

From Insight to Advocacy:

Addressing Family Caregiving as a National Public Health Issue





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National Alliance for Caregiving

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From the National Alliance for Caregiving

For more than twenty years, the National Alliance for Caregiving has led public policy research and advocacy efforts to support America's family caregivers. This work and the work of our colleagues has led to increased national attention to the issue of caregiving and the demands put on our aging population. In understanding the demands put on a caregiver, we've often looked at individual circumstance – how does caregiving affect an individual's career, social life, finances, and retirement security?

This paper aims to answer a broader question – what is the impact of caregiving on the public's health? In March 2017, we examined the relationship between public health issues, public health policy, and family caregiving at our annual caregiving advocacy meeting hosted in conjunction with the American Society on Aging. We know that caregiver stress can lead to serious health problems as our population rapidly ages and the number of available family caregivers in younger generations diminishes. This led us to ask the question: "Is Family Caregiving the Next Public Health Crisis?"

The program featured informed insights from public health experts, diverse perspectives from caregiving innovators, and actionable solutions from engaged advocates. Likewise, we hope that this paper will provide an overview of the challenges and opportunities in public health for caregivers and the professionals who serve them. To move the conversation forward, this paper includes recommendations for state and local caregiver coalitions, in addition to national advocates and health care providers, on how they can effectively advocate on behalf of America's family caregivers in the realm of public health and public policy.

The conversation does not stop there. This March we will reconvene the National Network of Caregiving Advocates for our annual meeting. This program, *Engaging Caregivers Across the Lifespan: The 12th Annual National Conference of Caregiver Advocates*, builds on work uncovered in our national discussions on the public health implications of caregiving. We'll be discussing how home and community based service delivery, family and patient-centered policy, workplace innovation, and corporate engagement can engage family caregivers and those who serve them in addressing the needs of this burgeoning stakeholder group.

To continue the process of transforming insight into advocacy, join us as we bring together a unique cohort of professionals equipped to uncover actionable solutions and strategies focused on the public and private sector to not only meet the needs of caregivers, but to also engage them as a vital and recognized stakeholder group in the United States.

We hope you will join us for this critical conversation.

Kind regards,

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Introduction

What is Family Caregiving and Why is it a Public Health Issue for Aging Societies?

Family caregivers are relatives, partners, friends, or neighbors who provide a wide range of assistance to individuals of all ages for health reasons or disabilities for reasons relating to their having a personal relationship rather than financial remuneration. Family caregivers may live with, or apart from, the person receiving care – and care may be of short or long duration.

Family caregivers are the predominant providers of long-term services and supports to persons with disabilities, and in general are thought to provide help that is of high quality and that is consistent with individual preferences. There is also an appreciation that family caregivers play a significant role in ongoing, routine chronic care processes – and of the potential benefits that may emanate from better educating and integrating them as a member of the care delivery team. While impossible to completely disentangle family caregiving from routine family and intergenerational transfers that occur throughout the life course, important individual and societal consequences emanating from these exchanges have been well documented. Establishing public policies that sustain and support families and friends who provide health-related assistance to persons living with chronic disease and disability, or recovering from acute health events is therefore a critical consideration to supporting population health.

The importance of considering family caregiving from a public health perspective is particularly relevant and timely at this juncture. Continued availability of family caregivers will be threatened by the higher rates of childlessness among baby boomers, smaller and more geographically dispersed families, and increasing participation of women in the labor force. At the same time, advances in medicine that save and extend lives increase the duration, complexity, and technical difficulty of care required by individuals with serious illness and disability. Family caregivers will undoubtedly continue to play a vital role in care delivery. However, their willingness to provide care and their effectiveness in doing so will depend on fundamental changes in the extent to which we formally recognize them as key contributors to the health of their relatives, integrate them into the formal provider systems, and support them to do their job. The stakes are high, particularly for high need, high-cost patients whose quality of life critically depends on the availability of a family caregiver, and for health systems responsible for providing high quality and cost-effective care.

Who are Family Caregivers?

The decision to provide assistance to a family member or friend is complex. Contributing factors include recipient and caregiver physical and mental well-being and health needs, individual personalities and dyadic quality, family structure, the size and strength of other established social networks and support, available financial resources, and competing employment and childcare obligations, as well as living environments, community supports and services, employer benefits, and relevant public policies. While the circumstances surrounding each situation and decision are unique, national surveys and observational data sets consistently show that family caregivers are predominantly middle-aged parents, daughters, or spouses, and that they typically either reside together (“co-reside”) or live within close proximity to care recipients. Approximately half of family caregivers are employed; employment rates are understandably higher among working age adults than spousal caregivers of older Americans, and secondary caregivers relative to those taking primary responsibility.

