

# **The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**



**National Council on Disability  
December 15, 2005**

National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, DC 20004

**The State of 21st Century Long-Term Services and Supports: Financing  
and Systems Reform for Americans with Disabilities**

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## **National Council on Disability**

*An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.*

### **Letter of Transmittal**

December 15, 2005

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to present to you our groundbreaking report, *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*.

NCD undertook research for this report because it has grown increasingly concerned about the (a) lack of a coherent national long-term services and supports (LTSS) public policy for all people with disabilities; (b) fragmented nature of service and support delivery systems, with uneven access and services provisions; and (c) LTSS costs of 22 percent or more of state budgets, which are fast becoming unsustainable. Additionally, NCD noted in undertaking research for this report that no single federal program, federal agency, or congressional committee is charged with the responsibility for the management, funding, and oversight of LTSS; however, 23 federal agencies are actively involved in LTSS using the NCD definition.

As reflected in this report, NCD believes that America needs a coherent and comprehensive framework for its LTSS policies, programs, and funding based on five interrelated assumptions. First, that people who are elderly and people with disabilities both 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 supports that is responsive to individuals under the age of 65, as well as Americans over 65 who may or may not have disabilities, without sacrificing individual choice and flexibility. Fourth, formal and informal caregiving must be sustained, including examination of 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.

NCD stands ready to work with you, members of your Administration, and the leadership in Congress in the months and years ahead as you work toward improving our nation's LTSS system.

Sincerely,

Lex Frieden  
Chairperson

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# Table of Contents

	Page
<b>Executive Summary</b> .....	13
Introduction.....	13
Findings.....	17
Recommendations.....	29
<b>Chapter 1</b> .....	37
<b>The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities</b>	
<b>Chapter 2</b> .....	187
<b>Future Market Demand and Understanding Costs of Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities</b>	
<b>Chapter 3</b> .....	281
<b>External Advisors and External Policymakers: Recommendations for Action</b>	
<b>Chapter 4</b> .....	339
<b>Moving Forward: Selected State Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities</b>	
<b>Chapter 5</b> .....	435
<b>Moving Forward: Local and Individual Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities</b>	
<b>Chapter 6</b> .....	489
<b>Recommendations for Incremental and Clean Slate Reform</b>	
<b>References</b> .....	515

# **Chapter 1: The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**

## **Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Picturing the Problem</b> .....	41
<b>Part II</b>	
<b>Charting the Course</b> .....	44
<b>Part III</b>	
<b>Forecasting the Need</b> .....	48
<b>Part IV</b>	
<b>Dragging Anchor</b> .....	55
<b>Part V</b>	
<b>Introducing the Captain</b> .....	62
<b>Part VI</b>	
<b>Meeting the Crew</b> .....	74
<b>Part VII</b>	
<b>Fueling the Engine</b> .....	84
<b>Part VIII</b>	
<b>Pushing Tugboats</b> .....	106
<b>Part IX</b>	
<b>Harnessing Favorable Winds</b> .....	113
<b>Part X</b>	
<b>Gathering Clouds</b> .....	117
<b>Part XI</b>	
<b>Recharting the Course</b> .....	125
<b>Appendix 1.A</b> .....	131
<b>Appendix 1.B</b> .....	132
<b>Appendix 1.C</b> .....	134

<b>Appendix 1.D</b> .....	136
<b>Appendix 1.E</b> .....	137
<b>Appendix 1.F</b> .....	139
<b>Appendix 1.G</b> .....	157

## **Chapter 2: Future Market Demands and Understanding Costs of Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**

### **Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Introducing Research Purpose and the Rich Picture Story Line.....</b>	<b>191</b>
<b>Part II</b>	
<b>Forecasting the Storm.....</b>	<b>193</b>
<b>Part III</b>	
<b>Tracking the Storm.....</b>	<b>197</b>
<b>Part IV</b>	
<b>Lowering the Lifeboats.....</b>	<b>216</b>
<b>Part V</b>	
<b>Approaching the Iceberg.....</b>	<b>225</b>
<b>Part VI</b>	
<b>Reviewing the Passenger Manifest .....</b>	<b>241</b>
<b>Part VII</b>	
<b>Moving Toward Reform.....</b>	<b>272</b>

**Chapter 3: External Advisors and External Policymakers:  
Recommendations for Action**

**Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	285
<b>Part II</b>	
<b>Approaches to Development</b> .....	287
<b>Part III</b>	
<b>Expert Panel Discussion and Recommendations</b> .....	321
<b>Part IV</b>	
<b>Conclusion</b> .....	327
<b>Appendix 3.A</b> .....	331

# **Chapter 4: Moving Forward: Selected State Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**

## **Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	343
<b>Part II</b>	
<b>Five State Case Studies</b> .....	348
<b>Part III</b>	
<b>Conclusion</b> .....	429
<b>Appendix 4.A</b> .....	433

# **Chapter 5: Moving Forward: Local and Individual Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**

## **Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	439
<b>Part II</b>	
<b>Conclusion</b> .....	486

## **Chapter 6. Recommendations for Incremental and Clean Slate Reform**

### **Table of Contents**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction to Incremental Reform .....</b>	<b>493</b>
<b>Part II</b>	
<b>Moving Forward—Improving the Current LTSS Ship .....</b>	<b>494</b>
<b>Part III</b>	
<b>The New Millennium LTSS Model.....</b>	<b>508</b>
<b>Part IV</b>	
<b>Ameriwell—The New Millennium LTSS Model.....</b>	<b>511</b>

# Executive Summary

## Introduction

Long-term services and supports (LTSS) is not only an issue for older Americans but also for younger individuals with disabilities, and any LTSS financing and system reform efforts must consider both populations.

The current LTSS system is funded primarily by state and federal programs. More specifically, Medicaid is the primary payer of LTSS in this country. Medicaid paid for 45 percent of the \$137 billion this country spent on LTSS in FY 2000. Yet, despite the amount of money that state and federal programs are allocating to LTSS, individuals and their families still pay out of pocket for nearly one-third of LTSS expenses.

Although the population of people who have disabilities and people who are elderly has indicated a preference for receiving LTSS in home- and community-based settings, a federal institutional bias exists. Presently, about 1.6 million people live in nursing homes, group homes, and other institutional facilities. At the same time, there are about 2 million to 2.4 million people on waiting lists or in need of some type of LTSS.

Options for LTSS are emerging. Aging and disability advocates are working with the health care industry to create a continuum of care, including such services as assisted living, adult day services, and home care. Governors have creatively used the Medicaid waiver process to increase home- and community-based services for people who are elderly and people with disabilities.

Although financing is the cornerstone of the LTSS issue, other issues are critical in building an adequate, seamless, and effective LTSS system to meet the increasing needs of aging baby boomers and the increasing numbers of individuals with disabilities who have LTSS needs. These issues include supporting family caregivers, addressing workforce shortages, improving the quality of LTSS services, and improving access to transportation and housing.

Recognizing, in particular, that the impending age wave of baby boomers will significantly increase the demand for LTSS in the coming decades, the National Council on Disability was interested in researching the issues of LTSS financing and systems reform. This report addresses those issues.

The development of long-term services and supports (LTSS) comprehensive policy will define the future economic independence of Americans with disabilities. Changing demographic and economic trends, here and abroad, will demand that the United States retool its programmatic and financial infrastructure to protect and promote individual dignity and independence of all Americans with disabilities. The development of sustainable and affordable LTSS public policy for the 21st century—funded through a unique combination of individual contributions, innovative private sector assistance, and public support—will provide a new security for Americans with disabilities to work and live independently. Although 20th century advances revolutionized the concept of health care and longevity for many Americans, increasing life expectancy by 30 years, they fell short in providing an affordable LTSS public policy for both the medical and nonmedical services and supports needed by many working Americans with disabilities. The United States is a world leader in extending life and eradicating disease, but it has failed to develop an LTSS public policy that truly integrates disability as a natural part of the human experience.

Few Americans think of LTSS for individuals under the age of 65 who are living and working in the community with significant disabilities. Many people do not realize that there is no LTSS public policy for individuals of moderate to middle income, whether over or under the age of 65. Private insurance is available for long-term care that, on average, is capped at a specific dollar amount, provides coverage for about three years, and is geared toward services and supports that cater to diseases of aging and not the needs of everyday working Americans with disabilities.

Ninety percent of Americans do not have long-term care insurance, and many do not have the financial savings to cover the costs of aging. Few insurance products are available that cover the costs of providing services and supports targeted for individuals and families challenged with lifelong disabilities under age 65. A recent actuarial study found that Americans at age 45 are more likely to become disabled than to die, and yet we continue to insure against loss of life

rather than against the risk of disability. There are no risk pools or insurance products designed to supplement the additional costs associated with living and working with a lifelong disability. There is little research or data that accurately captures what this means for planning the financial future of an individual born today with a lifelong disability.

Disability prevalence is rising in the under-age-65 population and, although it has decreased slightly for seniors, it will begin to rise sharply as the current senior population of 34 million doubles over the next 20 years. Inherently, most Americans think of LTSS as long-term care for seniors in nursing homes with severe chronic disabilities. This bias is a holdover from the 1960s, when Medicaid and Medicare were first established, and reflects a system of care that is outdated and no longer cost-effective. Although the movement today is to provide services and supports in the home and community through an array of waivers, more than 50 percent of Medicaid resources for LTSS continue to support individuals in nursing facilities or intermediate care facilities for the mentally retarded (ICF/MRs).

In 2001,<sup>1</sup> the United States spent \$1.24 trillion (or about \$5,500 per person) on personal health care services, with 12 percent (or \$151.2 billion) spent on LTSS. Although 70 percent of the 53 million Medicaid beneficiaries are children and mothers, more than half of the \$276.1 billion spent in 2003 was for populations who are aging (15 percent) and with disabilities (15 percent). The predominant disability populations receiving Medicaid LTSS are those with mental retardation and developmental disabilities (MR/DD) and low-income seniors who rely on both Medicaid and Medicare. Between 9 million and 12 million Americans need help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and 3.5 million are under 65 years of age. The literature also reports that 25 million individuals with chronic severe disabilities under age 65 are probably in need of some LTSS, but these individuals are often not counted or found eligible because of income or family assets, or they fall outside the realm of traditional functional assessments that use ADLs and IADLs as measurements. There is also confusion about what definition of disability should be used to assist policymakers in studying LTSS needs. Finally, LTSS are not portable and are highly dependent on the fiscal and budgetary priorities and obligations of each state.

In addition, about one-fifth of the U.S. population is uninsured or underinsured, with more than 18,000 American lives lost each year because of gaps in insurance coverage, at an economic cost between \$65 billion and \$139 billion annually from premature death, preventable disability, early retirement, and reduced economic output. Rising double-digit inflation costs for health care continue to confound state and federal efforts to reign in overall health and LTSS spending. The probability of sustaining future promises to current social policy and its beneficiaries is low if the demographics are correct: Fewer workers will mean lower payroll contributions and less money available to fund past and future commitments. The research suggests that the problem is beyond incremental reform and requires immediate attention.

A “rich picture” methodology was used to introduce the problem this report addresses. The picture captures the current health care and LTSS system. The field of management often uses a rich picture systems methodology, that is, “an innovative tool that encapsulates knowledge relevant to strategic reform.” For the disability field, the use of the rich picture allows people with intellectual impairments and other cognitive challenges to grasp the essence of the research through a visual representation and dialogue. The picture and narrative relied on the review of primary and secondary research documents; one-on-one open-ended interviews with key stakeholders in the disability, long-term care, and health care fields; review of congressional records and attendance at a number of hearings; and the convening of a national expert advisory panel on LTSS.

The setting for the rich picture is the ocean, with the current LTSS and health care ship heading toward an iceberg that represents the barriers and challenges to systems reform. The cast for this rich picture provided the substantive descriptions and main body of research and analysis about the barriers and challenges of navigating through the current system of LTSS. The presentation of the research in this format was purposeful so that the reader and the researcher could begin the voyage together with a snapshot of the problem. It was intended that a new picture would emerge as the researchers integrated the findings from the other chapters of the research. The final picture is a new ship, “AmeriWell,” that is designed to provide LTSS for all Americans regardless of income or category of disability through innovative funding from individuals and families, the private sector; and the Federal Government. AmeriWell will delink aging and disability populations from

both Medicaid and Medicare that require LTSS to form a new LTSS program that provides services and supports to middle-and low-income Americans with disabilities.

The purpose of this research is to produce new knowledge and an understanding of current experience with and the future need for affordable LTSS for people with disabilities. The following findings provide a broad overview of the four areas researched for this report. Chapter recommendations are provided here in brief, but a detailed summary is available in chapter 6. All footnotes and references can be found in the original text, except where otherwise noted.

## **Findings**

### **1. Little Political or Public Understanding of Current and Future LTSS Needs (Chapter 1)**

- A. There is little public or political interest in putting LTSS onto the national agenda, although state Medicaid spending represents 22 percent of overall state budgets and is fast becoming unsustainable.
- B. Fifty-nine percent of Americans have given little or no thought to the issue of LTSS and the costs associated with aging or disability.
- C. Most Americans do not understand the current system of LTSS, how it is funded, or who is eligible for services. Many people do not understand that Medicaid is the primary provider of LTSS for all populations—both young and old—and that eligibility is income sensitive.
- D. The development of affordable LTSS is the missing link in making work a reality for many Americans with disabilities.

### **2. Fragmentation of Federal System of LTSS (Chapter 1)**

- A. There is no single federal program or federal agency charged with the responsibility for management, funding, and oversight of LTSS at home and in the community. More than 20 federal agencies and almost 200 programs provide a wide range of assistance and services to people with disabilities.<sup>2</sup>
- B. 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.

- C. 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 that provides portability across states.

### **3. Policymakers Continue to Avoid the Hard Questions (Chapter 1)**

- A. Twenty years of research and exercises in forecasting future visions for LTSS have failed to answer the following questions: What services should be guaranteed to individuals unable to provide for themselves? What protections from catastrophic loss, financial or otherwise, should be afforded, and, most important, who will pay? How is the current LTSS policy working, and does it meet the needs of today's population with disabilities?

### **4. Favorable Court Decisions Post-ADA for Future LTSS (Chapter 1)**

- A. Positive forces for change began with the passage of the Americans with Disabilities Act (ADA) in 1990; they were followed by the Supreme Court decision in *Olmstead* in 1999 and the subsequent Administration actions in 2000, and continued to the present. They 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.

### **5. Future of LTSS Formal and Informal Workforce Unclear (Chapter 1)**

- A. Population demographic changes because of aging, reduced fertility rates, increased women in the workforce, and changing family makeup predict there will be fewer unpaid family workers and an increased demand for paid workers.
- B. The role of government in addressing the challenges of the current formal and informal workforce is unclear.
- C. The majority of LTSS workers providing paid care are often without health insurance and other employee benefits and experience frequent job turnover.

### **6. LTSS Policy Not Just for Seniors (Chapter 2)**

- A. Most data for LTSS favors individuals age 65 and older with diseases of aging. Policymakers and researchers need accurate data to calculate current and future LTSS

utilization and costs to develop a clear consensus as to who is to be covered by an LTSS system and how eligibility will be calculated.

**7. Disability Definitions Need Clarification (Chapter 2)**

- A. Disability definitions range from a medical diagnostic approach to a functional assessment approach that uses ADLs and IADLs. There is no aggregated data on the overall costs and utilization rates using the NCD/AARP definition for LTSS that includes transportation, nutrition, and housing.
- B. There are 38 million people under age 65 reporting some level of disability and, of this Group, 25 million have a specific chronic disability; however, many of these individuals are not eligible for LTSS.
- C. Using the functional definition of disability based on ADLs and IADLs, the estimated population in need of LTSS under age 65 ranges from a conservative figure of 3.5 million to more than 10 million.

**8. Future Demographic Trends Predict That Many Americans of All Income Levels Will Need Access to Affordable LTSS (Chapter 2)**

- A. Regardless of the definition of the target population, there is clear and undisputable data that the number of people over age 65 with ADL and IADL limitations is growing and will double by 2030.
- B. Twenty percent of people age 65 and over will require assistance with at least one ADL and 50 percent will require assistance by age 85. The number of people in need of assistance with two ADLs will grow from 1.8 million to 3.8 million by 2045.

**9. Disability Rates Declining for Seniors and Impact on Future LTSS Utilization and Costs Is Unclear (Chapter 2)**

- A. The rate of disability has declined in the 65-and-older population, mostly for IADLs. It is less clear whether this decline is due to health improvements or environmental changes because of increased technology for durable medical equipment, including assistive technology. However, the rate of disability for individuals 85 years and older is expected to rise as this population triples over the next 30 years.

**10. Disability Rates Rising for Individuals Under Age 65 and Impact on Future LTSS Utilization and Costs Is Unclear (Chapter 2)**

- A. The rate of disability for individuals under age 65 is rising in diabetes, obesity, and mental illness. Little data is available that accurately predicts how this will impact future LTSS utilization, costs, and service delivery.
- B. It is unclear what LTSS truly looks like for individuals under age 65 across disabilities and specific age groups for those working and living independently. The research shows that individuals under age 65 are heterogeneous and have specific needs according to gender, age, and type of disability that are quite different from individuals over the age of 65.

**11. Individuals Under Age 65 Receive Less Personal Assistance and Are More Likely To Be Nonwhite (Chapter 2)**

- A. Individuals with two or more ADL limitations and personal assistance needs under the age of 65 estimated a shortfall of 16.6 hours of help per week and were more likely to be nonwhite, female, and living alone.
- B. Paid personal assistance services go primarily to people 65 and older, and working-age people 65 and under rely more on unpaid personal assistance services.

**12. Increased Life Expectancy for People with Lifelong Disabilities and Its Impact on LTSS Utilization and Costs Unstudied (Chapter 2)**

- A. Individuals with lifelong disabilities, such as Down syndrome, cerebral palsy, and mental retardation, are living longer and the impact on utilization of LTSS services and future costs is unclear from the current literature.
- B. It is unclear what future services and supports, including access to housing, transportation, and nutrition, will be in most demand for people under age 65 with lifelong disabilities living and working in the community.

**13. LTSS Needs Among Minority Populations and Impact on Future Utilization and Costs Needs Study (Chapter 2)**

- A. Black children are 13 percent more likely than white children to have a reported ADL limitation. A recent Government Accountability Office study confirmed that the black population has higher disability rates and lower lifetime earnings and shorter life expectancies than whites.
- B. The issues of poverty, lack of insurance, and continued segregation from affordable and consistent health care will increase the future needs and costs for LTSS for minority nonwhite populations in the U.S., which are projected to make up 50 percent of the American population by 2050.

**14. Growing Prevalence of Mental Illness and Its Impact on Future LTSS Utilization and Costs Unknown (Chapter 2)**

- A. The prevalence of chronic disease and deaths caused by noncommunicable disease in the United States between 1990 and 2020 will increase from 28.1 million to 49.7 million, an increase of 77 percent.
- B. Mental illness will rank number two after heart disease and replace cancer by 2010 as having a greater impact on death and disability. Medicaid is the principal public payer for mental health services and represents 36 percent of the \$48 billion in spending. It is unclear what the future LTSS needs and costs will be for people with mental illness.

**15. Medicaid LTSS Not Designed to Support Growing Need of Middle-Income Population (Chapter 2)**

- A. The current system of LTSS is designed for low-income individuals and is unsustainable under the current system of health care that has expanded Medicaid options to provide services and supports to an array of middle-income and uninsured individuals.
- B. There are 57 million working-age Americans between 18 and 64 with chronic conditions such as diabetes, asthma, or depression, and more than one in five (12.3 million) live in families that have problems paying medical bills. Many are not eligible for LTSS services because they have assets above prescribed limits.

- C. The number of chronically ill people with private insurance who spend more than 5 percent of their income on out-of-pocket health care costs increased by 50 percent, to 2.2 million people, in 2003.
- D. The impact on LTSS costs are unclear for 6.6 million individuals with chronic care needs who are uninsured and go without needed care (42%), delay care (65%), or fail to get needed prescriptions (71%), but they will impact future need and costs without timely intervention.

#### **16. Growth in Medicaid Spending Is Unsustainable (Chapter 2)**

- A. Eligibility and service pathways to state Medicaid programs have expanded to meet the growing needs of 53 million low-income, middle-income, and uninsured acute care and LTSS beneficiaries, and reflect the growing challenges of economic downturns, increased health premiums, increased longevity, a low savings rate, and slower wage growth.
- B. Twelve percent of \$329 billion combined state and federal funds in 2005 was spent on LTSS.<sup>3</sup>
- C. Seven million individuals are dually eligible for full Medicare and Medicaid benefits and another 1 million receive assistance with copays and deductibles; combined, this represents 42 percent of all Medicaid expenditures.
- D. The ability of states to respond to current and future LTSS needs is beyond their capacity and resources as long as health care costs continue to rise at double-digit rates.

#### **17. Two-Thirds of Medicaid Spending for Optional and Not Mandatory Service (Chapter 2)**

- A. Two-thirds of Medicaid spending is for population groups and services technically defined as optional, and 90 percent of all long-term care Medicaid services are optional. It is unclear how vulnerable people with disabilities are, with the majority of their services and funding falling under optional categories.
- B. Seventy-five percent of home- and community-based services (HCBS) waivers are for people with MR/DD and are used to purchase LTSS. The other 25 percent are used for people with physical disabilities and older people. There are three small waiver programs that serve individuals with a primary diagnosis of mental illness, accounting

for 0.2 percent of HCBS waiver expenditures. Further research is needed to explore the LTSS needs of the 25 percent population using HCBS.

**18. Medicaid Administrative Costs Need Further Research (Chapter 2)**

- A. Research is needed to further determine whether Medicaid administrative costs meet the federal basic guidelines that “costs be allowable, reasonable, and allocable for reimbursement under Federal awards.”<sup>4</sup>

**19. Many Uninsured Americans Are Working (Chapter 2)**

- A. Forty-nine percent of the 45 million uninsured Americans are either self-employed or work for companies with fewer than 25 employees.
- B. More than 50 percent of low-income employees of small firms with incomes below 200 percent of the federal poverty level are uninsured.
- C. More than 2 million health care paraprofessionals report wages below the poverty line, do not work full time, and do not receive benefits.

**20. Long-Term Care Insurance Designed Mostly for Seniors and Not Individuals Under 65 with Disabilities (Chapter 2)**

- A. Private LTSS insurance is targeted to individuals age 65 and older and often to specific disease categories. One insurance company reported that more than 50 percent of its LTSS insurance claims paid are for Alzheimer’s and other forms of dementia.

**21. Risk of Disability Is Higher Than Premature Death at Age 45 (Chapter 2)**

- A. The risk of disability is higher than premature death and is higher for older people than younger, and females are more likely to become disabled than males. A 45-year-old individual earning \$50,000 per year and suffering a permanent disability could lose \$1,000,000 in future earnings.
- B. The public overestimates the help that is available from public disability insurance programs—Social Security Disability Insurance (SSDI) and other state-mandated, short-term programs. Workers compensation benefits cover only disabilities caused by injury or illness arising on the job—only an estimated 4 percent of disabilities.

**22. Congress Needs Research on the Current and Future Utilization and Costs of LTSS for Individuals Under Age 65 and Their Informal Workforce (Chapter 2)**

- A. Congress needs sufficient data on LTSS costs and utilization for individuals across the spectrum of disabilities under age 65 to develop a sustainable and affordable LTSS policy.
- B. Congress needs sufficient data that responds to the demographics that predict a decrease in the current population of informal caregivers (valued at \$200 billion a year) and the impact of this trend on the development of a future LTSS workforce.
- C. Research is needed on the different public and private cost-sharing scenarios that focus on the under-age-65 population with disabilities and the relationship between public financing and private insurance to develop affordable products that insure against future risk of developing or being born with a disability.

**23. Changing Global Demographics and Economic Impact on Future LTSS Policy Unclear (Chapter 2)**

- A. The global economic picture and changing demographics, in addition to the current U.S. federal budget deficit, raise new questions about the sustainability of current entitlement and social programs and their impact on beneficiaries with disabilities.
- B. Current state and federal budget deficits and funding priorities jeopardize a patchwork system of services and supports that do not meet the current needs of the target population, let alone those projected into the future.

**24. Role of Caregiving and Workforce Issues in Understanding Future LTSS Costs Unclear (Chapter 2)**

- A. 44.4 million American caregivers age 18 and over provide unpaid care to an adult age 18 or older. Six out of 10 of these caregivers work while providing care; most are women age 50 years or older.
- B. Jobs for nurses' aids are expected to grow by 23.8 percent, while the employment of personal care and home health aides may grow as much as 58.1 percent between 1998 and 2008.

- C. It is unclear how many workers (the “gray market”) are hired and supervised by consumers who pay for their own care, although the numbers are thought to be substantial.
- D. Direct care workers (3.1 million) are in short supply and have nearly a 100 percent turnover rate in nursing facilities; home care agencies have annual turnover rates between 40 and 60 percent.
- E. Direct care workers have low median hourly wages of \$9.20 an hour and one-fifth (far more than the national average of 12 to 13 percent) earn incomes below the poverty level; 30 to 35 percent of all nursing home and home health aides who are single parents receive food stamps.

**25. LTSS Not Portable Across States (Chapter 2)**

- A. LTSS are not portable and cannot be moved with an individual from state to state, and current LTSS costs are not a customized response to individual needs.
- B. Current costs reflect matching an individual’s circumstances to available services and supports, based on federal eligibility criteria, with degrees of consumer choice and direction that vary based on the state in which the individual lives.
- C. The fiscal health of each state (and its ability to provide the necessary match to draw upon federal Medicaid resources) determines the scope and array of the current LTSS system for low-income Americans with disabilities and seniors.
- D. The personal assistance service needs of an individual in California could be similar to someone living in Mississippi, and yet the availability of services and funding may vary dramatically.

**26. LTSS Public Policy Is Necessary to Increase Positive Employment Outcomes for People with Disabilities (Chapter 2)**

- A. It is unclear how Americans with lifelong disabilities under age 65 can become self-sufficient and economically independent through work and build careers without substantial LTSS reform that allows asset growth and more innovative public-private support for LTSS.

- B. It is unclear how Americans with or without disabilities will provide for their own health care and LTSS in the future without changes in savings behavior and the development of insurance products that protect against the risk of disability.

**27. External Advisor and External Policymaker Findings for LTSS Action Similar to State Findings (Chapter 3)**

- A. Similar to the state findings, the advisory group encouraged moving any LTSS policy discussion away from the current medical status and disability type to a standardized assessment process to evaluate functional needs related to ADLs and IADLs.
- B. There is a need to reevaluate financial eligibility criteria and develop an expanded benefits menu that organizes service options from a presumption of individual preference for remaining at home and in community settings. The panel, without describing benefits coverage in detail, recognized that different people have different needs. As a result, the benefits coverage based on functional assessment must be flexible, individualized, and comprehensive. Nursing home level of care should be shifted from an entitlement status to an option of last resort.
- C. The system should offer more consumer choice and direction in determining needs, creating a service plan, and directing and managing provider selection and service delivery.
- D. The system should provide incentives to support and encourage family caregiving, and consider tax incentives to help defray expenses of dependent care for LTSS.
- E. Federal authorities should agree on key outcomes and a measurement system. Shared information and data collection and analysis across agencies in multiple settings should help improve understanding of cost-effectiveness based on different service delivery models. Performance outcomes should focus on wellness, productivity, inclusion, and independence.
- F. The cost should be spread across all wage earners over a lifetime as part of a social insurance financing framework. Similar to the approach of social security and Medicare, individual needs will vary over a life span.

- G. The system should decouple eligibility for benefits from current requirements of impoverishment for individuals and families.
- H. The system should provide support and incentives to encourage family support and informal caregiving to be balanced with public funding and responsibility. Key outcomes should be defined on an individual and systems level that focuses on wellness, productivity, inclusion, and independence.

**28. Selected State Strategies for LTSS Are Promising (Washington, Vermont, Minnesota, Texas, and Indiana) (Chapter 4)**

- A. States have ongoing, intensive, comprehensive planning processes that involve a full range of stakeholders—from state officials to providers to advocates and people with disabilities themselves—and the commitment and support of the governor and legislature.
- B. Planning includes realistic accounting of the state’s fiscal situation, availability of federal money, community partnership building, implementation of cost-limited regulatory changes, and benchmark settings to measure results.
- C. States are experimenting with merging, consolidating, and combining nursing home and HCBS dollars to better allocate funds according to the needs of people with disabilities and developing single-point-of-entry systems at the local level to encourage easier access to LTSS.
- D. States are experimenting with global budgeting that allows budgeting practices to blend (to some degree) institutional care and HCBS dollars and allows states the flexibility to respond to the preferences of people with disabilities to remain at home or in the community.
- E. States are broadening HCBS to allow greater numbers of people with disabilities the opportunity to direct their own care (for example, hiring, training, and supervising their workers).

**29. States Are Living Laboratories for Future LTSS Policy Development (Chapter 4)**

- A. The *Olmstead* decision stimulated executive and legislative review of the current system of service delivery, unmet needs of target populations, and where the dollars are being expended.

- B. Cross-agency planning is most effective when the consumer stakeholder voice is included as part of the process to develop recommendations for systems reform.
- C. Structural changes have involved substantial reorganization to an umbrella department for multiple target populations with long-term support and service needs.
- D. Expanded use of Medicaid waivers is common to broaden benefits and LTSS to subpopulations.
- E. The most restrictive policy most frequently identified was the Medicaid institutional bias.
- F. There remains confusion in the use of language regarding long-term care and LTSS.
- G. All selected states have waiting lists for specific target subpopulations, although states may limit services and operate the waiver on less than a statewide basis.
- H. Current budget challenges at a state level have compelled states to reexamine the balance between public and private responsibility for LTSS, evaluate approaches to target individuals based on an assessment of level of need, and seek to identify strategies that encourage coverage of supports through some type of insurance coverage and other private sector resource sharing.

**30. Local and Individual Strategies for LTSS Require Fresh, Creative Thinking That Reanalyzes the Use of Public and Private Resources (Chapter 5)**

- A. There is growing recognition that a fundamental shift in values is occurring as states move LTSS to the community and home and out of the institutions. Individuals with disabilities are being provided with more choices to live independently.
- B. New housing models with cooperative organizational structures are providing a realignment of service and financial relationships at an individual and community level and recognize the importance of consumer choice and direction.
- C. New economic models for managing assets include pooled trusts, supportive corporations, time banks, and child trust funds, and raise important questions about public versus private responsibility to create and manage a social safety net for individuals deemed in greatest need of long-term support.

## **Recommendations for Incremental and Clean Slate Reform (See Chapter 6 for full text and implementation lead for each recommendation)**

### **1. Increase Policymaker Knowledge and Understanding of Public and Private Costs and Benefits of LTSS for People with Disabilities Under Age 65 and Their Families (Chapter 5)**

A. The lack of data that presents a complete and accurate picture of the costs for LTSS for families with children or adults with disabilities was a key finding by NCD researchers. Despite multiple studies by the Congressional Budget Office (CBO) and other federally sponsored research centers on the costs of long-term care for seniors, the population under age 65 with disabilities has not been a priority. The traditional definition of long-term care identified acute care needs as well as nonmedical services and supports for seniors. Today's definition of long-term care has changed to reflect the ongoing growth and integration of disability into mainstream culture. LTSS for people 65 years and younger is about many nonmedical services and supports, such as personal assistance, assistive technology, financial management, housing, transportation, and nutrition. How people are assisted in compensating for loss of ADLs will define their future earnings potential and economic independence.

### **2. Design and Implement a Multifaceted Action Plan of Monitoring and Oversight of State Activities to Meet Their ADA Obligations as a Result of the *Olmstead* Court Decision (Chapter 5)**

A. The *Olmstead* Supreme Court decision in 1999 provides important legal support for states' current efforts to rebalance their LTSS systems toward home- and community-based settings. The Administration, through an Executive Order and grant activities, has taken seriously the Court's decision and mandated a state planning process to improve and expand community-based choices for people with disabilities. More than \$200 million has been awarded by the Centers for Medicare and Medicaid Services (CMS) to states on a competitive basis to promote system changes. Despite these efforts, litigation continues to expand in class action suits. In more than 25 states, individuals with disabilities have been frustrated with the pace of change and the slow movement of funding away from nursing homes and institutional settings to communities.

B. The Office for Civil Rights at the Department of Health and Human Services (HHS) and the Justice Department have the responsibility to monitor and oversee *Olmstead* state plan implementation. As both agencies have done on numerous occasions in the past related to ADA, there is an opportunity to be proactive and design and implement an action plan that evaluates individual state efforts to meet the *Olmstead* community imperative mandate. Each state should be rebalancing its financing, reducing the number of individuals with disabilities residing in nursing homes, diverting others from entering nursing homes, and putting in place the infrastructure for expanded HCBS for individuals with disabilities.

**3. Decouple Eligibility for Home- and Community-Based Services Under an HCBS Waiver from a Determination of Nursing Home Eligibility (Chapter 5)**

- A. It is necessary to remove the institutional bias in the Medicaid program to give Medicaid beneficiaries greater choice in how financial assistance is provided to cover a range of LTSS. The clear majority of stakeholders recognized the overwhelming consumer preference for HCBS. Two complementary options deserve immediate attention from Congress and bipartisan support.
- B. The first option is to shift the HCBS program from its current waiver status to a state plan requirement. Eligibility would be delinked from nursing home eligibility and states would receive an increased federal match under their state cost-sharing agreement for services provided in this category as part of their Medicaid reimbursement for authorized expenditures. CMS would set guidelines for a functional assessment process and minimum threshold of services to be covered, including personal assistance services.
- C. The second complementary option would be that federal funding follows the person from a nursing home to a community setting as part of a person-centered plan and self-directed budget. The Money Follows the Person (MFP) option would continue for a three-year period to help support successful community transition. Both options are currently part of legislative proposals before Congress. MFP and the Medicaid Community Attendant Services and Supports Act (MiCASSA) deserve to be the focus of hearings before the end of the year.

**4. Increase Support for Families and Significant Others in Their Role as Informal and Unpaid Caregivers for Individuals with Disabilities Over and Under the Age of 65 (Chapter 5)**

A. Eligibility for LTSS and the scope and intensity of covered services varies significantly from state to state. States have considerable discretion in determining who their Medicaid programs cover. Despite state variability in criteria for Medicaid eligibility and scope of benefits, in all states, individuals with disabilities are dependent on informal caregivers, including parents, family members, and significant others. The estimated benefit of informal caregiving exceeds \$200 billion annually. Services should be designed to support, not supplant, the role of the family and actions of informal caregivers. Increased support for informal caregiving could be achieved through implementation of a complementary set of recommendations. There is a need to address the lack of portability from state to state for Medicaid LTSS.

**5. Improve the Supply, Retention, and Performance of Direct Support Workers to Meet Increasing Demand (Chapter 5)**

- A. As part of the *Olmstead* guidance, CMS should issue an advisory letter to state Medicaid directors directing corrective action to achieve parity of compensation across the environments where direct support workers are located.
- B. CMS should continue to fund demonstration projects to allow states to test innovative strategies to improve the recruitment, supply, retention, and performance of direct support workers.
- C. Funding should be authorized for collaborative demonstration projects between the U.S. Departments of Labor and HHS that promote collaboration between community colleges and disability-related organizations to develop a high-quality set of competencies to be taught in a new support worker certificate program that expands supplies of quality workers to meet market demand in home- and community-based settings.
- D. Worker cooperatives should be piloted and tested with the assistance of the Departments of Agriculture, Labor, and HHS to explore improved consumer-caretaker relationships.

**6. Mandate Coordination and Collaboration Among Federal Agencies to Align Public Policy and Transform Infrastructure to Be Responsive to Consumer Needs and Preferences for a Comprehensive System of LTSS (Chapter 5)**

A. Although Medicaid and Medicare dominate the landscape of funding authorities for LTSS, NCD researchers documented the complexity and fragmentation of multiple systems with different rules of eligibility and lack of information on access to and availability of resources. The fragmentation and coordination challenges carry over from the executive to the legislative branches of government, in which different committees in the Senate have different controlling authority than committees in the House of Representatives. Although Program Assessment Rating Tool (PART) reviews by the Office of Management and Budget (OMB) are incorporating common performance measures across agencies and programs, *there is no focus on cross-department and agency collaboration*. The nature of LTSS requires more than 200 programs and 20 agencies to improve their coordination of resources at the community level, where they will benefit the end-user. No single recommendation can respond to this significant challenge. NCD recommends that the appropriate agencies and congressional committees implement the following set of recommendations:

- Hold congressional hearings to evaluate possible options for improvement of multiple department collaboration to provide access to information and supports and services to meet the long-term needs of people with disabilities under and over age 65.
- Require the Department of Housing and Urban Development (HUD) and HHS to document current efforts and future plans to improve and expand the availability of affordable, accessible housing that is coordinated with services/supports, when needed. Establish an Interagency Council on Meeting the Housing and Service Needs of Seniors and Persons with Disabilities.<sup>5</sup> (See chapter 6 for a description of the full role of the council.)
- Add to the PART performance criteria indicators that will evaluate documented outcomes from intra-agency and cross-agency collaboration to meet LTSS needs of people with disabilities. Consider possible financial incentives for agencies that

document valued outcomes from LTSS system collaboration. Report annually to Congress on individual agency performance in this area.

- Issue a new Executive Order charging CMS to chair a time-limited workgroup (six months) on LTSS that includes representation by HUD, HHS, the Social Security Administration (SSA), and the Departments of Education, Labor, Justice, Transportation, Treasury, and Agriculture to identify policy barriers and facilitators to an improved comprehensive, coordinated system of LTSS for people with disabilities under and over age 65 that maximizes interagency collaboration, promotes consumer direction, and increases consumer choice and access to affordable supports and services in home- and community-based settings.

**7. Improve and Hold States Accountable for Rebalancing Their Systems to Support LTSS (Chapter 5)**

- A. Study states that are having success with a global budgeting approach to move their LTSS system from an institutional bias to be anchored by HCBS and home- and community-based supports.
- B. Develop a template in consultation with states to be used to evaluate and measure current expenditures for LTSS in institutional versus home- and community-based settings. Such a template would be developed jointly by CMS and CBO to allow for consistent, comparative benchmarking from year to year within and among states.

**8. Increase Understanding of the Possible Relationship Between an LTSS Insurance Product and Publicly Financed LTSS (Chapter 5)**

- A. Congressional interest remains high to understand and explore further the possible relationship between the current market for long-term care insurance products and a reduced dependence on Medicaid and Medicare for long-term support needs. With the growing cost of Medicaid and Medicare documented by NCD researchers, there is growing interest in forging a new level of partnership with the insurance industry that explores both the expansion of product options and the possible cost savings to the public system. For people with disabilities under age 65, no such insurance product yet exists, and little is known about the risk factors in terms of potential utilization by the target

population and how to achieve affordable pricing. Even with the adoption of several of the other major recommendations proposed in this report, it is unlikely that a revised Medicaid program will ever meet the needs of all people who are seeking LTSS.

- B. Conduct a feasibility study of possible new insurance products and options regarding relationship to the Medicaid program to evaluate possible strategies to partner an LTSS insurance product with supplementary Medicaid coverage for people with disabilities under age 65. Consider price, benefit coverage, caps in coverage, and eligibility for Medicaid LTSS, and project market demand and needed incentives to share risk among stakeholders: the government, the consumer, and the insurance industry. The possible collaboration would include the assistant secretary for planning and evaluation (APSE) at HHS, CMS, and a private insurer.
- C. Pilot test such a product or products to evaluate cost benefits to all critical stakeholders. Such a pilot must recognize that LTSS must be individualized to accommodate the needs and desires of the individuals receiving assistance and that the services and supports must reflect consumer preference for noninstitutional settings. Such an insurance product must achieve several objectives: It must be affordable, flexible, responsive to consumer needs and preferences, and sustainable over time with federal oversight.

**9. Improve Consumer Understanding, Knowledge, and Skills to Develop a Person-Centered Plan and Self-Direct an Individual Budget (Chapter 5)**

- A. The Cash and Counseling Demonstrations and the Independence Plus Waivers have produced early positive findings of increased consumer satisfaction with the self-direction of individual budgets, the selection of support providers, and increased choice in development of person-centered plans. Individuals with disabilities and their families should be given the opportunity to plan, obtain control, and sustain the services that are best for them in preferred home- and community-based settings. For people with disabilities who have been given few choices in the past regarding services and supports and service delivery options, consumer self-direction requires information, education, and training to build the critical skills needed to make informed decisions.

- B. Access to information about service options, streamlined procedures for determining eligibility for various public benefits, and new infrastructure will need to be developed to assist with programmatic and financial management.
- C. Recommendations that recognize the principles of individual self-direction and responsibility for prudent and effective management of public resources are critical to the development of the LTSS system of the future.
- D. The system should continue to provide competitive grants that establish Aging and Disability Resource Centers (ADRCs) in all 50 states that provide one-stop access to information and individualized advice on long-term support options, as well as streamlined eligibility determinations for all publicly funded programs.
- E. The system should establish, with funding from CMS, a National Resource Center on Consumer Self-Direction that identifies and disseminates best practice information on person-centered plan development, self-directed management of individual budgets, and examples of multiple funders combining funds within an individual budget to achieve common negotiated performance objectives.
- F. The system should require states, as part of their HCBS waiver implementation, to provide education and training to eligible Medicaid beneficiaries on effective and meaningful participation in person-centered planning, management of individual budgets, and negotiation with service and support providers.
- G. The system should establish a cross-agency workgroup that involves CMS, the Administration on Aging (AOA), SSA, the Administration on Developmental Disabilities, HUD, the Office of Special Education and Rehabilitative Services at the Department of Education, and the Department of Labor to accelerate options for states to bundle and/or braid public funds within a self-directed individual budget with streamlined and accelerated eligibility procedures.

**10. Continue to Educate People with Disabilities, Their Families, and Other Critical Stakeholders About LTSS Challenges in Public Policy and Practice and Document Further Consumer Needs, Costs, and Preferences for a Comprehensive, Accessible, and Affordable System (Chapter 5)**

- A. This report documents the current crisis and the impending “perfect storm.” It is a complex and confusing picture, not easy to grasp and even more difficult to change as we move forward. NCD must continue to put the spotlight on the critical set of challenges that in the next 20 years may touch more than half the population of our country. For people with unmet LTSS needs today, NCD must continue the public education process through outreach activities and direct discussion with the disability community and policymakers.
- B. A series of audio conferences and a national summit of key leaders and stakeholders should be held to continue to document the findings and build consensus on possible policy and practical solutions.

**Recommendations for Clean Slate Reform: Year 2049 (See Chapter 6 for full text and implementation leads and future model)**

- 1. AmeriWell is a Prefunded, Mandatory, Long-Term Services and Support Model That Provides All Americans of Any Age with Coverage from Birth Based on Criteria of Risk and Functioning, and Not Category of Disability (Chapter 6)**
  - A. AmeriWell delinks LTSS from Medicaid and Medicare, creating its own governing agency, regulations, oversight, and congressional committee.
  - B. The contributions of individuals and families, the private sector, and the Federal Government fund AmeriWell. A “penny pool” is established through private stock transactions to supplement LTSS costs for impoverished and vulnerable Americans previously served under Medicaid and Medicare.
  - C. Medicaid remains a primary safety net for mothers and children. Medicare continues to provide its health and acute care and limited home services to individuals 65 and older who are not Medicaid eligible or on SSDI.

## **Chapter 1**

# **The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**



# Table of Contents

## Chapter 1

	<b>Page</b>
<b>Part I</b>	
<b>Picturing the Problem</b> .....	41
<b>Part II</b>	
<b>Charting the Course</b> .....	44
<b>Part III</b>	
<b>Forecasting the Need</b> .....	48
<b>Part IV</b>	
<b>Dragging Anchor</b> .....	55
<b>Part V</b>	
<b>Introducing the Captain</b> .....	62
<b>Part VI</b>	
<b>Meeting the Crew</b> .....	74
<b>Part VII</b>	
<b>Fueling the Engine</b> .....	84
<b>Part VIII</b>	
<b>Pushing Tugboats</b> .....	106
<b>Part IX</b>	
<b>Harnessing Favorable Winds</b> .....	113
<b>Part X</b>	
<b>Gathering Clouds</b> .....	117
<b>Part XI</b>	
<b>Recharting the Course</b> .....	125
<b>Appendix 1.A</b> .....	131
<b>Appendix 1.B</b> .....	132

<b>Appendix 1.C</b> .....	134
<b>Appendix 1.D</b> .....	136
<b>Appendix 1.E</b> .....	137
<b>Appendix 1.F</b> .....	139
<b>Appendix 1.G</b> .....	157

## **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.*

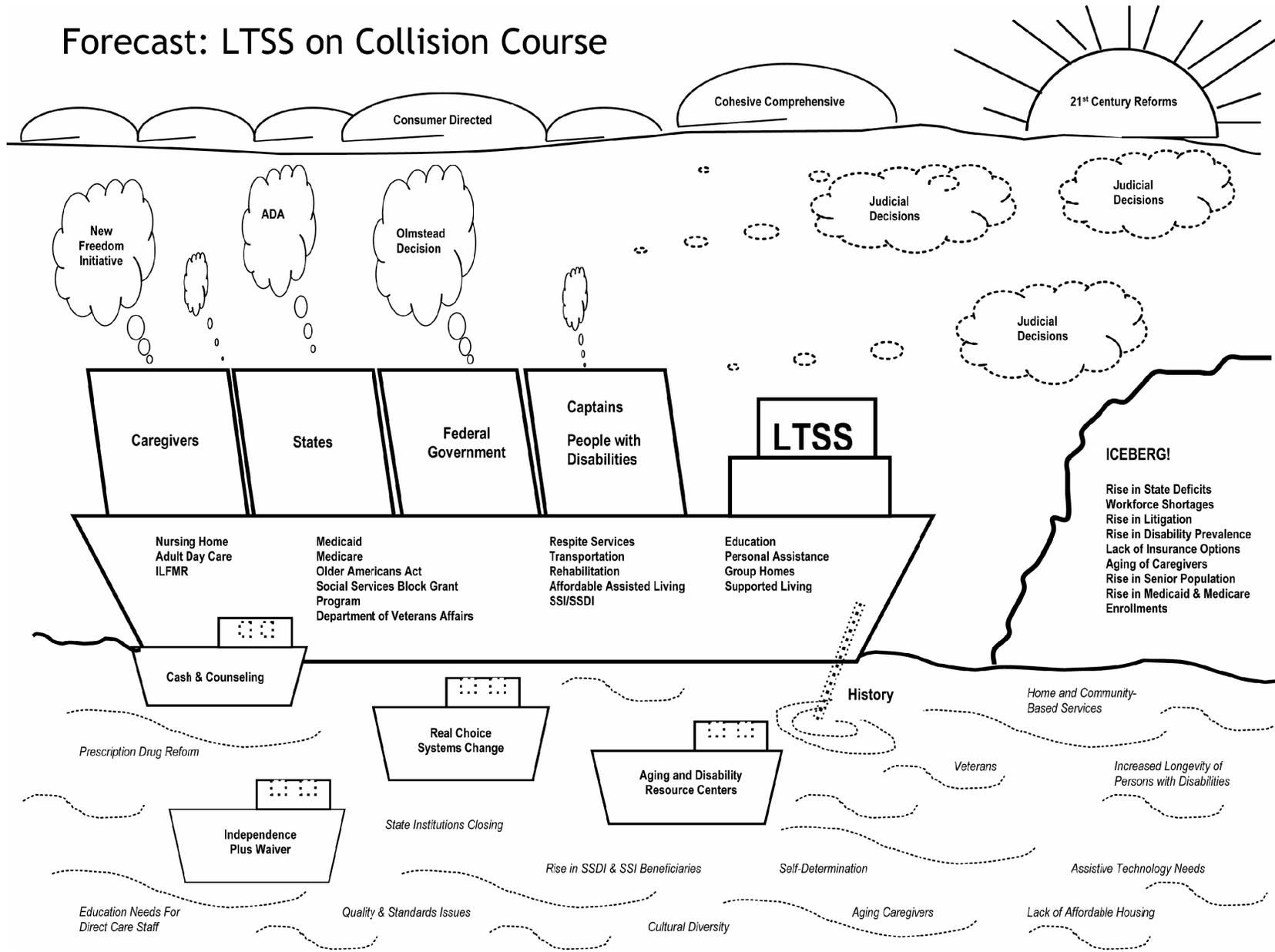
Some people say that a picture is worth a thousand words. The field of management often uses a “rich picture” systems methodology, “an innovative tool that encapsulates knowledge relevant to strategic reform.”<sup>6, 7, 8, 9</sup> It is often described in the management literature as a “soft systems 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 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.

# Forecast: LTSS on Collision Course



## **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.<sup>10</sup> 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.<sup>11</sup> 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,<sup>12</sup> 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.<sup>13</sup> 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."<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup>

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 institutional 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<sup>19</sup>

### ***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.<sup>20</sup> Most participants were married, college educated, healthy, and had incomes between \$50,000 and \$100,000 and assets over \$100,000.<sup>21</sup> According to the Administration on Aging (AOA) Profile of Older Americans 2000,<sup>22</sup> 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.<sup>23</sup> 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.<sup>24</sup>

### ***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.<sup>25</sup>

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 happening 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.”<sup>26</sup> 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.<sup>27</sup> 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.<sup>28</sup> 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.<sup>29</sup> 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.<sup>30</sup> 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.<sup>31</sup> 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.”<sup>32</sup>

### ***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.<sup>33, 34</sup> 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.<sup>35, 36</sup>

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.<sup>37, 38</sup>

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.<sup>39, 40</sup> 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.”<sup>41</sup> 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.

#### **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***

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.<sup>42</sup> 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.<sup>43</sup> 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.<sup>44</sup>

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.<sup>45</sup>

## 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*

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.”<sup>46</sup> 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.<sup>47</sup> 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).<sup>48</sup>

**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)*

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.<sup>49</sup>

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.<sup>50, 51</sup> This “dilemma of difference”<sup>52</sup> 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.”<sup>53</sup> 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.”<sup>54</sup> 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.<sup>55</sup> 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.<sup>56</sup> 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.<sup>57</sup> 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.”<sup>58</sup>

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.<sup>59</sup> 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.<sup>60</sup>

The first hospitals were primarily of a “religious and charitable nature” and provided care for the sick rather than medical cures.<sup>61</sup> 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.<sup>62</sup> 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.<sup>63, 64</sup> At this time, mental illness was considered treatable, and “moral treatment” consisted of work, education, and recreation.<sup>65</sup> 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.<sup>66</sup> 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.<sup>67</sup>

### ***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.<sup>68</sup> These laws dated back to the 1500s and were inherited from our European ancestors.<sup>69</sup> 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.<sup>70</sup> 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 five 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.”<sup>71</sup>

### ***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.<sup>72</sup> 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.<sup>73</sup>

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.<sup>74</sup> However, the legacy of the state hospital continues today, with 60,000 people remaining in state mental institutions, compared with 559,000 in 1955.<sup>75, 76</sup>

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***

*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.*

**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

#### ***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.<sup>77, 78</sup> 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.<sup>79</sup> Among those 85 years and older, 21 percent were in nursing homes, and another 49 percent were community residents with LTC needs.<sup>80</sup>

## ***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.**<sup>81, 82, 83</sup> **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.<sup>84</sup> 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.<sup>85</sup>

## ***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.<sup>85</sup> 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.<sup>86</sup>

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

- |  |
|--|
| <ul style="list-style-type: none"><li>• 6 million seniors need LTSS</li><li>• 4.5 million receive LTSS in home and community</li><li>• 1.5 million receive LTSS in skilled nursing facility</li><li>• 60% rely on unpaid caregivers</li><li>• 7% rely on paid LTSS</li></ul> |
|--|

## ***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).

***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.***<sup>87, 88, 89, 90</sup> 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.<sup>91</sup> 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).<sup>92</sup>

**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.

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.<sup>93</sup> 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.<sup>94</sup> For people over age 65 (N=34 million), 12 percent were community residents and 5 percent were nursing home residents reporting functional limitations.<sup>95</sup> 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.<sup>96</sup> 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.<sup>97</sup> 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.<sup>98</sup>

### ***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.<sup>99, 100</sup> Some individuals with Alzheimer's may have no ADL dependency, but they cannot function independently.<sup>101</sup> 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.<sup>102, 103</sup>

### ***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.<sup>104</sup> In 1980, only 4 percent of wage-earning adults needed help with ADLs, compared with 5.2 percent by 1996.<sup>105</sup> 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).<sup>106</sup> 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.<sup>107</sup>

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.<sup>108</sup> 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<sup>109</sup> 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.<sup>110, 111</sup>

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),<sup>112</sup> 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.<sup>113</sup> 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.<sup>114</sup> 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<sup>115</sup> 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).<sup>116, 117</sup>

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.<sup>118</sup>

### ***SSI Recipients***

According to the 2004 CFDA,<sup>119</sup> 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.<sup>120</sup> 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?<sup>121</sup> 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.<sup>122</sup> 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.<sup>123</sup> 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.”<sup>124</sup>

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.<sup>125</sup> 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.<sup>126</sup>

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%), musculoskeletal problems (28.7%), and heart disease (10.8%).<sup>127</sup>

### ***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.<sup>128</sup> 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.<sup>129</sup> The largest category of Medicaid spending for dual eligibles includes LTC, including nursing facilities, home- and community-based services (HCBS), institutions for individuals with mental retardation, and other LTC services.<sup>130</sup> 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.<sup>131</sup>

### ***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.<sup>132</sup> 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.<sup>133</sup>

### ***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.<sup>134</sup> 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.”<sup>135</sup>

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.<sup>136</sup> 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.<sup>137</sup>

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.”<sup>138</sup> 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.<sup>139</sup> 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.”<sup>140</sup> 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.”<sup>141</sup>

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 than the older adults.<sup>142</sup> 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.<sup>143</sup>

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.<sup>144</sup> 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.<sup>145</sup> A MetLife analysis estimated aggregated costs of caregiving employees to employers nationwide ranged between \$11.4 billion per year and \$29 billion per year.<sup>146</sup> 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.<sup>147</sup> It is estimated that Americans provide 120 million hours of unpaid care to elders with functional disabilities living in community settings.<sup>148</sup> 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.<sup>149</sup> 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.<sup>150</sup>

Lechner,<sup>151</sup> 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<sup>152</sup> 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.<sup>153</sup>

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.<sup>154</sup> 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.<sup>155</sup> 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.<sup>156</sup> 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.<sup>157</sup> In defining the relationship between caregiver and care recipient, 83 percent were identified as related by family or marriage.<sup>158</sup>

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%).<sup>159</sup>

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%).<sup>160</sup> 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.<sup>161</sup>

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.<sup>162</sup> 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.<sup>163</sup>

- 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%).<sup>164</sup>
- Over the period of caregiving, family members providing intense personal care can lose as much as \$659,000 in wages, pensions, and Social Security.<sup>165</sup>
- 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.<sup>166</sup>
- An assessment of family caregiver strengths, needs, and preferences constitutes the foundation for developing appropriate and quality LTSS.<sup>167, 168</sup>

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.<sup>169</sup>

### **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%).<sup>170</sup> 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.<sup>171</sup> 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.<sup>172</sup>

Unfortunately, workforce challenges are expected to get worse as the baby boom generation ages and places more demands on the LTSS system.<sup>173</sup>

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.<sup>174</sup> 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.<sup>175</sup>

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.<sup>176</sup>

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.<sup>177</sup> 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.<sup>178</sup> However, typical free market forces are constrained by the dominance of Medicare and Medicaid as the majority

fundes 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.<sup>179</sup>

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.<sup>180</sup> 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.”<sup>181</sup> 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.<sup>182</sup> 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.<sup>183</sup>

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.<sup>184</sup>

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.<sup>185</sup> 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.<sup>186</sup> 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,<sup>187</sup> with the National Governors Association (NGA) reporting a 9.3 percent growth in FY 2003.<sup>188</sup> 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.<sup>189</sup>

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.<sup>190</sup> 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.<sup>191</sup> 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.<sup>192</sup>

## Part VII

### Fueling the Engine

*An examination of the key federal programs (entitlements and other discretionary 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.

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*

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.

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.<sup>193</sup>

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.<sup>194</sup> 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.<sup>195, 196, 197</sup>

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.<sup>198</sup>

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.<sup>199</sup>

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."<sup>200</sup> 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<sup>201</sup>

While Section 1902(a) (23) of the Social Security Act establishes the right of Medicaid beneficiaries to choose their own provider,<sup>202</sup> 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.<sup>203, 204</sup>

### ***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.<sup>205, 206</sup>

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.<sup>207</sup>

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.<sup>208</sup>

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.<sup>209</sup>

**Table 1.4. Medicaid HCBS Waivers by Population**<sup>210</sup>

<b>Population</b>	<b>Number of States</b>
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.<sup>211</sup> 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.<sup>212</sup>

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.<sup>213</sup> 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.<sup>214</sup>

### **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.<sup>215</sup>

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.<sup>216</sup>

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.<sup>217, 218</sup>

## **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.<sup>219</sup>

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.<sup>220</sup> 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.<sup>221</sup>

### ***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.<sup>222</sup>

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<sup>223</sup> (estimated by HUD as 1.1 million to 1.4 million people) of the households with worst-case housing needs in the United States.<sup>224</sup> 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.<sup>225</sup>

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.<sup>226</sup> 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,<sup>227</sup> 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)<sup>228</sup> 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).<sup>229</sup>

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.”<sup>230</sup> 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.<sup>231</sup>

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.<sup>232</sup> 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.”<sup>233</sup>

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.”<sup>234</sup> 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.<sup>235</sup>

## ***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.<sup>236</sup>

According to a USDA report to Congress,<sup>237</sup> 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.<sup>238, 239</sup>

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.<sup>240</sup>

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.<sup>241, 242</sup> 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.<sup>243, 244, 245</sup> 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.<sup>246</sup>

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.<sup>247</sup>

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.<sup>248</sup>

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*,<sup>249</sup> 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.<sup>250</sup>

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.<sup>251</sup>

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 qualify 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.<sup>252</sup>

### ***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*<sup>253</sup> 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.<sup>254</sup> 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."<sup>255</sup>

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.<sup>256</sup>

Respite care is also an allowable service under the HCBS waivers and is included in a majority of state waivers to targeted eligible individuals.<sup>257</sup> 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.<sup>258</sup>

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.<sup>259</sup>

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.<sup>260</sup>

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."<sup>261</sup>

## **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.<sup>262</sup>

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.<sup>263</sup>

Based on preliminary positive findings, HHS awarded on a competitive basis new Cash and Counseling Demonstration projects in 11 states in October 2004.<sup>264</sup>

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.<sup>265</sup>

## ***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.<sup>266</sup>

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.<sup>267</sup> 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.<sup>268</sup> 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.<sup>269</sup> Appendix 1.E provides an overview of all 50 states with initiatives to improve access to LTSS.<sup>270</sup>

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.<sup>271</sup> 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.<sup>272</sup> 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.”<sup>273</sup>

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.<sup>274</sup>

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.<sup>275</sup> 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.<sup>276</sup>

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.”<sup>277</sup>

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<sup>278</sup> and of its predecessor, the Rehabilitation Act of 1973,<sup>279</sup> 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.<sup>280</sup>

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,<sup>281</sup> 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.<sup>282</sup>

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.”<sup>283</sup> 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.”<sup>284</sup>

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.”<sup>285</sup>

### ***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.<sup>286</sup> 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.<sup>287</sup> The Supreme Court stated that “Unjustified isolation . . . is properly regarded as discrimination based on disability.”<sup>288</sup> 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.<sup>289</sup>

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.<sup>290</sup> 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.<sup>291</sup>

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.<sup>292</sup>

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.<sup>293</sup>

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.<sup>294</sup> In 2004, a second progress report was issued that further updates federal agency efforts to promote community integration.<sup>295</sup>

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.<sup>296</sup> 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.<sup>297</sup> 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.<sup>298</sup> 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.<sup>299</sup> Under Medicaid law, there is an entitlement to institutional services that must be included in a state’s Medicaid program.<sup>300</sup> There is no similar entitlement for home and community LTSS.<sup>301</sup> 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.<sup>302</sup> However, a state may select the services, define their scope, and target a specific group of Medicaid beneficiaries under an HCBS waiver.<sup>303</sup>

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.<sup>304</sup> 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.<sup>305</sup>

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.<sup>306</sup> 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.<sup>307</sup> 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.<sup>308</sup> 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.<sup>309</sup> 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.<sup>310</sup>

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.<sup>311</sup> 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.<sup>312</sup> 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*,<sup>313</sup> 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.<sup>314</sup>

The Second Circuit denied relief, ruling that *Olmstead* reaffirms that ADA does not require a state to offer a new type of Medicaid service.<sup>315</sup> 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.”<sup>316</sup> Plaintiffs were requesting new services, as New York does not provide safety monitoring to individuals with physical or mental disabilities.<sup>317</sup>

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.<sup>318</sup> 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*,<sup>319</sup> 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.<sup>320</sup> 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.<sup>321</sup> In September 2002, OHCA notified participants that it would impose a cap of five prescriptions per month on Advantage participants, effective October 1, 2002.<sup>322</sup> The state, meanwhile, continued to provide unlimited prescriptions to patients in nursing facilities.<sup>323</sup>

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.<sup>324</sup>

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.”<sup>325</sup> 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.”<sup>326</sup> 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.<sup>327</sup>

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.”<sup>328</sup> *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*,<sup>329</sup> 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.”<sup>330</sup>

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.”<sup>331</sup> 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.<sup>332</sup>

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.”<sup>333</sup> 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.<sup>334</sup>

## **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.<sup>335</sup> 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.”<sup>336</sup>*

*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?<sup>337</sup>

### **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.<sup>338</sup>

### **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.<sup>339</sup>

### **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.”<sup>340</sup>

### ***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.<sup>341</sup>



## 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+
<b>Total</b>	100%	20%	79%
<b><i>Gender</i></b>			
Male	39%	44%	37%
Female	61	56	63
<b><i>Race of Caregiver</i></b>			
White	73%	69%	74%
African American	12	16	11
Hispanic	10	11	10
Asian American	4	4	4
<b><i>Age of Caregiver</i></b>			
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
<b><i>Marital status</i></b>			
Married/living with partner	62%	53%	63%
Single, never married	18	22	17
Separated/divorced	14	17	14
Widowed	6	7	6
<b><i>Education attainment</i></b>			
High school or less	34%	41%	33%
Some college	27	3	26
Technical school	3	2	3
College graduate	22	18	23

	<b>Total</b>	<b>Caregivers of recipients 18-49</b>	<b>Caregivers of recipients 50+</b>
Graduate school +	13	8	14
<b><i>Current employment</i></b>			
Employed full time	48%	54%	47%
Employed part time	11	12	10
Not employed	41	33	43
<b><i>Household income</i></b>			
<\$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](http://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 <a href="http://www.cashandcounseling.org">www.cashandcounseling.org</a>	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.
Aging and Disability Resource Centers (ADRCs)	Administration on Aging and Centers for Medicare and Medicaid Services (CMS)  \$19 million 2003–2006 <a href="http://www.adrc.org">www.adrc.org</a>	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 <a href="http://www.hcbs.org">www.hcbs.org</a>	States are funded to build infrastructure and pursue policy changes that result in “effective and enduring improvements in community long-term support systems.”	Focus on sustainable system changes concerning the approach to service delivery, exercise of meaningful choices

<b>Long-Term Services and Support: Reform Strategies</b>			
<b>Initiative</b>	<b>Funders</b>	<b>Focus</b>	<b>Evaluation</b>
		<p>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.</p> <p>Other grants focus on comprehensive system reform efforts.</p>	<p>with expanded support options to live in the most integrated setting appropriate, rebalancing of funding to expand community living preferences and priorities, and nursing home diversion and transition.</p> <p>All states have one or more grants.</p>
Independence Plus Waiver Demonstration	<p>CMS</p> <p><a href="http://www.cms.hhs.gov/independenceplus">www.cms.hhs.gov/independenceplus</a></p>	<p>States are funded through the HCBS waiver authority to offer individualized budgets and consumer self-direction.</p> <p>Nine states have been approved:</p> <p>California, New Hampshire, Louisiana, South Carolina, Maryland, Florida, North Carolina, Connecticut, and Delaware</p>	<p>Focus on cost savings, consumer satisfaction and outcomes, and other benefits of consumer direction.</p>

Source: Author's compilation.

## Appendix 1.D

### Overview of Cash and Counseling Demonstrations

	<b>Arkansas</b>	<b>New Jersey</b>	<b>Florida</b>
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
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](http://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	
Massachusetts	x	x	x	x	x	x
Michigan	x	x		x	x	x
Minnesota	x			x	x	x
Mississippi				x		x

State	Integrated LTC Systems	Streamlined Eligibility Determinations	Expanded Eligibility	Nursing Facility Resident Transition*	Informed Consumer Choice	Other**
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
<b>Total</b>	<b>32</b>	<b>20</b>	<b>16</b>	<b>43</b>	<b>45</b>	<b>38</b>

\*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](http://www.hcbs.org), accessed June 2005.

## Appendix 1.F

### Federal Tables

**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
<b>Medicare Part A</b>	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
<b>Medicare Part B</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.	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	No

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
				Durable medical equipment at home.						39,477,000	
<b>Medicare Part D</b>	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
<b>Medicaid</b>	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](http://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
<b>Independent Living State Grants</b>	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
<b>Centers for Independent Living</b>	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

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
<b>Special Programs for the Aging</b>	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
<b>Senior Companion Program</b>	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
<b>Medicaid HCBS Waiver</b>	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

<b>Domains And Programs</b>	<b>Year Authorized</b>	<b>Responsible Agency</b>	<b>Eligibility</b>	<b>Scope of Service</b>	<b>Consumer Directed</b>	<b>Consumer-Perspective Quality</b>	<b>State/ Local Partners</b>	<b>Financing Mechanism</b>	<b>Innovation or Systems Change</b>	<b>Utilization: Trends Over Time</b>	<b>Universal Design</b>
<b>Social Services Block Grant</b>	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](http://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
<b>Social Security</b>	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
<b>Supplemental Security Income (SSI)</b>	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

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
<b>Social Security Disability Insurance (SSDI)</b>	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](http://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
<b>Housing and Urban Development (HUD) 811</b>	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
<b>HUD 202</b>	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

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
<b>HOME</b>	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
<b>Community Development Block Grant (CDBG)</b>	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

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
<b>HOPE VI</b>	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
<b>Housing Opportunities for Persons with AIDS (HOPWA)</b>	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
<b>Continuum of Care Program (COC):</b> 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

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
<b>Section 8 Housing Choice Voucher Program</b>	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
<b>Family Self-Sufficiency (FSS) Program</b>	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

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
<b>Section 502 Rural Housing Service</b>	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](http://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
<b>Capital Assistance Program for Elderly Persons and Persons with Disabilities Section 5310</b>	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
<b>Job Access Reverse Commute Section 5311</b>	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

<b>Domains and Programs</b>	<b>Year Authorized</b>	<b>Responsible Agency</b>	<b>Eligibility</b>	<b>Scope of Service</b>	<b>Consumer Direction</b>	<b>Consumer-Perspective Quality</b>	<b>State/ Local Partners</b>	<b>Financing Mechanism</b>	<b>Innovation Or Systems Change</b>	<b>Utilization: Trends Over Time</b>	<b>Universal Design</b>
<b>United We Ride State Coordination Grants</b>	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](http://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
<b>Title III Part C Nutrition Services Elderly Nutrition Program (ENP)</b>	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

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
<b>Senior Farmers' Market Nutrition Program (SFMNP)</b>	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
<b>Food Stamps Reauthorization Act</b>	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](http://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
<b>Assistive Technology Act of 1998</b>	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](http://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
<b>National Family Caregiver Support</b>	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](http://www.cfda.gov), accessed June 2005.

