

August 29, 2022

Ms. Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare & Medicaid Services,  
U.S. Department of Health and Human Services  
Attention: CMS-4203-NC  
P.O. Box 8013  
Baltimore, MD 21244-8013

***Delivered Electronically***

***RE: Medicare Program; Request for Information on Medicare (CMS-4203-NC)***

Dear Administrator Brooks-LaSure,

The Rosalynn Carter Institute for Caregivers (RCI) appreciates the opportunity to provide comments to update and improve the Medicare Advantage (MA) program. We urge CMS to view caregiver status as a social determinant of health and to more adequately leverage MA as a vehicle for improving caregivers' lives by encouraging MA plans to offer an increased number and types of caregiver supports through their plans.

The Rosalynn Carter Institute for Caregivers (RCI) was established in 1987 by former First Lady Rosalynn Carter to promote the health, strength, and resilience of family caregivers at every stage of their journey. RCI fulfills its promise to champion the family caregiver by building cross-sector partnerships, developing and providing evidence-based programs, conducting vital research and data collection, and advocating for public policy.

### **Caregivers At A Glance**

In the U.S., there are more than 53 million family caregivers providing care to a loved one who is aging, ill, or disabled. Beyond those 53 million people currently serving as a family caregiver, caregiving is an issue that will affect every American at some point in their lives. As Mrs. Carter often reminds us, "There are only four kinds of people in the world: those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need them." While family caregivers span all demographics and walks of life, certain characteristics are worth noting:

- Women and minority caregivers are more likely to report higher intensity caregiving roles.<sup>1</sup>
- Hispanic, African American, and LGBTQ individuals are disproportionately likely to serve as family caregivers.<sup>2</sup>

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<sup>1</sup> [https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI\\_Recalibrating-for-Caregivers\\_2020.pdf](https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI_Recalibrating-for-Caregivers_2020.pdf)

<sup>2</sup> Ibid.

- Family caregivers comprise an estimated 18 and 22 percent of the U.S. labor force.<sup>3</sup>
- Caregivers experience disproportionate physical, emotional, and financial strain as a result of their caregiving responsibilities.<sup>4</sup>
- Family caregivers bear great financial strain, even when they provide care themselves. A 2016 AARP report found that 78 percent of family caregivers have out-of-pocket costs related to caregiving, spending on average nearly 20 to 26 percent of their personal income.<sup>5</sup>
- The estimated economic value of family caregivers' unpaid contributions is approximately \$470 billion.<sup>6</sup>

There are many items in the Request for Information that are relevant to caregivers and improving caregivers' health. RCI has focused our responses on those where we have specific recommendations for CMS. With limited funding, it is imperative that every dollar is maximized to support family caregivers who do so much for their care recipients and our economy. We welcome the opportunity to work collaboratively with CMS to maximize programmatic effectiveness and elevate caregivers across all federal programs and policies.

1. *What steps should CMS take to better ensure that all MA enrollees receive the care they need, including but not limited to the following:*
  - a. *Enrollees from racial and ethnic minority groups.*
  - b. *Enrollees who identify as lesbian, gay, bisexual, or another sexual orientation.*
  - c. *Enrollees who identify as transgender, nonbinary, or another gender identity.*
  - d. *Enrollees with disabilities, frailty, other serious health conditions, or who are nearing end of life.*
  - e. *Enrollees with diverse cultural or religious beliefs and practices.*
  - f. *Enrollees of disadvantaged socioeconomic status.*
  - g. *Enrollees with limited English proficiency or other communication needs.*
  - h. *Enrollees who live in rural or other underserved communities.*

**Caregiving status is not typically considered a social determinant of health, but it should be.** Like those who do not have college degrees or who have been diagnosed with a chronic disease, caregivers face considerable vulnerabilities and greater health risks. Overall, America's 53 million family caregivers are more likely than their non-caregiving peers to suffer from adversity as a result of their caregiving, including poorer health, reduced financial security, and greater levels of stress. Nearly one-third of people caring for terminally ill loved ones suffer

<sup>3</sup> <https://www.rosalynncarter.org/wp-content/uploads/2022/03/Invisible-Overtime-White-Paper.pdf>

