IMPROVING THE LONG-TERM CARE LANDSCAPE FOR LGBTQ+ ADULTS THROUGH HOME- AND COMMUNITY-BASED CARE REFORM

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ABSTRACT

Across the country, Medicaid-eligible individuals face widespread challenges in accessing appropriate long-term care, but LGBTQ+ elders face unique barriers to care and are especially vulnerable to discrimination, making this issue particularly pressing. In light of historical and continued discrimination against LGBTQ+ individuals across the country, home- and community-based services present a safer option for LGBTQ+ adults to receive long-term care. However, home- and community-based care is administered through Medicaid waivers that present state-specific barriers to desired care. First, not all states allow legally responsible individuals, such as spouses, to be paid caregivers for their family members. Second, states can implement waiting lists or other restrictions on waiver services that prevent eligible individuals from accessing care. Third, there are no explicit protections in place under federal Medicaid rules to protect LGBTQ+ individuals from discrimination and states have not adopted protective policies.

Establishing home- and community-based services as mandatory benefits under Medicaid would circumvent waiting lists. Allowing all family members to be paid caregivers would increase caregiver options for beneficiaries. Implementing cultural competency trainings would strengthen the caregiver workforce to better meet the needs of LGBTQ+ adults without access to family caregivers. Finally,

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improving data collection among Medicaid recipients with long-term care needs to gather information on gender and sexual orientation will allow Medicaid programs to better understand and serve their beneficiaries.

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INTRODUCTION

Across the country, Medicaid-eligible[1] individuals face widespread challenges with their long-term care needs, but LGBTQ+ adults face unique barriers to obtaining care and are more vulnerable to discrimination which makes this issue particularly pressing.[2] Federal actions like the American Rescue Plan are temporarily increasing access to care for this vulnerable population,[3] but more needs to be done to ensure equity and safety in long-term care for LGBTQ+ individuals—most importantly by increasing opportunities to receive care at home.

LGBTQ+ elders are at risk of abuse or inadequate treatment in institutional long-term care settings.[4] First, older LGBTQ+ Americans are at a high risk of entering institutional long-term care settings as a result of historic social isolation from relatives and policies that make home-based care inaccessible.[5] Second, LGBTQ+ individuals across the country face discrimination daily which threatens their health and well-being, and there are well documented instances of discrimination impacting care and health for older LGBTQ+ Americans in long-term care.[6] Third, nursing facilities are overburdened and already failing

1. Medicaid is a federal and state health insurance program for people with low income. Eligibility requirements are determined at the state level. *See Program History*, MEDICAID.GOV, https://www.medicaid.gov/about-us/program-history/index.html (last visited Nov. 1, 2022).

2. *See generally* MOVEMENT ADVANCEMENT PROJECT & SAGE, UNDERSTANDING ISSUES FACING LGBT OLDER ADULTS (2017), https://www.lgbtmap.org/file/understanding-issues-facing-lgbt-older-adults.pdf.

3. *See Sharita Gruberg, The American Rescue Plan Act Will Significantly Address LGBTQ Poverty*, CTR. FOR AM. PROGRESS. (Apr. 13, 2021), https://www.americanprogress.org/article/american-rescue-plan-act-will-significantly-address-lgbtq-poverty/; American Rescue Plan Act of 2021, H.R. 1319, 117th Cong. §§ 1002, 7401 (2021).

4. *See* MOVEMENT ADVANCEMENT PROJECT & SAGE, *supra* note 2, at 17.

5. LGBT Elder Advisory Comm., *The Blank Canvas of LGBT Elder Care in Philadelphia*, PHILA. GAY NEWS (June 15, 2018, 6:09 PM), https://epgn.com/2018/06/15/the-blank-canvas-of-lgbt-elder-care-in-philadelphia/ ("Without support systems that enable aging independently, LGBT elders are more likely to rely on nursing homes or other institutional settings to provide long-term care.").

6. Ellen Rand, *Vulnerable LGBT Elders Are Going Back into the Closet*, SILVER CENTURY FOUND. (Mar. 28, 2017), https://www.silvercentury.org/2017/03/with-aging-and-illness-some-lgbt-people-opt-for-the-closet/.

to meet licensing and quality standards and are trending towards business practices that prioritize profit over diversity and inclusion initiatives.[7] Without state policies that explicitly require training and culturally-competent care for LGBTQ+ residents, it is unlikely that these facilities will be safe spaces for LGBTQ+ residents.

This Note highlights the state policy choices that continue to harm LGBTQ+ adults and the federal initiatives that only minimally reduce the burden on LGBTQ+ individuals and families navigating long-term care needs. Ultimately, this Note suggests that home- and community-based care is a valuable and preferable alternative to institutional care for the aging LGBTQ+ population. Under Medicaid, home- and community-based services (HCBS), also known as home- and community-based care, refers to long-term care services that are administered in a beneficiary's home or community rather than in an institutional setting, such as a nursing facility.[8]

In order to ensure greater equity in access to long-term care for LGBTQ+ individuals, this Note asserts that HCBS should be administered as a mandatory Medicaid benefit with mandatory paid spousal care, greater protections against discrimination, and increased training opportunities for culturally-competent caregiving. Further, this Note argues that by increasing access to Medicaid HCBS and implementing comprehensive policies that prioritize diversity and inclusion, the long-term care landscape will operate more effectively for all stakeholders.

I. MEDICAID PROGRAM OVERVIEW

Medicaid is the national public health insurance program for low-income people in the United States.[9] Medicaid is one of the

7. *See* E. Tammy Kim, *This Is Why Nursing Homes Failed So Badly*, N.Y. TIMES: OP. (Dec. 31, 2020), https://www.nytimes.com/2020/12/31/opinion/sunday/covid-nursing-homes.html.

8. *Home & Community Based Services*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/index.html (last visited Nov. 1, 2022).

9. Robin Rudowitz, Rachel Garfield & Elizabeth Hinton, *10 Things to Know about Medicaid: Setting the Facts Straight*, KAISER FAM. FOUND. (Mar. 6, 2019), https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/.

largest budget items for states and the federal government as the program covers approximately 81.1 million people nationally.[10] As an entitlement program based on income, Medicaid is expansive, covering one in five Americans, many of whom have complex care needs.[11] With significant variation across states, Medicaid programs primarily provide health coverage to low-income adults, children, pregnant women, elderly adults, and people with disabilities.[12] Medicaid is structured as a federal-state partnership, overseen by the Centers for Medicare & Medicaid Services (CMS).[13] Under this structure, Medicaid programs are funded by both state and federal dollars and are subject to certain federal regulatory requirements.[14] Those requirements include mandatory coverage for certain populations, coverage of certain services, and other quality and procedural requirements.[15]

States have flexibility in administering Medicaid programs.[16] For example, states determine who to include within their covered populations and what models they will use to deliver services.[17] Although states may cover additional services, state plans must, at minimum, provide coverage for nursing facility services, inpatient and outpatient hospital services, and home health services.[18] Mandatory home health services are medical in nature and do not include services that support activities of daily living (ADLs)—such as toileting, eating, dressing, or

10. *Medicaid*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/index.html (last visited Nov. 1, 2022).

11. Rudowitz et al., *supra* note 9.

12. *Medicaid Eligibility*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/eligibility/index.html (last visited Nov. 1, 2022).

13. *National Medicaid & CHIP Program Information*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/index.html (last visited Nov. 1, 2022).

14. ALLISON MITCHELL, EVELYNE P. BAUMRUCKER, KRISTEN J. COLELLO, ANGELA NAPILI, CLIFF BINDER & JULIA A. KEYSER, CONG. RSCH. SERV., R43357, MEDICAID: AN OVERVIEW 1 (2021), https://crsreports.congress.gov/product/pdf/R/R43357/16 [hereinafter MEDICAID: AN OVERVIEW].

15. *See* 42 U.S.C. §§ 1396a(10)(A), 1396d(1)–(5), (17), (21), (28).

16. *See* MEDICAID: AN OVERVIEW, *supra* note 14.

17. Rudowitz et al., *supra* note 9.

18. *See* 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(1), (2)(A), (4)(A), (7).

bathing—that are typically provided under Medicaid HCBS waivers.[19] The exclusion of Personal Assistance Services from mandatory Medicaid benefits creates a gap in care for people who simply need safety supervision or assistance with activities of daily living but wish to remain at home.[20] Implicitly, Medicaid long-term care policies prioritize institutional care for individuals though many could receive better care in their own homes.[21]

A. *Long-Term Care Settings*

Medicaid is the primary payor of long-term supports and services (LTSS) care in the United States, which includes skilled-nursing care, hospice care, and home health care.[22] Although anyone may require LTSS at any point in their life as a result of illness or injury, it is more common for individuals to require long-term care as they age.[23] Thus, the likelihood of LTSS patients qualifying for both Medicaid and Medicare increases with age.[24] Although Medicare is the federal program responsible for elderly and disabled individuals, the program is restricted in its spending on LTSS and primarily covers acute and post-acute care such as skilled nursing and home health services.[25]

Long-term supports and services include a range of care services including institutional care and home- and

19. Activities of Daily Living (ADLs) are most commonly supported under Medicaid through home- and community-based "personal care" services. *Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) & Medicaid*, AM. COUNCIL ON AGING, https://www.medicaidplanningassistance.org/activities-of-daily-living/ (Mar. 9, 2022).

20. *Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, NAT'L HEALTH L. PROGRAM (Mar. 16, 2021), https://healthlaw.org/news/bill-to-expand-medicaid-home-and-community-based-services-introduced-in-congress/.

21. *Id.*

22. *See* KIRSTEN J. COLELLO, CONG. RSCH. SERV., IF10343, WHO PAYS FOR LONG-TERM SERVICES AND SUPPORTS? 1–2 (2021), https://crsreports.congress.gov/product/pdf/IF/IF10343.

23. *See id.*

24. *See id.*

25. *Id.* at 2.

community-based care.[26] Under Medicaid, institutional care refers to specific services covered, as authorized in the Social Security Act,[27] including nursing facilities, inpatient psychiatric services, intermediate care facilities, and home- and community-based services.[28] "Institutions" are residential facilities that assume comprehensive care responsibilities for residents, including room and board.[29] Medicaid beneficiaries must meet their state's requirements for institutional level of care, a measure of physical functional ability, medical needs, cognitive impairment, and behavioral problems.[30] States can determine how services within institutions are billed.[31] For example, states may decide whether to bundle payment for all services within institutions or to bill each service, like physical therapy, separately.[32] States may also choose to implement long-term supports and services under a capitated payment structure referred to as "managed care."[33] Under federal standards, long-term care facilities such as nursing homes are subject to state-based licensing and certification requirements.[34]

Home- and community-based services (HCBS) are a form of long-term supports and services that allow Medicaid beneficiaries to receive covered services within their own home or community, as opposed to within an institutional facility.[35]

26. *Id.* at 1; *Institutional Long Term Care*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/index.html (last visited Nov. 1, 2022).

27. 42 U.S.C. §§ 1396–1396w–6 (Title XIX of the Social Security Act authorizing Medicaid).

