Paying Family Caregivers to Provide Care during the Pandemic–and Beyond

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About this Series

This Spotlight is part of the AARP Public Policy Institute's LTSS Choices initiative. This initiative includes a series of reports, blogs, videos, podcasts, and virtual convenings that seeks to spark ideas for immediate, intermediate, and long-term options for transforming long-term services and supports (LTSS). We will explore a growing list of innovative models and evidence-based solutions—at both the national and international levels—to achieve system-wide LTSS reform.

We recognize the importance of collaborating and partnering with others across the array of sectors, disciplines, and diverse populations to truly transform and modernize the LTSS system. We invite new ideas and look forward to opportunities for collaboration.

For all questions and inquiries, please contact Susan at LTSSChoices@aarp.org.

Introduction

As the COVID-19 pandemic reshapes long-term care in America, an increasing number of older Americans are relying on family members to provide the care they need, allowing them to live safely at home. While this shift offers an option for families, it also puts households under financial, emotional, time-related, and other types of strain. In essence, these family caregivers are often performing the tasks of paid professionals who work both in nursing facilities and through in-home visits.

Paying family members to provide care is a cost-effective option with unique advantages that help ensure a rapidly aging American population can receive the care needed to live at home.

Background

Family caregivers' value in terms of dollars has been well documented. The total economic value of unpaid family caregiving was estimated at approximately $470 billion in of 2017, and this number will only increase as more Americans than ever are turning 65 and older.[1,2] And now, as the

[1]Susan Reinhard et al., "Valuing the Invaluable: 2019 Update," AARP Public Policy Institute, Washington, DC, November 2019, https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf.

[2]Mark Mather, Paola Scommegna, and Lillian Kilduff, "Fact Sheet: Aging in the United States—Population Reference Bureau," Population Reference Bureau, Washington, DC, July 11, 2019, https://www.prb.org/aging-unitedstates-fact-sheet/.

COVID-19 pandemic reshapes long-term care in America, family caregivers' contributions are growing in unique ways. An increasing number of older people and adults with physical disabilities are relying on family members for the care they need, allowing them to live safely at home. Yet, while this shift offers an option for families, it also adds financial, emotional, and time-related strains on households. In essence, these family caregivers are often performing the tasks of paid professionals who work both in nursing facilities and through in-home visits—and in some cases, these tasks are even taking away from caregivers' own needed work hours.

One solution is to provide some level of compensation to family caregivers—compensation that might otherwise go to nursing facilities or home care workers. The concept certainly resonates with family caregivers. In one recent national study (completed before the onset of the COVID-19 pandemic), a majority (65 percent) of family caregivers of adults said they would find a program under which they were paid for at least some of their caregiving hours to be helpful. Those who were in high-intensity care situations and those reporting moderate-to-high levels of financial strain were especially supportive of being paid for some of the hours of care they provided (76 percent and 74 percent, respectively).[3]

The difficulty of managing a highly contagious disease—COVID-19—in institutional settings has generated new public scrutiny toward the nation's existing long-term services and supports (LTSS) system and galvanized national interest in improving it. As shown in this report, paying family members to provide care is a cost-effective option with unique advantages that can help ensure that older people and people with disabilities with LTSS needs receive the care they need, from the caregivers they prefer, and in the home setting. Investing in paid family caregiving will also help states adapt their LTSS systems to better meet rising levels of need in a cost-effective way.

Creating systemic change in LTSS requires changes in Medicaid policy, because Medicaid is the primary funder of LTSS in the United States.[4] Thus, this report will focus primarily on paid family caregiving that takes place within Medicaid-funded LTSS. However, it will also include analysis of self-direction programs serving older people and adults with physical disabilities across all funding sources, including state-funded programs and Veteran-Directed Care. A full list of all self-direction programs serving these populations is available in Appendix 1.

Understanding Medicaid Long-Term Services and Supports

Medicaid provides LTSS via two models: institutional care (i.e., nursing home care) and home- and community-based services (HCBS). HCBS is a cost-effective alternative to institutional care that allows people to live and receive services at home and in other community settings. While state Medicaid agencies continue to shift away from institutional care toward lower-cost HCBS alternatives, Medicaid still pays for most institutional care provided in America. As of 2018, Medicaid paid for the care of 62 percent of nursing home residents nationwide.*

In 2013, for the first time, more Medicaid dollars were spent on HCBS than on institutional care. Today, both the total amount of Medicaid dollars spent on LTSS and the percentage of Medicaid LTSS dollars spent on HCBS continue to grow year over year. Given that Medicaid is the largest payer of LTSS and that HCBS is now the dominant service delivery model within Medicaid, improving Medicaid-funded HCBS is perhaps the most effective way to improve the nation's LTSS delivery system as a whole.

*"An Overview of Long-Term Services and Supports and Medicaid: Final Report," Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, Washington, DC, August 6, 2018. https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report.

[3]AARP and National Alliance for Caregiving, *Caregiving in the United States 2020* (Washington, DC: AARP, May 2020), https://doi.org/10.26419/ppi.00103.001.

[4]Nga Thach and Joshua Wiener, "An Overview of Long-Term Services and Supports and Medicaid: Final Report," Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, Washington, DC, August 6, 2018, https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report.

