

MOVING FORWARD ON BEHALF OF FAMILY CAREGIVERS IN THE U.S.

DESIGNING A PUBLIC-PRIVATE FUND TO
SUPPORT RESEARCH AND INNOVATION



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Foreword

Recognition and support for family caregivers in the United States is gaining momentum. In late 2017, the National Institutes of Health convened two summits on caregiving – a two-day event on the Science of Caregiving across the lifespan and the first-ever national Research Summit on Dementia Care, highlighting the needs of family caregivers in the fight against Alzheimer’s disease and related dementias.

Early in 2018, Congressional leaders on both sides of the aisle passed and President Trump signed into law the RAISE Family Caregivers Act (P.L. 115-119) to create a strategy to support family caregivers across the lifespan, cementing the collective effort of the congressional Assisting Caregivers Today Caucus and the caregiving advocacy community. Shortly thereafter, Congress passed, and the President signed the VA Mission Act of 2018 (P.L. 115-182) which will expand the reach of the existing caregiver support program to Veterans of all eras, not just post-9/11 conflicts.

The nation has begun to recognize the essential role that unpaid friends and family members play in supporting individuals with ongoing health and assistance needs. Yet these informal support systems are not sufficient to support the many Americans with care needs. Policymakers need pathways that will encourage businesses, entrepreneurs, think tanks and incubators to find sustainable marketplace solutions to support and augment the support provided by family caregivers across the lifespan.

With a grant from the Robert Wood Johnson Foundation, we were honored to host a one-day summit on Public-Private Innovation in Family Caregiving in April 2018. This paper captures the multi-stakeholder input of that summit and offers a roadmap for next steps. We are looking forward to continuing the conversation on how to foster innovative research for family caregivers. Let us know your thoughts as we embark on this endeavor, either by emailing info@caregiving.org or calling **(301) 718-8444**.

Kind regards,



C. Grace Whiting, J.D.
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Gail Gibson Hunt is the Founder of the National Alliance for Caregiving. As a national expert on family caregiving and long-term care, she has led public policy research and advocacy efforts in family caregiving for more than twenty years in the United States and internationally. Among other national leadership roles, Ms. Hunt currently serves as a commissioner for the Center for Aging Services Technology (CAST), a member of the Board for the Long-Term Quality Alliance (LTQA), and a member of the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI)

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of nearly 60 national organizations focused on advancing family caregiving through research, innovation, and advocacy across the lifespan, in the U.S. and internationally. The Alliance conducts research, performs policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.

Summit Participants

This paper was written following a multi-stakeholder roundtable held in Washington, D.C. on April 24, 2018. Summit participants provided input and ideas on this topic, which was then compiled by the National Alliance for Caregiving into the summary and recommendations below.

Many thanks go to the National Alliance for Caregiving team who supported this project, including the Director of Strategic Initiatives Patrice A. Heinz, Director of Advocacy Michael R. Wittke, B.S.W., M.P.A., and Operations Associate and Special Projects Coordinator Maja Pašović, M.A., M.Ed.

For more information about this paper, please email info@caregiving.org.

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Introduction

In 2016, the National Academies of Science, Engineering, and Medicine (NASEM) released the report *Families Caring for an Aging America*. The report was prepared by an expert panel convened to examine what was known about family caregiving in the United States and to identify policies that would better support unpaid friend or family caregivers of older adults (family caregivers). According to the *Families* report, at least 17.7 million people in the United States are family caregivers for an individual 65 years of age or older with a significant health problem or disability.¹

The report outlines the underlying factors that make action to develop policies that support family caregivers essential. For example, there is a rapidly increasing number of older Americans and a concomitant number of “shrinking families.” Not only does family caregiving have personal consequences for those family members who are providing care, but care may be complicated by systemic barriers such as difficulty in dealing with medical professionals or providers of home-based care, or in some cases, being excluded from shared decision-making with the person receiving care and their providers. The report points out that while there are effective interventions that could engage and support family caregivers, few family caregivers have access to these assessments and other professional interventions that could support both the family caregiver and the older adult.

