

CONGRESSIONAL STORIES OF FAMILY CAREGIVING

Challenges, Rewards,
and a Call to Action

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Proceedings of a Capitol Hill Briefing



On November 7, 2017, six members of the U.S. House of Representatives stepped away from busy schedules of attending hearings and crafting legislation to share deeply personal stories of their experiences with family caregiving. In addition to being legislators, they are daughters, sons, and spouses who have faced the immense challenges and invaluable rewards of caregiving. As such, they join the more than 34 million Americans counted by the National Alliance for Caregiving and the AARP Public Policy Institute who care for a loved one 50 years or older. The Gerontological Society of America (GSA) hosted *Congressional Stories of Family Caregiving* with the support of The John A. Hartford Foundation and in partnership with AARP, the Alzheimer's Association, and the National Alliance for Caregiving.

The experiences reported by the representatives illustrate many of the family caregiving challenges identified by a panel of experts in *Families Caring for an Aging America*, a 2016 report issued by the National Academies of Sciences, Engineering, and Medicine (the National Academies). The legislators were invited to share their personal stories of family caregiving to illustrate that the caregiving experience and the challenges that accompany it are shared by Americans of all levels of income, employment, and education.

"Caregivers are . . . our nation's silent heroes."

—U.S. Representative Jim Langevin

This commonality persists despite dramatic differences. Members of Congress are usually relatively affluent and often highly educated. Their occupation requires that they be familiar with such programs as Medicare and Medicaid, such legislation as the Older Americans Act, and other health- and aging-related government initiatives. They have access to policy staff and experts who can answer questions about health and long-term services and supports (LTSS). Nevertheless, their accounts of family caregiving hardships echo those of family caregivers across the country. "It's hard," **Representative Jacky Rosen (NV-3)** commented, "no matter how smart you are, no matter how much schooling you have." Their personal, emotional accounts help support family caregivers by amplifying calls for action to implement proven interventions, to enact public policies to ensure the availability of caregiver supports, and to research strategies and plan ways to address the challenges facing family caregivers and the health care system.

This briefing is another step in a journey begun in 2014 when, recognizing the burgeoning crisis of a system poorly equipped to respond to the rapidly increasing numbers of older Americans who need LTSS, 15 funders jointly asked the National Academies to analyze family caregiving of older adults. In response, the National Academies assembled a committee of experts, many of whom are GSA members. The charge was to formulate "recommendations for public- and private-sector policies to support the capacity of family caregivers to perform critical caregiving tasks, to minimize the barriers that family caregivers encounter in trying to meet the needs of older adults, and to improve the health care and long-term services and supports provided to care recipients" (p. 3). (Here and below parenthetical cross-references refer to the resulting report, *Families Caring for an Aging America*.)

In her welcome to briefing attendees, moderator **Rani Snyder**, program

director for The John A. Hartford Foundation, emphasized the startling statistics in the report. Snyder explained that by 2060 the number of older Americans will double to 98 million. "Nearly 70% of people who reach the age of 65 are going to need help with daily activities," she continued, "and they will need that help for a long time. The average is about three years. That kind of assistance can include everything from keeping track of medications . . . to helping with bathing and hygiene needs, to really complex nursing and medical tasks. It's taxing. Even when you want to do it, it's really hard. And it's largely provided by friends and families."

The first member of Congress to speak at the briefing, **Representative Jan Schakowsky (IL-9)**, helped frame the briefing further, emphasizing the importance of family caregivers to older Americans. Drawing on statistics from the AARP Public Policy Institute's *Valuing the Invaluable: 2015 Update*, she explained that "nearly one in five family caregivers provides more than 20 hours of caregiving every week in addition to working a paying job." Quoting the National Alliance for Caregiving's "Caregiver Profile," she said, "The typical U.S. caregiver is a 49-year-old woman who works outside the home and spends more than 20 hours per week providing unpaid care to her mother."