# APPENDIX 1.G

## Congressional Oversight of Federal Programs

### Federal Health Care Programs

Program Name	Purpose	Act* <i>Original Act or most recent Congressional activity</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Medicare (Part A) (Medicare Hospital Insurance)</b>	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
<b>Medicare (Part B) (Medicare Supplementary Medical Insurance)</b>	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
<b>Medicare (Part D)</b>	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 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

Program Name	Purpose	Act* <i>Original Act or most recent Congressional activity</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.						
<b>Medicaid</b>	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,	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

Program Name	Purpose	Act* <i>Original Act or most recent Congressional activity</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	copayments, and deductibles of qualified Medicare beneficiaries meeting certain income requirements. More limited financial assistance is available for certain Medicare beneficiaries with higher incomes.						
<b>Medicaid, Home- and Community-Based Services (HCBS) Waiver</b>	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	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

Program Name	Purpose	Act* <i>Original Act or most recent Congressional activity</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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. 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* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Independent Living State Grants</b>	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
<b>Centers for Independent Living</b>	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
<b>Special Programs</b>	Grants are made to any	Older Americans Act	Committee	Varies	(1) Committee	Varies	Department of

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>for the Aging: Discretionary Projects</b>	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.	of 1965, P.L. 89-73, July 14, 1965, 79 Stat. 218, codified at 42 U.S.C. sec. 3001	on Health, Education, Labor, and Pensions		on Education and the Workforce, (2) Energy and Commerce		Health and Human Services, Administration on Aging
<b>Special Programs for the Aging: Grants for Supportive Services and Senior Centers</b>	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.						
<b>Senior Companion Program</b>	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
<b>Medicaid Home- and Community-Based Services (HCBS) Waiver</b>	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	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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. There are no specific services that must be offered in an HCBS waiver program.	(P.L. 97-35, Title XXI, Aug. 13, 1981, 95 Stat. 783) (codified at 42 U.S.C. sec. 1396n)					
<b>Social Services Block Grant</b>		Social Security Act, Title XX, as amended; Omnibus Budget Reconciliation Act of	Varies	Varies	Varies	Varies	Department of Health and Human Services, Administration for Children and

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
		1981 (P.L. 97-35) (codified at 42 U.S.C. sec. 1397 et seq.)					Families
<b>Social Security</b>	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Supplemental Security Income</b>	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
<b>Social Security Disability Insurance</b>	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* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Section 811</b>	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
<b>Section 202</b>	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
<b>HOME Investment</b>	HOME provides formula grants to states and	Cranston-Gonzalez National Affordable	Committee on Banking,	Subcommittee on Housing and	Committee on Financial	Housing and Community	Department of Housing and Urban

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Partnerships Program</b>	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.	Housing Act (NAHA), Title II (P.L. 101-625, Nov. 28, 1990, 104 Stat. 4079) (codified at 42 U.S.C. sec. 12721)	Housing, and Urban Affairs	Transportation	Services	Opportunity Subcommittee	Development, Community Planning, and Development
<b>Community Development Block Grant (CDBG) Programs</b>	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
<b>Homeownership and Opportunity for People Everywhere (HOPE) VI</b>	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	Quality Housing and Work Responsibility Act of 1998 (P.L. 105-276, Title V, Oct. 21, 1998, 112 Stat. 2518)( <i>codified at</i> 42 U.S.C. sec. 1437c-1, 1437z-1 <i>et. seq.</i> , 1437w, 1437bbb-1 et seq.) <i>see also</i> , HOPE VI Program Reauthorization and Small Community	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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 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.	Mainstreet Rejuvenation and Housing Act of 2003 (P.L. 108-186, Title IV, Dec. 16, 2003, 117 Stat. 2693)					
<b>Housing Opportunities for Persons with AIDS (HOPWA)</b>	The HOPWA Program was established to address the specific needs of people living with	AIDS Housing Opportunity Act (Housing Opportunities for	Committee on Banking, Housing, and Urban	Subcommittee on Housing and Transportation	Committee on Financial Services	Housing and Community Opportunity Subcommittee	Department of Housing and Urban Development, Community

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.	People with AIDS Act of 1991 (HOPWA) (P.L. 101-625, Title VIII, Subtitle D, Nov. 28, 1990, 104 Stat. 4375) ( <i>as codified at 42 U.S.C. sec. 12901 et. seq.</i> )	Affairs				Planning, and Development
<b>Supportive Housing Program</b>	The Program is designed to promote the development of supportive housing and supportive services to assist homeless people in the transition from	McKinney-Vento Homeless Assistance Act (Stewart B. McKinney Homeless Assistance Act) (McKinney Act) (P.L. 100-77, July 22,	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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	1987, 101 Stat. 482) ( <i>codified at 42 U.S.C. sec. 11301 et. seq.</i> )					

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	serious mental illness currently residing on the streets who may not yet be ready for supportive services.						
<b>Section 8 Housing Choice Voucher Program</b>	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Section 502 Rural Housing Service</b>	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* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Capital Assistance Program for Elderly Persons and Persons with Disabilities</b>	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 Environment 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* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Elderly Nutrition Program (ENP)</b>	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
<b>Senior Farmers' Market Nutrition Program (SFMNP)</b>	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	<p>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.</p>						

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Community Food Projects (Food Stamps)</b>	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* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Assistive Technology Act (ATA) of 1998</b>	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.						

### Caregiver Support/Respite Care

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>National Family Caregiver Support Program (NFCSP)</b>	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	Older Americans Act Amendments of 2000, section 316, (P.L. 106-501, Nov. 13, 2000, 114 Stat. 2226) ( <i>codified at 42 U.S.C. sec. 3030s, 3030s-1, 3030s-2, 3030s-11, 3030s-12</i> )	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	<p>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.</p>						

### Civil Rights Protections

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Americans with Disabilities Act (ADA)</b>	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
<b>Civil Rights of Institutionalized Persons Act (CRIPA)</b>	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.	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.						
<b>Rehabilitation Act (Section 504)</b>	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	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.						
<b>Fair Housing Act (FHA)</b>	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	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

Program Name	Purpose	Act* <i>Original Act</i>	Senate		House of Representatives		Agency, Office
			Committee	Subcommittee	Committee	Subcommittee	
	<p>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.</p>						



## **Chapter 2**

# **Future Market Demand and Understanding Costs of Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**



## **Table of Contents**

### **Chapter 2**

	<b>Page</b>
<b>Part I</b>	
<b>Introducing Research Purpose and the Rich Picture Story Line</b> .....	191
<b>Part II</b>	
<b>Forecasting the Storm</b> .....	193
<b>Part III</b>	
<b>Tracking the Storm</b> .....	197
<b>Part IV</b>	
<b>Lowering the Lifeboats</b> .....	216
<b>Part V</b>	
<b>Approaching the Iceberg</b> .....	225
<b>Part VI</b>	
<b>Reviewing the Passenger Manifest</b> .....	241
<b>Part VII</b>	
<b>Moving Toward Reform</b> .....	272



## **Part I**

### **Introducing Research Purpose and the Rich Picture Story Line**

*Long-Term Services and Support Financing and Systems Reform*

#### ***Purpose***

The purpose of chapter 2 is to explore and understand the future market demand and costs of long-term services and supports (LTSS) for individuals with disabilities through a review and analysis of the literature and in-depth case studies of six individuals to better understand the current experience with and future need for affordable LTSS nationwide for Americans with disabilities.

#### ***Rich Picture Story Line***<sup>342</sup>

The setting for chapter 2 is the LTSS ship heading toward the iceberg in the waters of reform. The iceberg represents barriers to reform; the state of the economy; state and federal deficits; rising health care costs; workforce shortages; increasing numbers of uninsured; low national savings; and increased longevity of all Americans. The setting in part II is an overview of the storm clouds: multidimensional financial and attitudinal challenges that compete for the attention of even the most skilled navigators. In part III, the consumer-directors chart their way through the demographic challenges and trends of the current and future LTSS system. The setting in part IV is the LTSS ship with its consumer-directors talking with other Medicaid beneficiaries about the rising costs. The waves are taking their toll, and it becomes evident that some passengers must be lowered onto lifeboats and given passage to safer waters. In part V, the ship will come face to face with the financial barriers to reform and lower its lifeboats yet again before hitting the iceberg. In part VI, six consumer-directors will introduce themselves and provide information about their journey and what they think their lives will look like in 2030. In part VII, the consumer-directors will summarize their findings and prepare for their final voyage into the waters of reform.

## ***Research Questions***

The Government Accountability Office (GAO) states clearly in its “21st Century Challenges: Reexamining the Federal Base of Government” that current fiscal policies in place today are economically unsustainable over the long term without unprecedented changes in tax and/or spending

Defining differences between needs, wants, affordability, and sustainability is fundamental to rethinking the design of our current health care system.

**GAO-05-325SP**

policies.<sup>343</sup> The report identifies emerging forces that are carving out a new position for the United States in the world today. Several of these forces—long-term fiscal imbalance, increasing global interdependence, changing economy, demographic shifts, science and technology advances, and quality-of-life trends—will directly impact the current and future viability of LTSS for Americans with disabilities. In addition, the report poses a set of 21st century questions intended to guide Congress in addressing current fiscal demands as well as future fiscal challenges in fine-tuning current and future public policy that covers discretionary spending, mandatory spending (including entitlements), and tax policies.<sup>344</sup>

This chapter will probe answers to the following questions:

- Who needs LTSS?
- How is the population projected to change over the next 25 years?
- What are the pathways for eligibility for LTSS and have they changed?
- Who is meeting the LTSS demands and financing them?
- What do we know about LTSS costs today and in the future?

## Part II

### Forecasting the Storm

#### *Overview of the Problem*

The United States is a nation at risk as it enters the 21st century with unsustainable social and fiscal policy to support its aging and disability population. Despite two centuries of economic progress, it is still without a sustainable internal infrastructure for the delivery of affordable health care and LTSS for all Americans.<sup>345, 346, 347</sup> Because of the intersection of many demographic changes over the next century—such as increased longevity; low fertility rates; changing patterns of marriage, divorce, and participation in the labor force and immigration; lower national savings; rising state deficits and health care costs—there is great concern about the future of LTSS for Americans with disabilities.<sup>348, 349, 350</sup>

The director of the Congressional Budget Office (CBO), in testimony on Social Security reform before the Committee on the Budget, U.S. House of Representatives, on February 9, 2005, testified that “a major achievement of reform is to resolve uncertainty about the future and that uncertainty is an economic cost in its most fundamental form . . . and the sooner the uncertainty is resolved the better served future beneficiaries will be.”<sup>351</sup> The director stated that the key uncertainty stems from a central policy question: To what extent should Social Security programs in the 21st century resemble the program in the 20th century? The Consortium for Citizens with Disabilities responded that Congress should request a beneficiary impact statement for every major component of any serious proposal and that, when evaluating any program that affects millions of individuals of all ages, it is essential for policymakers to look beyond the budgetary change to understand the actual impact on people’s daily lives.<sup>352</sup>

There are 38 million Americans under age 65 reporting some level of disability<sup>353</sup> and, of this group, 25 million (11 percent of the nonelderly population) have a specific chronic disability.<sup>354</sup> Fifty-three percent have private insurance, 20 percent are covered under Medicaid, 15 percent are uninsured, and 12 percent have Medicare and other types of insurance.<sup>355</sup> There are 8.1 million Americans with disabilities on Medicaid and another 6 million on Medicare who are

under age 65.<sup>356</sup> The Medicaid beneficiaries with disabilities are substantially more impaired than other individuals with disabilities. About 50 percent have a physical impairment, one-fourth have some limitation in performing activities of daily living (ADLs), and 40 percent have severe mental symptoms or disorders.<sup>357</sup>

Most of the research on aging defines a person as needing LTSS if he or she requires another person's help with one or more ADLs or instrumental activities of daily living (IADLs). Using this definition, there are 9.5 million people with LTSS needs, and 36 percent (3.56 million) are nonelderly, including residents of nursing home and intermediate care facilities for the mentally retarded (ICF/MRs).<sup>358</sup>

The comptroller general of the GAO has called for a “fundamental reexamination” of America’s spending and tax priorities because of the mounting long-term fiscal challenges primarily caused by known demographic trends and growing health care costs.<sup>359</sup> A national forum of leading experts convened to explore the gap in public understanding of the nature and magnitude of the long-term fiscal challenge and to examine strategies for marketing the problem to the public to begin the dialogue about solutions. The problem was described as “too big to be solved by economic growth, or making modest changes to existing spending and tax policy.”<sup>360</sup> The seriousness of the problem is reflected in the growing imbalance between discretionary and mandatory spending. In 1964, two-thirds (67 percent) of total federal spending was discretionary; in FY 2004, this share had shrunk to about 39 percent.<sup>361</sup>

Key barriers identified at the national forum were similar to the barriers identified in chapter 1 of this report: gaining public and political will; lack of consensus among leaders on the nature, extent, and timing of the nation’s fiscal problem; lack of possible solutions; and lack of public understanding of the problem.<sup>362</sup> This phenomenon is perplexing: Despite years of national symposiums, thousands of published research studies, and millions of dollars spent on the economics of America’s troubled social and fiscal policy, we are still without reform.<sup>363</sup>

Testimony on the crisis in long-term care (LTC) spending was heard on April 19, 2005, before the Subcommittee on Health of the House Committee on Ways and Means, U.S. House of Representatives. Noticeably absent was research about the service and support needs and

challenges of people with disabilities who are under the age of 65. Congress and the American public still think only of aging when they discuss issues of LTSS. Even the research is scarce on the prevalence and demographics of people using LTSS under age 65. As the current debate heats up, it will be imperative that disability research is developed that provides comprehensive data on what it costs to live with a lifelong disability.

The current system of LTSS is based on policy and purpose written 40 years ago for low-income Americans on public assistance, children, the elderly, and people with disabilities. Although Medicaid and Medicare have made many improvements over the past four decades, their fundamental purposes were not designed to meet the needs of the current aging and disability demographics. Today, less than 20 percent of people on Medicaid are on welfare; 30 percent of the population includes the elderly and people with disabilities, and the other 70 percent includes mostly children and families who need health insurance.<sup>364</sup> Despite legislation that allows states to shift services and supports from the nursing home to the community, Medicaid continues to spend 64.3 percent (\$73.1 billion) for care in nursing facilities and ICF/MRs, mainly for people with disabilities.<sup>365</sup> Medicaid spending has gone from 8 percent of state budgets in 1985 to 22 percent in 2003.<sup>366</sup> Seven million people with disabilities receive both Medicaid and Medicare (dual eligible) and account for 42 percent of all state Medicaid spending.<sup>367</sup>

Although Americans make more money than the rest of the world, they spend more.<sup>368</sup> Many people with disabilities and seniors who are not eligible for public benefits are not financially prepared to pay for the costs of LTSS (only 7% have annual incomes of \$50,000 or more).<sup>369, 370</sup> A private room in a nursing home in 2003 was \$66,000 on average and a home health aide averaged \$18 per hour. People with disabilities under age 65 are poorer and have less work history than today's retired seniors (35% have incomes hovering around the federal poverty level). Individuals with disabilities on Supplemental Security Income (SSI) who are working (more than 323,000) are challenged by disincentives in the policy that discourage earnings and prevent the development of assets that could provide resources to pay a fair share of the costs for LTSS.<sup>371</sup>

Few Americans with lifelong impairments purchase LTC insurance because of the cost and the reluctance of the insurance industry to underwrite high-risk populations.<sup>372, 373</sup> Yet, a few major

investment houses are marketing financial planning products for special needs populations, which appeal to parents challenged with providing for the long-term future of a child with a lifelong disability. Ten percent of Americans have purchased LTC insurance, but for people with disabilities, many of the standard policies cater more to medical rehabilitation and less to the nonspecific needs of those who have a chronic illness or long-term impairment. Under the current system, it is unclear how families and communities plan to support a child born today with a lifelong disability that will require extraordinary costs.

The trend to drop employer-based health care is growing as annual health care premiums continue to rise.<sup>374</sup> The Institute of Medicine estimates that 18,000 lives are lost each year because of gaps in insurance coverage at an economic cost between \$65 billion and \$139 billion annually from premature death, preventable disability, early retirement, and reduced economic output.<sup>375</sup>

The shrinking workforce, both paid and unpaid, providing the majority of LTSS is unstable, underpaid, and untrained.<sup>376</sup> The family unit that provides the majority of unpaid care today (women in their 50s) will change in the future.<sup>377</sup> More women are opting out of motherhood and remaining single or divorced.<sup>378</sup>

America must construct a new system for individuals who need LTSS to go to school, to work, or to be retired at home. Most important, it needs a system that will promote independence and self-sufficiency in an affordable and dignified way.

## **Part III**

### **Tracking the Storm**

#### *Demographic Trends in Long-Term Services and Supports*

#### ***Defining Long-Term Services and Supports***

The 21st century LTSS policy is guided by a strong federal and state commitment toward home- and community-based services (HCBS) and is an important milestone for people with disabilities. The shifting of costs from institutional spending to community-based service spending is providing the infrastructure and capacity for people with disabilities to work, go to school, and live independently. The evolution of the current system of LTSS requires a definition that identifies the scope and depth of services needed that is inclusive of people with disabilities under the age of 65.<sup>379</sup>

The NCD supports a broad definition of LTSS that reflects the essential needs for maintaining a quality of life with maximum dignity and independence. Housing, transportation, nutrition, technology, personal assistance, and other social supports are included in the NCD definition of LTSS.<sup>380</sup>

The AARP definition of long-term services and supports provides a good overview of the breadth and depth of what a long-term services and support policy means today:

LTSS refers to a wide range of in-home, community-based, and institutional services and programs that are designed to help individuals of all ages with physical or mental impairments who have lost or never acquired the ability to function independently. LTSS include assistance with performing self-care activities and household tasks, habilitation and rehabilitation, adult day services, case management, social services, assistive technology, job modification, and some medical care. LTSS are provided in a variety of settings, including at home, in assisted living and other supportive housing settings, and in nursing homes.<sup>381</sup>

The AARP Policy Book explains that people with disabilities prefer to use the phrase “long-term services and supports” rather than “long-term care” because of possible implications concerning dependence or paternalism. The movement to provide services and supports in the community

rather than in an institution is the result largely of the work of disability advocates who have worked for decades to control the direction of their services and supports outside the traditional facility or institution. Federal and state legislation and the Supreme Court have responded with a flurry of demonstration projects and decisions that have favored noninstitutional living. However, federal and state Medicaid spending for LTSS continues to favor institutional care (nursing facilities and ICF/MRs), with the balance spent on HCBS.<sup>382</sup>

The Congressional Research Service (CRS) found that different disability groups have focused on different aspects of consumer-directed LTSS to fit their individual needs, including the use of individual budgets and other self-empowering strategies for managing and directing their own services and supports.<sup>383</sup> The CRS reported that

Individuals with physical disabilities and who are aging have generally focused on personal care services. For individuals with developmental disabilities, consumer direction has been referred to as “self-determination” and has often included other long-term care services in addition to personal care services, such as respite and adult day care. For individuals with serious and persistent mental illness, opportunities for consumers to direct their own services have not been as prevalent, although there is a growing interest in consumer empowerment, peer-support services, and peer participation in treatment.<sup>384</sup>

No research found estimated overall costs for an individual with a lifelong impairment based on the definitions used here for LTSS. The productivity losses, societal costs, direct medical and nonmedical utilization rates, housing, and living expenses for a person living with a lifelong disability are important statistical data that when aggregated would help build a true economic picture for policy and budget discussion. There are studies that have looked at prevalence and mortality rates of particular categories of disability but have not included other relevant variables about what it takes for a family to raise a child with a severe chronic lifelong disability.<sup>385</sup>

The importance of introducing a new definition for LTSS is that it will describe to policymakers and budget directors the unique issues and economic profile of living with a disability under the age of 65. The current focus on LTC for people over 65 was underscored in an April 2004 paper from the CBO on “Financing Long-Term Care for the Elderly.” One page was dedicated to “nonelderly people.” The study found that, in general, people younger than 65 use LTC services

for different reasons than people over 65 years of age, referring to mental illness, mental retardation, and neurological conditions.<sup>386</sup> The CBO paper does report that Medicaid is the largest funder for LTC for impaired people under the age of 65 and that, since 1992, the program has grown 4.8 percent annually. The CBO report is directed to Congress and provides little information about the LTSS needs of people with disabilities under the age of 65, other than that they are mostly Medicaid dependent. It is clear that Congress would need more information about the 14 million Americans under age 65 on Medicaid and Medicare to better understand the demographics, costs, and service needs of those receiving LTSS through public programs who are working, going to school, living at home, or retired. New LTSS policy must include not only the aging cohort of Americans with disabilities but also the under-65 cohort.

When actuaries prepare assumptions about the future, they look at a number of factors. The actual future income and expenditures for a new system of LTSS will depend on many factors, including the size and characteristics of the population receiving benefits, the size and level of benefit amounts, and the number of workers and their earnings. None of the proposals for reforming the current LTSS system provided assumptions about future costs (see chapter 3) that included the full array of factors, such as the following: birthrates, death rates, immigration, marriage and divorce rates, retirement-age patterns, disability incidence and termination rates, production gains, wage increases, medical and nonmedical costs, inflation, and many other demographic, economic, and program-specific factors.<sup>387</sup>

Even demographic data about the nonelderly users of LTSS who are living in institutions (including group homes) is not readily available, because the various surveys used to collect this data do not encompass all institutional settings.<sup>388</sup> The Disability Supplement to the National Health Interview Survey (NHIS-D) is a household survey of nonelderly community dwellers and does not include group homes that in 2004 represented about 7 percent of the population with mental retardation and developmental disabilities (MR/DD). The National Long-Term Care Survey (NLTCS) draws from Medicare enrollment files and community and institutional residents, and the researchers found that “no such population-based survey exists for the non-elderly using long-term services and supports and no combination of existing surveys can be said with confidence to provide a similarly comprehensive view of the non-elderly.”<sup>389</sup> One survey

did collect data in 1987—the National Medical Expenditure Survey, Institutional Population Component—and, at the time, did include nursing homes, ICF/MRs, and licensed personal care homes for residents of all ages.<sup>390</sup> However, its successor survey in 1996—the Medicaid Expenditure Panel Survey (MEPS)—restricted data collection to nursing homes only. The authors estimated that about 416,000, or 0.4 million people (MR/DD and mentally ill in state mental institutions, residential facilities, government general hospitals, private hospitals, and VA medical centers), are left out of national surveys of nonelderly recipients of LTSS. This population is not always reflected in the national figures used to represent the number of people under 65 years of age needing services and supports.

Table 2.1 combines two national survey data sets to compare community-based service use and nursing home use for individuals under 65 years of age with nonusers of community service. Females are more likely to receive community-based services and be in nursing homes than males in the general public; 4.8 percent of community-based service users are widowed, compared with 10.3 percent of nursing home residents and 1.8 percent of nonusers; individuals receiving both community-based services and nursing home services were 50 percent more likely to have an education of less than 12 years; and community-based users had twice the poverty rate of nonusers.<sup>391</sup> There was no single data set to provide national estimates for elderly and nonelderly LTC users in both community and institutional settings.<sup>392</sup>

**Table 2.1. Demographics of Long-Term Service and Supports, Community-Based Users and Nonusers<sup>393</sup>**

<b>Characteristics</b>	<b>Nonusers of Community Services</b>	<b>Community-Based Services Use &lt;65</b>	<b>Nursing Home Residents &lt;65</b>
<b>Population (Thousands)</b>	155,200 (97.8%)	3,364 (2.1%)	138 (0.1%)
<b>Mean Age (Years)</b>	38	45	51
<b>Gender</b>			
Female	50.8	57.6	51.0
Male	49.2	42.4	49.0
<b>Race</b>			
White	83.2	77.0	76.1
Black	12.0	19.0	19.2
Other	04.9	04.0	04.7
<b>Marital Status</b>			
Married	65.9	57.3	16.4
Widowed	01.8	04.8	10.3
Never Married	22.0	29.2	46.3
Separated/Divorced	10.2	18.4	27.0
<b>Education</b>			
Less Than 12 Years	15.3	34.3	42.0
12 Years	37.1	39.4	23.8
Greater Than 12 Years	46.9	23.5	16.9
Missing	0.70	02.7	16.4
<b>Poverty</b>	10.2	26.0	N/A
<b>Level of IADL/ADL Disability</b>			
IADL Only	N/A	55.9	07.7
1-2 Adls	N/A	26.7	14.5
3-6 ADLS	N/A	17.4	75.5
<b>Functional Limitations</b>			
Lower Body Only	05.1	33.3	N/A
Upper Body Only	00.8	1.6	N/A
Upper And Lower Body	01.5	38.1	N/A
Neither	92.2	26.2	N/A
<b>Use of Mobility Equipment</b>	00.8	25.0	13.0
<b>Use of Wheelchair</b>	00.1	12.7	65.2
<b>Difficulty Seeing</b>	01.6	17.4	30.2
<b>Difficulty Hearing</b>	03.5	11.3	12.8
<b>Difficulty Communication</b>	00.3	11.6	16.6
<b>Difficulty Understanding</b>	00.4	09.8	12.0
<b>Mental Retardation</b>	00.1	11.6	N/A

N/A = not available.

## ***People Who Use Long-Term Services and Supports***

The development of public policy for LTSS requires finding a common ground for defining eligibility. The review of the literature found definitions for disability that identify function (ADLs, IADLs), chronic illness, children with chronic illness, census data on perceived disability, and work disability. The accepted definitions of eligibility are the two major ones, provided by Medicaid and SSI, which are used most often in the literature and are the gateway to services and supports for millions of Americans with disabilities.

Seventy-eight percent (5.6 million) of people with disabilities in FY 2000 enrolled in Medicaid through SSI; the remaining 22 percent (8.1 million) were categorized as “other” (some on Medicare). It is estimated that about 25 million Americans under the age of 65 with chronic disabilities need some help with ADLs<sup>394</sup> but often do not meet the criteria of total disability required by Social Security until their conditions are in the advanced stage.<sup>395</sup> Examples include people with HIV and multiple sclerosis. The CRS data estimates that 3.4 million people with disabilities under age 65 receive an array of LTSS (mostly in their homes and unpaid), but this varies depending on each state’s fiscal capacity or changing economic condition.

## ***Emerging Demographics of Long-Term Service and Support Use***

Trends for chronic disease and disabilities are showing increases. The prevalence of chronic disease and deaths caused by noncommunicable disease in the United States between 1990 and 2020 will increase from 28.1 million to 49.7 million, an increase of 77 percent. Overall heart disease, in terms of both death and disability, will be greater than any other illness. Cancer will rank second. By the year 2010, mental illness, namely unipolar major depression, will have a greater impact on death and disability than cancer.<sup>396</sup> Medicaid has become the principal public payer of mental health services at 36 percent, with Medicare spending 22 percent, and state and local governments spending 35 percent with another 7 percent coming from the Federal Government, totaling \$48 billion.<sup>397</sup> The most common chronic disability conditions relate to mental health, mental retardation, cognitive impairment, and learning disability.

The impacts of these trends and further analyses have varied predictions for prevalence and future health care costs. However, the challenge inherent in consolidating the medical and nonmedical needs for LTSS into population characteristics with cost estimates differs based on criteria and the definition of disability used. The following definitions and estimates of disability prevalence are good examples of how complex and confusing this can be.

### ***Use of ADLs and IADLs in Measuring Functional Ability***

The definitions used in describing the ability of individuals to function independently in the community are ADLs and IADLs. ADLs include a person's ability to perform the following functions: bathing, dressing, eating, toileting, getting in or out of bed or a chair, and getting around inside the home. IADLs include preparing meals, going outside the home, managing money, using the telephone, taking prescription medications, and doing housework.<sup>398</sup> For people with intellectual impairments, the ADL and IADL criteria do not always accurately represent their functioning capacity. Further research is being done on expanding criteria to better serve people with intellectual impairments. The estimate of community-based LTSS, among the nonelderly is 2.1 percent (over 3.4 million) receiving assistance with ADL or IADL tasks.

The likelihood of needing help with ADLs rises with age. It is estimated that, by age 65, 10 to 20 percent of individuals will require assistance with at least one or more ADL and that, by age 85, 50 percent will require assistance.<sup>399</sup> Demographers predict a dramatic impact on the prevalence of disability and use of LTSS in the coming decades. People who need help with at least two ADLs will increase from 1.8 million (1996–2000) to 3.8 million (2045–2049). The number of nursing home residents and residents in alternative living facilities over age 65 will increase from 2 million in 2000 to 2.6 million in 2020 and 4.5 million in 2050. The number of home-based services users will increase from 5.4 million in 2000 to 7.2 million in 2020 to 10.5 million in 2050.<sup>400</sup>

The research concludes that disability has declined in the over-65 population for those who reported needing help with IADLs. The decline represented a 3.9 percentage point decline in elderly people receiving help from someone with ADLs and IADLs and a 1.4 percentage point increase in elderly people who managed ADLs in the community with assistive devices only.<sup>401</sup> The study also found a 3.7 percentage point drop in help with money management

between 1984 and 1989, when Social Security direct deposit became the norm, raising the question of whether IADL declines reflect improvements in health or improvements in the physical environment. Researchers suggest that the overall decline may be driven by environmental and not health-related changes. Increases in technology and greater availability of services and durable medical equipment, including assistive technology, are thought to have contributed to the decline. The mean number of IADLs for which people with disabilities received assistance declined over the 15-year study, but the mean number of ADLs for which assistance was received increased for people with disabilities living in institutions and in the community. If the IADL rate continues to decline, researchers will study the relationship among savings in Medicare, Medicaid, and LTSS.<sup>402</sup>

Definitions of disability in the literature vary from ICD-9 Codes to subjective criteria, such as a child's ability to play. The scope of the population with disabilities was not consistent; for example, parameters such as age range, setting of services, and service types used to segment and measure the population. In addition to the use of ADLs and IADLs, four additional definitions are listed in table 2.2.

**Table 2.2. Disability Definitions**

<b>Disability Categories</b>	<b>Disability Definitions</b>	<b>Demographics</b>
Functional <sup>403</sup>	Limits in or inability to perform a variety of physical activity, serious sensory impairment (e.g., unable to read a newspaper, even with glasses), serious symptoms of mental illness, long-term care needs, use of an assistive device (e.g., wheelchair), developmental delay in a child that is identified by a physician, and inability to perform age-appropriate functions.	47.6 million Americans 6.1 million children 25.7 million working-age adults 15.8 million elderly
Work <sup>404</sup>	Limitations or the inability to work as a result of a physical, mental, or emotional health condition.	16.9 million working-age adults (18-64 years of age)
Perceived <sup>405</sup>	Individuals who reported that they considered themselves to have a disability or were considered by others to have a disability.	19 million Americans 2 million children 11.1 adults (18-63 years of age) 6 million elderly
Public Program Recipients Under Age 65 <sup>406</sup>	Includes people covered by government funding programs, Special Education or Early Intervention Services, and/or disability pensions.	13.8 million individuals 4.7 million children 9.1 million adults age 18-64 65 and older not included in this definition

A study from the Research Institute and Training Center on Community Living at the University of Minnesota examined the service use by and needs of adults with functional limitations (FLs) or intellectual disabilities/developmental disabilities (ID/DD) between the ages of 18–35 and 35–64. The researchers found that people with ID/DD have substantially more limitations in ADLs, learning, communication, self-direction, and economic self-sufficiency compared with people with FLs only. Women with ID/DD 35 years and older were more likely to have economic problems than women under age 35 with FLs only. Gender differences were found in the two populations—more males were found in both age categories with ID/DD and more females were found in the FL category age 35 and older. This study has important policy implications because it suggests that, within different categories of disability, there are different

service needs that get overlooked, and that a more careful study of the gender and age differences between groups may be needed.

Another challenge for individuals with disabilities under the age of 65 with personal assistance needs is receiving the necessary hours of support. A recent study estimated the shortfall in hours of help and adverse consequences and found that individuals who needed help with two or more of the five basic ADLs had a shortfall of 16.6 hours of help per week compared with those whose needs are met.<sup>407</sup> Those with unmet needs were more likely to be nonwhite, to be female, and to live alone. The shortfall in hours as a percentage of needed hours is twice as great for people who live alone. Both groups in the study found those who live with someone and those who live alone experienced adverse consequences in 29 out of the 34 measures tested, including weight loss, dehydration, falls, burns, and dissatisfaction with the help received. People who live alone and have unmet needs are 10 times as likely to go hungry, 20 times more likely to miss a meal, and 5 times as likely to lose weight.<sup>408</sup>

Personal assistance services (PAS) are provided to about 13.2 million noninstitutionalized adults, representing an average of 31.4 hours of PAS each week.<sup>409</sup> Of these, 3.2 million people received an average of 17.6 hours of paid help, and 11.7 million received an average of 30.7 hours of unpaid help. This study found that older people are likely to receive paid PAS and that working-age people rely more on unpaid PAS.

The policy implications of these studies suggest that future LTSS policy should consider the number of working individuals under age 65, their specific needs for PAS, and the impact that adequate and consistent PAS might have on future earnings and long-term employment for working-age individuals with disabilities.

### ***Children and the Need for Long-Term Services and Supports***

A report by the U.S. Department of Health and Human Services (HHS), “Children with Severe Chronic Conditions on Medicaid,” used 360 disease-specific codes (ICD-9 Codes) to define children with physical and mental health disabilities.<sup>410</sup> In addition to the diagnosis codes, the

criteria for disability included hospital utilization criteria. Physical disability utilization criteria included the following:

- 3 or more hospital admissions;
- 20 or more days of inpatient hospital care;
- total outpatient payment of \$5,000 or more; and
- total payment of \$20,000 or more.

Mental health disability criteria included the following:

- 30 days or more of inpatient hospital care with any of the primary psychiatric diagnoses; and
- outpatient payments of \$5,000 or more for any of the primary psychiatric diagnoses.<sup>411</sup>

A 1995 summary by the Assistant Secretary for Planning and Evaluation (ASPE) identified 4,536,300 American children with disabilities. This report defined disability as difficulty with certain functions or abilities (e.g., playing) because of a physical or mental health impairment.<sup>412</sup> This summary also stated that determining the prevalence of disability was difficult due to varied definitions; however, it reported that 4,536,300 children in the United States had a disability and that 98 percent lived in the community and 2 percent (91,800) lived in institutions; 1,200 children lived in nursing homes; and 1,100 lived in homes for individuals with physical disabilities. Another 29,500 children were in facilities for the mentally ill, and 60,000 were in MR/DD facilities.<sup>413</sup> The report did note that there are 148,000 children in correctional facilities, on whom data on disability was not available.

Of the 51 American million children ages 5 through 17 in 1994, less than 1 percent were likely to need LTSS; 1.3 percent had problems with mobility; 5.5 percent with communication; 10.6 percent with learning; 12.3 percent needed help with one or more ADLs; and 0.9 percent were likely to need LTSS for self-care. Fifty-nine percent of people with MR/DD are under the age of 17; 38 percent are between 17 and 64 years of age; and 3 percent are over the age of 65.<sup>414</sup>

The leading causes of disability in children reported in the 1995 ASPE summary were learning disabilities (1,372,200), speech disorders (1,096,000), MR/DD (720,500), mental illness (462,800), and respiratory conditions such as asthma (362,200).<sup>415</sup>

### ***People Over Age 65***

In 1999, people 65 years or older numbered 34.5 million. This represents 12.7 percent of the U.S. population, about one in every eight Americans. The number of older Americans has increased 3.3 million (10.6) percent since 1990, compared with an increase of 9.1 percent for the under-65 population.<sup>416</sup>

Since 1900, the percentage of Americans over 65 has tripled, and the number has increased 11 times, from 3.1 million to 34.5 million.<sup>417</sup> A child born in 1998 could expect to live 76.7 years, about 29 years longer than a child born in 1900. The major part of this increase is due to reduced death rates for children and young adults. Two million people turned 65 in 1999 (5,422 per day). In the same year, 1.8 million people 65 years of age or older died, resulting in a net increase of 200,000 (558) per day.<sup>418</sup> Life expectancy in the United States rose dramatically in the 20th century from about 47 years in 1900 to about 73 years for males and 79 years for females in 1999. This increase is mainly due to improvements in environmental factors, such as sanitation, and the discovery of antibiotics.<sup>419</sup>

By 2030, there will be about 70 million Americans over the age of 65. People over 65 represented 13 percent of the population in 1999; this percentage will grow to 20 percent by 2030. Minority populations are projected to represent 25.4 percent of the elderly population in 2030, up from 16.1 percent in 1999.<sup>420</sup>

In 1998, the majority (67%) of the elderly was noninstitutionalized and lived in a family setting. Approximately 10.8 million (80%) of older men and 10.7 million (58%) of older women lived in families. The proportion living with a family decreased with age. Forty-five percent of those over 85 years lived in a family setting. About 13 percent of older people (7% men, 17% women) were not living with a spouse but were living with children, siblings, or other relatives. About 3 percent of men and 2 percent of women (718,000) of the older population lived with

nonrelatives.<sup>421</sup> A small number (1.47 million, 4.3%) of the over-65 population lived in nursing homes in 1997, and the percentage increased dramatically with age, ranging from 1.1 percent for people 65–74 years to 4.5 percent for people 75–84 years and 19 percent for people over the age of 85.<sup>422</sup>

In 1999, 16.1 percent of people over age 65 were minorities: 8.1 percent were African American, 2.3 percent were Asian, and less than 1 percent were American Indian or Native Alaskan. Hispanic origins represented 5.3 percent of the older population.<sup>423</sup>

In 1999, about half (52%) of people over age 65 lived in nine states: California had over 3.6 million; Florida, 2.7 million; New York, 2.4 million; Texas, 2 million; and Pennsylvania, 1.9 million. Ohio, Illinois, Michigan, and New Jersey each had over 1 million.<sup>424</sup>

In 1999, people over 65 constituted 14 percent or more of the total population in 10 states: Florida, 18.1 percent; Pennsylvania, 15.8 percent; Rhode Island, 15.6 percent; West Virginia, 15.1 percent; Iowa, 14.9 percent; North Dakota, 14.6 percent; South Dakota, 14.4 percent; Connecticut, 14.3 percent; Arkansas, 14.2 percent; and Maine, 14 percent. In 11 states, the over-65 population increased by 17 percent or more between 1990 and 1999: Nevada, 61 percent; Alaska, 55 percent; Arizona, 31 percent; Hawaii, 30 percent; Colorado, Utah, and New Mexico, 23 percent; Delaware, 21 percent; South Carolina and North Carolina, 19 percent; and Texas, 17 percent.<sup>425</sup>

**Table 2.3. Population Projections Five-Year Age Groups**<sup>426</sup>

Age group	July 2004	July 2030
65–69 years	9,928,000	19,844,000
70–74 years	8,375,000	17,878,000
75–79 years	7,432,000	14,029,000
80–84 years	5,432,000	9,638,000
85–89 years	2,954,000	5,077,000
90–94 years	1,351,000	2,457,000
95–99 years	425,000	1,015,000
100 years and older	88,000	381,000

Twenty percent of people 65 and older (about 6 million) need some level of LTSS. The mean age is 80.5 years and the person is most likely to be a widowed white female. Forty percent who are living in the community are cognitively impaired, with Alzheimer's disease, mental retardation (7%), or senility, or have ADL needs. Forty percent living in the community have informal care, 25.1 percent have both informal and formal care, 4.6 percent have formal care, and 29.6 percent have care in an institution.<sup>427</sup>

The next few decades will bring an unprecedented increase in the size of the elderly population. Major factors to consider in predicting the impact of the aging population follow:

- The aging U.S. population, in particular the growth in the proportion of the people age 85 and over, will place increasing demands on our fragmented LTC system. The demands are uncertain.
- LTC will continue to be a woman's issue.
- The LTC population will become more ethnically diverse.
- Aging is not geographically uniform.
- Americans are unprepared to pay for LTC.<sup>428</sup>

### **Chronic Care Demographics**

About 57 million working-age Americans, 18–64 years old, live with chronic disease conditions such as diabetes, asthma, or depression. In 2003, more than one in five (12.3 million) people with chronic diseases lived in families that had problems paying medical bills.<sup>429</sup>

Chronic diseases—such as cardiovascular disease (primarily heart disease and stroke), cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems. Seven of every 10 Americans who die each year (more than 1.7 million people) die of a chronic disease. Chronic disabling conditions cause major limitations in activity for more than 1 in every 10 Americans (25 million people).<sup>430</sup>

Eight of the top 10 causes of death in the United States in 1997 were due to chronic diseases: heart disease (31.4%), cancer (23.3%), stroke (6.9%), chronic obstructive pulmonary disease (4.7%), pneumonia/flu (3.7%), diabetes (2.7%), kidney disease (1.1%), chronic liver disease (1.1%).<sup>431</sup> Only unintentional injury (4.1%) and suicide (1.3%) are not related to chronic disease.

The main contribution to chronic disease is exposure to risk factors, such as tobacco use, unhealthful diets, lack of physical activity, and alcohol use.<sup>432</sup>

Estimates of chronic disease costs include the following:

- More than 90 million Americans have a chronic illness.
- Chronic diseases account for 70 percent of all deaths in the United States.
- Medical costs of people with chronic diseases account for more than 75 percent of the nation's \$1.4 trillion medical care costs.
- Chronic diseases account for one-third of the years of life lost before age 65.
- The direct and indirect costs of diabetes are nearly \$132 billion a year.
- Arthritis annually results in estimated medical care costs of more than \$22 billion and estimated total costs (medical and lost productivity) of almost \$82 billion.
- The estimated direct and indirect costs associated with smoking exceed \$75 billion annually.
- In 2001, approximately \$300 billion was spent on all cardiovascular diseases. Over \$129 billion in lost productivity was due to cardiovascular disease.
- Direct medical costs associated with physical inactivity were nearly \$76.6 billion in 2000.<sup>433</sup>

Despite annual spending of over \$500 billion, half of the people with chronic illnesses do not receive appropriate care:

- 27% of individuals with hypertension (high blood pressure) are adequately treated;

- 50% of diabetics have controlled blood sugar, lipid, and blood pressure levels;
- 35% of eligible people with atrial fibrillation receive anticoagulation;
- 25% of people with depression are receiving adequate treatment;
- 44% of people with heart failure who experience a hospital stay are readmitted with the same problem within six months;<sup>434</sup>
- 50% of the elderly fail to receive pneumococcal vaccine; and
- 50% of heart attack victims fail to receive beta-blockers.<sup>435</sup>

A large study examined 439 indicators of 30 chronic diseases (6,712 people) in the United States. Findings showed that people received only 54.9 percent of scientifically indicated care. The study concluded that the “defect rate” in the quality of American health care is approximately 45 percent. Recommendations of the study were to clarify national goals for improvement, change the care delivery processes/systems, change the organizations that deliver care, and change the environment of professional medical practice.<sup>436</sup>

Another rationale for unmanaged chronic care was found in a study of 6.6 million uninsured people living with chronic conditions, with almost half reporting problems paying medical bills. Of the chronically ill with medical bill problems, 42 percent went without needed care, 65 percent delayed care, and 71 percent failed to get needed prescription drugs, all due to cost concerns.<sup>437</sup>

Between 2001 and 2003, the proportion of low-income chronically ill people with private insurance who spent more than 5 percent of their income on out-of-pocket health care costs grew from 28 percent to 42 percent, a 50 percent increase to 2.2 million people.<sup>438</sup>

Inequalities in income and education underlie many health disparities in the United States. They are intrinsically related and often serve as a proxy for each other. In general, population groups that suffer the worst health status and chronic disease morbidity/mortality are those that have the highest poverty rates and the least education. In 1996, the total number of whites below the poverty level was 12 percent, compared with African Americans (28 percent) and Hispanics (29 percent).<sup>439</sup>

According to a Kaiser Family Foundation survey in 2003, people with disabilities use the health care system frequently, with more than half (57%) having seen a physician four or more times in six months and 18 percent reporting two or more visits to the emergency room in the past six months.<sup>440</sup> While only 15 percent of the survey respondents say they have no regular doctor, one in four reports having trouble finding a doctor who understands his or her disability. When it comes to finding a doctor who accepts their insurance, 17 percent of the sample reported having had such problems, with higher rates reported by those covered by Medicaid.<sup>441</sup> Seventeen percent of those with a mental disability said the cost of mental health services is a serious problem for them. Prescription drug costs affected 32 percent of the respondents, and 36 percent of those taking prescription drugs admitted having skipped doses of the drug, split pills, or gone without filling a prescription. Twenty-one percent of the people who use equipment to manage their disability say they have serious difficulties paying for it.<sup>442</sup> Those with disabilities were less likely than the general population to receive preventive services and they received those services considerably less frequently than is generally recommended. Less than half of all female respondents reported having a mammogram in the past year, and only about a third of all men reported having a prostate examination. Only 41 percent reported having a dental examination in the past year.<sup>443</sup>

### ***Racial and Ethnic Disparities***

Healthy People 2010 cites race and ethnicity differences as a factor in chronic disease mortality and morbidity. The U.S. infant mortality rate is down, but the infant death rate among African Americans is still more than double that of whites. Heart disease rates are 40 percent higher for African Americans than for whites. The death rate for all cancers is 30 percent higher for African Americans compared with whites; for prostate cancer, it is more than double than for whites. The death rate from HIV/AIDS for African Americans is more than seven times than that for whites. Hispanics living in the United States are twice as likely to die from diabetes than non-Hispanic whites. Although constituting only 11 percent of the total population in 1996, Hispanics accounted for 20 percent of the new cases of tuberculosis. Puerto Ricans have a low infant birth-weight rate that is 50 percent higher than that for whites. Hispanics also have higher rates of high blood pressure and obesity than non-Hispanic whites.<sup>444</sup>

By 2050, people of color are expected to make up nearly half of the U.S. population.<sup>445</sup> A study analyzed data on 419,843 children 17 years and younger from 1979 to 2000 and found 22,758 with disabilities living in the community.<sup>446</sup> Disparities in the prevalence of ADL difficulties caused by chronic conditions or disability in the black and white non-Hispanic population were found to increase over time. Black children had higher prevalence rates in disability, due in part to differences in poverty status. The prevalence of difficulty with ADLs for white children increased over time to 47 percent—or 40.7 per 1,000 to 59.7 per 1,000 children in the population. For black children, the prevalence increased 77 percent—or 37.9 per 1,000 to 67.1 per 1,000 children in the population. Black children were 13 percent more likely than white children to have a reported activity limitation.

The prevalence of disability caused by chronic conditions has increased markedly for both black and white children. In the past, white children were in the mild chronic category. Researchers believe that the higher rates of disability are due, in part, to the increased exposure to poverty, racial disparities, lack of education, social opportunities, restricted access to care, increased exposure to environmental causes of disability, poor nutrition, and poor quality health care.

The death rate for 13 to 15 leading causes of death are higher and life expectancy is lower for black Americans than for white Americans. Asthma prevalence rates are higher for blacks, and there are more premature births and deaths in infancy.

The Kaiser Family Foundation reported nonelderly uninsured rates by race and ethnicity in 2003: 13 percent white; 20 percent Asian/Pacific Islander; 21 percent black; 28 percent American Indian and Native Alaskan; other, 1.8 percent; and 34 percent Latino.<sup>447</sup>

Combined, 36 percent of the 53 million Americans with disabilities are black and Latino (U.S. Census Bureau 2000). A recent GAO study confirmed that the black population has higher disability rates, lower lifetime earnings, and shorter life expectancy than whites.<sup>448</sup> Sixteen percent of workers who are black die before the age of 62. Twenty-seventy percent of the Social Security Disability Insurance (SSDI) benefits are for the black and Latino population. The study found that people of color are receiving more public benefits over a lifetime than they contribute in payroll taxes.<sup>449</sup>

The demographic profile of individuals receiving both Medicaid and Medicare (7 million dual eligibles) shows that 4 million dual eligibles are mostly nonwhite widowed women over the age of 65 with multiple chronic disabilities. The dual eligible population is a major factor in the current problem, as it represents about 14 percent of the Medicaid population. In FY 2000, of the total Medicaid service spending of \$168.1 billion, \$70.8 billion or 42 percent was attributed to dual eligibles in payment for Medicaid covered benefits and in deductibles and coinsurance for Medicare services.<sup>450</sup>

### ***Summary***

If not addressed, the issues of poverty, lack of insurance, and continued segregation from affordable and consistent health care will increase the future needs and costs for LTSS. The increase in disability and prevalence in young black and white children cannot be ignored as we seek to design LTSS policy for the future. Despite disagreement among researchers, policymakers, and the consumer populations as to appropriate methods to define and determine which person with a disability has unmet needs, there is a common understanding that the number of people in need is growing at a rate that is far beyond current capacity of federal programs to respond.

The next section will provide an overview of the current pathways to LTSS for people with disabilities and the change in purpose, services, eligibility, and costs.

## Part IV

### Lowering the Lifeboats

*Medicaid's expanding purposes, pathways, services, and costs for people with disabilities.*

The grandfather of LTSS is Medicaid,<sup>451</sup> whose original purpose was to provide health care and nursing home care to very low-income families with dependent children, poor elderly, and disabled individuals.<sup>452</sup> The concept of LTC was not developed in the early years of Medicaid, and nursing home care represented the narrow scope of what it meant to age in America in the 1960s. Today, there are many additions to the original federal Medicaid purpose that reflect the growing trend for beneficiaries to receive services and supports in the home and the community and less in the nursing home. In FY 2003, 53.0 million Americans were enrolled in Medicaid, including 24.8 million children and 13.6 million aged, blind, or disabled individuals.<sup>453</sup> Total Medicaid assistance payments for FY 2002, not including administration, were “\$246.3 billion and the four largest categories were: nursing facilities—19.3% of the total; inpatient services (general and mental hospitals)—14.3%; prepaid health care (capitation payments—managed care organizations)—13.3%; and prescription drugs—9.5%.”<sup>454</sup>

The relevance and purpose of LTSS for Americans with disabilities has never been more important as the United States addresses its current social and fiscal obligation to meet the growing demands of an increased disability and aging population over the next century. The concept of LTSS for people with disabilities has evolved over the past 40 years as the expectations and image of people with disabilities has changed. Clearly, in order to work, people with lifelong impairments need access to affordable nonmedical supports and services, as well as ongoing reliable and affordable health care. For aging Americans with disabilities, the same holds true—all need affordable supports and services and health care to maintain dignity and independence.

State Medicaid programs receive their funding from federal Medicaid funds that are not capped and rise to meet state Medicaid spending. The match from federal Medicaid depends on a state's per capita income—the higher the income, the lower the match. Nationally, the federal match pays for roughly 57 percent of total Medicaid spending.<sup>455</sup> Geography plays an important role in

the uneven distribution of services and supports, because poorer states often have fewer resources to spend, larger populations of seniors to serve, and higher disability rates.<sup>456</sup> The menu of services under Medicaid is listed in state plans. Mandatory services are services that all states opting to have a Medicaid program must provide to all of their citizens. Optional services are additional and states can limit the number of enrollees and services.<sup>457, 458</sup>

**Mandatory Medicaid services that all states must cover include the following:** hospital care (inpatient and outpatient); physician services; laboratory and X-ray services; family planning services; health center and rural health clinic services; nurse midwife and nurse practitioner services; early and periodic screening, diagnostic, and treatment (EPSDT) services and immunizations for children under age 21; nursing home care; and home health services for those eligible for nursing home care.<sup>459</sup>

**Optional services that states may choose to cover include the following:** basic medical and health care services (including prescribed drugs);<sup>460</sup> services that support people with disabilities to live in their communities, such as personal care services (37 states offer personal care, 2003); rehabilitative and or clinic services (29 states offer rehabilitative services, 2003); case management services (49 states, 2003); and small group homes that operate as intermediate care facilities for persons with mental retardation and developmental disabilities for 15 or fewer residents; aides, therapies, and related professional services.<sup>461</sup> Services involving short- or long-term institutional stays include inpatient psychiatric hospital services for children and young people under age 21; nursing facility services for children and young people under age 21; ICF/MRs with more than 15 residents; inpatient hospital services for people age 65 or older with mental illness in institutions for mental diseases (IMDs); and nursing facility services for people age 65 or older with mental illness in IMDs.<sup>462</sup>

Medicaid's purpose and scope and pathways to services grew and by the 1980s there were more than 50 distinct population groups wanting to become eligible in states programs.<sup>463</sup> Many new eligibility pathways were added to the Medicaid statute, including coverage of higher income children and pregnant women as well as other elderly and disabled individuals.<sup>464</sup> Most recently, the Medicaid statute allowed states to extend benefits to women

with breast or cervical cancer, uninsured individuals with tuberculosis, immigrants (with certain conditions), and certain other working individuals with disabilities.<sup>465</sup> Today, more than one-third of Medicaid beneficiaries participate in new pathways added since the 1980s; the introduction of HCBS waivers and other programs has allowed for insurance coverage of vulnerable populations not previously eligible.<sup>466</sup>

In a 2005 report to the National Governors Association (NGA), researchers from Health Management Associates report that Medicaid's \$300 billion program (\$134 billion is for LTC programs)<sup>467</sup> has mushroomed into a constellation of several programs that include the following:

- an insurance program for low-income, uninsured children and some parents and pregnant women;
- a program of chronic care and LTC for people with disabilities, mental illness, and low-income elderly;
- a supplement to Medicare for low-income seniors and people with disabilities, and a support for those awaiting qualification for Medicare on the basis of permanent disability; and
- a source of funding for safety nets for hospitals and community health centers that serve a disproportionate share (DHS) of the uninsured.<sup>468</sup>

The report made the distinction that two-thirds of Medicaid spending is for population groups and services technically defined as optional and 90 percent of all LTC Medicaid services today fall under the optional category.<sup>469</sup> States are making cuts to many of the optional services as they struggle with the addition of 8.4 million beneficiaries and a one-third increase in program spending between 2000 and 2003.<sup>470</sup> In 2003, 49 states and the District of Columbia implemented Medicaid cuts, according to the Kaiser Commission on Medicaid and the Uninsured, and 32 states revisited their initial cuts and made more. Cost-containment measures implemented included the following: 37 states reduced or froze provider payments to hospitals and nursing homes; 45 states implemented prescription drug cost controls; 27 states report that they cut or restricted Medicaid eligibility; 25 states reduced benefits; and 17 states increased copayments.<sup>471</sup>

The Kaiser Commission Report added that a number of states were planning further cuts to their LTC spending and medically needy programs (allows individuals to “spend down” to qualify by reducing medical expenses from income) and that *any* cuts could affect access to health care for people with disabilities who rely mainly on Medicaid for a number of important services.<sup>472</sup> Reform proposals over the past few years have suggested federal caps for Medicaid spending that would eventually phase out optional services; these services would either be institutionalized by the states, and the costs absorbed, or they would no longer be offered due to lack of funds. Any cuts to the current menu of optional benefits would erode services and supports that are the lifeline for millions of low-income people with disabilities.<sup>473, 474</sup>

Low-income people with disabilities have benefited from the growing purpose of Medicaid and continue to enter the program through a complex mix of mandatory and optional pathways for eligibility.<sup>475</sup>

The following highlights of the mandatory and optional pathways that are specific to people with disabilities under Medicaid provide an overview of the programs, the states involved, and, in some instances, the costs.

### ***Mandatory***

- ***Supplemental Security Income (SSI): This is a means-tested cash assistance, mandatory program for aged, blind, and disabled individuals*** whose incomes are less than 74 percent of the federal poverty level. ***One exception is the “209(b) option that allows states (about 11 states in 2004) to set eligibility standards that are more restrictive than current SSI standards,”*** using SSI income, resource, and disability standards in place on January 2, 1972. Individuals who qualify for SSDI may also qualify for Medicaid.<sup>476</sup>
- ***Qualified Medicare Beneficiary (QMB): This applies to certain low-income individuals (<100% of poverty) who have disabilities as defined under SSI and who are eligible for Medicare cost-sharing expenses paid by Medicaid.*** Medicaid pays Medicare Part B premiums, deductibles, and coinsurance for Medicare-covered benefits but no Medicaid

benefits unless individuals qualify for Medicaid through other eligibility pathways (e.g., via SSI, medically needy, or the special income rule.)

- ***Specified Low-Income Beneficiary: This applies to individuals who are eligible for Medicare cost-sharing and whose incomes are less than 100–120 percent of poverty.*** Medicaid pays Medicare Part B premium.

### ***Optional***<sup>477</sup>

- ***State Supplemental Payment (SSP) benefits with state-only dollars*** on a monthly basis help cover items such as food, shelter, clothing utilities, and other daily necessities. SSI applicants must be allowed to deduct medical expenses from their income when determining financial eligibility for Medicaid. This is sometimes referred to as “spend down” and is critical to working people with disabilities. (In October 2001, 21 states reported providing this coverage to people with disabilities and 3 states provided this coverage only to people who are blind.)<sup>478</sup>
- ***Omnibus Budget Reconciliation Act of 1986 offered states an option for covering people whose income exceeds SSI or 209(b) levels up to 100 percent of the federal poverty level.*** In 2003, 20 states and the District of Columbia used this option.
- ***Special income rule, the “300 percent” rule,*** allows states to extend Medicaid to certain individuals with incomes too high to qualify for SSI, but who are eligible for nursing facility or other institutional care. The Miller Trust allows applicants under this rule to place income in excess of the special income level into a trust, making the state the beneficiary after death.
- ***Medically Needy Program*** extends Medicaid coverage beyond the aged and people with disabilities to families with children who do not meet the applicable income (or resource) requirements for other eligibility pathways. States may set their medically need monthly limits for a family of a given size at any level up to 133 1/3 percent of the former AFDC (now TANF) program standard. (In FY 2003, 35 states and the District of Columbia had medically needy programs, and 33 of these programs were extended to people age 65 and older and people with disabilities.)

- **Rules for working people with disabilities on SSI** are linked to an individual’s ability to work and earn income and “engage in substantial gainful activity” (SGA). A person is considered able to engage in SGA if his or her earnings exceed \$830 per month for 2005; \$1,380 for people who are blind. Under a waiver called 1619(a), SSI law permits states that extend Medicaid to SSI working recipients to receive Medicaid even when they are working above the SGA level. As an individual’s earnings increase, his or her cash benefits are gradually reduced through a special income disregard formula.<sup>479</sup>
- **Ticket to Work and Work Incentives Improvement Act of 1999 (TWIIA) allows states to raise their Medicaid income and asset limits for individuals with disabilities who work.** States may require that working individuals with disabilities “buy-in” to the Medicaid program by sharing in the costs of their coverage. **Medicaid buy-in** allows states to expand Medicaid coverage to working individuals with disabilities between the ages of 16 and 34, with incomes and resources as defined by the state, and allows states to impose premiums and other cost-sharing on individuals who qualify (in 2002, 25 states).<sup>480</sup> **Under TWIIA, the medical improvement group option** targets individuals with cyclical or periodic disabilities who are working at the federal minimum wage at least 40 hours a month or who meet other definitions approved by HHS. Three states currently participate in this option: Connecticut, Indiana, and Missouri.<sup>481</sup>
- **Katie Beckett Option** allows children to stay in their homes who would otherwise be institutionalized, and parents’ income are not attributed (21 states have this option). Tax Equity and Fiscal Responsibility Act 1982.
- **Home- and Community-Based Service Waivers** allow states, through a waiver process, to provide at-risk individuals with services at home (49 states use HCBS waivers, introduced in 1981 and currently serving almost 1 million Americans.) The federal HCBS waiver authorized by Congress in 1981 is the principal Medicaid program that underwrites LTSS for the MR/DD population in the United States. Federal spending for HCBS grew for MR/DD from \$1.2 billion in 1982 to \$7.2 billion in 2002. The average state ICF/MR cost in 2002 was \$134,619 per resident per year, compared with the HCBS cost per participant of \$35,215.<sup>482</sup> The waiver provides the financing mechanism for states to expand their menu of community supports that

promote economic independence and self-sufficiency for people with MR/DD. State data revealed that by 2002 all states but Mississippi were spending more for community services than for institutional services.<sup>483</sup>

In 2002, national spending for MR/DD was \$34.6 billion, and combined individual and family support spending of \$4.4 billion constituted 13 percent of nationwide funding; 53 percent was allotted for supported living and personal assistance; 32 percent for family support, and the remaining 15 percent funded supported employment activities.<sup>484</sup>

For FY 2003, HCBS increased 9.3 percent from \$16.9 billion to \$18.6 billion.<sup>485</sup> Three-fourths of HCBS waivers (nearly \$14.0 billion) are used to purchase LTSS for people with MR/DD.<sup>486</sup>

The other 25 percent of waiver expenditures were for people with physical disabilities and older people and totaled \$4.2 billion in FY 2003: Brain injuries accounted for \$163 million (a 59% increase from FY 2002); HIV or AIDS and technology-dependent or medically fragile people accounted for an additional 0.9 percent of all waiver spending (about \$167 million in FY 2003). There were three small waiver programs, which served individuals with a primary diagnosis of mental illness, accounting for 0.2 percent of HCBS waiver expenditures.<sup>487</sup>

- **Family Support Services** for MR/DD consist of any community-based services administered or financed by the state MR/DD agency that provide “vouchers, direct cash payments to families, reimbursement, or direct payments to service providers which the state agency identified as family support.”<sup>488</sup> Examples of family supports are “cash subsidy payments, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support programs, education and behavior management services, and the purchase of specialized equipment.”<sup>489</sup> All 50 states reported a family support initiative in 2002 (the District of Columbia did not provide a family support initiative).
- **Supported Employment** began in the early 1980s as long-term support for workers with developmental disabilities to enhance and supplement the states’ vocational rehabilitation services already in place. Supported employment refers to “small business enterprise,

work crews, enclaves within industry and individual job placements.”<sup>490</sup> The research in this field overwhelmingly shows that people with developmental disabilities want paid jobs in the community. In 2002, 24 percent of all vocational and day program participants in the United States worked in supported or competitive employment and the other 76 percent received services in sheltered employment, day activity, or day habilitation programs. States spent \$662,768,320 in 2002 on supported employment for 112,417 MR/DD participants.<sup>491</sup>

HCBS waiver spending for supported employment grew since the Balanced Budget Act of 1997 removed the requirement that HCBS-supported employment participants be previously institutionalized.

- **Supported Living** for MR/DD is “housing in which individuals with MR/DD choose to live and ownership is by someone other than the support provider and the individual has an individualized support plan.” Forty-seven states reported providing supported living services to 95,223 individuals in 2002, at a cost of \$2.0 billion. The national average for supported living was \$20,643, with a range of \$2,196 in Mississippi to \$124,544 in Oklahoma.<sup>492</sup>
- **Personal Assistance** is “support provided to people living in their own homes financed by either state funds or federal/state Medicaid funds and defined by the state as ‘personal assistance.’”<sup>493</sup>

In 2002, for MR/DD, 22 states had initiatives with combined supported living and personal assistance spending of \$2.3 billion, which constituted 7 percent of the total MR/DD spending. Expenditure data ranged from \$844 in West Virginia to \$89,354 in Oklahoma, with a national average of \$14,146.<sup>494</sup> The Federal Government has encouraged supported living through legislation: The Medicaid Community Supported Living Arrangement (CSLA) legislation enacted in 1990 endorsed supported living principles and provided funding for eight states to establish statewide supported living initiatives.

Medicaid spending for acute care and LTC combined in 2002 was \$91,889 billion for the blind/disabled category compared with \$51,733 billion for the aged, \$31,247 billion for children, \$23,493 billion for adults, and \$4,282 billion for foster care children.<sup>495</sup> Spending for the aged

was higher in two service categories compared with the same two service categories for the blind/disabled: (1) LTSS spending for the aged was \$35,242 billion versus \$29,554 billion for the blind/disabled; (2) nursing facility services spending for the aged was \$30,002 billion versus \$8,770 billion for the blind/disabled. Personal support services were higher for the blind/disabled—\$8,262 billion compared with \$3,505 billion for the aged.<sup>496</sup> The aged and blind/disabled categories combined represent 15 percent of the total Medicaid population.

### *Summary*

The growth of eligibility pathways for Medicaid beneficiaries with disabilities and the rising costs reflect the intense needs of its major beneficiaries: people with mental retardation and developmental disabilities. Reform efforts to date have been incremental and represent the path of least resistance. As the country ages and more people enter Medicaid, it is unclear how the current fiscal safety net for the MR/DD population can be sustained by states that will be addressing the additional costs of prescription drug benefits as well.<sup>497</sup>

The changes to the Medicaid program have become the path of least resistance for incremental reform. Part V will describe the many challenges in forecasting future demographic trends and gaps in services and supports.

## Part V

### Approaching the Iceberg

*Economic and financial challenges to reform.*

#### ***Global Challenges***

The current agenda for 21st century Americans with disabilities must include a clear examination of how aging (both at home and abroad) will affect the economic well-being of people with disabilities to live fully independent and meaningful lives. A 2005 report by McKinsey & Company found that aging will cause a global wealth shortfall over the next two decades and that growth in household financial wealth will slow by more than two-thirds (from 4.5 percent historically to 1.3 percent going forward), with the United States the largest source of the global shortfall (\$19 trillion) because of its dominant share of global wealth.<sup>498</sup> Left unchecked, this trend “could significantly reduce future economic and health care needs of aging populations.”<sup>499</sup>

Public solutions that focus on limiting public obligation for LTC financing do our nation a disservice.

*Dr. Judy Feder, April, 19, 2005  
Testimony U.S. Congress on LTC*

The staff at the International Monetary Fund in January 2004 reported that the growing imbalance between what the U.S. Government has promised to pay in future benefits and its expected revenues would require “an immediate and permanent 60 percent hike in the federal income tax, or a 50 percent cut in Social Security and Medicare benefits.”<sup>500</sup> Many federal reports confirm the growing fiscal insolvency of these programs, using different economic models and projections of costs, and all agree that the current growth is unsustainable.<sup>501, 502</sup>

America is also highly dependent on foreign capital and is currently importing far more goods and services than it is exporting; it is becoming more indebted to foreign countries.<sup>503</sup> Western Europe and Japan are aging more rapidly than the United States and may need additional capital to finance their own growing deficits. The growing global debt due to the war on terror and other factors combined with the rising costs for health care and the growing number of seniors without

sufficient retirement income to cover their LTC responsibilities place major pressure on current federal programs like Medicaid.

In his forward to Jeffrey Sachs' book *The End of Poverty—Economic Possibilities for Our Time*, Bono wrote that America “can be the generation that no longer accepts that an accident of latitude determines whether a child lives or dies—but will we be that generation?” Sachs' premise is that we can end poverty in the world in this generation if we choose, and he lays out an extraordinary plan to do so. America has its own poverty right now and, although it is much unlike the extreme poverty Bono and Sachs talk about, these Americans are in need of their own champions and a plan. People with disabilities are the poorest of the poor—among working adults, “nearly 40% of people with disabilities have family incomes less than 200% of poverty compared to 22% of the non-disabled.”<sup>504</sup>

As discussed in chapter 1, the United States is a noncontender in the life expectancy race compared with other countries that spend much less per capita. The World Health Organization's (WHO) Disability-Adjusted Life Expectancy measure is used to examine health data in every nation in the world, starting with life expectancy then subtracting years of ill health after weighting the level and duration of each disability.<sup>505</sup> In the 2000 survey, the United States came in 24th for life expectancy at 70 years. The survey found that Americans die earlier and spend more time disabled than people in most other industrialized countries. One WHO executive said that “portions of our population are very poor and suffer from the poor health more characteristic of a poor developing country rather than a rich industrialized one.”<sup>506</sup>

The disparities in health outcomes and disability are increasing for Americans under age 65 because of poverty, rising rates of obesity and diabetes, and increased longevity for individuals with lifelong disabilities, such as Down syndrome and mental retardation. The disparity in poverty rates is evident among seniors: 8.3 percent of whites live in poverty compared with 22.7 percent of black seniors and 20.4 percent of Hispanic seniors. The highest poverty rate (58.8%) is experienced by older Latino women who live alone.<sup>507</sup>

Healthy People 2010 estimated that direct medical and indirect annual costs associated with disability are more than \$300 billion, or 4 percent of the gross domestic product (GDP). This

total cost includes \$160 billion in medical care expenditures (1994 dollars) and lost productivity approaching \$155 billion.<sup>508</sup>

### ***Federal Roles in Financing LTSS***

Medicare and Medicaid programs are the fastest growing entitlement programs and together account for 62.5 percent of the \$151.2 billion spent on LTSS in 2001.<sup>509</sup> Medicaid's federal share as a percentage of GDP will grow from today's 1.5 percent to 2.6 percent in 2035 and 4.8 percent in 2080.<sup>510</sup> Medicare's federal share will triple as a share of GDP from 2.7 percent to 7.5 percent by 2035 and reach 13.8 percent in 2080. Social Security spending will grow as a federal share of the GDP from 4.3 percent today to 6.3 percent in 2035 and will reach 6.4 percent in 2080. Combined, all three programs are projected to double by 2035.<sup>511</sup> If the current federal health and retirement programs continue to grow at these rates, by 2040 federal revenues will be adequate to pay little more than interest on the federal debt.<sup>512</sup> By 2010, the share of the population age 65 and older will begin to climb, with profound implications: Social Security and Medicare (the Hospital Insurance portion) are pay-as-you-go programs—as the ratio of workers to retirees declines, so will the income for these programs.<sup>513</sup>

The GAO report also found that the prevalence of disability will go up, although it has had a steady decline over the past 16 years (it was noted earlier that the reasons may be environmental rather than health-related.) In 2000, one in five adults had unmet needs for LTSS. That need is expected to double by 2020.

States do not have the fiscal capacity to assume the primary role for their aging and disability populations without significant federal participation. The following data describes how integral the federal role is in partnership with states to finance current LTSS:

- ***Of the \$1.24 trillion spent on all U.S. personal health care services in 2001, \$151.2 billion (12 percent) was spent on LTSS.***<sup>514</sup>
- ***Total Medicaid Spending for acute care and LTSS in 2003 was \$276.1 billion and exceeded net outlays for Medicare.***<sup>515</sup> ***The federal share for Medicaid in 2003 was \$161.0.***

- **Total spending for LTSS was \$150.2 billion in 2001; Medicaid financed 48 percent, or \$73.1 billion, of the federal share,** with 64.3 percent covering care in nursing facilities and ICF/MRs and the balance spent on HCBS. The national average Medicaid nursing home payment is \$97 per day or \$2,942 per month. There is variation by state; for example, Florida has an average monthly Medicaid nursing home cost of \$3,496 compared with Iowa's average monthly cost of \$2,275. The average U.S. annual cost of assisted living is \$28,548.<sup>516</sup>
- **Medicare financed 18.0 percent, or \$33 billion, of total LTC expenditures in 2003,** with 54 percent for skilled nursing facility care and the balance for home health care.<sup>517</sup>
- **Families and individuals financed 20 percent, or \$38 billion, of out-of-pocket expenditures in 2003,** mostly for nursing home care (82%).<sup>518</sup> In the early 1960s, nearly half of health care spending was financed by individuals, with the rest provided by public programs and health insurance.<sup>519</sup> By 2002, individual out-of-pocket spending at the point of service was estimated to be 14 percent.<sup>520</sup>
- **Donated care represented 36 percent of LTSS care in 2004, at a cost estimated between \$103 and \$218 billion.**<sup>521</sup> Using the \$218 billion estimate, this represented approximately \$24,000 per senior.
- **Private LTC insurance represented 9.6 percent (\$16 billion) of all U.S. spending on LTC insurance in 2003,** with 52 percent for nursing home care and the balance for home health care.<sup>522</sup>
- **Other federal programs provided 5.9 percent, or \$151.2 billion,** for 2001 and included the Older Americans Act and the Social Services Block Grant (SSBG) program (Title XX of the Social Security Act), both of which fund a variety of community-based services. In 2001, the Older Americans Act was amended to authorize the National Family Caregiver Support Program (NFCSP), which offers assistance to family caregivers of the frail elderly. Some states supplement SSI to help low-income individuals pay for HCBS or to reside in nonmedical residential settings such as board and care homes. Certain programs under the Rehabilitation Act of 1973 provide a range of supportive services to people with disabilities. The Department of Veteran Affairs (VA) provides a wide range of LTC

services to the nation's veterans that include nursing home, domiciliary, home health care, and assistance to caregivers. Tax benefits for LTC include a limited deduction for LTC expenses and insurance premiums, tax-exempt insurance benefits, and the dependent care tax credit.<sup>523</sup>

GAO, in "21st Century Challenges: Reexamining the Base of the Federal Government," provided policymakers and government agencies with a compendium of areas considered ripe for review and reexamination, along with a framework for evaluating and identifying the issues and solutions. Question 4 of the GAO framework concerns affordability and cost-effectiveness. If we inserted LTSS into the formula, this is how the questions would look:<sup>524</sup>

- Are LTSS affordable and financially sustainable over the long term, given known cost trends, risks, and future fiscal imbalances?
- Is LTSS using the most cost-effective or net beneficial approaches when compared to other tools and program designs?
- What would be the likely consequences of eliminating the program, policy, function, or activity?
- What would be the likely implications if its total funding is cut by 25 percent?

