



Improving Medicare at Home for Beneficiaries and Family Caregivers

Recommendations from an Expert Working Group



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On behalf of the Health, Medicine & Society Program (HMS) of the Aspen Institute and Cascada Consulting, I am honored to present this consensus action report, *Improving Medicare at Home for Beneficiaries and Family Caregivers*.



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The recommendations advanced here are designed to strengthen Medicare policies and practices to create a financially sustainable system that offers beneficiaries and their unpaid family caregivers equitable access to quality home-based services and support.

The report builds on a high-level convening held May 26, 2023 at the Aspen Institute's headquarters in Washington, DC, which brought together researchers, practitioners, individuals with lived experience, and other leaders, all preeminent experts in the field. This Working Group, in turn, built on in-depth research conducted by Cascada Consulting. In addition to interviews with policymakers, government and community representatives, and providers, researchers probed the experiences and perspectives of family members who provide care to Medicare beneficiaries. That input revealed both their commitment to caring for loved ones at home and the enormous burden the role carries in the absence of adequate medical and social support.

Recognizing that Medicare has not kept pace with the health system's shift away from hospitals and into the home, the Working Group considered how best to design interventions that will better meet the needs of Medicare beneficiaries, their family caregivers, and society as a whole. Their recommendations fall into three broad categories: strengthening the role of the federal Center for Medicare and Medicaid Services, developing mechanisms to ease the burdens on caregivers, and adding to the knowledge base through research and demonstration projects.

Risa Lavizzo-Mourey (President Emerita, Robert Wood Johnson Foundation; Professor, University of Pennsylvania School of Medicine) and Sheila Burke (Chair, Government Relations and Public Policy Group, Baker Donelson; Adjunct Lecturer, Kennedy School of Government, Harvard University) cochaired the Working Group. Alan Weil, editor-in-chief of *Health Affairs*, moderated the discussion and HMS communications consultant Karyn Feiden drafted this report. We are very grateful to all of them, as well as to the Commonwealth Fund, which supported this project. Their commitment, and the contributions of the Working Group members, reflect the urgency of the need. Medicare has to change, bipartisan support for family caregiving seems within reach, and there are both immediate and longer-term strategies for making a difference. Now is the time for action.

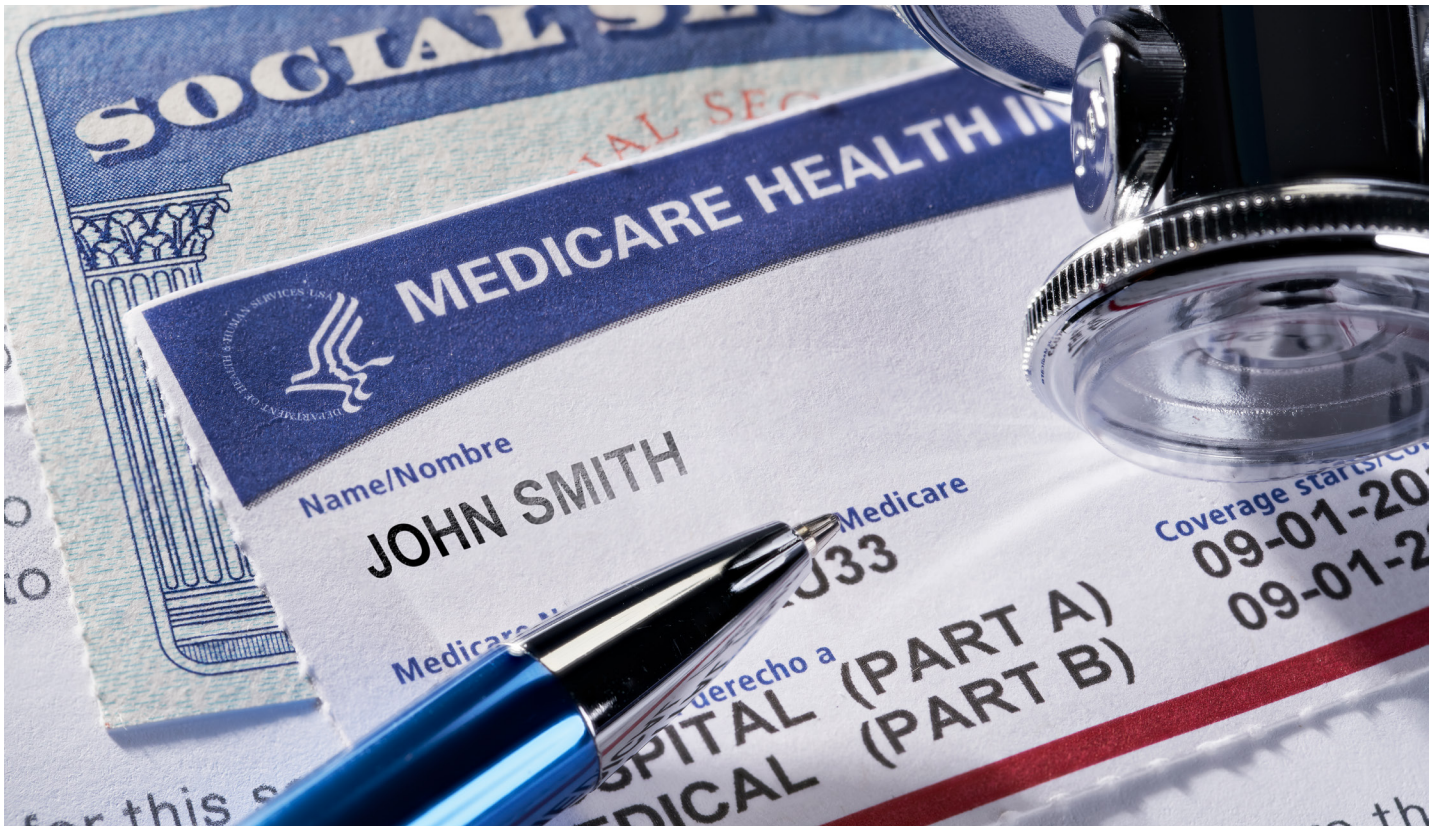
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| | |
|----|--------------------------|
| 2 | Report |
| 16 | References |
| 18 | Participants and Staff |
| 24 | Program Conveners |
| 25 | Research Acknowledgments |

Medicare, the federal health insurance program covering 65 million Americans ages 65 and older and younger people with disabilities, pays much of the costs of hospital, outpatient, and physician visits, prescription drugs, and other acute and some postacute care services. What it does not cover, except under limited circumstances, is home-based healthcare.

