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Historical Mismatch Between Home-Based Care Policies And Laws Governing Home Care Workers

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ABSTRACT **Americans generally want to remain in their homes even if they develop chronic health problems or disabilities that qualify them for nursing home care. While family members or friends provide the preponderance of home-based support, millions of Americans use paid personal assistance services (PAS). Inexorable demographic trends are increasing the numbers of people who need paid home-based PAS, with this need rapidly outstripping the capacity of the paid PAS workforce. While many factors contribute to this widening discrepancy, its roots reach back more than eighty years to asynchrony among various policies affecting home-based supports for people with functional impairments and policies affecting home-based PAS workers. Finding solutions to the growing gap between demand for the services and the PAS workforce requires policies that cut across societal sectors and align incentives for consumers, workers, and other key stakeholders.**

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Even with severe functional impairments from chronic disease or disability, most Americans want to continue living in their homes and communities instead of moving to nursing homes.[1] Nevertheless, without adequate supports from relatives or friends—the vast informal caregiver workforce—people with significant impairments in activities of daily living (ADLs) require paid personal assistance services (PAS) to live at home. Nearly eight million Americans needing ADL supports currently reside at home, and roughly 15 percent with high-level needs receive paid PAS.[2,3] With the aging of the baby boomers and other demographic trends, the numbers of people needing paid home-based PAS will grow significantly in coming decades. A mismatch between this rising demand for home-based PAS and the paid PAS workforce has been growing for many years, with the gap nearing crisis proportions.[4]

Many factors have contributed to this discrepancy, including some reaching back to the nation's founding—such as the legacies of socioeconomic segregation and slavery.[5(p11)] Even with the transformative New Deal, for more than eighty years an asynchrony has existed between various policies affecting home-based supports for people with functional impairments and policies affecting home-based PAS workers. Despite early policies favoring institutionalization, governmental initiatives (for example, laws and court rulings) from the 1960s onward have moved almost uniformly toward community-based care—albeit with entrenched regional variations. In contrast, early federal labor laws carried marks of institutional sexism and racism. Only recently have federal labor regulations covered home-based workers, most of whom are women of color. Thus, while policies targeting consumers have steadily increased the demand for home-based PAS, federal labor policies for decades have excluded home-based PAS, hampering efforts to recruit and retain workers.

This article examines the historical disconnect between policies relating to consumers who need paid ADL supports and those affecting home-based PAS workers. This topic is complex, with many contributing factors. We concentrate on policies in three areas: the settings of supportive services, consumers' civil rights, and workers' rights.

Settings Of Supportive Services

From colonial times to the mid-nineteenth century, Americans with homes and resources received health care and supportive services at home, shielded from the hazards of poverty. People who needed ADL assistance, were poor, and fell into meritorious need categories—such as older people, widows, and children—received minimal subsistence in almshouses (that is, poorhouses), often in wretched conditions. Residential facilities for genteel but homeless older women emerged in the early nineteenth century in America. The progenitors of nursing homes, these private facilities generally demanded substantial entrance fees and certificates documenting good character.[6] For most impoverished older people, however, almshouses remained their only option—despite growing recognition by 1930 of their miserable conditions and high operational costs.

In parallel developments, biological causes of disability were increasingly recognized. From the nineteenth to the mid-twentieth century, this led medical and other professionals to place many people who were blind or deaf or who had an intellectual, developmental, or mental health disability in institutions. Proponents asserted that these facilities provided humanitarian custody, grounded in science and progressive thinking.[7] These institutions built upon "optimistic assumptions about the possibilities of reform, rehabilitation, and education" by isolating residents "from the corrupting, tempting, and distracting influences of the world."[8(p11)] Despite this early optimism, institutional programs frequently degraded into custodial minimalism, with deplorable living conditions and sometimes abusive staff members.[9]

