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FROM ALMSHOUSES TO NURSING HOMES AND COMMUNITY CARE: LESSONS FROM MEDICAID'S HISTORY

Sidney D. Watson*

INTRODUCTION

Home and community-based services are support and long-term care services that offer an alternative to institutional care for those who need assistance with life's daily activities. For Lois Curtis of Atlanta, one of the plaintiffs in the *Olmstead v. L.C.*[1] who spent most of her life in mental institutions, it means a live-in companion who helps her with the day-to-day activities of living in her own home, like managing finances, cooking meals, and keeping track of medications.[2] For Larry McAfee, another Georgian who was quadriplegic, community-based services involved round-the-clock personal care, wheelchair accessible bathrooms and kitchens, a specialized computer, and a specially adapted van.[3]

Home and community-based services allow children, adults and the elderly to be in the community rather than cut off from the community as typically happens in nursing homes and other institutions. After moving into her own home, Lois Curtis reconnected with her family, made new friends and became a successful folk artist with well received gallery showings in Atlanta and other cities.[4] Larry McAfee—who once asked the Georgia courts to allow him to end his life when he was forced to live in hospitals

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[1] Olmstead v. L.C., 527 U.S. 581 (1999).

[2] *Id.*

[3] JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 288 (1994). Mr. McAfee died in 1995. *See* Obituaries, *Larry McAfee, 39: Sought Right to Die*, N.Y. TIMES, Oct. 5, 1995, *available at* http://www.nytimes.com/1995/10/05/obituaries/larry-mcafee-39-sought-right-to-die.html?pagewanted=1.

[4] *See Olmstead*, 527 U.S. 581 (1999).

and nursing homes—worked from home using his specialized computer, visited friends and family in his van, and described himself as living a "good" life that gave him "hope."[5]

Medicaid is the primary payer for community-based care and support.[6] While most home care is provided unpaid by friends and families, some people need more or different support than friends and families can provide while others do not have family or friends upon whom to rely.[7] Typical private insurance does not cover long-term care—either in the community or in an institution.[8] Medicare only provides limited post-acute long-term care through its home health and skilled nursing home benefit.[9] For many people, like Lois Curtis and Larry McAfee, Medicaid is the only source of funding for community-based services.

But Medicaid has a well-known institutional bias that steers people with long-term care needs into nursing homes.[10] State Medicaid programs must cover nursing home care while most home and community-based services are optional.[11] Qualifying for Medicaid home and community-based services can often be, at best, a battle

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[5] SHAPIRO, *supra* note 3, at 288.

[6] *Filling in the Long-Term Care Gaps: Testimony of Diane Rowland, Sc.D., Executive Vice President, Henry J. Kaiser Family Foundation, Hearing on "Role of Private Insurance in Long-Term Care" Before the S. Spec. Comm. on Aging*, 111th Cong. (2009), *available at* http://aging.senate.gov/events/hr210dr.pdf [hereinafter Rowland Testimony]; KAISER COMM'N ON MEDICAID FACTS, KAISER FAMILY FOUND., MEDICAID AND LONG-TERM CARE SERVICES AND SUPPORTS (2009), *available at* http://www.kff.org/medicaid/upload/2186_06.pdf [hereinafter KFF FACT SHEET]. Medicaid accounts for 40% of all long-term care expenditures compared with 23% for Medicare and 95% for private insurance.

[7] Rowland Testimony, *supra* note 6, at 2 (stating that nearly 80% of those with long-term needs who live in the community have care that is provided by friends and family, and only 8% rely exclusively on paid assistance).

[8] *Id.* However, there is some move to try to create a separate private long-term care insurance industry.

[9] *Id.* at 4.

[10] KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., ADVANCING ACCESS TO MEDICAID HOME AND COMMUNITY-BASED SERVICES: KEY ISSUES BASED ON A WORKING GROUP DISCUSSION WITH MEDICAID EXPERTS (2009), *available at* http://www.kff.org/medicaid/upload/7970.pdf.

[11] 42 U.S.C. § 1396d(a)(xiii)(1) (2006); *see also* KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: DATA UPDATE, at 1 (2009), *available at* http://www.kff.og/medicaid/upload/7720-03.pdf [hereinafter KFF DATA UPDATE].

and, at worst, a long wait list for services.[12] Many, like Larry McAfee, end up with Medicaid but shunted into nursing homes rather than home and community-based services.[13]

This article examines the social and legislative history of Medicaid to understand the forces that created and perpetuate Medicaid's nursing home bias. Part I offers a legislative history of social welfare in America showing how the Social Security Act, with its emphasis on cash pensions and public assistance, was intended to move care from institutions—the old almshouses for the poor—into the community, but instead spurred a new private nursing home industry.[14] Part II describes the demand for long-term care that led Congress to create cooperative federal/state vendor payment programs to pay for medical and remedial care that both encouraged the growth of nursing homes and lead directly to creation of Medicaid.[15]

Part III explains why Medicaid—and not Medicare—funds long-term nursing home care. It is no accident that Medicaid is the largest funder of long-term care in America: Congress intended Medicaid to be the legislative vehicle for funding long-term care—both in the community and in nursing homes. Part III also explains why nursing homes are a mandatory Medicaid service and how Medicaid requirements pushed nursing homes into becoming large, impersonal institutions rather than evolving into more home-like settings conducive to "living in community."[16] It also explains how Medicaid pushed people with disabilities into new forms of nursing homes by authorizing payment for intermediate care facilities (ICF/MRs) and

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[12] *See* GARY A. SMITH, HUMAN SERVICES RESEARCH INST., STATUS REPORT: LITIGATION CONCERNING HOME AND COMMUNITY SERVICES FOR PEOPLE WITH DISABILITIES (2007), *available at* http://www.hsri.org/docs/litigation052307.pdf (listing litigation on behalf of individuals seeking access to Medicaid funded home and community-based services).

[13] Larry McAfee and Lois Curtis only gained access to Medicaid home and community-based services after going to court. Lois Curtis finally obtained community services as a result of the Supreme Court's decision in *Olmstead*. Larry McAfee received community-based services after publicity over this right to die lawsuit prompted Georgia law makers to fund a Medicaid community-based program. Rebecca McCarthy, *McAfee Moving to New Home*, ATLANTA J.-CONST., Aug. 22, 1990, *available at* 1990 WLNR 2073248.

[14] *See* discussion *infra* Part I.

[15] *See* discussion *infra* Part II.

[16] *See* discussion *infra* Part III.

intermediate care facilities for the mentally retarded (ICF/MRs).[17] In sum, Part III describes how Medicaid's institutional bias developed over time.

Part IV turns to an examination of Medicaid's statutory authority to cover home and community-based long-term care. Medicaid's statutory structure has always authorized states to cover an extraordinary range of both medical and social services to help people live in the community.[18] Over the years, Congress has continually expanded the community-based services that states can cover through Medicaid. Medicaid's nursing home bias is not inherent in its statutory structure. Instead, it results from a variety of historical events.

I. FROM POOR LAWS TO SOCIAL SECURITY: FROM ALMSHOUSES TO NURSING HOMES

In colonial and 19th Century America, most care was home care. Medical and nursing care, even surgery, was done at home.[19] A home atmosphere was viewed as the ideal place to be cared for, and in an era before the development of germ theory and modern theories of scientific medicine the home was far safer than institutional care.[20]

Institutions were for the "deserving" poor: public almshouses—also called poorhouses—housed those with disabilities, mental illness, contagious diseases, incurable illnesses and alcoholism alongside children and widows.[21] Rooted in the Elizabethan Poor Laws, this "indoor relief" was the only form of public welfare. Poverty, disability, and illness were viewed as moral failings and almshouses were meant to reform through order and structure.

Almshouses were also intended to protect society from the corrupting influence of the poor and feeble.[22] Admission was

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[17] *See* discussion *infra* Part III.

[18] *See* discussion *infra* Part IV.

[19] CHARLES ROSENBERG, THE CARE OF STRANGERS: THE RISE OF AMERICA'S HOSPITAL SYSTEM (1987); PAUL STARR, SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 35–37 (1982).

[20] ROSENBERG, *supra* note 19, at 21.

[21] *See, e.g., id.* at 17.

