remarkable scholarship: 185 peer-reviewed articles that have contributed insights into the disparities in dementia across racial and ethnic groups. Like a lot of folks on this panel, you have spent a lot of time on these issues.

I wanted to cite for you, Dr. Manly, a report by the National Academy of Sciences, Engineering, and Medicine this past February, which said, "To live well with dementia, people need care, services, and supports that reflect their values and preferences, that build on their strengths and abilities, promote well-being, and address needs that evolve as cognitive impairment deepens." said the National Academy of Sciences, Engineering, and Medicine.

Our discussion this morning clearly shows we have a ways to go to achieve this goal. Closing the disparities gap in Alzheimer's disease for African American and Hispanic adults must, of course, be part of this discussion.

Dr. Manly, here is the question: Can you say a few words about what more needs to be done to ensure that all people with dementia and their caregivers can live well for as long as possible and that no one group is left behind? Where do we go from here? I know in your testimony—I guess it is on page seven—you offer a series of recommendations, but just on this part of your testimony and, of course, your scholarship, what would you recommend?

Dr. MANLY. Thank you, Senator Casey. I think the first thing I would recommend is something that we have been talking about throughout the morning, which is the investment in research in Alzheimer's disease and related dementias. I think that we have noted some of the ways that that investment has really transformed the research space for Alzheimer's disease, and one way that it has done that is by leveraging studies that were already existing that had been very successful in reaching some of the populations that experienced disparities in Alzheimer's disease, but that these studies had done that for other diseases like hypertension, like diabetes. These studies are now being—I think "converted" is a little strong of a word, but being utilized to study Alzheimer's disease.

In order to do that, the Alzheimer's researchers have had to be very innovative, to innovate screening measures, cognitive screening measures that can be incorporated into those studies. A lot of those measures need to be done over the phone because these studies are national studies. A lot of these studies need to employ people all over the country to go out and take blood and do in-person assessments for those participants.

I think that we are seeing a tremendous amount of innovation that gets to people where they live, and that is really the key part of the other recommendation that I have about improving care for minoritized populations and making sure that these populations are not left behind, as you mentioned, which is that the neighborhood level is where we need to focus, the local level.

I think that what we are finding is that families need options. Dementia is a long course, and those options change as the disease changes. What this means is incentivizing different stages of care and services in the neighborhood so that they are available where people live, and we know that some neighborhoods have high proportions of Black and Hispanic people who are living with Alzheimer's disease. We know that from the studies I mentioned before, so those are my recommendations, Senator.

The CHAIRMAN. Doctor, thanks very much.

I will turn to Ranking Member Scott.

Senator TIM SCOTT. Thank you, Chairman, and thank you all once for being here.

Let me just say to both of our staffs, who spent a lot of time putting this hearing together, I am impressed by the quality and the caliber of our witnesses. I am impressed by the way that this naturally flows. I want to say thank you to my Aging Committee staff as well as yours who have just spent a lot of time and energy on an important topic. This could be the most expensive disease our Nation ever sees, and so spending quality time discussing this issue should not be overlooked. Thank you for your leadership on that issue.

As we say oftentimes, in a former life I sold long—term-care policies, so I recognize the importance of funding some of the priorities that we have, especially on Alzheimer's and other related dementia disease, that this is, in fact, something that we are going to have to get our arms around, the funding of the help for providing for this important disease.

I would ask the whole panel, A, I am not sure how familiar you all are with the insurance business and long—term care; but, B, I know that what we do not do very well is market the importance of making decisions when you are in your 40's about acquiring some of the policies when they are really affordable. When you are in your 60's, that is a significant conversation, but still an important conversation. I know that my mother, she works as a nurse's aide. She is a caregiver and has been to my grandmother who passed away with dementia as well as my grandfather just four years ago, and as a 47-year practitioner providing assistance and care, one of the options that she has was buying a long-term-care policy at work. I would love to, A, know do you all think we are doing a good job on marketing and informing the public on the importance of making that decision in their 40's while it is affordable; or, B, I know that it is not the only answer because for some families we all recognize that it would just not be affordable perhaps in any budget. I do think that this is an important issue and a part of the solution that we have not spent a lot of time on, as you probably are already aware. I think that we need to do a better job of informing, educating, marketing in communities that can benefit from more information and more knowledge, not just on what Medicaid does, because we typically get there at the end and not at the beginning. There are some things that we could do from a preemptive standpoint.

For the whole panel, I would love to hear your recommendations or suggestions from a marketing standpoint. If you do not want to talk about the long-term-care insurance component, make sure that we have enough information coming into communities, whether we should be doing field hearings, frankly, in our states, in the communities where there is a high concentration. This is such an important issue that sometimes more information leads to better education, leads to better outcomes, and then that reduces the spending trajectory that we are on.

I will stop, and I know you have two doctors and two amazing caregivers. I will stop and shut up and listen. If you will turn your microphone on?

Dr. SUPIANO. Yes, so thank you, Senator Scott. It is an important issue, and I will confess I am not competent to fully delve into the health care economics of the long-term—care insurance market, as you say, and how this could be better promoted at younger ages when it would be more affordable. I think you have correctly stated that for the majority of our citizens who are saddled with education debts on their own or for their children and all the other demands on their household economics, long-term-care insurance is perhaps down on those priorities.

Perhaps the solution—so I do not have the health care economics solution in that respect, and I am not equipped with enough information about how to address that need for long-term-care insurance specifically. Perhaps a more general solution, whether long-term-care services are being paid for by the insurance industry or by the government, through Medicaid or Medicare, perhaps a solution is to do what we can to find models of care that are more affordable ways of providing long-term-care services and supports.

For example, we know that the most expensive spectrum of that care is in skilled nursing facilities or nursing homes, so any strategies that we could invest in early on by supporting people and advancing the home and community-based services we have been talking about this morning, programs that I mentioned in my testimony, the Care Ecosystem, the CAPABLE model, PACE programs, other things like this to find more cost-effective ways to deliver long-term-care services and supports in the home on the front end, to avoid those perhaps ultimate necessary space in long-term care, perhaps lowering the ultimate cost of long-term-care services and supports is where we should be focusing our attention, and then we can address who the appropriate funder for that should be. That would be my take on this.

Senator TIM SCOTT. Thank you, sir.

I am not sure if I have time, Chairman, for another question. I will just go ahead until I see someone—I see Senator Rosen. I am not sure if she is prepared to go now or not. She is shaking her head yes, so I will stop talking. This is interesting. All right. Thank you for sending those very obvious cues to stop talking.

The CHAIRMAN. Ranking Member Scott, thank you.

We will turn to Senator Rosen.

Senator ROSEN. Thank you. That is the challenge of Zooming in. We are all running back and forth, so thank you. This is a really important hearing. My mother-in—law was on the Alzheimer's spectrum before she passed, and I know firsthand how it worked, everything, all the work that is going on here, the caregiving that it takes and what it feels like to be a family member going through this.

Currently, one in nine Nevadans older than 65 live with Alzheimer's disease, and, unfortunately, Nevada also has the third fastest growing dementia population in the United States. To respond to the challenges that Alzheimer's disease is imposing on our state and, of course, all around this country, Nevada's universities and research partners have stepped up in a big way.

For example, the UNLV Center for Transformative Neuroscience recently received a $3 million grant from the National Institute on Aging which will help them publish their annual review of Alzheimer's medications in the development stage. Additionally, the Lou Ruvo Center for Brain Health in Las Vegas also received a $3 million NIA grant to establish the Nevada Exploratory Alzheimer's Disease Center, which is going to help fill an existing research gap in how people living in rural areas all across this country might experience Alzheimer's disease.

Dr. Supiano, can you talk to us a little bit about how the current lack of research on rural patients living with Alzheimer's, the challenges they may have getting supportive care, to help them treat the disease or cope with it and their family members? How might this impact smaller communities and populations? How do you think the research being conducted in Nevada will inform providers and patients in this really important conversation for all of us?

Dr. SUPIANO. Yes, thank you, Senator Rosen. As your neighbor in Utah, I am very familiar with the demographics that you describe, which are very similar in Utah as they are for you in Nevada, and also the very rural nature of our two states. You have raised a very important aspect of needs for research to expand to these areas.

I mentioned earlier in my response to Senator Collins with the support for the Geriatric Workforce Enhancement Program, one of the things that we have been funded to do through our GWEP is to reach out across the state and provide education and support for staff in long-term-care settings across the State of Utah. This includes an outreach to the tribal nations in Utah—there are seven tribes in Utah—and important outreach to Native Americans in addressing the health disparities and their risk for cognitive impairment and dementia.

The other thing I brought up earlier is one of the unintended consequences or benefit of COVID is that our ability to deliver telehealth resources to rural areas has really stepped up in the last year and opened up an opportunity. That carries with it a need and perhaps a request in that respect, as I know you would resonate with, is to better support broadband access to rural communities so that those telehealth delivers can be given.

The other aspect—and Ms. Lahmeyer spoke to this in terms of support groups—is being able to distant support groups, which we are doing through our GWEP program in Utah, to disseminate the supports and the care that is needed across the state to rural areas is another aspect of research that could be further expanded.

It is a very important issue, and I think as your neighbor we can work very closely with your investigators at the University of Nevada and others to make those advances.

Senator ROSEN. I look forward to that, and I want to just add to that a little bit about respite care and how important it is for those caregivers. Caregiving is a never-ending job, 24/7. It is oftentimes thankless. Finding respite care is burdensome, costly. Family members can feel guilty who feel that they need even a weekend off. I only have a few seconds, so, Ms. Lahmeyer, a lot of caregivers face fatigue and burnout, and so could expanding access to respite care—how do you think it might help prevent elder abuse and just improve our caregiving as you might see that?

Ms. LAHMEYER. Yes, we see so much stress in our caregivers, and through our support groups and such, we are always offering seminars and little workshops on managing stress and through our Powerful Tools for Caregivers classes that are now over at the University of Utah from Oregon, but we see the stress on these caregivers just kind of melt away once they find out that they can really take time to take care of themselves. Just like the oxygen mask on the airplane, who do you put it on first? We really try to educate our caregivers about the need to take care of themselves. Being able to access vouchers and through a respite coalition or through the Area Agencies on Aging, for caregivers to be able to take a weekend off and have someone or pay a family member through those vouchers to be able to go into the home and stay with the family so the caregiver can get a break. Even the four hours a day here at the ARK, the caregivers just see the value and they feel so relieved when they come to pick their loved on up in the afternoon and know that they had a good time and the caregiver has had a break away. That respite time is just so important for these caregivers and also the education that they are able to provide through our workshops and things.