<sup>4</sup> [https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI\\_Recalibrating-for-Caregivers\\_2020.pdf](https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI_Recalibrating-for-Caregivers_2020.pdf)

<sup>5</sup> [https://www.aarp.org/content/dam/aarp/research/surveys\\_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf](https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf)

<sup>6</sup> <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>

from depression.<sup>7</sup> These disparities are magnified among racial, ethnic, gender, and sexual minorities. Minority populations are overrepresented in caregiving roles, with at least 30 percent of family caregivers identifying as a racial minority.<sup>8</sup>

Even before the COVID-19 pandemic, family caregivers have served as the backbone of the U.S. healthcare system. Caregiving has been a demanding and isolating job but never more so than during the pandemic. Caregivers provide the majority of daily supports to individuals who require help with basic life activities as the result of underlying complex medical conditions.<sup>9</sup> Unfortunately, if a caregiver's health fails, it's not simply the deterioration of the health of the caregiver at risk, but also the care recipient, magnifying the negative impact on society.

As specified in President Biden's January 2021 Executive Order<sup>10</sup>, the term 'underserved communities' refers to populations sharing a particular characteristic and are adversely affected by persistent poverty or inequality – which applies to caregivers. As the Department works to advance equity across all of its programs, **we urge CMS to assure that status as a family caregiver is considered, that caregiver physical and mental health needs are assessed, and that they receive the supports they need to maintain or improve their health. Supporting caregivers will advance health equity.**

Among other things, the Executive Order required each federal agency to explore opportunities to collect demographic data to monitor and evaluate inequities over time. We encourage CMS to leverage an opportunity to collect data about caregivers through this process, as it would provide invaluable and standardized data across federal programs and would begin to fill an identified gap related to caregiver research and evaluation. Better knowledge of caregivers, both Medicare Advantage enrollees who are caregivers and caregivers who support Medicare Advantage enrollees, and their needs would allow for better, more targeted program design, evaluations of outcomes, as well as driving additional connections of caregivers to available resources.

In addition to facing health disparities, the MA program is incentivized in multiple ways to ensure that caregivers' needs are met. Specifically, MA plans should not forget the value that family caregivers bring in helping manage chronic conditions, provide care coordination, and other home supports. While the caregiver is focused on the care recipient, we fear no one is focusing on the caregiver.

**The MA program has a real opportunity to leverage its platform to focus on caregivers of MA enrollees *and* MA members who are themselves caregivers.** We would argue that supporting caregiver health—including mental health—and wellbeing is not

<sup>7</sup> <https://www.rosalynncarter.org/working-while-caring-rosalynn-carter-institute-sounds-alarm-on-behalf-of-employed-family-caregivers/>

<sup>8</sup> [https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI\\_Recalibrating-for-Caregivers\\_2020.pdf](https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI_Recalibrating-for-Caregivers_2020.pdf)

<sup>9</sup> <https://aspe.hhs.gov/sites/default/files/private/pdf/261036/LifetimeRisk.pdf>

<sup>10</sup> Executive Order (EO) 13985, titled "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government"

only the right thing to do, but also a prudent strategy for avoiding unnecessary utilization, and therefore costs to the plan.

2. *What are effective approaches in MA for screening, documenting, and furnishing health care informed by social determinants of health (SDOH)? Where are there gaps in health outcomes, quality, or access to providers and health care services due partially or fully to SDOH, and how might they be addressed? How could CMS, within the scope of applicable law, drive innovation and accountability to enable health care that is informed by SDOH?*

Caregivers live within a diversity of contexts, some of whom are more at risk than others. Caregivers who live in rural areas, for example, are more likely to have lower household incomes, lower education levels, and to report being in fair or poor health than caregivers living in urban environments.<sup>11</sup> Likewise, for Black caregivers, researchers have found that a complex interaction of sociocultural and environmental stressors—including experiences with racism and discrimination, cultural norms, financial concerns, and environmental safety—influence caregiving and self-care.<sup>12</sup> In addition, caregivers who come from marginalized populations are less likely to have access to the supports that benefit caregivers in more privileged positions, such as better leave and health care benefits. It is incumbent upon our nation—including CMS—to advance solutions that address these disparities and create more equity through public health interventions.

