

Long-term Care and Caregiving, Including Measurement and Support of Informal Care

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Executive Summary

On May 3, 2022, the Board on Health Care Services (BHCS) of the National Academies of Sciences, Engineering, and Medicine convened an expert panel to address Long-term Care and Caregiving, including Measurement and Support of Informal Care. The panel's six presenters provided insight into research priorities that may help improve formal long-term care (LTC) and informal caregiving for people living with dementia.

Presenters emphasized four main research priorities, including utilizing an economics framework to improve care for people with Alzheimer's disease and related dementias (ADRD), disseminating opportunities to support family caregivers, identifying successful state-based and international models for innovative long-term care, and defining the key elements of high-quality home-based care in order to focus opportunities for improvements. Cutting across all of these priorities is the need to improve data collection and definitions of metrics as well as the need to alleviate racial, socioeconomic, and gender inequities in caregiving burden. BHCS members considered the Medicaid *Money Follows the Person (MFP)* program to be of particular interest for improving long-term caregiving and considered a future workshop with NIA to investigate that program further.

Utilizing an Economics Framework to Improve Dementia Care

The economics of care for people living with ADRD center on several unique factors, including the need for economic decision-making by cognitively impaired patients, the conflict between structural insurance incentives and preventive/treatment needs, and the lack of metrics that demonstrate the value of informal caregiving. Potential areas for improvement involve dynamic contracts, coordinated end-of-life plans, quantification of the labor value of family caregivers, and revisions to Medicare's value proposition to reflect that value.

Research Opportunities

1. Improve models of how cognitively impaired individuals and their caregivers make LTC decisions and assess whether and how they and their agents respond to price and quality signals.
2. Examine whether healthcare decision-making patterns documented in people who are not cognitively impaired—such as the possibility that cost sharing reduces use of high-quality care—are observed in people living with ADRD and their caregivers.
3. Investigate how dynamic contracts between patients, providers, and caregivers might be designed and enforced as a strategy to reinforce the agency of people living with ADRD and to equip altruistic agents to improve care.
4. Explore how to calibrate insurer and provider demand and supply incentives in order to improve care.
5. Identify reimbursement and regulatory barriers to implementing integrated care and delivery models, which can replace expensive hospital stays with home-based care. Mine existing longitudinal data from sources such as the Money Follows the Person demonstration to promote these models' refinement and expansion.

6. Develop models that accurately capture the economic value of unpaid caregiving—which disproportionately affects women and people of color—and that are accessible to policymakers.
7. Assess the potential cost savings of family caregiving and define ways that Medicare spending can be structured to incentivize them.

Disseminating Opportunities to Support Family Caregivers

Millions of Americans deliver care to sick and elderly relatives, which creates significant financial, emotional, and physical burdens. The RAISE Family Caregiver Advisory Council was established by federal legislation in 2018 to provide recommendations to increase family caregivers' access to support. The Council will release a national strategy on family caregiving in Fall 2022, which is expected to identify include action steps to increase recognition and support for family caregivers.

Research Opportunities

1. Develop methods to quantify the impact of caregiver support on care quality.
2. Explore ways to implement the RAISE Family Caregiver Advisory Council National Strategy on Family Caregiving, to be released in Fall 2022.
3. Identify innovative state and local programs that support family caregivers and investigate barriers to and means of scaling these programs in other states and localities.
4. Consider ways to improve and expand self-directed Medicaid programs that compensate family caregivers.

Identifying Innovative Models for Community-Based Care

Innovators outside the United States offer valuable models of holistic, community-based care that might be adapted to structure, deliver, and maintain care in the U.S. Models in Norway, Sweden, and the United Kingdom all provide examples of community-based care that can improve outcomes and lower costs. A variety of domestic models also offer opportunities to improve care and control costs, including Community Aging in Place Advancing Better Living for Elders (CAPABLE), the Medicaid *MFP* program, the integration of payments across Medicare and Medicaid, and the use of Medicaid 1115 waivers.

Research Opportunities

1. Develop metrics that demonstrate the impact of state support for home and community care services on rates of Medicaid spending.
2. Assess forms of policy engagement that encourage state-level executive commitment to comprehensive aging plans and what features of those plans correlate with better state-level outcomes.
3. Evaluate what aspects of the Reablement program, which builds multidisciplinary teams devoted to addressing patients' own desires, are most adaptable to specific U.S. healthcare systems and structures.
4. Extend the Esther Network's model of patient journey analyses to more states within the U.S.

