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## RATIONALIZING HOME AND COMMUNITY-BASED SERVICES UNDER MEDICAID

LAURA D. HERMER\*

Well, hopefully, I'm hoping my daughter Melissa will be here for me. She's seen me give care to her father, her sister, her husband. She's seen me do all of that. She's heard me give care over the phone to other people, to her children, and to her; so I'm hoping on her, but if it's too much of a strain, I'm not going to really worry about that if it doesn't come to be her. She has a life to live, you know; she may be sick herself, so I can't put that on her, that it's got to be her. I can't do that. But I would hope so.<sup>1</sup>

Few of us want to think about, let alone plan for, the prospect that we will likely need long-term services and supports (LTSS), whether delivered in a nursing facility, at home, or elsewhere, as we age.<sup>2</sup> It is difficult enough to convince people to save for retirement, let alone to provide for their possible long-term care needs.<sup>3</sup> None of us want to contemplate the prospect of debilitation, dependence, and possibly irreversible decline that would require us to seek assistance with activities of daily living (ADLs), such as bathing, dressing, and other self-care. No one wants to be faced with the prospect of needing regular help with instrumental activities of daily living (IADLs), such as cooking, cleaning, and paying one's bills, which were once performed without much thought and with little exertion. No one looks forward to moving from one's home into an institution where one can receive nursing care from strangers, possibly for the remainder of one's life.

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\* Associate Professor, Hamline University School of Law. Thanks to Kate Kruse for helpful comments on an earlier draft of this article.

1. Laura M. Girling & Leslie A. Morgan, *Older Women Discuss Planning for Future Care Needs: An Explanatory Framework*, 26 J. AGING & HEALTH 13 (2014) (quoting 65 year-old interviewee).

2. The phrase "long-term care" is being replaced by "long-term services and supports." The former carries the connotation of care delivered in a nursing home, whereas the latter is meant to encompass assistance with all activities of daily living and instrumental activities of daily living, no matter where such assistance is delivered. *See, e.g.*, Susan C. Reinhard et al., *How the Affordable Care Act Can Help Move States Toward a High-Performing System of Long Term Services and Supports*, 30 HEALTH AFF. 447, 448-49 (2011).

3. COMM'N ON LONG-TERM CARE, REPORT TO THE CONGRESS 25 (Sept. 30, 2013), available at <http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>.

These issues contribute to the failure of most Americans to set aside enough money to pay for a protracted period of LTSS following retirement. While few Americans have sufficient resources to pay out-of-pocket for all the LTSS they will need, most of us will ultimately require them.<sup>4</sup> Only about one-third of Americans age sixty-five or older will never receive LTSS from any source.<sup>5</sup> Home health care is expensive, and nursing facility care far more so.<sup>6</sup> With the percentage of elderly Americans projected to grow from fifteen percent to twenty-one percent of the population between 2015 and 2035, the need for LTSS, and the concordant need to fund these services, will only become more pressing over the next two decades.<sup>7</sup>

For those requiring nursing facility care, spending down assets until one qualifies for Medicaid is often the only viable course of action. But others who need LTSS commonly remain in their homes as they age, rather than move into assisted living facilities or other institutions. Some people are able to afford regular assistance at home and prefer such care to other possible alternatives. Yet even these individuals often end up also relying on family members and friends for assistance. Many others—even those who qualify for Medicaid—must make do with whatever assistance they can cobble together themselves, if they wish to remain in the community rather than move to a nursing facility. Medicaid coverage for community-based services is at best a patchwork that varies substantially from state to state and is often not available for many people in need.

This article examines efforts states are making to expand access to community-based services for elderly and disabled Medicaid beneficiaries and suggests several options that might improve such access nationally. Like much of Medicaid, Medicaid LTSS have developed through a complex process of accretion.<sup>8</sup> Policymakers appear only rarely to have considered an overarching view of such services and the needs of those who require them. Rationalizing Medicaid LTSS will accordingly require not only additions but also substantial pruning, and may even warrant a reconsideration of who should have ultimate authority to develop and direct such services. Part I provides a brief history of public programmatic support for LTSS over the last forty-five years. Part II

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4. *Id.* at 4, 113.

5. *Id.* at 10.

6. *See infra* p. 3 and note 14.

7. U.S. Census Bureau, *2012 National Population Projections: Summary Tables, Table 3. Percent Distribution of the Projected Population by Selected Age Groups and Sex for the United States: 2015 to 2060 (NP2012-T3)*, CENSUS.GOV (Dec. 2012), <http://www.census.gov/population/projections/files/summary/NP2012-T3.xls>.

8. *See, e.g.*, Sara Rosenbaum, *Medicaid at Forty: Revisiting Structure and Meaning in a Post-Deficit Reduction Act Era*, 9 J. HEALTH CARE L. & POL'Y 5, 10 (2006) (noting that, despite its underlying “elegant[ce],” “[o]ver its lifetime, Medicaid has been transformed by an astounding agglomeration of legislative provisions and interpretive guidelines and rules”).

details changes to programs offering home and community-based services (HCBS) under the Affordable Care Act (ACA) and institutions of new ones. Part III discusses challenges facing Medicaid HCBS programs and provides a number of options for change.

#### I. A BRIEF HISTORY OF FEDERAL/STATE FINANCIAL SUPPORT FOR LTSS

Before the end of their lives, most elderly Americans need LTSS of some kind, whether minor or substantial. According to the Commission on Long-Term Care, a person turning sixty-five will require an average of \$47,000 in LTSS over the remainder of their lives.<sup>9</sup> The distribution, however, is “highly skewed.”<sup>10</sup> Some will need no LTSS at all; many others will need only modest amounts.<sup>11</sup> Half of all persons turning sixty-five will ultimately spend nothing on LTSS—despite about one-third of that group needing LTSS and likely receiving it from unpaid individuals—and another quarter less than \$10,000.<sup>12</sup> Yet approximately six percent will require care costing in excess of \$100,000.<sup>13</sup>

For those who must pay, LTSS are expensive: the average cost of a home health aide is over eighteen dollars per hour, which quickly adds up if an individual is paying out-of-pocket.<sup>14</sup> A year of nursing facility care in a private room currently costs over \$87,000.<sup>15</sup> Most private health insurance policies do not cover nonmedical expenses—a category into which many, if not most, LTSS fall.<sup>16</sup> Only about ten percent of Americans age fifty or over carry long-term care insurance, and that number is declining.<sup>17</sup> It is unsurprising, therefore, that an estimated forty-two million family caregivers provided LTSS at any given time in 2009.<sup>18</sup> Most of these services were unpaid and usually were provided by female family members or friends.<sup>19</sup> A 2012 study by the

9. COMM’N ON LONG-TERM CARE, *supra* note 3, at 23.

10. *Id.*

11. *Id.* at 23-24.

12. *Id.* at 25.

13. *Id.*

14. TERENCE NG ET AL., MEDICAID HOME AND COMMUNITY-BASED SERVICES PROGRAMS: 2010 DATA UPDATE 13 (Mar. 2014), available at [http://kaiserfamilyfoundation.files.wordpress.com/2014/03/7720-07-medicare-home-and-community-based-services-programs\\_2010-data-update1.pdf](http://kaiserfamilyfoundation.files.wordpress.com/2014/03/7720-07-medicare-home-and-community-based-services-programs_2010-data-update1.pdf). See also GENWORTH FINANCIAL, GENWORTH 2014 COST OF CARE SURVEY 4 (2014), available at [https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568\\_032514\\_CostofCare\\_FINAL\\_nonsecure.pdf](https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_032514_CostofCare_FINAL_nonsecure.pdf) (finding the average cost of a home health aide to be \$19/hr.).

15. GENWORTH FINANCIAL, *supra* note 14, at 17. The average cost of a semi-private room is \$77,000. *Id.* at 16.

16. See, e.g., COMM’N ON LONG-TERM CARE, *supra* note 3, at 27.

17. *Id.*

18. *Id.* at 12.

19. *Id.*

American Association of Retired Persons (AARP) found that if one assumes such services to be compensated at \$11.16 per hour—far less than the average cost of home care—then the value of unpaid family caregiving in 2009 was nearly \$450 billion.<sup>20</sup> This figure is more than double the actual amount spent on paid caregiving in 2011.<sup>21</sup> The Commission on Long-Term Care estimated that the lost productivity of individuals providing unpaid caregiving in 2004 was thirty-four billion dollars.<sup>22</sup>

The problem is made more acute by the abysmal job many Americans do in saving for their retirement needs, and the misconceptions they have regarding the adequacy of their savings. On the one hand, according to the Employee Benefits Research Institute, just over fifty percent of retirees in 2014 reported that they felt “very confident” or “somewhat confident” that they had sufficient assets to pay for any LTSS they might need.<sup>23</sup> Nearly seventy percent were either “very” or “somewhat” confident that they did a good job preparing financially for retirement.<sup>24</sup> Sixty-six percent of this cohort had saved money for retirement, rather than relying solely on Social Security.<sup>25</sup> Yet on the other hand, fifty-eight percent of the retirees who responded had less than \$25,000 in savings.<sup>26</sup> Included in that group are the twenty-nine percent who had less than \$1,000.<sup>27</sup> Only twenty-eight percent had \$100,000 or more in savings.<sup>28</sup> Predictably, those in the lowest income quartiles save the least, and are most at risk of failing to save enough to cover basic needs, uninsured health expenses, and LTSS.<sup>29</sup> It is both practically and psychologically difficult

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20. LYNN FEINBERG ET AL., INSIGHT INTO THE ISSUES NO. 51, VALUING THE INVALUABLE: 2011 UPDATE, THE GROWING CONTRIBUTIONS AND COSTS OF FAMILY CAREGIVERS 2 (June 2011), available at <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>.

21. COMM’N ON LONG-TERM CARE, *supra* note 3, at 12.

22. *Id.*

23. RUTH HELMAN ET AL., EMP. BENEFIT RESEARCH INST., NO. 397, THE 2014 RETIREMENT CONFIDENCE SURVEY: CONFIDENCE REBOUNDS – FOR THOSE WITH RETIREMENT PLANS 12 (2014), available at [http://www.ebri.org/pdf/briefspdf/EBRI\\_IB\\_397\\_Mar14.RCS.pdf](http://www.ebri.org/pdf/briefspdf/EBRI_IB_397_Mar14.RCS.pdf).

