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## AHEAD OF NATIONAL FAMILY CAREGIVERS MONTH, SENS. MARKEY, CAPITO INTRODUCE LEGISLATION TO ALLEVIATE ADMINISTRATIVE BURDENS FOR FAMILY CAREGIVERS

*Family caregivers provide \$600 billion in unpaid care every year*

[Bill Text \(PDF\)](#)

Washington (October 24, 2023) – Senator Edward J. Markey (D-Mass.), chair of the Senate Health, Education, Labor and Pensions (HELP) Subcommittee on Primary Health and Retirement Security, and Senator Shelley Moore Capito (R-W.Va.) introduced the *Alleviating Barriers for Caregivers (ABC) Act*, legislation that would require the Centers for Medicare and Medicaid Services (CMS), Social Security Administration (SSA), and Children’s Health Insurance Program (CHIP) to review their eligibility, processes, procedures, forms, and communications to reduce the administrative burden on family caregivers. The legislation would then annually require CMS, SSA and CHIP to report to Congress about any issues they are facing and any next steps they are taking to support family caregivers.

Family caregivers serve as a primary source of support for seniors and people with disabilities of all ages. In the United States alone, there are more than 48 million family caregivers. More than half of family caregivers act as an advocate for their loved one with care providers, community services, or government agencies. However, one-in-four family caregivers have said they want help with forms, paperwork and eligibility for services. Many report competing responsibilities while experiencing serious emotional, physical, and finance challenges.

“When my mother suffered from Alzheimer’s, my father was her caregiver in our home in Malden,” **said Senator Markey**. “Caregivers serve on the frontlines of our nation’s health care system by giving our families and friends the care and support they need to remain in their homes and communities with their loved ones. However, our aging and disabled community members can’t get the care they need if their caregivers – the backbone of their treatment – are struggling to navigate complex, burdensome, and stressful processes each and every day while also still managing day-to-day family and professional responsibilities. The *Alleviating Barriers for Caregivers Act* will help lift the weight off caregivers by clearing the red tape that so often gets in their way.”

“As a caregiver for my parents during their struggle with Alzheimer’s disease, I know personally the level of responsibility put on family caregivers and the burdens, which can be created by federal process and procedure,” **said Senator Capito**. “Caregivers in West Virginia and across our country put family first and balance multiple priorities at once, which is why we must do all we can to alleviate roadblocks that could delay and even prohibit them from receiving the support they need. I’m proud to introduce the *Alleviating Barriers for Caregivers Act*, which will help accomplish this goal by easing the administrative burdens many of our family caregivers face.”

A copy of the legislation can be found [HERE](#).

Cosponsors in the Senate include Senators Kyrsten Sinema (I-Ariz.), Susan Collins (R-Maine), Bob Casey (D-Pa.), and Thom Tillis (R-N.C.).

The *Alleviating Barriers for Caregivers Act* is endorsed by AARP, Gerontological Society of America, Alzheimer’s Association, Rosalynn Carter Institute for Caregivers, National Association of Councils on Developmental Disabilities, Caring Across Generations, Justice in Aging, The Arc of the United States, National Council on Independent Living, UsAgainstAlzheimer’s, Alzheimer’s Foundation of America, American Association on Health and Disability, National Academy of Elder Law Attorneys, United Cerebral Palsy, Adapt Montana, Lakeshore Foundation, Association of University Centers on Disabilities, USAging, Healthcare Leadership Council, Disability Policy Consortium, National MS Society, National Consumer Voice on Quality Long-term Care, National Association for Home Care & Hospice, Christopher & Dana Reeve Foundation, Family Caregiver Alliance, Alliance for Aging Research, Medicare Rights Center, Triage Cancer, American Heart Association, ALS Association, Alliance for Retired Americans, National Marrow Donor Program, LeadingAge, American Society on Aging, American Network of Community Organizations and Resources, Autism Speaks, Special Needs Alliance, Michael J. Fox Foundation for Parkinson’s Research, Aging Life Care Association, Well Spouse Association, Japanese American Citizens League, Home Care Association of America, National Respite Coalition, National Health Council, Paralyzed Veterans of America, National Alliance for Caregiving, and Southeast Asian Resource Action Center.

“Family caregivers are the backbone of our nation’s long-term care system, and they are overwhelmed with their responsibilities and time spent managing their loved one’s care. The *Alleviating Barriers for Caregivers Act* could help save family caregivers valuable time and reduce their stress by making it easier to navigate resources, eligibility, benefits, and health systems when providing care. AARP thanks Senators Markey, Capito, Sinema, Collins, Casey, and Tillis for working together on this and urges Congress to swiftly pass this important bipartisan legislation,” **said Nancy LeMond, Executive Vice President and Chief Advocacy and Engagement Officer of AARP.**

federal programs. RCI looks forward to continued collaboration around this effort in the time ahead," **said Dr. Jennifer Olsen, CEO of the Rosalynn Carter Institute for Caregivers.**

