

Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act

Initial Report to Congress

Prepared by: RAISE Family Caregiving Advisory Council

With assistance from: Administration for Community Living,
an operating division of the U.S. Department of Health and Human Services



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The Family Caregiving Advisory Council



The Family Caregiving Advisory Council at its inaugural meeting in August 2019.

The [Recognize, Assist, Include, Support, & Engage \(RAISE\) Family Caregivers Act of 2017](#), (Public Law 115-119) called for the establishment of the Family Caregiving Advisory Council (the council) to advise and provide recommendations, including identified best practices, to the Secretary of the U.S. Department of Health and Human Services (HHS) on recognizing and supporting family caregivers (RAISE Family Caregivers Act of 2017, 2018). The report that follows is the council's initial report to Congress.

This report outlines progress to date on the council's efforts to evaluate and document the experiences and unmet needs of the nation's family caregivers in the current environment. The report includes 26 recommendations that were developed in response to a broad range of information-gathering efforts conducted between 2019 and 2021. These efforts included a formal request for information (RFI) from family caregivers, a series of listening sessions and focus groups, and more than a dozen briefings from experts in the field, along with the considerable personal and professional insight members of the council brought to its deliberations. These recommendations, each of which includes a rationale statement developed during council meetings, will serve as the foundation for a forthcoming National Family Caregiving Strategy. The strategy is described in section 3 of the RAISE Family Caregivers Act.

The RAISE Family Caregivers Act called for the appointment of 15 members of the public to serve as voting council members. In addition to providing a wealth of professional expertise, several members are family caregivers or individuals with disabilities who receive assistance and support from one or more family caregivers. The appointed council members include:

- Ben Bledsoe, M.H.A., President/CEO of the Consumer Direct Care Network
- Joe Caldwell, Ph.D. family caregiver and the Director of the Community Living Policy Center at the Lurie Institute for Disability Policy, Brandeis University
- Diane Caradeuc, family caregiver and federal government retiree
- James S. Cheely, family caregiver and project manager with a General Contracting company from Glasgow, Kentucky
- Jisella Dolan, family caregiver and Global Chief Advocacy Officer for Home Instead Senior Care®
- Brenda Gallant, R.N., Executive Director of the Maine Long-Term Care Ombudsman Program
- Catherine Alicia Georges, Ed.D., RN, FAAN, family caregiver and AARP's National Volunteer President from June 2018 to June 2020
- Rhonda J.V. Montgomery, Ph.D., family caregiver and co-founder of TCARE, Inc.
- Nancy Murray, M.S., family caregiver and President of The Arc of Greater Pittsburgh at ACHIEVA
- James Murtha, III, MSW, disability rights advocate and mental health therapist/faith-based counselor for St. Vincent Catholic Charities of Lansing, Michigan
- Casey R. Shillam, Ph.D., RN, family caregiver and dean and professor of the University of Portland School of Nursing
- Alan B. Stevens, Ph.D., family caregiver and the Vernon D. Holleman-Lewis M. Rampy Centennial Chair in Gerontology at Baylor Scott & White Health
- Deborah Stone-Walls, family caregiver and member of the National Association of Area Agencies on Aging (n4a)
- Theresa Tanous, MHA, family caregiver and federal government retiree
- Carol Zernial, M.A., Executive Director of the WellMed Charitable Foundation

The RAISE Family Caregivers Act correspondingly called for participation from non-voting members representing the federal departments and agencies that play a role in caregiver support, long-term services and supports (LTSS), labor and workforce, government financial policies, community service, and impacted populations. The statute specifically called for participation from the administrators (or designees) of the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS), both within HHS, and the Secretary for Veterans Affairs (or designee). In addition, the following agencies are represented on the council:

- The Administration for Children and Families (ACF)
- AmeriCorps
- The Centers for Disease Control and Prevention (CDC)
- The Consumer Financial Protection Bureau (CFPB)
- The Food and Drug Administration (FDA)
- The Health Resources and Services Administration (HRSA)
- The Indian Health Service (IHS)
- The National Institute on Aging (NIA), National Institutes of Health (NIH)
- The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- The Office of the National Coordinator for Health Information Technology (ONC)
- The Substance Abuse and Mental Health Services Administration (SAMHSA)
- The U.S. Department of Agriculture (USDA)

For more information, visit the [RAISE Family Caregiving Advisory Council website](#).

Letter from the Acting Administrator of the Administration for Community Living

Family caregivers have long been the backbone of America's caregiving infrastructure. Each year, more than 53 million people provide a broad range of assistance to support the health, quality of life, and independence of someone close to them (AARP and National Alliance for Caregiving, 2020). Millions of older adults and people with disabilities would not be able to live in the community without that support, and replacing it with paid services would cost an estimated \$470 billion each year (Reinhard, Feinberg, Houser, Choula, & Evans, 2019).

Providing that support is rewarding, but it can be challenging. When family caregivers do not have training, support, and opportunities for rest and self-care, their own health, well-being, and quality of life suffer. Their financial future can also be put at risk – lost income due to family caregiving is estimated to be a staggering \$522 billion each year (Chari, Engberg, Ray, & Mehrotra, 2015).

About 1 in 7 of us is serving as a family caregiver at any given time, and more than two-thirds of us can expect to need assistance with some tasks as we age. With the populations of both older adults and people with disabilities growing, there has been an increasing recognition in recent years that supporting family caregivers is a critical public health issue that affects all of us.

The COVID-19 pandemic laid bare the fragility of our nation's system of LTSS. Together, we witnessed the impact of the longstanding shortages in the workforce that provides paid care, our dependence on volunteers, and the extent to which family caregivers must fill the gaps when services are not available. The pandemic also exacerbated the challenges of family caregiving. Balancing work, family, and caretaking became even more difficult, and in many cases, caregivers had to completely leave the workforce. The pandemic has created a new urgency and momentum to address caregiving.

We now have an unprecedented opportunity to achieve – and go far beyond – the goals Congress established in the RAISE Family Caregivers Act. As part of our country's recovery from the COVID-19 pandemic, President Biden has made clear that strengthening our care economy is key. Under his Build Back Better plan, he is calling for significantly increased funding for home and community-based services, and propose to increase pay and benefits to address the direct care workforce crisis. The Build Back Better plan also calls for paid family and medical leave, which is crucial to supporting family caregivers. Those investments, together with the National Family Caregiving Strategy that will be informed by this report and the ongoing work of the RAISE Family Caregiving Advisory Council, have the power to transform our system.

Of course, this transformation must include the voices of family caregivers, and this report draws heavily from input received through more than 1,600 comments submitted by caregivers and advocates and from listening sessions the council held during the COVID-19 pandemic.

I want to express our deepest gratitude to the members of the council for their hard work on this report, and to the family caregivers who shared their stories and input. I also want to thank the National Alliance for Caregiving (NAC) for their support in collecting and publishing caregiver stories that introduce each of the chapters in this report and so poignantly illustrate the needs it addresses. Finally, ACL thanks our partners, without whom this important work would not have been possible: The John A. Hartford Foundation, the National Academy for State Health Policy (NASHP), Community Catalyst, the LeadingAge LTSS Center @UMass Boston, and the panel of nationally recognized experts on family caregiving convened by NASHP to support the council.

As this report shows, we have our work ahead of us if we are to truly *Recognize, Assist, Include, Support, and Engage* the millions of family caregivers in the United States of America. We stand on the edge of a once-in-a-lifetime opportunity to bring that vision to life, and we are committed to seizing it.

Alison Barkoff
Acting Administrator
Administration for Community Living
U.S. Dept. of Health & Human Services

Executive Summary

The U.S. population is currently experiencing exponential growth in the population of older adults and people with disabilities. This increase is expected to accelerate over the coming decades. By 2030, there will be 77 million people 65 years and older (United States Census Bureau, 2017). Many of these people will experience “limitations in physical health and functioning, mental health, and/or cognitive functioning” (National Academies of Sciences, Engineering, and Medicine, 2016). For example, today, more than 5 million Americans live with a diagnosis of Alzheimer’s disease or a related dementia (ADRD). As the population of older adults increases, researchers anticipate the number of people living with ADRD will double by 2060 (Matthews, et al., 2019). The majority of these individuals will need day-to-day assistance and support from one or more family members in order to retain their independence, quality of life, and well-being.

Meanwhile, the population of people of all ages with disabilities and functional limitations is also growing. According to the 2018 American Community Survey (ACS), 40.6 million Americans (12.6% of the population of children and adults) currently have a disability or impairment (United States Census Bureau, 2018). While some are eligible to receive assistance through state and federal programs, most people who need community-based care rely on uncompensated assistance from family caregivers (Reinhard, Feinberg, Houser, Choula, & Evans, 2019).

Despite the fact that humans have always cared for each other (and will continue to do so), family caregiving as a public health issue has been largely overlooked until recently in many public policy areas (National Academies of Sciences, Engineering, and Medicine, 2016). Developing the infrastructure and systems to appropriately **recognize, assist, include, support, and engage** family caregivers has never been more important. This is true for individuals, families, communities, and the nation as a whole. Many people are happy to provide support to their friends and family members and willingly step into this role. They find it rewarding and are glad that the person they support receives the care and assistance he or she needs. However, without education, counseling, assistance, and support, the experience of caregiving can be a difficult one for some people. Despite the rewards of caregiving—the satisfaction and comfort of knowing that the person they support is receiving quality care—many describe the journey of caregiving as a “lonely” experience (AARP and National Alliance for Caregiving, 2020).

“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

-Carol Zernial, M.A., caregiver & Family Caregiving Advisory Council member

When it comes to determining the exact number of family caregivers in the U.S., national estimates vary. These differences make it difficult to statistically gauge the need for support and develop systems of evidence-informed supports to address those needs. For example, the [2017 Panel Study of Income Dynamics](#) estimated that **26.4 million people** were providing caregiving support to adults with physical limitations in “a typical week” (Freedman & Wolff, 2020). That number more than doubles if the reference period is expanded to one year. In the 2020 update to [Caregiving in the U.S.](#), AARP and NAC estimated that **53 million people** supported “an adult or child with special needs” in the past year (AARP and National Alliance for Caregiving, 2020). Caregiver prevalence rates are also shaped by other factors such as how researchers define caregiving, the types of caregivers interviewed, the ages of the people receiving support, the methods used to identify and recruit caregivers, as well as survey instruments used (Mudrazija & Johnson, 2020).

Even though estimates of caregiver prevalence vary, one thing is not in dispute: Our nation’s system of long-term services and supports (LTSS), which includes both community-based services and institutional care such as that provided in nursing homes, could not function without the contributions of family members, who provide a wide range of assistance and supports across all care settings. In fact, the nation’s millions of family caregivers are commonly referred to as a “safety net” to millions of Americans who rely on their support for quality of life, independence, and autonomy, all of which are important components of self-determined living.

Researchers estimate the economic value of the unpaid support family caregivers provide to adults with limitations in daily activities at \$470 billion (Reinhard, Feinberg, Houser, Choula, & Evans, 2019). But the contributions to the lives of others—including society as a whole—are impossible to measure. These contributions, however, often leave caregivers financially, emotionally, and physically depleted and socially isolated.

When family caregivers are untrained, unsupported, and do not have opportunities to engage in meaningful self-care and rest (i.e., respite care), the experience of family caregiving can negatively impact their physical health and mental health. For example, multiple studies have shown that caregivers are at greater risk of depression and mental health issues when compared to non-caregivers (Mudrazija & Johnson, 2020). A significant portion report “high physical strain,” “substantial physical problems,” and are more likely to report experiencing “fair or poor health” than the general population (Mudrazija & Johnson, 2020). However, a growing body of research has shown that when caregivers receive assistance that is appropriate to their needs, both they and

the people they support experience improvements in well-being and quality of life (National Academies of Sciences, Engineering, and Medicine, 2016).

“As a nurse and palliative care scholar, I have the knowledge and skills to manage the most complex of patient situations. Yet, the moment I became a family caregiver for my parents, I had no idea what to do. I was no longer the palliative care “expert,” but the scared daughter of parents I dearly love. I now have a very different perspective: regardless of one’s education, background, or experience, family caregiving is very personal and complicated, even for an ‘expert.’”

-Casey Shillam, Ph.D., RN, family caregiver and co-chair of the Family Caregiving Advisory Council

Supporting caregivers also can address some of the financial challenges that come with caregiving. When family caregivers have to take time off work or leave the work force, it can impact their financial health over both the long- and short-term (Mudrazija & Johnson, 2020). For individuals providing long-term caregiving, lack of workplace flexibilities and limited access to paid leave for caregiving can make it difficult to balance employment and assisting a family member. As a result, many family caregivers, especially those in low-wage or part-time jobs, may reduce work hours, switch to part-time work, or temporarily leave the workforce (Mudrazija & Johnson, 2020). In one study, 15% of adult caregivers who stopped working reported that they did so “because their job provided inadequate flexibility” (Spillman & Urban Institute, 2016).

When Congress passed the [Recognize, Assist, Include, Support, & Engage \(RAISE\) Family Caregivers Act](#), it established the [RAISE Family Caregiving Advisory Council](#) (the council) and authorized the development of a National Family Caregiving Strategy. The aim of the strategy is to enable family caregivers to provide the best care possible without sacrificing their own physical, mental, emotional, and financial well-being in the process.

Even though family caregiving includes a wide variety of activities and is provided by a cross-section of people representing all ages and backgrounds, the council identified five unifying characteristics of the experience of family caregiving that drive the need for a more holistic approach to supporting family caregivers:

1. First, there is a **significant personal relationship** (or connection) between family caregivers and the people who receive support. Some caregivers provide assistance out of a wellspring of love and concern, but personal feelings are not always the driving force. Other caregivers provide care in response to tradition, culture, family expectation, and other factors. Often some combination of these reasons shapes the experience of family caregivers.

2. Second, caregivers provide support so that family members and close friends can **maintain their independence, dignity, engagement, and/or quality of life.**
3. Third, they often **provide this support without a formal assessment** of the needs of the person receiving care or the caregiver's own needs. That means they may have to take on tasks they do not know how to do, or do not feel comfortable doing, and have little access to training or assistance. They learn on the job and "in the moment," which can make an already complex task both stressful and exhausting. On top of this, there is little recognition of the difficulty of their responsibilities.
4. Fourth, the nature of **family caregiving is becoming ever more complex** in the modern era as it extends to more medical, administrative, and care coordination activities than ever before. Whereas caregiving at one time might have meant helping with activities of daily living (ADLs), now it can include medication management, dealing with insurance payers, technical support for electronic equipment and medical devices, coordinating care across systems, and much more.
5. Lastly, because they often are overlooked and have few consistent supports, the experience of being a family caregiver, no matter how emotionally rewarding, can leave caregivers **financially, emotionally, and physically depleted and socially isolated.**

While family caregiving often takes place in the home or similar setting, it is important to note the responsibilities do not end when the person receiving support goes into a hospital, nursing home, or hospice. Many times, the family caregivers' responsibilities then shift from that of a direct support provider to those of an administrative or care and services coordinator role. In other situations, family caregivers might assist with the care provided in a nursing home or serve as a bridge between facility staff and the care recipient, helping to smooth the way for care to be provided or to build trust between their family member and staff. In these situations, the support needed by family caregivers might shift caregivers' responsibilities, which means that caregivers will need to learn new skills, sometimes on short notice. These family caregivers also need support.

As the population of older adults and people with disabilities grows and the need for supports and services to sustain their independence and well-being increases, government spending on long-term care will become unsustainable without the contributions of family caregivers. Timely action to strengthen the national infrastructure of policies, structures, and systems to ensure sustainability by supporting family caregivers today and in future decades, cannot be overstated. To do this in a meaningful way, however, recommendations must focus on areas that have the potential for greatest impact.

The first step in such an approach is understanding the needs of family caregivers. For that reason, the members of the council were appointed based on their professional expertise and personal experiences. Council members recognized that because the experience of caregiving is so varied, even their own perspectives are not enough to address the multiplicity of caregiver circumstances and needs across the nation, especially in today's rapidly changing environment.

As a result, to understand more fully the diverse experiences of family caregivers amid the dynamic nature of the current landscape, the council embarked on a multifaceted effort to solicit input from a broad range of experts and thought leaders. Efforts included reviewing the work of other caregiving-focused councils and task forces, convening focus groups, and conducting interviews, all of which were made possible thanks to generous support from The John A. Hartford Foundation. The council also gathered information about existing federal support for caregivers through the development of the Inventory of Federal Caregiver Support Programs and Initiatives (required under the RAISE Family Caregivers Act). They received briefings from a range of nationally recognized experts on key caregiving issues, and opened council meetings to participation by members of the public via live chat after social distancing mandates necessitated a shift to online meetings starting in March 2020.

The most significant information-gathering effort of the council was the release in late 2019 of a formal request for information (RFI) through the Federal Register. The RFI yielded more than 1,600 responses from caregivers of every age and walk of life. Some of these responses were deeply moving testimonials detailing the joys and heartache of providing support to others while trying to navigate complex health care and social service systems, raise children, maintain employment, and find time for self-care. Other responses came from professional and advocacy organizations providing nuanced insight into such topics as nutrition, education, mental health, and how the challenges faced by the paid caregiving workforce, or direct support professionals, overlap with the needs of unpaid family caregivers. More than 30 quotations from the RFI responses are included throughout this report.

The RFI results were interpreted and analyzed by researchers at the University of Massachusetts. The resulting report, [In Their Own Words-Caregiver Priorities and Recommendations: Results from a Request for Information](#) by Pamela Nadash, Ph.D.; Taylor Jansen, M.S.; Eileen J. Tell, M.P.H.; and Marc Cohen, Ph.D., provides quantitative and qualitative analysis and discussion of the trends identified in the RFI. To address the broad mandate of the RAISE Family Caregivers Act, the council also commissioned two other subject-specific reports to explore the interaction between the Medicaid and Medicare programs and family caregiving. The reports include:

- [Medicaid Supports for Family Caregivers](#) by Neva Kaye and Salom Teshale, Ph.D.
- Issue Brief: [Medicare and Family Caregivers](#) by Judith A. Stein, Executive Director, and David A. Lipschutz, Associate Director, of the Center for Medicare Advocacy.

These three documents were developed with funding from The John A. Hartford Foundation and assistance from the National Academy for State Health Policy (NASHP). They were published independently of this report in 2020 and 2021 to assist the council in its deliberations. They do not necessarily reflect the views of ACL or HHS.

The council used the findings of its information-gathering efforts to develop the recommendations presented in this report. The recommendations include:

- [Five recommendations](#) that address the need for **increased awareness of family caregiving**.
- [Five recommendations](#) for increased emphasis on **integrating the caregiver into processes and systems** from which they have been traditionally excluded.
- [Nine recommendations](#) for increasing access to **services and supports to assist family caregivers**.
- [Four recommendations](#) to increase financial and workplace protections for caregivers.
- [Three recommendations](#) to drive better and more consistent **research and data collection** to assist in the development and dissemination of systemic policies and interventions that can help family caregivers in meaningful ways.

Each of the 26 recommendations is supported by a 100-250 word rationale statement that explains why the council believes the recommendation, if implemented widely, can positively impact family caregivers. These statements were developed by members of the council during a series of sub-committee meetings. The council agreed that the recommendations should be further illustrated with the voices and stories of real caregivers. The [National Alliance for Caregiving](#) (NAC) identified and interviewed 26 diverse caregivers representing a range of caregiving situations and needs. Their voices are featured throughout this report as a series of section dividers that personalize and underscore the recommendations, while emphasizing the need for action. Most stories include a hyperlink to a video of the actual caregiver interview.

The recommendations are the first step to developing a national strategy that will drive increased recognition and support for family caregivers. The recommendations will provide the foundation of the strategy, which will also include details about specific actions and timelines for the advancement of the recommendations. The strategy will outline critical actions that can be taken at the federal and state levels, by local

communities, philanthropic organizations, and educational bodies, as well as health care and LTSS providers, and others to better support family caregivers in ways that reflect their diverse needs. The strategy will focus on areas such as person- and family-centered care; assessment and service planning; information, education, and training supports; respite options; and financial and workplace security issues. The strategy will also provide a roadmap for the nation to strengthen its support and recognition of the critical role family caregivers of all ages play in health care and long-term support systems.

As the nation considers how to address inequities in communities across the nation and rebuild the economy in the wake of a worldwide pandemic, the needs of family caregivers must be considered. The nation's millions of family caregivers give selflessly so others can live meaningful lives with dignity and independence. Their contributions to the well-being of others and the nation's economy can come at great personal cost to themselves, their families, their finances, and their health.

The release of this report is an initial and critical step in helping family caregivers move toward a better future. In this future, as they are integrated into existing systems and policies, family caregivers will have a culturally sensitive, flexible, and affordable system of supports that meet their needs and support them in meaningful ways. They will be recognized for their contributions and will recognize their own efforts as part of a formal activity. They will receive the assistance they need to perform their tasks, whether it is education, advice, or practical help. They will be included in key decisions, including policy decisions, about family caregiving. They will receive support, whether financial or practical, so they can choose to continue to be caregivers. And perhaps most importantly, as the true experts in family caregiving, they will be engaged in all efforts to assist other caregivers who are just starting out.

The council recognizes that achieving this ambitious vision will take time. The field of caregiving is so diverse that there are few simple solutions. The challenges to ensuring family caregivers are supported, so that they, in turn, can assist others are significant. Working with ACL and its partners, the council is committed to surmounting every obstacle and creating a better future for all caregivers of older adults and people of all ages with disabilities.

The nation's millions of family caregivers and the people they support and assist deserve nothing less.

Why Recognizing Family Caregivers is Critical

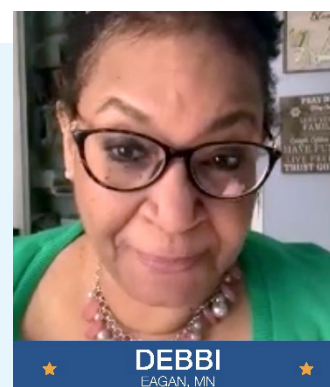
It is no accident that the first word of the RAISE Family Caregivers Act acronym is “recognize.” Across the nation, millions of parents, partners, spouses, adult and minor children, friends, and neighbors provide billions of dollars in unpaid assistance and support each year to individuals of all ages with chronic or other health conditions, disabilities, and functional limitations. Their tremendous sacrifices of time, energy, and financial support enable people receiving support to maintain their independence, dignity, and quality of life. Yet, until recently, family caregivers have gone largely *unrecognized* in the community, in social service and health care settings, and even within families.

To support the council, 26 caregivers from across the nation shared their personal stories with National Alliance for Caregiving (NAC). The recorded interviews are available [on the ACL YouTube channel](#). Throughout this report, they appear as brief sketches to highlight the diverse ways that caregivers support their family members, and how that support, in turn, shapes the life of the caregiver. The stories are a testament to the complex and demanding responsibilities that caregivers take on, often with no training and little formal recognition or acknowledgement.

Too often, the public—and even professionals—do not fully understand the role families play in helping people with disabilities maximize independence. They underestimate its complexity, the time and energy required, and the benefits of support. [Debbi, who lives in Minnesota](#), is an example of a caregiver who has learned “on the job” how to advocate for her son while also educating providers about her role as a caregiver. Her efforts underscore how increased understanding and decreased bias can pave the way for a more holistic approach to connecting caregivers and people with disabilities with the services and supports they need. For more, refer to [Recommendation 1.1](#) and [Recommendation 3.4](#).

When Debbi’s son was born premature and bleeding in his brain, the doctors gave him two weeks to live. Debbi has now been caring for him, along with the rest of her family, for 27 years.

Debbi is not a stranger to hardship. Her husband was a career Marine and was often gone when their children were young. Her family has experienced racial prejudice and harassment because of her son’s disability, resulting in neighbors turning the sprinklers on her son’s nurses or calling the police to get their cars ticketed. A past employer discriminated against her and spoke openly to colleagues stating that the time she needed to take off for family medical leave was problematic. She had frequently encountered doctors who judged her based on certain biases and dismissed her concerns.

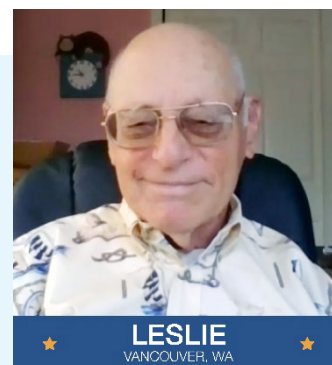


Her son required 24/7 nursing, and it was difficult to find ethical and trained nurses. Sometimes he was harmed through negligence, causing more acute hospitalizations. Debbi has had to fight constantly to get insurance to cover his needs and keep him stable. Once, while he was in brain surgery, Debbi had to stand in the parent surgery waiting room and call an attorney because insurance would not cover the cost of the procedure he was receiving at that very moment.

Before her son was born, Debbi had experienced some serious health problems with her other children, which turned out to be a blessing in disguise. When her oldest child was sick, Debbi found an extremely supportive pediatrician/physician team. These doctors stuck with Debbi for a long time and took on her younger son’s case when he was born. They got her the training and resources she needed to be a caregiver, and they taught her to be an advocate.

Family caregivers are often critical to ensuring that people who need assistance receive high quality care. However, for this to happen, it is important for providers to assess the caregiver’s needs, their concerns, and their comfort level with specific tasks. [Les lives in Washington State](#). His story illustrates the value of culturally sensitive assessments to determine which services and supports will best enable people to balance the responsibilities of caregiving with addressing their own needs. For more, refer to [Recommendation 2.2](#).

Now in their 80s, Les and his wife have been together since they were 16 years old. In 2014, his wife began having cognitive impairments and, through several tests, it was determined that she had Alzheimer’s disease. Her diagnosis was caught early. Over time, as her cognitive function declined and she began forgetting how to make coffee and needing some help with grooming and dressing, Les felt he couldn’t leave her at home alone anymore, he realized he was becoming a 24-hour-a-day caregiver.



He and his wife ran into an issue Les says he has heard about from countless caregivers: independence versus safety. Les felt the need to protect his wife while she wanted to maintain her independence; these competing priorities continue to be a struggle.

Les feels cognitive assessments should be a routine part of visits of older patients to physicians, and physicians need to learn the correct questions to ask caregivers about the person for whom they are caring. Les and his wife have a fantastic support system in their community, from a local caregiver support group for those with cognitive impairments, to neighbors and congregation members who spend time with her going on walks, doing puzzles, and bringing them wonderful meals. It was through this network that Les has been able to learn about problems he may face as a caregiver and how to deal with them. By a friend’s recommendation, he found a trained companion for his wife, whom she gets along with, providing care for Julie while allowing him respite and time to run errands.

Helping families maintain their financial health is a core element of maintaining the caregivers' well-being and is critical to meeting the overall goals of the person receiving support. As a caregiver who left her career at a young age, [Jennifer M., who lives in Florida](#), is an example of a caregiver at greater risk of impoverishment later in life. Her story demonstrates how, without early identification and assistance, family caregivers can easily spend down their own resources, leaving them at significant financial risk later in their own lives. For more, refer to [Recommendation 1.3](#) and [Recommendation 4.4](#).

Jennifer M. is a caregiver for her younger brother, who was wounded in Iraq in 2005, and her mother, who suffered a stroke in 2007. Jennifer feels that early intervention for caregivers is important because it can help alleviate some of the negative impacts, both physical and mental, of caregiving. The longer anxiety and stress build unchecked, the greater the negative long-lasting physical impacts. Jennifer M. feels health care providers should create care plans for caregivers, not just for care receivers. Learning the importance of self-care at the beginning of someone's caregiving journey will enhance their overall resiliency and longevity.



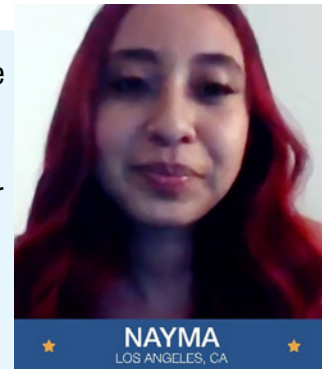
Jennifer M. left her career at a young age. During that time, she couldn't save for retirement or contribute to Social Security and, because she is not the spouse of the people she supports, she didn't have health care benefits. Jennifer would have benefited from early access to financial and legal planning tools. Jennifer M. believes people aren't saving to become a caregiver, so when they do, they are making great financial sacrifices. Personally, her caregiving journey has cost her over \$750,000 from medical, travel, respite, and childcare expenses, as well as a lack of income.

As a participant in VA's Program of Comprehensive Assistance for Family Caregivers, Jennifer M. received a stipend, access to mental health care, and respite care. These resources were valuable to her; however, she wishes the respite care was provided directly from the VA, and not a third-party vendor that added to the complexity of receiving the benefit. Additionally, the respite care providers often weren't familiar with military conditions resulting from war, such as traumatic brain injuries which occurred during bombings. This required Jennifer's brother to re-tell his story over and over, which could be emotionally draining. She feels most respite care providers are prepared to care for older patients, not someone younger like her brother.

Jennifer would like policymakers to understand that every caregiver and person receiving support is unique; solutions and services don't work the same in every situation. We need programs that offer one-on-one social support to identify and provide what a caregiver needs and support them in learning how to ask for and accept help.

[Caregiving youth, like Nayma](#), often put their own lives on hold to support family members, but they frequently go unrecognized. As a sibling caregiver, she often misses time at work to perform caregiving tasks for both of her siblings and to support her parents. The adoption of policies that increase federal, state, and local recognition of caregivers, including sibling caregivers, and that offer flexible employee-centered workplace policies and practices that support work/life balance are just two examples of supports that can assist younger caregivers. For more, refer to [Recommendation 1.4](#) and [Recommendation 4.2](#).

While Nayma’s siblings live with their parents, Nayma is the backbone of her siblings’ care team. Their parents came to the United States from Mexico as adults and have faced difficulties overcoming the language barrier. Nayma’s past, present, and future are shaped by her role as a caregiver, yet her contribution is often discounted.



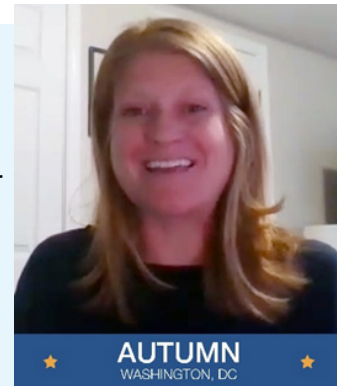
Her brother was diagnosed with autism spectrum disorder (ASD) when he was three years old. He couldn’t speak until he was six years old. Before then, Nayma was the only person in the family who could understand what he was trying to convey. Nayma’s brother is now twenty-four years old and has significant support needs to maintain his quality of life. He has depression and takes medication, which is a dynamic Nayma struggles to navigate. Her sister is fourteen years old and was only recently diagnosed with ASD. Her trouble with social skills, such as keeping appropriate distance from others around her, has made it difficult for Nayma’s sister to make friends. Her sister relies on Nayma to help her handle the challenges of being a teenager while also living with an intellectual disability.

As a millennial, Nayma recently entered the workforce. However, Nayma’s part-time job didn’t qualify her for paid sick leave or paid family and medical leave benefits to support her caregiving responsibilities. Nayma’s caregiving situation became even more difficult when her mother became sick and had to be hospitalized and put on bed rest, preventing her from being able to work. Like Nayma, Nayma’s father didn’t have any paid leave benefits available to him and was expected to continue to go into work in order to bring home a paycheck to help support his family. Nayma has no other family in the United States to help support her parents and siblings. Ultimately, a tremendous amount of responsibility has fallen on Nayma’s shoulders.

Nayma walks a fine line as she is expected to be a sister, a daughter, a caregiver, and the family communicator. She agonizes over what is going to happen when her parents are gone—Nayma knows she will be her siblings’ caregiver for life.

[Young adult caregivers, like Autumn](#), are often overlooked by medical providers. Often, caregiving education materials and supports do not apply to their age demographic and needs. Autumn’s story highlights the value of adopting policies that include family caregivers of all ages in the care team, and increasing access to culturally appropriate services and supports. For more, refer to [Recommendation 2.1](#) and [Recommendation 3.1](#).

Autumn was 32 when her mother was diagnosed with a progressive neurodegenerative disease. As the only child of a single mother, Autumn knew she would be her mother’s caregiver one day, but neither she nor her mother expected that day to be when her mother was only 59. As her mother’s condition worsened, she moved her into Autumn’s studio apartment. Eventually, Autumn moved them both into an apartment that could better accommodate their needs.



Autumn was able to get her mother approved for Adult Day Care Center Services provided by the Department on Aging in Washington, D.C. These services were essential in allowing her to keep her mother at home while Autumn continued working full time. She was able to drop her mother off three times a week at the adult day care center. Autumn paid for an in-home aide for the other two days of the week. Autumn feels that these services saved her sanity, but she admits her stress continued to increase exponentially as her mother needed increasing levels of care. She often felt she was on a hamster wheel, as she constantly needed to reassess and ramp up services as her mother’s condition continued to decline. She recalls countless sleepless nights, tears, and constant grief over slowly losing her mother, all while continuing to try to provide the best care possible. Additionally, the financial strain continued to grow, and she ultimately had to take out medical loans, which she is still paying off four years after her mother’s passing.

Autumn wants our society to recognize and normalize the experience of younger caregivers. She wants policy leaders to recognize the need for more funding in the Aging Network to cover home based community services for the pre-Medicare and non-Medicaid population. She wants legislators to increase awareness of the challenges of caregivers and raise the country’s commitment to caregivers. Autumn says caregivers need to have access to support and those services need to be available in a timely manner – not weeks, months, or years.

