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Unpaid Dementia Caregiving: A Policy and Public Health Imperative

Joseph E. Gaugler, PhD*[✉]

Division of Health Policy and Management, School of Public Health, University of Minnesota-Twin Cities, Minneapolis, Minnesota, USA.

*Address correspondence to: Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care & Aging and Director, BOLD Public Health Center of Excellence on Dementia Caregiving, School of Public Health, University of Minnesota, D351 Mayo (MMC 729), 420 Delaware Street S.E., Minneapolis, MN 55455 USA. E-mail: gaug0015@umn.edu

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Even a cursory review of epidemiological data indicates that Alzheimer's disease and related dementias (ADRD) have become a common facet of life for many in the United States. More than 6 million people in the United States are currently living with dementia, and there are 11 million unpaid family members, friends, acquaintances, or others (i.e., caregivers) who offer extensive and often long-term help to people with ADRD ([The Alzheimer's Association, 2021](#)). The scope and potential for ADRD to overwhelm informal (i.e., unpaid) caregivers in the United States have emphasized the need to elevate unpaid dementia caregiving as a public health priority. This paper describes policy solutions to address caregiving concerns and summarizes current initiatives to further elevate dementia caregiving as a public health priority in the United States via the Building Our Largest Dementia (BOLD) Infrastructure Act.

Public Policy Implications of Caregiving

Informal caregiving is, whether recognized or not, at the core of long-term care policy in the United States. Studies that have attempted to estimate the sheer economic value of informal caregiving to adults in the United States (by considering the costs to replace family or other unpaid caregivers with in-home health providers, for example) have resulted in staggering numbers: \$470 billion, which

far outstrips the amount of funding nursing homes or home health agencies receive ([Reinhard et al., 2019](#)). A principal goal of long-term care policy is to alleviate the high and often catastrophic costs of residential long-term care (e.g., long-stay nursing home admissions) on state and federal Medicaid budgets. However, this goal rests on the assumption that older persons can and are able to live at home successfully via existing informal care that is supplemented by a patchwork of community-based long-term services and supports (LTSS). Included among current policy strategies adopted by states to reduce residential long-term costs are rationing and targeting of services, shifting Medicaid and other public funding sources away from residential care and towards community-based supports, and focusing on consumer-directed options or choices that allow older people self-determination in how they utilize LTSS ([Gaugler, 2016](#)).

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Clearly, the U.S. long-term care system is heavily dependent on informal care. But is this arrangement truly sustainable? An earlier analysis by the AARP ([Redfoot et al., 2013](#)) demonstrated that the number of caregivers available to assist

older persons in need is likely to decline precipitously in the next several decades, leading to what some call a “family care gap” (Gaugler, 2021a). Recent reviews of the informal caregiver supply literature suggest more research is needed to incorporate various trends in disability, unmet needs, and support when estimating the extent of informal caregiving supply (Spillman et al., 2020). Nonetheless, the costs and harms of not addressing the family care gap include exacerbated unmet care needs, safety concerns, and increased reliance on residential long-term care, all of which will result in costly, adverse outcomes for older persons and their communities. For this reason, an integrated public health and public policy strategy is likely necessary to “bridge” the family care gap (Gaugler, 2021b; Plichta, 2018).

Although dementia is often considered alongside other chronic conditions, there is a strong case to be made from both public health and policy perspectives that dementia is *the* chronic condition that complicates the management of other chronic illnesses. There is extensive evidence suggesting ADRD as a prime driver of increased health costs, as well as adverse events in older adulthood. For example, when compared to those with chronic conditions without dementia, Medicare beneficiaries with the same co-occurring conditions *and* dementia accounted for three times greater Medicare costs. The diagnosis of ADRD, as well as the severity of cognitive impairment, often emerge as potent predictors of falls, hospitalizations, hospital readmissions, and institutionalization among older people. Similarly, when compared to caregivers of other chronic conditions, stress, negative mental health outcomes, and health risks are exacerbated among dementia caregivers (for a review of this literature, see [The Alzheimer’s Association, 2021](#)).

