

**Written Testimony on Family Caregiving in the United States and New York State  
Submitted to the Senate Special Committee on Aging**

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Chair Scott, Ranking Member Gillibrand, and Members of the Committee:

Thank you for the opportunity to testify on the vital issue of family caregiving in the United States. I am the Executive Director of the Association on Aging in New York State and represent the 59 Area Agencies on Aging (AAA) in New York. AAA's across the country are deeply committed to serving caregivers and keeping older adults in their homes and communities. Caregiving is not just a social issue, but also a major economic force that supports the health care system. This is done at a fraction of the fiscal cost of institutional settings, but more importantly, it protects the dignity and autonomy of older adults and individuals with disabilities. It is also paramount to understand that supporting Older Americans and caregivers should be an expectation, as older individuals contribute 1/3 of all economic output in the country, at almost 9 trillion dollars annually, and provide over 60% of all Federal income taxes.

Caregiving is a cornerstone of our nation's healthcare system, yet it remains largely underrecognized in policy and funding decisions. Across the country, millions of Americans provide essential care to family members and loved ones with chronic illness, disability, or age-related needs, often without compensation or formal support. Additionally, services for caregivers under the *Older Americans Act* for non-Medicaid eligible individuals have not kept pace with the growing need, which is leaving caregivers on long waiting lists to receive assistance. In New York there are more than 4.1 million caregivers making up over 26% of the adult population. They provide uncompensated care at an economic value of over \$39 billion per year. Nationally, unpaid caregiving is worth over a trillion dollars per year.

National data shows that roughly one in four caregivers, or about 15 to 17 million Americans, are part of the 'sandwich generation,' simultaneously caring for both children and aging relatives. Sandwich generation caregivers face intense and competing caregiving demands. They must navigate multiple complex systems that do not coordinate with each other with limited access to financial, emotional, or logistical support. Family caregivers, especially members of the Sandwich Generation, function as an extension of the formal healthcare system, enabling their loved ones to remain in their homes and communities while reducing reliance on institutional care.

Although much of the Sandwich Generation's caregiving work is unpaid, it often comes at a great personal cost. For working caregivers, there are enormous implications for workforce participation, financial stability, and even their personal health. Working caregivers are often forced to reduce their work hours, take unpaid leave, or exit the workforce prematurely. These disruptions can result in lost wages, diminished retirement savings, and long-term financial insecurities. Additionally, the demands of caregiving have dire consequences for caregivers' physical and mental health. Research indicates that 85% of sandwich generation caregivers report at least one adverse mental health symptom, and that serious suicidal ideation is reported by approximately half of working caregivers in a 30-day period. This is eight times the odds of adults who are not in caregiving roles. Sandwich generation caregivers have the highest documented mental health impact rates of any caregiver group. There is simply no opportunity to focus on one's own health when struggling to fulfill employment and caregiving demands for children and aging relatives.

At the same time, unpaid caregiving generates substantial cost savings by delaying or preventing more expensive forms of institutional care. In New York State, our average client is an 83-year-old, low-income female who lives alone, with 4-10 chronic conditions and needs assistance with Activities of Daily Living (ADLs) and more intense Instrumental Activities of Daily Living (IADLs). Without family support, these individuals would be forced to impoverish themselves to qualify for Medicaid services. AAAs serve these people in their homes and communities on average for 7 years for less than \$10,000 per year. This saves the Medicaid systems hundreds of millions of dollars each year. The AAA system provides these services across the country. They are needed now more than ever due to H.R. 1 and its drastic cuts to Medicaid.

The enacted reconciliation package included the largest cuts to Medicaid in program history and significantly reduced its federal spending over the next decade (estimated in the hundreds of billions to over \$1 trillion depending on scoring). H.R. 1's changes to Medicaid will have significant downstream effects on long-term care and caregiving systems by reducing federal Medicaid spending growth and shifting greater financial responsibility to states. As Medicaid is the primary payer for long-term services and support, including Home- and Community-Based Services (HCBS) and a large share of nursing facility care, any reduction in federal funding places pressure on state budgets to absorb rising costs. In practice, states typically protect mandatory Medicaid services first, which means optional programs such as HCBS are more vulnerable to reductions, stricter eligibility, reduced service hours, or expanded waiting lists, which are already years long in some places. As a result, the effect of H.R. 1's state implementation is likely to intensify caregiver burden, constrain access to community-based services that support aging in place and disability independence, and accelerate systemic strain across both institutional and home-based long-term care settings.

