Act on RAISE
A Campaign for Action on the National Strategy to Support Family Caregivers

VIA ELECTRONIC SUBMISSION AT REGULATIONS.GOV

August 12, 2024

Rohit Chopra, Director
c/o George Karithanom, Regulatory Implementation &
Guidance Program Analyst, Office of Regulations
Consumer Financial Protection Bureau (CFPB)
1700 G Street NW
Washington, DC 20552

RE: 2024 NPRM FCRA Medical Debt Information, RIN 3170-AA54, Docket No. CFPB-2024-0023

Dear Director Chopra and Colleagues:

Thank you for the opportunity to provide comments on the Proposed Rule regarding a Prohibition on Creditors and Consumer Reporting Agencies Concerning Medical Information (Regulation V)[i] ("Proposed Rule"). We applaud the Consumer Financial Protection Bureau (CFPB) for its leadership in recognizing the crippling effects of medical debt for people with significant illness, disability, or chronic disease and their family caregivers.

More than 53 million people in the United States care for someone with a healthcare need or disability.[ii] Family caregivers, in the aggregate, are the foundation of the nation's long-term care system. They provide an estimated at $600 billion in economic value to the United States, by supplementing the gaps in formal care systems through their support of people with long-term care and healthcare needs.[iii]

Many family caregivers shoulder the cost of long-term services and supports out of their own pockets, forgoing their own financial security on behalf of the person who needs care. Some carry debt to cover healthcare costs. Most risk their own economic mobility and financial security by losing wages, retirement income, and career opportunities because of the demands of caregiving. Caregivers also are more likely to carry debt and have issues managing debt, including debt related to their health and wellness. The research is clear: caregivers are more likely to help others manage finances, more likely to subsidize the cost of other's care, more likely to be in medical debt, and are less prepared for their own financial future.[iv] Because of this, caregivers have greater difficulty building credit and wealth.

With this in mind, the National Alliance for Caregiving has joined with the undersigned colleague organizations to provide public comments in support of the Proposed Rule. **The Proposed Rule aligns with national efforts to help family caregivers maintain financial security and economic mobility, while simultaneously easing stressors of financial caregiving.** Thus, we respectfully submit our comments as follows.

I. The National Strategy to Support Family Caregivers aims to enable family caregivers to provide care "without negative impacts to their near- and long-term financial health" and the Proposed Rule supports this aim.

For more than 25 years, the National Alliance for Caregiving (NAC) has supported a vision of a society that values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) non-profit coalition, our mission is to build partnerships in research, advocacy, and innovation to improve the lives of family caregivers. We achieve this goal through partnerships with like-minded organizations and advocates.

The Act on RAISE Campaign,[v] led by NAC, is an example of this type of partnership. Working with organizations in aging, patient advocacy, disability advocacy, and family caregiving, Act on RAISE provides social sector support to implement the National Strategy to Support Family Caregivers ("National Strategy"). Congress authorized the National Strategy under the RAISE Family Caregivers Act and charged the Administration for Community Living (ACL) with finding consensus between national organizations, government agencies and entities, and other key stakeholders.[vi]

The 2022 National Strategy[vii] articulates in its goals the need to "[e]nsure financial and workplace security for family caregivers" (Goal 4). The Goal further describes the National Strategy's desired outcome that "family caregivers can provide care without negative impacts to their near- and long-term financial health" (Outcome 4.1).[viii]

a. The Proposed Rule protects the caregiver's ability to build credit and plan ahead.

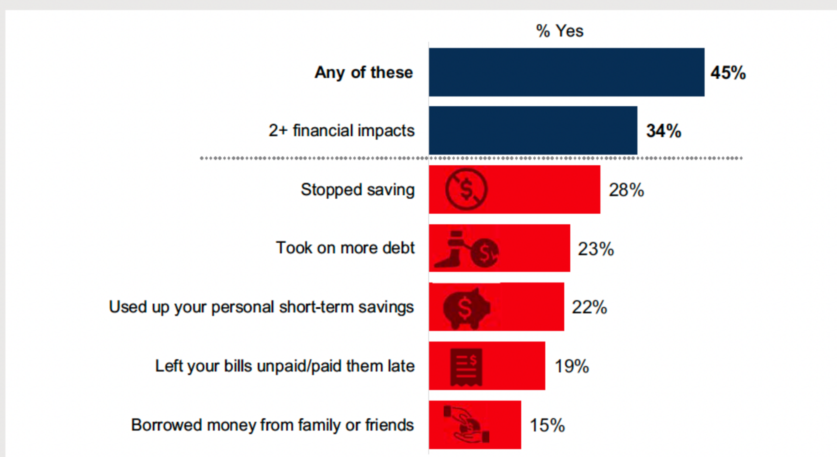
As described in *Caregiving in the U.S. 2020*, "The economic effects of family caregiving can result in financial strain with substantial financial consequences."[ix]

This strain is related to care activities, including shouldering direct costs of healthcare, navigating indirect costs of lost wages or interrupted careers, and managing the caregiver's own expenses.