Dementia is a significant driver of health-care costs and poses significant challenges to families and other unpaid caregivers as well as health-care systems, but when compared to other chronic conditions dementia has rarely served as a public health priority for many states or local public health departments. The same could have been said for the federal level as well, although the 2012 National Alzheimer’s Project Act significantly bolstered the availability of research funding for ADRD and has also elevated the cure, prevention, and treatment of dementia as issues of national importance. This paper summarizes key, recent policy milestones as they relate

to informal caregiving, and reviews current efforts to elevate unpaid dementia caregiving as a matter of public health concern.

Policy Milestones in Informal Caregiving

Development of a National Family Caregiving Strategy

The Commission on Long-Term Care issued a report in 2013 that emphasized the need for a national family caregiving strategy (Lipson, 2015), which came to fruition in 2017 with Congress passing the Recognize, Assist, Include, Support, and Engage Family Caregivers Act (RAISE). RAISE charged the Department of Health and Human Services to craft a national family caregiver strategy that advances the integration of family-centered approaches across care settings; advances assessment and coordination across transitions that incorporate care recipients and family caregivers; provides information, education, and similar supports; provides respite solutions; and addresses the employment concerns or financial well-being of caregivers (Administration for Community Living, 2021b). Beginning in August of 2019, the full RAISE Advisory Council (which included 15 federal and 15 non-federal members representing a range of professional and personal expertise in caregiving) convened nine times. The meetings culminated with an initial report to Congress in September 2021 that included 26 recommendations across five key goals (see [Table 1](#)). These recommendations will serve as a “road map” to integrate the 26 recommended actions into local, state, and perhaps national initiatives to better support unpaid caregivers. It remains unclear whether these recommendations will be formally enacted upon or adopted to guide expanded support for caregivers, particularly through legislation that funds the recommended actions. Nonetheless, the initial report from the RAISE Advisory Council provides a structure and a set of necessary policy actions to advance informal caregiving support, as well as to elevate caregiving as a public health concern.

Expanded Family Caregiving Support Services

The National Family Caregiver Support Program was initiated in 2000 and, at the time, was a significant policy

Table 1. RAISE Family Council–Recommended Goals for a National Caregiver Strategy

Recommended Goals
Increased awareness of family caregiving.
Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded.
Increased access to services and supports to assist family caregivers.
Increased financial and workplace protections for caregivers.
Better and more consistent research and data collection.

Note: See [Administration for Community Living, 2021b](#). Abbreviation: RAISE = Recognize, Assist, Include, Support, & Engage.

milestone that offered direct assistance to unpaid caregivers. Funded via the Older Americans Act, the program features family caregiver support professionals located in or contracted by area agencies on aging throughout the United States. The National Family Caregiver Support Program helped 700,000 individuals in 2014 (the most recent year data are available; Administration for Community Living, 2021a). Although an important milestone when it was initiated, financial support of the National Family Caregiver Support Program was relatively flat from 2013 to 2017 (approximately \$150 million per year or less over that span). Appropriations for the program have increased to a little under \$190 million by 2021 (Greg Link, Administration for Community Living, personal communication, 2022). As a comparison, the Veterans Administration (VA) received roughly \$1 billion in 2021 to operate its robust caregiver support program (Kathleen Kelly, Family Caregiver Alliance, personal communication, 2022). As of 2014, there were approximately 5.5 caregivers of military veterans in the United States, and as of 2016 the Program of Comprehensive Assistance for Family Caregivers of the VA served 32,000 caregivers at a cost of over \$1 billion (with most of the expenses due to the monthly stipends offered to caregivers as part of this program; Ramchand et al., 2014; Sperber et al., 2018). “Right-sizing” the financial support of the National Family Caregiver Support Program so it is more equitable and can reach a greater number of families in need is thus an important policy consideration.