Rep. Schakowsky and her husband cared for her father in their home for the last seven years of his life, and she expressed gratitude for the opportunity to return the gift of a caring parent. In the length of her caregiving experience, the congresswoman is in the company of about a third of family caregivers: the National Academies' report documents that more than 84% of family caregivers spend at least 2 years on caregiving, almost 35% of family caregivers spend 5 to 10 years caregiving, and more than 15% provide care for more than 10 years.

Common Threads

Although each family caregiving story is unique, the National Academies' report identified common threads present in many family caregiver experiences. The report provides data on the negative and positive impacts of caregiving, which sometimes occur simultaneously (p. 91).

Alan Stevens, PhD, GSA Fellow and director of the Center for Applied Health Research at Baylor Scott & White Health, Temple, TX, served on the National Academies' expert committee and spoke at the November 7 briefing. "Every caregiving story," he told the audience, quoting a caregiver, "is like a fine old antique tapestry." Each tapestry tells a story, Dr. Stevens said, and each one is woven in a unique way. He observed that the congressional stories of family caregiving "emphasize the variability in caregiving and how family caregiving is influenced by how much money you have, the culture you come from, [and] the relationship that you have with the person you're caring for." Nevertheless, Dr. Stevens continued, although each family caregiving "tapestry" is unique, "there are facts now in front of us that tell us that while there is this great diversity, which we need to embrace, there are also common threads that we now know. And those common threads are well defined in the report *Families Caring for an Aging America*."

Several members of Congress touched on the common threads in their briefing remarks about their own family caregiving. Common threads identified by both the National Academies' report and the briefing speakers included fragmentation of care and services that makes it difficult for family caregivers to identify and access the different kinds of care their loved one might need; the failure of providers, health care systems, and LTSS to recognize the role the caregiver plays in supporting the well-being of his or her loved one; the financial impact of caregiving; the emotional toll wrought by the mental and physical stress of

caregiving; and the rewards of being able to provide assistance and care to a loved one.

Fragmented Care

Many of the briefing speakers expressed frustration with the difficulty of navigating the healthcare system for their loved ones. They described spending hours trying to locate services for their loved ones. They shared their confusion about program requirements. Their stories detailed the daunting task of attempting to keep track of and manage services and treatments for their loved one across multiple physicians and other service providers.

Rep. Schakowsky commented on how time-consuming and frustrating it can be for family caregivers to navigate the health system for their loved ones: "Some of those caregiving hours I'm talking about, additional hours, are spent just navigating the [health care] systems that can be very complicated and sometimes mysterious to a lot of people who find themselves now as caregivers." She explained that she couldn't have cared for her father at home for seven years without the support of her family and paid caregivers. She went on to warn that the nation faces a shortage of paid caregivers and needs millions more. "With an aging society," she said, "we need to focus on resources for family caregivers. If there is no family able to help, we must ensure that our direct caregivers are equipped to provide necessary assistance." But as our population ages, she said, our health care workforce continues to face shortages. She called for action: "It's time that we invest in the quality of care our seniors deserve."

Representative Michelle Lujan Grisham (NM-1), a former head of the state agency on aging in New Mexico, remarked on the fragmentation of the health care system as well. She explained that formerly her mother was mainly challenged by functional limitations, but now her mother is suffering from growing cognitive impairments. Lujan Grisham has cared for her mother at home in the community and continues caring for her now that her mother lives in an

assisted living facility. Lujan Grisham said caregiving responsibilities don't stop even if you have help and assistance with the costs of care: "I have to navigate every medical appointment. I have to do all the follow-up. It doesn't matter that she's in assisted living." In sum, she said, "I have to be on it every single minute of every single day."

Further, Lujan Grisham illustrated how complicated the health care system can be, even for a highly educated, capable person: "I mean, it's really hard, and I'm a lawyer, and I've been doing leadership jobs most of my career. I used to have a background in math and engineering, and when I can't figure it out using an Excel spreadsheet—what I've paid for under Medicare, what I'm paying for a tax deduction for my mom, what I'm doing as a caregiver, or how to match the meds—imagine what that's like for somebody with less education or expertise, who's trying to navigate it and deal with it. It's impossible."

