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## Home and Community-Based Long-Term Services and Supports: Health Reform's Most Enduring Legacy?

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## HOME AND COMMUNITY-BASED LONG-TERM SERVICES AND SUPPORTS: HEALTH REFORM'S MOST ENDURING LEGACY?

MARSHALL B. KAPP\*

The most recent major iteration in the continuous narrative of reform of American health care financing and delivery centers around Congressional enactment of the Affordable Care Act (ACA)<sup>1</sup> at the end of 2009. In its implementation phase, the ACA has been beset (to put it mildly) by a plethora of legal,<sup>2</sup> political,<sup>3</sup> technical,<sup>4</sup> economic,<sup>5</sup> and ethical<sup>6</sup> challenges and the ultimate achievement of the ACA's purported fundamental goal—universal access to affordable, high quality health care—is far from assured. Only time

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1. The Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), was amended by the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010), thus creating the Affordable Care Act.

2. See JOSH BLACKMAN, UNPRECEDENTED: THE CONSTITUTIONAL CHALLENGE TO OBAMACARE xxii-iv (2013).

3. Timothy S. Jost, *Beyond Repeal—A Republican Proposal for Health Care Reform*, 370 NEW ENG. J. MED. 894, 894 (2014).

4. See, e.g., Robert Pear et al., *From the Start, Signs of Trouble at Health Portal*, N.Y. TIMES, Oct. 13, 2013, at A1.

5. See, e.g., BUREAU OF ECONOMIC ANALYSIS, U.S. DEP'T OF COMMERCE, BEA 14-28, GROSS DOMESTIC PRODUCT: FIRST QUARTER 2014 (THIRD ESTIMATE) (2014) (finding that national health care expenditures have exploded with the advent of the ACA); see also Scott Gottlieb, *Here's How Much Health Plan Premiums Spiked Over the Last Four Years of Obamacare's Rollout*, FORBES, <http://www.forbes.com/sites/scottgottlieb/2014/04/07/how-much-have-health-plan-premiums-spiked-over-the-last-four-years-of-obamacares-rollout-heres-the-data/> (Apr. 7, 2014, 5:00pm); see also Letter from Linda E. Fishman, Senior Vice President, Am. Hosp. Ass'n, to Patrick Conway, Acting Dir. of the Innovation Ctr., Ctrs. for Medicare & Medicaid Servs. (Apr. 17, 2014) (submitting that the ACA's models for Accountable Care Organizations (ACOs) will not be sustainable in the long run unless CMS makes significant changes to encourage more provider participation).

6. See U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-14-305R, DEPARTMENT OF HEALTH AND HUMAN SERVICES: SOLICITATIONS OF SUPPORT FOR ENROLL AMERICA 7 (2014) (reporting on successful efforts by the Obama Administration to extract, if not extort, donations from several private entities, including entities directly regulated by DHHS, to be used by DHHS to encourage individuals to apply for government financial benefits provided under the ACA).

will tell whether a number of key components of this highly touted landmark legislation, focusing on expansion of health insurance to new populations, survives, let alone meet the expectations of ACA proponents.<sup>7</sup> As reluctantly acknowledged by one leading fair-minded commentator, “The new law’s full implications will not be known yet for many years, and much of what has been claimed about the law is sadly overblown or unduly self-congratulatory.”<sup>8</sup>

Putting aside the ill-fated Community Living Assistance Services and Supports Act (CLASS) portion of the ACA<sup>9</sup> and some additional public disclosure requirements imposed on nursing facilities,<sup>10</sup> long-term services and supports (LTSS)<sup>11</sup> unfortunately were not a pressing priority of either the ACA drafters or its supporters. It is, therefore, ironic that perhaps one of the most lasting and important legacies of the present health reform era may well be its

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7. See, e.g., Rick Mathis, *The Story of a Law, A Look at Its Future*, 33 HEALTH AFF. 720, 720 (2014) (“[P]ersistent public fears, along with any additional hiccoughs in implementing the ACA, would well endanger the law’s survival beyond the current administration.”); see also David Shivers, *Medical Executive Says Future of Affordable Care Act Unclear*, ALBANY HERALD (Apr. 1, 2014), <http://www.albanyherald.com/news/2014/apr/01/medical-executive-says-future-of-affordable-care/>.

8. Richard L. Kaplan, *Analyzing the Impact of the New Health Care Reform Legislation on Older Americans*, 18 ELDER L. J. 213, 214 (2011). In the same vein, two of the ACA’s strongest proponents admit:

Ultimately, success of the coverage expansions of the law will be judged by their effect on a set of variables: the numbers of uninsured Americans, the adequacy of insurance (which will perhaps best be judged by the number of people who remain underinsured), and the affordability of private coverage. It may take years, however, before we can render a considered judgment on these critical outcomes.

David Blumenthal & Sara R. Collins, *Health Care Coverage under the Affordable Care Act – A Progress Report*, 371 NEW ENG. J. MED. 275, 275 (2014) (citation omitted).

9. See *infra* notes 116-121 and accompanying text.

10. Nursing facilities are now required to disclose, for posting on the CMS Nursing Home Compare website, information regarding: ownership of the facility and any affiliated parties, 42 U.S.C. § 1320a-3(c)(2)(C) (2012); governing board and organization structure, 42 U.S.C. § 1320a-3(c)(2)(A)(ii)-(iii), (5)(D) (2012); staffing data, including number of residents, hours of care per day per resident, staff turnover, and staff length of service, 42 U.S.C. § 1395i-3(i)(1)(A)(i) (2012); number, type, severity, and outcomes of substantiated complaints, 42 U.S.C. § 1395i-3(i)(1)(A)(iv) (2012); adjudicated criminal violations by the nursing facility or its employees, including elder abuse violations that occur outside of the facility, 42 U.S.C. §§ 1395i-3(i)(1)(A)(v)(II), 1396r(i)(1)(A)(v)(II) (2012); and civil monetary penalties levied against the facility, its employees, and its contractors or other agents, 42 U.S.C. § 1395i-3(i)(1)(A)(v)(III) (2012).

11. Over the past several years, the term “Long-Term Supports and Services” has come largely to replace the previously used term “Long-Term Care” in most practice and policy making circles. See, e.g., Julie Robison et al., *Long-Term Supports and Services Planning for the Future: Implications from a Statewide Survey of Baby Boomers and Older Adults*, 54 GERONTOLOGIST 297, 298 (2014). Consequently, the newer vocabulary will be used throughout the present article.

impact on the permanent expansion of home and community-based long-term services and supports (HCBLTSS).

This article discusses the ongoing evolution in the Long-Term Care (LTC) of older<sup>12</sup> Americans<sup>13</sup> away from institutional arrangements and toward HCBLTSS. More specifically, the actual and potential role of the ACA and other facets of health reform in promoting or inhibiting the success of HCBLTSS in meeting the needs of an aging population are analyzed and future challenges are identified.

### I. AN OVERVIEW OF LONG-TERM SERVICES AND SUPPORTS

LTSS “is provided to people who need assistance to perform routine daily activities over an extended period due to disability or chronic illness.<sup>14</sup> It includes a broad range of medical and nonmedical services and supports provided by professionals as well as unpaid care provided by family and friends.<sup>15</sup> LTSS may be provided in community-based or institutional settings.”<sup>16</sup> Approximately fifty-seven percent of the twelve million LTSS recipients in the United States are age sixty-five or older.<sup>17</sup>

Traditionally, the strict demarcation between the two categories of institutional versus home and community-based services (HCBS) depended solely on the type of physical location where the services were provided. Nursing homes, assisted living facilities, and other residential care communities ordinarily were considered loci of institutional care, while adult day service centers, home care (including home health care, personal, and

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12. This article concentrates primarily on HCBLTSS for older persons, but much of the discussion here is also pertinent to younger disabled individuals. The modern initiatives toward HCBLTSS in the aging field owe much of their origin to the Independent Living model pioneered by young disabled adults beginning in the 1960s. *See, e.g.*, Rosalie A. Kane, *Reflections of a Disability Activist: A Conversation with Bob Kafka*, GENERATIONS, Spring 2012, at 64, 64; *see also* Edward F. Ansello, *Public Policy Writ Small: Coalitions at the Intersection of Aging and Lifelong Disabilities*, PUB. POL’Y & AGING REP., Fall 2004, at 1 & 3; *see also* JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 258-68 (1993).

13. This article concentrates on the situation in the United States, but the movement toward HCBLTSS for older individuals with Activity of Daily Living (ADL) impairments is an international phenomenon. *See* JOSHUA M. WIENER ET AL., AARP PUB. POL’Y INST., CONSUMER-DIRECTED HOME CARE IN THE NETHERLANDS, ENGLAND, AND GERMANY 1 (2003), for an international comparison perspective.

