Disability, Long-Term Care and Health Care in the 21st Century

Michael Morris • Johnette Hartnett

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AND
JOHNETTE HARTNETT

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Part I

PICTURING THE PROBLEM

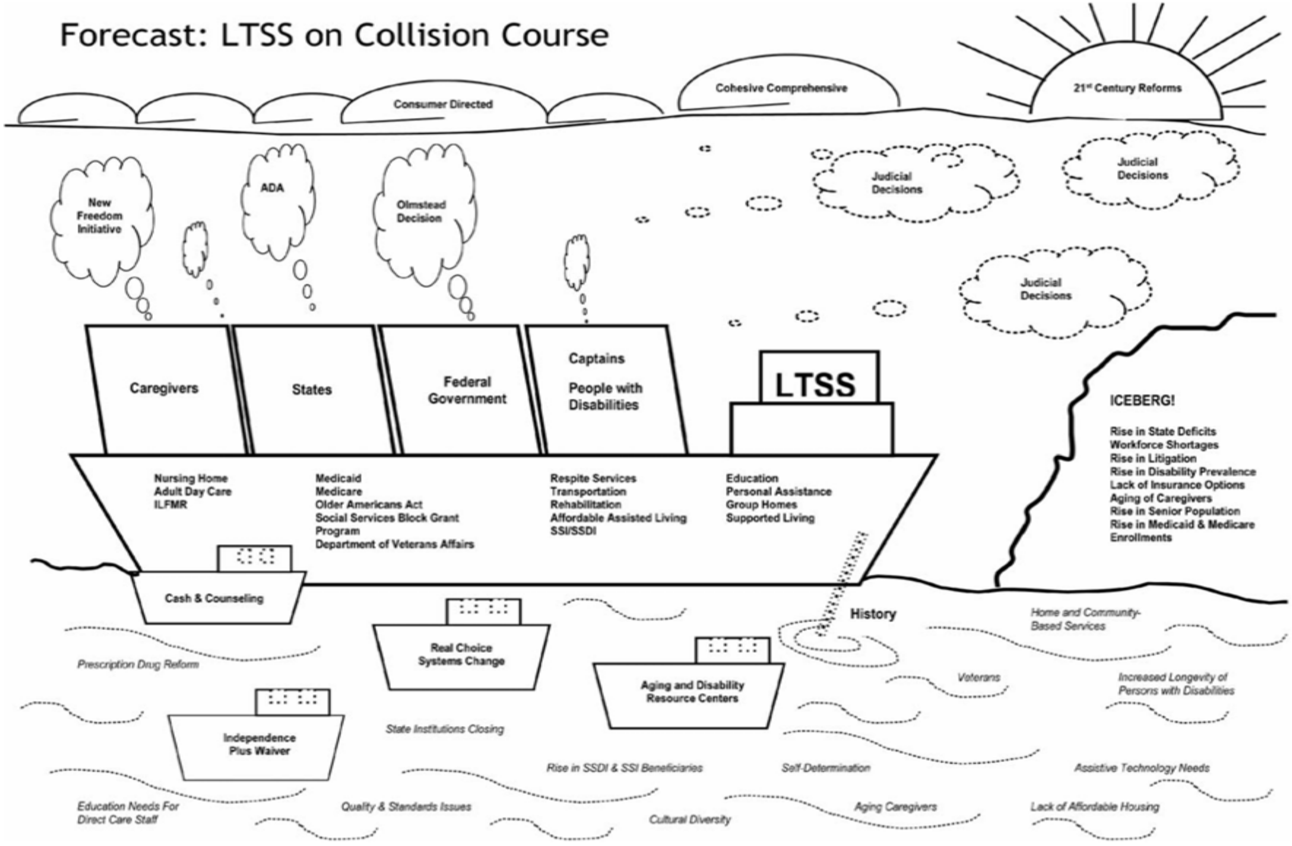
The “rich picture” methodology for presentation of the state of long-term services and supports financing and systems reform research.

Some people say that a picture is worth a thousand words. The field of management often uses a “rich picture” systems methodology, “an innovative tool that encapsulates knowledge relevant to strategic reform.” [1, 2, 3, 4] It is often described in the management literature as a “soft systems methodology” for linking hard and soft facts in a cartoon-like representation to illustrate a complex problem simply and clearly. The following research is presented using the rich picture methodology to capture the current long-term care and long-term services and supports (LTSS) crisis. The picture and narrative rely on expert research from the past and present, as well as on one-on-one open-ended interviews with key stakeholders in the fields of disability, long-term care, and health care.

The setting for the rich picture is the ocean, with the current LTSS ship heading toward an iceberg that represents the barriers and challenges to systems reform. The “cast” for this rich picture will provide the substantive descriptions and body of research and analysis about the barriers and challenges of navigating through the current system of LTSS. The presentation of the research is purposeful, so that the reader and the researcher can begin the voyage together with a snapshot of the problem.

The purpose of this research is to produce new knowledge and understanding of current experience with and future need for affordable LTSS for people with disabilities. This research on the State of LTSS Financing and Systems Reform is the first part in a five-part series that will tell the story of the current LTSS system

Forecast: LTSS on Collision Course



to set the stage for the exploration of future market demands and current gaps in supply; to explore promising state practices and challenges; and to picture what the 21st century’s comprehensive, consumer-responsive system might look like and make policy recommendations.

The research is based on five assumptions. First, people with disabilities, whether young or old, desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Second, the current financing mechanisms (public and private) will become unsustainable in the near future without significant reform. The system must be affordable to all Americans regardless of income levels and must consider opportunities to leverage public and private support in new ways without impoverishing beneficiaries. Third, there is an opportunity with the changing demographic picture of the United States to explore the possibilities of a universal approach to the design and financing of services and supports that is responsive to individuals under the age of 65, as well as seniors with disabilities, without sacrificing individual choice and flexibility. Fourth, formal and informal caregiving must be sustained, examining family needs and workforce recruitment and retention challenges. Fifth, the approach to quality must examine consumer direction and control of resources in addition to traditional external quality assurance mechanisms.

Part II

CHARTING THE COURSE

An overview of the context for systems reform and the challenges inherent in navigating the current waters for people with disabilities and seniors.

Historians will remember the last half of the 20th century for its legacy of public policy in health care, education, disability, and civil rights. It will fill the archives of history as to how a young country, barely 200 years old, grappled with developing and implementing equitable and just policy for all its citizens. Although the flurry of disability policy has waxed and waned with the political, economic, and social changes of the greatest century in history, it nevertheless started a critical dialogue about the rights and responsibilities of all people, of all abilities, toward each other.

The United States enters the 21st century with 35 million people over 65 years of age in relatively good health with independent lifestyles and less than 5 percent in skilled nursing homes. Not bad outcomes for a young country when one considers that, historically, only 2 to 3 percent of the world's population has ever lived beyond 65 years of age. In less than a century, life expectancy in the United States has increased by 30 years. This phenomenon has also increased the life span of people with lifelong disabilities, such as Down syndrome and mental retardation. The increase in longevity is attributed to advances in technology, sanitation, education, health care, and the environment, coupled with an abundance of social and fiscal policy that has provided the first-ever experiment for how a democracy ought to work for its citizens of all abilities.

Over the second half of the 20th century, health care legislation evolved to help working Americans meet the rising costs associated with health care and living longer. The initial Medicare legislation was designed to insure seniors for acute care needs and short-term rehabilitation, and Medicaid was to provide health care for poor women, children, and people with disabilities. For people with chronic, long-term care needs, the nursing home became the primary option for care. In the 1960s, there was no companion legislation developed alongside Medicare and Medicaid that addressed the needs of LTSS. The civil rights debate was in full swing, but the debate about the rights of people with disabilities to services and supports outside a state hospital was in its infant stage. The education movement to integrate people with disabilities into the mainstream classroom was a decade away. It was assumed that families would provide the supports and services and housing for their own family members with lifelong disabilities; if they could not, the alternative was a nursing home or a state institution.

It was not surprising that the 1960s Medicaid legislation covered institutional care and considered it the right response for seniors and people with disabilities with long-term needs. The movement to close state hospitals, ironically, began before the Medicare and Medicaid reform in the 1960s. Deinstitutionalization was viewed by some as an ethical and moral imperative indicative of the changing philosophy of care and civil rights for people with disabilities. However, others saw it as an opportunity to reduce state costs and take advantage of the new federal legislation that would provide states with resources for institutional care such as group homes, intermediate care facilities, and nursing homes.

Today, most Americans, whether with a lifelong disability or a short-term chronic illness, want to receive LTSS in their homes and their communities. In the early 1800s, the first health caregivers were women from local benevolent societies and churches who visited the sick and the indigent in their homes. In the early 1900s, hospitals and state institutions for people with mental retardation grew, and caregiving, although still very much home based, was provided by professionals like nurses, nursing assistants, and social workers. Today, the majority of formal and informal (paid and unpaid) caregivers who provide LTSS are still women. Since 1981, Medicaid policy revisited the home- and community-based notion of caring by offering waivers to states that allow federal-state Medicaid dollars to be spent on optional services rather than just on institutional and home health care. However, the use of waivers is optional and varies dramatically from state to state, and waivers serve less than 1 million low-income people needing LTSS.

It is estimated that between 9 and 12 million people over the age of 18 (459,000 under age 18) need LTSS for everyday self-care needs such as dressing, eating, toileting, shopping, paying bills, or taking medication. Demographers predict that the senior population of 35 million will double by 2030 and, although disability rates have declined for this age group, will begin to climb as the category of the oldest of the old, 85 years and above, increases. The functional as well as chronic and acute care needs of people under 65 years of age are growing at a faster rate than for those over 65 years of age, in part because of improved medical technology, increased life expectancy, increase in asthma, higher prevalence of diabetes and obesity, and deterioration in a number of self-reported health statistics. [5] Eighty percent of adults receive LTSS in the community in which they live, although 64.3 percent of the Medicaid dollars support caregiving for people in nursing homes and other facilities.

The United States spent about $1.24 trillion on all U.S. personal health care services in 2001, with 12.2 percent (or $151.2 billion) spent on LTSS. [6] Medicaid was the major source of funding, followed by personal out-of-pocket pay, Medicare, private long-term care insurance, and a small group of other federal programs. The Congressional Budget Office predicts that the need for services and supports will only grow and that more than half of Americans will need LTSS at some point in their lives. The good news is that the need will be sporadic for most and long term for but a few. The bad news is that the current system is designed for low-income individuals who are nursing home eligible. There are many people with disabilities, young and old, who will never meet the stringent income and functioning requirements for care under the current system. It is ironic that poverty has become the criterion for receipt of LTSS when the United States spends about $5,500 per person on health care, 50 percent more than any other nation in the world.

Financial eligibility criteria for receipt of LTSS through Medicaid require that individuals have extremely low assets and income to receive services. Although demographers and economists have forecast the current crisis, few Americans have saved enough to support any serious long-term care needs. More than 50 percent of Americans have no access to company pension plans, [7] and only about 10 percent have long-term care policies. As many as 45 million Americans have no health insurance. Thirty-four percent of people with disabilities have incomes below $25,000 a year, and more than 60 percent are asset poor (have only enough money to survive for three months at the federal poverty rate). More than 22 percent of Americans are unbanked, which means they are not saving or investing for future long-term care needs.

Economists are exploring how the increased longevity and decreased fertility rates will ultimately affect overall the productivity rates of the American workforce and the ability of the American taxpayer to sustain current financing for the delivery of the current long-term care system. Although there is much debate about the economic health of a variety of our current entitlement programs, there is agreement that there is a growing imbalance between what the Federal Government will collect in future benefits and what it has promised to pay. Before the new prescription drug legislation of 2004, Comptroller General David Walker of the Government Accountability Office (GAO) said that GAO simulations for the year 2040 demonstrated that, without reform, federal income taxes could rise drastically and the nation could see a 50 percent reduction in current spending. [8] Actuaries are challenged to provide insurance companies with lifetime cost projections for people with severe and chronic disabilities who are living longer. Insurance companies are nervous about predicting future costs for long-term care as health care costs continue to rise and the profile of the typical senior continues to change.

Although today's delivery and design of LTSS are guided by a philosophy that is consumer directed and noninstitutional, the funding mechanisms are rooted in policy that is 40 years old and that favors "episodic responses to chronic and acute care needs rather than nonspecific causes related to old age or as a result of a lifelong disability." [9] Regardless of one's philosophy or biases, the current system is fast becoming financially unsustainable. Even the generous federal waivers that make it possible for about 1 million Americans to receive services outside a skilled nursing home come without financial guarantees and are dependent on the fiscal health of each state. It is highly unlikely that states will be able to sustain many of these innovative programs without significant reform in the near future. The current health care system needs a "companion" system of services and supports that provides a constellation of consumer-driven options that are supportive, rehabilitative, medical, and affordable and ensures that people with disabilities and seniors have dignity and independence. The future of LTSS is the gateway to a new industry that has the potential to provide a menu of services that not only maintain or sustain activities of daily living (ADLs) as in the past, but also promote quality aging and healthier lifestyles for all people with disabilities.

Part III

FORECASTING THE NEED

A snapshot of public perceptions creating the barriers and challenges to setting the course for long-term services and supports reform.

CONFUSION AND MISPERCEPTIONS

Many Americans (59%) report giving “very little thought” or “no thought at all” to the issue of long-term care (LTC), and one-third believe that, if they do need LTC services, Medicare or Medicaid will pay the bill. [10] The National Endowment for Financial Education sponsored a think tank on the issues of LTC and concluded that many Americans are experiencing a “disconnect” from planning for the realities of LTC. [11] A national study on LTC insurance found consumers confused about exactly what is meant by LTC—some thought it was an entitlement, others a personal responsibility, and still others were unsure whether it was about housing, services, or both. [12] The study found that 25 percent of those surveyed believed that Medicare or Medicaid would pay for LTC; 34 percent reported that they would never need LTC insurance; and 68 percent reported they would purchase it in the future when and if needed. [13]

A survey by the National Governors Association (NGA) found that 85 percent of Americans over the age of 45 have no public or private insurance protection against the cost of LTC, and states must adopt innovative strategies to encourage citizens to plan to finance their own LTC needs. The survey found that many people have the following common misperceptions about Medicare coverage for LTC costs:

- Unaware that Medicare covers only 100 days of skilled nursing care following a hospital discharge and does not contain a long-term component providing for extended community or intuitional care
- Widespread lack of awareness regarding the high costs associated with LTC
- Wariness about paying LTC insurance premiums to cover services that may not be needed for decades
- Unaffordable LTC insurance premiums for lower-middle-income people
- Lack of knowledge about the availability of other LTC financing vehicles such as reverse mortgages
- Limited options for lower-middle-income people to avoid spending down into Medicaid
- Lack of stigma or consequences for individuals choosing to spend down to Medicaid [14]

ATTITUDES AND PREFERENCES

A survey of participants in a four-state Robert Wood Johnson Foundation partnership for the LTC insurance demonstration project measured attitudes of the participants about purchasing LTC insurance. The evaluation reported that individuals who did not have family members to count on for LTSS and who believed in self-reliance rather than government involvement were more likely to purchase an LTC insurance policy. [15] Most participants were married, college educated, healthy, and had incomes between $50,000 and $100,000 and assets over $100,000. [16] According to the Administration on Aging (AOA) Profile of Older Americans 2000, [17] only 14 percent of family households with a head of household 65 years and older earned incomes between $50,000 and $74,000. Married seniors far outrank their single or never-married and divorced or separated colleagues. Only 4 percent of single or never-married individuals and 8 percent of the divorced or separated are age 65 or older. [18] So attitudes about self-reliance versus government involvement for married well-off seniors are probably quite different than the attitudes of 32 million seniors reporting a median working income of $14,425, with 34 percent reporting a working income of less than $10,000 and 23 percent reporting $25,000 or more. [19]

POSTELECTION VIEWS

America's Health Insurance Plan (AHIP) reported its 2004 postelection survey findings regarding health care issues of 1,000 people who voted in the 2004 presidential election and found that 8 out of 10 people considered health care to be very important but ranked issues of values, Iraq, the economy, and terrorism before health care. Affordability of health care was considered important by 67 percent of respondents, and 27 percent were concerned about providing insurance coverage for more of the uninsured. Almost half reported that the health care system has features that work well and features that need significant changes. Eighty-three percent of voters were satisfied with their health insurance coverage, while only 15 percent were dissatisfied. [20]

Finally, the Kaiser Family Foundation/Harvard School of Public Health Survey, January 2005, reported its findings on the Health Care Agenda for the New Congress. The most important issues or problems the President and Congress should deal with were the war in Iraq (27%), the economy (17%), and health care (10%). The Democrats listed health care as number three of five top priorities, and the Republicans ranked health care as number four out of five top priorities.

LACK OF POLITICAL AND PUBLIC WILL

The brief review above indicates that the issue of health care, not to mention the issue of LTSS, is not on the public or political radar. There is a disconnect from what people think and believe and what is actually happening in the states and, to some extent, what is happing on the federal level. This could be attributed to the fact that the LTC system is designed for low-income recipients, and surveys and polls reflect the views and perceptions of middle- and upper-income populations. However, with less than 10 percent of the American population purchasing LTC insurance, there is a question of how Americans are actually planning for their aging years. Even the large volume of research on the topic of LTC and LTSS reflects a high level of interest and importance by policy leaders, national think tanks, and major federal agencies. The misperceptions about the role of public programs in providing LTC for the average American are serious because they reflect a lack of planning and understanding of the issue. The lack of public and political will should be of great concern to policymakers advocating for people with disabilities and seniors in light of projected federal budget cuts for programs that many believe are growing at unsustainable rates, such as Social Security, Medicaid, and Medicare.

Durenberger (2003) writes that the LTC debate “lacks a strong wedge” because, unlike Social Security and its monthly check, there is no frequent reminder of the need for LTSS in everyday life. Most Americans believe that LTC “signifies an unstoppable decline that ends in death.” [21] Many are in denial that LTC is connected to their financial security and should, in fact, be a part of their retirement portfolio. What salient issue will create the wedge is unclear, although the suggestion to link it to financial security is excellent and should be parlayed into retirement planning for every American.

In addition, Durenberger suggests clarity about what is important and what is urgent to include in the LTC debate. On the urgent side, he recommends the issue of reimbursement and the increased Medicaid matching rates that pushed many states into deficit. The Kaiser Commission on Medicaid and the Uninsured confirmed that 50 states and the District of Columbia implemented Medicaid cost-containment strategies for FY 2003 and FY 2004 and announced plans to make cuts in their Medicaid programs by limiting eligibility, cutting benefits, or restructuring prescription drug payment and coverage. [22] State budget-cutters are reported as particularly targeting nursing home reimbursement rates, with Illinois implementing a 5.9 percent reduction in its nursing home reimbursement rates, and the Kansas Legislature reducing its nursing home budget by $8.9 million. [23] On the important side of the debate, Durenberger recommends discussion of financing reform, systemic change, consumer-directed care, and housing. Although these are the issues most frequently researched, he suggests that they are not as critical to states’ current crises and immediate functions. [24] Durenberger explains that the integration of the urgent and the important issues must be part of the wider national dialogue. The wisdom in this advice is obvious: If the current policy structure for LTSS is breaking the bank for states, alternative strategies must be introduced on a national level to supplement the states in meeting the demands of their aging populations. Although some states are moving forward with their own Medicaid reform, it is unclear what the outcomes will be. A case in point is the recent announcement by Governor Jeb Bush of Florida that his administration is proposing a transformation of the state’s $14 billion Medicaid program that serves 2.1 million vulnerable, disabled, and elderly Floridians. Medicaid spending since 1999 has increased 112 percent and, if reform is not made, there is a fear that it will collapse under its own weight. [25] The reform efforts are defined as a patient-centered vision with three components: basic care, catastrophic care, and flexible spending.

Robyn Stone (2003) reinforces Durenberger's proposition about the important issues when she writes that consumer choice has become the "mantra" of many policymakers, but is a "vacuous" promise at best in the absence of knowledge about options to make informed choices about LTC options. [26] She asserts that communicating about public benefits requires money and a marketing strategy. Unfortunately, as seen in the welfare reform of the late 1990s, the lack of marketing information initially caused a significant drop in the benefit rolls for people receiving food stamps, Medicaid, and other programs because of the lack of knowledge or understanding of the rules and policies associated with the new law.

Joanne Silberner, a health policy correspondent for National Public Radio, writes that the problem with the current debate about health care and LTC is that it is an "endless debate" and is not newsworthy, and that the lack of media coverage is due to the lack of anything new happening. She compares the LTC issue with Medicare:

"Paul Kleyman, the editor of *Aging Today*, is quite passionate about issues of aging and LTC. He once complained to me that 'the zookeepers in politics keep shouting that we have to worry about the pachyderm Medicare before we cover LTC.' The editors at NPR concur. Medicare is a topic that we can cover because it is an issue with clear political agendas. LTC however, is more muddied, and it is not a pachyderm. So the media covers a budget fight, policy changes, bankruptcies, and scandals involving LTC." [27]

NEW LANGUAGE AND DEFINITIONS

The challenge for the architects of the 21st century's LTSS system is not just about public perception and lack of media coverage but about language and actions. The current Administration's assertive actions following the 1999 Supreme Court *Olmstead* decision has asked states to develop and implement plans for less-restrictive community options in care settings of the consumer's choice. [28, 29] The disability rights movement has spearheaded the rights of people with disabilities to live in the least-restrictive environment and has expanded the domain of membership in what was once perceived as an LTC system for people on social welfare and the old and frail. [30, 31]

The use of people-first language, the dropping of the "care" from long term, and services defined as "consumer directed" or "consumer centered" reflect a movement toward a more universal language and acceptance of the evolution of how we think about the multigenerational aspects of aging, disability supports, and services. Kane describes the transition of these slogans into policy, such as the Medicaid home- and community-based waivers, which use client-employed workers; or the Cash and Counseling Demonstrations, during which the Medicaid benefit is cashed out for those who opt for a monetary, although discounted, benefit. [32, 33]

Several models designed by the leaders of the self-determination movement for people with developmental disabilities demonstrated promising outcomes with consumer-driven budgets, which are now being tested across the age span in a few states. [34, 35] The next generation of individuals with disabilities and older Americans will benefit because of the sharing and borrowing of language and policy across the aging spectrum and disability world that preceded current reform efforts.

The definition of LTSS covers a daunting range of issues, needs, and services. The Congressional Record Service defines LTC as “a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness or frailty.” [36] LTSS include much more than health care and is composed of a variety of services and supports essential to maintain quality of life with maximum dignity and independence for individuals with disabilities and individuals over and under 65 years of age. Services and supports include housing, transportation, nutrition, technology, personal assistance, and other social supports to maintain independent living.

HEALTH OUTCOMES—ANOTHER REASON FOR REFORM

Most LTSS are nonmedical and, when combined with the financing mechanisms that favor acute care and institutional care, it is like trying to fit a circle in a square. An examination of health outcomes for the current system may provide a rationale for why a new financing and delivery system is needed.

A recent study produced by researchers from the Robert Wood Johnson Foundation surveyed decades of studies as far back as 1970 as to why people die premature deaths. The study found that 64 percent of premature deaths are due to nonmedical environmental or social or behavioral inputs. [37] This is not surprising when one realizes that the focus of health policy over the past 40 years has not been on prevention or services and supports that could help people with disabilities maintain quality lives or help people with chronic illnesses stabilize conditions. Currently, only 3 percent of total health care expenditures in the

United States are spent on well care, including preventive care. [38] Although the United States spends 50 percent more than 29 other countries in the developed world for health care, its health indicators—such as infant mortality and life expectancy—do not reflect this. Although the United States surpasses all other countries in its spending (13 percent of its gross domestic product), 20 percent of Americans remain uninsured for health care services and 90 percent are uninsured for LTC insurance. [39]

Why We Die Premature Deaths

30%	genetic predispositions
14%	social circumstances
5%	environmental exposures
40%	behavioral patterns
10%	shortfalls in medical care

Longman, 2004, p. 99

The LTSS debate may be seen as a political nonstarter when referenced by the media only in the context of disability and aging, but it underscores the unpreparedness of the current system to handle the biggest demographic challenge in the history of its young country. A textbook commonly used in health policy graduate courses concludes in its chapter on LTC that the subject is largely ignored for several reasons: a focus on the “cure rather than the care” in medicine today; the view of LTC as a low-status service within the health care system; the lack of sustainable and affordable financing mechanisms; and the psychological challenges of coping with a disability at the end of life—all these reasons perpetuate denial and lack of decision making about the problem. [40]

Part IV

DRAGGING ANCHOR

An overview of the role of history in the evolution of today’s understanding and future forecasting of long-term services and supports financing and systems reform.