It is clear from the research that the current funding mechanisms to support LTSS (primarily coming from Medicaid) are exceeding states' capacity and still not providing many of the services needed for a growing younger and older population that is not MR/DD or on Medicaid. In addition to the patchwork system of publicly financed LTSS, private LTC insurance is an alternative financing strategy.

### ***Medicaid and Private Insurance***

The sources for individual health care coverage for the elderly and people with disabilities are Medicare, Medicaid, and private insurance. All health care coverage plans have certain covered services and gaps in coverage. The type of health care coverage determines access to the kind of

care and services and supports people with a disability over and under age 65 receive. Each health care coverage plan covers different services and different populations.

Medicaid provides coverage for most medical services, mental health care, LTC, and prescription drugs. The single benefit used by the largest number of Medicaid recipients is prescription drugs. In FY 2002, 24.4 million Medicaid beneficiaries used this benefit, followed by physician services, which were used by 22.1 million recipients.<sup>525</sup> (The prescription drug benefit will shift to Medicare in 2006, and it is unclear what the impact of this change will be for people with disabilities, particularly those receiving both Medicare and Medicaid.)<sup>526</sup>

Fourteen percent of the U.S. population (40.8 million) used Medicaid and the State Children's Health Insurance Program (SCHIP) in 2001 as their primary source of health insurance.<sup>527</sup> Enrollees are described as "heterogeneous" in terms of the duration of their enrollment and the extent to which they rely on Medicaid and SCHIP as their sole source of coverage.

The CRS described three distinct groups using Medicaid and SCHIP in 2001:<sup>528</sup>

- **18.8 million relied solely on both Medicaid and SCHIP for the entire year;** 69 percent were children under age 19 and none were aged.
- **12.3 million used both Medicaid and SCHIP for part of the year** and were uninsured for two-thirds of the months they spent without Medicaid/SCHIP. Job-based health insurance covered nearly all of the remaining months; 1.8 million experienced a loss of job-based coverage during the year, and 61 percent were linked to policyholders (spouse or parent) who experienced substantial disruption in their employment and insurance status. An additional 14 percent were linked to policyholders who were employed but experienced a drop in wages.<sup>529</sup>
- **9.7 million never relied solely on Medicaid** during the year and had other sources of coverage; under 23 percent were children, but nearly half (46%) were aged.<sup>530</sup>

The report highlights the common theme of poverty across these three groups, as well as differences by race. Thomas Shapiro found that two out of every five American families do not

have enough money to live at the poverty line for three months and defines this phenomenon as being “asset poor.”<sup>531</sup> Fifty-four percent of black families are asset poor compared with 26 percent of white families. It is estimated that only 7 percent of American seniors have enough resources for one year of nursing home care,<sup>532</sup> and that cost of care is 20 percent higher in urban areas than in rural areas. In New York, California, and Massachusetts, the cost of urban care was found to be 40 percent higher than in nonurban areas.<sup>533</sup>

The demographics of the Medicaid insured population, when broken into the three categories above, suggest a high vulnerability to rising health care costs and dependence on family members (69% of 12.8 million children) for coverage. The growth in spending and enrollment is due in part to downturns in the economy; the increase in health premiums (in 2001, job-based health insurance premiums increased by 10.9% while workers’ earnings and overall inflation increased by less than half that amount); and the availability of expanded covered under public programs like Medicaid/SCHIP.<sup>534</sup>

The Economic and Social Research Institute found that nearly 49 percent of the uninsured are either self-employed or work at firms with fewer than 25 workers or for companies with fewer than 10 employees, of which only 52 percent offer insurance.<sup>535</sup> Over 50 percent of low-income employees of small firms with incomes below 200 percent of the federal poverty level are uninsured.<sup>536</sup> A 1999 report of the President’s Advisory Commission, “Consumer Protection and Quality in the Health Care Industry,” found that 600,000 of the 2 million health care paraprofessionals (nursing aides, home health aides, and home care aides) do not work full time and receive benefits and report wages below the poverty line.<sup>537</sup> (For an in-depth review, see “Supply and Demand Puzzle” in this section.)

### **Private Insurance**

Over 6 million Americans own LTC insurance (about 10% of the U.S. population) and 50 percent of the claims paid are for Alzheimer’s and other forms of dementia.<sup>538</sup> Genworth Financials (which provides LTC to 15 million customers in 22 countries) reports that cognitive claims since 1993 have increased 35 percent and that the annual dollar amount paid out has experienced a twelvefold increase, reaching approximately \$120 million for cognitive care

claims in 2003.<sup>539</sup> The allocation of cognitive claims was noted as moving from nursing homes to home health care and assisted living facilities.

Thomas Stinson, CEO of Genworth Financials, has more than 30 years of experience in the LTC insurance business. In his testimony before Congress, he reported that the average age of people buying LTC insurance has shifted dramatically from postretirement to preretirement—from age 69 to age 59.<sup>540</sup> Ten percent of those age 65 and older entering nursing homes will be there for five years or more, with average costs for 2004 at \$179 per day; assisted living facilities cost \$79 per day; and certified home care is about \$20 per hour. The top 13 companies providing LTC insurance had paid out \$8 billion in claims through 2002 and offer policies to individuals ranging in age from 18 to 99; they provide a \$50 to \$600 per day benefit.<sup>541</sup> Stinson confirmed what many studies have reported (see chapter 1, public opinion): that many Americans underestimate the financial risks involved with aging and do not understand the limits of Medicare. The focus of Stinson's testimony to Congress was on the aging population and not the specific needs of people with disabilities under the age of 65. However, the fact that 50 percent of LTC policies are covering cognitive claims suggests that more research is needed on the type of insurance coverage required by people under age 65.

### **State Partnerships for Long-Term Care and Medicaid**

The National Association of Health Underwriters (NAHU) was represented at the April 19, 2005, hearing of the U.S. House of Representatives Ways and Means Committee on Long-Term Care; association representatives testified that 8 out of 10 people in America are not insured for the catastrophic expense of nursing home care (currently estimated at \$70,000 annually).<sup>542</sup> Janet Trautwein of NAHU testified that the LTC partnership programs currently being offered in several states provide incentives for individuals who purchase private insurance and exhaust their benefits provided by the LTC insurance partnership policy to receive Medicaid as the payer for their LTC expenses. Policyholders are allowed to keep personal assets equal to the benefits paid by the original LTC policy. Mark Meiners also testified at this hearing that the partnership program can save Medicaid costs and that projected potential savings by 2017–2020 would produce a 7 percentage point decline in Medicaid's share of the LTC bill.<sup>543</sup> Current savings are in the range of \$8 to \$10 million.<sup>544</sup>

## **Disability Insurance**

The lack of disability insurance was described as the “missing piece in the financial security puzzle” for Americans with disabilities and is an indication that the public underestimates the risk of having a disability.<sup>545</sup> The Task Force for the Disability Chart Book found the following:

- The risk of a disability during a worker’s career is significant, as are the consequences to the individual and family financial security. (The increase in SSDI beneficiaries confirms this first finding.)<sup>546, 547</sup>
- The risk of disability is higher than premature death and is higher for older people than younger people, and females are more likely to become disabled than males. The majority of disabilities are caused by illnesses and not serious accidents (p. 4).
- Females have the highest risk of disability at age 35, at 29 percent, compared with a 20 percent risk for males (p. 7).
- The financial risk of disability is great and stops income and prevents retirement savings. A 45-year-old, currently earning \$50,000 per year and suffering a permanent disability, could lose \$1,000,000 in future earnings (p. 13).
- The public may overestimate the help that is available from public disability insurance programs (SSDI and other state-mandated, short-term programs provide a safety net but do not ensure financial security). Workers compensation benefits cover only disabilities caused by injury or illness arising on the job—only an estimated 4 percent of long-term disabilities. The SSDI definition for disability excludes many workers who qualify for private disability benefits (p. 29).<sup>548</sup>

## ***Supply and Demand Puzzle***

The issues of identification of current and projected future costs of an LTSS system are further complicated by the role of informal caregiving. There are no agreed-upon definitions for caregivers for the elderly and people with disabilities, especially when they are family and friends. Little consensus exists among the states about the recognition of families as a central component of the LTC system, such as in state statutes, in other state policies, or in the provision

of other home- and community-based care programs and services. Providing explicit support to family and friends of frail elders represents a paradigm shift. Viewing the family caregiver as a “consumer” or “client” is a relatively new concept for many state agencies.<sup>549</sup>

Many policymakers and states disagree about whether family and informal caregivers should be considered clients or consumers in the LTC system and whether they should have access to their own support services.<sup>550</sup> Yet, according to the Kaiser Family Foundation Survey, only 8 percent of people with disabilities turn to professional sources for assistance, such as home health aides and personal assistants. Two-thirds rely on family members and friends as an important source of support.<sup>551</sup>

According to the National Alliance for Caregiving and AARP, 44.4 million American caregivers age 18 and older provide unpaid care to an adult age 18 or older. Six out of 10 of those caregivers either work or have worked while providing care. Eighty-three percent are caring for a relative. Most of the caregivers (69%) are women. Most of the people receiving caregiving are women (65%) who are widowed (42%). Most care recipients are 50 years old or older (80%) and live in their own home. The typical caregiver is a 46-year-old woman who has at least some college experience and provides unpaid care to a widowed woman age 50 or older.<sup>552</sup>

The middle-aged women who currently provide much of the care, both formally and informally, will decrease in relative number, creating a situation in which the demand for LTC workers could substantially outstrip the supply.<sup>553</sup>

The most frequently reported unmet needs for caregivers are finding time for themselves (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%). To cope, 73 percent of caregivers say praying helps them with the caregiving stress, 61 percent talk with or seek advice from friends and relatives, and 44 percent say they read about caregiving in books.<sup>554</sup>

Family members and other informal caregivers, such as friends and neighbors, are the backbone of the LTC system, providing largely unpaid assistance to loved ones with chronic illnesses and disabilities. Without question, the economic value of family care is staggering. In 1998, HHS

estimated that replacing donated LTC services for seniors with professional care would cost between \$50 billion and \$103 billion. Another recent analysis estimated the value of informal care of impaired people of all ages in 1997—measuring it as forgone wages of the caregiver—at \$196 billion.<sup>555</sup> At an estimated value of \$257 billion nationally (in 2000 dollars), informal caregiving greatly surpasses the costs associated with home health care (\$32 billion) and nursing home care (\$92 billion).<sup>556</sup>

The Older Americans Act of 2000 authorized NFCSP as a national program with the following support to caregivers:

- information to caregivers about available services;
- assistance to caregivers in gaining access to supportive services;
- individual counseling, support groups, and caregiving training to assist caregivers in making decisions and solving problems related to their role;
- respite care to temporarily relieve caregivers from their responsibilities; and
- supplemental services, on a limited basis, to complement care provided by caregivers.<sup>557</sup>

While this legislation offers new resources for caregivers, more research is needed to learn more about the programs that some states have designed and their impact and cost savings.

While caregiving by family and friends is ancient, it is not fully understood. The term “caregiver” needs to be defined. Caregiver prevalence studies should use the same definitions and parameters to gather better information. Issues such as caregiver training, caregiver burden and stress, negative impact on the physical health of caregivers, services they provide, and the economic impact of caregiving, especially the impact on work, need to be understood.<sup>558</sup>

Outcomes and costs for caregiving and quality measures for the safety and health of the care recipient would address the value and gaps in caregiving.

## **Workforce Shortage and Recruitment and Retention Challenges**

The demand for LTSS is growing. The cost is growing. The supply of paid workers, skilled and unskilled, to respond to the market demand is declining. The challenge for policymakers is not only to focus on workforce shortages and related costs of education, training, wages, and benefits but also to solve the puzzle of the role and relationship of informal caregiving to paid providers. Who is going to meet the growing demand for providing services and supports as informal caregiving decreases?

The workforce shortage is both a supply and demand problem. As the aging of the baby boom generation increases seniors' share of the population from 12.6 percent in 2000 to 20.5 percent in 2040, the demand for LTC services is virtually certain to increase. The population's aging will also cause a decline in the share of the population that is of a working age. In 2000, the ratio of people of working age to people of retirement age was 4.7. In 2040, the ratio is forecast to fall to 2.6.<sup>559</sup> There will be a shortage of workers and taxpayers, along with an increasing demand for health care services. It is not simply a supply-and-demand issue. Other issues affect the shortage, such as wages and the job itself.

As with most health care professions, there is a shortage of nurses and home care workers for LTC. As of 2002, the health care workforce included nearly 2.2 million registered nurses (RNs), about 700,000 licensed practical nurses (LPNs), and about 3.1 million paraprofessional workers, including nurse home health, personal care aides, and home care aides. The Health Resources and Services Administration forecast projects that the demand for RNs and LPNs in nursing homes will increase by 44.2 percent and 47.9 percent, respectively, between 2000 and 2020. The demand for RNs and LPNs in home health agencies is expected to increase by 43.8 percent and 53.8 percent, respectively, during the same period. According to the Bureau of Labor Statistics (BLS), jobs for nurses aides are also expected to grow by 23.8 percent, while the employment of personal care and home health aides could grow at a much more rapid rate of 58.1 percent between 1998 and 2008.<sup>560</sup> These statistics do not count the "gray market"—workers hired and supervised by consumers who pay for their own care, whose numbers are thought to be substantial.<sup>561</sup> This sector of paraprofessionals in the home—the home care worker—is

consistently in BLS estimates of the top 20 fastest and largest job growth occupations. Over a half million new home care jobs will be created by 2012.<sup>562</sup>

This shortage in workers is occurring as the baby boomers age and the incidence of chronic disease is on the rise. The basic argument is that the aging of the baby boomers over the next few decades, along with improvements in longevity generated by medical advances, will cause a dramatic increase in the elderly population requiring LTC.<sup>563</sup> Government estimates suggest that the number of people using paid LTC services—in a nursing facility, alternative residential care facility such as assisted living, or at home—could nearly double, increasing from 15 million in 2000 to 27 million in 2050.<sup>564</sup> In the future, the labor force, on the whole, will not be growing as fast as either the LTC population or the population at greatest risk of needing LTC (i.e., people age 85 or older).<sup>565</sup>

Economists generally believe that market forces tend to eliminate shortages in the labor market (or elsewhere), especially with the passage of time. If wages and benefits are free to adjust, worker shortages in the short term should lead to higher compensation levels in a given market, which then should attract workers to that field and thereby ease the shortage. However, a number of factors might limit the speed of any such adjustment.<sup>566</sup> Factors may include competition for these workers, content of the job, conditions of work, and the ability to increase wages.

In particular, the shortage in direct care workers (paraprofessionals, nursing assistants, personal and home care aides, and home health aides) will have the greatest impact on community and home-based LTSS. The profile of the direct care worker is a woman who is 37 to 41 years old. Slightly over half of the direct care workers are white and non-Hispanic. About one-third are African American and the rest are Hispanic or other ethnicities. One-fourth of direct care workers are unmarried and living with children, compared with 11 percent of the total U.S. workforce. Two-fifths (41%) have completed their formal education with a high school diploma or general education diploma (GED). Another 38 percent have attended college.<sup>567</sup>

There is a shortage of direct care workers. Direct care work is unattractive in the LTC and health care sectors, and in the overall workforce, for many reasons. The content of the job and conditions of work may be one factor. In particular, care for the elderly may not be considered appropriate or

appealing work for other potential labor pools, such as less-skilled men, and stressful work conditions might limit other potential candidates as well.<sup>568</sup> Another indicator is the high staff turnover in the LTC sector. Studies have found that the turnover rate in nursing facilities is nearly 100 percent for nursing aides. Home care agencies have annual turnover rates between 40 percent and 60 percent.<sup>569</sup> Possible explanations for the high turnover rates among nursing personnel in the LTC sector include relatively low wages, limited or no benefits, and greater physical and emotional exertion than is required in many other jobs in the health care sector.<sup>570</sup>

The wages are low. In 2003, the median hourly wage for all direct care workers was \$9.20, significantly less than the median wage of \$13.53 for all U.S. workers. Almost a fifth of direct care workers—far more than the national average of 12 percent to 13 percent—earn incomes below the poverty level, and 30 to 35 percent of all nursing home and home health aides who are single parents receive food stamps.<sup>571</sup> The financial ability for this sector to generate higher wages and benefits will be limited by the constraints on third-party payers, such as Medicaid and Medicare, which are and will continue to be pressured to reduce costs under the weight of a growing retirement population.<sup>572</sup>

There is little access to health benefits for the direct care worker, because the work is part time or the worker is self-employed. Home health aides average 29.2 hours per week, and nursing aides, orderlies, and attendants average 32 hours.<sup>573</sup> Because the work is part time, the worker often has to patch together a few jobs to make ends meet. In 1999, one-third (32.1%) of home care aides and one-fourth (25.2%) of certified nursing assistants in nursing homes had no health insurance, compared with one-sixth (16%) of all U.S. workers.<sup>574</sup>

The elasticity of the labor supply reflects the responsiveness of workers in any sector to the wages offered in that sector. A fairly elastic labor supply indicates that workers will respond in large numbers to higher wages.<sup>575</sup> Again, wages will not be the only factor that affects the transition of workers to LTC. If the willingness of people to work in LTSS depends heavily on the extent to which they enjoy providing care to the elderly; or if less-skilled men and other demographic groups (such as youth or the near-elderly) are not amenable to providing such work

or view it as less prestigious or as a low-status occupation, the elasticity of the labor market for this sector will be relatively low.<sup>576</sup>

The following are other variables that shift the labor supply and that vary from state to state:

- Labor market demographics: This includes the population from which the LTC workers is typically drawn. The share of the population composed of less-educated (with a high school diploma or less) middle-aged women and/or immigrants.
- Unemployment rate: The local unemployment rate should also affect the relative supply to the LTC industry, as it reflects the amount of competition available from other low-wage occupations.
- Low-wage worker policies: Policies to improve the wages and benefits of low-wage workers overall should have some positive effects on the labor supply to the LTC sector. These policies might include state minimum wages above the national level, federal and state-earned income tax credits, or a generous SCHIP.
- Long-term support worker policies: Regulations might limit the supply of workers by imposing training or other requirements that make it harder to generate LTC workers. On the other hand, innovative recruitment or training programs could have more positive effects.
- Wages and employment in competing occupations/industries: Wages in competing sectors, such as hospitality and child care, are important for determining the potential willingness of workers to enter the long-term services sector from these other sectors.<sup>577</sup>

The issues for direct care workers and the labor supply must be understood on the national, state, and local levels. Among the top issues to be addressed are salary, full-time work, and benefits, balanced with long-term service funding for Medicare and Medicaid. For the success of consumer-directed programs and other Medicaid waiver programs, the workforce issues and shortages need to be resolved.

## *Summary*

The documented growing demand for LTSS in the home and community raise new questions for researchers and policymakers about current costs and projected future costs for the under- and over-65 populations with disabilities. The cost conundrum is further exacerbated by four important factors.

First, insufficient data is available on LTSS costs for individuals across the spectrum of disabilities under age 65. Second, there is insufficient data on the costs of responding to a decreasing population of informal caregivers and the development of an appropriately trained and paid workforce. Third, there is a lack of agreement on the role and responsibility of the government versus individuals and families to cover the costs of current and future LTSS needs. Without research to explore different public and private cost-sharing scenarios, particularly for the under-65 population with disabilities, it would be difficult to explore the relationship of public financing and private insurance.

The fourth and final factor transcends the specific challenges of development of a responsive LTSS system for the targeted population. The global economic picture and changing demographics, in addition to the current federal budget deficit, raise questions about the political will to maintain current entitlements, let alone craft a new system.

## **Part VI**

### **Reviewing the Passenger Manifest**

*Case studies of the costs and services and supports for six individuals with disabilities: 2005–2030.*

There is no better way to identify the reality of the environment we are attempting to research than by referring to the human element. The following case studies present information about the lives of six individuals with disabilities, with information on services accessed and costs (when available) associated with their needs on an annual basis and projected 25 years out. Four of the cases present information on physical and cognitive disabilities. Given the predictions regarding an aging population, one case is based on a chronic medical condition (diabetes) and another on Alzheimer's. No two case studies were completed in the same state.

#### ***Crystal's Story***

##### **General Description**

Crystal is a one-year-old girl living with her single, 20-year-old mother, Ruth, in Vermont. Crystal was born prematurely at 27 weeks. Crystal and her mother had home health nurse visits because she was at high risk due to prematurity. Crystal's mother and nurse had noticed that Crystal was not developing motor skills normally and had a preference for one side. She was diagnosed with cerebral palsy (CP) at six months. She is now being evaluated for seizures because she has periods of staring.

Crystal is tiny and below normal for weight and height. She is withdrawn and quiet most of the time, although she smiles at Ruth. Crystal's left arm muscles are stiff (spastic) and she does not sit up on her own. She tries to roll over in one direction, although she does not crawl. Crystal coos and makes noises, is bottle-fed, and does well with pureed baby food. She is gaining weight and, like all babies, likes being in her carriage and going for rides.

Crystal and Ruth live in a rented mobile home in rural southern Vermont. The town they live in is 40 minutes from the nearest hospital or city. Ruth worked as a waitress during her pregnancy. She has not returned to work since Crystal was born because of Crystal's medical problems and

not having adequate day care. Ruth and Crystal are now on public assistance. Ruth's mother, Jean, lives in the same area and works full time as a secretary for a cement company. She visits Ruth frequently. Crystal's father is not involved with the family.

### **Diagnosis and Level of Functioning**

CP is a developmental disability that appears early in life, manifested by difficult control of movement and posture. With a relationship to the central nervous system and damage to parts of the brain, it may occur before, during, or after delivery.<sup>578</sup> There are four types of CP. Spastic CP, in which the muscles are stiff and permanently contracted, affects 70–80 percent of individuals with CP. Doctors often describe the type of spastic CP an individual has based on which limbs are affected (e.g., both legs, one side, or all four limbs).<sup>579</sup>

It is a challenge to assess Crystal's level of growth and development because of her prematurity, although her type of CP seems to be located on the left side of her body. She can grasp and reach with her right hand and is being evaluated for seizures and mental retardation. About 45 percent of children with CP have epilepsy. Seventy percent of people with CP have other disabilities, including mental retardation.<sup>580</sup> Crystal is too young to be evaluated for ADLs or IADLs.

### **Present Services and Costs**

The home health nurse referred Ruth and Crystal to FIT, the Family, Infant and Toddler Program. FIT is Vermont's response to the Individuals with Disability Education Act (IDEA), which requires states to have a program or services to assess and support children with special health needs and delays in development to reach their full potential. FIT is a family-centered system of early intervention for children from birth to three years who have or may have special health needs and/or delays in development. After age three, the local school system is responsible for the coordination and delivery of supportive and educational services through an Individual Education Plan (IEP).

FIT did the original assessment and referrals for Crystal. Because Ruth has no private insurance, all the costs are assumed by the state of Vermont. If Crystal were eligible for SSI and received Medicaid, some of the cost would be incurred by the Medicaid connection to SSI, which is both federal and state funded. They arranged for Crystal to be seen and followed by a developmental

pediatrician who has a monthly Vermont Children with Special Needs clinic in the nearby city. Through FIT, the early childhood educator has developed with Ruth, Jean, and other professionals an IEP for Crystal. Crystal has been assigned a case manager through FIT to help Ruth with access and coordination of services. Crystal has physical therapy twice a week for muscle and joint flexibility and development. She has an occupational therapist who does play therapy and fine motor coordination with Crystal. A dietitian visits with Ruth to talk about nutrition and food planning, because children with CP burn more calories. An early education and parenting specialist works with Ruth, Jean, and Crystal on parenting and bonding with a child with special needs.

A social worker is working with Ruth on her financial and housing situation. The mobile home is not handicap-accessible and the town she lives in does not have a special education department in its school system. They are discussing moving into a more accessible home and considering moving to the city, where more services are available and there is a school with a special education department. If Ruth does not move to the city, Crystal will be transported daily to the city school, which is 40 minutes each way.

The social worker and parenting specialist are concerned about Ruth. She is often overwhelmed with the care of Crystal and her own lack of social contacts. Her friends do not visit her anymore, and she can only go out when Jean can come over and babysit.

Transportation is becoming an issue because Ruth's car is old and she does not have the money to buy a new one. She uses the Red Cross for transportation for medical visits for Crystal. This is a service the Red Cross provides for rural families in southern Vermont.

Ruth is now on public assistance for income through the Office of Economic Services and Vermont Health Access Program (VHAP) for health coverage (Medicaid). She receives a supplemental payment from the state and food stamps. With the help of the social worker, she is looking for funding for a special stroller and chair for Crystal. She may have access to a Payer of Last Resort Pool, which is available through FIT. The state of Vermont has reorganized its agencies for people with disabilities into one department, the Department of Aging and Independent Living, to better coordinate and administer services to the elderly and individuals

with disabilities. (Crystal would be eligible also for an SSI payment and Medicaid through that eligibility, and Ruth would continue to be covered under the public assistance program.)

## Annual Costs

### Public Assistance:

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<b>Temporary Assistance to Needy Families</b>	<b>\$ 6,420 (2004 dollars)<sup>581</sup></b>
<b>State Subsidy Payment to Family</b>	<b>\$ 2,802 (2002 dollars)<sup>582</sup></b>
<b>State Flexible Family Funding</b>	<b>\$ 1,122 (2004 dollars)<sup>583</sup></b>
<b>Food Stamps</b>	<b>\$ 2,400 (2004 dollars)<sup>584</sup></b>
<b>Personal health care costs (average personal health costs)</b>	<b>\$10,437 (1993 dollars)<sup>585</sup></b>
<b>Supplemental Security Income</b>	<b>\$ 4,032 (estimated child payment)<sup>586</sup></b>

## Future Services and Costs

In 2030, Crystal will be 27 years old. Crystal's history has been a difficult one. Her mother, Ruth, left her at the age of six. Ruth said she just couldn't take it anymore. They had never moved out of the mobile home and Crystal had been traveling almost two hours back and forth from a special education program in the city. She had no friends locally and was very isolated, just like her mother, Ruth. Jean, Crystal's grandmother, became the parent and guardian for Crystal. They continued to live in rural Vermont and traveled to the school and other services. Jean was better able to cope with Crystal's care, and they developed a very loving relationship. Crystal graduated from high school, but never found employment and had continued to live with her now aging grandmother. They took care of each other. They had refused any services for people with disabilities. They had had no contact with the Department of Aging and Independent Living since Crystal finished high school. When Crystal was 25, Jean could no longer care for herself or Crystal. Jean contacted the Center for Independent Living for help.

Crystal has been assigned a case manager from the Department of Aging and Independent Living. Because she can no longer live with her grandmother, Crystal has agreed to go into a small group home in the city to transition her to more independence and the possibility of employment.

Crystal is able to do all of her ADLs in an adaptive environment. She can walk with a leg brace and cane with some difficulty. She now has a motorized wheelchair.<sup>587</sup> She has the potential to assume her IADLs with adequate training. When she lived with her grandmother, Jean managed the money and shopping.

Crystal had a full evaluation by the Center for Independent Living. She is receiving psychological counseling. Crystal is withdrawn, has low self-esteem, and is moderately depressed. She was rejected by her mother, had no friends due to her rural isolation, and misses her grandmother. She had been evaluated for mental retardation as a child and was found to have normal intelligence. She did finish high school but did not receive any vocational training or further education.

Crystal’s plan for independence is full employment, her own apartment, and case management. Crystal agrees with the plan but is not sure she can do it. Her present services through an HCBS waiver include vocational training, psychological counseling, group living, socializing activities at the Center for Independent Living, and IADL training. She visits her grandmother every week. She receives SSI from SSA and medical insurance through VHAP (Medicaid).

**Annual Costs**

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<b>Supplemental Security Income</b>	<b>\$ 6,624 (2003 dollars)<sup>588</sup></b>
<b>VHAP (Medicaid) (average personal health costs)</b>	<b>\$10,437 (1993 dollars)<sup>589</sup></b>
<b>Group Housing</b>	<b>\$40,000 (2004 dollars)<sup>590</sup> (estimated national average)</b>
<b>HCBS Waiver</b>	<b>\$35,215 (2003 dollars)<sup>591</sup></b>

**Case Summary**

Crystal’s story represents a number of themes, including a child with disabilities born in a rural setting, a family caregiver system, the availability and fragmentation of state services, and consumer direction. The rural setting led to financial difficulties and isolation. While the FIT program did provide home visits, for the majority of Crystal’s life, the rural setting meant

transportation issues, employment issues for the mother, lack of availability of day care and school services, and social isolation from schoolmates and other social services. The state provided intense, family-oriented services and support for the first three years of Crystal's life, but as she grew older, Crystal fell between the cracks and received no services for a period of time. However, at 27, she was able to reconnect to support services provided by the state. The support of her family was mixed. Her mother was overwhelmed and left, and a loving grandmother assumed her care. However, her grandmother continued the social isolation and, therefore, Crystal has been delayed reaching full independence. The level of consumer direction is not clear. Did Crystal prefer social isolation with her grandmother or did she not fully understand her choices? The costs have clearly increased as Crystal has moved from family care to more independent living.

## ***Robert's Story***

### **General Description**

A Wisconsin resident, Robert, is a 45-year-old man with schizophrenia complicated by a developmental disability. The voices that he hears constantly and responds to verbally are poorly controlled by medication. He has an average IQ. He is overweight with poor posture, is not secure on his feet, and has a history of numerous broken arms. Although he often looks unkempt, his clothes are clean, his hygiene is good, and he is nonviolent. Robert appears shy and withdrawn when he is fighting the voices and has limited eye contact and slurred speech that he can correct if he is asked to speak more clearly.

Robert was diagnosed with behavioral issues, developmental issues, and emotional disturbance when he was in elementary school. He was placed in a school for emotionally disturbed children, attended public high school with the support of a special needs department, and had some vocational training. When he was 23, he worked for one year in a supermarket but fell and broke his arm. He refused to go back to work.

Robert lives with his elderly, retired parents and goes to day habilitation (sheltered workshop). He had lived in a group home in the past, but he did not want to stay in that setting because he did not like his roommates. For the majority of his life, he has lived with his parents. He is the

second oldest of five siblings. Two of his brothers and one sister live nearby in Wisconsin. One sister lives in New Jersey. Robert is very involved with his family and visits his sister in New Jersey every year with his parents. Robert is friendly with some of the participants in his day program. Robert has a network of past teachers and counselors that he calls on the telephone every week. Some of these relationships have existed for more than 30 years. He enjoys music, football, and vacations with his family. He is able to take public transportation and go shopping at the mall by himself.

### **Diagnosis and Level of Functioning**

According to the National Institutes of Health, schizophrenia is a chronic, severe, and disabling condition. People with schizophrenia often suffer terrifying symptoms, such as hearing internal voices not heard by others (hallucinations) or believing that other people are reading their minds, controlling their thoughts, or plotting to harm them. Approximately 1 percent of the population develops schizophrenia—more than 2 million Americans suffer from the illness in a given year. Children over the age of five can develop schizophrenia, but it is very rare before adolescence. Antipsychotic drugs are the best treatment now available, but they do not cure schizophrenia or ensure that there will not be further psychotic episodes.<sup>592</sup>

Robert takes antipsychotic drugs and regularly sees a psychiatrist for medication management. The antipsychotic drugs do not fully control his hallucinations. Over the years, he has been admitted for acute psychiatric hospital care when he is nonfunctioning because of the hallucinations. In a recent hospital admission, he was found to have high cholesterol, for which he now takes medication regularly. After that admission, he was referred to an internal medicine physician for medical care. It is not unusual for people with disabilities to have their medical care focused on their disabilities and not to have recommended preventive examinations and routine screenings.

Robert is able to do his ADLs with oversight from his parents. Robert manages his weekly allowance and is able to go shopping and take the bus. In the past, he has flown alone to visit his sister with his parents getting him on the plane and his sister being there when he arrives. He has

not been able to live independently, cook his own meals, or manage a household. Robert participates in decisions about his life and trusts his parents and family.

### **Present Services and Costs**

Robert meets the Wisconsin definition for adults with serious mental illness and, because of his balance and speech difficulties, meets the developmental disabilities definition. Chronic mental illness means a mental illness that is severe in degree and persistent in duration, which causes a substantially diminished level of functioning in the primary aspects of daily living and an inability to cope with the ordinary demands of life, which leads to an inability to maintain a stable adjustment and independent functioning without long-term treatment and support and which may be of lifelong duration. Chronic mental illness includes schizophrenia, as well as a wide spectrum of other severely disabling psychiatric conditions, but it does not include organic mental disorders or a primary diagnosis of mental retardation or of alcohol or drug dependence.<sup>593</sup> An individual who also has been diagnosed with developmental disabilities has more difficulty with daily living skills and often lacks the ability to live without some amount of daily support.

Wisconsin has been a national leader and an incubator in the area of services for the treatment of people with mental illness.<sup>594</sup> The Wisconsin Administrative Code, Chapter HFS 63, mandates each county to have a Community Support Program (CSP).

A CSP is a coordinated care and treatment program providing a range of treatment, rehabilitation, and support services in the community through an identified treatment program and staff, ensuring ongoing therapeutic involvement and individualized treatment for people with severe and persistent mental illness. The array of required treatment services available to CSP consumers includes crisis intervention; symptom assessment, management, and education; medication prescription and monitoring; psychiatric evaluation and treatment; and family, individual, or group psychotherapy. The required array of rehabilitation services available to CSP consumers includes vocational assessment, job development, and vocational supportive counseling; social and recreational skill training; and individualized support, training, and assistance in ADLs. The required array of support services available to the CSP consumers

includes assistance in obtaining needed physical and dental care, legal services, transportation services, acquisition of financial support and benefits, and housing supports. Case management is an integral part of CSP services. CSP case management includes coordination of assessment and treatments, coordination of referrals, assessment and monitoring of symptoms, providing supportive therapy, and symptom education. Case management also includes advocacy on behalf of consumers; education, support, and consultation with consumers, parents, families; and other supports.<sup>595</sup> CSP is an HCBS waiver program for Medicaid, and the county in which the program resides pays the state portion. Because the counties are required to know what their constituents want and need, the programs vary by county. There is also a statewide quality assurance program for mental health services to collect client-specific data and measure consumer-oriented quality.

Robert lives at home and attends a day habilitation program that is part of the CSP in the county. Day habilitation provides him with education, supportive therapy, socialization, and other activities. His case manager sees him at least once a month there. He is able take public transportation to and from the program. The CSP also covers his visits with the psychiatrist and medication management.

Robert receives SSI and has Medicaid for health coverage. Robert also receives SSDI and Medicare from his retired parental work record, because he was disabled before he was 22 years of age, was never married, and does not have a sufficient work record of his own.

Robert's parents are both retired and middle class. They are his guardians and have power of attorney. They meet with the case manager once a year and as needed. When they are on vacation and Robert does not go with them, Robert stays with one of his brothers. His parents are members of the National Alliance for the Mentally Ill of Wisconsin and attend the local chapter meetings.

## Annual Costs

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<b>Community Support Services</b>	<b>\$ 6,030 (2001 dollars)<sup>596</sup></b>
<b>Community Treatment Services</b>	<b>\$ 1,211 (2001 dollars)<sup>597</sup></b>
<b>HCBS Waiver</b>	<b>\$36,528 (2002 dollars)<sup>598</sup></b>
<b>Supplemental Security Income and Social Security Disability Insurance</b>	<b>\$ 7,104 (2003 dollars)<sup>599</sup></b>
<b>Medicaid plus Medicare (average personal health costs)</b>	<b>\$21,236 (2000 dollars)<sup>600</sup></b>

## Future Services and Costs

In 2030, Robert will be 71 years old. As his parents aged, he agreed to live in a community residential home. When his parents were alive, he would come home for a weekend day and his parents would take him out one evening during the week for dinner. After both of his parents died, his siblings assumed the same schedule. He spends one weekend day with one of his three siblings in the area and another sibling takes him out to dinner once a week. His youngest brother is now his guardian and has power of attorney.

Robert still has daily hallucinations. He is more unstable on his feet and uses a walker. He has developed high blood pressure and adult onset diabetes. He is more withdrawn and is often talking back to the voices. He does not want to go to a day habilitation program anymore. He likes to watch television, especially sports, and listen to music. He still spends part of each day phoning friends, siblings, and teachers from his past. He will walk around the yard or sit on the porch. He no longer wants to go on the bus by himself. He can still do his ADLs with reminders from the residential staff; the staff also help him with money management. The CSP provides him with medical care, dental care, psychiatric care, medication management care, and case management.

## Annual Costs

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<b>Community Residential Services</b>	<b>\$10,159 (2001 dollars)<sup>601</sup></b>
<b>Community Treatment Services</b>	<b>\$ 1,211 (2001 dollars)<sup>602</sup></b>
<b>HCBS Waiver</b>	<b>\$36,528 (2002 dollars)<sup>603</sup></b>
<b>Supplemental Security Income and Social Security Disability Insurance</b>	<b>\$ 7,104 (2003 dollars)<sup>604</sup></b>
<b>Medicaid/Medicare (estimated average personal health costs)</b>	<b>\$21,236 (2004 dollars)<sup>605</sup></b>

### Case Summary

Robert's story represents a number of themes, including the family caregiving system, a well-coordinated state system, and consumer direction. Robert's family has a very strong sense of family responsibility. His parents cared for Robert his whole life while fostering independence and utilizing public and private support. The siblings have continued the support of Robert, as he is an integral member of his family. The state of Wisconsin has well-coordinated services, including acute care and LTC. Robert has benefited from coordinated services and case management. Robert has directed his life with the support of his family. The cost of services has been substantial, even with the family caregiving. The success of Robert's story is consumer direction with active family support in a state with well-coordinated services.

### *Lucy's Story*

#### General Description

Lucy is an 18-year-old girl with mental retardation. She lives at home in Massachusetts with her parents, who are a lawyer and a manager, and her younger brother, who is four years younger. Their home is in a small middle- to upper-class town northwest of Boston. Lucy attends a public high school. According to Massachusetts Chapter 766 and the Federal IDEA, the public school system must provide her with education and appropriate services until she is 22 years old. Lucy has been attending a full day of classes in the school's special education department. She has had prevocational training to be able to clean trays and tables in the school cafeteria. This year, she

will be attending half-day vocational training as a health care assistant and half-day classes in the school's special education department.

Lucy's social activities are parent-directed. She has attended dance classes and theater classes. She is involved and has competed in the Special Olympics for swimming and downhill skiing. She has four girlfriends. Three are from her special education class and the fourth is a girl she has known since elementary school. She usually talks with them on the telephone and attends school activities and dances with them. Lucy has a friend she calls her "boyfriend" whom she met through Special Olympics. She talks with him on the phone, but they do not see each other outside of the Special Olympics. Lucy lives at home with her parents, who have power of attorney for her.

### **Diagnosis and Level of Functioning**

The definition of mental retardation, according to the American Association on Mental Retardation, is as follows:

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18. The five assumptions to the application of the definition are (1) Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture; (2) Valid assessments consider cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors; (3) Within an individual, limitations coexist with strengths; (4) An important purpose of describing limitation is to develop a profile of needed supports; and (5) With appropriate personalized supports over a sustained period, the life function of the person with mental retardation generally will improve.<sup>606</sup>

Lucy has cognitive development delay. Her IQ is 64. Her speech is slow. Her reading, writing, and math skills are at a first-grade level. While she is shy at times, she can be friendly with people she knows, and she communicates back and forth with peers and adults in a limited but effective way. She has no physical limitations or chronic illnesses. She can perform ADLs, such as bathing, dressing, and eating, with reminders from her parents. She would have difficulty with IADLs, such as money management, some shopping, and traveling.

## **Present Services and Costs**

The local education system is responsible for much of Lucy's past training and costs. According to Massachusetts' Chapter 766, the school system must provide education, training, and counseling up to the age of 22. The school has provided a special need education, vocational training, and speech and language therapy to work on her vocabulary, word retrieval, and language processing for appropriate responses. She has had ongoing counseling with the school social worker about adaptation and appropriate social behaviors.

Because Lucy is 18, she is starting to transition to the adult support system through the Massachusetts Department of Mental Retardation. She is presently being reevaluated by the Regional Eligibility Team. The Regional Eligibility Team will do an Individual Support Plan (ISP) to determine the adequate, most appropriate, and least restrictive supports she will need. The ISP will include Lucy and her parents. The local provider for the Massachusetts Department of Mental Retardation, through an approved ISP, will continue her vocational training, provide her with activities for continued socialization, and assign her a service coordinator. The service coordinator is a case manager who will do ongoing assessments and provide information, crisis intervention, and advocacy.

Lucy will continue to live at home while she is in vocational training. She is also staying involved with the Special Olympics. Lucy will no longer be covered by her parents' private health insurance. She will go on MassHealth, which is Massachusetts' Medicaid. She will also be eligible for SSI through the Social Security Administration.

Her family will also be able to access support services. Family support services consist of any community-based service administered or financed by the state MR/DD agency providing vouchers, direct cash payments to families, reimbursement, or direct payments to service providers, which the state agency identified as family support. Examples of family support include cash subsidy payments, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support, education and behavior management services, and the purchase of specialized equipment.<sup>607</sup> While Lucy's family is upper middle class, they take

advantage of family counseling and in-home training through the local Department of Mental Retardation provider.

### Annual Costs

<b>Average Cost per Special Education Student</b>	<b>\$13,542 (2003 dollars)<sup>608</sup></b>
<b>Supplemental Security Income</b>	<b>\$ 6,624 (2003 dollars)<sup>609</sup></b>
<b>HCBS Waiver</b>	<b>\$42,536 (2002 dollars)<sup>610</sup></b>
<b>Average MassHealth Cost (estimated average MA personal health care cost, per capita)</b>	<b>\$21,820 (2000 dollars)<sup>611</sup></b>
<b>Family Support</b>	<b>\$ 2,653 (2002 dollars)<sup>612</sup></b>

### Future Services and Costs

In 2030, Lucy will be 44 years old. It is expected that at that time she will be working as a health care assistant in an assisted living facility under a supported employment program of the local Department of Mental Health provider and an HCBS waiver. Supported employment consists of MR/DD state agency–financed programs for long-term employment support, with the goal of developing independent work skills leading to competitive wages for individuals with mental retardation.<sup>613</sup> She will be earning minimum wage or above and have her health benefits through her employer.

Lucy will live in a supported living apartment through an HCBS waiver. Supported living includes housing in which individuals choose where and with whom they live, in which ownership is by someone other than the support provider, and in which the individual has a personalized support plan that changes as his or her needs and abilities change.<sup>614</sup> Lucy’s housing is provided by the local Department of Mental Retardation. She takes the bus to her job and to go shopping.

Her parents still live nearby and have power of attorney. Lucy, her parents, and the service coordinator are discussing a long-term plan for Lucy as her parents’ age. They are discussing

whether her brother, who lives out of state, should have power of attorney or whether they should appoint a guardian.

Lucy is still very involved with her parents. Lucy goes to church with her family, goes on vacation with them, and spends holidays with them. She also has social activities through the local Department of Mental Retardation provider. Lucy has a boyfriend whom she sees regularly. Lucy remains healthy, although she is now overweight.

### **Annual Costs**

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<b>Housing Support</b>	<b>\$23,752 (2002 dollars)<sup>615</sup></b>
<b>Employment Support</b>	<b>\$12,377 (2002 dollars)<sup>616</sup></b>
<b>HCBS Waiver</b>	<b>\$42,536 (2002 dollars)<sup>617</sup></b>
<b>Estimated Supplemental Security Income (earned wages would determine exact amount)</b>	<b>\$ 6,624 (2003 dollars)<sup>618</sup></b>
<b>Medicaid</b>	<b>\$21,820 (2000 dollars)<sup>619</sup></b>

### **Case Summary**

Lucy's story represents a number of themes, including the family caregiving system, a well-coordinated service system at the local level, and consumer direction. The success of Lucy's family caregiving is that the family has resources. They are well educated and have a middle- to upper-class income. They know how to advocate for Lucy and foster her independence and socialization. The services available to Lucy are at the local level, including the town school system. The school system coordinates the transition to the local provider for the Department of Mental Retardation. Lucy has the advantage of a local agency that will support and coordinate care and independence. Because her parents have fostered her independence, Lucy can direct her life within the context of her abilities. Many of the earlier costs were assumed by the local school system and her parents. The costs increased as she assumed a more independent but supported life, although she earns an income and has medical coverage through her employer.

## ***Miguel's Story***

### **General Description**

Miguel is 27 years old and a resident of Colorado. He sustained a spinal cord injury at the level of T-4 (fourth thoracic vertebrae) in a car accident one year ago. He is wheelchair bound and is in his first year of rehabilitation.

Miguel came to the United States from Central America when he was 12 years old and lived with his parents and two sisters in Arizona. Miguel speaks English and graduated from high school but has poor reading and math skills. Since high school, he has worked in the food industry as a dishwasher and short-order cook. He moved to Colorado three years ago with two friends to work at a ski resort in the kitchen as a cook. The pay was better and the resort offered low-rent housing to the staff. One night, after work, he was in a single-car accident. He hit a patch of ice and went off the road and hit a number of trees. He was thrown from the car and broke his back.

Miguel has had two surgeries on his back. The first was to stabilize the dislocation of his spine with a spinal fusion. Six months later, he had a rod placement to further stabilize his back. He was in rehabilitation after the first surgery. Since the second surgery, he has received his rehabilitation in a nursing home, where he receives both physical therapy and occupational therapy. He is hoping to be discharged to an apartment that is handicap-accessible with the support of a personal assistant.

His parents and sisters from Arizona have visited him three times since his accident and would like Miguel to move back home so they can be more involved in his life. His friends from work visited him at first, but now, a year later, they rarely come by.

### **Diagnosis and Level of Functioning**

Spinal cord injury (SCI) occurs when a traumatic event results in damage to cells within the cord or severs the nerve tracts that relay signals up and down the spinal cord. The most common types of SCI include contusion (bruising of the spinal cord) and compression (pressure on the spinal cord). Severe SCI often causes loss of control over voluntary movement and muscles of the body

and loss of sensation and function below the point of injury, including loss of bowel and bladder control and sexual dysfunction.<sup>620</sup>

There are 11,000 new cases of SCI each year, and 247,000 Americans are living with SCI. The most common cause is motor vehicle accidents and the second most common cause is violence, such as a gunshot wound. Most SCIs occur in men between the ages of 16 and 30. Thirty-four percent of SCIs result in incomplete or quadriplegia (paralysis of all four limbs) and 25.1 percent result in complete paraplegia (lower limb paralysis).<sup>621</sup>

Miguel has a spinal cord injury at the T-4 level. He has paraplegia (loss of muscle control and sensation in his legs). He also has some paralysis of his trunk, which means he has difficulty sitting. His injury did not affect his diaphragm and he has no breathing problems.

For his ADLs, Miguel has full use of his arms and hands. He can feed himself and participate in his hygiene and dressing. With rehabilitation and appropriate aids, he will be able to swing his lower trunk and transfer into a wheelchair. With rehabilitation, his ability to balance while sitting and leaning forward, backwards, and sideways is improving. Miguel needs significant assistance in the beginning of the day with hygiene, dressing, and getting in the wheelchair and again with settling for night.

For IADLs, Miguel still needs assistance. The language barrier, especially the written word, is difficult. He does not always understand medical language, consent forms, and instructions. Transportation resources are limited, so his ability to go out of the nursing home is limited. He is able to manage his money.

Miguel is very angry. He is angry about the accident and his injury and has not accepted his disability. His isolation and language issues frustrate him and he feels useless. His psychological state is impeding his rehabilitation and he is receiving counseling from a social worker.

### **Present Services and Costs**

Miguel is presently living in a nursing home that provides rehabilitation, including physical therapy, occupational therapy, and social work. The social worker has helped him get SSI

through the Social Security Administration and Medicaid, through the State of Colorado. Miguel now has an income and medical coverage. In the nursing home, Medicaid pays all medical expenses and the SSI is paying for housing and food.

Miguel will have access to services for adults with disabilities through Colorado's Office of Adult, Disability and Rehabilitation Services (ADRS). ADRS's mission is to ensure the safety of Colorado's adults and individuals with disabilities, and their rehabilitation needs. This office promotes personal choice, independence, and improved quality of life. The program goals of this office are to help clients develop and exercise their individual competencies and talents, and to achieve the highest possible levels of rehabilitation, employment, community participation, and independence.<sup>622</sup>

Miguel would like to have his own apartment that is accessible. With a personal assistant in the morning and evening, Miguel could probably live independently. However, in Colorado, there is a waiting list for housing. More than 1,200 families remain on the Supportive Housing and Homeless Programs waiting list for rental assistance.<sup>623</sup> Miguel is on that waiting list.

There is also a shortage of direct care staff, nationally and in Colorado. Miguel cannot go into an apartment without a personal assistant for ADLs. High turnover and low wages have resulted in personal care boarding homes, assisted living, and nursing homes reaching a crisis state for the industry.<sup>624</sup>

The nursing home social worker has also referred Miguel to the vocational rehabilitation program in Colorado, The Division on Vocational Rehabilitation provides job coaching, adjustment training, and on-the-job training to offer one of the best opportunities for individuals with the most significant disabilities to secure and maintain gainful employment in integrated work settings in the community.<sup>625</sup> Eligibility determination is usually completed within 49 days.

Colorado is experiencing the largest shortfall in revenue in over 60 years. Colorado suffered an \$869 million dollar shortfall in State FY 2002–03. A \$900 million dollar shortfall is anticipated for state FY 2003–04. This will result in deeper and more significant program reductions at the state level. Little assistance from the Federal Government can be expected because recent federal

funding is flat.<sup>626</sup> The recovery from Colorado’s last major recession, over two decades ago, took 42 months. The recovery from the current recession is projected to be slower and more uncertain.<sup>627</sup> This current fiscal situation in Colorado will result in increasing waiting lists for services and delays in new services, such as expansion of the Independent Living Centers.

**Annual Costs**

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<b>Nursing Home</b>	<b>\$42,000 (1999 dollars)<sup>628</sup></b>
<b>Health Care and Income</b>	<b>\$25,394 (2004 dollars)<sup>629</sup></b>
<b>Social Security Disability Insurance</b>	<b>\$10,404 (2004 dollars)<sup>630</sup></b>
<b>Estimated Annual Medicaid</b>	<b>\$21,457 (2000 dollars)<sup>631</sup></b>

It is noted that the first year of costs, including health care and living expenses for a person with a spinal cord injury and paraplegia, is \$249,549 in 2004 dollars.<sup>632</sup>

**Future Services and Costs**

In 2030, Miguel is 53 years old and living in a board and care home. Also called an adult care home or group home, this home offers housing and personal care services to between 3 and 16 residents who are assigned to a bed. Group home services such as meals, supervision, and transportation are usually provided.<sup>633</sup> Miguel has a personal assistant for his ADLs when one is available. When one is not available, he pays someone at the board and care home under the table for help. Miguel is capable of assisting with his hygiene and toileting. He can prepare meals, go shopping, and manage his own money. He can transfer from bed to wheelchair and back to bed. He has a motorized wheelchair paid for by Medicaid after he developed chronic shoulder problems from his manual wheelchair. With the motorized wheelchair, he is able to travel where he needs to go in his neighborhood.

Miguel did start vocational rehabilitation but was frustrated by the language barrier and inadequate transportation services. His vocational rehabilitation counselor was concerned about his mental health. They had difficulty finding a Spanish-speaking counselor and Miguel was not open to talking about his disability or his anger. He dropped out of the program because he was

frustrated. He has maintained an income through SSDI and SSI and medical insurance through Medicare and Medicaid.

He remains very frustrated by his disability, social isolation, and language barrier. He drinks alcohol daily and is at times belligerent. He has been evicted from other housing situations in the past, and a number of personal assistants refuse to care for him. None of his old friends are in touch with him. His family still calls him and encourages him to come to Arizona, but he is afraid of losing his benefits. His social life is based on the people in his board and care home and the local bars. He has no steady relationships. Because of his drinking, he is on a waiting list for vocational rehabilitation and is not welcomed in an independent living center. Miguel has no case manager or coordination of care.

His health has been affected by his alcohol abuse, mental health issues, chronic urinary tract infections, and pressure sores. The latter two conditions are related to his paraplegia and place him at risk for septicemia, which is an infection of the blood system and can be fatal. He receives his care at an outpatient clinic and the local emergency room. At times he is admitted to the hospital or has home care services for his infections and falls. He does not have a regular doctor and his care is based on each individual incident of infection or fall. He does not have coordinated care, nor does he have any preventive care or screenings. Most of the time, he either does not understand the physician's instructions or he does not follow them. Medicaid covers his occasional prescriptions. He is not receiving any treatment for his alcohol abuse or his mental health issues.

## Annual Costs

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<b>Social Security Disability Income</b>	<b>\$10,404 (2004 dollars)<sup>634</sup></b>
<b>Medicare and Medicaid</b>	<b>\$16,854 (1995 dollars)<sup>635</sup></b>
<b>HCBS Waiver (Board and Care Home)</b>	<b>\$29,120 (1997 dollars)<sup>636</sup></b>
<b>Personal Assistance Services (3 hours per day)</b>	<b>\$19,656 (2003 dollars)<sup>637</sup></b>

### Case Summary

Miguel's story represents a number of themes, including a language barrier, complications added by substance abuse, lack of a family support system, lack of portability of services from one state to another, and lack of state funding for services. A SCI is a sudden-onset disability, and a negative, angry response is not unusual. An unhealthy response to disability, such as substance abuse, is also not unusual. The entire situation is compounded by the language barrier and social isolation. Miguel is at high risk. Because of a recession and budgetary restraints, state services are not coordinated or even available. There are long waiting lists. His health care is not coordinated. Miguel has and will continue to fall between the cracks. He will not reach his potential for rehabilitation and independence. Without addressing his anger, depression, and alcohol abuse, it is hard to say whether his rehabilitation will ever be consumer directed.

### *Howard's Story*

#### General Description

Howard is a 72-year-old man living in Redondo Beach, a suburb of Los Angeles, California. Howard lives with his wife, Sophie, who is 68 years old. They have three children, ages 48, 45, and 39, and eight grandchildren. Howard retired five years ago from a small aerospace firm located in Los Angeles, where he worked as a design engineer technician. Sophie also retired five years ago from where she worked part time in a physician's office as a registered nurse. Howard and Sophie live together in a two-bedroom modest condominium three blocks from the Pacific shore. They like to walk every morning along the beach, and twice a week they volunteer at the local high school for literacy program.

Howard and Sophie drive one weekend a month to visit with each one of their children and grandchildren, going to San Diego, Berkeley, and Pasadena. They have a circle of friends their own age who visit together frequently, occasionally meeting for lunch at a local cafe. Howard and Sophie enjoy attending their local community symphony concerts.

Howard and Sophie have been relatively healthy. Howard has some difficulty walking due to a leg injury from an auto accident 25 years ago. However, he is able to walk unassisted. Howard has mild hypertension, which is being treated with an antihypertension medication he takes once per day. Sophie is a breast cancer survivor, and has been disease free for the past eight years. Howard and Sophie have Medicare as their primary insurance.

During the past six months Sophie noticed that Howard was being forgetful, with such things as having read the morning paper, and he increasingly did not recall time spent at the high school literacy program. Recently, Howard was walking with his three-year-old grandson during a visit to San Diego and was unable to remember his way back to his daughter's home one block away. Howard went to his physician and after evaluation was diagnosed with early Alzheimer's disease.

### **Diagnosis and Level of Functioning**

Alzheimer's disease is a disorder of the brain's nerve cells that slowly impairs memory, thinking and behavior, and is eventually fatal.<sup>638</sup> The three stages of Alzheimer's disease follow:

- Mild. A person starts to lose short-term memory. He or she may forget names of friends, appointments, or new information.
- Moderate. The person needs more help with ADLs. Agitation, confusion, and anger are common.
- Severe. The person can no longer make decisions, has difficulty speaking, or may not recognize loved ones.<sup>639</sup>

### **Disease Impact**

- An estimated 4.5 million Americans have Alzheimer's disease. The number of Americans with Alzheimer's has more than doubled since 1980.

- In 2050, the number of individuals with Alzheimer's could range from 11.3 to 16 million.
- Increasing age is the greatest risk factor for Alzheimer's. The disease affects 1 in 10 individuals over 65 and nearly half of those over 85.
- A person with Alzheimer's will live an average of 8 years to as many as 20 years from the time of symptom onset. From the time of diagnosis, people with Alzheimer's survive about half as long as those of similar age without the disease.
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are estimated at \$100 billion.
- Alzheimer's disease costs American business \$61 billion a year—\$24.6 billion covers Alzheimer's health care and \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism, and worker replacement.
- Seven out of 10 people with Alzheimer's disease live at home, where family and friends provide their care. Additional paid care average \$12,500 per year. Families pay almost all of this out of pocket.
- Half of all nursing home residents have Alzheimer's disease.
- The average cost for nursing home care is \$24,000 per year but can exceed \$70,000 per year depending on the state or area of the United States.
- The average lifetime cost of care for an individual with Alzheimer's is \$174,000.
- By 2010, Medicare costs for beneficiaries with Alzheimer's are expected to increase 54.4 percent, from \$31.9 billion in 2000 to \$49.3 billion. Medicaid expenditures on residential dementia care will increase 80 percent, from \$18.2 billion to \$33 billion in 2010.<sup>640</sup>
- On average, a worker who takes care of an older sick relative, such as a person with Alzheimer's disease, loses \$659,139 in lost wages, pension benefits, and Social Security income.<sup>641</sup>

## **Services and Costs**

Howard and Sophie attended a local Alzheimer's support group at the recommendation of the nurse practitioner in their physician's office. The support group provided them with information on community resources and a support network of Alzheimer caregivers.

Two years after the diagnosis, Howard was able to remain physically independent. He remained engaged in all his social relationships; however, his memory loss was increasing at a slow but noticeable rate. Howard and Sophie continued to do the activities they enjoyed together. There were increasing times that Howard would become very frustrated and angry at his memory loss. Howard and Sophie discussed Howard's illness with their children and developed a living will outlining Howard's wishes for medical treatment should he become incapable of expressing his wishes.

Three years after the diagnosis, Sophie had to accompany Howard whenever he went outside their home. Howard could no longer drive. He required some help with bathing and dressing, and required the use of a cane when walking. Sophie and Howard visited less with their friends and no longer traveled to see their children. Howard and Sophie stopped their volunteer work. Friends and family were supportive and would visit Sophie and Howard in their home.

Four years after the diagnosis Howard was able to carry on short simple conversations, but his short-term memory was severely impaired. Sophie had to dress and bathe Howard. Howard was incontinent during the night and required toileting reminders during the day. Sophie became dependent upon friends to stay with Howard so she could go the store and the bank and complete errands. Howard had one hospitalization after a fall in the shower. His hospital stay was only two days for evaluation of a possible head injury, at a cost of \$3,500. Medicare reimbursement for rehabilitation to the subacute facility was not possible after his hospitalization because Howard did not have a three-day qualifying hospital stay. The hospital case manager arranged for home physical therapy to evaluate Howard and Sophie's home for safety and assistive devices to aid Howard's mobility. Sophie was concerned about being able to manage Howard alone: getting him out of bed, and in and out of a chair. The Home Health Agency providing the physical therapy did evaluate Howard for home health services and found that while Howard was in need

of physical care, his needs were not at a skilled level of nursing care. Therefore, help was not covered under Medicare. The cost of two weeks (6 one-hour visits) of home health services was \$2,500. Sophie and her children met together to evaluate the medical resources available to them and to plan for Howard's increasing physical dependence and mental deterioration. The concern of the children at this time was Sophie, who was becoming more isolated and no longer able to provide the total physical care Howard required.

Howard met the eligibility requirements for the California Medicaid Waiver Program. The program is for adults who require nursing facility care but wish to remain at home.<sup>642</sup> Services provided in the home include nursing, case management, therapies, and home aide assistance. A Medicaid waiver allows the state to waive portions of the Social Security Act referring to Medicaid and implement services that otherwise may not be covered under Medicaid, may be more cost-effective, or may enable a senior to remain in the least restrictive environment (i.e., the home).<sup>643</sup> Howard remained in the Medicaid Waiver program for one year at a cost of \$14,760. Medicaid Waiver Services provided an aide to bathe Howard and help him into a chair three times per week. A home health nurse visited once per month to evaluate Howard and his care plan. Howard died at home at age 77; Sophie was 73. During Howard's last six months of life, his youngest son, who is single and employed full time, took a six-month unpaid leave from work to stay with Sophie and Howard. The son provided total care for Howard and helped Sophie, who became increasingly exhausted and unable to provide for all of Howard's needs. Howard and Sophie's other two children provided financial support for the son who took a leave from his job.

### **Case Summary**

Alzheimer's disease as depicted in this case is typical of the disease course and impact. Howard's family, namely his wife, was responsible for the majority of his increasing physical needs.<sup>644</sup> Alzheimer's disease, as this case represents, is one that results in caregivers' isolation and causes a long-term burden on a caregiver's emotional, physical, and financial resources. As in this case, the LTC needs of those with Alzheimer's disease are not medically acute or reimbursable under the benefit structure that currently exists.

## *Elise's Story*

### **General Description**

Elise is a 56-year-old African-American woman living in a rural Mississippi community. Elise is a widow, has a high school education, and lives alone. She has two adult daughters; one who lives in New York City and one daughter who is an officer in the Army, currently on active duty and stationed in Germany. Elise works part time (20 hours per week) at a local hardware and feed store as a checkout clerk. Additionally, she works at home babysitting a neighbor's two toddlers three mornings a week. Elise is active in her church and sings in the choir every Sunday morning. Although they are distant in geography, Elise is close to her two daughters. They speak to each other every week by telephone. Elise has several woman friends with whom she socializes on a regular basis. Social activities include church events and a sewing group. Elise does not have a car. She walks to work and church, which are both one block from her apartment.

Elise's annual income from working is \$10,400, plus a pension from her deceased husband, which provides her an additional \$875 per month. Her total annual income is \$20,900. Elise has no health insurance.

Elise has smoked half a pack of cigarettes per day for the past 41 years. She is sedentary in her lifestyle, and is overweight by 65 pounds. Elise was diagnosed with diabetes five years ago and is insulin dependent. She has been hospitalized twice for high blood sugar and has recently had difficulty walking due to an open wound on her left foot. She self-administers insulin. She has a glucose monitor; however, she cannot afford the test strips to measure her blood glucose levels three times per day.

### **Diagnosis and Level of Functioning**

Diabetes is a disease that affects the body's ability to produce and use insulin. Insulin is a hormone made in the pancreas. Insulin is used to get glucose (sugar) from the food eaten into the cells of our body to be used as a source of energy. With diabetes, the body either doesn't make enough insulin or can't use the insulin it produces very well. Glucose then builds up in the blood.

Type 1 Diabetes usually appears in children and young adults, while Type 2 Diabetes usually appears after age 40; however, children who are overweight are at high risk for developing Type 2 Diabetes. Another type of diabetes, Gestational Diabetes, appears during pregnancy. Women who develop gestational diabetes are at greater risk for developing Type 2 Diabetes later in life. In 2000, Mississippi ranked second in the United States in overall prevalence of diabetes, after Puerto Rico.

The Mississippi State Health Department estimates that 9.3 percent of Mississippi's adult population had diabetes in 2001. That's an increase from 7.6 percent in 2000. In 2001, nearly 190,000 individuals age 18 and over reported that they had been diagnosed with diabetes, and estimates are that another 95,000 have not yet been diagnosed. In total, it is estimated that more than a quarter million (285,000) Mississippians had diabetes in 2001. About 750,000 Mississippians are at increased risk of undiagnosed (Type 2) diabetes because of the risk factors of age, obesity, and sedentary lifestyle (lack of exercise).<sup>645</sup>

Diabetes is the seventh cause of death by disease in the United States, affecting an estimated 16 million people nationwide. It is the leading cause of heart disease, kidney disease, adult onset blindness, amputations, and stroke. In Mississippi, according to the Center for Disease Control (CDC), approximately 285,000 people have diabetes. Of those, 90,000 are unaware that they have it. Most people who are undiagnosed have no symptoms.

### **Diabetes Prevalence**

Nationally, 2.3 million (10.8 percent) of African Americans have diabetes; however, one-third of those affected do not know it. In Mississippi, figures for 1996 showed that 56,253 African Americans were diagnosed with diabetes, and a like number of cases went undetected.

- One in four African Americans between the ages of 65 and 74 has diabetes.
- African Americans are 1.7 times more likely to develop diabetes than are white Americans.
- The number of African Americans diagnosed with diabetes tripled between 1963 and 1993.

- One in four African-American women and one out of five African-American men over 50 has diabetes.
- African-American women are at a higher risk for developing gestational diabetes during pregnancy than white women.
- Diabetes is the fifth leading cause of death for African Americans between the ages of 45 and 64, and the third leading cause of death for those 65 and older.<sup>646</sup>

### **Diabetes Complications**

African Americans experience higher rates of at least three of the serious complications of diabetes: blindness, amputation, and end-stage renal disease (kidney failure).

Diabetic retinopathy is a term used for all anomalies of the small blood vessels of the retina caused by diabetes, such as weakening of blood vessel walls or leakage from blood vessels. African Americans are twice as likely to suffer from diabetes-related blindness.

Diabetes is the most frequent cause of nontraumatic lower-limb amputations. The risk of a leg amputation is 15 to 40 times greater for a person with diabetes. Each year 56,000 people lose their foot or leg to diabetes. African Americans are 1.5 to 2.5 times more likely to suffer from lower-limb amputations; 10 to 21 percent of all people with diabetes develop kidney disease. In 1995, 27,900 people initiated treatment for end-stage renal disease (kidney failure) because of diabetes. African Americans with diabetes are 2.6 to 5.6 times more likely to suffer from kidney disease, with more than 4,000 cases of end-stage renal disease each year.<sup>647</sup>

The per capita medical expenditures totaled \$13,243 for people with diabetes and \$2,560 for people without diabetes in 2002. The projected increase in the numbers of people with diabetes suggests that the annual cost in 2002 dollars could rise to an estimated \$156 billion in 2010 and to \$192 billion by 2020.<sup>648</sup>

### **Future Services and Costs**

Elise does not qualify for Mississippi Medicaid because her income is greater than \$826 per month in 2003 and she has not been determined medically eligible.<sup>649</sup>

In 2005, Elise will have two hospitalizations due to uncontrolled diabetes. The second hospitalization will be for surgery on the infected open wound on her foot. After the surgery, Elise will not be able work her part-time job at the hardware store. She will start the application process for SSI and SSDI.

In 2006, Elise will qualify for Mississippi Medicaid, and receive an annual medical benefit of \$2,969.<sup>650</sup> She will also be eligible to apply for both SSI and SSDI through the Social Security Administration, because she is no longer able to work due to her diabetes. This year, Elise had four more episodes of acute uncontrolled diabetes. She has not been able to return to her part-time job. She is at high risk of a below-the-knee amputation caused by the early stages of necrosis in her lower left leg. The medical expenses for Elise in 2006 are \$20,500.

Late in 2006, Elise will have a below-the-knee amputation and experience a postoperative heart attack. She will be admitted to a nursing home posthospitalization and will undergo a slow recovery and rehabilitation. The expense of the surgery and nursing home care will be \$38,000.

By the end of 2006, Elise will no longer be able to participate in her social activities or maintain her home without assistance. She will become depressed and withdrawn, and will not follow her prescribed diet, exercise, or insulin regime.

Elise is admitted to a nursing home after a lengthy hospitalization and development of a larger right leg ulcer, which is failing to heal. Elise spends the next two years in a nursing home (\$16,010 per year) under a Medicaid benefit.<sup>651</sup> If she had SSDI, Medicare would also provide medical support to the nursing home. In addition to the nursing home stay, Elise has four acute hospital admissions. She undergoes a right below-knee amputation and experiences a second heart attack due to severe vascular disease caused by the uncontrolled diabetes and smoking history. Elise continues to live in the nursing home. In 2009, she signs advanced directives defining her wishes for no further treatment to prolong her life.

Elise has six hospitalizations in 2009 at a cost of \$72,000. Each subsequent hospitalization is due to vascular insufficiency, heart failure, and renal failure caused by uncontrolled diabetes. Elise refuses dialysis for the acute renal failure. She expires in January 2010 in the nursing home. The

cause of death is acute renal failure. The total medical expenses for Elise's care from 2005 to 2010 was more than \$202,000.

### **Case Summary**

Diabetes is a disease characterized by a lack of control of blood sugar. Although inadequate control of blood sugar levels can cause acute clinical problems and require hospitalization, in general, the most common health consequences of diabetes are chronic rather than acute.<sup>652</sup>

Elise's case exemplifies the chronic characteristics of diabetes: poor healing of a lower leg wound leading to amputation, compromised cardiac function, and an increasingly impaired renal function. Her disease was difficult to control because of her excess weight, smoking, and inability to monitor her blood sugar. Progression of disease eventually affected Elise's ADLs and IADLs, making her totally dependent on others for her care.

### ***Case Studies Summary***

These six case studies move the discussion from the abstraction of numbers and dollars to real people and their families in a struggle to find a coordinated, comprehensive response to their LTSS needs. Despite the diversity of challenges associated with varying types of disability and multiple secondary conditions, the underlying human element is the desire to live independently and with dignity.

The examples of real-life struggles today and projected changes 25 years later in 2030 help capture both the complexity and significance of designing an LTSS system sooner rather than later. Several key findings can be offered from an analysis of the six life stories of individuals with chronic, intellectual, physical, and mental disabilities.