28. *See Institutional Long Term Care*, *supra* note 26; *Long-Term Services & Supports*, PA. HEALTH L. PROJECT, https://www.phlp.org/en/issues/long-term-services-and-supports (last visited Nov. 1, 2022).

29. *Institutional Long Term Care*, *supra* note 26.

30. *Id.*; *What is Nursing Home Level of Care & Its Importance to Medicaid Eligibility*, AM. COUNCIL ON AGING, https://www.medicaidplanningassistance.org/nursing-home-level-of-care/ (Mar. 15, 2022).

31. *Institutional Long Term Care*, *supra* note 26.

32. *Id.*

33. DEP'T OF HEALTH & HUM. SERVS., CTRS. FOR MEDICARE & MEDICAID SERVS., SUMMARY–ESSENTIAL ELEMENTS OF MANAGED LONG TERM SERVICES AND SUPPORTS PROGRAMS 1 (2013), https://www.medicaid.gov/Medicaid/downloads/mltss-summary-elements.pdf.

34. *Institutional Long Term Care*, *supra* note 26; 42 C.F.R. § 431.703.

35. *Home & Community Based Services*, *supra* note 8.

Under Medicaid, HCBS refers specifically to home- and community-based care that is administered through a Medicaid waiver but is not a mandatory Medicaid benefit.[36] Other home health services provided by medical professionals, such as physical therapy, speech therapy, or skilled nursing provided within a patient's home, are mandatory Medicaid benefits available to all Medicaid enrollees.[37] However, HCBS supports an individual's daily living needs in activities like dressing, bathing, eating, or safety supervision, and can be administered by family members, friends, or professional home care aids.[38] As with institutional care, states set level of care requirements for Medicaid HCBS beneficiaries; however, because of the waiver structure, states can tailor these requirements even further for each waiver population.[39]

B. *Medicaid Waivers for Home- and Community-Based Services*

States were first provided opportunities to implement waiver services for home- and community-based services under Congress's addition of section 1915(c) to the Social Security Act in 1983.[40] Waiver services allow state Medicaid programs to extend services to particular populations outside of the standard Medicaid requirements.[41] Some examples of waiver services include expanding or restricting the state's standard

36. *See Home & Community Based Services Authorities*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html (last visited Nov. 1, 2022) [hereinafter *Authorities*].

37. *What Is Home Health Care*, ALL. FOR HOME HEALTH QUALITY & INNOVATION, https://ahhqi.org/home-health/what-is (last visited Nov. 1, 2022); *Home Health Services*, MEDICAID.GOV, https://www.medicare.gov/coverage/home-health-services (last visited Nov. 1, 2022).

38. *Home and Community Based Services (HCBS) Via Medicaid Waivers Assist Seniors in Aging at Home*, AM. COUNCIL ON AGING, https://www.medicaidplanningassistance.org/medicaid-hcbs-waivers/ (Dec. 22, 2021).

39. *Home & Community Based Services 1915(c)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited Nov. 1, 2022) [hereinafter *Services 1915(c)*].

40. 42 U.S.C. § 1396n(c); *Authorities*, *supra* note 36.

41. *Services 1915(c)*, *supra* note 39.

Medicaid eligibility criteria, including income and resource limits.[42] Under section 1915(c), states may implement home- and community-based services through the State Plan or under a waiver such as 1915(c), 1915(i), 1915(j), and 1915(k) waivers.[43] Each of these options provides slightly different mechanisms for implementing home- and community-based services, for example by limiting services to certain geographic areas or medical diagnoses, establishing a new Medicaid eligibility group specifically for home- and community-based services, permitting family or friends to provide services, or securing enhanced federal match for home- and community-based services under a State Plan.[44] Section 1115 of the Social Security Act creates the authority to allow states to experiment with pilot or demonstration projects.[45] States use this policy lever to test home- and community-based service models.[46]

The Medicaid State Plan "is an agreement between [the] state and the [f]ederal government describing how [the] state administers its Medicaid . . . program[] . . . [and] assur[ing] that [the] state will abide by [f]ederal rules" in order to claim matching federal funds for Medicaid activities.[47] Where any Medicaid program or service is offered to beneficiaries under the state plan, whether it is a mandated service or implemented voluntarily by the state, the program must conform to federal access and equity standards.[48] Under federal regulations, Medicaid programs are required to ensure statewide availability of any benefit offered under the state plan,[49]

42. *See id.*

43. *Id.*; 42 U.S.C. § 1396n(c), (i)–(k).

44. §§ 1396n(a)(1)(A), (c)(1), (i), (j)(5)(c).

45. *Medicaid Section 1115 and Home and Community Based Services Waivers*, NAT'L HEALTH L. PROGRAM, https://healthlaw.org/our-work/policy/medicaid/medicaid-waivers/ (last visited Nov. 1, 2022).

46. *Id.*

47. *Medicaid State Plan Amendments*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html (last visited Nov. 1, 2022).

48. *See* 42 C.F.R. § 431.40 (2022).

49. 42 U.S.C. § 1396a(a)(1).

comparability of services in amount, duration, and scope throughout the state,[50] and consistency for all applicants in terms of income eligibility groups.[51]

In contrast to state plan benefits, Medicaid waivers offer specific circumstances when states can circumvent these requirements.[52] Medicaid waivers allow states to waive some federal Medicaid rules governing institutional care in order to administer specific services in the state.[53] In particular, home- and community-based service waivers offer states an opportunity to meet an individual's daily nursing facility care needs without requiring them to be in a nursing facility.[54] The primary populations targeted for home- and community-based services waivers are those with intellectual or developmental disabilities, seniors, and adults with physical disabilities.[55] Less commonly, states provide waiver services for medically fragile or technology dependent children, individuals with HIV or AIDS, individuals with mental illness, or individuals with traumatic brain injury.[56] Although the services provided under Medicaid waivers can vary, most waivers provide support for activities of daily living (ADLs) and instrumental activities of daily living (IADLs).[57] Caregiving may include direct hands-on assistance with tasks, verbal cueing to allow the individual to complete a task on their own, or safety supervision or monitoring to help reduce a risk of injury.[58]

50. *Id.* § 1396a(a)(10)(B).

51. *Id.* § 1396a(a)(10)(C)(i)(III).

52. *Authorities*, *supra* note 36.

53. *What Is a Medicaid Waiver? Your Guide to Medicaid Home and Community Based Services*, ASSISTEDLIVING.ORG, https://www.assistedliving.org/what-is-a-medicaid-waiver/#a_definition_of_medicaid_waivers (Aug. 26, 2022).

54. *Services 1915(c)*, *supra* note 39.

55. *See* MaryBeth Musumeci, Molly O'Malley Watts & Priya Chidambaram, *Key State Policy Choices About Medicaid Home and Community Based Services*, KAISER FAM. FOUND. (Feb. 4, 2020), https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/.

56. *Id.*

57. *Id.*; *see Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) & Medicaid*, *supra* note 19.

58. *See id.*

Typically, states implementing HCBS waivers have a two-level assessment protocol that is independent from the standard Medicaid approval process for assessing eligibility. The first level, need-based eligibility,[59] establishes whether an individual's health needs rise to the level required by the waiver.[60] The second level, financial eligibility, establishes whether an individual meets certain income and asset limits, that can be more or less restrictive than standard Medicaid program eligibility expectations.[61]

States set eligibility requirements for individuals seeking waiver services and can implement any evaluation process to determine level of need, within the bounds of federal regulation, prior to approving waiver services.[62] Under federal regulation, states must ensure that all individuals receiving home- and community-based care through waiver services are evaluated to determine whether they meet the criteria for the level of care provided in a hospital, nursing facility, or intermediate care facility.[63] States must also provide periodic reevaluations, at least annually, to ensure that individuals enrolled in waiver services continue to need that level of care.[64] In addition, states may approve waiver services for individuals who might need such services within a month of the assessment.[65]

CMS does not mandate use of any particular assessment tool for determining eligibility.[66] Therefore, states are free to adopt an existing assessment tool or to develop one that meets federal

59. *Home and Community Based Services (HCBS) Via Medicaid Waivers Assist Seniors in Aging at Home*, *supra* note 38.

60. *Id.*

61. *See id.*; Musumeci et al., *supra* note 55.

62. *Services 1915(c)*, *supra* note 39.

63. 42 C.F.R. § 441.302(c) (2022).

64. *Id.* § 441.302(c)(2).

65. *Id.* § 441.302(c)(1).

66. DEBRA J. LIPSON, ASSESSMENT AND CARE PLANNING MEASURES 8 (2019), https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measures-brief-1-assessment-care-planning.pdf.

expectations of "reasonabl[y]" determining need.[67] The majority of states rely on standardized assessment tools created for specific population assessments like age related disability, physical disability, or traumatic brain injury assessments.[68] Federal guidance regarding assessment tools for care planning is broad; states must only specify the "amount, duration, and scope of each service that it provides for—(1) [t]he categorically needy; and (2) [e]ach covered group of medically needy."[69] States may not, however, "arbitrarily deny or reduce the amount, duration, or scope of a required service . . . to an otherwise eligible beneficiary solely because of the diagnosis, type of illness, or condition."[70]

Medicaid beneficiaries have the right to initiate an appeal if they believe an assessment of need is incorrect or insufficient.[71] The right to appeal an adverse benefit determination is derived from the constitutional right to due process under the Fourteenth Amendment.[72] *Board of Regents v. Roth* supports the long-held understanding that Medicaid beneficiaries have a property interest in their Medicaid benefits and reserve entitlement to such benefits.[73] *Goldberg v. Kelly* established the standard for proper notice and the opportunity for a hearing *before* welfare benefits are terminated.[74] Under "Managed Care" rules, states administering managed care programs must establish a grievance and appeal system, as well as procedures like internal review and state fair hearing, with external medical review as an optional element.[75] As a waiver program, not all home- and community-based services are managed care

67. *Home & Community Based Services*, *supra* note 8.

68. *See id.*; LIPSON, *supra* note 66, at 5.

69. 42 C.F.R. § 440.230(a).

70. *Id.* § 440.230(c).

71. Elizabeth Dickey, *Medicaid Home and Community-Based Waiver Services (HCBS)*, NOLO, https://www.nolo.com/legal-encyclopedia/medicaid-home-community-based-waiver-services-hcbs.html (last visited Nov. 1, 2022); 42 C.F.R. § 438.402.

72. U.S. CONST. amend. XIV, § 1.

73. *See* Bd. of Regents of State Colls. v. Roth, 408 U.S. 564, 577 (1972).

74. *See* 397 U.S. 254, 263–64 (1970).

75. 42 C.F.R. § 438.402.

services.[76] States have the option to administer home- and community-based services explicitly under their managed care program.[77] Under this option, states can choose to operate 1915(c) waivers concurrently with 1115 or 1915(b)(1) waivers.[78] This metric is important because where states do not mandate Managed Care enrollment, waiver participants are left with limited appeal rights.[79]

1. *Financial safeguards in home- and community-based services waivers*

Although states have been working to increase access to community-based care, nursing care expenditures are still high.[80] In 2015, Medicaid spending on nursing home care exceeded fifty-five billion, covering approximately 1.4 million people.[81] At the time, there were forty-eight million people in the United States over the age of sixty-five, accounting for fifteen percent of the population, and this number is expected to reach ninety-eight million by 2060.[82] As a mandated service under Medicaid, nursing home care receives federal matching funds within the constraint of medical necessity.[83] In contrast,

76. Managed care is a healthcare delivery system that aims to manage cost, utilization, and quality of care through contracted agreements between state Medicaid agencies and managed care organizations under a per-member-per-month payment schedule. *Managed Care*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/managed-care/index.html (last visited Nov. 1, 2022).

