Fulfilling the *Olmstead* Decision's Right to Home-Based Care in 2022: Paying Spousal Caregivers

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ABSTRACT: In Olmstead v. L.C.*, the Supreme Court held that individuals are entitled to receive skilled care in the least restrictive setting appropriate to their care needs. This was a major advancement for many older adults and individuals with disabilities living in institutional facilities but wishing to receive care in their home or community. In the years since the* Olmstead *decision, the use of home and community-based care ("HCBS") has dramatically increased as an alternative to institutional care. However, a lack of available care providers has led to months- and years-long waiting lists for those in need of care who wish to receive HCBS care through their state Medicaid programs.*

This Note argues that state Medicaid programs should allow spouses to be reimbursed as a Medicaid recipient's HCBS care provider. This would increase the pool of available caretakers, while also alleviating the financial strain those informally taking care of a partner can face. Fifteen states currently allow spouses to be paid as caretakers through federal waivers of traditional Medicaid program requirements. This Note analyzes the key policy choices these states make to allow spouses to be paid caretakers while managing program fraud and abuse concerns—and argues that additional states should follow suit.

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INTRODUCTION

The United States is facing a health care crisis of pandemic proportions, and it's not COVID-19. Our population is aging at an unprecedented rate, and with this trend comes an increase in the number of individuals requiring care assistance.[1] While this care can be provided in a nursing facility setting, individuals have a right to receive this care in their communities.[2] Indeed, when presented with the choice, most people would prefer to stay in their homes rather than transition to a facility setting.[3] However, the availability of health care workers to provide home and community-based care ("HCBS") has not kept pace with demand.[4] By 2025, it is estimated that there will be a shortage of 446,300 home health care workers.[5] This gap leaves seniors, those with disabilities, and their families with few options. Many must make the difficult choice of either foregoing services or moving to a nursing facility, even though this care could be provided less expensively in their homes with the proper support.

The right to receive care in one's home and community, rather than an institutional setting, was established in the 1999 Supreme Court decision of *Olmstead v. L.C.*[6] *Olmstead* was a landmark decision for disability and elder rights advocates, and in the years since, care provision outside of institutional settings has grown dramatically.[7] Subsequent case law has indicated that this protection applies not only to those individuals who are currently institutionalized and wish to be in the community, but also individuals who face a threat of institutionalization due to a lack of community-based services.[8]

In the years since the *Olmstead* decision, state Medicaid programs have continued to invest in community-based options as an alternative to institutional

1. *See* Amy Baxter, *Where the Home Health Aide Shortage Will Hit Hardest by 2025*, HOME HEALTH CARE NEWS (May 6, 2018), https://homehealthcarenews.com/2018/05/where-the-home-health-aide-shortage-will-hit-hardest-by-2025 [https://perma.cc/F8JE-TG7B].

2. Olmstead v. Zimring *ex rel.* L.C., 527 U.S. 581, 597 (1999).

3. *New Public Opinion Poll Finds Strong Support for Home Health, Choose Home Care Act*, CISION PR NEWSWIRE (Sept. 14, 2021, 12:00 PM), https://www.prnewswire.com/news-releases/new-public-opinion-poll-finds-strong-support-for-home-health-choose-home-care-act-301376457.html [https://perma.cc/PRR6-DGE7].

4. Baxter, *supra* note 1.

5. *Id.*

6. *Olmstead*, 527 U.S. at 597.

7. *Id.*

8. Pashby v. Delia, 709 F.3d 307, 322–23 (4th Cir. 2013).

care.[9] However, due to a national shortage of home health care workers to provide this care in non-institutional settings, *Olmstead* protections are threatened.[10] When an individual wishes to receive care in their community but there is no one available to provide it, they face a risk of institutionalization. Indeed, there are over 800,000 people in the United States who qualify for community-based care but are unable to receive it because of the lack of care providers.[11]

State Medicaid programs are combatting home care staffing shortages and increasing choice in services by offering consumer-directed care options. Consumer-directed service programs provide the individual requiring care with the power to recruit their own at-home care aides.[12] In many states, this means that a friend or family member can be employed by the individual to provide their care. [13]

Unfortunately, in thirty-five states, spouses are excluded from the category of employable care providers.[14] Allowing spousal reimbursement could alleviate both staffing shortages and mitigate the financial burden spouses face when acting in an informal caregiving role.[15] States can use Medicaid program waiver flexibilities to add spouses as allowable caregivers.[16] Though some states may have been hesitant to add spouses as paid providers to their Medicaid programs because of fraud and abuse concerns, there are a variety of tools states can use to prevent program abuse.[17]

This Note argues that states should reimburse spousal caregivers as paid HCBS providers under their Medicaid programs to address the home care staffing shortage. To lay the groundwork for this approach, in Part II, this Note begins by providing background context on the long-term care industry, the right of individuals to receive care in a community setting, and Medicaid's role in providing HCBS. Part III then discusses the lack of home and community-based care providers and the exclusion of spouses from most state Medicaid HCBS programs. In Part IV, this Note offers a solution to this problem by

9. SALOM TESHALE, WENDY FOX-GRAGE & KITTY PURINGTON, PAYING FAMILY CAREGIVERS THROUGH MEDICAID CONSUMER-DIRECTED PROGRAMS: STATE OPPORTUNITIES AND INNOVATIONS 2–10 (2021).

10. *Fact Sheet: Why Older Adults Need Bold Investment in Medicaid HCBS*, JUST. IN AGING (July 21, 2021), https://justiceinaging.org/fact-sheet-why-older-adults-need-bold-investment-in-medicaid-hcbs [https://perma.cc/GV6Y-B77X].

11. *Id.*

12. A.E. Benjamin, Ruth Matthias & Todd M. Franke, *Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home*, 35 HEALTH SERVS. RSCH. 351, 352 (2000).

13. *Id.* at 361.

14. *See Spouses Can Be Paid Caregivers for Their Husbands or Wives*, PAYING FOR SENIOR CARE (June 16, 2021), https://www.payingforseniorcare.com/paying-spousal-caregivers [https://perma.cc/Y9JV-L2MX] (listing the fifteen states with programs that pay spouses to be caregivers).

15. *See* discussion *infra* Section IV.B.

16. *See* discussion *infra* Section II.D.2.ii.

17. *See* discussion *infra* Sections IV.C–.D.

analyzing approaches states can take to add spouses as compensable care providers and address the concerns that have prevented states from doing so up until now. By describing a variety of approaches, this Note provides a solution that is flexible enough to fit the needs of any state and its Medicaid program structure.

I. THE LONG-TERM CARE INDUSTRY AND THE RIGHT TO COMMUNITY-BASED CARE

To understand the need for spousal pay in long-term care settings and how states can go about doing so, this Part discusses the primary types of long-term care and home and community-based services available. After an overview of the current landscape, this Part describes the growing need for long-term care that will persist into the future if left unaddressed. This Part then discusses the *Olmstead* decision, which provided individuals with the right to care in community-based, rather than institutional, settings and further increased the demand for home-based care options. Finally, this Part concludes by describing the important role the Medicaid program plays in structuring and funding consumer-directed home and community-based services.

A. LONG-TERM CARE AND HOME AND COMMUNITY-BASED SERVICES

Long-term care is a term used to describe a variety of services and delivery methods that fall under the general umbrella of assisting individuals with medical and personal care needs.[18] Examples include nursing homes, assisted living facilities, and adult day care programs.[19] Long-term care is a continuum and can range from living in one's own home with a few hours per day of support services to twenty-four-hour supervision in a facility.[20] This means that there are a range of care settings and providers that an individual can choose from to meet their particular needs. On the high-need end of the spectrum, skilled nursing facilities provide twenty-four-hour care, are staffed by registered nurses, and offer skilled services such as physical therapy, occupational therapy, speech therapy, and medication management.[21] On the low-need end of the spectrum, continuing care retirement communities can offer independent housing options for residents who need minimal assistance such as meal services and transportation.[22]

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18. *What Is Long-Term Care?*, NAT'L INST. ON AGING (May 1, 2017), https://www.nia.nih.gov/health/what-long-term-care [https://perma.cc/3W9A-G3LS].

19. *Id.*

20. *See generally* Kimberlyn McGrail, *Long-Term Care as Part of the Continuum*, 10 HEALTHCAREPAPERS 39 (2011) (discussing long-term care and the different forms it can take).

21. *Nursing Home/Skilled Nursing Facility Care*, CTR. FOR MEDICARE ADVOC., https://medicareadvocacy.org/medicare-info/skilled-nursing-facility-snf-services [https://perma.cc/2VTZ-ZSL2].

22. Maureen Stanley, *Continuing Care Retirement Communities (CCRCs)*, SENIOR LIVING (June 28, 2021), https://www.seniorliving.org/continuing-care-retirement-communities [https://perma.cc/2ABK-WLTL].

Long-term care is not limited to the institutional setting. In fact, even individuals that need an institutional level of care can receive it in the comfort of their homes and communities with the aid of HCBS.[23] Like long-term care, HCBS is a general term that can encompass a variety of services across a range of need levels.[24] The same medical services provided in a skilled nursing facility, such as skilled nursing care, occupational therapy, speech therapy, and physical therapy, can be provided to individuals in their homes.[25] Less intensive social services can similarly be provided in a home-based setting by home health aides. These services can include assistance with personal care, such as dressing, bathing, toileting, eating, meal services, transportation, and home modifications, to name a few.[26]

HCBS care has many benefits compared to an institutional setting.[27] First, it is less costly than care in a nursing home or assisted living facility by an average of almost $1,600 per month, or $19,200 annually.[28] It can also better support an individual's spiritual and cultural needs, allow individuals to stay in familiar surroundings, and provide people with the opportunity to stay involved in their local community.[29] Because of these advantages, HCBS are a popular choice for those needing care, and Medicaid HCBS programs have grown significantly in recent years.[30]

B. THE GROWING NEED FOR LONG-TERM CARE

Today, there are over 49.2 million Americans over the age of sixty-five.[31] This number has increased thirty-three percent since 2006 and "is projected to almost double to [ninety-eight] million in 2060."[32] As the population ages, so will the need for long-term care. Although three percent of those aged sixty-five to seventy-four require caregiving services, this number increases to twenty-two percent by age eighty-five.[33] Though the need for long-term care services increases with age and across all age groups, there are also twenty

23. TESHALE ET AL., *supra* note 9, at 4.

24. *Home- and Community-Based Services*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Dec. 1, 2021, 8:00 PM), https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs [https://perma.cc/4ZNG-K9Q8].