Family structure is influential to who assumes the role of primary caregiver, as well as the duration and intensity of assistance. Married older adults tend to depend on their spouses, while unmarried persons with disabilities are more likely rely on an adult child, siblings, parents, or other relatives. Caregiving arrangements are dynamic, and fluctuate based on both recipients’ needs, and caregivers’ physical capabilities. The experience of providing and receiving care varies within and across subgroups. For example, spouses tend to have smaller networks and provide assistance of greater intensity whereas the network of secondary caregivers available to children and racial and ethnic minorities appears to be larger. Recent years have brought a growing awareness of the challenges experienced by young adult caregivers, caregivers who provide assistance from long distances, those with limited financial resources, and caregivers who are older themselves.

The Growing Care Gap

Population aging has important implications for service delivery systems and the health care professional and direct care workforce. It is estimated that 3.5 million additional health care professionals will be needed by 2030, including more than one million additional direct-care workers who will be needed by 2018. Eldercare is projected to be the fastest-growing employment sector within the health care industry. Within 20 years, one in five Americans will be over 65, of whom an estimated 90 percent will have one or more chronic conditions. Adults over 65 account for nearly 26 percent of all physician visits, 47 percent of all hospital stays, 34 percent of all prescriptions, 34 percent of all physical therapy patients, and 90 percent of all nursing homes stays. 7.7 million people will have Alzheimer’s disease in 2030, up from 4.9 million in 2007. Yet the number of workers in many eldercare professions is actually declining – precisely at a time when their services are needed more than ever before.¹

¹ Eldercare Workforce Alliance. (2011). “3.5 Million Workers Needed by 2030 to Care for Older Adults, Current Levels of Workforce Already Stretched.” Available at: <https://eldercareworkforce.org/newsroom/press-releases/article:3-5-million-workers-needed-by-2030-to-care-for-older-adults-current-levels-of-workforce-already-stretched/>.

The Data Challenge

While there are many national surveys of America's family caregivers, these national surveys often vary in methodology, making it challenging to articulate the scope of the impact of caregiving on the population at large. The Caregiving in the U.S. 2015 study,² conducted by the National Alliance for Caregiving and AARP, relied on a national, probability-based online survey panel of randomly selected participants who were statistically representative of the demographics of the United States. The survey asked respondents aged 18 and older whether they have provided unpaid care to an adult or child within the past 12 months. Using this methodology, *Caregiving in the U.S. 2015* estimated that approximately 43.5 million adults have provided unpaid care to an adult or child and approximately 34.3 million Americans provided care to an adult aged 50 or older.

Specific to eldercare, the National Study of Caregiving (NSOC)³ surveys family caregivers of older adults receiving help for health and functioning reasons who respond to The National Health and Aging Trends Study, using a one-month recall period. NSOC estimates from 2011 identified 17.7 million family caregivers assisting community-living older adults ages 65 and older.

Other national surveys have also estimated national prevalence. For example, Pew Research Center⁴ estimated in 2013 that 39% of U.S. adults (as many as 90 million individuals) were caring for an adult or child in the past year. RAND Corporation,⁵ in conducting a study of military and Veteran caregivers, estimated that there are approximately 22.6 million family caregivers across the lifespan.

As monitoring and surveillance are foundational to public health and public policy, data infrastructure is a central element of any public health strategy to support America's caregiving families. The National Academy of Sciences study on *Families Caring for an Aging America*,⁶ recommended that the government should "[e]xpand the data collection infrastructures within the U.S. Departments of Health and Human Services, Labor, and Veterans Affairs to facilitate monitoring, tracking, and reporting on the experience of family caregivers." Working together as a community to routinely assess the status of caregivers will help public health professionals understand the effects of efforts to support families as America ages.

² National Alliance for Caregiving and AARP Public Policy Institute. (2015). *Caregiving in the U.S. 2015*. Available at: http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.

³ National Health & Aging Trends Study. (Retrieved 12-18-2017). "NSOC FAQ." Available at: <https://www.nhats.org/scripts/NSOCFAQ.htm>.

⁴ S Fox, M Duggan, and K Purcell. (2013). *Family Caregivers are Wired for Health*. Available at: <http://www.pewinternet.org/2013/06/20/family-caregivers-are-wired-for-health/>.

⁵ R Ramchand, T Tanielian, et al. (2014). *Hidden Heroes: America's Military Caregivers*. Available at: https://www.rand.org/pubs/research_reports/RR499.html.

⁶ R Shulz and J Eden, ed. National Academies of Sciences, Engineering, and Medicine. (2016). *Families Caring for an Aging America*. Available at: <https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america>.