To be able to fully inform effective approaches in MA on how to better support caregivers, we need to first understand more about caregivers’ needs in a caregiver-centric, standardized way. **There is significant opportunity to advance equity through recognizing caregivers as a highly vulnerable group and prioritizing opportunities to understand this population and their needs.** CMS should acknowledge that caregivers are, as a group, a more vulnerable population than non-caregivers, and devise specific actions and activities across its suite of programs to assess, monitor, and evaluate impacts on caregiver physical and behavioral health more adequately.

Additionally, **CMS should require plans to ask members through the HRA process if they are a caregiver and if they have a caregiver.** Current guidance requires SNPs to include information about caregivers of enrollees during the HRA process and to coordinate care with caregivers in the Individualized Care Plan (ICP), Interdisciplinary Care Team (ICT), and Care Transition Protocols.<sup>13</sup> CMS should expand these requirements to other MA plan types to ensure caregivers are part of the care planning process for their enrollees.

<sup>11</sup> Bouldin ED, Shaull L, Andresen EM, Edwards VJ, McGuire LC. Financial and health barriers and caregiving-related difficulties among rural and urban caregivers. *The Journal of Rural Health*. 2018;34(3):263–74.

<sup>12</sup> Cothran FA, Paun O, Strayhorn S, Barnes LL. (2020) “Walk a mile in my shoes:” African American caregiver perceptions of caregiving and self-care. *Ethnicity & Health*.

<sup>13</sup> <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/mc86c05.pdf>

As outlined above, we know that caregivers have worse health outcomes and believe that caregiver status should be considered an SDOH. Identifying caregiver status is a first step in providing services and supports that meet caregiver needs. We encourage CMS to work with ACL to craft guidance for MA plans specifically around ways they can and should identify, assess, and support caregivers. For example, if a member is a caregiver, we recommend that CMS encourage and remind plans of the benefits of assessing their health needs and status and providing them with care coordination, closed loop referrals to community resources, and potentially other supports available from the plan. If the member has a caregiver, CMS could remind plans that they can request authority to communicate with the caregiver about the beneficiary, and clarify that MA plans can support the caregivers of members through supplemental benefits, and other authorities, such as QIA. Plans can also provide closed loop referrals to community resources. Further, we encourage CMS and MA plans to collect and use information from caregivers about the impact of any services they receive on their mental and physical health. This is especially important in the context of special needs plans (SNPs), which tend to serve complex care populations who rely on caregivers for daily supports, but would be valuable for all MA plans.

3. *What are examples of policies, programs, and innovations that can advance health equity in MA? How could CMS support the development and/or expansion of these efforts and what data could better inform this work?*

One specific program that can help to advance equity in MA is the supplemental benefit authority, which provides a new mechanism for supporting caregivers within the Medicare program. While supplemental benefit authority is limited by availability of plan rebate dollars, introduction of expanded supplemental benefits allows plans to offer long-term services and supports-like benefits in Medicare. Although these benefits are not as comprehensive as long-term services and supports, they still provide services that would be otherwise unavailable to many Medicare Advantage enrollees.

Two specific benefits under the Expanded Primarily Health-Related Benefits (EPHRB) authority that can benefit caregivers are the in-home support services (IHSS) and support for caregivers of enrollees benefit. IHSS assist individuals with disabilities and/or medical conditions in performing Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) within the home. Services must be provided by individuals licensed by the state to provide personal care services, or in a manner that is otherwise consistent with state requirements.<sup>14</sup> Support for caregivers of enrollees is defined as respite care provided through a personal care attendant or the provision of short-term institutional-based care to ameliorate the enrollees' injuries or health conditions or reduce the enrollees' avoidable emergency and healthcare utilization. Respite care should be for short periods of time and may include services such as counseling and training courses for caregivers of enrollees.<sup>15</sup> Both of these services can provide

<sup>14</sup> <https://www.nahc.org/wp-content/uploads/2018/05/HPMS-Memo-Primarily-Health-Related-4-27-18.pdf>

<sup>15</sup> Ibid.

needed help to caregivers who can sometimes become overwhelmed with the responsibilities of their caregiving role. IHSS can take over some of the more intensive duties the caregiver performs, such as ADL care. This can reduce the burden of care on the caregiver and provide needed relief. Caregiver supports and respite care can also help caregivers by providing a support system that can reduce caregiver burden. While some respite care may involve in-home support or short-stay institutional care, counseling and training opportunities can educate caregivers on effective care planning and delivery.

