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November 30, 2022

The Honorable Xavier Becerra  
Secretary  
Department of Health and Human Services  
330 C Street SW  
Washington, DC 20201

Dear Secretary Becerra,

The Rosalynn Carter Institute for Caregivers (RCI) appreciates the opportunity to comment on the 2022 National Strategy to Support Family Caregivers (Strategy). We hope that our comments will assist the RAISE Family Caregiver Advisory Council (RAISE Council) to identify priorities for implementation and future updates of the Strategy. We strongly support efforts led by the Department of Health and Human Services (HHS), specifically the Administration for Community Living (ACL), to elevate family caregivers and we applaud the intentional cross-sector collaboration led by the RAISE Council.

The Federal Actions to the Strategy provide long overdue visibility on federal commitments to caregivers. Similarly, the initial Inventory of Federal Support Programs and Initiatives offers useful background. The inclusion of diverse caregiver stories describing some of the universal aspects of care and the critical distinctions between experiences contributes to the analysis. Finally, the “first principles” that the RAISE Council applied in assessing recommendations (person and family-centered approaches, trauma and its impact, diversity, equity, inclusion, and accessibility, the direct care workforce) can collectively serve as a “north star” as the Strategy moves into implementation.

Former First Lady Rosalynn Carter founded RCI in 1987 to promote the health, strength, and resilience of family caregivers. As the RAISE Council emphasized, transformative change for caregivers will require the meaningful engagement of multiple sectors and effective partnerships – strong, collective engagement. To that end, we have highlighted RCI’s programs and exploratory priorities that align with the goals of the Strategy (Appendix A and B). In short, these areas represent where we would like to play a leading role as a partner in implementing the initial actions of the Strategy.

Fundamental structural and systems reforms are needed for effective implementation of the Strategy. Additional supports, including financing, are needed to comprehensively address caregiver health and wellbeing. Caregivers must be recognized as a population rather than segmenting them by the conditions or diagnosis of care recipients. Moreover, RCI’s priority principle is to redesign structures and systems to proactively center caregiver health and wellbeing and not to add to their caregiving tasks by requiring caregivers to self-identify or seek out supports without assistance.

While the Administration for Community Living (ACL) administers essential programs supporting caregivers across the country and has provided leadership and expertise in stewarding the RAISE Council and the development of the Strategy, current funding and authority limit ACL's ability to fully realize and compel the promise of the Strategy. Other federal agencies enabled with stronger authority and significantly more resources, the Centers for Medicare and Medicaid Services, for example, have focused on the value of the caregiver in supporting the beneficiary but have not yet focused on the caregiver as the client. RCI's comments are not a critique of ACL or any other federal agency, but rather an assessment of both the current landscape and the likelihood of effectively implementing the Strategy if there are no changes made within the federal infrastructure.

Moreover, the Strategy – and the work of the RAISE Council – was primarily funded through philanthropy. More than legislative and regulatory authority, funding signals the value and importance of any program. The RAISE Strategy is a compilation of 345 commitments by fifteen separate federal agencies, yet in the proposed 2023-24 Health and Human Services Department budget there are no budgetary appropriations at the required scale for cross-agency implementation.

Federal investments targeted exclusively to support family caregivers total \$1.6 billion, amounting to 0.3 percent of the estimated economic value that they provide.<sup>1</sup> For the estimated 53 million caregivers nationwide, current federal investments to support complex, diverse needs total a mere \$30 per caregiver. Additionally, federal investment in caregiver support is not equitable across care recipient conditions (as the current system is largely organized) or payor. Although critical, the vast majority of the \$1.6 billion in federal direct caregiver support (\$1.4 billion) is available only to caregivers of veterans meeting certain qualifying criteria.<sup>2</sup> RCI recommends that the RAISE Council focus the next iteration of the Strategy on finance reform.

Committed and sustained leadership, bolstered by meaningful authority and funding, to pull on the strongest levers for change is required to move the RAISE Strategy immediately into implementation and transform the system for the nation's caregivers. **To elevate and focus unprecedented federal representation, investment, and coordination of caregiver support across federal agencies, former First Lady Rosalynn Carter called for the establishment of a new Office of Caregiver Health at the Department of Health and Human Services within the Office of the Secretary.** Leadership at this level will ensure that family caregivers are represented in health policy, regulation, program, and budget negotiations across HHS. A centralized office can dismantle silos that are barriers to progress by creating ways to consider the universal needs of caregivers, regardless of care recipient condition and payor.

