



of Wisconsin Disability Organizations

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# Sustaining the Valuable Work of Caregivers

## FAQ: Developing a State Caregiver Waiver

How does Wisconsin's caregiver shortage impact the economy? Why should Wisconsin be concerned about a caregiver shortage?

Both people with disabilities and older adults across Wisconsin need daily caregiving supports to stay in their homes and communities and out of costly institutional care. The shortage of paid caregivers is a crisis now, and the need for these workers is projected to increase by an additional 20,000 workers by 2026<sup>1</sup>. Currently, 70% of personal care agencies are unable to staff all hours of care that Wisconsinites need on a daily basis, and 93% of agencies find it difficult to fill job openings.<sup>2</sup> The annual turnover rate is more than 50% and can be as high as 67%<sup>3</sup>.

In Wisconsin, 85% of individuals with disabilities who require direct care for some or all of their support cannot find paid help<sup>4</sup>. People with disabilities rely on family<sup>5</sup> caregivers to make up for gaps in paid support; many rely on family caregivers to provide some or a large proportion of the caregiving needed<sup>6</sup>.

The pressure on family caregivers is mounting, unsustainable and is impacting Wisconsin employers. Many family caregivers report being forced to reduce hours or leave the workforce entirely in order to care for family members, incurring risk to their own financial futures in the process. Many family caregivers may contribute care for multiple family members at the same time including aging adults, individuals with disabilities, and children. The Society for Human Resource Management estimates every time a company loses an employee, it costs the equivalent of six to nine months' salary to replace and retrain a replacement — and two or three times more than that for highly-skilled employees.<sup>7</sup>

Without family caregivers contributing their labor, most of these caregiving hours would otherwise have to be paid for by Medicaid.

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<sup>1</sup> National Alliance for Caregiving 2015 Report on Caregiving in the U.S.

<sup>2</sup> Family & Individual Needs for Disability Supports Community Report 2017. [https://www.thearc.org/file/documents\\_finds/FINDS\\_report-2017-FINAL-VERSION.pdf](https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf)

<sup>3</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>4</sup> In 2016, a statewide survey of more than 500 people who rely on direct care services and their families found 95% had trouble finding workers, 85% did not have enough workers to cover all their shifts, 43% couldn't find a worker 7 or more times per month, and 60% said they get sick more often when they do not have enough staff. Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

<sup>5</sup> The term "Family Caregiver" includes immediate and extended family members, domestic partners, friends, neighbors, volunteers or others who provide help and supports so that individuals can remain living in the community.

<sup>6</sup> Family members and friends reported spending an average of 57 hours each week in a support role for those with disabilities assisting with everything from feeding to dressing, providing behavior supports and managing finances. Family caregivers are reporting greater unmet needs, and with a paid workforce crisis they simply cannot find help.

<sup>7</sup> <https://www.peoplekeep.com/blog/bid/312123/employee-retention-the-real-cost-of-losing-an-employee>

## What factors are contributing to Wisconsin's caregiving crisis?

Lack of benefits—including health insurance, paid sick and family leave, retirement, dependent care, commuter benefits etc.—is a major factor contributing to direct care professionals leaving the workforce.

Paid caregiver wages are dependent on Medicaid rates; these critical jobs are also low-income positions. In Wisconsin, the average paid caregiver's wage is \$10.47 per hour. Many skilled caregivers are leaving the profession for other low wage jobs without benefits that have a slightly higher hourly rate. Others want to contribute more caregiving hours, but must restrict their incomes in order to preserve their access to BadgerCare health care. Family caregivers—who often reduce hours or are forced to leave the workforce entirely—face loss of income and employer-sponsored benefits.

An estimated 29% of Wisconsin's Home and Community Based waiver workforce (e.g. those working in people's homes and community settings through programs like Family Care, IRIS, Partnership) and 35% of Nursing home workers are below 100% Federal Poverty Level (FPL)<sup>8</sup> and rely on Medicaid-funded BadgerCare for access to health care<sup>9</sup>. Low income family caregivers also depend on BadgerCare, especially when their caregiving contributions limit their participation in the workforce.