From a macro perspective, family caregiving impacts a caregiver's ability to work, resulting in direct economic effects of nearly $44 billion from lost wages, absenteeism, and productivity.[x] Other estimates of the opportunity cost of caregiving has estimated an impact high as $522 billion annually, for eldercare alone.[xi] support such as Social Security.

On an individual level, the financial costs of caregiving have ripple effects into the caregiver's future, negatively impacting their ability to save for retirement and

Figure 57. Top Financial Impacts as a Result of Caregiving



M6. As a result of providing care to your [relation], have you ever experienced any of these financial things?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

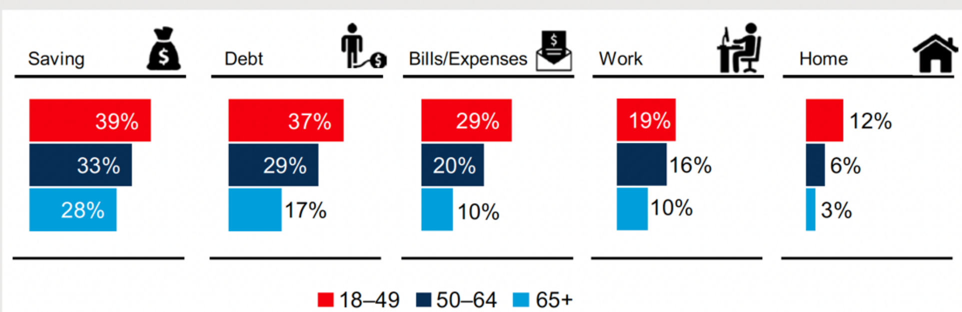
Note: Respondents may select more than one response; results add to greater than 100 percent.

National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*, caregiving.org/research/caregiving-in-the-us qualify for government. One in 10 caregivers want more help managing their own finances,[xii] reflective, perhaps, of the fact that half of caregivers face financial issues because of caregiving.[xiii]

Of the caregivers who report negative financial impacts because of caregiving, 28% stopped saving, 23% took on more debt, 19% left bills unpaid or paid them late, and 15% borrowed money from family or friends (see chart above).[xiv] Others reported challenges with student loan payments (5%). Medical complexity or high-intensity care situations worsened the financial impact; for example, among caregivers of adults with disabilities, nearly half (47%) reported that caregiving negatively impacted their overall financial situation.

While most caregivers face financial strain, the negative financial impacts of caregiving are not equitably distributed. Low-income families experience financial strain as a higher percentage of their overall household income. Households with under $50,000 in annual income are more likely to report that they stopped saving (42%), took on debt (38%), or stopped paying bills or other expenses (32%) compared to wealthier households. Caregivers at the start of their careers, including young adults, are also more likely to report financial strain and at higher rates than those of adults age 50 or older.[xv] The strain on lower-income households may translate directly into higher rates of medical debt, as analysis from the Kaiser Family Foundation indicated that those with household incomes under $40,000 were more likely to carry medical or dental debts.[xvi]

Figure 59. Financial Impacts as a Result of Caregiving by Caregiver Age



Experience change in at least one impact related to ...

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*, caregiving.org/research/caregiving-in-the-us

Caregivers from diverse racial and ethnic backgrounds also report higher rates of financial strain. For example, *Caregiving in the U.S. 2020*[xvii] found that Black American caregivers and Hispanic caregivers were more likely to report negative financial impacts due to caregiving. This, combined with the distribution of medical debt across communities of color, is particularly worrying. The Kaiser Family Foundation analysis found that[xviii] at least half of Black (56%) and Hispanic (50%) adults have medical or dental debt, compared to 37% of Whites.

More broadly, research from the Urban Institute has found similar disparities in the distribution of debt and access to credit across demographic backgrounds.[xix] Access to mortgage credit found that the Black-White homeownership gap is "wider now than it was before the passage of the Fair Housing Act." Even after controlling for income, households of color have lower homeownership rates than White households. Young adults[xx] in majority-Black and majority-Hispanic families are more likely to have lower median credit scores, making it more difficult for these communities to build wealth. As the demographics of the United States continue to change, family caregivers are more likely to be in multi-cultural, multi-generational households. This includes many in Black and African American, Hispanic, and Asian-American households where caregiving is a generational activity centered around the family home. Protecting caregivers from the weight of medical debt helps to address current inequities in the availability of and access to credit.

