**International Approaches to Family Caregiver Support:
Lessons for the United States**

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Submitted to Graduate Faculty of

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2017

University of Pittsburgh

Graduate School of Public Health

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**ABSTRACT**

The issue of family caregiver support is intrinsically tied to public health. Each year in the US, family caregivers provide billions of dollars of uncompensated care to disabled elderly relatives and parents, while at the same time, risking a detrimental impact on their own physical, mental, social, and financial health. Finding effective policy approaches to support family caregivers is a large piece of the puzzle for long term care in the United States.

This essay examines whether innovative international approaches to family caregiver support could inform and advance current US policy. The study focuses on legal recognition of caregiver status in Belgium and the mandatory caregiver assessment in the United Kingdom (UK). Like in Belgium, formal legal caregiver recognition would allow US policymakers to leverage the existing policy infrastructure at the state and federal level to support family caregivers, potentially providing a mechanism for greater employment flexibility, tax benefits, and formal recognition of the economic contributions of caregiving. The UK approach to caregiver assessment provides a model for caregiver well-being, goals, and supports to be integrated into long term care planning in a more structured way.

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# 1.0 INTRODUCTION

As the population ages, more adults will need assistance with day-to-day activities such as getting dressed, eating, and moving around the house. Responsibility for helping aging parents with these activities often falls on their adult children, and in particular, their adult daughters. An estimated 17.7 “informal” or “family caregivers” provided assistance to aging relatives in the United States. [1] These caregivers represented nearly eight percent of the United States adult population in 2011. [1]

Population aging is also a global concern, as life expectancy has increased to the point where nearly all individuals – whether in a low, middle, or high income country – can anticipate living beyond age 60. Effectively addressing long term care (LTC) needs will become a greater challenge as the global population ages. Family caregivers are an essential part of the LTC puzzle, and many countries, including the United States, have invested resources and implemented programs designed to support family caregivers. This paper explores family caregiver policy approaches taken by two countries, Belgium and the United Kingdom (UK) and provides background information on the nature of the long term care systems in these countries. Specifically, this paper examines the potential for implementation of formal legal recognition for family caregivers and mandatory caregiver assessments. These policies may be instructive for the United States as we consider approaches to support family caregivers. Formal legal recognition of caregivers would provide an efficient mechanism to extend benefits available under existing law, such as the Family and Medical Leave Act (FMLA) and state tax codes, to family caregivers. Mandatory assessments of family caregivers at the local level would provide an improved understanding of caregivers’ need and ensure that caregivers are receiving appropriate services and supports. Further, data from assessments would allow national, state, and local programs which support family caregivers to strengthen their service offerings in a way that is responsive to actual need and does not waste limited resources.

# 2.0 BACKGROUND

Policies and laws supporting family caregivers exist at the federal, state, and local level in the US. Key challenges facing these programs include limitations in funding, public awareness, and the scope of the authority of these programs. The United States lacks a universal system of LTC financing and delivery. Very few Americans carry private LTC insurance, but more than half of the population over 65 is likely to develop a disability which will require LTC services.[2] On average, individuals turning 65 today will spend $138,000 on LTC costs, but over 60 percent of Americans between 55 and 64 have less than $50,000 in retirement savings.[2, 3] Individuals who lack private LTC insurance and do not have adequate savings to purchase LTC services may end up spending their savings down to the poverty level to qualify for assistance from Medicaid or relying extensively on unpaid assistance from family caregivers. Given impending demographic shifts, further activity is necessary to meet the needs of the aging population and their caregivers.

## 2.1 POLICIES IMPACTING CAREGIVERS

The National Family Caregiver Support Program (NFCSP) provides matching funds to states based on their share of the elderly population (aged 70+) and is funded at approximately $150 million annually. State NFCSP services must include the provision of information about available support services, assistance in gaining access to services, counseling, training and support groups, respite care, and other supplemental services selected at the discretion of the state.[4] For example, some states offer home modifications, transportation services, and assistive technology through the program.[5] Through the NFCSP, 1,046,159 caregivers received services in 2013.[6] While over 90 percent of participants reported satisfaction with the program, close to one-third reported difficulty in accessing services.[6] The NFCSP was created in 2000, as an amendment to the Older Americans Act.

Another federal program, the Lifespan Respite Care Program (LRCP) of 2006, provides grants to states to support respite care.[7] The program is funded at approximately $2.5 million annually, a significantly lower amount than the $30 to $95 million authorized by the original legislation.[6] Funding levels for the LRCP were first established in 2009, while Congress was debating the Affordable Care Act (ACA), and remained low in subsequent years, during the debate over the fate of the ACA’s universal, voluntary LTC insurance program, the Community Living Assistance Services and Supports Act (CLASS Act). As of 2016, 35 state and DC received grants from the LRCP ranging from $75,000 to $200,000. LRCP supports states in making respite care available to family caregivers through activities such as information dissemination, building community partnerships, and volunteer training. [8]

