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The Policy and Politics of Community-Based Long-Term Care

Alison Barnes
Marquette University Law School, alison.barnes@marquette.edu

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The Policy and Politics of Community-Based Long-Term Care

Alison Barnes[*]

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[*] Professor of Law, Marquette University Law School, Milwaukee, WI. B.A., University of Florida, 1978; J.D., University of Florida, 1985. Former Senior Policy Analyst for the United States Special Committee on Aging and the Intergovernmental Health Policy Project at George Washington University, Professor Barnes teaches health law and elder law. She is co-author with Lawrence W. Frolik of the casebook, *Elderlaw*, and a forthcoming reference for practitioners to be published by the American Law Institute/American Bar Institute.

I. INTRODUCTION

The health services industry in the United States is in transition. Financing is changing from primarily fee-for-service to capitated payments, and control of service delivery and quality assurance are moving from individual physician dominance to institutional control.[1] The states and private sector are making sweeping changes in the finance and delivery of health care and are likely to proceed with increased determination with the failure of federal legislative reforms in the 103d Congress.[2] Indeed, the provisions of the most comprehensive health care reform bill, President Clinton's Health Security Act,[3] mirrored and anticipated the evolution of the health care market.

The impetus for change includes the demand for more effective cost containment than has been achieved by the implementation of prospective payments systems in government programs.[4] Health care costs increased from over $600 billion in 1990 ($2566 per person) to nearly $900 billion in 1993 ($3380 per person),[5] far more than in other developed countries with similar constellations and rates of disease.[6] States are motivated to curb

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[1] *See* Dan Morgan, *While Washington Talked: Health Care Reform Is Taking Shape in the Private Sector Without Help from Congress*, WASH. POST WKLY., Sept. 12-18, 1994, at 31 (discussing the shift to "managed care" as the preferred method of providing health care services in the private sector); Robert Pear, *States Again Try Health Changes as Congress Fails*, N.Y. TIMES, Sept. 16, 1994, at A1. *See generally* Mark A. Hall, *Institutional Control of Physician Behavior: Legal Barriers to Health Care Cost Control*, 137 U. PA. L. REV. 431 (1988).

[2] States that have adopted substantial reforms include California, Florida, Hawaii, Minnesota, New York, Oregon, Tennessee, Vermont, and Washington.

[3] S. 1757, 103d Cong., 1st Sess. (1993); H.R. 3600, 103d Cong., 1st Sess. (1993). The plan was developed by the President's Task Force on National Health Care Reform, headed by Hillary Rodham Clinton. An amended plan was introduced in the Senate by Majority Leader George Mitchell and in the House by Representative Richard Gephardt.

[4] 42 U.S.C. § 1395ww (Supp. V 1993) (outlining prospective payments system for hospitals implemented in 1982); *id.* § 1395 w-4 (discussing payments for physician services); 42 C.F.R. §§ 405, 413, 415 (1992) (phasing in of resource-based relative value scale for physician payments between 1992 and 1996); *see* Bruce C. Vladeck, *Medicare's Prospective Payment System at Age Eight: Mature Success or Midlife Crisis?*, 14 U. PUGET SOUND L. REV. 453, 454 (1991) (proclaiming the Prospective Payment System a fiscal and administrative success). Without comprehensive cost controls, short funding in public programs merely results in cost shifting to private payers.

[5] Sally T. Burner et al., *National Health Expenditures Projections Through 2030*, 14 HEALTH CARE FINANCING REV. 1, 29 (1992).

[6] According to the United Nations 1994 Human Development Report, the United States spent 13.3% of its gross domestic product ("GDP") on health care. By comparison, Canada

spending on medical assistance programs for the poor,[7] and private sector entities are seeking mergers to consolidate providers into tightly managed delivery systems in order to maximize economies of scale.[8] Equally important to legislative change is the desire for access to coverage, an array of services, and modes of delivery acceptable to an increasingly dissatisfied health care consumer population.[9]

Individual opinion regarding the need for reform is mixed.[10] However, it is undisputed that United States health care coverage[11] is increasingly fragmented. A growing number of Americans fail to maintain adequate

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spent 9.9%; Japan, 6.8%; and the United Kingdom, 6.6% of its GDP. *See* Paul Spector, *Failure, by the Numbers*, N.Y. TIMES, Sept. 24, 1994, at A12. Most countries use GDP as the official measure of the total value of economic activity, rather than gross national product ("GNP"). The difference between the two measures is that GNP takes into account all economic activity of citizens living outside the nation's borders, whereas GDP involves only economic activity conducted within the geographical boundaries of the country.

[7] Total spending on Medicaid almost doubled to $92 billion in 1991, from $49.3 billion in 1987, with most of the growth concentrated in the last two years. CONGRESSIONAL RESEARCH SERV., MEDICAID: RECENT TRENDS IN BENEFICIARIES AND SPENDING (Mar. 27, 1992). Medicaid (called medical assistance ("MA") in some states and "Medi-Cal" in California) is authorized under Title XIX of the Social Security Act to provide medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. 42 U.S.C. § 1396 (Supp. V 1993). It is financed by a mix of state and federal funds (the federal portion ranging from 50% to 83%) according to a formula keyed to the average per capita income in the state. States submit plans developed under federal guidelines identifying how mandatory and selected optional services will be delivered to its citizens. Since all states must enact balanced budgets, unlike the federal government which can run a deficit, the pressure to control costs is intense.

[8] *See, e.g.*, Owen S. Mudge & Allan Gibofsky, *The Developing Applications of Antitrust Laws to Hospital Mergers*, 15 J. LEGAL MED. 355, 363-77 (1994) (four hospital merger antitrust cases).

[9] Dissatisfactions with American health care are many and varied. *See, e.g.*, S.S. Neumann, *Your Bill: $1,575. We Pay: $222. Have a Nice Day*, N.Y. TIMES, Oct. 23, 1993, at A13; Lynda Richardson, *Too Ill to Learn: Health System Fails to Meet Students' Needs, Educators Say*, N.Y. TIMES, Oct. 10, 1993, at A16; Ellen E. Schultz, *Beware of Coverage Gaps in Today's Health Plans*, WALL ST. J., Sept. 29, 1993, at C1.

[10] *See, e.g.*, Richard Morin, *A Health Care Reform Post-Mortem*, WASH. POST WKLY., Sept. 12-18, 1994, at 37 (noting that the number of Americans who believe the health care system needs to be "completely rebuilt" declined from 55% in April 1993 to 37% in August 1994, while the percentage who said only minor changes were needed nearly doubled).

[11] In 1994, the United States remained the only developed country with health care programs only for elderly persons (Medicare) and some very poor persons (Medicaid) because health care programs developed from welfare initiatives. In Europe and the United Kingdom, health care programs developed from labor reform movements covering persons of all ages and income levels. *See* LAWRENCE A. FROLIK & ALISON P. BARNES, ELDERLAW 300-02 (1992).

insurance coverage, either because they cannot, or choose not to, afford its rising costs or because preexisting conditions cause insurers to deny coverage.[12] Since about three-fourths of United States health insurance is employment-based, job changes produce the most policy lapses, and more people are uninsured in a weak economy.[13] As a result of coverage gaps, approximately twenty-five percent of Americans will lack health care coverage at some time between 1993 and 1998.[14] The sharpest increase in uninsured rates has been among middle class children over age seven.[15] Health care reform is therefore inevitable and in progress; the rate of change, choice of services, administration, and ultimate effectiveness remain to be determined.[16]

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[12] *See generally* EMPLOYEE BENEFIT RESEARCH INST., SOURCES OF HEALTH INSURANCE AND CHARACTERISTICS OF THE UNINSURED: ANALYSIS OF THE MARCH 1991 CURRENT POPULATION SURVEY (1992). An estimated 38 million Americans were uninsured in 1992, and an equal number were underinsured (i.e., having coverage inadequate to avert a financial disaster in the event of a serious or prolonged illness), an increase of four million people since 1987.

[13] John K. Iglehart, *The American Health Care System: Introduction, Health Policy Report,* NEW ENG. J. MED., Apr. 2, 1992, at 962.

[14] *See Number of Uninsured Americans Reached 36.6 Million in 1991,* NEWS RELEASE (Employee Benefits Research Inst., Washington, D.C.), Oct. 30, 1992, at 1 (news release on file with author). Most uninsured individuals live in households in which at least one person is employed, usually for low wages in such industries as food services, hospitality, and agriculture, in which health care coverage is not typically offered by employers. CONGRESSIONAL RESEARCH SERV., SPECIAL COMM. ON AGING, NO. 100-0, INSURING THE UNINSURED: OPTIONS AND ANALYSIS 2-3 (1988) [hereinafter INSURING THE UNINSURED].

[15] Jenifer D.C. Cartland & Beth K. Yudkowsky, *State Estimates of Uninsured Children,* HEALTH AFF., Spring 1993, at 144, 146.

[16] Several possible plans for national health care reform are outlined by legislative proposals in the 103d Congress. *See Health Care Reform: Fate of Bill Depends on Whether Coalition Can Be Forged,* Health Care Pol'y Rep. (BNA) (Jan. 10, 1994) (outlining key features of competing reform plans). Washington, D.C. state proposals are outlined in Deborah L. Rogal & W. David Helms, *Tracking States' Efforts to Reform Their Health Systems,* HEALTH AFF., Summer 1993, at 27.

Proposed changes fall generally into two categories: reform of health care financing mechanisms and reform of health services organization and delivery for cost containment. Typically, financing reforms either require employers to provide employee insurance, to contribute to a public trust fund, or to expand expenditures and eligibility for subsidized care. Reform of delivery systems either group together health care personnel to provide access to comprehensive health services for a set price, or establish insurance purchasing cooperatives to limit premiums through bargaining power.

Managed competition, the cornerstone of President Clinton's plan and a component adapted by most proposals, uses all four approaches to limit entrepreneurial profits. *See* CONGRESSIONAL RESEARCH SERV., HEALTH CARE REFORM: MANAGED COMPETITION CRS-1

One of the most problematic aspects of health care reform is the absence of well-developed and funded plans for providing long-term home and community-based care to aged and disabled persons.[17] Changes in medical technology and life expectancy have caused a dramatic increase in the number of individuals with chronic illnesses[18] which limit their ability to care for themselves.[19] Though many persons with disabilities from chronic conditions or advanced age[20] are unable to afford appropriate

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(Jan. 6, 1993).

[17] Community-based chronic care encompasses such medical and social services as home health, housekeeping, congregate and home delivered meals, and transportation. In addition, it includes housing, with or without services. Services for aged persons with disabilities have more often been termed "long-term care," while services to younger adults have been called "chronic care." The reasons for and results of this split in terminology, funding, and delivery are discussed in this article. *See infra* notes 31-70 and accompanying text. With a growing recognition among policy makers that such a division poses obstacles to enacting legislation for effective services programs, there is a trend to include all ages in proposals for home and community-based care initiatives. In accord with that view, this article will use the terms interchangeably, preferring "long-term care" as the term most often heard in the health reform debates. *See generally* A.E. Benjamin, *An Historical Perspective on Home Care Policy*, 71 MILBANK Q. 129 (1993) (labeling home care a re-discovered type of assistance).

[18] STEVEN A. SCHROEDER, ROBERT WOOD JOHNSON FOUND., ANNUAL REPORT 1993: CHRONIC HEALTH CONDITIONS 1, 1 (1993) (citing the number of American with disabilities as over 35 million). Figures vary widely according to the criteria of disability. *See* FAMILIES USA FOUND., THE HEAVY BURDEN OF HOME CARE 10 (1993) [hereinafter HOME CARE STUDY] (noting that 8.1 million persons living in the community have disabilities).

"Disability" refers to a limitation in function or activity resulting from a physical or mental impairment. Chronic condition refers to the presence of a specific diagnosed impairment that may or may not result in a functional or activity limitation. Since both people with disabilities and people with chronic conditions, as groups, have difficulty gaining access to an adequate range of health-related services , they are considered together in this article. A full consideration of programs and policies on mental impairments is beyond the scope of this article.

[19] Major activities include both self-care activities of daily living ("ADL") and instrumental activities of daily living ("IADL") such as meal preparation, shopping, managing money, using the telephone, and doing housework. CYNTHIA M. TAEUBER, U.S. DEP'T OF COM., SIXTY-FIVE PLUS IN AMERICA 3-11 (1992); *see infra* note 43 and accompanying text.

[20] Most chronic conditions are caused by a disease, such as diabetes, asthma, arthritis, epilepsy, arteriosclerosis, or muscular dystrophy. Some are caused by injury or a condition such as congenital heart disease. While chronic illness is not synonymous with advanced age, incidence increases with age and is more prevalent among older women. TAEUBER, *supra* note 19, at 3-11. For example, among those 80 years of age and older, 70% of women and 53% of men had two or more of the nine common conditions of arthritis, hypertension, cataracts, heart disease, varicose vein, diabetes, cancer, osteoporosis or hip fracture, and stroke. *Id.*

care,[21] existing public benefits fail to meet their needs, and private insurance coverage for long-term care is relatively costly and rare.[22] Restrictions on acute care benefits are increasing the demand for home and community-based care[23] and contribute to the change in provider organizations from small nonprofit providers to minor components of large, for-profit corporations.[24] In addition, the highest inflation rate in service costs has moved from acute care to long-term care.[25]

Despite apparent need, proposed legislation falls short of bridging the gap between health care and long-term care. Most state reforms perpetuate an acute care bias by deferring long-term care proposals until the completion of feasibility studies or by making home and community-based services optional.[26] President Clinton's proposal, based on a policy of identifying long-term care as an important component of health care reform, proposed to provide some long-term home and community-based care for severely disabled persons.[27] However, the services would be limited to those

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[21] *See* discussion *infra* parts IIB, IIIA.