Yet the changing landscape of the delivery system has moved many health services away from institutions and into the home. This is what many Medicare beneficiaries prefer, but the Medicare system itself has not adapted to accommodate their needs. The resulting gaps mean that millions of unpaid family caregiversⁱ are providing a broad range of assistance to beneficiaries as they recover from illness, move through rehabilitation, or deal with chronic health challenges. Without more medical and social support from a reconfigured Medicare system, the overwhelming burden on family caregivers will only grow heavier.

Of the estimated 42 million unpaid caregivers in the United States who provide home care for someone age 50 or older, 90 percent are the adult children, spouses, in-laws, or other relatives of those needing care. Sixty percent of those caregivers are women, evidence of a disproportionate gender impact, and 62 percent were employed at some point in the previous year.¹ AARP estimates the economic value of unpaid caregiving to be approximately \$600 billion in 2021.² An aging population will intensify the pressures. By 2060, nearly one in four Americans will be 65 or older, and the number of people ages 85 or older will triple.³

To address this burgeoning challenge, the Health, Medicine & Society Program of the Aspen Institute, in partnership with Cascada Consulting, convened 13 people with diverse expertise in aging and disability issues to examine family caregiving for Medicare beneficiaries. The Working Group which met in person in May 2023, was cochaired by two leaders in the field: Sheila Burke, MPA, RN, FAAN, chair of the Government Relations and Public Policy Group at Baker Donelson and adjunct faculty at the John F. Kennedy School of Government at Harvard University, and Risa Lavizzo-Mourey, MD, MBA, President Emerita, Robert Wood Johnson Foundation. The project is supported by the Commonwealth Fund.

ⁱ In this report, the term family caregivers is used as it is in the Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017: “An adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation” (Pub. L. No. 115-119, 132 Stat. 23, 24, 25, 26 and 27 [2018]).

ⁱⁱ Quotes throughout the document are edited from Working Group comments.

“Medicare was not designed to care for people who are living longer, with more challenges and a different demand for services. It was designed to deal with an episode of illness where you go into the hospital, you get treated, you’re done. The world has changed and people’s needs have changed.”ⁱⁱ

The purpose of the convening was to highlight the urgency of the problem and to reach consensus on a set of policy recommendations designed to do the following:

- Advance a more equitable and financially sustainable system for providing home-based services.
- Strengthen support for family caregivers by easing their economic, physical, and mental health burdens and better equipping them to shoulder their responsibilities.
- Improve quality of life for Medicare beneficiaries while potentially reducing costs for the Medicare program.

The priority actions outlined in this paper reflect the consensus of the Working Group, informed by a literature review and additional research that was commissioned specifically for this project and conducted by Cascada Consulting. Cascada's effort included six focus groups, a survey of 1,000 unpaid family caregivers of Medicare beneficiaries, and interviews of 20 national experts on Medicare and related health policy issues (these individuals differed from the experts who participated in the Working Group).

The action framework presented here recognizes the urgency of equity both for the Medicare beneficiaries in need of care and for the caregivers on whom they rely. As stated in *First Principles: Cross-Cutting Considerations for Family Caregiver Support*, which is part of a national strategy to identify priorities for action: "Caregiving affects all families—but it does not affect every family equally."⁴ Many policies and institutions have left certain groups of caregivers, including those from communities of color and those caring for people with disabilities, with little recognition or support.

Some beneficiaries are forced to spend down their limited resources to become eligible for Medicaid, the joint federal-state program for low-income populations that covers significantly more home care and nursing home costs than Medicare. Others fall into the "forgotten" middle of the Medicare-eligible population, neither qualifying for Medicaid nor having adequate resources to pay privately for caregiver services. Their unsustainable burden is exacerbated by continuing out-of-pocket expenses for food, transportation, and other routine costs.

Additionally, caregivers who step out of the labor force lose not only their income, their health insurance, and other workplace benefits but also the Social Security credits that provide the bedrock of retirement for most Americans.⁵ All of that contributes to intergenerational poverty, with its deleterious health consequences that have a vastly disproportionate impact on populations of color and on women.

"We want to find ways to help people live successfully at home as long as possible, because that is what people want, and it is what is better for them in terms of quality of life and in terms of economics."

The Big Picture Today

- The landscape of healthcare delivery under Medicare has evolved away from institutions and into the home. While this reflects the preference of many beneficiaries and their families, it also means that unpaid caregivers shoulder the cost and care burden, rather than having Medicare do so. A reconfigured system of medical and social support is essential for beneficiaries to remain safely at home without overwhelming their caregivers.
- The Medicare program as currently constructed does not provide sufficient home-based services to promote recovery, rehabilitation, and health maintenance. A system overhaul could particularly benefit those who are currently able to live in the community with the assistance of a family caregiver, but are at risk for institutional care if their health deteriorates.
- Family caregivers fill many of the gaps in home health and other supportive services and thus help sustain the Medicare program by delivering home-based care without compensation. Yet as care providers they are not considered part of the healthcare team and their voices often go unheard.
- While most family caregivers want to keep their loved ones at home, they often struggle to provide the required care while also meeting their own needs and those of other family members. Systemic inequities mean that the financial and emotional burdens of caregiving fall disproportionately on people of color, women, and people living in rural areas.
- Well-designed interventions that combine formal and informal healthcare and social support would demonstrate respect for the wishes of Medicare beneficiaries and their families while potentially reducing Medicare's costs. It would also help to reduce burdens on family caregivers who are disproportionately women and women of color.