[22] *Id.*

provided grudgingly for fear it would foster dependence and laziness, and almshouses were typically undesirable places where only those who had nowhere else to go sought help. Administered and financed by towns and counties, aid tended to be ad hoc, decentralized and often erratic.[23]

By the early 20th Century, a variety of new, less unsavory institutions evolved to care for many of those who had depended on almshouses. Voluntary private and public hospitals began to care for, and even cure, those with shorter-term illnesses.[24] Mental asylums supposedly offered new medical cures for mental illness.[25] Special residential schools began to care for and educate children and adults who were blind and deaf.[26] Orphanages were established for children.[27] Left behind in the county and municipal almshouses were the feeble elderly, chronically ill, physically disabled, and those with mental retardation.[28]

The Great Depression of the 1930s overwhelmed the almshouse system: the tidal wave of human need was too great for the patchwork system of local institutions to absorb.[29] The economic dislocations of the depression also softened social attitudes towards the poor as muck racking news reports exposed the harsh conditions in the almshouses. As the depression deepened, public support grew to close the almshouses and replace old-style "indoor relief" with new-style "outdoor relief," cash payments to people to support themselves in the community.

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[23] ROBERT STEVENS & ROSEMARY STEVENS, WELFARE MEDICINE IN AMERICA: A CASE STUDY OF MEDICAID 5 (1974).

[24] ROSENBERG, *supra* note 19; STARR, *supra* note 19, at 147–54. Churches founded voluntary hospitals to care for their own poor and cities began to support public hospitals. Voluntary private hospitals served respectable travelers and the morally worthy poor with treatable conditions. *Id.*

[25] DAVID J. ROTHMAN, THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC 130–54 (1971). Modern readers might question this description of institutions for the mentally ill as "not unsavory" but social reformers like Dorothea Dix advocated for creation of such special institutions for their care and treatment. *See* DAVID BARTON SMITH, REINVENTING CARE, ASSISTED LIVING IN NEW YORK CITY 39 (2003).

[26] SMITH, *supra* note 25, at 40.

[27] ROTHMAN, *supra* note 25, 206–236.

[28] BRUCE VLADECK, UNLOVING CARE: THE NURSING HOME TRAGEDY 33 (1980).

[29] SMITH, *supra* note 25, at 43.

The Social Security Act of 1935 embodied this new approach to American social welfare, creating cash benefit programs to provide the elderly and needy with the money to support themselves at home rather than in institutions. The Social Security Act created three types of cash benefit programs: the federal contributory work-related social security system, a mandatory federal/state contributory unemployment system, and a series of cooperative federal/state means-tested public assistance programs for the "worthy poor"—Old Age Assistance (OAA), Aid to the Blind (AB), and Aid to Dependent Children (ADC).[30]

The Social Security Act was an epochal event in American social welfare. It reflected a belief that public assistance recipients should, and could, be trusted to spend their benefits as they saw fit and that use of "in-kind" benefits was unnecessary, demeaning, and stigmatizing.[31] The disabled would continue to be cared for through "indoor relief" in a variety of institutions including mental asylums, tuberculosis sanitariums, public hospitals, and schools for the deaf.

The Social Security Act also created a legal framework for cooperative federal/state programs that has become the model for many American social welfare programs including Medicaid—state designed and state administered programs jointly funded by the federal and state government.[32] State participation is voluntary, but states that choose to participate must operate under a "state plan" approved by the federal government to receive federal financial assistance to offset the costs of the program.[33] Programs must operate uniformly statewide and under state supervision, moving responsibility for the poor from the local to the state level in an attempt to assure a more consistent safety net than that provided by the old local almshouses.

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[30] Social Security Act, ch. 531, 49 Stat. 620 (1935). Title I is Old Age Assistance, Title III is Unemployment Compensation, Title IV is Aid to Dependent Children, and Title X is Aid to the Blind.

[31] VLADECK, *supra* note 28, at 36.

[32] *See* Social Security Act, 49 Stat. 620, 620–48 (1935) (OAA); *id.* at 627 (ADC); *id.* at 645 (AB). The structure for the three cooperative federal/state programs was identical.

[33] *Id.*

In cooperative federal/state programs, federal law sets minimum requirements, but states retain great discretion. The first cooperative federal/state programs, OAA, AB, and ADC, specified very few federal requirements. States were free to decide which of the three public assistance programs to offer and could set eligibility and payment levels as they saw fit.[34] As a result, the new SSA public assistance programs offered more uniformity within states, but varied dramatically from state to state.[35]

However, two federal law requirements shaped both the original cooperative federal/state public assistance programs and future programs, particularly Medicaid. First, federal law placed a ceiling on federal matching funds, but no floor.[36] For example, the Social Security Act provided for a fifty percent match on monthly payments of up to thirty dollars for OAA recipients.[37] States were free to use their own funds if they wished to spend more, but they had no federal financial incentive to do so. They were also free to spend as little as they wanted.[38]

Second, federal law specifically provided that states could not claim federal matching funds for assistance to "an inmate of a public institution."[39] The new cooperative federal/state programs could not be used to support local government almshouses. Responsibility for aid to the poor had shifted from the local level to federal and state governments. Just as importantly, assistance was to be provided via cash benefits to support living at home, not in public institutions.

However, studies had shown that most of the aged and infirm in almshouses were physically or mentally unable to care for themselves.[40] To compound the problem, the Social Security Act

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[34] *Id.*; *see also* STEVENS & STEVENS, *supra* note 23, at 12.

[35] STEVENS & STEVENS, *supra* note 23, at 12.

[36] Social Security Act, 49 Stat. at 621 (OAA); *id.* at 628 (ABD); *id.* at 646 (AB).

[37] Social Security Act, 49 Stat. at 621 (OAA). The upper limit was the same for Aid to the Blind. *Id.* at 646. The maximum for ADC was $18 for the first child and $12 for any additional. *Id.* at 628.

[38] VLADECK, *supra* note 28, at 36.

[39] Social Security Act, 49 Stat. at 621 (OAA); *id.* at 646 (Aid to the Blind); *id.* at 631 (providing that Aid to Children could only be paid to children residing in a "place of residence" maintained by a caretaker relative).

[40] SMITH, *supra* note 25, at 40–41.

contained no provision for publicly funded health insurance.[41] It quickly became apparent that many of the frail elderly needed more care and support than could be provided at home, and new private institutions stepped in to fill the void.

Soon there was a boom in proprietary "rest homes" and "convalescent homes" for the elderly.[42] Since colonial times the elderly had been "boarded out" for a fee in private households and the new OAA payments fueled demand for boarding homes. Social workers barred from placing the least competent and most needy elderly clients in public institutions turned to private ones. Moreover, many OAA recipients who had taken care of themselves or had been cared for by families opted to use their new purchasing power to pay for institutional care.[43] By the time of World War II, the seeds of a new nursing home industry had sprouted.[44]

Following World War II, the aged who were physically and mentally able to live at home used their pensions and OAA checks to do so, and those in boarding homes became older, sicker and frailer. Boarding homes responded by offering more nursing and personal care, transforming themselves into a new for profit nursing home industry.[45] By the early 1950s, old age pensions and OAA cash grants—which were intended to provide support for the elderly to live at home—had created the American nursing home industry.[46]

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[41] *See* Social Security Act, 49 Stat. at 631; STARR, *supra* note 19, at 270–80. The Act did give states funds on a matching basis for maternal and infant care, rehabilitation of crippled children, and general public health work.

[42] VLADECK, *supra* note 28, at 37–38. "In the first few years after passage of the SSA, the new pensions and public assistance payments had little impact on the number of elderly residing in almshouses because of the lack of availability of private sources of institutional care." *Id.* at 37. While New York and a few other states actively moved their almshouse residents into private boarding homes, most states took a more passive role and just let the almshouse system wither away as residents slowly aged and died. SMITH, *supra* note 25, at 43.

[43] VLADECK, *supra* note 28, at 37.

[44] *Id.* at 39.

[45] *Id.*

[46] *Id.* at 36–39; *see also* COMMITTEE ON NURSING HOME REGULATION, INSTITUTE OF MEDICINE (IOM), IMPROVING THE QUALITY OF CARE IN NURSING HOMES 239 (1986) [hereinafter IOM].

II. THE GROWING DEMAND FOR LONG-TERM CARE: THE COOPERATIVE FEDERAL/STATE FUNDING MODEL EVOLVES

In the decade leading up to 1965 and the passage of Medicaid, cooperative federal/state payments fueled the growth in nursing homes. In 1954, the nation had two hundred and sixty thousand nursing home beds.[47] By 1965, the number had almost doubled, reaching approximately half a million.[48] Through the decade, cooperative federal/state funds were the primary source of funding, paying for just over half of the nursing home residents in 1954 and rising to sixty percent in 1965.[49] By 1965, cooperative federal-state payments to nursing homes totaled four hundred and forty-nine million dollars.[50] A series of Social Security Act amendments—in 1950, 1956, and 1960—boosted cooperative federal state funding for nursing homes by expanding eligibility and authorizing states to make vendor payments to nursing homes. These amendments set the stage for Medicaid to become the nation's public funder of long-term care.