25. *Id.*

26. *Id.*

27. *Id.*

28. Karen Dorman Marek, Frank Stetzer, Scott J. Adams, Lori L. Popejoy & Marilyn Rantz, *Aging in Place Versus Nursing Home Care: Comparison of Costs to Medicare and Medicaid*, 5 RSCH. GERONTOLOGICAL NURSING 123, 123 (2012).

29. *Home- and Community-Based Services*, *supra* note 24.

30. TESHALE ET AL., *supra* note 9, at 4.

31. ADMIN. FOR CMTY. LIVING, 2017 PROFILE OF OLDER AMERICANS 1–2 (2018).

32. *Id.*

33. *Id.*

million older Americans and Americans with disabilities that require help with activities of daily living.[34]

With increased demand for long-term care also comes increased demand for individuals to provide this care, either formally or informally. In the United States, 4.5 million individuals are employed as direct care workers who provide care to people with disabilities and other functional limitations that prevent them from completing daily tasks without assistance.[35] Informally, 43.5 million individuals provide unpaid care annually.[36]

C. THE OLMSTEAD *DECISION: THE AMERICANS WITH DISABILITIES ACT'S RIGHT TO CARE IN COMMUNITY-BASED SETTINGS*

As the need for long-term care has grown, so has scrutiny over where this care is provided. In the 1999 landmark Supreme Court Case of *Olmstead v. L.C.*, the Supreme Court held that under the Americans with Disabilities Act ("ADA"), plaintiffs with disabilities who currently resided in long-term care facilities were entitled to receive care in their community.[37] This Part begins by describing the key law applied in the *Olmstead* decision, including Title II of the ADA and the regulations implementing it. With this background, this Part then summarizes the *Olmstead* decision and why it was a critical turning point in recognizing the rights of individuals with disabilities. Finally, this Part concludes by discussing the *Olmstead* decision's lasting impact and the subsequent case law that has applied *Olmstead* and expanded its reach.

1. The Americans with Disabilities Act Title II and Implementing Regulations

The ADA, passed in 1990, was a watershed civil rights law that prohibited discrimination in public life against those with disabilities.[38] After enactment of the ADA, it became illegal to discriminate against individuals with disabilities in areas "including jobs, schools, transportation, and all public and private places that are open to the general public."[39] The ADA is comprised of five titles, each of which deal with discrimination in different public sectors.[40]

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34. Kristi L. Kirschner, Lisa I. Iezzoni & Tanya Shah, *The Invisible COVID Workforce: Direct Care Workers for Those with Disabilities*, THE COMMONWEALTH FUND: TO THE POINT (May 21, 2020), https://www.commonwealthfund.org/blog/2020/invisible-covid-workforce-direct-care-workers-those-disabilities [https://perma.cc/M28T-68BX].

35. *Id.*

36. *Caregiver Statistics: Demographics*, FAM. CAREGIVER ALL. (2016), https://www.caregiver.org/resource/caregiver-statistics-demographics [https://perma.cc/PET2-F8VD].

37. Olmstead v. Zimring *ex rel.* L.C., 527 U.S. 581, 607 (1999).

38. ADA NAT'L NETWORK, AN OVERVIEW OF THE AMERICANS WITH DISABILITIES ACT 1 (2017), https://adata.org/sites/adata.org/files/files/ADA_Overview_final2017.pdf [https://perma.cc/R8ZJ-ZH4S].

39. *Id.*

40. The Americans with Disabilities Act of 1990 §§ 101–513, 42 U.S.C. §§ 12101–12213 (2018); *see also Americans with Disabilities Act (ACA)*, INC. (Feb. 6, 2020), https://www.inc.com

Relevant to this discussion is Title II, which pertains to discrimination in public services, including state and local governments.[41] More specifically, under Title II is Section 202 which provides that individuals with disabilities cannot be excluded from any public service or activity because of their disability.[42] Under Section 204(a), Congress gave the Attorney General the power to create regulations to implement Title II, subtitle A.[43] Relevant to this discussion are 28 C.F.R. § 35.130(d) ("integration regulation") and 28 C.F.R. § 35.130(b)(7) ("reasonable-modifications regulation").[44]

The integration regulation requires "[a] public entity [to] administer . . . programs . . . in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[45] "Most integrated setting" has been defined as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."[46] At a basic level, the purpose of this regulation is to allow the same access to community resources to those with disabilities as those without disabilities.[47]

The "reasonable modification" regulation requires "public entit[ies to] make reasonable modifications . . . to avoid discrimination on the basis of disability."[48] A modification is reasonable when it "would [not] fundamentally alter the nature of the service, program, or activity."[49] An alteration is fundamental when it "is so significant that it alters the essential nature of the goods, services, facilities, privileges, advantages, or accommodations offered."[50] This means that if an establishment offers services for one individual or a group, it must offer reasonable accommodations so that all individuals can

/encyclopedia/americans-with-disabilities-act-ada.html [https://perma.cc/399H-TWQM] (describing in greater detail the four sections of the ADA).

41. 42 U.S.C. §§ 12131–12165; U.S. Dep't of Just., *Information and Technical Assistance on the Americans with Disabilities Act: State and Local Governments (Title II)*, ADA.GOV [hereinafter *Information and Technical Assistance*], https://www.ada.gov/ada_title_II.htm [https://perma.cc/4GQ9-USRM]. The other Titles of the ADA include Title I—Employment, Title III—Public Accommodations and Services Operated by Private Entities, and Title IV—Miscellaneous Provisions. *See* 42 U.S.C. §§ 12101–12213.

42. *See* 42 U.S.C. § 12132 ("[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.").

43. *See Id.* § 12134.

44. *See* Olmstead v. Zimring *ex rel.* L.C., 527 U.S. 581, 592 (1999).

45. *Id.* (quoting 28 C.F.R. § 35.130(d) (1998)).

46. *Id.* (quoting 28 C.F.R. pt. 35 app. A (1998)).

47. *See* U.S. DEP'T OF JUST., CIV. RTS. DIV. DISABILITY RTS. SECTION, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND OLMSTEAD V. L.C. (2020) [hereinafter *DOJ Statement on Integration Mandate*], https://www.ada.gov/olmstead/q&a_olmstead.htm [https://perma.cc/NU6A-DFX8].

48. *Olmstead*, 527 U.S. at 592 (quoting 28 C.F.R. § 35.130(b)(7)).

49. *See id.* (quoting 28 C.F.R. § 35.130(b)(7)).

50. *Reaching Out to Customers with Disabilities: Lesson One: Policies, Practices, and Procedures*, ADA, https://www.ada.gov/reachingout/lesson12.htm [https://perma.cc/P6RJ-Z7J4].

access that service, regardless of their disability.[51] In practice, a simplified example of this would be modifying a dish at a restaurant—while substituting certain ingredients would be a reasonable modification, making an entirely different dish would not.[52]

2. The *Olmstead* Decision

Individual plaintiffs can bring actions against public entities under Title II Section 12123 of the ADA when they believe their right to be free from discrimination has been violated.[53] The *Olmstead* suit was brought by two women with mental health conditions that had been receiving care in institutional settings, even though their health care providers certified that they could receive care safely in a community setting.[54] The plaintiffs alleged that the State violated Title II of the ADA, pertaining to state and local governments,[55] by not placing them in a community setting after it was designated appropriate by their health care providers.[56] In interpreting the integration and reasonable modification regulations, the *Olmstead* decision held that "unjustified isolation . . . is properly regarded as discrimination based on disability."[57] Supporting this holding, the Court elaborated that placing individuals in institutional settings when not required further perpetuated the idea that those with disabilities cannot "participat[e] in community life."[58] Additionally, institutionalization limits true community integration, from "family relations" to "educational advancement."[59] Addressing the limitations of the "reasonable modification" regulation, the Court recognized that states were limited by the resources at their disposal. However, when evaluating community-based care options available, states must not solely be guided by cost concerns, "but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably."[60] In other words, while states can consider costs in choosing the community-based programming they will offer, they must also prioritize ensuring that the services individuals receive in a community setting are comparable to those received in an institutional setting.

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51. *See id.*
52. *See id.*
53. 42 U.S.C. § 12123.
54. *Olmstead*, 527 U.S. at 593–96.
55. *Information and Technical Assistance*, *supra* note 41.
56. *Olmstead*, 527 U.S. at 593.
57. *Id.* at 597.
58. *Id.* at 601.
59. *Id.*
60. *Id.* at 597.

3. *Olmstead*'s Impact on Subsequent Disability-Rights Litigation

In the years since the *Olmstead* decision, subsequent case law has made it clear that the *Olmstead* protections described above do not just apply to individuals that are already institutionalized, like the plaintiffs in *Olmstead*. These protections also apply to individuals that currently *do* receive care in community settings but face a threat of institutionalization.[61] An individual need not wait to be institutionalized to be able to make an *Olmstead* claim.[62] Cases from the Fourth Circuit and Tenth Circuit, as well as guidance by the U.S. Department of Justice ("DOJ"), all clearly indicate that the ADA and the Rehabilitation Act's[63] protections are not limited to those individuals already in institutional settings.[64] Rather, an individual in a community setting can present an ADA or *Olmstead* claim when there is a serious risk of institutionalization (for example, due to lack of community-based services).