Senator ROSEN. Well, thank you all for your work. We all care about our families and our parents and grandparents, and I hope we all live better, longer, whether it is Alzheimer's or other kinds of chronic diseases that may come along with aging, and supporting our families who—we all love each other. We want to take care of each other. That is really important.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Rosen, thanks very much. I want to thank you for appearing in our hearing today. I will close out with just some brief comments today.

First of all, I want to thank Ranking Member Scott and, as he mentioned, our staffs who made this hearing possible.

I also want to thank, of course, our witnesses for their testimony and their insights. I think Ranking Member Scott made an excellent point earlier when he talked about how capable and dedicated and experienced this witness panel was. We are certainly grateful for that when we are discussing these important issues that relate to Alzheimer's and dementia generally.

As we lift the shroud of this pandemic, we also have to think about how we can bolster supports for those afflicted with Alzheimer's disease. Of course, that support also is support for their families. We cannot leave them behind as we head toward recovery. I believe that the American Rescue Plan has made great strides toward ensuring that people will disabilities and older adults can access services to help them live full and meaningful lives.

Congress should also pass the American Jobs Plan to spur economic growth and strengthen both our physical infrastructure as well as our human infrastructure, so we can provide help to families.

I was noting earlier and I did not make reference to it, but I wanted to make reference to one line from Ms. Montanez's statement. She said, and I am quoting—at the end of your testimony, Katelyn, you said, “I am here as a daughter, niece, and granddaughter of Alzheimer’s.” When we talk about these initiatives to help families in the upcoming opportunity, we are, of course, thinking about families like hers. We are grateful that each of our witnesses was willing to come and provide the benefit of your experience, the benefit of your family’s experience, and, of course, the benefit of your scholarship and work in this area. You have enlightened all of us.

I will now turn to Ranking Member Scott, and then I will just have some brief comments at the end. Ranking Member Scott?

Senator TIM SCOTT. Thank you, Chairman Casey, for your dedication to this really important topic. To the Alzheimer’s Association, your stakeholders around the country, thank you all for tuning in and spurring action on behalf of Congress. This is, as I said at the beginning, not a Republican or a Democrat issue. This is not even a bipartisan issue. This is an American issue. This is a global issue that we have an opportunity to lead on.

To the two caregivers on the panel, thank you both. Peg Lahmeyer, from my great State of South Carolina, God bless you for your work and dedication and sharing your story. Katelyn, we certainly learned a lot listening to really the impact that Alzheimer’s is having on your life and so many others.

Dr. Manly, I think you have done a really good job of pointing out the disparity within the Alzheimer’s disease itself. African Americans have a 57 percent more chance of being diagnosed with Alzheimer’s, and 63 percent of the folks diagnosed in my State of South Carolina have been women. We are going to focus our attention on making sure that we focus on diversity in the trials that we are seeing in many of the drugs that are coming forward, because that is a really important component and one that I talked about during the pandemic for the COVID vaccine. It is critically important in Alzheimer’s as well, and I think that there is a lot that we can do, that we should do, and I think if we get it done, we will see the kind of results that we need to bend that curve in the communities that are most fragile and economically strapped.

I would also like to say that protecting our intellectual property protections is so important for us to continue to see—one of America’s greatest assets is our IP, continue to deliver more and more solutions and hopefully therapies for Alzheimer’s. It is one of the areas that we are a global leader, and we need to maintain that biomedical innovation that is creating solutions for the world’s greatest diseases. In short, innovation of this sort is an incredibly high-reward proposition, but it is also high risk. We need to do everything in our power that we can to encourage the dynamism and the all-hands-on-deck approach that we have seen from the pandemic and if we could transfer that to Alzheimer’s, I think we would find solutions faster.

The one thing I have learned about, when this country comes together to fight back the greatest health care attack we have seen in my lifetime, we get things done faster than ever. Literally having a vaccine less than a year is something that was said to be impossible to do, yet we had it done. If we had the same energy and synergy toward Alzheimer’s, I believe—and I could be wrong, but I believe we could have similar results in unbelievable time, what-ever that is. I think with you all's expertise and, frankly, with the pain of your stories, we can move forward together in finding solution.

Chairman, thank you again for leading on this hearing, and I look forward to your final thoughts.

The CHAIRMAN. Ranking Member Scott, thanks very much, and I want to thank you for your work.

I also want to thank again our witnesses for their time today and also the expertise and passion they bring to these issues.

If any Senators have additional questions for the record or statements to be added, the hearing record will be open for seven days, until next Thursday, May 27th.

Thank you all for participating today, and this concludes our hearing. Thanks, everybody.

[Whereupon, at 11:22 a.m., the Committee was adjourned.]

# APPENDIX

# Prepared Witness Statements

Statement Testimony Prepared For:
Hearing titled "Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges"
United States Senate Special Committee on Aging

By:
Mark A. Supiano, M.D.
D. Keith Barnes, M.D. and Dottie Barnes Presidential Endowed Chair in Medicine
Professor and Chief, Division of Geriatrics, University of Utah School of Medicine
Executive Director, University of Utah Center on Aging

May 20, 2021

Chairman Casey, Ranking Member Scott, and members of the Special Committee on Aging, thank you for providing me this opportunity to present my perspective on the exciting approaches that are available today supporting the goal to take aim at Alzheimer's Disease and Related Dementias (ADRD). I am a board-certified geriatrician at the University of Utah School of Medicine where I am Professor and Chief of the Geriatrics Division and Executive Director for the University of Utah Center on Aging. I have provided primary care for older adults for the past 30 plus years. In my primary care geriatrics medical home clinic, with the support of an interprofessional team of providers, I evaluate patients who present with cognitive concerns, diagnose and treat ADRD, and provide ongoing longitudinal care for these patients, and their families and caregivers. I provide whole-person centered care – not limited to just their cognitive concerns. In this regard, I should disclose that I do not consider myself to be an Alzheimer's Disease expert. However, I do have expertise in caring for persons who have dementia, and often many other chronic medical conditions. My research expertise is focused on mechanisms of vascular aging and the age-related increase in blood pressure, also known as geriatric hypertension. I will discuss how vascular aging and hypertension have emerged as key actors in the ADRD story – particularly with the good news that there are effective approaches to prevent cognitive impairment. I am an investigator with two clinical trials that are evaluating vascular risk factors for ADRD – SPRINT MIND and PREVENTABLE. In addition, I am a member of the Research Roundtable for the Alzheimer's Association's Centers for Disease Control and Prevention: BOLD Public Health Center of Excellence on Dementia Risk Reduction supported by the "Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act" – PL115-406. Finally, I am a member of the American Geriatrics Society Board of Directors.

## Definitions, the Grand Challenge and Grand Opportunity

Cognitive impairment is not normal aging. Rather, memory loss and limitations in other cognitive abilities develop as part of a disease process. The continuum of cognitive decline from mild cognitive impairment (MCI) to progressively more severe levels of dementia is shown in **Figure 1**. MCI is a discrete clinical condition diagnosed when there are limitations in memory or another cognitive ability, but the individual remains able to perform her or his daily activities. It is an obligatory precursor that in many individuals progresses to dementia, defined by the point when impairments in daily activities develop. Dementia should be thought of as a syndrome, not a cause. Alzheimer's Disease is a common, but only one of a host of conditions that cause dementia. It is of critical importance to evaluate an individual with a dementia syndrome diagnosis so that its cause may be identified. It is also important to understand that ADRD does not present in isolation, but is more often the dominant comorbidity among many other chronic medical conditions and medications that an older adult may be managing. Hence, the need for comprehensive, person-centered care.

ADRD is a "Grand Challenge" facing our society and medical science in the 21st century. Statistics from the Alzheimer's Association are that an estimated 6 million Americans are living with ADRD in 2021, and 11 million Americans are providing unpaid care for persons with ADRD. Alzheimer's Disease is the only one of the top ten leading causes of death in the United States that is increasing in prevalence. In the last 10 years, heart disease deaths have decreased by 7.3% while deaths from AD have increased by 145%. The estimated costs of health care, long-term care and hospice for ADRD in the US is estimated to be $355 billion currently and expected to grow to $1.1 trillion by 2050.

Addressing ADRD is a significant and important undertaking in Utah where the ADRD statistics are even more sobering. Driven by the aging demographic trends in Utah, demographic projections estimate that the number of people with AD in Utah will increase from the current 34,000 to 42,000 – a 24% increase – by 2025. The Utah Department of Health has created a state plan for Alzheimer's Disease and Related Dementias 2018-2022 which is currently being implemented.

ADRD also is a "Grand Opportunity" for academic research. Scientific advances in neuroscience, genetics, informatics, and imaging provide new abilities to probe disease mechanisms and inform practical solutions for diagnosis and management. These research advances open the door to investigations into mechanisms of cognitive resilience and characterize resiliency factors as moderators between neuropathology and dementia in ADRD. The National Institutes of Health AD Research Summit in 2015 identified "Understand all aspects of healthy brain aging and *cognitive resilience* to inform strategies for

AD prevention" as one of the transformative concepts that summit participants agreed was critical to the future of AD research. NIA has developed the AD+ADRD Research Implementation Milestones to represent a research framework detailing specific steps and success criteria towards achieving the goal of the National Plan to Address Alzheimer's Disease to treat and prevent AD and ADRDs by 2025.

**Effective strategies to prevent and treat MCI and ADRD are available**

There is not yet a proven, safe, disease-modifying treatment for individuals diagnosed with Alzheimer's Disease. Several promising approaches – antibody therapies that are directed to reduce the levels of the abnormal ß-amyloid protein in the brain that are believed to cause damage to brain cells – are currently under investigation. There is much hope that one or more of these amyloid immunotherapies will become available to prevent AD progression early in the disease course.

There is a growing body of evidence that effective strategies to prevent and treat MCI and ADRD are available today. The 2020 dementia prevention, intervention, and care report from the Lancet Commission concluded, "Together the 12 modifiable risk factors account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed. The potential for prevention is high and might be higher in low-income and middle-income countries (LMIC) where more dementias occur."[1] **Figure 2**, taken from the Commission's report, illustrates the relative contributions across the life span for each of these *modifiable* risk factors – less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, infrequent social contact, excessive alcohol consumption, head injury, and air pollution.

