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Meeting the Integration Mandate: The Implications of *Olmstead* for the Home Care Workforce

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In the 1999 ruling on Olmstead v. L.C. *ex rel.* Zimring*, the Supreme Court upheld the right of all individuals to live independently in their own homes and communities and placed an explicit obligation on states to provide the supports and services that are required to fulfill that right. Progress toward fulfilling* Olmstead *has been hindered, however, by inadequate attention to building and strengthening the home care workforce—a workforce which provides the daily personal assistance that makes community integration possible for many individuals with disabilities. This Article describes the home care workforce and the drivers of growing demand for their services—in the context of the "rebalancing" trend in the long-term services and supports system—before discussing entrenched workforce challenges and policy solutions, focusing primarily on compensation, training and career development, and scope of practice. Along with other policy and practice interventions, action in these three areas is essential for improving home care job quality, stabilizing the workforce, and ensuring that community-based services are available for all those who seek them.*

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I. INTRODUCTION

In *Olmstead v. L.C.* ex rel. *Zimring,* the Supreme Court ruled that the unnecessary institutionalization of individuals with disabilities constitutes unlawful discrimination under the Americans with Disabilities Act (ADA).[1] By protecting the right of individuals to be free from unjustified segregation on the basis of disability, and to live independently in their own homes and communities, the 1999 ruling also placed an explicit obligation on states and public entities to provide the supports and services that are required to fulfill that right.[2]

In the two decades since *Olmstead*, an estimated 50,000 individuals with physical disabilities, intellectual and development disabilities, and mental illness have benefitted from statewide settlements "giving them the opportunity to receive health, residential, employment, and day services in their communities and . . . to leave, or avoid entering, segregated institutions."[3] Countless more have been impacted by the broader "rebalancing" trend in the long-term services and supports (LTSS) sector—i.e., the shift in public spending from nursing homes and other congregate settings to home and community-based settings—which originated in the 1970s and gained considerable momentum in the years after *Olmstead*.[4]

Progress toward fulfilling *Olmstead*'s "integration mandate" has been hindered, however, by inadequate attention to building and strengthening the home care workforce—the workforce which provides the daily personal assistance that is essential for many individuals with disabilities to live independently in the community.[5] Despite the escalating demand for their services and the increasing complexity of their role, home care workers continue to struggle to attain basic elements of job quality, such as livable wages, sustainable schedules, training and

1. *See* Olmstead v. L.C. *ex rel*. Zimring, 527 U.S. 581, 582 (1999).

2. *See* Sara Rosenbaum, *The* Olmstead *Decision: Implications for State Health Policy*, 19 HEALTH AFF. 228, 231 (2000) ("States have the lead responsibility for reshaping health systems to meet the *Olmstead* standard.").

3. *Department of Justice Celebrates 20th Anniversary of the Olmstead Supreme Court Decision Protecting the Rights of Americans with Disabilities*, DEP'T OF JUST.: JUST. BLOGS (June 19, 2019), https://www.justice.gov/opa/blog/department-justice-celebrates-20th-anniversary-olmstead-supreme-court-decision-protecting.

4. *See* Jennifer Ryan & Barbara Coulter Edwards, *Rebalancing Medicaid Long-Term Services and Supports*, HEALTH AFF. (Sept. 17, 2015), https://www.healthaffairs.org/do/10.1377/hpb20150917.439553/full.

5. A 2013 Senate report on states' progress toward fulfilling the community living promise of the ADA and *Olmstead*, as one example, does not contain a single reference to workforce issues or solutions. STAFF OF S. COMM. ON HEALTH, EDUC., LABOR, AND PENSIONS, 113TH CONG., SEPARATE AND UNEQUAL: STATES FAIL TO FULFILL THE COMMUNITY LIVING PROMISE OF THE AMERICANS WITH DISABILITIES ACT (2013).

career development opportunities, and more.[6] Due to this confluence of policy changes, demographic trends, and job quality concerns, the home and community-based services (HCBS) sector is struggling to fill home care jobs and maintain a sufficient and stable workforce.[7]

This Article begins by briefly describing the direct implications of the landmark *Olmstead* case before placing it in the broader context of LTSS rebalancing, describing an illustrative array of policies, demonstration programs, and other initiatives that have been implemented over the past several decades to promote HCBS. The next section provides a detailed snapshot of home care workers as the primary providers of personal assistance services in the community and quantifies the growing demand for this workforce with reference to demographic as well as legal and policy drivers. The final section discusses longstanding and persistent workforce-related challenges to fulfilling *Olmstead*'s integration mandate and offers promising policy solutions, focusing on three areas: compensation, training and career development, and scope of practice. A brief comment is also provided on the opportunities to invest in the home care workforce that have arisen through payment reforms such as managed care and value-based payment.

II. *OLMSTEAD VS. L.C.* AND THE LONG-TERM SERVICES AND SUPPORTS SYSTEM

A. An Overview of the LTSS System in the United States

Long-term services and supports (LTSS) include the range of health and personal assistance that individuals may require when they experience difficulty completing daily activities such as bathing, preparing and eating meals, and managing medications.[8] Family members and friends provide the bulk of this assistance,[9] but when individuals' needs surpass the capacity of their unpaid caregiving networks—or when relying on unpaid caregivers in not an option or a preference—then paid LTSS become a lifeline.

Total spending on LTSS in the United States was estimated at approximately $379 billion in 2018 (not including the value of uncompensated care provided by family members and friends).[10] LTSS are primarily financed by Medicaid (52%)

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6 . *See* KEZIA SCALES, PHI, ENVISIONING THE FUTURE OF HOME CARE: TRENDS AND OPPORTUNITIES IN WORKFORCE POLICY AND PRACTICE 42–51 (2019), https://phinational.org/resource/envisioning-the-future-of-home-care-trends-and-opportunities-in-workforce-policy-and-practice.

7. *Id.* at 28–29.

8. ERICA REAVES & MARYBETH MUSUMECI, KAISER FAMILY FOUND., MEDICAID AND LONG-TERM SERVICES AND SUPPORTS: A PRIMER 1-2 (2015), http://files.kff.org/attachment/report-medicaid-and-long-term-services-and-supports-a-primer.

9. Susan C. Reinhard et al., *Valuing the Invaluable: 2015 Update*, AARP PUB. POL'Y INST. INSIGHT ON THE ISSUES, 1, 3 (July 2015), https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf.

10. MOLLY O'MALLEY WATTS, MARYBETH MUSUMECI & PRIYA CHIDAMBARAM, KAISER FAMILY FOUND., MEDICAID HOME AND COMMUNITY-BASED SERVICES ENROLLMENT AND SPENDING 2 (2019), http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending.

and other public and private payers (20%), with just a quarter of services paid out-of-pocket (16%) or through private insurance (11%).[11] The low balance of personal spending stems from the fact that the cost of paid LTSS exceeds most consumers' ability to pay.[12] Adults with disabilities are more likely to be poor than those without, given the high long-term costs of living with disabilities (especially more severe disabilities).[13] This disparity renders it impossible for most adults with disabilities to attain and maintain the level of income and assets that would be required to pay for LTSS privately.[14] Older people who develop LTSS needs, on the other hand, may initially be able to pay for their services out-of-pocket, but many spend down their assets to the point that they qualify for Medicaid assistance.[15]

Because Medicaid is the single largest payer of LTSS, Medicaid is most directly responsible for fulfilling *Olmstead*, including by increasing investment in the home care workforce—but there are two key features of the Medicaid program that complicate progress toward this goal. First, although it is jointly funded by the federal government and states, Medicaid is administered at the state level through a range of state plan and waiver programs (described *infra* Section II.C). Second, although there is extensive variation in eligibility pathways and criteria for Medicaid LTSS coverage across states,[16] Medicaid for the most part serves individuals who are poor or who become impoverished[17]—because it is a means-tested public assistance program rather than a universal insurance program like Medicare. Taken together, these Medicaid design features mean that changes in the LTSS landscape nationwide can be achieved incrementally at best, and only through considerable multi-stakeholder efforts to overcome resistance to the increased public spending that is required.

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11. *Id.*

12. In 2019, the median annual cost for a shared room in a skilled nursing home was $90,155, and the median cost for one year of home care services (for 44 hours/week) was nearly $53,000. *Cost of Care Survey 2019*, GENWORTH (Oct. 9, 2019), https://www.genworth.com/aging-and-you/finances/cost-of-care.html.

13. Debra L. Brucker et al., *More Likely to Be Poor Whatever the Measure: Working-Age Persons with Disabilities in the United States*, 96 SOC. SCI. Q. 273, 273 (2014); *see* John Cullinan et al., *Estimating the Extra Cost of Living for People with Disabilities*, 20 HEALTH ECON. 582, 597 (2011).

14. *See* Stephanie R. Hoffer, *Making the Law More ABLE: Reforming Medicaid for Disability*, 76 OHIO ST. L.J. 1255, 1260 (2015). A number of states also have Medicaid "buy-in" options that allow working-age adults with disabilities with incomes that are above the eligibility threshold to pay a monthly premium for Medicaid coverage. *See* MEDICAID AND CHIP PAYMENT AND ACCESS COMMISSION, FUNCTIONAL ASSESSMENTS FOR LONG-TERM SERVICES AND SUPPORTS 71 (2016), https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf [hereinafter MACPAC].

15. *See* JOSHUA M. WIENER ET AL., SCAN FOUND., MEDICAID SPEND DOWN: NEW ESTIMATES AND IMPLICATIONS FOR LONG-TERM SERVICES AND SUPPORTS FINANCING REFORM 1–2 (2013), https://www.thescanfoundation.org/sites/default/files/rti_medicaid-spend-down_3-20-13.pdf.

16. *See* WATTS ET AL., *supra* note 10, at 3; MACPAC, *supra* note 14, at 68.

17. *See* REAVES & MUSUMECI, *supra* note 8.

B. Olmstead*: Defining Home and Community-Based Services as a Civil Right*

The Americans with Disabilities Act (ADA) was enacted by Congress in 1990 to provide a "clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."[18] The ADA applies to discrimination against individuals with disabilities in all areas of public life, including employment, education, and transportation, and in all public and private places that are open to the general public. The definition of disability covers individuals who have "a physical or mental impairment that substantially limits one or more major life activity" as well as those who have previously had a disability and those who are "regarded as having a disability."[19]

Title II of the ADA prohibits discrimination against individuals with disabilities in all federal, state, and local government programs, services, and activities, stating that: "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[20] The implementing regulations for Title II—which were based on regulations issued under Section 504 of the Rehabilitation Act of 1973—require that public entities "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities,"[21] which are defined as those which enable individuals with disabilities "to interact with nondisabled persons to the fullest extent possible."[22] By contrast, segregated settings are defined as settings that are "populated exclusively or primarily with individuals with disabilities" and that limit individuals' autonomy, privacy, and ability to engage in community life.[23] Importantly, this integration mandate applies to all individuals with disabilities who receive any type of publicly-funded LTSS, including those who are currently in institutional settings but also those who are at risk of institutionalization without preventive and/or supportive community-based services.[24]

In 1995, a case was brought against the Georgia State Commissioner of Human Resources (Tommy Olmstead) on behalf of Lois Curtis (L.C.) and Elaine Wilson (E.W.), two women with developmental disabilities and mental health problems.[25] Both women had been voluntarily admitted to the Georgia Regional Hospital's psychiatric unit, but they were subsequently prevented from being discharged, despite their health care providers' assertions that they could live in the community

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18. 42 U.S.C. § 12101(b)(1) (2018).

