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CONSUMER-DRIVEN LONG TERM CARE: SHAPING THE GOVERNMENT'S ROLE

Marshall B. Kapp*

INTRODUCTION

In the traditional, historical American model of home and community-based long-term care (HCBLTC) for individuals with serious and ongoing impairments in the ability to perform activities of daily living (ADLs), most of the important operational facets (the who, what, where, when, and how) of service financing and delivery have depended mainly on who is paying the bill.¹ When the individual service recipient personally pays for desired services, that person is respected as a consumer and gets to negotiate the content of the service delivery agenda, at least to the extent that there exists a competitive marketplace of service providers vying for business in the individual's locale. By contrast, when third-party payers (ordinarily governmental entities) are involved, the HCBLTC services received by the person with ADL impairments are primarily driven by the policies and instructions of the agencies

* Marshall B. Kapp was educated at Johns Hopkins University (B.A.), George Washington University Law School (J.D. with Honors), and Harvard University School of Public Health (M.P.H.). He is the Garwin Distinguished Professor of Law and Medicine at Southern Illinois University School of Law. He also has a faculty appointment in the Department of Medical Humanities in the Southern Illinois University School of Medicine. From 1980 through 2003, he was a faculty member in the School of Medicine at Wright State University in Dayton, Ohio. From 1998–2001, he was designated Wright State University's Frederick A. White Distinguished Professor of Service. In 2004, he was granted Professor Emeritus status from Wright State University. Professor Kapp is the author or coauthor of a substantial number of articles, book chapters, and reviews.

1. MARSHALL B. KAPP, *THE LAW AND OLDER PERSONS* 95 (2003).

delivering or coordinating services, within well-delineated programmatic constraints established by service funders.² Consumers have limited choice and control about their own long-term care (LTC) once enrollment in the public financing program has commenced.

The traditional agency or funder-driven HCBLTC paradigm emphasizes professionally-ascertained client needs and the paramount goal of client safety. In addition, it seeks to accomplish its primary objectives of quality control and consumer protection through the application of direct command-and-control regulation (i.e., regulatory "Thou shalt" and "Thou shalt nots") of service providers' conduct.³ This regulation is done, for example, via professional and organizational licensing by the states, and federal or state structural conditions yoked to providers' participation in specific public funding programs such as Medicaid.⁴ Additional legal tools relied on in this regard are the threat of civil and criminal liability for violation of quality standards and the endangerment of client safety.⁵ The policy assumption underlying the traditional model is that the behavior of service providers needs to be pushed constantly in the direction of client protection. Creating anxiety among providers about potential personally adverse legal consequences for jeopardizing client safety is likely the most effective way to achieve that behavioral objective. Put differently, the envisioned ideal role of the law is to prevent, detect, and punish provider malfeasance.⁶ An appropriate descriptive image is one of the law as a shield, placing a protective barrier between the older consumer and

2. See Lori Simon-Rusinowitz & Brian F. Hofland, *Adopting a Disability Approach to Home Care Services for Older Adults*, 33 GERONTOLOGIST 159, 160-61 (1993).

3. See KAPP, *supra* note 1, at 69-82 (2003) (discussing the legal climate in long term care).

4. Marshall B. Kapp, *Home Health Care Regulation: Is it Good for the Patient?*, 1 CARE MGMT. J.: J. LONG TERM HOME HEALTH CARE 251-257 (1999).

5. *Id.* at 251.

6. Robert L. Kane, *Changing the Face of Long-Term Care*, 17(4) J. AGING & SOC. POL'Y at 1, 13-14 (2005).

those who would engage in mistreatment.

CONSUMER-DRIVEN HCBLTC: BACKGROUND

As already noted, the idea of consumer-driven LTC is nothing novel as applied to individuals who have the financial means—through personal pensions, invested savings, or private long-term care insurance policies⁷—to pay for services themselves. The power of the purse is the power to negotiate, at least insofar as choices of service providers are available within a particular community. Similarly, a rich tradition of consumer-driven LTC has developed over the past several decades in the context of publicly funded LTC services for younger seriously disabled persons who desire to define and control the parameters of their service plans.⁸

However, over the past decade there has been a broad conceptual and practical shift, even for the substantial proportion of the older American population that depends on public dollars to finance their HCBLTC.⁹ This shift, which represents a logical expansion of the informed choice doctrine beyond its original application to clinical medicine¹⁰ and the more recent consumer-driven health care contexts,¹¹ has been toward consumer-driven LTC delivery models within which the

7. See Joan Quinn et al., *Long-Term Care Insurance: Care Management Practice Issues*, 5 CARE MGMT. J.: J. CASE MGMT., Spring 2004, at 25, 27-28.

