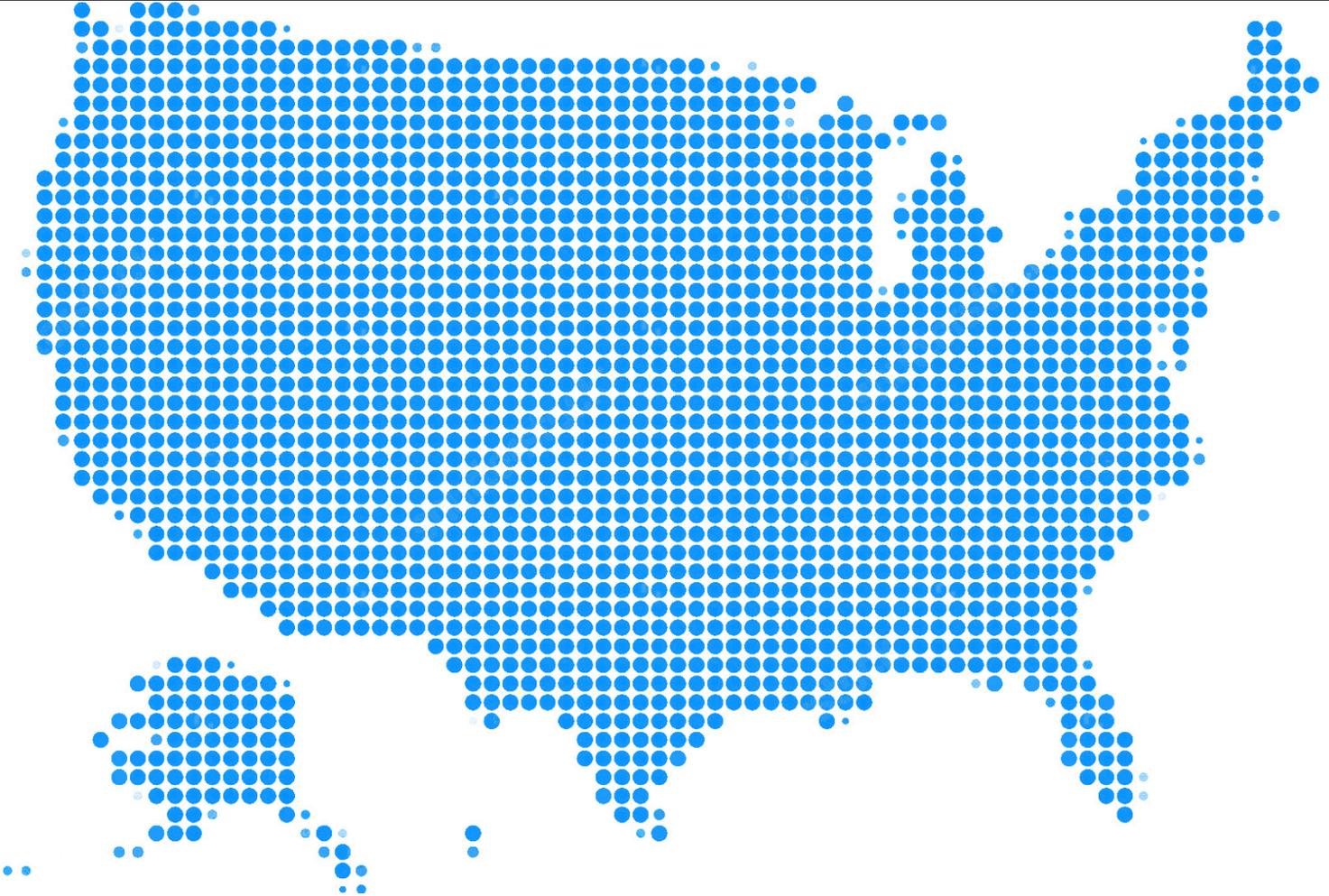




University of Pittsburgh



The Stern Center for Evidence-Based Policy



Addressing the Needs of Caregivers at Risk: A New Policy Strategy

April, 2016

The Stern Center for Evidence-Based Policy

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Executive Summary

Family caregivers are at the front lines of caring for the aging US population.

Every day in the United States, 10,000 baby boomers turn 65. With this dramatic increase in the aging population, a growing number of Americans who want to age in place at home will have limited ability to care for themselves due to chronic conditions, trauma, or illnesses as well as inadequate personal savings. Family and friends provide the vast majority of care to this population. Caregivers are largely uncompensated for the work they do, untrained to perform complex care tasks, and are shouldering an increasing number of economic and health risks. The situation for caregivers and their loved ones is unsustainable.

This report maps the landscape of federal and state policies designed to address the economic and health needs of family caregivers.

To understand the extent to which public policy in the United States currently recognizes and responds to caregiver needs, this report surveys potential federal and state policy levers that exist to address three key goals: (1) alleviating financial hardships for caregivers; (2) promoting flexible employment for caregivers; and (3) providing services and supports to caregivers. Our analysis focuses on six policy levers, and discusses the inherent limitations and current evidence on the effectiveness of each policy. Some of these levers represent proposed amendments to existing policy frameworks while others are policies that have already been implemented but could be expanded further.

Current policy frameworks have not adapted to meet the needs of a growing number of family caregivers.

Our analysis revealed that the existing landscape of caregiver policy is a patchwork of small, uncoordinated programs that do not yet meet the current and future needs of this population. Whereas caregivers provide over 90 percent of the long-term care received by 12 million Americans, their access to financial support, flexible employment and social supports that would facilitate and enhance the care they provide is highly limited. Several of the policy levers we identified—especially comprehensive caregiver tax benefits and Social Security benefits—do not yet exist in any comprehensive sense. Others, the Family and Medical Leave Act (FMLA), for example, are severely limited in the kinds of benefits they provide to caregivers. Finally, policies like the National Family Caregiver Support Program (NFCSP) and Medicaid participant-directed services vary significantly from state to state and serve a small number of caregivers compared to the number that could potentially benefit from these programs.

There are numerous policy options on the agenda that could meaningfully address caregiver needs.

A comprehensive program that includes the elements identified in this report could improve significantly on policy proposals currently under consideration in Congress and in state legislatures. The number of bills relevant to family caregivers is small and policymaker attention to issues such as social security and tax benefits is particularly low. Nevertheless, we are likely to see increased national attention to this issue in the coming years. Both Democratic presidential candidates and at least one Republican candidate have placed supporting family caregivers on their list of policy priorities. Further, in November of 2015, a bipartisan coalition in Congress created the Assisting Caregivers Today (ACT) Caucus. While the current state of caregiving policy in the United States is embryonic at best, the evidence in this report suggests that policymakers have a wide variety of policy options to build on to improve economic and health outcomes for caregivers and the 12 million Americans who need their help.

Introduction

Every day in the United States, 10,000 baby boomers turn 65. With this dramatic increase in the aging population, a growing number of Americans have a limited ability to care for themselves due to chronic conditions, trauma, or illnesses. Family and friends provide the vast majority of care to this population, many of whom lack personal savings. These caregivers are uncompensated for the work they do, untrained to perform complex care tasks, and are shouldering an increasing number of economic and health risks. The situation for caregivers and their loved ones is unsustainable.

Despite the scale and scope of this problem, there are significant barriers to the development and adoption of effective policies to address the challenges of the caregiver population. In this report, we identify the most pressing problems associated with informal caregiving in the United States and assess the landscape of existing and proposed policies that could help to address those problems in the immediate future. Future studies will simulate the effects of these policy choices on the availability and cost of long-term care in the United States. We will also test scalable interventions at the local level that could be a part of a comprehensive solution to the looming caregiver crisis.

The Problem: Caregivers at Risk

There are 12 million Americans with limited ability to care for themselves due to chronic conditions, trauma, or illnesses. Although dominated by the elderly, this group also includes adults battling conditions like cancer and veterans with mental and physical ailments after serving in America's longest military operations. Due to a wave of aging baby boomers, this number will double by the year 2050.

Family and friends provide the vast majority of care to this population.¹ Two out of every three older people with disabilities get all their care from their family members.² These caregivers not only help older Americans navigate the health system, they increasingly perform complicated medical or nursing tasks—caring for wounds, administering medications, and operating specialized medical equipment.³ Thus by providing care to their grandparents, parents, spouses, and friends, millions of Americans help to keep aging Americans in their homes longer, thereby reducing the overall cost of their care.⁴

Employment Impact. While family members and friends are the first line of long-term care for Americans who need it, most lack the resources to provide consistent, high-quality care. Since they are not compensated for the care they provide, many caregivers lose work hours or are forced to quit their jobs. As a result, they lose hundreds of thousands of dollars in wages and benefits.⁵ Family and friends also have little access to appropriate training and other supportive services, which can create gaps in care.⁶

Health Impact. Caregivers are also at higher risk for health problems compared to those who do not provide care. Caregivers miss or delay primary and other preventative care and have higher levels of stress, chronic physical health disease, depression, and anxiety. All are substantive risk factors for hospitalization, emergency department use, and other unplanned care that contributes to unnecessary health care costs.⁷

A declining supply of potential caregivers is also likely to add to the burdens of family and friends who provide care. Today there are more than seven potential family caregivers aged 54 to 64 for every person who may need care over the age of 80. By 2030, that ratio will decline to 4:1.⁸

Financial and Fiscal Impact. Assistance with daily activities such as bathing and eating are referred to as “long term services and supports” or LTSS. The taxpayer-funded Medicaid program is the largest payer for LTSS in the United States, accounting for around 43% of the nearly \$340 billion spent on LTSS each year. However, current estimates of total spending on LTSS do not capture the value of informal care provided by friends and relatives. The estimated value of informal caregiving is between \$470 to over 520 billion dollars annually.^{10,11}

Family caregivers who cannot provide care, due to personal or economic difficulties must turn to other sources of care for their loved ones. Individuals in need of assistance who exhaust their own financial resources for home health services (such as a personal care aide) or nursing home residency may eventually end up in the Medicaid program, which will increase the strain on federal and state budgets. The Congressional Budget Office (CBO) estimates that spending on LTSS as a percent of the GDP could more than double by 2050. Those at highest risk of spending down into Medicaid eligibility have fewer income and assets, were disproportionately female, minorities, and those with a lower level of education, health, and functional status.¹²

The Caregiver Policy Landscape

Given the key challenges discussed above, a comprehensive policy framework would allow family caregivers to maintain employment and financial stability, provide necessary care to loved ones, and avoid negative health consequences. To understand the extent to which public policy in the United States currently recognizes and responds to caregiver needs, we surveyed potential federal and state policy levers that exist to address three key goals: (1) alleviating financial hardships for caregivers; (2) promoting flexible employment for caregivers; and (3) providing services and supports to caregivers. Our analysis focuses on six policy levers, and discusses the inherent limitations and current evidence on the effectiveness of each policy. Some of these levers represent proposed amendments to existing policy frameworks while others are policies that have already been implemented but could be expanded further.

