



A Day, A Week, A Year, A Life

Family Caregivers on the Front Line

August 2023



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Who is a Family Caregiver?



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Family Caregivers

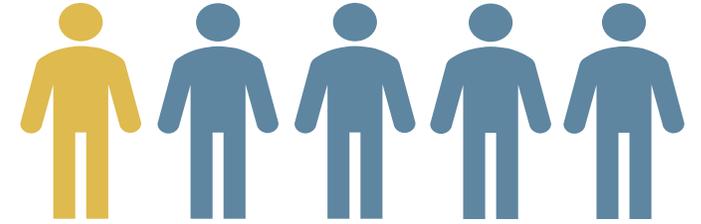
A family caregiver is a person who assists a relative with short- or long-term limitations. It can be through either formal (paid) or informal (unpaid) supports.



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One in Five



- Nearly 20% of Americans were providing unpaid care to an adult with needs in 2020.
- It is estimated that 45% of those unpaid caregivers have experienced at least one negative financial impact due to caregiving.
- Difficulties faced by this population continue to trend upwards as we move forward in the national caregiver shortage



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**Nationwide Caregiver Shortage
Felt By Older Adults**

**US caregiver shortage impacting 65
and older population**

**Caregiver shortage hits rural areas the
hardest**

**Caregiver shortage: 'No pool of
people to pull from now'**

**Pandemic-fueled shortages of home health
aides strand patients without care**

A shortage of health aides is
forcing out those who wish to
get care at home

**Caregiver shortage worsens throughout the
country as population ages**

**AT-HOME HEALTH CARE PROVIDERS
EXPERIENCING A SHORTAGE OF CAREGIVERS**

Caregiver Turnover Strains Households
The supply of home health aides isn't meeting growing demands as
America ages and many people prefer to stay out of facilities

**Shortage of paid caregivers keeps family members up
at night, hoping for 'something sustainable'**



Alison Barkoff

Administration for
Community Living

“The shortage of direct care workers has become a **national crisis** and a serious civil rights issue. Increasing numbers of people with disabilities and older adults who want to live in the community – a right protected by the Americans with Disabilities Act and other civil rights laws – are unable to get the services they need to do so.”

