April 22, 2026

The Honorable Mike Johnson
Speaker of the House
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Hakeem Jeffries
House Minority Leader
U.S. House of Representatives
Washington, D.C. 20515

The Honorable John Thune
Senate Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Chuck Schumer
Senate Minority Leader
United States Senate
Washington, D.C. 20510

RE: Protecting Medicaid Beneficiaries and Their Caregivers, while Ensuring Program Integrity

Dear Speaker Johnson, Leader Jeffries, Leader Thune, and Leader Schumer:

On behalf of the National Alliance for Caregiving (NAC), I write to express our strong shared commitment to protecting the integrity of the Medicaid program, for the tens of millions of Americans who depend on it, for the family caregivers who sustain them, and for the taxpayers who fund it. More than 63 million Americans, a 45 percent increase since 2015, serve as family caregivers, and approximately 11.2 million of them participate in programs that provide some form of payment for the work they do providing care under Medicaid or other programs.[1] Medicaid HCBS has been a bipartisan success story that aligns with what most people want as they age or live with a disability, to remain at home for as long as possible. We urge Congress to ensure that program integrity efforts are designed with precision and care, so that people with disabilities, chronic conditions, or older adults who rely on these services to remain safely in their homes and communities, and the family and professional caregivers who care for them are not harmed.

Home and Community-Based Services Are a Bipartisan Success Story Worth Protecting

Home and Community-Based Services (HCBS), and family caregivers' essential role, deserve particular attention in this discussion. For more than four decades, Congress, on a strongly bipartisan basis, has built a system that allows people with disabilities and older adults to receive the care they need in their homes and communities rather than in costly institutional settings. In fact, a 2022 Mathematica analysis estimated that Medicaid spending per person was $48,143 for institutional LTSS users compared to

[1] Caregiving in the US 2025. Washington, DC: AARP. July 2025. https://doi.org/10.26419/ppi.00373.001

$16,491 for people receiving HCBS.[2] Moreover, the average annual cost of nursing home care per person exceeds $108,000, compared to just $42,000 in Medicaid spending for HCBS recipients.[3] HCBS result in better outcomes for beneficiaries and are a fiscally responsible alternative to nursing home placement.

Family caregivers—spouses, adult children, parents of children with disabilities—are integral to making this system work, often providing unpaid or modestly compensated support that complements formal Medicaid services.

These are not simple tasks. Fifty-five percent of family caregivers perform medical and nursing tasks - administering injections, managing catheters, monitoring vital signs, and operating medical equipment such as oxygen tanks and nebulizers - tasks that in any other setting would be handled by trained health professionals. On average, caregivers provide 27 hours of care per week, and 24 percent provide 40 or more hours - the equivalent of a full-time job.[4] We are concerned by statements and proposals to prohibit family caregivers from being paid for this work. Characterizing this level of care as something families simply "do for free" ignores the clinical complexity, physical demands, and round-the-clock commitment it requires.

Program Integrity is Critical

Instances of fraud – such as false claims, billing for services not rendered, or exploitation of vulnerable populations – must be taken seriously, as they divert resources and can undermine program integrity. However, these cases should be understood in the broader context of a program that delivers critical care to millions of individuals with chronic conditions, people with disabilities, and family caregivers. It is critical to ensure that oversight efforts do not disrupt access to the vital services Medicaid provides. Program integrity tools already exist such as state Medicaid Fraud Control Units, state Electronic Visit Verification (EVV) use as mandated under the 21st Century Cures Act, compliance programs, and revalidation of credentials, and should continue to be deployed and supported. The Department of Health and Human Services Office of Inspector General, the Department of Justice, and state Medicaid fraud control units have long-standing authorities to investigate and prosecute fraud. These mechanisms work. When they are used - carefully, on the basis of evidence, and in coordination with states - they protect both the program's finances and the people it serves.

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[2] Murray, Caitlin, Cara Stepanczuk, Alexandra Carpenter, and Andrea Wysocki. "Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022." Mathematica, August 29, 2024.

[3] AARP, Home Care Cost LTSS, https://ltsschoices.aarp.org/scorecard-report/2023/dimensions-and-indicators/home-care-cost, (last accessed 4/25/2025).

