

POLICY RESEARCH BRIEF

THE EMPLOYMENT IMPACTS OF BEING A FAMILY CAREGIVER

INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

Research Issue

Family members often play essential roles in the lives of people with intellectual and developmental disabilities, including providing medical, emotional, financial, and day-to-day support. Most individuals with disabilities live in their family home, whether or not they receive formal services. Family members who are the primary providers of support often have to make choices related to employment that can affect their long-term financial well-being, including leaving the workforce altogether.

Because people may be supporting their family members well into adulthood, this has important implications for the household's long-term and short-term financial health as well as the person leaving the workforce. The person who left the workforce loses income, benefits, and contributions to Social Security or retirement plans. This may lead to reductions in available financial resources for the household. Caregiving has primarily been the role of women, leaving them more than twice as likely to live in poverty as their peers who do not provide supports to a family member.

Study Background

The Family & Individual Needs for Disability Supports (FINDS) survey was conducted in 2023 with caregivers who were family members or friends of someone with IDD and provided support. The study did not include direct support professionals or other caregivers whose primary relationship with individuals with IDD was as a paid support person. The survey was completed by 3,118 people, including respondents from every state, the District of Columbia, Puerto Rico, and Guam.

POLICY FORUM



This Policy Forum for this issue of Policy Research Brief will be **Friday, February 16, 2024 at 1–2:30 p.m. Central on Zoom.** [Register here.](#)

The Policy Forum is a bi-monthly web-based presentation and facilitated discussion exploring

research published in the most recent *Policy Research Brief*. Please visit the website, z.umn.edu/icipolicyforum, for details and to view previous forums.

Policy Recommendations

Family caregivers indicated policy recommendations that would be most beneficial to them. These included government programs, policy changes, and employer-provided benefits:

Government Policy Changes

- An income tax credit or deduction for caregivers to offset the cost of care.
- A partially paid leave of absence from work for caregivers who are employed.
- A program where caregivers could be paid for at least some of the hours they provide support.

Employer-Provided Benefits

- An employee assistance program that provides case management services.

Help navigating the special education or adult services systems as a benefit employers provide.

Key Findings

Nine of ten caregivers reported at least one employment-related effect related to supporting their family members.

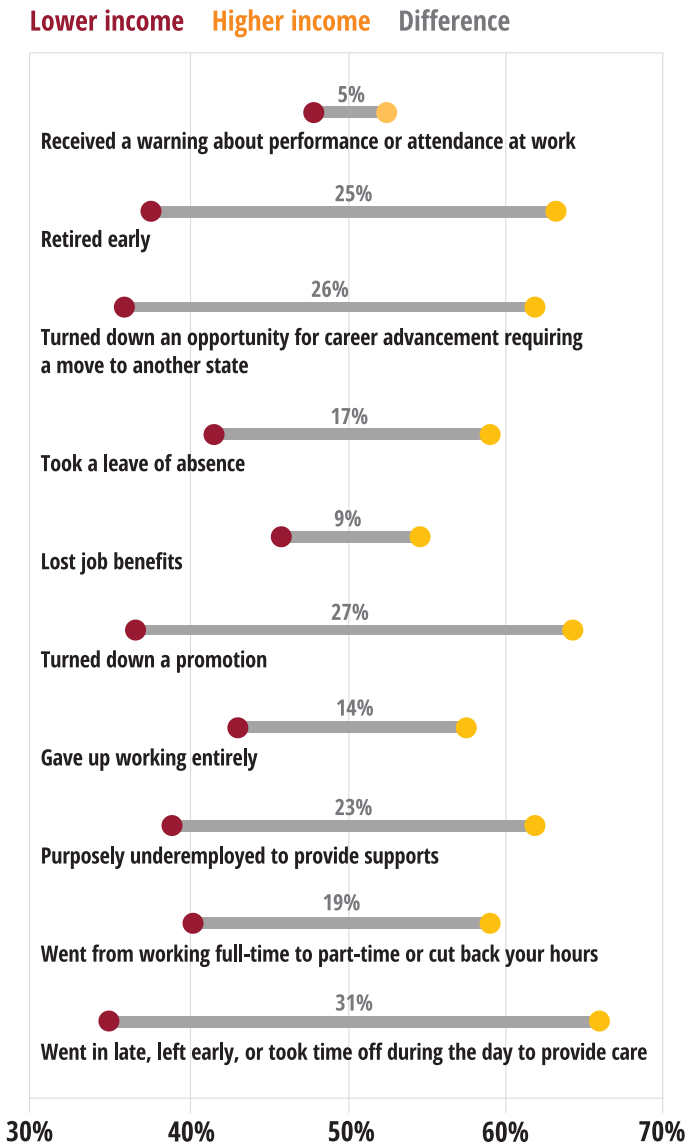
The economic effects are likely different for people who may lose wages if they are late for work or miss shifts than those for those with flexible work schedules.