Representative Debbie Dingell (MI-12) recounted her experience three years ago, when her husband (former Congressman John Dingell) was hospitalized in intensive care. In spite of her professional expertise on health care issues, she was frustrated with program requirements and navigating the system. "Medicaid is the single biggest source of [funding for] long-term care in this country," she pointed out, but emphasized how difficult it can be to qualify for services. "People don't understand it. They don't understand that you have to be destitute to qualify for it. It's a bureaucracy that even those of us who are educated, intelligent, [and] have access to the experts . . . can't navigate. Fundamentally, we've got to restructure long-term care in this country." Dingell also discussed a common misperception among older adults and family caregivers that Medicare will pay for long-term care, when in fact it does not cover most of the LTSS that many people need and does not provide pay for a family caregiver.

Representative Jacky Rosen (NV-3) chose to quit her job as a computer analyst when both her parents and her in-laws became ill at the same time because she knew they needed

Common Caregiving Threads

- Fragmented Care
- Lack of Recognition
- Financial Impact
- Emotional Toll
- Rewards

her. "They all got old and ill at the same time. Four people, four journeys, one me." She acknowledged that she found navigating the health system difficult as well: "It's hard to navigate. It's hard no matter how smart you are, no matter how much schooling you have. My husband is a physician. I'm a computer analyst. Sometimes you can't navigate the waters of assisted living, rehab, nursing homes, skilled care. Just all of it—Social Security, Medicare, pensions."

The National Academies' report recognizes the dilemma: "The experiences of caregivers in advocating for older adults mirror the difficulties that many Americans face in obtaining high-quality, high-value health care services. Care delivery is fragmented; there is little, if any coordination between the health care and LTSS sectors; provider reimbursement policies discourage providers from taking the time to speak with individuals about their preferences, needs, and values; services are costly; and [an] individual's access to understandable and timely health information is often elusive" (p. 212).

Lack of Recognition

Fragmented care is often made worse by the failure to recognize the value the caregiver provides. The National Academies' report confirms that "despite the integral role that family caregivers play in the care of older adults with disabilities and complex health needs, they are often marginalized or ignored in the delivery of health care and LTSS and are often ignored in public policy as well" (p. 4). The report details the negative consequences this lack of recognition causes, including "impeding

information sharing between family caregivers and providers of care, tense and adversarial health system interactions, and expensive and unwanted care that is inconsistent with older adults' preferences" (p. 213).

In cases in which complex care must be administered by the family caregiver at home, this lack of recognition often leaves the caregiver without training. "Caregivers need specialized knowledge and skills relevant to their particular needs, as well as broadly defined competencies, such as problem solving and communication skills," according to the report, "Yet the available evidence indicates that many caregivers receive inadequate preparation for the tasks they are expected to assume. In the 2015 National Alliance for Caregiving and AARP Public Policy Institute survey, half (51 percent) of caregivers of older adults age 50 and older with Alzheimer's disease or dementia reported that they provide medical/nursing tasks without prior preparation" (p. 90). Finally, lack of recognition leaves legions of family caregivers without other supportive services they need to successfully manage the stress of family caregiving.

Representative Jim Langevin (RI-2) offered an insightful perspective on family caregiving: "As someone who lives with a disability, I have a unique appreciation for the challenges people with disabilities live with and those who need caregivers, but also for the personal challenges family caregivers themselves face on a daily basis." Rep. Langevin lost mobility in his arms and legs at age 16 because of an accidental gunshot. He expressed deep appreciation for the care provided by families, noting that "family caregivers provide \$470 billion in unpaid care," but, he said, they need respite. He lamented the failure of society to recognize the important role they play: "Part of my work in Congress has been to increase awareness, support, and respite for the very people who provide so much care to others, our family caregivers. These caregivers are, I think, in so many ways our nation's silent heroes and don't get enough attention or recognition, or expression of appreciation that they really do deserve." Briefing moderator

Snyder concurred. She noted that the average family caregiver will help a loved one for 3 years and that "family caregivers provide over 80%—I'm just going to put an exclamation point on that—over 80% of the long-term care but remain invisible to the health care system and to society."

