

# Workforce shortage strains unpaid family caregiver's jobs, finances and time

## Who relies on unpaid caregivers?

**85%**

In Wisconsin, **85%** of individuals with disabilities who require direct care for some or all of their support cannot find paid help<sup>1</sup>.

■ People with disabilities rely on unpaid (often family) caregivers to make up for gaps in paid support; many rely on unpaid caregivers to provide some or a large proportion of the caregiving needed.

■ **An estimated 7.3 million people** with Intellectual or Developmental Disabilities (I/DD) live in the United States, with the majority living in their family home and receiving support from a family member.

**40%**

**40%** of the people receiving caregiving from unpaid caregivers are people with disabilities<sup>2</sup>.

## Who are Wisconsin's unpaid caregivers?

■ Nationally, **43.5 million adults** provide unpaid care to an adult or child<sup>3</sup>

**In Wisconsin, an estimated 549,000 informal caregivers are providing 588,000 million hours of care, valued at nearly \$6 billion dollars<sup>4</sup>.**

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

■ 25% of these unpaid family caregivers are over 60 years old; another 35% of caregivers are between ages 41-59<sup>5</sup>.

**60%**

In Wisconsin **60%** of people with intellectual and developmental disabilities (of a total of 54,202) live with their family.

## What is the impact of the caregiver workforce crisis on family caregivers?

■ BPDD hears from families across the state that they have often had to rearrange schedules and even leave their jobs to fill in caregiving gaps.

■ 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<sup>6</sup>.

■ **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>8</sup>.

■ A 2016 AARP report found the average caregiver **spends nearly 20% of their income** on out of pocket costs<sup>9</sup>.

**95%**

**95%** of working caregivers in the survey report that caregiving has impacted their employment.

**91%**

**91%** of working caregivers reported going in late.



**32%**

**32%** of working caregivers reported leaving the workforce entirely<sup>7</sup>.

**33%**

**33%** of working caregivers turned down a promotion.

**55%**

**55%** of working caregivers cut back on their hours.

# Family caregivers are impacted by changes and cuts to public benefit programs

- Many people with disabilities depend on Medicaid-funded programs (like Family Care and IRIS) and services (ForwardHealth card) to provide the personal care and other direct support services they need to keep them in the community and out of expensive institutions.
- 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.
- Unpaid family caregivers may be faced with leaving the workforce themselves or faced with sending the person with a disability to an expensive Medicaid funded institution, like a nursing home (these facilities are also experiencing a workforce crisis).
- 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.



## Recommendations



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.



**Improve family leave act policies** and work with private sector to create flexible options that can accommodate family caregivers and employer's needs.



**Charge the Centers for Medicare and Medicaid Services** with developing, testing and implementing provider payment reforms that motivate providers to support and engage family caregivers<sup>10</sup>.



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WITH DEVELOPMENTAL DISABILITIES

<sup>1</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>2</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>3</sup> National Alliance for Caregiving 2015 Report on Caregiving in the U.S.

<sup>4</sup> National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

<sup>5</sup> Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017. <http://stateofthestates.org>

<sup>6</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>7</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>8</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>9</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>10</sup> From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Crisis. 2018. <https://www.caregiving.org/publichealth/>