24. *Id.*

25. *Id.* at 14.

26. *Id.* at 16 (figure excludes the value of a respondent’s primary residence or defined benefit plans).

27. *Id.*

28. *Id.*

29. JACK VANDERHEI, EMPLOYEE BENEFITS RESEARCH INST., “SHORT” FALLS: WHO’S MOST LIKELY TO COME UP SHORT IN RETIREMENT, AND WHEN? 2, 4 (June 2014) (finding that 81% of the lowest-income quartile households and 38% of the second-lowest income quartile households are projected to be at risk of financially falling short of retirement needs within two decades after retirement, as compared to 8% of the highest-income quartile households).

to save for projected needs far in the future when one does not have enough money to meet basic needs in the present.<sup>30</sup>

Given that approximately 6.7 million elderly Americans need LTSS in the United States using the most recent estimates,<sup>31</sup> most possess inadequate savings,<sup>32</sup> and not all have or want friends or family to provide them with care, many elderly people would have to do without necessary LTSS, if not for Medicaid.<sup>33</sup> Today, state Medicaid programs must cover certain institutional LTSS and home health services, and additionally may cover HCBS through waiver programs and/or state plan amendments.<sup>34</sup> Medicaid now pays for approximately sixty-two percent of all LTSS.<sup>35</sup> Before Medicaid was enacted, however, obtaining coverage for LTSS would have been difficult. In the middle decades of the 20th century, a small amount of state and local (and later federal) public assistance existed to help cover nursing home care for approximately half of all seniors receiving such services.<sup>36</sup> The programs all

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30. MONIQUE MORRISSEY & NATALIE SABADISH, RETIREMENT INEQUALITY CHARTBOOK: HOW THE 401(K) REVOLUTION CREATED A FEW BIG WINNERS AND MANY LOSERS 29 (Econ. Pol'y Inst. ed., 2013).

31. COMM'N ON LONG-TERM CARE, *supra* note 3, at 3.

32. *Id.* at 4.

33. *Id.*

34. KRISTEN J. COLELLO, CONG. RESEARCH SERV., R43328, MEDICAID COVERAGE OF LONG-TERM SERVICES AND SUPPORTS 1-3 (2013). Home and community-based services are optional Medicaid services that include private duty nursing services; medical assistance to individuals for case management services, homemaker/home health aide services and personal care services, adult day health services, respite care, and other medical and social services that can contribute to the health and well-being of individuals and their ability to reside in a community-based care setting. 42 U.S.C. § 1396n(d)(5)(C)(i) (2013). Home health services are mandatory services for anyone who qualifies for Medicaid nursing facility services. 42 U.S.C. § 1396a(a)(10)(D) (2013). Services include home visit services provided by a registered nurse or a licensed practical nurse; home visits provided by a qualified home health aide; private duty nursing; personal care services; therapy (occupational/physical therapy and speech-language problems) services; and medical supplies, appliances and durable medical equipment. *See* 42 U.S.C. § 1396a (2013); *see also infra*, notes 47 and 54.

35. COMM'N ON LONG-TERM CARE, *supra* note 3, at 30.

36. JERRY SOLON ET AL., NURSING HOMES, THEIR PATIENTS, AND THEIR CARE 22-24 (1956) (noting that while public assistance covered as little as 25% of elderly nursing home residents in some states, public assistance covered as much as 70% in others). State Old-Age Assistance programs, jointly funded by localities, individual states, and the federal government through the Social Security Act of 1935, were the primary source of public funding available to help elders cover nursing home care prior to MAA. *See, e.g.*, ISADORE J. ROSSMAN & DORIS R. SCHWARTZ, THE FAMILY HANDBOOK OF HOME NURSING AND MEDICAL CARE 36 (1958) (describing individual state public assistance programs); *see also* WIS. STAT. § 49.20 (1959) (defining "old-age assistance" as instantiated in the State of Wisconsin, and generally identifying eligibility, benefits, and funding sources); *see also* Fred R. Brown, *Nursing Homes: Public and Private Financing of Care Today* (1958), reprinted in 21 SOCIAL SECURITY BULLETIN 3, 6

existed at the state or local level, and were piecemeal at best.<sup>37</sup> Starting in 1960, elderly people who lacked the means to furnish their own medical care, and who lived in a state that reliably participated in the program, might be able to rely on Medical Assistance to the Aged (MAA).<sup>38</sup> MAA—Medicaid’s precursor—was a welfare program that sought to assist seniors while at the same time making receipt of assistance sufficiently unpleasant to help curb reliance on it. A 1963 congressional report described the situation of an individual applying for MAA:

To secure whatever medical services may be provided, the applicant for MAA must shroud himself in the welfare cloak. He must present a case proving, in essence, that he cannot take care of himself. He must document the insufficiency of his resources by stating, precisely, the amount and source of his income, and the value of each asset. In many States, similar statements are demanded of his relatives. These statements are then, of course, subject to extensive investigation. These investigative and processing procedures take time, often creating a substantial delay between the onset of need and authorization of aid. Finally, his state may be one of those which ultimately recover the cost of the MAA services provided by means of liens, extending to his home and collectible after death.<sup>39</sup>

Nursing facility care could be limited under MAA. Only twenty-one of the twenty-nine states participating in MAA in 1963 offered coverage for nursing home services, and some of those that did participate put limitations on services.<sup>40</sup> For example, Tennessee would cover only ninety days of nursing home care in a 365-day period.<sup>41</sup> Others—echoing situations pertaining to some states today—paid so little that it was difficult for beneficiaries to obtain the care they needed.<sup>42</sup> As the quote above implies, some states additionally required individuals seeking assistance under MAA to prove not merely that they were impoverished, but also that their adult children could not provide for their care.<sup>43</sup>

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(1958) (noting that, out of 45 states reporting, 43 covered nursing home care through old-age assistance or another public program).

37. See, e.g., SOLON ET AL., *supra* note 36, at 22.

38. S. SPECIAL COMM. ON AGING, SUBCOMM. ON HEALTH OF THE ELDERLY, 88TH CONG., MEDICAL ASSISTANCE TO THE AGED: THE KERR-MILLS PROGRAM 1, 44 (Comm. Print 1960-63).

39. *Id.* at 29. As for the comprehensiveness of MAA, the congressional report noted that only four states – Hawaii, Massachusetts, New York, and North Dakota – could be said to offer “comprehensive” plans covering all major categories of services without substantial limitations. *Id.* at 41.

40. *Id.* at 47.

41. *Id.* at 96.

42. *Id.*

43. *Id.* at 31-32 (observing that 12 states at the time of the report had a “family responsibility” provision, requiring relatives of the applicant to prove that they lacked the means to help support the applicant).

Medicaid did away with some of the more onerous requirements of MAA, such as the “family responsibility” provision, and also was more stringent in both the types and the amount, duration, and scope of benefits it required states to provide if they wished to participate in the program.<sup>44</sup> Like MAA, it offered coverage for nursing home care.<sup>45</sup> However, in keeping with its focus on ensuring a level floor for beneficiaries, Congress made nursing home care a mandatory benefit under Medicaid, rather than an optional one as had been the case under MAA.<sup>46</sup> Payment for HCBS did not become part of the Medicaid program until later. Home health care—constituting medical and skilled nursing services, rather than assistance with ADLs<sup>47</sup>—was first added as a mandatory benefit for eligible beneficiaries in 1970.<sup>48</sup> While Medicaid regulations permitted states to offer optional personal care services (PCS) through their state plans starting in 1975, most states largely refrained from doing so.<sup>49</sup> Non-institutional assistance with ADLs and other types of HCBS

44. See, e.g., Laura Hermer, *Medicaid, Low Income Pools, and the Goals of Privatization*, 17 GEO. J. ON POVERTY L. & POL’Y 405, 408 (2010).

45. 42 C.F.R. § 440.210(a)(1) (2002); S. SPECIAL COMM. ON AGING, SUBCOMM. ON HEALTH OF THE ELDERLY, *supra* note 38, at 47.

46. Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 1905 (1965).

47. 42 C.F.R. § 440.70(a)-(b) (2012). CMS defines home health services as:

- (a) . . . the services in paragraph (b) of this section that are provided to a beneficiary--
- (1) At his place of residence, as specified in paragraph (c) of this section; and
  - (2) On his or her physician’s orders as part of a written plan of care that the physician reviews every 60 days, except as specified in paragraph (b)(3) of this section.
- (b) Home health services include the following services and items. Those listed in paragraphs (b)(1), (2) and (3) of this section are required services; those in paragraph (b)(4) of this section are optional.
- (1) Nursing service, as defined in the State Nurse Practice Act, that is provided on a part-time or intermittent basis by a home health agency as defined in paragraph (d) of this section, or if there is no agency in the area, a registered nurse who--
    - (i) Is currently licensed to practice in the State;
    - (ii) Receives written orders from the patient’s physician;
    - (iii) Documents the care and services provided; and
    - (iv) Has had orientation to acceptable clinical and administrative recordkeeping from a health department nurse.
  - (2) Home health aide service provided by a home health agency.
  - (3) Medical supplies, equipment, and appliances suitable for use in the home. . . .
  - (4) Physical therapy, occupational therapy, or speech pathology and audiology services, provided by a home health agency or by a facility licensed by the State to provide medical rehabilitation services. (See § 441.15 of this subchapter.).