The 1950 Amendments to the Social Security Act added another cooperative federal/state public assistance program for the "permanently and totally disabled" (APTD) similar to OAA for the aged and AB for the blind.[51] The new APTD program resulted in a sudden shift of people with disabilities from municipal hospitals and almshouses to private nursing homes, as local governments used the new cooperative federal/state program to shift costs to the federal and state governments.[52]

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[47] VLADECK, *supra* note 28, at 43. The first national survey of nursing homes reported 9,000 "nursing homes" and "personal care homes with skilled nursing" with 260,000 beds. *See also* IOM, *supra* note 46, at 238 (Ninety-six percent were privately owned and 86% were for-profit businesses).

[48] IOM, *supra* note 46, at 247. The number of nursing homes did not increase dramatically, but the existing facilities added beds. VLADECK, *supra* note 28, at 45.

[49] IOM, *supra* note 46, at 239.

[50] STEVENS & STEVENS, *supra* note 23, at 34.

[51] Social Security Act Amendments of 1950, ch. 809, 64 Stat. 477, 555. The amendments also added a provision to adding coverage for a needy caretaker relative to the Aid to Dependent Children Program (ADC), transforming that program into Aid to Families and Dependent Children (AFDC). *Id.* at 551.

[52] SMITH, *supra* note 25, at 47.

The 1950 amendments also contained three other provisions that would became mainstays of cooperative federal/state funding and that had a direct impact on the growth of nursing homes. First, the amendments authorized cooperative federal/state public assistance payments to residents of public "medical facilities" while retaining the prohibition on federal matching funds to an "inmate in a public institution."[53] Congress hoped that counties and municipalities would convert their remaining almshouses into public facilities providing medical care along with custodial services, thus addressing both a perceived need for more nursing home beds and growing dissatisfaction with private nursing homes.[54] Federal law continued to prohibit the use of federal matching funds for those in institutions for mental disease, whether public or private institutions, to prevent states from shifting the costs of state mental hospitals to cooperative federal/state funding.[55]

Second, the 1950 amendments authorized states to use public assistance funds to pay medical and nursing home providers directly as well as issuing public assistance checks to recipients: this created the first government "medical assistance" for public assistance recipients.[56] The 1950 amendments gave states the option of paying part of the recipient's public assistance check directly to the nursing home or other provider.[57] The 1956 amendments also authorized states to create separate "categorical medical vendor programs" for whichever categories of public assistance they wished—aged, blind, permanently and totally disabled, or families with dependent children.[58]

Congress gave states explicit authority to use cooperative federal/state dollars to cover nursing home care and other types of long-term care and support services. The 1950 amendments

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[53] Social Security Act Amendments of 1950, 64 Stat. at 549 (OAA); *id.* at 554 (AB); *id.* at 557 (APTD).

[54] VLADECK, *supra* note 28, at 40.

[55] Social Security Act Amendments of 1950, 64 Stat. at 549 (OAA); *id.* at 557 (APTD); *id.* at 554 (AB). The prohibition also applied to tuberculosis institutions.

[56] *See id.* at 549 (OAA); *id.* at 557 (APTD); *id.* at 551 (AFDC); *id.* at 554 (AB).

[57] *Id.* at 549 (OAA); *id.* at 554 (AB); *id.* at 556 (APTD).

[58] Act of Aug. 1, 1956, ch. 836, 70 Stat. 807, 846.

authorized states to cover both "medical care" and "any type of remedial care recognize under State law."[59] The categorical medical vendor program was to "help needy families and individuals attain the maximum economic and personal independence of which they are capable."[60] While the long-simmering debate over national health insurance was stalled, Congress began to transform the cooperative federal/state public assistance programs into government funding for long-term care for the needy.[61] While the Social Security Act of 1935 was intended to end almshouse care, it was evolving into a funding mechanism for the successor to the almshouses, nursing homes.

Third, the 1950 amendments provided that states making medical vendor payments to residents of medical facilities had to establish a program to license institutional providers, including nursing homes.[62] Most states had no nursing home licensing prior to 1950, but within a few years most did. While state licensing requirements varied dramatically, most were weak and many went totally unenforced. Over the years, state licensing laws began pushing nursing homes toward a mini-hospital model making them larger, more institutional, and less home like.[63]

However, even as Congress expanded states' ability to use federal matching funds to pay for nursing home care, caps on federal matching funds resulted in inadequate state payment rates contributing to poor conditions in nursing homes.[64] At the time of the 1950 amendments, the maximum federal contribution for each APTD, OAA or AB recipient was thirty dollars of the first fifty

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[59] Social Security Act Amendments of 1950, 64 Stat. at 549 (OAA); *id.* at 551 (AFDC); *id.* at 554 (ATB); *id.* at 557 (APTD).

[60] Act of Aug. 1, 1956, 70 Stat. at 848–50. The purpose of the program was also "to strengthen family life" and "promote the health of the nation."

[61] JONATHAN ENGLE, POOR PEOPLE'S MEDICINE, MEDICAID AND AMERICAN CHARITY CARE SINCE 1965, at 48 (2006). For a discussion of the politics surrounding the health reform in the 1940s and 1950s, see STARR, *supra* note 19, at 270–86. Another 1950 amendment also authorized payments to beneficiaries in public institutions. IOM, *supra* note 46, at 238. In 1954, Congress authorized federal Hill Burton grants to public and private entities to construct nursing homes. IOM, *supra* note 46, at 239.

[62] Social Security Act Amendments of 1950, 64 Stat. at 548 (OAA); *id.* at 553 (ATB); *id.* at 556 (APTD). The provision also applied to public assistance payments made to residents of medical facilities.

[63] VLADECK, *supra* note 28, at 41–44.

[64] *Id.* at 45–46.

dollars paid by the state for cash assistance and medical vendor payments combined.[65] The 1956 amendments creating the categorical medical vendor programs authorized a separate federal cap, but they were also extraordinarily low, the maximum federal match was only six dollars per adult or three dollars per child.[66]

The cooperative federal/state framework left states with great discretion, and support for long-term care varied tremendously from state to state.[67] Ten states had no categorical medical vendor payment program at all,[68] while two states—New York and Massachusetts—accounted for over half of all vendor payments for nursing home care.[69] In many states, low eligibility levels for public assistance excluded many needy aged and disabled residents from nursing home vendor payments.[70]

The 1960 amendments to the Social Security Act dramatically increased both eligibility and funding for nursing home care. The Kerr-Mills Act, officially titled Medical Assistance for the Aged (MMA), was an effort to stave off attempts to enact universal health insurance for elderly.[71] Modeled on the 1956 categorical medical vendor programs, Kerr-Mills contained a number of new federal law provisions crafted in response to perceived deficiencies in both the cash assistance medical vendor program and the categorical programs.[72] Kerr-Mills sought both to entice poorer states to

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[65] Social Security Act Amendments of 1950, 64 Stat. at 548 (OAA); *id.* at 553 (ATB); *id.* at 556 (APTD); STEVENS & STEVENS, *supra* note 23, at 32. AFDC ceilings were even lower: $16.50 of the first $27 a month spent on the first child, with a similar percentage but a lesser amount for each additional child. 64 Stat. at 550 (AFDC).

[66] Act of Aug. 1, 1956, ch. 836, 70 Stat. 807, 846 (six dollars per OAA, APTD, and AB recipient, and three dollars per child and six dollars per adult ADC recipient). Instead of being a monthly upper limit on payments for which a federal match could be claimed, the Medical Care program upper limit used a formula that was multiplied by the total number of recipients.

[67] STEVENS & STEVENS, *supra* note 23, at 26. Many states imposed arbitrary limits on services. Missouri covered hospital care but only for emergencies or acute serious illness, and payment was limited to 14 days per admission. Nursing home care was covered, but reimbursement was limited to $65 per month or $100 per month if the patient was completely bedridden.

[68] VLADECK, *supra* note 28, at 45.

[69] *Id.*

[70] *Id.*

[71] Act of Sept. 13, 1960, Pub. L. No. 86-778, 74 Stat. 924, 987; STEVENS & STEVENS, *supra* note 23, at 26; VLADECK, *supra* note 28, at 46.

