

CAREGIVER CRISIS COALITION OF WISCONSIN

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Caregiver Crisis Coalition of Wisconsin
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Time is Running Out to Fix the Caregiver Crisis!

In recent years, it has become clear that the biggest threat to the lives of older adults and people with disabilities in Wisconsin who need long-term care services is the Caregiver Crisis: an increasingly acute shortage of caregivers in every sector of the long-term care system. This crisis is impacting every community in Wisconsin, but it is particularly severe in many rural areas. The Caregiver Crisis Coalition is calling on the state legislature to take serious action now in this state budget to reverse the ominous trend which is putting more Wisconsin residents at risk every year. Unless the landscape for caregivers improves substantially in the 2023-2025 biennium, it is virtually certain that the trends described below will continue to grow.



Elderly Parents Under Stress

Susan, the mother of an adult with a developmental disability in south central Wisconsin, says when there are staff shortages “the viability of the care system rests on elderly parents providing home care with no pay”. “What will happen when my husband and I are no longer able to do that?” “There’s a lack of a safety net in Wisconsin for those needing support.” “I am determined to see caregiving become a profession that can provide a reasonable standard of living, including health care and retirement benefits.”

About the Caregiver Crisis Coalition

The Caregiver Crisis Coalition (CCC) is a statewide coalition composed of aging and disability advocates, provider associations, workforce coalitions, workforce development agencies, IRIS consultant agencies, Aging and Disability Resource Centers, and fiscal employment agencies. The Purpose of the CCC includes: increasing the pool of qualified long-term care workers for children and adults; reducing barriers preventing potential workers from becoming caregivers; improving training, supervision and support of caregivers; improving pay, benefits and working conditions to be competitive with other employment opportunities; and emphasizing the mission-driven, professional nature of the work.

Compelling Evidence* that the Caregiver Crisis is Getting Worse

- 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 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 caregiver 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.
- Caregiver vacancies in Wisconsin 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.
- Provider agencies are unable to expand their capacity to meet unmet demand for services; in fact, the opposite is happening. Provider capacity is often decreasing so that providers are unable to serve the number of people they served in the past.
- 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.



We have never been fully staffed for more than a week for the past 3 years. "

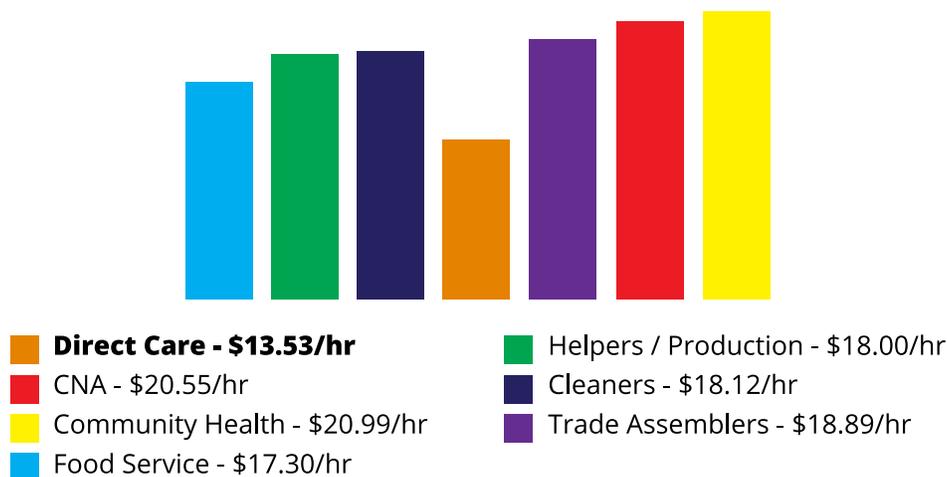
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*Sources for this proposal include a recent Survival Coalition survey of family members and long-term care recipients, "The LTC Workforce Crisis: A 2022 Report" (WHCA, WiCal, WALA, Leading Age WI, DSPN), the Wisconsin Personal Services Association, the Wisconsin Family and Caregiver Support Alliance (WFACSA), UW-Madison Division of Extension's Employers and Working Caregivers survey, the National Partnership for Women and Families, and other sources.