77. Musumeci et al., *supra* note 55.

78. Alabama, Florida, Iowa, Idaho (only for dual-eligible individuals), Illinois, Kansas, Massachusetts (frail elderly population only), Maine, Michigan, and Pennsylvania chose to mandate managed care enrollment for HCBS waiver beneficiaries. *Id.* Among implemented HCBS 1915(c) waivers, only eight chose to mandate enrollment to managed care for elderly and disabled populations. *Id*.

79. MARYBETH MUSUMECI, KAISER FAM. FOUND., A GUIDE TO THE MEDICAID APPEALS PROCESS 15 (2012), https://www.kff.org/wp-content/uploads/2013/01/8287.pdf.

80. *See* KAISER FAM. FOUND., MEDICAID'S ROLE IN NURSING HOME CARE 1–3 (2017), https://files.kff.org/attachment/Infographic-Medicaids-Role-in-Nursing-Home-Care.

81. *Id*.

82. *Id*.

83. *See Medicaid Coverage of Nursing Home Care | When, Where and How Much They Pay*, AM. COUNCIL ON AGING, https://www.medicaidplanningassistance.org/medicaid-and-nursing-homes/ (Dec. 14, 2021).

home- and community-based services are permitted under 1915(c) waivers, one of the most common Medicaid waiver options, but are required to remain cost-neutral to nursing home care, discouraging comprehensive care.[84]

A key provision of the 1915 waiver programs is that states are mandated to restrict spending on home- and community-based programs to the amount that would have otherwise been spent on nursing facility level of care.[85] This capitation system incentivizes efficient use of waiver funding at the state level but has facilitated implementation of utilization controls for vulnerable waiver populations.[86] States commonly adopt restrictions related to the number of people enrolled in a waiver program, the number of service hours approved per individual, the amount spent per enrollee on waiver services, or by geographic limits.[87] Most states employ at least one of these cost-containment strategies; of the fifty-one states and territories to have implemented waiver services, forty-one states report using waiting lists for eligible individuals.[88]

2. *Beneficiary safeguards in home- and community-based services waivers*

Home- and community-based care is an ever-growing sector of long-term care services with significant research supporting the value of funding opportunities for aging at home with regard to patient outcomes as well as economic sustainability.[89] Receiving care at home allows approved individuals to maintain a critical connection to their communities or families

84. Sahar Takshi, *Home Sweet Home: The Problem with Cost-Neutrality for Older Americans Seeking Home- and Community-Based Services*, 5 ADMIN. L. REV. 25, 27 (2019).

85. *Services 1915(c)*, *supra* note 39.

86. *See* Musumeci et al., *supra* note 55.

87. *Id.*

88. *Id.*

89. *See* Michelle Martin, *The Benefits of Providing LTSS Through Home- and Community-Based Services*, UNITED HEALTHCARE (Jun. 24, 2021), https://www.uhccommunityandstate.com/content/topic-profiles/ltss/the-benefits-of-providing-ltss-through-home--and-community-based.

and age with dignity, in a manner consistent with the individuals' health and wellness goals.[90]

The shift towards community-based care is rooted both in financial data and health outcomes data—nursing facility care has historically been a costly Medicaid budget item and dangerous for facility residents and staff.[91] Advocacy to move individuals with long-term care needs out of institutions began in the 1950s as concerns grew regarding poor living conditions for institutionalized people suffering from severe mental illness.[92] There was also a movement towards increasing access to more effective treatment options that could allow such individuals to be safe and well cared for at home.[93]

The Supreme Court's landmark 1999 decision in *Olmstead v. L.C.* clarified the effect of the Americans with Disabilities Act (ADA), thereby establishing the rights of individuals with disabilities to resist isolation and segregation in institutional care.[94] Under *Olmstead*, Medicaid programs are required to provide services for individuals with disabilities in the most integrated setting appropriate for their needs.[95] Specifically, states must provide community-based services for such individuals with disabilities "who would otherwise be entitled to institutional services when: (a) "such placement is appropriate;" (b) "the affected person does not oppose such treatment;" and (c) "the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities."[96]

90. *See id.*; Joanne Binette & Kerri Vasold, *2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus*, AM. ASS'N. OF RETIRED PERS., https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html (July 2019).

91. *See* MEDICAID & CHIP PAYMENT & ACCESS COMM'N, TWENTY YEARS LATER: IMPLICATIONS OF OLMSTEAD V. L.C. ON MEDICAID'S ROLE IN PROVIDING LONG-TERM SERVICES AND SUPPORTS 1–7 (2019), https://www.macpac.gov/wp-content/uploads/2019/07/Twenty-Years-Later-Implications-of-Olmstead-on-Medicaids-Role-in-LTSS.pdf.

92. *Id.* at 1.

93. *See id.*

94. *See* Olmstead v. L.C., 527 U.S. 581, 607 (1999).

95. *See id.* at 602.

96. *Id.* at 607.

Ten years after this ruling, the Obama Administration allotted funding for expanding independent living centers and support for community integration.[97] The Department of Justice, in response to involvement in over forty *Olmstead* cases between 2009 and 2012, published technical guidance regarding the rights of people with disabilities and the specific expectations of state and local governments to comply with the ADA's community integration mandate which requires states to administer programs in the most integrated setting appropriate for the needs of people with disabilities.[98]

II. IMPACT OF MEDICAID LONG-TERM CARE POLICIES ON LGBTQ+ ADULTS

Historically, the LGBTQ+ community has experienced high rates of poverty and are more likely than non-LGBTQ+ people to live in poverty.[99] Controlling for other factors commonly known to predict poverty, lesbian, bisexual, and transgender women are collectively seventeen percent more likely to be poor compared to cisgender, heterosexual women.[100] Alarmingly, transgender people have a thirty-eight percent higher risk of living in poverty than cisgender, heterosexual women and a seventy percent greater risk of living in poverty compared to cisgender, heterosexual men.[101] In light of this, LGBTQ+ people rely on Medicaid at higher rates than

97. MaryBeth Musumeci & Henry Claypool, Olmstead*'s Role in Community Integration for People with Disabilities Under Medicaid: 15 Years After the Supreme Court's* Olmstead *Decision*, KAISER FAM. FOUND. (June 18, 2014), https://www.kff.org/report-section/olmsteads-role-in-community-integration-for-people-with-disabilities-under-medicaid-issue-brief/.

98. *Id.*

99. KELLAN E. BAKER, ASHE MCGOVERN, SHARITA GRUBERG & ANDREW CRAY, THE MEDICAID PROGRAM AND LGBT COMMUNITIES OVERVIEW AND POLICY RECOMMENDATIONS 1, 4 (2016), https://cdn.americanprogress.org/wp-content/uploads/2016/08/08125221/2LGBTMedicaidExpansion-brief.pdf.

100. M. V. LEE BADGETT, SOON KYU CHOI & BIANCA D.M. WILSON, LGBT POVERTY IN THE UNITED STATES: A STUDY OF DIFFERENCES BETWEEN SEXUAL ORIENTATION AND GENDER IDENTITY GROUPS 4 (2019), https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf.

101. *Id.*

non-LGBTQ+ people.[102] While a significant portion of the LGBTQ+ community was uninsured prior to the Affordable Care Act, uninsured rates decreased by over half between 2013 and 2016 following Medicaid expansion.[103] A 2018 study estimated that 1,171,000 LGBT adults were enrolled in Medicaid as their primary source of health care coverage.[104] Many of these beneficiaries receive coverage for health needs associated with HIV, as HIV remains a significant contributor of long-term care needs among the LGBTQ+ community.[105] Over fifty percent of HIV positive people are impacted by an HIV associated neurocognitive disorder that negatively impacts memory, motor skills, and cognitive function.[106] These specific deficiencies are common issues that lead people to require personal assistance services.[107]

Under current state Medicaid policies, LGBTQ+ individuals are at a disadvantage. Even if a state is willing to pay for home-based services, the shortage within the domestic care workforce may mean that LGBTQ+ individuals are at a higher risk of joining home- and community-based services waitlists absent a friend or family member available to care for them.[108] Moreover, where self-directed personal care programs are

102. ARIELLE BOSWORTH, GINA TURRINI, SARADA PYDA, KIEAUNA STRICKLAND, ANDRE CHAPPEL, NANCY DE LEW & BENJAMIN D. SOMMERS, HEALTH INSURANCE COVERAGE AND ACCESS TO CARE FOR LGBTQ+ INDIVIDUALS: CURRENT TRENDS AND KEY CHALLENGES 5 (2021), https://aspe.hhs.gov/sites/default/files/2021-07/lgbt-health-ib.pdf.

103. *See id.* at 4.

104. NAT'L LGBTQ TASK FORCE, NAT'L HEALTH L. PROGRAM, NAT'L ASIAN PACIFIC AM. WOMEN'S F., NAT'L BLACK WOMEN'S REPROD. JUST. AGENDA & NAT'L LATINA INST. FOR REPROD. HEALTH, WHY MEDICAID IS AN LGBTQ ISSUE 2 (2019), https://healthlaw.org/wp-content/uploads/2019/06/WhyMedicaidIsAnLGBTQIssue.pdf.

105. *See* SAGE & NAT'L RES. CTR. ON LGBT AGING, FACTS ON LGBT AGING 3 (2021), https://www.sageusa.org/wp-content/uploads/2021/05/sage-lgbt-aging-final-2021.pdf.

106. *Id.*

107. *See Home and Community Based Services (HCBS)*, MEDICARERESOURCES.ORG, https://www.medicareresources.org/glossary/home-and-community-based-services-hcbs/ (last visited Oct. 26, 2022).

108. MEDICAID & CHIP PAYMENT & ACCESS COMM'N, STATE MANAGEMENT OF HOME- AND COMMUNITY- BASED SERVICES WAIVER WAITING LISTS 10 (2020), https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf; MOVEMENT ADVANCEMENT PROJECT & SAGE, *supra* note 2, at 11–15.

available, the person willing and able to provide paid care for LGBTQ+ individuals may not be a permitted paid caregiver as a legally responsible family member under state Medicaid restrictions. LGBTQ+ adults often are isolated from family, or do not have children to rely on for care and are more likely to live alone.[109] Because of this, LGBTQ+ individuals are less likely to have someone available to provide informal or even formal support, and therefore are more likely to need facility care or a professional caregiver.[110]

A. *History of LGBTQ+ Discrimination in Long-Term Care*

The COVID-19 pandemic highlighted weak points in America's long-term care system, namely structural failings in residential facilities. Long-term care facilities gained national attention during the COVID-19 pandemic as nursing homes became hotspots for the spread of infections.[111] Nursing home conditions leading up to the pandemic, such as infection control and staffing shortages, played a significant role in the impact of COVID on residents.[112] Outcomes were worse for Medicaid recipients; multiple studies found an association between COVID-19 infection rates and the number of residents in a facility insured under Medicaid.[113]

Even where COVID-19 spread was contained, mortality rates increased as a result of imposed resident isolation and resulting

109. *See* Angela Houghton, *Maintaining Dignity: A Survey of LGBT Adults Age 45 and Older*, AM. ASS'N OF RETIRED PERS. (Mar. 2018), https://www.aarp.org/research/topics/life/info-2018/maintaining-dignity-lgbt.html.