42 C.F.R. § 440.70(a)-(b) (2012).

48. Social Security Amendments of 1967, Pub. L. 90-248, 81 Stat. 224 (1968).

49. See, e.g., Nancy A. Miller, *Medicaid 2176 Home and Community-Based Care Waivers: The First Ten Years*, HEALTH AFF., Winter 1992, at 162, 168 (noting that, in 1982, such services accounted for only an average of 1.2% of all Medicaid long term care expenditures, and that expenditures had risen only to 2.8% of all Medicaid long term care expenditures by 1990).



not involving skilled nursing did not become available except in limited circumstances until 1981, when Congress amended the Social Security Act to include what became Section 1915(c), which provided a vehicle by which states could seek waivers from federal Medicaid law to establish more limited Medicaid coverage for HCBS.<sup>50</sup> States that sought and obtained approval from the Department of Health and Human Services (HHS) under Section 1915(c) could offer Medicaid coverage for PCS for individuals who were otherwise eligible for institutional care under a state's Medicaid plan, but only in certain regions of the state, or only to specific populations such as those with developmental disabilities, or only up to a capped number of individuals, while still receiving federal matching funds to pay for the services.<sup>51</sup> By July 1987, thirty-seven states had a waiver in place to offer PCS of some kind to at least some portion of their Medicaid population.<sup>52</sup> Four years later, all states except Alaska and Arizona had at least one such waiver.<sup>53</sup> For states that did not want to go through the waiver process and were willing to offer HCBS to all eligible Medicaid beneficiaries, Congress formally made PCS an optional, reimbursable service under state Medicaid plans in 1993.<sup>54</sup> In 1999, federal

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50. Omnibus Budget Reconciliation Act of 1981, Pub. L. 97-35, § 2176(c)(1), 95 Stat. 357 (1981) (“The Secretary may by waiver provide that a State plan approved under this part may include as ‘medical assistance’ under such plan home or community-based services (other than room and board) approved by the Secretary which are provided pursuant to a written plan of care to individuals with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a skilled nursing facility or intermediate care facility the cost of which could be reimbursed under the State plan.”). *See also* GARY SMITH ET AL., U.S. DEPT. OF HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY BASED SERVICES: A PRIMER 1 (2000) (“When first enacted, Federal Medicaid funding for meeting the long-term service needs of people with disabilities and chronic conditions was available mainly when the person was placed in an institutional setting (e.g., a nursing home), with few avenues for securing Medicaid dollars to support individuals in their homes and communities. State dollars (and, in some cases, Federal dollars) funded ‘home care’ programs, but only on a limited basis.”)

51. FRANK J. THOMPSON, MEDICAID POLITICS: FEDERALISM, POLICY, DURABILITY, AND HEALTH REFORM 111 (2012). *See also* Allen J. LeBlanc et al., *State Medicaid Programs Offering Personal Care Services*, HEALTH CARE FINANCING REV., Summer 2001, at 155, 156-57.

52. H.R. COMM. ON ENERGY & COMMERCE, SUBCOMM. ON HEALTH & THE ENV'T, MEDICAID SOURCE BOOK: BACKGROUND DATA AND ANALYSIS 367 (1988). States had considerable discretion in defining the types of services offered. *See, e.g.*, LeBlanc et al., *supra* note 51, at 157. As a condition of receiving such services, many states required recipients to pay all but a set percentage of their income to the state, often leaving such individuals with income amounting to less than the federal poverty level to cover their living expenses. *Id.* at 367-68.

53. Miller, *supra* note 49, at 163.

54. Omnibus Budget Reconciliation Act of 1993, Pub. L. 103-66, § 13601(a)(5), 107 Stat. 301-302 (1993) (codified at 42 U.S.C. § 1396d (a)(24) (2012)). Unless defined differently by a state under the terms of a waiver,

guidance further expanded coverage to IADLs, such as housework, laundry, food preparation, and money management.<sup>55</sup>

Despite states' broad take-up of Section 1915(c) waivers and slowly increasing take-up of state plan coverage of HCBS, Medicaid HCBS still saw little penetration for many years. Section 1915(c) waivers accounted for only 4.3% of all Medicaid long-term care expenditures in 1990.<sup>56</sup> This changed over the following decade. State participation in PCS waiver programs increased an average of over seventeen percent per year between 1992 and 1998.<sup>57</sup> By 2000, twenty-seven states covered PCS under their state Medicaid plans, all of which to at least a limited degree, under a waiver.<sup>58</sup> The percentage of Medicaid long-term care spending on HCBS rose to twenty-eight percent of all Medicaid LTSS spending by the same time.<sup>59</sup> The next decade brought further growth. Between 1997 and 2009, spending on state plan PCS and HCBS waivers grew at an annual average of 11.4% and 12.4%, respectively.<sup>60</sup> By the time Congress was debating what was to become the ACA in 2009, HCBS expenditures had grown to comprise forty-five percent of all Medicaid long-term care spending.<sup>61</sup>

In 1999, the Supreme Court weighed in on the issue of providing HCBS to individuals in need of services, in lieu of institutional care. The majority in *Olmstead v. L.C.* held that "unjustified isolation . . . is properly regarded as discrimination based on disability," and that states should provide community

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(a) Personal care services means services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for individuals with intellectual disabilities, or institution for mental disease that are--

- (1) Authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State;
- (2) Provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and
- (3) Furnished in a home, and at the State's option, in another location.

(b) For purposes of this section, family member means a legally responsible relative.

42 C.F.R. § 440.167(a)-(b) (2012).

55. SMITH ET AL., *supra* note 50, at 12.

56. *Id.* at 165.

57. *Id.* at 13.

58. *Id.* at 12-13.

59. OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING & EVALUATION, U.S. DEP'T OF HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 8 (2000).

60. Steve Eiken et al., *Medicaid Long-Term Care Expenditures in FY 2009*, THOMSON REUTERS Table 1 (Aug. 17, 2010), [http://leg.mt.gov/content/Publications/fiscal/interim/finance\\_mty\\_nov2010/Managed-Care-Costs.pdf](http://leg.mt.gov/content/Publications/fiscal/interim/finance_mty_nov2010/Managed-Care-Costs.pdf).

61. *Id.* at 2. Spending on HCBS from state to state, however, has always varied substantially, and hence became a target for congressional action in the ACA. *Id.* at 4. *See also infra* notes 68-71 and associated text.

placement for disabled individuals where such placement is appropriate, where the disabled individual does not oppose such placement, and where such placement can be reasonably accommodated.<sup>62</sup> However, as the Senate observed in the ACA, access to HCBS did not improve to a degree that the Senate found sufficient or desirable following *Olmstead*:

In 2007, 69 percent of Medicaid long-term care spending for elderly individuals and adults with physical disabilities paid for institutional services. Only 6 states spent 50 percent or more of their Medicaid long-term care dollars on home and community-based services for elderly individuals and adults with physical disabilities while 1/2 of the States spent less than 25 percent. This disparity continues even though, on average, it is estimated that Medicaid dollars can support nearly 3 elderly individuals and adults with physical disabilities in home and community-based services for every individual in a nursing home. Although every State has chosen to provide certain services under home and community-based waivers, these services are unevenly available within and across States, and reach a small percentage of eligible individuals.<sup>63</sup>

Accordingly, provisions in the ACA that affect Medicaid in the context of elderly and disabled populations have a strong bias toward encouraging HCBS. The ACA expanded Medicaid state plan options for HCBS,<sup>64</sup> extended and expanded the Money Follows the Person (MFP) demonstration,<sup>65</sup> instituted the Community First Choice program (CFC),<sup>66</sup> and instituted the Balancing Incentives Program (BIP).<sup>67</sup> These programs have already borne fruit: now, nearly half of all LTSS spending goes for HCBS—a vast change from the situation that pertained less than a decade earlier.<sup>68</sup> Medicaid spending for non-

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62. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597, 607 (1999). Numerous articles have provided detailed analyses of *Olmstead* in the context of LTSS—a task which I do not undertake here. For a couple such analyses, see generally Sara Rosenbaum et al., *Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 95 (2002) (providing a detailed analysis of the possible impact of *Olmstead* in light of related Medicaid cases); Patricia E. Kefalas Dudek, *Using The Olmstead Decision As An Advocacy Tool For Your Clients*, NAELA Q., Winter 2002, at 4, 4-5 (providing an analysis of the decision and examples of how it could be used in client advocacy).

63. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2406 (a)(4), 124 Stat. 119, 306 (2010).

64. Patient Protection and Affordable Care Act § 2402(b)(6)(A) (codified at 42 U.S.C. § 1396n (2012)).

65. Patient Protection and Affordable Care Act § 2403 (codified at 42 U.S.C. § 1396a (2012)).

66. Patient Protection and Affordable Care Act § 2401 (codified at 42 U.S.C. § 1396n(k) (2012)).

67. Patient Protection and Affordable Care Act § 10202 (codified at 42 U.S.C. § 1396d (2012)).

68. Substantial variation still exists among the states, however. Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FFY 2012*, TRUVEN HEALTH ANALYTICS

institutional LTSS increased over the last fifteen years from constituting eighteen percent of total Medicaid LTSS spending in 1995 to 49.5% in 2012.<sup>69</sup> At the same time, despite the increased number of elderly individuals served,<sup>70</sup> LTSS spending as a percentage of total Medicaid spending has declined from a high of forty percent in 1996 to a low, in the most recent year available, of thirty-four percent in 2012.<sup>71</sup> The latter is a promising statistic. As we will see, however, the optional and piecemeal character of these programs limits their full potential.

An additional, optional feature of some HCBS programs deserves mention before moving on. Rather than allowing beneficiaries merely to choose a home health agency or other entity through which to receive PCS in a community setting, many states in many of their different Medicaid HCBS programs allow beneficiaries to “self-direct” their services, either by directly hiring, supervising, and firing caregivers, by directing how their individual Medicaid HCBS budget will be spent, or both.<sup>72</sup> This feature derives from the Cash and Counseling program in the late 1990s, which in turn developed out of other, smaller self-direction demonstration programs.<sup>73</sup>

The Cash and Counseling program was premised on the notion that beneficiaries would do better on a variety of outcomes if they were able to choose and supervise their own caregivers in their homes, rather than requiring beneficiaries to accept caregivers chosen by home health agencies or other entities.<sup>74</sup> Participants in the program were given funds with which to pay caregivers, as well as counseling on how to select and supervise caregivers.<sup>75</sup> Three states initially participated: Arkansas, Florida, and New Jersey.<sup>76</sup> The program fared well in studies comparing outcomes for its participants versus outcomes for individuals receiving traditional HCBS.<sup>77</sup>

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5-6 (Apr. 28, 2012), <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/LTSS-Expenditures-2012.pdf>.