The current system of responses to individual needs is dependent on state-specific differences in coverage and resource allocation. Families and friends are a critical component of an informal caregiving system that is eroding as America ages. Without federal intervention and financial assistance, no state can begin to cope with the growing demand for HCBS. Current state and federal budget deficits and funding priorities jeopardize a patchwork system of services and

supports that do not meet the current needs of the target population, let alone those projected into the future.

### ***Summary of Findings***

LTSS cannot be looked at in isolation from other health care needs, including acute care and mental health service needs. The range of needs across age and type of disability highlight the importance of service coordination, access to information, and need for support of the family as well as the individual with disabilities. Current costs are not a customized response to individual needs. Costs reflect matching an individual's circumstances to available services and supports, based on federal eligibility criteria, with degrees of consumer choice and direction varied based on the state in which the individual lives. Medicaid, Medicare, and Social Security dominate the cost profiles and projections, with the quality of services and support most evident with active family intervention. The projected costs are dependent on, at a minimum, no loss of entitlements as we know them today. The evolution of a consumer-responsive comprehensive system demands additional analysis of the costs of raising and supporting, at home and in the community, individuals across a spectrum of functional need from birth through the aging process. Supporting families in their unpaid caregiving will help keep public costs lower. However, the balancing of public and private responsibility for caregiving must be confronted directly by policymakers through incentives, respite options, flexibility, and portability of services and skills training.

## **Part VII**

### **Moving Toward Reform**

#### ***Defining who needs LTSS.***

The development of public policy for LTSS requires finding a common ground for defining eligibility. There is not yet a common agreement among the critical stakeholders as to who needs LTSS. Most data and definitions are based on individuals age 65 and older. The definitions range for the target population from a medical diagnostic approach to a functional assessment. It is impossible for policymakers and researchers to accurately calculate current and future costs without a clear consensus as to who should be covered by an LTSS system.

#### ***Growth in population over age 65 needing LTSS.***

Regardless of the definition of the target population, there is clear and undisputable data that the number of people over age 65 with ADLs and IADLs is growing and will double by 2030. Twenty percent of people age 65 and over will require assistance with at least one ADL, and 50 percent will require such assistance by age 85. People in need of assistance with two ADLs will grow from 1.8 million to 3.8 million by 2045.

#### ***Declining disability prevalence for individuals age 65 and older and rising disability rates for those 65 and under.***

The research concludes that disability has declined in the 65-and-older population using ADLs and IADLs as measurement. It is less clear whether this decline is due to health improvements or environmental changes aided by increased use of durable medical equipment, including assistive technology. The prevalence of disability in those 65 and younger is rising using the chronic condition definition of disability. The increased longevity of people with lifelong disabilities and its impact on the need and future costs for LTSS are unclear from the current literature.

***Changes in disability prevalence across the age span and their impact on future LTSS costs are unclear.***

There are 38 million people under age 65 reporting some level of disability; of this group, 25 million have a specific chronic disability. Depending on the definition used, the estimated population in need of LTSS under age 65 ranges from a conservative figure of 3.5 million to more than 10 million.

As the prevalence of disability and use of LTSS increases in the under-age-65 population, it is unclear from the research what effect this growth will have on the future costs and services of the LTSS system. It is less clear how many individuals under the age of 65 are in need of assistance with ADLs and IADLs when different definitions of disability are used. There is no aggregated data on the overall costs of LTSS using the NCD/AARP definition, which includes transportation, nutrition, and housing. It is less clear what services and supports truly look like for individuals under age 65, across disabilities and specific age groups, for those working and living independently. The research shows that individuals under age 65 are heterogeneous and have specific needs according to gender, age, and type of disability.

***Disparities in LTSS needs among minority populations and impact on future LTSS costs.***

A further challenge was found in understanding the correlation between the disparities in LTSS needs among minority populations and the impact on future utilization and costs for LTSS. Black children were reported to be 13 percent more likely than white children to have a reported activity limitation. A recent GAO study confirmed that the black population has higher disability rates and lower lifetime earnings and shorter life expectancies than whites. The issues of poverty, lack of insurance, and continued segregation from affordable and consistent health care will increase the future needs and costs for LTSS for a population that is projected to make up 50 percent of the American population by 2050.

Individuals with two or more ADL limitations and personal assistance needs under the age of 65 estimated a shortfall of 16.6 hours of help and were more likely to be nonwhite females and to live alone. People who live alone are 10 times more likely to go hungry, 20 times more likely to miss a meal, and 5 times as likely to lose weight. Paid assistance for personal assistance services (PAS) goes primarily to people 65 and older, and working-age people 65 and under rely more on unpaid PAS.

### ***Growing prevalence of mental illness and impact on future LTSS costs.***

The prevalence of chronic disease and deaths caused by noncommunicable disease in the United States will increase from 28.1 million to 49.7 million between 1990 and 2020, an increase of 77 percent. Mental illness will rank number two after heart disease and will replace cancer by 2010 as having a greater impact on death and disability. Medicaid is the principal public payer for mental health services and represents (36%) of the \$48 billion in spending. It is unclear what the future LTSS needs and costs will be for this population.

### ***Uncertainty of future utilization and costs for LTSS.***

Future utilization and costs for LTSS are highly uncertain because of the rising cost of health care, fiscal challenges of federal and state governments, increased longevity of high-cost disability populations, increased prevalence of chronic conditions, and the changing philosophy regarding where and how LTSS are delivered.

There are 57 million working-age Americans (18–64) with chronic conditions such as diabetes, asthma, and depression; more than one in five (12.3 million) live in families that have a problem paying medical bills. The number of chronically ill people with private insurance who spend more than 5 percent of their income on out-of-pocket health care costs increased from 28 percent in 2000 to 42 percent in 2003, a 50 percent increase to 2.2 million people. Less than 55 percent of people with chronic conditions receive scientifically indicated care, and the “defect rate” in the quality of American health care is approximately 45 percent.

The impacts on LTSS costs for 6.6 million individuals with chronic care needs who are uninsured and go without needed care (42%), delay care (65%), or fail to get needed prescriptions (71%) are unclear, but without timely intervention they will affect future need and costs.

Eligibility and service pathways to state Medicaid programs have expanded to meet the growing needs of their uninsured and LTSS beneficiaries and reflect the growing challenges of economic downturns, increased health premiums, increased longevity, a low savings rate, and slower wage growth. The ability of states to respond to current and future LTSS needs is beyond their capacity and resources.

***Medicaid has added many new eligibility pathways and programs over its 40-year history and extends benefits to many middle-income Americans who are aging and faced with catastrophic LTSS costs.***

Two-thirds of Medicaid spending is for population groups and services technically defined as optional; these services account for 90 percent of all LTC Medicaid services. Optional services are currently undergoing cuts across the country as states struggle with unsustainable growth in costs and caseloads. It is unclear how vulnerable people with disabilities are, with the majority of their services and funding falling into optional categories.

Seventy-five percent of HCBS waivers are for people with MR/DD and are used to purchase LTSS. The other 25 percent are used for people with physical disabilities and older people. Three small waiver programs serve individuals with a primary diagnosis of mental illness, accounting for 0.2 percent of HCBS waiver expenditures. Further research is needed to explore the LTSS needs of the other 25 percent using HCBS.

Medicaid spending for acute care and LTC for the blind/disabled category was \$91,889 billion; \$51,733 billion for the aged category; and \$59,022 billion for children, adults, and foster care children.

All Medicaid beneficiaries, when broken into the following three categories, demonstrate a high vulnerability to rising health care costs and dependence on family members for health coverage and LTSS:

- Almost 70 percent of the Medicaid caseload (18.8 million) are children; the rest are adults who rely solely on Medicaid for both Medicaid and SCHIP for an entire year.
- About 12.3 million used both Medicaid and SCHIP for part of the year and were uninsured for two-thirds of the months they spent without Medicaid/SCHIP; job-based health insurance covered nearly all the remaining months over an entire year.
- About 9.7 million never relied solely on Medicaid during the year and had other sources of coverage; less than 23 percent were children, but nearly half (46%) were seniors.

***Most uninsured Americans are working and many are LTSS paraprofessionals.***

Forty-nine percent of uninsured Americans are either self-employed or work for companies with fewer than 25 employees or fewer than 10 employees, of which only 52 percent offer insurance. Over 50 percent of low-income employees of small firms with incomes below 200 percent of the federal poverty level are uninsured. Over 2 million health care paraprofessionals do not work full time, do not receive benefits, and report wages below the poverty line.

Private LTSS insurance is targeted to individuals age 65 and older and highly targeted to specific diseases such as Alzheimer's. More than 6 million Americans own LTSS insurance, and 50 percent of the claims paid are for Alzheimer's and other forms of dementia.

The risk of disability during a worker's career is significant, as are the consequences to the individual's and the family's financial security. The risk of disability is higher than premature death and is higher for older people than younger people; females are more likely to become disabled than males. A 45-year-old earning \$50,000 per year and suffering a permanent disability could lose \$1,000,000 in future earnings. The public underestimates the help that is available from public disability insurance programs (SSDI and other state-mandated, short-term

programs). Workers compensation benefits cover only disabilities caused by injury or illness arising on the job—only an estimated 4 percent of disabilities.

***Lack of data on current and future costs for the under- and over-65 populations with disabilities raises new questions for researchers and policymakers.***

The documented growing demand for LTSS in the home and community raises new questions for researchers and policymakers about current costs and projected future costs for the under- and over-65 populations with disabilities. The cost conundrum is exacerbated by four important factors.

First, there is insufficient data on LTSS costs for individuals under age 65 across the spectrum of disabilities. Second, there is insufficient data on the costs of responding to a decreasing population of informal caregivers and the development of an approximately trained and paid workforce. Third, there is a lack of agreement on the role and responsibility of the government versus individuals and families to cover the costs of current and future LTSS needs. Without research to explore different public and private cost-sharing scenarios that focus on the under-age-65 population with disabilities, it would be difficult to explore the relationship of public financing and private insurance.

***Disability insurance is the missing piece in the financial security puzzle for Americans with disabilities.***

The fourth and final factor transcends the specific challenges of development of a responsive LTSS system for the targeted population. The global economic picture and changing demographics, in addition to the current federal budget deficit, raise questions about the political will to maintain current entitlements, let alone craft a new system.

***The issues of identification of current and projected future costs for LTSS are further complicated by the role of formal and informal caregiving, and by workforce shortage and retention issues.***

There are 44.4 million American caregivers age 18 and over who provide unpaid care to an adult age 18 or older. Six out of 10 of these caregivers work while providing care; most are women age 50 years or older. The value of donated care is estimated to be more than \$200 billion, and it is unclear from the literature how the changing demographics will affect the unpaid care industry and whether there will be cost-shifting to paid care as fewer women become available in the future.

It is unclear who is going to meet the growing demand for providing services and supports as the role of the informal caregiver decreases. The workforce shortage is both a supply and demand problem. As the 65-and-over population increases, the 65-and-under working-age population will decrease and there will be a shortage of workers and taxpayers. In addition, there is a shortage of nurses and home care workers for LTSS. Jobs for nurse's aides are expected to grow by 23.8 percent, while the employment of personal care and home health aides may grow as much as 58.1 percent between 1998 and 2008. It is unclear how many workers (the "gray market") are hired and supervised by consumers who pay for their own care, although the numbers are thought to be substantial.

Direct care workers (3.1 million) are in short supply and have nearly a 100 percent turnover rate in nursing facilities; home care agencies have annual turnover rates of 40–60 percent. Direct care workers have low median hourly wages of \$9.20 an hour, and one-fifth (far more than the national average of 12–13 percent) earn incomes below the poverty level; 30–35 percent of all nursing home and home health aides who are single parents receive food stamps. The financial ability for this sector to generate higher wage and benefits is limited by the constraints of third-party payers, such as Medicaid or Medicare, which are and will continue to be pressured to reduce costs under the weight of a growing retirement and disability population.

***Americans with disabilities struggle to find a coordinated, comprehensive response to their LTSS needs despite the diversity of challenges associated with the varying types of disability.***

The current system of response to individual needs is dependent on state-specific differences in coverage and resource allocation. Families and friends are a critical component of an informal caregiving system that is eroding as America ages. Without federal intervention and financial assistance, no state can begin to cope with the growing demand for home and community based-services. Current state and federal budget deficits and funding priorities jeopardize a patchwork system of services and supports that do not meet the current needs of the target population, let alone those projected into the future.

LTSS cannot be looked at in isolation from other health care needs, including acute care and mental health service needs. The range of needs across age and type of disability highlights the importance of service coordination and access to information, and need for support of the family as well as the individual with disabilities. Current costs are not a customized response to individual needs. Costs reflect matching an individual's circumstances to available services and supports, based on federal eligibility criteria, with degrees of consumer choice and direction varying according to the state in which the individual lives. Medicaid, Medicare, and Social Security dominate the cost profiles and projections, with the quality of services and support most evident with active family intervention. The projected costs are dependent on, at a minimum, no loss of entitlements as we know them today.

The evolution of a comprehensive, consumer-responsive system demands additional analysis of the costs of raising and supporting, at home and in the community, individuals across a spectrum of functional need from birth through the aging process. Supporting families in their unpaid caregiving will help keep public costs lower. However, the balancing of public and private responsibility for caregiving must be confronted directly by policymakers through incentives, respite options, and skills training.

***Americans with disabilities need to be represented in the current public policy discussion about the future of LTSS.***

How Americans will decide to solve the current demographic challenges of an aging and growing disability population is unclear. Few proposals have provided a total picture of what LTSS means to people with disabilities from birth till death.

As Americans age there will be fewer workers contributing to the pay-as-you-go resources in Medicare and Social Security to keep even the current system afloat. It is unclear how Americans with lifelong disabilities under age 65 can become self-sufficient and economically independent through work and build careers without substantial LTSS reform that allows asset growth and public support for LTSS. It is unclear how Americans will provide for their own health care and services and supports in the future without substantial savings and insurance against the risk of disability.

***LTSS are not portable across states.***

LTSS are not portable and cannot be moved with an individual from state to state, and current LTSS costs are not a customized response to individual needs. Current costs reflect matching an individual's circumstances to available services and supports, based on federal eligibility criteria, with degrees of consumer choice and direction that vary according to the state in which the individual lives. The fiscal health of each state and its ability to provide the necessary match to draw on federal Medicaid resources determines the scope and array of LTSS for seniors and low-income Americans with disabilities. The personal assistance service needs of an individual in California could be similar to those of someone living in Mississippi and yet the availability of services and funding would vary dramatically.

## **Chapter 3**

### **External Advisors and External Policymakers: Recommendations for Action**



**Table of Contents:  
Chapter 3**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	285
<b>Part II</b>	
<b>Approaches to Development</b> .....	287
<b>Part III</b>	
<b>Expert Panel Discussion and Recommendations</b> .....	321
<b>Part IV</b>	
<b>Conclusion</b> .....	327
<b>Appendix 3.A</b> .....	331



## **Part I**

### **Introduction**

The picture of a ship at sea comes into focus. It struggles in choppy waters to make progress, becoming more aware of the impending storm. State and federal budget deficits, competing budget priorities between homeland and social security, and domestic and global needs make it even more difficult to navigate safe passage. Demographic shifts, science and technology advances, and changing expectations of an aging baby boomer population to maintain and control the quality of independent living produce sporadic thunder but do not yet hold the sustained interest of the ship's crew.

As sudden as lightning streaking through a dark sky, current events attract media and public attention to the complexity of competing portraits of human identity: life with all its freedom defined by intellectual and physical capacity, and disability defined by decline and devalued in some economic terms by limited return on investment. For two weeks, the plight of Terry Schiavo was the focus of national media attention—the front page on newspapers and the lead story on the evening news.

On March 31, 2005, Terry Schiavo died, 13 days after her feeding tube was removed as a national debate continued about the ethics, politics, and spiritual significance of her life and death.<sup>653</sup> Her plight raised new questions for policymakers, the courts, and families nationwide about who makes decisions about when life is worth living and when it is not. President Bush issued a statement lamenting that attempts at congressional intervention were not successful to override the decision of Schiavo's husband: "The essence of civilization is that the strong have a duty to protect the weak."

What has been lost in much of the media attention to the Schiavo case is the shift of the spotlight from decision making about the end of life to the growing numbers of Americans living every day in need of assistance with activities of daily living (ADLs) to be able to achieve an enhanced level of human dignity and independence. A hundred years ago, the end of life was typically more sudden as a result of disease or injuries. With the advances of medical technology, there are

growing numbers of Americans with chronic conditions, below and above 65, whose quality of life will be defined by the level of supports and personal assistance that can be accessed through government financial assistance.

The Schiavo family's conflicts about who should decide to end a life and the attempts at judicial and legislative intervention to substitute public for private decision making should send an urgent message to all of us to revisit public responsibility to individuals with significant disabilities, who are not dead yet! The moral high ground needs to move beyond emotion and ideology to a much-needed evaluation of public responsibility to recognize disability as a natural part of human experience with social and economic implications, to protect the "weak," preserve human dignity, and enhance independent living through access to needed long-term services and supports.

Are policymakers across the political spectrum ready to debate the role and responsibility of federal and state government to protect the right to live with dignity, which recognizes the need to confront the economic terms of meeting such objectives with financial assistance for LTSS?

Terry Schiavo's life and death transfixed the nation. At this writing, one week later, there is no shortage of expert opinions on policy options to consider bringing the ship forward in choppy waters and the impending storm. This chapter offers multiple perspectives of diverse stakeholders who recognize the urgency and importance of confronting these complex challenges sooner rather than later.

The recommendations for action are broken into two parts. The first part offers a summary and analysis of selected approaches to future policy development by leading organizations and think tanks navigating their way through the diverse interests and needs of state government, providers, individuals with disabilities, and families. The second part offers the perspective of an Expert Panel assembled by the National Council on Disabilities to share their personal experiences and expertise on consumer direction, public financing, the workforce, and service delivery options to respond to pressing needs of individuals and families across the diverse spectrum of age, geography, disability, and economic class.

## **Part II**

### **Approaches to Policy Development**

NCD researchers compared and contrasted policy recommendations for improving access, availability, and quality of LTSS for individuals with disabilities that have been produced by six different national organizations:

- National Academy for State Health Policy (NASHP)
- National Governors Association (NGA)
- National Academy of Social Insurance (NASI)
- Congressional Budget Office (CBO)
- Americans Disabled for Attendant Programs Today (ADAPT)
- American Association for Retired Persons (AARP)

Despite varied roles and relationships to advising policymakers at the federal level, the alignment of strategies proposed and the sense of urgency to move forward are more consistent than might be expected. All have a similar starting point. Demand is growing for LTSS that will not be able to be ignored by policymakers and that will require changes in structure and financing to respond to consumer preferences for home and community options. The greatest variance among organization proposals can be distinguished by the degree of fiscal commitment to a guaranteed coverage of a comprehensive benefits package organized around consumer needs and preferences.

#### ***National Academy for State Health Policy***

NASHP is a nonprofit organization dedicated to helping states achieve excellence in health policy and practice. NASHP conducts research on emerging trends and challenges for states to respond to the needs of children and adults for health care and LTSS. Activities include policy analysis, training, and technical assistance to states, and convening regional and national forums to enable diverse stakeholders to share innovative and collaborative strategies related to service delivery, financing, management, and quality issues.

In January 2005, NASHP published a report on improving health and long-term care (LTC) coverage for low-income Americans.<sup>654</sup> The report, “Making Medicaid Work for the 21st Century,” was a year-long effort undertaken by NASHP to develop recommendations that would improve the Medicaid program. A workgroup was convened of state officials and national experts representing a broad range of stakeholder interests. The focus of discussion was on the federal-state relationship in Medicaid and its financing of health care, LTC, and LTSS. Medicaid beneficiaries become entitled to benefits adopted by the state; however, the terms and conditions for a state to receive financial assistance are defined by policies and requirements of the Federal Government. Federal rules define benefits that are mandatory and a menu of others that are optional and defined by the state in terms of scope and population areas covered. The workgroup focused on three core areas for improvement: revising the eligibility process for Medicaid financing of community-based LTSS, incentives to encourage states to offer expanded coverage of community-based services and supports, and restructuring the system to improve beneficiary access to a full-range of at-home or community-based services.

### **Revise Eligibility for Medicaid**

The workgroup agreed to an overarching goal: that Medicaid should “serve eligible populations through policies and enrollment processes that maximize coverage and ease administration.” The workgroup identified several features of current Medicaid eligibility rules that were particularly challenging. There is little consistency across states in how they define and value income and assets when determining whether an applicant meets Medicaid financial eligibility criteria.<sup>655</sup> Existing eligibility rules are more expansive for individuals in an LTC institution rather than in the community.<sup>656</sup> The workgroup recommended that a minimum national income eligibility threshold be established, with states having the flexibility to expand coverage to individuals and families above the eligibility floor. The national minimum eligibility threshold would require states to cover all individuals with household incomes up to 100 percent of the federal poverty level. This new requirement would be phased in over four years, and the Federal Government would offer an enhanced match for new eligibles. Implementation of this recommendation would provide Medicaid coverage to 5.3 million new individuals, including 4 million of the uninsured. When fully implemented, the estimated cost would be \$16.6 billion per year, with an estimated federal share of \$11.2 billion.<sup>657</sup> When fully phased in, state Medicaid spending would increase

by 4.1 percent. The workgroup also recommended that states have the option to eliminate the assets test for all Medicaid populations. States do not currently have the option to eliminate it for Medicaid enrollees whose eligibility is tied to Social Security Income (SSI).

Separate from financial eligibility for Medicaid, the workgroup also recommended that states be allowed to set different functional criteria for institutional and community-based services and supports.<sup>658</sup> Separate standards would allow the provision of community-based supports before an individual's condition deteriorates to the point that institutional care is the only option.

### **Modify the Benefits Package**

The second core area of focus for the workgroup was on the benefits package and correcting the balance between institutional and home- and community-based services and supports. With more than 20 years of experience, and with community supports waiver applications tied to cost neutrality as compared to institutional care, it is time to move to a state plan option. The workgroup recommended that states be allowed to replace 1915(c) waivers with a home- and community-based services (HCBS) program with the following components:

- States would submit a plan to the Centers for Medicare and Medicaid Services (CMS) describing the services to be covered. Once approved, the program would continue without renewal requirements.
- States could set a higher income threshold for admission to an institution and a lower threshold for the HCBS program.
- The program would not be subject to existing waiver requirements (cost neutrality, time-limited approvals, and links to nursing home level of care).
- States would have the discretion to set caps on participation and distinguish service options for subpopulations.<sup>659</sup>

The workgroup recommended that, under the new HCBS programs, states be allowed to choose to provide optional populations (those with incomes above the minimal national eligibility threshold) with more restrictive choices of services and supports.<sup>660</sup> Two other recommendations

from the workgroup would offer the consumer greater ability to manage and direct the delivery of services. States should be encouraged to expand Cash and Counseling Demonstrations that provide beneficiaries with an individual budget to purchase and manage their own service delivery.<sup>661</sup> States should also be encouraged to expand Money Follows the Person beyond transitioning nursing home residents to individual residents of intermediate care facilities for the mentally retarded (ICF/MRs) and for individuals with long-term mental illness<sup>662</sup>

As part of the approach to expanding benefits, the workgroup also proposed two other recommendations to improve beneficiary access. Building on the early results from the Aging and Disability Resource Centers (ADRCs), states would be encouraged to create single entry points to provide Medicaid beneficiaries and applicants with information and assistance in determining eligibility and service needs. A complementary suggestion by the workgroup is that all beneficiaries seeking long-term services should provide a standardized assessment to help determine needs and service options to meet those needs. Assistance would be provided to help access appropriate services and supports.

### **Provide Financial Incentives to States to Rebalance the Program**

The final area for improvements focused on current policies governing Medicaid financing. Medicaid is currently an open-ended entitlement to eligible individuals and states. As an entitlement, the Federal Government must reimburse the state for the federal portion of the cost for every dollar spent on Medicaid-covered services for eligible individuals. States' matching rates vary based on the size of low-income populations. The minimum 50 percent federal matching rate ensures that states will receive a minimum level of federal cost-sharing.

The workgroup recommended the creation of fiscal incentives to encourage and support the rebalancing of their LTSS system to favor home and community. The suggested approach would offer states a temporary, higher match on community-based services, combined with a continuation of Systems Change Grants to support infrastructure development.<sup>663</sup> The enhanced match would be conditional, with a state required to document progress in serving more people in homes and communities, measured as a percentage of the total number of beneficiaries receiving long-term support, or as a decline in Medicaid-paid nursing home bed days.<sup>664</sup>

The workgroup emphasized in its concluding comments that the proposed set of recommendations related to changes in eligibility criteria, the menu of benefits, and financing are interrelated and must be viewed as a whole. Strengths of the NASHP proposal include the creation of a minimum national financial eligibility level for Medicaid, regardless of what state one lives in, to ensure coverage for all Americans with incomes below the federal poverty level; a simplified community services program to replace the waiver; and fiscal incentives to states to relocate their resources away from institutional settings. The reduction of the number of uninsured individuals is estimated at about 4 million, or 10 percent of the total group.<sup>665</sup> Although the increased projected federal and state costs are not insignificant (\$16.6 billion), it is a step forward to reduce variability among states and provide important benefits coverage to a class of individuals with significant need. The replacement of the “waiver” context for HCBS and the conversion to a “program” not tied to institutional cost comparisons, with the added push of fiscal incentives, is a major step forward.

However, the proposed program offers states the flexibility of carving out covered populations and limiting geographic scope as a way of containing costs. The approach does not yet create a true parity between the entitlement to skilled nursing care and home- and community-based LTSS. The recommendations to create financial incentives to states to reallocate their system as part of the design, development, and expansion of home- and community-based LTSS are not accompanied by any projections of cost.

This set of recommendations from NASHP focuses exclusively on improvements to Medicaid. As a result, it does not look at a broader policy framework for expansion of coverage of LTSS across funding options and other existing federal authorities.

The following table summarizes key recommendations from the NASHP report.

**Table 3.1. National Academy for State Health Policy**

Report/Recommendation: “Making Medicaid Work for the 21st Century,” January 2005.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
Focuses only on Medicaid changes	<p>Create a minimum national income eligibility threshold to cover all individuals with household incomes up to 100 percent of the federal policy level.</p> <p>Set different functional criteria for institutional and community-based services and supports.</p>	<p>Eliminate the relationship of cost neutrality between Home- and Community-Based Services (HCBS) waivers and institutional care.</p> <p>Create a new HCBS program as a state Medicaid plan option.</p> <p>States define the benefits coverage regarding long-term services and supports (LTSS) and can set caps to participation.</p>	<p>Create single entry points to provide Medicaid beneficiaries and applicants assistance with determining eligibility based on service needs.</p> <p>States would be encouraged to provide eligible participants an individual budget to purchase and manage their own service delivery.</p> <p>Programs would continue without waiver renewal requirements.</p> <p>States could set a higher income threshold for admission to an institution and a lower threshold for the HCBS program.</p> <p>States allowed to carve out covered populations and limit geographic coverage.</p>	<p>To accelerate rebalancing the LTSS system, states would receive a higher match on a temporary basis for HCBS.</p> <p>States would be required to document progress in serving more people in HCBS and a decline in Medicaid paid nursing home bed days.</p> <p>Continue Systems Change Grants from Centers for Medicare and Medicaid Services (CMS) to help states with building capacity, policy changes, and infrastructure development.</p>	<p>Viable approach to end institutional bias of Medicaid.</p> <p>Fiscal incentives for states to rebalance LTSS system.</p> <p>Create Medicaid state plan option.</p> <p>Encourage use of consumer-directed individual budgets.</p> <p>Create single points of entry to overcome system fragmentation.</p>	<p>Approach is optional, not required for states.</p> <p>States can carve out who is eligible, limit scope of benefits, and waive statewide coverage.</p> <p>Further research is needed on cost of proposal.</p> <p>Does not look outside of Medicaid at other federal authorities.</p>

## ***National Governors Association***

The NGA is the collective voice of the nation's governors. In 2003, NGA Chairman Governor Dirk Kempthorne of Idaho created a task force to identify public policies that can help individuals live independently and with dignity.<sup>666</sup> In his charge to the task force, Kempthorne urged the group to advance best practices in community care. "Overwhelmingly, Americans want to remain in their communities and places they call home."<sup>667</sup> In describing the scope of inquiry, Kempthorne encouraged an examination of effective transportation systems, emerging technologies, and reliable housing options, as well as identification of innovative practices to encourage and assist caregivers.<sup>668</sup> Over the course of the past 15 months, through numerous forums and public policy research, the Lifetime of Health and Dignity Task Force developed multiple recommendations for future policy development. The discussion frequently returned to focus on the Medicaid and Medicare programs, which are the dominant federal means of assistance for our nation's most vulnerable citizens, who would otherwise lack the means to afford the health care and LTSS they need.

At their winter 2003 meeting, the governors adopted a statement of principles to be considered concerning any proposal to reform Medicaid. Included in the statement of principles is a finding that "the Medicaid statute has failed to keep pace with the changing health care system, current medical practices, and the needs of Americans in the 21st Century."<sup>669</sup>

The proposed principles or policy framework adopt a core set of concepts that are reflected in the recommendations reviewed and analyzed from other national-level organizations. There is a need for more flexibility for states in the management of the Medicaid program. Current HCBS waiver authority must be revised to rebalance the current system of supports to favor community versus institutional settings.<sup>670</sup> However, the NGA platform goes farther to address a range of issues of major concern to the governors and states. All three recommendations touch the sensitive issue of cost and allocation of responsibility if changes and improvements are to be made to enable all Americans to live longer with independence and dignity.

- The Medicare and Medicaid programs are interrelated, and any change made to Medicare, whether to strengthen its solvency, address its financing, or for other purposes, should be considered in conjunction with reforms to Medicaid.
- The Federal Government should pay 100 percent of the cost of any new Medicaid mandates imposed under an Act of Congress, federal regulation, or court decision based on federal laws and regulations.
- It is also unacceptable for Medicaid to be the only LTC program in the country. Other sources of coverage, whether federal, employer based, personal, familial, or community based, must be developed.<sup>671</sup>

It is not surprising that the governors are concerned about increased costs and the shifting of responsibility to the states. The last three Administration budget proposals have targeted Medicaid for federal cost reductions that would shift increased responsibility for beneficiaries to states.<sup>672</sup> Total Medicaid spending has increased rapidly in recent years. In the past four years, Medicaid spending has increased by more than 50 percent.<sup>673</sup> Over the past two decades, the average share of state budgets set aside for Medicaid spending increased from 8 percent in 1985 to 22 percent in 2003.<sup>674</sup> In 2005, Medicaid spending will surpass spending for elementary and secondary education as the largest single item in overall state budgets.<sup>675</sup> According to CMS and the Congressional Budget Office, Medicaid spending is expected to continue to grow at a rate exceeding state revenue growth, driven by caseload growth, an aging population in greater need of assistance, and medical advances.<sup>676</sup>

Despite cost concerns, the NGA task force explored additional, diverse options to change the current system of LTSS. A recommended list of “20 Actions Governors Can Take” was developed that divides proposed actions into four major categories: (1) promote community-based care; (2) support family caregivers and home care workers; (3) encourage personal financial planning; and (4) promote health and wellness.<sup>677</sup> All 20 recommendations are based on promising practices in one or more states concerning services for seniors. Several would require federal policy reform. However, many would also benefit individuals with disabilities at a younger age in need of LTSS. The review of 13<sup>678</sup> of the 20 recommendations was selected

because of their relevance to the larger target audience of individuals with disabilities below and above the age of 65.

### **Promote Community-Based Care**

- 1. Promote elder-ready communities to enable individuals to live in their homes and neighborhoods as long as possible.** Based on the livable communities framework,<sup>679</sup> state and local governments can work together to improve availability of affordable housing and transportation, and provide financial assistance with home modifications to enable an individual with the onset of disability to “age in place.”
- 2. Establish fast-track eligibility for HCBS.** Following a hospital stay, individuals are routinely referred to nursing homes instead of being offered community-based services. Hospital discharge planners are often more familiar with nursing home eligibility rules than with options for coverage of in-home or community care. Several states have streamlined the eligibility process for HCBS waivers and established presumptive eligibility for community care that makes services available within 48 hours.
- 3. Improve access to long-term support options by developing Web-based information and assistance systems.** With the complex set of rules and requirements that determine eligibility for services and supports and that are often different for each public funder and from state to state, numerous states are now developing information-rich Web sites to provide consumer-friendly information to determine support options and individual eligibility. Computer-based information systems are complemented by counselor support in local neighborhood centers.
- 4. Establish one-stop shops.** Pioneered in Wisconsin, multiple sites are now piloting ADRCs with financial support from CMS and the Administration on Aging. Assistance is provided to both public- and private-pay individuals to better coordinate information and access to multiple federal, state, and local programs.
- 5. Include consumer direction in all state community-based service programs.** Building on positive evaluations from selected state Cash and Counseling Demonstrations, consumer direction is an essential program design element that allows individuals with disabilities to have maximum choice and control over their support plan, including assessment of needs,

determination of how those needs will be met, selection of providers, and management of costs within an individual budget.

- 6. Coordinate transit funding sources.** Access to reliable transportation services can be strengthened through linking transportation resources to health and social service programs. Improved coordination between state and local governments and public and private service providers can improve availability in urban and rural settings.

### **Support Family Caregivers and Home Care Workers**

- 7. Improve the tax treatment of caregiver expenses.** State caregiver tax credits generally range from \$500 to \$1,500. At least 26 states and the District of Columbia have either refundable or nonrefundable tax credits for dependent care that generally benefit low-income taxpayers.
- 8. Expand Family and Medical Leave Act (FMLA) benefits.** FMLA provides employees of businesses with at least 50 employees with at least 12 weeks of unpaid leave each year to care for a newborn or seriously ill family member, or to recover from their own serious health conditions. To further support family caregivers, the federal FMLA provisions could be expanded to cover employees in workplaces with fewer than 50 employees, allow leave for family medical needs that are not covered by the federal law, extend the periods for family and medical leave, and offer paid leave benefits.
- 9. Inform home care workers about eligibility for federal tax credits.** Tax refunds for a low-income worker with a family can be significant—up to \$4,200 under the provisions of the earned income tax credit (EITC). Volunteer tax preparation assistance is available in most major cities.<sup>680</sup>
- 10. Encourage and assist in developing employer health insurance purchasing pools.** Several states have organized public authorities that serve as employer of record for self-employed home care workers to create a purchasing pool. Between 40 and 45 percent of paraprofessional home care workers lack health coverage. Health coverage options will help attract and retain direct care workers.
- 11. Connect in-home workers to existing supports for taxes, housing, health care, transportation, and other service needs of low-wage workers.** Selected states have created

direct care worker resource centers and have coordinated worker recruitment and links to support services through the workforce development system of One-Stop Career Centers.<sup>681</sup>

- 12. Encourage personal financial planning.** Selected states are offering limited tax credits or deductions to encourage purchase of LTC insurance premiums. Encourage more consistent coverage across states with tax incentives for purchase of policies that benefit other family members.
- 13. Promote the use of reverse mortgages for long-term supports.** Reverse mortgages allow homeowners to stay in their homes while cashing in on the equity they have invested. Funds received in a lump sum, as monthly payment over a fixed period of years, as a lifetime annuity, or as a flexible line of credit are considered tax free and do not count as income toward social security, Medicare, or Medicaid benefits. The full loan amount, including principal and interest, is repaid to the lending institution when the borrower or borrower's spouse sells the home, moves, or dies.

With its statement of principles for Medicaid reform and the breadth of recommendations for the creation of a more comprehensive system of support for individuals with disabilities to live with independence and dignity, NGA has offered possible ways to reexamine the current policy framework. Although there are no cost projections for any of the specific proposals, there are clear concerns about sharing the costs with the states. NGA wants any new federal Medicaid mandate to be 100 percent funded by the Federal Government. There is an understanding that no single federal program or funding authority offers a full solution to increasing long-term services demands and changing consumer preferences. There is an interest in embracing consumer direction and choice, as well as state commitment to continued expansion of the benefits options that support the family and recognize the important role of family caregiving, which reduces public costs. A comprehensive solution will need to improve collaboration among federal, state, and local government and public and private sector interests. The NGA recommendations make it clear that the allocation of costs is at the center of future discussions and debate.

The following table summarizes the NGA recommendations.

**Table 3.2. National Governors Association**

Report/Recommendation: “Lifetime of Health and Dignity Task Force,” 2004.  
 “Policy Resolution HHS-27,” Winter Meeting, 2005.  
 “Twenty Actions Governors Can Take,” 2004.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
Focus on Medicaid and Medicare, but with the recognition that other strategies must be developed, including employer-based, family, and private sector solutions.	<p>Establish fast-track eligibility for home- and community-based services (HCBS).</p> <p>Consider presumptive eligibility for HCBS based on functional assessment of needs.</p> <p>Involve the consumer actively in assessment of needs and determination of an individual service plan to meet those needs.</p>	<p>Does not define the benefits coverage for HCBS.</p> <p>Does promote the elder-ready or livable communities concept and encourages state and local governments to work together to improve availability of affordable housing and transportation, and financial assistance with home modifications.</p>	<p>Establish One-Stop Shops to better coordinate information on eligibility and access to diverse public and private services and supports.</p> <p>Improve information access by developing Web-based information systems.</p> <p>Include consumer direction in all state community-based programs.</p>	<p>Federal Government should pay 100 percent of the cost of any new Medicaid mandates.</p> <p>Any changes to Medicare must address the impact on Medicaid, which shares costs between the Federal Government and the states.</p> <p>Improve tax benefits for dependant care to help families with the expenses of informal caregiving.</p> <p>Encourage and assist in developing employer health insurance purchasing pools to help attract and retain direct care workers.</p> <p>Promote the use of reverse mortgages to increase personal funding to pay for long-term services and supports (LTSS).</p> <p>Expand family and medical leave benefits to further support family caregivers.</p>	<p>Recognition of the multiple dimensions to the challenges being faced by individuals and families in growing numbers.</p> <p>Endorse livable communities framework to improve coordinated accessible transportation and housing strategies.</p> <p>Support consumer-directed individual budgets and active consumer choice and management of public resources.</p> <p>Support improved information access and presumptive eligibility for community services based on a functional assessment rather than on the institutional care bias of current system.</p> <p>Support expanded tax benefits for families involved in dependent care and assistance in health coverage for direct care workers to help with recruitment and retention challenges.</p>	<p>Takes strong position against any new unfunded federal mandates as a solution. Any improvements to coverage under Medicaid must be 100 percent federally financed.</p> <p>The cost issue steers NGA recommendations away from changing the current HCBS waiver process or creation of new state plan option or entitlement.</p> <p>Expansion of tax benefits for family caregiving needs additional research related to cost and analysis of the impact related to a public system of supports.</p>

## *National Academy of Social Insurance*

NASI is a nonprofit organization made up of the leading experts on social insurance. Members include policy analysts in income security and health care financing, economists, political scientists, administrators of public and private benefit programs, and practitioners in related fields. Social insurance encompasses broad-based systems for insuring workers and their families against economic insecurity caused by loss of income from work and the cost of health care. NASI convenes study panels to conduct research and issue findings and policy recommendations.

In January 2003, the Study Panel on Medicare and Chronic Care in the 21st Century issued a report titled “Building a Better Care System.” When Medicare was first established in 1965, it was modeled after the health insurance system of that time. Medicare served primarily as a claims payer. Its benefits package and reimbursement systems were not designed for chronic conditions.<sup>682</sup> The study panel adopted a definition of a chronic condition as “a condition which lasts (or is expected to last) a year or longer, limits what a person can do, and requires ongoing care.”<sup>683</sup> The report identified the cost of managing chronic conditions as substantial. A disproportionate amount of Medicare dollars are spent on beneficiaries with chronic conditions. Beneficiaries with five or more chronic conditions account for 20 percent of Medicare spending.<sup>684</sup>

The need to manage chronic conditions has increased over the past two decades. The number of beneficiaries is expected to continue to grow from 40 million in 2001 to 77 million by 2030. The number of beneficiaries over age 85—those with the greatest chronic care needs—is projected to grow from 4.3 million to 8.5 million over the same period.<sup>685</sup> The report also noted that the disabled population under the age of 65 has grown even faster than the aged population. Enrollment rose from 2.2 million in 1975 to 5.6 million in 2000. By 2017, Medicare is expected to cover 8.5 million individuals with disabilities.<sup>686</sup>

The study panel adopted three principles for selecting policy changes to promote better chronic care:

- Medicare should recognize and aim to focus on beneficiaries’ needs and preferences.
- Payment should support recommended models of care delivery.

- Policies should aim for efficient care with beneficiaries getting the best value for the dollars spent. Policies should help beneficiaries maintain function and quality of life.<sup>687</sup>

The panel’s recommendations include a long-term vision for Medicare and six short- to mid-term requirements. The long-term vision entails a shift in focus to chronic care with access to needed services to enhance function and quality of life and financial protection from costs that pose barriers to needed supports.<sup>688</sup> There would be a seamless continuum across acute, chronic, long-term, and end-of-life care.

To achieve the long-term vision, the panel recommended six key areas for improvement, some of which could be implemented immediately.

- 1. Provide beneficiaries with financial protection from chronic conditions.** To limit cost-sharing requirements, add an annual cap on out-of-pocket expenditures for covered services.
- 2. Expand the continuum of care beyond those services presently covered by Medicare.** The current statute prohibits payment for services that are “not reasonable or necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member” (1862 (a)).<sup>689</sup> The panel recommended a change in statutory language to prohibit payment for services that “are not reasonable and necessary for the prevention, diagnosis, treatment of illness or injury, or to improve, maintain, or slow the decline of function.”<sup>690</sup> This change would shift the Medicare focus to allow for coverage of preventive and rehabilitative services that would enhance function and quality of life. The panel suggested the addition of a prescription drug benefit as the most important addition for management of chronic conditions. The report was written before the passage by Congress in 2003 of the Medicare Modernization Act.<sup>691</sup> Other suggested changes in coverage included durable medical equipment, with the specific intent of maintaining or restoring function and support of rehabilitation as a tool to improve, maintain, or slow the decline of function.<sup>692</sup>
- 3. Promote new models of care.** The panel adopted the position that incremental changes in policy will not be sufficient to significantly improve the system of services and supports for individuals with chronic conditions. Services must be integrated for individuals dually eligible for Medicare and Medicaid. Payments should support the redesign and expanded

benefits coverage. The risk adjustment of evaluation and management codes should be considered. Add-on payments for beneficiaries with specific chronic conditions would compensate providers for longer visits, additional supports, and coordination with other providers to improve the quality of care.<sup>693</sup> The panel also suggested the design and testing of a variety of payment models for different subpopulations.

- 4. Strengthen the role of CMS as a purchaser of services.** The panel supported the use of enhanced payments to providers who provide high-quality chronic care. The panel recognized the challenges of implementation of such a system and suggested that CMS fund demonstrations to improve measures and measurement on the quality of chronic care and examine strategies to make the information available to beneficiaries. Quality-of-care reporting requirements would eventually be required of individual providers, physician groups, and health plans.<sup>694</sup>
- 5. Support enhanced information systems.** Medicare should support the implementation of information systems that track beneficiaries across multiple providers and care settings. Information systems should transition to longitudinal electronic records from handwritten case files. The panel notes that information systems can proactively facilitate care, reduce provider errors, and improve CMS oversight and assessment of quality of care, highlight potential areas for improvement, and provide evidence of which practices optimize quality of care.<sup>695</sup> CMS should also promote the collection and standardization of health and functional assessment data. The current separate measures and information systems for different provider settings make it difficult to track an individual's health, function, and quality of life across care settings.<sup>696</sup>
- 6. Implement and support funding for research and demonstration projects.** The panel suggested that CMS sponsor a wide variety of research and demonstration projects. Projects to consider included alternative models of care management, research on risk adjustment, options to increase family participation in care and support decisions, and other approaches to improve quality of care for specific subpopulations with functional and cognitive limitations.<sup>697</sup>

The NASI panel did not attempt to project the costs of implementing their recommendations. It did, however, prioritize their top three suggestions for federal policymakers. Their priority

recommendations were to limit beneficiary costs by adding an annual cap for out-of-pocket expenses, support new models of care by risk-adjusting evaluation and management codes, and implement an information system that tracks beneficiaries across multiple providers and care settings. The panel's focus on care reflects the influence of the medical system historically on a population increasingly determined to have a greater role in assessment and management of service and support plans.

There is recognition of the need for change that would significantly alter and improve the Medicare program for a growing population that is younger and more disabled. These changes will require significant additional spending of public resources. The NASI panel was more narrowly focused on a single federal program and did not look at the interrelationship of other federal authorities outside of Medicare and Medicaid. Analysis and measurement of quality of life for people with chronic conditions would evaluate alternative care settings for rehabilitation and enhanced function. However, challenges of affordable housing and aging-in-place at home were beyond the scope of inquiry. The panel suggests testing alternative payment models but leaves the scope of options to future research and demonstration activities. The panel does offer an important shift in focus for Medicare that suggests the possible framework for a more comprehensive set of benefits "to improve, maintain, or slow the decline of function."

The following table summarizes the NASI recommendations.

**Table 3.3. National Academy of Social Insurance**

Report/Recommendation: “Medicare and Chronic Care in the 21st Century—Building a Better Care System,” 2003.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
<p>Focuses only on changes to Medicare and the growing population with chronic conditions. Does recognize the interrelationship with Medicaid for future policy development.</p>	<p>Allow payment for services that are reasonable and necessary for the treatment of illness or injury to improve, maintain, or slow the decline of function.</p>	<p>Expand coverage to include durable medical equipment with the specific intent of maintaining or restoring function and support of rehabilitation as a tool to improve, maintain, or slow the decline of function.</p> <p>Shift the focus of Medicare to chronic care with access to needed services to enhance function and quality of life.</p>	<p>Services must be better integrated for individuals dually eligible for Medicare and Medicaid.</p> <p>Support improved information systems that track beneficiaries across multiple providers and care settings.</p> <p>Standardize health and functional assessment data across care settings.</p> <p>Support research and demonstrations to learn more about approaches to improve quality of care for specific subpopulations with functional and cognitive limitations.</p>	<p>Limit beneficiary cost-sharing with an annual cap on out-of-pocket expenditures for covered services.</p> <p>Consider risk adjustment of evaluation and management codes with add-on payments to cover costs of beneficiaries with the need for more intensive supports.</p> <p>Conduct additional research to understand more about cost and the impact of a risk-benefit approach and options to increase family participation in care and support decisions.</p>	<p>Support of new models that are at risk of adjusting evaluation and management codes under Medicare.</p> <p>Improve coordination across funders and care settings through an enhanced information system that tracks beneficiaries across multiple providers.</p> <p>Recognize the need to change coverage of Medicare for a growing population that is younger and more disabled.</p> <p>Limit out-of-pocket expenses annually for beneficiaries.</p>	<p>There are no cost projections for this proposed change in coverage and focus of Medicare.</p> <p>Narrow focus on Medicaid and Medicare leaves out consideration of other federal authorities also affecting quality of life for the targeted population with a specific emphasis on coordination between housing assistance and service needs.</p>

## ***Congressional Budget Office***

The CBO conducts policy research at the request of members of Congress and congressional committees. Its mission is to provide independent, objective information to help consider policy options for the future. At the request of the House Budget Committee, the CBO's Health and Human Services Division analyzed the current state of financing for LTC and delineated a range of policy approaches to consider for future policy development. A report entitled "Financing Long-Term Care for the Elderly" was issued in April 2004. In keeping with its mandate to provide impartial analysis, the report contains no recommendations. However, CBO does provide a careful analysis of the current context to consider increasing costs affected by demographic trends that demand the attention of policymakers. Although the target population is more narrow than the larger group of individuals across the age span with LTSS needs, the CBO analysis is relevant and helpful to the understanding of recent growth in public spending and the possible relationship between public and private financing.

CBO explains that the need for LTC is already substantial, even without the aging of the baby boom generation. The doubling of the senior population by 2040 is expected to further intensify demand for services. CBO defines "long-term care" as

the personal assistance that enables impaired people to perform daily routines such as eating, bathing, and dressing. Such services may be provided at home by family and friends; through home- and community-based services such as home health care, personal care, and adult day care; or in institutional settings.<sup>698</sup>

With the exception of room and board covered by Medicaid for individuals who qualify for skilled nursing facilities, the CBO analysis does not explore, within the context of LTC, alternative less restrictive places to live and public and private financing options. Within the definition of LTSS adopted by CBO, the report explains that most costs are provided through personal resources. Most seniors with a need for assistance with at least four aspects of daily life rely on informal caregiving.<sup>699</sup> Donated caregiving is most common among lower-income groups and among seniors who live close to people willing to provide it, such as family members. CBO estimates that replacing the donated costs with professional care would cost between \$50 billion and \$103 billion in 2004 dollars.<sup>700</sup>

The CBO report acknowledges that, in general, people who are younger than 65 use LTC for different reasons than do people who are over 65. Seniors in need of LTSS generally are adversely affected by physical problems such as arthritis and heart disease. Younger individuals with disabilities are more likely to be affected by mental retardation and mental illness.<sup>701</sup> Medicaid is by far the biggest funder of LTSS for individuals under the age of 65, and the program spending for this group continues to grow significantly with the shift from institutional care to HCBS.<sup>702</sup>

The CBO report sets out three options to respond to growing demand for LTSS. The first set of proposals would tighten eligibility for Medicaid and limit Medicare's home health benefits. The second set of proposals explores the relationship between LTC insurance and public coverage under Medicaid. It seeks to alter the incentives that encourage people to spend down assets to become financially eligible for Medicaid for private LTC insurance. The third set of options would expand public programs that finance LTSS.

- 1. Restrict growth in LTC spending by Medicaid and Medicare.** The rationale for this suggestion is that, by placing new restrictions on eligibility and benefits, individuals with disabilities and families would turn to private market solutions that would be developed to respond to the need.<sup>703</sup> One approach would be to tighten existing limits on income and assets that would delay some applicants' entry into the Medicaid program and discourage others from applying at all. Such a proposal would probably most adversely affect individuals with disabilities under age 65. These individuals are the least likely candidates for any market-driven product of LTC insurance, because their need for services and supports is more intense and costly. As a group, they are the least likely to be able to afford premiums that would be risk-adjusted and most likely be at the higher end.
- 2. Improve the functioning of the market for private LTC insurance.** This second proposal seeks to improve the relationship between Medicaid coverage and coverage under private insurance policies. The first part of the proposal is to standardize LTC policies.<sup>704</sup> Such an approach would make it easier for companies to compare premiums for uniform sets of benefits. It might lead to more competition among insurers and possibly drive prices down. A standard benefits package that conforms to government standards might also help prevent

insurers from tailoring policies to appeal only to healthier purchasers or those with less intense needs. CBO's analysis of this approach suggests that standardization of benefits may block the objective it was meant to achieve.<sup>705</sup> A required minimum set of benefits and consumer protections might be so comprehensive that insurers would have to charge higher premiums, with the result that consumer interest would decline. An additional disadvantage discussed is that standardization could prevent insurers from offering a variety of products to meet the needs of a very diverse consumer audience. A second part of this proposal would allow consumers to supplement Medicaid coverage with private policies. Current rules do not allow enrollees to hold supplemental private insurance. Applicants for Medicaid must exhaust all other sources of LTC financing, including benefits offered by private insurance. Allowing Medicaid beneficiaries to supplement coverage with private insurance would conserve public resources.

The Long-Term Care Insurance Partnership Program that began as a four-state model, and will be expanding to a nationwide model in the near future, allows people who have exhausted or used most of their private LTC insurance benefits to qualify for Medicaid and exempt all or some of their assets from Medicaid estate recovery requirements.<sup>706</sup> Several states are experimenting with partnership policies that allow individuals with more modest means to purchase less expensive, shorter-term coverage and still protect some or all of their assets.<sup>707</sup> In the partnership policy, some or all of the policyholder's savings are allowed to be designated as uncountable assets for determining current and future eligibility for Medicaid. What is unknown is whether the partnership policy approach reduces or increases Medicaid spending. In a small study conducted in California's partnership program, a savings of \$1.3 million was calculated for 18 individuals who used private policies versus Medicaid coverage.<sup>708</sup> It was noted that it was unclear whether the participants in this study had transferred assets before applying to Medicaid.

CBO concludes that, without question, partnership policyholders would generate more Medicaid expenditures, because they would be allowed to qualify without first exhausting all assets.<sup>709</sup> What is not as clear is how Medicaid expenditures might be affected by people who would not have purchased insurance at all. CBO questions whether people without

insurance have a diminished incentive to preserve their finances. By exhausting their resources, they qualify for Medicaid that much faster.<sup>710</sup>

- 3. Expand public programs that finance LTC.** This third set of proposals is described by CBO as the most costly and would “probably worsen the fiscal difficulties the future demographic changes are expected to bring if current law remains unchanged.”<sup>711</sup> Three approaches are offered to expand the menu of benefits and the group of individuals who would be eligible for the enhanced menu of LTSS. Similar to the NASHP proposal, the Federal Government and states could raise the current limits on assets and income so that more individuals met the program criteria for financial eligibility. CBO suggests that such an approach is likely to depress further the development and sale of private insurance products. It is also likely to shift costs away from out-of-pocket spending by individuals who, under the new criteria, would probably have had to spend down more of their assets. A second part of this approach would be to expand benefits under Medicare. Suggested expanded benefits include home health services and respite care to promote and support informal caregiving.<sup>712</sup> CBO again points out that any expansion of benefits will reduce consumer interest in private insurance products. A third option suggested by CBO for consideration is to look at several types of tax credits as an alternative to expanded direct public funding. CBO proposes a tax credit to taxpayers who are “functionally impaired or who have a functionally impaired dependent.”<sup>713</sup> A tax credit as an alternative to a defined program benefit offers beneficiaries a greater degree of choice and control about the type of services to be purchased and the providers to be selected. CBO does not offer more details on the amount of the tax credit or whether it would be available to individuals and families below a certain income level.

The CBO report offers a set of options that recognize demand for services and their resultant costs. The proposals have not been analyzed in terms of specific projected costs to implement or the comparative costs of selecting one of the three approaches over another. The CBO report does raise important concerns about the relationships among out-of-pocket spending, informal caregiving, private insurance coverage, and federal spending by Medicaid and Medicare. Decisions about changes in financial eligibility will have an impact on the development, design, and utilization of private insurance products. CBO urges more study of how partnership

products, which seek to balance individual and public spending, could respond to growing needs for LTSS for individuals with disabilities. Without more federal involvement to require private policies to conform to particular design standards, it is an unlikely option for individuals with disabilities with diverse needs.

The following table summarizes the CBO recommendations.

**Table 3.4. Congressional Budget Office**

Report/Recommendation: “Financing Long-Term Care for the Elderly,” 2004.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
CBO offers three policy options with an analysis of each approach. CBO does not recommend one option over another.	<p>Restrict growth in longer-term care spending by Medicare and Medicaid by placing new restrictions on eligibility by tightening income and asset limits.</p> <p>Expand eligibility to provide an expanded menu of long-term services and supports (LTSS).</p>	<p>Increase government involvement with the private long-term care (LTC) insurance market by requiring a standard benefits package that must be made available.</p> <p>Allow consumers to supplement Medicaid coverage with private insurance policies.</p> <p>Expand benefits coverage under Medicare, including coverage of respite care, to promote and support informal caregiving.</p>	CBO explores ways of complementing public programs with private LTC insurance without losing public eligibility.	<p>Consider a variety of tax credits as an alternative to expanded direct public funding to reimburse individuals and families for the expense of LTSS.</p> <p>Allow consumers to use private insurance to help reduce public costs.</p>	<p>CBO raises important concerns about the relationship between out-of-pocket spending, private insurance coverage, and public spending on LTSS.</p> <p>CBO urges more research about the costs and benefits of the relationship between insurance products and publicly financed benefits.</p> <p>Use of tax credits to help support the expense of family caregiving.</p>	<p>Narrow focus of analysis on expansion or reduction of coverage through Medicaid and Medicare.</p> <p>Need for further research on cost and benefits of linking insurance product coverage with Medicaid eligibility.</p>

## *Americans Disabled for Attendant Programs Today*

ADAPT has a history of organizing the disability community using civil disobedience and similar nonviolent direct action to achieve its goals. The organization was founded by individuals with disabilities in Denver as American Disabled for Accessible Public Transit and began its first national campaign in the 1980s, to improve access to public transit for people with disabilities. ADAPT members nationwide began to organize in 1990 for the reallocation of 25 percent of federal and state Medicaid dollars from institutional programs to consumer-controlled HCBS and supports. The reaction of ADAPT members to HCBS waivers has been one of disappointment. Inconsistent coverage from state to state, both in terms of limited eligibility and benefits coverage, has left too many individuals with disabilities and their families with few choices outside of nursing homes and other large institutions.<sup>714</sup> As a possible solution to the institutional bias of Medicaid, ADAPT developed a legislative proposal designed to encourage states to provide more HCBS. First introduced in the 105th Congress in 1997, two similar legislative proposals stalled in the House Subcommittee on Health and Environment and the Senate Finance Committee.<sup>715</sup> In the 106th Congress, and each subsequent legislative session through 2004, related versions of the ADAPT proposal have been introduced but have not secured sufficient support for passage.

The ADAPT policy recommendations focuses on three core areas for improvement of the Medicaid program. They focus on eligibility, access to benefits that are consumer directed, and financing strategies to encourage states to rebalance their services and supports away from institutions to home and community settings. The Medicaid Community Attendant Services and Supports Act (MiCASSA) does not propose the creation of a new entitlement. However, it does propose to offer states more flexibility in the use of federal funds to establish a national program of community-based attendant services and supports for people with disabilities, regardless of age or type of disability. In the version of the proposal introduced in the 108th Congress in 2003, congressional findings indicated that the goals of the Nation properly include providing families of children with disabilities, working age adults with disabilities, and older Americans with

- a. a meaningful choice of long-term services and supports in the most integrated setting appropriate to their needs;
- b. the greatest possible control over the services received and, therefore, their own lives and futures; and
- c. quality services that maximize independence in the home and community, including in the workplace.<sup>716</sup>

To achieve these goals, the ADAPT legislative proposal would establish a mandatory Medicaid plan benefit for coverage of community-based services and supports to be transitioned over a four-year period.

- 1. Expand coverage of LTSS.** Rather than a plan option or an inclusion as a benefit under an HCBS waiver, the ADAPT proposal would require all states who choose to participate in the Medicaid program to include a new set of benefits for community-based attendant services and supports. Services and supports in the benefit would cover assistance with tasks necessary to assist an individual in accomplishing ADLs and IADLs; and the acquisition, maintenance, and enhancement of skills required to accomplish ADLs and health-related functions. Support includes hands-on assistance; supervising and/or cueing; and help to learn, keep, and enhance skills to accomplish such activities.<sup>717</sup> ADLs include eating, toileting, grooming, dressing, bathing, and transferring. IADLs include meal planning and preparation, managing finances, shopping, household chores, phoning, and participating in the community.<sup>718</sup> Services must be provided in the most integrated setting appropriate to the needs of the individual based on an individual plan.<sup>719</sup>

Not included under the benefit are the provision of room and board for the individual, special education, and related services provided under the Individuals with Disabilities Education Act; vocational rehabilitation services provided under the Rehabilitation Act, assistive technology devices and services, durable medical equipment, and home modifications.<sup>720</sup> The list of excluded services and benefits is an attempt to not duplicate coverage available through some other federal program authority, such as special education, vocational rehabilitation, or an HCBS waiver. It does not attempt to offer new resource

support for affordable and accessible housing, even though Medicaid continues to cover room and board only in nursing home settings.

For a state plan amendment with the new mandatory community-based services and supports benefit to be approved, a state must establish an extensive quality assurance program to maximize consumer independence and consumer control in both agency-provided and other delivery models.<sup>721</sup>

**2. Adopt current standards of eligibility for community-based services and supports.**

Eligibility for the new benefit would include any individual who (1) is eligible for medical assistance under the state plan, (2) is determined to need the level of care provided in a nursing facility or an intermediate care facility for the mentally retarded, and (3) chooses to receive these services and supports in a community setting.<sup>722</sup> Financial eligibility would be the same as currently required for nursing home eligibility—up to 300 percent of the SSI level. States would have the option to adopt a higher threshold.

**3. Offer states financial assistance to rebalance their systems.** The ADAPT proposal offers states enhanced federal matching assistance for those who move ahead with the redesign and rebalancing of their systems. The proposal also offers states additional reimbursement for the provision of community-based services and supports to an individual for whom costs exceeds 150 percent of the average cost of providing nursing facility services but who chooses to receive assistance at home or in community settings.<sup>723</sup>

The ADAPT proposal attempts to provide the consumer of LTSS with more options and choices outside nursing facilities and institutions. It offers states additional federal financial assistance to rebalance the service delivery system away from an institutional bias. As a mandatory benefit in a state's Medicaid plan, policymakers may have significant concerns about the number of individuals who would seek to apply for the community-based benefits and add costs to the Federal Government and states. The ADAPT proposal does not include cost projections.

The proposal offers no additional policy options to respond to the growing demand for affordable and accessible housing. The ADAPT proposal continues to influence policy debates as to possible approaches for federal financial assistance to follow an individual involved in nursing

home traction. The possible strategy of different levels of federal financial participation for support of states that try to rebalance their systems deserves further research on cost and utility.

The following table summarizes the ADAPT recommendations.

**Table 3.5. Americans Disabled for Attendant Programs Today**  
 Report/Recommendation: “2003 Legislative Proposal—Medicaid Community Attendant Services and Supports Act,” 2003.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
Focus on changes to Medicaid to expand coverage of home- and community-based services (HCBS).	<p>Similar eligibility requirements as currently exist for Medicaid, including financial eligibility and individual determination of need for a level of care provided in a nursing facility or an Intermediate Care Facility for the Mentally Retarded.</p> <p>The change would be to honor individual preference to receive those services in a community setting.</p>	<p>Benefits are expanded to cover assistance with the activity of daily living or instrumental activities of daily living including meal planning and preparation, managing finances, shopping, household chores, and community participation.</p> <p>Services must be provided in the most integrated setting appropriate to the needs of the individual.</p>	<p>Rather than a state plan option or an inclusion as a benefit under an HCBS waiver, the ADAPT proposal would establish a new mandatory plan requirement for all states that choose to participate in the Medicaid program.</p> <p>A state must establish an extensive quality assurance program to maximize consumer independence and control in both agency-provided and other delivery models.</p>	<p>States are offered enhanced financial matching assistance to move ahead with system design and rebalancing.</p> <p>States are offered additional financial assistance for individuals who participate and for whom costs exceed 50 percent of the average costs of providing nursing facility services to an individual, but who prefers to receive assistance at home or in community settings.</p>	<p>Adding a mandatory benefit will provide the eligible population access to needed services not tied to an institutional model in all states. The choice of participation is not left to the discretion of the states if they want to continue to participate in the Medicaid program.</p> <p>Financial incentives are offered to encourage state participation.</p> <p>Consumer-directed service planning and implementation is emphasized.</p>	<p>A mandated service meets great resistance from federally focused budget analysts and state governments who are cost-sharing partners in the Medicaid program.</p> <p>There is no consideration of supports from other federal authorities, such as housing and transportation, which are part of a larger framework for discussion of an expanded long-term supports and services system.</p> <p>Further cost analysis is needed to fully understand the implications of implementation of the ADAPT proposal.</p>

## ***American Association for Retired Persons***

AARP is a national nonprofit membership organization. Its membership is diverse, including individuals in their 50s who are working and enjoy a comfortable standard of living as well as those over 80 who are struggling with minimal resources. Each year AARP, with input from its members, develops a set of policy recommendations to help improve economic security, health and LTSS, and independent living. *The Policy Book* for 2005 offers an analysis of the current environment, articulates a list of principles to frame future policy development, and offers a detailed and comprehensive set of policy recommendations to improve access, availability, and quality of LTSS for individuals in need, regardless of age or income.<sup>724</sup>

AARP's description of the current environment recognizes that for many Americans, advancing age means an increasing likelihood of chronic illness and disability. However, AARP, utilizing census data, points out that millions of younger adults and children also need LTSS. If a broad functional definition of "disability" is used to include individuals who need assistance with one or more ADLs or IADLs, AARP estimates that 11.5 million individuals of all ages have disabilities severe enough to require LTSS.<sup>725</sup> With the aging of the population over the next 25 years and continued improvements in health care, the class of individuals needing services and supports will grow dramatically.<sup>726</sup> Other factors identified by AARP in the current environment included changing consumer preference for HCBS as a first choice, dependence on unpaid family caregiving, and limited coverage of Medicaid and Medicare with private LTC insurance not filling the void for many individuals in need of assistance because of high cost or adverse selection.<sup>727</sup>

AARP takes a strong position on the need for comprehensive reform and offers 11 principles that should be used to evaluate any new policy proposals.<sup>728</sup>

- 1. Long-term services and supports should receive adequate public financing through a social insurance program.** Under social insurance programs, individuals pay into the system and are subsequently entitled to benefits when they are needed. The costs are spread across an entire population, which is the financing mechanism for Social Security and Medicare.

- 2. Implementation of a comprehensive public LTSS system should be phased in.**  
Expansion of services requires development of the needed infrastructure, including building the capacity of a workforce to respond to long-term individual support needs.
- 3. A comprehensive range of LTSS should be guaranteed to all who need them, regardless of age or income.** Uniform assessments should determine whether a person meets eligibility criteria for the program, and what type and level of service a person requires. The range of services includes in-home assistance, community services, a full range of supportive housing options, institutional care, rehabilitative services, assistive technology, and assistance with home modifications. Consumer choice and direction should also be key elements of assessment of need and service delivery management.
- 4. Public LTSS should give meaningful support to family and friends who provide caregiving.** Any new national program should support, not necessarily replace, caregiving by family and friends.
- 5. Private sector insurance should supplement public LTSS financing.** Any private sector approach should be subject to strong standards to protect consumers from inadequate products or deceptive marketing practices.
- 6. Provider payments should be adequate.** Reimbursement for services and supports must be reasonable and offer appropriate incentives to deliver quality services and to attract and retain qualified staff.
- 7. Cost-containment mechanisms should be built into the comprehensive long-term support program.** Appropriate mechanisms should promote efficiency in service delivery, tying the amount of benefits to disability levels. However, cost containment should not reduce access to adequate and affordable services and supports.
- 8. The Federal Government and state governments are responsible for monitoring and ensuring the delivery of quality services.** To protect the health and safety of consumers, both levels of government should swiftly and vigorously apply sanctions when needed to enforce laws and regulations concerning the quality of services and supports being provided.
- 9. LTSS should promote consumer independence, dignity, autonomy, and privacy.** The design and delivery of services should promote concepts of consumer choice and direction.

The framework for decision making should recognize and support consumer choices to the maximum extent possible.

10. **The rights of consumers receiving LTSS should be protected.** Consumers receiving services should have a private right of action in court to ensure their rights. The list of protections should include the right to timely information concerning their care, including access to records, the right to keep personal possessions, and the right to express grievance without fear of reprisal.
11. **Consumers of LTSS have a right to privacy.** Regardless of the long-term service setting, consumers should have private areas for visitation, security protections for personal property, and access to private telephones.

In addition to these principles to help design and evaluate future policy proposals, *The Policy Book* offers more detailed strategies for consideration by the Federal Government and state government that are divided into six core areas: creating a consumer-directed system, support for family caregivers, expanding HCBS, development of appropriate health and functional criteria, preserving access and quality, and coordination and integration of LTSS.

1. **Creating a consumer-directed system.** The underlying philosophy presumes that consumers are the experts on their own service needs and that meaningful choice can be introduced into all service environments. As AARP explains it, the potential benefits of consumer direction include cost savings, flexible and more individualized service packages, increased consumer satisfaction with management of service provision, and use of family caregivers, which increases the pool of available providers.<sup>729</sup> Efforts to establish or offer consumer-directed services and supports should include guidelines and standards for care, consumer direction, counseling to assist people in arranging for services, flexibility in selection of providers, and choice to return to traditional agency-directed HCBS.<sup>730</sup> AARP indicates that not everyone may be an appropriate candidate for consumer-directed services. Screening guidelines should be developed with timely grievance and appeal procedures for consumers dissatisfied with, or turned down for, services.<sup>731</sup>
2. **Support for family caregivers.** AARP recommends that LTSS cover respite care and adult day services that supplement caregiving by family and friends. Five specific proposals

suggested by AARP include extending the Family and Medical Leave Act to provide paid leave and cover more workers for longer periods, additional tax benefits to help underwrite some percentage of costs associated with unpaid caregiving, increased funding for the National Family Caregiver Support Program, amending the SSI rules so that they do not reduce benefits for people living with family members, and public education to encourage employers to take advantage of existing tax incentives, such as flexible spending accounts for dependent care.<sup>732</sup>

AARP also suggests that federal and state policies should allow payment to relatives and friends who provide LTSS as part of an individual plan. However, the AARP recommendation does not respond to the concerns of policymakers that such policies will simply shift costs from the individual family to government and not necessarily expand supports in response to individual needs.