Finally, the report includes recommendations to develop a national strategy for caregivers, and additional recommendations to strengthen the supports available for caregivers of older adults. These recommendations address economic policies that benefit working caregivers, the evaluation of caregiver interventions, an expansion of data collection to better understand the experience of family caregiving and more responsive mechanisms in the Medicare and Medicaid programs, and within the U.S. Department of Veterans Affairs (VA).

The NASEM committee proposed the following:

- » That the incoming administration at the U.S. Department of Health and Human Services (HHS) in 2017 would work with other cabinet secretaries to design and execute a national family caregiver strategy.
- » That strategies be designed and implemented in the Centers for Medicare and Medicaid Services (CMS) and the VA to identify and assess family caregivers and to develop and implement provider payment policies that support family caregivers across “all modes of payment and models of care.”
- » That there is a need to strengthen the capacity of health and social service providers to recognize and engage family caregivers and to provide evidence-based support services and referrals.

¹ Note that estimates of the number of family caregivers in the United States vary across national surveys. The *Caregiving in the U.S. 2015 study*, conducted by the National Alliance for Caregiving and AARP, estimates that there are as many as 43.5 million family caregivers across the lifespan providing unpaid care to an adult or child. For more, see National Alliance for Caregiving (2018). “The Data Challenge,” *From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Issue*. Retrieved from https://www.caregiving.org/wp-content/uploads/2018/01/From-Insight-to-Advocacy_2017_FINAL.pdf

Other recommendations addressed the need to expand the National Family Caregiver Support program at the Administration for Community Living (ACL) and existing evidence-based intervention programs for caregivers by:

- » Establishing policies that support caregivers in the workplace;
- » Expanding research in caregiving; and
- » Developing an innovation fund to accelerate the pace of change.

The final recommendation to develop an innovation fund (also known as “Recommendation 3”) is now receiving attention and action in the current project described in this document. Recommendation 3 calls on the U.S. Secretaries of HHS, the Department of Labor, and the VA to work with leaders in health care and long-term services, technology, and philanthropy to set up a public-private fund for innovation and research that will accelerate change and address the needs of caregiving families.²

The National Alliance for Caregiving (NAC), a non-profit organization that has been working on behalf of caregiving families since 1996, took up this challenge. With funding from the Robert Wood Johnson Foundation, NAC organized and hosted a meeting of a diverse group of stakeholders to discuss and design a response that would move the bar forward on the development of a public-private fund aligned with the vision provided in Recommendation 3.

Convened in Washington, D.C. in April 2018, the meeting began by defining how such a fund could be structured and what the specific function of such a fund would be. Participants discussed and identified key stakeholders who would be important to the development of the fund and discussed the creation of an Advisory Committee that would provide oversight to the development of the fund.

A work plan to turn the development of an innovation fund into a reality was discussed at the stakeholder meeting including a paper summarizing the input of the stakeholder meeting. Drafts of this paper were reviewed by the meeting attendees. Future work includes systematic dissemination of the key takeaways to an expanded group of organizations and individuals who can foster the development of a research and innovation fund with the purpose of moving the caregiving agenda forward.

² The full text of Recommendation 3 reads: “The Secretaries 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.”

Ideas Generated by the Summit Participants

Three members of the NASEM committee on Family Caregiving participated in the summit. Other participants included representatives from federal agencies, including the Administration for Community Living (ACL), the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), the U.S. Department of Veterans Affairs (VA), and the U.S. Department of Health and Human Services (HHS).

Non-profit and private sector representative participated as well, including the AARP Public Policy Institute; Aging2.0; Anthem, Inc.; Family Caregiver Alliance; Family Caregiving Institute; UC Davis - Betty Irene Moore School of Nursing; Genworth Financial; Grantmakers in Aging; GreatCall; Humana; LeadingAge: Center for Aging Services Technologies (CAST); New Mexico State University; Pfizer; the Gerontological Society of America; the John A. Hartford Foundation; the Johns Hopkins University Bloomberg School of Public Health; and the Transamerica Institute/Transamerica Retirement Solutions. Key suggestions and potential direction provided by participants are outlined below.