Passage of the Social Security Act (SSA) of 1935 was partially motivated by the humanitarian goal of giving poor older people sufficient resources to move from almshouses into their own homes. As US Supreme Court Justice Benjamin Cardozo wrote in upholding the SSA's constitutionality, "The hope behind this statute is to save men and women from the rigors of the poorhouse" as their life "journey's end is near."[6] Nonetheless, from 1935 through the mid-1970s SSA policies favored the institutionalization of people who required supportive care. Under the initial SSA, federal dollars available to states for the means-tested Old Age Assistance program applied only to people who did not reside in public facilities, such as almshouses. This policy buttressed the developing private nursing home industry. Amendments to the SSA in 1950 required that payments for medical care go directly to nursing homes instead of beneficiaries receiving supports from Social Security programs, which further strengthened nursing facilities. These amendments created separate categories of public assistance and placed "homecare firmly within the realm of 'welfare'" rather than the standard health care delivery system.[5(p50)]

President John F. Kennedy similarly advantaged nursing homes in the Community Health Services and Facilities Act of 1961. This law aimed to increase community-based health services for people who were elderly or had chronic health conditions. Nonetheless, under the Hill-Burton program, it gave states funds to construct public nonprofit nursing homes. (In contrast, President Kennedy's Community Mental Health Act of 1963 focused specifically on constructing mental health care delivery systems throughout communities, thus supporting efforts in the late 1960s and 1970s to deinstitutionalize mentally ill people.)

The 1965 amendments to the SSA authorized Medicare and Medicaid (in Titles XVIII and XIX, respectively), which perpetuated distinctions between entitled "beneficiaries" and means-tested "recipients." Consistent with policies starting with New Deal chronic illness programs, "long-term care ended up on the welfare side of the equation…[and] Medicaid evolved into America's long-term care program. This outcome thrust recipients, family members, and care workers into a persistent battle against the stigmatization and insecurity of welfare."[5(p86)]

From its inception, Medicaid—a joint federal-state program, like most earlier welfare initiatives—required all participating states to cover nursing home care for recipients ages twenty-one and older. Over time, laws and policies evolved strongly away from institutionalization and toward community-based care. In 1970 home health care became a mandatory benefit for recipients who were eligible for nursing facility care because of their functional impairments (see online appendix exhibit A).[10] The SSA's 1975 amendments (Title XX) aggregated federal assistance to states for social services into a single grant, incentivizing states to decrease inappropriate institutional care and move toward home and community-based services. Over the past three decades several Medicaid waiver programs, such as Section 1915(c), have extended options for state Medicaid programs to

Policies that affect consumers who require paid ADL assistance have increasingly supported their efforts to live at home.

provide such services as alternatives to institutional care (appendix exhibit A).[10]

Evolving Medicaid waiver provisions have directly affected the PAS workforce in two major ways. First, in the late 1990s Medicaid authorized family members of consumers to become paid PAS providers, not including "legally responsible" relatives (that is, spouses and parents). Starting in 2005, under Section 1915(j) waivers, states could pay legally responsible relatives as PAS providers. In states choosing this option, these changes expanded the pool of potential PAS workers and compensated family caregivers, who otherwise might forgo paid employment to assist their relative. Second, Medicaid's state options increasingly expanded from the traditional "agency model" (that is, home care agencies hire, train, and supervise PAS workers) to consumer direction (that is, consumers hire, train, and supervise the workers)—which is consistent with a core tenet of the disability rights movement.

Consumers' Civil Rights

For centuries, authorities dispensing subsistence support struggled to distinguish "deserving" people with disability from those feigning it.[11] In the nineteenth century new tools for "objectively" diagnosing disease—such as the stethoscope, microscope, ophthalmoscope, spirometer, and radiograph—made physicians the arbiters who validated disability. This "*medical model* views disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided…by professionals."[12] The medical model underpins Social Security's disability insurance program, instituted in the mid-1950s. To qualify, applicants must submit medical evidence from their physicians that documents chronic health conditions that prevent "substantial gainful activity."[13] The medical model presumes that, directed by their physicians, people will strive individually to overcome their impairments.