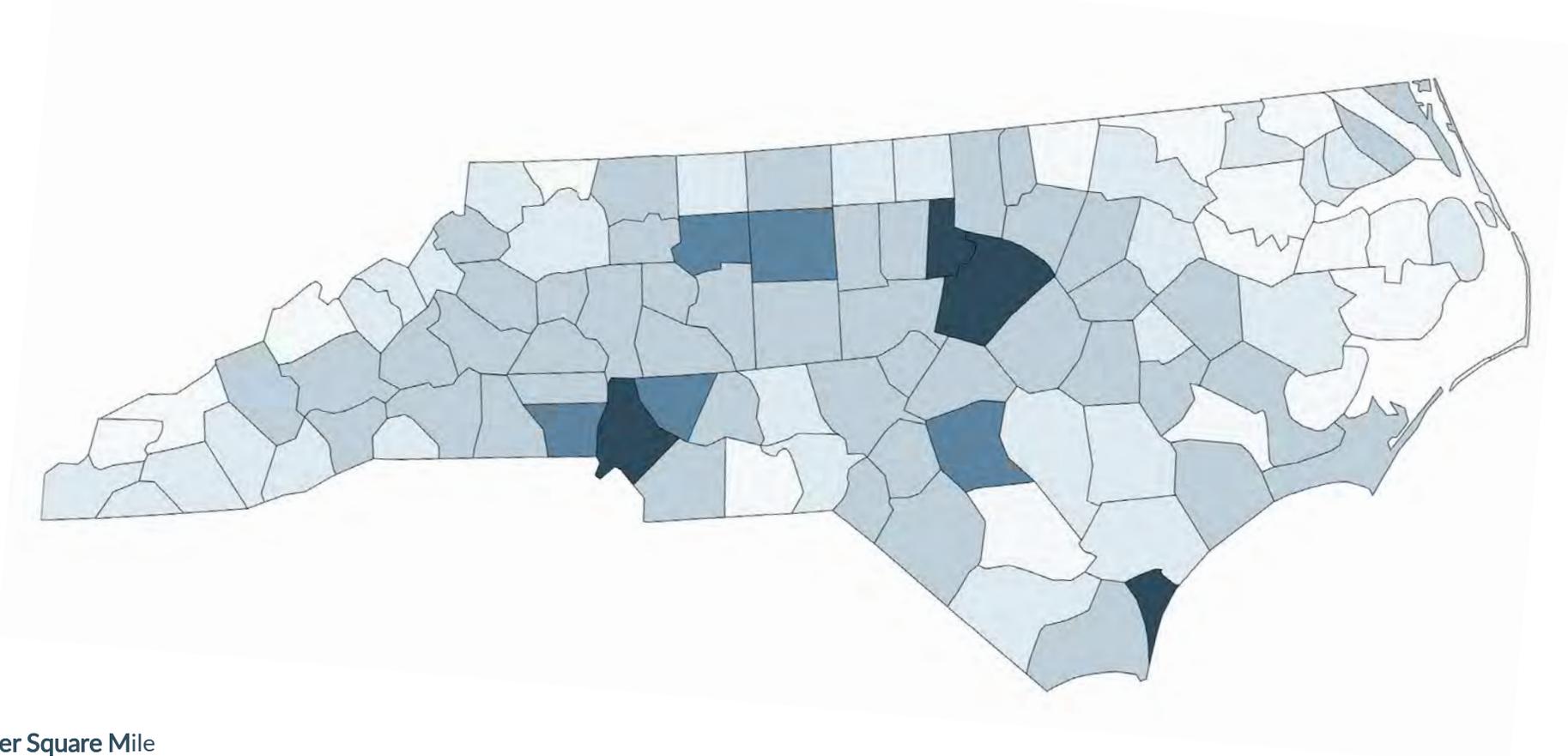
We need **1.3 million** direct care workers just to keep up with demand.

Impact of the Caregiver Shortage



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North Carolina Population Density



Average Persons Per Square Mile

- Less than 50
- 50-99
- 100-499
- 500-999
- Over 1,000

Source: 2020 US Census

The Impact on Family Caregivers



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A Day in the Life of a Family Caregiver



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Melissa Schlemmer

IN  DAY

Policy Maker Challenges



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Using Stakeholder Feedback to Guide Policy Making

The Impact of Expanding Family Caregivers in Self-Direction



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“We can care for her in a way that [will] keep her nurtured and loved.”