[72] STEVENS & STEVENS, *supra* note 23, at 26; VLADECK, *supra* note 28, at 46.

participate and to set more federal minimum standards upon state participation. It also put into place statutory language that would define Medicaid's role as funder of long-term care, as well as Medicaid's nursing home bias.

First, Kerr-Mills gave states authority to provide medical vendor payments not only for OAA public assistance recipients but also on behalf of the "medically needy," elderly individuals whose income was above state public assistance eligibility levels but insufficient to meet their medical bills.[73] This provision was particularly important for those elderly who had Social Security pensions too high to qualify for OAA but too low to cover the costs of nursing home care.

Second, Kerr-Mills placed no ceiling on federal matching funds and created a federal matching formula that favored poorer states.[74] Unlike prior cooperative federal/state programs that capped the amount of federal funding, Kerr-Mills provided that states were entitled to a federal match for all costs paid under an approved state plan.[75] States were guaranteed a minimum federal match of fifty percent and as much as eighty percent of their costs, depending upon the state's per capita income.[76]

Third, Kerr-Mills required states to cover both "some institutional and some non-institutional care and services."[77] States were not required to cover nursing home or other long-term care, but Kerr-Mills contained the first statutory definition of "medical assistance" specifying the categories of services that state could cover. "Medical assistance" explicitly included both nursing home and community-based long-term care, through a statutory list that included, among other things, "skilled nursing-home services," "home health," "private duty nursing," "physical therapy and related services," "prosthetic devices," and an incredibly broad catch-all category "any

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[73] Act of Sept. 13, 1960, 74 Stat. at 987; STEVENS & STEVENS, *supra* note 23, at 29.

[74] Act of Sept. 13, 1960, 74 Stat. at 987, 990–92.

[75] *Id.*

[76] *Id.*

[77] *Id.* at 987, 988. Kerr-Mills continued to support patients in any institution for TB or mental diseases. *Id.* at 991. The prohibition on federal support to institutionalize those with TB or mental illness was extended to forbid payments on behalf of individuals with a diagnosis of TB or psychosis in a medical institution for longer than 42 days. *Id.*

other medical care or remedial care recognized under State law."[78] States retained discretion to define the various categories of medical assistance and set licensing standards. In particular, "skilled nursing home services" was left undefined leaving out a relatively strict, medically-oriented definition that had appeared in the House version of the bill but dropped in conference committee.[79]

Kerr-Mills authorized states to create far more comprehensive medical and long-term care programs for the needy aged than the universal health insurance for the aged bills then being considered by Congress.[80] Kerr-Mills's purpose—like that of 1950 and 1956 medical vendor programs—was to help "individuals attain self-care" not just to pay for acute care medical treatment.[81] Kerr-Mills was not just a health insurance program; it was a public assistance program, steeped in the tradition of the Social Security Act, aiming to provide the worthy elderly poor with support to live in the community as well as nursing homes.

But as a comprehensive medical assistance program for the country's needy aged, it became evident that "Kerr-Mills was a flop."[82] Nine states failed to adopt the program, and Georgia and Mississippi only had programs on paper, never appropriating any state money to support their programs. Only five states had comprehensive Kerr-Mills programs—New York, California, Massachusetts, Minnesota and Pennsylvania—and they received sixty-two percent of federal Kerr-Mills funds even though they had only thirty-one percent of the nation's elderly and the lowest rate of federal match.[83] Kerr-Mills failed in its effort to entice more states to set up medical assistance programs. Most of the growth in Kerr-Mills was the result of wealthy states moving services once paid for through the medical vendor programs to the more advantageous Kerr-

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[78] *Id.* at 991. States could also cover inpatient hospital services, physicians' services, outpatient hospital or clinic services, dental services, laboratory and x-ray services, prescribed drugs, eyeglasses, dentures, and diagnostic, screening and preventive services.

[79] VLADECK, *supra* note 28, at 46.

[80] *See* ENGLE, *supra* note 61, at 30–34.

[81] Act of Sept. 13, 1960, 74 Stat. at 987.

[82] VLADECK, *supra* note 28, at 46.

[83] STEVENS & STEVENS, *supra* note 23, at 31–34.

Mills. Poor states remained unconvinced that they could afford Kerr-Mills, even with an eighty percent federal match.[84]

However, Kerr-Mills had a dramatic impact on nursing home care in the states where it operated. By 1965, Kerr-Mills was supporting half of all nursing home residents and one–third of Kerr-Mills expenditures were going to nursing homes.[85] Between 1960 and 1965, boosted by Kerr-Mills, federal/state vendor payments to nursing home increased ten fold, from $47 million to $449 million.[86]

Historians do not quite understand why Kerr-Mills had such a dramatic impact on the nursing home industry and so little impact on other types of care, but Bruce Vladeck has hazarded some theories. First, it is likely that proprietary nursing homes—for profit ventures with no history of charity care—were more aggressive than other providers in seeking Kerr-Mills reimbursement. State payments under Kerr-Mills were typically low compared to prevailing charges and many physicians and even hospitals continued to provide free services rather than engage in the paperwork involved in trying to claim Kerr-Mills payments.[87]

Second, nursing home placement provided welfare and hospital social workers with an easy solution for any number of problems—social isolation, mental illness, even chronic disease. Elderly public assistance recipients who were hospitalized but not sick enough to need on-going hospital care could be discharged to nursing homes and the cost charged to Kerr-Mills. Admission to the hospital increasingly meant discharge to a nursing home. With few other options available, there seemed to be a huge demand for nursing home care and a terrible "shortage" of nursing home beds.[88]

Third, by giving states the option to cover "medically needy" elderly, Kerr-Mills created a spend-down effect. When eligibility for government assistance is tied to the amount of medical bills relative to income, many individuals qualify only when they encounter large

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[84] *Id.* at 33.

[85] VLADECK, *supra* note 28, at 47.

[86] STEVENS & STEVENS, *supra* note 23, at 34.

[87] VLADECK, *supra* note 28, at 47.

[88] *Id.*

medical expenses. The monthly costs of nursing home care were one of the most expensive types of care used by the elderly and the costs involved in a typical two-year nursing home stay were likely to exhaust the resources of all but the most affluent. "Medically needy" eligibility thus greatly widened the pool of elderly who could qualify for Kerr-Mills nursing home payment.[89]

What is undisputed is that Kerr-Mills and the other cooperative federal-state medical vendor programs were the primary source of funding for nursing home care. In 1954, cooperative federal/state funds paid for just over half of all nursing home residents. By 1965, their share had risen to sixty percent.

By 1965 and the coming of Medicaid and Medicare, nursing homes had replaced almshouses as institutions for the needy frail elderly and those with disabilities.[90] Nursing homes were places where most people were admitted because of poverty or, if they lived long enough, they became poor. State-set payment rates remained low, and while conditions may not have been quite as bad as the old almshouses, "[m]ost facilities were substandard, had poorly trained or untrained staff, and provided few services."[91] Most people view them as dreaded forms of imprisonment rather than a place of refuge.[92]

III. MEDICAID AND NURSING HOMES

Kerr-Mills fueled the growth of nursing homes, but Medicaid threw accelerant on the fire. In 1965, cooperative federal and state vendor payments to nursing homes totaled $449 million; by 1967 the figure had increased over six-fold with Medicaid payments of $3.5 billion.[93] Medicaid, like Kerr-Mills before it, funded nearly half of all nursing home patients and over forty percent of all nursing home costs.[94] Nursing home bed capacity more than doubled from 1963 to

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[89] *Id.* at 48.

[90] SMITH, *supra* note 25, at 42.

[91] IOM, *supra* note 46, at 242.

[92] SMITH, *supra* note 25, at 42.

[93] VLADECK, *supra* note 28, at 47, 69.

[94] ENGLE, *supra* note 61, at 128.

1973, expanding to 1,174,900 and exceeding the number of hospital beds.[95] While the coming of Medicaid increased the number of elderly living in nursing homes by forty percent, it had an even more profound effect on people with developmental disabilities: between 1960 and 1975, the number of people with developmental disabilities living in nursing homes increased by over 600%.[96]

In 1965, after fifteen years of debate and deliberation, Congress finally enacted Medicare and Medicaid. Just as the Social Security Act of 1935 created three types of cash benefit programs, the equally epochal Social Security amendments of 1965 created two types of government support for medical care: Medicare, a contributory health insurance program for the elderly, and Medicaid, a cooperative federal/state medical assistance program for the "worthy poor"—public assistance recipients and the medically needy.[97] After 15 years of deadlock between proponents of a social insurance approach to funding health care and those who favored a means-tested public assistance model, Wilbur Mills, one of the authors of Kerr-Mills and the powerful chairman of the House Ways and Means Committee, brought the two camps together by including both approaches in one bill.[98]

Described as both strange alchemy and politically brilliant, combining Medicare and Medicaid in one bill meant not only marrying two approaches to social welfare—universal coverage and means-testing—it also meant marrying two quite different philosophies of the role of government funding for medical care.[99] Medicare was meant to be "health insurance."[100] Like the private health insurance offered to working-age Americans at the time, Medicare offered financial protection in times of serious illness for acute care hospital and physician care and related services. In contrast, Medicaid was rooted in the Social Security Act's

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[95] SMITH, *supra* note 25, at 50.