—Policy Perspectives on Public Health— and Family Caregiving

The Public Health Caregiving Surveillance Brief

Family caregivers who provide unpaid assistance and help to people with chronic health conditions or disabilities are the backbone of community support in the US. Caregiving is an important public health issue that impacts relationships, health status, and quality of life across the lifespan for both caregivers and care recipients.⁷ Although caregiving is not a new phenomenon and research on the experience, health effects, and impacts of caregiving has been ongoing for decades, until relatively recently there was limited population-level data available on caregiving.⁷ Surveillance data on public health topics is critical because it provides an evidence base upon which to make informed decisions about allocating resources, targeting programs, and developing policy.⁸

The Behavioral Risk Factor Surveillance

The Behavioral Risk Factor Surveillance System (BRFSS) is one of the primary sources of public health surveillance data in the United States. The BRFSS is conducted annually in all US states and territories to assess a variety of health-related topics including diet, physical activity, health care access, and health conditions.⁹ In 2015, it collected information from more than 400,000 community-dwelling adults age 18 and older. Each year, the BRFSS includes a set of core questions that are asked in all states and states may additionally include optional modules or other questions of their own design to their surveys. Data are aggregated across states by the Centers for Disease Control and Prevention (CDC) and made available to the public on their website.

The Caregiver Module

In 2005, CDC and the Association for Prevention Teaching and Research provided funding to Dr. Elena Andresen, an epidemiologist, to develop and pilot test a module of questions about caregiving to be used on the BRFSS, called the Caregiver Module.¹⁰

⁷ RC Talley and JE Crews. (2007). "Framing the public health of caregiving." *Am J Public Health*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/17194871>.

⁸ LM Lee and SB Thacker. (2011). "The Cornerstone of Public Health Practice: Public Health Surveillance, 1961-2011." *Centers for Disease Control and Prevention*. Available at: <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6004a4.htm>.

⁹ AH Mokdad. (2009). "The Behavioral Risk Factors Surveillance System: Past, Present, and Future." *Annu Rev Public Health*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/19705555>.

¹⁰ B Neugaard, EM Andresen, et al. (2007). "Characteristics and Health of Caregivers and Care Recipients--North Carolina, 2005." *MMWR Morb Mortal Wkly Rep*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/17538528>.

The Caregiver Module screens all BRFSS respondents using the question, “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?” People who say “yes” are classified as caregivers and then report on the intensity and duration of their caregiving, problems they encounter as a caregiver, and their greatest care needs. The Caregiver Module underwent systematic evaluation to assure respondents understood the questions and it was included as an optional BRFSS with support from the Healthy Aging Program at the Centers for Disease Control and Prevention (CDC).¹¹ In 2009, the caregiver screening question was included on the BRFSS core, asked of all participating states and territories, enabling state-level estimates of caregiving prevalence.

During 2015, 24 states included the Caregiver Module on their BRFSS. For the Caregiving module, participants were ≥ 18 years old, who indicated if they were a caregiver. Caregivers also reported on the intensity and duration of the caregiving situation, problems that they encounter as a caregiver, and their greatest care needs. Additionally, for those who are not a caregiver, they are asked if they anticipate becoming a caregiver in the next 2 years.

The Healthy Brain Initiative

Although caregivers of people with Alzheimer’s disease or other dementias make up a small proportion of all caregivers (9% in BRFSS in 2015), the caregiving burden associated with Alzheimer’s disease is high.^{12,13,14,15} Public Health’s role is crucial in monitoring and supporting persons living with Alzheimer’s and their family caregivers. CDC’s Healthy Brain Initiative (HBI) is the Federal public health response for Alzheimer’s.¹⁶ It began in 2005 through a Congressional appropriation that established the Alzheimer’s-specific segment of the Healthy Aging Program. The HBI addresses cognitive health from a public health perspective to catalyze action at the state and local level. The Healthy Brain Initiative: *The Public Health Road Map for State and National Partnerships, 2013-2018*,¹⁷ the second in the Road Map series, was released in 2013. This Road Map, which was designed to complement the National Plan to Address Alzheimer’s Disease,¹⁸ identifies 35

11 LA Anderson, VJ Edwards VJ, et al. (2013). “Adult Caregivers in the United States: Characteristics and Differences in Well-Being, By Caregiver Age and Caregiving Status.” *Prev Chronic Dis*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/23948336>.

12 M Baumgarten. (1989). “The Health of Persons Giving Care to the Demented Elderly: A Critical Review of the Literature.” *J Clin Epidemiol*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/2685178>.

13 RC Dillehay and MR Sandys. (1990). “Caregivers for Alzheimer’s Patients: What We are Learning from Research.” *Int J Aging Hum Dev*. Available at: <http://journals.sagepub.com/doi/abs/10.2190/2P3J-A9AH-HHF4-00RG>.

14 C Zucchella and M Bartolo. (2012). “Caregiver Burden and Coping in Early-Stage Alzheimer Disease.” *Alzheimer Dis Assoc Disord*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/21537145>.

15 Alzheimer’s Association. (2016). *Alzheimer’s Disease Facts and Figures*. Available at: http://www.alz.org/documents_custom/2016-facts-and-figures.pdf.