69. *Id.* at 5.

70. CONG. BUDGET OFFICE, PUB. NO. 4240, RISING DEMAND FOR LONG-TERM SERVICES AND SUPPORTS FOR ELDERLY PEOPLE 7 (June 2013).

71. *Id.* at 4.

72. *Self-Directed Services*, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html> (last visited Sept. 12, 2014).

73. *Id.*

74. RANDAL BROWN ET AL., CASH AND COUNSELING: IMPROVING THE LIVES OF MEDICAID BENEFICIARIES WHO NEED PERSONAL CARE OR WHO NEED PERSONAL CARE OR HOME AND COMMUNITY-BASED SERVICES 1 (2007), available at <http://www.mathematica-mpr.com/~media/publications/PDFs/ccpersonalcare.pdf>.

75. *Id.* at 3.

76. *Id.* at 1-2.

77. *Id.* at 90-92.

The final report on the Cash and Counseling demonstration program by Mathematica Policy Research found in each of the three states that the Cash and Counseling population was less likely to report unmet needs than the control group, significantly less likely to have experienced rude or disrespectful care, and significantly more likely to be satisfied with the way the caregiver helped around the house, with overall caregiving arrangements, and with their way of spending their lives.<sup>78</sup> Cash and Counseling cost more money, but overall Medicaid expenditures for the treatment versus the control groups were only slightly increased in Florida and New Jersey (albeit significantly so in Arkansas).<sup>79</sup> Caregivers also benefited under Cash and Counseling. Many previously unpaid caregivers received payment under the program.<sup>80</sup> Treatment group caregivers were more satisfied with the care they provided to beneficiaries, and were also significantly less likely than the control caregivers to say that caregiving impeded their privacy or social life, or, except in Florida, caused emotional strain.<sup>81</sup> In part, as a result of the successes documented under the Cash and Counseling demonstration, federal law allows states to opt to offer self-directed HCBS through waivers or their state plan.<sup>82</sup> As will be discussed further below, self-directed services are also available under programs instituted under the ACA.

## II. SECTION 1915(C) WAIVERS AND CHANGES TO MEDICAID HCBS UNDER THE ACA: PRUNING THE WEEDS, OR ADDING TO THEM?

By sheer number, Section 1915(c) waivers have been, and still are, the most common vehicle by which states make Medicaid coverage for HCBS available to their residents.<sup>83</sup> Nearly all states have a Section 1915(c) HCBS waiver for elderly or elderly and disabled people.<sup>84</sup> Merely residing in a state

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78. *Id.* at 49.

79. *Id.* at 56. The researchers determined that part of the discrepancy was attributable to the failure of the state to deliver authorized amounts of care to control group members. In Arkansas, control group members received only about 80% of the care authorized for them, as compared to about 100% for the treatment group. *Id.*

80. *Id.* at 72 (noting figures of 29% in Florida, 42% in New Jersey, and 56% in Arkansas).

81. *Id.* at 75-77.

82. *See, e.g., Self-Directed Services, supra* note 72. The Deficit Reduction Act of 2005 first permitted states to institute self-directed plans without a waiver. 42 U.S.C. §1396n(j) (2012); Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57,854, 57,855 (Oct. 3, 2008) (codified at 42 C.F.R. pt. 441) (containing further information about the history of self-directed personal care services).

83. DIANE JUSTICE, STATE HEALTH POLICY BRIEFING, IMPLEMENTING THE AFFORDABLE CARE ACT: NEW OPTIONS FOR MEDICAID HOME AND COMMUNITY BASED SERVICES 2 (Oct. 2010), available at [http://www.nashp.org/sites/default/files/LTSS\\_SCAN-FINAL-9-29-10.PDF](http://www.nashp.org/sites/default/files/LTSS_SCAN-FINAL-9-29-10.PDF).

84. Only Arizona, Hawaii, Rhode Island, and Vermont lack a specific waiver for HCBS under § 1915, as they include such services instead under a § 1115 waiver. *See, e.g., Medicaid*

possessing one or more Section 1915(c) waivers, however, does not guarantee access to coverage for state residents who need services. In fact, before the ACA, states seeking a Section 1915(c) waiver were required to target each waiver at only one of several specific populations or groups: elderly or disabled individuals, or both; individuals with intellectual or developmental disabilities, or both; individuals with mental illnesses, and “others,” such as children and individuals with AIDS.<sup>85</sup> Thus, for example, one study found that in 2001, 231 individual state Section 1915(c) waivers existed, ninety-four of which involved the elderly and disabled, seventy-six for individuals with intellectual or developmental disabilities, twenty for individuals with traumatic brain or spinal cord injuries, and forty for “others.”<sup>86</sup>

Political scientist and health policy scholar Frank Thompson, among others, has discussed the fragmentation that has resulted in HCBS because of this waiver policy. Not only has it promoted infighting among groups competing for scarce resources, according to Thompson, but it has also “chipped away at Medicaid’s initial statutory commitment to provide ‘equal’ benefits to all who meet the eligibility criteria within a state’s borders.”<sup>87</sup> Because they permit states to obtain exemptions from federal statewidedness, comparability, and population requirements, they allow states to introduce and expand variability in coverage between different state regions and populations. Waivers, at least, offer a check on state variability by requiring approval from the Secretary of HHS.<sup>88</sup> Yet under the Deficit Reduction Act of 2005 (DRA), Congress removed even this restriction.<sup>89</sup> The DRA empowered states to offer PCS that could vary in statewidedness and cover only capped populations through their state plans, rather than via waivers, through the enactment of a State Plan Amendment Option for HCBS in Section 1915(i) of the Social Security Act.<sup>90</sup>

The ACA undid some of the variability permitted in Medicaid state plans for HCBS under 1915(i), but not all. First, while it allows states to target specific populations for HCBS under Section 1915(i) and to vary the amount,

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*Benefits: Home and Community-Based Service Waiver*, KAISER FAMILY FOUND. (2012), <http://kff.org/medicaid/state-indicator/home-and-community-based-services-waiver/>.

85. CTRS. FOR MEDICARE & MEDICAID SERVS., PUB. NO. 2249-F/2296-F, FACT SHEET: SUMMARY OF KEY PROVISIONS OF THE 1915(C) HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVERS FINAL RULE 1 (Jan. 10, 2014), available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/1915c-Fact-Sheet.pdf>.

86. Martin Kitchener et al., *Medicaid Home and Community-Based Care: National Program Trends*, 24 HEALTH AFF. 206, 208 (2005).

87. THOMPSON, *supra* note 51, at 119, 128.

88. 42 U.S.C. §1396n(i)(1) (2012).

89. Deficit Reduction Act of 2005, Pub. L. 109-171, § 6086, 120 Stat. 121-122 (2006).

90. THOMPSON, *supra* note 51, at 117.

duration, and scope of HCBS benefits from one population to another,<sup>91</sup> it removes the ability of states to cap enrollment in HCBS, establish waiting lists, and vary services based on geography merely by amending their Medicaid state plans.<sup>92</sup> It permits states to offer full Medicaid benefits to individuals eligible to receive HCBS.<sup>93</sup> It also allows states to cover certain individuals with incomes up to 300% of the Supplemental Security Income level (nearly \$26,000 per year for an individual in 2014),<sup>94</sup> rather than limiting income to 150% of the Federal Poverty Level<sup>95</sup> (\$17,505 for a single individual in 2014).<sup>96</sup> States may allow beneficiaries to choose friends or non-legally liable relatives as caregivers and have them be reimbursed for their services.<sup>97</sup>

Section 1915(c) waivers are still available, however, so states may still seek to circumvent these rules if they wish. If history is any guide, states will likely continue to make substantial use of the flexibility that they offer.<sup>98</sup> A state might choose to seek a waiver rather than opt for a state plan amendment if, for example, it wanted to preserve the option to cap enrollment, institute a waiting list for services, or vary eligibility or service options based on geography.<sup>99</sup> It remains to be seen whether states will choose to cover HCBS via a state plan amendment versus waiver. To date, only thirteen states have

91. 42 U.S.C. §1396(i)(7)(A) (2012).

92. 42 U.S.C. §1396n(i)(1)(C) (2012). *See also* CTRS. FOR MEDICARE & MEDICAID SERVS., PUB. NO. 10-015, IMPROVING ACCESS TO HOME AND COMMUNITY-BASED SERVICES 5 (2010).

93. 42 U.S.C. §1396(a)(10)(A)(ii)(XXII) (2012). *See also* State Plan Home Community-Based Services, 79 Fed. Reg. 2989, 2949 (Jan. 16, 2014) (to be codified at 42 C.F.R. § 441). To be eligible for services, individuals must either be unable to perform at least 2 ADLs or must require significant assistance with respect to them. *See* 42 U.S.C. §1396n(i)(1)(D) (2012).

94. SOC. SEC. ADMIN., ANNUAL REPORT OF THE SUPPLEMENTAL SECURITY INCOME, 1 (2014). *See also* State Plan Home Community-Based Services, 79 Fed. Reg. 2948, 2955 (Jan. 16, 2014) (to be codified at 42 C.F.R. § 441).

95. Notice, Annual Update of the HHS Poverty Guidelines, 79 Fed. Reg. 3593 (Jan. 22, 2014).

96. 42 U.S.C. § 1396n(i)(6)(A) (2012). This option is only available with respect to individuals who would be eligible under an existing § 1915(c), (d), (e), or §1115 waiver.

97. 42 U.S.C. § 1396n(i)(1)(G)(iii)(III)(cc) (2012). Reimbursement would of course require caregivers to meet any applicable state requirements for caregivers performing the relevant level of service. *See infra* notes 177-83.

98. Nancy A. Miller et al., *Trends and Issues in the Medicaid 1915(c) Waiver Program*, HEALTH CARE FINANCING REV., Summer 1999, at 139, 140.