5. Conduct sustained exploration of the Medicare *MFP* program, which shifts funds from institutional settings to community settings with a track record of successful outcomes, and assess outcome measures that maximize the program's performance.
6. Investigate the means by which CMS could launch a specific, targeted 1115 waiver to provide up-front funding for care coordination.
7. Design comprehensive studies of how whole care systems integrate, rather than just how their individual parts work.
8. Explore ways to reform the Medicare Advantage plan to provide holistic and integrated care coordination that reduces denials and improves uptake of aid for drivers of health disparities, such as housing.

Defining Home-Based Care and Promoting Caregiver Training

Identifying homebound populations and identifying how they are cared for is necessary to evaluate healthcare utilization, address unmet care needs, and locate opportunities to innovate. Many homebound individuals are cared for by family members who lack training, which has serious implications for quality of care. Four major problems create barriers to home health training: lack of data to identify caregivers, lack of communication with providers about caregiver needs, lack of reimbursement for caregiver training, and lack of tailored interventions for home care settings. Innovative efforts can address each of these deficits.

Research Opportunities

1. Improve ways of identifying homebound individuals in order to characterize the scope and needs of this population.
2. Measure the quality of care for homebound patients and identify gaps, unmet needs, and opportunities to improve care and reduce burdens on healthcare systems.
3. Investigate the quality of training caregiver training programs, which are often either non-existent or reported as inadequate, particularly for populations experiencing health disparities.
4. Design approaches to measuring the effects of caregiver training on improvements in quality of care.
5. Explore new ways of capturing caregiver data in patient records and of improving interoperability in order to fully leverage data systems for research and clinical goals.
6. Develop and test a person-centered caregiver self-assessment for inclusion in patient records.
7. Investigate means of reforming Medicare to directly reimburse providers for interaction with and training of caregivers.
8. Employ the embedded pragmatic clinical trial model to develop and test tailored interventions for home care delivery that produce clinically meaningful outcomes and that acknowledge and account for social determinants of health.

Meeting Summary

Economics of Dementia

Courtney Coile

The economics of care for Alzheimer's disease and related dementias (ADRD) involve several complex factors, which include the capacity for patients to make economic decisions during cognitive decline, the role of caregivers in making economic decisions for patients, the alignment of incentives and funding mechanisms for long-term care (LTC) facilities to improve patient outcomes, the relative availability of health care workers, and the costs and labor market impacts associated with informal caregiving. Interrogating these factors reveal research opportunities that can help improve care for patients living with ADRD and their caregivers.

Conceptual Framework of the Economics of Alzheimer's Disease and Dementia

The costs of ADRD care are complex and difficult to quantify, in part because they encompass both formal LTC and informal caregiving. Several statistics indicate the likely scope of those costs: 70 percent of Alzheimer's disease patients die in LTC facilities; over 50% of LTC residents have Alzheimer's disease or dementia; and some research suggests that approximately one third of informal care recipients over age 70 have probable dementia or cognitive impairment.

These costs create a resource allocation problem that unfolds in several interdependent dimensions. At the broadest level, some kinds of investments may reduce the probability that individuals will develop ADRD or may improve the health and well-being of people living with ADRD. Many of these investment decisions rest with policy makers, who consider their relative costs and benefits and seek to maximize the value to society when deciding which investments to make. An understanding of tradeoffs is key to this process—for example, spending more on ADRD drug development that could benefit future generations may mean spending less on care for ADRD patients today. Individuals also make decisions, such as choosing whether to purchase formal LTC insurance or how much and what type of ADRD care to buy, while operating within an environment that has been shaped by the decisions of policy makers. Businesses evaluate potential returns from private investments in ADRD drug development or LTC provision.

These challenges of resource allocation are not unique to ADRD, but several features do distinguish its economic dynamics. The first are the cognitive constraints that impair individuals' choices and therefore create a need for altruistic agents to help patients make economic decisions. The second is the lack of a clear understanding of basic mechanisms of dementia, which imposes a long development time for pharmaceutical agents that creates a mismatch between business incentives to invest in research and the social need for more interventions for people living with ADRD.

Economists currently do not have adequate models of how cognitive constraints affect economic choices. Existing frameworks, such as the idea of frictions and mental gaps or memory-based rationality, may not be appropriate for explaining the decisions of cognitively-impaired consumers. In addition, the role of agents who make choices for cognitively impaired

individual has not been sufficiently studied in the literature. Adult children may have altruistic or exchange motives, while state caregivers are bounded by regulations. Dynamic contracts between patients, insurers, and caregivers could be drafted to help protect individual choices before they begin to experience significant cognitive decline, but how such contracts could be enforced is not yet well understood.