RCI grounds our work in the voices of caregivers, and this idea of coordination is one that resonates:

*“As a long-time caregiver to a mother with Multiple Sclerosis and dementia, I am pleased that there is a National Strategy to Support Family Caregivers. However, the four reports that make up the Strategy are complicated, and some recommendations are vague, which can make it difficult to formulate concrete solutions.*

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<sup>1</sup> RCI analysis of federal program investments that directly benefit family caregivers. FY 2022 Appropriations levels used for discretionary programs.

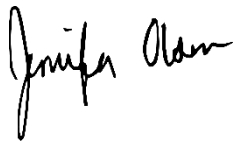
<sup>2</sup> Based on FY 2022 Appropriations levels.

*I strongly support RCI's plan to call for an Office of Caregiver Health within the Office of the Secretary in HHS. This could help ensure that the voices of family caregivers continue to be heard in future policies and legislation, implementation of recommendations from the National Strategy, future iterations of the National Strategy, and as part of the RAISE Family Caregiving Advisory Council."*

*-Family caregiver and RCI 4Kinds Advocate*

RCI thanks the Department and ACL for their leadership in developing the RAISE Strategy. We welcome the opportunity to work collaboratively. If you have any questions concerning our comments, please do not hesitate to contact me at 229-928-1234.

Sincerely,

A handwritten signature in black ink that reads "Jennifer Olsen". The signature is written in a cursive, flowing style.

Jennifer Olsen, DrPH  
Chief Executive Officer

cc:

Alison Barkoff, Acting ACL Administrator and Assistant Secretary for Aging

## APPENDIX A RCI INITIATIVES THAT ADVANCE RAISE STRATEGY GOALS

Several RCI program initiatives, described below, align with the goals of the RAISE Strategy. Some of these simultaneously advance more than one of the Strategy's goals and each entails engaging partners and family caregivers (Goal 2). We offer these program details to make public our commitments to helping advance the Strategy to strengthen caregiver health, wellbeing, and resiliency. RCI agrees with the RAISE Council that meaningful change will not occur without engaging new sectors and building sustained, effective partnerships. Our initiatives engage, for example, employers, an early childhood program, first responders, and, of course, caregivers.

Meaningful change will also require stronger coalitions with the intention to leverage expertise, relationships, and skills and a commitment to report on progress toward objectives and goals. We ask that the RAISE Council create a mechanism for collecting, across sectors, this type of data and provide quarterly updates so that collectively we can track and advance the goals of the Strategy.

### GOAL 1: INCREASE AWARENESS OF AND OUTREACH TO FAMILY CAREGIVERS

RCI will amplify the voices of family caregivers, setting policy priorities based on their needs and preferences and engaging them in public policy advocacy. RCI's priority principle is to redesign structures and systems to proactively center caregivers' health and wellbeing and not to add to their caregiver tasks by requiring them to self-identify or seek out supports without assistance.

As important as direct support for caregivers is, it is insufficient to address the scale of the challenges. RCI programs help us provide a caregiver-centered and informed view to guide public policy and field leadership. Informed by caregiver perspectives and experience, RCI's policy priorities are aimed at removing barriers and reducing stressors for caregivers created by systems beyond the reach of programs. As described in *Recalibrating for Caregivers: Recognizing the Public Health Challenge*, released in 2020, RCI will continue to advocate for building a system that can proactively identify and support caregivers *rather than solely relying* on caregivers to self-identify and seek resources.<sup>3</sup>

The 53 million caregivers in this country represent a powerful constituency, capable of moving meaningful change. Together they can support the development of a robust social safety net that meets caregiver needs across economic status, race, ethnicity, and geography. RCI will continue to organize caregivers and former caregivers through the 4Kinds Network to offer a community of peer support and – importantly – action. This network will inform our own programs, and support caregivers in public policy advocacy.

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<sup>3</sup> Rosalynn Carter Institute for Caregivers. (2020, October). *Recalibrating for Caregivers: Recognizing the Public Health Challenge*. [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)

### GOAL 3: STRENGTHEN SERVICES AND SUPPORTS

Through its 35-year history, RCI developed programs, including RCI REACH (Resources for Enhancing Alzheimer’s Caregiver Health), Operation Family Caregiver (OFC), Operation Caregiver Support, and Dealing with Dementia (DWD), based on validated methods of providing coaching and support to caregivers. RCI strengthens these programs through continual evaluation and by providing technical assistance to partners who also provide direct support to caregivers. Over the next year we will strengthen services and support for bereaved caregivers, first responders supporting caregivers during disasters, and children who are caregivers.