Broadly speaking, all caregivers face a higher risk of unmanageable debt directly related to the direct and indirect costs of caregiving. Analysis from the 2023 Retirement Confidence Survey found that caregivers are more likely to report that debt is a problem in their household than those without family care responsibilities (64% of caregivers to 52% of non-caregivers).[xxi] Financial pressures placed on caregivers often extend far beyond the caregiving relationship itself, endangering the caregiver's own future retirement and advanced age. For example, family caregivers who had retired from the workforce were more likely to report that their overall lifestyle in retirement is "now worse" than they expected (31% vs. 20% of non-caregivers).

Across all demographic groups, the Proposed Rule prevents creditors from penalizing family caregivers for the financial strain of caregiving, particularly with respect to medical debt. Caregivers need support to achieve economic goals such as homeownership, starting a new business, and obtaining competitive jobs that require credit checks. Families should not be penalized for taking care of each other—rather it should be possible for people to care for each other without facing lower credit scores and less access to credit.

b. The Proposed Rule would remove barriers that make it more difficult for family caregivers to support someone with health or long-term care needs.

The caregiver's role in managing finances for someone in their care is varied and extensive. A growing number of family caregivers help the person in their care with managing finances (58% in 2020, compared to 52% in 2015).[xxii] A third of these financial caregivers found managing finances to be extremely time-consuming, particularly when caring for someone with a high care need or caregivers of people with mental health, emotional health, or cognitive impairments.[xxiii] This is not surprising, given that financial caregiving activities can range from family-centered supports such as managing a family budget, helping to pay bills, and reconciling accounts to more formal roles such as serving as a fiduciary, being designated as a representative payee for Supplemental Security Income (SSI), and acting as a financial agent through a power of attorney or similar instrument.

A report from the TIAA Institute and the New Courtland Center for Transitions and Health at the University of Pennsylvania School of Nursing[xxiv], in looking at these various roles, found that as many as 90% of caregivers provided financial support. This support can include both paying for expenses — such as housing, home modifications, medical, and transportation costs — and coordinating financial affairs — including paying bills, monitoring bank accounts, handling insurance, filing taxes, and managing investments.

The Proposed Rule's restriction on the repossession of medical equipment as collateral for medical debts is key to supporting caregivers as partners in providing home and community-based care. This is critically important to the nearly 6 in 10 family caregivers help with medical/nursing tasks.[xxv] These activities include giving injections, helping with tube feeding, catheters and colostomy care, and other complex care responsibilities. These activities also include operating medical equipment such as hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

In many cases, the family caregiver who provides and supplements long-term care needs for an older adult or person with disability. Removing medical equipment because of a past-due medical bill prevents the caregiver from adequately supporting the person in their care. This has a ripple effect – making it more likely that the older adult or person with a disability will need to go to a facility or hospital for care, which in turn raises healthcare costs and potentially worsens health outcomes. That in turn may create high medical costs, which results in higher risk of medical debt. By restricting reporting related to medical debts and the repossession of needed medical equipment, the Proposed Rule makes it easier for the caregiver to provide care.

II. The Proposed Rule protects caregivers who shoulder debt on behalf of the person who needs care.

In addition to financial strain, many caregivers take on medical debt on behalf of the person who needs care.

Research from the Kaiser Family Foundation (KFF)[xxvi] found that roughly half of people who report carrying medical debt (46%) did so because of someone else's care (12%) or their care and someone else's combined (34%). Parents may carry medical debt for children, including parents of children with special needs, rare diseases, or other disabilities that often have high costs of care. Adult children may take on the debt of an emergency hospitalization for a parent; an adult sibling may take on the debt of their brother or sister who is receiving treatment for cancer. Others may be guarantors on medical bills or jointly manage accounts, making the caregiver responsible for debt repayment.

The presence of medical debt creates barriers to receiving medical care.[xxvii] The KFF study found that one in seven adults with medical debt were denied care from their provider due to unpaid bills. Those with medical debt are more than twice as likely to report that they skipped or postponed needed care because of the cost. As one woman described, "I have skipped picking up prescriptions or seeking treatment, so my bill doesn't continue to get higher." This type of cost-benefit analysis pits consumer debt against the very real need to address health and dental issues before they worsen and increase costs, which in turn adds additional stress to the caregiving experience.