### 2.1.1 Employment

The Family and Medical Leave Act (FMLA) of 1993 allows employees of qualified employers to take up to 12 weeks of unpaid leave to care for a sick spouse, child, or parent.[9] FMLA provides a federal minimum standard for employee medical leave, but some states have expanded family medical leave to include paid leave and additional categories of employers.[10] While FMLA can provide temporary assistance to family caregivers, the law is designed to address acute periods of illness, not ongoing long term services and supports (LTSS) needs. Further, many low-income workers do not use FMLA out of fear of losing their job (17 percent) or inability to afford unpaid leave (46 percent).[11]

According to recent estimates, family caregivers provided an estimated 37 billion hours of unpaid care to adults with activities of daily living (ADL) limitations in 2013, which is worth an estimated 470 billion dollars.[12] Family caregiving responsibilities can place a strain on employment. In 2015, 49 percent of working age caregivers reported taking time off of work, leaving early, or going in late to accommodate their caregiving responsibilities, 15 percent took a leave of absence from work, and 14 percent reduced their work hours or selected a less demanding job.[13] Foregoing paid employment, higher pay, or more working hours to meet family caregiving responsibilities depresses the accrual of Social Security benefits over the family caregiver’s lifetime.[10]

### 2.1.2 Financial Policies

Some states offer tax benefits to family caregivers to help offset the costs of caring for a family member. These costs include time spent away from paid employment and investment in home modifications and supplies. Family caregiver tax credits are typically small and underutilized. For example, in Georgia, the maximum tax benefit is capped at $150 annually, and in Oregon, the family caregiver tax credit was terminated in 2015 due to underuse. [10]

At the federal level, the Dependent Care Tax Credit (DCTC) allows working individuals to claim a portion of their caregiving expenses as a tax credit. DCTC is applicable to caregiving expenses for children or a spouse or other dependent who is incapable of self-care.[14] While the DCTC could potentially be utilized for respite care expenses, the credit is only available if the dependent lives with the family caregiver. The credit is not available for family caregivers with aging parents in a separate residence. About half of states allow family caregivers to deduct a percentage of their federal DCTC from their state tax obligations.[10]

The United States also offers a cash benefit to aged and disabled individuals with limited income and assets through the Supplemental Security Income (SSI) program.[15] The Social Security Disability Insurance (SSDI) program provides a cash benefit to qualifying individuals who cannot work due to disability.[15] SSI and SSDI may provide payment to elderly individuals who are cared for by a family caregiver, but whether an individual is receiving informal care is not a factor in SSI or SSDI eligibility.

During the 2016 election, the Trump campaign indicated an interest in making tax deductions for elder care available to working parents. The campaign also proposed savings accounts for elder and child care which would permit tax-deductible contributions and tax-free appreciation.[16] Currently, no tax credit for family caregivers exists at the federal level.

### 2.1.3 Medicaid

Over the past 20 years, Medicaid spending on home and community based care (HCBS) rose from 18 percent in 1995 to 53 percent in 2014.[17] HCBS spending first surpassed institutional Medicaid spending in 2012, and continues to trend upward. Several decades of Medicaid policy have emphasized deinstitutionalization, the idea that individuals with disabilities should be integrated into and cared for by the community rather than in a nursing facility. Section 1915(c) and 1915(i) waivers are formal mechanisms that allow states to deliver LTSS in the community rather than in institutions. Though Medicaid finances formal, paid supports (such as direct care workers) for those with LTSS needs, unpaid family caregivers also play a key role in community based LTSS. Increasingly, HCBS waiver programs are considering the role and needs of the family caregiver when evaluating beneficiary needs.

Assessing the needs of a disabled care recipient and developing a service plan which incorporates that individual’s needs and goals is an important aspect of many HCBS waiver programs. However, many waiver programs do not include assessments of family caregivers, and this type of assessment is not a mandatory aspect of HCBS waivers. According to a survey conducted by the AARP, fewer than half of all states include any family caregiver-related questions in their client assessment, and only 30 percent of states offered an assessment which included questions about the caregiver’s health and well-being, a determination of the caregiver’s feelings of stress and being overwhelmed, and an inquiry into what services and supports the caregiver needs.[18]

New regulatory requirements enacted by the Centers for Medicare and Medicaid Services (CMS) in 2014 added a mandatory caregiver assessment to 1915(i) waivers.[19] If a family caregiver is required to carry out any portion of a Medicaid beneficiary’s service plan, 1915(i) waiver regulations mandate an assessment of caregiver capacity and needs.[20] CMS declined to include specific requirements for the contents of the caregiver assessment in the new rule. Additionally, CMS declined to add a caregiver assessment requirement to the 2016 Medicaid managed care final rule, opting instead to allow states to develop their own assessment standards.[21]

About half of states are working to transition Medicaid LTSS delivery to managed care, known as “MLTSS”. A recent survey found that family caregivers are acknowledged in many of these MLTSS contracts between states and managed care organizations (MCOs).[22] The specifics of the contracts vary. Some include family caregivers as a source of information for care coordinators, while other contracts provide for caregiver training and an assessment of caregiver health, well-being, and knowledge.[22]

# 3.0 INTERNATIONAL APPROACHES TO FAMILY CAREGIVING

Over the next several decades, many countries will see the demand for long term care increase as the population ages. As demonstrated by countries such as the UK, the presence of a comprehensive national health care system does not guarantee the presence of a comprehensive LTC system. Many Organisation for Economic Co-operation and Development (OECD) nations are implementing reforms to strengthen their ability to provide LTC, using a variety of different strategies. As in the United States, publicly funded LTC coverage, private LTC insurance, and family caregivers all play a role in these LTC systems.