19 . *What is the Definition of Disability Under the ADA?*, ADA NAT'L NETWORK, https://adata.org/faq/what-definition-disability-under-ada (last visited Feb. 23, 2020).

20. 42 U.S.C. § 12132 (2018).

21. 28 C.F.R. § 35.130(d) (2016).

22. 28 C.F.R. pt. 35 app. A (2010).

23. U.S. DEP'T OF JUSTICE, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II FOR THE AMERICANS WITH DISABILITIES ACT (2011). https://www.ada.gov/olmstead/q&a_olmstead.htm.

24. *See id.*

25. *See Olmstead*, 527 U.S. 581 (1999).

with appropriate supports.[26] The case was eventually heard by the Supreme Court, which ruled that "unjustified isolation . . . is properly regarded as discrimination based on disability" under Title II of the ADA.[27] The 1999 ruling reflected two "evident judgements": first, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and second, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[28]

Olmstead represented a historic victory for the disability rights movement, providing the legal justification for efforts to overcome segregation based on LTSS needs.[29] Since 1999, advocates have brought *Olmstead* claims in numerous courts on behalf of individuals from a range of long-term care settings and with different types of disabilities.[30] The 1999 ruling made it clear that the mandate to provide services in the community is not "boundless," given resource limitations; rather, states are required to make "reasonable accommodations" to policies, procedures, or practices when necessary to avoid discrimination, but are excused from this requirement if the modifications are deemed to "fundamentally alter" the overall service system.[31] Therefore, many lawsuits rest on arguments about what constitutes "reasonable accommodation" versus "fundamental alteration."[32]

In one recent *Olmstead* claim, five plaintiffs receiving Medicaid-funded long-term care services filed a complaint in 2015 in the Northern District of Florida against the secretary of Florida's Agency for Health Care Administration (AHCA).[33] The plaintiffs in *Parrales et al. v. Dudek* were diverse, including a young woman with paralysis due to a genetic neurological disorder and a woman in her nineties with partial paralysis and mild dementia.[34] The complaint asserted that the state, since transitioning to managed care for Medicaid LTSS enrollees beginning in 2013, had failed to adequately monitor the authorization and provision of services for these enrollees, leading to widespread inconsistencies and heightened risk of institutionalization.[35] Under the terms of the settlement, which was reached after more than a year of litigation, AHCA was required above all to ensure that managed care plans "provide an array of home and community-based

26. *See id.* at 581.

27. *Id.* at 597.

28. *Id.* at 600–01.

29. *See* Lance Robertson, *A Milestone for Community Living: Reflecting on 19 Years of* Olmstead, ADMIN. FOR CMTY. LIVING (June 22, 2018), https://acl.gov/news-and-events/acl-blog/milestone-community-living-reflecting-19-years-olmstead.

30. *See* U.S. Dep't of Justice, Civil Rights Div., *Olmstead Enforcement - Cases By Issue*, INFO. AND TECHNICAL ASSISTANCE ON THE AMS. WITH DISABILITIES ACT, https://www.ada.gov/olmstead/olmstead_cases_by_issue.htm.

31. *See Olmstead*, 527 U.S. 581, at 582–84 (1999).

32. *See* TERENCE NG ET AL., UCSF NAT'L CTR. FOR PERS. ASSISTANCE SERVS., HOME AND COMMUNITY-BASED SERVICES: INTRODUCTION TO OLMSTEAD LAWSUITS AND OLMSTEAD PLANS 5 (2008).

33. *See generally* Nancy E. Wright, *Case Note on* Parrales et al. v. Dudek, 14 NAELA J., no. 1, 2018.

34. *See id.* at 3–4.

35. *See id.* at 4–5.

services that enable enrollees to live in the community and to avoid hospitalization."[36] AHCA updated the contract language for managed care plans to include new rules related to the assessment of enrollees' care needs and the availability of ongoing maintenance therapies (such as respiratory therapy), among other provisions, and agreed to oversee the assessment process and survey enrollees about the sufficiency of services.[37] This case exemplifies how the ADA and *Olmstead* can be used to tie the disparate experiences of individuals to a single cause: namely, correcting the state's failure to fulfill the integration mandate and protect its residents' civil rights to live in the community.

C. The Olmstead Case in the Context of "Rebalancing"

The *Olmstead* case built on and significantly accelerated the shift in LTSS provision from institutions to the community. This section highlights key milestones in this "rebalancing" trajectory in Medicaid LTSS expenditure—which represents the majority of spending on LTSS, as noted above.

When it was created in 1965 as an amendment to the Social Security Act, Medicaid perpetuated an "institutional bias" in LTSS that originated in previous provisions of the Act—it only required participating states to cover nursing home care and relegated home health and personal assistance services to optional benefits.[38] Despite this original bias, LTSS funding and service delivery soon began incrementally shifting toward HCBS. The rebalancing trend was primarily driven by cost considerations, but it also aligned with consumers' preferences and enhanced health and wellbeing outcomes.[39] Home health care became a mandatory Medicaid benefit in 1970, and personal care became a state plan option in 1975.[40] Then, in 1981, the Omnibus Budget Reconciliation Act (OBRA) established Section 1915(c) waivers to enable states to provide HCBS for targeted groups of individuals who would otherwise require an institutional level of care.[41] These 1915(c) waivers, which have now been implemented by forty-seven states and the District of Columbia, have become the primary vehicle for HCBS provision.[42] As another federal development, the Cash & Counseling demonstration program was launched in 1996 to test the viability of providing personal assistance services in the community through a consumer-directed model, whereby individuals are given

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36. 43 Fla. Admin. Reg. 59G-4.192 (Apr. 23, 2017).

37. *See* Wright, *supra* note 33.

38. *See generally* Lisa I. Iezzoni, Naomi Gallopyn & Kezia Scales, *Historical Mismatch Between Home-Based Care Policies and Laws Governing Home Care Workers*, 38 HEALTH AFF. 973 (2019).

39. *See* CHARLIE LAKIN ET AL., THE EFFECTS OF COMMUNITY VS. INSTITUTIONAL LIVING ON THE DAILY LIVING SKILLS OF PERSONS WITH DEVELOPMENTAL DISABILITIES? (2011), http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf.

40. *See 1915(c) Waivers*, MACPAC, https://www.macpac.gov/subtopic/1915-c-waivers.

41. *See Home & Community-Based Services 1915(c)*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited Feb. 23, 2020).

42. *See* MARYBETH MUSUMECI, PRIYA CHIDAMBARAM & MOLLY O'MALLEY WATTS, KAISER FAMILY FOUND., KEY STATE POLICY CHOICES ABOUT MEDICAID HOME AND COMMUNITY-BASED SERVICES 3 (2020), http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services.

a flexible budget and authorized to employ their own workers directly.[43] A joint venture between the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Cash & Counseling was initially implemented in three states (Arizona, Florida, and New Jersey), and then replicated in twelve other states.[44] It led to exponential growth in Medicaid-funded consumer-direction programs.[45]

In the years since *Olmstead*, an array of policies, demonstration programs, and other initiatives have been implemented to accelerate rebalancing. One of the first examples was the Real Choice Systems Change Grant Program, which was established in fiscal year 2001 by the Centers for Medicare and Medicaid Services (CMS).[46] This program was designed to help states develop the necessary regulatory, administrative, programmatic, and funding infrastructure to enable individuals with disabilities or chronic conditions to "live in the most integrated community setting of their choice; exercise meaningful choice and control over their living environment, services, and service providers; and obtain high-quality services in a manner consistent with their preferences."[47]

Then, in 2005, the Deficit Reduction Act created Money Follows the Person (MFP), arguably the first formal rebalancing program.[48] Through the MFP program, participating states earned an enhanced federal match (above the regular federal Medicaid spending match) to provide a range of services—from short-term moving assistance to full-time personal assistance services—to help individuals transition from nursing homes to the community.[49] States could use the enhanced match amount to implement system-wide rebalancing strategies, for instance to

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43. *See* L. De Milto, *Cash & Counseling: Program Results Report*, ROBERT WOOD JOHNSON FOUND. (Feb. 28, 2015), https://www.rwjf.org/en/library/research/2013/06/cash---counseling.html. Note that the term "consumer" is used throughout this Article to describe those who receive home care services; other possible terms include "client," "enrollee," "participant," and "beneficiary."

44. Evaluations of the Cash & Counseling demonstration found that the program significantly reduced unmet need, improved quality of life for participants, produced equal or better health outcomes, and had beneficial effects for informal and paid caregivers. *See, e.g.*, Barbara L. Carlson et al., *Effects of Cash and Counseling on Personal Care and Well-Being*, 42 HEALTH SERVS. RES. 476 (2007); Leslie Foster et al., *Improving the Quality of Medicaid Personal Assistance Through Consumer Direction*, 22 HEALTH AFF. 162 (2003); Leslie Foster, Stacy B. Dale & Randall Brown, *How Caregivers and Workers Fared in Cash and Counseling*, 42 HEALTH SERVS. RES. 510 (2007).

45. MERLE EDWARDS-ORR & KATHLEEN UJVARI, AARP PUB. POL'Y INST., TAKING IT TO THE NEXT LEVEL: USING INNOVATIVE STRATEGIES TO EXPAND OPTIONS FOR SELF-DIRECTION 1 (2018), https://www.aarp.org/content/dam/aarp/ppi/2018/04/taking-it-to-the-next-level.pdf.

46. *Real Choice Systems Change Grant Program*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/real-choice-systems-change-grant-program/index.html (last visited Feb. 23, 2020).

47. *Id.*

48. MOLLY O'MALLEY WATTS, ERICA L. REAVES & MARYBETH MUSUMECI, KAISER FAMILY FOUND., MONEY FOLLOWS THE PERSON DEMONSTRATION PROGRAM: HELPING MEDICAID BENEFICIARIES MOVE BACK HOME 1 (2014), https://www.kff.org/wp-content/uploads/2014/04/8581-b-money-follows-the-person-demonstration-program_helping-medicaid-beneficiaries-move-back-home.pdf.