110. *See id*.

111. *See* Shamik Giri, Lee Minn Chenn & Roman Romero-Ortuno, *Nursing Homes During the COVID-19 Pandemic: A Scoping Review of Challenges and Responses*, 12 EUR. GERIATRIC MED. 1127, 1127 (2021).

112. *See id*. at 1130–31.

113. Nancy Ochieng, Priya Chidambaram, Rachel Garfield & Tricia Neuman, *Factors Associated with COVID-19 Cases and Deaths in Long-Term Care Facilities: Findings from a Literature Review*, KAISER FAM. FOUND. (Jan. 14, 2021), https://www.kff.org/coronavirus-covid-19/issue-brief/factors-associated-with-covid-19-cases-and-deaths-in-long-term-care-facilities-findings-from-a-literature-review/.

loneliness.[114] Studies show that loneliness is associated with poor health outcomes including cognitive decline, depression, and physical decline.[115] Nursing home residents experienced these outcomes with ferocity during COVID-19 lockdowns where residents reported high rates of depression and significant unplanned weight loss as a result of being secluded in private rooms without access to communication with other residents or family members.[116]

Psychological burdens, like loneliness and depression, are common among the LGBTQ+ community broadly; the nursing home setting only exacerbates these conditions.[117] As a result of a lifetime of condemnation, harassment, and prejudice in housing, employment, healthcare, and public accommodations, LGBTQ+ elders are at an increased risk of negative economic outcomes and health challenges.[118] Indeed, exposure to anti-LGBTQ+ discrimination increases a person's risk of poor mental health and physical health.[119] Depression, anxiety, suicidality, substance use, and PTSD are common mental health consequences of discrimination, as are elevated stress hormones, cardiovascular disease, and poor self-reported health.[120]

Moreover, because LGBTQ+ seniors also report fear of homophobia or transphobia, they may be hesitant to disclose

114. The Ed. Bd., *Nursing Home Patients Are Dying of Loneliness*, N.Y. TIMES: OP. (Dec. 29, 2020), https://www.nytimes.com/2020/12/29/opinion/coronavirus-nursing-homes.html.

115. Michael Levere, Patricia Rowan & Andrea Wysocki, *The Adverse Effects of the COVID-19 Pandemic on Nursing Home Resident Well-Being*, 22 J. AM. MED. DIR. ASS'N 948, 949 (2021).

116. *See id.* at 951.

117. *See* Samantha Molina, *For LGBTQ Seniors, COVID-19 Worsens an Epidemic of Loneliness*, CRONKITE NEWS (Feb. 24, 2021), https://cronkitenews.azpbs.org/2021/02/24/for-lgbtq-seniors-covid-19-worsens-an-epidemic-of-loneliness/.

118. *The Costs of COVID-19 for LGBT Older Adults*, LAMBDA LEGAL (Apr. 28, 2020), https://www.lambdalegal.org/blog/lgbt-older-adults-seniors-elders-coronavirus.

119. *What Does the Scholarly Research Say About the Effects of Discrimination on the Health of LGBT People?*, CORNELL UNIV., https://whatweknow.inequality.cornell.edu/topics/lgbt-equality/what-does-scholarly-research-say-about-the-effects-of-discrimination-on-the-health-of-lgbt-people/ (last visited Oct. 26, 2022).

120. *Id.*

their LGBTQ+ identities in care settings.[121] This fear is not without justification. Many LGBTQ+ elders are at higher risk of elder abuse, neglect, or exploitation.[122] In 2001, a study found that sixty-five percent of lesbian, gay, and bisexual elders experienced victimization because of their identities, and twenty-nine percent reported being physically attacked.[123] By hiding their identities, they risk self-imposing limitations on the care that they need.[124]

Although there is minimal data on health outcomes or incidences of abuse or neglect among LGBTQ+ elders, past experiences of discrimination shape medical decision-making and limit the care options for LGBTQ+ elders.[125] For individuals who fear sharing their LGBTQ+ identities with providers, living in a nursing facility is likely to exacerbate these mental and physical manifestations of stress.[126] LGBTQ+ individuals are more likely to have limited social and familial circles.[127] Gay men in particular are more likely to live alone and to be unmarried in comparison to lesbian women.[128] Further, LGBTQ+ individuals report feeling less connected to friends, neighbors, family, and other communities while living in long-term care facilities.[129] This means that when it comes time to need long-term care assistance, options for the LGBTQ+ community are limited.[130]

121. KECK SCH. OF MED. OF USC, NAT'L CTR. ON ELDER ABUSE, NAT'L RES. CTR. ON LGBT AGING & SAGE, MISTREATMENT OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) ELDERS 4 (2021), https://ncea.acl.gov/getmedia/ed85bf0d-b7a8-4467-80d3-3a5d78898c29/NCEA_RB_LGBT2021.aspx [hereinafter MISTREATMENT OF LGBT ELDERS].

122. *Id.*; SUSAN LINDA WESTWOOD, ABUSE AND OLDER LESBIAN, GAY BISEXUAL AND TRANS (LGBT) PEOPLE: A COMMENTARY AND RESEARCH AGENDA 1, 6 (2018), https://eprints.whiterose.ac.uk/138097/1/Westwood_Submission_Jnl_Elder_Abuse_Neglect_Accepted_October_2018.pdf.

123. MISTREATMENT OF LGBT ELDERS, *supra* note 121, at 2.

124. *Id.* at 4.

125. *See What Does the Scholarly Research Say About the Effects of Discrimination on the Health of LGBT People?*, *supra* note 119; MISTREATMENT OF LGBT ELDERS, *supra* note 121, at 4.

126. Rand, *supra* note 6; MISTREATMENT OF LGBT ELDERS, *supra* note 121, at 4.

127. *See* MOVEMENT ADVANCEMENT PROJECT & SAGE, *supra* note 2, at 11–15.

128. *Id.* at 14.

129. *See id.* at 23.

130. *See id.* at 46–47.

B. *Barriers for LGBTQ+ Adults in Home- and Community-Based Services*

While institutional care may be the best option for some people with long-term care needs, the overwhelming majority of adults would prefer to receive care in their own home.[131] But HCBS is not available to everyone who wants it. Restrictions on who can be employed as a paid caregiver for an individual, inadequate support for the direct care workforce, and federal and state policies adjacent to family caregiving create a long-term care environment that is particularly unfavorable for the LGBTQ+ community.[132] The COVID-19 pandemic prompted policy actions that increased support for people with long-term care needs and their families in the short term, but these issues deserve more permanent solutions.[133]

1. *Restrictions on paid spousal care*

The Medicaid HCBS assessment process is designed to be person-centered and considers existing supports available to the patient to determine what additional services are medically necessary.[134] The assessment and care planning process considers informal family or community support provided to the applicant and, with respect to family members, is grounded in the expectation that family members are supposed to care for their parent, child, or spouse without compensation.[135] This

131. *See* ASSOC. PRESS-NORC CTR. FOR PUB. AFFS. RSCH., LONG-TERM CARE IN AMERICA: EXPECTATIONS AND PREFERENCES FOR CARE AND CAREGIVING 5–7 (2016), https://www.longtermcarepoll.org/wp-content/uploads/2017/11/AP-NORC-Long-term-Care-2016_Trend_Report.pdf.

132. *See infra* Sections II.B.1, II.B.2.

133. *See* Emily Kowalik, *Care in the Time of COVID: Addressing the State of Family and Medical Leave in Light of the COVID-19 Pandemic*, 47 NOTRE DAME J. LEGIS. 105, 118–22 (2021); Sharon Ward-Fore, *Changes COVID-19 Brought to Long-Term Care Facilities*, INFECTION CONTROL TODAY (Dec. 13, 2021), https://www.infectioncontroltoday.com/view/changes-covid-19-brought-to-long-term-care-facilities.

134. *Home and Community Based Services*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Jan. 10, 2014), https://www.cms.gov/newsroom/fact-sheets/home-and-community-based-services.

135. *See id.*; *Caregiving*, FAM. CAREGIVER ALL., https://www.caregiver.org/resource/caregiving/ (last visited Sept. 15, 2022) [hereinafter *Caregiving*].

element of the care planning process creates the opportunity for contention, particularly in circumstances such as COVID-19 where countless Americans found themselves jobless or working from home.[136] If, under these temporary circumstances, family members began providing unpaid care, a Medicaid program could incorrectly assume or assert that paid caregiving is unnecessary because of sufficient informal support. Family members and applicants have the right to assert that they are not legally required to provide unpaid caregiving.[137] Admitting that unpaid caregiving is not feasible for a family member may be challenging for some, especially for parents and spouses who are culturally expected to care for their loved ones with chronic conditions without compensation.[138]

While providing unpaid care may be feasible for some families, the burden of care is notably higher for individuals in the LGBTQ+ community who are more likely to be disconnected from relatives as a result of their sexual orientation or gender presentation.[139] Although recent federal efforts have filled in some gaps in care and support experienced by LGBTQ+ individuals and families, some states uphold Medicaid waiver policies that disproportionately harm the LGBTQ+ community.[140]

136. *See* Deb Gordon, *Caregiving Was Already Hard; Covid-19 Made It Nearly Unbearable*, FORBES (Feb. 16, 2021, 3:43 PM), https://www.forbes.com/sites/debgordon/2021/02/16/caregiving-was-already-hard-covid-19-made-it-nearly-unbearable/?sh=58c2743f5d1a.

137. Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2,948, 3,008 (Jan. 16, 2014) ("The planning process must not compel unpaid services."); *see also* Liz Seegert, *Some States Flout HCBS Medicaid Rules by Requiring Unpaid Family Caregiving*, ASSOC. OF HEALTH CARE JOURNALISTS (July 5, 2016), https://healthjournalism.org/blog/2016/07/some-states-flout-hcbs-medicaid-rules-by-requiring-unpaid-family-caregiving/; 42 C.F.R. § 441.301(c)(2)(v) (2022).

138. *See Caregiving*, *supra* note 135.

139. *See* ALZHEIMER'S ASS'N & SAGE, ISSUES BRIEF: LGBT AND DEMENTIA 5 (2018), https://www.alz.org/media/documents/lgbt-dementia-issues-brief.pdf.

140. *See Home & Community-Based Services 1915(c)*, MEDICAID, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited Oct. 26, 2022).