While this paper focuses on Medicaid-funded LTSS waivers and Veteran-Directed Care, these are just two types of public programs that pay family caregivers to provide care. Other programs that do this include Medicaid HCBS state plan amendment (SPA) personal care programs and Department of Veterans Affairs, Program of Comprehensive Assistance for Family Caregivers (PCAFC). Under a SPA for personal care, a state can establish policies about whom the Medicaid enrollee can hire, including whether or not the enrollee can hire legally responsible family members.[5] The PCAFC program provides caregivers of eligible Veterans a monthly financial stipend, access to resource, education, and supportive services.[6]

Pandemic Phenomenon: Long-Term Care Concerns Magnified

The COVID-19 outbreak has intensified longstanding problems in long-term care. Nursing homes were among the first COVID-19 "hotspots" in the United States,[7] with their residents' death rates from the virus far exceeding those of the general population. As of December 4, 2020, 38 percent of COVID-19 deaths in America were among nursing home residents and staff, in spite of such individuals composing just 5 percent of total COVID-19 cases.[8] During the initial outbreak of the pandemic, inadequate infection control and prevention practices, shortages in personal protective equipment, insufficient staffing, and high levels of interpersonal contact all contributed to environments in which the spread of the disease was difficult to control, even after nursing homes implemented strict isolation protocols for residents.

Meanwhile, the pandemic has only exacerbated nursing homes' challenges related to social isolation. Residents' family members, long-term care ombudsmen, and clinicians across the nation continue to report that isolation and loneliness from nursing home lockdowns are causing significant declines in residents' physical and mental health.[9]

While nursing homes have battled these widely publicized issues, the COVID-19 pandemic has also exacerbated service delivery challenges for people who receive HCBS. An ongoing nationwide shortage of direct care workers and high turnover within the industry has made it difficult for people who need LTSS in home- and community-based settings to reliably receive the full amount of care they need.[10]

[5]Neva Kaye and Salom Teshale, "Medicaid Supports for Family Caregivers," National Academy for State Health Policy, Washington, DC, October 2020, https://www.nashp.org/wp-content/uploads/2020/10/Medicaid-Supports-for-Family-Caregivers.pdf.

[6]Additional information about the Program of Comprehensive Assistance for Family Caregivers is available at https://www.caregiver.va.gov/support/support_benefits.asp#:~:text=The%20Program%20of%20Comprehensive%20Assistance,or%20after%20September%2011%2C%202001 and https://www.federalregister.gov/documents/2020/07/31/2020-15931/program-of-comprehensive-assistance-for-family-caregivers-improvements-and-amendments-under-the-va.

[7]Mike Baker, "Nursing Home Linked to 37 Coronavirus Deaths Faces Fine of $600,000," *New York Times*, April 17, 2020, https://www.nytimes.com/2020/04/02/us/virus-kirkland-life-care-nursing-home.html.

[8]"More Than 100,000 U.S. Coronavirus Deaths Are Linked to Nursing Homes," *New York Times*, December 2020, https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html.

[9]Emily Paulin, "Is Extended Isolation Killing Older Adults in Long-Term Care?", AARP, September 3, 2020, https://www.aarp.org/caregiving/health/info-2020/covid-isolation-killing-nursing-home-residents.html.

[10]"Direct Care Workers in the United States: Key Facts," Paraprofessional Health Institute, September 8, 2020, https://phinational.org/wp-content/uploads/2020/09/Direct-Care-Workers-in-the-United-States-2020-PHI.pdf.

Low wages are a primary driver of that shortage. According to the Bureau of Labor Statistics, the median hourly wage for a personal care aide was $12.71 in 2019[11]—far lower than the US median hourly wage of $19.33 for the same year.[12] Meanwhile, jobs that offer similarly low wages, such as those in the fast food industry,[13] typically do not impose a level of physical[14] and emotional strain comparable to what direct care workers routinely experience.

The shortage of direct care workers will only grow, as the Bureau of Labor Statistics projects that "home health and personal care aides" will add more jobs than any other occupation in America from 2019 to 2029.[15] Since the majority of workers' wage rates are set by Medicaid and not subject to market forces, attracting an adequate number of new direct care workers to professional caregiving will require substantial increases in Medicaid reimbursement rates for personal care and home health services.

While low wages have always limited the growth of the home care workforce, COVID-19 has generated changes that further limit the availability of professional caregivers. School and daycare closures have compelled some direct care workers to stay home with their children or care for their own loved ones, limiting their ability to provide home care to others. Since many direct care workers serve multiple clients in the same workweek, workers have had well-founded concerns about personally contracting the SARS-CoV-2 virus that causes COVID-19 and unknowingly spreading the virus across multiple households.

Turning to Family Caregivers

As a result of these and other challenges, such as government-mandated lockdowns, older people and adults with physical disabilities have turned to family members even more for the care they need. Family caregiving offers key advantages to limit care recipients' risk of contracting COVID-19. For example, when a person receives care from a family member with whom they already live, the act of providing care is unlikely to expose either party to additional risk of contracting COVID-19. This stands in stark contrast to the risks posed by receiving services from direct care workers who often serve multiple clients, or the risks inherent in nursing homes. Even family members who do not live with the care recipient offer a lower-risk caregiving scenario compared with a home care worker who travels from client home to client home, which increases the risk of the worker contracting and spreading COVID-19.

While paying family caregivers is not a new concept, the vast majority of family caregivers are unpaid. However, paying family caregivers has become more urgently needed and more commonly used to help meet the rising demand for care, an issue that has been magnified by the pandemic. However, prior to the initial COVID-19 outbreak, many states had longstanding restrictions on the types of family members who Medicaid beneficiaries could hire as caregivers. A recent study showed that, of

[11]"Home Health Aides and Personal Care Aides," US Bureau of Labor Statistics, September 1, 2020, https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm.

[12]Elise Gould, "State of Working America Wages 2019: A Story of Slow, Uneven, and Unequal Wage Growth over the Last 40 Years," Economic Policy Institute, Washington, DC, February 20, 2020, https://www.epi.org/publication/swa-wages-2019/.

