Examining Long-Term Care Episodes and Care History for Medicare Beneficiaries:

Analytic Framework and Analysis Plan

Final Report to the

Centers for Medicare and Medicaid Services

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CHAPTER I. INTRODUCTION

Project Overview

The increasing longevity of the U.S. population and the movement of the “Baby Boom” generation into older ages, where risks and expenditures for chronic disease, functional decline, and long-term care use are high, add urgency to the need for more information about the elderly at risk for long-term care use and the interactions between the public programs that furnish their care. This information is important for predicting program costs; understanding how service and financing coordination or integration can be optimized to contain federal and state costs and maximize elderly’s outcomes; improving capitated payment methods; and further developing a range of current program initiatives regarding, for example, nursing facility quality improvement, chronic disease management, and promotion of non-institutional forms of long-term care.

Historically, the availability of national and longitudinal data for research into these issues has been limited essentially to large administrative data sets with limited types of variables of interest and to variable-rich but small-sample surveys. However, after years of development, patient assessment information is now available because of the implementation of Medicare prospective payment systems (PPSs) for skilled nursing facilities (SNFs) as of July 1998, home health agencies as of October 2000, and inpatient rehabilitation facilities (IRFs) as of January 2002. The nursing home patient assessment data are available regardless of payer (Medicare, Medicaid, and private), and the home health patient assessment data are available for Medicare-covered and Medicaid-covered utilization (and intermittently for private-pay utilization). In addition, Medicaid administrative data can now be more easily linked to Medicare administrative data, and is becoming available in a relatively more uniform format across states. Finally, variable-rich survey data on Medicare beneficiaries can be linked to these claims and assessment data as well. The culmination of these now-available data sources present new opportunities for better understanding the health and service use trajectories of beneficiaries and understanding where policy may be able to affect outcomes and trajectories.

To efficiently maximize the information value and policy relevance of analyses using these massive and complex data sets, it is important to have a strong conceptual and methodological framework regarding long-term care; a thorough background in the research literature on elderly’s health and service use; knowledge of the benefit structure, payment policies, and administrative data files of the Medicare and Medicaid programs; and understanding of the public policy questions and clinical/gerontological issues that ideally inform and shape analyses that can be conducted using these data.

In this multi-year project we are assisting the Centers for Medicare and Medicaid Services (CMS) with four overall activities. First, we are identifying a theoretical framework and building a methodological and empirical underpinning for the integrated analysis of Medicare and long-term care risks and use among the elderly population. This framework and underpinning accommodates currently available data and will apply to longer data series as they become available. Second, we are designing population cohorts that can support a range of policy-relevant analyses; are identifying specific research questions we propose to address; and are developing preliminary statistical analysis plans to apply to these cohorts under this scope of effort. Third, we are finalizing detailed methodological and statistical analysis plans; are constructing the analytic files necessary to build the study cohorts and support our current (and future) analyses; and are documenting the replicable methodology we use to create the files. Fourth, we are applying these developmental efforts to the actual conduct of our analyses, and are interpreting and discussing the findings given the foundation of our developmental efforts and in collaboration with our clinical and policy experts.

Project Activity in Phase One

Our primary efforts in phase one of this project have been comprised of several qualitative activities with the aim of developing policy relevant and clinically appropriate study cohorts, research questions, and statistical analysis plans. These activities included discussions with clinical consultants about medical and gerontological issues that affect the selection and design of study cohorts, design of research questions, and later the interpretation of findings; discussions with Medicare, Medicaid, and long-term care policy experts to identify and prioritize policy issues and broad research areas for our focus; discussions with Medicaid data experts to identify Medicaid claims data issues pertinent to our development of cohorts, analysis plans, and analytic files; reviews and syntheses of Medicare and Medicaid program spending and utilization statistics to highlight key sources of public financing pressure and to point to initial areas of analytic focus; discussions of conceptual models of the progression to long-term care to provide an overall framework for consideration of our analyses; review and synthesis of empirical studies of the determinants of long-term care use; and review of cross-cutting methodological issues in measurement of key concepts and in statistical modeling methods. Analyzing all of the 12 or so research questions that we suggest in our statistical analysis plans (Chapter IV) requires a substantial amount of analytic file construction effort that involves multiple data years, multiple data file types, complex variable creation, and detailed documentation requirements, followed by an equally substantial effort in statistical analysis, data interpretation, and report and manuscript preparation. As the next steps in this project, final selection of research questions and number of states selected for our Medicaid claims analyses will be finalized in conjunction with CMS staff, and analytic file development activities will begin.

Overview and Organization of Report

In the remainder of Chapter I, we address the significance and relevance of the project and the magnitude of the issue of health care and long-term care spending among the elderly. Specifically, we first highlight current federal program initiatives and pressing policy issues that can be furthered by analyses from this project's data set. We then describe the magnitude of the issue by reviewing public program expenditures for elderly acute care, post-acute care, and long-term care service use; the interaction of public program spending; and private spending for long-term care.

In Chapter II, we first formulate a conceptual framework that will allow us to identify where this project's analyses fit within the larger framework of progression to long-term care, and will help us to identify implications for developing our empirical models. This discussion begins with a review of the existing models of disability and models of health service and long-term care use. We could find no existing model integrating the two. In the rest of the chapter we summarize the published literature regarding factors associated with the use of specific forms of long-term care (nursing facility, home care), post-acute care, and hospital admissions among long-term care users and its application to this project. We borrow from Anderson and Newman's (1973) model of health care utilization in the organization of the factors discussed in the literature review.

In Chapter III, we introduce the three main population cohorts we propose to develop and use for analyses in this project. Cohort 1 is based on hospitalizations with a principal diagnosis of congestive heart failure and allows for analyses of, for example, determinants of long-term care use versus no use, and of the timing of entry to a nursing facility. Cohort 2 is based on elderly identified with heart conditions in the Medicare Current Beneficiary Survey (MCBS) and allows for analyses of, for example, the role of social support and income in affecting the timing of and types of long-term care use. Cohort 3 is based on all nursing facility entrants in a set of selected states and allows for analyses of, for example, the major events that precipitated entry and the course of care following entry. The chapter describes these cohorts in detail, including their rationale and their general utility for analyses in the project. The chapter then discusses four analytic/measurement issues that cut across the three cohorts and that we view as important to consider in preparation for conducting specific analyses on each of the cohorts.

In Chapter IV, we first summarize the type of statistical analysis methods used in the literature to study changes in health, utilization, and spending, and then describe the cohort analyses we propose. For each cohort, we pose several specific research questions for analysis; identify the outcome measures of interest for the questions (and the basic identification of the outcome measures in the data); discuss the right-side variables of interest (and their basic identification in the data); and state the statistical methods used for the questions.

In Chapter V, we review the data file requirements for each cohort, describe the basic process of developing and documenting the project's analytic files, and conclude by noting the next steps to be taken in the project.

Four appendices also are included in the report. Appendix 1 highlights comments from our panel of clinical experts. Appendix 2 provides brief summaries of the literature regarding three clinical conditions that we considered (stroke, congestive heart failure, and hip fracture) for use in cohort 1. Appendix 3 describes the three surveys we considered for linking with the project's core claims and assessment data: the Medicare Current Beneficiary Survey (MCBS)**,** the National Long Term Care Survey (NLTCS), and the Health and Retirement Study/Study of Assets and Health Dynamics Among the Oldest Old (AHEAD). The MCBS is the source data selected for cohort 2. Appendix 4 summarizes program services, participation rates, and spending on 1915(c) waiver programs operating in selected states. Control for state waiver participation may be an important control in our analyses of nursing facility use. References specifically cited in each chapter/appendix of this report are listed at the end of each chapter/ appendix.

Project Relevance to CMS Program Initiatives and Policy Issues

This project offers the unique opportunity to combine and use an extensive amount of patient claims and assessment data from the Medicare and Medicaid programs, and to conduct analyses on a range of policy and research issues relevant to the elderly's use of Medicare and long-term care services. In the rest of this chapter, we highlight major program activities and initiatives that can be furthered by analyses on the project's data, and identify several specific research and policy issues that could be explored. While the potential analyses far outnumber those to be addressed under this scope of work, the discussion illustrates the current and future value of the project data, and helps policymakers and researchers identify and prioritize questions that can be examined using the data.

Major Program Activities

The relevance and application to four major federal and state program initiatives are highlighted: care integration efforts for dually-eligible and other high-risk elderly, chronic disease management demonstrations and programs for beneficiaries, section 1915 Medicaid waiver programs (for dual-eligible beneficiaries meeting requirements for nursing facility care), and quality monitoring and improvement efforts for nursing facility short-stay patients (SNF patients) and long-stay residents.

The dually-eligible population is an identifiable group that has complex health care needs, consumes a disproportionate share of both federal and state resources, and often is underserved. This group provides numerous opportunities for care coordination or program integration activities that focus on, for example, health promotion, disease management, chronic care coordination, acute care and long-term care coordination, cost containment, and research into care strategies, risk management and innovative financing. These opportunities can have direct application to care improvement and payment policy initiatives in fee-for-service Medicare, to capitation payment system refinements in Medicare's managed care program, and to current program integration benefit options such as the Program of All Inclusive Care for the Elderly (PACE). Further, many similar care improvement and coordination opportunities exist regarding the near-poor and other vulnerable or high-risk elderly that are not (or not yet) eligible for Medicaid. A fundamental requirement for research into the dual population or those at risk for dual enrollment is the availability of linked data that allows one to profile for the dually-eligible population their Medicare and Medicaid service utilization, health and functional status, and full balance of federal and state payments. Also important is the ability to identify the Medicare and long-term care utilization and path prior to dual status, and the monthly patterns of Medicaid eligibility and enrollment. This project and its data (Medicare claims, Medicaid claims, and patient assessment data) provide the opportunity to examine many of these issues.

Disease management programs are a growing strategy of both private and government providers and payers in attempts to improve quality of care and to control expenditures. In 2001, 97% of private sector health plans used using at least one type of disease management program, and over half used programs for at least four conditions. The three most commonly targeted conditions are diabetes, asthma, and congestive heart failure (Center for an Aging Society, 2004). In addition, almost one-half of all state Medicaid programs are developing or using disease management programs (National Governors Association, 2003); 15 coordinated care demonstrations currently are being developed for beneficiaries in fee-for-service Medicare, and other similar demonstrations are slated as well (Foote, 2003). Findings stemming from this project potentially could assist public and private developers of disease management programs, through the project's focus on the patterns and determinants of both Medicare and long-term care utilization. Most disease management plans focus on hospital and ambulatory care use of community-dwelling individuals, but the additional information of long-term care use and its interactions with Medicare use among elderly with specific chronic conditions will be increasingly important, with the aging of disease management program participants.

The Medicaid Home and Community-Based Services 1915(c) Waiver Program allows states to develop programs (and receive federal matching funds for them) that provide home and community-based services to Medicaid-covered individuals otherwise cared for in institutions. While the waiver mechanism was established by Congress in 1981, states did not pursue them in substantial numbers until the Olmstead ruling in 1999.[1] Currently, all states have at least one HCBS 1915(c) waiver program (except Arizona, which provides long-term care services through an 1115 waiver).[2] Most states implement multiple waiver programs that target different categories of individuals (e.g., elderly, adults (elderly and non-elderly) with physical disabilities, children with physical disabilities, etc). The use of waiver programs has grown substantially in the last few years, making them an increasingly important subject for analysis. While program evaluations of waivers are necessary, measurement of states' waiver participation among the elderly also will be an increasingly important factor to address in studies of nursing facility risk and use by the elderly. Specific services used by a given individual participating in a waiver program cannot be analyzed using this project's data, however numerous studies with a broader focus on waivers are possible, as is the use of state-specific waiver participation rates in other studies using these data.

While nursing home quality has been a subject of extensive research and government attention (e.g., Institute of Medicine, 2001) implementation of the Medicare PPS for skilled nursing care introduced a concern for monitoring the quality of care to Medicare-covered patients in these facilities, and perhaps heightened the need to monitor care quality for facilities' long-stay residents as well. Over the past several years, CMS has devoted substantial efforts in researching, developing, and implementing measurable quality indicators (QIs), which are intended to assist in monitoring and improving the care for individual post-acute patients and long-stay residents in nursing facilities, as well as quality measures (QMs), which are case-mix adjusted measures intended for comparing nursing facility quality, holding their case-mix constant (Morris, et al. 2003; Abt Associates, 2004). The value of these quality efforts can be

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[1] In June 1999 the U.S. Supreme Court ruled in L.C. & E.W. vs. Olmstead that it is a violation of the Americans with Disabilities Act (ADA) for states to discriminate against individuals with disabilities by providing institutional care when the individual could be served in a community-based setting. States are required to provide HCB services if treatment professionals determine that it is appropriate, if the individual does not object to a HCB placement, and if the state has the resources to provide HCB services. The Court suggests that a state can establish compliance with the ADA if it has a comprehensive, effective plan for placing eligible people in HCBS programs and a waiting list for the programs and that people will be moved off the list at a reasonable pace (Fox-Grage et al. 2004).

[2] Throughout this report, "HCBS waiver" or "waiver" refers to the HCBS 1915(c) waiver program.

enhanced in part by their utilization by the research community in studies such as this. The QIs and QMs offer, depending on the analysis, a more refined set of outcome variables or set of control covariates, and allow for important characterizations of facilities and residents in analyses of long-term care patterns and nursing facility resident outcomes. The use of these measures in research studies may ultimately aid in the refinement of the measures and in the main goal— the improvement of care furnished by nursing facilities.

Long-Term Care Research and Policy Issues

A range of research and policy issues that span both medical and long-term care use and both federal and state program resources can be explored using these project data. Some of these issues include:

- Understanding the major paths and time-lines to nursing facility entry (to aid efforts to slow and prevent nursing facility entry).
- Understanding the major paths and expenditure patterns leading to Medicaid enrollment (to aid efforts to slow and prevent Medicaid eligibility for vulnerable beneficiaries).
- Understanding the types of hospital admissions and their determinants among the long-term care population (to aid efforts to reduce recurrent or potentially avoidable hospitalizations among the long-term care population; to aid quality monitoring and improvement efforts by facilities, states, and the federal government).
- Understanding characteristics of long-term care providers that are associated with changes in patient health or functional status (to aid quality monitoring and improvement efforts by facilities, states, and the federal government).
- Understanding the role of socio-economic factors in patterns of long-term care use (to aid efforts to increase or assist the social support of long-term care users and reduce their need for institutionalization).
- Identifying the levels of and differences in out-of-pocket burdens of long-term care users (to understand its role in long-term care choices and to inform the design of service programs, public program benefits, and private insurance policies).
- Understanding patterns of service use and expenditures across Medicare and Medicaid programmatic lines (to aid efforts by the programs to coordinate care for dual eligible beneficiaries).
- Understanding patterns of service use and expenditures by type of care— acute, post-acute, and long-term care (to assess potentially new determinants of use (e.g., health system ownership and networks of care); to identify potentially new areas for program and care coordination (e.g., for Medicare beneficiaries who are not dually eligible).

- Understanding patterns of service use and expenditures by type of condition or functional level (to aid the development disease management and chronic care programs, and understanding the need for general versus more tailored programs).

- Understanding changes in care patterns associated with time, or with changes in functional status or disease state (to aid in the long-run use or projected needs of chronic care or disease management programs; to aid quality monitoring and improvement efforts by facilities, states, and the federal government).

- Understanding changes in patient status, care patterns, and expenditures in the period before death (to aid efforts to coordinate end-of-life care and improve hospice and other end-of-life care programs).

- Understanding aggregate patterns of acute, post-acute, and long-term care service use (to aid federal and state government efforts in projecting future expenditures, staffing needs, and facility and community program needs).

- Understanding differences in patterns and preferences in long-term care by racial, ethnic, or cultural groups (to identify and address inequities in access to care or service provision, and to identify key issues where racial and ethnic outreach efforts and program initiatives would be of most benefit).

- Identifying differences in long-term care patterns by geography, such as by market areas, urban/rural status, and by state (to aid understanding of geographic variation in health care expenditures and sources of variation; to provide information for competitively-based health care pricing initiatives; to assist states in their long-term care program planning).

The mounting importance of efforts by federal and state policymakers to understand these issues and, ultimately, to devise methods to improve care and control costs associated with Medicare and long-term care use can be seen in the following review of public expenditures for care under the Medicare and Medicaid programs.

Spending Overview

The Medicare and Medicaid programs spent about $193 billion in 2000 for services to 34.3 million elderly Medicare fee-for-service beneficiaries.[3] This was about 17% of national personal health care expenditures (Levit, et al. 2003). This estimate excludes program spending for those in managed care plans, who were about 19% of elderly Medicare beneficiaries in

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[3] 2000 is the latest year for which program statistics for both Medicare and Medicaid have been published. Unless otherwise noted, statistics for 1999 used in this section are taken or calculated from CMS (2003). and statistics for 2000 were provided by CMS in advance of the publication of the Medicare and Medicaid Statistical Supplement 2002. Medicaid data for 1999 and 2000 were tabulated from MSIS data available on the CMS web site at http://www.cms.gov/medicaid/mcaidsad.asp.

1999.[4] If Medicare payments per managed care enrollee are assumed to be roughly the average for fee-for-service beneficiaries in 2000 ($5,352), then combined program spending for the 12.2%[5] of the population who were elderly beneficiaries would be roughly 20% of national personal health care spending.

Medicare and Medicaid spending for health care and long-term care will increase dramatically in the coming decades because of the strong association among rising age, declining health, and increasing frailty. The U.S. population age 65 or older was 12.4% of the population in 2000 but is projected to rise to nearly 15% of total population by 2015 and to 20% by 2035. The proportion of the elderly who are age 85 or older-- for whom the risks of disability and long-term care are very high-- is projected to rise to 15% of the elderly by 2035 (U.S. Census Bureau, 2000). Disability and long-term care are important for both Medicare and Medicaid because both acute and long-term care spending for elderly enrollees with disability are high relative to spending for the nondisabled. Long-term care spending falls most heavily on the Medicaid program because it covers facility and community-based long-term care.

Growth in the population most at risk for disability and long-term care has implications for the magnitude of total health and long-term care spending, the proportion attributable to the elderly, and the proportion that is publicly financed. Research has shown that the size of birth cohorts and the proportion surviving to age 65, which jointly determine the number of elderly coming onto the Medicare program, are more important for health care costs than are increases in longevity after age 65 (Spillman and Lubitz 2000). Increasing longevity has different implications, however, for predominantly acute Medicare spending than for long-term care spending. Medicare spending rises at a decreasing rate with longevity, while long-term care costs rise at an increasing rate. As a result, increases in longevity increase the share of total spending attributable to long-term care. All else equal, longevity increases thus are likely to increase the share of total spending for the elderly borne by the Medicaid program and private payers because these sources bear most of the financial burden of long-term care.

Table I-1 shows combined spending, spending by program, and the distribution across and within programs for the key services we discuss in this chapter.[6] The Medicare program accounted for about 77% of combined program spending for elderly beneficiaries in 2000, an average $5,826 per elderly FFS beneficiary.[7] The Medicaid program spent an average $11,929

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[4] Calculated from CMS 2003a,Table 6.

[5] Based on enrollment estimates from CMS found at http://www.cms.hhs.gov/statistics/enrollment/natltrends/hi_smi.asp, and population estimates from the 2000 Census (Hertzel and Smith 2001)

[6] Hospice services are not discussed here, although they typically include personal supportive and other long-term care services. They represented about 2 % of total Medicare spending in 2000. Medicaid hospice spending data were not available by age. CMS statistics and the MSIS data do not report hospice separately. Medicaid spending for other services not specified in summary data and for other more specialized services or groups (eg, mental facilities and facilities for the mentally retarded or developmentally disabled) also are excluded. These excluded services represent about 12 % of Medicaid spending for the elderly. These were excluded because we focus on more general modeling of long-term care needs among the elderly.

