Recommendations to Support Family Caregivers with ARPA

The American Rescue Plan Act (ARPA), Section 9817, offers a 10% enhanced FMAP rate to states that enhance, expand or strengthen home- and community-based services, which includes help for those who care for a family member. When funding goes toward the following three services, states can expand caregiving support and strengthen the family caregiver’s emotional, physical and financial well-being.

1. **Caregiving is a Workforce Crisis: PROVIDE COMPENSATION**

The shortage in the direct care workforce means more and more family members provide care. By increasing funding for consumer-directed programs, more family members can be hired to provide care. In addition, states can expand the definition of family so that spouses and parents of minor children who provide care can be paid.

"It takes every penny to keep my husband alive.” ~ a family caregiver

2. **Caregiving is a Mental Health Crisis: PROVIDE COUNSELING**

Family caregivers feel the emotions for two -- for their carees and for themselves. Family caregivers often keep their emotions to themselves out of concern for upsetting their caree. During regular sessions with a counselor or coach, family caregivers of all ages can express themselves honestly and release the pressure they feel from carrying the intense caregiving emotions, including their worry, frustration and guilt.

"I always feel ‘on’. I used to come home from work and be myself and now I have to put on my fake face. I anticipate the worst all the time. I hate being a caregiver in my home. My mother-in-law falls a lot, can’t speak clearly at all, can’t do hardly anything by herself, and cries all the time. It’s heart-wrenching!”

~ a family caregiver

3. **Caregiving is a Humanitarian Crisis: GIVE A BREAK**

In our informal survey, family caregivers rate their stress level at 4.13 on a scale from 1 to 5 with 5 being the most stressed. With an influx of funding for respite services, family caregivers of all ages can get a much-needed break. Research validates the return-on-investment for respite is significant.

“Between work, caregiving responsibilities, housework, chores, laundry, cooking, I am spread very thin. I never get a day off, I never get to sleep in.” ~ a family caregiver

"Respite care so that I can have a break would be a blessing!"
Supporting Organizations
The growing list of organizations that support our recommendations include:

American Association of Caregiving Youth  Modern Elder Academy
Caregivers of New Jersey  Nancy's House
Caregivers on the Homefront  Open Caregiving
Caring Across Generations  Parkinson Foundation of Oklahoma
Coalition of Certified Caregiving Consultants  The Purple Sherpa
HomeCare Association of Louisiana  TCARE Inc.
Loving Them Forward

View our complete list of supporting organizations and add your support: careyearsacademy.com/funding/

Research References

- Family caregivers who received four or more hours of respite per week through the National Family Caregiver Support Program experienced a decrease in self-reported caregiver burden over time while the Comparison caregivers without NFCSP respite experienced an increase in caregiver burden.
- In 2010, the caregiver support ratio was more than 7 potential family caregivers for every person 80+. This ratio is projected to decline to 4 to 1 by 2030 and to fall to less than 3 to 1 in 2050.
- The need for health aides (at home and in medical settings) is soaring: by 2026, 7.8 million workers will be required.
- As baby boomers age into Medicare, nearly half of U.S. health spending will be financed by federal, state, and local governments.
- Family caregivers are a core piece of the health care system and Long Term Services & Supports (“LTSS”) as well as the main source for long-term care for adults living at home and in the community.
- Ninety-five percent of older adults with LTSS needs living in a community setting received help and care from family caregivers.
- Studies, including the HHS Economic Impacts of Programs to Support Caregivers: Final Report, suggest that family caregiving reduces public and private spending on LTSS, including outlays on nursing facilities.
- Family caregivers experience higher levels of financial, emotional, and physical health difficulties than non-caregivers and are more likely to suffer from depressive symptoms and mental health problems than non-caregivers.
- Family caregiver quotes taken from surveys on stress, compassion fatigue and the financial impact of caregiving conducted by The Caregiving Years Training Academy.

"I feel fragmented, like nothing is getting done well, which makes me feel inadequate to the caregiving role."