8. See generally Simon-Rusinowitz, *supra* note 2 (discussing greater autonomy of personal assistance choices in younger disabled persons compared to older persons); Nancy N. Eustis, *Consumer-Directed Long-Term Care Services: Evolving Perspectives and Alliances*, 24 GENERATIONS, Fall 2000, at 10-12.

9. See MARY JO GIBSON ET AL., AARP PUB. POL'Y INST, ACROSS THE STATES: PROFILES OF LONG-TERM CARE (6th ed. 2004) (discussing the percentage of persons in each state utilizing public funds for HCBLTC); see also Richard L. Kaplan, *Cracking the Conundrum: Toward a Rational Financing of Long-Term Care*, U. ILL. L. REV. 47, 57-73 (2004) (discussing the extent of coverage for long-term care provided by the two government programs older Americans rely upon for HCBLTC, Medicare and Medicaid).

10. See RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 53-101 (1986).

11. Marshall B. Kapp, *Patient Autonomy in the Age of Consumer-Driven Health Care: Informed Consent and Informed Choice*, 2 J. HEALTH & BIOMEDICAL L. 1, 19-24 (2006).

older consumer is empowered to control the structural and operational components of the service plan.¹² This shift in the gerontological sphere has been fueled by a variety of social, economic, political, and legal factors.¹³

Publicly financed consumer-driven HCBLTC models vary significantly across the states in structure and operation.¹⁴ These models are funded through a combination of federally approved state Medicaid waivers authorized by 42 United States Code 1396n(c),¹⁵ dedicated state appropriations,¹⁶ and (at least for the time being) private foundation demonstration project grants.¹⁷ The precise methods of transmitting compensation to LTC providers (e.g., via vendor payments made directly by the governmental or private insurer versus entrusting clients with vouchers or cash to spend themselves, with professional counseling¹⁸) vary from program to program. Contemporary experimentation with consumer-driven models of LTC is by no means limited to the United States,¹⁹ and several countries have

12. Robyn I. Stone, *Consumer Direction in Long-Term Care*, 24 GENERATIONS, Fall 2000, at 5; see also Barbara W. Schneider, et al., *Consumer-Directed Care*, in THE ENCYCLOPEDIA OF ELDER CARE 152-154 (M.D. Mezey ed., 2004).

13. See generally CONSUMER VOICE AND CHOICE IN LONG-TERM CARE (Suzanne R. Kunkel & Valerie Wellin eds., 2006) (discussing new customer satisfaction models for long-term care).

14. DONNA LIND INFELD, NAT'L ASS'N OF STATE UNITS ON AGING & NAT'L COUNCIL ON THE AGING, STATES' EXPERIENCES IMPLEMENTING CONSUMER-DIRECTED HOME & COMMUNITY SERVICES: RESULTS OF THE 2004 SURVEY OF STATE ADMINISTRATORS, OPINION SURVEY & TELEPHONE INTERVIEWS 6-10 (2004), http://www.nasua.org/pdf/20026_text.pdf (last visited Mar. 8, 2007).

15. Nancy A. Miller et al., *Strengthening Home and Community-Based Care Through Waivers*, 18 J. AGING & SOC. POL'Y 1, 2-4 (2006); U.S. GEN. ACCT. OFF., LONG-TERM CARE: FEDERAL OVERSIGHT OF GROWING MEDICAID HOME AND COMMUNITY-BASED WAIVERS SHOULD BE STRENGTHENED 03-576 at 5-10 (2003).

16. LAURA L. SUMMER & EMILY S. IHARA, GEORGETOWN UNIVERSITY, STATE-FUNDED HOME & COMMUNITY-BASED SERVICE PROGRAMS FOR OLDER PEOPLE 1-4 (2004), http://assets.aarp.org/rgcenter/post-import/2004_11_hcbs.pdf (last visited Jan. 20, 2007).

17. See, e.g., ROBERT WOOD JOHNSON FOUNDATION, GRANT RESULTS TOPIC SUMMARY: FORMAL LONG-TERM CARE 5 (discussing partners in care giving: the dementia services program grant that provides funding for consumer driven HCBLTC).

