

THE CAREGIVER BURDEN: THE IMPACT OF THE CURRENT BUREAUCRATIC SYSTEM ON CAREGIVERS AND OLDER AND DISABLED INDIVIDUALS

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I. Introduction

On July 1, 2024, Governor Glenn Youngkin of Virginia signed multiple bills into law in an attempt to alleviate the burdens that many caregivers face on a daily basis.¹ These laws were enacted with the goal of making it easier for family members to be paid to provide care for their loved ones who are disabled and unable to care for themselves. As Americans age, unpaid family caregivers are becoming more and more common, and these caregivers have to give up opportunities, lose income, and make many other personal sacrifices in order to provide care for their loved ones. While there are currently many government programs and benefits available to unpaid caregivers, most of these programs require strict documentation and recordkeeping with government agencies and the local, state, and federal levels. Other benefits might be helpful to caregivers, but the majority of caregivers are unaware of the program or how to begin the application and eligibility process.

Although there have been some attempts to simplify the laws and documentation requirements that caregivers must complete in order to be compensated for the care they provide, the process remains overly complicated and places a burden on caregivers that makes it very difficult for them to navigate the complicated public benefits system. Most government agencies are underfunded and therefore understaffed, making the wait to obtain benefits impossibly long for caregivers and older individuals who are already in crisis. Finally, public programs and other solutions available to caregivers are often so narrowly construed as to make these benefits unavailable to all but a very select group of individuals. These circumstances thus discourage unpaid family caregivers from seeking compensation for the work they do on behalf of their loved ones, adding to the significant burden the caregiver is already facing.

II. The Price of Caregiving

There is no question that being a caregiver takes a personal toll on those providing the care. Studies have shown that people serving as caregivers to older individuals suffer psychological, emotional, and economic consequences.² According to the Alzheimer's Association, as of 2024, there are approximately 342,000 unpaid caregivers in Virginia alone, representing 662 million hours of unpaid care per year for a total of \$12.572 billion in unpaid care.³ Caregivers for spouses with dementia are more likely to delay healthcare for themselves and are more likely than other caregivers to "become increasingly frail during the time between becoming a caregiver and their spouse's death."⁴ In Virginia, 64.1% of dementia caregivers reported that they have at least one chronic

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¹ See Jahd Khalil, *Multiple New Caregiving Laws Take Effect Monday*, VPM NEWS (June 27, 2024), <https://www.vpm.org/news/2024-06-27/dd-waiver-dmas-caregiving-developmental-disability-home>.

² Heejung Kim et al., *Predictors of Caregiver Burden in Caregivers of Individuals with Dementia*, 68 J. ADVANCED NURSING 846, 848 (2011).

³ ALZHEIMER'S ASS'N, 2024 ALZHEIMER'S DISEASE FACTS AND FIGURES 47 (2024).

⁴ *Id.* at 50.

condition, 31.2% reported feeling depressed, and 15.1% reported that they themselves are in poor physical health.⁵ Adding to the emotional burden is that unpaid caregivers are more likely to divorce, with 80% reporting that their caregiving responsibilities put a strain on their marriage.⁶

Caregivers also make significant economic sacrifices. Unpaid caregivers spend an average of 26% of their own income on caregiving-related expenses each year, whether from personal care items for the person (such as medications, incontinence supplies, or clothing) or as a result of increased household expenses such as food, utilities, or home renovations (such as wheelchair ramps or bathroom grab bars).⁷ Not only do caregivers pay out of their own pockets for their family members' care, but data has shown that they also cut back on their own personal spending and do not save as much money in order to provide for their loved one—in fact, 27% of unpaid caregivers have less than \$1,000 in emergency savings, and half live paycheck to paycheck.⁸

In addition to the actual cost of caregiving, unpaid caregivers pay an opportunity cost as well. According to a study by Guardian, women who care for their mothers have median lost wages of \$24,500 over a two-year period.⁹ The Alzheimer's Association has reported that 47% of caregivers missed work time due to their caregiving responsibilities, with 9% of caregivers giving up working entirely while 6% were forced into an early retirement.¹⁰ Unfortunately, caregivers do not always feel comfortable discussing their situation with their employer for fear of the stigma that such a role often has. Caregivers may worry about being perceived as not dedicated to their job or as potentially unreliable employees.¹¹ Therefore, many unpaid caregivers simply end up retiring or cutting back hours rather than seeking workplace accommodations.

III. Understaffed Government Agencies Increase Caregiver Stress

Even with the help of public benefits such as Medicaid programs and veterans' benefits, caregiving is a difficult task. Unfortunately, the very benefits that are supposed to make the caregiver's role easier often add to the stress by imposing onerous documentation requirements on caregivers who are applying for or seeking to maintain these benefits. Public benefits applications are hefty, with most applications requiring dozens of pages of verifications along with a confusing application format. Often, caregivers feel the need to hire an attorney or other professional to help them with the process, adding further expenses to the already steep cost of care. Most government benefits, such as Medicaid long-term care supports and services, require an annual renewal process as well, so the burden of paperwork and dealing with confusing deadlines is never quite over.

The difficulty with obtaining public benefits does not stop once the application is submitted. Government agencies in charge of approving or reviewing the application are understaffed and overworked, which often leads to a delay in applications being reviewed and approved. In its 2022-2024 Strategic Plan, the Department of Medical Assistance Services ("DMAS"), the agency responsible for reviewing and approving Medicaid applications, revealed that while it continues to work on ways to retain and hire employees, "DMAS still has concerns regarding DMAS' retention of essential workforce members. Retirements and resignations could potentially have a significant impact on the agency's operations."¹² When it comes to Medicaid, Virginia suffers from particularly difficult budget issues—for 2023 and 2024, DMAS reported a \$632 million budget shortfall.¹³

The Veterans Benefits Administration (the "VA") has not been spared from these issues. The VA offers a pension called the Aid and Attendance Pension for veterans and their spouses who require the aid and attendance

⁵ *Id.* at 51.

⁶ GUARDIAN LIFE INS. CO. OF AM., *STANDING UP AND STEPPING IN: A MODERN LOOK AT CAREGIVERS IN THE U.S.* 11 (2023).

⁷ *Id.*

⁸ *Id.*

⁹ *Id.*

¹⁰ ALZHEIMER'S ASS'N, *supra* note 3, at 53.

¹¹ GUARDIAN LIFE INS. CO. OF AM., *supra* note 6, at 16.

¹² DEP'T OF MED. ASSISTANCE SERVS., *2022-24 STRATEGIC PLAN*, DMAS No. 602, at 2 (Va. 2024).

¹³ Michael Martz, *Virginia Medicaid Program Faces \$632M Hole*, RICHMOND TIMES-DISPATCH (Nov. 9, 2024), https://dailyprogress.com/news/state-regional/government-politics/virginia-medicare-shortfall-youngkin-tax-cuts/article_a52f701f-e003-5674-bfd3-3f5aa75bcb16.html.

of someone else to succeed in their daily lives.¹⁴ Individuals receiving this pension must require help with their activities of daily living and, similar to Medicaid, there are strict asset and income requirements that must be met in order for a veteran or surviving spouse to qualify for this pension. Once the individual qualifies, they will receive a tax-free pension that can supplement the cost of care in a facility or at home.¹⁵ This pension can help unpaid caregivers find relief by allowing them to hire professional caregivers for respite care and can also ease the financial burden that paying for care places on veterans and their families.

Unfortunately, this pension is not widely advertised, and many veterans and their families are unaware that it exists and that they qualify (or could easily become eligible) for the pension.¹⁶ For those who are aware of the pension, it can take several months after the application is submitted before their application is processed and they begin receiving retroactive and ongoing benefits. In July 2024, the Government Accountability Office (“GAO”) released a report that revealed the VA has failed to implement most of the recommendations that the GAO made in 2021 in an attempt to improve efficiency of the claims process.¹⁷

While the federal and state governments are clearly aware of the difficulties caregivers face when it comes to obtaining financial relief to pay for their loved ones’ care, the government at all levels has taken few steps to alleviate the burden on caregivers it creates. When coupled with the emotional, psychological, and financial toll that unpaid caregivers must confront, the constant delays and confusion created by these understaffed government agencies can often completely discourage caregivers from seeking assistance at all. The VA denies about 88% of caregiver program applications—not because they lack merit, but because the correct verifications and application requirements have not been met, and the VA does not have the staff to assist applicants with their claims in a meaningful way.¹⁸ Understandably, caregivers who are already overworked and overwhelmed with their duties often give up on applying for assistance after facing multiple roadblocks.

