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|  | Valuing those who care |
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|  | Building an Effective National Strategy to Support Family Caregivers |
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Valuing those who care

Building an Effective National Strategy to Support Family Caregivers

# **Executive Summary**

While now is a time to celebrate all of the technological, medical, and social advances that have allowed for people to live well into the later stages of life, it imperative to look ahead and prioritize the issues that impact older Americans and determine what action will be necessary to meet the needs of the growing population of elders and their families in the 21st century. At the heart of the aging phenomenon is the essential role that friends and family play in the support of this vulnerable population. This seemingly “invisible” workforce of family caregivers may be mighty in numbers, at nearly 44 million people strong, however in terms of social support, they are very vulnerable. As the first line of assistance for most aging individuals who need long-term care services and supports (LTSS), family caregivers are vulnerable to the negative financial, emotional, and physical repercussions of providing care while the infrastructure to assist them and their loved ones is crumbling and virtually ineffective.

We are at a critical juncture at this time in the United States. The aging population is growing at an enormous rate at the same time the ratio of caregivers to care for older adults is diminishing. Without a proper and effective national strategy to support family caregivers, the potential exists for the collapse of the informal supports for our elders and thus a system-wide failure of the LTSS. At both the state and national level, the economic consequences of an ineffective LTSS system already impacts millions of Americans. The value of the “unpaid” contributions of family caregivers is enormous and the economic impact will be much greater if family caregivers are not recognized as a valuable part of the success of the overall system and thus supported by both public policy and practice.

It is time to formalize the current piece-meal efforts that are struggling to support family caregivers throughout the country and build an effective national strategy to support the individuals that are considered the backbone of our long-term care system. Building an effective national program will require expertise from both the public and private sectors. Professional interdisciplinary research is also necessary to validate the case for the economic and social advantage of supporting the family caregivers in the United States. It is imperative that we bring these stakeholders together in a formal way to build an effective national strategy to prepare for the challenges and opportunities of an aging society.

Specifically, the work of the short-lived Federal Commission on Long-Term Care must be continued. From a national standpoint, adequate funding must be appropriated at a national level in order to deliver sufficient and coordinated programs and services to family caregivers and their families. The legislation under current consideration needs to be enacted by Congress to help defray some of the financial costs of caregiving. Congress must immediately reauthorize previous legislative acts that have been rendered dormant because of political and fiscal stalemates. Equally important, as an essential component in the ongoing success of the LTSS, the voices of the caregivers must be heard. Finally, the conversations on the value of caregiving must move from the kitchen to the boardrooms and legislative halls.

# **Context and importance of problem**

Giving the sheer number of people caring for older loved ones in the United State, family caregivers are certainly not alone. Due to the lack of social and public policy support however, many may feel like it. Family caregiving is broadly defined and refers to the unpaid assistance with activities of daily living and/or medical tasks provided to relatives, partners, friends, or neighbors (Family Caregiver Alliance, 2015). Family caregivers are the first line of assistance for most people in need of LTSS, helping loved ones navigate the complex health and LTSS systems and facilitating communication with providers (Feinberg, 2014). A recent survey reported that nearly 43.5 million people in the United States care for adults over the age of 50 (Alzheimer’s Association, 2011).

Due to the size of the aging population and the vital role they play in providing assistance to those in need, family caregivers are considered the backbone of the long-term care system. It is estimated that the value of the informal care provided by family caregivers was $450 billion per year in 2009- up from $375 billion in year 2007 (Feinberg, et al., 2011). To provide perspective, this amount is more than the total Medicaid spending in 2009, including both federal and state contributions for both health care and LTSS ($361 billion); more than twice total paid LTSS, regardless of payer source ($203 billion in 2009); and nearly four times Medicaid LTSS spending in 2009 ($119 billion) (Feinberg, et al., 2011).

Without the vital support of family members and friends, many older adults would struggle to remain in the community and would likely be forced to utilize institutional services at an earlier point in their lives. The potential dwindling effectiveness of this seemingly “invisible army” of family caregivers, coupled with the concern over the viability of the primary federal programs, such as Medicaid, Medicare, and Social Security, has many aging experts raising red flags about the future and security of the overall system of support for older adults in the United States (Singer, Biegel, & Ethridge, 2010).

Despite the size of the caregiving population and the valuable service they provide, there is little by way of effective social programming or public policies in place to help them provide care to a growing aging population. This may be due, in part, to the fact that providing informal care to family members has always been considered a family responsibility and thus, a “private” matter (Hudson, 2015; Feinberg, 2014). Changes within the traditional family structure are making it hard for families to provide the type of elder support that was typical in the past (Hudson, 2015).