HISTORY AS PROLOGUE

> **June 1867**
> My view you know is that the ultimate destination of all nursing is the nursing of the sick in their own homes… I look to the abolition of all hospitals .. but no use to talk about the year 2000.
>
> ***Florence Nightingale***
> ***(See Footnote 56)***

In the 20th century, the United States Congress tried six times to pass national health care, but failed. A critical reason given for this failure was the lack of consensus that health care should be a right for all citizens in a free society, subsidized in part by the Federal Government. Nineteenth-century Americans fiercely embraced the idea of individualism and the belief that the working and middle classes never took money not earned. The only exception to this revered ideology was the military half-pensions that began during the Revolutionary War. The sentiment of the 19th century Victorian middleclass was unwavering, holding steadfast to the belief that “American greatness depended at the very least on idle and working-class Americans not accepting benefits they had not earned.” [41] However, our 19th century forefathers did develop the concept of the truly needy and took on the responsibility (state and local) for funding the first poorhouses and institutions. The strong characteristic of individualism prevailed, however, and today’s social policy reflects the belief that poverty is an individual problem and not the result of an economic system. [42] Unlike Western Europe, Canada, and Japan, the United States has never embraced the concept of universal entitlements and is last with respect to its public share of total health care expenditures when compared with other industrialized countries (45.4% public and 54.6% private), Canada (69.4% public and 30.6% private), and Japan (79.5% public and 20.5% private). [43]

George Lundberg, MD, an editor of the *Journal of the American Medical Association* for 17 years, wrote that the failure of recent health reform efforts was based on an erroneous assumption that the American public would accept one level of health care across the board any more than it has accepted one mode of transportation or housing or fashion. [44]

The current system of health care was designed more than 40 years ago and was the United States’ second major attempt since the passage of Social Security in 1935 in providing income security for its working seniors, poor mothers and children, and people with disabilities. Health reform efforts over the last several years have been described as “incremental” and reflective of the overall public and political opinion (see part III of this chapter) of the insured. However, what is notably absent from the current debate is reliable research that spells out the needs and perceptions about the current LTSS from the uninsured, underinsured, and people with disabilities.

The dilemma is that American public policy, although based on social movements and general premises of reason and knowledge, has become homogenized and does not truly represent the needs of those who are marginalized, such as the poor and people with disabilities. [45, 46] This “dilemma of difference” [47] is found in traditions that lean heavily on universal imperatives that dictate what society ought to do, resulting in public policy that is “value neutral.” [48] Richard Bringewatt, president and chief executive officer of the National Chronic Care Consortium, describes the challenge this way: “ The focus needs to be shifted from the needs of provider systems that were established in 1965 to the needs of tomorrow. There is no health policy in this country today—only budget policy.” [49] The Consortium for Citizens with Disabilities—a national coalition of organizations working together to advocate for national public policy that ensures the self-determination, independence, participation, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society—is even clearer with its opposition to any Medicaid reform efforts that threaten the services and guarantees currently available under law to people with disabilities. [50] The consortium and many of its members know that the dilemma of juxtaposing budget policy over social policy is that it ignores the human element and, in this case, people with disabilities and the primary purpose of the policy in the first place. Should the costs of providing personal assistance for a working mother who needs help in getting from her bed to her wheelchair every day take precedence over her need to provide for her family and manage her life? The dilemma of difference is that it sets aside an issue such as LTSS as belonging to "the other" and therefore reduces the sense of obligation or responsibility of the majority. This dilemma is also seen in the multitude of research articles reviewed for this report about the financing of LTSS reform. The "beneficiary story"—how changes in funding would affect people with disabilities and their everyday lives over time—is noticeably absent from almost all analyses. Without this information, policymakers and the public are only privy to half the story: the monetary side of the policy and not the human side about the impact of the policy on the lives of millions of Americans with disabilities.

Forecasting a future system of reform requires a look back at the patterns and trends that paved the way to today's philosophy of caring and delivery of services and supports. The American system of health care has two distinct histories. The first, from the 1700s to the early 1900s, was based on a model for caring that was mostly a charity model, delivered by churches and benevolent groups and subsidized by local communities and state governments. [51] Charity care was mostly nonmedical care given to the sick and indigent by volunteers and nurses in the home and the poorhouses. The second history began in the 1900s and is the for-profit health care model we have today, which is highly professionalized and focused more on cure and treatment than on care.

The following two sections will provide a sketch of the evolution of American culture and its impact and implications for navigating the current state of LTSS system reform for people with disabilities with the hope of "dragging anchor" and moving the dialogue for reform forward.

EVOLUTION OF AMERICAN CULTURE AND ITS PHILOSOPHY OF CARING—1800S

The underwriting of human life began in the United States in the 1830s as the first life insurance policy was written, signaling a major shift in American values.

Never before had America found it necessary to insure a person's life in the event of death. Mortality was high in the early 19th century (about 42 years) and the concept of life insurance buffered the frequency of death by providing financial security for young families left behind. In the 1860s, the average marriage lasted 15 years before one partner died. Today, by contrast, it is not uncommon for a married couple to celebrate a 60th wedding anniversary.

In the 1850s, Charles Darwin introduced the theory of evolution that forever changed the Puritan tradition. Scientific discoveries promoted new ways of thinking, such as the germ theory, sparking religious debate. If germs caused disease, what was the role of the Divine? Two thousand years of western thought on immortality and the afterlife were suddenly under attack. As with the evolution in the sciences, philosophy was experiencing similar challenges. Metaphysics and moral philosophy were shunned as knowledge of opinion and not knowledge of fact. A new breed of thinkers, weary of their European experience of superstition, bigotry, religious persecution, and barbarism, emerged with the skepticism of the ancients and the optimism of the newfound sciences. [52] The Enlightenment fathers, as they called themselves, ironically produced many of the same philosophies they had crossed the ocean to leave behind. Immanuel Kant described his age as the "Age of Enlightenment, but not an enlightened age." [53]

The religious and social values of 19th century America began to change dramatically as religious clauses were dropped from wills that for centuries had been the measure of a man's character as well as his financial worth. As this change occurred, the familiar Victorian deathbed scene with its personal attending clerics all but disappeared as the once-public hour of death became private. [54] The tradition of burying the dead from home changed as the local cabinetmaker was asked to open up his parlor and assume the responsibilities for the care and burying of the deceased. By the 1890s, the death-care industry was born. [55]

The first hospitals were primarily of a "religious and charitable nature" and provided care for the sick rather than medical cures. [56] The growth in biomedical science and technology between 1870 and 1920 altered the purpose of the early hospitals and the type of services rendered. A new medical profession of trained professionals emerged and the number of hospitals grew from 178 in 1873 to more than 4,300 in 1909. [57] In the 1840s, a few state mental hospitals were opened and championed by an extraordinary advocate for people with mental illness, Dorothea Dix, who was successful in garnering state support. [58, 59] At this time, mental illness was considered treatable, and "moral treatment" consisted of work, education, and recreation. [60] It was not long before the populations and expenditures grew and the standards of care declined. Institutions became warehouses and one of America's worst legacies. It is important to note that the first institutions were often built in the country and away from mainstream activities. Originally, this was done to create a serene environment. However, similar to the placement of the early cemeteries away from mainstream cities, this created a stigma, that the people in institutions should be hidden and feared. Unfortunately, this stigma prevails to this day about many people with disabilities, even those not in institutions.

Although institutional care was gaining popularity during this time, 80 percent of Americans, whether ill, aged, or dying, were cared for in their homes, in contrast to today, when more than 80 percent die in institutions. [61] The shift from home care to institutional care during the 1800s did mean new jobs with the growth of new industries and the emphasis on professional care. However, charity care survived well into the early part of the 1900s, predominately for health care. Insurance for health care was introduced in 1929, although it did not really take hold until the 1940s, when Blue Cross Insurance was introduced as a method to help pay for the support of hospitals. [62]

EARLY SETTLEMENT AND PAUPER LAWS

In colonial America, the early settlement and pauper laws were adopted to confine the movement of the poor and indigent from one town to neighboring communities, and it was considered illegal for people to move from one town to another without express permission of the town fathers. [63] These laws dated back to the 1500s and were inherited from our European ancestors. [64] Local laws favored towns regarding the wandering poor and people with mental illness or, as they were called then, the “mentally deficient.” It was not uncommon for local overseers of the poor to try to remove people who were “crippled, feeble, and mentally deficient” from the town budgets by marrying them off or removing them from the town under some technicality regarding their inheritance or the town’s settlement laws. It became increasingly difficult to monitor settlement and pauper laws as the population considered “mentally ill and mentally defective” grew.

The problem of housing for the poor and people with disabilities was addressed with the establishment of poorhouses or almshouses, and legislation allowed towns to tax citizens to build, purchase, or hire a house of correction or workhouse in which to confine and set their poor to work. [65] For example, by 1834, in the state of Vermont, the first institution for the “relief of the insane” was initiated with a $10,000 grant from woman in New Hampshire, and the Vermont legislature, in an unprecedented gesture, appropriated $2,000 annually for fives years to help with the costs. The Vermont Asylum of the Insane (known today as the Brattleboro Retreat) was opened in 1836. It was not until 1921, however, that Vermont enacted laws in favor of the “crippled and handicapped,” almost 100 years after it provided funding for a state asylum for mental illness. It was not until 1884 that the state assumed total support for “mentally defective paupers” regardless of residency; by 1891, it had opened the Vermont State Asylum in Waterbury for the “insane.” [66]

20TH CENTURY—FROM CHARITY CARE TO FOR-PROFIT CARE

By the 1950s, a new for-profit system of health care had evolved as a result of advances in sanitation, specialization of medicine, and the further development of medical research, including discoveries such as insulin, antibiotics, and anesthesia. [67] Federal legislation responded to the problems of employment for people with disabilities as early as the 1920s with the passage of the Federal Rehabilitation Act. The growth in the medical sciences, coupled with this legislation, encouraged the development of rehabilitation medicine for people with physical disabilities and influenced the quality of life immensely. In addition, the field of psychiatry grew and new medications for the treatment of people with mental illness advanced and precipitated the long overdue deinstitutionalization movement that began in the 1950s. The need for health insurance grew because of several of the following factors: as a response to poverty and the aftermath of the Great Depression in the 1930s; as a response to a collective bargaining agreement of the Federal Government that limited wage increases to workers but not fringe benefits during World War II; as a response to the passage of the Hill-Burton Act in 1946 that supplied funds to underwrite new hospital construction; and as a response to the passage of Medicare in 1965. [68]

The evolution of care from the home to the almshouse to the state mental hospital to the private nursing home and now back to the home and community has one underlying theme: that is, historically, Americans have provided for the care of their family, loved ones, and the poor with disabilities. Primary resource documents on what the early charity care looked like were beyond the scope of this study. However, it is clear that the care was primarily comfort care with little or no medical oversight, and the first professionals on the scene, as early as the 1830s, were the visiting nurses or, as they are known today, the Visiting Nurse Association. [69] However, the legacy of the state hospital continues today, with

60,000 people remaining in state mental institutions, compared with 559,000 in 1955. [70, 71]

As this brief review demonstrates, a new landscape for democracy emerged during this period in American history. The discovery of electricity; the inventions of the telegraph, photography, and the steam engine; the building of American railroads; and the opening of public schools, coupled with the religious and social revolutions, provided the foundation for Americans to negotiate their future responsibilities and commitments to each other. However, for people with disabilities, there was little negotiating about rights or access to much of this new landscape. From the opening of the first state hospital in the 1840s, it would take over a century before the dialogue about the rights of people with disabilities to live, work, and be educated would begin. America would continue to sort out its human obligations, and accompanying fiscal responsibilities at the federal and state level, in creating a democracy and social contract that included people with disabilities.

Part V

INTRODUCING THE CAPTAIN

An introduction to people with disabilities, the consumer-directors of the long-term services and supports system voyage.

MEET MARY

Table 1.1. Growth in Aging Population

Age	FY 2000	FY 2050
65-74	18 million	35 million
75-85	12 million	26 million
85 +	4 million	28 million

Mary is 42 years old, recently widowed, and living in a small rural town in the South. Mary has cerebral palsy and has been in a wheelchair most of her life. Her husband was her primary caregiver and helped with daily activities such as dressing and cooking, and he dropped her off at work every day. Mary works in a day care center 35 hours a week. She depended on her husband's health insurance but will no longer receive it now that he has died. She owns a home but has little equity and savings of about $10,000. Her husband worked construction and had a small pension plan that provides her with $250 a month. Without her husband's income and health insurance, she may be forced to sell the house. Mary now needs to hire a personal assistant but is unsure how she will pay for the services. She has never received public benefits and does not know what is available. Someone told her she may receive a Social Security Survivor benefit, but she is not sure. Although she has had cerebral palsy since she was very young, she has always been independent. Mary did apply for LTC insurance because she has no family or relatives but was denied at age 40.

PEOPLE USING LONG-TERM SERVICES AND SUPPORTS

Demographers predict that the 34 million Americans 65 years of age and older will double over the next half of the century. The breakdown of that increase is found in table 1.1 and describes the growth of three age groups and includes individuals in institutions. [72, 73] It is estimated that this growth will impose significant pressure on federal and state budgets that fund Medicaid, because as individuals age, the prevalence of disability is expected to rise. [74] Among those 85 years and older, 21 percent were in nursing homes, and another 49 percent were community residents with LTC needs. [75]

OVER AGE 65

It is estimated that between 9 and 12 million people over the age of 18 receive LTSS for everyday self-care needs. [76, 77, 78] Six million people over the age of 65 receive services and supports, with 4.5 million receiving these services and supports in their home and 1.5 million receiving them in a skilled nursing facility. Overall, 60 percent of seniors rely exclusively on unpaid caregivers (spouse and children) and 7 percent rely exclusively on paid services. Research is showing a slight decline in disability in the population over 65 years of age, which is attributed to an overall healthier aging population. [79] Stone predicts, however, that the decline in disability in people 65 and older will be overshadowed by the dramatic increase in the 85-plus population. [85]

UNDER AGE 65

Currently, there are 3.4 million people under age 65 receiving services and supports in their home or community and another 0.16 million in nursing homes and other facilities. [80] Overall, nearly three-quarters of the people living in the community rely exclusively on unpaid caregivers and only 6 percent rely exclusively on paid services. The functional as well as chronic and acute care needs of people under age 65 are growing at a faster rate than for those over age 65, in part because of improved medical technology, increased life expectancy, increase in asthma, higher prevalence of diabetes and obesity, and deterioration in self-reported health statistics. [81]

Table 1.2. Long-Term Services and Supports (LTSS) for Seniors with Disabilities Age 65+

- 6 million seniors need LTSS
- 4.5 million receive LTSS in home and community
- 1.5 million receive LTSS in skilled nursing facility
- 60% rely on unpaid caregivers
- 7% rely on paid LTSS

ENTRANCE REQUIREMENTS

Entrance into the world of LTSS is based on the functional and financial profile of an individual. The functioning capacity of an individual to maintain independence is measured by assessing a person’s need for assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs).

Table 1.3. Long-Term Services and Supports (LTSS) for People Under Age 65 with Disabilities

- 3.4 million < 65 need LTSS
- 3.2 million receive LTSS in home and community
- 0.16 million in nursing homes and intermediate care facilities
- 75% rely exclusively on unpaid caregiving
- 6% rely exclusively on paid services.

ADLs includes bathing, eating, dressing, toileting, mobility, and transferring from a bed to a chair. IADLs are tasks necessary for independent community living and include money management, shopping, light housework, telephoning, cooking, reading, writing, taking medications, and accessing transportation. [82, 83, 84, 85] In addition to the ADLs and IADLs, LTSS include a medical component that provides monitoring and routine help for chronic disease; a rehabilitative component that provides maintenance or stabilization of a lifelong condition; and a supportive component that provides companionship, social support, comfort care, and symptom management for people struggling with chronic disease. [86] LTSS cover chronic illnesses (arthritis, cancer, heart disease, emphysema, Alzheimer's disease, cystic fibrosis); impairments (blindness, hearing loss, paralysis); developmental disabilities (cerebral palsy, genetic or congenital defects, seizure disorders); and injuries (paralysis from head and spinal cord injuries and burns). [87]

Of the 12 million Americans reporting LTC needs using ADLs and IADLs as a benchmark, 57 percent were over the age of 65, 40 percent were under 65 years of age, and 3 percent were children. [88] The prevalence of functional limitations among people under age 65 (N=229 million) was 2 percent for community residents and 0.1 percent for nursing home residents. [89] For people over age 65 (N=34 million), 12 percent were community residents and 5 percent were nursing home residents reporting functional limitations. [90] Functional limitations increase with age, and 21 percent of individuals 85 years old and older were in nursing homes, compared with 5.4 percent between the ages of 75 and 84. [91] Nationally, patients in nursing facilities averaged 3.89 ADL limitations. Virginia reported a high of 4.33 ADL limitations and Illinois a low of 3.32 ADL limitations. [92] The Urban Institute Long-Term Care Chart Book 2001 reports that, of the 51 million children ages 5 through 17 in 1994, less than 1 percent were likely to need some type of long-term assistance. [93]

CHALLENGES OF USING ADLS AND IADLS

Many individuals with a disability may be able to function without performing most IADLs, but they probably could not get through a day without performing most ADLs. In addition to the functional and instrumental ADL measurement, cognitive functioning and dementia are also measured but often difficult to assess. [94, 95] Some individuals with Alzheimer's may have no ADL dependency, but they cannot function independently. [96] The literature reports that there are probably many people with cognitive limitations that go unidentified because of the complexity of measuring various types of cognitive impairments. [97, 98]

UNEMPLOYMENT AND ADLS AND IADLS

Economists are studying why there seems to be a decline in employment since the Americans with Disabilities Act (ADA) was passed in 1990. They report that people who are unable to work are 10 times as likely as the rest of the disability population to need assistance with ADLs, and 5 times as likely to need help with IADLs. [99] In 1980, only 4 percent of wage-earning adults needed help with ADLs, compared with 5.2 percent by 1996. [100] The decline in working capacity and/or the need for increased assistance with ADLs and IADLs is another variable for consideration for demographers predicting the future costs of LTSS needs.

RECIPIENTS OF SUPPLEMENTAL SECURITY INCOME AND SOCIAL SECURITY DISABILITY INSURANCE

The Social Security Administration (SSA) administers two income maintenance programs that provide cash benefits based on disability or blindness: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). These programs pay cash benefits to individuals who are unable to work for a year or more because of a disability. The SSI programs include asset and resource limits as part of their eligibility requirements to receive Social Security maintenance payments. A large percentage of people using LTSS are receiving SSDI and SSI.

SSI maintenance programs provide payments for total disability, not partial or short-term disabilities. The definition of disability under Social Security may be different from other programs. According to a recent GAO report, the definition of disability under both of these programs is the same.

> An individual must have a medically determinable physical or mental impairment that (1) has lasted or is expected to last at least 1 year or to result in death and (2) prevents the individual from engaging in substantial gainful activity (SGA). [101] Moreover, the definition specifies that for a person to be determined to be disabled, the impairment must be of such severity that the person not only is unable to do his or her previous work but, considering his or her age, education, and work experience, is unable to do any other kind of substantial work that exists in the national economy. [102]

For most people, the medical requirements for disability payments are the same under SSI and SSDI, and the same process determines a person’s disability. While eligibility for SSDI is based on prior work under Social Security, SSI disability payments are made on the basis of financial need. It is important to note that eligibility for other government benefits can affect the amount of an individual’s Social Security benefits. Some people have to pay federal income taxes on their Social Security benefits. This usually happens only if their total income is high. For people accessing tax credits for LTSS, the impact of income on the receipt of federal benefits can be troublesome. [103] In general, benefits will continue as long as an individual is considered disabled; cases are reviewed periodically to see if recipients are still disabled.

SOCIAL SECURITY DISABILITY INSURANCE

In 1956, Title II [104] of the Social Security Act established the SSDI program, which authorized a program of federal disability insurance benefits for workers who have contributed to the Social Security Trust Fund and have become disabled (or blind) before retirement age. These contributions are the Federal Insurance Contributions Act (FICA) social security tax paid on their earnings or those of their spouses or parents. Spouses with disabilities and dependent children of fully insured workers (often referred to as the primary beneficiary) also are eligible for disability benefits upon the retirement, disability, or death of the primary beneficiary. [105, 106]

After becoming disabled, individuals have a waiting period of five months before receiving cash benefits. In addition to cash assistance, SSDI beneficiaries receive Medicare coverage after they have received cash benefits for 24 months. Beneficiaries’ SSDI benefits convert to Social Security retirement benefits when beneficiaries reach the currently approved retirement age.

To qualify for Social Security disability benefits, an individual must have worked long enough and recently enough under Social Security. Individuals may earn up to a maximum of four work credits per year. The amount of earnings required for a credit increases each year as general wage levels rise. Family members who qualify for benefits on an individual’s work record do not need work credits.

The number of work credits needed for disability benefits depends on an individual’s age when he or she becomes disabled. Generally one needs 40 credits, 20 of which were earned in the last 10 years, ending with the year one becomes disabled. Younger workers may qualify with fewer credits.

SSDI RECIPIENTS

According to the 2004 Catalog of Federal Domestic Assistance (CFDA), [107] it is estimated that for FY 2004 an average of 7,664,000 disabled workers and their dependents will receive monthly cash benefits. During FY 2005, the number receiving benefits is expected to increase to 7,996,000. Researchers report a 67 percent rise in the SSDI rolls during the 1990s. In 2000, the program provided cash and medical benefits to 5 million working-age (18–64) adults with impairments, one-fifth to individuals who also receive SSI cash benefits, and Medicare after a 24-month waiting period. [108] Early findings attribute the growth in this population to a correlation between relaxed eligibility criteria in the 1980s and an increase in program generosity for low-wage workers. [109] It is also reported that the SSI rolls have increased over this same time period. It is unclear how these trends will affect the LTSS system's sustainability, but it is clear that a rise in these populations, in addition to the convergence of the baby boomers and a rise in the 85-plus population, will require serious actuarial evaluation.

SUPPLEMENTAL SECURITY INCOME PROGRAM

In 1974, Title XVI [110] of the Social Security Act established the SSI program, a federally administered cash assistance program for individuals who are older, blind, or disabled and meet a financial needs test (income and resource limitations). [111, 112]

The SSI program operates in the 50 states, the District of Columbia, and the Northern Mariana Islands. The program also covers blind or disabled children of military parents stationed abroad and certain students studying outside the United States for a period of not more than one year. The Federal Government funds SSI from general tax revenues. The basic SSI amount is the same nationwide. However, many states add money to the basic benefit. Some states pay benefits to some individuals to supplement their federal benefits. Some of these states have arranged with SSA to combine their supplementary payment with the federal payment into one monthly check. Other states manage their own programs and make their payments separately.

Unlike the SSDI program, SSI has no prior work requirements and no waiting period for cash or medical benefits. Eligible SSI applicants generally begin receiving cash benefits immediately upon entitlement and, in most cases, receipt of cash benefits makes them eligible for Medicaid benefits. [113]

SSI RECIPIENTS

According to the 2004 CFDA, [114] in FY 2003, an average of 6,553,000 people per month were federal SSI recipients. It is estimated that in FY 2004, an average of 6,711,000 recipients received monthly cash benefits. During FY 2005, the average number receiving payments is estimated to be 6,867,000 per month. These totals and estimates do not include people who receive only state supplementary payments, some of which are administered by the SSA for the states as part of the SSI program.