3. **Expand HCBS.** AARP urges the expansion of federal funding for LTSS through multiple federal authorities, including Medicaid, the Older Americans Act, and the Social Services Block Grant (SSBG) program.<sup>733</sup> AARP also recommends more vigorous enforcement of the Americans with Disabilities Act, with more active oversight of state activities to implement plans in response to the *Olmstead* decision and its community inclusion mandate.<sup>734</sup>

To expand HCBS, AARP describes multiple strategies. There is no single policy option that can produce the comprehensive system of supports that is currently unavailable. Budgets and policies must be designed to eliminate institutional bias and expand access under the HCBS waivers. Specific policy options should allow states more flexibility to set separate eligibility criteria for nursing facility care and waiver options.<sup>735</sup> Other options to be considered include

- enacting laws that ensure nurse delegation to home care workers of certain tasks that provide adequate consumer protection and liability protection;
- initiating nursing home diversion programs with a comprehensive range of services to meet health and functional needs; and

- supporting volunteer service credit banks for expanding access to LTSS. These community services should not be used as alternatives to public responsibility for funding adequate supports.<sup>736</sup>
4. **Development of appropriate health and functional criteria.** AARP suggests that eligibility for LTSS should be based on functional needs. Appropriate measures should recognize the diversity of the population to assess functional needs of individuals with physical impairments, cognitive impairments, and chronic illness.<sup>737</sup> Eligibility for people with physical disabilities would be based on difficulty in performing two of the five basic ADLs.
  5. **Preserve access and quality for people with cognitive disabilities.** AARP indicates that, despite the high prevalence of cognitive disabilities among nursing home residents, few have access to mental health professionals. The policy approach suggested by AARP is to require cooperative agreements with Area Agencies on Aging and community mental health centers to meet the needs of older people in the community. AARP urges changes in federal requirements for all skilled nursing facilities to include mandatory annual review of changes in the physical and mental condition of mentally ill or mentally retarded nursing facility residents to ensure that they receive necessary treatment and services in the most appropriate care setting.<sup>738</sup>
  6. **Improve coordination and integration of services and supports.** Arranging for appropriate services is a daunting task for most individuals and families. Services and funding are divided among multiple agencies. An essential part of a comprehensive system is effective case management and service coordination. Policy recommendations include
    - establishing a single point of entry for people seeking publicly or privately funded services;
    - ensuring that case management is available through a community organization that is not a direct service provider (to avoid conflict of interest);
    - requesting state certification and annual continuing education for case managers;
    - ensuring that individual service plans are based on functional needs, not ability to pay; and
    - requiring the development of the plan in partnership with the individual and family, with an emphasis on a person-centered approach.<sup>739</sup>

AARP recognizes that development and implementation of many of the proposed recommendations will be costly. Medicaid and Medicare are the two largest public programs; they account for more than 50 percent of the cost of the current imperfect system of LTSS. Smaller public programs that provide LTSS, such as the Older Americans Act and the SSBG program, account for less than 2 percent of total expenditures on long-term services.<sup>740</sup>

Consistent with AARP principles for development and design of any new proposal for policy reform, an approach to financing must have the government and individuals sharing responsibility. Public financing must be “progressive, broadly based, stable, and capable of growing with enrollment.”<sup>741</sup> AARP supports the development of a publicly financed social insurance program that would have individuals pay into the program and be entitled to benefits defined in law, including a cash payment option, when they need services. Eligibility for this entitlement should be based on functional criteria and “take into account cognitive, physical, and social limitations, and the need for support, supervision, and training.”<sup>742</sup> Although there are no cost projections for this policy framework, AARP explains that the most important way to control costs associated with LTSS is to avoid unnecessary institutionalization by providing HCBS in response to standard individual assessments and individual plans.<sup>743</sup> Other approaches suggested to achieve cost savings include improved data collection to evaluate services and outcomes and cost-effective allocation of resources; global budgeting strategies for states that combine nursing home and community services expenditures into a single pool, which enables a state to rebalance more efficiently the use of public dollars in community settings; and consumer self-directed budgets to manage their own service plans.<sup>744</sup>

In a separate section of *The Policy Book*, AARP documents that housing is the single largest expenditure category for older households.<sup>745</sup> Housing figures prominently in an individual’s quality of life and, depending on the availability of services and supports, can have a major influence on whether an individual can age in place and remain independent. The rising housing costs and the challenges of linking affordable and accessible housing options with needed long-term supports requires improved coordination of multiple federal, state, and local public agencies that have separate management responsibilities for housing and supported services.<sup>746</sup> AARP recommends that the Department of Housing and Urban Development (HUD) establish a high-

level office or senior staff member to develop and coordinate policy on housing and services.<sup>747</sup> Similar high-priority action is needed at CMS to identify strategies to improve coordination with HUD and link affordable housing objectives with access to community-based LTSS.

Of the six national level organizations with policy recommendations to review and analyze, AARP offers the broadest set of strategies to develop a comprehensive system for all Americans who seek to remain independent and in the community. The adoption of the social insurance model to spread costs across the largest number of people to finance a menu of benefits that enhance function and preserve individual freedom and choice offers a framework for reform that requires further research and evaluation. The recognition that there is a public and private responsibility to share risk moves the policy discussion from the narrow focus of Medicaid to the larger context of community and multiple federal authorities with responsibilities for housing, social and human services, and civil rights. The larger context for policy framework also recognizes the need to improve coordination among those federal authorities to develop a seamless, one-stop system that is responsive to the consumer in need of information, access, and user-friendly service delivery options that respect consumer preferences

The following table summarizes the AARP recommendations.

**Table 3.6. American Association for Retired Persons**

Report/Recommendation: The Policy Book: AARP Policies 2005.

Scope of Approach	Eligibility	Benefits Coverage	System Design	Financing	Strengths	Weaknesses
<p>Comprehensive framework for policy recommendations.</p> <p>Focus on individuals with defined functional needs over age 50.</p> <p>Build a social insurance program to spread cost for a comprehensive long-term services and supports (LTSS) system.</p>	<p>A comprehensive range of LTSS should be guaranteed to all who need them, regardless of age or income.</p> <p>Uniform assessment process should determine eligibility for the type and level of services based on functional needs.</p>	<p>Range of service includes in-home assistance, community services, a full range of supportive housing options, rehabilitative services, assistive technology, and home modification assistance.</p> <p>LTSS should provide meaningful support to family and friends who provide caregiving.</p>	<p>Comprehensive LTSS should be phased in to allow development of needed infrastructure, including workforce development. Private sector insurance should supplement public LTSS financing.</p> <p>Framework for decision making should recognize and support consumer choices and direction. Federal and state policies should help underwrite some percentage of costs associated with family caregiving.</p> <p>Eliminate institutional bias of Medicaid and allow home- and community-based services (HCBS) waivers to have separate eligibility for home and community services. Improve coordination among federal authorities. At a local level, improve case management and service coordination with a single point of entry.</p> <p>At a federal level, require senior lead staff at Department of Housing and Urban Development (HUD) and Centers for Medicare and Medicaid Services (CMS) to work together to improve coordination between housing and services. Improve federal monitoring of response of states to Olmstead mandate.</p>	<p>Public financing must be progressive, broadly based, stable, and capable of growing with enrollment.</p> <p>Establish a publicly financed social insurance program that would have all wage earners pay into a system and then be entitled to benefits defined in law, including the choice to self-direct a service management plan.</p> <p>To control costs, eliminate the institutional bias of Medicaid, encourage global budgeting by states, and improve data collection to evaluate services and outcomes in different settings with consumer-directed budgets.</p>	<p>Offers the broadest set of strategies to advance a comprehensive LTSS system.</p> <p>Adoption of social insurance model would spread costs and provide cost-sharing with a large pool of participants who will need benefits at different levels in the future.</p> <p>Recognition of need for increased funding under other federal authorities, including HUD, the Justice Department, and the Administration on Aging, to expand other needed supports and oversight of civil rights protections.</p> <p>Recognizes the need to improve system coordination at a federal, state, and local level through shared information systems, one-stop resource centers, and agreement on assessment approaches to determine need to be matched with public and private resources.</p>	<p>Need for further analysis of costs with a social insurance model based on different assumptions about cost allocation with individual and family responsibility, government support at a federal and state level, and possible role of private insurance.</p> <p>Need to develop additional core elements of such an approach and analyze its impact on current federal authorities based on eligibility and benefits coverage.</p>

## **Part III**

### **Expert Panel Discussion and Recommendations**

On February 24, the National Disability Institute of the NCB Development Corporation, in concert with the National Council of State Legislatures (NCSL), convened an Expert Panel to discuss the current state of federal policy concerning LTSS for people with disabilities and a possible framework for future policy recommendations. The panel members represented diverse experience and expertise regarding consumer choice and control; formal and informal caregiving; the support options available under Medicaid, Medicare, and other social service funding streams; the relationships between federal policy and state reform efforts; aging and disability service delivery; individual budgets; and risk management.

The panel was convened to provide advice to NCD and to produce new knowledge and understanding of current experience with, and future need for, affordable LTSS nationwide for Americans with disabilities of all ages.

There were two parts to the discussion with panel members. The first part of the discussion was reactions to research findings on the current state of LTSS for individuals with disabilities, both above and below the age of 65. The second part of the discussion was to provide advice and recommendations on future policy development to establish a comprehensive system of HCBS that enable individuals with disabilities to have expanded choice and direction to live independently and with dignity.

The findings from the first phase of research on current federal experience were summarized for the panel. Key findings identified were the fragmentation of service delivery; inconsistent policy with an institutional bias; and variance of access to needed supports based on age, income, type of disability, and geography. The challenges of program coordination resulted from separate and distinct authorities across the Federal Government having responsibility for program rules on eligibility and scope of benefits coverage. The complexity and fragmentation in the legislative branch also made it difficult to bring together responsible federal authorities for oversight and produce consensus for further policy development. In a post-*Olmstead* environment, state budget

pressure and federal discretionary grants are significant factors accelerating state interest in reexamining infrastructures, the budget process, consumer-directed service delivery, cross-agency and intergenerational collaboration, and public and private partnerships. The pace of change varies by state and perception of progress with comprehensive reform and realignment of systems to enhance consumer choice, and direction varies by stakeholder class. Litigation continues in over half the states as people with disabilities challenge the pace of change, with particular focus on realignment of resources to support expansion of home and community choices.

The discussion by the panel of current challenges reaffirmed the scope of issues identified in the research on current experience. The public policy discussion of private individual accounts for younger workers has heightened interest in, and evaluation of, who is responsible for long-term needs and what they will cost. Beyond discussions of an entitlement to retirement income, is there a public responsibility to vulnerable populations for LTSS? What are the dividing lines between public and family responsibility? The Expert Panel did agree that current federal and state budget obligations and future projections will intensify the need to reexamine the current approach to support of HCBS. Demographic changes will continue to add further stress on the role of the public system, as fewer caregivers will be available to support unpaid caregiving within a family. Panel members described the current system as

- not working effectively for many individuals with disabilities and their families;
- inconsistent in scope with significant variability across states;
- dominated by an institutional bias that defines the policy framework;
- fragmented;
- impacting budgets as costs are growing with increasing demand from diverse stakeholders;
- forcing individuals and families to be impoverished to be eligible for benefits;
- inflexible;
- limiting individual choices;
- complex;

- confusing;
- divisive as groups compete for resources;
- devaluing; and
- out of balance, as waived services and supports are optional and not required.

There was agreement that the current picture cannot be ignored. The range of challenges is intergenerational, as more individuals and families seek public assistance to remain independent with LTSS. The lack of community options and the costs are overwhelming individuals and families who seek alternatives to skilled nursing facilities. Changing expectations of aging baby boomers will compel policymakers to ask new questions:

- Are we investing in the right things?
- Do we understand enough about the costs of HCBS to make an economic argument for policy change?
- Do we need to look beyond a budget rationale to adoption of a critical principle for future public policy development that supports living independently at any cost?

There was agreement from the panel that additional research is needed to understand more about the full set of costs of living at home or in the community and what cost savings, if any, are possible from nursing home diversion. Additional questions were raised about the cost savings achieved from family support and informal caregiving. Concern was expressed about some states and projects that are using a consumer-directed individual budget approach to long-term supports as a strategy to reduce individual and systems expenditures. There was general agreement that policy development that uses a cost-savings rationale for expansion of LTSS must proceed with caution. More needs to be learned about the relationship between paid and informal caregiving and the cost benefits of consumer-directed individual budgets as the management structure for service delivery.

Panel members cited current demonstration projects funded by CMS and the Administration on Aging that will help policymakers and other future stakeholders learn more about the costs and

benefits of consumer-directed service delivery. Other demonstration initiatives, such as the ADRC and Workforce Development projects, were identified to help key stakeholders increase their understanding about the cost benefits of streamlined access to information and services, improved coordination of supports and services, and workforce skill development and retention.

The second part of the discussion followed a summary of specific state efforts at innovation related to service delivery, financing, and consumer choice. Participants were asked to frame a new picture that sets out a different set of expectations for all Americans and that recognizes disability as a natural part of human experience. The panel members offered multiple strategies for systems change.

The majority of suggestions affirmed recommendations from one or more of the six organizations that are reviewed and analyzed in the first part of this chapter. The overwhelming agreement of the panel was to create a policy framework that recognizes the important and essential federal responsibility to contribute public resources and that sets consistent expectations for states to establish a comprehensive system. Such a system of supports must respond to the long-term support needs of the target population over a life span, in the least restrictive environment.

Recommendations from the panel focused on the essential elements of a comprehensive system, including eligibility, benefits coverage, infrastructure, and financing.

- **Determine eligibility based on functional need.** The panel urged movement away from current medical status and disability type to a standardized assessment process to evaluate functional needs related to ADLs and IADLs.
- **Reevaluate financial eligibility criteria.** Although not specific with what would be an appropriate income and asset test, the current threshold, which in effect requires individuals and families to spend all assets to be eligible for Medicaid, must be changed.
- **Develop an expanded benefits menu that organizes service options from a presumption of individual preference for remaining at home and in community settings.** The panel, without describing benefits coverage in more detail, recognized that different people have different needs. As a result, the benefits coverage based on functional

assessment must be flexible, individualized, and comprehensive. Nursing home level of care should be removed from an entitlement status to an option of last resort.

- **Offer more consumer choice and direction in determining needs, creating a service plan, and directing and managing provider selection and service delivery.** The panel suggested that all eligible consumers have a choice to direct an individual budget as an alternative to traditional agency direction of services.
- **Provide incentives to support and encourage family caregiving.** Consider tax incentives to help defray expenses of dependent care for LTSS.
- **Reach agreement across federal authorities on key outcomes and a measurement system.** Shared information and data collection and analysis across agencies in multiple settings should help improve understanding of cost-effectiveness based on different service delivery models. Outcomes to be focused on performance are wellness, productivity, inclusion, and independence.
- **Spread the cost across all wage earners over a lifetime as part of a social insurance financing framework.** Similar to the approach of Social Security and Medicare, individual needs will vary over a life span. However, there is a basic safety net to help with the sharing of costs for a comprehensive system. The panel did not develop the specifics of such a proposal. Further research would be needed to calculate individual cost scenarios and system capacity to respond.

The panel did not expect to reach an agreement in one meeting on the details of a social insurance solution. There was a sense in the group that, during the next five years, policymakers will struggle with multiple options to improve the current system in response to increasing demand. Rather than predict the range of policy options to be considered, the panel suggested a framework to evaluate any future proposal. The beginning framework is a set of questions, or lenses, through which to evaluate future policy proposals.

Any new proposals to reform Medicaid and Medicare should be evaluated from an impact perspective on low-income individuals with disabilities. States should be able to modify asset and income lists to determine eligibility for a menu of LTSS.

Any reform proposal must be evaluated to determine the following:

- Does it simplify and expand eligibility?
- Does it improve coordination, access, and choice?
- Does it compel states to rebalance institutional and HCBS systems?
- Does it allow states to set financial and functional criteria for eligibility?
- Does it encourage families to continue informal caregiving through tax incentives and mandated family leave benefits?
- Does it encourage multiple points of entry and informed decision making on support options?
- Does it encourage consumer direction and offer the option of management of individual budgets?
- Does it favor one group over another because of age or functions?
- Does its approach to financing reduce eligibility or benefit coverage?
- Does the approach to financing spread risk and costs across a larger population to help reduce individual liability and spread costs across multiple shareholders in an equitable way to minimize adverse impact on individuals because of age, disability, location, or income status?

## Part IV

### Conclusion

In a new report of the U.S. Government Accountability Office (GAO), entitled “21st Century Challenges: Reexamining the Base of the Federal Government,” major emerging forces are identified that will require the Federal Government to rethink its entire approach to policy design, priorities, and management.<sup>748</sup> According to David Walker, Comptroller General of the United States, “There is a daunting long-term fiscal outlook.”<sup>749</sup> Competing demands from existing federal entitlements—Social Security, Medicaid and Medicare, and other federal commitments to respond to the nation’s global war against terrorism and homeland security needs—present only a partial picture of expected federal spending in the future. Government spending continues to increase across the board as the federal role has grown in addressing a wide range of needs.<sup>750</sup> The growing imbalance between expected federal spending and tax revenues will ultimately require the nation to decide what level of federal benefits and spending it wants for which segments of the American population, and how it will pay for these benefits.

According to the GAO report, one of the significant forces that will place new demands on government in the future is an aging and more diverse population.<sup>751</sup> An additional significant force is the rapid pace of change in science and technology, which offers new opportunities to maintain function and independence. However, these advances raise their own unique vulnerabilities, risks, and privacy and equity concerns.<sup>752</sup> These and other cited trends—evolving foreign policy, a changing economy, build-up of homeland security, growing federal deficit, and increasing divide between rich and poor—will cause policymakers to conclude that all the government’s existing programs, policies, and activities cannot continue as “givens.”<sup>753</sup> GAO concludes that many of the government’s programs were designed decades ago to address earlier challenges informed by life expectancies, health conditions, organizational structures, technologies, and management models of prior eras.<sup>754</sup> GAO offers policymakers and the American people a set of questions to help address what the Federal Government does and how it does it. Key questions include the following:

- Is the federal role warranted?
- Are benefits targeted to those most in need?
- Is it affordable and sustainable over time?
- Are policies consistent with best practice?
- How do we measure success?
- Are all applicable costs and benefits being considered?<sup>755</sup>

The lens offered by the Expert Panel takes a very similar approach to that of the GAO. Evaluation of current federal programs and policies—as well as future proposals to transform the government’s role as a funder, provider, and manager of a comprehensive system of LTSS for people with disabilities—must consider relevance and responsiveness to changing demands and consumer preferences. The Expert Panel and six organizations representing diverse stakeholder interests within and outside government all agree that there is a need for a fundamental federal presence to offer expanded financial assistance that is adequate to support a growing population as it lives with maximum independence and dignity at home and in community settings. There is an equally strong concurrence of opinion that, for low-income members of the target population and for individuals with significant disabilities, the private markets and state and local governments will not be able to respond to the demand and cost of LTSS without the Federal Government playing a role as a funder.

There are differences of opinion among the analyzed groups as to the scope of benefits, the interrelationships of existing federal authorities, and how and to whom to allocate costs. Most promising for future policy development is the extent of interest in increasing consumer protection in an assessment process to determine functional need; to develop an individualized service plan; to have a choice of service environments and providers; and to control, if interested and appropriate, an individual budget. All groups and the Expert Panel agree that current Medicaid policy, with its institution bias, must end, but they disagree about the extent of flexibility states would be allowed to exercise to define eligibility, benefits coverage, service provider options, and cost-sharing.

The majority of the groups and the Expert Panel express strong support for improving access and information to the target population about program eligibility and available public and private resources. There is also strong support for assisting families with some tax relief to reduce expenses of informal caregiving, and to expand respite care options to provide further assistance to individuals and families engaged, in some way, in meeting the support needs of individuals with disabilities.

The combined number of recommendations for future policy development offered totals more than 40. Although the strategies proposed would most directly affect the Medicaid and Medicare programs and CMS, other federal authorities that would be affected are the Administration on Aging, Social Security Administration, and the Departments of Labor, Treasury, and Justice. Most recommendations require additional research that would project costs for specific program amendments. The analysis of this body of recommendations helps underscore differences of opinion about targeted versus more comprehensive strategies. It is apparent, however, that the longer we wait, the more painful and difficult the choices will become.



## APPENDIX 3.A

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February 24, 2005

Washington, DC

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## **Chapter 4**

# **Moving Forward: Selected State Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**



**Table of Contents:**  
**Chapter 4**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	343
<b>Part II</b>	
<b>Five State Case Studies</b> .....	348
<b>Part III</b>	
<b>Conclusion</b> .....	429
<b>Appendix 4.A</b> .....	433



## **Part I**

### **Introduction**

The current picture of long-term services and supports (LTSS) documented by families, policymakers, researchers, and service providers is complex, confusing, and frustrating. It is a ship struggling with the weight of escalating costs and an increasing number of passengers seeking access and safe passage. Services and supports are scattered throughout numerous federal programs, with uncertain points of entry and different rules of eligibility defined by geography, income level, age, and nature and type of disability.

There is no comprehensive national policy focused on LTSS that is free from the medical model and institutional bias of long-term care (LTC). However, at the state and local levels, there is a push to move forward: setting new policies, reallocating resources, testing new service delivery approaches, and engaging individuals with disabilities and families in a public dialogue to redesign the ship to support a consumer-responsive system that encourages choices, seeks flexibility in service delivery, invests in public-private collaboration, and values the role of formal and informal caregivers. None of the highlighted activities can offer a comprehensive roadmap to reform of existing systems. However, each highlighted state or local system focuses a spotlight on innovative thinking, including policies, processes, and methods of administration to help guide the redesign efforts for the future.

This chapter identifies and highlights selected activities at the state and local levels that are leading toward increased access to LTSS with federal and state dollars. A growing number of states are reevaluating their current systems to identify a range of options for consumers to remain in their own homes or communities rather than be forced into more restrictive environments and skilled nursing facilities. Researchers selected five states to profile and analyzed current activities that are in different stages of development toward the goal of comprehensive, person-centered service and support programs.

## *Five State Study*

The barriers that the selected states had to overcome to achieve preferred and valued results suggest opportunities for the Federal Government to reform LTSS at the national level. Indeed, many of the innovations implemented by the five states have been made possible by recent federal policies and programs that have recognized the hurdles states have to overcome to help people with disabilities lead meaningful, independent lives. The New Freedom Initiative has provided states with grants to achieve the following:

- assist individuals to move out of nursing homes into community settings;
- create regional information and assistance centers that serve as one-stop shopping for consumers to meet their needs for services and supports;
- adopt and improve consumer-directed features in their home care programs and train consumers on their use; and
- form community partnerships to develop accessible and affordable housing and transportation for people with disabilities.

While many of these grants have been modest in amounts, they have helped to keep the momentum going in states faced with tight budgets. The five states selected are using these grants and adopting a variety of strategies to achieve their goals for rebalancing their LTSS systems. They are at different stages in this process. At one extreme is Washington, which has taken a step-by-step approach over more than 20 years to expand home- and community-based services (HCBS). At a different point in the spectrum is Texas, which has only recently embarked on a major overhaul of state agencies that administer LTSS, while also continuing a large-scale effort to move thousands of people out of nursing homes into community living.

The five states were selected because of several characteristics identified as common to the states and instrumental to their expansion of HCBS. These characteristics include a strategic planning process, systems reorganization, involvement of consumers in shaping new policy, and interagency collaboration. These five states were chosen to reflect geographic diversity and unique program design and development.

The mandate for planning has generally come from the governor or the legislature. These states have also developed consensus about the direction to take their programs through involvement of key stakeholders from all parts of the community, including advocates, providers, and policymakers. Most of the selected states have a tradition of discussion and collaboration over public policy issues.

Pulling together state agencies that have responsibilities for LTSS has been a starting point (or at least a necessary element) for making services more accessible to consumers and responsive to their needs in the states under review. States that place the responsibility for both nursing homes and home- and community-based care under the same state agency provide greater flexibility for that agency to allocate funds based on the needs of its clients rather than having separate silos for those funds.

Each state has developed some unique programs or approaches to serving people with disabilities. **Washington** was one of the first states in the country (in 1983) to take advantage of the then-new federal Medicaid HCBS initiative, the HCBS waiver program.<sup>756</sup> **Vermont** is pioneering a global budgeting approach to providing services that will pool nursing home and HCBS funds to allow people with disabilities to select whichever option they prefer. The state will establish priorities for meeting the needs of people with disabilities by dividing these people into those with the highest needs (who are the state's first priority) and those with less high or moderate needs.

**Minnesota** has embarked on an ambitious project to review and prioritize public and private financing options for LTSS so the state can develop a campaign to ensure an optimal combination of the two. The goal is to help address the critical public financial situation that could develop when baby boomers age and need services and supports. **Texas** has broken new ground with a Medicaid managed care system that is serving more than 60,000 aged and disabled people in one area of the state. The state is also revamping its agency structure to provide consumers with easier access to services. The effort, which could take three to five years to complete, involves 12 agencies, 200 programs, and about 50,000 state employees. **Indiana** has a state-funded home- and community-based care program that is so highly valued by consumers

and public policymakers that the program has received ever-rising appropriations, even though the state has been facing difficult fiscal times.<sup>757</sup>

Each state case study is divided into sections that discuss programs and services for different groups of people with disabilities. Additional sections outline residential options and consumer-directed initiatives. A final section singles out two particularly innovative projects in each state.

Taken together, these five state case studies offer an optimistic and encouraging picture of the possibilities for reforms in LTSS. They suggest additional steps that can be taken at the federal level to continue to help states move forward in the evolution of a comprehensive system of support for individuals with disabilities that favors consumer choice and control.

The following table offers a summary of each state’s reform strategies and its significance to future policy development.

**Table 4.1. Five States: Long-Term Services and Supports Reform Strategies**

State	Reform Strategies	Importance
Indiana	<p>Public-Private Long Term Care (LTC) Insurance Program—links purchase of private LTC insurance with Medicaid coverage of long-term services and supports (LTSS).</p> <p>State-funded Community and Home Options to Institutional Care for the Elderly (CHOICE) program is for low-income individuals who do not qualify for Medicaid and/or are waiting for Medicaid services. Covered services are case management, home health supplies and services, personal assistance services, transportation, respite care, home delivered meals, and adaptive aids and devices.</p> <p>The program is administered by the Area Agencies on Aging. Twenty percent of service dollars must be used by people with disabilities under the age of 60.</p>	<p>Tax deduction for cost of premium. For every dollar of benefits that a policy pays out, the purchaser earns \$1 of asset protection to remain eligible for Medicaid.</p> <p>Targets a population not on Medicaid with a sliding fee schedule based on income level.</p>

State	Reform Strategies	Importance
Vermont	<p>Coordination of LTSS for people who are aging and/or disabled.</p> <p>One department includes Aging, Physical Disabilities, and Developmental Disabilities.</p> <p>A global budgeting approach allows the state to combine Medicaid home- and community-based services (HCBS) waiver funds with the state's nursing home appropriation.</p>	<p>Single agency improved information flow to consumers.</p> <p>Removes institutional bias and offers eligible people community choice and expanded service options.</p> <p>Increased consumer satisfaction and cost savings.</p>
Washington	<p>Balanced global funding of institutional services and LTSS with consolidated administration under the Department of Social and Human Services.</p> <p>With a focus on movement out of nursing homes, state general revenue funds (up to \$816) are available to help a person move from a nursing home to a less restrictive setting. State funds are also used to pay for assistive technology.</p>	<p>Improved coordination in the delivery of services with a client-centered integrated service plan that is managed by a service broker.</p> <p>State investment in one-time transition costs.</p>
Minnesota	<p>Examination of long-term support insurance options to balance public and private responsibility.</p> <p>Creation of benchmarks to assess change over time in state system (for example, a percent of long-term care dollars spent on institutional versus community support).</p> <p>Shared Care is part of the state's Medicaid Personal Care Assistance Choice Program. With Shared Care, two consumers can share a personal assistant, with the cost divided between two people. The worker will be paid one and one-half times the regular rate.</p>	<p>Seek to identify tax incentives and other means to maximize private resource utilization and still achieve state policy goals.</p> <p>Ability to assess change in the state system over time.</p> <p>An approach to increase wage levels and still achieve consumer satisfaction.</p>
Texas	<p>Reorganization of administration with integrated eligibility determination process.</p> <p>Movement of Medicaid funding from its nursing home budget to its budget for Community Care Programs.</p>	<p>Will allow an integrated application process for medical, food, and other LTSS. Money Follows the Person from a nursing home to the community.</p> <p>More than 3,000 individuals have made the transition from nursing home to community living coordinated with supports.</p>

## Part II

### Five State Case Studies

#### *Washington*

*Washington is among the leaders among states seeking to create and maintain a balanced long-term care system that offers real choices for consumers among an array of settings and service options.*<sup>758</sup>

—National Academy for State Health Policy for  
the Community Living Change Collaborative,  
November 2003

#### **Introduction**

Like its neighbor, Oregon, Washington began its efforts to limit institutionalization and expand HCBS for people with disabilities in the 1980s, long before most other states. Washington was one of the first states to take advantage of what was then a new federal option: Medicaid HCBS waiver programs, which allow a state to offer people at risk of institutionalization a chance for community care instead.

In FY 2003, Washington spent \$1.6 billion on Medicaid-funded LTSS, of which about \$770 million (49.5 percent) was allocated to institutional care (nursing facilities and institutions for people with mental retardation or developmental disabilities, MR/DD). Another \$784 million (50.5 percent) went to HCBS. This contrasts sharply with the national average allocation, which is about 70 percent for institutional care and 30 percent for HCBS. Over half of the public expenditures for LTSS in Washington are noninstitutional, and more than 75 percent of participants receive community-based services rather than institutional care.

Allowing consumers the opportunity to direct their services themselves is another important feature of Washington's HCBS programs. The HCBS programs strongly promote choice. Washington has also been in the forefront of states in realizing the importance of providing assistance to family caregivers to enable them to continue caring for family members. The state developed its own program of family caregiver supports before the enactment of the National Family Caregiver Support Program.

The state has also realized the importance of developing a stable and trained workforce of direct care workers if quality care is to be provided to people with disabilities. The creation by voter initiative and legislation of the Home Care Quality Authority in 2000 is unique among states in its concept and operation.

Perhaps as important as anything else to Washington's ability to create a comprehensive system has been its management of most services for people with disabilities in one agency. The Department of Social and Health Services (DSHS) serves one in five Washington residents (with health as well as support services) and, in some of the mostly rural counties, more than one-third of the population.<sup>759</sup> Within DSHS, the Aging and Disability Services Administration (ADSA) has responsibility for nursing homes as well as HCBS and for people with developmental disabilities as well as the frail elderly and other adults with disabilities. This single-agency focus has made it possible for the state to shift resources from institutions to community services and to coordinate services for people with disabilities who have complex health, mental, and long-term support needs that span several agency programs.

## **Background**

The total population of Washington was about 6 million in 2002. The state experienced a 21 percent increase in population from 1990 to 2000, compared with a national population increase of 13 percent. The number of people age 65 and older in 2000 totaled 662,000, or 11.2 percent of the total population. Between 1990 and 2000, the state saw a 15.1 percent increase in the number of elderly. From 2000 to 2025, the Census Bureau predicts a 131 percent increase in this age group in Washington, the sixth highest growth rate in the country.<sup>760</sup>

The number of people with a disability totaled 981,007 in 2000. The state has a relatively homogeneous population with only 3.2 percent black, 5.5 percent Asian, and 7.5 percent Hispanic. The number of people with incomes below the poverty level totaled 10.6 percent of the population in 2000.<sup>761</sup>

More than three-fourths of the state's residents live in urban areas. In 2003, the state had the largest budget deficit in its history: \$2.4 billion.

## **Integrating Services for People with Disabilities**

Washington has been gradually evolving a strategy of integrating LTSS for people with disabilities. In 1986, the state consolidated administration of all long-term supports for older people and people with disabilities into the Aging and Adult Services Administration under the umbrella of the DSHS. The Mental Health Division (MHD) and the Division of Developmental Disabilities (DDD) were also located within the umbrella agency.

Kathy Leitch, assistant secretary of ADSA, says that the 1986 reorganization brought nursing homes and HCBS together under one administration. “There was always this push,” she says, “that the nursing home entitlement got in the way of providing home- and community-based services.” The purpose of the reorganization, she adds, “was to organize around consumers and have an array of options available to them.”

The department estimated that almost 25,000 people received services from two or more of the following DSHS programs in 1999: mental health, aging and adult services, alcohol and substance abuse, and developmental disabilities. In November 2000, DSHS began developing the No Wrong Door care coordination project to design integrated case coordination models for people and families served by several different DSHS programs. The project involves multidisciplinary teams made up of staff from various DSHS programs, local community organizations, and other supports of the person and family. A “client-centered integrated service plan” is developed and a service broker/coordinator then manages joint planning and coordinated delivery of services.

One example of service integration was the October 2002 the creation of the Aging and Disability Services Administration (ADSA) in DSHS, which combined aging programs from the former Aging and Adult Services Administration (including nursing facilities as well as community-based programs) with developmental disabilities programs (both residential centers and community programs). Mental health and alcohol and substance abuse programs remain within the Health and Rehabilitation Administration in DSHS.

## **Expansion of Community Supports**

Washington has steadily increased the number of people who receive home and community services, while decreasing the number of nursing home residents. State officials say they can place two people in community services for the cost of one person in a nursing home.

In FY 1992, 19,330 people were being provided publicly funded HCBS; by FY 2003, that number had grown to 33,729. Over the same period, the Medicaid caseload in nursing homes had dropped from 17,353 to 12,943.<sup>762</sup> About 33,000 people are now receiving community services from the Division of Development Disabilities through Medicaid Personal Care, Family Support Services, or Community Residential Services, compared with 1,330 people in the state's Residential Habilitation Centers (RHCs).<sup>763</sup>

Moving people out of nursing homes whenever possible has become a major priority for the state. Four funds are available to assist people with their transitions to the community:

- *Medical Institution Income Exemption Fund.* Beneficiaries who qualify for Medicaid nursing home care must pay all their income toward the cost of their care, except for a personal needs allowance. Under the income exemption, a new nursing facility resident may keep income, up to 100 percent of the federal poverty level, for a six-month period. Residents can use this income to maintain their home in the community by paying rent, mortgage, property tax, insurance, and/or utility payments.<sup>764</sup> This means that a person who may have a short stay in a nursing home is less likely to face the prospect of losing his or her residence during that period.
- *Residential Care Discharge Allowance.* This allowance provides up to \$816 in state general revenues to help a person move from a nursing home or other residential setting (such as an assisted living facility or adult family home) to a less restrictive setting.
- *Civil Money Penalties.* The state uses fines paid by nursing homes with deficiencies to help people in such nursing homes move to another facility or to an alternative residential setting. The amount is limited to \$800 per resident but may be higher if the facility has been decertified or if an emergency exists in which residents must be relocated.

- *Assistive Technology Fund.* State general revenues are used to pay for assistive and adaptive technology, as well as durable medical equipment; evaluations; training; or minor home modifications. The average request is for about \$2,000; requests for more than \$10,000 must be reviewed by state officials.<sup>765</sup>

**Programs for individuals who are elderly and/or physically disabled:** The major program serving older people and young adults with disabilities is the Medicaid HCBS waiver program, the Community Options Program Entry System (COPEs). An average monthly caseload in April 2004 was 23,110 people—almost 15,000 of these people were receiving in-home services and the remainder were in residential settings.<sup>766</sup> Expenditures for FY 2003 totaled about \$295 million. (For more detailed information on COPEs, see “Innovative Practices” below.)

Washington also operates a Medicaid Personal Care program that provides services to people who need assistance with at least one activity of daily living (ADL), such as dressing, bathing, or self-medication. The average monthly caseload in April 2004 was about 11,000 people. Expenditures totaled \$226 million in FY 2003. The state also offers limited home care services through the state-funded Chore Program, which provides personal care and help with household tasks. However, the state’s budget crunch in 2002 and 2003 resulted in cutbacks in this program.

**Programs for people with developmental disabilities:** Washington has faced a number of challenges with regard to its services for people with developmental disabilities. For example, a 1999 study found that the DDD was “fully serving the needs of only 62 percent of its caseload.”<sup>767</sup>

A 1999 lawsuit, *The Arc of Washington State v. Lyle Quasim*, charged that the state failed to provide LTSS with reasonable promptness to people with developmental disabilities. Another lawsuit, *Boyle v. Braddock*, filed in December 2001, alleged that the state had failed to make available the full range of services offered through the Community Alternatives Program to program participants.<sup>768</sup> Both cases were combined for purposes of oral arguments before the Ninth Circuit Court scheduled for October 2004.

The secretary of DSHS appointed a Developmental Disabilities Strategies for the Future Stakeholder Workgroup in 1997 to help develop a plan for the future needs of people with

developmental disabilities. At its inception, the Stakeholder Workgroup stated that choice and self-determination should be the “foundation for restructuring services and supports” for people with developmental disabilities. Its many recommendations after five years of work included enhancing case management services, increasing wages of direct care staff, and encouraging self-directed services.<sup>769</sup> Direct care workers have received modest wage increases in recent years, although the state’s fiscal problems continue to make this a contentious issue for policymakers. Consumer direction has been incorporated into the new Medicaid waiver programs discussed below.

The case management recommendations, however, became part of a larger overhaul of management practices because the workgroup’s efforts were soon followed by critical reviews of the DDD by the Centers for Medicare and Medicaid Services (CMS) and by Washington’s Joint Legislative Audit and Review Committee. Their reports were critical of the agency’s assessment and case management processes and management controls. One major response of the Department of Social and Health Services was to merge DDD with the Aging and Adult Services Division. The reorganization included mandates from the DSHS secretary for organizational, management, and service delivery reforms for DDD.

One change seeks to address issues concerning DDD’s procedures for assessing potential applicants for its programs and then allocating resources to its clients. The change involved replacing the agency’s single Medicaid HCBS waiver program, the Community Alternatives Program (CAP), with four waivers, each of which is targeted toward a particular subset of the potential client population.<sup>770</sup> The 10,500 people who were receiving services under the CAP were to be moved into the new waiver program that was most appropriate for each person’s situation. These waivers were approved by the Federal Government in December 2003 and officially replaced the CAP waiver on April 1, 2004. The programs and the groups they cover follow:

- **Basic Waiver:** Individuals who live with family or in their own homes and have a “strong natural support system.” The family/caregiver’s ability to continue to provide care may be at risk but can be continued with additional services. These services include physical and occupational therapy, behavior management, emergency assistance, respite

care, specialized medical equipment, specialized psychiatric services, supported employment, and transportation.

- **Basic Plus Waiver:** Individuals who live with family or in another setting with assistance. They are at high risk of out-of-home placement. Clients are eligible for all the general services covered in the Basic Waiver plus skilled nursing, adult family home, and adult residential care services.
- **Core Waiver:** Individuals who require residential habilitation services or live at home but are at immediate risk of out-of-home placement. Services include residential habilitation and all the Basic Plus services, except emergency assistance, adult family home, and adult residential care services.
- **Community Protection Waiver:** Individuals who require 24-hour staff supervision and require therapies and/or other habilitation services. They live in or are moving into the community.<sup>771</sup> Services include all Core Waiver services, except personal care, respite, community access, adult family home, and adult residential care services.

Participants in these programs can hire, train, and supervise workers they choose, or they can elect to have agency services. Because the number of people with developmental disabilities has increased significantly in recent years, demand for services has been greatly exceeding supply. The state reported that 5,000 people were on a waiting list for the Family Support Program, with an average wait for services of about 18 months. (Family Support helps people find and pay for respite care, therapy, special equipment, and participation in community activities.)<sup>772</sup>

Another major issue for the agency has been the future of the state's five RHCs that provide 24-hour residential housing for individuals with developmental disabilities needing institutional care. At their peak in 1967, the centers had a combined population of 4,000 residents. By 2004, that population had shrunk to 1,100 residents after the state had begun closing some of the facilities.

**Programs for people with mental illness:** The state has made vigorous efforts to move long-term psychiatric state hospital patients into community settings. Those efforts have resulted in the closure of 178 psychiatric state hospital beds between December 2001 and April 2003.<sup>773</sup>

The foundation of the state's mental health system is a network of local mental health managed care plans called Regional Support Networks (RSNs). Services include crisis services; individual or group therapy; medication evaluation, prescription, and management; and case management. Each RSN is allotted a specific amount of money to provide these services to people in its area and an allotment of beds for people who need hospitalization at state hospitals. Most RSNs also use private psychiatric inpatient facilities closer to home.<sup>774</sup>

The DSHS received a \$1.4 million federal Real Choice Systems Change Grant in 2002 to improve services for adults and older adults with co-occurring medical and behavioral disorders. A draft report on the grant in March 2003 noted that only one in three adult DSHS clients with a diagnosis in the group, including dementia and other organic disorders, was served by the MHD in FY 2001. A high percentage of older adults leaving state hospitals, the report said, are never seen in community services.<sup>775</sup>

In response, DSHS began an Expanding Community Services (ECS) Initiative, which received funding in the FY 2001–2003 state budget. The goal is to fund the development and operation of community support services for long-term state hospital patients who are facing barriers to discharge. Community funding is becoming available through closure of some state hospital wards.<sup>776</sup>

### **Residential Options**

The residential alternatives for people with disabilities include adult family homes that can provide care for up to six residents, and boarding homes licensed to care for seven or more people. “Boarding homes” is a term that covers adult residential care (ARC), assisted living, and enhanced ARC. Services in ARC homes include lodging, meals, general supervision of residents, and assistance with personal care. Enhanced residential care services include the services provided through an ARC contract and limited nursing services.

Washington has more than 2,000 adult family homes that provide room, board, laundry, supervision as needed, and assistance with ADLs. Boarding homes that provide assisted living services offer a private unit with a private bathroom and help with personal care tasks that do not require a professional worker. Some boarding homes specialize in nursing services, while others serve individuals with mental health problems, developmental disabilities, or dementia.

A Medically Needy Residential Waiver program pays for personal care and other services for aged, blind, or disabled people in adult family homes, assisted living facilities, and enhanced ARC facilities. Medicaid funding was available for about 2,900 residents of assisted living facilities in 2000; that number had grown to 3,762 in 2002.<sup>777</sup>

In 1995, the state moved licensing and oversight responsibility for assisted living from the Department of Health to DSHC, which also has enforcement authority over nursing facilities. The legislature enacted a law in 1997 to establish a consultative approach to help assisted living providers meet state licensing requirements. The Quality Improvement Consultation Program, as it was called, employed a staff of consultants to advise and train assisted living providers. The nine regionally based consultants conducted site visits, led training sessions, and responded to telephone inquiries.<sup>778</sup>

After six months of operation, about 82 percent of providers voluntarily participated in the program. Evaluations conducted six months and two years after the program started found a large majority of providers expressing satisfaction with the program. Among residents assessed by the consultants on more than one visit, 86 percent showed improvement in various aspects of care, such as administration of medications and assistance with ADLs.

The program fell victim to budget cutbacks in the FY 2003 budget, however, and ended in June 2002. The U.S. General Accounting Office (GAO) found that the number and percentage of facilities that had incurred penalties “fell substantially” after implementation of the program. The state imposed fewer civil fines, conditions on licenses, license revocations, and summary suspensions.<sup>779</sup>

Washington has received a four-year Coming Home grant from the Robert Wood Johnson Foundation to help the state explore development of affordable models of housing with services for the elderly and adults with disabilities. Part of the grant calls for setting up focus groups to obtain input from the disability community on current housing and new models.<sup>780</sup>

## **Workforce Issues**

*Direct Care Workers:* Initiative 775 enacted by Washington voters in 2001 established the Home Care Quality Authority “to regulate and improve the quality of in-home care services by recruiting, training, and stabilizing the workforce of individual providers.”<sup>781</sup> The 2002 legislature incorporated the text of the initiative in state law. In May 2002, the governor appointed the authority’s nine-member board, which held its first meeting in June 2002.

The authority is developing a referral registry for individual home care providers, which is to be available by July 2005, and providing training opportunities for consumers and providers. The authority has a mandate to recruit providers and then match consumers to qualified providers in both routine and emergency situations.

After the passage of the initiative, the Service Employees International Union, which represents about 26,000 home care workers in Washington, negotiated a contract with the state that called for a \$2.07 per hour increase and a package of state-subsidized benefits. But the money to implement the contract required legislative approval, and the state had hit a severe revenue shortfall.

The contract was rejected in the 2003 legislative session, although the budget did include \$25 million to cover a \$0.75 per hour raise for home care workers. Then, the union won legislative approval in March 2004 for a revised contract that called for a \$0.50 per hour raise as well as new health and workers’ compensation benefits. Home care workers saw their wages rise from \$7.18 per hour in 2001 to \$8.93 in 2004.<sup>782</sup>

*Family Caregivers or Informal Care:* Washington has also strengthened its support for family caregivers over the years. The state estimates that more than 540,000 family caregivers are helping adults who have chronic illnesses or serious disabilities.<sup>783</sup> A respite care program established statewide in 1989 had a \$2.8 million budget in FY 2003. A state family caregiver support program was started in October 2000, with an annual budget of \$610,000. When the National Family Caregiver Support Program was enacted that year, Washington was allocated about \$2.4 million.<sup>784</sup>

Washington has also devoted considerable efforts to ethnic family caregivers. The state has used two federal Alzheimer's Disease Demonstration Grants to target Chinese, Hispanic, Korean, and Native American communities as well as rural communities.

### **Consumer Direction**

Washington has long been a state that promotes consumer-directed care for participants in its home- and community-based programs. Participants in the Medicaid Personal Care program and COPES may use workers from home care agencies or hire independent providers. However, state policy requires clients who need more than 112 hours of service a month to use an independent provider rather than an agency, which was intended as a cost-containment measure and to address shortages of home care workers, particularly in rural areas. For this reason or because of preference, the majority of in-home clients use independent providers rather than agencies.

In the Medicaid-funded programs, participants may hire family members but not a spouse or parent of a client. A 1998 survey by the Aging and Adult Services Administration found that 52 percent of independent providers were family members. Independent providers, including family members, must submit to criminal history background checks and complete a state-designed training course. After hire, a worker must take a two-hour orientation course, take 28 hours of mandatory training within the first 120 days of hire, and take 10 hours of continuing education each year thereafter.

In addition to hiring and supervising his or her worker, the consumer trains the worker regarding individual needs and health-related tasks. A case manager determines the client's eligibility for the program and the number of hours of service the worker may provide. The client signs the timesheets; the case manager authorizes services and payment. The state cuts a check, which it sends directly to the worker.

The state applied in 2004 for a Robert Wood Johnson grant to implement a Cash and Counseling project, which will allow eligible Medicaid participants to receive a monthly allowance to be spent to hire their own workers, including relatives. The project will also provide counseling and financial assistance to help clients plan and manage their

responsibilities, including choosing a fiscal agent if they wish to maintain their accounts, write checks, withhold taxes, and file tax returns.

### **Innovative Practices**

Two key innovative practices in Washington include one program that has been the foundation of the state's successful HCBS system for almost 20 years (COPES) and one demonstration program that has only recently been implemented (the Medicaid Integration Partnership).

***The Community Options Program Entry System (COPES):*** The heart of the home- and community-based system in Washington is COPES, begun in 1983. It is one of the largest HCBS waiver programs in the country in terms of number of participants, with more than one-third of the participants age 18 to 64 years old. Not only does the program provide assistance with personal care and household tasks in the home, COPES also funds services in adult family homes, assisted living facilities, and enhanced ARC facilities.

To qualify for COPES services, an individual must be at risk of nursing home care and need assistance with two or more ADLs or be cognitively impaired. The financial eligibility standard is 300 percent of Supplemental Security Income (SSI). Initial functional and financial eligibility determinations are carried out by local ADSA caseworkers throughout the state. If a client receives services at home, an Area Agency on Aging worker will assume case management responsibilities for that person. If the client enters a residential facility to receive services, the state agency caseworker will retain the case management function.

Covered services include assistance with personal care and household tasks, adult day care, environmental modifications, home delivered meals, personal emergency response systems, and specialized medical equipment and supplies. Other services include skilled nursing and home health aide services that are beyond the amount, duration, and scope of regular Medicaid services, as well as training and transportation to meet therapeutic goals.

***Medicaid Integration Partnership:*** This is a demonstration program aimed at bridging the gaps that exist for many high-risk clients of the DSHS who are eligible for or are receiving services from different divisions of the department. The project is aimed at individuals with complex

medical conditions, cognitive impairment, mental illness, addiction disorders, and physical and developmental disabilities who make heavy use of medical, hospital, or nursing home services; prescription drug services; or mental health services. The goal is to provide these clients with an integrated package of services “to slow the progression of illness and functional disability, reduce unnecessary emergency room and hospital visits, and reduce the overall cost of care.”<sup>785</sup>

Agencies involved include the Office of the Secretary of DSHS, ADSA, the Medical Assistance Administration (Medicaid), the Budget Office, and the Research and Data Analysis Division. An intra-agency workgroup began developing the demonstration project to be implemented during the FY 2003–05 biennium. The legislature authorized DSHS to combine and transfer funds for Medicaid clients in this program from the separate budget categories for the ADSA, Alcohol and Substance Abuse, Mental Health, and Medical Assistance (Medicaid) program budgets into the 2003–05 biennium. Enrollment is expected to reach at least 4,000 people.

One of the first steps in the project was to analyze the Medicaid population in terms of demographics, use of services, and cost and setting of care. The workgroup has been working on coordinating arrangements for health care, mental health, substance abuse benefits, and LTSS. In addition to the state agencies working together, the project envisions community partnerships made up of groups of medical, behavioral, and long-term service providers in one or two counties. Funding streams will be integrated into a single monthly capitated payment for medical services, prescription drugs, LTSS, and behavioral health.

The program must evaluate changes in cost, utilization, and client outcomes. In January 2005, the department will prepare a Medicaid waiver proposal that outlines further steps in Medicaid integration that the state wishes to pursue, including fully integrating Medicare and Medicaid funding and services.<sup>786</sup>

### **Future Plans and Challenges**

The pressures brought through class action lawsuits on behalf of people with mental illness and individuals with developmental disabilities have pushed the state to advance its community-based agenda despite severe budget and fiscal pressures. Although the commitment to increasing community services for people with disabilities remains strong, tensions over budget issues have

slowed some actions to improve LTSS, such as raising wages and benefits for direct care workers or expanding state-funded programs such as the Chore Program.

At the same time, however, the state's Medicaid agency has been looking at enhanced rates for boarding homes that serve people with dementia, says Bernard Dean, senior fiscal analyst of the House Appropriations Committee. ADSA Assistant Secretary Leitch points out that some specialized dementia care boarding homes that have been developed in the state are at least \$50 per day cheaper than nursing homes and delay nursing home placement. Pat Thibaudeau, the ranking member of the Senate Health and Long-Term Care Committee, believes that the legislature also has "to figure out a better way to fund nursing homes," pointing to a number of nursing home closures and the potential need for some facilities to care for baby boomers in the future.

As the agency charged with *Olmstead* planning, DSHS completed a draft plan in December 2002, but the agency described its work as an ongoing process. The Washington *Olmstead* plan "is intended to be a living document, subject to continuous planning and change," the agency said. The goals are to continue to divert people from institutional admissions by creating sufficient options in home and community settings, and to help people already in institutions make the transition to the community.<sup>787</sup> The state will be tested through its fiscal difficulties to realize these goals.

The reorganization within DSHS also poses challenges for the state as the newly created ADSA strives for cohesion and coordination among its somewhat disparate parts.

As DSHS increasingly promotes the delivery of services through teams from different parts of the agency, it will be learning whether efficiencies can be achieved and the quality of care improved for all its clients.

## ***Vermont***

*Vermont's long-term care system is "characterized by collaboration among key agencies, advocates, and other stakeholders. It is built upon the principle of maximizing participant choice of services, providers and living arrangements."*

—MEDSTAT report for CMS, 2003

### **Introduction**

Although a small rural state, Vermont has built an enviable record of providing LTSS for people with disabilities that enhance their independence and dignity and promote choice. This system has evolved through years of planning since the 1990s and is built on a firm commitment to the goals articulated in legislation and program administration for providing services that reflect each individual's needs and choices.

The key components of Vermont's programs are extensive and ongoing planning, expanded HCBS, residential options, worker initiatives, and self-directed services. Agencies for different populations with disabilities have collaborated on a number of projects, and a recently implemented reorganization plan will unite most agencies for people with disabilities under one umbrella department.

Vermont's efforts are strengthened by the close partnership between the state and 10 local coalitions throughout the state. These coalitions bring together advocates and providers to collaborate on ways to improve service design, options, and coordination in each geographic area.

Significant milestones in Vermont's planning for and development of home- and community-based options for people with disabilities include Act 160, which was enacted in 1996, and "Shaping the Future of Long Term Care" reports, which have been issued since 2000. Act 160 laid the groundwork for rebalancing the state's system of LTSS from an institutional approach to greater emphasis on home- and community-based options. The "Shaping the Future" reports set out goals and measure progress toward meeting those goals for the elderly and people with disabilities.

## **Background**

Vermont had a population of about 616,600 people in 2002, forty-ninth in the country. Encompassing only about 9,250 square miles, the state has a population density of 65.8 people per square mile (compared with the U.S. average of 79.6 people per square mile). The population is largely white and nonpoor—96.8 percent white with a poverty rate of 9.4 percent (compared with the national average of 12.4 percent poor).

The state had 77,510 people age 65 and older in 2002. The number of people age five and older with a disability totaled 97,167 in 2000.<sup>788</sup> The state estimates that 3,835 people were living in the community in 2003 who required assistance with at least two ADLs. Forty-five percent of these individuals were low income. The state estimates that by 2013, this number will grow to 5,464 people (a 42 percent increase).<sup>789</sup>

In the 1980s, Vermont's public officials began to review the state's LTSS, which consisted largely at that time of institutional care, Older Americans Act services, and a small state-funded attendant care program. A set of recommendations for expansion of community services came out of a 1986 report to the state legislature and a 1988 commission headed by the lieutenant governor. As a result of this work, the state developed a Medicaid home care waiver program, and provided additional state funds for adult day services and homemaker services.

Another outcome was the creation of the Department of Aging and Disabilities (DAD) in 1989, which issued a 1991 report "Long Term Care in Vermont." A major recommendation of that report was that the state allocate for community services at least 30 percent of total public funds for institutional and home- and community-based care.<sup>790</sup>

## **Integrating Services for People with Disabilities**

Until 2004, Vermont did not integrate or coordinate LTSS for all people with disabilities. Separate administration and program operations existed for aged and disabled people in DAD and for developmentally disabled and mentally ill people in the Department of Developmental and Mental Health Services (DDMHS), although both departments were located in the Agency of Human Services.

Significant progress has been made, however, in coordinating all services and supports for elderly people, people with disabilities, and people with developmental disabilities through a reorganization that has been in the planning stages since 2002 and was implemented in 2004. The reorganization has resulted in the creation of the Department of Aging and Independent Living, which pulls together programs from DAD and developmental disabilities services from DDMHS (which was abolished as an agency). The reorganization also locates mental health services in the Department of Health, along with programs from the Division of Alcohol and Drug Abuse.<sup>791</sup> (Throughout this report, the names of the former agencies will be used in most cases because the services and programs to which the report refers evolved through the years under those agencies.)

This effort at coordination and consolidation of services came about when the Vermont General Assembly in the FY 2003 Appropriations Act instructed the Agency of Human Services to recommend a comprehensive plan for reorganization of the agency's operations. For six months (July 1, 2003, to December 31, 2003), the agency consulted a wide range of Vermont consumers, providers, state employees, and stakeholders through surveys, focus groups, regional stakeholder meetings, regional and state advisory groups, and a statewide conference.

The agency said that "widespread agreement" emerged that it needed "to do a better job" in several areas, which included integrating the state's approach to LTSS "so that consistent support and services are available based on the need of the individual or family, rather than by diagnosis or geographic region of the state." The system, the agency said, "tolerated significant disparities and inequities that inhibit too many children and adults with disabilities from receiving vital services and supports they need to live independently in integrated community settings."<sup>792</sup>

When the legislature backed the reorganization, says Peter Youngbaer, executive director of the Vermont Coalition on Disability Rights, lawmakers felt that a key component had to be a "detailed financial plan." The state's director of long-term care services, Brendan Hogan, says that the state has experienced incremental changes in the years since passage of Act 160. With reorganization, he says, "There is more of an overall strategy." Completion of the reorganization is expected to take about three years, with final implementation scheduled for mid-2006.

Putting developmental disabilities services into a single department with aging and physical disabilities was a “real step forward,” says Debra Leese Baker, executive director of the Vermont Independent Living Center. Coordination is still sometimes difficult, she says, because “mental health remains in another department.”

It should be noted that, before the reorganization, the various agencies with responsibilities for services for people with disabilities often collaborated on various projects. For example, a 1999 Workforce Task Force begun in DAD was later expanded to include DDMHS and DDD. DAD and DDMHS jointly administer the ElderCare Initiative, begun in FY 2001 to provide mental health services for older adults in their homes (see below).

Another major collaborative activity has been the work by DAD, DDD, and DDMHS on a series of activities funded by a \$2 million, three-year federal grant under the Real Choice Systems Change Grant program. The objectives for the project include the following:

- improving and coordinating information flow to consumers to ease their ability to navigate service delivery systems;
- identifying best practices to foster self-determination and self-advocacy among consumers;
- supporting workforce development (discussed in greater detail below under “Workforce Issues”);
- developing a Medicaid waiver to eliminate a bias toward institutional care (see “Innovative Practices” below); and
- researching the option and implementing a pilot program to provide direct funding to people with developmental disabilities and their families.

All three agencies are involved in the first three objectives, the Medicaid waiver application is a project of DAD, and direct consumer funding is a project of DDS. In May 2004, the agencies applied to CMS for a no-cost extension that would continue the projects through autumn 2005.<sup>793</sup>

### **Public/Private Partnerships**

In the process of expanding its HCBS, Vermont has “achieved remarkable consensus on policy goals,” according to one study, “among state officials, the disability community, aging advocates, service providers and program participants themselves.” Creating a state-level coalition “consisting of all relevant stakeholders,” the report said, helped the state reach consensus on policy goals and strategies for realizing those goals.<sup>794</sup>

After the 1991 “Long-Term Care in Vermont” report, stakeholder groups consisting of people with disabilities, the elderly, and providers convened at the local level. These groups provided community input into the process that led to passage of Act 160. After that, DAD used a small amount of the 160 funds to support the transition of 10 stakeholder groups around the state into coalitions.

The coalitions have been “widely credited with fostering collaborations among various stakeholders and improving access to services.”<sup>795</sup> The coalitions developed business plans that focused on filling local gaps in services in the first years of their existence. The 10 LTC coalitions operate in areas generally corresponding to county boundaries. They have been given authority by DAD to select either an Area Agency on Aging or a home health agency in their region to coordinate management of the Home-Based and Enhanced Residential Care Medicaid Waiver Programs, and they now oversee the Housing and Supportive Services Program as well.

### **Expansion of Community Supports**

Act 160 laid the groundwork for a multiyear effort to limit institutionalization of people with disabilities who need services and supports by expanding home care and other community residential options. Act 160 linked increased funding for HCBS to reduced growth in nursing facility expenditures for the four years following passage of the law. The state had estimated that spending on nursing home care would increase 8 percent a year, the rate of growth experienced between 1983 and 1996. Act 160 provided that any savings realized by the state from spending less on nursing homes than the projected amount could be used to finance expanded community options.

When the legislation was enacted, 3,600 people were residents of nursing homes; as of December 2003, the number of nursing home residents had dropped to 3,256. In 1992, about 22

percent of Vermont's population age 85 or older lived in nursing homes. By 2002, 15 percent of that age group were living in nursing homes.<sup>796</sup>

**Programs for individuals who are elderly and/or physically disabled:** The following are the major programs for seniors and people with disabilities that are administered by DAD: Home-Based Medicaid Waiver Program, Attendant Services Program (ASP), Traumatic Brain Injury Medicaid Waiver, Enhanced Residential Care Medicaid Waiver, Adult Day Services Program, Homemaker Program, and Housing and Supported Services.

Personal care services are provided in the Home-Based Medicaid Waiver Program. These include assistance with essential daily activities such as dressing, bathing, eating, grooming, toileting, mobility, and transferring. Assistance may also be provided for other activities, such as medication management, meal preparation, cleaning, and shopping. The program also pays for up to 720 hours a year of respite care services for family caregivers. The program has more than 1,300 participants

The ASP also provides assistance with the daily activities described above, but allows for several models of consumer-directed care. A program assessor completes an in-depth assessment of an applicant's needs in his or her home. Then an eligibility committee (consisting of program participants) reviews the assessment and authorizes a specific number of hours of service per day.

The program has four different components. The state-funded Participant-Directed or Medicaid Participant-Directed Programs are for people who need assistance with at least two ADLs and who can manage their own care. A third ASP component is a state-funded Personal Services Program for people who need assistance with at least one ADL or meal preparation. The fourth ASP component is the Group-Directed Attendant Care Program for people who need four or more hours of attendant services daily.

The Enhanced Residential Care Waiver Program provides personal care, case management, activities, and 24-hour staffing for people who live in residential care homes or assisted living facilities. The program serves about 200 people a year in 38 licensed Level III residential care homes. (For further information on residential care homes, see "Residential Options" below.)

The Adult Day Services Program offers personal care and meals, therapeutic activities, and professional nursing services in adult day settings. The Homemaker Program provides homemaker services for people with one or more ADL deficiency and/or cognitive impairment. The Housing and Supported Services Program provides services and coordinates access to existing community services for residents of congregate housing. (For further information on this program, see “Residential Options” below.)

**Programs for people with developmental disabilities:** The state has created comprehensive community-based services for people with developmental disabilities through the DDMHS. The services that the state has developed have led to the following results:

- Vermont ranks first among the states in the number of people with developmental disabilities per 100,000 population who receive supported employment.
- The state is fourth in the nation in terms of total family support spending per family with a person with developmental disabilities.<sup>797</sup>
- Vermont has the nation’s highest percentage of people with developmental disabilities living in residential settings of three or fewer residents.<sup>798</sup>
- The only public institution in Vermont for people with developmental disabilities, the Brandon Training School, was closed in November 1993.

The Developmental Disabilities Act of 1996 laid out 12 principles of service that included employment, accessibility, meaningful choice, individualized support, and health and safety, among others. DDD has contracts with 15 nonprofit developmental services providers: 10 Designated Agencies in each geographic region of the state and 5 Specialized Services Agencies that provide services to meet distinctive individual needs.

In FY 2003, the agency provided supports to 2,889 people, which agency officials say represents only 25 percent of the eligible population. Medicaid funds 99 percent of developmental services through the Home- and Community-Based Waiver Program that served 1,918 people in FY 2003.

Participants have choices for the management of their services: self-direction, agency management, “shared” management between an agency and the consumer, or family management.

A smaller state-funded program, Flexible Family Funding, provides up to a maximum of \$1,122 annually to eligible families with children or an adult family member who lives at home. The money can be used for services and supports at the family’s discretion. (Families receiving Flexible Family Funding can also get services under the Medicaid waiver program if they are eligible.)<sup>799</sup>

The Federal Government has praised Vermont’s program for people with developmental disabilities for its attention to each participant’s needs. For further information on the state’s approach, see “Innovative Practices” below.

**Programs for people with mental illness:** A Medicaid waiver program provides services for the chronically and persistently mentally ill through a network of community mental health agencies. The FY 2003 appropriation for community-based services for adult mental health was \$35.6 million. Programs include Community Rehabilitation and Treatment (CRT), Adult Outpatient Services, and Emergency Services.

The CRT program, which had about 3,200 clients in FY 2003, provides medication prescription and monitoring, and helps clients find and keep a job and locate housing. The program also assists clients in getting an education and provides social and recovery skills. Adult Outpatient Services, which has served more than 7,000 people annually in recent years, offers a range of mental health services, such as evaluation and family, individual, and group therapy. People are typically seen for 1 to 10 visits.

Emergency services are available 24 hours a day, 365 days a year to evaluate mental health crises and to provide or arrange whatever treatment or support is needed to cope with the crisis. The program serves about 7,600 people annually. Consumer/Family Initiatives services include information, advocacy and referral, and training for providers. Support groups and telephone emotional support are also available.<sup>800</sup>

**ElderCare Initiative:** A joint program of DAD and DDMHS, the ElderCare Initiative was started in FY 2001 with a \$250,000 appropriation. Clinicians provide outreach, case identification, and home-based mental health treatment services for adults age 60 or older. The most frequent diagnosis is depression, with a small percentage of cases of substance abuse or dementia. At the local level, the program is run by the state's five Area Agencies on Aging and 10 community mental health centers.<sup>801</sup>

### **Residential Options**<sup>802</sup>

The first "Shaping the Future of Long Term Care" report called for the development of additional supportive housing, such as enhanced residential care, assisted living, group-directed congregate housing, and adult family care. Although state officials say that significant progress has been made in developing new housing models, getting the models up and running has been difficult. In some parts of Vermont, older people have a two- to five-year wait for affordable housing.

Vermont's first licensed affordable assisted living residence opened in July 2003. The 28 apartments were all leased or under signature within three months of opening. Other entities are in various stages of developing assisted living residences, with the state hoping to produce a specific plan for future growth in 2004. (People in assisted living facilities and residential care homes who are Medicaid-eligible can receive Medicaid-covered services through Vermont's Assistive Community Care Services Program.)

Residential care homes are state-licensed group living arrangements designed to meet the needs of people who cannot live independently but who may not need the level of care provided in nursing homes. Assistance in residential care homes primarily includes help with daily activities such as bathing, dressing, and eating. There are two levels of these facilities: Level III homes provide nursing overview but not full-time nursing care, and Level IV homes do not provide nursing overview *or* nursing care.

Other housing options in the planning or development stage include the following:

- *Consumer-directed congregate living arrangements* that provide individual apartments and shared caregivers for a small number of young adults with severe mobility

impairments. One nine-unit site in Burlington is being evaluated by the state for future planning replication.

- *Adult family care*, an arrangement in which an older person or a young adult with a disability lives with an unrelated family that provides housing, personal care, and supportive services. This option is in the development stage in a few areas; the state hopes to expand the concept statewide sometime in 2005.
- *Housing and Supportive Services (HASS)* provide service coordination and gap-filling supportive services to people living in 29 congregate housing sites. The goal of HASS is to allow residents to age in place, thus avoiding or delaying institutional placement. Wellness initiatives, exercise programs, and community meals are provided. As of June 2003, about 800 people were participating in this program.
- *Homeshare Vermont*, a program currently in only a few areas of Vermont, brings together a homeowner who needs support and assistance with a caregiver looking for a place to live. In 2003, a match-up program in Central Vermont opened through the collaboration of multiple partners in the area.

### **Workforce Issues**

As with most states, Vermont has problems finding enough direct care workers for its home care and residential programs, a situation that is exacerbated by the sparse population in rural areas. A study by DAD found that turnover rates ranged from 35 to 60 percent in nursing homes and home health agencies, and up to 400 percent in residential care homes.<sup>803</sup> The state has attempted to address these shortages in several ways:

- Used savings in the nursing home budget in FY 2001 to increase payment rates for the consumer-directed option in waiver programs. (After a year's experience, a worker would be paid \$10 an hour, on average.)
- Enacted wage pass-through<sup>804</sup> legislation for nursing homes. The legislature appropriated \$6.3 million in FY 2001, \$8.7 million in FY 2002, and \$8.3 million in FY 2003.

- Applied part of a federal Systems Change Grant to establish a paraprofessional organization, the Vermont Association of Professional Care Providers. The association will give workers an opportunity to help shape their training and work conditions.

Another major effort has been the creation of a community coalition led by the Community of Vermont Elders (COVE) with a demonstration grant from the Better Jobs/Better Care (BJBC) program<sup>805</sup> to develop quality criteria for nursing homes and other LTC providers that include staff development and support, working conditions, and recognition for workers. One outcome of the effort was the appropriation by the 2004 legislature of \$7 million in extra funding to support nursing home rate rebasing that will augment funds for direct care staff. The coalition also won a 5 percent increase (to \$50 per day) in rates for assistive community care services in residential care homes.

DAD and the Vermont Health Care Association have collaborated to develop a “Gold Star” designation program to improve staff retention in nursing homes.<sup>806</sup> The program was designed by nursing home professionals and state staff to promote nursing homes that agree to use best practices with their employees. Nursing facilities must meet criteria in seven areas (the examples for each component are taken from descriptions in the BJBC newsletter).<sup>807</sup>

- *Staff recruiting:* Honest depiction of job duties and expectations and involvement of direct care workers in interviewing.
- *Orientation and training:* Well-developed orientation and hands-on training and mentoring for new employees.
- *Staffing levels and work hours:* Flexible scheduling, worker control over hours, and safe workloads.
- *Professional development and advancement:* Career ladders, mentoring opportunities, and training in specialized care.
- *Supervisory training and practices:* Training for all supervisory staff, accessible supervisors, and respect for all workers.

- *Team approaches*: Involvement of direct care staff in care planning, permanent assignments for patient care, and regular communication among team members.
- *Staff recognition and support*: Rewarding years of service with pay increases or opportunities for advancement, counseling resources, and strategies to express appreciation and respect.

Nursing facilities are to be given flexibility in how they implement the practices within their own facilities. A nursing home must be a participating Gold Star facility to qualify for one of the five \$25,000 Quality of Care awards given by DAD each year.

### **Consumer Direction**

Providing consumers with the opportunity to choose their own services and providers and to direct their own care has been a key element of Vermont's programs for people with disabilities. The "Principles of Developmental Services" for people with developmental disabilities, for example, talks about "meaningful choices" that ensure that "each recipient is directly involved in decisions that affect that person's life." Another principle states that "adults, regardless of the severity of their disability, can make decisions for themselves...."<sup>808</sup> Vermont policymakers strongly support the concept because of consumer preference, cost-effectiveness, and shortages of paid providers, particularly in rural areas.

For the elderly and older adults with physical disabilities, self-directed services have been integral to programs managed by DAD. The agency provides consumers with a "Consumer and Surrogate Directed Services Employer Handbook." In 1997, the state began offering enrollees in the Medicaid Home-Based Waiver Program the option of directing their own care, and a year later, provided a surrogate-directed choice.

Currently, half of all personal care hours under the Home-Based Waiver Program are used by people who manage their own care or have a surrogate for this role.<sup>809</sup> According to Patrick Flood, commissioner of the Department of Aging and Independent Living, this widespread use of consumer-directed services saves the state money that can be applied to expanding HCBS. "We were paying \$24 per hour for a home health aide," he said, compared to \$12 for consumer-

directed care.” “If we didn’t do this, we would not have been as successful in shifting dollars to home- and community-based services,” he adds.

Individuals in the state-funded participant-directed component of the ASP may even hire their own spouses to provide their care. Participants recruit, select, and supervise their workers, and develop work schedules. The participant and attendant complete, sign, and submit biweekly time reports to a designated payroll agent, who approves the payment and mails a check to the worker.