IV. Current Caregiver Documentation Requirements Under the Commonwealth Coordinated Care Plus Waiver

Lawmakers in Virginia have made it clear that there is a need for documentation and paperwork for all care providers, irrespective of the fact that the appropriate care was actually provided. In *Department of Medical Assistance Services v. Ablix Corporation*, the court of appeals stated that “the purpose of the Medicaid program is not only to provide needed medical services and equipment, but also to do so in a fiscally responsible manner.”¹⁹ The federal government requires that state agencies assure financial accountability for the funds it spends for home and community-based services.²⁰ In *Ablix*, DMAS issued a decision requiring that Ablix Corporation, a home health care provider, reimburse DMAS for personal care services and respite care services to the tune of over \$200,000 as a result of its failure to maintain adequate documentation of the care it provided.²¹

The elderly individual in this case was receiving care under the Elderly or Disabled with Consumer Direction (“EDCD”) Waiver, which has since been merged with other programs and reclassified as the Commonwealth Coordinated Care (“CCC”) Plus Waiver.²² The current law in Virginia, under the CCC Plus

¹⁴ U.S. DEP’T OF VETERANS AFFAIRS, ADJUDICATION PROCEDURES MANUAL M21-1.IX.ii.1.A (2024).

¹⁵ *VA Aid and Attendance: Everything Caregivers Need to Know*, GIVERS (May 8, 2023), <https://www.joinivers.com/learn/va-aid-attendance>.

¹⁶ *VA Benefits and Eligibility Criteria for Aid and Attendance aka Housebound Rating*, NAT’L VETERANS FOUND., <https://nvf.org/va-aid-and-attendance-benefits/> (last visited Nov. 6, 2025).

¹⁷ U.S. GOV’T ACCOUNTABILITY OFF., VA DISABILITY BENEFITS: TRAINING FOR CLAIMS PROCESSORS NEEDS TO BE ENHANCED, No. GAO-24-107510 (2024).

¹⁸ *Senators Hassan, Murray Lead Bipartisan Call to Improve VA Caregivers Program for Veterans and Their Families*, MAGGIE HASSAN (Feb. 22, 2022), <https://www.hassan.senate.gov/news/press-releases/senators-hassan-murray-lead-bipartisan-call-to-improve-v-a-caregivers-program-for-veterans-and-their-families>.

¹⁹ *Dept. of Med. Assistance Servs. v. Ablix Corp.*, 2015 Va. App. LEXIS 82 (Va. Ct. App. 2015).

²⁰ 42 C.F.R. § 441.302(b) (2024).

²¹ *Ablix*, 2015 Va. App. LEXIS 82 at 5.

²² *Id.* at 6.

Waiver, allows for “consumer-directed personal care attendants”; that is, personal care providers, who can be family members or friends, who are not employed with a specific home care agency.²³ The idea behind this program is that it allows individuals to receive care at home rather than in a nursing home or other facility, encouraging family or other caregivers to provide care to their loved ones.²⁴ In order to maintain these benefits and receive payment for the care they provide, caregivers and care recipients must submit to periodic “utilization reviews” to ensure compliance with policy and regulations.²⁵ During these reviews, staff will visit the caregiver on-site and conduct interviews with the individual, the family, or others.²⁶ Caregivers are required to provide billing records to the auditor.²⁷ The reviewer will then determine whether the services delivered were appropriate and whether the services continue to be needed.²⁸

In *Ablix*, the care providers did not complete the required forms, and the care providers included multiple service types on one form instead of using separate forms for each service type.²⁹ Therefore, they were required to reimburse DMAS over \$200,000—not because the agency had not provided the care or because there was anything improper about the care, but because Ablix did not provide the proper documentation to obtain compensation for the care.³⁰ In a similar case in which a care provider was required to reimburse DMAS for failing to keep adequate records, *1st Stop Health Services v. Department of Medical Assistance Services*, the Director of DMAS acknowledged that there was no dispute over whether the care had occurred; instead, the issue was with the proper forms not being completed.³¹ DMAS and the federal government have allowed documentation requirements to become the priority rather than honoring the spirit of the law, which is that caregivers who actually provide the care they are claiming to have provided receive adequate compensation for doing so.

While the caregivers in *Ablix* and *1st Stop* were agencies, the same documentation is currently required for individual caregivers under the CCC Plus Waiver. In fact, the CCC Plus Manual includes a 13-page chapter on billing procedures and documentation instructions for caregivers and a 15-page chapter on periodic reviews that DMAS carries out to ensure these procedures are met.³² Consumer-directed caregivers are strongly encouraged to complete a form on a weekly basis that details whether the attendant assisted with any of the six activities of daily living (bathing, dressing, feeding, transferring, toileting, and incontinence assistance), along with helping with tasks such as turning or changing positions, personal grooming, and supervision.³³ They also are encouraged to certify on a daily basis whether they have assisted with wound care, range of motion activities, vital signs, or medication management.³⁴ Given the above statistics on the time constraints and stressors that caregivers already face, these documentation requirements can place an unbearable burden on people who are already taking on a high level of responsibility. The CCC Plus Manual requires providers to refund payments from DMAS if they fail to maintain the proper records or documentation to support their claims, even if the care actually took place.³⁵