## Why can't workers get insurance on the exchanges?

Low-income workers lack significant savings to cover deductibles—which frequently require large lump sum payments before a portion of health care costs are covered--, co-payments for prescriptions or services, and the portion of health care bills that are not covered by insurance.

For paid caregivers whose salaries are tied to a fixed Medicaid reimbursement rate, those reimbursement rates are not adjusted annually and have not kept up with increases to the cost of living or rapidly rising health care costs. Even though increases in exchange plan premiums are subsidized by tax credits such that the net amount paid is a fixed percentage of income, rising health care costs can result in significant increases in co-pay and coinsurance obligations that cannot be accommodated. Likewise, low income workers that select plans with lower premiums may not be able to afford the higher deductibles that offset lower monthly payments.

## Why create a Caregiver waiver program?

The Centers for Medicaid Services (CMS) recommended states extend Medicaid health care coverage to caregivers as a strategy to stabilize their workforces serving long term care participants. Wisconsin has an existing model that could be used to create a caregiver waiver that allows caregiver participants to pay a premium for Medicaid health care coverage specifically to address the workforce crisis<sup>10</sup>. A “Medicaid buy-in waiver” for caregivers is a cost-effective and sustainable approach to retain workers.

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<sup>8</sup> Annual income of \$12,140 for an individual, \$25,100 for a family of four  
[https://www.acf.hhs.gov/sites/default/files/ocs/2018\\_hhs\\_poverty\\_guidelines.pdf](https://www.acf.hhs.gov/sites/default/files/ocs/2018_hhs_poverty_guidelines.pdf)

<sup>9</sup> <https://phinational.org/policy-research/workforce-data-center/>

<sup>10</sup> CMS Guidance, Suggested Approaches for Strengthening and Stabilizing the Medicaid Home Care Workforce August, 2016,  
<https://www.medicaid.gov/federal-policy-guidance/downloads/cib080316.pdf>

This approach benefits workers because it allows them to earn more, save more, and pay a sliding scale premium that is based on income. Workers between 100 and 300% FPL often do not have their own employer sponsored insurance<sup>11</sup>, and may not have the cash flow necessary to pay deductibles, co-pays, and coinsurance associated with exchange plans.

Extending Medicaid health care insurance to paid and family caregivers while allowing them to earn and save more is a significant value that can make caregiving jobs more attractive, encourage worker retention, and enable workers to contribute more caregiving hours—thereby increasing caregiving capacity without increasing the number of workers--without affecting Medicaid eligibility.

For low-income family caregivers, ensuring they can take care of their own health acknowledges their caregiving contributions that are benefitting the state and extends them a benefit in exchange for their caregiving work.

Improving worker retention through the extension of health care coverage benefits the overall Medicaid program. Caregivers are typically caring for the highest cost Medicaid populations. Home and Community Based caregivers working in Medicaid-funded long-term care programs—Family Care, IRIS, Pace, Partnership—keep aging adults and people with disabilities living in their homes and out of more expensive Medicaid-funded institutional settings<sup>12</sup>.

Improving worker retention also provides administrative savings for institutions, hospitals, and provider agencies. The costs associated with constantly recruiting, hiring, and training a transient workforce is significant. A more stable workforce provides individuals with better care whether they are living in their homes or institutional settings.

Wisconsin's successful Medicaid Assistance Purchase Plan (MAPP) work incentive program<sup>13</sup> can serve as a model for a caregiver waiver.

## Who would be eligible for the caregiving waiver?

The eligibility for this Medicaid Buy-In program would be based on occupation (paid caregiver) or contribution of 20 informal caregiving hours per week<sup>14</sup>, as well as meeting income and asset limits.