I. Background & Introduction

“As we know, there is a shortage of caregivers of all kinds and the modern family structure does not have a homemaker to take on that role. We need to stop looking at caregiving as a family role only and recognize the appropriate intervention that will address the problem.”

-Response to the ACL RFI

Every day, in all communities across the nation, millions of family members and friends set aside their immediate and long-term needs to support parents, grandparents, spouses, partners, siblings, children and adults with disabilities, and others who require their assistance to maintain independence, health, and quality of life (AARP and National Alliance for Caregiving, 2020). These family caregivers provide uncompensated assistance each year to others with everything from household chores to providing assistance with activities of daily living (ADLs), such as eating, bathing, and dressing; instrumental activities of daily living (IADLs), such as shopping, managing finances or handling transportation; or medical/nursing tasks, such as managing medicines, wound care, or preparing special diets (Reinhard, Feinberg, Houser, Choula, & Evans, 2019). They also supervise paid workers, coordinate services, and advocate for the people they support.

The exact figures vary depending on the research source and methodology. This disparity reflects the fact that family caregiving has many manifestations and definitions. It is so deeply entwined with daily life that it is notoriously difficult to count and measure. Some people are not even aware that their efforts on behalf of others count as “caregiving.” Nonetheless, researchers estimate, based on 2017 survey data, that at least **26.4 million people** serve as family caregivers each week (Freedman & Wolff, 2020). That number rises to **53 million people** (1 in 5 Americans) when researchers seek information about caregiving over the past year (AARP and National Alliance for Caregiving, 2020). Almost 40% of these people identify as racial and/or ethnic minorities (AARP and National Alliance for Caregiving, 2020). Other researchers have used the Department of Labor’s American Time Use Survey to estimate that caregivers provide **30 billion hours of uncompensated care each year** (Chari, Engberg, Ray, & Mehrotra, 2015).

These figures do not include the populations of caregivers that are often missed in prevalence research. For example, according to the [American Community Survey \(ACS\)](#), **2.3 million grandparents** are responsible for the basic needs of one or more grandchildren under age 18 living with them (United States Census Bureau, 2019). Meanwhile, approximately **3.4 million child caregivers** under age 18 are serving as secondary caregivers for an adult. Information on the number of children who are primary caregivers to other children or their parents or grandparents is incomplete, but

it could be as many as **5.4 million children** (AARP and National Alliance for Caregiving, 2020).

There is a growing recognition in the U.S. of the need to [support the paid caregiving workforce](#)—the direct support professionals, many of whom are women of color who provide long-term services and supports through Medicaid or private agencies. Closely linked to this is the need to also recognize, assist, include, support, and engage family caregivers. Just like professional caregivers, they are part of the engine that drives this nation—just as roads, bridges, and information technology infrastructure connect people to work and school, so too do caregivers, both paid and unpaid, connect people who need support to lives of independence and meaning.

Family caregivers support a broad range of people and needs across a range of settings. They play an integral part in helping older adults maintain quality of life and independence. They support children and adults with physical, sensory, cognitive, intellectual, developmental, and psychiatric disabilities in maintaining their dignity and autonomy as they navigate social structures that can limit opportunities for full community inclusion. They support injured veterans returning from new wars and those who bear the physical and mental scars of decades-old battles.

The vast majority of caregivers take on their responsibilities at short notice and with no training, and provide their assistance with little public acknowledgement. They work relentlessly, sometimes for years without breaks of any kind. In so doing, they may neglect their own health, putting them at higher risk for a range of conditions, including heart disease, diabetes, anxiety, and depression.

Because their efforts are often intensely time consuming, some sacrifice their financial security by reducing work hours or leaving the work force entirely. This increases the likelihood—especially among women—of living in poverty as their age advances. These challenges increase for people in underserved populations who are already at significant risk of health disparities, such as communities of color, rural, and frontier communities, and LGBTQ+ populations (American Psychological Association, 2011). Caregivers who live with disabilities experience all of these factors in addition to the challenges associated with living with a disability.

There are multiple names for these individuals: the most common is “family caregiver,” with the word “family” used to underscore the emotional connection between the two parties and to remind us that these caregivers differ from those who provide care to others in the course of their employment. At the same time, some disability advocates may use the terms “care partner” to emphasize the equal standing between the person with a disability and the person helping to facilitate their independence and autonomy. Among some families, depending on cultural background, the word “caregiver” is never

even used. In many cultures, assisting older adults and people with disabilities is seen as “just what family does” – regardless of the complexity, stress, or financial cost.

No matter what we call them, these millions of people who support others share common life experiences. First, there is a significant personal relationship or connection between caregivers and the people receiving support. Some caregivers provide assistance out of a wellspring of love and concern. Others provide care due to cultural traditions or family expectations. Often, some combination of these factors shapes the experience of family caregivers. Second, they provide support so that family members and close friends can maintain their independence, dignity, engagement, and quality of life. They often provide this support without a formal assessment of their needs, with little training, no assistance, and little recognition. As a result, their contributions to the well-being of others come at significant cost to their own physical, mental, emotional, and financial well-being.

Against a backdrop of increasing prevalence of family caregiving, the nature of family caregiving is becoming ever more complex as it extends to more medical and administrative tasks and care coordination activities than ever before. Finally, because they often are overlooked and have few consistent supports, the experience of being a family caregiver, no matter how emotionally rewarding, can leave caregivers financially, emotionally, and physically depleted and socially isolated.

How this Report Defines “Family,” “Family Caregiver,” and “Person Receiving Support”

In this report and throughout the council’s work, the word “family” is used broadly to denote those with biological or legal connections and families of choice. It also acknowledges the fact that “family caregiver” is not the same as “next of kin.” The person receiving support has the right to decide and designate who their preferred family caregiver is—it should never be decided by social services or medical professionals.

Because every family is unique, this makes it difficult to definitively define “family caregiving.” The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 defines the term “family caregiver” as:

“An adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation” (RAISE Family Caregivers Act of 2017, 2018).

In this report and the ensuing work of the RAISE Family Caregiving Advisory Council (the council) the term “family caregiver” is expanded to its broadest and most inclusive sense to encompass:

“All unpaid individuals of all ages who are caring for individuals with disabilities, chronic or other health conditions, and/or functional limitations.”

This term includes family members, partners, friends, kinship and grandfamily caregivers, and the untold millions of youth across the nation who care for family members, regardless of the type of assistance needed. It includes part-time caregivers and full-time caregivers. While it is used as a singular noun in this report, the council also recognizes that in some families multiple individuals serve in this role. It is important to note that some federal programs define “family caregiver” in statute. The statute definition may not be the same as the definition used in this report.

Terms also vary for the people receiving support. In many cases, they are referred to as “family members.” This is especially true in the disability community. The council determined that to differentiate between family members providing support and those who are receiving support, the term “**person receiving support**” would be used.

The New Landscape of Family Caregiving

In previous generations, women who were not in the labor force—typically daughters or daughters-in-law—provided caregiving to children, people with disabilities, or adults with functional or cognitive support needs associated with aging (Wolff & Kasper, 2006). Even though many of these caregivers took on tasks associated with nursing (e.g., wound care and administering medicines), there was a perception that caregiving mostly involved helping with activities of daily living—bathing, toileting, dressing, and eating.

“Most all of the images of caregivers show a late middle aged adult caring for an elderly adult. The image of the disabled adult child being cared for by the parent are more rare (sic). And, rarer still, the image of the older adult caring for the younger adult child with mental health diagnosis.”

-Response to the ACL RFI

Today we recognize that family caregivers do so much more. They perform a wide variety of time-consuming tasks from interacting with medical and service providers, to making appointments, to navigating an increasingly complex landscape of insurance and health care coverage requirements. Fifty-eight percent of family caregivers help manage the finances of the person receiving support, and more than half serve as an advocate either at the clinical level or with community services and government

agencies (AARP and National Alliance for Caregiving, 2020). In addition, they are increasingly providing ever-more complex health and medical care at home (including pain management), navigating complicated and fragmented health care and systems of long-term services and supports (LTSS), and serving as surrogate decision makers (National Academies of Sciences, Engineering, and Medicine, 2016). The majority of caregivers—especially those who are low-wage workers—do all of this without adequate paid leave or job protections, forcing them to choose between supporting others and earning a paycheck (Mudrazija & Johnson, 2020).

While there are commonalities across caregiving, it is important to consider that caregivers and the individuals they support are not a homogenous group. No two caregivers are the same, just as no two people who receive support are the same. As a result, the strategies to support caregivers have to be informed first by supporting the caregiver as a unique person.

More People Than Ever Before Need Caregivers

The need for family caregivers rises every day. By 2040, there will be more than 80.8 million people over the age of 65, more than twice as many as there were in 2000 (Administration for Community Living, 2021). As people are living longer, they are more likely to acquire multiple chronic conditions. For example, while there are currently an estimated 5 million people (1.6% of the U.S. population) living with Alzheimer’s disease and related dementias (ADRD) in the United States, the prevalence is expected to more than double (to 3.3% or 13.9 million people) by 2060 (Matthews, et al., 2019). Caring for a person with Alzheimer’s or a related dementia can be particularly intensive. In 2020, caregivers of people with dementia provided an average of 1,369 hours of care per caregiver per year, with more than half of those caregiving providing care for more than four years (Alzheimer’s Association, 2021). As a result, more family caregivers than ever before will be needed to help these individuals maintain their health, well-being, and quality of life (United States Census Bureau, 2018).

Meanwhile, the populations of people of all ages with disabilities and functional limitations is also growing. According to the 2018 ACS, 40.6 million Americans (12.6% of the population of children and adults) currently have a disability or impairment (United States Census Bureau, 2018). The vast majority of individuals needing assistance with things like transportation, case management, homemaker services, and nursing care, rely on unpaid support from family and friends first. In some cases, this support is supplemented by Medicaid-funded LTSS for those who are eligible. Of the approximately 10.9 million individuals with LTSS needs living in the community and 1.8 million nursing home residents, 92% receive assistance from family caregivers, and only 13% receive any form of paid assistance (Kaye, Harrington, & LaPlante, 2010).

Currently, there is little national data about the prevalence and needs of people with intellectual and developmental disabilities (IDD). According to the [Wingspread Report](#), there are more than 4.7 million individuals who have IDD in the U.S. “More than 75 percent of these citizens live in their communities without formal disability services and rely on their families for varying levels of support” (Hecht, Reynolds, Agosta, McGinley, & Moseley, 2011). In fact, the most recent report of [Residential Information Systems Project](#) found that only 17% of individuals with IDD receive formal services from the IDD service system, and 60% of individuals receiving services live at home with family (Larson, et al., 2020). In 2019, 60% of family caregivers of people with IDD are themselves over the age of 60 (Administration for Community Living, 2021).

The population of people with IDD is expected to grow as adults with IDD are living longer at the same time that diagnosis rates among children are increasing (Auerbach, Perry, & Chafouleas, 2019). Many of these individuals will require assistance from friends and family for their entire lives (Hecht, Reynolds, Agosta, McGinley, & Moseley, 2011). A growing number of adults with IDD live at home with aging caregivers. Approximately 24% of adults with IDD living at home reside with family caregivers age 60 years and older. Another 35% reside with caregivers between the ages of 41 to 59 years (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). Those family caregivers will need additional assistance and supports if they are to continue caregiving successfully over time.

“At present, family caregivers of older adults with lifelong disabilities (Down syndrome, autism, cerebral palsy, intellectual disabilities, etc.) face a daunting obstacle: time. They are aging beyond their capacity to care for their aging children.”

-Response to the ACL RFI

In recent decades, world events have also contributed to the increased need for family caregivers. Since 2001, the number of veterans with disabilities has increased significantly. In 2019 there were an estimated 4.7 million veterans with a service-connected disability (United States Bureau of Labor Statistics, 2020). The post-9/11 generation of injured veterans, those who served after September 2001, typically have complex care needs. Fifteen percent of post-9/11 veterans have paralysis or spinal cord injury compared to 6.3% of veterans of other generations and 6.8% of the general population. Veterans receiving support are also more likely than members of the general population to have a disability that impairs physical movement, post-traumatic stress disorder, major depressive disorder, substance abuse disorder, and traumatic brain injury (Ramchand, et al., 2014). Because post-9/11 veterans are often younger than other people receiving support, they will require caregiving assistance from parents, siblings, spouses, and children for decades into the future (Ramchand, et al., 2014).

In addition, as noted, millions of grandparents and extended families across the nation step up each year to care for children who cannot remain with their parents due to factors such as substance use, incarceration, death, and financial instability. A significant portion of those children have been exposed to trauma. As a result, they often need a combination of education, counseling, health care, and other services and supports in order to learn and develop. Their kin and grandparent caregivers also require support, assistance, and counseling. Many of the grandparents raising these children have disabilities, and as they age, their own need for caregiving will increase (Generations United, 2018).

Finally, as the effects of the COVID-19 pandemic continue, more people than ever before are finding themselves becoming family caregivers with little preparation, training, or support. This is due to a number of factors including the absence of in-person educational options, social isolation, reluctance to enter or remain in congregate care, and the still unknown complications related to post-COVID-19 conditions and chronic COVID-19. As with other factors related to the pandemic, the effect on women, particularly women of color, has been profound. According to the U.S Bureau of Labor Statistics, women accounted for the majority of people leaving the labor force in September of 2020 (United States Bureau of Labor Statistics, 2021).

Compound and Multiple Caregiving

It is important to note that not all caregivers support just one individual. Twenty-four percent of caregivers provide care to more than one person at a time (AARP and National Alliance for Caregiving, 2020). This is referred to as “compound caregiving” and is often seen with “sandwich generation” caregivers (the estimated 47% of middle aged adults who are caring for children and aging parents at the same time) and caregivers of people with IDD who also take on caregiving responsibilities for a partner, parent, or other child (Taylor, Parker, Patten, & Motel, 2013).

While most caregiving discussions focus on one primary caregiver, in reality, many families have multiple caregivers who collaborate to create a caregiving safety net that ensures the individual has the support he or she needs to remain independent for as long as possible. This can include a combination of family caregiving from multiple individuals plus assistance from direct support professionals and, in some circumstances, help from volunteers (for example volunteer respite care). This “multiple caregiving” model is particularly associated with intensive caregiving situations, such as dementia care. People with dementia living in the community are more likely than other older adults to rely on multiple unpaid caregivers (often family members); a third of older adults with dementia rely on three or more unpaid caregivers (Alzheimer’s Association, 2021).

Out of the Shadows

Because family caregiving typically takes place away from the public arena—within the heart of the personal home (i.e., bedrooms, bathrooms, kitchens), and during treasured family experiences like vacations, parties, and weddings, or during critical health care experiences when the family caregiver is the sole care provider in a clinic waiting room, emergency department, or hospital room—the needs of family caregivers are often not recognized (National Academies of Sciences, Engineering, and Medicine, 2016). Family caregiving in America has traditionally existed off-stage, away from the spotlight.

“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

-Carol Zernial, M.A., caregiver & Family Caregiving Advisory Council member

A consequence of this is that some people who support family members do not see themselves as caregivers. This is especially prevalent in ethnically and culturally diverse communities where people are more likely to identify as a family member “doing what families do.” A lack of awareness of caregiving can make it difficult for agencies that provide services to family caregivers to find and reach those individuals. It also means that people do not seek out services that could assist them. This situation may hamper data collection and measurement efforts. For example, if the number of caregivers is unknown, it is impossible for providers to assess their needs and for economists to measure the economic value of their contributions to society.

This challenge is further compounded by the fact there are few depictions of family caregiving in popular print and media culture. All too often, news media limits coverage to stand-alone awareness-raising stories driven by advocacy organizations (e.g., National Family Caregivers Month, which takes place during November). Despite the fact that family caregiving is a significant public health issue, caregiver voices are not always part of public discourse; they are sometimes ignored by health care providers and their contributions can be overlooked or discounted by policy makers (National Academies of Sciences, Engineering, and Medicine, 2016).

The current national conversation on care and caregiving as part of the national infrastructure—with input from key stakeholder organizations (including faith-based communities) and the media, with similar messages and themes—is a good starting point for increased public awareness about the forthcoming National Family Caregiving Strategy. But there is a long way to go. Caregivers often describe the work of caregiving as, while personally fulfilling, an exhausting and isolating task. Some even lack awareness of the limited supports and resources available to assist them. That is unfortunate because without support, the caregiving role often takes a significant toll and can lead to increased levels of stress, depression, physical and mental health impact, isolation, family strain, and financial and legal challenges.

Whether advocating for special education services, navigating an increasingly complex and fragmented health care system, or providing complex medical care, family caregivers benefit when providers and systems solicit input about their needs and take action based on that information. Inclusion in person-centered planning, with the agreement of the care recipient, can ensure that the needs of both the caregiver and the person receiving support are understood and considered. Education, training, and support services have the potential to enable them to be more effective in their caregiving and potentially even reduce the cost of care for the person receiving support.

“Education is needed for all aspects of caregiving. We caregivers are expected to perform a greater and greater variety of medical procedures that we do not have the training or knowledge to perform.”

-Response to the ACL RFI

Reliable and current information from trusted sources on meeting the challenges their unique caregiver situations present can reduce burnout and stress. Access to affordable, quality, and flexible options for respite care that allows them time to look after their own well-being, can enable caregivers to be more confident and continue to provide care for longer. Financial and employment assistance, if needed, can help them balance the fiscal and time-based costs of caregiving with the other responsibilities and commitments in their lives (National Academies of Sciences, Engineering, and Medicine, 2016).

Recognizing and Supporting Family Caregiving is Vital

Families and family caregivers are the safety net for millions of Americans, yet they are often the least supported member of the network. Successful outcomes from family caregiving requires that caregivers are supported by training, financial assistance, greater inclusion in health care and social services systems, and opportunities to take a meaningful break.

These basic caregiving supports are more important today than ever. Just at a time when caregiving is becoming more complex, there are fewer people available to provide family care. Due to changes in family structures and the increasing prevalence of families where both adults participate in the workforce, the share of families with a potential stay-at-home caregiver—as was the case in previous generations—has sharply declined (Veghte, Bradley, Cohen, & Hartmann, 2019). That means a wider range of family members of all ages are now taking on caregiving responsibilities, and they must balance those duties with competing demands for their time and energy. In many families, multiple part-time caregivers are coordinating their efforts to support one person.

While families across the nation provide caregiving support to family members, the burden of caregiving disproportionately affects families of color. Most studies

indicate that Black and African American older adults are about twice as likely to have Alzheimer's or other dementias as older whites. Some studies indicate Hispanic older adults are about 1.5 times as likely to have Alzheimer's or other dementias as compared to older whites (Alzheimer's Association, 2021). These individuals will require caregiving support from family members, and as the disease progresses those caregiving responsibilities typically grow increasingly time intensive. "Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia" (Alzheimer's Association, 2021). As a result of their caregiving responsibilities, caregivers of people with Alzheimer's disease or other dementias who are employed are more likely than caregivers of other people to move from full-time to part-time work, take a leave of absence, lose their benefits, retire early, and/or "give up work entirely" (Alzheimer's Association, 2021).

These significant disparities highlight the necessity of culturally sensitive services and supports, including [caregiver assessments](#) that uncover the unique needs, preferences, and comfort level of each individual caregiver within the context of his or her family. Of particular note is the finding that caregivers of color, particularly African American and Hispanic caregivers, often report "feeling invisible" in medical settings. Even though they may be knowledgeable about their family member's history and symptoms, they frequently experience a "poor response or dismissal," when trying to communicate on behalf of a family member (Singleton, 2020).

Finally, the COVID-19 pandemic has focused a spotlight on the needs of family caregivers, the logistical complexities they face, and the prevalence of health disparities in underserved populations. According to the CDC, members of diverse populations are "at increased risk of getting sick, having more severe illness, and dying from COVID-19." They are also more likely to be negatively impacted by the "economic, social, and secondary health consequences of COVID-19 mitigation strategies such as social distancing" (Centers for Disease Control and Prevention, 2020). For example, to reduce the risk of infection, many health care providers responded in some ways that impacted individuals that rely on family caregivers. Limiting visitors within health care delivery settings and a shortage of adequate personal protective equipment also affected family caregivers in complex ways.

The pandemic has also underscored inequities in access to technology necessary to facilitate appointments. It has also increased caregiver burden and stress, most notably through the unrelenting nature of pandemic caregiving, potentially causing for some, and greater risk of burnout. Just as the availability of vaccines gave people a "dose of hope," so too does the council hope that the recommendations contained in this report and the development of the National Family Caregiver Strategy can provide the millions of family caregivers across the nation with a dose of hope that more support and recognition for family caregivers will be forthcoming.

“I would like to offer for any ‘decision maker’ to spend a day with me and my family and see what it truly takes to care for someone with significant impact of a disability. I think only then can we move forward with an actual picture of what we ... are up against.”

-Response to the ACL RFI

These combined forces are increasing the pressure on family caregivers in unprecedented ways. If left unaddressed, these pressures and the resulting effects—social isolation, burnout, financial impoverishment, ill-health—will negatively impact families for generations to come. Services and supports to assist caregivers must be equitably available so that all caregivers can maintain their physical, mental, and financial health while supporting and assisting others now and into the future.

Caregiving: A Force for Good

When caregiving is discussed publicly, it is often associated with terms such as “burden” and “caregiver stress.” While caregiving pressures are significant and caregivers need support, education, and assistance, caregiving can be an immensely enriching experience and one that connects individuals across generations.

In fact, several studies find that caregiving builds confidence and problem-solving skills and strengthens relationships. For example, a study of spouse caregivers found that the time caregivers spent helping their spouse predicted positive affect; the more time they helped, the happier they felt (Poulin, et al., 2010). Caregivers also value the assurance of knowing their family member is receiving the support he or she needs (National Academies of Sciences, Engineering, and Medicine, 2016). Additional advantages reported by caregivers include:

- Spending meaningful time with the person receiving support.
- Strengthening intergenerational bonds.
- Knowing that a family member is receiving more holistic care that family caregivers provide.
- Increased self-confidence that comes with surmounting complex challenges (Mudrazija & Johnson, 2020).
- Learning to become more compassionate and patient.

The presence of these positive experiences can mitigate some of the challenges faced by family caregivers, however it does not fully erase those challenges. As the National Academies Press noted, “these positive effects can co-exist with the negative impact of caregiving. Caregivers can simultaneously feel highly distressed and report that they derive benefit from the caregiving experience” (National Academies of Sciences, Engineering, and Medicine, 2016).

Day-to-Day Assistance to Millions

Family caregivers also benefit their fellow members of society. Millions of people are able to live more independently, with dignity and self-determination, while experiencing a better quality of life thanks to family caregivers. Examples include:

- **Older adults and people with intellectual and developmental disabilities (IDD) who are affected by early onset Alzheimer’s disease and related dementias** who require assistance with ADLs or IADLs. According to the Alzheimer’s Association, nearly half of all caregivers of older adults are supporting an individual with Alzheimer’s or another dementia (Alzheimer’s Association, 2021).
- **People of all ages living with chronic health conditions**—such as cancer, diabetes, and arthritis—who may need assistance navigating complex health care systems, managing symptoms and medication side effects, and maintaining quality of life.
- **Frail older adults** who may need assistance with bathing, toileting, dressing, and eating, or getting to doctor’s appointments and managing multiple medicines.
- **Adults and children with IDD** who may require practical assistance with ensuring that the individual’s basic needs and rights are respected and protected. They also assist with access to and coordination of the supports needed for health, well-being, independence, and opportunities for community inclusion, integrated employment, and self-determination whether the individual is living with them or in their own home (Hecht, Reynolds, Agosta, McGinley, & Moseley, 2011). Parents and other family members of individuals with IDD often provide medical, behavioral, financial, and other daily supports beyond what most families provide and they provide this assistance across the [LifeCourse](#).
- **Veterans with injuries or chronic conditions**, including traumatic brain injuries, limb loss, and mental health issues like post-traumatic stress disorder (PTSD), who may benefit from care provided by individuals versed in military culture and caring for the unique needs of our nation’s veterans.
- **Medically fragile children and adults** who need round-the-clock care from a team of family caregivers and skilled nursing professionals working in close concert.
- **Children in the full-time care of relatives** such as grandparents or close family friends who may need special education, behavioral health services, and help to thrive despite previous adverse childhood experiences.
- **People of all ages who reside in nursing homes, board and care, and assisted living facilities, and other residential care communities** who rely on family caregivers for assistance to maintain their health, safety, welfare, and well-being.

“The challenges and rewards of family caregiving are much more than any research study has ever captured. Families struggle, they look for help and support, they laugh, they cry. They do all of this for the family member that has the greatest need. Yet, the demands of work and the needs of other family members continue. Balancing all of the demands can be overwhelming.”

-Alan Stevens, Ph.D., family caregiver & Family Caregiving Advisory Council Co-chair

Society Benefits from Family Caregivers

Society as a whole benefits from the work of family caregivers. Numerous studies have noted that the formal services of the system are not designed to replace family caregivers. Yet they are an essential component of a continuum of care that is provided by family caregivers. In undertaking caregiving, unpaid friends and family members are essential in supporting individuals with ongoing and long-term health and assistance needs. The services provided by family caregivers cannot be separated from the services included within the nation’s LTSS system, based on eligibility.

The estimates of the value of caregiving vary depending on how the value of caregiver’s time is calculated (Mudrazija & Johnson, 2020). Family caregivers of adults with Alzheimer’s disease and related dementias provided an estimated \$257 billion of unpaid care in 2020 (Alzheimer’s Association, 2021). Researchers at AARP estimate that it would cost the nation \$470 billion to replace all of the care across the lifespan and all conditions provided by family caregivers (Reinhard, Feinberg, Houser, Choula, & Evans, 2019). Meanwhile, using different data sources (the [American Time Use Survey](#)), researchers estimate the economic value of caregiving just for older adults to be close to \$522 billion (Chari, Engberg, Ray, & Mehrotra, 2015). In addition, grandparents save the child welfare system billions of dollars each year by stepping up to become primary caregivers to their grandchildren instead of allowing them to be placed in the child welfare system (Generations United, 2018).

The availability of a family caregiver is also associated with fewer and shorter hospital stays and reduced home health care use for older adults. Several studies have found that the availability of caregivers delays nursing home entry (Kelly, Wolfe, Gibson, & Feinberg, 2013).

The Costs of Failing to Support Family Caregivers

Policies and interventions that support family caregivers also have the potential to benefit society over time. Because long-term care is expensive and not covered by Medicare, some people use Medicaid to fund their long-term care if they qualify. Enhancing caregiver supports and services that drive independence for older adults and people with disabilities is an important tool in managing federal long-term expenditures (National Academies of Sciences, Engineering, and Medicine, 2016). The costs of failing to address caregiver needs are expected to increase as the number of

people across the lifecourse who require assistance increases. This is particularly true in light of the growing population of older adults and the increasing need for caregivers to support people living with ADRD (Matthews, et al., 2019).

Supporting family caregivers through education, assistance, and flexible workplace policies can have long-term financial benefits for the nation. Despite the benefits that family caregivers bring, their efforts often come at significant personal and financial cost. Family caregivers also often have to choose between providing care to a person receiving support and remaining in the workforce, saving for the future, or addressing their own basic needs. Helping caregivers flourish in their roles allows them to provide care longer. This is important because the stress and physical demands of caregiving, especially intensive forms of caregiving, such as dementia care, have been shown to have an impact on physical health (National Academies of Sciences, Engineering, and Medicine, 2016). In fact, a 2017 study of spouse caregivers found that decreased caregiver well-being, especially fatigue, correlated with more emergency department visits and higher Medicare spending (Ankuda, et al., 2017).

“Many families quit their jobs to care for family members, and lose not only the difference in income, but also the pay into Social Security.”

-Response to the ACL RFI

The importance of taking action now to ensure policies and services are in place to assist the family caregivers of those individuals cannot be overstated. The President’s Build Back Better plan calls for opportunities to expand and train the direct care workforce to support these individuals—but paid care alone is not enough. Family caregivers will continue to need to assist and support others. Recently proposed changes to how the nation supports family caregivers have the potential, if passed, to create a national comprehensive paid family and medical leave program. This is an important piece in supporting family caregivers, but they will also need education and training, services and supports like counseling and respite care, and increased ongoing recognition by society.

Incremental Progress in Recognizing Family Caregivers

With the passage of the RAISE Family Caregivers Act, Congress took an important step in continuing more than four decades of legislative progress on behalf of family caregivers. In 1966, President Lyndon B. Johnson established what is now known as the President’s Committee for People with Intellectual Disabilities (PCPID). This committee advises the President on ways to improve the quality of life experienced by people with intellectual disabilities and their families. While the Great Society programs of the 1960s did not include provisions for caregivers, by 1975 Congress had amended the [Older Americans Act \(OAA\)](#) to include funding for adult day care services. While the statute did not directly refer to adult day care as respite care for caregivers,

it laid the groundwork to providing caregivers complimentary and supplementary care options addressing respite and financial needs.

In 1978, Congress clarified the use of adult day services as a form of family respite, placing it within a coordinated system of community long-term care services. This legislation was significant because it formally established investments in the well-being of the family caregiver as a means of supporting the person receiving support. Additional amendments in the 1980s further solidified recognition—supported by research—of the significant positive impact the well-being and ability of caregivers can have on people living with Alzheimer’s disease and related dementias. Expansions to Medicare and Medicaid in the 1980s continued the process of beginning to formally recognize the role of family caregivers. In 1981, family caregivers benefited indirectly from the addition of Medicaid’s home and community-based services (HCBS) programs. The following year, Congress added a hospice benefit to Medicare that specifically included respite care for caregivers.

In 1990, Congress passed the [Americans with Disabilities Act \(ADA\)](#), a comprehensive law prohibiting discrimination against people with disabilities. The ADA also prohibits discrimination against a caregiver based on “association with” an individual with a “disability” as defined by the ADA.

This increasing recognition of caregivers continued through the 1990s with the inclusion in the OAA of training, counseling, and information services for caregivers, in addition to in-home respite care and expansion of eligibility limits. The [1993 Family Caregiver Support Act \(S.1072\)](#), for example, sought to amend the Social Security Act to enable states to establish programs to support informal caregivers. Also in 1993, the [Federal Family and Medical Leave Act](#) established worker rights of up to 12 weeks of unpaid, job-protected leave to care for oneself or certain family members: child, spouse, or parent. During that time, a number of states rolled out caregiver initiatives offering such services as respite, information and resources, support groups, case management, and education and training programs.

In June 1999, a landmark Supreme Court decision in [Olmstead v. L.C., 527 U.S. 581](#) held that “unjustified segregation” of people with disabilities is against the law under the ADA. As a result, many states have expanded their HCBS systems as part of their larger efforts to achieve *Olmstead* compliance.

The establishment of the [National Family Caregiver Support Program](#) (NFCSP) in 2000 marked a significant expansion in support for family caregivers by formally recognizing family caregivers and providing a range of services to allow them to help their family members remain independent for as long as possible. These services include connecting caregivers to private and voluntary agencies that can assist them, counseling and training, and respite care options. Even more importantly, NFCSP

funding is provided to every state, territory, and tribe, requiring the establishment of a basic set of services and supports available to family caregivers.

That same year, the [Developmental Disabilities Assistance and Bill of Rights Act of 2000 \(DD Act\)](#) stipulated that the [56 State DD councils](#) include representation by people with disabilities and their caregivers, guardians, and/or parents paving the way for more family-centered community services, individualized supports, and other forms of assistance (Administration for Community Living, 2017).

In 2006, the Lifespan Respite Act expanded access to respite to people of all ages across the nation. It sought to increase availability of respite options for family caregivers of children and adults with physical, cognitive, and intellectual disabilities.

For further discussion on the NFCSP and the Lifespan Respite Program, refer to [Section III, Existing Federal Approaches to Assist Caregivers](#).

In 2010, the [Caregivers and Veterans Omnibus Health Services Act \(PL 111-163\)](#) directed the U.S. Department of Veterans Affairs to establish a Program of Comprehensive Assistance for Family Caregivers and a Program of General Caregiver Support Services, collectively referred to as VA's Caregiver Support Program, thus establishing caregiver support in the nation's largest integrated health system. The National Academies of Sciences, Engineering, and Medicine convened an expert committee in 2014 to examine what is known about the nation's family caregivers of older adults. The final report, *Families Caring for an Aging America*, found that while the need for family caregivers across the nation is growing, efforts to address that need proactively were modest at best. Accordingly, the report recommended that Congress convene a council to develop a National Family Caregiving Strategy (National Academies of Sciences, Engineering, and Medicine, 2016). That recommendation engendered the passage of the RAISE Family Caregivers Act of 2017.

Not all legislative activity on behalf of family caregivers has occurred at the federal level. Numerous states have begun enacting legislation to better recognize and support family caregivers. The [Caregiver Advise, Record, Enable \(CARE\) Act](#) to support caregivers when patients enter hospitals and to help caregivers understand what will be needed when patients are discharged. (Reinhard S. C., Young, Ryan, & Choula, March 2019). While provisions vary by state, since 2014, 44 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands have implemented CARE Act policies that require hospitals to advise people of their opportunity to identify a family caregiver (Reinhard, Young, Ryan, & Choula, March 2019).

The forthcoming National Family Caregiving Strategy builds on these previous efforts and the significant achievements from states and communities that have pioneered innovative caregiver support initiatives. When implemented, the strategy will chart a

course for the nation to better support family caregivers to address their needs. It will identify actions that communities, providers, government, and others can take to recognize and support the family caregivers who put their own lives on hold to assist a broad cross-section of Americans every day.