[13]"Food and Beverage Serving and Related Workers," US Bureau of Labor Statistics, September 1, 2020, https://www.bls.gov/ooh/food-preparation-and-serving/food-and-beverage-serving-and-related-workers.htm.

[14]According to a 2018 PHI report, the direct care workforce provides extensive physical assistance for people who receive LTSS. Occupational injury rates for LTSS direct care workers are among the highest in the United States. Stephen Campbell, "Workplace Injuries and the Direct Care Workforce," PHI, Bronx, NY, April 2018, https://phinational.org/wp-content/uploads/2018/04/Workplace-Injuries-and-DCW-PHI-2018.pdf.

[15]"Most New Jobs," US Bureau of Labor Statistics, September 1, 2020, https://www.bls.gov/ooh/most-new-jobs.htm.

What Is Self-Direction?

Self-direction is a model of HCBS in which the individual who receives services decides how, when, and from whom those services will be delivered. Self-direction is a flexible alternative to "traditional" HCBS, in which a person receives services from a worker employed by a home care agency and the person generally has less control over how his or her services are delivered.

In most cases, a person who self-directs will legally serve as the employer of his or her workers. If the person is unable or unwilling to serve as an employer, he or she can designate someone he or she knows and trusts to serve in that role. People who self-direct use a Financial Management Services entity to handle compliance and administrative responsibilities related to being an employer, such as processing payroll and paying taxes, on their behalf.

Participants in self-directed programs often choose to hire family, close friends, or neighbors as paid caregivers. It is common for participants to prefer to receive services from someone they already know and trust, particularly when assistance with intimate tasks like bathing and dressing is required.

While these jobs typically do not require a specialized skillset or formal training, it is not uncommon for complex care to be part of their role. Meanwhile, family, close friends, or neighbors hired as caregivers can come with a major asset: since caregivers in self-direction frequently already know the person to whom they are providing services, they often begin formal employment with a deep understanding of how to provide care to that person, in addition to having some form of personal relationship with him or her.

Common job duties include assistance with bathing, dressing, eating, and toileting, as well as meal preparation, housekeeping, and providing transportation. Many workers in self-direction also manage complex responsibilities, such as medication management, injections, and catheter care.

As of 2019, there were over 250 self-direction programs in the United States, and the number of participants who self-direct continues to grow year over year.* The number of self-direction programs and these programs' policies on whether participants can hire family caregivers are tracked as part of the National Inventory of Self-Directed LTSS Programs, in support of the 2020 Long-Term Services and Support State Scorecard. The majority of self-direction is funded by Medicaid, although some programs are funded by the Veterans Administration, state tax revenues, and other sources. Each state sets its own rules for determining whether a resident of the state is eligible for participation in Medicaid-funded LTSS.

*Edwards-Orr et al., "National Inventory of Self-Directed Long-Term Services and Supports Programs."

262 programs nationally, across all populations and funding sources, that allowed people who needed LTSS to hire their own staff (see What Is Self-Direction? textbox), 144, or well over half, did not allow at least some types of family caregivers to be paid for their work.[16] This proved a barrier to more widespread paid family caregiving, until the public health emergency resulting from the COVID-19 outbreak spurred states to action.

When COVID-19 cases mounted during the spring of 2020, state Medicaid agencies swiftly expanded their self-direction programs (see What Is Self-Direction? textbox) to allow more family members to be hired and paid as caregivers.[17] Such action

[16]Merle Edwards-Orr et al., "National Inventory of Self-Directed Long-Term Services and Supports Programs: For the AARP State Scorecard of Long-Term Services and Supports," AARP Public Policy Institute, Washington, DC, September 2020.

[17]Molly Morris, "Appendix K Tracker," www.appliedselfdirection.com, August 28, 2020, https://www.appliedselfdirection.com/resources/appendix-k-tracker.

was taken to protect continuity of care for vulnerable individuals, the majority of whom are older people and people with physical disabilities. Over 15 states issued temporary emergency rule changes permitting Medicaid waiver programs to give participants in self-direction programs the choice to hire family members to provide their care. Medicaid-funded self-direction programs are available in all states and the District of Columbia and offer a clear pathway that can enable states to allow family members to be paid to provide care to older family members and adult family members with disabilities.[18]

According to a Public Partnerships analysis of 10 states' Medicaid self-direction programs serving older people and adults with physical disabilities with an institutional level of care, 25 percent of all direct care workers who supported self-directed clients in 2019 had a familial relationship with the person to whom they provided services.[19] According to the same analysis, in 2019, 16 percent of workers in self-direction lived full time in the same household as the person to whom they provided services.[20] This number varied by state and was often higher in more rural states. An analysis of a Minnesota self-direction program serving older people found that approximately 44 percent of program participants lived with their caregiver in 2019, and that the median age of program participants was 76.[21]

What Gets in the Way of Enabling a Promising Resource

In spite of the advantages of providing pay for family caregivers, the concept has met certain barriers. As noted above, prior to the COVID-19 outbreak, states commonly imposed restrictions on the types of family members who could be hired to provide paid services in Medicaid-funded self-direction.[22] One of the most common restrictions states imposed is that a person may not hire his or her spouse as a paid caregiver, with the rationale that caring for one another is a responsibility inherent in the spousal relationship. However, in a pandemic environment, this restriction can force spousal caregivers to leave the house to go to work while hiring an outside caregiver to enter the home and care for his or her spouse—a situation that is clearly suboptimal from a risk management perspective.