16 Centers for Disease Control and Prevention (CDC). (Last Accessed 10-3-2017). “Healthy Brain Initiative: Healthy Aging.” Available at: <https://www.cdc.gov/aging/healthybrain/index.htm>.

17 Centers for Disease Control and Prevention (CDC). (Last Accessed 10-3-2017). “Healthy Brain Initiative: Road Map: Healthy Aging for Older Adults.” Available at: <https://www.cdc.gov/aging/healthybrain/roadmap.htm>.

18 Office of the Assistant Secretary for Planning and Evaluation (ASPE). (2016). “National Plan to Address Alzheimer’s Disease: 2016 Update.” Available at: <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2016-update>.

actions that state and local public health agencies and their partners can implement to promote cognitive health and address cognitive impairment and the needs of caregivers. These actions are categorized into four traditional domains of public health: monitor and evaluate, educate and empower, develop policy and mobilize partnerships, and assure a competent workforce.

The Roadmap is under revision and the 2018-2023 action items will be released mid-2018, with an emphasis on early diagnosis of Alzheimer's disease and diagnosis disclosure, risk reduction for Alzheimer's, and caregiving for persons with Alzheimer's.

A major focus of CDC's efforts to support the actions of the HBI Road Map is to monitor and evaluate, emphasizing caregiving surveillance at the state-level using the BRFSS Caregiver Module. CDC provides annual data for action for public health professionals and decision makers at the state level for both cognitive decline and caregiving, which is disseminated widely through state-specific products produced in collaboration with the Alzheimer's Association.¹⁹ Additionally, CDC launched the Healthy Aging Data Portal,²⁰ which provides access to a range of national, regional, and state data on older adults. Users can examine data on key indicators of health and well-being of older Americans, such as tobacco and alcohol use, screenings and vaccinations, mental and cognitive health, and caregiving. The Portal enables public health professionals and policymakers to examine a snapshot of the health of older adults in their states in order to prioritize and evaluate public health interventions.

Using Caregiver Surveillance Data

The Caregiver Module has provided valuable information about the prevalence of caregiving,^{10,11} the experiences of different types of caregivers,^{21,22} and the health behaviors and potential impacts of providing care.^{23,24,25,26} Given the increasing evidence that family caregivers help people with chronic conditions better

19 Alzheimer's Association. (Last Accessed 10-3-2017). "Data Collection: Public Health." Available at: <http://www.alz.org/publichealth/data-collection.asp>.

20 Centers for Disease Control and Prevention (CDC). (Last Accessed 10-3-2017). "Healthy Aging Data: Healthy Aging for Older Adults." Available at: <https://www.cdc.gov/aging/agingdata/index.html>.

21 EL DeFries, LC McGuire, et al. (2009). "Caregivers of Older Adults with Cognitive Impairment." *Prev Chronic Dis*. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2687852/>.

22 ED Bouldin, L Shaull, (2017). "Financial and Health Barriers and Caregiving-Related Difficulties Among Rural and Urban Caregivers." *J Rural Health*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/28940539>.

23 See n. 22.

24 L McGuire, EL Bouldin, et al. (2010). "Examining Modifiable Health Behaviors, Body Weight, and Use of Preventive Health Services Among Caregivers and Non-Caregivers Aged 65 Years and Older in Hawaii, Kansas, and Washington Using 2007 BRFSS." *J Nutr Health Aging*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/20424805>.

25 KH Winter, ED Bouldin, and EM Andresen. (2010). "Lack of Choice in Caregiving Decision and Caregiver Risk of Stress, North Carolina, 2005". *Prev Chronic Dis*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/20158969>.

26 CT Kusano, ED Bouldin, et al. (2011). Adult Informal Caregivers Reporting Financial Burden in Hawaii, Kansas, and Washington: Results from the 2007 Behavioral Risk Factor Surveillance System. *Disabil Health J*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/22014670>.

manage their conditions and engage in health promoting behaviors^{27,28,29,30,31} it is important to assure the health of caregivers and to provide them the support necessary to continue providing care. Population-based surveillance data on caregiving is a vital component of understanding caregiver's needs and developing appropriate programs and strategies to deliver this support. The Caregiver Module enables state-level data collection about the health, quality of life, and behaviors of caregivers to better understand their activities and needs. States can use the module to raise awareness of the extent of caregiving and to highlight current and future public health service needs for caregivers.

— Supporting Families Caring for an — Aging America

National discussions on public health and caregiving look to examine the role of caregivers in existing systems of care, identify needed changes in structures and processes, how these changes might be monitored and assessed, and who should be accountable for these changes. First, it is critical to identify structural and process barriers that limit caregivers' ability to provide effective care to caregivers of all older adults with illness and disability, including those with serious illness. Addressing these barriers will require fundamental changes in the way American society: (1) identifies and assesses caregivers; (2) supports them; and (3) trains health care and long-term services and supports (LTSS) providers to effectively engage caregivers.