Purpose of the Summit

The purpose of the summit was to support the establishment of a multi-stakeholder innovation fund for caregiving research that will accelerate change in addressing the needs of family caregivers. The summit discussion focused on:

- » Defining the public-private innovation fund;
- » Discussing the role of an Advisory Committee to oversee future steps;
- » Discussing how projects are to be evaluated;
- » Defining next steps, including the development and dissemination of a summit paper with potential milestones; and
- » Identifying the need to reach out to additional public-private partners.

Importance of a Fund for Caregiving Research and Innovation

The NASEM committee representatives suggested that a public-private fund for caregiving research and innovation was important for the following reasons:

1. A fund would accelerate work on behalf of family caregivers;
2. A fund would create a multi-stakeholder framework that increases the awareness of family caregiving and resources that could help improve the quality of life for caregivers;

3. A public-private fund across multiple stakeholders provides a “single point of entry” for services or supports; and
4. Public-private partnership could help bring leaders and funders to the issue and support the need to invest in this population.

One committee member suggested that the Recommendation 3 was essential to achieving progress in support of family caregivers because the public sector could not accomplish the work needed on its own. In addition, the fund could engage new stakeholders in the issues that surround caregiving, including those who have not yet begun to work in this space. For example, CMS has had limited involvement in providing family caregiving support or innovations in post-acute care to date. Groups like faith communities, philanthropic organizations, public relations organizations, consumer groups, disability groups, higher education institutions, and community groups may also become more engaged in caregiving support.

What Agencies/Organizations Should be Involved in the Public/Private Partnership Fund?

Summit participants had a robust discussion about the role of various public and private sector leaders in the development of an innovation fund for caregiving research. The role of states and federal government as well as private industry was discussed. Summit participants believed that a multi-sector approach is required to move on to the development of the fund. Engaging private organizations, federal agencies, philanthropy, and others with the public or governmental initiative is of essential importance in this endeavor.

Perspectives on Philanthropic and Corporate Engagement

Summit participants provided a perspective on philanthropic and corporate engagement. One foundation representative noted that the bulk of philanthropy is local; the views of state and local communities tend to get ignored in discussions about national programs. Local communities question whether innovation makes the community better. In many cases, community-based foundations can implement ideas more quickly and on a lower budget—such as creating pilot programs to test ideas.

While aging is a hard sell in the philanthropic community, family caregiving is a topic that is increasing in interest. Funders may not necessarily approach caregiving from the perspective of the older person who needs care from the family member. Some foundations may be willing to fund broader issues like at-risk or underserved populations. For example, a charge to address women in poverty may also support work on behalf of low-income family caregivers in the workplace or those who leave the workplace to provide care. Some attention is being paid to the formal and informal structures of care: the formal care provided by the health care system versus the “free-for-all system” to provide informal care, with very little regulatory framework to guide that work.

Another foundation shared that family caregiving is one of its top three priority areas, guided by the recommendations and findings outlined in the NASEM *Families* report. Philanthropic partners with national and state or regional interests have come together to host a “Funders Collaborative” with the purpose of information sharing on family caregiving topics. Participating organizations include the John A. Hartford Foundation, the Archstone Foundation, the Robert Wood Johnson Foundation, and the Retirement Research Foundation. State and local foundations participate as well, including the Santa Barbara Foundation, the Endowment for Health, the Health Foundation for Western and Central New York, and the California HealthCare Foundation.

