

## ENHANCING AUTONOMY AND CHOICE IN SELECTING AND DIRECTING LONG- TERM CARE SERVICES

*Marshall B. Kapp*

In this article Professor Kapp suggests that the national debate over the delivery of long-term care services should reject the traditional model of professional domination, which an individual has only the right of "negative autonomy," in favor of a new model which empowers individuals with the right to proactively participate in the design and implementation of their service plans. In calling for this paradigmatic shift, Professor Kapp begins his discussion with an examination of client demands for community-based long-term care services while considering the financing, regulatory, and structural response to this demand. Professor Kapp then undertakes a cogent discussion of the "conflicting values and public policy aims complicating the expansion of client autonomy in the design and delivery of LTC services" as well as possible models for the future. Finally, Professor Kapp explores many of the questions and policy opportunities that would arise in the implementation of a new client choice delivery system. Professor Kapp's article will be of great interest to attorneys working closely with elderly clients in developing long-term care strategies as well as all Americans interested in the ongoing debate over the future of our health care system.

### Introduction

Within the broad national discussion regarding health care reform that has recently taken place, and is likely to continue, among American citizens and their political leaders, a variety of proposals concerning important changes in the financing and delivery of long-

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Marshall B. Kapp is Professor, Departments of Community Health and Psychiatry, Wright State University School of Medicine, and Director, Office of Geriatric Medicine & Gerontology there. This paper was prepared with the support of Contract #M3-0516.0, U.S. Congressional Office of Technology Assessment. Opinions expressed are solely those of the author.

term care (LTC) services have emerged.<sup>1</sup> In most of these proposals, eligibility for participation would be based chiefly on the client's disability status, rather than on his or her chronological age. LTC proposals under discussion strongly emphasize home and community-based services, which both clients<sup>3</sup> and society generally prefer over institutional placement.

Recently, policy analysis of LTC reform has begun to shift away from a limited concern with financial coverage, eligibility criteria, and access to expanded services.<sup>4</sup> An implicit assumption of professorial domination over the planning and implementation of those services has evolved toward wider attention to issues of client choice and control. This enlarged approach to the subject was exemplified by provisions in the Health Security Act<sup>5</sup> proposed by President Clinton in 1994 stating that:

The State may not subject consumer-directed providers of personal assistance services to licensure, certification, or other requirements which the Secretary finds not to be necessary for the health and safety of individuals with disabilities. Title II, Subtitle B, § 2102 (a)(2)(C). To the extent possible, the choice of an individual with disabilities (and that individual's family) regarding which covered services to receive and the providers who will provide such services shall be followed. Title II, Subtitle B, § 2102 (a)(2)(D). The term "consumer-directed" means, with reference to personal assistance services or the provider of such services, services that are provided by an individual who is selected and managed (and, at the individual's option, trained) by the individual receiving the services. Title II, Subtitle B, § 2104 (g)(2)(A).

Despite the apparent demise of ambitious attempts to restructure the entire health care financing and delivery system through legislative and regulatory processes, Congress's opportunity to change the prevailing paradigm of choice and control regarding LTC services persists. Continuing debate about health care reform, and

1. See generally Alison Barnes, *The Policy and Politics of Community Based Long Term Care*, 19 NOVA L. REV. 487 (1995).

2. For purposes of consistency and simplicity in this article, the term "client" will be used to designate the individual receiving long-term care services, rather than "patient," "consumer," "customer," "recipient," "beneficiary," or any other number of other potential terms. No particular implications regarding "political correctness" should be drawn from this choice of language.

3. See Alben D. Spiegel, *Home Care: Doing Right for the Wrong Reason*, 93 N.Y.U. L. REV. 190 (1993).

4. See Chai R. Feldblum, *Home Health Care for the Elderly: Programs, Problems and Potentials*, 22 HARV. J. ON LEGIS. 193 (1985); Marshall B. Kapp, *Options for Long Term Care Financing: A Look to the Future*, 42 HASTINGS L.J. 719 (1991).

5. H.R. 3600, 103d Cong., 2d Sess. (1994); S. 1757, 103d Cong., 2d Sess. (1994).

ally its LTC component, offers the chance to move from the traditional model of professional domination, in which the client has only right of negative autonomy to accept or reject recommended interventions, toward more of a right of positive autonomy,<sup>6</sup> which encompasses proactive participation in the actual design and implementation of his or her personal service plan.

It should be noted at the outset that, although most of the recent legislative proposals focus on expanded public sector financing of LTC, the bulk of this article's discussion of issues concerning enhanced client choice will be as pertinent for private third-party financing of LTC as for public programs. It must also be noted that, although most of the recent health reform proposals would rely extensively on substantial state action inspired by federal incentives or mandates,<sup>7</sup> Congress's power regarding some of the issues discussed in this article will be limited by principles of federalism.

This article commences with an outline of client demand for community-based LTC services, followed by a brief description of current financing, regulatory, and structural responses to this demand. The following section analyzes conflicting values and public policy issues complicating the expansion of client autonomy in the design and delivery of LTC services. This article then discusses programmatic models for the future and explores the compatibility of these competing models with case management for the client. This is followed by an exploration of operational questions and policy opportunities arising in the actual implementation of a new client choice paradigm in the LTC sphere.

### Client Demand

Demand for home and community-based LTC services in the United States is substantial.<sup>8</sup> The Health Care Financing Administration estimates that approximately 42.6 million people, or sixteen per-

6. Bart J. Collopy, *Ethical Dimensions of Autonomy in Long-Term Care*, GENERAL REPORT, Supplement 1990, at 9, 11.

7. For the states' perspective on changes in the long-term care system, see generally U.S. GEN. ACCOUNTING OFFICE, *LONG-TERM CARE REFORM: STATES' VIEWS ON KEY ELEMENTS OF WELL-DESIGNED PROGRAMS FOR THE ELDERLY* (1994) (GAO S-94-227) [hereinafter *LONG-TERM CARE REFORM*].

8. P. SHORT & J. LEON, U.S. DEP'T OF HEALTH & HUMAN SERVS., *USE OF HOME AND COMMUNITY SERVICES BY PERSONS AGED 65 AND OLDER WITH FUNCTIONAL DIFFICULTIES*, NATIONAL MEDICAL EXPENDITURE SURVEY, RESEARCH FINDINGS 5 (1990) (HHS PUB. NO. (PHS) 90-3466); Barnes, *supra* note 1, at 493-500.

cent of the U.S. population, have a physical or mental disability. A subset of these individuals, 12.6 million people, require long-term care, which is defined as needing assistance in either activities of daily living (ADLs) (i.e., bathing, dressing, moving in or out of bed or a chair, toileting, or eating) or instrumental activities of daily living (IADLs) (e.g., housecleaning, meal preparation, transportation, or financial management). The need for assistance may stem from acute or chronic medical (including mental and developmental) conditions. Individuals in the chronic category represent about twenty-five percent of the total population of individuals with disabilities and about five percent of the U.S. population.<sup>9</sup>

Of those individuals in need of long-term care, approximately 42.1% are under sixty-five years of age—half a million of the 12.6 million individuals in need of long-term care are children, 4.8 million are nonelderly disabled adults, and 7.3 million are elderly individuals. These diverse population groups present a variety of service needs and preferences, in terms of type, intensity, and delivery method.<sup>10</sup> The different ethnic and cultural backgrounds of disabled persons also contribute to this variety.

Most individuals who need long-term care live in the community, as opposed to an institution—10.3 million and 2.3 million persons, respectively. In Ohio alone, over 168,000 older individuals received long-term care services in the home in 1990.<sup>11</sup>

The need for LTC services will be exacerbated in coming years with the rapid anticipated growth of the aging population. Persons sixty-five years of age or over numbered 31.2 million in the 1990 census, or 12.5% of the population.<sup>12</sup> This segment of the population is expected to grow to 52 million, or 17.7% of the total, by 2020.<sup>13</sup> Those eighty-five years old or over are expected to increase from 3.1 million in 1990 to 6.5 million in 2020.<sup>14</sup> The likelihood of disability increases with age; 10.5% of persons age sixty-five to seventy-four require assistance with ADLs, increasing to 51.2% for those individuals

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9. Bruce C. Vladek et al., *The Changing Face of Long-Term Care*, HEALTH CARE FINANCING REV., Summer 1993, at 5, 6.

10. JoAnn Damron-Rodriguez, *Case Management in Two Long-Term-Care Populations*, J. CASE MGMT., Winter 1993, at 125.

11. SHAHLA A. MEHDIZADEH & ROBERT C. ATCHLEY, SCRIPPS GERONTOLOGY CTR., *THE ECONOMICS OF LONG-TERM CARE IN OHIO* 3 (1992).

12. Vladek et al., *supra* note 9, at 6.

13. *Id.*

14. *Id.*

eighty-five years of age or older, with a total of 7.3 million presently in need of assistance for functional limitations.<sup>15</sup> Concomitant with the aging process, these limitations usually become over time more severe and chronic. The need for home care services is directly related to the degree of an individual's functional limitations.<sup>16</sup>

## Current Approaches to Home and Community-Based Long-Term Care

### Services and Funding

The modern home care enterprise is complex and multidimensional,<sup>17</sup> and its accompanying terminology is often used in an inconsistent and confusing fashion. The U.S. General Accounting Office has defined home and community-based LTC services as "health, personal care, and social services provided over a sustained period to persons who live outside of congregate residential settings and who have lost the capacity for self-care because of a chronic condition or illness."<sup>18</sup>

Home care may be broken down into three separate, although frequently related, categories of services that may supplement, complement, or substitute for institutional care.<sup>19</sup> Home health care consists of medical and skilled nursing interventions such as diagnosis and treatment, nursing care, medications, physical and speech therapy, and the provision of medical supplies and equipment.<sup>20</sup> In 1992, there were over 8,200 licensed home health agencies in this country.<sup>21</sup> The nonmedical components of home care include personal care and homemaker services.

5. *Id.*
6. Lisa Fredman et al., *Functional Limitations Among Home Care Users in the National Health Interview Survey Supplement on Aging*, 32 GERONTOLOGIST 641 (1992).
7. See generally ADMINISTRATION ON AGING, U.S. DEP'T OF HEALTH & HUMAN SERVICES, INFRASTRUCTURE OF HOME AND COMMUNITY BASED SERVICES FOR THE FUNCTIONALLY IMPAIRED ELDERLY: STATE SOURCE BOOK (1994); ANNE P. WERNER & JAMES FREDMAN, UNITED SENIOR HEALTH COOP., HOME CARE FOR OLDER PEOPLE: A CONSUMER'S GUIDE 7 (1993).
8. U.S. GEN. ACCOUNTING OFFICE, LONG-TERM CARE: STATUS OF QUALITY ASSESSMENT AND MEASUREMENT IN HOME AND COMMUNITY-BASED SERVICES (1994) O-PEMD-94-19 [hereinafter LONG-TERM CARE].
9. See PETER KOMLOS-HROBSKY, NATIONAL SENIOR CITIZENS LAW CTR., AN ADULT'S GUIDE TO HOME CARE FOR THE ELDERLY (1988).
10. Council on Scientific Affairs, American Medical Ass'n, *Home Care in the 1990s*, 263 JAMA 1241 (1990); Spiegel, *supra* note 3.
11. Genevieve W. Strahan, *An Overview of Home Health and Hospice Care: Preliminary Data from the 1993 National Home and Hospice Care Survey*, ADMIN. DATA, July 22, 1994, at 256.