[96] ENGLE, *supra* note 61, at 128.

[97] *See* Act of July 30, 1965, Pub. L. No. 89-97, 79 Stat. 286.

[98] STEVENS & STEVENS, *supra* note 23, at 46–48.

[99] *Id.* at 53.

[100] Act of July 30, 1965, 79 Stat. 286. Medicare is titled "Health Insurance for the Aged."

commitment to provide public support for the needy so they could live in the community. Medicaid's purpose was to provide both "medical assistance" and "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care."[101] Medicaid would provide government funding for social support services and long-term care as well as hospital and physician care.[102] It would fund both nursing home care and community based care.

Medicaid was the successor to Kerr-Mills; it was intended to expand, improve and replace Kerr-Mills and the 1956 categorical medical vendor programs.[103] It was also an incremental fix intended to offer more comprehensive medical and support services to all public assistance recipients and others of the worthy poor whom states deemed medically needy.

Medicaid built on the statutory framework of the prior cooperative federal/state medical vendor programs but finally succeeded, through a combination of financial carrots and sticks, in enticing all the states—even the poorest—into the new program.[104] States still had to contribute a share of the costs, but as with Kerr-Mills, the federal Medicaid match was opened ended, more favorable to poorer states, and even higher than Kerr-Mills, ranging from a minimum of fifty-five percent up to eighty-three percent.[105] The legislation enticed states to join by providing those that opted into Medicaid a favorable Medicaid federal match for their cash public assistance programs as

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[101] *Id.* at 346. Though the 1965 Social Security Act amendments titled Medicare as "Health Insurance," Medicaid was "Grants to States for Medical Assistance." *Id.* at 291, 343.

[102] These different purposes were reflected in the different administrative agencies that initially administered the two programs. Medicare, as insurance-based, was administered by a new Bureau of Health Insurance in the Social Security Administration. Medicaid was allocated to the Bureau of Family Services of the Welfare Administration. The bureau's Division of Medical Services had been responsible for Ker-Mills and retained responsibility for the new Medicaid program. VLADECK, *supra* note 28, at 52–53.

[103] The Senate Report on the new Medicaid program was entitled "Improvement and Extension of Kerr-Mills Medical Assistance Program." *See* STEVENS & STEVENS, *supra* note 23, at 51.

[104] STEVENS & STEVENS, *supra* note 23, at 61. By January 1, 1970, only Alaska and Arizona opted not to participate figuring that it was not in their financial best interest to use state dollars to help fund medical assistance when their needy residents were primarily Native Americans and Eskimos, groups already under the federal government's medical assistance program. However, Alaska opted into Medicaid in 1972. Arizona finally joined in 1982.

[105] Act of July 30, 1965, 79 Stat. at 351.

well.[106] Moreover, states had to opt into Medicaid if they wanted to continue to take advantage of federal matching assistance because the medical vendor programs and Kerr-Mills ended December 31, 1969.[107]

Medicaid expanded eligibility by requiring that states cover all public assistance recipients—those who received ABTD, AB and AFDC as well as OAA.[108] States were no longer able to pick and choose among groups receiving assistance, favoring the elderly or blind over people with disabilities or families with children. Moreover, Medicaid guaranteed that people with disabilities who qualified for state APTD and AB programs that were federalized in 1972 as Supplemental Security Income (SSI) had access to Medicaid.[109]

Medicaid also gave states the option to cover other aged, disabled, blind and dependent families with children who had incomes above state public assistance levels but whom the state deemed to be to be "medically needy."[110] Giving states the option to cover the medically needy allowed states to create more generous medical assistance programs without expanding public assistance eligibility. It also opened the door for increased institutionalization of people with disabilities in nursing homes as they could qualify as medically needy when the cost of nursing home care was compared to their income.

Because Medicaid was the successor to Kerr-Mills, it had to cover nursing home care. Congress could not wipe out public funding for

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[106] STEVENS & STEVENS, *supra* note 23, at 60–61.

[107] *Id.* States were also guaranteed a federal match equal to at least 105 percent of federal funds received for Kerr-Mills and other medical vendor programs in 1965. To force states to use the Medicaid dollars to expand services rather than merely supplant expenditures, as had happened extensively with Kerr-Mills, states were required to maintain their existing "state effort," meaning they had to contribute at least as much money to Medicaid as they did to Kerr-Mills and the other medical vendor programs.

[107] Act of July 30, 1965, 79 Stat. at 351.

[108] *Id.* at 349, 351. States were also required to cover those who would be eligible for public assistance programs were it not for a state provision prohibited by Medicaid, i.e. a durational resident requirement, age requirement higher than age 65, or age requirement excluding those 18–21 from eligibility for AFDC.

[109] However, the federal law link to public assistance excluded from Medicaid all those who did not fit the old categories of the "worthy poor"—excluding from Medicaid many people with disabilities who could not meet the stringent standards for "permanent and total disability" by SSI. Medicaid was born as a public assistance program tied to old concepts of "worthy poor."

[110] *See* Act of July 30, 1965, 79 Stat. at 351.

the half a million nursing home residents being supported by Kerr-Mills. State Medicaid programs were required to cover "skilled nursing home services," for adult public assistance recipients, and had the option of covering nursing home care for the medically needy, thus grandfathering in nursing home eligibility for the elderly who had been supported by Kerr-Mills.[111] As enacted in 1965, Medicaid provided no statutory definition of "skilled nursing home services."[112] Instead, the federal government initially allowed states to use lax state standards assuring that nursing homes that had received support from Kerr-Mills could continue to be part of the new Medicaid program.[113]

At the same time, advocates of Medicare were careful to exclude long-term nursing home care from its coverage.[114] Wilbur Cohen, President Johnson's chief strategist on the Medicare bill, was concerned that nursing home coverage would open up a bottomless pit of demand that would destroy the delicate political budgetary balance needed to support Medicare through mandatory payroll deductions.[115] Cohen was also well aware that nursing home care tended to be more custodial than medical. Medicare was to be health insurance for medical needs, not a program of social support services.[116] But Cohen and others also thought that a limited post-hospital convalescent and rehabilitative care benefit could save Medicare money on hospital costs, so Medicare, as enacted in 1965, covered up to 100 days of "post-hospital extended-care."[117] Cohen invented the statutory phrase "extended-care" to indicate that Medicare would only pay for medically intensive and rehabilitative care, not the primarily custodial "skilled nursing home" care provided by nursing homes that had been paid for by Kerr-Mills and the

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[111] *Id.*

[112] *Id.*

[113] VLADECK, *supra* note 28, at 59.

[114] *Id.* at 48–49.

[115] *Id.* at 49.

[116] Act of July 30, 1965, 79 Stat. at 291 (titling Medicare as "Health Insurance for the Aged"); *see also* STEVENS & STEVENS, *supra* note 23, at 53.

[117] Act of July 30, 1965, 79 Stat. at 292; VLADECK, *supra* note 28, at 49.

medical vendor programs and would be absorbed into Medicaid.[118] However, the Medicare "extended care" program immediately encountered problems because few nursing homes could offer that level of medical and rehabilitative services.[119]

At the time of passage of Medicaid and Medicare, no one really considered how the two new programs would fit together, but over the next decade Medicare pushed Medicaid toward a more medical model of nursing home care and both programs, concerned about the poor quality of care, pushed nursing homes to became larger and more institutional.[120] Horror stories about poor conditions in Medicaid-funded nursing homes prompted Congress to amend Medicaid in 1967, just two years after its enactment, to add a federal statutory definition of "skilled nursing facility" (SNF) that required, among other things, 24 hour nursing services, supervision by a full-time registered nurse, and building code requirements.[121] In 1972, Medicare dropped its "extended-care" coverage and both programs began paying for SNFs with Medicare paying for post-hospital, short-term rehabilitative stays and Medicaid paying for long-term care.[122]

Many of the older, smaller mom and pop homes could not meet the stricter building code standards imposed by the new unified Medicare and Medicaid regulations. Instead, the new regulations spurred a building boom of larger, more institutional, hospital-like nursing homes. The greater standardization and predictability created by federal regulation of nursing homes also produced the potential for economies of scale that had not been possible before and national nursing home chains began to emerge.[123]

More generous cost-based reimbursement also prompted both an increase in new for profit nursing home beds. From the beginning,

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[118] VLADECK, *supra* note 28, at 49.