Structural Challenges to High Quality Care

Well-documented shortages in the LTC workforce are a barrier to improving care for people living with ADRD. LTC facilities are limited in their ability to raise wages due to the inflexibility of Medicaid reimbursement; low wages contribute to tight labor markets, which in turn can lead to lower quality of care. Indeed, some evidence suggests that increases in wages can improve both staff retention and care. However, increases in labor costs can also lead some health care systems to rely on medications rather than allocate resources to staff, which can also detract from quality of care. Interestingly, areas with higher immigration tend to have better quality of nursing home care.

The number of settings and payers involved in ADRD care can lead to inefficiencies that undermine quality. For example, cost-sharing between insurers and patients has been shown to lead to reductions in all kinds of care, including high-value care, although it remains unclear how this dynamic affects dementia patients. In addition, the fact that different insurers typically provide health care coverage at different stages of life means that insurers at earlier stages of life have less incentive to cover preventive measures whose effects will benefit another insurer in the future. LTC facilities may also shift end-of-life patients living with ADRD to hospitals to avoid higher costs and fixed rates of reimbursement, which can reduce care quality. Coordinated care plans can help mitigate these quality issues, but they are not widely used.

The Economics of Informal Care

Informal care is an underrecognized source of caregiving labor for people with ADRD, making up billions of hours of care for millions of people each year. This informal care raises health equity issues, because women provide the majority of this unpaid labor. Identifying ways to quantify and articulate the value of informal care is a key research opportunity. Informal care could be quantified by replacement costs, which are defined by the cost of care if an informal caregiver were replaced by a formal caregiver, or they could be defined by the lost wages of informal caregivers who reduce their participation in the paid workforce. Research suggests that informal caregiving reduces labor supply both in the short and long term and that the difficulty of reentering the work force can lead to total costs that are seven times lost wages alone. However the costs of informal care are measured, estimates suggest they are similar to formal care costs, indicating that large uncompensated costs are shouldered by the informal labor force. Caregivers also not only lose income, but also experience mental and physical health impacts of caregiving.

State of the Research and Opportunities for Progress

The economics of ADRD care expose several gaps and opportunities for future research. Overall, policymakers should consider how best to spend ADRD-related government

expenditures and should consider the potential implications of compensating informal caregivers. In addition, several questions about incentives in LTC care require specific study in relation to people living with ADRD. For example, if healthier patients populate assisted living facilities, it could lead to higher average costs of care for the sicker patients in traditional LTC facilities, putting stress on these facilities. Further, it is not clear whether patients are price-sensitive in choosing LTC or informal ADRD care, nor whether home-based or hospice care indeed reduces costs for ADRD requirements. In addition, although providers generally compete when information about quality is available to patients, it is unclear whether this dynamic would work in the context of ADRD; LTC providers may actually sometimes provide lower quality care, possibly to discourage unprofitable patients.

Other research questions related to the economics of ADRD care include:

- The process by which cognitively impaired individuals make decisions
- The role of altruistic agents (family and government) in improving outcomes
- How dynamic contracts might improve outcomes and how they can be enforced
- Whether and how people living with ADRD and their caregivers respond to price and quality signals
- How to calibrate insurer and provider demand and supply incentives to improve care
- How [providing informal](#) ADRD [care](#) affects the labor supply and health of caregivers

Brief Overview on Long-Term Care and Caregiving

Wendy Fox-Grage

Informal caregiving accounts for major portions of caregiving labor and can lead to financial, physical, and emotional strains. The Recognize, Assist, Include, Support and Engage Family Caregivers (RAISE) Act was passed by Congress in 2018 to improve coordination across government programs that assist family caregivers and care recipients. The RAISE Act established the Family Caregiving Advisory Council, which was tasked with creating the country's first national Family Caregiver Strategy. To support the Council's work, the National Academy for State Health Policy (NASHP), with support from The John A. Hartford Foundation, created the RAISE Act Family Caregiver Resource and Dissemination Center to develop family caregiving resources. This set of entities has the opportunity to identify, disseminate, and support the implementation of best practices.

Challenges for Caregivers

Approximately 53 million Americans provide care to sick and/or elderly family members. These individuals often do not self-identify as caregivers, but they provide the majority of care received by a family member. Caregiving roles are rewarding but both physically and emotionally challenging; they can involve bathing, toileting, cooking, providing injury care and medications, and navigating insurance and health care systems, and report poorer health outcomes due to chronic stress and low self-care. Some estimates show that family caregivers pay an average of a quarter of their annual income on caregiving expenses and collectively lose approximately \$522 billion in income annually due to reduced work hours or workforce exits.