Examples of public/private partnerships that receive funding from the philanthropic space include:

- » The Administration for Community Living (ACL)’s **Business Acumen Initiative**, which funds the National Association of Area Agencies on Aging (n4a) to train Area Agencies on Aging on business skills as part of the Aging and Disability Business Institute;
- » The Health Resources and Services Administration (HRSA)’s **Geriatric Workforce Enhancement Program (GWEP)** with a coordinating center through the American Geriatrics Society;
- » **The Paul B. Beeson Emerging Leaders Career Development Award in Aging**, a joint initiative from the National Institute on Aging (NIA), the John A. Hartford Foundation, and the National Institute on Neurological Disorders and Stroke (NINDS), which includes an annual meeting and support for early-stage investigators (primarily clinically-trained physicians) to pursue improved health care outcomes in aging; and
- » Support to scale the **Independence at Home Demonstration** at the CMS Innovation Center, which evaluates the delivery of home-based primary care, and funding for the clinical data registry.

Innovators from the private and non-profit sectors shared additional considerations for fostering research and innovation in family caregiving.

GreatCall—a corporation focused on technology to support both older people aging in place and their caregivers. GreatCall has conducted research on family caregivers and their willingness to adopt technology. Their findings indicate that only a small number of caregivers are using technology (7%). Barriers to adoption include cost, awareness, and trust. While smart phone use for adults over 65 years of age is growing, many older adults are reluctant to use high-tech devices, even where suggested by the family caregiver. Research on caregiving can support private innovation efforts, such as identifying how to address barriers to technological supports.

LeadingAge (CAST)—a large national nonprofit that represents nonprofit long-term care facilities. LeadingAge has an extensive technology special interest group that includes many of the larger innovators in the aging space, known as the Center for Aging Services Technologies (CAST). Some trends identified by CAST that may impact caregiving research and innovation include:

- » Increase in the use of mobile technology, including tablets and smartphones;

- » Increasing demand on bandwidth;
- » Modern technologies increasing ease of use and accessibility, including the latest wave of natural language processing;
- » Increasing need to be aware of cyber security issues—from protecting data in Electronic Health Records to the “Internet of Things,” such as connecting sensors in the home;
- » Major barriers for scalability of innovations due to state-to-state variability of the Medicaid program presenting regulatory and operational issues.
- » Growing need to design technology to support caregiving across the lifespan and for all care partners, not just the adult child. Spousal caregivers who are themselves older adults should be engaged in design and direct care workers should be considered.

The Gerontological Society of America—a large interdisciplinary association devoted to research, education, and practice in the field of aging. GSA’s work in aging has highlighted the need to recognize that when designing for caregivers, the care recipient may be older, but the caregiver is aging as well. The impact on the caregiver as he or she ages can affect innovation and research. But innovators and researchers should take a lifespan approach to caregiving, as many potential supporters of a research fund may be interested in other populations—such as younger workers, women—who are impacted by technology. Technology should be part of innovative solutions, but the research agenda should also include high-touch solutions.

Pfizer—a global biopharmaceutical company with previous work to support family caregiving research across the lifespan, including work on dementia caregiving and supporting caregivers in the workplace. Pfizer has worked with the CDC on research, including a 2015 project between the CDC Division of Blood Disorders within the National Center on Birth Defects and Developmental Disabilities, the California Rare Disease Surveillance Program, and Pfizer to collect longitudinal data on sickle cell disease. Likewise, Pfizer participates in the Accelerating Medicines Partnership (AMP) with the NIH, in addition to other public-private partnerships.

Discussants noted that the European Union has provided funding for the **Innovative Medicines Initiative**. The \$5,000,000 contribution will be put into a fund that others in private industry will match. Funding will support the consortium’s efforts to draft a multi-stakeholder plan; all the stakeholders together create a Request for Proposals and then jointly select the awardees to work on the plan. In this case, the Innovative Medicines Initiative is working through the EU Commission.

In reflecting on the role of philanthropy and corporations, the summit participants identified some strategies for a potential research that may accelerate innovation:

- » Review and consolidate existing research, making it easier for entrepreneurs to access data;
- » Identify ways to overcome acceptance barriers for caregiver technologies;

- » Identify the best ways to support caregivers financially—for example, in the workplace or through tax credits;
- » Include family caregivers in current payer models. Regulatory changes may be necessary, to coordinate or streamline services under Medicare and Medicaid³;
- » Promote data-driven decision making, including return on investment.