Personal care, often referred to as personal assistance services (PAS) by younger disabled individuals, is delivered by workers referred to as personal care attendants or home health aides, and consists of assistance with basic ADLs. Strictly speaking, homemaker workers or certified nurse assistants (CNAs) deliver homemaker or environmental care which consists of assistance with IADLs that must be performed before ADLs can be undertaken successfully.<sup>22</sup> Personal and homemaker services often are combined in their actual delivery to the client so as to maintain well-being, personal appearance, comfort, safety, and interaction beyond the home.<sup>23</sup> Personal and homemaker services are frequently informally provided by family members or friends of the client in conjunction with, or in place of, formal paid providers.

A complicating factor in this arena is the difficulty of placing certain discrete activities squarely within one category. For instance, it often is difficult to categorize the administration of medications or the operation of certain medical devices as a health rather than a personal care service. The implications of the permeable boundaries of home and community-based care are further elucidated below.<sup>24</sup>

A variety of administrative functions often accompany these three basic direct services. The role of these administrative functions and their implications for client autonomy are discussed below under the rubric of case management.<sup>25</sup>

Public financing for these various services is substantial but quite restricted.<sup>26</sup> The Medicaid program<sup>27</sup> currently finances physician-ordered home health services and may, at a state's option, provide an entitlement to personal care services prescribed by a physician or authorized under an approved state plan. In addition, state programs run under federally authorized Medicaid waivers pay for a variety of primarily nonmedical support services.<sup>28</sup> However, these

22. See Paul D. Phillips et al., *Quality Assurance Strategies for Home-Delivered Long Term Care*, 15 *QUALITY REV. BULL.* 156 (1989).

23. See SIMI LITVAK ET AL., *WORLD INST. ON DISABILITY, ATTENDING TO AMERICA* (1987).

24. See *infra* notes 132-35 and accompanying text.

25. See *infra* notes 98-106 and accompanying text.

26. Carol L. Estes & Thomas Bodenheimer, *Paying for Long-Term Care*, 160 *W.J. MED.* 64, 66 (1994); S. Mitchell Weitzman, *Legal and Policy Aspects of Home Care Coverage*, 1 *ANNALS HEALTH L.* 1 (1992).

27. Social Security Act, 42 U.S.C. § 1396 (1994). See generally Ellice Fatoullah, *Mandatory Medicaid Home Care for the Elderly*, *ELDER L. REP.*, Mar. 1993, at 1, 1.

28. U.S. GEN. ACCOUNTING OFFICE, *MEDICAID LONG-TERM CARE: SUCCESSFUL STATE EFFORTS TO EXPAND HOME SERVICES WHILE LIMITING COSTS* 4-5 (1994) (GAO-

waivers may severely restrict eligibility for coverage. Medicare<sup>29</sup> finances home-based services that are focused on skilled nursing and therapy rather than nonmedical support services and that are less likely to be used as a form of long-term support. Limited numbers of dollars are also available under Older Americans Act<sup>30</sup> initiatives, social service block grants,<sup>31</sup> and initiatives run with general state revenues.

Private third-party payment for the health component of home-based services, through health maintenance organizations, Blue Cross, and commercial insurers, is growing but still limited.<sup>32</sup> The majority of private dollars for these services, and certainly for nonhealth services provided in the home, come directly out of the pockets of clients and families.<sup>33</sup>

## B. Regulation

The health component of home care currently is regulated in a variety of respects under a panoply of federal and state statutes and regulations and the case law interpreting them.<sup>34</sup> These forms of formal accountability include: state licensure of home health agencies as entities; state licensure of the individual professionals who staff home health agencies; federal Medicare-Medicaid Conditions of Participation;<sup>35</sup> business regulations regarding health planning and certificate of need, antifraud and abuse, and antitrust; and voluntary accreditation for home health agencies administered by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the National League of Nursing's Community Health Accreditation Program (CHAP). In addition, home care agencies and their staffs are potentially civilly liable for damages for negligently caused client injuries.<sup>36</sup>

HEHS-94-167) [hereinafter MEDICAID LONG-TERM CARE]; Barnes, *supra* note 2, at 514-16.

29. Social Security Act, 42 U.S.C. §§ 1395b-1395ccc (1988 & Supp. IV 1993); C.C. Hulin & J.S. Hulin, "Medicare Home Health Coverage," *ELDER L. REP.*, Apr. 1993, at 1.

30. 42 U.S.C. § 3001.

31. *Id.* §§ 1397a-1397e.

32. Weitzman, *supra* note 26, at 19-23.

33. Barnes, *supra* note 1, at 498-500.

34. Sandra H. Johnson, *Quality-Control Regulation of Home Health Care*, 26 HOUS. L. REV. 901, 922 (1989).

35. U.S. GEN. ACCOUNTING OFFICE, *MEDICARE: ASSURING THE QUALITY OF HOME HEALTH SERVICES* 10 (1989) (GAO-HRD-90-7).

36. MARSHALL B. KAPP, *GERIATRICS AND THE LAW: PATIENT RIGHTS AND PROFESSIONAL RESPONSIBILITY* 189-94 (2d ed. 1992).

Further, a home care agency may be exposed to civil damages under product liability principles for defects in the medical equipment that it supplies to clients.<sup>37</sup>

### C. Case Management

As noted above, home and community-based services often are delivered in conjunction with a variety of administrative functions. These administrative functions generally are lumped together under the single term "case management." Although other labels for this conglomeration of different functions have been suggested, such as "care management" and "care coordination," the term "case management"—although objectionable to some—is the most widely accepted of these labels and therefore the one used in this article. However, wherever possible, in an attempt at analytic precision this article refers to the particular administrative task or function involved, rather than to the generic term.

Case management is defined as a mixture of functions directed at coordinating and negotiating existing resources to assure needed, appropriate, and continuous care for individuals on a case-by-case basis.<sup>38</sup> Case managers come from a variety of educational backgrounds and prior professional experiences and work for an array of state, local, and private health and social service organizations, including individual proprietary firms. Financial models of case management include: brokered services in a fee-for-service system; the service management model, in which the case manager has an individual capped account on which to draw; and case management as part of a comprehensive prepaid managed care plan.<sup>39</sup>

Among the specific functions or services performed by a LTC case manager for a community-based client are: (1) assessment of client need and eligibility; (2) care planning and allocation; (3) implementation of the plan by arranging for and coordinating service delivery; (4) monitoring the quality, appropriateness, and outcome of services; (5) reassessment and review of the plan; and (6) discharge or

37. *Id.* at 194-96.

38. U.S. GEN. ACCOUNTING OFFICE, LONG-TERM-CARE CASE MANAGEMENT: STATE EXPERIENCES AND IMPLICATIONS FOR FEDERAL POLICY (1993) (GAO-HRD-93-52) [hereinafter LONG-TERM CARE CASE MGMT.]; Monika White, *Case Management*, in THE ENCYCLOPEDIA OF AGING 147-50 (George L. Maddox et al. eds., 2d ed. 1995).

39. James E. Fanale et al., *Care Management*, 39 J. AM. GERIATRICS SOC'Y 431, 432-33 (1991).

termination from services.<sup>40</sup> Wherever feasible, these administrative functions will be discussed separately rather than under the case management catch-all.

#### IV. Conflicting Values and Public Policy Aims

Potential models for financing and delivering home and community-based LTC services ought to be evaluated according to their likelihood of promoting important policy goals. As noted earlier, the precept of personal autonomy or self-determination has emerged in recent discussions and consumer polls<sup>41</sup> as a fundamental value to be preserved and enhanced in any expanded program of home and community-based LTC services.<sup>42</sup> This precept is embodied in some form in virtually all client bill of rights statements regarding home care.<sup>43</sup>

A growing body of empirical evidence shows that the perception of personal control plays a critical role in an individual's long-term physical and emotional health and well-being.<sup>44</sup> Enhanced client autonomy is associated with the practical benefits of fostering independence over time, reducing the client's risk of abuse and neglect by others, and increasing the client's satisfaction with those aspects of service which are important indicators of quality care.<sup>45</sup> Feelings of control contribute to positive client behaviors, tending to reduce the phenomenon of "learned helplessness."<sup>46</sup>

40. See ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGER'S DILEMMA (Rosalie A. Kane & Arthur L. Caplan eds., 1993); NATIONAL COUNCIL ON AGING, CASE MANAGEMENT STANDARDS: GUIDELINES FOR PRACTICE 8-11 (1988).

41. LONG-TERM CARE, *supra* note 18, at 14-15.

42. See, e.g., NATIONAL LONG TERM-CARE RESOURCE CTR., UNIV. OF MINN., QUALITY, AUTONOMY, AND SAFETY IN HOME AND COMMUNITY-BASED LONG-TERM CARE: TOWARD REGULATORY AND QUALITY ASSURANCE POLICY (1995); cf. NATIONAL LONG-TERM CARE RESOURCE CTR., UNIV. OF MINN., INDIVIDUAL CHOICE AND ETHICAL ISSUES FOR ELDER RIGHTS PROGRAMS: DOING RIGHT WITH RIGHTS (1995) [hereinafter NATIONAL LONG-TERM CARE RESOURCE CTR., INDIVIDUAL CHOICE].

43. See, e.g., NATIONAL COUNCIL ON AGING, *supra* note 40, at 5; see also WORLD INST. ON DISABILITY, RESOLUTION ON PERSONAL ASSISTANCE SERVICES (1991).

44. See Brian F. Hofland, *Autonomy in Long-Term Care: Background Issues and a Programmatic Response*, 28 GERONTOLOGIST 3, 5-6 (1988); Judith Rodin, *Aging and Health: Effects of the Sense of Control*, 233 SCIENCE 1271 (1986).

45. John Capitman & Mark Sciegaj, *A Contextual Approach for Understanding Individual Autonomy in Managed Community Long-Term Care*, 35 GERONTOLOGIST 533 (1995).

46. See generally Jerome Avorn & E. Langer, *Induced Disability in Nursing Home Patients: A Controlled Trial*, 30 J. AM. GERIATRICS SOC'Y 397 (1982).