[22] Sales of long-term care insurance policies totaled 2.9 million at the end of 1992, an increase of about 500,000 policies in one year. The number of policies has increased an average of nearly 30% annually since 1987. *Sales of Long-Term Insurance Increase,* 3 Health Law Rep. (BNA), at 291 (Mar. 3, 1994) (citing survey results from the Health Insurance Association of America, Washington, D.C.).

[23] Barbara Bronson Gray, *Geriatric Nursing Is Becoming a Key Field,* AGING TODAY, Sept.-Oct. 1994, at 5.

[24] Carroll L. Estes, *Crisis in Health Care Reform and the Culture of Caring,* AGING TODAY, May-June 1994, at 3.

[25] *See* Dan Morgan, *Nursing Homes: The "Sleeping Giant,"* WASH. POST WKLY., Feb. 14-20, 1994, at 9.

[26] *See* CENTER FOR POL'Y RESEARCH, NATIONAL GOVERNORS' ASS'N, STATE HEALTH CARE REFORM INITIATIVES (1992). Plans in Colorado, Delaware, Maine, Maryland, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, and Virginia, for example, include no specified expansion of long-term care services. Florida will seek federal permission to expand home and community-based long-term care. Hawaii established a long-term care financing advisory board. Montana plans tax incentives for family care and long-term care insurance. Vermont established a Health Care Authorization Board to develop recommendations for long-term care services.

[27] H.R. 3600, 103d Cong., 1st Sess. (1993); S. 1757, 103d Cong., 1st Sess. (1993) (establishing a program for home and community based services separate from Medicare and general health care plans). The only other federal proposal with a defined long-term care benefit is the McDermott/Wellstone Bill. S. 491, 103d Cong., 1st Sess. (1993); H.R. 1200, 103d Cong., 1st Sess. (1993). The bill includes home and community-based care (as well as nursing home care) in the benefits package. The bill has received consideration primarily as a "marker" establishing the broadest scope of nationalized health care benefits under a single payer system.

selected by each state for its citizens and would be subject to capped allocations.[28] In addition, the proposal had no concrete plan to fund an array of services.[29] In general, there is little agreement on how to respond to the complex questions of the organization and financing of chronic care.[30]

This article examines the evolution of long-term care in response to the needs of the United States population and the practical and policy justifications for including home and community-based care in the current wave of health care reform. The article concludes with consideration of specific issues and recommendations in the financing and delivery of publicly funded home and community-based care.

II. THE NEED FOR LONG-TERM CARE COVERAGE

The meaning of "long-term care" varies from state to state and program to program. At its most comprehensive, long-term care includes a wide array of health and social services, institutional care, and adapted or dedicated housing to meet the needs of persons who have lost some capacity for self-care. Long-term care services are usually differentiated by the settings in which they are provided: either in nursing homes and other institutions or in home and community-based settings. Two adult populations, traditionally considered separately in policy and programs, utilize community-based long-term care: adults with impairments from injury or chronic illness, and aged persons with chronic impairments or the general frailty of extreme old age.

A. *Defining Community-Based Long-Term Care*

Community-based long-term care includes congregate living arrangements with supportive services and community-based assistance such as home health care, congregate and home delivered meals, transportation, and

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[28] H.R. 3600, 103d Cong., 1st Sess. (1993); S. 1757 § 2103, 103d Cong., 1st Sess. (1993).

[29] *See* April Thompson, *Healthcare Professionals Eye Gaps in Clinton LTC Reforms,* AGING TODAY, May-June 1994, at 8.

[30] *See* Erik Eckholm, *Haunting Issue for U.S.: Caring for the Elderly Ill,* N.Y. TIMES, Jan. 27, 1990, at A1; Tamar Lewin, *Strategies to Let Elderly Keep Some Control,* N.Y. TIMES, Jan. 28, 1990, at A1; Martin Tolchin, *Paying for Long-Term Care: The Struggle for Lawmakers,* N.Y. TIMES, Jan. 29, 1990, at A1; Lisa W. Foderaro, *Want a Comfortable Old Age? Plan for Care Experts Advise,* N.Y. TIMES, Jan. 30, 1990, at A1.

shopping assistance.[31] Other long-term care services, such as respite care[32] and adult day care,[33] help family caregivers cope with their continuous responsibilities.[34] The great majority of persons needing long-term care reside in the community.[35]

Formal long-term care is a relatively recent innovation, defined primarily by government programs intended to extend or substitute for caregiving families. The need for government assistance arises from a combination of demographic, technological, philosophical, and sociological changes in American society. Perhaps most important are longer life spans resulting in extended old age and unprecedented survival rates from disabling illnesses due to new medical technology.[36] Simultaneously, families are less likely to be available as caregivers; they tend to live far away, and women, the traditional caregivers, have entered the work force and are no longer available to provide care.[37] Nevertheless, most assistance is still provided informally by family members and others.[38]

Appropriate housing is also critical to the well-being of disabled and elderly persons living in the community, although housing has traditionally been funded separately from services. Factors which distinguish a home from a prison for incapacitated residents may include: access to transportation and shopping, neighborhood safety, availability of informal help and oversight by concerned neighbors, relatives, and friends, access to formal services, such as home health care and home delivered meals, and user-

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[31] CONGRESSIONAL RESEARCH SERV., LONG-TERM CARE FOR THE ELDERLY 1 (1993). Long-term care also includes legal services for adult protective services, guardianship, and other forms of surrogate decision making, which are beyond the scope of this article.

[32] *See* ELDERLAW, *supra* note 11, at 538-40 (short-term, substitute care either inside or outside the home, in the absence of the primary caregiver).

[33] "Adult day care is a community-based group program designed to meet the needs of functionally impaired adults through . . . a variety of health, social and related support services in a protective setting during any part of a day but less than 24-hour care." NAT'L COUNCIL ON THE AGING, STANDARDS FOR ADULT DAY CARE 20 (1984).

[34] *See* ALISON P. BARNES, INTERGOVERNMENTAL HEALTH POL'Y PROJECT, GEO. WASH. U., CHRONIC CARE: AN OVERVIEW OF 1992 STATE LEGISLATIVE ACTIVITY 21 (1993).

[35] "Contrary to popular belief, *less than one-half* of chronically disabled persons living in the community . . . [are] elderly." ROBERT B. FRIEDLAND, EMPLOYEE BENEFITS RESEARCH INST., FACING THE COSTS OF LONG-TERM CARE 54 (1990).

[36] ELDERLAW, *supra* note 11, at 6-11.

[37] HOUSE SELECT COMM. ON AGING, PUB. NO. 99-611, EXPLODING THE MYTHS: CAREGIVING IN AMERICA 11-12 (1987) [hereinafter EXPLODING THE MYTHS].

[38] HOME CARE STUDY, *supra* note 18, at 10 (noting that two-thirds of persons with disabilities relied exclusively on informal, unpaid caregivers in 1992).

friendly design of entrances and in-home facilities.[39] Some older people, who stayed in their homes while their neighborhoods deteriorated, are isolated from assistance. Appropriate housing must also be affordable housing, taking into account the fact that many elderly and disabled persons have limited resources to finance the extra services that enable them to live as independently as possible.[40]

Because many persons with disabilities can manage most of their life activities with only occasional assistance and/or watchful oversight, and because it is natural for many to prefer the company and informal help of individuals with similar concerns, housing for persons with disabilities has often gravitated toward group living. Visiting services, such as homemaking, home health care, and home delivered meals, are also provided more efficiently where a number of recipients live in close proximity.[41]

B. *Persons with Chronic Disabilities and Health Care Coverage*

According to a definitive 1984 survey, an estimated 37.3 million Americans, age fifteen and older, have at least one physical functional limitation due to a chronic condition.[42] Over fifteen million people required assistance with activities of daily living ("ADL") such as bathing, dressing, grooming, eating, transferring and using the toilet, or instrumental activities of daily living ("IADL") such as meal preparation and light housework.[43] In 1993, the number of persons receiving assistance has increased to an estimated thirty-five million.[44]

The status of younger persons with disabilities is particularly significant to health care reform because of their higher than average health-related costs and lack of private health insurance. People with severe disabilities

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[39] Jon Pynoos, *Housing the Aged: Public Policy at the Crossroads in* HOUSING THE AGED: DESIGN DIRECTIVES AND POLICY CONSIDERATIONS 7 (1987).

[40] *See* ELIZABETH D. HUTTMAN, HOUSING AND SOCIAL SERVICES FOR THE ELDERLY 52-53 (1977).

[41] *See* ELDERLAW, *supra* note 11, at 765-66.

[42] Andrew I. Batavia, *Health Care Reform and People with Disabilities*, HEALTH AFF., Spring 1993, at 40, 42 (citing UNITED STATES BUREAU OF THE CENSUS, CURRENT POPULATION REPORT SERIES, P-70, 1984 SURVEY OF INCOME AND PROGRAM PARTICIPATION, NO. 8, TABLE C (1985)).

[43] FRIEDLAND, *supra* note 35, at 54. Functional status based on an evaluation of ADLs and IADLs was developed in the 1960s by Sidney Katz. *See* Sidney Katz et al., *Studies of Illness in the Aged, The Index of ADL: A Standardized Measure of Biological and Psychosocial Function*, 185 JAMA 914 (1963); Sidney Katz et al., *Progress in the Development of the Index of ADL*, GERONTOLOGIST, Spring 1970, at 20.

[44] SCHROEDER, *supra* note 18, at 1.

are estimated to use an average of six times the health care resources as those with no disabilities.[45] Many lack adequate health care coverage. Those who are unemployed[46] are excluded from the country's most common source of group insurance, and less than twenty-eight percent of persons under age sixty-five with disabilities were eligible for Medicare[47] or Medicaid benefits.[48] Just over fifteen percent have no insurance—about the same proportion as persons without disabilities.[49] However, people with disabilities are far more likely to be underinsured and to spend a substantial proportion of their incomes on health-related care.[50] The family incomes of persons with disabilities are much lower on average than those of persons without disabilities. In 1992, nearly one-half had incomes under $15,685, the lowest family income quintile for the population as a whole.[51]

Individuals with disabilities are also subject to exclusion from coverage, due to the structure of the casualty insurance market, which utilizes experience rating to set premiums according to anticipated costs.[52] A person with a disability is likely to be literally priced out of the market for coverage. Once without coverage, an individual may find that insurers are unwilling to issue a policy at any price or that coverage for specific services is denied because of the preexisting condition.[53]

The second population of long-term care users, age sixty-five and older, raises significant concerns because it is expected to double by the middle of the next century.[54] In 1990, thirty-one million Americans, or nearly

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[45] *See* Gerben DeJong et al., *America's Neglected Health Minority: Working-age Persons with Disabilities*, 67 MILBANK Q. 311 (Supp. 1989).

[46] "Fewer than 40% of people with disabilities are employed; only about 25% work full time." Batavia, *supra* note 42, at 51 (citing LOUIS HARRIS & ASSOC., N.Y., INT'L CTR. FOR THE DISABLED, THE ICD SURVEY OF DISABLED AMERICANS: BRINGING DISABLED AMERICANS INTO THE MAINSTREAM (1987)).

[47] An individual qualifies for Medicare coverage after two years of eligibility of Social Security Disability Income benefits. 42 U.S.C. § 1395c (1988).

[48] TAEUBER, *supra* note 19, at 4-11.

[49] ROBERT GRISS, WORLD INST. ON DISABILITY, ACCESS TO HEALTH CARE (1988).

[50] Persons with disabilities who received home care in 1992 had average expenses of $5415 and paid $1700 out-of-pocket. HOME CARE STUDY, *supra* note 18, at 3.

[51] *Id.* at 10.

[52] *See* INSURING THE UNINSURED, *supra* note 14, at 21.

[53] According to one study, 16.6% of working age persons with disabilities had services denied because of preexisting condition exclusions. ROBERT GRISS & S. HANSON, WORLD INST. ON DISABILITY, THE ADEQUACY OF PRIVATE AND PUBLIC HEALTH INSURANCE AMONG PERSONS WITH DISABILITIES OR CHRONIC ILLNESS (1988).

[54] TAEUBER, *supra* note 19, at 2-1.

thirteen percent, had reached the age of sixty-five.[55] Over the next twenty years, the elderly population will increase steadily but unspectacularly, due to low birth rates during the Depression. After 2010, however, the number of people reaching their sixty-fifth birthday each year will soar and remain high until around 2030, when the last baby boomer reaches the threshold of old age.[56] By then, people age sixty-five or older are expected to make up twenty percent of the population.

Dramatic demographic growth is already occurring in that portion of the population age eighty-five and older, due to increasing life expectancies.[57] In 1990, there were approximately three million people age eighty-five and older.[58] By the year 2010, it is estimated that this number will double to 6.1 million. By 2030, given current trends, there will be over eight million people age eighty-five and over.[59]

Older people are more likely to suffer from chronic conditions which limit their ability to care for themselves.[60] Multiple impairments and longer recovery periods from acute illnesses contribute to longer hospital stays. As a result, it is estimated that people age sixty-five and older (comprising 12.6% of the United States's population) account for one-third of the nation's annual health care expenditures, or about $300 billion out of a total $900 billion in 1993.[61] It is not widely doubted that growth in the aging population contributes substantially to rising health expenditures,[62] though one analysis indicates that other factors, including medical inflation and greater volume of services, have been more significant causes since 1970 and will account for most of the increase until 2005.[63] After that time, the aging of the population is likely to cause rapid acceleration in health care spending unless effective cost containment is implemented.[64]

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[55] *Id.* at 2-3.