99. Under the ACA, states are now permitted to combine different populations (e.g., elderly or developmentally disabled people) into a single waiver if they wish, rather than requiring individual waivers for each. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., PUB. NO. 2249-F/2296-F, *supra* note 85.

opted for state plan coverage under the ACA out of the thirty-one states that cover such services through a state plan amendment.<sup>100</sup>

The ACA additionally extends and liberalizes the MFP rebalancing demonstration program. MFP is intended to encourage states to transition suitable individuals from Medicaid-covered institutional care to community-based care. As conceived prior to the ACA, it offers an increased Federal Medical Assistance Percentage (FMAP) for such individuals for their first year of residence in the community, and may be limited, at a state's option, to only selected geographic areas in a given state.<sup>101</sup> The ACA does not change these features in any respect. Rather, it makes only two small alterations. First, the demonstration was set to expire in 2011.<sup>102</sup> The ACA extends it to 2016.<sup>103</sup> Additionally, the ACA amends the program so that individuals who have resided in an institution for only a minimum of ninety days, rather than six months, are eligible to participate.<sup>104</sup> Forty-four states and the District of Columbia participate in MFP.<sup>105</sup> The program, however, is quite small; between 2008 and 2012, it served a total of just over 30,000 individuals, with an additional 5,000 served in 2013.<sup>106</sup> Results, however, appear promising. Those who participated in MFP tend to remain in the community; a Kaiser Family Foundation study found, for example, that only about eleven percent of participants were re-institutionalized.<sup>107</sup>

The ACA offers no new financial carrots in its amendment and expansion of the Section 1915(i) HCBS state plan option and MFP. Rather, those financial carrots may be found in two new programs created by the ACA: the CFC and BIP. At first glance, the CFC program, which is a new state plan option under Section 1915(k), appears identical in many respects to the state

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100. *Medicaid Moving Forward*, KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., (June 2014), <http://kaiserfamilyfoundation.files.wordpress.com/2014/06/7235-07-medicaid-moving-forward2.pdf>.

101. 42 U.S.C. §§ 1396a(c)(9)(A),(B) (2012).

102. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2402(a)(1)(A), 124 Stat. 304 (2010) (codified at 42 U.S.C. § 1396a note).

103. *Id.*

104. Patient Protection and Affordable Care Act § 2403(a)(2)(1)(A) (codified at 42 U.S.C. § 1396a note).

105. *Money Follows the Person (MFP)*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Money-Follows-the-Person.html> (last visited Sept. 21, 2014).

106. CAROL IRVIN ET AL., MATHEMATICA POLICY RESEARCH, MONEY FOLLOWS THE PERSON: 2012 ANNUAL EVALUATION REPORT 7 (2013); Molly O'Malley Watts et al., *Money Follows the Person: A 2013 State Survey of Transitions, Surveys, and Costs*, KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND. (April 2014), [http://kaiserfamilyfoundation.files.wordpress.com/2014/04/8581-money-follows-the-person\\_a-2013-survey-of-transitions-services-and-costs1.pdf](http://kaiserfamilyfoundation.files.wordpress.com/2014/04/8581-money-follows-the-person_a-2013-survey-of-transitions-services-and-costs1.pdf).

107. O'Malley Watts et al., *supra* note 106, at 9.



plan option available under Section 1915(i).<sup>108</sup> If taken up, however, CFC must be made available to all applicable individuals otherwise eligible for Medicaid, and does not offer states the option of creating a new eligibility category for individuals needing HCBS.<sup>109</sup> Also notably, CFC services must be self-directed by the beneficiary or his/her representative.<sup>110</sup> The self-direction component, in conjunction with the absence of an option to target services to a particular population, makes Section 1915(k) strongly resemble a more robust version of Section 1915(j), which instituted Cash and Counseling as a state plan option under the DRA.<sup>111</sup> The new CFC statutory language additionally contains a mandatory evaluation component requiring states to track data concerning the individuals participating in the program.<sup>112</sup> As an incentive to induce states to take up CFC, Section 1915(k) increases the federal matching rate by six percent.<sup>113</sup> Few states have done so to date, however. HHS has approved only California's and Oregon's plans, and only four others are currently awaiting approval.<sup>114</sup> The Secretary of HHS suggested in her 2014 interim report to Congress on the program that both budgetary concerns and the availability of greater flexibility through the use of Section 1915(c) waivers are among the factors contributing to limited participation.<sup>115</sup>

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108. *See generally* KATHLEEN SEBELIUS, DEP'T OF HEALTH & HUMAN SERVS., COMMUNITY FIRST CHOICE: INTERIM REPORT TO CONGRESS AS REQUIRED BY THE PATIENT PROTECTION AND AFFORDABLE CARE ACT OF 2010 (P.L. 111-148) (2014), *available at* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Interim-Community-First-Choice-Report-to-Congress-2014CLEAN.pdf>.

109. *Id.* at 3.

110. 42 U.S.C. § 1396(k)(1)(A)(iv) (2012). The services must be "selected, managed, and dismissed by the individual, or, as appropriate, with assistance from the individual's representative; . . . controlled, to the maximum extent possible, by the individual or where appropriate, the individual's representative, regardless of who may act as the employer of record; and . . . provided by an individual who is qualified to provide such services, including family members (as defined by the Secretary)." *Id.*

111. 42 U.S.C. § 1396(k)(1) (2012); 42 U.S.C. § 1396(j)(1) (2012). As of 2012, despite its comparatively lax requirements, only five states participated in § 1915(j) under their state plan: Arkansas, California, New Jersey, Oregon, and Texas. The states spent a combined total of \$236 million in FY 2012, with the lion's share consumed by California. STEVE EIKEN ET AL., CTRS. FOR MEDICARE AND MEDICAID SERVS., MEDICAID EXPENDITURES FOR LONG TERM SERVICES AND SUPPORTS IN FFY 2012 at 75, 76, 102, 110, 116 (2014).

112. 42 U.S.C. § 1396n(k)(5)(B) (2012).

113. 42 U.S.C. § 1396n(k)(2) (2012). Relatedly, the statute also imposed a maintenance of effort requirement for the first 12 months that a state participates in CFC. 42 U.S.C. § 1396n(k)(3)(C) (2012).

114. SEBELIUS, *supra* note 108, at 6.

115. *Id.* at 6-7. We will return to this matter further below. *See infra* note 171 and accompanying text.

The other new program under the ACA offering increased federal financial participation is BIP. Like MFP, BIP is intended to induce states to expand their HCBS programs.<sup>116</sup> BIP offers an increased federal match for Medicaid HCBS between October 1, 2011 and September 30, 2015 to states that spend fewer than fifty percent of their LTSS dollars on HCBS.<sup>117</sup> Participating states must submit a plan for increasing their provision of Medicaid HCBS, including the institution of steps such as “no wrong door” application systems, presumptive eligibility, and case management services.<sup>118</sup> States that spent less than twenty-five percent of their LTSS Medicaid expenditures on HCBS in 2009 must seek to achieve a target of spending more than twenty-five percent of their Medicaid LTSS dollars on HCBS by October 1, 2015.<sup>119</sup> Such states will receive a five percent increase in their FMAP for the duration of the program.<sup>120</sup> States that spent at least twenty-five percent but less than fifty percent of their Medicaid LTSS dollars on HCBS in 2009 must seek to spend more than fifty percent on HCBS by October 1, 2015, and, in return, receive a two percent increase in their FMAP for Medicaid HCBS expenditures.<sup>121</sup> Twenty states are currently participating.<sup>122</sup> The limited data that exists for the program to date provides that the six states that were participating as of 2012 have all increased the proportion of their LTSS spending that is allocated to HCBS—a promising result, but quite preliminary.<sup>123</sup>

### III. CHALLENGES FACING MEDICAID HCBS PROGRAMS, AND OPTIONS FOR CHANGE

As we have seen, the federal government has gradually sought over the last three decades to entice states into allocating more of their Medicaid LTSS funds toward HCBS and away from institutional-based care. It has done so by instituting a variety of optional programs in which states may choose to participate. Each time the federal government has recalibrated its approach to Medicaid HCBS, it has chosen to add new programs or amend and expand old ones. It has not generally eliminated programs along the way.

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116. EDWARD KAKO, ET AL., THE BALANCING INCENTIVE PROGRAM: IMPLEMENTATION MANUAL 9 (2013).

117. 42 U.S.C. § 1396d note (2012); *Balancing Incentive Program*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html> (last visited Sept. 13, 2014).

118. 42 U.S.C. § 1396d note.

119. *Id.*

120. *Id.*

121. *Id.*

122. *State Health Facts: Balancing Incentive Program*, KAISER FAMILY FOUND., <http://kff.org/medicaid/state-indicator/balancing-incentive-program/> (last visited Sept. 5, 2014).

123. Eiken et al., *supra* note 68, at Tables AJ and AK.

This has led to a number of problems. First, there is a bewildering array of programs. States may choose to offer both targeted waiver programs and state plan options. In some cases, beneficiaries may have access only to traditional services, while others may be self-directed. Some individuals who are eligible for Medicaid may be eligible to participate in one or more HCBS programs, while others may not. Each is subject to rules which, in the main, are often quite similar, but which vary in subtle respects. Each, additionally, offers very similar if not identical benefits, which may be provided by identical caregivers across programs.

Take California's array of Medicaid HCBS programs, for example. California offers PCS through its state Medicaid plan, not to generally eligible elderly individuals, but rather to both categorically eligible and medically needy individuals with intellectual or developmental disabilities.<sup>124</sup> California participates in the MFP demonstration, although it has had substantial difficulties in doing so: to date, it has successfully transitioned only 827 individuals between 2008 and 2011, despite having received approximately forty-one million dollars in connection with the program over the same period.<sup>125</sup> It also, as noted above, is one of only two states currently participating in the CFC.<sup>126</sup> Yet it additionally has eight current Section 1915(c) waivers.<sup>127</sup> No fewer than three of these waivers cover an array of different services such as homemaker, home health, environmental

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124. CTRS. FOR MEDICARE & MEDICAID SERVS., ATTACHMENT 3.1-I, 1915(I) HCBS STATE PLAN HCBS STATE PLAN SERVICES ADMINISTRATION AND OPERATION: CALIFORNIA 1, 4, 6-7 (stating to qualify for state plan services, individuals must demonstrate "[a] need for habilitation services, as defined in Section 1915(c)(5) of the Social Security Act (42 U.S.C. § 1396 *et seq.*), to teach or train in new skills that have not previously been acquired, such as skills enabling the individual to respond to life changes and environmental demands (as opposed to rehabilitation services to restore functional skills); and [a] likelihood of retaining new skills acquired through habilitation over time; and [a] condition which results in major impairment of cognitive and/or social functioning, representing sufficient impairment to require interdisciplinary planning and coordination of special or generic services to assist the individual in achieving maximum potential, that continues, or can be expected to continue, indefinitely; and [t]he existence of significant functional limitations in at least three of the following areas of major life activity, as appropriate to the person's age[:] Receptive and expressive language; Learning; Self-care; Mobility; Self-direction; Capacity for independent living." *Id.* at 8-9.