By the mid-1960s roiling social and political forces had coalesced to contest the medical model.[14] Edward V. Roberts, who was quadriplegic from childhood polio, became a major leader of this transformative movement. The University of California Berkeley initially rejected his undergraduate application, arguing that iron lungs were too large for dormitory rooms. When Roberts ultimately matriculated at Berkeley, he advocated for PAS, peer counseling, and other services—organized and run by people with disability—to support their living on campus and participating in university life. In 1972 Roberts and other disability rights advocates founded the first center for independent living, where they "redefined independent living from 'tasks one could perform without assistance' to 'the quality of one's life with help.'"[5(p102)] They argued that people with disability, rather than health care professionals, best understood their needs and how to address them. Roberts and his disability advocate peers founded the independent living movement based on principles of self-determination, consumer direction, comprehensive service supports, and community integration. These principles were codified in the 1978 amendments to the 1973 Rehabilitation Act (see below), which established centers for independent living nationwide that were run by and for people with disability (appendix exhibit B).[10]

This independent living philosophy transformed views of disability. According to the World Health Organization, "The *social model* of disability…sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual" but instead results from complex social factors.[12] Improving the lives of people with disability therefore "is the collective responsibility of society at large[,]…an attitudinal or ideological [issue] requiring social change, which at the political level becomes a question of human rights."[12]

The Rehabilitation Act of 1973 amended vocational rehabilitation policies that had existed for fifty years. Motivated by disability rights advocates, the law went much further, extending civil rights protections to this population. Section 504 of the act became the first federal statute to prohibit disability-based discrimination—specifically in federal programs, programs receiving federal dollars, federal employment, and employment by federal contractors (appendix exhibit B).[10] Citing cost concerns, successive administrations blocked the implementation of Section 504 until public pressure from disability rights protesters forced its implementation in 1977. Throughout the 1980s President Ronald Reagan tried to dismantle Section 504's regulations. Nonetheless, it survived and served as the model for the Americans with Disabilities Act (ADA) of 1990, which prohibits disability-based discrimination—including in employment, public services, and private services provided to the public (for example, private physicians' offices). The ADA amendments in 2008 clarified Congress's intention to broadly cover people under the law's definition of *disability*.

The ADA has had wide-ranging effects, with the US Supreme Court's ruling in 1999 in *Olmstead v. L.C.* having major implications for home-based supports.[15] *Olmstead* involved Lois Curtis and Elaine Wilson, both of whom had mental illness and developmental disabilities and had agreed to enter Georgia Regional Hospital's psychiatric unit. (Tommy Olmstead was Georgia's human resources commissioner.) Although their health care professionals felt that Curtis and Wilson could live with supports in the community, Georgia kept them in the hospital (once trying to discharge Wilson to a homeless shelter, a move that she contested). Curtis and Wilson sued, arguing that Georgia's failure to support them in the community violated the ADA.[16] The women won their case 6–3 under the ADA's Title II, which prohibits state and local governments from excluding people with disability from participating in or receiving public program benefits (in this case, Medicaid).

Writing the Court's *Olmstead* opinion, Justice Ruth Bader Ginsburg asserted, "The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community setting perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life…; and institutional confinement severely diminishes individuals' everyday life activities." She noted that the ADA took "a more comprehensive view of the concept of discrimination." However, Ginsburg observed that "the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless."

Although *Olmstead* confirmed the civil rights of people with disability to live in their homes and communities, it could not ensure the financial resources to make that happen. The Supreme Court cannot compel state Medicaid programs to spend specified amounts on home-based services such as PAS. Nonetheless, the presence of *Olmstead* protections affected states' Medicaid decisions. According to Sara Rosenbaum, "Like the proverbial stone thrown into water, *Olmstead* produced ripple effects that helped propel forward a considerable level of interest in how Medicaid might be restructured to favor community integration."[17(p595)]

Workers' Rights

Informal caregivers—the vast workforce of friends and family—are typically presumed to offer their services as a "labor of love." However, paid PAS has been perceived as "unskilled work that allegedly any woman could perform."[5(p9)] Furthermore, "black, immigrant, and poor white women long have undertaken these jobs," devaluing this labor because of these gender and racial associations.[5(p9)] Multiple factors have thus conspired to stigmatize paid PAS, including not only such societal attitudes but also local, state, and federal policies extending back to the New Deal.