Refinancing LTSS

The state of Washington’s Long-Term Services and Supports Trust Act aims to enhance older people and family caregivers’ access to community-based LTSS in the United States (HB 1087 and SB 5331). Signed into law in May 2019, the Long-Term Services and Supports Trust Act operates as a payroll tax, where employers contribute to the Trust to result in an up to \$36,000 benefit. Residents can utilize the benefit to purchase community-based LTSS, including adult day services, in-home help, home modification services, and family caregiver education (Kinnaman, 2020). Washington remains the only state to have formally implemented a comprehensive strategy to enhance the financing of and access to LTSS, although various other models have been considered in several other states (Gaugler, 2021b, p. 436).

Efforts to Elevate Unpaid Dementia Caregiving as a Public Health Priority

The Centers for Disease Control and Prevention’s (CDC’s) efforts to elevate ADRD and informal dementia care as a public health issue came into focus in 2005, when the CDC partnered with the Alzheimer’s Association and a number of other leading organizations to develop the 2007 and first Healthy Brain Initiative (HBI) Road Map

(Olivari et al., 2020). The most recent iteration of the HBI Road Map is the 2018–2023 version (*The Alzheimer’s Association and Centers for Disease Control & Prevention, 2018*). A notable feature of the 2018–2023 HBI Road Map is the inclusion of a series of concrete actions with the goal of advancing policy, practice, and environmental changes that aim to advance dementia and dementia care (both formal and informal) as a critical public health issue. The four domains of action identified as most critical for state and local or tribal public health agencies to address are: (a) educating and empowering the nation; (b) developing policies and mobilizing partnerships; (c) assuring a competent workforce; and (d) monitoring and evaluating dementia and dementia caregiving data, including prevalence and health effects. The CDC and Alzheimer’s Association have created a number of tools to assist states and other public health entities in addressing these areas, including infographics, webinars in the use and dissemination of data generated from the Behavioral Risk Factor Surveillance System (BRFSS), and an online resource compendia (Olivari et al., 2020).

One issue that may impede efforts to advance dementia caregiving as a public health imperative more locally is how public health and aging services are funded and operated. The activity in aging and dementia programming or services in many states and localities are often directed by aging services networks and not departments of health. The funding support for aging services, dementia care dissemination, and similar initiatives is largely derived from Older Americans Act funding directed to state aging service networks (e.g., the National Family Caregiver Support Program in area agencies on aging; see above). In part because of this “siloeing” effect of funding, the extent to which aging service providers and local, state, or tribal public health agencies (the latter of which receive funding from different entities that may not prioritize aging) partner on dementia-specific initiatives varies widely.

To address the need to elevate dementia as a public health concern and build partnerships between aging service networks and public health agencies, the BOLD Infrastructure for Alzheimer’s Act was passed into law on December 31, 2018 (P.L. 115-406). The principal objective of the BOLD Act is to create a national infrastructure that has as one of its principal foci the support of unpaid dementia caregivers. Specifically, the BOLD Act directs the CDC to: (a) establish a Public Health Center of Excellence that focuses on the support of unpaid dementia caregivers; (b) provide funding support to departments of health, which should include a focus on educating and supporting caregivers; and (c) enhance the timely analysis and reporting of data. Per the goal of providing funding support, the BOLD Act provides funding directly to health departments within states, political subdivisions of states, tribes, and tribal organizations across the United States ($n = 23$ to date) to facilitate and advance public health infrastructure

related to dementia caregiving through policy and health-care system transformation, coalition building, and service innovation. “Core Capacity” health department recipients of BOLD Act funding aim to develop or update state, local, or tribal dementia strategic plans (which should include efforts to improve surveillance and support for unpaid caregivers) using the 2018–2023 HBI Road Map as a guide. “Enhanced” health department recipients aim to implement existing dementia plans in their state or communities. Public health departments that are recipients of BOLD Act funding use data to drive their priorities and initiatives to better support unpaid family or friend caregivers. By establishing a more robust public health infrastructure to address informal dementia caregiving, innovative local and national policy innovations will emerge that better address the many complications and challenges of dementia caregiving.