Concerns about family members committing fraud by billing for hours not worked also motivated these policy choices restricting family from serving as paid caregivers. However, research shows that fraud is extremely rare in Medicaid-funded self-direction and does not occur at a higher rate than in other Medicaid personal care services.[23]

[18] Applied Self-Direction, "2019 Self-Direction Inventory," unpublished database, November 2020. Data were initially collected as part of the 2019 National Inventory of Publicly Funded Self-Directed Long-Term Services and Supports Programs in the United States Survey for the *2020 Long-Term Services and Supports State Scorecard*. Susan Reinhard, et al., "Long-Term Services and Supports State Scorecard, 2020 Edition," AARP Public Policy Institute, Washington, DC, September 24, 2020, http://www.longtermscorecard.org/~/media/Microsite/Files/2020/LTSS%202020%20Reference%20Edition%20PDF%20923.pdf.

[19] Public Partnerships, "Self-Direction in Medicaid Home and Community-Based Waiver Programs Serving Participants Requiring Nursing Facility Level of Care," unpublished paper, Boston, MA, July 2020.

[20] Ibid.

[21] Accra Care, "Self-Direction Data," unpublished database, August 2020.

[22] Edwards-Orr et al., "National Inventory of Self-Directed Long-Term Services and Supports Programs."

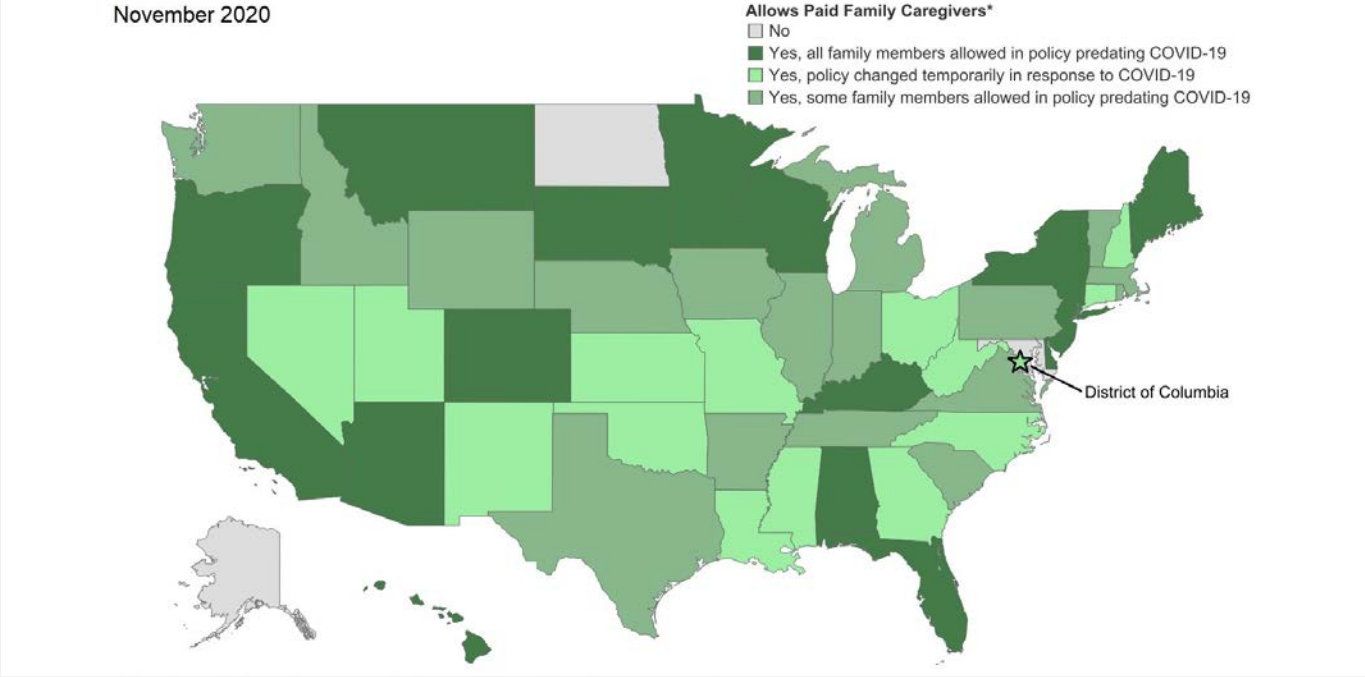
[23] Jennifer Schore, Leslie Foster, and Barbara Phillips, "Consumer Enrollment and Experiences in the Cash and Counseling Program," *Health Services Research* 42, no. 1, pt. 2 (2007), 446–466, https://doi.org/10.1111/j.1475-6773.2006.00679.x.

A Pandemic-Inspired Shift

The map in Figure 1 highlights state policies prior to and during the COVID-19 pandemic that allow individuals receiving HCBS services in self-directed programs across Medicaid and state funding sources—that is, 1915(c) waivers, state plans, and non-Medicaid state programs—to hire and pay family members to provide their care.[24] A full list of self-direction programs serving older people and individuals with physical disabilities across all funding sources is available in Appendix 1.

States that made temporary rule changes in response to COVID-19 have not yet decided whether these changes will become permanent features in their programs. However, in evaluating such decisions regarding fostering a strong paid family caregiver base, states should consider that Medicaid reimbursement rates at their current levels are not sufficient to attract an adequate number of

Figure 1. State Policies Allowing Paid Family Caregiving in Self-Directed Programs for Adults Ages 65+ and Adults with Physical Disabilities



*See Appendix 1 for information on family member restrictions by program type in each state.

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.