Since the formation of the council, additional legislation has been passed that advances recognition and inclusion of family caregivers. The [MISSION Act of 2018](#), expanded access to the VA's Program of Comprehensive Assistance for Family Caregivers to caregivers of eligible veterans of all eras, in a phased approach. Previously, only caregivers of eligible veterans who incurred or aggravated a serious injury on or after September 11, 2001 were eligible for this program. This expansion represented one of the largest federal investments to date in a comprehensive program to support caregivers.

“Unless we teach more families ‘how to fish’ we will bankrupt ourselves with burned out caregivers who go down before their care receiver, and/or need to prematurely place their frail loved one in a skilled nursing facility which depletes their funds at the speed of light, leaving taxpayers with an increased burden.”

-Response to the ACL RFI

The RAISE Family Caregivers Act

The [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act of 2017](#), Public Law 115-119, which was signed into law in January 2018, seeks to address this diverse and complex issue through the development of a National Family Caregiving Strategy. To achieve this vision, Congress directed the Secretary of HHS to:

- **Establish the council** of federal and non-federal representatives to provide recommendations and identify best practices to promote improvement of the federal, state, and community systems that support family caregivers. A key expectation of the RAISE Family Caregivers Act was that council deliberations and recommendations be informed by extensive public engagement.
- **Develop the National Family Caregiving Strategy** with detailed recommendations designed to recognize and support family caregivers, and deliver effective and efficient mission-aligned programs, supports, and services that place the person receiving support and the caregiver at the center of person- and family care delivery, as appropriate, in all care delivery settings, and assessment and service planning, including advance planning services and hospice- and palliative care. Additionally, the strategy will identify and integrate evidence-based or promising practices and innovative models undertaken nationally or internationally, including respite options, financial security and workplace issues, information, education and training supports, referral, and care coordination.

- The purpose of this initial report to Congress is to document the progress of the council since its inception in 2019 and to provide the council's initial recommendations for **recognizing, assisting, including, supporting, and engaging** the millions of family caregivers who provide support to others. As required by the RAISE Family Caregivers Act, this report includes:
 - ◆ The identification of challenges faced by family caregivers, including financial, health, and other challenges, and existing approaches to address such challenges.
 - ◆ An overview of federally funded efforts to address those challenges.
 - ◆ A discussion of how family caregiving impacts the Medicare program, the Medicaid program, and other federal programs.
 - ◆ Recommendations to improve and better coordinate federal programs and activities to recognize and support family caregivers. Also included are opportunities to improve the coordination of such federal programs and activities with state programs and to effectively deliver services based on the performance, mission, and purpose of a program while eliminating redundancies, avoiding unnecessary duplication and overlap, and ensuring the needs of family caregivers are met.

The public input requirement, intended to inform recommendations, involved efforts to collect, analyze, and synthesize input from stakeholders, including members of the public. Most notably, the council invited caregiving thought leaders to brief the council on a range of caregiving-related issues. In December 2019, ACL issued a formal request for information (RFI) from the public through the Federal Register and on the ACL website on family caregiver needs, challenges, and priorities.

To reach the broadest possible cohort of respondents, the RFI was also promoted on ACL's social media platforms and through its digital newsletter. More than 1,600 responses were submitted to the RFI. Researchers at the University of Massachusetts in Boston conducted a formal analysis of the responses. That analysis and the input received from guest speakers, along with the council's own expertise informed their deliberations along with the development of the recommendations outlined in this report. [Section II](#) offers an overview of an RFI analysis conducted by researchers at the University of Massachusetts in 2020.

Role of the Administration for Community Living (ACL)

In May 2019, the Secretary of HHS delegated authority for implementation of the RAISE Family Caregivers Act—and the related Supporting Grandparents Raising Grandchildren (SGRG) Act—to ACL. The work of the SGRG Advisory Council complements the efforts of the RAISE Council by focusing on the needs of

grandparents and other older relatives who are raising children. A 2020 amendment to the OAA formalized ACL's authority to implement both Acts.

Since 2000, ACL has administered the NFCSP. ACL also administers the Lifespan Respite Care Program, which funds community-based respite services for “family caregivers of children and adults of all ages with disabilities.”

Understanding and addressing the needs of caregivers is integral to the mission of ACL. The agency was created in 2012 around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. ACL's formation brought together AoA, the Office on Disability, and the Administration on Developmental Disabilities. Since its creation, ACL has continued to grow and assume new responsibilities each year. ACL funds services administered by the [Aging and Disability Networks](#), which include national, regional, state, and local organizations that support community living options for older adults and people with disabilities. ACL also advocates across the federal government for older adults, people with disabilities, and families and family caregivers; and invests in training, education, research, and innovation.

Public, Private Partnership

Recognizing the importance of developing a National Family Caregiving Strategy that included the voices of all stakeholders, The John A. Hartford Foundation (JAHF), collaborated with ACL starting in 2018 on implementation of the RAISE Family Caregivers Act to ensure consistent representation and sharing of resources across programs, states, and leading not-for-profits focused on caregiving. JAHF was a key driver of the landmark 2016 study, [Families Caring for an Aging America](#), which called for the development of a national caregiving strategy (National Academies of Sciences, Engineering, and Medicine, 2016).

JAHF awarded a three-year grant to NASHP to provide the council with resources and expertise in state and regional planning. The grant established NASHP's [RAISE Family Caregiver Resource and Dissemination Center](#) as a national focal point for resources, technical assistance, and policy analysis for states and the broader stakeholder caregiver community.

Since late 2019, the council, ACL, and NASHP have been actively gathering public comments and compiling research on best practices and supportive public policy so that the council has access to timely information on how federal, state, and local governments—together with non-profits—can do a better job of supporting family caregivers. Key NASHP activities include:

- Convening a faculty of nationally recognized experts and thought leaders from across the aging and disability continuum to provide consultation and insight from previous efforts to support caregivers.
- Synthesizing [key recommendations from 27 family caregiving reports](#)—covering aging and disability populations around the world—written in the past decade to create a tool for assisting the council in developing its own recommendations (Fox-Grage, 2020).
- Engaging [Community Catalyst](#), in conjunction with [The LeadingAge LTSS Center @UMass Boston](#), to analyze public responses to the RFI and conduct the listening sessions.
- Collaborating with the [National Alliance for Caregiving](#) to produce a series of caregiver stories from their national network of caregiving coalitions.

Establishing the Family Caregiving Advisory Council

Within the RAISE Family Caregivers Act, Congress stipulated that the council reflect the diversity of caregiving situations today. Accordingly, it called for non-voting members representing the federal departments and agencies that play a role in caregiver support or LTSS. The RAISE Family Caregivers Act also called for participation from members of the public who could represent each of the following caregiver constituencies:

- Accreditation bodies.
- Employers.
- Family caregivers.
- Health care and social service providers and providers of LTSS.
- Individuals with disabilities, veterans, and older adults who need LTSS.
- Paraprofessionals.
- State and local officials.

ACL published a call for nominations in the Federal Register in October 2018; 270 unique nominations were received, many of them from highly qualified individuals. In selecting the nominees, ACL weighed breadth of experience, qualifications, and geographic and regional distribution to ensure the council reflected the dynamic nature of the family caregiving landscape. Of the council members selected, many are—or have been—either caregivers, people receiving support, or both. A complete list of council members along with their biographies is available on the [Family Caregiving Advisory Council website](#).

Council Deliberations

In August 2019, the council convened in Washington, D.C. During the meeting—and subsequent in-person and virtual meetings—council members and guest speakers shared and discussed personal experiences, results, and strategies from advocacy efforts, and findings of national research and state-driven task forces. Throughout 2020, the council conducted substantive deliberations—moving to an online platform during the COVID-19 pandemic. Common among all discussions were the following themes:

- The importance of recognizing the **diversity of needs** among caregivers and people receiving support across the lifecourse.
- The need to support the **well-being of family caregivers** and the people receiving support.
- A shared vision for **integrating family caregivers** into—and empowering them within—the health care system.

The public participated in the virtual meetings through chat discussions. ACL staff reviewed the transcripts and comments submitted via the chat to ensure all perspectives, resources, and suggestions were considered for this report and the strategy.

“Life is complicated, and families are complicated; we need to be able to address the needs of all families and their complexities...”

-Melissa Gerald, Ph.D., program director at the National Institutes of Health (NIH)

Inherent in council discussions was a focus on balancing the perspectives and needs of caregivers of older adults with those of care partners and family members of people with disabilities. To ensure the council was working for a shared understanding of the diversity of caregiver needs and situations, NASHP provided technical assistance to the council by developing an [annotated bibliography of key family caregiver research](#) that included an overview of several of the major studies conducted in recent decades. This resource contributed to the work of the council by providing a nuanced portrait of how the nature of caregiving is shaped by age, geography, education, income, cultural background, and health of both the caregiver and the person receiving support. In addition to the resources provided in the annotated bibliography, the following reports informed the development of the council recommendations:

- [Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities](#)
- [Military Caregivers: Cornerstones of Support for our Nation’s Wounded, Ill and Injured Veterans](#)

- [Raising the Children of the Opioid Epidemic: Solutions and Supports for Grandfamilies](#)
- [NASHP Inventory of Key Family Caregiver Recommendations](#)

Over the course of its first full year of deliberations, the council received briefings from the following recognized experts in the field of family caregiving:

- Richard Schulz, Ph.D., director of the Center for Caregiving Research Education and Policy, University of Pittsburgh, spoke on the challenges of caring for an aging America.
- Grace Whiting, J.D., president and CEO of NAC, addressed national trends and issues, specifically those observed in four landmark statistical studies conducted by NAC.
- Tamar Heller, Ph.D., director of the Institute for Health Research and Policy at the University of Chicago, provided an overview on research findings related to the needs and experiences of caregivers of people with disabilities.
- Donna Benton, Ph.D., research associate professor of gerontology at the University of Southern California Leonard Davis School of Gerontology, shared insights and lessons learned from the California Task Force on Family Caregiving.
- Lynn Friss Feinberg, M.S.W., senior strategic policy advisor at the AARP Public Policy Institute, outlined the need for a comprehensive paid family leave for employees.
- Jill Kagan, director of the ARCH National Respite Network and Resource Center, provided a presentation on respite care and how it affects caregivers.
- Scott Beach, Ph.D., director of the Survey Research Program at Center for Social & Urban Research, University of Pittsburgh, and Joe Caldwell, Ph.D., director of the Community Living Policy Center at the Lurie Institute for Disability Policy, Brandeis University, gave a presentation on data and research specifically highlighting the major gaps and the enhancement needed to improve caregiver access to resources.
- Judith A. Stein, J.D., and David Lipschutz, J.D., executive director and associate director respectively, of the Center for Medicare Advocacy, presented an overview of a brief they developed for the council on [Medicare and Family Caregivers](#).
- Bea-Alise Rector, M.P.A, director of the Washington State Department of Social and Health Services Medicaid and State Programs provided an overview of state models for supporting caregivers of people eligible for Medicaid.

- Pamela Nadash, Ph.D., associate professor in the Department of Gerontology at the University of Massachusetts, and Eileen Tell, M.P.H, a researcher with The LeadingAge LTSS Center @UMass Boston, provided multiple briefings to the council including qualitative analysis of the findings of the RFI from the public about family caregiving and the findings of over a dozen caregiver focus groups.
- Helen Lamont, Ph.D., senior long-term care analyst in HHS' Office of Disability, Aging, and Long-Term Care Policy, led a discussion exploring ways the council could coordinate its recommendations with those of the [National Alzheimer's Project Act \(NAPA\) Advisory Council on Alzheimer's Research, Care, and Services](#)

Collectively, the broad efforts of the council and its partners have ensured the goals and recommendations proposed below were considered in the context of previous recommendations made by other task forces and committees considering the needs of family caregivers, and are based upon the fullest possible understanding of the experiences and needs of today's caregivers and their expanding role.

Family Caregivers Can't Do It Alone; They Need Assistance

The second word in the RAISE acronym is “assist.” This is important because one universal truth of family caregiving is that most caregivers need a hand. Multiple caregivers responding to the RFI called caregiving a “lonely” experience, in large part because caregiving is something each person learns to do on their own, typically on short notice and usually while juggling the rest of their lives at the same time. The stories of caregivers that follow illustrate how helping people navigate the world of caregiving—for example, applying for benefits, understanding eligibility for support programs, obtaining information about proven practices, supervising paid workers, and learning to advocate on behalf of themselves and their family member—can make a dramatic difference in their ability to provide the best support over time.

Help for caregivers—and by extension, the people they support—can come in many forms. It can include access to trusted websites, phone consultations and follow-ups, accompanying a family member on appointments to apply for services or benefits, help completing forms and paperwork and understanding eligibility requirements, and can be delivered by a range of people including case managers, options counselors, social workers, direct support professionals, and trained volunteers.

According to a recent analysis conducted by the Alzheimer's Association, 11.2 million caregivers in the U.S. are currently providing uncompensated care to family members. Sixty percent of those caregivers are women (Alzheimer's Association, 2021). Sheryl, who lives in New York, is like many of these dementia caregivers in that she rarely has time for a break. She often finds herself “on call 24/7.” Her story underscores the importance not only of providing relevant services, but also of conducting rigorous

research to develop evidence-based programs and services so that diverse caregivers, like Sheryl, have the freedom and flexibility to pursue outside interests. For more, refer to [Recommendation 5.2](#).

Sheryl’s husband has dementia and Parkinsonian symptoms. Sheryl does everything in the household from finances to house repairs and cooking, cleaning, and maintaining their way of life. Sheryl has found it hard to take over her husband’s duties as well as her own.



Two years ago, when her husband was officially diagnosed, Sheryl took over his finances and found unpaid bills and double subscriptions. When she attempts to change the name on their accounts over into her name, companies want to talk to her husband, which is not possible due to his condition. She must continuously fight to prove she is her husband’s proxy. She says she feels like a widow but without the authority becoming an actual widow provides. Like many individuals who come out as LGBTQ, Sheryl doesn’t feel safe revealing her sexual orientation. In her case, this includes to medical professionals, whom she worries will not take her or her concerns about her husband seriously in light of her sexual orientation. Carrying the weight of this worry, on top of caregiving, is incredibly stressful for her.

For Sheryl, caring for someone with dementia means you are on call 24/7, and it is beyond anything she said she had experienced as a mother. With a child, she could find breaks and alone time, but Sheryl doesn’t find this to be the case with her husband since she can never be sure he will stay safe. There are locks on everything in the house.

Although Sheryl has used respite before, she also finds it very stressful because someone else is coming into her space. She has provided years of free service and care to her husband and feels the least that can be done is to make services easier to access, such as removing the red tape needed to get Medicaid. Sheryl has been told to hire a lawyer to help her, but she neither has the money nor the energy to make that happen.

[Whitney, who lives in Maryland](#), experienced “high-intensity caregiving,” which is where the caregiver is providing many hours of care with little to no support. While she was able to maintain full-time employment while caregiving, she nonetheless struggled to meet her caregiving expenses. Because of her work, she did not qualify for caregiving support. Her story highlights just one of the many gaps in caregiver supports and services available for working families. It underscores the need for asset protection for all caregivers and the benefits of increasing the availability of counseling, training, and peer support to help them manage and navigate the financial instability associated with the caregiving experience. For more, refer to [Recommendation 3.3](#) and [Recommendation 4.3](#).

Caring for both her two-year-old and her husband, while maintaining full-time work as an attorney, was the hardest thing Whitney ever had to do, and she constantly battled with whether she was providing enough care and attention to each of them. Whitney cared for her husband, who was diagnosed with brain cancer, for more than forty hours a week due to a decline in cognitive function that he experienced preventing him from being left alone.



Whitney believes that having a medical professional stop by occasionally to help with medical tasks would have helped her immensely. Yet, Whitney neither qualified financially for any program that would provide this, nor did she have enough money to pay for it herself. As she was learning to navigate the confusing system of receiving her husband's financial benefits, she had to get her Congresswoman involved because the money wasn't coming, and the mortgage on her home needed to be paid. Later, when her husband spent 9 months in hospice, Whitney was able to borrow leave from coworkers so she could care for him, which made her feel supported and valued as an employee.

Whitney described her time as a caregiver as living in a bubble with a high amount of emotion, stress, and worry, where it was impossible to think straight. She would have benefitted from a connection to caregivers going through the same experience as her.

[Tom, a Minnesota caregiver](#), is one of the 39% of family caregivers who identify as male. His story is an example of how important it is that caregivers, service providers, and health care professionals have access to a robust body of trusted, standardized, and evidence-based information about caregiving and how best to support family members. Without this body of work, many family caregivers, like Tom, have to make decisions based off their own best guess of what they feel is best for the person receiving support. To address this issue, the nation needs a national infrastructure of standardized information and best practices about family caregiving. For more on establishing a national infrastructure with standardized data on caregiving, refer to [Recommendation 5.1](#).

Tom's wife started asking her doctors about her memory issues at age 52 but didn't receive the official diagnosis of early onset Alzheimer's disease until age 57. His wife's condition led Tom to ultimately leave his non-profit work and move him and his wife into Senior Housing. Five years later, as his wife's condition continued to get worse, Tom had to place her in a memory care group home. His wife struggled with what was happening to her. Her new reality was hard for her to accept. Three years after that, Tom had to move her again to a memory care environment that included nursing



care. She tested positive for COVID-19 and was placed in a COVID unit where 18 people died. Fortunately, she recovered but is now receiving hospice care. Tom’s caregiving efforts revolve around her end of life needs. He makes sure family members can see her via Zoom meetings, and he is arranging for her burial place and final services.

Tom found navigating the health care system very challenging and felt as if the providers and specialists weren’t communicating or collaborating with one another. He often made decisions based off his own best guess – not with any real guidance from any provider. He feels he was successful in receiving services only because he was so persistent and applied for services more than once. Tom thinks it’s important for caregivers to connect with someone, such as a care manager, who knows the system and can help navigate all the different agencies and departments.

After his wife’s diagnosis, Tom and his wife reached out to their community and were part of forming the first “Giving Voice” chorus, which helped those with the disease and their caregivers sing together. This program has now gone international. They also found a support group specific for those with early onset Alzheimer’s and their caregivers. The members of this group provided helpful tips and resources, including the importance of hiring an elder law attorney to help financially plan for current and future expenses. Tom admits the elder law attorney was expensive but worth it. Tom feels that his spiritual strength has helped him through his caregiver journey. He believes spirituality should be practiced every day, just like exercise. He says it has helped him frame each day, helping set a context into moving into a new day and letting go of what happened the day before. His faith community has been a source of comfort during the past 10 years.

[Jennifer H.’s story](#) illustrates the critical importance of supporting caregivers during emergencies. For example, the current pandemic has disproportionately affected family caregivers. Her story also serves as a reminder of the importance of training professionals to recognize caregivers and treat them and their family members with compassion and respect, as well as make appropriate referrals that can help them carry out their tasks in the best possible way. For more, refer to [Recommendation 2.5](#) and [Recommendation 3.7](#).

In 2011, Jennifer H. first noticed that her mother was having trouble with her short-term memory. Jennifer didn’t believe it was serious at first, but, over time, her mother’s condition escalated to include paranoia, getting lost or confused easily, suffering from hallucinations, making calls to 911 to report serious crimes that hadn’t happened, and leaving home for days at a time without telling anyone where she was going. Jennifer’s family tried watching her all the time, but found this wasn’t possible, and Jennifer’s mother continued to leave home without her family’s knowledge. When they took the car keys away, her mother took the golf



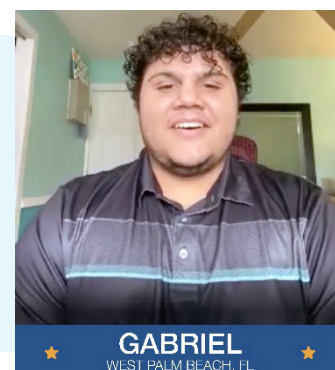
cart, and when they took that away, she wandered away by foot. One night in 2018, after leaving her home on foot, Jennifer’s mother was hit by a car. This unfortunate event ultimately helped the family finally get an official diagnosis of dementia and secure care in an assisted living facility.

The COVID-19 pandemic has brought new concerns about the care her mother is receiving. Since visits to her mother’s assisted living facility aren’t allowed, Jennifer hasn’t been able to witness the care received and hasn’t been informed of any of her mother’s health changes. However, due to a recent hospitalization, she learned her mother is now completely incontinent. When she asked the staff at the assisted living facility about it, they commented that her mother really needed plastic mattress pads. Jennifer worries her mother has been laying on a soiled mattress for months. Now, the family has hired a full-time caregiver to be with her mother to ensure she is receiving proper care but wonders how long they can afford that additional expense on top of the \$6,000 they are already spending per month for the assisted living facility.

Jennifer was surprised by the insensitivity she encountered by specialists and feels that health care providers and community services, such as police departments, need systemic improvements on aging related social issues and health conditions. Although the police department had been trained to handle Alzheimer’s, the main obstacle with care was her mother being an adult. They could not take her in for assessment under [a local law], which is used for mental health crises. There is a huge barrier for the family getting family members with dementia the care they need, especially those with paranoia and hallucinations. She found there to be huge gaps in time between the initial recognition that there is a problem, getting an official diagnosis, and finally getting help. Education for social services needs to focus on caregiver needs, how to obtain in-home care for families to be able to keep their family members safe, and how to financially plan and manage the expenses of caregiving.

[Gabe, who is from Florida](#), is just one of an estimated 3.4 million child, tween, and teen caregivers in America. Many caregiving youth assist parents or other relatives who are also caregiving. That is why Gabe calls caregiving a “team sport.” That idea speaks to the importance of a holistic approach that values and recognizes caregivers of all ages by using culturally sensitive and age-appropriate strategies to identify and assist caregivers; when everyone works toward the same goal, the whole team wins. For more, refer to [Recommendation 1.3](#) and [Recommendation 2.2](#).

A recent high school graduate, Gabe grew up in a household with his mom, 3 siblings (he is the youngest), and his grandpa who had a serious mental illness. Gabe spent much of his childhood helping around the house and caring for his grandpa. Being a caregiver at such a young age was difficult as he didn’t really know how to handle his grandpa’s outbursts, wandering or talking to himself. His behavior was confusing, but it was also Gabe’s norm.



As Gabe got older, his responsibilities grew. By 8th grade, he was routinely helping his family by doing the laundry and grocery shopping. Once Gabe could drive, he would take his grandpa to his medical appointments. Living in Florida, the family has had to worry about disaster preparedness because they had to factor in his grandpa's mental health condition, his age, his ability to leave the house, and their ability to get him to safety.

Gabe has always felt older than his peers. He routinely had to miss out on school opportunities and events, because there was always stuff that had to be done. He says he essentially became the man of the house. He was able to fix things when they broke, and he helped his mom make family decisions. While Gabe was juggling home, school, and caregiving, his mom was juggling home, work, and caregiving. She was burnt out too. He was often frustrated, but he learned to deal with each moment, each day.

Although his grandpa passed away in 2020, Gabe has been shaped by his caregiving journey and wants the memory of his grandpa to live on. Gabe wishes society would remember that it's not just the person who needs care that needs help—the family needs help, too. He wishes more people would talk about mental health. He has struggled with his own mental health and knows how hard it is to share those feelings. He thinks society should view caregiving as a team sport—in which everyone works to help each other.

II. Current Understanding of Family Caregiving

Family caregiving is as old as humanity itself, yet it did not emerge as an important area of psychological research until the 1980s. In 1980, Steven Zarit, Ph.D., and colleagues published a study that explored the experience of stress among caregivers of older, frail adults living with dementia. The study found that the so-called “caregiver burden” was decreased when the caregivers received assistance from other relatives. Over the ensuing 40 years, extensive research has expanded our understanding of the psychological, social, health, and economic impact of caregiving and the effects of interventions and public policies on caregivers. Yet, despite such progress, today’s family caregivers continue to provide hundreds of billions of hours of uncompensated care each year while remaining largely unrecognized as the primary social safety net that they are.

“My husband and I have three adult children with Down syndrome, and that is a lifelong journey and adventure.”

-Nancy Murray, M.S., caregiver & Family Caregiving Advisory Council Co-chair

The passage of the RAISE Family Caregivers Act comes at a pivotal time in our nation’s history. While the role of the family caregiver has always been part of American family structure, the nature of the tasks is changing. Family caregiving today involves more intense and complex care, including performing non-medical (i.e., administrative) and medical tasks and managing multiple health conditions that often include pain management (Reinhard S., et al., 2019). At the same time, the people who are able to undertake caregiving responsibilities is also changing. Today’s family caregivers are a diverse population spanning all ages, genders, education and socioeconomic levels, ethnicities, and cultures. Because of this rich diversity, interventions to support them must be equally diverse and flexible enough to understand and meet their needs (Reinhard S., et al., 2019).

Who Are America’s Family Caregivers?

As previously discussed, the number of family caregivers is difficult to determine, in part due to the many definitions of caregiving and differing methodologies for counting. According to the *Caregiving in the U.S. 2020*, more than 1 in 5 Americans (**53.0 million adults**) have provided care to an adult or a child with a disability at some time in the past 12 months. Other data collection sources that look at different spans of time or use different definitions of caregiving, arrive at different figures, and those differing figures have implications for estimates into the economic value of caregiving.

These numbers do not include the millions of grandparents age 60 and older who are responsible for the basic needs of one or more grandchildren under age 18 living with them. Nor does it include child caregivers between the ages of 8 and 18 who are

helping adults in their homes with caring for siblings, parents, or aging relatives. It also does not include the invisible caregivers—children who are primary caregivers for their parents, grandparents, and others.

Despite the many unknowns, one theme is consistent. The number of caregivers is expected to grow significantly, as the population of people living with multiple chronic conditions and disabilities increases in the coming decades and more complex care shifts to community-based care.

Family caregivers are a demographically diverse group that reflect the U.S. population. In fact, family caregiving is so commonplace that when former First Lady Rosalynn Carter testified before the Senate Special Committee on Aging in 2011 she noted that “...there are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.” (Family Caregiving Issues and the National Family Caregiver Support Program, Written Testimony of Former First Lady Rosalynn Carter, 2011).

Family caregivers live in every state and community: rural areas, small towns, and large cities. Some caregivers participate in paid employment; some are part-time caregivers, others care full-time for one person or for multiple individuals. Caregiving occurs in all family types and at all incomes and educational levels. It also affects people of all gender identities and sexual orientations (AARP and National Alliance for Caregiving, 2020).

Yet, caregiving is such a diverse activity that these statistics still fail to tell the whole story. Significant differences exist within racial and ethnic populations of family caregivers and those differences affect the experience of caregiving. The experiences and cultural values of diverse communities, including how and where they choose to care for family members vary widely. “Each racial and ethnic community has its own unique needs, responds to caregiving differently, and is informed by expectations, traditions and cultural norms that are critically important” (Choula, Snyder, & The John A. Hartford Foundation, 2020). For example, researchers have found that African American and Hispanic caregivers are more often in high-intensity care situations than white and Asian American caregivers (Choula, Snyder, & The John A. Hartford Foundation, 2020). On the other hand, Asian American caregivers often report feeling higher levels of emotional stress than African American or Hispanic caregivers. Even within populations, there are different responses to caregiving (Choula, Snyder, & The John A. Hartford Foundation, 2020). Family caregiving is an activity that involves families working together over time; this can be complicated when different generations have differing perspectives on what constitutes the best care. Because of these nuanced differences, approaches to supporting caregivers must be culturally sensitive, flexible, multifaceted, and adaptive. There is no one-size-fits-all solution to the challenges faced by families when it comes to caregiving, and interventions to support family caregivers need to be individualized.

Estimated Number of U.S. Adults Who Are Caregivers (in millions)

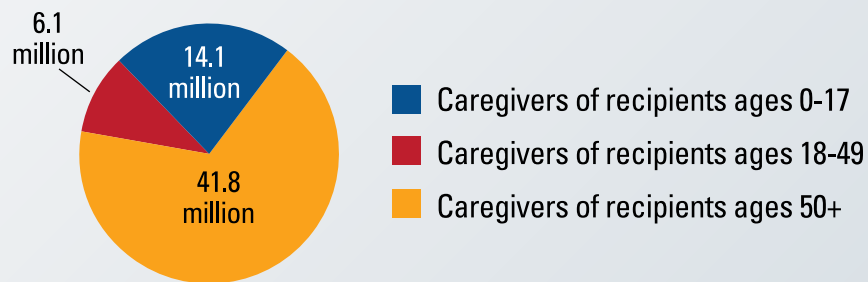


Figure 1. 2020 Prevalence of adult caregivers in the U.S. of children with disabilities and adults over age 18 according to the Caregiving in the U.S. 2020 survey conducted by the National Alliance for Caregiving and AARP.

Family Caregiving Tasks

“The time and energy that caregivers must devote to administrative and care management responsibilities cannot be overstated. As a professional in the field, I was well aware of the burdens of caregiving, I did not, however, fully understand the weight of time and frustrations that caregivers incur as primary advocates and care managers, until I became a full-time caregiver for my husband.”

-Rhonda Montgomery, Ph.D., caregiver & member of the Family Caregiving Advisory Council

The notion that caregiving is only about personal care or assistance with ADLs is outdated. While 60% of today’s caregivers do assist with at least one activity of daily living, such as assisting with getting in and out of bed, dressing, toileting, bathing, feeding, or dealing with incontinence, they also take on a wide range of other tasks. These include:

- Medical tasks:** Research has consistently shown that a substantial portion of family caregivers are providing physical and mental health care support. According to NAC, half of all caregivers give medicines, pills, or injections. African American and Hispanic caregivers are more likely to help with medical tasks than white caregivers. Performing medical tasks also correlates to care intensity (the number of hours of care provided); in other words, caregivers who provide more hours of care are more likely to perform medical tasks (AARP and National Alliance for Caregiving, 2020). Meanwhile, drawing on weighted estimates from linked nationally representative disability and family caregiver surveys, the National Health and Aging Trends Study (NHATS) found in 2011 that of 14.7 million family caregivers of community-dwelling older adults, 44.1% provided “substantial help with health care activities.” The study found that these caregivers tended to be older than

caregivers who provided no health care help, and were less likely to rate their health as excellent or very good than caregivers who provided some help. Among older adults receiving “substantial help with health care activities,” 45.5% had dementia, and 34.3% had severe disability (Wolff, Spillman, Freedman, & Kasper, 2016).

In order to perform these tasks, family caregivers have to have and understand information and terminology about complex medical conditions, available treatments, and possible side effects. A significant proportion of family caregivers provide physical, wound care, and other complex medical procedures and tasks. An increasing number manage chronic and acute pain. Caregivers also help make decisions about participation in research studies, and they often take on the reporting, transportation, and other logistical tasks associated with involvement in clinical trials (McCleary, May 2019).

- **Emotional and mental health support:** According to NAC, 8.4 million Americans are providing care to an adult with a behavioral health issue. According to the [CDC](#), an additional 1 in 6 U.S children under age 8 have a mental disorder. The rates are higher for children who live in poverty; 22% of children living below the federal poverty level have a mental disorder. The caregiving tasks associated with mental health support vary widely. For some, it may involve listening and talking through problems. At other times, it can mean ensuring the person receiving support has opportunities to engage in enriching activities. For caregivers of people with serious mental illness, family caregiving may involve bridging health care systems and providers, connecting the person receiving support to mental health services, support groups, or counseling, and administering or tracking use of prescribed medicines. Due to stigma around mental health issues, half of caregivers say it is difficult to talk to others about the mental or emotional health issues associated with behavioral health caregiving. This is a key contributor to isolation and loneliness for this caregiver population (National Alliance for Caregiving, February 2016).

“The time that can be wasted on hold on the phone just waiting for help is ridiculous.”

-Response to the ACL RFI

- **Administrative management:** Caregivers’ responsibilities also often extend beyond traditional direct care to making phone calls, dealing with health insurance payers, and communicating with a wide range of professionals including: physicians, physician assistants, nurses, nurse practitioners, social workers, educators, psychologists, pharmacists, physical and occupational therapists, certified nursing assistants, home health and direct support professionals, and others. During these calls, caregivers must navigate the differing levels of understanding among professions about the role of family caregivers and how best to integrate them into health care conversations. In circumstances where

the person receiving support participates in a self-direction program, the family caregiver may be expected to supervise or train workers.

These tasks can be extremely time consuming and often reduce available time to provide hands on care for family members. Analysis of data from the baseline 2011 NHATS and the companion National Survey of Caregiving found that more than 3 in 4 caregivers were assisting with at least one health system interaction task in 2007. Activities that members of the council report completing in the course of their own caregiving include:

- ◆ Making phone calls to multiple providers seeking appointments or advice. This task often includes repeated calls, spending time “on hold,” or leaving messages and waiting for return calls. It also may require navigating multiple websites.
- ◆ Coordinating schedules for medical procedures across multiple providers.
- ◆ Repeatedly completing forms and explaining medical histories.
- ◆ Dealing with, and paying, invoices from multiple providers even when the invoices stem from a single medical event.
- ◆ Communicating with pharmacies to obtain, track, and administer medications.
- ◆ Communicating with insurance companies to gain, or appeal for, approval to help assure payment.

In addition, many caregivers manage all or some aspects of the personal finances of the person receiving support. Thirty percent of caregivers report this is a time-consuming task (AARP and National Alliance for Caregiving, 2020). Caregivers who provide more hours of care per week, often report a greater burden associated with managing personal finances.