Rep. Dingell explained that addressing the lack of recognition of caregivers and shining a light on them was part of her motivation for participating in the briefing: "We need to tell the real stories so that America understands we have a crisis in this country. And ignoring it isn't going to make it go away. It's going to get worse. And it's about who our soul, heart, and conscience are as a nation."

Financial Impact

Caregiving's financial impact was another common thread found in both the National Academies' report and the stories of the briefing speakers. The members of Congress described impacts ranging from having to use their own funds for insurance copayments or services not covered by insurance to sacrificing income by leaving full-time employment to serve as a caregiver. The amount of financial impact absorbed by the family caregiver is influenced by the financial situation of the care recipient (i.e., presence or absence of a pension, amount of savings, etc.) as well as the complexity of the care recipient's health needs. The National Academies' report notes that "caregivers of significantly impaired older adults are the most likely to suffer economic effects" (p. 126). Some studies, the report notes, have found that financial distress associated with caregiving "increases the likelihood that women experience poverty and/or reliance on public assistance" (p. 126).

Rep. Rosen, who left full-time employment to assume caregiving responsibilities, explained that her experience in caring for her father-in-law, who had a pension, was different from that of caring for her father, who had no pension. "My father-in-law had a pension and that was great. He was a 50-year employee of the City of Los Angeles. But my dad was a salesman. No pension. [He] relied on Social

Security. Things were very different when they needed care."

For **Rep. Lujan Grisham**, the funding provided for her mother's care through Medicaid reduces, but does not eliminate, the expenses she incurs. Although her mother lives in an assisted living facility paid for through Medicaid, Lujan Grisham pays an additional fee so that her mother can have a private room. She also pays for her mother's personal grooming care, undergarments, snacks, and transportation. And of the time when her mother was ineligible for Medicaid, Lujan Grisham said, "You bet every single month I dipped into my savings to make all of my mother's Medicare copayments because there was no way she had the resources."

In sharing her family caregiving experience, **Rep. Dingell** commented on the particularly pronounced financial impact of family caregiving on women: "Women are leaving the workforce when called upon to provide family caregiving. Their income becomes less, their retirement is less, their Social Security is less. We need to take a comprehensive look at the entire system and figure out what we're doing for long-term care." Moderator **Snyder** reported that the financial toll described by the congressional members is not uncommon: "According to AARP, losses in lifetime earnings for caregivers age 50 and older amount on average to more than \$300,000."

Financial risk is not evenly distributed in caregiving. "Research also shows," according to the National Academies' report, "that family caregivers of significantly impaired older adults are at the greatest risk of economic harm, in part because of the many hours of care and supervision and the costs of hiring help. Caregiver surveys find that several other factors are associated with financial harm including co-residence with or residing a long distance from the older adult; limited or no availability of other family members to share responsibilities and costs; and, if employed, limited or no access to paid leave or a flexible workplace. Caregivers who cut back on paid work hours or leave the workforce to meet caregiving responsibilities lose income, receive

reduced Social Security and other retirement benefits (because of fewer hours in paid employment) and may incur significant out-of-pocket expenses for the older adult's care" (p. 5).

Emotional Toll

An important and prevalent challenge for many family caregivers is the emotional toll of caregiving. **Rep. Schakowsky** put it this way: "We are glad to do it and feel rewarded by caregiving for our loved ones, but if the demands are heavy over time, we can also become exhausted and stressed and sick ourselves. We feel like we should be able to handle this caregiving role on top of busy work and family schedules and feel guilty as our energy fades." Psychological and physical health can suffer. "Substantial evidence," according to the National Academies' report, "indicates that family caregivers of older adults are at risk compared to non-caregivers; they have higher rates of depressive symptoms, anxiety, stress and emotional difficulties. Evidence also suggests that caregivers have lower self-ratings of physical health, elevated levels of stress hormones, higher rates of chronic disease, and impaired health behaviors" (p. 111).