Existing Federal Public-Private Partnerships

Participants from ACL, NIH, CDC, and the VA provided perspectives on public engagement and the following examples of existing public-private partnerships to foster innovation, noting that there is much variation across agencies and institutes of government.

Administration for Community Living (ACL)

ACL has four distinct programmatic centers: the Administration on Aging, the Administration on Disabilities, the Center for Integrated Programs, and the National Institute on Disability. ACL grant programs and other initiatives support both the individual and their caregivers and include specialized supports such as support for Alzheimer’s disease, a national registry of services for older adults known as the Eldercare Locator, and services for Holocaust survivors (including person-centered trauma care).

ACL administers the **National Family Caregiver Support Program**, under the Older Americans Act, which provides support for caregiving services to Area Agencies on Aging (often organized as non-profit organizations). Title IV of the Older Americans Act permits grant-making to nonprofits, academia, and tribal organizations to address a broad range of objectives related to education and training, including the Aging and Disability Resource Centers, and opens the door for public-private partnership.

While the **Business Acumen Initiative** is one of the more visible partnerships, others include grant-funding opportunities that go to private innovators (such as technology companies). As the aging network works to address the changing service delivery landscape, there is renewed interest in partnering with health care providers to be part of delivery system reform.

Centers for Disease Control and Prevention (CDC)

The CDC conducts the **Behavioral Risk Factor Surveillance Survey (BRFSS)** which collects data on health-related risk behaviors, chronic health conditions, and use of preventive services. The state-based survey instrument has a caregiver module and a cognitive decline module funded by each state. More than twenty states use some form of the caregiver module, and data from the BRFSS can be aggregated at the national

³ Companies noted the challenges in scaling long-term services and supports (LTSS) because of variations in state Medicaid programs.

level. Organizations such as the Alzheimer’s Association use the BRFSS data on family caregivers as part of their research on the impact of dementia on families.

Other examples of public-private partnerships at the CDC include their public health roadmaps, such as the **Healthy Brain Initiative**. The CDC is a partner in the National Collaborative on **Childhood Obesity Research**, which also includes the National Institutes of Health (NIH), the U.S. Department of Agriculture (USDA), and the Robert Wood Johnson Foundation. Federal funding for programs such as these are typically dedicated to specific projects, with strict guidelines around what can be funded.

National Institutes of Health (NIH)

The Foundation for the NIH (FNIH), a 501(c)(3) nonprofit charitable organization, chartered by the U.S. Congress, raises private funds and cultivates public-private partnerships in support of the mission of the NIH. FNIH supports a range of activities, including research partnerships, scientific education and training programs and scientific conferences and events. When necessary, the FNIH can facilitate the exchange of ideas between NIH and private partners, involving other federal agencies, as appropriate, in a pre-or non-competitive environment that may not be possible otherwise.

Office of the Director, the Office of Science Policy NIH Public-Private Partnerships Program coordinates the process to establish collaborations, including public-private partnerships, with the FNIH.

Veterans Affairs (VA)

The U.S. Department of Veterans Affairs (VA) has several initiatives to support family caregivers, including the **VA Caregiver Support Program** and the **Veterans’ Family, Caregiver, and Survivor Advisory Committee**, chaired by Senator Elizabeth Dole of the Elizabeth Dole Foundation, a non-profit dedicated to supporting military and Veteran caregivers. The Advisory Committee includes representatives from government, the private sector, and non-profits to look at gaps in caregiving research and to identify survey tools that can identify the needs of Veteran caregivers.

