

## Family Caregiver Advocacy

For too long our country has looked at care as something families have to figure out on their own. Too often, families are stretched thin and many feel like they've personally failed in some way. Right now, there are 53 million unpaid family caregivers in the U.S. By 2040, that number is expected to DOUBLE. Today's family caregivers are often expected to perform highly complex tasks, including medical tasks, care coordination, administration, and technological support – activities that extend well beyond the help with activities of daily living that were the hallmark of family caregiving in years gone by. Caregivers and those who need care deserve more than a crumbling, patchwork system that leaves more gaps than it fills. We want to live in a country where people have community, support, and solutions for their increasing care needs so they don't feel so alone. And we can start right here in Wisconsin. The only way we can get better care for our loved ones, better support for our families, and better jobs for direct care workers is by shifting how our culture values care.

So let's start with some national facts:

- 10,000 people in the U.S. turn 65 every day
- 70% of people over age 65 need long-term care for an average of 3 years
- 80% of care is provided by family members
- 1 year in a nursing home can cost of \$80,000 and Medicare doesn't pay
- In 2021 dementia family caregivers in the US provided an estimated \$271 billion in unpaid caregiving. That total is \$470 billion for all family caregivers of older adults in the US.
- Currently, there are no estimates for the value of the countless hours that family caregivers devote to other types of care—for example, those providing 24/7 care to medically fragile children, those supporting the independence of people with disabilities, caregiving youth who help parents and grandparents, or family caregivers providing care to more than one person. Similarly, it is impossible to estimate the financial value of the care provided by kin and grandparent caregivers, many of whom are older adults.

In Wisconsin:

- ~20% of Wisconsinites provide caregiving to a friend or family member who has a health problem or disability. In the next 2 years, 13% more of Wisconsinites expect to become a caregiver.
- Caregivers provide an average of 19 hours per week of care. 76% reported managing household tasks. 40% reported assisting with personal care tasks.
- The average age of caregivers in Wisconsin is 60.
- 54% of caregivers in WI are in the workforce and 26% have children under the age of 18 in the household. When caregivers can no longer balance their caregiving with other responsibilities, they must reduce their hours or leave their job altogether — further exacerbating their financial burden as well as the economic burden
- In addition, Wisconsin is experiencing an acute shortage of direct care workers in every sector of the long term care system and is particularly severe in rural areas such as northwest Wisconsin.

From a 2022 Wisconsin Survey and Long Term Care report:

- Half of the families surveyed cannot find sufficient workers to provide the care they need.
- Half of the families say that without the care from family members, their loved one would need to be placed in a residential facility.
- Over half of family caregivers report that their current situation is unsustainable.
- In a long-term care system, which has statutory guarantees that aim to eliminate waiting lists, we now have a new kind of waiting list in Wisconsin: More and more people waiting to get services from provider agencies which have diminished capacity due to the direct care worker crisis. For some of these people, it's not safe to live at home without home care so they are forced to consider nursing home admission (at a much higher cost to the State's Medicaid budget).
- There's not enough funding and not enough workers (at current wage rates) to enable provider agencies to expand to meet the increased demand for their services.
- Due to staff shortages in provider agencies, the staff who remain on the job are often overextended and expected to work overtime to fill in the gaps in the individual care plans. For members with active families, family members are also expected to provide more hours of care (often unpaid). Neither of these responses to the crisis are viable long-term solutions.
- Direct care worker vacancies in WI residential facilities have risen from 13% in 2016, to 24% in 2020, to the unprecedented level of 28% in 2022 (more than doubling rate in just 6 years). This compares to a 7% vacancy rate in the national job market and a 9% vacancy rate in the healthcare sector in 2022.
- A recent survey showed that over 18,000 people in Wisconsin sought services from a long-term care provider in 2022 but were denied or delayed service due to staff shortages.
- Families are expending huge amounts of time and energy to find workers, often to no avail.
- Many providers are reporting that workers are leaving to take better paying jobs in fast food restaurants, gas stations, convenience stores and other jobs with better pay and/or benefits.

Wisconsin has accomplished a lot in terms of supporting family caregivers and the people they care for and is looked at as a leader in the country. Every Wisconsinite has access to Aging & Disability Resource Centers and recently expanded access to dementia care specialists, along with small amounts of caregiver funding to help families with expenses. Our publicly funded long-term care waitlists have ended and the State is working on initiatives to increase and streamline the direct care workforce, yet there is more to do. Senator Quinn & Representative Armstrong, would you please consider the following recommendations and out-of-the box thinking proposed:

Current proposed legislation that will benefit family caregivers and the persons they care for:

- AB 259/SB 263 100-day Rx drug supplies under SeniorCare and amending a related admin. Rule.
  - We have heard from many family caregivers who are responsible for picking up prescriptions for loved ones, that this would save their loved one money and save the caregivers time and trips to the pharmacy.
- AB 478/SB 469 Allowing the enactment of family and medical leave ordinances.
  - This legislation would allow local municipalities to enact paid family and medical leave policies that would benefit working family caregivers (over half work) and professional caregivers.
- AB 418/SB 407 Healthy aging grants and making an appropriation.
  - Funding under this bill would go to DHS and be contracted with the Wisconsin Institute for Healthy Aging. The evidence-based programs they support include Powerful Tools for Caregiving and both caregivers and older adults will benefit from falls prevention efforts.