[24]Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, "Medicaid Home and Community-Based Services Enrollment and Spending—Issue Brief," The Henry J. Kaiser Family Foundation, Washington, DC, February 4, 2020, https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/.

direct care workers into the professional home care workforce. Meanwhile, COVID-19-related budget shortfalls will make it unlikely that states will be able to raise Medicaid reimbursement rates in the near term, given their obligation to balance their budgets.[25]

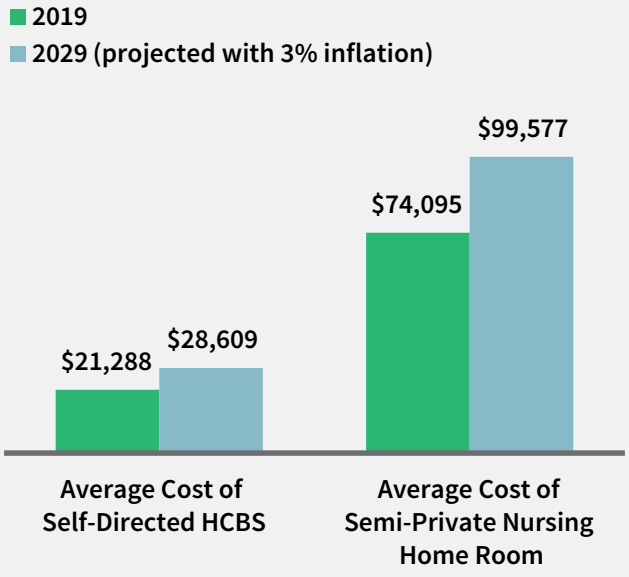
Expanding opportunities for paid family caregivers can help states ensure they have adequate caregiving resources to meet rising demand. The demands of family caregiving are often so great that the time required for caregiving often precludes caregivers' ability to maintain other employment. Without receiving monetary compensation for services provided, family caregiving is far less sustainable over the long term. In addition, paying family caregivers not only expands the pool of available caregivers but also frees up more of the limited professional direct care workforce to provide services to those for whom family caregiving is not an option. As a first step, states should consider permanently easing restrictions on the type of family caregivers eligible to be paid through Medicaid self-direction programs.

Paying Family Caregivers Benefits the Whole Family

In addition to expanding the caregiver pool, the option of paying family caregivers benefits both caregivers and recipients, and even the family as a whole. Family caregiving already serves an undervalued but critical role in mitigating the growing strain on the LTSS system. As Americans continue to live longer, family members increasingly are providing ever more complex care at home and may be doing so for longer periods than ever before.[26] A family caregiver's responsibility to provide the high level of care that many older people require can make it difficult or even impossible for the caregiver to simultaneously maintain another job. By paying family caregivers through self-direction, the need to maintain other employment is mitigated, which will help expand access to HCBS for older people and people with physical disabilities.

Expanded access to HCBS is a successful outcome both for people who need LTSS and for taxpayers. The vast majority of adults ages 50 and older would rather live at home as they age than live in a nursing home,[27] and nursing home care is far costlier on average than is self-directed HCBS

Figure 2. Comparing Costs of Self-Directed HCBS to Nursing Home Care, 2019–29 (projected)



Sources: American Council on Aging, "Medicaid Coverage of Nursing Home Care: When, Where and How Much They Pay," Medicaid Planning Assistance, San Francisco, CA, January 7, 2020, https://www.medicaidplanningassistance.org/medicaid-and-nursing-homes/; Public Partnerships, "Self-Direction in Medicaid Home and Community-Based Waiver Programs Serving Participants Requiring Nursing Facility Level of Care," unpublished paper, Boston, MA, July 2020.

[25] Sally Mabon, Marissa Korn, and Heather Howard, "State Budget Actions in Response to COVID-19 and the Impact on State Health Programs," State Health & Value Strategies, Princeton, NJ, July 31, 2020, https://www.shvs.org/an-early-look-at-state-budget-actions-in-response-to-covid-19-and-the-impact-on-state-health-programs/.

[26] Susan Reinhard et al., "Home Alone Revisited: Family Caregivers Providing Complex Care," AARP Foundation, Washington, DC, April 2019, https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf.

[27] Joanne Binette and Kerri Vasold, "2018 Home and Community Preferences: A National Survey of Adults Age 18-Plus," AARP Research, Washington, DC, August 31, 2018, https://doi.org/10.26419/res.00231.001.

serving Medicaid 1915(c) waiver program recipients who require an institutional level of care. As shown in figure 2, the following graph, the disparity in Medicaid cost between self-directed HCBS and nursing home care is projected to dramatically increase over the next 10 years.

According to the multistate Public Partnerships analysis, participants ages 65 and older and adults with physical disabilities in Medicaid-funded self-direction programs who would otherwise be eligible for nursing home care received, on average, a monthly budget of $1,774 for self-directed care in 2019.[28] This figure stands in stark contrast to the average cost of a Medicaid-funded semi-private nursing home room, which was $6,175 per month in 2019.[29]

Looking beyond cost, paid family caregiving through self-direction can offer a critical lifeline to families that want to provide care to a family member but cannot otherwise afford to do so. Therefore, paid family caregiving through self-direction answers multiple needs: the person who needs care can age in place among close family members; the family caregiver earns modest income for the difficult work he or she performs, which facilitates the sustained provision of low-cost HCBS while possibly lessening the impact of the caregivers' lost job hours; and costly institutionalization is delayed or avoided entirely.

Conclusion

The COVID-19 pandemic has highlighted the necessity of paying family caregivers to strengthen the nation's strained home care workforce and make the practice of caregiving more sustainable for families that want to keep a family member or close friend at home and in the community. Importantly, paid family caregiving provides a low-risk treatment option for vulnerable adults during pandemics and supports the whole family in a cost-effective way. It maximizes older adults' stated preferences for care while supporting people who want to age at home rather than live in institutional settings. Given the volume of national recommendations that have already been made about family caregiving, this report's recommendations are hardly novel.[30] However, the urgency brought on by the COVID-19 pandemic has further underscored their necessity, both in the near and long term.

