



## NEWS RELEASE

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Caregiving fact sheet attached

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### Wisconsin Siblings Thankful for Caregivers

This Thanksgiving week, Wisconsin siblings of people with disabilities are thankful for family and professional caregivers honoring them with the [WisconSibs Sibling's Choice Award](#). The three winners were each nominated by siblings of people with disabilities. **Harriet Redman, Appleton**, Executive Director of WisconSibs presented the awards. Winners were announced at an event sponsored by [Outagamie Caregiver Coalition](#) in Appleton.

**November is National Family Caregivers Month** and as the month closes and we celebrate Thanksgiving, it is a great time to honor the more than 53 million Americans who care for a family member, friend, or neighbor.

More than one in five Americans are providing care, without pay, to a family member, friend or neighbor, according to a 2020 survey by the National Alliance for Caregiving and AARP.

And more than 60 percent of caregivers, in addition to their caregiving responsibilities, also hold "real" jobs. Turns out caregivers have bills to pay, too.

Most people are surprised that eighty percent (80%) of Wisconsin residents who need long term care receive that support from family and friends at home, not in nursing homes or other facilities.

**Joel Lillo, Appleton**, received a *2021 WisconSibs Sibling's Choice Family Caregiver Award*. Joel cares for Jordan, a young man living with autism and was nominated by Jordan's sister, **Karenn Zills of West Allis**.

*“Dad has continued to keep Jordan’s needs in focus, even while managing the health crisis related to my mom’s cancer diagnosis. He continually advocates for getting Jordan items and services that will better his life. I truly had not appreciated everything that my dad has done for Jordan until I moved out and started working in the community with those living with mental health conditions. I see how families often step back, but my dad continues to step up to the everyday challenges of caring for Jordan and my mom.”*



**Johanna Wicklund, Green Bay, WI** nominated her parents for a 2021 WisconSibs Sibling’s Choice Family Caregiver Award.

*She writes in her nomination, “Judy and Robert provide daily personal care for my twin brothers. My parents who are in their 70s and 80s and provide round the clock TLC for my two amazing brothers. They seem tireless and grateful to care for the twins, when in fact they are exhausted. My mother went into high gear during the pandemic when all my brothers’ community support services stopped.*

*Before the pandemic, my parents would go on a date night (which sometimes was a simple grocery run) when they had respite care. Since the pandemic began, they haven’t had respite care, so their self-care currently includes things like doing a virtual yoga class and going for walks...and eating chocolate.”*

Professional care is often a loving family’s best resource for support that allows an individual with disabilities to live to their fullest potential or provide a break for family caregivers. This year, the winner of the WisconSibs Sibling’s Choice Professional Caregiver Award was **Baily Hubbard, Belleville, WI**.

**Ava Foley, an 18-year-old sibling from Belleville, Wisconsin** nominated her brother’s respite provider.

*“I believe Baily should be honored with the Siblings Choice Award because she is someone who Max is always excited to see and brightens his day. Every time she walks in the door my brother*

*has a huge smile and gives her the biggest hug. She is always pushing Max in a positive way to get out of his comfort zone and exposing him to new social situations. She also sticks up for him and educates others who aren't as knowledgeable about people with disabilities.*

*She is a very generous and selfless person who is always willing to help others."*

This is the 12<sup>th</sup> year for the award presentation sponsored by WisconSibs. Nominations are accepted from brothers or sisters of individuals with disabilities. Nominations recognize either family caregivers or professional individuals, including service providers, physicians, attorneys, financial professionals, legislators and advocates who serve and support individuals with disabilities. The awards help siblings acknowledge and honor a caregiver's contribution to the independence and quality of life of a person with a disability.

WisconSibs, Inc offers support to siblings of all ages in the Fox Valley and throughout Wisconsin through peer support programs, education and networking opportunities, social activities, future planning programs, and leadership development. For more information, go to <http://wisconsibs.org>

WisconSibs, Inc is a member of the [Wisconsin Family and Caregiver Support Alliance](#) (WFACSA) and the [Outagamie Caregiver Coalition](#) to address the needs of family caregivers, including siblings.