*Bereavement.* <sup>45</sup> RCI will advocate that states collect data on bereavement through the Behavioral Risk Factor Surveillance System (BRFSS) to assess prevalence and garner more information on the effects on caregivers. In addition to the loss of an important person in their lives, caregivers may also grieve the loss of the identity, purpose, and structure of the caregiving role. Feelings of relief, anger, and guilt often complicate caregiver bereavement and there are few spaces in our culture where these feelings are honored and can be expressed.

RCI will disseminate best practices for supporting caregivers through bereavement and expand the use of a toolkit for professional caregivers working in nursing homes, assisted living facilities, and home health agencies, and community organizations supporting caregivers. Equipping the field to support bereaved caregivers will enhance providers’ and employers’ understanding of associated risk and protective factors. With these insights, they can take preventive measures, reduce vulnerability, and offer continuity of support during periods of loss.

*Support During Disasters.* Recent research from RCI and Duke University School of Medicine<sup>6</sup> demonstrates that caregivers experience unique burdens during natural disasters (e.g. hurricanes, floods and pandemics). Access to community support varies as they manage the tasks required for care recipients’ health and safety. Our findings indicate the need for public health reinforcement of pre-planning and targeted support. RCI will elevate caregiver needs and identify community resources available to support their health and safety with first responder training, planning, toolkits, and caregiver registries. As part of this work, RCI and the Veterans Administration will be working together to increase support for caregivers through disaster preparedness. RCI and VA will develop curricula and content related to disaster emergency management for caregivers of Veterans.

*Supporting Children Who are Caregivers.* RCI partners with Sesame Workshop to provide recognition and support for children who are caregivers. Sesame Workshop and RCI joined forces in 2020 to support caregiving in military and veteran families with young children. Under this initiative, RCI

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<sup>4</sup> Verdery, A. M., Smith-Greenaway, E., Margolis, R., & Daw, J. (2020). Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. *Proceedings of the National Academy of Sciences of the United States of America*, 117(30), 17695–17701. <https://doi.org/10.1073/pnas.2007476117>

<sup>5</sup> Miles, T. P., Allegra, J. C., Ezeamama, A., Simpson, C., Gerst-Emerson, K., & Elkins, J. (2016). In a longevity society, loss and grief are emerging risk factors for health care use: Findings from the health and retirement survey cohort aged 50 to 70 years. *The American Journal of Hospice & Palliative Care*, 33(1), 41–46. <https://doi.org/10.1177/1049909114552125>

<sup>6</sup> Boucher, N. A., McKenna, K., Dombeck, C. B., Clark, A. G., Wang, K., Olsen, J. M., & Shepherd-Banigan, M. (2022). Caregiving in U.S. gulf states during natural disasters and COVID-19. *Gerontology and Geriatric Medicine*, 8, 23337214221133719. <https://doi.org/10.1177/23337214221133719>

delivers Sesame Street for Military Families’ resources – including videos and activities – to children through Operation Family Caregiver, a coaching program for military and veteran caregivers. Sesame Workshop’s materials help children understand how to safely express complicated or confusing feelings, how their parent’s illness or injury may change over time, and how to describe their family’s new situation.

*“As a former child caregiver of my dear mother, I recognize that my experience was unique yet, not uncommon. I was a young teen when she suffered a major stroke and was unable to care for herself. I stepped into the role of caring for her hygiene needs, taking her to medical appointments as well as finding ways to stimulate her mind and more. Looking back, I needed access to resources such as counseling to assist me in coping and how to navigate life as a young adult. We need policy makers to show up for this overlooked yet underserved population of child caregivers to be their voice and give them what they need in such difficult times.”*

-Former child caregiver and RCI 4Kinds Advocate

#### **GOAL 4: ENSURE FINANCIAL AND WORKPLACE SECURITY**

RCI will work with employers to develop workplace supports and policies that help to reduce caregiver stressors and keep caregivers attached to the workforce.