With respect to the social implications of caregiving, many family caregivers are at risk of financial loss, as well as emotional, physical, and psychological stress. Given that family caregivers often experience the negative effects on their own emotional and physical health, finances and retirement security, social networks, and careers, family caregiving is now considered a public health concern (Feinberg, 2014; Talley & Crews, 2007). In addition, as individuals try to stay in their homes rather than moving into nursing homes, family care is becoming complex with caregivers performing difficult nursing tasks with little preparation, training or support (Feinberg, 2014).

Within the scope of United States public policy, support for family caregivers still remains the “elephant in the room.” Perhaps the breadth of the issue, as well as the enormous figures associated with the cost of informal care, has hardened resistance to enacting meaningful public policies (Lisbon, 2015). The reality however, is that the strain on family caregivers will only become greater as the number of older adults outpaces the number of caregivers available to provide care (Feinberg, 2015).

# **Critique of Policy Options**

The recent White House Conference on Aging called upon Americans to take stock in the value of caregiving and find ways to meet the needs of the growing number of older adults and 21st century families (Poo, 2015). One of the conference’s moderators, David Hyde Pierce, profoundly stated, “to age is to live and to care is to be human” emphasizing that aging is not only about *older* Americans, but rather *all* Americans. The conference also illustrated that we are falling far short of much needed policies and programs to support family caregivers. Public policy regarding formal support for family caregiving has been characterized by piecemeal programs, funded mostly under the Medicare and Medicaid programs, that are relatively small in scope and marked by a lack of consistency (Singer, Biegel, & Ethridge, 2010).

“To age is to live and to care is to be human.” David Hyde Pierce, White House Conference on Aging, 2015

In 2013, Congress commissioned the Commission on Long-Term care policy to prepare a plan for the delivery and financing of LTSS (Commission on Long-Term Care, 2013). Created as part of the American Taxpayer Relief Act (ATRA), the Commission had an extremely limited budget and life span. Within a few months, it issued a report to Congress calling for a broad national strategy to address the needs of family caregivers. While the recommendations were vague, the Commission acknowledged that the focus of LTSS supports and services should shift to “person-and family-centered care” with family caregivers a critical player in the dyad (Feinberg, 2015). While the report was timely and highlighted the need for support for family caregivers, it lacked the depth and breadth needed move the political gridlock and to motivate a polarized Congress to take action.

Caregiving In the Workplace

From an economic standpoint, many family caregivers are forced to make a choice between employment and family responsibilities. Nearly 74% of caregivers are employed and struggle to balance jobs and caregiving tasks (Chen, 2014). The choice to leave the workforce predominately prevails, putting caregivers at great risk of great financial strain. The federal Family and Medical Leave Act (FMLA) was enacted in 1993 and in terms of family caregiving, allows certain employees of covered employers to take up to 12 workweeks of unpaid, job protected leave for a parent or spouse who has a serious health condition (U.S. Department of Labor, 2015).

In reality, FMLA has serious pitfalls as only certain workers, typically upper management or high-income earners, are covered for the unpaid leave. Some covered workers cannot use the FMLA because the relationship of the person they care for is not a covered category (Feinberg, 2013). Also, many employees who are eligible for leave under FMLA do not utilize it because they cannot afford to take time off without pay. In some cases, caregiving employees who are eligible for leave under FMLA choose not to take the unpaid leave because they fear the negative employment consequences within the workplace (Chen, 2014).

Family Caregiver Support

Family caregiving has only recently been considered an essential part of the community system of care worthy of public funding (Singer, Biegel, & Ethridge, 2010). Over the past twenty years, a sprinkling of federal programs have been established to provide services and support to family caregivers, though they have struggled to substantially reduce caregiver burden or delay nursing home admission primarily due to the lack of financial funding (Lipson, 2015). Without the appropriate financial resources, many lack the scope to manage the growing needs of families and are rendered essentially ineffective by a lack of consistency and coordination (Singer, Biegel, & Ethridge, 2010).

Specifically, the National Family Caregiver Support Program (NFSP) was authorized under the Older Americans Act of 1965 and provides grants to the states, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Under this program, the states provide services to caregivers such as: information about available services; assistance in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care, and supplemental services, on a limited basis (Administration on Aging, 2015). Sadly, although the number of family caregivers has increased over the last fifteen years, the funding for NFSP has remained flat at $150 million, which amounts to $21 per recipient (Fox-Grage & Ujvari, 2014 as cited in Lipson, 2015).