## RELATED FACTS:

### The State of Family Caregiving in Wisconsin

#### Definitions

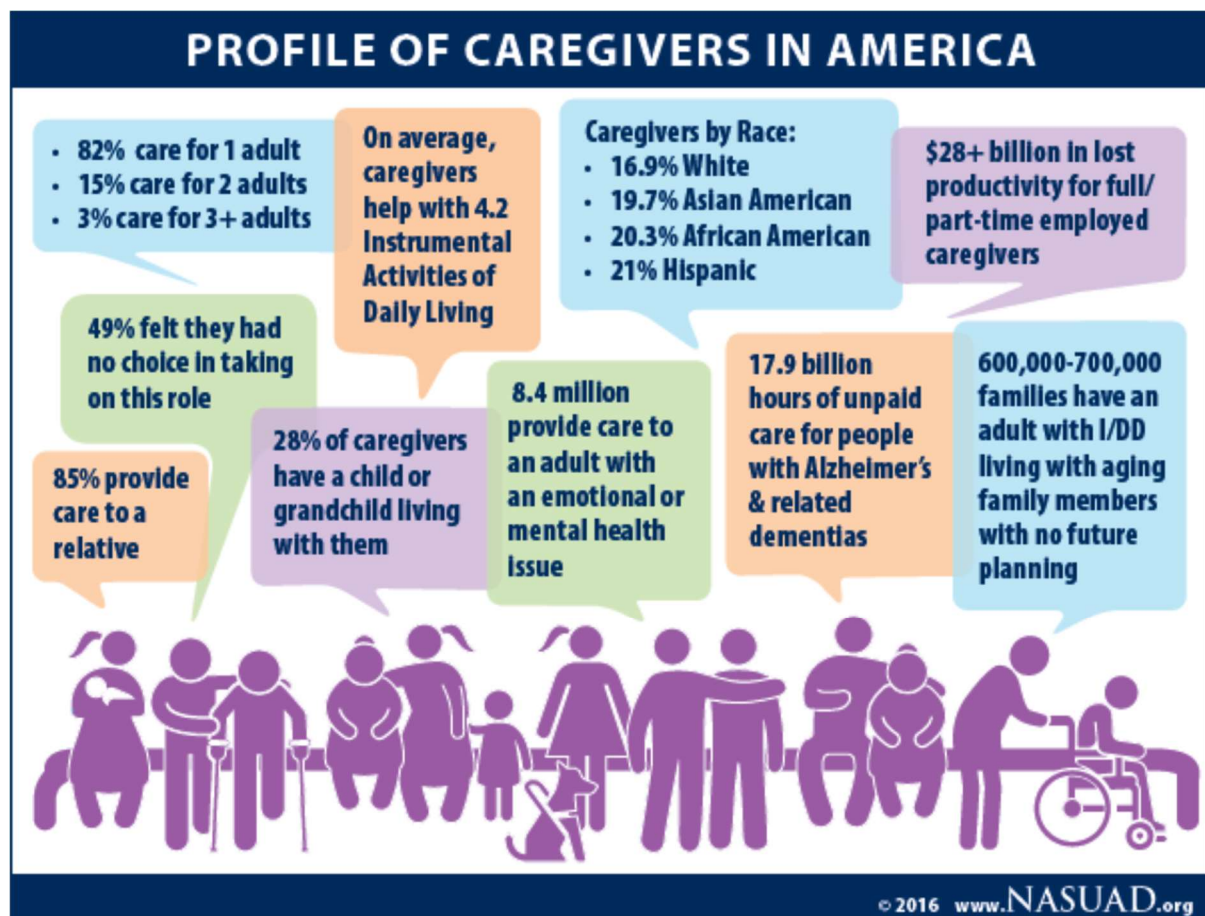
A **caregiver** - sometimes called an **informal caregiver** - is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.

**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)

<https://www.benefitspro.com/2021/2021/01/27/how-employers-can-flatten-the-caregivercrisis-curve/>

**[Do Caregivers Really Need a Month of Their Own?](#)**