[119] Cohen and Congress hoped that Medicare's coverage of "extended-care" would entice the hospital and nursing home industries to provide new, more medically intensive services. *Id.* at 50. For a discussion on how this theory fared in practice, see *id.* at 52–57.

[120] *Id.* at 58–59; SMITH, *supra* note 25, at 52.

[121] Act of Jan. 2, 1968, Pub. L. No. 90-248, 81 Stat. 821, 906; IOM, *supra* note 46, at 242; VLADECK, *supra* note 28, at 58–59.

[122] VLADECK, *supra* note 28, at 68.

[123] SMITH, *supra* note 25, at 51.

Medicare, concerned that low welfare rates had contributed to poor care, paid nursing homes based upon their "reasonable costs."[124] In 1972, Congress, concerned about on-going problems in nursing home quality and owner complaints about reimbursement rates, passed social security act amendments requiring state Medicaid agencies to also reimburse nursing homes on a "reasonable cost-related basis."[125] In place until 1980, Medicaid cost-based reimbursement for nursing home care both fueled nursing home expansion and helped great a powerful lobby.[126]

At the same time, other Medicaid provisions encouraged states to shift people with mental and developmental disabilities into nursing homes. Medicaid continued the long-standing prohibition on using federal matching funds to support care for adults under age sixty-five in an institution for mental diseases.[127] The IMD exclusion combined with mandatory Medicaid eligibility for APTD/SSI recipients and mandatory coverage of nursing home care for adults created an incentive for states to move those with long-term mental illness and developmental disabilities out of state-funded facilities and into Medicaid-supported nursing homes.

But it was obvious that people with intellectual and developmental disabilities did not need the around-the-clock nursing care required by the Medicaid SNF requirements. In 1971, under pressure from the states and nursing homes, Congress created a lower-level of nursing home coverage requiring just enough medical care to justify being

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[124] Act of July 30, 1965, Pub. L. No. 89-97, 79 Stat. 286, 296; VLADECK, *supra* note 28, at 52.

[125] VLADECK, *supra* note 28, at 68. The amendment was to take effect July 1, 1974.

[126] *See id.* at 68–69. The regulations did not become effective until January 1, 1978. *See* Joshua M. Weiner & David G. Stevenson, *Repeal of the "Boren Amendment": Implications for Quality of Care in Nursing Homes*, URBAN INST., Dec. 1, 1998, at 1, http://www.urban.org/UploadedPDF/anf30.pdf (noting that nursing home cost-based reimbursement was replaced by a different formula in 1980).

[127] Act of July 30, 1965, 79 Stat. at 352. The Act also prohibited funds from being used to support those under age 65 in TB hospitals or for payment for care or services to an "inmate of a public institution." *Id.* at 356. However, for the first time states were given the option to cover persons age 65 or older in mental or tuberculosis institutions. By 1965 Congress had already begun to fund community services for those with mental illness and the Medicaid IMD exclusion was testimony to the burgeoning community care movement in the mental health field as well as Congressional concern that federal funds not supplant state funds. By the time Medicaid was enacted, Congress envisioned the future of mental health treatment as community-based rather than institution-based. Sara Rosenbaum, Joel Teitelbaun & Alexandra Steward, Olmstead v. L.C.: *Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 96 n.12 (2002).

dubbed a "nursing home."[128] These new "intermediate care facilities" (ICFs) and "intermediate care facilities for the mentally retarded" (ICF/MR)[129] were a financial god-send for the states because they were less expensive than SNFs.[130] They also offered older, smaller nursing homes that could not meet the new SNF standards a way to continue to get Medicaid funding. In many states, ICFs and ICF/MRs became the dumping ground where substandard nursing homes that could not meet SNF standards ended up.[131]

By 1975, hundreds of thousands of children and adults who had been housed in state mental institutions were in newly certified, Medicaid financed ICF and ICF/MR "nursing homes."[132] Indeed, while the number of elderly living in nursing homes increased by forty percent between 1960 and 1975, the number of mentally retarded living in nursing homes increased by over 600% during the same time period.[133] By 1980, nearly half of the national's nursing homes were classified as ICFs.[134]

With the advent of Medicaid, national expenditures on nursing home care jumped from $800 million to $4.2 billion during the 1960s, the bulk of the increase coming from state Medicaid funds. Nursing home bed capacity more than doubled from 1963 to 1973, expanding to 1,174,900 beds and exceeding the number of hospital beds.[135] From 1970 to 1976, Medicaid expenditures on nursing home care nearly tripled, continuing the Kerr-Mills tradition of cooperative federal state funding for nearly half of all nursing home patients and over forty percent of all nursing home costs.[136]

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[128] Act of December 28, 1971, Pub. L. No. 92-223, 85 Stat. 802, 809; IOM, *supra* note 46, at 242.

[129] Act of December 28, 1971, 85 Stat. at 809.

[130] VLADECK, *supra* note 28, at 63.

[131] IOM, *supra* note 46, at 242–49.

[132] VLADECK, *supra* note 28, at 63–64.

[133] ENGLE, *supra* note 61, at 128.

[134] VLADECK, *supra* note 28, at 65. In 1987, Congress abolished the distinction between SNFs and ICFs, requiring nursing facilities to provide both skilled and intermediate level of care. GARY SMITH ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 11 (2000), http://aspe.dhhs.gov/daltcp/reports/primer.pdf.

[135] SMITH, *supra* note 25, at 50.

[136] ENGLE, *supra* note 61, at 128.

Medicaid accelerated the growth in the use of nursing homes, which had been under way since the coming of Social Security and OAA benefits. By making nursing home care free for all senior citizens without assets, nearly half of the elderly in 1975, Medicaid provided a powerful incentive to families to institutionalize parents, who might previously have moved in with grown children or sought the part-time care of a home health aide.[137] By offering states a federally funded alternative to state psychiatric hospitals, nursing homes also became the place to institutionalize those with developmental disabilities and long-term mental illness.

IV. MEDICAID AND HOME AND COMMUNITY-BASED SERVICES

Medicaid never funded nursing home care to the exclusion of community care. With roots stretching back to the Social Security Act's commitment to provide public support for the needy so they could live in the community, Medicaid's purpose always included providing "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care."[138] States have always had ample statutory authority to use Medicaid to fund home and community-based services.

The 1965 Medicaid Act gave states the option to cover all the community-based services that had been permitted under Kerr-Mills: home health, private duty nursing, physical therapy and related services, and prosthetic devices.[139] The new Medicaid Act also carried over from Kerr-Mills the incredibly broad catchall optional category "any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State law," giving states authority to cover practically any type of social service, community support, medical or long-term care as long as it was supplied by a state-licensed provider.[140] The original 1965 Act also gave states a new option to cover other

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[137] *Id.*

[138] Act of July 30, 1965, Pub. L. No. 89-97, 79 Stat. 286, 346.

[139] *Id.* at 351–52.

[140] 42 U.S.C. § 1396d(a)(xiii)(6) (2006).

"rehabilitative services," a new broad category that allows states to provide a wide range of supportive services in the community, particularly to people with mental illness.[141]

Moreover, almost immediately, Congress took steps to rebalance the bias inherent in Medicaid's mandatory coverage of nursing home care by making some home and community-based services mandatory. In 1968, Congress made home health services mandatory for adult public assistance recipients and those medically needy recipients for whom states covered nursing home care.[142] This statutory amendment requires states to cover home health care for adults eligible for Medicaid nursing home care.

In 1989, Congress made *all* community-based services mandatory for children when it strengthened the Early Periodic Screening Diagnostic and Treatment (EPSDT) program to require states to cover all medically necessary treatment services for children.[143] The EPSDT mandate makes not only home health benefits a mandatory service for children but also every category of "optional" services for adults including rehabilitative services, physical therapy, and any other home based care that can be covered under any Medicaid category including the broad catchall category "any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State

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[141] Act of July 30, 1965, 79 Stat. at 351. Many states use it to cover psychosocial rehabilitation services, which—when combined with services offered through the personal care and targeted case management options—can meet a wide range of service and support needs for persons who have mental illness. SMITH ET AL., *supra* note 134, at 11.