Caregiver Crisis Coalition Proposals for the 2023-25 State Budget

1. A 25% Increase in Family Care capitation rates, with a commensurate increase in IRIS rates

- We need a much bigger increase in Family Care base rates than the modest increases during the last two years. Only a major increase will enable providers to reestablish competitive wages for the direct care workforce to sustain our long-term care system over the long term and provide sufficient funding to incentivize them to grow and expand their operations. Higher rates are also necessary to encourage new provider entrants to the market.
- The benefit provided by the 2021 DHS directed provider rate increases has been significantly eroded due to the higher-than-normal inflation of 2021 and 2022. This, along with the growing workforce shortage, has left providers in an increasingly difficult position.
- Without a substantial rate increase, long-term care providers will not be able to improve their competitiveness, and as a result Managed Care Organizations (MCOs), IRIS Consultant Agencies (ICAs), and long-term care participants will continue to see a deterioration in provider networks in the form of downsizing and closures. That will increasingly result in more Medicaid recipients losing access to necessary community-based care.
- The need for a 25% increase is derived from a 2022 comparison of average direct care worker wages in Wisconsin to the average wages of other occupations which are competing for the same workers:



This is consistent with reports from a variety of Family Care and IRIS providers who have indicated that they need at least 25%-30% increases in reimbursement rates in order to pay competitive wages and reduce their high current job vacancy rates.



**Good, reliable caregivers
don't want to work for
less than \$14/hr. "**

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Additional Recommendations Related to Funding Increase:

- Increase capitation rates for Family Care MCOs by 25%, allow MCOs some flexibility to pass on the increase to providers in a way that accounts for differences in the labor markets in different parts of the state.
- Include budget language to ensure that 85-90% of the rate increases are used for salary and benefits of direct care workers, but also to ensure that the funding increase does not result in unfunded administrative requirements to payers.
- Direct DHS to develop a reliable method to ensure that the IRIS individual budget-setting algorithm is revised to achieve comparable increases to those in Family Care
- Monitor DHS' development of new rate minimums (which could be announced during this state budget session); if the new minimums would represent a significant step forward, ensure there is sufficient funding in the biennial budget to implement these minimums during the 2023-2025 biennium.
- Add budget language to require automatic inflationary increases in Family Care and IRIS rates in the future.

2. Increase Medicaid Personal Care (MAPC) rates to cover the actual costs incurred by MAPC provider agencies (benefits children and adults)

- A major increase in MAPC rates is required, as determined by a survey of MAPC provider agencies conducted by the Wisconsin Personal Services Association
- Current MAPC rate = \$23.44/hour; WPSA survey indicates that MAPC providers need \$32.63/hour to cover actual costs

Recommendation: Raise the reimbursement rate for MAPC by 39% to \$32.63/hour



I'm his primary caregiver and I had a stroke

Hannah, the mother of a young man with autism and epilepsy in southeast Wisconsin, says, "My son needs 1-on-1 care. His IRIS budget has enough funding to pay for it, but he has had ZERO services or supports until recently" (because no workers were available). "Last year, I had a stroke. I don't know what will happen to my son if I can no longer care for him sooner than I expected. Who will love him? Who will fight for him?" "I need to know that my son will have the opportunity to lead a full life whether I am beside him or not."

3. Create a Family Caregiver Tax Credit (benefits children and adults)

- Nearly 80% of people caring for an adult family member face regular out-of-pocket costs resulting in average annual spending of over \$7000.
- The workforce crisis has forced more family members to cut back on their paid work in order to care for family members who need care - a family caregiver tax credit would help to relieve some of the fiscal impact felt by families who choose to care for their loved ones at home.

Recommendation: Support the Governor's Current Budget Proposal. Create a tax credit of up to \$500/year for individuals who pay for items that directly relate to the care or support of a family member who requires assistance with one or more daily living activities.