1. Alleviating Financial Hardships

Caregiver Tax Benefits

Description: Caregiver tax benefits aim to incentivize the provision of care for those who qualify.

State of Play: Federal tax benefits for family caregivers have been proposed but not enacted.¹³ However, a number of states have enacted policies that provide tax benefits to family caregivers. Some states specifically allow family caregivers to claim a tax credit for qualified expenses associated with caring for elderly or disabled individuals. About half of states offer tax benefits to individuals paying for care for a dependent family member, but this credit is predominately used for child care and is only available to family caregivers in limited circumstances.

The federal Dependent Care Tax Credit (DCTC) is available to working individuals who pay a provider to care for their child or another dependent. To qualify for the credit, the care recipient must be either under 13 or have a physical or mental defect that makes them incapable of self-care. Additionally, the care recipient must live in the same residence as the tax payer for more than half of the year.¹⁴ Thus, the credit is largely claimed by parents of minor children and not typically useful for individuals caring for an elderly parent with a separate residence.¹⁵ Additionally, the credit cannot be claimed by an adult child who is paying for their elderly parent to reside in a

nursing facility or other institution rather than the home. The credit cannot be used if the care provider is the spouse, child, or dependent of the tax payer or the parent of the care recipient, which restricts the tax credit as a means to deduct compensation for family caregivers.¹⁶

Many states match the benefits offered by the DCTC by allowing tax payers to deduct a percentage of their federal DCTC from their state taxes as well (see **Appendix A** for a list of states which currently offer a state extension of the DCTC).¹⁷

Evidence of Impact: Little research has been conducted on the effectiveness and use of family caregiver tax credits. Some states are considering terminating these tax credits due to underutilization. This underutilization is likely the result of the narrow structure of the laws as well as the lack of public knowledge of the tax benefit. Legislation to renew the tax credit in California has been proposed several times. In Oregon, a tax credit for qualified expenses to keep an individual out of a nursing home is terminating this year due to underutilization.¹⁸ On average, 40 Oregonians claimed the credit annually.¹⁹ The total amount claimed was \$10,000, but only \$4,000 in claims actually reduced tax liability.²⁰

Social Security Benefit

Description: This modification of the existing Social Security program would allow family caregivers to claim benefits for time spent providing care to a family member but outside of the labor force. The rationale behind this proposal is that the decision to provide care leaves workers with much less retirement income than those who stay connected to the labor force.²¹ As one study has shown, taking five or more years off to provide care during working years leaves older adults twice as likely to have low Social Security benefits as those who did not leave the labor force to serve as caregivers. These opportunity costs can also be expected to limit the supply of family caregiving itself.²²

State of Play: Currently, the Social Security program does not provide benefits to family caregivers.

Evidence of Impact: Some research has suggested there would be potential benefits of expanding the Social Security Act to credit individuals for providing up to 12 weeks of unpaid care per year to an immediate family member with a serious medical condition.²³ In one simulation of the program, a 42-year-old female who earns \$12 an hour and who has worked part-time for 20 hours per week for the past four years would see up to 60 percent of her lost earnings replaced. Numerous policy options related to this recommendation—including job-tenure requirements, benefit formulas, and care-recipient requirements—warrant further research.



2. Promoting Flexible Employment

Family Medical Leave Act

Description: The Family and Medical Leave Act of 1993 (FMLA) guarantees up to 12 workweeks of unpaid leave to each leave year to qualifying employees for specified family and medical leave reasons and, pursuant to amendments to the law, up to 26 workweeks of leave in a single 12-month period to care for a seriously ill or injured covered service member. **Exhibit I** describes some core elements of FMLA coverage.

Exhibit 1. FMLA Coverage

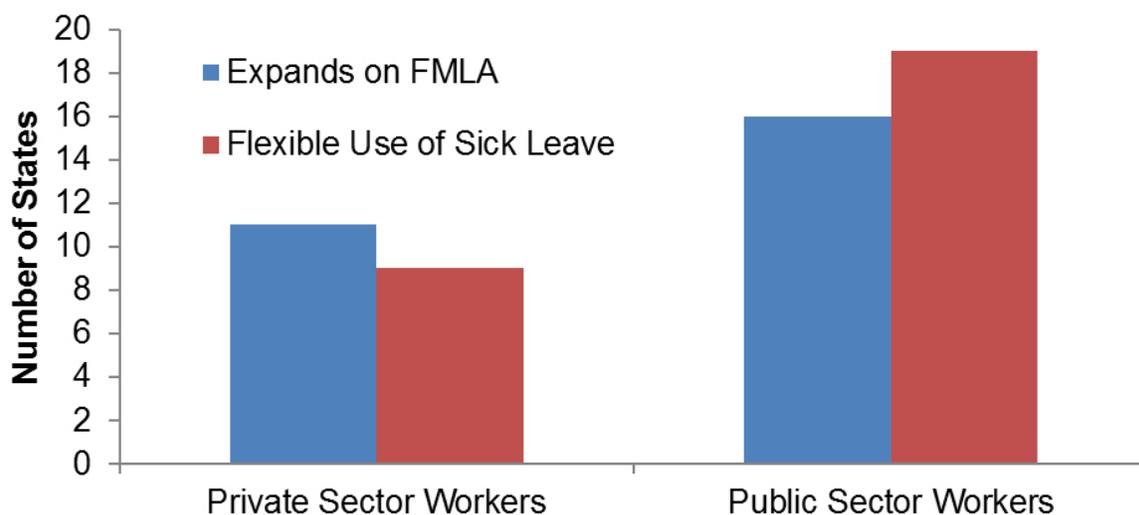
Employers Covered	Private Employers of 50 or more Employees in at least 20 weeks of the current or preceding year Public agencies, including state, local, and Federal Employers Local education agencies covered under special provisions
Employees Eligible	Worked for Employer for at least 12 months - which need not be consecutive; worked at least 1,250 hours for Employer during 12 months preceding leave; and employed at Employer worksite with 50 or more Employees or within 75 miles of Employer worksites with a total of 50 or more Employees
Leave Amount	Up to a total of 12 weeks during a 12-month period; however, leave for birth, adoption, foster care, or to care for a parent with a serious health condition must be shared by spouses working for same Employer
Type of Leave	Unpaid leave for birth, placement of child for adoption or foster care, to provide care for Employee's own parent (including individuals who exercise parental responsibility under state law), child, or spouse with serious health condition, or Employee's own serious health condition
Definition of Serious Health Condition	Illness, injury, impairment, or physical or mental condition involving incapacity or treatment connected with inpatient care in hospital, hospice, or residential medical-care facility; or, continuing treatment by a health care provider involving a period of incapacity: (1) requiring absence of more than 3 consecutive calendar days from work, school, or other activities; (2) due to a chronic or long-term condition for which treatment may be ineffective; (3) absences to receive multiple treatments (including recovery periods) for a condition that if left untreated likely would result in incapacity of more than 3 days; or (4) due to any incapacity related to pregnancy or for prenatal care

Source: U.S. Department of Labor

State of Play: Currently, nearly 60 percent of employees nationwide meet all criteria for coverage and eligibility under FMLA. According to a recent survey, 13 percent of all employees took leave for a qualifying FMLA reason in 2012.²⁴ 18 percent of those who took leave did so to care for an ill relative. By contrast the majority of leaves (55 percent) were taken for the employee’s own illness. Most of these leaves were short. 42 percent of leave events were 10 days or less. Less than a fifth (17 percent) lasted more than 60 days.²⁵ Among those eligible employees surveyed with an unmet need for leave, 41 percent reported needing leave for a parent’s, spouse’s, or child’s health condition.²⁶ By contrast 55.6 percent of eligible employees with an unmet need for leave reported needing leave to attend to their own illness.²⁷

The FMLA also allows states to set standards that are more expansive than the federal law and many states have chosen to do so. Here we focus only on policies applicable to older adults (i.e. we exclude policies focused solely on maternity). The coverage of these policies varies significantly from state to state, however. As **Exhibit 2** shows, only 11 states expand on the FMLA for private-sector workers. 16 states expand on the FMLA for public-sector workers. Similarly, only 9 states offer private sector employees flexibility in allocating their own paid sick-leave to the care of a family member. 19 states offer the same option to public-sector workers. 24 states currently have not expanded upon the FMLA or offered flexible sick-leave policies.

Exhibit 2. State Family Leave Policies Expanding on FMLA, by Type of Employment



Among states that offer private-sector expansions upon the FMLA, most continue to offer unpaid leave. The same is true of states with public-sector expansions. Extensions of this unpaid leave vary significantly, as do employer coverage and employee eligibility criteria. Only three states, California, New Jersey and Rhode Island, offer paid family and medical leave. All three states fund their programs through employee-paid payroll taxes and are administered through their respective disability programs. The state of Washington passed a paid family leave law in 2007, originally to take effect in October 2009, but the law was never implemented and subsequent legislation has indefinitely postponed its implementation.

Similarly, laws allowing employees to allocate their paid sick leave to care of an ill relative vary from state to state. Among states where such policies apply to private-sector workers, less than half allow employees to reallocate all of their paid sick leave. By contrast, public-sector workers enjoy a great deal more flexibility (see **Appendix B** for examples of these policies).