Vermont Independent Living Center director Debra Leese Baker says that consumer direction also needs to be made available to people with psychiatric disabilities. Even with consumer direction options for the other programs, she says, finding workers is difficult because of the low pay and benefits for direct care workers. She points to the state-funded participant-directed program, which allows spouses to be paid as aides but which is underfunded because of the state’s fiscal constraints. “We hope we’ll get permission under the new Medicaid 1115 waiver to pay spouses,” she says.<sup>810</sup>

### **Innovative Practices**

While Vermont has a number of noteworthy initiatives and practices, probably the most significant are its waiver proposal to create equal access to either nursing home or home- and community-based care and its comprehensive community care system for people with developmental disabilities.

***The 1115 Medicaid waiver proposal:*** DAD filed a 1115 Research and Demonstration Waiver proposal in October 2003 with CMS after a year-long planning process with providers, advocates, and consumers. The program would allow the state to create a program without an institutional bias by combining Medicaid HCBS waiver funds with the state’s nursing home appropriation in a “global budget.”<sup>811</sup> (Vermont spent a total of \$133 million in FY 2004 for all LTSS, including nursing home care.)

Eligible elderly people or people with disabilities would have the option of receiving either Medicaid-covered HCBS or care in a nursing home. People choosing HCBS will not have to wait for a slot to open up in the Medicaid waiver program.

The state proposes to establish a priority system for eligible people, who will be placed into three groups: highest need, high need, and moderate need. The highest need group, who must meet the state's Medicaid financial eligibility criteria,<sup>812</sup> will be entitled to either nursing home care or HCBS. The high need group will not be legally "entitled" to LTSS, but will be served to the extent that funds are available. These consumers will also have to meet Medicaid financial but not functional eligibility criteria. The moderate need group will consist of people who do not meet nursing home or HCBS waiver eligibility criteria but are believed to be at risk for institutionalization based on their assessed care needs. (Functional eligibility criteria for each group are listed in Attachment 4.A.)

Service options for the highest and high need groups are the same: case management, personal care, adult day services, respite, companion services, assistive technology and home modifications, emergency response system, enhanced ARC, or nursing facility care. The type and amount of services depend on the assessed strengths and needs of each individual. For consumers with moderate need, service options will include case management, adult day services, and/or homemaker services.

At the time of the state's application, 2,200 people were "entitled" to nursing home care in the state. State officials believe an additional 800 people will benefit from an entitlement to either nursing home care or HCBS. As of October 2004, the state had not yet received formal federal approval of the proposal, although most details had been worked out by the state and CMS. State officials estimated a July 1, 2005, start for the program.

***A model developmental disabilities system:*** In a review of the state's renewal request for its Medicaid HCBS waiver program for people with MR/DD, CMS said that the Vermont system for this population serves as a model for other states.<sup>813</sup> The federal agency said

Vermont's home- and community-based services waiver for individuals with mental retardation and developmental disabilities continues to reflect the commitment and dedication of the Division of Developmental Services, other involved State officials, service providers and other stakeholders to provide high quality developmental services and opportunities for enjoyment of life in the community to all people receiving developmental services.

Goals and outcomes defined in Vermont's Developmental Disabilities Act of 1996 and its implementing regulations are reflected in all systems operating within the waiver. DDS staff continue to strive to improve all aspects of the program. Their focus on continued growth in the quality of individualized planning and consumer involvement, health and wellness, provider oversight, and accountability in the utilization of resources for outcomes-based service delivery, can serve as a model for other home- and community-based services waiver programs.<sup>814</sup>

The federal agency said that DDS ensured ongoing quality in its program through "availability of full information, individualized supports, meaningful choices, community participation and employment, accessibility, health and safety, trained staff, and fiscal integrity." The CMS report noted that Individualized Support Agreements (care plans) use a person-centered approach, which sometimes includes brief histories of the participant's experiences and goals, often written in the participant's own words.

DDS has produced a document called "Individual Support Agreement Guidelines," intended for a consumer audience to help participants understand the process and to provide information about supports, approvals, and making changes. The CMS report also noted that all consumers whose case files were reviewed had current documentation of their need for an intermediate care facility for the mentally retarded (ICF/MR)<sup>815</sup> level of care and therefore of their eligibility for HCBS waiver services.

### **Future Plans and Challenges**

A DAD goal that was articulated in the "Shaping the Future of Long-Term Care" reports has been to establish a county minimum of 40 HCBS waiver slots for every 60 Medicaid-funded nursing home beds. Five of the state's 13 counties had reached or exceeded that goal by 2003, with several other counties "poised" to reach the goal, according to DAD.<sup>816</sup> Setting these goals and implementing the planning efforts to reach them has helped the state to learn which counties "need more infrastructure building," says Peter Youngbaer of the Coalition on Disability Rights.

Youngbaer also notes that the state is in the middle of an *Olmstead*<sup>817</sup> planning process, and is developing a plan that will be more comprehensive than the "Shaping the Future" reports. The *Olmstead* plan, he says, will encompass education, transportation, housing, health care, and other relevant issues.

An effort is also under way to better manage care for people who need both medical and chronic care services. Vermont was one of nine states that participated with the Hartford Foundation to establish PACE (Programs of All-Inclusive Care for the Elderly) in their states. In Vermont, the plan is for these programs to operate in Burlington and Rutland, with about 100 clients in each of the two areas. The legislature appropriated \$100,000 for planning work.

Although Vermont did not experience as severe a fiscal crisis as many other states in 2002 and 2003, funds have been tight for initiatives, such as improving direct care worker wages and benefits or increasing funds for accessible and affordable housing. Agency officials talk about waiting lists for certain services or programs, such as the Flexible Funding Program for families of people with developmental disabilities .

Vermont continues to evolve its system of LTC services and supports, which reflects a commitment to offering options to people with disabilities about where they will live, what kinds of services they will receive, and how they want to direct those services.

## **Attachment 4.A**

### **Functional Criteria for 1115 Waiver Program<sup>818</sup>**

#### ***Highest Need Group***

- Individual needs extensive or total assistance with one or more of the following: toileting, eating, bed mobility, and transfer and needs *at least* limited assistance in any other ADL; or
- Individual has a severe impairment with decision making skills *or* a moderate impairment with decision making skills *and* one of the following behavioral symptoms/conditions that is not easily altered: wandering, verbal abuse, physical abuse, inappropriate behavior, or resists care; or
- Individual has any of the following conditions or treatments that require skilled nursing assessment, monitoring, or care on a *daily basis*: Stage 3 or 4 skin ulcers, IV medications, end-stage disease, ventilator/respirator, potential feedings, sectioning, nasogastric tube feeding, or second- or third-degree burns; or
- Individual has an unstable medical condition that requires skilled nursing assessment, monitoring, and care on a *daily basis* related to conditions or treatments, including but not limited to (19 conditions or treatments are listed that include dehydration, internal bleeding, therapy, aphasia, transfusions, surgical wounds, oxygen respiratory, and cerebral palsy).

#### ***High Need Group***

- Individual who requires extensive to total assistance on a daily basis with any of the following ADLs: bathing, dressing, eating, toileting, and/or physical assistance to walk. Individual requires skilled teaching on a daily basis to regain control or function with ADLs, gait training, speech, range of motion, or bowel and/or bladder training; or
- Individual who has impaired judgment or decision making skill that requires constant or frequent redirection for ADLs *or* one of the following behaviors that require a controlled

environment to maintain safety: constant or frequent wandering, inappropriate behavior, or aggression; or

- Individual who has any of the following conditions or treatments that require skilled nursing assessment, monitoring, and care on less than daily basis and an aggregate of daily services, including rehabilitation therapy: wound care, medication injection, end-stage disease, potential feeding, suctioning, ventilator/respirator, nasogastric feeding, and severe pain management.

### ***Moderate Need Group***

- Individual requires supervision or any physical assistance three or more times in seven days with any single or combination of ADLs or IADLs,<sup>819</sup> or
- Individual has impaired judgment or decision making skills that require general supervision on a daily basis, or
- Individual requires at least monthly monitoring for a chronic health condition, or
- Individual's health condition would worsen if LTC services are not provided or if services are discontinued.

## **Minnesota**

*We envision a long-term care system that supports self-determination, provides services that meet consumer needs, provides high-quality care, (and) ensures efficiency and affordability.*

—Minnesota Long-Term Care Task Force, January 2003

### **Introduction**

In 2001 the Minnesota Legislature enacted a series of measures to expand LTSS that built on a set of recommendations issued by a task force the year before. The goal was to reduce institutionalization of people with disabilities and expand the availability of home- and community-based options. Although the task force work and the subsequent legislation were framed with a focus on the older population, the state has also been steadily improving community options for other disability groups as well.

As a result of these efforts, Minnesota closed almost 5,000 nursing home beds from FY 2001 to FY 2003. The number of people age 65 and older served through publicly funded HCBS grew from 23,000 to nearly 30,000, a 25 percent increase, over those years.<sup>820</sup> Minnesota has also seen a surge in housing options for people with disabilities that has included a doubling in the number of assisted living residences over the previous five years.

The state has also made a major effort to provide most people with disabilities an opportunity to direct their own services. That option has been available for many years in selected counties to participants in the Medicaid Personal Care program and in the Medicaid HCBS waiver program for people with mental retardation and related conditions. With federal approval, the state plans to extend consumer direction in 2005 to all counties and to its other four Medicaid waiver programs, as well as to two managed care programs that provide a combination of Medicare and Medicaid health and LTSS.

### **Background**

The total population of Minnesota in 2000 was about 5 million people. The number of people age 65 and older totaled almost 600,000, which was 12.1 percent of the total population (compared with the national average of 12.4 percent).<sup>821</sup> The population is largely white (89.4

percent) with 3.5 percent who are black, 2.9 percent Asian, and 2.9 percent Hispanic. People who are foreign born constitute 5.3 percent of the state's total population.

Individuals with incomes below the poverty level in 2000 account for 7.9 percent of the population (for people age 65 or older, the percentage was 8.2 percent). Fourteen percent of the population age 21 through 64 reported having a disability, as did 36.9 percent of the over-65 population.<sup>822</sup>

### **Integrating Services for People with Disabilities**

The Minnesota Department of Human Services (DHS) is an umbrella agency that ensures basic health care for low-income Minnesotans, provides economic assistance, and assists people with disabilities and the elderly. The department's FY 2004–2005 biennial budget includes a little more than one-third of the state's total public spending.<sup>823</sup> In outlining department priorities in 2003, DHS included a goal of providing “more consistent services across all of the home- and community-based waivers through development of a common services menu and a common screening tool.”<sup>824</sup> The DHS agencies with major responsibilities for services for people with disabilities include the following:

- The **Disabilities Services Division**, which encompasses services for people with developmental disabilities, traumatic brain injuries, physical disabilities, and chronic medical conditions;
- The **Mental Health Division**, which provides support to counties that are the local mental health authorities; and
- The **Aging and Adult Services Division**, which provides protective services, supportive assistance, and alternative housing arrangements for older people and vulnerable adults.

A different form of integration that Minnesota has pioneered is the Minnesota Senior Health Options program that provides Medicare and Medicaid benefits through an integrated care coordination model to a voluntarily enrolled group of older people who are eligible for both Medicare and Medicaid. About 5,000 people in 10 Minnesota counties receive their care through a provider network they select. Enrollees live in both nursing homes and community settings.<sup>825</sup>

Another model of integration is the demonstration project mandated by the 2003 Legislature that moves the Medicaid Elderly Waiver HCBS program into the Pre-Paid Medical Assistance Program, thus integrating medical care and LTC for elderly Medicaid recipients who are at risk of institutionalization.<sup>826</sup> This program, originally scheduled for implementation July 1, 2004, was delayed six months to a year to give counties and health plans a chance to negotiate a role for counties in this new managed care model.<sup>827</sup>

### **Expansion of Community Supports**

In 1980, Minnesota's nursing home utilization rate was the highest in the country, 8.8 percent of people age 65 and over. In 1983, the state began providing HCBS for Medicaid-eligible older people at risk of institutionalization through the Elderly Waiver program. At the same time, the state established a parallel state-funded Alternative Care program for older people of low income who were not eligible for Medicaid.<sup>828</sup>

Despite these efforts, high nursing home utilization rates continued. In 1996, Minnesota spent 92.6 percent of its Medicaid LTC dollars on nursing homes, ranking seventh out of 50 states in the proportion of those Medicaid expenditures going to nursing home care. The result was the formation of a Long-Term Care Task Force composed of Minnesota legislators and state agency officials in 2000 to address gaps in the state's programs and delivery of LTSS, and to develop strategies for addressing those issues.<sup>829</sup>

The task force issued a report, "Reshaping Long-Term Care in Minnesota," in January 2001.<sup>830</sup> A number of its recommendations were enacted into law by the 2001 Legislature, including the appropriation of \$183 million to carry out many of the provisions, including the funding of community service grants to pay startup, capital, and other costs for developing supportive housing and HCBS in areas where current resources were judged inadequate to meet needs. Examples of some of the 200 community services grants that were awarded in 2002 and 2003 include the following:

- **Ageless Care Options**—Coordinate care, provide licensed home care services for older adults in four senior apartment buildings in the town of Grygla, and two senior apartment

buildings in Warroad, provide adult day services and transportation services for residents of the senior apartments and other older people in both towns.

- **Sholom Home East**—Purchase a van to deliver kosher meals for 30 to 40 people, and add restrooms and shower/tub for Adult Day Service program in St. Paul.
- **First Care Medical Services**—Provide assisted living services to at least 18 clients in four subsidized senior apartment buildings in Fosston, Minnesota.
- **Lutheran Social Services**—Provide assisted living services to 40 people in three affordable apartment buildings in Carver County.
- **Highland Manor, Inc.**—Construction of 16 units of low-income senior housing in New Ulm in conjunction with a Section 202 grant from the U.S. Department of Housing and Urban Development (HUD), register the building as housing with services, and provide licensed home care.
- **Eventide Home Association**—Close Eventide 50-bed nursing facility in Mountain Lake and convert it into 14 units of affordable assisted living plus, out-of-home respite, and an 8-unit dementia care facility; collaborate with Good Samaritan Village to delicense 15 nursing facility beds and create private rooms.
- **Western Community Action, Inc.**—Use volunteer drivers and public transit buses to provide transportation in Marshall to distant medical clinics and local senior support services.

Other initiatives supported by the legislation included expanding in-home services programs, providing incentives for nursing homes to voluntarily close beds or convert them into assisted living, authorizing grants for providers who developed best practices and innovation in delivering services, and creating scholarship programs for direct care workers in nursing homes.<sup>831</sup> (Further details on the scholarship programs are provided in Section VI, Workforce Issues.)

In February 2002, the Minnesota DHS issued a report, “Keeping the Vision,” detailing progress on addressing local gaps in long-term services. The 2001 legislation had called for a local analysis and planning process to assess how well counties were currently meeting the long-term needs of older people. The services and supports most frequently rated by local authorities as

being inadequate included transportation, in-home respite and caregiver support, and chore services. Counties cited lack of start-up funding, lack of staff, and low reimbursement as barriers to further development. Other barriers included service delivery problems in rural areas, and lack of awareness of services by many seniors.

Local communities had also reported a shortage of accessible and affordable housing.<sup>832</sup> By early 2004, the DHS was able to report that 93 percent of counties reported that there were more home and community care options in their counties in 2003 than in 2001. Sixty percent of the counties described their supply of HCBS as “adequate.” As evidence of the increased availability of community services, the number of people receiving such publicly funded services totaled 38,555 in FY 2003, an increase of almost 60 percent over the number of participants in FY 2000.

**Programs for individuals who are elderly and/or physically disabled:** Four of Minnesota’s five Medicaid HCBS waiver programs cover elderly and physically disabled people: the Elderly Waiver, Community Alternatives for Disabled Individuals, Community Alternative Care, and the Traumatic Brain Injury Waiver. The fifth Medicaid waiver program is for people with mental retardation and related conditions (see below).

Six services are part of all five waiver programs: case management, homemaker services, home modifications, extended personal care assistant services (assisting with daily activities such as bathing and dressing),<sup>833</sup> respite care, and transportation. (Other services specific to a individual waiver program are noted within the descriptions for that program.)

*Elderly Waiver:* One of the largest publicly funded HCBS program operated by Minnesota is the Medicaid Elderly Waiver (EW) program, which grew from 9,772 participants in FY 2000 to 13,405 people in FY 2003. Services can be provided not only in the home but also in assisted living facilities, foster care homes, and residential care.

Two new services for the EW were approved by the Federal Government in April 2004: transitional supports and consumer-directed community support. Transitional supports are intended to help cover the activities and expenses incurred in moving from a nursing home to the community, such as expenses related to establishing housing such as lease or rental deposits,

essential furniture, and utility set-up fees and deposits. Consumer-directed community supports refers to a model of self-direction that the state has made available in other Medicaid waiver programs for several years, and will now implement in the EW program in April 2005. (For further details on self-directed models of care, see “Consumer Direction” below.)

*Community Alternatives for Disabled Individuals:* This is a waiver program for children and adults under age 65 who would otherwise require a nursing home level of care. The category includes people with physical disabilities or mental illness. Enrollment more than doubled from FY 2000 to FY 2003—from 3,957 participants to 8,420 participants.<sup>834</sup> An additional service provided under this program is supported employment.

*Community Alternative Care:* A small program, the waiver covers children and adults who are chronically ill or medically fragile and who require a level of care provided at a hospital. In FY 2003, CAC had 165 participants. An additional service covered under this program is extended prescription medication.<sup>835</sup>

*Traumatic Brain Injury:* Eligible individuals include people with a traumatic or acquired brain injury that is not congenital, who have significant cognitive and behavioral needs related to the injury, and who require the level of care provided in a specialized nursing facility. The program had 861 participants in FY 2003.

Two state-funded programs cover community services for older people as well. One is the Alternative Care (AC) program serving people whose income and assets would be inadequate to fund a nursing home stay for more than 180 days. Although the program reached a total enrollment of 12,233 people in 2002, the caseload dropped to 11,709 people in FY 2003 and was dropping further by the end of calendar year 2003, according to state officials. In the face of serious budget shortfalls, the 2003 Legislature had taken actions to reduce program expenditures, such as tightening eligibility criteria, expanding monthly fees, and imposing state recovery provisions (liens).<sup>836</sup>

Another state-funded home care program is the Consumer Support Grant program, which is an alternative offered to participants in the Medical Assistance (Medicaid) home care program who

can choose to switch to this consumer-directed model. They receive a grant to purchase the services of a personal care attendant and they can purchase supplies. The amount of the grant is based on an assessment by a case manager and on the prevailing rate for the provider they choose to use. They can receive their grant in the form of cash, vouchers for services, or direct payments to vendors.

**Programs for people with developmental disabilities:** The Medicaid Mental Retardation/Related Conditions (MR/RC) waiver program (which many other states call mental retardation/developmental disabilities) received about 79 percent of total Minnesota Medicaid waiver program expenditures in FY 2003. The number of recipients almost doubled from 8,313 participants in FY 2000 to 15,704 participants in FY 2003.<sup>837</sup>

In FY 2002, Minnesota spent \$139 per capita on the MR/RC waiver program, which was the second highest per capita rate in the country and three times the national average. Compared with the national average, Minnesota spent 22 percent *less* per capita on institutional care for people with mental retardation.<sup>838</sup>

In addition to the services available in all the waiver programs, the MR/RC program covers supported living and day training/habilitation. Supported living refers to a set of related services, including training and assistance in self-care, communication, interpersonal skills, sensory and motor development, money management, health care, community living, leisure and recreation, and reduction in challenging behaviors. Almost 70 percent of expenditures for the program goes to supported living services.<sup>839</sup>

According to state reports, the program has changed substantially since the late 1990s. For example, the state introduced consumer-directed community supports in certain counties in 1998, which allows recipients and their families to select their services and employ friends and family members if they wish. In FY 2003, almost 3,300 MR/RC waiver recipients chose consumer direction.<sup>840</sup>

In 2001, the state instituted an open enrollment period to reduce the program's long waiting list. The result was an increase of more than 5,500 people to the waiver program, a 50 percent jump

in the program's caseload. However, faced with state budget shortfalls, DHS reduced the rate of growth in the county budgets for the MR/RC waiver program in 2003. (DHS sets the county budgets for the waiver program, which counties may not exceed unless they pay for the excess.)

Still, the state reports that 3,485 people were waiting for MR/RC services as of June 30, 2003. Legislative researchers point out, however, that more than 2,600 people in this group were living with their immediate family, or an extended family member, and may have been receiving other Medicaid home care services, family support grants, or other publicly funded assistance while on the MR/RC waiting list.<sup>841</sup>

**Programs for people with mental illness:** The 1987 Minnesota Comprehensive Adult Mental Health Act established basic standards for a statewide network of services for this population. It is a state-supervised, county-administered system. The counties either provide services directly or have contracts with local mental health providers. Community Mental Health Centers located throughout the state provide a range of services such as outpatient treatment, medication management, and community-based services. Seventy-two residential treatment facilities generally have 16 beds or less and provide 24-hour supervised treatment for people who require a more restrictive, supervised setting before they can move to more independent living in the community.

Public mental health services are developed by each county board and must include (1) education and prevention services; (2) emergency services—24 hours a day, seven days a week; (3) outpatient services—individual, group, and family therapy, diagnostic assessments, medication management; (4) community support services—designed to help an individual function and remain in the community; (5) residential treatment services—a 24-hour program in a community residential setting; (6) acute care hospital inpatient treatment; (7) regional treatment center inpatient services; and (8) case management.

In 1997, Minnesota began a Mental Health Initiative intended to encourage counties to work together through greater regional planning to reduce reliance on facility-based care for people with mental illness (particularly care in the five state hospitals) through alternative service delivery models in the community. The state wanted to get away from an 87-county approach, state officials say, and instead encourage counties to develop service packages that could cross

county lines. Sixteen initiatives emerged out of this effort, with the largest regional grouping involving 18 counties working together.<sup>842</sup>

The initiatives have included expanded crisis services, housing and supports, and Assertive Community Treatment teams that provide intensive case management. The state also moved 250 state employees out of the state hospitals to work in mental health centers and other community facilities.

The Minnesota Legislature also turned its attention to adult mental health reform legislation in 2003, fostering a broad array of community-based mental health services, including a range of housing options. The intent was to develop services in closer proximity to where people lived, rather than forcing them to travel to regional treatment centers. The goal is the development of natural support systems, such as smaller hospital units, crisis response services, in-home supports, and long-term residential supports.<sup>843</sup>

A public-private partnership is also developing around mental health issues in Minnesota. The formation of the Minnesota Mental Health Action Group grew out of meetings among government officials and health care providers in 2002 to try to determine why people with mental health issues were increasingly being diverted to hospitals far from their communities for assistance and treatment. The organization now consists of mental health providers, hospitals, private organizations, health plans, advocates, and government agencies. An example of the activities that this effort has spawned is an East Metro Adult Crisis Stabilization Collaborative that involves three counties, three hospitals, four major health plans, and DHS. The group meets bimonthly and provides oversight to a mobile crisis response team.<sup>844</sup>

### **Residential Options**

Minnesota has seen an explosion of housing development for people with disabilities in recent years, particularly the development of assisted living residencies. Between 1997 and 2004, the number of residences doubled from 426 to 907, and the number of units tripled, rising from 13,000 to slightly more than 40,000 units. State officials say the state now has more assisted living residences and units than it has nursing homes and nursing home beds. Some of the

growth can be attributed, officials say, to nursing homes converting a portion or all of a facility into assisted living.<sup>845</sup>

The number of participants living in assisted living facilities and receiving services through the EW or the AC programs rose from 4,285 clients in 2000 to 7,403 clients in 2003. Nearly all these people were living in assisted living plus settings that provide 24-hour supervision.<sup>846</sup>

About 4,800 residential settings in the state come under the broad heading “group residential housing”; about 4,000 provide adult foster care, which are private homes that provide housing for up to five people. About 13,600 people were being provided adult foster care in 2003. About 9 percent were seniors, and 52 percent of the clients under age 65 were participants in the MR/RC Medicaid waiver program.<sup>847</sup>

### **Workforce Issues**

The Long-Term Care Task Force, in its 2001 report, gave significant attention to the issues affecting both the paid direct care workforce and the informal network of family caregivers. The report noted that Minnesota was experiencing a severe shortage of workers in health and LTC. In terms of family caregivers, the report pointed out that Minnesota had one of the highest labor force participation rates for women in the country, thus indicating the need for “supplemental assistance that working women need ...to provide care to frail relatives.”<sup>848</sup>

One measure that has evolved out of the concern about recruitment and retention of workers in nursing homes is a small scholarship program. The state has offered funds to nursing homes to provide scholarships to lower-wage employees who work at least 20 hours per week. The scholarships, which have averaged about \$1,000 for each eligible worker, can be used for any educational program that would lead to advancement within the facility or to a career in LTC, such as a certified nursing assistant training for a licensed practical nurse or registered nurse degree. The state set no limit on how much scholarship money an individual facility could distribute. Whatever a facility did spend was factored into its rate the following year.

In the first year (ending September 30, 2002), about 90 percent of the state's facilities gave out scholarships to just over 3,000 employees for a total of \$3 million. In the second year, about 75 percent of facilities gave out more than 2,400 scholarships that totaled \$2.5 million.<sup>849</sup>

Another direct care worker model than Minnesota has implemented is called Shared Care; it is available to people participating in the state's Medicaid Personal Care Assistance Choice program. This program allows people receiving personal care services to direct those services themselves. With Shared Care, two consumers can share a personal assistant, with the cost divided between the two people. One example would be a personal assistant helping two participants to go shopping together, for which the worker will be paid one-and-a-half times the regular rate.<sup>850</sup>

To help family caregivers of children with mental retardation, Minnesota provides a Family Support Grant, available to families with incomes up to \$76,170 in annual adjusted gross income (2003). Grants may not exceed \$3,000 per calendar year, and can be spent in any way that would help the family keep their child at home.

### **Consumer Direction**

In March 2004, the Federal Government approved Minnesota's request to expand consumer direction statewide to all its Medicaid waiver programs and to the Minnesota Senior Health Options (MSHO) and Minnesota Disability Health Options (MnDHO) programs. Consumer direction had been an option for people covered by the MR/RC waiver program since 1998, but only in 37 counties. DHS immediately began developing a timetable for full implementation of this expanded Consumer-Directed Community Supports (CDCS) program by April 2005.

As described in a DHS bulletin, the consumer-direction option

includes a range of allowable services and supports that can be tailored to meet an individual's needs. Recipients are able to describe services and supports in ways that are meaningful to them and customize supports to best meet identified needs. Part of the flexibility built into CDCS is the ability to completely customize one's community support plan.<sup>851</sup>

The participant directs development of his or her own Community Support Plan (care plan). The plan must delineate “individual specific parameters,” which include service outcome, how it will be met, what training and qualifications are required of providers, how the service will be monitored, and what the payment will be. DHS sets individual budgets, and all services and supplies must be provided within the budget amount. County or health plan case managers determine whether the Community Support Plan assures the participant’s health and safety, and they authorize services and complete an annual reassessment of the client.

Each participant must have a Fiscal Support Entity (FSE) to pay providers or workers. The FSE must provide, at a minimum, payroll assistance, and offer participants a range of services that allow the client to select how much autonomy he or she wants in employing, managing, and paying for services and supports. Clients will hire, fire, manage, and direct their workers.<sup>852</sup>

A \$900,000 federal grant under the Systems Change Grants for Community Living program is being allocated to a program called Pathways to Choice: Minnesota’s Consumer-Directed Personal Assistance Program. In describing its grant proposal, DHS noted that although the state has been offering consumer direction options to participants in the Medicaid Personal Care and several HCBS waiver programs, a chronic worker shortage has been a major factor limiting the use of the option. DHS planned to address this problem by developing a Consumer-Initiated Partnership and Support (CIPS) model. Through CIPS, consumers will access each other’s natural supports, such as family and neighbors, to provide personal care services.<sup>853</sup>

Consumers will have access to a registry of available workers to help match personal care attendants who want to work more hours with consumers who need more assistance. Workers on this registry will be paid a higher rate because provider agencies will charge only a fiscal intermediary fee.<sup>854</sup>

DHS planning director LaRhae Knatterud said the state had recently received a Robert Wood Johnson Foundation grant to educate people about consumer direction, including people who are not on Medicaid. According to Knatterud, the state would like to encourage consumers buying privately to consider consumer direction with an agency providing fiscal intermediary services.

## **Innovative Practices**

Minnesota's planning process for expanding its LTSS has involved establishing benchmarks to measure progress, a unique feature of state reform efforts. Another feature unique to Minnesota is its focus on how services and supports are financed. The 2003 Legislature called for the DHS to complete a study of nongovernmental resources, and to consider options to help individuals and families use their own resources to pay for needed LTSS.

### *Setting Benchmarks for Long-Term Care Reform*

The Minnesota Long-Term Care Task Force not only established priorities for a number of its strategies, it also set benchmarks to assess change in the state's system. The first five benchmarks are listed below, with the changes that have taken place as noted in the 2003 "Status of Long-Term Care in Minnesota" report:

- *Percent of public long-term care dollars spent on institutional vs. community care for persons 65+.*

This benchmark measures the relative proportion of the state's and each county's total budget for nursing home care and for community care (Medicaid EW program, state-funded AC program, and Medical Assistance Home Care program). Minnesota's use of nursing home care was higher than the national average with the statewide proportion of expenditures for institutional care at 86 percent in 2001, 14 percent for community care. In 2003, the proportion had shifted to 80/20, with expenditures in the 87 counties ranging from 67.2/32.8 percent in Crow Wing County to 96.5/3.5 percent in Cook County.

- *Percent of nursing home residents 65+ that is case mix A.*

"Case mix A" is defined as a less-disabled class of residents who have limitations in four to five daily activities (such as bathing, dressing, and eating) but no special conditions and no nursing rehabilitation needs. The state believes many of these residents can be maintained in the community if proper supports are available.

This benchmark is in the process of being redefined because the case mix A system was replaced in October 2002, and the benchmark now needs to use measures in the new system. In 2002, 16 percent of nursing home residents were case mix A.

- *Percent of Elderly Waiver and Alternative Care recipients that is case mix B–K.*

This benchmark measures the percent of seniors in the EW and AC programs that need more intensive services to remain in the community because of greater difficulties with daily activities. In 2002, 37.2 percent of statewide clients in these two programs had the higher case mix levels. That proportion had increased to 39.7 percent in 2003, indicating that more intensive services *were* being provided to keep people in their homes and communities despite a high disability level.

- *Ratio of nursing home beds per 1000 persons 65+.*

Minnesota's ratio of nursing home beds per 1,000 people has been higher than the national average. The Minnesota ratio was 83.9 beds per 1,000 people 65 and older in 1993. By 2002, the ratio was down to 65.7 beds per 1,000 (compared with 49 per 1,000 nationally). There is wide variation among counties, with the ratio ranging from 132.3 in Norman County to 22.4 in Anoka County.

- *Percent of EW/AC recipients in assisted living that is case mix B–K.*

This benchmark measures the proportion of disabled recipients in assisted living settings, with case mix scores of B–K reflecting need for intensive services. To reduce reliance on nursing homes, the state needs an adequate supply of housing options that offer high levels of services. In 2003, 54 percent of assisted living residents receiving publicly funded services were in the case mix B–K category.

The state concluded in its 2003 status report that the five benchmarks

indicate that the measures are changing in the direction called for in the 2001 reform. The percent of total public long-term care dollars spent on institutional care is declining, and the proportion spent on community care is increasing. The ratio of nursing home beds per 1000 has continued its downward trend....

The “most dramatic” change, the report notes, has been the “increased percentage of more disabled clients supported in the community with the EW and AC programs.”<sup>855</sup> Knatterud says the state is “going in the right direction on all the benchmarks.”

### *Public-Private Financing Study*

The 2003 Legislature called for the DHS to complete a study by January 2005 of nongovernment resources for LTSS, and to look at the feasibility of various options to help individuals and families use their own resources for this purpose. “New sources of non-governmental funds to pay for long-term care are increasingly seen as options that could blunt some of the projected growth in government entitlements for long-term care services,” says a DHS fact sheet on the project.<sup>856</sup> The options include the following:

- Health insurance options, especially the inclusion of LTC in Medicare supplemental plans.
- LTC insurance options, including incentives to purchase such insurance and expansion of individual and group-based products.
- Life insurance annuities and combined life and LTC insurance products.
- Reverse mortgage products and other options that make use of home equity.
- Universal LTC tax/savings plans, similar to a plan passed by the Hawaii legislature but vetoed by the governor.
- Personal savings and pensions.
- Family care, including incentives for families to provide services or supports or to pay for services and supports through special loans.

The results of this analysis, says the department, will be a listing of these options from strongest to weakest in terms of their ability to achieve the state’s policy goals and maximize private resources. “Our goal is to find the right way to ‘slice and dice’ this set of options so they work in Minnesota,” says Knatterud. The department will attempt to identify the most effective tools to implement the options, such as tax incentives and consumer education and information.<sup>857</sup>

DHS and the Minnesota Board on Aging sponsored a series of briefings on these financial issues throughout 2004 that included bringing in national experts to discuss possible approaches, such as LTC insurance, reverse mortgage products, and various tax savings plans. The last of the briefings in December 2004 was intended to be a statewide conference to review all private financing options that had been explored in the previous regional briefings, and to obtain input from Minnesotans on which options they considered to have the greatest potential to meet their needs. To inform and involve the public in this effort, DHS began distributing an email newsletter in December 2003, and posting notices on the DHS Web site about briefings, forums, and focus groups being held as part of the project.

The DHS also has asked the University of Minnesota to apply national data from the Employee Benefit Research Institute on future retirement income and assets to Minnesota. The report is expected to help the state determine the capacity of Minnesotans to pay for health and LTC costs in the future and suggest options for addressing the adequacy of income and assets.<sup>858</sup>

Forty-eight percent of Minnesota's top 25 public and private employers offer LTC insurance, compared with a national average of about one-third of all large private employers. The state of Minnesota has been offering an LTC insurance plan to its employees since 2000 (and later to retirees). When the plan was opened in October/November 2000, initial enrollment was 11,000 people (75 percent employees, 22 percent spouses, and 3 percent parents of employees). The 18 percent rate of participation of the 61,000 eligible state employees was the highest initial enrollment of any public employee LTC insurance plan in the country.<sup>859</sup> (For details on the plan's major features, see Attachment 4.B.)

### **Future Plans and Challenges**

Like many other states, Minnesota has had to grapple recently with budget deficits and shrinking expenditures, resulting in some tightening of human services spending. For example, the 2003 legislature limited increases in enrollment and reduced spending for the Medicaid HCBS waiver programs. Still, Minnesota has been moving forward on many fronts that significantly expand the options available to people with disabilities to live and work in the community and to self-direct their personal care services.

The landmark work of the Long-Term Care Task Force continues to generate ideas and to stimulate initiatives. The Task Force set benchmarks to measure the state's progress in rebalancing its LTC system, and status reports help to keep the momentum going. In Minnesota, the 87 counties deliver LTSS, and their efforts are being bolstered by community service grants from the state and other state general revenue dollars. Minnesota is also devoting considerable attention to the question of the most effective way to encourage greater personal financial responsibility for LTSS to conserve public resources for its most vulnerable populations. Its review of these issues should produce significant proposals in 2005 for other states to consider.

## Attachment 4.B

### Minnesota Long-Term Care Insurance Plan for State Employees<sup>860</sup>

The state offers two LTC insurance plans, one for state employees and their spouses and parents, and another for retirees and their spouses. The plans differ in underwriting, benefits, and costs. The employee plan has 48 possible plan combinations; the retiree plan has 32 plan combinations.

The main decisions an employee or retiree must make are as follows:

- *Lifetime maximum amount.* For an employee, six possible limits are provided from \$100,000 to \$600,000. For retirees, four limits are possible from \$58,400 to \$219,000.
- *Daily benefit amount.* The maximum dollars that can be paid out each day is either \$80 or \$120 per day.
- *Inflation protection.* Participants can choose a lifetime 5 percent automatic benefit increase (no premium increases) *or* a guaranteed benefit option that allows the participant to purchase additional coverage in the future.

Premiums are based on the participant's age when coverage becomes effective and will not increase as the employee ages. Examples include \$20.03 a month for a 45-year-old and \$47.16 for a 65-year-old. (These premiums, which were the cost of the plan in 2001, remained constant through 2004.) Costs could be lower because Minnesota law allows residents to claim a tax credit of up to 25 percent of LTC premiums paid, or \$100 a year, whichever is lower.

The benefits include assistance at home, adult day care centers, assisted living facilities, or nursing homes. The plan pays for a variety of services for people who are unable to care for themselves because of an injury, chronic illness (such as arthritis), acute episode (such as a stroke), or cognitive impairment (such as Alzheimer's).

## ***Texas***

*The Legislature envisioned...a health and human services system which is not simply more efficient and cost effective...but which is transformed in very fundamental ways to significantly improve the quality of services provided to Texans who need these services.*

—H.B. 2292 Transition Plan, November 2003

### **Introduction**

For many years, Texas had a system of LTSS that was heavily dependent on institutional care rather than on HCBS. The state had excess bed capacity in its nursing homes and a high institutionalization rate for people with developmental disabilities. This pattern began to change beginning in the late 1990s.

In response to the U.S. Supreme Court *Olmstead* decision, then-Governor George W. Bush issued an Executive Order in September 1999 directing the Texas Health and Human Services Commission (HHSC) to review community services and supports available to people with disabilities in Texas and to propose improvements. With the creation of the Promoting Independence Advisory Board that year, work began on expanding access to community services.

A Promoting Independence Plan was delivered to the 77th Legislature in January 2001, with a revised plan issued in December 2002. The recommendations in these plans, and subsequent actions by the legislature, have produced a number of initiatives that have greatly increased opportunities for people with disabilities to leave institutions to live in the community and to direct their own services and providers.

One of the most important of these innovations, called the Rider 37 initiative (named for the rider to the state appropriations act that set it in motion), has resulted in the relocation of thousands of institutionalized Texans to community settings since its enactment in 2001. (Texas was also one of the first states to pioneer the concept of Money Follows the Person<sup>861</sup> in connection with its deinstitutionalization drive, which a number of other states have adopted.)

Even before the Promoting Independence initiative began, however, Texas was also breaking new ground with its STAR+PLUS demonstration program—a Medicaid pilot project to integrate

delivery of acute and long-term services through a capitated managed care system. Today, the project serves more than 60,000 aged and disabled people in Harris County (the Houston area).

## **Background**

The total Texas population in 2003 was almost 22 million people, ranking second only to California. About 15 percent of the population had incomes at or below the poverty level in 2001. From 1998 to 2000, Texas had the eighth highest rate of poverty in the nation. The percentage of the population age 65 or older totaled 9.9 percent, compared with the national average of 12.4 percent. About 3.6 million people had one or more limitations in ADLs in 2002.

Fifty-two percent of the population is white and 11.5 percent is black. Nearly one in three Texans are of Hispanic origin (32 percent compared with the national average of 12.5 percent). People who are foreign born constitute 13.9 percent of the population.<sup>862</sup>

## **Integrating Services for People with Disabilities**

***Reorganization to improve integrated service delivery:*** The Texas HHSC was created in 1991 to oversee the state's health and human services departments, which included the Texas Department of Mental Health and Mental Retardation (TDMHMR), Department of Human Services, and Department on Aging. As this umbrella agency grew, it came to encompass 11 separate agencies that have administered more than 200 programs, employed about 50,000 state workers, and operated from more than 1,000 different locations across the state.<sup>863</sup>

In May 2003, the Texas legislature enacted H.B. 2292, consolidating the duties and functions of the 12 agencies into a structure composed of HHSC and four new departments. The transition plan for the new organization noted that

Texans who seek the services and protections on the state's health and human services enterprise today face a bewildering array of organizations, office locations, and overlapping (sometimes conflicting) programs and services. ...there is a lack of coherence and a lack of integration in the services being provided to individual clients, groups of clients, or geographic areas.<sup>864</sup>

Although the new departments were all in place by the summer of 2004, full implementation was expected to take three to five years.<sup>865</sup>

Two of the new departments took over responsibility for all the services for people with various disabilities:

- **Department of Aging and Disability Services (DADS):** Consolidates the mental retardation and state school programs of the former TDMHMR, the community care and nursing home services programs of the former Department of Human Services, and the aging services (mostly Older Americans Act programs) from the Department on Aging.
- **Department of State Health Services:** Consolidates the health programs and the mental health community services and state hospital programs formerly operated by TDMHMR and the services formerly provided by the Texas Commission on Alcohol and Drug Abuse.<sup>866</sup>

The other two departments are the Department of Family and Protective Services (child and adult protective services and child care regulatory services) and the Department of Assistive and Rehabilitative Services (services for the blind and visually impaired and deaf and hard of hearing and early childhood intervention services.)

A major issue for the new DADS involves the separate local service systems and processes of the three agencies that have been merged. The Department on Aging operates, for example, through 28 Area Agencies on Aging, many of which are housed in regional municipal governing bodies. The Department of Human Services operates through 400 local offices in 10 regions that serve all of the state's 254 counties. TDMHMR provides services through local authorities in each county that provide services to people with mental retardation directly or through a network of local providers. The opportunity exists, says DADS commissioner Jim Hine, of creating "a consistent, integrated and accessible 'front door' for service delivery."

Another important feature of the reorganization is the integrated eligibility determination process. The proposed redesign of the state systems will allow Texans to apply for medical and aged and

disabled services, food, and cash assistance in person, through the Internet, over the telephone, by fax, or by mail. Call centers are to be established to receive and process applications.<sup>867</sup>

Another pilot program is integrating funding and services for people with mental health and substance abuse problems. Begun in 1999, NorthSTAR is an initiative of TDMHMR and the Texas Commission on Alcohol and Drug Abuse that is operating in the Dallas area to provide a single system of care for mental health and chemical dependency treatment.

The 2003 legislature directed the Health and Human Services Commission to expand managed care further. HHSC contracted with the Lewin Group in 2003 to project the cost impact of such an expansion. Based on the consultant's findings, HHSC has developed a framework for expansion.<sup>868</sup>

### **Expansion of Community Supports**

The Promoting Independence Advisory Board became the S.B. 367 Interagency Task Force on Appropriate Care Settings for Persons with Disabilities after passage of S.B. 367 in May 2001, which called for status reports on HHSC plans to "ensure appropriate care settings for persons with disabilities." In its December 2002 report, the task force noted a number of steps that had already been taken, such as the following:

- the creation of relocation specialists to help assist people who were making the transition from institutions to community residential settings,
- the development of a new Texas Home Living Medicaid waiver program by TDMHMR to enable the state to move people off waiting lists, and
- provision of housing vouchers for people transitioning from nursing homes.

**Programs for individuals who are elderly and/or physically disabled:** Texas operates a number of Medicaid HCBS waiver programs, Medicaid state plan services, and state-funded services under what DHS calls its Community Care Program for the elderly and adults with disabilities. (These programs have now been folded into DADS.) The *major* programs that serve the largest number of people include the following:<sup>869</sup>

### *Medicaid-Funded Programs*

- ***Primary Home Care*** is a Medicaid Personal Care program under the Medicaid State Plan. It is the largest Texas community care program in terms of participants, with an average monthly caseload of about 51,900 people of all ages who have limitations in at least one personal care task. The program provides personal care services (assistance with daily activities such as bathing and dressing), homemaking, and medical escort services.
- ***Community Attendant Services*** is a variant of the Primary Home Care program for people with slightly higher incomes. The financial eligibility standard is an annual income of up to 300 percent of SSI, or \$1,656 a month in 2003. The program served an average of almost 35,000 people per month in 2003.
- ***Community-Based Alternatives (CBA)***, which is a Medicaid HCBS waiver program, had an average monthly caseload of about 30,300 people in FY 2003. Services include personal assistance, adaptive aids, medical supplies, adult foster care, assisted living/residential care, nursing, respite care, home-delivered meals, and home modifications.
- ***Day Activity and Health Services*** are offered as an optional Medicaid State Plan service under rehabilitation services. The program provides nursing and personal care; noon meals and snacks; physical rehabilitation; transportation; and social, recreational, and educational activities. Individuals may receive up to 10 hours of services per day, five days a week. In 2003, this program provided day services to a monthly average of almost 16,000 people.

### *State-Funded Programs*

- ***In-Home and Family Support*** provides direct grants to beneficiaries or their families, up to a maximum of \$3,600 annually. About 3,800 people receive an average cash subsidy of \$150 per month. (They may also be eligible for a one-time grant of up to \$3,600.) This program is for people of any age with a physical disability that substantially limits the person's ability to function independently. People with incomes at or above 105 percent of the state's median income must contribute to the cost of services on a sliding fee schedule. Grants may be used for therapies, medications, skills training, transportation,

respite care, equipment, home modifications, or adaptive aids, or personal assistant services for medically fragile people.

- ***Consumer-Managed Personal Assistant Services*** targets adults age 18 or older with disabilities who are capable of self-directing workers who provide personal care. Contract agencies determine client eligibility and the amount of care needed. These agencies also develop a pool of potential personal assistants and provide emergency backup if an assistant fails to show. The program serves about 700 people a month.

**Programs for people with mental retardation/developmental disabilities:** Until the reorganization of the HHSC agencies, programs for people with MR/DD were split between the Department of Human Services and TDMHMR. DHS operated the Medicaid Community Living Assistance and Support Services (CLASS) program for people with developmental disabilities. The definition of the eligible population for these services is “persons with related conditions,” which is defined as severe disabilities other than mental retardation (such as epilepsy, brain injuries, and spina bifida) that originated before age 22. The caseload was about 1,800 people per month in FY 2003.

TDMHMR has operated the HCBS Medicaid waiver program for people with mental retardation, which served an average monthly caseload of about 6,700 people in FY 2003. Both waiver programs offer the same menu of services as do the waiver programs for the elderly and physically disabled: nursing, respite care, home modifications, therapies, adaptive aids and supplies, and emergency response systems. The CLASS program also offers personal attendant services.

In 2000, TDMHMR implemented a process known as the Community Living Options Process for individuals living in state-operated campus facilities and community ICF/MR programs. The process helps identify individuals who want to seek an alternative living arrangement. The department may provide Medicaid waiver services to these individuals, but the waiting list for such services is very long. As of February 2004, there were 908 ICF/MRs in Texas (including 13 state schools and 895 public or private ICF/MRs) serving more than 12,400 individuals).<sup>870</sup>

Governor Rick Perry issued an Executive Order (R.P. 13) in April 2002 directing TDMHMR to develop a Medicaid “essential services” waiver called the Texas Home Living Waiver. The intent is to move people who are Medicaid-eligible but currently receiving state-funded services to the Medicaid waiver program, thus freeing up state general revenues to create additional program slots for people on the waiting list. Services covered by this program include community support, day habilitation, supported employment, specialized therapies, minor home modifications, adaptive aids, and dental treatment.

Eligible recipients for these waiver services are people whose needs can be met within a \$10,000 per year cost ceiling. The department identified 1,915 people whose current general revenue-funded community services cost between \$3,500 and \$10,000 per year. The Federal Government approved the waiver application in February 2004; enrollment was scheduled to begin in April 2004.

Despite this array of community programs and services, there were still 5,000 people in the 13 State Mental Retardation Facilities in 2003. In addition, waiting lists for community services continue to be very large. In September 2002, 11 individuals and The ARC of Texas filed a class action complaint against HHSC, the Department of Human Services, and TDMHMR for failing to provide people with MR/DD with community-based options and services. The complaint charged that about 17,500 people with mental retardation were on waiting lists for HHCS services and another 7,300 people had requested but not received CLASS waiver services. Final adjudication of all issues in the case had not been reached as of October 2004.<sup>871</sup>

**Programs for people with mental illness:** TDMHMR has been contracting with 39 Community Mental Health Centers, which are also called Local Mental Health Authorities, across the state, and NorthSTAR, a Medicaid managed care plan that serves seven counties in the Dallas region. (The Texas DHS now has responsibility for mental health programs.) Each authority develops policy and coordinates and allocates resources within its local service area, and generally contracts with another organization to provide actual services.

A key model for service is the Assertive Community Treatment (ACT) program, a national program endorsed by the National Alliance for the Mentally Ill and adopted in Texas in 1995.

ACT clinical and rehabilitation staff provide psychiatric, substance abuse, nursing services, medication management, employment, and housing services through one service delivery system. The teams also work with families to provide education and support.

About 50 teams throughout the state provide these services to people with severe and persistent mental illness who have not responded to traditional mental health approaches. The typical recipient of services has schizophrenia or another serious mental illness, such as bipolar disorder or major depression, and has experienced multiple psychiatric hospital admissions.<sup>872</sup>

S.B. 367 (2002) required TDMHMR to identify people who have been admitted to state mental health facilities three or more times in 180 days or less as being at imminent risk of requiring placement in an institution. The legislation required the state to develop strategies to meet the needs of these people in the community. Monthly reports track this population for the local community mental health authorities so that intensive services can be focused on this group.<sup>873</sup>

### **Residential Options**

“Affordable, accessible, integrated housing remains an integral part of successfully transitioning individuals from institutional care into the community,” noted the S.B. 367 Task Force.<sup>874</sup>

Governor Perry and the Legislature requested that HHSA, DHS, and the Texas Department of Housing and Community Affairs (TDHCA) develop a housing assistance program to assist with these transitions from nursing homes to residential settings.

Also pursuant to Governor Perry’s April 2002 Executive Order, TDHCA sets aside funds to serve people with disabilities who want to move out of institutions to community settings. The department set aside \$2 million to go to nonprofits, public housing authorities, and units of local government that want to provide Tenant Based Rental Assistance (TBRA), which include rental subsidies, security deposits, and utility allowances (for 24 months). The income of a consumer assisted with TBRA cannot exceed 80 percent of the area median income, and 90 percent of the people assisted must have incomes below 60 percent of the area median income.

An eligible entity could apply for up to \$500,000. Although the department sent out information and held workshops across the state with more than 600 entities (nonprofits, housing authorities,

and independent living centers), the program got off to a slow start. In 2003, only four applications were received and approved for a total of \$442,681 to provide rental assistance to 40 people. After potential housing applicants said that the 6 percent administration fee allowed by the department was too low, the TDHCA raised that fee to 10 percent. But only one other application was approved in July 2004 for \$103,194 to help 10 more people with rental assistance.<sup>875</sup>

In August 2001, the housing agency received 35 out of 400 housing vouchers made available nationwide by HUD under a program called Project Access Housing Choice Voucher Program. The vouchers are provided to people with disabilities who want to leave nursing homes to live in the community. The vouchers help them to move into subsidized housing. The first Project Access Housing Choice Voucher was issued in Texas in August 2002.<sup>876</sup>

The DHS also created Transition to Life in the Community grants, a new statewide service within the In-Home and Family Support program. The program targets people moving from nursing homes to the community, and provides grants in amounts up to a maximum of \$2,500 to be used for set-up costs. As of August 2003, the program had helped 91 individuals with initial rent and utility deposits, and other relocation-related expenses and household items.<sup>877</sup>

Adult foster care is provided in DHS-enrolled homes. This service provides 24-hour living arrangements, and includes meal preparation, housekeeping, and help with personal care. Residential care in DHS-licensed facilities provides services to eligible adults who require access to services on a 24-hour basis, but who do not need daily nursing intervention.<sup>878</sup>

### **Consumer Direction**

In July 2002, Texas was one of the first states to receive approval from CMS for the implementation of consumer direction in multiple Medicaid HCBS waiver programs and in the Medicaid state plan. Four Texas programs had put consumer direction into practice in September 2001: three programs in DHS/DHS—CLASS, the Deaf/Blind waiver, and the Consumer-Managed Personal Assistant Services programs; and one program in TDMHMR—In-Home and Family Support program. In January 2002, consumer direction was added to the Medicaid Primary Home Care (personal care) program in DHS. With the added federal approval in 2002, Texas was able to provide vouchers for participants of the CBA and STAR+PLUS programs.<sup>879</sup>

Consumers can manage, recruit, hire, supervise, and fire their workers. A fiscal agent handles employer-related administrative functions, such as payroll and tax-related reports, and provides back-up personal assistants when a worker is sick or fails to show up. A more limited version of consumer direction is the Consumer-Managed Personal Assistant Services model. The program contracts with licensed agencies to provide personal assistants. The agency determines consumer eligibility and the amount of care needed, develops a pool of potential workers, and provides emergency backup. The client supervises the worker.

Use of consumer direction was moving slowly in some programs, however. HHSC reported the utilization rate of CDCS varied from a high of 28 percent in CLASS to a low of .07 percent in the CBA program and Primary Home Care. The HHSC report noted that the state faced a key challenge in ensuring that enrollees in the home- and community-based programs “are aware of and sufficiently educated about” consumer direction.<sup>880</sup>

To help consumers understand the concept and how they can use consumer direction, Texas sought and was granted a federal Systems Change Grant. The grant will help the state test two models of consumer control in one region, then statewide. One model calls for participants to manage their own budgets *and* hire and supervise their workers, while under the other model, participants will handle the personnel duties but not have budget responsibility.

### **Innovative Practices**

Texas is breaking new ground with several of its LTSS projects. Other states have developed projects similar to the two described below, but Texas stands out because of the considerable number of people with disabilities involved in these efforts and also by specific strategies the state has adopted. In the Rider 37 initiative, the state and its community partners have devoted significant resources to facilitate the transition from nursing home to community living for the participants.

The STAR+PLUS project integrates acute and long-term services for Medicaid recipients. One of the health maintenance organizations in the pilot received approval from CMS in 2002 to operate as a Medicare+Choice plan.<sup>881</sup> For dual-eligible people who choose this plan, the state has removed the three-prescription-per-month limit that applies to other project participants.

***Rider 37 (Money Follows the Person):*** A number of factors were responsible for the passage of Rider 37, including the U.S. Supreme Court's *Olmstead* decision, the creation of the Promoting Independence Advisory Board and its subsequent development of a plan and recommendations, and legislative action to implement some of those recommendations.

In September 2001, the Texas legislature included a rider in the state appropriations act (Rider 37), which allowed the Texas DHS to move Medicaid funding from its nursing facility budget to its budget for Community Care Programs when a Medicaid recipient moves from a nursing facility into a home or other residence in the community. The program is called Money Follows the Person.<sup>882</sup> A nursing home resident who wants to move to the community does not have to wait for a slot to open up in a Community Care Program, particularly the Medicaid waiver programs that have long waiting lists.

The state has entered into relocation contracts with various organizations, such as independent living centers, that have helped to publicize the effort, identify individuals who want to move to the community and are eligible to do so, and then assist them in making the move. These organizations received Community Awareness and Relocation Services funding to publicize the project and to help individuals make the transition to the community. For the latter, grants of up to \$2,500 per individual are available as start-up funds for furniture, utility and security deposits, and other essentials.

As of the end of February 2004, more than 3,400 people had made the transition from an institution to the community under the Rider 37 program and its successor amendment, Rider 28. One-third of the participants were under age 65, with the remaining two-thirds age 65 and older. Within about half of the regions in the state, between one-third and one-half of the people who relocated moved into assisted living facilities. Within other regions, greater percentages of individuals moved into their own homes or family homes. (Advocates have noted, however, that lack of affordable and accessible housing still presents a significant barrier for people moving out of nursing homes.)<sup>883</sup>

Many observers believe that strong and persistent work from organized advocates has been essential to the success of the Rider 37 effort to date, as has been the ongoing partnership and

collaboration among advocates, DHS, and other groups. The Promoting Independence Interagency Task Force, which formalized this collaboration, has been called a task force “with high visibility and powerful influence.”<sup>884</sup>

In September 2003, the Federal Government gave Texas a grant of more than \$730,000 to help educate employees and advocates involved in the transition process about community care options so they could better assist people leaving nursing homes to make appropriate community choices.

#### *Integrated Funding and Services for Acute and Long-Term Services*

Senate Concurrent Resolution 55 in the 74th legislative session required the HHSC to pilot a cost-neutral model for the integrated delivery of acute and long-term services for aged and disabled Medicaid recipients in Harris County. The project required getting federal approval for two Medicaid waivers, 1915(b) and 1915(c), in order to mandate participation and to provide home- and community-based services. The Federal Government approved the waivers in February 1998.

STAR+PLUS is a single capitated managed care delivery system that was serving 63,630 people as of July 1, 2004. For people who are dually eligible for Medicare and Medicaid (about half of the enrollees), STAR+PLUS covers LTSS, and Medicare provides primary and acute care. Participants may choose from two HMOs.

While dually eligible people constitute only 23 percent of the state’s Medicaid population, they account for almost 60 percent of Medicaid’s expenditures. Controlling costs for this population was a major reason for the demonstration, as was offering a way to provide a continuum of care with a wide range of options and increased flexibility to meet individual needs.<sup>885</sup>

LTSS provided by the HMOs include day activity and health services and personal assistance. Additional services include adaptive aids, adult foster home services, assisted living, emergency response services, medical supplies, minor home modifications, nursing services, respite care, and therapies. A care coordinator is responsible for coordinating the client’s acute and long-term services, even if the client is a dually eligible person who receives Medicare services from a provider not affiliated with the STAR+PLUS HMO.

## **Future Plans and Challenges**

In addition to STAR+PLUS, the state has undertaken to test consolidation of a number of different Medicaid waiver programs for different groups of people with disabilities. The 75th legislative session called for HHSC to conduct the three-year pilot in one county. Under this demonstration, called the Consolidated Waiver Program, HHSC provides a single array of services to multiple populations with different types of physical disabilities who are sharing common providers with consistent rates.

The pilot began in December 2001 and serves about 200 people annually. It combines funding from five Medicaid HCBS waiver programs. Applicants must be waiting for Medicaid waiver services from one of the five programs and must meet level-of-care criteria for ICF/MR care or meet the medical necessity criteria for nursing home care. The target population is people who are medically fragile or have mental retardation.

In the legislative session immediately following issuance of the Promoting Independence Plan, legislators appropriated expansion monies for all the state's community waiver programs, the development of transition services, and alternative family-based options for children. For example, \$63 million was appropriated for FY 2002 to provide community services for 5,600 people on waiting lists. In addition, the state received five federal Real Choice Systems Change Grants in 2003 that totaled \$3.3 million. One initiative that will be funded with this money is the Creating a More Accessible System for Real Choice for Long-Term Care Services (the Texas Access Project). In two areas of the state, models of "system navigation" will be tested to help individuals and families cut through state government bureaucracy and red tape to obtain needed LTC services.

Still, in the face of the bleak budget situation that developed in Texas, progress on expanding community options slowed. Long waiting lists for community services remain a major challenge for the state. However, the Promoting Independence Plan made clear that the state viewed its response to the *Olmstead* decision as an ongoing process. State officials say they intend to continue moving forward in their effort to identify individuals who want to move out of nursing homes to the community, help those individuals make that transition, reduce waiting lists for

community services, and coordinate all LTSS.<sup>886</sup> The restructuring of the human services agencies, which will take several years to complete, offers the possibility of greatly improved coordination and integration of publicly funded services for people with disabilities, but it also involves a substantial amount of work and commitment on the part of agency personnel as well as many other stakeholders.

## ***Indiana***

*Indiana has a long history of innovation and support for community-based long-term care.*

—Family Caregiver Alliance, 2002

### **Introduction**

Indiana began moving away from institutional care for people with disabilities and toward expanded HCBS in the early 1990s. Legislative and gubernatorial actions led to the creation of commissions and task forces to study the state’s LTSS and to recommend ways to shift greater resources to HCBS. The early 1990s also saw the creation of the state-funded Community and Home Options to Institutional Care for the Elderly (CHOICE) program, and a Medicaid HCBS waiver program for people with MR/DD.

A quick look at Indiana’s statistics shows, however, that the state still must overcome significant hurdles if it is to meet its goal of shifting greater resources toward home- and community-based care for people with disabilities. About 76 percent of its Medicaid LTC dollars (\$1.5 billion) were allocated to institutional care in FY 2003, compared with the national average of 67 percent. The state has, however, made significant strides in the last several years to build on its earlier initiatives, and considerable pressure has been placed on state agencies by advocates and lawmakers to continue the momentum.

From 1992 to 2000, the state reduced funding for institutional settings by 52 percent, compared with a 16 percent reduction nationally. From 2001 to 2003, the state helped to create options for more than 4,800 elderly and 2,000 people with disabilities to live in their homes and communities. A priority for the state is the expansion of community services for 1,000 more people with developmental disabilities.<sup>887</sup>

### **Background**

Indiana calls itself “the crossroads of America.” A midwestern state, Indiana had a total population of about 6.1 million people in 2000, 87.5 percent of whom are white. Only 8.4 percent of the state population is black and 3.5 percent is Hispanic. The population age 65 and

older totals about 752,000 (one in eight Hoosiers), of whom about 42 percent have some limitation in two or more ADLs, as do about 18.5 percent of the population age 21 to 64.<sup>888</sup>

About 9.5 percent of the population had incomes at or below the poverty level in 2000 (compared with the national average of 12.4 percent).

### **Integrating Services for People with Disabilities**

The Family and Social Services Administration (FSSA) is an umbrella agency that houses the Division of Disability, Aging and Rehabilitative Services (DDARS) and the Division of Mental Health and Addiction (DMHA). Within DDARS are the Bureau of Aging and IN-Home Services and the Bureau of Developmental Disabilities. This structure was created by the Indiana General Assembly in 1991 “to better integrate the delivery of human services.”<sup>889</sup>

FSSA had a \$6.3 billion budget in FY 2003. The agency acts as the safety net for nearly a million Hoosiers, about one in six people in the state. In 1992, the IN-Home Services program was created, bringing together funding from a variety of programs for the elderly and people with disabilities: the state-funded CHOICE program, Older Americans Act and Social Services Block Grant programs, and seven Medicaid HCBS waiver programs.

For these programs, the state’s 16 Area Agencies on Aging act as single entry points, providing information about options and assistance in applying for benefits. All community services for the elderly and people with disabilities are integrated and delivered through the Area Agencies on Aging. In 1998, the National Governors Association (NGA) recognized Indiana for its interagency collaboration and innovations. Two strengths of the Indiana system, the NGA said, were the authority given to case managers to blend funds for home care and the decentralization of power across Indiana’s Area Agencies on Aging.<sup>890</sup>

### **Public-Private Partnership**

Indiana is one of only four states that are participating in a public-private LTC insurance program that links purchase of private LTC insurance with Medicaid coverage of LTSS. The program promises protection from estate recovery of a Medicaid-covered nursing home

resident's assets after death if the individual has purchased LTC insurance that initially paid for the institutional care.<sup>891</sup>

The Indiana program offers two types of asset protection: dollar-for-dollar and total asset protection. Under the dollar-for-dollar option, for every \$1 of benefits that a policy pays out, the purchaser earns \$1 of asset protection. To earn total asset protection, on the other hand, the consumer must purchase a policy in an amount that equals or exceeds a specified amount (a state-set dollar amount), which was \$187,613 in 2004.<sup>892</sup>

The enabling legislation for the program was enacted in 1987; federal approval was received in December 1991. The first policies became available in May 1993. By September 2004, about 31,000 people age 19 through 90 had purchased policies from the 12 insurance companies that have been approved by the state to sell the policies. Fifty-three percent of the purchasers were under the age of 65 (average age of purchasers was 62). About 80 percent of the policies purchased included coverage for both nursing home care and home and community care.<sup>893</sup>

Through legislation enacted in May 1999, Indiana residents who pay premiums for partnership policies could (beginning with the 2000 tax year) receive a 100 percent tax deduction for the cost of the premiums. There is no cap on the deduction. Indiana has also made LTC insurance a pretax insurance option for all state employees.

### **Expansion of Community Services**

Over the years, Indiana has had a much higher than average supply of nursing home beds and high rates of institutionalization for people with disabilities. Of total Medicaid LTC expenditures in Indiana in FY 1997, about 91 percent went to institutional care and 9 percent to HCBS. By FY 2003, that split had dropped to 76 percent for institutional care and risen to 24 percent for HCBS.<sup>894</sup> From 1992 to 2000, the state reduced funding for institutional settings by 52 percent.<sup>895</sup>

The state's focus on community services was given impetus by several commissions in the late 1990s and subsequent years. The first major development was the 1997 passage of S.B. 317, which called for community options for people with developmental disabilities. An S.B. 317

Task Force appointed by the governor developed a comprehensive plan of reforms in 1998. The state has since devoted significant resources to implementing the S.B. 317 plan.

In September 2000, Governor Frank O'Bannon issued an Executive Order that identified the FSSA as the agency in charge of planning to address the issues raised by the U.S. Supreme Court *Olmstead* ruling in 1999, which called for greater community integration of people with disabilities. The Executive Order required FSSA to conduct a comprehensive study of services for people with disabilities and to recommend ways to improve community integration.

The agency released a plan on June 1, 2001: "Indiana's Comprehensive Plan for Community Integration and Support of Persons with Disabilities."<sup>896</sup> The plan called for greater consumer choice, support for the informal family network, strengthened quality assurance, workforce development, and improved access to HCBS through expanded information and assistance.

The next development was the creation by Governor O'Bannon in July 2002 of the Governor's Commission on Home- and Community-Based Services, which released an interim report in December 2002 and its final report in June 2003. The commission made 16 recommendations in its interim report and 28 additional proposals in its final report.<sup>897</sup> The commission's goal, it said, was to develop short- and long-term strategies to create or expand community options for people with disabilities. (For further details on the commission's work, see "Innovative Practices" below.)

Building on the recommendations of the Governor's Commission was the enactment of S.B. 493 in 2003, which makes it a matter of state policy for FSSA to establish "a comprehensive program of home- and community-based services to provide eligible individuals with care that is not more costly than services provided in institutions." Its provisions include raising the monthly income standard for the Medicaid Aged and Disabled Waiver program to 300 percent of the SSI standard (having the effect of qualifying more people for Medicaid coverage under the waiver), adding 20,000 Medicaid HCBS waiver slots (without additional cost to the state), and adding spousal impoverishment provisions to the Aged and Disabled Waiver (also a recommendation of the Governor's Commission).<sup>898</sup>

The legislature failed to fund the provisions of S.B. 493, however, in the face of declining state revenues. Nevertheless, the Governor's Commission chair Katie Humphreys believes that the general purpose of S.B. 493 is to "eliminate barriers to care, increase community capacity, and support consumer choice." Legislative analyst Kathy Norris points out that lawmakers thought it important to authorize 20,000 waiver slots, for example, even if money could not be found immediately to allow filling the slots. Once the slots are available, Norris says, they can be funded at a later date when the revenue outlook improves.

In FY 1998, total expenditures for the state's seven Medicaid HCBS waiver programs was \$52 million. That total had reached almost \$295 million in FY 2003. By that year, the seven waiver programs were serving a combined total of more than 7,600 individuals.<sup>899</sup>

**Programs for individuals who are elderly and/or physically disabled:** The two major HCBS programs for this population, as administered by the Bureau of Aging and IN-Home Services, are the Medicaid Aged and Disabled Waiver program and the state-funded CHOICE program. A waiver program for coverage of services in assisted living facilities was approved by the Federal Government in July 2002.

*Aged and Disabled Waiver program:* This waiver program was established in 1990. In 2002, the state added about 1,600 slots to the program to bring the total number of slots up to 6,000. However, due to budget restrictions, the state was serving only about 4,000 people under the program in 2004. Services include case management, attendant care, homemaker services, respite care, adult day services, adaptive aids and devices, and environmental home modifications.

*CHOICE program:* Beginning as a pilot program in several counties in 1988, CHOICE went statewide in 1992. The program was funded at about \$48.7 million and served 11,272 people in FY 2003. The average monthly care plan cost about \$538. As of January 31, 2004, 10,776 individuals were on a waiting list for CHOICE services. (For further details on CHOICE, see "Innovative Practices" below.)

**Programs for people with mental retardation/developmental disabilities:** Indiana has made "tremendous progress in the past four years in reducing reliance on institutions and in

establishing the HCBS waiver as a major funding source for community developmental disabilities service expansion,” according to a 2004 report.<sup>900</sup> The beginnings of this expansion of community services was passage of S.B. 317 in May 1997. This law called for the creation of a 12-member task force whose responsibility was to prepare a comprehensive plan of implementation for the future of community living arrangements for people with MR/DD.

The task force issued a report in 1998 (“Comprehensive Plan for the Design of Services for People with Developmental Disabilities”) that called for the implementation of person-centered planning and person-centered funding for all people with developmental disabilities. Other recommendations included redirecting funding in the developmental disabilities system away from congregate settings to integrated housing and day services, and expanding community capacity to support people with developmental disabilities, and their families, particularly those who had been waiting for services because of the lack of sufficient resources in the system.<sup>901</sup>

In response to the recommendation on person-centered planning, the state promulgated a rule in May 2003 (460 IAC 7) that mandates the use of a person-centered planning process, including the development of an Individualized Support Plan (ISP) for all people getting services from the Bureau of Developmental Disabilities Services (BDDS), whether they are receiving supportive services in their homes or communities, receiving services and supports from group home providers, or living in ICF/MRs. The resources to help implement the ISP are allocated through an Individual Community Living Budget, which becomes a financial agreement between the individual, the provider agency, and the BDDS.

The state agency also adopted a policy for residents who moved to the community from Central State Hospital, which closed in 1994, that allowed the funds that supported those individuals at Central State to be used for their community supports. “Funding following the person was a key vision of the 317 plan,” BDDS officials said in 2003, “and we continue to make progress in this area.”<sup>902</sup>

The agency has also been able to report significant progress on the 317 Task Force recommendation about redirecting funding from congregate to community settings. Of the 10 private ICF/MRs, only three were still open in 2004. In 1999, the state had been serving 834

people in private ICF/MRs; that number had dropped to 343 by the end of 2003. The population of the State Development Centers went from 800 people in 1999 to less than 500 people in 2003 and was expected to drop to about 200 people by 2005. In addition to Central State Hospital, two other State Developmental Centers (New Castle and Northern Indiana) were closed in 1998.

