

Caregivers with Disabilities: An Overlooked & Under-supported Caregiving Population

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Research Overview: Who are Caregivers with Disabilities? *Plain Language Version*

Words to know:

- **Alzheimer's:** a disease that affects memory, thinking, and behavior. People with Alzheimer's disease may struggle to remember important information or act differently than they usually do.
- **Behavioral Risk Factor Surveillance System (BRFSS):** a survey that talks about issues people have. 'Surveillance' means to watch over or keep track of something. The survey asks people about their health, like not having enough money for food.
- **Dementia:** a general term for medical conditions that affect someone's memory, thinking, and behavior. Alzheimer's is a type of dementia.
- **LGBTQ:** a short way of saying 'Lesbian, Gay, Bisexual, Trans, and Queer.'

What did the researchers do?

We looked at information about adults who care for family or friends. We call those adults a 'caregiver.' We got information about caregivers from a survey. A survey is a way to gather information from a group of people. The survey asks the same questions to learn about people's opinions and experiences. The survey we used is called the Behavioral Risk Factor Surveillance System (BRFSS).

We wanted to answer two main questions:

1. **Who are caregivers with disabilities?** How are their lives different from caregivers who do not have disabilities?
2. **How good is the health or wellbeing of caregivers with disabilities?** Do they have more health problems than caregivers without disabilities?

Why is this important?

Many people do not realize that people with disabilities are caregivers. People often think that disabled people only receive care and do not give it. But that is not true. The data from the Behavioral Risk Factor Surveillance System (BRFSS) survey shows that 36 percent of adult family caregivers in the United States have a disability. Disabled people are more likely to be family caregivers than people without disabilities.

Showing how caregiving affects people with disabilities can help lawmakers and program leaders create better laws and programs. Any program that is supposed to help family caregivers must be easy to use and open to people with all kinds of disabilities.

What did we find?

There are differences between caregivers with disabilities and caregivers without disabilities.

- Caregivers with disabilities are more likely to:



Be older (65 years old or older).



Be LGBTQ+.



Live in the countryside/rural areas.



Not be married.



Be American Indian/Alaska Native or Multiracial.



Not have children living at home.

- Caregivers with disabilities also have fewer resources. This means they:



Make less money.



Have less education.



Are less likely to own a home or have a job.

What did we find? (continued)



Caregivers with disabilities are more likely to have public health insurance, like Medicaid or Medicare. Or, they have no insurance at all.



Caregivers with disabilities are more likely to provide care to a partner, sibling, grandchild, or friend. They often help someone with a long-term illness, mental illness, or memory loss. This includes things like Alzheimer's disease, dementia, or another cognitive disability.



Caregivers with disabilities also provide more intense care. This means they

Have been caregiving for a longer time.

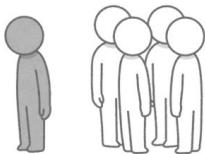
Work longer hours each week.

More likely to help with personal care and household tasks.

Caregivers with disabilities have worse social and health outcomes.



They have trouble meeting basic needs. Caregivers with disabilities have a hard time paying for housing. Many do not have enough money for food. They are more likely to lose their job. They have a hard time getting around (transportation).



Caregivers with disabilities do not get enough social or emotional support. They are more likely to feel stressed, lonely, and isolated from others.



They face other health risks. Caregivers with disabilities do not get enough sleep. They have more long-term health conditions and worse mental health. And, they often cannot get the health care they need.

Introduction

There are more than
63 million
family caregivers living
in the United States.
That's 1 in 4 adults.



There are more than 63 million family caregivers (one in four U.S. adults) who support people with disabilities and chronic health conditions living in the United States today.¹ Caregivers include parents, grandparents, spouses and partners, children, siblings, friends, and neighbors. The number of caregivers has increased substantially over the last decade, reflecting the growing importance of family caregivers in a national context where formal long-term services and supports systems are fragmented, challenging to access, and prone to funding shortfalls.

Though public awareness surrounding the importance of supporting family caregivers has increased in recent years, it is still often assumed that caregiving relationships operate in one direction, wherein a person without disabilities provides support to someone with a disability or chronic health condition. In this way, people with disabilities are framed solely as recipients of care and are rarely thought of as providers of care. Recent data from the Behavioral Risk Factor Surveillance System (BRFSS) challenges this assumption.

An estimated 36% of adult family caregivers in the U.S. are disabled themselves. In fact, people with disabilities are more likely to be family caregivers than people without disabilities. Specifically, 24% of disabled adults are family caregivers, compared with 19% of nondisabled adults.

Over a third of adult family caregivers are disabled themselves.

~36%

Despite disabled caregivers making up over a third of the caregiving population in the United States, we do not know much about their caregiving experiences or health and well-being, and current efforts to support family caregivers have not accounted for the needs of caregivers with disabilities. For example, the National Strategy to Support Family Caregivers, which was developed in part by the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council, recognizes that certain populations are disproportionately affected by caregiving issues.² One of the goals of the National Strategy is to expand data, research, and evidence-based practices to support family caregivers. The Strategy discusses the need to prioritize outreach efforts and programs that uplift caregiving populations who historically have been excluded from such efforts. However, caregivers with disabilities have not been recognized as one of these populations. Thus, the purpose of this brief is to shed greater light on this largely unrecognized subpopulation of caregivers.