[56] *Id.* at 2-4 to 2-5.

[57] *Id.* at 2-4.

[58] *Id.* at 2-3.

[59] TAEUBER, *supra* note 19, at 2-2.

[60] UNITED STATES SENATE SPECIAL COMM. ON AGING, AM. ASS'N OF RETIRED PERSONS, FED. COUNCIL ON THE AGING, & U.S. ADMIN. ON AGING, AGING AMERICA: TRENDS AND PROJECTIONS 112 (1991) [hereinafter AGING AMERICA].

[61] Burner et al., *supra* note 5, at 1.

[62] *But see* Robert H. Binstock, *Healthcare Costs Around the World: Is Aging a Fiscal 'Black Hole'?*, GENERATIONS, Winter 1993, at 37 (arguing that the impact is overstated).

[63] Daniel N. Mendelson & William B. Schwartz, *The Effects of Aging and Population Growth on Health Care Costs*, HEALTH AFF., Spring 1993, at 119, 120.

[64] *See id.* at 120-23.

Over ninety-eight percent of persons age sixty-five and over are covered by Medicare,[65] and thus add little to statistics on the number of uninsured Americans. A substantial proportion are underinsured, however, as the Medicare hospital insurance deductible rises,[66] and co-payments for hospital and physician care increase with the cost of health care.[67] Most purchase a Medicare supplement, or "Medigap" policy, which must cover these costs[68] and may also cover additional items such as prescription drugs.

However, some older people cannot afford the Medigap premiums. The median income of elderly individuals in 1989 was a modest $9422—approximately half that of comparable younger adults.[69] Income to people age eighty-five and older averages about seventy-five percent of income to younger retirees (under $7000 annually). Twice as many women as men have incomes below the poverty line and, among women age eighty-five and older, one in five is poor.[70] The oldest and poorest living alone are often the most in need of care, and the least able to meet patient financial responsibilities.

C. *Individual Payment for Long-Term Care*

Individuals might finance long-term care costs privately by saving enough to pay for care.[71] Government might encourage such savings by providing favorable tax treatment as it does for individual retirement accounts.[72] Who among the elderly can afford chronic care is a matter of some controversy. The median assets in an elderly household totaled over

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[65] In 1987, for example, only 300,000 persons age 65 and older were uninsured. INSURING THE UNINSURED, *supra* note 14, at 2.

[66] 42 U.S.C. § 1395r-s (1988). The Medicare Part A (hospital insurance) deductible was $694 in 1994, a figure adjusted annually by the Department of Health and Human Services to reflect the average cost of one hospital day nationwide. The Medicare Part B deductible remains at $100 and the cost of the first three pints of blood supplied.

[67] In 1994, through days 61-90 of hospitalization, a Medicare beneficiary incurs co-payments of $174. An additional 60 "lifetime reserve days" are available, for co-payments of $348 a day.

[68] 42 U.S.C. § 1395ss (Supp. V 1993).

[69] *See* TAEUBER, *supra* note 19, at 4-6 to 4-8 (discussing income distribution among the elderly).

[70] *Id.*

[71] ALICE RIVLIN & JOSHUA WIENER, CARING FOR THE DISABLED ELDERLY: WHO WILL PAY? 53-58 (1988).

[72] For more information on individual medical accounts ("IMA"), which are similar to the more familiar individual retirement accounts ("IRA"), see *id.* at 19, 109-22.

$70,000, higher than any age group except age fifty-five to sixty-four.[73] About one-third of the elderly have assets valued at more than $100,000.[74] The distribution of income and assets varies enormously, however. Only ten percent of persons age eighty-five and over have assets over $100,000.[75] Among people over sixty-five, widows have a net worth only forty percent of the net worth of families with the head of the household in the same age group.[76] Most assets consist of home equity, rather than cash.[77] Seventy-five percent of elderly people own their own homes, and eighty percent of the homeowners have no mortgage.[78] Home equity represents eighty-nine percent of net wealth for elderly homeowners.[79]

The low average incomes and high health-related expenses of many adults with disabilities make it impossible to consider self-financing a complete solution for long-term financing. A substantial proportion of elderly people could afford such expense only by liquidating home equity. Though reverse income mortgages[80] could be structured to protect a mortgagor who outlives the term of the mortgage, Americans are ambivalent about requiring individuals to expend their life savings, particularly by encumbering ownership of the home.[81]

One might ask whether the underfunding of retirement is a temporary phenomenon, a result of unanticipated longer lives. The current generation

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[73] *Id.* at 4-17.

[74] *Id.*

[75] *Id.*

[76] AGING AMERICA, *supra* note 60, at 39.

[77] An older homeowner can access equity by taking out a "reverse annuity mortgage," which commits the lender to paying monthly payments for a fixed term based on the value of a house. Generally, homeowners with mortgage balances less than 25% are allowed to borrow up to $100,000, or up to 80% of the unmortgaged value of their homes. To help prevent a forced move at the end of the pay out, many mortgages require the lender to wait to take possession of the home. However, the strategy does not assure the former homeowner will have sufficient income to maintain the house once the payments stop. The concept has had limited success in attracting mortgagors. *See generally* NATIONAL CTR. FOR HOME EQUITY CONVERSION, AMERICAN ASS'N OF RETIRED PERSONS, HOME EQUITY CONVERSION IN THE UNITED STATES: PROGRAMS AND DATA 1 (1991).

[78] U.S. SENATE SPECIAL COMM. ON AGING, S. REP. NO. 261, DEVELOPMENTS IN AGING: 1991, at 294 (1992) [hereinafter DEVELOPMENTS IN AGING].

[79] FRIEDLAND, *supra* note 35, at 179.

[80] Reverse mortgages provide a series of monthly loan advances to homeowners with repayment of all interest and principal deferred until an agreed-upon future time. *See* ELDERLAW, *supra* note 11, at 606-13.

[81] For more information on spending down assets for long-term care benefits, see *infra* notes 183-90 and accompanying text.

of elderly people is the first to experience in large numbers the effects of extended old age and retirement. It is therefore reasonable to think that many would have saved more in anticipation of their current situation and that future generations of elderly people should be in a better position to anticipate the true costs of their retirement years and save accordingly. Instead, opportunities to save for retirement are quite limited for many workers, particularly those in the growing minimum wage culture.[82] The immediate costs of housing, health care, and education for children is beyond the means of many; the cost of elder care is significant for some "sandwich generation" adult workers who find themselves providing elder care and child care simultaneously.[83]

Only a minority of the next generation of retirees will be able to live comfortably on their savings and pensions. Some will need assistance in the form of subsidized housing and services, and a small proportion will require assistance to obtain extended long-term care. As with health care, individual savings are not enough.

III. A RIGHT TO LONG-TERM CARE?

Given the need for community-based care, it is remarkable that such assistance is not readily available for a modest cost, like public utilities. To determine why, a good starting point is an examination of the societal values that have impeded development of long-term care programs, or of reasons society is reluctant to invest in the task of care for impaired members. Further, it is reasonable to consider whether the obligations of society to less

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[82] *See* Guy Gugliotta, *The Minimum Wage Culture: As America Gets Lean to Compete, Our Working Underclass Is Growing*, WASH. POST WKLY., Oct. 3-9, 1994, at 6. The culture includes workers who, at minimum wage, earn $8500 annually, and a growing contingent of part-time, temporary, and pieceworkers. In 1992, the Labor Department counted 2.5 million temporary employees nationwide, three times the number counted in 1978. *Id.* Virtually all temporary employees lack health care benefits.

[83] *See* EXPLODING THE MYTHS, *supra* note 37, at 26-27 (stating that 166,000 women provided elder care and child care simultaneously in 1987); *see also* Joan M. Mitric, *Baby Boomers Not Yet Ready for Prime Time*, AGING TODAY, May-June 1994, at 1 (reporting on a symposium on retiring baby boomers). Symposium speaker Richard A. Easterlin, economist at the University of Southern California, predicts baby boomers will have more funds for retirement than their parents because more of them went to college and more women will have pensions. An opposing opinion was presented by Ken Dychtwald, president of AgeWave Marketing Research Corp., who predicts baby boomers are not planning to cover retirement costs. *Id.* at 2.

capable persons, or an interest in social order through individual well-being, warrant the implementation of long-term care programs.[84]

A. *The Values of Long-Term Care*

Reluctance to provide long-term care may be found in the undervaluing of members of society with less than full physical or mental abilities. The treatment of older people is based to some degree on ageism, a negative perception of individuals due solely to their chronological age.[85] A more recent outgrowth of ageism is hostility directed specifically toward the ill and disabled elderly.[86] Particularly in America, society has responded to physical impairment and emotional need among the elderly with a denial of full personhood and respect,[87] a view that has been termed "gerontophobia."[88] As a result, elderly people are more likely to receive inferior quality professional services, particularly in health care.[89]

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[84] *See* Jeffrey Merrill, *A Test of Our Society: How and for Whom We Finance Long-Term Care*, INQUIRY, Summer 1992, at 176-77.

[85] A recent study of the relationship between age and "do not resuscitate" ("DNR") orders, corrected for differences in severity of illness is instructive. The study found that in general hospital populations physicians issued the same proportion of DNR orders for persons age 65 to 75 as for younger persons, about one and a half times as many DNR orders for patients age 75 to 85, and about two and a half times as many for patients age 85 and over. The finding is particularly disturbing since the instrument used to predict whether the patient would survive, the Mortality Probability Model, already includes an adjustment for age. DNR was defined broadly as less than full care, including withholding cardiopulmonary resuscitation in the event of cardiac arrest. Daniel Teres, Address at the First Concurrent Meeting of the American Association of Bioethics, Society for Health and Human Values, Society for Bioethics Consultation, and American Society of Law, Medicine, and Ethics (Oct. 7, 1994).

[86] *See* Alison P. Barnes, *The More Things Change: Principles and Practices in Reformed Guardianship, in* IMPACT OF THE LAW ON OLDER ADULT'S DECISION-MAKING CAPACITY (Michael Smyer et al. eds., forthcoming).

[87] *See* Madelyn A. Iris, *Guardianship and the Elderly: A MultiPerspective View of the Decisionmaking Process*, GERONTOLOGIST, Supp. June 1988, at 39, 44.

[88] Elias S. Cohen, *The Elderly Mystique: Constraints on the Autonomy of the Elderly With Disabilities*, GERONTOLOGIST, Supp. June 1988, at 24, 27.

[89] DIANA CRANE, THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS 52 (1975) (equating advanced age with a decline in social value); DAVID SUDNOW, PASSING ON: THE SOCIAL ORGANIZATION OF DYING 104-05 (1967). The Harvard Malpractice Study found that the risk of adverse events increased nearly tenfold with increasing age. *See* REPORT OF THE HARVARD MEDICAL PRACTICE STUDY TO THE STATE OF NEW YORK, PATIENTS, DOCTORS AND LAWYERS: MEDICAL INJURY, MALPRACTICE LITIGATION, AND PATIENT COMPENSATION IN NEW YORK 6-23 to 6-25 (1990).

A similar distortion of reality applies to lives of persons with disabilities, who are often treated with "thoughtlessness and indifference" and "benign neglect."[90] Sometimes considered less than human[91] or as examples of cruel or indifferent fate,[92] persons with disabilities have been removed and hidden from the mainstream of society.[93] The courts have found that competent, aware individuals are justified in their wishes to die rather than live with their disabilities.[94]

Society's negative perception has informed the advocacy of persons with disabilities for integration into mainstream society and equal opportunity. The disability rights movement began in the 1960s, paralleling the civil rights and women's movements, and includes among its principles the importance of individual empowerment and consumer involvement.[95] Advocacy groups lobby for legislation to support the rights of persons with disabilities to join the mainstream of society in employment and housing. The groups emphasize self-reliance and other traditional American ideals to the exclusion of a genuine discussion of the special health, social services,

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[90] Alexander v. Choate, 469 U.S. 287, 295 (1985).

[91] *See* Kent Hull, *Foreword—The Specter of Equality: Reflections on the Civil Rights of Physically Handicapped Persons*, 50 TEMP. L.Q. 944, 946-47 nn.13 & 14 (1976-1977), (citing ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY 3 (1963)).

[92] Paul K. Longmore, *Screening Stereotypes: Images of Disabled People*, SOC. POL'Y, Summer 1985, at 31, 32 (deformity of the body symbolizes deformity of the soul).

[93] *See* Jonathan C. Drimmer, *Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for People With Disabilities*, 40 UCLA L. REV. 1341, 1343 (1993) (depicting attitudes towards persons with disabilities as pity for their losses and denial of equal status with the non-disabled).

[94] *See, e.g.*, Bouvia v. Superior Ct., 225 Cal. Rptr. 297, 300 (Ct. App. 1986) (holding that a 28 year old college-educated woman with cerebral palsy was justified in her request to starve herself to death); McKay v. Bergstedt, 801 P.2d 617, 628-32 (Nev. 1990) (approving a quadriplegic man's petition to remove a ventilator). In *McKay*, the court reasoned that the petitioner was competent to determine whether he was "willing to have a devastated life continued artificially," ignoring the significance of his father's recent diagnosis of terminal illness. *Id.* at 621; *see also* Rebecca Dresser & John Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 J.L. MED. & HEALTH CARE 234, 236 (1989).