- **Transportation:** Eighty percent of caregivers assist with transportation, and lack of transportation is a key social determinant of health (AARP and National Alliance for Caregiving, 2020). Lack of transportation can have a significant effect on quality of life and independence for people with disabilities and older adults as well as limit their ability to receive timely access to medical care. “The lack of transportation in some communities makes it more difficult for individuals to get to doctor appointments, shop for groceries and other basic necessities, attend religious services, and participate in social events. Individuals who are cut off from communities and interactions can feel socially isolated, impacting their health and well-being” (AARP, 2020). In areas with limited public transportation options, providing transportation or helping an individual access transportation can be a critical aspect of caregiving.

- Coordination and advocacy assistance:** Family caregiving involves an array of medical, physical, emotional, financial, legal, and provider coordination and advocacy issues. Caregivers can serve as advocates, taking notes at medical meetings and working with health insurance payers for authorizations. They also interact with courts for legal concerns, child welfare agencies, schools, child care agencies, and adult day health and respite care providers. Care coordination is not easy; a third of caregivers report finding this aspect of caregiving to be difficult (AARP and National Alliance for Caregiving, 2020).

Caregivers also participate in critical advocacy efforts in their communities to advance awareness of the needs of people receiving support. They work with and arrange the services of community-based organizations, paid LTSS, and special education services (National Academies of Sciences, Engineering, and Medicine, 2016). Over half of family caregivers report engaging in advocacy activities which can include ensuring the needs of the person receiving support are met, and working with policy makers to champion long-term change (AARP and National Alliance for Caregiving, 2020).

- Education:** If the caregiver is a grandparent raising a grandchild, he or she may defer their own self-care to perform such tasks as taking a child to school, shopping for school supplies and groceries, coordinating special education and medical services, helping with homework and school projects, and planning enrichment activities (Generations United, 2018). If the grandparent becomes ill and the role reverses, there is often no one to assist the child with their education.

Forgotten Caregivers: Children and Teens

An often-overlooked segment of the caregiving community are children, teens, and young adults who care for parents, grandparents, and siblings. Advocates refer to these young caregivers as “caregiving youth.”

Research on caregiving youth remains limited, in part because many families are reluctant to volunteer information on child caregivers (National Alliance for Caregiving in Collaboration with United Hospital Fund, 2005). A 2005 study found that more than half of caregiving youth help with bathing, dressing, getting in and out of beds and chairs, toileting, and feeding. One in 6 child caregivers helps a family member communicate with doctors or nurses, and 15% of those aged 12 and older make calls and engage in care coordination. While data is still emerging, research also suggests that younger caregivers are more likely to support someone with a behavioral health condition (Reinhard S., et al., 2019).

The COVID-19 pandemic is increasing the number of young people caring for family members. For a real-life example of how one teenager is adapting to her role as a family caregiver, read [Role Reversal: Covid Increases Ranks of Child Caregivers](#), published in March 2021 by Kaiser Health News.

Caregiving youth report feeling “appreciated” for this help, however it comes at a cost. They often have to choose between providing support and schooling, homework, sports, and friends. A fifth of students who drop out of high school do so to care for a family member (Bridgeland, Dilulio, & Burke Morison, 2006).

“It seems as though we’re trying to behave like an adult to support the person we’re taking care of but like we’re still children.”
- Youth Caregiver response during August 2020 Listening Session

To expand the council’s understanding of how family caregiving impacts youth, the [American Association of Caregiving Youth](#) (AACY), Community Catalyst, and the LeadingAge LTSS Center @UMass Boston collaborated to conduct an online focus group in August 2020 that included a group of teens caring for family members with serious illnesses and/or chronic conditions. While the teens were all based in Florida, they represented a broad cross-section of racial and ethnic backgrounds.

The teens in the focus group reported that they supported adults with a range of care needs and conditions (e.g., cancer, arthritis, diabetes, and mobility challenges), and performed many tasks, including transferring, help with mobility, personal care needs, medication management, and help with instrumental activities of daily living (laundry, housekeeping, meal preparation, and more). While the teens admitted to feeling stressed, having to make sacrifices, feeling easily irritated and isolated, and having difficulty controlling anger or impatience, they expressed loyalty to the people receiving support.

As anticipated, a noted observation of the listening session was the lack of existing support systems and learning opportunities in place for these caregiving youth. A few participated in a school-based [Caregiving Youth Project](#). This program identifies caregiving youth in school and extends critical caregiving support services to the home, as well as providing out of school activities. For many of the participants in the focus group, this program was the only formal intervention they received. A few mentioned informal supports such as being able to talk to other family members who might also be teen caregivers.

When it came to discussing the types of programs the youth thought would help, the idea of a summer camp experience or an online support group were well received. Some felt they could benefit from learning relaxation, meditation, and other self-calming techniques. After one teen described her experience with an affordable mental health intervention, others saw value in that as well. The notion of “taking a break” or having a caregiver come to the home so they could have time off was well received. The teens talked about needing help handling certain situations especially around providing medication, helping with mobility, and care transfers.

“I want to learn how to like, if she’s sitting on a chair...like I want to know how to properly lift her up without causing any pain to her.”

-Youth Caregiver response during August 2020 Listening Session

Despite the challenges, the teens, like their adult caregiver counterparts, agreed that caregiving was a source of tremendous satisfaction and pride. One teen expressed the feelings of many caregivers—regardless of age—when they noted: *“The more you pour into others, the more you have to pour into yourself. Being a caregiver can be very nice and rewarding because you know you’re doing something for someone that you care about.”*

The 2019-2020 ACL Request for Information (RFI) on Family Caregiving

The RAISE Family Caregivers Act calls for the National Family Caregiving Strategy to include the perspectives of family caregivers. While the council brings significant and broad understanding of the challenges and needs of family caregivers, there was a recognition that the rapidly changing and diverse nature of family caregiving would be best captured through a focused data collection effort.

In December 2019, ACL issued an RFI inviting caregivers, family members, and other stakeholders to share their perspectives on family caregiving. The response was unprecedented, yielding 1,613 unique responses, 75% of which were from family caregivers across the age spectrum and from a wide range of economic and demographic backgrounds. The remaining responses were from advocacy groups (11%), community-based organizations (10%), government (2%), universities (2%), and other researchers (1%) (Nadash, Jansen, Tell, & Cohen, 2020).

A team of researchers at the University of Massachusetts Boston, led by Pamela Nadash, Ph.D., conducted qualitative data analysis of the RFI results. The researchers used an analytical approach called grounded theory to identify and tabulate caregiver priorities and concerns. Grounded theory differs from traditional scientific models of research where the researchers develop a working hypothesis and then collect data to assess that hypothesis. Instead, the researchers reviewed each RFI response and manually applied codes to mark key ideas and themes as they emerged.

The effort involved coding the 1,600-plus caregiving responses, and resulted in a report that builds upon, and validates, previous research by identifying present caregiver priorities and concerns. As the authors note, “prominent among the themes of the responses and recommendations were concerns about caregivers’ personal finances and future financial security, which caused caregivers significant stress and worry” (Nadash, Jansen, Tell, & Cohen, 2020).

“As the person with disabilities, I not only have caregiving from family for medical appointments, food, medical care for seizures and helping with many other issues I have such as balance and weakness in legs and speech problems, but they also have to help with my 6 year old...They have gone above and beyond what they should have to do right before retirement and my coming in to live and be cared for gives them very little break. If they both need to go somewhere and it interferes with my rest then it brings on more seizures. They are my rock and they deserve to have some support and assistance also for what they are doing!”

-Response to the ACL RFI

The RFI included three questions; for one of the questions, respondents selected which of a list of potential actions to support caregivers were important to them. They could select as many actions as they preferred. Not surprisingly, the majority of respondents indicated interest in services and programs that could assist them in their caregiving duties, particularly those that were person- or family-centered. In fact, these two topics each garnered responses from at least half of respondents (See Figure 3). Meanwhile, 46% of respondents noted that respite options were important to them. An almost equal number of respondents cited care transitions and coordination as an important concern (45%), followed by financial security (42.3%) and information, education, training, and/or referral (39.5%) (Nadash, Jansen, Tell, & Cohen, 2020).

Respondents also noted the importance of caregiver assessments (26.7%), developing solutions to workplace issues (26.5%), the availability of care coordination in hospice (21.5%), the importance of palliative care (21.5%), and the need for advance care planning (24.4%). While these latter five topics received relatively fewer responses, it is worth noting that in each instance at least 20% of respondents selected these items, highlighting the diversity of concerns affecting family caregivers and the importance of multi-dimensional responses. The study authors note that the priorities of family caregivers tended to align with those of other respondents to the RFI (Nadash, Jansen, Tell, & Cohen, 2020).

Two of the RFI questions were open-ended, asking respondents to describe in their own words:

1. A pressing family caregiving need or concern.
2. A suggestion for a recommendation that would help them address the identified concern.

The ways that respondents answered the open-ended questions reveal the significant pressures caregivers face. Because ACL did not limit the length of each open-ended response, many of the respondents wrote deeply personal essays about their caregiving journey. They shared their stories in writing that was immediate, raw, and at times heartbreaking.

For the question asking about a pressing need, many respondents found it difficult to limit their response to a single item. One respondent appeared to speak for many when they noted, *“There isn’t a way to narrow this down to one need; the lack of support is far too great.”*

Another wrote, *“Just one? Where do you start? I’m exhausted.”*

And a third commented, *“I cannot pick just one area: There are limited providers (behaviorist or others) who are capable and competent to help families and children with developmental disabilities and behaviors. There are limited competent, capable people and/or funds to assist in providing respite care. There are limited funds to assist with providing transportation.”*

Across the RFI responses, respondents specifically requested stipends and tax deductions to alleviate the financial challenges created by their caregiving responsibilities. There were a number of calls for increased workplace flexibilities for family caregivers. These requests seemed to encompass both a need for actual flexibility with regard to taking time off and a need to shift the perception that caregivers are not able to be committed employees; a significant number of respondents remarked on missed promotions, lost benefits, and lower lifetime earnings due to being a family caregiver. One respondent noted, for example, *“I do not have children and am the medical power of attorney for my two aunts and uncle. I have spent a significant amount of time out of work caring for them and have only my paid vacation time available to me to take that time off.”*

Similarly, many respondents noted the challenges associated with hiring direct support professionals (or volunteer respite care) to supplement the support provided by family members. Other respondents, who were receiving caregiver supports and services, commented on inflexibilities and inefficiencies in the delivery system that made the services they were receiving less helpful than they could be if they were more flexible.

Respondents noted a need for education and training—both formal caregiver training and more medical providers taking the time to talk to them. Some of the suggestions were practical in nature. For example, one respondent suggested that medical providers dictate caregiver instructions into the patient’s medical file for future reference by the care team, the patient, and potential secondary caregivers.

Finances were a prominent theme in the responses, both explicitly and implicitly. “This theme included concern about the ability to accommodate care recipients’ needs (including costs associated with health care, health supplies and equipment, housing, and support services) as well as concerns about caregivers’ own financial needs, both in the short and longer terms. Concern about personal finances also frequently

incorporated family caregivers’ ability to support other family members in addition to the care recipient” (Nadash, Jansen, Tell, & Cohen, 2020).

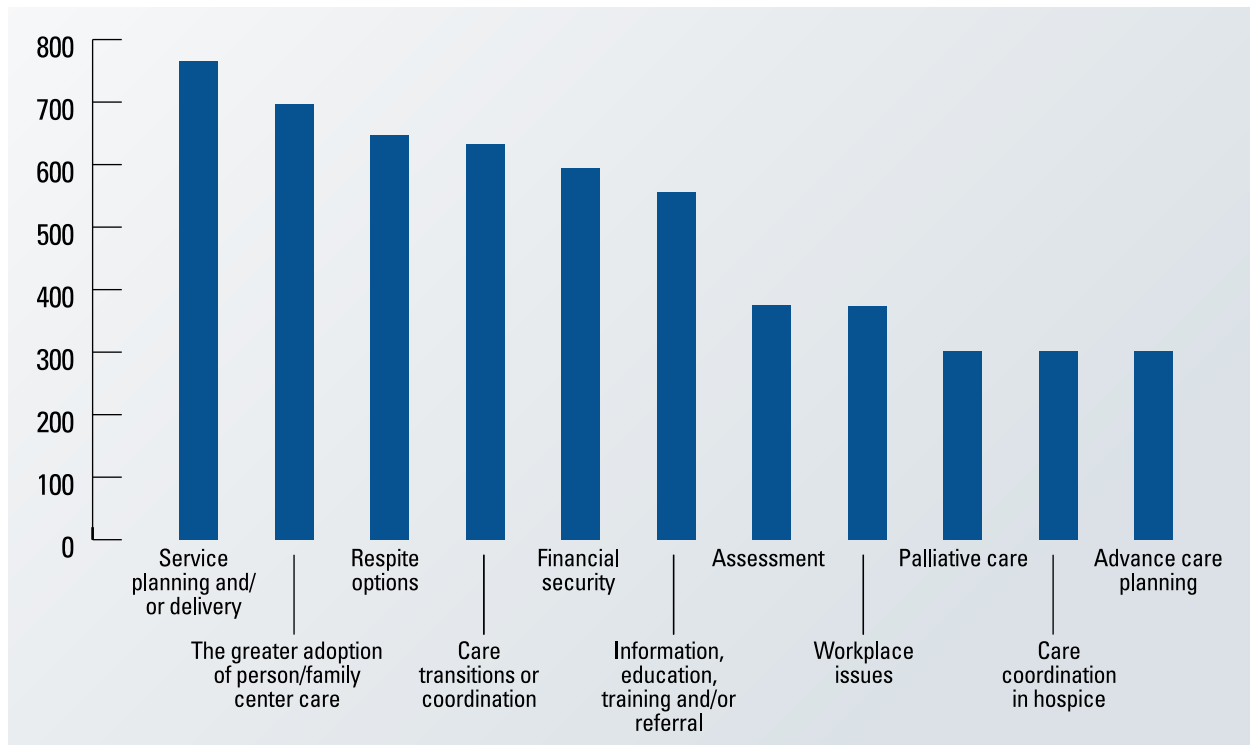


Figure 2. Close-ended RFI responses to a question in which respondents responded to a list of issue areas and selected all that were important to them.

“Respite is something that is **DESPERATELY** needed by every single caregiver of someone with the kind of long-term care needs I have described above! I know this because I am one of several thousand members of a Facebook group specifically for Caregivers of people with Parkinson’s disease. Everyday I read their post[s] and it’s truly heartbreaking, because most every one of them have no one, not one single person, who will come along side of them to offer relief!”

-Response to the ACL RFI

Finally, woven throughout the RFI responses were references to the need for a health break. Respondents used a variety of terms for what professionals refer to as respite, including “break,” “vacation,” “time off,” “downtime,” and “relaxation.” Regardless of terms used, respondents consistently remarked that caregiving can be all-consuming and deeply exhausting. This aligned with a body of research into caregiver burnout. Caregivers need time to rest. More importantly, they need time to attend to their own financial, social, physical, and emotional well-being without sacrificing the safety and well-being of the person receiving support.

One limitation of the study is that the RFI closed in February 2020, before the full implications of the COVID-19 pandemic became apparent. While the results do not include the impact of the pandemic on family caregivers, they do document the significant and pressing needs of caregivers—needs that the public health crisis has exacerbated. The final report, [In Their Own Words—Caregiver Priorities and Recommendations: Results from a Request for Information](#), is available on the [RAISE Family Caregivers Resource and Dissemination Center website](#).

The findings of the RFI reinforced and clarified existing understanding of the challenges faced by, and needs of, family caregivers across the life course. They also reflect the findings of [Families Caring for an Aging America](#) a landmark 2016 report from the National Academies of Sciences, Engineering, and Medicine, which was developed through a meta-analysis of existing research into caregiving. That study looked at the research around certain aspects of family caregiving, including psychological effects, both positive and negative, in addition to the physical and social effects. These parallels appear most notably in the impact of caregiving on the caregiver. Both the National Academies report and the RFI note physical and psychological outcomes of caregiving that have an overall negative effect on health and well-being, changes in health behaviors among caregivers (i.e., missing self-care appointments), and changes in relationships. Both sources show, using different language and examples, that the intensity of caregiving has an impact on the negative psychological effects of caregiving (National Academies of Sciences, Engineering, and Medicine, 2016).

The RFI responses, along with the qualitative analysis conducted by Dr. Nadash, et al., contributed significantly to the council’s process for developing the 26 recommendations and ensuring those recommendations are responsive to the needs of today’s caregivers. They also used the information gathered in the RFI about caregiver priorities to inform a series of focus groups designed to support the development of the National Family Caregiving Strategy. For further discussion of the needs of family caregivers, as noted in both the RFI and through council deliberations, refer to [Section II, Current Understanding of Family Caregiving](#).

The Intersection Between Family Caregiving and the Direct Care Workforce

“The job of paid caregivers... should be elevated to establish caregiving as a professional career path... Direct care workforce jobs should not be seen as dead-end jobs and all funding sources should be leveraged to increase their value and promote the profession of caregiving.”

-Response to the ACL RFI

The COVID-19 pandemic has brought attention to a crisis that has been developing over recent decades among paid caregivers. These professional caregivers are known by a range of terms, in part defined by their specific tasks. Sometimes they are known

as home health and personal care aides or, more generally, direct care workers. Some paid caregivers are “certified Nursing Assistants” who are subject to state laws and regulations. For the purposes of consistency, this report uses the broadly general term “direct support professionals” (DSPs) to describe the population of employees who provide caregiving support in the home or in assisted living communities, and other community-based residential care settings as part of their paid employment. That support can include “essential activities performed every day, including bathing, dressing, eating, toilet care, and transferring/mobility” or it can extend to “tasks associated with living independently, such as preparing meals, shopping, housekeeping, managing medications, and attending appointments” (Campbell, Del Rio Drake, Espinoza, & Scales, 2021).

While the mission of the Family Caregiving Advisory Council is to develop recommendations and a national strategy to support family caregivers, it recognizes the need to consider the many contributions of DSPs in supporting the autonomy and independence of individuals. The nation’s 4.6 million DSPs and the care infrastructure they support are an implicit part of any discussion about family caregiving. That is because they often complement the efforts of family caregivers either by providing support so they can take a break or go to work—or by working in tandem with them to ensure the needs of the person receiving support are fully met. Many people with disabilities who receive state Medicaid-funded HCBS still need to augment those services with the assistance of family caregivers to remain maximally independent.

“If family caregivers are the backbone of the long-term services and supports system— with appropriate support, connections and resources, paid caregivers are the connective tissue that keeps the backbone of the system together.”

James Murtha, MSW, disability advocate & Family Caregiving Advisory Council Member

In the past 30 years, the pipeline of direct support professionals has not kept pace with the need. Contributing factors include “low wages, scant benefits, limited training, and lack of career advancement opportunities” for workers (President’s Committee for People with Intellectual Disabilities, 2017). The DSP workforce is predominantly female (87%). It is extremely diverse and relies heavily on immigrant workers; the majority are people of color, including 30% who are Black or African American, and 18% who are Hispanic or Latinx. Seven percent are Asian or Pacific Islanders and 4% identify as other races or ethnicities. The direct care workforce also tends to be older; while the median age is 41, more than a third are over age 55 (up from just 19% a decade ago).

Finally, and critically for this population, the median hourly wage for this population of workers is \$12.27. In 2018, the average income was just over \$20,000 per year. As a result, 42% of the DSPs receive public assistance (Campbell, Del Rio Drake, Espinoza, & Scales, 2021). “The low level of compensation contributes to the

difficulty of attracting people into these jobs, particularly when they can earn more at a neighboring hospital or fast-food restaurant” (Spetz, Stone, Chapman, & Bryant, 2019). Those who do choose to work as DSPs often work more than one job—or multiple part-time jobs—just to make ends meet.

Other factors, such as occupational safety, lack of career mobility, and education and training challenges combine to further destabilize the DSP workforce. As a result, home health agencies often struggle to recruit, train, and, most importantly, retain staff (Spetz, Stone, Chapman, & Bryant, 2019). The median turnover rate for DSPs in 2017 was close to 67%. This has implications for family caregivers because high turnover has been linked to “increased risk of pressure ulcers, contractures, injuries, emergency department visits, and hospital admissions” for people receiving care (Spetz, Stone, Chapman, & Bryant, 2019).

The high turnover rate has been exacerbated during the pandemic as a population of mostly low-wage, female workers left the workforce (Ewing-Nelson & Tucker, 2021). In April and May 2020, for example, Latinas and Black women had the highest levels of unemployment, 16.6% and 20.1%, respectively (Ewing-Nelson & Tucker, 2021). “As a result, [DSPs] and their employers have lacked sufficient resources to deliver quality care through this crisis, which has disproportionately impacted the populations that make up most of their clients and residents: older adults (specifically those with certain underlying conditions), people with disabilities, and people of color” (Campbell, Del Rio Drake, Espinoza, & Scales, 2021).

Many respondents to the RFI articulated frustration and challenges with finding and retaining quality DSPs for their family members. The shortage of workers is projected to continue to grow as the population ages and more people need assistance to remain independent.

“We need more qualified paid caregivers for AUTISTIC ADULTS. For many adults diagnosed with Autism Spectrum Disorder (ASD), the mother has been their only caregiver since they aged out of the school system. There is no family help for me as I age nor for my adult autistic son as he ages. I am dependent on paid caregivers. Ideally, we need two in-home paid caregivers and right now we can’t find 1. American[s] do not want caregiver jobs for seniors or ASD. The majority of [certified nursing assistants] CNAs and [licensed practical nurses] LPNs do not know anything about Autism.”

-Response to the ACL RFI

CMS notes in its [Long-Term Services and Supports Rebalancing Toolkit](#) that for Medicaid, “the impact of HCBS workforce issues, such as workforce shortages and staff turnover, on the quality of service is direct and immediate” (Centers for Medicare

& Medicaid Services, 2020a). Workforce issues increase costs for Medicaid providers and reduce the cost effectiveness and quality of care for beneficiaries. People with IDD, for example, who experience high rates of turnover among their direct support professionals, have more emergency department visits, experience more instances of abuse and neglect, and have more injuries than people who do not experience similar turnover (Friedman C., 2020). The well-being of family caregivers is also affected when they find themselves re-training direct care workers, repeatedly introducing their family member to new person, or covering for “no shows.”

The challenges of the DSP workforce extend beyond families who receive support through Medicaid-funded programs. Even for families with the ability to pay out of pocket for some support, it is difficult to find and hire qualified personnel, and families quickly find that over time the expenses add up or increase. Third-party payers, such as private insurance or Medicare, often do not reimburse for the types of services most often associated with family caregiver support (e.g., counseling, information, education and, in most cases, respite), leaving many families caught between lack of availability and lack of affordability.

When professional assistance from DSPs is not available to families, either because it is unavailable or unaffordable, caregiving tasks typically fall to family members—sometimes with no notice and without consideration of their other responsibilities. This has been particularly notable during the COVID-19 pandemic, when many people with disabilities lost access to LTSS and their family caregivers were expected to step in full-time to provide support, while still juggling all the other responsibilities in their lives.

While the Build Back Better plan seeks to create more jobs in the direct care workforce, this is only a first step. Real change for DSPs and family caregivers on this issue will involve action from multiple sectors working together to improve training, opportunities for small businesses that provide community-based services, public awareness campaigns that change the narrative around what it means to provide care, and more avenues for collaboration between paid and unpaid caregivers. Recognizing that DSPs are an important complement to the efforts of family caregivers, the council developed [Recommendation 3.9](#) specifically to strengthen the paid workforce.

In the statement below, council member James Murtha, shares his perspective as a person who benefits from family caregiving in tandem with the support of direct service workers. His story also highlights the importance and value of a person-centered approach that achieves the critical balance of supporting the caregiver without prioritizing his or her needs over those of the person receiving support:

“I am a member of the council, a social worker, a disability advocate, and a loving son. I am also a quadriplegic and receive help from a state home care assistance program. We are lucky to live in a country that provides this. However, I need 24 hour care but only receive five hours per day. My situation, and that of others with complex physical disabilities, as well as the elderly, is destitute and getting worse.

Family caregivers can't do it all. It really does take a village. Nearly all families taking care of a family member rely on hired caregivers. Family caregivers are the backbone of the caregiving workforce; hired caregivers are the connective tissues that keep the family together. Not enough government dollars are given to people like me who need significant help. As importantly, it is withheld from home care providers that employ and pay the caregivers we need. Home care providers are expected to pay insurance, taxes, Social Security, and unemployment for employees. After these expenses and paying their workers, care providers only make three dollars an hour for every client served. Fewer and fewer home care providers are participating with Medicaid. Caregivers are often untrained, turnover and quitting is constant, and make minimum wage.

There is a growing caregiver shortage. The population of older adults, as well as people with complex physical needs is also growing. **The caregiver shortage is critical. Without changes, soon it will be catastrophic.** Families can't do it all. During Covid, all my caregivers quit, and I had to live with my parents. My parents are in their late 60s. My mom has arthritis in her hands and my dad has a bad back. I live with the guilt of deteriorating their health and quality of life. The federal government and states must prioritize the most vulnerable in society.

We give the minimum to the people who need the most. We must change our paradigm and shift our outlook on what it means to thrive and how we value others. We as a society must realize that if we choose to build a nation that protects and ensures quality of life for those in dire need, each of us will guarantee our very own quality of life will be protected and ensured when our needs are dire.”

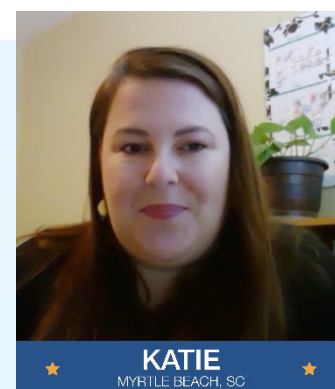
It's Time to Include Family Caregivers in Systems and Policies

Congress chose the word “include” for the RAISE Family Caregivers Act because there exists a longstanding pattern of policymakers and health systems overlooking the voices and needs of caregivers. In the stories that follow, five female caregivers—wives, mothers, daughters—demonstrate the tremendous contributions they can and do make to support the well-being of their family members and the system of LTSS. Yet, too often, their presence and efforts are taken for granted without consideration of their needs and preferences. It is time for the perspectives and needs of family caregivers to be included in policy development and decisions, care planning and delivery, and the design of research studies and data collection efforts.

Individuals with IDD have a civil right to support, to live and fully participate in their communities throughout their lives. Because of the role that families continue to play in the lives of their family members with IDD, they must be included as part of the system of support. Yet, [Katie's story](#) below is not unique—too many families of people with disabilities continue to be excluded from care discussions even when they will be an integral part of implementing the plan of care. Her story highlights both the importance of ensuring family caregivers are considered when policies and practices that affect beneficiaries are proposed and the need for increased availability of promising and evidence-informed practices to support family members of people with disabilities. For more, refer to [Recommendation 2.4](#) and [Recommendation 5.3](#).

Katie is the mother of a 20-year-old son born with physical and intellectual disabilities caused by a rare disease. The factors of her son's care have been constantly changing, meaning the caregiving process has changed as well. As her son's primary caregiver and advocate, Katie is the one who deals with the medical professionals. Even with a background in health care, switching her son from a pediatric team to an adult one when he turned 18 was extremely difficult. Katie has encountered doctors who she feels do not listen to her and question how she responds to her son's symptoms. She feels she needs to essentially interview every new doctor to see if their approach aligns with the health goals she has for her son, and she has learned to be very direct in stating her expectations. Without proper supports in place, Katie cannot step back from her caregiving role to be a mother.

Due to her care responsibilities for her son, Katie had to move into a part time position at her job, taking a pay decrease and losing her leave. She and her husband have not been able to save for their future, and her husband has had to work multiple jobs to cover the costs of traveling to see medical specialists for their son. They cannot claim a tax break on these trips



because of her and her husband's income level—she feels she is being punished by the system for working.

Katie's son's needs require a whole team of doctors, yet Katie has never been able to sit down with them as a team. She is constantly managing medical professionals, making sure everyone has the same information and is going in the same direction. Simply being able to meet with all her son's doctors at once would save Katie time, money, and a lot of work, improving the quality of her and her family's life.

[Jeannette, a post-9/11 military spousal caregiver](#), had to leave her job in order to provide her husband with the caregiving support he needed. Even in the presence of paid supports, she had trouble finding the assistance she needed. Her story is a reminder of the value of volunteers and volunteerism as a means of augmenting the support family caregivers provide, and the importance of developing policies that enable caregivers to stay in the workforce and build a secure retirement. For more, refer to [Recommendation 3.6](#) and [Recommendation 4.2](#).

Jeannette's husband returned from Iraq with Post Traumatic Stress Disorder, Traumatic Brain Injury, signs and symptoms of Chronic Traumatic Encephalopathy, and advanced bone and disc degeneration. His symptoms got worse over time, but Jeannette knew things were forever changed from the very beginning when he was easily angered, confused, and often called her to ask where he was. She knew that their marriage roles had changed – she was now the rock, the decision maker, and 100% in charge of their lives.



Jeannette cared for her husband at home but found difficulty in balancing her work life and home life, and she ended up leaving her beloved job. Once she quit, she felt that others didn't understand why she couldn't manage both work and caregiving, and she felt discriminated against because she chose her husband over her career. Later, when she tried to find part-time employment, she found it very difficult to find organizations willing to provide the support and flexibility she needed. She felt that once potential employers learned about her husband, her caregiving role, and that she left her last job due to her care responsibilities, they just weren't interested in giving her a chance to prove herself.

Jeannette participated in the VA's Caregiver Support Program, and while she did receive some basic care training, the program didn't prepare her emotionally for the challenges of caring for someone who struggled with anger, memory issues, and someone who had a hard time comprehending the world around him. Sadly, Jeannette's husband can no longer live at home. His care needs have exceeded what she can provide. She would like to find a mid-level care home for him to keep his service dog, but the VA only offers State Homes, where his dog won't be allowed to live, and in which Jeannette fears she will no longer be considered a caregiver

even though she will still be deeply involved in his care. Jeannette says that, “being a caregiver is the loneliest job you will ever have, but it is also the most grateful job you will ever have.”

Many people do not learn about caregiving until life circumstances change. This means that new caregivers often do not know what kinds of assistance would help them or where to start looking for assistance. [Sherry, a working spouse caregiver](#), is an example of the importance of family caregiver assessments as a first step to developing a caregiver support plan and recommendations that support them to remain in the workforce, while also reducing the negative financial impacts that all too many caregivers experience. For more, refer to [Recommendation 2.2](#) and [Recommendation 4.2](#).

Sherry is a caregiver for her husband, who was diagnosed with Parkinson’s disease. At the start of her caregiving journey, Sherry struggled to find caregiving communities, and it was difficult for her to share her concerns with others. However, once she made those connections, and found others that shared her feelings and experiences, she felt more supported.



Sherry believes that policy makers need to realize that services for caregivers and care receivers are similar. She feels a focus on the care team would be helpful and those services should be viewed as part of a family wellness plan. Services that Sherry believes would be helpful to her as a caregiver include in-home therapy for her or her children, in-home bible study, and a health coach so she can maintain her own health. These supportive services would help her be the best caregiver she can be.

Sherry feels that once you become a caregiver, your identity changes. In the beginning of her journey, she struggled with depression, as she felt there was a stigma attached to all the changes her new reality brought about – and that stigma made difficult decisions even harder. As a corporate executive, she felt torn between her professional responsibilities and the needs of her husband. She felt judged at work for missing meetings, having assignments given away, losing a board seat – all part of her own story of loss. She wishes her employer had incentives to go beyond workplace policy and look for innovative and flexible ways to support her. Ultimately, it took her 7 years and 3 employers to find a place that truly allowed her to work and be the caregiver she and her husband needed her to be. Caregiving is an expensive experience. Sherry worries about finances a lot – many caregivers struggle with bankruptcy and ruined credit. Sherry agrees that there need to be innovative solutions to prevent these detrimental impacts of caregiving to minimize caregiver burden and loss.

Respite care provides short-term relief for primary caregivers. It can be just an afternoon off or a break that lasts for several days or weeks. Despite the well-documented value of respite, many family caregivers literally never get a break. This

can be due to lack of awareness of respite options, the cost of respite, or even difficulty finding trusted providers. [Abena's story](#) below underscores the importance of both early identification of caregivers and, once they are identified and assessed, connecting them to high-quality, setting-appropriate and caregiver-defined respite services. For more, refer to [Recommendation 1.3](#) and [Recommendation 3.2](#).

Abena's husband was diagnosed with a brain tumor in 2013, shortly after she became pregnant with their first child. Her husband lived with his tumor for a little over four years before passing away. Abena did almost everything for him, from managing his medication to coordinating appointments, to discussing his care options. When her maternity leave ended, she was working full-time. She wasn't sleeping, taking breaks, or going to the doctor herself, something she said she didn't even manage to do until her husband had passed. She was unable to maintain her high intensity role at work and had to be moved to another position.



Respite, giving her and her husband time together without the kids to process what was happening, would have been a huge break for her. Abena thinks a regular check-in would have been helpful from someone who understood her situation, such as other wives of brain tumor patients. Abena believes that she could be that person for someone else now.

Abena sees herself as lucky for having her and her husband's co-workers donate leave to them. However, she thinks employers need to be given a structure to offer caregivers options that fit their needs, so that the employee does not have to struggle to find a solution.