- Paid Family Caregiver



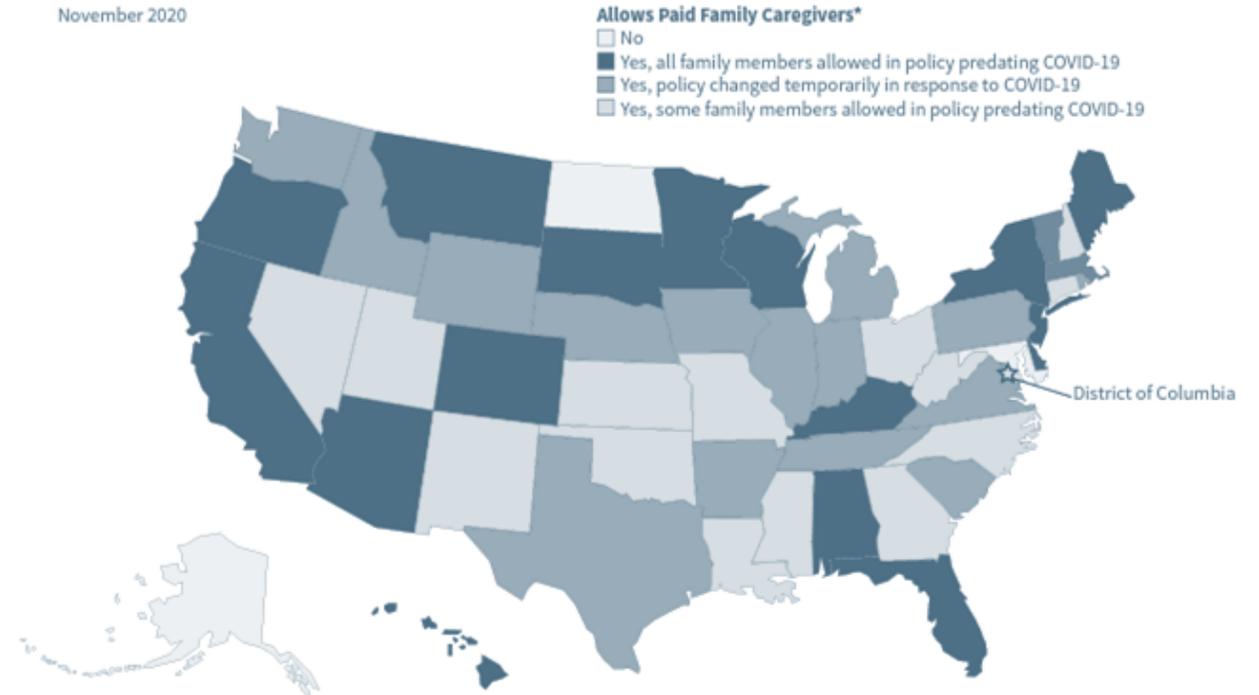
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Limited Provisions

While most programs allow some family members to provide care, in self-directed programs, immediate or close family members such as spouses, parents, or children are often restricted.

CMS policy highlights their main concern with family caregivers:

“[Ensuring that] participant choice and control be preserved when legally responsible relatives are paid for providing care.”



Source: AARP Public Policy Institute, 2020 Long-Term Services and Supports State Scorecard (Washington, DC: AARP Public Policy Institute, 2020); Centers for Medicare & Medicaid Services, Emergency Preparedness and Response for HCBS 1915(c) Waivers,* Baltimore, MD, November 2020.