4. Eliminate Income Cliffs for Childcare Assistance

- Many paid caregivers cannot work full-time because their income would exceed the income limits for childcare school nutrition programs, SNAP/Foodshare, TANF and subsidized housing
- The obstacles preventing part-time workers from increasing their hours are a major factor that has exacerbated the caregiver crisis.
- According to the NCSL (National Conference of State Legislatures), "the risk of falling off a 'benefits cliff' is particularly likely for people making between \$13. and \$17. per hour" (i.e., a major portion of Wisconsin's paid caregivers)
- We are proposing to address the cliff for childcare assistance first, because many providers report that this is a major obstacle for people to accept caregiver employment.

Recommendation: Expand income eligibility for childcare assistance, increase the level of subsidy, and provide for transitional childcare assistance as families' incomes increase

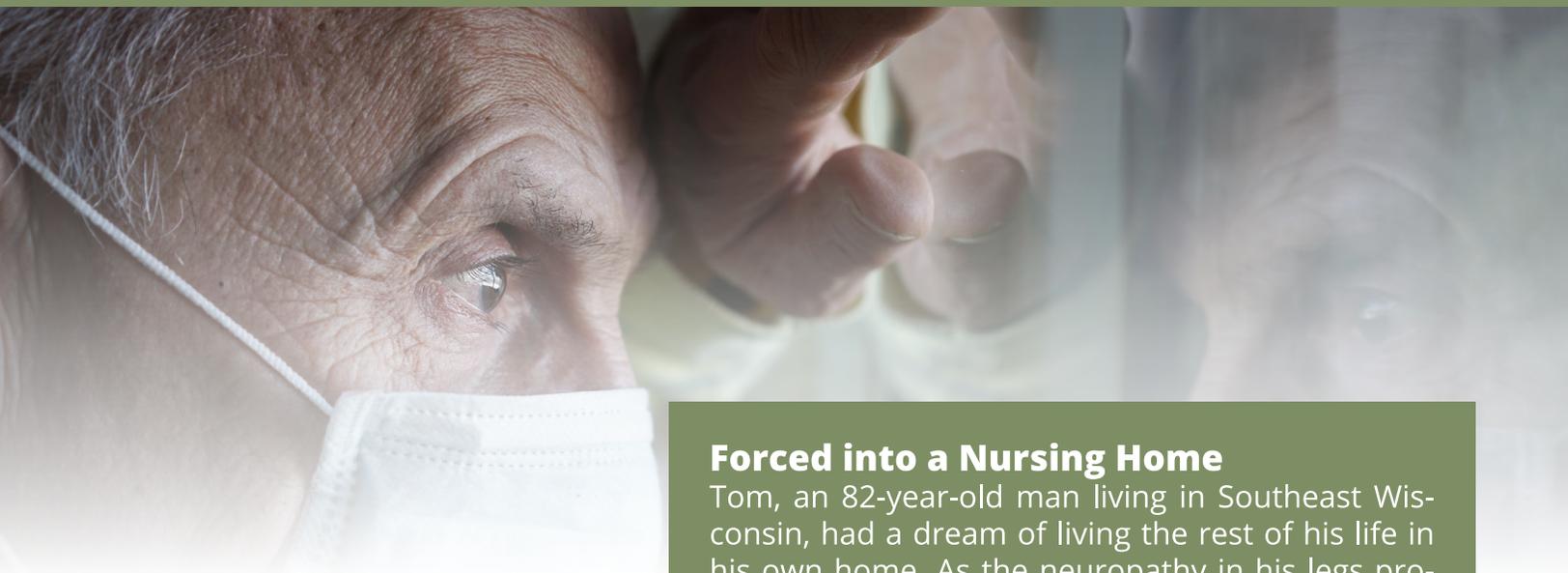
5. Expand the Family and Medical Leave Act (FMLA) (benefits children and adults)

- Many family caregivers in Wisconsin report a major difficulty they face when providing unpaid care to their family members. For those caregivers who have paid jobs outside the home, they often cannot afford to take unpaid time off from their job to provide the care that their family member needs. This has not only exacerbated the caregiver crisis; it has also resulted in some caregivers having to quit their jobs and some families having to explore an out-of-home placement for their family member (which can mean a sizable increase in Medicaid spending for that person).
- Families provide 80% of the care for children and adults with disabilities and older adults. 60% of these families provide more than 40 hours of caregiving in a week, the equivalent of a full-time job.
- The caregiver crisis has had a major detrimental impact on the employment of family caregivers. 2/3 of family caregivers have decreased their paid employment hours outside the home or have left their jobs.