Family caregivers are often not recognized by the healthcare system to which they contribute. Members of racial and ethnic minorities are less likely to identify themselves as caregivers, and caregivers in families of choice, such as LGBTQ families, are particularly unlikely to be recognized by formal healthcare institutions. Rural caregivers have even less access to paid providers than those in other areas and spend an average of 3.8 additional hours providing care to family members. The pandemic has exacerbated many of these challenges.

Resources about Caregivers

The RAISE Family Caregiver Resource and Dissemination Center has acted as a resource for state and federal policymakers as well as stakeholders by developing caregiving resources, supporting the development of policy recommendations, convening experts, and buttressing related state-level activities. The Center has released a Faces of Caregiving video series that showcases family caregivers sharing personal stories of their difficulties with lost income and retirement funds; putting careers on hold or losing careers entirely; bearing medical loan payments long after a loved one has died; sacrificing sleep, health, and financial wellbeing; and grappling with anxiety. Caregivers in the video reported that they were naïve to the demands of caregiving when they began providing it and observed that they were rarely asked by healthcare providers how they could be supported.

Solutions for Caregivers

The RAISE Family Caregiving Advisory Council, which is composed of federal and nonfederal members—including many caregivers and advocates—was tasked by the RAISE Act with issuing a report to Congress on challenges faced by family caregivers and programs available to support them. That report, released in September 2021, identified 26 recommendations that federal and state governments, employers, researchers, and healthcare providers could take to improve conditions for caregivers. The Council's next step is to publish a national strategy on family caregiving to implement these recommendations.

NASHP's RAISE Center coordinates closely with the Council and complements its work with a focus on state-level policy. The Center has released a series of reports that identify best state-level practices that can be disseminated and adopted more broadly. Notable proposals in these reports include providing caregiving support through Medicaid via respite care and "consumer-directed" or "self-directed" programs. The data presented in these reports also highlight gaps that can be translated into actionable research questions and areas of focus for policymakers.

Future of Home and Community-Based Long-Term Care

Kate McEvoy, Maureen Bisognano

Innovators outside the United States have developed holistic, community-based care models with the potential to reimagine how LTC is structured, delivered, and maintained. The Reablement model in Norway helps keep aging people in their homes and the "Esther" network in Sweden helps optimize aging people's interactions with healthcare systems. In both programs, a focus on patient perspectives becomes a guiding principle to help aging citizens obtain the care they need.

In the United States, many factors stand in the way of improving long-term services and supports (LTSS). However, numerous innovations have been identified to improve care and restructure systems to address inequities. These solutions include engaged, state-level executive leadership to adopt and support strategic aging plans; Medicare and Medicaid collaboration to support programs with successful track records, such as Money Follows the Person (MFP); and solutions that comprehensively address the economic insecurity of the long-term care workforce.

Reimagining Models of Care

To address crowding and budget overruns in healthcare institutions, Norwegian innovators developed the Reablement system, which orchestrates occupational therapists, physiotherapists, nurses, and social workers to organize care into a coherent program that focuses on addressing patients' own desires and needs. A team of Reablement coaches provides independence training to aging patients who have recently been discharged from a hospital; in one representative case study, aging patients spent about 10 hours with a homecare team practicing everyday activities, and then after this initial program, the team provided an average of 30 minutes of home-based care per week.

Another innovative system in Sweden, known as the “Esther” network, uses a different approach to reorganize formal LTC. Based on the persona of an older woman named Esther, this program used data collected from various parts of Swedish health care and social systems to create patient journeys modeling how patients might engage with healthcare providers throughout a year, and then trained leadership in various institutions to adjust their systems to help keep patients like “Esther” in their homes. This model is now being implemented in Toronto and San Francisco.

In a 2012 article in the *New England Journal of Medicine*, Dr. Michael Barry and Ms. Susan Edgman-Levitan advocated shifting the focus of LTC from the question of “what’s the matter” to the question “what matters to you.” The *What Matters To You?* concept has since become a set of innovative approaches to long-term care that centers not an ailment to be fixed, but the desires of patients to be achieved. The program led to substantive policy changes in Norway, where patient management boards in hospitals were redesigned to include not just typical medical monitoring data, but also a display of patients' care preferences. Similar innovations have spread to 50 countries, where they have reduced the length of hospital stays, improved outcomes, and lowered costs.