Abena received training to take care of her husband, especially when he was undergoing chemotherapy and taking steroids. Towards the end of her husband's life, Abena wanted to bring him home from the rehabilitation hospital. In order to do so, she was taught everything from how to get him out of bed to how to administer his medication. She thought she was being taught these things as a back-up, but when hospice began, she realized she was expected to be a full-time nurse. At that time, she had to leave her job altogether in order to care for her husband. Abena feels that she cared for her husband in the way she wanted. She feels she did the best she could with the options available to her, and it was an honor for her to care for him.

Almost a quarter of family caregivers are caring for more than one person, an increasingly common phenomenon known as multiple caregiving. [Melissa](#) and caregivers like her, often juggle responsibilities and have to make hard choices about where to focus their attention, especially when travelling long distances to provide support. The council's recommendations that caregivers—including secondary caregivers—be included in care coordination, and its call to increase access to supportive services,

have the potential to make a big difference for this growing population of caregivers. For more, refer to [Recommendation 2.3](#) and [Recommendation 3.1](#).

Melissa was the secondary caregiver for her father, who had Lou Gehrig’s disease, and is now the primary caregiver for her husband, who suffers from chronic pain. With her father, Melissa realized right away she was a caregiver as he was on a ventilator, needed a feeding tube, and required many hours of care. For her husband, her role as a caregiver was a more gradual realization. Melissa’s father lived three hours from her, so when she was caring for him, she was not around for her husband, and sometimes, it was hard not to feel as if she was neglecting one of them for the other. However, Melissa enjoyed supporting her mother in caregiving for her father because they both understood how the other was feeling.



The COVID-19 pandemic made it difficult for Melissa to care for her husband because non-medical treatment was harder to come by. Melissa’s hours at work also increased, intensifying her need for services and supports. Living in a rural area, supports were already hard to come by under normal circumstances. Melissa feels something helpful to caregivers in rural areas would be bringing care to people rather than making them travel to receive care.

Melissa feels that making caregivers aware of the supports they are eligible for and where they can access them, would make their job easier, as well as putting caregiver resources in one location to reference. Telehealth appointments have been very helpful for both Melissa and her husband, and Melissa is hopeful that they will continue beyond the pandemic.

III. Existing Federal Approaches to Assisting Caregivers

Over recent decades, a number of approaches have emerged to support family caregivers, including direct support programs that address a range of caregiver needs, single service approaches where specialists offer interventions that fill specific caregiving gaps, training and education initiatives aimed at increasing confidence and efficacy among caregivers, and peer-to-peer interventions that include counseling, training, and respite. Often, successful efforts begin in communities or states, as either grass roots efforts or part of a demonstration project.

In fact, existing federal efforts to support caregivers were often an attempt to bring to scale successful approaches tested at the state and local levels. A proven example of this is the National Family Caregiver Support Program, which had its genesis in several successful state caregiver programs. Despite limited funding, since the passage of the National Family Caregiver Support Act in 2000, a growing body of federal programs and initiatives have emerged to coordinate and disseminate information, best practices, and services for family caregivers. Congress’ call for a National Family Caregiving Strategy—which is to be informed by the development of an inventory of existing federal programs—is an important step in the realization of a vision where caregivers across the nation can receive the assistance they need in a coordinated and efficient manner.

Overarching Considerations of Effective Caregiver Support

While there are many ways to assist caregivers, the recognized first step involves understanding caregiver needs in relation to the care needs of the person receiving support (Refer to [Recommendation 2.2](#)). Without a systematic approach to assessing the overall needs of the family, developing a comprehensive system of support for the caregiver is compromised, which, in turn, exposes the family caregiver to negative consequences linked to the caregiving experience (e.g., burden, stress, depression, poorer than expected health outcomes).

“There are so many complex things and processes that have to be followed and, when in the midst of a crisis, [it is] very difficult for even the most educated and proactive to figure [it] out. The lack of education in the medical field and even the hospital settings, where it seems to be so routine for staff, that fail to recognize how this is impacting a family as a human being. I feel that most medical doctors and those that may not care for the elderly patient or one with super special needs is not there. Everyone ‘assumes’ that all is done for a person when in assisted living, skilled nursing, etc. There is no understanding of how medications are handled and what a nightmare it is when you have a hospital visit and then have to transition

back to assisted living and hope and pray the paperwork transfers without a hitch without errors. I find the lack of empathy on this entire topic with the majority of medical staff and hospital staff appalling and so frustrating. They forget there is truly another person at the end of the conversation.”

-Response to the ACL RFI

Over the past two decades there have been increasing calls from professional societies, advocacy organizations, and consensus committees for a standardized, universally available assessment of the family caregiver as an important component of a person- and family-centered care planning process. Thus, the development of numerous approaches and tools focused on caregiver assessment have merged in recent years. Some are designed for specific populations. Others are designed to be a comprehensive assessment of a variety of caregiving situations. Two evidence-based approaches to caregiver assessment are 1) the [BRI Care Consultation](#) used with caregivers of adults with dementia and other conditions, and 2) a comprehensive caregiver assessment tool, the [Tailored Caregiver Assessment and Referral](#) (TCARE).

Caregiver assessments can take place in the home or a clinical setting—or in some cases over the phone or via telehealth. A typical assessment might involve a trained professional or peer caregiver asking the family caregiver—in a non-judgmental way—about:

- Their caregiving tasks.
- Their comfort level and confidence performing these tasks (including the use of or interest in using technologies related to caregiving).
- Their overall emotional and physical well-being.
- Their own goals.
- Their ability and willingness to continue to be a caregiver.
- The types of supports they feel would be most helpful to them.
- Their legal and financial needs.
- The levels of paid and unpaid support they currently have.
- Their basic eligibility for existing services and supports (level of impairment, household or individual income, VA status, etc.).

The answers to these questions form the basis of a culturally sensitive plan for helping the caregiver continue to provide support. Interventions can involve education and counseling, respite opportunities, soliciting other family members to assist with caregiving, role modeling caregiving for the caregiver, and fostering the idea that the family caregiver is not alone. As noted previously, caregiver assessments have the potential to improve caregivers’ understanding of their needs, as well as determine their ability to continue to provide support. When implemented across populations, they can provide meaningful data about systemic caregiving needs and identify gaps in programming.

Caregiver Assessment: A Tool for Understanding What the Caregiver Needs

Caregiver assessment is a systematic process of gathering information about (1) the caregiver's challenges, needs, strengths, and resources; (2) the needs of the person receiving support; (3) the caregiver's ability to help meet those needs; and (4) caregiver interactions or relationships with health care teams and/or LTSS systems. The findings of the assessment form the basis of a customized caregiver support plan and can include care consultation, training, respite, and other supports (Feinberg & Houser, 2012).

For further discussion about the important role of caregiver assessments in supporting family caregivers, refer to [Section III. Existing Federal Approaches to Assisting Caregivers](#).

Comprehensive Direct Support Programs

Across the federal government, there are programs, supports, and other interventions designed to support family caregivers. One proven approach to directly supporting caregiving is with a model of programming that offers multiple, flexible service options that are responsive to caregiver needs as they change over time (Avison, et al., 2018). Typically, these models include information and/or training for caregivers, assistance with navigating services (including understanding options for supports), counseling and/or training of community mental health professionals to better understand and address caregiver-specific needs, and respite care. Other ancillary services may include employment assistance, transportation, or advice on accessing services and supports. These direct support models also can support indirect services and infrastructure development through research and policy development that leverages their work with family caregivers.

The federal government funds three specific programs that are structured to directly address a broad array of caregiver issues for eligible family caregivers:

- The NFCSP, established in 2000 and operated by ACL, provides grants to states and territories that fund Area Agencies on Aging to provide a range of services that assist family and informal caregivers to care for their family members at home for as long as possible. Services include:
 - ◆ Information for caregivers about a range of supports, resources, and services.
 - ◆ Assistance in gaining access to services that help connect caregivers with services offered by private, public, and voluntary agencies or through insurance.

- ◆ Caregiver education/training, individual counseling, and support to help caregivers better manage their responsibilities and cope with the stress of caregiving.
 - ◆ Respite care provided by trained caregivers delivered at home, at adult day programs, or in other facilities, so that caregivers can rest or attend to their own needs.
 - ◆ Supplemental services such as transportation, home modifications, and medical or incontinence equipment.
- The VA Caregiver Support Program (CSP) offers an array of services to family members and friends who care for veterans, including on-line courses, face-to-face classes, telephone support, and peer support.
 - These services are offered in addition to the support provided to families and caregivers across VA by clinicians as part of a veteran’s care. Every VA medical center has dedicated Caregiver Support Program staff who assist with information and referrals to these programs. Many of the following programs are also available to veterans who serve as the family caregiver to a non-veteran. These programs include:
 - ◆ A 6-week online workshop for caregivers of veterans of all eras, with text support.
 - ◆ Caregiver self-care courses.
 - ◆ Website and Caregiver Support Line.
 - ◆ Telephone education and support groups.
 - ◆ Peer support.
 - Kinship Navigator Programs are funded by the Administration for Children and Families (ACF). These services assist kin and grandparent caregivers in communities across the nation in learning about and accessing programs and resources to meet the needs of the children they are raising, to provide help for the family as a whole to safeguard stability, and to promote partnerships among public and private agencies (Child Welfare Information Gateway, 2019). These federal programs are models that show promise for holistically supporting the needs of family caregivers. A [comprehensive evaluation of the NFCSP](#) conducted from 2016 to 2018, found that “caregiver use of the services made available by the NFCSP helped them continue in their role for longer periods, an important factor in delaying or preventing the institutionalization” (Avison, et al., 2018).

Kinship Navigators Help Kin and Grandparent Caregivers Navigate a Path to Success

Kinship navigator programs seek to provide information and offer referral and follow-up services to grandparents and other relatives raising children, to link them to the benefits and services that they or the children need. [SHARE New Mexico](#) is a successful example of an effective kinship navigation program embedded within a more comprehensive family caregiver program. SHARE serves as a “first stop” to connect caregivers with existing resources such as family support, trauma assistance, support groups, legal aid, benefits assistance, and community resources.

Meanwhile, in an evaluation of the suite of caregiver services offered at the Atlanta VA Health Care System, the caregiver support programming was found to be beneficial to caregivers through such mechanisms as increased knowledge of dementia, greater social support, increased self-efficacy to care for the veteran, behavior modification, and an emphasis on caregiver well-being (Biello, et al., 2019).

“With very limited funding under the National Family Caregiver Support Program in the state of [redacted], our Area Agencies on Aging have only been able to serve a very small and limited amount of the thousands of family caregivers in our state.”

-Response to the ACL RFI

The significant challenge, as noted, relates to scalability. Each of these promising programs limit eligibility to specific caregiver populations—in this case, Veterans, adults and/or their caregivers, or grandparent caregivers. Millions of family caregivers do not fall into these groups and do not have access to a comprehensive direct support caregiver program. Instead, they are left to fashion their own support systems while juggling the needs of the family member they care for and their own well-being. It is worth noting that even within the programs, access is not equally distributed. There are often lengthy waitlists for many of these programs and significant unmet need around the country for services for individuals who meet eligibility criteria.

Single-Service Approaches

An alternative to the wrap-around model of caregiver support is the use of stand-alone programs—such as respite care, counseling, or support groups—that address discrete caregiver needs. A key example of an effective single service is the [Lifespan Respite Care Program](#), which is administered by ACL. The program helps build and sustain “systems of accessible, community-based respite care for family caregivers of children and adults of all ages with special needs.”

Respite Care: An Essential Caregiver Support

While caregivers report significant emotional and spiritual rewards from the caregiving experience, they also experience physical and emotional issues as a result of the demands of their caregiving responsibilities. The concept of respite as a supportive service is based on the premise that giving caregivers a break from daily, ongoing caregiving responsibilities will benefit their physical and emotional health and enable them to provide caregiving support for longer. Despite the benefits, respite remains an underutilized support for family caregivers. To advance understanding of the value of respite, the ARCH National Respite Network and Resource Center convened a work group in 2015 to develop a research agenda for respite care. The work group defined the term “respite care” as:

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.”

For more information on currently available respite care programs, refer to [Section III. Existing Federal Approaches to Assisting Caregivers](#).

This is important because respite has been found in several studies to improve family caregiver resilience and benefit their physical and emotional health. One study found that respite can improve resilience in caregivers of people living with dementia, which is often a particularly intense form of caregiving, especially when people are in the advanced stages of the illness (Roberts & Struckmeyer, 2018).

Single-service interventions, like respite care services, benefit from greater flexibility and adaptability to changing environments. However, many caregivers experience barriers to accessing these services. The COVID-19 pandemic has increased awareness among families of the need for respite at the same time that, due to risk of infection for both care providers and the people receiving support, many services have suspended operations. Recognizing the need for increased awareness of the value of respite and greater access to services, the council developed [Recommendation 3.2](#), which specifically focuses on expanding use of respite care.

“I have heard the phrase ‘I wish I had known about you sooner’ countless times from exhausted family caregivers.”

-Response to the ACL RFI

Training and Education

A significant body of research has shown that caregivers need education and information to be more successful in their roles. Family caregivers need trusted information on a range of topics, from how to perform functions necessary to provide care (e.g., dressing changes, managing pain, etc.), to how to deal with behaviors (in the case of dementia), to managing stress and emotional challenges that can come with being a caregiver.

A successful example of the effectiveness of caregiver education and training at the federal level is ACL's Alzheimer's Disease Programs Initiative (ADPI). Caregivers of people living with dementia receive training to manage the complex emotions and grief associated with dementia and to manage challenging behaviors. ADPI is dedicated to meeting this challenge by developing what is known as "dementia capability" in states and expanding it in communities. This effort involves funding community-based projects that include training and education specifically for family caregivers of people living with dementia. The program seeks to expand the network of local knowledge and support by training members of the surrounding community in how to recognize the signs of dementia and interact with people living with dementia.

To date, ADPI has trained a wide array of individuals, including paid caregivers, social workers, attorneys, financial professionals, law enforcement, first responders, food service workers, and small business owners. Together, this expansion of community-wide understanding of the needs of people living with dementia and their caregivers provides a foundation for more effective systems of services and supports.

Training is not the only effective method of educating caregivers so they can be successful in their role. Outreach in the form of educational materials also plays an important role. The Consumer Financial Protection Bureau produces [Managing Someone Else's Money guides](#) for the millions of family caregivers who manage money or property. Since 2013, when the guides became available, more than 1,411,038 copies of the guides have been requested for distribution.

Education and training is an area ripe for development because caregiver research has shown "that education and skills training can improve caregiver confidence in managing daily care challenges" (National Academies of Sciences, Engineering, and Medicine, 2016). Increased mastery can boost caregiver confidence, which in turn can lead to reductions in stress and perception of burden.

Peer-to-Peer Approaches

Peer support models pair individuals new to a caregiving situation with someone who has previous experience in the role. Nearly a third of family caregivers have been providing support for five years or more years (AARP and National Alliance

for Caregiving, 2020). These family caregivers have amassed significant knowledge and expertise that is different from the kinds of support formal systems offer. In many cases, these experienced family caregivers are ideally positioned to lend their perspectives and expertise to others with less experience in the role. Peer-to-peer supports can help to reduce reliance on the formal system; as such, it is effective for where there may not be many formal supports available.

For people with IDD, the role of family is unique, and often central in the support and care provided across the lifespan. From 2012-2017, ACL funded the [Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities](#) to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. One of the key approaches identified was peer-to-peer support. One of the reasons for this is that parents of individuals with IDD trying to identify and access appropriate services often find the systems of support complicated and overwhelming. Peer support enables families to navigate systems more effectively, learn from the experiences of other families, feel less alone, and gain hope, ideas, and information.

Caregiver peer support is not readily available in existing service delivery models. One notable federal exception is the [Caregiver Peer Support Mentoring Program](#) which is available as part of VA's Caregiver Support Programming.

Supporting Caregivers in Indian Country: Insights from the ACL Title VI Programs

The OAA established grants for community planning, social services, research, and development for older persons. In 1978, the Act was amended to establish Title VI programs to provide nutrition and supportive services for American Indians, Alaska Natives, and Native Hawaiians (AI/AN/NH). A further expansion added caregiver support services to Title VI, including support for grandparents and other elders raising children. ACL administers the Title VI programs with recognition of the strengths and resiliency of Native elders and with respect for Native communities' sovereignty, culture, and self-determination. A core value of the Native American Caregiver Support Services, as expressed by Tribal leaders, is that the program should not replace the tradition of families caring for their elders. Rather, it provides support that strengthens the family caregiver's role.

In FY2020, Congress authorized \$2.23 billion for ACL under the OAA. Despite significant need, only half of one percent of that figure (just \$10.3 million) was allocated to support Native American family caregivers under Title VI. Currently, ACL oversees 233 individual grants to over 400 Tribal organizations across the nation for Title VI caregiver services; typical services offered by these grants include:

- Information and outreach on topics related to providing care, such as insurance coverage, dementia, diabetes, and substance misuse. In 2018, the program provided approximately 199,495 contacts to provide information on services and programs to 42,198 unduplicated AI/AN/NH elders and their families (Administration for Community Living, 2018).
- Access Assistance. Examples include home visits to assess the needs of both caregivers and recipients of care, help with accessing insurance, Medicare, or medical services and referrals to local health clinics or other medical providers.
- Counseling, support groups, and training. In 2018, the program provided 125,480 units of assistance to 18,346 unduplicated AI/AN/NH elders (Administration for Community Living, 2018).
- Respite care, most typically in the form of payments to a respite care worker (often a family member) for a certain number of hours per week or per month. In 2018, the program provided 245,586 units of respite services to 3,280 unduplicated AI/AN/NH caregivers caring for elders or grandparents caring for their grandchildren (Administration for Community Living, 2018).
- Supplemental services such as supplies and equipment available through lending closets, for example, that support them in their caregiving roles.

A nuanced understanding of cultural beliefs and values toward caregiving in Native communities can assist providers of supportive services to integrate those values into services and demonstrate cultural humility and respect. This, in turn, can help AI/AN/NH caregivers feel their values and beliefs are respected, improving trust and increasing uptake of beneficial supports. Since 2016, an evaluation team has been conducting a three-year study of ACL’s Title VI programs to better understand how Tribal organizations operate their Title VI programs and to measure and document the impact of the programs.

“You never know how wonderful respite is until you don’t have it. And you know, I never knew, so I just adjusted my time and my life to caring for my husband. But now to have it, oh it’s so lovely.”

-Tribal elder comment during a focus group as part of the [ACL Title VI Evaluation](#)

Year 3 of the evaluation focused specifically on caregiver support services, including support for grandparent and kinship caregivers. The evaluation used a mix of information that grantees already collect, as well as new sources of information to describe the implementation and outcomes across services. During site visits held in March, April, and May of 2019, the evaluation team conducted focus groups and interviews to understand caregivers’ experiences with the program, including met and unmet needs related to spirituality; social connectedness and isolation; physical,

mental, and emotional health and wellness; and independence and quality of life. The evaluation and focus group findings revealed that:

- Caregiving, including raising grandchildren, is a rewarding, yet challenging, experience for members of AI/AN/NH communities.
- Many caregivers do not self-identify as caregivers and as a result, may not consider themselves eligible for services.
- When services are received through Title VI, they provide important support to improve the caregiver's overall quality of life.
- Many caregivers view their Title VI program's services holistically and often do not distinguish between services specifically intended to support caregivers in comparison to services intended to support elders. For example, Title VI-supported nutrition and supportive services offered to elders often supported caregivers in their caregiving role(s).
- Many caregivers, including those already receiving some services, were not aware of the breadth of services available or had only recently become familiar with the program.

AI/AN/NH families have a strong tradition of cultural emphasis on in-home care, respect for elders, and community. Yet various forms of historical trauma are significant factors in the lives of Native families, and this history shapes how decisions are made to access services. Funding and delivering supports that recognize and respect the dynamic nature of the caregiver/person receiving support relationships in Native communities is critical for the effective delivery of services to assist them. The final report of the evaluation will be released in 2021 and will be available on the [Services for Native Americans \(OAA Title VI\) webpage](#). ACL is using the preliminary findings to refine program delivery, most recently in developing tools that Tribal organizations can use to improve data collection and stakeholder communication.

To review an overview of the Year 3 evaluation, refer to [Evaluation of the ACT Title VI Programs Year 3 Interim Report](#). For more information on supporting the needs of caregivers in Native communities, refer to [LTSS Research: Annotated Literature Review Caregiver Support in Indian Country](#). A series of [case studies describing AI/AN/NH caregiver support programs at six locations](#) is available on the CMS website.

Inventory of Federal Caregiver Support Programs and Initiatives

In addition to developing recommendations to support family caregivers, the RAISE Family Caregivers Act called for the council to develop a comprehensive inventory of federal programs that assist family caregivers. In 2020, the council embarked on an

information gathering effort to begin developing such an inventory of federal programs that provide some form of direct or indirect assistance to family caregivers.

Information-Gathering Process

Members from both the Family Caregiving Advisory Council and the Supporting Grandparents Raising Grandchildren Advisory Council representing federal agencies responded to a call for information from the ACL Administrator. Each Federal council representative was responsible for surveying his or her home institution to gather specific knowledge important to caregivers and their families and communities, and the staff and organizations who care for those caregivers. Council members also provided referrals to agencies not represented on the council, such as the Treasury Department, to ensure a broad collection of information. When complete, the council will use this information to increase transparency and improve alignment of caregiving support efforts across the federal government while at the same time avoiding duplication of effort and the creation of gaps in service when developing the National Family Caregiving Strategy.

As of May 2021, the council had collected information from the following agencies:

- U.S. Department of Health and Human Services (i.e., multiple operating divisions)
- U.S. Department of Education
- U.S. Department of Labor
- Consumer Financial Protection Bureau
- AmeriCorps
- U.S. Department of Veterans Affairs

Overview of Findings

Within the responses from these agencies, as expected, there was considerable variability in how agencies defined support to caregivers, program scope, level of administration, services provided, and targeted consumers. *In fact, one of the main revelations of the inventory is that there does not exist across the federal government a definition of what a caregiver is, nor are there clear definitions of what constitutes a program, as the GAO previously noted.* Some agencies referred to collections of resources as “programs,” where others used to the same term to describe multi-billion-dollar efforts that addressed a range of caregiver needs.

The inventory process identified 50-plus total programs, although not all federal agencies participated. Three programs funded by the federal government were identified as ones that are holistically caregiver-centered and provide an array of services for a wide range of caregiver needs:

- ACL with its National Family Caregiver Support Program and Lifespan Respite Care Program.
- The Veterans Health Administration's Caregiver Support Program.
- HHS' Administration for Children and Families (ACF) Kinship Navigator Program.

However, because by Congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency, the reach of these programs is limited. In addition, despite identifying a range of programs that offer some level of support to family caregivers, in the initial review, the council was not able to assess or measure to what extent those programs met the existing needs of the nation's millions of family caregivers.

Different congressional authorities and legislative priorities have created a piecemeal approach to various aspects of caregiving. There are no programs that cover the broad array of supports for caregivers of people with disabilities of all ages. In other ways, the piecemeal approach has led to overlaps between disparate programs. For example, six separate programs operated by three different federal agencies address—to some degree—the needs of rural caregivers. The programs, such as the Rural Health Care Services Outreach Program, a series of grants funded by the Health Resources and Services Administration (HRSA), tended to address isolation, much-needed improvements to care delivery, and access to timely quality care in rural settings. However, it was not clear on initial review which of these efforts included practical resources that might benefit, for example, a rural caregiver in need of transportation to a medical appointment—an important challenge for rural caregivers. Nor were any programs identified in 2020 that addressed the pressing need among rural individuals for improved telecommunications and broadband access and increased digital literacy.

In addition, several agencies identified person-centered initiatives and programs. An example of this is the Patient Listening Sessions offered by the U.S. Food and Drug Administration (FDA). Programs such as this are not aimed specifically at caregivers, but caregivers are important stakeholders who benefit from their existence. If those person-centered services were removed, it is likely that more tasks would fall to the family caregiver.

“The bureaucracy is a stone wall that [family caregivers] don’t know how to climb, and there is no one to teach them. Hard earned money is spent when a grant is available. Services go unused. The ailing family member doesn’t receive the most care that they could receive because the family caregiver is left alone to find their way, blindfolded, exhausted, scared, and guilty that the one they love is depending on them and they aren’t able to find the help that they suspect is out there—somewhere.”

– *Response to the ACL RFI*

In sum, the council found that the federal government provides some level of support to family caregivers. However, this figure belies the fact that one of the most commonly cited concerns of family caregivers is the lack of consistent government support. This appears throughout the literature and in the RFI and reflects the experience of multiple council members and public participants in council deliberations. Moreover, the existing patchwork of family caregiver programs is not flexible and culturally sensitive enough to address the needs of diverse populations, nor the size of the caregiving population. This was particularly evident in RFI comments indicating caregivers are not aware of existing programs or do not feel existing programs are flexible enough to meet their needs.

The programs identified during the information-gathering process were diverse in size, scope, and mission. There also appeared to be four root causes for the development and maintenance of federal caregiver support efforts:

- Caregiver specific funding was authorized or mandated by way of legislation.
- Caregiver support programming was developed because it was wrapped into a set of services and supports that addressed the needs of the given population.
- Caregiver support was an area of interest that was through specific funding lines as demonstration projects, or through research grants.
- Caregiver support education was considered so critical that the organization developed services or educational strategies within existing budget lines.

Because of these foundational disparities, the programs identified rarely appeared to be holistically caregiver-centered in their design. Rather, the support of the caregiver was often a secondary focus of the effort. For example, the programs administered by HHS focus on health care or social services, even though some services to caregivers are available. Programs administered by the Department of Education, focus, as one would expect on childhood education. There does not appear to be a unifying set of definitions of caregiving or of ways of measuring caregiver needs and tracking efficacy. As previously noted, there is no consensus on the statistical prevalence of caregiving. This suggests that there are differing perspectives across federal agencies of the need for interventions to support family caregivers.

These disparities create dissonance between existing programs, which reduces the effectiveness of broad caregiver support efforts. A summary comparison of the list of submitted program descriptions against the five priority (recommendations) areas identified by the council and adopted in November 2020 reveals significant gaps in programs and initiatives that focus on increasing awareness of family caregiving and those that address its related financial challenges. At the same time, while there were a relatively robust number of programs that appeared to conduct research or engage in data collection about caregiving, there does not appear to be coordination across these efforts or a consistent mechanism for information sharing. Finally, while the greatest number of programs offered services and supports to assist caregivers, the anecdotal findings of the RFI suggest that those services are difficult to access and many caregivers do not know they exist, suggesting a need for a mechanism for national coordination of information about services and supports, similar to the Kinship Navigator programs, described here.

In addition, funding mechanisms also varied considerably, which can affect administrative flexibility. Some of the federal efforts, such as the National Family Caregiver Support Program, are funded by way of public law and legislative authority. Other organizations appear to have developed pathways within their operations to pursue supports and strategies that have been found to be important and effective within a unique population served by the agency or within of the area expertise of the agency. An example of this is the [Family Support Technical Assistance Center](#), funded by the Substance Abuse and Mental Health Services Administration, which provides support to family and caregivers of children who experience serious mental illness and/or substance use disorders.

“Although there are many government agencies at all levels whose missions are to provide support, the reality is that the needed support is not there. I have checked online resources and have contacted various agencies but ultimately find myself isolated without support.”

-Response to the ACL RFI

Most of the programs identified were modest in size and funding. Only three agencies offered programs that focused specifically on the needs of the caregiver as a primary driver of program design:

- ACL’s NFCSP and Lifespan Respite Care Program.
- The Veterans Health Administration’s Caregiver Support Program.
- HHS’ Administration for Children and Families’ (ACF’s) Kinship Navigator Program.

Because by congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency—the reach of these programs is

limited. Funding for these programs is also limited. This fragmentary and disparate approach creates missed opportunities for more comprehensive support that comes at significant risk to the ability of family caregivers to support their family members over time. It also hampers the ability to develop and evaluate best practices for caregiver support because most existing programs focus on populations defined by specific, but disparate factors such as disease (e.g., cancer caregiving), Medicaid status, age of the caregiver or person receiving care (National Family Caregiver Support Program). These categorizations limit the ability to collect data that reflects the true complexity and heterogeneity of family caregiver needs.

A significant limitation of the information-gathering process was the fact that even within specific agencies, not all programs were easily identifiable as direct or indirect sources of support to family caregivers. It quickly became clear to ACL staff that developing the inventory would necessarily be an iterative process as awareness increases across the federal government about systemic information gathering as a necessary step in developing programs that support family caregivers. For this reason, the [Inventory of Federal Caregiver Support Programs and Initiatives](#) will be updated over time with updates provided to the council.

The Interplay between Family Caregiving and the Medicaid and Medicare Programs

Two of the most significant and well-known programs that assist—or have the potential to assist—family caregivers are Medicaid and Medicare. The RAISE Family Caregivers Act calls for an analysis of the relationship between federal programs and caregiving. Specifically, the statute calls for “an evaluation of how family caregiving impacts the Medicare program, the Medicaid program, and other Federal programs” (RAISE Family Caregivers Act of 2017, 2018).

The passage of Medicare and Medicaid in 1965 created health coverage systems for adults over age 65 and people with low income, and later for people with disabilities. Prior to Medicare, only about half of older adults had some type of hospital insurance (Moon, 1996). The program was expanded in 1972 to cover certain people under age 65 who have a long-term disability. Today, 60 million people (18% of the population) receive Medicare benefits either through Medicare’s traditional fee-for-service program, or through Medicare Advantage plans, which are offered by private insurance companies that contract with Medicare.

Medicaid & Caregiving

As previously noted, Medicaid is the primary payer of LTSS, covering just over half of all spending for such services and supports in the nation (Murray, Tourtellotte, Lipson, & Wysocki, 2021). Medicaid is administered as a joint federal-state program between the federal government and individual states, the District of Columbia, and

the territories. According to the [February 2021 Medicaid & CHIP Enrollment Data](#), 74.2 million people were enrolled in Medicaid (Centers for Medicare & Medicaid, 2021).

Although the federal government pays a portion of Medicaid costs, individual states administer and operate the program within federal guidelines. Each state’s program is unique; they differ from one another depending on beneficiary demographics, program goals, appropriations, revenues, and priorities of the specific state. To qualify for Medicaid, individuals must meet certain categorical and financial requirements. Eligibility for specific long-term services and supports is then determined based on functional requirements of the individual (Centers for Medicare & Medicaid Services, 2020b). These criteria differ by state. According to the [Medicaid and CHIP Scorecard](#), some states have chosen to deliver Medicaid benefits and additional services through managed care delivery systems. States may also use statutory authorities to offer coverage or extend specific benefits to a target population. This variability has a significant impact on family caregivers trying to navigate the health care system.

Most Medicaid-funded efforts to support family caregivers are through home and community-based services (HCBS). There are a number of Medicaid mechanisms by which states can directly or indirectly support Medicaid enrollees and their family caregivers. These vary considerably by state and can include:

- Managed care plans.
- [Health homes](#).
- [1915\(c\), 1915\(j\), 1915\(k\), and home and community-based services waivers](#)
- The [section 1915\(i\) State Plan Home and Community-Based Services benefit](#),
- [1115 demonstrations](#).
- [Money Follows the Person \(MFP\) demonstration grants](#).

States can also establish specific policies relating to caregiver support, such as requiring caregiver assessments or offering referrals to services that can provide practical assistance to the caregiver, such as respite care (Auffill, Burgdorf, & Wolff, 2019). “Consumer directed” or “[self-directed personal assistance](#)” benefits can be provided under these programs and demonstrations, and can also be provided under section 1915(j) of the Social Security Act, and under Home and Community-Based Attendant Services and Supports State Plan Option (Community First Choice) under section 1915(k) of the Act; these sections can also allow a beneficiary to hire family members as paid caregivers. However, these are options provided to states and there is widespread state variation in adoption of these Medicaid options and benefits (Auffill, Burgdorf, & Wolff, 2019).

Yet, despite the availability of multiple mechanisms within Medicaid to assist family caregivers, in reality, access to HCBS through Medicaid that enable family caregivers to continue to provide care is limited. Caregivers, including respondents

to the RFI and members of the council, report confusion, frustration, and stress associated with understanding program and application processes and accessing Medicaid-funded services.

“When it got to a point that I could no longer afford to pay for 24/7 care, I begged Medicaid and local [redacted] representatives to help me keep him home where he was happy and thriving. But they said that, in [redacted], if he wanted to remain on Medicaid, he would have to go into a nursing home. They were willing to spend all that money to institutionalize him, when just helping me financially would have kept him home. We already had a hospital bed and all the other needed paraphernalia.... So, my father unhappily spent the last year and a half of his life in a nursing home.”

-Response to the ACL RFI

Many families find it difficult to access Medicaid waiver services even when they do qualify. Because funding for Medicaid waiver programs permits states to determine the number of participants they will serve, and is in part dependent on appropriations within state budgets, there are considerable budget gaps which lead to lengthy waitlists and difficulties obtaining approval for these expanded services.

According to the Kaiser Family Foundation, 820,000 people are on waiting lists for HCBS waivers across the nation, but because of differences in how states target populations, these waiting lists are not uniform (Musumeci, O’Malley Watts, & Chidambaram, 2020). It is also important to note that for individuals with IDD, waiting lists may be a particular challenge in some states. The average wait time is more than three years but can be decades for some individuals and their families (Friedman C., 2017).