In this brief, we present data from the 2021-2023 BRFSS. These data provide essential context that can inform policy and advocacy efforts to support family caregivers with disabilities. We first describe who disabled caregivers are, highlighting how their demographics and caregiving experiences differ from nondisabled caregivers. We then examine social determinants of health, social and emotional well-being, and other

health-related outcomes at the intersection of disability and caregiver status. Findings show that disabled caregivers experience heightened levels of social, economic, and health disadvantage. We then call attention to policy recommendations based on the findings. Current and future programs to support family caregivers must be accessible, inclusive, and responsive to the needs of caregivers with disabilities.



A Note on Terminology

We use the terms ‘caregiver with disabilities’ and ‘disabled caregivers’ interchangeably in this report to reflect the varied preferences of disabled individuals [and of members of different disability communities], some of whom prefer person-first language [and find it more respectful of their full humanity] while others prefer identity-first language [for similar reasons].³⁻⁴ There are longstanding advocacy movements on both sides of the disability language debate that we acknowledge and affirm. For this reason, and because we discuss disability as a general category rather than as separate subpopulations, we have chosen to use person-first and identity-first language interchangeably.

We also recognize that there are diverse perspectives on terminology related to “caregiving.”⁵ These terms can imply a one-directional, medicalized, paternalistic, or dependent relationship, and many people with disabilities express that they do not need to be taken care of, but rather they need support to live independently.⁶ Other disabled people have reclaimed the term “care,”

recognizing the importance of care work as an act of survival and resistance to ableist systems.⁷ In this brief, we use terminology related to care and caregiving to refer to supports provided by family members or friends rather than paid support workers, such as direct support professionals hired through agencies. The term “caregiver” also helps bridge policy spaces, aging networks, and the disability community. We understand care to be a mutual process and practice of interdependence.

Additionally, some of the disability language used in BRFSS (e.g., impairment, long-term illness, infirmity/frailty) does not align with the language used among the disability community and may be offensive.⁸ For example, there are questions that use deficit-based language or that conflate disability with health or illness. This brief seeks to avoid reinforcing deficit-based language or conflating disability with health or illness and instead highlight the diverse roles and experiences of people with disabilities who provide support or assistance to others.

Methods

Where does the data come from?

We used data from the 2021-2023 Behavioral Risk Factor Surveillance System (BRFSS).⁹ BRFSS is a telephone-based health survey coordinated by the Centers for Disease Control and Prevention. States and territories collect BRFSS data on an annual basis. The sample is representative of adults ages 18 years and older in the United States. The BRFSS questionnaire asks about demographic information, disability status, health risk behaviors, and other health or healthcare experiences. States also decide whether to administer a

variety of optional modules that include questions or topics beyond those covered in the core survey. This brief uses data from three state-optional modules: Caregiver, Social Determinants, and Sexual Orientation. We combined multiple years of BRFSS data (2021-2023) to have a larger sample of states that administered the Caregiver module. The CDC BRFSS website describes which states conducted the optional modules by category in each year.¹⁰

How does BRFSS measure disability and caregiver status?

BRFSS includes the standard six questions from the American Community Survey to determine if someone has a disability. Someone is considered disabled if they said yes to one or more of the six disability questions:

1. Are you deaf or do you have serious difficulty hearing?
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

4. Do you have serious difficulty walking or climbing stairs?
5. Do you have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

The Caregiver module identifies whether someone is a caregiver using the following question: "During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?"



How did we analyze the data?

We first compared different personal and household characteristics for disabled caregivers and nondisabled caregivers. These characteristics include:

- Race/ethnicity
- Sex assigned at birth
- Sexual orientation and gender identity
- Rurality
- Age group
- Marital status
- Children in the household
- Homeownership
- Labor force participation
- Educational attainment
- Household income
- Health insurance coverage

We then compared caregiving contexts for disabled caregivers and nondisabled caregivers, including information about the person that the caregiver supports (referred to as the “care recipient”) and information about the intensity of caregiving and types of assistance they provide. This includes the questions below:

- What is the relationship of the person being supported to the caregiver?
- What is the primary disability or health condition of the person the caregiver supports?
- Does the person the caregiver supports also have Alzheimer’s disease, dementia, or another cognitive disability?
- How long has the caregiver been providing support?
- On average, how many hours per week does the caregiver provide support?
- In the past 30 days, has the caregiver supported the person with managing personal care, such as giving medications, feeding, dressing, or bathing?
- In the past 30 days, has the caregiver supported the person with managing household tasks, such as cleaning, managing money, or preparing meals?