18. Kevin J. Mahoney & Kristin Simone, *History of and Lessons from the Cash and Counseling Demonstration and Evaluation*, in CONSUMER VOICE AND CHOICE IN LONG-TERM CARE 43, 43-56 (Suzanne R. Kunkel & Valerie Wellin eds., 2006).

19. Kee-Lee Chou, et al., *A Proposal for a Voucher System for Long-Term Care in*

demonstrated more than a decade's worth of substantial positive experience with these models.²⁰

Under the consumer-driven LTC paradigm, quality control and direct protection of consumers against provider malfeasance remain legitimate, but now secondary, functions of the law. The main function of the law under consumer-driven LTC is affirmative. Specifically, the law is expected to enable, empower, and facilitate the informed, capable, and voluntary exercise of consumer autonomy or self-determination within a competitive, affordable marketplace of good quality services and goods. Here, the law should be envisioned as a sword with which consumer rights—most notably, the right to informed choice—can be carved out.

The parameters of the government's proper role within the emerging consumer-driven HCBLTC paradigm are discussed below. These parameters include both autonomy-enhancing initiatives and the regulatory limits that arguably ought to be imposed as a matter of client protection, even under a consumer-driven model of HCBLTC.

NECESSARY REGULATORY OVERLAY

Several states have been operating consumer-directed HCBLTC programs for more than twenty years.²¹ These state programs include a significant number of older persons "without any evidence of significant problems for older consumers."²² The

Hong Kong, 17 J. AGING & SOC. POL'Y 85, 88-91, 95-97 (2005).

20. JANE TILLY, AARP PUB. POL'Y INST., CONSUMER-DIRECTED LONG-TERM CARE: PARTICIPANTS' EXPERIENCES IN FIVE COUNTRIES, ISSUE BRIEF 36, 3-8 (1999), <http://www.aarp.org/research/housing-mobility/homecare/aresearch-import-196-IB36.html> (last visited Mar. 19, 2007).

21. See generally BARBARA COLEMAN, ET AL., NATIONAL CONFERENCE OF STATE LEGISLATURES, FORUM FOR STATE HEALTH POLICY LEADERSHIP, STATE LONG-TERM CARE: RECENT DEVELOPMENTS & POLICY DIRECTIONS 2003 UPDATE (July 2003), <http://www.ncsl.org/programs/health/forum/ltc/LTC2003.pdf> (last visited Mar. 20, 2007) (discussing the planning and implementation of a number of states' HCBLTC programs).

22. JUDITH E. HEUMANN, AARP PUB. POL'Y INST., CONSUMER-DIRECTED PERSONAL CARE SERVICES FOR OLDER PEOPLE IN THE U.S., ISSUE BRIEF 64, 1 (2003), http://assets.aarp.org/rgcenter/health/ib64_cd.pdf (last visited Mar. 20, 2007).

available empirical evidence supports the workability of this model.²³ Nevertheless, private arrangements between consumers and independent contractors for HCBLTC services entail a panoply of risks for the consumer (as well as for in-home LTC workers).²⁴ In some circumstances, attempted consumer direction will fail.²⁵ Even, and perhaps especially, under a robust consumer-driven LTC model, a certain amount of governmental regulation is essential to protect consumers.

For instance, access to the courts must remain available to consumers to enforce the terms of private contracts entered into by those consumers with private LTC insurers and sellers of LTC goods and services. Consumers will only be willing to continue to negotiate and join in contracts to the extent they feel confident that the bargained-for terms will be enforced legally if they are not complied with voluntarily. Additionally, civil tort remedies, in the form of monetary damages, must remain available to particular consumers who are seriously injured because of private provider deviation from acceptable standards of care (i.e., negligence) or intentional misconduct such as client physical or financial abuse.

REGULATING THE INFORMATIONAL ENVIRONMENT

The consumer-driven model begins with an informed consumer. This, in turn, requires that adequate, appropriate, comprehensible information about the benefits, risks, and costs of various alternative services and service providers be readily available to consumers who expect to direct the details of their

23. LARRY POLIVKA & JENNIFER R. SALMON, FLORIDA POLICY EXCHANGE ON AGING, CONSUMER-DIRECTED CARE: AN ETHICAL, EMPIRICAL, AND PRACTICAL GUIDE FOR STATE POLICYMAKERS 10-20 (2001), http://www.fpeca.cas.usf.edu/chltc/PDF_Files/CDCfinalreport62101.pdf. (last visited Mar. 20, 2007).