Almost all of the briefing speakers alluded to emotional distress caused by their family caregiving experiences. "The body of evidence on negative effects," the report asserts, "is far larger than that on positive effects" (p. 91), and it posits that "negative psychological effects of caregiving span a continuum ranging from the perception that caregiving is stressful or burdensome, to symptoms of depression and/or anxiety, to clinical depression diagnosed by a health professional, to impaired quality of life" (p. 92). These types of effects, including stress, exhaustion, emotional distress, and feelings of being overwhelmed, are reflected in the experiences of the members of Congress.

Representative Chris Smith (NJ-4), whose mother lived with his family for almost a year, shared that his family, though fully committed to caring for his mother, was heartbroken by her ordeal. After one trip to the emergency room, his mother expressed her fear and disorientation:

"I thought I was lost and you would never find me." He recounted his wife's dedication to his mother, including "24/7 monitoring. We had a child monitor hooked up to our room and hers, and we had one eye to it, just like you do with a newborn, to make sure if something's happening, we're down into her room to try to mitigate a problem." Rep. Smith's mother spent her life working as a successful accountant in the family business. Her illness reduced her cognitive ability to the point that she was unable to write a check, causing Rep. Smith and his family distress as they watched her inexorable decline.

"It was really one of the worst times in my life," **Rep. Dingell** said of her abrupt introduction to family caregiving when her husband was admitted to the intensive care unit three years ago. "I know that I am luckier than 99.9% of the people in this country," she said, "yet, suddenly, when you're a caregiver, you're overwhelmed. Where do you go for help? How do you find someone to help in the house? What does it mean? What are you supposed to do?" It was then, Dingell said, when she "learned what a broken health care system we have."

Dr. Stevens emphasized that the National Academies' report cites research showing significantly poorer outcomes for caregivers who undertake high-intensity caregiving: "If you're caring for someone with Alzheimer's disease or for someone with physical frailty, we know that often results in more negative consequences." The report draws distinctions: "Caring for persons with high care needs such as persons with dementia or self-care needs creates more difficulties for the caregiver than persons with lesser needs. These caregivers also report relatively high rates of exhaustion, being overwhelmed, and not having enough time for themselves" (p. 91). Prevalence of emotional difficulty increased with caregiving responsibilities, ranging, for example, from being reported in 38% of caregivers whose loved one did not have dementia and had only one self-care need to being reported in 56.5% of caregivers whose loved one had dementia and had two or more self-care needs (p. 92).

"The effects of caregiving are not all negative. Numerous surveys suggest that, for some, caregiving instills confidence, provides lessons on dealing with difficult situations, brings them closer to the care recipient, and assures that the care recipient is well-cared for."

Rewards

In sharing the story of the Texas family caregiver who likened family caregiving to an antique tapestry, **Dr. Stevens** emphasized that the caregiver urged him not to forget "to look for the gold and silver threads." The National Academies' report indicates that "the effects of caregiving are not all negative. Numerous surveys suggest that, for some, caregiving instills confidence, provides lessons on dealing with difficult situations, brings them closer to the care recipient, and assures that the care recipient is well-cared for" (pp. 111-113).

These positive aspects were emphasized by briefing speakers as well. Without exception, the congressional speakers described family caregiving experiences as meaningful, positive, and motivated by love. They recognized their good fortune in having education, economic stability and social support that helped them cope with the challenges.

Rep. Schakowsky said, "It was a real blessing to be able to [care for my father], but I couldn't have done it without the support." **Rep. Lujan Grisham** expressed her deep appreciation for her mother's care for her as a child, "I had the best childhood you could imagine . . . If you could script it, I got it." Although her mother lives in an assisted living facility, Lujan Grisham "breaks her out on weekends" to spend more time with her and give her a change of scenery.

Rep. Langevin described the transformative influence family caregivers had on him after his injury at age 16: "Although my life changed dramatically, it was my parents and other people in my circle of family and friends and throughout the community that really reminded me that despite losing my mobility, I still had enormous potential to do other things in life." Their encouragement and support, he said, made him "fortunate to pursue a career in public service where I can encourage change and empower others who strive despite the obstacles that they face." He praised family caregivers' ability to "foster family stability and help those with chronic and disabling conditions avoid very costly out-of-home placements." He referenced Chinese philosopher Lao Tzu: "From caring, comes courage."