The Proposed Rule protects caregivers from being penalized for medical debts that they may carry on behalf of the person in their care. The elimination of the medical debt exception allows caregivers to build credit independent of any medical debt of the person they are caring for, allowing them to plan for their own future. For caregivers who need good credit to secure employment, this protects the privacy of the person with care needs and allows the caregiver to avoid having to disclose their caregiver status at work, which may lack protections against family-related discrimination.

We would urge the CFPB to consider expanding its education on medical debt as it relates to caregiving, as part of the Final Rule. Unfortunately, the information available to caregivers about how to navigate debt on behalf of the person in their care is confusing and often wrong. Many caregivers are unsure of what protections, if any, exist with respect to debt collectors. This is especially challenging during advanced illness, as a caregiver who is actively grieving is forced to navigate calls about medical debt.

Dr. Fumiko Chino of the Memorial Sloan Kettering Cancer Center eloquently illustrated this challenge in her Congressional testimony last month before the Senate Committee on Health, Education, Labor and Pensions[xxviii]:

"Here's the thing I know now as an oncologist about when young people get cancer, their bodies are so healthy, they can handle so much aggressive treatment, their capacity to absorb set back after set back is so high… until suddenly they can't. It was in the grey of winter that Andrew died at age 28, leaving me in an empty house, with an empty future, and a stack of bills.

Even though Andrew was gone, the debt remained. I was hounded by debt collectors, one even called me when I was at his funeral.

The debt was like a black cloud over my head; it followed me and cast a shadow over my entire future. It wasn't until years later that I discovered that, despite the threatening phone calls and letters, I wasn't legally responsible for Andrew's medical debt. The debt died with him. Even today, I get calls from collectors trying to cash in on his sickness."

There are opportunities to make the implementation of the Proposed Rule clearer. For example, the definition of "medical debt information" in the Proposed Rule does not include debts for medical care that may be charged to a credit card, even if the debt is on a medical credit card that was offered for payment of services by the provider. Understanding the limitations of regulating third-party debt, we would ask that the CFPB further evaluate potential predatory impacts of additional forms of medical debt on family caregivers and the person in their care. Many caregivers may not realize that medical debt collected by third parties would not fall under the protections of the Proposed Rule.

Additionally, family caregivers need better information about how medical debt may impact them at the end of the caregiving journey. Many individuals who do not have access to long-term care may "spend down" to Medicaid[xxix] either through state spend down programs or through legal and financial planning. At the end of life, these individuals may die without assets or an estate to cover the cost of pre-existing medical debt or other costs not covered by Medicaid. This may mean the caregiver bears the debt that the estate cannot pay, and caregivers may be unaware of the available protections (as illustrated in Dr. Chino's testimony, above).

Caregivers may also be impacted by Medicaid estate recovery after their loved one dies.[xxx] Due to mandatory Medicaid estate recovery, which often wipes out the estate, the lack of assets to cover the cost of care may spill over into other forms of debt for caregivers. This is also true in situations where a caregiver may have joint ownership of an account that is used to pay for medical bills or where a caregiver has paid for medical costs using their own credit card.

Given these nuances, we would ask that the CFPB expand its consumer-facing information to include the possibility of inherited medical debt, particularly for family caregivers. This may include identifying what additional supports might be available to families in these situations to avoid untenable financial debt related to the direct and indirect costs of caregiving, calling upon the expertise of the Act on RAISE Steering Committee and Campaign Partners listed below.

III. Thank You

For the reasons described above, we fully support the Proposed Rule and applaud the CFPB for its leadership in protecting the financial health of older adults and people with disabilities. Thank you for your leadership and for the opportunity to provide comments on this important and timely issue.

If you need to reach us, please contact Mike Wittke, VP of Policy and Advocacy at mike@careigiving.org.

Sincerely,

Act on RAISE Steering Committee and Campaign Partners

Alzheimer's Association/Alzheimer's Impact Movement*

Benjamin Rose Institute on Aging

Caring Across Generations*

Child Neurology Foundation

Dignity Alliance Massachusetts

Diverse Elders Coalition*

East Central Illinois Area Agency on Aging, Inc.

Elizabeth Dole Foundation*

Family Caregiver Alliance

Family Caregiver Center of New Mexico

Grantmakers In Aging

Greater Wisconsin Agency on Aging Resources, Inc.

Hawaii Family Caregiver Coalition

Justice In Aging*

MTO Cares

NAMI Middlesex

National Alliance for Caregiving*

Rosalynn Carter Institute*

USAging*

**Steering Committee Members*

[i] 89 C.F.R. § 51682 (2024).