- 77% Went in late, left early, or took time off during the day to provide care
- 55% Purposefully underemployed in order to provide supports
- 51% Went from working full-time to part-time or cut back your hours
- 41% Gave up working entirely
- 41% Took a leave of absence
- 34% Turned down a promotion
- 32% Turned down an opportunity for career advancement in different state
- 27% Lost any of your job benefits
- 26% Received a warning about performance or attendance at work
- 25% Retired early

Households with lower and higher household incomes experience different economic effects of caregiving.

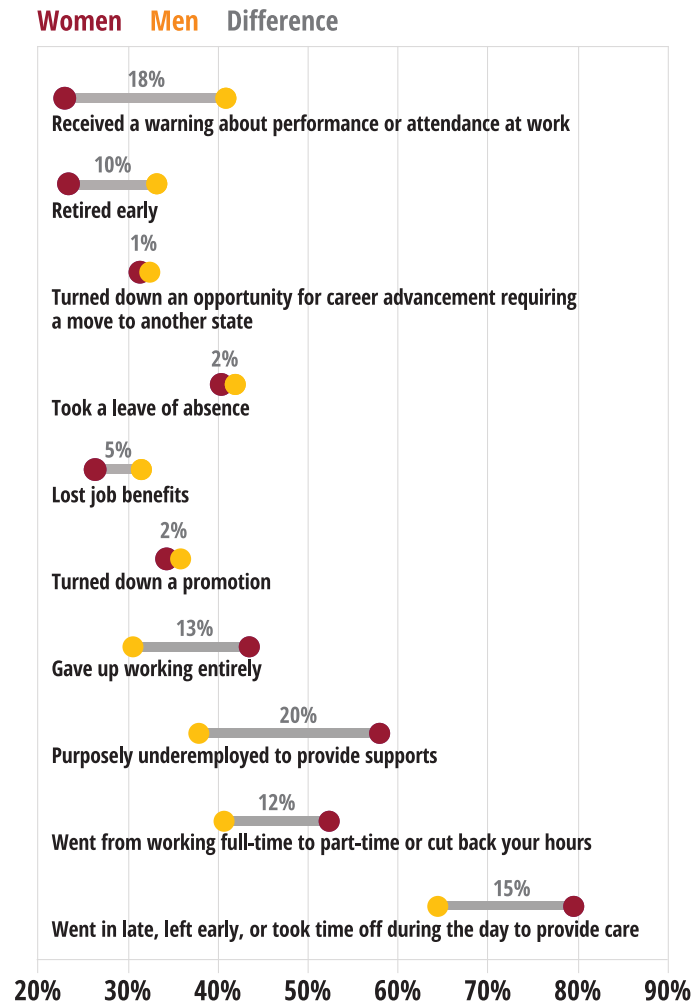
Households with lower incomes may have jobs that do not offer flexibility such as being able to come to work late. They may also have only one wage earner.

Higher income households often have two wage earners and may have the resources to leave the workforce, retire early, or cut back hours.



Economic outcomes related to caregiving vary by gender.

Women are more likely than men to be the primary support person for their family member with IDD. This may explain why they are likely to include work part time or stopping work altogether. Outcomes experienced by men are more likely tied directly to a specific job, such as changes in benefits or taking a leave of absence.



[Download a 2-page PDF of this issue of Policy Research Brief](#)

The University of Minnesota is an equal-opportunity educator and employer. This document is available in alternative formats upon request.

This project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services, Cooperative Agreement #90DNPA0001-05 with supplemental funding from the National Institutes on Disability, Independent Living and Rehabilitation Research Grant #90RT5019. Grantees undertaking projects under government sponsorship are encouraged to freely express their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDILRR policy.

The University of Minnesota stands on Miní Sóta Makhóche, the rightful homelands of the Dakhóta Oyáte. We recognize the U.S. did not uphold its end of these land treaties. It is the current and continued displacement of the Dakhóta Oyáte that allows the University to remain today.

Ongoing oppression and discrimination in the United States has led to significant trauma for many people of color, immigrants, people with disabilities, and other oppressed persons. At ICI, we affirm our commitment to address systemic racism, ableism and all other inequalities and forms of oppression to ensure inclusive communities.

Published November 2023

Guest Editor: Lynda Lahti Anderson

Editor-in-Chief: Julie Bershadsky

Graphic design: Connie Burkhart

Research cited:

Anderson, L., Sutcliffe, T. J., Pettingell, S. A., & Hewitt, A. (2018). *Employment outcomes and paid leave for caregivers of children with intellectual or developmental disabilities*. [Research Brief 9]. Family Support Research and Training Centre, University of Illinois at Chicago. <https://doi-org.ezp2.lib.umn.edu/10.13140/RG.2.2.14125.54248>