Structural and Process Barriers to Effective Care

In order to fulfill their roles, caregivers serve as the glue that connects health care and social service providers to the individual in need of care. They interact with physicians, nurses, social workers, psychologists, pharmacists, physical and occupational therapists, direct care workers, and others. In addition to being direct care providers for the patient, they also serve as the primary source of information about the patient's health history, abilities, and preferences. Yet, family caregivers are often marginalized in the delivery of health care and LTSS.

27 JE Aikens JE, R Trivedi R, et al. (2015). "Integrating Support Persons into Diabetes Telemonitoring to Improve Self-management and Medication Adherence." *J Gen Intern Med*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/25421436>.

28 B Aggarwal, M Liao, and L Mosca. (2013). "Medication Adherence is Associated with Having a Caregiver Among Cardiac Patients." *Ann Behav Med*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/23536121>.

29 B Aggarwal, M Liao, et al. (2010). "Low Social Support Level is Associated with Non-Adherence to Diet at 1 Year in the Family Intervention Trial for Heart Health (FIT Heart)." *J Nutr Educ Behav*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/20696617>.

30 RB Trivedi, CL Bryson, et al. (2012). "The Influence of Informal Caregivers on Adherence in COPD Patients." *Ann Behav Med Publ Soc Behav Med*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/22422104>.

31 L Mosca, B Aggarwal, et al. (2012). "Association Between Having a Caregiver and Clinical Outcomes 1 Year After Hospitalization for Cardiovascular Disease." *Am J Cardiol*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/21962999>.

A confluence of structural and process barriers impedes effective partnerships between family caregivers and other providers of care. The prevailing emphasis on supporting individual autonomy and safeguarding the privacy of personal health information limits family caregivers' access to information that is appropriate and beneficial when they are responsible for coordinating care or managing treatments. Medical providers are not compensated for time spent educating family caregivers about patients' medical conditions and treatments, nor are they trained to have those conversations. Although clinical assessments used to formulate treatment plans commonly include questions for patients about the availability of help, caregivers are not asked about their ability to provide care or their relevant knowledge, and receipt of training in performing caregiving tasks is inconsistent at best. The availability and adequacy of family caregiving is simply assumed.³²

Guidance on how to address these issues is provided by the recent National Academies of Sciences, Engineering, and Medicine report on family caregiving,³³ which calls for transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today's emphasis on person-centered care needs to evolve into a focus on person- and family-centered care. Although focused specifically on caregiving for older adults, the recommendations apply equally well to caregiving for adults of all ages. We focus here on those policy recommendations relevant to the key structures and processes of care that need to be changed in order to fully integrate caregivers into health care and LTSS systems.

Identifying and Assessing Caregivers

Caregivers' circumstances vary widely and in ways that affect their availability, capacity, and willingness to assume critical responsibilities. Evidence from randomized clinical trials indicates that most effective interventions begin with an assessment of caregivers' risks, needs, strengths, and preferences.^{34,35} Yet most health and LTSS providers do not assess the health, skills, employment, and willingness of family caregivers and provide them little, if any, training to carry out the complicated medical procedures, personal care, and care coordination tasks they are expected to provide. Indeed, the lack of systematic assessment of family participation in health and LTSS not only affects the experience of family caregivers and care recipients, it also precludes knowledge of how their involvement influences the quality of clinical care and social services and undermines credible accounting of the value family caregivers bring to the health care delivery system and to society.

Optimizing the role of family caregivers will minimally require systematic attention to the identification, assessment, and support of family caregivers throughout the care delivery process. How might this be achieved? First, caregivers need to be identified in both the care recipient's and the caregiver's medical record (see Table 1).

³² See n.6

³³ AS Kelley. (2014). "Defining 'Serious Illness.'" *J Palliat Med*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/25115302>.

³⁴ SH Belle, L Burgio, et al. (2006). "Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups." *Ann Intern Med* 2006. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/17116917>.

³⁵ SJ Czaja, LN Gitlin, et al. (2009). "Development of the Risk Appraisal Measure: A Brief Screen to Identify Risk Areas and Guide Interventions for Dementia Caregivers." *J Am Geriatr Soc*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/19453305>.

This acknowledges their role as part of a care team and sensitizes providers to the importance of engaging the caregiver when making patient treatment plans. Second, caregivers should be screened to identify those at risk for adverse health outcomes and whose circumstances may place the person they care for in harm's way. Achieving this goal will require new tools that assess caregivers' strengths, limits, needs, and risks in relation to the range of tasks they are expected to perform. Assessments should minimally include caregivers' health and functional status, their level of stress and well-being, their ability to perform required tasks, and the types of training and supports they might need to enact their role. These assessments should occur during all key provider patient/caregiver encounters, including wellness exams, physician visits, admission and discharge from hospitals and emergency rooms, and chronic care coordination and care transition programs.