*Employer Engagement.* We engage employers by appealing to their interest in workforce recruitment, retention, and engagement, assisting them to think creatively about how they can strengthen support for employee caregivers and help to advance structural reforms. RCI focuses employers on both their role in developing effective supports for their workforce and deepening their understanding of the gaps and weaknesses in the broader structural context of care<sup>7</sup> – in other words, broadening the lens through which employers consider and evaluate workplace supports. *Employers cannot solve all the challenges inherent in work and care and their employee caregiver investments will not be fully leveraged by status quo public policies.* RCI recognizes that employers hold substantial political power and that an array of stakeholders are looking for C-suite leadership and innovation on the intersection of work and care.

We will organize innovation labs with employers in industry sectors with operations and workflows that cannot be done remotely, where flexibility must be creatively considered, and with a concentration of hourly workers. We will support employers in developing pilot programs to test supports that keep employee caregivers attached to the labor market by reducing stress and protecting financial security. These innovation labs will also focus employers on the public policy context and the availability and affordability of home and community-based services.

*“If systems are not put into place to help working caregivers, they will eventually burn out. Our greatest hope is that they last longer than the one they are caring for. The working caregiver’s challenge to maintain one’s mental, physical, and financial health is enormous. A caregiver who*

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<sup>7</sup> Lerner, D. (2022, January). Invisible overtime: What employers need to know about caregivers. Rosalynn Carter Institute for Caregivers. <https://www.rosalynncarter.org/wp-content/uploads/2022/03/Invisible-Overtime-White-Paper.pdf>

*works full time is like someone who has been given a sort of death sentence, where their only crime is that they loved another enough to see them through a difficult time in their life.*

*As a staff employee, I was not afforded the same favor as was given to higher-ranking employees when members of their families were in need of care. There is a great disparity in the workplace between those who are extended flexibility in their schedule and those who are not. It varies depending on your position in the company and the level of compassion of your boss. If it were policy, it would be more equitable.*

*I was once told that it would not be “fair” if I were allowed to work remotely as it was assumed that I was getting ‘paid’ to care for my mother; with the implication that I would be “working another job” at home while on company time. Anyone who is getting paid to care for a loved one is most likely using those resources to keep a roof over both of their heads.”*

- Family caregiver & RCI 4Kinds Advocate

## **GOAL 5: EXPAND DATA, RESEARCH, AND EVIDENCE-BASED PRACTICES**

RCI will continue to center caregivers in research and encourage others to do so. We will support our research efforts and those of others with the first Caregiver Data Platform as a resource for researchers to share and access data. Our research agenda for the next twenty-four months will include an investigation of caregiver typologies.

*Building a Caregiver Data Platform (CDP).* RCI is building the nation’s first CDP that will serve as a repository for decades of caregiver research data, creating a new resource for collaboration across organizations and research institutions. RCI will build this platform for organizations to share data from studies and end-phase research initiatives. The siloed approach to collecting caregiver data, across conditions, agencies, and funding source, must be overhauled to accelerate the needed learning about the epidemiology of caregiving. This work will also require cross-sector partners and the application of approaches from other fields of study. By 2024, we are committed to building a secure community-use platform for caregiver data and for initially populating the platform with data from our thirty-five years of program delivery. We will invite organizations and researchers to securely share data for their use and analysis and accelerate progress by combining efforts as has been done in other disciplines.

*Caregiver Typologies.* Caregiver experiences are not homogenous which complicates the development and evolution of effective programs and policies. Currently, caregiver experiences are largely categorized by the disease state or condition of the care recipient. While condition can be critical to shaping experience, we are developing a different framework of experience (caregiver “typology”) across the dimensions of burden, intensity, and duration. Along with our partners at Duke University, RCI launched the caregiver typology initiative to better understand how caregiver experiences align with a typology of need –the similarities that might be categorized and used to develop and target more effective programs and policies. A draft framework will be shared with stakeholders and caregivers in 2023 to further refine the categories and ensure that it is useful to an array of sectors.

## APPENDIX B AREAS FOR EXPLORATION

Below we highlight RCI’s exploratory priorities to strengthen policy and programmatic support for the nation’s caregivers. These explorations, like our current work, are aligned with the five goals of the Strategy and include consideration of the Council’s First Principles. As we discussed in Appendix A, RCI’s priority principle is to redesign structures and systems that proactively center caregivers’ health and wellbeing and do not rely on caregivers to self-identify, seek out supports alone, or add to their caregiving tasks. We recognize that some essential reforms, such as financing, may be politically challenging today but nonetheless must be pursued, even incrementally, to create the environment and conditions for more transformative change.