As the primary facilitator of federal lawsuits to enforce the ADA, the DOJ has provided guidance on how serious the "threat of institutionalization" needs to be to constitute an *Olmstead* violation in a community-based setting.[65] In its 2011 guidance, the DOJ indicated that they would find a "sufficient risk of institutionalization" when inadequacies in community-based services "will likely cause a decline in health, safety, or welfare that would lead to the individual's eventual placement in an institution."[66] However, as described in *Olmstead*, a state is not required to make changes that would "fundamentally alter" their

61. Pashby v. Delia, 709 F.3d 307, 322 (4th Cir. 2013).

62. *Id.*

63. The Rehabilitation Act was passed in 1973 and was the "predecessor" to the ADA. *See* Shirley Wilcher, *The Rehabilitation Act of 1973: 45 Years of Activism and Progress*, INSIGHT INTO DIVERSITY (Sept. 17, 2018), https://www.insightintodiversity.com/the-rehabilitation-act-of-1973-45-years-of-activism-and-progress [https://perma.cc/4GH4-CCBE]. Similar to the ADA, its purpose was to advance the ability of those with disabilities to participate fully in society. *See id.* It "was the first legislation to address the notion of equal access for individuals with disabilities through the removal of architectural, employment, and transportation barriers." *Id.*

64. *Pashby*, 709 F.3d at 322 (discussing DOJ guidance and stating that "individuals who must enter institutions to obtain Medicaid services for which they qualify may be able to raise successful Title II and Rehabilitation Act claims because they face a risk of institutionalization"); Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1181 (10th Cir. 2003) (concluding that *Olmstead* protections are not limited to those who are institutionalized); *DOJ Statement on Integration Mandate*, *supra* note 47.

65. *Information and Technical Assistance*, *supra* note 41.

66. *DOJ Statement on Integration Mandate*, *supra* note 47. The Trump Administration took a step back from the vigorous enforcement of *Olmstead* protections by the Obama Administration. *See generally DOJ Withdraws Olmstead Employment Guidance*, CTR. FOR PUB. REPRESENTATION, https://www.centerforpublicrep.org/initiative/doj-withdraws-olmstead-employment-guidance [https://perma.cc/3798-FVAM] (rescinding Obama-era guidance related to the application of *Olmstead* in employment). However, the Biden Administration has indicated that it will aggressively enforce *Olmstead* protections, making the Obama-era guidance a good indicator of enforcement to come. *The Biden Plan for Full Participation and Equality for People with Disabilities*, BIDEN HARRIS, https://joebiden.com/disabilities [https://perma.cc/8HQM-X2ET].

Medicaid program.[67] Instead, the court will evaluate if there is a prohibited discrimination present by looking for the existence of disparities in treatment between community-based services and services offered in an institutional setting.[68]

D. THE ROLE OF MEDICAID IN CONSUMER-DIRECTED HOME AND COMMUNITY-BASED SERVICES

The majority of long-term care is funded by the Medicaid program,[69] which is financed jointly by federal and state governments.[70] Generally, the Medicaid program exists to pay for the health care of low-income individuals.[71] However, even individuals who are financially independent can quickly go bankrupt when they must begin to pay for long-term care.[72] "[F]or a semi-private room in a nursing [facility]," Americans can expect to pay an average of $6,844 per month, or over $82,000 annually.[73] Thus, individuals in need of long-term care spend down their assets until they qualify financially for the Medicaid program.[74] Understandably, this cost, combined with an aging population increasingly in need of long-term care, has placed a significant cost burden on the Medicaid program.[75] In 2019, state and federal governments

67. Olmstead v. Zimring *ex rel.* L.C., 527 U.S. 581, 592–97 (1999).

68. *See, e.g.*, *Fisher*, 335 F.3d at 1181 (determining that there was a genuine issue of material fact whether imposing a five-prescription cap for HCBS beneficiaries—but not institutional beneficiaries—created irreparable harm for HCBS beneficiaries.).

69. ERICA L. REAVES & MARYBETH MUSUMECI, KAISER FAM. FOUND., MEDICAID AND LONG-TERM SERVICES AND SUPPORTS: A PRIMER 1–9 (2015), https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer [https://perma.cc/GBU5-4DUC].

70. SAMANTHA ARTIGA, ELIZABETH HINTON, ROBIN RUDOWITZ & MARYBETH MUSUMECI, KAISER FAM. FOUND., CURRENT FLEXIBILITY IN MEDICAID: AN OVERVIEW OF FEDERAL STANDARDS AND STATE OPTIONS 3 (2017), https://www.kff.org/medicaid/issue-brief/current-flexibility-in-medicaid-an-overview-of-federal-standards-and-state-options [https://perma.cc/BT67-WWEZ].

71. Jean Hearne & Julie Topoleski, *An Overview of the Medicaid Program*, CONG. BUDGET OFF. (Sept. 18, 2013), https://www.cbo.gov/publication/44588 [https://perma.cc/VH7J-WCZN].

72. Teresa Wiltz, *Getting Older, Going Broke: Who's Going to Pay for Long-Term Care?*, PEW (July 25, 2019), https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2019/07/25/getting-older-going-broke-whos-going-to-pay-for-long-term-care [https://perma.cc/2RPW-D29G].

73. *Costs of Care*, LONGTERMCARE.GOV (Feb. 18, 2020), https://acl.gov/ltc/costs-and-who-pays/costs-of-care [https://perma.cc/N4HR-MZE6]. While the average cost of a semi-private room annually is $82,000, in some states this average is well over $300,000. For example, in Alaska, the cost of "[a] semi-private room averages over $330,000 per year." *Nursing Home Costs by State 2022*, WORLD POPULATION REV., https://worldpopulationreview.com/state-rankings/nursing-home-costs-by-state [https://perma.cc/39GJ-YRBG].

74. *See generally Costs of Care*, *supra* note 73 (discussing the average costs of long-term care); *Medicaid*, LONGTERMCARE.GOV, https://acl.gov/ltc/medicare-medicaid-and-more/medicaid [https://perma.cc/42DB-2ACE] (explaining state Medicaid programs).

75. Richard W. Johnson, *Policy Forum: The Strains and Drains of Long-Term Care*, 10 AM. MED. ASS'N J. ETHICS, 397, 397–99 (2008).

spent approximately $129 billion in Medicaid funding for long-term care.[76] These long-term care expenses account for one-third of total Medicaid program expenditures.[77]

Cost concerns, combined with the individual choice concerns prevalent in *Olmstead*, have led to increased investment and growth in HCBS programs by Medicaid as an alternative to institutional long-term care.[78] Provision of HCBS is run by the states, subject to federal approval.[79] Because states receive federal financial assistance for their Medicaid programs, states must operate within federal standards in order to receive federal matching funds.[80] One of these federal standards includes providing long-term care and home health services.[81] The federal government provides the states with a high level of flexibility in how they structure delivery of home health services, subject to required federal approval.

1. Consumer-Directed HCBS

One popular way states use this flexibility in their HCBS delivery is through consumer-directed HCBS. In fact, every state and Washington, D.C. provides some form of consumer-directed services option for its beneficiaries.[82] Traditionally, state Medicaid programs provide HCBS through an agency model.[83] Under this approach, Medicaid contracts with private home health care agencies, who provide the staff and are reimbursed to provide HCBS care to individuals in their homes.[84] By contrast, under the consumer-directed model, "the recipient of services . . . assumes responsibility for most of the organizational tasks traditionally performed by agencies."[85] These programs provide the individual requiring care or their legal representative with the power to recruit and select their care aides, as well as the subsequent training

76. *Distribution of Fee-for-Service Medicaid Spending on Long Term Care*, KAISER FAM. FOUND., https://www.kff.org/medicaid/state-indicator/spending-on-long-term-care [https://perma.cc/GBT3-A8SS].

77. Jenny Yang, *Medicaid Long-Term Care Services Expenditures in the United States from FY 1990 to FY 2020*, STATISTICA (Oct. 25, 2021), https://www.statista.com/statistics/245415/medicaid-spending-on-long-term-care-services-in-the-us-since-1990 [https://perma.cc/B69G-FQSV].

78. *See* TESHALE ET AL., *supra* note 9, at 2–5.

79. ARTIGA ET AL., *supra* note 70, at 7–9.

80. *Id.* at 3–7.

81. *See* MARYBETH MUSUMECI, MOLLY O'MALLEY WATTS & PRIYA CHIDAMBARAM, KAISER FAM. FOUND., KEY STATE POLICY CHOICES ABOUT MEDICAID HOME AND COMMUNITY-BASED SERVICES 2 (2020), https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-issue-brief [https://perma.cc/W6DC-4FY3].

82. TESHALE ET AL., *supra* note 9, at 3–5.

83. Benjamin et al., *supra* note 12, at 352.

84. *Id.*

85. *Id.*

and monitoring required.[86] In many states, this means that a friend or family member can be employed by the individual to provide their care. [87]

The consumer-directed model has been associated with increased safety, higher levels of satisfaction, and a better ability to address unmet care needs than the traditional agency model.[88] Moreover, individuals who choose their own care providers are better able to find caretakers who meet their linguistic preferences and other person-specific needs they may have.[89] Because of the above distinctions, consumer-directed services are better able to prioritize the autonomy, choice, and self-determination of individuals requiring care.[90] Like the *Olmstead* decision's expanded recognition of individual choice in *where* care is provided, consumer-directed services mirror the same sentiments in respecting choice in *who* provides that care.