14. Robison et al., *supra* note 11, at 298.

15. *Id.*

16. *Id.*

17. *See* H. Stephen Kaye et al., *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*, 29 HEALTH AFF. 11 (2010); CAROL V. O’SHAUGHNESSY, NATIONAL HEALTH POLICY FORUM, NATIONAL SPENDING FOR LONG-TERM SERVICES AND SUPPORTS (LTSS) 2 (2014).

homemaker services), and hospice programs outside of a dedicated hospice “house” have generally been characterized as HCBS.

This rough categorization is in the process of significant change, potentially in both directions.<sup>18</sup> On January 16, 2014, the Centers for Medicare and Medicaid Services (CMS) promulgated a Final Rule amending Medicaid regulations pertaining to the definition of HCBS in state Medicaid plans under the Section 1915(c) waiver program (as amended by the ACA).<sup>19</sup> Under this Rule, for purposes of permitting the federal portion of Medicaid dollars (Federal Financial Participation (FFP) or Federal Medical Assistance Percentage (FMAP)) to be used in a state to purchase HCBLTSS services for an eligible beneficiary, the definition of HCBLTSS will no longer be determined exclusively on the basis of physical location. Rather, federal regulators considering Section 1915(c) waiver applications will look to the nature and quality of client experiences in the care setting. Specifically, to qualify for HCBS designation, a care setting must: be integrated in, and support full access to, the greater community; be selected by the individual from among varied setting options; ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint; optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them.<sup>20</sup> Waiver applications authorized under Section 1915(c) of the Social Security Act (SSA)<sup>21</sup> will be discussed further below.<sup>22</sup>

There are multiple payment sources for LTSS, whether institutional or HCBS.<sup>23</sup> Private sector payment sources may include out-of-pocket payments made by the service receiver or family members or friends on the receiver’s behalf. Payments may be made through private LTC insurance policies.<sup>24</sup> However, when paid, formal care is needed, many people cannot afford to

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18. See, e.g., Mauro Hernandez, *Disparities in Assisted Living: Does It Meet the HCBS Test?*, GENERATIONS, Spring 2012, at 118, 118 (expressing reasons for skepticism about the usual characterization of assisted living as a form of HCBS); see also Robert Jenkins et al., *Can Community-Based Services Thrive in a Licensed Nursing Home?*, GENERATIONS, Spring 2012, at 125, 126 (emphasizing the goals of HCBLTSS, rather than the physical site of service delivery).

19. Home and Community-Based Services Waivers, 79 Fed. Reg. 2,947, 2,947 (Jan. 16, 2014).

20. CTRS. FOR MEDICARE & MEDICAID SERVS., CMS 2249-F/2296-F, FACT SHEET: SUMMARY OF KEY PROVISIONS OF THE HOME AND COMMUNITY-BASED SERVICES (HCBS) SETTINGS FINAL RULE (Jan. 10, 2014).

21. 42 U.S.C. § 1396n(c) (2013); 42 C.F.R. § 441.300 (2000).

22. See *infra* notes 77-85 and accompanying text.

23. INST. OF MEDICINE & NAT’L RESEARCH COUNCIL, FINANCING LONG-TERM SERVICES AND SUPPORTS FOR INDIVIDUALS WITH DISABILITIES AND OLDER ADULTS: WORKSHOP SUMMARY 2 (2014).

24. See generally Yong Li & Gail A. Jensen, *The Impact of Private Long-Term Care Insurance on the Use of Long-Term Care*, 48 INQUIRY 34 (2011) (regarding private long-term care insurance).

cover these expenses out-of-pocket,<sup>25</sup> and very few people purchase private LTC insurance.<sup>26</sup> Public sector payment sources include, most prominently, Medicare (which pays mainly for post-acute care, short-term rehabilitation) and Medicaid (accounting financially for almost half of all national LTC expenditures).<sup>27</sup> “Medicaid is the primary payer for long-term services and supports (LTSS) for four million Americans—children, adults, and seniors—who experience difficulty living independently and completing daily self-care activities as a result of cognitive disabilities, physical impairments, and/or disabling chronic conditions.”<sup>28</sup>

Besides Medicaid, the Older Americans Act funnels federal dollars through a network of State Units on Aging (SUA) and Area Agencies on Aging (AAA) to fund an array of community-based services, such as home-delivered and congregate meals, transportation, senior centers, legal assistance, health promotion, and adult day programs.<sup>29</sup> Many states and localities have authorized programs to serve older community-dwelling residents through separate state or local appropriations or the proceeds of dedicated ballot initiatives. Additionally, the Department of Veterans Affairs provides funding for certain community-based services to eligible veterans and their dependents.<sup>30</sup>

25. Steven Mendelsohn et al., *Tax Subsidization of Personal Assistance Services*, 5 DISABILITY & HEALTH J. 75 (2012) (regarding tax subsidies available to assist with out-of-pocket payments).

26. KAISER COMM’N ON MEDICAID & THE UNINSURED, THE HENRY J. KAISER FAMILY FOUND., FACT SHEET: FIVE KEY FACTS ABOUT THE DELIVERY AND FINANCING OF LONG-TERM SERVICES AND SUPPORTS 2 (Sept. 2013) [hereinafter FIVE KEY FACTS]; Leslie A. Curry, Julie Robison, Noreen Shugrue, Patricia Keenan, & Marshall B. Kapp, *Individual Decision Making in the Non-Purchase of Long-Term Care Insurance*, 49 GERONTOLOGIST 560 (2009).

27. FIVE KEY FACTS, *supra* note 26, at 2; Terence Ng et. al., *Medicare and Medicaid in Long-Term Care*, 29 HEALTH AFF. 22 (2010).

28. KAISER COMM’N ON MEDICAID & THE UNINSURED, THE HENRY J. KAISER FAMILY FOUND., FACT SHEET: MEDICAID LONG-TERM SERVICES AND SUPPORTS: AN OVERVIEW OF FUNDING AUTHORITIES (Sept. 2013), available at <http://kff.org/medicaid/fact-sheet/medicaid-long-term-services-and-supports-an-overview-of-funding-authorities> [hereinafter FUNDING AUTHORITIES]; KIRSTEN J. COLELLO, CONG. RESEARCH SERV., R43328, MEDICAID COVERAGE OF LONG-TERM SERVICES AND SUPPORTS 1 (2013). See also MARYBETH MUSUMECI & ERICA L. REAVES, KAISER COMM’N ON MEDICAID & THE UNINSURED, THE HENRY J. KAISER FAMILY FOUND., MEDICAID BENEFICIARIES WHO NEED HOME AND COMMUNITY-BASED SERVICES: SUPPORTING INDEPENDENT LIVING AND COMMUNITY INTEGRATION, (Mar. 2014), available at <http://kff.org/medicaid/report/medicaid-beneficiaries-who-need-home-and-community-based-services-supporting-independent-living-and-community-integration> (profiling nine older and disabled individuals and their needs for HCBLTCSS).

29. Programs for Older Americans, 42 U.S.C. §§ 3001-3058ff (2010).

30. *Geriatrics and Extended Care: Home and Community Based Services*, U.S. DEP’T OF VETERANS AFF., [http://www.va.gov/geriatrics/guide/longtermcare/Home\\_and\\_Community\\_Based\\_Services.asp](http://www.va.gov/geriatrics/guide/longtermcare/Home_and_Community_Based_Services.asp) (last visited July 21, 2014).

In terms of influencing direction or control over the mundane but essential details of an individual's LTC set-up (the "who, what, where, when, and how" questions), the source of payment for services is the most crucial factor.<sup>31</sup> An individual paying out-of-pocket is economically empowered to exercise full consumer direction. An individual whose care is being purchased through the benefits provided by a private LTC insurance policy similarly can make and effectuate decisions regarding the details of his or her own LTC plan, subject only to restrictive coverage requirements in the insurance policy. By contrast, with one notable exception,<sup>32</sup> historically individuals who were reliant on public funding sources to obtain services had rather limited meaningful input into plan details, with the important choices being directed by the funding agency (ordinarily the state Medicaid agency or its local delegate). Only relatively recently have some strides been made in opening up financial empowerment opportunities for consumer-directed LTSS for consumers unable to pay for their services themselves, by moving from an indemnity model of payment by the government agency to a disability model of enabling the consumer to purchase, and pay for, desired services directly.<sup>33</sup>

One consequence of the traditional funding agency-controlled model of LTC, coupled with the basic statutory structure of the Medicaid program<sup>34</sup> and exacerbated by the unintended transinstitutionalization of severely, chronically mentally ill people, who in earlier times would have resided in large public psychiatric asylums,<sup>35</sup> has been a heavy reliance on nursing homes as the primary locus of care for Medicaid-dependent people with serious Activities of Daily Living (ADL) impairments.<sup>36</sup> "Whereas most HCBS are optional for states, nursing facility care is a mandatory Medicaid state plan service, with the result that states' LTSS spending historically has been skewed in favor of institutional care."<sup>37</sup> States are required to cover nursing facility services, including room and board, for beneficiaries ages twenty-one and over, under

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31. According to the cynical (but accurate) version of the Golden Rule, "He who has the gold gets to make the rules." Tyler Perry, IZ QUOTES (2014), <http://izquotes.com/quote/144577>.

