

**FOREWORD:
HOPE AND CHALLENGES IN LONG-TERM SERVICES AND
SUPPORTS**

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The U.S. Congress established the Commission on Long-Term Care (Commission) in 2012. Its charge was to identify a plan for the financing and implementation of a “comprehensive, coordinated, and high-quality system”¹ for the delivery of long-term services and supports for the full range of persons—both young and old—who live with serious physical or cognitive limitations. Unlike many current efforts to address substantial questions of access to essential care and services, the Commission was a bipartisan effort with its members appointed by the President and the leadership of both parties in Congress.² Even though it was not plagued by the ideological wars that have characterized other health reform initiatives, the Commission fell short of accomplishing its ultimate task. The Commission’s work produced an official report and recommendations³ supported by only nine of its members (including members picked by both Democrats and Republicans) with six of its members (also representing both parties) rejecting the report.⁴ Five of the Commission members who rejected the official report and recommendations produced a dissenting report and recommendations.⁵ With only six months to do its work, it is not surprising that the Commission didn’t meet its goal, but attributing its failure solely to the press of time would be mistaken. In fact, the essential challenge set by Congress for the Commission was to create an entirely new system where none exists. Merely refining or expanding current finance and

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1. American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 643(b)(1), 126 Stat. 2313, 2358 (2013) [hereinafter American Taxpayer Relief Act of 2012].

2. Commission members were selected by both parties, nine by Democrats and six by Republicans. *Id.* § 643(c)(1).

3. COMM’N ON LONG-TERM CARE, REPORT TO THE CONGRESS (2013) [hereinafter COMMISSION REPORT].

4. *Id.* at 1.

5. COMM’N ON LONG-TERM CARE, A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS (2013). [hereinafter DISSENTING REPORT] The Commission members signing on to the Dissenting Report are Laphonza Butler, Henry Claypool, Judith Feder, Lynnae Rutledge, and Judith Stein. *Id.*

delivery systems for long-term care and support for the twelve million persons who currently require these services,⁶ as well as for their families and caregivers, will not get the job done, as the fine articles in this Symposium effectively illustrate.

Although the Commission was divided on solutions, the need to make progress in the financing and delivery of long-term care and support is quite urgent. In its official report, the Commission emphasizes that the number of persons needing long-term care and support services is growing exponentially while the number of family caregivers available to provide essential and usually unpaid services is declining.⁷ Currently, public programs pay for two-thirds of the cost of long-term services and supports, and the demographics of the increasing need for services and the decreasing pool of unpaid caregivers portend a public budget crisis as well as unbearable private costs. As the Commission report states: “The need is great. The time is now.”⁸

Communicating this sense of urgency, however, is difficult as the financial, physical, and emotional costs of caring for persons in need are essentially invisible. Currently, obligations of care and financing are borne largely by family caregivers and at great cost. Nearly eighty percent of persons in need of long-term services and supports live at home and receive assistance solely from family and friend caregivers.⁹ Although estimates vary somewhat, caregivers generally provide seventeen to twenty-two hours of care weekly over an average duration of 4.6 years.¹⁰ Nearly seventy percent of these so-called “informal caregivers” report having to adjust their employment (rearranging their work schedule, taking unpaid leave, or decreasing work hours).¹¹ Clinically significant symptoms of depression arise in forty to seventy percent of informal caregivers, and approximately twenty percent report a decline in their own health.¹²

In addition, many of the services most needed by this population are often not viewed as “health care” and so have not been incorporated into the

6. COMMISSION REPORT, *supra* note 3, at 3.

7. *Id.* at 5.

8. *Id.* at 6.

9. DISSENTING REPORT, *supra* note 5, at 2.

10. NAT'L ALLIANCE FOR CAREGIVING, CAREGIVING IN THE U.S. 4-5 (2009).

11. LYNN FEINBERG ET AL., AARP PUB. POLICY INST., VALUING THE INVALUABLE: 2011 UPDATE: THE GROWING CONTRIBUTIONS AND COSTS OF FAMILY CAREGIVING (2011) [hereinafter 2011 UPDATE], available at <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>; LYNN FEINBERG & RITA CHOULA, AARP PUB. POLICY INST., UNDERSTANDING THE IMPACT OF FAMILY CAREGIVING ON WORK (2012), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf.