Next, we explored social and health outcomes at the intersection of disability and caregiver status. Specifically, we ran logistic regression models that allowed us to compare social determinants of health, social and emotional well-being, and other health-related outcomes across four groups: nondisabled non-caregivers, nondisabled caregivers, disabled non-caregivers, and disabled caregivers. The specific outcomes we looked at include:

Social Determinants of Health

- Housing insecurity
- Food insecurity
- Job insecurity
- Transportation barriers

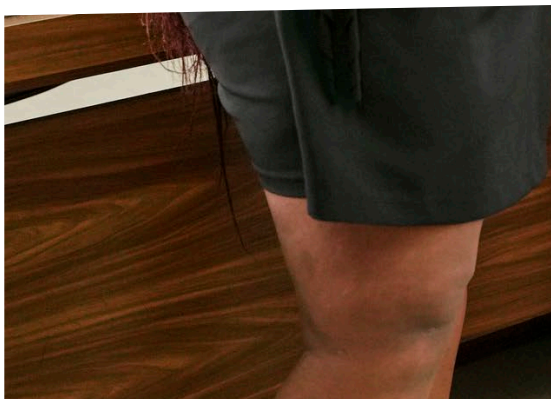
Social and Emotional Well-being

- Lack of social and emotional support
- Stress
- Loneliness
- Social isolation

Other Health-related Outcomes

- Not enough sleep
- Poor mental health
- Chronic health conditions
- Barriers to healthcare access

In all the models, we adjusted for various personal and household characteristics, including sex assigned at birth, age, marital status, parenthood, education, employment, health insurance coverage, and year. All our analyses of the BRFSS data were weighted to be representative of adults in the United States.



Who are disabled caregivers?

The 2021-2023 BRFSS data show that disabled caregivers make up about 36% of the adult family caregiver population. Disabled adults are also 1.3 times more likely to be caregivers than nondisabled adults. Approximately 24% of disabled adults are caregivers, whereas 19% of nondisabled adults are caregivers. There are many significant differences in the personal or household characteristics and caregiving contexts of caregivers with and without disabilities.

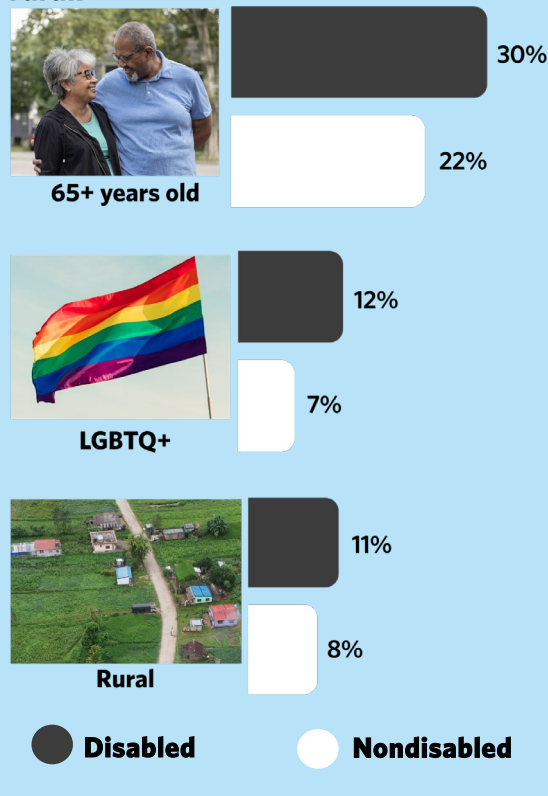
Personal & Household Characteristics

Caregivers with disabilities differ from caregivers without disabilities in terms of race/ethnicity, age, gender and sexual orientation, rurality, marital status, parenthood, socioeconomic factors, and health insurance coverage (Table 1).

Examining racial and ethnic differences indicates that **disabled caregivers are more likely than nondisabled caregivers to be American Indian or Alaska Native non-Hispanic (NH) or Multiracial NH and less likely to be Asian NH.** The percentage of caregivers who are White NH, Black NH, Hispanic/Latine, Native Hawaiian/Pacific Islander NH, or another race NH is similar across disability status.

Specifically, 30% of disabled caregivers

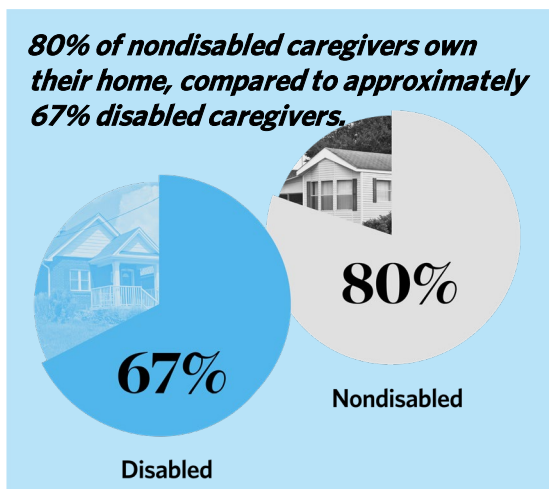
Compared with nondisabled caregivers, disabled caregivers are more likely to be older, LGBTQ+, and rural.



versus 22% of nondisabled caregivers are age 65 years or older. Disabled caregivers are nearly twice as likely to be LGBTQ+ than nondisabled caregivers (12% vs. 7%, respectively). Caregivers with disabilities are also more likely to live in a rural community (11%) than caregivers without disabilities (8%). Further, disabled caregivers are less likely than their nondisabled counterparts to be currently married or coupled and less likely to have children in the household.

