



## Press Release: Frazzled and Fried, WI family caregivers living in crisis

### FOR IMMEDIATE RELEASE

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The relentless shortage of paid caregivers is negatively impacting family caregivers, Wisconsin's workforce, and the larger economy.

A statewide survey of almost five hundred family caregivers reveals family caregivers are providing 80% of the care for children and adults with disabilities and older adults, often caring for multiple people simultaneously.

The volume of care provided across the lifespan is incredible and unsustainable. More than 80% have already been caregiving almost ten years, another 30% for twenty years. 1 out of 10 report caregiving for more than thirty years.

"It's years. Decades. Huge proportions of the caregiver's total lifespan," said Beth Swedeen, Survival Coalition Co-Chair. "And family caregivers see no relief, most expecting they will have to continue this role for years."

Caregivers are working around the clock and there is no break. The survey confirms family caregivers are doing the work during most non-first shift hours, evening, overnight, and weekends. When paid staff doesn't show up or can't be found, family caregivers' step in, and they must do it a lot. One-third report scrambling to cover one or more daytime shifts that were scheduled to be provided by paid staff each week.

"If you are able to work, chances are you are caregiving the times you are not working, morning, evening and weekends," said Kit Kerschensteiner, Survival Coalition Co-Chair. "If you have caregiving responsibilities during the day, or are constantly stepping in for emergency caregiving duties, it gets hard to work."

More than 50% of caregivers spend more than half of the hours in a day, every day, caregiving. In a week, two-thirds report spending more than 40 hours—the equivalent of a full-time job—on caregiving duties. An additional one out of five report spending at least 20 hours—the equivalent of a part time job—on caregiving duties.

Two thirds of family caregivers report caregiving responsibilities have affected their ability to work. More than 40% have left the workforce entirely and another 20% have been forced to reduce their hours to part-time.



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“Wisconsin’s workforce is losing human capital because we haven’t valued the paid caregiving workforce that allows families to continue careers and jobs,” said Patti Becker, Survival Coalition Co-Chair. “The cost of doing nothing is exponentially high. Failing these workers, fails families, businesses, and Wisconsin’s economy.”

Families are the back up for paid help that isn’t there. There is no back up for family caregivers.

“Family caregivers are working in isolation as the only support for their loved ones. They know if they don’t do it, there is no one else,” said Beth Swedeen, Survival Coalition Co-Chair. “Many also know they can’t do it forever.”

Half of the family caregivers responding to the survey are unable to find anyone to hire and are providing all the care. Half say if they become unable to do the work, their loved one would be forced into an expensive Medicaid-funded institutional setting.

“We know people want to live independently. We need to invest in ways to keep people living in their homes or we will spend more on places people don’t want to be,” said Kit Kerschensteiner, Survival Coalition Co-Chair.

## Testimonials from people with disabilities and family caregivers

### Andy Thain (Thorp, Wisconsin)

*“I’m in my mid-30s and I have cerebral palsy. Since before I was a teenager, I have relied on in-home care to help with the activities of daily living that most people complete without thinking about it. If I had the support, I needed I could confidently live in my own apartment, have a full-time job and make plans to be more active in my community. As things stand now it is sometimes a struggle to even get the bare minimum of the support, I need even though I am fortunate enough to be able to rely on family members. The scariest part of this whole conversation is what will happen if my family is no longer able to support me?”*

### Stacey Ellingen (Oshkosh, Wisconsin)

*“I’m 37 years old, and have Athetoid Spastic Cerebral Palsy. I use a power wheelchair to get around, and I use an app on my phone to communicate. I need assistance with all of my basic needs such as toileting, showering, dressing, and eating. I rely on caregivers to assist me with these things every single day. When I can’t fill a shift or a worker calls in or doesn’t show, my parents have to come up to help me. This puts a huge burden on them. They live 45 minutes away and are retired. The last few months I’ve had more than 15 to 20 shifts open each month. I can’t even find people to interview.”*



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Anne Karch (Madison, WI)

*“The caregiver shortage in Wisconsin is a crisis that has profoundly changed the lives of people with disabilities and their families. In February of 2020, our daughter Rachel was supported with a live-in overnight caregiver and a team of week day caregivers. On the weekends we cared for her, having been able to do our jobs and volunteer work during the week knowing that she was well cared for. Today, two and a half years later, she has no live-in caregiver, so is stuck with her parents covering the overnights and several of the weekday shifts as well. My husband and I are exhausted, and I have had to cut back on most of my volunteer work because I cannot fulfill my obligations to others.”*