Even though federal regulations stipulate that Medicaid service plans cannot compel unpaid assistance by family members, in practice, many people who qualify for certain Medicaid services may encounter barriers to access because of definitions incorporating the presence of a family caregiver. For example, Florida’s “medical necessity” definition allows MCOs to deny Medicaid-funded services on the grounds that those services are provided for caregiver convenience. This definition has been cited in legal cases to justify reduced levels of services, even when the “convenience” is the caregiver’s need to maintain employment (Carlson, 2016). At least twelve other states have similar provisions in their state’s Medicaid medical necessity definitions, creating significant barriers to family caregivers in accessing respite care, maintaining employment, and ensuring their own well-being (Carlson, 2016).

While managed care plan regulations acknowledge family caregivers, and about half the states now provide LTSS to some Medicaid beneficiaries through managed care plans, at present, caregiver support services are limited (Reinhard, Feinberg, Houser, Choula, & Evans, 2019). Managed care plans can voluntarily provide so called “value-

added services” to their enrollees, such as benefits counseling and behavioral health counseling for family caregivers, but it is worth noting that the cost of those services are not considered in payments to plans under the regulations at 42 CFR 438.3(e)(1).

One program that does directly benefit caregivers is spousal impoverishment protection. While protections for spouses of people living in nursing homes have been available for some time, it was only in 2014 that they were extended to the spouses of all people receiving Medicaid services in the community. A limitation of the program is that states can only use the spousal impoverishment protections when they are authorized by Congress. Currently, that extension is temporary. It remains to be seen if family caregivers of the future will benefit from this protection, (The Consolidated Appropriations Act, 2021 (enacted on December 27, 2020) extended the HCBS spousal impoverishment protections through September 30, 2023). The amount of assets that are protected vary by state; according to the [2020 Long-Term Services and Supports State Scorecard](#), only seven states permit a spouse to keep the maximum amount of income and assets allowed under federal guidelines (AARP, 2020).

Few states provide access to caregiver training or education in their HCBS programs (Friedman, Caldwell, Rapp Kennedy, & Rizzolo, 2019). Despite federal regulations requiring caregiver assessments in some HCBS (i.e., 1915(i) state plan benefits, if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan), the 2020 Long-Term Services and Supports State Scorecard found that while 41 states now conduct assessments of family caregivers, “most of these family caregiver assessments happen in smaller family caregiver support programs rather than in the broader Medicaid programs” (AARP, 2020).

Another consideration regarding support of caregivers is states’ movement toward providing enrollees options to receive services in home and community-based settings rather than in institutional settings. While historically, long-term services and supports have been provided in institutional settings, recent decades have seen a shift toward providing more HCBS options. The process of shifting the proportion of expenditures away from institutional settings and toward HCBS is a process known as “rebalancing.” Federal initiatives including the MFP demonstration and the Balancing Incentives Program (BIP); rulings such as the 1999 Supreme Court decision in [Olmstead v. L.C.](#), which decreed that individuals with disabilities must have equal access to receipt of community-based services; and regulations around services provided through Medicaid authorities that require settings to be truly community-based, contribute toward supporting a movement of services toward home and community-based settings. This shift toward HCBS and person- and family-centered care has also allowed opportunities for Medicaid enrollees to receive care from providers they are familiar with, including, in certain situations, family members (Centers for Medicare & Medicaid Services, 2020a).

NASHP Issue Brief: Medicaid and Family Caregiving

To more fully examine how flexibilities to states as part of rebalancing impact family caregiving, especially in light of opportunities provided by CMS during the COVID-19 pandemic, researchers at NASHP developed, [Medicaid Supports for Family Caregivers](#). In this 2020 report, NASHP noted family caregivers play an important role in states' rebalancing efforts to help Medicaid enrollees remain in their homes and communities rather than enter an institution (Kaye & Teshale, 2020). Their contributions also help offset the cost of personal care services and can delay the need for more costly services, such as hospital and nursing facility services. While a detailed statistical analysis of the economic value of family caregiving to state Medicaid programs has yet to be developed, the economic impact of caregiving is significant.

State Medicaid programs support enrollees directly, and can indirectly support caregivers through training, services, and sometimes payment. However, the report notes that “there are strong indications that family caregivers could benefit from additional supports, especially those targeted to meet caregivers' specific needs. These supports would, in turn, benefit the Medicaid enrollees receiving their care” (Kaye & Teshale, 2020).

Innovative strategies to address critical issues in family caregiver support are underway in some states. The report provides detailed case studies on Medicaid innovations to address critical family caregiver issues, including:

- Colorado, for the In-Home Supportive Services (IHSS) program provided under its three 1915(c) waivers, waives scope of practice laws that dictate what medical services can be provided by which providers (and in some cases, the setting of those services). This flexibility enables family caregivers to be paid to provide skilled health-related activities (Kaye & Teshale, 2020).
- In Florida, the managed care organization (MCO) that serves children and youth with special health care needs (CYSHCN) provides behavioral health services for family caregivers as a value-added service, as required under the MCO's [contract](#) with the state (Kaye & Teshale, 2020).
- Georgia has, within its Elderly and Disabled [1915\(c\) waiver](#), established a mechanism to identify and deliver individualized training to family caregivers that is based on information collected through the care coordination process (Kaye & Teshale, 2020).
- Tennessee, via contract, requires its MCOs to conduct formal caregiver assessments and plan to meet needs identified in the assessment (Kaye & Teshale, 2020).

- In Washington, the state developed two benefits that support family caregivers of older adults, paid for five years using federal funds provided under the state's section 1115 demonstration. One benefit supports unpaid caregivers of Medicaid-eligible individuals (Kaye & Teshale, 2020). The other is for individuals at risk of becoming Medicaid-eligible and incorporates supports for an unpaid caregiver or enrollee services for those who do not have an unpaid caregiver. Both benefits are intended to support care recipient choice and avoid or delay placement in a long-term care facility (Kaye & Teshale, 2020).

An examination of these and other state strategies, research, and input from state officials by NASHP led to the identification by the authors of the report of four interdependent actions that the federal government could take to improve family caregiving as part of the National Family Caregiving Strategy.

1. Foster the spread of innovative family caregiver support strategies tested by leading states.
2. Support the efforts of states to continue to advance their existing innovations and develop new ones.
3. Conduct a comprehensive, systematic effort to identify and disseminate information about states' innovative and tested family caregiver strategies that would help other states choose and implement the strategies that would work best for them, especially in the areas of cost and effectiveness.
4. Measure the number, demographics, contribution, needs, and priorities of the family caregivers who provide support to Medicaid beneficiaries (Kaye & Teshale, 2020).

NASHP concluded the report by noting that these important actions must be considered in light of the COVID-19 pandemic. The pandemic has had “an impact on state budgets [that] will, at least temporarily, make it difficult for states to contemplate implementing any new policies, especially those that require upfront investments” (Kaye & Teshale, 2020). However, aiding family caregivers in their efforts to help the people they support to remain in their own homes could reduce the impact of the pandemic.

In addition, NASHP noted the potential to expand on successful efforts to make HCBS accessible for beneficiaries and families during COVID in 2020, through flexibilities such as telehealth. “The pandemic, however, has also created a window of opportunity during which the federal government can prepare to support states and [that] state officials can use to consider their options” (Kaye & Teshale, 2020).

Although more research is needed to determine the cost effectiveness of federal and state funded HCBS, they are much more aligned with priorities of consumers and their families (Spillman & Urban Institute, 2016). Such services are also in keeping

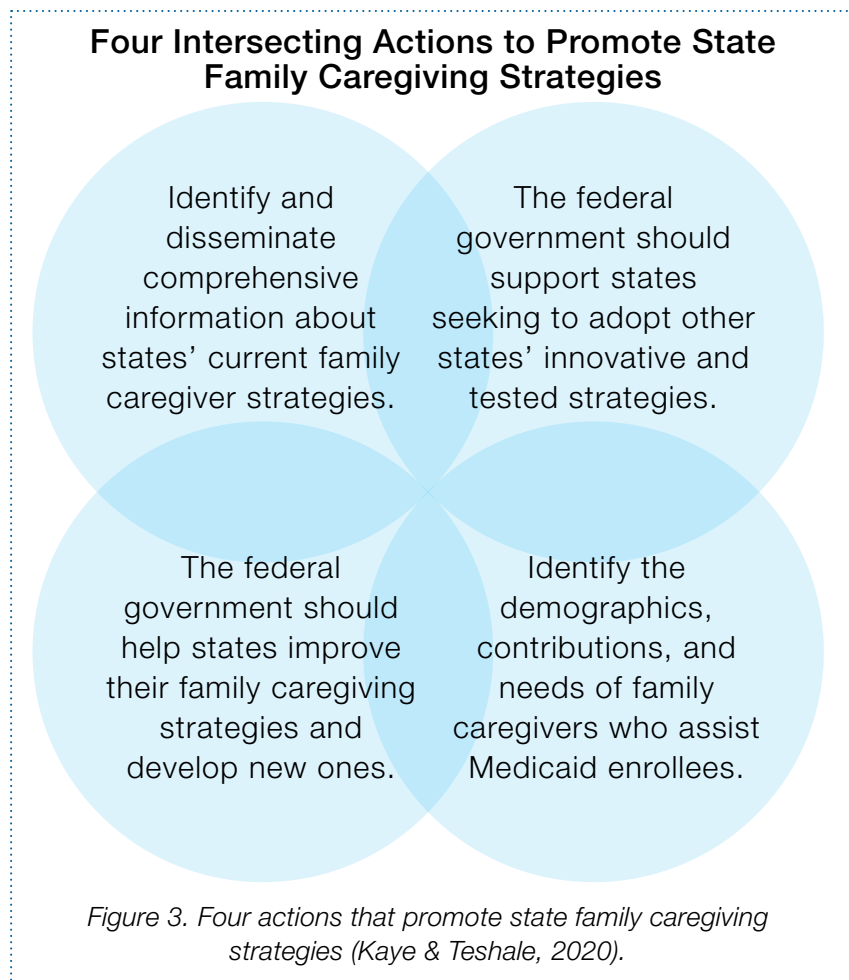
with the U.S. Supreme Court’s decision in *Olmstead*, which found that the “unjustified institutionalization of persons with disabilities” violates the Americans with Disabilities Act.

Medicare & Caregiving

Medicare is the federal health insurance program for adults over age 65, people of all ages with disabilities, and people with end-stage renal disease. It pays for some, but not all medical expenses. Different parts of Medicare help cover specific services. Part A covers hospital and skilled nursing facility stays as well as hospice and some home care. Part B

covers doctor visits, medical supplies, and preventative services. Part D helps pay for prescription medicines (Centers for Medicare & Medicaid Services, n.d.). If a person participates in a [Medicare Advantage Plan](#), he or she receives Medicare-covered services through a private company approved by Medicare.

While Medicaid offers an array of avenues for supporting family caregivers, the picture is very different with Medicare, which provides payment for medical services and hospice care for beneficiaries only. It does not provide direct coverage for family caregivers of beneficiaries. Nor does it compensate caregivers for time spent supporting the medical needs of Medicare beneficiaries. To assist the council in fully understanding the role Medicare could play in supporting caregivers of beneficiaries, [The John A. Hartford Foundation](#) commissioned the [Center for Medicare Advocacy](#) (CMA) to develop an issue brief to inform their work. CMA’s issue brief, [Medicare and Family Caregivers](#), “examines the role Medicare currently plays, and could play, in assisting beneficiaries and their family caregivers” (Center for Medicare Advocacy, 2020).



The brief raises two issues relevant to the intersection of caregiving and Medicare. As noted above, Medicare does not provide any direct services and supports to family caregivers, however, some Medicare programs do indirectly assist family caregivers. The brief notes that of all of Medicare’s benefits, the home health benefit has the greatest potential to positively impact family caregivers through more comprehensive care of the beneficiary. This is because some family caregivers are providing uncompensated services which Medicare would be liable to provide under the provisions of the home health benefit.

For Medicare beneficiaries who qualify, the home health benefit provides health and rehabilitative care for persons who are homebound and can include:

- Part-time or “intermittent” skilled nursing care.
- Physical therapy.
- Occupational therapy.
- Speech-language pathology services.
- Medical social services.
- Part-time or intermittent home health aide services (personal hands-on care).
- Injectable osteoporosis drugs for women.

According to the CMS Home Health Quality Reporting Program webpage, in 2019, 5,266,931 beneficiaries received home health services through 7,439,849 quality episodes of care (Centers for Medicare & Medicaid Services, 2021). “These counts include Medicare Fee for Service, Medicare Advantage, and Medicaid beneficiaries for whom Outcome and Assessment Information Set (OASIS) data collection is required” (Centers for Medicare & Medicaid Services, 2021).

Unfortunately, many families who legally qualify for the home health services benefit under Medicare are denied or do not have access to the benefit (Center for Medicare Advocacy, 2020). The brief noted that “As the population ages, and lives longer with chronic conditions, the need for family caregiving, and support for caregivers, is increasing. Concurrently, however, access to Medicare-covered home health aide care continues to decline” (Center for Medicare Advocacy, 2020).

One reason for this decline, the brief noted, is inaccurate and inconsistent information about eligibility, including the duration of care. “Medicare beneficiaries are often given inaccurate information regarding Medicare home health coverage in general, and home health aides in particular. Sometimes they are told Medicare simply does not cover home health aides” (Center for Medicare Advocacy, 2020).

If the beneficiary is not receiving Medicare home health services, families often find themselves providing caregiver support—and sometimes nursing care—at

their own expense, or foregoing care for the person receiving support. The council determined that, without further study, it is impossible to assess the precise scale of uncompensated support caregivers provide and for which Medicare could be responsible, were the beneficiary deemed eligible.

“It is extremely stressful caring for an elderly family member. In addition to caring for ourselves, the doctor [appointments], shopping, housekeeping, etc. Since by doing this care at home for FREE, it would be only most appropriate that Medicare pay for someone to come in and help the care giver. As we, the care givers are saving Medicare a HUGE amount of money by us taking care of our spouses.”

-Response to the ACL RFI

To realize a vision of Medicare more fully supporting family caregiving, both legislative and administrative changes would be required. The issue brief concluded with three recommendations that could, if implemented, increase support for family caregivers. The recommendations made by CMA in its issue brief include:

- “Ensure the scope of current allowable home health benefits, generally, and home health aides, specifically, are actually provided. Simply put, ensure that current law is followed.
- Create a new stand-alone home health aide benefit that would provide coverage without the current skilled care or homebound requirements, using Medicare’s existing infrastructure as the vehicle for the new coverage.
- Identify other opportunities for further exploration within and without the Medicare program, including additional Medicare revisions, demonstrations, and initiatives overseen by the Center for Medicare & Medicaid Innovation” (Center for Medicare Advocacy, 2020).

The council recognizes that these recommendations are substantial. In at least one case, the creation of a new benefit using Medicare’s existing infrastructure is beyond the scope of the council to approve. Such a change would require Congressional mandate.

IV. Recommendations to Recognize, Assist, Include, Support, & Engage Family Caregivers

“As we put together a report to Congress on FAMILY CAREGIVING, what better IMAGE than a HOME. We are talking about creating an environment where PEOPLE can obtain the most appropriate benefit to them to remain in their HOME—family care.”

—James Cheely, dad, caregiver & member of the Family Caregiving Advisory Council

While family caregiving is universal, there is no singular experience of caregiving. Caregiving takes many forms, and it changes over time. It is a vastly heterogeneous activity that differs for each caregiving situation depending on a variety of circumstances. These include, but are not limited to:

- Sociodemographic factors (e.g., age, sex, education, migration background and ethnicity, religious affiliation, marital status, household, employment, and income).
- The intensity and/or type of caregiving tasks.
- The caregiver’s perceptions of caregiving needs.
- The caregiver’s own health and functioning.
- The types of social/professional supports available to the caregiver.
- The stage of the illness or condition experienced by the person receiving support.
- The nature of the prior relationship between caregiver and the person receiving support.
- The physical home location and environment.
- When caregiving occurs within the life course of the caregiver.
- If the caregiver is caring for other members in the family including children.
- Whether the family has access to medical care and community based services.

Some people become caregivers gradually and over time. For others, it happens in the space of a few hours. The responsibilities can last for days, years, or the rest of one’s life. For family caregivers of children and adults with IDD, caregiving lasts the lifetime of the caregiver, and a significant concern for these caregivers is the well-being of their family member once they (the caregiver) can no longer provide support.

The health of the caregiver also affects the caregiving experience. Many caregivers forego their own medical care during times of intense caregiving and older caregivers are themselves at risk of illness and chronic health conditions. The presence or absence of family or extended family who are available and willing to help is also a differentiator. The geographic distance between the caregiver and the person receiving support, and the transportation and health care access challenges faced by residents of rural areas can have a dramatic effect on the caregiving experience. Lastly, cultural

expectations shape caregiving and the kinds of supports that would benefit any given caregiver (Pinquart & Sorenson, 2005).

No two days in the life of a caregiver are the same. In fact, on any given day, caregivers manage a range of responsibilities to help a care recipient maintain their dignity and independence. Each of these tasks is, in turn, shaped by a constellation of internal and external factors, including, but not limited to, the needs of the person receiving support and the ability of the caregiver to meet those perceived and objective needs.

“Caregivers have taken on the role of nursing staff for these children with complex medical needs. Other family members do not feel comfortable providing the level of medical care these children require. This often leads to caregiver burnout/health issues, trips to the Emergency Department, and divorce among parents of children with special needs due to the stress.”

-Response to the ACL RFI

The types of support that benefit caregivers also differ depending on family and situation. When it comes to caregiving, there is no one-size-fits-all answer. Interventions and policy changes must take into consideration the diversity of caregivers and caregiving situations. For example, during the COVID-19 pandemic, as more caregivers provided round-the-clock care with reduced access to services and supports, there was an increased need for respite services. However, what constitutes “respite” for the spouse of an older adult living with dementia (typically an adult day program) differs significantly from what the parent of a child with autism who also has educational needs would view as an equivalent form of respite.

Yet, despite the immense diversity in the caregiving experience, consistent themes emerged in the council’s deliberations—both in the discussions of the existing research and their own experiences as caregivers and people receiving support. These themes were supported by the findings of the RFI. Foremost among these themes is the commitment among family caregivers to providing the best care possible for the people they support. Other significant themes to emerge from the council’s body of analysis were that caregivers need assistance in the form of services and supports and that caregiving exacts a significant financial toll on families.

Without services and supports, many families take a “do-it-yourself approach” to caregiving. This can leave them stressed, burned out, and often in poorer health than when they started. Because caregiving is not something people generally plan for, it is by nature reactive. Caregivers rarely receive training, which means they learn by doing—putting them at risk of making mistakes and missing opportunities to adopt best practices. It also leaves them vulnerable to unexpected life events, changes in

the condition of the person receiving support which they may feel they have somehow contributed to, and disaster situations—as most recently seen with the pandemic.

They often provide their caregiver support without being included in discussions with providers about their ability or willingness to provide support—it is simply taken for granted that caregivers, regardless of their individual capabilities, will cover whatever tasks need to be done—including those not covered by public and private insurance. Finally, like anyone in a stressful job, caregivers need to take a meaningful and healthy break—but finding the time and someone to cover their caregiving responsibilities is difficult for many families.

Caregiving also affects financial health. During the course of providing support, caregivers often spend money out-of-pocket. If they leave the work force or reduce working hours, they often experience reduced income. This means they save less for the future, contribute less to Social Security, often forego medical insurance, and have a smaller cushion of savings to fall back on—if they have any savings. Some families that responded to the RFI describe the financial fall-out of caregiving as “catastrophic.”

Vision for the Future Where Family Caregivers are Recognized and Supported

These interconnected and overlapping challenges permeate the caregiver experience. If one need is left unaddressed (for example the need for respite), it can impact other aspects of caregiving (such as caregiver fatigue) and ultimately risks a person’s ability to continue caregiving. The council organized the challenges into five priority areas which formed the foundation for a vision of a future state that recognizes and supports caregivers.

In the council’s vision, when the National Family Caregiving Strategy is fully implemented, family caregivers’ physical, emotional, and financial well-being will be meaningfully improved as a result of **expanded awareness, outreach, and education** about the tremendous work they do. Family caregivers will be **recognized, engaged, and supported as key partners with providers of health care and LTSS**. To enable them to carry out their caregiving responsibilities, they will have access to a broad array **of flexible person- and family-centered programs, supports, goods, and services**. They will meet the diverse and dynamic needs of both caregivers and the person receiving support, recognizing that families will need different forms of support depending on their unique needs and circumstances—and these needs can and will change. At the same time, their **lifetime financial and employment security will be protected and enhanced**. And finally, they will be active participants in a robust **national data and research infrastructure** that seeks to document their experiences; translate evidence into best practices and develop person- and family- centered interventions; and measure progress toward the National Family Caregiver Strategy. From this vision, the council developed five goals encompassing awareness,

inclusion, services and supports, financial protections, and increased understanding through research.

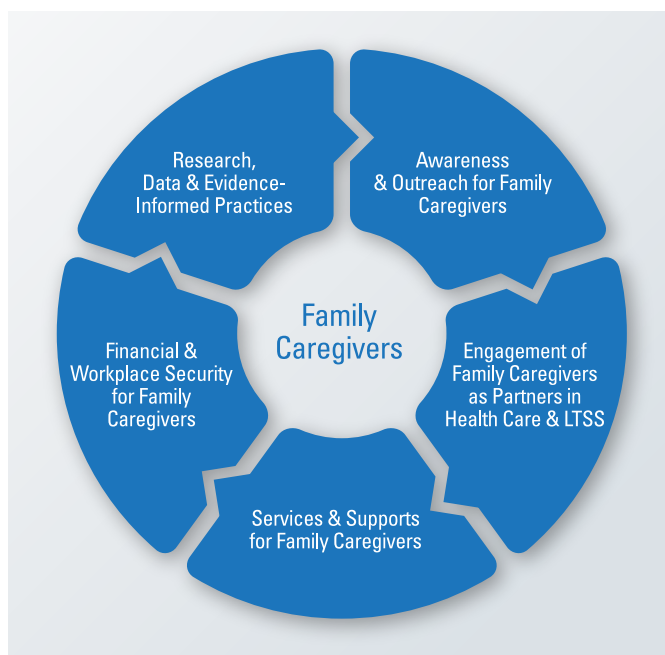
These goals were founded on a set of guiding principles adopted by the council at its inaugural meetings:

- “Family caregiver” is an inclusive and holistic term that includes all who are caring for individuals across the lifecourse with chronic or other health conditions, disabilities, or functional limitations.
- Promoting adoption of person- and family-centered care puts the person and family at the center of care teams, acknowledging the challenges of possible conflicting goals.
- Efforts to support family caregivers should advance the autonomy, choice, and ability of the person receiving support to engage meaningfully in their communities and include caregivers to help guide the care and support needed.
- Recommendations should recognize and support family caregivers in a fair and impartial manner that accounts for financial impact and respects and appreciates their complexity, diversity, and dignity.
- The National Family Caregiving Strategy will be a “living document” with ongoing actions, created in partnership with family caregivers, to be taken by federal, state, and local governments, communities, providers, and others while fostering cross-discipline and cross-sector collaboration.

Over many months, logical and practical recommendations emerged that could begin moving the nation toward the achievement of the stated goals. The council heard presentations from experts in Medicare, Medicaid, Alzheimer’s disease, research, employment leave, respite care, and services and supports. Multiple studies were reviewed in development of the recommendations. Most notably, as part of its technical support to the council, NASHP conducted analysis on 27 key family caregiving reports written in the past decade, reviewing more than 800 recommendations. From this analysis, NASHP developed a list of the most common recommendations, which the council reviewed and considered in the development of its own recommendations.

On November 18, 2020, the Family Caregiving Advisory Council adopted 26 recommendations aimed at establishing a national approach to addressing the needs of family caregivers of all ages and circumstances. These recommendations serve as the foundation for the National Family Caregiving Strategy that will begin development this year. The strategy will outline critical actions that can be taken at the federal and state levels, by local communities, as well as by health and long-term services

providers, and others to better support family caregivers in ways that reflect their diverse needs. The strategy will focus on areas such as person- and family-centered care; assessment and service planning; information, education, and training supports; respite options; and financial and workplace security issues. The strategy will also provide a roadmap for the nation to strengthen its support and recognition of the critical role family caregivers of all ages play in health care and long-term support systems.



Expand Awareness, Outreach, and Education for, and about, Family Caregivers

Caregivers are often forgotten, invisible, overlooked. Many people—including medical professionals—do not understand the nature of the work, the home environment, and the complexity of the responsibilities that caregivers take on. Amid a wide array of daily tasks, most family caregivers are not aware of the services that could assist them—especially when they are new to caregiving. By the time they do access services, they are often in crisis mode.

One reason for this is many people performing caregiving tasks do not realize they are caregivers. Sometimes people resist labeling their contributions as “caregiving” for cultural reasons. Others think of them as inherent in their role as parent, spouse, child, or neighbor or are reluctant to ask for assistance (McCleary, 2019). And finally, some people do not want to take on the negative perceptions associated with the caregiver role (McCleary, 2019). As a result, many caregivers do not seek assistance in their families and communities or through formal services and supports.

“When I first entered my caregiving journey, I did not self-identify as a caregiver. I was just a daughter helping out her mom. But as her vascular dementia worsened, I accepted the reality that I was going to have to shoulder all the responsibilities that come with being a caregiver... This crushingly stressful experience is COMMON.”

-Response to the ACL RFI

Because of these factors, families are often in desperate need of information, support, services, and assistance to navigate the caregiving journey, but do not know what kind

of help is available, whom to ask, or if it is worth taking the time out from caregiving to find answers to these questions. As our population changes, language barriers may also play a role in communication gaps. At the same time, many policy makers and legislators are not aware of the needs, issues, and challenges faced by older adults, injured veterans, people with disabilities, and family caregivers. While social service providers within ACL-funded Aging and Disability Networks and those funded by the Veterans Health Administration actively seek to address the needs of family caregivers, social services across many other domains are only beginning to include family caregivers in their planning. Many health care professionals are not aware of the needs of family caregivers and do not refer them to the types of supports that could help them—if they were more widely available. Many grandparent caregivers report a lack of understanding of their situations, even from education and health care professionals. The end result is that these groups are not reflected in data collection efforts and they miss out on critical services and supports that could promote their health and well-being and—indirectly—that of the person receiving support (Eifert, Adams, Dudley, & Perko, 2015).

Caregivers also report a lack of understanding and appreciation from their social networks and families. One respondent to the RFI spoke for many when they noted, “Siblings not helping is another toll to contend with.”

The council recognized that assisting and supporting family caregivers requires both raising awareness and educating communities about family caregiving. To address this, Goal 1 and the council’s first five recommendations focus on awareness and outreach to and for family caregivers. Additional action steps will be released as part of the National Family Caregiving Strategy.

Goal 1: Family caregivers’ physical, emotional, and financial well-being will meaningfully improve as a result of expanded awareness, outreach, and education.

Recommendation 1.1: Increase public awareness and recognition of the diverse needs, issues, and challenges family caregivers face and of the importance of recognizing and supporting them.

Rationale: Family caregivers provide billions of hours of unpaid support each year. Their caregiving allows the person to remain in the setting of their choice, thus ensuring a higher quality of life than they may experience in a care facility. The family caregiver’s role—its complexity, commitment, and the benefits of support—is not fully understood by those who have not had the experience. As a consequence, they often are unseen and unheard, working around the absence of tools, policies, and social networks. A better understanding of the family caregiver’s role

throughout the care continuum—its breadth, depth, and many evolving activities—can raise awareness and inform or motivate those in a position to increase support. Increased awareness and recognition of family caregivers creates a better understanding, appreciation, and motivation for cross-disciplinary and cross-sector collaboration to affect changes—in new products, services, policies, and legislation—that recognize, assist, include, support, and engage family caregivers in meaningful ways.

Recommendation 1.2: Increase family caregivers’ self-identification and awareness of—and access to—information, services, and supports across a range of topics.

Rationale: Many family members do not think of themselves as “caregivers.” Instead, they self-identify as a parent, grandparent, sibling, child, spouse, partner, friend, or neighbor. As a result, they often do not look proactively for resources and supports. Some may feel guilty looking for support because they feel it is their duty to provide care. They are often not counted in data-collection efforts about family caregiving. Self-identifying with the role, understanding the many facets of the caregiver role, learning when and how to seek assistance, and knowing where to access needed education, training, and skills are important for meeting needs.

Recommendation 1.3: Improve outreach efforts to family caregivers to ensure early identification and access to services and supports.

Rationale: Families and family caregivers are generally a “safety net” of support. However, they often have little awareness of the wide range of medical, physical, emotional, financial, legal, educational, provider coordination, and advocacy assistance that may be necessary. They typically have little awareness on how to obtain needed information. Effective outreach can increase awareness of family caregiving—especially in multicultural or immigrant communities and with family caregivers from non-English-speaking backgrounds—allowing more family caregivers to be recognized and access beneficial programs and services.

Recommendation 1.4: Support the development, or revision of, state, territorial, tribal, and local planning that focuses specifically on recognizing, including, and supporting family caregivers of all ages and is aligned with the National Family Caregiving Strategy.

Rationale: Too often, families and family caregivers are not meaningfully included in the planning or policy development processes undertaken by state, territorial, tribal, and local governments. Often, the focus is only on the person receiving support. Supporting families across the lifecycle should be an integral feature of planning efforts and is an important opportunity to assist them in a holistic way. For maximal impact, such planning efforts should align with the National Family Caregiving Strategy.

Recommendation 1.5: Promote the expansion and role of public/private partnerships at all levels that recognize, assist, include, support, and engage family caregivers.

Rationale: Public-private partnerships can be catalysts for needed change. To create a system that truly supports families, multiple sectors—both public and private—must work together. No single sector can do it alone. Communities, health care providers, LTSS providers, and others can help by recognizing and supporting family caregivers in a manner that reflects their diverse needs. There is a particular need to engage the private sector—employers and industry—to better recognize and support employees who are family caregivers.

Engage Family Caregivers as Partners in Health Care and Long-Term Services and Supports

Even though they are called upon to play an integral role in the care of others, today's health care systems do not generally formally recognize family caregivers. They are often excluded from care planning for which they will have to provide coordination and treatment decisions (National Academies of Sciences, Engineering, and Medicine, 2016). A 2017 survey of family caregivers found that only 10.7% communicated often with the health care team of the person receiving support (Wolff, Freedman, Mulcahy, & Kasper, 2020). One of the reasons for this involves a lack of awareness of the role of family caregivers; health professionals are not trained in person and family-centered care and therefore may not be comfortable or see the value in including caregivers in discussions, or the care recipient may not wish them to participate.

“All too often I see that our services and programs are too fragmented, difficult to interpret, left up to various interpretations and take far too long to be processed leaving caregivers to fend for themselves and perhaps even worse by giving them false hopes and too little help that comes far too late.”

-Response to the ACL RFI

Family caregivers are often a critical link to ensuring that the instructions of medical providers are implemented outside of the physician's office or hospital. They are often also in the best position to identify symptoms that mean additional medical intervention should be sought out, suggesting that the inclusion of the family caregiver in the health care team has the potential to improve outcomes. Providing quality care for the person receiving support—whether cancer treatment or community-based services—often requires a nuanced understanding of the family caregiver's situation, their cultural preferences, their needs, and their ability to perform caregiving tasks. However, rarely are these factors identified or addressed in the recipient's medical records or care plan—even when the care depends upon the contributions of family caregivers (Feinberg & Houser, 2012).

Moreover, when policies are developed, the needs of caregivers are rarely taken into account. Anecdotal accounts abound of people being discharged from hospitals to homes that are unprepared to receive them because the caregivers were not involved in the medical and discharge decision making process. This problem is so prevalent that of the 37 “typical failures in discharge planning” identified by the Health Services Advisory Group, the first item on the list is: “Failure to actively include the patient and family caregivers in identifying needs and resources and planning for the discharge.” In addition, electronic health records (EHRs) have the potential to identify family caregivers; identify caregiver permissions, as authorized by the person receiving support, in various provider and care settings; and facilitate appropriate record and information sharing, yet at this time, the focus of EHRs has been on patient information, rather than the patient and his or her caregiver or caregivers (Wolff, Darer, & Larsen, Family Caregivers and Consumer Health Information Technology, 2016).

Numerous studies have shown that talking with caregivers directly to better understand their needs, problems, resources, and strengths helps them to maintain their health and sustain their ability to provide care. This, in turn, enables them to prevent or postpone nursing home placement—when appropriate—of the people receiving support (Kelly, Wolfe, Gibson, & Feinberg, 2013). As of 2021, 44 states have passed the CARE Act to address these issues, but all care transitions—whether from a hospital to a skilled nursing facility or between providers of social services—should take into consideration the needs of the people responsible for carrying out the plan.

Sixty-five percent of caregivers report communicating with doctors on behalf of their family members (AARP and National Alliance for Caregiving, 2020). Yet they are not universally identified in health records and in many systems do not have access to EHRs. The predominant focus of health information technology to date has been directed at use of EHRs by patients (Wolff, Darer, & Larsen, Family Caregivers and Consumer Health Information Technology, 2016). People with complex medical needs—the types of conditions more likely to benefit from integrated information—are far more likely to require assistance from family caregivers. Accordingly, these caregivers typically perform a range of tasks that are included in EHRs, such as scheduling appointments, communicating with providers, coordinating care and care transitions, and tracking and managing medications. Yet, their role in health information technology is “largely undefined and poorly understood” (Wolff, Darer, & Larsen, Family Caregivers and Consumer Health Information Technology, 2016).