SOCIAL SECURITY REFORM

There are currently 3.3 workers for each Social Security beneficiary; however, by 2031, it is estimated that there will only be 2.2 workers for each beneficiary. [115] The future financial stability of the Social Security benefits program is a major challenge for future policymaking regarding the design of the LTSS system.

The current political focus on a partial privatization of Social Security for younger workers raises important questions that require research demonstrating the impact of reform on the various populations currently receiving benefits. How would reform preserve current resources supporting the most vulnerable beneficiaries who cannot contribute to the system? How would reform impact the stability of the SSI and SSDI programs? Would recipients be dependent on market fluctuations or would privatization not affect the SSI and SSDI programs? [116] The sections below will describe the maze of beneficiaries needing LTSS and the challenges inherent in communicating this information accurately and compellingly to the policymakers.

CHRONIC ILLNESS AND THE NEED FOR LONG-TERM SERVICES AND SUPPORTS

People with chronic illnesses are also in need of LTSS reform. About 57 million working-age Americans live with chronic conditions such as diabetes, asthma, or depression and, in 2003, one out five people (or 2.3 million) had trouble paying medical bills. [117] Of the 35 million people on the original Medicare plan (5 million are on Medicare+Choice), 87 percent have one or more chronic conditions, 65 percent have multiple chronic conditions, and one-third have one or more chronic conditions that are considered serious. [118] Chronic illness is defined as an “illness, functional limitation, or cognitive impairment that lasts (or is expected to last) at least one year; limits what a person can do, and requires ongoing care.” [119]

The National Academy of Social Insurance found that Medicare coverage for chronic illness is lacking in its coverage for a variety of functional and maintenance rehabilitative services, including coverage for durable medical equipment supports that usually are only covered if used primarily in the home. [120] In addition, beneficiaries reported that it is often difficult to find physicians who can address functional and cognitive issues and that more education about self-management supports, evidenced-based protocols, health assessments, and telephone follow-up calls is needed. [121]

Chronic impairment is measured by the number of ADLs and IADLs a person needs, whereas eligibility for SSI and SSDI for people under age 65 is based on the ability or lack of ability to work on specific jobs. Menton reported that, “the major social security reasons for disability entitlement younger than age 65 are not obesity and asthma but (in 2000) job impairments caused by chronic psychiatric problems (27.4%), muscoskeletal problems (28.7%), and heart disease (10.8%). [122]

DUAL ELIGIBILITY—RECIPIENTS OF BOTH MEDICAID AND MEDICARE

Also requiring LTSS are the 7 million “dual eligibles” who qualify for both Medicare and Medicaid services. [123] Sixteen percent of Medicare beneficiaries are dually eligible, and 4.9 million are older than 65 years of age and represent 30 percent of the spending for the Medicare population. Thirteen percent are under the age of 65 with a disability. Seventeen percent of the Medicaid population is dually eligible and, in FY 2000, represented 43 percent of the total Medicaid service spending of $168.1 billion. [124] The largest category of Medicaid spending for dual eligibles includes LTC, including nursing facilities, home- and community-based services (HCBS), institutions for individuals with metal retardation, and other LTC services. [125] Medicare spending for dual eligibles is limited to primary and acute care services. The dually eligible population is the most fragile of all the groups discussed in this section; they are disproportionately poor, over age 85, nonwhite, female, and unmarried, with multiple functional and cognitive impairments, and represent almost half of all Medicare beneficiaries with Alzheimer’s disease. [126]

MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES POPULATION

In 2002, there was an estimated population of 4,556,966 people with mental retardation and developmental disabilities (MR/DD). Sixty-one percent of this population lives with a family caregiver, 15 percent with a spouse, 14 percent in their own household, and 10 percent in supervised residential settings. [127] Total public spending for MR/DD services in the United States in 2002 was $34.64 billion. There is an array of LTSS, including the following: family support services for people with MR/DD, such as programs and resources to support cash subsidy payments, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support programs, education, and behavior management services; and supported employment, supported living, and personal assistance designed to increase individual choice and control over service delivery. [128]

ONE SIZE DOES NOT FIT ALL

Most people do not understand the dollar cost associated with living with a disability. The "costs of entry" for working, learning, living, and fully participating in life are higher than the comparable unit costs for people without disabilities. [129] Research has examined the economic costs of mental retardation, cerebral palsy, hearing loss, and vision impairment and found that "productivity losses make up the largest fraction of overall costs, accounting for 72 to 83 percent of costs, and direct medical and non-medical costs account for the rest." [130]

According to Stephen Mendelsohn, people working with a mobility impairment, blindness, or deafness have tremendous add-on costs for transportation and assistive and communication technology. [131] Whether they need an accessible vehicle with a lift or one fitted with adaptive driving controls, materials in Braille or synthetic speech or large-print output to access a computer, or a TTY for communicating over the voice telephone, the associated costs are higher than for people without disabilities. [132]

In the area of services, a "sign-language interpreter, the reader, the attendant service provider, the computer trainer with specialized knowledge of the interface between complex networked systems and access technology must be found and paid for." [133] Many health policymakers may not be familiar with the nonmedical supports and services that are unique to people with disabilities and the add-on costs that are incurred to live normal lives.

Researchers found that access and experience with various services for adults in community settings does vary depending on the type of disability, age, and gender for people age 18 to 35 versus those age 36 and older. [134] In a controlled study between people with one or more substantial functional limitations who do not meet the criteria of having a developmental disability and people with developmental disabilities, those with developmental disabilities had poorer outcomes and were more likely to "receive, need or be waiting for supports or services." [135] The study also found age differences between the two groups when divided according to age, with those age 36 and older having "more needs for assistance with specific skills, and more trouble getting around outside of their homes, and having received more services and supports related to health care needs." [136]

Younger adults with disabilities were more likely to need or participate in employment programs, social skills and communication supports, mental health services, and generic transportation options that the older adults. [137] This study also looked at gender and important differences were noted. Women were more likely to need assistance with IADLs and tended to have more needs for LTC and assistance, transportation, and health care. Men with disabilities were more likely to be in the workforce and have independent travel options. This study illustrates the importance of understating the subpopulations of people under age 65 and the variation in their needs according to a number of variables, such as age, gender, and category of disability. It is clear that "one size does not fit all" in providing services and supports to people with disabilities.

A Kaiser Family Survey found that 66 percent of people with a disability who were uninsured postponed care and 60 percent skipped doses of needed medication and that this was common behavior for people under 65 years of age. For people receiving both Medicaid and Medicare, 38 percent postponed care and 32 percent skipped doses of needed medication. For people with a disability on Medicare only, 60 percent postponed care and 58 percent skipped doses of needed medication. [138]

It is clear that the target audience for LTSS is not homogeneous and varies in age, gender, ethnicity, and category of disability and use of federal programs. Reform efforts need to develop clarity and consensus about how to define future services and supports considering the changing demographics, different eligibility criteria, rising need, and political urgency.

BACK TO MARY

The current system of LTC has little room to accommodate a circumstance like Mary's. She can either keep working and try to live on the $1,100 plus $250 a month she gets and pay for a personal assistant and try to keep her house, or she could seek to be determined disabled under SSDI's rules. To support her case, she would have to reduce her work hours so that her income would be less than $810 a month. If she applied for SSDI, she would have to wait two years for Medicare. If she is determined disabled by SSDI, she may qualify for a home- and community-based waiver (if there is one in her state and there isn't a waiting list) under Medicaid and for Medicaid coverage if her income is at or below 300 percent of SSI (this applies in most states). If Mary applied for SSI, she would have to divest herself of all assets except for $2,000 and, if she were found eligible, she would receive Medicaid immediately.

Right now, her only access to either Medicare or Medicaid is to meet disability requirements set by SSI/SSDI. And eligibility for those programs doesn't necessarily mean she will be able to get a personal assistant, but they at least open up the possibility of getting one and having health insurance. Mary may have no choice but to quit her job and apply for SSI or SSDI.

Part VI

MEETING THE CREW

An introduction to the navigators of the long-term care ship and their role as providers and consumers of services and supports.

CAREGIVER CREW

Half of all Americans in their 50s will need LTSS in their lifetime and, by 2010, 50 percent of the workforce (people in their 40s and 50s) will be involved in caring for an older parent or family member with a disability. [139] This responsibility is already costing employers an estimated $1,000 to $2,500 per employee in reduced productivity, lost work time, time off, and stress-related absences. [140] A MetLife analysis estimated aggregated costs of caregiving employees to employers nationwide ranged between $11.4 billion per year and $29 billion per year. [141] Stone reports that 50 percent of people with disabilities and older Americans who lack a family member network live in nursing homes, compared with 7 percent of the same population with families. [142] It is estimated that Americans provide 120 million hours of unpaid care to elders with functional disabilities living in community settings. [143] Sixty-seven percent of elders rely solely on unpaid help; 86 percent of elders with the greatest risk of nursing home placement (three plus ADLs) live with family members and receive about 60 hours of family care per week, supplemented by 14 hours of paid assistance. [144] Women give 75 percent of the caregiving; 31 percent are in the labor force; 66.6 percent work full time, and they provide 18 hours of care a week and are, on average, 60 years old. Two-thirds of the women with paying jobs report conflict between their jobs and caregiving. [145]

Lechner, [146] in one of the few studies examining racial and ethnic differences among African-American working caregivers, found less support from supervisors and less flexible policies regarding family concerns than experienced by white caregivers. Neal and Wagner [147] reported a slightly higher prevalence of caregiving among African-Americans and Hispanic families compared with Caucasian families.

Demographers predict that more women will have less time to provide the traditional caregiving as workplace pressures continue to grow. Many employee benefit programs include education about elder care, but they need updating and expansion to include the multigenerational aspects of providing more comprehensive life care for employees with caregiving responsibilities for individuals with disabilities.

Also, on the LTSS ship is the workforce that provides care in the nursing homes, intermediate care facilities for the mentally retarded (ICF/MRs), group homes, supported living, individual homes and apartments, and assisted living arrangements throughout the country. In the next 10 years, 5.3 million health care workers will be needed—3.1 million to fill new jobs and 2.2 million to replace people who have left the workforce. [148]

In FY 2002, family members provided “informal” residential care to 2.79 million of the 4.56 million people with developmental disabilities in the United States, representing six times the number of people served by the formal out-of-home residential care system (460,455).

Formal and informal caregiving, paid and unpaid, are essential elements of the current system of LTSS for individuals with disabilities across the age span. Caregivers provide a range of activities with the time expended, ranging from a few hours per week to more than 40 hours per week. The demand on the caregiver will vary by individual situation and relationships. [149] The value of people who care for adult family members or friends and were not paid has been estimated between $200 billion and $257 billion annually. [150] In results of a new study released by the National Alliance for Caregivers, an estimated 44.4 million American caregivers (21% of the adult population) age 18 or older are providing unpaid care to an adult age 18 or older. [151] It further estimates that 22.9 million households are affected by the presence of an unpaid caregiver—that represents 21 percent of all U.S. households. [152] In defining the relationship between caregiver and care recipient, 83 percent were identified as related by family or marriage. [153]

Several key distinctions emerged from looking at caregivers for individuals 50 and older and caregivers for individuals 18 to 49 years old.

- Caregivers who help someone 50 or older tend to be older than caregivers who help someone between the ages of 18 and 49 (mean age 47 years versus 41 years). The average (mean) age of a younger care recipient (18–49) is 33 years and the average (mean) age of a care recipient age 50 or older is 75 years.
- Two in three (66%) of caregivers who help someone between the ages of 18 and 49 years are employed full or part time, compared with 57 percent of caregivers who help someone age 50 or older.
- Caregivers who help someone 50 or older tend to be better educated and earn higher incomes than those helping recipients between 18 and 49. For example, 37 percent of those caring for people 50 and older have a college degree, compared with 26 percent of those helping 18- to 49-year-old recipients; and 44 percent helping the older set make $50,000 or more, whereas only 35 percent of caregivers helping those 18 to 49 do so.
- While caregivers who care for someone 50 or older tend to be helping their mothers (34%), grandmothers (11%), or fathers (10%), those helping someone 18 to 49 are much more likely to be caring for an adult child (27%), a sibling (15%), or a nonrelative (25%).
- Caregivers of younger care recipients (18 to 49) most commonly report mental illness or depression as the biggest problem or illness for the person they care for (23%). On the other hand, caregivers of older care recipients (50 and older) most commonly report the main problem or illness as aging (15%), cancer (9%), diabetes (9%), Alzheimer’s (8%), and heart disease (9%).
- Caregivers of younger care recipients (18 to 49) are more likely to report being primary caregivers (70%) than caregivers of older care recipients 50 and older (54%), and tend to be living with the recipient (33%) more often than caregivers helping recipients 50 and older (22%). In fact, only 38 percent of those helping 18- to 49-year-old recipients report the presence of some other type of unpaid help, whereas 65 percent of those helping recipients 50 and older have done so.
- One in three (33%) caregivers of younger care recipients (18 to 49) report assisting the person they care for with at least one ADL, whereas more than half (55%) of caregivers helping older recipients do so. Instead, caregivers of people 18 to 49 are more likely performing IADLs, especially helping manage finances (79%) and transportation (77%).

- While nearly half (46%) of caregivers helping someone 50 or older not in a nursing home receive some type of paid help, only 23 percent of those caring for 18- to 49-year-old recipients have done so.
- Caregivers who help younger care recipients provide an average of $205 per month financial support. Caregivers who help older care recipients provide an average of $197 per month. Caregivers of younger care recipients are more likely to report financial hardship (25% rate 4 or 5 on a 5-point scale) than caregivers of older care recipients (9%) and to report having requested information about how to get financial help for the recipient (35% versus 22%). [154]

Appendixes 1.A and 1.B highlight some further distinctions between caregivers for younger versus older adults with disabilities.

Regardless of the age of the caregiver and the age of the recipient of assistance, 67 percent of caregivers reported needing assistance with one or more of the following challenges: finding time for myself (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%). [155] Almost half the caregivers reported spending more than 8 hours per week helping the relative or friend for whom they provide assistance and almost one in five report providing 40 or more hours of assistance. [156]

Services provided weekly as a caregiver, in priority order or frequency, include transportation, shopping, housework, managing finances, preparing meals, arranging services, dressing, bathing, toileting, and feeding. [157] These findings reaffirm conclusions by other studies conducted by the Federal Government and private researchers during the past 10 years:

- Family caregivers provide approximately 80 percent of all LTSS for family members and friends across the life span. [158]
- Out-of-pocket medical expenses for a family with a family member with a disability or chronic condition who needs help with ADLs are more than 2.5 times greater than for a family without a member with a disability (11.2% of income compared with 4.1%). [159]
- Over the period of caregiving, family members providing intense personal care can lose as much as $659,000 in wages, pensions, and Social Security. [160]
- Respite care, one of the most frequently requested family support service, has been shown to help sustain family stability, avoid out-of-home

placements, and reduce the likelihood of abuse and neglect. However, respite care remains in short supply for all age groups. [161]

- An assessment of family caregiver strengths, needs, and preferences constitutes the foundation for developing appropriate and quality LTSS. [162, 163]

As a key human resource to navigate the ship in the future, family caregiving is an essential part of the system of LTSS. However, from a philosophical and financial perspective, there is little agreement on how best to divide responsibility between the public and private sectors, between families and government.

As a starting point, the National Alliance for Caregiving sets out several defining principles to develop an appropriate balancing of interests:

> Public policy must not assume that family members can always provide assistance for a frail elder or person with disabilities. Public policy also must not assume that the availability of family members or others to provide uncompensated assistance is the criterion to be used to allocate long-term support resources. An assessment of family caregiver strengths and needs must be a part of a more comprehensive assessment of need for the individual and family. [164]

WORKFORCE CHALLENGES

Between 2002 and 2012, the Bureau of Labor Statistics projects employment growth in demand nationally for direct care workers at more than double (33.8%) the projected growth in overall employment nationally (14.8%). [165] Based on a 2003 survey of state Medicaid agencies, 35 states continue to consider workforce issues in the delivery of long-term services a serious issue. [166] The shortage of qualified, reliable direct care/support workers has a direct impact on the health and safety of individuals with disabilities in need of assistance with ADLs. But it also has a direct impact on the health and well-being of family caregivers who must take on added responsibilities, much of which require training and support they do not have. [167]

Unfortunately, workforce challenges are expected to get worse as the baby boom generation ages and places more demands on the LTSS system. [168]

At the national level, two major initiatives, one public and one privately funded, have started to respond to challenges of workforce recruitment and retention. In 2003, the U.S. Department of Health and Human Services (HHS) awarded demonstration projects to five states to pilot and evaluate a range of activities, including making health insurance coverage available to direct care workers and creating training and mentoring programs to improve worker skills. [169] At the end of 2003, the Robert Wood Johnson Foundation funded coalitions in an additional five states to implement policy and practice changes to improve the ability to attract and retain high-quality direct care workers in home and community settings. [170]

At a state level, a recent trend in public policy is to tie outcomes related to certain quality measures to increased reimbursement for long-term service providers. The ability to tie outcomes effectively to reimbursement will depend on states' development of the necessary data and evaluation systems to collect and analyze required data to verify that the intended outcomes have been achieved. [171]

For the past three years, challenges with budget shortfalls at the state level have resulted in reductions, termination, or delays in a number of direct care workforce initiatives to improve wages and benefits as well as education and training programs. [172] It is premature to evaluate findings from either the national or state initiatives described. In a paper prepared for the American Association of Homes and Services for the Aging and HHS, which described approaches to be considered in modeling the future supply and demand for LTC workers, Holzer points out that economists generally believe that market forces tend to eliminate shortages in the labor market over time. If wages and benefits are free to adjust, worker shortages should lead to higher compensation levels in a given market, which should then add to the supply of labor in that field and result in easing the shortage. [173] However, typical free market forces are constrained by the dominance of Medicare and Medicaid as the majority funders of LTSS. Both public financing systems will continue to be pressured to reduce costs based on their rate of growth, growing demand for services, and the larger picture of budget deficits at the federal and state level.

FEDERAL DECISION-MAKING CREW

Paid and unpaid caregivers are most affected by the federal decision-making crew. Authority for decision making in the executive and legislative branches of the Federal Government is dispersed among many key stakeholders with a complicated chain of command.

The critical question of who will lead future policy development requires an analysis of who is authorized at a federal level with decision-making authority. Such an analysis reveals that there is no single federal agency charged with the development of a comprehensive and coordinated system of LTSS. The evolution of public policy regarding LTSS does not rest with a single congressional committee in the House or Senate. The navigators for the ship at the federal level in the executive and legislative branches of government face a daunting challenge to pull the pieces together across entitlements and discretionary authority and multiple jurisdictions. The tables in Appendix 1.G divide current programs and services that are relevant to the discussion of future policy development into nine major areas of life domains: federal health care, social and in-home supports, income maintenance, housing, transportation, nutrition, technology, civil rights, and caregiver support. The lines of authority and oversight in the Senate are not the same as those in the House of Representatives. There are five full committees in the Senate with distinct authorization and oversight responsibilities for specific programs, services, and benefits. In addition, there is a separate budget and appropriations process with additional full committees with specific responsibilities on the House and Senate sides. Within the executive branch of government, there are a dozen agencies within six departments charged with responsibility for the implementation of the identified specific programs, services, and benefits.

Executive Order 13217, issued by President George W. Bush in 2001, directs all the relevant federal agencies to evaluate their policies, programs, and regulations to determine whether any changes are needed to improve the availability of community-based services for individuals with disabilities. There have been two published reports on federal agency actions to date. [174]

Under a new initiative of the Office of Management and Budget, a Program Assessment Rating Tool (PART) has been created to evaluate whether federal programs are effective and well managed across all federal agencies. [175] A shortcoming of PART, identified in the recent report of the President's Committee for People with Intellectual Disabilities (PCPID), is that PART "does not conduct an assessment across agencies and programs." [176] A specific program may score well as currently configured and yet not be effectively collaborating with other federal programs and agencies or organizations outside the Federal Government. [177] PCPID calls for an "enriched PART to create a new culture of measurement and accountability that raises expectations for policymakers, service providers, parents, and individuals with disabilities" and guides government to respond more efficiently and effectively to the demands of the target population for improved personal and economic freedom. [178]

The crew reflect the complex set of relationships among formal and informal caregivers and multiple decision makers with specific designated roles and responsibilities spread through the executive and legislative branches of the Federal Government. Competing interests seek to protect and preserve their share of federal expenditures as demand continues to grow for affordable health care as well as LTSS for a changing American population.

STATE CREWS

The states are the engines that drive the delivery and financing of health care and LTSS in this country. Their fiscal health determines how much flexibility and innovation they have to fuel their health care system. Most states want to create a more balanced delivery system of LTSS to meet the rising demands of their aging populations with and without disabilities and have used the federal-state Medicaid home- and community-based waivers for this purpose. Wiener reports that two important outcomes of the waiver demonstrations have been the consumer-directed home care movement and the use of nonmedical residential settings, such as assisted living and adult family homes. [179]

A number of states (18 in 2003) offer a tax deduction or credit to their residents who purchase LTC insurance. However, only 10 percent of Americans currently have LTC insurance, and a 2002 survey found that substantial increases in premiums and rate stability continue to challenge further expansion and marketing to middle- and lower-income Americans. [180] A few states have developed public-private partnerships for people who have purchased LTC insurance and still need assistance after exhausting their coverage and savings options to come under the state's Medicaid coverage. Participation in the federal Medicaid LTC insurance partnership program is considered low. [181] Early results suggest that of the 181,600 policies approved since 1993, 88 people (0.5 percent) received Medicaid coverage for their LTC needs and a total of $2.8 million in assets are protected for people in California, Connecticut, and Indiana. Over half of the purchasers, in a survey of California and Connecticut, had assets of greater than $350,000; in Indiana, 60 percent of purchasers had assets greater than $350,000. Contrast this with 20 percent of purchasers in California and Connecticut who have assets of less than $100,000 (excluding the home). It is clear that this opportunity has traction for people with substantial assets. But there is concern that a federal-state policy such as Medicaid designed to provide health coverage to low-income mothers and children should help nonpoor Americans protect their assets.

The National Conference of State Legislatures (NCSL) reports that Medicaid accounts for 20 percent of all state spending, and the largest single source of public funding for LTSS grew by more than 13 percent between FY 2001 and FY 2002, [182] with the National Governors Association (NGA) reporting a 9.3

percent growth in FY 2003. [183] The report found that states cut, froze, or provided only small increases for nursing home reimbursement rates, and froze new admissions to home care programs.

The NGA reports that the cost of LTC is rising and that, by 2030, institutional health care is expected to cost $200,000 a year compared with $57,000 in 2004 for a semi-private room. Average home health care costs today are $20,000 a year; by 2030, they are projected to rise to $75,000. [184]

In light of state budget gaps totaling $78 billion for state FY 2004, the Center on Budget and Policy Priority reported that Medicaid, State Children's Health Insurance Program (SCHIP), and other health care enrollment reductions would affect an estimated 1.2 to 1.6 million low-income people, half of whom are children and half of whom are parents, seniors, people with disabilities, childless adults, and immigrants. [185] Thirty-four states report adopting such cuts.

However, NCSL reports that states, despite their troubled economies, declining tax revenues, and expanding Medicaid costs, are making progress on LTC. [186] Many states report implementing pilot programs and, with the help of federal systems, change grants have made some progress at restructuring LTC and have begun to craft improved access to LTSS. [187]

Part VII

FUELING THE ENGINE

> An examination of the key federal programs (entitlements and other discretional funding sources that are means and nonmeans tested) that provide the fuel for the current system of long-term services and supports.

Even the most seasoned professional may be surprised to learn the number of federal programs that make up the constellation of LTSS, their budgetary priorities, and their rules and regulations. At the federal and state levels, there are many networks that provide and fund an array of services and supports for people with mild to severe disabilities, with mild to severe chronic illness, and who are young and old, male or female, rich and poor, and ethnically diverse.

