

# 2022 American Caregivers Study: The Facts on Disability & Special Needs Planning



The 2022 American Caregivers Study examines the emotional and financial concerns of caregivers providing support for a loved one with a disability or special needs. The study presents findings from a nationwide survey of 766 U.S. adults ages 18+ who have current caregiving responsibilities for a family member or loved one with special health needs or expect to in the future.

## KEY FINDINGS

**Caring for a loved one with a disability or special needs can be a rewarding experience — at the same time, it may involve tremendous personal sacrifice**



The average caregiver for a loved one with a disability has provided care for **9 years on average**, according to survey respondents.



of caregivers admit to being so focused on caregiving duties they **put off addressing their own needs**

77%



74%



A majority rely now or plan to rely in the future on a combination of **their own or another family member's work income** (77%) or **Government Benefits** (74%) to pay for care

## Most took on care responsibilities by default



took on their care responsibilities **by default**



**volunteered** for their care responsibilities



took on responsibilities after a **family discussion**

**And the bonds forming their care network are varied, going beyond family connections**

**40%**

of respondents identified as a **close family friend**

**39%**

of respondents said they were a **parent** of someone who has special health care needs





## The pandemic made things harder for caregivers—some worry the impact is long term

**40%** of caregivers expect **ongoing challenges** through the pandemic for securing resources, getting health care for loved ones, and even working as a family to provide care



**33%** permanently lost or reduced their source of **work income**



**67%** said they felt **more isolated** due to the pandemic—and **24%** fear this may be a long term situation.



On the plus side, **31%** expect **greater workplace flexibility** to continue

## Concerns among caregivers vary, with top concerns including:



**32%**

What happens when I am no longer able to provide care?



**26%**

Personal burnout



**26%**

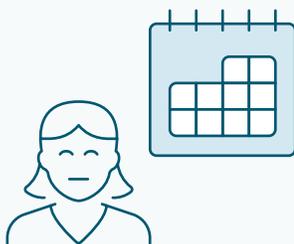
Concern about making the best decisions for our loved one



**22%**

The impact providing care is having on my health

## The call to care tends to come sooner, and last longer for women



- The average caregiver spends nearly **1 full work week** (34.4 average hours each week) providing care, with women reporting **30% more hours** than men
- On average, **women spend 3.6 years longer than men** providing care for their loved ones with special needs, according to survey respondents.
- Female caregivers who are also employed either full or part time spend an average **36.2 hours each week** on caregiving, **35% more hours** than men who are employed

## Caregivers who have acted found putting a plan in place was easier than expected

Creating a plan for...	Easier than expected	More difficult than expected
My own self-care	<b>39%</b>	<b>28%</b>
Communication plan for family members	<b>46%</b>	<b>24%</b>
Current expenses	<b>35%</b>	<b>29%</b>
Future expenses	<b>33%</b>	<b>35%</b>
Understanding government funds available	<b>33%</b>	<b>39%</b>
Joining local support community	<b>46%</b>	<b>24%</b>

# One practical solution to improve the caregiving situation is to actively seek out help from one's employer, and yet, only 54% of caregivers indicate they looked into their available workplace benefits.

Other top advice from experienced caregivers includes seeking assistance as well as:



Get others involved—  
don't go it alone



Prioritize—you can't  
handle everything



Learn all you can about  
your loved one's condition



Be an advocate for your  
loved one



Focus on self-care to keep  
yourself healthy



Find out what financial/  
other support services  
are available



## Planning Can Help—But the Best Time to Act Is Now

It can be overwhelming to sort through the different resources which may be available to provide continuous care for your loved one with special needs. We've organized a list of factors to consider when planning for your loved one into a [Special Needs Planning Guide](#), where you can find support assessing resources, and addressing benefits, financials, and legal needs. Additional resources can be found at our special hub for [caring for a loved one with special needs or disabilities](#).



## About the American Caregivers: Caring for a Loved One with Disabilities Study

This study presents findings from a nationwide survey of 766 U.S. adults ages 18+ who have current caregiving responsibilities for a family member or loved one with special health care needs or expect to in the future. Interviewing for this survey was conducted May 20-30, 2022 by Engine Insights, Inc., which is not affiliated with Fidelity Investments. The results of this survey may not be representative of all adults meeting the same criteria as those surveyed for this study.

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