Opportunities for LTSS Reform and Inhibiting Factors

International examples provide a model for potential reforms to LTSS within the United States, which faces a growing older population, workforce shortages, significant overreliance on family caregiving, and growing health disparities. Systemic LTSS reform can simultaneously address these various challenges: it could help adults over 50 stay in their homes as they age, (a desire expressed by 70% of respondents to AARP's 2021 Home and Community Preference survey); could meet family caregivers' desire for assistance in dealing with caregiving-related challenges to their physical and mental health and economic security; could help states control the rate of

Medicaid spending increases by providing a lower-cost alternative to LTC facilities; and could help free resources for states to invest in services for other social needs, including housing and food security.

However, several major factors inhibit progress in LTSS reforms, including a lack of state-level executive prioritization and lagging innovation in Medicare and Medicaid financing models. An AARP score card that assesses the quality of state services demonstrates that a common denominator in highly scored states is a gubernatorial-level commitment to developing comprehensive aging plans that guide policy choices and investments. State-level Master Plans on Aging formalize strategic directions through comprehensive roadmaps that encompass a broad range of domains, a 10+-year planning period, executive leadership, a structural lens, public/private partnerships, iterative developmental curves, and measurable outcomes.

Financing for LTSS has also not kept pace with needs at the federal, state, and local levels. The Center for Medicare and Medicaid Services' (CMS) has considered alternatives to traditional fee-for-service mechanisms, but they remain too small in scale, too limited in duration, and too risk averse. Although Medicare Advantage plans have the potential to provide holistic and integrated care, evidence demonstrates a troubling record of denials of service, costs that exceed traditional fee-for-service models, and a mediocre uptake of benefits that would address major drivers of health disparity, such as housing. One path to improvement would integrate payments across Medicare and Medicaid for multifaceted programs such as Community Aging in Place Advancing Better Living for Elders (CAPABLE), which combines nursing, occupational therapy, and handyman services. CMS could also launch a specific targeted 1115 waiver, which could provide up-front funding for patient care coordination. CMS could also make permanent the Medicaid MFP plan, which shifts funds from institutional settings into communities and has a successful track record. To optimize these and other programs, cross-sector analytics could be utilized to track the effectiveness of interventions.

A third challenge is the gap in coverage faced by individuals in the middle of the economic spectrum, who have too many resources to qualify for Medicaid but not enough to fund their own LTSS. State-level innovation may help address this challenge; for example, Washington State has an exemplary insurance model that provides state-based, payroll-funded long-term care which could be assessed for potential nationwide expansion.

Finally, any plans to reform LTSS structures must also include a comprehensive agenda to improve the economic security of the direct care workforce and thereby also address both staffing shortages and quality of care. Although some discussion has focused on wage increases, a broader agenda should also encompass costs of training, benefits (including affordable health insurance and retirement savings), and opportunities for professional advancement.

Reimagining Home-Based Care: Challenges and Innovations in Meeting the Long-Term Care Needs of Patients and Caregivers

Katherine Ornstein, Julia Burgdorf

Identifying homebound populations is necessary to evaluate healthcare utilization, address unmet care needs, and locate opportunities to innovate. Assessing the landscape of home-based care reveals significant healthcare disparities and demographic shifts that create more potential care gaps. One area for improvement with high potential impact is home health training for informal caregivers, who deliver major portions of various categories of care. Significant barriers currently prevent such training, including a lack of data systems to identify informal caregivers, limitations in communications regarding caregiver needs, lack of reimbursement for provider training for caregivers, and underdeveloped interventions that have yet to be tested in real-world settings. However, opportunities to surmount these barriers are also available; these opportunities include an expansion of access to home health care; improvements to models that assess caregiver needs and modifications to healthcare recordkeeping systems to include caregiver data; and development of tailored interventions that can address social determinants of health and produce clinically meaningful outcomes.

Identifying Homebound Populations

In order to reimagine home-based care, the specific populations that require care must be identified. The COVID-19 pandemic exposed gaps in care even as it exacerbated vulnerabilities for homebound patients. For example, a case study of an older patient who contracted COVID-19 highlighted how providers, distant relatives, and a neighbor all had to collaborate to arrange ad-hoc hospice care. This episode reveals the need for more efficient coordination between healthcare providers and informal caregivers.

Despite the increased visibility of the importance of home-based care access, homebound patients themselves are often not visible and are difficult to identify. A nationally representative 2011 study demonstrated that approximately two million older adults are homebound, which is larger than the total U.S. nursing home population—and more recent studies suggest these numbers are growing. Estimates suggest that 15 percent of adults over 70 are homebound, and they are more likely to be in lower income quartiles, experience dementia, and have significant comorbidities. This population often has reduced access to primary care and experiences high hospital admission rates and emergency department visits.