2. Authority for Delivering Medicaid Consumer-Directed HCBS

States apply for federal approval to offer consumer-directed HCBS through two main mechanisms: state plan amendments and waivers.[91] Each serve distinct functions and have different approval processes.[92] Whether a state chooses to structure their HCBS program through a state plan amendment or waiver is specific to that individual state and what Medicaid programmatic structures they already have in place.[93] Additionally, states can use a combination of state plan amendments and waivers in constructing their consumer-directed HCBS programs.[94] This Section begins by providing the background information necessary to understand both state plan amendments and waivers. Next, this Part focuses on the key policy choices a state must make when determining which waiver or state plan amendment to use, including financing, caps on enrollment, and level of care requirements.

i. State Plan Amendments

As a condition of receiving federal funding for their Medicaid programs, states must submit a state plan, which "is a formal, written agreement between

86. *Id.*

87. *Id.* at 361.

88. *Id.* at 360.

89. *Id.* at 361.

90. Valerie J. Bogart, *Consumer Directed Assistance Program Offers Greater Autonomy to Recipients of Home Care*, N.Y. STATE BAR ASS'N J., Jan. 2003, at 8, 8–13.

91. KAREN TRITZ, CONG. RSCH. SERV., RL32219, LONG-TERM CARE: CONSUMER-DIRECTED SERVICES UNDER MEDICAID 11–13 (2006).

92. KELLI DEPRIEST, SOHA VAZIRI, KARLYN TUNNELL & CAROLINE ADAMS, INST. FOR MEDICAID INNOVATION, MEDICAID 101: AN OVERVIEW OF STATE PLAN AMENDMENTS & WAIVERS 2–5 (2021), https://www.medicaidinnovation.org/_images/content/2021-IMI-Medicaid_201_Waivers-Report.pdf [https://perma.cc/3SA3-RDBF].

93. *See id.*

94. *See* TESHALE ET AL., *supra* note 9, at 4–5 (describing how states develop consumer-directed programs).

a state and the federal government . . . describing how that state administers its Medicaid program."[95] The plan describes required rules that the state agrees to abide by, any optional programs or services the state will implement, and how the state will determine program eligibility.[96] When states want to make changes to this plan, they do so through a state plan amendment.[97] State plan amendments are required when "states propose a change to any component of the Medicaid program."[98] The authorities for states to make changes that allow HCBS to be self-directed through their state plan include: the 1915(i) HCBS State Plan Option, the 1915(j) Self-Directed Personal Assistance Services State Plan Option, and the 1915(k) Community First Choice State Plan Option.[99] Each of these plans are named after the sections of the Social Security Act to which they pertain.[100]

ii. Waivers

States can also apply for waivers to receive federal permission to deviate from federal program requirements.[101] Waivers allow states to add to services[102] and eligible populations[103] and experiment with new payment and delivery models.[104] Waivers relevant to HCBS delivery include the 1915(c) Home and Community-Based Services Waiver, "which is authorized under Section 1915(c) of the Social Security Act,"[105] and the 1115 Demonstration Waiver, which is authorized under Section 1115 of the Social Security Act.[106] The Section 1915(c) waiver is the main way that states offer HCBS to individuals

95. *State Plan*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/subtopic/state-plan [https://perma.cc/PMC9-N5VS].

96. *Id.*

97. *Id.*

98. DEPRIEST ET AL., *supra* note 92, at 2.

99. RACHEL K. DRESSEL & DIANNE KAYALA, CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID 101: OVERVIEW OF THE PROGRAM 17–18 (2015), https://na.eventscloud.com/file_uploads/f8d33cebe966f297dda14f96558e8f48_8-Medicaid101_OverviewoftheProgram_HCBSConference201581015_B.pdf [https://perma.cc/Y567-F7UR].

100. *Id.*

101. ARTIGA ET AL., *supra* note 70, at 5–11.

102. Hearne & Topoleski, *supra* note 71.

103. *Id.*

104. *Waivers*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/medicaid-101/waivers [https://perma.cc/4W9S-HWLK].

105. TRITZ, *supra* note 91, at 5–7.

106. *1115 Medicaid Waivers: From Care Delivery Innovations to Work Requirements*, THE COMMONWEALTH FUND (Apr. 6, 2018), https://www.commonwealthfund.org/publications/explainer/2018/apr/1115-medicaid-waivers-care-delivery-innovations-work-requirements [https://perma.cc/874T-JNT5].

with disabilities, with thirty-five states choosing this approach in whole or in part.[107]

iii. Financing

When choosing which state plan amendment or waiver is best to implement their HCBS program, a key consideration that differentiates what options are available is the source of program financing. Some state plan amendments and waivers must be cost neutral, while others need not. "Cost neutral" is a budget neutrality requirement.[108] Cost neutrality, or budget neutrality, means that the program change that the state proposes must not cost the state Medicaid program more than the cost would be without the change.[109] This is determined on a per capita basis.[110] For example, if a state wanted to allow Medicaid recipients' spouses to be reimbursed in their HCBS program, they must do so in a way that costs the same or less than the average per capita cost of providing care to a Medicaid recipient in an institutional setting.[111]

Another financing consideration is the availability of federal matching funds. As described in Section II.D, the Medicaid program is financed jointly by the states and the federal government.[112] In addition to the general federal matching funds that a state receives, the federal government sometimes provides additional federal matching funds to incentivize participation in particular programs. Relevant to this discussion is the 1915(k) state plan amendment option, which is an example of this. The 1915(k) option was included as part of the Affordable Care Act with the purpose of providing "person-centered" HCBS.[113] Thus, if the state modifies their HCBS delivery using this method, they can receive federal matching funds that are not available under other state plan amendment and waiver options.

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107. *1915(c) Waivers by State*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Dec. 1, 2021, 7:02 PM), https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/1915-c-waivers-by-state [https://perma.cc/P782-BJ66].

108. NAT'L HEALTH POL'Y F., GEO. WASH. UNIV., THE BASICS: MEDICAID WAIVERS AND BUDGET NEUTRALITY 1 (2009), https://collections.nlm.nih.gov/master/borndig/101515308/Medicaid%20Waivers%20and%20Budget%20Neutrality.pdf [https://perma.cc/5QQJ-XNS3].

109. *Id.*

110. *See 1915(c) Waivers*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/subtopic/1915-c-waivers [https://perma.cc/27JG-MRYB] (describing how the cost neutrality requirement "mean[s] that states must provide assurances that the average per capita expenditures for covered HCBS services will not exceed 100 percent of the average per capita expenditures that would have been made for the level of care provided in an institution").

111. *Id.* State plan amendment options 1915(i), (j), and (k) do not have a cost neutrality requirement. *See Waivers*, *supra* note 104. Both 1915(c) and 1115 waiver options must be cost neutral. *See id.*

112. *See* discussion *supra* Section II.D.

113. KENYA CANTWELL, CTRS. FOR MEDICARE & MEDICAID SERVS., SELF-DIRECTED SERVICES UNDER MEDICAID § 1915(J) AND (K) STATE PLAN AUTHORITIES 15–16 (2017), https://www.appliedselfdirection.com/sites/default/files/Self%20Direction%20under%201915j%20and%20k%20Slides_0.pdf [https://perma.cc/WU6N-9425].

iv. Caps on Enrollment

States must also decide whether or not they want the ability to cap enrollment on their HCBS programs. Certain waivers and state plan amendments allow states to limit the number of individuals that can receive HCBS through their HCBS program, while other amendments and waivers do not.[114] The ability to cap enrollments can provide states with a greater level of financing predictability.[115] However, critics have argued that such caps "[do] not further the objectives of the [Medicaid] program."[116]

v. Level of Care Requirements

States can determine whether or not individuals must require an institutional level of care before they can receive HCBS. In other words, under this approach, for an individual to be eligible to receive HCBS, their care needs must be high enough that they would otherwise be eligible for care in a nursing facility.[117] Like caps on enrollment, this is a way that states can limit the number of individuals eligible for their HCBS programs and increase financing predictability.[118] Across the variety of state plan amendments and waiver options, most states require individuals to need a nursing home level of care before they are eligible for HCBS.[119] Despite the flexibilities that these various waivers and state plan amendments offer, their potential utility is limited due to a shortage of HCBS providers, as described further below.

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114. States can cap the number of people enrolled in an HCBS program under the 1915(j) state plan amendment and the 1915(c) waiver. *See id.* at 8; *Waivers*, *supra* note 104. States are not allowed to cap the number of people enrolled under the 1915(i) state plan amendment, 1915(k) state plan amendment, and 1115 waiver. *See* DENISE TYLER, MELISSA HUNTER, NATALIE MULMULE & KRISTIE PORTER, U.S. DEP'T OF HEALTH & HUM. SERVS., ASSISTANT SEC'Y FOR PLAN. & EVALUATION, OFF. OF DISABILITY, AGING, & LONG-TERM CARE POL'Y, THE USE OF 1915(I) MEDICAID PLAN OPTION FOR INDIVIDUALS WITH MENTAL HEALTH AND SUBSTANCE USE DISORDERS, at iv (2016), https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//173071/1915iSPA.pdf [https://perma.cc/CT4P-YNBB]; CANTWELL, *supra* note 113, at 17; TRITZ, *supra* note 91, at 6.

115. *See* GRETCHEN JACOBSON, TRICIA NEUMAN & MARYBETH MUSUMECI, KAISER FAM. FOUND., WHAT COULD A MEDICAID PER CAPITA CAP MEAN FOR LOW-INCOME PEOPLE ON MEDICARE? 1–5 (2017), https://files.kff.org/attachment/Issue-Brief-What-Could-a-Medicaid-Per-Capita-Cap-Mean-for-Low-Income-People-on-Medicare [https://perma.cc/KJA2-4W6E] (describing how a similar federal per capita proposal could provide greater federal cost predictions).

