



For Immediate Release
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National Survey Demonstrates the Strain on Wisconsin Families Supporting Loved Ones with Disabilities

Madison, WI – Wisconsin families with a loved one with intellectual or developmental disabilities (I/DD) are feeling the pressures of caregiving now more than ever according to a new national survey released this week by The Arc. Nearly 100 Wisconsin families responded to the national Family & Individual Needs for Disability Supports or FINDS survey that gathered responses from 3,398 unpaid caregivers in 2017.

Ninety-five percent of all caregivers who responded said they were stressed out with nearly half describing themselves as very or extremely stressed. An estimated 7.3 million people with I/DD live in the United States, with the majority living in their family home and receiving support from a family member. In Wisconsin 60% of people with intellectual and developmental disabilities (of a total of 54,202) live with their family. In 2015 – 25% of these family caregivers were over 60 years old; another 35% of caregivers are between ages 41-59.¹

- Here are complete results of the 2017 FINDS survey: https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf
- Data tables for all survey questions: https://www.thearc.org/file/documents_finds/18_6_5-FINDS-Community-Report-Data-Tables.pdf

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.

“While there are a few bright spots in this survey such as more individuals with I/DD working in competitive employment, and fewer students in separate classrooms since the 2010 FINDS survey, caregivers are reporting greater unmet needs,” says Lisa Pugh, State Director for The Arc Wisconsin. “The caregiver shortage is hitting these families hard. They simply cannot find help.”

¹ Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017. <http://stateofthestates.org>

Wisconsin's Survival Coalition of Disability Organizations recently reported that 85% of people responding to a state survey could not find enough direct care workers to meet their daily needs. Nearly 9 in 10 (92%) of respondents in the national survey indicated they could not find workers.

The FINDS study also revealed that:

- Most caregivers (54%) reported that they did not have a plan for the future. Caregivers share a long list of concerns about what will happen to their loved one with disabilities when they are no longer able to support them.
- 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 said these obligations are affecting their abilities to address personal needs, tend to other family duties and stay afloat professionally.
- Almost all working caregivers in the survey (95%) report that caregiving has had some impact on their employment. (91% reported going in late; 55% cut back on their hours; 33% had turned down a promotion).
- Roughly nine of 10 FINDS caregivers reported some out-of-pocket expenses related to their family member's disability (92%). Two-thirds (67%) reported expenses of \$1,000 or more per year. One-third (36%) reported expenses totaling \$5,000 or more per year.

The Arc Wisconsin is part of the statewide [Wisconsin Family and Caregiver Support Alliance](http://wisconsinfamilyandcaregiver.org/alliance) that is working to address the needs of families providing care to people with disabilities and older adults. Learn more here: <http://wisconsinfamilyandcaregiver.org/alliance>

The Arc Wisconsin advocates for and serves people with Intellectual and Developmental Disabilities (I/DD), including Down syndrome, autism, Fetal Alcohol Spectrum Disorders, cerebral palsy and other diagnoses. The Arc Wisconsin has 15 local chapters and is connected to a network of more than 650 chapters across the country promoting and protecting the human rights of people with I/DD and actively supporting their full inclusion and participation in the community throughout their lifetimes and without regard to diagnosis.

Editor's Note: The Arc is not an acronym; always refer to us as The Arc, not The ARC and never ARC. The Arc should be considered as a title or a phrase.