Although the CCC Plus Waiver allows for personal care attendants who are not medical professionals to be paid caregivers, these family members or friends are still required to undergo many of the same procedures are

²³ 12 VA. ADMIN. CODE § 30-120-935(G)(4) (2024); VA. DEP'T OF MED. ASSISTANCE SERVS., COMMONWEALTH COORDINATED CARE PLUS WAIVER MANUAL IV 4–5 (2024), <https://vamedicaid.dmas.virginia.gov/sites/default/files/2023-12/CCC%20Plus%20Waiver%20chapter%204%20%28updated%2012.29.23%29.pdf>.

²⁴ *Waivers*, DMAS, <https://www.dmas.virginia.gov/for-members/benefits-and-services/waivers/> (last visited Nov. 10, 2025).

²⁵ VA. DEP'T OF MED. ASSISTANCE SERVS., *supra* note 23.

²⁶ *Id.* at 5.

²⁷ *Id.*

²⁸ *Id.* at 3.

²⁹ *Dept. of Med. Assistance Servs. v. Ablix Corp.*, 2015 Va. App. LEXIS 82, at 8 (Va. Ct. App. 2015).

³⁰ *Id.* at 5.

³¹ *1st Stop Health Servs. v. Dep't of Med. Assistance Servs.*, 756 S.E.2d 183, 187–89 (Va. Ct. App. 2014).

³² VA. DEP'T OF MED. ASSISTANCE SERVS., COMMONWEALTH COORDINATED CARE PLUS WAIVER MANUAL V, ch. V, VI (2025), https://vamedicaid.dmas.virginia.gov/sites/default/files/2025-11/CCC%20Plus%20Waiver%20Chapter%20V%20%28updated%2011.6.25%29_Final.pdf.

³³ VA. DEP'T OF MED. ASSISTANCE SERVS., CONSUMER-DIRECTED EMPLOYER OF RECORD MANUAL 35, 57 (2021),

https://vamedicaid.dmas.virginia.gov/sites/default/files/202307/CCC%20Plus%20Appendix%20C%20%28updated%209.1.21%29_Final.pdf.

³⁴ *Id.* at 58.

³⁵ VA. DEP'T OF MED. ASSISTANCE SERVS., *supra* note 23, ch. VI, at 2.

registered nurses or licensed practice nurses who provide the same care. Similar to a medical professional applying for any caregiving position, personal care attendants are required to have a satisfactory work record and two references from prior job experience—a requirement that may be impossible to meet if a caregiver has put off having a career or paying job to take care of a loved one.³⁶ Along with receiving regular tuberculosis screenings, they also must be willing and able to attend caregiver training at any time upon the request of the individual receiving the care, their family, or the Virginia Department of Social Services (“VDSS”).³⁷ If someone is the sole caregiver for an elderly adult who cannot be left alone, attending these trainings could be a hardship both for the caregiver and the person who needs the care. These periodic trainings may also require the caregiver to take time away from work or other personal obligations, adding to the responsibilities they are already managing.

Under the CCC Plus Waiver, the personal care attendant cannot be the spouse of the individual receiving care. Until recently, if caregiving services were rendered by other family members or caregivers living with the individual receiving care, there had to be “written, objective documentation” as to why there is no one else who is able to provide services to the individual.³⁸ The process was so complicated that DMAS provided a flow chart to determine whether the caregiver could be reimbursed depending on their relationship to the member.³⁹ Rather than encouraging the family unit to provide care to elderly or disabled relatives, these rules actually worked to deter caregivers from pursuing these benefits.

Thankfully, the Virginia General Assembly passed a law that went into effect on July 1, 2024, in an attempt to remedy some of these problems. This new law, House Bill 909, directs DMAS to seek federal authority to modify the program rules for home and community-based services waivers to eliminate the requirement that, in order for a caregiver to receive reimbursement for personal care services, no one else be available to provide services to the member.⁴⁰ Because this legislation was passed so recently, it remains to be seen whether this will have a permanent positive impact on the caregiver burden. Because Medicaid is a federal program administered by the individual states, Virginia still must seek and obtain federal authority before these rules can be modified successfully.