The ratio of elderly individuals is increasing across the globe. According to the OECD, the percent of individuals over age 80 in OECD countries will more than double between 2010 and 2050, from 4 to 10 percent.[23] By 2050, the total number of individuals over age 60 could reach 2.1 billion, compared to 900 million in 2015.[24] This population shift will lead to a rise in the demand for long term care workers, and the amount that OECD countries currently spend on long term care (LTC) as a percent of GDP could double or triple over the next 40 years.[23]

The ratio of elderly (over 65) as a proportion of working age individuals (aged 15 to 64) is also increasing. According to the World Bank, the United States and most OECD countries are in the middle of the continuum for the age dependency ratio. This ratio compares the number of working age people to the population above working age (65 years or older) and below working age (15 years old or younger). At 22 percent between 2011 and 2015, the United States is much younger than “super-aging” countries like Japan (37 percent) and much older than nations such as Ethiopia (6 percent) or Guatemala (8 percent).[25] The US is also slightly younger than Belgium (at 28 percent) and the United Kingdom (27 percent).[25]

Family caregivers play a major role in providing LTC services in many countries and provide support to individuals with varying levels of need. In the United States, 90 percent of individuals receiving assistance with long term services and supports in the home receive some level of assistance from a family caregiver.[26] Approximately 10 percent of adults over age 50 in OECD countries are family caregivers, and about two-thirds of that population are women.[23] The benefits available to these caregivers, such as payment or flexible work arrangements, vary depending on their country of residence. Within the United States, interstate variances are also evident. The intensity of services delivered by family caregivers also varies. Some elderly individuals have relatively simple mobility needs, while others have more complex needs that can stem from comorbid physical and cognitive conditions. About half of family caregivers in the US provide care to a “high need” adult, meaning someone who have dementia and need assistance with at least two ADLs, such as bathing, eating, dressing, and getting out of bed.[1] In Northern European countries, only 10 percent of caregivers provide more than 10 hours of assistance per week, but in some other countries, the typical burden on caregivers is more profound.[23] For example, in Spain and Korea, more than half of all caregivers provide at least 20 hours of assistance per week.[23] Most informal, unpaid caregiving is provided by a spouse or the adult child of a disabled parent. In Belgium, 74 percent of unpaid care is provided by one of these two groups, and in the UK, that number is 66 percent.[23]

Most OECD nations have taken some action to provide or finance the provision of LTSS, either in an institutional setting or in the home or community. Almost universally, family caregivers are an essential and significant contributor of LTC. Like the United States, most OECD nations are high utilizers of family caregivers (“informal carers” in European literature). Relatively high reliance on family caregivers is the norm across numerous different types of LTC systems, whether the LTC system is universal and government sponsored (like Germany or Japan[27]), mostly private (like Italy or the United States), or mostly private with few formal service providers (like China).[28] The exceptions to high rates of informal caregiver use are countries such as the Netherlands, Denmark, and Sweden, which are characterized by high rates of public spending, formalized systems of LTC provision, and low rates of private LTC spending.[29] Researchers comparing the need for LTC (in terms of the population requiring assistance with multiple ADLs) across various OECD countries with the utilization of informal caregivers noted that presence of a “strong welfare state” seemed to encourage lower use of informal caregivers.[29] A survey of 21 member states in the European Union found that 16 provide some cash benefit to family caregivers, making it the most common form of formal support available.[30] The rules and regulations attached to the use of the cash benefit varies by country. Some countries require that family caregivers exclusively use cash benefits to purchase formal care (France), some countries permit the caregivers to use the cash for other purposes (Sweden), and some contribute cash benefits on behalf of the caregiver to a public retirement scheme (Germany).[30] The generosity of the benefit also varies, with Hungary offering 87 Euros (approximately 91 dollars) per month and Spain offering 727 Euros (approximately 758 dollars) per month.[30]

This paper examines the applicability of innovative approaches to family caregiver support policies which could provide insight to US policy makers. Specifically, this paper looks at a legal recognition of caregiver status in Belgium and the mandatory caregiver assessment in the United Kingdom (UK). Belgium’s policy is valuable to explore because of its flexibility. Caregiver recognition would allow US policymakers to leverage the existing policy infrastructure at the state and federal level to support family caregivers. Compared to other European nations, the UK is placing a heavy emphasis on caregiver support through assessment. As the US transitions toward greater recognition and assessment of caregivers in Medicaid, the UK policy is a helpful guide. To support this analysis, a brief overview of the long term care and family caregiver support system in these two countries follows.

## 3.1 BELGIUM

Long term care in Belgium is a mix of public and private coverage. For those with LTC needs, Belgium provides nursing care and a means tested cash benefit at the federal level, as well as residential care and home care at the regional level. While the federal government finances health care for all citizens, financing and administration of LTC is divided between federal, regional and local authorities.[31] Home and residential nursing care are provided by the federal government as part of the mandatory public health insurance program.[31] The federal share of LTC is financed through contributions from employers and employees, retirees, and general taxes. Residential care services are provided by local “Public Centres for Social Welfare.” The federal government sets the maximum number of beds that each residential facility may have, and delegates oversight and monitoring of these facilities to regional authorities.[31] Federal coverage for nursing care delivered in the home requires a prescription from a physician certifying that the patient has adequate need.