49. MOLLY O'MALLEY WATTS, ERICA L. REAVES & MARYBETH MUSUMECI, KAISER FAMILY FOUND., MONEY FOLLOWS THE PERSON: A 2013 STATE SURVEY OF TRANSITIONS, SERVICES, AND COSTS 2 (2014), https://www.kff.org/wp-content/uploads/2014/04/8581-money-follows-the-person_a-2013-survey-of-transitions-services-and-costs1.pdf.

reduce waiting lists for HCBS waiver programs or to provide transition support for individuals who were not eligible for direct MFP assistance.[50] Authorized through 2011 initially and then extended through 2016 by the Patient Protection and Affordable Care Act (ACA) (then extended again through the end of 2019), MFP has helped over 88,000 individuals across almost all states move back into the community, with spending totaling nearly $3.7 billion.[51]

The Deficit Reduction Act also provided states with new options for providing HCBS, namely through 1915(i) waivers, which enable states to offer state-plan HCBS to a particular population with functional needs that require less than an institutional level of care, and 1915(j) waivers, which allow states to develop consumer-directed programs.[52] Five years later, the ACA created another HCBS option, the Community First Choice 1915(k) waiver program. Through Community First Choice, participating states receive a six-percentage point increase in federal matching payments for home-based personal assistance services offered under their Medicaid state plans.[53] The ACA also established the Balancing Incentive Program, which ultimately provided $2.4 billion in enhanced federal matching payments to help participating states achieve a "balancing benchmark" of at least 50% of Medicaid LTSS dollars spent on HCBS.[54]

Supporting these incremental efforts to expand HCBS, CMS released a final rule in 2014, which clarifies the definition of "integrated settings" for the purposes of Medicaid reimbursement. Specifically, the rule details which LTSS settings are reimbursable under section 1915(c), 1915(i), and 1915(k) HCBS waivers and categorically excludes others—including nursing homes, mental health facilities, intermediate care facilities for individuals with intellectual disabilities, and hospitals.[55] The rule requires that HCBS settings be integrated into and support full access to the greater community; be selected by the individual from among

50. Eric D. Hargan, *Report to the President and Congress: The Money Follows the Person (MFP) Rebalancing Demonstration*, DEP'T OF HEALTH AND HUMAN SERVS. 3 (2017), https://www.medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf.

51. Michelle Diament, *Trump Extends Program Helping People Leave Institutions*, DISABILITY SCOOP (Aug. 20, 2019), https://www.disabilityscoop.com/2019/08/20/trump-extends-program-helping-people-leave-institutions/27038.

52. *Home & Community-Based Services 1915(i)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915i/index.html (last visited Feb. 23, 2020); *Self-Directed Personal Assistant Services 1915(j)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/self-directed-personal-assistant-services-1915-j/index.html (last visited Feb. 23, 2020).

53. *Community First Choice (CFC) 1915(k)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html (last visited Feb. 23, 2020).

54. *Balancing Incentive Program*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/balancing-incentive-program/balancing-incentive-program/index.html (last visited Feb. 23, 2020).

55. Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 2949–51 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441, and 447), https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider.

different options; ensure individual rights of privacy, dignity, respect, and freedom from coercion and restraint; optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them.[56] All states and D.C. are required to develop statewide transition plans to ensure that HCBS settings that receive Medicaid funding meet these standards.[57] As of March 2019, ten states had received final approval of their transition plans and thirty had received initial approval.[58]

Altogether, these policies, programs, and related developments—initiated before *Olmstead* but accelerated thereafter—have dramatically impacted Medicaid LTSS spending. In the early 1980s, HCBS accounted for less than 10% of all Medicaid spending on LTSS.[59] By the late 1990s, that proportion had increased to 25%—and in 2013, for the first time, the majority of Medicaid LTSS funds were spent on HCBS.[60] By 2016, the most recent year of spending data available, 57% of the $167 billion Medicaid LTSS spending went to HCBS.[61]

Nonetheless, there is still a long way to go toward fulfilling *Olmstead*'s integration mandate. States are still not required to offer personal care services under their Medicaid state plans; nursing facility care and home health services remain the only two mandatory benefits. There is still considerable inequity in the balance of LTSS expenditures, ranging from just 27% of total Medicaid LTSS spent on HCBS in Mississippi to 81% in California.[62] As noted above, there is also extensive variation in individuals' eligibility for coverage from state to state, meaning that consumers with the same level of need and financial resources may or may not be eligible for services depending on where they live, which waiver programs are in place, what eligibility pathways and criteria apply, and what assessment tools are used.[63] For example, one review of functional eligibility criteria and service allocation found that "some states may only require needed assistance in at least one ADL and a medical certification, while other states

56. *Id.* at 2959–60.

57. Brian Neale, *CMCS Informational Bulletin: Extension of Transition Period for Compliance with Home and Community-Based Settings Criteria*, DEPT. OF HEALTH AND HUMAN SERVS. 1 (May 9, 2017), https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/cib050917.pdf.

58. Lois A. Bowers, *CMS Issues New Guidance on HCBS Final Rule, But Provider Concerns Remain*, MCKNIGHT'S SENIOR LIVING (Mar. 25, 2019), https://www.mcknightsseniorliving.com/home/news/cms-issues-new-guidance-on-hcbs-final-rule-but-provider-concerns-remain.

59. *See* AUDRA WENZLOW ET AL., IMPROVING THE BALANCE: THE EVOLUTION OF MEDICAID EXPENDITURES FOR LONG-TERM SERVICES AND SUPPORTS (LTSS), FY 1981-2014, at 2 (2016), https://www.medicaid.gov/sites/default/files/2019-12/evolution-ltss-expenditures.pdf.

60. *See* MOLLY O'MALLEY WATTS & MARYBETH MUSUMECI, KAISER FAMILY FOUND., MEDICAID HOME AND COMMUNITY-BASED SERVICES: RESULTS FROM A 50-STATE SURVEY OF ENROLLMENT, SPENDING, AND PROGRAM POLICIES 4 (2018), http://files.kff.org/attachment/Report-Medicaid-Home-and-Community-Based-Services.

61. *See* STEVE EIKEN ET AL., MEDICAID EXPENDITURES FOR LONG-TERM SERVICES AND SUPPORTS IN FY 2016 at i (2018), https://www.medicaid.gov/sites/default/files/2019-12/ltssexpenditures2016.pdf.

62. *See id*. at i, 7.

63. *See* MACPAC, FUNCTIONAL ASSESSMENTS FOR LONG-TERM SERVICES AND SUPPORTS 68–72 (2016), https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf.

require extensive assistance with specified ADLs."[64] Another review of the tools states use to assess functional needs found upwards of 120 different assessment tools in use across Medicaid programs.[65] Further, over 707,000 people were on waiting lists for HCBS waiver programs across 40 states at last count—with an average waiting period of 30 months, ranging from 4 to 66 months—and waiting list numbers have increased every year for nearly a decade.[66] Finally, investment in the workforce that supports the home care workforce is falling far short of growing demand, as described in the next section.

III. THE ROLE OF THE HOME CARE WORKFORCE IN FULFILLING THE INTEGRATION MANDATE

The home care workforce includes all direct care workers who support individuals with disabilities and older adults in the community to accomplish "major life activities,"[67] live with independence, and participate in family and community life. Nonetheless, this workforce is often peripheral to legal and policy discussions about community integration. For example, the proposed Disability Integration Act of 2019—which would strengthen and extend the ADA—explicitly identifies a need to improve housing options but makes no reference to workforce supply.[68] In this section, we turn the spotlight on this critical workforce.

A. A Brief Introduction to the Home Care Workforce

The home care workforce comprises three occupational categories as defined by the Bureau of Labor Statistics Standard Occupational Classification (SOC) system. Personal care aides (SOC 39-9021) assist individuals with activities of daily living (ADLs, including bathing, dressing, and eating) and instrumental activities of daily living (IADLs, such as housework, meal preparation, errands, and more).[69] These workers—who are known by a range of job titles in the field, including personal attendant and personal support worker, among many others—

64. *See* SUSAN M. TUCKER & MARSHALL E. KELLEY, DETERMINING NEED FOR MEDICAID PERSONAL CARE SERVICES 5 (2011), http://www.thescanfoundation.org/sites/default/files/TSF_CLASS_TA_No_6_Medicaid_Assessment_Determining_Need_FINAL.pdf.

65. *See* MEDICAID AND CHIP PAYMENT AND ACCESS COMMISSION, FUNCTIONAL ASSESSMENTS FOR LONG-TERM SERVICES AND SUPPORTS 68 (2016), https://www.macpac.gov/wp-content/uploads/2016/06/Functional-Assessments-for-Long-Term-Services-and-Supports.pdf.

66. *See* MARYBETH MUSUMECI, PRIYA CHIDAMBARAM & MOLLY O'MALLEY WATTS, KAISER FAMILY FOUND., KEY QUESTIONS ABOUT MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER WAITING LISTS 2–3 (2019), http://files.kff.org/attachment/Issue-Brief-Key-Questions-About-Medicaid-Home-and-Community-Based-Services-Waiver-Waiting-Lists.

67. 42 U.S.C. § 12102.

68. *See* S.117, 116th Cong. § 6(b)(6) (2019).

69. U.S. Bureau of Labor Statistics, *Home Health Aides and Personal Care Aides*, OCCUPATIONAL OUTLOOK HANDBOOK (last visited Feb. 23, 2020), https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm; U.S. Bureau of Labor Statistics, *Nursing Assistants and Orderlies*, OCCUPATIONAL OUTLOOK HANDBOOK, HEALTHCARE (last visited Feb. 23, 2020), https://www.bls.gov/ooh/healthcare/nursing-assistants.htm.

provide the majority of the non-medical supports that are required to fulfill the *Olmstead* integration mandate.[70] Home health aides (SOC 31-1011) and nursing assistants (SOC 31-1014) working in home and community settings provide similar assistance, but they may also fulfill certain clinical tasks under the supervision of a licensed professional, such as blood pressure readings, range-of-motion exercises, catheter or ostomy care, and limited forms of medication administration, among others.[71]

Although they are not separately classified by the Bureau of Labor Statistics, direct support professionals are a distinct group of direct care workers who primarily support individuals with intellectual and developmental disabilities.[72] The on-the-job responsibilities of direct support professionals tend to differ significantly from those of other home care workers who support older adults or individuals with physical disabilities. For example, direct support professionals often coach their clients and assist them with finding and maintaining employment, which are not typical duties for other home care workers.[73]

Across the board, home care workers operate in relative isolation, in most cases with limited training, oversight, or support, and their work can be both physically and emotionally demanding.[74] Their role requires a range of technical and interpersonal skills, particularly as they serve individuals with increasingly complex needs.