Defining Home-based Care

Home-based care can be divided into LTSS and clinical services: clinical services include specialists, medical providers, and skilled care, such as therapists and social workers, while LTSS ranges from community-based services to residential care. Access to care is unequal and only about 12 percent of homebound individuals can access home-based clinical services, with family caregivers often filling gaps and typically providing the main source of home-based care. Unequal access is an acute issue for the caregivers of approximately two million adults who are currently at the end-of-life. Family caregiving incurs intergenerational costs, which can range from financial support and co-residence to help with daily activities. The structural assumption

that family caregiving is available also raises concerns for the 10 percent of the homebound population who do not have partners or children who would provide end-of-life care.

Home Health Training Needs

Current statistics expose significant home health training needs for family caregivers. 3.4 million Medicare beneficiaries receive home health care each year, and one in three of the patients receive this care have dementia. Clinicians report that 87 percent of home health episodes require a caregiver to help implement the plan of care, and for episodes experienced by dementia patients, that proportion rises to 94 percent. Care plans for homebound patients can require assistance with numerous activities, all of which may require training. The percentage of patients who require assistance include:

- 85 percent requiring instrumental activities of daily living such as bathing and toileting
- 83 percent requiring advocacy or care coordination
- 80 percent requiring assistance with day-to-day activities
- 65 percent requiring medication management
- 57 percent requiring safety and supervision
- 37 percent requiring medical procedures such as injury care
- 20 percent requiring medical equipment management

Moreover, 58 percent of caregivers provide help with five or more of these activities. Yet seven in ten caregivers receive no training, and when training is available—typically in settings where patients receive transitional care from discharge to home—41 percent of caregivers describe that training as inadequate. These training deficits have significant impacts on health outcomes: patients are twice as likely to be hospitalized during a home health episode if the caregiver is untrained.

Barriers to Home Health Training

At least four major deficits create barriers to home health training: lack of data to identify caregivers, lack of communication with providers about caregiver needs, lack of reimbursement for caregiver training, and lack of tailored interventions that might support caregivers in home care settings. Providers often have little or conflicting information about caregivers, particularly for patients who have dementia and who require a network of caregivers. When providers do know the identity of caregivers, communication between them is often not structured around training or other caregiver needs. Limited Medicare reimbursement often means that provider interactions with caregivers are short, episodic, and not focused on training. Interventions for home care settings, which might offset some of these issues, have often been tested only in limited research settings and are misaligned with real-world scenarios.

Opportunities for Supporting Caregivers in Home Health Settings

Addressing gaps in home health support has a variety of benefits. Over the short term, caregiver support can reduce the risk of patient hospitalization; over the long term, support reduces burdens on caregivers and can delay institutionalization and Medicaid entry. In addition, caregiver support can help address the needs of underserved populations, who rely

heavily on caregivers, are older, tend to have chronic conditions or dementia, and are often non-white and dually enrolled in Medicaid.

99 percent of Medicare beneficiaries live in zip codes where Medicare Home Health Agencies are available, which exposes an opportunity for agencies to provide more caregiver-focused support. But more expansive solutions are needed that directly target the key challenges of caregiver data, communication, reimbursement, and targeted interventions. To address the lack of data, some locations are capturing information about caregivers in patient records, and this approach could be expanded. To ensure access to the data, interoperability of electronic health record systems could be improved. Improved models that assist providers in assessing caregiver needs would also be useful; Dr. Burgdorf and her team are developing one such model. Medicare could reimburse providers directly for caregiver education. Tailored interventions could be developed through embedded pragmatic clinical trials to produce clinically meaningful outcomes—as well as address social determinants of health.

Discussion

Ex-U.S. Models of Patient-Centered Care

Several programs outside the United States provide potential models for improving care by centering patient needs. The *What Matters To You?* program is being investigated and adopted by thousands of groups globally, and its impact has already shown that when providers prioritize the desires of patients, care plans change with striking speed. The *Buurtzorg* model in the Netherlands is also a notable program that organizes neighborhood care teams to provide support services; that model has both increased patient satisfaction and cut costs. A similar model on Jersey Island in the United Kingdom engages postal workers to check regularly on older residents. Japan has a robust home care model that involves frequent communication with patients, which could be replicated in part through the use of telemedicine in the U.S.

Supporting Caregivers

Numerous studies have documented the heavy burden of caregiving on informal caregivers, but some current and prospective programs could provide caregiver support. For example, over 300 Medicaid waiver programs can provide structured respite for caregivers, although coverage varies widely across states. Expanding support will likely require cultural change within Medicaid, where skepticism about family caregivers is widespread and compensation programs for their labor are limited; federal support for family caregivers could help catalyze change in this area. Participants noted that spending to support family caregiving is much smaller than the sums cancer patients pay for medicines with marginal efficacy, which highlights the need to rebalance priorities to support home care.