In 2006, the Lifespan Respite Care Act was enacted to award $2.5 million in grants each year to states to develop, operate, or supplement respite care services (Lipson, 2015). Respite is defined under the Act as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult” (Lifespan Respite Care Act of 2006). Respite is one of the five areas covered in NFSP, however, the Lifespan Respite Care Act is the only federal program that solely addresses family caregiver respite issues (Rose, Noelker & Kagan, 2015). Although recent evidence suggests that respite has tangible benefits for caregivers, care receiver, and their families; it remains an underutilized preventative resource (Rose, Noelker & Kagan, 2015). Similar to NFSP, the effectiveness of the respite programs has been hindered by the lack of sufficient funding.

In 2014, appropriation of the act declined to $2.36 million due to the national budget crisis and sequestration cuts applied to all discretionary programs (Rose, Noelker & Kagan, 2015). Unfortunately, the appropriations for both NFCSP and Lifespan Respite Care Act were only authorized until 2011(Lifespan Respite Care Act of 2006). New reauthorization legislation has recently been proposed in conjunction with bills to address the respite needs of veterans (S. 2243 and H.R. 4892). Support for the reauthorization legislation is promising since it has been linked with the increasing desire to address veterans’ needs at a federal level and future funding is necessary in order for the states to sustain the progress made since 2009 (Rose, Noelker & Kagan, 2015).

In addition to programming at the federal level, 29 states are testing a care model under the umbrella of Medicare known as the Program of All-Inclusive Care for the Elderly (PACE) that allows interdisciplinary teams to allocate funds to provide respite care, counseling, and additional hours of community center attendance to alleviate family caregivers’ stress (Singer, Biegel, & Ethridge, 2010). Each of the state PACE programs are relatively small in scale and are only equipped to serve a small segment of the population. In addition, there has been very little published data showing its effectiveness, particularly for Medicaid expenditures (Hansen & Hewitt, 2012). Despite the fact that it is not intended to be *the* solution to care for older adults, it is one solution that acts as a benchmark of what success can look like when “incentives in care, financing, coordination, and outcome are aligned” (Hansen & Hewitt, 2012, p. 43).

Financial Security

For many caregivers, the largest burden is the financial via out-of-pocket costs, lost income, and retirement benefits (Lipson, 2015). For the most part, Medicaid, Medicare and Social Security are the primary sources of support for family caregivers (Singer, Biegel, & Ethridge, 2010). In 2011, the Community Living Assistance Services and Support Act was established under the Patient Protection and Affordable Care Act (ACA) and provided a voluntary, self-funding long-term care insurance program for Americans. Since private long-term insurance is costly, the CLASS program would provide a financing opportunity for long-term care services “to support personal choice and independence to live in the community” (Colello & Mulvey, 2013). Under the CLASS program, benefits could be used to compensate family caregivers. Unfortunately, the long-term stability of the program could not be verified by the Department of Health and Human Services (HHS) thus stalling administrative implementation. Subsequently, Congress repealed CLASS and ended the possibility of providing some assistance for the financial strain of being a caregiver under the Act.

At the state level, some progress is being made to test model programs that allow public funds to be used to pay family members and to provide financial assistance to caregivers. In California, the In-Home Supportive Services Program provides funds directly to individuals with disability and allows individuals to pay family members for providing care (Singer, Biegel, & Ethridge, 2010). Subsequent evaluations of the program have shown positive outcomes for family caregivers, as well as being cost-neutral for the state (Sciegaj, Simone, & Mahoney, 2007, Feinberg, Wolkwitz, & Golstein, 2006 as cited in Singer, Biegel, & Ethridge, 2010).

# **Policy Recommendations**

Continue the Work of the Federal Commission on Long-Term Care

In order for the United States to adequately address the impending wave of age-related issues expected within the next fifty years, the creation of a comprehensive and effective national strategy for supporting family caregivers and their families will have to be the priority of policymakers and private sector industries going forward. With only a six-month window to convene and make recommendations to legislators, the Federal Commission on Long-Term Care called for a broad strategy to address the needs of family caregivers as important component to building a more responsive, meaningful, and effective approach to delivering LTSS (Feinberg, 2014).

It is critical that Congress re-commissions a long-term care policy group, similar to the Federal Commission on Long-Term Care, to work on the recommendations brought forth by the Commission. It is also important that the group be comprised of representatives from government (both local and national), communities, LTSS providers, employers, advocacy groups, and researchers; and be provided with adequate time to make specific and actionable recommendations. The long-term vision of a long-term care policy group of this scope would help accelerate the development of evidence-based caregiver support services and improve the experience of the care for individuals receiving LTSS (Feinberg, 2014).