Home care workers may be employed by home care agencies, employed directly by consumers through publicly funded consumer-directed programs, hired and paid directly by consumers on the "gray market," or co-employed by a consumer and an agency (the "agency with choice" model) or fiscal intermediary.[75] This variation complicates efforts to address workforce concerns, as each service-delivery model raises a different set of policy and regulatory considerations. There is also complexity within each service-delivery model; in particular, Medicaid-funded consumer-directed programs vary significantly from state to state. A chief difference is between the employer authority and budget authority models of consumer direction.[76] Under employer authority, consumers are authorized to hire, schedule, supervise, and dismiss their own personal assistance workers (described hereafter as "independent providers").[77] By contrast, under the broader budget authority model, consumers receive a monthly budget with which to purchase a range of goods and services to meet their assessed needs, including but usually not

70. *Id.*

71. *Id.*

72. *See* PRESIDENT'S COMM. FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, REPORT TO THE PRESIDENT 2017, AMERICA'S DIRECT SUPPORT WORKFORCE CRISIS: EFFECTS ON PEOPLE WITH INTELLECTUAL DISABILITIES, FAMILIES, COMMUNITIES AND THE U.S. ECONOMY 13 (2017), https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF.

73. *Id.*

74. CLARE L. STACEY, THE CARING SELF: THE WORK EXPERIENCES OF HOME CARE AIDES 92–102 (2011).

75. SCALES, *supra* note 6, at 32–40.

76. SUZANNE CRISP ET AL., ROBERT WOOD JOHNSON FOUND., DEVELOPING AND IMPLEMENTING SELF-DIRECTION PROGRAMS AND POLICIES: A HANDBOOK (2010), https://www.bc.edu/content/dam/files/schools/gssw_sites/nrcpds/cc-full.pdf.

77. *Id.* at 1, 9–20.

limited to personal assistance.[78] A key advantage of budget authority is that it enables consumers to set competitive wages for their workers, which is critical for improving job and service quality and sustainability, as discussed below. Of the forty-nine states (not including Alaska) and D.C. that provide a consumer-directed option in at least one Medicaid HCBS waiver program, all allow employer authority while thirty-three offer budget authority.[79]

The home care workforce is overwhelmingly comprised of women (87%) and people of color (62%).[80] Nearly one in three home care workers (31%) was born outside the United States.[81] The median age for home care workers is forty-six, and 30% are aged fifty-five and over (compared to just 11% in the youngest age cohort, aged sixteen to twenty-four years old).[82] The majority of home care workers (54%) have a high school education or less, including the 19% who did not complete high school.[83] Taken together, these demographic characteristics describe a workforce comprised of individuals who are disproportionately likely to face limited employment opportunities in the broader labor market.[84] This is both a legacy of the devaluation of care work[85] and a reflection of persistent job quality concerns.

B. Workforce Supply and Demand Concerns

In 2002, the earliest year since *Olmstead* for which comparable data are available, there were approximately 539,700 home care workers.[86] By 2008, that number had grown to 898,600 workers, and by 2018, the home care workforce had expanded to 2.3 million workers.[87] This startling rate of growth is projected to continue in the years ahead: in the next decade alone, from 2018 to 2028, the home care workforce is projected to add over one million new jobs.[88] These figures do

78. *Id.*

79. *See* MUSUMECI ET AL., *supra* note 42, at 15.

80. *See* PHI, U.S. HOME CARE WORKERS: KEY FACTS 2–3 (2019), https://phinational.org/resource/u-s-home-care-workers-key-facts-2019.

81. *Id.* at 3.

82. PHI, WORKFORCE DATA CENTER, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Age (last visited Feb. 23, 2020).

83. PHI, KEY FACTS, *supra* note 80.

84. Jay Shambaugh & Ryan Nunn, *How Women are Still Left Behind in the Labor Market*, BROOKINGS INST. (Apr. 10, 2018), https://www.brookings.edu/blog/up-front/2018/04/10/how-women-are-still-left-behind-in-the-labor-market; Devah Pager & Hana Shepherd, *The Sociology of Discrimination: Racial Discrimination in Employment, Housing, Credit, and Consumer Markets*, 34 ANNUAL REVIEW OF SOC. 181, 186–87 (2008); David Neumark, Ian Burn & Patrick Button, *Is It Harder for Older Workers to Find Jobs? New and Improved Evidence from a Field Experiment*, 127 J. POL. ECON. 922, 966–67 (2019); Alina Mariuca Ionescu, *How Does Education Affect Labour Market Outcomes?*, 4 REV. APPLIED SOCIO-ECONOMIC RES. 130, 140–41 (2012); Andrew J. Robinson, *Language, National Origin, and Employment Discrimination: The Importance of the EEOC Guidelines*, 157 U. PA. L. REV. 1513, 1514 (2009).

85. Paula England, *Emerging Theories of Care Work*, 31 ANN. REV. SOC. 381 (2005).

86. Unless otherwise indicated, all data in this section (III.B) are cited from PHI, WORKFORCE DATA CENTER, https://phinational.org/policy-research/workforce-data-center (last visited Feb. 23, 2020).

87. PHI, WORKFORCE DATA CENTER, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Employment+Trends (last visited Feb. 23, 2020).

88. *Id.*

not fully account for independent providers employed through publicly funded consumer-directed programs, however—and likely exclude most home care workers employed through the private-pay gray market, a largely unregulated segment of the industry that serves a wide swathe of consumers who do not (yet) qualify for public LTSS funding but who cannot afford or choose not to pay privately for agency-based home care services.[89]

The growth of the home care workforce reflects, to some extent, the rebalancing of LTSS described in the previous section. From 2008 to 2018, the number of nursing assistants in nursing homes actually declined by 3%, compared to a 151% growth rate among home care workers, and the nursing assistant workforce is expected to lose an additional 19,300 jobs from 2018 to 2028.[90] However, sociodemographic changes are also driving up demand for this workforce. First, the population is growing older.[91] Between 2016 and 2060, the number of adults in the United States aged 65 and over is projected to nearly double, from about 49.2 million to over 94.6 million, and the number of those aged 85 and over is projected to nearly triple, from about 6.4 million to over 19 million.[92] Because personal assistance needs and formal LTSS use increase with age,[93] the demand for LTSS will increase in line with population aging, but as access to HCBS increases (and as inequities in HCBS access across race/ethnicity[94] and rurality[95] are addressed), demand for these LTSS services in particular will increase even more quickly. Finally, as life expectancy for individuals with disabilities continues to improve due to advances in health care and medical technology, a larger number of younger people with disabilities today will require LTSS in the future, driving up demand even further.[96]

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89. SCALES, *supra* note 6, at 39–40.

90 . PHI, WORKFORCE DATA CENTER, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Employment+Trends (last visited Feb. 23, 2020);
PHI, WORKFORCE DATA CENTER, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Employment+Projections (last visited Feb. 23, 2020).

91. Press Release, U.S. Census Bureau, Older People Projected to Outnumber Children for First Time in U.S. History (Mar. 13, 2018), https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html.

92. Projected Age Groups and Sex Composition of the Population Table, U.S. CENSUS BUREAU, https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html (last visited Feb. 23, 2020) (select "Table 2. Projected age and sex compositions of the population.").

93. LAUREN HARRIS-KOJETIN ET AL., NAT'L CTR. FOR HEALTH STATISTICS, LONG-TERM CARE PROVIDERS AND SERVICES USERS IN THE UNITED STATES, 2015–2016, at 3 (2019) https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf; NAT'L CTR. FOR HEALTH STATISTICS, CTRS. FOR DISEASE CONTROL AND PREVENTION, FIGURE 12.2: PERCENTAGE OF ADULTS AGED 65 AND OVER WHO NEEDED HELP WITH PERSONAL CARE FROM OTHER PERSONS, BY AGE GROUP AND SEX: UNITED STATES, 2018, https://public.tableau.com/views/FIGURE12_2/Dashboard12_2?:showVizHome=no&:embed=true.

94. Zhanlian Feng et al., *The Care Span: Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options*, 30 HEALTH AFF. 1358, 1362–63 (2011).

95. ANDREW F. COBURN ET AL., RURAL POL'Y RES. INST., RURAL LONG-TERM SERVICES AND SUPPORTS: A PRIMER 6–9 (2017), http://www.rupri.org/wp-content/uploads/LTSS-RUPRI-Health-Panel-2017.pdf.

96 . Raji Thomas & Michael Barnes, *Life Expectancy for People with Disabilities*, 27 NEUROREHABILITATION 201, 204 (2010).

At the same time, the supply of family caregivers is decreasing, for a range of reasons, even though family members and other natural supports continue to provide the lion's share of personal assistance to individuals with disabilities and older adults in the community.[97] With more women participating in the labor force, there are far fewer full-time caregivers than in previous generations. Families are smaller and more geographically dispersed, and divorce rates are increasing among older people.[98] Family caregivers may develop their own health care needs, which impact their caregiving capacity.[99] Along with policy trends and population aging, these factors are compounding the pressure on the paid home care workforce.

C. The Problem: Job Quality Does Not Reflect Growing Demand

Despite their central role in fulfilling the promise of *Olmstead*—and facilitating LTSS rebalancing overall—home care workers continue to struggle for recognition and compensation.[100] As stark evidence, the median hourly wage for home care workers in 2018 was $11.52 per hour and their median annual earnings in 2017 were just $16,200.[101] Personal care aides earn the least; their median hourly wage is $11.40, compared to $11.77 for home health aides and nursing assistants working in home care.[102] Nursing assistants working in nursing homes, in contrast, earn a median hourly wage of $13.38—meaning that even in the context of rebalancing, home care agencies and consumers have a clear disadvantage compared to nursing homes in the competition for workers.[103] Moreover, compensation has held steady over time, rather than increasing to match demand

97. SUSAN C. REINHARD ET AL., AARP PUB. POL'Y INST., VALUING THE INVALUABLE: 2015 UPDATE 13 (2015), https://www.aarp.org/content/dam/aarp/pphi/2015/valuing-the-invaluable-2015-update-new.pdf.

98. Renee Stepler, *Led by Baby Boomers, Divorce Rates Climb for America's 50+ Population*, PEW RES. CTR. FACTTANK (Mar. 9, 2017), https://www.pewresearch.org/fact-tank/2017/03/09/led-by-baby-boomers-divorce-rates-climb-for-americas-50-population.

99. Family Caregiver All., *Caregiver Statistics: Health, Technology, and Caregiving Resources* (last visited Feb. 23, 2020), https://www.caregiver.org/caregiver-statistics-health-technology-and-caregiving-resources.

100. Robyn Stone et al., *Predictors of Intent to Leave the Job Among Home Health Workers: Analysis of the National Home Health Aide Survey*, 57 GERONTOLOGIST 890, 890–92, 896–98 (2017); Anna C. Faul et al, *Promoting Sustainability in Frontline Home Care Aides: Understanding Factors Affecting Job Retention in the Home Care Workforce*, 22 HOME HEALTHCARE MGMT. & PRAC. 408, 409 (2010); Peter Kemper et al., *What Do Direct Care Workers Say Would Improve Their Jobs? Differences Across Settings,* 48 GERONTOLOGIST 17, 22–24 (2008); Candace Howes, *Love, Money, or Flexibility: What Motivates People to Work in Consumer-Directed Home Care?*, 48 GERONTOLOGIST 46, 46–47 (2008); A.E. Benjamin & Ruth E. Matthias, *Work-Life Differences and Outcomes for Agency and Consumer-Directed Home-Care Workers*, 44 GERONTOLOGIST 479, 479–80, 487 (2004).