125. Jenni Bergal, *States Encounter Obstacles Moving Elderly and Disabled into Community*, KAISER HEALTH NEWS, (May 24, 2012), <http://www.kaiserhealthnews.org/stories/2012/may/24/states-obstacles-moving-elderly-disabled.aspx>. See generally Eiken et al., *supra* note 68, at 19, Table AK (demonstrating California does not, however, participate in BIP, as its share of Medicaid LTSS dollars allocated to HCBS exceeded 50% in 2009, hence making the state ineligible for the program).

126. See SEBELIUS, *supra* note 108, at 6.

127. *Waivers*, MEDICAID.GOV, [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers\\_faceted.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers_faceted.html) (last visited Sept. 5, 2014) (searching for California § 1915(c) waivers from filter box).

accessibility adaptations, care management, respite care, supplemental personal care, adult day care, adult day support center, communication, housing assistance, nutritional services, protective services, purchased care management, supplemental chore, supplemental health care, supplemental professional care assistance, supplemental protective supervision, and transportation.<sup>128</sup> Additional waivers cover elderly and/or nonelderly populations for a panoply of the same or other services, some targeted to specific groups such as individuals of all ages with HIV/AIDS or medically fragile children in need of palliative care, and others to individuals of all ages with intellectual or developmental disabilities or those residing in San Francisco.<sup>129</sup> Some limit the number of participants;<sup>130</sup> others do not.<sup>131</sup> Some limit penetration of the waiver by geographic region;<sup>132</sup> others do not.<sup>133</sup> Some put a dollar value limitation on services provided under the waiver;<sup>134</sup> others do not.<sup>135</sup>

As long as states continue to have an option to limit HCBS to specific population groups in specific geographic areas by specific dollar amounts, most available evidence to date suggests they will continue to do so, no matter how sweet a deal the federal government might offer for them instead to opt to offer coverage under their state plan. States are already required, as a condition of participating in Medicaid, to provide institutional care to eligible

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128. *California Waiver Factsheet*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/CA-Waiver-Factsheet.html#CA0431> (last visited Sept. 5, 2014).

129. *Id.*

130. See §1915(c) *Home and Community-Based Services Waiver, Nursing Facility/Acute Hospital Waiver (NH/AH) – Transition and Diversion Waiver: California*, CTRS. FOR MEDICARE & MEDICAID SERVS. (approved Jan. 1, 2012), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/CA0139.zip>.

131. See §1915(c) *Home and Community-Based Services Waiver for Californians with Developmental Disabilities: California*, CTRS. FOR MEDICARE & MEDICAID SERVS. (approved Mar. 29, 2012), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/CA0336.zip>.

132. See §1915(c) *Home and Community-Based Services Waiver, Multipurpose Senior Services Program: California*, CTRS. FOR MEDICARE & MEDICAID SERVS. (approved July 1, 2009), <https://www.cms.gov/MedicaidStWaivProgDemoPGL/downloads/CA0141R0400.zip>.

133. See §1915(c) *Home and Community-Based Services Waiver Pediatric Palliative Care Waiver: California*, CTRS. FOR MEDICARE & MEDICAID SERVS. (approved Apr. 1, 2012), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/CA0486.zip>.

134. See, e.g., §1915(c) *Home and Community-Based Services Waiver, Nursing Facility/Acute Hospital Waiver (NH/AH) – Transition and Diversion Waiver: California*, *supra* note 130.

135. See, e.g., §1915(c) *Home and Community-Based Services Waiver for Californians with Developmental Disabilities: California*, *supra* note 131, at 31-32, 34.

individuals.<sup>136</sup> HCBS cost far less to deliver than institutional care: homemaker services and home health aide services cost around \$45,000 per year to deliver, as compared to more than \$87,000 per year for nursing facility care.<sup>137</sup> It would therefore seem that with respect to individuals who both wish to and reasonably can live in the community with proper supports, states would be interested in providing them with HCBS in lieu of institutional care. Yet states' use of waivers with service and monetary caps inhibits this outcome. In 2012, nearly 524,000 individuals were on waiting lists for HCBS in thirty-nine states.<sup>138</sup> Such individuals remained on these lists for an average of two years.<sup>139</sup>

States may in part be concerned about offering less-fettered access through state plan amendments because of the "woodwork effect."<sup>140</sup> We know there is pent-up demand for Medicaid HCBS; the waiting lists certainly evidence this.<sup>141</sup> But even more worrisome is the vast quantity of unpaid services provided by family and friends of individuals in need of LTSS. Recall the AARP study finding the value of unpaid care, at just over eleven dollars per hour, to total about \$450 billion per year.<sup>142</sup> As the AARP study notes, this figure is nearly equal to the amount of money that the federal government spends annually on Medicare services.<sup>143</sup> It is entirely possible, therefore, that if states loosen controls on Medicaid HCBS spending by expanding access to services under their state plans, for instance, then many more individuals will ultimately receive HCBS than just those who used to receive institutional services – hence the now defunct requirement that for each individual who gained Medicaid HCBS, one Medicaid institutional bed had to be emptied.<sup>144</sup> The phenomenon has received wide discussion.<sup>145</sup> Evidence to date suggests

136. See, e.g., COLELLO, *supra* note 34, at 5.

137. GENWORTH FINANCIAL, *supra* note 14, at 12-13, 17.

138. TERRENCE NG & CHARLENE HARRINGTON, KAISER FAMILY FOUND., MEDICAID HOME AND COMMUNITY-BASED SERVICES: 2010 DATA UPDATE 11 (2014), available at [http://kaiserfamilyfoundation.files.wordpress.com/2014/03/7720-07-medicaid-home-and-community-based-services-programs\\_2010-data-update1.pdf](http://kaiserfamilyfoundation.files.wordpress.com/2014/03/7720-07-medicaid-home-and-community-based-services-programs_2010-data-update1.pdf).

139. *Id.* at 12.

140. See, e.g., THOMPSON, *supra* note 51, at 120.

141. See NG & HARRINGTON, *supra*, note 138 at 12.

142. FEINBERG ET AL., *supra* note 20, at 2 and associated text.

143. *Id.* at 3.

144. See, e.g., THOMPSON, *supra* note 51, at 112 (discussing the "cold bed" rule).

145. See, e.g., *Id.* at 120-21 (discussing different features of the phenomenon). See also Steve Eiken et al., *An Examination of the Woodwork Effect Using National Medicaid Long-Term Services and Supports Data*, 25 J. AGING & SOC. POL'Y 134, 134 (2013) (arguing that no strong evidence exists to support the likelihood of the woodwork effect coming about as states transition to greater use of HCBS); Mitch LaPlante, *The Woodwork Effect in Medicaid Long Term Services and Supports*, Presentation at the 2012 National Home and Community Based Services Conference (2009), available at [http://www.nasuad.org/documentation/hcbs\\_2012/HCBS%2020](http://www.nasuad.org/documentation/hcbs_2012/HCBS%2020)

that the woodwork effect is unlikely to become a substantial problem if states continue loosening their limitations on access to Medicaid HCBS, given the reduction in LTSS spending as access to HCBS has expanded.<sup>146</sup> However, states may well suppose, notwithstanding these studies, that it is the continued existence of controls such as waiting lists that has led to the slow, modest increase in growth in LTSS expenditures overall, including expenditures for HCBS, and that eliminating caps on enrollment or expenditures among some populations could lead to alarming program growth.

States have been particularly reluctant to take up HCBS programs that make self-direction of services a central feature. Both Section 1915(j), which codified the Cash and Counseling demonstration program and made it available to individuals receiving Medicaid HCBS under either Section 1915(c) or Section 1915(i), and Section 1915(k), which instituted the CFC under the ACA, make self-direction of services key.<sup>147</sup> Yet despite the outcomes achieved in the Cash and Counseling demonstrations, and despite beneficiary preferences for self-directed services, neither Section 1915(j) nor Section 1915(k) has seen more than minimal state take-up.<sup>148</sup> Additionally, in those states that do offer self-direction of services, whether through their state plans or via waiver, at least one study suggests few individuals receiving HCBS participate in the option. In 2012, the National Association of States United for Aging and Disabilities surveyed all fifty states on self-direction in their Medicaid-funded LTSS.<sup>149</sup> In the responding states,<sup>150</sup> only an average of just over 6,000 individuals participated in self-directed Medicaid state plan HCBS.<sup>151</sup> Even fewer, on average, participated in self-directed Medicaid HCBS waiver programs, at an average of 1,200 individuals per waiver.<sup>152</sup>

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12%20Presentations1/HCBS%202012%20Presentations1/Tuesday/400/Potomac%206/MPL%20HCBS%20Conference%20Final.pdf (finding little if any evidence of a woodwork effect emerging between 1995 and 2010).

146. See Eiken et al., *supra* note 145, at 134; LaPlante, *supra* note 145, at 24, 26. See also H. Stephen Kaye, *Gradual Rebalancing of Medicaid Long-Term Services and Supports Saves Money and Serves More People, Statistical Model Shows*, 31 HEALTH AFF. 1195, 1198 (2012) (finding that “states that gradually increased their spending on home and community-based services saved money compared to the amounts that they would have spent had they done nothing to shift expenditures away from institutional services”).