Belgium also has an array of semi-residential facilities, such as assisted living-type service flats and adult day centers that care for elderly adults while the usual caregiver is at work. The availability of semi-residential facilities has increased in recent years in Belgium, indicating that individuals in residential facilities are more likely to be severely disabled.[31] As in the US, the overall trend in Belgium is toward delivery of LTC in the community rather than in an institution – between 1997 and 2007, the number of patients using home-based care increased at three times the rate of the use of nursing facility care.[31]

Home care services are regulated at the regional level by Cooperation Initiatives in Home Care (*Samenwerkingsinitiatieven Thuiszorg or* “SIT”). These SITs work to ensure coordination among the various public and private entities involved in home care, including physicians, home health providers, and social workers.[31] Individuals who qualify based on ADL and Instrumental ADL limitations may receive a designated number of subsidized hours of home based care. These personal and home care services are financed by taxes and means-tested contributions by care recipients, and are provided by local public agencies or privately staffed home health firms.[31]

Flanders has a unique LTC program. Flemish LTC insurance is funded by a combination of general tax revenue and individual contributions from adult residents.[31] This program provides a monthly cash allowance for the purchase of residential or home care to Flanders residents who have a qualifying level of ADL and IADL need.[32] The program is not means tested, and is only available in a limited geographic area to those that have paid into the program for at least five years.[32] Contributions to the program are mandatory in the Dutch speaking areas of Belgium and voluntary in the Brussels-Capital region.[32]

### 3.1.1 Financial Benefits

The affordability of LTC services not covered by national public insurance is still a concern in Belgium.[31] Home and residential nursing visits are covered by the federal government, but home care visits by lower skilled direct care workers are not covered. As noted above, subsidized home care is provided at the regional level. Additionally, while residential facility nursing care is covered at the federal level, room and board are not covered.[33] In 2006, 54 percent of the population over age 80 and 31 percent of the population over 65 received informal care.[30]

Belgium provides a cash benefit to care receivers, the “Allowance for Assistance to Elderly Persons” (allocation pour l'aide aux personnes âgées/tegemoetkoming voor hulp aan bejaarden) which individuals can spend on formal care or informal caregivers.[30] This cash benefit is organized at the federal level, and a similar benefit is also available to non-elderly disabled individuals (“integration allowance” or “allocation d'intégration/integratietegemoetkoming”).[32] Access to this program is means tested, and takes into account social security benefits and the income of other non-family household members.[32] Eligibility for the elderly assistance Allowance is granted to individuals with reduced autonomy as a result of ADL and IADL limitations, as certified by a physician or multidisciplinary care team controlled by the Federal public service for social security.[32] The Allowance varies based on the “category” of dependency (i.e., the severity of need).[32] Both the Allowance and federally provided LTC nursing benefits are tax free. Tax deductions are available to households caring for non-elderly disabled co-resident.[23]

Because access to the federal Allowance for home care is means tested, some individuals do not qualify. These individuals will often pay out of pocket to hire their own personal care workers. Paying any domestic service worker, including home health care aides or maid services, is regulated by the government and must be done using “service cheques,” which are vouchers that allow individuals to purchase domestic services.[31]

### 3.1.2 Flexible Leave for Employees

About two-thirds of OECD nations provide some form of flexible leave for caregivers, though this leave is unpaid in the majority of countries.[23] In most countries which offer paid leave, the duration is limited to one month or less, reflecting a policy aimed at caring for individuals with acute or terminal illness, rather than ongoing LTSS needs. In contrast, Belgium offers a up to one year of paid leave for family caregivers, which employees can utilize in periods of one to three months.[23] “Medical assistance leave” is available to caregivers of family members or co-residential relatives, with certification from a physician that the care recipient requires continual care.[23] Employees may take this leave on a part or full time basis, and are protected from being fired by their employer for an additional three months after returning to work.[23] Small firms (fewer than 10 employees) may object to the employee’s leave if it will cause serious detriment to the business. Belgium establishes a uniform minimum compensation requirement for employees utilizing this benefit.[23] Belgium also offers another type of paid leave, palliative care leave, which is shorter in duration and allows employees to leave work for one to two months to care for a terminally ill parent.[23]

Belgium also offers paid leave which is longer in duration than most other OECD nations, and part time employees can access this benefit for up to five years.[32] For full time employees, “Time Credit” (*Crédit temps*) can be taken for up to a year, with a minimum of at least three months, on a full or partial basis.[34] Part-time employees can take up to two years of leave, and workers who only work 1/5th of the work week can take up to five years leave.[34] Belgium establishes a minimum compensation level for individuals utilizing this benefit, which varies according to whether the individual is employed in the public or private sector.[23] Time credit is not available until the employee has been in the workforce for five years, and spent at least two years at their current employer.[34] Employees may also take emergency leave to address unforeseen circumstances such as the hospitalization of a family member or accident, for a duration of 10 days for a private sector employee and up to 45 days for a public sector employee.[23]