Integrating family caregivers as appropriate into health care settings and decision-making processes will require a layered approach, including educating medical and social services professionals about caregiving and implementing processes to accurately assess caregivers and address their needs. The council recognized that involving caregivers in treatment decisions and care planning, and adequately planning resources and training when the care plan changes, leads to improved quality of care

for the care receiver and increased ability to perform tasks with decreased stress for the caregiver. The council also noted that it is important to acknowledge the vital role of self-determination and not assume that the next-of-kin is a caregiver who should be automatically included in health care decisions or access to EHRs, without approval from the person receiving care. To address this, Goal 2 and the council's related set of recommendations focus on integrating family caregivers into health care settings and decision-making processes through a layered approach, including educating health care professionals, assessing caregivers and their needs, and ensuring that the preferences of the person receiving support are prioritized. Additional action steps will be released as part of the National Family Caregiving Strategy.

Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of health care and long-term services and supports.

Recommendation 2.1: Identify and include family caregivers as essential members and partners in the care team of the person receiving support.

Rationale: While family caregivers are integral in the health and well-being of the person receiving support, they are often not considered part of the care team and their role is not fully understood. Even when acknowledged, caregivers often are assigned tasks without regard to their current workload or abilities. Identifying the family caregiver will achieve the full complement of the care team and ensure appropriate inclusions and information dissemination. Understanding the scope of the caregiving role, and their level and method of training, will lead to the proper engagement of assigned tasks, with communication, acknowledgement, and, if accepted, the appropriate support. Regardless of which care team member is responsible for the task, family caregivers help ensure quality care. Appropriate inclusion of the caregiver has the potential to improve outcomes.

Recommendation 2.2: Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.

Rationale: The caregiver role is poorly understood by those surrounding the caregiver. When providers identify family caregivers and ask them about their own needs and preferences, as well as their willingness and ability to provide support, they gain a better understanding of abilities and potential needs. Information gathering should be based on a reliable and evidence-based set of questions. Assessments should not solely be based on the diagnosis of the person needing support, but could include the needs of the family as appropriate, in a variety of situations and settings.

Recommendation 2.3: Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and the person receiving support.

Rationale: Family caregivers often are *de facto* care coordinators who help navigate different systems of providers and services. However, sometimes caregivers and the people they are supporting fall through the cracks when switching providers or health care settings and information is not conveyed. Improvements to care coordination could be achieved by involving the family caregivers as part of transition planning.

Recommendation 2.4: Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in health care systems.

Rationale: The caregiver, and in some cases the family as a whole, needs to be considered when assessing and understanding the potential impacts of changes to health care policy and practice. Such actions may have unforeseen impacts on the family. Consideration and understanding of how such changes may affect those providing support can minimize unanticipated negative impacts and ensure greater integration of family members in the delivery of services and supports.

Recommendation 2.5: Strengthen the training of health care, social service, and allied health professionals to maximize family caregiver engagement and referrals to services in the community.

Rationale: The lack of an adequately trained direct support workforce—especially in geriatrics, public health, palliative care, mental health, substance use, and related topics—impairs the ability to provide person- and family-centered care. The training of such providers includes not only initial academic curriculum but also continuing education and clinical experiences. These professionals should be able to effectively recognize and respond to the needs of caregivers. These competencies that directly affect family caregivers could be included in training, textbooks, licensure, and certification/recertification exams.

Increase Access to Services and Supports for Family Caregivers

Caregiving requires significant investments of time that often come at the expense of employment, other relationships, social engagement, and self-care on the part of the caregiver. Caregivers also delay their own treatment and/or receive inadequate health care treatment when they most need it. One in 4 caregivers found it difficult to take care of their own health (23%) and a similar proportion report caregiving has made their own health worse (23%) (AARP and National Alliance for Caregiving, 2020). Evidence also suggests that caregivers have lower self-ratings of physical health, more

chronic disease, and impaired health behaviors compared to non-caregivers (National Academies of Sciences, Engineering, and Medicine, 2016).

Family caregivers of people with dementia have an extensive and well-documented risk of caregiver distress due to the intense, and often protracted nature of their caregiving. Examples of the negative outcomes noted over recent decades experienced by caregivers of people with dementia include financial risks, “impaired life quality (depressive symptomatology, burden, stress); physical morbidities; suicidal ideation; and dementia” (Gitlin, Marx, Stanley, & Hodgson, 2015).

“I’m exhausted. I work full time to support my own family, stay at my parent’s home because of their state of being and try to maintain my own piece of mind. ... Besides the poop and pee, washing clothes, preparing meals, cleaning, arranging doctor visits, investigating resources, filling out forms, putting them back to bed when they are up during the night, picking them up off the floor if they fall, maintaining finances, dispensing medication, ordering medication, filing taxes, paying taxes, buying groceries and on and on and on. Not only caring for all of their needs but trying to maintain my own.”

-Response to the ACL RFI

Although many family caregivers say that caring for a child with a disability has had a positive impact on their lives, they report that there is little support for the life-long physical demands of caring for a person with a disability. They experience negative mental and emotional health outcomes due to chronic stress. “Specifically, caregivers of children with developmental disabilities report persistent feelings of anxiety, depression, guilt, and overall psychological distress at a higher rate than non-caregivers. Chronic stress related to the daily, long-term challenges faced by family caregivers of children with development disabilities has been linked to increased risk of heart disease, cancer, gastrointestinal disorders, high blood pressure, overweight/obesity, asthma, and reduced immune functioning.” In addition, family caregivers often deprioritize their own care (Auerbach, Perry, & Chafouleas, 2019).

In addition, caregiving can reduce opportunities for social engagement for the caregiver. Many Kinship caregivers, for example, report having to pass on social invitations or events after they took in grandchildren. Over time, this leads to changes in one’s social network that can be difficult to repair for a busy caregiver. Isolation is not limited to grandparent caregivers. The AARP and the National Alliance for Caregiving report that 20% of family caregivers say they feel alone (National Academies of Sciences, Engineering, and Medicine, 2016).

“We have a 23 year old son with severe autism who is nonverbal. My husband and I provide round-the-clock care for him 24 hours per day, 7 days per week. There are 168 hours in a week and we provide 132 hours of direct, in-home, hands-on care; that is the equivalent of 3.3 full-time jobs (jobs that are unpaid). He has programming for the remaining 36 hours per week, and during those 36 hours we are always on ‘stand-by’ duty via phone.”

-Response to the ACL RFI

One way to address these challenges is through caregiver services and supports. Family caregiver services and supports include information about managing chronic conditions and available services, assistance in gaining access to services and supports, education and training on direct care skills, and respite care (to provide temporary relief from caregiving tasks). Support services may also include counseling, short-term therapy groups to increase coping skills, family meetings, in-person and online support groups, and assistive technologies (Kelly, Wolfe, Gibson, & Feinberg, 2013). Unfortunately, many caregivers find these services difficult to access.

Caregivers rarely receive education and training to help them

Most family caregivers learn by doing. For family caregivers of older adults, the responsibility of caregiving sometimes begins with a middle-of-the-night call from a hospital or comes over time with the increasing awareness that a parent or relative needs more support than previously recognized. Few kinship caregivers anticipate having to take on full responsibility for young children during the so-called “golden years.” Family caregivers of children and adults with disabilities who have been supporting their family members for a long period of time, sometimes become experts in the needs of the person receiving care. But as needs change over time, the role and expectations change, often without notice.

“Caregiver training should start upon diagnosis of a condition requiring care and take place by providers in every setting such as physician office, hospital, outpatient rehab, inpatient rehab, and home health care.”

-Response to the ACL RFI

As health care becomes more complex, care coordination often becomes more difficult. Caregivers, who may not be included in patient care decisions, find care coordination difficult. In addition, according to *Home Alone Revisited*, half of family caregivers are performing medical and/or nursing tasks. Increasingly, these caregivers are responsible for difficult tasks, such as preparing special diets, managing incontinence, and dealing with pain—often with little or no training (Reinhard S., et al., 2019). Inadequately trained family caregivers are left to care despite the fear of making a life-threatening mistake (National Academies of Sciences, Engineering, and Medicine, 2016).

For all family caregivers, understanding the many facets of the caregiver role, and knowing where to access needed education, training, and skills are all essential to successfully meeting the care needs of the person receiving support. Similarly, many family caregivers report significant gaps in the skills of paid caregivers they have tried to hire to supplement their efforts.

As use of telehealth increases, it is also critical to ensure that technology accessibility; broadband access, equipment, and training, are more readily available to family caregivers to ensure more equitable access for those who need technology as a health utility, a social connector, and for ongoing caregiver support services.

Unplanned Events and Emergencies

Caregivers report they are always in “reaction mode.” Many note that there is little time for planning or advance preparation. That means that any potential emergency—a sick child, a lost job, a pandemic—can disrupt the balance of a caregiving situation. While no one can predict every possible crisis, putting systems in place to manage known uncertainties is an essential and necessary support for family caregivers. This can reduce anxiety and minimize the negative impacts of emergencies. In addition, it can ensure emergency responders have the information they need to respond to caregivers and the people they support during a crisis.

The changes in the nature of caregiving have been both highlighted and accelerated by the COVID-19 public health emergency. From personal protective equipment shortages, to closures of services, to vaccine distribution, every stage of the pandemic has shone an increasingly bright light on the role of family caregivers.

For families that were already providing care at home, COVID-19 may have increased caregiving responsibilities. This was largely due to interrupted access to services and supports, concerns about the well-being of family members, and the additional logistical and care coordination challenges associated with caring for a family member during a crisis. Research conducted by the National Rehabilitation Research and Training Center on Family Support, found that “the pandemic ... increased their caregiving responsibilities,” and that providing care became more emotionally, physically, and financially difficult (University of Pittsburgh, 2020). An already marginalized population, family caregivers found themselves wondering who would care for their family members if they got sick when states failed to prioritize them in the same category as the direct care workforce and front line workers for vaccine distribution.

“It took the 2020 pandemic to alleviate long standing challenges for caregivers as service delivery (including groceries, training, support, medical visits) and work transitioned to virtual and more accessible methods. It took the same pandemic to expose the critical significance of the paid workforce to the well-being of people with disabilities and family caregivers, who already were vulnerable from being long underserved due to marginal or non-existent services. They were left stranded to fend in unimaginable ways when services upon which they relied became inaccessible. Those who provide or receive home care deserve a comprehensive standard of protection like that afforded to their counterparts who reside or work in health care settings.”

-Theresa Tanous, MHA, caregiver & member of the Family Caregiving Advisory Council

In addition, thousands of families who previously relied on adult day health programs for respite and therapy for people living with Alzheimer’s disease and related dementias found themselves with limited support at a time when the needs of the person requiring support increased because they were not receiving the services they previously relied upon. Some respite programs moved online quickly, but technological issues were a challenge for many families and did not provide the type of respite that allowed caregivers to perform other tasks or take a meaningful break.

No Time for Planning Ahead

While caregivers are focused on supporting their family member, the needs of people receiving support change over time. As a result, caregivers must constantly adapt. Preparing for change and learning new techniques may not be easy for caregivers who are so often just trying to get through each day. Caregivers themselves change as they age, as life events happen, and as their ability to perform certain tasks evolves. Caregivers of all ages, especially caregivers who support adult children, need assistance with planning for their own futures and the future care of the person receiving support. This is a significant need among current caregivers and people receiving support. According to NAC, fewer than half of caregivers report that their family member has or had plans in place for future care. Only 45% of all caregivers indicate they have plans in place for their own future care; the numbers are even lower for caregivers earning less than \$50,000 per year (AARP and National Alliance for Caregiving, 2020).

“What happens when a primary family caregiver suddenly falls ill? Who will step up to care for their loved one who is unable to care for themselves? What happens when there are no family members, neighbors or friends available at a moment’s notice?”

-Response to the ACL RFI

The council recognized that caregivers need a range of assistance to facilitate their caregiving, now and in the future, and to address the gaps in their lives created by the responsibilities of caregiving. Because of the diverse nature of family caregiving, any interventions must be flexible and adaptive enough to respond in a culturally sensitive way to the unique needs of each family. To address this challenge, Goal 3 and the council’s related set of recommendations focus on achieving an end state where family caregivers’ well-being will meaningfully improve as a result of expanded, easy-to-access and culturally sensitive supports and services. Additional action steps will be released as part of the National Family Caregiving Strategy.

Goal 3: Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods, and services that meet the diverse and dynamic needs of family caregivers and people receiving support.

Recommendation 3.1: Increase access to meaningful and culturally relevant information, services, and supports for family caregivers.

Rationale: Family caregivers need trusted, reliable, and accessible information, services, and supports that are responsive to their immediate needs. Too often, families spend valuable time and energy navigating multiple referrals and sources to obtain services and supports—and then may still be unable to fulfill their needs due to inconsistent eligibility requirements, waiting lists, large out-of-pocket costs, or supports that are not geared toward their situation. Meeting the needs and preferences of the family is only possible when there is both an understanding of and the ability to deliver requested services and supports. Meeting the needs and preferences of the family is more likely to result in successful outcomes for them and the person receiving support.

Recommendation 3.2: Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.

Rationale: Family caregivers often say they need a “break” from caregiving. Respite services give family caregivers that temporary break, so they can have time to care for their own well-being and mental health. However, the vast majority of family caregivers never use respite, citing barriers such as cost, availability, inconsistent provider training, and reluctance to leave their family member in someone else’s care. Some people receiving support also resist being cared for by an unfamiliar person. Ensuring the affordability, quality, and availability of respite care is a critical component of a holistic approach to supporting families.

Recommendation 3.3: Increase the availability of diverse counseling, training, peer support, and education opportunities for family caregivers, including evidence-informed interventions.

Rationale: Many caregivers provide complex supports including those of a medical nature. Some are asked to perform caregiving tasks they may not feel comfortable or able to do, and need support through training and education. However, training and education opportunities specifically for unpaid caregivers—such as in caregiving basics, medical/nursing tasks, financial caregiving, legal issues, mental health support, communication, physical tasks, caregiver self-care, and/or end-of-life care—are not widely available. Family caregivers may also feel stress from challenges that arise during caregiving. They may need access to counseling and peer support from those who understand their caregiving situation. Evidence-informed interventions to provide training and education opportunities will help family caregivers develop skills and give them the confidence and tools to provide care.

Recommendation 3.4: Expand caregiver support programs and services that maintain the health and independence of families by increasing access to housing, safe living accommodations, food, and transportation, and by reducing social isolation.

Rationale: Family caregivers need more than support with the tasks related to caregiving. They also need a holistic approach that ensures they have access to accessible housing and home repair support, dietary needs, transportation, and social engagement. These social determinants of health contribute to their ability to maintain their own well-being and that of the person receiving support. Adequately addressing these factors is an important investment that could contribute to long-term cost savings.

Recommendation 3.5: Encourage use of technology solutions as a means of supporting family caregivers.

Rationale: Technology can help support family caregivers and the people receiving support to meet regular support needs, especially when caregivers cannot be there in person. However, it is only helpful if people have equal access and skills to use it. The COVID-19 pandemic highlighted the importance of technology as a means of supporting both caregivers and people receiving support. Examples include telehealth, online training, counseling, and support groups. As a result, there is a significant opportunity to expand the use of technology, including access to evidence-based treatments from trained practitioners, and make it part of standard efforts to support family caregivers.

Recommendation 3.6: Expand use of vetted volunteers and volunteerism as a means of supporting family caregivers.

Rationale: Many caregivers have great need for support, which is often unaffordable or unavailable. Volunteers have long been a mainstay of the LTSS system providing respite, meal delivery, transportation, and social interaction while being relatively cost effective for both programs and families. Expanding volunteer opportunities can both increase the availability of direct supports and create a path for expanding the direct care workforce. It is important to note, however, that coordination and training of volunteers requires an investment so they have adequate supports to remain engaged in their volunteerism.

Recommendation 3.7: Improve the support of family caregivers during emergencies (e.g., pandemics, natural/human-caused disasters).

Rationale: Emergencies can encompass many events, including weather, pandemics, natural and human-caused disasters, and economic instability. Family caregivers continue to support those who are the most at-risk and vulnerable during these times. They can benefit from both short- and long-term emergency preparedness planning. Yet, formal systems have not yet been put in place to support structures for caregivers to use in crisis response. For example, localities knowing which caregivers in the community will need additional help during emergencies can allow for coordinating immediate support and response. Putting systems in place to support caregivers during times of crisis, and to support them in developing emergency plans, may help lessen the impact of emergencies on caregivers and the people receiving support.

Recommendation 3.8: Increase the prevalence and use of future planning to ensure family members have the needed supports in place throughout the life of the person receiving support.

Rationale: Planning activities are proactive measures that provide the guideposts for prudent resource management and sound decision making, as well as timely skills, resources, and training acquisition. For some individuals with lifelong disabilities, future planning is needed when aging family caregivers can no longer provide care and other family members assume greater caregiving roles. The bottom line is family caregivers want a game plan. Supporting caregivers by providing resources to proactively approach future planning can help caregivers put plans in place, honor the wishes of the person receiving support, and meet care goals. Planning also can help conserve financial resources and maintain the caregiver's personal well-being.

Recommendation 3.9: Increase and strengthen the paid LTSS and direct support workforce.

Rationale: Paid care workers provide an essential service, supporting the needs of a wide range of individuals including older adults, people with disabilities, and children and youth with serious long-term support needs. However, there is a shortage of paid workers, especially direct support workers such as personal care attendants, home health aides, and nursing assistants. They face low pay, a lack of benefits, and few opportunities for career development, which contributes to high turnover and creates significant challenges for family caregivers in finding reliable, quality care. Strategies include focusing on recruitment and retention of direct care workers; improving wages, benefits, and uptake of self-direction, and other career or employment incentives.

Ensure Financial and Workplace Security for Family Caregivers

Financial issues are a significant challenge for many family caregivers and cannot be overstated. As people are living longer and requiring more care, family caregivers need to plan for a longer period of time providing increasingly expensive support. This includes stretching their budgets over a longer period of time. Forty-five percent of all caregivers report that caregiving has affected their personal finances. Nineteen percent have left bills unpaid or paid them late, while another 15% have had to borrow money from family or friends. One in 10 struggles to cover basic expenses.

“Our family was devastated by my son’s accident, and then further devastated by the financial ruin that has followed.”

-Response to the ACL RFI

Costs associated with recipients’ needs (e.g., health care, health supplies and equipment, and housing and support services)

Family caregivers frequently cover medical and personal expenses for the person receiving support. They pay for food, meals, entertainment, clothing, housing, and transportation. They often also pay medical bills—or the portions not covered by insurance payers—such as co-pays, pharmacy bills, home modifications, medical equipment, incontinence supplies, and personal protective equipment (Administration for Community Living, 2021). Family caregivers also purchase supports and services—for example, special education services or home care—for their family members when they are not available from community, state, or federal programs (National Academies of Sciences, Engineering, and Medicine, 2016).

A 2016 caregiving cost study conducted by AARP found that three-quarters of family caregivers surveyed incurred out-of-pocket monetary costs as a result of caregiving.

The estimated per family spending on family caregiving was roughly \$7,000 per year (\$6,594). Of this, household expenditures (e.g., rent, mortgage, home modifications) accounted for 41% of spending, while medical expenses accounted for a quarter of spending. Out-of-pocket spending was higher for certain groups of caregivers. Families supporting an individual living with dementia, tended to spend more money out-of-pocket than other families. In addition, while white families in the survey reported spending an average of 14% of their income on caregiving, the Hispanic and Latino caregivers who participated in the study spent 44% of their income on caregiving, and the African American caregivers spent 34% of their income on caregiving (Rainville, Skufca, & Mehegan, November 2016).

Workplace protections and supports for caregivers

At the same time that family caregivers are experiencing significant out-of-pocket monetary expenses as part of their caregiving, their ability to maintain consistent income levels is often threatened by workplace policies that are not flexible enough for family caregiving. Financial issues stemming from lack of workplace flexibilities and protections for caregivers was a prominent theme in the RFI.

Unlike previous generations, most family caregivers today work in paying jobs. In fact, 61% of caregivers are employed, and they work an average of 35.7 hours per week. Those figures increase for younger caregivers. Almost three-quarters of caregivers under age 49 are employed. Family caregiving has a significant impact on their work lives. More than two-thirds of working caregivers have had to make an accommodation at work (cutting back on hours, for example) to allow them to juggle their caregiving responsibilities (AARP and National Alliance for Caregiving, 2020).

“Employers need education about caregiving to better understand the complexity and scope of the issue. Employers should offer benefits for family caregivers such as flex time, telecommuting, increased sick time/personal leave, on-site educational opportunities and support groups, improved Family Leave policy that includes all types of caregivers (not just parents) and paid leave, caregiver tax credit and improved [Employee Assistance Program] EAP Support and Referral.”

-Response to the ACL RFI

According to the National Business Group on Health, 70% of working caregivers experience work problems due to their role (Burden, 2019). Intensive caregiving (defined as providing 21 or more hours of care per week), notes AARP, is “associated with early retirement and other work-related impacts, such as giving up work entirely, reducing work hours, or taking a less demanding job” (Feinberg L. F., 2019). A study by the GAO estimated that 68% of working caregivers who support either a spouse or a parent had to adjust their schedules (arriving late to work, leaving early, or taking time off) as a result of their caregiving (Burden, 2019).

These accommodations come at significant risk to the long-term financial stability of family caregivers. In addition to lost wages, caregivers may lose health insurance or Social Security and retirement benefits and miss out on career opportunities when they reduce hours or leave the workforce (even temporarily). There is evidence that caring for a parent in mid-life substantially increases a woman’s risk of living in poverty in older age. Even in the short-term, because many employed family caregivers do not have paid sick days or paid family leave benefits—a day missed from work can have a significant impact on the financial well-being of the family (National Academies of Sciences, Engineering, and Medicine, 2016). This issue has intensified during the pandemic.

Even if caregivers are eligible for time off work, many are simply not aware of their right to do so or do not feel comfortable due to fears of bias or stigma related to family caregiving. Over a quarter century ago, the Family and Medical Leave Act (FMLA) was signed into law, giving covered workers access to 12 weeks of unpaid parental, medical, and caregiving leave. Yet only 59% of American workers have access to FMLA leave due to coverage limitations. Other caregivers do not qualify due to definitions of qualified caregivers under the current law.

These statutory limitations can have a ripple effect. This was most notable, in the issue of paid leave, in 2020 with the passage of the [Families First Coronavirus Response Act](#), which required certain employers to provide employees with paid sick leave or expanded family and medical leave for specified reasons related to COVID-19. While the statute provided paid time off work for parents of a child who was sick or had lost services due to closures and lockdowns, it did not cover leave for family caregivers, including caregivers of adult children no longer able to access services such as adult day care.

In fact, while some employers have provided paid leave and some states have implemented paid leave policies, the overwhelming majority of family caregivers report having no paid family leave at their workplace. If a caregiver needs to miss work, he or she goes without a much-needed paycheck. That has created a significant barrier to taking time off to care for a family member, particularly for low-wage workers (Feinberg L. F., 2019). Caregivers cannot do it all. Without universal workplace protections for family caregivers, family caregiving will continue to involve painful choices between providing care and earning a living.

Financial security for the future

When it comes to future financial security, many family caregivers are so focused on the struggle to pay rent and put food on the table that long-term planning is not possible. Yet, the financial risks associated with caregiving are significant, and they compound over time. Many people never recover financially from the costs of family caregiving. Research has found a positive correlation between caregiving and lower

income later in life. Family caregivers who disrupt their careers or leave the labor force to meet full-time caregiving demands face substantial economic risk and short-term and long-term financial consequences by losing salary, personal retirement savings, eventual Social Security and retirement benefits, career opportunities, and overall financial well-being (Feinberg L. F., 2019). Several respondents to the RFI noted the challenge of qualifying for Social Security benefits as a direct result of their caregiving.

These factors have special significance for female caregivers for whom the likelihood that they will live in poverty and/or rely on public assistance later in life increases with caregiving (Wakabayashi & Donato, 2006). To mitigate the risk of future impoverishment, some family caregivers have to make financial and business decisions on the part of themselves and the person receiving support. That can be a difficult task to do at the beginning of the caregiving experience. Many caregivers are not aware of benefit programs that could help them protect their assets. Others assume they would not qualify if they did take the time out from caregiving to apply. Helping caregivers address the financial risks of caregiving through assistance programs and support with long-term financial planning has the potential to help break the well-recognized cycle of caregivers experiencing declining health due to their caregiving tasks and potentially requiring caregiving assistance themselves.

“I’m not anywhere [near] rich, just above the Medicaid cut off. I have to take my chances that I can handle my husband until he passes because to get help in a care facility will require me to be stripped of my modest assets.”

-Response to the ACL RFI

To address the financial challenges that come with caregiving and to ensure caregivers have the tools to make fiscally sound decisions, family caregivers need a range of financial supports and education services to help prevent impoverishment. The council recognized that family caregivers risk their financial security due to numerous financial challenges brought about from caregiving. To address this, Goal 4 and the council’s related set of recommendations focus on decreasing the negative financial impacts for family caregivers on both a short- and long-term basis. Additional action steps will be released as part of the National Family Caregiving Strategy.

Goal 4: Family caregivers’ lifetime financial and employment security is protected and enhanced.

Recommendation 4.1: Decrease the negative financial impacts for family caregivers on both a short- and long-term basis.

Rationale: Personal finances and future financial security are a significant source of stress for family caregivers. They are concerned about the ability to accommodate

the needs of the person receiving support (including costs associated with health care, health supplies and equipment, housing, and support services) as well as their own needs, now and into the future. Concern about finances also frequently incorporates family caregivers' ability to care for other family members in addition to the person receiving support. Financial health is a core component of maintaining the caregivers' well-being and is critical to meeting the overall goals of the person receiving support and the caregiver.

Recommendation 4.2: Advance the development and broad adoption of employee-centered flexible workplace policies and practices that support work/life balance and maintain performance when personal circumstances change.

Rationale: More than half of working age adults are family caregivers. Many of them have had to miss work because of their caregiving roles, and some of them have ultimately had to reduce their working hours, take a leave of absence, or leave the workforce altogether. Flexible policies and practices can provide caregivers with employee benefits and the tools to balance their work and caregiver role, allowing them to remain in the workforce longer. In return, employers can gain employees' loyalty, retention, and expertise. Public-private partnerships can facilitate financial security and employment policies for family caregivers and prevent discrimination against caregivers in the workplace.

Recommendation 4.3: Increase the availability, and use of, financial education and planning tools for family caregivers.

Rationale: Family caregivers often selflessly respond to the immediate health and financial needs of the person receiving support. They are typically thrown into the role, and a lack of properly managed finances and planning can lead to financial stress. Parents of children with lifelong disabilities, in particular, worry about the future for their children. Financial planning tools and resources for people with disabilities, special needs trusts, and other financial services can empower the caregiver and the person receiving support.

Recommendation 4.4: Improve the affordability of long-term services and supports and reduce out-of-pocket costs for families through public and private payers.

Rationale: Given that the average cost of home based care is about \$35,000 a year and residential care is even more costly, middle-class families do not have the resources to pay for LTSS. Most people receiving support from family caregivers do not meet the strict financial eligibility requirements for public assistance. Medicare does not cover these expenses, and few people have private long-term care insurance or other mechanisms to pay for care. Providing families with choices from an array of financial options available from public/private partnerships can allow

them to pay, and pay longer, for LTSS. Families, the government, and the private sector could benefit by working together on a range of options to help pay for LTSS.

Increased Research, Data, and Understanding of Evidence-Based Practices

Despite the growing body of research into family caregiving, few sources of comprehensive representative data currently exist. Most national surveys do not contain questions that identify family caregiving. Nor are caregivers included in biomedical clinical trials or medical product development. In addition, understanding of the caregiving experience and effective interventions, including best practices, consequences of workplace supports or lack thereof, and paid leave remains limited.

Refer to [The Changing Landscape of Family Caregiving in the United States](#) by Vicki A. Freedman and Jennifer L. Wolf for a discussion of current data sources and the challenges associated with measuring and defining family caregiving.

One analysis of family caregiving for older adults found estimates from eight different surveys ranged from three to 36 million between 1985 and 2010. As noted in the introduction to this report, the current prevalence of unpaid family caregivers is at least 26.4 million in a typical week (Freedman & Wolff, 2020). That number extends to 53 million when considering a one-year timeframe (AARP and National Alliance for

Caregiving, 2020). This wide variance is attributed to differences in data collection depending on the source of information (the person providing care or receiving care), whether (and if so, how) the age of the person receiving support is limited (e.g., to over or under a particular age); the specific types of assistance that are mentioned (e.g., providing physical care, helping with household tasks, assisting with medical care, or providing emotional support); whether the purpose of the care is linked to the recipients' health and functioning, whether a time horizon over which help is provided (e.g., in the past year or month) is mentioned or a minimum duration required; whether the sample is limited to particular types of caregivers (e.g., primary caregivers or spousal caregivers) (Wolff, Freedman, Mulcahy, & Kasper, 2020).

In addition to a lack of standardized data, to date, research has focused on the experiences of adult caregivers. There is no major body of work into the experiences of caregiving youth. A 2017 RAND study commissioned by the Elizabeth Dole Foundation found that there have been no studies or evidence-based research looking at the impact of caregiving on military children, even though these children often perform caregiving tasks (Ramchand, et al., 2014). Similarly, there is little information on the impacts of sibling caregiving or the needs of youth who live in families where the parents are full-time caregivers to other family members.

In addition, little is known about the effectiveness of various strategies, such as cultural competence training, to address the needs of caregivers, with almost no studies available that evaluate possible interventions. Similarly, an understanding of the caregiving experience and effective interventions remains limited. While biomedical trials focusing on patients are plentiful, research projects that capture health information about caregivers are less common. That is slowly beginning to change (Gray & Firpo-Cappiello, 2018). Some research, for example, is under way to assess how integrating family caregivers into cancer trials affects the well-being of the caregiver, the person receiving care, and the outcome of the trial. But researchers have a long way to go in measurably assessing just what kinds of interventions can more effectively assist caregivers and what actions caregivers themselves can take to prevent burnout.

When it comes to research into caregiving, what currently exists is insufficient. Caregivers have not been included in medical device and drug research trials. This lack of participation and information limits the ability to fully measure and assess intervention efficacy, and foregoes opportunities to learn or gain insight for improvements. Finally, when studies do assess caregiver experiences, they often assume the caregiver perspective is part of the patient experience (McCleary, May 2019). In so doing, they fail to distinguish the experience of the person receiving support from that of the caregiver and risk reducing the autonomy and independence of the person receiving support. For example, more than 200 dementia caregiving interventions tested with randomized clinical trials over the past three decades have been found to be efficacious (Gitlin, Marx, Stanley, & Hodgson, 2015). However, they largely remain inaccessible to the population that needs them (Gitlin, Marx, Stanley, & Hodgson, 2015). As the nation looks toward expanding medical research, especially in the wake of the pandemic, studying the role of family caregiving in disease progress and management as well as studying interventions that can assist caregivers are critical. By establishing a national discourse that deepens scientific understanding of all aspects of caregiving, the nation will be better able to identify and support caregivers, which should promote proactive planning and outreach so that care needs are addressed before they become overwhelming.

The [2020 NIA National Dementia Care Summit](#) identified a number of gaps and opportunities in research on caregiving and caregivers of people with dementia.

In 2021, National Academies of Sciences, Engineering, and Medicine released a consensus study on care interventions for individuals with dementia and their caregivers. The study, [Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward](#), proposed three recommendations

to strengthen future research into dementia caregiving. Specifically, with regard to improving research and data collection, the consensus report recommended:

- Prioritize strong, pragmatic, and informative methodologies when identifying funding priorities.
- Prioritize the inclusion of research that promotes equity, diversity, and inclusion across the full range of populations and communities.
- Support research capable of providing the evidence that will ultimately be needed to make inclusive decisions and implement interventions in the real world (National Academies of Sciences, Engineering, and Medicine, 2021).

While the recommendations are dementia-specific, they have some applicability to family caregiving in general and are in line with the council’s overall assessment that including caregivers and refining data and data collection methods can expand the understanding of caregiver needs and care delivery interventions and/or outcomes. To address this, Goal 5 and the council’s related set of recommendations focus on increasing family research and dissemination of promising and evidence-informed practices and using a robust infrastructure that facilitates and supports the necessary methods and practices to achieve this. Additional action steps will be released as part of the National Family Caregiving Strategy.

Goal 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiving Strategy.

Recommendation 5.1: Establish a national infrastructure using standardized data, questions, and definitions for obtaining, analyzing, and disseminating information about caregivers and their experiences.

Rationale: While there is sufficient data to illustrate the importance of family caregiving, formal caregiving data collection processes at a national level are still lacking. State, tribal, local, and federal programs need data collection processes on family caregiving across the lifecourse that are consistent and comparable between programs and governmental entities, to better refine and coordinate services for family caregivers. A nationally coordinated focus on data collection can raise awareness about collecting caregiving data at the state and local levels, and support data collection on a diverse range of caregiver populations. Better and more consistent data could be collected through the development of a core set of family caregiver questions that could be added to existing national and state surveys. A formal data collection process coordinated at a national level would support a body of evidence to develop, plan, and coordinate resources, services and supports; and help identify and document the economic value of family caregiving.

Recommendation 5.2: Increase family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and the person receiving support.

Rationale: Research is needed to better document the needs and impact of caregiving on diverse types of caregivers across the lifecycle. This research is also needed to better understand employment practices on the caregiving experience and document the value of paid leave, and to close service gaps, especially among underserved populations in rural areas, and under-represented communities of color. There is also a need to better understand and document how sexual orientation or gender identity impact the caregiving experience, and how to better support these communities.

