



## Families Caring for an Aging America

### DETAILS

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### AUTHORS

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Richard Schulz and Jill Eden, Editors; Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine

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## SUMMARY<sup>1</sup>

Family caregiving affects millions of Americans every day, in all walks of life. At least 17.7 million individuals in the United States are family caregivers of someone age 65 and older who needs help because of a limitation in their physical, mental, or cognitive functioning. As a society, we have always depended on family caregivers to provide the lion’s share of long-term services and supports (LTSS) for our elders. Yet the need to recognize and support caregivers is among the most significant overlooked challenges facing the aging U.S. population, their families, and society.

For decades, demographers, gerontologists, health researchers, health care professionals, economists and other experts have called attention to the nation’s rapidly aging population. However, little action has been taken to prepare the health care and LTSS systems for this unprecedented demographic shift. By 2030, 72.8 million—more than one in five U.S. residents—will be age 65 or older. The greatest growth will be in the numbers of the “oldest old,” the population that is most in need of help because they are the most likely to have physical, cognitive, and other functional limitations.

The increasing diversity of older Americans may further increase the demand for caregivers because data indicate that older African-American and Hispanic adults have been more likely than white adults to have functional impairments. In less than 15 years, nearly 3 in 10 older Americans will identify as a member of a minority group. Differences in culture, along with differences in income, education, neighborhood environments, lifetime access to health care, and occupational hazards will have a significant impact on the need for care, the availability and willingness of family caregivers to provide it, and the most effective and appropriate ways to provide caregiver support. Developing programs and services that are accessible, affordable, and tailored to the needs of diverse communities of caregivers presents significant challenges.

While the need for caregiving is rapidly increasing, the pool of potential family caregivers is shrinking. Families have fewer children, older adults are more likely to have never married or to be divorced, and adult children often live far from their parents or may be caring for more than one older adult or their own children. In the past, families could rely on women to provide what is often referred to as eldercare, especially daughters, daughters-in-law, and wives who were not in the workforce. Today, the typical caregiver is still female. But that caregiver is almost as likely as a male caregiver to be employed, to need employment income, and to have limited schedule flexibility to juggle caregiving, work, and other responsibilities.

### OBJECTIVE OF THE STUDY

In 2014, 13 private foundations, the Alliance for Aging Research, Alzheimer’s Association, the Archstone Foundation, California Health Care Foundation, The Commonwealth

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<sup>1</sup> This summary does not include references. Citations appear in subsequent chapters.

Fund, The Fan Fox and Leslie R. Samuels Foundation, Health Foundation of Western and Central New York, The John A. Hartford Foundation, May and Stanley Smith Charitable Trust, The Retirement Research Foundation, The Rosalinde and Arthur Gilbert Foundation, Santa Barbara Foundation, and Tufts Health Plan Foundation, as well as the U.S. Department of Veterans Affairs (VA), and an anonymous donor came together to ask the National Academies of Sciences, Engineering, and Medicine to develop a report with recommendations for family caregiving of older adults.

Box S-1 presents the charge to the committee. This study has three principal objectives:

- to assess the prevalence and nature of family caregiving of older adults as well as the impact of caregiving on individuals' health, employment, and overall well-being;
- to examine available evidence on the effectiveness of programs, supports, and other interventions designed to support family caregivers; and
- to assess and recommend policies to address the needs of family caregivers and to minimize the barriers that they encounter in trying to meet the needs of older adults.

The committee's charge raises questions about the boundaries between the responsibilities of individuals, families, and government. By its very nature, family caregiving of older adults is both a personal and private issue as well as a public and societal concern. From the individual perspective, one's involvement in caregiving for his or her elders is, in part, a matter of personal, spousal, or filial responsibility. Yet, for generations, the American public has also assumed collective responsibility in helping to protect the well-being of the nation's older adults through government programs such as Social Security, Medicare, Medicaid, the Area Agencies on Aging, and others. The committee recognizes that the role of the individual versus that of society overall is often a matter of public debate.

**BOX S-1****Charge to the Committee on Family Caregiving for Older Adults**

An ad hoc Institute of Medicine committee will develop a report with recommendations for public- and private-sector policies to support the capacity of family caregivers to perform critical caregiving tasks, to minimize the barriers that family caregivers encounter in trying to meet the needs of older adults, and to improve the health care and long term services and supports provided to care recipients.