24. NAT'L PRIVATE DUTY ASS'N, CONSUMER AND WORKER RISKS FROM THE USE OF NURSE REGISTRIES AND INDEPENDENT CONTRACTOR COMPANIES 2-4 (Sept. 15, 2003), <http://www.premierhomecare.org/images/privatehomecare.pdf> (last visited Mar. 20, 2007).

25. Marshall B. Kapp, *When Consumer Direction Fails: Assigning Legal and Ethical Responsibility in Worst-Case Situations*, in CONSUMER VOICE AND CHOICE IN LONG-TERM CARE 251, 251-260 (Suzanne R. Kunkel & Valerie Wellin eds., 2006).

own HCBLTC. Ideally, consumers should be educated, trained, and supported by objective professional sources to exercise their choices in the manner that best accomplishes a particular consumer's personal goals and preferences.²⁶ Legal initiatives can positively influence the informational environment in several ways.

Government mandates the collection and public dissemination of a slew of comparative data concerning the quality of services rendered by particular LTC providers.²⁷ Further research is needed to clarify how consumers actually use this information to select providers and monitor their performance. The Federal Trade Commission (relying on statutory authority stemming from Congress' constitutional power to regulate interstate and foreign commerce) and its state counterparts (relying on the states' inherent police power to protect and promote the general health, safety, and welfare of the community) should promulgate rules criminalizing false and misleading advertising or other misrepresentations by service and product sellers. False, misleading commercial speech, designed to sell a service or product rather than to inform political debate, is not protected against governmental prohibition under the free speech clause of the United States Constitution's First Amendment.

Further, consumers who are defrauded by deceptive practices must be able to seek monetary damages for their injuries in individual civil tort claims brought in state courts. Additionally, government has a valuable role to play in setting standards for the sales practices of private LTC insurance companies, including regulation regarding product advertising.

26. Courtney B. Davis et al., *Person-Centered Planning Training for Consumer-Directed Care for the Elderly and Disabled*, 6 CARE MGMT. J.: J. CASE MGMT. 122, 124-127 (2005); Robert L. Kane, et al., *Who Recommends Long-Term Care Matters*, 46 GERONTOLOGIST 474, 474-75 (2006).

27. Vincent Mor, *Improving the Quality of Long-Term Care with Better Information*, 83 MILBANK Q. 333, 336-37 (2005).

REGULATING TO ASSURE AN AUTONOMOUS CONSUMER

Actual consumer preferences lie at the heart of the consumer-driven LTC paradigm. Those consumer preferences trump policy makers' and LTC practitioners' externally generated and imposed ideas about what consumers *should* desire.

Under the traditional agency or funder-driven LTC model, consumers were forced to make a tradeoff.²⁸ They forfeited choice regarding most of the details of their own LTC in exchange for the protection against the risk of harm purportedly provided by an extensive web of command-and-control regulation and tort and criminal liability potential surrounding service delivery.²⁹ It must be noted that the assumption about the prophylactic consequence of legal regulation underlying the traditional LTC model has not yet been subjected to rigorous empirical analysis; it persists as an article of faith among adherents of the regulatory approach.³⁰

The consumer-driven LTC paradigm, by contrast, de-emphasizes the safety preservation function of legal intervention and, instead, more strongly emphasizes its autonomy enhancement potential. An important policy-relevant assumption, therefore, is that this tradeoff of assumed safety for tangible control over LTC details is acceptable, if not affirmatively desirable, to the majority of potential LTC consumers and/or their families or other surrogates.³¹

There is a corollary to this assumption about a tolerance, if not a positive preference, for increased autonomy even at the cost of some increased exposure to risk of harm (put differently, a preference for quality of life over quality of care): namely, the supposition that the great majority of consumers and/or their

28. See generally KAPP, *supra* note 1, at 91-120, (2003) (discussing the shift of long-term care towards consumer choice).

29. *Id.* at 91-97, 101-103.

30. See NAT'L COUNCIL ON DISABILITY, CONSUMER-DIRECTED HEALTH CARE: HOW WELL DOES IT WORK? (2004) <http://www.ncd.gov/newsroom/publications/2004/pdf/consumerdirected.pdf> (last visited Mar. 20, 2007).