Despite the availability of this benefit, workers are more likely to take parental leave than family care leave, and Belgian companies report that part-time workers are more likely to be on maternal care leave (80 percent) than family care leave (10 percent).[32]

### 3.1.3 Other Supports

Belgium also offers training and education, respite care, and counseling services to family caregivers.[23] These services are provided by non-profits at the local level, and are not part of a formalized federal benefit scheme.[35]

## 3.2 UNITED KINGDOM

Like Belgium, the UK provides medical care through a mandatory universal coverage scheme, the National Health Service (NHS), and many long term care services are delegated to the local level. At the national level, the NHS provides non-means tested financial support for nursing facility care and cash allowances for disabled individuals and caregivers.[36] At the local level, social service agencies provide means tested benefits, such as home care, meals, and respite care.[36]Also like Belgium, there is regional variation in LTC benefits available in the UK. Scotland, offers more generous LTC benefits than the rest of the country. Scotland provides personal care services to all residents living in institutional or community based settings.[37] In the rest of the UK, publicly supported personal care and home based services are a safety net offered only to those with severe needs.[38]

Funding for long term care comes from a combination of public and private sources, including the NHS, local governments, charities, and out of pocket spending by care recipients.[38] Available LTC services include for-profit and non-profit residential care homes, nursing homes, adult day care, private home care, meal delivery, therapy, and home nursing services.[38] Local social service authorities are funded by grants from the central government and local taxes, and can receive increased government funding by demonstrating high performance across indicators such as the timeliness of assessments and the number of individuals able to live independently in their home.[38]

A majority of LTSS in the UK is provided by informal caregivers. The number of adults receiving informal care in the UK reached approximately 2.2 million in 2010.[39] Though the number of adults receiving informal care has held steady over between 2000 and 2010, intensity of service use has increased. The number of adults who need help from a caregiver every day or more (rather than a few days a week or less) increased from 70 percent in 2000 to 76 percent in 2010.[39] The number of disabled elderly individuals receiving care from their adult children is expected to increase by 90 percent between 2005 and 2041.[38] Even among individuals who meet the income and resource requirements to qualify for public assistance with personal care, those with no source of informal care are prioritized.[38] To access publicly subsidized formal LTC services, individuals are assessed by the social services department of a local authority.[38] Determining the benefit allocation and services an individual will receive based on this assessment varies depending on the local authority, but often individuals are assigned a care manager who assists with the purchase and coordination of services.[38] Care recipients may also elect to receive their care budget in the form of a cash payment which they can use to purchase LTSS. Means testing determines the amount of the individual’s budget.[38]

In 2002, the Fair Access to Care initiative introduced a four tier rating system for the severity of an individual’s long term care needs (Critical, Substantial, Moderate, or Low need). This ranking system was intended to help standardize the outcomes achieved by individuals, and does not impose mandatory standards for the award of benefits. For example, a “critical” beneficiary is at risk of serious detriment to life, health, or social participation, while a “low” need beneficiary may be at risk of being unable to carry out one or two personal care or employment-related tasks.[38] Due to budgetary constraints, many local authorities have elected to restrict eligibility for services to individuals in the critical or substantial tiers.[36]

The Care Act of 2014 made significant changes to the UK’s LTC system. Under the new law, local authorities are responsible for activities which prevent functional decline among care recipients. The law calls on local authorities to “provide or arrange for the “provision of services, facilities or resources” which will reduce the service and support needs of caregivers and care recipients in the future.[40]

### 3.2.1 Financial Benefits

In addition to means tested benefits which may come in form of actual in kind services provided by local authorities or a budget for the purchase of such services, individuals may also receive an “Attendance Allowance.” This Allowance is not means tested and is available to individuals over age 65 who can demonstrate six months of need for assistance with basic bodily functions (ADL-type) or supervision to protect themselves or others from substantial harm.[38] The Attendance Allowance is a cash payment which compensates disabled individuals and can be used at the discretion of the recipient.[38] The benefit is available without regard to other public benefits an individual is entitled to, including sickness or old-age benefits.[32] However, individuals residing in a residential care setting paid for by a local authority cannot receive the Attendance Allowance.[32]

The UK also offers a cash benefit to family caregivers called the “Carer’s Allowance.” Caregivers receiving this benefit do not have to be related to the care recipient by blood or marriage or live with the recipient.[32] The benefit is only available to those providing a significant amount of care (35+ hours per week) and earning less than £100 ($124 USD) per week.[38] Additionally, recipients must provide care to someone receiving an Attendance or Disability Allowance and cannot be full time students. Compensation is currently set at £62.10 (approximately 77 US dollars) per week, reflecting a desire on the part of policy makers to provide compensation for lost earnings, not a wage for caregivers.[38] The Allowance is not tax deductible.