[95] The disability movement emphasized the importance of support in attaining a decent quality of life after recuperation. Sara D. Watson, *Reality Ignored: Health Reform and People with Disabilities*, J. AM. HEALTH POL'Y, Mar.-Apr. 1993, at 49, 50 (noting that people with disabilities provide the starkest example of the health system's misguided emphasis on acute care to the exclusion of all other types of care).

and housing needs of their constituency.[96] The effects of bias are likely to be exacerbated by cost containment.[97]

Social forces in favor of long-term care might also lack power to implement change because of the predisposition of the American national character toward decisive individual action and swift resolution.[98] The incompatibility of such a view with long-term care is distinctly apparent when the methods and results of services delivery are contrasted with those of the current health care culture of scientific, high technology medicine. Physicians are trained in dedication to decisive intervention and cure, resulting in an inclination toward aggressive and invasive treatment and to heroic measures in attempts to defeat the effects of ill health or injury. The culture of long-term care delivery, by contrast, suggests ambivalence regarding the usefulness of many repetitive acts of assistance, any of which are of debatable significance to the ultimate well-being of the person receiving care. Persons with chronic disabilities by definition are not cured, though symptoms might be alleviated. Generally, the goal of care is to maintain capabilities and mental health. Sometimes, the goal is to alleviate suffering and fear from inevitable decline. There is little opportunity for technological heroism. Even the site of care has an ambivalent quality, a quality of compromise to accommodate conflicting interests and values, in contrast with the institutional settings of acute care in which professional opinion and goal orientation dominate.[99] Home and community-based care is provided in all-purpose, sometimes inconvenient environments, in which the needs and wishes of the person with chronic impairment coexist with the needs and wishes of caregivers. As a result, the care itself must represent a compromise between caregiver and care receiver regarding the choice and timing of assistance.[100]

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[96] *See id. See generally* Sara D. Watson, *An Alliance at Risk: The Disability Movement and Health Care Reform*, AM. PROSPECT, Winter 1993, at 60, 62.

[97] *See infra* notes 114-36 and accompanying text.

[98] Many have observed that the American view is predicated on individualism, rather than the good of society. *See e.g.*, David Brown, *Darwin's Theory of Health Care: Coverage for All Means Less Care for Many*, WASH. POST WKLY., Sept. 19-25, 1994, at 24. "In American medicine, the ascendancy of the individual exists in nearly pure form. American physicians are taught (and believe) that the 'good of the patient' is the one consideration that trumps all others." *Id.*

[99] The doctrine of informed consent is law's effort to balance the power of the physician to control the course of treatment by providing the patient with the ultimate trump card of refusal. *See* ELDERLAW, *supra* note 11, at 933-50.

[100] Bart Collopy et al., *The Ethics of Home Care: Autonomy and Accommodation*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 1, 2.

Viewed in the context of health care in the late twentieth century, the narrow focus of acute care on physical improvement has failed to provide a sense of well-being for many. That viewpoint has never been monolithic and currently is yielding to more humane values, which would make health care more personalized and would better accommodate the unique needs of individual patients.[101] Such values are more suitable than traditional American values to the provision of effective long-term care, and their growing authority is compatible with the enactment of national publicly-funded long-term care.

Although prejudice against persons who are aged or have chronic disabilities may be pervasive, it is difficult to argue convincingly for such a basis for public policy. Even those who advocate age-based discrimination for health care cost containment are referring to acute care, not comfort care.[102] Rather, it appears the idea is widespread that basic home care represents values the society would like to cultivate, values neglected by the health care system to the dissatisfaction of its patients.

Despite the volume of long-term care legislation and programs,[103] there is no constitutional right to assistance for persons who are aged or disabled and living in the community. Government programs provide only a small fraction of assistance,[104] and the right to equal protection generally does not extend to appropriations from public funds without statutory authorization. Nevertheless, programs create standards which do attach once services are available. These standards generally tend to assure the fair determination of eligibility, the opportunity to object to a denial of services, and the right to appeal a denial to an impartial decision maker. The existence of service programs tends to drift in the direction of a right to

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[101] *See, e.g.*, Bruce Jennings et al., *Ethical Challenges of Chronic Illness*, HASTINGS CENTER REP., Supp. Feb.-Mar. 1988, at 6-8. The authors note that the distinction between "person" and "patient" goes to the heart of a new bioethics, challenging the concept of patient, the nature of the relationship between physician and patient, and the basis of medical decisionmaking. *Id.*

[102] *See* Daniel Callahan, *What is a Reasonable Demand on Health Care Resources? Designing a Basic Package of Benefits*, 8 J. CONTEMP. HEALTH L. & POL'Y 1, 9 (1992) (advocating care over cure and public good over personal health as rationale for defining a health care benefits package).

[103] More than 80 federal programs support long-term care, if retirement and disability income benefits are included with social services and housing programs. CONGRESSIONAL RESEARCH SERV., FINANCING AND DELIVERY OF LONG-TERM CARE SERVICES FOR THE ELDERLY CRS-6 (May 25, 1988).

[104] *See* EXPLODING THE MYTHS, *supra* note 37, at 4 (indicating that "the bulk of long-term care is provided by informal caregivers").

receive care.[105] A statute providing a benefit may imply action in good faith on the part of government to assure that eligible persons can receive it. As a result, an individual may have an enforceable legal claim, based on the right to a minimum quality of life which is unavailable without state assistance.

B. *The Least Restrictive Alternative*

In *Dixon v. Weinberger*,[106] the United States District Court for the District of Columbia found that the plaintiffs, who were involuntarily committed mental hospital patients, had a right to community-based care. The court observed that the fundamental goal of the governing statute was to return patients, through care and treatment, to a full and productive life in the community as soon as possible.[107] It found that the 1964 District of Columbia Hospitalization of the Mentally Ill Act must be broadly construed so that authorized social and medical services would meet the goals, and that care must allow some patients to elect community-based services.[108] The funding formula for the Act placed responsibility for developing community-based services with the District of Columbia and federal governments.[109] It created a plaintiff's right to have public funds spent for their community-based care to enable the patient to leave the institution.

Commentators have recognized the similarity between the situations of civilly committed patients and persons institutionalized in nursing homes.[110] Over the past twenty years, society has recognized the tension

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[105] Regarding rights to housing derived from benefits, see Frank I. Michelman, *The Advent of a Right to Housing: A Current Appraisal*, 5 HARV. C.R.-C.L. L. REV. 207, 209 (1970) (noting that a "movement in the general direction of a . . . right to be housed" was justified by the policy that every American family should have a decent home).

[106] 405 F. Supp. 974, 979 (D.D.C. 1975); *see also* Covington v. Harris, 419 F.2d 617 (D.C. Cir. 1969); Burnham v. Department of Pub. Health, 349 F. Supp. 1335, 1339 (N.D. Ga. 1972). In *Covington*, the court held that the mental hospital administration had not made a reasonable decision in confining to maximum security a man with an I.Q. of 38, a diagnosis of psychotic reaction, and a 25 year old murder conviction. The court reasoned that there was no evidence that he was dangerous and that he had a right to the least restrictive form of treatment likely to effect improvement. *Id.* at 623-24, 628.

[107] *Dixon*, 405 F. Supp. at 976. The court relied on the 1964 District of Columbia Hospitalization of the Mentally Ill Act.

[108] *Id.* at 977-78.

[109] *Id.* at 978-79.

[110] *See, e.g.*, Lawrence A. Frolik, *Plenary Guardianship: An Analysis, a Critique and a Proposal for Reform*, 23 ARIZ. L. REV. 599, 603 (1981) (concluding that guardianship

between fundamental liberties and benevolent assistance such as nursing home placement, and has opted for guardianship, which typically results in institutionalization, with similar due process standards to those required for civil commitment.[111] Further, it is reasonable to find, even in the absence of specific least restrictive alternative language, that the purpose of providing community-based care is to enable an individual to maximize self-care. The concept is an easy fit with changes in health care delivery to outpatient procedures and early hospital discharges, and is supported by legislative cost containment. Less intensive services imply less expense.

Dixon is not widely followed since courts have seldom been willing to find that the intention to provide assistance supports an order for creation of an entire system of service delivery.[112] However, statutes conferring benefits may find in the courts special sensitivity to their broader purposes, and to the vulnerability of the intended beneficiaries.[113]

C. *Disability and Discrimination*

Statutes may also provide important statements of public policy regarding persons with disabilities which support the appropriateness of public long-term care benefits. The Americans with Disabilities Act of 1990

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reform should include procedural reforms); Annina M. Mitchell, *The Objects of Our Wisdom and Our Coercion: Involuntary Guardianship for Incompetents*, 52 S. CAL. L. REV. 1405, 1421-22 (1978-1979) (discussing the lack of constitutional due process in competency hearings); *see also* Cathrael Kazin, Comment, *"Nowhere to Go and Chose to Stay": Using the Tort of False Imprisonment to Redress Involuntary Confinement of the Elderly in Nursing Homes and Hospitals*, 137 U. PA. L. REV. 903, 905 (1989) (arguing that elderly nursing home patients can use the tort of false imprisonment to protect their legal rights).

[111] *See* Alison P. Barnes, *Florida Guardianship and the Elderly: The Paradoxical Right to Unwanted Assistance,* 40 U. FLA. L. REV. 949, 968-70 (1988).

[112] *See* Michelman, *supra* note 105, at 212. Statutes authorizing benefits "are understood, rather, as the public talking to itself and its agents—ordering, guiding, legitimating, and to some extent predicting the conduct of public affairs. But when the duly appropriated . . . money runs out, lawsuits do not pry loose more money—despite unappropriated authorizations or unfilled need." *Id.*

[113] *See* ELDERLAW, *supra* note 11, at 540-53. The authors discuss the series of cases arising from a class action in Colorado. *See, e.g., In re* Estate of Smith, 557 F. Supp. 289, 299 (D. Colo. 1983) (noting that "[t]here is a manifest need for improvement in the conditions of nursing homes and the care which is provided to welfare patients"), *rev'd sub nom.* 747 F.2d 583 (10th Cir. 1984). On appeal, the Tenth Circuit Court of Appeals found that the Secretary of Health and Human Services ("HHS") had more than a passive role in handing out money to the states for nursing home care and required the agency to redesign its quality assurance system to focus on resident assessment. *Smith*, 747 F.2d at 583.

("ADA"),[114] for example, prohibits discrimination against qualified persons with disabilities in public services, regardless of the receipt of federal financial assistance to service providers.[115] Specifically, Title II of the ADA provides that no qualified individual with a disability shall be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. The ADA, like its predecessor, the Rehabilitation Act of 1973,[116] has been applied to health programs to determine whether their structure and benefits are discriminatory.

The Clinton administration initially considered the Oregon Basic Health Services Plan[117] to be in violation of the ADA. The Oregon Plan is the most comprehensive design for cost containment and public allocation of health resources enacted by the states. It proposed, in pertinent part, to amend the state's Medicaid program, upon approval by federal authorities, by expanding the number of eligible beneficiaries and placing certain limitations on their benefits based on a formula used to rank the value of various treatments to be funded by the state. The Oregon ranking consists of seventeen categories of care, ranked as "essential,"[118] "very important,"[119] and "valuable to certain individuals."[120]

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[114] 42 U.S.C. §§ 12101-12213 (Supp. V 1993); *see* Lawrence Gostin, *The Americans with Disabilities Act and the U.S. Health Care System*, HEALTH AFF., Fall 1992, at 248.

[115] The Act also prohibits discrimination against the disabled in employment, public accommodations, and telecommunications. 42 U.S.C. §§ 12112, 12182 (Supp. V 1993). A person with a disability is one who has a physical or mental impairment that substantially limits one or more of that individual's major life activities, has a record of such an impairment, or is regarded as having such an impairment. *Id.* § 12102(2)(A)-(C). On regulations interpreting the ADA, see generally Bonnie P. Tucker, *The Americans with Disabilities Act of 1990: An Overview*, 22 N.M. L. REV. 13 (1992).

[116] 29 U.S.C. §§ 701-794 (1988 & Supp. II 1990).

[117] OR. REV. STAT. §§ 316.096, 317.113, 353.725, 353.765, 353.775, 414.025-.750, 735.605-.650 (Supp. 1992).

[118] The essential category includes such condition-treatment categories as "acute fatal," or conditions that require treatment to prevent death, ranked according to whether they result in full recovery; maternity care; and preventive care for children. OFFICE OF TECHNOLOGY ASSESSMENT, EVALUATION OF THE OREGON MEDICAID PROPOSAL 6 (1992) [hereinafter MEDICAID PROPOSAL].

[119] The important classification includes treatments for conditions which are "acute nonfatal," prioritized according to whether the patient is returned to the previous state of health. *Id.*

[120] This category of care includes treatments that expedite recovery from self-limiting conditions and infertility treatment. *Id.*

Through a process of public hearings and professional consultation, the Oregon Health Care Commission ranked medical care into 709 condition-treatment ("CT") pairs, prioritized under the three categories according to their net benefit. The legislature determined, and will redetermine annually, how much to allocate to health care, the extent to which services are likely to be funded for all eligible persons, and the cut-off line below which no CT will be funded by the state. As a result, the state can fund health services for all of its citizens up to the federal poverty line, covering all major diseases women and children experience and some services which are not mandated for Medicaid programs under federal guidelines.[121]

Critics of the plan pointed out that services "valuable to certain individuals" refer to a greater proportion of disabled than able persons.[122] Waiver of the federal requirement that Medicaid provide all "medically necessary" services, including some of those in this category, is discriminatory because services which fall below the cut-off may be critically important to persons with disabilities. For example, the list assigned a value of 690 to liver transplants for alcoholic cirrhosis (above the cut-off of 587), but assigns a value of 366 to transplants for non-alcoholic cirrhosis.[123] Since there is no difference in the likelihood of a successful transplant in itself (without complicating multiple impairments or assumptions about patient behavior), the decision regarding coverage is made on the basis of the existence of a disabling condition, alcoholism.[124]

The rankings would present less risk of bias against persons with disabilities if evidence of societal values, gathered in a public survey, were eliminated. The suspect component of CT ranking is "quality-of-life" with which all chronic services are weighted.[125] To the extent treatments are

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[121] The services mandated by Medicaid include dental services, and diagnostic and screening for adults. OREGON DEP'T OF HUMAN RESOURCES, OFFICE OF MEDICAL ASSISTANCE PROGRAMS, THE OREGON HEALTH PLAN 25 (1992).