101 . PHI, WORKFORCE DATA CENTER, DIRECT CARE WORKER MEDIAN HOURLY WAGES ADJUSTED FOR INFLATION, 2008 TO 2018, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends (last visited Feb. 23, 2020); PHI, WORKFORCE DATA CENTER, DIRECT CARE WORKER MEDIAN ANNUAL EARNINGS, 2017, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Earnings (last visited Feb. 23, 2020).

102. PHI, WORKFORCE DATA CENTER, DIRECT CARE WORKER MEDIAN HOURLY WAGES ADJUSTED FOR INFLATION, 2008 TO 2018, https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends (last visited Feb. 23, 2020).

103. *Id.*

(or to match rising wages in other sectors, such as retail[104]): from 2008 to 2018, inflation-adjusted wages for home care workers increased by less than a dollar (from $10.83 to $11.52).[105] There was some variation between personal care aides (whose hourly wages increased by $1.07 during that period) and home health aides (whose wages only increased by forty-three cents)—nonetheless, personal care aides still earn less than home health aides.[106]

Low wages and low annual earnings lead to a high rate of poverty in the home care workforce. Nearly one in five (18%) home care workers lives below the federal poverty line, 29% live below 138% of the poverty line, and nearly half (48%) live below 200% of the poverty line.[107] Because of their low-income status, 53% of home care workers receive some form of public assistance, primarily Medicaid and food assistance.[108]

Given these job characteristics coupled with the challenging nature of the work—and in the context of a tight labor market characterized by intense competition for entry-level workers—it is unsurprising that turnover and job vacancy rates are high in this workforce. Although there is no national estimate on turnover among home care workers, turnover has generally been reported at 50% or higher.[109] A recent annual Home Care Pulse survey of private-duty home care agencies, meaning agencies that provide non-medical services and supports, found that turnover reached a historic peak of 82% in 2018, a 15% increase over the previous year.[110]

Job vacancy rates are even more difficult to ascertain, but evidence from various sources indicates a growing workforce shortage. Three out of four respondents to the 2017 Home Care Pulse survey, for example, cited caregiver shortages as one of their three most pressing concerns.[111] As a state-level example, workforce data in Minnesota showed an 8% vacancy rate among personal care aides in 2017—amounting to more job vacancies than in any other occupation besides retail salespeople.[112] A recent survey in Wisconsin found that 93% of personal care providers were struggling to fill job openings and 70% were unable to staff all authorized hours, while 95% of consumers with physical disabilities

104. Amy Baxter, *Amazon Lures Workers from Home Care*, HOME HEALTH CARE NEWS (Feb. 5, 2018), https://homehealthcarenews.com/2018/02/amazon-lures-workers-from-home-care.

105. Id.

106. PHI, U.S. HOME CARE WORKERS: KEY FACTS 5 (2019), https://phinational.org/resource/u-s-home-care-workers-key-facts-2019.

107. *Id.* at 6.

108. *Id.*

109. PHI, PAYING THE PRICE: HOW POVERTY WAGES UNDERMINE HOME CARE IN AMERICA 4 (2015), https://phinational.org/resource/paying-the-price-how-poverty-wages-undermine-home-care-in-america.

110. Robert Holly, *Home Care Industry Turnover Reaches All-Time High of 82%.*, HOME HEALTH CARE NEWS (May 8, 2019), https://homehealthcarenews.com/2019/05/home-care-industry-turnover-reaches-all-time-high-of-82.

111. Carlo Calma, *How Home Care Companies Can Get Caregivers to 'Stay,'* HOME HEALTH CARE NEWS (July 26, 2017), https://homehealthcarenews.com/2017/07/how-home-care-companies-can-get-caregivers-to-stay.

112. SCALES, *supra* note 6, at 29.

were struggling to find workers directly.[113] Likewise, nearly 90% of home care agencies surveyed in Massachusetts in 2016 and 2017 reported that workforce challenges were their top concern.[114]

These turnover and job vacancy issues extend across the HCBS sector, regardless of how services are financed; in other words, recruitment and retention are universal challenges, as individuals and agencies compete for workers against each other and employers in other sectors. However, workforce challenges are particularly pronounced for Medicaid-funded services, which operate on the slim margins afforded by reimbursement rates, with little flexibility to increase wages or offer other advantages to potential workers.

In turn, workforce instability impedes the formation of strong, sustained relationships between consumers and their home care workers. As a result, at best, consumers are required to constantly orient new workers to their needs and preferences. At worst, they are at higher risk of unmet need, inappropriate care, and adverse outcomes such as avoidable emergency room visits or hospitalizations, and, ultimately, unnecessary institutionalization.[115] For these reasons, the growing gap between the demand for home care and the supply of home care workers indicated by the workforce data above—and experienced as a daily crisis in the field—presents a major barrier to fulfilling the promise of *Olmstead*.

IV. Entrenched Workforce Challenges and Promising Policy Solutions

This section discusses three areas that states must address (among others) to improve home care jobs and strengthen the home care workforce: compensation, training and career development, and scope of practice rules. The section concludes by briefly highlighting new opportunities to invest in the workforce.

A. Compensation for the Home Care Workforce

An essential step toward addressing the home care workforce crisis is to ensure that home care jobs are compensated at a competitive rate—to recruit and retain a steady supply of strong candidates for the role. This step will require raising wages

113. PHI, State of Care: Wisconsin's Home Care Landscape 3, 9–10 (2017), https://phinational.org/wp-content/uploads/2017/09/wisconsin_home_care_landscape_phi_2017_0.pdf.

114. Press Release, Home Care Aide Council, MA Home Care Aide Industry Study Data Released (May 31, 2018), https://www.hcacouncil.org/news/403155/MA-Home-Care-Aide-Industry-Study-Data-Released.htm.

115. David Russell et al., *Continuity in the Provider of Home Health Aide Services and the Likelihood of Patient Improvement in Activities of Daily Living*, 25 Home Health Care Mgmt. & Prac. 6, 6–7 (2012); Robert Newcomer, Taewoon Kang & Julia Faucett, *Consumer-directed Personal Care: Comparing Aged and Non-aged Adult Recipient Health-related Outcomes Among Those with Paid Family Versus Non-Relative Providers*, 30 Home Health Care Servs. Q. 178, 178–97 (2011). Evidence from the nursing home context about the links between direct care staff turnover and service quality is also instructive here. *See, e.g.*, Alison M. Trinkoff, et al., *Turnover, Staffing, Skill Mix, and Resident Outcomes in a National Sample of US Nursing Homes*, 43 J. Nursing Admin. 630, 630–36 (2013); Nicholas Castle & John Engberg, *Staff Turnover and Quality of Care in Nursing Homes*, 43 Med. Care 616, 616–26 (2005).

above the minimum wage and addressing part-time scheduling norms so that home care workers can attain sufficient hours to earn a livable wage.[116]

A long-standing barrier to improving compensation for home care workers has been their exclusion from the wage and work-hour protections of the Fair Labor Standards Act (FLSA). When it was passed in 1938, the Act excluded "domestic workers," a category (comprising mainly women and people of color) that included cooks, housekeepers, maids, gardeners, and other employees providing household services in private homes, including personal assistance services.[117] The FLSA was amended in 1974 to include domestic workers, but so-called "companionship services"—which included home care services provided by both personal care aides and home health aides, whether hired privately or contracted through a home care agency—were still explicitly exempted.[118]

The law was challenged in court in 2002 by Evelyn Coke, a New York City home care worker who sued her employer for back pay for years of overtime.[119] The case reached the Supreme Court in 2007, which unanimously decided against Coke, ruling that her employer's actions were legal under the FLSA companionship exemption.[120] The Court also ruled, however, that the Department of Labor could revisit the companionship exemption with a view to bringing home care workers under FLSA protections.[121]

Four years later, President Obama asked the Department of Labor to extend the FLSA to cover home care workers and, after a lengthy rule-making process, the Department published a final rule narrowing the companionship exemption in October 2013.[122] The new rule was not implemented until late 2015, however, after being challenged by industry groups and then upheld by the U.S. Court of Appeals for the D.C. Circuit.[123] Under the final rule, now in full force, home care agencies can no longer claim the companionship exemption to the FLSA under any circumstances, and private employers can only claim the exemption if the worker provides primarily "fellowship and protection."[124] If the companionship includes any medically-related tasks, the exemption does not hold.[125] Outside of the exemption, home care workers must be paid at least the federal or state minimum wage, whichever is higher, for the first forty hours of the work week; overtime at

116. STEPHEN CAMPBELL, PHI, THE PART-TIME DILEMMA FOR DIRECT CARE WORKERS (2018), https://phinational.org/wp-content/uploads/2018/03/Part-Time-Dilemma-PHI-2018.pdf.

117. Lisa I. Iezzoni, Naomi Gallopyn & Kezia Scales, *Historical Mismatch Between Home-Based Care Policies and Laws Governing Home Care Workers*, 38 HEALTH AFF. 973, 973–80 (2019).

118. *Id.*; Fair Labor Standards Amendments of 1974, Pub. L. No. 93-259, §§ 7(b)(1), (2), 88 Stat. 55, 62 (1974).

119. Long Island Care at Home, Ltd. v. Coke, 551 U.S. 158, 164 (2007).

120. *Id.* at 175–76.

121. *Id.* at 175.

122. NAT'L EMP'T LAW PROJECT ET AL., U.S. DEPARTMENT OF LABOR HOME CARE RULE: WHAT'S NEXT? (2015), https://phinational.org/wp-content/uploads/legacy/flsa-implementation-state-toolkit.pdf.

123. Home Care Ass'n of Am. v. Weil, No. 14-cv-967 (D.D.C. Dec. 22, 2014).

124. U.S. DEP'T OF LABOR, FACT SHEET: APPLICATION OF THE FAIR LABOR STANDARDS ACT TO DOMESTIC SERVICE, FINAL RULE 1 (2013), https://www.dol.gov/whd/regs/compliance/whdfsfinalrule.pdf.