"For far too long, our country's 53 million caregivers have had to navigate a crumbling, patchwork system filled with barriers and administrative burden. Our current model for care is broken and in need of modern fixes, and that is why the *Alleviating Barriers for Caregivers Act* is an important step to ensuring systemic change for these caregivers. We deserve to live in a country where people have community, support, and real solutions for all their care needs. Working to build a more robust system, one that dismantles barriers to programs that already should be helping caregivers, will help millions access the services they need, save time and money, and empower us all to make our own choices when it comes to our care," **said Nicole Jorwic, Chief of Campaigns and Advocacy at Caring Across Generations.**

"Being a caregiver to someone living with Alzheimer's is already an incredibly difficult and emotionally draining job. When you layer on top of it the daunting task of navigating our country's complex healthcare coverage system, it can become downright overwhelming for even the smartest person. This bill is an important step toward making it easier for caregivers to fully advocate on behalf of their loved ones to ensure they have access to the diagnostic, pharmaceutical, and treatment services they need. We are grateful to Senators Markey, Capito, Sinema, Collins, Casey, and Tillis for their continued leadership on behalf of Alzheimer's patients," **said George Vradenburg, Chair and Co-founder of UsAgainstAlzheimer's.**

"USAgging applauds Senators Markey and Capito for their leadership in the introduction of the *Alleviating Barriers for Caregivers Act*. Family caregivers are the backbone of our nation's long term care system yet often encounter communication and other barriers when working with the federal government to advocate for and on behalf of their loved ones. This bill is a great step forward in breaking down those barriers. We look forward to supporting this and other efforts to ensure that caregivers are given the recognition and assistance they need and deserve," **said Sandy Markwood, CEO of USAgging.**

"Our concern is that these federal caregiver programs are so complicated, they become virtually inaccessible, discouraging family and friends from providing caregiving services. The ABC Act is the first step to holding CMS and SSA accountable for eliminating these barriers to caregiving so people with intellectual and developmental disabilities can live their lives in the community," **said Robin Troutman, Deputy Director at National Association of Councils on Developmental Disabilities.**

"There is increasing urgency to address the emotional, physical, and financial challenges faced by family caregivers. The Healthcare Leadership Council supports the *Alleviating Barriers for Caregivers Act* and its goal of simplifying and streamlining policies and procedures while enhancing the caregiver experience through improved communication channels and increased understanding of available assistance programs. This is a step in the right direction to reduce red tape and meaningfully impact the lives of caregivers and their families," **said Mary Grealy, President of Healthcare Leadership Council.**

"If enacted, this legislation will significantly help caregivers support their loved ones by making it easier for them to access the benefits they deserve. People with chronic diseases and disabilities rely on their caregivers to help maintain their health and independence, and any steps we take to help them is welcome and needed," **said Randall Rutta, CEO at National Health Council.**

"The ABC Act would move us closer to realizing the vision outlined in our National Strategy to Support Family Caregivers by helping caregivers navigate access to essential benefits. We look forward to working with Senators Markey and Capito to address the challenges America's 53 million family caregivers face in coordinating care for themselves and their loved ones," **said Jason Resendez, President and CEO of the National Alliance for Caregiving.**

"Family caregivers are absolutely essential to the well being of hundreds of thousands of people with disabilities. During the worst days of the COVID-19 pandemic, we saw both how family members stepped up to keep family members who lost Personal Care Attendants independent and alive, and just how many hoops these caregivers have to jump through. As Massachusetts' largest statewide disability rights organization, we strongly support this sorely needed bill to ease the administrative burden caregivers face," **said Colin Killick, Executive Director of Disability Policy Consortium.**

In September, Senator Markey introduced a resolution to recognize the importance of the *Rehabilitation Act of 1973* on the lives of individuals with disabilities. In June, Senators Markey, Collins and Mark Warner (D-Va.), co-chairs of the Congressional Task Force on Alzheimer's Disease, celebrated the passage of their *NAPA Reauthorization Act* to reauthorize the *National Alzheimer's Plan Act* until 2023 and the *Alzheimer's Accountability and Investment Act*, which extends requirements for the NIH to submit to Congress an annual budget estimating the budget necessary to meet NAPA implementation goals and find a cure for Alzheimer's disease. In January, Senator Markey led his colleagues in a letter to the Secretary of Health and Human Services and the CMS Administrator urging them to reconsider a 2013 national coverage determination (NCD) that limited Medicare coverage of certain brain imaging procedures critical for diagnosing Alzheimer's disease. As a Congressman in 2010, Senators Markey and Ron Wyden (D-Ore.) created the Independence at Home program that provides seniors, including individuals with Alzheimer's disease and other dementia, the option to receive primary care services at home. In February 2012, then-Representative Markey introduced the bipartisan *Spending Reductions Through Innovations in Therapies (SPRINT) Act*, which would spur innovation in research and drug development for high-cost, chronic health conditions such as Alzheimer's disease.