### 3.2.2 Flexible Leave for Employees

In the UK, caregivers are 30 percent more likely than other workers to hold a temporary rather than full time employment position.[23] Working age caregivers are more likely to experience poverty and leave employment or switch to part time employment.[23] The UK does not offer paid medical leave for employees. Employees are permitted to take unpaid leave of a reasonable duration (typically a few days) to care for a family member. Per the Work and Families Act of 2006, employees who have worked at least 26 weeks may request an undefined duration of time off to care for an immediate family member, and their employer may only refuse for “significant business reasons.”[38]

### 3.2.3 Other Supports

Depending on location, local entities may provide training and education, respite care, and counseling services for informal caregivers.[38] Whether benefits such as respite care are means tested varies by jurisdiction.[37] The Care Act of 2014 requires all local authorities in England to offer information on resources and support available to caregivers and care recipients.[41]

See Table 1 for a summary of the policies from the United States, Belgium, and the United Kingdom.

# 4.0 INNOVATIVE APPROACHES TO FAMILY CAREGIVER SUPPORT

# 4.1 LEGAL RECOGNITION FOR CAREGIVERS

In Belgium, law 2014/203605 provided formal legal recognition of caregiver status. This status is not currently tied to specific financial or social rights, but legislators plan to use the formal legal designation to expand the rights of family caregivers.[42] The legal recognition of caregiver status is granted and renewed annually by submitting a sworn declaration that the person is a caregiver. The care recipient or their representative must provide consent. The federal government will determine the maximum number of care recipients with whom a caregiver may be formally affiliated.

Under the law, informal caregivers (“*aidants proches*”) must be adults or emancipated minors, must not be employed as a caregiver in a professional capacity, must deliver care in affiliation with at least one professional caregiver, and must have a close relationship with the care recipient.[43] The law enumerates the circumstances under which formal caregiver status may be terminated, including: at the request of the care recipient or caregiver, upon the death of the care recipient, when the care recipient no longer has care needs sufficient to grant a “dependency” status, when the care recipient is permanently supported by a formal residential facility, when the caregiver no longer meets the recognition criteria established by this law, or in cases of violence, abuse, fraud or neglect on the part of the caregiver.[44]

Insights into the possible uses of the legal recognition of family caregiver status come from an extensive analysis performed by Universities in Namur and Brussels.[45]

*Flexible Work Arrangements*. The legal recognition of family caregiver status could introduce greater uniformity into the availability of credit temps benefits. Rather than varying benefits according to public or private sector status, a uniform scheme could apply to all caregivers, and simplify the variations that exist for full and part time workers. Caregiver status could also be used to grant employees access to a flexible leave program established specifically to benefit caregivers, which would run parallel to current programs such as the Medical Assistance leave. For example, a benefit consisting of 25 days per year that could be used as needed to provide informal care, help care recipients visit their physician, or intervene in a crisis.[45] Caregiver status could also help employees avoid termination, by creating a kind of rebuttable presumption that the fulfillment of their duties as a caregiver, absent other circumstances, should not justify their termination.[45]

*Financial Benefits*. Caregiver status could be used to pay out cash benefits to individuals missing work to provide informal care to family members, to recognize time spent providing care when calculating an individual’s pension, or to expedite the award of unemployment benefits.[45] Additionally, “caregiving” could be treated like an emergency or other extraordinary circumstance that permits employees to miss work without harming the accrual of their pension.

*Liability Issues*. Caregiver status could help reduce uncertainty when families are purchasing insurance, and allocate civil or criminal responsibility in situations where caregivers or care recipients are injured in the course of providing or receiving care. For example, in the context of a family liability insurance policy, a family caregiver may provide the same services as a domestic servant, but would not be correctly classified by the insurance policy. This leaves a gap between the risks assumed by the caregiver and their eligibility for coverage from the insurer.[44] Similarly, Belgian law requires individuals to purchase insurance for domestic workers who work a certain number of hours per week, as these workers are at risk of injury from the services they perform.[44] Caregivers are also at risk of physical injury from tasks such as helping an aging relative use the bathroom or get out of bed. Legal recognition could extend these insurance coverage requirements to family caregivers.

## 4.2 CAREGIVER ASSESSMENTS

Policies in the UK require assessments of both care recipients and caregivers. Local authorities administer caregiver assessments to determine what type of supports caregivers need, addressing areas such as physical and mental well-being, employment goals, and parenting responsibilities.

The Carer’s Rights movement in the UK has expanded the recognition of caregiver needs over the past decade, and resulted in legislation to expand the scope of the caregiver assessment. The Carers (Recognition and Services) Act of 1995 requires local authorities to provide caregiver assessments at the request of the caregiver. The assessment was to review the ability of the caregiver to “provide and to continue to provide care for the relevant person,” and the information generated by the assessment must be factored into decisions about the allocation of benefits to individuals with qualifying LTC needs.[46] The Carers Equal Opportunities Act of 2004 made changes to the assessment. Under this law, local authorities are required to inform caregivers of their right to an assessment, which helps to bolster the number of carers able to receive an assessment. Additionally, the scope of the caregiver assessment was expanded, to include elements such as the preferences and goals of the caregiver with respect to employment and leisure activities.[47] Questions about employment were included in the 2004 legislation in response to a survey of caregivers which found that the desire to continue employment was not addressed by the previous assessments.[48]