125. *Id.*

time-and-a-half of their base pay; and travel time between clients who are assigned by a single employer.[126]

Passed nearly two decades after *Olmstead*, the FLSA home care rule represented a watershed moment for the home care workforce. But rather than being hailed as an unequivocal victory, the rule generated considerable concern about the potential negative impact on both workers and consumers—if not matched by a guarantee of increased Medicaid funding to cover the new wage mandate.[127] The Department of Justice (DOJ) anticipated these concerns, explicitly calling on states to consider their obligations under the ADA and *Olmstead* when making plans to implement the final rule.[128] In a 2014 Dear Colleague letter, DOJ made clear that "states need to consider reasonable modifications to policies capping overtime and travel time for home care workers, including exceptions to these caps when individuals with disabilities otherwise would be placed at serious risk of institutionalization."[129] There is limited published evidence available on states' and employers' strategies for implementing the FLSA home care rule.[130] However, reports from the field indicate that providers have attempted to contain costs by limiting overtime, which has forced workers to spread their work hours over more than one employer and compromised care continuity for consumers.[131]

As well as meeting the increased costs associated with the final home care rule—and other mandates, such as minimum wage increases, which have been implemented in twenty-one states in 2020 alone[132]—states must also consider how to ensure that home care jobs are competitive relative to other entry-level jobs. Otherwise, home care agencies and consumers will continue to struggle to attract workers who might receive a higher wage, more favorable hours, or other employment benefits in other sectors. The first step is to increase Medicaid reimbursement rates, engaging stakeholders in developing a transparent rate-

126 . PHI, *FLSA Facts: Understanding the Revised Companionship Exemption* (Oct. 6, 2015), https://phinational.org/resource/flsa-facts-understanding-the-revised-companionship-exemption.

127. *See* JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH LAW ET AL., ACTION STEPS FOR CONSUMERS AND ADVOCATES REGARDING THE NEW HOME CARE RULE: HOW TO PREVENT SERVICE CUTS AND PROTECT CONSUMER-DIRECTED PROGRAMS (2014), https://www.ndrn.org/images/Documents/Media/Joint_home_care_advocacy_action_steps.pdf (describing a range of concerns about the potential unintended consequences of new rule and how to address them).

128. U.S. Dep't of Justice and Dep't of Health and Human Servs., Dear Colleague Letter Regarding States' Olmstead Obligations When Implementing the New FLSA Rule Regarding Home Care Workers (Dec. 15, 2014), https://www.ada.gov/olmstead/documents/doj_hhs_letter.pdf.

129. *Id.*

130. For an exception, the Office of Disability, Aging and Long-Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) recently published a report on state efforts to comply with the FLSA home care rule in consumer-directed programs in particular. *See* PAMELA J. DOTY, MARIE R. SQUILLACE, AND EDWARD KAKO, ANALYSIS OF STATE EFFORTS TO COMPLY WITH FAIR LABOR STANDARDS ACT PROTECTIONS TO HOME CARE WORKERS, ASPE (2019), https://aspe.hhs.gov/system/files/pdf/263206/FLSAimpl.pdf. The Government Accountability Office is also currently conducting a study of the implementation of the FLSA home care rule across states (according to email correspondence with the author).

131. SCALES, *supra* note 6, at 50.

132. Nat'l Conference of State Legislators, *State Minimum Wages: 2020 Minimum Wage by State* (Jan. 6, 2020), https://www.ncsl.org/research/labor-and-employment/state-minimum-wage-chart.aspx.

setting methodology to ensure that home care agencies and self-directing consumers receive sufficient funds to meet wage mandates and offer competitive wages.

Beyond increasing reimbursement rates, states can implement requirements to ensure that workers experience the benefit of those increases, for example, by setting sector-wide wage floors or enacting wage pass-through legislation. For example, Colorado passed a law in May 2019 requiring the state's Department of Health Care Policy and Financing to request an 8.1% increase in the reimbursement rate for services delivered to consumers through HCBS waivers; to pass along 100% of the increase to direct care workers in fiscal year 2019–2020 and 85% in the following fiscal year; and to document that the increase went to workers.[133] The law also requires that the hourly minimum wage for home care workers should be set at $12.41 per hour (exceeding the state minimum wage of $11.10), and tasks the Department of Health Care Policy and Financing and the Department of Public Health and Environment with establishing a process for reviewing and enforcing initial and ongoing training for this workforce.[134] Through this legislation, Colorado recognized the need not just to raise reimbursement rates overall but also to ensure that the increase results in a competitive wage for workers.

Wage pass-throughs have been implemented by a number of states over time, with evidence of positive impacts on the workforce. One early study of data from the 1996 and 2001 panels of the Survey of Income and Program Participation found that direct care workers in states with pass-through programs (twenty-three states at the time) earned as much as 12% more per hour than the same workers in other states, after the pass-throughs were implemented.[135] However, this type of legislative or executive action is very difficult to implement in the context of ever-tightening Medicaid budgets and political polarization, and pass-through amounts are often very small and/or temporary, if they are successfully implemented at all.

On a different order of magnitude, states are beginning to consider new models of LTSS financing and service-delivery that would better account for both population need and workforce capacity. Washington State, for example, recently became the first state to enact a social insurance system for long-term care through the Long-Term Care Trust Act.[136] Funded through a payroll tax (beginning in 2022), the program will provide a daily allowance of $100 for eligible state residents (from 2025), which can be spent on a range of services and supports, including in-home personal assistance.[137] Other states may follow suit in transforming the LTSS system; Michigan, for example, has commissioned a long-

133. S.B. 19-238, 2019 Reg. Sess. (Colo. 2019).

134. *Id.*

135. Reagan A. Baughman & Kristin Smith, *The Effect of Medicaid Wage Pass-Through Programs on the Wages of Direct Care Workers*, 48 MED. CARE 426, 426 (2010).

136. *See* Ron Lieber, *New Tax Will Help Washington Residents Pay for Long-Term Care*, N.Y. TIMES (May 13, 2019), https://www.nytimes.com/2019/05/13/business/washington-long-term-care.html?login=email&auth=login-email.

137. *Id.*

term care insurance feasibility study for the state to explore new financing options.[138] The study includes a workforce component to assess the capacity of the workforce to meet current and future LTSS needs.[139]

In developing social insurance models, states can explicitly integrate workforce development and job quality considerations. For example, states might: increase the wage floor for all home care workers; enhance training requirements and systems; institute supervision training plans and standards; create a long-term workgroup to oversee direct care workforce issues; and more.[140]

B. Training and Career Pathways for Home Care Workers

Another essential strategy for improving the availability and quality of HCBS for consumers is to improve training and career development opportunities for home care workers. Training helps ensure workers are prepared with the technical and interpersonal skills they need to meet consumers' needs safely and appropriately. Robust training is especially important in the context of growing acuity in HCBS[141]; to ensure that workers protect their own and their clients' safety[142]; and to prepare workers to interact effectively with consumers, family members, and other members of the care team.[143] Well-developed, adequately funded training opportunities also help improve the profile of home care as a career option, which is critical for recruitment and retention.[144] With the opportunity to attain recognized credentials, workers can craft a career in direct care that allows lateral and vertical job mobility. Without such portable credentials, they may leave the field altogether when they leave a particular home care position.[145]

However, the current training landscape for home care workers is fragmented and inconsistent. Only home health aides are subject to any federal training standards: to be employed by a Medicare-certified home health agency, home

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138. S.B. 0848, 99th Leg., Reg. Sess. (Mich. 2018).

139. *Id.*

140. *See* ROBERT ESPINOZA, STEPHEN CAMPBELL & KEZIA SCALES, PHI, WORKFORCE MATTERS: THE DIRECT CARE WORKFORCE AND STATE-BASED LTSS SOCIAL INSURANCE PROGRAMS 3 (2019), https://phinational.org/resource/workforce-matters.

141. KEZIA SCALES, PHI, IT'S TIME TO CARE: A DETAILED PROFILE OF AMERICA'S DIRECT CARE WORKFORCE 8 (2020), https://phinational.org/resource/its-time-to-care-a-detailed-profile-of-americas-direct-care-workforce.

142. Home care workers currently experience disproportionate rates of occupational injury, particularly musculoskeletal injuries. In 2016, injury rates were 144 injuries per 10,000 personal care aides and 116 per 10,000 home health aides, compared to 100 injuries per 10,000 workers across all U.S. occupations. STEPHEN CAMPBELL, PHI, WORKPLACE INJURIES AND THE DIRECT CARE WORKFORCE 3 (2018), https://phinational.org/resource/workplace-injuries-direct-care-workforce.

143. *See, e.g.*, JO MORIARTY ET AL., SOCIAL CARE INSTITUTE FOR EXCELLENCE, RESEARCH BRIEFING 34: COMMUNICATION TRAINING FOR CARE HOME WORKERS: OUTCOMES FOR OLDER PEOPLE, STAFF, FAMILIES AND FRIENDS (2010), https://www.scie.org.uk/publications/briefings/briefing34; SCALES, *supra* note 6, at 52.

144. SCALES, *supra* note 6, at 52.

145. *See* BIANCA FROGNER & JOANNE SPETZ, UNIV. OF CAL. S.F. HEALTH WORKFORCE RESEARCH CTR. ON LONG-TERM CARE, ENTRY AND EXIT OF WORKERS IN LONG-TERM CARE 31 (2015), https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/Report-Entry_and_Exit_of_Workers_in_Long-Term_Care.pdf.

health aides must complete at least seventy-five hours of pre-service training and twelve hours of annual in-service training.[146] Training standards for personal care aides, by contrast, are determined at the state level—with little uniformity across states, or in many cases, within a single state.[147] Seven states do not have *any* training requirements for personal care aides, and only fourteen states have uniform training standards for all agency-employed workers.[148] Where there are training-related regulations in place, they tend to be minimal; only about half of all states, for example, stipulate a minimum number of training hours for personal care aides under any set of regulations.[149]

A key dilemma confronting efforts to establish standardized minimum training requirements for home care workers—as a sector-wide workforce development strategy—is how to account for workers employed through consumer-directed programs. The majority of states and programs do not regulate training for independent providers, up to 70% of whom are consumers' family members and friends.[150] This approach is consistent with the principles of autonomy and independence that are central to the consumer-directed model.[151] It is also pragmatic: training regulations potentially limit the labor pool from which consumers can hire workers, which may exacerbate the risk of service gaps and unmet needs that consumers already face.[152] On the other hand, the lack of training standards raises quality assurance questions: namely, do workers have the competencies they need to provide safe and appropriate services, and do workers and consumers alike know their rights and responsibilities under the terms of the employment contract? As noted above, a lack of recognized training credentials can also limit lateral or upward job mobility for these workers, which can lead to higher levels of workforce attrition.

Although debates about training standards for independent providers often pit consumer advocates against workforce advocates, there is considerable overlap in goals related to quality, safety, workforce supply, and more. Indeed, in 2011 a diverse cross-section of advocates released a consensus document which suggests that acceptable training standards can be forged when:

1. Training strategies are developed at the local or state level with collaboration from a range of stakeholders;

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146. 42 C.F.R. § 484.36 (2011).

147. *See Personal Care Aide Training Requirements by State*, PHI, https://phinational.org/advocacy/personal-care-aide-training-requirements (last visited Feb. 23, 2020).