[122] *See* James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?* 68 NOTRE DAME L. REV. 581, 583 (1992-1993). Exemption of the elderly from the Oregon Plan reflects the difficulty in obtaining Medicare waivers and the political power of some elderly groups; it does not assure that the aged will be spared future discrimination.

[123] *Id.* at 591.

[124] This position is one adopted by DHHS Secretary Dr. Louis Sullivan. *See id.* at 584 n.17, 592 n.53 (citing Letter from Dr. Louis Sullivan to Barbara Roberts, Oregon Governor (Aug. 3, 1992)).

[125] Essential care also includes "chronic fatal" treatment which improves life span and quality of life; very important services include "chronic nonfatal" treatment such as hip replacement; services valuable to certain individuals includes a category "fatal or nonfatal" in which treatment causes minimal or no improvement in quality of life. MEDICAID

for chronic disabilities which do not yield a return to total health and function, they are more likely to fall outside funding limits.

The federal agency granted Oregon a Medicaid waiver upon receiving a revised state plan deleting all effects of data generated by references to "quality-of-life" judgments. Federal monitors also imposed conditions on the plan to protect against discrimination, requiring that Oregon re-rank the CT pairs without relying on data concerning the patient's return to an asymptomatic state.[126] Further, before denying treatment, the state must ensure that an individual does not have a covered condition that would entitle that individual to treatment.[127]

The Oregon Plan controversy suggests that societal reaction to disability is so strong that even well-intended initiatives may be deeply flawed, and the ADA is a strong statement of society's intention to prevent discrimination which might provide a remedy. However, the ADA does not prohibit disparate treatment based on real differences in health care use and costs among individuals, or even based on actuarially sound categories of individuals. The state is not obligated to provide as much care as is required to make a person with disabilities as healthy as possible.[128]

The difference is illustrated by *Alexander v. Choate*,[129] in which the Supreme Court found that section 504 of the Rehabilitation Act of 1973[130] did not support a claim for disparate impact on persons with disabilities when the State of Tennessee reduced authorization for inpatient hospital days for Medicaid beneficiaries from twenty to fourteen per year.[131] The evidence showed that 27.4% of all disabled Medicaid beneficiaries required more than fourteen days of inpatient care, as opposed to only 7.8% of non-

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PROPOSAL, *supra* note 118, at 6. The more control the government has over health services, and the tighter the squeeze on acute care, the more likely courts will be sympathetic to individuals seeking assistance.

On the misuse of quality-of-life standards in evaluating the needs and wishes of persons with disabilities, see Teresa H. Paredes, *The Killing Words? How the New Quality- of-Life Ethic Affects People with Severe Disabilities*, 46 SMU L. REV. 805 (1992); Nancy K. Stade, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV. 1985 (1993).

[126] The original 709-item list of conditions was consolidated into a list of 688 items, and the cut-off line moved from 587 to 568.

[127] Garvey, *supra* note 122, at 581. Advocacy groups continue to assert that the Oregon Plan violates the ADA. *See infra* notes 117-24 and accompanying text.

[128] *See Alexander*, 469 U.S. at 287.

[129] *Id.*

[130] Title II of the ADA is to be interpreted consistently with *Alexander*. *See* 28 C.F.R. § 35 app. A at 440 (1992).

[131] *Alexander*, 469 U.S. at 289.

disabled beneficiaries.[132] Reversing the Sixth Circuit decision that plaintiff/respondents had made a prima facie case by showing disparate impact and ordering the state to explain its choice, the Supreme Court rejected the argument that section 504 prohibits all actions disparately affecting persons with disabilities.[133] Rather, the state needed only to make "reasonable" modifications in programs in order to accommodate persons with disabilities; it did not need to make "substantial" or "fundamental" changes in the program.[134]

Thus, the Court left the door open for claims to reasonable changes in public programs to accommodate the needs of persons with disabilities due to age or chronic conditions and left significant questions about what is an "undue burden."[135] Clearly, an order to make community-based care available is likely to create a significant burden on a state. However, it is also unclear to what extent that burden should be weighed against the benefit, which, as in *Dixon*, might be the difference between an acceptable lifestyle and unwanted, unnecessary institutionalization.[136] The variety of statutes passed by the states concerning health care reforms, including not just home and community-based care but also policies on access and the purposes of acute care programs, might imply that individuals have a right to access which the state must support.

D. *Patient Dumping*

Another federal health care law which might provide insight into long-term care policy is the Emergency Medical Treatment and Active Labor Act of 1986 ("EMTALA"),[137] which was enacted to prohibit hospitals and physicians from refusing care to indigent patients in emergencies or transferring them to other facilities for other than medical reasons, i.e.,

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[132] *Id.* at 290, 291 n.3.

[133] *Id.* at 298.

[134] *Id.* at 300.

[135] *See* Steven F. Stuhlbarg, *Reasonable Accommodations Under the Americans with Disabilities Act: How Much Must One Do Before Hardship Turns Undue?*, 59 U. CIN. L. REV. 1311, 1330-39 (1991).

[136] Institutionalization for frail, elderly persons is frequently followed by rapid physical decline and death. *See* Jerry Avorn & Ellen Langer, *Induced Disability in Nursing Home Patients: A Controlled Trial*, 30 J. AM. GERIATRICS SOC'Y 397, 399-400 (1982) (lack of control may be expected to have negative effects on happiness, alertness, socialization, health, and mortality rates).

[137] 42 U.S.C. § 1395dd (1988) (enacted as part of the Consolidated Omnibus Budget Reconciliation Act of 1986).

"patient dumping." The legislation was targeted at the growing practice of sending potentially high-cost patients away from hospital emergency rooms because they are uninsured or will generate low reimbursements through state Medicaid programs. The statute requires hospital emergency rooms and their physicians to provide medical examination and treatment required to stabilize the medical condition or to transfer the individual to another facility only after assuring that the facility has available space and qualified personnel, and has agreed to accept transfer.[138]

Absence of community-based care is a form of patient dumping which has already been created by the prospective payment system for Medicare hospital care. With the inception of prospective payment, the number of Medicare hospital stays dropped ten percent and the length of stay declined from 9.5 days to 7.5 days.[139] Investigations by Congress showed that hospital discharge planners had difficulty securing needed home care services.

With the enactment of health care reform managed care, it is possible that still more patients will be "dumped" from the acute care system, unable to qualify for nursing home care under Medicare's restrictive skilled care standards, and unable to secure or afford home care. The lack of a coherent system of community-based care creates a population of individuals who have inadequate support for a reasonable quality of life at home. The omission undermines the reasons to provide public health benefits programs, making it likely the individual will deteriorate and need re-institutionalization. It deprives the patient of the opportunity to live at home, in the least restrictive environment. It also perpetuates a pattern of substituting higher-cost institutional services for lower-cost home care, thereby sabotaging attempts at cost containment.[140] The government's control of the acute care system through the managed care structure suggests a responsibility to prevent such dumping.

It is also likely that patients with multiple impairments and poor prognoses, specifically the aged and disabled, will be denied acute care intervention. This might come about either by overt age-based/disability-based rationing, by which the public financing system excludes specific services for persons over a given age on the assumption the benefits are too

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[138] *Id.* § 1395dd(b)-(c).

[139] ELDERLAW, *supra* note 11, at 441-43.

[140] Research into the cost-efficiency of home care versus institutional care yields very mixed results. *See* William G. Weissert & Susan C. Hedrick, *Lessons Learned from Research on Effects of Community-Based Long-Term Care*, 42 J. AM. GERIATRICS SOC'Y 348 (1994).

limited,[141] or cost-based rationing, by which the state declines to cover certain high-tech, high-cost procedures. The original Oregon Plan,[142] for example, represented both of these types of rationing.[143] Critics say it still does, though federal authorities are satisfied the state is making only cost-based choices.

While none of these statutes provides for any specific long-term care services, any one of them might in the right circumstances be the basis for a claim for long-term care from states which restrict acute care to aged or disabled persons. The more severe the restrictions placed by the state on acute care, and the greater control exercised by the state over health care expenditures, the more likely it is that individuals will claim assistance in securing long-term care. For those who can pay, the claim might be one of access to qualified providers.[144] For those who cannot pay the full cost directly, the state might be responsible for establishing a funding mechanism.

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[141] Elderly people are denied treatment through professional and family decisions to enter do-not resuscitate orders. *See* Joan M. Teno et al., Simulation of Potential Impact of Futility Guidelines in Seriously Ill Adults, Address at the First Concurrent Meeting of the American Association of Bioethics, Society for Health and Human Values, Society for Bioethics Consultation, and American Society of Law, Medicine, and Ethics (Oct. 7, 1994). The address studied decisions about life sustaining treatment and total hospital charges for 4301 seriously ill patients in two hospitals, applying a prognostic model to determine who was expected to survive for two months, and calculating savings if life sustaining treatment was stopped on the third day. *Id.* Patients used a median of seven days of hospital admission at a median cost of $40,909. Researchers concluded that only some patients with poor prognoses could be identified, such persons die quickly (more than two thirds within three days), and that life sustaining treatment is already being withheld for most of the patients. As a result, savings would be modest and would be distributed somewhat inequitably. *Id; see also* Daniel R. Longo et al., *"Do not Resuscitate:" Policy and Practice in the Long-Term Care Setting*, J. LONG-TERM CARE ADMIN., Spring 1988, at 5.

[142] *See supra* notes 118-28 and accompanying text.

[143] Another rationing technique, situated at the professional rather than the legislative level of discretion, is a decision of medical futility. Services which are futile would certainly not provide the patient any benefit for the condition being treated, such as a lobotomy for a complaint of influenza, or more controversially, bone marrow therapy for advanced breast cancer. Physicians' decisions regarding futility are not purely scientific because many cannot keep pace with the speed of technological advances and simple biases such as ageism. *See* Crane *supra* note 89, at 52; *see also* Stuart Younger, *Who Defines Futility?,* 260 JAMA 2094, 2094 (1988).

[144] *See infra* notes 201-04 and accompanying text.

IV. LONG-TERM CARE IN HEALTH CARE REFORM

It is also essential to determine what mix of private and public funds should be used to finance care, the nature of need which will trigger eligibility, and which long-term care services best respond to the needs of the population.[145]

A. *Public Benefits*

Determining how to choose, fund, and deliver any new program of long-term care benefits requires an understanding of existing public programs. It is estimated that over eighty federal social services and housing programs fund some aspect of long-term care,[146] each with its own rules for eligibility and definition of services.[147] Because funds devoted to social services programs shrank throughout the 1980s[148] and health care reform proposals are calling into question the very definition of health services, it is not unexpected to find that most long-term care benefits are provided as aspects of health.

1. Health Programs

The principal health care program for the elderly, Medicare, pays chronic care benefits only incidentally, when a patient recovering from an acute episode cannot be discharged from a hospital. Medicare's nursing home benefits are limited to skilled care provided after a hospital discharge,[149] and its home care benefits, while theoretically quite generous, are limited to home health aide care delivered in conjunction with skilled care on an intermittent basis to persons who are homebound.[150] The Medicaid program's benefits are more comprehensive, because it is intended to be a program of last resort. In addition to mandatory categories of health

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[145] Merrill, *supra* note 84, at 186 (noting in contrast that existing long-term care programs were designed from the perspective of how to pay providers).

[146] Other public programs fund long-term care indirectly, through income assistance such as Social Security retirement and disability benefits. Health and social services are also funded by federal block grants for low income elderly and by state community care programs.

[147] *See* LONG-TERM CARE FOR THE ELDERLY, *supra* note 31, at 41.

[148] DEVELOPMENTS IN AGING, *supra* note 78, at 334.

[149] 42 C.F.R. § 409.30 (1992).

[150] *See id.* §§ 409.40-.46.

care benefits and nursing home care[151] and home health care for persons eligible for such nursing services, states may elect to provide any of thirty-two optional services, such as dispensing eyeglasses, prescription drugs, dental services, and personal care.[152] All Medicaid services are required by federal law to be equally available to all eligible persons on a statewide basis,[153] and must be of an amount, duration, and scope adequate to achieve the objectives of the program.[154]

Home and community-based care outside the traditional acute care model have been the subject of growing interest in the states. Since 1981, federal law has allowed states to use Medicaid funds for a wide variety of home and community-based services upon approval of state applications for a waiver of state-wide proportion and equal access requirements.[155] Under most waivers, individuals are eligible only if, but for the services, they would need nursing home care, and the cost does not exceed nursing home costs.[156] Waiver programs vary greatly in size and services. Most serve a single population with disabilities, such as mentally retarded persons, the aged, or physically or mentally disabled adults.[157]

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[151] The traditional division into nursing home levels of care (skilled, intermediate, and custodial) has been eliminated from federal regulation. Instead, states are authorized to use case-mix reimbursement plans approved by federal authorities, which specify the amount of payment a facility will receive according to the nature of care an individual resident requires. *See* ELDERLAW, *supra* note 11, at 519-23.

[152] 42 U.S.C. § 1396d(a) (1988) (mandatory and optional services).

[153] *Id.* § 1396a(a)(1).

[154] *See, e.g.*, Clark v. Kizer, 758 F. Supp. 572 (E.D. Cal. 1990) (finding that low dentist reimbursement rates which severely restricted the number of providers in the state were not a violation of federal requirements that services meet the objectives of the program).