State Medicaid agencies, therefore, should consider implementing permanent policies that encourage and facilitate paid family caregiving. To start, states should consider easing restrictions on the types of family members who can provide paid services via Medicaid-funded self-direction programs. While raising Medicaid reimbursement rates to attract more professional direct care workers may not be possible during a time of budget shortfalls, allowing family members to join the paid home care workforce expands access to cost-effective and safe HCBS for Medicaid beneficiaries who need it. States should also ensure that easy-to-understand information about their self-direction opportunities is available in a variety of formats to help expand access to these programs. Also, further investing in respite and other caregiver support services can help relieve the substantial emotional and physical burdens of caregiving.

[28]Public Partnerships, "Self-Direction in Medicaid Home and Community-Based Waiver Programs."

[29]American Council on Aging, "Medicaid Coverage of Nursing Home Care: When, Where and How Much They Pay," Medicaid Planning Assistance, San Francisco, CA, January 7, 2020, https://www.medicaidplanningassistance.org/medicaid-and-nursing-homes/.

[30]Wendy Fox-Grage, "Inventory of Key Family Caregiver Recommendations—The National Academy for State Health Policy," National Academy for State Health Policy, Washington, DC, April 14, 2020, https://www.nashp.org/inventory-of-key-family-caregiver-recommendations.

Finally, both individuals who receive unpaid care from a family member and the family caregivers themselves are encouraged to learn more about self-direction opportunities in their state. Even if a given state restricts paid family caregiving, self-direction can broaden people's access to care by allowing them to hire friends and neighbors. While most self-direction is funded through Medicaid, other funding options exist, such as state-funded programs and the Veteran-Directed Care program. A list of all self-direction programs as of 2019 is available at https://www.appliedselfdirection.com/self-direction-programs.

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Appendix 1 – State-by-State Analysis of Family Caregiver Rules in Self-Direction Programs Serving Older People and People with Physical Disabilities

Updated November 2020. Restrictions are subject to change at any time.

State	Program Name	Funding Source	Family Caregiver Restrictions
Alabama	Elderly and Disabled Waiver	Medicaid 1915(c)	No restrictions
	Personal Choices	Medicaid 1915(j)	Personal Choices does not allow spouses or legally responsible individuals.
	SAIL Waiver	Medicaid 1915(c)	SAIL Waiver does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Tuscaloosa	Veterans Affairs	No restrictions
Alaska	Veteran-Directed Care – Anchorage	Veterans Affairs	No restrictions
Arizona	Arizona Health Care Cost Containment System	Medicaid 1115	No restrictions
	Veteran-Directed Care – Tucson	Veterans Affairs	No restrictions
Arkansas	Independent Choices	Medicaid State Plan	Independent Choices does not allow spouses.
	Veteran-Directed Care – Fayetteville	Veterans Affairs	No restrictions
	Veteran-Directed Care – Little Rock	Veterans Affairs	No restrictions
California	In-Home Supportive Services Plus Option	Medicaid State Plan	No restrictions
	Personal Care Services Program	Medicaid State Plan	Personal Care Services Program does not allow spouses.
	Veteran-Directed Care – San Diego	Veterans Affairs	No restrictions
Colorado	Consumer-Directed Attendant Support Services	Medicaid 1915(c)	Restrictions lifted under Appendix K*
	In-Home Support Services	Medicaid 1915(c)	Restrictions lifted under Appendix K
	Veteran-Directed Care – Denver	Veterans Affair	No restrictions
	Veteran-Directed Care – Grand Junction	Veterans Affairs	No restrictions

*Appendix K is a formal document that states can submit to the federal government to request temporary changes or modifications to their waiver(s) during an emergency. The purpose of Appendix K is to ensure states are able to act quickly to address emergencies, such as a pandemic or natural disaster.