Table 1. Caregiver Assessment

WHO	WHEN	WHAT	WHERE	ASSESSOR
Identify primary caregiver responsible for patient care; entered in patient and caregiver medical record	<ul style="list-style-type: none"> Wellness/follow-up visits for patient/caregiver Care transitions (admission/ discharge from hospitals, emergency rooms/rehab facilities to home) Chronic care transitions/ change in patient status Regular follow-up monitoring 	<ul style="list-style-type: none"> Health/ functional and emotional status of caregiver Knowledge and skills for required care tasks Willingness to carry out required tasks Financial and human support resources available to caregiver Training and support needed 	<ul style="list-style-type: none"> Physician offices Receiving/ discharge facility Caregiver/ patient home Hospital 	<ul style="list-style-type: none"> Primary care provider Discharge planners In-home assessors Caregiver specialists

Key initial steps to implementing this recommendation will require identification and refinement of caregiver assessment tools appropriate to the care delivery context of the care recipient, identification and training of assessors, and evaluation of provider work flow to determine where and when assessments take place. The health, functional ability, and care needs of the patient should be a key factor in determining the fit between patient needs and caregiver capacity, which in turn should inform the training and support needs of the caregiver.

With few exceptions, there are no financial incentives for providers to identify, assess, or support family caregivers or penalties for not doing so. For example, the Caregivers and Veterans Omnibus Health Services Act of 2010 established a mechanism for reimbursement/workload credit for services provided to family caregivers, but the focus is primarily on caregivers of younger veterans.³⁶ The Centers for Medicare and

³⁶ 111th Congress. (2009 - 2010). Public Law 111-1963 - May 5, 2010: Caregivers and Veterans Omnibus Health Services Act of 2010. Available at: <https://www.congress.gov/111/plaws/publ163/PLAW-111publ163.pdf>.

Medicaid Services should be charged with developing, testing and implementing provider payment reforms that motivate providers to engage family and support caregivers. Payment reforms should include clearly articulated performance standards that hold providers accountable for caregiver engagement, training, and support by explicitly including caregiver outcomes in quality measures. Outcome measures should include caregiver satisfaction with provider encounters, adequacy of training and instructions provided, caregivers' confidence and efficacy in performing required tasks, and the adequacy of support services provided.

The recommendations made above stand in sharp contrast to the current reality of caregiver assessment in our health care system. The Caregiver Advise, Record, Enable (CARE) Act enacted in more than 35 states is one small step in the right direction as it encourages hospitals to: (1) record the name of the family caregiver at the time of hospital admission of their loved one; (2) provide family caregivers with adequate notice prior to hospital discharge; and (3) provide simple instruction of the medical tasks they will be performing when their loved one returns home.³⁷ Proposed national legislation such as the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act is a bipartisan bill that would create a national plan to support the more than 40 million Americans caring for older adults, spouses, children with disabilities, veterans and other people who need care in order to live independently.^{38,39}

Supporting Caregivers

Guidance on how best to support caregivers can be gleaned from a large body of intervention research aimed at improving caregiver and patient outcomes. Education and skills training improve caregiver confidence and the ability to manage daily care challenges. Training strategies that involve active participation of the caregiver are particularly effective in achieving positive outcomes.⁴⁰ Counseling, self-care, relaxation training, and respite programs can improve caregiver and patient quality of life.^{41,42} Technology-based caregiver support, education, and skills training can be an effective and efficient alternative for enhancing caregiver knowledge and skills.⁴³

Despite the demonstrated effectiveness of a wide range of caregiver services and supports, few of these intervention strategies have moved from research settings to everyday health and social service programs.

37 AARP. (Last Accessed 12-18-17). "New State Law to Help Family Caregivers." Available at: <http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>.

38 114th Congress. (2015 – 2016). Senate Bill 1719: RAISE Family Caregivers Act. Available at: <https://www.congress.gov/bill/114th-congress/senate-bill/1719>.

39 BA Given and SC Reinhard. (2017). "Caregiving at the End of Life: The Challenges for Family Caregivers." *Generations*. Available at: <https://search.proquest.com/openview/99f5f726c76991721142102d2676520/1>.

40 R Schulz, A O'Brien, et al. (2002). "Dementia Caregiver Intervention Research: In Search of Clinical Significance." *Gerontologist*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/12351794>.

41 SH Belle, L Burgio et al. (2006). "Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups." *Ann Intern Med*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/17116917>.

42 MS Mittelman, SH Ferris SH, et al. (1995). "A Comprehensive Support Program: Effect on Depression in Spouse-Caregivers of AD Patients." *Gerontologist*. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/8557206>.