Currently, the LTSS system is fragmented in its approach to service provision and oversight, budgetary priorities, and, most important, issues related to quality of life from the perspective of the individual requiring services and support. Since older adults and individuals with disabilities receive services through separate networks, it is critical to understand not only the demographics but also what consumers of LTSS need in order to have a reasonable quality of life. This section of the report provides a clear picture of the current federal experience in providing these services to individuals who require support.

The working definition of LTSS introduced earlier in this report includes a variety of services and supports essential to maintain quality of life with maximum dignity and independence for individuals who are elderly (age 65 and older) and individuals with disabilities. Services and supports include housing, transportation, nutrition, technology, personal assistance, and other social supports to maintain independent living.

The federal legislative and regulatory involvement includes Medicaid, Medicare, Medicaid Home- and Community-Based Waivers, the Department of

Housing and Urban Development (HUD) generic and elderly- and disability-specific programs that underwrite housing and supportive services, independent living services under the Rehabilitation Act, programs funded under the Older Americans Act, nutrition programs, and transportation programs relevant to either or both populations, as well as the Community Services Block Grant and other social services programs administered by HHS and relevant to the target population.

> The growth rate on Medicaid is rapidly reaching its breaking point. While the federal fiscal relief package that ended in June was a welcome reprieve for states, it was only a temporary band-aid for a much more serious ailment.
>
> ***Ray Scheppach***
> ***NGA Executive Director 2005***

Each of the identified federal programs attempts to address quality-of-life domains. Quality-of-life domains are defined in terms of what a person requires to live life in a holistic manner and thus should be viewed as integrative in nature. In developing the quality-of-life domains, the research team considered what a person requiring assistance with daily activities would need to remain independent and maintain the ability to live in the least restrictive environment. These quality-of-life domains include the following:

- health care;
- social support, personal assistance, and home care;
- housing;
- transportation;
- nutrition;
- technology; and
- caregiver support.

The tables in Appendix 1.F provide an overview of specific federal programs authorized in each of the seven defined quality-of-life domains. For each program, information is provided on the legislative authority, the responsible administrating agency, the targeted eligibility group, and the scope of services that may be provided. In addition, each program authority has been reviewed to identify (1) the extent of consumer direction and control of service delivery and (2) the direct consumer involvement in quality oversight, the approach to federal-state partnerships, the promotion of systems change activities, funding patterns over a three-year period, and any shift toward universal design to meet the needs of individuals with disabilities across a wide age span.

The review and analysis of 23 programs across the seven quality-of-life domains reveals a patchwork approach that began in 1965 with the establishment of the Medicaid and Medicare programs. Over the past 40 years, LTSS policy was added on as optional services to Medicaid policy. States began to allow services and supports funded through Medicaid to be provided in the home and community to eligible individuals. [188]

Unlike the majority of programs profiled and analyzed in the other quality-of-life domains, an entitlement program guarantees eligible individuals a specified level of benefits. Congress must appropriate funds sufficient to cover the costs associated with entitlement benefits and services. The other profiled programs must survive the annual appropriations process and the struggle for limited dollars available for all domestic spending.

MEDICAID AND MEDICARE

Medicaid Program

Medicaid represents a federally supported, state-administered, means-tested entitlement program that is financed by the state and Federal Government and is the nation’s major public financing program for providing health and long-term coverage to low-income people. [189] Medicaid LTC services are generally offered through the Medicaid state plan and/or an HCBS waiver. The Medicaid state plan is the document that states submit to the Federal Government for approval that describes the eligibility groups and covered services. State plan services must be available statewide to all Medicaid enrollees who qualify for the service. Within federal guidelines, states set their own income and asset eligibility criteria for Medicaid. Federal assistance is provided to states for coverage of specific groups of people and benefits through federal matching payments based on the state’s per capita income. [190, 191, 192]

Within broad national guidelines established by federal statutes, regulations, and policies, each state:

- establishes its own eligibility standards;
- determines the type, amount, duration, and scope of services;
- sets the rate of payment for services; and
- administers its own program. [193]

While states generally have discretion in determining which groups their Medicaid programs will cover, including the financial criteria for eligibility, to be eligible for federal funds, states are required to provide Medicaid coverage for certain individuals to include the following:

- low-income people who are over age 65;
- blind or disabled;
- members of families with dependent children;
- low-income children and pregnant women;
- recipients of SSI in most states;
- certain Medicare beneficiaries; and
- in many states, medically needy individuals. [194]

As with the eligibility criteria, states have considerable flexibility within their plans; however, there are mandatory requirements if federal matching funds are to be received. A state's Medicaid program must offer medical assistance for certain basic services to most categorically needy populations such as "home health care for persons eligible for skilled nursing services." [195] States may also use federal matching funds to provide optional services to include the following:

- Diagnostic services
- Clinic services
- ICF/MRs
- Prescribed drugs and prosthetic devices
- Optometrist services and eyeglasses
- Nursing facility services for children under age 21
- Personal care
- Transportation services
- Rehabilitation and physical therapy services
- HCBS [196]

While Section 1902(a) (23) of the Social Security Act establishes the right of Medicaid beneficiaries to choose their own provider, [197] consumer direction beyond this provision varies considerably.

Medicaid LTC expenditures in FY 2002 equaled $82.1 billion, approximately 34 percent of total Medicaid expenditures, which equaled $243.5 billion for 39 million enrollees. Medicaid LTC expenditures in FY 2003 equaled $83.8 billion, approximately 32 percent of total Medicaid expenditures, which equaled $259.6 billion for approximately 41.9 million enrollees. Financial assistance to states ranged from $2.4 million to $28.2 billion with an average of $3.3 billion. [198, 199]

Medicaid Home- and Community-Based Services Waiver Program

In addition to the Medicaid state plan, states have the option, upon federal approval, to provide HCBS for Medicaid-eligible people who might otherwise be institutionalized. HCBS may be offered as a supplement to, or instead of, optional services available through the state plan. Section 1915(c), which authorizes HCBS waivers, was added to Title XIX of the Social Security Act by P.L. 97-35, the Omnibus Budget Reconciliation Act of 1981, to encourage the provision of cost-effective services to Medicaid recipients in noninstitutional settings. Before P.L. 97-35, the Medicaid program provided little coverage for LTC services in a noninstitutional setting, but offered full or partial coverage for such care in an institution. In an effort to address these concerns, Section 2176 of P.L. 97-35 was enacted, adding Section 1915(c) to the Act. [200, 201]

The HCBS waiver program affords states the flexibility to develop and implement creative alternatives to institutionalizing Medicaid-eligible individuals. The program recognizes that many individuals at risk of institutionalization can be cared for in their homes and communities, preserving their independence and ties to family and friends, at a cost no higher than that of institutional care.

Two primary criteria determine eligibility for 1915(c) waiver programs: financial eligibility for Medicaid and functional eligibility for the services provided, which is generally tied to eligibility for institutional care. Recipients of waiver services must meet both criteria. [202]

Before the creation of the HCBS waiver program, financial eligibility requirements for Medicaid were less stringent for institutional services than for home-based services, which made it easier for people to enter institutions than to receive care in the home. The waiver program helped to correct this institutional bias by allowing states to set financial eligibility limits for income that were as much as 300 percent of the federal SSI benefits, generally the same level used for a nursing facility. The functional eligibility criteria for waiver services vary widely from state to state and vary by waiver target population within a given state. Currently, there are 285 waivers nationwide serving 900,000 individuals with disabilities. The service mix includes case management, personal care, environmental adaptations, habilitation, transportation, assisted living services, and respite care. [203]

Forty-nine states now have HCBS programs under §1915(c) of the Social Security Act, the HCBS waiver program. (Arizona offers its HCBS program under a §1115 waiver.) These and other programs allow states to target specific population groups and limit the number of participants to control costs. Individuals with developmental disabilities or mental retardation constitute 38 percent of waiver program participants and 75 percent of expenditures. The elderly and people with physical disabilities account for 62 percent of participants and 25 percent of program expenditures. [204]

Table 1.4. Medicaid HCBS Waivers by Population [205]

Population	Number of States
Elderly/people with disabilities	49
Mental retardation/developmental disabilities	46
Technology-dependent children	17
HIV/AIDS	17
Brain injury	15
Mental illness	3

Medicare Programs (Part A and Part B)

Medicare provides the foundation for our nation’s financing of health care for older Americans. Authorized by Congress in 1965 as Title XVIII of the Social Security Act, Medicare is a federal health insurance program for eligible elderly people or eligible people with disabilities. [206] Known in 1965 as Health Insurance for the Aged and Disabled, Medicare generally covers individuals age 65 and over to complement the retirement, survivors, and disability insurance benefits under Title II of the Social Security Act. [207]

Traditionally, Medicare has consisted of Part A, Hospital Insurance (HI), which reimburses hospitals and other covered entities of the program, and Part B, Supplementary Medical Insurance, which provides supplemental medical insurance benefits. The Balanced Budget Act (BBA) of 1997 (P.L. 105-33) established Part C, the Medicare+Choice program, which expanded beneficiaries' options for participation in private sector health care plans. [208] Since 2004, the Supplementary Medical Insurance component has included Medicare Part B and Part D. Part B pays for physician, outpatient hospital, home health, and other services for the aged and disabled; and Part D will initially provide access to prescription drug discount cards and transitional assistance to low-income beneficiaries. In 2006 and later, Part D will provide subsidized access to drug insurance coverage on a voluntary basis for all beneficiaries and premium and cost-sharing subsidies for low-income enrollees. [209]

Medicare Part A—Hospital Insurance Component

Individuals eligible for Medicare Part A include people who are age 65 or over and eligible for Social Security or Railroad retirement benefits; people who have been eligible for Social Security or railroad retirement disability benefits for at least 24 months; and/or workers who are insured and have end-stage renal disease (ESRD), as well as their spouses and children.

The Medicare HI component covers the following services:

- inpatient hospital care—initial deductible required if admitted, in addition to copayments for stays beyond 60 days;
- skilled nursing care—if the care follows within 30 days of a hospital stay of 3 days or more and is considered medically necessary, limited to 100 days;
- home health agency—covers the first 100 visits only after a 3-day hospital stay or a skilled nursing facility stay. There is no copayment or deductible for home health under Part A; and
- hospice care—provided to terminally ill patients with life expectancies of 6 months or less. No deductible to be paid by enrollee, but there is coinsurance for prescriptions and inpatient respite care. [210]

Medicare Part A is financed mainly through a mandatory payroll tax at a tax rate of 1.45 percent of earnings, paid by each employee, and matched by the employer. People who are self-employed pay at a rate of 2.90 percent. According to the Centers for Medicare and Medicaid Services (CMS), additional funding sources for Part A include the following:

- a portion of the income taxes levied on Social Security benefits paid to high-income beneficiaries;
- premiums from certain people who are not otherwise eligible and choose to enroll voluntarily;
- reimbursements from the general fund of the U.S. Treasury for the cost of providing HI coverage to people of certain ages who retired when the program began and were unable to earn sufficient quarters of coverage;
- interest earnings on its invested assets; and
- other small miscellaneous income sources. [211]

In 2003, according to CMS, 40.9 million people utilized Part A of Medicare, including 34.9 million people age 65 and over and 6 million individuals with disabilities. It is estimated that in 2004, there will be 41.6 million enrollees (35.3 aged and 6.4 disabled), and by 2010, 46.3 million. [212, 213]

Medicare Part B—Supplementary Medical Insurance Component

Individuals age 65 and older, and all people entitled to coverage under Part A or the HI component of Medicare, are eligible for enrollment in Part B of Medicare, also known as Supplementary Medical Insurance, on a voluntary basis by payment of a monthly premium.

Services provided under Medicare Part B must be deemed medically necessary or prescribed as preventive by a physician. Services that are not covered by Medicare include nursing care that is long term, custodial care, dentures and dental care, eyeglasses, hearing aids, and most prescription drugs. Services that are covered include the following:

- physicians’ and surgeons’ services (including some authorized services rendered by chiropractors, podiatrists, dentists, and optometrists);
- emergency department or outpatient clinic, including same-day surgery and ambulance services;
- home health not covered under Part A;
- laboratory tests, X-rays, and other diagnostic radiology services, and certain preventive care screening tests;
- ambulatory surgical center services in a Medicare-approved facility;
- most physical and occupational therapy and speech pathology services;
- comprehensive outpatient rehabilitation facility services, mental health care prescribed by physician;

- radiation therapy, renal dialysis, and some organ and bone marrow transplants;
- approved durable medical equipment for home use; and
- drugs and biologicals that cannot be self-administered. [214]

Financing for Part B of Medicare includes premium payments paid by enrollees ($66.60 in 2004) in combination with funds from the general fund of the U.S. Treasury. [215] According to CMS, beneficiary premiums cover only 25 percent of expenditures, making the general fund from the U.S. Treasury the largest source of funding for Medicare Part B. Supplementary Medical Insurance benefits in 2003 served 38.5 million (33.1 million aged and 5.3 million disabled). It was estimated that, in 2004, there would be 40 million enrollees, and by 2010, 43 million. [216]

MEDICAID AND MEDICARE

Combined, the federal-state Medicaid and federal Medicare programs provide states with more than 50 percent of their LTSS funding. Originally, the programs had different goals, different target audiences, and different funding mechanisms with no provision for home- and community-based LTSS. As we have read in previous sections of this report, just understanding what the different eligibility criteria for services and supports are for the various populations requesting them is pretty complex. When we look at what actually is mandated under Medicaid and Medicare, we realize that today's LTSS programs are add-ons and are funded primarily (outside of institutional care) as optional services. The rising need for LTSS caused by the changing demographics over the past decade has not been acknowledged by Congress as an issue that needed to be addressed. States have been challenged to find creative ways to provide services and supports through the use of federal waivers. In a way, the granting of waiver authority was a little like giving states a credit card to buy LTSS that were not yet budgeted for, either on the state or federal level.

States are at a crossroads and cannot continue to meet the LTSS needs of their citizens without federal assistance. The dually eligible population—the most fragile of all the populations and the most in need of services and supports—is consuming an inordinate amount of Medicare and Medicaid dollars. In a December 2004 letter to Congress and the Administration, the NGA wrote that it was "unacceptable" that Medicaid costs were growing at a rate of 12 percent per year and averaging 22 percent of state budgets. The letter cited two main causes of this growth: a 33 percent increase in caseloads over the past four years and LTC costs. Medicaid currently finances 70 percent of all care for nursing home residents. [217]

It should be no surprise to policymakers that the baby boomers are getting older and will have an increasing need for services and supports to remain independent. And it is old news that people with disabilities have always needed access to services and supports to compensate for their disabilities so they can live fully engaged lives.

OTHER QUALITY-OF-LIFE DOMAINS

Out of the quality-of-life domains identified social support, personal assistance, and home care are possibly the most important for individuals requiring LTSS. Unfortunately, these are also the most fragmented domains and perhaps the most underfunded, depending on how one measures and defines them relative to specific programs. Independent Living State Grants, Centers for Independent Living, Special Programs for the Aging, the Senior Companion Program, the Medicaid HCBS waiver program, and the Social Services Block Grant are the six related federal programs associated with this quality-of-life domain.

Appendix 1.F, table 2 highlights the fact that no fewer than five federal agencies are responsible for the programs that attempt to mediate these important domains. Additionally, eligibility criteria vary tremendously by age, disability, and income. Only two of the programs are designed to support both frail elders and individuals with disabilities.

The degree of consumer direction is difficult to identify because the majority of these federally funded programs have delegated decision making to the local level. The variance relative to the scope of services is just as difficult to measure because of the same issues but does vary from support of the operation of Independent Living Centers to implementation and coordination of social services and home health through Medicaid state plan options and waivers.

Eligibility criteria vary for each program but are most variable with respect to the Medicaid and HCBS waiver programs that exist in those states. The states have discretion with respect to eligibility and the services that are provided.

HOUSING

Of the quality-of-life domains analyzed, none is more underfunded than affordable and accessible housing. According to HUD's latest Worst Case Housing Needs Report, people with disabilities make up at least 25 percent [218] (estimated by HUD as 1.1 million to 1.4 million people) of the households with worst-case housing needs in the United States. [219] Some of these individuals are actually homeless and without housing of any kind. An Urban Institute study on homelessness indicates that of the 800,000 people who are homeless on any given night, 46 percent of adults have some type of disability. [220]

HUD and the U.S. Department of Agriculture (USDA) are the two federal agencies identified that administer federal-related programs that address the housing needs of the elderly and adults with disabilities. Nine programs are administered by HUD and one by USDA. Appendix 1.F, table 4 highlights the relevant federal housing programs.

Across the nation, the reconfigurations relative to accessible and affordable housing initiatives that are under way at the state level, in general, include two primary efforts: (1) developing more state and local programs that help keep people who are disabled, frail, or cognitively impaired at home; and (2) community-based residential alternatives for people who are elderly and disabled who can no longer manage at home but do not need the 24-hour subacute care/skilled nursing environment provided in nursing homes. To make these institutional alternatives available to people with low incomes, states use a variety of state- and Medicaid-funded approaches to deliver home-based and residential services.

Nationally, on average, a person with a disability receiving SSI benefits would be priced out of the private housing market because he or she would need to pay over 105 percent of the monthly SSI check to rent a modest one-bedroom unit at the published HUD Fair Market Rent. Without housing assistance, through some type of government-funded direct support to the individual or subsidized housing to a developer, low-income individuals who are aging and/or disabled will not find an affordable place to live. [221] Without some type of housing assistance—such as government-funded subsidized housing—low-income people with disabilities and frail elders are unable to afford decent and safe housing of their choice in the community.

In the past 30 years, states have continued to evolve their approach to housing and related services for people with disabilities. In general, states have moved away from an institutional model of segregated facilities that tie together housing and service needs to a variety of smaller community-based living options. To varying degrees, these community living alternatives are intended to provide more choices and independence for the targeted populations. With the authorization by Congress in 1981 of the Medicaid HCBS waiver, there have been new options for states to consider in supporting community integration. However, despite these increases, Medicaid payment policy does not cover housing or meal costs in a home- or community-based setting, although Medicaid does factor these costs into payments for nursing homes. In recent years, people with disabilities and individuals who are aging have been consistent in articulating essential principles to frame housing choices and related services to meet their needs. People with disabilities have pushed to separate housing choices that are affordable and accessible from the provision of LTSS.

Federal and state housing programs can target households with incomes up to 50–60 percent of the median income, or even higher in some cases. Although government housing agencies are producing new “affordable” housing every year, in many instances, this new supply of housing is not affordable to people with SSI incomes. This is true because most federal and state programs help pay for the one-time cost of developing the housing (e.g., the cost of acquisition/rehabilitation or new construction of housing) but do not fund the ongoing cost of operating the housing (e.g., insurance, maintenance/repairs, reserves, property management costs, utilities, etc.).

To make “affordable housing” truly affordable to people with disabilities and frail elders, an ongoing rent subsidy or operating subsidy is needed to ensure that all of the operating costs can be covered.

Of the quality-of-life domains of the long-term support system identified, housing appears to be the least fragmented; however, access remains a problem. While most of the federal-related programs are funded by HUD, they are underfunded, the eligibility criteria are restrictive, and consumer choice and control are limited. The trend toward shifting institutional care to home- and community-based support and services will not be realized if housing is not considered a priority area relative to LTSS for people with disabilities.

TRANSPORTATION

Appendix 1.F, table 5 highlights the important transportation programs. The ability to access transportation is critical to living a full life. Having access to transportation is one of the quality-of-life domains that enable individuals requiring LTSS to maintain their independence and dignity; that is, for many it represents the vehicle to participation. For instance, transportation is the key to connecting individuals to the services and supports they need, such as visiting family and friends and participating in community activities (social, recreation, and community participation); taking care of their health needs, such as doctor and hospital visits, as well as the ability to purchase needed medical supplies, including prescriptions; securing and maintaining employment; advancing their educational goals and careers (attending school and educational advancement institutions); and providing for their nutritional and routine needs, such as the ability to access shopping centers.

The Department of Transportation funds programs that focus on the specific transportation needs of transportation-disadvantaged populations. The programs include the Job Access and Reverse Commute Grants, which are aimed at connecting low-income individuals to employment and support services; the Capital Assistance Program, which provides financial assistance to nonprofit organizations for meeting the transportation needs of elderly people and people with disabilities; and the United We Ride State Coordination Grants, which assist states that want to strengthen or jump-start efforts to coordinate human service transportation.

According to a recent GAO report on the transportation-disadvantaged populations, [222] there are 62 federal programs that can fund transportation services for certain transportation-disadvantaged populations, which include some elderly people, people with disabilities, or low-income people who have transportation needs, such as the ability to provide their own transportation, or who have difficulty accessing conventional public transportation. Most of these programs are administered by four federal agencies: the Departments of Transportation, HHS, Labor, and Education. Programs that can fund incidental transportation services include health and medical programs or job-training programs. For example, the Medicaid program (administered by HHS) spent an estimated $976.2 million on transportation in FY 2001. The Community Transportation Association of America (CTAA) [223] identified several programs that provide transportation for the target audience, including Workforce Investment Act programs (administered by the Department of Labor), and Vocational Rehabilitation Grants (administered by the Department of Education). [224]

Although it appears that numerous federal programs exist to assist the transportation-disadvantaged population, research conducted by the GAO relative to these programs concluded that fragmentation and lack of coordination within supporting agencies continue to be a challenge; therefore, there is a need to coordinate the transportation services offered by these federal programs to provide "improved customer service and substantial cost savings." [225] Efforts toward coordinating transportation services were identified and addressed in 1986 through the creation of the Coordinating Council on Human Services Transportation by the Department of Transportation and HHS, which was renamed the Coordinating Council on Access and Mobility in 1998. In January 2004, the Departments of Labor and Education joined the council. The council was charged with coordinating and addressing issues of transportation access and mobility in their respective programs. [226]

One significant effort of this council was the launch of the United We Ride initiative in December 2003. The United We Ride program represents a five-part transportation coordination initiative developed by the four federal agencies. [227] This initiative moves to improve federal leadership and commitment "by establishing coordination as a priority and providing some dedicated financial support and proactive technical assistance." [228]

The members of this council and its mandate were further enhanced through Executive Order 13330 on Human Service Transportation Coordination, issued by President Bush on February 24, 2004, "to enhance access to transportation to improve mobility, employment opportunities, and access to community services for persons who are transportation-disadvantaged." The order established the Interagency Transportation Coordinating Council on Access and Mobility within the Department of Transportation, which expands the members of the 1998 council. The membership of this council now includes secretaries from the Departments of "Transportation, Health and Human Services, Education, Labor, Veterans Affairs, Agriculture, Housing and Urban Development, and the Interior, the Attorney General and the Commissioner of Social Security and such other federal officials as the Chairperson of the Council may designate." [229] According to the language of the Executive Order, it was issued based on the following findings and principles:

(a) A strong America depends on citizens who are productive and who actively participate in the life of their communities.

(b) Transportation plays a critical role in providing access to employment, medical and health care, education, and other community services and amenities. The importance of this role is underscored by the variety of transportation programs that have been created in conjunction with health and human service programs, and by the significant Federal investment in accessible public transportation systems throughout the Nation.

(c) These transportation resources, however, are often difficult for citizens to understand and access, and are more costly than necessary due to inconsistent and unnecessary Federal and State program rules and restrictions.

(d) A broad range of Federal program funding allows for the purchase or provision of transportation services and resources for persons who are transportation-disadvantaged. Yet, in too many communities, these services and resources are fragmented, unused, or altogether unavailable.

(e) Federally assisted community transportation services should be seamless, comprehensive, and accessible to those who rely on them for their lives and livelihoods. For persons with mobility limitations related to advanced age, persons with disabilities, and persons struggling for self-sufficiency, transportation within and between our communities should be as available and affordable as possible.