The public face of the 1930s Great Depression was largely unemployed men. Nonetheless, poor women who had subsisted through domestic labor also suffered widespread job losses. Nationwide, the New Deal's Visiting Housekeeper Program offered these women employment, providing crucial income to them and free help with housework and child care to needy households (appendix exhibit C).[10] These visiting housekeepers were not considered "nurses" or "maids," but under the supervision of registered nurses and caseworkers, "they performed laborious household tasks" while "ministering to the ill."[5(p19)]

During its existence, the New Deal's Works Progress Administration (WPA) supported 38,000 housekeeping jobs across forty-five states and the District of Columbia,[5(p23)] providing the major source of work relief for black women. Southern employers complained that these housekeeping jobs, which paid more than textile and agricultural work, "caused labor shortages, undermining the racial caste system."[5(p23)] However, program policies aimed to preserve traditional gender and racial roles. The WPA supported just one worker per family, typically male "breadwinners." Syphilis testing was required for workers involved with domestic labor, which demonstrated "official concern with protection of the white household."[5(p25)] These WPA origins linked paid home care with the legacy of "slavery and segregation that racialized the labor and defined it as low paid and unskilled."[5(p11)]

Alongside New Deal programs to provide jobs, President Franklin D. Roosevelt sought broad policy changes to increase low wages. He faced

Solutions to widening gaps between demand for paid PAS and the required workforce must consider policies across societal sectors.

strong headwinds from industry and the Supreme Court, which issued multiple antilabor rulings from the 1910s through the mid-1930s. After his 1936 landslide victory, President Roosevelt; his labor secretary, Frances Perkins; and others worked to draft legislation that could survive constitutional challenges and overcome staunch opposition from Southern legislators, who fought efforts to extend labor protections to domestic and agricultural workers. President Roosevelt's ultimate strategy linked labor protections to interstate commerce, where the federal government has regulatory authority. With this restriction, the Fair Labor Standards Act (FLSA) of 1938 covered just 20 percent of workers nationwide, including only 14 percent of female workers and few black workers.[18]

Decades later, War on Poverty programs specifically targeted these workers, especially African American women (appendix exhibit C).[10] The programs aimed not only to employ low-income women but also to stabilize their families.[5] Nonetheless, program structures sometimes disadvantaged workers who provided home-based PAS to adult consumers. For example, by treating these workers as "independent contractors," program policies relegated them to lower wages (appendix exhibit C).[10]

The Department of Labor categorizes home-based PAS as "domestic work," which includes heterogeneous services—ranging from housekeeping to child care, cooking, and gardening—performed in or around private homes. Because domestic labor falls outside interstate commerce, decades elapsed before domestic workers finally attained wage and work hour protections with the 1974 FLSA amendments. However, these 1974 amendments explicitly excluded home care workers from protection, deeming their labor to constitute "companionship services."

Legislators excluded companionship services from FLSA provisions based on notions that these workers provide social supports to older people with modest incomes. Lawmakers reasoned that minimum wage protections might force older people to fire "lifelong loyal employees," and they deplored this "sorry state of affairs."[18] Without evidence, legislators asserted that these so-called companions were "casual workers" who were not the primary wage earners for their families.

In 1975, when policy makers in the Department of Labor wrote regulations implementing FLSA's 1974 amendments, they considered continuing to cover employees of home care agencies, who had been included under previous FLSA provisions.[19] However, the final rules withdrew these protections. The rules interpreted the companionship exemption broadly, applying it to nearly all workers who provided PAS, social support, and other household services for older people and those with disabilities—as well as to home health and PAS workers who were paid privately or publicly through Medicaid. The Department of Labor's regulations also exempted workers employed by home care agencies. "This represented a contraction of rights" and resulted in excluding "hundreds of thousands of domestic workers from basic wage and hour protections."[18] Thus, despite escalating demand for PAS workers, the department's 1975 regulations impeded their recruitment and retention.

Another several decades ensued with efforts to counteract consequences of the companionship exemption and bolster the PAS workforce. In the 1980s the Service Employees International Union (SEIU) began recruiting home care workers. Workers themselves formed groups such as Domestic Workers United in New York to gain labor protections from states. To generate public support, workers' groups publicized powerful stories about individual workers and arguments about the moral imperatives of their work, highlighting how PAS empowers consumers. Nevertheless, despite important local victories, home care workers remained exempt from FLSA protections into the new century.