32. *Pension: Aid & Attendance and Housebound*, U.S. DEP'T OF VETERANS AFF., [http://benefits.va.gov/pension/aid\\_attendance\\_housebound.asp](http://benefits.va.gov/pension/aid_attendance_housebound.asp) (last visited July 21, 2014).

33. W. Thomas Smith, *An Overview of Long-Term Care Services and Support in America*, 29 MISS. C. L. REV. 387, 402-03 (2010).

34. See 42 U.S.C. § 1396 (2010); see also Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 954 (2010).

35. GERALD N. GROB, *FROM ASYLUM TO COMMUNITY: MENTAL HEALTH POLICY IN MODERN AMERICA* 268-270 (1991).

36. "In the United States, the supply of nursing home beds was almost twice the supply of residential care community beds, and about six times the allowable daily capacity of adult day services centers." LAUREN HARRIS-KOJETIN ET AL., NAT'L CTR. FOR HEALTH STATISTICS, *LONG-TERM CARE SERVICES IN THE UNITED STATES: 2013 OVERVIEW* 38 (2013).

37. FUNDING AUTHORITIES, *supra* note 28, at 1.

their Medicaid state plan.<sup>38</sup> States have the option to cover nursing facility services for beneficiaries under age twenty-one.<sup>39</sup>

Today, though, in both consumer-directed and agency-directed models, a slow but steady process of policy and infrastructure development has resulted in increasing opportunities, relatively speaking, for HCBLTSS rather than nursing home placement even for Medicaid-dependent people.<sup>40</sup> For the past several decades, the federal government has pushed, at first rather tentatively and experimentally,<sup>41</sup> in this policy direction.<sup>42</sup> Some states have been early adopters and vigorous leaders in this effort,<sup>43</sup> while others have lagged behind.<sup>44</sup> Nonetheless,

[S]tates now have a broad range of coverage options to select from when designing their LTSS programs. In general, Medicaid law provides states with two broad authorities, which either cover certain LTSS as a benefit under the

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38. COLELLO, *supra* note 28, at 5.

39. *Id.*

40. See generally Rosalie A. Kane, *Thirty Years of Home and Community-Based Services: Getting Closer and Closer to Home*, GENERATIONS, Spring 2012, at 6, 9-10.

41. See generally Robert Applebaum, *Channeling: What We Learned, What We Didn't, and What It All Means Twenty-Five Years Later*, GENERATIONS, Spring 2012, at 21 (analyzing the federal government's 1980-1985 Long-Term Care Channeling Demonstration initiative).

42. Bruce C. Vladeck, *Long-Term Care: The View from the Health Care Financing Administration*, in PERSONS WITH DISABILITIES: ISSUES IN HEALTH CARE FINANCING AND SERVICE DELIVERY 19, 21 (Joshua M. Wiener, Steven B. Clauser, & David L. Kennell, eds., 1995). Vladeck states:

[T]here has been significant progress in noninstitutional long-term care. Ten years ago [1985], considerable discussion centered on the need to develop and expand community-based services so that the growing demand for long-term care would not be filled solely by institutions. Last year [1994], HCFA [the predecessor agency to CMS] had an average daily census in Medicaid Home and Community-Based Services Waiver (HCBSW) programs of almost a quarter of a million people—a fraction of the number of people residing in nursing homes on any given day, but an increase of almost exactly 250,000 in average daily census of such programs over the last decade.

*Id.* at 21.

43. See Charley Reed, *A Matter of Balance: Washington and Oregon States' Long-Term-Care System Model*, GENERATIONS, Spring 2012, at 59, 60-61; see also Kathy Leitch et al., *Homecare in Washington State Moves Toward an Independent Provider Attendant Care Model*, GENERATIONS, Spring 2012, at 107, 111.

44. Susan C. Reinhard, *Diversion, Transition Programs Target Nursing Homes' Status Quo*, HEALTH AFF., Jan. 2010, at 44, 45 (“Progress has been understandably uneven among the states.”). The strongest predictor of a state's positive ranking on a comparative scorecard recently issued by the AARP Public Policy Institute was the percentage of the state's Medicaid dollars going to fund HCBLTSS as opposed to nursing homes. See SUSAN C. REINHARD ET AL., AARP, COMMONWEALTH FUND, & SCAN FOUND., RAISING EXPECTATIONS: A STATE SCORECARD ON LONG-TERM SERVICES AND SUPPORTS FOR OLDER ADULTS, PEOPLE WITH PHYSICAL DISABILITIES, AND FAMILY CAREGIVERS 1, 34 (2014), available at [http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard\\_LTSS\\_Scorecard\\_web\\_619v2.pdf](http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf).



Medicaid state plan or cover home and community-based LTSS through a waiver program which permits states to ignore certain Medicaid requirements in the provision of these services.<sup>45</sup>

The number of American nursing home residents aged sixty-five and older decreased by twenty percent from 2000 to 2013.<sup>46</sup> Nursing home occupancy rates are also falling.<sup>47</sup> There are several explanations for the considerable shift among LTSS consumers away from nursing home placement<sup>48</sup> and toward HCBLTSS.<sup>49</sup> First, most (albeit not all)<sup>50</sup> people, even including those with substantial ADL impairments (including dementia),<sup>51</sup> fear nursing home placement and would much prefer to remain at home.<sup>52</sup>

45. COLELLO, *supra* note 28, at summary page.

46. U.S. CENSUS BUREAU, P23-212, 65+ IN THE UNITED STATES: 2010 at 1, 134 (June 2014) available at <http://www.census.gov/content/dam/Census/library/publications/2014/demo/p23-212.pdf>.

47. See Press Release, Nat'l Inv. Ctr. for the Senior Housing and Care Indus., Seniors Housing Occupancy Continues on Upward Path, Rent Growth Accelerates and Construction Level Shows Marginal Decrease (July 11, 2014), available at <https://www.nic.org/press/2014/data-release-july-2014.aspx>.

48. Despite this sizable shift, nursing homes remain an important component, and generally the default response, of the LTC landscape in the United States. *Id.* See also LAUREN HARRIS-KOJETIN ET. AL., NAT'L CTR. FOR HEALTH STATISTICS, LONG-TERM CARE SERVICES IN THE UNITED STATES: 2013 OVERVIEW 26 (2013) ("On any given day in 2012, there were . . . [on average] 1,383,700 residents in [American] nursing homes."); Christine E. Bishop & Robyn Stone, *Implications for Policy: The Nursing Home as Least Restrictive Setting*, 54 GERONTOLOGIST S98, S102 (2014) ("[A] residential setting offering 24-hr licensed nursing care and substantial personal assistance may still be the least restrictive accommodating place to live for some older adults and persons with disability— better from the perspective of autonomy and dignity as well as quality and cost.")

49. Regarding the financial implications of this shift for the LTC industry, see Tim Mullaney, *Nursing Homes Suffering from Reimbursement Shifts to Home Care, Market Analysis Finds*, MCKNIGHT'S LONG-TERM CARE NEWS & ASSISTED LIVING (May 14, 2014), [http://www.mcknights.com/nursing-homes-suffering-fromreimbursement-shifts-to-home-care-market-analysis-finds/article/346816/?DCMP=EMCMCK\\_Daily&spMailingID=8587935&spUserID=MjMzMDEzNTYzNwS2&spJobID=3014](http://www.mcknights.com/nursing-homes-suffering-fromreimbursement-shifts-to-home-care-market-analysis-finds/article/346816/?DCMP=EMCMCK_Daily&spMailingID=8587935&spUserID=MjMzMDEzNTYzNwS2&spJobID=3014).

50. See Complaint at 12, 23-24, Carey et al. v. Christie, No. 1:12-cv-02522-RBM-AMD (D.N.J. 2012); see also Sciarillo ex rel. St. Amand v. Christie, No.113-03478 (SRC), 2013 BL 345071, at \*8-10 (D.N.J. 2013) (trying to compel states to keep institutions available for those who might want to continue to live in them, under a theory of the positive right of willing Medicaid beneficiaries to remain institutionalized).

51. Debra L. Cherry, *HCBS Can Keep People With Dementia at Home*, GENERATIONS, Spring 2012, at 83, 83 ("Most people with Alzheimer's or vascular dementia prefer to be cared for at home, so more than 80 percent of dementia care is provided in the community by families— whether blood or fictive.")

52. See Marshall B. Kapp, "A Place Like That": *Advance Directives and Nursing Home Admissions*, 4 PSYCHOL., PUB. POL'Y & L. 805, 805-06 (1998) (discussing the antipathy of most people toward the thought of life in a nursing home).