116. Joan Alker, *CMS Clarified Enrollment Caps in Medicaid Waivers Will Not Be Permitted*, GEO. UNIV. HEALTH POL'Y INST. CTR. FOR CHILD. & FAMS. (Apr. 25, 2013), https://ccf.georgetown.edu/2013/04/25/cms-clarified-enrollment-caps-in-medicaid-waivers-will-not-be-permitted [https://perma.cc/EAL8-EW9Y].

117. Sahar Takshi, *Home Sweet Home: The Problem with Cost-Neutrality for Older Americans Seeking Home- and Community-Based Services*, 5 ADMIN. L. REV. ACCORD 25, 30–32 (2019).

118. *See* JACOBSON ET AL., *supra* note 115, at 2–9.

119. *Medicaid Eligibility for Medicare Beneficiaries Who Need Long-Term Care in the Home or Community*, MEDICAREINTERACTIVE.ORG, https://www.medicareinteractive.org/get-answers/cost-saving-programs-for-people-with-medicare/medicare-and-medicaid/medicaid-eligibility-for-medicare-beneficiaries-who-need-long-term-care-in-the-home-or-community [https://perma.cc/M8R4-HELU].

II. *OLMSTEAD* RIGHTS ARE THREATENED DUE TO HCBS STAFFING SHORTAGES

While progress has been made in increasing the availability of HCBS through litigation and Medicaid state plan amendments and waivers, as mentioned above, the ability to provide care to individuals in their communities has been hindered by a large shortage of home health workers. When individuals cannot receive care in their homes, they may have no choice but to receive care in a nursing facility. This lack of choice is antithetical to the rights established in the *Olmstead* decision and more expensive for state Medicaid programs. Although consumer-directed HCBS programs attempt to increase the labor pool by allowing individuals to designate a family member to provide care, the potential reach of these programs is limited by many states excluding spouses from providing this care. This Part proceeds by focusing in detail on the interrelated problems of HCBS staffing shortages, burdens on informal caretakers, and the exclusion of spouses from consumer-directed HCBS.

A. HCBS STAFFING SHORTAGES

There are over 800,000 people in the United States who qualify for HCBS care but are unable to receive it because of a lack of care providers.[120] Across all the states, the average wait time to receive care was thirty-nine months in 2018.[121] However, in some states, wait times can range as high as fourteen years.[122] The reasons for this staffing shortage are multifaceted and complex, but they include low wages and benefits for HCBS caretakers, high turnover rates, burnout, educational barriers, and new challenges presented by the COVID-19 pandemic.[123]

Currently, the home health industry cannot retain workers due to challenges including low pay, strenuous work, and more attractive employment alternatives.[124] Home health care providers, on average, make less than $12 per hour.[125] This places almost "one-quarter of home health aides liv[ing] below the federal poverty line."[126] Unlike other low-wage jobs, home

120. *Fact Sheet: Why Older Adults Need Bold Investment in Medicaid HCBS*, *supra* note 10.

121. MEDICAID & CHIP PAYMENT & ACCESS COMM'N, STATE MANAGEMENT OF HOME- AND COMMUNITY-BASED SERVICES WAIVER WAITING LISTS 4 (2020), https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf [https://perma.cc/94MG-SZVA].

122. *Id.* at 7.

123. *See* Milli Legrain, *Why Do One in Five Home Health Aides Live in Poverty?*, THE GUARDIAN (Sept. 18, 2019, 2:01 AM), https://www.theguardian.com/us-news/2019/sep/18/us-healthcare-jobs-wages-women [https://perma.cc/QE9B-7C49]; David Totaro, *Health Aides' Low Wages Threaten Home Health Care, a Necessity for Millions*, STAT (Apr. 9, 2019), https://www.statnews.com/2019/04/09/home-health-aides-low-wages [https://perma.cc/LTC6-SK5K].

124. *See* Totaro, *supra* note 123.

125. *Id.*

126. *Id.*

health care providers are required to complete a minimum of seventy-five hours of training.[127] The work can also be strenuous—both physically and emotionally.[128] Because of these drawbacks and low pay, there are incentives for home health aides to seek alternative employment. Large companies such as Amazon and Walmart can offer better pay and benefits for lower-risk work.[129] Indeed, the turnover for home health care workers is very high. In 2020, over one-third of home health care aides left their jobs.[130]

The COVID-19 pandemic has further compounded these challenges to providing HCBS care. Home health aides left the workforce due to infection concerns and lack of proper personal protective equipment.[131] Because of the direct patient contact required for the job, home health care workers experienced higher rates of COVID-19 transmission than other professions.[132]

Although vaccination availability for COVID-19 has mitigated some of these concerns, it has also brought new concerns to light. The home health care industry is faced with further workforce shortages as states impose vaccination requirements, with many workers choosing to leave the workforce rather than comply with these mandates.[133] With an aging population and higher demands for at-home care, the shortage of home health-care providers is expected to worsen. By 2025, there is expected to be a shortage of 446,300 home health care workers.[134]

B. THE BURDEN ON INFORMAL AND FAMILY CAREGIVERS

Inadequate home health care options can lead to family members shouldering the majority of the care needs for their loved ones. Informally, 43.5 million individuals provide unpaid care annually.[135] Of these unpaid caregivers, twelve percent, or 5.22 million caregivers, are the care recipient's

127. *Home Health Aide Training Requirements by State*, PHI, http://phinational.org/advocacy/home-health-aide-training-requirements-state-2016 [https://perma.cc/UVR9-PEQJ].

128. Legrain, *supra* note 123.

129. Totaro, *supra* note 123.

130. Robert Holly, *Home Health Turnover Rate Hits 22.18%*, HOME HEALTH CARE NEWS (Oct. 27, 2020), https://homehealthcarenews.com/2020/10/home-health-turnover-rate-hits-22-18 [https://perma.cc/DDV5-UTES]

131. TYLER ET AL., *supra* note 114, at 2–10.

132. Theresa A. Allison, Anna Oh & Krista L. Harrison, *Extreme Vulnerability of Home Care Workers During the COVID-19 Pandemic—A Call to Action*, 180 JAMA INTERNAL MED. 1459, 1459–60 (2020).

133. Sharon Otterman, *How a Vaccine Mandate Could Worsen a Shortage of Home Care Aides*, N.Y. TIMES (Nov. 1, 2021), https://www.nytimes.com/2021/10/07/nyregion/ny-vaccine-mandate-home-care-aides.html [https://perma.cc/7B3T-MKZU].

134. Baxter, *supra* note 1.

135. *Caregiver Statistics: Demographics*, *supra* note 36.

spouse or partner.[136] Caretakers who dedicate significant amounts of their own time to caregiving, defined as more than twenty-one hours per week, "are nearly 4 times more likely to be caring for a spouse/partner."[137] Many caregivers provide care on top of full-time jobs.[138] Others quit their jobs to provide this care.[139]

This unpaid caregiving has staggering economic consequences. On average, caregivers pay $10,000 annually in caregiving expenses out of their own pockets and lose an average of thirty-three percent of their income due to time spent caregiving.[140] Nationally, the opportunity cost of unpaid family caregiving is estimated to be $522 billion.[141]

C. EXCLUSION OF SPOUSES FROM CONSUMER-DIRECTED HCBS

The consumer-directed HCBS care model offers a way of alleviating staffing shortages by tapping into a different labor pool—family and friends. Although these individuals may not want to work as home health aides, they may want to provide these services for their loved ones. Or, in many cases, they are already providing these services for their loved ones but are uncompensated for their care. However, in thirty-five states, spouses are excluded from being paid caretakers for their partners.[142] Spouses are excluded from such programs because of traditional conceptions of the role of a spouse to provide this care.[143] Relatedly, there can be line-drawing problems between reimbursable caregiving responsibilities and spousal roles. Finally, states have been reluctant to reimburse spouses under consumer-directed HCBS programs because of concerns about fraud and abuse.[144]

Spouses may be excluded from payment for home care services because their efforts are often seen by society as an expected, and non-compensable, duty of marriage: It is assumed that "in both the research arena and the 'real

136. Brad Breeding, *The State of Unpaid Family Caregiving in the U.S.*, MY LIFESITE (June 15, 2020), https://mylifesite.net/blog/post/state-of-unpaid-family-caregiving-in-u-s [https://perma.cc/7PGZ-LKRB].

137. *Caregiver Statistics: Demographics*, *supra* note 36.

138. John Schall, *Caregiving Is Forcing Women 50+ to Leave the Workforce*, FORBES (Oct. 10, 2016, 4:10 PM), https://www.forbes.com/sites/nextavenue/2016/10/10/caregiving-is-forcing-women-50-to-leave-the-workforce/?sh=7abc1307138d [https://perma.cc/UM43-AFFW].

139. *Id.*

140. *Id.*

141. Stipica Mudrazija, *Work-Related Opportunity Costs of Providing Unpaid Family Care in 2013 and 2050*, 38 HEALTH AFFS. 1003, 1004 (2019) (citing Amalavoyal V. Chari, John Engberg, Kristin N. Ray & Ateev Mehrotra, *The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey*, 50 HEALTH SERVS. RSCH. 871 (2014)).

142. *Spouses Can Be Paid Caregivers for Their Husbands or Wives*, *supra* note 14.

143. *See id.*; Susan M. Allen, Frances Goldscheider & Desirée A. Ciambrone, *Gender Roles, Marital Intimacy, and Nomination of Spouse as Primary Caregiver*, 39 THE GERONTOLOGIST 150, 150–57 (1999); Twila L. Perry, *The "Essentials of Marriage": Reconsidering the Duty of Support and Services*, 15 YALE J.L. & FEMINISM 1, 10–29 (2003).