Challenges and Opportunities

The following key findings, which emerge from research and the expertise of Working Group participants, underscore the importance of responsive policymaking that supports the recommendations of this report:

- **Home-based care plays an increasingly important role for Medicare beneficiaries.** Demographic changes, medical advances, innovative technology, new care delivery and payment models, an emerging respect for person-centered care, and the influence of the COVID-19 pandemic have combined to elevate the role of home-based care. Various service models already exist to meet a broad spectrum of medical and nonmedical needs at home, but all have a limited reach, and most rely on significant support from unpaid family caregivers.^{6,7,8}
- **Home care offers advantages to Medicare beneficiaries, their families, and the Medicare program itself.** Most Medicare beneficiaries prefer to receive care in the familiarity and comfort of home, rather than in an institution, a preference that is generally echoed by family caregivers. Importantly, while one-third of caregivers surveyed in the Cascada survey said they were expected to take on that responsibility, and one-quarter reported that there was no one else to do so, most unpaid family caregivers did not view their work solely as a burden. Two-thirds of respondents said they wanted to help the person for whom they were caring and that they felt appreciated. However, as care needs increased, they found the burden increasingly heavy and more difficult to manage. For older adults, having a family caregiver may reduce their use of healthcare and decrease their risk of institutionalization,⁹ potentially reducing Medicare's obligation to pay for care in acute and subacute facilities.
- **As care shifts from institutional to home-based settings, family caregivers face intense pressures that put them at risk of burnout.** Family members who provide medical and personal care to Medicare beneficiaries with significant needs generally do so without being compensated, adequately prepared for their new caregiving responsibilities, trained to learn how to handle them, or offered respite services.¹⁰ Cascada's survey findings suggest the scale of the burden. Almost half the surveyed caregivers have been providing care for two or more years, and more than one-third do so more than 40 hours a week, in some cases essentially providing around-the-clock care. Administering medications; providing assistance with wound care, injections, and catheterization; and ensuring safe transfers from bed to bathroom are examples of the responsibilities many shoulder. They are also a crucial link to the medical system, scheduling appointments, arranging transportation, and communicating with providers.



Additionally, caregivers often face significant financial burdens, including the loss of their own jobs.¹¹ More than half (58 percent) of those surveyed said they had sacrificed or adjusted paid employment to manage their caregiving responsibilities. They often assume significant out-of-pocket expenses for medical equipment, supplies, and other health services that Medicare does not cover for the beneficiary as well as for home modifications, transportation, and basic living expenses.¹² These monetary and nonmonetary harms threaten caregivers' own short-term and long-term security.

The consequences are evident in a 2020 AARP and National Alliance for Caregiving report, which found that the complex burdens of caregiving can jeopardize the health of family caregivers.¹³ The Cascada survey confirms this finding—nearly half of the responding caregivers said they felt depressed, 60 percent felt anxious, and 61 percent reported feeling burned out at least some of the time. Caregivers also commonly delay seeking healthcare for themselves. Caregivers of color, who have fewer financial resources on average, also report greater difficulty in meeting their own expenses.^{14,15}

- **Caregivers say more support would help them maintain their caregiving roles and lessen the likelihood that their family members would require institutional care.** Financial assistance is a priority—75 percent of Cascada survey respondents said that being reimbursed for out-of-pocket expenses would be helpful, 71 percent said the same about being compensated for their work, and 69 percent said that financial assistance to hire a paid caregiver would help some or a lot. Caregivers also said they need easier access to information about Medicare and other public and community-based benefits. More than three-quarters (77 percent) of survey respondents said that a health advocate would help them better navigate the healthcare system, and more than two-thirds (68 percent) thought that care coordination by a social worker or another trained professional would help.

These caregivers also need respite—almost two-thirds (63 percent) said that a temporary break would be helpful. Adult day care, services from a paid caregiver, and other interventions to provide significant relief, especially when 24/7 care is required, could reduce burnout and allow caregivers to work.



Framing the Action Steps

As the findings suggest, at least some of the services that allow Medicare beneficiaries to remain at home fall outside the realm of traditional medical services. But the concept that social needs and support for activities of daily living play a significant role in health, and therefore that coverage should be available to meet those needs, is not reflected in the core principles of Medicare. “That is not the premise of the Medicare program, it’s not the statutory structure of the Medicare program, it’s not the payment structure of the Medicare program,” one Working Group member asserted. Moreover, any home-based social support provided to beneficiaries and caregivers is not likely to demonstrate measurable population-wide benefits quickly, making it more difficult to attract policymaking attention and support.

Comprehensive models of care within Medicare remain the exception. But as the American population grows older and lives longer with chronic conditions, the primary reliance on family caregiving to provide the necessary palette of medical and social services to sustain beneficiaries at home looks increasingly unsustainable. Three factors make this a particularly opportune moment to consider how best to modify existing structures. First, the experience of the COVID-19 pandemic is a reminder that health systems have the capacity to shift quickly in urgent times and offers important lessons about how and why that can happen. Second, the US Department of Health and Human Services, in Healthy People 2030, has identified the promotion of social determinants of health, such as food and transportation services, as key to integrating social needs with medical needs to improve health and reduce health disparities.²⁰ Third, technology, including artificial intelligence, is at an inflection point, offering innovative new tools to support caregivers in navigating services while also presenting them with the challenge of providing more intensive care at home.

Several government actions have set the stage for progress. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 mandated the development of the National Strategy to Support Family Caregivers. Released by the US Department of Health and Human Services and delivered to Congress in 2022, the strategy includes some 350 actions that the federal government can take to support family caregivers and identifies an additional 150 actions that can be adopted at other levels of government or within the private sector.²¹ In December 2022, the Centers for Medicare & Medicaid Services (CMS) leadership highlighted the importance of caregiving and outlined opportunities for Medicare to address the needs, including through its annual physician fee schedule.² More recently, President Biden signed an executive order directing most cabinet-level agencies to expand access to affordable care and to support both care workers and family caregivers.²³

“What are the barriers today to giving Medicare beneficiaries greater access to caregiver services? What is it in the current structure of the Medicare program that prevents some of this from occurring? Understanding that is where the statutory changes or the regulatory changes will begin.”