31. Kapp, *supra* note 25, at 251-60.

surrogates are capable of intelligently making such tradeoffs of some degree of increased exposure to risk of harm in order to obtain and maintain desired forms of LTC from desired providers under desired conditions.³² One (but only one) way that such capability might be measured would be by comparing the consistency of consumer choices with the intent of program planners.³³ Consumer self-determination could be exercised either independently, in collaboration with family, friends, or significant others, or by informally (i.e., without the involvement of formal legal sanction) delegating decision making authority to another individual(s) selected and trusted by the consumer.

It makes little sense to devise a LTC model predicated on assumed consumer preferences unless we also assume most consumers are able to act autonomously, by making important decisions voluntarily, competently, and as an outcome of rational manipulation of sufficient information, and that persons lacking this capacity represent an exceptional category within the much larger relevant population. Moreover, LTC by definition involves the use of a frequently changing array of services over an extended period of time; hence, proponents of consumer-driven LTC must assume most consumers' adequate capacity to function as autonomous decision makers exists not just at the outset of LTC but on a continuing, ongoing basis as well.

Nevertheless, even the most vigorous proponents of consumer-driven LTC acknowledge that there will be some (albeit a relatively small) percentage of older disabled HCBLTC candidates who lack, temporarily or permanently, sufficient cognitive and/or emotional capacity to act as autonomous consumers despite any amount of informational and social support.³⁴ States could fulfill their *parens patriae* obligation to

32. See Kapp, *supra* note 25, at 98-101 (discussing consumers' ability to make decisions regarding their care).

33. Hongdao Meng et al., *Effect of a Consumer-Directed Voucher and a Disease-Management-Health-Promotion Nurse Intervention on Home Care Use*, 45 GERONTOLOGIST 167, 167-176 (2005).

34. Marshall B. Kapp, *Consumer Choice in Home and Community-Based Long-Term*

protect these individuals by enacting legislation requiring (except in those situations where the candidate has previously been adjudicated incompetent by a court as part of a guardianship or conservatorship proceeding) HCBLTC candidates be evaluated to determine if they currently possess sufficient decisional capacity to participate in a consumer-driven service model.

Regarding those who are determined to lack adequate present decisional capacity, advocates of consumer-driven LTC suppose that there exist suitable mechanisms for surrogate decision making about LTC (including HCBLTC options).³⁵ This assumption contains two general components. First, it is assumed that legal advance planning mechanisms, primarily proxy directives (i.e., durable powers of attorney) supplemented by instruction directives (i.e., living will-like instruments), concerning LTC decision making either exist or can be created to assist almost all decisionally incapacitated LTC candidates to have their previously indicated LTC preferences followed. Further, it is assumed that these legal devices will be created in a timely fashion (i.e., while the consumer is still decisionally capable) by most individuals who will become decisionally incapacitated at some point in the future. Moreover, there is faith that reliance on these advance planning documents in real circumstances requiring specific decisions will achieve the results, in terms of the shape of the LTC service plan, the consumer had intended to achieve.

To assist in the fulfillment of this set of assumptions, the states should amend their respective advance directive statutes to expressly authorize the execution of both proxy and instruction directions specially referring to planning for HCBLTC (and, for that matter, for future nursing home care³⁶). Moreover, federal or state statutes could be enacted, analogous

Care: Policy Implications for Decisionally Incapacitated Consumers, 19(4) HOME HEALTH CARE SERVICES Q., 2001, at 17, 23-24 (2001).

35. See Kapp, *supra* note 25, at 107-108 (discussing surrogates).

36. See Marshall B. Kapp, 'A Place Like That': *Advance Directives and Nursing Home Admissions*, 4 PSYCHOL. PUB. POL'Y & L. 805, 815-817 (1998).

to the Patient Self-Determination Act of 1990,³⁷ that compel hospital discharge planners, physicians, and designated others to inquire of a patient or the patient's surrogate, at designated points in time (such as when the hospital discharge planning process commences), whether the patient had previously executed an advance LTC directive.³⁸ When, as usually would be the case, no advance LTC directive had been previously executed, the law could require the discharge planner, physician, or other professional to offer to assist the patient to execute such a document. To aid in the enforcement of these LTC directives, state LTC directive statutes could contain provisions mandating that discharge planners, area agencies on aging, and other participants who would be involved in the individual's HCBLTC respect and implement the instructions contained in a directive (subject to resource constraints and exceptions based on potential ethically unacceptable risks of harm to the vulnerable individual). Even under such exceptional circumstances, the involved professionals should be prohibited from interfering with a transfer of the consumer to other providers who are willing and able to honor the consumer's LTC advance directive.