(f) The development, implementation, and maintenance of responsive, comprehensive, coordinated community transportation systems is essential for persons with disabilities, persons with low incomes, and older adults who rely on such transportation to fully participate in their communities. [230]

NUTRITION

Nutrition, like housing and transportation, represents another essential LTSS that the elderly and people with disabilities require to maintain quality of life and to help them maintain independent living. At the beginning of the 20th century, life expectancy was less than 50 years—at that time individuals did not face things such as chronic long-term illness or the need for special care that can come from aging into one’s 70s, 80s, and even 90s. However, by 1950, with the advent of provisions such as better nutrition, clean water, pasteurized food, and refrigeration, life expectancy had increased to 63 years. [231]

According to a USDA report to Congress, [232] the investment in nutrition assistance in the United States has been a critical tool in fighting undernutrition and related health problems. It is well established that good nutrition is fundamental to proper growth, development, health, and performance. Diet is widely recognized as a central component of health promotion and disease prevention. Scientific evidence increasingly supports the fact that good nutrition is essential to health, self-sufficiency, and quality of life. [233, 234]

People with disabilities and special health care needs frequently have nutrition problems, including growth alterations, metabolic disorders, poor feeding skills, medication-nutrient interactions, and partial or total dependence on enteral or parenteral nutrition. Poor health habits, limited access to services, and long-term use of multiple medications are considered risk factors for additional health problems. [235]

There are three main federal-related nutrition programs that address the nutritional needs of the elderly and individuals with disabilities: the Elderly Nutrition Program (HHS), and the Senior Farmers' Market Nutrition Program and Food Stamps Program (Department of Agriculture).

The relationships among appropriate nutrition services, positive health outcomes, and reduced health care costs for older adults and individuals with disabilities continue to be established. [236, 237] Good nutritional status and personal well-being benefit both the individual and society: Health is improved, dependence is decreased, hospitalization stays and time required to recuperate from illness are reduced, and utilization of health care resources is contained. [238, 239, 240] While food is sustenance required by every living being to survive, access to proper nutrition remains a substantial problem for the elderly and people with disabilities. Many of these individuals have low incomes and do not receive enough in retirement or disability benefits to meet all of their expenses and to purchase healthy and nutritious meals.

ASSISTIVE TECHNOLOGY

LTC encompasses a broad range of services and supports that the elderly and individuals with disabilities require to maintain a long-term quality of life. Assistive technology (AT), like health care and social support services, can play an important part in helping individuals to maintain their independence by improving access and coordination. AT represents any item, piece of equipment, or product system—whether acquired commercially off the shelf, modified, or customized—that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. [241]

AT can be as simple as a walker to make moving around easier or an amplification device to make sounds easier to hear (for example, talking on the telephone or watching television). It could also include a magnifying glass that helps someone who has poor vision read the newspaper, or a small motor scooter that makes it possible to travel over distances that are too far to walk. In short, anything that helps the elderly and people with disabilities continue to participate in daily activities is considered AT.

AT services also include things like home modification, such as architectural changes and permanent installation of equipment. Architectural changes can include adding ramps and other structures to enter, move about in, or exit the home; widening doorways; retrofitting a bathroom; and lowering countertops and making other modifications to an eating area or kitchen.

Other examples of AT include large-screen computer monitors and remote control devices to operate lamps, radios, and other appliances. AT devices can assist most people—of all ages—to be more functional and independent; they can make the difference between dependence and independence. [242]

The Assistive Technology Act (ATA) of 1998, reauthorized with amendments in 2004, is a federal program that acknowledges and addresses the benefits of providing AT to enable individuals with disabilities to participate in society.

The ATA has three main purposes: to sustain and strengthen the capacity of states to address the AT needs of people with disabilities; to support investment in technology across federal agencies; and to support microloan programs for the purchase of AT devices or services. [243]

For the elderly and individuals with disabilities, AT may make the difference between being able to live independently and having to get long-term nursing or home health care. AT for both target groups is critical to the ability to perform simple ADLs, such as bathing and going to the bathroom, as well as more complex tasks, such as using a computer.

According to the executive summary from the NCD report *Federal Policy Barriers to Assistive Technology*, [244] individuals of all ages can benefit from AT; however, the benefit for individuals with disabilities “changes the most ordinary of daily activities from impossible to possible. In an ideal climate, no person with a disability should be denied the opportunity to obtain assistive technology and transfer its inherent potential into viable, life-fulfilling endeavors.” Furthermore, in its concluding remarks, the NCD report states that “it is clear that the current patchwork of federal policies has barriers and gaps, leaving many people with disabilities without the benefits of assistive technology.”

Currently, no single private insurance plan or public program will pay for all types of AT; however, Medicare will cover up to a percentage of the cost of AT for items that are traditionally considered “medical and/or medically needy.” However, the need for LTC often extends well beyond the “medically needy” period; therefore, these LTSS would not be covered. Some state-run Medicaid programs may cover AT, and seniors eligible to receive veterans benefits may be able to purchase needed AT through this program. [245]

In 2000, money was appropriated for Title III of the Assistive Technology Act of 1998 (P.L. 105-394) authorizing the Alternative Financing Program (AFP), which is designed to assist states in establishing or maintaining alternative financing projects to increase access to AT for individuals with disabilities. This program allows individuals with disabilities and their family members to access a funding alternative to public assistance programs to purchase AT devices and services. [246]

Existing funding sources for the acquisition of AT devices and services do not meet the needs of all individuals with disabilities of all ages. These individuals may encounter barriers to obtaining AT devices because they either do not quality for services from these systems or are unable to obtain payment for their particular piece of equipment. Some states have attempted to reduce or eliminate these barriers through the establishment of an AFP. Unfortunately, these programs are underfunded and not every state has one. According to the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) Alternative Financing Technical Assistance Project, FY 2003 grantees only include 23 states and three territories. [247]

CAREGIVER SUPPORT

While some federal and state programs exist to provide LTSS to the elderly and individuals with disabilities, most long-term support is provided in the United States by family members or other informal caregivers. These caregivers include spouses, adult children, and other relatives or friends.

The HHS report *Delivering on the Promise* [248] states that recent studies confirm that the majority of direct care (about 64 percent) to people with disabilities is provided by families, friends, and neighbors. This same report cites that 95 percent of the elderly who need assistance have family members involved in their care. This report concurs with other studies that state that these caregivers receive little, if any, direct assistance and often “face tremendous financial and emotional pressures.” Finally, the inadequacy of caregiver supports, such as respite care, “poses significant challenges to community integration for individuals with disabilities and their families.” Evidence does suggest that the provision of supportive services “can diminish caregiver burden, permit caregivers to remain in the workforce, and enable people with disabilities [this can also apply to the elderly] to remain in community settings.”

It is clear, then, that because caregivers play such an important role, services that sustain a caregiver’s role and maintain his or her emotional and physical health are an important component of any HCBS system. [249] Respite care is one program option that may provide the support needs that caregivers require. Respite care represents “short-term supervision, assistance, and care provided due to the temporary absence or need for relief of recipient's primary caregivers. This may include overnight, in-home or out-of-home services." [250]

The National Family Caregiver Support Program (NFCSP), the federal-related program that addresses the quality of life domain of caregiver support, recognizes the role of families in providing LTSS.

The NFCSP calls for all states to work in partnership with Area Agencies on Aging, as well as local community service providers, to provide the following five basic services for family caregivers:

- information to caregivers about available services;
- assistance to caregivers in gaining access to supportive services;
- individual counseling, organization of support groups, and caregiving training to assist caregivers in making decisions and solving problems related to their caregiver roles;
- respite care to enable caregivers to be temporarily relieved from their caregiver responsibilities; and
- supplemental services on a limited basis, to complement the care provided by caregivers. [251]

Respite care is also an allowable service under the HCBS waivers and is included in a majority of state waivers to targeted eligible individuals. [252] Policymakers have traditionally designed Medicaid benefits based upon specific eligibility criteria defining needs of individuals. Both in-home and out-of-home respite services introduce additional complexities from a policy perspective as they require an assessment of family need.

CONCLUSION

Changing demands and expectations of individuals with disabilities and families continue to pressure states to reevaluate their approach to deliver consumer-responsive services and supports. Regardless of the identified quality-of-life domain and analysis of the current menu of federally supported services, there was a lack of choices for the targeted audience to effectively respond to growing demand. There is a level of complexity that leaves consumers and professionals bewildered by the rules and procedures to determine eligibility for specific supports and services. States are developing client assessment instruments to assess a person's ability to perform ADLs (eating, bathing, dressing, mobility, and toileting); cognitive and emotional status; social, housing, and environmental circumstances; and nutrition and family/friend support networks. Several states also use this instrument to determine qualifications for (and to help a client choose from) a menu of program options, including Medicaid waiver and state plan services, state-funded services, and Social Services Block Grant programs. [253]

States also reported efforts to make their delivery systems more efficient and user friendly by establishing single-entry-point systems or no-wrong-door systems to help eliminate the confusion consumers have about choices for LTSS. [254]

Thirty-one states and the District of Columbia have implemented single-entry-point systems, which combine information and referral, client assessment, eligibility determination, care plan development, authorization, and quality assurance in one entity at the local level. Some of these systems also coordinate with the client's physician or hospital discharge planner to facilitate movement among services and settings. [255]

These new state efforts build upon a no-wrong-door philosophy. Regardless of which agency one may access to seek assistance, that agency is prepared to provide information and connect the individual to needed services and supports. Despite these efforts at systems reform, at a community level, there remains great confusion among consumers and government agencies about who should supply which services, whether some services even exist, and who may be eligible. As one commenter explained before the Federal Commission on Affordable Housing and Health Needs for Seniors in the 21st Century, "The current 'crazy-quilt' tapestry of services and shelter options make it difficult to fully grasp their complexities, let alone try to access them." [256]

Part VIII

PUSHING TUGBOATS

An overview of promising practices that are moving the current system toward reform.

Many state demonstration projects for LTC, which are funded in part by federal and private foundation funds, are responsible for the current innovations occurring in states for people with disabilities and senior Americans. Initiatives such as the Real Choice Systems Change (RCSC) grants from CMS are facilitating demonstrations and compliance with *Olmstead*, greater alliance among the aging and disability communities, and a "lifespan" approach to policy change. Cash and Counseling and Independence Plus consumer-directed care and caregiving programs that allow greater autonomy for people with disabilities (of any age) to direct the hire and choice of personal caregivers, single-point-of-entry programs to create more effective access to services, and affordable assisted living and housing options for low-income seniors (such as NCB Development Corporation's and the Robert Wood Johnson Foundation's Coming Home Program) are all pushing forward the possibilities of new thinking. [257]

As the second Administration of President George W. Bush begins to unveil its priorities, multiple demonstration initiatives launched in the first term continue to support state efforts to expand consumer choices to live independently at home and in community settings coordinated with needed services. Appendix 1.C highlights four initiatives that are the "tugboats" pushing forward state changes in service delivery, financing, administration, consumer direction, and quality oversight.

CASH AND COUNSELING DEMONSTRATIONS

The Cash and Counseling Demonstrations are offering states the opportunity to experiment and innovate with cost-effective choices between institutional and community-based systems.

The Cash and Counseling Demonstrations jointly funded by the AOA and the Office of Planning and Evaluation at HHS builds on an initial partnership that began in 1996 with the Robert Wood Johnson Foundation to pilot and evaluate consumer-directed models for long-term supports in three states: Arkansas, Florida, and New Jersey (see Appendix 1.D). Under these demonstrations, each state provided beneficiaries with disabilities with a flexible monthly allowance to pay for personal care services according to a budget developed by the individual and approved by the state. The individual hired, supervised, and managed the services provided by direct care workers that include family members. Appendix 1.D describes the primary features of each state's demonstrations.

Based on a comparison with a control group of individuals who received services through a traditional agency-based provider, participants in the demonstration (1) were more satisfied with the services they received; (2) reported a higher quality of life; (3) had fewer unmet needs for personal care; (4) received more paid care (especially adults under age 65); and (5) did not have more adverse events or health problems. [258]

Based on preliminary positive findings, HHS awarded on a competitive basis new Cash and Counseling Demonstration projects in 11 states in October 2004. [259]

The Cash and Counseling Demonstrations are not without criticism from some members of the disability community. In testimony before the House Energy and Commerce Committee, Bob Williams, co-director of Advancing Independence—a forum that promotes responsible changes to Medicare and Medicaid needed to enhance the health and independence of Americans with disabilities of all ages—articulated a number of specific concerns, including the following:

- The notion that self-directed individual budgets is an approach that everyone can or wants to use: It might not work well for someone without a natural support network to turn to that can help manage the relationships with service providers and resulting costs.
- The methods for calculating individual budgets must be fair and reflect changing levels of need over time.

- The need for consumer education and individual assistance in assessment of needs, the creation and management of an individual budget, and the management of service provider relationships. [260]

ESTABLISHMENT OF AGING AND DISABILITY RESOURCE CENTERS

During the past two years, FY 2003 and FY 2004, CMS teamed up with the AOA to create one-stop Aging and Disability Resource Centers (ADRCs) to assist individuals and families learn about and access LTSS. CMS and AOA funded on a competitive basis projects in 23 states to design, pilot, and evaluate a more coordinated approach to LTSS through a single point of entry. The pilot projects are now building on the earlier experience that began in the late 1990s in Wisconsin. The centers in Wisconsin serve as clearinghouses for information about LTC and LTSS options and eligibility. As an information clearinghouse, the ADRC offers advice and assistance to individuals with disabilities across the age spectrum as well as to physicians, hospital discharge planners, and other professionals who work with older people or people with disabilities. Services offered through the single entry point can be grouped into six major areas:

- **Information and Assistance**. Provide information to the general public about services, resources, and programs in areas such as disability and LTC-related services and living arrangements, health and behavioral health, adult protective services, employment and training for people with disabilities, home maintenance, nutrition, and family care. Resource center staff will provide help to connect people with those services and to also apply for SSI, Food Stamps, and Medicaid as needed.
- **LTC Options Counseling**. Offer consultation and advice about the options available to meet an individual’s LTC needs. This consultation will include discussion of the factors to consider when making LTC decisions. Resource centers will offer pre-admission consultation to all individuals with LTC needs entering nursing facilities, community-based residential facilities, adult family homes, and residential care apartment complexes to provide objective information about the cost-effective options available to them. This service is also available to other people with LTC needs who request it.

- **Benefits Counseling**. Provide accurate and current information on private and government benefits and programs. This includes assisting individuals when they run into problems with Medicare, Social Security, or other benefits.
- **Emergency Response**. The resource center will ensure that people are connected with someone who will respond to urgent situations that might put someone at risk, such as a sudden loss of a caregiver.
- **Prevention and Early Intervention.** Promote effective prevention efforts to keep people healthy and independent. In collaboration with public and private health and social service partners in the community, the resource center will offer both information and intervention activities that focus on reducing the risk of disabilities. This may include a program to review medications or nutrition, home safety review to prevent falls, or appropriate fitness programs for older people or people with disabilities.
- **Access to the Family Care Benefit.** For people who request it, resource centers will administer the LTC Functional Screen to assess the individual’s level of need for services and eligibility for the Family Care benefit. The Wisconsin Family Care benefit combines HCBS waiver funds with non-state waiver-only funds. Once the individual’s level of need is determined, the resource center will provide advice about the options available to him or her: to enroll in Family Care or a different case management system (if available), to stay in the Medicaid fee-for-service system (if eligible), or to privately pay for services. [261]

It is too early to determine the impact of the ADRC demonstrations on the target populations. AOA and CMS will evaluate whether the Resource Centers increase informed decision making and consumer satisfaction with access to needed LTSS in the most integrated setting. Over a three-year period, each of the pilot states is expected to have at least one operating center that demonstrates improvements in the state’s ability to manage public resources, monitor program quality and costs, and improve assessment of need and effective coordination of services to limit unnecessary use of high-cost options, including nursing facilities.

REAL CHOICE SYSTEMS CHANGE GRANTS

As part of the President’s New Freedom Initiative (NFI), funds competitively awarded to states during the past four years are intended to be catalysts for systems change to enable people of all ages with a disability to (1) live in the most integrated community setting suited to their needs; (2) have meaningful choices about their living arrangements; and (3) exercise more control over the services they receive. [262] The four rounds of competition have challenged states to focus on specific areas of intervention to help rebalance funding toward expanded community choices, improve consumer participation and direction, monitor quality, and build better links between housing and services. CMS has awarded more than 200 grants and over $200 million, with the typical grant period extending for three years and the majority of states having at least one award. [263] Findings from the Second Annual Report on Grantee Activities include relevant activities that are laying the foundation for LTSS reform. In the area of consumer direction, grantees in 41 states are incorporating principles of consumer direction in service delivery through changes in administrative rules and regulations, and training and education for consumers, families, and providers. Grantees in 22 states have successfully transitioned a total of 1,214 individuals with disabilities from institutional to community settings. The state budgeting and reimbursement grantees in 38 states are developing changes to their long-term support systems that adapt individualized budgeting, strategies to allow dollars to follow a person from institutional settings to the community, and new payment rates and reimbursement methods. The workforce recruitment and quality grantees in 39 states have initiatives to increase wages and benefits, have training to improve skills and development of career ladders, and are testing new recruitment strategies. The quality assurance grantees in 25 states are implementing initiatives to redefine quality measures, adding a consumer focus to monitoring activities, and developing data systems for quality monitoring. [264] Appendix 1.E provides an overview of all 50 states with initiatives to improve access to LTSS. [265]

The current findings of the Research Triangle Institute Report for CMS recognize the limitations of the data analyzed, which primarily comes from grantee self-reporting. As grantees continue to design and implement multiple systems change strategies made possible by federal RCSC funding during the next four years, new understanding and knowledge will become available to shape future decisions about the structure and design of consumer-responsive LTSS. An additional new round of competitive funding for states in the summer of 2005 will invite states to propose further activities to support comprehensive systems reform.

INDEPENDENCE PLUS INITIATIVE

Independence Plus was first announced in May 2002 to encourage individual or family direction of supports and services that keep people in the community through the development and direction of individualized budgets. [266] In August 2004, California became the sixth state approved by CMS under the Independence Plus program. It is expected to benefit more than 60,000 Californians with disabilities who will be allowed to direct their own personal care services rather than have their care designed by a home health agency. [267] Under the Independence Plus waiver, consumers and families will be involved in planning all aspects of service delivery of personal assistance services, including but not limited to the hiring, direction, and appraisal of service providers. According to Mark McLellan, administrator of CMS, “Allowing persons with disabilities and their families to engage in self-direction is a high priority for the Bush Administration and my agency.” [268]

The Independence Plus waiver approach to self-direction is a part of the Bush Administration’s efforts to expand funding resources for LTSS at home and in community settings. State and federal expenditures have increased under HCBS waivers from $13.9 billion in FY 2001 to an estimated $20.7 billion in FY 2004. Between 2001 and 2004, a total of $68.7 billion will be spent to support HCBS waivers. [269]

Each of the eight states with approved Independence Plus waivers has targeted a specific group of eligible individuals with disabilities, such as adults with physical disabilities, individuals with a developmental disability, or individuals with disabilities who are over age 65. The scope of services offered also varies in scope, from personal assistance services in California to personal care services, respite services, and other services needed to maintain independent lives in South Carolina. All participating states will require individualized budgets directed with the assistance of a service coordinator and a fiscal intermediary to help with financial management services. [270] It is too early to evaluate the impact of these design elements on the targeted beneficiaries or the larger state systems.

CONCLUSION

The combination of these four initiatives provides both financial and philosophical support to a long-term service system that needs to be reframed and transformed with active participation of people with disabilities and their families.

In an August 2004 letter to state Medicaid directors, CMS reaffirmed its support for states in the implementation of the principles of Money Follows the Person. CMS explains that the term as follows:

> Money Follows the Person refers to a system of flexible financing for long-term services and supports that enables available funds to move with the individual to the most appropriate and preferred setting as the individual's needs and preferences change. It is a market-based approach that gives individuals more choice over the location and type of services they receive. A system in which Money Follows the Person is also one that can incorporate the philosophy or self-direction and individual control in state policies and programs. [271]

CMS, through these four important initiatives and letters of policy guidance, is pulling the ship forward to allow people to have expanded choice and control of the services and supports they need.

Part IX

HARNESSING FAVORABLE WINDS

An overview of selected, important legislative and executive branch activities.

AMERICANS WITH DISABILITIES ACT

The new paradigm of disability maintains that disability is an "interaction between characteristics (e.g., conditions or impairments, functional status or personal and social qualities) of an individual and characteristics of the natural, built, cultural, and social environments." [272] Favorable winds from the legislative, judicial, and executive branches of the Federal Government in the past 15 years have embraced this new paradigm.

The passage of ADA in 1990 [273] and of its predecessor, the Rehabilitation Act of 1973, [274] reflect a basic shift in public understanding of disability and its meaning in the broader society. Both laws have embraced community integration as an essential core concept, although ADA changed the basic terminology of the Rehabilitation Act and broadened the goal of community integration of people with disabilities to extend to all facets of life, not merely federally assisted programs. [275]

Although much of the public attention and research inquiry regarding ADA has attempted to evaluate the impact of ADA civil rights protections regarding business practices and employment discrimination, [276] the purpose of ADA is far broader. For individuals with disabilities, the ADA preamble states the following:

> The nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency. [277]

Title II of ADA, which applies to publicly operated and funded programs and services, provides the framework for community integration and movement away from separate and segregated services. "No qualified individual with a disability shall by reason of such disability, be excluded from participation in or denied the benefits of the services, programs, or activities of a public entity, or be the subject of discrimination by any such entity." [278] The Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." [279]

According to the preamble to these implementing regulations, the "most integrated setting" means "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." [280]

THE OLMSTEAD DECISION

Nine years later, the favorable winds (or new momentum) for redirecting the ship (or current system of LTC entitlements and other federal funding sources) that could embrace community inclusion and integration principles resulted from the U.S. Supreme Court decision in *Olmstead v. L.C.* and the interpretation of Title II of ADA. The *Olmstead* decision affirmed the right of people with disabilities to choose how to live their lives and have greater control over their daily activities in the most integrated settings. [281] The Supreme Court made it clear that it is a violation of ADA for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting. [282] The Supreme Court stated that "Unjustified isolation . . . is properly regarded as discrimination based on disability." [283] It observed that (1) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (2) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Under ADA, states are obliged to:

> make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity. [284]

The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the state; and how the provision of services affects the ability of the state to meet the needs of others with disabilities.

NEW FREEDOM INITIATIVE

Favorable winds picked up greater force with the February 2001 announcement by President George W. Bush of a comprehensive set of proposals called the New Freedom Initiative (NFI) to reduce barriers to full community integration for people with disabilities. [285] The initiative, which is designed to help ensure that Americans with disabilities participate more fully in the life of their communities, states the following:

> Americans with disabilities should have every freedom to pursue careers, integrate into the workforce, and participate as full members in the economic marketplace. The New Freedom Initiative will help tear down barriers to the workplace, and help promote full access and integration. [286]

With the NFI, President Bush continued the policy direction started by his father when he signed ADA into law. The initiative continues to support the coordinated activities of the Federal Government and state governments to remove barriers that impede opportunities for community participation. The NFI represents an important step in working to ensure that all Americans with disabilities have the opportunity to learn and develop skills, engage in productive work, and choose where to live and participate in community life. [287]

As part of the NFI, on June 18, 2001, President Bush issued Executive Order 13217, "Community Based Alternatives for Individuals with Disabilities." The Executive Order directs six federal agencies—including the Departments of Justice, Education, and Labor, as well as HHS, HUD, and the SSA—to evaluate their policies, programs, and regulations to determine whether any should be revised or modified to improve the availability of community-based services for people with disabilities. In that order, the President emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination, that the United States is committed to community-based alternatives for individuals with disabilities, and that the United States seeks to ensure that America’s community-based programs effectively foster independence and participation in the community for Americans with disabilities. [288]

The order also charged the Federal Government with providing assistance to states and localities to swiftly implement the *Olmstead* decision. In response, federal agencies have undertaken several initiatives, including clarifying federal statutes and regulations to assist in the transition of institutionalized individuals into more integrated settings and increasing federal funding for programs and projects aimed at expanding opportunities for community living. In March 2002, the Bush Administration issued its first report, “Delivering on the Promise: A Compilation of Individual Federal Agency Reports of Actions To Eliminate Barriers and Promote Community Integration.” The report identifies more than 400 steps to removing barriers and improving community integration. [289] In 2004, a second progress report was issued that further updates federal agency efforts to promote community integration. [290]

The current Administration, through a series of letters from the CMS to states, has enjoined states to develop and implement plans for less restrictive community options for LTSS that respect consumer choice. [291] The majority of states have both *Olmstead* plans and cross-agency and stakeholder workgroups to focus on policy development, capacity building, and systems change to steer the ship to promote consumer choice and direction.