[7] Data from the 2002 Medicare and Medicaid Statistical Supplement Table 16, as provided by CMS.

per elderly enrollee. The far higher Medicaid program spending per service user is driven in large part by the high cost of nursing facility care, which is used by 28% of elderly Medicaid beneficiaries. Although elderly enrollees were only about 10% of all Medicaid enrollees in 2000, they accounted for more than one-quarter of Medicaid program payments. About 12% of elderly Medicare beneficiaries are dually-eligible (i.e., dually-enrolled) for both programs.[8]

Acute Care Spending

Although long-term care is costly for both individuals and the Medicaid program, acute care is far more important for combined program spending. Medicare-covered inpatient hospital care, physician and related services, hospital outpatient services, and prescription drugs covered by Medicaid accounted for 71.4% of total Medicare and Medicaid payments for the elderly in 2000. Medicare payments for these services account for 87% of Medicare payments for the elderly. Because Medicaid is not the primary payer for these costs and covers only about 12% of elderly Medicare beneficiaries, its share is much less. Direct Medicaid payments[9] for these services accounted for 19.6% of total Medicaid spending for the elderly and 6.3% of combined Medicare and Medicaid acute care spending for this group.

Inpatient Hospital

Inpatient hospital spending is the largest category of total program spending for elderly beneficiaries. Combined Medicare and Medicaid spending for inpatient hospital care for the elderly was $73.7 billion in 2000, about 38% of combined program spending for all services. Medicare payments of $72 billion in 2000 were almost 98% of combined inpatient hospital payments and nearly half of total Medicare program payments for elderly FFS beneficiaries. In contrast, Medicaid inpatient spending for elderly beneficiaries was only $1.6 billion, less than 4% of Medicaid spending for the elderly. Medicare inpatient hospital spending per elderly person served was $12,057 in 2000, compared with Medicaid payments of $2,303.

Physician and Related Services

Physician and related services are the second largest category of spending for the elderly, accounting for $45.6 billion, or nearly 24% of combined program spending in 2000. Medicare program payments were about 98% of combined physician services spending and represented 30% of Medicare payments for elderly FFS beneficiaries. Medicare payments per elderly beneficiary served were $1,791 in 2000. Medicaid payments in this category include payments for physicians, other practitioners, clinics, x-ray and lab, and prescription drugs. Of the total $6.4 billion Medicaid spent on these services for elderly beneficiaries, prescription drugs accounted for 83%.

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[8] Calculated from 2000 MSIS data available on the CMS web site at http://www.cms.gov/medicaid/mcaidsad.asp and enrollment estimates from CMS found at http://www.cms.hhs.gov/statistics/enrollment/st00aged.asp

[9] Medicaid premium payments for Medicare coverage of dually eligible beneficiaries and capitation payments are not included.

Table I-1: Medicare FFS and Medicaid Spending ($millions) for the Aged, 2000

	Spending			Percent of total spending		Percent of program spending		
	Medicare	Medicaid	Total	Medicare	Medicaid	Medicare	Medicaid	Total
Total	148,488	44,503	192,991	76.9	23.1	100.0	100.0	100.0
Inpatient	72,041	1,630	73,671	97.8	2.2	48.5	3.7	38.2
Physician and related services[a]	44,506	6,424	50,929	87.4	12.6	30.0	14.4	26.4
Outpatient	12,588	667	13,256	95.0	5.0	8.5	1.5	6.9
Total acute	129,135	8,721	137,856	93.7	6.3	87.0	19.6	71.4
NF	10,066	27,058	37,124	27.1	72.9	6.8	60.8	19.2
HHA	6,524	718	7,242	90.1	9.9	4.4	1.6	3.8
HHA+PSS[b]	6,524	3,407	9,931	65.7	34.3	4.4	7.7	5.1

Source: Medicare and Medicaid Statistical Supplement 2002, Tables 16 and 104, provided by CMS, and computed from downloaded MSIS data

Note: The Total row includes all spending by Medicare or Medicaid. Column totals and percents do not sum to the Total row because we do not itemize Medicare payments for hospice services (2 percent of Medicare spending) or Medicaid payments for hospice, other unspecified services, and payments for mental facilities and facilities for the mentally retarded or developmentally disabled (combined about 12 percent of Medicaid spending for the aged).

[a] Medicaid estimate includes other practitioners, clinic services, and prescription drugs

[b] Medicaid home care and personal support from MSIS data

Outpatient Hospital

Outpatient hospital services account for another $13.3 billion, or 7% of combined program spending. Medicare outpatient hospital spending accounted for about 95% of combined program spending on these services and 8.5% of total Medicare payments. Payments per person served were more similar across the two programs for these services than for other acute care. Medicare payments per elderly beneficiary served were $693, and Medicaid payments per elderly beneficiary were $504.

Post-Acute and Long-Term Care Spending

While both programs cover acute and post-acute care, Medicaid is the sole public payer for long-term care. Because the same type of providers— primarily nursing facilities and home health care agencies— provide a large proportion of both post-acute and long-term care, it can be difficult to isolate the two in spending estimates. This was especially true for Medicare home health services prior to the Balanced Budget Act (BBA) of 1997. After the BBA, the line is more clearly drawn for Medicare, but the state-federal nature of Medicaid and the flexibility states have in eligibility and coverage of long-term care through regular program benefits and waivers makes it more difficult to arrive at total spending estimates for long-term care.

Nursing Facility Care

Nursing facilities are the largest provider of both post-acute and long-term care. Total Medicare and Medicaid spending for care in nursing facilities was $37.1 billion in 2000, or nearly one-fifth of combined program spending. About 27% of combined spending was for Medicare-covered care (i.e., short-term, post-acute, skilled care), representing about 7% of Medicare spending. The remaining 73% was for long-term care covered by Medicaid,[10] which accounts for more than 60% of total Medicaid spending for elderly beneficiaries. Less restrictive financial eligibility rules and the high cost of this care make it a common avenue to Medicaid eligibility. Medicare payments per skilled nursing facility (SNF) user were $7,239, while Medicaid spending per NF beneficiary was $22,477.

Home Care

Total home care spending and its distribution between post-acute and long-term care for the elderly is difficult to obtain from published sources for several reasons, but primarily because of wide variation across states in how they provide and report Medicaid long-term care benefits. Combined program spending for home health and personal supportive benefits using the only readily available source of Medicaid data by age was about $9.9 billion, or about 5% of combined program spending, but this total probably does not capture all Medicaid long-term home care.

Home health care for those requiring skilled services such as nursing or therapy is the only home care covered under both programs. In 2000, the two programs combined spent $7.2

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[10] Since 1991, Medicaid SNF and intermediate care facility services were unified, and CMS statistics no longer distinguish Medicaid stays as SNF or other NF stays.

billion on services reported as home health care for the elderly. Medicare payments were $6.5 billion, 90% of total spending for this service. Of this Medicare total, post-acute home health covered by Medicare Part A was $2.7 billion, or 41%.[11] The remaining $3.8 billion was covered under Part B. Payments per Part B beneficiary were about 40% higher than those for Part A, reflecting the limitations on the post-acute benefit since the BBA. Medicare home health payments per user were $2,594 ($2,022 for Part A, and $3,230 for Part B). Medicaid home health payments per elderly enrollee were $3,140.

Accurate estimates of other Medicaid home care for the elderly are difficult to obtain. Tabulations of Medicaid Statistical Information System (MSIS) data allow analysis by age but they are considered less accurate than HCFA 64 financial reports (which are tied to payments), and they do not contain sufficient detail on services and payments to allow confident identification of all long-term care spending. States may not report long-term home care services uniformly as home health or personal support services, and reporting practices have changed over time. Services provided through Medicaid waiver programs are not identified separately in the MSIS data, so that tabulation of the identifiable categories— home health and personal support services— does not capture all waiver program payments (Lutzky, et al. 2000). Waiver programs have been the fastest growing area of Medicaid long-term home care, but growth has been substantially lower among the aged than among the mentally retarded and developmentally disabled population.

Nevertheless, MSIS data may provide the best available data on home care for the elderly. Tabulations for 2000[12] indicate that total spending for home health and personal support services for elderly enrollees were $3.4 billion, with personal support services accounting for about 79% of the total. Medicaid personal support services spending per elderly enrollee was nearly $5,000.

Spending and Utilization Trends

Prior to the BBA, both post-acute and long-term care spending were growing at a much faster rate than acute care spending, heightening concern about the impending retirement of the large Baby Boom cohorts. After the BBA, trends in spending have been volatile as the result of the payment systems changes for Medicare post-acute care (Levit, et al. 2004). The impacts of these changes have been large enough to drive overall trends as well as Medicare trends, despite the minority role of these services in spending. Table I-2 shows total program payments for the services we consider, spending by service and program, and the average annual percentage growth rate for the period 1995 through 2000.

Most notable is the large negative impact of the post-BBA payment system changes on Medicare home health payments and the shift from Part A post-acute benefits to Part B,

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[11] Since the BBA, the first 100 days of Medicare home health following a 3-day hospital or SNF stay is covered by Part A. Days beyond the first 100 days and other home health care not associated with a hospital or SNF stay is covered under Part B. Prior to the BBA, home health was predominantly a Part A benefit. Medicare payments per person served were similar under the two benefits (based on 1995 data reported in the 1997 Statistical Supplement).

[12] Tabulations of MSIS data downloaded from http://www.cms.gov/medicaid/mcaidsad.asp.

beginning with the introduction of the Interim Payment System and continuing under the PPS. While the impact of prospective payment on Medicare SNF payments is evident in 1999, unlike the impact on Medicare home health, it was not sufficient to result in a negative growth rate over all. Figure I.1 shows the rate of spending growth over the period for all services combined and illustrates the importance of Medicare home health in the overall trend in both total spending and Medicare spending for the elderly. Both had negative growth rates in 1998 and 1999 when the payment system changes had their largest impacts. Spending growth had been accelerating in the periods prior to 1998 and rebounded in 2000. This growth has continued since, with a peak in 2001, followed by some moderation in 2002 (Levit, et al. 2004).

Table I-2: Spending by Service and Program (in millions), 1995 through 2000

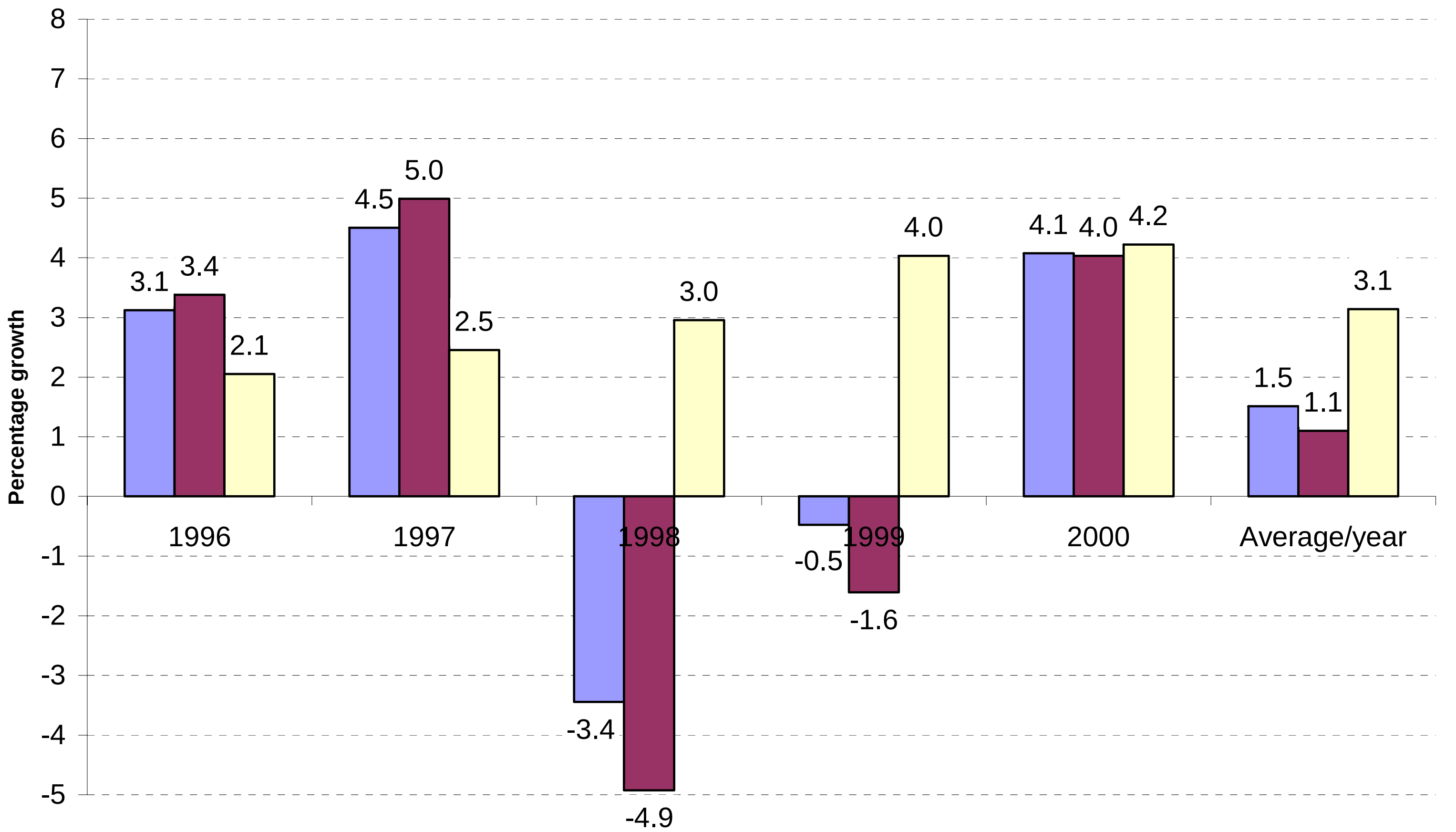
	1995	1996	1997	1998	1999	2000	Average percent growth per year
Listed services[a]	$171,152	$176,497	$184,447	$178,098	$177,252	$184,474	1.5
Medicare	$137,952	$142,616	$149,735	$142,360	$140,074	$145,725	1.1
Medicaid	$33,200	$33,881	$34,712	$35,738	$37,179	$38,750	3.1
Acute care total	122,539	124,808	130,503	129,010	131,218	137,420	2.3
Medicare	116,477	118,364	123,833	122,053	123,769	129,135	2.1
Medicaid	6,062	6,444	6,670	6,957	7,448	8,285	6.4
Inpatient hospital total	69,905	70,527	74,361	72,619	72,946	73,671	1.1
Medicare	67,855	68,483	72,430	70,748	71,290	72,041	1.2
Medicaid	2,050	2,044	1,931	1,871	1,656	1,630	- 4.5
Part B Physician total	37,335	37,923	38,887	39,112	40,933	45,138	3.9
Medicare	36,718	37,229	38,096	38,417	40,298	44,506	3.9
Medicaid	617	694	791	695	635	633	0.5
Outpatient hospital total	12,438	13,280	13,912	13,473	12,767	13,256	1.3
Medicare	11,904	12,652	13,307	12,888	12,181	12,588	1.1
Medicaid	534	628	605	585	585	667	4.6
Prescription drugs							
Medicaid	2,861	3,078	3,343	3,806	4,572	5,355	13.4
Total post acute/long term care	48,613	51,689	53,944	49,088	46,035	47,055	- 0.6
Medicare	21,475	24,252	25,902	20,307	16,304	16,590	- 5.0
Medicaid	27,138	27,437	28,042	28,781	29,731	30,465	2.3
Nursing Facility total	31,589	33,398	35,399	36,453	35,769	37,124	3.3
Medicare SNF	7,441	9,010	10,708	10,924	9,191	10,066	6.2
Medicaid NF	24,148	24,388	24,691	25,529	26,578	27,058	2.3
Home care total	17,024	18,292	18,545	12,635	10,265	9,931	- 10.2
Medicare total	14,034	15,243	15,194	9,383	7,113	6,524	- 14.2
Part A Post acute	13,835	15,027	14,976	5,284	2,581	2,679	- 28.0
Part B Home Health	199	216	218	4,100	4,532	3,845	80.7
Medicaid total[b]	2,990	3,049	3,351	3,252	3,152	3,407	2.6

Source: Medicare and Medicaid Statistical Supplement 2002, Tables 16 and 104, provided by CMS, and computed from downloaded MSIS data

[a] Hospice benefits are not discussed in this review, although they typically include personal supportive and other long term care services. They represented about 2 perc of total Medicare spending in 2000, but Medicaid data for hospice services were not available by age. Neither published CMS statistics nor the MSIS data report hospice Medicaid spending for other services not specified in summary data and for other more specialized services or groups, such as mental facilities and services for the menta or developmentally disabled also are excluded from the review. While these latter services and groups are part of the long term care system, our focus is on more genera of long term care needs for the elderly.

[b] Medicaid personal supportive services spending was not available from published sources prior to 1999. Total probably understates Section 1915(c) home community based services waiver spending because states differ in where this spending is reported.

Figure I.1: Rate of Growth in Medicare, Medicaid and Combined Spending for the Elderly, 1995-2000



Includes inpatient hospital, physician supplier, nursing facility, Medicare home health and Medicaid home health and personal and supportive services

Also notable, however, is the accelerating growth in spending for Medicaid's elderly enrollees from 2.1% between 1995 and 1996 to 4.2% between 1999 and 2000. Accelerating growth rates for total Medicaid spending since 2000 are reported in Levit, et al. (2004), with most of the increase in growth rate attributed to the elderly and disabled. The key element in the increased growth rate for aged Medicaid enrollees between 1995 and 2000, however, is not long-term care, but rather the 13.4% average annual growth rate in Medicaid-covered prescription drugs, which accounted for 12% of Medicaid spending for elderly enrollees in 2000 (3% of combined Medicare and Medicaid spending). Levit, et al. (2004) report some moderation in the growth rate of Medicaid drug spending since 2000. Drug spending growth between 1995 and 2000 was bolstered by an average 2.6% per year growth in Medicaid home care.

Acute, Post-Acute, and Long-Term Care Spending Growth

Figures I.2 and I.3 focus on rates of growth in spending for acute care and for post-acute and long-term care, respectively, between 1999 and 2000. This period may provide a more reliable picture of underlying trends in these services than the longer period including the short-run impacts of Medicare payment system changes. In addition, although we almost certainly do not capture all Medicaid home care, for these two years MSIS data provide a more consistent measure of home health and personal supportive services than available for the prior years.

Acute care spending for the elderly grew 4% between 1999 and 2000 (Figure I.2), a larger increase than for post-acute and long-term care. This was primarily due to payments for physician services, which grew 10%. Program payments for inpatient hospital care grew only 1%. Levit, et al. (2004), however, report a deceleration in the growth rate for Medicare physician spending in 2002, and an accelerated growth rate for hospital spending. Again, the high growth rate for Medicaid acute care spending is driven primarily by the drug benefit. Although Medicaid outpatient hospital spending had the largest growth rate (14%), it accounted for less than 2% of Medicaid spending for the elderly.

Post-acute and long-term care spending for the elderly (Figure I.3) grew only about 2% between 1999 and 2000, although higher growth rates for both facility and home-based care have occurred since (Levit, et al. 2004). For Medicare, 9.5% growth in SNF spending between 1999 and 2000 more than overcame an 8.3% decline in Medicare program payments for home health. Both Medicaid nursing facility and home care spending grew between 1999 and 2000, nursing facility spending by a relatively modest 1.8% and home care spending by just over 8%.

Acute, Post-Acute, and Long-Term Care Utilization Rates and Spending per User

Growth in spending per user of services appears to have been more important for spending growth between 1999 and 2000 than growth in the number of users for both acute care and for facility-based post-acute and long-term care (Figures I.4 and I.5). Home-based post-acute and long-term care showed much more dramatic and mixed changes in both the number of users and spending per user, some of which are suggestive of interactions between Medicare and Medicaid for the long-term care population as the result of Medicare payment systems changes (Figure I.6).