[155] *See* 42 U.S.C. § 1396n (1988).

[156] *See* CONGRESSIONAL RESEARCH SERV., MEDICAID HOME AND COMMUNITY-BASED CARE PROGRAMS CRS-25 (1992). The most numerous type of waiver is the 1915(c) (formerly called a "2176 waiver," in each case after authorizing legislation) under which states can offer selected home and community-based services to individuals who otherwise would be institutionalized, or elderly persons at risk of institutionalization. The waiver process requires the state to show that the community-based services result in reduction in the nursing home bed capacity within the state, the so-called "cold bed formula," which has prevented a number of states with a shortage of nursing home beds from qualifying.

[157] *See* DONNA FOLKEMER, AMERICAN ASS'N FOR RETIRED PERSONS, PUB. POL'Y INST. NO. 9405, STATE USE OF HOME & COMMUNITY-BASED SERVICES FOR THE AGED UNDER MEDICAID: WAIVER PROGRAMS, PERSONAL CARE, FRAIL ELDERLY SERVICES AND HOME HEALTH SERVICES (1994) (providing results of a survey of the various Medicaid home and community-based care options offered by states to persons with disabilities).

In New York, in fiscal year 1991-1992, for example, the Nursing Home Without Walls program provided a very broad range of services, including homemaking, nursing, respite, In 1990, Congress introduced a new waiver program, Optional Home and Community-based Services for the Frail Elderly,[158] through which states may provide a broad range of home and community-based care[159] to "functionally disabled" individuals[160] who are sixty-five years of age or older and who receive Supplemental Security Income[161] or who qualify as medically needy under the state's Medicaid eligibility guidelines.[162] Any person over age sixty-five is entitled to receive a determination of functional

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and adult day care, to 12,993 people statewide at a cost of $92.5 million. In Louisiana, by contrast, the Adult Day Health Care program provided that service alone to 305 persons statewide at a cost of $300,000. *See* Ellice Fatoulah, *Medicaid Home Care for the Elderly and Persons with Disabilities,* 26 CLEARINGHOUSE REV. 882 (1992).

[158] Called "4711 waivers" after the authorizing § 4711 in the Omnibus Budget Reconciliation Act of 1990, codified at 42 U.S.C. § 1396d(a)(23) (Supp. IV 1992).

[159] States may provide homemaker/home health aide services, chore services, personal care, respite care, adult day care, and training for family members in caring for the individual, in addition to more traditional services.

[160] This includes adults of all ages who are unable to perform three or more ADLs or who require cuing to perform them. Persons with Alzheimer's disease and related dementias typically require cuing, i.e., an attending person to prompt a physically capable person to perform ordinary activities of daily living when mental impairments prevent sufficient comprehension or concentration.

The 4711 eligibility standards were adopted for home and community-based care in the Health Security Act. The Act defines an "individual with disabilities" as someone who meets one or more of the following conditions:

1) Requires hands on or stand-by assistance, supervision or cuing to perform three or more activities of daily living ("ADL"s) and is expected to require such assistance for at least 100 days;

2) Presents evidence of severe cognitive or mental impairment, as defined by the Act, and the need for specified assistance, which is expected to last at least 100 days;

3) Has severe or profound mental retardation according to a protocol specified by the Secretary;

4) For children under the age of six, has a severe disability or chronic medical condition and who without receiving personal assistance services would require institutionalization, and is expected to require such services for at least 100 days.

S. 1757, 103d Cong., 1st Sess. (1993); H.R. 3600, 103d Cong., 1st Sess. (1993).

[161] 42 U.S.C. § 1381 (1988). Supplemental Security Income ("SSI") provides a guaranteed minimum income for individuals who are aged, blind, or disabled, who have insufficient workforce participation to be eligible for SSDI.

[162] Medically needy eligibility applies to individuals who meet all the criteria for categorical eligibility for Medicaid (i.e., are aged, blind, or disabled, or living in a family eligible to receive Aid for Dependent Children) but have income above cash assistance eligibility levels. Individuals qualify for Medicaid assistance by a "spenddown" process which allows them to deduct incurred medical expenses from excess income until that income is within categorically eligibility levels. Thereafter, medical expenses are paid by the Medicaid program. *See* 42 C.F.R. §§ 435.200-.350 (1994).

disability, which is conducted by a multi-disciplinary team. However, very few states have applied for 4711 waivers, and still fewer have received them due to restrictive rules and funding. Funds must be allocated in proportion to the number of low-income elderly persons living in the state, and federal costs cannot exceed $200 million over five years beginning in 1991. In addition, the cost of services for a particular recipient is capped at fifty percent of the statewide average Medicaid per diem rate for skilled nursing care.[163] In sum, the services cannot be delivered effectively to the state's chronically disabled population because the state is too drastically underfunded, on both programmatic and individual levels.

Waiver programs allow the states to try new services on target populations. Costs are manageable because the waiver authorization avoids creating an entitlement. Waivers are effective indefinitely if renewed periodically by the federal government. The limited target population of many waivers also prevents implementation problems such as worker shortages. On the other hand, limited benefits may not assist those in greatest need, and the unfairness to those who cannot receive services would be perceived as intolerable if there was agreement on long-term care as a social good which should be equally available to all regardless of the ability to pay market value. In terms of health care benefits, the waiver authorization is tantamount to declaring the services permanently experimental. The variation in services and target populations may be appropriate, cost-efficient choices for the state budgets, but not for all citizens. The expanding use of the waiver process indicates not only widespread need for public long-term care benefits, but also which benefits are most effective.[164]

2. Housing Programs

The financing and administration of housing programs has traditionally been a state-federal partnership, with federal guidelines determining most of the assistance generally available to citizens of the states. Policy and practice regarding housing for disabled and elderly persons has been in flux for over a decade, as impaired but functional people are turned away from institutional care and back into the community to rely on less intensive

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[163] *See* 42 U.S.C. § 1396d (Supp. IV 1992).

[164] The most common waiver services are homemaking and personal care. *See generally* FOLKEMER, *supra* note 157. The Health Care Financing Administration eased waiver rules in the fall of 1994; eliminating the "cold bed formula" and making other changes which will enable more states to provide more home and community-based care. *See HCFA Eases Medicaid Waiver Process—Again*, MCKNIGHTS LONG-TERM CARE NEWS, Oct. 1994, at 3.

service settings. National housing policy is called upon to define the alternative settings appropriate for impaired persons of widely varying needs, and states are challenged, despite their generally severe economic constraints, to participate in programs that meet their citizens' needs. The economic incentive is potential savings in more costly institutional care programs.

Three concepts have dominated the prospects for housing elderly and disabled persons: public housing,[165] congregate housing,[166] and rental subsidies.[167] Unfortunately, since the late 1970s, public policy has favored the idea that subsidizing rents for existing dwellings throughout the community is a more economical mechanism than the other options. Emphasis shifted for more than a decade from "supply side" assistance with building to "demand side" housing allowances,[168] and beneficiaries were to some extent dispersed throughout the community. While such policy has some benefit for non-disabled low-income families, it is counterproductive for persons with disabilities who are in need of visiting services.

The principal program of housing and services is the Congregate Housing and Services Program ("CHSP"), authorized as a demonstration in 1978.[169] The program was intended to prevent premature institutionalization of elderly and handicapped residents of federally subsidized housing by providing non-medical, in-home services and was found by Congress to be quite successful. However, the program has never flourished or grown, in part due to poor management of services by the Department of Housing and Urban Development and its grantees.[170] While the program has been reviewed and re-authorized after suspension of a number of projects during

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[165] 24 C.F.R. § 941 (1994); *see* ELDERLAW, *supra* note 11, at 682-83.

[166] *See* 12 U.S.C. § 1701g (1988); 24 C.F.R. § 885 (1994); ELDERLAW, *supra* note 11, at 683-85.

[167] ELDERLAW, *supra* note 11, at 676-77.

[168] *See* URBAN INSTITUTE, HOUSING AMERICA: LEARNING FROM THE PAST, PLANNING FOR THE FUTURE 6 (1990).

[169] *See* HOUSE SELECT COMM. ON AGING, PUB. NO. 100-650, DIGNITY, INDEPENDENCE, AND COST EFFECTIVENESS: THE SUCCESS OF THE CONGREGATE HOUSING SERVICES PROGRAM XI (1987).

[170] *See, e.g.*, Gonzalez v. St. Margaret's House Housing Dev. Fund, 668 F. Supp. 187 (S.D.N.Y. 1987) (supporting the controversial mandatory meals program in elderly congregate housing). HUD was found to have altered the tone and substance of the reports of independent evaluators to portray services programs as negatively as possible. *See* ELDERLAW, *supra* note 11, at 772-74.

the HUD scandals of 1989,[171] it is not clear whether, or how, the persistent problems will be solved while the programs are under HUD's authority.

The greatest growth in housing for persons with disabilities in the past decade has been in assisted living, which combines the medical aspects of long-term care with a model of supported housing and social services. The assisted living movement for non-elderly chronically disabled people emphasizes utilization of community-based services in a neighborhood or project with non-disabled persons. For the elderly, assisted living more often contemplates a specialized housing project where a range of services can be delivered by staff or visiting professionals. Initiated in the private sector for more affluent older people, assisted living facilities may now receive Medicaid support under new waiver rules.[172]

B. *Of Means Tests and Subsidies*

The most apparent type of means testing is financial, i.e., a bureaucratic process to ascertain whether an individual's income and assets fall within established limits before providing services at public expense. However, another type of means testing is at least as important in determining an impaired individual's ability to remain in the community: the extent of social support provided by family members and others. It is reasonable to consider whether either or both should be implemented in a national long-term care program. If implemented in tandem with social insurance, subsidies would be provided for premiums for low-income individuals. If the benefits are paid from general funds, like Medicaid, low-income individuals would be eligible.

1. Financial Responsibility

Many assumptions about financial eligibility criteria are dictated by the current era of deficits and shortages. Clearly, a program with financial means testing is more acceptable because, having fewer eligible recipients, it is cheaper. It is also perceived to be fairer, in that means testing targets assistance to those individuals who cannot purchase assistance; services in chronic short supply will not be "wasted." On the other hand, means testing is universally disliked by prospective beneficiaries, given its potential to be

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[171] *See* David Johnston, *Radical Rehab: There's Far to Go in Cleaning Up the H.U.D. Mess*, N.Y. TIMES, Aug. 13, 1989, at 4-1; HUD REFORMS ACT IMPACTS ELDERLY HOUSING PROGRAMS, AMERICAN ASS'N OF HOMES FOR THE AGING 4 (1990).

[172] *See Assisted Living Providers Cash in on New Waiver Format*, MCKNIGHTS LONG-TERM CARE NEWS, July 1994, at 6.

stressful, labor-intensive, and a demeaning invasion of ordinarily private matters. Because determining eligibility is simple only for the very poor, it is also expensive for the state. In addition, complex rules, the need for proof, and incentives to cheat the system produce unfair results which burden individuals and erode the legitimacy of the system itself.

Programs with and without means testing have been enacted for elderly persons, and their current status reveals the likely path to pursue with any new program. The principal non-means tested program is the Older Americans Act of 1965 ("OAA"),[173] which provides an array of community services to older persons.[174] The OAA originally was interpreted to prohibit providers from inquiring into the financial capabilities of service recipients.[175] Over the years, successive amendments have required providers to target older persons with the greatest economic or social need,[176] particularly in the nutrition program which receives nearly seventy percent of the total budget allocation.[177] While the legislation did not establish procedures for a means test, it required providers to assure that actual recipients are those most in need as defined by the amendments. The

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[173] 42 U.S.C. §§ 3001-3057 (1988).

[174] The Act contains six titles: Title I includes broad social policy statements regarding improving the lives of all older persons in areas of income, health, housing, long-term care, and transportation. *Id.* §§ 3001-3003. Title II establishes the administrative structure of the program, including the Administration on Aging and the Federal Council on Aging. *Id.* §§ 3011-3020d. Title III authorizes nutrition programs and related services under the administration of State Agencies on Aging and Area Agencies on Aging. *Id.* §§ 3021-3030p. Title IV provides for funding of research, training and demonstration programs. *Id.* §§ 3030aa-3037b. Title V provides for a job creation program for older workers. 42 U.S.C. §§ 3056-3056g (1988). Title VI authorizes supportive and nutrition services for older Indians and native Hawaiians. *Id.* §§ 3057-3057n.

[175] The OAA was based on legislative intent to benefit "the older people of our Nation." *Id.* § 3001. As well as to "assist our older people to secure equal opportunity to the full and free enjoyment of . . . [r]etirement in health honor, dignity—after years of contribution to the economy." *Id.* §§ 3001, 3001(6). Some of the services provided are not limited to persons in economic need, such as "protection against abuse, neglect, and exploitation." *Id.* § 3001(10).

[176] "[G]reatest economic need" is defined as "'need resulting from an income level at or below the poverty levels established by the Office of Management and Budget'" ($6810 for a single person in 1992). "'[G]reatest social need'" is defined as "'need caused by noneconomic factors, which include physical and mental disabilities, language barriers, and cultural, social or geographical isolation including that caused by racial or ethnic status which restricts an individual's ability to perform normal daily tasks or which threatens such individual's capacity to live independently.'" *See* CONGRESSIONAL RESEARCH SERV., OLDER AMERICANS ACT: REAUTHORIZATION AND FY 1993 BUDGET ISSUES 3 (1993)).

[177] *Id.* at 2.