A lawsuit filed in 2002 by Evelyn Coke, a New York City home care worker, finally precipitated substantive change. A Jamaican-born single mother of five, Coke had worked many years for a Queens home care agency. Starting early each morning, she bathed and dressed her clients, prepared meals for them, helped them eat, and assisted them with medications. Coke reported loving her job, but she sometimes worked three consecutive twenty-four-hour shifts, earning $7 an hour without overtime payments.[19] In

2001, hit by a car and unable to work, Coke sought legal advice. Reviewing her pay stubs, Coke's lawyer found that she had worked seventy hours in some weeks without receiving the minimum wage and overtime compensation required by New York State. In 2002 Coke sued her home care agency for unpaid wages and questioned whether Congress had intended the Department of Labor to exempt home care workers employed by agencies.

Coke's case reached the Supreme Court, which heard oral arguments in April 2007. The home care agency asserted that overtime payments would precipitate "tremendous and unsustainable losses." New York City estimated that its Medicaid costs could rise by $250 million with new overtime payments, which would threaten massive service cuts.[19] In June 2007 the Supreme Court ruled unanimously against Coke, indicating that the Department of Labor had absolute authority to issue regulations exempting home care workers from FLSA protections.

The 2007 Supreme Court ruling again galvanized advocates for home care workers to exert pressure on Congress to overturn the companionship exemption. SEIU arranged for presidential candidate Barack Obama to shadow a home care worker in Oakland, California.[20] After learning that the worker needed two jobs to make ends meet, had no sick leave or vacation time, and relied on food banks, Obama announced that he would end the companionship exemption for home care workers if elected.

In 2011 President Obama asked the Department of Labor to extend the 1974 FLSA wage and work hour protections to home care workers, and the department initiated lengthy public rule making.[18] Supporters argued that protecting wages and work hours would improve the quality of home care jobs, reduce staff turnover, and thus enhance consumers' experiences. Although important consumer groups applauded this FLSA change, others did not. At a 2013 Department of Labor listening session, one prominent disability rights advocate argued, "Increasing the cost of home and community based services by requiring overtime pay, without increasing the Medicaid rates or raising the Medicaid caps for available funding, will result in a reduction in hours of personal assistance, forcing some people with disabilities into unwanted institutionalization."[18] Proposed FLSA regulatory changes have been linked directly to the 1999 *Olmstead* decision, which suggested that "the Americans with Disabilities Act should be interpreted as prohibiting government agencies from setting policies that would increase institutionalization of people with disabilities, defining the undue institutionalization of people with disabilities to be a form of unlawful discrimination. That is, the Department of Labor was legally bound to consider the argument of disability advocates that including homecare workers in minimum wage and overtime protections may increase rates of institutionalization."[18] Disability advocacy organizations that supported regulatory change—citing matters of fairness, equality, and interdependence of workers and clients—provided powerful counterpoints. Furthermore, states that had already implemented wage and work hour reforms for home care workers did not demonstrate higher institutionalization rates.

The Department of Labor issued its revised regulations in October 2013, narrowing the definition of *companionship services* so that home care workers who provided ADL supports would no longer be considered "companions" and thus would gain FLSA protections. Another legal challenge ensued, from an association of home care agencies. That case rose through the lower courts until reaching the Supreme Court—which refused to hear the case on June 27, 2016.

The new FLSA regulations, giving home care workers wage and work hour protections, could finally take effect. Preliminary evidence from the field suggests that effects on workers have been mixed, however. For example, many employers have introduced new scheduling practices to eliminate or reduce overtime. This means that workers must piece together hours with different employers and are still working overtime without additional compensation. The effects of these FLSA regulations on PAS workers requires monitoring.