Building upon our existing work and that of our partners, we will explore where and how we can lead change in four areas we consistently hear from caregivers and the caregiver community: 1) financing for care; 2) caregiver-centered navigation; 3) using evidence to build high-quality systems; and 4) respite. During the upcoming year, we will conduct the necessary analysis, including conversations with caregivers, stakeholders, and policymakers, to inform specific prioritized recommendations. RCI looks forward to the opportunity to collaborate on the explorations described below.

A note on the workforce: RCI recognizes that strengthening comprehensive caregiver support goes hand-in-hand with paid workforce reforms. The effectiveness of family caregiver supports will be limited if the workforce continues to receive few opportunities for advance-skill training, low compensation, and no employer benefits. We will engage partners who have been critical to elevating and focusing policy attention on the direct care workforce to assess pathways to advance mutual interests. RCI is supportive of initiatives to strengthen the labor market conditions of the direct care workforce as it is necessary to decrease caregiver burden, provide respite, and strengthen quality care. Additionally, we support these efforts because they counter long-standing structural inequities as the majority of care workers are women of color and immigrants. However, if wages are increased without simultaneously addressing long-term care financing, many caregivers will continue to struggle with out-of-pocket costs or will simply be unable to afford professional support.

### FINANCING

***How can we develop financing solutions that will allow families to access services and supports, whether through financial assistance or other direct services such as navigation, respite, counseling, and informational resources?***

The current care system, including long and short-term care, is expensive, varies in quality, and is difficult for consumers to understand and navigate. As the RAISE Strategy notes “most people receiving



support from family caregivers do not meet the financial eligibility requirements for public assistance” which leaves the vast majority of caregivers without accessible and affordable support services.<sup>8</sup> In addition, the Strategy states that “a significant portion of the long-term actions related to financial security require Congressional or federal regulatory reform.”<sup>9</sup> **RCI recommends that the RAISE Council prioritize and focus the next iteration of the Strategy on finance reform.**

ACL funds the predominant programs providing direct supports for caregivers of someone who is not receiving Medicaid or VA benefits. Funding for ACL’s caregiver and Home and Community-based Supports and Services programs total a relatively meager \$627 million in FY 2022, when considering the breadth of caregivers needing support services – an average of less than \$12 per caregiver per year.

***Recognize the gaps for middle-income caregivers***

*The plight of middle-income caregivers is often overlooked and therefore they may lack needed support. Many middle-income caregivers may face financial difficulties if their loved ones are not eligible for Medicaid but not wealthy enough to be able to afford good quality, long-term in-home care. If the maximum income requirements for Medicaid in-home care were at higher amounts, allowing some in-home assistance to be covered by Medicaid, it might allow more middle-income persons with illness, disability, and/or cognitive impairment to remain in their homes longer with the help of family caregivers. This could save money for Medicaid in delaying long-term facility placement.*

***Increase the approach and scale of paying family caregivers***

*With an estimated over 53 million caregivers at the same time there is a severe direct care workforce shortage, the federal and state governments should do more to expand waivers so that more people could be eligible to be paid for the time they spend caregiving for loved ones. This could help provide a modest income for family caregivers, also allowing them to accrue Social Security credits for their own future retirement. It could be especially helpful for caregivers who have had to reduce the amount of time they can work or drop out of the workforce altogether.”*

-Family caregiver and RCI 4Kinds Advocate

Fee for Service Medicare may offer limited supports, largely via hospice or home health. Hospice is accessible only at the end of life and research indicates a widespread and substantial misunderstanding of the scope and duration of the Medicare home health benefit as well as concerns about equitable access.<sup>10</sup> The Medicare home health benefit is designed to offer home aide services that could relieve

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<sup>8</sup> RCI’s analysis of FY 2022 Appropriations levels.

<sup>9</sup> The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren. (2022, September 21). *2022 national strategy to support family caregivers: Federal actions*. Administration for Community Living (ACL).  
[https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyFamCaregivers\\_FedActions.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_FedActions.pdf)

<sup>10</sup> <https://www.commonwealthfund.org/publications/other-publication/2022/jul/improving-medicare-home-health-benefit-lessons-medicaid>

caregiver burden, but the average number of home health aide visits in a 30-day episode is only 0.6.<sup>11</sup> RCI supports individuals having access to their available Medicare benefits, including the full scope of home health benefits for which they qualify, including home health aide services.