The concept of client autonomy takes on special meaning in the context of long-term care. Although most attention in acute care situations has focused primarily on the dramatic, "four alarm" issues such as resuscitation, withholding or withdrawing life-sustaining treatments, or decisions to hospitalize the patient, in long-term care the decisions that are most important to the client's sense of control and quality of life probably are the everyday, mundane choices that usually are taken for granted.<sup>47</sup> As one author has noted:

Because home care is a long-term, often permanent element in the life of the frail elderly, its toll is different from acute care, where patients may be willing to bear the invasions of care precisely because the invasions are short-term and hold out the promise of a return to previous levels of freedom and functioning. Temporary submission to caregivers is borne for the sake of long-term autonomy. But when care is enduring and when it involves not merely medical treatment but assistance with the basic activities of daily life, it can have a highly invasive effect on the freedom and self-determination of an elderly person. There is no short-term surrender for long-term gain, only the prospect of further surrender as frailty and dependency increase.<sup>48</sup>

Thus, for the home care client, control concerning the routine and minutia of care may be central. For instance, what time will the personal assistant arrive? What food will be brought into the home, how will it be prepared, and when will it be served? When will the client get dressed, and with what attire? When will various client activities be scheduled? What will be cleaned in the home and when? How will furniture be arranged? Most important, how will the personal assistant be located, hired, and fired?<sup>49</sup>

The meaning of autonomy diverges substantially among different population groups needing LTC services.<sup>50</sup> For the frail elderly, their advocates, and gerontological professionals, the medical model and its reliance on the informed consent doctrine has largely prevailed. Under the medical model, gerontological professionals assess needs and devise and propose intervention plans that the dependent

47. See generally TERRIE WETLE & LESLIE C. WALKER, INSTITUTE OF LIVING, AUTONOMY ISSUES IN CASE MANAGEMENT (1994).

48. Bart J. Collopy, *An Introduction to Home Care: What Are the Issues?*, in HOME HEALTH CARE OPTIONS: A GUIDE FOR OLDER PERSONS AND CONCERNED FAMILIES 13-14 (Connie Zuckerman et al. eds., 1990).

49. Peter J. Ferrara, *Expanding Autonomy of the Elderly in Home Health Programs*, 25 NEW ENG. L. REV. 421, 427-30 (1990).

50. See Edward F. Ansello & Nancy N. Eustis, *A Common Stake? Investigating the Emerging Intersection of Aging and Disabilities*, GENERATIONS, Winter 1992, at 5, 6-8.

client is expected to accept or reject. This is a model of negative autonomy, in which the client's right of control is limited to permitting or refusing to authorize the professionals' proposed course of action.

Recognition of autonomy in home and community-based LTC as generally more a matter of personal choice and control over everyday routine than an exercise in accepting or rejecting discrete, dramatic technological interventions tends to downplay the value of the medical model and its reliance on informed consent regarding personal care and homemaker issues. Most participants and observers would concur that informed consent/refusal is a proper paradigm in the strictly medical environment or pertaining to strictly medical decisions, where delineation of reasonable options depends heavily on the physician's technical expertise and experience. By contrast, LTC is—or surely ought to be—more of a seamless continuum. The Independent Living (IL) model of Personal Assistance Services (PAS) zealously embraced and endorsed by younger, mainly physically disabled persons and their advocates is more consumer-oriented and concerned with independence when it comes to personal assistance and homemaker issues. The IL model thus seems much more consistent with the realities and goals of community-based long-term care<sup>51</sup> and should be especially appealing to persons in the aging community who advocate for the older individual's right to “age in place.”<sup>52</sup>

The IL model has been described as follows:

The movement's fundamental premise is that individuals with disabilities are handicapped primarily by barriers in their environments rather than by their impairments or disabilities. Consequently, if such barriers are removed, disabled individuals can function normally in society. One such barrier was, and continues to be, the lack of adequate access to appropriate long-term-care services for people with disabilities. . . . Under this model, the disabled person is considered an active recipient of services and recruits, selects, manages, and directs his or her own service provider, known as a “personal assistant.” The personal assistant typically is not trained as a healthcare professional and is not supervised by a professional. In short, the care recipient is a “con-

51. Andrew I. Batavia et al., *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disability*, 16 J. HEALTH POL., POL'Y & L. 523 (1991); Gerbin DeJong et al., *The Independent Living Model of Personal Assistance in National Long-Term-Care Policy*, GENERATIONS, Winter 1992, at 89; L. Simon-Rusinowitz & Brian F. Hofland, *Adopting a Disability Approach to Home Care Services for Older Adults*, 33 GERONTOLOGIST 159 (1993).

52. J.A. Racino & Judith E. Heumann, *Independent Living and Community Life: Building Coalitions Among Elders, People with Disabilities, and Our Allies*, GENERATIONS, Winter 1992, at 43, 45.

sumer" of services, not a patient. The personal assistant is accountable to the consumer, not to a supervising nurse or agency. The personal assistant who provides services to the disabled person acts, in a sense, as an extension of the disabled person and follows the individual's directions as to how to meet his or her needs. . . . The IL model is based directly on the philosophy of the IL movement, which assumes that the disabled individual is a self-directed consumer of services capable of managing his or her life.<sup>53</sup>

The IL model inherently distinguishes between negative autonomy, which forces the client to react to a professional initiative, and positive or affirmative autonomy, which promotes an active, participating client as the controlling partner in all aspects of service planning and implementation. The IL model not only recognizes the distinction between decisional autonomy (i.e., the cognitive capacity to make and express preferences) and executional autonomy (i.e., the physical ability to independently carry out one's choices),<sup>54</sup> but also recognizes that client purchasing power built into a LTC financing system's design can empower the client to purchase the link between these different types of autonomy.

As part of their broader health reform agenda, Congress and the state legislatures have a historic opportunity to move the paradigm of home and community-based LTC from the traditional, structured dependency medical model toward the more assertive IL model. Legislation should express a clear (although rebuttable) presumption for the latter model in matters pertaining to client control over service design and delivery. Emphasizing the positive autonomy dimension favors services that are structured to maximize the client's choice and control, rather than services that rely on a client's negative right to refuse (i.e., to "take or leave") proffered items selected by professionals from a highly restricted menu.

When creating this affirmative programmatic presumption, however, policy makers must keep in mind that different individuals vary widely in their preferences for personal participation in specific decisions. Frail older clients, for example, may choose to voluntarily restrict their own choices by delegating many care decisions to a family member or professional case manager. Research into the relative importance of autonomy compared with other values indicates substan-

53. DeJong et. al., *supra* note 51, at 90.

54. Bart J. Collopy, *Autonomy in Long Term Care: Some Crucial Distinctions*, GERONTOLOGIST, Supplement 1988, at 10; Rosalie A. Kane, *Case Management in Long-Term Care: It Can Be Ethical and Efficacious*, J. CASE MGMT., Fall 1992, at 76, 74.

tial heterogeneity among community dwelling persons regarding ultimate preferences. Among these competing values are dignity, safety, security, comfort, and relief from anxiety.<sup>55</sup>

For many clients, staying in one's own home and thereby avoiding placement in an institution is the paramount aim; for others, identification of the least restrictive alternative depends not on the physical setting of care but instead on the totality of circumstances. Some have critically suggested that too much emphasis, especially among older persons, on the physical aspect of autonomy (i.e., staying out of a nursing facility) may obfuscate the broader psychological and spiritual facets of autonomy.<sup>56</sup>

In particular, individuals differ widely concerning their preferences, as well as in their capacities and preparation for participation in (1) determining initially their own service plans, with many wishing a practice design role but some content with only an informed consent veto power and (2) ongoing service management once the plan is underway.<sup>57</sup> For those wishing an active role in this second respect, "informed direction" or "informed management" are more accurate concepts than the traditional informed consent description.

The vast majority of clients are more concerned with *how* and *what* services are delivered, and by *whom* and *when* (all qualitative elements), than with the quantity of services provided.<sup>58</sup> Securing and maintaining control over these qualitative elements may be examined in terms of several distinct components of a long-term care system within which meaningful choice might be exerted:<sup>59</sup> (1) Which services are covered financially; (2) What are the entry circumstances; (3) What is the role, if any, of a case manager; (4) What services comprise the care plan; (5) Who will provide the care and how will they be paid; (6) What are the details of the daily routine; and (7) Under what circumstances may the care plan be exited? Clients often vary greatly in their preferences about the degree of personal involvement in shaping and answering each of these programmatic questions.

55. On the tension among these competing values, see generally NATIONAL LONG-TERM CARE RESOURCE CTR., *INDIVIDUAL CHOICE*, *supra* note 42.

56. Elias S. Cohen, *What Is Independence?*, GENERATIONS, Winter 1992, at 49, 51; Simon-Rusinowitz & Hofland, *supra* note 51, at 49.

57. Charles P. Sabatino & Simi Litvak, *Consumer-Directed Homecare: What Makes It Possible?*, GENERATIONS, Winter 1992, at 53.

58. See CHARLES P. SABATINO, AMERICAN BAR ASS'N, *LESSONS FOR ENHANCING CONSUMER-DIRECTED APPROACHES IN HOME CARE* (1990).

59. See Capitman & Sciegaj, *supra* note 45.

Stated somewhat differently, it is less helpful to inquire about client choice in the abstract than to pose the issue in context: Choice about *what aspect* of the client's life?<sup>60</sup> Autonomy takes on different meanings and different forms for different individuals in varied situations. The peculiarities of each person's situation influence the range of choices available, the person's understanding of those choices and their associated freedom, and that person's autonomy as defined and respected by others.

The rich heterogeneity of attitudes and preferences regarding autonomy<sup>61</sup> among potential LTC clients firmly underscores the need for a national policy which assures the availability of a variety of service financing and delivery models rather than the inflexible bureaucratic imposition of any single model—even one sincerely intended to promote autonomy—on all home and community-based clients. Legislative overgeneralization and oversimplification, even in what most people would consider a socially desirable direction, must be guarded against. Presenting a client with the stark choice, for example, between community versus institutional care (a common scenario in many Medicaid-waiver nursing home diversion programs), without affording meaningful client involvement in the specific design of those community services that form the alternative to institutionalization, does little to promote the client's real autonomy interests.

The construction of a viable public policy in this area must commence with the acknowledgement that the amount of resources available for home and community-based LTC for persons with disabilities is, and always will be, finite. Hence, some form of "gatekeeping" or rationing mechanism for distributing scarce resources will be an essential component of the long-term care system. The majority of clients are more likely to confront limitations on the availability of appropriate, desired services than the need to fend off unwanted services by overly paternalistic providers.

Despite the reality of limited resources, there must also be a recognition that client choice is more ethereal than factual if clients can choose only from a limited range of meaningful service options. In most situations, a "take it or leave it" environment, although theoretically presenting a set of alternatives, is grossly insufficient to effectuate

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60. *Id.*

61. Terrie Wetle, *A Taxonomy of Ethical Issues in Case Management of the Frail Older Person*, J. CASE MGMT., Fall 1992, at 71.

ate the client's true, proactive autonomy. LTC options ought to comprise a broad continuum of services, with the emphasis and clear policy preference for those delivered in the home and community, but with various types of institutional placement available if needed and desired by the client. Thus, allocation of a sufficient, albeit not unlimited, amount of resources are a minimum requirement for assuring an environment of real client choice and control.

Furthermore, even within a system marked by limited resources, public policy should be characterized by an explicit presumption in favor of client choice. Put differently, rationing decisions concerning home and community-based services should be made, as much as feasible, on a bottom-up, rather than a top-down, basis. The exact method for accomplishing these decisions depends on the specific financing and delivery model selected by the client in the first place.<sup>62</sup>

If a model is used in which someone other than the client (i.e., a case manager or other gatekeeper) controls expenditures for services, the client's rights can be protected by legislating strict procedural due process requirements for making rationing decisions, including the client's right to administratively and judicially appeal service allocation decisions.<sup>63</sup> In long-term care models that convey the "power of the purse" on the client directly, the client would do the rationing personally by choosing how to spend the specific number of dollars allocated to the client's care. That dollar amount could be computed either according to a straight *per capita* basis (arguably the simplest formula) or according to a severity of disability scale (arguably fairer but more complicated). Unlike an external gatekeeper, the client has no inherent conflict of interest between advocacy and fiscal responsibility—only a limited budget within which to make the personal, value-driven tradeoffs that are most appropriate for that unique client.