Figure I-2: Rate of Growth in Acute Care Spending for the Elderly, 1999 to 2000

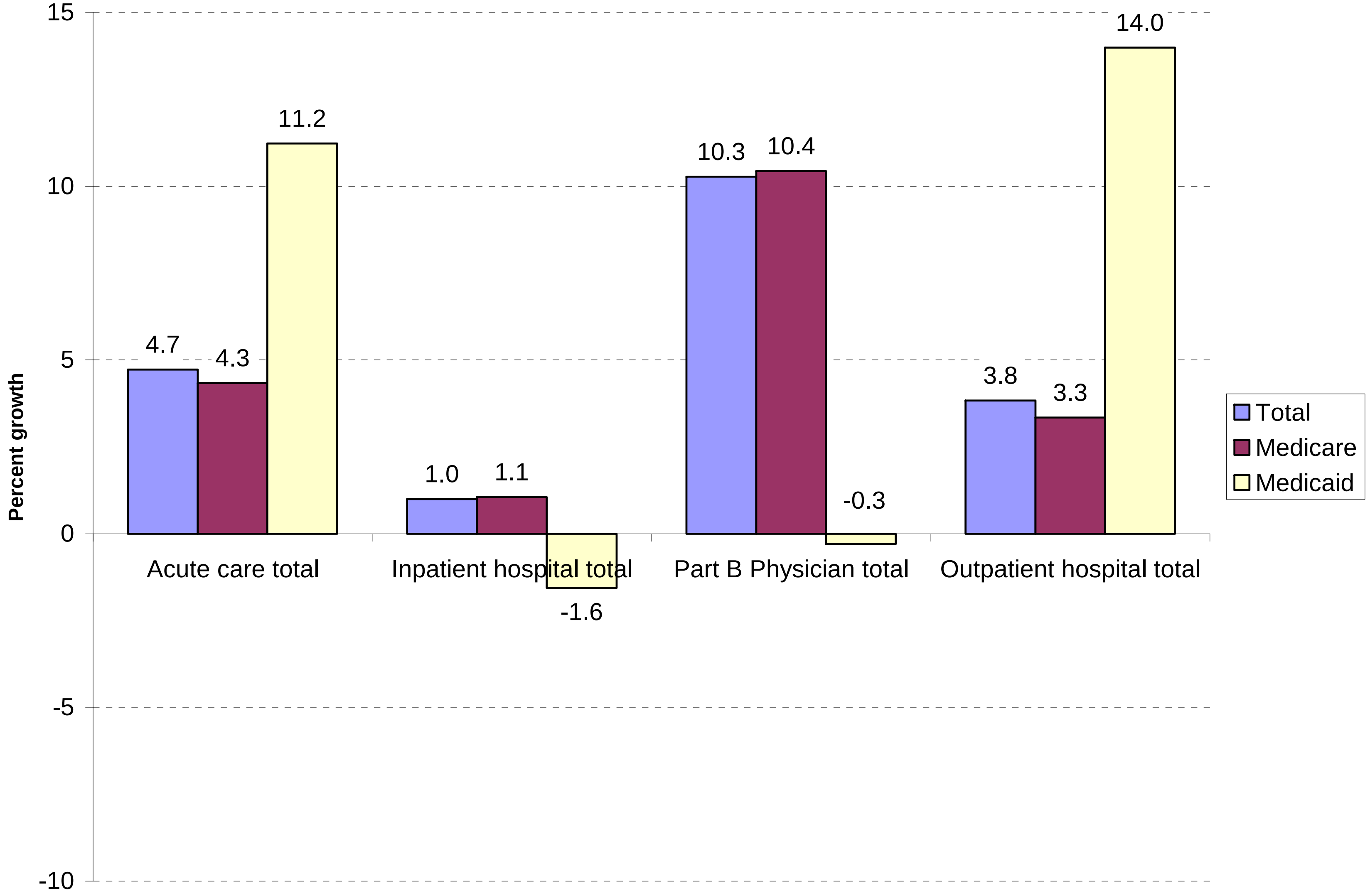


Figure I-3: Rate of Growth in Spending for Post-acute and Long-Term Care for the Elderly, 1999 to 2000

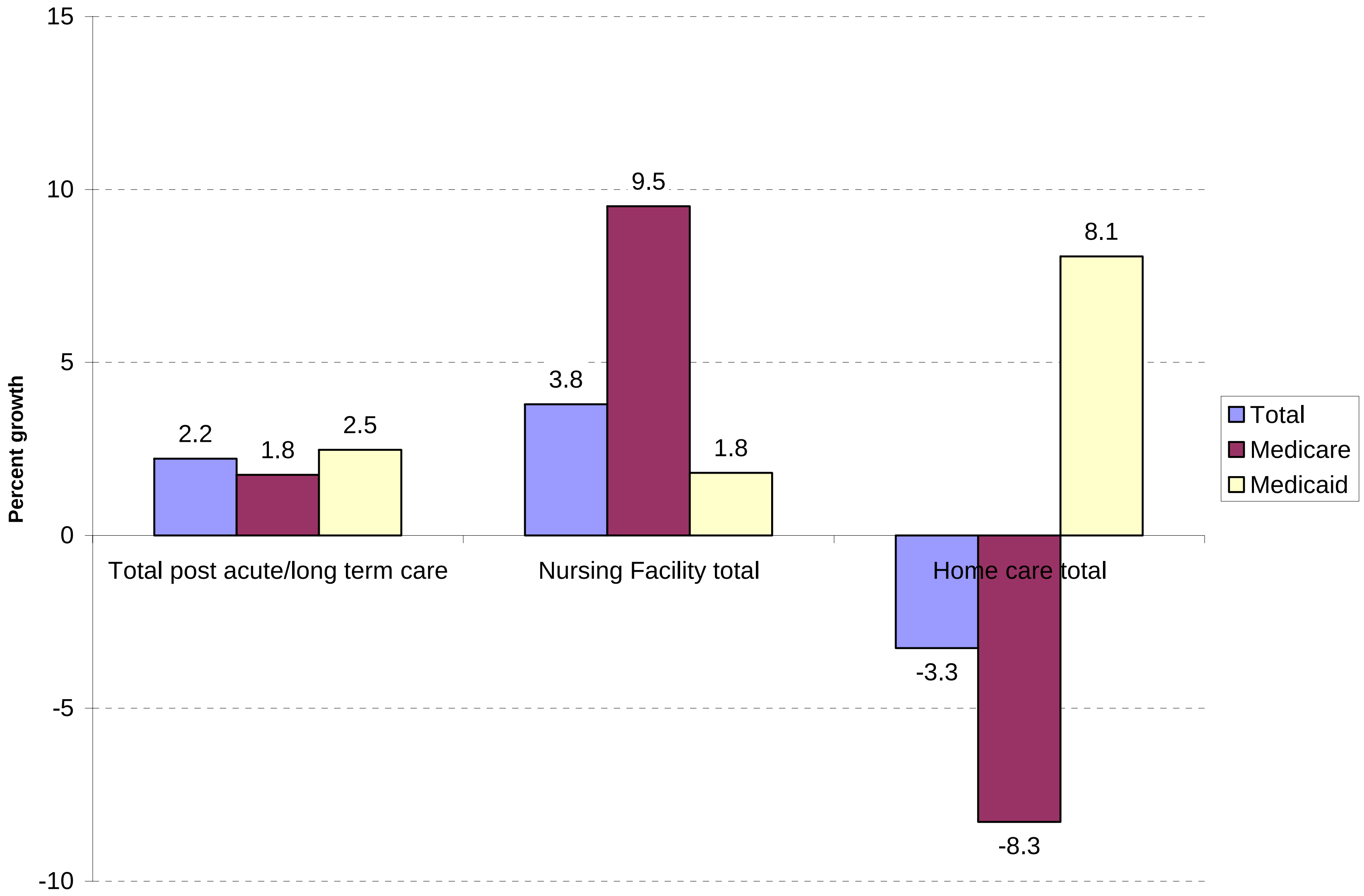


Figure I-4: Percent Change in Enrollees Using Acute Care Services and Per User Spending 1999-2000

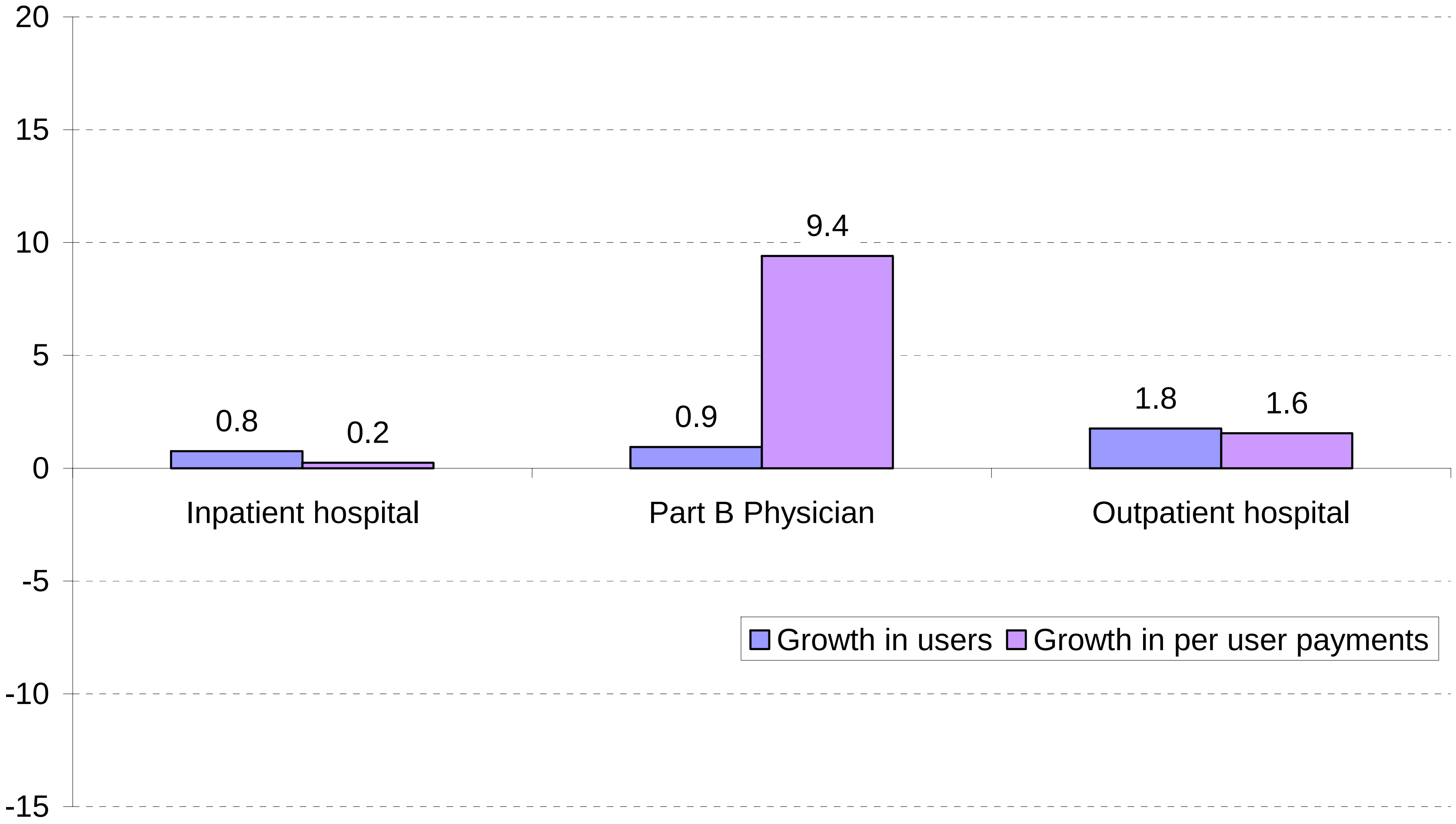


Figure I-5: Percent Change in Enrollees Using Post-Acute and Long-Term Care Services and Per User Spending 1999-2000

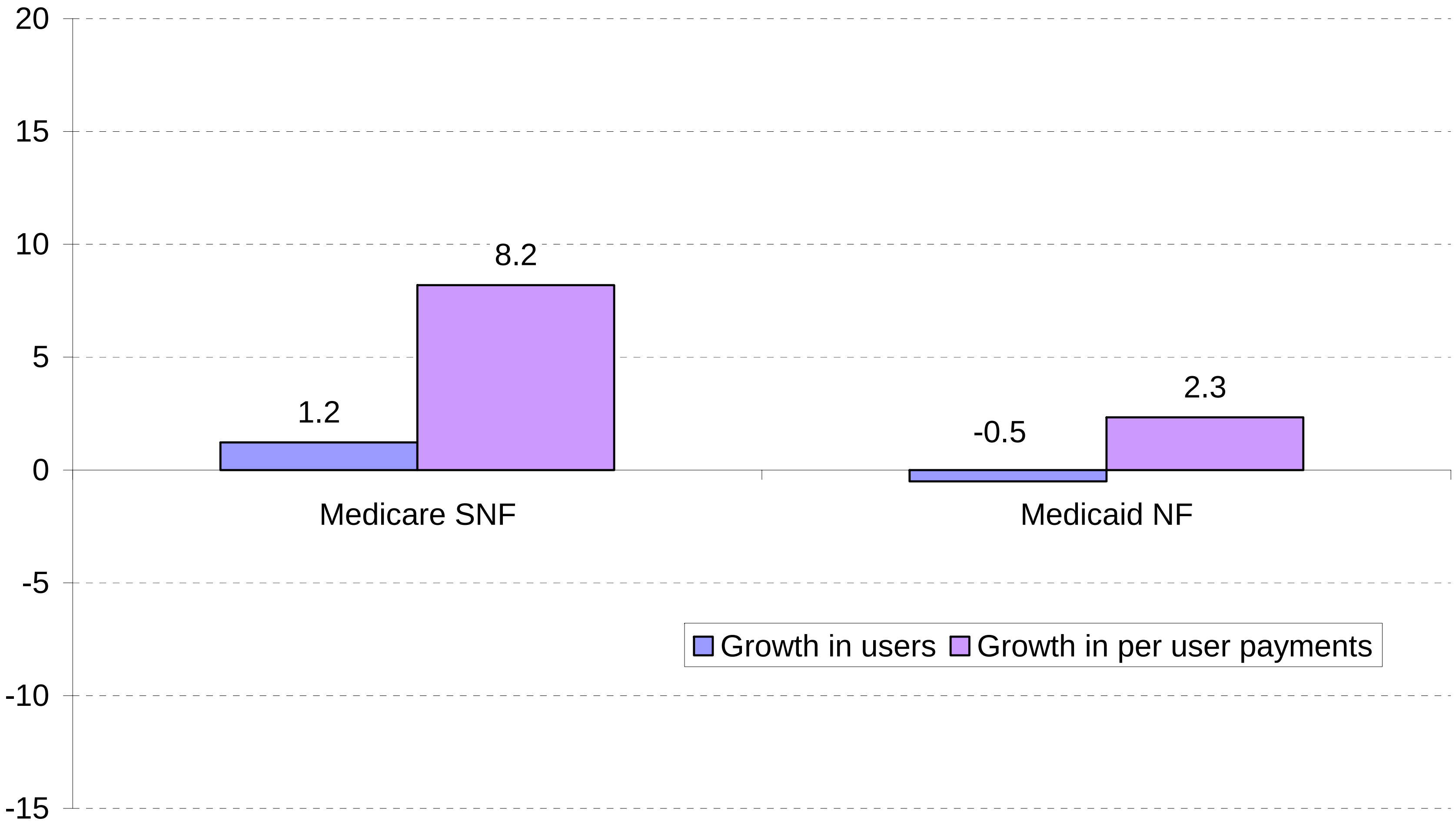
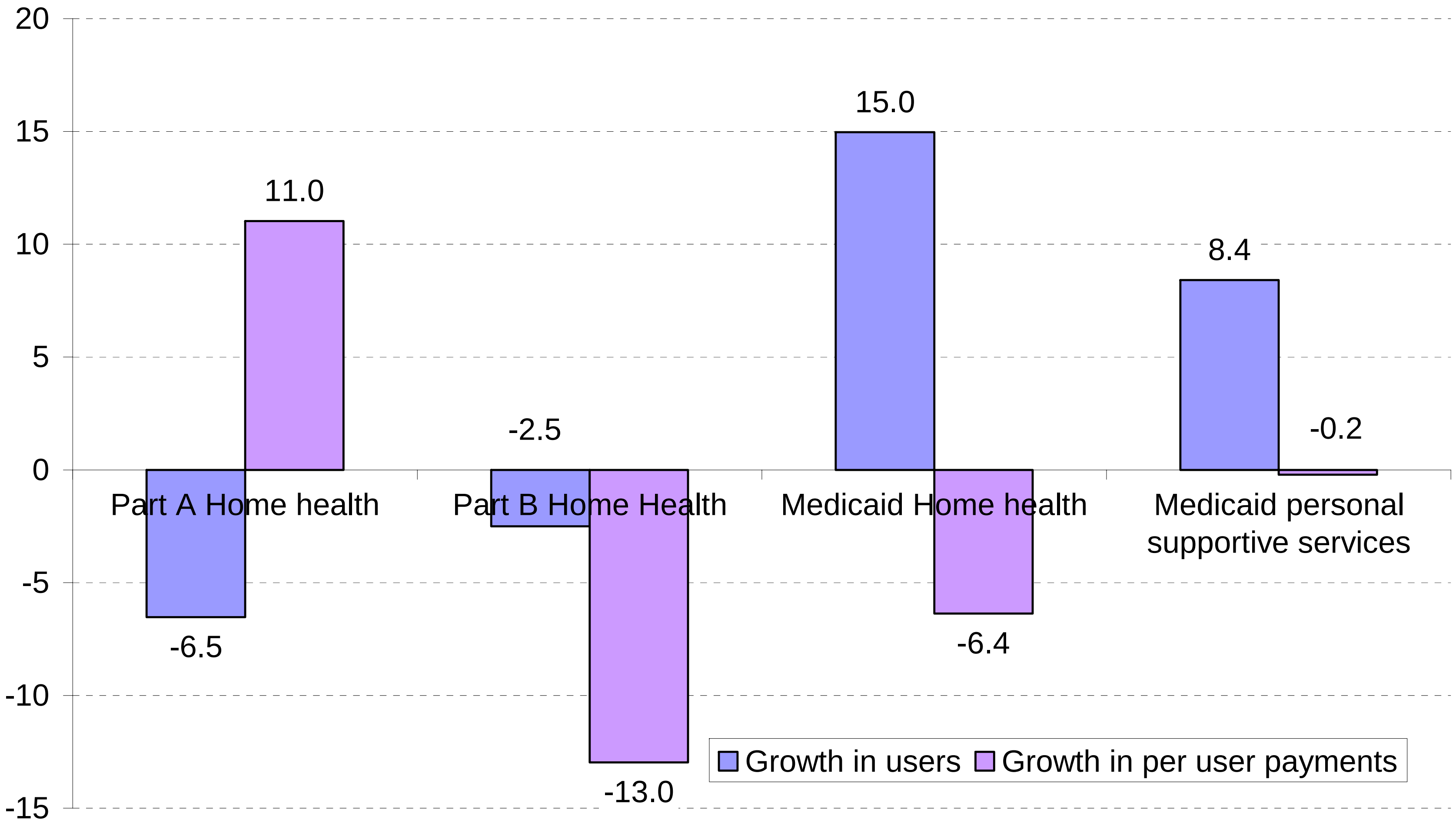


Figure I-6: Percent Change in Enrollees Using Post-Acute and Long-Term Care Services and Per User Spending 1999-2000



For acute care (Figure I.4), growth in the number of persons using inpatient and physician services roughly tracked the 0.9% increase in Medicare elderly beneficiaries. Payments per user increased by only 0.2% for inpatient care, but by 9.4% growth for physician services, which may reflect trends in recent years toward higher volume and intensity of services (Levit, et al. 2004). Outpatient services continued to expand in importance, with the number of users of outpatient services growing by 1.8 percent, about double the growth in enrollment, and per user program payments increasing at a similar rate.

Facility-based post-acute and long-term care spending growth also can be attributed primarily to higher payments per user rather than increases in the number of users (Figure I.5). Growth in the number of Medicare SNF users was only slightly higher than enrollment growth, and the number of Medicaid nursing facility users dropped slightly. Per user payments, however, increased for both types of care, notably by 8.2 percent for Medicare post-acute care. In the case of Medicare, the increase in per user payments is due to a combination of payment increases for SNFs in response to provider reaction to reduced payments under the BBA (Levit, et al. 2003) and increases in the acuity of patients and intensity of services provided (Rhoades and Sommers 2003). For Medicaid, the more modest increase may reflect in part trends toward a sicker, more disabled nursing facility population observed in recent years (Spillman, Liu, and McGilliard 2002; Rhoades and Sommers 2003; Sahyoun, et al. 2001; Rhoades and Krauss 1999; Spillman and Pezzin 2000).

Home care (Figure I-6) shows a very different pattern clearly dominated by the impacts of Medicare payment system changes. While neither published program data nor studies of the IPS and PPS to date provide direct evidence, the pattern also may suggest interactions between the Medicare and Medicaid programs as prospective payment affected the availability of less skilled supportive services through the Medicare benefit.

Between 1999 and 2000, there was a dramatic decline in the number of users of Medicare Part A home health, which is linked to a prior hospital or SNF stay, and a smaller decline in users of the Part B benefit, which is not. Payments per user of Part A services rose dramatically, however, while payments per Part B user declined.[13] Over the same period, there was a 15 percent increase in the number of users of Medicaid home health and an 8.4 percent increase in users of personal supportive services, accompanied by decreases in per user spending for Medicaid home health.

The pattern for Medicare home health would seem consistent with studies finding that the IPS and PPS reduced the rate of Medicare home health use, particularly among Medicaid beneficiaries, but had even more dramatic impacts on the mix and duration of services, with increases in the share of services that were skilled and reduction in less skilled personal-care type services (McCall, et al. 2001; Murtaugh, et al. 2003). In a model controlling for functional status and Medicaid enrollment, Liu, Long and Dowling (2003) found no differential impact on Medicaid enrollees, but did find significantly larger decreases in the number of Medicare visits for those with ADL limitations, both with and without a prior hospital stay. This could be

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[13] Because published data do not provide unduplicated numbers of users for Part A and Part B home health combined, those who had a hospital or SNF stay and received more than the 100 days covered by Part A would appear in both the Part A and Part B estimates.

suggestive of reductions in less skilled visits, although the study did not examine changes in the number of visits by type of visit. Differential reductions in less skilled visits could have the effect of increasing per user costs for Part A episodes and differentially reducing the cost of Part B episodes if Part B episodes were less heavily weighted toward skilled care. This seems plausible since they are not linked to either prior hospital or SNF use, whereas Part A benefits are. Murtaugh, et al. (2003) found a narrowing of the differential in Medicare home health use, mean visits, and mean payments between Medicaid enrollees and other Medicare home health users under both the IPS and the PPS. They speculated that this might reflect smaller shifts between skilled services and less skilled services for Medicaid eligibles because of their greater need for supportive services.

The increase in the number of users of Medicaid services between 1999 and 2000 and the decrease in spending per user could suggest a shift to Medicaid of less skilled services for dual eligibles as Medicare access to supportive services was reduced. This has been suggested but not documented in the literature (McCall, et al. 2001).

Interaction of Disability, Long-Term Care, and Spending

Review of combined Medicare and Medicaid spending and recent trends in spending and utilization confirms that acute care, by its sheer volume--particularly inpatient hospital care--is the most important driver of spending. Even small rates of growth generate large increases in spending. Rates of growth in post-acute and long-term care spending, which were growing much faster than acute care spending prior to the BBA, have moderated, although recent experience suggests higher growth rates since payment systems have stabilized. Because long-term care represents $3 out of every $5 Medicaid spends on elderly enrollees, it is disproportionately important for Medicaid spending.

These observations identify the services that are most important from the standpoint of utilization and spending, but they do not highlight the disproportionate importance of those disabled and at risk for or already using long-term care in use rates and spending. Research has documented that those who are disabled and those who are dually eligible for Medicare and Medicaid (most of whom are either disabled, or are in poor health and at risk of becoming disabled), have far higher costs for both acute and long-term care and are at higher risk of using the most costly services.

Dually-eligible elderly beneficiaries present a laboratory for examining paths through the health care system of those at risk for long-term care for three main reasons. First, as noted, they are at higher risk of disability than other elderly beneficiaries and often are already disabled. In fact, high expenses due to chronic disease or long-term care are the primary route to becoming eligible for Medicaid for those who do not already qualify financially. Second, despite large interstate differences in Medicaid program eligibility rules and benefit structure, utilization differences attributable to differences in insurance coverage are lessened in comparing service use and spending within the dually-eligible population. Finally, unlike the rest of the Medicare elderly, all of their service use can be observed in program data.

Disabled Elderly

Evidence from the MCBS shows that Medicare spending is not only higher for the disabled, but also that it rises with level of functional impairment (Liu, Wall, and Wissoker 1997). Elderly Medicare enrollees with functional impairment only in instrumental activities of daily living or IADLs (activities such as meal preparation and light housework associated with the ability to live independently) had Medicare spending 60% higher than those without IADL limitations. Limitations in 1 or 2 activities of daily living or ADLs (personal care activities such as bathing and dressing associated with greater frailty) increased spending by a factor of 2.5, and limitation in 3 or more ADLs, by a factor of 3.7. Being in an institution had an impact on Medicare spending similar to that for 1 or 2 ADL limitations among community residents.

The researchers also examined how changes in function affect Medicare spending by comparing spending in the following year for persons whose functional status had changed in the period prior to the measurement of spending. They found evidence of some persistence of higher spending even for those whose functioning improved, but a key finding for modeling was that proximate functional status had similar impacts regardless of prior functional status. For example, those with ADL limitations or in an institution had Medicare spending about 2.5 times those for persons with no limitations in both periods, regardless of functional status in the prior period.

A second study using MCBS data found that average Medicare spending for beneficiaries with limitations in at least one ADL was $8,060 in 1992, nearly four times that of beneficiaries with no ADL limitations (Komisar, Hunt-McCool, and Feder 1997). Based on the rate of ADL limitations among the elderly in 1999 (Spillman 2004), this spending ratio would imply that the 12% of elderly beneficiaries with ADL disability in that year accounted for more than a third of Medicare spending. Komisar, et al. found that utilization and spending by those with ADL limitation were higher for every type of Medicare service. For example, they were twice as likely to have inpatient hospital expenses, and their average inpatient spending if hospitalized was higher than for those with no limitations. Those with 3 or more ADL limitations were 10 times more likely to use SNF care than those with no limitations.

Medicare spending also differed by residence, with the highest spending among those with moderate to severe limitations who remained in the community. For example, their inpatient hospital spending was twice that for similarly limited beneficiaries in nursing facilities, presumably because of the greater access to medical supervision and services in facilities, although the dynamics of hospitalization of nursing facility residents is a complex issue.

Dual-Eligible Elderly

Research using Medicaid and Medicare claims from 4 New England states found that Medicare spending for dual-eligible elderly was substantially higher than that for elderly Medicare-only beneficiaries, and also found large differences in total (Medicare and Medicaid) spending by dual-eligibles, depending on residential setting and on whether Medicaid home and community-based waiver services were being received (Saucier et. al. 1998). Those in nursing facilities had combined spending a third higher than community residents receiving waiver services, in large part due to the high cost of nursing facility care. In turn, those receiving waiver services (who are deemed by their states to be eligible for nursing facility care) had spending more than 2 ½ times (272%) greater than community residing dual-eligibles not receiving waiver services. Consistent with the findings of Komisar, et al. for the disabled elderly, waiver participants had total Medicare spending 2.5 times that for nursing facility residents, and their Medicare inpatient hospital spending was twice that for nursing facility residents.

Liu, Long, and Aragon (1998) examined the role of health status in higher costs for the dually eligible using the 1993 MCBS. They also found results for the dually eligible similar to those found by Komisar, et al., for the disabled, but found that health and functional status explained much of the difference. Dual-eligibles were more likely to use each Medicare service type, particularly SNF services, and had Medicare expenditures approaching four times spending for other elderly beneficiaries. They were over twice as likely to be 85 years of age or older, have chronic conditions associated with higher spending, and were more than 5 times as likely to have Alzheimer's disease. Most of the differential in spending was explained by demographic characteristics, presence of selected medical conditions, and the number of ADL limitations. After controlling for these factors, the spending differential was reduced to 45% higher for all Medicare services combined, 42% higher for acute care and about 19% higher for SNF, home health, and hospice care. The higher costs for acute care were due to higher per user costs, while the higher post-acute and hospice costs were attributable to both a higher likelihood of use and higher spending per user. The authors focused on the remaining differential spending margin as an indicator of the share of the dual-eligibles' higher costs that might be addressed by service delivery innovations and program coordination.

Some of the difference may reflect other factors, such as supplemental insurance coverage status. High out-of-pocket costs relative to income can be a barrier to care for those most at risk for functional decline and long-term care use. In their study using MCBS data, Maxwell, et al. (2002) estimated that average out-of-pocket spending for medical care alone (i.e., excluding long-term care) among the elderly was $3,757 in 2002, and consumed 22.3% of their income. The top 10% of elderly paid $6,523 or more out of pocket, and the top 10% of those elderly with functional limitations and/or chronic conditions paid $9,174 or more out of pocket. Along with health status, supplemental insurance status is a key factor associated with levels in out-of-pocket spending. Maxwell, et al. (2002) found that at each point in the distribution of out-of-pocket spending among the elderly, Medigap policyholders spend roughly $1000 more than those with employer-based coverage, who in turn spend about $1000 more than those with no private supplemental coverage. Among each group, roughly half of out-of-pocket spending goes toward uncovered services, namely prescription drugs. The higher out-of-pocket spending among Medigap policyholders is due largely to higher prescription drug utilization and payment of the full price of supplemental policy premiums. The authors' analyses indicated that about 12% of all community-residing elderly beneficiaries have only FFS Medicare coverage. Others have some form of supplemental coverage through Medicaid enrollment, Medigap plans, employer-based plans, or are enrolled in Medicare managed care.

Private Costs, Residential Setting, and Spend-Down

Private costs for both acute and long-term care clearly are also important in considering how individuals move into disability and through the long-term care system and how individuals progress to Medicaid eligibility. Levit, et al. (2003, 2004) indicate that private spending growth for both home health and nursing facility care have been lagging since the implementation of Medicare prospective payment for post-acute care, although this trend may have reversed in 2002 for home health. They speculate that the slower growth reflects in part an increase in privately paid long-term care in alternative residential care settings, often referred to collectively as assisted living. While there is wide disagreement about the size of the population in these settings, although current estimates suggest it may be between 2% and 3% of the elderly. There was about 60% growth in the number and percent of the elderly population in such settings between 1992 and 1998 (Spillman, Liu and McGilliard 2002), and there is general belief that growth is continuing.

Most dually-eligible elderly beneficiaries begin with very low income and assets, but others become dually eligible because they spend down their assets and income paying for medical services and long-term care. This occurs particularly for the 5% of elderly beneficiaries residing in nursing facilities in any given year. An estimated 44% of 65 year olds ultimately will enter a nursing facility (Spillman and Lubitz 2002). Based on estimates from the mid-1990s, of those using nursing facilities 43% will be dually eligible— 27% at first admission and 16% by spending down (Spillman and Kemper 1995). Nonetheless, while spend-down is much more likely for those entering nursing facilities, most of the dually eligible and most who spend-down are community residents (Liu, et al. 1990; Tempkin-Greener, et al. 1993).

Shifts to care other than in nursing facilities is likely to increase the proportion of dual-eligibles and the proportion of those who spend-down who reside in the community. Although nursing facility care costs more ($4,500 per month on average), median costs for assisted living are still high ($2,000 to $2,500 per month), and higher for settings with more amenities or for special care groups, such as Alzheimer's patients (AARP 2001). In 2002, 41 states covered Medicaid long-term care services (excluding room and board) for 102,000 residents of assisted living and board-and-care facilities, under either their state personal care benefit or HCBS waivers (Mollica 2002). Although the numbers are still small, the rate of growth is large. In 1998, only 28 states were covering benefits in these settings for about 40,000 Medicaid enrollees. Based on the Medicare expenditures described above for community residents and waiver participants, private and public trends toward non-institutional long-term care may resulted in increased Medicare spending without necessarily reducing Medicaid spending.

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CHAPTER II. CONCEPTUAL FRAMEWORK AND REVIEW OF EMPIRICAL LITERATURE

Conceptual Framework

The prior chapter pointed to particular areas where our project should focus, in terms of utilization, determinants of utilization, important interactions (such as between residential setting and program payments), and potential points as which to modify the paths of at-risk beneficiaries through the health and long-term care system. In this chapter, we formulate a conceptual framework that will allow us to identify where our analyses in this project fit within the larger framework. We review models of disability, health care use, and long-term care use, and demonstrate how they can be conceptually integrated to form a framework for our analyses. Because our focus is on individuals and how they progress through the health and long-term care system, we do not consider models of prevalence of disability or service use at the population level.

We rely on two overarching frameworks. The first is of the progression to disability from the 1991 Institute of Medicine report *Disability in America: Toward a National Agenda for Prevention*, which is based on work by Nagi (1965, 1991). The second is the model of health services use developed by Andersen, which is now ubiquitous in health services research (Andersen and Newman 1973).

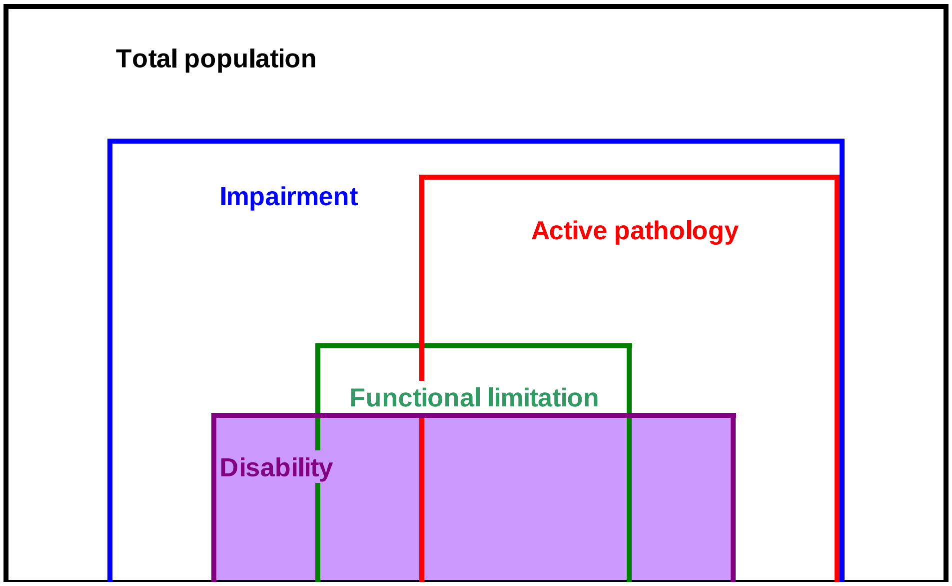
Conceptual Framework for Disability

In the Nagi framework, illustrated in Figure II-1 and adapted from the IOM report, pathology represents changes at the cellular or tissue level due to disease or injury, leading to impairment in the function of an organ or organ system, for example, damage due to heart attack, or hip fracture after a fall. Impairment may or may not lead to functional limitation in the performance or capacity of the person, for example, inability to lift heavy objects, walk distances, or climb a flight of stairs. Whether a particular impairment results in functional limitation depends on individual factors, such as level of fitness and muscle strength, which are affected by such factors as age and other existing impairments and conditions. Functional limitation, in turn, may or may not lead to disability, which is the inability to carry out personal, familial, and societal roles and tasks.

Disability is the least clinically measurable of the concepts because it depends not only on physical and cognitive capacity, but also on what activities an individual expects or is expected to perform, the individual's social and physical environment, and on how inability to carry out those activities is defined. For our work, we rely primarily on performance of IADLs, ADLs, and cognitive impairment. ADLs have become the standard in defining disability among the elderly and are the most commonly collected measures in assessment and survey data. IADLs often are associated with cognitive impairment. In addition, ADLs and cognitive impairment are commonly used in determining eligibility for either public or private long-term care benefits. For example, to be eligible for benefits under a private long-term care insurance policy qualifying under the Health Insurance Portability and Accountability Act of 1996

(HIPAA), an individual must be limited in at least 2 ADLs of 5 (eating, bathing, dressing, toileting and transfer) or cognitively impaired.

Figure II-1: A Model of Disability



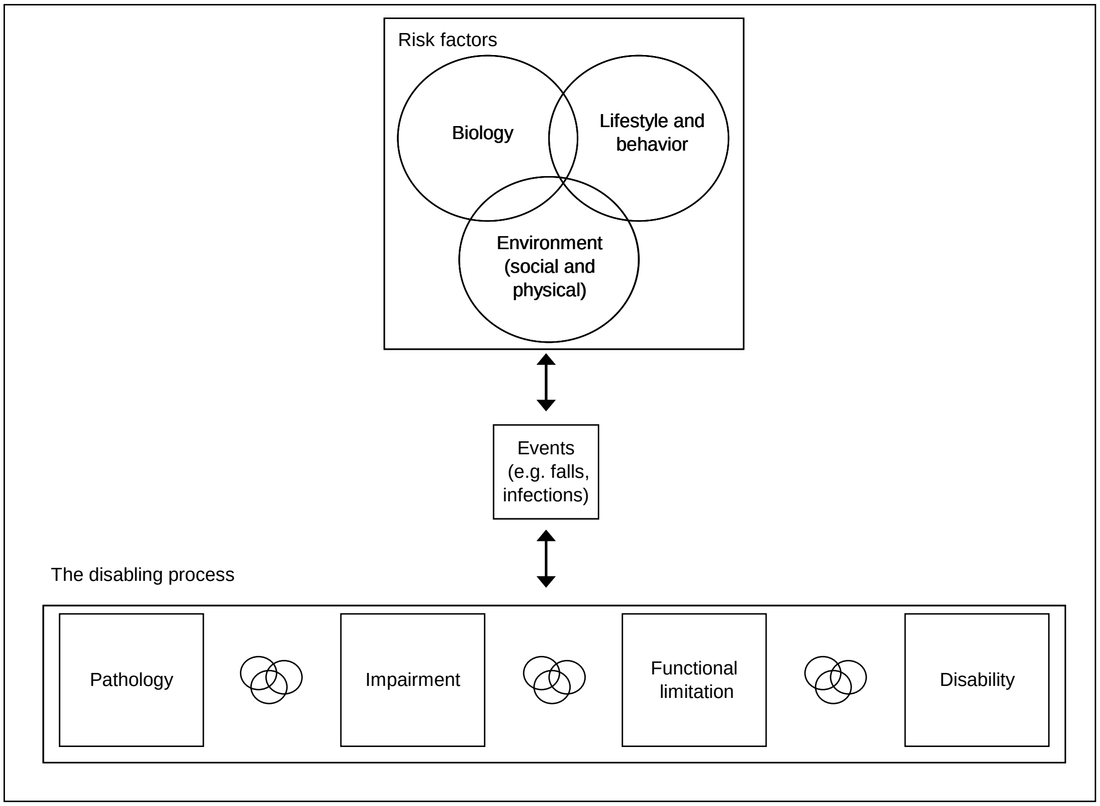
Source: IOM (1991)

From this basic framework, the IOM report goes on to lay out a model of disability (Figure II-2). The initial set of large interlocking circles represents risk factors that are associated with development of conditions that may lead to the disabling process. Three inter-related domains are represented:

- biological factors internal to the person and beyond individual control (e.g. genetic, aging, interactions between biologic risk factors);
- environmental factors external to the person over which the individual has little or no control (e.g. exposure to physical risks, social context, and the interaction between social and physical environment); and
- lifestyle and behaviors comprising choices and habits over which the individual has considerable control (e.g. drug and alcohol abuse, overeating, tobacco use).

These risk factors may affect both the likelihood that events that *may* lead to the disabling process occur and the likelihood that a given event *actually* leads to the disabling process. The interlocking circles between each stage in the disability process represent factors, notably health service utilization, that may intervene and affect the likelihood of progression to the next stage. As with the initial risk factors, there are multiple domains for these factors, including biological, socioeconomic, and environmental. Although there is no explicit expression of time, these

Figure II-2: Institutes of Medicine Model of the Disabling Process

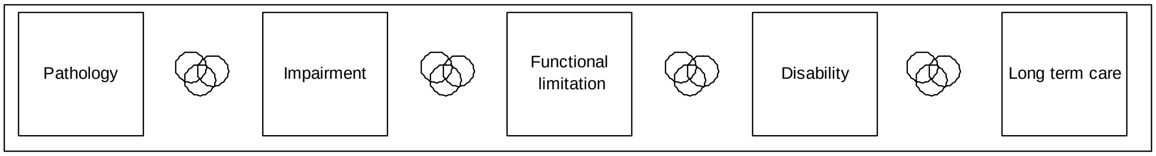


Source: IOM (1991)

factors might also be thought of as affecting the length of time until progression to the next stage. These factors may differ between each stage of the process, for example, medical intervention may be most important in progression from pathology to impairment, or from impairment to functional limitation, whereas rehabilitation may become important in whether impairment leads to functional limitation or whether functional limitation is resolved before progressing to disability. Environmental factors and economic resources play an important role in the progression from functional limitation to disability, for example, whether there are environmental barriers to performing necessary activities and whether the individual has the financial resources to remove or reduce environmental barriers (e.g. home modifications that allow independent performance).

The definition of disability is important at this point, and provides a link between the model of disability and long-term care. Disability may be defined as inability to perform necessary activities independently without either assistive devices or other adaptive measures (again, home modifications, for example) or human assistance. Long-term care is by definition the latter— dependence on long-term human assistance. Thus, long-term care can be conceptualized as an additional step in the disabling process, with its own set of intervening factors that affect whether an individual with disability functions independently or requires long-term care (Figure II-3). As with the other stages in the process as modeled by IOM, whether an individual with disability progresses to long-term care (or how quickly) is affected by biologic factors (e.g., comorbidities, muscle strength, and general fitness); psychological, socioeconomic, attitudinal and social factors (e.g., whether family members are available to provide supportive services); environmental factors; and use of other services (e.g., rehabilitation).

Figure II-3: Progression to Long-Term Care



When long-term care is provided by family members, friends, or others who are not paid, it is referred to as informal long-term care, and, in fact, such informal care represents the majority of long-term care. When it is provided by individuals who are paid, it becomes long-term care service use. Long-term care is often characterized as supportive services, for example assistance with IADLs and ADLs. As the experience of the Medicare home health benefit in recent years suggests, however, it often occurs in a context where long term medical (or skilled) care also is needed. In turn, although such skilled care often is provided by paid providers, substantial amounts of this long term skilled care may also be provided by informal caregivers, particularly family members who may provide medical services that an unskilled paid worker could not by law.

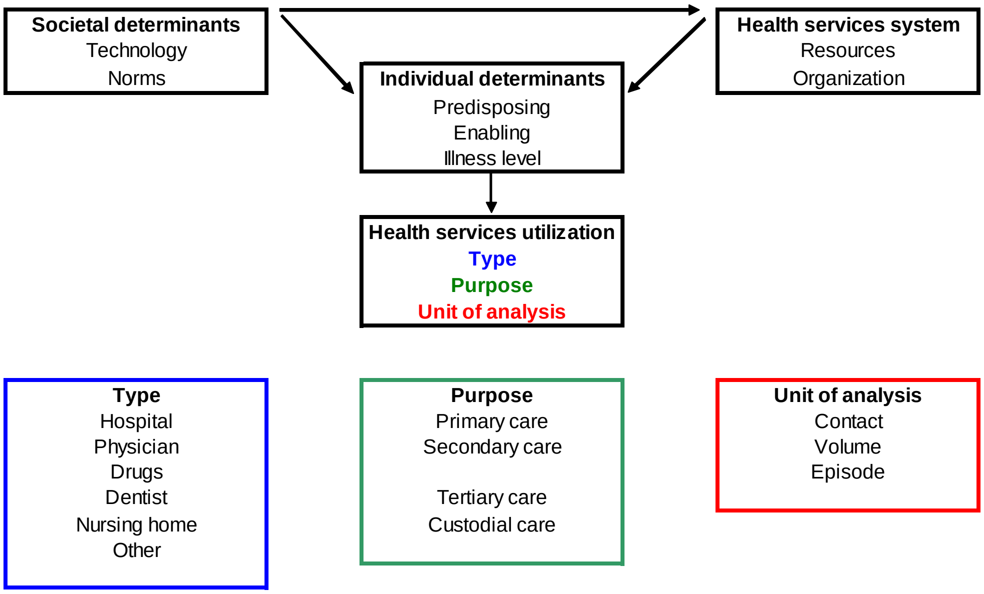
Although we do not explicitly consider informal provision of medical or skilled care, the availability of informal support may affect not only use of long-term care services but also use of medical services. Further, the inter-relationship between long term medical needs and long-term care needs is important to the consideration of how cohorts of beneficiaries move through the system and in the sorting of individuals between care arrangements, such as between institutional or home-based care.

Conceptual Framework for Service Use

The theoretical framework for medical care utilization developed in Andersen and Newman (1973) is the most common framework used for modeling both acute and long-term care use (Figure II-4). Anderson’s framework provides a model of how service utilization may intervene in the disabling process. Service use is modeled as a function of societal and health care system factors and individual determinants.

Like the environmental factors in the IOM model of disability, societal and health care system factors are conditions that exist at the macro level and are largely beyond the control of the individual, and include technology, shared norms and health system resources and organization. Clearly this environment changes over time in ways that affect the paths an individual takes through the health care system, above and beyond individual needs, and that may affect the progression of disability. For example, technological advances that have made organ and joint replacements and cataract surgery commonplace and growth in non-institutional long-term care options affect practice norms and societal expectations, and may affect the risk and course of the disabling process.

Figure II-4: Framework for Formal Health Services Utilization



Source: Andersen and Newman (1973)

Individual determinants are classified as those that predispose or enable the individual to use health care services, which exist whether or not the individual has a proximate cause for seeking services, and perceived illness or risk of illness, frequently referred to as need, which prompts the seeking of care. Predisposing factors include demographic characteristics and other variables reflecting social environment, such as availability of potential family caregivers in the case of long-term care use, and attitudes that affect the tendency to use health care. Age and gender, though not themselves indicators of illness, are considered predisposing characteristics, as are prior illness or disability status, which may affect both whether risk or need is perceived and the propensity to seek care once need is perceived. Enabling characteristics are factors affecting access to services and include measures of individual and family resources (such as income and insurance) and community characteristics (such as availability and variety of providers). Operationally, community factors often include such variables as region and rural/urban location and, in the case of long-term care, public program characteristics, in addition to specific provider supply. Finally, need factors include such characteristics as perceived and evaluated disease and functional status. Given the level of perceived need, enabling factors capturing ability to pay for services often are found to be the most important predictors of service use and of choice of provider, when more than one option is available.

Finally, utilization is characterized by the type, purpose, and unit of analysis. Care may be primary or preventive, secondary treatment of illness or injury, tertiary treatment to manage chronic disease, or custodial or long-term care (primarily thought of at the time the model was developed as nursing facility or institutional care). The unit of analysis may be the event of care (e.g. physician visit, hospital admission), quantity of care (e.g. number of visits, length of stay, cost per hospital day) or episode (e.g. all care associated with an event or condition, such as hospitalization, rehabilitation, and return to home or institutionalization).

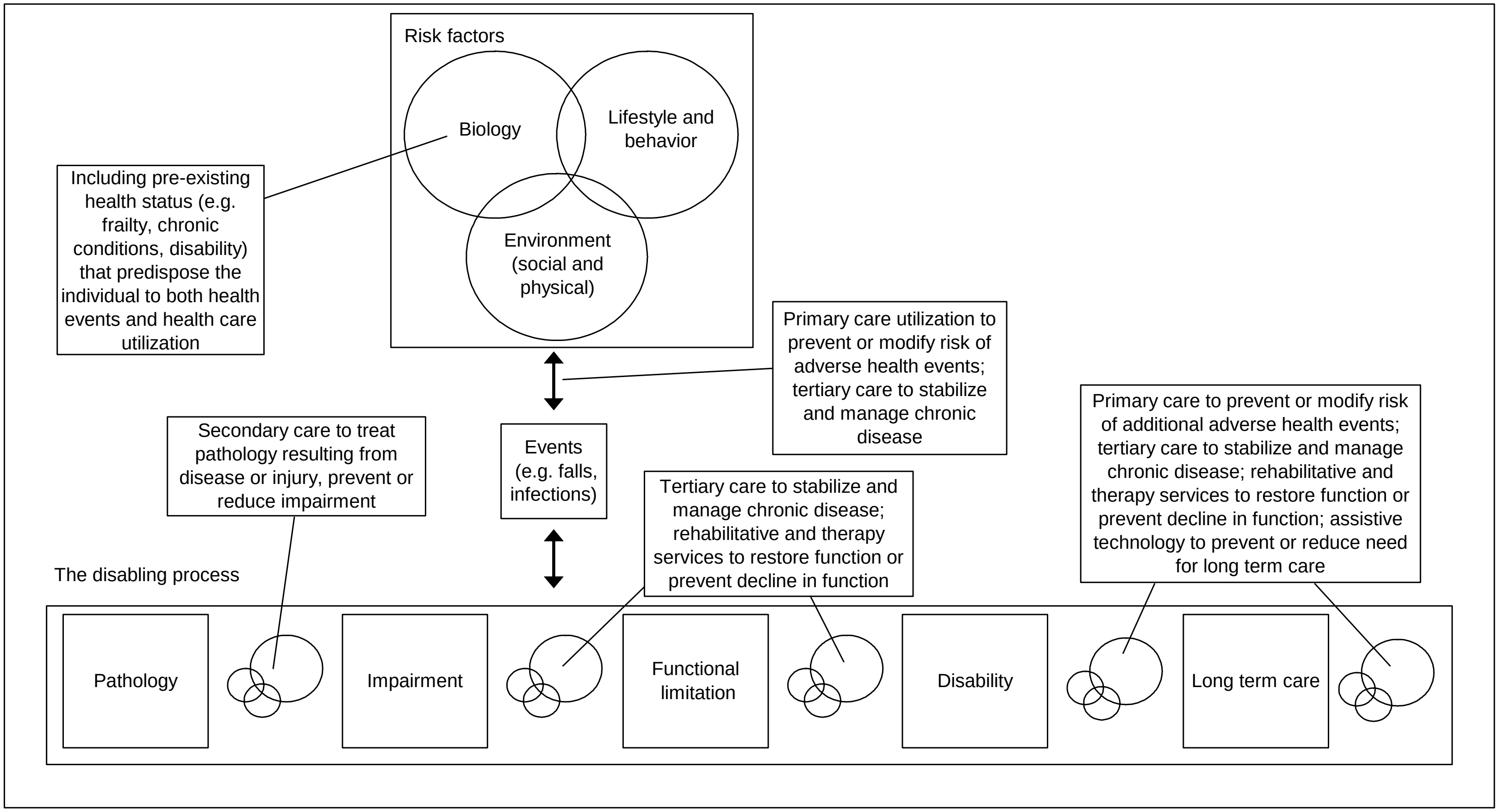
Important distinctions can be made regarding individual and agent decision with respect to the three aspects of care. The largest arena for individual discretion is the decision to seek care, with the greatest discretion occurring for primary care. Once care is sought, the provider, to a greater or lesser extent depending on the situation and type of care, influences the quantity, location, and nature of subsequent care. This agency role probably is most evident in secondary care for the treatment of disease and recuperation, and tertiary care to manage chronic disease, although considerable individual discretion remains. A pertinent example for the population at risk for long-term care is the choice of post-acute care, which may be affected by such factors as provider relationships and assessment by hospital discharge planners of the individual's capacity for rehabilitation. Individual discretion remains important for compliance in both the volume of services and the content of the episode of care, but is likely to be strongly influenced or limited by agency decisions, as well as environmental factors, such as availability of alternative providers and payment system features.

Combining the Models

Together these two models provide our conceptual framework for how beneficiaries at risk for long-term care move through the health care system (Figure II-5). Health care utilization can be conceptualized as being one of the domains of factors intervening and potentially affecting the risk or speed of progression between any two stages in the progression, and each stage itself represents a predisposing characteristic implying different risks or need for care. Thus, members of any cohort defined by medical conditions, functional status, or long-term care situation can be located at a point in the framework, and an individual's location in the progression can be considered as affecting the risks and outcomes of events and utilization, as well as being a potential endpoint defining a cohort for retrospective study.

Examples of the potential types of cohorts (or cohort definition criteria) that we considered in this project include disease state (e.g., congestive heart failure), health or utilization event (e.g. hospitalization), functional state (e.g., ADL limitations requiring long-term care), long-term care setting (e.g. nursing facility resident), and combinations of the three. An individual's location in the process may define the cohort to which that individual belongs, may help conceptualize how relative risks should be modeled for a given event, and may help determine limits that should be placed on a cohort in order to isolate a particular issue.

Figure II-5: Framework for Integrating Disability and Service Use Models



Using a cohort of elderly hospitalized for a stroke as an example, this cohort may include persons at various points in the progression— individuals with no prior functional limitation, individuals with functional limitation due to another unrelated condition (e.g. arthritis), or individuals already in long-term care (e.g. nursing facility residents). Depending on the research question, it may be desirable to include all groups and control for differential risks and prior contact with the health care system as implied by an individual's location in the disabling process (e.g. differential costs of treatment, length of stay, or post-acute care setting, controlling for existing impairment from comorbidities, functional status, and residential setting). Or, it may be desirable to exclude groups from the cohort (e.g. time to first nursing facility admission among community residents).

This framework helps provides a means for conceptualizing and viewing the major events, intersections, and paths of acute and long-term care utilization. It also helps provide a framework for considering our cohort analyses and their utility, for considering specific research questions, and for developing optimal and data- or budget- constrained study designs.

Summary of the Empirical Literature on Determinants of Long-Term Care

Overview

To inform our development of cohort studies based on our conceptual model, we reviewed recent empirical studies of utilization of acute, post-acute, long-term care, and transitions among care settings. We focused on risk factors and other characteristics that have been used in modeling relevant outcomes; findings with respect to sign, significance, and magnitude of impacts, and measurement issues that may affect the importance of various characteristics across outcomes. We assembled a database of roughly 125 pertinent journal articles, most of them published from 1992 to the present, and selected 82 for closer review. Of those, 59 were empirical studies we review further (Table II-1).[14] In collecting this literature, we relied in part on a review by Miller and Weissert (2000). Their review examined 78 national and subnational longitudinal studies published between 1985 and 1998 that modeled four relevant outcomes: institutionalization, hospitalization, broadly defined functional impairment, and mortality. We therefore focused primarily on more recent articles, although like Miller and Weissert we found that recent studies sometimes used data from as long ago as the 1980s. Results of additional reviews regarding alternative functional status measures, comorbidity status measures, selected chronic conditions, and state waiver programs are discussed in Chapter III. Results of our review of literature on modeling methodologies for health outcomes and setting placement are discussed in Chapter IV.

We began with a base of relevant literature known to the principal investigators and review of reference lists in these studies. We also conducted online searches, primarily using the National Library of Medicine's MEDLINE/PubMed, by topic and outcome and used the related

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[14] Our entire database consists of roughly 400 articles and reports reviewed to date in this project. The other topics are, for example, public, private, and out-of-pocket expenditures for medical and long-term care; state waiver program activities; risk factor and utilization articles regarding stroke, hip fracture, and CHF patients; and articles reviewed in our assessment of health measurement methodologies and statistical modeling of health outcomes and care placement.

articles search to identify additional sources when we found articles that were particularly relevant. Specific outcomes included in our review included nursing facility admission and utilization, home health and other home care, post acute care, hospitalization.

Organization

Our review generally follows the structure suggested by both the IOM model of progression to disability and the Andersen and Newman model of health services organization, but using the language of the latter: predisposing, need, and enabling characteristics, especially those reflecting the individual's health care system context. We focus more attention on health-related predisposing factors and need factors and on enabling factors, and less on demographic factors, such as age, race and gender. Demographic factors are ubiquitous in models and present in both administrative and survey data, although interpretation of results is complicated by correlations between these variables and other direct need and enabling factors. Andersen and Newman noted that need ranks highest in explaining observed utilization, demographic factors and family resources are of medium importance, and community-level resources are of low importance. They argue that an ideal distribution of health care would minimize the importance of all factors except need and demographic factors, which would be maximized, the latter because of demographic differences in health risks and needs.

We kept in mind several factors in our review, including how the structure of models (e.g. longitudinal or cross-sectional) may affect the performance of individual risk factors, how individual factors may be affected by the inclusion or omission of related measures, how recursive effects and endogeneity issues may arise, and how data limitations that preclude inclusion of some measures may affect interpretation of the impacts of others.

Using marital status as an example, being married is reliably associated with a lower rate of admission to a nursing facility in cross-sectional studies and, in fact, was cited anecdotally by our clinical experts as a factor affecting referrals to rehabilitation. Yet, Miller and Weissert found that being married had a negative impact on institutionalization in only 8 of 21 longitudinal studies they reviewed and was not a significant predictor in 8 of 9 studies of hospitalization and 10 of 12 studies of functional limitation. Other variables included in a model also may affect findings of significance, particularly for factors such as marital status that may operate primarily as proxies for other factors, rather than having direct impacts on outcomes. Contrary to the findings for marital status, Miller and Weissert found that greater familial support and greater caregiver support reduced the likelihood of institutionalization, while presence of an informal caregiver significantly *increased* the likelihood of both hospitalization and institutionalization, perhaps reflecting greater care needs. Living alone, which is clearly related to marital status, was found to be a significant predictor of institutionalization. These findings may suggest that the role of a spouse as the primary source of informal care is more important than other factors that also may be proxied by marital status, such as greater financial means and higher financial limits for Medicaid eligibility for married long-term care recipients.

Table II-1: Catalog of Covariates in Recent Studies of Determinants in Long-Term Care, Post-Acute, and Inpatient Utilization

	Setting																			
	Nursing Facility				Mediciad Home Care				Medicare SNF				Medicare Home Health Care				Hospitalization			
Articles (#)	16				7				9				12				15			
Covariates	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)
Need																				
Physical Function																				
ADL	11	2		9	3	1		2	4			4	10			10	7	2	1	4
IADL	3			3	2			2					6			6	1			1
Cognitive Function																				
Cognition	7	1		6	1			1	2	1		1	4	4			1		1	
Alzheimer	2			2													2	1		1
Dementia	4			4													4	1	3	
Behavior Problems	2	1		1					1	1										
Mental Status													2	2			1			
Depression	1	1											1		1		1	1		
Schizophrenia																	2		2	
Condition																				
All Heart Disease	1			1					3		3		8	4	1	3	5	1		4
Arthritis	1		1						1		1		2	2			2	1		1
Cancer	2	2							1		1		4	3		1	3	1		2
Circulatory																	2			2
Diabetes	1			1									5	1		4	6	1		6
Digestive	1	1															2	2		
Drugs	1			1																
Gastrointestinal																	1	1		
Hip Fracture	1			1					3		1	2	2	1		1	3	2		1
Hypertension													1	1			4	2	1	1
Incontience	3	3											1			1				
Infections																	2	2		
Neoplasm																	2	1	1	
Parkinson's Disease									1			1	1	1			2	1		1
Respiratory	1	1							2		2		4	4			4			4
Skin																	*1*	*1*		
Stroke	2		1	1					3			3	4	4			4	3		1
Ulcers																	2			2
Ventilator Support									1		1									
Other																				
Prior Hospitalization	2	2							1			1	3	1		2	2	1		1
Self-Rated Health (poor)	3	1		2									3	2		1	2		1	1
Weight Change/BMI	2			2													3	1		2
Enabling																				
Wealth																				
Wealth	1	1											1	1						
Income	6	1	1	4					1		1		4	3		1	2	2		
Home Owner	2	1	1						1	1										
Assests--Protected	2			2	1	1			1	1			1	1			1	1		
Assests--Spend Down									1	1										
Insurance																				
Private Insurance					1	1			1	1			1	1						
Medicare MCO									4		2	2								
Medicare and Medicaid	1	1							2			2	2	2			2	2		
Medicare	2	1	1						2		1	1	1		1		2	1	1	
Medicaid	2			2	3	1		2	1	1			1	1						
Medicaid Eligible	1			1																
Other																				
Prolems Obtaining Care																	1	1		
Region (Difference)	6	4		2					3			3	6	4		2	5			5
Predisposing																				
Individual																				
Age	12			12	4			4	5	1	1	3	8	2		6	10	3	0	7
Gender--Female	12	6	6		2	2			5	1	1	3	10	8		2	8		8	
Race--Nonwhite	11		11		7	5	1	1	3		3		9	5	1	3	5		2	3
Education	5	4	1		1	1							7	7			2	1	1	
Social Situation																				
Lives with Spouse																	1	1		
Lives Alone	3	2		1	1			1					3	2		1	1	1		
Unmarried	10	5	5		3	1	1	1	3	1	2		7	1	1	5	1	1		
Informal Caregivers(#)	3	2	1																	
Family Size									1	1										

Table II-1, continued. Catalog of Covariates in Recent Studies of Determinants in Long-Term Care, Post-Acute, and Inpatient Utilization

	Setting																			
	Nursing Facility				Mediciad Home Care				Medicare SNF				Medicare Home Health Care				Hospitalization			
Articles (#)	16				7				9				12				15			
Covariates	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)	#	NS	S(-)	S(+)
Children	1	1			1		1						3	3						
Grandchildren													1	1						
NH LOS									1		1						1		1	
New Admission																	2			2
Market and Facility																				
State Policy																				
Waivers (#)													1	1						
CON	1		1		2	1		1												
CON HHC					1		1													
Construction Moratoria	1		1		1	1														
Local vs State Control					1	1														
Liberal Ideology					2	2														
Area Characteristics																				
Income Level					1	1											1			1
Federal Matching Rate					1	1														
Per Capita Income					5	1		4												
Per Capita AARP Membership					1	1														
Percent Urban																	1	1		
Area Supply																				
HH Agencies													2			2				
Hospital Beds									2	2							1			1
Medicaid ICFs													1		1					
NF Beds	2	1		1	2	1	1										2		2	
SNFs					1		1						2		2					
Physicians					1			1												
Facility Financial Status/Management																				
For Profit Ownership													2	2			5	1		4
Change in Ownership																	2	2		
Cash Flow																	2			2
Private Payment Rate																	1	1		
PPS									2			2	3			3				
Medicaid NF Rate ($10 Increase above $75)	1	1															1		1	
Operating Tenure																	2	1	1	
Management																	2			2
OSCAR Deficiency Status																	2		2	
Facility Case-Mix																				
% allocate Medicaid	1	1											2			2				
Medcaid Paid Days																	2			2
Medicare Paid Days																	2		2	
Private Payer Days																	1			
Facility Case Mix																	3	1	2	
Facility Staffing/Services																				
RN Staffing Expenses																	2	2		
LPN Expenses																	2			2
ICF																	2		2	
SNF-- On Site Med. Staff/Expar	1		1														3		3	
Inpatient Surgery									1			1								
Special Care Unit																	1		1	
Surgery Physician Office																	1			1
Surgery Outpatient																	1			1
Social HMO	1		1		1			1												
Female Participation Rate					1			1												

Source: Urban Institute analysis of recent literature.

They also may suggest that marital status may be an important control for differences in potential family support in the absence of other more specific measures.

Predisposing Characteristics Other Than Health

Predisposing factors are grouped into three categories: demographic, social structure, and beliefs. In many ways they are the most difficult to interpret because, as in the discussion of marital status, they often have explanatory and policy importance primarily because of their association with other, more direct factors that may be difficult to measure or absent from a particular data source. Therefore, the importance of predisposing factors may be reduced or eliminated with effective controls for enabling, and especially need factors, either through selection of a cohort with similar health or utilization characteristics or through careful controls for illness level or a combination of the two.

Demographic factors are exogenously determined (e.g. gender, age, race), but like marital status, they may serve as markers for other factors that are relevant for policy considerations. Examples are the association of gender, age, and race/ethnicity with different genetic or biological risks for disease and disability. Women live longer, are at lower risk for some diseases such as heart attack, associated with a quick progression to death, and are at higher risk for chronic disease and for frailty and disabling diseases associated with advanced age, such as Alzheimer’s disease and osteoporosis (Verbrugge 1990; Guralnik, et al. 1997; Gold, et al. 2002). They are also more likely to outlive a spouse, so that they are less likely to have this primary source of informal support. Different racial or ethnic groups also have different risks for disease (e.g. a higher risk of developing hypertension) and may have different attitudes or beliefs about service use.

Race/ethnicity and other exogenous factors related to social structure and beliefs, such as family structure (especially marital status) and educational attainment, may proxy a complex of socioeconomic factors that may affect health, access to care, attitudes that affect whether and at what point in the disability process care is sought, and treatment patterns at a given stage in the process. Other such factors, for example, having children, are exogenous, but proxy factors such as receiving informal support that are endogenous to some outcomes, such as use or type of post-acute care, use of formal home care or nursing facilities, and even hospitalization. In this review, we focus primarily on age, gender, race, and measures of social support, and ignore other factors such as education, which are less often included and less often found to be significant predictors of the outcomes we consider.

Demographic Factors

In their review of longitudinal studies, Miller and Weissert found that age was a strong and consistent predictor of institutionalization, functional impairment and mortality. Only 11 of 20 models showed a significant relationship between age and hospitalization, 6 a positive relationship, and 5 a negative relationship, with models using national data supporting a positive relationship. Our review similarly found advanced age to be a significant predictor of the outcomes we reviewed, although there were differences in its importance across outcomes. A positive impact was found in all 12 studies of nursing facility use, 6 of 8 studies of home health care (2 not significant), all 4 studies of community-based long-term care, 3 of 4 studies of post-acute care (1 not significant), and 7 of 10 studies of hospitalization (1 not significant).

Miller and Weissert found female gender to be a negative predictor of hospitalization and mortality and not a significant predictor of institutionalization (although 5 of 7 significant results among 47 total models showed a negative relationship) or functional limitation, for which 19 of 24 studies showed no significant impact and the remaining 5 significant results were mixed in sign. Our results were generally similar, with 6 of 12 studies of nursing facility use (6 not significant) and 8 of 8 studies of hospital admission showing a significant negative relationship. No significant relationship was found for home health use or community based long-term care, and a negative relationship was found in and 3 of 5 studies of post-acute care (1 not significant). This lack of relationship or relationship seemingly at odds with the well-documented higher use of services by women demonstrates the extent to which observed gender differences may be narrowed by controls for health, age, and other factors. For example, three of the six studies finding that women were less likely to enter nursing facilities analyzed samples of persons already receiving formal community long-term care (Bauer 1996, Borrayo, et al. 2002, Phillips, et al. 2003a) and a fourth included extensive controls for conditions, functional status, age and enabling factors (Lakdawalla 2003).

The Miller and Weissert review analyzed race in terms of nonwhite versus white race. Being nonwhite was negatively related to institutionalization, and not a significant predictor of functional impairment, mortality, or hospitalization, although among 11 total models, nonwhite race was found to be a significant predictor of hospitalization in two models using national data and a significant negative predictor in two models using subnational data. Our findings were generally similar, with a significant negative relationship in 11 of 11 studies of nursing facility use and 3 of 3 studies of post-acute care. Being nonwhite had no significant impact in 5 of 9 home health studies and 5 of 7 studies of community-based long-term care. Results were mixed for hospitalization, with 2 of 5 studies negatively related and 3 positively related to nonwhite race/ethnicity. As with gender, the evidence suggests that context and other factors, particularly need factors, appear to be important. For example, blacks are less likely to be admitted to hospitals from the general population (Aliyu, et al. 2004, Wolinsky, et al. 2004), but both blacks and Hispanics are more likely to be admitted for ambulatory care sensitive conditions (Culler, et al. 1998, Laditka, et al. 2003).

Social Structure

Although social structure can be defined much more broadly, in the context of long-term care, the most important factors and those most included in empirical models relate to family structure (e.g. marital status, number or presence of children) because of their role as a support system and source of informal care. Further, they are inter-related, as in the discussion of marital status above and may have different impacts depending on the outcome and context. For example, Reschovsky (1998b) found that being married reduced nursing facility admission among both private payers and Medicaid eligibles but in another study (1998a) found no significant impact on SNF entry, consistent with findings in Liu, et al. (1999). Generally Miller and Weissert found that social support reduced the likelihood of institutionalization but had little impact on either hospitalization or functional impairment. Our findings were similar, with factors relating to family structure and availability of informal care generally either insignificant or mixed with respect to sign when they were significant in the relatively few cases where they were included in models of home health care, community-based long-term care, post-acute care, and hospitalization. Two final points to be about models using social support measures is that both receiving informal care and the decision to live with others may reflect unmeasured frailty, and both are jointly determined with the use of formal long-term care services, so that models of home care need to take their endogeneity into account (Kemper 1993; Pezzin, Kemper, and Reschovsky 1996).

Need Characteristics

The conceptual framework for disability and service use places individual health characteristics as central in the process that leads to dependence on long-term care. Indeed, some measures of need are almost definitional in their relationship to long-term care. ADL dependence is sometimes referred to as “long-term care use” as it implies at least informal care, and it is generally a pre-requisite for both public and private insurance coverage of institutional and community based nursing care. In the IOM model of disablement, ADL dependence flows in part from disease pathology beginning at the molecular level that can lead to physical or mental impairment. Thus when analyses seek to identify predictors of future long-term care use, it is useful to include a variety of individual health measures, as they are available.

Miller and Weissert (1998) found that in most studies, health needs generally had either significant positive or insignificant effects on the risks of institutionalization, hospitalization, functional decline and mortality. Our review of the literature since 1998 produced a very similar picture. As implied by Table II-1, there is a very broad range in the number and type of covariates used in the models of the articles we reviewed. A clear difficulty in summarizing the effects of any variable is that no two studies control for the same factors and use samples representing the same populations. Further, for some measures (e.g., ADL disability) each study operationalizes the measure differently, so summarizing the associated risks numerically is impossible. Finding significant effects in one study and insignificant effects in another is not necessarily unexpected, so the existence of a consistent pattern over multiple and disparate studies provides the most convincing evidence of a relationship.

In these studies of nursing facility use, community based long-term care, hospitalization, and post acute care use, ADL disability was the most commonly studied measure of health needs. In the studies of institutional and community based long-term care in which an ADL measure was used as a risk factor, it was significantly associated with higher risk in all but three cases where its effect was insignificant (See, for example, Lo Sasso and Johnson 2002; Borrayo, et al. 2002; Dunlop, et al. 2002; Laditka 1998; Phillips, et al. 2003; Reschovsky 1998a,b; Muramatsu and Campbell 2002; Allen, et al. 2001; Lee, et al. 2001) In studies of facility and community based post-acute care, ADL disability significantly increased risk in every study in which it was used. (See Yip, et al. 2002; Reschovsky 1998a; Gage 1999; Langa, et al. 2001; Fried, et al. 2001; Pezzin and Kasper, 2002; Henton, et al. 2002; Dunlop,, et al. 2002; Cagney and Agree, 1999; Picone and Wilson 1999.) The results in studies of hospitalization are mixed, although the majority of studies find that ADL disability is associated with higher risk of hospitalization (See Dunlop 2002; Aliyu, et al. 2004; Mor, et al. 1994; Wolinsky, et al. 1994). These findings confirm those of Miller and Weissert.

Findings from studies examining the risks of IADL disability are fewer, but in each one, for every outcome studied, IADL disability was found to increase risk. While Miller and Weissert found no consistent relationship to hospitalization risk, the one study we reviewed showed higher risk for the IADL disabled. (See Lo Sasso and Johnson 2002; Bharucha, et al. 2004; Dunlop, et al. 2002; Muramatsu and Campbell 2002; Allen, et al. 2001; Cagney and Agree, 1999; Picone and Wilson 1999; Mor, et al. 1994)

Self-rated health was used in relatively few studies, and was found to increase risks in only some of these. Miller and Weissert, in contrast, found that self-rated health had a strong relationship to institutionalization and hospitalization risks. (See Lo Sasso and Johnson 2002; Phillips, et al. 2003; Mor, et al. 1994) Cognitive impairment significantly increased risk of institutionalization in the studies examined by Miller and Weissert, and did so in 6 of the 7 studies we reviewed. (See, for example, Lo Sasso and Johnson 2002; Reschovsky 1998a,b; Miller, et al.1998)

Studies of the risks associated with a variety of chronic diseases were also relatively rare in our review, but in the cases in which there was overlap with the Miller and Weissert studies, our findings are generally consistent with theirs. Miller and Weissert find some increased risks of institutionalization associated with heart disease, hip fracture, dementia, mental disorders/depression, and digestive disorders. They find no increased institutionalization risk associated with cerebrovascular disease, cancer, arthritis, nervous system conditions (e.g., Parkinson's) or metabolic conditions (e.g., diabetes). The studies we reviewed generally show the same patterns, although the number in which these conditions were included was small and often focused on a single condition. The use of chronic conditions was far more common in studies of hospitalization risk (See Carter 2003a,b; Dunlop, et al. 2002; Culler, et al. 1998; Wolinsky, et al. 1994). Heart disease, respiratory disease, diabetes and stroke were found in multiple studies to significantly increase hospitalization risk.

Enabling Characteristics

The place in the framework where policy is most likely to have an effect on long-term care use is what Andersen and Newman term enabling factors. For individuals with health needs who are predisposed to use care, economic and policy factors combine to determine whether services are available and affordable. The individual level factors like income, wealth, and insurance coverage affect affordability, and thus demand. Market level factors affect price and supply. Federal, state, and local policy can affect both the demand and supply.

Miller and Weissert's review found relatively few significant relationships between enabling factors and use of nursing facilities or hospitals. Most of the studies they reviewed found no significant effect of income on either type of care. Home ownership was found to be inversely related to nursing facility use, but was not typically included in hospitalization studies. Insurance coverage, and in particular Medicaid coverage, was found to have few significant effects on either outcome, but when significant results were found, they indicate a positive relationship. On the supply side, nursing facility bed supply was found to be associated with increased nursing facility use in most cases studied, while hospital bed supply had no effect on any outcome studied. Facility characteristics were found to affect the outcomes of those already residing in a facility, though only in a few studies. Finally, state policy was rarely studied in the literature reviewed by Miller and Weissert, and among the studies including it, only one found a significant relationship between Medicaid eligibility and reimbursement policies and nursing facility use.

Our review of studies examining individual level (demand side) factors finds them consistent with the Miller and Weissert summary. Income, Medicaid eligibility/enrollment, and not owning a home were found to increase demand for nursing facility care. (Reschovsky 1998a,b; Jenkins 2001; Dunlop, et al. 2002). There were few significant effects of economic resources on PAC use or hospitalization risk, however.

Of the market level factors, while there were some findings of regional differences in risks of nursing, post-acute care, and hospitalization, there were few studies we reviewed that looked at market characteristics as a predictor of utilization. Of those that did, making generalizations about the findings is complicated by the variety of measures used and the specific research questions addressed. Taken together, there is some evidence that supply factors do affect utilization. For example, one study examined the effect of SNF beds on the use of Medicare home health and found an inverse effect. The same study found that the number of home health agencies in an area is positively correlated with the number of people using home health services (Picone and Wilson 1999). Another found that nursing facility beds and home health utilization are negatively correlated. Several studies and have found that hospital utilization increases in areas with more hospitals (Fisher, et al. 2000, 2003a,b; Intrator and Mor 2004). There is some research on the effect of nursing facility characteristics (e.g., staffing levels, profit status, and Medicaid reimbursement) on patient outcomes that tends to find significant effects (Carter 2003; Intrator and Mor 2004; Carter and Porell 2003; Zimmerman, et al. 2004).

Similarly, studies of policy variables are varied and not easily generalizable. Topics range from the effects of prospective payment systems and the effects of nursing facility construction moratoria and Social HMOs to and the percentage of state budgets spent on Medicaid and certificate of need requirements (Spector, et al. 2004; Murtaugh, et al. 2003; Fisher, et al. 2003a,b; Grabowski 2002; Cohen and Tumlinson 1997; Harrington, et al. 2000). As with market characteristics, published studies show results generally consistent with theoretical predictions of policy effects.

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CHAPTER III. COHORT DEVELOPMENT AND CROSS-COHORT METHODOLOGICAL ISSUES

This chapter introduces three study cohorts, which we aim to develop and use for the analysis of several specific research questions in this project. Below, we first define each cohort in detail and then discuss the rationale behind key definitional issues for each cohort. We then discuss four analytic measurement issues that cut across the cohorts and are preliminary to conducting our statistical analyses (functional status measurement, comorbidity measurement, characterization of potentially avoidable hospitalizations, and inclusion of measures of state waiver participation).

Cohort Overview

As noted in the project overview in Chapter I, this study relies on a newly available and synergistic combination of data,[15] which allow for the exploration of a wide range of acute care and long-term care policy and research questions. To analyze any given question, cohorts of similar individuals must be defined and extracted from the data. Cohorts can be selected from any period of time (up to the latest available data years) and from several types of criteria, such as disease state (e.g., congestive heart failure or stroke); functional state (e.g., ADL limitations); service utilization or event (e.g., hospitalization, ambulatory care utilization for a given chronic disease); or setting (e.g. nursing facility resident, user of community-based long-term care, etc).

Our process of developing study cohorts and identifying key research questions was informed by panel meetings and discussions with Medicare, Medicaid, and long-term care policy experts in CMS and in the research community; and by discussions with the project's clinical consultants. The policy discussions helped prioritize the project's policy applicability and key research areas. Our clinical consultants included three clinician/researchers, who provided real-world perspectives and clinical expertise in considering potential study populations, research questions, and clinically related outcomes and measurement issues. Appendix 1 highlights areas of input from the consultants. Two basic strategies further guided the development of the cohorts. First, we sought cohorts that are flexible enough to permit the analysis of multiple policy issues and research questions. This leverages the value of the data and the project resources. Second, we sought cohorts that are complementary. This leverages the value of the analytic findings and their implications, and reflects the breadth of our conceptual long-term care model.

Our first cohort is a national cohort of community-dwelling elderly hospitalized in 1999 with congestive heart failure. Key issues we will analyze for this cohort (which are described in Chapter IV's discussion of statistical analysis plans) include the determinants of long-term care use, type of use, and time to long-term care entry. Cohort 2 is a nationally representative sample of elderly with heart conditions selected from the 1999 Medicare Current Beneficiary Survey (MCBS). Key issues we will analyze here include the role of social and financial support in the entry into and types of long-term care use. Cohort 3 consists of all nursing facility entrants in

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[15] As noted earlier, the core data available for the project include nursing facility and inpatient rehabilitation facility patient assessment data (collected for all stays); home health agency patient assessment data (collected for publicly-covered episodes and intermittently for private episodes); analytic extracts of Medicaid claims and eligibility data; and Medicare claim and enrollment data.

1999, in a set of about four selected states. Example analyses here include identification of acute events that precipitated entry, and analyses of the course and quality of care following entry.

Cohort 1: Elderly Hospitalized for Congestive Heart Failure

The first cohort comprises all community-dwelling elderly whose first hospitalization for congestive heart failure (CHF) occurred in 1999.[16] Claims data prior to hospitalization are extracted for this population to construct comorbidity (or health risk) measures, and non-Medicare MDS assessments are scanned for 6 months prior to hospitalization to limit the cohort to community dwellers.[17] The primary proposed focus is to follow this cohort through their acute, post-acute, and long-term care encounters until long-term care entry, death, or the end of our available data (likely 2002). Thus, the cohort encompasses both users and non-users of long-term care, and allows for analyses of the risks for long-term care and the differences in care patterns between eventual long-term care users versus non-users.

Long-term care is identified in the data from the presence of non-Medicare MDS and OASIS assessments (and, non-Medicare assessments are identified by the lack of a corresponding Medicare SNF stay or home health episode). Using assessment data rather than Medicaid claims data to identify long-term care use permits the construction of a national cohort. Because of resource constraints, using Medicaid data would limit the cohort to residents in a small number of states.

Key considerations in designing this cohort include selection of the health condition; exact identification of the condition in the data (e.g., hospital principal diagnosis or principal and secondary diagnoses; hospital DRG assignments; any encounter's principal diagnosis or principal and secondary diagnoses); and time period for identifying the hospitalization (e.g., choosing a given year, versus identifying the first encounter). In addition to CHF, we gave serious consideration to stroke and hip fracture— two conditions also prevalent among the elderly, commonly treated in post-acute settings, and commonly found among long-term care users. Literature on the economic burden, care utilization, and risk factors for these three conditions are summarized in Appendix 1.

Selecting Congestive Heart Failure

Limiting this cohort to a specific condition was highly recommended by our clinical consultants, and is a first step in controlling for health status in our analyses on the cohort. We know from the literature and from the consultant input that the pattern of functional decline and acute care utilization can differ markedly across conditions (e.g., Lunney, et al. 2003), and the risk of, or time to long-term care entry may differ as well. We could construct the cohort to

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[16] Congestive heart failure is a clinical condition resulting from failure of the heart to maintain adequate circulation. It is manifested by pulmonary edema which is the result of excessive, diffuse accumulation of fluid in the alveoli and interstitial tissue of the lung. The inability of the heart to contract and relax normally causes pulmonary edema. This inability may be due to an underlying condition such as cardiac arrhythmia, long-standing hypertension, amyloidosis, hemachromatosis, chronic pericarditis, myocardial disease, or valvular disease.

[17] For example, Wang, et al.'s (1998) chart review of 231 CHF patients suggests that nursing facility residence is independently associated with earlier death and hospitalization compared to community-dwelling individuals.

include multiple conditions and then control for condition on the right-hand side of our statistical models, but the clinicians were concerned that this would obscure the identification and analysis of potentially divergent acute care and long-term care patterns.

We selected CHF for 4 main reasons. First, it is the leading condition in the community-dwelling and nursing facility elderly population. Additionally, there is a high level of interest in CHF among of the disease management community. Third, we sought a condition with a relative short "tail" of long-term care use so that our episodes would not be subject to right-censor data problems. As additional years of assessment data and Medicaid analytic extracts become available, conditions with longer average long-term care utilization will not be as subject to this problem. Finally, CHF was one of several conditions recommended by our clinicians. The first two issues are discussed here.

CHF is a leading cause of morbidity and mortality in the US— about 4.6 million individuals have CHF and about 550,000 new cases are diagnosed each year (Weintraub, et al. 2002). The condition accounts for about 957,000 hospitalizations annually. Over the last decade, CHF hospitalization rates among the elderly rose above their overall hospitalization rate (Kozak, et al. 2001). Rehospitalization accounts for a large share of CHF hospital encounters—about 30% to 50% of elderly are readmitted within six months after their initial hospital discharge (Shah, et al. 1998). AHRQ estimates that about 795,000 elderly with CHF had preventable hospitalizations in 1999, costing the Medicare program an estimated $4.6 billion in hospital payments (Foote 2003). About 14% of beneficiaries in traditional Medicare have CHF. Their per capita total Medicare spending averaged about $16,000 in 1999, over 3 times the overall Medicare per capita spending of about $5,000.

In addition to being both the leading principal diagnosis and DRG of Medicare hospitalizations (Table III-1), CHF is the fourth most common principal diagnosis among SNF admissions (behind breathing exercises, hip fracture, and acute cardiovascular disease); and the sixth most common principal diagnosis of physician services (behind diabetes, metabolic imbalances, hypertension, other chronic heart disease, and cardiac dysrhythmias).[18] Patients hospitalized for CHF comprise a very large *volume* of post-acute users, ranking third in the number of live DRG cases admitted to post-acute care in 1996, behind hip or knee replacement and stroke. CHF does not rank as high (19th in rank) in terms of the *share* of live DRG cases discharged to post-acute care (MedPAC 1998). National data on the admitting diagnosis among long-term nursing facility residents were not found, but the major diagnostic category (MDC) that comprises CHF (diseases of the circulatory system) accounted for 23% of Medicaid-covered nursing facility resident admissions in 1997. For comparison, that MDC is the most common MDC of elderly hospital admissions, SNF admissions, and physician visits, accounting for 29%, 21%, and 17% of those provider encounters, respectively, in 1999.

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[18] Acute hospital, SNF, and physician services statistics are from Health Care Financing Review *Statistical Supplement, 2001 (CMS 2003)*, Table 27 (acute hospital), Table 41 (SNF), and Table 63 (physician services).

Table III-1: Top Ten DRGs, 1999

DRG	Description	Total discharges (#)
127	Heart failure and shock	676,145
89	Simple pneumonia and pleurisy, age>17 with CC	544,490
88	Chronic obstructive pulmonary disease	411,275
209	Major joint and limb reattachment procedures of lower extremity	340,300
14	Specific cerebrovascular disorders except transient ischemic attack	329,430
116	Other permanent cardiac pacemaker implant or PCTA with coronary artery stent implant	311,335
430	Psychoses	302,195
462	Rehabilitation	251,750
182	Esophagitis, gastroenterology and misc digestive disorders, age >17 with CC	237,215
296	Nutritional and miscellaneous metabolic disorders, age>17 with CC	237,100

Source: Health Care Financing Review Statistical Supplement, 2001 (CMS 2003), Table 29.

Given the health and economic burden of CHF, the condition is a leading subject in the clinical research literature, and also of health plan and provider development of chronic disease management programs. Disease management programs are a growing strategy of both private and government providers and payers to help improve care quality or quality of life and to control expenditures. In the private sector in 2001, 97% of health care plans were using at least one disease management program, and 50% had implemented programs for 4 or more conditions. Programs for CHF were the third most common program type (behind diabetes and asthma), with 83% of plans having a CHF program (Center for an Aging Society, 2004). Currently, nearly one-half of all states are using or developing disease management programs for their Medicaid programs (National Governors Association, 2003). On the federal level, CHF is one of the conditions addressed in 11 of 15 coordinated care demonstrations that are being conducted under traditional Medicare (Foote 2003).

The disease management programs of commercial health plans and state Medicaid programs generally have not been formally evaluated (Foote 2003), and the federal demonstrations are just getting underway.[19] Analyses of this cohort could be potentially useful to the design and implementation of these large-scale programs, for example by yielding longer-run information about care patterns and functional trajectories. This is in contrast to the generally shorter time frame represented in the clinical research literature on the outcomes and cost-savings of CHF hospitalization prevention studies. The large-scale CHF programs developed by health plans are largely based this literature. Our MEDLINE search identified hundreds of clinical studies on hospitalization prevention programs, over 10 fairly recent randomized trials, and several reviews and meta-analyses of the studies and trials.

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[19] Disease management industry representatives recently highlighted the success of Florida's Medicaid CHF management program during Congressional testimony. The program is associated with a 39% decrease in hospitalization days among participants over a two year period, yielding a net savings of $4.4 million (Selecky 2003).

CHF management programs are designed to prevent CHF rehospitalizations through activities such as nurse management and monitoring, and patient education and self-monitoring. In those with advanced CHF, for example, weight monitoring and immediate intervention to avoid fluid buildup around the heart is a critical aspect of management and hospitalization prevention (Nohria, et al. 2002). Case monitoring and patient education regarding adherence to drug therapy is another key component, along with diet and exercise, depression management, and smoking cessation. Outcomes measured in the literature typically included the number of hospitalizations over a given period (often 3, 6, or 12 months); costs associated with the admissions; and measures of quality of life such as fatigue, depression, and sense of control over the condition. Most of the reviews and meta-analyses of the programs indicate significant decreases in hospitalization and thus costs associated with CHF, and moderate improvements in quality of life (e.g., Phillips, et al. 2004; Balinsky and Muennig 2003; Grancelli, et al. 2003; Ahmed 2002a,b; McAlister, et al. 2001; Rich 1999; and Philbin 1999).

In contrast to the large number of studies on medical management and hospitalization prevention for CHF patients (and the vast amount of literature on drug therapies for CHF), the literature specifically regarding CHF individuals' use of long-term care appears to be quite limited. Among the few studies identified, Ahmed, et al. (2002) analyzed the hospitalizations of nursing facility residents with CHF; Ahmed (2003) examined care quality for nursing facility residents with CHF; and in another study Ahmed, et al. (2003) studied nursing facility admission following hospitalization. (As we frequently found in the "nursing home" literature, this study surely reflected Medicare-covered SNF admissions, even though the authors termed them only "nursing home" admissions.) Nonetheless the study yielded insights regarding the CHF long-term care population in its finding that 80% of those discharged to (presumably) SNF care were nursing facility residents prior to hospitalization.

Using ICD-9-CM Codes to Define the Cohort

Two main interrelated issues in the definition of the cohort are: 1) whether elderly beneficiaries are selected based on the presence of any Medicare CHF encounter (in either Part A or B claims) or on only hospitalizations with CHF as the principal diagnosis; and 2) whether the cohort comprises individuals starting at their first CHF diagnosis (or first CHF hospitalization) or individuals selected over a given period (such as a particular year) regardless of date of onset of the condition.

Ideally, we would define the cohort using individuals' initial diagnosis of CHF. This definition captures those who have CHF but are never hospitalized, and allows for analysis of the entire utilization and expenditure trajectory of individuals with CHF. There are two main problems with this definition, as applied to our project data. First, we must balance the benefits of this ideal design against the resource intensity and time consumption in scanning the universe of Medicare Part B claims (an extraordinarily large file) and in scanning those claims for the multiple years necessary to identify first diagnoses. Second, we are concerned that these "start dates", or first diagnosis dates, would result in long-term care use among some cohort members before the national availability of our MDS assessment data (January 1999). We prefer to analyze long-term care use after that date, to ensure availability of the MDS data. Relatedly, if only post-1998 (post-MDS) disease onset cases are used, we may have right-censor data problems, in that our data file may end before long-term care entry occurs for some cohort members. A second option is to define the cohort based on presence of any CHF diagnosis in 1999. This option would reduce the amount of scanning necessary on the universe of Part B claims, would ensure that MDS assessments are available for users of SNF and nursing facility care, and would capture individuals who never are hospitalized for CHF. The clinical concern with this option is that it introduces a false disease onset date; in addition this definition still requires the resource-intensive scanning of the universe of Part B claims.

Instead, we define the cohort as one consisting of individuals who incur their first, or index, CHF hospitalization (as classified in the principal diagnosis field) in 1999.[20] We isolate index admissions by scanning the prior five years of admissions for the given individual, counting back from the month that the 1999 hospitalization occurred (or earliest month, if multiple CHF admissions occurred in the year). Scanning a five-year look-back window is chosen because the median survival time of CHF is roughly five years past diagnosis (or, the five year mortality rate is about 50% to 60%). First CHF hospitalization is clearly a meaningful and sentinel event in the course of CHF, and thus is a rational starting point (other than first CHF diagnosis) for longitudinal assessments of patients' health and functional characteristics and their medical and long-term care use. We select 1999 as the base year to ensure MDS availability for SNF and nursing facility stays. Some right censoring will occur in this design, but less so than with a first-diagnosis cohort. The one-year mortality rate after index hospitalization is about 33% (Jong, et al. 2002), and the two-year rate is about 60% to 70%. As seen in the cohort 3 discussion below, we intentionally capture in that cohort any non-hospitalized individuals with CHF (as well as hospitalized individuals) who enter nursing facilities for long-term care. Finally, we note that some articles in the clinical literature define CHF hospitalizations as those reimbursed under DRG 127 rather than using ICD-9-CM diagnosis codes. Our approach regarding this is guided by input from our clinical consultants. Ultimately, we define the cohort using the principal diagnosis field because it produces a meaningful cohort based on the clinical reason for hospitalization rather than the treatment regimen and level of payment received by the hospital.

Comparing the three main alternatives in defining the cohort, our method addresses our concerns about using project resources efficiently, identifying meaningful start dates, capturing SNF and long-term care use after MDS data are available, capturing long-term care entry on a population before right-censor data problems are likely to occur in our data, and (through cohort 3) including analyses of both hospitalized and non-hospitalized CHF patients who use long-term care.

Cohort 2: Elderly with Heart Disease (MCBS Respondents)

As we know from the literature, contextual information regarding an individual's system of social support and economic status is an important determinant in the use of formal long-term care, controlling for functional status and other direct measures of health. While the patient assessment data available in this project includes functional status and other assessment information, the information is collected only on users of SNFs, nursing facilities, IRFs, and home health agencies. Also, the assessment instruments' questions on a given domain vary, and

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[20] ICD-9-CM codes indicating CHF are shown in table IV-1.

thus the information collected is not uniform across care settings. One desirable avenue in this project, then, is to merge a survey dataset with the core data of claims and assessments, to capture uniform and universal functional status data, as well as additional contextual information that is important to long-term care analyses.

To address this, the second cohort comprises elderly respondents in the 1999 MCBS. We intentionally select a cohort for forward-looking analyses similar to the analyses on cohort 1. Thus, the main focus is to follow the population through the course of their Medicare and long-term care encounters, and enable analyses related to the risk of and entry time to long-term care. Given the survey release schedule, the cohort will be followed through 2000 (and possibly through 2001). With the survey information linked to the claims information, we will be able to assess the relative association of the various domains of factors (diagnostic, functional, economic status, social support, etc) in the risk and use of long-term care.

In addition to allowing for a broader range of right-side variables, this survey-supplemented cohort expands on the cohort 1 definition in two key ways. First, it consists of survey participants who have any of six heart or heart-related conditions: hardening of the arteries, hypertension, myocardial infarction, angina pectoris/coronary heart disease, “other” heart conditions, and diabetes (because it often is a precursor to hypertension and heart disease) (Table III-2).[21] Comorbidity controls become increasing important in this cohort relative to cohort 1. However, the broader condition definition is statistically necessary because of the small sample size of a survey-based cohort relative to a claims-based cohort.

Second, in this cohort the diagnosis can have occurred at any time prior to the base year (1999), because we will use the survey respondents’ answers to questions regarding whether they “ever” have been told by a physician that they have the condition(s). This cross-section of individuals, in terms of placement on the disease and functional continuum, is desirable in this cohort because right-censoring data problems with the survey would occur in an “index diagnosis” cohort definition.

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[21] As a check on the sensitivity of our findings, analyses will also be run excluding persons who report only diabetes without other cardiovascular conditions.

Table III-2: Prevalence of Medical Conditions among MCBS Respondents, by Institutional Status, 2000

	Community		Nursing Facilility		Total		
Condition	Number	Percent	Number	Percent	Number	Percent	**Total as Percent of all Respondents**
Hypertension	**5,932**	**94**	**402**	**6**	**6,334**	**100**	**58**
Arthritis	5,922	97	215	3	6,137	100	57
Other Heart Conditions	**3,195**	**100**	**0**	**0**	**3,195**	**100**	**32**
Cataract Surgery	2,616	97	91	3	2,707	100	25
Cancer/Tumor	1,891	97	54	3	1,945	100	18
Diabetes	**1,795**	**92**	**160**	**8**	**1,955**	**100**	**18**
Osteoporosis	1,580	93	125	7	1,705	100	16
Myocardial Infarction	**1,535**	**95**	**82**	**5**	**1,617**	**100**	**15**
Angina Pectoris/CHD	**1,448**	**96**	**61**	**4**	**1,509**	**100**	**14**
Emphysema, Asthma, COPD	1,416	92	115	8	1,531	100	14
Hardening of Arteries	**1,207**	**92**	**107**	**8**	**1,314**	**100**	**12**
Stroke	1,178	91	123	9	1,301	100	12
Rheumatoid Arthritis	1,041	100	0	0	1,041	100	10
Mental Disorder	711	89	92	11	803	100	7
Broken Hip	418	90	47	10	465	100	4
Partial Paralysis	407	31	918	69	1,325	100	12
Alzheimer's	320	65	176	35	496	100	5
Parkinson's	139	72	54	28	193	100	2
Amputation (Arm or Leg)	111	90	12	10	123	100	1
Mental Retardation	26	100	0	0	26	100	0

Note: Conditions selected for cohort three are in bold.

Source: Urban Institute analysis of MCBS Cost and Use File, 2000

Selection of Survey Source

We select the MCBS for this cohort but also considered in particular the Health and Retirement Study/Study of Assets and Health Dynamics Among the Oldest Old (HRS/AHEAD and the National Long Term Care Survey (NLTCS). We selected the MCBS for three overriding reasons. First, it is repeated annually, compared with every five years for the NLTCS and every two years for the HRS/AHEAD. Second, it can be linked with the project's core files of assessment data, Medicare claims, and Medicare enrollment data. (Linking with Medicaid is not feasible in this project, given the number of states that would be necessary to link to ensure a sufficient sample size). The NLTCS is linked with Medicare claims and enrollment data; claims linkage on the HRS/AHEAD has been delayed by HIPAA concerns. Finally, the MCBS includes Medicare beneficiaries in both the community and facilities, in contrast to the HRS/AHEAD, which is a survey of the noninstitutional population.

The MCBS is a nationally representative survey of Medicare beneficiaries residing in the community or facilities, conducted by Westat, Inc. for the Centers for Medicare and Medicaid Services. It is a rotating longitudinal panel survey that follows representative samples of Medicare beneficiaries over a four-year period. The annual sample is about 12,000 persons, including an over-sample of those age 85 or older. The AHEAD survey is a nationally representative longitudinal household survey of persons born before 1924, conducted by the University of Michigan for the National Institute on Aging. Individuals were first interviewed in 1993. In 1998 the survey was merged with the companion Health and Retirement Survey, which began in 1992 with a cohort of persons age 51 to 61, and augmented, to represent the entire population age 51 or older. The survey has particularly extensive information on respondents' social support and financial situation. The NLTCS is a nationally representative survey of elderly Medicare beneficiaries conducted by the Census Bureau under the direction of Duke University Center for Demographic Studies and funded mainly by the National Institutes on Aging. The survey focus is on identifying those who are chronically disabled in one or more ADLs or IADLs, and collecting detailed information on their demographic characteristics and social, physical, economic, and long term care situation. It is designed to produce cross-sectional and longitudinal estimates for studying change in the health and functional status of the elderly, as well as identifying the availability of personal, family, and community resources for caregiving.

There are pros and cons of using these different surveys. Key advantages of using the MCBS include the ease of merging the survey data with other administrative data, the presence of several common survey items across the community and facility residing respondents, as well as availability of functional status and contextual information regarding respondents. The main weaknesses are its somewhat small sample size regarding beneficiaries identified as disabled or using long-term care and the four-year followup. The key strengths of using the AHEAD survey are its longitudinal framework and its uniquely detailed information on the socioeconomic status of the elderly, in addition to questions regarding health and functional status. The main limitations of the study are its small sample size of disabled elderly (relative to the MCBS and NLTCS), its lack of facility-residing respondents, and difficulty in currently obtaining permission to link the survey data to our core project data. The survey leaders indicate that these linking opportunities will be finalized in the near future. Key advantages of the NLTCS are its large sample of disabled respondents (e.g., roughly 1,000 facility-residing, 5,000 community-residing respondents, and 3,000 chronically disabled respondents in the 1999 survey wave), and the rich contextual information. Its main limitations are that it is a periodic rather than annual survey, and that many of the survey items (particularly health condition items) are not consistent or not available for institutional respondents.

Overall, each of these surveys would provide uniquely valuable information to this project and would accommodate somewhat different types of analyses and research questions on the progression and use of long-term care. Incorporating all three surveys at the outset would be redundant. Each survey would add valuable functional status and contextual data, however, and is worthy of consideration for future analyses in the project. Given the selection, we describe the MCBS more fully here. Appendix 2 provides detail regarding the AHEAD and NLTCS surveys.

Medicare Current Beneficiary Survey

Westat, Inc. annually conducts the MCBS for CMS. The survey collects information on a nationally representative sample of Medicare beneficiaries residing in the community or facilities. Key advantages of potentially using the MCBS with this project include the ease of merging the survey data with other administrative data, the common survey items among both community and facility residing respondents, as well as its functional status and contextual information regarding respondents. The main weakness is its somewhat small sample of beneficiaries identified as disabled or using long-term care.

The MCBS is a rotating longitudinal panel survey that follows representative samples of Medicare beneficiaries over a four-year period. The annual sample is about 12,000 persons, including an over-sample of those age 85 or older (Adler 1994; Laschober and Olin 1996; CMS 2002). A supplemental sample is drawn and interviewed in the fall of each year (September through December) to replace participants being retired from the sample, to replenish cells depleted by refusals and death, and to correct for coverage errors in the initial sampling frame (CMS 2002). Since 1994, the supplemental sample has been representative of beneficiaries alive and eligible on January 1 of the survey year. The full sample represents all beneficiaries who were enrolled in Medicare during the calendar year. Weights are constructed to be used for full-year and round estimates.

The "Cost and Use" component of the MCBS contains a wide range of information on the survey participants, including data regarding health status, supplemental insurance information, income, prescription drug expenditures, out-of-pocket expenditures, social support, as well as health care use and Medicare program payments. For beneficiaries in fee-for-service Medicare, the health care encounter and payment data from the survey are reconciled with participants' actual Medicare claims. For each respondent, an initial baseline interview elicits information on non-changing characteristics (such as date of birth, gender) and the core survey questionnaire, administered each fall between September and December, provides information on personal and health characteristics that change over time (such as income, living arrangement, and health and functional status).

The health-related survey questions include items on overall health status (such as self reported health status, presence of selected medical conditions), service use (such as counts of admissions or health system encounters, by type of provider), and functional status. Functional status is measured using ADL and IADL items. ADL items capture limitations in personal care, while IADLs (such as housework, meal preparation, financial management) capture limitations more related to the ability to live independently (Lawton and Brody, 1969). The MCBS asks individuals whether they receive any personal assistance or supervision in conducting the activities. Five ADLs (bathing, dressing, toileting, transferring, and eating) and three IADLs (telephoning, shopping, and money management) are used in facility interviews. As noted below, additional ADL questions were added in the 1997 survey round.