The lack of resilience in family caregiver systems is also a cause for concern. Informal caregiving systems generally do not have plans for crises, so if caregivers become ill themselves or are otherwise unable to provide care, the home care system can break down. Moreover, the lack of caregiver training can increase risk of breakdown, causing emotional stress for caregivers while also creating potentially dangerous situations for patients. Although some kinds of training—

such as training for dementia interventions—can be delivered successfully and improve caregiver systems, the same may not be true for all patients, whose needs can vary dramatically. Typically nurses and health aides provide caregiver training when opportunities are available, but they receive little credit or compensation for that work.

Support for caregivers also requires attention to health disparities and the unequal burden on caregivers of color. Families of color are more likely than white families to provide home care to elderly members, in part because white families tend to utilize institutional care more than home care; however, cultural differences are hard to capture in studies. Although training can help support caregivers and thus ameliorate these burdens, it may also project the standards of professional caregiving labor onto unpaid caregivers, which can reinforce demands on their time. This demand is most likely to affect women and specifically women of color.

Participants discussed what specific kinds of research should be conducted on health disparities in home care. One area of study is the importance of caregiver-clinician interactions: when Dr. Burgdorf's team interviewed clinicians about caregiver needs, answers revealed that assessments were often highly subjective and this subjectivity created risks of exacerbating disparities. Qualitative research on caregiving interactions within homes would also be useful, but such assessments are quite challenging. Specific locations, such as New York State, have implemented promising programs to address disparities that could be assessed for their impact and scalability. Finally, comprehensive studies of how whole systems integrate, rather than just how individual parts work, will chart important directions for future research.

Policy Solutions

Dr. Julie Robison's survey of the effects of the MFP program found that patients receiving home care had significantly better outcomes than those who were institutionalized. Moreover, surveyed caregivers reported improved support systems, as well. However, the MFP program requires continual reauthorization, and the most recent attempt at reauthorization through the Biden administration's Build Back Better plan has foundered as that bill has stalled in Congress. Dr. Berwick suggested that the National Academy of Sciences could hold a workshop for NIA that focuses solely on this program; such a workshop could focus on how home care reduces Medicaid growth and expenditures, which is a topic of widespread lawmaker interest.

Hospital discharge represents a key intersection of patients, health care systems, and caregivers and thus an opportunity for public policy to provide more support for home care. Some states use Home and Community-Based Services (HCBS) Medicaid waivers to increase home care at discharge, but this policy presents challenges. Many health care systems are set up specifically for patients to transition from hospitals to nursing homes, and new policies need to ensure that transitions to home care receive equally robust attention. Policymakers and researchers involved with MFP consider discharge a major area of focus and are studying methods of smoothing home care pathways, but greater uptake and monitoring are needed to improve these transitions. Additionally, funding from states and CMS for home care transitions must be better integrated into these efforts.

Few politically acceptable options are currently available for providing insurance to cover long-term care. Private insurance struggles with providing coverage; available options cover only earlier stages of disability and cap benefits. The Wish Act, which is a public private partnership to provide insurance coverage, also is not sufficient, because patients often die before they can obtain coverage under its provisions. Financing federal programs would be possible, but only with politically unpopular taxes on wealth or with spending caps on benefits. Medicare was not originally designed to become the nation's primary payer for long-term care, and its evolution into that role has shifted care costs to states. That has made states an important engine of experimentation with improved care models, and state-level programs that have demonstrated success should be shared more broadly.

Although targeted support for caregiving is needed, policies to address broader socioeconomic drivers of care disparities are also critical. Without access to essential needs such as housing, for example, individuals cannot take advantage of home care. The COVID-19 pandemic exposed significant and persistent inequities in access to such essential needs, including food and economic insecurity affecting families of color. Funding should be optimized to address these broader issues that pose health risks.

Addressing Workforce Needs

The formal home care workforce urgently needs more support, particularly given high levels of turnover. More caregiving programs should work to demonstrate how workforce supports impact care quality. Washington, Oregon, and Iowa all have exemplary models for training direct care professionals and home-based caregivers, and these models offer an opportunity to document that impact.