148. *Id.*

149. *Id.*

150. *See, e.g.,* Candace Howes, *Upgrading California's Home Care Workforce: the Impact of Political Action and Unionization*, 4 ST. OF CAL. LAB. 71, 86 (2004); Mallory Noe-Payne, *As Workforce Shortage Looms, Family Caregivers Fill the Gap*, WVTF (Sept. 18, 2019), https://www.wvtf.org/post/workforce-shortage-looms-family-caregivers-fill-gap; Bea Rector, Director, Wash. State Dep't of Soc. & Health Serv., Presentation: The Important Role of Family Caregivers in Washington State's Long-term Services and Support Systems (Nov. 29, 2017), https://www.milbank.org/wp-content/uploads/2017/12/Rector.pdf.

151. *Self-Direction*, APPLIED SELF-DIRECTION, http://www.appliedselfdirection.com/self-direction (last visited Feb. 23, 2020).

152. *See* Kevin J. Mahoney et al., *Unmet Needs in Self-directed HCBS Programs*, 62 J. GERONTOLOGICAL SOC. WORK, 195, 195–215 (2018).

2. Training requirements are funded independently of individuals' budgets;
3. Training requirements recognize the unique experience of family members and friends who are hired through consumer direction; and
4. Training curricula, where standardized, are designed in collaboration with consumers and workers and reflect the values and practices of self-determination.[153]

In tandem with efforts to implement acceptable training standards for independent providers, states and other entities can take steps to ameliorate the pressing recruitment challenges faced by consumers. A leading strategy is to create "matching service registries" to directly connect consumers with potential workers. These online platforms enable consumers to post open shifts online, and often to specify the type of assistance or worker that they require. Jobseekers can use the registries to find clients and shifts, and in some cases can create profiles showcasing their training, skills, and experience. There are currently fourteen matching service registries operating in ten states.[154]

Along with the lack of consistent training standards, there is also limited funding for home care workers' training programs. Entry-level training costs are not reimbursable through Medicaid,[155] with some exceptions, and workforce development funds (for example, through the 2014 Workforce Innovation and Opportunity Act) tend to prioritize occupations that offer better compensation and career development opportunities, such as licensed nursing rather than direct care roles.[156] As a result of these funding limitations, most training interventions—from small-scale pilots to national demonstration projects—tend to be grant-funded and therefore not sustained.[157] For example, one of the most coordinated efforts to improve training standards and programs for personal care aides to date was the Personal and Home Care Aide State Training Demonstration Program (PHCAST), which was funded through the ACA from 2010 through 2012 (with some grantees permitted no-cost extensions through 2014).[158] The six participating states—California, Iowa, Maine, Massachusetts, Michigan and North Carolina—developed training programs (varying in length from 50 to 120 hours), created

153. *See* BOB KAFKA ET AL., GUIDING PRINCIPLES FOR PARTNERSHIPS WITH UNIONS AND EMERGING WORKER ORGANIZATIONS WHEN INDIVIDUALS DIRECT THEIR OWN SERVICES AND SUPPORTS 7 (2011), http://www.appliedselfdirection.com/sites/default/files/Guiding%20Principles%20with%20Signatures.pdf (discussing the conditions required for acceptable training standards).

154. *Matching Service Registries*, PHI, https://phinational.org/advocacy/matching-service-registries (last visited Feb. 6, 2020).

155 . NAT'L DIRECT SERV. WORKFORCE RESOURCE CTR., COVERAGE OF DIRECT SERVICE WORKFORCE CONTINUING EDUCATION AND TRAINING WITHIN MEDICAID POLICY AND RATE SETTING: A TOOLKIT FOR STATE MEDICAID AGENCIES 2 (2013), https://www.medicaid.gov/sites/default/files/2019-12/dsw-training-rates-toolkit.pdf.

156. This claim is based on the author's personal communications with workforce development experts and other stakeholders since 2017.

157. *Id*.

158. *See* Jennifer Craft-Morgan et al., *Testing U.S. State-Based Training Models to Meet Health Workforce Needs in Long-Term Care*, 43 AGEING INT'L 123, 123–140 (2018); Anne Montgomery & Daniel Wilson, *PHCAST: Final Evaluation Underscores Urgency of Building Out Comprehensive, Competency-Based Training for Direct Care Workers*, PHI (July 14, 2016), https://phinational.org/phcast-final-evaluation-underscores-urgency-of-building-out-comprehensive-competency-based-training-for-direct-care-workers.

competency assessments, and trained both new and incumbent workers.[159] Although it had some lasting impact in each of the six states, the PHCAST program did not fundamentally transform the training landscape for personal care aides—for example, it did not lead to the creation of minimum national training standards or the widespread adoption of tested training models.[160]

As well as better entry-level training standards and programs, ongoing training and career advancement opportunities are also needed—to ensure that all home care workers have the necessary skills to meet consumers' needs as well as to provide a viable career ladder for experienced home care workers, and thereby to retain more workers in the field while also maximizing their contribution.[161] Linking to Section IV.A, it is critical to connect career advancement with increased compensation, to ensure that workers are financially incentivized to pursue further training and take on additional responsibilities.

A key example of an advanced role for home care workers is a senior aide role. With appropriate training and support, a senior aide can support entry-level workers, provide enhanced assistance for consumers and family caregivers, help resolve care challenges, and/or serve as a resource to the interdisciplinary care team, among other responsibilities. Other advanced roles for home care workers include peer mentor, to support both new and incumbent workers in navigating on-the-job challenges; assistant trainer, to support the delivery of entry-level or in-service training and provide one-on-one support to trainees; and assistant coordinator, to help improve care coordination.

Advanced roles for home care workers have been successfully pilot-tested[162] but rarely scaled up to the state level. Washington State offers an exception to the rule by offering an Advanced Home Care Aide Specialist role.[163] An apprenticeship program offered by the SEIU 775 Benefits Group, which is a partnership between the union and the state, the program provides seventy hours of advanced training for experienced home care workers.[164] Trainees are paid to attend the program, receive an additional fifty cents per hour upon completion, and earn a nationally recognized apprenticeship certification from the Department of Labor. The state is also developing a Behavioral Health Advanced Home Care Aide program, to develop the workforce that will enable those with severe and persistent mental illness to receive services at home.[165]

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159. HEALTH RES. AND SERV. ADMIN., DEP'T. OF HEALTH AND HUMAN SERVS., REPORT TO CONGRESS: PERSONAL AND HOME CARE AIDE STATE TRAINING (PHCAST) DEMONSTRATION PROGRAM EVALUATION 6, 13–14, (2016), https://www.hrsa.gov/sites/default/files/about/organization/bureaus/bhw/reportstocongress/phcastreport.pdf

160. *Id.*

161. Kirstin Falzon, *One Company's Solution for Filling the Coming Demand for Home Care Providers*, WORKING NATION (May 11, 2017), https://workingnation.com/one-companys-solution-filling-coming-demand-home-care-providers.

162. *See* David Russell et al., *Preparing Home Health Aides to Serve as Health Coaches for Home Care Patients with Chronic Illness: Findings and Lessons Learned from A Mixed-Method Evaluation of Two Pilot Programs*, 29 HOME HEALTH CARE MGMT. & PRAC. 191, 192 (2017); Falzon, *supra* note 161.

163. *See National Apprenticeship Certification*, SEIU 775 BENEFITS GROUP, https://www.myseiubenefits.org/national-apprenticeship-certification (last visited Feb. 23, 2020).

164. *Id.*

165. *See* Grace Kiboneka, Presentation at the Nat'l Acad. of State Health Policy Ann. State Health Policy Conference: Supporting Washington State's Long-term Services and Supports Workforce (Aug. 16, 2018),

C. Scope of Practice Limitations in Home Care

A third workforce-related barrier to meeting the promise of *Olmstead* is the inconsistency in rules and regulations concerning what home care workers, including both personal care aides and home health aides, are authorized to do. The allowed "scope of practice" for home care workers is determined primarily by nurse practice acts, as well as by other laws, regulations, and norms of practice; and therefore varies considerably by state, program, occupational role, and service-delivery model.[166]

Nurse practice acts determine, at the state level, which nursing or health maintenance tasks can only be performed by or under the direct supervision of a licensed nurse.[167] Nurse practice acts range from broad (with no limits on delegation) to narrow (specifying a limited number of allowable tasks or settings), with variation in between.[168] When they are narrow or conservatively interpreted (by home care agencies or by individual nurses), nurse practice acts can strictly limit what workers are able to do—which can, in turn, undermine consumers' access to the care they need. According to AARP's 2017 LTSS State Scorecard, which measures state-level LTSS system performance from the viewpoint of consumers and their families, sixteen states have broad nurse delegation rules (compared to nine in 2013), meaning that they permit nurse delegation of all sixteen health maintenance tasks measured by the scorecard.[169] Thirty-two states and D.C. allow nurse delegation of at least twelve tasks, while four states do not allow delegation of any of the tasks.[170]

The variation across states in nurse delegation rules is exacerbated by intra-state variation in how the rules apply to each type of home care worker. Agency-employed workers are covered by nurse practice acts, while unpaid family caregivers and independent providers (hired directly by consumers) are generally exempt (implicitly or explicitly).[171] This raises concerns about inequity for consumers, depending on the model of service-delivery they are enrolled in—that

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https://custom.cvent.com/024D0492CF3C4ED1AEDC89C0490ECDEE/files/event/E097A8FCDDD34B0CAFD1DC01FFFFC9B8/7e608e0d4f7a4712a968d921b595dd9atmp.pdf.

166. Susan C. Reinhard, *A Case for Nurse Delegation Explores a New Frontier in Consumer-Directed Patient Care*, 34 GENERATIONS 75, 75–77 (2010); *see* Joanne Spetz et al., *Home And Community-Based Workforce For Patients With Serious Illness Requires Support To Meet Growing Needs*, 38 HEALTH AFF. 902, 905 (2019); JOANNE SPETZ, HEALTHFORCE CTR. AT UCSF, HOME HEALTH AIDES AND PERSONAL CARE ASSISTANTS: SCOPE OF PRACTICE REGULATIONS AND THEIR IMPACT ON CARE, 5–10 (2019). To note, "scope of practice" refers primarily to the services that a health care provider can perform under the terms of their professional license. Since home care workers are not licensed by a professional body, the term is used loosely here to describe the activities that they are allowed or authorized to perform by nurse practice acts and other statutes and regulations.

167. *See* Reinhard, *supra* note 166.

168. SUSAN REINHARD, U.S. DEP'T. OF HEALTH AND HUMAN SERVS., CONSUMER DIRECTED CARE AND NURSE PRACTICE ACT 4–8 (2001), https://aspe.hhs.gov/basic-report/consumer-directed-care-and-nurse-practice-acts.

169. SUSAN REINHARD ET AL., AARP PUB. POL'Y INST., PICKING UP THE PACE OF CHANGE: A STATE SCORECARD ON LONG-TERM SERVICES AND SUPPORTS FOR OLDER ADULTS, PEOPLE WITH PHYSICAL DISABILITIES, AND FAMILY CAREGIVERS (2017).