When the task force report was published in 1998, \$467 million was being spent by the state for services for people with developmental disabilities, of which only \$110 million was going toward community services. About 5,000 people were on waiting lists for services.<sup>903</sup> The total number of people with development disabilities in residential settings increased 34 percent between FY 2000 and FY 2004. Group homes have been one of the community alternatives for people with developmental disabilities. These are residences for four to eight individuals that include 24-hour supervision by paid staff, who help residents develop daily living skills.

Follow-up services for supported employment have also been expanding. In 2000, about 1,800 people received these services after getting a job. The number had increased to 2,300 people by 2002, and BDDS has set a goal of 3,700 by June 30, 2005. Medicaid spending for the HCBS waiver program for people with developmental disabilities increased 360 percent from FY 2000 to FY 2004, while ICF/MR spending dropped 16 percent. However, while the number of people in the waiver program totaled 5,139 in FY 2004, more than 11,000 people still were on a waiting list for services.<sup>904</sup>

The two major Medicaid waiver programs for people with developmental disabilities are the following:

*Developmental Disabilities Waiver:* Originally established in 1992 as the ICF/MR waiver, the program was amended in 2001 to become a Developmental Disabilities waiver program with expanded services, which range from adult day services to case management and crisis assistance. Recreational, occupational, speech, physical, and music therapy are offered as well as community education and therapeutic activities (an annual allowance to pay for the costs of community activities). Other services include environmental modifications, family and caregiver training, specialized medical equipment, and transportation. Services under the waiver can also

be provided in adult foster care facilities (limited to four people per residence), and in 24-hour residential care facilities.

The Federal Government approved an amendment in July 2003 to the Developmentally Disabled and Autism waiver programs to provide a Community Living Budget. This program provides a \$1,000 allowance to people moving out of institutional care to community settings. The allowance pays for the client's initial security deposit on an apartment, essential furnishings, pest eradication, and set-up fees for utilities and telephones. The program was originally entirely state funded, but moving the program under Medicaid allows for a 62 percent federal match.<sup>905</sup>

*Support Services Waiver:* This program was created to address a problem that had arisen with the Developmental Disabilities waiver. The resources of that program were not proving sufficient to cover the expenses of providing adult day services for many recipients, including activities to help individuals get ready for jobs, supported employment follow-up, and sheltered workshops.

Begun in April 2002, the Support Services program offers a family allowance of up to a maximum of \$13,500 per person annually and is intended for people living at home with their families or other informal caregivers. The program includes all the services provided under the Developmental Disabilities waiver program except for adult foster care or residential services and environmental modifications. Enrollment totaled 3,550 people in FY 2004; several thousand people were on a waiting list for the services.

For people not financially eligible for Medicaid, state funds provide an array of services that allow individuals with developmental disabilities to live in their own homes. State funds may be used when other funds are not available, such as when a Medicaid recipient loses eligibility for that program.<sup>906</sup> State funds are also available to cover rent and meals (Residential Living Allowance) for people in residential facilities whose services are being covered by the Medicaid Development Disabilities waiver program; Medicaid does not cover rent and meals.

**Programs for people with mental illness:** DMHA reports that 38,194 adults with serious mental illness were served in the community in FY 2001. That number had increased to 42,076 by FY 2003.<sup>907</sup> DMHA contracts with managed care providers, which are generally Community

Mental Health Centers or networks of several centers. These centers, of which there are 31 in the state, receive an annual allocation for each person they enroll.

The primary source of services and supports for adults with serious mental illness is the Hoosier Assurance Plan (HAP). This program accounts for almost 80 percent of funded treatment services provided by DMHA. People eligible for HAP must qualify for Medicaid or Food Stamps, or have incomes that fall at or below 200 percent of the federal poverty level. They must also meet certain evaluation criteria as determined by mental health professions. The agency estimates that 59 percent of eligible adults (people with mental illness who meet the low-income requirements) are enrolled in HAP.

HAP does not pay for 100 percent of a person's care. Each individual in the program is expected to contribute toward the cost of care based on a sliding fee scale applied to the person's income.

The Mental Health Centers are responsible for providing a continuum of care that includes individualized treatment planning to increase patient coping skills and symptom management, 24-hour-a-day crisis intervention, case management, and outpatient services, such as substance abuse services, counseling, and treatment. The centers must also offer residential services, day treatment, family support services, and medication evaluation and monitoring. The centers also provide supported employment services; the state estimates that more than 1,200 people have been helped to find jobs from 1999 to 2003.

### **Residential Options**

“...if development of new housing initiatives is not aggressively pursued,” said the Governor’s Commission on Home- and Community-Based Services, “the State is likely to find itself in the position of having developed a plethora of new service options yet have no consumers to utilize them.”<sup>908</sup> Giving people with disabilities options to live in the community in small residential settings rather than in institutions has been a major challenge for Indiana. For example, the national average for individuals with MR/DD living in settings of six people or fewer was 61 percent in 2000; in Indiana, the rate was only 44 percent.<sup>909</sup>

In the 1970s, Indiana created two state-funded programs, Assistance to Residents in County Homes and the Room and Board Assistance Program for residents of board and care facilities. These programs subsidize the difference between a resident's income and the state-approved daily rate for a county home or a licensed residential care facility. In 1992, the two programs came under the authority of the DDARS, and in 2000 merged into the Residential Care Assistance Program (RCAP).

In 2003, there were 19 county homes and 42 licensed board and care homes. In addition to providing financial assistance for room and board, the program offers residents a personal needs allowance (\$52 a month in 2003) and medical assistance. About 2,500 people were in the program at the end of FY 2003; these are people who cannot live independently but who do not need nursing home level of care. They must be financially eligible for Medicaid or SSI. Total expenditures for the program were about \$14 million in FY 2003.<sup>910</sup>

Of the 3,700 households receiving housing assistance through Indiana's Housing Choice Voucher Program (Section 8) rental assistance program in FY 2001, two-thirds had an elderly or disabled family member. In that year, however, 7,000 households were on the preapplication list waiting for assistance.<sup>911</sup>

Another project that attempts to create opportunities for people with disabilities to own or rent homes is the Back Home in Indiana Alliance. The state has funded the project through the Indiana Housing Finance Authority and the Governor's Planning Council for People with Disabilities. The alliance is a coalition of various organizations that includes Fifth Third Bank, Irwin Mortgage, the Indianapolis Neighborhood and Housing Partnership, Indianapolis Resource Center for Independent Living, and Independent Residential Living of Central Indiana. Also involved are Fannie Mae and HUD.<sup>912</sup>

The project, which is housed in Indiana University's Institute on Disability and Community, connects people with disabilities and their families to housing organizations and resources. A preliminary financial assessment is conducted; potential clients must have incomes at or above 30 percent of the local median income. If the applicant meets this standard, he or she is directed to a homeownership counseling and educational organizations that will provide information

about low-cost lending and the steps an applicant must take. Alliance staff say that the key factor sustaining this project is “the development of partnerships with organizations experienced in housing, advocacy, and supporting people with disabilities.”<sup>913</sup>

Indiana has also created two other housing possibilities for people with disabilities in recent years. The state submitted an application to the Federal Government for a Medicaid Assisted Living Waiver that was approved in July 2002. By FY 2004, the program was serving 70 people, with 36 people on a waiting list. The Aged and Disabled Waiver was amended to include a new congregate care option that was approved by the Federal Government in 2003.

### **Workforce Issues**

In 2001, the General Assembly authorized the creation of a Governor’s Commission on Long Term Caregivers. The mandate of the commission, which began meeting in 2002, was to review information and data related to long-term caregivers; evaluate the adequacy of the state’s training programs; and make recommendations to increase the supply of certified nurse aides, licensed practical nurses, and registered nurses in health facilities, home health care, and other community-based settings. The commission made a number of recommendations to strengthen education and training opportunities for direct care workers, improve workplace conditions, and develop recognition programs for the workers.<sup>914</sup>

In 2002, the General Assembly enacted a bill that permits certain individuals who are not licensed health care professionals to provide health-related services to people receiving in-home care under the CHOICE program and the Medicaid HCBS waiver programs. The workers are called personal services attendants. The DDARS was charged with developing a registry of these workers.

### **Consumer Direction**

A key recommendation of the Governor’s Commission on Home- and Community-Based Services was that all applicable Medicaid waiver programs “should include and implement the consumer-directed care service option.”<sup>915</sup> Although 2001 legislation had given recipients of CHOICE the option of directing their attendant care services workers, only 140 program participants were exercising that option in 2004.

The state requested an amendment to the Aged and Disabled Waiver in November 2001 to allow self-directed attendant care, which was approved by the Federal Government in January 2002. Indiana applied for and was awarded a \$1.4 million Real Choice Systems Change Grant in 2002 to develop systems that support consumer choice and consumer-directed care. Another \$725,000 federal grant that year for community personal assistance services and supports calls for the development of a pilot model of self-directed care based on the work of three local coalitions. The coalitions are to include an Area Agency on Aging, an Independent Living Center, a nursing home, and other support providers and advocacy groups. The goal of the project is to develop a system whereby self-directed personal attendant care “is a realistic and accessible service for any individual who chooses to live in the community.”<sup>916</sup>

The FSSA noted in 2004 that efforts to expand self-directed care had been complicated by fiscal intermediary issues. The Area Agencies on Aging administer CHOICE and the Aged and Disabled Waiver programs. The Area Agencies on Aging reported concerns about how they would handle their fiscal intermediary responsibilities and about how to limit their liability regarding “employer of record” issues.<sup>917</sup> However, the state was moving ahead in mid-2004 to issue a request for proposals for an organization to serve as fiscal intermediary.

### **Innovative Practices**

Indiana has been a pioneer in two very different directions for expansion of LTSS. Through the actions of a broad-based commission on HCBS, bolstered by gubernatorial and legislative support, the state has put into place, in effect, a graduated schedule of reforms that should enable it to keep its reform momentum going even in the face of tough fiscal times. At the same time, the state has managed to develop and strengthen a state-funded home- and community-based program that has strong and continuing support from the political and advocacy communities.

***Governor’s Commission on Home- and Community-Based Services:*** The commission called its report with its comprehensive series of recommendations “a blueprint for reform in Indiana.” Mindful of the state’s tight fiscal situation at the time, but also because of the “opportunities presented by the upcoming legislative session,” the commission said it tried to frame many of its initial recommendations in terms of achievable results. For example, in its December 2002

Interim Report, the commission said it proposed to identify the “most significant of the long-term care service delivery barriers and to develop comprehensive recommendations in response.”<sup>918</sup> Taking note of this strategy, NCD said in September 2003 that the commission’s “effort to prioritize activities that could begin immediately and at little short-term cost is exemplary and should serve as a model for other states.”<sup>919</sup>

One such immediate activity with little short-term cost was pursuing federal grant opportunities. The FSSA lost no time in applying for such grants and reported that it received a total of \$6.4 million in FY 2002 and FY 2003, mostly from the Real Choice Systems Change Grant program under the New Freedom Initiative. One \$1.4 million federal grant helped to create and staff the Governor’s Commission and also went toward the distribution of mini-grants to communities around the state to stimulate creative community thinking about independent living for people with disabilities. The state awarded \$430,000 to 12 communities in February 2003 and another \$320,000 to 11 communities in May 2003 in mini-grants of up to \$40,000.

Projects were to encourage innovation in community living, housing, transportation, supported employment, and caregiver support. Activities funded through the mini-grants include, for example, training for Indianapolis housing suppliers and consumers to increase the availability of community-based housing for people with disabilities, support for Bloomington’s continuum of services for adults with developmental disabilities and/or mental illness, and the development of resources in New Palestine that enable homeowners with disabilities to access home repair or modification services.<sup>920</sup>

Other commission recommendations also saw quick action by the state, such as implementing spousal impoverishment provisions in the Aged and Disabled Waiver program similar to the provisions applicable to nursing home care.<sup>921</sup> A waiver amendment to allow this action was approved by the Federal Government in February 2003. (For additional information on commission proposals and subsequent state actions, see Appendix 4.A.)

One major commission recommendation (i.e., to raise the monthly income standard for the Aged and Disabled Waiver program to 300 percent of SSI), however, proved to be more problematic because of cost concerns. An initial state estimate of the additional first-year cost of the change

was \$2.7 million. FSSA contracted with the Lewin Group to conduct a more comprehensive analysis of the fiscal impact of this proposed change and the addition of 20,000 waiver slots mandated by S.B. 493. The report was due by November 2004.

The commission also established Benchmarks for Measuring Success for each of its recommendations. For example, for the Adult Foster Care Medicaid waiver program, the benchmarks included implementation of the program, development of an adult foster care consumer base (with the number of consumers increasing each quarter), and development of an adult foster care provider base (with the number of providers increasing each quarter). However, the commission expired at the end of 2003, leaving open to question how monitoring would be conducted in the future.

***CHOICE:*** Although many states offer limited state-funded services for people whose low incomes still do not qualify them for Medicaid-funded services, Indiana has a 12-year-old comprehensive state-funded program that continues to be popular not only with consumers and advocates but also with legislators and other policymakers. The CHOICE program has lasted through tough fiscal times and continues to gain strength.

The CHOICE program has received national recognition since its inception in the late 1980s, largely because it fills a gap for low-income people who are not eligible for or are waiting for Medicaid services. People must be at least 60 years of age (or any age with disabilities) and unable to perform at least two ADLs as determined by an assessment.

There are no financial eligibility requirements for CHOICE. However, cost-sharing on a sliding fee scale is required of people with annual incomes between 150 percent and 350 percent of the federal poverty level. People with incomes below 150 percent of the poverty level are not required to pay for services; people with incomes above 350 percent must pay the entire cost of their services.

Covered services include case management, home health supplies and services, attendant care, homemaker services, respite care, home-delivered meals, adult day care, transportation, minor home modifications, adaptive aids and devices, and other necessary services. The program is

operated locally by Area Agencies on Aging. At least 20 percent of an Area Agency on Aging's CHOICE service dollars must be used for people under the age of 60 with disabilities.

### **Future Plans and Challenges**

Although Indiana still has many challenges to face to overcome its earlier bias toward institutionalization, the state has made considerable progress in recent years in offering many more people with disabilities the option of living independently in the community. The strides made in the last two to three years are impressive compared with the state's past record in providing home- and community-based options for people with disabilities. The state-funded CHOICE program continues to receive strong ongoing support from public officials.

The executive and legislative branches of the Indiana government have shown a convincing commitment to continuing this forward movement. In 2003, the state set a goal of creating community options for 1,000 more seniors and 1,000 more people with disabilities over two years.<sup>922</sup> Several federal grants are helping to keep the momentum going, and local efforts supported by mini-grants should help develop new initiatives.

Representative Peggy Welch, vice chair of the Assembly Public Health Committee, says that "implementing what we've got and how to pay for it" is a major challenge for lawmakers. Legislators are committed to expanding home- and community-based care, she says, but they worry about the short term. "We seem to be improving our economic status," she says, but FY 2005 "will be a tough budget year."

Another key stakeholder, Beth Quarles, chair of the Indiana Independent Living Center, is concerned that no group is charged with monitoring activities that have been recommended by the Governor's Commission. "We need a group to conduct follow-up reviews," she says, and to distribute results to stakeholders around the state. Federal or state money needs to be invested in that follow up, she adds.

## **Attachment 4.C**

### **Selected Recommendations of the Governor's Commission on Home- and Community-Based Services**

The status of some of the commission recommendations was provided by FSSA secretary Cheryl G. Sullivan in a November 10, 2003, letter to commission chair Katie Humphreys. Secretary Sullivan said that "in prioritizing its efforts and commitment given available resources," all 18 of the commission's recommendations that were directed to FSSA could not be accomplished within the commission's proposed time frame.

- *Implement a diversion project that presents consumers with real alternatives to nursing home placement.* FSSA worked with Area Agencies on Aging (AAAs) to provide discharge planners in hospitals to offer consumers community alternatives to nursing home care. In addition, FSSA worked with the AAAs, Independent Living Centers, and the Nursing Home Coalition to fund two separate conversion team projects to work with families in moving individuals from nursing homes. The agency hoped to pilot the project in other parts of the state. As of March 2004, there had been 780 diversions (people who chose alternatives to nursing home care) and 60 conversions (people who left nursing homes for home and community settings).
- *Reduce to 20 days the time involved in determining Medicaid eligibility and in initiating services.* Applicants must often wait months, the commission said, for the process to be completed. The process had been reduced to 39 days and, as of August 2003, the agency had established a centralized Medicaid financial eligibility determination unit.
- *Develop the infrastructure for a consumer-directed program that includes policies for fiscal intermediary services; information, education, and training for consumers, workers, and providers; a training curriculum for case managers; and a marketing plan.* FSSA received a \$725,000 Systems Change Grant in 2002 to expand consumer-directed personal attendant care under the Aged and Disabled Waiver. The state has developed a Consumer Manual and an Attendant and Case Management Manual available for use electronically and in print versions.

- *Add Adult Foster Care as a service to the Aged and Disabled Waiver program.* FSSA said that Adult Foster Care was a service component of the waiver and explained how the agency was working to expand the service. FSSA had finalized Foster Care Certification Standards, and was working on outreach for the program. The agency said quality assurance “would be a major challenge” as the program expanded, but it had applied for and received federal grant funding to “enhance the infrastructure” for quality assurance.
- *Fully and immediately develop the Assisted Living Waiver.* The program had been funded since July 1, 2001, but had signed up few providers. The secretary reported that the agency had hired a manager to specifically direct this program in early 2003. After that, FSSA developed new application materials and a marketing presentation for the program. The agency presented the material at the annual conference of the Indiana Association of Assisted Living Facilities as well as at three regional meetings. FSSA also reported having engaged in discussions with two major assisted living providers and public housing authorities in three areas.
- *Expand Adult Day Services efforts.* FSSA said it continued to increase community-based options and had 42 certified sites to provide Adult Day Services. Because of increased marketing, the agency said, it was receiving on average three contacts per week of entities interested in becoming providers of these services. FSSA said it was “working closely” with the Indiana Association of Adult Day Services in providing technical assistance for new providers.

## **Part III**

### **Conclusion**

Key shared features of the movement forward by the five selected states are (1) an ongoing intensive planning process that involves policymakers with all critical stakeholders, (2) organization changes in the management of budget and service delivery, and (3) a focus on expansion of consumer choices to respond to individualized needs.

**The planning process.** A number of factors combine to make for an effective planning process:

- A comprehensive endeavor that involves a full range of stakeholders—from state officials to providers to advocates and people with disabilities themselves—and the commitment and support of the governor and legislature.
- Final plans with realistic recommendations that take into account the state's fiscal situation but also take advantage of available federal money, develop community partnerships, and implement cost-limited regulatory changes.
- The setting of benchmarks to measure results and to place responsibility for tracking and reporting the results to policymakers and the public.

**Structural changes.** Although it is difficult for states to quantify the impact of merging and consolidating state agencies, state officials believe that services can be delivered more effectively and efficiently after such moves. They also argue that combining nursing home and home- and community-based dollars means that they can allocate funds according to the needs of people with disabilities rather than to cost centers.

Consolidation at the state level also means local-level changes that can make access to services easier for consumers and that simplify and speed the application process. There is also a trend toward establishing single-point-of-entry systems at the local level that has been adopted by many states and encouraged through federal grants to make for easier access to LTSS.

**Global budgeting.** States are hampered in expanding HCBS by budgeting practices that maintain separate line items for nursing homes and HCBS and by separate funding sources, such as Medicaid, Older Americans Act funds, and state general revenues, which are often administered by separate agencies. Several of the study states have developed strategies to use savings from limiting nursing home use or to transfer dollars that were previously allocated to nursing homes to people who move from those institutions to community settings.

The most far-reaching approach, however, has been to budget for both institutional care and HCBS within the same agency and to tap pooled funds to meet care needs in any setting. Called “global budgeting” by some policymakers, this practice allows states the flexibility to respond to the preferences of people with disabilities to remain at home or in the community.

**Broadening home- and community-based services.** Allowing greater numbers of people with disabilities the opportunity to direct their own care (hiring, training, and supervising their workers) has become a major objective not only of the five selected states but of many other states as well. Federal grants are helping many states consider how to educate consumers about the option, provide them with training, and set up fiscal intermediaries to assist consumers with bookkeeping and taxpaying. The selected states are also using the Medicaid waiver amendment process to broaden benefits, help more people, and provide services in a variety of residential settings.

What each of these five states has accomplished provides lessons to be learned for future policy development at the state and federal levels. An analysis of activity across the five selected states resulted in the identification of 10 findings that will help inform the design of the 21st century LTSS system:

1. Response to the *Olmstead* decision stimulated executive and legislative review of the current system of service delivery, unmet needs of target populations, and where the dollars are being expended.
2. Cross-agency planning with consumer stakeholder voice was included as part of the process to develop recommendations for systems reform.

3. Structural changes have involved substantial reorganization to an umbrella department for multiple target populations with LTSS needs.
4. Change in structure has given emphasis to streamlining eligibility determinations, improving access to information for consumers, and rebalancing funding between community and institutional settings.
5. All five states have embraced principles of self-determination with varying degrees of choice and control. This has led to expanded opportunity for greater numbers of people to manage and direct support and service plans with the assistance of service brokers/coordinators and fiscal intermediaries.
6. The states continue to expand their use of Medicaid waivers to broaden benefits and long-term services to subpopulations.
7. All five states have encountered federal policy barriers that restrict their flexibility, increase their costs, and reduce capacity to meet individual needs at home or in the least restrictive settings. The most restrictive policy most frequently identified was the Medicaid institutional bias.
8. There remains confusion in the use of language regarding long term care and long term supports and services. The traditional term has been “long-term care.” Long-term care is the more frequently used term to describe needs that include personal assistance with daily living activities through nursing facility services and home care. The confusion often is a result of the medically oriented funding base of the primary funding stream (Medicaid), which covers a range of LTC services, including institutional and community-based services. Medicaid community-based services include personal care, targeted case management, home health, transportation, habilitation, and home modifications. The language being used is not keeping up with the philosophy as the pace of change varies across states.
9. All selected states have waiting lists for specific target subpopulations, even though states may limit services and operate the waiver on less than a statewide basis.
10. Current budget challenges at the state level have compelled states to reexamine the balance between public and private responsibility for LTSS, evaluate approaches to target

individuals based on an assessment of level of need, and seek to identify strategies that encourage coverage of supports through some type of insurance coverage and other private sector resource sharing.

## Appendix 4.A

### Stakeholders Interviewed for State Case Studies

- State Senator Linda Berglin, Chair, Minnesota Health and Human Services Budget Committee
- Pat Casanova, Director of Waiver Services, Indiana Division of Disability, Aging, and Rehabilitation Services
- Cathy Cochran, *Olmstead* Coordinator, Washington State Department of Social and Health Services
- Bernard Dean, Senior Fiscal Analyst, Washington State House Appropriations Committee
- Melissa Durr, Executive Director, Area Agency of Aging; Chair, Hoosiers for Options (represents the major long-term care stakeholders in Indiana)
- Patrick Flood, Commissioner, Vermont Department of Aging and Independent Living
- Marc Gold, Director, Texas Medicaid Long-Term Care Policy
- Emily Hancock, Director of Long-Term Care, Indiana Office of Medicaid Policy and Planning
- Brendan Hogan, Director of Long-Term Care Services, Office of Vermont Health Access
- Adelaide Horn, Deputy Director, Texas Department of Aging and Disabilities
- Katie Humphreys, Consultant, Health Evolutions; Chair, Indiana Governor's Commission on Home- and Community-Based Services; Former Secretary, Family and Social Services Administration
- Lois Johnson, Chair, Minnesota Independent Living Center
- Steve Kappel, Associate Fiscal Analyst, Vermont Joint Fiscal Office of the Legislature
- LaRhae Knatterud, Planning Director for Aging Initiatives, Minnesota Department of Human Services

- Debra Leese Baker, Executive Director, Vermont Independent Living Center
- Kathy Leitch, Assistant Secretary, Aging and Disability Services Administration, Washington State Department of Social and Health Services
- Steve Lerch, Senior Research Economist, Washington State Institute for Public Policy
- Kathy Norris, Senior Fiscal and Program Analyst, Office of Fiscal Management Analysis, Indiana Legislative Services Agency
- State Representative Pat O'Donnell, Vermont Appropriations Committee
- Beth Quarles, Chair, Indiana Independent Living Center
- State Senator Pat Thibaudeau, Ranking Member of the Washington State Health and Long-Term Care Committee
- State Representative Peggy Welch, Vice Chair, Indiana Public Health Committee
- Peter Youngbaer, Executive Director, Vermont Coalition on Disability Rights; former state legislator

## **Chapter 5**

# **Moving Forward: Local and Individual Strategies for 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities**



**Table of Contents**  
**Chapter 5**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction</b> .....	439
<b>Part II</b>	
<b>Conclusion</b> .....	486



## **Part I**

### **Introduction**

At the individual, family, and community levels, the public and private sectors are working together to design new strategies to provide accessible, affordable long term services and supports to meet the needs of individuals with disabilities and people who are aging. Criteria used to identify promising practices included the documentation of (1) alternative financing approaches or relationships; (2) support of consumer choice and direction; (3) nontraditional housing and service delivery models that expand supply and access; (4) response to workforce quality and retention challenges; (5) support of family caregivers; (6) promotion and preservation of resources and assets; and (7) replication potential.

Each of the highlighted initiatives builds on strengths of partnerships at the local level and offers the target audience expanded choices for community inclusion and participation. None offer comprehensive solutions to the challenges of meeting LTSS needs in the future. However, similar to the profiled state experiences, each highlighted strategy offers policymakers additional possibilities for inclusion in a more comprehensive systems approach to LTSS needs in the future.

The following table provides an overview of the selected local or individual strategies that realign service and financial relationships. For each initiative, the table includes a brief description, what can be learned from the implementation of the strategy, and program contact information.

**Table 5.1. Selected Local and Individual Strategies**

<b>Worker Cooperatives—Waushara County, Wisconsin</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
<p>The home care worker co-op helps about 82 individuals who are elderly and/or who have disabilities live independently in their own homes. The 74 worker-owner members now enjoy higher wages, workers compensation, health insurance, and profit sharing. Was a finalist this past year in the Harvard “Innovations in American Government” award. The U.S. Department of Agriculture is looking at replication with planning grants to projects in Hawaii, Washington, Colorado, and Nebraska.</p>	<p>Response to workforce issues of low pay and poor retention. Different approach to organize service delivery.</p>	<p>Kathleen McGwin, Executive Director                      Cooperative Care                      PO Box 620                      402 E. Main Street                      Wautoma, WI 54982                      Phone: 920-787-1886  <i>mcgwin@co-opcare.com</i>  <a href="http://co-opcare.com/">http://co-opcare.com/</a></p>
<b>Time Banks/Time Dollars—Washington, D.C.</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
<p>Time Banks are based on the concept of people using their time as money. Communities that are “cash-poor, time rich,” are able to trade their time providing each other with valuable services to benefit people with disabilities and families. The system is based on equality: one hour of help means one Time Dollar.</p>	<p>Provides a way for individuals with time to give, but little income, to get the services they need. The elderly and individuals with disabilities are able to secure personal assistance, shopping, and other support services they may need. They are also able to offer services themselves on behalf of people with similar challenges.</p>	<p>Time Dollar Institute                      5500 39<sup>th</sup> Street, N.W.                      Washington, DC 20015                      Phone: 202-686-5200  <i>contact@timedollar.org</i>  <a href="http://www.timedollar.org">http://www.timedollar.org</a></p>

<b>Together We Can—New York City</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
One of two approaches to affordable housing that offer nontraditional choices to individuals with disabilities with limited income. Together We Can offers affordable cooperative living with limited equity shares to keep prices well below market rate.	Response to unmet critical need for affordable housing without being locked into specific service menu or provider.	Jim Gray, Vice President Together We Can NCB Development Corporation 1725 Eye Street, N.W., Suite 600 Washington, DC 20006 Phone: 202-336-7642 <a href="mailto:jgray@ncbdc.org">jgray@ncbdc.org</a> <a href="http://www.ncbdc.org/">http://www.ncbdc.org/</a> (The link can be found under “Affordable Co-op Housing.”)
<b>No Place Like Home Communities—Robbinsdale, Minnesota</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
One of two approaches to affordable housing that offers nontraditional choices to individuals with disabilities with limited income. No Place Like Home Communities offers homeownership and subsidized rental options within a rehabilitated multifamily development that also includes a range of supportive services.	Response to unmet critical need for affordable housing without being locked into specific service menu or provider.	Emily Fuerste, Executive Director No Place Like Home Communities 4101A West Broadway Robbinsdale, MN 55422 Phone: 763-537-0170 <a href="mailto:info@nplhc.org">info@nplhc.org</a> <a href="http://www.nplhc.org">http://www.nplhc.org</a>
<b>Self-directed Support Corporation—Baltimore, Maryland</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
A Microboard designs supports for one person as an alternative to traditional long-term care providers. The Board members of a legal nonprofit corporation make a personal commitment to the individual with a disability to assist with person-centered planning. It is recognized by the state as the employer of record to provide or purchase support services for the individual.	Different approach to service delivery and consumer direction.	Jackie Golden Inclusion Research Institute 1010 Wisconsin Avenue, N.W. Suite 340 Washington, DC 20007 Phone: 202-338-7253 <a href="mailto:jlgolden@comcast.net">jlgolden@comcast.net</a> <a href="http://www.inclusionresearch.org">http://www.inclusionresearch.org</a>

<b>Pooled Trust—Bedford, New Hampshire</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
Pooled Trusts provide an efficient and economical way to have trust funds administered for people with disabilities that will supplement the benefits offered by public programs. The assets placed in trust by parents or others are allocated to a separate subaccount. The assets from all subaccounts are pooled together to invest and manage as one larger amount.	Financial service that offers responsible decision making and protection of assets to remain eligible for means-tested government benefit programs.	Enhanced Life Options Group 15 Constitution Drive, Suite 169 Bedford, NH 03110 Phone: 603-472-2543 <i>contact@elonh.org</i> <i>http://www.elonh.org/</i>
<b>Child Trust Fund—United Kingdom</b>		
<b>Description</b>	<b>What Can Be Learned</b>	<b>Contacts</b>
Through the Child Trust Fund, each child born in Great Britain from September 2002 is eligible to receive government funds for the purpose of opening an account that matures at age 18. Families below the poverty level will receive an additional allocation of funds double that of other children at birth.	A similar strategy with restricted use of funds for children determined to have a certain level of need for future long-term supports and services might be evaluated as an alternative (supplemental or complementary financing strategy to current college 529 plans or individual retirement accounts).	Child Trust Fund Office Waterview Park Mandarin Way Washington, NE38 8QG, United Kingdom Phone: 08453-021470 <i>childtrustfundoffice@ir.gsi.gov.uk</i> <i>http://www.childtrustfund.gov.uk/Homepage/fs/en</i>

## ***Worker Cooperatives—Waushara County, Wisconsin***

### **Background**

Many individuals who require long-term supports and services (LTSS) may only need assistance with such activities as dressing, bathing, feeding, shopping, meal preparation, and housework to allow them to live independently in their own homes. Research suggests that home care maintains the recipient's dignity and independence. The supports and services that home care workers can provide to these individuals allow them to remain in their homes, providing them with a preferred alternative to a nursing home or other facilitated care setting. In addition to helping to maintain a person's dignity and independence, in-home care is much more cost-effective than institutional care.<sup>923</sup> Research also clearly documents that the demand for home care will only increase as the population ages, especially as the baby boom generation nears retirement. By 2030, one in five Americans will be over the age of 65. In many rural areas, the elderly already have reached this critical mass. Home care providers have traditionally been a key factor in helping people continue living in their own homes and not going into a nursing home. While this in-home, direct care services model has helped save counties and states money, it has also stretched limited financial resources.

Despite the growing demand and cost-effectiveness of in-home care, there is a serious shortage of home care workers. Low wages and lack of benefits provide a disincentive for people to enter into this profession. Turnover within the industry is very high—between 40 and 60 percent annually—and in a tight labor market, individuals can easily work in less stressful retail or service industries for similar wages.

Like many counties in the state of Wisconsin, Waushara County has struggled to find enough appropriate direct care providers for its elderly and disabled populations. Waushara is one of the state's poorer counties and it is also rural, which forces home care workers to drive significant distances between clients. The county's economic status, low wages for home care workers, lack of benefits, and rural nature made finding and keeping direct care providers a challenge.<sup>924, 925</sup> Prior to the creation of Cooperative Care, Waushara County Department of Human Services (DHS) developed the In-Home Providers Program to serve the rural elderly and individuals with

disabilities. For more than 20 years, DHS paired homemaker and personal care providers with low-income adults with disabilities and frail elderly residents who qualified for state-funded programs or Medicare. In this arrangement, care providers were not county employees, but rather considered domestic workers hired by the service recipient and paid by a third-party fiscal intermediary; that is, the client was the actual employer, but the county was the fiscal intermediary. The county was charged with handling the payroll and all other financial details, as well as scheduling worker home visits, providing employee background checks, and helping clients find in-home service providers.

This arrangement stretched limited public resources and left care providers without workers compensation and benefits. Compounding the situation, state and federal funding did not keep pace with cost-of-living expenses, resulting in lower-than-average wages. In Waushara County, this posed a potential liability because another rural Wisconsin county with a similar arrangement had recently been sued to cover medical costs incurred by a caregiver's injury on the job. Despite the existence of a third-party fiscal intermediary, the Internal Revenue Service (IRS) has ruled that counties in this arrangement are the true employers and therefore liable for workers compensation and payroll reporting.

Lu Rowley, director of Waushara County's DHS, recognized that the delivery of home care services, which allowed the low-income elderly and individuals with disabilities to live independently in their own homes, came at the expense of their low-income caregivers. For years, care providers had asked the county for higher wages and benefits, but tight budgets had prevented the director from accommodating their requests. The DHS director heard about a co-op approach to addressing the challenges faced by home care workers in south Bronx, New York—Cooperative Home Care Associates (CHCA)—that pioneered the first home care worker cooperative in the United States in 1985, and decided to apply for a state grant to allow Waushara County to explore utilizing the worker co-op model in a rural setting. The DHS director felt that Waushara County could form a similar worker-owned co-op. The county could sign a contract with the co-op to continue providing services to its low-income elderly and disabled residents. As a private company, the co-op could also serve counties beyond Waushara

and care for private clients. By combining public and private revenue sources, it might be possible for a worker-owned co-op to offer much-needed benefits and perhaps higher wages.

### **Program Description**

Founded in 2001, Cooperative Care is a worker-owned cooperative in rural Waushara County. It provides homemaker and certified nursing assistant care to the elderly and individuals with disabilities in their homes. Each worker-member owns a share of the cooperative and has one vote. Workers share the cooperative's profits and sit on its board of directors, where they help direct company policy and strategic planning. Cooperative Care is the first such co-op in the Midwest and came together as a result of a unique collaboration among the federal, state, county, and private sectors. By sharing a vision and working together, social workers, administrators, and caregivers joined together to build an organization that has the potential to serve as a model for state counties and direct care workers.<sup>926, 927, 928</sup> Cooperative Care started with an experienced workforce in desperate need of higher wages and basic benefits. Most of the worker-owner members are lower-income white women from a rural county with limited employment opportunities. All are ideologically committed to home care and have chosen to work in the field although they would earn slightly higher wages in institutional settings. A fair percentage of the providers are employed to care for their family members who would otherwise be institutionalized.

Cooperative Care offers the care providers comprising its membership a kind of organizational ownership that they had never enjoyed nor probably even imagined. It also provides them with member benefits that are not often found in this field of work (the lack of these benefits is one of the key reasons why there is such high turnover). Membership in Cooperative Care provides worker-owners with profit sharing, with each member's share based on the number of hours worked during the past year. Workers receive differential pay for unscheduled work and are paid extra for filling in when a colleague misses a scheduled shift. Workers are reimbursed for time spent traveling between clients, which is especially important given the rural nature of the county. Workers are guaranteed a minimum of one hour's pay for any assignments that last less than an hour. Benefits also include nine paid holidays a year, overtime pay, paid vacation time, and subsidized health insurance for those who work at least 30 hours a week, as well as a flexible benefit plan, liability insurance, and worker's compensation.

For its home care clients, Cooperative Care provides a stable, committed, and professional workforce. For the county, it takes the scheduling and financial management of home care workers out of the county's hands, freeing up case managers to better focus on providing the best social services possible.

## **Core Program Elements**

### *Staffing*

Cooperative Care has an executive director and a five-member worker-owner board of directors, who are voted into office by caregivers. Qualified worker-owner applicants must be certified home health aides or nursing assistants, and applicants must have state certification or be prepared to obtain it on their own. If membership is granted, the new worker-owner pays a one-time \$50 membership fee for a share in the co-op.

Initially, Cooperative Care was able to tap into an existing core of providers, which required no recruiting efforts. It expanded on a 20-year-old program and thus was able to build upon strong support from both the county and the community. Cooperative Care utilized partnerships and collaborations on the county, state, and federal levels. On the county level, it utilized the expertise of the director of DHS, a nurse, social workers, and the county board. On the state level, Cooperative Care applied for grants and used the money to hire a local organizer and tap into resources to assist in research and support. It utilized the services of a local nonprofit to review the business plan and offer advice on the financial aspects of starting up and running a co-op. At the federal level, the U.S. Department of Agriculture (USDA) provided co-op technical assistance, co-op services advice, and a 2004 grant/loan fund to explore other co-ops.

Cooperative Care used representatives from other co-ops to help set up the accounting system and get advice on dealing with conflict resolution. Finally, the University of Wisconsin Center for Cooperatives (UWCC) provided board members with training videos, conflict resolution, legal direction, and research.

### *Funding and Expenditures*

Waushara County received a Community Options Program (COP) Community Links grant from the state of Wisconsin to explore the feasibility of forming a cooperative. COP is a state-funded

program to provide assessments, case plans, and community services as an alternative to nursing home placements for all disability groups as well as the frail elderly. A \$125,000 loan from the state bank provided the start-up money, 20 percent of which was spent on capital expenditures. The rest covered payroll until the cooperative achieved adequate cash flow. The cooperative is now funded entirely by client payments (it has a contract with the county) and its \$50 membership fees.

### *Technical Assistance*

To help facilitate the co-op development process, the director of Waushara County's DHS brought in Margaret Bau, an expert on co-ops. In her job with the USDA Rural Development in Stevens Point, Wisconsin, Bau had advised and helped develop numerous rural cooperatives. She knew what was involved, how to develop a business plan, and how to structure the governing board. The organized plan that Bau and Dianne Harrington, a social worker and the other project coordinator, used to build Cooperative Care mirrored the 10-step model for building a co-op developed by the USDA.<sup>929, 930, 931</sup> The following are the 10 steps:

1. Hold an exploratory meeting with others who have a similar interest and determine whether you have common needs and desire to address those needs as a group.
2. Select a steering committee to guide the group through the formation process.
3. Conduct a survey of potential members.
4. Analyze markets for products, supplies, and services.
5. Prepare a business plan.
6. Incorporate the business.
7. Adopt bylaws and select a board of directors.
8. Find investment funds—including member investment needed to carry out the business plan.
9. Hire management and employees, and acquire facilities and equipment.
10. Begin operations.

## **Lessons Learned and Accomplishments**

The cooperative started with 61 caregivers in June 2001; as of December 2004, it had 74 members, with about 63 active. Of this group, all but two are certified nursing assistants. Two members are homemaker aides. The co-op has 82 active clients. Financially, Cooperative Care exceeded its fiscal projections. Year-end profits for 2001 exceeded \$41,000. After prepaying part of the business loan and setting aside funds for capital reserves, cash patronage refunds were distributed at the first annual meeting. Checks averaged \$440 but were as high as \$1,000, based on the number of hours worked. At the end of the co-op's second year of operation, net profits totaled more than \$65,000, which was distributed to its members as retained equity and as cash payout.

Every year since its inception, worker-owners have received increases equivalent to hourly raises per hour worked. For example, in 2002 (for the year 2001), worker-owners received an increase of \$1.39 per hour worked (14 percent for workers who earned \$9.75 and 18 percent for workers who earned \$7.75/hour). In 2004 (for the year 2003), worker-owners received an increase of \$0.58 per hour worked (6 percent for workers who earned \$9.75/hour and 7.4 percent for workers who earned \$7.75/hour). Harvard's John F. Kennedy School of Government named Waushara County and Cooperative Care as one of 99 semifinalists (out of a pool of 800 applicants) in the prestigious 2002 Innovations in American Government Awards. Wisconsin Rural Partners named Cooperative Care as Wisconsin's Top Rural Development Initiative for 2003.

In 2002, a survey was developed to assess the impact of the formation of the cooperative on the satisfaction worker-members feel with their jobs. The survey was administered in the fall of 2002. Forty-three members (69 percent) completed surveys. Analysis of survey responses indicated that Cooperative Care members were generally and uniformly satisfied with most aspects of their jobs. The formation of the cooperative in June 2001 seems to have had an overall positive impact on the job satisfaction of current members. That impact is both tangible (increased wages and access to benefits) and intangible (an increased feeling of investment in the organization's management and well-being and a greater sense of security and stability).<sup>932</sup> In an effort to gauge consumer satisfaction with Cooperative Care's providers, the co-op conducted a consumer survey in the summer of 2002.<sup>933</sup> The survey asked consumers whether they were satisfied with eight different aspects of the care they received from Cooperative Care members.

Forty people responded. The results indicated that consumer satisfaction with services performed during the co-op's first year of operation was extremely high—an average of 96 percent of the respondents reported they were satisfied with each of the eight aspects of care. This suggests great satisfaction with all facets of provider service. A ninth question asked whether the consumer was satisfied, overall, with the services receive. Ninety-seven percent of respondents answered yes.

The development and building of the Cooperative Care workers co-op in Waushara County has been able to offer advantages for its workers, its consumers, and for the county of Waushara. Worker-owners experience personal empowerment and increased professional self-esteem; they receive professional benefits, stability, better pay, and job satisfaction; and they have a voice in their business and enjoy profit participation. Because of the low turnover, consumers are receiving consistent service from satisfied and conscientious workers. Cooperative Care offers Waushara County a stable and dependable provider source. It removes the operational burden from the county, as well as the potential of IRS liability. Finally, the co-op helps the families of providers.

### ***Time Banks/Time Dollars—Washington, D.C.***

#### **Background**

Time Banks are based on the concept of people using their time as money. People build credits for time they put into voluntary activities in providing health or social care and other worthwhile work in their communities. Communities that are “cash-poor, time rich” are able to trade their time, providing each other with valuable services such as assistance for the elderly and individuals with disabilities, and family support. The Time Bank/Time Dollar idea was developed by Edgar Cahn in 1980 when, at the age of 46, he suffered a massive heart attack. Recuperating in the hospital and “feeling useless,” he dreamed up Time Dollars as a new currency to provide a solution to massive cuts in government spending on social welfare. Seven years later, at the London School of Economics, Cahn developed his theoretical explanation for why the currency should work. He came back to the United States and started putting service credits (not yet called Time Dollars) into operation. Cahn described the idea as working like a blood bank or babysitting club:

Help a neighbor and then, when you need it, a neighbor—most likely a different one—will help you. The system is based on equality: One hour of help means one Time Dollar, whether the task is grocery shopping or making out a tax return. Credits are kept in individual accounts in a “bank” on a personal computer. Credits and debits are tallied regularly. Some banks provide monthly balance statements, recording the flow of good deeds.<sup>934, 935</sup>

The result of this conceptualization represents a parallel economy using time as the medium of exchange and, by doing so, making connections between people and rebuilding a sense of trust. Time Banks create a reciprocal relationship between people and institutions, as well as between people and people, which ordinary volunteering finds harder to achieve. It allows almost anybody in society, including the elderly and individuals with disabilities, to give something back. In the Time Bank concept, the focus shifts from people’s problems to their abilities: Time Banks focus on people’s assets, what they can do. Time Dollars and Time Banking can serve as a tool for social change.

Each local Time Bank has a broker who facilitates time exchanges and keeps track of members’ time accounts. This method is of particular benefit to individuals with time to give but little income to get the services they need. For the elderly and individuals with disabilities, they are able to secure caring, shopping, sitting, and other support services they may need. They are also able to offer services themselves, which may be telephone or e-mail based or include other supportive/advocacy services on behalf of people with similar challenges. Time Banks are currently in operation worldwide.

### **Program Description**

In the United States, Time Banks use a currency called Time Dollars. Time Dollars represent a special, tax-exempt form of money that anyone can earn by using time, energy, skills, and talents to help others. One hour of service provided to another human being or to the community earns one Time Dollar. A Time Dollar Exchange is formed whenever Time Dollars are earned and spent. Anyone can earn Time Dollars through membership in a Time Dollar Exchange. Time Dollar Exchanges use Time Dollars in two main ways. One way is through generalized helping and the other is through “specialized” activities that are targeted to a specific outcome. Time Dollar

Exchanges offer a way to provide social networks that support the elderly and individuals with disabilities, making it possible for them to live independently in their own homes.<sup>936, 937, 938, 939</sup>

Time Dollars represent an alternative currency that can be used to recognize, validate, and reward the work of people seeking to build community. Because everyone earns Time Dollars at the same rate, regardless of what they are able to contribute, Time Dollars measure and reward the efforts people put in and send the message that every individual counts in ways that money simply cannot. At the same time, Time Dollars provide purchasing power to individuals whose contributions are often unrecognized in the market economy. For example, they are used to access food, clothing, computers, legal services, health care services, housing, and rides to the store. Members of Time Dollar organizations help each other in ways that family and neighbors have traditionally done.

Co-Production as an idea was also developed by Edgar Cahn in 1993, in which he worked out a theory to explain why and how Time Dollars could so profoundly change the dynamics of social welfare programs. The concept behind Co-Production is that all individuals, no matter how frail, fragile, damaged, even delinquent, can feel valued for contributions that they are able to make in their family, neighborhood, or community. Co-Production contains a different understanding of the role of clients and beneficiaries in that it regards all people as assets and as co-producers of outcomes. This nonmonetary, unmeasured sector of the economy also includes housework and efforts that go into caring for relatives.<sup>940, 941, 942</sup>

Cahn first used the term “Co-Production” to explain his particular approach to training lawyers. Students at the University of the District of Columbia School of Law are trained on the job by providing legal support for people and communities who need it but can’t normally afford it—and this is where Co-Production comes in, because the students do not provide their services for free. They charge out their time in Time Dollars. The recipients of legal advice pay their bills by earning Time Dollars themselves, either by passing on what they have learned to somebody else or by helping out in the community in some other way.

Co-Production includes four core values: assets, redefining work, reciprocity, and social capital. Assets as a core value recognize that the real wealth of a society is its people. Every human being

can be a builder and a contributor. Redefining work as a core value recognizes that work must be redefined to include whatever it takes to rear healthy children, preserve families, make neighborhoods safe and vibrant, care for the frail and the vulnerable, attack injustice, and make democracy work. Reciprocity as a core value recognizes that the impetus to give back is universal. Wherever possible, we must replace all forms of one-way acts of helping with two-way transactions, so that “You need me” becomes “We need each other.” Finally, human beings require a social infrastructure as essential as roads, bridges, and utility lines. Social networks require ongoing investment of social capital generated by trust, reciprocity, and civic engagement.

When Time Dollars are earned and spent by individuals who are elderly or individuals with disabilities—who find they have no one to turn to except professional caregivers for the support and help they need—then every one of the four core values of Co-Production comes into play. All those who earn Time Dollars are viewed as assets—their contributions are redefined as work—the Time Dollar earned sets up an obligation on the recipient who paid out the Time Dollar to contribute, in turn, to someone else; and, in the process, new social networks of mutual help and mutual trust are formed. In return for the help they receive from professionals, clients use their own strengths to contribute to the organization’s mission, preferably by using their talents and skills to help others. Measuring and rewarding those contributions—simply by recognizing the effort, commitment, and worth—lifts the contribution to the status of work and, in doing so, can transform a top-down relationship between professionals and clients into an equal, reciprocal one.

In communities across the country, Time Dollars as a tool and Co-Production as an approach have enabled the people for whom the market economy has little or no use to contribute in ways that go far beyond volunteering.

### **Core Program Elements**

#### *Technical Assistance*

The role of the Time Dollar USA Institute is to promote Time Dollars and Co-Production and to nurture and nourish the network of independent Time Dollar initiatives established by community groups, social service agencies, local governments, community action programs, and

so on.<sup>943, 944</sup> In this role, the institute facilitates links and exchanges of knowledge between new and well-established Time Dollar initiatives worldwide. It offers publications and provides how-to and learning materials, such as its Web site, workshops, and training. The institute makes available speakers for forums, conventions, and other public events. It developed Timekeeper software designed for use by Time Dollar Exchanges to keep accounts for Time Dollar members and to match providers to recipients. The software is free and downloadable from the Web site.

### **Lessons Learned and Accomplishments**

Experience using Time Dollars and Co-Production<sup>945, 946</sup> has shown that these concepts can save money. Research at Member to Member in Brooklyn, New York (see example below), has shown reductions in the costs of caring for customers under the social health maintenance organization (HMO) Elderplan. Local networks and support allow members to care for one another, resulting in the ability to remain in their own homes and out of nursing homes longer. Similar efficiency has been shown in a range of other Co-Production programs. Government-funded research in the United Kingdom has shown that rewarding individuals with Time Dollars attracts community involvement from some of the hardest-to-reach sections of the population, including people with disabilities. Programs that successfully incorporate Co-Production have been praised by participants and foundations alike for their ability to increase a sense of local trust and safety and cross racial divides. Research has shown over and over again that people who are active in their community are healthier, and Co-Production promotes active engagement in families, neighborhoods, and communities. An additional program benefit has been the sustained involvement over time of participants. Both in the United Kingdom and the United States, research on programs that use Time Dollars has shown that involvement grows the longer participants have been involved. At the New England Time Dollar Exchange Network (NETEN), member engagement (number of hours put in by participants) leaped by 150 percent in the fifth year of membership. (See more information about the New England Network below.)

#### *Example of Time Dollars Building Co-Production: Elderplan, Brooklyn, New York*

Elderplan, a social HMO in New York serving the elderly population of Brooklyn, Queens, and Staten Island, was one of the first organizations in the world to use Time Dollars as a method of delivering Co-Production in its Member to Member program. Since its inception in 1987, it has

created long-term relationships that function as a supportive, extended family for its members, many of whom would otherwise suffer from isolation. The HMO's elderly clients are given the option of signing up for the Member to Member Time Dollar Exchange. Enrollment in Member to Member means that clients can receive help from other members who earn Time Dollars for providing the help. By encouraging members to support other members, the HMO found that health benefits extended not just to those being supported, but also to those who were doing the helping. The result has been a marked increase in health, a decrease in the need for nursing home institutionalization, and a reduction in the social isolation and depression that is known to have serious health consequences.<sup>947, 948, 949, 950</sup>

Beyond the large-scale visibility and financial advantages, there are individual savings associated with Member to Member as well. Each day that a stay in the hospital can be shortened because of the Time Dollar program saves Elderplan \$1,000. One avoided nursing home stay saves \$35,000. The support, encouragement, and assistance that Member to Member participants provide to each other also reduces the costs incurred when medication isn't taken regularly or in the right dose, and that same support can provide the early intervention needed to reduce costs and risk when chronic conditions worsen. Since Member to Member's inception, Elderplan has come to rely on the program's built-in monitoring system to manage those costs (as well as others) effectively. Recent research confirms that only 1 to 2 percent of customers leave Elderplan every year when they are involved in Member to Member, whereas the voluntary disenrollment rates for Elderplan's competitors and other HMOs is normally between 10 and 15 percent. Research also found that interventions regarding medications and hospitalization were significantly lower for Time Dollar participants than for other members of Elderplan.

Contact information:

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[www.elderplan.org/programs/member\\_to\\_member.shtml](http://www.elderplan.org/programs/member_to_member.shtml)

*Example of a Time Dollar Network: New England Time Dollar Exchange Network*

It was in late 1995 that Richard Rockefeller, the founder of NETEN (formally known as Maine Time Dollar Network), first heard Edgar Cahn speak about Time Dollars. Up to that point, most of Rockefeller's philanthropy dollars had supported environmental issues. However, after hearing Cahn speak, he realized that we cannot expect people to take care of our environment if we are not first taking care of each other. Rockefeller felt compelled to bring the concept of Time Dollars to Maine and began to share his vision in 1996. In 1997, Maine hosted an International Time Dollar Congress in cooperation with Cahn, bringing together 40 Time Dollar programs from all over the world.<sup>951, 952</sup>

In 1998, the New England Time Dollars Exchange Network set its strategic direction to create a model Time Dollar exchange on Portland's Munjoy Hill and to replicate that model throughout Maine. Between 1998 and 2003, NETEN became a leader in the International Time Dollar movement. NETEN created a successful Time Dollar exchange and began to replicate the model in several New England communities: Portland, Brunswick, Rockland, Lewiston, Mount Desert Island, and Millinocket, Maine; Manchester and North Conway, New Hampshire; and Lynn, Massachusetts. Its membership grew from 90 individuals in 1998, who exchanged 1,540 hours of services, to a statewide membership of just under 1,000, who exchanged 25,000 hours of services in 2003. During these five years, the members exchanged well over 50,000 hours of services, a market economy value of over \$800,000 (using United Way's average volunteer hourly rate of \$16.07). NETEN hosted and mentored Time Dollar exchange groups in the United States from Massachusetts, New Hampshire, Oklahoma, Florida, California, Colorado, Indiana, and Pennsylvania; and around the world from England, Scotland, Singapore, Canada, Japan, and France.

NETEN's current strategic direction is responding to and capitalizing on the growing interest in the Time Dollar concept. The plan extends NETENs reach from Maine to all of New England and addresses issues of capacity, sustainability, governance, and technology. The goals through 2008 include reframing its geographic scope to include all of New England; increasing the number of exchanges from 14 to 60; increasing the number of members participating in exchanges from 875 to 15,000; and increasing the number of hours exchanged from 18,000 to 300,000.

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A study conducted in 2004<sup>953</sup> summarizes information collected through 30-minute, face-to-face interviews with 12 local Time Banks at the Time Banks International Conference. The purpose of the interviews was to begin to gather qualitative data on what is happening at the local level so that best practices and lessons learned can be shared across the global network. Questions focused on organizational structure, partnerships, and sources of funds in order to look at how local Time Banks can make more efficient use of resources and enhance sustainability.

In terms of the sources of funds, members of local Time Banks in the United States all rely on federal, state, and city/county dollars. Federal sources include Americorps/VISTA, the Department of Housing and Urban Development (HUD), National Emergency Grant, and the Substance Abuse and Mental Health Services Administration. State sources included the Departments of Education, Mental Health, and Social Services; and city/county sources included public schools and county government. With the exception of the Americorps/VISTA program, government dollars typically go to a Time Bank that operates as part of a larger agency. With the exception of some of the Time Banks that are part of the network in New England, the local Time Banks are likely to have difficulty pursuing a comprehensive family/individual donor strategy without additional support to develop the capacity to do so. All of the Time Banks interviewed have less than 2.75 full-time enrollees (FTEs), with most relying on the equivalent of one or less than one paid staff member. Most do not currently have the administrative systems, staffing, or specialized skills to build and manage a database, develop materials, and conduct the necessary relationship-building and follow-up.

Four out of the 10 local U.S. Time Banks interviewed report doing mini-fundraisers and hosting special events to raise money. The events are important for community building as members typically earn Time Dollars for organizing and staffing the fundraiser. Other costs are covered through in-kind member contributions and local sponsors. Agency-based Time Banks rely on their parent organization for overhead and other resources (e.g., event space, administrative support), which considerably reduces their need to raise cash for operating expenses other than personnel. Well-established agencies typically have visibility in the community, as well as partnerships and funding relationships that can be further developed to include the Time Bank. The challenge to being agency-based is often the need for a cultural shift—in terms of how staff and clients interact and relate to each other—and, as a result, the Time Banks model can be difficult to implement effectively. None of the U.S. Time Banks interviewed reported receiving funds from private foundations. This may reflect an organization’s stage of development, geographic area, or capacity for foundation research, relationship-building, and grant writing. Only one organization mentioned an effort to earn revenue by selling cookbooks with local and outdoor cooking recipes. This initiative is in the early stages and has not been tested.

In terms of the partnerships, members of local Time Banks in the United States report that they have been able to marshal resources and improve the variety of services offered to members through creative partnerships. Partnerships are a key component of sustainability, in terms of recruiting and retaining members, gaining visibility in the community to attract funders, and reducing operating expenses through exchanges. Partners will typically offer resources in kind; earn Time Dollars, and donate them back to the Time Bank; earn Time Dollars and spend them “hiring” members to cover staffing needs; or allow members to purchase services in Time Dollars that normally have a cash fee. In the latter case, members pay cash for any products that are needed to complete the service (e.g., food for catering, bike parts for a tune-up). Based on the interviews, the following types of partners are emerging:

- large organizations that rely on large numbers of volunteers, require minimal training, and have a standardized orientation process in place—examples include hospitals or local chapters of a national nonprofit (e.g., Red Cross);

- small businesses, nonprofits, or local government offices with temporary staffing or volunteer needs that require minimal training; and
- small businesses and nonprofit organizations that occasionally need skilled labor that is outside their area of expertise (e.g., repairs, landscaping).

In terms of products, local Time Banks in the United States report that members are exchanging Time Dollars for products, mainly by earning a specified amount of Time Dollars and redeeming them for donated items (e.g., computers). The obvious challenge with product Time Dollar exchanges is pricing. It is difficult to attach a time value to a product, and the local Time Banks are reluctant to take on the responsibility of setting prices. Exceptions that are occurring at some of the New England Time Banks include products that are exchanged in an aggregate amount. For example, members of a local New England Time Bank—Katahdin—may exchange one Time Dollar for one meal from the daily menu at the local hospital’s cafeteria. Members set their own prices, negotiating (independent of the Time Bank) what a particular product is worth in Time Dollars. For example, some members of a local Time Bank—Portland—have offered items for sale to other members in Time Dollars or in Time Dollars plus some amount of cash.

*Time Bank Spotlight: Portland East End (Portland, Maine)*

In addition to the summary of findings from the interviews with the local Time Banks listed above, the specific outcomes of the interview with the Portland East End Time Bank are highlighted below. The Portland East End Time Bank operates independently as a member of the New England Time Banks Network. It provides a good illustration of the strategies and resources utilized to run a successful local Time Bank.

**Table 5.2. The Portland East End Time Bank**

Start date (month/year)	Pilot in 1996; up and running in 1998
Membership	Open
Number of members (as of August 2004)	600+
Total FTEs	2.75
Americorps/VISTA	1 (ABLE = program funded by AARP; 2 seniors volunteer each work 20 hours/week)
Sources of funds	Individual donors (80–90 percent); AARP; event sponsorship; local churches; and government (federal)
Member/community activities	Monthly potlucks with themes; Day of Sharing (community service); and Holiday Bazaar. Fundraisers include cookie and lemonade sales; Tastes Around the World; and gift wrapping (paper is provided by the Portland Exchange and Time Dollar members do the wrapping for customers shopping at local businesses).
<b>Examples of exchanges with local organizations that help the Time Bank to reduce its operating expenses</b>	
Advertising	The local newspaper accepts 1 Time Dollar to run a small ad to promote events sponsored by the Time Bank. The newspaper spends its Time Dollars to hire members when extra clerical help is needed.
<b>Examples of products and services available to members through partnerships with local businesses, schools, health care providers, and other nonprofits.</b>	
Theater tickets (Access to the Arts)	The theater earns Time Dollars by donating tickets that members can then buy with Time Dollars. The theater relies on members to help with ushering, mailings, filing, and hanging posters.
Adult education classes (Portland Adult Education)	Members can take classes using Time Dollars. In exchange, members provide tutoring to other students.
Physical and mental health services (True North)	The practice automatically receives 4 Time Dollars each month from the Time Bank. Members pay 2 Time Dollars per session for services. Members get a 10 percent discount on supplies.
Aikido classes	Members can take classes for Time Dollars. In exchange, the business relies on members for Web site and brochure design.
Acupuncture	On a limited basis, members can pay for services with Time Dollars (the provider limits the number of clients per month). In exchange, the business relies on members to provide catering services for open house events.
Advertising	Members can post ads on the Time Banks Web site in exchange for 1 Time Dollar. A staff member scans all ads before posting.
<b>Examples of individual member to member product exchanges</b>	
Car Used furniture	Members post items for sale and negotiate the price in Time Dollars with each other.
Homemade gifts	At the annual Holiday Bazaar, members bring homemade goods that they buy/sell for Time Dollars.

## *Affordable Housing*

### **Background**

Throughout the United States, advances in research care, corresponding increases in frailty and cognitive impairments,<sup>954</sup> and the *Olmstead* decision are forcing states to reconfigure their LTSS systems for elders and individuals. According to HUD's latest Worst Case Housing Needs Report, people with disabilities make up at least 25 percent<sup>955</sup> (estimated by HUD as 1.1 million to 1.4 million people) of the households with worst case housing needs in the United States.<sup>956</sup> 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 ties 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 home- and community-based services (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.

According to a 2004 report by NCD,<sup>957</sup> individuals with disabilities identified that their satisfaction with their housing situation is the primary factor for either remaining in or moving from their communities. Satisfaction—according to this target population—depends on two key factors: affordability and accessibility. Affordable and sustainable homeownership is a virtue that has been embraced by housing advocates and by the Bush Administration. Widely cited dividends resulting from homeownership include both individual and societal benefits. While a number of programs have extended ownership to people at increasingly lower income levels, roadblocks continue to exist, such as rapidly escalating housing costs—both rental and ownership, particularly in urban environments; low credit ratings among those aspiring to

homeownership; predatory lending and the not-surprising default rate; unanticipated postpurchase expenses; escalating monthly expenses; and the absence of a network to support new homeowners as they confront these challenges.<sup>958</sup> Compounding the homeownership challenges faced by individuals with low incomes is that, increasingly, affordable rental housing is being lost as HUD-insured mortgages and low-income housing tax credits expire, which threatens significant displacement and loss of affordable housing units as these properties face pressure for conversion to market-rate housing stock.

As the supply of affordable units grows increasingly tight, new sources of affordable housing must be found: affordable homeownership opportunities that combine support services as an option for individuals with disabilities and the elderly.<sup>959</sup> To significantly increase homeownership rates of lower-income families in light of the rapidly escalating cost of housing, other alternative mechanisms need to be considered, such as multifamily structures with condominium and cooperative ownership. Multifamily homeownership, whether it is organized as a condominium or a cooperative, is often an entryway to homeownership, providing ownership at a substantially lower cost than single-family homes.

A housing cooperative is formed when people join together to own or control the building in which they live. They form a corporation and pay a monthly amount (maintenance fee) that covers operating expenses. Residents buy shares or a membership in the co-op, but the cooperative owns the building, land, and any common areas. Members pay a fixed amount each month that covers the mortgage, property taxes, insurance, administrative expenses, maintenance, and reserves. Costs are typically less than either rental or single-family housing in the same neighborhood. Cooperative housing represents a viable homeownership alternative that provides affordable, quality living space and a number of social benefits. Particularly in high-cost markets, cooperative housing is an effective means for households with little savings and limited income to achieve homeownership. Cooperatives provide residents with the stability and opportunity to keep more of their income and to improve their lives.<sup>960, 961, 962</sup>

Cooperative housing offers an affordable homeownership alternative that can lower, or at least stabilize, housing costs, especially if it is a Limited Equity Cooperative (LEC). A LEC is created

when restrictions are placed on the resale of cooperative interests to make them affordable to multiple generations of purchasers. Unlike properties made affordable by programs such as the low-income housing tax credit (LIHTC) or Mitchell-Lama, which expire after a set period of time, LECs remain as sources of affordable homeownership in perpetuity. Like all kinds of affordable housing, subsidies are needed to make most affordable LEC projects feasible. Subsidies invested in cooperative housing result in homeownership that is affordable to the tenants in residence at the time of conversion. With the benefit of subsidy, cooperatives can be made available to households of very low income. For example, a family earning less than \$20,000 per year, and with as little as \$2,000 in savings, can qualify for ownership in a cooperative.<sup>963</sup>

Because cooperatives are owned and managed by their residents, they are uniquely suited to offer alternatives to forcing seniors and individuals with disabilities into institutions. Homeownership in a group setting of people with similar needs and lifestyles gives those who may not be capable of living on their own many viable opportunities for independence and autonomy with mutual support. Co-ops can leverage the community to offer a customized level of care that suits the needs of their members. The residents decide what services are appropriate and then provide them on a volunteer basis or pay for them together, often getting services like personal aides and transportation at greatly reduced rates. Those who would normally find themselves in group homes or other institutional settings can achieve independence, along with a sense of community and responsibility, in a cooperative.<sup>964</sup>

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.

## **Program Description**

This section examines two approaches to affordable housing that offer nontraditional choices to individuals with disabilities and the elderly with limited income. Together We Can offers affordable cooperative living with limited equity shares to keep prices well below market rate. No Place Like Home Communities (NPLHC) offers homeownership and subsidized rental options within a rehabilitated multifamily development that also includes a range of supportive services.

### ***Together We Can—New York City***

Together We Can is a project of the NCB Development Corporation (NCBDC). Building on its successful history in cooperative housing finance, NCBDC launched Together We Can in late 2003 as a three-year project to build the capacity of community-based development organizations to engage in cooperative development, increase the number of public and private partners, and provide financing for the rehabilitation of rental properties and the conversion of these properties to affordable cooperative homeownership. Together We Can promotes cooperatives as an effective means of preserving affordable housing and creating homeownership opportunities for low-income families. Through this initiative, housing units are preserved as affordable to serve as vehicles for family stabilization and wealth creation for low-income families and important anchors for neighborhood revitalization.<sup>965, 966, 967</sup>

The Together We Can program promotes the use of the cooperative model as an effective means of preserving affordable housing and creating homeownership opportunities for very low-income families in New York City. In 2004, NCBDC began working in New York City, where public-private partnerships are already an effective tool for community development. Over the course of this project, the goals will be to more fully address the need for affordable housing in New York City by creating at least 1,600 units of affordable cooperative homeownership; to build the capacity of community-based development organizations to develop affordable housing; and to demonstrate the effectiveness of the cooperative model to enable low-income residents to become homeowners and maximize partnering and leveraging opportunities to preserve existing affordable housing. Together We Can will also increase personal wealth by creating homeownership and equity-building opportunities for low-income families.

Implementation of the program builds on existing partnerships with the Department of Housing Preservation and Development (HPD) of the City of New York, the Urban Homesteaders Assistance Board (UHAB), community-based development organizations (CBOs), the local HUD office, financial institutions, and private foundations. The Together We Can initiative has the potential to provide permanent, affordable homeownership for low-income families during the three years of the program. In addition, by building the capacity of CBOs, it also has the potential to build an infrastructure of capability and expertise—creating a pipeline of affordable cooperative housing development and multiplying the impact of this initiative.

### ***No Place Like Home Communities—Robbinsdale, Minnesota***

NPLHC began in 1996 as a committee of families of people with disabilities and special education and social services professionals (organized by Intermediate School District 287) who were committed to helping young adults with disabilities achieve as much independence as possible. This group wanted to find a means of developing stable, long-term supportive housing for adults with disabilities so they could make full use of their abilities. The group evolved into an incorporated nonprofit organization in 2001, with 501(c)(3) designation received in 2002. NPLHC was named by the adults with disabilities who were going to live in the organization's pilot project—Adair Apartments.<sup>968, 969, 970, 971</sup>

NPLHC is best known for its work in the area of supportive, affordable housing and homeownership. It is one of the first organizations in the country to approach permanent, accessible, affordable, supportive homeownership in a way that promotes economic independence and self-direction among people with disabilities by helping them achieve financial equity in their homes and emotional equity in their lives. In 2001, NPLHC acquired an apartment complex consisting of three buildings with 11 units each in Robbinsdale, Minnesota. NPLHC developed a financing model that dealt effectively with the limited public resources available for supportive affordable housing. The NPLHC model is based on the understanding that, while all of the residents with disabilities who will live in NPLHC housing are low-income, some of their families have adequate assets to buy an affordable unit with supportive services for their family member with a disability, while others require public subsidy even to rent a unit with

services. NPLHC’s pilot site—Adair Apartments—contains 15 purchased condominium units and 15 rental units subsidized through a variety of public funding sources. Through this model, NPLHC developed 30 units of supportive housing for people with disabilities, with public subsidies covering the cost of 15 units, thus doubling the effectiveness of public funding for affordable housing.

In addition to affordable housing, NPLHC provides service coordination, crisis management, conflict resolution, and activities to promote social growth, self-advocacy, and independent living. These services, which are offered through NPLHC’s on-site Resource Center, ensure a critical safety net for adults with disabilities who are striving to become independent citizens. Participation in the Resource Center services and activities is completely voluntary for residents. In this model, NPLHC gives adults with disabilities the freedom to make their own decisions, while offering crucial supports to sustain them on their path to independence.

### **Core Program Elements**

#### *Funding and Expenditures*

#### *Together We Can*

Together We Can works with foundations to fund and offer a loan fund for predevelopment expenses; a credit enhancement fund to provide a partial guarantee of the cooperative mortgages to attract investors and build understanding of and confidence in cooperative loans; and a capacity-building resource fund for CBOs.

#### *No Place Like Home Communities*

Asset-building activities currently sponsored by NPLHC include accessible, affordable, supportive homeownership and conversion of Section 8 renters to homeownership through innovative down payment and closing cost programs. The development of a financial literacy and first-time homebuyer education program known as “This Is Mine!” covers basic banking, credit, budgeting, saving, loans, fraud, and consumer rights, and helps to develop emotional equity through long-term relationships with highly trained volunteer mentors. Programs help individuals with disabilities, their families, and their employers understand and use favorable tax provisions and savings programs through Individual Development Accounts (IDAs) and 529

plans. Business planning, including securing microenterprise loans for home-based businesses owned and operated by individuals with disabilities, and solutions that more responsibly serve individuals with disabilities who are the beneficiaries of supplemental needs trusts.