The BOLD Public Health Center of Excellence on Dementia Caregiving

The BOLD Public Health Center of Excellence for Dementia Caregiving’s (PHCOE-DC’s) primary mission is to disseminate tools and promising practices to public health agencies (as well as other organizations) to best support unpaid family members, friends, or others who provide care to people living with dementia. The PHCOE-DC aims to support and provide technical assistance and information to local, tribal, and state public health agencies (such as Core Capacity and Enhanced BOLD Act recipients) in their design, development, and implementation of supportive systems, environments, and policies that elevate and connect dementia caregiving programs, initiatives, and educational outreach. The PHCOE-DC supports and initiates new public health strategies for dementia caregivers via three activities: (a) providing technical assistance to adopt dementia caregiving–related communication approaches; (b) disseminating various resources, including webinar series, toolkits, and similar materials to educate and engage with public health agencies and elevate unpaid dementia caregiving as a public health priority; and (c) serving as a nexus to create connections and collaboration across the public health, aging service, and research networks to advance dementia caregiving initiatives.

The PHCOE-DC operates in close partnership with the CDC and a robust, engaged network of 26 leading national organizations and stakeholder engagement groups that represent people with ADRD and their caregivers from diverse communities, care contexts or settings, and backgrounds (see [Figure 1](#)). The national network of the PHCOE-DC is core to the function of the Center, as it allows for centralized and person-centered messaging of dementia caregiving materials, tools, events, and best practices, as well as dissemination through numerous channels and platforms to effectively reach state, local, and tribal public health and many other organizations across the United States. A key

leadership component within the PHCOE-DC is the Health Equity Task Force, which provides expertise and guidance to consistently prioritize issues and adaptations central to reaching target populations, such as African American, Latino, Native American or American Indian, and LGBTQ (lesbian, gay, bisexual, transgender, and queer) dementia caregivers, among others.

A core dissemination activity since the PHCOE-DC’s inception in September 2020 has been a robust series of online seminars, panels, and discussions that focus on the various public health dimensions of dementia caregiving. For example, beginning in May 2021 the PHCOE-DC’s Health Equity Task Force created an online seminar series on cultural adaptation in dementia caregiving. Additional webinar topics have included leveraging BRFSS data to inform policy action in dementia caregiving; dissemination, implementation, and adaptation of evidence-based dementia caregiver interventions; and dementia caregiving as a public health priority ([Gaugler et al., 2022](#)).

The PHCOE-DC has also engaged public health agencies, health-care systems, and aging service providers by offering technical assistance on several issues relevant to advancing policies, systems, and environments in their efforts to support informal dementia caregivers. Among the challenges addressed in these technical assistance consults ($n = 16$ consultations to date) are how to sustain evidence-based dementia caregiver interventions; identifying methods and collaborations to facilitate more effective dissemination of evidence-based dementia caregiver interventions to enhance their reach and adoption; synthesizing existing findings on the cost-effectiveness of dementia caregiver interventions (to educate potential adopting organizations on the return on investment when implementing these programs); specifying successful dementia care collaborative models; and tailoring messaging for state departments of health to use in their social media campaigns.

As the PHCOE-DC enters its second year, the Center plans to continue and to expand its robust dissemination and engagement efforts with public health networks across the United States. In June 2022, the PHCOE-DC will convene a national conference on the public health challenges and opportunities of dementia caregiving. The main audience for the conference includes local, tribal, and state public health organizations; aging service professionals; researchers; and others involved in supporting dementia caregivers ([Gaugler et al., 2022](#)). The Center also aims to pivot to the dissemination of peer-reviewed publications to augment its public-facing dissemination efforts in order to further establish a public health agenda that fully incorporates, values, and supports unpaid caregivers of people with dementia.

The public health ramifications of dementia caregiving are considerable and demand a range of policy innovations at the federal, state, and local levels to ensure that:

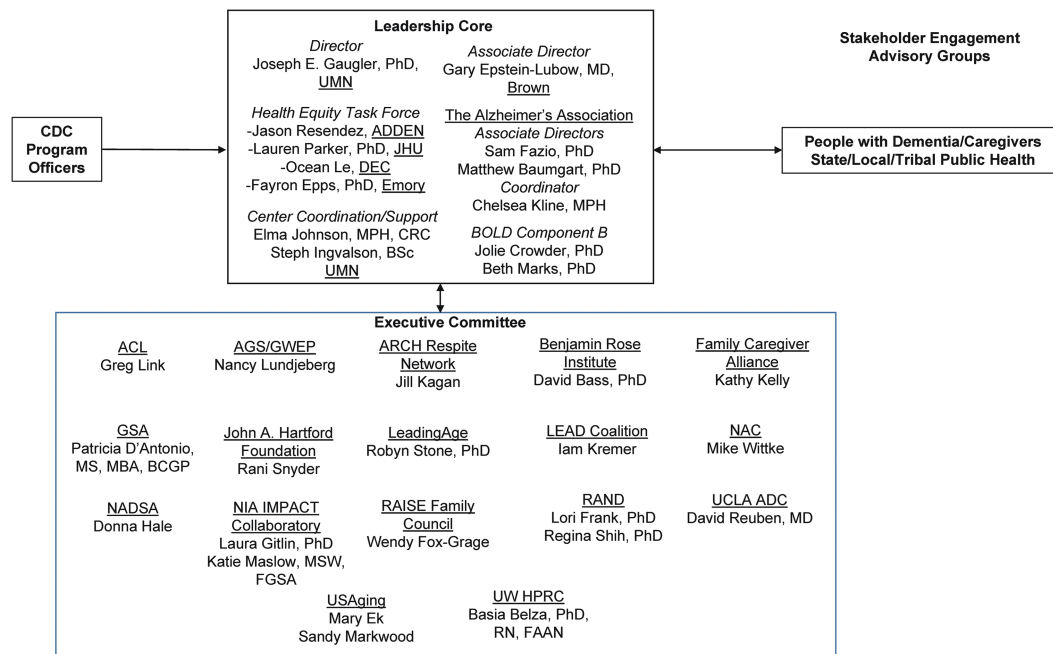


Figure 1. PHCOE-DC network. Abbreviations: ACL = Administration on Community Living; ADDEN = Alzheimer's & Dementia Disparities Equity Network; AGS/GWEP = American Geriatrics Society/Geriatric Workforce Enhancement Program; ARCH = Access to Respite Care and Help; BOLD = Building Our Largest Dementia; CDC = Centers for Disease Control and Prevention; DEC = Diverse Elders Coalition; GSA = Gerontological Society of America; JHU: Johns Hopkins University; LEAD = Leaders Engaged in Alzheimer's Disease; NAC = National Alliance on Caregiving; NADSA = National Adult Day Services Association; NIA IMPACT = National Institute on Aging Imbedded Pragmatic Alzheimer's disease and Alzheimer's Disease-Related Dementias Clinical Trials; PHCOE-DC = Public Health Center of Excellence on Dementia Caregiving; RAISE = Recognize, Assist, Include, Support, & Engage; RAND = Research and Development; UCLA ADC = University of California Los Angeles Alzheimer's Disease Center; UMN = University of Minnesota; UW HPRC = University of Washington Health Promotion Research Center.

(a) dementia is ensconced as a public health priority and viewed as a social determinant of health; (b) caregiving for people with dementia is recognized as core to relevant policy or public health innovation; and (c) informal caregivers are included as an integral part of health-care teams for those living with dementia. Working with its various partners, the BOLD PHCOE-DC aims to contribute to ongoing public health and policy efforts to center caregiving as essential in the prevention, diagnosis, and treatment of dementia.

Looking to the Future

Since the National Alzheimer's Project Act in 2012, critical developments in both science and policy have prioritized and advanced dementia caregiving as a topic of interest (see Figure 2). Although each of these milestones have diverse policy and scientific objectives, they share the common aim to improve support and well-being of unpaid dementia caregivers. For example, a significant milestone in dementia care science was the initiation of the National Institute on Aging (NIA) Imbedded Pragmatic Alzheimer's Disease/ADRD Clinical Trials (IMPACT) Collaboratory. The NIA IMPACT Collaboratory features experts from more than 30 academic and health-care institutions throughout the United States, with the aim of embedding evidence-based dementia care interventions

into real-world health-care contexts. The NIA IMPACT Collaboratory, along with parallel milestones such as the BOLD Act, recognize and highlight the need to bridge the traditional chasm of science and the real-world, lived experiences of family members, friends, and other informal caregivers.