Home and community-based LTC policy reformers also presume that, to the maximum extent possible, limited resources should be devoted to the purchase of direct client services, instead of being diverted to administrative activities. There are two reasons for this position: (1) regulation acts as an obstacle to the realization of client

62. See *infra* notes 85-97 and accompanying text for a discussion of alternative models.

63. See JANE H. YUROW, NATIONAL COUNCIL ON AGING, CLIENT DUE PROCESS RIGHTS IN COMMUNITY LONG-TERM CARE: A POLICY RESEARCH REPORT (1991); *Care Management*, 39 J. AM. GERIATRICS SOC'Y 429 (1991).

autonomy, and (2) a dollar spent on administrative costs is a dollar not available to purchase actual services.

The last decade has produced a remarkable evolution in public attitudes regarding the wisdom and efficacy of government oversight, through extensive command-and-control regulation, of the programs designed to improve the public's well-being. Previously, the prevailing wisdom favored detailed, comprehensive regulation concerning all aspects of a public program's design and operation as the only means to assure satisfactory quality for the client and accountability for the taxpayer. Today, by contrast, a significant consensus has formed that intrusive regulation often acts less as an effective accountability tool than as an inflexible barrier to appropriate client choice and professional discretion, making programs less, rather than more, responsive to intended beneficiaries. "Regulation is currently part of the problem" when it comes to promoting client autonomy.<sup>64</sup>

In addition, unnecessary regulation generates substantial administrative costs for programs and thus diverts precious dollars away from direct client services. For these reasons, a reformed home and community-based LTC system should strive to minimize government regulation regarding design and operational details, leaving those matters primarily to client choice and control and maximizing the resources available for the purchase of direct services. LTC reform ought to empower individuals, not bureaucracies. Regulations should be promulgated only if they specifically intend to promote client autonomy, such as those requirements for the disclosure of information about available services to the client or for the establishment of educational opportunities for the client. Most important, client autonomy cannot be added at the conclusion of the policy formulation process after all the other program facets have been established. This is what occurs in the medical model, where the informed consent ritual usually is observed as a bothersome administrative afterthought following design of the treatment plan by the physician.

Rather, autonomy is a philosophy and a fundamental goal which must be incorporated into the LTC financing and delivery system at its inception. Because the structure of the financing and delivery model through which a client receives home and community-based services establishes a distinct set of relationships, rights, and responsi-

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64. Brian F. Hofland & Debra David, *Autonomy and Long-Term Care Practice: Conclusions and Next Steps*, GENERATIONS, Supplement 1990, at 91, 93.

bilities, the particular delivery model adopted directly constricts or enhances the range of choice and control opportunities open to the client. Ultimately, the party who designs the service system sets the array of available options—i.e., writes the menu from which selections may be made—and hence controls the client's life.

Charles Sabatino's study of six state consumer-directed home care programs conducted for the Commonwealth Fund found:

While many tend to think of goals and philosophy as too abstract to make much difference, an express philosophy of client control emphasizing responsiveness to client preference and flexibility seems to make a tangible difference to the "culture" and experience of a program. Such a philosophy seems to come alive if it is iterated and reiterated at all levels of staffing and procedure.<sup>65</sup>

Thus, policy makers should be guided by the principle that

consumer choice and control can become a reality only if the structure and process of delivery systems are built from the ground up on this premise. Imposing a right of consumer choice on a system after the fact will ultimately not succeed, for the controlling parameters will already be entrenched in a traditional provider-controlled mode.<sup>66</sup>

The public's commitment to the philosophy of enhancing client choice and control, as well as opportunities for effectuating that philosophy in practice, can be incorporated into any service model. It is to an analysis of how this might be accomplished, within an array of service models, that this article turns after an examination of current barriers.

## V. Current Barriers

Based on the foregoing discussion, the basic thrust of prudent public policy should presume client choice and control over the details of home and community-based LTC within a broad spectrum of financing and delivery models equipped to accommodate individual values and preferences. The present LTC system largely fails to embody the principles enunciated in the previous section. A complex web of existing regulations and agency and professional practices substantially limits—either by intentional design or by operation—client influence, let alone actual choice and control, concerning who may

65. See SABATINO, *supra* note 58, at 32.

66. See Sabatino & Litvak, *supra* note 57, at 57.

provide (and be paid for providing) which services and under what circumstances.<sup>67</sup>

What are the sources of these restrictive regulations and practices? Although these sources are manifold, this section discusses several types of regulations that may be especially amenable to correction through public policy.

One current shortcoming is the dominant role of case managers and other service gatekeepers whose client advocacy commitment is compromised by an inherent conflict of goals.<sup>68</sup> Gatekeepers function within a world of finite resources that, especially within an increasingly managed care environment, must be equitably distributed among many competing needy clients. Consciously or not, gatekeepers have a strong incentive to emphasize economic efficiency in their allocation of services, because increasingly they themselves are at financial risk for inefficiency and waste.<sup>69</sup> This management goal may conflict in practice with the gatekeeper's desire to respect client autonomy, because the client's choices are not always the most rational from the standpoint of the total system's distribution of resources and cost containment objectives.<sup>70</sup> Indeed, it has been argued that the gatekeeper has a legitimate, even ethical obligation, at least regarding the medical component of home care, to judge honestly the objective need (as opposed to the client's desire) for particular services<sup>71</sup> and "to advocate for social responsibility."<sup>72</sup> Gatekeeper/client discordance may arise for this reason regarding both the allocation and the monitoring of services.<sup>73</sup>

No realistic long-term care system could expect to eliminate the inevitable tension between resource limitations and individual client

67. See Capitman & Sciegaj, *supra* note 45; Ferrara, *supra* note 49, at 430-41; Marshall B. Kapp, *Improving Choices Regarding Home Care Services: Legal Impediments and Empowerments*, 10 SAINT LOUIS U. PUB. L. REV. 441 (1991); Sabatino & Litvak, *supra* note 57.

68. Rosalie A. Kane, *Case Management: Ethical Pitfalls on the Road to High-Quality Managed Care*, QUALITY REV. BULL. 161 (1988).

69. Carol H. Hennessy, *Autonomy and Risk: The Role of Client Wishes in Community-Based Long-Term Care*, 29 GERONTOLOGIST 633 (1989).

70. See Fanale et al., *supra* note 39, at 435; Robert L. Kane & Rosalie A. Kane, *The Impact of Long-Term-Care Financing on Personal Autonomy*, 14 GENERATIONS Supplement 1990, at 86.

71. See Laird L. Miller & Joanne E. Miller, *Selecting Medical Case Management Programs: The Employer's/Purchaser's Perspective*, 15 QUALITY REV. BULL. 121 (1989).

72. Norman Daniels & Joanne E. Sabin, *Commentary: When Is Home Care Medically Necessary?*, HASTINGS CENTER REP., Summer 1991, at 37.

73. See Hennessy, *supra* note 69.

prerogatives. However, public policy makers have the ability to structure a new system by changing the locus for resolving this tension, at least concerning personal assistance and homemaker services. Specifically, the present system which relies on professional gatekeepers to make difficult, value-laden tradeoffs in individual cases between general fiscal responsibility and particular client preferences, functioning in effect as double agents on behalf of both payer and client,<sup>74</sup> could be replaced. Instead, the decisions about those tradeoffs (and their attendant risks) could be transferred to the client personally, by giving the client a finite amount of resources to manage within which he or she would be empowered to arrange and direct chosen services.

Another obstacle to client autonomy at present is the tendency for case managers, other gatekeepers, and direct service providers to focus on the client's professionally perceived service needs and risks of harm. This emphasis on needs (prevalent even in supposed "client oriented" models of case management)<sup>75</sup> and risks is driven by the ethical principle of beneficence, or doing good and preventing harm, that underlies the philosophy, education, and practice of the helping professions. It is underscored by the predilection of many LTC managers and professionals to assume much too readily decisional incapacity and dependency on the part of their clients.

Some disabled individuals certainly face a possibility of neglect or abuse if left on their own. The problem is that, taken too far, professional behavior driven by the desire to help and protect disabled clients can diverge widely from the client's goals of choice and satisfaction,<sup>76</sup> reinforce learned helplessness, and amount to parentalism rather than support.<sup>77</sup>

Some providers resist client control over the details of a service plan because they interpret this development as decreasing the caregivers' control over prevention or mitigation of risk factors. Hence, control, even over client objection, is often asserted in the name of beneficence. Justice Brandeis warned Americans almost three-quarters of a century ago that "[e]xperience should teach us to be most on our guard to protect liberty when the Government's pur-

74. Susan M. Wolf, *Beyond the Double Agent: Toward a Systemic Ethics of Case Management*, in *ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGER'S DILEMMA*, *supra* note 40, at 59.

75. LONG-TERM CARE CASE MANAGEMENT, *supra* note 38, at 14.

76. LONG-TERM CARE, *supra* note 18, at 3.

77. Kane, *supra* note 68, at 163.

poses are beneficent."<sup>78</sup> The same admonition might be applied to many health and social service agencies. Besides its adverse autonomy implications, overprotectionism at its extreme can lead to professional conduct that actually is counterproductive and even harmful to client welfare (e.g., regulations that do not permit the client's family members to perform certain in-home tasks because they lack professional credentials) and that therefore also violates the precepts of beneficence and nonmaleficence (avoidance of harm).<sup>79</sup>

The philosophically and educationally based managerial and professional bias toward externally imposed protection of the client from any foreseeable harm frequently is exacerbated by anxiety on the part of the gatekeeper and service providers about potential exposure to civil liability for negligence (i.e., malpractice) if the foreseen risk materializes and the client suffers an injury. Although popularly held perceptions concerning the legal risks of home and community-based scenarios are quite free-floating and exaggerated, they nonetheless are widespread, sincere, and exert a powerful influence over professional behavior.<sup>80</sup>

Considerations of economic protectionism also cannot be ruled out as a partial explanation for gatekeeper and provider-bias toward controlling details of the service plan. For some providers, claims of concern about accountability may operate as a pretext for protection of one's own practice territory from competition by others of the client's choosing.

Unduly risk averse professional behavior that compromises client choice and control may be addressed through public policy on at least a couple of levels. First, support can be provided to educational programs to inculcate respect for client autonomy, to appreciate the human costs (e.g., sacrifice of client happiness) of overprotection, and to recognize that trade-offs between protection and freedom may be imperative if the latter is not to be sacrificed altogether.<sup>81</sup>

78. *Olmstead v. United States*, 277 U.S. 438, 479 (1928) (Brandeis, J., dissenting).

79. Mary B. Mahowald, *When Breaking May Be Keeping*, in *ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGER'S DILEMMA*, *supra* note 40, at 168; Kathleen E. Powderly, *Process of Legitimizing Rule Breaking*, in *ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGER'S DILEMMA*, *supra* note 40, at 176.