Our recommendation is that all Home and Community Based caregivers<sup>15</sup>, facility-based caregivers<sup>16</sup>, and family caregivers contributing at least 80 hours of caregiving per month with incomes more than

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<sup>11</sup> According to the Kaiser Health Foundation 57% Wisconsinites have employer sponsored health insurance benefits. Low wage workers are less likely to have employer sponsored plans. (2017 data)

<sup>12</sup> On average, it is at least 30% less expensive for people to live in community settings as compared to institutional settings; for many individuals the Medicaid savings associated with living in the community are far greater than 30%.

<sup>13</sup> Wis. Stats. 49.472 outlines the MAPP program.

<sup>14</sup> 20 hours per week (or 80 hours per month) is the equivalent of a half time job, and is consistent with the level of work requirements that will be implemented in the BadgerCare program. To recognize that caregiving duties may fluctuate from week to week, we recommend that the total number of hours contributed be assessed on a monthly basis, and is assessed cumulatively in cases where an family caregiver is providing care for multiple individuals (children, adults with disabilities, and aging adults).

<sup>15</sup> HCBS workers that provide the types of services and supports delivered in the home or that are intended to increase the inclusion and engagement of the participant in the community in our long-term care programs (Family Care, IRIS, PACE, Partnership, CLTS).

<sup>16</sup> Facility-based caregivers include workers proving the types of services and supports delivered nursing homes, assisted living, and hospitals associated with routine daily care and activities of daily living.

100% FPL and less than 300% FPL and assets less than \$15,000<sup>17</sup> are eligible to participate in the caregiver waiver. 300% FPL is a little more than \$37K pre-tax for an individual or about \$77K for a family of four<sup>18</sup>. 70 and 71% of Home and Community Based and Facility based caregivers are below 300% FPL<sup>19</sup>.

## Why is it essential to include all types of caregivers in this waiver?

In Wisconsin, an estimated 549,000 family caregivers are providing 588,000 million hours of care, valued at nearly \$6 billion dollars<sup>20</sup>. Without informal family caregivers contributing their labor, most of these caregiving hours would otherwise have to be paid for by Medicaid. Many family caregivers may be caring for an aging adult(s), an adult with disabilities, and/or children with disabilities at the same time.

95% of working caregivers report that caregiving has impacted their employment. 55% of working caregivers cut back on their hours: 32% of working caregivers report leaving the workforce entirely<sup>21</sup>.

40% of the people receiving caregiving from family caregivers are people with disabilities<sup>22</sup>. Family members and friends reported spending an average of 57 hours each week in a support role for those with disabilities assisting with everything from feeding to dressing, providing behavior supports and managing finances. Caregivers are reporting greater unmet needs, and with a paid workforce crisis they simply cannot find help.

Family caregivers are contributing care hours at great cost to themselves. They may be forced to leave the workforce, lose insurance, and lower incomes over time may leave them more at risk for future long-term reliance on public benefit programs.

A 2016 AARP report found the average caregiver spends nearly 20% of their income on out of pocket costs<sup>23</sup>. A survey of informal family caregivers found that 92% of caregivers reported some out-of-pocket expenses related to their family member's disability. 67% reported expenses of \$1,000 or more per year; 36% reported expenses totaling \$5,000 or more per year<sup>24</sup>.

## How many caregivers would this waiver help?

There are an estimated 185,000 paid caregivers working in Home and Community Based long term care and facility-based long-term and residential care facilities<sup>25</sup>.

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<sup>17</sup> This asset level is consistent with Wisconsin's Medicaid Assistance Purchase Plan (MAPP) program, the Medicaid work incentive Buy In program for people with disabilities.

<sup>18</sup> 2019 federal Poverty guidelines.