1992 amendments to the OAA associated more support services with Title III and its targets,[178] and included a new provision, Title VII, authorizing programs for prevention of abuse and neglect and the provision of legal assistance.[179] The administration of Title VII funds differs from Title III in that states can bypass administration by the network of federal administrative Area Agencies on Aging. States were also given permission to transfer funds between service and nutrition programs to maximize their ability to meet the needs of target groups.

The pattern of the OAA represents a number of policy choices for community-based long-term care so that age is no longer a proxy for need. When the OAA was enacted, approximately one third of the population age sixty-five and older had incomes below the official poverty level; many had no reasonable access to health care since Medicare and Medicaid were enacted in the same year; and the elderly living alone were excluded from public housing.[180] Currently, the picture is more complex.[181] In the absence of a clear sense of need, the focus of assistance has shifted to persons who are physically frail and vulnerable to exploitation by others.

The authorization in the OAA is similar to the authorization in Medicaid waivers, in the that the benefits are not an entitlement; rather, benefits are limited to the funds allocated and, but for community pressure, could be zeroed out at any time. Also, benefits are targeted to a specific group perceived to be in greatest need. The concept is quite similar to

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[178] *See* CENTER FOR SOCIAL GERONTOLOGY, BEST PRACTICE NOTES ON THE DELIVERY OF LEGAL ASSISTANCE TO OLDER PERSONS 3-4 (1994) [hereinafter DELIVERY OF LEGAL ASSISTANCE].

[179] *Id.* at 6-7; 42 U.S.C. §§ 3058-3058k (Supp. V 1993).

[180] DELIVERY OF LEGAL ASSISTANCE, *supra* note 178, at 4.

[181] Though the official rate of poverty among the elderly is about 12%, the figure is misleading, primarily because the official poverty line for retirees is different than for other age groups. Poverty is probably more widespread among the aged than in any other adult age group, particularly among such subgroups as older women, minorities, the oldest old, and elderly people living alone. *See* VILLERS FOUND., ON THE OTHER SIDE OF EASY STREET: MYTHS AND FACTS ABOUT THE ECONOMICS OF OLD AGE 12 (1987).

Changes in benefits for the aged reflect conflict over "intergenerational equity," and concern over competing needs such as assistance and education for children. *See, e.g.*, Paul S. Hewitt & Neil Howe, *Generational Equity and the Future of Generational Politics*, GENERATIONS, Spring 1988, at 10 (slow economic growth and increase in the aged population dictates a reallocation of resources); Ronald F. Pollack, *Serving Intergenerational Needs, Not Intergenerational Conflict*, GENERATIONS, Spring 1988, at 14 (many elderly persons are still in need of economic and other assistance).

health care reform proposals, in that the services are intended to be available to those in need, but are subject to a budget cap—a capped entitlement.[182]

The problems with means testing long-term care, particularly for the elderly who have accumulated some assets, are amply illustrated by the current process of qualifying for Medicaid nursing home care. Generally, a single applicant must have less than $2000 in assets to qualify for Medicaid assistance.[183] In most states, however, an applicant whose assets exceed the Medicaid eligibility limit can "spend down" by deducting incurred medical costs until the value remaining is small enough to qualify for Medicaid assistance. If a Medicaid applicant sells an asset for less than its fair market value, for instance by giving it to a family member, the value may be counted as money available to pay the nursing home bill.[184] As a result, an applicant can be denied eligibility for a period in proportion to the amount transferred.[185] The state is entitled, under federal law, to examine the applicant's financial records for up to thirty-six months prior to the time of application.[186]

Some individuals simply make illegal transfers when faced with long-term institutionalization, but generally such transfers are quite modest in value. Some applicants, often with legal assistance, use more sophisticated strategies: placing the applicant's funds into a joint account from which the new joint owner can withdraw at will; placing funds in trust with someone other than the applicant as beneficiary; buying an annuity which pays upon the applicant's death; or making "multiple divestments," so periods of penalty overlap and the applicant is eligible when the retained assets run out.[187]

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[182] *See* S. 1757, 103d Cong., 1st Sess. (1993); H.R. 3960, 2d Sess. (1993); H.R. Con. Res. 2d Sess. (1993) (the cap on federal payments to alliances would be $10.3 billion in 1996; $28.3 billion in 1997; $75.6 billion in 1998; $78.9 billion in 1999; and $81 billion in 2000).

[183] The amount is set by the state, and excludes such resources as a homestead. *See* 42 U.S.C. § 1382b(a)(1) (1988); 20 C.F.R. § 416.1212 (1994).

[184] 42 U.S.C. § 1396p(c)(2)(C) (Supp. V 1993).

[185] *Id.* § 1396p(c)(1)(E)(i)-(iii) (the amount transferred is divided by the average cost of nursing home care per month, yielding the number of months of ineligibility).

[186] *Id.* § 1396p(c)(1)(B).

[187] For example, Mrs. Jones transfers to her son just under $30,000 in January, and care costs $3000 per month; Mrs. Jones is ineligible for 10 months. In February, she transfers just under $27,000, incurring a penalty of nine months concurrent with the first penalty; and so on. Mrs. Jones can transfer just under $165,000 and still be eligible for Medicaid in November. New strategies after legislation prohibiting concurrent penalties include variations on a "half a loaf" theory which substantially accelerate eligibility.

While all of these strategies have been addressed by legislation in many states,[188] new ways to qualify replace them so long as individuals want to preserve their property and receive the benefits.[189] The Medicaid eligibility game began when benefits were extended to middle-class persons who were concerned with saving and managing their money and were likely to seek legal counsel regarding the precise meaning of eligibility rules. Such individuals reject the rules governing a culture of poverty according to which authorities require that Medicaid beneficiaries turn over all information requested and accept without meaningful explanation the authorities' decision about what help will be given. A middle-class view, in contrast, requires the applicant to be aware of the rules and make use of exceptions as one would in preparing a prudent tax return.[190]

Because it makes no sense to drive an individual living in the community into poverty before providing coverage for home and community-based care, a public long-term care program is likely to have similar difficulty writing airtight eligibility guidelines. Means testing for community-based long-term care would be time-consuming, contentious, and expensive.

2. Family Responsibility

Many would hesitate to provide formal long-term care assistance on the assumption that informal care providers would abandon their roles when

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[188] Michigan, for example, will nullify trusts funded by Medicaid applicants to divert assets and income to others. Iowa considered legislation to increase the federally-determined 30 month terms it can "look back" for asset transfers at less than fair market value and declare a nursing home resident ineligible for Medicaid assistance. Many states are emphasizing estate recovery programs similar to those which in 1992 netted $22 million in California, $13.4 million in Wisconsin, and $2 million in Maryland.

[189] Some Medicaid officials believe it is more often the adult children of Medicaid applicants who use such tactics to preserve their inheritance.

[190] The opportunity for middle class eligibility for Medicaid nursing home benefits increased substantially when Congress extended protection for spouses of nursing home residents in the Medicare Catastrophic Coverage Act of 1988. If a spouse is institutionalized, federal law allows a one time transfer to the spouse living the community of half the couple's assets, up to $70,740 in 1993. The institutionalized spouse must spend down, but states must allow the community spouse to keep at least $14,148.

Income generally belongs to the person in whose name it is received, though the community spouse with limited income can claim a maintenance needs allowance from the income of the institutionalized spouse. *See* 42 U.S.C. § 1396r-5(b)(1) (1988); BRIAN BURWELL, MIDDLE-CLASS WELFARE: MEDICAID ESTATE PLANNING FOR LONG-TERM CARE COVERAGE 1 (1991).

formal help becomes available.[191] Limiting formal assistance to needs that cannot be met by family or friends also limits the dreaded "woodwork effect," a metaphor for the number of persons in need who are expected to appear with the creation of a public long-term care benefit. Certainly, the existence of family or other social support is relevant to an individual's ability to live at home because the existence of social supports is the most significant factor in determining whether an individual will be institutionalized.[192] The actual effect of adding formal care is difficult to measure and explain, as is the balance of social and economic issues which make family withdrawal from care such a sensitive issue.[193] Possibly, formal services would partially replace informal care at increased public expense, but the lives of caregivers and care receiver would be enhanced. Also, formal services might primarily enable informal caregivers to carry on longer, resulting in a public savings.

The consensus of studies is that some informal caregivers do stop.[194] The extent is small, and the substitution appears to be primarily in IADLs, such as making and driving to appointments. The caregivers most likely to reduce their participation were those who were not closely related to the care recipient, such as friends or neighbors, and relatives other than spouses and children. It is unclear whether caregivers overall provide more or less care when formal care is available.[195]

States have been reluctant to enforce family support laws which might create intrafamily hostility and violence, and nearly all have eliminated such statutes. The privacy of the caregiving relationship, particularly among family members, makes it very difficult for the state to detect abuse and

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[191] *But see* LEONARD HEUMANN & DUNCAN BOLDY, HOUSING FOR THE ELDERLY 19 (1982) (the family is not abandoning in large numbers its role as primary housing and support provider to the functionally impaired elderly, but fewer family members are available on a 24-hour basis). *See generally* Susan L. Ettner, *The Effect of the Medicaid Home Care Benefit on Long-Term Care Choices of the Elderly*, ECON. INQUIRY, Jan. 1994, at 103 (indicating that home care subsidies reduce the probability of at-risk elderly entering nursing homes, but also increases the substitution of formal for informal care, thus raising costs).

[192] *See* Lawrence A. Frolik & Alison P. Barnes, *An Aging Population: A Challenge to the Law*, 42 HASTINGS L.J. 683, 700-03 (1991).

[193] Martin B. Tracy, *Government Versus the Family: The False Dichotomy*, GENERATIONS, Winter 1993, at 47, 48.

[194] Peter Kemper et al., *Community Care Demonstrations: What Have We Learned?*, HEALTH CARE FIN. REV., Summer 1987, at 87, 94.

[195] *Id.*

intervene.[196] Given that families do not abandon care in significant numbers, it is very likely that informal supports should be taken into account only when the care is voluntarily and consistently provided, because the caregiving relationship leaves the person with disabilities vulnerable to financial exploitation and physical abuse.

C. *Long-Term Care Insurance*

The need for long-term care has the characteristics of an insurable event, i.e., it has a very high cost, but is unlikely to happen. Long-term care insurance is an alternative which has gained a modest market in the past decade. Long-term care coverage typically pays an indemnity benefit of, say, $100 per day of nursing home care up to a maximum term per admission, and perhaps a maximum per policy holder. In addition, a number of states require that long-term care policies provide home care benefits, which may be substituted for nursing home care.[197] Coverage is improving with the adoption of model standards by the states.[198]

Whether long-term care insurance is too expensive is a matter of some debate. Some analysts estimate that at an average cost of $1346 annually for a sixty-seven year old, a basic long-term care policy is unaffordable for eighty percent of potential purchasers.[199] Insurance proponents assert, on the other hand, that the definition of affordability should include consideration of home equity assets, rather than fixing on a percentage of income alone.[200] Proponents also argue that the sale of long-term care insurance policies is inhibited by the existence of Medicaid long-term care benefits,

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[196] *See* Barnes, *supra* note 86 (family guardianships cannot be monitored without destructive effects on the caregiving relationship). The most recent example of caregiver abuse is in durable powers of attorney. *See generally* GOVERNMENT LAW CTR. OF ALBANY LAW SCH., ABUSE AND THE DURABLE POWER OF ATTORNEY: OPTIONS FOR REFORM (1994).

[197] Several major insurers offer policies which cover twice as many home care days as nursing home days.

[198] *See* AN EMPTY PROMISE TO THE ELDERLY?, CONSUMER REP., June 1991, at 425, 431 [hereinafter CONSUMER REP.].

[199] *See* GENERAL ACCT. OFFICE, NO. 90-154, LONG-TERM CARE INSURANCE: PROPOSALS TO LINK PRIVATE INSURANCE AND MEDICAID NEED CLOSE SCRUTINY 12 (1990). Affordability is typically defined as between 5% and 10% of income for health insurance. *See also* RIVLIN & WIENER, *supra* note 71, at 20.

[200] *See* DEVELOPMENTS IN AGING, *supra* note 78, at 215 (state-by-state analysis shows that in no state can more than 25% afford the average cost of nine basic long-term care insurance plans).

which provide a safety net for indigent nursing home residents.[201] A higher level of risk might prompt many more individuals to purchase coverage in advance, even if paying the premiums required the purchaser to liquidate assets.

However, there are significant problems with marketing effective long-term care coverage, primarily because of the long lag between purchase and benefits payout. Many policies lack mandatory inflation protection; most policies sold to date will lapse without paying benefits. Many fail to include nonforfeiture provisions, so all premiums paid over the years are lost if the purchaser lets the policy lapse.[202] If the policy continues in force without inflation protection, coverage will almost certainly be inadequate by the time it is needed.[203] In addition, there are no standard definitions which would clarify the extent of coverage.[204] While there are well-written policies on the market which take all these concerns into account, they are expensive. Indeed, when a sixty-five year old purchaser elects all three, premiums increase over two hundred percent.[205]

Premiums could be reduced, however, by having a single program of long-term care coverage which would eliminate as much as thirty-five percent of the cost of a policy.[206] For example, California's Public Employees Retirement System ("CalPERS") will create the nation's first

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[201] *See, e.g.*, LTC NEWS AND COMMENT, SPECIAL EDITION ON MEDICAID ESTATE PLANNING 4 (Jan. 1991) (including excerpts from previous editions by Steven Moses and Brian Burwell highlighting the "Medicaid muddle," i.e., the efforts of middle class elderly to qualify for Medicaid nursing home assistance); *see also infra* notes 189-90 and accompanying text.