State	Program Name	Funding Source	Family Caregiver Restrictions
Connecticut	Community First Choice	Medicaid 1915(k)	Community First Choice does not allow spouses or legally responsible individuals.
	Connecticut Home Care Program for Elders	Medicaid 1915(c)	Connecticut Home Care Program for Elders does not allow spouses or legally responsible individuals.
	Personal Care Assistance Program	Medicaid 1915(c)	Personal Care Assistance Program does not allow spouses or legally responsible individuals. Personal Care Assistance Program under Appendix K does not permit "liable family members."
	Veteran-Directed Care – New Haven	Veterans Affairs	No restrictions
Delaware	Attendant Services Program	State funded	No restrictions
	Diamond State Health Plan Plus	Medicaid 1115	No restrictions
District of Columbia	Elder and Person with Physical Disabilities Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Veteran-Directed Care – District of Columbia	Veterans Affairs	No restrictions
Florida	Florida Long-Term Care Waiver	Medicaid 1915(c)	No restrictions
	Veteran-Directed Care – Bay Pines	Veterans Affairs	No restrictions
	Veteran-Directed Care – Gainesville	Veterans Affairs	No restrictions
	Veteran-Directed Care – Miami	Veterans Affairs	No restrictions
	Veteran-Directed Care – Orlando	Veterans Affairs	No restrictions
	Veteran-Directed Care – Tampa	Veterans Affairs	No restrictions
	Veteran-Directed Care – West Palm	Veterans Affairs	No restrictions
Georgia	Elderly and Disabled Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Independent Care Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Veteran-Directed Care – Atlanta	Veterans Affairs	No restrictions
Hawaii	QUEST Integration	Medicaid 1115	No restrictions
	Veteran-Directed Care – Honolulu	Veterans Affairs	No restrictions
Idaho	Aged and Disabled Waiver	Medicaid 1915(c)	Aged and Disabled Waiver does not allow legally responsible individuals or spouses.
	Veteran-Directed Care – Boise	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
Illinois	Persons with Disabilities/Physically Disabled	Medicaid 1915(c)	Persons with Disabilities/Physically Disabled does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Chicago	Veterans Affairs	No restrictions
	Veteran-Directed Care – Danville	Veterans Affairs	No restrictions
	Veteran-Directed Care – Hines	Veterans Affairs	No restrictions
	Veteran-Directed Care – Marion	Veterans Affairs	No restrictions
	Veteran-Directed Care – North Chicago	Veterans Affairs	No restrictions
Indiana	Aged and Disabled Waiver	Medicaid 1915(c)	Aged and Disabled Waiver does not allow spouses or legally responsible individuals.
Iowa	Consumer Choices Option	Medicaid 1915(c)	Consumer Choices Option does not allow spouses or legally responsible individuals.
	Consumer-Directed Attendant Care	Medicaid 1915(c)	Consumer-Directed Attendant Care does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Iowa City	Veterans Affairs	No restrictions
Kansas	Frail Elderly Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Physical Disability Waiver	Medicaid 1915(c)	No restrictions under Appendix K
Kentucky	HCBS Transitions	Medicaid 1915(c)	No restrictions
	HCBS Waiver	Medicaid 1915(c)	No restrictions
	Veteran-Directed Care – Lexington	Veterans Affairs	No restrictions
	Veteran-Directed Care – Louisville	Veterans Affairs	No restrictions
Louisiana	Community Choices Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Veteran-Directed Care – Shreveport	Veterans Affairs	No restrictions
Maine	Elderly and Adults with Disabilities Waiver	State funded	Elderly and Adults with Disabilities Waiver does not allow spouses or legally responsible individuals.
	In-Home and Community Support Services for Elderly and Other Adults	Medicaid 1915(c)	No restrictions
	Veteran-Directed Care – Togus	Veterans Affairs	No restrictions
Maryland	Veteran-Directed Care – Perry Point	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
Massachusetts	Moving Forward Plan Community Living	Medicaid 1915(c)	Moving Forward Plan Community Living does not allow legally responsible individuals or spouses.
	Moving Forward Plan (MFP) Residential Supports	Medicaid 1915(c)	MFP Residential Supports does not allow legally responsible individuals or spouses.
	Senior Care Options Personal Care Attendant (PCA) Program	Medicaid State Plan	Senior Care Options PCA Program does not allow legally responsible individuals or spouses.
	Veteran-Directed Care – Bedford	Veterans Affairs	No restrictions
	Veteran-Directed Care – Boston	Veterans Affairs	No restrictions
Michigan	MI Choice	Medicaid 1915(c)	MI Choice does not allow legally responsible individuals.
	MI HealthLink	Medicaid 1915(c)	MI HealthLink does not allow legally responsible individuals or spouses.
	Veteran-Directed Care – Ann Arbor	Veterans Affairs	No restrictions
	Veteran-Directed Care – Battle Creek	Veterans Affairs	No restrictions
	Veteran-Directed Care – Detroit	Veterans Affairs	No restrictions
	Veteran-Directed Care – Iron Mountain	Veterans Affairs	No restrictions
	Veteran-Directed Care – Saginaw	Veterans Affairs	No restrictions
Minnesota	Community Access for Disability Inclusion	Medicaid 1915(c)	No restrictions
	Consumer-Directed Community Supports	Medicaid 1915(c)	No restrictions
	Consumer Support Grant	State funded	No restrictions
	Deaf Blind Consumer Directed	State funded	No restrictions
	Personal Care Assistance Choice	Medicaid State Plan	Personal Care Assistance Choice does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Sioux Falls	Veterans Affairs	No restrictions
Mississippi	Independent Living Waiver	Medicaid 1115	Independent Living Waiver Appendix K does not allow legally responsible individuals.
	Veteran-Directed Care – Gulf Coast	Veterans Affairs	No restrictions
	Veteran-Directed Care – Jackson	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
Missouri	Independent Living Waiver	Medicaid 1915(c)	Independent Living Waiver Appendix K does not allow family living in the same household, spouses, or legally responsible individuals.
	State Plan Consumer-Directed Services	Medicaid State Plan	State Plan Consumer-Directed Services does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Kansas City	Veterans Affairs	No restrictions
	Veteran-Directed Care – St. Louis	Veterans Affairs	No restrictions
Montana	Big Sky	Medicaid 1915(c)	No restrictions
	Veteran-Directed Care – Missoula	Veterans Affairs	No restrictions
Nebraska	Nebraska's Personal Assistance Services	Medicaid State Plan	Nebraska's Personal Assistance Services does not allow spouses or legally responsible individuals.
Nevada	HCBS Waiver for Persons with Physical Disabilities	Medicaid 1915(c)	No restrictions under Appendix K
New Hampshire	Choices for Independence	Medicaid State Plan	No restrictions under Appendix K
	Veteran-Directed Care – Manchester	Veterans Affairs	No restrictions
New Jersey	Personal Assistance Services Program	State funded	No restrictions
	Personal Preferences Program	Medicaid State Plan	Personal Preferences Program does not allow legally responsible individuals.
	Veteran-Directed Care – Lyons	Veterans Affairs	No restrictions
New Mexico	Centennial Care 2.0	Medicaid 1115	No restrictions under Appendix K
	Veteran-Directed Care – Albuquerque	Veterans Affairs	No restrictions
New York	Community First Choice	Medicaid 1915(j)	Community First Choice does not allow spouses.
	Enhanced In-Home Services for the Elderly	State funded	No restrictions
	Veteran-Directed Care – Albany	Veterans Affairs	No restrictions
	Veteran-Directed Care – Syracuse	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
North Carolina	Community Alternative Program for Adults with Disabilities	Medicaid 1915(c)	No restrictions under Appendix K
	Veteran-Directed Care – Asheville	Veterans Affairs	No restrictions
North Dakota	Veteran-Directed Care – Fargo	Veterans Affairs	No restrictions
Ohio	My Care Ohio	Medicaid 1915(b/c)	My Care Ohio restrictions lifted under Appendix K
	PASSPORT	Medicaid 1915(c)	PASSPORT restrictions lifted under Appendix K
	Veteran-Directed Care – Chillicothe	Veterans Affairs	No restrictions
	Veteran-Directed Care – Toledo	Veterans Affairs	No restrictions
Oklahoma	ADvantage Care	Medicaid 1915(c)	No restrictions under Appendix K
	Medically Fragile Waiver	Medicaid 1915(c)	No restrictions under Appendix K
Oregon	1915(j)	Medicaid 1915(j)	No restrictions
	K Plan	Medicaid 1915(k)	No restrictions
	Veteran-Directed Care – Portland	Veterans Affairs	No restrictions
	Veteran-Directed Care – Roseburg	Veterans Affairs	No restrictions
	Veteran-Directed Care – White City	Veterans Affairs	No restrictions
Pennsylvania	Aging Waiver	Medicaid 1915(c)	Aging Waiver does not allow spouses
	Independence Waiver	Medicaid 1915(c)	Independence Waiver does not allow spouses.
	Attendant Care Waiver	Medicaid 1915(c)	Attendant Care Waiver does not allow spouses.
	Veteran-Directed Care – Coatesville	Veterans Affairs	No restrictions
	Veteran-Directed Care – Philadelphia	Veterans Affairs	No restrictions
Rhode Island	Personal Choice (aka Consumer Choice)	Medicaid 1115	Personal Choice does not allow legally responsible individuals or spouses.
South Carolina	Community Choices	Medicaid 1915(c)	Community Choices does not allow spouses or legally responsible individuals.
South Dakota	Assistive Daily Living Services	Medicaid 1915(c)	No restrictions
Tennessee	TennCare CHOICES	Medicaid 1115	TennCare CHOICES does not allow individuals to hire anyone who lived with the member within the past five years. A family member cannot be hired to replace "natural supports" that the family member would generally provide to enhance the quality and security of life for the LTSS recipient.
	Veteran-Directed Care – Nashville	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
Texas	Consumer Managed Personal Attendant Services	State funded	Consumer Managed Personal Attendant Services does not allow legal guardians.
	STAR+PLUS	Medicaid 1115	STAR+PLUS does not allow spouses.
	Veteran-Directed Care – Dallas	Veterans Affairs	No restrictions
	Veteran-Directed Care – Houston	Veterans Affairs	No restrictions
	Veteran-Directed Care – San Antonio	Veterans Affairs	No restrictions
	Veteran-Directed Care – Temple	Veterans Affairs	No restrictions
Utah	Aging Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	New Choices Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Physical Disabilities Waiver	Medicaid 1915(c)	No restrictions under Appendix K
	Veteran-Directed Care – Salt Lake City	Veterans Affairs	No restrictions
Vermont	Choices for Care	Medicaid 1115	Choices for Care allows parents to be paid only if they are not the guardian. Spouses cannot be paid for assisting with independent activities of daily living (IADLs) or respite, but can be paid for companion services.
	Flexible Choices	Medicaid 1115	No restrictions
	Participant-Directed Attendant Care – General Fund	State funded	No restrictions
	Veteran-Directed Care – White River Junction	Veterans Affairs	No restrictions
Virginia	Commonwealth Coordinated Care Plus	Medicaid 1915(c)	Commonwealth Coordinated Care Plus does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Hampton	Veterans Affairs	No restrictions
	Veteran-Directed Care – Richmond	Veterans Affairs	No restrictions
	Veteran-Directed Care – Salem	Veterans Affairs	No restrictions