80. See Ferrara, *supra* note 49, at 441-45.

81. Bob Kafka, *Perspectives on Personal Assistance Services*, *INDEPENDENT LIVING*, Winter-Spring 1994, at 11.

Additionally, statutes can be enacted at the national and/or state levels that clarify malpractice exposures and immunities for LTC gatekeepers and providers who permit risky situations to develop or persist in order to comply with client choices. With decisional rights come risks, and clients who competently, knowingly, and voluntarily insist upon service plans entailing foreseeable risks ought to be expected to accept the consequences of their decisions.<sup>82</sup> Assumption of risk statutes, as well as express legislative language authorizing family members to administer medications and operate designated equipment, would diminish fears of liability serving as an excuse for shortchanging client autonomy.

A pragmatic impediment to greater client autonomy in home and community-based LTC today is the severe shortage of qualified, willing workers to provide desired services, frequently even where sufficient funding is present.<sup>83</sup> In addition to creating serious problems for families of disabled individuals,<sup>84</sup> the scarcity of personal assistance and homemaker personnel de facto limits clients' ability to direct the *who* (and indirectly the *what* and *when*) aspects of their own care. Appropriate public policy responses to workforce problems exerting an adverse impact in this sphere are discussed below.

## VI. Alternative Models

Although a number of variations exist, current and potential methods for financing and delivering home and community-based long-term care to disabled individuals may be clustered into five models.<sup>85</sup> These models are: (1) the home care providers work directly as employees of the governmental unit that operates the program; (2) the governmental unit contracts for services with an independent home care agency; (3) the client contracts directly with a home care agency

82. See Marshall B. Kapp, *Home Care Client-Centered Systems: Consumer Choice vs. Protection*, GENERATIONS, Supplement 1990, at 33, 34-35.

83. Penny H. Feldman, *Theme Issue: Frontline Workers in Long-Term Care*, GENERATIONS, Fall 1994, at 5; see also PENNY H. FELDMAN, *WHO CARES FOR THEM? WORKERS IN THE HOMECARE INDUSTRY* (1990).

84. Sue Shellenbarger, *Home Aide Shortage Upsets Delicate Balance*, WALL ST. J. June 1, 1994, at B1.

85. See Kapp, *supra* note 67; Kapp, *supra* note 82; Marshall B. Kapp, *Home Care Service Deliverers: Options for Consumers*, in HOME HEALTH CARE OPTIONS: A GUIDE FOR OLDER PERSONS AND CONCERNED FAMILIES 43-58 (Connie Zuckerman et al., eds. 1990).

for services; (4) the client hires and directs an independent home care provider, but the governmental unit acts as the client's fiscal agent; and (5) the client is given cash directly by the governmental unit and is responsible for all aspects of employing the home care provider.

These models represent a rough continuum of client choice and control and, as urged earlier, an ideal long-term care system would include each client's option to utilize any of these models at particular points in time. Forcing any particular model, even one that ostensibly maximizes choice, on a client who prefers otherwise is inconsistent with the spirit of autonomy. These Agency Provider (AP) (1, 2, and 3) and Independent Provider (IP) (4 and 5) models are not mutually exclusive for any specific client. Home and community-based LTC is often fragmented, and multiple models may be employed simultaneously. For example, a client might hire and direct an independent provider for long-term personal and homemaker services, with the governmental unit acting as fiscal agent, while receiving short-term, periodic health-related services through a home care agency with which the governmental unit has contracted.

All other things being equal, Models 3, 4, and 5 are farthest along on the autonomy continuum. These are models of economic empowerment, which the government could implement by providing either vouchers, refundable tax credits, or cash directly to the client. Providing preferential tax treatment for individual savings accounts devoted to future LTC expenses also would promote this objective. These models are most consistent with the Independent Living (IL) movement described earlier, with its emphasis on maximizing client control, self-esteem, and independence in the community.

A number of persuasive rationales support an economic empowerment model of home and community-based LTC over traditional regulatory approaches predicated on the supposition that clients uniformly need to be protected from their own managerial ineptitude. First, granting clients the purchasing clout to hire, fire, and determine wage increases would provide them with their choice of personal attendants (within workforce availability constraints) and support family members and other informal caregivers who are presently ineligible for third-party payments. It also would induce the hired attendants to be more responsive to the client's needs and preferences.<sup>86</sup>

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86. See Ferrara, *supra* note 49, at 450.

Second, because providers would be compensated as a direct result of choices made by the client rather than a government bureaucracy, they would have an incentive to overcome their institutional and professional biases against autonomy. To compete for client vouchers or cash, providers would be more flexible in developing and offering a broader array of services and innovations from which clients might select.<sup>87</sup> Market demand would dictate product supply.

Third, economic empowerment equals efficiency in service plan design. Clients spending their own limited money or vouchers must consider the opportunity costs of purchasing one available service over another, resulting in an efficient mix of services. Clients would only purchase services when their expected benefits exceeded their costs, because they would not want to waste their own finite resources that might be used for other purposes. The added costs to providers for any choices the client may make would be incorporated into the service price, and this pricing behavior would consequently force clients to recognize the true costs of their choices.<sup>88</sup> For instance, scheduling of particular services at desired times for the client may be inconvenient and inefficient for the provider. A system in which the client directly feels the economic cost of that inefficiency, through a higher price, permits (indeed forces) the client to determine how important that specific scheduling decision is, i.e., whether it is "worth" the price to him or her.<sup>89</sup> Efficiency is also served by reducing third-party direction. Administrative cost savings should be realized from a reduction in billings and claims handling.

Fourth, contrary to first impressions, the economic empowerment model actually reduces the potential problem of program abuse by clients. The client is free to spend the voucher or cash on anything desired; therefore, there is no possibility of unauthorized uses. Because there would be no service restrictions, the possibility of non-compliance is eliminated. Client eligibility criteria and benefit amounts would be set with this feature in mind. Because the client is empowered to venture into the marketplace to obtain services, the choices created by the cash or voucher do not provide an opportunity

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87. *Id.* at 451.

88. *Id.*

89. See Joan D. Penrod, *Charting of Clear Solutions to Complex Problems*, in *ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGER'S DILEMMA*, *supra* note 40, at 191.

for the client to abuse the public program to obtain additional services or resources personally or for others.

Consequently, policy makers can be confident that funds will be used for purposes that the client views as most needed and beneficial. Policy makers may learn more about clients' needs and preferences by monitoring the choices they make with program funds. Under alternative systems, by contrast, where incentives to assure efficient decisions are not present, bureaucratic imposition of a particular service plan is more likely to generate waste and inefficiency of taxpayer resources.<sup>90</sup>

For those persons who are able to take advantage of them (ordinarily older individuals), the tax-favored savings account route to economic empowerment offers even more autonomy protection than the voucher, cash payment, or refundable tax credit mechanisms. Under savings accounts, clients would have more control over the amount of cash available, by saving funds during working years and varying the amount and timing of payments in retirement. Clients could determine for themselves when they need services, rather than depend on a bureaucratic determination of eligibility. Clients also could choose to leave some or all of their saved funds to their children or other heirs.<sup>91</sup>

An economic entitlement and empowerment model of public benefit program design is hardly a new or radical idea.<sup>92</sup> Among the long-standing examples of federal programs entailing successful direct cash or voucher payments to eligible beneficiaries are Aid to Families with Dependent Children (AFDC), the Food Stamp program, the Department of Veterans Affairs Housebound and Aid and Attendance Programs, and those established under the Social Security legislation, including the SSA retirement, survivors, and disability programs (Social Security Disability Insurance/SSDI<sup>93</sup> and Supplemental Security Income/SSI).

Furthermore, several states over the past decade have experimented successfully with various versions of an economic entitlement and empowerment approach to public benefits for persons with disa-

90. See Ferrara, *supra* note 49, at 451-52.

91. *Id.* at 452.

92. See, e.g., KATHLEEN A. CAMERON, UNITED SENIORS HEALTH COOP., INTERNATIONAL AND DOMESTIC PROGRAMS USING "CASH AND COUNSELING" STRATEGIES TO PAY FOR LONG-TERM CARE (1993).

93. See Laurel Beedon, *Autonomy as a Policy Goal for Disability and Aging*, GENERATIONS, Winter 1992, at 79.

bilities. Among these programs are:<sup>94</sup> (1) the California "In-Home Supportive Services" (IHSS) program; (2) the Colorado "Home Care Allowance" (HCA) program; (3) the Maine "Home Based Care" (HBC) program; (4) the Oklahoma "Non-Technical Medical Care" (NTMC) program; (5) the Oregon "Medicaid Home and Community-Based Services Waiver" and "Oregon Project Independence" (OPI) programs; and (6) the Wisconsin "Community Options Program" (COP). Additionally, Ohio operates an "Optional State Supplement" (OSS) cash assistance program designed to divert low-income, at-risk individuals from institutional placement into family-like group home arrangements. Among other relevant state activities are the Connecticut Departments of Mental Retardation and Social Services' payments to families of disabled children, cash assistance programs administered by the Texas Department of Mental Health and Mental Retardation and the Texas Department of Human Services, cash payments to families of developmentally disabled persons by the Florida Department of Health and Rehabilitative Services, West Virginia's cash assistance program filtered through local nonprofit organizations,<sup>95</sup> and the Pennsylvania Family Support Services county option of cash payments to families of mentally retarded children. Connecticut is also experimenting currently with a client home care self-direction option.

Many European and other Western industrialized countries provide citizens with some form of cash disability allowance for long-term care.<sup>96</sup> Several private long-term care insurance policies (e.g., those sold by UNUM and Aetna) now offer a cash benefit choice for the policyholder.<sup>97</sup> (Private disability insurance policies, of course, have always paid cash benefits.) Under sponsorship of the Robert Wood Johnson Foundation, United Seniors Health Cooperative (Washington, DC) is presently engaged in a research and demonstration project designed to help states implement "Cash and Counseling" programs for persons with disabilities.

94. SABATINO, *supra* note 58; Sabatino & Litvak, *supra* note 57.

95. See generally Marc Greidinger et al., *Key Legal Issues in Funding and Administering Family Support Services for Persons with Disabilities*, 18(2) MENTAL & PHYSICAL DISABILITIES L. REP. 215 (1994).

96. CAMERON, *supra* note 92, at 2-14; B. COLEMAN, AARP PUBLIC POLICY INST., *EUROPEAN MODELS OF LONG TERM CARE IN THE HOME AND COMMUNITY* (1994).