Part X

GATHERING CLOUDS

An overview of recent judicial decisions that are challenging long-term services and supports reform efforts.

Despite these favorable winds, the past six years have seen a growing number of court cases concerning access to LTSS at home and in community settings for individuals with disabilities. [292] Individuals with disabilities and their families have grown increasingly impatient at the pace of change. The Supreme Court in its *Olmstead* decision set a general standard for state behavior in the future. If a state had “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings and a waiting list moved at a reasonable pace,” then there would be no effective claim for a violation of Title II of ADA. [293] However, the Court did not elaborate what constituted a “reasonable pace” or an “effectively working plan.” The *Olmstead* “community integration” imperative set a new expectation that a state rebalance its allocation of public resources away from institutional services in nursing facilities to a new mix of HCBS. In the past 40 years, public expenditure of a majority of federal dollars in the Medicaid program has paid for institutional services. [294] Under Medicaid law, there is an entitlement to institutional services that must be included in a state’s Medicaid program. [295] There is no similar entitlement for home and community LTSS. [296] Under Section 1915(c) of the Social Security Act, a state has the option of offering community services as an alternative to institutional eligibility criteria. [297] However, a state may select the services, define their scope, and target a specific group of Medicaid beneficiaries under an HCBS waiver. [298]

For the past 10 years, Medicaid expenditures for home- and community-based LTSS have grown rapidly. Between 1990 and 2003, HCBS waiver expenditures increased more than tenfold to $18.6 billion. [299] In 1990, home and community services represented just over 10 percent of Medicaid long-term service expenditures. In 2003, the share of HCBS funding had grown to 33 percent of Medicaid long-term service funding. [300]

Several significant factors lie behind the storm clouds of increased litigation. Multiple research studies have documented the interest of people with disabilities across the age span to remain in their own homes and communities rather than more restrictive nursing facilities or institutional settings. [301] The majority of states have long waiting lists for multiple HCBS waiver programs, despite the state authority to limit the number of people who participate in the waivers. [302] Federal monitoring and enforcement of the *Olmstead* "community integration" imperative has yet to become a priority of the Department of Justice Civil Rights Division. No complaint has been filed or settlement reached with a state that challenges "the reasonable pace" of implementation of a state's plan to expand home and community support and service options.

However, protecting the rights of institutionalized people with disabilities continues to remain a priority for the Civil Rights Division of the Department of Justice. [303] In August 2004, the Justice Department found California in violation of Title II of ADA by failing to provide services in the most integrated setting. [304] The findings resulted from an investigation of Laguna Honda Hospital and Rehabilitation Center in San Francisco. Laguna Honda is one of the largest publicly operated nursing homes in the country, with an average daily census of 1,041 residents. For a nursing home, Laguna Honda serves an unusually high number of residents under the age of 55—approximately 22 percent of the total residents. This segment of the population tripled from 1990 to 2000 and continues to increase.

The Justice Department found evidence that California had failed to ensure that residents had meaningful access to community alternatives. Instead, the investigation concluded that nursing home placements were authorized without requiring assessments to evaluate the appropriateness of HCBS. Individuals in the nursing facility were also not informed later of available community options.

The Justice Department as part of the Laguna Honda investigation did examine the California *Olmstead* plan to expand community options. The Justice Department concluded the following:

> The plan lacks data regarding institutionalized persons with benchmarks and timetables for diverting and transitioning current nursing facility residents into community settings. [305]

Appendix 1.E lays out the Justice Department's detailed remedial measures to be implemented by California as a response to cited violations of ADA. Remedial measures focus on changes to the assessment process for revised policies and procedures to enable the target group to make fully informed decisions, community capacity to provide services in more integrated environments, and appropriate training for case managers and care coordinators. [306] The proposed remedial measures and approach to the analysis of a state's *Olmstead* plan with requirements of benchmarks and timelines offer considerations for future Justice Department intervention on a systematic basis across all states.

In addition to federal action, as of October 2004, legal action on behalf of individuals with disabilities had been filed in 25 states. [307] The challenges to state policies can be grouped into two broad categories:

- **Access to Medicaid Home and Community Services.** The majority of these cases involve individuals with disabilities who want but cannot obtain HCBS. Challenges relate to both individuals with disabilities on waiting lists for services and individuals with disabilities who are currently in nursing or other LTC facilities.
- **Limitations on Availability or HCBS Comparable to Services Offered in More Restrictive Settings.**The majority of these cases challenge state policies that affect the scope and quality of Medicaid services in the home or community setting. Several cases have challenged the adequacy of payments or rate setting for coverage of specific community-based services that create an unfavorable balance toward availability in institutional rather than community settings.

Recent decisions are mixed from across the federal circuits as different fact situations and legal theories seek to extend and define the Supreme Court's *Olmstead* decision. Three cases illustrate the storm clouds ahead as individuals with disabilities seek to clarify and extend judicial interpretation of the *Olmstead* "community integration" imperative.

NEW TYPES OF MEDICAID SERVICE ARE NOT REQUIRED FOR THOSE SEEKING HOME CARE

Rodriguez v. City of New York (1999)

In *Rodriguez v. City of New York,* [308] a class of Medicaid-eligible individuals with mental disabilities sought to have the city include "safety-monitoring" services along with other personal care services in its Medicaid personal care program. The individuals claimed that without safety-monitoring services they would be unable to continue living in their homes and would require institutionalization. [309]

The Second Circuit denied relief, ruling that *Olmstead* reaffirms that ADA does not require a state to offer a new type of Medicaid service. [310] The court relied on a footnote in *Olmstead,* which provided that "States must adhere to ADA's nondiscrimination requirement with regard to the services they in fact provide." [311] Plaintiffs were requesting new services, as New York does not provide safety monitoring to individuals with physical or mental disabilities. [312]

Notably, however, nothing in this footnote or in the court's discussion of the fundamental alteration defense states that new services would never be required to comply with ADA. In fact, the court's discussion of the defense makes clear that the only factors to be considered in determining what constitutes a fundamental alteration are the cost of providing integrated services, the resources available, and the needs of others. [313] The language cited in *Rodriguez* appears simply to reflect the court's clarification that ADA does not create an entitlement to a specific "standard of care," but instead requires that once a state chooses to provide services, it must not discriminate by providing those services in an unnecessarily segregated setting.

INSTITUTIONALIZATION IS NOT A PREREQUISITE FOR INDIVIDUALS TO BE COVERED BY TITLE II: REDUCING BENEFITS TO THOSE OUTSIDE OF INSTITUTIONAL SETTINGS WHILE MAINTAINING BENEFITS TO THOSE IN INSTITUTIONAL SETTINGS: FISHER V. OKLAHOMA HEALTH CARE AUTHORITY (2003)

In *Fisher v. Oklahoma Health Care Authority*, [314] the Tenth Circuit was presented with the question of whether institutionalization is a prerequisite for the application of *Olmstead.* Here, the Tenth Circuit interpreted *Olmstead* to allow people with disabilities who, by reason of a change in state policy, stand imperiled with segregation to challenge that state policy under ADA's integration regulation without first submitting to institutionalization. [315] The *Fisher* holding's importance to the greater community of people with disabilities cannot be stressed enough. After *Fisher*, individuals with disabilities living in community settings were protected from state efforts to institutionalize or, in some cases, reinstitutionalize them. The case prohibits a state from presenting individuals with a Hobson's choice between remaining in the community under dangerous constraints or entering state-supported institutions to gain access to needed services.

Oklahoma, through the Oklahoma Health Care Authority (OHCA), provided prescription drug benefits to Advantage Program participants in the community as well as residents in institutional settings. [316] In September 2002, OHCA notified participants that it would impose a cap of five prescriptions per month on Advantage participants, effective October 1, 2002. [317] The state, meanwhile, continued to provide unlimited prescriptions to patients in nursing facilities. [318]

The Tenth Circuit interpreted *Olmstead* and ADA's integration regulation to cover those living in community settings. To act the other way would present Medicaid recipients with another choice. They could choose to live in the community but accept benefits that were not comparable to those with similar conditions living in institutions or they could enter an institution and receive complete care but forgo the benefit of living in the outside community. [319]

Like so many other *Olmstead* cases, the Tenth Circuit also explored the "fundamental alteration" language used by the Supreme Court. Oklahoma defended the five-prescription cap in two ways: (1) the HCBS waiver program is optional, and (2) " [g]iven . . . the State financial crisis," Oklahoma's move to reduce an optional program rather than eliminate it altogether is reasonable, a fiscal crisis fundamental alteration defense." [320] The Tenth Circuit expeditiously rejected the first defense, noting that, under Title II of ADA, "a state may not amend optional programs in such a way as to violate the integration mandate." [321] The Tenth Circuit articulated a boundary to a state's use of the fundamental alteration defense, noting that the fact that a program is optional does not allow the defense to be successful. Instead, noted the court, the fact that a program is optional and subject to state-proposed changes does not automatically constitute a fundamental alteration in the state's services and programs and limit a state's liability under Title II of ADA. [322]

While not rejecting the fiscal crisis fundamental alteration defense, the Tenth Circuit stated that courts will scrutinize state actions that impede integration rather than deferring to reasonable state judgments. "The fact that Oklahoma has a fiscal problem, by itself, does not lead to an automatic conclusion that preservation of unlimited medically necessary prescription benefits for participants in the Advantage program will result in a fundamental alteration." [323] *Fisher* further clarifies the lines initially drawn by the Ninth Circuit in *Townsend* by defining that "fiscal decisions" does not mean the courts will defer to state judgments any time the state acts and defends its action by asserting fiscal crisis.

ACCESS TO QUALITY CARE IN COMMUNITY SETTINGS: BALL V. BIEDESS (2004)

In *Ball v. Biedess,* [324] Medicaid recipients receiving home-based care alleged that the Arizona Health Care Cost Containment System (AHCCCS) was supplying an insufficient number of home care workers for HCBS beneficiaries. The plaintiffs charged that under the federal Medicaid Law and ADA, the AHCCCS administration is required to make home and personal attendant services available in a scope and amount necessary to allow individuals receiving Medicaid services to live in the community. The failure to provide an adequate number of home care workers threatened to force these individuals, in their desire for adequate medical care, into nursing facilities.

The District Court ruled that the AHCCCS program failed to ensure that recipients of HCBS received the prescribed services. The court ordered AHCCCS to make extensive reforms to ensure that it "provide [s] each individual who qualifies for its services with those services for which the individual qualifies without gaps in service." [325]

The court, citing the public health regulations, stated that agencies must make payments to home and personal attendant service workers that are sufficient to "to enlist enough providers so that services under the plan are available to recipients at least to the extent that those services are available to the general population." [326] AHCCCS, the court ordered, must establish payment rates and enlist a sufficient number of providers to ensure that Medicaid recipients who are qualified to receive community-based care receive quality of care and have access to such care. [327]

The ruling, like that in *Fisher*, represents a victory for Medicaid recipients in community-based settings. The courts are consistently prohibiting states from presenting those in community-based care settings with a Hobson's choice of remaining in the community with limited services or receiving a full array of supports and services only in restrictive institutional settings. "Institutionalization is not a viable choice," wrote the *Ball* court, "for patients who qualify for AHCCCS programs but do not receive the services to which they are entitled." [328] Recipients of Medicaid services must not be forced, through state funding decisions or state inaction, to choose between inadequate access to needed LTSS in the community and institutionalization.

Budget problems will continue to serve as the leading defense used by states for slowing the pace of systems reform and rebalancing public expenditures to support a more comprehensive set of choices for individuals with disabilities to live at home and in community settings with needed LTSS.

Current judicial decisions represent a glimpse of divergent views of analysis regarding the future balancing of interests between state discretion in fashioning the LTSS system with public resources and consumer expectations for expanded choices to benefit from services in the least restrictive environment. The slow pace of comprehensive reform continues to bring judicial intervention. Over a dozen states have agreed to court settlements that will accelerate the development of community supports and choices for targeted classes of individuals with disabilities. [329]

Part XI

RECHARTING THE COURSE

A final checklist of challenges and forecast summary for navigating the rough waters of reform.

Archeologists discovered the tomb of the “boy king” Tutankhamun in Egypt’s romantic Valley of the Kings in 1922, 3,000 years after his death. [330] Some say it was the richest discovery in the history of mankind, uncovering five burial chambers and more than 5,000 works of art. The Untold Story describes the intrigue of professional archeologists and their relentless passion for uncovering antiquity. It is rumored that the major benefactor for the project died shortly after illegally entering one of the burial chambers not yet sanctioned by the Egyptian government. However, there was little information uncovered about Tutankhamen except for a lonely quote found on the last shrine [chamber] surrounding his great sarcophagus, “I have seen yesterday; I know tomorrow.” [331]

Archeologists spent their whole careers digging for the tomb of Tutankhamun and, in the end, the prize was the world’s grandest collection of rare objects of art. The King Tut exhibit was shown around the world and eventually ended up in an Egyptian museum, where deterioration rapidly set in due to inadequate preservation. The significance of the find was major in the world of archeology but left many unanswered questions as to who the 15-year-old boy-king was as a person and a ruler.

CONCLUDING THOUGHTS

As the nation drags anchor and moves forward on this voyage that will rechart the delivery and financing of LTSS, it is important to think about what archeologists interested in aging and disability might find 1,000 years from now if they were to visit the first decade of the 21st century. What policies would they find that reflected how a country only a few hundred years old responded to its growing population with disabilities and extended life span? What values and beliefs would these policies reveal about the democracy?

The current crisis in health care and LTSS is at a crossroads. How Americans respond to the critical issues facing millions of its seniors and young people with disabilities will determine the health of the nation for generations to come. The picture presented today identifies little public or political interest in putting these issues onto the national agenda. It is, however, first on the agenda of every state budget committee. At 22 percent of the budget, the rising costs of health care and LTSS are no longer sustainable. This fiscal crisis will cause rough waters for the LTSS voyage and for the identified captain and crew.

This review found that the current federal experience provides a complex picture over time of response to a growing segment of the population in need of LTSS to maintain their dignity and independence in daily living. Depending on where you live, your age, your economic status, and the nature of your disability, you will face different options and levels of response to home- and community-based needs.

There is no single federal program or federal agency charged with responsibility for management, funding, and oversight of LTSS at home and in the community. There is no single entry point at a community level for individuals with disabilities and seniors to learn about and access service and support options. There are multiple federal programs with varying policy objectives that embrace the values of consumer choice and independence in daily living, but there is no comprehensive, integrated delivery system. There are also differences in service philosophy and administration between programs for individuals with disabilities under age 65 and those for seniors.

The tugboats are full of young people and seniors with disabilities who continue to push forward with the need for consumer direction and control and more responsibility for managing support options and caregivers. There remains significant disagreement about the elements of a comprehensive LTSS system, the relationship between the medical model as the dominant paradigm versus a social empowerment model of consumer choice and control, and how to balance family caregiving with public responsibility for long-term supports.

This chapter on current federal experience provides a rationale for rethinking current public policy regarding LTSS. Disability is a natural part of the human experience over time. At some point, many Americans will need assistance with such activities as dressing, bathing, eating, and daily living. The current system of entitlement provides maximum assistance with daily living and personal assistance in the most restrictive environments, skilled nursing facilities. Integrated delivery systems that build on a presumption of support at home and in the community must be built through the design and development of consistent policy goals across all federal agencies. The captains are left with a final checklist of challenges and a brief summary of forecasts for navigating the rough waters of reform.

CHECKLIST OF CHALLENGES

- **Financial.** Runaway costs of state Medicaid spending and impact on people and children with disabilities.
- **Policy.** Lack of coherent public policy that people with disabilities should have access to LTSS to maintain lifestyle and independence.
- **Political.** Unwillingness of Congress to put the issue of LTSS on the national agenda, although the issue is very high on state agendas because of rising costs.
- **Public Perception.** Low interest in and understanding of the urgency and importance to all Americans of the current growing crisis in the need for LTSS.
- **Federal System.** Fragmented across agencies, with no single agency managing or coordinating reform.
- **State Systems.** Fragmented delivery systems with uneven access and service provisions depending on the state’s fiscal health.
- **Workforce.** Role of government in addressing the challenges of the current workforce of caregivers, both formal and informal.
- **Legislation.** Current system of LTC is unbalanced toward institutional and restrictive environments.
- **Demographic Shifts.** The impact of extended life expectancies, decreased fertility rates, and more women in the workforce, along with rising disability rates for those age 65 and under.
- **Needs.** More consumer direction and control and understanding of what LTSS are needed for people across disabilities, gender, age, and ethnic background.

FORECAST SUMMARY

Forecast: Ask the Hard Questions

William Scanlon writes that most exercises in forecasting visions for LTSS policy do not address the following hard questions about goals and outcomes: What services should be guaranteed to individuals unable to provide for themselves? What protections from catastrophic loss, financial or otherwise, should be afforded? Most important, who will pay for these protections? [332]

Forecast: Don't Forget the Beneficiaries

Robert Schalock suggests a three-part test to evaluate future policy development that focuses on the following:

- The individual beneficiary and the impact of any changes in eligibility, funding, and services delivery on their lives related to independence, productivity, community, and personal well-being.
- The service delivery level, and any changes in service delivery patterns and the conversion of the system away from programs and toward individuals that allows for personal control and individual choice and is truly based on the type and intensity of individualized needed supports.
- The societal level and its ability to integrate disability policy, funding, and outcomes-based evaluation with equality of opportunity, full participation, independent living, and economic self-sufficiency. [333]

Forecast: Prepare to Navigate Choppy Waters and Difficult Storms

The 2004 NCD report *Consumer-Directed Health Care: How Well Does It Work?* identified five factors that stand in the way of change in policy and practice to expand consumer choice and participation in an LTSS system for the future:

- Beware of the institutional bias of Medicaid in the use of HCBS waivers that require states to demonstrate cost neutrality with a comparison of costs to institutional care.

- Expect to find an underpaid, shrinking labor force that is unable to keep up with growing demand.
- Recognize that the increasing share of total budget costs now averages 22 percent of state budgets.
- Look out for consumer and caregiver education and skill-building programs needed by beneficiaries to develop the skills to set goals and take responsibility for managing budgets and service delivery.
- Do not expect to see common definitions in research that has effectively evaluated outcome and cost data for consumer-directed services. [334]

Forecast: Look for the Favorable Winds

Positive forces for change began with the passage of ADA in 1990, followed by the Supreme Court's *Olmstead* decision in 1999 and the subsequent Administration actions from 2000 to the present. These forces provide a platform to support policy and program changes for a long-term support system that embraces consumer choice to live in the least restrictive environment at home and benefit from community participation. Look also for new court decisions pushing the states to accelerate systems change.

Forecast: Keep the Deliberations Fair

Estes and Linkins suggest that the approach to LTSS in the United States for beneficiaries and family caregivers must be one that is "socially just, that promotes gender, ethnic, intergenerational, and class justice through a system that is accessible, affordable, and universal." [335]

WORDS FOR SAFE TRAVEL

Rheinhold Niebuhr, a Protestant theologian, wrote about the "social gospel" movement in the early part of the 20th century and reminded Americans that designing just policy cannot be done from some esoteric ethic that may or may not apply to a certain group of people and that Americans must first and foremost agree on what it means to be human and what it means to be just. [336]

Appendix 1.A.

COMPARING CAREGIVER CHARACTERISTICS BY AGE OF RECIPIENT

	Recipients 18–49	**Recipients 50 or Older**
Average recipient age	33	75
Relationship	Adult child, sibling, or nonrelative	Mother, grandmother, or father
Problems/Illnesses	Mental illness, depression, or emotional problems financial problems	Aging, Alzheimer's, cancer, diabetes, heart disease, mobility, blindness
Average caregiver age	41	47
Demographics	Working	Retired, married
Support	Primary caregivers feel financial hardships	Receive more funding Provide three or more activities of daily living

Base*:* 1,247 caregivers in the United States.

Source*:* Caregiving in the United States, National Alliance for Caregiving, and American Association of Retired Persons, 2004.

Appendix 1.B.

DEMOGRAPHIC PROFILE OF CAREGIVERS BY AGE OF RECIPIENT

	Total	Caregivers of recipients 18–49	Caregivers of recipients 50+
Total	100%	20%	79%
Gender			
Male	39%	44%	37%
Female	61	56	63
Race of Caregiver			
White	73%	69%	74%
African American	12	16	11
Hispanic	10	11	10
Asian American	4	4	4
Age of Caregiver			
Under 35 years old	26%	42%	22%
35–49	32	30	33
50–64	30	19	32
65 or older	13	9	13
Mean (years)	46 yrs	41 yrs	47 yrs
Marital status			
Married/living with partner	62%	53%	63%
Single, never married	18	22	17
Separated/divorced	14	17	14
Widowed	6	7	6
Education attainment			
High school or less	34%	41%	33%
Some college	27	3	26
Technical school	3	2	3

	Total	**Caregivers of recipients 18–49**	**Caregivers of recipients 50+**
College graduate	22	18	23
Graduate school +	13	8	14
Current employment			
Employed full time	48%	54%	47%
Employed part time	11	12	10
Not employed	41	33	43
Household income			
<$30K	25%	32%	22%
$30K–$50K	26	27	25
$50K–$75K	18	19	18
$75K–$100K	9	9	9
$100K +	15	7	17

Source*:* National Alliance for Caregiving and AARP. (2004) Caregiving in the U.S. Available at: www.caregiving.org/04finalreport.pdf.

Appendix 1.C.

FEDERAL DEMONSTRATIONS

Long-Term Services and Support: Reform Strategies			
Initiative	**Funders**	**Focus**	**Evaluation**
Cash and Counseling	Administration on Aging, Robert Wood Johnson Foundation, Office of Planning and Evaluation, and APSE at the Department of Health and Human Services $25 million 2004–2006 www.cashandcounseling.org	Individuals of various ages and disabilities direct their own supportive services and hire their own care managers with an individualized budget. Eleven new states funded in October 2004 that follow pilots in Florida, New Jersey, and Arkansas. New states are Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia.	Independent evaluation will study costs, consumer satisfaction, access to home-based services, and quality-of-life changes.

Appendix 1.C. (Continued)

Long-Term Services and Support: Reform Strategies			
Initiative	**Funders**	**Focus**	**Evaluation**
Aging and Disability Resource Centers (ADRCs)	Administration on Aging and Centers for Medicare and Medicaid Services (CMS) $19 million 2003–2006 www.adrc.org	Create a single, coordinated system of information and access for all people seeking long-term support to enhance individual choice and informed decision making. The 23 states funded are Louisiana, Maine, Maryland, Massachusetts, Minnesota, Montana, New Hampshire, New Jersey, Pennsylvania, Rhode Island, South Carolina, West Virginia, Arkansas, Alaska, California, Florida, Georgia, Illinois, Indiana, Iowa, New Mexico, North Carolina, and Wisconsin.	Will evaluate whether the Resource Centers increase informed decision making, meaningful choice, and access to long-term services and supports in the most integrated setting.
Real Choice Systems Change Grants	CMS $200 million 2001–2007 www.hcbs.org	States are funded to build infrastructure and pursue policy changes that result in “effective and enduring improvements in community long-term support systems.” There have been four rounds of funding that states have competed for that target specific theme areas, such as integrating long-term supports with accessible affordable housing, improving and expanding personal assistance services that are consumer directed, and enhancing quality management systems.	Focus on sustainable system changes concerning the approach to service delivery, exercise of meaningful choices with expanded support options to live in the most integrated setting appropriate, rebalancing of funding to expand

Appendix 1.C. (Continued)

Long-Term Services and Support: Reform Strategies			
Initiative	**Funders**	**Focus**	**Evaluation**
		Other grants focus on comprehensive system reform efforts.	community living preferences and priorities, and nursing home diversion and transition. All states have one or more grants.
Independence Plus Waiver Demonstration	CMS www.cms.hhs.gov/ independenceplus	States are funded through the HCBS waiver authority to offer individualized budgets and consumer self-direction. Nine states have been approved: California, New Hampshire, Louisiana, South Carolina, Maryland, Florida, North Carolina, Connecticut, and Delaware	Focus on cost savings, consumer satisfaction and outcomes, and other benefits of consumer direction.