An example of a public-private partnership at the VA would be the **VA Caregiver Support Program**, which provides information, education, and health services through a mix of government, non-profit, and other providers. Programs like the **Choose Home** initiative bring together multiple stakeholders to help severely wounded/injured Vets and their families avoid unnecessary institutionalization and stay in the home. **Choose Home** works to integrate community-based organizations into the models of care and to develop Centers of Excellence. Another program example would be the **Campaign for Inclusive Care**, funded through USAA, which is a partnership between the VA and non-profit organizations to create a blueprint for private-sector physicians to provide better support to family caregivers. Finally, the **National Military and Veteran Caregiver Network** provides peer-to-peer, evidence-based online network for caregivers, led by the American Red Cross in partnership with Bristol Myers Squibb and the VA.

Role of the Federal Government

While many participants agreed that the federal government should play a role in the creation of a public-private fund, there was a recognition that the federal government cannot act alone in supporting such a fund. Strong public-private partnership is needed to make changes that are meaningful to the nation's family caregivers. Agencies are often burdened with administrative "red tape" that can work against innovation and create regulations that may not be responsive to the need in the field.

Further research is needed to identify a proper mechanism or existing model. Some potential solutions included working within a foundation (such as the CDC Foundation or the Foundation for the NIH). In addition, participants noted the need to include state-based caregiver supports as an integral component of the overall initiative. The Center for Medicare and Medicaid Innovation (CMMI) (also known as the Innovation Center) was suggested as a key partner to the effort to support an innovation fund. The Innovation Center has focused on developing innovative models of health care delivery that can be scaled to larger health systems. Models tested by the Innovation Center aim to address the triple aim of health care reform and have, in-part, addressed models that include caregivers (such as the Independence at Home model).

Regardless of who hosts the fund, the participants agreed that the federal government should be involved in any national public-private fund for family caregiving research and innovative models of care. While various agencies fulfill distinct roles, a common goal related to this endeavor is to protect the health and safety of the nation. For instance, HHS houses the Medicaid and Medicare programs under CMS, which provide health insurance coverage for older adults and those under a certain income threshold. ACL, also under HHS, offers those living with health conditions or disability direct community services and supports family caregivers. The CDC works to promote prevention and protect the health through scientific analysis and translating scientific discoveries into public health practice. The NIH and its related institutes conduct biomedical research aimed at finding cures or treatment for diseases, and other research to improve the delivery of care. Each of these stakeholders has a part to play in supporting innovative research on behalf of family caregivers and should be engaged in the creation of the fund, the development of its goals and structure, and the evaluation of the fund's impact.

Additional Stakeholders

As stated earlier, potential stakeholder groups for the fund include entrepreneurs, technology companies, employers, long-term care and health service providers, government (local and state as well as federal) entities, policymakers, health system advocacy organizations, and academics. In addition to these groups, others might include: payors, health care companies, faith-based communities, philanthropic organizations, public relations organizations, caregiver advocates and coalition leaders, consumer groups, disability groups, and higher education.

Hosting the Fund

Several federal agencies were identified by the summit participants as potential “homes” for the fund including the CMS Innovation Center, the National Institute of Nursing Research at NIH, and the Agency for Healthcare Research and Quality. A consensus was reached that a foundation, such as the CDC Foundation, would be the best option for this fund.

While federal agencies are important and critical partners in this endeavor, a fund placed within a foundation would allow more responsiveness and flexibility for innovation and timely action. Most federal partners agreed with this approach, as federal fiscal procedures can, at times, be difficult to maneuver if the fund were to be held within a federal agency structure.

Principles of the Fund

The summit participants had an open discussion about the principles and what the fund could be. The following principles were articulated:

- » An innovation fund should support those caregivers at most risk, including caregivers affected by economic insecurity and instability.
- » It is important to develop foundational tools such as assessment tools, information data systems, and educational training programs for health providers and caregivers.
- » The work needs to have an evaluation component that is determined at the onset of the work and that it is transparent throughout the process, so lessons learned as a result of the outcomes of the fund are made widely available.
- » Innovation is a pipeline and there are many evidence-based innovations that have been demonstrated to be effective, but which are not moving forward due to lack of funding. Demonstrations are essential to move this along as is the involvement of payers participating in the demonstration. The ability to scale models nationwide may rely on return on investment data.
- » Technology is a valuable tool in supporting caregivers, but lower income families may not have adequate access to the Internet or smart phones, for example.
- » The fund should constitute a single innovation fund, with flexibility to tailor responses to the needs of different organizations and stakeholders. Individual philanthropic organizations may not contribute to a general fund because each funder has its own identity and rules for funding. The fund could also serve as a funding hub where proposals and funders are brought together and matched, so that specific funding streams are kept intact and tied to specific projects and outcomes.

