

The Disability and Aging Collaborative &



March 20, 2024

The Honorable Jan Schakowsky
United States Representative
2367 Rayburn House Office Building
Washington, DC 20515

Dear Representative Schakowsky:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Long Term Services and Supports (LTSS) Task Force and the Disability and Aging Collaborative (DAC) write to express our strong support for the *Stop Unfair Medicaid Recoveries Act*, H.R. 7573. This legislation would prohibit Medicaid estate claims, except in rare cases where benefits were incorrectly paid.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. DAC is a coalition of approximately 40 national organizations that work together to advance long-term services and supports policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability, labor, and aging organizations.

Federal law currently requires state Medicaid programs to seek repayment of certain Medicaid benefits provided to people with disabilities and older adults. Specifically, states must recover costs for long term services and supports (LTSS) used by people age 55 or older, such as home and community-based services or nursing facility services. The claim for repayment is enforced against the heirs of deceased enrollees, often forcing children to sell their parent's family home to cover the lien.

Medicaid estate recovery specifically targets people with disabilities, older adults, and their families. Because Medicaid-funded LTSS is the only realistic source of LTSS for most people, estate recovery programs do not encourage people to “plan ahead” and avoid using Medicaid—they simply punish the families of those who have a health condition that requires LTSS. Medicaid estate recovery also punishes families for being poor, as those with higher incomes can often safeguard their assets to avoid estate recovery.

Medicaid estate recovery undermines efforts to preserve intergenerational wealth among the nation's most economically oppressed populations, reinforcing cycles of poverty and wealth inequity. The low Medicaid income and asset limit criteria make it very difficult to retain even meager savings. A home, however, is considered a permissible non-cash asset under Medicaid's eligibility rules and, therefore, is likely a recipient's most substantial asset.¹ Homeownership, often the result of decades of financial sacrifice and monthly mortgage payments, is an effective means of building wealth.² Medicaid estate recovery, however, deprives low-income families of achieving economic stability through homeownership, as it often forces surviving family members to sell the family home or take on debt to satisfy a state's claim. This policy disproportionately impacts people of color, who, due to historic and ongoing discriminatory policies in housing and finance, have less access to family wealth and alternative financing, hindering their ability to cover estate claims. The policy is also discriminatory because home equity makes up a larger portion of overall wealth in Black families when compared to white families.³

Medicaid estate recovery also adversely affects homelessness and access to affordable housing.⁴ This policy leads to the displacement of some surviving family members who could have otherwise remained in their family home had it not been for an estate claim. Such displacement increases homelessness and intensifies the demand for affordable housing. Therefore, Medicaid estate recovery contradicts the concerted efforts of federal, state, and local policymakers to mitigate the housing crisis.

Medicaid estate recovery is not an effective funding source for state Medicaid programs. The amount recouped through estate recovery constitutes only a small fraction of Medicaid LTSS expenditures.⁵ The evidence strongly supports eliminating estate

¹ MACPAC, Report to Congress on Medicaid and CHIP, [ch. 3](#) (Medicaid Estate Recovery: Improving Policy and Promoting Equity), at 89 (March 2021). The analysis found that three-quarters of Medicaid decedents had a net wealth of less than \$48,000.

² Urban Institute, [Closing the Gaps: Building Black Wealth through Homeownership](#), 2020.

³ Ibid.

⁴ See KFF Health News, [After People on Medicaid Die, Some States Aggressively Seek Repayment from Their Estates](#), 2023 for examples of the impact of estate recovery on Medicaid recipients and their surviving family members.

⁵ MACPAC, Report to Congress on Medicaid and CHIP, [ch. 3](#) (Medicaid Estate Recovery: Improving Policy and Promoting Equity), at 89 (March 2021). MACPAC analysis finds that Medicaid estate recovery recoups only about 0.55 percent of total fee-for-service LTSS spending. This percentage is likely overestimated because many states provide Medicaid LTSS through managed care.

recovery, as its minor financial benefits for states are far outweighed by the significant harm it inflicts on low-income families' ability to build intergenerational wealth.

As advocates working on behalf of populations using Medicaid LTSS, we support the full elimination of Medicaid estate recovery through *The Stop Unfair Medicaid Recoveries Act, H.R. 7573*. We thank you for your commitment to individuals with disabilities and older adults, and we look forward to working with you to pass this critical legislation to advance equity and justice for these populations.

Sincerely,

Allies for Independence
American Civil Liberties Union (ACLU)
American Network of Community Options and Resources (ANCOR)
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Care in Action
Caring Across Generations
Center for Medicare Advocacy
CommunicationFIRST
Disability Policy Consortium
Diverse Elders Coalition
Epilepsy Foundation
Justice in Aging
Medicare Rights Center
Muscular Dystrophy Association
National Academy of Elder Law Attorneys
National ADAPT
National Association for Homecare and Hospice
National Association of Councils on Developmental Disabilities
National Consumer Voice for Quality Long-Term Care
National Council on Independent Living
National Disability Institute
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Health Council
National Health Law Program
National PACE Association
National Partnership for Women & Families
TASH
The Arc of the United States
The Autistic People of Color Fund
United Spinal Association
Well Spouse Association