Source*:* Author’s compilation.

Appendix 1.D.

OVERVIEW OF CASH AND COUNSELING DEMONSTRATIONS

	Arkansas	**New Jersey**	**Florida**
State program name	Independent Choices	Personal Preference	Consumer-Directed Care
Implementation date	December 1998	November 1999	May 2000
Authority for personal assistance services	Medicaid state plan: personal care option	Medicaid state plan: personal care option	Section 1915(c) HCBS waivers
Populations served	Elderly and adults with a physical disability	Elderly and adults with a physical disability	Elderly, adults with a physical disability, and children with a developmental disability
Territory covered	Statewide	Statewide	Central and South Florida: Elderly and adults with a physical disability Statewide: Children and adults with developmental disabilities
Average monthly cash allotment	$350	$1,300	$300

Appendix 1.D. Continued

	Arkansas	New Jersey	Florida
Formula for determining cash allotment	A rate corresponding to an individual's assessed number of hours of personal care reduced between 0% and 30% to account for actual number of hours service used versus projected use.	Amount based on the numbers of hours in the individual's previous personal care assessment multiplied by the state's hourly rates for personal care.	Individual's historic Medicaid HCBS waiver expenditures reduced between 8% and 17% to account for actual use of services versus projected use.
Final caseload (for evaluation)	2,008 people	1,762 people	2,820 people

Source*:* University of Maryland, Center on Aging, Cash and Counseling At-a-Glance, at www.hhp.umd.edu/AGING/CCDemo/ataglance.html, accessed June 2005.

Appendix 1.E.

50 States, the District of Columbia, and U.S. Territories with Initiatives to Improve Access to Long-Term Care Services

State	Integrated LTC Systems	Streamlined Eligibility Determinations	Expanded Eligibility	Nursing Facility Resident Transition*	Informed Consumer Choice	Other**
Alabama	x			x	x	x
Alaska		x		x	x	x
Arkansas	x	x		x	x	x
California				x	x	x
Colorado	x	x		x	x	x
Connecticut	x			x	x	
Delaware	x		x	x	x	x
District of Columbia	x	x	x	x	x	x
Florida	x			x	x	x
Georgia	x			x		x
Guam	x	x		x	x	
Hawaii	x	x			x	x
Idaho	x		x	x	x	x
Illinois	x	x		x	x	x
Indiana		x	x	x	x	
Iowa	x			x	x	
Kansas			x	x	x	
Kentucky				x	x	x
Louisiana	x	x	x	x	x	x
Maine						x
Maryland				x	x	

Appendix 1.E. Continued

State	Integrated LTC Systems	Streamlined Eligibility Determinations	Expanded Eligibility	Nursing Facility Resident Transition*	Informed Consumer Choice	Other**
Massachusetts	x	x	x	x	x	x
Michigan	x	x		x	x	x
Minnesota	x			x	x	x
Mississippi				x		x
Missouri	x	x		x	x	x
Montana					x	x
Nebraska	x			x	x	
Nevada				x	x	x
New Hampshire	x	x		x	x	x
New Jersey	x			x		x
New York				x		
North Carolina	x		x	x	x	
North Dakota					x	
No. Mariana Islands	x				x	
Ohio	x			x	x	
Oklahoma		x	x	x	x	x
Oregon					x	
Pennsylvania	x	x	x	x	x	x
Rhode Island	x			x	x	x
South Carolina	x			x	x	x
Tennessee	x		x	x	x	x
Texas	x			x	x	x
Utah	x			x	x	x
Vermont	x	x	x	x	x	x
Virginia					x	x
Washington		x	x	x	x	x
West Virginia		x	x	x	x	x
Wisconsin	x	x	x	x	x	x
Wyoming		x	x	x	x	x
Total	32	20	16	43	45	38

*NFT transition and diversion activities encompass a range of activities, including increasing housing availability and accessibility, developing peer support networks, and developing outreach materials and conducting outreach.

**This category includes the areas of community education, housing, home modifications, assistive technology, and transportation.

Source*:* HCBS, www.hcbs.org, accessed June 2005.

Appendix 1.F.

FEDERAL TABLES

(CONTINUED ON NEXT PAGE)

Table 1. Federal Health Care Programs

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Directed	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation	Utilization: Trends Over Time	Universal Design
Medicare Part A	Social Security Act Amendments of 1965, Title XVIII, Part A	Centers for Medicare and Medicaid Services (CMS)	Age, qualified disability	Hospital insurance for elderly and disabled who qualify, short-term acute care, skilled nursing care, home health, hospice care.	No	No	Yes	Direct Payments	No	FY 03 $150,970,000,000 FY 04 est $166,182,000,000 FY 05 est $181,350,000,000 2003 enrollees 40,884,000 2004 est enrollees 41,607,000 2005 est enrollees 42,280,000	No
Medicare Part B	Social Security Act Amendments of 1965, Title XVIII, Part B	CMS	Age, qualified disability	Supplemental health insurance, home health, outpatient rehabilitation services, physical, speech and occupational therapy. Durable medical equipment at home.	Varies	Varies	Yes	Direct Payments	No	FY 03 $121,628,633,000 FY 04 est $127,976,000,000 FY 05 est $140,705,000,000 2003 enrollees 38,369,000 2004 est enrollees 38,928,000 2005 est enrollees 39,477,000	No

Table 1. (Continued)

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Directed	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation	Utilization: Trends Over Time	Universal Design
Medicare Part D	Social Security Act Amendments of 2003	CMS	Age, qualified disability	Prescription drugs.	No	No	No	Direct benefit	No	Estimates of costs exceed $100 billion	N/A
Medicaid	Social Security Act, Title XIX, 1965	CMS	Means/ disability	Skilled nursing, home health, case management, personal care, rehabilitation.	Varies	Mix	Yes	Federal/ state cost share: entitlement	No	FY 03 $169,105,405,000 FY 04 est $177,232,410,000 FY 05 est $183,302,865,000 2003 enrollees 41,900,000 2004 est enrollees 42,900,000 2005 est enrollees 43,600,000	No

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 2. Federal Social Support, Personal Assistance Services, and Home Care Programs

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Directed	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation or Systems Change	Utilization: Trends Over Time	Universal Design
Independent Living State Grants	Rehabilitation Act 1973 Title VII	Department of Education (DOE), Office of Assistant Secretary for Special Education and Rehabilitative Services	Disability	Support operation of statewide independent living councils (SILCs)	N/A	Yes	Yes	Formula Grants	Yes	FY 03 $22,151,000 FY 04 est $22,020,000 FY 05 est $22,020,000 FY 2003 78 designated state units received funds	No
Centers for Independent Living	Rehabilitation Act 1973 Title VII	DOE, Office of Assistant Secretary for Special Education and Rehabilitative Services	Disability	Establishment and operation of CILs or SILCs	Yes	Yes	Yes	Competitive Grants	Yes	FY 03 $69,545,000 FY 04 est $73,563,000 FY 05 est $73,563,000 Grants support the operation of approximately 320 centers	Yes

Table 2. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Directed	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation or Systems Change	Utilization: Trends Over Time	Universal Design
Special Programs for the Aging	Title III, Part B 1965	Administration on Aging (AOA)/Department of Health and Human Services (HHS)	Age (60+)	Implementation and coordination of community-based supportive services	No	Varies	Yes	Formula Grants	Varies	FY 03 $355,673,000 FY 04 est $353,888,665 FY 05 est 357,000,000 FY 2003 56 grants awarded FYs 2004 and 2005 56 grants anticipated	Varies
Senior Companion Program	Domestic Volunteer Service Act 1973	Federal Agency Corporation for National and Community Service	Senior Companions (60+); adults served (21+); one or more activity of daily living (ADL) limitation and at risk for institutionalization	Engaging people (60+) and providing supportive services to disabled adults	Varies	Yes	Yes	Matching Grants	No	FY 03 $45,255,000 FY 04 est $45,255,000 FY 05 est $45,548,000	No

Table 2. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Directed	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation or Systems Change	Utilization: Trends Over Time	Universal Design
Medicaid HCBS Waiver	Omnibus Reconciliation Act (OBRA) Section 2176 1981	CMS	Means test, state variation medically needy, and waivers specific to a target population (elderly, mental retardation, physical disabilities, brain injury)	Respite care, personal care, habilitation, environmental adaptations, assistive technology, service coordination	Varies	Varies	Yes	State/ federal cost share	Yes	FY 02 $16.3 billion FY 03 $18.6 billion FY 04 $19 billion	Varies
Social Services Block Grant	Social Security Act, Title XX, OBRA 1981	Administration for Children and Families, HHS	Means tested, low-income individuals and families	Grants to states for support of social services programs	Varies	No	Yes	Formula Grants	No	FY 03 $1.7 billion FY 04 est $1.7 billion FY 05 est $1.7 billion FY 2003 57 grants awarded FYs 2004 and 2005 est 57 grants	Varies

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 3. Federal Income Maintenance Support Programs

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation or Systems Change	Utilization: Trends Over Time	Universal Design
Social Security	Social Security Act of 1935	Social Security Administration (SSA)	Retired workers (62+)	Replace lost earnings due to retirement	Yes	N/A	No	Direct payments with unrestricted use	No	FY 03 $330,606,100,000 FY 04 est $345,573,400,000 FY 05 est $354,307,700,000 2003 enrollees 32,408,700 2004 est enrollees 32,749,900 2005 est enrollees 33,136,400	N/A
Supplemental Security Income (SSI)	Social Security Act of 1935, Title XVI	SSA	Means test, 65+, or qualified disabled	Ensure minimum level of income	Yes	N/A	Some states supplement	Direct payments—nonrestricted	No	FY 03 $32,535,000,000 FY 04 est $34,285,000,000 FY 05 est $38,363,000,000 2003 enrollees 6,553,000 2004 est enrollees 6,711,000 2005 est enrollees 6,867,000	N/A

Table 3. (Continued)

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation or Systems Change	Utilization: Trends Over Time	Universal Design
Social Security Disability Insurance (SSDI)	Social Security Act of 1935, Title II	SSA	Qualified disabled workers under full retirement age	Ensure minimum level of income	Yes	N/A	Yes	Direct payments—nonrestricted	No	FY 03 $69,788,000,000 FY 04 est $76,639,000,000 FY 05 est $81,821,000,000 2003 enrollees 7,330,000 2004 est enrollees 7,664,000 2005 est enrollees 7,996,000	N/A

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 4. Federal Housing Programs

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Housing and Urban Development (HUD) 811	2000	HUD	Disability/18+ /means test	Supportive housing for people with disabilities, group homes, apartments, cooperatives	No	No	Local	Formula and competitive grants for local nonprofit sponsors	No	FY 03 $250,515,000 FY 04 est $250,570,000 FY 05 est $248,700,000 FY 2003 Funded 1,484 units FY 2004 Anticipate similar level of funding	Varies
HUD 202	1959	HUD	62+/means test	Supportive housing for people who are aging, congregate living	No	No	Local	Formula and competitive grants for local nonprofit sponsors	No	FY 03 $783,286,000 FY 04 est $778,320,000 FY 05 est $773,320,000 FY 2003 Funded 5,980 units FY 2004 Anticipate similar level of funding	Varies

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
HOME	1990	HUD	Means test individuals and families	Grants to state/cities for affordable housing development and rehabilitation	No	No	Yes	Block grants to state and large MSAs 80/20 funding mix	Yes	FY 03 $1,946,167,500 FY 04 est $1,963,745,140 FY 05 est $2,082,000,000 As of 9-30-03, 758,504 units committed; 491,482 units were completed; and 92,286 families received tenant-based rental assistance	No

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Community Development Block Grant (CDBG)	1974	HUD	Means test individuals and families	Grants to state/cities for housing and community development	No	No	Yes	Block grant to state and large MSAs	No	FY 03 $3,037,677,000 FY 04 est $3,031,592,000 FY 05 est $3,026,721,000 FY 2004 Approx 1,100 units of local government eligible to receive grants	No
HOPE VI	1995	HUD	Means test eligible for public housing	Affordable redevelopment of public housing	No	No	Yes	Grants to public housing authorities	Yes	FY 03 $595,144,000 FY 04 567,530,000 FY 05 141,000,000	Yes

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Housing Opportunities for Persons with AIDS (HOPWA)	1992	HUD	Means test for people living with HIV/AIDS	Supportive housing/services for people with AIDS and coresident family members	No	No	Yes	Grants to states	Yes	FY 03 $290,102,000 FY 04 $294,751,000 FY 05 est $294,751,000	No
Continuum of Care Program (COC): Supportive Housing Program, Shelter Plus Care, Single-Room Occupancy (competitive) and Emergency Shelter Grants (ESG) (noncompetitive)	1996	HUD	Homeless individuals and others eligible for transitional housing services	Development of housing and supportive services for homeless individuals and families	No	No	Yes	Grants to states	Yes	FY 02 $969,000,000 (COC) $150,000,000 (ESG) FY 03 $1.1 billion (COC) $159,000,000 (ESG)	No

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Continuum of Care Program (COC): Supportive Housing Program, Shelter Plus Care, Single-Room Occupancy (competitive) and Emergency Shelter Grants (ESG) (noncompetitive)	1996	HUD	Homeless individuals and others eligible for transitional housing services	Development of housing and supportive services for homeless individuals and families	No	No	Yes	Grants to states	Yes	FY 02 $969,000,000 (COC) $150,000,000 (ESG) FY 03 $1.1 billion (COC) $159,000,000 (ESG)	No

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Section 8 Housing Choice Voucher Program	1975	HUD	Means test	Rental assistance to low-income families, elderly, and people with disabilities	Yes	No	Yes	Grants to states and local housing agencies	No	FY 03 $11,272,905,390 FY 04 est $14,712,340,909 FY 05 est $13,339,000,000 FY 2003 Approx 2,077,000 vouchers available FY 2004 est 2,100,000 vouchers	No

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Family Self-Sufficiency (FSS) Program	1990	HUD	Families who receive assistance under the housing choice voucher program are eligible to participate in the FSS program.	Encourages communities to develop local strategies to help assisted families obtain employment that will lead to economic independence and self-sufficiency.	Yes	Yes	Yes	No specific funding is provided by HUD. Public Housing Authorities (PHAs) that administer a FSS program will provide opportunities for families participating in the housing choice voucher program to also receive assistance under the FSS program	Yes	N/A	No

Table 4. (Continued)

Domains And Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Section 502 Rural Housing Service	1949	U.S. Department of Agriculture (USDA)	Means test for individuals and families at low incomes	Direct and guaranteed loans to build, buy, or improve applicant's permanent residence	Yes	No	Yes	Formula	No	Direct Loans FY 03 $1,037,864,233 FY 04 est $1,351,392,000 FY 05 est $1,100,000,000 Guaranteed Loans FY 03 $3,086,764,226 FY 04 est $3,123,000,000 FY 05 est $2,715,000,000 FY 2002 Total of 14,727 new direct loans and 29,218 guaranteed loans were made	No

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 5. Federal Transportation Programs

Domains and Programs	**Year Authorized**	**Responsible Agency**	**Eligibility**	**Scope of Service**	**Consumer Direction**	**Consumer-Perspective Quality**	**State/ Local Partners**	**Financing Mechanism**	**Innovation Or Systems Change**	**Utilization: Trends Over Time**	**Universal Design**
Capital Assistance Program for Elderly Persons and Persons with Disabilities Section 5310	1975	Federal Transit Administration (FTA)/ Department of Transportation (DOT)	Elderly/ disabled	Provide efficient and coordinated specialized transport	No	No	Yes	Formula grants	No	FY 03 $92,901,000 FY 04 est $98,361,000 FY 05 est $88,280,000	No
Job Access Reverse Commute Section 5311	1999	FTA/ DOT	Welfare recipients Low-income people	To develop transportation services to connect to employment and support services	No	No	Yes	Project grants	Yes	FY 03 $135,618,000 FY 04 est $153,993,000 FY 05 est $135,461,000 Services in 45 states plus the District of Columbia have been funded through more than 300 grants and grant amendments	No

Table 5. Continued

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
United We Ride State Coordination Grants	2004	FTA/ DOT	Transportation-disadvantaged (individuals with low incomes, older adults, people with disabilities)	To assist states that want to strengthen or jump start efforts to coordinate human service transportation	No	Yes	Yes	State grants	Yes	The total amount available for grants will be at least $1,000,000 for up to 50 awards. Funding will range from $20,000 to $35,000 per grant.	Varies

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 6. Federal Nutrition Programs

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Title III Part C Nutrition Services Elderly Nutrition Program (ENP)	Older Americans Act 1965	Administration on Aging (AOA) /Department of Health and Human Services (HHS)	60+ and spouse and coresident disabled	Support to states for nutrition services congregate or in home	No	Yes	Yes	Formula/ matching 85% federal/15% nonfederal	No	Congregate FY 03 $384,591,798 FY 04 est $386,352,989 FY 05 est $388,646,000 Home delivered FY 03 $180,984,902 FY 04 est $179,917,188 FY 05 est $180,985,000 FY 2003 56 grants FY 2004/05 est 56 grants	No

Table 6. (Continued)

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope Of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Senior Farmers' Market Nutrition Program (SFMNP)	2002	USDA	60+/ means tested	Support to states for low-income elders to buy fresh food at farmers' markets and roadside stands	Yes	No	Yes	Grants to states	Yes	FY 03 $0 FY 04 $0 FY 05 est $20,000,000 FY 2003 Grant levels to state agencies totaled $16.8 million, including $1.8 million in unspent funds from FY 2002.	No
Food Stamps Reauthorization Act	2002	USDA	60+ or SSI disabled, means tested	Nutrition-related assistance	Yes	Yes	Yes	Grants to states	Yes	Direct Payments FY 03 $24,606,021,000 FY 04 est $29,301,274,000 FY 05 est $31,976,563,000	No

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 7. Federal Assistive Technology Programs

Domains and Programs	Year Authorized	Responsible Agency	Eligibility	Scope of Service	Consumer Direction	Consumer-Perspective Quality	State/ Local Partners	Financing Mechanism	Innovation Or Systems Change	Utilization: Trends Over Time	Universal Design
Assistive Technology Act of 1998	1998, reauthorized 2004	The Office of the Assistant Secretary for Special Education and Rehabilitative Services Department of Education	Individuals with disabilities	States may provide assistance to statewide community-based organizations or directly to individuals with disabilities of all ages	No	Yes	Yes	Project grants (discretionary) Project grants (contracts)	No	FY 03 $26,227,000 FY 04 est $25,943,000 FY 05 $21,524,000 FY 2003 26 awards were made	Yes

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Table 8. Federal Caregiver Support Programs

Domains and Programs	**Year Authorized**	**Responsible Agency**	**Eligibility**	**Scope of Service**	**Consumer Direction**	**Consumer-Perspective Quality**	**State/ Local Partners**	**Financing Mechanism**	**Innovation Or Systems Change**	**Utilization: Trends Over Time**	**Universal Design**
National Family Caregiver Support	Older Americans Act, as amended, Title III, Part E and VI, Part C.	Administration on Aging	Family caregivers, grandparents, and older individuals who are relative caregivers	Information and referral, respite, training	Varies	Varies	Yes	Formula grants 75% federal and 25% nonfederal	Yes	FY 03 $155,234,375 FY 04 est $159,056,000 FY 05 est $161,867,000	Varies

Source*:* Catalog of Federal Domestic Assistance. General Services Administration, Office of Governmentwide Policy, Office of Acquisition Policy, Regulatory and Federal Assistance Publication Division. www.cfda.gov, accessed June 2005.

Appendix 1.G.

CONGRESSIONAL OVERSIGHT OF FEDERAL PROGRAMS

Federal Health Care Programs

Program Name	Purpose	Act* Original Act or most recent Congressional activity	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Medicare (Part A) (Medicare Hospital Insurance)	To provide hospital insurance protection for covered services to people age 65 or above, to certain disabled people, and to individuals with chronic renal disease.	Social Security Act Amendments of 1965, Title XVIII, Part A, P.L. 89-97	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	Committee on Ways and Means	(1) Health, (2) Social Security	Department of Health and Human Services, Centers for Medicare and Medicaid Services

Federal Health Care Programs (Continued)

Program Name	Purpose	Act* Original Act or most recent Congressional activity	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Medicare (Part B) (Medicare Supplementary Medical Insurance)	To provide medical insurance protection for covered services to people age 65 or over, to certain disabled people, and to individuals with end-stage renal disease who elect this coverage.	Social Security Act Amendments of 1965, Title XVIII, Part B, P.L. 89-97	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	Committee on Ways and Means	(1) Health, (2) Social Security	Department of Health and Human Services, Centers for Medicare and Medicaid Services
Medicare (Part D)	Under Part D of the Social Security Act, the Medicare program includes a voluntary prescription drug benefit. Beneficiaries entitled to Part A and enrolled in Part B, enrollees in Medicare Advantage private fee-for-service plans, and enrollees in Medicare Savings Account Plans will be eligible for the prescription drug benefit. The prescription drug benefit is available to eligible individuals beginning January 1, 2006.	Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P. L. No. 108-173, 117 Stat. 2066, codified at 42 U.S.C. sec. 1395w-101)	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	Committee on Ways and Means	(1) Health, (2) Social Security	Department of Health and Human Services, Centers for Medicare and Medicaid Services

Federal Health Care Programs (Continued)

Program Name	Purpose	Act* Original Act or most recent Congressional activity	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Medicaid	To provide financial assistance to states for payments of medical assistance on behalf of cash assistance recipients, children, pregnant women, and the aged who meet income and resource requirements, and other categorically eligible groups. In certain states that elect to provide such coverage, medically needy people, who, except for income and resources, would be eligible for cash assistance, may be eligible for medical assistance payments under this program. Financial assistance is provided to states to pay for Medicare premiums, copayments, and deductibles of qualified Medicare beneficiaries meeting certain income requirements. More limited financial assistance is available for certain Medicare beneficiaries with higher incomes.	Medicaid Act (Aug. 14, 1935, ch. 531, Title XIX, as added July 30, 1965, P.L. 89-97, Title I, § 121(a), 79 Stat. 343)	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	(1) Committee on Ways and Means (2) Committee on Energy and Commerce	Ways and Means: (1) Health, (2) Social Security; Energy and Commerce: Subcommittee on Health	Department of Health and Human Services, Centers for Medicare and Medicaid Services

Federal Health Care Programs (Continued)

Program Name	Purpose	Act* Original Act or most recent Congressional activity	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Medicaid, Home- and Community-Based Services (HCBS) Waiver	Program gives states flexibility to design programs to meet the specific needs of defined groups. States may create programs to serve the elderly, people with physical disabilities, developmental disabilities, mental retardation, or mental illness. States may also target programs by specific illness or condition as well as people with acquired or traumatic brain injury. States can make home- and community-based services available to individuals who would otherwise qualify for Medicaid only if they were in an institutional setting. States may offer a variety of services to participants under an HCBS waiver program and are not limited to the number of services that can be provided. States may use an HCBS waiver program to provide a combination of both traditional medical services as well as nonmedical services.	Social Security Act (Aug. 14, 1935, c. 531, Title XIX, § 1915, as added and amended Aug. 13, 1981, P.L. 97-35, Title XXI, §§ 2175(b), 2176, 2177(a)), Medicare and Medicaid Amendments of 1981 (P.L. 97-35, Title XXI, Aug. 13, 1981, 95 Stat. 783) (codified at 42 U.S.C. sec. 1396n)	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	(1) Committee on Ways and Means, (2) Committee on Energy and Commerce	Ways and Means: (1) Health, (2) Social Security; Energy and Commerce: Subcommittee on Health	Department of Health and Human Services, Centers for Medicare and Medicaid Services

Federal Health Care Programs (Continued)

Program Name	Purpose	Act* Original Act or most recent Congressional activity	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	There are no specific services that must be offered in an HCBS waiver program. There is no limit on the number of services that can be offered under a single waiver program as long as the waiver retains cost-neutrality and the services are necessary to avoid institutionalization.						