Many evidence-supported programs for family caregivers are limited in terms of availability and in the practicality of delivering services in applied settings. The inclusion of family caregivers as research partners in the design and the delivery of services has been found to play an important role in the successful utilization and sustainability of needed services. Research on the impact of caregiving interventions and their return-on-investment is needed to determine the effectiveness in sustaining family caregivers, limiting the cost of institutional care, and scaling up successful supports and interventions.

Recommendation 5.3: Increase the promotion, translation, and dissemination of promising and evidence-informed practices to support family caregivers in the delivery of health care and long-term services and supports.

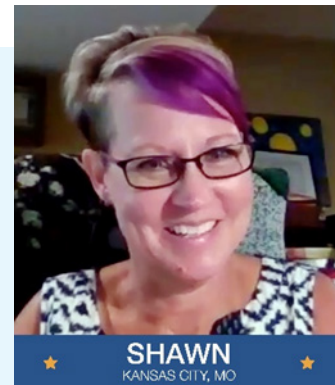
Rationale: A major barrier to implementing family caregiver interventions is translating the research into real-world settings. What is known about effective interventions is that they must be multi-component and address both the pragmatic and the emotional elements of caregiving. Working with diverse communities to develop services and models that best meet their needs, and expanding and replicating promising practices that are person- and family-centered are critical. It is also important to be able to monitor the experiences of caregivers to identify best practices and facilitate dissemination. Building on evidence-informed services for caregivers is fundamental to helping organizations scale up practices and supports that are proven to be impactful and cost-effective.

Family Caregiver Support Needs Should be Addressed

The second-to-last word in the RAISE acronym is “support.” Because they play a critical role in the health and well-being of others and caregiving can impact their own health, support is critical to ensuring the long-term success and well-being of family caregivers. But in order to be successful in their roles, **caregivers need support in the form of respite, education, assistance navigating social service systems, and help mitigating the tremendous financial burdens many family caregivers face.** The stories below show how today’s caregivers make personal sacrifices to support their family members and the financial toll the caregiver role has taken on them.

For [Shawn, a caregiver spouse of an injured veteran](#), making time for self-care is the key to continuing in her role as a caregiver. She, like many caregivers, struggles to find time for a healthy and meaningful break from her responsibilities. Her husband’s needs are so intense that even when someone is providing care in her absence, she feels she must remain accessible to assist if something unexpected happens. For more on the importance of respite that truly provides a meaningful and healthy break from caregiving, refer to [Recommendation 3.2](#).

Shawn has been caring for her veteran husband for 7 years and is an integral part of his care team. Her husband told her about his PTSD and recovering from alcoholism on their very first date. However, Shawn did not fully understand the extent of his condition and its impact on her at the time. She did not realize most of her time would be spent taking care of him, rather than spending time as a couple. The first time Shawn had to talk her husband through a severe flashback associated with his PTSD, she realized she was a caregiver.



Shawn is the type of person who understands she needs breaks for her own mental health, but that still doesn’t make them easy to achieve. When Shawn does things for herself, she ensures she stays in touch with her husband and has others providing care for him. Shawn also recommends that caregivers go to therapy for themselves, in order to have someone to celebrate the highs with and to find support during the lows.

She feels that it can be easy to lose who you are in the role of being a caregiver. Although her husband is set up for retirement, if something happens to him, she would be left with nothing due to quitting her career to take care of him. She now has no retirement and would not get any of his benefits should he pass before she does. Shawn believes that by ensuring caregivers get paid for what they do – providing tax breaks or setting up job recruitment fairs for caregivers – will mean that their livelihood is more likely to be secure.

In the midst of caregiving, it can be hard to find time to navigate differing eligibility requirements across multiple social service programs. Meanwhile, it can be difficult for [caregivers like Sarah](#), or the people they support, to assess what, if any, caregiving needs they may have in the future. This means that over time the administrative hurdles faced by family caregivers to secure needed social services and supports can become overwhelming, leading families to spend their own money securing assistance as care needs increase. That is why it is critical to ensure the impacts of policy and practices on family caregivers are studied and understood before changes are made in health care systems. At the same time, there is a significant need for increases in future planning to ensure family members have the needed supports in place throughout the life of the person receiving support, and to decrease the negative financial impacts for family caregivers on both a short- and long-term basis. For more, refer to [Recommendation 2.4](#), [Recommendation 3.8](#), and [Recommendation 4.1](#).

Sarah spent several years caring for her brother who suffered from cognitive decline, endured physical challenges, and was diagnosed with COPD. He used alcohol to cope with his conditions, which complicated the care Sarah provided. After her brother passed, Sarah realized his behavior was so time consuming that she overlooked early signs of her mother’s cognitive decline. It dawned on Sarah that she had become her mother’s full-time caregiver when her mother’s ceiling fan caught on fire, and rather than calling the fire department, she called Sarah. Sarah’s husband was diagnosed with early onset Alzheimer’s disease at the age of fifty-five. As a professional engineer, he knew he wasn’t his former self when he began to lose his ability to complete calculus equations that he could previously do in his head.



Now, Sarah is providing more than forty hours of care per week. Her caregiving tasks include bathing and toileting, preparing meals, providing transportation, administering pills and injections, and managing finances. Her caregiving duties prevent her from spending time with her grown children and grandchildren. As Sarah’s role as a caregiver demanded more of her time, she was forced to reduce her hours working as a school administrator. Eventually, she felt compelled to retire and leave the workforce entirely. Sarah’s stress as a caregiver is exacerbated by the dynamic of living with her mother, which is particularly difficult for her husband, causing Sarah further distress.

Sarah lives in a rural part of the country and she has long been discouraged by the lack of available services in her area. There are three general practitioners, but no specialists, and in her experience, general practitioners don’t know how to help her with the support she needs.

Her mother has assets which are tied up in the family property. While Sarah and her family realize they can sell her mother’s property to provide her mother with a long-term care solution,

the land is a significant part of their heritage. Therefore, it is important to Sarah’s family that care for her mother remains at home as much as possible. If Sarah’s mother were to require nursing home care, Sarah and her family could lose everything in order to cover expenses.

Caregivers like [Zuzette](#) and [TeriLynne](#) are juggling multiple caregiving responsibilities and coordinating care. Their story is a reminder of difficulties faced by caregivers in rural areas and the need for state, territorial, and tribal planning, including a single source for information that focuses on the coordination of caregiver supports and services, such as access to housing, safe living accommodations, food, transportation, and tools for reducing social isolation. For more, refer to [Recommendation 1.4](#) and [Recommendation 3.4](#).

Zuzette and TeriLynne are from the Gila River Indian Community and have cared for their aging parents, as well as their own children, two of whom have chronic conditions. Zuzette is the primary caregiver for her and TeriLynne’s mother, and supported their mother in the care of their father until his death in June 2020.



In 2013, Zuzette and TeriLynne’s father was diagnosed with dementia – their mother was his primary caregiver, but they were both in their 70s. Zuzette realized she needed to help her mother care for her father in order for her mother to stay as healthy as possible. In 2019, her mother was hospitalized with a liver disease. After that event, Zuzette’s responsibility increased as she needed to make and attend both of her parents’ doctor’s appointments and help with transportation, medication management, and all other household needs. While her father was moved to an assisted living facility, Zuzette continued to care for her mother.

Zuzette and TeriLynne’s parents live on the tribal reservation, but TeriLynne lives 35 minutes away. She tries to balance caregiving responsibilities with her sister, Zuzette, who lives closer to their parents and often handles more caregiving tasks. This often leaves Zuzette feeling overwhelmed and TeriLynne feeling guilty. They feel caring for family members is a valued part of Native American culture.

TeriLynne has struggled balancing work with her caregiving duties. In the past, TeriLynne had to take a lot of time off to care for her parents, leading her supervisor to write her a bad evaluation. Fortunately for TeriLynne, her supervisor has now had her own caregiving experiences and is better prepared to understand and support TeriLynne’s challenges.

TeriLynne feels the hardest part of being a caregiver is learning how to be a caregiver. She wants employers to learn how they can better support employees who are caregivers with

benefits, such as paid leave, flexible work schedules, and work-from-home options. TeriLynne also wants caregivers to have more access to educational trainings, so they can feel more confident in their role. Caregivers “run and run – they never know where the finish line is” and to succeed they need more educational opportunities, and physical and emotional support.

Zuzette didn’t realize she was a ‘caregiver’, and not just a daughter helping her parents, until she attended an Older Americans Title VI conference and took a quiz designed to identify caregivers. The conference changed her perspective – she realized that money had been delegated to support caregivers like herself, and it made her want to share that information with other people in a similar situation. Since then, Zuzette has done extensive research on resources available in her state. She feels there should be one agency dedicated to assisting caregivers; this ‘one-stop’ agency could provide support, connection to needed resources, and planning services for caregivers to financially and emotionally prepare for next steps.

Zuzette’s caregiving journey has been physically and emotionally tiring, but she feels that it’s important to make her parents’ well-being a priority in her life. Recently, Zuzette became ill and her doctors told her it was due to dehydration, not eating well, and not exercising. Now, Zuzette is trying to balance the need to care for herself with her caregiving tasks.

Letty, a caregiver who lives in rural Arizona, *has a hard time finding caregiving supports and services* in her immediate area. She also suffers from her own health issues. She is an example of the millions of family caregivers across the nation who must forego support because they cannot access services in their own or neighboring communities. For these caregivers, increased use of technology, such as culturally relevant telehealth, online trainings, and support groups can mean the difference in being able to sustain their caregiving role and prevent burnout. For more, refer to [Recommendation 3.1](#) and [Recommendation 3.5](#).

Letty’s mother, who had dementia, has since passed on, but Letty still cares for her father. Letty herself is suffering from health issues on top of the support she provides to her parents, and finds it difficult to find the time and the ability to travel to and from clinical appointments.

Letty lives in a rural area in Arizona and has a hard time finding caregiving supports and services. Her calls for information have gone largely unanswered, and when she does find caregiver training or supports in larger cities such as Tucson, she often doesn’t have the resources to travel that far. If more caregiving training was made available online, Letty feels she’d have a much easier time accessing it and learning how to best be supported in her role.

Letty has also described the challenges she has experienced in obtaining needed resources for her parents’ care. She was unable to obtain a replacement Medicare card for her mother, who



had dementia and could not remember the answers to her security questions. She’s had trouble getting oxygen for her father, a life-sustaining resource, because she couldn’t afford the up-front payment. When her mother passed, Letty could not access a bank account her mother held because her father, who is still alive, also has his name on the account. Though her father could access the account, he would need a driver’s license, which he cannot get without traveling to the DMV, something he no longer has the ability to do.

Letty has been fortunate enough to receive in-home medical help from a doctor who visits her parents. Letty attributes her ability to be a successful caregiver to the help she receives from her in-home doctor. Without this help, she doesn’t believe she’d have been able to take care of her father for as long as she has.

Caregivers who are forced to leave the workforce because of the high demands of caregiving are at greater risk of poverty later in life. As [Gary’s story](#) indicates, his wife’s early retirement “decimated her retirement and Social Security,” highlighting the need for policies that both ensure the needs of family caregivers are understood before changes are made in health care systems, and decrease the negative financial impacts faced by family caregivers. For more, refer to [Recommendations 4.1 - 4.4](#).

Gary is no stranger to the world of caregiving after helping care for his mother-in-law for 25 years. Not long after he and his wife were married, his wife’s mother began forgetting things, like her car keys. When she was diagnosed with Alzheimer’s, Gary’s wife retired to look after her, and Gary became a secondary caregiver.



In Gary’s culture, there is a great respect for elders and a shared understanding that children will take care of their parents when needed. Gary’s wife did not hesitate to retire early, even though it decimated her retirement and Social Security to take care of her mother. As Gary describes, his “filial piety” is something Gary and his wife endeavor to pass on to their children, whom they occasionally brought into the caregiving bubble to help with their grandmother and whom they leaned on for support.

As a secondary caregiver, Gary acted as the “backup quarterback.” It was his job to look after his wife, anticipate her needs, and do the things around the house that would make her caregiving role easier, such as cooking and cleaning. Gary was aware of the fact that he had the privilege of “returning to the bench” when he needed a break, but that his wife was in a constant haze of being alert, aware, and ready for action, so he did his best to share in the tasks that he could.

Gary and his wife put off a lot of their life because they did not think they would be caring for as long as they did. They are part of 11% of caregivers who care for 10 years or more. Gary feels

that caregivers, especially those who care for many years, need some sort of support in order to avoid relying on the social safety net themselves. Gary believes that better state and federal policy for caregivers could help with this problem.

For [family caregivers like Rona](#), who are nurturing and supporting children with developmental disabilities, caregiving is a lifelong event. With the persistent nature of day-to-day caregiving, there is little time for self-care or to plan for the future. Rona's story illustrates the critical importance of ensuring family members have the opportunity to take meaningful breaks from their caregiving responsibilities. For more, refer to [Recommendation 3.2](#).

Rona lives in rural Oklahoma and is the mother of three children. Her youngest child is a 13-year-old with Down syndrome. Her daughter is non-verbal and has significant intellectual disabilities. She can't be left unattended. Though Rona feels fortunate that she and her husband are employed and that they have health insurance, she is frustrated because even with two health insurance plans they constantly fight to secure approval for support services critical to their daughter's well-being. The insurance company has even approved requests for in-home therapy, only to cancel it later stating that it never should have been approved at all.



Rona works in an office setting she truly enjoys. She recognizes that her work supports her in ways other than just financially. Her work provides a break from her house, and challenges her mind – which improves her outlook on life and helps her deal with the stress of caregiving. Rona's boss has come to understand that she requires some flexibility in her schedule as it is not uncommon for Rona to have to leave work immediately if her daughter's school calls. In the beginning, Rona felt guilty about leaving work for these short periods and would often work without taking breaks to prove she was still a good employee. Rona enjoys her job but if it wasn't for the year round caregiver duties she would take a more career oriented job like she held in the past and enjoyed. This current job gives her summers off which is a huge deal for a caregiver without good options for care for an almost adult child.

Respite services are very important to Rona and her family. Respite allows her to be a mom to her other children, attend to her own medical needs, and even have an occasional date with her husband. Respite gives her guilt free time away from caregiving and allows her daughter to stay in her routine.

Rona expects to be a caregiver for the rest of her life or for the rest of her daughter's life. It's doubtful her daughter will ever be able to live on her own. Rona worries about what would happen to her daughter if she or her husband die, or if Rona and her husband end up needing care themselves in the future. She stated, "It's very sobering to think about."

V. International Approaches to Supporting Family Caregiving

With the development of its slate of recommendations, the next step for the council is the drafting of the National Family Caregiving Strategy. A key step in developing the strategy was to review approaches to supporting family caregivers on other shores.

International caregivers face many of the same daily challenges as U.S. caregivers. They also experience similar personal rewards. However, while in the U.S. caregiving has, until now, largely been viewed as a family matter—one often addressed in the private realm, overseas there has long been a perception that caregiving is inextricably linked to human rights. A strong caregiving movement—known as “carer rights”—exists in Europe. This movement holds that people have a basic right to provide care to others, to be cared for, and to engage in self-care, without jeopardizing their financial health, their personal well-being, or their jobs.

There is also a growing recognition worldwide that providing tangible empowerment and support to caregivers has economic value in that it not only creates opportunities for independence for people receiving support, but has implications for the economic mobility of caregivers—a group that has been traditionally marginalized.

“Many organizations around the globe—grassroots, nongovernmental, governmental, healthcare, educational, and corporate—are working to address the unmet needs of caregivers,” notes a 2017 white paper developed by a number of caregiver advocacy groups, including the [International Alliance of Carer Organizations](#). These organizations are developing practical solutions to improve caregivers’ health and well-being, often across borders and regions, (Embracing Carers, 2017).

For example, the most progressive countries, including Belgium, France, Germany, and the Netherlands, have adopted policies to promote flexible arrangements for all workers—regardless of their caregiving responsibilities. Some, such as Germany also allow for payment and training of family caregivers (AARP, 2017). Others, the U.K., for example, offer workplace flexibilities specifically developed for family caregivers. A third subset of countries, including, for example, Spain and France, are making progress toward implementing policies to reconcile caregiving with employment through initiatives such as unpaid leave for caregiving tasks.

A frequently noted international trend involves financial support to family caregivers. Ireland, Slovakia, Luxemburg, and Canada offer cash payments either directly to the caregiver or to the person receiving support to purchase home care—including in some cases, care provided by relatives. In Slovakia, family caregivers also receive

health insurance and other social contributions from the state in exchange for their caregiving (UNECE, 2019).

In tandem with policy initiatives, an increasing number of international private firms are implementing caregiver support programs. The European Foundation for the Improvement of Living and Working Conditions conducted an information gathering effort in 2017 that highlighted 50 company initiatives across 10 member states that support workers with caregiver responsibilities (Embracing Carers, 2017). Most notable among them is British Telecommunications (BT), which is based in 61 countries. BT attributes a 20% annual increase in production to “embracing flexible work accommodations for caregivers.”

While some countries are taking a broad approach to caregiver support, others are focusing on the needs of specific populations of caregivers. Many national dementia care plans have expressly stated goals to support family caregivers. According to a 2020 report developed by the U.K.-based World Dementia Council, a broad variety of dementia-friendly initiatives are being undertaken in Japan. For example, in 2019, the Government of Japan announced a cross-ministerial dementia policy package called the Framework for Promoting Dementia Care. This framework focuses on risk reduction and inclusion of people living with dementia. It will continue the momentum built by the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan), which was released in 2012 and the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan), released in 2015.

Despite these achievements, for some countries, there remains significant work to be done to identify and strengthen the voices of unpaid caregivers. In India for example, unpaid caregivers are not formally recognized. Because that country’s census does not collect data about the prevalence of caregiving, little is known about their numbers, needs, or circumstances. The Rights of Persons with Disabilities Act of 2016 offered a provision for reimbursing caregivers who assist people with severe disabilities; however, it was not implemented.

For more on global efforts to support caregivers of people living with ADRD, refer to [Impacts of Dementia Friendly Initiatives](#) developed by the World Dementia Council.

In other countries, there is little existing infrastructure in place to either acknowledge or support family caregivers. In Ukraine, for example, no formal recognition of caregiving by family members and no educational programs exist. Moreover, due to rising inflation, many people in the country who might otherwise provide family caregiving, emigrate to work as paid caregivers in countries like Italy. That leaves Ukraine’s growing population of older adults and people with disabilities to rely on remittances and institutionalization for long-term care, unless neighbors and community groups are available to provide ad hoc supportive services.

Implementation of a Caregiver Strategy in Australia

Caregivers—or “carers” as they are known outside the U.S.—make up about 12% of the Australian population, or 5.65 million people. Seventy-one percent of them are women. For nearly half a century, the Australian government has been exploring and testing how best to support this population (International Alliance of Carer Organizations, 2019).

In the early 2000s, national programs were developed to support caregiving youth, indigenous caregivers, and grandparent caregivers. In 2010, Australia passed the Carer Recognition Act which acknowledges the significant role of caregivers and the importance of ensuring their needs are considered in policies, programs, and services that affect them. The Australian government further solidified this vision when it released its National Carer Strategy 2011. The strategy allocated \$60 million (AU) to support and assist caregivers and mandated that they have the same “rights, choices, opportunities and capabilities to participate in the economic, social and community life” as do other Australians (Commonwealth of Australia, 2011).

Today, each state and territory has a non-government, non-profit organization that advocates on behalf of caregivers. This is in addition to providing services and support directly to caregivers. The Australian government provides funding for caregiver support groups, respite care, mental health supports, and HCBS for the person receiving support. A national online portal launched in 2019 provides a range of supports for caregivers including counseling, peer support, coaching, and caregiver education and training. All of these resources were developed and tested by caregivers in the public and private sectors.

Caregivers in Australia still have some way to go until they feel fully supported in the workplace. Despite robust workplace protections, two-thirds of working caregivers report that their caregiving “sometimes” or “often” interferes with their jobs. But efforts of the last decade appear to be changing expectations around work and caregiving. Survey data reveals that, in New South Wales, caregiving is now viewed as a community responsibility and most caregivers say they feel comfortable talking about their caregiving responsibilities in the work place (Carers NSW Australia, 2018).

Engage Family Caregivers Every Step of the Way

The final word in the RAISE acronym is “engage.” Too often, clinical and social services providers and policy makers do not actively engage (or involve) family caregivers in the care process and decision making. Their presence and support of family caregivers is taken for granted. When decision makers do engage with caregivers, there is often an underlying assumption that they are a homogenous group with similar needs, preferences, and availability to support any and all necessary tasks. Yet, no two caregivers are exactly alike, even if the circumstances that made them a caregiver are the same. The stories of Allen, Beth, Jim, and Laura illustrate the importance of understanding and embracing the fact that every caregiver has a unique story. Community resources, workplace policies, and social service programs that engage and adapt to meet the diverse needs of each caregiver have the power to dramatically improve the well-being, independence, and quality of life of caregivers and the people they assist.

When caregivers are supported by a network of friends, neighbors, and community volunteers, they are better able to navigate the challenges of family caregiving. [Not all caregivers have an established network of social support, like Allen did](#), however. This underscores the need to engage caregivers early in their caregiving journey through a caregiver assessment, the findings of which can be used to develop support plans that are culturally relevant, meaningful, and engaging. For more, refer to [Recommendation 2.2](#), [Recommendation 3.1](#) and [Recommendation 3.6](#).

In 2016, Allen and his wife adopted three sibling sisters from India and began the process of building a loving home. Tragedy struck in 2018 when Allen’s wife discovered that she had Stage IV cancer. Sadly, after a short but “hard shot” battle, she passed away in 2020.

Allen’s greatest support in his care journey came in the form of his church community. He and his family are part of what Allen called a “large small church,” a big community where everyone knows each other. Before the COVID-19 pandemic, Allen found support from his spiritual community when they would bring his family meals and offer to watch the girls or to do work around the family’s home, such as yardwork and cleaning. During the pandemic, members of his community send Allen’s family restaurant gift cards, which Allen finds helpful to easily pick up food whenever he and his family need.

Allen pointed out that caregivers of cancer patients are often overlooked. Cancer treatments for the patient are covered under health insurance, but respite considerations for the caregiver are generally not, since cancer itself can be fairly well covered under health insurance. Caregivers such as Allen would benefit from policies that promote respite services, tax breaks, and



financial incentives for employers to better accommodate caregivers. During the pandemic, Allen found it especially difficult to be able to be there for his wife while she was seeking treatment. Due to COVID restrictions, patients were not allowed to have visitors with them during their treatments. Having someone to support them during treatment is vital to many cancer patients. Allen had been struggling to keep her out of the hospital much as possible during this time. For her last two chemotherapy appointments, which he always attended with her, he had to let her go alone. Allen would like policymakers to understand that caregiving is a full-time, full-attention job, and that caregivers need support on all levels in order to do that job.

[Caregivers like Beth](#), who have a strong network of assistance and engagement, nonetheless experience the loneliness and isolation that is so often a part of caregiving. Her story is an example of why it is critical that providers look below the surface to assess the needs of each and every caregiver to ensure they are engaged with meaningful and culturally relevant support. For more, refer to [Recommendation 3.1](#).

Beth’s husband was diagnosed with colon cancer in 2016. He had surgery immediately upon diagnosis and, due to some complications, remained in the hospital for three weeks, where Beth stayed with him the entire time. Her husband eventually went into remission but passed away due to the cancer in 2018.



Beth described her caregiving experience as “ideal” in the sense that her husband’s family was entirely made up of medical personnel, and that her own father had passed from the same cancer that her husband had. Though she had experience and familiarity on her side, caregiving was still extremely difficult. Her husband wanted to maintain his independence throughout and was not the type to ask others for help, so a lot of the care he needed fell on Beth.

Her husband’s care required seeing a doctor in New York, while they lived in D.C. Their insurance did not cover countless Amtrak trips, hotel stays, and food costs between both cities. They were fortunate to have the cost of these things crowdfunded for them through a supportive community. Due to the amount of time her husband spent in the hospital, Beth had to become fluent in the medical language to advocate for him. She had to know when and what medication he needed, and every time there was a new doctor, she had to re-explain his situation and fight for the correct care. Beth’s mindset turned to ignoring her own needs for fear of detracting from what he needed.

Having found solace in other young widows, she now looks back and wishes she had been introduced to a group of young caregivers like herself, because nobody else could really understand what she was going through. Their brief time at home towards the end of his life, away from the hospital, was the most precious time to them, even though Beth had to spend that time as his nurse.

[Comprehensive family caregiver support programs like the one in which Jim and his wife participate](#), help ensure they are engaged and included in all relevant care coordination and transitions for their daughter, a Veteran. For too many caregivers, this is not the case. Many family caregivers feel like bystanders, causing them to feel unprepared to meet their caregiving responsibilities. For more on the importance of recognizing the diverse needs of family caregivers and the fact that they play an integral role in health care planning and delivery, refer to [Recommendation 1.1](#) and [Recommendation 2.3](#).

Jim and his wife care for their veteran daughter since she was in a car accident while stationed in Italy as an Army Captain. She suffered a traumatic brain injury and was in a coma for almost a year. Their daughter now needs 24/7 care. She has a feeding tube, has challenges with swallowing, needs help with all her activities of daily living, and spends most of her days either in her power wheelchair or in her bed.



They have 4-5 full-time paid caregivers who help provide around-the-clock care. Jim says that if it weren't for military benefits, they would be bankrupt. Their daughter officially retired four years ago and is in the Veteran Directed Care Program. This program has funds dedicated to paying for paid caregivers. The program pays for about half of their daughter's annual \$150,000 caregiver expenses and her retirement money pays for the other half. Jim feels the VA is a good institution and is helpful in many areas, however, he said it can be very frustrating at times for families to have to ask for supportive services more than once. Eventually the VA agrees to the services, but only if the family is persistent.

The Veteran Directed Care Program is a program that addresses the broader topic of caregiving. It allows the family to hire caregiver(s) to help in the care of their veteran family member. The family provides training on how to provide the care they want the veteran to receive, and the result is personalized medicine for the person receiving support. Jim said these caregiving jobs pay between \$15-20 per hour, and the care provider gets to work with one family, usually for a long period of time. They do far more than just medical tasks—they provide meaningful care that has a profound effect on the entire family's quality of life. Jim feels the cost of caring for someone at home is far less expensive than caring for them in an institution, making the Veteran Directed Care Program an ideal resource for caregivers of veterans. Jim believes policymakers should provide all caregivers with the support they need and the recognition they deserve.

In the world of family caregiving, [Laura's story](#) would be considered a success. Despite her husband's critical health condition, Laura was able to continue working full-time and attend all of her husband's medical appointments. Yet, as Laura acknowledges in her story, "luck, education, and social status" played a critical role in her ability to provide her husband the best care possible. It should not be that

way. Based on her experience, Laura believes that changes to workplace policies are critical to ensuring “everyone gets to have a caregiving experience where they can devote their time, energy, and love wholly to the person they are caring for.” For more, refer to [Recommendation 4.2](#).

Laura spent two years caring for her husband, who was diagnosed with stage IV neuroendocrine pancreatic cancer. They proceeded with chemotherapy, radiation, and surgery to close off blood vessels in his liver that were feeding the cancer. Her husband then underwent an extensive surgery involving an organ transplants for five of his organs. Unfortunately, he had multiple complications requiring him to spend nearly seven months in the hospital. Ultimately, Laura’s husband lost his fight with cancer as the cancer returned to his bones.



As his caregiver, Laura attended all her husband’s doctor visits and hospital stays, taking extensive notes from their many appointments with various teams of doctors and medical staff. She kept track of his medication, which as a transplant patient, was a major task with over a dozen medications given daily at different times, managed several pumping systems (both IV and gastric tube feeds) as well as ostomy care, insulin for steroid-induced diabetes, and extensive daily data collection. His condition left him very weak, so Laura needed to lift her husband to move him from his bed to his wheelchair and back multiple times every day, as well as be able to deadlift him off the floor.

Even though Laura’s caregiving journey was extremely stressful, and emotionally and physically exhausting, she recognizes that she was fortunate. Laura’s place of employment offered excellent insurance and a lot of flexibility to allow her to remain working full-time while caring for her husband. The Affordable Care Act allowed Todd to come onto her insurance with a pre-existing condition, and barred any lifetime coverage caps, which would have been triggered with the surgery alone. Laura’s experience taught her that luck, education, and social status should not play into being able to provide good care to your family member. Most caregivers caring for someone with a condition like her husband’s might have spent tens of thousands of dollars in transportation, childcare, and home aides to help lift him multiple times a day; they would probably need to apply for family leave under the Family and Medical Leave Act (FMLA) to get three months of unpaid leave. Laura would like to see policy changes that ensure everyone gets to have a caregiving experience where they can devote their time, energy, and love wholly to the person they’re caring for.

VI. Conclusion

Scope of this Report

Family caregiving encompasses a broad spectrum of activities. When a person becomes a family caregiver, every aspect of their life can be affected, including personal identity, relationships, finances, employment, physical health, mental health, etc. It is not possible for a single report to address every aspect of family caregiving and how it impacts individuals, families, and society. In developing this initial report to Congress in late 2020 through summer 2021, the council focused solely on meeting the requirements of the RAISE Family Caregivers Act. There is much more to be said about caregiving than is articulated in this report. In developing the National Family Caregiving Strategy, the council will explore topics that are beyond the scope of this report. Those include the quickly evolving landscape emerging as a result of the President's Build Back Better plan, which, if passed, will affect family caregivers.

The Road Ahead: A National Family Caregiving Strategy

In November 2020, the council adopted 26 recommendations to improve and better coordinate federal, state, tribal, and community programs and activities to recognize and support family caregivers. These recommendations are a critical component in the development of the National Family Caregiving Strategy. They cover a range of critical issues the nation must address in bold and meaningful ways in order to demonstrate that it values the contributions of family caregivers and it recognizes that people become caregivers for a host of reasons and their caregiving has measurable impacts on their physical, mental, and financial health and well-being. These recommendations provide a path to better recognizing and supporting family caregivers, and in turn, supporting independence and self-determination for millions of older adults and people with disabilities. Even more important, the recommendations, when fully implemented, will ensure family caregivers are able to continue to support others while successfully balancing their own needs and responsibilities.

Over time, as the recommendations are integrated into the existing caregiver support systems and national, state, and community policies, they will ensure that family caregivers have a culturally sensitive, flexible, and affordable system of supports and services that meet their needs and assist them in meaningful ways. The council recognizes that this work will not happen overnight; the road ahead will be long, and there will be many obstacles. The field of caregiving is so diverse that there are few simple solutions. The nation faces significant challenges as it works to ensure our family caregivers are supported, so that they, in turn, can support the people they care for. Working with ACL and its partners on the development of the National Family Caregiving Strategy, the council is committed to surmounting each challenge that arises, to achieve the original vision of the RAISE Family Caregivers Act.

The timing could not be better. As the nation recovers from the COVID-19 pandemic, now is the time to rebuild the infrastructure that supports family caregivers so they are prepared for the future. As the nation considers how to address inequities in communities across the nation, it is important to remember that those inequities extend to family caregivers. The nation's millions of family caregivers give selflessly so others can live meaningful lives with dignity and independence. Their work comes at great personal costs to themselves, their families, their finances, and their health. This is especially true for caregivers of color and those who live in underserved communities or lack access to supports and services.

“We must change our paradigm and shift our outlook on what it means to thrive and how we value others.”

-James Murtha, MSW, member of the Family Caregiving Advisory Council

Through wide adoption and uptake of the 26 recommendations in this report and the forthcoming National Family Caregiving Strategy, an alternative vision for family caregivers is possible. In that vision, family caregivers will be truly recognized for their contributions and they will recognize their own efforts as part of a formal activity; they will receive the assistance they need to perform their tasks, whether it is education, advice, or practical help; they will be included in key decisions, including policy decisions, about family caregiving; they will receive support, whether financial or practical, so they can continue to be caregivers; and most importantly, they will be engaged in all future work to aid family caregivers.

The nation's millions of family caregivers—and the people they support—deserve no less.

Acronyms and Abbreviations

- ACL: Administration for Community Living
- ACS: American Community Survey
- ADA: Americans with Disabilities Act
- ADPI: Alzheimer's Disease Programs Initiative (ACL)
- BRFSS: Behavioral Risk Factor Surveillance System
- CDC: Centers for Disease Control and Prevention
- CFPB: Consumer Financial Protection Bureau
- CMA: Center for Medicare Analysis
- CMS: Centers for Medicare & Medicaid Services
- CSC: Caregiver Support Coordinator (VA)
- CSP: Caregiver Support Program (VA)
- HCBS: Home and community-based services
- HHS: U.S. Department of Health and Human Services
- IDD: Intellectual and Developmental Disabilities
- JAHF: The John A. Hartford Foundation
- LGBTQ+: Lesbian, gay, bisexual, transgender, queer and/or questioning, and others
- LTSS: Long-term services and supports
- MCOs: Managed Care Organizations
- NAC: National Alliance for Caregivers
- NAPA: National Alzheimer's Project Act
- NASHP: National Academy for State Health Policy
- NFCSP: National Family Caregiver Support Program (ACL)
- NHATS: National Health and Aging Trends Study
- OAA: Older Americans Act
- PCPID: President's Committee for People with Intellectual Disabilities (ACL)
- RAISE: Recognize, Assist, Include, Support, & Engage Act of 2017
- RFI: Request for Information
- SGRG: The Supporting Grandparents Raising Grandchildren Act of 2017
- VA: U.S. Department of Veterans Affairs

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