97. CAMERON, *supra* note 92, at 26.

## VII. The Role of Case Management

Case management was alluded to briefly above<sup>98</sup> as an amalgamation of administrative functions connected to LTC client assessment, care planning and allocation, plan implementation, plan monitoring, plan reassessment and review, and possible discharge or termination of the client from the care plan. As the number of disabled individuals continues to escalate, the service delivery system becomes more fragmented, and American families tend to disburse geographically, case management has become a significant growth industry.<sup>99</sup>

Some have criticized case management as simply another superfluous layer of bureaucracy diverting scarce resources away from "hands-on client services, while others support case management as an essential component of any "responsive and responsible" expanded public LTC program.<sup>100</sup> The present and possible models for interactions among case managers, clients, and home care providers are numerous and diverse.<sup>101</sup> Most importantly, case management should not automatically be assumed to represent the antithesis of client autonomy.<sup>102</sup> Case management and client direction can be compatible; the key element is the degree of client choice and control in the selection and direction of the case manager as well as other aspects of care.<sup>103</sup>

For example, particular case management services may be superimposed on any of the LTC models described above without the client's approval; ironically, in a number of the ostensibly client-directed programs enumerated in the previous section, case managers ordinarily assign the client to a particular service model and arrange important aspects of care with little or no prior client consultation or participation. Alternatively, specific tasks may be performed by

98. See *supra* notes 38-40 and accompanying text.

99. See, e.g., Eugene Carlson, *Small Firms Increasingly Target Market for Parent Care*, WALL ST. J., Nov. 17, 1989, at B2.

100. Joan Quinn, *Health Care Reform: Where Will Case Management Fit In?*, 2 CASE MGMT. 118 (1993); *Care Management*, *supra* note 63, at 429.

101. ROSALIE A. KANE & JENNIFER FRYTAK, NATIONAL LONG-TERM CARE RESOURCE CTR., UNIV. OF MINN., MODELS FOR CASE MANAGEMENT IN LONG-TERM CARE: INTERACTIONS OF CASE MANAGERS AND HOME CARE PROVIDERS 1 (1994).

102. Kafka, *supra* note 81, at 13.

103. Rosalie A. Kane et al., *Conclusion: Toward an Ethic of Case Management*, ETHICAL CONFLICTS IN THE MANAGEMENT OF HOME CARE: THE CASE MANAGEMENT DILEMMA, *supra* note 40, at 249, 257-58.

case manager at a client's behest in any service model, thereby enhancing autonomy.

Client empowerment ordinarily does not constitute an either/or, zero sum proposition vis-à-vis case management.<sup>104</sup> In fact, establishment of an array or continuum of financing and service models would allow the client optimum choice and control regarding the presence or absence of particular case management functions at various points in time. At certain times when need for particular services is especially intense (e.g., when the client is first entering the LTC system, during home recuperation from surgery or a serious acute illness, or after a personal assistant has resigned or been fired), case management may complement and facilitate client direction. In some cases, the client may even wish to waive or give up aspects of autonomy, temporarily or otherwise, partially or totally, in return for comfort, security, or other values with higher personal priority.<sup>105</sup>

In a true client-directed model, each separate case management function would be subject to negotiation and ultimate client choice. The client's decision to engage the support of a case manager for any specific LTC function should be an informed one. Among other things, the client should be told about any confidentiality breach risks, pertinent mandatory abuse and neglect reporting requirements, and financial conflicts of interest that could affect the case manager's behavior. Thus, case management for any specific aspect of care should be one more choice among the array of choices available to the client.<sup>106</sup> This basic design feature of an effective LTC system recognizes and responds to the vast diversity of client preferences, including those concerning the exercise of autonomy in each care-related decision and task.

### VIII. Operational Questions and Policy Opportunities

The design and implementation of an array of LTC financing and delivery models that enhance client choice and autonomy present a variety of challenging operational questions and policy opportunities. These detail-related issues are outlined in this final section.

104. SABATINO, *supra* note 58, at 35.

105. *Id.* at 9.

106. Capitan & Sciegaj, *supra* note 45, at 47.

**A. Eligibility**

A LTC program must have a mechanism for determining which individuals are eligible to participate as clients of the program. The chief proposals recently under consideration have relied upon an assessment of an individual's capacity to independently perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). This emphasis on functional abilities is preferable to eligibility criteria based either upon chronological age (the present Medicare approach), which has no automatic connection to need, or financial means testing (the present Medicaid approach), with its perverse behavioral incentives and social stigma.<sup>107</sup> Nonetheless, relying on ADL and IADL assessment as the predicate for LTC program participation entails at least two weaknesses.

First, current techniques for measuring an individual's independent performance of ADLs and IADLs are highly imperfect. Validity and reliability of assessments depend greatly on the experience and expertise of the evaluator and inevitably entail a significant degree of subjectivity.

Second, utilization of an ADL and IADL orientation makes the client a passive object to be observed and evaluated by an external professional, as opposed to an active participant exercising autonomy by playing a meaningful role in judging his or her own service needs. "The omission of clients from the assessment process is ironic given the intrusive and intimate nature of personal assistance services."<sup>108</sup> It ignores the fact that most potential LTC clients know themselves better than a professional evaluator brought in for the single purpose of eligibility assessment.

For these reasons, the LTC system should be designed to maximize potential clients' involvement in assessing their own need for services. Economic empowerment models enumerated earlier, particularly individual LTC savings accounts and refundable tax credits, that force clients to make decisions using their own dollars are most likely to assure accurate and responsible assessments. Other LTC financing models will necessarily rely to some extent on professional evaluations of eligibility, but they should be designed and operated in a manner that encourages and facilitates client (and family) input concerning the need for services.

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107. See LONG-TERM CARE REFORM, *supra* note 7, at 5-6.

108. Simon-Rusinowitz & Hofland, *supra* note 51, at 163.

### B. Benefits

A LTC system must also have a mechanism for determining the particular benefits to which eligible individuals are entitled. Again, economic empowerment models that allow, and indeed compel, individual clients to spend their own dollars and thus make their own decisions about how much they will spend and on what specific services—without regulatory restriction—are most compatible both with enhanced autonomy and with economic efficiency and accountability. Even in financing and delivery models that spend public dollars, the principle of autonomy argues against rigid regulatory restrictions on the services purchased by the client and in favor of maximizing the client's active role in defining benefits by taking part in the design of his or her own service plan.

### C. Training and Information for Clients, Case Managers, and Service Providers

The exercise of autonomy cannot occur in a vacuum. An essential foundation for enhancing client autonomy in an expanded LTC system is an assurance (1) that clients will receive adequate information about possible alternatives to allow meaningful (i.e., informed) decision making, (2) that clients (and their families, when applicable) will receive sufficient training concerning the managerial functions of designing and implementing a high quality LTC service plan, and (3) that case managers and service providers will receive training regarding those aspects of their jobs that affect client autonomy.

One serious impediment to informed client choice in this area is the reluctance by case managers and other logical information sources to provide clients with honest, complete information and their own professional opinions and recommendations concerning the quality of specific competing service providers.<sup>109</sup> This reluctance is largely the result of anxiety about potential liability under anti-steering provisions of current federal antitrust statutes in the event the information source has criticized and recommended against a particular service provider. This liability anxiety in many instances is well-founded. Paradoxically, the antitrust laws' intent to assure theoretical "free choice" conflicts in many actual instances with a client's right to make *informed* choices.

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109. Capitman & Sciegaj, *supra* note 45.

To reduce this obstacle to autonomy, Congress should consider amending the antitrust laws to permit case managers and others to render accurate information and professional opinions to clients regarding the relative quality of competing LTC service providers, as long as the case manager or other information source does not have any financial conflict of interest influencing the advice being given. Congress also could address this concern by mandating case managers to disclose specific items of information to clients about applicable community-based service options, thereby preempting the antitrust anti-steering prohibitions.

In order to use information in an autonomous fashion, clients must be trained in the practical, everyday management functions of home and community-based LTC, namely, how to find, hire, supervise, pay, evaluate, and terminate independent or agency service providers. Autonomy in these matters does not come naturally to most people, especially those whose current service environment has instilled traits of learned helplessness. The present level of knowledge, sophistication, and preparation among the general public regarding these mundane but basic tasks and about available home and community-based LTC choices and resources is rudimentary at best.<sup>110</sup>

The federal government could play an important role in addressing this deficiency by funding various forms of client managerial skill development programs. In such an initiative, peer education among clients should be given high priority; the training programs of the Department of Health and Human Services' Maternal and Child Health Bureau for the parents of disabled children are an example of this valuable approach. A number of other publicly and privately sponsored educational and support programs that empower clients and/or their families to successfully engage in specific functions falling within the case management rubric exist and may also serve as models to be promoted.<sup>111</sup> Providing funding for the production and dissemination of written materials can be an effective means of public education and therefore, empowerment.<sup>112</sup> Much of the past emphasis on regulating client rights to react to professional initiatives (i.e., informed conser

110. MARGARET K. STRAW, AMERICAN ASS'N OF RETIRED PERSONS, HOME CARE ATTITUDES AND KNOWLEDGE OF MIDDLE-AGED AND OLDER AMERICANS 2 (1991).

111. See, e.g., Lynn R. Friss, *Family Caregivers as Case Managers: A Statewide Model for Enhancing Consumer Choice*, 2 J. CASE MGMT. 53 (1993).

112. See WERNER & FIRMAN, *supra* note 17.

and refusal) ought to be reconceptualized as government's responsibility to improve the client's daily managerial capacities.<sup>113</sup>

The federal government, through grants and contracts, also can facilitate the training of professional case managers and LTC service providers in areas pertinent to client autonomy. Attitudes held by these individuals about client autonomy vary widely.<sup>114</sup> Subject areas, among others, amenable to training include mediation and conflict resolution skills, communication techniques, appropriate responses to client/case manager disagreements about the care plan, and decisional capacity (discussed below) assessment skills. Technical assistance centers to develop curriculum and conduct training activities could be established, utilizing implementation of the Americans with Disabilities Act (ADA)<sup>115</sup> as an instructive model.

Legislation should facilitate and encourage training of case managers and service providers. Besides its enhanced environment for client autonomy, such training should improve generally the quality of services available. However, training in this sphere should not be legally required as a precondition of providing case management or direct care services. Such a requirement, besides creating a variety of enforcement problems, likely would have the effect of noticeably shrinking the available pool of potential service providers and consequently restricting the opportunities for client choice and control.

#### D. Decisional Capacity/Competence

Every adult (defined in virtually all the states for personal decision making purposes as a person more than eighteen years old) is legally (*de jure*) presumed to be cognitively and emotionally capable of making her own life choices. In reality, though, a number of clients or potential clients of the LTC system *de facto* have significant impairments in their capacity to understand information, to assess the information in light of their personal values and preferences, and to appreciate the consequences of their choices. The exact magnitude of cognitive dysfunction among the LTC client population is difficult to measure and its manifestations vary widely,<sup>116</sup> but it is certainly large

113. Charles P. Sabatino, *Client-Rights Regulations and the Autonomy of Home-Care Consumers*, GENERATIONS, Supplement 1990, at 21.

114. WETLE & WALKER, *supra* note 47, at 31-32.

115. 42 U.S.C. §§ 12101-12213 (1994).

116. BARRY S. FOGEL ET AL., AARP PUBLIC POLICY INST., COGNITIVE DYSFUNCTION AND THE NEED FOR LONG-TERM CARE: IMPLICATIONS FOR PUBLIC POLICY 2-10 (1994).

and serious enough to present a difficult operational and policy challenge, especially in the context of client-designed and directed LTC.