12. *Selected Caregiver Statistics, Mental and Emotional Effects of Caregiving Experienced by Caregivers, Impact of Caregiving on Caregiver's Physical Health*, FAMILY CAREGIVER ALLIANCE, <https://caregiver.org/selected-caregiver-statistics> (last visited Feb. 24, 2014).

mainstream health care delivery system. Instead, these essential supports—assistance in bathing, transfer, cooking, transportation, financial management, cueing—are viewed as lying outside the scope of health insurance and outside the responsibility of health care providers. Consistent with this framework, the Commission’s report addresses “long-term services and supports” as distinct from “health care services.”¹³

Finally, in my experience, there is also a hefty dose of denial in discussions about the personal risk of seriously debilitating medical conditions due to illness or injury or accompanying advanced age. The denial of personal risk of needing long-term care and support is particularly puzzling when the financial and health risks of providing uncompensated aid to a family member or friend are taken into account. Failing to view this risk as shared among all of us produces a view that the responsibility for care and financing lies with the individual rather than the community as a whole. In fact, the report issued by the dissenting members of the Commission emphasizes that “we’re all at risk” and offers this realization as a prime motivation for moving forward on public policy regarding long-term services and supports.¹⁴ Finally, the prospect of shifting the very substantial costs of long-term services and supports out of the private circle of family and friends (currently estimated at equivalent to \$450 billion of unpaid services annually)¹⁵ and into the public sphere is daunting.

In the first article in this Symposium, Marshall Kapp delves into the complexities of the Medicaid payment system for long-term care. Currently, the federal-state Medicaid program is essentially the only public financing program that pays for substantial long-term care services with the Medicare program paying only for very narrowly bounded services for nursing home or home care. Kapp rightly points out that the focus of Medicaid financing historically has been on institutional nursing home care. In fact, much of Medicaid financing of non-institutional long-term care has grown out of efforts to reduce the costs to state budgets of nursing home care rather than as a coherent effort to provide adequate services and support in the community. Kapp argues that the Affordable Care Act (ACA) did very little of substance to address the availability of long-term care and services especially in the context of community-based services.¹⁶ While the ACA did little on its own, however,

13. COMMISSION REPORT, *supra* note 3, at 7.

14. DISSENTING REPORT, *supra* note 5, at 17.

15. 2011 UPDATE, *supra* note 11.

16. The ACA included Community Living Assistance Services and Support Act (CLASS) to increase private coverage of long-term-care services and to expand non-institutional care for frail individuals. The financing plan for CLASS involved a voluntary payroll deduction plan, with significant limits on premiums and a floor for benefits, and was to be implemented only if it could be operated without deficit. Failing this requirement, CLASS was repealed in the same statute that established the Long-Term Care Commission. American Taxpayer Relief Act of 2012, *supra* note 1, § 642.

Kapp points out that the Act created opportunities for the states to shift their Medicaid payment policies more toward community-based services should they choose to do so. It is Kapp's hope that indeed they will.

In the second article in this Symposium, Katie Dean and David Grabowski argue that financing and payment reforms in long-term care must be tied to reform in delivery systems to achieve greater efficiency and effectiveness. Focusing on services for persons whose care is paid for by both Medicare and Medicaid (usually referred to as dual eligibles), Dean and Grabowski paint a landscape of costly dysfunction where financial incentives stimulate excessive costs, poor outcomes, and discontinuity of care. Their major point is that payment reform standing alone will not produce "comprehensive, coordinated and high-quality" care for persons needing long-term care. They prove this point by examining the outcomes of the demonstration project on Nursing Home Value-Based Payment, conducted from 2009 to 2012. The project provided financial incentives to nursing homes for performance improvement on a number of factors designed to improve outcomes of nursing home care and to reduce unnecessary hospitalization. Studies of the impact of the payment project demonstrated, however, that there was little change in behavior regarding nursing home to hospital transfers despite financial incentives. Dean and Grabowski make a compelling argument that payment reform is inadequate standing alone to stimulate improvement in both quality and efficiency in long-term care and that serious reform is needed in the design of systems through which care is delivered.

Judy Feder, who served as a member of the Commission and who signed the dissenting report, addresses the foundational issue of allocating the risk of long-term care expense as between individuals and the larger community. Feder marshals compelling evidence concerning the risk of catastrophic long-term care expense. She effectively demonstrates that the incidence and magnitude of risk of need for long-term services and supports fit the classic presentation of insurable risks, i.e., risks that are best handled by spreading across as broad a population as possible. She also demonstrates, however, why a private insurance system is unequal to the task and why a public-private partnership in insuring for long-term services and supports is essential. Her call is buttressed by the human costs, which she describes, of abandoning patients and caregivers to their own resources.