The age-related vascular contributions to ADRD have been the focus of my own research interest. These mechanisms are illustrated in **Figure 3**.[2] I am an investigator with the Systolic Blood Pressure Intervention Trial (SPRINT) Memory and Cognition in Decreased Hypertension (MIND) clinical trial funded by the National Institutes of Health (ClinicalTrials.gov, NCT01206062). This study demonstrated that among those with hypertension, intensive management of systolic blood pressure (SBP) to a treatment goal of 120 mm Hg reduced the development of mild cognitive impairment (MCI) by 19% [3] and slowed the accumulation of white matter hyperintensities in the brain [4]. This landmark study offers hope that a new paradigm is needed to develop strategies that may delay MCI and AD. In her editorial to the SPRINT-MIND publication, Dr. Yaffe stated, "*Indeed, the timing is right to investigate multidomain risk reduction strategies personalized for older adults and their individual risk profiles. Eventually this modifiable risk factor approach could be combined with disease-modifying* *drugs so that one day, it will be possible to identify persons at risk of AD and related dementia (either by biomarkers, genetics, or cognitive symptoms) and offer an effective strategy for prevention of cognitive impairment*."[5] The Pragmatic Evaluation of Events And Benefits of Lipid-lowering in Older Adults (PREVENTABLE) (ClinicalTrials.gov NCT04262206) is a pragmatic clinical trial currently being conducted in 20,000 adults age 75 years and older that is evaluating whether a commonly used heart medication – a statin – will be beneficial in preventing MCI and dementia.

In parallel with efforts to provide disease modifying treatments for AD, the importance of implementing existing preventive strategies cannot be overstated. The most effective way to decrease ADRD prevalence is to postpone its onset. A two-year delay in dementia onset would translate to 2.2 million fewer Americans developing dementia in 2040 – a 20% reduction [6] (**Figure 4**).

There are effective, evidenced-based, dementia care programs that could be implemented today. The Care Ecosystem pragmatic clinical trial of people with dementia and their caregivers evaluated a telephone-based care delivery approach using a care team navigator supported by a team of dementia specialists (advanced practice nurse, social worker and pharmacist). There were significant improvements in caregiver quality of life, depression and burden, and a reduction in emergency room utilization.[7] Another innovative program is "Community Aging in Place—Advancing Better Living for Elders (CAPABLE; ClinicalTrials.gov NCT01743495)" that targets supporting low-income older adults to age in place. Its approach teams a nurse, an occupational therapist and a handy worker to address the home environment and to improve safety and independence. The study demonstrated lower likelihood of inpatient and long-term service use and lower over-all Medicaid spending.[8]

**Recommendations:**

These recent advances in strategies to prevent cognitive impairment and to provide effective dementia management services lead me to conclude with the following recommendations:

1. *Promote Prevention Strategies*

Promoting cognitive screening is an important precursor to implementing prevention strategies. Creating a dementia aware society where cognitive screening is normalized will help to reduce the stigma that often accompanies a dementia diagnosis. The need for early detection of cognitive impairment is all the more relevant today so that preventive strategies and treatments may be initiated early. Requiring validated, objective, screening tests of memory and cognition in the Medicare Annual Medicare Wellness visit is one strategy to accomplish this.

Implementing public health strategies that target modifiable dementia risk factors that will be recommended as an outcome from the CDC BOLD Infrastructure programs will be critically important. Many of these modifiable risk factors disproportionally impact underserved populations with adverse social determinants of health. Mitigating the impact of these health disparities is urgently needed.

2. *Develop a Dementia-competent workforce*

Most dementia care is provided by primary care health professionals. All members of the health care team will require education and training to competently evaluate and manage patients with cognitive impairment and dementia. In parallel, there is a need to expand the number of geriatrics health care professionals, including geriatricians and cognitive specialists, to meet the demands for appropriate diagnosis of patients with dementia.

There is a special need to support hands-on caregivers and the direct care worker (in home and in long term care settings) workforce to equip them to care for persons with dementia. This support should include ensuring living wages, benefits and paid family leave.

3. *Support Dementia Management Programs and Family Caregivers*

There is a pressing need to provide options so persons with dementia and their families and caregivers can access the right care, in the right setting, at the right time. Efforts to expand home and community-based services (HCBS) and making evidence-based programs like the Care Ecosystem and CAPABLE more broadly available will help decrease excess health care system utilization and avoid premature placements in skilled nursing facilities. The recently introduced bipartisan "Comprehensive Care for Alzheimer's Act" is designed to support the development and evaluate dementia care management programs like these. At the same time, we must work to improve nursing home care so that this setting is available to families who can no longer support their loved one at home.

4. *Continue to invest in ADRD Research*

The recent infusion of ADRD research support has already begun to yield important results such as those I have cited. Ensuring that more ADRD clinical trials appropriately include participants across the lifespan without upper age limits[9], include appropriate racial, ethnic, and gender diversity,[10,11] and incorporate geriatrics relevant outcomes such as cognitive function (as is being done in the PREVENTABLE study) is important in this regard, especially when FDA approval of new therapies is being considered. Future research is sorely needed to identify mechanisms for cognitive resilience, promoting cultural awareness, and addressing the disproportionate impact of health disparities in developing cognitive impairment.

Thank you for giving me the opportunity to share my perspective with you today. I look forward to addressing your questions and comments.

## Figures

Figure 1: The cognitive impairment continuum.

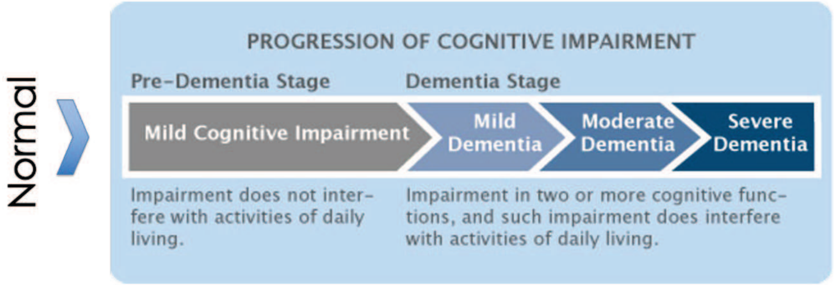


**Figure 2**. Population attributable fraction of potentially modifiable risk factors for dementia. [1]

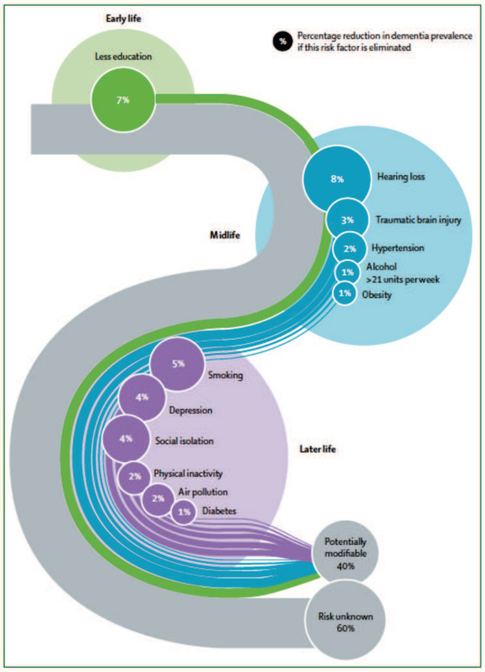
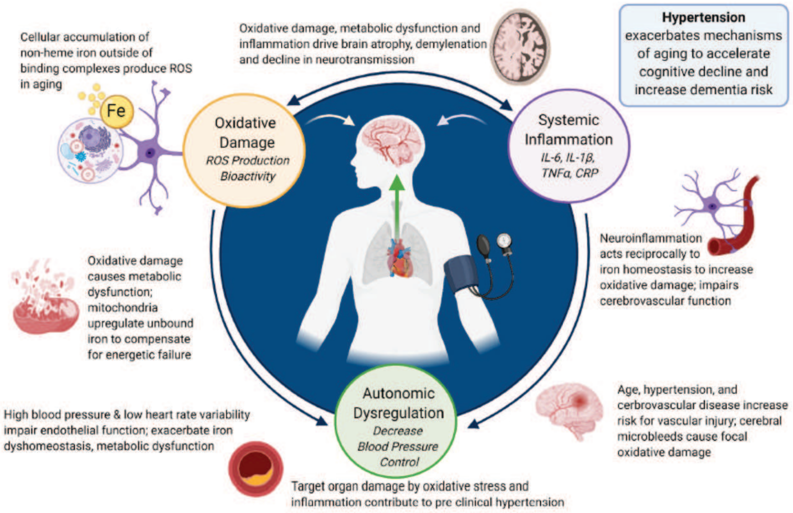


**Figure 3**: Putative pathways for hypertension to increase risk for cognitive decline in aging and neurodegenerative disease [2]



Cellular accumulation of non-heme iron outside of binding complexes produce ROS in aging

Oxidative damage, metabolic dysfunction and inflammation drive brain atrophy, demylenation and decline in neurotransmission

**Hypertension** exacerbates mechanisms of aging to accelerate cognitive decline and increase dementia risk

Neuroinflammation acts reciprocally to iron homeostasis to increase oxidative damage; impairs cerebrovascular function

Oxidative damage causes metabolic dysfunction; mitochondria upregulate unbound iron to compensate for energetic failure

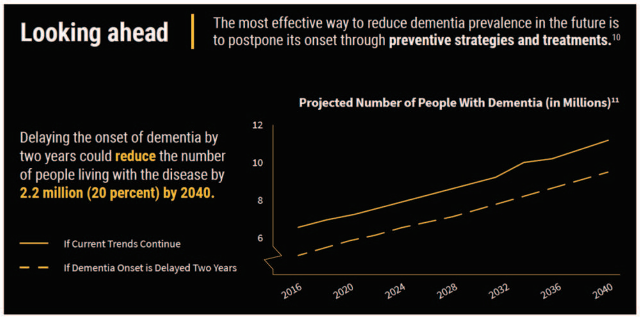
Age, hypertension, and cerbrovascular disease increase risk for vascular injury; cerebral microbleeds cause focal oxidative damage

High blood pressure & low heart rate variability impair endothelial function; exacerbate iron dyshomeostasis, metabolic dysfunction

Target organ damage by oxidative stress and inflammation contribute to pre clinical hypertension

**Fig. 1.** A summary figure describing putative pathways for hypertension to increase risk for cognitive decline in aging and neurodegenerative disease. Midlife hypertension accelerates neurodegeneration and cognitive decline in aging, and increases the risk for Alzheimer's disease and related dementia (ADRD). Although hypertension is a modifiable risk factor, successful blood pressure control with antihypertensive treatment does not reduce the risk for ADRD. This suggests hypertension may act upon antecedents of age-related neurodegeneration. The three pathways reviewed were (1) oxidative damage and metabolic dysfunction; (2) systemic inflammation; and (3) autonomic control and heart rate variability. The pathways reflect cumulative and progressive changes in nervous system function and health that are typical in aging, contribute to the development of hypertension and drive neural and cognitive decline, which chronic high blood pressure further exacerbates. The pathways interact to create a self-propagating cascade that subsequent blood pressure control may slow, but not halt, to account for dementia risk. Abbreviations: ROS—reactive oxygen species; IL-6 and IL-1β—interleukin-6 and − 1β; TNFα—tumor necrosis factor alpha; CRP—C-reactive protein. Figure created with BioRender.com.