170. *Id.*

171. Reinhard, *supra* note 166, at 76.

is, a consumer may have their needs met through a consumer-direction program, but would not be able to receive the same level of support from an agency-employed worker.[172]

States have explored a number of strategies for resolving these inconsistencies and ensuring that home care workers can work to the top of their skill set. The New Jersey Board of Nursing, for example, adopted new regulations in 2016 that explicitly authorize nurses to exercise discretion over delegation to home health aides, including delegation of tasks related to medication administration. The regulations were amended after a pilot program on enhanced nurse delegation showed positive outcomes, including more timely medication administration for consumers, improvements in their peace of mind, health, and independence, and better family respite.[173] Moreover, the evaluation found that delegation helped address unmet need: in approximately one out of five cases, the delegated task had not been performed at all prior to delegation, while in other cases, the task had been performed irregularly or without authorization.[174]

Taking another approach, New York State recently created an Advanced Home Health Aide role to expand delegation while also formalizing an advanced role for home care workers.[175] With additional training and certification, advanced home health aides are authorized to administer medications, under nurse delegation and supervision, to medically stable consumers.[176] New York State's nurse practice act was amended more than two decades ago to explicitly allow consumer-directed personal care aides to perform a range of nursing tasks, including medication administration, that are not permissible for agency-employed workers.[177] Therefore, enactment of the Advanced Home Health Aide role achieves some parity, in principle, between home health aides and independent providers in the state. However, there is a lack of designated funding for advanced home health aides' training, supervision, or wage increases, which renders uptake of the new role very unlikely.

As a final example, the California Future Health Workforce Commission has proposed creating a "universal home care worker" occupation in the state which would lay out a very clear career development pathway for home care workers.[178]

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172. *Id.*

173. JENNIFER FARNHAM ET AL., RUTGERS CTR. FOR ST. HEALTH POL'Y, NEW JERSEY NURSE DELEGATION PILOT EVALUATION REPORT 20 (2011), https://www.state.nj.us/humanservices/dds/documents/Report%20Formatted%2010may11%20with%20covers.pdf.

174. *Id.*

175. Allison Cook, *New York Legislature Passes Advanced Home Health Aide Legislation*, PHI (June 21, 2016), https://phinational.org/new-york-legislature-passes-advanced-home-health-aide-legislation.

176. N.Y. State Educ. Dep't, *Practice Information: Advanced Home Health Aides*, OFFICE OF THE PROFESSIONS, http://www.op.nysed.gov/prof/nurse/nursing-ahha.htm (last visited Feb. 23, 2020).

177. *See* MARY LOU BRESLIN, IMPROVING SUPPORT FOR HEALTH MAINTENANCE IN HOME AND COMMUNITY-BASED SERVICES: HOW STATES ADAPT NURSING RULES FOR THE COMMUNITY FIRST CHOICE PROGRAM 5 (2018), https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Improving%20Support%20for%20Health%20Maintenance%20in%20HCBS.pdf.

178. CAL. FUTURE HEALTH WORKFORCE COMM'N, MEETING THE DEMAND FOR HEALTH: FINAL REPORT OF THE CALIFORNIA FUTURE HEALTH WORKFORCE COMMISSION 140 (2019),

The remit of the workforce commission, which was convened in 2017, was to create a comprehensive strategy for closing the gap between the existing health care workforce and the one that will be needed in the future. As one of their recommendations for strengthening the health care workforce overall, the commission proposed a universal home care worker occupation with three competency-based levels, ranging from non-medical personal care to "paramedical services for the most complex cases," with the latter requiring amendments to California's nurse practice act.[179] Importantly, the commission recommended that each occupational level must be accompanied by enhanced compensation to match the additional training and responsibilities involved.[180]

D. New Opportunities to Invest in the Home Care Workforce

Major shifts in the health care financing and delivery landscape present potential new opportunities to improve training, develop career pathways, and boost compensation for home care workers. Value-based payment and managed care are two key opportunities.

Value-based payment refers to payment arrangements based on the value rather than volume of services provided—with value generally defined as higher quality at a lower cost. The overarching goal of value-based payment is to incentivize health care providers to make quality improvements that benefit both consumers and the health care system. The number of states and territories that have implemented any type of value-based payment program in health care overall has increased from just one in 2008 to forty-eight in 2018, and these programs are now well-established in primary, acute, and skilled nursing care settings.[181]

Now being introduced incrementally in home care, value-based payment can be leveraged to improve home care jobs and increase recruitment and retention.[182] Value-based payment arrangements may be used in home care to incentivize providers' workforce investments directly, by rewarding progress on defined workforce measures, or indirectly, by rewarding outcomes that are most sensitive to the contribution of a strong, well-prepared workforce.[183] The sector is still struggling to identify a manageable set of quality outcomes for the home care setting, however.[184] The rate of potentially avoidable hospitalizations is one

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https://futurehealthworkforce.org/wp-content/uploads/2019/03/MeetingDemandForHealthFinalReportCFHWC.pdf.

179. *Id.*

180. *Id.* at 34.

181. CHANGE HEALTHCARE, VALUE-BASED CARE IN AMERICA: STATE-BY-STATE 66–67 (2019), https://inspire.changehealthcare.com/stateVBRstudy.

182. *See generally* Allison Cook, *In Value-Based Payment, the Direct Care Workforce Matters,* PHI (Apr. 8, 2019), https://phinational.org/in-value-based-payment-the-direct-care-workforce-matters.

183. *See* ALLISON COOK, PHI, VALUE-BASED PAYMENT AND THE HOME CARE WORKFORCE: WHAT NEW YORK CAN TEACH OTHER STATES 2–3 (2019), https://phinational.org/resource/value-based-payment-and-the-home-care-workforce-what-new-york-can-teach-other-states.

184. NAT'L QUALITY FORUM, QUALITY IN HOME AND COMMUNITY-BASED SERVICES TO SUPPORT COMMUNITY LIVING: ADDRESSING GAPS IN PERFORMANCE MEASUREMENT 2 (2016), https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_Measurement.aspx.

possible measure, serving as a good indicator of health care utilization and cost, but outcomes such as independence and community engagement may be equally important for consumers—and most directly influenced by home care workers.[185] Another factor limiting the potential impact of value-based payment on workforce development goals is the timing of payments.[186] If payments are disbursed as rewards rather than upfront investments, home care agencies will struggle—given the low margins afforded by Medicaid reimbursement rates—to invest in workforce-related strategies, such as better training or advanced roles, for achieving value-based payment goals.[187]

The second notable trend in the health care landscape is the shift to managed long-term care. In traditional fee-for-service arrangements, providers are reimbursed for each service they deliver.[188] By contrast, in managed care, Medicaid (or another payer) pays a set per-member/per-month capitated payment to a managed care organization to serve a particular group of consumers.[189] As of 2017, twenty-four states were operating Medicaid managed long-term services and supports (MLTSS) programs, up from sixteen states in 2012 and just eight states in 2004.[190]

Since capitated payments are tied to the individual rather than a particular care setting, the managed care model can potentially align with rebalancing efforts and help fulfill *Olmstead*—as long as states build relevant incentives and expectations into their managed care contracts. For example, states can require managed care plans to provide evidence of their efforts to identify individuals at risk of institutional admission and to transition institutionalized individuals back to the community[191]—and can also build explicit workforce expectations into their contracts. Arizona's managed LTSS plans, for example, are contractually required to collect direct care workforce data, to use those data to develop workforce development plans, and to coordinate with providers to implement workforce interventions.[192] Pennsylvania's new managed care system, as another example, requires managed care plans to promote direct care workforce innovations, including in terms of training, career advancement, and participation in care

185. COOK, *supra* note 183, at 6.

186. *Id.* at 5.

187. *See id.*

188. MACPAC, *Medicaid 101: Provider Payment and Delivery Systems*, https://www.macpac.gov/medicaid-101/provider-payment-and-delivery-systems (last visited Feb. 23, 2020).

189. *Id.*

190. Elizabeth Lewis et al., *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*, TRUVEN HEALTH ANALYTICS 3, 7 (2018), http://www.advancingstates.org/sites/nasuad/files/mltssp-inventory-update-2017.pdf.

191. ARI NE'EMAN, UNIV. OF CAL. S. F. CMTY LIVING POL'Y CTR., MANAGED LONG-TERM SERVICES AND SUPPORTS: CONTRACT PROVISIONS RELATED TO TRANSITION AND DIVERSION FROM INSTITUTIONAL PLACEMENT 2–5 (2019), https://clpc.ucsf.edu/publications/managed-long-term-services-and-supports-contract-provisions-related-transition-and.

192. ARIZ. HEALTH CARE COST CONTAINMENT SYS., AHCCCS CONTRACTOR OPERATIONS MANUAL: 407 WORKFORCE DEVELOPMENT 3 (2018), https://www.azahcccs.gov/shared/Downloads/ACOM/PolicyFiles/400/407_Workforce_Development.pdf.

coordination activities.[193] Finally, Tennessee is currently implementing an extensive direct care workforce development strategy through the LTSS component of the TennCare managed care program.[194]

V. CONCLUSION

The 1999 *Olmstead* case provides an invaluable civil rights-based legal rationale for transitioning LTSS from institutions to the community, in alignment with individuals' preferences and the broader rebalancing trend in Medicaid payment and service provision. But the workforce that makes community living possible for many individuals—through the provision of personal assistance and other daily supports—has largely been absent from *Olmstead* legislation in the years since. Considering the entrenched job quality concerns faced by home care workers and the magnitude of the recruitment and retention challenges overwhelming the HCBS sector, addressing the workforce component of deinstitutionalization may be perceived as requiring "fundamental alterations" which lie beyond the *Olmstead* remit.[195] However, as described in this Article, there are a range of "reasonable accommodations" that states can make, such as: implementing reimbursement rate increases with pass-through requirements; improving training standards and career development opportunities; addressing scope of practice and delegation laws, policies, and/or norms of practice; and including workforce issues in new payment arrangements, such as managed care and value-based payment contracts. Looking ahead, legal advocates must consider whether and how the workforce can be incorporated in future *Olmstead* cases. Also, all stakeholders need to advocate for a more coordinated and sustained approach to strengthening and stabilizing the home care workforce at the local, state, and national levels—to meet the rapidly escalating need for LTSS services that are provided in individuals' own homes and communities.

193 . PA. DEP'T OF HUM SERVS., COMMUNITY HEALTHCHOICES AGREEMENT 44 (2009), http://www.healthchoices.pa.gov/cs/groups/webcontent/documents/document/c_272140.pdf.

194. *See, e.g.*, Charla Long, *QuILTSS Workforce Development Forum*, YOUTUBE (May 12, 2016), https://www.youtube.com/watch?v=BjVFRwWM36E&feature=youtu.be.

195. Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581, 595 (1999).