Self-Direction as a Primary Mechanism for Paying Family Caregivers

How Self-Direction Works

Participants have decision-making authority over their own care

- Recruit, hire, train & supervise their caregivers
- The person with a disability becomes the legal employer
- Workers (including family) are employed by the service recipient

Paying Family Members

Most Medicaid programs allow family caregivers to be paid when they provide "extraordinary care"

CMS Technical Guide Definition

"Care exceeding the range of activities that a legally responsible individual would ordinarily perform... necessary to assure the health and welfare of the participant and avoid institutionalization."



Self-Direction by the Numbers

Early Development

First programs emerged in the 1960s, But the 1990s pioneering and extensive evaluations of participant-directed care models drive adoption

Pandemic Response

Many states newly allowed paying legally responsible individuals for the first time

23% growth from 2019-2023

2011: 739,711

2013: 811,218

2016: 1,058,889

2019: 1,234,214

2023: 1,520,267



Available to a wide array of populations

Works across age groups and disability types

- 90% of states offer via Medicaid 1915(c) waivers
- 75% of states offer self-direction funded by VHA





Positive Impact of Paid Family Caregiving

"It is just so wonderful to be able to compensate him for the very important work that he does...

I'll always take somebody that I know personally over having to hire somebody from the community."

Ryan, Care Recipient

Research-Backed Benefits

- Superior quality outcomes
- Enhanced safety & trust
- Culturally competent care
- Practical advantages

Strong Evidence Base

- Gold-standard evaluation
- Minimal fraud/abuse
- Cross-population success

"I am her paid caregiver and it has been life-changing for us. I'm able to stay home and take care of her as her medical needs become more complex."

Doris, Mother and Caregiver



Current Challenges & Policy Recommendations

The Misconceptions Problem

"They don't understand that we're just families — not agencies... all we get is local health officials accusing us of fraud — outright — at public meetings."

The Reality: Despite robust evidence, uninitiated policymakers often assume families will misuse the system for monetary gain

Strengthen systems

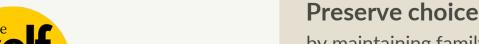
rather than eliminating beneficial programs -- 20% report having no choice but to hire family due to workforce shortages

Educate decision-makers

with evidence showing successful paid family caregiving models

Distinguish between fraud and errors

including unintentional time-tracking or mistakes with complex program rules



by maintaining family hiring options --60% of participants prefer hiring a mix of family and non-family

Address workforce shortages

through improved wages and system improvements



Presentation References

Self-Direction Services Overview, CMS

Self-Direction National Inventory, AARP

Paying Family Caregivers through Medicaid Consumer-Directed Programs: State Opportunities and Innovations, NASHP

1915(c) Waiver Technical Guide, CMS

Bridging the Gap: Insights into Strengthening the Self-Directed Workforce, Applied Self-Direction

National Core Indicators – IDD Survey from 23-24, NCI Adult Family Survey

From Snap Bracelets to Smart Watches: Paid Family Caregiving Research Over the Years, Applied Self-Direction

What Does Research Tell Us About a Policy Option to Hire Relatives as Caregivers?, Oxford Academic

Paid Family Caregiving: What Does It Look Like in Practice?, Applied Self-Direction

Local in-home support workers at risk due to proposed state budget cuts, CapRadio

Idaho parental disability caregiver program to end, following federal approval, Idaho Capital Sun

Additional Resources

Commentary: Social Experimentation at Its Best: The Cash and Counseling Demonstration and Its Implications: Health Services Reserach Journal

Self-Directed Services in Medicaid Home- and Community-Based Services MACPAC

Caring Families: Paying Family Caregivers
Topic Brief: NASDDDS

A Solution, with or without Pandemic: Let Individuals Hire Family for Care: AAPR/LTSS Choices Blog

Fraud in Self-Directed Personal Care Services: What Does the Data Tell Us?: <u>Applied Self-Direction</u>