**Figure 4**: Impact of ADRD Preventive Strategies [6]



**Looking ahead**

The most effective way to reduce dementia prevalence in the future is to postpone its onset through **preventive strategies and treatments.**[10]

Delaying the onset of dementia by two years could **reduce** the number of people living with the disease by **2.2 million (20 percent) by 2040.**

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**Additional Resources:**

2020 Update of the National Plan to Address Alzheimer's Disease https://aspe.hhs.gov/pdf-report/national-plan-address-alzheimers-disease-2020-update

National Data: https://www.alz.org/media/Documents/alzheimers-facts-and-figures-infographic.pdf

Utah Data: https://www.alz.org/media/Documents/utah-alzheimers-facts-figures-2021.pdf

Utah Alzheimer's Disease State Plan: Utah's State Plan for Alzheimer's Disease and Related Dementias 2018-2022. Version 1.0. (2017) Salt Lake City, Utah: Utah Department of Health https://livingwell.utah.gov/docs/Alzheimers_StatePlan.pdf

Alzheimer's Association Trajectory Report: https://www.alz.org/media/Documents/trajectory-report-infographic.pdf

CDC BOLD Initiative: https://www.cdc.gov/aging/bold/index.html

## Testimony of Jennifer Manly, PhD

## Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges

**United States Senate Special Committee on Aging**

**May 20, 2021**

Chairman Casey, Ranking Member Scott, and Distinguished Members of the Committee, thank you for the opportunity to share information on the challenges we face in meeting the needs of people with Alzheimer's disease and their caregivers.

### *Introduction:*

My name is Jennifer Manly. I am a Professor of Neuropsychology in Neurology at the Gertrude H. Sergievsky Center and the Taub Institute for Research in Aging and Alzheimer's Disease at Columbia University. I have been the Principal investigator or a Co-Investigator on over 45 successful grant applications and authored more than 185 peer-reviewed articles that have contributed insights into disparities in dementia across racial and ethnic groups. My research has explored how early life inequalities, including school policies and educational opportunities influence risk and resilience for cognitive decline and biomarkers of brain health, as well as measurement of cognitive function among Black or African American and Latinx or Hispanic older adults. I am one of the lead investigators for several large longitudinal studies that include adults from diverse racial, ethnic, linguistic, and socioeconomic backgrounds, including the Washington Heights-Inwood Columbia Aging Project (WHICAP), Offspring Study of Mechanisms for Racial Disparities in Alzheimer's Disease (Offspring), and the Reasons for Geographic and Racial Differences in Stroke Study (REGARDS). I also lead the School Quality in Project Talent Aging Study and was the PI of the multi-site African American Alzheimer's Disease Genetics Study.

### *Overview:*

Over the last decade we have seen a tremendous increase in the federal investment for research on Alzheimer's disease. While this investment has accelerated our understanding of the heterogeneity of the disease and has allowed us to engage a more diverse group of Americans in Alzheimer's research, little progress has been made in decreasing racial/ethnic disparities in the development of Alzheimer's disease (AD), or equitable care for those living with AD.[1] Today, my goal is to shed some light on ways we can narrow disparities in Alzheimer's disease risk, diagnosis, and access to care and long term services.

### *Alzheimer's Disease 101:*

Before discussing dementia inequalities, I would like to provide a brief overview of the disease.

*Dementia vs AD*

Dementia is an umbrella term for cognitive difficulties that have their onset in adulthood that affect a person's ability to independently perform everyday activities. Cognitive abilities that can be affected by dementia include memory, language, attention, spatial abilities, problem-solving, and other thinking skills. As result, as the disease progresses, individuals with dementia need help making decisions and increased supervision, and ultimately, they may require full-time, long-term care.

There are several different types of dementia, and each type is associated with a unique set of clinical characteristics and cognitive profile. Alzheimer's disease is the most common cause of dementia; it accounts for approximately 60%-80% of all dementia cases.[2] As people get older, they are at higher risk for developing Alzheimer's disease. People with a family history of Alzheimer's are also at higher risk.

*Symptom Onset & Course of Alzheimer's Disease*

Alzheimer's disease is a clinical syndrome that is caused by loss of brain function. It has a gradual onset, and is a progressive disease that becomes worse with time. The neuropathology (abnormal changes in the brain) associated with AD appears in the fifth and sixth decade of life, many years before the onset of symptoms. The first symptoms usually occur in older adulthood and are typically subtle problems with memory that may be noticeable to the individual and their family and friends, but do not interfere with everyday activities. Over time memory problems worsen and other areas of cognitive function also decline. Gradually, the ability to independently complete complex daily activities, such as driving, learning new routines, remembering appointments, finances, following a recipe, doing laundry, and housecleaning, begins to decline. Eventually, cognitive impairment gets to the point where an individual is no longer able to remember names and faces of family members, and complete very basic tasks such as toileting, dressing, and/or feeding. At the severe stage of the disease, individuals are no longer able to swallow.

*Diagnosis*

There is no single test to diagnose Alzheimer's disease. Rather, a formal diagnosis requires gathering information from a variety of sources, including obtaining medical and family history, reports from family or close friends about changes in thinking skills and behavior, blood tests and brain imaging such as MRI and PET scans, and cognitive tests conducted by a trained specialist such as a neuropsychologist, to carefully assess changes in memory and thinking skills.

Access to cognitive testing is important because there is often a disconnect between burden of neuropathology and clinical symptoms, such that two people with the same amount of brain disease (or neuropathology) can have different severity of memory deficits. Brain autopsy of people who did not have dementia and who die in their 80's and 90's shows that many of them have neuropathological changes that look just like people who had dementia. This imperfect link between neuropathological burden and cognitive function is called cognitive reserve or cognitive resilience. This is important because while we are searching for treatments to stop the neuropathology associated with AD, there may be ways to slow progression or prevent dementia by increasing cognitive reserve or resilience.

Access to neuropsychological testing and a full diagnostic workup is also important because other subtypes of dementia, such as Vascular Dementia and Lewy body dementia can have similar symptoms to Alzheimer's Disease. Accurate diagnosis based on a comprehensive diagnostic assessment is important to determine the right treatments, and the right types of family supports and planning that may be needed.

Researchers have identified abnormal levels of proteins, such as beta-amyloid and tau, as well as vascular changes in the brain, that are associated with loss of cognitive function in people with Alzheimer's disease. However, recent trials of drugs that remove amyloid from the brain suggest that it might not be enough to remove the abnormal proteins once they are already present in the brain, to slow cognitive decline or prevent dementia.

### *Incidence & Prevalence of AD*

Currently, an estimated 6.2 million Americans age 65 and older are living with AD.[3] That is more than 1 in 9 people age 65 and older living in the United States. By 2025 the number of those living with AD is expected to increase by 16% to 7.2 million. By 2060, that number is expected to reach 13.8 million.[2] Younger or Early Onset Alzheimer's disease, defined as onset of symptoms before the age of 65, is less common; researchers think that anywhere from 4 – 5% of all of the people with AD had symptom onset before age 65.

### *Disparities*

Rates of AD are higher among Black or African Americans and Latinx or Hispanics than non-Hispanic White older adults.[4–9] In other words, at the same age, a higher proportion of Black and Hispanic older adults live with AD than White older adults. More women are affected by Alzheimer's disease (AD) than men because women live longer, and age is the primary risk factor for AD. Of the approximately 6.2 million Americans age 65 and older currently living with AD, about 3.8 million are women.[2] Women also represent approximately two-thirds of the dementia caregivers in the United States.[10–12] It is now well established that people who had fewer opportunities to receive education when they were children, are at higher risk for Alzheimer's disease later in life.[13,14] There is evidence that early life residence in a "Stroke Belt" state, including states that Committee members represent, such as Georgia, North Carolina, and South Carolina, leads to higher risk for AD, even if you move out of the Stroke Belt .[15,16]

Overall, Alzheimer's disease is underdiagnosed. In other words, only about half of the people who have Alzheimer's disease ever receive a formal diagnosis by a doctor. There is evidence that missed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among older Whites.[17–19]

### ***Dr. Manly's Research***

For the past 23 years I have been an investigator for a community-based longitudinal study of aging and dementia,[7] where I have worked closely with the older residents of the Washington Heights, Hamilton Heights, and Inwood communities of Northern Manhattan in New York. These communities are primarily African American and Caribbean Hispanic. The older adults in this incredibly strong and vibrant community have taught me about their life experiences and allowed my research team to partner with their families. I have seen how structural inequalities in education, housing, jobs, and access to quality and culturally and linguistically appropriate health care influence and maintain disparities in AD risk, diagnosis, and care.

My work largely focuses on understanding why disparities in Alzheimer's disease and dementia are maintained and how to narrow or eliminate them. Our research suggests that the core explanation for disparities in dementia is structural inequalities. There are historical and contemporary policies that have created unequal access to resources and may increase exposure to stressors throughout life. These conditions get "under the skin" at a very young age and account for racial/ethnic disparities in Alzheimer's disease as people get older. For example, the United States has a long legacy of denying Black Americans equal access to high quality education, and this legacy has been shown to have an impact on health of older adults. Segregation of schools in the South and the North was accomplished through local laws and state-level resources for public schools varied widely across states. Across all U.S. States, before and after Brown v. Board of Education, racist policies and residential segregation forced Black children to attend underfunded schools that had large student/teacher ratios, shorter term length, lower teacher salaries, inadequate budgets for supplies and school buildings, and discriminatory disciplinary policies. Many older residents of Washington Heights immigrated from the Dominican Republic, where, especially in the rural areas, there was very little governmental investment in education, and fewer opportunities for children to go to school or to learn to read or write. My research team found that that later life dementia risk and cognitive decline are influenced by early-life educational policies in the places where people went to school. This work suggests that investment in schools that serve Black and Hispanic children would narrow inequalities in dementia.