[142] Act of Jan. 2, 1968, Pub. L. No. 90-248, 81 Stat. 821, 902. The statutory language of this provision has generated confusion. It provides: "home health services for any individual who, under the State plan, is entitled to skilled nursing home services." Because state plan coverage of nursing facility services is mandatory for categorically eligible persons age 21 and older receiving public assistance, home health services are mandatory also. If a state chooses to cover nursing facility care for younger persons, or for the medically needy, home health services become mandatory for these groups as well. 42 C.F.R. § 441.15(b) (2009). The federal regulations defining mandatory home health benefits require states to cover not just nursing and home health aide services but also medical supplies, medical equipment, and appliances suitable for use in the home. For an excellent discussion of the home health benefit, *see* SMITH ET AL., *supra* note 134, at 7.

[143] 42 U.S.C. § 1396a(a)(43), d(r)(5) (1993). ESPDT also requires that states cover four separate, periodic screening services—medical, vision, hearing, and dental screening services—and includes immunizations, lead blood tests, and health education. *See* 113 CONG. REC. 2883 (1967), where President Johnson sums up the goal of the EPSDT program when introducing the legislation.

law."[144] Over the years, as Congress continued to expand the options available to states to cover home and community-based services, the EPSDT mandate made these services mandatory for children.

States have had the option, since the mid-1970s, to cover personal care services.[145] Personal care—sometimes referred to as attendant services—assists individuals with activities of daily (ADL) living like bathing, dressing, eating, toileting and transferring from abode to a chair. Personal care can also assist with activities such as personal hygiene, light house work, laundry, meal preparation, transportation, grocery shopping, using the telephone medication management, and money management, all of which are typically group together and classified as Instrumental Activities of Daily Living (IADLs). For persons with cognitive impairments, personal care can also include "cueing," which involves prompting and supervision to help some perform an activity of daily living or instrumental activity of daily living.[146]

Personal care services are one of the most important social support services that help people live in the community and avoid institutionalization.[147] Medicare does not cover personal care because it is not considered a "medical" treatment. For the same reason, private insurance rarely covers personal care.[148] Only Medicaid, with its roots going back to the Social Security Act's commitment to provide both social as well as medical support for community living, covers personal care for those who need it.

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[144] SMITH ET AL., *supra* note 134, at 11. EPSDT covers the broadest possible array of Medicaid services including personal care and other services that help children stay at home with their families. "For example, Wisconsin covers up to eight weeks of intensive in-home services for children with serious emotional disturbances, including parental skill training in behavior management techniques." *Id.*

[145] SMITH ET AL., *supra* note 134, at 11–12. The personal care option was first established administratively under the Secretary of Health and Human Services' authority to add coverage over and above those spelled out in Section 1905 of the Social Security Act, if such services would further the Act's purposes. In 1993, Congress added "personal care" as a listed optional category, amending the provision in 1994 to make explicit the non-medical nature of personal care by providing that personal care services did not need to be physician ordered or nurse supervised. See 42 U.S.C. § 1396d(24) (2006) and 42 C.F.R. § 440.167 (2009) for the present statutory and regulatory authority.

[146] SMITH ET AL., *supra* note 134, at 11.

[147] KFF DATA UPDATE, *supra* note 11, at 4.

[148] *See* Rowland Testimony, *supra* note 6.

In 1981, Congress created the Section 1915(c) Home and Community-based (HCB) Waiver to allow states to use Medicaid funds to pay for services not otherwise permitted by the Medicaid Act as long as the services are required to keep a person from being institutionalized in a nursing home, ICF, ICF/MR or hospital, and as long as home based services are no more expensive than institutional care.[149] Today, Section 1915(c) HCB Waiver services are, by far, the most important category, accounting for sixty-six percent of community-based care, compared with twenty-two percent for personal care and twelve percent for the mandatory home health benefit.[150]

Section 1915(c) HCB Waivers provide states with incredible flexibility to pay for respite care, adult day care, habilitation and other supportive services like transportation, home modifications, and emergency alert systems that do not fit within other Medicaid categories.[151] While the Medicaid Act, like other cooperative federal/state programs, typically requires that services be available statewide and that all those who are categorically eligible receive the same set of Medicaid services, under Section 1915(c) HCB Waivers states may offer different groups different sets of services, offer services only in certain geographic locations and waive certain federal rules for counting income to allow more individuals to be eligible for Medicaid services.[152] Section 1915(c) HCB Waivers allow states flexibility to design specialized programs to meet the

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[149] Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357; Sandra J. Tanenbaum, *Medicaid Eligibility Policy in the 1980s: Medical Utilitarianism and the "Deserving" Poor*, 20 J. HEALTH POL. POL'Y & L. 933, 941 (1995). Regulations are located at 42 C.F.R. § 440.70(b)(3) (2009).

[150] *See* KFF DATA UPDATE, *supra* note 11. In 2006, Medicaid recipients using home and community-based services were fairly evenly distributed among these three services: 30 percent used home health, 31 percent used personal care, and 39 percent used HCBS Waiver services. *Id.* at 5 fig.4.

[151] In 2006, Congress created a new home and community-based state plan option. Pub. L. No. 109-171, 120 Stat. 4 (2006), *amended by* Tax Relief and Health Care Act of 2006, Pub. L. No. 109-432, 120 Stat. 2922. The state plan option gives states similar authority to cover home and community-based services via a state plan option rather than a waiver. *See* KAREN TRITZ, CRS REPORT FOR CONGRESS, MEDICAID'S HOME AND COMMUNITY-BASED SERVICES STATE PLAN OPTION: SECTION 6086 OF THE DEFICIT REDUCTION ACT OF 2005 (2006).

[152] Jane Perkins & Randy Boyle, *Addressing Long Wait Lists for Home and Community-Based Care Through Medicaid and the ADA*, 45 ST. LOUIS U. L.J. 117, 125 (2001).

specific needs of specific groups—be they adults with development disabilities, people with traumatic brain injuries, or those who are ventilator dependent. However, Section 1915(c) is also the only provision in Medicaid that allows states to place a cap on the number of individuals eligible for services.[153] Just as crucial, Section 11915(c) HCB Waivers cannot be used to cover room and board.[154]

In 1986, Congress created a state option to allow Medicaid to pay for free standing "targeted case management" services to help Medicaid recipients "gain access to needed medical, social, educational and other services."[155] Targeted case management services are a crucial aid in coordinating the variety of services that are often necessary to facilitate living in the community rather than being institutionalized.

Throughout the 1980s, Congress also gave states increasing options to expand Medicaid financial eligibility for adults and children living in the community to offset the nursing bias created by Medicaid spend down and other financial eligibility rules that do not count the income and assets of parents and spouses for persons institutionalized for thirty days or longer.[156]

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[153] *Id.* at 125–30.

[154] 42 C.F.R. § 441.310 (2009).

[155] Pub. L. No. 99-509, 100 Stat. 1874 (1986) (adding section 915(g) to the Social Security Act). States already had the option to cover case management via HCBS waivers or through the "case management" option. This new optional category allowed states to cover case management without its being bundled in a package of HCBS waiver services. The option is termed "targeted" because the statutory amendment specifically provides that this option is exempted from the Medicaid statute's comparability and statewide requirements. States may thus "target" case management only to specified groups of Medicaid recipients, such as children in school settings, adults with bi-polar disorder, or women with breast cancer, and on a less than statewide basis. SMITH ET AL., *supra* note 134, at 14.

[156] *See* Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, Pub. L. No. 97-248, § 134, 96 Stat. 324. The 1982 amendments, called Katie Beckett provisions, after the child whose plight brought the issue to the attention of the Reagan administration, gave states the option to exclude the income and resources of parents for children up to 18 years of age who require the level of care provided in an institution but for whom community-based care is appropriate and for whom the cost of home care is no more than the cost of institutional care. SMITH ET AL., *supra* note 134, at 14; *see also* Act of July 17, 1988, Pub. L. No. 100-360, 102 Stat. 683. In 1988, the Medicare Catastrophic Coverage Act created special financial eligibility rules for institutionalized persons, allowing a spouse who remained in the community to retain more income and resources rather than being forced to use almost all their income to support care in the institution. Congress also gave states the option to extend these financial protection rules to spouses of individuals receiving HCBW services in the community. Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1860. Since 1999, states have also been able to continue Medicaid coverage of people with disabilities who return to work. 42

By the mid-1980s Congress had put in place a whole array of options for states to cover community-based services to redress Medicaid's nursing home bias. However, in 1988, only ten percent of Medicaid long-term care spending was going to community-based services. By 1999, when *Olmstead* shone a light on Medicaid's nursing home bias, the percentage had only risen to twenty-eight percent.[157] When *Olmstead* was decided, half the states, including Georgia, spent less than eight percent of their Medicaid long-term care dollars on home-based services. Only five states were spending more than twenty percent, and Oregon and New York nudged the national figures upward by spending forty to fifty percent on community care.[158] The problem was not the failure of the Medicaid statute to give states sufficient authority to cover home and community-based care. It was the states' failure to take advantage of the options they had available under Medicaid.