Much more needs to be done. An evolving home care system for Medicare beneficiaries and family caregivers will likely need to include a professional caregiving component. But professionalizing the workforce and defining the roles of both unpaid and paid caregivers are not straightforward measures. For one thing, many spouses, children, siblings, or other relatives and friends caring for a loved one at home do not even identify themselves as caregivers. On the paid side, much of the labor force providing home care is composed of immigrants and women of color, including many who are paid privately. Determining the skills and training needed to safely care for Medicare beneficiaries, while maintaining an adequate pool of workers and factoring in the affordability of care, will necessarily require a flexible menu of home health options.

Flexibility is also imperative because beneficiaries have different needs, and these can change quickly. A chronic illness in a high-functioning 75-year-old requires a different response than one for a frail 90-year-old who has fallen. Anyone can have an acute event layered onto other health challenges that suddenly alters the mix of home health services they require. Some people need dedicated service to recover from a specific condition; others will need it continually, with no endpoint.

Eligibility criteria for reimbursable, Medicare-covered home health needs to be redefined, as does the nature of the services provided. Decisions must also be made about who qualifies as a caregiver, how many hours they are expected to dedicate to the role, and what services they must be qualified to provide. “We aren’t saying that every time anybody takes care of somebody at home, for whatever reason, Medicare will provide coverage,” warned one Working Group member.

Targeting beneficiaries whose functional status can be maintained or improved with additional support is likely to yield the most robust payoff from a cost-benefit perspective. An example is an individual with congestive heart failure, a condition that can sometimes lead to multiple hospitalizations. “In preventing these hospitalizations, you can definitely save money,” a Working Group member said. “In a chronic condition where there is decrease in function over time, you will also save a lot of heartache down the line if you can keep a person more functional.”

In all likelihood, there will be no one-size-fits-all approach but rather differing solutions to meet different needs, with thought given to which benefits should be available, and to whom, based on assessments of the beneficiary’s needs and caregiver capacity. A deeper understanding of how the caregiving response is altered by circumstances, including racial, ethnic, and sociodemographic differences and cultural norms, will provide a valuable springboard for responsive solutions.

“The family model isn’t sustainable without some contribution from professional caregivers.”

Beyond Medicare beneficiaries and their families, many other stakeholders have vested interests in an effective caregiving system. States, for one, assume significant costs to care for their Medicaid population, making them potential allies in developing Medicare policies that could prevent beneficiaries from having to spend down their resources to qualify for Medicaid.

The private sector has a potential role as well. The rapid acquisition of home health agencies by private companies suggests there is a business interest here, although the complexity and expense of complying with Medicare regulations could mean incentives may be needed for them to engage with the program.

The urgent need to modernize home care for Medicare beneficiaries is underscored by the alarming and undercounted problem of physical, mental, and financial elder abuse.²⁴ “It comes when people aren’t prepared to provide care, or when they just decide not to,” said one Working Group member. “We should really talk about the ways in which not helping caregivers creates the risk of elder abuse.”

Cost issues are certain to dominate legislative and regulatory debates about family caregiving within Medicare. No attempt was made to cost out the recommendations advanced in this report, but budgeting considerations are clearly paramount. In any calculation, the expense of new programs or benefits must be weighed against the consequences of taking no action. “You have to spend money to avoid spending more money,” emphasized a Working Group member. “If this voluntary jerry-rigged system fails, how many more people will wind up in the hospital—patients first and then caregivers second? We need to explain to the nation the cost consequences of not doing this.”

Importantly, the issue of how Medicare can better support the caregiving needs of its beneficiaries intersects with a vast array of other societal challenges. A comprehensive strategy will also need to consider immigration, given that so much of the paid caregiver labor force comes from other countries; assess opportunities to adjust Social Security credits to account for the time unpaid caregivers spend away from the workforce; and ensure the financial stability of both the Social Security and Medicare trust funds. While policy details here are beyond the purview of this Working Group, they are critical elements of an enduring approach.

“The states actually have a lot of skin in the game here as they see this population coming towards them and spending down rapidly into Medicaid.”

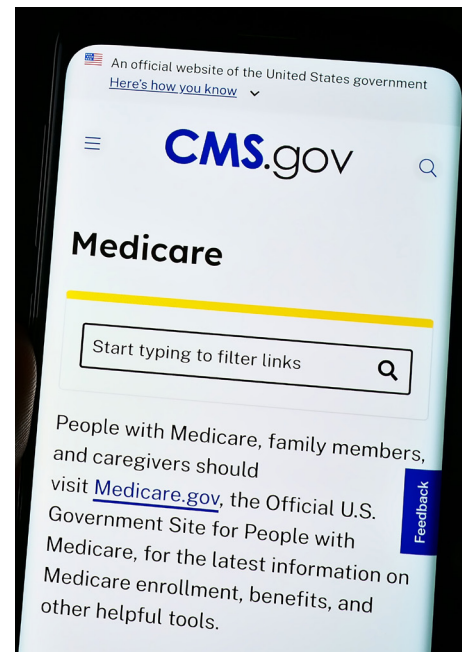
Policy Recommendations

The recommendations that follow build on the Working Group's commitment to equity, consumer participation, and a family-directed approach designed to let Medicare beneficiaries make their own decisions about how to spend the available resources, to the degree possible. Many of these could be implemented as part of the Medicare benefits package but meeting caregiving needs also means identifying levers that go beyond Medicare's purview. Improving coordination with the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), and elevating the role of health systems, educators, and community-based organizations with dedicated public sector funds, could also help to foster a more responsive system.

The recommendations here are organized into three categories: strengthening the role of CMS, supporting caregivers, and growing knowledge.

Strengthening the Role of CMS

- **Identify the locus of responsibility within Medicare where efforts to better meet the needs of beneficiaries at home could be lodged.** CMS could directly identify immediate and longer-term opportunities to engage Medicare in family caregiving, centralize knowledge about the needs of beneficiaries and family caregivers, and enable a coordinated approach to meeting them, or it could coordinate with other entities, such as the Administration for Community Living, to do so. Assessing existing resources and policies, and overseeing the research, training, and navigator functions proposed in this document, could be priority activities. This approach could allow CMS to help fill knowledge gaps, serve as a liaison to programs and services both within and outside Medicare, and guide a community engagement component designed to identify and respond to the needs of beneficiaries.
- **Reconsider eligibility criteria to broaden the home care benefits available to Medicare beneficiaries.** Current criteria for receiving home health Medicare services, especially the requirement that a recipient be homebound, greatly shrinks the eligible population. A number of alternative eligibility guardrails, such as functional status or level of risk for potentially avoidable nursing home care, could be considered if the homebound requirement were eliminated. Another approach to broadening home care benefits would be to offer an early intervention targeted at populations most likely to improve medically with time-limited benefits that promote long-term stability.