Generally, to qualify for long-term supports and services under Medicaid, an individual must not have over a certain amount of income or assets.[141] For certain programs, states may include a spouse's income or resources in this eligibility calculation, meaning that for married couples, such income requirements can place a financial burden on a partner of an individual requiring long-term care.[142] The federal spousal impoverishment rules, enacted in 1988 under the Medicare Catastrophic Coverage Act,[143] seek to protect a spouse's assets by preventing the spouse from having to get rid of or "spend down" existing shared money in order for their spouse to receive care through a Medicaid long-term services and supports program.[144] This federal protection was originally intended only to cover institutional care, leaving states the option to use 1915 waiver authority to extend coverage to Medicaid home- and community-based care beneficiaries as well.[145] At the time, protection from costs of institutional care was an appropriate policy focus, considering that facility-based care was the most common setting for long-term care, which in 1995, accounted for eighty-two percent of LTSS expenditures.[146] In 2014, Section 2404 of the Affordable Care Act required mandated spousal impoverishment rules for all home- and

141. *See id*.

142. *See id*.

143. Medicare Catastrophic Coverage Act of 1988, Pub. L. No. 100-360, 102 Stat. 683.

144. *See* MARYBETH MUSUMECI & MOLLY O'MALLEY WATTS, POTENTIAL CHANGES TO MEDICAID LONG-TERM CARE SPOUSAL IMPOVERISHMENT RULES: STATES' PLANS AND IMPLICATIONS FOR COMMUNITY INTEGRATION 3–5 (2019), https://files.kff.org/attachment/Issue-Brief-Potential-Changes-to-Medicaid-Long-Term-Care-Spousal-Impoverishment-Rules; *Spousal Impoverishment Rules*, MEDICARERESOURCES.ORG, https://www.medicareresources.org/glossary/spousal-impoverishment-rules/ (last visited Oct. 26, 2022).

145. *See* MUSUMECI & O'MALLEY WATTS, *supra* note 144, at 5–6; *Home & Community-Based Services 1915(c)*, *supra* note 140.

146. *See* MUSUMECI & O'MALLEY WATTS, *supra* note 144, at 8; *see also* CAITLIN MURRAY, ALENA TOURTELLOTTE, DEBRA LIPSON & ANDREA WYSOCKI, MEDICAID LONG TERM SERVICES AND SUPPORTS ANNUAL EXPENDITURES REPORT: FEDERAL FISCAL YEARS 2017 AND 2018 16 (Jan. 7, 2021), https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf.

community-based service waivers.[147] These protections have survived short term renewals since the expected 2018 expiration but have not yet secured permanence.[148]

Importantly, states are expected to approach Medicare determinations through a person-centered planning perspective that takes into consideration existing informal support such as unpaid care from family members or friends.[149] For example, determinations of need are based on self-reported occurrences or needs, such as the need for assistance with walking because of recent falls.[150] In this case, if a patient does not report any recent falls, the Medicaid program could think the patient's need for walking assistance is not critical.[151] However, it is possible that the individual has not fallen because they have been receiving effective informal care from a family member who pays close attention to them. Further, although there is a cultural assumption that spouses, parents, or adult children provide uncompensated care for their loved ones, any informal care considered in the planning process is expected to be provided willingly and voluntarily by the family member.[152]

Although a spouse may deeply want to provide care for their partner, the financial realities for families enrolled in Medicaid may not permit the resulting loss of income.[153] Low-income

147. CTR. FOR MEDICAID & CHIP SERVS., DEPT. HEALTH & HUM. SERVS., INFORMATIONAL BULLETIN: EXTENSION OF THE SPOUSAL IMPOVERISHMENT RULES FOR MARRIED APPLICANTS AND RECIPIENTS OF HOME AND COMMUNITY-BASED SERVICES 1 (May 4, 2021), https://www.medicaid.gov/federal-policy-guidance/downloads/cib050421.pdf.

148. Everette James & Meredith Hughes, *Making Spousal Impoverishment Protections Permanent*, HEALTHAFFAIRS (Dec. 7, 2021), https://www.healthaffairs.org/do/10.1377/forefront.20211202.923254/full/.

149. *See* DEBRA J. LIPSON, MATHEMATICA, HCBS QUALITY MEASURE ISSUE BRIEF: ASSESSMENT AND CARE PLANNING MEASURES 7 (2019), https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measures-brief-1-assessment-care-planning.pdf.

150. *See* Molly O'Malley Watts, MaryBeth Musumeci & Meghana Ammula, *State Policy Choices About Medicaid Home and Community-Based Services Amid the Pandemic*, KAISER FAM. FOUND. (Mar. 4, 2022), https://www.kff.org/medicaid/issue-brief/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic/.

151. *See id*.

152. *See Caregiving*, *supra* note 135; Kowalik, *supra* note 133, at 105.

153. *See* Kowalik, *supra* note 133, at 125.

families relying on Medicaid services often do not have the financial flexibility for a spouse to risk losing part or all of their income to care for a loved one.[154] Instead of taking time off, the spouse must prioritize their job over their partner in order to ensure continued income for the family.[155] Without a source of income, the individual needing care may simply be required to forego care while their partner is at work.[156]

Under federal Medicaid rules, home- and community-based personal care services cannot be provided by any family member of the beneficiary who is a legally responsible relative.[157] Moreover, the Code of Federal Regulations withholds federal matching funds for services provided by a beneficiary's spouse.[158] "Legally responsible" refers to parents of youths and spouses.[159] However, CMS chose to override this restriction in 2005, allowing states the option, under Medicaid Home and Community Based Services Waivers, to pay legally responsible relatives for personal care services.[160] States that administer home- and community-based services through the State Plan Personal Care option do not qualify for this exemption.[161] However, not all states have chosen to compensate legally responsible family members for home- and community-based care.[162] Considering the reality of many LGBTQ+ individuals' social and familial circles,[163] it is likely that a significant number of LGBTQ+ adults requiring care only

154. *See id.*

155. *See id.*

156. *See id.*

157. 42 C.F.R. § 440.167(a)(2).

158. *Id.* §§ 441.360(g), 440.181.

159. LEGIS. BUDGET & FIN. COMM., FAMILY CAREGIVERS IN PENNSYLVANIA'S HOME AND COMMUNITY-BASED WAIVER PROGRAMS, H.R. 2014-241, at 5–6 (2015), http://lbfc.legis.state.pa.us/Resources/Documents/Reports/527.pdf.

160. *Id.* at 7.

161. *See id.* at 6.

162. *Spouses Can Be Paid Caregivers for Their Husbands or Wives*, PAYING FOR SENIOR CARE, https://www.payingforseniorcare.com/paying-spousal-caregivers (June 16, 2021); *see also* Musumeci et al., *supra* note 55.

163. *See* Westwood, *supra* note 122, at 12.

have a spouse to rely on. This policy, in effect, restricts LGBTQ+ individuals to the single option of facility-based care.

Even for states that permit paid spousal care under Medicaid, hourly wages for caregivers across the country are low.[164] In Pennsylvania, for example, wages for community-based caregivers range from eleven dollars to sixteen dollars per hour.[165] In comparison, direct care workers across the country received an average of $13.56 per hour in 2020.[166] For some families, this hourly rate may be less than their current wages, considering that the average hourly wage for workers across the United States is nearly $30 per hour.[167] Families with one source of income are at greater risk of financial hardship if the primary income earner must become a full-time care giver.[168]

While other strategies for transferring assets to family or friends are not legally allowed under Medicaid provisions, some states do not prohibit or otherwise penalize applicants from pursuing a divorce and asset transfer process.[169] "Medicaid Divorce" is the common name for the practice of couples pursuing divorce so that one partner can meet income and resource limits and qualify for necessary Medicaid benefits.[170] Some law firms even advertise a specialty in maximizing beneficial outcomes for access to Medicaid benefits

164. *See Spouses Can Be Paid Caregivers for Their Husbands or Wives*, *supra* note 162.

165. *Can a Family Member Get Paid to Be a Caregiver in Pennsylvania?*, JEVS CARE AT HOME, https://jevsathome.org/family-member-paid-caregiver/ (last visited Oct. 26, 2022).

166. PHI NAT'L, DIRECT CARE WORKERS IN THE UNITED STATES: KEY FACTS 2 (2021), https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2/.

167. *See id.*; Indeed Ed. Team, *What Is the Average Hourly Wage in the US?*, INDEED https://www.indeed.com/career-advice/pay-salary/average-hourly-wage-in-us (Mar. 30, 2021); *see also May 2021 National Occupational Employment and Wage Estimates United States*, U.S. BUREAU OF LAB. STATS., https://www.bls.gov/oes/current/oes_nat.htm (Mar. 31, 2022).

168. *See* Kowalik, *supra* note 133, at 126.

169. *See* Lisa Ellen Brodoff, *Planning for Alzheimer's Disease with Mental Health Advance Directives*, 17 SEATTLE UNIV. ELDER L.J. 239, 278–79 (2010); *Should You Consider a Medicaid Divorce When One Spouse Requires Care and One Does Not?*, AM. COUNCIL ON AGING, https://www.medicaidplanningassistance.org/medicaid-divorce/ (Jan. 6, 2022).

170. *See* Brodoff, *supra* note 169, at 278–79; Jonathan E. Fields, *Grey Divorce: Tips for the Matrimonial Practitioner*, 29 J. AM. ACAD. MATRIM. LAWS. 101, 116 (2016).

through divorce.[171] While the process of legally de-coupling is a painful one for couples who would otherwise not wish to end their marriage, the option may be particularly jarring for homosexual couples who have only recently secured equal marriage opportunities and protections.[172]

2. *Unsupported direct care workforce*

Even where individuals successfully qualify for home- and community-based care, there are still barriers to receiving adequate services.[173] First, shortages of home care providers across the country mean that Medicaid agencies cannot find caregivers for patients.[174] Where professional services are unavailable, family members bear the burden of providing unpaid care; however, they may risk their jobs and income in an attempt to meet the needs of their loved ones.[175] Further, in the few states that permit spouses or legally responsible individuals to become paid caregivers, the low hourly pay for their work may increase financial strain on the family.[176]

Nationally, shortages of care providers mean that patients who have qualified for care, or have already been receiving

171. *See, e.g.*, *Medicaid Divorce,* WEINBERGER DIVORCE & FAM. L. GRP., https://www.weinbergerlawgroup.com/divorce/medicaid/ (last visited Oct. 26, 2022).

172. *See id.*; *see also* Obergefell v. Hodges, 576 U.S. 644, 681 (2015) (holding that the Due Process Clause and the Equal Protection Clause of the Fourteenth Amendment of the United States Constitution protect the fundamental right to marry for same-sex couples).

173. *See Direct Care Workforce Shortages Have Worsened in Many States During the Pandemic, Hampering Providers of Home and Community-Based Services*, KAISER FAM. FOUND. (Aug. 10, 2021), https://www.kff.org/coronavirus-covid-19/press-release/direct-care-workforce-shortages-have-worsened-in-many-states-during-the-pandemic-hampering-providers-of-home-and-community-based-services/ [hereinafter *Direct Care Workforce Shortages Have Worsened in Many States During the Pandemic*].