Rep. Smith said that despite "having broken hearts" over his mother's ordeal, which included brain surgery at the University of Pennsylvania, a long recuperation, and her mental confusion, he and his family "absolutely cherished her living with us." He said what continues to inspire his family to this day are his mother's "extraordinary faith, her love, her goodness, her empathy for others, and her courage."

A Road Map For Action

The caregiving stories presented by members of Congress as well as the findings of the National Academies' report reveal that "caregivers are potentially at increased risk for adverse effects on their well-being in virtually every aspect of their lives, ranging from their health and quality of life to their relationships and economic security" (p. 91). Further, *Families Caring for an Aging America* outlines actions available to address these adverse effects. "There are opportunities," Dr. Stevens said, "and I hope that with this report, we are challenged to move beyond our inactivity, our lack of engagement, and say, 'Now is the time to act!' We have a road map for action, and we can make a difference in the lives of family caregivers."

Action by Practitioners in the Field: Research, Effective Interventions, and Promising Programs

In addition to recommending policy actions, the National Academies' report urges practitioners in the field to adopt a range of interventions proven effective in supporting family caregivers, including assessment of caregivers' risks, needs, strengths, and preferences; education and skills training; counseling, self-care, relaxation training, and respite programs; personal counseling and care management; and integrating caregivers into the hospital discharge process (p.199).

Though research, including randomized controlled trials, has proven the effectiveness of a range of caregiver interventions, the report notes that "few of these interventions have moved from the research phase to everyday health and social service settings" (p. 199). Among the reasons are that the "intervention is not reimbursable under Medicare or other coverage sources" and that "organizations do not have the resources to train staff to provide the intervention" (p. 199).

In her closing remarks at the briefing, **Patricia D'Antonio**, senior director of professional affairs and membership for GSA, noted that many GSA members are working to move the proven interventions documented in the National Academies' report from research into practice. She explained how many of GSA's patient-centered projects also have profound relevance for their family caregivers. D'Antonio shared the example of GSA's National Adult Vaccination Program. She said "When I'm out educating policy makers about immunizations, I'm often talking about the impact on family caregivers. When an older adult is infected with pneumonia or with shingles, their trajectory changes—not just for them, but also for their family caregivers—because we know that older adults don't bounce back the same way a younger person might after a bout of pneumonia, leading to increased burden on the caregiver."

Another reason for optimism was shared by **Ms. Snyder**, who described

several projects supported by The John A. Hartford Foundation meant to improve information and support for family caregivers:

- ◆ The Benjamin Rose Institute on Aging and the Family Caregiver Alliance are developing a web-based resource that helps health and social service organizations compare and select evidence-based caregiver support programs for implementation.
- ◆ Planning is underway for replication of the University of California, Los Angeles, Alzheimer's and Dementia Care program, a comprehensive co-management program that utilizes nurses as dementia care managers in primary care clinics to help patients with dementia and their families. Initial evaluations provide evidence that this care program improves quality, results in better clinical outcomes for patients and caregivers, and reduces Medicare costs.
- ◆ AARP is working to secure passage of model state legislation known as the CARE Act which requires the identification, notification, and education of the family caregivers of individuals who are hospitalized. The Foundation is partnering with AARP to learn and share best practices from states that have implemented the law, as well as develop resources for health care providers and caregivers.

Dr. Stevens described how he personally plans to apply the report's recommendations to his work at Baylor Scott & White Health: "I work in a large health care system and have the opportunity to look for ways in which we can improve the way we engage family caregivers. . . . If we want to bend the cost curve, we must engage our family caregivers. We must respect them, and we must have them involved in plans of care and treat them as a member of the care team who is present when critical decisions are made."