### *Technical Assistance*

#### ***Together We Can Program Financing and Technical Assistance Tools***

Through the Together We Can initiative, NCBDC offers technical assistance to experienced nonprofit developers who want to offer affordable homeownership options. Together We Can works to increase affordable homeownership by building developers' capacity to develop affordable cooperatives.

#### **Lessons Learned and Accomplishments**

A 2004 study<sup>972</sup> of LECs in the United States and Canada found that LECs provide high-quality, safe, affordable housing for low-income families; contribute to stable, economically and ethnically diverse neighborhoods; can fulfill some economic and social needs more successfully than rental housing, particularly for groups that have special needs or where housing is especially expensive or distressed; offer stable housing costs in hot real estate markets and resistance to default in down markets, while requiring similar or lower subsidies than comparable rental housing; and can be an attractive housing alternative for a substantial portion of renters and some homeowners who spend more than 50 percent of their income on housing.

#### *NCBDC and the Together We Can Program: Impact and Experience*

In its 20 years of operation, NCBDC and its affiliate, National Cooperative Bank (NCB), have financed \$500 million supporting the development of 30,000+ units of affordable cooperative and rental housing. The Together We Can initiative started off strong. It obtained \$15.7 million for renovations and expenses related to co-op conversion for 425 units; it leveraged \$19.5 million in public funds and \$5 million more for 120 units; and it developed a new co-op training curriculum in the fall of 2004. In October 2004, it hosted an Affordable Cooperative Housing Roundtable with the Ford Foundation and Harvard Joint Center for Housing Studies in New York City to increase the visibility and understanding of co-ops in the affordable housing community. Together We Can won the HUD technical assistance contract in Metropolitan New

York City and secured funding from Fannie Mae Foundation, Surdna, Wells Fargo Foundation, MSN Fund/Cooperative Development Foundation, and Bank of America Foundation.<sup>973</sup>

### *No Place Like Home Communities: Impact and Experience*

NPLHC is currently working with local community groups of adults with disabilities, their parents, social workers, educators, and community leaders to develop new projects in Washington, Ramsey, and suburban Hennepin County that will serve a minimum of 120 individuals with disabilities by the end of 2006. Ultimately, NPLHC hopes to serve as a recognizable national model for homeownership and asset development for people with disabilities.<sup>974</sup>

In early 2004, NPLHC began working with NCBDC and its National Disability Institute to strategize NPLHC's expansion across Minnesota and the Upper Midwest. NCBDC is exploring partnering further with NPLHC to develop more opportunities for accessible, affordable, supportive homeownership in the Twin Cities area and the Upper Midwest. NCBDC brings the creativity, financial expertise, mission orientation, and willingness to explore nontraditional forms of financing that NPLHC needs to develop a long-term version of its model for people with disabilities. NPLHC has been acknowledged as one of the first organizations in the country to approach permanent, accessible, affordable, supportive housing in a way that promotes economic independence and self-direction among people with disabilities by helping them achieve financial equity in their lives. Its unique financial model, utilizing both public and private resources, has garnered national attention from disability advocates, policymakers, and funding sources.

### ***Self-Directed Support Corporation—Baltimore, Maryland***

#### **Background**

The conceptualization of Microboards came from David and Faye Wetherow in the Canadian province of Manitoba in 1984. The Wetherows formed the first Microboard around a young man leaving an institutional setting. A Microboard, which does not have a specific legal meaning, is formed when a small (micro) group of committed family and friends join together with a person who lives with challenges to create a nonprofit society (board). Together this small group of people addresses the person's planning and support needs in an empowering and customized

fashion. A Microboard comes out of the person-centered planning philosophy and is therefore created for the sole support of one individual.<sup>975, 976</sup>

At the time the Wetherows began developing the Microboard concept, there were only three ways that the Canadian government would finance community support services in Manitoba: (1) by licensing and funding a limited number of residential or day program “spaces” under the auspices of incorporated nonprofit societies or proprietary agencies; (2) by paying board and care rates to the proprietors of commercial residential facilities; and (3) by paying the equivalent of board and care rates to foster families for children and adult home provider rates for adults. In all three instances (except for foster care), the government was funding an agency to operate a certain number of program spaces or slots. This had several implications for the people served. If an individual who needed supports did not happen to fit an open “slot,” the person would be forced to wait until an agency developed and the government funded a new slot or a different kind of slot. Functionally, this showed up in the form of waiting lists. If a person was being served in an existing slot, and the type of service represented by that slot did not fit that person’s actual needs, there was very little opportunity to change the service configuration, because alternative slots were almost always full and had long waiting lists. Because there were such powerful disincentives to make changes, people who were able to make advances remained in mismatched service arrangements. The express premise of many services—which was that they would be “transitional” to other, less restrictive services—was inoperable because actual movement was limited or entirely absent. On the other hand, people who began experiencing increasing challenges or difficulties were forced to remain in services that could no longer meet their needs. Because of the congregate nature of most services, people were extensively disconnected from relationships and opportunities in the larger community. With rare exceptions, the places these individuals lived, worked, and played, and the days of their lives, were entirely defined by the agencies that supported them.

The intention of the Microboard was to bring the structures for providing supports more in line with person-centered and family-centered principles. The Microboard was designed to allow people to move (1) from agency funding to funding individual support services; (2) from agency-type governance structures to supports directly governed by the individuals being supported and

their friends and family members; (3) from relatively inflexible service structures to supports that could adapt rapidly to changes in a person's needs, interests, relationships, and environments; and (4) from lives defined by services to lives increasingly defined by companionship, connection, and contribution in the broader community.

The structure of the first Microboards began with a simple question: "What is the smallest unit of human organization that would be eligible to receive agency-level funding?" The answer was a three-person nonprofit corporation that could be organized to support as few as one named individual; hence, the "Microboard." In 1989, the first large-scale application of Microboards was developed by the Vela Microboard Association in British Columbia, Canada, to develop the concept into a critical service option for people with developmental disabilities. Since its inception, Vela has helped set up over 170 Microboards in Canada.

Ensuring access to key health and support services was included as one of the lessons learned from the community initiatives for adults with disabilities that are described in the 2004 NCD report on livable communities.<sup>977</sup> One of the priority action steps listed in the area of health care is

allowing money to follow the person to the most appropriate and preferred care setting to create a more equitable balance between institutional and community-based services, eliminate barriers to care, and provide consumers with choice over the location and type of services provided.

This is in concert with the Microboard concept.

### **Program Description**

The Self-Directed Support Corporation (SDSC) model was established in October 2001 by the Inclusion Research Institute (IRI) as a project of national significance funded by the Administration on Developmental Disabilities. The SDSC model was created to adapt the concept of the Microboard to the legal, regulatory, and service delivery system for people with developmental disabilities in the United States. The U.S. adaptation was developed using existing service delivery components that are widely accepted in the disability community. From a service perspective, the SDSC model and similar small boards serve as independent incorporated nonprofit entities, established to negotiate, receive funds, organize, and manage

supports around one person and/or the person's family. In addition, the SDSC serves as a personal support circle. The state funds the SDSC directly. The SDSC is the employer of record and independently purchases the goods and services it needs, just as the members of an ordinary household would purchase the goods and services they need. The SDSC has complete freedom as to where and from whom it purchases goods and services. For example, if the SDSC wants to purchase payroll services rather than spending its time doing the payroll, it can purchase that service from a bank, a commercial payroll service, or a private bookkeeper, or it may join with other SDSCs to form a cooperative payroll service. If the SDSC doesn't like the service it is receiving, it can change the source at will, just as an ordinary family may change lawyers or change banks.<sup>978, 979, 980</sup>

The SDSC approach is another option that provides an opportunity for public dollars to serve the person with a disability, while providing accountability to the Federal Government and state governments. An SDSC becomes the administrative body of the resources that the person with the disability requires. It differs from traditional support services because the board members (together, the provider) serve only one person. Because support services are provided to only one person, states may choose to be more flexible with regulations. However, an SDSC must follow the accounting requirements of both the Federal Government and the state government. It undergoes yearly audits to ensure accountability to both of these entities. It is subject to the same audits and reviews by state agencies as any other licensed service provider. It also must follow labor laws and nursing regulations.<sup>981, 982</sup>

The foundation of the SDSC model is six building blocks<sup>983</sup> that interlock to form a foundation on which people with disabilities and their families can strive to build a life that offers real opportunities for security, dignity, and contribution. These building blocks are personal support; person-centered planning; responsive and flexible individual assistance; individual funding; transition of existing services; and community development. Supports are designed using the principles and tools of self-determination to meet the individual's unique support needs. The components of the SDSC model have been derived from emerging best practices in self-determination described by Moseley and Nerney,<sup>984, 985</sup> including the following:

- ***Flexible Individual Budgeting***

The overall objective is to change state service delivery systems to actively support, encourage, and enable people to directly control the services they receive and the resources provided on their behalf.

- ***Individually Created Budgets***

The person with a disability, with freely chosen family and friends, should develop the budget for the supports he or she is to receive.

- ***Open Budgeting Process***

The amount of the budget should be set through a process that involves the individual in a discussion that identifies the person's needs, the supports required to meet those needs, the presence of natural or alternative means that can be used to meet needs, and the costs of the support to be provided.

- ***Authority Over Personnel***

The individual budget is designed to enable the person to supervise and direct the staff who provide support. Even if the person receiving services delegates responsibility to another organization (or individual) to be the employer of record, the budget development and implementation process recognizes the primary authority of the individual over personnel.

- ***Flexibility***

Within approved amounts, budgets are designed to support the reasonable movement of dollars from line item to line item, as long as the essential supports are maintained.

- ***Administrative Structure***

The overall administrative and funding structure is designed to support individual budgeting at two levels: (1) funding is allocated from the state to the fiscal intermediary in a manner and form that enables the organization to meet the financial and accounting demands that are

necessary to sustain a large number of individual budgets for people receiving services; and (2) funding is allocated from the “provider” to the individual through a mechanism that easily pays for the variety of support alternatives that may be chosen.

- ***Personally Directed and Controlled Planning Process***

The planning process must respect and reflect the central role of the individual in the determination of its content and scope. Recognizing that the authority for decision making rests with the consumer moves person-centered planning to the next step by validating the authority of the individual to choose the service provider, directly control how resources allocated on his or her behalf will be spent, supervise the staff who provide supports, and define how he or she will participate in the overall service delivery system.

- ***Independent Support Coordination***

The function of support coordination, or brokerage, is separate from support provision. Ideally, support coordination is offered by an independent organization or individual that is able to work solely on behalf of the consumer without conflicting interests or responsibilities. In this context, the support coordinator functions to facilitate the transfer of power and control from the current system to the individual.

- ***Autonomous Fiscal Intermediary Services***

In many cases, the fiscal intermediary is the private nonprofit organization established by and for the individual to hold the funds that have been provided, including financial services to people for functions typically performed by the business offices of agencies and corporations. These activities may include, among other things, Medicaid billing; check writing for all bills; administration of personnel issues, such as employer of record services, tax withholding, worker’s compensation, and health insurance; and the management of other taxes and benefits that might be appropriate, depending on the individual’s budget. The fiscal intermediary works for the individual and remains accountable for ensuring compliance with all federal and state laws.

## **Core Program Elements**

### *Staffing*

The board of directors of an SDSC is responsible for identifying what is important to the person receiving the supports. The board is not a paid entity, which keeps it free of conflict of interest. As with any board, it must keep records, manage the budget, and ensure that policies and procedures are followed.

### *Funding and Expenditures*

The costs of establishing an SDSC are in setting up the agency. These vary from state to state, but the main cost is the incorporation process. This is done through the state entity that oversees the taxation and assessment process. Usually the cost is anywhere from \$40 to about \$150.

Usually funding for the supports that the person with the disability requires is obtained through the state's Medicaid HCBS waiver. The HCBS waiver dollars come from both state and federal Medicaid dollars. The state is responsible for writing its own waivers and is responsible for matching the federal dollars. Each state's match is different and, because the state writes its own waivers, each state may have different policies and regulations in place. However, the funding stream for the SDSC is the same as for any other provider agency.

### *Technical Assistance*

Some states have created Microboard associations to assist families and other entities that wish to establish an SDSC or a small board. These associations provide development, support, and training. The Inclusion Research Institute (IRI) provides guidance, resources, and tools for creating an SDSC on its Web site.<sup>986</sup>

## **Lessons Learned and Accomplishments**

The IRI has been tracking the establishment of SDSCs and the Microboard approach. Currently, there are approximately 100 SDSCs (or some form of this model) across the United States. The numbers are growing rapidly, with about 75 more SDSCs in some phase of exploration or start-up. States that already have these small boards include Maryland, Colorado, Oregon, Missouri, Utah, Oklahoma, Virginia, Pennsylvania, Arizona, Minnesota, California, and Tennessee. States that are in the process of developing them include Nevada and New York.

*SDSC Spotlight: Joshua's House Incorporated*

Jackie Golden, executive director of IRI, shared the story of her son, Joshua, and how the SDSC model made a difference in his life as well as his family's life. Joshua's House Incorporated (JHI) is the SDSC that was designed to deliver the supports Joshua needs to live successfully and be fully included in his community. JHI is a provider agency that provides custom-designed supports for Joshua. For Joshua and his family, JHI delivers his supports using the principles and tools of self-determination.<sup>987, 988</sup>

Joshua Golden is a survivor of traditional support networks. Since Joshua was eight years old, he has been receiving some type of public supports. The supports never fully matched Joshua's needs and often hurt him both physically and mentally. The Goldens explored the SDSC model and wondered why they could not become the provider of Joshua's supports. The Goldens understood the need for accountability regarding public funds, but they also knew that Joshua needed control over his supports, and they felt that the system was taking too long to catch up with his needs. Therefore, they believed that the SDSC model was the answer. Joshua has significant cognitive disabilities and requires full-time care. JHI incorporated and then applied for and became a licensed provider of supports for Joshua. JHI is the employer of record.

The Goldens formed a nonprofit, JHI, around Joshua and became the legal entity to receive Joshua's allotted Medicaid dollars. Only individuals who care and share a vision for Joshua serve on the board of directors for JHI on a volunteer basis. The board, committed to Joshua, ensures that Joshua receives services that match his needs, desires, and lifestyle. He is in control, with the assistance of people who want him to be successful.

***What does this mean for Joshua?*** It means that Joshua no longer has to deal with a system that does not value him as a person. He can select who comes into his life, as he is the director and decision maker of his support team, balanced with others who care about him.

***What does this mean for Joshua's family?*** Joshua's sister and his parents serve on his board, along with Joshua. The board also has five other members. The key for the Goldens was to include people with a vision and commitment who are willing to spend time with Joshua. It also means a support network for Joshua's family. No longer is it only his parents looking to secure

Joshua's future. Now his legal board of directors is working for him. For Joshua's sister, she knows that she will have people to help her with Joshua when his parents are no longer around; it is a support team for her as well. While the SDSC has been a lot of work, it is also the most wonderful thing that has happened to the Golden family. Joshua truly can have a life that is his own, and his family can finally sleep at night, knowing that people who care about him are involved in his life.

### ***Pooled Trust—Bedford, New Hampshire***

#### **Background**

Making financial arrangements for an individual with disabilities is an important part of planning for future needs. These arrangements help ensure that there will be some financial security when a parent or guardian can no longer provide help. Because of the various factors that need to be considered, making these arrangements can be quite complex. Arrangements include a family's finances, the family member's needs, and government benefits or other assets of the family member with a disability. Many individuals with disabilities receive means-tested benefits, such as Supplemental Security Income (SSI) and Medicaid. Means-tested benefits are benefits available to people with minimal income and minimal assets or resources. If a person's income or assets/resources exceed the specified limit, he or she will not be eligible for the benefit. Often, for example, parents or others plan for the future financial security for their child with a disability by leaving the child an inheritance. If an individual receives SSI and/or Medicaid and has access to more than \$2,000 in assets, he or she would lose eligibility for SSI and Medicaid.

One way to provide for the financial security of someone with a disability without jeopardizing government benefits is by using a trust. Trusts hold money or property that the grantor (the person who sets up the trust) leaves for the benefit of another person (the beneficiary). Unlike a gift or inheritance through a will, a trust usually contains carefully written instructions on when and how to use the trust's assets. Trusts may be designed to distribute assets to one or more beneficiaries at certain times or under certain conditions. Some trusts make distributions to the beneficiary (or beneficiaries) over time. Others instruct the trustee to distribute only the trust's earnings (from interest or investments) or the amount the trustee thinks the beneficiary needs.

Some trusts may require the accumulation of all income for distribution at a future time.<sup>989, 990</sup>

Supplementary discretionary trusts are designed so that the principal (the amount put in the trust account) and its earnings (from interest or investments) supplement the beneficiary's basic care and do not replace the public funds required to pay for this care. This kind of trust is good for the SSI and Medicaid recipient whose assets may not exceed a specific level. The trust grantor can carefully direct that the trust not pay for services covered by Medicaid or other benefits received as a result of the child's disability. Instead, the trust would require the trustee to provide funds for certain items, services, or other expenses not covered by SSI and Medicaid. These types of trusts may also be set up for someone who is not on SSI and Medicaid.

Two federal laws support trusts for individuals with disabilities who receive Medicaid and SSI. The Omnibus Budget Reconciliation Act of 1993 (OBRA 93) is a federal law that affects how people with disabilities can have a trust and still qualify for Medicaid. The Foster Care Independence Act of 1999 is a federal law that affects how people with disabilities can have a trust and still qualify for SSI. Both laws allow many people with disabilities to place their own money into a trust and become (or remain) eligible for Medicaid and SSI.

### **Program Description**

Pooled trust programs enable families or other caregivers, and in some cases individuals with disabilities, to establish relatively inexpensive and effective trust accounts that provide supplemental funds for the person with a disability while protecting him or her from losing important government benefits. In lieu of establishing an individual trust account, families set up a subaccount with a trust program.<sup>991</sup> Pooled trust programs provide a convenient and economical way to have trust funds administered for people with disabilities that will supplement the benefits offered by entitlement programs. These programs normally use a discretionary irrevocable trust for supplemental needs. The assets placed in the trust by parents or others are allocated to a separate subaccount. The assets from all subaccounts are pooled to be invested and managed as one larger amount. Records are maintained of the amount of each person's trust and the amount spent for that individual. The program divides the trust earnings among the individual subaccounts in shares equal to the amount that each subaccount has in the pooled amount.

Using a pooled trust program offers many advantages. Parents may not have or know someone who is willing to be a trustee. Trust programs usually have knowledgeable staff and volunteers who will serve as the trustee or manager of the trust. An individual trustee could die, move away or not fulfill the trustee role for some other reason. Trust programs offer continuity, as the program does not depend on just one individual. The trust document used by programs usually has been developed and reviewed by attorneys with expertise in this area of law. There is also the likelihood that publicly funded agencies have reviewed the trust document for compliance with their agency regulations. Banks and trust companies will not accept or manage a trust that is not funded at a threshold amount. Depending on the bank, the trust account may have to be several hundred thousand dollars or more. Parents who cannot afford to fund a large trust are often able to fund an adequate account in a pooled trust program. Pooled trust program staff or volunteers often have expertise and experience with people who have disabilities. The volunteer board of the program may also include legal and financial experts, family members of people with disabilities, and advocates. Trust programs usually work closely with banks and trust companies to maintain trust accounts and can tap the expertise of financial institutions. This relationship can help maintain good financial accountability without incurring high fees for the beneficiaries. One of the most significant advantages of using a pooled trust program is the expertise brought to managing the trust and making the required reports after it begins to make disbursements.

### **Core Program Elements**

#### *Staffing*

A pooled trust program usually undertakes the daily management of the trust subaccounts. This includes handling requests for and expediting disbursements, maintaining each subaccount's records, reporting to various agencies that might be affected by disbursements, preparing necessary reports (e.g., tax-related reports), and generally managing the program. Many trust program representatives also spend considerable time meeting with families about the program and assisting families and others with future planning. Pooled trust programs are set up as or administered by a nonprofit organization. They may be under the auspices of or closely connected to one or more disability-related organizations. Groups like state and local chapters of The Arc, Goodwill, the National Alliance for the Mentally Ill (NAMI), and others have been active in establishing pooled trust programs.

Some pooled trust programs include direct care coordination services for their beneficiaries or contract with care coordinators to provide services. Services vary depending on the agency and the services provided, but the care coordinator may visit the beneficiary, be present at meetings about the individual, advocate on the individual's behalf, and provide related services as needed. Usually the costs of these services are covered by the individual's trust funds and are charged hourly.

### *Funding and Expenditures*

Pooled trust programs typically work closely with a bank, trust company, or other financial institution. Some pooled trust programs have banks serve as the trustee for the program's funds, while other pooled trust programs are their own trustees and may use the bank as an investment manager or a co-trustee.

Pooled trust programs usually must charge fees for their services. However, compared with managing an individual trust, by pooling resources for investment and management, pooled trust programs can minimize costs, so that fees are usually reduced considerably.

### **Lessons Learned and Accomplishments**

As one of its projects, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, in conjunction with The Arc, conducted a study to identify, develop, and evaluate techniques that assist individuals with developmental disabilities and their families to plan for future needs, including future financial needs. This included research to determine the best practices in pooled trust programs.<sup>992, 993, 994</sup> The project used a community-based model of aging-in-place for families of people with intellectual and developmental disabilities. The aims of the project were to increase understanding of quality practices in pooled trust programs; to aid families in using trust programs or alternatives; and to increase the family's ability to develop effective future plans that address financial, legal, and service/support areas. The study had three research questions: What information do families and individuals need to make an informed choice about using pooled trust programs? How are pooled trust programs organized and what services do they offer? What are the experiences and levels of satisfaction of families who have used pooled trust programs? Three studies were conducted to answer the research questions.

The research conducted on best practices in pooled trust programs identified the following key findings and potential implications. Families' needs for information on guardianship and alternatives, trusts, and planning for supports and services are well documented. However, early studies indicate that few families conduct financial planning for a family member with a disability. Heller and Factor<sup>995, 996</sup> found that only 31 percent of families in their study contacted an attorney to initiate planning. The survey (study 3) conducted by this project heard primarily from families that were engaged in future planning. Seventy-four percent of the 223 respondents had a financial plan in place for their family member with a disability. Only 5 percent of these respondents used a pooled trust. Many of the 26 percent who had not developed a financial plan assumed that such planning for the relative with a disability was just for people who are wealthy. This supports the importance of educating families about options other than a trust established with a financial institution. The use of a pooled trust is one option; however, it is not universally available, as only 22 states are known to have pooled trusts operating, and not all of these are available to families statewide.

*Pooled Trust Program Spotlight: Enhanced Life Options, Bedford, New Hampshire*<sup>997, 998</sup>

The Enhanced Life Options Group, established in 1993, is a nonprofit organization that develops and carries out enhanced life option plans for people with disabilities. It provides information, consulting, advocacy, mentoring, and trust-related services for the disabilities community, including special needs trusts, supplemental needs trusts, pooled trusts, and trusts for independent living. There are nine directors, most of whom have a person with disabilities in their family. Board members also have professional skills, including law enforcement and banking. Board members have been active professionally in New Hampshire's disability community for many years, working for nonprofit organizations such as NAMI New Hampshire and the Parent Training and Information Center. The Enhanced Life Options Group is a member of the New Hampshire Brain Injury Association, NAMI New Hampshire, The Arc national organization, Planned Lifetime Assistance Network (PLAN), and the National Guardianship Association.

The Enhanced Life Options Group offers two different types of pooling arrangements: (1) individually tailored trusts with pooling provisions; and (2) a master trust arrangement in which the family does not create the trust but joins a trust already created. In addition to providing trust

services, the group participates with the New Hampshire Community Loan Fund in MoneyWorks in a program that makes Individual Development Accounts (IDAs) available. MoneyWorks IDAs are matched savings accounts designed to help eligible low-income people with disabilities accumulate resources for education, homeownership, and small business development in the Manchester and Portsmouth, New Hampshire, areas. The Enhanced Life Options Group has also participated with Project Dollars and Sense in a study of work incentives in the disabilities community, which was funded in part by the U.S. Social Security Administration, to provide Individual Career Account (ICA) demonstration projects in the Manchester and Keene, New Hampshire, areas. Project Dollars and Sense ICAs are microgrants designed to help remove work-related financial barriers for people with disabilities.

### ***Child Trust Fund—United Kingdom***

#### **Background**

The British government believes that saving and asset ownership are an important complement to the three main pillars of its welfare strategy: work and skills, income, and public services. Regular savings provide individuals with a pool of financial assets for times of adversity, for planning for retirement, or to enhance long-term independence and opportunity. The government has implemented several programs to extend the benefits of saving and asset ownership through Individual Savings Accounts, Stakeholder Pensions, and the Pension Credit. But there is strong evidence to suggest that lower-income households are not saving enough for themselves, or their children, to enjoy the benefits and opportunities of asset ownership.<sup>999, 1000</sup>

The British government looked at a number of ideas to ensure that the benefits of saving are more widely available. One possible vehicle that was explored for delivering the government's objectives was the Child Trust Fund (CTF). A CTF would be a universal account, opened for all children at birth, with an endowment paid in by the government, based on the principle of progressive universalism—every baby would receive an endowment, but those in families on lower incomes would receive a larger lump sum. A CTF would meet the government's objectives for saving and widening opportunity by ensuring that all young adults, regardless of their families' circumstances, begin their adult lives with some level of assets. This would provide all children

with the benefits of having savings (i.e., security, opportunity, long-term independence), with those children most in need receiving the most help from the government.<sup>1001</sup>

### **Program Description**

In April 2003, Gordon Brown, MP, chancellor of the Exchequer, announced the CTF for all children born on and since September 1, 2002. The CTF, which became operational in April 2005, represents a long-term savings and investment account opened for each child, into which the government will make an initial payment of either £250 or £500 (approximately \$465 or \$930, respectively), depending on the family's gross income. Children from lower-income families—those below the Child Tax Credit (CTC) limit—will receive an additional £250, because the government believes that children from higher-income families are more likely to have their funds supplemented by parents and grandparents. This additional amount will be added to the account once the CTF award for that year is confirmed. About a third of the children will be eligible to receive the additional contribution. This ensures that the CTF is both a universal and progressive policy—helping to extend opportunity to all while targeting support at those most in need.<sup>1002, 1003, 1004, 1005, 1006</sup>

The saving ethic across the United Kingdom as a whole is low, and it is hoped that the launch of the CTF will reverse this trend. The goal is to ensure that every child, no matter what family circumstances it is born into, will have a nest egg for the future, which each child will be encouraged to take an active interest in. The main aim for the CTF is to educate parents and children about the importance of saving from an early age, to provide for the future, to establish a saving habit, and to aid in the financial education of young people. To date, nowhere else in the world has a government committed its resources to such a program. It represents a public-private partnership in that it relies on private sector financial institutions as the vehicle to achieve universal asset-building goals.

Entitlement to a CTF account will automatically be linked with entitlement to child benefit, which reaches virtually all children living in the United Kingdom. The notice of the child benefit award will automatically trigger issuance of the CTF voucher. In addition, the government is putting in place special arrangements to ensure that CTF accounts will be

opened for children looked after by local authorities or under equivalent arrangements in Scotland, who do not qualify for child benefits. From early 2005, the government will begin to send out the vouchers to the parent/guardian to open a CTF plan from an approved provider. Before the dissemination of the vouchers, the government will be contacting parents and guardians to confirm their child's eligibility.

CTF accounts are owned by the child and in the child's name. Annual statements will be sent to the child throughout the 18 years the CTF account is open. The CTF account will not affect any CTC benefits the family receives, and neither the parent/guardian nor the child will pay tax on income and gains in the account. However, there may be fees associated with the provider's administration charges. Private contributions may be made to the account up to £1,200 (approximately \$2,200) per year after taxes, and account holders may transfer their accounts among providers at any time and as many times as desired at no charge. The plan will mature on the child's 18th birthday, at which time the child will receive the assets; there will be no restrictions on what the money can be spent on. The funds are not accessible until age 18. Financial institutions are not required by law to offer CTF accounts. However, those that wish to—including banks, brokers, investment managers, and life insurers—must be approved as accepted providers by the Financial Services Authority (FSA, the independent industry regulator). The government wants to ensure the development of a competitive CTF market that provides simple, good value, and accessible CTF accounts with adequate incentives to save.

While children are eligible who were born beginning September 1, 2002, the CTF did not become operational until April 2005. Therefore, if a child was born between September 1, 2002, and April 4, 2005, he or she will receive slightly more, because the child was eligible prior to the issuance of the voucher. The CTF vouchers issued to children before the operational date in 2005 will have a higher value than the standard voucher to recognize this fact. Each child will receive a second, as yet undetermined, payment on his or her seventh birthday. As well as helping the accounts to grow, these age-related payments will be a useful reminder of the CTF account. As with the additional contribution, a flat rate payment will be distributed to all children, and an additional payment will be made to children in lower-income families. In the exceptional cases

in which a parent or guardian chooses not to claim the child benefit, the child will not be eligible for a CTF account.

## **Core Program Elements**

### *Technical Assistance*

The design of the CTF—including an additional government contribution to the account at the age of seven, annual statements issued by providers to all children, teaching and learning resources for use in the classroom, and a dedicated Web site—will help children engage with their accounts and make the best use of the assets at account maturity. The government also wants parents to actively engage with the CTF and will provide resources to ensure that parents are helped to make choices about their child’s CTF, including an information pack to be issued alongside the CTF voucher, and will work with the FSA to ensure that consumer information activity includes the CTF.<sup>1007</sup> The detailed information packet for parents will include such information as a full explanation of the CTF rules; details of all CTF providers; an explanation of the different types of accounts available; a step-by-step guide to opening an account; and sources for further information and guidance. In addition, the packet will include illustrations showing the impact of a range of investment choices and contribution levels on account growth and the risks associated with these choices.

The CTF, by linking with the school curriculum, will build on financial education by ensuring that every young person has access to a financial asset, increasing the relevance of financial education for all and helping young people understand the advantages of saving. To support learning through the CTF and related topics in the classroom, the government will commission the development of a range of CTF teaching and learning resources. The resources will help children improve their financial capability and will be clearly linked in different parts of the curriculum. These resources will be designed to meet the child’s needs at different ages, beginning with an introduction to the basic concepts of saving and moving toward guidance on possible uses of financial assets, including continuing to save, as the young person’s CTF nears maturity. The government will promote and make available these resources to all schools.<sup>1008</sup>

## **Lessons Learned and Accomplishments**

It is too early to highlight any lessons learned and accomplishments; however, enhanced functional literacy is being documented as a byproduct for both children and families as a result of implementation of the CTF. As a universal benefit, the CTF provides opportunities to devise new teaching and learning materials, using the fund as a tangible example of a savings/investment product.<sup>1009, 1010</sup> The CTF provides an opportunity to promote financial awareness among children and young adults and to give them a real-life savings vehicle that can be associated with financial education. Schools will be able to use the CTF as an example in their financial education work, and this in turn could encourage children's and young people's interest in their accounts. According to the FSA, there are various ways in which children and their families could be encouraged to be involved with their CTFs. Saving could be encouraged at school. Many schools operate school banks (in some cases this is a credit union). Teenagers ages 15–17 who have a maturing CTF could be encouraged to make decisions about its use and be given the necessary understanding to make informed decisions. This could happen as part of existing work done in schools and colleges; for example, as part of work-related learning, as part of career education, when considering options for higher education (and how that might be funded), or when considering training or self-employment options. Various government initiatives dealing with young people can incorporate the CTF concept into their programs.

While there are no known outcomes, it is a good practice, and the U.S. government could benefit from the approach the British government is taking through this public-private partnership of universal asset building. In the United States, a similar strategy with restricted use of funds for children determined to have a certain level of need for future LTSS might be evaluated as an alternative (supplemental or complementary) financing strategy to current college 529 plans or individual retirement accounts. A 2004 Aspen Institute Brief<sup>1011</sup> evaluates the approach the British government has taken and discusses some issues and implications for a similar child account policy for the United States. According to the brief, while the CTF represents a significant advance in savings structures, government-provided matching funds through direct payment or refundable tax credits would be an even more effective incentive to encourage families in lower-income brackets to save. A drawback to the CTF is that its incentives to save do not expand on existing tax-based incentives to the full extent possible. A policy created in the

United States could be designed specifically to stimulate asset acquisition, limiting the use of funds to investment in higher education or a small business, a down payment on a house, or a retirement account. In addition to stimulating asset acquisition, such restrictions would also be consistent with existing U.S. asset-building and long-term saving policies. Further, according to the brief, a hybrid system in which accounts are offered by a government-sponsored entity and by private financial institutions would maximize consumer protection and the quality of product offerings. Access to a government-sponsored account would give families the choice of a basic account with low costs and good service. The private sector financial institutions' product design expertise and marketing creativity would raise the accounts' visibility, thereby stimulating greater participation and higher account balances. An additional benefit of the hybrid system is that the existence of quality low-cost government accounts would stimulate competition among private sector providers.

## **Part II**

### **Conclusion**

LTSS reform requires leadership, creativity, capital, and risk-taking. The waters of reform are rough and costly. It is clear that states cannot take on the burden of reform without substantial federal involvement. There is, however, a growing recognition that a fundamental shift in values is occurring as states move services and supports to the community and home and out of the institutions. Individuals with disabilities are being provided with more choices to live independently. The shift to a system that is not anchored by a medical model and an institutional bias requires fresh, creative thinking that reanalyzes the use of public and private resources.

The examples provided of realignment of service and financial relationships at an individual and community level recognize the importance of consumer choice and direction. The two examples of cooperative organizational structures that provide places to live that are affordable and that improve support workers' level of compensation and job satisfaction offer viable options to respond to the current and growing imbalance of demand versus system capacity to respond to need. The three examples related to management of assets—pooled trusts, support corporations, and CTFs—raise important questions about public versus private responsibility to create and manage a social safety net for individuals deemed in greatest need of long-term support.

These experiments in progress challenge society and policymakers to offer a new role as resource managers to individuals and families who traditionally have been the consumers of social services. The CTF offers the boldest experiment in redefining public responsibility to all children and families regardless of where they live, their economic status, and immediate needs. It also raises new questions about traditional policymaking that has defined and calculated need based on economic status. Access to supports and services as an entitlement has historically been means tested for individuals under the age of 65. The CTF offers a new approach to the social contract between a nation and its citizens that places enhanced value on asset development as a foundation for future public policy development.

The Time Bank exchange of value offers further opportunities to rethink the value and purpose of a community to support all its members with an exchange of resources to respond to defined needs. Proponents of the Time Bank exchange are quick to point out that it cannot replace government intervention. However, it can be a cost-effective approach to augment and complement a social safety net that responds to needs in a way that recognizes disability as part of the human experience to be embraced by community inclusion.

What is most refreshing about all the identified examples of local and individual strategies is that they do not begin with the assumption that the existing framework of government resources is the essential building block for the delivery of LTSS. These strategies do not start with Medicaid or Social Security to build and design a community-based system. However, each example of community and family development strategies embraces three fundamental principles to help design the ship that may offer safe passage in the future:

1. Consumer choice and direction is an essential design principle that must rebalance risk and responsibilities between government and the target audience.
2. Communities should be supported by government through tax and social policy to support formal and informal caregiving, recognizing the value of cooperative principles of ownership to improve affordability and worker and consumer satisfaction.
3. Asset development is a lifespan challenge that should be a fundamental principle of all future policymaking, which should reward all children and families for saving for the future to respond to planned and unexpected needs as a result of disability as a natural part of the human experience.

Although each of these selected individual and local strategies has promising early evidence of success, as a group they represent works in progress that deserve the increased attention of policymakers to expand replication options and continue the collection of data to further test results over a longer period of time. The challenge for future policymakers is to identify ways to embrace these concepts and nontraditional system approaches in the design of the future system.



## **Chapter 6**

# **Recommendations for Incremental and Clean Slate Reform**



**Table of Contents:**  
**Chapter 6**

	<b>Page</b>
<b>Part I</b>	
<b>Introduction to Incremental Reform .....</b>	<b>493</b>
<b>Part II</b>	
<b>Moving Forward—Improving the Current LTSS Ship .....</b>	<b>494</b>
<b>Part III</b>	
<b>The New Millennium LTSS Model.....</b>	<b>508</b>
<b>Part IV</b>	
<b>Ameriwell—The New Millennium LTSS Model.....</b>	<b>511</b>



## **Part I**

### **Introduction to Incremental Reform**

The recommendations offered are anchored by the original set of assumptions that emphasizes the value of consumer choice and direction, the importance of access and sustainability both programmatically and financially, the preference for home- and community-based long-term services and supports (LTSS), and the necessity of federal leadership, financial investment, and oversight. The original assumptions have been sustained and correlated by the research and supported by experts across the diverse spectrum of stakeholders: government, policy analysts, service providers, people with disabilities, and families.

The recommendations have been divided into two parts. The first set of recommendations represents a comprehensive set of strategies that would move the ship of LTSS forward at a slower pace.

The second set of recommendations would establish a new millennium policy with multiple financing streams to sustain LTSS for Americans with disabilities across the age span, regardless of geography, level of personal resources, and family support. The second set of recommendations represents the construction of a new ship to navigate the rough waters expected.

Both sets of recommendations recognize that there is no single or simple policy solution to the challenges documented in this report. Both sets of recommendations identify specific agencies and committees within the executive and legislative branches of the Federal Government that would have the lead role to move forward with implementation and, where appropriate, additional research. Although there may be disagreements about which path will increase the probability of the LTSS ship's safe passage through troubled waters, there is strong, overwhelming support for focusing on these issues now rather than later. With the perfect storm ahead, Congress and the executive branch cannot afford to keep missing the boat. LTSS comprehensive policy development will define us as a nation. It is imperative that the United States retool its programmatic and financial infrastructure to protect and promote individual dignity and independence within the context of supportive families and communities to meet its growing economic and demographic challenges.

## **Part II**

### **Moving Forward—Improving the Current LTSS Ship**

- 1. Increase policymaker knowledge and understanding of public and private costs and benefits of LTSS for people with disabilities under age 65 and their families.**

#### **Implementation Lead:**

- Office of Assistant Secretary for Planning and Evaluation, Department of Health and Human Services (HHS)**
- Congressional Budget Office (CBO)**
- General Accountability Office (GAO)**

The lack of data presenting a complete and accurate picture of the costs for LTSS for families with children with disabilities and adults with disabilities was a key finding by NCD researchers. Despite multiple studies by CBO and other federally sponsored research centers on the costs of long-term care (LTC) for seniors, the younger population with disabilities under age 65 has not been a priority. The traditional definition of LTC identified acute care needs as well as nonmedical services and supports for seniors. Today's definition of LTC has changed to reflect the ongoing growth and integration of disability into mainstream culture. LTSS for people 65 years and younger is about many nonmedical services and supports, such as personal assistance, assistive technology, financial management, housing, transportation, and nutrition. How a person is assisted in compensating for loss of activities of daily living (ADLs) will define their future earnings potential and economic independence.

Cost studies are needed that evaluate, in a systematic and comprehensive manner, the extra costs of raising a child with a disability and continued support of the person as an adult. Such studies should examine differences of support needs reflected by cost for individuals with a range of functional limitations in family settings and other home, community-based, and more restrictive skilled nursing environments. Other differences to be analyzed should relate to diversity of race, ethnic background, gender, disability, and geography. Protocols should examine the costs to consumers and families as well as the costs to government (with specific government funders

identified and quantified) and other institutional payers as part of the evaluation of different program models. Administrative versus direct service costs should be scrutinized. As recommended by the NCD report “Consumer-Directed Health Care: How Well Does It Work?” (October 2004), well-defined guidelines are needed to accurately capture the role of families and individuals in paying for LTSS to avoid the risk of cost-shifting to families as supports and services move from institutional to community-based settings.

More needs to be learned about the cost benefits of consumer-directed services and support plans and improved coordination and collaboration in the delivery of services through Aging and Disability Resource Centers (ADRCs).

An additional area of focus is to increase understanding of the cost benefits of LTSS insurance products as they are brought to market and customized to respond to the needs of individuals with disabilities under age 65. Finally, the CBO should be tasked with projecting the costs of LTSS for individuals with disabilities under age 65 over the next 30 years based on a consumer-directed service delivery model and alternative options for public and shared private responsibility for costs without current impoverishment rules. CBO should also investigate the impact on public costs of making available comprehensive community-based LTSS, with particular attention to possible reduced demand and costs for nursing home placements.

All three agencies should be charged with preliminary reports ready for the next term of Congress in January 2006 and complete reports by the end of the year.

**2. Design and implement a multifaceted action plan of monitoring and oversight of state activities to meet their Americans with Disabilities Act (ADA) obligations as a result of the *Olmstead* Supreme Court decision.**

**Implementation Lead:**

- **Office for Civil Rights, Department of Health and Human Services**
- **Civil Rights Division, Department of Justice**

The *Olmstead* Supreme Court decision in 1999 provides important legal support for states' current efforts to rebalance their LTSS systems toward home- and community-based settings. The Administration, through an Executive Order and grant activities, has taken seriously the Court's decision and mandated a state planning process to improve and expand community-based choices for people with disabilities. Over \$200 million has been awarded by the Centers for Medicare and Medicaid Services (CMS) to states on a competitive basis to promote system changes. Despite these efforts, litigation continues to expand in class action suits. In more than 25 states, individuals with disabilities have been frustrated with the pace of change and the slow movement of funding away from nursing homes and institutional settings to communities.

The Office for Civil Rights at HHS and the Justice Department have the responsibility to monitor and oversee *Olmstead* state plan implementation. As both agencies have done on numerous occasions in the past related to ADA, there is an opportunity to be proactive and design and implement an action plan that evaluates individual state efforts to meet the *Olmstead* community imperative mandate. Each state should be rebalancing its financing, reducing the number of individuals with disabilities residing in nursing homes, diverting people from entering nursing homes, and putting in place the infrastructure for expanded home- and community-based supports for individuals with disabilities. The action plan should require site visits in all states within the next 24 months; consumers and other interested stakeholders should be provided with notice of the state visit and offered an opportunity to meet with federal officials. State status reports on current efforts should be made public and available for comment. Federal monitoring reports would also be made public. Annually, both agencies would submit to Congress a report on their monitoring and oversight activities. Both the House and Senate Judiciary Committees should hold annual oversight hearings to monitor federal and state activities and hear from people with disabilities and their families.

### **3. Decouple eligibility for home- and community-based services (HCBS) under an HCBS waiver from a determination of nursing home eligibility.**

#### **Implementation Lead:**

- **Senate Finance Committee**

- **House Energy and Commerce Committee**
- **Centers for Medicare and Medicaid Services**

There are multiple suggestions from the Expert Panel and other key stakeholders as to how to amend current public policy to remove the institutional bias in the Medicaid program. All amendments would give Medicaid beneficiaries greater choice in how financial assistance is provided to cover a range of LTSS. The clear majority of stakeholders recognize the overwhelming consumer preference for HCBS. Two complementary options deserve immediate attention from Congress and bipartisan support. The first option is to shift the HCBS program from its current waiver status to a state plan requirement. Eligibility would be delinked from nursing home eligibility, and states would receive an increased federal match under their state cost-sharing agreements for services provided in this category as part of their Medicaid reimbursement for authorized expenditures. CMS would set guidelines for a functional assessment process and the minimum threshold of services to be covered, including personal assistance services.

The second, complementary, option would be that federal funding follows the person from a nursing home to a community setting as part of a person-centered plan and self-directed budget. The Money Follows the Person (MFP) option would continue for a three-year period to help support successful community transition. Both options are currently part of legislative proposals before Congress. MFP and the Medicaid Community Attendant Services and Supports Act (MiCASSA) deserve to be the focus of hearings before the end of the year.

**4. Increase support for families and significant others in their role as informal and unpaid caregivers for individuals with disabilities over and under the age of 65.**

**Implementation Lead:**

- **Office on Disability, Department of Health and Human Services**
- **Administration on Aging, Department of Health and Human Services**

- **House Ways and Means Committee**
- **Senate Finance Committee**

Eligibility for LTSS, and the scope and intensity of covered services, varies significantly from state to state. States have considerable discretion in determining whom their Medicaid programs will cover. Despite state variability in criteria for Medicaid eligibility and scope of benefits, in all states, individuals with disabilities are dependent on informal caregivers, including parents, family members, and significant others. The estimated benefit of informal caregiving exceeds \$200 billion annually. Services should be designed to support, not supplant, the role of the family and actions of informal caregivers. Increased support for informal caregiving could be achieved through implementation of a complementary set of recommendations. Address the lack of portability from state to state for Medicaid LTSS.

- Enact the Lifespan Respite Care Act to award grants or cooperative agreements to develop statewide lifespan respite care programs. Lifespan respite care is a coordinated system of accessible community-based respite care services for family caregivers, regardless of the individual's age, race, ethnicity, or special need.
- Establish a National Resource Center on Lifespan Respite Care to maintain a national database and provide training, technical assistance, and information.
- Amend the tax code to allow an additional standard deduction for any family who spends in excess of \$2,000 for the care of a family member with a disability. The deduction would be allowed for costs related to personal assistance services, technology-related assistance, transportation, respite care, medication, and adult day programs or workplace supports. Expenses would be disqualified if they are reimbursed by insurance or a public resource.
- Authorize a study, coordinated by the Departments of Labor and HHS, to determine the costs to the economy—in terms of education, employment, income forgone, and transfer payments—as a result of the demands of family caregiving for parents, family members, and significant others.

- Pilot test and evaluate the use of Time Banks as a nontraditional strategy at the community level to enhance opportunity and consumer satisfaction with informal caregiving.
- Increase by 20 percent the funding level for the National Family Caregiver Support Program to expand respite care options and improve training and support for caregivers. Require improved coordination of program activities with other similar program efforts directed to support caregivers for individuals with disabilities under age 65.

**5. Improve the supply, retention, and performance of direct support workers to meet increasing demand.**

**Implementation Lead:**

- **U.S. House of Representatives, Committee on Education and the Workforce**
- **Senate Committee on Health, Education, Labor, and Pensions**
- **Departments of Labor, Health and Human Services, and Agriculture**

As demand grows for in-home and community-based support workers, and as informal caregivers become less available, public policy must pay increasing attention to critical challenges that relate to direct care/support employment. NCD researchers documented numerous state efforts to raise wages, improve quality through education and training, and change the nature of the relationship between consumer and caregiver.

The supply, retention, and performance of direct support workers can be enhanced by implementation of the following set of recommendations:

- As part of the *Olmstead* guidance, CMS should issue an advisory letter to state Medicaid directors directing corrective action to achieve parity of compensation across the environments where direct support workers are employed. Home- and community-based workers must earn wages that are comparable to those of workers who perform similar duties in other care settings.

- Continue to fund demonstration projects by CMS to allow states to test innovative strategies to improve the recruitment, supply, retention, and performance of direct support workers.
- Authorize funding for demonstration projects between the Departments of Labor and HHS that promote collaboration between community colleges and disability-related organizations to develop a high-quality set of competencies to be taught in a new support worker certificate program that expands supplies of quality workers to meet market demand in home- and community-based settings.
- Pilot test the establishment of additional worker cooperatives with the assistance of the Departments of Agriculture, Labor, and HHS, to explore improved consumer-caregiver relationships.

**6. Mandate coordination and collaboration among federal agencies to align public policy and transform infrastructure to be responsive to consumer needs and preferences for a comprehensive system of LTSS.**

**Implementation Lead:**

- **Centers for Medicare and Medicaid Services**
- **Department of Housing and Urban Development (HUD)**
- **Senate Finance Committee**
- **Senate Committee on Banking, Housing, and Urban Affairs**
- **House Subcommittee on Health and Environment**
- **Department of Transportation**
- **Social Security Administration**
- **House Committee on Education and Workforce**

Although Medicaid and Medicare dominate the landscape of funding authorities for LTC and LTSS, NCD researchers documented the complexity and fragmentation of multiple systems with different rules of eligibility and lack of information on access to and availability of resources.

The fragmentation and coordination challenges carry over from the executive branch to the legislative branch, where different committees in the Senate have different controlling authority than committees in the House of Representatives. Although Program Assessment Rating Tool (PART) reviews by the Office of Management and Budget (OMB) are incorporating common performance measures across agencies and programs, **there is no focus on cross-department and agency collaboration.** The nature of LTSS requires more than a dozen programs and agencies to improve the coordination of resource at the community level, where it will benefit the end-user. No single recommendation can respond to this significant challenge. NCD recommends that the appropriate agencies and congressional committees implement the following set of recommendations:

- Hold congressional hearings to evaluate possible options for improvement of collaboration across multiple departments to provide access to information and supports and services to meet the long-term needs of people with disabilities under and over age 65.
- Require HUD and HHS to document current efforts and future plans to improve and expand the availability of affordable accessible housing coordinated with services and supports when needed. Establish an Interagency Council on Meeting the Housing and Service Needs of Seniors and Persons with Disabilities.<sup>1012</sup> The council's role would be as follows:<sup>1013</sup> “(4) To improve coordination among the housing and service-related programs and services of federal agencies for persons with disabilities and seniors and to make recommendations about needed changes with an emphasis on (a) maximizing the impact of existing programs and services; (b) reducing or eliminating areas of overlap and duplication in the provision and accessibility of such programs and services; and (c) making access to programs and services easier for persons with disabilities and seniors around the country; (5) To increase the efficiency and effectiveness of existing housing and service related programs and services which serve the target populations; (6) To establish an ongoing system of coordination among an within such agencies or organizations so that the housing and service need are met in a more efficient manner. MEMBERSHIP: The council shall be composed of the following: (1) the Secretary of Housing and Urban Development or a designee of the Secretary; (2) the Secretary of Health and Human Services or a designee of the Secretary; (3) the Secretary of

Agriculture or a designee of the Secretary; (4) the Secretary of Transportation or a designee of the Secretary; (5) the Secretary of Labor or a designee of the Secretary; (6) the Secretary of Veterans Affairs or a designee of the Secretary; (7) the Secretary of the Treasury or a designee of the Secretary; (8) the Commissioner of the Social Security Administration or a designee of the Commissioner; (9) the Administrator of the Centers for Medicare and Medicaid Services or a designee of the Administrator; (10) the Administrator of the Administration on Aging or a designee of the Administrator; (11) the head (or designee) of any other federal agency as the council considers appropriate; (12) state and local representatives knowledgeable about the needs of the target population. CHAIRPERSON: The chairperson of the Council shall alternate between the Secretary of Housing and Urban Development and the Secretary of Health and Human Services on an annual basis. The Council shall prepare an annual status report on activities to the President and Congress with policy recommendations.”

- Add to the PART performance criteria indicators that will evaluate documented outcomes from intra-agency and cross-agency collaboration to meet the LTSS needs of people with disabilities. Consider possible financial incentives for agencies that document valued outcomes from LTSS system collaboration. Report annually to Congress on individual agency performance in this area.
- Issue a new Executive Order to charge CMS to chair a time-limited workgroup (six months) on LTSS that includes representation by HUD, HHS, Social Security Administration (SSA), Education, Labor, Justice, Transportation, Treasury, and Agriculture to identify policy barriers and facilitators to an improved comprehensive coordinated system of LTSS for people with disabilities under and over age 65 that maximizes interagency collaboration, promotes consumer direction, and increases consumer choice and access to affordable supports and services in home- and community-based settings. The final report to the President would include recommendations for policy and practice changes and any appropriate program consolidation.

**7. Improve and hold states accountable for rebalancing their system to support LTSS.**

**Implementation Lead:**

- **Centers for Medicare and Medicaid Services**
- **Congressional Budget Office**
- **General Accountability Office**

Selected states are having success with a global budgeting approach to move their LTSS systems from an institutional bias to be anchored by home- and community-based services and supports. CMS Real Choice Systems Change Grants have accelerated the pace of change in a number of states that recognize the changing expectations of the consumer population to have more control and independence with access to appropriate supports. The consumer population in each state wants more information on the progress their state is making to rebalance the system and expand their choices in the most independent setting possible.

- Develop a template, in consultation with states, to be used to evaluate and measure the states' current expenditures for LTSS in institutional versus home- and community-based settings. Such a template would be developed jointly by CMS and CBO to allow for consistent comparative benchmarking from year to year within a state and among states. CMS would require an annual updated report that would identify expenditures by cost category in terms of services/supports, funding streams, and populations. States would be expected to achieve an agreed-upon level of improvement annually, related to negotiated indicators. A system of rewards would be considered that would allow up to a 5 percent increase in federal matching funds under the Medicaid program for certain agreed-upon LTSS expenditures. CMS would make available on its Web site the comparative analysis of state expenditures, according to agreed-upon benchmarks.

**8. Increase understanding of the possible relationship between an LTSS insurance product and publicly financed LTSS.**

**Implementation Lead:**

- **Centers for Medicare and Medicaid Services**

- **Assistant Secretary for Planning and Evaluation, Department of Health and Human Services**

Congressional interest remains high to understand and explore further the possible relationship between the current market for LTC insurance products and a reduced dependence on Medicaid and Medicare for long-term support needs. With the growing cost of Medicaid and Medicare documented by NCD researchers, there is growing interest in forging a new level of partnership with the insurance industry that explores both the expansion of product options and the possible cost savings to the public system. For people with disabilities under age 65, no such insurance product yet exists and little is known about the risk factors in terms of potential utilization by the target population and how to achieve affordable pricing. Even with adoption of several of the other major recommendations proposed in this report, it is unlikely that a revised Medicaid program will ever meet the needs of all persons who seek LTSS.

- Conduct a feasibility study of possible new insurance products and options regarding their relationship to the Medicaid program to evaluate possible strategies to partner an LTSS insurance product with supplementary Medicaid coverage for people with disabilities under age 65. Consider price, benefit coverage, caps in coverage, and eligibility for Medicaid LTSS, as well as project market demand and needed incentives to share risk among stakeholders: the government, the consumer, and the insurance industry. The possible collaboration would include APSE at HHS, CMS, and a private insurer.
- Pilot test such a product or products to evaluate cost benefits to all critical stakeholders. Such a pilot must recognize that LTSS must be individualized to accommodate the needs and desires of the individuals receiving assistance and that the services and supports must reflect consumer preference for noninstitutional settings. Such an insurance product must achieve several objectives: be affordable, be flexible, respond to consumer needs and preferences, and be sustainable over time with federal oversight.

**9. Improve consumer understanding, knowledge, and skills to develop a person-centered plan and self-direct an individual budget.**

**Implementation Lead:**

- **Centers for Medicare and Medicaid Services**
- **Administration on Aging**
- **Administration on Developmental Disabilities**
- **Social Security Administration**

The Cash and Counseling Demonstrations and the Independence Plus waivers have produced early positive findings of increased consumer satisfaction with the self-direction of individual budgets, the selection of support providers, and increased choice in the development of person-centered plans. Individuals with disabilities and their families should be given the opportunity to plan, obtain, control, and sustain the services that are best for them in preferred home- and community-based settings. For people with disabilities who have been given few choices in the past regarding services, supports, and service delivery options, consumer self-direction requires information, education, and training to build the critical skills needed to make informed decisions.

Access to information about service options, streamlined procedures for determining eligibility for various public benefits, and new infrastructure will need to be developed to assist with programmatic and financial management.

The following set of recommendations recognizes the principles of individual self-direction and responsibility for prudent and effective management of public resources as critical to the development of the LTSS system of the future.

- Continue to provide competitive grants that establish Aging and Disability Resource Centers (ADRCs) in all 50 states that provide one-stop access to information and individualized advice on long-term support options, as well as streamlined eligibility determinations for all publicly funded programs. With joint funding from CMS and the Administration on Aging, the ADRCs should provide education and training to individuals with disabilities on informed decision making in the development of person-centered plans and the management of individual budgets.

- Establish, with funding from CMS, a National Resource Center on Consumer Self-Direction that identifies and disseminates best practice information on person-centered plan development, self-directed management of individual budgets, and examples of multiple funders braiding funds within an individual budget to achieve common negotiated performance objectives. The center should also provide assistance to states on methodology for development of individual budgets and strategic alliance options with financial institutions for the effective and efficient management of resources that have been allocated on an individualized basis.
- Require states as part of their HCBS waiver implementation to provide education and training to eligible Medicaid beneficiaries on effective and meaningful participation in person-centered planning, management of individual budgets, and negotiation with service and support providers.
- Establish a cross-agency workgroup including CMS, the Administration on Aging, SSA, the Administration on Developmental Disabilities, HUD, the Office of Special Education and Rehabilitative Services at the Department of Education, and the Department of Labor to accelerate options for states to bundle or braid public funds within a self-directed individual budget with streamlined and accelerated eligibility procedures. Findings and recommendations shall be made to the President and Congress within 90 days, with the report to be made public for review and comment.

**10. Continue to educate people with disabilities, their families, and other critical stakeholders about LTSS challenges in public policy and practice and document further consumer needs, costs, and preferences for a comprehensive, accessible, and affordable system.**

**Implementation Lead:**

- **National Disability Institute/NCB Development Corporation**
- **A major insurance company**
- **A major financial service company**
- **National disability organizations**

- **American Association of Retired Persons**
- **National Council on Disability**

This report documents the current crisis and the impending perfect storm. It is a complex and confusing picture, not easy to grasp and even more difficult to change as we move forward. NCD must continue to put the spotlight on this critical set of challenges that, in the next 20 years, may touch over half the population of our country. For people with unmet LTSS needs today, NCD must continue the public education process through outreach activities and direct discussion with the disability community and policymakers.

- Conduct a series of audio conferences and a national summit of key leaders and stakeholders to continue to document the findings and build consensus on possible policy and practical solutions.

The focus of the discussion must be based on a core set of principles identified by the Expert Panel reflecting the following:

- ***Individual authority***—the ability to manage, direct, and control the nature and delivery of supports received.
- ***Personal choice***—the freedom to choose the services and the provider that best meet the person’s needs.
- ***Individual support***—the resources to enable people with disabilities, as well as families and seniors, to make informed decisions regarding the services received.
- ***Productivity***—the focus of LTSS must be on giving people the assistance they need to live full and productive lives.
- ***Participation***—people receiving support need to be involved at all levels of the decision-making process, from policy to implementation.

## **Part III**

### **The New Millennium LTSS Model**

#### ***Year 2049***

The United States successfully built a health care and LTSS ship through an array of public-private funding mechanisms. Many of the demographic predictions made by economists and policymakers at the beginning of the 21st century did come true. There were fewer workers and more retirees and fewer federal resources to cover promised benefits. It became evident by the middle of the 2010s that reform was necessary in Social Security, Medicare, Medicaid, civil service pensions, and military pensions. The United States had committed \$25 trillion in future benefits that were unfunded. Japan, Italy, and Spain experienced population declines that affected everyone's international trade markets and increased global workforce shortages.

Business leaders in the United States began to see their profit margins eroded with the rising costs of health care and were concerned that their ability to compete globally would decline unless the problem was solved. Although disability advocates and researchers and policymakers had tried to put the issue of LTSS and health care on the national agenda for decades, it was the business community that actually positioned it for reform.

Today, in 2049, 50 percent of Americans are nonwhite and a majority are low-income workers. The overall health of Americans is better and many people are living longer, including people with lifelong disabilities such as Down syndrome, cerebral palsy, and intellectual impairments. Life expectancy has increased and, although there are different configurations of the “family unit,” families continue to play an important role in the care and housing of their members— young and old. The nursing home facility of the mid- and late 20th century is all but obsolete, and housing with variations in services is mostly community based and provided by family members and a new cadre of professionals. Although the movement in the late 20th century was toward consumer-directed care in the community, the challenge of finding affordable housing for many retired Americans and Americans with disabilities, including appropriate and affordable services and supports, remained a large barrier. Many Americans had not saved or insured

adequately against the costs of aging, retirement, or disability. In 2005, LTSS public policy depended on many variables falling into place. Even if an individual or family met the income and disability eligibility criteria for LTSS, many states could not afford to offer the necessary services and supports because of budget deficits. Because Medicaid programs were state-specific, many people with disabilities could not move their LTSS benefit from one state to another. The country was not prepared to address the health and service and support needs of its fast-growing demographics, which included more working individuals under the age of 65 with disabilities and the doubling of its senior population. Many middle-income seniors had nowhere to turn but to Medicaid, and state and federal spending fast became unsustainable.

Disability rates did decline for the senior population, as predicted in 2005. Even for those 85 and older, modern medicine and technology began to eradicate diseases associated with aging, such as Alzheimer's, visual and hearing impairments, and other physical conditions that once limited mobility. Scientific breakthroughs for diabetes, obesity, and mental illness helped to decrease the incidence of chronic disabilities in the under-65 population as well. The incidence of lifelong disabilities, such as cerebral palsy and Down syndrome, were unchanged, but new insurance products became available and through shared risk pools were helpful in defraying the costs of living with a lifelong disability. Individuals with disabilities were no longer expected to live in impoverishment to receive assistance for the additional costs associated with compensating for limitations in ADLs. Unemployment for people with disabilities declined as increased services and supports were provided. The workplace became more accessible for people with disabilities as technology increased its accessibility and employers became adept at providing the necessary accommodations.

Today, in 2049, health care policy is universal and includes a basic menu of services focused primarily on prenatal care, prevention services, routine checkups, prescription drug management, and nonmedical services and supports. Healthy environments and healthy behaviors are considered the centerpiece for a healthy country. All Americans now have access to an array of basic health services that are mandatory, similar to the requirement that all drivers had automobile insurance during the second half of the 20th century. The disproportionate costs for health services for the uninsured declined as the new system focused on quality outcomes and cost management and

universal coverage. However, boutique health care continued to grow and is now a popular alternative for many Americans with private resources; it includes personalized health services from spa membership to monthly plastic surgery treatments to home visits by a physician.

HCBS replaced the institutional nursing home model of the mid-20th century and regional centers provided neighborhood triage and mobile units to reduce the costs of transportation and manage costs and outcomes. Housing for seniors and people with disabilities emerged that linked independent living with choice and new options. Group homes were converted into cooperatives, and individuals with disabilities became shareowners in an array of alternative housing models that promoted equity. Unemployment for people with disabilities declined and, for the first time in a century, working Americans included many individuals with disabilities.

The movement toward health care reform, including LTSS, began in 2005 as a small group of researchers and policymakers unveiled a new model for the LTSS ship “AmeriWell,” which provided a new roadmap for innovative funding and product development for people with disabilities.

## **Part IV**

### **AmeriWell—The New Millennium LTSS Model**

#### **Implementation Lead:**

- **Center for Medicaid Services**
  - **Congressional Committee on LTSS**
  - **Wall Street investment firms**
  - **Major health insurance companies**
  - **National Academy of Science**
- 
- AmeriWell is a prefunded, mandatory LTSS system that provides all Americans of any age with coverage from birth based on criteria of risk and functioning and not category of disability. AmeriWell delinks LTSS from Medicaid and Medicare, creating its own governing agency, regulations, oversight, and congressional committee.
  - The AmeriWell Center is the third division of CMS and is required to produce an annual report to the President and Congress that provides an update on fiscal and programmatic status.
  - AmeriWell Part A begins with a individual/family account established at birth for all Americans. AmeriWell Part A provides LTSS for all Americans of all ages based on criteria of risk and functioning and not ability to pay. AmeriWell Part A is funded through individual/family contributions made to individual/family-assigned accounts beginning at birth with premiums paid by wage earners on a sliding scale and assessment of functioning and risk. A basic LTSS menu provides services and supports most desired and utilized by people with disabilities, whether working or retired.
  - AmeriWell Part B will provide LTSS and health care and prescription drugs for individuals who are both Medicare and Medicaid eligible because of poverty and disability status.

- Every American has an AmeriWell Account Plan (AWAP) that is an actuarially agreed-upon amount adjusted for inflation over time based on the cost projections of a specific lifelong disability, such as cerebral palsy, Down syndrome, or a physical impairment. In addition, an individual is assessed as to risk and functioning over time for any benefit adjustment. For example, a person with cerebral palsy who needs help with two ADLs but is functioning well on his or her own is given the necessary services and supports for work. Assuming that this person is not considered at immediate risk or need of other services, he or she is assigned a capped amount based on this data.
- Each child is given an AmeriWell account at birth, funded by the parent wage earner. If a child is born with a significant disability, the parental account that has accrued over time will be opened and used for the child. If a child has no parents, AmeriWell Part B will kick in and provide a defined amount of services and support based on the individual's AWAP.
- The AmeriWell premiums are set aside in an AmeriWell Trust Fund that has public-private oversight and provides a financial pool to cover LTSS.
- Individuals and families also have the option to create private AmeriWell Freedom Accounts that are tax deductible up to \$10,000 per year. These accounts are similar to the college 529 plans, and each state has the option of teaming up with private investment firms to offer choices regarding investment options, flexible and guaranteed rate of return, and/or annuities.
- AmeriWell Part B raises revenue through a sales commission levied on daily stock transactions to create a fund (Penny Pool) to defray the disproportionate share of care provided to uninsured/underinsured, dual-eligible persons (those who receive both Medicare and Medicaid). The Penny Pool helps states meet the needs of impoverished individuals with disabilities and the aging.
- AmeriWell allows Medicaid to stay true to its original mission to serve as a safety net for low-income mothers, children, and people under age 65 and provides a buy-in option for individuals who are working with a disability, who are working but do not have insurance on the job, or who lose coverage because of a lost job. All aging and disability populations (30% of the Medicaid caseload in 2005) have been moved into AmeriWell.

- AmeriWellPlus is a program for Social Security Disability Insurance beneficiaries and dependent recipients who previously fell under Medicare. This account provides LTSS, health insurance, and prescription drugs, and its funding is shared with Medicare and the Penny Pool.
- AmeriWell is a national program and provides LTSS portability from one state to another.

**2005**

**Medicaid**  
Children & Moms  
People with Disabilities and Aged  
LTSS and Health Care

**Medicare**  
Seniors  
SSDI Recipients (<65)  
Low-income people  
receiving both  
Medicare & Medicaid

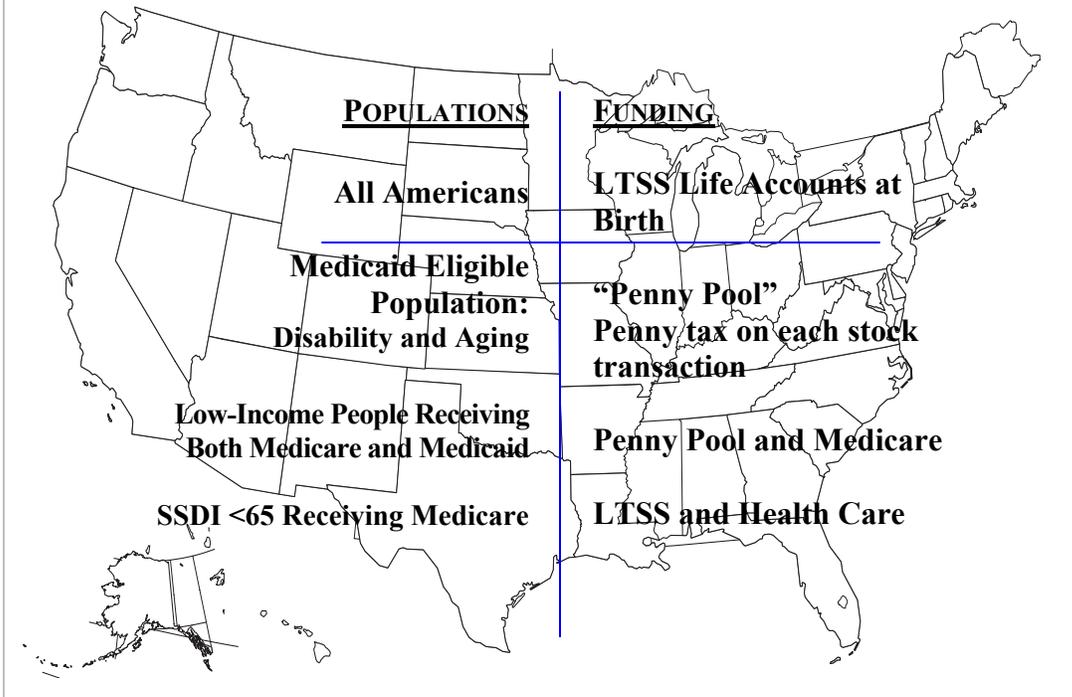


**2049**

**Medicaid**  
Children & Moms  
Safety Net

**Medicare**  
Seniors 70+

**AmeriWell**



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<sup>738</sup> Ibid., 7-33.

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<sup>740</sup> Ibid., 7-74.

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<sup>753</sup> Ibid., 12.

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<sup>756</sup> These programs allow states to waive usual Medicaid rules about eligibility “entitlement” for Medicaid services. Rather than having to provide HCBS services to any person who meets Medicaid eligibility requirements, a state may create a program for specific populations, such as aged people, traumatic brain injury individuals, or people with MR/DD who meet the income eligibility.

<sup>757</sup> Information was collected from state agency Web sites, planning documents, *Olmstead* and task force reports, and legislative budget and research documents. Additional information was obtained from state agency officials through telephone and e-mail communications. Many states have created task forces to consider strategies for addressing concerns raised by the 1999 Supreme Court *Olmstead* decision that inappropriate institutionalization of people with disabilities constitutes discrimination as defined by ADA. Telephone interviews were conducted with several key stakeholders in each state. (Names and titles of these stakeholders are provided in Appendix 4.A). Selected comments from these interviews appear in the state case studies. The views and recommendations of these stakeholders on needed federal reforms are also summarized in the conclusion to this chapter.

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- <sup>817</sup> The U.S. Supreme Court ruled in 1999 that states would be violating ADA if they provide care to people with disabilities in institutional settings when they could be more appropriately served in home- or community-based settings. Most states have responded, at least initially, by preparing plans that lay out goals and actions for expanding HCBS for people with disabilities
- <sup>818</sup>“Vermont’s Response to Questions from 1115 Federal Review Team: Responses to December 2003 Questions from CMS.” Available at: [www.dad.state.vt.us/1115waiver/11204Responsespdf](http://www.dad.state.vt.us/1115waiver/11204Responsespdf).
- <sup>819</sup> Instrumental activities of daily living, such as shopping or telephoning.
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- <sup>828</sup> State of Minnesota Long-Term Care Task Force. (January 2001). “Reshaping Long-Term Care in Minnesota.” Final Report.
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