174. *See id.*

175. *See* Molly O'Malley Watts, MaryBeth Musumeci & Meghana Ammula, *State Medicaid Home & Community-Based Services (HCBS) Programs Respond to COVID-19: Early Findings from a 50-State Survey*, KAISER FAM. FOUND. (Aug 10, 2021), https://www.kff.org/coronavirus-covid-19/issue-brief/state-medicaid-home-community-based-services-hcbs-programs-respond-to-covid-19-early-findings-from-a-50-state-survey; Kowalik, *supra* note 133, at 106.

176. *See* PHI NAT'L, *supra* note 166, at 1; Kowalik, *supra* note 133, at 106.

care, are unable to receive home-based services.[177] A 2021 national survey found that Medicaid home- and community-based care infrastructure declined during the pandemic, with workforce shortages having the greatest impact on home-based services.[178] The 2021 survey cited "low wages, high turnover, and limited opportunities for career advancement" as driving factors in the workforce deficit.[179] While demand for access to care at home has been increasing for years, the COVID-19 pandemic propelled the push towards care at home without sufficient resources to serve everyone.[180]

3. *Insufficient protections for LGBTQ+ adults in long-term supports and services*

Although issues surrounding access to services under home- and community-based care have been heard by courts, few plaintiffs have seen success in challenging waiver provisions under existing standards of interpretation.[181] Medicaid beneficiaries have limited options for actionable litigation against Medicaid programs, specifically challenging access to home- and community-based services.[182] Thus, challengers have attempted to address the issue of long waiting lists for waiver services, arguing that the "reasonable pace" standard articulated in *Olmstead* with regard to applicants' movement through the waiting list for care was not met.[183] Courts have consistently relied on the fundamental alteration

177. *Direct Care Workforce Shortages Have Worsened in Many States During the Pandemic*, *supra* note 173.

178. O'Malley Watts et al., *supra* note 175.

179. Joan Stephenson, *Report Highlights Medicaid Home and Community-Based Services' Struggles with Worker Shortages, Closures*, JAMA HEALTH F. (Aug. 24, 2021), https://jamanetwork.com/journals/jama-health-forum/fullarticle/2783621.

180. O'Malley Watts et al., *supra* note 175.

181. *See, e.g.*, Williams v. Wasserman, 164 F. Supp. 2d 591, 633–38 (D. Md. 2001). Courts have asserted that due to the complexity of Medicaid issues, these decisions are not best decided by judges alone. *See id.* Rather, judges have relied on those more familiar with the details. *See also* Martin v. Taft, 222 F. Supp. 2d 940, 986 (S.D. Ohio 2002).

182. *See* Larisa Antonisse, *Strengthening the Right to Medicaid Home and Community Based Services in the Post-COVID Era*, 121 COLUM. L. REV. 1801, 1841–43 (2021).

183. *Id.* at 1805; Olmstead v. L.C., 527 U.S. 581, 605–06 (1999).

framework articulated in *Olmstead* to hold that states are allowed to continue operating waiver programs with slow waitlists and without promise of providing all eligible beneficiaries home- and community-based care.[184] Litigation in this area has proven to be unsuccessful at increasing access to home- and community-based care through *Olmstead* arguments.[185]

4. *Efforts to address a complex long-term care landscape*

COVID-19 has exposed the value of the caregiving workforce in the United States at a large scale, resulting in a positive movement towards protections for compensation of all caregivers at the federal level—LGBTQ+ caregivers included.[186] The pandemic simultaneously unearthed the magnitude of under-compensation for these vital services and critical faults in federal infrastructure outside of Medicaid.[187] Additionally, recent efforts show an increased understanding of the complexity of the long-term care landscape.[188] Under the American Rescue Plan, enacted in March of 2021, states had the opportunity to receive a ten-percentage-point increase in federal contribution to home- and community-based services through March 31, 2022.[189] States retained discretion in distribution of these increased funds.[190] Only one state chose to use the entire federal matching assistance percentage (FMAP)

184. *See* Antonisse, *supra* note 182, at 1805.

185. *See id.* at 1842.

186. *See* Jennifer Sullivan, *States Should Act Quickly for New Home- and Community-Based Services Funding*, CTR. ON BUDGET & POL'Y PRIORITIES (May 19, 2021, 9:19 AM), https://www.cbpp.org/blog/states-should-act-quickly-for-new-home-and-community-based-services-funding.

187. *See* Mandar Bodas, Kaushik P. Venkatesh, Lyndsey Gallagher, Margaret Ziemann & Rhea Kalluri, *Will States Use 'Rescue Plan' Funding to Give Direct Care Workers a Raise?*, HEALTH AFFS. (Nov. 9, 2021), https://www.healthaffairs.org/do/10.1377/forefront.20211104.851752/full/.

188. *See, e.g.*, American Rescue Plan Act of 2021, Pub. L. No. 117-2, 135 Stat. 4 (2021).

189. Sullivan, *supra* note 186; American Rescue Plan Act § 9817(b)(1).

190. Sullivan, *supra* note 186; American Rescue Plan Act § 9817(b)(2).

to increase pay for home- and community-based care workers.[191]

Not long after, in June of 2021, Democrats in the House of Representatives proposed a bill "[t]o amend title XIX of the Social Security Act to expand access to home and community-based services (HCBS) under Medicaid."[192] The bill, called the Better Care Better Jobs Act, offered $100 million to states, expanded financial eligibility, required regular reporting, required states to implement strategies to strengthen the home- and community-based services workforce, expanded supports for family caregivers, and instituted a permanent increase in federally matched dollars by 10% to states delivering home- and community-based care.[193]

In contrast to institutional care, HCBS provides a solution to infectious disease spread, encourages community engagement, and permits individuals greater dignity in their care and environment.[194] However, without designation as a mandatory Medicaid benefit, HCBS is still deprioritized in comparison to nursing facility services.[195] The health benefits of home- and community-based care support greater federal investment in population-wide access to home- and community-based services.[196] However, there are still elements of the Medicaid home- and community-based services program that hinder LGBTQ+ health and safety, even policy issues outside of Medicaid such as family medical leave benefits. The Family Medical Leave Act (FMLA) has historically been reserved for relatives either through blood or marriage.[197] For unmarried

191. Bodas et al., *supra* note 187.

192. Better Care Better Jobs Act, H.R. 4131, 117th Cong. (2021); *see* Kezia Scales, *Better Care Better Jobs Act Could Transform Direct Care Jobs*, PHI NAT'L (July 13, 2021), https://phinational.org/better-care-better-jobs-act-could-transform-direct-care-jobs/.

193. Scales, *supra* note 192.

194. *See Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, *supra* note 20.

195. *See* Musumeci et al., *supra* note 55.

196. *See Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, *supra* note 20.

197. *See* Kowalik, *supra* note 133, at 114.

LGBTQ+ elders whose trusted circle may only include "chosen families," those not related to the individual but whom they rely on for emotional or other support, FMLA would not apply to workplace absences for any time spent caring for their friend.[198] While recent legislation offers support to families struggling to support needy family members, funding without permanent structural change to Medicaid and other federal programs will continue to harm LGBT elders in need of long-term care.[199]

III. SOLUTIONS TO IMPROVE LONG-TERM CARE FOR LGBTQ+ ADULTS

Specifically for LGBTQ+ individuals, increased access to care at home will increase health outcomes. For LGBTQ+ people who have experienced social isolation or discrimination based on their identity, living in their preferred community would ensure continued access to existing social supports.[200] The freedom to live authentically must be considered as a key element of mental and physical health outcomes.[201] Considering the fear of discrimination or mistreatment among older LGBTQ+ individuals, it is likely that access to one trusted caretaker may be more appealing to LGBTQ+ individuals than navigating an unfamiliar, rotating team of staff and other residents at a facility.[202] Further, it is more feasible to connect people to resources in their community in comparison to

198. *See* ANGELA HOUGHTON & NII-QUARTELAI QUARTEY, MAINTAINING DIGNITY UNDERSTANDING AND RESPONDING TO THE CHALLENGES FACING OLDER LGBT AMERICANS 1, 10 (2020), https://www.aarp.org/content/dam/aarp/research/surveys_statistics/life-leisure/2020/maintaining-dignity-lgbt-reformatted.doi.10.26419-2Fres.00217.006.pdf; *FMLA Frequently Asked Questions*, U.S. DEP'T OF LAB. WAGE & HOUR DIV., https://www.dol.gov/agencies/whd/fmla/faq (last visited Nov. 1, 2022).

199. *See* Better Care Better Jobs Act of 2021, H.R. 4131, 117th Cong. (2021); *see also* Sullivan, *supra* note 186.

200. *See* MISTREATMENT OF LGBT ELDERS, *supra* note 121, at 2.

201. *See* Cara Imperato, *LGBT Assisted Living Communities - Finding a Gay-Friendly Facility*, SENIOR ADVICE, https://www.senioradvice.com/articles/LGBT-assisted-living-communities-finding-a-gay-friendly-facility (last visited Nov. 1, 2022).

202. *See id*.

institutional care that is not a specifically LGBTQ+ care facility.[203]

Federal legislation should be enacted that classifies HCBS as a mandatory Medicaid benefit and states should implement comprehensive policies that increase awareness of LGBTQ+ needs and improve the Medicaid program's capacity for gaining valuable information about the Medicaid population's demographics and corresponding health needs. As a mandatory benefit, states would no longer be permitted to waive statewide requirements or prolong access to care through lengthy waitlists.[204] Federal action is required because action through the courts is unlikely to yield any profound result and court cases are subject to being overruled by new legislation.[205]

Finally, HCBS programs must be supported by comprehensive policies and procedures that aim to better understand the LGBTQ+ population and protect vulnerable patients from discrimination. Data is a valuable tool for quality and outcomes improvement across all aspects of healthcare administration.[206] Increasing opportunities for LGBTQ+ individuals to share their personal identities in a way that does not threaten their safety will allow Medicaid programs to better understand the demographics and needs of their patient populations.[207] One way to ensure that individuals feel comfortable sharing their identities is to explicitly include protections against discrimination on the basis of sexual orientation or gender identity across all long-term care settings. Additionally, mandatory trainings that discuss the history and care considerations of LGBTQ+ individuals will ensure that all care providers have greater awareness of and sensitivity

203. *See id*.

204. *See Home & Community Based Services 1915(c)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited Nov. 1, 2022); Antonisse, *supra* note 182, at 1805.

205. *See* Antonisse, *supra* note 182, at 1841–43.

206. *How Big Data in Health Care Influences Patient Outcomes*, TUL. UNIV. SCH. PUB. HEALTH & TROPICAL MED. (July 7, 2021), https://publichealth.tulane.edu/blog/big-data-in-healthcare/.

207. *See id*.

towards the individuals they serve. Together, these protections and procedures will ensure that LGBTQ+ adults receive appropriate care with dignity.