Key Data Gaps

A variety of state-level data gaps and inconsistencies prevent researchers from answering key questions about how to improve care. Caregiver data are often missing from state-level Medicaid data, and although CDC has a system for collecting caregiver information—called the Behavioral Risk Factor Surveillance System (BRFSS)—it is optional and not all states utilize it. One particularly helpful kind of caregiver data would demonstrate the return on investment for home care and caregivers, in part because such data are typically a prerequisite for state-level policymakers to implement new programs. MFP is one successful model of a program that has collected longitudinal data to help answer questions about hospital revisits and other improvement on outcomes. Connecticut has been a leader in this area and could share its models with other states. In addition to these state-level data gaps, state-level program *variance* has created major challenges for collecting comprehensive nationwide data.

Even when data are available, privacy rules, lack of flexibility, and institutional barriers have all created roadblocks to using it in research efforts. Trust and partnerships need to be developed between researchers and institutions to improve data collection. Methodological issues are also important: some survey data demonstrate quality improvements in home care, evidencing less incidence of fraud, mismanagement, and abuse, but methods of measuring quality indicators have been inadequate overall and need to be improved.

Appendix 1. Virtual Meeting Agenda

May 3, 2022

10:30	Economics of Dementia <i>Courtney Coile, Wellesley College (Virtual)</i>
10:45	Brief Overview on Long-Term Care and Caregiving <i>Wendy Fox-Grage, National Academy of State Health Policy</i>
11:00	Future of Home and Community-Based Long-Term Care <i>Kate McEvoy, Milbank Memorial Fund</i> <i>Maureen Bisognano, Institute for Healthcare Improvement</i>
11:30	Discussion with Board Members and NIA staff
12:00	Working Lunch
12:45	Assessing the Impact of Innovations in Financing and Policy for Long-Term Care and Caregiving <i>Katherine Ornstein, Mount Sinai</i> <i>Julia Burgdorf, Center for Home Care Policy & Research</i>
1:15	Discussion with Board Members and NIA staff
1:45	Update on HCS projects <i>Sharyl Nass</i>
2:15	Plans for the Fall 2022 virtual meeting
2:30	Adjourn

Appendix 2. List of Participants

BHCS Board Members

Donald Berwick, Board Chair
Andrew Bindman, Kaiser Permanente
Niranjan Bose, Gates Foundation
Neil Calman, Icahn School of Medicine at Mount Sinai
Paul Chung, Kaiser Permanente
Patricia Davidson, University of Wollongong
Martha Daviglus, University of Illinois Chicago
Jennifer DeVoe, Oregon Health & Science University
Richard Frank, Harvard University
Cindy Gillespie, Arkansas Department of Human Services
Lauren Hughes, Farley Health Policy Center
Elmer Huerta, MedStar Washington Hospital Center
Sharon Inouye, Harvard Medical School
John Lumpkin, Blue Cross and Blue Shield
Faith Mitchell, Urban Institute
David Pryor, Ascension Health
Julie Robison, University of Connecticut Health
William Sage, University of Texas at Austin
Hardeep Singh, U.S. Department of Veterans Affairs
Laurie Zephyrin, The Commonwealth Fund
Michael Zubkoff, Dartmouth College

Presenters

Maureen Bisognano, Institute for Healthcare Improvement
Julia Burgdorf, Center for Home Care Policy & Research
Courtney Coile, Wellesley College
Wendy Fox-Grage, National Academy for State Health Policy
Kate McEvoy, Milbank Memorial Fund
Katherine Ornstein, Mount Sinai

National Institute on Aging, Division of Behavioral and Social Research (BSR)

Lisbeth Nielsen, Director, BSR
Partha Bhattacharyya, Program Director, BSR
Minki Chatterji, Program Official, Population and Social Processes Branch
Melissa Gerald, Program Official, Individual Behavioral Processes Branch
Theresa Kim, Program Official, Population and Social Processes Branch
Emerald Nguyen, Program Official, Population and Social Processes Branch
John Phillips, Chief, Population and Social Processes Branch
Luke Stoeckel, Program Director, Individual Behavioral Processes Branch

HCS Staff

Sharyl Nass, Board Director

Laura Aiuppa

Francis Amankwah

Alexandra Andrada

Rachel Austin

Erin Balogh

Crystal Bell

Lori Brenig

Torrie Brown

Marjani Cephus

Bernice Chu

Ruth Cooper

Jennifer Flaubert

Adrienne Formentos

Jennifer Flaubert

Carolyn Fulco

Annalee Gonzales

Joseph Goodman

Laurene Graig

Rukshana Gupta

Karen Helsing

Tracy Lustig

Marc Meisnere

Tochi Ogbu-Mbadiugha

Carol Mason Spicer

Arzoo Tayyeb

Nakita Varman

Roberta Wedge

Anesia Wilks

Rose Li & Associates (Contractor)

Jay Weixelbaum