[O]lder people still generally prefer to age in place in their own homes, often because they fear that moving to a collective or institutional living environment will inevitably mean losing their independence. Theorists have explained this fear as reflecting the disempowering effect of institutional settings in reducing people's sense of self-determination, in creating and reinforcing dependencies through their organizational structures, and in reducing personal and functional independence because they are run as impersonal and regimented living environments. From the perspectives of policy makers, practitioners, and older citizens themselves, remaining independent in later life has therefore often been synonymous with remaining in one's own home for as long as possible.<sup>53</sup>

Moreover, family members often support this sentiment,<sup>54</sup> as do many professionals in gerontology.<sup>55</sup> Many individuals also are apprehensive about losing their sense of purpose in life if they move to a senior living setting.<sup>56</sup>

Second, there is widespread support for the position that HCBLTSS usually is cost-effective in the long run as compared to providing institutional care.<sup>57</sup> This belief that "the most effective way to lower long-term care costs, and to delay or prevent [more expensive] nursing home placement, is through home and community based services (HCBS),"<sup>58</sup> appears to be substantiated by the available empirical evidence.<sup>59</sup> "Community-based [LTSS] can be

53. Sarah Hillcoat-Nallétamby, *The Meaning of "Independence" for Older People in Different Residential Settings*, 69B J. OF GERONTOLOGY: SERIES B: PSYCHOL. SCI. & SOC. SCI. 419, 419 (2014).

54. Carol Levine et al., *Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care*, 29 HEALTH AFF. 116, 118 (2010) ("Rebalancing long-term care away from institutions and toward home and community-based services is a policy goal shared by older adults and their family caregivers, albeit for different reasons.").

55. *But see* Naomi Karp & Erica Wood, *Choosing Home for Someone Else: Guardian Residential Decision-Making*, 2012 UTAH L. REV. 1445, 1463 (2012) (finding that considerations of client needs and safety are paramount concerns of guardians deciding upon residential placements for their clients).

56. Wendy Lustbader, *It All Depends on What You Mean by Home*, GENERATIONS, Winter 2013-14, at 20.

57. Charlene Harrington et al., *Do Medicaid Home and Community Based Service Waivers Save Money?*, 30 HOME HEALTH SERV. QUART. 198, 201-202 (2011).

58. Christopher M. Kelly & Jerome Deichert, *A Cost-Effective Way to Care for an Aging Population*, GOVERNING (Mar. 31, 2014), <http://www.governing.com/gov-institute/voices/col-aging-population-cost-effective-homecommunity-based-care.html>.

59. Wendy Fox-Grage & Jenna Walls, *State Studies Find Home and Community-Based Services to Be Cost-Effective*, AARP PUB. POL'Y INST. SPOTLIGHT 2 (Mar. 2013), [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf). *But see* 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, 143 (2013) ("The data do not provide strong evidence that the shift toward HCBS significantly increased or decreased Medicaid spending.").

substantially less expensive than institutional care.”<sup>60</sup> This comparative cost-effectiveness is largely attributed to the fact that HCBLTSS frequently relies heavily upon the unpaid (“informal”)<sup>61</sup> support provided by family members and friends, whereas institutional care is more dependent on paid professionals. The centrality of family and friends’ support is discussed further below.<sup>62</sup>

Caution must be exercised, however, in placing too much emphasis on the cost-effectiveness proposition.

Ironically, although we celebrate evidence-based practice in some spheres, this shift in LTSS [from institutional to HCB services] has occurred with little or no empirical evidence of its efficacy or comparative effectiveness. Like the civil rights and disability rights movements before it, this change was doing the right thing . . . [S]urprisingly few studies have compared the effectiveness of community and institutional care for older people . . . Rather than bemoan the dearth of hard evidence that HCBS is more cost effective than nursing homes, it is time to concentrate on applied research about which characteristics of HCBS work best for which goals and for whom.<sup>63</sup>

As a third explanation for the deinstitutionalization of LTC, there is believed to be a robust connection between feelings of independence, fostered by participation in HCBLTSS, and experienced quality of life.<sup>64</sup> It must be acknowledged, however, that a small number of commentators have speculated about the potential negative effects of reduced external oversight and accountability with HCBLTSS as compared to the pervasive regulatory web<sup>65</sup>

60. Karp & Wood, *supra* note 55, at 1469. *But see* Leitch et al., *supra* note 43, at 110-11 (explaining that unionization of caregivers and the associated collective bargaining process has caused the cost of HCB to increase dramatically).

61. Lynn Friss Feinberg, *Family Caregiving: There’s Nothing Informal About It*, AARP BLOG (May 1, 2014), <http://blog.aarp.org/2014/05/01/family-caregiving-theres-nothing-informal-about-it/>.

62. *See infra* notes 129-44 and accompanying text.

63. Robert L. Kane & Rosalie A. Kane, *HCBS: The Next Thirty Years*, GENERATIONS, Spring 2012, at 131, 131-32. For critiques of the philosophy that social policies and programs ought to be based on intuition about “doing the right thing,” without requiring proof that those policies and programs will actually work to effectively produce desired long-term results for the intended beneficiaries, *see, e.g.*, MARVIN OLASKY, *THE TRAGEDY OF AMERICAN COMPASSION* 101 (1992) (explaining the failure of compassionate American social welfare policy to alleviate the problems of poverty); *see also* THERESA FUNICIELLO, *TYRANNY OF KINDNESS: DISMANTLING THE WELFARE SYSTEM TO END POVERTY IN AMERICA* 210-11 (same).

64. MARY JO GIBSON, AARP PUB. POL’Y INST., *BEYOND 50.3: A REPORT TO THE NATION ON INDEPENDENT LIVING AND DISABILITY* (2003), *available at* [http://assets.aarp.org/rgcenter/il/beyond\\_50\\_il.pdf](http://assets.aarp.org/rgcenter/il/beyond_50_il.pdf).

65. *See generally* MARSHALL B. KAPP, *THE LAW AND OLDER PERSONS: IS GERIATRIC JURISPRUDENCE THERAPEUTIC?* 29-67 (2003) (regarding the regulatory web engulfing nursing facilities in the United States).

generally encompassing the nursing facility environment.<sup>66</sup> Thus far, though, compelling national scandals regarding the former have not emerged, but reports of awful nursing facility resident mistreatment are still plentiful.<sup>67</sup>

Finally, the states are under legal<sup>68</sup> and associated political advocacy<sup>69</sup> pressure to provide LTSS to beneficiaries whose care is subsidized by Medicaid or other state funds in the most integrated service setting possible, if that is the client's desire. The most integrated service setting model driving many state deinstitutionalization initiatives<sup>70</sup> is based on the Supreme Court's interpretation of Title II (Public Services) of the Americans with Disabilities Act (ADA)<sup>71</sup> in *Olmstead v. L.C.*,<sup>72</sup> where the plurality opinion held that:

[s]tates are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.<sup>73</sup>

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66. Howard Gleckman, *We All Want to Live at Home in Old Age, But Know Nothing About the Quality of Care We'll Get There*, FORBES (Mar. 19, 2014, 11:11 PM), <http://www.forbes.com/howardgleckman/2014/03/19/we-all-want-to-live-at-home-in-old-age-but-know-nothing-about-the-quality-of-care-we'll-get-there/>; Will Pridmore, *Expanded Home and Community-Based Services Under the PPACA and LGBT Elders: Problem Solved?*, 22 ANNALS OF HEALTH L. 108, 119 (2013).

67. OFFICE OF INSPECTOR GEN., DEP'T OF HEALTH & HUMAN SERVS., OEI-06-11-00370, ADVERSE EVENTS IN SKILLED NURSING FACILITIES: NATIONAL INCIDENCE AMONG MEDICARE BENEFICIARIES (2014).

68. Robert Garner, *Litigation as a Tool for Forcing Accountability in State-Based Long Term Care Settings for the Intellectually and Developmentally Disabled: An Illinois Focus*, 22 ANNALS OF HEALTH L. 121, 126-27 (2013).

69. See, e.g., Letter from Cindy Mann, Dir., Ctrs. for Medicare & Medicaid Servs., to State Medicaid Directors (May 20, 2010), available at <http://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd10008.pdf>; see also Herb Sanderson, *Improving Long-Term-Care Supports Means Advocating Inside and Out*, GENERATIONS, Spring 2012, at 74, 75.

70. Dann Milne, *Olmstead, New Freedom and Real Choice System Change Grants: Bringing the Disability Movement to Older Adults*, GENERATIONS, Spring 2012, at 44, 45-46 (regarding state deinstitutionalization initiatives).

71. 42 U.S.C. §§ 12101-12213 (2012).

72. *Olmstead v. Zimring*, 527 U.S. 581, 582 (1999). The scholarly literature analyzing *Olmstead* and its LTC implications is voluminous. See, e.g., Kevin M. Cremin, *Challenges to Institutionalization: The Definition of "Institution" and the Future of Olmstead Litigation*, 17 TEX. J. C.L. & C.R., 143, 144 (2012) (analyzing *Olmstead* and its LTC implications.); see also Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 4 (2012).