Action on Policy Solutions

Each of the legislators who spoke at the briefing promotes policy solutions to address family caregiving challenges. Many of the bills they support incorporate recommendations of the National Academies' report. Legislation introduced in the 115th Congress includes:

- ♦ **Geriatrics Workforce and Caregiver Enhancement Act, H.R. 3713**, which would support geriatrics education and training to address the elder care workforce shortage, promote interdisciplinary team-based care, educate and engage family caregivers, and improve the quality of care delivered to older adults (Sponsor: Rep. Schakowsky). Much of the language of H.R. 3713 has also been incorporated into the **EMPOWER Act of 2017, H.R. 3728**.
- ♦ **Lifespan Respite Care Reauthorization Act of 2017, H.R. 2535**, which would extend lifespan respite care programs (services for family caregivers of children and adults with special needs) through fiscal year 2022 (Sponsor: Rep. Langevin; Cosponsors: Rep. Schakowsky and others).
- ♦ **Military and Veteran Caregiver Services Improvement Act of 2017, H.R. 1472**, which would expand eligibility for the program of comprehensive assistance for family caregivers of the Department of Veterans Affairs, to expand benefits available to attendees under such program, to enhance special compensation for members of the uniformed services who require assistance in everyday life (Sponsor: Rep. Langevin; Cosponsors: Reps. Lujan Grisham, Rosen, Schakowsky, Smith, and others).
- ♦ **Care Corps Demonstration Act of 2017, H.R. 3493**, which would authorize grants for local care corps programs through which qualified volunteers provide care, companionship, and other services to seniors and individuals in need (Sponsor: Rep. Lujan

Grisham; Cosponsors: Rep. Dingell and others).

- ♦ **Kevin and Avonte's Law of 2017, H.R. 4221**, which would reauthorize the Missing Alzheimer's Disease Patient Alert Program and promote initiatives that would reduce the risk of injury and death relating to the wandering characteristics of some children with autism (Sponsor: Rep. Smith).
- ♦ **BOLD Infrastructure for Alzheimer's Act, H.R. 4256**, which would expand activities related to Alzheimer's disease, cognitive decline, and brain health under the Alzheimer's Disease and Healthy Aging Program (Sponsor: Rep. Brett Guthrie [KY-2]; Cosponsors: Rep. Smith and others).
- ♦ **Credit for Caring Act, H.R. 2505**, which would amend the tax code to provide a tax credit for long-term care expenses (Sponsor: Rep. Tom Reed [NY-23]; Cosponsors: Reps. Lujan Grisham, Rosen, and others).
- ♦ **RAISE Family Caregivers Act, H.R. 3759**, which calls for the establishment and maintenance of a family caregiving strategy (Sponsor: Rep. Gregg Harper [MS-3]; Cosponsors: Reps. Dingell, Langevin, Lujan Grisham, Rosen, Schakowsky, and others)

Conclusion

When it comes to addressing the challenges of family caregiving, it is easy for policy makers and health care practitioners to be overwhelmed, like family caregivers themselves, by the immensity of the undertaking. It is a large, multi-faceted, and complex issue. As the members of Congress pointed out, a "quick fix" will not solve these problems.

Rep. Lujan Grisham, citing the enormous value of the services provided by family caregivers, said, "If we don't shore up caregivers, no financial supports will be enough." She encouraged briefing attendees and listeners to "embrace the enormous

contributions of family caregivers by investing in the families who are willing to help us, and create a brand new dynamic that shifts the conversation, creates intergenerational awareness, and gives caregivers and their care partners respect and dignity."

It is clear that we can no longer ignore the challenges of family caregiving and the immense contribution of family caregivers to our health care system. Publication of *Families Caring for an Aging America* moved the nation closer to the goal of investing in family caregivers as a resource. Progress continues in the efforts of GSA, The John A. Hartford Foundation, other national partners, and the work of practitioners nationwide. The report's evidence and conclusions are illustrated by the experiences shared by members of Congress on November 7—experiences shared by so many American families. The expert recommendations from the report call for action and point to effective evidence-based interventions. The members of Congress at the briefing called for action on their legislative solutions, as well. The time for action is now. We must ensure that the gold and silver threads of our nation's family caregiving tapestries can shine through.