The traditional approach to the phenomenon of client cognitive impairment has been to categorize individuals rigidly as either decisionally capable or decisionally incapable. Such a categorization often is made (erroneously) on the basis of clinical diagnosis rather than on the basis of a functional assessment. For persons deemed decisionally incapable, either through judicial adjudication in the context of a guardianship/conservatorship proceeding or by the working, clinical judgment of a health care professional, surrogate or proxy decision makers usually are looked to—rather than the client herself—as the source of informed consent to or refusal of services. Many assume that, in any new LTC system, professionals performing all aspects of case management on behalf of the client will be an indispensable element.<sup>117</sup> At the least, clients with questionable cognitive abilities likely would be steered toward Agency Provider (AP) financing and delivery models rather than Independent Provider (IP) models.

Even when utilized within medical circumstances that properly involve a model of informed consent to or refusal of discrete technological interventions, existing state systems for dealing with the issue of decisional incapacity and surrogate decision making are imperfect. These systems consist of guardianship/conservatorship proceedings, advance directives, family consent statutes, and informal “muddling through.” In the LTC context, these imperfections are more apparent still.

One reaction to this situation might be promulgation of more command-and-control regulation. Federal attempts to preempt or tamper with existing state methods of dealing with incapacitated decision makers and surrogate decision making would be unrealistic and counterproductive. The same may be said about legislation attempting to standardize—on either the state or individual case management levels—methods and criteria for assessing decisional capacity. Assessing decisional capacity is notoriously complicated, ambiguous, decision-specific, and subject to fluctuation over time, and current assessment methods are highly ad hoc.<sup>118</sup> Nonetheless, a federal requirement for uniform capacity assessment standards likely would

117. *Id.* at 22; Quinn, *supra* note 100, at 118.

118. See generally Marshall B. Kapp, *Evaluating Decisionmaking Capacity in the Elderly: A Review of Recent Literature*, 2 J. ELDER ABUSE & NEGLECT 15 (1990).

engender, in addition to other problems, mere paperwork compliance and a tremendous unproductive diversion of resources into developing and completing forms with little positive substantive impact; national experience with the Minimum Data Set (MDS) provisions of the Omnibus Budget Reconciliation Act (OBRA) of 1987<sup>119</sup> regarding nursing facilities should serve as a clear warning in this respect.

Other public policy strategies are likely to be more fruitful. These strategies should be guided by the overriding aim to avoid or defer the expense, time, and emotional turmoil associated with unnecessary guardianship/conservatorship proceedings for clients of questionable capacity or de facto incapacity. From an autonomy perspective, such formal proceedings are a last resort to be used when the system has otherwise failed to protect the client's interests through informal proxy structures. A revised LTC system might avoid this outcome in several ways.

First, when an LTC landscape is comprised of an array of financing and service delivery models that are equipped to accommodate a client population with varying degrees of decisional capacity, more personalization is possible. Second, each of the financing and delivery models should be structured to recognize and accommodate the fact that capacity for most individuals is decision-specific; even the client with a severely compromised ability to make major, dramatic kinds of choices (usually medical in nature) may be capable enough to have and express firm preferences about mundane but important facets of everyday life such as what and when to eat, how to dress, and when (or if) to bathe. Many case managers with an autonomy philosophy already go to great lengths to ascertain and fulfill the wishes of even quite cognitively impaired clients.<sup>120</sup>

Public policy also can promote autonomy for the decisionally compromised LTC client by encouraging states to amend, where necessary, their proxy or surrogate advance directive statutes to explicitly authorize individuals with current decisional capacity to execute a document delegating to a named agent the right to make nonmedical decisions about home and community-based services; most state durable power-of-attorney statutes already permit such an advance delegation of authority to another. Further, public policy should

119. Omnibus Budget Reconciliation Act of 1987, §§ 1395i-3(a)-(h), 1396r(a)-(h) (1992 & Supp. 1995).

120. Terrie Wetle et al., *Balancing Safety and Autonomy: Defining and Living with Acceptable Risk*, 31 GERONTOLOGIST 237 (1991).

encourage individuals, while they still maintain unquestioned decisional capacity, to execute such advance planning instruments.

State laws should be amended, where necessary, to create a clear presumption that, in the absence of a proxy or surrogate advance directive regarding home and community-based services decisions, the client and family taken together are able and empowered to make decisions regarding each aspect of designing, implementing, monitoring, and revising the specific client's LTC plan. The Individuals with Disabilities Education Act (IDEA),<sup>121</sup> Part H, is an existing model of a public program treating the family as a capable decision-making unit.

Most important, public policy in this sphere could move away from the traditional focus on the stark decisional capacity versus incapacity distinction and facilitate instead a more sensitive and nuanced inquiry about what types of supports are needed to enable the client to direct his or her care to the maximum extent feasible. Social, legal, and economic supports, including those that empower the family as a capable decision-making unit, that assist a cognitively compromised client to act capably enough in a particular situation should be afforded priority over mechanisms that treat autonomy as a sequential phenomenon to be transferred in toto from the client to a surrogate at the distinct moment that capacity disappears.

### **E. Roles of the Family**

The client's family<sup>122</sup> may occupy at least two different but connected roles in the context of home and community-based LTC that are related to the definition and exercise of client autonomy. These are the roles of decision maker and service provider.

Questions relating to the family's decision-making authority, especially when the client is cognitively compromised, are difficult in the pure medical model despite the presumption there that autonomy belongs to the client and that families should be involved only to the extent of the client's wishes or the client's inability to speak for himself or herself. Questions about the family's role are more complex in long-term care, where the family's central participation in im-

121. Education of the Handicapped Act Amendments of 1986, Pub. L. No. 457, 100 Stat. 145 (1986).

122. The term "family" is used here in a very broad sense to include, where appropriate, friends, neighbors, and others besides those related to the client by blood or marriage, with whom the client has a social and psychological relationship similar to that found among members of traditional families.

mentation of the care plan makes its involvement in initial plan design and continuing reevaluation both unavoidable and appropriate. The client/family dichotomy of the medical decision-making model makes no ethical or practical sense when the family is expected to act as a service provider based on the care plan.

Ordinarily, there should be a presumption that the client and family functioning together are a capable and autonomous decision-making unit. Without discounting the possibility of conflicts of interest or even outright abuse within families, public policy should begin with a strong presumption in favor of client/family empowerment, leaving open access to formal mechanisms for disempowering the family upon proof of client wishes or family misconduct dictating otherwise.

In most home settings, families provide the bulk of direct hands-on personal and homemaker services for disabled individuals.<sup>123</sup> Empowering the client in reality often means empowering his or her family support system. Substantial data show that the widespread notion that most younger family members today prematurely abandon their older relatives upon the onset of disability is a myth.<sup>124</sup> National estimates are that eighty-five percent of the clients who need long-term supportive care receive it from family and friends.<sup>125</sup>

A fundamental goal of public policy should be encouragement of family caregiving, as a supplement to or substitute for formal LTC services.<sup>126</sup> The current system, however, overwhelmingly works against empowerment of the family as home and community-based caregiver, both through narrow restrictions on reimbursement and state professional licensure laws that place family members in "legal purgatory for engaging in certain beneficial activities.

Although families provide a tremendous volume of in-home care to their disabled relatives, such caregiving often exacts a heavy personal, physical, and emotional toll.<sup>127</sup> Not incidentally, there is frequently a substantial financial burden, in terms of lost opportunity

123. See Joan D. Penrod et al., *Who Cares? The Size, Scope, and Composition of the Caregiver Support System*, 35 GERONTOLOGIST 489 (1995).

124. Ethel Shanas, *Social Myth as Hypothesis: The Case of the Family Relations of Older People*, 19 GERONTOLOGIST 3, 6 (1979).

125. Council on Scientific Affairs, American Medical Ass'n, *supra* note 20, at 1243.

126. See ROBERT M. PIERCE, *LONG-TERM CARE FOR ELDERLY: A LEGISLATOR'S GUIDE* 31 (1987).

127. FOGEL ET AL., *supra* note 116, at 11-13.

costs. In Ohio in 1990, ninety-seven percent of home care was uncompensated, nearly all of it provided by family and representing an economic value of \$5.3 billion.<sup>128</sup> Yet, current Medicaid regulations as well as most state laws (with several notable but limited exceptions)<sup>129</sup> prohibit the payment of public monies to family caregivers. Ironically, the simple fact of a blood or marriage relationship generally disqualifies a person as a paid caregiver who otherwise could be chosen by the client and financially compensated for services performed. In the case of many LTC clients, these restrictions force relatives to enter or remain in outside paid employment rather than to provide home care to the client, and the restrictions thus severely limit client choice in the provider selection facet of designing a service plan.

Legal restrictions on family caregiver payment ought to be eliminated in any expanded home and community-based LTC system. Removing such restrictions would encourage and enable more family caregiving. This development, in turn, would enhance client choice and control by providing many clients with a broader range of options about the "who" element of their care; it is assumed that a substantial percentage of clients would prefer family caregiving as a substitute for or supplement to care provided entirely by strangers. Besides being preferred by many clients, family caregiving will also frequently be of higher quality, because family members have a stronger personal ethical commitment and personal attachment to the client's well-being than even the most conscientious professionals.<sup>130</sup>

Further, there is evidence refuting the prevalent but erroneous assumption that paying family members for giving care that is now provided largely without compensation would unleash a massive "woodwork effect" or "moral hazard" phenomenon of exaggerated service demand in response to public money supply. Data appear to indicate that expansion of family caregiver compensation is unlikely to create an immense and unnecessary new drain on program resources.<sup>131</sup>

Another factor inhibiting family caregiving is the existence of restrictive state statutes and regulations that confine the performance of certain activities to licensed professionals. Most state nurse practice

128. MEHDIZADEH & ATCHLEY, *supra* note 11.

129. PIERCE, *supra* note 126, at 140-41.

130. NATHAN L. LINSK ET AL., WAGES FOR CARING: COMPENSATING FAMILY CARE OF THE ELDERLY 217-25 (1992).

131. *Id.* at 203; SABATINO, *supra* note 58, at 17.

acts explicitly exempt from their coverage personal care and home-maker services provided by family (and in most cases by friends also) to relatives in their own homes. The legal picture is complicated, though, when the services in question are arguably health-related. Differences in perspective feed the ambiguity; activities that professionals label health-related and requiring professional attention may be considered by the client to be a normal part of everyday life that do not necessitate professional interference.<sup>132</sup>

For instance, no state expressly empowers family members to administer medications; neither do most states explicitly prohibit family members from doing so. It is generally accepted that family members may help (e.g., open, hold, or even empty medicine containers) the client to take over-the-counter medications. The ability of family members to administer prescription medications without technically violating their state nurse practice act is more problematic. The picture becomes cloudier still when the inquiry is whether other arguably health-related tasks such as operating sophisticated equipment may be assigned to family members.

Although criminal prosecutions of family members under these provisions of state nurse practice acts have been virtually nonexistent,<sup>133</sup> Congress should encourage the states to amend their respective nurse practice acts and other relevant professional licensure statutes to clarify the permissible role of the family, at least regarding medications and medical machinery in the home. Those state statutes that are unduly restrictive in this regard should be liberalized to allow family members to provide without legal apprehension a broad range of services, including in-home health-related services. Oregon's registered nurse delegation regulations<sup>134</sup> and California's licensure exception for "paramedical" services<sup>135</sup> are examples of this approach.

