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Alison Barkoff
Acting Administrator and Assistant Secretary for Aging
Administration for Community Living
U.S. Department of Health & Human Services
330 C St. SW
Washington, DC 20201

With a copy to: RAISE Act Family Caregiving Advisory Council members

Dear Ms. Barkoff, and Members of the Advisory Council:

Well Spouse Association (“WSA”) applauds the 2022 National Strategy to Support Family Caregivers. We are pleased to see that the Strategy provides a coordinated and broad roadmap to improve the lives of family caregivers (and by extension, our care recipients). There are many important actions described in the Strategy at every level of government, from localities up through numerous federal agencies. **This is an important start.**

Going forward, we ask the Administration for Community Living and RAISE Act Family Caregiving Council to **focus additional specific attention to the almost 6 million¹ spousal caregivers** in the US, which Well Spouse Association represents and supports. The needs of spousal caregivers often differ from those of other family caregivers and merit consideration - **our caregiving tends to be more medically intensive², supports more ADLs for our care recipients³, is performed more often without any outside help⁴, and may have a longer duration than other caregivers⁵. Inequities of care that impact marginalized populations (e.g., race, rural location, language barriers) add even more weight. Our caregiving carries a higher financial cost for our families (and necessarily, our care recipients, given combined finances)⁶, and we are often excluded from programs available to other caregivers. Finally, prolonged caregiving extracts a high price on our physical and mental health⁷, including deeply painful losses of intimacy and companionship in our relationships. WSA’s tagline, “when one is sick, two need help,” is apt.**

We are concerned the National Strategy, despite its many good recommendations, should say more to address the needs of spousal caregivers:

- **Spousal caregivers need direct representation in the national discourse** on caregiving. Please include WSA, the only US organization specifically for spousal caregivers, as one of the many groups you rely on for the National Strategy. We have nominated a well-qualified candidate to the 2022 RAISE’s Advisory Council – help us elevate voices that can help you meet our needs.

- Many of the Federal Actions pertain to collecting new datasets around caregiving, which we support – but please ensure that these datasets **capture the full experience of spousal caregiving**. As one example, one 2019 CDC survey⁸ described in the Federal Actions provided responses of “40+ hours per week of care” and “5+ years” duration at most – many spousal caregivers provide 24x7 care for years, and 49% of spousal caregivers have cared >3 years per AARP⁹ – some for decades). Many of the Federal Actions also fall under agencies with mandates to help seniors or people with disabilities, which excludes the 53% of spousal caregivers ages 18-64¹⁰ and the many caregivers whose partners are living with chronic disease but do not identify as disabled. **Data and research that don’t account for our actual experiences won’t yield programs that support us.**
- Similarly, please ensure the services and supports under the Strategy reach the broad spousal-caregiver population. Some Federal Actions are too narrow as described, reflecting age, disease, or program limitations (for instance, non-medical respite care will not help the many spousal caregivers handling complex medical needs; yet this is a group of caregivers that is especially in need of respite). Ensure outreach happens where we are – you will find us on social media and in doctors’ offices, not researching deep into agency websites. And many of us lack the tools (broadband, devices) to leverage online services.
- We encourage the Council to **address topics not included** in the Strategy – examples include how the loss of intimacy impacts spousal caregivers’ mental health, the pervasiveness of trauma related to caregiving, how to encourage healthcare providers to include caregivers in training and education, and how to support caregivers that face abuse from our partners (often a function of their illness) but can’t leave due to our partners’ limitations.
- We urge the Council to **take a deeper dive into existing programs** that have particular impact on spousal caregivers. Examples include Medicaid’s pervasive bias in favor of institutional care over home care, the urgent need to make Medicaid’s spousal impoverishment protections permanent for home care, easing Medicaid’s stringent financial eligibility requirements for long-term care, and requiring states to permit spouses to be paid caregivers for their ill spouses under Medicaid.

Spousal caregivers, and WSA, will continue to advocate for programs that are not included here and are politically unachievable presently – including affordable and universal long-term care and health insurance, home-based services, respite programs, national paid family leave, and a trained workforce of direct care professionals to help us. Family caregivers largely bear the cost of these programs now - an estimated \$470 billion in uncompensated care in 2017¹¹, equating to 14% of all health care expenditures that year¹². **We look forward to the day when politicians have the courage and will to bring these programs to the American public.**

Well Spouse Association and our community of spousal caregivers welcome the opportunity to bring our unique perspective to this critical discussion.

Sincerely,

Bob Mastrogiovanni, Chair, WSA Board
Laurel Wittman, President, WSA
Larry Bocchiere, Co-Chair, WSA’s Social Action Committee
Sheldon Friedman, Co-Chair, WSA’s Social Action Committee

¹ 12% of the 48 million US caregivers per NAC/AARP's [Caregiving in the US 2020 Report](https://aarp.org/ppi/info-2020/caregiving-in-the-united-states.html) (aarp.org/ppi/info-2020/caregiving-in-the-united-states.html),

² Per NAC/AARP, those caring for a spouse/partner more often help with medical/nursing tasks (72%) than all other caregivers (56%). Those caring for a spouse/partner are most often in the high-intensity category (59%) of the Level of Care index, more so than those caring for a parent/parent-in-law (35%), other relative (44%), or non-relative (31%).

³ Those caring for a spouse/partner help with 5.1 out of 7 Instrumental Activities of Daily Living for their care recipients (versus 4.4 IADLs across all caregivers).

⁴ Per NAC/AARP, 66% for spousal caregivers, versus 29% for all caregivers.

⁵ Per NAC/AARP, when care recipients are younger (ages 18 to 49), care duration is longest at 7.9 years (on average, significantly longer than the 3.9 years of care provided when caring for someone age 50 or older).

⁶ Per NAC/AARP, those caring for a spouse/partner experience 2.4 financial impacts, more than those caring for a non-relative (1.3), parent/parent-in-law (1.5), or some other relative (1.8).

⁷ Per NAC/AARP, in 2020, the proportion of spousal caregivers reporting their health was "excellent" or "very good" was only 32%, and that reflected a decline from 45% per NAC/AARP's 2015 report.

⁸ cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf

⁹ aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-providing-complex-chronic-care-spouses-AARP-ppi-health.pdf

¹⁰ 53% per caregiving.pitt.edu/sites/default/files/NCFS%20Spousal%20Caregivers.pdf

¹¹ press.aarp.org/2019-11-14-Valuing-the-Invaluable-Series

¹² cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical

