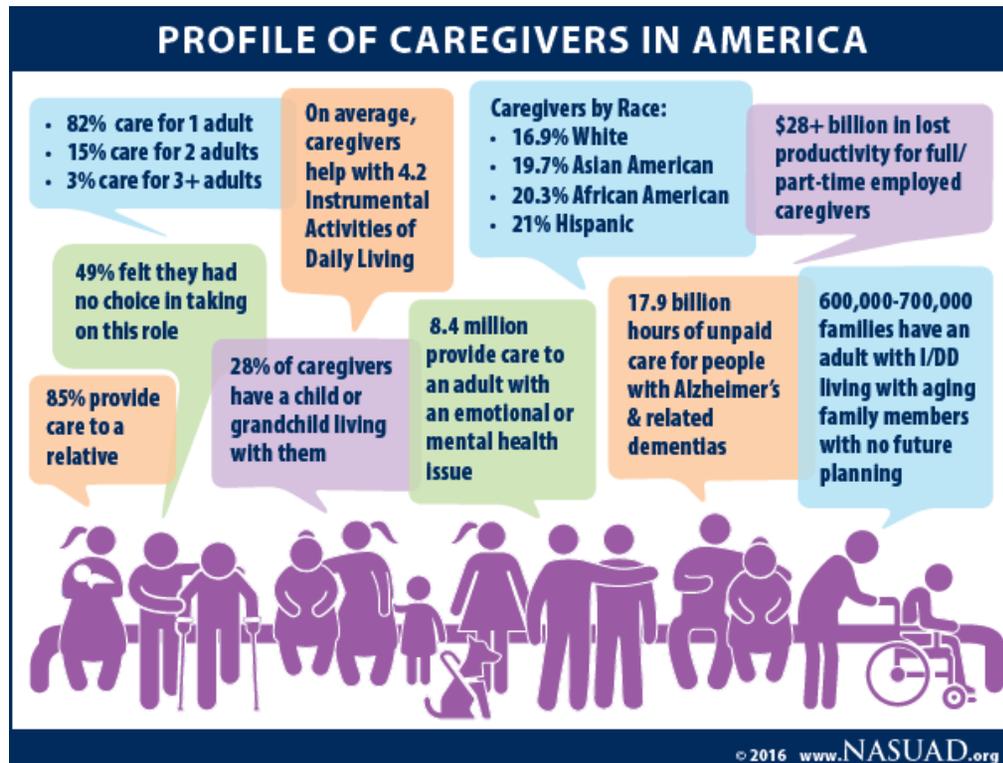




## The State of Family Caregiving in Wisconsin and Nationally



### Definitions

A **caregiver** - sometimes called an **informal caregiver** - is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.

**Formal caregivers/Direct Care Workers** are paid care providers providing care in one's home or in a care setting (day care, residential facility, long-term care facility). For the purposes of the present fact sheet, displayed statistics generally refer to caregivers of adults.

### Heavy Reliance on Family Caregivers in Wisconsin

In Wisconsin a shortage of formal caregivers or direct care workers has created a crisis for people with disabilities, older adults, and their families. The need for direct care workers is projected to increase by an additional 20,000 workers by 2026<sup>1</sup>. In 2016, a statewide survey of more than 500 people who rely on direct care services and their families found 85% did not have enough workers to cover all their shifts 60% said they get sick more often when they do not have enough staff<sup>2</sup>. Families are the backbone of the caregiving industry in Wisconsin, providing an estimated 80% of all care.

# Local Caregiver Feedback: The Family & Individual Needs for Disability Support Survey<sup>3</sup>

## How does caregiving affect employment?

- 92% caregivers reported going in late or leaving early because of caregiving responsibilities.
- 83% of respondents worked for pay outside of caregiving responsibilities in the 12 months prior to the survey.
- 71% of caregivers reported cutting back hours.
- 52% reported giving up working.
- 42% turned down a promotion.
- 36% did not take job opportunities that require moving out of state.
- 31% reported losing benefits.
- 21% received warnings about attendance or work performance.

## How is caregiving affecting parents?

- 98% report some level of stress. 50% are very or extremely stressed.
- 94% report challenges finding time for self-care.
- 91% report challenges balancing other family responsibilities.
- 83% report out-of-pocket expenses related to their family members needs of more than \$1,000 per year.
- 65% report challenges meeting their own health needs.

## What worries caregivers about the future for their family member?

- 93% worry the quality of support will go down if they are not there to advocate.
- 90% worry she/he will have to live somewhere she/he does not want to live.
- 86% worry she/he will not have enough friends and social activities.
- 85% worry she/he will have difficulty advocating for what she/he needs.
- 85% worry she/he will not be able to contribute to major life decisions or receive support for self-determination.
- 84% worry there is no one else to provide the support they are giving.
- 82% worry her/his health will deteriorate.
- 82% worry some form of abuse or neglect might occur.

1. State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>
2. Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>
3. Family & Individual Needs for Disability Support Report 2017 (Institute. on Community Integration and The Arc of the United States)