Let Caregiver Voices Be Heard

In a recent survey conducted by the National Alliance of Caregivers (2015), family caregivers had reasonable and somewhat modest requests for future public policy and programs of support. With regard to financially supportive public policies, family caregivers preferred some reimbursement for the hours of care provided, an income tax credit, and a partially paid leave of absence from work (National Alliance for Caregiving, 2015). In additional to public policies to enhance financial security, family caregivers also requested supportive policies, such as permitting the inclusion of the caregiver’s name on care recipient’s medical chart, requiring facilities to provide instruction on medical/nursing tasks, informing caregiver of major decisions about recipient care, and providing access to respite services (National Alliance for Caregiving, 2015). It is important that policymakers consider these requests and let the family caregivers’ voices be heard.

Make Funding of LTSS a Priority

Adequate public funding for caregiver support and wellbeing is critical to the success of the LTSS. Overall, the total public funding for caregiver support programs remains at only a few hundred million dollars and is barely a fraction of the overall value of family caregiving (CBO, 2013, as cited in Lipson, 2015). As the demand for caregiving continues to grow along with the aging population and as state and federal budgets are limited, it is imperative to find innovative ways to better support family caregivers. A complete and comprehensive review of current state and federal programming should be conducted to ensure that the delivery of supports and services is being carried out in the most financially efficient manner and to determine whether overall funding might be allocated more effectively within the programs to provide more comprehensive support of family caregivers. The financing for LTSS must be looked at as part of the national conversation. In addition, reauthorization of the Lifespan Respite Care Program, as well as NFSCP, is essential to coordinate and enhance the crucial support provided by family caregivers.

Make Support of Family Caregiving Part of the National Debate

For the first time in history, family caregiving has become a policy item on the political platforms of the 2016 presidential candidates. Perhaps the heightened awareness comes from a “caregiving curve” that is catching up with politicians as they begin the address caregiving needs within their own family situations (Lipson, 2015). While it is a start, the candidates are mainly focusing on modest tax credits that would likely only mitigate a small portion of the financial implications of caregiving. In order to affect the changes necessary to create the supportive public policies, the debate must be carried out on a national level. It is critical that the voting power of the over 40 million caregivers, along with their care recipients, is used to bring public policy discussion to the forefront of political agendas. National advocacy groups, such as AARP, National Alliance for Caregiving, and the Family Caregiver Alliance, are essential in keeping political leaders focused on advancing effective public policies necessary to support family caregivers and their families. It is time to move the conversations about family caregiving from the kitchen tables in America to the boardrooms and halls of Congress.

Support Working Caregivers by Passing Supportive Legislation

Better workplace leave policies and the protection of family caregivers from employment discrimination should be a heightened priority among policymakers (Feinberg, 2014). No one should have to choose between caring for a loved one and their own future financial security. Current legislation within Congress is being considered that would allow for temporary paid leave for family caregivers as well as credit for caregiving for the determination of Social Security benefits. Passage of the Healthy Families Act (H.R. 932) would establish a national paid family and medical leave insurance program funded by payroll contributions from the employee and employer. The national insurance program created under the act would enable caregivers to stay in the workforce, bolster their earnings and savings over time, and allow for greater productivity and growth within the U.S. economy. Furthermore, the Social Security Caregiver Credit Act (H.R. 3377) would provide a Social Security earnings credit to caregivers who leave the labor force or reduce their work hours to care for a loved one. Both of these pieces of legislation are a start and provide further the support for the protection of the financial well being of family caregivers.

In Conclusion

Developing an effective national strategy that enhances current LTSS programming, as well as fosters the innovation in the delivery of care and support, will be necessary as we look ahead to the future of long-term care in the United States. Coordinated and comprehensive support to family caregivers will not only produce cost savings to the general public, it will also make the provision of unskilled care provided by family members stronger. It is important that discussions of policy initiatives do not put the goal of cost reduction over the other social benefits of providing the highest quality of care (Singer, Biegel, & Ethridge, 2010). Furthermore, policymakers can aim not only to alleviate the stress on family caregivers, but also to create an opportunity for caregivers to realize the benefits of caring for themselves as well as their care recipients (Singer, Biegel, & Ethridge, 2010). Given the economic implications of an aging population, changing demographics, and caregiver strain, the United States must devise policies to “more effectively preserve and promote informal caregiving, and support those who shoulder the financial responsibility of caring for those who cannot care for themselves” (MacArthur Foundation, 2012, p. 4).

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