43 SJ Czaja, CC Lee, R Schulz. (2013). "Quality of Life Technologies in Supporting Family Caregivers." In: Richard Schulz, ed. (2013, pp. 245-260). *Quality of Life Technology Handbook*. Boca Raton, FL: CRC Press/Taylor and Francis Group.

Key questions that need to be addressed in pursuing widespread implementation of proven interventions include who should deliver these support strategies, where and when should they be delivered, how can they be integrated into the existing workflow of provider organizations, and who should pay for their delivery and evaluation? The National Family Caregiver Support Program (NFCSP) of the Administration for Community Living is one example of a federal program that incorporates elements of evidence-based caregiver interventions into broad based service programs for caregivers.⁴⁴ These relatively modest efforts should be scaled up and expanded. At the same time, we should continue to support efficacy trials aimed at developing and refining support strategies for caregivers.

Enhancing Competencies of Health Care and LTSS Providers to Engage Caregivers

Providers should see family caregivers not just as a resource in the treatment or support of a person, but rather as a partner in that enterprise who may need information, training, care, and support. Achieving and acting on that perspective requires that providers have the skills to recognize a caregiver's presence, assess whether and how the caregiver can best participate in overall care, engage and share information with the caregiver, recognize the caregiver's own health care and support needs, and refer the caregiver to needed services and supports.

A wide range of professionals and direct care workers are likely to interact with family caregivers - physicians, nurses, social workers, psychologists, pharmacists, occupational therapists, physical and other rehabilitation therapists, certified nursing assistants, physician assistants, and others. Professional organizations in nursing and social work have led the way in taking steps to establish standards for person- and family-centered care that includes the caregiver. Similar efforts are needed across the health care and social service professions.^{45,46} Federal support is needed from the U.S. Department of Health and Human Services (HHS) for the development and enforcement of competencies for identifying, assessing, and supporting family caregivers by health care and human service professionals. Achieving this goal requires that specific competencies are identified by provider type, including competencies related to working with diverse family caregivers. These competencies should in turn shape the development of educational curricula and training programs designed to teach them. Professional societies and accrediting bodies should develop educational curricula and support their systematic evaluation and implementation, and should convene and collaborate with state agencies and professional organizations to incorporate competencies into standards for licensure and certification.

⁴⁴ Administration for Community Living. (Last Accessed; 6-20-2017). National Family Caregiver Support Program (NFCSP). Available at: <https://www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program>.

⁴⁵ National Association of Social Workers. (2010). NASW Standards for Social Work Practice with Family Caregivers of Older Adults. Available at: <https://www.socialworkers.org/LinkClick.aspx?fileticket=aUwQL98exRM%3D&portalid=0>.

⁴⁶ K Kelly, S Reinhard, A Brooks-Danso. (2008). "Professional Partners Supporting Family Caregivers." Am J Nurs. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/18797211>.

Taking Action and Next Steps

What Caregiver Advocates Can Do

- » **Form or join a state or local caregiving coalition.** Communities at the national, state, and local levels have begun to develop collaborative efforts to meet the needs of family caregivers. Coalitions are undertaking efforts to help caregivers through information and referral services, educational outreach, and advocacy. These communities are realizing that collaboration brings together the personal experience and professional expertise that can meet the needs of caregivers. This voice speaks for the changes needed in the delivery of services, for recognition of the valued role of caregivers, and in policies and regulations. The coalition's vision of improvement in the lives of caregivers serves as the catalyst for effective advocacy.
- » **Advocate on behalf of existing programs that support caregivers.** Caregiver advocates should develop a basic understanding of programs offered under the Older Americans Act, such as the National Family Caregiver Support Program, and administered through the Administration of Community Living under the Department of Health and Human Services. These programs are typically aimed at supporting those in the community with serious conditions or disabilities across the lifespan.
- » **Advocate for policies that are needed to expand services and supports, protect the financial security of caregivers, reform health care and social service systems, and enhance the health and wellness of caregivers.** We know through assessment data that caregivers would like: classes about caregiving, such as giving medication; help in getting access to services; caregiver support groups; individual counseling to help cope with caregiving; and respite care.
- » **Educate policy makers on the prevalence of caregiving.** Utilize tools such as the Caregiver Module, which has valuable information about the prevalence of caregiving, the experiences of different types of caregivers, and the health behaviors and potential impacts of providing care. Population-based surveillance data on understanding caregiver's needs and developing appropriate programs and strategies to deliver this support.
- » **Educate health systems to understand how to better work with caregivers.** Use tools such as the Healthy Aging Data Portal to understand and communicate key indicators of health and well-being of older Americans. CDC provides annual data for action for public health professionals and decision makers at the state level for both cognitive decline and caregiving, which is disseminated widely through state-specific products produced in collaboration with the Alzheimer's Association.