5. Expand the Family and Medical Leave Act (FMLA) (Continued)

- 62% of employees in Wisconsin cannot even access unpaid leave (due to the size of their employer or the number of hours they are working)
- Only 23% of Wisconsin workers currently have access to paid family and medical leave through their employer.
- 12 states have paid Family and Medical Care Leave programs: California, Colorado, Connecticut, Maryland, Massachusetts, New Jersey, New York, Oregon, Rhode Island, Delaware, New Hampshire and Washington DC

Recommendation: Create a Wisconsin Family and Medical Leave Insurance (FMLI) program, an insurance program under which employees who pay into the program can receive pay while taking family or medical leave. This differs from the current Family and Medical Leave Act (FMLA) which only provides unpaid leave. All employees (including part-time workers) who worked for any employer, as well as self-employed individuals, who work at least 680 hours during the year prior to making a claim would be eligible for the program. Participants would be eligible for up to 12 weeks of paid family or medical leave insurance benefits.



Wages are one of the top issues in retaining employees. "

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Forced into a Nursing Home

Tom, an 82-year-old man living in Southeast Wisconsin, had a dream of living the rest of his life in his own home. As the neuropathy in his legs progressed and he began to experience memory loss, he needed more assistance with transfers, toileting and meal preparation. He was unable to increase his home care hours sufficiently to maintain his health and safety in his home. And on some days, there was no worker available to provide the hours of care in his service plan. As he said to his friends, "This is a nightmare." After one more bad fall, he had to move into a nursing home and sell his house. Sadly, he has given up hope of returning to the community.

6. Increase Funding for Respite Services (Benefits for Children and Adults)

- While many people in Family Care and IRIS can obtain paid respite services in their individual service plans, some older adults and people with disabilities are not eligible for Family Care or IRIS services. Counties receive a modest amount of state funding to provide respite services to these individuals.
- The current funding levels for counties are grossly inadequate - many people who need respite cannot get it.
- County Aging and Disability Resource Centers agree that this is a serious unmet need.
- Current funding statewide is only \$350,000/year for 72 counties.

Recommendation: Increase funding to \$550,000/year statewide

7. Medicaid Expansion (Benefits for Children and Adults)

- Wisconsin is now one of only 11 states that has opted not to expand Medicaid at a highly favorable federal matching rate (AL, NC, SC, GA, FL, TN, TX, WY, MI, KS, WI)
- One of the major detrimental impacts of this is the inability of many paid caregivers to establish healthcare eligibility via the Badger Care program because their income exceeds income eligibility limits - - this is a significant deterrent for many people to accept a paid caregiver job.

Recommendation: Accept the federal option of expanding Medicaid while the opportunity still exists



Dementia Families Need a Tax Break

Alice, the wife of a man with Alzheimer's in the Fox Valley, says "We moved to our dream home near Minocqua to enjoy the life we worked hard to experience." When his disease progressed, "our doctor saw what caregiving was doing to me". The doctor told me that in our rural area, "there is no support for you and your husband here". So we had to move into town. But even there, "the disease doesn't get better; it doesn't let up, it won't go away; it WILL continue to wear families down until CHANGES are made. We are RIGHT here and we need an assist. One thing that government could do is provide tax breaks to dementia families."

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Thank You - Caregiver Crisis Coalition

The Caregiver Crisis Coalition (CCC) thanks you for considering its proposals and recommendations.

Questions? Contact:

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