73. See *Olmstead*, 527 U.S. at 582.

## II. HCBLTSS PRE-ACA OPPORTUNITIES FOR MEDICAID BENEFICIARIES

State HCBLTSS deinstitutionalization initiatives, in partnership with the federal government, were well underway prior to enactment of the ACA.<sup>74</sup> The review of pre-existing HCBLTSS programs presented here certainly is not comprehensive.<sup>75</sup> However, two of the most important pre-ACA opportunities for accomplishing non-institutional care of people who are both dependent on public funding and characterized by significant impairments in carrying out multiple ADLs were the Section 1915(c) Medicaid waiver program and the Cash and Counseling Option.<sup>76</sup>

### A. Section 1915(c) Waivers

As explained earlier,<sup>77</sup> Section 1915(c) of the SSA, enacted as part of the Omnibus Budget Reconciliation Act (OBRA) of 1981,<sup>78</sup> permits states to apply to the Department of Health and Human Services (HHS) for initial three-year waivers (thereafter renewable for five-year periods) to use Medicaid dollars, including the FMAP, to pay for the following community-based services for Medicaid beneficiaries who otherwise would require institutional care: case management, homemaker/home health aide/personal care services, adult day care, habilitation, respite, day treatment/partial hospitalization, psychosocial rehabilitation, chronic mental health clinic services, and other services as approved by HHS.<sup>79</sup> Enrollment caps and population targeting are permitted and statewide application is not required. The service plan may be administered under either a consumer-directed or agency model.<sup>80</sup> Section 1915(c) waivers are often referred to generally as HCBS waivers.<sup>81</sup>

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74. See Press Release, The White House Office of Press Sec'y, President Obama Commemorates Anniversary of *Olmstead* and Announces New Initiatives to Assist Americans with Disabilities, (June 22, 2009) (on file with White House Office of Press Secretary); see also CTR. FOR MEDICAID, CHIP, & SURVEY & CERTIFICATION, DEP'T OF HEALTH & HUMAN SERVS., SMDL# 10-008, COMMUNITY LIVING INITIATIVE (2010) [hereinafter COMMUNITY LIVING INITIATIVE]. The Community Living Initiative (CLI) was created in 2009.

75. See generally COLLELO, *supra* note 28; see also FUNDING AUTHORITIES, *supra* note 28, at 2.

76. See *supra* note 17; see also Deficit Reduction Act of 2005, Pub. L. 109-171, § 6086, 120 Stat. 4 (2006).

77. See *supra* note 21 and accompanying text.

78. Omnibus Budget Reconciliation Act (OBRA) of 1981, Pub. L. No. 97-35, 95 Stat. 357 (1981); 42 C.F.R. §440.70(b)(3) (1998).

79. See Bagenstos, *supra* note 72, at 2.

80. See FUNDING AUTHORITIES, *supra* note 28, at 2.

81. COLLELO, *supra* note 28, at 17-18. In a related vein, under § 1115 of the Social Security Act, codified at 42 U.S.C. § 1315(a), DHHS may approve 3 to 5-year waivers allowing states to use Medicaid funds in ways that would not otherwise be permissible under 42 U.S.C. § 1396a for experimental, pilot, or demonstration projects that are likely to assist in promoting Medicaid program objectives and are projected to be budget neutral. See ROBIN RUDOWITZ ET AL., KAISER

The January 16, 2014 regulatory changes to this waiver program attempt to ensure that the services funded under this waiver are homelike in spirit and environment beyond just their physical setting. One important aspect is the new requirement of a person-centered planning process involving an assessment of family caregivers' needs,<sup>82</sup> expanding on a mandatory basis a practice that states had only engaged in voluntarily and haphazardly previously.<sup>83</sup> States will be expected to take a more active role in promoting choice and control by consumers over the services they receive with public dollars.<sup>84</sup> It is expected that consumer advocates will closely monitor state performance in this arena.<sup>85</sup>

### B. Cash and Counseling Option

Between 1996 and 2009, three states (Arkansas, Florida, and New Jersey) received demonstration grant funding and technical assistance for implementing programs, and twelve others received grant funding and technical assistance for replicating programs, under the auspices of a "Cash and Counseling" initiative jointly conducted by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation of HHS.<sup>86</sup> The Cash and Counseling State Medicaid Plan option

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COMM'N ON MEDICAID & THE UNINSURED, ISSUE BRIEF: THE ACA AND RECENT SECTION 1115 MEDICAID DEMONSTRATION WAIVERS, (Feb. 2014), available at <http://kaiserfamilyfoundation.files.wordpress.com/2014/02/8551-the-aca-and-recent-section-1115-medicaid-demonstration-waivers1.pdf> (last visited July 21, 2014). The ACA imposed new requirements regarding the process through which DHHS considers and approves §1115 experimental, pilot, or demonstration projects, specifically mandating transparency in the review of applications for new projects or extensions of existing projects, an opportunity for public comment on applications, and the DHHS Secretary publishing public evaluations of each waiver annually and at the conclusion of a project. See Sidney Watson, Presentation at 37<sup>th</sup> Annual Health Law Professors Conference of American Society of Law, Medicine & Ethics, Medicaid's Messy Federalism: Welfare, Social Insurance & Social Justice (June 6, 2014), available at <http://hlp2014.conferencespot.org/56819-aslmea-1.1178563/t-002-1.1178936/f-005-1.1179055/a-007-1.1179056/ap-028-1.1179057>.

82. 42 C.F.R. § 441.720(a)(2) (2014).

83. KATHLEEN KELLY ET AL., AARP PUB. POL'Y INST., PUB. NO. 2013-13 11-12, LISTENING TO FAMILY CAREGIVERS: THE NEED TO INCLUDE FAMILY CAREGIVER ASSESSMENT IN MEDICAID HOME- AND COMMUNITY-BASED SERVICE WAIVER PROGRAMS, (Dec. 2013).

84. Wendy Fox-Grage, *The New Federal Rule on Home and Community-Based Services: All Eyes on the States*, AARP BLOG (Feb. 12, 2014), <http://blog.aarp.org/2014/02/12/the-new-federal-rule-on-home-and-community-based-services-all-eyes-on-the-states/>.

85. See generally Eric Carlson et al., *Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS*, NAT'L SENIOR CITIZENS LAW CTR. (May 2014), <http://www.nslc.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf>.

86. ROBERT WOOD JOHNSON FOUND., GRANT ID NO. CAS, CASH & COUNSELING (June 11, 2013), available at [http://www.rwjf.org/content/dam/farm/reports/program\\_results\\_reports/2013/rwjf406468](http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2013/rwjf406468).

was created by the Deficit Reduction Act of 2005 (DRA) as Section 1915(j) of the SSA.<sup>87</sup> If a state successfully applies to HHS to include this optional program in its Medicaid State Plan, then the state is permitted to offer eligible individuals cash or vouchers with which to arrange their own HCBLTSS. Within certain regulatory constraints, the Medicaid beneficiary is authorized to “exercise choice and control over the budget, planning, and purchase of self-directed personal care services, including the amount, duration, scope, provider, and location of service provision.”<sup>88</sup> This is a budget authority model of participant-directed services (PDS).<sup>89</sup>

Case managers are available to counsel the consumer/participant in managing his or her budget through the HCBLTSS assembly and management process. As noted by one commentator, “The [Cash and Counseling] program is important because it shows that, with proper support (‘counseling’), persons with mild cognitive impairment can still direct their personal care in a way that respects independence and enhances quality of life.”<sup>90</sup> The program is a good example of the concept that policy scholars Richard Thaler and Cass Sunstein label “libertarian paternalism,” in which individual choice is respected and maximized, but its practical exercise is informed and “nudged” by the accompanying “choice architecture.”<sup>91</sup> This approach contrasts with a strong paternalism that would sacrifice consumer choice for the sake of maximizing external regulatory protection.<sup>92</sup>

### III. IMPACT OF THE ACA ON HCBLTSS

Title II, Subtitle E, Section 2406 of the ACA contained a Sense of the Senate that “Congress should address long-term services and supports in a comprehensive way that guarantees elderly and disabled individuals the care

87. Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6087, 120 Stat. 4 (2006). *See also* Julia Belian, *State Implementation of the Optional Provisions of the Deficit Reduction Act*, 9 MARQ. ELDER’S ADVISOR 63, 82-83 (2007).

88. Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57,854 (Oct. 3, 2008) (to be codified at 42 C.F.R. pt. 441).

89. Pamela Doty et al., *How Does Cash and Counseling Affect the Growth of Participant-Directed Services?*, GENERATIONS, Spring 2012, at 28, 28.