Evidence of Impact: Existing research suggests that the effects of family and medical leave are positive. Recent research has also shown that a two-year unpaid leave generates modest increases in intensive caregiving and substantial decreases in nonwork among women during and after intensive care provision. This leave also reduces early withdrawal from the formal workforce. On the other hand, a caregiver allowance for intensive caregivers generates substantial increases in intensive care provision but discourages work among those who ever intensively provide care.²⁸ Following implementation of state programs, most businesses reported no negative effect on profitability. A survey of 253 employers affected by California’s paid family leave initiative found that over ninety percent reported no noticeable or a positive effect on profitability, turnover, and morale.²⁹ Yet the FMLA program does not cover a large percentage of family caregivers, the majority of whom are working women and less-educated workers. Research has shown that low-wage workers are less likely to take unpaid family or medical leave.³⁰ Studies have indicated African American, Latino, and low-wage employees were most likely to report employer non-compliance with FMLA.³¹

3. Providing Services and Supports

National Family Caregiver Support Program

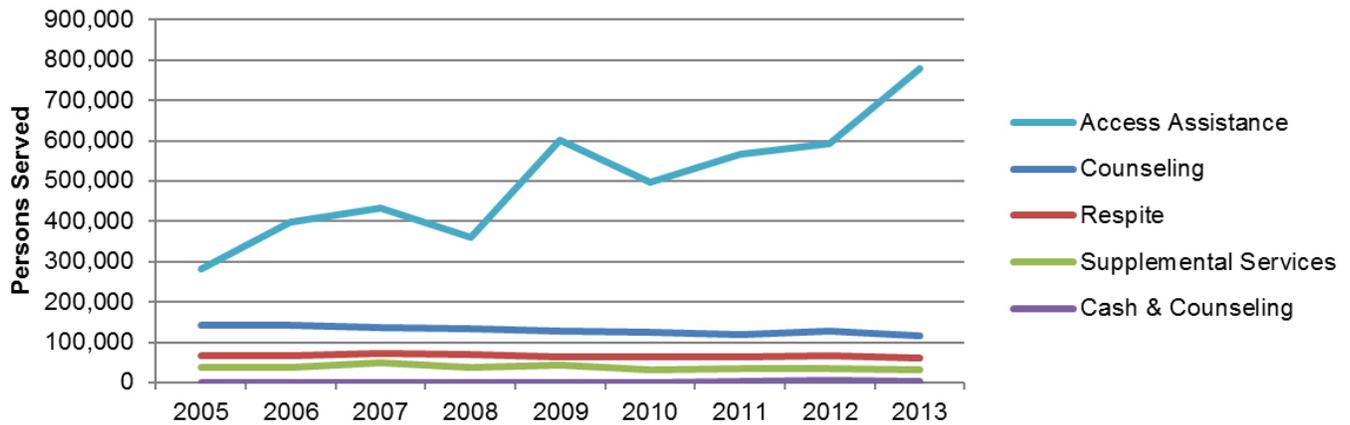
Description: The National Family Caregiver Support Program (NFCSP), established in 2000 under Title III-E of the Older Americans Act (OAA), provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Individuals served include adults (over 18) caring for a family member who is either: 60 years or older, or has Alzheimer’s disease and related disorders and cognitive dysfunction. The law requires the state to give priority to elderly individuals with cognitive problems. Additionally the law allows 10 percent of state allotments for grandparents or other relatives (over 55) caring for a child (under 18) or a disabled adult. The federal program does not explicitly require means testing, but does specify that states must give priority to older individuals with the greatest social and economic need. At the state level, some programs impose income-based eligibility requirements. For example, in Pennsylvania, program recipients must have a household income of less than 380 percent of the federal poverty level (FPL). Benefits in Pennsylvania are available on a sliding scale, and households must be below 200 FPL to access the maximum benefit available.³²

Currently, the NFCSP provides seven categories of service to eligible family caregivers (see **Appendix C** for full description), including counseling on decision-making; respite care, including services provided in-home, at senior centers, and in institutional settings; supplemental services including home modifications and assistive technologies, cash vouchers for counseling; assistance in service access; and information on available resources.

State of Play: The caregiver clientele for all NFCSP service categories but information services is small, but has grown in recent years, on target with the goals of the Administration for Community Living.³³ This trend is largely driven by an increase in caregiver use of access assistance (see **Exhibit 3**). In FY 2013, the NFCSP provided counseling and training to 125,948 caregivers and respite services to 63,080 caregivers.³⁴ NFCSP also provided 1.15 million contacts to family caregivers to help them locate and access public and private services.³⁵ These figures are small compared to the potential number of clients served. Analysis of data from the National Long-Term Care Survey and Informal Caregiver Data suggests that, compared to assistive devices, house modifications, and personal or nursing care, services explicitly identified with informal caregivers (i.e. respite

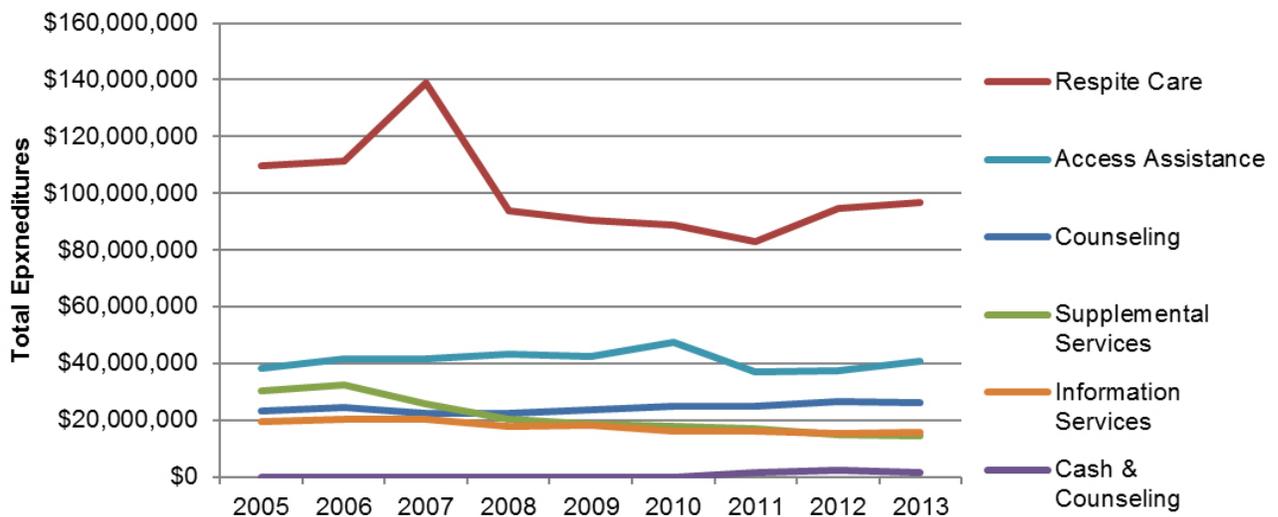
and support group service) were rarely used.³⁶ Survey results from 2013 indicate that the majority of program participants across all NFCSP are white daughters or wives or care recipients. Additionally, most participants are located in the South (see **Appendix D** for additional data). Across all categories of service under NFCSP, total expenditures have either declined or stayed relatively constant between 2005 and 2013, with the largest decline occurring in respite care. (see **Exhibit 4**).

Exhibit 3. Persons Served in Selected NFCSP Service Categories, 2005-2013



Source: Aging Integrated Database

Exhibit 4. Total Expenditures in NFCSP Service Categories, 2005-2013



Source: Aging Integrated Database

Evidence of Impact: The number of studies on the outcomes of NFCSP is highly limited. The first formal evaluation study of the program since it was enacted in 2000 is not slated for completion until 2017.³⁷ Nevertheless, existing evidence suggests that the program has successfully maintained a high satisfaction, with 94.6 percent of users rating the program’s services as good or excellent.³⁸ According to data from the 2014 National Survey of Older Americans Act Participants, without caregiver support services, the care recipient would instead:

- Live in a nursing home instead of the community (59%);
- Live in an assisted living facility (18%);
- Live in the home of another family member or friend (8%); or
- Live in the caregiver’s home (7%).³⁹

Lifespan Respite Care Act

Description: The Lifespan Respite Care Act of 2006 aimed to create a “coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.”⁴⁰ Each state Lifespan Respite Care Program (LRCP) involves a partnership between a state agency, a state respite coalition, and an Aging and Disability Resource Center (ADRC). The ADRC serves as a single point of entry for individuals seeking long term care services and administers certain aspects of state’s long term care system. The ARDC and the state agency may be a single integrated entity.

The program is specifically aimed at family caregivers, defined as “an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.” Individuals with special needs require care and supervision to meet their basic needs and prevent harm to themselves or others.

State of Play: The Administration on Aging (AOA) started distributing grants for the Lifespan Respite Care Program in 2009. The LRCP requires the Secretary to coordinate with the National Family Caregiver Support Program and other respite care programs when distributing funding. The 2006 Act authorized between \$30 million and nearly \$95 million annually for the LRCP between 2007 and 2011, but the program has consistently been funded at \$2.5 million annually since 2009. The Program was funded at \$2.4 million in 2015, and the President’s budget request \$5 million for FY 2016.⁴¹

As of 2014, 32 states and DC had received at least one grant from the LRCP.⁴² The first round of grantees in 2009 were: Alabama, Arizona, Connecticut, DC, Illinois, Nevada, New Hampshire, North Carolina, Rhode Island, South Carolina, Tennessee, and Texas. These 12 states each received up to \$200,000 for a three year project. In 2011 and 2012, 10 states received competitive expansion supplements to focus on providing respite services to meet demand and fill gaps in service.⁴³ In 2014, 16 states received three year grants to work on integrating respite care into long term services and supports (LTSS) reform activities at the state level and sustaining the Lifespan Respite Care Program beyond the three year grant period.⁴⁴ These awards ranged from \$75,000 to \$200,000, and averaged at \$126,278.