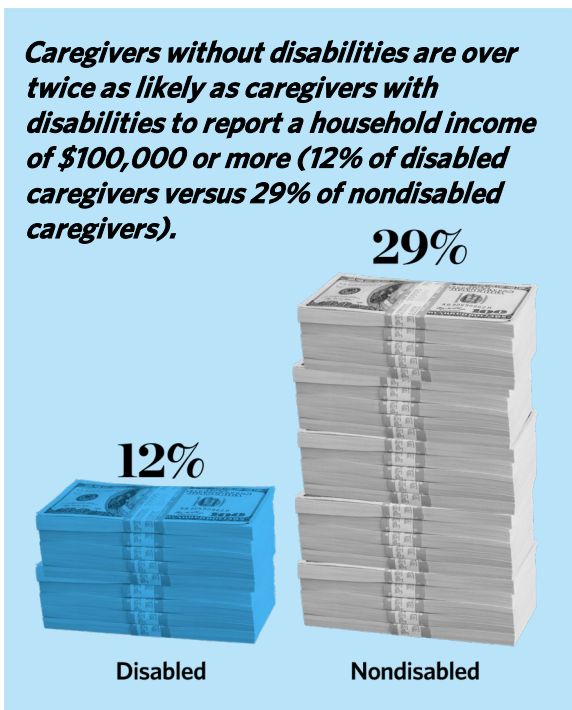
There are also key socioeconomic differences between caregivers with and without disabilities, with disabled caregivers reporting lower rates of homeownership, employment, education, and income.

Around two-thirds (67%) of disabled caregivers own their home versus 80% of nondisabled caregivers. Caregivers with disabilities are much more likely than caregivers without disabilities to be out of the labor force, whether they report being unable to work (17%) or are out of the labor force for other reasons (36%). Among disabled caregivers, 38% are employed and 9% are unemployed but seeking work. In comparison, 62% of nondisabled caregivers are employed and 6% are unemployed but seeking work.



In terms of educational attainment, nearly half of caregivers with disabilities (47%) have a high school degree or less, and only 18% have a college degree or more. Among caregivers without disabilities, just under a third (32%) have a high school degree or less, and 34% have a college degree or more.

Household income differs significantly, with 31% of disabled caregivers versus 12% of nondisabled caregivers reporting household income less than \$25,000.



Health insurance coverage also differs between caregivers with and without disabilities, with disabled caregivers being more likely to have public health insurance or no coverage.

Around a third (32%) of disabled caregivers versus 58% of nondisabled caregivers have private health insurance coverage, such as a plan through an employer or the Marketplace. Compared with 35% of nondisabled caregivers, 59% of disabled caregivers have public health insurance coverage, such as Medicare, Medicaid, TRICARE, or other government sponsored program. Further, 9% of disabled caregivers versus 7% of nondisabled caregivers are uninsured.

Caregiving Context

There are many ways in which caregiving contexts differ for caregivers with and without disabilities, including information about the person the caregiver supports and the intensity of caregiving responsibilities (Table 2).

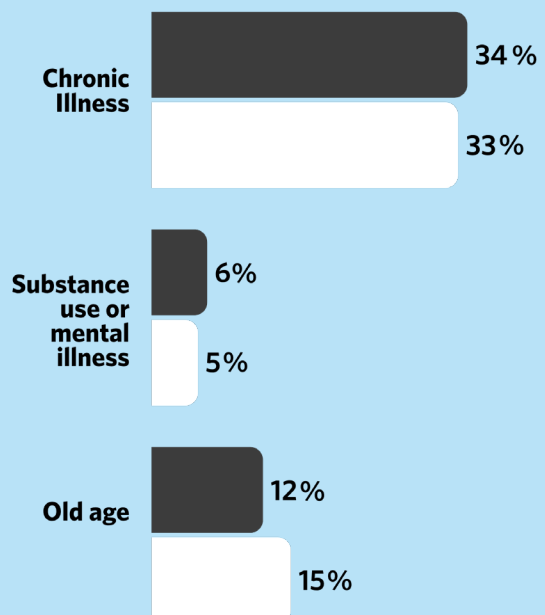
Examining the type of relationship between the caregiver and the person they support reveals that **disabled caregivers are more likely than nondisabled caregivers to provide support to a spouse or live-in partner, sibling, grandchild, or non-relative/family friend.** Regardless of disability, the most common caregiving relationship is adults supporting their aging parents. 30% of disabled caregivers and 40% of nondisabled caregivers are supporting a parent.



There are some differences between caregivers with and without disabilities in terms of the primary disability or health condition of the person the caregiver is supporting. Disabled caregivers are more likely than nondisabled caregivers to support

someone whose main disability or health condition is a chronic illness (34% vs. 33%, respectively) or mental illness or substance use disorder (6% vs. 5%, respectively). Disabled caregivers are less likely than nondisabled caregivers to support someone whose main disability or health condition is old age (12% vs. 15%, respectively). The percentage of caregivers who are supporting someone whose main disability is Alzheimer's disease, dementia, or other cognitive disability, a developmental disability, or an injury or other condition is similar across disability status. However, disabled caregivers are more likely than nondisabled caregivers to support someone who also has Alzheimer's disease, dementia, or other cognitive disability in addition to another primary disability (16% vs. 13%, respectively).