- **Develop a community-based coordinating system, funded by Medicare, to help beneficiaries and their caregivers access medical and nonmedical home care, including health-related social services.** Reimbursing navigation services; providing the training necessary to produce a cadre of diverse, culturally sensitive advocates (and reimbursing the social service agencies and schools that provide such training); and using existing and emerging information technology resources effectively will likely streamline access to an appropriate mix of services and enhance care coordination. Coordinated services include both those available directly through the Medicare program and those lodged in community organizations and health systems.

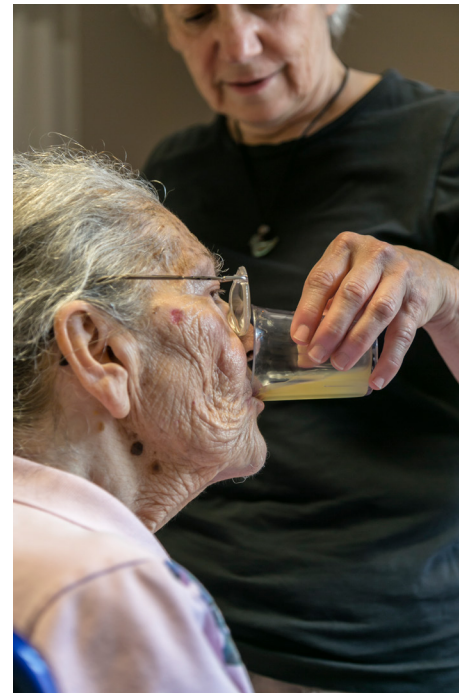
Specifically, these navigation services, coupled with a centralized, online information resource, can link qualifying Medicare beneficiaries to Medicaid, the Supplemental Nutrition Assistance Program (SNAP), Part D prescription subsidies, and other safety net programs. Any database should include the full spectrum of available social services and other community-based supports, such as transportation services, home modification programs, counseling, and Meals on Wheels. As one Working Group member said, “It would help the mental health of the caregivers immensely to be able to call and get a live human and just say, she’s 87, she has dementia but now she has an abscessed tooth. Where do I go? Where is the place that you can get good care, respectful care?”

“We need to really double down on community-based infrastructure support so that when you identify a problem, you can actually do something about it.”

Supporting Caregivers

- **Offer caregivers of Medicare beneficiaries a package of services that enhances their skills, knowledge, and emotional health and eases the financial strain associated with caregiving.** Any such package should build on what caregivers themselves say they need, emphasizing evidence-based approaches that help engage and retain the caregivers. Beyond access to a centralized and coordinated system to facilitate navigation and linkage to the services and information resources outlined above, the following measures can help ease their burdens:
 - » Training to support the capacity to monitor health status, administer medication, and deliver complex medical care to a family member.
 - » Enhanced availability of smart technology and internet connections to expand access to outside expertise and remote monitoring.
 - » Respite care, including support groups, adult day care, and support from paid aides and other health professionals.
 - » Access to mental health services, which should be available not only to address clinical diagnoses, such as depression, but also to help caregivers deal with stress and burnout.

- » Reimbursement for the out-of-pocket expenses that caregivers incur to help Medicare beneficiaries remain at home, such as adult diapers, hygienic products, and other nonprescription medical supplies.
 - » Attributing a salary to caregivers who leave the paid labor force to eliminate the current Social Security penalty. Eligibility for workplace benefits, such as paid leave, workers' compensation, and unemployment insurance, could also protect caregivers from falling into poverty or incentivize more people to assume a caregiving role. These measures would require broader policy and payment changes outside the scope of the current Medicare program.
 - » Consideration of a demonstration initiative that would combine the federal government resources available in CMS, CDC, and HRSA to fund community-based services for Medicare beneficiaries and to provide a paid benefit to family caregivers.
- **Develop mechanisms to embed more knowledge and sensitivity to the needs of family caregivers within the health system. Approaches could include the following:**
 - » Ensuring that the caregiver of choice is identified in the electronic medical record.
 - » Screening Medicare beneficiaries to identify social needs both as a routine part of medical care and as a component of other services delivered in community-based settings.
 - » Exposing nurses, social workers, physicians, and other practitioners to the responsibilities of family caregivers during their clinical training, whether through home visits, videos, or focus groups that showcase caregiver concerns.
 - » Using technology to put systems in place that allow multiple providers on both the clinical and social service sides to exchange data.
 - » Providing reimbursement for family meetings so that physicians can bring in social workers or other social support providers.



Growing Knowledge

- **Build the evidence base essential to effective policymaking.** Collecting comprehensive data on the need for, and use of, home-based family caregiving, and its correlation with outcomes and costs, is essential to understand disparities in service access and quality and to assess the effects of policy change on equity, appropriateness of care, and the bottom line.

Clearly, criteria will need to be established to determine the service needs that trigger public sector support. Robust studies that look at specific subsets of Medicare beneficiaries—such as those with dementia, those with cancer, and those who are cognitively intact but frail—could inform targeted policies.

Importantly, studies should distinguish among the diverse situations of both family caregivers and beneficiaries. Key questions include: Who is being served and who is providing the care? What services do beneficiaries seek out and under what circumstances? How do needs differ based on degree of medical and social challenges? What lessons do Medicaid and dually eligible populations offer? Building in patient-reported metrics will help track the extent to which beneficiaries feel heard, supported, and treated equitably.

Studying existing models could also inform policymaking. Specifically, there is much to be learned from the Program of All-Inclusive Care for the Elderly model, the navigation resources available through the Area Agencies on Aging and the Aging and Disability Resource Centers, and the caregiving support provided through hospice programs. The US Department of Veterans Affairs and Medicaid also have experience in supporting caregivers that merits study. Given the value of effective service coordination, it would also be useful to understand the challenges that have faced efforts to integrate Medicare and Medicaid services for dually eligible populations.