A. *Mandatory Home- and Community-Based Services*

The first step in increasing access to long-term care for LGBTQ+ adults is to move the provision of Medicaid HCBS from waiver programs to mandatory benefits under each states' Medicaid program. While waivers can be useful to states, they ultimately restrict access to care. Waivers create an opportunity for states to tailor benefits to meet the needs of a smaller subset of their populations without having to conform to all standard Medicaid rules.[208] Waivers also give states the flexibility to innovate and to bend their Medicaid budget to meet the unique needs for their populations while limiting spending on services.[209] However, this flexibility can lead to disparate treatment for vulnerable populations, like older LGBTQ+ beneficiaries, because they have less family support on average and may be less inclined to invite a stranger into their home for fear of mistreatment. [210]

Various options are available at the state and federal levels to increase access to home- and community-based care in the short term.[211] In the long term, establishing HCBS as a mandatory Medicaid benefit would increase access to care by streamlining the application process, reducing wait time for services, and ensuring stability in access to benefits.[212] As mandatory benefits, states would no longer be permitted to restrict HCBS

208. *See* Musumeci et al., *supra* note 55, at 14.

209. KELLI DEPRIEST, SOHA VAZIRI, KARLYN TUNNELL & CAROLINE ADAMS, MEDICAID 101: AN OVERVIEW OF STATE PLAN AMENDMENTS & WAIVERS 2 (2021), https://www.medicaidinnovation.org/_images/content/2021-IMI-Medicaid_201_Waivers-Report.pdf.

210. *See* HOUGHTON & QUARTEY, *supra* note 198, at 17, 22, 45–46.

211. *See* BIPARTISAN POL'Y CTR., STREAMLINING AND SIMPLIFYING MEDICAID HCBS AUTHORITIES 13–14 (2021), https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2021/10/BPC-HBCS-Report_R02.pdf/.

212. *See id.* at 15, 18; Antonisse, *supra* note 182, at 1805; MISTREATMENT OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) ELDERS, *supra* note 121, at 3.

to specific geographic areas or to delay access to care through lengthy waitlists.[213] Mandatory home- and community-based services would most closely resemble the structure of Section 1915(i) State Plan waiver services in that there are no established limits on the number of enrolled beneficiaries and therefore no waitlist.[214]

Mandating access to HCBS through Medicaid would streamline the administration of such services.[215] At present, states can offer home- and community-based care through multiple waivers, or even supplement payment for care through non-Medicaid programs.[216] Apart from Medicaid State Plans, waivers raise administrative concerns such as making a complicated and confusing process for beneficiaries and care providers.[217] Waivers also thwart positive data collection efforts seeking to better understand the needs of states' Medicaid populations because not everyone who may be eligible for the programs understand that they can apply.[218] Without accurate information about the Medicaid population, Medicaid programs cannot appropriately meet the needs of their beneficiaries.[219]

Establishing home- and community-based care as a mandatory Medicaid benefit would facilitate consistency across states for beneficiaries to access the full range of medically-necessary long-term care without the restrictions imposed by waivers.[220] Under the proposed solution, states

213. *See Assessing the Health and Welfare of the HCBS Population*, AGENCY FOR HEALTHCARE RSCH. & QUALITY (Dec. 2012), https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/hcbs/findings/find3.html.

214. *See* Musumeci et al., *supra* note 55, at 10.

215. BIPARTISAN POL'Y CTR., *supra* note 211, at 5–6.

216. *See* AMBER CHRIST & TIFFANY HUYENH-CHO, USING DATA FOR GOOD: TOWARD MORE EQUITABLE HOME AND COMMUNITY-BASED SERVICES IN MEDI-CAL 7 (2021), https://www.chcf.org/wp-content/uploads/2021/11/UsingDataGoodHCBSMediCal.pdf; BIPARTISAN POL'Y CTR., *supra* note 211, at 5–6.

217. *See* BIPARTISAN POL'Y CTR., *supra* note 211, at 5, 16.

218. *See id*. at 16–17.

219. *See id*. at 17.

220. *Home and Community Based Services*, *supra* note 134; BIPARTISAN POL'Y CTR., *supra* note 211, at 16.

would still have the freedom to determine what constitutes "medical necessity" within long-term care and to establish their own formulas for calculating hours of paid caregiving.[221] It also follows that state Medicaid offices would still maintain authority over determining the number of hours of paid care a beneficiary is eligible to receive, thereby maintaining control over spending on caregiving regardless of whether the caregiver is a family member or not.[222] Control over Medicare determinations, definitions of "medical necessity" and eligibility would insulate states from any perceived federal overreach and protect the Medicaid budget.[223]

The HCBS Access Act, drafted by Senators Brown, Hassan, and Casey, and Representative Dingell, proposes HCBS as a federally mandated Medicaid benefit.[224] However, this bill falls short of protecting the needs of LGBTQ+ individuals who need home- and community-based care. This bill does not include, but should for the benefit of LGBTQ+ families, permanent protections against spousal impoverishment, increased resources for preventing abuse or neglect, and protocols for reporting abuse or neglect.[225] Thus, additional, more comprehensive legislation is still needed to achieve an equitable outcome for LGBTQ+ individuals.[226]

221. *See* OFF. OF THE ASSISTANT SEC'Y FOR PLAN. & EVALUATION, U.S. DEP'T OF HEALTH & HUM. SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 65, 102, 107 (2010), https://aspe.hhs.gov/sites/default/files/private/pdf/76201/primer10.pdf.

222. *See id.* at 111.

223. *Id.* at 93–94.

224. Press Release, Rep. Dingell and Sens. Hassan, Brown & Casey, Discussion Draft of the Home and Community Based Access Act (HAA) (Mar. 16, 2021), https://debbiedingell.house.gov/uploadedfiles/home_and_community-based_services_access_act_-_memo_ad.pdf; *Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, NAT'L HEALTH L. PROGRAM (Mar. 16, 2021), https://healthlaw.org/news/bill-to-expand-medicaid-home-and-community-based-services-introduced-in-congress/.

225. *See* Press Release, Rep. Dingell and Sens. Hassan, Brown & Casey, *supra* note 224; *Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, *supra* note 20.

226. *See* Press Release, Rep. Dingell and Sens. Hassan, Brown & Casey, *supra* note 224; *Bill to Expand Medicaid Home and Community Based Services Introduced in Congress*, *supra* note 224.

B. *Universal Access to Paid Spousal Care*

Paid spousal caregiving is a critical element of successful home- and community-based care programs for LGBTQ+ adults and their families.[227] Historically, there have been several factors and fears contributing to states' reluctance to adopt policies for legally responsible relatives to become paid caregivers.[228] Policymakers have cautioned against paid family caregiving, citing concerns of fraud, increased costs to the Medicaid program, lack of oversight over care delivery, challenges with labor laws, and other legal challenges implicating family caregiving.[229] However, research has shown that costs towards beneficiaries who received home care provided by a legally responsible family member are lower than those for beneficiaries who receive care from others.[230]

In California, a state that allows for paid spousal care, data shows that "[e]xpenditures were lower among those with spouse providers ($1,075 nonaged [sic], $770 aged) and highest among those with nonrelative providers ($1,679 non-aged, $1,388 aged)."[231] Further, "among persons aged 65 years and older, those with spouse paid caregivers had significantly fewer ACS hospital admissions and fewer nursing home placements."[232] The findings show that Hispanic and Asian beneficiaries were more likely to choose a spouse or other family member as their caregiver.[233] Though the reasoning for

227. *See Special Concerns of LGBTQ+ Caregivers*, FAM. CAREGIVER ALL., https://www.caregiver.org/resource/special-concerns-lgbt-caregivers/ (last visited Nov. 1, 2022).

228. *See* Robert J. Newcomer, Taewoon Kang & Pamela Doty, *Allowing Spouses to Be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures*, 52 GERONTOLOGIST 517, 518 (2012); *see also* Jennifer Wolff, Karen Davis, Mark Leeds, Lorraine Narawa, Ian Stockwell & Cynthia Woodcock, *Family Caregivers as Paid Personal Care Attendants in Medicaid*, JOHNS 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 (last visited Nov. 1, 2022).

229. Wolff et al., *supra* note 228.

230. Newcomer et al., *supra* note 228, at 525.

231. *Id.*

232. *Id.* at 528.

233. *Id.* at 529.

this trend is undetermined, factors such as shared culture, language, or values may play a significant role in caregiver choice.[234] Such factors are arguably similar to values held by LGBTQ+ beneficiaries.

Under federal waiver authority, states are permitted to set limits on the number of hours of home- and community-based services covered per day, week, or annually.[235] As a cost containment strategy, this helps states comply with the federal requirement that spending on home- and community-based services not exceed the cost of institutional care.[236] Unfortunately, this cost-saving mechanism appears to be fundamentally at odds with the goal of providing care for people who would otherwise require nursing facility care. Under a capitation structure, individuals are at risk of not receiving the full extent of care they need to maintain their health and safety.[237] States require beneficiaries to undergo assessments to determine care needs, but capitation powers give Medicaid programs the freedom to arbitrarily deny the full number of hours of paid care that is deemed medically necessary for an individual as a result.[238] Under mandatory HCBS benefits, capitation on care determinations should be on par with those imposed in institutional care, or explicitly excluded.

LGBTQ+ adults in all states would benefit from permanent access to paid spousal care. However, current federal standards restrict this option.[239] Under the current federal standards, paid personal care services cannot be provided by a legally responsible relative unless a state decides to allow for such services under Medicaid waiver authority.[240] Updated statutory

234. *See, e.g.*, Junko Takeshita, Shiyu Wang, Alison W. Loren, Nandita Mitra, Justine Shults, Daniel B. Shin & Deirdre L. Sawinski, *Association of Racial/Ethnic and Gender Concordance Between Patients and Physicians with Patient Experience Ratings*, JAMA NETWORK, Nov. 2020, at 1, 6–7.

235. *See* Musumeci et al., *supra* note 55.

236. *Services 1915(c)*, *supra* note 39.

237. *See id*.

238. *See* Musumeci et al., *supra* note 55.

239. 42 C.F.R. § 440.167(a)(2) (2022).

240. *Id.* § 440.167.

language must ensure that this provision no longer limits who can provide care, and instead creates the opportunity for states to detail how family care providers will be employed and managed. Under the waiver model, states can articulate the requirements of paid family caregivers including whether they can be independent providers or be employed by a caregiving agency.[241] Many states currently allow patients to have independent caregivers, but about half of states offering personal care state plan benefits require caregivers to be employed by an agency.[242] Under mandatory home- and community-based services, states could retain discretion over caregiver requirements.

C. *Protections Against Discrimination, Abuse, and Fraud*

Elder abuse and Medicaid billing fraud are common concerns among long-term care advocates and Medicaid administrators.[243] Elderly individuals are vulnerable to physical abuse, neglect, and financial abuse at the hands of their caregivers, and nearly one in ten people over the age of sixty-five in the United States experienced abuse in 2018.[244] The issue is particularly common within nursing homes.[245] For example, over 9,700 complaints of abuse were filed against nursing homes in 2013.[246] Long-term care facilities, like nursing homes and hospice, are also the most common perpetrators of fraud in Medicaid billing.[247]

241. *See* Musumeci et al., *supra* note 55.

242. *Id.*

243. *See Elder Abuse Statistics*, NURSING HOME ABUSE CTR., https://www.nursinghomeabusecenter.com/elder-abuse/statistics/ (Jan. 16, 2020); *see also* Bailey Wendzel, Ian Deitz, Nicholas Engle, David Favre, Andrea Fenster, Nickolas Foran & Allen Gehring, *Health Care Fraud*, 56 AM. CRIM. L. REV. 1033, 1035 (2019).