[4] Caregiving in the US 2025. Washington, DC: AARP. July 2025. https://doi.org/10.26419/ppi.00373.001

A central challenge in the current environment is the conflation of improper payments with intentional fraud. Improper payments are payments that should not have been made, that were made in an incorrect amount, or whose appropriateness cannot be determined due to lacking or insufficient documentation. For example, if a provider or managed care plan is paid less than the correct amount, that payment is defined as improper. According to federal data, in fiscal year 2024, the overall Medicaid improper payment rate was 5.1 percent. Nearly 80 percent of those improper payments resulted from insufficient documentation or missing administrative steps, not deliberate wrongdoing. Moreover, data show that when improper payments have occurred, it is often because of problems related to the *providers and managed care plans*, not the patients or their caregivers. For example, in conducting audits to detect improper payments, CMS has identified errors that the states have made in screening providers for eligibility. In other words, most billing irregularities reflect administrative complexity and compliance gaps rather than criminal intent.

The distinction between improper payments and fraud matters enormously. Policies designed to address one problem can cause serious harm if they are applied indiscriminately to the other. Enforcement strategies calibrated to root out criminal fraud are appropriate and necessary, and we support CMS' efforts in recent years to strengthen its internal auditing function. We also call on CMS to implement all outstanding recommendations made by the Government Accountability Officer and the HHS Office of Inspector General to improve its prevention and detection of improper payments. However, broad payment freezes or sweeping sanctions based on billing anomalies without distinguishing documentation errors from intentional deception risk collateral damage that falls hardest on patients and their caregivers, not on fraudulent actors.

NAC's own 2025 national research reinforces why precision matters here. Nearly half of all family caregivers - 47 percent - experience at least one negative financial impact as a result of caregiving, including stopping saving, taking on debt, or being unable to afford basic expenses. Far from profiting from these programs, paid family caregivers are not exempt from these hardships: the data show that payment for care typically covers only part of the hours provided, with 83 percent of paid caregivers also providing additional unpaid care to their loved one.[5] Broad enforcement actions that sweep in legitimate family caregivers alongside bad actors would devastate families who are already financially strained and have no substitute care arrangements in place.

When specific instances of fraud occur in HCBS, they should be targeted and prosecuted. But characterizing the entirety of home and community-based care as inherently fraud-prone risks destabilizing a system that millions of Americans and their caregivers depend on for daily survival. Disrupting access to personal care, attendant services, or other HCBS supports does not eliminate need, but rather shifts people into nursing homes and other institutional settings that are far more expensive for the program and far more restrictive for the individual.

[5] Caregiving in the US 2025. Washington, DC: AARP. July 2025. https://doi.org/10.26419/ppi.00373.001

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Principles for a Balanced, Effective Approach

NAC urges Congress to ensure that Medicaid program integrity efforts are guided by the following principles:

- **Target enforcement on intentional wrongdoing.** Policies should distinguish deliberate fraud from administrative error, with consequences proportionate to the nature of the violation. Providers should be given clear guidance and reasonable opportunity to correct documentation deficiencies before punitive action is taken.
- **Protect continuity of care.** Enforcement actions including payment suspensions or provider exclusions should include safeguards to ensure that beneficiaries are not left without access to essential services. Prior notice, care transition planning, and beneficiary protections must be built into any program integrity action that affects the delivery of care. One in five family caregivers already rate their own health as fair or poor, and 28 percent report difficulty finding affordable local services for their care recipients. Disruptions to HCBS access—even temporary ones—fall on caregivers and families who have no financial cushion and no backup system.[6]
- **Use evidence-based, proportionate tools.** Program integrity actions should be grounded in solid evidence of systemic violations, not in spending trends or anomalies alone. High utilization of a service category can reflect genuine need and effective access, not fraud. Analytical methods should be calibrated accordingly.
- **Support states as partners, not adversaries.** States administer Medicaid and bear significant responsibility for program integrity. Federal oversight should be collaborative and constructive, working with states to strengthen compliance systems, share data, and build administrative capacity.

Medicaid is not an abstraction. It is the primary source of long-term care for millions of Americans with disabilities and chronic conditions. Specifically, HCBS is, for many families, the only thing standing between a loved one being able to stay in their own home or having to move to an institution. Protecting Medicaid's integrity and protecting its beneficiaries are not competing goals; they are the same goal, pursued with the right tools and the right safeguards and in partnership with states.

[6] Caregiving in the US 2025. Washington, DC: AARP. July 2025. https://doi.org/10.26419/ppi.00373.001

More than one in two family caregivers felt they had no choice in taking on their role. Those caregivers experience nearly twice as many poor mental health days, significantly higher physical strain, and three times the rate of isolation compared to those who felt they had a choice.[7] These are not bad actors gaming a system – they are Americans doing what their families need them to do, often at great personal cost.

We stand ready to work with Congress, CMS, and other stakeholders to ensure the people Medicaid was designed to support are firmly centered in any legislation. We welcome the opportunity to discuss these principles further and to offer our perspective as policy and oversight efforts develop.

Respectfully submitted,

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[7] Ibid

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