[ii] National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020* p.4 (2020), https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf.

[iii] Susan G. Reinhard, Selena Caldera, Ari Houser, Rita Choula, *Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers* (AARP, 2023) p.1, https://www.aarp.org/pri/topics/ltss/family-caregiving/valuing-the-invaluable-2015-update/.

[iv] Craig Copeland, *Caregivers and Retirement: Findings from the 2023 Retirement Confidence Survey* (EBRI Issue Brief No. 586, 2023), https://www.ebri.org/docs/default-source/pbriefs/ebri_ib_586_rcscaregivers-13july23.pdf.

[v] Act on RAISE, National Alliance for Caregiving, https://www.actonraise.org/about/ (last visited July 29, 2024).

[vi] *See* Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017 ("RAISE Family Caregivers Act"), Pub. L. No. 115-119, 132 Stat. 23-27 (2018).

[vii] The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren, *2022 National Strategy to Support Family Caregivers* pp.70-79 (ACL, 2022), https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers-2.pdf.
[viii] *Id.* at 71.
[ix] *See supra* note ii pp. 56 – 61 ("H. The Financial Situation of Caregivers").
[x] Dan White, Dante DeAntonio, Bridget Ryan, & Matt Colyar, *The Economic Impact of Caregiving* (BlueCrossBlueShield, 2021), https://www.bcbs.com/the-health-of-america/reports/the-economic-impact-of-caregiving.
[xi] Amaloavoyal V. Chari, John Engberg, Kristin Ray, & Ateev Mehrotra, *The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey* (RAND 2014), https://www.rand.org/pubs/external_publications/EP66196.html.
[xii] *See supra* note ii p. 74.
[xiii] *See supra* note ii p. 57 and Figure 57.
[xiv] *Id.*
[xv] *See supra* note ii pp. 56-61 and Figure 59.
[xvi] *See supra* note ii pp. 56 – 61 ("H. The Financial Situation of Caregivers").
[xvii] *See supra* note ii pp. 60 – 61 including Figure 61.

[xix]Aniket Mehrotra, Daniel Pang, Jun Zhu, Jun Hyun Choi, & Janneke Ratcliffe, Evidence of Disparities in Access to Mortgage Credit (Urban Institute: Housing Finance Policy Center, 2024), https://www.urban.org/sites/default/files/2024-03/Evidence_of_Disparities_in_Access_to_Mortgage_Credit.pdf.
[xx] Thea Garon, "Young Adults' Credit Trajectories Vary Widely by Race and Ethnicity," Urban Wire (Urban Institute, 2022), https://www.urban.org/urban-wire/young-adults-credit-trajectories-vary-widely-race-and-ethnicity, (last visited July 29, 2024).
[xxi] *See supra* note iv.
[xxii] *See supra* note ii p. 33.
[xxiii] *See supra* note ii pp. 33-34.
[xxiv] Surya P. Kolluri, Mary D. Naylor, and Janet Weiner, *Playing the Long Game: How Longevity Affects Financial Planning and Family Caregiving* p.5 (TIAA Institute, 2023), https://www.tiaa.org/content/dam/tiaa/institute/pdf/insights-report/2023-10/tiaa-institute-upenn-how-longevity-affects-financial-planning-ti-november-2023.pdf.
[xxv] *See supra* note ii pp. 45 including Figure 36.
[xxvi] Lunna Lopes, Audrey Kearney, Alex Montero, Liz Hamel, & Mollyann Brodie, *Health Care Debt in The U.S.: The Broad Consequences of Medical and Dental Bills* (KFF, 2022), https://www.kff.org/health-costs/report/kff-health-care-debt-survey/.
[xxvii] *Id.*
[xxviii] What Can Congress Do to End the Medical Debt Crisis in America? Hearing Before the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP Committee), 118th Cong. (2024) (statement of Fumiko Ladd Chino, MD), https://www.help.senate.gov/hearings/what-can-congress-do-to-end-the-medical-debt-crisis-in-america (last accessed July 31, 2024).
[xxix] *See, e.g., Medicare for Older Adults: What is Medicaid Spend Down?* (National Council on Aging, 2024), https://www.ncoa.org/article/what-is-medicaid-spend-down (last accessed August 1, 2024.
[xxx] *See, e.g.,* Paula Span, *When Medicaid Comes After the Family Home*, N.Y. Times, March 16, 2024, at https://www.nytimes.com/2024/03/16/health/medicaid-estate-recovery-seniors.html.