

April 2, 2025

The Honorable Mike Crapo
Chairman
U.S. Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member
U.S. Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

CC: Members of the U.S. Senate Committee on Finance

Dear Chairman Crapo, Ranking Member Wyden, and Members of the Committee,

On behalf of the Act on RAISE campaign, which brings together aging, patient, and caregiving advocacy stakeholders across the caregiving continuum to strengthen our nation's first-ever [National Strategy to Support Family Caregivers](#) (National Strategy), **we are writing to highlight importance of Medicaid for our nation's more than 53 million family caregivers.**¹

Family caregivers are the backbone of our healthcare and long-term care systems and economy, providing an estimated \$600 billion in uncompensated care while serving as essential partners to both patients and healthcare providers.²

We implore the Committee to consider how potential policy changes and cuts in Medicaid could impact the economic and physical health of the millions of family caregivers in every community who provide on-going, complex care for people with a serious illness, disability, or aging related issues.

Medicaid Cuts Come in Many Forms and Will Harm Family Caregivers

Many of the Medicaid policy changes under discussion in Congress, even those that don't ostensibly target the nearly 9.4 million older adults and 12.5 million people with disabilities

¹ AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>

² Reinhard, Susan C., Selena Caldera, Ari Houser, and Rita B. Choula. Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers. Washington, DC: AARP Public Policy Institute. March 8, 2023. <https://doi.org/10.26419/ppi.00082.006>

enrolled in Medicaid,³ **could shift a significant financial burden to states and local governments.** This fiscal dynamic would have an outsized impact on rural and poorer states.⁴ Regardless of the policy structure through which it occurs, **cost-shifting to states of this possible magnitude could force states to cut more popular, cost-effective, but optional Medicaid services, such as home and community-based long-term care (HCBS).**⁵

HCBS Allows People to Stay at Home and Offers Consumers Choice

HCBS funded via Medicaid are more economical than unnecessary and often unwanted institutional care, the majority of which Medicaid also pays for. **Medicaid-funded HCBS also offers consumers a choice of how, where, and when they receive care at home and in their communities.** All states offer HCBS and any significant cuts to Medicaid would push them towards the harmful choice of limiting, or eliminating, essential long-term care that 4.5 million older adults and people with disabilities, and their caregivers depend on to stay healthy and independent at home and in their communities.⁶

Medicaid HCBS includes services such as adult day programs, transportation to and from medical appointments, assistance with eating, bathing, and dressing, and help with housekeeping and laundry. **These support services are vital to families caring for older adults, people with disabilities, and families managing Alzheimer’s disease, dementia, Parkinson’s disease, organ transplants, and children with complex medical needs.** Through state Medicaid HCBS programs, family caregivers can also receive training to provide better care, counseling and access to support groups. HCBS are a lifeline for family caregivers

³ Kaiser Family Foundation. State Health Facts. Medicaid Enrollees by Group. 2021. Data accessed February 13, 2025: <https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/?dataView=0¤tTimeframe=0&selectedDistributions=seniors--individuals-with-disabilities&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

⁴ Georgetown University Center for Children and Families. Cuts to Medicaid Will Shift Costs to Families, Providers, and Will Be Especially Harmful to Rural Communities. Georgetown University Center for Children and Families, January 15, 2025. <https://ccf.georgetown.edu/2025/01/15/cuts-to-medicaid-will-shift-costs-to-families-providers-and-will-be-especially-harmful-to-rural-communities/>.

⁵ ibid 2.

⁶ KFF. How Do Medicaid Home Care Programs Support Family Caregivers? KFF, January 13, 2025. <https://www.kff.org/medicaid/issue-brief/how-do-medicaid-home-care-programs-support-family-caregivers/>.

by allowing many caregivers to continue to work outside the home to support their families while juggling caregiving duties.⁷

Importantly, Medicaid HCBS also promotes consumer choice in care. According to recent research from KFF, **nearly all states allow consumer-directed care as part of HCBS, which allows beneficiaries to select their caregiver and provide a stipend to their caregivers.**

Consumer-directed care is optional, but very popular and cost-effective. It allows the Medicaid enrollee to choose who cares for them (usually family caregivers) as well as when and what type of care they receive. Consumer-directed care offers a lifeline to care, especially for those who live in **rural areas** where there are **persistent shortages of direct care workers.**

Access to Medicaid coverage is also essential to help family caregivers address and manage their own chronic conditions and serious illnesses. According to the Centers for Disease Control and Prevention (CDC), during 2021-2022, family caregivers showed poorer health across multiple measures compared to non-caregivers, with worse outcomes in 13 of 19 key health indicators including smoking, depression, and chronic conditions.⁸ Often, family caregivers do not have access to affordable private insurance for themselves, making Medicaid a lifeline not only for their own wellbeing, but also for the people they care for.

Medicaid is a Fiscally Sound Investment in Families

Instead of considering budgetary policy that could harm family caregivers and their care recipients, shifting many of these current recipients of HCBS to more costly institutional care, **we urge lawmakers to see Medicaid as a fiscally sound investment in supporting family caregivers and strengthening American families.**

We look forward to working with all Members Congress to implement meaningful and fiscally responsible strategies. If you have any questions about this letter, please contact Elaine

⁷ ibid 1.

⁸ Kilmer G, Omura JD, Bouldin ED, et al. Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022. MMWR Morb Mortal Wkly Rep 2024;73:740–746. DOI: <http://dx.doi.org/10.15585/mmwr.mm7334a2>.

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Sincerely,

Act on RAISE Steering Committee and Campaign Partners

National Alliance for Caregiving

AARP

Agnes McCarthy Caregiver Foundation

American Association of Caregiving Youth, Inc.

American Geriatrics Society

American Society on Aging

The Arc

The Association for Frontotemporal Degeneration

Benjamin Rose

Caring Across Generations

Diverse Elders Coalition

Family Caregiver Alliance

Family Caregiver Center of New Mexico

Gerontological Advanced Practice Nurses Association (GAPNA)

Gerontological Society of America

Hale Hau`oli Hawai`i

NC Caregiving Collaborative

National Coalition on Aging

National Health Council

National Respite Coalition

University Settlement Society of New York

Women's Institute for a Secure Retirement