Lack of adequate financing impacts caregivers across sectors, including federal government employees. While the RAISE Strategy recommends that private sector employers step up and expand their support of employee caregivers, there is no parallel recommendation that the federal government strengthen its commitment to employee caregivers – across agencies, occupational categories, and geographic location. Providing support to the two million civilian federal employees would reduce their burden significantly and signal a strong commitment of the federal government to leading efforts on behalf of employee caregivers. Just this month, the Office of Personnel Management (OMB) suspended new applications for federal employee long-term care insurance policies, with reports that the underwriter, Hartford, pressured OMB to scale back because the program is financially unsustainable.

## **CAREGIVER-CENTERED NAVIGATION**

***How can caregivers be recognized and valued in their role beyond direct care, including their roles as the primary coordinator, project manager, financial advisor, and insurance agent?***

Long-term care and healthcare delivery is complex and multidisciplinary, and caregivers need help navigating it.

Each system, including healthcare, home and community-based services, and public health, that interacts with a care recipient and their caregiver should be required to implement a standardized caregiver assessment to ensure that appropriate referrals are made to support the caregiver's health and needs. Despite reference to caregiver assessments in the Older Americans Act,<sup>12</sup> many services and organizations focus on care recipient needs and not those of the caregiver. There is some early evidence of success of state grantee networks developing their own assessments<sup>13</sup>. However, much more could be learned to drive program and policy effectiveness if minimum standards for caregiver assessments were developed at the federal level and implemented across systems. In addition, the assessment structure could provide a mechanism for collecting standardized data across states, grantees, and programs. Standard assessment criteria would also lead to better and more consistent data collection of caregiver demographics, needs, and preferences.

Beyond addressing the complex web of state and federal programs and policies that family caregivers are forced to navigate, HHS should recognize caregivers as an important part of the long-term care team. The Caregiver Advise, Record, Enable Act (CARE Act), enacted in 45 states and territories, requires hospitals to inform patients of an opportunity to identify and include a caregiver in their Electronic Health Record (EHR), provide advance notice of the discharge date, and assist caregivers in

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<sup>11</sup> [https://www.medpac.gov/wp-content/uploads/2022/03/Mar22\\_MedPAC\\_ReportToCongress\\_Ch8\\_SEC.pdf](https://www.medpac.gov/wp-content/uploads/2022/03/Mar22_MedPAC_ReportToCongress_Ch8_SEC.pdf)

<sup>12</sup> Older Americans Act, Section 373(b) and (j)

<sup>13</sup> Miller, L., Vanags, K., & Wiltgen, K. (2021, Nov. 28). *Opinion: Family caregivers, raise your hands, find relief*. Des Moines Register. <https://www.desmoinesregister.com/story/opinion/columnists/iowa-view/2021/11/28/family-caregivers-should-raise-their-hands-find-relief/8629095002/>

understanding the tasks and procedures to continue care at home.<sup>14</sup> The implementation of the CARE Act provides a foundational step toward incorporating caregivers in the health care team through education, training, and post-discharge communication. However, the quality of the implementation across the country varies and there are substantial gaps in education, services, and supports that could be implemented during the hospital stay. Moreover, there should be an assessment of how this infrastructure can be designed to proactively consider and support caregiver health and well-being and protect against adding more tasks to a caregiver’s already full plate. Dr. Courtney Van Houtven, in a recent Health Affairs article, describes several actions that could strengthen and build upon the CARE Act.<sup>15</sup> Specifically, standardizing the caregiver fields in EHR and providing for more than one entry, offering virtual participation opportunities during the morning and afternoon provider rounds, better tools and processes for communication among caregivers, families, and providers, and more attention to the unique needs of caregivers of cognitively impaired patients.

RCI commends CMS for its commitment to include caregivers in the discharge planning process for their loved ones by updating the final discharge regulation, as outlined in the Strategy.<sup>16</sup> In alignment with the RAISE Council, RCI believes that identifying services and supports for caregivers starts with a review of family caregiver strengths, needs, and preferences. By meaningfully incorporating caregiver voices and feedback in this process, CMS can ensure a more effective discharge planning regulation and better support the health and well-being of caregivers.