We do not yet know exactly what it is about schooling that lowers risk for dementia, but one strong possibility is that more years of school, and a higher quality education, leads to the credential and skills needed to get better jobs, earn more money, live in healthier neighborhoods, and lower exposure to stress. There is some evidence that the benefits of higher education are not as strong in Black people as they are among Whites, suggesting that racism in school, at work, in housing, and in health care impedes Black people from converting educational credentials to lasting brain health later in life. This research suggests that investment in neighborhoods, housing, and health care in racial and ethnic communities that are underserved, and advancing racial equity in institutions would have a positive impact on later life brain health of our nation.

### ***Disparities in Dementia Services, Care, & Caregiving***

There are also racial/ethnic disparities in the diagnosis and care of individuals with AD, including availability of support services and time spent on caregiving.[20–23]

*Dementia Services*

Primary care providers who practice in communities with increased African American and Latinx populations (compared with White) have fewer community resources to refer patients to behavioral health professionals.[24] Where I work in Washington Heights and Harlem, there are very few neurologists, psychiatrists, geriatricians, and neuropsychologists who are fluent in Spanish, who can provide language-concordant diagnosis and care for Spanish speaking older adults. Those that are bilingual in Spanish and English have long waiting lists of patients and families who need an assessment. The lack of community resources is also striking for providers who practice in rural areas, regardless of neighborhood-level insurance status. Primary care physicians in urban communities with larger proportions of minoritized and uninsured populations have the greatest unmet need for local behavioral health professionals. Lack of culturally appropriate resources for dementia diagnosis and care is a key reason why African Americans and Hispanics with dementia are less likely than White people with dementia to have a formal diagnosis, and are more advanced in their disease when they are diagnosed.

In order to close this gap, we should invest in training programs that graduate qualified, culturally competent behavioral health professionals with specialty training in dementia care. Diversity and cultural competence of these trained professionals is key to responding to the needs of older adults from traditionally underserved communities who are at higher risk of developing cognitive impairment and AD. To improve patient access to behavioral health services, behavioral health professionals must practice in the neighborhoods where underserved communities live. Behavioral health professionals who provide dementia care should be incentivized to practice in communities that are traditionally underserved. In other words, narrowing inequalities in dementia services will require policy that focuses on the neighborhood or local level, increasing options for families seeking dementia serviced in the places that they live. We need to increase the number of providers who have the individual skills, cultural competencies, and capacity to provide dementia care services.

There is a need for investment in capacity and coordination of community health centers and/or older adult day centers that provide direct services within underserved communities, with specific strategies for improving access to brain health services and dementia assessments.[25] One other tool for meeting high demand for dementia diagnosis and care in underserved communities is telehealth. However, federal investment must be expanded to address culturally relevant telehealth solutions for dementia diagnostic services and ongoing care in both rural and urban settings.[25]

*Family Caregiving*

More than 11 million Americans provide unpaid care for people with AD or other dementias.[27] Unpaid caregivers in each of the four most populous states provided care valued at more than

$10 billion.[2] In 2020, unpaid family caregivers of people with AD provided an estimated 15.3 billion hours of unpaid help.[2] Many of these family caregivers are employed, working full-and part-time jobs while caregiving.[28] Approximately one-quarter of dementia family caregivers are "sandwich generation", caring not only for an aging parent, but also for a child.[28] There is uneven access to paid family leave, because Black and Hispanic individuals are less likely to hold a job that provides paid family leave.[29,30]

People from minoritized backgrounds are more likely to rely on informal and unpaid family care for people with dementia than to employ formal direct care workers. Our healthcare system has not earned the trust of many Americans from minoritized backgrounds [31–33] and, as a result, even if they can afford it, many choose to keep caregiving responsibilities among family members. Racial and ethnic differences in family caregiving is also related to the high cost of paid care inside and outside of the home. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid $11,571 out of pocket annually for health care and long-term care services not covered by other sources.[2] Medicare covers home health services, such as part-time skilled nursing care, home health aide (personal hands-on) care, therapies and medical social services in the home, but does not include homemaker or personal care services. Although Medicare covers care in a long-term care hospital, skilled nursing care in a skilled nursing home, and hospice care, long-term care in a nursing home is not covered by Medicare.[34] While Medicaid may cover some services that Medicare does not, these benefits vary state-to-state, as do the criteria to receive home-based care.[35]

### ***Gaps in the Dementia Care Workforce***

#### *Direct Care Workers*

Direct care workers play an important role in home-based care. This workforce largely consists of women of color, many of whom have less than a high school education and were born outside of the US.[36] Direct care workers earn low wages and experience high turnover.[37] About 25% of direct care workers have an income below 138% of the federal poverty line and 42% rely on public assistance. Studies have shown that compensation for direct care workers plays a key role in turnover rates.[38]

Direct care jobs are often viewed as "dead-end jobs" because they are offered little career advancement. It is time to elevate the value of the direct care workforce to be consistent with the essential role that these carers play in the wellbeing of our society. Facilitating career advancement opportunities within direct care will help strengthen recruitment and retention, and this stability and training produces better quality of life among people with dementia and their families. Workers who are offered opportunities for advancement can mentor, support, and supervise other workers entering the field, which will increase the retention of direct care workers overall.[38,39]

Language is often cited as a barrier to receiving dementia-related care.[40] One of the biggest challenges for families in Washington Heights is that most of the doctors who provide specialized dementia care do not speak Spanish. Using an interpreter for any medical visit has limitations, but this is even more of a barrier to quality care when the patient has cognitive deficits. In communities like Washington Heights, bilingual home health care workers are a necessity, and highly sought after. In the dementia care workforce, bilingual staff are a valuable, under-recognized and underpaid resource.

### *Recommendations*

1) Several studies show that Black and Hispanic older adults are at higher risk of Alzheimer's Disease than non-Hispanic Whites, and that these disparities are linked to structural inequalities that begin early in life. My research suggests that investment in schools that serve Black and Hispanic children, in neighborhoods, housing, and health care among racial and ethnic communities that are underserved, and advancing racial equity in institutions would narrow inequalities in dementia.
2) Early and accurate diagnosis of dementia is at the core of provision of dementia services, yet there are fewer resources to refer patients to dementia care professionals in underserved communities. Limited number of clinicians who can provide language concordant dementia assessment creates long waiting lists and delays diagnosis in many underserved communities. Investing in training programs that increase the number of culturally competent dementia care providers, innovating and broadening dementia care options in neighborhoods with a higher impact of dementia among minoritized people, and incentivizing clinicians to practice in these communities would help to narrow the gap in dementia care and services.
3) Investment in the direct care workforce will improve quality of life among people with dementia and their families and narrow disparities in care. Investment in the direct care workforce must take an equity-focused approach that is geared toward restoring access and allocating resources to communities that are currently underserved by most dementia care services. This may include, for example, targeted recruitment and training of community members interested in health care careers, and increased reimbursement for skills such as bilingualism, that help narrow gaps in access to high quality, culturally and linguistically appropriate services.
4) Expansion of paid family leave is an equity issue for dementia care and services, because while people from minoritized backgrounds are more likely to rely on family caregiving, they are also less likely to hold a job that provides paid family leave.

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## Statement of Peg Lahmeyer, Executive Director and Co-Founder, The Ark of South Carolina, Summerville, South Carolina

Thank you to the Senate Special Committee on Aging, Chairman, Senator Casey and Ranking Member, Senator Scott. Thank you for the opportunity to testify about my experiences as a caregiver and the founder and Executive Director of The ARK of SC for 25+ years

Growing up in rural Alabama with older parents and much older siblings, I witnessed how our family and extended family cared for each other and nurtured each other during tough times and good times. These impactful life experiences shaped my life.

My family expanded to Summerville, SC with a wonderful husband, 6 children and step children to include the adoption in 1986 of an "at risk" teenager.

My mother was diagnosed at age 76 with Alzheimer's. Multiple visits showed the continual decline for both of my parents. My father, age 80, was Mother's caregiver for 8 years when he called to say he needed help. We moved her to a long term care facility in Montgomery which was 45 miles from my dad. It was devastating for both of them. My father died in 1990 at the age of 90. We moved Mother to live with us. I was granted Conservatorship. Working full time, I resigned to be her caregiver. I worked part time delivering newspapers so I could be at home during the day.

After discussing the plight and needs for caregivers to "have a break" and support, I was asked to start a group social respite at our church. Brookdale National Group Respite Program provided seed grant funding. In January 1996 The ARK opened its doors.

Needing skill care, my mother moved into an Alzheimer's specific long term care in 1995 before The ARK opened. She died in 1997 at the age of 93. Her legacy lives on through The ARK.

I sought every opportunity to speak to ANYONE—church, civic, fraternal organizations, businesses, governmental groups, clubs and anywhere there was an audience. The local Chapter of the Alzheimer's Association in Charleston was just starting and I became involved in many of their educational committees, fundraising, and eventually as a Board Member.

As a previous business person, I believe in the power of the Chamber of Commerce. Becoming a member has opened many doors for support and growth. Nonprofits are essential to the community.

The ARK provides so much more than respite to five counties in the Lowcountry of SC.

Services include:

- Four Respite half days a week in Summerville
- Bus Service provided since 2000
- A Satellite respite center in Harleyville weekly
- Four support groups in Berkeley and Dorchester counties (one specific to wives only)
- An Early Memory Loss Program weekly

The NOAH (Neighborhood Outreach Alzheimer's Help) Project provides:

- Caregiver educational classes, memory screenings, health and resource events
- Law Enforcement/First Responders training–Evidenced based and Certified through the S.C. Criminal Justice Academy
- Workshops and train the trainer programs, both in person and virtual
  Powerful Tools for Caregivers (PTC)—6 week evidenced based
  Class Leader Training (CLT) for Professionals

All of these services are provided by five full-time and four part-time staff. They are devoted, passionate, fun loving, supportive and caring.