- » It is important to involve the Department of Defense and the Veteran's Administration because there is considerable need for military families and veterans related to family caregiving.
- » Any innovation fund should support programs that are person-and family-centered. This focus will ensure that initiatives are friendly for the end-user.



Next Steps and Considerations

The summit participants identified a series of next steps for an Advisory Committee to begin working toward the implementation of a fund, as follows:

- » Create a committee structure for the planning and development of a fund and invite members to the Advisory Committee.
- » The fund development phase should last between six and twelve months, with an intensive six-month start. During this period, the Advisory Committee should develop a timeline for stakeholder engagement, key milestones, and metrics for success.
- » The Advisory Committee should identify the key focus areas for the fund that complement existing work in the field. Suggested focus areas include technology and models of care practice.
- » Evaluate the feasibility of a fund, including potential sources of revenue and the feasibility or creation of an ongoing entity to manage the fund. Determine whether incremental steps might be appropriate. Tasks for the Advisory Committee should include:
 - *Ensuring that the fund is fluid, responsible, flexible, and nimble;*
 - *Identifying a “home” for the fund through consultation with industry experts and the Advisory Committee;*
 - *Determining structure and functions of the fund, including a decision-making process for the Advisory Committee;*
 - *Identifying criteria for funding projects to support caregivers themselves, such as services, education, and training;*
 - *Establishing parameters to create clarity about the use of funds;*
 - *Developing an overall strategic approach to sustaining the fund over time; and*
 - *Beginning incorporation and/or creation of the fund.*

Potential outcomes of the fund might include:

- » Identified research deliverables that will advance family caregiving innovation;
- » New and ground-breaking research that is truly person and family-centered;
- » Innovations that integrate the values of the “triple-aim”⁴ with family caregiving.
- » Projects that measure caregiver satisfaction and quality of life;
- » Projects that can be scaled and quickly implemented, while still meeting the needs of family caregivers and those whom they care for; and
- » Research on the cost-effectiveness of proposed innovations.

⁴ The “triple-aim” is a framework developed by the Institute for Healthcare Improvement to “optimize” health system performance. Elements of the triple aim include improving the patient experience, quality of care and patient satisfaction; improving the health of populations and a reduction in the per capita cost of health care.

An Urgent Need for Action

In January 2018, caregiving advocates and Members of the Congressional Assisting Caregivers Today (ACT) Caucus supported legislation to create a national strategy for caregiving in line with recommendations from the Families report and the 2013 Long-Term Care Commission. Signed into law, the **RAISE Family Caregivers Act (Public Law No: 115-119)** requires the Secretary of Health and Human Services to form a multi-stakeholder advisory committee to recommend a plan for caregivers in the U.S. The work to move ahead with a national plan to address caregiving across the lifespan aligns with the need to fund innovative research that will secure private sector engagement on family caregiving issues.

The NASEM committee behind the Families report called for a change in the policies and practices related to the role of families in the support of older adults, suggesting that the “emphasis on person-centered care needs to evolve into a focus on *“person-and family-centered care.”*”

The language of the RAISE Family Caregivers Act requires the government to engage in partnership with both public and private partners, by requiring the Secretary of HHS to work with other federal agencies, Congress (including the Senate Health, Education, Labor and Pensions Committee, the Senate Special Committee on Aging, and the House Education and Workforce Committee), state agencies and others in the creation of a family caregiving strategy. Additional stakeholders are identified in the legislation as necessary to developing the strategy for caregivers, including: family caregivers; older adults with long-term services and supports needs; individuals with disabilities; health care and social service providers; long-term services and supports providers; employers; paraprofessional workers; state and local officials; accreditation bodies; Veterans; experts and advocacy organizations engaged in family caregiving; and federal agency representatives.