State	Program Name	Funding Source	Family Caregiver Restrictions
Washington	Community First Choice	Medicaid 1915(k)	Community First Choice does not allow spouses or legally responsible individuals.
	New Freedom	Medicaid 1915(c)	New Freedom does not allow spouses or legally responsible individuals.
	Roads to Community Living	Money Follows the Person	Roads to Community Living does not allow spouses.
	Veteran-Directed Care – Seattle	Veterans Affairs	No restrictions
	Veteran-Directed Care – Spokane	Veterans Affairs	No restrictions
	Veteran-Directed Care – Walla Walla	Veterans Affairs	No restrictions
West Virginia	Aged and Disabled Disability Waiver	Medicaid 1915(c)	No restrictions under Appendix K
Wisconsin	Family Care	Medicaid 1915(c)	No restrictions
	Include, Respect, I Self-Direct – Self-Directed Elderly and Physical Disability	Medicaid 1915(c)	No restrictions
	Veteran-Directed Care – Milwaukee	Veterans Affairs	No restrictions
	Veteran-Directed Care – Tomah	Veterans Affairs	No restrictions
Wyoming	Community Choices	Medicaid 1915(c)	Community Choices does not allow spouses or legally responsible individuals.
	Veteran-Directed Care – Cheyenne	Veterans Affairs	No restrictions