In 2018, we acquired a home to move our services and staff to enable expansion.

Through the shutdown and pandemic, our social program closed for 7 months. The Staff immediately started calling/emailing caregivers, creating fun activity baskets that were delivered to their homes. Zoom was our salvation for workshops and PTC/CLT, memory screenings, and support groups. Caregivers and families felt less isolated and connected. The CLT classes reached as far as Alaska and one in July 2021 includes British Columbia professionals.

When we returned to full time programming, we saw the decline in our ARK families because of the isolation and lack of socialization and realize how important our programs are for caregivers and care receivers' well-being. Now, we are seeing the effects of dementia to include not only the baby boomers but now the millennials are experiencing caregiving and in some cases early onset dementia.

Funding for grassroots organizations is paramount. Additional State funding for Aging services is critical especially for Alzheimer's support programs. Families need to afford in home care as well. With the support of South Carolina's Office on Aging we have been able to build our education program. More funding for all aging services is needed as the numbers are growing each and every day.

Thank you

### Statement of Katelyn Montanez, Family Caregiver, Ephrata, Pennsylvania

Chairman Casey, Ranking Member Scott, and members of this Committee, thank you for the opportunity to testify before the Committee about my experiences as a caregiver for my father. My hope is that, in sharing my story, others who are impacted by this disease will feel less alone. I am a social worker and an advocate for my father and for the millions of Americans who have family or loved ones living with Alzheimer's and other dementia. I'm here today to share my personal experience as a caregiver for my father, Luis, who was diagnosed with younger-onset Alzheimer's at age 54.

More than 6 million Americans are living with Alzheimer's—my father's story represents only one set of unique challenges which individuals and caregivers live with every day. My hope is that my testimony effectively conveys my father's story, and underscores the importance of what this hearing is based around—expanding the support of daily and long-term care needs of people with dementia, which includes the support of their caregivers.

Like many other individuals, Alzheimer's disease can be traced hereditarily in my family. My grandmother passed away from Alzheimer's at age 62. My father's sister passed away last year from the disease, and currently, another aunt of mine is living with the disease, requiring her to reside in a nursing home.

My father began showing symptoms of Alzheimer's in his early 50's, but he wasn't formally diagnosed until 2015 at the age of 54. After he began displaying symptoms my family was familiar with, my parents visited a few providers to see if they could figure out his neurological and other health issues. Each doctor my father visited didn't recognize the signs of younger-onset Alzheimer's. Prior to his diagnosis, it became my mother's responsibility to attempt to understand how to navigate resources that could be available to my family. My dad was unable to earn a living for his family and just stayed home, confused and disoriented. He had been a custodian at a local school and now we were faced with a difficult new reality as a family. My mom and I were both working full time and we were unable to provide the 24-hour supervision he needed. The delay in diagnosis and fragmented care he received, left us feeling frustrated, alone, and unable to access much-needed supports and services. It was an incredibly challenging time for us. At first, when he was assessed for home- and community-based services, he wasn't eligible because he could still do many things on his own-but that was only on good days. On bad days, he wasn't able to do anything.

I am a social worker, I know the system well, and I had to fight to get him the services he needed. Unfortunately, it took cutting through many layers of red tape, hundreds of pages of paperwork, and most distressing of all, nearly 5 years to receive the care and support services he needed.

While the emotional toll of younger-onset Alzheimer's is something which I have channeled into advocating for individuals like my father, there are significant costs for individuals living with their disease and their families. This placed a large financial responsibility on both my mother and I as his caregivers and now the financial support for our family. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families—either through out-of-pocket health and long-term care expenses, or from the value of unpaid care. I am part of that statistic—I ended up leaving my first year of graduate school to come home in order to help with his care.

Last fall, we were fortunate enough to finally get him Medicaid home and community-based services through the waiver program in Pennsylvania. A medical social worker helped us through the application process and with the numerous assessments and paperwork that had to be done. It shouldn't be this hard for people to receive services they need.

My father has been receiving home- and community-based services now for about 7 months. I know this Committee's hearing today is focused on the importance of these services, and I cannot tell you how thankful I am that we have been able to have access to them. We recently had to move my dad to my sister's house because my mom was no longer able to take care of him. The transition was difficult because he understands what is happening.

The services he's receiving give him an aide for 3 hours per day and meals on wheels. When he was living with my mom, the aides would help clean the house, help my dad with breakfast, and even take him on short car rides. Now that he's living with my sister, the aides take him on walks and sometimes even bring along my sister's dogs. The aides also come in the evening to give my sister a chance to run errands and have a break. We've also run into some issues: right now my sister hasn't been able to find an aide for my dad because of the high burnout and turnover rates.

With someone living with Alzheimer's or dementia, consistency of care, including who is providing the care, is essential. Unfortunately, burnout and turnover are very common with home health aides. Being an aide is hard work with little pay. Aides should be paid more for the work they do and have better access to dementia education and training for their workers. If aides received proper training to work with individuals living with Alzheimer's and dementia, they would have the tools they need to help redirect, would understand common behavioral issues, and it could lead to more successful interactions. People living with Alzheimer's have good days and bad days and having better trained aides who get paid higher wages would bring more consistency for my dad, and a better quality of life for him and our family.

Congress has continued to keep Alzheimer's and dementia top of mind when working on important issues like home- and community-based services. Chairman Casey, I'm grateful for your leadership on this important and deeply personal issue. I am a passionate advocate for my dad and for others living with Alzheimer's and other dementia. It's important to me that people living with Alzheimer's—including those who are younger than 60—are able to receive the care and support they need. Strengthening these services is not only essential, it will help people like my father live with family members for as long as possible before having to receive care in a nursing home setting. I want to start my own non-profit to help families like mine to have better access to available services to help the person they love remain at home longer.

After my dad's diagnosis, it felt like a struggle to get the information we now know we needed. The fragmented, improperly managed care he received only added to our struggle. It would have been and would continue to be incredibly beneficial to my family if we had more comprehensive care for my dad. As you've heard from my testimony, caring for an individual with Alzheimer's or another dementia poses unique challenges. Thankfully, dementia care management can ease these challenges, improve the quality of care, and reduce costs. Unfortunately, dementia care management programs have not developed within the current Medicare fee-for-service system. Legislation like the bipartisan Comprehensive Care for Alzheimer's Act (S. 1125 / H.R. 2517) would ask the Center for Medicare and Medicaid Innovation to test a different payment structure for dementia care management. It aims to reach diverse populations, rural areas, and medically underserved communities so everyone has an opportunity for more comprehensive care. This bill has the potential to streamline today's complicated health care maze for people living with dementia and their caregivers—making this easier will provide a better quality of life for individuals like my father.

I am Puerto Rican, and unfortunately that means I am at greater risk of developing the disease. Hispanic Americans are one and one-half times more likely to develop Alzheimer's disease but we are historically underrepresented in Alzheimer's and other dementia clinical trials. In fact, in 2018, across all clinical drug trials—not just Alzheimer's—Hispanic Americans represented only 1 percent and Black Americans represented only 5 percent of trial participants, despite representing 18 percent and 13 percent of the population, respectively. The best available evidence suggests that this trend is similar in Alzheimer's research. The underrepresentation of these populations, as well as Asian and Native Americans, not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved drug or diagnostic may affect the population most likely to need the therapy. Senators Ben Ray Lujan and Collins introduced the bipartisan Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548), to increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff and reducing participation burden. I ask the Committee and other Members of Congress to support this bill to ensure current and future research includes increased numbers of Blacks, Hispanics, Asian and Native Americans in clinical trials to ensure everyone, including my family, benefits from advances in Alzheimer's science.

Throughout the past few days, I've virtually joined the Alzheimer's Impact Movement and the Alzheimer's Association, along with over 2,100 advocates from across the country to make a difference in our nation's capital. I am here as a daughter, niece, and granddaughter of Alzheimer's. We all are and we will continue to be a voice for people who have lost theirs. Congress must ensure all communities have access to high-quality, culturally appropriate services and supports. Additionally, I respectfully ask you to increase access to home and community-based services for individuals living with Alzheimer's and dementia including individuals living with younger-onset Alzheimer's disease or other dementia. Please continue to make Alzheimer's research a priority and to work together to pass critical legislation like the Comprehensive Care for Alzheimer's Act (S. 1125/H.R. 2517) and the Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548/H.R. 3085) to help other families like mine receive the support and services we all need and deserve. Thank you for inviting me to speak, listening to my story, and for all you have done. Please continue to join us in the fight to end Alzheimer's for generations to come.

# Questions and Responses to the Record

## Questions for the record To Dr. Mark A. Supiano

## From Senator Kelly

**Question**:

Dr. Supiano, in recent years, we've seen some really exciting advancements in technology and artificial intelligence, especially related to how AI can be used in medicine. With Alzheimer's, we know it's important to diagnose early, so neurons in the brain are still alive-before clinical symptoms appear. In 2019 a study was done that used virtual reality to help diagnose Alzheimer's because the part of the brain that handles navigation skills is often among the first targeted by this disease. If someone wears a VR headset, a provider can gauge any navigation challenges the person is facing, and that could be an early clue. If we can do this with VR, what else do you think is on the horizon? In your opinion, how far can technology take us to solve the Alzheimer's epidemic?

**Response**:

It seems evident that advances in preventing and managing the epidemic of Alzheimer's and Related Dementias (ADRD) will need to derive from multiple dimensions - basic neuroscience, public health measures to improve social determinants of health, caregiver support, improving early child education, and in the area of age-friendly living environments and dementia friendly communities. In this context, technological advances including in artificial intelligence (AI) will undoubtedly also contribute to both improved, perhaps earlier, diagnosis and management.

To cite one example of the level of interest in the VR example you cite, failures in navigation due to topographical disorientation are early markers of pathological aging, particularly in Alzheimer's Disease. This year the University of Utah Center on Aging program I direct funded a pilot grant titled, ″Effects of Older Age on Sensory Integration in Navigation.″ (a psychologist, Dr. Sarah Creem-Regehr is the Principal Investigator) The study is developing and testing the feasibility of a VR paradigm that varies cues for navigation and allows for assessment of performance. The project aims are to identify and understand the changes in navigation that occur as a new paradigm for assessing and identifying pathological age-related cognitive decline.

Therefore, investments in technology and AI should be made to complement the other areas I have listed.