The latest reform to caregiver assessments was enacted in the Care Act of 2014. This law requires the performance of a caregiver assessment when “it appears to the local authority that a carer may have needs for support,” rather than when the caregiver specifically requests an assessment.[40] Additionally, the assessment must be performed even if the caregiver does not meet the previous thresholds for providing a “substantial” amount of care per week. Under the Care Act, local authorities are required to perform an assessment of the care recipient and the caregiver regardless of the local authority’s view on their apparent level of need or financial resources.[41] Local authorities are permitted to combine assessments (i.e., conducting a review of the needs and capacities of both the caregiver and the care recipient at one time) and to combine forces with other public entities (i.e., working with NHS providers conducting a medical needs assessment of an individual).[41]

Per the text of the Care Act of 2014, the assessment must address the following:

* the ongoing ability of the caregiver to provide care;
* the willingness of the caregiver to provide care;
* the impact of the caregiver’s duties on their well-being;
* the caregiver’s goals for day to day life, and
* whether support will help the caregiver achieve their desired outcomes for day to day life.[40]

Local authorities are required to consider the well-being of both the care recipient and caregiver in carrying out all of their duties under the Care Act. The Act defines well-being across several dimensions, including personal dignity; physical and mental health and emotional well-being; participation in work, education, training or recreation; domestic, family and personal relationships; and control by the individual over day-to-day life.[40]

Following the caregiver assessment, the local authority must generate a “support” plan for the caregiver if certain conditions are met. Specifically, this support plan is mandatory if the caregiver falls below a certain financial threshold, or if the caregiver exceeds the resource limitations, but requests the local authority’s assistance. Per the text of the Care Act of 2014, the support plan will:

* Include an inventory of the needs identified in the assessment;
* Identify which needs the local authority will meet and how it will meet them;
* Provide a personal budget specifying how much the identified needs will cost and what proportion of the cost will be covered by the local authority rather than the caregiver;
* Contain advice and information about what can be done to meet the needs not addressed by the local authority; and
* Explain what actions the caregiver can take to prevent or delay the development of future needs for care and support.[40]

LTC in the UK relies extensively on family caregivers. The Carer’s Rights movement recognizes that caregivers must be supported if they are to continue to effectively play their important role in LTC. Caregiver assessments enable local authorities to gain a thorough understanding of caregiver needs, responsibilities, and goals. Using this information, local authorities can refer family caregivers to appropriate services and supports in the community and provide financial assistance, as needed, to ensure caregivers are successfully connected to these services.[49]

##

# 5.0 APPLICABILITY OF EUROPEAN MODELS TO U.S. POLICIES

## 5.1 LEGAL RECOGNITION

As noted in the discussion above, legal recognition of family caregiver status could provide a helpful tool across multiple areas of US law. One of key challenges to implementing a formal family caregiver recognition is defining what constitutes a family caregiver. The language of the Belgian statute is brief and it is likely that implementing a similar recognition in the US would involve an extensive regulatory process. That said, a formal legal recognition for caregivers would assist in the implementation of a wide array of beneficial policies discussed below.

*Family and Medical Leave*. The benefits available to employees under the FMLA varies, depending on employer and state leave laws. Legal recognition of caregivers provides a tool which could be used in a variety of ways, and applied to reforms at either the state or federal level within the US. Such uses include increasing the benefits available for caregivers, articulating a new flexible leave policy (such as 25 days of flex time), or creating a rebuttable presumption that, absent other justification for termination, employees should not be fired for fulfilling their duties as a family caregiver.

*Tax Status*. Several states provide tax credits to family caregivers, to help offset the expenses associated with caregiving, such as home modifications or supplies (i.e., adult diapers or prescription drugs). Fewer than half of states also allow family caregivers to deduct a portion of their federal Dependent Care Tax Credit (DCTC) from their state return.[50] The DCTC applies to qualified expenses for dependent care financed by working individuals.[14] Application of this credit to family caregivers is complicated by the restrictions in the law – the DCTC only applies to dependents in a shared residence, and thus cannot help adult children caring for an aging parent with a separate residence.[10] Legal recognition of caregivers could provide a streamlined way expand access to the DCTC for family caregivers. For example, working individuals who also formally qualify as caregivers could be permitted to claim qualified expenses for an elderly parent, regardless of residence.

*Social Security*. The estimated value of unpaid, informal caregiving in the US is in the hundreds of billions. Time spent providing care to an aging relative or parent results in lost earning potential and reduces lifetime earnings, which negatively impacts the Social Security benefits an individual will receive. Individuals who are legally recognized as caregivers could receive a credit toward their lifetime earnings for the purposes of calculating Social Security benefits. Whether this benefit should also include caregiving for children is beyond the scope of this paper, which focuses on meeting the increased demand for LTC in the aging population. Formal legal recognition of family caregivers would allow this benefit to remain narrow in scope or expand as appropriate.

## 5.2 FAMILY CAREGIVER ASSESSMENTS

If Medicaid made the requirement for caregiver assessments mandatory, the caregiver assessment in the UK could provide a framework. With its well-being dimension, the UK assessment incorporates the basic considerations of mental and physical health raised by the AARP, as well as the need to inquire about social supports that would benefit the caregiver. However, the UK assessment adds several beneficial dimension to this baseline – it requires a consideration of the goals of the caregiver and the creation of a support plan for the caregiver that provides financial planning information, and summary of identified needs, and information about how to fulfill those needs. The burden associated with creating this report would create additional complexity for service coordinators affiliated with Medicaid, but would provide an invaluable resource to family caregivers.