Disabled caregivers are more likely to provide care to people with chronic illnesses rather than to those whose disability is from old age.



Caregivers with disabilities provide higher intensity caregiving than caregivers without disabilities.

Compared with nondisabled caregivers, disabled caregivers provide support for a longer duration and more hours per week. For example, disabled caregivers are more likely to have been providing support for more than 5 years (35%) than nondisabled caregivers (30%). They are also more likely to be full-time caregivers, with 26% of disabled

caregivers providing support for 40 hours or more per week, on average, compared with 19% of nondisabled caregivers. The types of caregiving responsibilities also differ between caregivers with and without disabilities. Caregivers with disabilities are more likely than caregivers without disabilities to be supporting individuals with personal care, such as bathing and dressing, or household tasks, such as cleaning or meal preparation.

Caregivers with disabilities generally provide care longer than their nondisabled peers. 35% of disabled caregivers have been providing support for more than 5 years.

Disabled Caregivers



35%

Nondisabled Caregivers



30%

How do social and health outcomes vary by disability and caregiver status?

We found evidence of social and health disparities at the intersection of disability and caregiver status across a variety of outcomes, including social determinants of health, social and emotional well-being, and other health-related outcomes. Findings reveal a similar stepwise pattern across all outcomes; nondisabled non-caregivers have the most positive outcomes, followed by nondisabled caregivers, then disabled non-caregivers, and then disabled caregivers have the most adverse outcomes.

This implies that there are compounded impacts of disability and caregiving that negatively impact social and health outcomes. Primarily resulting from structural ableism, being disabled is associated with more negative outcomes. Similarly, due to insufficient caregiver supports, being a caregiver is associated with more negative outcomes. When we combine disability and caregiver status, we find that caregivers with disabilities have the highest risks of negative social and health outcomes.

Social Determinants of Health

Compared with nondisabled caregivers and non-caregivers with and without disabilities, **disabled caregivers experience greater housing, food, and job insecurity and transportation barriers** (Figure 1).

About 18% of disabled caregivers report being unable to pay their mortgage, rent, or utility bills in the past year. This is compared with housing insecurity estimates of 13% for disabled non-caregivers, 7% for nondisabled caregivers, and 5% for nondisabled non-caregivers.

About 8% of disabled caregivers report that they ran out of food in the past year and couldn't afford more, whereas 5% of disabled non-caregivers, 3% of nondisabled caregivers, and 2% of nondisabled non-caregivers had this experience of food insecurity.

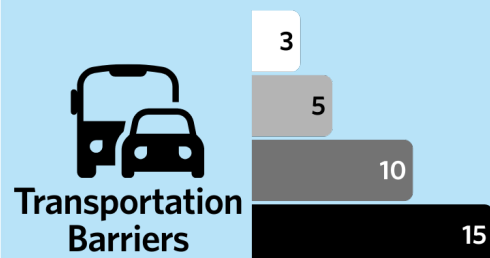
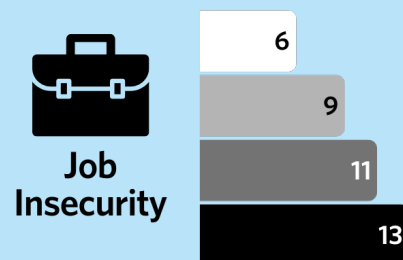
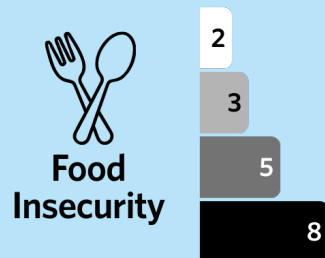
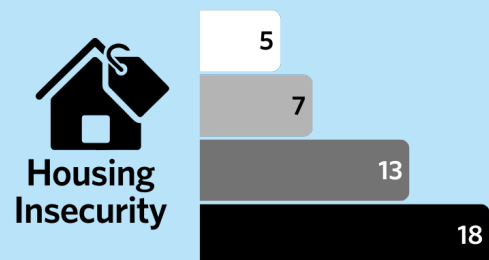
In terms of job insecurity, 13% of disabled caregivers, 11% of disabled non-caregivers, 9% of nondisabled caregivers, and 6% of nondisabled non-caregivers lost their job or had their hours reduced in the past year.

Disabled caregivers are also more likely to experience transportation barriers. Specifically, 15% of disabled caregivers report that a lack of reliable transportation kept them from medical appointments, meetings, work, or getting the things they needed for daily living in the past year. This is compared with 10% of disabled non-caregivers, 5% of nondisabled caregivers, and 3% of nondisabled non-caregivers.

Figure 1: Comparing social determinants of health by disability and caregiver status

Bar chart = % of...

- Nondisabled Non-caregivers
- Nondisabled Caregivers
- Disabled Non-caregivers
- Disabled Caregivers



Social and Emotional Well-being

Compared with nondisabled caregivers and non-caregivers with and without disabilities, **disabled caregivers experience lower well-being, including a lack of social and emotional support and higher stress, loneliness, and social isolation** (Figure 2).