Although steps are being taken to assist unpaid caregivers, many of the regulations currently in place only serve to heighten difficulty for family members living with their loved ones to receive payment for the care they provide; in fact, many caregivers might be discouraged from seeking Medicaid reimbursement in the first place because they lack the time, training, knowledge, or initiative to obtain the required documentation and complete the requirements to become a paid caregiver.

V. Caregiver Child Exception to Medicaid Transfer Penalty Rules

One Virginia law that can greatly benefit children who live with and provide care for their elderly parents is called the “caregiver-child” exception to Medicaid asset transfer restrictions. Under normal circumstances, Virginia Medicaid rules penalize applicants who make gifts or uncompensated transfers within five years of applying for Medicaid benefits, including long-term care supports and services.⁴¹ This means that an individual cannot give away their assets, including their primary residence, within five years of applying for Medicaid if they want to avoid a penalty period. This rule applies to personal gifts to individuals as well as transfers to trusts. As of 2024, for every \$7,023 in gifts or uncompensated transfers made within five years of applying for Medicaid

³⁶ 12 VA. ADMIN. CODE 30-122-460(D)(7)(c) (2024).

³⁷ *Id.* at (D)(8)(f-g).

³⁸ *EPSDT Personal Care Services*, VA. DEP’T OF MED. ASSISTANCE SERVS. (Aug. 21, 2019), https://vamedicaid.dmas.virginia.gov/sites/default/files/2023-07/EVV_EPSDT%20%20Personal%20Care%20Srvs%20%28updated%208.21.19%29%20-%20FINAL.pdf.

³⁹ VA. DEP’T OF MED. ASSISTANCE SERVS., CONSUMER-DIRECTED ATTENDANT DOCUMENTATION FORM, No. DMAS-487 (2009).

⁴⁰ H.B. 909, Ch. 0646, Reg. Sess. (Va. 2024).

⁴¹ DEP’T OF MED. ASSISTANCE SERVS., ELIGIBILITY MANUAL M1450.400.C.3 (2007).

benefits, the Medicaid applicant will be ineligible for Medicaid benefits for one month.⁴² However, Virginia allows for an exception to this rule: if a child has lived with their parent for a minimum of two years, caring for their parent in a way that has allowed them to avoid the need for a nursing home or other Medicaid benefits, the parent can transfer their primary residence to their child using a deed of gift without being penalized for doing so.⁴³

Unfortunately, many children who provide care to their parents are unaware of this exception, which requires a good deal of documentation to obtain. Along with the deed of gift, applicants must submit an evaluation from their medical provider stating that they have needed a certain level of care for at least two years.⁴⁴ Those hoping to benefit from this exception to the gifting rules must also submit an affidavit from a neighbor or other associate who can verify that the child has been living with their parent for at least two years prior to the date of the Medicaid application. In reality, the average caregiver would be unaware of this benefit or how to properly obtain it without consulting an experienced elder law attorney first.

VI. Care Agreements and Shared Expense Agreements

Caregivers can also be paid for their services without their loved one receiving Medicaid benefits through traditional care agreements. The individual needing care and the previously unpaid caregiver can execute an agreement in which the caregiver receives an hourly rate to provide basic caregiving services for their loved one. As long as the care is documented and spelled out clearly in the agreement, these payments do not constitute a gift that would cause any difficulty if the individual later applied for Medicaid.⁴⁵

However, these agreements require strict proof—the caregiver must keep a detailed log of how many hours per day they provide care and exactly what care is provided. In order to make a case for their hourly rate, many caregivers may choose to employ a geriatric care manager or other medical professional to evaluate their loved one and determine what services they need. Of course, hiring a geriatric care manager is an additional time commitment and expense that many caregivers simply do not have. The reality is that income under these care agreements must be reported as taxable income to the IRS and local tax authorities. Many caregivers do not want to have their tax liability increased as a result of the care they provide to their family member.

As previously discussed, family caregivers spend a great deal of their own funds making sure their loved ones are cared for properly. This is especially true if the elderly or disabled individual is living in the home—expenses such as groceries, water usage, power usage, cable and internet, and gas will increase exponentially if unpaid caregivers have their parents living in their home. Thankfully, Virginia law allows caregivers, and those receiving the care, to sign a shared expense agreement in which the person living in the caregiver's home pays their pro rata share of utilities, home maintenance, and other expenses.⁴⁶ Unlike payment under care agreements, this additional payment does not have any tax consequences for the caregiver. However, the expenses must be carefully documented with proof of utility bills and invoices or receipts for all expenses paid under the shared expense agreement.⁴⁷ If these payments are not properly documented, DMAS may see these payments as uncompensated transfers, or gifts, and impose a penalty accordingly if the individual receiving care ever needs to apply for Medicaid benefits. Many people may be receiving informal payments from their loved ones to “help out with the bills” without understanding the need for strict documentation and records for these payments. For those who document it properly, shared expense agreements can be a boon for caregivers with loved ones living in their home.