The RAISE Family Caregivers Act identifies several areas of focus for the national strategy, many of which would be bolstered by research and innovation from public and private stakeholders. The legislation notes the role not only of government, but communities, health and long-term care providers, and others to support family caregivers. Focus areas include: family-centered care; assessment and service planning; information, education, and training support including hospice care, palliative care, and advance care planning; respite; and financial security and workplace issues.

As the RAISE Family Caregivers Act committee begins to form, this multi-stakeholder group will work to create a plan to be released within three years of enactment. This provides an opportunity for a public-private fund to align with the development of a Family Caregiving Strategy under the RAISE Family Caregivers Act.

In summary, discussants felt that a public-private fund for caregiving research and innovation and its planned approach will have multiple benefits in addition to financial support for new research. These benefits included engagement of groups and organizations that had not previously worked on caregiving, an opportunity for unique partnerships to produce important outcomes for caregivers, and an increase in awareness and understanding of the issues facing family caregivers and those who support them.



References

Schulz, R & Eden, J. (Eds.) (2016). *Families Caring for an Aging America*, National Academies of Sciences, Engineering & Medicine. The National Academies Press, Washington, DC. 2016.

<http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx>

RAISE Family Caregivers Act (P.L. 115-119) (2018).

<https://www.congress.gov/bill/115th-congress/house-bill/3759>

Institute for Healthcare Improvement. *The IHI Triple Aim Initiative*.

<http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>; see also Berwick, D., Nolan, T., and Whittington, J. The Triple Aim: Care, Health and Cost. *Health Affairs* 27:3 (May/June 2008).

<https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.27.3.759>

Examples of Existing Public-Private Partnerships

Accelerating Medicines Partnership (AMP)

www.nih.gov/research-training/accelerating-medicines-partnership-amp

Behavioral Risk Factor Surveillance Survey (BRFSS)

www.cdc.gov/brfss/index.html

Biomarkers Consortium

<https://fnih.org/what-we-do/biomarkers-consortium>

Business Acumen Initiative

www.acl.gov/programs/strengthening-aging-and-disability-networks/improving-business-practices

Geriatric Workforce Enhancement Program (GWEP)

<https://bhw.hrsa.gov/grants/geriatrics>

Healthy Brain Initiative

www.cdc.gov/aging/healthybrain/index.htm

Independence at Home Demonstration

<https://innovation.cms.gov/initiatives/independence-at-home>

Innovative Medicines Initiative

www.imi.europa.eu

National Collaborative on Childhood Obesity Research

www.nccor.org

National Family Caregiver Support Program

www.acl.gov/index.php/programs/support-caregivers/national-family-caregiver-support-program

Partnership for Accelerating Cancer Therapies (PACT)

<https://fnih.org/what-we-do/current-research-programs/partnership-for-accelerating-cancer-therapies>

Summit on The Science of Caregiving: Bringing Voices Together (August 7 – 8, 2017)

www.ninr.nih.gov/newsandinformation/events/pastevents/caregivingsummit

The BRAIN Initiative

<https://braininitiative.nih.gov>

The Paul B. Beeson Emerging Leaders Career Development Award in Aging

www.afar.org/research/funding/beeson

VA Caregiver Support Program

www.caregiver.va.gov

VA: Campaign for Inclusive Care, National Military and Veteran Caregiver Network

www.elizabethdolefoundation.org/campaign-inclusive-care

VA: Choose Home

See www.va.gov/ADVISORY/docs/Minutes-VFCSACOct2017.pdf, Opening Remarks: Summary.

Veterans' Family, Caregiver, and Survivor Advisory Committee

www.va.gov/ADVISORY/Veterans_Family_Caregiver_and_Survivor_Advisory_Committee.asp



National Alliance for Caregiving

www.caregiving.org