As a result of the *Olmstead* decision, the federal government engaged in a concerted effort to educate states about how to use Medicaid to cover home and community based services to reduce reliance on nursing home and other institutional care.[159] Throughout the 1990s additional statutory amendments to Medicaid gave states additional options to broaden personal care services, expand eligibility for Section 1915(c) HCB Waiver services, and made qualifying for Medicaid easier for people with disabilities.[160]

Most recently, in the Deficit Reduction Act (DRA) of 2005, Congress authorized three new options to encourage states to offer

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U.S.C. 1396a(a)(10)(A)(ii)(XV) (2006). For additional information, see generally SMITH ET AL., *supra* note 134, and CONGRESSIONAL RESEARCH SERVICE, MEDICAID SOURCE BOOK: BACKGROUND DATA AND ANALYSIS (A 1993 UPDATE) (1993).

[157] SMITH ET AL., *supra* note 134, at 8.

[158] *Id.*

[159] *See, e.g.*, *id.* at 3.

[160] *See id.* at 10. In 1993, Congress removed the requirement for physician authorization and nurse supervision for personal care services, also giving states explicit authority to provide personal care services outside the home. In 1997, Congress removed the "prior institutionalization" requirement for receipt of supported employment services through section 1915(c) HCB Waivers. Congress also created the option for states to allow people with disabilities to buy-into Medicaid by paying a premium. In 1999, Congress created additional buy-in options. *Id.*

more Medicaid home and community-based services.[161] First, Congress created a new home and community based (HCB) state plan option giving states similar authority to cover home and community-based services as that provided by Section 1915(c) HCB Waivers, but via a state plan option rather than a waiver.[162] The new HCB state plan option means that states may offer the full panoply of HCB Waiver services without having to go through the waiver process. Moreover, the HCB state plan option removes the requirement that HCB services be limited to those requiring institutional level of care while requiring that states establish more stringent eligibility requirements for institutional services. It continues to permit states to cap enrollment, maintain waiting lists and offer HCB services without providing services on a statewide basis.[163]

The DRA also gave states the option to allow for self-direction of personal assistance and other services without the need for a waiver.[164] Self-direction allows individuals to hire their own assistants rather than having to go through home health or other agencies. The option permits states to use the "cash and counseling" model of providing participants with an individual budget to purchase personal care and related services that are part of a plan of care.[165]

Finally, the DRA also authorizes the Secretary to grant competitive awards to states to increase the use of community services as compared to nursing home care.[166] These "Money Follows the Person" grants provided for enhanced federal Medicaid matching funds for twelve months for each person transitioned from an institution to the community during the demonstration period.[167]

The most recent data shows that, as a result of *Olmstead* and efforts at the federal level to educate and encourage states to redirect

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[161] Pub. L. No. 109-171, 120 Stat. 4 (2006), *amended by* Tax Relief and Health Care Act of 2006, Pub. L. No. 109-432, 120 Stat. 2922 (2006).

[162] Pub. L. No. 109-171, 120 Stat. 4, 121 (2006).

[163] JEFFREY S. CROWLEY, KAISER FAMILY FOUND., MEDICAID LONG-TERM SERVICES REFORMS IN THE DEFICIT REDUCTION ACT 12–14 (2006), *available at* http://www.kff.org/medicaid/upload/7486.pdf.

[164] Pub. L. No. 109-171, 120 Stat. 4, 127 (2006).

[165] CROWLEY, *supra* note 163, at 14–16.

[166] Pub. L. No. 109-171, 120 Stat. 4, 102 (2006).

[167] CROWLEY, *supra* note 163, at 9.

their Medicaid funding from nursing home care to home based care, Medicaid funding for community based services has now risen to forty-one percent of all Medicaid long-term care spending.[168] But while national statistics have risen substantially, the gap among the states had also widened: Mississippi is still spending only twelve percent on community-based services, while at the top-end, five states are now spending between sixty to seventy-five percent of their Medicaid long-term care dollars on community-based care.[169] At the bottom, almost one third of the states (sixteen) spend less than a third of their long-term care dollars on home and community-based care.[170]

Moreover, demand for Medicaid community-based services far outstrips the supply: thirty-eight states report waiting lists for Section 1915(c) HCB Waiver services with almost 400,000 people waiting for services.[171] Some of this shortfall in waiver services is the result of state legislatures' unwillingness to appropriate state tax dollars to help fund additional HCBW slots. However, even where state appropriations were available, a severe shortage of community care personnel and other resources limit waiver slots.[172]

CONCLUDING THOUGHTS: LESSONS FROM MEDICAID HISTORY

The legislative history of Medicaid reminds us that Medicaid is something different from and more than mere health insurance. It is a social welfare program that evolved from the desire to give people the resources they need to live independently in the community. Medicaid has not inadvertently or accidentally come to be the nation's primary funder of long-term care. It was intended to pay for

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[168] KAISER COMM'N ON MEDICAID FACTS, KAISER FAMILY FOUND., MEDICAID AND LONG-TERM CARE SERVICES AND SUPPORTS (2009), *available at* http://www.kff.org/medicaid/upload/2186_06.pdf.

[169] Kaiser State Health Facts, http://www.statehealthfacts.org (last visited Apr. 8, 2010). The five states spending over 60% on community care are Washington, Minnesota, Oregon, New Mexico, and Vermont.

[170] Kaiser State Health Facts, *supra* note 169.

[171] KAISER FAMILY FOUND., WAITING LISTS FOR MEDICAID 1915(C) HOME AND COMMUNITY-BASED (HCBS) WAIVERS (2008), *available at* http://www.statehealthfacts.org/profileind.jsp?rgn=1&cat=4&ind=246; *see also* KFF DATA UPDATE, *supra* note 11, at 11.

[172] *See generally* Perkins & Boyle, *supra* note 152 (discussing the shortage of community long-term care services).

long-term care and community support services, not just medical care.

Contrary to popular misconception Medicaid has always covered home and community-based long-term care.[173] Medicaid is rooted in the Social Security Act's commitment to provide public support for the needy so they can live in the community. Medicaid's purpose is to provide "rehabilitation and other services to help . . . families and individuals attain or retain capability for independence or self care."[174] Medicaid's persistent nursing home bias has never come from federal rules prohibiting states from funding home and community-based services.

When Medicaid was originally enacted the nation already had a large nursing home industry ready, willing and eager to accept the new Medicaid funding. The nursing home industry fought to get Medicaid funding and keep Medicaid funding. They lobbied Congress to create new, lower levels of nursing home care—ICFs and ICF/MRs—thereby creating new kinds of institutions for people with disabilities. No such cadre of community care providers existed in 1965. As the decades have gone by, home and community-based providers have evolved, but there has always been—and continues to be—too few community caregivers for the demand for community-based services.

Medicaid's persistent nursing home bias is partly the result of the fact that the statute makes nursing home care a mandatory service. But ICFs and ICF/MRs are optional services, and states were quick to embrace them because they perceived them to be of benefit to their state tax coffers and (mistakenly) to people with disabilities. Making home and community-based services a mandatory category would certainly push the most laggard states to begin making a serious investment in home and community-based services, but even that is unlikely to be a panacea.

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[173] *See, e.g.*, Letter from Bob Williams, Deputy Assistant Secretary, Office of Disability, Aging, and Long-Term Care Policy, DHHS, to readers (Oct. 2000), *in* SMITH ET AL., *supra* note 134 ("When Medicaid was first enacted, payment for long-term services was made solely to institutions such as nursing homes.").

[174] *See* discussion *infra* Part III.

We are still learning how to provide and fund community-based care. It was the challenge of the depression era Social Security Act and remains a challenge today. Medicaid's cooperative federal state structure provides states with an extraordinary set of tools to help provide social supports and long-term care for people with disabilities to live in the community. But it also requires political will at the state level.