147. See *supra* notes 108-111 and accompanying text.

148. See *supra* notes 108-111 and accompanying text.

149. NAT'L ASS'N OF STATES UNITED FOR AGING & DISABILITIES, CONSUMER DIRECTED PERSONAL CARE SERVICES 1 (2012), available at <http://nasuad.org/documentation/Surveys/Consumer%20Directed%20Services.pdf>.

150. Only 16 states responded, leading to a small sample size. *Id.* at 1.

151. *Id.* at 2.

152. The study offers no information concerning whether this is by participant choice, by state design, or due to some other reason. *Id.*

It may be that states are leery of embracing the marginally increased costs that the Cash and Counseling demonstration states experienced.<sup>153</sup> They may, alternatively, be concerned about the increased risk of fraud and abuse where beneficiaries are permitted to self-direct their services. The Cash and Counseling demonstration found little evidence of increased fraud and abuse in any of the three states participating in the program.<sup>154</sup> However, in 2012 the Office of the Inspector General (OIG) observed that self-directed Medicaid service models, such as Cash and Counseling and CFC, are “particularly vulnerable to ... fraud schemes,” because services are provided largely by unregulated, unskilled, unlicensed providers in unregulated settings.<sup>155</sup> The federal government is particularly concerned about programs that permit beneficiaries to choose family members or friends as caregivers, whom the Department of Justice claims are frequently “ghost employees,” with whom beneficiaries split the money provided to the beneficiary for services.<sup>156</sup> OIG observed in a 2012 report that states lack sufficient resources to sufficiently oversee PCS provision, and had inadequate control over payment.<sup>157</sup> It is true that Medicaid PCS account for the most instances of fraud actions, but the matters are often exceptionally small.<sup>158</sup> In one case, for example, a caregiver was apprehended when his ostensibly service-receiving girlfriend informed the authorities that the caregiver had been collecting payment for services supposedly delivered while the Medicaid beneficiary had in fact been in prison.<sup>159</sup> The amount of money in question totaled only several thousand dollars.<sup>160</sup>

Any salaciousness aside, a common feature of these claims involves a quotidian lack of attention to detail. In seven audits that it completed in 2012, OIG found that the high error rates of most of the states in question involved: (1) failure to provide proper documentation to support billings; (2) failure of services to meet state assessment or prior authorization requirements; (3)

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153. See *supra* note 79 and accompanying text (discussing increased costs of C&C).

154. BROWN ET AL., *supra* note 74, at 40–41.

155. OFFICE OF INSPECTOR GEN., PERSONAL CARE SERVICES: A PORTFOLIO I (2012), available at <http://oig.hhs.gov/reports-andpublications/portfolio/portfolio-12-12-01.pdf> (herein after “Personal Care Services”); JASON WEINSTOCK, OFFICE OF INSPECTOR GEN., PROTECTING PERSONAL CARE SERVICES FROM FRAUD AND ABUSE 3 (2013), available at [http://nasuad.org/documentation/HCBS\\_2013/Presentations/9.11%204.00-5.15%20Washing ton.pdf](http://nasuad.org/documentation/HCBS_2013/Presentations/9.11%204.00-5.15%20Washing%20ton.pdf).

156. Press Release, U.S. Attorney’s Office, Southern District of Illinois, Program Fraud Indictments Announced (July 11, 2013), available at [http://www.justice.gov/usao/ils/News/2013/July/07112013\\_Medicad%20Press%20Release.html](http://www.justice.gov/usao/ils/News/2013/July/07112013_Medicad%20Press%20Release.html) [hereinafter “Fraud Press Release”].

157. WEINSTOCK, *supra* note 155, at 5.

158. PERSONAL CARE SERVICES, *supra* note 155, at ii.

159. Fraud Press Release, *supra* note 156.

160. Press Release, U.S. Attorney’s Office, Southern District of Illinois, “Home Alone 3” (June, 5 2014), available at [http://www.justice.gov/usao/ils/News/2014/Jun/06052014\\_Home%20Alone%203%20Press%20Release.html](http://www.justice.gov/usao/ils/News/2014/Jun/06052014_Home%20Alone%203%20Press%20Release.html).

failure of services to meet state supervision requirements; (4) failure of service providers to meet state qualification and/or training requirements; and (5) overlap of service provision dates with provision of institutional care under Medicare or Medicaid.<sup>161</sup> OIG blamed insufficient state oversight in a number of respects for these problems.<sup>162</sup> These included inadequate monitoring of HCBS programs; inadequate preauthorization processes; ineffective accrediting organizations; failure to document provider qualifications; failure to conduct monitoring site visits of PCS agencies; and inadequate controls to help prevent paying improper PCS claims.<sup>163</sup>

OIG has recommended a number of actions to help prevent fraud in Medicaid PCS. These actions include reducing “significant variation” in state requirements for PCS providers by establishing minimum federal qualification standards; requiring states to enroll or register all PCS providers; and establishing federal standards for documentation of service provision, including a requirement that service dates and provider names be given.<sup>164</sup> It is questionable how likely any of these changes are to be made in the near future. If evidence in other contexts is any guide, states will not likely be eager to yield authority for determining and overseeing these standards to the federal government, and Congress will not be quick to act.<sup>165</sup>

There are no obvious, failsafe solutions to these problems. However, several policy options may offer some improvement. First, the federal government could assume responsibility for LTSS provided to the elderly. Most elderly individuals who qualify for Medicaid also qualify for Medicare: the “dual eligible” population.<sup>166</sup> Most duals receive most of their medical services through Medicare, with Medicaid picking up many or all of the premium payments and out-of-pocket expenses.<sup>167</sup> Medicaid, on the other hand, covers most of duals’ LTSS. For most of the two programs’ history,

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161. *Id.*

162. *Id.*

163. *Id.*

164. PERSONAL CARE SERVICES, *supra* note 155, at 6-7.

165. Juliette Forstener Espinosa, *Reimagining Federal and State Roles for Health Reform Under the Patient Protection and Affordable Care Act*, RESEARCH INSIGHTS 1 (Feb. 3, 2010), <http://www.academyhealth.org/files/publications/ResInsightsReformRoles.pdf>; Abigail R. Moncrieff, *Federalization Snowballs: The Need for National Action in Medical Malpractice Reform*, 109 COLUM. L. REV. 844, 844 (2009).

166. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM: AFFORDABLE CARE ACT PROVISIONS RELATING TO THE CARE OF DUALY ELIGIBLE MEDICARE AND MEDICAID BENEFICIARIES 1 (May 2011), *available at* <http://kff.org/health-reform/issue-brief/affordable-care-act-provisions-relating-to-the/>.

167. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID COVERAGE OF MEDICARE BENEFICIARIES (DUAL ELIGIBLES) AT A GLANCE 1 (September 2014), *available at* <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/MLN-Publications-Items/CMS1244469.html>.



there has been little, if any, coordination between Medicare and Medicaid for duals; hence, duals traditionally have had, and most continue to have, poor, if any, coordination of care, multiple health cards, and multiple rules, grievance processes, etc.<sup>168</sup> As one common example, duals may access Medicare acute care benefits without having to go through any obvious intermediary, but must access Medicaid wrap-around services through managed care.<sup>169</sup> Additionally, even where there is some coordination of Medicare and Medicaid benefits, some services – most notably LTSS – are “carved out” and covered through different (and typically uncoordinated) means.<sup>170</sup> Because of the different payers involved, and because Medicare services are reimbursed more generously in most states than Medicaid services, there is also gamesmanship involved in the provision of services and allocation of responsibility for payment.<sup>171</sup>

The notion of federalizing LTSS and other Medicaid services for the elderly is not a new idea.<sup>172</sup> However –notwithstanding the ACA’s program to better coordinate care for duals – its time may have arrived. Medicaid LTSS for the elderly are fragmented and uncoordinated. Care may be available under several different and overlapping programs. Individuals can try to research programs in their state on their own, but are more likely left needing to seek information and assistance from workers at state agencies or local nonprofit organizations. Federalizing care would make these problems readily solvable. It would simplify the institution of uniform standards for coverage of LTSS nationally, and make it more politically palatable to institute uniform standards for LTSS provider qualification and documentation. Whether the federal

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168. MELANIE BELLA & LINDSAY PALMER, CTR. FOR HEALTH CARE STRATEGIES, INC., ENCOURAGING INTEGRATED CARE FOR DUAL ELIGIBLES 3 (July 2009), *available at* [http://www.chcs.org/media/Integrated\\_Care\\_Resource\\_Paper.pdf](http://www.chcs.org/media/Integrated_Care_Resource_Paper.pdf); DST HEALTH SOLUTIONS, COVERING THE DUAL ELIGIBLE POPULATION (July 2014), *available at* <http://dstsystems.com/assets/static/health-solutions/whitepaper-register2.html>.

169. *See, e.g., Dual-Eligible Beneficiaries of Medicare and Medicaid: Characteristics, Health Care Spending, and Evolving Policies*, CONG. BUDGET OFFICE 11 (2013), [http://www.cbo.gov/sites/default/files/44308\\_DualEligibles2.pdf](http://www.cbo.gov/sites/default/files/44308_DualEligibles2.pdf); *see also* Harris Meyer, *The Coming Experiments in Integrating and Coordinating Care for ‘Dual Eligibles’*, 31 HEALTH AFF. 1151, 1152 (2012).

170. As one option, the federal government could, as it did with the Medicare Part D benefit, use a clawback mechanism by which to extract funding from the states. It would, however, risk another legal action of the sort undertaken by several states following the enactment of Part D, with an uncertain outcome. *See generally* *Texas v. Leavitt*, 126 S.Ct. 2915 (2006) (mem.).

171. *See, e.g.,* David C. Grabowski, *Medicare and Medicaid: Conflicting Incentives for Long-Term Care*, 85 MILBANK Q. 579, 583-585 (2007) (discussing the different ways in which different entities game the system).