#### Additional Ideas to Support Family Caregivers:

- **Establish standards for facilities and provider agencies to designate themselves as providing “memory or dementia care”.** Currently, there are no standards, training or otherwise, for facilities and other provider agencies to label themselves as offering “memory/dementia care”. The fallout has been excruciating for families, resulting in unnecessary price hikes, resident evictions, and lack of care. In addition the lack of dementia training for staff result in high turnover, with staff unable to provide proper care for people living with dementia.
  - Incentivize MA rates for facilities who provide proper dementia training for staff and adhere to established standards.
- **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.
- **Expand Wisconsin Family and Medical Leave Policies.** Many 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.**
- **Encourage clinicians and providers to conduct formal assessments of family caregiving needs. Create incentives for health care systems to incorporate family caregivers into healthcare decision making for the person receiving care.**
- **Introduce a range of incentives to encourage employers to adopt caregiver-friendly practices, including tax incentives.**
- **Launch a State public long-term care social insurance program that includes benefits for kin and grandparent caregivers.** Medicaid programs must always compete with other state budget items, like transportation and education—leaving far too many consumers without enough support and hindering vital job quality improvements. As a leading example, Washington State has established a Long-Term Care Trust that, beginning in 2025 will provide a daily benefit of \$100 (up to a lifetime benefit of (\$36,500) to people who require assistance with three or more activities of daily living. Although many consumers will have lifetime expenditures that exceed this amount, this program will be the nation’s first universal long-term care benefit and could mark a significant turning point in LTSS financing. (<https://wacaresfund.wa.gov/>)

- **Increase affordable access to reliable broadband internet in rural Wisconsin.** Utilizing technology (i.e. automatic medication dispensers, gps locator devices, smartphone, etc.) would reduce reliance on in-person caregiver tasks and allow people to remain at home longer.
- **Increase funding for family caregivers to use respite care, both in-home and at facilities.** Respite care prevents burnout for family caregivers and allows people to remain at home longer. There are few facilities in northwest Wisconsin who provide respite care (allowing family caregivers to travel/attend events like a wedding) and those that do, the cost is expensive (avg. \$280/day). In-home respite care costs \$25-\$30/hour in our area.
- **Increase funding to Aging and Disability Resource Centers (ADRCs) by \$30 million to equalize historical funding disparities, fully fund required contracted services for a growing customer base and provide an additional \$25 million to add critical services to all ADRC operations across the state.**
- **Protect vulnerable older adults by increasing the state contribution to Home-Delivered Meal (HDM) Services to \$5.95 million.** Home-delivered meals can serve an older adult for roughly the same cost as a day in the hospital or 10 in a nursing home. Every \$25 a state spent per year per older adult on home-delivered meals resulted in an estimated 1% decrease in the population of “low-care” nursing home residents, who have the functional capacity to live in the community.

Direct care workers are an essential part of supporting an aging rural population, particularly as individuals favor aging in place over nursing homes and require in-home assistance with activities of daily living. Additionally, residential care residents and long-term care residents depend on direct care workers to keep them safe and provide the care, service, and support they need to thrive. The following ideas would assist in ensuring our direct care workforce is robust in northwest Wisconsin:

- **Increase Medicaid Personal Care (MAPC) rates to cover the actual costs incurred by MAPC provider agencies (benefits children and adults).** Wisconsin Personal Services Association surveyed agencies and determined a 39% increase in reimbursement rate to \$32.63/hour is needed to cover actual costs.
- **Increase RN Supervisory rates to cover the actual costs incurred by MA provider agencies.** A RN is required to assess a person monthly and every time they are discharged from a hospital or facility.
- **Establish a minimum wage of \$25/hour for direct care workers or provide a % of property tax/rent relief for direct care workers.** Caregiving is not something everyone can do, and those that do are extraordinary people. Direct care workers deserve a fair wage and benefits for the important work they do. Factories, fast food, and gas stations pay more than the average wage of a direct care worker. Providing a % of property tax/rent relief would allow retired people an opportunity to participate in the direct care workforce, even at part-time hours, helping alleviate the crisis. A similar program called the Senior Tax Exchange allows for this for older adults who volunteer at schools.
- **Increase awareness of direct care worker career pathways. Incentivize school districts who incorporate awareness. Establish a pathway to earn college credit or provide college scholarship credit to high school students who provide direct care work in their community.**

*\*Reference documents for stated statistics are available through our office.*