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,[1] 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.[2]

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.[3]

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."[4]

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.