**Question**:

Dr. Supiano, the Medicare Annual Wellness Visit requires a structured cognitive assessment to take place. only 1 in 3 older adults know this is supposed to happen, and only 16 percent of those surveyed said it has taken place. Only 47 percent of primary care providers say the cognitive assessment is part of their standard protocol. Those providers who don't do the assessment say it's usually because the patient doesn't have symptoms, or because the provider doesn't have enough time.

This is a problem. If we aren't assessing patients, it's more likely this disease will be caught too late and the damage will be irreversible. as more treatments become available, this time becomes more crucial.

From the federal level, what should we do to make sure the right incentives are there for these evaluations and assessments-and then, diagnoses-to take place?

**Response**:

Improving the completion rates for the Medicare Annual Wellness Visit (AWV) among all Medicare beneficiaries and, requiring an objective screening cognitive test are important goals in two key respects.

First, the age-friendly health system initiative that is becoming a prevalent feature of health systems across the country is based on the goal of ensuring that every older adult receives care that encompasses the four Geriatric ″M″ health care domains (What matters most, mobility, medications and mentation) at every encounter in the health system. (see: http://www.ihi.org/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx ) The AWV is structured to review components in each of these four domains. Its completion each year will ensure that this level of care is being delivered.

Second, as noted in your question, the AWV will not adequately capture the mentation (dementia screening) ″M″ absent requiring that an objective cognitive screening test be included. The most recommended test that can be easily integrated into the AWV is the ″Mini-Cognitive Assessment.″ This integration has been accomplished at the University of Utah Health (and many others) and has been in place for many years.

In addition, the 2021 Update to the National Plan to Address Alzheimer's Disease (released December 2021, https://aspe.hhs.gov/reports/national-plan-2021-update ) The plan's Strategy 2.B to Ensure Timely and Accurate Diagnosis aligns with the need to broadly screen for cognitive impairment. Similarly, the state of Utah's State Alzheimer's Disease (2018-2022, https://livingwell.utah.gov/docs/Alzheimers—StatePlan.pdf ) includes a goal to create a ″Dementia Aware Utah,″ specifically to promote the use of Medicare preventive service benefits for the detection of cognitive decline and/or impairment, which commenced in 2011 under the Patient Protection and Affordable Care Act. This would include the addition of a cognitive screening assessment into the AWV.

Thus, at the Federal level, steps could be taken to tie Medicare reimbursement and funding to an AWV cognitive screening assessment requirement. In addition, setting expectations that all health systems that receive Federal funding are certified as ″Age-Friendly Health Systems″ would advance this goal.

## Questions for the record To Dr. Jennifer Manly

### From Senator Kelly

**Question**:

Dr. Manly, over the next several years, Arizona is expected to have the fastest growth rate in the country of people living with Alzheimer's. It is especially concerning that Alzheimer's is overrepresented and underdiagnosed in African American and Latino communities.

Given your research, how will AI and new technologies change our capabilities to diagnose Alzheimer's in African American and Latino patients?

**Response**:

Dear Senator Mark Kelly,

One of the major barriers to diagnosing Alzheimer's disease (AD) in minoritized populations is lack of access to specialty behavioral health services, such as neurologists, psychiatrists, geriatricians, and neuropsychologists. Telehealth is an important technological tool that will help meet the high demand for dementia diagnosis and care in underserved communities. Expansion of Federal investment in culturally relevant telehealth solutions is necessary for this tool to be beneficial in these populations.[1]

There have also been several new and exciting studies looking at how AI models can predict subtle changes in functioning that are often early markers of AD. Some of these algorithms use clinical information, like medical history, brain imaging, and cognitive test performance,[2,3] to predict AD years before diagnosis. Other algorithms have used more real-world everyday markers, such as speech patterns and word usage[4] or missed payments on credit accounts and subprime credit scores.[5]

These technological advances have the potential to improve access for minoritized populations by reducing the necessity of traveling to a clinic. They also have the potential to reduce provider bias in making specialist referrals by alerting providers of patients most at risk for AD. However, these approaches can only be as accurate, reliable, and helpful as the data they're given. Minoritized populations are less likely to be represented in the datasets that AI algorithms are developed.[6] This raises the potential for algorithmic biases that may further increase AD disparities. While more research is required to maximize use of AI and new technologies for earlier and more accurate detection of AD, it is imperative that African American, Latinx, Indigenous, and Asian people be included in this research as participants and in research leadership positions. This should be a requirement that is tied to funding.

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## Questions for the record To Peg Lahmeyer and Katelyn Montanez

### From Senator Kelly

**Question**:

Ms. Lahmeyer and Ms. Montanez, in Arizona, the Pima Council on Aging in Tucson received a $1 million grant last year from the Administration on Community Living to support individuals living with Alzheimer's and dementia. PCOA is planning to use their grant funding on initiatives to help Tucson become a more dementia-friendly community, improve screening and referral of people with Alzheimer's through client service systems, create memory cafes-which provide individuals with Alzheimer's and dementia a safe space to socialize and surround themselves with people with similar experiences-and partner with local businesses to train and support caregivers in the workplace.

I want to ask about this last piece that's based on a concept called United for Caregivers@Work. The idea is that so many people are caregivers in their personal lives, but that doesn't just impact their personal lives-it impacts their professional lives too. It impacts their whole lives.

Could you speak to the difference it makes for companies and employers to step up in this way? What are the most important strategies for employers to use to support employee caregivers? What strategies aren't widespread enough?

**Response from Ms. Lahmeyer**:

Senator Kelly, Thank you for these great questions.

1) Could you speak to the difference it makes for companies and employers to step up in this way?

Provide a more holistic approach of care to include family, caregiver, care receiver, AND workplace. With this support the employer would see less absenteeism, more productivity, and better mental health for the employee. More than likely fewer workplace injuries causing Workers' Compensation claims because the caregiver/employee is being recognized and supported.

Providing a work environment where the employee/caregiver feels no fear, retaliation or repercussions if and when they voice their need to have Family Leave to fulfill the needs of their care receiver at home. Without this understanding, the employee often has to leave their loved one at home to come to work and then be distracted and worried throughout the work day which interferes with job performance.

2) What are the most important strategies for employers to use to support employee caregivers?

Many caregivers are working while facing the stresses of caregiving and needing to work weigh heavily on their shoulders which affects their well-being both at home and at work.

a. Workplace support should include offering Lunch and Learns about managing stress and/or after work support groups for family caregivers to have education and learn of outside resources. From these education opportunities, they learn they are not alone.

b. Partnering with the community to offer "In House" Resource Fairs at least annually that include health screenings, memory screenings, community resources such as in-home care, day programs for care receivers, hospice care, long term care, medical support, aging networks

c. Offer Flex Hours to enable employee to adjust work hours to handle caregiver needs

d. Provide paid personal days in addition to PTO

e. Create a Caregiver Account that employees can input funds for future use with Employer Match

f. Tax Relief for Employers who provide the Caregiver Account to employees

3) What strategies aren't widespread enough?

As far as we are aware, there is no standard model program to support caregivers in the workplace. We have worked with companies individually.

We would like to learn more and work toward some of these suggestions being implemented. Thank you

**Response from Ms. Montanez**:

I wholeheartedly agree that being a caregiver for an individual living with Alzheimer's or dementia is a duty which impacts every aspect of a caregiver's life, both personally and professionally. As an advocate, I believe supporting initiatives such as paid family leave, general flexibility for caregivers to take care of loved ones, and informational resources and support are positive initiatives employers could take in helping individuals with Alzheimer's and other dementias and unpaid family caregivers.

As I mentioned in my testimony, there are emotional costs and quantifiable costs associated with caregiving. My own experiences included both my mother and I acting as caregivers and as the main means of financial support for my father and our family. Even as my father is currently having my sister act as his full-time primary caregiver, the end of the pandemic will require her to be back in an office setting. There are many unknown elements about what that will mean for her job, and the flexibility she will likely need while trying to balance her career and taking care of our dad.

It's clear to me that without a national paid family leave policy, many caregivers are at risk having to make a choice of taking care of a loved one or losing their job and income. The Committee's interest in caregiver support resources encourages me that these challenges can continue to be worked on for my family and millions of other families like mine.

## Questions for the record To Peg Lahmeyer

### From Senator Lee

**Question**:

Ms. Lahmeyer, several members of this committee and I have been working for a while now to extend and expand a ″universal charitable deduction.″ The UCD, as we call it, would enable everyone who gives to charity to receive tax relief (typically, only higher-income individuals are able to deduct their charitable giving from the taxes they owe). Studies of the UCD suggest that it would stimulate small-dollar giving and strengthen ties between Americans, their communities, and local institutions.

How have local support and small-dollar giving played a role in ARK's success in caring for Alzheimer's patients in the Charleston area?

**Response**:

Senator Lee, Thank you for this great question.

Without local support and small dollar giving we would not be able to provide essential services to our families attending The ARK. Many local organizations and businesses have not only contributed monetarily but have donated supplies to The ARK for our respite programs and educational classes. Local support allows us to continue making a difference in the lives of those living with this debilitating disease and the caregivers providing care for them. This raises awareness with the business and private sector communities.

Some of the ways they contribute besides monetarily include:

- Corporate donors donate daily supplies to operate the respite center
- In-Kind donations from local businesses for property and repair needs include services needed such as lawn maintenance, bus repair, HVAC needs, meals for donor and staff/board events. In trade the donor receives sponsorship and advertising opportunities/perks for our signature fundraising events such as our Annual Race for The ARK (22 years) and Dancing with The ARK's Stars (11 years)
- Restaurants offer mini fundraisers to donate a percentage of their sales to the charity
- Memorials designated to the charity
- Staff Give Back—members make monthly donations and contribute mileage for job obligations

This local support and small-dollar giving makes it a success, raises awareness, and supports all of our programs. Although we concentrate on five Lowcountry counties we never turn down a valid resource and request for help.

# Additional Statements for the Record

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

## United States Senate Special Committee on Aging
## Hearing on "Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges"

**May 20, 2021**

The Alzheimer's Impact Movement (AIM) and the Alzheimer's Association appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing entitled "Taking Aim at Alzheimer's: Frontline Perspectives and Caregiver Challenges." We thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. This statement provides an overview on the importance of home- and community-based services (HCBS), streamlining care structure and support for individuals with Alzheimer's, robust Alzheimer's public health and research funding through the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), and enhancing diversity in clinical trials.