The committee will focus on family caregivers of older adults, typically age 65 and older. The report will analyze the prevalence of family caregiving and the demographic, societal, and technological trends that influence it. It will also examine caregivers' roles and responsibilities, both current and expected in the future, and the impact of the caregiver role on individual health, employment, and well-being. Caregivers' unmet needs and the gap between the projected demand for caregivers and the population available to serve as caregivers will be assessed and differences associated with race/ethnicity, culture, rural residence, and geography will be examined.

The report will also review the evidence of the effectiveness of potential supports for family caregivers and care recipients across a range of settings, including, for example, in medical homes and other primary care settings, home- and community-based settings, acute care hospitals, and residential facilities. These might include, for example, models of team-based care that include the family caregiver as member; approaches to training providers regarding the caregiver role; and models for training caregivers for their various roles.

**WHO IS A FAMILY CAREGIVER?**

The committee agreed that the term family caregiver should be used to reflect the diverse nature of older adults' family and helping relationships. Some caregivers do not have a family kinship or legally defined relationship with the care recipient, but are instead partners, neighbors, or friends. Many older adults receive care from more than one family caregiver, and some caregivers may help more than one older adult. The circumstances of individual caregivers and the caregiver context are extremely variable. Family caregivers may live with, nearby, or far away from the person receiving care. Regardless, the family caregiver's involvement is determined primarily by a personal relationship rather than by financial remuneration. The care they provide may be episodic, daily, occasional, or of short or long duration.

Although this study focuses on caregivers of adults ages 65 and older, the committee recognizes that many other people need caregiving. This report's conclusions and recommendations are likely to apply to family caregivers regardless of the care recipient's age.

**WHAT CAREGIVERS DO**

Families traditionally have provided emotional support and assisted their older members with household tasks and personal care. Today, family caregivers still assume these roles but they also provide health and medical care at home, navigate complicated and fragmented health

care and LTSS systems, and serve as surrogate decision makers. Medicare and other payer's financial incentives encourage shorter hospital stays with the implicit expectation that family members can support the older adult at home and manage the transition from hospital to home and back again. Providers expect family caregivers—with little or no training—to handle technical procedures and equipment for older adults at home, such as feeding and drainage tubes, catheters, and tracheostomies, and to manage and monitor their condition. Family caregivers describe learning by trial and error and fearing that they will make a life-threatening mistake.

In order to fulfill the numerous roles that they play, family caregivers must interact with a wide range of providers in a variety of systems. They communicate with physicians, physician assistants, nurses, nurse practitioners, social workers, psychologists, pharmacists, physical and occupational therapists, certified nursing assistants, home health and personal care aides, and others. They provide information about older adults' health histories, social supports, medications, past diagnoses, and previous treatments and surgeries (especially if the older adult is forgetful or has dementia). They also work with and arrange the services of community-based organizations.

Despite the integral role that family caregivers play in the care of older adults with disabilities and complex health needs, they are often marginalized or ignored in the delivery of health care and LTSS, and are often ignored in public policy as well. Paradoxically, family caregivers may be excluded from treatment decisions and care planning while the providers who exclude them assume their availability to perform the wide range of tasks prescribed by the older adults' care plan. Numerous systemic barriers impede effective engagement with family caregivers, including emphasis on the bioethical concept of individual autonomy, misinterpretation of the privacy requirements of the Health Insurance Portability and Accountability Act's, payment rules that discourage providers from spending time communicating with caregivers, and a health insurance model oriented to individual coverage.

### **THE PERSONAL IMPACT OF CAREGIVING**

Substantial evidence indicates that family caregivers of older adults are at risk compared to non-caregivers; they have higher rates of depressive symptoms, anxiety, stress, and emotional difficulties. Evidence also suggests that caregivers have lower self-ratings of physical health, elevated levels of stress hormones, higher rates of chronic disease, and impaired health behaviors. Numerous factors predispose caregivers to adverse outcomes, including sociodemographic factors; intensity or type of caregiving; perceptions of the care recipient's physical, psychological, and existential suffering; lack of choice in taking on the caregiving role; the caregiver's health and physical functioning; the social and professional supports they receive; and the care recipient's home physical environment. Caregivers transitioning from a low-to-high intensity role also report greater adverse effects compared to others.

