

# The Disability and Aging Collaborative &



CONSORTIUM FOR CITIZENS  
WITH DISABILITIES

March 7, 2022

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

Dear Representative Schakowsky:

The Consortium for Citizens with Disabilities (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. The Disability and Aging Collaborative (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 and aging organizations.

The undersigned members of the CCD Long Term Services and Supports (LTSS) Task Force and DAC write to express our strong support for the *Stop Unfair Medicaid Recoveries Act*, H.R. 6698. This long-overdue legislation would prohibit Medicaid estate claims, except in the rare cases where benefits were incorrectly paid.

As you know, federal law currently requires state Medicaid programs to seek repayment of certain Medicaid benefits that are provided to people with disabilities and older adults, even if the state would prefer not to do so. Specifically, states must seek to recover costs of people over age 55 who use LTSS, 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. These rules can discourage people from enrolling in Medicaid in the first

place and threaten the economic stability of families that are already in financially precarious positions.

Medicaid estate recovery specifically targets people with disabilities, older adults, and their families. While the mandate was originally created to protect “program integrity” and to fund LTSS, it does neither. 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 or develop a health condition that requires LTSS. Second, estate recovery is a poor source of funding for LTSS programs. Although recovery varies between states, nationally the recouped amount funds only a small fraction of the cost of LTSS.

Instead of furthering legitimate government goals, Medicaid estate claims prevent families from building generational wealth through homeownership, exacerbating existing economic inequities. These rules are especially detrimental to families of color that have lower homeownership rates because of discriminatory lending and housing policies, and the families of people with complex medical needs, who need months or years of nursing care or equivalent home and community-based services (HCBS).

We thank you for your commitment to individuals with disabilities and older adults, and we look forward to working with you to pass this important legislation.

Sincerely,

ADAPT of Texas  
American Psychological Association  
Autistic Self Advocacy Network  
Brain Injury Association of America  
Caring Across Generations  
Center for Medicare Advocacy  
Coalition of Texans with Disabilities  
CommunicationFIRST  
Disability Policy Consortium  
Disabled in Action of PA and Philly ADAPT  
Easterseals  
Epilepsy Foundation  
Ga ADAPT n2n  
Gulf Coast ADAPT  
Justice in Aging  
MassADAPT  
Medicare Rights Center  
National Academy of Elder Law Attorneys  
National Association for Home Care and Hospice  
National Association of Councils on Developmental Disabilities  
National Association of State Head Injury Administrators  
The National Consumer Voice for Quality Long-Term Care

National Council on Independent Living  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Health Law Program  
National Multiple Sclerosis Society  
National PACE Association  
National Respite Coalition  
Paralyzed Veterans of America  
Personal Attendant Coalition of Texas  
Special Needs Alliance  
Summit Independent Living, Missoula MT  
The Arc of the United States  
Well Spouse Association