<sup>19</sup> <https://phinational.org/policy-research/workforce-data-center/>

<sup>20</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>21</sup> Family & Individual Needs for Disability Supports Community Report 2017. [https://www.thearc.org/file/documents\\_finds/FINDS\\_report-2017-FINAL-VERSION.pdf](https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf)

<sup>22</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>23</sup> The Cost of Family Caregiving: Out-of-Pocket Spending Surprisingly High. AARP. 2016 <https://www.aarp.org/caregiving/financial-legal/info-2017/out-of-pocket-cost-report.html>

<sup>24</sup> Family & Individual Needs for Disability Supports Community Report 2017. [https://www.thearc.org/file/documents\\_finds/FINDS\\_report-2017-FINAL-VERSION.pdf](https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf)

<sup>25</sup> 112,000 is the estimate for all HCBS workers, including roles like personal care, home health care, day services, employment services and supports, and other roles that fulfill the care plans for long-term care participants (Family Care, IRIS, PACE, Partnership). There are almost 74,000 workers in long-term care and residential facilities like group homes, nursing homes, and assisted living.

30% (55,000) of these paid caregivers are estimated to be already in BadgerCare. 74,000 workers have incomes above 100% and below 300% FPL. 30% have incomes above 300% FPL.

The 74,000 paid workers with incomes above 100% FPL and below 300% FPL are the population that would be eligible for the caregiver waiver with an additional 55,000 with incomes below 100% FPL who would be eligible to move from BadgerCare into the new caregiver waiver.

As of July, 2018, 158,014 parents and caretaker relatives were at or below 100% FPL and were enrolled in BadgerCare<sup>26</sup>. Of the remaining 390,986 family caregivers in Wisconsin, it is assumed that a significant number would not be eligible for the waiver because they have incomes above 300% FPL, have access to private insurance through an employer or spouse, or are not contributing the volume of care required. It is estimated that income, asset, and other waiver requirements would limit the number of family caregivers such that the waiver is targeting the low-income family caregiver population providing a volume of care that impacts their ability to work full or part time.

## How would this caregiver waiver be structured?

Wisconsin's current successful Medicaid Assistance Purchase Plan (MAPP) work incentive program provides a model that can be used to structure a caregiver waiver. Wis. Stats. 49.472 outlines the MAPP program.

The Caregiver waiver that we are proposing would include:

- Access to health care coverage and services provided under the Medicaid State Plan.
- Ability for participants to earn up to 300% FPL rather than 100%
- Ability for participants to retain \$15,000K in assets
- Ability to have an Independence account for workers to save earnings (up to \$15,000K) from employment (the amount in an independence account does not count towards the asset limit).
- Exclusions from income and assets (for example employer retirement contributions, exclude commuter vehicles from assets etc.)
- Sliding scale premium assessed to participants for Medicaid coverage that is tied to the individual's income
- In cases where a participant has access to private insurance, the waiver could pay private insurance premiums or deductibles if that is determined to be cheaper than providing Medicaid services.<sup>27</sup>

Like the MAPP program, Medicaid operates as the payor of last resort. In cases where there is private insurance Medicaid picks up the bills and services that private insurance does not.

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<sup>26</sup> Parents and caretaker relatives with income up to 100% of the FPL qualify for BadgerCare Plus. 2018 statistics 2019 Legislative Fiscal Bureau information paper 41

([http://docs.legis.wisconsin.gov/misc/lfb/informational\\_papers/january\\_2019/0041\\_medical\\_assistance\\_and\\_related\\_programs\\_informational\\_paper\\_41.pdf](http://docs.legis.wisconsin.gov/misc/lfb/informational_papers/january_2019/0041_medical_assistance_and_related_programs_informational_paper_41.pdf))

<sup>27</sup> MAPP does this for employers sponsored health insurance premiums, purchasing of individual coverage offered by an employer, and Medicare premiums. That provides real dollar benefits to workers without having them switch fully to the new Medicaid waiver.

Unlike the caregiving waivers proposal, MAPP participants (people with a primary diagnosis of mental health and people with disabilities) are generally higher cost Medicaid populations. Caregivers are part of the lower cost able bodied Medicaid population.