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

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2020, more than 11 million unpaid caregivers provided an estimated 15.3 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of over $257 billion. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. Nearly one-fourth of Alzheimer's and dementia caregivers are "sandwich generation" caregivers — caring for both someone with the disease and a child or grandchild.

### Comprehensive Care for Alzheimer's Act

Caring for an individual living with Alzheimer's or another dementia poses unique challenges. Thankfully, dementia care management can ease these challenges, improve the quality of care, and reduce costs. More than 95 percent of individuals with dementia have one or more other chronic conditions, the management of which is complicated by an individual's cognitive impairment. Individuals with dementia rely heavily on family members to provide a large amount of care, which is often intrusive and exhausting. Too often, those with Alzheimer's and their caregivers are forced to fend for themselves in the complicated maze of the health care and social support systems.

Dementia care management can ease the challenges this maze presents, improving the quality of care and reducing costs. Elements of dementia care management models include care coordination and navigation, management of chronic conditions, and caregiver education and support. However, a change in payment structure is necessary to enable the success of a dementia care management model.

Earlier this year, Senators Debbie Stabenow and Shelley Moore Capito, along with Representatives Brian Higgins, Darin LaHood, Paul Tonko, and Brett Guthrie introduced the bipartisan Comprehensive Care for Alzheimer's Act (S. 1125/H.R. 2517) which would ask the Center for Medicare and Medicaid Innovation to test a different payment structure for dementia care management. The model would establish high standards of care, pay providers a monthly amount based on the complexity and quality of patient care, ensure caregivers are supported, and require outreach to underrepresented populations including diverse communities, rural areas, and medically underserved areas. The bill has the potential to streamline today's complicated health care maze for people living with dementia and their caregivers.

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The Alzheimer's Impact Movement and the Association strongly support the Comprehensive Care for Alzheimer's Act and thank the members of this Committee who have cosponsored this legislation.

**Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act**

Alzheimer's and other dementia disproportionately affect older Black and Hispanic Americans compared to older Whites. In fact, Black Americans are twice as likely to develop Alzheimer's, and Hispanic Americans are one and a half times more likely to develop the disease. Much of the Alzheimer's research to date has not included sufficient numbers of Black, Hispanic, Asian, or Native Americans to be representative of the U.S. population. The underrepresentation of these populations not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the populations most likely to need the treatment.

The bipartisan Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548), introduced by Senators Ben Ray Lujan and Susan Collins, would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities.

AIM and the Association strongly support the ENACT Act and urge the Committee and other members of Congress to support this bill to ensure current and future research includes increased numbers of Blacks, Hispanics, Asian and Native Americans in clinical trials to ensure everyone benefits from advances in Alzheimer's science.

**Home- and Community-Based Services**

Over 80 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, and nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while giving them an opportunity to manage and improve their own health. As the number of people living with dementia increases, the need to access affordable HCBS will grow.

People living with Alzheimer's or other dementias use a wide range of long-term supports and services including adult day service, residential care facilities, nursing homes, and respite care. Medicaid should adopt a core set of HCBS that are specifically designed for people with dementia. A core set of HCBS will allow people living with dementia to continue to remain in their communities and be independent for as long as possible.

The Alzheimer's Impact Movement and the Alzheimer's Association are grateful for the focus of Congress and the Administration on expanding access to HCBS for Medicaid beneficiaries.

*Expand Medicaid Long-Term Services and Supports (LTSS) Eligibility and Services*

Today's strict income and asset limits for Medicaid LTSS mean that older adults are only eligible if they have low incomes or have already spent down their savings and other assets on their LTSS needs. To avoid the impact of spend-down on an already vulnerable population, the federal maximum should be the baseline for all states on income, assets, and home equity limits.

In addition to financial eligibility, older adults seeking Medicaid LTSS coverage must also meet functional eligibility criteria, typically by demonstrating a need for assistance with daily self-care. Functional eligibility criteria needs to include and properly weight issues related to cognitive impairment, particularly in regard to prompting, monitoring, and supervision of daily activities in order to properly include individuals living with dementia.

The Alzheimer's Impact Movement and the Alzheimer's Association support the expansion of Medicaid LTSS eligibility and services.

*Expand the PACE Model*

The Program of All-Inclusive Care for the Elderly (PACE) model is able to provide the entire continuum of care and services to seniors with chronic care needs while maintaining their independence in their homes for as long as possible. The PACE program includes important services such as adult day care, physical and occupational therapies, meals, medical care, home health care, and others. A dementia-specific PACE program would greatly benefit persons living with dementia and their families as it would allow people to age in place longer and access necessary HCBS.

The Alzheimer's Impact Movement and the Association are proud to support the PACE Plus Act (S. 1162) introduced by Chairman Casey. The PACE Plus Act would strengthen and expand access to the PACE program by increasing the number of PACE programs, expanding the number of seniors eligible to receive PACE, and incentivizing states to grow their PACE programs.

*Enhance and Support a Dementia Capable HCBS Workforce*
Direct-care workers, such as nurse aides, home health aides, and personal and home care aides provide most of the paid long-term care to older adults living at home or in residential settings. Direct-care workers have difficult jobs, and they may not receive the training necessary to provide dementia care. Studies have shown that staff training programs to improve the quality of dementia care in nursing homes and hospitals have modest benefits. Federal requirements should be adjusted to raise training hours from 75 to 120, and include instructional content with a stronger focus on knowledge and skills related to caring for individuals with Alzheimer's and other dementias.

The Alzheimer's Impact Movement and the Alzheimer's Association support strengthening the HCBS workforce through increased wages, benefits, support, and career advancement opportunities. We are supportive of the proposals as outlined in the American Jobs Plan in order to address these workforce issues, and recognize these priorities are especially important, as the majority of home care workers are disproportionately women of color.

*Expand Money Follows the Person and Spousal Impoverishment Protections*
The high utilization rate of long-term care services and nursing home services by people with dementia translates into high costs to Medicaid. While it is well-known that Alzheimer's imposes a huge out-of-pocket financial hardship to families, most individuals with Alzheimer's will spend down their income and assets and eventually qualify for Medicaid. The average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias were 23 times as great as the average Medicaid payments for Medicare beneficiaries without dementia. Extending programs such as the Money Follows the Person and spousal impoverishment for married individuals receiving Medicaid-funded HCBS will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid.

The Alzheimer's Impact Movement and the Alzheimer's Association support extensions and eligibility adjustments for Medicaid Money Follows the Person and protections from spousal impoverishment for married individuals receiving Medicaid-funded HCBS.

**Appropriations**

*Alzheimer's Research Activities at the National Institutes of Health*
In December 2020, Congress appropriated a $300 million increase for Alzheimer's research funding in Fiscal Year (FY) 2021, bringing the annual allocation to over $3.1 billion. This significant increase builds upon several years of historic funding increases and is an important investment in research. These funding increases have enabled significant advances in understanding the complexities of Alzheimer's and have been critical to progress toward the primary research goal to effectively treat and prevent Alzheimer's by 2025. This research investment has led to the Food and Drug Administration (FDA) approval of PET scans to identify two biomarkers that help clarify an Alzheimer's diagnosis. Biomarkers are essential for identifying early signs of the disease, before an individual has cognitive damage from dementia, and for developing effective ways to prevent and treat the disease. A simple blood test for

Alzheimer's is also closer than ever before — breakthrough research has found that specific markers in the blood may be able to detect changes in the brain 20 years before Alzheimer's symptoms occur.

However, even with this great progress, there is still much left to be done. Investment in Alzheimer's research is still only a fraction of what's been applied over time to address other major diseases. It is vitally important that NIH continues to build upon these, and many other, promising research advances. Increased funding would enable scientists to conduct more inclusive, efficient, and practical clinical trials; increase knowledge of risk and protective factors in individuals and across diverse populations; discover better biomarkers to detect disease and monitor treatment response; pursue a precision medicine approach to detect the disease earlier and tailor treatment plans to an individual's unique symptoms and risk profile; and leverage emerging digital technologies and big data to speed discoveries. AIM and the Alzheimer's Association urge Congress to continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research at NIH by an additional $289 million in FY 2022.

*BOLD Act funding*

As scientists continue to search for a way to cure, treat, or slow the progression of Alzheimer's through medical research, public health plays a critical role in promoting cognitive function and reducing the risk of cognitive decline. Now more than ever it is apparent how crucial it is to have an established infrastructure in place to respond to public health threats.

In 2018, Congress acted decisively to address Alzheimer's as an urgent and growing public health threat through the passage of the bipartisan BOLD Act. This law authorizes $100 million over five years for the CDC to build a robust Alzheimer's public health infrastructure across the country focused on public health actions that can allow individuals with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. Congress appropriated $10 million for the first year of BOLD's implementation in FY20, which allowed CDC to award funding to three Public Health Centers of Excellence (PHCOEs), focused on risk reduction, caregiving and early detection, and 16 public health departments across the country. These State, local and tribal public health department recipients are creating statewide dementia coalitions, hiring dementia coordinators and developing or updating Alzheimer's and other dementia strategic plans. The $15 million Congress appropriated for the second year of BOLD's implementation in FY21 will help fund additional public health departments and expand the impact of this crucial work into more communities across the country.

While these are important steps forward, CDC must receive the full $20 million authorized in the law for FY2022 to ensure the meaningful impact that Congress intended. AIM and the Alzheimer's Association urge Congress to include the full $20 million for BOLD's continued implementation at CDC in FY2022. Activities supported by the requested $20 million in FY22 would enable CDC to award additional PHCOEs, focused on important priorities such as Tribal Health and avoiding preventable hospitalizations, and expand the number of state, local and tribal public health departments across the country that receive funding for Alzheimer's public health activities.

## Conclusion

The Alzheimer's Impact Movement and the Alzheimer’s Association appreciate the steadfast support of the Committee and its continued commitment to highlighting and advancing policies important to the millions of families affected by Alzheimer’s and other dementia. Thank you, Chairman Casey and Ranking Member Scott, for your continued commitment to supporting individuals living with Alzheimer’s disease and other dementia, and their families. We look forward to working with the Committee in a bipartisan way to address the challenges facing Alzheimer’s caregivers and families including prioritizing Alzheimer’s research funding, expanding access to HCBS, and enacting the Comprehensive Care for Alzheimer’s Act (S. 1125/H.R. 2517) and the Equity in Neuroscience and Alzheimer’s Clinical Trials (ENACT) Act (H.R. 3085 / S.1548).