In her contribution to the Symposium, Laura Hermer examines the issues surrounding the relative lack of support for non-institutional home and community-based services (HCBS) for long-term care. In describing the history of Medicaid coverage for HCBS, Hermer explains the reason that publicly financed HCBS operates as a disjointed patchwork rather than as a system and, further, why access to HCBS is so inadequate. Acknowledging the growing proportion of the Medicaid long-term care dollar that goes to HCBS, Hermer nonetheless identifies several significant obstacles to the emergence of

an adequate and coherent system of publicly financed non-institutional long-term care. She points, for example, to the fear that expanding payment for non-institutional services will increase state Medicaid budgets and that support for self-directed care will produce a “woodwork effect” in which previously unpaid family care will land on the public budget. Hermer argues that a federalization of payment for HCBS is important to resolve the inadequacies of the current patchwork approach. She cautions, however, that political support is a determining factor in whether better access to necessary long-term care in the community will be available.

Finally, Malcolm Harkins addresses one of the most persistent issues in nursing home care: the question of the appropriateness and effectiveness of regulatory efforts to ensure that public dollars are purchasing and residents are receiving care that is of adequate quality. Harkins’ article provides an interesting history of the development of the federal Nursing Home Reform Act in the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987).¹⁷ OBRA 1987 represented a radical reform of nursing home regulation and survives today, thirty years after its enactment, as the core of federal regulation of the quality of nursing home care paid for by Medicare and Medicaid. Harkins acknowledges that the consensus among resident advocates and providers both is that the quality standards adopted in OBRA 1987 are still viewed as “appropriate and largely well done” and that the enforcement remedies are “likewise generally appropriate.” Harkins is highly critical, however, of the inspection process used by the state and federal governments to measure performance of individual nursing homes. In particular, Harkins notes that the survey protocols used to monitor nursing home quality produce inconsistent and inaccurate results. Although the incidence of undetected or uncited violations of standards (false negatives) exceed the incidence of inappropriately cited violations (false positives) by a factor of four to five times, Harkins emphasizes that both are equally inaccurate. He faults the political arena for highlighting only the false negatives and using that data as evidence that the inspection process is too lax. Harkins presents in great detail both the necessity of and the challenges to developing an inspection process for nursing homes that would be both consistent and accurate. He emphasizes particularly that the operation of the CMS consumer-oriented Nursing Home Compare web site magnifies the impact of inaccuracies in survey results. Harkins focuses exclusively on nursing home regulation, but his documentation of the experience of CMS in attempting to restrain surveyor judgment in detecting violations of outcomes-oriented standards over the past nearly thirty years since OBRA 1987 should be a caution to current efforts to move health care regulation generally toward outcomes standards. It may

17. Omnibus Reconciliation Act of 1987, Pub. L. No. 100-203, 101 Stat. 1330-1339 (Dec. 22, 1987).

appear, for example, that measuring performance on outcomes standards would be a relatively data-driven, nondiscretionary exercise. Indeed, if outcomes standards are simplistic, rely on easily available data, and are applied over a sufficiently large number of individuals, monitoring outcomes performance is likely to reflect that simple design. If outcomes standards operate over smaller populations, especially when applied to individuals, and incorporate more clinically complex standards, however, it is likely that clinical discretion in the detection of violations in individual facilities will take on more complexity as well.

Each of the articles in this Symposium details the great challenges present in moving toward a financing and delivery system that will assure “comprehensive, coordinated, and high-quality” care and support. There is a small but quite effective Medicare/Medicaid payment and delivery system, however, that demonstrates success on many of the points made by the authors of the articles in this Symposium, including the emphasis on community-based care, the need for a broader definition of long-term care services beyond what is usually considered health care, and the necessity of focusing on redesign of delivery systems as well as forms of payment. The Program of All-Inclusive Care for the Elderly (PACE) is a model of community-based long-term care for Medicaid and Medicare beneficiaries, and its performance provides a hopeful counterweight to the rather discouraging documentation of the obstacles to reform.