144. *See* Perry, *supra* note 143, at 8–9.

world'. . . having a spouse is an indicator of caregiver availability."[145] This sentiment is rooted in the idea of marriage as a contract.[146] Within this contract is "the duty of support and services,"[147] which "requires one spouse to provide the other with a minimum level of material support so as to prevent homelessness or starvation and to meet other basic human needs."[148] However, the applicability of this doctrine in a modern context has been challenged. It has been criticized as being rooted discrimination and sexism and for being incompatible with the flexibility of modern marriage structures.[149]

Relatedly, spouses providing care for their partners can create "line drawing" problems. As described in Section IV.D.1, in programs that allow for spousal reimbursement, the care they provide must be "beyond the care normally expected of a spouse."[150] Where do one's duties as a spouse end and duties as a caregiver begin? If a caregiver could be paid to make meals for an individual, should their spouse also be reimbursed for this? It can be difficult to draw lines both programmatically and within individual relationships. A perceived challenge of reimbursing family caregivers is that family caregivers will be reimbursed for expected care that they would have provided whether or not they were caretakers, such as making meals and providing transportation.[151]

Although well-intentioned spouses may have difficulty distinguishing between duties as a spouse and duties as a caregiver in good faith, there is also concern about individuals intentionally taking advantage of consumer-directed HCBS options. The nature of HCBS makes monitoring for fraud and abuse more difficult. Unlike in institutions, where there is direct supervision of care, HCBS are provided in an individual's home, without supervision.[152] According to the Centers for Medicare and Medicaid Services ("CMS"), "[s]everal cases have been prosecuted where an attendant falsely claimed to have provided care."[153] In a five-year period, the Office of Inspector General has opened over two hundred investigations related to fraud and abuse in

145. Allen et al., *supra* note 143, at 150.

146. Perry, *supra* note 143, at 3.

147. *Id.* at 14–15.

148. *Id.* at 3.

149. *Id.* at 5–6.

150. TESHALE ET AL., *supra* note 9, at 5; *see infra* Section IV.D.1.

151. Jennifer Wolff et al., *Family Caregivers as Paid Personal Care Attendants in Medicaid*, JOHN HOPKINS BLOOMBERG SCH. OF PUB. HEALTH, https://www.jhsph.edu/research/centers-and-institutes/roger-c-lipitz-center-for-integrated-health-care/issue-brief-family-caregivers.html [https://perma.cc/CEP9-GC85]; *see infra* Section IV.D.1.

152. CTRS. FOR MEDICARE & MEDICAID SERVS., VULNERABILITIES AND MITIGATION STRATEGIES IN MEDICAID PERSONAL CARE SERVICES 1–4 (2018), https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/FraudAbuseforProfs/Downloads/vulnerabilities-mitigation-strategies.pdf [https://perma.cc/H2VC-D55U].

153. *Id.* at 6.

personal care-aide services.[154] In addition to overt fraud, there can be waste and abuse of program funds if the Medicaid program is paying for unnecessary services.[155] It's estimated that improper payments cost Medicaid programs $4.7 billion in 2016.[156]

Beyond economic costs, abuse of consumer-directed HCBS also comes at the expense of the individual in need of care-assistance and can manifest in abuse, neglect, and exploitation.[157] According to the Department of Justice, neglect by caregivers is the largest underreported form of elder abuse.[158] Family caregivers can be more likely to perpetrate abuse than other caretakers.[159] Common reasons for this distinction include factors such as "caregiver burden," "caregiver anxiety," and "caregivers' perception of aggressive behavior in the care recipient."[160]

III. SOLUTION: INCLUDE SPOUSES AS ALLOWABLE PAID CAREGIVERS IN HCBS WAIVER PROGRAMS

States can alleviate existing HCBS staffing shortages and lessen the financial barriers spouses face when providing unpaid care to their partners by allowing spouses to be paid caregivers under Medicaid self-directed service programs. States can do so by modifying an existing HCBS waiver or applying for a new waiver. There are multiple ways states can successfully add spouses to their programs in order to benefit them. There are also a variety of safeguards states can institute to alleviate the concerns associated with paying spouses, as described in Section IV.C.

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154. *Combating Waste, Fraud, and Abuse in Medicaid's Personal Care Services Program: Testimony Before the United States House of Representatives, Comm. on Energy and Com., Subcomm. on Oversight and Investigations*, 115th Cong. 1–9 (2017) (testimony of Christi A. Grimm, Chief of Staff, Off. of Inspector Gen., Dep't of Health and Hum. Servs.), https://docs.house.gov/meetings/IF/IF02/20170502/105909/HHRG-115-IF02-Wstate-GrimmC-20170502.pdf [https://perma.cc/ADT2-G4EX].

155. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 152, at 7–18.

156. *Id.* at 6.

157. *See Combating Waste, Fraud, and Abuse in Medicaid's Personal Care Services Program: Testimony Before the United States House of Representatives, Comm. on Energy and Com., Subcomm. on Oversight and Investigations*, 115th Cong. 5 (2017) (testimony of Christi A. Grimm, Chief of Staff, Off. of Inspector Gen., Dep't of Health and Hum. Servs.) ("For example, in 2016 OIG investigated a PCS attendant who submitted duplicate time sheets to claim payment for services not rendered to multiple clients with developmental disabilities. Although Medicaid was paying the PCS attendant to clean and cook for the clients and help integrate them into the community, some clients lived in squalor. The PCS attendant also endangered clients by driving while impaired by pain pills.").

158. DEP'T OF JUST. ELDER JUST. INITIATIVE, RURAL AND TRIBAL ELDER JUSTICE RESOURCE GUIDE 8–10 (2018), https://www.justice.gov/elderjustice/book/file/1110846/download [https://perma.cc/J4PY-XZSX].

159. Francesc Orfila et al., *Family Caregiver Mistreatment of the Elderly: Prevalence of Risk and Associated Factors*, BMC PUB. HEALTH, Jan. 22, 2018, at 1, 2.

160. *Id.* at 3–12. State Medicaid programs can address these concerns by employing third-party intermediaries to monitor for abuse. *See* discussion *infra* Section IV.D.3. Additionally, states can prevent caregiver burnout by employing external care providers to assist spouses. *See* discussion *infra* Section IV.D.4.

A. Modifying Existing HCBS Waivers to Add Spouses

States have the ability to modify their existing HCBS waivers to include spouses as eligible paid providers in their HCBS programs. The flexibility of HCBS waiver programs, described in Section II.D.2, makes modifying existing HCBS waivers a relatively easy vehicle for states to add spouses as qualified consumer-directed care providers. Depending on the waiver type a state chooses, it can establish program parameters to narrow who is eligible. As described above, examples of these parameters include limits to the number of individuals that a waiver can cover, or the level of acuity required before an individual is eligible to receive care under the program.[161]

B. Approaches

Looking to states that have allowed spouses to be paid caretakers, there are two primary approaches they have taken when employing spouses and other family members. These are the home health agency approach and the beneficiary-as-employer approach. Rather than suggest one model as "best" for a state to implement, this Section discusses both in detail so states can choose a model that best fits with their current Medicaid HCBS framework.

1. Home Health Agency Approach

The first way states can approach paying spouses as caregivers is by contractually creating an employment relationship between the spouse and a home health agency.[162] Thus, the spouse is an employee of the home health agency who can then provide care to their partner. This approach offers the benefit of utilizing relationships with home health agencies that are already in place.[163] The beneficiary does not need to take on additional responsibility in directing the services, as the management and financing functions are handled by the home health agency.[164] This is the approach that Arizona's Agency with Choice Program takes.[165] As a managed care state, Arizona's approach is uniquely authorized through a 1115 waiver.[166] As stated above, this approach must be budget neutral and the state cannot cap the number of individuals that are eligible for the program.[167]

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161. *See* discussion *supra* Section II.D.2.

162. *See Arizona Medicaid Agency with Choice Program*, PAYING FOR SENIOR CARE (Feb. 18, 2021), https://www.payingforseniorcare.com/arizona/medicaid-waivers/agency-with-choice [https://perma.cc/WD69-DA26].

163. *Id.*

164. *Id.*

165. *Id.*

166. *Arizona Section 1115 Demonstration Waiver*, AHCCCS (2022), https://www.azahcccs.gov/Resources/Federal/waiver.html [https://perma.cc/86S6-5GSR].

167. *See* discussion *supra* Sections II.D.3.i–.ii.

2. Beneficiary-as-Employer Approach

The second way states pay spouses does not utilize a third-party home health agency, but instead makes the individual receiving care the responsible employer.[168] As the responsible employer, the individual, rather than the state Medicaid program or a home health agency, has the responsibility of arranging for their care. This can include choosing their caretaker, the services they need, how much they will reimburse for the services, and payment for the services.[169] Thus, an individual requiring care can choose their spouse as their caretaker, and then may be placed in charge of handling administrative functions, such as payment. This is the approach Colorado takes in its Consumer-Directed Attendant Support Services program. The program includes detailed guides to help the beneficiary assess the services they need and who is best to provide this care.[170] States vary in the extent of autonomy they give to individuals who wish to self-direct their services, as described further in Section IV.C.

C. BENEFITS

Allowing spouses to be reimbursed as paid caregivers through state consumer-directed HCBS programs would decrease the strain on the caregiving system. Benefits of this approach include a greater number of available care providers, increased consumer choice and satisfaction, and decreased strain on caregivers. Moreover, from a political feasibility perspective, states have incentives to act now.

1. Greater Number of Care Providers

Allowing spouses to be reimbursed as paid caretakers under consumer-directed HCBS programs can help address staffing shortages. As mentioned above, 5.22 million caregivers are the care recipient's spouse or partner.[171] In thirty-five states, spouses cannot be paid caretakers for their partners.[172] This is a large pool of individuals that could provide care formally, reducing HCBS waiting lists and the financial strain on caretakers.