90. Sarah Moses, *A Just Society for the Elderly: The Importance of Justice as Participation*, 21 NOTRE DAME J. L. ETHICS & PUB. POL’Y 335, 360 (2007). *See also* Pamela Doty et al., *New State Strategies to Meet Long-Term Care Needs*, 29 HEALTH AFF. 49 (2010) (evaluating the federal Cash and Counseling demonstration project as successful despite challenges related to costs, staffing and organizational issues, new infrastructure requirements, and resistance from some stakeholders).

91. *See generally* RICHARD H. THALER & CASS R. SUNSTEIN, *NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS* (2009).

92. *See, e.g.*, Eric M. Carlson, *Trends and Tips in Long-Term Care: Who Benefits — or Loses — From Expanded Choices?*, 18 ELDER J. L. 191 (2010).

they need.”<sup>93</sup> One prong of fulfilling that aspiration entails encouraging the expansion of HCBLTSS. “States have been working to rebalance their LTSS spending and can expand HCBS through waivers and options newly established and expanded by the Affordable Care Act; incentives for states to expand the range of HCBS include enhanced federal funding, flexibility in setting financial eligibility levels and needs based criteria, and population targeting.”<sup>94</sup> In this way,

The Affordable Care Act statute signed into law by President Obama in March 2010 expands the scope of the CLI and opportunities available to states to promote and support community living for people with disabilities. This expanded role deepens the focus on the relationship between home and community-based services and accessible, affordable medical services.<sup>95</sup>

The ACA is likely to exert an impact in the HCBLTSS arena both by authorizing expansions of pre-existing programs and the creation of new HCBLTSS options for the states, and hence for their citizens.

#### A. *Section 1915(i) Expansion*

Pursuant to the DRA, Section 1915(i) of the SSA authorized states to include an optional provision in their State Medicaid Plans under which they could use Medicaid funds, including the FMAP, to provide HCBLTSS to eligible individuals. Prior to that enactment, a state could use Medicaid funds for that purpose only if it obtained a Section 1915(c) State Medicaid Plan waiver; that is, states could not incorporate spending on HCBLTSS as an option in the Plan itself. The ACA further expands the range of state flexibility under Section 1915(i) by: making more potential consumers financially eligible for Section 1915(i) HCBLTSS; creating new optional Medicaid eligibility groups; allowing states to target specific populations rather than requiring universal application; and expanding the roster of services the states may offer to consumers.<sup>96</sup>

#### B. *Community First Choice State Plan Option*

The ACA, through Section 1915(k) of the SSA, authorizes states to include a Community First Choice (CFC) Option in their respective State Medicaid Plans.<sup>97</sup> Under this option, states are authorized to use Medicaid funds to purchase HCBS attendant services and supports (personal care services (PCS))

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

94. FUNDING AUTHORITIES, *supra* note 28, at 1.

95. COMMUNITY LIVING INITIATIVE, *supra* note 74.

96. FUNDING AUTHORITIES, *supra* note 28, at 2.

97. Home and Community-Based Services Waivers, 79 Fed. Reg. 2948, 2949 (Jan. 14, 2014).



for individuals who otherwise would need an institutional level of care. Individuals with incomes up to 150% of the federal poverty level, or up to the state limit for nursing facility services if higher, are eligible to receive support.<sup>98</sup> Participating states will receive a permanent six percent increase in their FMAP for CFC services.<sup>99</sup> States are allowed to choose an agency or a consumer-directed service delivery model under this option, or a combination of each.

### C. *Money Follows the Person*

Created originally by the DRA 2006 at the urging of the National Association of States United for Aging and Disabilities (NASUAD), the Money Follows the Person (MFP) Demonstration Program authorized the awarding of federal grants to assist states to transition Medicaid-dependent persons out of institutions and back to home or community settings.<sup>100</sup> States choosing to experiment with this program have found the transition process to be very complex.<sup>101</sup> The ACA amended the DRA and attempts to incentivize states to participate in the MFP grant program by offering enhanced FMAP for qualified services for one year for each beneficiary who successfully transitions back to a community setting. Also, Medicaid funds can be used now under MFP for supplemental services (“extra HCBS,” such as overnight companions, additional hours for a personal care worker, and peer support to help people adapt to life outside an institution) that would not otherwise match (with federal dollars) to facilitate the institutional-HCBLTSS transition.

### D. *Home Health Services Option*

The ACA offers states a new State Medicaid Plan choice to provide home health services (including comprehensive care management, care coordination, health promotion, comprehensive transitional care/follow-up, consumer and family support, referral to community and social support services) for Medicaid-eligible recipients satisfying certain qualifications. To be qualified, a person must have either at least two chronic conditions, one chronic condition and be at risk for a second, or a serious and persistent mental health condition.<sup>102</sup> The incentive for states to voluntarily participate in this program

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98. *Id.*

99. *Id.*

100. For earlier historical background, see Susan C. Reinhard, *Money Follows the Person: Un-burning Bridges and Facilitating a Return to the Community*, GENERATIONS, Winter 2012, at 52, 53-54 (2012).

101. See Dena Stoner & Marc S. Gold, *Money Follows the Whole Person in Texas*, GENERATIONS, Winter 2012, at 91, 91-93 (2012).

102. FUNDING AUTHORITIES, *supra* note 28, at 2.

is the promise of a two-year ninety percent-enhanced FMAP per enrolled beneficiary.<sup>103</sup>

*E. Balancing Incentive Program*

The ACA creates a Balancing Incentive Program (BIP) under the title “Incentives for States to Offer Home and Community-Based Services as a Long-Term Care Alternative to Nursing Homes.”<sup>104</sup> BIP supplies federal matching funds through September 2015, to encourage states to initiate specific structural reforms to move Medicaid LTSS consumers out of institutions and into the community.<sup>105</sup> The required structural reforms include a “no wrong door—single entry point system” for enrolling consumers, “conflict-free case management services,” and the use of core standardized assessment instruments to determine a consumer’s needs and design that person’s services and supports plan.<sup>106</sup> The financial incentive is structured such that the worse a state had been in the past in terms of its bias toward spending its Medicaid money on institutional rather than community-based LTC, the bigger its FMAP increase under BIP.<sup>107</sup>

*F. Spousal Impoverishment*

The ACA contains a temporary (set to expire December 31, 2019) expansion of spousal impoverishment protections for individuals who qualify for Medicaid HCBLTSS. Pursuant to this provision, states must disregard the income of the non-service-receiving (community) spouse, who may keep half of the couple’s joint assets without jeopardizing the Medicaid eligibility of the individual who is receiving services.<sup>108</sup> Previously,<sup>109</sup> this disregard of a community spouse’s assets applied only if the Medicaid eligible service recipient resided in a nursing home.<sup>110</sup> The ACA expansion protects community spouses of all HCBLTSS waiver participants, as well as those who qualify for the HCBLTSS state plan benefit and the community-based attendant services benefit. The rationales for this mandate to the states are to assure that spouses of individuals needing LTC are not forced to sell the family home and other assets to pay for the needed LTC and to make sure that the

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103. *Id.*

104. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 10201, 124 Stat. 923 (2010).

105. Patient Protection and Affordable Care Act § 10201 at 927.

106. *Id.*

107. FUNDING AUTHORITIES, *supra* note 28, at 2.

108. Patient Protection and Affordable Care Act § 2404 (codified at 42 U.S.C. § 1396r-5).

109. Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6071 (b)(2), 120 Stat. 4, 103 (2006), *amended by* Patient Protection and Affordable Care Act § 2404.

110. *Id.*

community spouse has enough income to live comfortably at home himself or herself. This spousal impoverishment provision predictably should improve access to HCBLTSS for people whose combined marital assets previously precluded them from Medicaid eligibility,<sup>111</sup> although concern has been expressed that the resulting substantial additional costs to the Medicaid program might motivate Congress to eventually eliminate the community spousal protection altogether.<sup>112</sup>

#### IV. POLICY AND PRACTICAL CHALLENGES

Successful realization of the potential benefits promised by the provisions in the ACA enumerated above is not assured. A number of significant policy and practical challenges must be identified, investigated, and addressed. The following list by no means purports to be all-encompassing, but it does include some of the most pressing areas requiring attention.

##### A. Funding

Foremost, of course, is the issue of securing and sustaining sufficient public funding for HCBLTSS. ACA supporters had hoped that the funding question would essentially be solved, or at least much softened, by including in the massive health reform legislation a Title VIII entitled “Community Living Assistance Services and Supports Act.” The CLASS Act purported to create a voluntary public LTC insurance product that would make HCBLTSS affordable for middle class people who need it,<sup>113</sup> thereby reducing reliance by this segment of the population on a Medicaid program originally designed to subsidize care for the poor but which had morphed into a planned *de facto* LTC financing mechanism for many individuals whose eligibility for Medicaid might have been avoided.

Under the CLASS Act, either the enrollee or the enrollee’s spouse would have had to be employed and pay premiums into the system for five years before receiving any benefits.<sup>114</sup> Once an individual became eligible by developing two functional disabilities, the benefit would have consisted of a

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111. Charlene Harrington et al., *Medicaid Home-and Community-Based Services: Impact of the Affordable Care Act*, 24 J. AGING & SOC. POL’Y 169, 184 (2012).