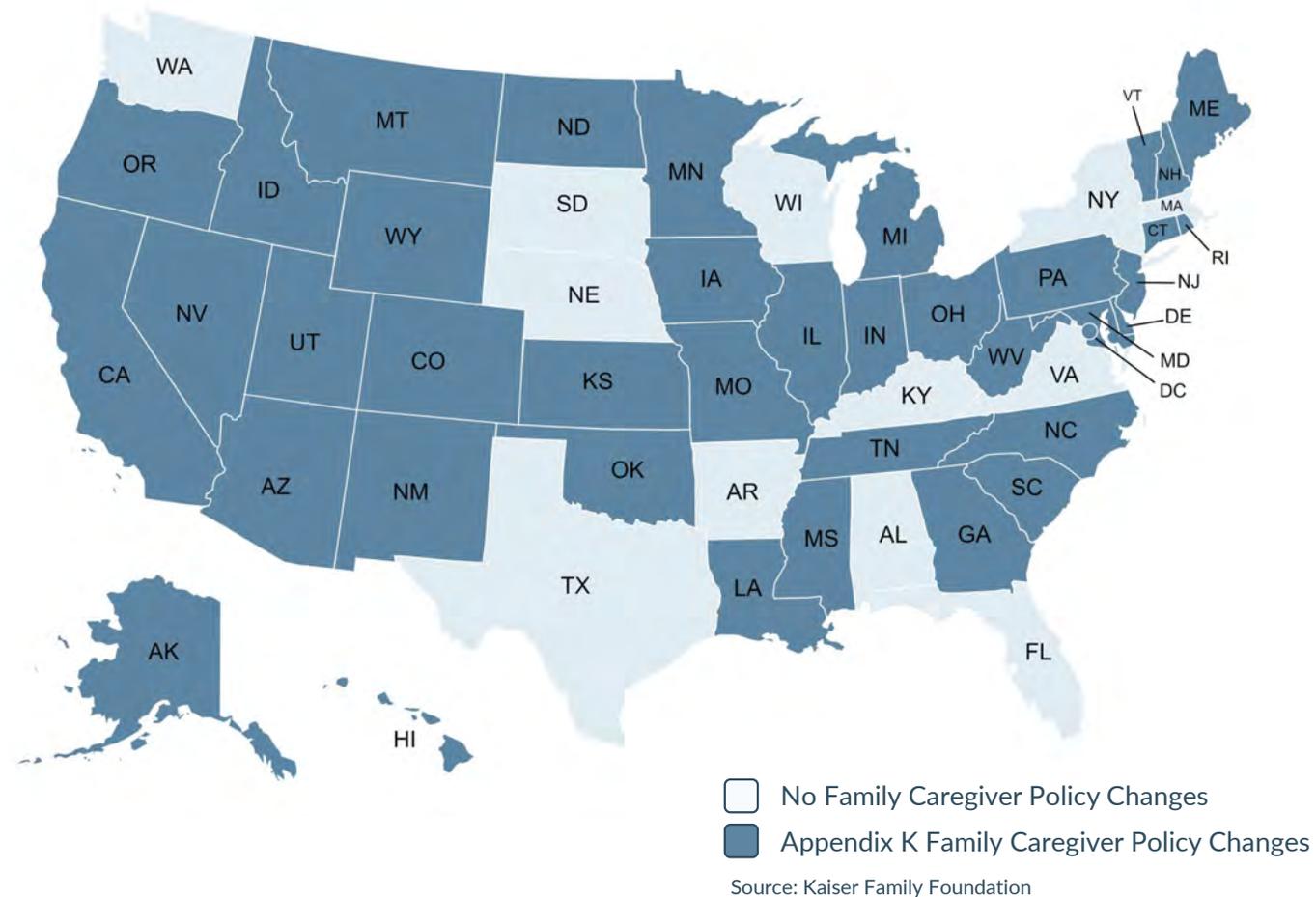


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Appendix K

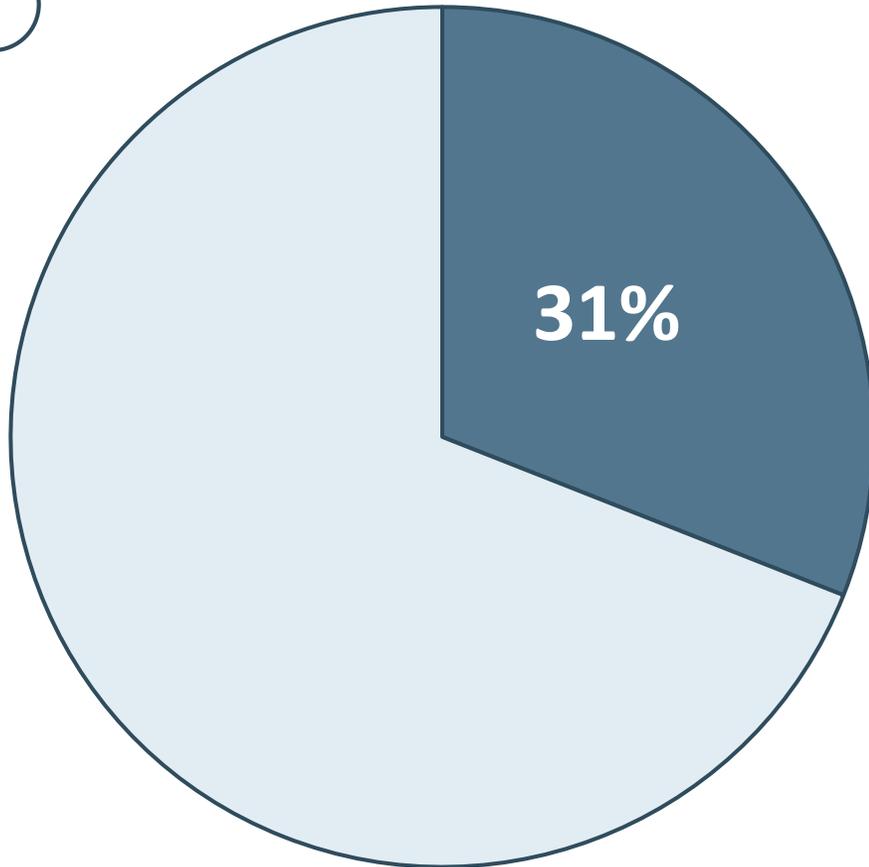
During the Public Health Emergency, several states implemented changes to their self-direction programs using Appendix K of the 1915(c) waiver.