168. *Self-Directed Services*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html [https://perma.cc/34Q6-73KP].

169. *Id.*

170. *See generally* CONSUMER DIRECT CARE NETWORK COLO., CDASS PROGRAM TRAINING MANUAL: SECTION 9 ATTENDANT SUPPORT MANAGEMENT PLAN (2021), https://consumerdirectco.com/wp-content/uploads/2021/08/Section-9_CDASS-Program-Manual_20210816.pdf [https://perma.cc/WA27-AAMG] (showing beneficiaries how to self-direct their own HCBS services and supports).

171. *See* Breeding, *supra* note 136.

172. *Spouses Can Be Paid Caregivers for Their Husbands or Wives*, *supra* note 14.

2. Increased Consumer Choice and Satisfaction

Studies have shown that individuals who self-direct their care are more satisfied with the care they receive.[173] Thus, by expanding the use of consumer-directed HCBS to include spouses, states could potentially increase program satisfaction for recipients. Additionally, having a spouse provide care can decrease concerns about the quality of care that the beneficiary receives.[174] Many spouses express the sentiment that they "are the most qualified for the job because of the consistent and reliable care they can provide."[175]

After the COVID-19 pandemic, having a spouse provide care can also alleviate concerns about spreading or catching the virus. Individuals requiring care assistance may be more vulnerable to COVID-19 due to comorbidities or other health risks.[176] Many home health care aides work multiple jobs or for multiple individuals requiring care, which increases their exposure to the virus.[177] Since a spouse is already part of the individual's familial unit, exposure to the virus can be reduced. Additionally, individuals may feel safer having a spouse provide their care. They can have a better idea of their exposure risk and vaccination status.

3. Decreased Strain on Caregivers

Compensating spousal caregivers for the care they provide can decrease the financial strain that spouses who are informal caretakers for their partner face, as described in Section III.B.[178] For some partners, it would alleviate the burden of a spouse having to choose between employment and caregiving.[179] For others, it would provide needed financial support for a caregiving path that they have already chosen. Finally, if spouses are employed as caregivers

173. MERLE EDWARDS-ORR & KATHLEEN UJVARI, AARP PUB. POL'Y INST., TAKING IT TO THE NEXT LEVEL: USING INNOVATIVE STRATEGIES TO EXPAND OPTIONS FOR SELF-DIRECTION 1–2 (2018), http://www.advancingstates.org/sites/nasuad/files/AARP1122_PP_SelfDirection_WEB.pdf [https://perma.cc/H344-MDSM].

174. Benjamin et al., *supra* note 12, at 352–62.

175. Amber Ferguson, *Unpaid Caregivers: How America Treats Women Caring for Paralyzed Partners*, THE WASH. POST (Aug. 6, 2021, 6:45 AM), https://www.washingtonpost.com/business/interactive/2021/caregiver-partner-paralyzed-marriage-pandemic [https://perma.cc/BUM7-QHXL].

176. *Underlying Medical Conditions Associated with Higher Risk for Severe COVID-19: Information for Healthcare Professionals*, CTRS. FOR DISEASE CONTROL & PREVENTION (Feb. 15, 2022), https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html [https://perma.cc/C88A-M5JF].

177. Yinfei Duan et al., Letter to the Editor, *Care Aides Working Multiple Jobs: Considerations for Staffing Policies in Long-Term Care Homes During and After the COVID-19 Pandemic*, 21 JAMDA 1389, 1390 (2020).

178. *See* discussion *supra* Section III.B.

179. *See* discussion *supra* Section III.B.

for their partners, the larger economic cost of these spouses not being part of the workforce can be reduced.[180]

4. Political Advantages to Acting Now

From a political perspective, now is a better time than ever to expand the availability of home health care services. Home health care enjoys wide public support, with ninety-four percent of Medicare beneficiaries saying they would choose home health care over an institutional setting if they had the choice.[181] According to the same public opinion poll, eighty-five percent of all adults believe that federal funding of home health care services is a high priority.[182] Additionally, the COVID-19 pandemic has upended the health care industry, making changes to how health care is delivered the norm rather than the exception.[183] Expanding the reach of home health care is favored across both sides of the political spectrum. Senators as ideologically different as Joni Ernst (R-IA) and Ben Cardin (D-MD) have introduced legislation to expand access to home health care.[184] It is an area of focus where both Republican and Democrat legislators have come together to support bipartisan legislation.[185] On the executive side, expanding access to HCBS has been a top priority of the Biden administration as well.[186]

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180. *See* discussion *supra* Section III.B.

181. *New Public Opinion Poll Finds Strong Support for Home Health, Choose Home Care Act*, *supra* note 3.

182. *Id.*

183. *See* ASPR TRACIE, COVID-19 HEALTHCARE DELIVERY IMPACTS 1 (2021), https://files.asprtracie.hhs.gov/documents/covid-19-healthcare-delivery-impacts-quick-sheet.pdf [https://perma.cc/5XLN-28FF] (describing how the pandemic has changed health care delivery and access in a variety of ways).

184. *See* Press Release, Senator Joni Ernst, Ernst Joins Bipartisan Effort to Support Health Care Access, Virtual Visitations for Iowa's Seniors (Aug. 10, 2020), https://www.ernst.senate.gov/public/index.cfm/2020/8/ernst-joins-bipartisan-effort-to-support-health-care-access-virtual-visitations-for-iowa-s-seniors [https://perma.cc/T63G-LUKZ]; *see also* Press Release, Senators Ben Cardin & Susan Collins, Cardin, Collins Introduce Bipartisan Bill to Improve Access to Home Health Care Furnished by Telehealth Amid Public Health Emergencies (Oct. 23, 2020), https://www.cardin.senate.gov/newsroom/press/release/cardin-collins-introduce-bipartisan-bill-to-improve-access-to-home-health-care-furnished-by-telehealth-amid-public-health-emergencies [https://perma.cc/4T83-P83X] (discussing Ben Cardin and Susan Collins introducing legislation to expand access to home health care).

185. *See* Press Release, Senator Joni Ernst, *supra* note 184; *see also* Press Release, Senators Ben Cardin & Susan Collins, *supra* note 184 (discussing bipartisan support for a home health care bill). Additionally, the Better Care Better Jobs Act, introduced in the Senate by Senator Casey of Pennsylvania, would also increase the federal matching rate that states receive for their HCBS programs. *See generally* Better Care Better Jobs Act, S. 2210, 117th Cong. § 104(b)(4) (2021) (outlining the proposed legislation).

186. Reed Abelson, *Biden Promised to Fix Home Care for Seniors. Much More Help May Be Needed*, N.Y. TIMES (Nov. 1, 2021), https://www.nytimes.com/2021/11/01/health/home-health-aides-health-care.html [https://perma.cc/H9CL-3Y6U]. President Biden's Build Back Better Framework, which is currently under negotiation, includes an investment of $150 billion for home-based care. Robert Holly, *Gutted Version of Biden's 'Build Back Better' Plan Still Includes $150 Billion for In-Home*

D. Remedying Fraud and Abuse Concerns

Because employing one's spouse can present difficulty assessing when caretaking responsibilities begin and end, states take varying approaches to assert some levels of control over the consumer-directed programs. These measures can help prevent fraud and abuse and ensure that the beneficiary is actually receiving the services they are entitled to.[187] States such as Colorado and Florida have addressed fraud and abuse by narrowing the scope of services that can be provided by caretakers. Similarly, states such as Louisiana and Oregon have set limits on the amount of time that can be reimbursed for by caretakers.[188] A majority of states involve some kind of intermediary entity besides just the caretaker and the spouse, ensuring that a neutral third-party is also involved in any reimbursement decision-making. Finally, states can use background checks to verify that spouses applying to be caretakers do not have a previous history that would indicate an increased propensity to commit fraud or abuse.

1. Narrowing the Scope of Services

To ensure only appropriate care is reimbursed, some states provide an explicit list of activities or definitions that a beneficiary can reimburse a caretaker for. For example, to solve conflicts of interest that arise when a family member is a care provider, Colorado's Consumer-Directed Attendant Support Services program states that spouses or family members can only be reimbursed for "extraordinary care." "Extraordinary care" is defined as "care that exceeds the range of care that a family member would ordinarily perform in the household on behalf of a person without a disability."[189] For example, most transportation and household maintenance would not be considered within the scope of "extraordinary care," while caretaking activities such as assistance with dressing, meals, and bathing may be permissible.[190] Because of the difficulty in

Care, HOME HEALTH CARE NEWS (Oct. 28, 2021), https://homehealthcarenews.com/2021/10/gutted-version-of-bidens-build-back-better-plan-still-includes-150-billion-for-in-home-care [https://perma.cc/2ZJL-CMK4]. This funding is aimed at reducing the waiting list for long-term care services and bettering working conditions for home health care staff. *Id.* The American Rescue Plan Act of 2021, aimed at helping the country recover from the COVID-19 pandemic, provides states with a temporary ten percent increase in federal funding for their HCBS programs. Press Release, The White House, Build Back Better Framework (Oct. 28, 2021), https://www.whitehouse.gov/briefing-room/statements-releases/2021/10/28/build-back-better-framework [https://perma.cc/F9FP-Y48K].

187. *See* discussion *infra* Sections IV.D.3–.5.

188. *See* discussion *infra* Section IV.D.2.

189. CONSUMER DIRECT CARE NETWORK COLO., CDASS PROGRAM TRAINING MANUAL: SECTION 3 AVAILABLE SERVICES 36 (2021), https://consumerdirectco.com/wp-content/uploads/2021/07/Section-3_CDASS-Program-Manual_07162021.pdf [https://perma.cc/W9JW-NVEG].