- **Design demonstration projects to learn more about what is most valuable to Medicare beneficiaries, their families, and the health system.** Conducted under the auspices of the Center for Medicare & Medicaid Innovation and designed with significant input from the affected communities, demonstration projects such as the Value Based Insurance Design Model²⁵ and the Realizing Equity, Access, and Community Health Model²⁶ can help to define priorities, identify appropriate target populations, evaluate quality, assess costs, and inform action. The research should be designed to account for differing needs among subgroups, including people with dementia and mental health challenges, and should initially target individuals who do not meet the need for nursing home care and are not dually eligible for Medicare and Medicaid.

The structure of Medicare Advantage plans and Medicare accountable care organizations makes them the logical sites to test new models and independently evaluate the quality and cost savings of program flexibilities designed to support caregivers. The recently announced Guiding an Improved Dementia Experience (GUIDE) model, which

“We can’t lump together everybody who is being cared for at home, or in a homelike setting, and expect to come up with a solution. We need to understand the varying obstacles and challenges that confront different populations.”

launches in July 2024 under traditional Medicare, could also be a setting for experimentation. GUIDE will provide a package of services to improve quality of life for people living with dementia, increase their capacity to remain in their homes and communities, and reduce strain on their caregivers.²⁷

- **Define, collect, and analyze performance measurements tied to clinical and patient-reported outcomes to assess the impact of home-based Medicare services.** Such measures, possibly accompanied by financial incentives to insurers who meet certain thresholds, can be used to determine whether Medicare beneficiaries and their caregivers are getting needed support. They can also foster competition and a drive for excellence, becoming a marketing tool to guide beneficiaries as they select their plans. The experience that Medicaid has had with performance measures may offer insights about what approaches work best.

“We need to document the cost-effectiveness of spending money on the front end so that we don’t have to do it on the back end.”

The Urgency of Now

The importance of Medicare, the needs and preferences of Medicare beneficiaries and their family caregivers, and the strength of the entire healthcare system all converge on a single message: Medicare needs to change. An aging population and the opportunities introduced by technology add to the sense of urgency, and the RAISE Family Caregivers Act and President Biden’s recent executive order indicate there is political support for action.

While some policy changes will take time to implement, many of the Working Group’s recommendations can be put in place quickly, providing a springboard for additional structural changes. Coupling immediate steps with longer-term strategies to respond to the needs of a changing healthcare environment can strengthen family caregiving and allow Medicare beneficiaries to remain in the safe and familiar environment of home. While the specifics are certain to be vigorously debated, strong bipartisan support for family caregiving seems plausible. The shared value that American families deserve help as they care for their loved ones may be enough to move policymakers on both sides of the political aisle toward consensus.

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CO-CHAIR

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Sheila P. Burke, MPA, RN, FAAN is strategic advisor and the chair of government relations and public policy group at the law firm of Baker Donelson. She is also an adjunct lecturer in public policy at the John F. Kennedy School of Government at Harvard University, a distinguished visitor at the O'Neill Institute for National and Global Health Law at Georgetown University, and senior advisor to the Bipartisan Policy Center.

Among past positions, Burke was chief of staff to former US Senate Majority Leader Bob Dole, deputy director of the Senate Committee on Finance, and chief operating officer of the Smithsonian Institution. Burke is a member of the National Academy of Medicine and the National Academy of Sciences, and a fellow of the National Academy of Public Administration and the American Academy of Nursing. She serves on the board of the Commonwealth Fund, Abt, and Ascension Health Care and is an advisor to the dean of the University of San Francisco School of Nursing. Burke holds an MPA from Harvard's Kennedy School and a BS in nursing from the University of San Francisco.



CO-CHAIR

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President Emerita, Robert Wood Johnson Foundation

A world-renowned expert in health policy and geriatric medicine, Risa Lavizzo-Mourey, MD, MBA, is President Emerita of the Robert Wood Johnson Foundation. She served as president and chief executive officer of the Foundation from 2003-2017 and, for 15 years before that, as a distinguished professor and administrator at the University of Pennsylvania. Lavizzo-Mourey has also served as the Robert Wood Johnson Foundation PIK Professor of Health Policy and Health Equity, and held joint faculty appointments in the Department of Health Care Management at The Wharton School, as well as in the Department of Family and Community Health, School of Nursing (both at the University of Pennsylvania).



DONNA BENTON

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Donna Benton, PhD, is a research associate professor of gerontology and director of the Family Caregiver Support Center at the USC Leonard Davis School of Gerontology. She is a member of the California Coalition on Family Caregiving, the Work Family Coalition, and the Elder Justice Coalition and continues to work on California's Master Plan for Aging.

Benton has worked in the field of aging for over 30 years. Her volunteer experience with the Gray Panthers in high school inspired her career as an advocate for improving how the natural process of aging is viewed. She is committed to promoting collaborative partnerships that enhance service delivery for families caring for older adults with long-term memory and health problems.



MERCEDES E. BERN-KLUG

Professor, University of Iowa

Mercedes Bern-Klug, PhD, MSW, MA, is a professor in the School of Social Work at the University of Iowa. Her area of research is family care for older adults with advanced chronic illness. She has conducted two national surveys of nursing home social services directors (special issue, *Journal of Gerontological Social Work*, Oct-Nov 2021) and edited the book, *Transforming Palliative Care in Nursing Homes: The Social Work Role* (Columbia University Press, 2010). Bern-Klug is a Gerontological Society of America fellow, a John A. Hartford Geriatric Social Work Faculty Scholars awardee, a Fulbright faculty scholar, and a fellow with the American Academy of Social Work and Social Welfare.



HENRY CLAYPOOL

Policy Director, Community Living Policy Center

Henry Claypool applies his lived experience with disability to inform healthcare and technology policy. He is an independent consultant and policy director at the Community Living Policy Center in the Heller School for Social Policy and Management at Brandeis University, which works to improve policies and practices to keep people with disabilities in the community. Previously, Claypool served as the director of the Office on Disability at the US Department of Health and Human Services and was principal architect of HHS's Administration for Community Living, which was established in 2012 and built around the fundamental principal that adults should be able to live independently and participate fully in their communities. He has also been senior advisor to the Administrator of the Health Care Financing Administration, now the Centers for Medicare and Medicaid Services. In that capacity, he worked on guidance to implement the US Supreme Court's Olmstead decision, which found that segregating people with disabilities is a form of discrimination under the Americans with Disabilities Act.