For information about programs and resources for family caregivers, please visit our partners: Alzheimer's Association www.alz.org, AARP www.aarp.org; National Alliance for Caregiving www.caregiving.org.

For more information on GSA's work on family caregiving, go to <http://bit.ly/NASEMCaregiving>. To get involved, e-mail us at profaff@geron.org.

Thank you to The John A. Hartford Foundation for its support and leadership on family caregiving: www.johnahartford.org.

Recommendations for Action from *Families Caring For an Aging America*

The National Academies of Sciences, Engineering, and Medicine report emphasizes the urgent need for action and the availability of effective interventions. Drawing on its well-researched findings, it asserts, "It is time to publicly acknowledge caregiving families. In today's world, family caregivers cannot be expected to provide complex care and support on their own. Family caregivers need greater recognition, information, and support to fulfill their roles and responsibilities and to maintain their own health, financial security, and well-being" (p. 6). The report urges action on the policy front as well as action by practitioners in the field.

In her framing of the briefing, **Ms. Snyder** stressed the report's value for policy makers. "Its recommendations have a long shelf life," she said, "to use as the opportunity arises." Indeed, the National Academies' report offers detailed recommendations for addressing the challenges described in the report and by members of Congress.

RECOMMENDATION 1: The committee calls upon the Administration that takes office in January 2017 to take steps to address the health, economic, and social issues facing family caregivers of older Americans. Specifically, the committee recommends that:

The Secretary of the U.S. Department of Health and Human Services, in collaboration with the Secretaries of the U.S. Departments of Labor and Veterans Affairs, other federal agencies, and private-sector organizations with expertise in family caregiving, develop and execute a National Family Caregiver Strategy that, administratively or through new federal legislation, explicitly and systematically addresses and supports the essential role of family caregivers to older adults. This strategy should include specific measures to adapt the nation's health care and long-term services and supports (LTSS) systems and workplaces to effectively and respectfully engage family caregivers and to support their health, values,

and social and economic well-being, and to address the needs of our increasingly culturally and ethnically diverse caregiver population.

The Secretaries should publicly announce and begin to implement the strategy by

1. executing steps allowable under current statutory authority;
2. proposing specific legislative action, where appropriate, to address additional steps;
3. convening and establishing partnerships with appropriate government (federal, state, and local) and private-sector leaders to implement the strategy throughout education, service delivery, research, and practice; and
4. addressing fully and explicitly the needs of our increasingly culturally and ethnically diverse caregiver population.

The Secretaries should issue biannual reports on progress and actions of the National Family Caregiver Strategy.

This strategy should include the following steps:

RECOMMENDATION 1-a: Develop, test, and implement effective mechanisms within Medicare, Medicaid, and the U.S. Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.

RECOMMENDATION 1-b: Direct the Centers for Medicare & Medicaid Services to develop, test, and implement provider payment reforms that motivate providers to engage family caregivers in delivery processes, across all modes of payment and models of care.

RECOMMENDATION 1-c: Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.

RECOMMENDATION 1-d: Increase funding for programs that provide explicit supportive services for family caregivers such as the National Family Caregiver Support Program and other relevant U.S. Department of Health and Human Services programs to facilitate the development, dissemination, and implementation of evidence-based caregiver intervention programs.

RECOMMENDATION 1-e: Explore, evaluate, and, as warranted, adopt federal policies that provide economic support for working caregivers.

RECOMMENDATION 1-f: Expand the data collection infrastructures within the U.S. Departments of Health and Human Services, Labor, and Veterans Affairs to facilitate monitoring, tracking, and reporting on the experience of family caregivers.

RECOMMENDATION 1-g: Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real-world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.

RECOMMENDATION 2: State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports, and implement similar programs.

RECOMMENDATION 3: The Secretaries of the U.S. Departments of Health and Human Services, Labor, and Veterans Affairs should work with leaders in health care and long-term services and supports delivery, technology, and philanthropy to establish a public-private, multi-stakeholder innovation fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families.

RECOMMENDATION 4: In all the above actions, explicitly and consistently address families' diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.