There also is the belief on the part of consumer-driven LTC advocates that willing and able individuals can easily be identified and convinced to step in to make choices on behalf of decisionally incapacitated LTC clients.³⁹ Additionally, it is assumed that an acceptable mechanism for holding these surrogates accountable for acting consistently with the consumer's wishes or, alternatively, in the consumer's best interests, can be created. A suitable process of accountability in this context would depend on several factors. These factors include, among others: the prospective achievement of sufficient consensus among interested stakeholders regarding appropriate

37. 42 U.S.C. §§ 1395cc(a)(1) & 1396a(a) (Westlaw current through March 15, 2007).

38. 42 C.F.R. § 489.102(a)(2) (Westlaw current through March 8 2007).

39. See generally KAPP, *supra* note 1, at 100, 107-08 (2003).

minimum and optimal qualifications for LTC decision making surrogates; agreement on the extent and limits of surrogates' decision making powers; development of efficient and effective ways of monitoring surrogates' performance as fiduciaries for decisionally incapacitated LTC clients; and implementation of aggressive but not overly intrusive strategies for intervening when the surrogacy system goes seriously awry.

The various states' adult protective services (APS) statutes could be amended to specifically address these factors in ways that facilitate the efficacy of surrogate decision making for matters pertaining to HCBLTC. These modifications to the present APS system could be made as an exercise of each state's inherent *parens patriae* authority to protect from harm those persons who are *de facto* unable to protect themselves and hence vulnerable to ethically and socially unacceptable risks.

REGULATING TO ASSURE THE AVAILABILITY OF ALTERNATIVES

Consumer choice, to be engaged in as a matter of private negotiation and agreement, is only meaningful as more than a slogan when consumers actually enjoy the opportunity to pick from and negotiate specific details with an array of potential local providers of LTC services and goods. To promote the welfare, and thus encourage the participation, of independent LTC service providers whose availability and willingness to sell their services is integral to the maintenance of a vibrant marketplace, government should attend to a variety of human resource matters.⁴⁰ These matters include application to independent providers of the wage and hour provisions of the Fair Labor Standards Act,⁴¹ workers' compensation and unemployment insurance provisions,⁴² the Social Security

40. See Charles P. Sabatino & Simi Litvak, *Liability Issues Affecting Consumer-Directed Personal Assistance Services*, 4 ELDER L.J. 247, 251-60 (1996); see also Marshall B. Kapp, *Health Care in the Marketplace: Implications for Decisionally Impaired Consumers and Their Surrogates and Advocates*, 24 S. ILL. U. L.J. 1, 21 (1999).

41. Sabatino & Litvak, *supra* note 40, at 274-85.

42. *Id.* at 288-91.

retirement system,⁴³ and disability programs.⁴⁴ To the extent the legal environment and other factors can promote the job satisfaction, safety,⁴⁵ and general well-being of independently-employed workers, those factors will contribute to the ultimate success of the consumer-driven LTC model.⁴⁶

Another central aspect of the legal environment concerns providers' exposure to litigation and liability risks. Proponents of consumer-driven LTC assume (without significant dispute from most advocates of the more traditional, professionally dominated service delivery model) that the prevailing legal environment (both actual and perceived) can exert a powerful effect on the behavior of people trying to avoid or minimize their own exposure to negative legal consequences.⁴⁷ Such defensive risk management behavior, whether or not it actually successfully reduces the actor's legal risk, may act either beneficially or anti-therapeutically on the lives of the intended beneficiaries (in this case, HCBLTC consumers) of the anxiety-producing legal environment.

In the LTC context, it is assumed that the actual or perceived climate relating to providers' legal risk exposure may affect the availability, quality, and price of HCBLTC services in any specific locality.⁴⁸ More specifically, proponents of consumer-driven HCBLTC assume that a legal environment that concentrates more (and is perceived as concentrating more) on enhancing consumer autonomy and less on constantly policing

43. *Id.* at 267-70.

44. *Id.* at 292-93.

45. See generally Teresa Scherzer, et al., *Integrating Occupational Health and Safety into the United States' Personal Assistance Services Workforce Research Agenda*, in CONSUMER VOICE AND CHOICE IN LONG-TERM CARE 89, 89-99 (Suzanne R. Kunkel & Valerie Wellin eds., 2006) (discussing occupational health and safety for personal assistance services workers).