These milestones and advancements notwithstanding, there is considerable risk if the policy recommendations of RAISE, the integration of dementia caregiving in public health via the BOLD Act, and the efforts to bridge science and practice via NIA IMPACT are not sustained. With the family care gap likely to become a reality in the upcoming decades, evidence-based services and supports will become even more necessary to either: (a) substitute for or replace unavailable unpaid dementia caregivers; or (b) supplement existing informal dementia caregivers so that they can continue to provide appropriate support that maintains their well-being. Incorporating the RAISE Family Council recommendations into specific, funded policies and services; leveraging the efforts of the BOLD Act to elevate dementia caregiving as a core public health concern of state, local, and tribal public health agencies; and continuing the welcome investment in science to shorten the "pipeline" from scientific discovery to dissemination or implementation of promising dementia care innovations are all pathways to better support unpaid dementia caregivers in the future.

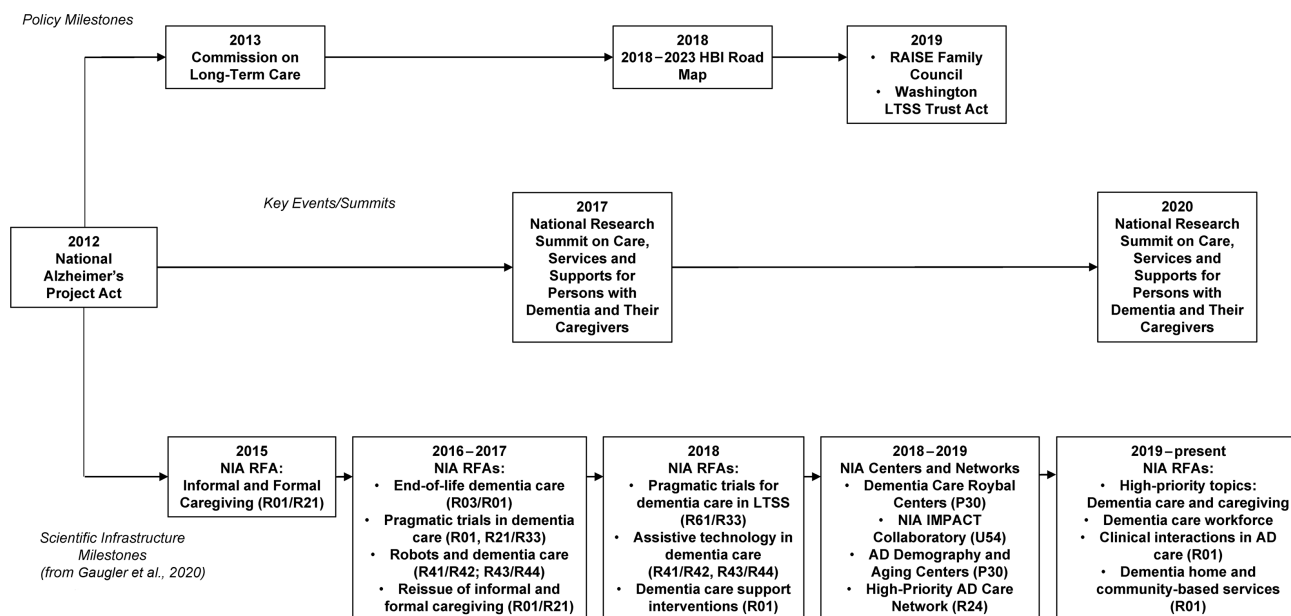


Figure 2. Key policy and scientific infrastructure milestones to advance informal dementia caregiving. Abbreviations: AD = Alzheimer's disease; HBI = Healthy Brain Initiative; IMPACT = Imbedded Pragmatic Alzheimer's Disease/Alzheimer's Disease and Related Dementias Clinical Trials; LTSS = long-term supports and services; NIA = National Institute on Aging; RAISE = Recognize, Assist, Include, Support, & Engage; RFA = request for applications.

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Conflict of Interest

None declared.

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