The original prototype for PACE, On Lok Senior Health Services, developed in the 1970s in San Francisco among Asian communities and eventually received federal grants to test payment and delivery systems for all-inclusive care for the elderly. Finally codified in the Balanced Budget Act of 1997,¹⁸ the first PACE program to be fully qualified for Medicare and Medicaid was established in St. Louis in 2001 by the Alexian Brothers who continue to operate the program.¹⁹ PACE is a small program nationally, currently numbering 106 programs in thirty-one states (up from forty-two programs in 2007),²⁰ but it holds lessons for those interested in creating a system of long-term services and supports for individuals with the most complex medical conditions and challenging living environments. On average, PACE participants are eighty years old, have eight or more medical conditions, and are taking twelve different medications upon their enrollment in PACE. A diagnosis of dementia is prevalent with forty-eight percent of the PACE

18. Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4802(a), 111 Stat. 251 (1997); 42 U.S.C. §1396u-4 (2012).

19. *National PACE Association: Who, What and Where is Pace?*, NAT'L PACE ASS'N, (2015), http://www.npaonline.org/website/article.asp?id=12&title=Who,_What_and_Where_is_PACE.

20. *Id.*

population having been diagnosed with the condition.²¹ Studies of PACE participants indicate that the PACE population is older and more cognitively impaired than the population receiving care through home health care or nursing homes.²²

All PACE participants must meet the criteria for admission to a nursing home under state requirements for Medicaid,²³ but PACE is designed to support these individuals in their own homes, reducing costs significantly. PACE payments are capitated, with rates varying considerably among the states. In exchange for the capitated payment, PACE bears all risks for an enrollee's health care, including hospitalizations and skilled nursing home care should the participant require those services.²⁴ PACE is a model of the reform advocated by Dean and Grabowski. It focuses intensely on systems for the delivery of care and support rather than relying solely on capitated payment for hoped-for but elusive gains in efficiency and health outcomes. Within the capitated payment allocation, PACE provides enrollees with social supports, wellness interventions, family respite, and transportation as well as all of their medical care. Although participants live at home, PACE programs operate physical sites that provide social events, lunch, and a complete health care clinic. PACE programs aggressively follow the care of their hospitalized enrollees to assure that care is appropriate and effective and intervene after discharge to assure continuity of care and to avoid readmission. Empirical research on PACE outcomes demonstrates consistently that PACE is effective. Mortality risks for PACE participants are significantly less than for individuals receiving home health care services or nursing home care.²⁵ As to the rate of hospitalization highlighted by Dean and Grabowski, PACE achieves significant results when compared to hospitalization of individuals residing in nursing homes or receiving home care. In a study published in 2014, hospital admission rates for PACE participants were twenty-four percent lower than hospitalization rates for dual eligibles residing in nursing homes and forty-three percent lower than dual eligibles receiving community-based care outside of PACE. Examining "potentially avoidable" hospitalizations, the study concluded that the PACE rate for this category of admissions was forty-four

21. *National PACE Association: Who does PACE Serve?*, NAT'L PACE ASS'N, (2015), http://www.npaonline.org/website/article.asp?id=50&title=Who_Does_PACE_Serve?.

22. *See, e.g.*, Darryl Wieland, et al., *Five-year Survival in a Program of All-Inclusive Care for the Elderly Compared with Alternative Institutional and Home-and-Community-Based Care*, 65 J. GERONTOL. A: BIO. SCI. & MED. SCI. 721 (2010).

23. CTRS. FOR MEDICARE & MEDICAID SERVS., CMS PUB. NO. 11341, QUICK FACTS FOR PROGRAMS OF ALL-INCLUSIVE CARE FOR THE ELDERLY (PACE) (2008), available at <http://www.medicare.gov/Pubs/pdf/11341.pdf>.

24. Micah Segelman, et al., *Hospitalizations in the Program of All-Inclusive Care for the Elderly*, 62 J. AM. GERIATRICS SOC'Y 320, 320 (2014).

25. *See generally* Wieland, *supra* note 22.

percent lower than individuals residing in nursing homes and sixty percent lower than those receiving non-PACE community-based care.²⁶

PACE offers a model of care that departs significantly from the range of long-term services and supports generally available to persons living with serious limitations in physical or mental functioning. Similarly, each of the articles in this Symposium envisions a better system of caring for the large numbers of persons of all ages who need significant support over the long-term to survive and thrive. One hopes that the spotlight that the Commission brought to these issues and the sophisticated and passionate work of the scholars participating in this Symposium will help prepare us for the unavoidable demographics of the future. There is nothing simple, however, about health care reform, whether it involves payment reform, reform in delivery systems, or reform in the tools used to monitor quality of care. This is especially so where, as in the case of long-term care, the needs have been ignored for so long.

26. Segelman, *supra* note 24, at 322.