While both benefits have been available since 2020, there are many MA enrollees who do not have access to these services. In 2022, 729 plans offer IHSS, and 160 plans offer support for caregivers of enrollees (14% and 3% of MA plans, respectively).<sup>16</sup> These are increases from the 233 plans with IHSS and 125 plans with support for caregiver of enrollees in 2020 (5% and 3% of MA plans, respectively). During the same period, the number of enrollees in plans that offer IHSS tripled (1,070,000 in 2020 vs. 3,220,000 in 2022), while the number of enrollees in plans that offer support for caregivers of enrollees dropped 11% from 880,000 in 2020 to 780,000 in 2022.<sup>17</sup> The 2022 enrollment represents 14% and 3% of MA enrollment, respectively.

Though the availability of these benefits has increased every year, there is difficulty when assessing the impact of these benefits on the health and well-being of MA enrollees. To understand how these benefits are addressing the needs of enrollees, **we recommend that CMS require Medicare Advantage plans to report data on the delivery, uptake, and, if available, performance of supplemental benefits for enrollees and their caregivers.** Transparent and accessible data on availability and use of such benefits (across racial and ethnic groups, income levels, rural/urban status and other factors) is critical for identifying potential disparities and opportunities to advance health equity goals. To this end, we suggest that CMS develop incentives for MA plans to submit data on supplemental benefits, including key demographic information, to support efforts to measure and ensure equitable access to these benefits. Additionally, CMS should develop a standardized set of measures that should be collected to allow comparisons of utilization and performance between similar benefit types.

**CMS should incentivize more plans take steps to create or expand caregiver benefits for MA beneficiaries.** Data collection that could support these efforts can include identifying members who are caregivers or receive help from a caregiver, utilization of caregiver benefits, and member satisfaction of caregiver benefits. One way CMS could encourage more plans to create or expand caregiver benefits is by allowing plans to count caregiver supports (that are not “benefits”) in the numerator of the medical loss ratio (MLR) as a quality improvement activity. Plans must spend 85% of every premium dollar on “medical benefits”. Stipulating caregiver supports as a medical rather than an administrative activity can increase plan interest and support. CMS could also allow plans that include caregiver support and related

<sup>16</sup> <https://atiadvisory.com/wp-content/uploads/2022/04/Data-Insight-Growth-in-New-Non-Medical-Benefits-Since-Implementation-of-the-CHRONIC-Care-Act.pdf>

<sup>17</sup> Ibid.

supplemental benefits to market year-round or have an additional rebate percentage. Supplemental benefits compete for a small amount of plan premium dollars. Adding dollars specifically for these benefits would greatly increase take-up among plans.

Given the inequity resulting from the built-in stratification of access to benefits under MA, strengthening equity will require changes in traditional Medicare and not just MA. A report by the Center for Medicare Advocacy found that one reason MA beneficiaries have limited access to home health benefits is that because “in-home support services (not attached to the home health benefit) are not covered by traditional Medicare, provision of such services is entirely voluntary and at the discretion of a given MA plan.”<sup>18</sup> Requiring Medicare to offer these benefits would mean that MA members would also have access to them.

4. *How are enrollees made aware of supplemental benefits for which they qualify? How do enrollees access supplemental benefits, what barriers may exist for full use of those benefits, and how could access be improved?*

MA enrollees may not fully understand what benefits they have access to within their plan, especially supplemental benefits. Many times, the burden of figuring out what is available to any given enrollee falls on the shoulder of a family caregiver, and the supplemental benefits that might best help can be confusing to understand, especially the eligibility criteria and how to access them. CMS must do a better job getting the right information to caregivers ahead of a crisis situation by screening for caregiver status as part of the health risk assessment (as discussed in our earlier response) and targeting MA enrollees in certain criteria that are likely requiring support of caregivers to manage their care.