Grantees are using LRCP funding for a variety of uses, including:

- Creation and adoption of statewide respite plans and/or policies to guide further development of respite and caregiver support programs;
- Development or enhancement of training programs for respite care providers to expand the cadre of trained respite professionals;
- Replication and expansion of respite delivery modalities with a particular focus on person- centered planning and consumer direction;

- Expansion of toll free “helplines,” dedicated websites and statewide respite registries to provide caregivers with information about available respite programs.
- Development and deployment of marketing and awareness campaigns designed to educate caregivers about the importance of their work and the necessity to take a break;
- Development of data collection methodologies to track service provision and programmatic outcomes;
- Broadening stakeholder collaborations to ensure representation of all age and disability groups, as well as the broadest possible cross section of the provider network;
- Convening focus groups of respite consumers to inform project activities; and
- Capacity building and network development at the local level to recruit and train volunteers to fill gaps in respite services, particularly in rural areas through partnerships with programs such as the Corporation for National Service (e.g., VISTA, Service Learning, Senior Companions, etc.); and
- Provision of direct respite services to family caregivers of children with intellectual and developmental disabilities, adults with physical disabilities, and older Americans.⁴⁵

Evidence of Impact: In 2009, 11% of caregivers over 50 reported using respite care, up from only 5% in 2004.⁴⁶ Nearly 30% of surveyed caregivers said that respite care was their first- or second-choice policy solution for caregiving challenges. Over 50% chose a \$3,000 tax credit for caregiving as their first or second choice policy solution.⁴⁷ Caregivers who provide more than 20 hours of service per week, support an individual with Alzheimer’s disease, a household income above \$100,000, and a high or medium level of burden are more likely to support respite care policies.⁴⁸ Many family caregivers are unable to access respite care. According to the National Respite Coalition, 90% percent of caregivers of adults⁴⁹ and 81% of caregivers of special needs children are unable to access respite care services.⁵⁰

Medicaid Consumer-Directed Services Programs

Description: Many Medicaid home and community-based service (HCBS) waivers contain a “self-” or “participant-directed” component which allows the waiver recipient to select and pay their own caregivers, including family caregivers.

State of Play: Some states place restrictions on which family members may be hired as caregivers, others do not. Many Medicaid HCBS waivers restrict “legally responsible persons” such as spouses or parents of minor children, from receiving payments as caregivers (a description of Medicaid HCBS programs can be found in **Appendix E**). **Exhibit 5** describes a sample of participant-directed Medicaid HCBS waivers in one state for each of the 10 Department of Health and Human Services Regions. As the data here suggests, the ability of individuals to hire family caregivers is highly variable, even among states with participant-directed waivers.

Exhibit 5. Survey of Participant-Directed Waiver Programs

State	PD Waiver Type and Title	Can family members be paid as caregivers?*
Connecticut (Region 1)	1915(c) Individual and Family Support Waiver	No
	1915(i) HCBS State Plan Amendment	Yes, but not the spouse, legal guardian, or a relative of the legal guardian
New York (Region 2)	1915(c) NYS OPWDD Comprehensive	No
Pennsylvania (Region 3)	1915 (c) Person/Family Directed Support Waiver	Yes, in limited circumstances
	1915(c) Attendant Care Waiver	No
	1915(c) HCBW for Individuals Aged 60 & Over Waiver	No
Georgia (Region 4)	1915 (c) Elderly and Disabled Waiver	No
	1915 (c) New Options Waiver	No
	1915 (c) Comprehensive Supports Waiver Program	No
	1915 (c) Independent Care Waiver Program	No
Indiana (Region 5)	1915(c) Aged and Disabled	No
Oklahoma (Region 6)	1915 (c) Advantage Waiver	Yes, in limited circumstances
	1915 (c) In-Home Supports Waiver for Children	No
	1915 (c) In-Home Supports Waiver for Adults	No
	1915 (c) Medically Fragile Waiver	Yes, in limited circumstances
	1915 (c) My Life My Choices Waiver	Yes, in limited circumstances
	1915 (c) Sooner Services Waiver	Yes, in limited circumstances
	1915(j) Self-Directed Personal Assistance Services State Plan Amendment	Yes
Nebraska (Region 7)	1915(c) Day Services Waiver for Adults w/DD	No
	1915(c) Comprehensive DD Waiver for Adults	No

	1915(c) Community Supports HCBS Waiver for Adults w/ID/DD	No
Utah (Region 8)	1915(c) Autism Waiver	No
	1915 (c) Waiver for Technology Dependent, Medically Fragile Individuals	No
California (Region 9)	1915(k) Community First Choice Option	Yes
	1915(j) Self-Directed Personal Assistance Services	Yes
Washington (Region 10)	1915 (c) New Freedom waiver	No

* Extent to which family member can be paid to provide personal care.

Evidence of Impact: Overall, the evidence suggests that, when implemented, participant-directed programs have positive outcomes. This finding has contributed to the expansion of such programs in the last twenty years. One particular example is the Cash and Counseling Demonstration and Evaluation (CCDE) – a large, randomized experiment of a participant-directed program. The three-state (Arkansas, New Jersey, Florida) comparative effectiveness study has the largest research base and the strongest evidence of efficacy of any PD program. The CCDE showed significant outcome differences between participants in Cash & Counseling (C&C) programs and their peers who were participants in the agency-based system. Independent evaluators concluded that individuals who participated in C&C reported fewer unmet personal care needs and improvement in a number of health outcomes and were more likely to be satisfied with the quality of their care and their caregivers.⁵¹

Discussion

Our analysis revealed that the existing landscape of caregiver policies is a patchwork of small, uncoordinated programs that do not yet meet the current and future needs of this population. Whereas caregivers provide over 90 percent of the long-term care received by 12 million Americans, their access to financial support, flexible employment and social supports that would facilitate and enhance the care they provide is highly limited (**Exhibit 6**). Several of the policy levers we identified—especially comprehensive caregiver tax benefits and Social Security benefits—do not yet exist in any comprehensive sense. Others, the FMLA for example, are severely limited in the kinds of benefits they provide to caregivers. Finally, policies like the NFCSP and Medicaid participant-directed services vary significantly from state to state and serve a small number of caregivers compared to the number that could potentially benefit from them.

Exhibit 6. Summary of Findings

Goal	Policy Lever	Status
1. Addressing Financial Hardships	Caregiver Tax Benefits	Limited to Dependent Care Tax Credit at federal level; vary across states
	Social Security Benefits for caregivers	Do not yet exist
2. Promoting Flexible Employment	Family and Medical Leave Act	Eligibility and benefits to caregivers are limited; expansions vary across states
3. Providing Services and Supports	National Family Caregiver Support Program	Varies across states; funding has declined in recent years.
	Lifespan Respite Care Act	Implementation is severely limited.
	Medicaid Participant-Directed Services	Varies across states

Exhibit 7. Current Congressional Legislation Relevant to Family Caregivers

Type of Legislation	Number of Active Bills
Expands Insurance Coverage of Caregiver Support Services	5
Creates Support Infrastructure (e.g. Adult Day Centers)	4
Expands National Family Caregiver Support Program	2
Caregiver Worker Rights	2
Caregiver Social Security Benefits	2
Caregiver Awareness (e.g. advisory council, registry)	2
Caregiver Tax Credits	1
Caregiver Training or Support	1
Total	19

Despite these limitations, the existing policies could serve as scaffolding for a more comprehensive program to respond to caregiver needs. This program could include some combination of the following:

- **Tax Credits:** Expansion of tax benefits at the state level; relax the definition of “dependent” and allowance for respite care as an expense under the federal Dependent Care Tax Credit;
- **Social Security:** Extension of Social Security credits for caregiving under either the retirement or disability insurance programs;
- **Family and Medical Leave:** Expansion of employer coverage, eligibility standards under the FMLA and incentive grants to states for paid caregiver leave programs;
- **National Family Caregiver Support Program:** A more generous federal match or enhanced targeting of federal match to states where demand is greatest;
- **National Lifespan Respite Care Act:** Increased appropriations to support state Lifespan Respite Care Programs; and
- **Medicaid Home and Community-Based Services (HCBS) Programs:** Collection and dissemination of best practices for including family caregivers in HCBS waiver programs.

A comprehensive program that includes these elements could improve significantly on policy proposals currently under consideration in Congress. As **Exhibit 7** shows, the number of bills relevant to family caregivers is small and congressional attention to issues such as Social Security and tax benefits is particularly low (see **Appendix F** for a full description of these bills). Nevertheless, we are likely to see increased national attention to this issue in the coming years. Both Democratic presidential candidates and at least one Republican candidate have placed supporting family caregivers on their list of policy priorities. Further, in November of 2015, a bipartisan coalition in Congress created the Assisting Caregivers Today (ACT) Caucus.⁵² While the current state of caregiving policy in the United States is embryonic at best, the evidence in this report suggests that policymakers have a wide variety of policy options to build on to improve economic and health outcomes for caregivers and the 12 million Americans who need their help.