As noted above, unions played important advocacy roles for paid PAS workers during efforts to change the FLSA companionship exemption. However, in recent years some home care workers have resisted unions, especially requirements to pay dues. Pamela J. Harris and other home care workers supporting participants in the Illinois Department of Human Services program for people with disability filed suit in 2010 against Gov. Pat Quinn, arguing that being required to make "fair share" payments to SEIU violated their rights under the First Amendment (freedom of speech) and the Fourteenth Amendment (freedom of association). *Harris v. Quinn* reached the Supreme Court, which decided the case 5–4 in June 2014. Justice Samuel A. Alito wrote the opinion for the conservative majority, which ruled that requiring home care workers to pay dues to the union violated their First Amendment rights.[21] In another 5–4 Supreme Court ruling, the 2018 decision in *Janus v. American Federation of State, County, and Municipal Employees, Council 31*[22] extended First Amendment protections to all public-sector employees who choose not to pay union dues. Since these unions had conducted collective bargaining, including for home care workers, the effects of these court decisions on PAS workers' wages requires monitoring. Anecdotal reports suggest that the *Harris v. Quinn* ruling motivated unions to make greater grassroots efforts to prove their value to home care workers.

Discussion

As described above, in recent decades policies that affect consumers who require paid ADL assistance have increasingly supported their efforts to live at home. Initiatives included expanding Medicaid coverage of paid personal assistance services in states choosing that option and civil rights protections for community integration under *Olmstead* (for public programs). However, from the Fair Labor Standards Act of 1938 to the final 2016 Supreme Court decision about companionship exemptions, federal labor laws failed to provide wage and work hour protections to home care workers. Two recent Supreme Court decisions that ended requirements for workers to pay membership dues raise questions about the future ability of labor unions to negotiate higher wages for PAS workers. Thus, while consumer-oriented policies heightened demand for these services, labor policies have hampered efforts to build the workforce.

The extent of policy mismatches extends well beyond those mentioned in this brief article. For instance, millions of Americans need paid PAS support, but because of even modest personal resources, they do not qualify for Medicaid. Some pay privately for PAS through home care agencies, while many others hire workers directly through the "gray market." In the home care context, the gray market segment—which is of unknown size—involves consumers' hiring and paying PAS workers privately out of pocket, as household employees, independent contractors, or unreported workers. Wealthier private-pay consumers can offer hourly wages above rates of public payers. With low Medicaid payment rates, this leaves PAS employers (consumers or agencies) that receive Medicaid reimbursement struggling to compete for workers with individual consumers who can offer slightly higher wages (although not necessarily other employment protections). Given the growing workforce shortage, this mismatch can undermine access to PAS workers for people who rely on Medicaid-funded PAS.

Anecdotal reports suggest that an impending Medicaid policy—the implementation of electronic visit verification for all home-based visits—could stifle PAS workforce recruitment and retention. This requirement, mandated by Section 12006 of the 21st Century Cures Act of 2016, requires electronic verification of service type, location, start and finish times, and more.[23] The verification aims to eliminate waste, fraud, and abuse in Medicaid home care services, although some advocacy groups question whether substantial fraud exists. States that do not implement the verification by January 1, 2020, will receive lower federal matching funds. Monitoring the effects of the verification's implementation on the PAS workforce will be important, given anecdotal reports that some workers and consumers view the verification as invading their privacy and indicating distrust.

Long-standing policies in other sectors also contribute to gaps between consumers' paid PAS needs and the available workforce. Housing and other policies that have caused segregation by income and by race or ethnicity mean that PAS workers, who are generally low income and disproportionally people of color, often live in neighborhoods distant from potential consumers. This is particularly problematic in regions with high housing costs. Inadequate, unreliable, or absent public transportation can prevent workers from taking PAS jobs. Federal immigration policies raise concerns, given that about 29 percent of home care workers are immigrants.[24] Ending temporary protected status for immigrants from certain countries and implementing policies that restrict permanent residency eligibility for immigrants using public assistance programs, even legally, could reduce the number of candidates for PAS work.

Solutions to widening gaps between demand for paid PAS and the required workforce must consider policies across societal sectors. Finding common ground among stakeholders' interests is critical. Acknowledging the societal value of PAS work is a critical step toward raising workers' wages, but these attitudinal changes run counter to decades of devaluing both the work and the workforce. Aligning diverse incentives to achieve the goals of both PAS consumers and workers will be essential to address the impending crisis in home-based care. ■

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