[202] Most purchasers allow their long-term care policies to lapse without collecting any benefits. *See* Albert B. Crenshaw, *State Regulators Target Long-Term Care Insurance*, WASH. POST, Nov. 8, 1992, at 8.

[203] *See* David G. Larson, *The State of the Art in LTC Insurance*, 3 LTC NEWS & COMMENT 5, 6 (April 1993).

[204] *See generally* GENERAL ACCT. OFFICE, No. 89-67, LONG-TERM CARE INSURANCE: STATE REGULATORY REQUIREMENTS PROVIDE INCONSISTENT CONSUMER PROTECTION 25-26 (1989). A Model Long-Term Care Insurance Act was approved by the Health Care Task Force of the American Legal Exchange Council for adoption by the states in March 1991. For state legislative activity in 1992, see ELDERLAW, *supra* note 11, at 18-22.

[205] *See* CONSUMER REP., *supra* note 198, at 430-31. Because of limits on coverage, a 15% risk of loss of assets would remain.

[206] The figure is based on the standards for loss ratios. The amount of premiums returned in the form of benefits would be a minimum 65%. The balance is profit to the insurer or is used for administrative costs.

self-insuring long-term care program in January 1995.[207] CalPERS has used the size of its purchasing alliance to negotiate a plan that has reduced premiums by about twenty-five percent.[208]

An alternative strategy to reduce premiums while limiting costs to state Medicaid programs was underway in several states in 1994. The Connecticut and New York programs represent two basic models of public/private partnership supported by the Robert Wood Johnson Foundation.[209] The Connecticut model, based on assets, disregards personal assets up to the amount paid for long-term care by private insurance on a dollar-for-dollar basis. The New York model, based on time, allows eligibility for Medicaid regardless of the amount of remaining after the individual has used private insurance to pay for three years of nursing home care or six years of home care, or a combination in which home care days substitute for nursing home days on a two-for-one basis. Insurers whose policies meet the standards of the partnership program provide their policyholder with the assurance of asset protection though coverage has significant limitations. In New York, policies cost between $1500 and $2000 for a person age sixty-five, and will at a minimum provide $100 per day nursing home benefit and a $50 per day home care benefit. In Connecticut, policies which pay $80 per day for one year of nursing home coverage and $40 for home care, with a 100 day elimination period and five percent lifetime inflation protection, cost $788-$947 annually. The buyer who makes a commitment to coverage for more than a year pays less annually. With a public/private partnership, approximately forty-one percent could afford long-term care coverage, with complete asset protection.[210]

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[207] *See* Paul Kleyman, *All Eyes are on California's Proposition 186*, AGING TODAY, Sept.-Oct. 1994, at 1.

[208] John Reichard, *Alliances May Open Door to Cheaper Long Term Care*, J. AM. HEALTH CARE, Sept.-Oct. 1994, at 20. Under the CalPERS proposal, a 40 year old would pay $46 per month for a policy that pays $120 a day for facility-based custodial care, with an annual adjustment of five percent for inflation. CalPERS will also negotiate with institutional and home care providers for lower rates, which will extend the benefits for policyholders.

[209] *See* ROBERT WOOD JOHNSON FOUND., PROGRAM TO PROMOTE LONG-TERM CARE INSURANCE FOR THE ELDERLY: PROGRAM OVERVIEW AS OF SEPTEMBER 1992 (1992) (on file with the author); Kevin J. Mahoney, *Financing Long-Term Care with Limited Resources: Combining the Resources of the Public and Private Sectors*, 4 J. AGING & SOC. POL'Y 35 (1992).

[210] The impact on Medicaid budgets is less significant than one might expect. New York, for example, anticipates a one percent decrease in its Medicaid long-term care budget. The Center on Aging at the University of Maryland, which includes the Robert Wood Johnson Foundation Program to Promote Long-Term Care Insurance for the Elderly,

A remaining significant problem with the current state of long-term care coverage is that policies are purchased primarily by persons with a relatively high expectation of need for care. Under a casualty model of insurance, such adverse selection results in high premiums which are set on the basis of expected losses. The purpose is not only to create an adequate pool for payment of benefits, but also to provide incentive for the insured to avoid risk-inducing behaviors. The theory is ineffective when it relates to individuals who already have a condition which imposes costs beyond the individual's control. The casualty model is particularly unfair when the cause of the disability itself was beyond the individual's control.[211]

The social model of insurance, by contrast, calculates expected loss in the aggregate, rather than individually, and sets an average premium for the entire insured population. The result is community rating, i.e., all individuals pay the same rate and receive as much in the way of benefits as they need. Incentives to reduce risks are typically included in a social insurance model through cost-sharing mechanisms, such as deductibles and co-payments. Managed competition proposals, including President Clinton's plan, are based on the social model. To make it effective, the risk pool must include a substantial number of individuals who pay premiums without having a need for care; a universal system would minimize premiums for all.

A social model of universal coverage is ideal for covering long-term care costs, provided participation is universal.[212] Persons with disabilities or frailties of age would pay just what others pay, which may be the greater burden but also offers the greater benefit. The cost would be minimized to the population as a whole.

D. *Managed Care and Competition*

A principal aspect of health care reforms is reorganization of the delivery system.[213] Health care services are to be delivered by organiza-

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estimates state savings will be up to seven percent of Medicaid budgets.

[211] Other regulatory changes are recommended in GENERAL ACCT. OFFICE, NO. 89-67, LONG-TERM CARE INSURANCE: STATE REGULATORY REQUIREMENTS PROVIDE INCONSISTENT CONSUMER PROTECTION 35 (1989).

[212] A social insurance model was recommended by the Pepper Bipartisan Commission on Comprehensive Health Care in 1989. Eligibility was based on ADL deficits, and benefits included a broad array of personal care, homemaker, shopping, respite, and other services in a medical/social model. PEPPER COMM'N, ACCESS TO HEALTH CARE AND LONG-TERM CARE FOR ALL AMERICANS 13 (1990).

[213] The other principal aspect, financing reform, is discussed in the section below.

tions of providers, or through insurance purchasing cooperatives which offer alternative packages of access to care (formerly called insurance policies) paying capitated costs, often only to specified providers. In capitated plans, tension between costs and quality of care is fundamental. Much health care reform rhetoric about the need for individuals to have their choice of a trusted physician arises from recognition of this tension in all cost-contained systems, and the hope the physician will continue to put the patient's good foremost.[214]

Long-term care programs, limited as they are in quantity and scope of services, are virtually all administered through case management programs, in which professionals determine eligibility, assess client needs, determine service needs, and prepare care plans requiring the procurement and coordination of services from inhouse staff and independent contractors. Throughout the course of care, case managers also monitor the quality of services and the appropriateness of services in light of the client's changing abilities.

One model of comprehensive case management in community-based care is the Miami Channeling Program, which makes the case manager an integral part of the financial planning process and permits the case manager a great deal of latitude in the allocation of services.[215] Another natural development from care management is so-called bundling of services. In community-based services the definitive bundle is the social/health maintenance organization, or S/HMO. Four projects have demonstrated the effectiveness of S/HMOs, which utilize standard assessments of function and self-rated well-being.[216] Other demonstrations have combined the delivery of acute medical care and long-term care services under one umbrella provider organization in fifteen projects of The Program of All-inclusive Care for the Elderly ("PACE"). The PACE program is financed, like an HMO, by capitated per person fees.[217] The elderly have had good results

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[214] E. Haavi Morreim, *Redefining Quality by Reassigning Responsibility*, 20 AM. J.L. & MED. 79, 84-86 (1994) (physicians have conflicting duties to patients and cost containment).

[215] *See* Donald Humphreys et al., *The Miami Channeling Program: Case Management and Cost Control in* CASE MANAGEMENT: GUIDING PATIENTS THROUGH THE HEALTH CARE MAZE 45, 49 (Karen Fischer & Ellen Weisman eds. 1988) [hereinafter CASE MANAGEMENT].

[216] *See* Ruby Abrahams & Sara Lamb, *Developing Reliable Assessment in Case-Managed Geriatric Long Term Care Programs in* CASE MANAGEMENT, *supra* note 215, at 117.

[217] When left to selective enrollment, S/HMOs are particularly susceptible to adverse selection, which is discussed below.

from the integration of services in such programs,[218] despite the conflict of interest posed by capitated payments.[219]

Long-term care management has been informed from the outset with ethical sensitivity to the conflicts between client need and scarce supply. The philosophy of care, as expressed in one national organization's practice guidelines, includes a commitment to addressing each client's unique needs in the context of family care.[220] Clients have the right to refuse any recommended service, to be notified in writing of any change in services, and to know the cost of service in advance.[221] Case management is considered a tool not only for cost containment, but for genuine improvements in the quality of services which are better attuned to the individual client.[222] While the ethical tensions are by no means resolved, they continue to have a prominent part in professional dialogue.[223]

E. *Quality Assurance*

A benefit to all from including long-term care in the health care reform package is the possible development of quality measures. Little has been done thus far to craft a single measure of quality in community-based, long-

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[218] A small but significant body of data has been gathered about the effectiveness of community-based services. For example, a survey of sixteen case managed community care for the elderly demonstrations funded by Medicaid or Medicare showed reductions in nursing home use with significant increases in self-rated health and psychological well-being. The use of hospital care and total costs were mostly unchanged. However, targeting services to those most at risk of nursing home placement increased the likelihood of savings. *See* Kemper et al., *supra* note 194, at 93-95.

[219] Sheldon M. Retchin et al., *How the Elderly Fare in HMO's: Outcomes from the Medicare Competition Demonstrations*, 7 HEALTH SERVS. RESEARCH 651 (1992). However, case management probably must be handled by the service provider to be effective. An analysis of data from the National Channeling Demonstration suggests that case management does not adequately address home care service problems, in part because many programs separate the two functions to avoid conflicts of interest.

[220] *See* NATIONAL INST. ON COMMUNITY BASED LONG-TERM CARE, NAT'L COUNCIL ON AGING, CARE MANAGEMENT STANDARDS: GUIDELINES FOR PRACTICE 3 (1988).

[221] *Id.* at 5.

[222] *See, e.g.*, Joan Quinn & Jean S. Burton, *Case Management: A Way to Improve Quality in Long Term Care*, *in* CASE MANAGEMENT, *supra* note 215, at 9, 11-12.

[223] *See, e.g.*, Phyllis M. Brostoff, *Ethical Dilemmas Facing Private Geriatric Case Managers*, *in* CASE MANAGEMENT, *supra* note 215, at 99; Rosalie Kane, *Case Management: Ethical Pitfalls on the Road to High-Quality Managed Care*, *in* CASE MANAGEMENT, *supra* note 215, at 27-30 (considering the conflicting roles of gatekeeper and advocate, and the opposing principles of autonomy and beneficence).

term care.[224] Even the traditional measure of setting the ideal and identifying and reducing errors is a haphazard process in long-term care. Providers have such a pessimistic view of the possible outcomes of care that the use of outcomes measures has not even begun.[225] A demonstration of total quality management techniques began in 1994.[226] Long-term care quality assurance has the potential to catch up with health care quality assurance; integrating the two into a single system can only help the development of both measures.

V. CONCLUSION

Clearly, society has a growing need for long-term care services.[227] Yet, existing service programs fail to address the real scope of need, or to assess the specific problems with meeting that need. The systemic problem lies in separate funding streams, and lack of coordination of providers and services at every level of administration and delivery. Perhaps most important at this juncture is the division between acute and long-term care; the former funded with nearly one sixth of the GDP, and the latter funded as an exception to the rules with a small fraction of that amount. Equally important to the future is the development of housing with services similar to assisted living in the private sector, which provides residents the non-medical services options they need to function independently.

The outcome of health care reform and the funding of long-term care should be addressed together because the very excellence of American health care results in a growing proportion of survivors—with disabilities. Given a mobile society with small families and a growing number of single person households, acute care patients cannot be released to their homes without support. Even those who can afford care will in many instances need assistance in identifying and supervising a provider. Regulating the home care industry is a half-measure which cannot remove the profit motive

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[224] 224. The National Channeling Demonstration provided information to consider in crafting quality assurance strategies. *See* U.S. DEP'T OF HEALTH AND HUMAN SERVS., HEALTH CARE FIN. ADMIN., EVALUATION OF COMMUNITY-ORIENTED LONG-TERM CARE DEMONSTRATION PROJECTS (1987).

[225] 225. Eleanor P. Kinney et al., *Quality Improvement in Community-Based, Long-Term Care: Theory and Reality*, 20 AM. J.L. & MED. 66-67 (1994).

[226] 226. *Id.* at 71.

[227] 227. According to a 1994 report by the General Accounting Office, the demand for long-term care services at all ages will outstrip current funding. GENERAL ACCT. OFFICE, NO. 94-140, LONG-TERM CARE: DEMOGRAPHY, DOLLARS AND DISSATISFACTION DRIVE REFORM (1994).

which simply cuts unprofitable services, requires minimum payments, and inflates government subsidies for services to indigent long-term care recipients. Only a broad package of benefits to meet genuine needs can succeed in the reform of health and long-term care.

The time is ripe for incorporating long-term care into the health care system as any reforms are enacted. Any savings recouped from widespread managed care must peak in the early years of the program; once the system is implemented and a baseline established, costs will surely rise slowly or quickly according to the effectiveness of cost containment and inflation generally. Also, a delay of little more than a decade will bring society to the brink of baby boomer retirement, when the numbers of potential care recipients will make long-term care a much bigger bullet to bite.

It may be said, realistically or cynically, that long-term care is politically impossible. If so, it is nevertheless essential to establish at every opportunity the scope of need, the models for optimum care, and the financing essential to reach the goal. Within the foreseeable future, long-term care must be integrated with health care to address the realities of chronic illness.