Additionally, Federal data and peer-reviewed analyses indicate that the United States has experienced the closure of more than 750 skilled nursing facilities since 2020, averaging roughly 150 closures per year, with continued closures driven by staffing shortages, rising labor and operating costs, and financial instability in facilities heavily reliant on Medicaid reimbursement. These closures are not occurring in isolation; they are part of a broader restructuring of the long-term care system in which institutional capacity is contracting while demand continues to grow. Care needs do not disappear when facilities close; they are instead shifted into home settings, placing additional strain on HCBS and, most significantly, on family caregivers. This, in turn, forces caregivers out of the workforce and threatens the independence and community of the older adults and people with disabilities who need that care. This dynamic underscores the urgency of strengthening both Medicaid HCBS infrastructure and federal caregiver support programs to prevent cost-shifting onto families without adequate training, respite, or financial assistance.

Lastly, the Administration for Community Living (ACL) must remain the independent authority for aging and disability resources instead of being absorbed into the broader Health and Human Services Agency structure as proposed in President Trump's Fiscal Year 2027 budget. As Sandwich Generation caregivers juggle their time and resources navigating childcare, education, and caregiving systems, ACL is one of the only federal agencies coordinating resources to support them at every juncture.

The solution to long-term care cannot be to rely on the unpaid labor of family members and loved ones. Not only is this approach burdensome, but it also ignores the reality that many older adults and people with disabilities lack the family support to rely on family caregivers. There are people who age alone with very little community support, and as Medicaid-funded systems are stretched, it is unclear who will care for them as they age.

To respond to these challenges, states like New York have focused on caregiving and community support. This includes free, online evidenced based caregiver interventions such as Trualta, which utilizes the Caregiver Intensity Index to assess caregivers and link them to services, the working caregiving initiative to screen and support New York State employees, and pilot programs in major employers to support working caregivers. Additionally, New York State is deploying a variety of technology-based services and interventions that support older individuals and caregivers by harnessing the power of Artificial Intelligence (AI) and technology to meet needs in the community. (see attached)

Regarding caregiving, there are key considerations that include the desperate need for funding at the Federal Level. Under the *Older Americans Act*, the primary federal support for family caregivers—the National Family Caregiver Support Program—receives only about \$200 million annually, representing less than 10 percent of total *Older Americans Act* funding. This is extremely limited funding, as family caregivers provide care valued in hundreds of billions of dollars each year, effectively serving as the unpaid backbone of our long-term care system. This imbalance highlights a clear gap between the critical role caregivers play and the level of federal investment dedicated to supporting them. Additionally, lawmakers should ensure robust funding for Medicaid, with an emphasis on programs that support people’s ability to age in place, as this is the overwhelming preference of older adults. Additionally, paid family and medical leave, flexible work arrangements, such as those outlined in Senator Gillibrand’s FAMILY Act, and supportive employers are critical in supporting caregivers. Caregivers should also have access to training for medical and caregiving tasks and should be formally recognized as part of the care team, including through compensation. Additionally, (S 2120) *Older Americans Act Reauthorization Act of 2025* needs to be passed, as services for caregivers are an essential part of the OAA.

Family caregivers represent a critical, yet largely invisible component of the national health care infrastructure. Contributions of caregivers reduce costs and allow millions of older and disabled Americans to remain in their homes and communities. They must be valued and served accordingly. We urge policy makers to not only deem family caregivers as heroes, but also enact legislation, funding, and policy that support their aging and disabled loved ones.

Thank you for the opportunity to testify at this hearing.

## Footnotes

1. AARP & National Alliance for Caregiving. *Caregiving in the United States 2025*.
2. AARP New York. *Caregiving in New York State: Prevalence and Characteristics*. 2023.
3. AARP Public Policy Institute. *Valuing the Invaluable: 2023 Update*.
4. National Alliance for Caregiving & AARP. *Caregiving in the United States 2020*.

## **New York State Office for the Aging Technology Innovations**

**Archangels** – Caregiver Intensity Index - ARCHANGELS works to support individuals who provide uncompensated care to someone else (caregivers). They focus on reframing how caregivers are seen, honored, and supported using a combination of data and stories, through public and private partnerships. The platform provides each caregiver with an intensity ‘score’ that not only validates their experience, but crosswalks them to state and local resources. This resource prioritizes helping individuals self-identify as a caregiver to provide supports and help, if needed.

**Trualta** - The New York Caregiver Portal, powered by Trualta, provides a vital support and training tool. The Caregiver Portal/Trualta teaches critical skills to reduce caregiver stress levels and increase confidence in one's caregiving abilities while connecting caregivers to other New York State resources. Trualta is evidenced based and reduces emergency department utilization by 30% for supported caregivers, and reduces skilled nursing facility placements. Trualta has saved \$11.48 million dollars in NYS since 2022 due to a reduction in emergency department visits, and delaying nursing home placements. Additionally, there have been over 5,573 online support groups held for caregivers.

**Relish** - Products include specially designed clocks, jigsaw puzzles, radios, brain teasers, and sensory activities for individuals with dementia.

**Memory Lane TV** - Memory Lane TV (MLTV) is a streaming, science-based behavioral and multisensory digital intervention designed to support people living with Alzheimer’s and related dementias and their professional and family care partners. Over 1,500 hours of positive, plot-free content is personalized for each user and is built to reduce agitation and depression, connect with the natural rhythms of the day, experience soothing memories, and find joy.

