

# Wisconsin is Facing a Caregiver Crisis That Must be Addressed

- In a 2016 Survival Coalition of Wisconsin Disability Organizations survey 85% of the more than 500 respondents said they cannot find enough direct care workers to meet their daily needs.

- People with disabilities rely on unpaid (often family) caregivers to make up for gaps in paid support.

- 40% of the people receiving caregiving from unpaid caregivers are people with disabilities.<sup>1</sup>

- In Wisconsin, an estimated 549,000 informal caregivers are providing 588,000 million hours of care, valued at nearly \$6 billion dollars.<sup>2</sup>



- A 2016 AARP report found more than half of family caregivers reported a work-related strain, such as having to take unpaid time off, and the average caregiver spends nearly 20% of their income on out-of-pocket costs.<sup>3</sup>

- Wisconsin disability organizations hear from families across the state that they have often had to rearrange schedules and even leave their jobs to fill in caregiving gaps.

- When family caregivers work fewer hours or leave their jobs to do caregiving work, their reduced income may result in increasing reliance on public benefits (Medicaid, SNAP, Public Housing) to remain stable.

- Changes or cuts to public benefit programs that reduce the hours of paid caregiving help or result in fewer workers providing services, put additional strain on family members providing care. Leaving the workforce or placing the person in an expensive Medicaid funded institution could result in unintended consequences.

- Wisconsin parents of children with special health care needs are more than three times more likely to report having to quit a job or reduce their work hours because of child care issues than are parents of children with no special health care needs.<sup>4</sup>

## Changes and cuts to public benefit programs harm caregivers and impact people with disabilities Paid caregivers' low wages mean they are on public benefits too

- 50% of the nation's caregiver workforce<sup>5</sup> rely on government-funded and means-tested benefits<sup>6</sup> (like Medicaid, FoodShare, and Public Housing).

- 25% of Wisconsin's caregiving workforce is living below the federal poverty level. More than half rely on some form of public assistance, including SNAP (35%) and Medicaid (29%).<sup>7</sup>

- A 2017 national analysis<sup>8</sup> found most workers have two or three jobs and have an average wage of \$10.72 per hour (below the federal poverty level for a family of four). In Wisconsin, the average worker's wage is \$10.47 per hour.

- National turnover rates for these critical positions top 45% (range 18-76%). In Wisconsin, the annual turnover rate is more than 50% and can be as high as 67%.<sup>9</sup>



■ In Wisconsin, the workforce shortage is a crisis now, and the need for these workers is projected to increase by an additional 20,000 workers by 2026.<sup>10</sup>

■ Currently, 70% of personal care agencies are unable to staff all hours needed, and 93% of agencies find it difficult to fill job openings.<sup>11</sup>

■ When there is no direct care worker, Wisconsin individuals with disabilities describe these common impacts on their daily lives: missing employment or having to leave employment altogether (38%), missed medical appointments (24%), missed meals (26%), missed medications or treatments (26%), being confined to bed all day (17%), and potential changes to housing (22%).<sup>12</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.<sup>13</sup>

## RECOMMENDATIONS:

- Congress should direct the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services to ensure that states include sufficient Direct Support Professional wages and compensation packages in their rate-setting methodologies for long-term services and supports to people with intellectual and developmental disabilities.
- The U.S. Department of Health and Human Services should work with states to expand utilization of self-direction in long-term services and supports so that family, friends, and neighbors can be hired as Direct Support Professionals.
- Members of Congress should act to remove the institutional bias of federal programs and eliminate waiting lists.
- Congress should protect the integrity of the Home and Community-Based Services (HCBS) Rule.



<sup>1</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>2</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>3</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>4</sup> Healthiest Wisconsin 2020 Report.

<sup>5</sup> Professional home health, personal care, direct care, and other community-based care workers support people with disabilities and older adults in their homes and keep them out of expensive Medicaid-funded institutional settings.

<sup>6</sup> Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy. [https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)

<sup>7</sup> State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

<sup>8</sup> Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy. [https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)

<sup>9</sup> State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

<sup>10</sup> State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

<sup>11</sup> Wisconsin Personal Services Association.

Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

<sup>12</sup> Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

<sup>13</sup> Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>