Implementation of caregiver assessments does not have to come via the Medicaid program. These assessments could be mandated and funded as an amendment to the National Family Caregiver Support Program, and carried out by local Aging and Disability Resource Centers (ARDCs) or Area Agencies on Aging (AAAs). ADRCs are information centers which help individuals with disabilities find appropriate services. Entities designated as ADRCs are often, but not always, the AAAs which provide services.[51] By housing the assessments in AAAs and/or ARDCs, uniform caregiver assessments could be offered to all family caregivers, whether or not they are providing support a Medicaid beneficiary. Caregiver assessments could inform and improve the caregiver supports and services offered by local AAAs. These assessments would provide more comprehensive data on whether available services are aligned with caregiver needs. Assessment data would provide greater insight into unmet caregiver needs

and ensure that any additional investments in NFCSP or Lifespan Respite programs are effectively allocating limited resources.

# 6.0 CONCLUSION

As the population ages, the need for long term care will increase across the globe. Many countries, including the United States, are exploring ways to cope with this anticipated demand. Currently, millions of family caregivers in the United States provide support to aging relatives and parents. Effective strategies to support caregivers will help ensure that these individuals are able to continue to provide support to aging individuals without sacrificing their own health, well-being, or economic security.

Innovative approaches to family caregiver support in Belgium and the UK could provide a model for US policymakers. Recently enacted Belgian law provides formal legal recognition of caregiver status. In the US, formal legal recognition would offer a mechanism to extend the family leave and financial benefits available under current law to family caregivers. In the UK, family caregiver assessments help ensure that the full range of caregiver needs, responsibilities, and goals are understood and addressed. In the US, mandating caregiver assessments would allow state and local authorities to better understand and meet caregiver needs, as well as effectively target limited resources.

Table 1. Summary of Family Caregiver Policies

|  |  |  |  |
| --- | --- | --- | --- |
| **Policy** | **United States** | **Belgium** | **UK** |
| *Federal Tax Benefit or Insurance Scheme*  | Federal Dependent Care Tax Credit (DCTC) is available to working individuals who pay a provider to care for their child or another dependent. Parents of minor children claim the credit most often. The credit cannot benefit a spouse caregiver or an adult child living outside of their parent’s residence.  | Permits tax deductions in households where one of the residents is disabled, including age-related disability.   | Financing for LTC services is a blend of national contributions, out of pocket spending, local contributions, and charitable donations.  |
| *State/Other Local Tax Benefit* | Georgia, Oregon, North Dakota, Missouri, Montana and Idaho offer a tax credit to family caregivers, based on either the individual’s status as a caregiver or caregiving expenditures. |  | Formal LTC services in the UK are provided at the local level and means tested.  |
| *Federal Family Medical Leave*  | 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. A majority of FMLA utilizers took time off for their own illness.  | Up to one year of paid leave is available. Employers must have serious business grounds to refuse a leave request. “Crédit temps” is a flexible leave program that workers can use for 1-5 years.  | Employees are allowed to take “reasonable” amount (a few days) of unpaid leave to care for family members. 2004 reforms added an employment dimension to caregiver assessments, to support caregivers seeking to stay in the workforce. |
| *State/Other Local Family Medical Leave* | FMLA allows states to set standards that are more expansive than the federal law and many states have chosen to do so. A handful of states offer *paid* medical leave. 9 states offer private sector employees flexibility in allocating their own paid sick-leave to the care of a family member, while 19 states offer the same option to public-sector workers. |  |  |
| *Social Security Benefit*  | Research in the US has explored allowing family caregivers to claim benefits under Social Security for time spent providing care to a family member but outside of the labor force, but this type of policy has not been enacted in the US.  |  | UK offers a state pension to individuals who have paid into the National Insurance system for a qualifying time period.  |
| *Caregiver Assessment and Recognition***Table 1****Continued** | Some state Medicaid waivers include caregiver assessments, but the US does not have a standardized caregiver assessment policy.  | Belgium has implemented formal legal recognition of caregiver status.  | “Carers Recognition and Services Act” requires local authorities to assess the abilities of individual at the carers request and use that info when determining what services to provide to care recipient. |
| *Respite Care* | The Lifespan Respite Care Act of 2006 provides grant funding to states and local entities to improve the availability and accessibility of respite services for family caregivers. This includes training and recruiting respite care workers and providing information about the availability of services.  |  | Grant programs in all UK countries provide free respite care, but some localities choose to means test. |
| *Hiring and Cash Benefits* | Under Medicaid waivers, participants have some flexibility to hire and pay their own caregivers. Some states place restrictions on which family members may be hired as caregivers, others do not.  | Availability and amount of direct, flat rate allowance for caregiver depends on local municipality.  | Allowance is available for those that spend more than 35 hours per week caregiving, provided they are not a full time student and their income does not exceed a certain threshold ($124/week).  |

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