MA Plans could also help coordinate clear information about the availability of these benefits for Medicare beneficiaries. A recent report by ATI and LTQA suggests there are opportunities to increase awareness and adoption of these benefits by targeting both MAO staff and members.<sup>19</sup> For example, plans and providers reported increased uptake of these benefits. Plans who saw increased uptake in these benefits emphasized the crucial role of care and case managers in supplying referrals. Plans reported providing additional educational sessions and materials to inform, as well as remind, care managers, brokers, and other member-facing staff about these new benefits.

While interviewees did not report primary care provider groups playing a large role in referrals, some plans flagged that these providers could be leveraged if the correct incentives were

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<sup>18</sup> Center for Medicare Advocacy. (June 2020). *Medicare and Family Caregivers*. <https://medicareadvocacy.org/wp-content/uploads/2020/06/Medicare-and-Family-Caregivers-June-2020.pdf>

<sup>19</sup> <https://atiadvisory.com/wp-content/uploads/2022/05/Fulfilling-the-Promise-of-the-CHRONIC-Care-Act-Policy-Recommendations.pdf>

employed. Additionally, some plans described making their benefit resources available on customer service portals. While plans are engaging in efforts to promote awareness within the plan, and uptake appears to be increasing, some plans still report low uptake and are exploring additional opportunities to market these services.

The SSBCI authority is complex and plans still wrestle with how to appropriately publicize and market these benefits in a way that is thorough, yet not misleading. Plans are attentive of this balance because, on one hand, they want members to access the benefit they have designed and rolled out. However, confusion around eligibility for these benefits may result in complaints to the plan, which may ultimately affect the plan's star rating. Because of the intricacy of these authorities and general lack of awareness of these benefits, many beneficiaries do not understand whether these benefits are available to them.

One way to increase access to these benefits is for plans to build networks of providers for beneficiaries to access, rather than having a beneficiary pay for services and receive reimbursement. Designing a benefit such that a beneficiary must first find a provider and then pay for services can be prohibitive, especially for low-income beneficiaries. While developing these networks takes effort on the part of the plan, it allows ease for the beneficiary and, ultimately, promotes access to these services.

Another factor inhibiting beneficiary knowledge of these benefits is lack of training and appropriate data tools for beneficiary resources. Beneficiary resources, especially brokers, agents, and state resources like SHIPs, lack sufficient resources to advise enrollees on these benefits. For brokers or agents, some of whom are contracted with multiple plans, continued education is necessary to keep brokers up to date on these benefits and eligibility criteria. It is vital that agents and brokers understand how to convey chronic condition eligibility for these services to prevent member confusion. SHIPs also face challenges advising beneficiaries on these benefits as they lack a centralized resource to reference for availability of non-medical benefits year over year.

As of 2022, Medicare.gov does show whether plans offer in-home support services, but not caregiver services. Beneficiaries who want to know whether caregiver supports are available would need to look through a plan's EOC to understand the details about the services, if available. Some caregivers may not be aware of resources that are provided by the plan and would not know to even look through EOCs to see whether a plan offers caregiver benefits. Our recommendation is that **CMS show all SSBCI and EPHRB benefits available in each plan when a beneficiary is searching for plans.**

Additionally, plans can be more proactive to identify situations when they can reach out to an enrollee who needs caregiver supports. For example, when an enrollee has an inpatient admission or a new chronic condition/serious diagnosis where a caregiver will be needed for the enrollee. In these situations, caregivers will be carrying a lot of burden trying to learn about the

diagnosis and trying to adjust their homes and lives to address new care recipient needs. MA plans can remind enrollees of their benefits that can improve the enrollee's health and wellbeing, while also reducing the burden of care on the caregivers.

### **Closing**

In closing, RCI wishes to thank CMS for their continued support of MA enrollees who are caregivers and the caregivers of MA enrollees. We welcome the opportunity to work collaboratively with CMS to maximize the effectiveness of benefits that target caregivers and ensure their needs are addressed as a part of the social determinants of health. If you have any questions concerning our comments, please do not hesitate to contact us directly at [jennifer@rosalynncarter.org](mailto:jennifer@rosalynncarter.org).

Sincerely,

Dr. Jennifer Olsen, DrPH

Chief Executive Officer

Rosalynn Carter Institute for Caregivers