**Zinnia TV** - For individuals with dementia, Zinnia TV is a therapeutic alternative to standard TV programming, which can trigger confusion, distress, and daytime sleeping. Exploring a meaningful topic on Zinnia TV can soothe, delight, and reinforce a person’s sense of identity. Video is slow moving, soothing and promotes respite for caregivers.

**Maphabit** - The MapHabit platform uses scientifically proven step-by-step guides to empower individuals with intellectual and developmental disabilities (IDD), autism, and traumatic brain injuries (TBI), as well as individuals living with Alzheimer's Disease and related dementias (ADRD), to master their daily routines. A library of over 1,000 maps covering daily tasks can be customized for everyone to reduce caregiver burden and foster independence.

**Ageless Innovation** - Since 2018, NYSOFA has been providing more than 38,000 animatronic pets to older adults who experience social isolation. These plush, "lifelike" robotic pets are designed to make realistic sounds and motions, providing comfort and companionship to individuals. In 2023, NYSOFA also partnered with the Association on Aging in New York (AgingNY) and community groups to bring Ageless Innovation's reimagined, intergenerational games to increase social connections. Sending 7,200 boxes of intergenerational games to CBOs.

**Intuition Robotics** - ElliQ is an AI care companion designed to foster independence and provide support for older adults through daily check-ins, assistance with wellness goals and physical activities, and more using voice commands and/or on-screen instructions. ElliQ is proactive and personalized.

**GetSetUp** - GetSetUp is a dynamic learning and discovery platform offering training on technology to bridge the digital divide while offering virtual classes tailored exclusively for older adults. With over 5,000 classes across 40 categories, including technology, fitness, nutrition, cybersecurity, health and wellness, and social activities, it caters to diverse interests and needs. GetSetUp empowers older New Yorkers to bridge the digital divide, age independently, and combat loneliness through its platform available around-the clock.

**Virtual Senior Center** - The Virtual Senior Center (VSC) was created in 2010 by Selfhelp Community Services to help homebound and socially isolated older adults stay connected to their community. The VSC offers robust programs designed for older adults, managed by social workers who provide intentional engagement. It fosters an inclusive and engaging environment where older adults can connect with one another from wherever they call home.

**Blooming Health** - The platform enables instant communication about vital information such as weather alerts, program deadlines, event reminders for evidence-based programs, nutrition education, and wellness programs, and social engagement opportunities in over 80 languages.

**Vivo** - Team Vivo is an evidence-based strength training and exercise program designed to increase strength and reduce falls and injuries related to falls. Team Vivo provides an online small group fitness program that, unlike videos or livestreamed classes, is a live and interactive two-way experience with measured outcomes. Vivo classes are designed to build strength and function through individualized feedback from a live trainer while also providing social engagement and building community that drives 98% monthly customer retention.

**Betterage** - BetterAge provides a population health solution through a web-based platform that measures what matters with respect to healthy aging and generates important insights for

individuals and organizations. A health and well-being assessment, aligned with the social determinants of health, provides in-depth insight into healthy aging at every scale. For older adults, a personalized health and well-being report and recommendations are provided, and organizations can review this data as they develop programs, set policy approaches, and work to maximize funding.

**Onscreen** - Onscreen turns TVs into interactive care hubs, making family video calls, telehealth, and virtual social events easily accessible for older adults that struggle with technology. The platform also includes a TV-based AI companion that helps with regular check-ins and provides companionship, simplifying daily interactions and enhancing quality of life for older adults and caregivers.

**LifeBio** - LifeBio is capturing the stories and life experiences of New York State older adults, especially people who are reaching end of life and those who may be receiving hospice or palliative care. LifeBio is an evidence-based life story/reminiscence therapy solution that records people's backgrounds, stories, and care preferences in their own voices with an easy-to-use app.

**SCCMedQR** – wearable band for instant information on older adults that can be scanned by EMS, ER's and hospitals and instantly connects with caregivers if QR code is scanned

**MyRosalie** – Up to 2 hours monthly of phone calls to combat social isolation by connecting older adults with others with same interests.

**Smart Hygiene** – AI bidet that cleans and washes older adults to reduce UTI's and fall risk in the bathroom – targeting older women with UTI history and fall risk.

**Essential Care Visitor Program** – Trains family in nursing homes to provide care to their loved on due to workforce shortage in facility to improve quality of care.

**Eversafe** – platform to protect financial and other information and to flag irregularities to prevent/combat financial exploitation

**FraudFindr** – platform to quickly analyze financial information to identify possible financial fraud.

**SilverShield** - makes it easy for people to spot and stop scams, all over SMS and email, no app or training required. Built and tested with hundreds of professionals (APS, FBI, case managers, tech trainers, senior centers)

