

n4a Input RE: ACL RAISE Family Caregiving Advisory Council RFI
February 7, 2020
Submitted Electronically: <https://acl.gov/form/public-input-raise>

One pressing family caregiving need/concern I would like to see addressed is:

We are experiencing a national caregiving crisis, and as such, the National Association of Area Agencies on Aging (n4a), which represents the country's 622 Area Agencies on Aging (AAAs) and is an advocacy voice in the nation's capital for the more than 250 OAA Title VI Native American aging programs, believes it is impossible to identify only one pressing need or concern that should be addressed in developing a national strategy to support family caregivers.

There are as many pressing needs and concerns as there are 40 million informal caregivers in the U.S., who are providing more than \$470 billion worth of support to family and friends annually—an amount that rivals the entire federal Medicaid budget. n4a members, and stakeholders of the National Aging Network, know all too well that each family's caregiving demands, obligations and stories are as different as the fingerprints on the hands fulfilling those caregiving duties.

However, according to Pew Research, roughly 70 percent of family caregivers are caring for an older adult. Furthermore, the average caregiver spends an estimated \$7,000 of their own money and 1250 hours every year providing care to loved ones. Whether they recognize it or not, communities, states and the federal government depend on the work of unpaid caregivers to meet the home and community-based services needs of a population that is aging faster than at any other point in the country's history.

Conversely, the population of available caregivers is not growing at the same rate of older adults needing care, thereby putting strain on an already taxed cohort of family caregivers. Therefore, we believe that it is vitally important that any federally directed, national strategy to support caregivers include a substantial focus on meeting the needs of those caring for an aging population.

The outlook is not entirely dire, however. Fortunately, there is a significant and longstanding national infrastructure that is focused on supporting the needs of family caregivers caring for older adults. The National Family Caregiver Support Program (NFCSP), first established in the 2000 reauthorization of the Older Americans Act as Title III E, is the only

nationwide program that provides formula-based grants to states and territories to deliver services and supports to family and informal caregivers.

These services—delivered locally through Area Agencies on Aging—include, but are not limited to, information to caregivers about available services; assistance to caregivers in gaining access to the services; access to individual counseling, support groups, and caregiver training; respite care; and other supplemental services. Funded annually at \$186 million, approximately 700,000 caregivers receive services through NFCSP. Furthermore, because these services are delivered through local, community-based providers, they are well-positioned to address the unique and individual needs of family caregivers.

However, despite being the only nationwide federal program solely focused on supporting family caregivers, funding is not nearly sufficient to meet the demand for services. According to a recent survey, nearly half of all Area Agencies on Aging that deliver core NFCSP programs had a waiting list for services. Given the financial value of the supports delivered by family caregivers, any national strategy should include a commitment to ensuring that vital caregivers have access to the services and supports that they need to continue caregiving for as long as possible. While the infrastructure and the network exists to achieve this goal—the scale and scope of federal funding for caregiver supports remains insufficient.

As the RAISE Family Caregiving Advisory Council develops a national strategy to improve caregiver supports, advisors should build upon the foundational components of the NFCSP. The Advisory Council must also ensure that other recommendations complement and supplement, rather than compete with or supplant, the robust and trusted infrastructure established by the NFCSP and the Older Americans Act.

I would like to offer this specific recommendation to address my need/concern:

n4a appreciates that the RAISE Family Caregiving Advisory Council is focusing on a mission to develop a national family caregiving strategy—including identifying actions that communities, providers, government and other stakeholders can take to promote greater adoption of person- and family-centered care in health care and LTSS settings; improve caregiver assessment and service planning; enhance information, education, training and supports; expand respite options; and address financial security and workplace issues.

These are all vitally important areas of focus, and with few exceptions are also key components of the mission of the National Family Caregiver Support Program and the Older Americans Act. Therefore, we urge the Advisory Council to include a recommendation that federal leaders bolster critical, existing, federal programs and infrastructure aimed at providing community-based, person-centered caregiver supports. The most significant barrier to supporting the vast majority of caregivers—those who are taking care of older adults—is limited funding for existing caregiver support resources.

The discrepancy is stark. Nationally, there are more than 40 million caregivers providing hundreds of billions of dollars of care for older adults. In FY 2020, the only nationwide program specifically targeted at supporting these caregivers was funded at less than \$200 million.

If we truly want to develop a national strategy for supporting caregivers, then stakeholders must start by addressing the dichotomy between the value of family caregiving to this country and the current funding level for existing caregiver support programs. In developing a national strategy for supporting caregivers, anything short of including a recommendation to significantly boost federal funding for existing, effective, trusted, nationwide community-based programs already aimed at meeting caregiver needs is suggesting improvements on the margins of the challenges.

Fortunately, there is precedent for this recommendation. In 2019, Senators Tim Kaine and Dick Durbin introduced the *Supporting America's Caregivers and Families Act*, a bill that would increase funding, training, and support for the more than 40 million family caregivers in America caring for older adults. Specifically, the bill would double the funding authorization level for the National Family Caregiver Support Program to \$360 million. Ultimately, this recommended authorization increase was not adopted in the most recent bipartisan proposal to reauthorize the Older Americans Act. However, n4a believes that this is the bold and visionary thinking required for the RAISE Family Caregiving Advisory Council to develop a truly meaningful national strategy to support family caregivers.

Additionally, n4a supports the continuation of funding for the Community Care Corps pilot projects to encourage communities to develop innovative strategies to support family caregivers. The Community Care Corps initiative is fostering volunteer engagement opportunities in communities to help caregivers by providing non-medical assistance to older adults and people with disabilities. These services can include tasks such as grocery shopping, house cleaning and providing transportation. By providing this individual help, Community Care Corps volunteers can relieve stress for over-taxed

caregivers and enable family caregivers to focus on more personalized caregiving tasks.

While there are many other recommendations that n4a could offer to the Advisory Council in developing a national strategy to better support family caregivers, we believe that substantially boosting federal investment in existing successful programs supporting informal caregivers is the most urgent, ready-to-deploy and needed strategy.