Appendix A: State Caregiver Tax Benefits

State	Offers State DCTC	Other Family Caregiver Tax Subsidy
Arkansas	Yes	
California	Yes	<p>Credit for: being a long term caregiver. The credit is not tied to expenses. AB 2871 created a non-refundable tax credit of \$500 for eligible long-term caregivers with incomes under \$50,000 (\$100,000 for a married couple filing jointly).</p> <p>Care Recipient: Eligible care recipients must be qualified by a physician as needing long term care for 180 consecutive days during the tax year. Long term care is defined in several ways, depending on age. For example, those over age 6 may qualify if they need help with 3 or more ADLs. Eligible caregivers do not have to be family members.</p> <p>Date: Per AB 2871, the tax credit would begin in 2000 and sunset in 2005. The legislature failed to pass AB 298, which would have extended the tax credit from 2005 to 2011. A similar credit was proposed in 2014 in AB 2606.</p>
Colorado	Yes	
Delaware	Yes	
DC	Yes	
Georgia	Yes	<p>Credit for: qualifying caregiving expenses. This law provides a tax credit for qualified caregiving expenses, such as respite care, equipment and supplies, and homemaker services. The credit covers up to 10% of annual expenses and cannot exceed \$150.</p> <p>Care Recipient: The services must be provided to a family member, related by blood, marriage, or adoption, who is over 62 or disabled.</p> <p>Date: The law is applicable to taxable years from 1999 onward.</p>
Hawaii	Yes	

Idaho	No	<p>Credit for: status as caregiver, who provides more than half of the support an elderly developmentally disabled individual. The credit is \$100 for each elderly individual, with a cap of 3 individuals.</p> <p>Care Recipient: Elderly (65+) individual with a developmental disability residing in the caregiver’s household.</p> <p>Date: Effective in 1981.</p>
Iowa	Yes	
Kentucky	Yes	
Louisiana	Yes	
Maine	Yes	
Maryland	Yes	
Minnesota	Yes	
Missouri	No	<p>Credit for: “shared care” tax credit of up to \$500 for caregiving expenses. Registered caregiver must provide uncompensated care to an elderly individual who lives in your residence for more than half of the year.</p> <p>Care Recipient: Elderly individual (60+) who is certified by a physician as physically or mentally incapable of living alone, needs assistance with enough activities of daily living to require institutional care, cannot drive, and is not receiving Medicaid funding or social services block grant funding.</p> <p>Date: Available starting in 2000.</p>
Montana	No	<p>Credit for: qualified caregiving expenses including home health agency services, personal-care attendant services and care in a long-term care facility, or long term care insurance. Covers 20-30% of qualified expenses, depending on income level.</p> <p>Care recipient: elderly (65+) disabled individual related by blood or marriage.</p> <p>Date: enacted in 1989.</p>

Nebraska	Yes	
New Mexico	Yes	
New York	Yes	
North Dakota	No	<p>Credit for: qualified care expenses for qualified services from a third party, including home health agency services, companionship, personal care attendant services, or other deductible medical expenses. Credit for 20 to 30% of qualified expenses, depending on caregiver income.</p> <p>Care Recipient: Elderly (65+) or disabled family member with an income below \$20,000 who is not receiving other federal or state assistance.</p> <p>Date: Enacted in 1997.</p>
Ohio	Yes	
Oklahoma	Yes	
Oregon	Yes	<p>Credit for: qualified care expenses, including food, clothing, medical care and transportation expenses so that care recipient is not unnecessarily placed in a nursing home. Credit is the lesser of \$250 or 8% of annual qualified expenses.</p> <p>Care Recipient: elderly (60+) individual whose household income is less than \$7,500, is certified by the Department of Human Services, and is not receiving certain benefits from the state.</p> <p>Date: Enacted in 1979, will expire this year.</p>
Rhode Island	Yes	
South Carolina	Yes	
Vermont	Yes	

Appendix B: State-Level Expansions of FMLA

Private Sector Expansions on FMLA

State	Leave Amount	Employer Coverage	Employees Eligible	Includes in-laws?	Additional Paid Leave?
CA	Up to six weeks	50+ Employees	Defined by State Disability Insurance program	No	Yes
CT	Up to 16 weeks in a 24-month period	75+ Employees (excluding parochial schools)	Worked 1000+ Hours in Previous Year	No	No
DC	Up to 16 weeks over a 24-month period	20+ Employees	Worked 1000+ Hours in Previous Year	Yes	No
HI	Up to 4 weeks during any calendar year	100+ Employees	Worked 6 months	Yes	No
ME	10 weeks during a 2-year period	15+ Employees	12 consecutive months with employer at same worksite	No	No
NJ	12 weeks in any 24-month period	50+ Full-Time Employees	12 months with employer; no less than 1000 hours	No	Yes
OR	12 weeks within any one-year period. Additional leave may be available in some circumstances.	25+ Full-Time Employees	Worked average of 25 or more hours/week and employed 180 days prior to leave	No	No
WA	12 weeks over a 1 year period	25+ Employees	12 months, no less than 1250 hours	No	No
WI	During a 12-month period: 2 weeks for serious health condition of parent, step-parent, child or spouse	50+ Permanent Employees	52 consecutive weeks with same employer, and at least 1000 hours	Yes	No

VT	12 weeks over a 1 year period; Plus 4 hours in any 30-day period in order to respond to a medical emergency	Employers of 15 or more for purposes of family leave	Average of 30 hours / week in preceding year	Yes	No
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RI	13 consecutive weeks in any 2 calendar years	Private Employers of 50 or more Employees	Any full-time Employees working on average 30 or more hours per week for 12 consecutive months (1560 hours)	Yes	Yes
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Public Sector FMLA Expansions in States Without Private Sector Expansions

State	Description
MN	Minnesota’s law provides up to six weeks of parental leave to employees who have worked at least part time in the previous 12 months
IL	Illinois’s public sector “family responsibility leave” law applies to full-time employees, regardless of tenure. Workers may take up to one year of leave to care for a new child or a disabled family member.
AK	Alaska’s public sector leave law applies to employees who have worked 910 hours over six months and grants workers 18 weeks of leave.
PA	Permanent management workers, non-represented workers and some workers covered by collective bargaining agreements are eligible for up to six months of leave to care for a family member with a serious health condition, including a pregnancy-related disability, provided they meet the federal FMLA eligibility requirements. All other permanent workers would need only have been employed for one year or more to qualify for up to 12 weeks of such leave.
VA	In addition, certain state workers, including those who participate in the state’s retirement system, are entitled to a few days per year of paid family or personal leave to address a family member’s illness, death or any other need. Workers with up to one year of tenure receive 32 hours per year; workers with longer tenure receive 40 hours per year.

Private Sector Flexible Sick Leave Policies

State	Length of sick leave time that can be allocated to care for ill family member
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CA	Up to half of workers' allotted leave each year
CT	Up to two weeks
DC	The number of days a full-time worker earns ranges from three to seven days, depending on employer size
HI	Up to 10 days for the care of a new child or to assist an ill family member.
ME	At least 40 hours of paid leave per year for the care of an ill child, spouse or parent.
OR	Employees may use all of their sick leave.
WA	Employees may use all of their sick leave.
WI	Employees may use all of their sick leave.
MD	Employees may use all of their sick leave.

Public Sector Flexible Sick Leave Policies in States Without Private Sector Policies

State	Limits on sick leave time that can be allocated to care for ill family member
NJ	None for workers that have earned sick leave
OH	None for workers that have earned sick leave
CO	None for workers that have earned sick leave
MO	None for workers that have earned sick leave
ND	Up to 40 hours
SC	Up to 10 days
TN	None for workers that have earned sick leave
TX	None for workers that have earned sick leave
UT	None for workers that have earned sick leave

Appendix C: Services offered under the National Family Caregiver Support Program

Counseling - Counseling to caregivers to assist them in making decisions and solving problems relating to their caregiver roles. This includes counseling individuals, support groups, and caregiver training (of individual caregivers and families).

Respite Care - Services which offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers. Respite Care includes: (1) In-home respite (personal care, homemaker, and other in-home respite); (2) respite provided by attendance of the care recipient at a senior center or other nonresidential program; (3) institutional respite provided by placing the care recipient in an institutional setting such as a nursing home for a short period of time as a respite service to the caregiver; and (for grandparents caring for children) summer camps.

Supplemental Services - Services provided on a limited basis to complement the care provided by caregivers. Examples of supplemental services include, but are not limited to, home modifications, assistive technologies, emergency response systems, and incontinence supplies.

Cash & Counseling - the range of services provided or paid for through allowance, vouchers, or cash which are provided to the client so that the client can obtain the supportive services which are needed. Since service units could be so diverse they would not provide meaningful results they are not included. States are able to use funds from Title III-B and III-E of the OAO to help support Medicaid participant directed services.

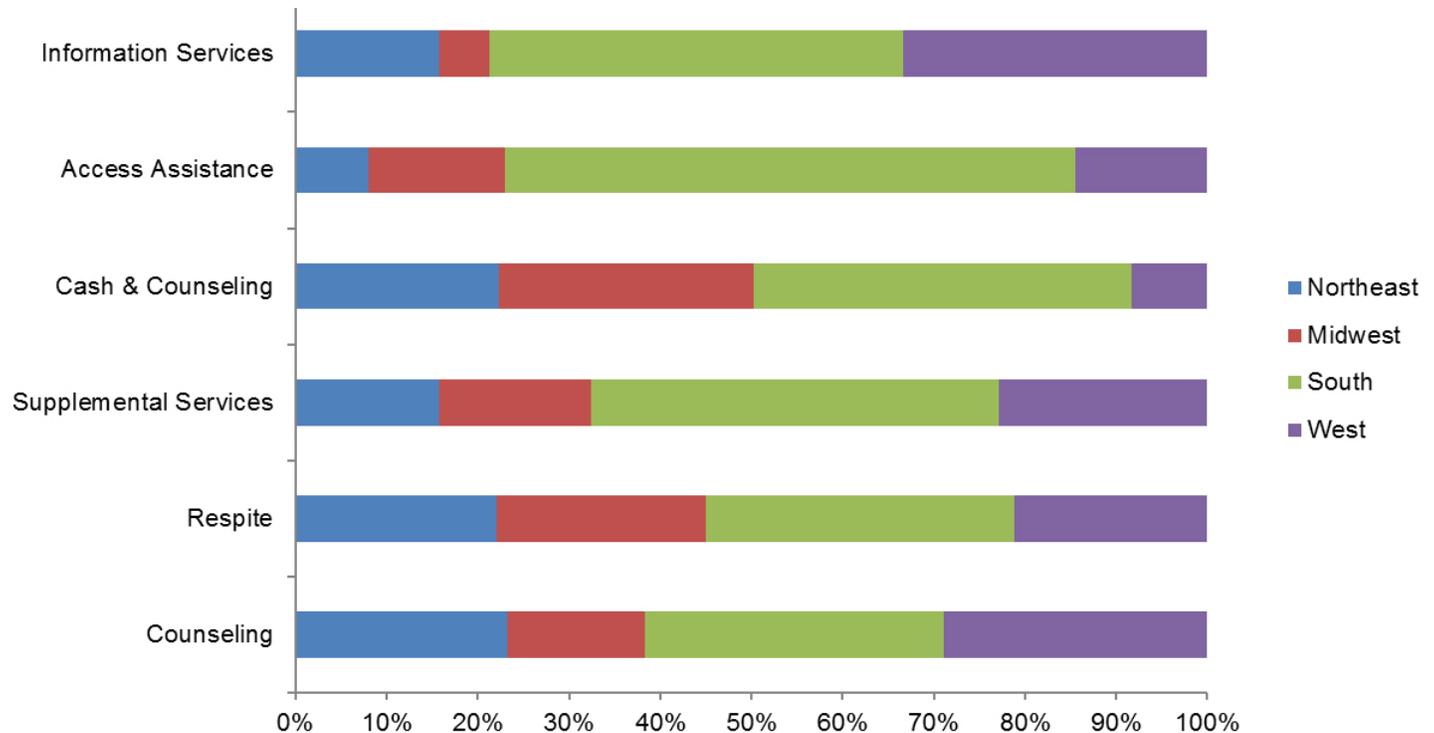
Access Assistance - a service that assists caregivers in obtaining access to the services and resources that are available within their communities. To the maximum extent practicable, it ensures that the individuals receive the services needed by establishing adequate follow-up procedures.

Information Services - a service for caregivers that provides the public and individuals with information on resources and services available to the individuals within their communities.

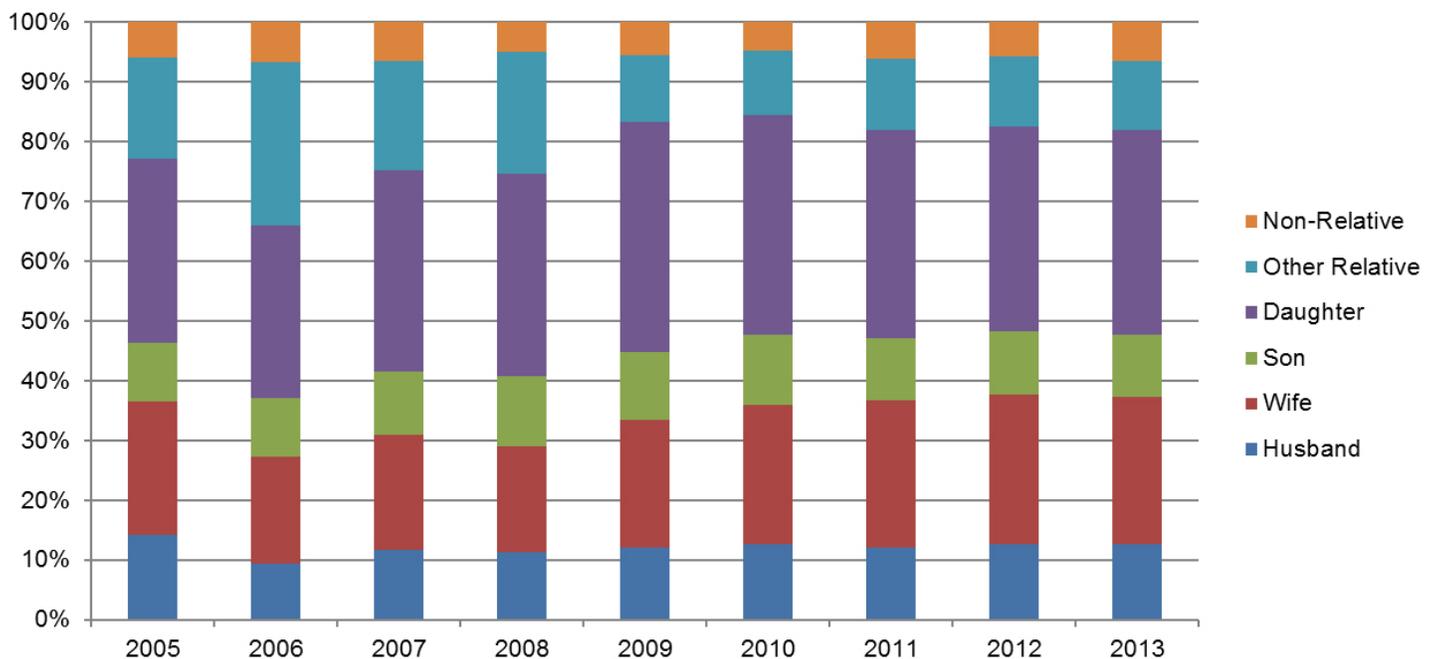


Appendix D: Data on National Family Caregiver Support Program Participation

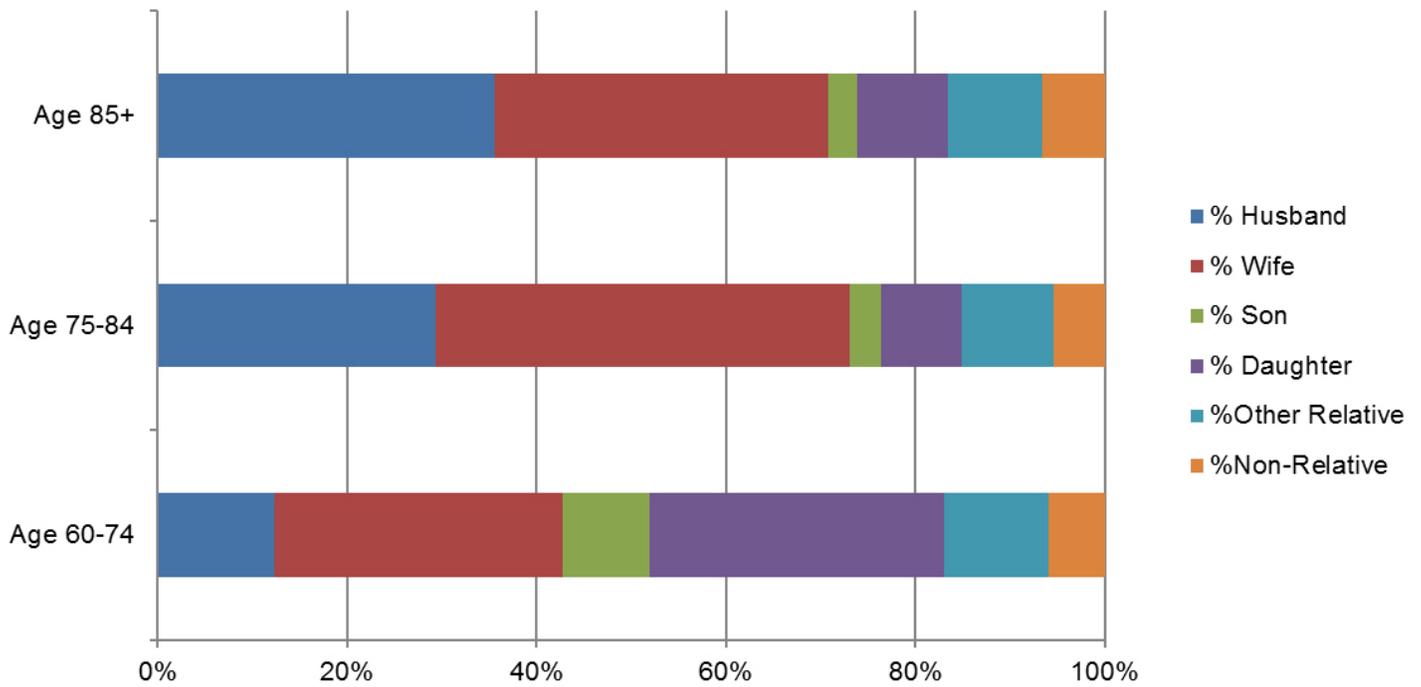
Percent (%) of Persons Served in NFCSP Service Categories by Census Region, 2013



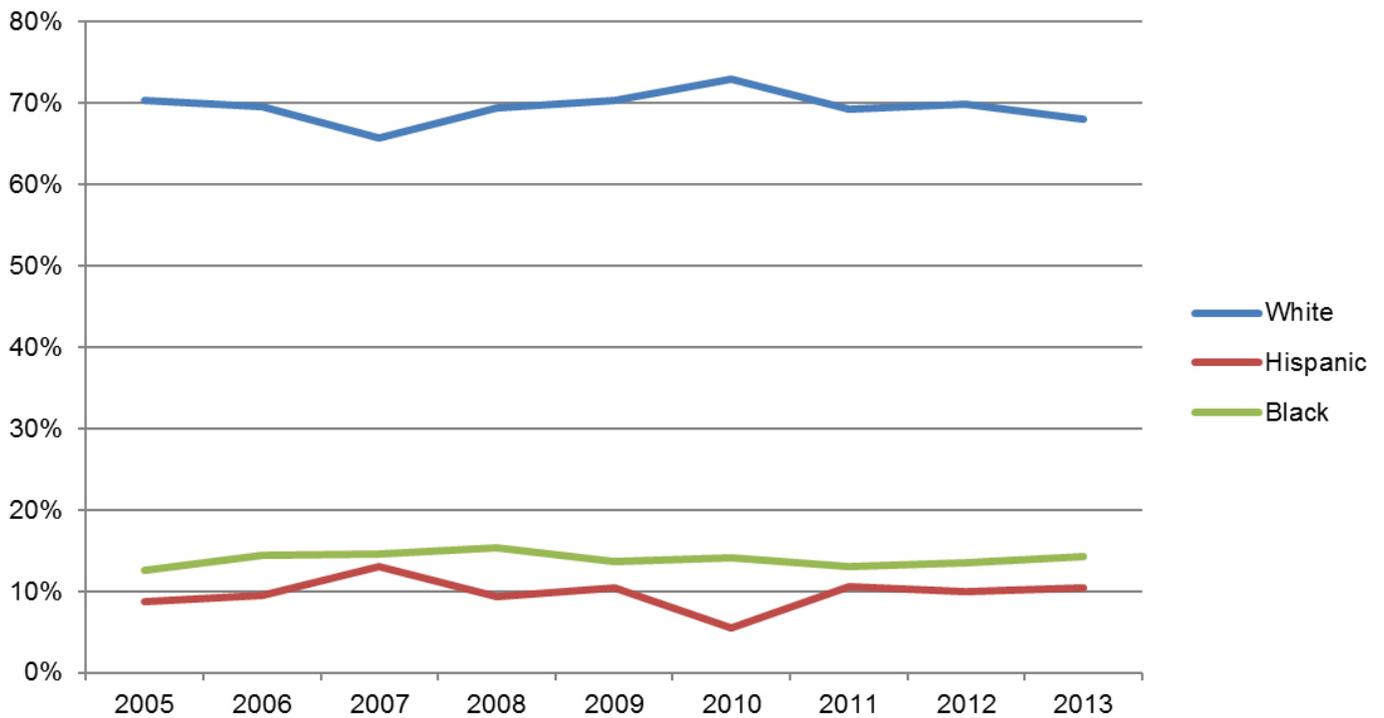
Title III-E Caregiver Relationship to Care Recipient, 2005-2013