## **USING EVIDENCE TO BUILD HIGH QUALITY SYSTEMS**

### ***How can we build toward a system where programs are designed and implemented with a research and evaluation mindset, to collectively build the evidence on their design and effectiveness?***

Due to the inherent complexity in both the healthcare system and caregiver experiences, the field lacks a comprehensive research agenda tailored toward program and policy application. As such, RCI supports the Strategy’s recommended actions on collecting data and standardizing measures. As referenced earlier in the comments, RCI also supports a more rigorous approach to program evaluation, evolution, and quality. Emerging research is not broadly disseminated and discussed across the field, let alone other sectors. Moreover, there is insufficient engagement between researchers, practitioners, and caregivers. Currently, symposiums and conferences are largely organized for and attended by researchers and usually within a disease-specific pillar. An annual or bi-annual summit could be organized featuring research across caregiving experiences, program practitioners, and advocates with the purpose of strengthening the research dissemination and connecting across the field to evolve programs and connect and strengthen advocacy initiatives.

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<sup>14</sup> AARP. (n.d.). *State law to help family caregivers*. <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>

<sup>15</sup> Houtven, C. (2022, October). *Standing up for my sister*. Health Affairs. <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00780>

<sup>16</sup> The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren. (2022, September 21). *2022 national strategy to support family caregivers: Federal actions*. Administration for Community Living (ACL). [https://acl.gov/sites/default/files/RAISE\\_SGRG/NatlStrategyFamCaregivers\\_FedActions.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_FedActions.pdf), p.22

Additionally, the Center for Medicare and Medicaid Innovation (CMMI) has an opportunity to incorporate caregiver considerations into the design of new payment and delivery models. As CMMI considers specialty care models including those focused on dementia, caregiver support should be included and evaluated. The inclusion of caregiver supports would help to build the evidence base for interventions to support caregivers within the Medicare and Medicaid programs.

## RESPITE

### ***How can respite be made accessible and affordable as a health intervention?***

Without access to short-term respite, caregivers and the quality of support provided to their loved ones will suffer. Serving as a family caregiver can be incredibly challenging, with research showing that unpaid or informal family caregivers are at increased risk for physical, emotional, and mental health problems. As primary providers of care and support to their loved ones, the importance of the health and wellbeing of caregivers themselves cannot be overstated.

Despite being a vital resource for caregivers that allows them access to the relief they need, discretionary funding for respite programs outside of Medicaid is virtually non-existent (\$7M in FY 2021 in ACL).<sup>17</sup> Many states also offer respite services as part of their Medicaid Home and Community-Based Services waiver. Medicare also offers a hospice benefit, which provides limited respite to family caregivers: beneficiaries and their caregivers may have up to 5 consecutive days of respite care in a short-term inpatient facility. However, only 0.2% of all hospice days were for inpatient respite care in 2020.<sup>18</sup> Hospice also provides Hospice Aide and Homemaker Services, to provide home care, as well as Continuous Home Care, which may help to relieve family caregivers.

In Medicare Advantage (MA), managed care plans have additional authority to offer services to support family caregivers. In 2019, CMS introduced new flexibility allowing plans to offer a broader set of new, supplemental benefits, Supports for Caregivers of Enrollees, In-Home Support Services (IHSS), and Adult Day Health Services which all align substantially with supports offered through Home and Community-Based Services, such as providing direct respite care, counseling, training, or resources/help lines for caregivers. About 17 percent (4.1 million) of MA members are enrolled in a plan offering at least one of these benefits.<sup>19</sup> Members enrolled in these plans may not access or be qualified to access these limited benefits, and there are limits on the total number of hours, or dollars, available to provide these services.

While RCI acknowledges the important Medicare benefits along with programs like Lifespan Respite Care and the respite services made available through the National Family Caregiver Support Program (NFCSP), short-term respite remains limited or inaccessible for far too many caregivers across the U.S.

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<sup>17</sup> RCI analysis of FY 2022 appropriations levels.

<sup>18</sup> Medicare Payment Advisory Commission. (2022, March). *Report to the Congress: Medicare payment policy*. MedPAC. [https://www.medpac.gov/wp-content/uploads/2022/03/Mar22\\_MedPAC\\_ReportToCongress\\_Ch11\\_SEC.pdf](https://www.medpac.gov/wp-content/uploads/2022/03/Mar22_MedPAC_ReportToCongress_Ch11_SEC.pdf)

<sup>19</sup> ATI Advisory analysis of CMS' MA Plan Benefit Package (PBP) data for Plan Year 2022.