Around 39 states created temporary policy changes related to provider qualifications that allow family and legally responsible individuals to provide care.



Utilization of Paid Parent of Minor Child Option in North Carolina's Community Alternatives Program (CAP/C)

31% of children served by GT Independence in North Carolina utilized the Appendix K flexibilities to utilize a parent as a paid caregiver.



"I don't know how we could have survived without it."

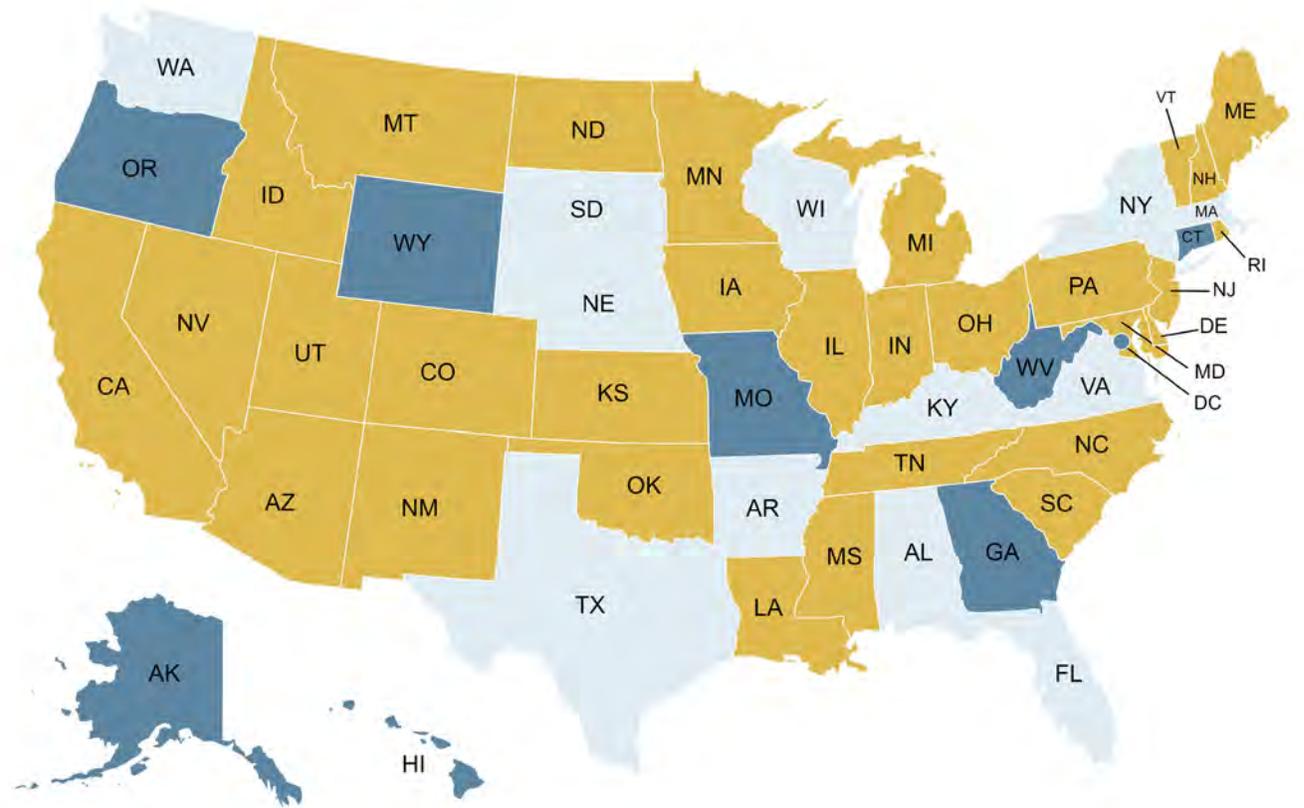
-Parent in North Carolina CAP/C



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After the PHE Ends

Despite continued challenges faced as a result of the direct care workforce shortage, only half of the states with Appendix K provisions intend to implement policy at the conclusion of the PHE to continue to allow family caregivers to provide formal care.



- Intended Permanent Policy Changes Allowing Family Caregivers*
- Family Caregiver "Appendix K" Flexibilities*
- No Additional "Family Caregiver" Flexibilities

*As of most recently available public information on or around 05/01/2023



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**Fraud, Waste, Abuse,
Oh my!**

Pre-Payment Reviews

-  Is the participant eligible for services?
-  Is the worker eligible to provide services?
-  Do shifts fall within the authorized amount?
-  Do the shifts overlap?
-  Are there flags on the account?



The Stigma

In many programs, certain family caregivers are not permitted as eligible providers of formal (paid) supports.

There is a belief that they're more likely to commit fraudulent activity despite real evidence. Some people also believe that family members shouldn't be paid for work they are already responsible for doing.



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Families worry over the future of Medicaid caregiver payments that were expanded during the pandemic

“States found that being flexible with caregiver payments helped keep residents served during the pandemic, said Kate McEvoy, executive director of the National Association of Medicaid Directors. She said surveys have shown, too, that people generally like receiving care from family members.

