

Caring for Wisconsin Family Caregivers

The key to remaining independent, engaged and connected

Core Member Organizations

- Aging and Disability Professionals Association of Wisconsin (ADPAW)
- Alzheimer's Association Wisconsin Chapter
- Wisconsin Adult Day Services Association (WADSA)
- Wisconsin Association of Area Agencies on Aging (W4A)
- Wisconsin Association of Benefit Specialists (WABS)
- Wisconsin Association of Nutrition Directors (WAND)
- Wisconsin Association of Senior Centers (WASC)
- Wisconsin Institute for Healthy Aging (WIHA)
- Wisconsin Senior Advocates
- Wisconsin Senior Corps Association (WISCA)
- Wisconsin Tribal Aging Unit Association

The Wisconsin Aging Advocacy Network (WAAN) is a collaboration of organizations and individuals working with and for Wisconsin's older adults to shape public policy and improve the quality of life for older people. WAAN advocates for all older adults by educating the community and policy makers on particular issues impacting older adults; mobilizing people on priority issues; and advocating for change.

WAAN State Issue Brief
November 2022

WAAN's Position: Caring for Wisconsin family caregivers saves the state money, helps working caregivers remain in the workforce and provides the supports needed to help sustain them in their caregiving roles.

Budget Priorities

- 1. Create a Wisconsin state tax credit (up to \$500) to ease the financial expenses of caregiving.** A Wisconsin income tax credit reimburses family caregivers for expenses—like assistive technology, adult day services and other needed equipment and services purchased for their loved ones.
- 2. Expand Wisconsin Family and Medical Leave Policies.** More Wisconsinites are filling the role of family caregiver and are struggling to maintain their outside employment. Many working caregivers are not covered by or able to access federal or state family and medical leave (FMLA) benefits including those who work for employers with fewer than 50 employees, workers caring for individuals outside their immediate family, and those who cannot afford to take unpaid leave. Expanding state leave policies to apply to employers with fewer than 50 employees and including grandparents, grandchildren, siblings and other extended family members or persons with close affinity relationship who are taking on increasing caregiving roles will save the state money, keep people working and provide the flexibility caregivers need to meet care responsibilities without fear of losing their job. Creating a paid family leave program would ensure those with access to family leave could afford to use it.
- 3. Increase Funding for Respite Service grants so more family caregivers can have access to respite opportunities and assistance to help pay for respite services.**



Legislative Requests

- 1. Keep flexibility in the Alzheimer's Family and Caregiver Support Program (AFCSP).** The caregiver workforce shortage and growth in the aging population place increased demands on family caregivers. Waivers provided during the COVID-19 pandemic have allowed the AFCSP program to pay family members to provide respite care and lift the annual 112-hour cap on respite care. **It is essential to continue these practices beyond 2023.** Family caregivers are leaving the workforce or reducing their work hours to meet caregiving obligations. A family stipend for care is necessary for individuals to stay at home, in their community, for as long as possible.

AFCSP funding has helped to offset the cost of his participation in adult day services... Receiving no other financial assistance, ever little bit helps toward easing the financial burden of his care.

— A Brown County caregiver who provides care for her husband living with dementia



Contact WAAN

Janet L. Zander, MPA, CSW

Advocacy & Public Policy
Coordinator

Greater Wisconsin Agency on Aging
Resources, Inc.

1414 MacArthur Rd., Ste A Madison,
WI 53714

Office: (715) 677-6723

Cell: (608) 228-7253

janet.zander@gwaar.org

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[https://gwaar.org/waan-issues-and-
initiatives](https://gwaar.org/waan-issues-and-initiatives)

- 2. Update AFCSP**—The program places a \$4,000/year cap on payment for goods and services for each person with Alzheimer’s disease in the household or facility (s. 46.87 (6)(b)1.). This cap amount was set in 1985 and is very out of date. According to the CPI Inflation Calculator, the current amount if adjusted for inflation would be equivalent in purchasing power to **about \$11,000 today.**¹ **The annual cap needs to be increased to at least \$11,000 and include annual adjustments for inflation.**
- 3. Pass the CARE Act**—The Caregiver Advise, Record, Enable (CARE) Act includes provisions to keep family caregivers informed about discharge plans for the patient and ensures caregivers receive explanation and training (as needed) for medical tasks they will need to perform at home.

Approximately 80 percent of care at home is provided by unpaid caregivers who spend an average of 20 hours a week giving care.² The majority (65 percent) of older adults with long-term care needs depend exclusively on family and friends, while nearly one-third (30 percent) supplement the care received from family with support provided by paid providers. **Whether an older person can remain at home is often dependent on the availability of care provided by family and friends.**³ Caregiving responsibilities include such tasks as grocery shopping, meal preparation, housekeeping, appointment scheduling and transportation, and often also include more intensive responsibilities like assisting with personal care (bathing, dressing, feeding), medication management and medical care (wound care, injections and other medical treatments).

There are nearly 600,000 family caregivers in Wisconsin providing an estimated 490 million hours of care valued at \$6.9 billion annually.⁴ According to a recent AARP report, over 60 percent of caregivers indicated they were also working full or part-time.⁵ The Wisconsin Employer and Family Caregiver Survey (2021) indicates 8 in 10 caregivers reported having their work life interrupted and **more than half of working caregivers indicated their current situation is unsustainable.** Nearly half (47 percent) of caregivers reported they have reduced their work hours 24 percent) or are considering leaving the workforce (23 percent).⁶

Individuals do not provide caregiving in isolation from the other roles and responsibilities in their lives. Family caregivers are also spouses/partners, parents, adult children, employees, community members and more. Each of these roles intersect with caregiving in different ways and at different times. According to recent AARP research, **nearly 80 percent of people caring for an adult family member face regular out-of-pocket costs** averaging annual spending of over \$7,000 (an average of **26 percent of their income**). Younger caregivers, those who are Hispanic/Latino or African American, and those caring for someone with Alzheimer’s disease/dementia or mental health issues shoulder the highest financial burdens.⁷ As caregiving responsibilities grow in number and complexity, costs associated with caregiving roles become increasingly harder to finance, and caregiving can overwhelm and undermine other dimensions of one’s life.

1. CPI Inflation Calculator
2. Administration for Community Living – LongTermCare.gov. Who Will Provide Your Care? Feb. 18, 2020. Retrieved on July 29, 2022 from <https://acl.gov/ltc/basic-needs/who-will-provide-your-care#:~:text=About%2080%20percent%20of%20care,hours%20a%20week%20giving%20care>.
3. Family Caregiver Alliance, National Center on Caregiving. Women and Caregiving; Facts and Figures. May 2003. Retrieved on July 18, 2022 from <https://www.caregiver.org/resource/women-and-caregiving-facts-and-figures/#>.
4. AARP Public Policy Institute, Valuing the Invaluable 2019 Update: Charting a Path Forward, State Estimates. Washington, D.C.: AARP. Nov. 2019. Retrieved on July 15, 2022 from <https://www.aarp.org/content/dam/aarp/ppi/2019/11/family-caregivers-data-by-state.pdf>.
5. AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>.
6. The Wisconsin Family and Caregiver Support Alliance. Wisconsin Employer and Working Caregiver Survey. May 2022. Retrieved on July 26, 2022 from <https://wisconsin-caregiver.org/employer-engagement-workgroup>.
7. Skufca, Laura, and Chuck Rainville. Caregiving Out-of-Pocket Costs Study 2021. Washington, DC: AARP Research, June 2021. <https://doi.org/10.26419/res.00473.001>.