Social Support, Personal Assistance Services, Home Care

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
			Committee	**Subcommittee**	**Committee**	**Subcommittee**	
Independent Living State Grants	To assist states in maximizing the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream American society, by providing financial assistance for providing, expanding, and improving the provision of independent living services.	Rehabilitation Act of 1973, as amended, Title VII, Chapter 1, Part B, 29 U.S.C. 796a-796e-3.	Committee on Health, Education, Labor, and Pensions	Varies	Committee on Education and the Workforce	Varies	Department of Education, Office of the Assistant Secretary for Special Education and Rehabilitative Services

Social Support, Personal Assistance Services, Home Care (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
			Committee	**Subcommittee**	**Committee**	**Subcommittee**	
Centers for Independent Living	The program awards grants to locally run nonprofit agencies that are operated by individuals with disabilities and that offer independent living services that include (1) information and referral, (2) independent living skills training, (3) peer counseling, and (4) individual and systems advocacy.	Rehabilitation Act of 1973, as amended, Title VII, Chapter 1, Part B, 29 U.S.C. 796a-796e-3.	Committee on Health, Education, Labor, and Pensions	Varies	Committee on Education and the Workforce	Varies	Department of Education, Office of the Assistant Secretary for Special Education and Rehabilitative Services
Special Programs for the Aging: Discretionary Projects	Grants are made to any public or nonprofit private agency, organization, or institution. These funds may be used to (1) demonstrate new methods and practices to improve the quality and effectiveness of programs and services, (2) evaluate existing programs and services, and (3) conduct applied research and analysis to improve access to and delivery of services to train professionals in the field.	Older Americans Act of 1965, P.L. 89-73, July 14, 1965, 79 Stat. 218, codified at 42 U.S.C. sec. 3001	Committee on Health, Education, Labor, and Pensions	Varies	(1) Committee on Education and the Workforce, (2) Energy and Commerce	Varies	Department of Health and Human Services, Administration on Aging

Social Support, Personal Assistance Services, Home Care (Continued)

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Special Programs for the Aging: Grants for Supportive Services and Senior Centers	Funds are awarded to states to develop and strengthen comprehensive and coordinated service delivery systems through designated state Agencies on Aging and area Agencies on Aging. In addition to supportive nutrition services, these may be used to support other services, including renovation, acquisition and alteration, and construction of multipurpose senior centers. The objective of these services and centers is to maximize the informal support provided to older Americans to enable them to remain in their homes and communities. Providing transportation services, in-home services, and caregiver support services, this program ensures that elders receive the services they need to remain independent.	Older Americans Act of 1965, P.L. 89-73, July 14, 1965, 79 Stat. 218, codified at 42 U.S.C. sec. 3001	Committee on Health, Education, Labor, and Pensions	Varies	(1) Committee on Education and the Workforce, (2) Energy and Commerce	Varies	Department of Health and Human Services, Administration on Aging

Social Support, Personal Assistance Services, Home Care (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Senior Companion Program	The program provides stipends, transportation, physical examinations, insurance, and meals for their volunteers. Assignment of Senior Companions to adults may occur in residential and nonresidential facilities and in their own homes.	Domestic Volunteer Service Act of 1973 (Volunteers in Service to America) (VISTA) (P.L. 93-113, Oct. 1, 1973, 87 Stat. 394) (codified at 42 U.S.C. sec. 4950)	Committee on Health, Education, Labor, and Pensions	Varies	Committee on Education and the Workforce	Varies	Federal Agency Corporation for National and Community Service
Medicaid Home- and Community-Based Services (HCBS) Waiver	Program gives states flexibility to design programs to meet the specific needs of defined groups. States may create programs to serve the elderly, people with physical disabilities, developmental disabilities, mental retardation or mental illness. States may also target programs by specific illness or condition as well as people with acquired or traumatic brain injury. States can make home- and community-based services available to individuals who would otherwise qualify for Medicaid only if they were in an institutional setting. States may offer a variety of services to participants under an HCBS waiver program and are not limited to the number of services that can be provided.	Social Security Act (Aug. 14, 1935, c. 531, Title XIX, § 1915, as added and amended Aug. 13, 1981, P.L. 97-35, Title XXI, §§ 2175(b), 2176, 2177(a)), Medicare and Medicaid Amendments of 1981 (P.L. 97-35, Title XXI, Aug. 13, 1981, 95 Stat. 783) (codified at 42 U.S.C. sec. 1396n)	Committee on Finance	(1) Health Care, (2) Social Security and Family Protection	(1) Committee on Ways and Means, (2) Committee on Energy and Commerce	Ways and Means: (1) Health, (2) Social Security; Energy and Commerce: Subcommittee on Health	Department of Health and Human Services, Centers for Medicare and Medicaid Services

Social Support, Personal Assistance Services, Home Care (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
	States may use an HCBS waiver program to provide a combination of both traditional medical services as well as nonmedical services. There are no specific services that must be offered in an HCBS waiver program.						
Social Services Block Grant		Social Security Act, Title XX, as amended; Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) (codified at 42 U.S.C. sec. 1397 et seq.)	Varies	Varies	Varies	Varies	Department of Health and Human Services, Administration for Children and Families
Social Security	Enables each state, as far as practicable under the conditions in such state, to furnish financial assistance to aged needy individuals. The Social Security Act authorizes to be appropriated for each fiscal year a sum sufficient to carry out the purposes of the social security program. The money made available under the Social Security Act is used for making payments to states that have submitted plans for old-age assistance and had them approved by the Secretary of Health and Human Services.	Social Security Act (Old Age Pension Act) (Aug. 14, 1935, ch. 531, 49 Stat. 620) (codified at 42 U.S.C. sec. 301 et seq.)	Committee on Finance	(1) Health Care, (2) Social Security	Committee on Ways and Means	(1) Health, (2) Social Security	Social Security Administration

Social Support, Personal Assistance Services, Home Care (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Supplemental Security Income	Establishes a national program to provide Supplemental Security Income to individuals who have attained age 65 or are blind or disabled.	Social Security Act, (Old Age Pension Act) (Aug. 14, 1935, ch. 531, title XVI, Sec. 1601), as added P.L. 92-603, title III, Sec. 301, Oct. 30, 1972, 86 Stat. 1465 *(*codified at 42 U.S.C. sec. 1601 et seq.)	Committee on Finance	(1) Health Care, (2) Social Security	Committee on Ways and Means	(1) Health, (2) Social Security	Social Security Administration
Social Security Disability Insurance	To replace part of the earnings lost because of a physical or mental impairment, or a combination of impairments, severe enough to prevent a person from working.	Social Security Act of 1935, Title II, as amended; (P.L. 96-265) (codified at 42 U.S.C. sec. 402, 416, 420-25)	Committee on Finance	(1) Health Care, (2) Social Security	Committee on Ways and Means	(1) Health, (2) Social Security	Social Security Administration

Federal Housing Programs

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
			Committee	**Subcommittee**	**Committee**	**Subcommittee**	
Section 811	The Section 811 program allows people with disabilities to live as independently as possible in the community by increasing the supply of rental housing with the availability of supportive services. The program also provides project rental assistance, which covers the difference between the HUD-approved operating costs of the project and the tenants' contribution toward rent.	Cranston-Gonzalez National Affordable Housing Act (NAHA) (P.L. 101-625, Nov. 28, 1990, 104 Stat. 4079) (codified at 42 U.S.C. sec. 8013)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Office of Housing

Federal Housing Programs (Continued)

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
Section 202	The Section 202 program helps expand the supply of affordable housing with supportive services for the elderly. It provides very low-income elderly with options that allow them to live independently but in an environment that provides support activities such as cleaning, cooking, transportation, etc.	Housing Act of 1959 (P.L. 86-372, Sept. 23, 1959, 73 Stat. 654) (codified at 12 U.S.C. sec. 1701q)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Office of Housing
HOME Investment Partnerships Program	HOME provides formula grants to states and localities that communities use—often in partnership with local nonprofit groups—to fund a wide range of activities that build, buy, and/or rehabilitate affordable housing for rent or homeownership or provide direct rental assistance to low-income people.	Cranston-Gonzalez National Affordable Housing Act (NAHA), Title II (P.L. 101-625, Nov. 28, 1990, 104 Stat. 4079) (codified at 42 U.S.C. sec. 12721)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Community Planning, and Development

Federal Housing Programs (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Community Development Block Grant (CDBG) Programs	To develop viable urban communities, by providing decent housing and a suitable living environment, and by expanding economic opportunities, principally for people of low and moderate income.	Housing and Community Development Act of 1974, Title I, (P.L. 93-383, Aug. 22, 1974, 88 Stat. 633) (codified at 42 U.S.C. sec. 5301 et seq.)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Community Planning, and Development
Homeownership and Opportunity for People Everywhere (HOPE) VI	Revitalization grants enable PHAs to improve the living environment for public housing residents of severely distressed public housing projects through the demolition, substantial rehabilitation, reconfiguration, and/or replacement of severely distressed units; revitalize the sites on which severely distressed public housing projects are located and contribute to the improvement of the surrounding neighborhood; lessen isolation and reduce the concentration of low-income families; build sustainable mixed-income communities; and provide well-coordinated, results-based community and supportive services that directly complement housing redevelopment and that help residents to achieve self-sufficiency, young people to obtain educational excellence, and the	Quality Housing and Work Responsibility Act of 1998 (P.L. 105-276, Title V, Oct. 21, 1998, 112 Stat. 2518)(*codified at* 42 U.S.C. sec. 1437c-1, 1437z-1 *et. seq.*, 1437w, 1437bbb-1 et seq.) *see also*, HOPE VI Program Reauthorization and Small Community Mainstreet	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Public and Indian Housing

Federal Housing Programs (Continued)

Program Name	**Purpose**	**Act* *Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
	community to secure a desirable quality of life. HOPE VI Demolition Grants enable PHAs to fund the demolition of severely distressed public housing units, the relocation of affected residents, and the provision of supportive services to relocated residents.	Rejuvenation and Housing Act of 2003 (P.L. 108-186, Title IV, Dec. 16, 2003, 117 Stat. 2693)					
Housing Opportunities for Persons with AIDS (HOPWA)	The HOPWA Program was established to address the specific needs of people living with HIV/AIDS and their families. HOPWA makes grants to local communities, states, and nonprofit organizations for projects that benefit low-income people medically diagnosed with HIV/AIDS and their families. HOPWA funding provides housing assistance and related supportive services as part of HUD's Consolidated Planning initiative that works in partnership with communities and neighborhoods in managing federal funds appropriated to HIV/AIDS programs. HOPWA grantees are encouraged to develop community-wide strategies and form partnerships with area nonprofit organizations.	AIDS Housing Opportunity Act (Housing Opportunities for People with AIDS Act of 1991) (HOPWA) (P.L. 101-625, Title VIII, Subtitle D, Nov. 28, 1990, 104 Stat. 4375) (*as codified at* 42 U.S.C. sec. 12901 *et. seq.*)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Community Planning, and Development

Federal Housing Programs (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Supportive Housing Program	The Program is designed to promote the development of supportive housing and supportive services to assist homeless people in the transition from homelessness and to enable them to live as independently as possible. Program funds may be used to provide: (1) transitional housing within a 24-month period as well as up to 6 months of follow-up services to former residents to assist their adjustment to independent living; (2) permanent housing provided in conjunction with appropriate supportive services designed to maximize the ability of people with disabilities to live as independently as possible; (3) supportive housing that is, or is part of, a particularly innovative project for, or alternative method of, meeting the immediate and long-term needs of homeless individuals and families; (4) supportive services for homeless individuals not provided in conjunction with supportive housing, and (5) safe havens for homeless individuals with serious mental illness currently residing on the streets who may not yet be ready for supportive services.	McKinney-Vento Homeless Assistance Act (Stewart B. McKinney Homeless Assistance Act) (McKinney Act) (P.L. 100-77, July 22, 1987, 101 Stat. 482) (*codified at* 42 U.S.C. sec. 11301 *et. seq.*)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Community Planning, and Development

Federal Housing Programs (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Section 8 Housing Choice Voucher Program	To aid very low-income families in obtaining decent, safe, and sanitary rental housing. For Welfare-to-Work rental vouchers, families must also meet special welfare-to-work criteria. Section 502 of the Public Housing Reform Act states that a purpose of the legislation is “consolidating the voucher and certificate programs for rental assistance under Section 8 of the United States Housing Act of 1937 (the USHA) into a single market-driven program that will assist in making tenant-based rental assistance more successful at helping low-income families obtain affordable housing and will increase housing choice for low-income families.”	Housing Act of 1937, Section 8(o), (as amended, 42 U.S.C. 1437(o))	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Public and Indian Housing
Section 502 Rural Housing Service	To assist very low, low-income, and moderate-income households to obtain modest, decent, safe, and sanitary housing for use as a permanent residence in rural areas.	Housing Act of 1949, Title V, Section 502, as amended, P.L. 89-117, 42 U.S.C. 1471 et seq.; P.L. 92-310 (codified at 42 U.S.C. sec. 1472 et seq.)	Committee on Banking, Housing, and Urban Affairs	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Agriculture, Rural Housing Service

Federal Transportation Programs

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Capital Assistance Program for Elderly Persons and Persons with Disabilities	To provide financial assistance in meeting the transportation needs of elderly people and people with disabilities where public transportation services are unavailable, insufficient, or inappropriate. The Section 5310 program is designed to supplement FTA's other capital assistance programs by funding transportation projects for elderly people and people with disabilities in all areas: urbanized, small urban, and rural.	(P.L. 103-272, § 1(d), July 5, 1994, 108 Stat. 807, and amended P.L. 105-178, Title III, § 3013(a), June 9, 1998, 112 Stat. 359) (codified at 49 U.S.C. sec. 5310)	(1) Committee on Commerce, Science, and Transportation, (2) Committee on Environ-ment and Public Works	(1) Commerce, Science, and Transportation–Surface Transportation and Merchant Marine Subcommittee, (2) Environment and Public Works—Transportation and Infrastructure Subcommittee	Committee on Transportation and Infrastructure	Highways, Transit, and Pipelines Subcommittee	Department of Transportation, Federal Transit Administration

Federal Nutrition Programs

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Elderly Nutrition Program (ENP)	Elderly Nutrition Program provides grants to support nutrition services to older people throughout the country. The Elderly Nutrition Program provides for congregate and home-delivered meals. These meals and other nutrition services are provided in a variety of settings, such as senior centers, schools, and in individual homes. Meals served under the program must provide at least one-third of the daily recommended dietary allowances established by the Food and Nutrition Board of the National Academies' Institute of Medicine.	Older Americans Act Amendments of 1992, Title III, Grants for State and Community Programs on Aging (P.L. 102-375, Sept. 23, 1992, 106 Stat. 1195) (codified at 42 U.S.C. sec. 3030p). Older Americans Act of 1965 (P.L. 89-73, July 14, 1965, 79 Stat. 218).	Health, Education, Labor, and Pensions Committee	Aging Subcommittee	(1) Energy and Commerce Committee, (2) Education and the Workforce Committee	(1) Energy and Commerce, Health Subcommittee; (2) Select Education Subcommittee	Department of Health and Human Services, Administration on Aging

Federal Nutrition Programs (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Senior Farmers' Market Nutrition Program (SFMNP)	SFMNP awards grants to states, United States Territories, and federally recognized Indian tribal governments to provide low-income seniors with coupons that can be exchanged for eligible foods at farmers' markets, roadside stands, and community-supported agriculture programs. The grant funds may be used only to support the costs of the foods that are provided under the SFMNP; no administrative funding is available. The purposes of the SFMNP are to (1) provide resources in the form of fresh, nutritious, unprepared, locally grown fruits, vegetables, and herbs from farmers' markets, roadside stands and community-supported agriculture programs to low-income seniors, (2) increase the domestic consumption of agricultural commodities by expanding or aiding in the expansion of domestic farmers' markets, roadside stands, and community-support agriculture programs, and (3) develop or aid in the development of new and additional farmers' markets, roadside stands, and community-support agriculture programs.	Farm Security and Rural Investment Act of 2002, sec. 4402, (Farm Bill, 2002) (P.L. 107- 171, May 13, 2002, 116 Stat. 134) (*codified at* 7 U.S.C. sec. 3007)	Committee on Agriculture, Nutrition, and Forestry	Research, Nutrition, and General Legislation Subcommittee	Committee on Agriculture	Department of Operations, Oversight, Nutrition, and Forestry Subcommittee	Department of Agriculture, Food and Nutrition Service

Federal Nutrition Programs (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Community Food Projects (Food Stamps)	To support the development of community food projects designed to meet the food needs of low-income people; increase the self-reliance of communities in providing for their own needs; and promote comprehensive responses to local food, farm, and nutrition issues.	Food Stamp Act of 1977 (Food Stamp Act of 1964), Section 25 (P.L. 88-525, Aug. 31, 1964, 78 Stat. 703) (codified as amended at 7 U.S.C. sec. 2034), amended by Federal Agriculture Improvement and Reform Act of 1996 (FAIRA), Section 401, (P.L. 104-127, Apr. 4, 1996, 110 Stat. 888) (7 U.S.C. sec. 2033-34).	Committee on Agriculture, Nutrition, and Forestry	Research, Nutrition, and General Legislation Subcommittee	Committee on Agriculture	Department of Operations, Oversight, Nutrition, and Forestry Subcommittee	Department of Agriculture, Food and Nutrition Service

Federal Assistive Technology Programs

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Assistive Technology Act (ATA) of 1998	To provide grants to states to support capacity building and advocacy activities, designed to assist the states in maintaining permanent comprehensive, consumer-responsive statewide programs of technology-related assistance for individuals with disabilities of all ages. Revises ATA state grant programs to direct the Secretary of Education to make AT grants to states to maintain comprehensive statewide programs designed to (1) maximize the ability of individuals with disabilities, and their family members, guardians, advocates, and authorized representatives, to obtain AT; and (2) increase access to AT. Requires states to use portions of AT grant funds for (1) state-level activities, including state financing system activities (which may include loan programs) to increase access to and funding for AT devices and services, as well as for programs for device reutilization, device loan, and device demonstration and information; and (2) state leadership activities, including training and technical assistance, public-awareness activities, and coordination and collaboration.	Assistive Technology Act of 1998 (P.L. 108-364, Dec. 25, 2004) (Codified as amended at 29 U.S.C. sec. 3001 et seq.)	Committee on Health, Education, Labor, and Pensions	Employment, Safety, and Training Subcommittee	Committee on Education and the Workforce	Workforce Protections Subcommittee	Department of Education, Office of the Assistant Secretary for Special Education and Rehabilitation Services

Caregiver Support/Respite Care

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
National Family Caregiver Support Program (NFCSP)	The NFCSP calls for the states, working in partnership with Area Agencies on Aging and local community-service providers, and tribes to provide a continuum of caregiver services, including information, assistance, individual counseling, support groups, training, respite, and supplemental services. These caregiver support services are available to adult family members or other individuals who are informal providers of in-home and community care to older people. Caregiver support services are also available to grandparents or older individuals who are relative caregivers for a child, age 18 and under. Priority consideration for services is to be given to people in greatest social and economic need, with particular attention to low-income older individuals, and older individuals providing care and support to people 18 and under with mental retardation and related developmental disabilities.	Older Americans Act Amendments of 2000, section 316, (P.L. 106-501, Nov. 13, 2000, 114 Stat. 2226) (*codified at* 42 U.S.C. sec. 3030s, 3030s-1, 3030s-2, 3030s-11, 3030s-12)	Committee on Health, Education, Labor, and Pensions	Aging Subcommittee	Committee on Education and the Workforce	Postsecondary Education, Training and Life-Long Learning Subcommittee	Department of Health and Human Services, Administration on Aging

Civil Rights Protections

Program Name	Purpose	Act* *Original Act*	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
Americans with Disabilities Act (ADA)	ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress. To be protected by ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. ADA does not specifically name all of the impairments that are covered.	Americans with Disabilities Act of 1990 (ADA) (P.L. 101-336, July 26, 1990, 104 Stat. 327) (codified at 42 U.S.C. sec. 12101-12117, 12131-12134, 12141-12150, 12161-12165, 12181-12189; 47 U.S.C. sec. 225)	Senate Committee on Health, Education, Labor, and Pensions, and Senate Committee on the Judiciary	Various	(1) Committee on the Judiciary, (2) Committee on Education and the Workforce	Subcommittee on the Constitution	Department of Justice, Civil Rights Division

Civil Rights Protections (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Civil Rights of Institutionalized Persons Act (CRIPA)	CRIPA authorizes actions for redress in cases involving deprivations of rights of institutionalized people secured or protected by the Constitution or laws of the United States. CRIPA is used by the Department of Justice to bring actions on behalf of those living in public nursing homes, facilities for those with cognitive disabilities, and psychiatric hospitals. The Civil Rights Division pursues cases under CRIPA, where public nursing homes or other public institutions have neglected or abused residents entrusted to their care, or have failed to meet residents' constitutional or federal statutory right to adequate care and services. These cases generally involve an extensive investigation of the conditions and practices at the facility, efforts to remedy the offending practices, and, where necessary, the filing of a CRIPA action. Resolution of CRIPA suits generally include reaching a written agreement with the jurisdiction that provides for remedial relief in each one of the areas in which the institution failed to meet the needs of the residents.	Civil Rights of Institutionalized Persons Act (CRIPA) (P.L. 96-247, May 23, 1980, 94 Stat. 349) (codified at 42 U.S.C. sec. 1997-1997j)	Senate Committee on the Judiciary	Various	Committee on the Judiciary	Subcommittee on the Constitution	Department of Justice, Civil Rights Division

Civil Rights Protections (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Rehabilitation Act (Section 504)	The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act. Section 504 states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives federal financial assistance or is conducted by any executive agency or the United States Postal Service. Each federal agency has its own set of Section 504 regulations that apply to its own programs. Agencies that provide federal financial assistance also have Section 504 regulations covering entities that receive federal aid. Each agency is responsible for enforcing its own regulations. Section 504 may also be enforced through private lawsuits.	Rehabilitation Act of 1973 (P.L. 93-112, Sept. 26, 1973, 87 Stat. 355) (codified as amended at 29 U.S.C. sec. 794)	(1) Committee on Health, Education, Labor, and Pensions, (2) Committee on Finance	Various	(1) Committee on Education and the Workforce, (2) Committee on Ways and Means	Subcommittee on the Constitution	Department of Justice, Civil Rights Division

Civil Rights Protections (Continued)

Program Name	**Purpose**	**Act*** ***Original Act***	**Senate**		**House of Representatives**		**Agency, Office**
Fair Housing Act (FHA)	The FHA, as amended in 1988, prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. Its coverage includes private housing, housing that receives federal financial assistance, and state and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. The FHA requires owners of housing facilities to make reasonable exceptions in their policies and operations to afford people with disabilities equal housing opportunities. The FHA also requires landlords to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as to common use spaces. (The landlord is not required to pay for the changes.) The Act further requires that new multifamily housing with four or more units be designed and built to allow access for people with disabilities.	Fair Housing Act (P.L. 90-284, Title VIII, Apr. 11, 1968, 82 Stat. 81) (codified at 42 U.S.C. sec. 3601-3619)	Committee on Finance	Various	(1) House Financial Services Referral, (2) Committee on Ways and Means, (3) House Judiciary	(1) Subcommittee on Housing and Community Opportunity, (2) Subcommittee on the Constitution	Department of Justice, Civil Rights Division and the Office of Program Compliance, and the Office of Fair Housing and Equal Opportunity at the U.S. Department of Housing and Urban Development

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