Title III-E Caregiver Relationship to Care Recipient by Age Group, 2013



Title III-E Caregiver Race, 2005-2013



Appendix E: Medicaid HCBS Waiver Programs

1915(c) HCBS Waivers: Through this program, nearly all states assist Medicaid beneficiaries eligible for LTSS by supporting an array of services that permit them to live in their homes or in community-based residential facilities.

1915(i) State Plan Home and Community-Based Services: Under section 1915(i) of the Social Security Act, states can offer a variety of participant-directed services under a State Plan Home and Community-Based Services (HCBS) benefit. Participants must meet State-defined criteria based on need and typically get a combination of acute-care medical services (like dental services, skilled nursing services) and long-term services (like respite, case management, supported employment and environmental modifications).

1915(j) Self-Directed Personal Assistant Services: Section 1915(j)(1) of the Social Security Act, added in section 6087 of the Deficit Reduction Act of 2005, would allow a State the option to provide, as “medical assistance,” payment for part or all of the cost of self-directed personal assistance services (PAS) provided pursuant to a written plan of care to individuals for whom there has been a determination that, but for the provision of such services, the individuals would require and receive State Plan personal care services, or section 1915(c) home and community-based waiver services.

1915(k) Community First Choice State Plan Option: Under Section 1915(k) of the Social Security Act, the “Community First Choice Option”, established by the Affordable Care Act of 2010, allows States to provide home and community-based attendant services and supports to eligible Medicaid enrollees under their State Plan. Beneficiaries can select the personal attendant of their choice, including friends, relatives, neighbors or service providers on county-specific registries with specific qualifications and skills. Currently, five states are pursuing these plans: California, Maryland, Montana, Oregon, and Texas.

Money Follows the Person Demonstration: There are currently 44 states, including the District of Columbia, participating in the Money Follows the Person (MFP) demonstration. MFP provides states with enhanced federal Medicaid matching funds for 12 months for each Medicaid beneficiary who transitions from an institution to the community. Currently, the role of family caregivers in the MFP is limited. A 2013 analysis found that only 5% of participants in MFP program used funds for respite, caregiver counseling, and training. 28 of 44 states offer respite, training, and caregiver counseling. This represents less than 1 percent of funds nationwide.⁵³

Managed Long-Term Services and Supports: Between 2004 and 2013, the number of state Medicaid programs that have managed LTSS for elders and persons with disabilities through various types of managed care programs grew from eight to 16, 13 of which offered participant direction. This trend is expected to continue.⁵⁴ A recent five-state survey of participant-direction within MLTSS (PD-MLTSS) in Arizona, Massachusetts, New Mexico, Tennessee, and Texas, suggest a high degree of variation in program characteristics.⁵⁵ All five states allow family members to be paid workers, but some set restricts or special conditions on legally-responsible family members or representatives. The most common was the inability of the spouse or other legally-responsible representative to be hired as a direct service worker. Tennessee has an additional hiring limitation for non-spouse relatives/friends where the participant cannot hire a person who has lived with them within the past five years. While Arizona allows spouses to be hired as direct services workers, there are some restrictions that are typical in other participant-directed Medicaid programs. For instance, the paid services provided by a family member or spouse cannot be an activity that would ordinarily be performed by a family member; payment of spouses is limited to 40 hours per week; and spouses require additional monitoring, including a quarterly review of expenditures.

Appendix F: Current Caregiver Legislation

Bill	Title	Description of Caregiver Provisions
HR 3467	Together We Care Act	<p>This bill amends the United States Housing Act of 1937 to direct the Department of Housing and Urban Development (HUD) to establish a pilot program to make grants on a competitive basis to eligible entities for the training of public housing residents as home health aides and providers of home-based health services to enable them to provide covered home-based health services (services for which medical assistance is available under a state Medicaid plan or for which financial assistance is available under this Act) to residents of: public housing who are elderly, disabled, or both; and federally-assisted rental housing who are elderly, disabled, or both, subject to HUD criteria.</p> <p>The grants may be used:</p> <ul style="list-style-type: none"> to establish a program to train public housing residents to provide covered home-based health care services to elderly and disabled public housing residents and to elderly and disabled residents of federally-assisted rental housing, for the transportation and child care expenses of public housing residents in training, and for the administrative expenses of carrying out such a program. <p>For any resident of public housing who is trained as a home health aide or as a provider of home-based health services under the program, any income received for providing covered home-based health services shall apply towards eligibility for benefits under federal housing programs as specified in this Act, based on length of time following completion of the training.</p>
S 704	Community Based Independence for Seniors Act	<p>(Sec. 3) This bill directs the Department of Health and Human Services (HHS) to establish a five-year Community-Based Institutional Special Needs Plan demonstration program to prevent and delay institutionalization under title XIX (Medicaid) of the Social Security Act (SSAct) among eligible low-income Medicare beneficiaries age 65 or older.</p> <p>HHS shall enter into agreements with up to five eligible Medicare Advantage (MA) plans under part C (Medicare+Choice) of SSAct title XVIII (Medicare) to conduct the demonstration program. Each eligible MA plan may enroll up to 1,000 eligible low-income Medicare beneficiaries in such program.</p> <p>A participating MA plan shall use the rebate the plan must provide to eligible low-income Medicare enrollees to furnish certain benefits, including homemaker services, home delivered meals, transportation services, respite care, adult day care services, and non-Medicare-covered safety and other equipment.</p>

S 2338	Lifetime Act	This bill requires the Department of Health and Human Services to award grants to enable eligible states to develop innovative programs to meet the unique need for long-term services and supports in the state.
S 1574	CARE Act	<p>Amends the Older Americans Act of 1965 to direct the Administration on Aging (AoA) of the Administration for Community Living of the Department of Health and Human Services to establish a community care wrap-around support demonstration program of grants to enable eligible entities to: (1) establish community care wrap-around support partnerships; and (2) carry out specified activities, including longitudinal care plans for each eligible older individual as well as medication management and medical nutrition therapy.</p> <p>Directs the AoA to provide funding through area agencies on aging, and other approved entities, to not-for-profit owners or managers of housing for a pilot project service packaged and targeted for residents of federally assisted housing.</p> <p>Directs the AoA, through a coordinated public education and outreach campaign carried out by the National Eldercare Locator Service, and in coordination with other appropriate federal agencies, to promote: (1) enhanced public awareness of the importance of advance planning for integrated long-term care; and (2) the availability of national, state, and local information and resources to assist in such planning, as well as the existence of area agencies and aging service providers to give direct assistance with it.</p>
S 2427	Disability Integration Act of 2015	The regulations shall require each public entity and LTSS insurance provider to provide the Attorney General and the Administrator with an assurance that the public entity or LTSS insurance provider— (D) issues, conducts, performs, provides, or funds policies and programs to support informal caregivers who provide services for individuals with LTSS disabilities.
HR 1450	Flexibility for Working Families Act	Authorizes an employee to request from an employer a temporary or permanent change in the terms or conditions of the employee's employment if the request relates to: (1) the number of hours the employee is required to work, (2) the times when the employee is required to work or be on call for work, (3) where the employee is required to work, or (4) the amount of notification the employee receives of work schedule assignments. Sets forth certain employer duties with respect to such requests.
HR 1200	American Health Security Act	Comprehensive health insurance program -- including CBLTSS

S.1549 Care Planning Act of 2015

Amends titles XVIII (Medicare) of the Social Security Act (SSAct) to cover advanced illness planning and coordination services furnished to an eligible individual with progressive illness, including Alzheimer's disease, by a hospice or other provider through an interdisciplinary team. Amends SSAct title XI with respect to the Center for Medicare and Medicaid Innovation and its selection for Phase I testing of innovative payment and service delivery models to reduce Medicare and Medicaid expenditures while preserving or enhancing the quality of care. Adds a model for payments to providers that furnish advanced illness care coordination services to eligible individuals who are entitled to, or enrolled for, benefits under Medicare part A (Hospital Insurance) and enrolled under part B (Supplementary Medical Insurance), but not enrolled under Medicare part C (Medicare+Choice).

Amends the Public Health Service Act to require the Department of Health and Human Services, in awarding grants, contracts, or agreements under provisions for quality measure development, to give priority to the development of quality measures that allow the assessment of various specified factors including the effectiveness, patient-centeredness (and, where relevant, family caregiver-centeredness), and accuracy of care plans, including documentation of individual goals, preferences, and values.

Authorizes the Secretary to award grants to certain entities to:

- develop online training modules, decision support tools, and instructional materials for individuals, family caregivers, and health care providers;
- establish a website and telephone hotline to disseminate such resources and any materials designed by the HHS Center for Faith-Based and Neighborhood Partnerships for faith communities; and
- conduct a national public education campaign to raise public awareness of advance care planning and advanced illness care.