RICHARD FRANK

*Senior Fellow, Economic Studies,
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Richard G. Frank, PhD, is a senior fellow in economic studies and director of the USC-Brookings Schaeffer Initiative on Health Policy. He is the Margaret T. Morris Professor of Health Economics, emeritus, in the Department of Health Care Policy at Harvard Medical School. From 2014 to 2016 he served as assistant secretary for planning and evaluation in the US Department of Health and Human Services. His research is focused on the economics of mental health and substance abuse care, long-term-care financing policy, healthcare competition, implementation of health reform, and disability policy. Frank served as an editor for the *Journal of Health Economics* from 2005 to 2014. He was awarded the Georgescu-Roegen Prize from the Southern Economic Association, the Carl A. Taube Award from the American Public Health Association, and the Distinguished Investigator Award from AcademyHealth. Frank also serves on the Health and Medicine Division Committee of the National Academy of Sciences, Engineering and Medicine.



TERRY FULMER

President, The John A. Hartford Foundation

Terry Fulmer, PhD, RN, FAAN, is president of The John A. Hartford Foundation in New York City, dedicated to improving the care of older adults. She serves as the foundation's chief strategist and her vision for better care of older adults is catalyzing the Age-Friendly Health Systems social movement. Fulmer also served on the independent Coronavirus Commission for Safety and Quality in Nursing Homes. Previously, she was distinguished professor and dean of health sciences at Northeastern University and founding dean of the New York University College of Nursing. Nationally and internationally recognized as a leading expert in geriatrics, she is also known for conceptualizing and developing the national Nurses Improving Care for Healthsystem Elders (NICHE) program and for her research on the topic of elder abuse and neglect. An elected member of the National Academy of Medicine, Fulmer is the first nurse to have served on the board of the American Geriatrics Society. She is also the first nurse to have served as president of the Gerontological Society of America, which awarded her the 2019 Donald P. Kent Award for exemplifying the highest standards for professional leadership in the field of aging.



SISTER CAROL KEEHAN

Former President and CEO, Catholic Health Association

Sister Carol Keehan, MS, BSN, is a member of the Daughters of Charity of Saint Vincent de Paul. Keehan served as a hospital CEO for 18 years and as president and CEO of the Catholic Health Association of the US for 14 years, where she worked closely with the White House and Congress in the successful effort to pass the Affordable Care Act. Most recently, Keehan chaired the Health Task Force of the Vatican's COVID Commission. Keehan's nursing career has included positions as a nurse aide, staff nurse, nursing supervisor, and vice president for nursing and she continues to consult in the Middle East with her community's hospitals. She holds a BS in nursing and a master of science in healthcare finance from the University of South Carolina.



EMILY LARGENT

Assistant Professor, University of Pennsylvania, Perelman School of Medicine

Emily A. Largent, JD, PhD, RN, is the Emanuel and Robert Hart Assistant Professor of Medical Ethics and Health Policy at the University of Pennsylvania Perelman School of Medicine. She holds a secondary appointment at Penn Law and is a senior fellow at the Leonard Davis Institute of Health Economics.

Largent's work explores the experiences of patients and care partners across the Alzheimer's disease continuum. Supported by grants from the National Institute on Aging and the Greenwall Foundation, her research includes topics such as disclosing Alzheimer's disease biomarkers to persons at risk for cognitive impairment, decision-making by persons with marginal capacity, dementia-friendly policies, and the ethical conduct of Alzheimer's research. She is an elected fellow of the Hastings Center and received the 2023 Baruch A. Brody Award in Bioethics. She was previously a fellow in the Department of Bioethics at the National Institutes of Health. Largent earned a degree in nursing from Penn Nursing, a PhD in health policy, with a concentration in ethics, from Harvard University, and a JD from Harvard Law School.



LOREN SAULSBERRY

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Loren Saulsberry, PhD, is an assistant professor in the Department of Public Health Sciences at the University of Chicago, where she studies policies that might significantly narrow health disparities. Specifically, she is interested in the experiences that Medicare beneficiaries have in managing chronic conditions, especially those underrepresented and medically underserved. Saulsberry is also the assistant program leader of the Cancer Prevention & Control Program at the University of Chicago Comprehensive Cancer Center. Before entering academia, she worked at the Kaiser Family Foundation's Program on Medicare Policy. Saulsberry received her PhD in health policy from Harvard University and is an alumna of the Dana Farber/Harvard Cancer Center's Training in Oncology Population Sciences Program.



EILEEN SULLIVAN-MARX

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Eileen Sullivan-Marx, PhD, MS, BSN, is dean of the New York University Rory Meyers College of Nursing and the Erline Perkins McGriff Professor of Nursing, as well as past president of the American Academy of Nursing. Prior to joining NYU, she was associate dean for practice and community affairs at the University of Pennsylvania School of Nursing, where she created community partnerships known as Healthy in Philadelphia to promote care and healthy activities for older adults. A distinguished nursing leader, educator, and clinician, she is known for research and innovative approaches to primary care; testing methods to pay nurses, particularly through Medicaid and Medicare; sustaining models of care using advanced practice nurses; and developing health policy in community-based settings.

Sullivan-Marx has been active in regional, state, and national policy. She chaired the Pennsylvania Commission on Senior Care Services in 2008, served on the Philadelphia Emergency Preparation Review Commission in 2006, and was an American political science Congressional fellow and senior advisor to the Office of Medicaid and Medicare Coordination in the Centers for Medicare & Medicaid Services. Sullivan-Marx is a fellow of both the New York Academy of Medicine and the Gerontology Society of America.