Research also shows that family caregivers of significantly impaired older adults are at the greatest risk of economic harm, in part because of the many hours of care and supervision and the costs of hiring help. Caregiver surveys find that several other factors are associated with financial harm including co-residence with or residing a long distance from the older adult; limited or no availability of other family members to share responsibilities and costs; and, if employed, limited or no access to paid leave or a flexible workplace. Caregivers who cut back on paid work hours or leave the workforce to meet caregiving responsibilities lose income, receive

reduced Social Security and other retirement benefits (because of fewer hours in paid employment) and may incur significant out-of-pocket expenses for the older adult's care.

Despite the array of negative consequences, caregivers also report positive outcomes. Numerous surveys suggest that, for some people, caregiving instills confidence, provides lessons on dealing with difficult situations, brings them closer to the care recipient, and assures them that the care recipient is well-cared for.

### **EFFECTIVE CAREGIVER INTERVENTIONS**

A robust body of research demonstrates that interventions aimed at supporting caregivers can significantly improve the quality of care delivered as well as improve the well-being and quality of life for both caregivers and care recipients. Interventions that have been tested through well-designed randomized clinical trials have involved a broad range of therapeutic techniques, have been applied in a variety of settings, and have been evaluated for a broad set of impacts on caregivers and care recipients. Well-designed randomized controlled trials (RCTs) have shown that education and skills training can improve caregiver confidence in managing daily care challenges; caregiver skill building and environmental modifications can improve quality of life for family caregivers and care recipients. They also demonstrate that these interventions may yield cost savings. When caregivers receive personal counseling and participate in care management programs, for example, nursing home admissions for older adults with dementia can decline. Integrating caregivers into the hospital discharge process has been shown to decrease re-hospitalizations and shorten lengths of stay. These approaches hold promise for meeting the needs of an increasingly diverse population of older adults and family caregivers.

### **A VISION FOR THE FUTURE**

This study confirms how essential family caregivers are to the health and well-being of older Americans. It also raises profound concerns about our dependence on family caregivers and the potentially serious health and economic risks that caregiving can entail. It is time to publicly acknowledge caregiving families. In today's world, family caregivers cannot be expected to provide complex care and support on their own. Family caregivers need greater recognition, information, and support to fulfill their roles and responsibilities and to maintain their own health, financial security, and well-being.

Effectively engaging and supporting caregivers of older Americans cannot happen overnight. New caregiver programs and policy reforms will carry new costs and require financing. As noted above, some portion of new investments may be offset by savings—from reductions in use of nursing home, home health, emergency room and inpatient hospital care. These savings are not likely to fully support all of this report's recommendations. Rigorous evaluation and transparency as to costs as well as benefits will be essential.

The committee also recognizes that the context for this report is a time of economic constraints, concerns about future financing of Medicare and Social Security, a wide range of competing demands for public dollars, and deep divisions among Americans about the role and size of government. Nevertheless, the rapid aging of the U.S. population and its impact on families and health care expenditures should not be ignored. If the needs of our older adults' caregivers are not addressed, we, as a society, risk compromising the well-being of our elders

and their families. Failure to take on these challenges also means a lost opportunity to discover the potential societal benefits of effectively engaging and supporting family caregivers in the care of older adults—both economic and otherwise. The public’s investment in family caregiving for older adults should be carefully considered and public dollars shepherded responsibly. As federal and state agencies move to develop new programs and supports to address the needs of family caregivers, it will be important to prioritize the needs of the most vulnerable caregivers and tailor eligibility appropriately.

## RECOMMENDATIONS

Family caregiving is a critical issue of public policy. The committee calls for a transformation in the policies and practices affecting the role of families in the support and care of older adults. Today’s emphasis on person-centered care needs to evolve into a focus on person- and family-centered care. The committee urges that support of family caregivers be recognized as an integral part of the nation’s collective responsibility for caring for older Americans.

**RECOMMENDATION 1: The committee calls upon the Administration that takes office in January 2017 to take steps to address the health, economic, and social issues facing family caregivers of older Americans. Specifically, the committee recommends that:**

**The Secretary of Health and Human Services, in collaboration with the Secretaries of Labor and Veterans Affairs, other federal agencies, and private-sector organizations with expertise in family caregiving, develop and execute a National Family Caregiver Strategy that, administratively or through new federal legislation, explicitly and systematically addresses and supports the essential role of family caregivers to older adults. This strategy should include specific measures to adapt the nation’s health care and long-term services and supports (LTSS) systems and workplaces to effectively and respectfully engage family caregivers and to support their health, values, and social and economic well-being, and to address the needs of our increasingly culturally and ethnically diverse caregiver population.**

The Secretaries should publicly announce and begin to implement the Strategy by:

1. Executing steps allowable under current statutory authority;
2. Proposing specific legislative action, where appropriate, to address additional steps;
3. Convening and establishing partnerships with appropriate government (federal, state, and local) and private-sector leaders to implement the Strategy throughout education, service delivery, research, and practice; and
4. Addressing fully and explicitly the needs of our increasingly culturally and ethnically diverse caregiver population.