HR 3071 Schedules That Work Act

Grants an employee the right to request that his or her employer change the terms and conditions of employment relating to:

- the number of hours or times the employee is required to work or be on call;
- the location;
- the amount of notification he or she receives of work schedule assignments;
- and
- minimizing fluctuations in the number of hours the employee is scheduled to work on a daily, weekly, or monthly basis.

HR 1559	Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act of 2015	<p>Medicare coverage of Comprehensive Alzheimer's Disease Care Planning Services: “(I) assistance understanding the diagnosis;</p> <p>“(II) assistance understanding medical and non-medical options for ongoing treatment, services, and supports; and</p> <p>“(III) information about how to obtain the treatments, services, and supports described in subclause (II); and</p> <p>“(ii) takes into account the eligible individual’s other co-morbid chronic conditions.</p> <p>“(B) The services described in this paragraph shall also include comprehensive medical record documentation, with respect to the eligible individual of the care planning services under subparagraph (A), by the physician or non-physician practitioner furnishing the services.</p>
S 1719	RAISE Family Caregivers Act	<p>Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2015 or the RAISE Family Caregivers Act</p> <p>(Sec. 3) This bill directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Caregiving Strategy.</p> <p>(Sec. 4) HHS shall convene a Family Caregiving Advisory Council to advise it on recognizing and supporting family caregivers.</p> <p>(Sec. 5) This Act shall terminate on December 31, 2025.</p>
HR 3821	Medicaid DOC Act	<p>To amend title XIX to require the publication of a provider directory in the case of States providing for medical assistance on a fee-for-service basis or through a primary care case-management system, and for other purposes.</p>
HR 3377	Social Security Caregiver Credit Act	<p>This bill amends title II (Old Age, Survivors and Disability Insurance) (OASDI) of the Social Security Act with respect to determining entitlement to and the amount of any monthly benefit, including any lump-sum death payment, payable under OASDI on the basis of the wages and self-employment income of any individual. Deems such an individual to have been paid a wage (according to a specified formula) during each month during which the individual was engaged for at least 80 hours in providing care to a dependent relative without monetary compensation for up to five years of such service. Makes this Act inapplicable in the case of any monthly benefit or lump-sum death payment if a larger benefit or payment would be payable without its application.</p>
HR 3090	Alzheimer's Caregiver Support Act	<p>This bill amends the Public Health Service Act to authorize the Department of Health and Human Services to make grants to public and nonprofit private health care providers to expand training and support services for families and caregivers of patients with Alzheimer's disease.</p>

S 879	Americans Giving Care to Elders (AGE) Act of 2015	<p>Amends the Internal Revenue Code to allow caregivers a tax credit for up to \$6,000 of the eldercare expenses incurred for their parents (or ancestors of such parents).</p> <p>Amends the Older Americans Act of 1965 to: (1) increase and extend funding for the National Family Caregiver Support Program through FY2019, and (2) require the Secretary of Health and Human Services to award a grant to or enter into a cooperative agreement with a public or private nonprofit entity to establish a National Resource Center on Family Caregiving to provide information on and support for family caregiver support programs.</p>
HR 3913	Lifespan Respite Care Authorization	<p>This bill amends the Public Health Service Act to extend lifespan respite care programs (services for family caregivers of children and adults with special needs) through FY2020.</p> <p>Each state agency awarded a grant or cooperative agreement for lifespan respite care must collect, maintain, and report to the Department of Health and Human Services data and records to enable monitoring and evaluation of the lifespan programs and activities.</p>
HR 263	Adult Day Center Enhancement Act	<p>Requires the Administration on Aging to initiate a comprehensive survey of current adult day programs that provide care and support to individuals, including young adults, living with neurological diseases or conditions such as multiple sclerosis, Parkinson's disease, or traumatic brain injury. Requires the Administration to identify ongoing successful adult day programs and which of these serve young adults with neurological diseases and conditions and develop best practices to help guide the establishment of additional successful adult day programs.</p> <p>Directs the Administration to establish a competitive grant program to fund adult day programs serving younger people with neurological diseases or conditions.</p> <p>Defines an "adult day program" as a program that provides comprehensive and effective care and support services to individuals living with neurological diseases or conditions and to their family caregivers and that may assist participants in ways that: (1) maintain or improve their functional abilities or otherwise help them adjust to their changing functional abilities; (2) prevent the onset of complications associated with severe forms of the disease or condition; (3) promote alternatives to placement in nursing homes; (4) reduce the strain on family caregivers taking care of a family member living with neurological diseases or conditions; (5) focus on supporting the emotional, social, and intellectual needs of a younger adult population; or (6) address the needs of veterans living with neurological diseases or conditions.</p>
S 192	Older Americans Reauthorization Act	<p>(Sec. 4) Reauthorizes appropriations for FY2016-FY2018 for: (1) specified supportive services, (2) congregate nutrition services, (3) home delivered nutrition services, (4) disease prevention and health promotion services, and (5) family caregiver support. Modifies the National Family Caregiver Support Program, making permanent the funding for the caregiver allotment. Redesignates grandparents and older individuals who are relative caregivers "older relative caregivers."</p>

S 786 Family and Medical Leave Insurance Act

Entitles every individual to a family and medical leave insurance (FMLI) benefit payment for each month beginning on the first day of the first month in which the individual meets the criteria specified below and ending 365 days later (benefit period), not to exceed 60 qualified caregiving days per period. Qualifies for such a benefit payment any individual who:

is insured for disability insurance benefits under the Social Security Act at the time his or her application is filed;
has earned income from employment during the 12 months before filing it;
has filed an application for a FMLI benefit in accordance with this Act; and
was engaged in qualified caregiving (any activity, except regular employment, for a reason entitled to leave under the Family and Medical Leave Act of 1993), or anticipates being so engaged, during the 90-day period before the application is filed or within 30 days after.

Prescribes a formula for determination of an individual's monthly FMLI benefit payment, as well as for the maximum and the minimum monthly benefit amounts.

Requires a FMLI benefit payment to be coordinated with any periodic benefits received from temporary disability insurance or family leave insurance programs under any state law or plan, local government, or an instrumentality of two or more states.

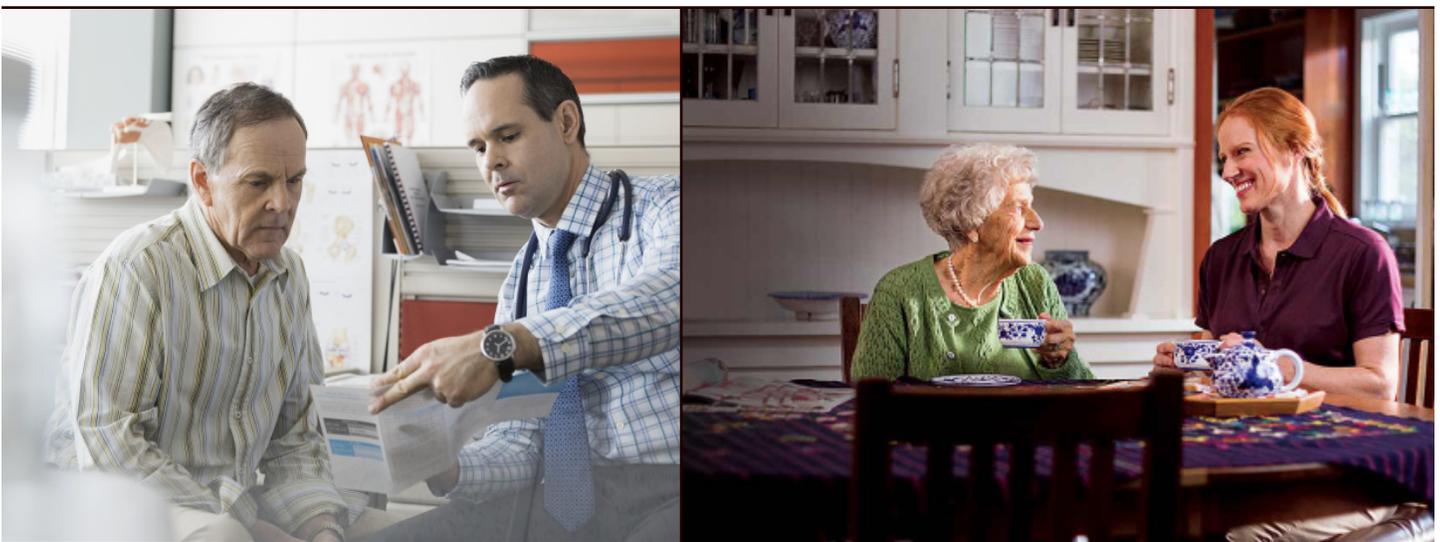
Prescribes criteria that makes an individual ineligible for a FMLI benefit payment.

Specifies prohibited acts by an employer, and penalties for violations.

Establishes the Federal Family and Medical Leave Insurance Trust Fund in the Treasury. Requires FMLI benefit payments to be made only from this Fund.

Prohibits the use of amounts from the Social Security Trust Fund or appropriated to the SSA to administer Social Security programs for FMLI benefits or administration.

Amends the Internal Revenue Code to impose a tax on every individual and employer, all self-employment income, and every railroad employee, employee representative, or railroad employer to finance the Federal Family and Medical Leave Insurance Trust Fund in the Treasury for FMLI benefits.



- ¹ Freedman VA, Spillman BC. Disability and Care Needs of Older Americans: An Analysis of the 2011 National Health and Aging Trends Study. Prepared for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Available at: <https://aspe.hhs.gov/basic-report/disability-and-care-needs-older-americans-analysis-2011-national-health-and-aging-trends-study#data>
- ² Doty P. The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans: a thirty year perspective. *Pub. Pol. & Aging Report* 2010; 20:3-9.
- ³ Reinhard SC, Levine C, Samis S. Home Alone: Family Caregivers Providing Complex Care. AARP Public Policy Institute, 2012. Available at: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf
- ⁴ See, e.g., Schulz R, Beach S. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999; 282(23): 2215-2219.
- ⁵ Metlife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for their Parents. Metlife Mature Markets Institute, 2011. Available at: <https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Caregiving-Costs-to-Working-Caregivers.pdf>
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