190. ROBIN E. COOPER, NAT'L ASS'N STATE DIRS. DEVELOPMENTAL DISABILITIES SERVS., CARING FAMILIES . . . FAMILIES GIVING CARE USING MEDICAID TO PAY RELATIVES PROVIDING SUPPORT TO FAMILY MEMBERS WITH DISABILITIES 15–16 (2010), https://health.maryland.gov/dda/pages

determining this, the state employs case managers to assess allowable services.[191] Similarly, Florida provides that the care assistant can be reimbursed for five specific categories of services, including "adult companion, homemaker, attendant care, intermittent and skilled nursing, and personal care services."[192]

Conversely, some states specifically indicate what services will not be covered. Colorado's program lists excluded services to prevent program fraud and abuse.[193] This includes a prohibition on payments while the beneficiary is in a long-term care facility or hospital, and a prohibition on double-billing for services that are "duplicative or overlapping."[194] Additionally, Colorado's manual specifies that companionship is not a reimbursable service.[195]

2. Narrowing Reimbursed Time

States also use time constraints either in combination with or independent of the scope of service constraints mentioned above. In Louisiana, rather than reimbursing the caretaker for each service provided, the caretaker instead receives a daily stipend, thus alleviating potentially difficult decision-making in what qualifies as a reimbursable service and what does not.[196] The caretaker is also monitored through a monthly home-visit to make sure they are providing the beneficiary with designated services.[197] Similarly, Oregon provides beneficiaries with a monthly direct deposit cash benefit.[198] The beneficiary themselves is provided with "the responsibility [of] negotiat[ing] the hourly rate they" will reimburse for care provided.[199] Beyond direct budgets, states can also place responsibility on beneficiaries for going over budget. In Colorado, if an individual goes more than 29.99 percent over an assessed budget, they are responsible for the additional cost to their care providers.[200]

/Developments/2015/Attachment%205%20Caring%20Families.pdf [https://perma.cc/7DNV-ST6B].

191. CONSUMER DIRECT CARE NETWORK COLO., *supra* note 189, at 36.

192. TESHALE ET AL., *supra* note 9, at 8.

193. CONSUMER DIRECT CARE NETWORK COLO., *supra* note 189, at 32–33.

194. *Id.*

195. *Id.*

196. LA. DEP'T OF HEALTH, OFF. FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES, COMPARISON CHART- BETWEEN COMPANION CARE AND MONITORED IN HOME CAREGIVING (MIHC) FOR THE ROW AND NOW 2 (2020), https://ldh.la.gov/assets/docs/OCDD/waiver/CompanionCareMIHCComparison.pdf [https://perma.cc/2ECC-D2AT].

197. *Id.* at 2–3.

198. OR. DEP'T OF HUM. SERVS., INDEPENDENT CHOICES 1 (2018), https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/de9057.pdf [https://perma.cc/44J5-6SR9].

199. *Oregon Independent Choices Program: Benefits & Eligibility*, PAYING FOR SENIOR CARE (Mar. 18, 2020), https://www.payingforseniorcare.com/oregon/independent-choices [https://perma.cc/3QHS-UGFB].

200. CONSUMER DIRECT CARE NETWORK COLO., *supra* note 170, at 151.

3. Employing Intermediaries

Third-parties outside of the beneficiary and their caretaker can also serve as checks to make sure services are delivered and reimbursed appropriately. The most common intermediary is called a fiscal-employer agent.[201] Fiscal-employer agents assist beneficiaries "by performing payroll and administrative functions."[202] By handling these functions, the fiscal-employer agent "protect[s] participants from financial risk."[203] Almost all programs that allow beneficiaries to self-direct their services make use of fiscal-employer agents.[204] Fiscal-employer agents can be provided by the state government or contracted through a third-party service.[205]

States also employ other intermediaries to manage functions outside of financial administration to prevent abuse of consumer-directed programs. Another common intermediary that states use is someone to assist the beneficiary in care planning functions. In Kentucky, this intermediary is called a "support broker."[206] The support broker helps the beneficiary navigate decision-making as an employer, including enrollment, developing a service plan, finding providers, and hiring and firing employees.[207] Similarly, in North Carolina, beneficiaries self-directing services are required to use a "care advisor." North Carlina states that "close communication" with the care advisor "is necessary to ensure accuracy of service provision, stewardship of public dollars, and safeguard of the assurances of the . . . waiver."[208] Finally, Montana takes a unique approach by requiring authorization from a health care professional before a beneficiary can choose to self-direct services.[209] The provider helps determine what the beneficiary's needs are, so that the

201. SUZANNE CRISP ET AL., ROBERT WOOD JOHNSON FOUND., DEVELOPING AND IMPLEMENTING SELF-DIRECTION PROGRAMS AND POLICIES: A HANDBOOK 1–10 (2010), https://www.appliedselfdirection.com/sites/default/files/Participant%20Direction%20Handbook.pdf [https://perma.cc/8FDS-WU9Z].

202. NAT'L RES. CTR. FOR PARTICIPANT-DIRECTED SERVS., FREQUENTLY ASKED QUESTIONS ABOUT USING A FISCAL/EMPLOYER AGENT 1–2 (2014), https://consumerdirectco.com/wp-content/uploads/2014/12/Frequently-Asked-Questions-About-Using-a-Fiscal-Employer-Agent-New_20151208.pdf [https://perma.cc/KEY2-H56P].

203. *Id.*

204. CRISP ET AL., *supra* note 201, at 1–10.

205. *See* THE STATE OF OR., REQUEST FOR AN AMENDMENT TO A 1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER 179 (2021), https://www.oregon.gov/dhs/Compass-Project/Documents/Adult-HCBS-Waiver.pdf [https://perma.cc/4DU3-UFBH].

206. *Participant Directed Services*, KY. CABINET FOR HEALTH & FAM. SERVS., https://chfs.ky.gov/agencies/dms/dca/Pages/cdo.aspx [https://perma.cc/L4XK-8527].

207. *Id.*

208. N.C. DIV. OF MED. ASSISTANCE, CMTY. ALTS. PROGRAM, INSTRUCTIONAL AND TECHNICAL GUIDE FOR CONSUMER-DIRECTION 9 (2017), https://files.nc.gov/ncdma/documents/Providers/Programs_Services/CAPC/CAP%20ConsumerDirection%20Technical%20Guide%2082017.pdf [https://perma.cc/VSM4-WSBY].

209. *Community Services for Seniors and People with Disabilities*, MONTANA.GOV, https://dphhs.mt.gov/sltc/csb [https://perma.cc/WT6M-F9PD].

appropriate services are provided. [210] Utilizing a third-party intermediary can also help combat abuse and exploitation concerns, as there is an outside entity that can monitor for problematic behavior.

4. Employing Multiple Individuals

Employing a spouse as a caretaker does not necessitate that the spouse alone provides care to the individual. Employing additional care staff in addition to the beneficiary's spouse can help ensure that the beneficiary's needs are being met and that the spouse does not experience caregiver burnout. For example, Colorado requires that when an individual self-directs services, they must choose a minimum of two personal care attendants to provide services, rather than a single individual.[211] Having more than one caretaker responsible for all of an individual's care can help with retention, prevent burnout, prevent gaps in services, and ensure the individual always has a back-up caretaker if an emergency arises.[212]

5. Conducting Background Checks

Requiring a spouse to undergo a background check before they can be a paid caregiver can also help alleviate program fraud and abuse concerns.[213] This can include background checks, both at the time of hire and periodically while they are a service provider, to make sure they do not participate in criminal conduct while they are an approved care provider.[214] There has been a push generally to strengthen background checks for care providers and spouses should not be exempted from these requirements. The Centers for Medicare and Medicaid Services recommends that states institute both criminal background checks and cross reference Adult Protective Services and Child Protective Services exclusion lists.[215] Additionally, the Affordable Care Act created a National Background Check Program that encourages states to implement standardized, comprehensive background checks for anyone who has direct patient contact.[216]

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210. *Id.*

211. *See Oregon Independent Choices Program: Benefits & Eligibility*, *supra* note 199; CONSUMER DIRECT CARE NETWORK COLO., *supra* note 170, at 148.

212. *See Oregon Independent Choices Program: Benefits & Eligibility*, *supra* note 199; CONSUMER DIRECT CARE NETWORK COLO., *supra* note 170, at 148–49.

213. *See* NAT'L RES. CTR. FOR PARTICIPANT-DIRECTED SERVS., FRAUD PREVENTION & DETECTION IN PARTICIPANT DIRECTION PROGRAMS 6–7 (2013), http://www.advancingstates.org/documentation/HCBS_2013/Presentations/9.11%208.30-9.45%20Potomac%202.pdf [https://perma.cc/KBD7-MMRA].

214. CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 152, at 9.

215. *Id.* at 10.

216. Karen Axelton, *Caregiver Background Check Best Practices*, GOODHIRE (June 03, 2020), https://www.goodhire.com/resources/articles/caregiver-background-check-best-practices [https://perma.cc/C4ER-MRJT].

CONCLUSION

In conclusion, though progress has been made to afford individuals the right to receive care in their community, as established by *Olmstead v. L.C.*, challenges still remain. With the COVID-19 pandemic further heightening the need for HCBS, now is the time that states should act to bolster their HCBS programs and reduce waiting lists. Spouses are a key demographic of individuals that are willing to provide this care or already providing it informally. Looking to states that allow spouses to be reimbursed as caretakers, there are a variety of approaches states can take to pay spouses as caretakers while maintaining program oversight and accountability. By doing so, states will not only save costs, but will increase quality of life and community connection for individuals, fulfilling the core goal and lasting legacy of the *Olmstead* decision.