Nearly half (46%) of disabled caregivers reported not usually getting the social and emotional support they needed in the past year. In comparison, we observe inadequate social and emotional support among 32% of disabled non-caregivers, 25% of nondisabled caregivers, and 17% of nondisabled non-caregivers.

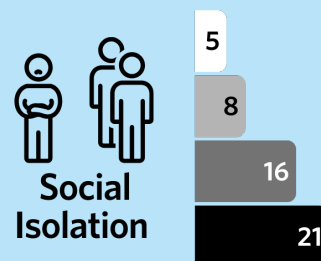
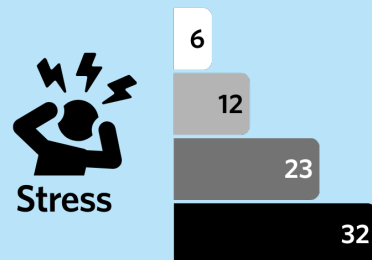
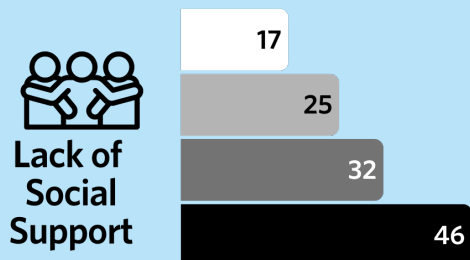
About 32% of disabled caregivers reported always or usually feeling stressed (tense restless nervous, anxious, or unable to sleep) in the past 30 days. In comparison, 23% of disabled non-caregivers, 12% of nondisabled non-caregivers, and 6% of nondisabled caregivers experienced chronic stress.

Disabled caregivers also experience heightened loneliness and social isolation, with 12% reporting they usually or always felt lonely and 21% usually or always felt isolated from others. In comparison, frequent loneliness was reported among 10% of disabled non-caregivers, 3% of nondisabled caregivers, and 3% of nondisabled non-caregivers. Frequent social isolation was reported among 16% of disabled non-caregivers, 8% of nondisabled caregivers, and 5% of nondisabled non-caregivers.

Figure 2: Comparing social and emotional well-being by disability and caregiver status

Bar chart = % of...

- Nondisabled Non-caregivers
- Nondisabled Caregivers
- Disabled Non-caregivers
- Disabled Caregivers



Other Health Outcomes

Compared with nondisabled caregivers and non-caregivers with and without disabilities, **disabled caregivers experience worse sleep, mental health, chronic health conditions, and healthcare access** (Figure 3).

Half of caregivers with disabilities report not regularly getting at least seven hours of sleep daily. In comparison, 42% of disabled non-caregivers, 35% of nondisabled caregivers, and 31% of nondisabled non-caregivers report not getting enough sleep.

A third of disabled caregivers have poor mental health, meaning their mental health was not good for 14 or more of the past 30 days. About 26% of disabled non-caregivers, 11% of nondisabled caregivers, and 7% of nondisabled non-caregivers report poor mental health.

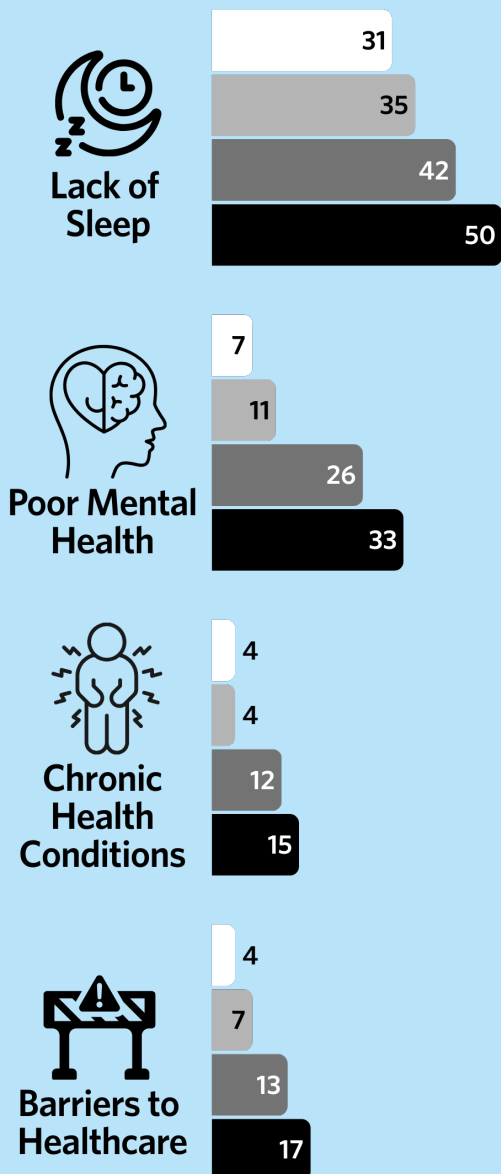
Caregivers with disabilities are also more likely to experience multiple chronic health conditions. Specifically, 15% of disabled caregivers, 12% of disabled non-caregivers, 4% of nondisabled caregivers, and 4% of nondisabled non-caregivers report four or more of the following: arthritis, asthma, cancer, COPD, depression, diabetes, heart disease, kidney disease, or stroke.