But she also noted that there are concerns both nationally and at a state level about the potential for fraud when paying family members as opposed to an agency that may be subject to more oversight. States also want to make sure that any family caregivers are trained properly and provide quality care.”

The Reality

Family caregivers work hard every day to provide for the needs of their family. In many situations, they are the best option to provide care, because they know their relative the best.

They have the potential to provide crucial support to resolving the current caregiver shortage. Data shows that instances of fraud are **not** increased in these arrangements.



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What Makes a Good Caregiver?

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Health



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Caring

Knowledgeable

Reliable

Dependable

Qualified

Supportive

Trustworthy

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Health**



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Does allowing family members to be paid caregivers work?



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GT Community Sherri and Her Mother, Lois

"I just felt kind of helpless...we started pretty much spending my dad's savings on help at night. Of course, [we] went through dad's funds and then I got a reverse mortgage on the house, and I was just watching funds constantly. ...I wanted her to have the best life ever, but it takes funding to do that and keep her in the house."





“People who self-direct show a strong sense of responsibility in regard to the services they use and the funds expended.” - NASUA

This is no different for participants who rely on family caregivers to provide necessary services.

Many of these family caregivers are providing services well beyond what they expect to be compensated for.



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 **Elevance**
Health

AARP
Real Possibilities

**Public Policy
Institute**

 **NASHP** | NATIONAL ACADEMY
FOR STATE HEALTH POLICY

 **Applied
Self-Direction**

AP Associated Press

KFF
HENRY J KAISER
FAMILY FOUNDATION

 **NASDDDS**
National Association of State Directors
of
Developmental Disabilities Services

**ADVANCING
STATES** 

Thank You!