⁴² *Id.* at M1450.630.

⁴³ *Id.* at M1450.400.

⁴⁴ *Id.*

⁴⁵ CONSUMER-DIRECTED ATTENDANT DOCUMENTATION FORM, *supra* note 39.

⁴⁶ I.R.S. Pub. 502 (2023).

⁴⁷ *Id.*

VII. Proposals for Future Caregiver Benefits

According to a recent study by the AARP (formerly the American Association of Retired Persons), one in four caregivers have reported that they need help in figuring out forms, paperwork, and eligibility for services.⁴⁸ Although the government has made attempts to alleviate the burden that red tape, such as documentation requirements, lengthy applications, confusing flow charts, and ever-changing rules, placed on caregivers on a daily basis, the fact remains that for the average unpaid family caregiver, the current situation is both confusing and overly burdensome. A drastic overhaul of the application and eligibility process for Medicaid, veterans' benefits, and other potential benefits for caregivers is needed in order to alleviate this aspect of caregivers' stress permanently.

The federal government has made some attempts to alleviate the burden that these strict documentation and application requirements impose on care providers. Senator Edward Markey and a bipartisan commission of 21 cosponsors have introduced the Alleviating Burdens to Caregivers Act (or "ABC Act"), which has the goal of requiring "the Administrator of the Centers for Medicare & Medicaid Services and the Commissioner of Social Security to review and simplify the processes, procedures, forms, and communication for family caregivers to assist individuals in establishing eligibility for, enrolling in, and maintaining and utilizing coverage and benefits" under federal benefits programs."⁴⁹ This proposed law has been endorsed by dozens of organizations benefitting seniors including the AARP, Gerontological Society of America, and the Alzheimer's Association.⁵⁰ Unfortunately, this proposed bill has been referred to subcommittees and has not had any action taken on it in either house of Congress since April 2024.⁵¹

A. Tax Credits and Incentives for Caregivers

Almost two in three unpaid caregivers feel that financial support in the form of an income tax credit would allow them to continue to care for their loved one in the home.⁵² The federal government does offer limited tax benefits for children who provide care for their parents. In limited circumstances, children might be able to claim their parent as a dependent on their income tax return. However, the rules for children wishing to do so are very strict and only apply in limited circumstances. For example, child caregivers cannot claim their parent as a dependent if their parent files a joint return with their spouse. They must have paid more than half of their parent's support in the last calendar year, and the parent's gross income for the calendar year must be less than \$5,050.⁵³ While some caregivers may benefit from these rules, the circumstances under which a child can claim a parent as a dependent are so narrow as to exclude the vast majority of child caregivers from being able to do so. Even when the limited circumstances do apply, the tax credit is only a maximum of \$1,100 per year.⁵⁴

Additionally, caregivers who are able to claim their parent as a dependent may be able to claim their parent's unreimbursed medical costs as an itemized deduction on their income tax return if the medical expenses of everyone claimed on the tax return is more than 7.5% of the filer's adjusted gross income.⁵⁵ The types of expenses that can be claimed as deductions include adult day care, bandages, eyeglasses, hearing aids, copayments and deductibles, medications, transportation for medical appointments, and medical equipment such as a cane or

⁴⁸ AARP, CAREGIVING IN THE U.S.: 2020 REPORT (2020).

⁴⁹ Alleviating Barriers for Caregivers Act, H.R. 8018, 118th Cong. § 2(b) (2024).

⁵⁰ Press Release, Office of Senator Ed Markey, Ahead of National Family Caregivers Month, Sens. Markey, Capito Introduce Legislation to Alleviate Administrative Burdens for Family Caregivers (Oct 24, 2023).

⁵¹ H.R. 8018.

⁵² AARP, *supra* note 48, at 81.

⁵³ *Frequently Asked Questions for Caregivers*, IRS, <https://www.irs.gov/faqs/irs-procedures/for-caregivers> (last visited Dec. 10, 2024).

⁵⁴ *Id.*

⁵⁵ I.R.S. Pub., *supra* note 46.

walker.⁵⁶ However, these items and services must specifically benefit the person receiving the care and not the entire household.

While these provisions are a good start to alleviating the difficulties that caregivers face, when one considers the fact that the average unpaid caregiver spends 26% of their income on paying for their loved one's care each year,⁵⁷ the rules that are currently in place fall dismally short of what most caregivers need to be made financially whole for caring for their parents. The federal government has also made some attempts to remedy this problem. In early 2024, members of Congress led by Senator Michael Bennett reintroduced the Credit for Caring Act of 2024. This proposed law would provide a nonrefundable tax credit for working family caregivers. This tax credit would be a maximum of \$5,000 for 30% of the cost of long-term care expenses that exceed \$2,000 during the previous taxable year.⁵⁸ A caregiver would be eligible for this benefit if they have earned income over \$7,500 in the previous year and pay for or incur expenses for providing care to a spouse or other dependent relative with long-term care needs.⁵⁹ The goal of this legislation is to offset a percentage of caregiving costs such as respite care, modifications to the home, and transportation. Unfortunately, as with the proposed ABC Act, this bill has not made any progress since it was introduced to the Senate in January 2024 and referred to the Committee on Finance.⁶⁰

In order to provide meaningful financial relief for caregivers, federal, state, and local governments need to make serious progress on passing legislation that will provide financial incentives for family caregivers to continue to care for their loved ones. Both the ABC Act and the Credit for Caring Act should be passed immediately in order to continue the important work that has been done to make sure caregivers have the assistance they need. Caregivers who have financial support will be more able to take time off from work, spend time with their loved one, and feel relief from the stress of the financial burden that caregiving places on them.

Furthermore, expanding the eligibility rules for family members to claim those to whom they provide care and offering significant tax credits for unpaid caregivers would provide caregivers with an incentive to continue to provide this care. Although it would come at an initial financial cost for the federal government, expanding these tax incentives could mean that fewer individuals need to apply for Medicaid long-term care supports and services and veterans' benefits such as the Aid and Attendance Pension and VA nursing homes. Enabling children and other unpaid caregivers to care for their loved one in the home, rather than placing them in a facility or hiring private caregivers, will offset a large percentage of the \$592 billion that the federal government spends on Medicaid on an annual basis.⁶¹

B. Paid Caregiver Programs

As previously discussed, there are very few circumstances under which an unpaid caregiver can begin to receive payment for the care they provide. Government programs such as the CCC Plus Waiver have so many documentation requirements that it is both confusing and discouraging for already overburdened caregivers to pursue this avenue. More informal caregiver agreements place a tax burden on caregivers because the funds they receive for providing care are added to their taxable income for that year. Many caregivers do not want to contend with either the paperwork and added documentation, or the increased tax liability that comes with receiving compensation in this way, when they were already providing the care without these added complications. In order to encourage caregivers to take advantage of the ability to get paid for their services, the government at all levels should consider minimizing or even eliminating the degree to which income derived from caring for a family member impacts the caregiver's reportable income.

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ Credit for Caring Act, S. 3702, 118th Cong. § 25F (2024).

⁵⁹ *Id.*

⁶⁰ I.R.S. Pub., *supra* note 46.

⁶¹ *Budget Basics: Medicaid*, PETER G. PETERSON FOUND., <https://www.pgpf.org/article/budget-explainer-medicaid/> (last visited Dec. 10, 2024).

C. Workplace Benefits

Unpaid caregivers who are employed elsewhere often suffer negative consequences in their careers, including discipline from employers, lost income, and lost opportunities at their place of employment, as a result of their duties at home. The federal government has taken steps to allow employees to take job-protected leave from work for many reasons, including the illness of a parent under the Family and Medical Leave Act (“FMLA”).⁶² However, the FMLA only applies to employees who have worked for a covered employer for at least 12 months.⁶³ “Covered employers” must have 50 or more employees if they are private companies (public agencies do not have an employee minimum).⁶⁴ Those who take time off under the FMLA can take up to 12 weeks of time off without fear of being terminated or demoted as a result of taking the leave.⁶⁵

While this benefit can help ease caregivers’ fears of suffering from retaliation as a result of taking off time to care for their parent, it does nothing to solve the problem of the lack of funding available for unpaid caregivers. The FMLA only offers unpaid leave.⁶⁶ In order to be paid during FMLA leave, employees must use up sick leave, vacation time, personal time, or other employer-provided benefits first.⁶⁷ Under Virginia’s version of the FMLA, employees are only eligible to take leave if their parent suffers from a “serious medical condition.”⁶⁸ A “serious medical condition” has a very specific definition, which includes overnight stays in a hospital or medical care facility; a period of incapacity for more than three consecutive calendar days; a period of incapacity due to a chronic serious health condition; or a period of incapacity that is permanent or long-term due to an incurable condition such as Alzheimer’s disease or terminal cancer.⁶⁹ Of course, requesting leave under the FMLA requires the completion of multiple forms and certifications in order for an employee to obtain it—an often difficult process during an even more difficult time for unpaid caregivers who may be experiencing a family crisis.⁷⁰

