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POLICY CHEAT SHEET

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Understanding Today's Federal Policy Landscape for Supporting Family Caregivers

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Family caregiving is increasingly common in the U.S. and is a familiar experience across geography, class, and race. Roughly 53 million Americans provided unpaid care for a family member or friend in 2020, an increase of more than 20 percent since 2015. Over the past decade, both state and federal policymakers have shown increasing interest in supporting family caregivers. Recent federal legislation is creating new opportunities to further these efforts.

This *Medicaid Policy Cheat Sheet* details the importance of family caregivers and reviews legislation, as well as efforts by the Biden Administration, to support this vital and typically unpaid workforce.

Who are family caregivers and what do they do?

Family caregivers — often adult children of older adults or spouses, but also close relatives, friends, or neighbors — perform tasks that home health aides or direct care workers would otherwise perform, such as managing medications, providing wound care, or offering emotional support. This is in addition to managing household chores and work, navigating the complex U.S. health care system, and coordinating care for their loved ones. There are myriad reasons a family caregiver may provide services: the individual receiving services is more comfortable with a family member or friend; there are no direct care workers available in a community; or the recipient cannot afford or is not eligible to hire a home health aide.

COVID-19 highlighted the close relationship between family caregivers and the economy. Many people have either left the workforce or are juggling unsustainable schedules to be a family caregiver. This dynamic has left jobs unfilled, as well as family caregivers without a steady income and in need of support.

What hardships do family caregivers face as a result of providing care?

Family caregivers help their loved ones maintain health and well-being and avoid the need for urgent care, benefitting the health system overall. However, they often suffer adverse health effects related to their caregiving obligations. Nearly a quarter of family caregivers note that caregiving made their health worse, according to a report from the National Alliance for Caregiving and AARP. Additionally, these negative effects often spill into their professional lives. Two-thirds of family caregivers work outside the home in addition to their family caregiving responsibilities, with approximately half noting that they regularly go to work late, leave early, or take time off to accommodate caregiving duties. Ten percent report retiring early or leaving the workforce entirely, leading to significant loss in wages and retirement savings.

How can legislation help family caregivers?

As the number of Americans receiving care at home rises, family caregivers need increased assistance to help them provide care to their loved ones confidently and safely, without suffering negative health effects or becoming financially devastated by leaving the workforce. Following is recently passed and proposed federal legislation aimed at supporting family caregivers:

- **RAISE Act:** The Recognize, Assist, Support and Engage (RAISE) Family Caregivers Act became law in 2018 under the Trump Administration. The RAISE Act requires the Secretary of the Department of Health and Human Services to develop a national caregiving agenda. This includes finding ways to support family caregivers and strategies to improve federal programs that affect family caregivers. The law spurred the creation of a RAISE Family Caregiving Advisory Council charged with developing recommendations to drive future policies. These recommendations include helping family members see themselves as official “caregivers” who deserve access to supports and services, expanding access to available caregiver resources, and ensuring that family caregivers are included as members of a patient’s care team.
- **American Rescue Plan Act:** This COVID-19 pandemic relief bill, signed by President Biden on March 11, 2021, supports family caregivers in multiple ways. The bill increases federal Medicaid funding to states by up to 10 percentage points to provide home- and community-based services (HCBS). Currently, 41 states have waiting lists for HCBS, with nearly 820,000 individuals waiting an average of 39 months to receive services. States must submit spending plans to the Centers for Medicare & Medicaid Services by this summer, regardless of their plans to expand HCBS. The American Rescue Plan also expands the child tax credit to give more money to family caregivers with children, and provides additional aid, such as \$1,400 relief checks and paid leave for federal workers. Since family caregivers often leave the workforce to care for loved ones, providing financial support for caregivers when they lose income can help soften the burden.
- **Proposed Legislation:** The Biden Administration recently unveiled two proposals that would significantly impact family caregivers. The American Families Plan proposes a national paid family leave and medical leave program. Currently, the U.S. does not offer

mandatory paid family leave, which leads to many workers — particularly women of color — returning to the workforce earlier than desired or leaving the workforce altogether. The American Families Plan would ensure 12 weeks of family, parental, or personal leave allowing caregivers to bond with a new child, take care of a sick family member, or grieve the loss of a loved one. Additionally, the American Jobs Plan would provide \$400 billion in additional funding for HCBS. While details are sparse, this additional funding could be used to strengthen the workforce of paid caregivers like home health aides who provide services to aging adults. An enhanced paid caregiver workforce would help unpaid family caregivers by making more resources available for families.

What's the bottom line?

Family caregivers have been historically overlooked, but the COVID-19 pandemic highlighted their importance in a new way. At both the state and federal level, there is a growing interest in recognizing the central role caregivers play in taking care of many older Americans or individuals with disabilities. The recent influx of federal funding to expand HCBS provides significant opportunities for stakeholders to develop enhanced supports for family caregivers. State policymakers, Area Agencies on Aging and Departments on Aging staff, and family caregivers alike should be encouraged by the growing momentum for policies supporting family caregivers.