***PREPUBLICATION COPY: UNCORRECTED PROOFS***

The Secretaries should issue biannual reports on progress and actions of the National Family Caregiver Strategy.

This Strategy should include the following steps:

**RECOMMENDATION 1-a: Develop, test, and implement effective mechanisms within Medicare, Medicaid, and the U.S. Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.**

Most health and LTSS providers do not assess the health, skills, employment, and willingness of family caregivers. Family caregivers are typically provided little, if any, information and 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 caregivers and care recipients, it also precludes knowledge of how their involvement influences the quality of clinical care and social services, limits the spread of evidence-based interventions that strengthen the well-being of family caregivers and their ability to promote and provide quality care, and undermines credible accounting of the value family caregivers bring to the health care delivery system and to society.

Given the growing national commitment to accountability and efficiency in care delivery, the committee concludes that the time is ripe to elevate family-centered care alongside person-centered care to the forefront of delivery system reform—rationalizing the roles of family caregivers and better supporting their involvement in the delivery process. Achieving that goal will require systematic attention to the identification, assessment, and support of caregivers throughout the care delivery process by:

- identifying caregivers in both the care recipient's and the caregiver's medical record;
- screening caregivers to identify those who are at risk themselves, or whether a mismatch between family caregiver capacity and older adults' health needs or circumstances place older adults in harm's way;
- assessing at-risk caregivers' strengths, limits, and needs across the full range of expected tasks—medical care, personal care, and coordination; and that, at a minimum, asks family caregivers about their own health and well-being, level of stress, and types of training and supports they might need to continue their role
- assuring that identification, screening and appropriate assessment occurs at each touch-point in care delivery—including delivery of publicly funded LTSS, annual wellness exams, physician visits, admission and discharge for hospitals and emergency rooms, and in chronic care coordination and care transition programs.

**RECOMMENDATION 1-b: Direct the Centers for Medicare & Medicaid Services to develop, test, and implement provider payment reforms that**



**motivate providers to engage family caregivers in delivery processes, across all modes of payment and models of care.**

As the predominant payers of care for older adults, Medicare, Medicaid, and the VA are essential to motivating appropriate provider practice. A number of recent initiatives have been taken to advance recognition of caregivers in Medicare and Medicaid coverage, payment, and delivery policies. In Medicare, hospitals are now expected to engage and support family caregivers in the discharge planning process as a part of the hospital's conditions of participation. New chronic care management and transitional care services codes allow providers to be paid for non-face-to-face communication with individuals and their caregivers about a beneficiary's care. Innovative delivery mechanisms implicitly encourage providers (through shared savings for quality care at lower costs) to actively engage caregivers as a resource in the care delivery process. In Medicaid, many states formally or informally assess family caregivers as part of the process for developing LTSS care plans. In the VA, the Caregivers and Veterans Omnibus Health Services Act of 2010 established a mechanism for reimbursement/workload credit for services provided to caregivers (mainly of younger veterans).

For the most part, however, these advances create the potential for, rather than a commitment to payment practices that support provider engagement with caregivers. That commitment requires

- the development and application of payment mechanisms to recognize providers' interaction with family caregivers when older adults are not present;
- the development and application of performance standards that hold providers accountable for caregiver engagement, training, and support in accessing the full range of health care and LTSS beneficiaries require, by explicitly including caregiver outcomes in performance measures;
- collaboration between the Centers for Medicare & Medicaid Services and the Administration for Community Living to incorporate evidence-based caregiver interventions and supports into covered benefits and to facilitate referrals to community-based LTSS; and
- adherence to the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care to provide quality care that is effective, equitable, understandable, respectful, and responsive to older adults' and caregivers' cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

**RECOMMENDATION 1-c: Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.**

To ultimately ensure high quality person- and family-centered care by the health and LTSS workforce, providers should see family caregivers not just as a resource in the treatment or support of an older person, but also as both a partner in that enterprise and as someone who may

need information, training, care and support. Achieving and acting on that perspective requires that all types of providers be able to:

- recognize a family 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
- help caregivers to obtain needed support by referring caregivers to appropriate services.