YULYA TRUSKINOVSKY

Assistant Professor of Economics, Wayne State University

Yulya Truskinovsky, PhD, a health economist who studies long-term care and aging, is an assistant professor of economics at Wayne State University. She studies how individuals and families make decisions about work and family caregiving for older adults and the impact of public programs such as Medicaid and paid family leave on families with caregiving needs. Her interdisciplinary research agenda is supported by grants from federal agencies, including the National Institutes of Aging and nonprofits such as the Sloan Foundation. Truskinovsky earned her doctorate in public policy from Duke University and was previously a Sloan Fellow in Aging and Work at the Harvard Center for Population and Development Studies.



REED TUCKSON

Managing Director, Tuckson Health Connections

Reed V. Tuckson, MD, FACP, is managing director of Tuckson Health Connections, LLC, a vehicle to advance initiatives that support optimal health and wellbeing. He is co-convenor of the Coalition for Trust in Health & Science, dedicated to bringing together the health-related ecosystem to address mistrust and misinformation, and remains active on the Black Coalition Against COVID, which he co-founded to mitigate the pandemic's impact in Washington, DC and nationwide. Coalition stakeholders include the four historically Black medical schools, the National Medical Association, the National Black Nurses Association, the National Urban League, and BlackDoctor.org.

Previously, Tuckson served as executive vice president and chief of medical affairs for UnitedHealth Group, a Fortune 20 company dedicated to health and wellbeing. In earlier positions, he was president of the Charles R. Drew University of Medicine and Science, senior vice president for professional standards at the American Medical Association, senior vice president for the March of Dimes Birth Defects Foundation, and commissioner of public health for Washington, DC. Tuckson has also held leadership roles at the National Institutes of Health and the National Academy of Medicine and on numerous federal advisory committees, and corporate, non-profit, and academic boards.



RUTH KATZ

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Ruth Katz, JD, MPH, is executive director of the Aspen Institute's Health, Medicine & Society Program, which brings together groups of thought leaders, decision-makers, and the informed public to grapple with health challenges facing the US in the 21st century and to pursue practical solutions for addressing them. She also serves as a vice president of the Aspen Institute and directs Aspen Ideas Health, the three-day opening event of the renowned Aspen Ideas Festival.

Prior to joining the Aspen Institute, Katz served as chief public health counsel (Democratic staff) with the Committee on Energy and Commerce in the US House of Representatives. She has also been Walter G. Ross Professor of Health Policy of the George Washington University Milken Institute School of Public Health, dean of that school, and associate dean for administration at Yale University School of Medicine. She is graduate of the University of Pennsylvania, holds a law degree from Emory University and an MPH from Harvard University.



BARBARA LYONS

Founder, Cascada Consulting

Barbara Lyons, PhD, is a leading expert on Medicaid, Medicare, and health policy issues affecting low-income populations. With 20-plus years of experience working for nonprofit organizations, she has devoted her career to improving how public programs work for people. Lyons specializes in identifying emerging health policy issues; designing, conducting, and collaborating on real-time, people-oriented policy research; and disseminating findings to the policy community through publications, convenings, presentations, testimony, and briefings. Before founding Cascada Consulting, she was a senior vice president at the Kaiser Family Foundation where she directed the Kaiser Commission on Medicaid and the Uninsured and previously served on the policy staff of the Commonwealth Fund Commission on Elderly People Living Alone. Lyons holds a PhD in health policy and finance from the Bloomberg School of Public Health at Johns Hopkins University.



ALAN WEIL

Editor-in-Chief, Health Affairs

Alan Weil, JD, MPP, has been editor-in-chief of *Health Affairs*, the nation's leading health policy journal, since 2014. He was the executive director of the National Academy for State Health Policy and a center director at the Urban Institute, and held a cabinet position as executive director of the Colorado Department of Health Care Policy and Financing, the state's Medicaid agency. An elected member of the National Academy of Medicine, Weil has been an appointed member of the Medicaid and CHIP Payment and Access Commission and a trustee of the Consumer Health Foundation in Washington, DC. He earned his master's degree in public policy from Harvard's Kennedy School of Government and a law degree from Harvard Law School.



Health, Medicine & Society Program

The Health, Medicine & Society Program of the Aspen Institute brings together influential groups of thought leaders, decisionmakers, and the informed public to consider health challenges facing the US in the 21st century and to identify practical solutions for addressing them. The rigorously nonpartisan work spans a range of timely topics—from the opioid epidemic, end-of-life care, and incarceration to health systems financing and innovation, public health communication, and much more. At the heart of most of its activities is a package of research, convenings, and publications that supports policymakers, scholars, advocates, and other stakeholders in their drive towards change.



The Aspen Institute

The Aspen Institute is a global nonprofit organization committed to realizing a free, just, and equitable society. Founded in 1949, the Institute drives change through dialogue, leadership, and action to help solve the greatest challenges facing the United States and the world. Headquartered in Washington, DC, the Institute has a campus in Aspen, Colorado, and an international network of partners.



Cascada Consulting

At Cascada Consulting, we strive to improve understanding of Medicare and Medicaid, identify gaps and disparities, and develop solutions to advance health coverage, promote health equity and affordability, and improve programs. We learn from the experiences of people, draw on the research evidence, collaborate with community partners, and communicate results to build solutions that work.



The Commonwealth Fund

The Commonwealth Fund is a private foundation that supports independent research on health care issues and makes grants to promote better access, improved quality, and greater efficiency in health care, particularly for society's most vulnerable, including people of color, people with low income, and those who are uninsured. Learn more about the Commonwealth Fund at www.commonwealthfund.org.

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Lyons, B., Andrews, J. (2023, October). *Caring for Medicare Beneficiaries at Home: Experiences and Priorities of Family Caregivers*. The Commonwealth Fund. <https://www.commonwealthfund.org/publications/issue-briefs/2023/oct/caring-medicare-beneficiaries-at-home-experiences-family-caregivers>

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Lyons, B., Andrews, J. (2023, November). Policy Options to Support Family Caregiving to Medicare Beneficiaries at Home. The Commonwealth Fund. <https://www.commonwealthfund.org/publications/issue-briefs/2023/nov/policy-options-support-family-caregiving-medicare-beneficiaries-at-home>

The video, [Caring for Medicare Beneficiaries at Home: Voices of Family Caregivers](#), shares the experiences of four family caregivers of Medicare beneficiaries interviewed as part of this research prepared in collaboration with Burness.