172. *See, e.g.,* John Holahan & Alan Weil, *Toward Real Medicaid Reform*, 26 HEALTH AFF. w254, w264 (2007) (suggesting as one of four options that the federal government assume responsibility for all care for those who are dually eligible for Medicare and Medicaid). *See also* Grabowski, *supra* note 171, at 596-97.

government would be willing to pick up the additional expense and administrative burden, however, is another matter.<sup>173</sup>

Alternatively, repealing Section 1915(c) of the Social Security Act is another option. States already have substantial flexibility in their choice of whether and how to cover Medicaid HCBS through state plan options. Under a state plan option, however, states would be prevented from instituting waiting lists or varying coverage based on geography.<sup>174</sup> Elimination of Section 1915(c) waivers would require substantial guidance and support in helping states to transition from such programs, on which nearly all states substantially rely for providing Medicaid HCBS, to state plans or other options. Additionally, because HCBS are optional under Medicaid, it may be that some states will opt to substantially limit or even eliminate coverage despite its cost-effectiveness, rather than risk a potential “woodwork” situation.

Neither of these options is likely to be currently politically palatable. Another politically problematic issue to consider, likely in conjunction with one of the first two, is how best to address the competency and payment of family caregivers. Federal law currently provides states with the option of reimbursing non-legally liable family members for the care they provide.<sup>175</sup> Although some permit this, many states have not taken up this option.<sup>176</sup> Federal law requires that family members meet the licensure or certification requirements of their state if they wish to be eligible for payment for those services.<sup>177</sup> Some types of care and assistance usually pose few problems. Neither the federal government nor some states require that those providing PCS, such as grocery shopping and other homemaking services, be licensed or

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173. See Grabowski, *supra* note 171, at 596-597.

174. See *supra* notes 91-92 and associated text.

175. 42 U.S.C. § 1396n(i)(1)(G)(iii)(III)(cc) (2012); 42 U.S.C. § 1396n(k)(1)(A)(iv)(III) (2012). Legally liable relatives may provide services, at a state’s option, under 42 U.S.C. § 1396n(j)(4)(B)(i) (2012) & 42 U.S.C. § 1396n(j)(4)(C)(ii) (2012). For Personal Assistance Services, instituted under the DRA, see 73 Fed. Reg. 57,854 (2009) (cash and counseling state plan option). See also 42 C.F.R. § 441.478(a) (2013) (giving states the option to permit beneficiaries to hire legally liable relatives for services through the program).

176. States are permitted to do this under the Cash and Counseling and the Community First Choice state plan options. See *supra* notes 74-75 and associated text. Other states permit individuals to hire family members and relatives under a 1915(c) waiver or 1915(i) state plan option for personal care services. See *supra* notes 108-10 and associated text.

177. Note that some states treat licensure and training requirements for family and friends versus HCBS agency employees and contractors differently. See, e.g., NAT’L ASS’N OF STATES UNITED FOR AGING AND DISABILITIES, TRAINING REQUIREMENTS FOR PERSONAL CARE ATTENDANTS: RESULTS OF JANUARY 2012 MINI-SURVEY 2 (2012), available at <http://nasuad.org/documentation/Surveys/Training%20Reqs%20for%20PCAs.pdf> (“[T]raining requirements are more stringent for agency-based PCAs than for consumer-directed PCAs”).

certified in order to be eligible for Medicaid reimbursement.<sup>178</sup> However, states such as New York, North Carolina, and Washington do.<sup>179</sup> Other types of care, such as assistance with transfers and taking medication, are considered more specialized, and those who provide them must meet home health aide requirements. Federal regulation requires home health aides to successfully complete both a seventy-five-hour training program and a state licensure or competency evaluation program.<sup>180</sup> Home health agencies offer the training program for free, but usually require those who attend to work for them for a minimum period of time (e.g., six months).<sup>181</sup> Otherwise, the program may cost several hundred dollars.<sup>182</sup> State licensure or evaluation constitutes an additional investment of time and money.<sup>183</sup>

Family members who provide care to loved ones must undergo training and credentialing when required to do so in order to be eligible for Medicaid reimbursement, just like any other service provider. Yet most of these family members are not looking for a new career; rather, they want simply to ensure that their loved one gets the care that he or she needs. A majority of friends and family who provide LTSS for loved ones are already gainfully employed.<sup>184</sup> In most cases, caregiving requirements disrupt family members' employment. An

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178. NE and WV are among these states. *See, e.g.*, 480 NEB. ADMIN. CODE § 5-001(b) (2012) (requiring staff at adult day care facilities providing personal care services to be overseen by a licensed nurse, but not requiring the personal care services staff themselves to be licensed); W. VA. DEP'T. OF HEALTH & HUMAN RES., WEST VIRGINIA MEDICAID PROVIDER MANUAL: CHAPTER 517- COVERED SERVICES, LIMITATIONS, AND EXCLUSIONS FOR PERSONAL CARE SERVICES 19 (2014) (requiring personal care services to be supervised by a registered nurse, but permitting such services to be rendered by individuals meeting only basic training requirements), *see also* 42 C.F.R. § 440.167 (2013) (detailing federal regulations).

179. OFFICE OF INSPECTOR GEN., PUB. NO. 12-12-01, PERSONAL CARE SERVICES: A PORTFOLIO 4-7 (2012).

180. 42 C.F.R. § 484.4 (2013); 42 C.F.R. § 484.36 (2013).

181. *See, e.g.*, *HHA Training Program*, UNITY HEALTH SYSTEM (2014), <https://www.unityhealth.org/jobs/nursing/training.aspx> (providing an example of free HHA training program and where subsequent employment is offered); *see also* *FREE Home Health Aide Training*, CENTERLIGHT HEALTH SYSTEM (2014), [http://www.centerlight.org/careers/category/free\\_home\\_health\\_aide\\_training](http://www.centerlight.org/careers/category/free_home_health_aide_training) (providing an example of free HHA training program and where employment might be offered at HHA).

182. *See, e.g.*, *American Red Cross offers Home Health Aide training for the first time in Willits*, AM. RED CROSS (Feb. 06, 2013), <http://www.redcross.org/news/article/American-Red-Cross-offers-Home-Health-Aide-training-for-the-first-time-in-Willits> (providing an example of the cost of a HHA training course); *see also* *Home Health Caregiver*, ST. LOUIS CMTY. COLL. (2014), <http://www.stlcc.edu/workforce-solutions/accelerated-job-training/Home-Health-Caregiver.html> (providing an example of the cost of a HHA training course).

183. *See, e.g.*, WASH. REV. CODE § 70.127.080 (2014) (providing application procedure and requirements for licensure in the State of Washington); *see also* WASH. ADMIN. CODE § 246-335-990 (2014) (providing fee amounts for home health agencies in the State of Washington).

184. FEINBERG ET AL., *supra* note 20, at 6.

AARP study found that nearly seventy percent of employed caregivers had to seek accommodation at their workplace for their caregiving responsibilities, including seeking a reduction of work hours and concomitant loss of wages.<sup>185</sup>

As discussed above, evidence suggests that individuals who need assistance with ADLs and IADLs and who are appropriate candidates for home or community-based care do better when they are given the opportunity to choose their own home health care providers.<sup>186</sup> Family and friends are often such caregivers of choice.<sup>187</sup> Yet one might wonder how much sense it makes to require family and friends, most of whom would never consider delivering such services but for a loved one's need, to go through the trouble and expense of attaining qualification and registration, simply so that they may recoup some of their lost wages by obtaining payment from Medicaid. It may instead make better sense to consider alternatives to paying such caregivers through Medicaid. A number of possibilities exist, including, for example enacting paid leave via the Family and Medical Leave Act (FMLA) leave.<sup>188</sup> The FMLA – applicable to employers with fifty employees or more – is long established and works well, at least in its currently uncompensated form, for the large majority of employers subject to its terms.<sup>189</sup> More than four-fifths of American employees work in firms subject to the FMLA.<sup>190</sup> Another possibility would be to offer weekly or monthly public stipends to family members and friends caring for loved ones, rather than payment for specific services rendered. Such a financial program, rather than being administered through Medicaid, would perhaps be more appropriately administered through an entity such as the

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185. *Id.*

186. See generally BROWN ET AL., *supra* note 74.

187. FEINBERG ET AL., *supra* note 20, at 11.

188. Family and Medical Insurance Leave Act, S. 1810, 113th Cong. §§ 5(a), 6(a)-(b)(1), 7(a)(2) (2013).

189. See ABT ASSOCIATES INC., FAMILY AND MEDICAL LEAVE IN 2012: FINAL REPORT 48 (2014).

190. *Statistics about Business Size (including Small Business) from the U.S. Census Bureau: Employment Size of Firms*, U.S. CENSUS BUREAU, <https://www.census.gov/econ/smallbus.html> (last revised Aug. 22, 2012). Note, though, that to be eligible for FMLA leave, employees must also have worked at least 1,250 hours over the most recent 12 months for the employer, meaning an average of at least 24 hours/week, which is more than the standard part-time amount. According to Boaz & Muller (1992), employees who were full time spent 20 fewer hours per week providing unpaid care than part-timers. Rachel F. Boaz & Charlotte F. Muller, *Paid Work and Unpaid Help by Caregivers of the Disabled and Frail Elders*, 30 MED. CARE 2, 149, 157 (1992). The FMLA may accordingly need to be amended to reduce the number of hours needed to qualify for its provisions, if it is to include many part-time workers.

Corporation for National and Community Service, which already has a Senior Corps Program.<sup>191</sup>

Such options, however, are incomplete, pose many problems, and would require far more consideration than what could be given here. Additionally, like the other options proposed above, they are unlikely to garner sufficient political support at present to be implemented at present. This does not mean, however, that such options ought not to be investigated further. Care delivered at home is one-third less expensive than institutional-based care. With respect to self-directed care, individuals who are able to participate in such programs are significantly happier with the care they receive, as well as with their way of life in general, than those who have more limited control over the provision of their services. We should be working to improve these services and make them available to all seniors who need assistance, but who are not so incapacitated that they need institutional care.

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191. One initiative of this service is to “increase the number of frail elderly and people with disabilities receiving assistance from the community to live independently.” CORP. FOR NAT’L & COMM. SERV., SENIOR CORPS OPERATIONS HANDBOOK 9 (2008), available at [http://www.nationalservice.gov/sites/default/files/documents/scp\\_handbook.pdf](http://www.nationalservice.gov/sites/default/files/documents/scp_handbook.pdf).