About 17% of disabled caregivers were unable to afford to see a doctor when they needed to in the past year. We also observed these barriers to healthcare access among 13% of disabled non-caregivers, 7% of nondisabled caregivers, and 4% of nondisabled non-caregivers.

Figure 3: Comparing other health outcomes by disability and caregiver status

Bar chart = % of...

- Nondisabled Non-caregivers
- Nondisabled Caregivers
- Disabled Non-caregivers
- Disabled Caregivers



Policy Implications

The Recognize, Assist, Include, Support, and Engage (RAISE) Act directed the establishment of the RAISE Family Caregiving Advisory. This Council, working with the Advisory Council to Support Grandparents Raising Grandchildren, developed the first ever National Strategy to Support Family Caregivers in 2022. The strategy sets a roadmap for federal, state, and local action across public and private sectors. It currently includes five overarching goals related to family caregiving:

- 1) Increase awareness of and outreach;
- 2) Advance partnerships and engagement with family caregivers;
- 3) Strengthen services and supports;
- 4) Ensure financial and workplace security; and
- 5) Expand data, research, and evidence-based practices.

As the National Strategy is implemented it is important to recognize caregivers with disabilities. This is a substantial caregiving subpopulation representing over a third (36%) of all caregivers. Similar to other caregiver populations, many caregivers with disabilities may not identify as caregivers themselves. Moreover, health and social service providers may not recognize the reciprocal nature of caregiving between individuals providing care and individuals receiving care. This has significant implications for identifying

and supporting caregivers with disabilities through outreach, caregiving assessments, and navigation programs. Caregivers with disabilities are more likely to rely on public health insurance, such as Medicare and Medicaid. Person-centered planning and other care planning within these programs provide opportunities to identify caregivers with disabilities, assess their needs, and assist them with caregiving services and supports.

Interventions, programs, and supports must also ensure they are fully inclusive and accessible to caregivers with a range of disabilities. Caregivers with disabilities are more likely to be older (65+), LGBTQ+, rural, American Indian/Alaska Native, and Multiracial. Programs such as the National Family Caregiver Support Program and Title VI Native American Caregiver Support Services that are part of the Older Americans Act are likely serving many caregivers with disabilities. Moreover, caregivers with disabilities are more likely to be providing high intensity caregiving (i.e., longer hours of care and duration), elevating their risks for negative health and social consequences of caregiving and needs for supports such as respite, training, and peer support. Existing evidence-based interventions might need to be adapted to make them more accessible for caregivers with disabilities.

Caregivers with disabilities are also more likely to be low-income and less likely to be employed. This has implications for financial security and workplace supports, such as financial supports through paid leave, caregiver

tax credits, and opportunities to be paid caregivers through self-direction programs. The extent to which supports reach low-income caregivers with disabilities and potential impacts on maintaining eligibility for disability supports need to be considered. For example, paying caregivers with disabilities might need additional financial planning to ensure payment through self-direction programs or stipends does not jeopardize their eligibility for Medicaid or other low-income programs.

The Administration for Community Living (ACL) is well situated to bridge

aging and disability networks to advance inclusion of caregivers with disabilities throughout implementation of the National Strategy.¹¹

ACL launched the National Caregiver Support Collaborative, which consists of technical assistance centers that align with the goals of the National Strategy.¹² These technical assistance centers are primarily focused on enhancing the aging network. However, ACL could build on these centers by better bridging with disability networks and organizations, such as the Developmental Disabilities Network and Centers for Independent Living.



Conclusion

This brief highlights characteristics of caregivers with disabilities, a sizeable but often unrecognized subpopulation of family caregivers. In addition, it highlights the intersectional nature of disability and caregiving. There are compound impacts of disability and caregiving that negatively impact social determinants of health, social and emotional well-being, and health-related outcomes. In general, we see negative impacts in these areas associated with being a person with disabilities. We also see negative impacts in these areas associated with being a caregiver. Combined, caregivers with disabilities are at the highest risk of experiencing negative outcomes. Caregivers with disabilities face the

highest levels of housing insecurity, food insecurity, and transportation barriers. They are least likely to receive social and emotional support and report the highest levels of social isolation and loneliness. They experience high levels of multiple chronic conditions and report the greatest levels of stress, difficulty sleeping, poor mental health, and unmet healthcare needs. To our knowledge, this is one of the first analyses to highlight characteristics and outcomes of this subpopulation. Additional research is needed to more fully understand the compound impacts of disability and caregiving for this subpopulation and how best to tailor interventions, policies, and practices to best support caregivers with disabilities.