112. Deborah Moldover, *An Analysis of the Federal Medicaid Statute’s Spousal Anti-Impoverishment Provision in Light of the Patient Protection and Affordable Care Act’s Medicaid Expansion and Current Federal Budgetary Constraints*, 22 ANNALS HEALTH L. ADVANCE DIRECTIVE 158, 167-168 (2013), available at <http://www.luc.edu/media/lucedu/law/centers/healthlaw/pdfs/advancedirective/pdfs/issue10/moldover.pdf> (last visited Aug. 24, 2014).

113. John Inglehart, *Long-Term Care Legislation at Long Last?*, 29 HEALTH AFF. 8, 8-9 (2010).

114. Marc Gregory Cain, *The Effects of the Patient Protection and Affordable Care Act on Medicaid: Will Seniors Have More Long-Term Care Options and an Easier Application Process?*, 4 EST. PLAN. & COMMUNITY PROP. L.J. 127, 141 (2011).

fifty-dollar per day cash payment, with no lifetime limits, that could have been used to pay for a nursing facility or to keep the beneficiary at home.<sup>115</sup>

The inherent and insurmountable problem with the CLASS Act was that its defective structural design made it financially nonviable from the very outset.<sup>116</sup> Participation was voluntary (in contrast to the mandatory health insurance individual purchase Maintain Minimum Essential Coverage provisions in the ACA).<sup>117</sup> For many people, the terms of taking part in CLASS (that is, the projected long-term payments versus benefits ratio) did not seem very inviting. That factor, coupled with the statutory prohibition on CLASS insurance underwriting by carriers (i.e., a prohibition against rejection of an applicant because that person was a member of a high risk category) made it highly predictable that the adverse selection problem<sup>118</sup> for CLASS would be at least as serious as—if not much worse than—the main problem that has inhibited the growth of private LTC insurance as a solution to the funding conundrum. As one commentator described the probable insurance “death spiral”:

Because those at greater risk for LTC will be more likely to enroll, on average, the result will be higher program costs overall, which, in causing premiums to rise, will further discourage better than average risks from participating. This, in turn, could make it even more difficult to spread program costs over a large population, thereby resulting in still higher premiums, possibly leading to the departure of additional better than average risks and so on down the line.<sup>119</sup>

By October of 2011, the Administration begrudgingly acknowledged financial reality and publicly announced that it would cease any efforts to implement CLASS.<sup>120</sup> In January 2013, Congress mercifully repealed CLASS

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115. *Id.* at 142.

116. Alexander N. Daskalakis, *Public Options: The Need for Long-Term Care, Its Costs, and Government's Attempts to Address Them*, 5 ST. LOUIS U. J. HEALTH L. & POL'Y. 181, 183 (2011) (“Although CLASS was designed to expand the number of Americans covered by non-Medicaid long-term care insurance, it was set up in a way that made it very difficult, if not impossible, to remain a fiscally solvent program without an alternative source of funding . . . under its current structure, the CLASS program could not have realistically remained fiscally solvent.”).

117. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1501, 124 Stat. 119, 242-244 (codified at 42 U.S.C. § 18091 (2012)). The Maintain Minimum Essential Coverage provision was upheld by the United States Supreme Court as a legitimate exercise of the Congressional Taxing and Spending power in *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S.Ct. 2566, 2593-2601 (2012).

118. Daskalakis, *supra* note 116, at 194 (“[a]dverse selection occurs when there are too many high-risk enrollees [i.e., enrollees who are likely to claim the benefits of the insurance policy sooner rather than later] and not enough low-risk enrollees.”).

119. Edward Alan Miller, *Flying Beneath the Radar of Health Reform: The Community Living Assistance Services and Supports (CLASS) Act*, 51 GERONTOLOGIST 145, 152 (2011).

120. Louise Radnofsky, *Long Term Care Gets the Ax*, WALL. ST. J. (Oct. 15, 2011), <http://online.wsj.com/news/articles/SB10001424052970204002304576631302927789920>.

altogether and the President immediately signed the repealing legislation.<sup>121</sup> Once the demise of the CLASS Act had become inevitable, Congress voted to replace it by establishing a Commission on Long-Term Care via Section 643 of the American Taxpayer Relief Act of 2012.<sup>122</sup> The Commission issued its Congressionally mandated report on September 30, 2013, endorsing a package of twenty-nine specific policy recommendations pertaining to service delivery, workforce development and maintenance, and finance.<sup>123</sup> This report was accompanied by an Alternative Report embodying the dissenting views of five Commission members who advocated the creation of a comprehensive public social insurance program for LTC in the United States.<sup>124</sup> Since their publication, both the main Commission Report and the Alternative Report have been totally, pointedly ignored by both Congress and the Executive branch, confirming the judgment that creation of a study body such as this is Congress' "most quintessentially worthless alternative."<sup>125</sup> To fill the resulting LTC policy abyss, the Bipartisan Policy Center in December 2013 launched a Long-Term Care Initiative "to raise awareness about the importance of finding a sustainable means of financing and delivering [LTSS] and, in late 2014, will propose a series of bipartisan policy options to improve the quality and efficiency of publicly and privately financed [LTC]."<sup>126</sup>

### B. Federalism

A second challenge, and one that is related to the funding issue, is the federal nature of the Medicaid program on which we continue to rely for public sector supported LTSS. Because Medicaid is a combination national-state program,<sup>127</sup> each state may exercise its prerogative concerning whether or not to participate in any of the optional State Plan or waiver programs contained in the ACA to promote HCBLTSS. State participation in the various HCBLTSS programs that the ACA attempts to foster is voluntary and the take-up volume

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121. American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2013) [hereinafter American Taxpayer Relief Act of 2012].

122. American Taxpayer Relief Act of 2012 at § 643.

123. See generally COMM'N ON LONG-TERM CARE, REPORT TO THE CONGRESS (2013); see also Richard G. Stefanacci, *Determining the Future of Long-Term Care*, 22 ANNALS LONG-TERM CARE 24 (2014).

124. Stefanacci, *supra* note 123, at 26-27.

125. Richard L. Kaplan, *Desperate Retirees: The Perplexing Challenge of Covering Retirement Health Care Costs in a YOYO World*, 20 CONN. INS. L.J. 433, 458 (2014).

126. *America's Long-Term Care Crisis: Challenges in Financing and Delivery*, BIPARTISAN POL'Y CTR. (Apr. 2014), <http://bipartisanpolicy.org/sites/default/files/BPC%20Long-Term%20Care%20Initiative.pdf> (last visited July 21, 2014).

127. The formal name of the Medicaid program is "Grants to States for Medical Assistance." 42 U.S.C. § 1396 (2012). See generally Nicole Huberfeld, *Federalizing Medicaid*, 14 U. PA. J. CONST. L. 431 (2011) (regarding the federal architecture of Medicaid).

and pace likely will depend in large part on whether sufficient financial incentives are made available, in the form of enhanced FMAP, to entice particular states to incur greater Medicaid obligations.

### C. *Maintaining and Enhancing Consumer-Directed Models*

By this point in time, support for consumer-directed models of HCBLTSS is well-established, and new policy and practice initiatives should reasonably be expected to move in this direction, at least as an option for service recipients who are dependent on public funds. These consumer-directed models certainly appear to be consistent with the general thrust of the ACA and related regulatory activities. Nonetheless, advocates for consumer-directed models must remain continually vigilant in repelling the anti-autonomy claims of mainly feminist theorists. Those claims portray consumer choice negatively as a neoliberal conspiracy to abdicate the state's non-delegable obligations to care directly for and/or regulate the care of vulnerable persons, as well as a conscious method of violating the organizational and collective bargaining rights of HCBLTSS workers.<sup>128</sup>

### D. *Reliance on Family Caregiving*

The overwhelming reliance now placed on the role of family caregiving in the entire HCBLTSS enterprise<sup>129</sup> presents serious challenges for the continued success and expansion of this endeavor in the future. (Instability of the paid, formal workforce also poses difficult but different questions for the future of HCBLTSS, and indeed for LTC more broadly.)<sup>130</sup>

Most Americans say they would feel morally obligated to provide assistance to a parent in a time of need.<sup>131</sup> Nonetheless, demographic trends, changing family structures, and the increasing involvement of women in the

128. See, e.g., Daniela Kraiem, *Consumer Direction in Medicaid Long Term Care: Autonomy, Commodification of Family Labor, and Community Resilience*, 19 AM. U. J. GENDER & SOC. POL'Y 671 (2011); MARTHA B. HOLSTEIN ET AL., *ETHICS, AGING, AND SOCIETY: THE CRITICAL TURN* 111 (Rose Mary Piscitelli ed., 2011).