Given the growing diversity of the older adult population as well as their caregivers, cultural competence in exercising these skills is essential to their effectiveness.

A range of professionals and direct care workers are likely to serve older people with family caregivers—physicians, nurses, physician assistants, social workers, psychologists, pharmacists, occupational therapists, physical and other rehabilitation therapists, certified nursing assistants, and home care aides. Professional organizations in social work and nursing have led the way in taking steps to build a workforce with the competencies necessary for person- and family-centered care. However, work to date falls far short of a systematic and comprehensive effort that should include

- identification of specific competencies, by provider type, to demonstrate effective practice, including competencies related to working with diverse family caregivers;
- development of educational curricula and training to instill those competencies;
- incorporation of those competencies into requirements for licensure, certification, and accreditation;
- articulation of standards of practice; and
- evaluation of practice using standardized quality of care metrics.

The federal government, in collaboration with professional societies, education programs, licensure and certification bodies, accrediting bodies, and other organizations, should move this effort forward. Specifically, action requires

- Federal support for the development and enforcement of competencies for identifying, assessing, and supporting family caregivers by health care and human service professionals and regulatory and accrediting organizations;
- The HHS Office for Civil Rights to clarify caregivers’ access to information by providing administrative guidance to health care and social service providers regarding the permitted uses and disclosures of protected health information to family caregivers and encourage providers to train their workforce regarding that clarification;
- Convening professional societies, training programs, accrediting bodies, and other organizations to develop educational curricula and support their systematic implementation and evaluation; and
- convening and collaborating with state agencies and professional organizations to incorporate competencies into standards for licensure and certification.

**RECOMMENDATION 1-d: Increase funding for programs that provide explicit supportive services for family caregivers such as the National Family Caregiver Support Program and other relevant U.S. Department of Health & Human Services programs to facilitate the development, dissemination, and implementation of evidenced-based caregiver intervention programs.**

A robust body of research demonstrates that interventions aimed at supporting caregivers can significantly improve quality of care as well as the well-being and quality of life for both caregivers and care recipients. Interventions that have been tested through well-designed RCTs have involved (separately or in combination) a broad range of therapeutic techniques, been applied in a variety of settings, and been evaluated for a broad set of impacts on caregivers and care recipients. Despite demonstrated effectiveness, however, promising interventions have not been disseminated and adopted in everyday settings. As a result, few caregivers have access to services that may lessen their health risks or improve their ability to help older adults effectively.

**RECOMMENDATION 1-e: Explore, evaluate, and, as warranted, adopt federal policies that provide economic support for working caregivers.**

Caregiving and employment are increasingly intertwined. Already about half of the nation's caregivers for older adults are employed. As noted above, working caregivers—especially those who care for people with dementia or with substantial personal care needs—are at risk of significant economic costs: loss of income; out-of-pocket cost for the care recipient; and lower lifetime earnings, savings, and retirement benefits. Low-wage and part-time workers are particularly vulnerable. Job discrimination may also affect caregivers' job security.

The Family and Medical Leave Act (FMLA) in 1993 was an important step toward providing working caregivers some help in balancing job and family responsibilities. However, the FMLA covers only certain family relationships, excluding daughters- and sons-in-laws, grandchildren, nieces and nephews, siblings and other friends and relatives who are caring for older adults; and it does not apply to employers with fewer than fifty employees. Perhaps even more important—eligible caregivers may be unable to afford the unpaid leave FMLA protects—and many American workers—especially low-wage workers—lack access to paid time off of any kind.

Four states—California, New Jersey, New York, and Rhode Island—have enacted paid family leave statutes and five states—California, Connecticut, Massachusetts, Oregon, and Vermont—have paid sick leave laws that require employers to allow workers a reasonable number of earned sick days to care for an ill family member (including some older adults). The states finance paid family leave through an insurance model that relies on minimal payroll taxes paid by employees. Although some employers report additional costs, initial evidence suggests that many have adapted to family leave requirements. These programs have the potential both to facilitate family caregiving and alleviate some of its economic hardships.