Table 1. Comparing characteristics of disabled caregivers and nondisabled caregivers

	Disabled Caregivers (%)	Nondisabled Caregivers (%)
Race/ethnicity		
White, non-Hispanic (NH)	67.7	68.7
Black, NH	14.1	13.5
American Indian/Alaska Native, NH	1.5	0.9
Asian, NH	1.2	2.8
Native Hawaiian/Pacific Islander, NH	0.3	0.3
Other race, NH	0.6	0.5
Multiracial, NH	2.9	1.8
Hispanic/Latine	11.7	11.7
Age 65+	29.5	22.3
Female sex	59.5	59.5
LGBTQ+	12.1	6.5
Lives in rural area	10.6	8.1
Married/coupled	53.8	64.5
Any children in household	28.5	33.6
Homeowner	67.5	80.1
Labor force participation		
Employed	37.8	62
Unemployed	8.6	6
Out of labor force	36.1	30.2
Unable to work	17.5	1.9
Education		
Less than high school	14.6	6.1
High school	31.9	25.5
Some college	36	34.1
College or more	17.5	34.3
Income		
Less than \$25,000	31.2	11.7
\$25,000 to less than \$50,000	34	25.5
\$50,000 to less than \$100,000	23.3	34.3
\$100,000 to less than \$200,000	9.7	22.4
\$200,000 or more	1.8	6.2
Health insurance		
Private	32.2	57.6
Public	59.2	35.1
No coverage	8.7	7.3

Table 2. Comparing caregiving contexts for disabled caregivers and nondisabled caregivers

	Disabled Caregivers (%)	Nondisabled Caregivers (%)
Relationship of the person being supported to the caregiver		
Parent	29.5	39.6
Child	10.4	9.6
Spouse/Live-in partner	21.1	16.1
Sibling	8.6	6.7
Grandparent	5.6	7
Grandchild	1	0.6
Other relative	7.3	6.6
Non-relative/Family Friend	16.5	13.8
Primary disability or health condition of the person being supported		
Alzheimer's disease, dementia, or other cognitive impairment disorder	9.7	10.4
Developmental disability	5.1	4.7
Chronic illness ^a	34.4	32
Mental illness or substance use disorder	6.4	4.8
Old age/infirmary/frailty	11.9	14.7
Injuries or Other	32.6	33.4
Person being supported also has Alzheimer's disease, dementia, or other cognitive impairment disorder	16.3	13.1
Duration of caregiving		
Less than 30 days	13.2	15.6
1 month to less than 6 months	12.5	13.2
6 months to less than 2 years	17.2	19.2
2 years to less than 5 years	21.7	22.2
More than 5 years	35.4	29.8
Hours per week of caregiving		
Up to 8 hours per week	46.3	55.2
9-19 hours per week	14.4	14.4
20-39 hours per week	13.4	11.6
40 hours or more per week	25.8	18.9
Support includes managing personal care tasks	53.6	50.4
Support includes managing household tasks	81.2	79.9

^a Chronic illness includes: arthritis/rheumatism, asthma, cancer, chronic respiratory conditions such as emphysema or COPD, diabetes, heart disease, hypertension, stroke, Human Immunodeficiency Virus (HIV), other organ failure or diseases such as kidney or liver problems

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References

1. AARP & National Alliance for Caregiving. (2025). *Caregiving in the US 2025*. AARP. <https://doi.org/10.26419/ppi.00373.001>
2. Administration for Community Living. (2026). *National Caregiver Support Collaborative*. Acl.Gov. <http://acl.gov/ncsc>
3. Andrews, E. E., Powell, R. M., & Ayers, K. (2022). The evolution of disability language: Choosing terms to describe disability. *Disability and Health Journal*, 15(3), 101328. <https://doi.org/10.1016/j.dhjo.2022.101328>
4. Blight, D. A. (2024, October 14). *Caregiver, Caretaker, Carer, or Care Partner: What's the Difference?* <https://caregivingkinetics.com/caregiver-caretaker-carer-or-care-partner/>
5. Caldwell, J., & Gladstone, J. (2025). Bridging Aging and Disability Networks to Support Aging Adults With Intellectual and Developmental Disabilities and Family Caregivers. *Public Policy & Aging Report*, 35(2), 37-42. <https://doi.org/10.1093/ppar/praf003>
6. Centers for Disease Control and Prevention (CDC). (2025, February 27). *CDC - BRFSS - 2023 BRFSS Modules Used by Category*. <https://www.cdc.gov/brfss/questionnaires/modules/category2023.htm>
7. Centers for Disease Control and Prevention (CDC). (2026, February 4). *2021-2023 Behavioral Risk Factor Surveillance System Survey Data*. <https://www.cdc.gov/brfss/index.html>
8. Leibowitz, C. (2015). *I am disabled: On Identity-First Versus Person-First Language*. The Body is not an apology. <https://dfwhcfoundation.org/wp-content/uploads/2018/10/I-am-Disabled.-On-Identity-First-Versus-People-First-Language-TBISNAA.pdf>
9. Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.
10. RAISE Act Family Caregiving Advisory Council, The Advisory Council to Support Grandparents Raising Grandchildren, & Administration for Community Living. (2022). *2022 National Strategy to Support Family Caregivers*. https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers-2.pdf
11. Stall, N. M., Campbell, A., Reddy, M., & Rochon, P. A. (2019). Words Matter: The Language of Family Caregiving. *Journal of the American Geriatrics Society*, 67(10), 2008-2010. <https://doi.org/10.1111/jgs.15988>
12. University of Waterloo. (n.d.). *Disability: Terminology and Key Concepts*. Retrieved January 30, 2026, from <https://uwaterloo.ca/university-relations/disability-terminology-and-key-concepts>