129. See, e.g., *Selected Long-Term Care Statistics: Family and Informal Caregivers*, FAMILY CAREGIVER ALLIANCE, <https://www.caregiver.org/selected-long-term-care-statistics> (last visited July 21, 2014); *Caregiver Statistics*, CAREGIVER ACTION NETWORK, <http://www.caregiveraction.org/statistics/> (last visited July 21, 2014).

130. Edward Alan Miller, *The Affordable Care Act and Long-Term Care: Comprehensive Reform or Just Tinkering Around the Edges?*, 24 J. AGING & SOC. POL'Y 101, 105-106 (2012); Robyn Stone & Mary F. Harahan, *Improving the Long-Term Care Workforce Serving Older Adults*, 29 HEALTH AFF. 109, 111 (2010); Bridget Haeg, *The Future of Caring for Elders in Their Homes: An Alternative to Nursing Homes*, 9 NAELA J. 237, 240 (2013) ("The supply of direct-care workers will not match the demand.").

131. PEW RESEARCH CTR., *THE DECLINE OF MARRIAGE AND THE RISE OF NEW FAMILIES* 44-45 (Paul Taylor ed., 2010), available at <http://www.pewsocialtrends.org/files/2010/11/pew-social-trends-2010-families.pdf>.

general paid workforce portend difficulty in recruiting and maintaining an adequate supply of family members to care at home for needy older relatives of the Baby Boomer generation.<sup>132</sup>

Additionally, family caregivers experience, beyond tangible financial and career sacrifices,<sup>133</sup> tremendous physical and emotional stresses, often manifesting as adverse changes in caregivers' own health and/or family conflict and dysfunction. The increasing number and complexity of tasks that family caregivers, especially spouses,<sup>134</sup> may undertake in order to keep their chronically disabled loved ones in a home setting exacerbate the caregiver stresses.<sup>135</sup> These stresses threaten the continued availability of sufficient numbers of family caregivers.<sup>136</sup> To deal with that threat, it is essential that respite and other forms of stress relief, reduction, and management be developed and made easily accessible to caregivers at risk in a timely manner.<sup>137</sup> Innovative approaches are necessary,<sup>138</sup> as the current state of support for stressed family caregivers is grossly inadequate.<sup>139</sup> The federal Family and Medical Leave Act (FMLA)<sup>140</sup> and a few individual state

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132. DONALD REDFOOT ET AL., AARP PUB. POL'Y INST., INSIGHT ON THE ISSUES NO. 85, THE AGING OF THE BABY BOOM AND THE GROWING CARE GAP: A LOOK AT FUTURE DECLINES IN THE AVAILABILITY OF FAMILY CAREGIVERS 1 (Aug. 2013).

133. See SUSAN C. REINHARD ET AL., AARP PUB. POL'Y INST., INSIGHT ON THE ISSUES NO. 86, EMPLOYED FAMILY CAREGIVERS PROVIDING COMPLEX CHRONIC CARE 7 (Nov. 2013) (stating that employed family caregivers reported negative impacts on their employment, including time off from work, missed professional opportunities, reduction of work hours, and exit from the paid workforce entirely).

134. SUSAN REINHARD, AARP PUB. POL'Y INST., INSIGHT ON THE ISSUES NO. 91, FAMILY CAREGIVERS PROVIDING COMPLEX CHRONIC CARE TO THEIR SPOUSES 4 (Apr. 2014).

135. Levine et al., *supra* note 54, at 118, 120.

136. Debra H. Kroll, *To Care or Not to Care: The Ultimate Decision for Adult Caregivers in a Rapidly Aging Society*, 21 TEMP. POL. & CIV. RTS. L. REV. 403, 407-409 (2012); 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, 450 (2011) ("Although most family caregivers fulfill their responsibilities out of love, loyalty, or a sense of duty, the accumulated strain over time can be overwhelming. Thus, it is critical that a high-performing system recognize and support unpaid caregivers, to help them maintain their own well-being as well as providing care.").

137. Linda Noelker & Richard Browdie, *Caring for the Caregivers: Developing Models that Work*, GENERATIONS, Winter 2012, at 103, 105-106.

138. See, e.g., Mary S. Mittelman & Stephen J. Bartels, *Translating Research into Practice: Case Study of a Community-Based Dementia Caregiver Intervention*, 33 HEALTH AFF. 587, 594 (2014); see also Marilyn G. Klug et al., *North Dakota Assistance Program for Dementia Caregivers Lowered Utilization, Produced Savings, and Increased Empowerment*, 33 HEALTH AFF. 605, 611-12 (2014).

139. Levine et al., *supra* note 54, at 120 ("Professionals often acknowledge that families are overwhelmed. And yet, when it comes time to send patients home, they are handed off to these same families for continued care.").

140. 29 U.S.C. § 2601 (2010).

counterparts<sup>141</sup> guarantee that an individual missing work for a period of time (up to twelve weeks under the FMLA) to attend to family caregiving responsibilities retains the right to return to his or her previous employment without penalty, but this legislation does not provide an entitlement to compensation for the work time missed.<sup>142</sup> Similarly, the “associational discrimination” provision of the ADA protects a worker against job discrimination based on the worker’s association (through, for example, a caregiving relationship) with a disabled individual, but does not assist the worker with compensation for the caregiving services themselves.<sup>143</sup> The morally and politically thorny, but emerging, set of issues pertaining to the possible use of public dollars to financially compensate family caregivers directly for their services are likely to be inescapable in future policy debates.<sup>144</sup>

## V. CONCLUSION

A growing older population with substantial dependency and multiple deficits in the capacity to adequately perform ADLs increasingly requires various LTSS. Government, particularly at the state level, has done much over the past several decades to rebalance publicly-funded LTC (mainly Medicaid) systems away from institutional settings and towards HCBLTSS. Nonetheless, important work still remains to be done in this direction. The challenges described in the preceding section will keep LTC scholars, advocates and activists, policymakers, and providers busy for the foreseeable future.

The ACA provides incentives and assistance for the rebalancing movement in several specific ways that are outlined in this article. Even though the HCBLTSS-associated provisions of the ACA form a relatively minor part of the total legislation, both in terms of the ACA’s attempted fundamental restructuring of the health care financing and delivery system and the amount of funding appropriated, these provisions may<sup>145</sup> turn out to create a more

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141. See, e.g., CAL. UNEMP. INS. CODE § 3301(a)(1) (2013).

142. Caroline Cohen, *California’s Campaign for Paid Family Leave: A Model for Passing Federal Paid Leave*, 41 GOLDEN GATE U. L. REV. 213, 213 (2011).

143. 42 U.S.C. § 12112(b)(4) (2010).

144. See, e.g., Haeg, *supra* note 130, at 247-254 (rejecting fears of fraud and abuse, moral hazard or a “woodwork effect,” and imperiled quality of care as sufficient policy reasons to prohibit the payment of Medicaid money to family caregivers); cf. Marshall B. Kapp, *For Love, Legacy, or Pay: Legal and Pecuniary Aspects of Family Caregiving*, 14 CARE MGMT. J. 205, 206-7 (2013) (describing the various financial and non-financial motives family caregivers might have and the probability of legal enforcement of caregivers’ financial expectations).

145. The ACA provisions make HCBLTSS success more likely, but definitely not assured. States have demonstrated a commitment to rebalancing services for elders and have made progress in increasing the ratio of HCBS participation for disabled when compared with institutional services. Nevertheless, the process of rebalancing HCBS spending for disabled



significant policy and practical legacy for the United States than is left by many of the more-heralded, more controversial ACA provisions whose ultimate impact on real lives is much more uncertain.

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remains long and slow. Hopefully, states will be able to take advantage of the new opportunities under the ACA to expand HCBS spending for elders and disabled in spite of the current financial problems. See Terence Ng & Charlene Harrington, *The Data Speak: A Progress Report on Providing Medicaid HCBS for Elders*, GENERATIONS, Winter 2012, at 14, 19 (2012).

APPENDIX—ALPHABET SOUP USED IN THIS ARTICLE

AAA	Area Agency on Aging
ADA	Americans With Disabilities Act
ADL	Activities of Daily Living
BIP	Balancing Incentive Program
ACA	Affordable Care Act
CFC	Community First Choice
CLASS Act	Community Living Assistance Services and Supports Act
CLI	Community Living Initiative
CMS	Centers for Medicare and Medicaid Services
DRA	Deficit Reduction Act
FFP	Federal Financial Participation
FMAP	Federal Medical Assistance Percentage
FMLA	Family and Medical Leave Act
HCBS	Home and Community-Based Services
HCBLTSS	Home and Community-Based Long-Term Services and Supports
HCBW	Home and Community-Based Services Waiver
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
LTC	Long-Term Care
LTSS	Long-Term Services and Supports
MFP	Money Follows the Person
NASUAD	National Association of States United for Aging and Disabilities
OBRA	Omnibus Budget Reconciliation Act
PCS	Personal Care Services
PDS	Participant-directed Services
SSA	Social Security Act
SUA	State Unit on Aging