Other policy measures have the potential to help safeguard caregivers' immediate and long-term economic security. An array of worthy proposals merits serious consideration. Refundable tax credits would enhance caregiver incomes. The Social Security caregiving credits to help reduce the impact of caregivers' foregone wages on retirement benefits, including family caregiver status as a protected class to protect caregivers under federal employment discrimination laws and provide employers with guidance and training on best practices to better support workers with caregiving responsibilities. Exploring the feasibility of these options will

require economic impact assessments that include not only the caregiver but also employers and federal and state agencies. Evaluating feasibility will also require that analyses take into account unintended consequences, such as the impact on caregivers' labor force participation.

As reliance on working caregivers grows, federal policy action across some or all of these lines is essential to promote economic security for all the nation's caregivers of older Americans. Federal, state, and local governments should accelerate efforts to expand and evaluate paid family and medical leave and paid sick leave policies.

**RECOMMENDATION 1-f: Expand 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.**

The nation lacks a basic data infrastructure and knowledge base to inform policy and monitor progress in supporting caregivers. Current data collection does not capture essential details on caregivers' characteristics or the outcomes of their caregiving activities. A robust surveillance system is needed. Routine, longitudinal, population surveys should assess family caregivers and be sufficiently powered to allow analyses of important subgroups of caregivers. Key variables include age, race and ethnicity, sexual orientation, rural or urban location, employment status, geographic proximity to care recipients, and care recipient condition. Concerted federal leadership and the engagement of experts (statisticians, care providers, researchers and policymakers) and professionals in public and private organizations will be essential.

**RECOMMENDATION 1-g: Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real-world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.**

Despite its valuable lessons learned from research on caregiver interventions, there are significant barriers to moving existing evidence-based interventions from the test phase into implementation in diverse clinical practice settings. Progress in caregiver support requires a new approach to research among federal agencies and private foundations to support large-scale multi-site research studies evaluating efficacy and cost-effectiveness of a range of caregiver interventions. The research agenda should be guided by a consensus conference among key stakeholders.

**RECOMMENDATION 2: State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports, and implement similar programs.**

As noted above, several states have led the nation in addressing working caregivers' access to family or sick leave. Twenty-nine states have also enacted the Caregiver Advise, Record, Enable (CARE) Act, requiring hospitals to ask people whether they wish to designate a family caregiver, and, if so, record the name of the caregiver when individuals are admitted;

notify the family caregiver if the individual is to be discharged to another facility or back home; and provide effective explanation of and instruction on the medical/nursing tasks (such as medication management, injections, wound care) that the family caregiver will need to perform at home.

In addition to efforts by the federal government to build on this experience in developing and implementing the recommended Caregiver Strategy, states can also independently advance caregiver and care recipient well-being by learning from other states and adopting best practices.

**RECOMMENDATION 3: The Secretaries of Health and Human Services, Labor, and Veterans Affairs should work with leaders in health care and long-term services and supports delivery, technology, and philanthropy to establish a public–private, multi-stakeholder innovation fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families.**

Addressing caregiver issues will require not only changes in the public sector but also the support and guidance of the private sector. Employers of all types have a vested interest in supporting caregivers. Insurance, health care, and technology companies, for example, can bring to bear both financial resources and expertise to address current and emerging challenges for caregivers. Multiple national and local private foundations, as well as nonprofit organizations, have already begun to invest in the implementation of a caregiver agenda. The public sector cannot achieve all necessary progress on its own; a public–private innovation fund could leverage private funding to complement public resources and fill gaps in public funding.

The fund, for example, could sponsor the development of market-driven approaches for lessening the strain of caregiving on families—targeting innovative services and products that are scalable and sustainable. Potential products include assistive technologies, remote monitoring and sensing systems, telehealth applications, and other tools to assist family caregivers and to enable older adults to continue living in their home and communities. These systems could also be linked to health care and social service providers to aid in care coordination efforts.

**RECOMMENDATION 4: In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.**

The future of caregiving for older Americans will be shaped not only by the growing older adult population needing care but also by the increasing ethnic and racial diversity of older people and their families. The National Caregiver Strategy should address the needs and values of diverse family caregivers. The strategy, including all of the above recommendations, should include specific goals for advancing support for diverse caregivers and the biannual report should specifically address progress of the strategy in meeting these goals. Specific steps that can be taken include the following:

- Making cultural competence a core aspect of provider competencies in working with family caregivers.
- Addressing critical gaps in our knowledge about the effectiveness of interventions for diverse populations are through both research and implementation efforts.

- Conduct monitoring in a way that allows for meaningful data on the health and well-being of diverse family caregivers as well as on the quality and outcomes of care.