244. *See Elder Abuse Statistics*, *supra* note 243.

245. *Id.*

246. *Id.*

247. SUZANNE MURRIN, OFF. INSPECTOR GEN., OEI-09-22-00020, MEDICAID FRAUD CONTROL UNITS FISCAL YEAR 2021 ANNUAL REPORT, at 23 (2022), https://oig.hhs.gov/oei/reports/OEI-09-22-00020.pdf [hereinafter FISCAL YEAR 2021 ANNUAL REPORT].

While LGBTQ+ individuals are less likely to be victims of abuse or discrimination based on their identity while receiving care at home, broad concerns regarding financial fraud and patient abuse in home- and community-based care are substantiated.[248] The Department of Health and Human Services reports that personal care services attendants account for significantly more billing fraud convictions than other provider types year over year.[249] Personal care and home care aids also account for the greatest number of convictions for patient abuse and neglect than other provider types.[250] In light of these persistent trends in convictions, the Centers for Medicare and Medicaid have identified clear strategies to curb potential issues of improper payments to caregivers in home- and community-based care.[251]

Patient abuse and Medicaid billing fraud are also major concerns in nursing home care.[252] Without improved data on who is reporting abuse and how they are reporting it, it is impossible to know whether these convictions accurately reflect actual trends in fraud and abuse across long-term care settings.[253] For example, individuals receiving care at home may report abuse by paid caregivers to their family members more easily than an individual who requires assistance with a telephone to talk to family from within a nursing home. Disconnect from family and friends was particularly bad during the COVID-19 pandemic as a result of rampant nursing home staffing shortages.[254]

248. *Id.* at 5, 7.

249. *Id.* at 5.

250. *Id.* at 7.

251. MEDICAID INTEGRITY INST., CTR. FOR PROGRAM INTEGRITY & CTRS. FOR MEDICARE & MEDICAID SERVS., VULNERABILITIES AND MITIGATION STRATEGIES IN MEDICAID PERSONAL CARE SERVICES 1 (2018), https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/FraudAbuseforProfs/Downloads/vulnerabilities-mitigation-strategies.pdf.

252. *See* FISCAL YEAR 2021 ANNUAL REPORT, *supra* note 247, at 23.

253. *See* CHRIST & HUYENH-CHO, *supra* note 216, at 5.

254. *See US: Concerns of Neglect in Nursing Homes,* HUM. RTS. WATCH (Mar. 25, 2021, 12:01 AM), https://www.hrw.org/news/2021/03/25/us-concerns-neglect-nursing-homes#.

The data compiled by the Department of Health and Human Services does not mention harms to LGBTQ+ residents because there are no LGBTQ+ specific anti-discrimination protections at the federal level.[255] Laws protecting LGBTQ+ adults against discrimination in nursing homes are state-dependent.[256] While nursing facilities can have their own policies, of those policies, only about eighteen percent protect residents based on LGBT identity.[257] The reported violations are derived from the Nursing Home Reform Act,[258] which established a minimum set of standards of care and rights for federally certified nursing homes to protect residents from abuse, neglect, and exploitation and ensured the rights of residents to be treated with respect and dignity in long-term care facilities.[259] These protections do not address issues of discrimination based on sexual orientation or gender expression.[260] Even though individuals may have the opportunity to choose a caregiver for care at home, LGBTQ+ individuals cannot pursue a claim of sex or gender-based discrimination since 42 C.F.R. section 495.356 only prohibits discrimination on the basis of race, color, national origin, disability, or age.[261]

Ultimately, CMS should amend the 42 C.F.R. section 495.356 nondiscrimination requirements to include discrimination based on sex or gender. States could also establish protections for LGBTQ+ people receiving long-term care in several ways.

255. *National Coming Out Day: Some LGBTQ+ Seniors Fearing Discrimination Go Back 'Into the Closet'*, SAGE (Oct. 11, 2021), https://www.sageusa.org/news-posts/national-coming-out-day-some-lgbtq-seniors-fearing-discrimination-go-back-into-the-closet/.

256. THE HUM. RTS. CAMPAIGN FOUND., LONG-TERM CARE EQUALITY INDEX 2021, at 6 (2021), https://www.sageusa.org/wp-content/uploads/2021/06/sage-lei-2021-report-final.pdf; *see also* Lois A. Bowers, *Senior Living – New Law Creates LGBT 'Bill of Rights' for California Assisted Living, Nursing Home Residents*, EQUAL. CAL. (Oct. 10, 2017, 12:52 PM), https://www.eqca.org/senior-living-new-law-creates-lgbt-bill-of-rights-for-california-assisted-living-nursing-home-residents/.

257. THE HUM. RTS. CAMPAIGN FOUND., *supra* note 256.

258. Nursing Home Reform Act, Pub. L. No. 100-203, 101 Stat. 1330-160 to -221 (1987).

259. *See* 42 C.F.R. §§ 483.10, 483.12 (2022).

260. *See id.*

261. *See id.* § 495.356.

As the guiding document for states administering Medicaid,[262] states could include within their State Plans a statement against discrimination based on sex or gender. Collectively, these efforts would better protect the LGBTQ+ community from discrimination, abuse, and fraud.

D. *Improved Understanding of LGBTQ+ Needs*

To improve care for the aging LGBTQ+ population, it is imperative that Medicaid programs engage in efforts to better understand the population and to better train their caregivers. Accordingly, states should implement better data collection regarding sexual orientation and gender identity and require cultural competency trainings for caregivers providing HCBS.

Diversity and inclusion initiatives across sectors have been proven to benefit organizations, individuals, and communities.[263] In the healthcare setting, diversity is associated with improved performance and outcomes for patients.[264] Data collection and evaluation are critical tools for diversity and inclusion initiatives and beneficial for Medicaid programs.[265] Across the board, there is relatively limited data on the intersections of diseases of aging, sexual orientation, and gender identity or expression.[266] Throughout Medicaid programs, regular data collection and evaluation inform strategic decisions.[267] Increased data on beneficiary demographics and experiences could not only improve states' decisions regarding provision of services but also would likely

262. *See id.*

263. *Why Diversity and Inclusion Matter (Quick Take)*, CATALYST (June 24, 2020), https://www.catalyst.org/research/why-diversity-and-inclusion-matter/.

264. L.E. Gomez & Patrick Bernet, *Diversity Improves Performance and Outcomes*, 111 J. NAT'L MED. ASS'N 383, 391 (2019).

265. *See Using Data for Evidence Based Action on Diversity and Inclusion*, ERNST & YOUNG (Aug. 9, 2019), https://www.ey.com/en_ie/consulting/using-data-for-evidence-based-action-on-diversity-and-inclusion.

266. *See* ALZHEIMER'S ASS'N & SAGE, ISSUES BRIEF: LGBT AND DEMENTIA 5 (2018), https://www.alz.org/media/documents/lgbt-dementia-issues-brief.pdf.

267. *See Reports and Evaluation*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.medicaid.gov/chip/reports-evaluations/index.html (last visited Nov. 1, 2022).

lead to greater efficiency and lower costs of administration in the future.[268]

States should bolster their caregiver workforce by increasing training opportunities and requirements for prospective and existing caregivers. Along with including a statement of anti-discrimination based on sex or gender in State Plans as discussed above, states could embed in their contracts with home health agencies a requirement that they facilitate trainings on cultural competency, specifically including discussions of sexual orientation, gender identity, and anti-discrimination.[269] California spearheaded efforts to combat discrimination in residential care facilities by requiring nurses, certified nurse assistants, licensed vocational nurses, and physicians who work in nursing facilities to complete a training program focused on the needs of and challenges faced by LGBTQ+ seniors.[270] While increasing access to paid care from trusted family and friends may meet the needs of many LGBTQ+ adults, those without such options may need to rely on a health aid who they have never met before. Trainings centering LGBTQ+ needs will allow LGBTQ+ individuals greater access to caregivers who can meet those needs.

CONCLUSION

The COVID-19 pandemic brought to light ongoing concerns regarding long-term care in the United States and facilitated a faster transition towards home- and community-based care.[271] Because of this, the already strained home- and

268. *See* DEBRA LIPSON, MARGARET COLBY, TIM LAKE, SU LIU & SARAH TURCHIN, MATHEMATICA POL'Y RSCH, INC., DEFINING AND MEASURING STATE MEDICAID SPENDING EFFICIENCY: A LITERATURE REVIEW 23 (2009), https://aspe.hhs.gov/reports/defining-measuring-state-medicaid-spending-efficiency-literature-review-0.

269. *See, e.g.*, S.B. 1729, 2008 Leg., Reg. Sess. (Cal. 2008) (codified as CAL. HEALTH & SAFETY § 1257.5).

270. *See id*.

271. *See* Oleg Bestsennyy, Michelle Chmielewski, Anne Koffel & Amit Shah, *From Facility to Home: How Healthcare Could Shift by 2025*, MCKINSEY & CO. (Feb. 1, 2022), https://www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/from-facility-to-home-how-healthcare-could-shift-by-2025.

community-based care infrastructure has failed to meet the needs of the general Medicaid population.[272] The impact on LGBTQ+ elders has been disproportionately negative.[273] Without access to culturally competent care, vulnerable LGBTQ+ individuals risk exacerbated mental and physical health conditions.[274] As the primary driver of systemic failure, staff shortages in the long-term care workforce could be reversed with systemic policy change.[275] Funding from various sources has allowed states to funnel improved wages for care providers, but the option for families to be compensated for caring for their loved ones has not seen widespread adoption across the states.

Universal paid family care would increase access for LGBTQ+ elders to receive care at home, improve health outcomes and general well-being for the LGBTQ+ population, and contribute to a stronger economy. Establishing home- and community-based care as mandatory benefits under Medicaid, with accompanying protections against discrimination, increased data on LGBTQ+ needs, and workforce support, would streamline provision of care and facilitate a nationwide foundation for caring for the aging U.S. population.

272. *See* DENISE TYLER, MELISSA HUNTER, NATALIE MULMULE & KRISTIE PORTER, COVID-19 INTENSIFIES HOME CARE WORKFORCE CHALLENGES 5–6 (2021), https://aspe.hhs.gov/sites/default/files/private/aspe-files/265686/homecarecovid.pdf.

273. *See The Cost of COVID-19 for LGBT Older Adults*, LAMBDA LEGAL (Apr. 28, 2020), https://www.lambdalegal.org/blog/lgbt-older-adults-seniors-elders-coronavirus.

274. *See* Arne Stinchcombe, Jeffrey Smallbone, Kimberley Wilson, Katherine Kortes-Miller, *Healthcare and End-of-Life Needs of Lesbian, Gay, Bisexual, and Transgender (LGBT) Older Adults: A Scoping Review*, GERIATRICS, Mar. 2017, at 1, 4.

275. *See* H. Xu, Orna Intrator & John R. Bowblis, *Shortages of Staff in Nursing Homes During the COVID-19 Pandemic: What are the Driving Factors?*, 21 J. AM. MED. DIRS. ASS'N. 1371, 1372 (2020).