VIII. Conclusion

The current systems and processes in place to help unpaid caregivers manage the stressful task of caring for a loved one are inadequate and overly complex. Unpaid caregivers in Virginia already suffer major consequences as a result of their caregiving duties including lost income, lost employment opportunities, and sacrifices to their financial and physical well-being.⁷¹ There are many benefits available to both caregivers and older or disabled individuals, but these benefits often have onerous application requirements. For example, the CCC Plus Waiver is so complex that DMAS has provided flow charts and has a large manual available to the public regarding eligibility.⁷² The VA offers a pension that could be used to supplement the cost of care for individuals living at home; however, most eligible veterans are unaware that the pension exists. There are potential tax benefits available to unpaid caregivers, but these benefits are limited in scope and are not sufficient to cover the personal expense that most caregivers incur on behalf of their loved ones.

While the current laws and benefits available are inadequate, there have been some attempts to reduce the strain on caregivers. Governor Youngkin passed several bills effective July 1, 2024 with the goal of simplifying

⁶² WAGE & HOUR DIV., U.S. DEP’T OF LABOR, FACT SHEET #28C: USING FMLA LEAVE TO CARE FOR SOMEONE WHO WAS IN THE ROLE OF A PARENT TO YOU WHEN YOU WERE A CHILD (2025).

⁶³ *Id.*

⁶⁴ The Family and Medical Leave Act, 29 C.F.R. § 825.102 (2025) (defining “Employer”).

⁶⁵ WAGE & HOUR DIV., *supra* note 62.

⁶⁶ *Id.*

⁶⁷ 29 C.F.R. § 825.207(a) (2025).

⁶⁸ *Id.* § 825.201(a).

⁶⁹ *Id.* § 825.102 (defining “Continuing treatment by a health care provider”).

⁷⁰ See WAGE & HOUR DIV., U.S. DEP’T OF LABOR, THE FMLA LEAVE PROCESS FLOWCHART (2025).

⁷¹ See *Standing Up and Stepping In: A Modern Look at Caregivers in the U.S.*, GUARDIAN (2023), <https://www.guardianlife.com/reports/caregiving-in-america>.

⁷² See, e.g., COMMONWEALTH COORDINATED CARE PLUS WAIVER MANUAL V, *supra* note 32.

the process of applying for public benefits and making it easier for unpaid caregivers to receive compensation.⁷³ Perhaps the most impactful of these new laws directs DMAS to seek federal authority to modify the program rules for home and community-based services waivers, eliminating the requirement that, for a caregiver to receive reimbursement for personal care services, no one else be available to provide services to the member. The federal government has introduced multiple proposed bills with the goal of simplifying and expanding the benefits available to caregivers, including the Alleviating Burdens to Caregivers Act and the Credit for Caring Act. Unfortunately, both pieces of legislation are currently stalled in Congress with no proposed timeline for passing these bills.

To encourage unpaid caregivers to continue the vital role they play in caring for their loved ones, the government at all levels must work to pass legislation that will simplify the process for applying for and obtaining benefits for both caregivers and disabled individuals. Benefits such as increased tax credits for caregivers, tax exemptions for funds received as a result of caring for family members, and eligibility for programs such as the CCC Plus Waiver should be expanded and simplified. The government and federal agencies should make an effort to advertise these new benefits once they are in place, along with other benefits that can help caregivers and their families such as the VA Aid and Attendance Pension and the caregiver child exception to Medicaid asset transfer rules.

Although expanding these benefits would result in higher expenses for the federal, state, and local governments that implement them, these changes would be self-sustaining in the long run. Allowing caregivers the resources and ability to stay at home with their loved ones will reduce, and in some cases completely eliminate, the need for older individuals to go to a nursing home, thus reducing the amount that is spent on Medicaid long-term care supports and services. Increasing these benefits will allow caregivers to be happier and more productive, decreasing the stress and negative consequences most caregivers face. As Americans continue to age, the government must make a sincere, urgent effort to do everything it can to alleviate the caregiver burden and ensure that family members are incentivized and empowered to provide for their loved ones in the home.

⁷³ Khalil, *supra* note 1.