What Health Systems Can Do

- » **Include caregivers as a vital member of the health care team.** Remember that caregivers interact with physicians, nurses, social workers, psychologists, pharmacists, physical and occupational therapists, direct care workers, and others. In addition to being direct care providers for the patient, they also serve as the primary source of information about the patient's health history, abilities, and preferences. It is imperative to ensure family caregivers are not marginalized in the delivery of health care and LTSS.
- » **Ensure caregivers have access to comprehensive training and information.** Ensure everyone on the care team, especially the caregiver, really understands the magnitude of the issue at hand to decrease the deterioration of the Physician - [Patient- Caregiver] Relationship. Provide print literature in the waiting rooms, regarding information about Dementia, Alzheimer's disease, typical AD medications and dosages, social materials – driving assessments, day care, or home health services.
- » **Identify and implement up-to-date best practices.** Create curricula for practitioners that follows a public health approach with flexible curriculum linked to public health competencies, designed for faculty to use with undergraduate public health courses, developed and evaluated to address this burnout that is felt from the medical school setting to the physician level.
- » **Guarantee and confirm that caregivers are included in intervention strategies.** Caregivers need to be identified in both the care recipient's and the caregiver's medical record and caregivers should be screened to identify those at risk for adverse health outcomes and whose circumstances may place the person they care for in harm's way. These assessments should occur during all key provider patient/ caregiver encounters, including wellness exams, physician visits, admission and discharge from hospitals and emergency rooms, and chronic care coordination and care transition programs.
- » **Ensure health systems are family-and patient-centered.** The present health system, where visits are closely monitored based on time, and "clicking" off the boxes for reimbursement, means that meaningful discussions rarely occur in a traditional office setting and the caregiver leaves the office with minimal useful information in hand and the sense of isolation.



What Policy Makers Can Do

- » ***Institute a national strategy recognizing and supporting caregivers.*** Policy makers need to pass the proposed national legislation, Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act which is a bipartisan bill that would create a national plan to support the more than 40 million Americans caring for older adults, spouses, children with disabilities, veterans and other people who need care in order to live independently. The Secretary of HHS, working with the Secretaries of Labor and Veterans Affairs, and others, should create and implement a National Family Caregiver Strategy that includes: A. Effective mechanisms to ensure that family caregivers are routinely identified and their needs are assessed and supported B. Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively C. Training of health care and social service providers to recognize, engage, and support family caregivers ([link to caregiver assessment](#)).
- » ***Ensure caregivers are included in health care team.*** Policy makers should support and expand the core components of the Caregiver Advise, Record, Enable (CARE) Act as it encourages hospitals to: (1) record the name of the family caregiver at the time of hospital admission of their loved one; (2) provide family caregivers with adequate notice prior to hospital discharge; and (3) provide simple instruction of the medical tasks they will be performing when their loved one returns home.
- » ***Scale programs that are evidence-based.*** Policy makers should expand programs such as REACH OUT, funding for programs that benefit American Indian and Alaska Native (AI/AN) caregivers, and the National Family Caregiver Support Program (NFCSP).
- » ***Ensure health care policies are patient-and family-centered.*** Future policies and practices affecting the role of families in the support and care of older adults should evolve from person-centered to person-and family-centered care to take steps to address the health, economic, and social issues facing family caregivers of those across the lifespan.
- » ***Improve payment incentives.*** The Centers for Medicare and Medicaid Services should be charged with developing testing and implementing provider payment reforms that motivate providers to engage family and support caregivers. Payment reforms should include clearly articulated performance standards that hold providers accountable for caregiver engagement, training, and support by explicitly including caregiver outcomes in quality measures. Outcome measures should include caregiver satisfaction with provider encounters, adequacy of training and instructions provided, caregivers' confidence and efficacy in performing required tasks, and the adequacy of support services provided. Medical providers are not compensated for time spent educating family caregivers about patients' medical conditions and treatments, nor are they trained to have those conversations. Although clinical assessments used to formulate treatment plans commonly include questions for patients about the availability of help, caregivers are not asked about their ability to provide care or their relevant knowledge, and receipt of training in performing caregiving tasks is inconsistent at best.

Family caregivers in the United States are faced with many challenges as they undertake a complex range of activities in the care of a family member or friend. Most care in our country occurs within the context of families of origin or adoption. Often family caregivers need to identify and coordinate services provided by complex health and social service systems that are difficult to navigate. Information discovered by caregivers is often provided in a terminology that is unfamiliar. No one organization or service within a community can meet the complex social, medical, physical, spiritual, or emotional needs of family caregivers. However, in the aggregate caregiver advocates, health systems and providers, and policy makers can address the public health issues that relates to our nation's family caregivers.

To learn more about efforts to advance research, and advocacy for America's family caregivers, visit
www.caregiving.org