Family caregiving for clients with disabilities is not without potential dangers. Monitoring and correcting quality problems in the home, particularly where a family's lack of care falls somewhat short of clear abuse or neglect, presents an obvious practical dilemma. Once family caregiving has commenced, it usually will be exceptionally difficult if not impossible for a client to "fire" a family member or change the terms and conditions of employment, especially when the

132. Kafka, *supra* note 81, at 13.

133. Kapp, *supra* note 67, at 464-65.

134. OR. ADMIN. R. § 851-45-011 (1995).

135. IN-HOME SUPPORTIVE SERVICES CH. 3-757.19.

client is dependent on the relative for housing, emotional support, and care, and the only alternative to the status quo is nursing home placement.

These potential shortcomings are not inconsequential, but they are far outweighed by the intrusion into the client's range of viable service choices created by the disincentives to family caregiving described above. On the whole, then, public policy should remove these barriers but also improve the capacity of local Adult Protective Services agencies to receive, investigate, and respond to reports of abuse and neglect taking place by family caregivers in the client's home. This oversight and corrective strategy is preferable to regulation that restricts client choice by prospectively restricting who may provide services, which also in effect may prescribe what services are available, when, and under which conditions.

#### F. Quality Control

When LTC service providers are paid professionals (as opposed to family caregivers), how should a home and community-based LTC system monitor quality in an effort to protect vulnerable clients and taxpayer dollars? What are the most appropriate oversight mechanisms?

Quality standards and enforcement techniques in this area vary widely today depending on payment source.<sup>136</sup> The traditional approach, even in states with Independent Provider (IP) LTC models, has been to enshrine client rights (usually of the negative autonomy or reactive type) in regulations, coupled with an elaborate regulatory survey and enforcement apparatus. The emerging consensus is that this strategy has not been very successful. Despite the large amount of energy and money expended in this administrative effort (resources that therefore are not available to purchase direct client services), quality problems—including fraud, abuse, and neglect—still persist in home and community-based LTC of disabled individuals.<sup>137</sup>

The public policy presumption in a redesigned LTC system ought to be against continued reliance on or expansion of the regula-

136. See LONG-TERM CARE, *supra* note 18, at 2.

137. See, e.g., LITTLE HOOVER COMM'N, COMMISSION ON CAL. STATE GOV'T ORG. & ECONOMY, UNSAFE IN THEIR OWN HOMES: STATE PROGRAMS FAIL TO PROTECT ELDERLY FROM INDIGNITY, ABUSE AND NEGLECT (1991); Hillary Stout, *Godsend for Many, Home-Care Industry Also Has Potential for Fraud and Abuse*, WALL ST. J., Nov. 21, 1991, at B1.

tory approach.<sup>138</sup> This approach, at best, makes the regulated party responsive to the values of the government, not to the client who is the purported beneficiary of the government program. In place of the regulatory paradigm, the locus of accountability should be shifted as much as possible to the particular client through the power of the purse. In other words, the marketplace acting through client purchasing decisions best safeguards the client. For the client, personal satisfaction is probably the most important criteria for any care plan. Service providers should need to compete on this dimension, as well as others, for the business of economically empowered clients, and those who do not provide satisfactory quality will be unable to operate for long in the new LTC marketplace. This is the same quality assurance philosophy already reflected in a panoply of long-standing public cash benefit programs, where the client is empowered to choose those purchases that will improve his perceived life satisfaction.

Government accreditation of case managers<sup>139</sup> and/or of the personal assistant and homemaker workforce should be rejected. Setting and enforcing minimum qualification standards would be more likely to shrink the size of the available personnel pool and artificially raise the price of those in the pool, thus restricting client choice among competing providers, than to appreciably improve the quality of services. Government involvement should be limited to funding initiatives that make training opportunities available to present and potential case managers and home and community-based LTC providers. Case managers and providers should be encouraged but not mandated to take advantage of these and other training programs. Clients could give an applicant's training history whatever weight they felt it deserved in the hiring decision. Government also could facilitate the process of clients screening worker applicants by, for example, enabling clients to conduct checks on an applicant's criminal record.

Reputable private organizations conducting voluntary accreditation programs in the home and community-based LTC arena should be permitted. They should not, however, be given any governmental imprimatur such as the "deemed status" that the Department of

138. Cf. Robert L. Kane, *Improving the Quality of Long-Term Care*, 273 JAMA 1376 (1995).

139. See LONG-TERM CARE CASE MGMT., *supra* note 38, at 3.

Health and Human Services has conveyed on the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) for Medicare purposes. The individual client could require accreditation of service provider applicants as he or she personally saw fit.

To supplement the marketplace as the centerpiece of quality control, existing state laws and public agencies relating to child and adult abuse and neglect would remain in place and be available for responding to reports by the client or interested third parties. Clients for whom LTC plans are designed by case managers or other gatekeepers should be afforded extensive due process appeal rights to contest details of their service plans with which they disagree.<sup>140</sup>

### G. Workforce Issues

Severe shortages of potential personal assistant and homemaker LTC personnel in many parts of the country now effectively restrict the client's range of choice concerning service provider and, indirectly, the other details of her service plan. Public policy must address the workforce shortage as a key element of any autonomy enhancement strategy.

One set of issues coming under this heading and amenable to change through public policy concerns the legal employment status of the home care worker.<sup>141</sup> In most existing LTC models, unless workers are clearly hired, fired, paid, directed, and supervised by a governmental or private agency, the employment status is ambiguous. Workers, especially in the Independent Provider (IP) model, frequently receive, beyond their basic hourly wage, no fringe benefits, employment such as health or life insurance, employer pension contributions, disability insurance, paid vacation or sick time, or worker's compensation. Responsibility, if any, for paying the employers' portion of FICA for the worker and withholding income taxes is often undefined. Additionally, the worker's status under the Fair Labor Standards Act, entailing such issues as minimum wage, maximum hours, and child labor requirements, may be cloudy.

This ambiguity surrounding fringe benefits plus uncertainty about other aspects of the employment situation are considerable disincentives for persons to be recruited to and retained within

140. See YUROW, *supra* note 63.

141. See Greidinger et al., *supra* note 95.

workforce, especially in IP arrangements.<sup>142</sup> By the same token, apprehension about undertaking possible financial liabilities as an employer has inhibited many eligible LTC clients from selecting the IP service model where currently available.

Public policy must clarify the employment status of workers providing home and community-based LTC, particularly within IP models. Here as elsewhere in the design of an expanded LTC system, flexibility and creation of a range of models from which the consumer may choose is desirable. Different aspects of the employment relationship might be treated in different ways; for example, liability for certain fringe benefits could be accepted by the government as a program cost, whereas for other purposes the worker is treated as an employee of the client or as an independent contractor. In the two latter situations, a governmental or private agency could function, at the client's choice, as the fiscal agent for payroll and other money handling functions without changing the worker's employment status. The central mission of public policy in this regard should be development of a range of LTC financing and delivery options in which the worker's employment status for specific purposes is clear to the worker, client, and relevant government agencies (e.g., Social Security Administration, state Worker's Compensation Bureau, Internal Revenue Service) at the inception of the employment relationship.

Any employment status options available concerning other home care workers should apply with full force to family caregivers. Providing family members with fringe benefits, in addition to compensating them with wages for work performed (discussed earlier) should go far in promoting the public policy of encouraging family caregiving as an available alternative for clients.

Finally, whether the client hires family caregivers or others, the IP model should not be conceived or promoted as a way to provide a cheaper alternative to Agency Provider (AP) models by shortchanging workers in their fringe benefits. Such an approach is seriously counterproductive in terms of client choice and control.

#### H. Tort Liability

Fear of being held civilly liable as an employer under a theory of vicarious liability/respondeat superior for client injuries that are neg-

142. See Margaret MacAdam, Implications of Recent Federal Changes for Home Care Worker Demand and Supply (1992) (unpublished manuscript on file with author).

ligently caused by a personal attendant or homemaker has been a factor inhibiting many governmental and private agencies from offering clients a full a range of LTC service options, both in terms of plan design and everyday implementation. Perception of legal risk has fueled provider agency imperatives for control, including control over risk factors thought to be engendered or worsened by client choices.

Although agency perceptions of their potential negligence liability exposure is grossly overblown,<sup>143</sup> these perceptions are nevertheless a powerful force against the realization of client autonomy. Public policy might address the damage to client choice and control caused by this risk aversion in several ways.

States could be given incentives to legislatively clarify the prospective rights and responsibilities among the various parties within home and community-based LTC relationships. Particularly, the common-law assumption of risk defense that would relieve a defendant agency from liability for the adverse consequences of choices made voluntarily, knowingly, and competently by the client or his or her surrogate could be codified in such a manner that even the most risk-averse provider can understand and accept. The state or local governments could agree to indemnify private providers for adverse legal judgments based on negligence, as is done currently in the New York City home care program.<sup>144</sup> Legislation could confer various kinds of legal immunity on potential defendants, particularly governmental or not-for-profit agencies providing case management or home and community-based LTC services. Forms of Alternative Dispute Resolution (ADR), such as voluntary arbitration, could be promoted to resolve tort claims in a more efficient, less costly manner.<sup>145</sup>

### I. Research Issues

One positive role for government is the funding and encouragement of research and demonstration projects that would rigorously test the validity of the presumptions expressed in this article and elsewhere regarding the value of enhancing client choice and control in the context of home and community-based LTC. It is not clear yet how to measure with any precision the "success" of autonomy, in LTC or elsewhere, but several structural and procedural questions arising

143. See Kapp, *supra* note 67, at 472-74.

144. Ferrara, *supra* note 49.

145. *Id.* at 454.

in particular financing and delivery models suggest themselves for analysis.

Among other things, there is and will be a need for qualitative research on the perceived experiences of clients regarding choice, their desire for participation in particular decisions, and their ranking of specific types of choices in terms of importance. Differences in perceptions among various racial, ethnic, and gender groups will need to be identified if public policy is to be made more sensitive to such considerations.<sup>146</sup>

Different LTC models will need to be evaluated in terms of the effectiveness of their client education, information, and advocacy components. Most importantly, government should promote research on the basic questions of who actually makes which choices and whether meaningful choices exist for anyone to make within particular financing and delivery models.

## IX. Conclusion

There are many Americans with various forms and degrees of physical and mental disability who need and desire home and community-based LTC services in some fashion. Any meaningful national health care reform initiative should incorporate a response to that need.

Such a public policy response should reflect a strong commitment to enhancing consumer choice and control concerning each of the several decision points within any LTC system. This article suggests strategies for combining our historic social responsibility for citizen well-being with a modern commitment to individualism and personal autonomy in the context of home and community-based LTC. Ultimately, central to the success of these public strategies is adherence to fundamental values held most dear by the clients to be served:

Be my friend, for I need one, but do not become my manager.  
And remember me, as my life and identity erode, as a person, not  
a case. Let me live and grow old in a place I know. It is enough  
that my body becomes a stranger and my thoughts unclear.  
Somewhere in here is still the aspiring hopeful person you once  
said would inherit the future.<sup>147</sup>

146. See Capitman & Sciegaj, *supra* note 45.

147. Jack Ossosky, *Untitled Poem*, 33 GERONTOLOGIST 2 (1993).