

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
- Culturally competent care
- Enhanced safety & trust
- 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

Preserve choice

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 Research 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: [AARP/LTSS Choices Blog](#)

Fraud in Self-Directed Personal Care Services: What Does the Data Tell Us?: [Applied Self-Direction](#)