46. See generally A.E. Benjamin & Ruth E. Matthias, *Work-Life Differences and Outcomes for Agency and Consumer-Directed Home-Care Workers*, 44 GERONTOLOGIST 479, 479 (2004) (discussing work-life of consumer home-care workers); see also Stacy Dale et al., *How Do Hired Workers Fare Under Consumer-Directed Personal Care?*, 45 GERONTOLOGIST 583, 583 (2005) (discussing the experience of workers hired under consumer-directed care).

47. Kapp, *supra* note 25, at 109.

48. See KAPP, *supra* note 1, at 70-73.

for provider malfeasance is likely to result in more providers of services and goods vying for economically empowered consumers' business in a competitive marketplace. This would happen by reducing providers' apprehension about potential regulators' aura of distrust and propensity to punish. That development, in turn, is likely to enhance the accessibility, affordability, and quality of LTC that consumers are able to purchase. That is because these are all attributes every provider wants to excel at in order to improve its own competitive position in the business world of empowered, informed purchasers.

The variety of LTC delivery models and legal climates occurring as a result of differing political forces in different jurisdictions will present natural opportunities for observational studies. These studies can focus on determining the cause and effect relationship between actual and perceived legal environments, on the one hand, and the accessibility, affordability, and quality of HCBLTC goods and services, on the other. These natural experiments can be supplemented by the analysis of evidence derived from specially designed demonstration projects initiated in selected willing jurisdictions. Conclusions drawn from the data produced by such natural and interventional studies should then be used to inform the regulatory development process, so that regulation in this arena becomes more empirically based rather than reliant on untested assumptions.

COMMAND AND CONTROL REGULATION AS AN ALTERNATIVE TO THE CONSUMER-DRIVEN MODEL

The starting factual precept of consumer-driven LTC is that at least a significant proportion of disabled adults, including older persons—even many of those with quite substantial ADL impairments—strongly want to manage all or many of the details of their own LTC rather than leave the most significant service delivery details to a professional agency or funding entity. This presumption is consistent with the contemporary

American cultural commitment to the ethical and legal value of autonomy. This belief in the desire for individual autonomy is a fundamental article of faith⁴⁹ nearly universally held among members of the LTC policy community, rising virtually to the level of a mantra.

Nonetheless, we know that there is some amount of heterogeneity on this matter among various components of the relevant population.⁵⁰ Individuals, deciding personally or through a surrogate, who want to receive HCBLTC services within a traditional regulatory model should be allowed and enabled to do so. It would ironically defeat the goals of the autonomy principle to force consumers to drive their own HCBLTC plans unwillingly. A scaled down version of the *status quo ante* needs to remain in place for those individuals, or alternatively a default mechanism in the same way that in the health care financing arena traditional Medicare Parts A and B remain in place to be chosen by beneficiaries who do not wish to join with the more than seven million individuals⁵¹ currently participating in the more autonomy-oriented Medicare Advantage-Part C option.

CONCLUSION

The paradigm shift to a consumer-driven model for the funding and delivery of home and community based long-term care for older, disabled individuals does not merely entail the removal of a preexisting regulatory regime in which the most important facets of the care plan were determined mainly by professionals and bureaucracies instead of the consumer. Rather, this shift

49. See GEORGE J. AGICH, *AUTONOMY AND LONG-TERM CARE* 7-12 (1993).

50. See Mark Sciegaj et al., *Consumer-Directed Community Care: Race/Ethnicity and Individual Differences in Preferences for Control*, 44 *GERONTOLOGIST* 489, 489 (2004) (finding that "consumer direction occurs along a continuum . . . and the importance of recognizing heterogeneity within racial/ethnic groups regarding consumer-directed care.").

51. Jane Zhang & Vanessa Fuhrmans, *Seniors Flock to Private Medicare Plans; Flexible Fee-for Service Policies Spur Growth in Alternatives to Government-Run Coverage*, WALL ST. J., Aug. 29, 2006, at D1.

calls for a new and different approach to regulation. This article has attempted to outline the necessary parameters of this new regulatory approach to HCBLTC. The specific form and contents of regulation in the era of consumer-driven HCBLTC will depend in significant measure on a rethinking of the role of government in the weighing and balancing of sometimes competing social values implicating both the enhancement of autonomy and protection of the vulnerable.