The MCBS also tracks respondents' changing residence, or institutional status. Initial interviews, whether conducted in the community or in a facility, are conducted and for each year a time line noting changes of residence is constructed for each person. This tracking is useful in conducting analyses of long-term care lengths of stay, episodes, and overall pathways. For respondents in institutions at the time of the survey, the MCBS also collects information about facility characteristics (such as number of beds, ownership) and types of services routinely furnished by the facility (such as nursing or medical care, supervision of self-administered medications, assistance with ADLs, or 24 hour supervision or nursing).[22] In the 1997 and later survey rounds, the survey timeline also specifies Medicare-covered or skilled stays in facilities, in addition to residential or long-term care stays in facilities. In prior years, SNF stays were not identified or incorporated in the timeline (although they can be identified by merging survey data with the respondents' SNF claims).

Also in 1997 and later survey rounds, the MCBS modified the medical condition, ADL, and IADL questions for participants residing in facilities so as to be more consistent with the MDS assessments required on all patients in Medicare-certified or Medicaid-certified nursing facilities. Information was taken from the most recent MDS assessment, if available, and otherwise from the admission assessment. Regarding medical conditions, the list of conditions was changed to correspond to the medical conditions section of the MDS instrument. Regarding ADLs, before 1997 respondents were asked whether the individual had difficulty performing each ADL "by himself/herself and without special equipment" because of health or did not do the activity because of health, and if health-related difficulty was reported, whether help or supervision was received for the activity. As of 1997, facility respondents were also asked to provide levels of dependency for each ADL, from independent to totally dependent (or the activity did not occur). There is no direct determination of health reasons if the activity did not occur. Regarding IADLs, before 1997 respondents were asked whether the individual had difficulty doing each IADL without help because of health or did not do the activity because of health. There was no follow-up question regarding whether help was received. The two changes would have a tendency to increase the number of persons reported to be dependent in IADLs or ADLs, but it is not clear that the difference would be large within the population living in long-term care facilities.

Cohort 3. Elderly Admitted to Nursing Facilities

The third cohort comprises all elderly who are newly admitted to a nursing facility, either as Medicaid-covered or private pay residents, in 1999. If multiple admissions are identified for an individual during 1999 then the first admission will be selected. Twelve months of patient assessment data and/or Medicaid claims will be scanned prior to the date of an individual's entry in 1999, to restrict the cohort to truly "new" entrants. (MDS data are not available for all facilities in all of 1998, but Medicaid claims will not identify any prior private-pay admissions.) Twelve months of prior Medicare data will be extracted, to construct baseline comorbidity measures and to permit limited analyses of pre-admission Medicare service patterns,

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[22] The MCBS defines a facility as having three or more beds and providing long-term care services throughout the facility or in a separate unit (CMS 2002). In addition to nursing facilities, long-term care facility types identified in the MCBS facility data are retirement home, domiciliary/personal care, mental health facility, institution for the mentally retarded/developmentally disabled, mental health center, life care/continuing care, assisted living facility, rehabilitation facility, and "other place".

expenditures, principal diagnoses, and DRGs.[23] The pre-admission Medicare utilization period in this cohort provides a bridge to cohort 1, by permitting analyses of the subset of individuals in this cohort who have CHF but were not hospitalized prior to nursing facility admission.

Our primary analytic focus of cohort 3 is to assess the trajectory of health events and expenditures from entry until either death or the end of our file (likely through 2000, given Medicaid data availability lags); the determinants of and time to Medicaid enrollment; and MDS-based indicators of functional status and care quality. Both one-year and two-year follow-up periods will be used from the date of entry. Policy-relevant covariates of interest in this cohort include resident payer status and facility characteristics, such as MDS-based and case-mix adjusted measures of facility quality (Table III-3). While hospitalization rates and survival rates of nursing facility residents are fairly common analyses in the nursing facility literature, our analyses of Medicaid spend-down and our use of CMS's nursing facility quality measures will in particular extend the literature on nursing facility use.

Table III-3: Enhanced Quality Measures for Nursing Facilities, 2004

Percent of long-stay residents:

-- whose need for help with daily activities has increased
-- who have moderate to severe pain
-- who were physically restrained during the 7-day assessment period
-- who spent most of their time in bed or in a chair during the 7-day period
-- whose ability to move about in and around their room declined
-- with a urinary tract infection
-- with worsening of a depressed or anxious mood
-- who have pressure sores (high risk and low risk measured separately)
-- who lose control of the bowel or bladder (low risk) and percent who have a catheter inserted during the 14-day period

Percent of short-stay patients:

-- who experienced moderate to severe pain during the 7-day assessment period.
-- with symptoms of delirium
-- with pressure sores

Meausures applying to all facilities: percent of:
-- elderly residents with pneumococcal polysaccharide vaccination
-- all residents with influenza vaccination

Source: CMS Nursing Home Quality Initiative, January 2004 available at http://www.cms.hhs.gov/quality/nhqi/

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[23] For example, in a Medicare claims study on 85,000 elderly nursing facility residents with CHF, Gambassi, et al. (2000) found that about two-thirds were hospitalized in the year prior to entry for coronary heart disease, hypertension, or other causes related to CHF.

To permit analyses of total public spending as well as to clearly identify conversion to Medicaid payer status, this cohort's analyses will use Medicaid claims data, along with Medicare claims and patient assessment data. Medicare and Medicaid enrollment files will be used to track dual-eligibility status. Using Medicaid claims also permits identification of transitions from nursing facilities to community settings for long-term care over the course of the follow-up periods (e.g., through tracking of claims for waiver services or for home care). The resource intensity associated with processing Medicaid data requires that we limit in this project the cohort to be drawn from roughly 4 states.

Summary

These cohort selections reflect a cumulative activity of literature review and policy and clinical discussions, as well as knowledge of the data sources involved. Our goal has been to construct three study populations that are flexible enough to permit the analysis of multiple policy issues and research questions, that overlap to some degree in terms of their clinical conditions and analyses that can be conducted on them, but yet are complementary in terms of the covariates available for study and the major issues that would be the likely focus of study on each cohort.

Cohorts 1 and 3 are complementary in multiple aspects. Regarding clinical conditions, cohort 1 consists only of hospitalized CHF patients, while cohort 3—a cohort of all nursing facility entrants-- includes the subset of CHF patients who were not hospitalized and ultimately enter nursing facilities. Regarding long-term care use, cohort 1 includes elderly at risk for long-term care, while cohort 3 comprises nursing facility entrants. Regarding care trajectories, cohort 1 focuses on the paths to long-term care entry, while cohort 3 focuses mainly on care and outcomes following nursing facility admission. (As mentioned above, limited analyses on the pre-entry period will provide a bridge between the two cohorts.) Cohorts 1 and 3 differ in terms of our proposed data sources and their national representativeness. Cohort 1 is a national cohort of patients (with CHF) at risk for long-term care, using all 50 states' and Washington DC's assessment data and Medicare claims data. Cohort 3 is drawn from a subset of states' Medicaid data (as well as assessment and Medicare claims data). This allows for analyses of total public spending, and identification of Medicaid home health use, waiver participation, and prescription drug expenditures.

Cohort 2 is designed to overlap and expand on cohort 1, both in terms of the cohort population and the range of covariates available for analysis. Cohort 2 expands on cohort 1 by including elderly ever identified at any health care encounter with any of five conditions related to heart disease. It further expands on the first cohort's range of available covariates by using MCBS survey data (in combination of patient assessment data and Medicare claims). The claims and assessment data will allow us to analyze, to the same level of detail as in cohort 1, the risk for long-term care use and individuals' trajectories of care. But survey information on, for example, out-of-pocket spending, income, insurance status, social support, as well as universally available information on functional status will enhance our understanding of the interaction of acute and long-term care and factors associated with use of long-term care. While it is possible to link Medicaid data with these data, the survey sampling methodology does not permit a statistically sufficient sample size using the number of state Medicaid files we propose to use.

Cross-Cutting Measurement Issues

Some variable measurement issues cut across the three cohorts we propose, and are preliminary to our statistical models analyses described in Chapter IV. In this section, we discuss four such issues—functional status measurement; comorbidity (or health status or risk) measurement; characterization of hospitalizations as potentially preventable or avoidable; and consideration of section 1915(c) Medicaid waiver participation.

Functional Status

Following Nagi (1965, 1991), most functional status tools measure limitations in physical mobility, however a wide range of specific tools is used in the literature (Table III-4). This range reflects in part the variety of objectives of the tools, such as identifying inpatient or outpatient rehabilitation potential, identifying nursing staff resource needs, or capturing a general concept of disability or of functional limitation. We identified functional status measurement tools applied in the literature that range from using one to 30 ADLs; that use two (most frequently), three, and four or more measurement levels; and that use either self-reports of usual performance or assessors' reports of peak performance. Weightings of the activities vary across scales as well, and in some cases scales are not used and individual ADLs are used as separate covariates. Even when a specific activity is the same across tools, the tools typically differ in the wording or the scaling of the limitation. It is clear that functional status is a critical determinant in the risk and use of long-term care. But as noted in Chapter II, the range across the literature in the methods used for measuring functional status and in the comprehensiveness of models analyzed makes it extremely difficult to generalize regarding the size and relative magnitude of the factor's importance.

While the use of a common measurement method would aid one's interpretation of the literature, researchers must consider their own measurement objectives (as well as their own resources and data sources) in selecting a measurement tool. For example, if functional status is to be analyzed across assessment methods (such as across OASIS and MDS patient assessment data), then one may want very basic indicators of functional limitation (e.g., presence/absence of bathing limitation, presence/absence of eating limitation) in order to avoid overinterpretation of differently worded questions and measurements of a single activity of limitation. If a single assessment instrument is always or primarily used, then more refined measures may be preferable. An appropriate tool should be one that was developed on a population very similar to one's research population (Van Swearingen and Brach 2001).

In the nursing facility literature we reviewed, some examples of functional status tools used are the number of ADL limitations (Reschovsky 1998a, 1998b), a sum of ADL limitations (Rubderg et al., 1996), and a sum of ADL and IADL limitations then split into three levels (Dunlop, et al. 2002). The number and selection of specific ADLs vary across studies as well. In studies on SNF patients, some tools used have included the Short-Form 36 (Yip, et al. 2002), an index of three ADLs (Arling, et al. 2000), and the Rehabilitation Outcome Measure (Angelelli, et al. 2000). Other functional status scales found in the course of our review include a weighted continuous measure (Hadley, et al. 2000), the Katz index (Levenson, et al. 2000) and the Kansas City Cardiomyopathy Questionnaire (Turvey, et al. 2003). A scale used frequently in the rehabilitation research literature is the Barthel index of physical functioning (Mahoney and Barthel 1965).

Some scales used for provider payment also are used as control variables in the literature. The Resource Utilization Groups, Version III ADL scale used in the SNF PPS uses 4 late-loss items (eating, toileting, bed mobility, and transferring) collected on the MDS. It was developed to predict nursing staff resource use among residents in nursing facilities, hence its emphasis on late-loss items. The Functional Independence Measure was developed to assess improvement in function of patients in the inpatient rehabilitation research and care setting. Partly since it is predictive of inpatient length of stay and stay costs, it is used in the Medicare PPS for inpatient rehabilitation facilities. The Physical Function Scale-10 is used in many outpatient rehabilitation settings and settings. (Medicare payment for outpatient rehabilitation is based on the Medicare physician fee schedule).

In choosing functional status measures in our analyses, we will construct measures using a generic tool, but also will test the use of more targeted measurements for the cohort and research question. In analyses that span MDS and OASIS assessment data, we will have to use very basic indicators of limitation in single activities and simple counts of the indicators.

Table III-4: Functional Status Measurement Tools: Examples from the Literature

Name	Variables Used	Description	Example References
Barthel ADL Index	Ten-item ADL measure includes: Mobility Transferring Toileting Bladder Bowel Eating Bathing Grooming Dressing Stairs	The original ten item index has a 3 point ordinal rating scale. Each item is rated in terms of whether the patient can perform the task independently, with some help, or is dependent on help (0 = unable; 1 = needs help; 2 = independent). An overall score is formed by summing scores on each rating. The Barthel index ranges from 0 (total dependence) to 100 (independent) in steps of 5. When computed from MDS, maximum value is 90 since ascending/descending stairs is not on MDS. An expanded 15 item version exists (Granger 1979, 1984; Fortinsky 1981), as well as a 1981 Granger version using a four-point response scale. Other modifications include a 3 point scale with total scores ranging from 0 to 20 (Collin, et al. 1988).	Mahoney and Barthel (1965). Functional Status Toolkit, Brown University, www.chcr.brown.edu/pcoc/functi.htm DataPro documentation
Functional Independence Measure (FIM)	13 functional items include: Bed/ Chair Transfer Tub/ Shower Transfer Toilet Transfer Toileting Bladder Bowel Eating Bathing Grooming Dressing/ upper Dressing/ lower Stairs Walking/ Wheelchair loco. 5 Cognitive items: comprehension expression social interaction problem solving memory	13 individual physical items (each rated 1 to 7) that measure independence in physical functioning. The FIM was based on the Uniform Data System for Medical Rehabilitation (UDS). The physical items were based on the Barthel Index. The original 18 item FIM Instrument includes 5 cognition items covering social interaction, problem solving, and memory. An alternative scoring approach argues that the 13 physical items should be scored separately from the 5 cognitive items (Linacre and Heinemann). MDS limitations: Tub/Shower Transfer and Toilet Transfer are included in MDS Bathing and Toileting ADLs, not broken out separately. MDS Dressing ADL includes upper and lower body and stairs is not on MDS.	Linacre, et al. (1994) Eilerstein, et al. (1998) Relles, et al. (2003) Functional Status Toolkit, Brown University, www.chcr.brown.edu/pcoc/functi.htm

Table III-4 (continued). Functional Status Measurement Tools: Examples from the Literature

Name	Variables Used	Description	Example References
Katz Index (Index of Independence in Activities of Daily Living)	Six Functions include: Transferring Feeding Toileting Bathing Continence Dressing	The index ranks adequacy of performance in six functions. Clients are scored yes (1) / no (0) for independence in each function. A score of 6 indicates full function; 4 indicates moderate impairment, and 2 or less indicates severe functional impairment. Scale has also been adapted as a Likert-type scale with each item assigned points according to a defined decision rule (e.g. 0 = no help needed; 1 = uses a device; 2 = needs human assistance; 3 = completely dependent) (Kane, 1985).	Shelkey and Wallace (1998) Katz, et al. (1963) Finch, et al. (1995) Functional Status Toolkit, Brown University, www.chcr.brown.edu/pcoc/functi.htm
MDS ADL Scales	MDS Short Form ADLs: Personal Hygiene Locomotion Toileting Eating MDS Long Form ADLs: Personal Hygiene Dressing Toileting Transfer Locomotion Bed Mobility Eating Self-Performance Hierarchy categories: Independent Extensive 2 Supervision Dependent Limited Total dependence Extensive 1	One hierarchical and two additive ADL scales were created. The MDS ADL - Long Form includes all seven of the ADL items with a range of 0 to 28. The MDS ADL - Short Form includes 4 items with one from early loss (personal hygiene), middle loss (toileting), middle loss movement (locomotion) and late loss (eating) ADLs. This scale has a range of 0 to 16. The MDS ADL Self-Performance Hierarchy is more complex. The hierarchical scale is a seven category scale that employs the four ADL items used in the MDS ADL - Short Form. It is based on a synthesis of the most consistent specification of early, middle, and late loss ADL items seen in the factor analysis and hierarchy.	Morris, et al. (1999)
RUG-III Index	Four ADLs from MDS: Bed Mobility Toileting Transferring Eating	Additive scale from 4 (independent) to 18 (total dependence).	1995-1997 Staff Time Measurement Study
Wolinsky Basic ADL Index	Five-item ADLS measure incorporates: Transferring Dressing Toileting Walking 20 feet	This assessment of function focuses on self-reported difficulty in ADL performance. Originally derived using data from the Longitudinal Study on Aging.	Wolinsky and Johnson (1991) Johnson, et al. (2001) Kramer, et al. (1997b)

Comorbidity

Scales and indices aiming to best use ADL information have been developed, tested, and frequently are used in the long-term care literature to measure functional status. Similar scales, as well as more complex systems, have been developed to exploit diagnostic coding information (Table III-5). Our review suggests that diagnosis measurement tools are used less frequently than functional status tools in the long-term care literature. Because functional status information is not uniformly and universally available in our data (except on the MCBS cohort), however, it may be particularly important to fully exploit our uniformly available diagnostic data. Studies using more complex measurements of comorbidity, have shown that the relative power of functional status over comorbidity in predicting outcomes such as mortality, nursing facility admission, and charges is typically smaller than when using simpler measures of diagnosis (e.g., McCall and Korb 1998; Fowles, et al. 1994).

The International Classification of Disease (ICD) diagnosis codes on the claims data provide a wealth of potential information for controlling for comorbidity in our analyses. Claims data diagnoses have been found to be highly reliable and valid in studies comparing them with medical records in the hospital and physician practice settings in particular. The decimal structure of the coding system itself allows for aggregated levels of descriptions of diagnoses.[24] Researchers sometimes use flags or counts of self-selected codes (or groups of codes) as comorbidity controls.

Several indices also have been developed to take advantage and make sense of the wealth of diagnostic information in national claims data, including the Charlson Index (Charlson, et al. 1987), the Deyo (Deyo, et al. 1992) and Romano (Romano, et al. 1993) adaptations of the Charlson Index, and the Elixhauser (Elixhauser, et al. 1998) system. Studies suggest that these indices are more predictive of outcomes than are simpler counts or flags of codes or code groups. The most frequently used system in the health services research literature seems to be the Charlson Index, originally designed for medical record studies, and Deyo’s adaptation, which applies the index to ICD-9-CM codes. Deyo’s method identifies 17 comorbidity groups and then applies a weighted single score. The adaptation was developed in a study of Medicare beneficiaries undergoing lumbar spine surgery; outcomes predicted included mortality, hospital length of stay, hospital charges, and discharge to SNF care.

Elixhauser’s system uses 30 comorbidity groupings, but it does not generate a single weighted score. It was developed on five condition groups of hospital patients (acute myocardial infarction, CHF, chronic obstructive pulmonary disease, hypertension with complications, and acute cerebrovascular disease). In the initial validation study of this system, which used the same five condition groups, Stukenborg, et al. (2001) found the Elixhauser method to be more predictive than the Charlson-Deyo adaptation of in-hospital mortality.[25] Studying the same outcome, Southern, et al. (2004) reached the same general conclusion regarding the two systems

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[24] Similarly, Berenson-Eggers type of service (BETOS) categories may be used in this project to identify aggregated, clinically meaningful descriptions of services furnished in the ambulatory setting.

[25] The authors also compared the use of diagnoses from the index stay versus index stay plus prior stays, and found that the prior admission information yielded “small” improvements in the performance both systems.

in their comparison of patients hospitalized for myocardial infarction. Though not discussed by the authors, one potential source of the difference is that Deyo's weighed score was not used in Southern and colleagues' analysis. The higher performance of Elixhauser's method in these studies is statistically significant, but is not extreme in magnitude.

Comprehensive classification systems are the next generation of developmental effort on diagnostic claims data. These systems were developed primarily for capitated payments to managed care plans and in some cases for provider profiling activities. They are becoming frequently used in the research literature to control for comorbidity. The earlier comorbidity systems were mainly developed on subsets of hospital patients to predict non-financial outcomes; the comprehensive classification systems mainly were developed on full claims populations (e.g., all provider encounters and all diagnostic conditions in Medicare claims) to predict annual charges or payments. Studies comparing the earlier comorbidity methods with the comprehensive classification systems suggest that the latter are more predictive of charges and payments (e.g., Ash, et al. 2003). Comparisons of these two general types of methods regarding non-financial outcomes were not found. Examples of comprehensive classification systems include Adjusted Clinical Groups or ACGs (Weiner, et al. 1996), Diagnostic Cost Groups or DCGs and Hierarchical Coexisting Conditions or HCCs (Ash, et al. 2000), Chronic Disability Payment System or CDPS (Kronick, et al. 200) and Clinical Risk Groups or CRGs (Averill, et al. 1999). Some comparisons of the classification systems have been conducted. While ACGs and ADGs have a stronger clinical orientation and, relatedly, are used for quality assurance and provider profiling activities as well as for payment (e.g., in several states' Medicaid managed care plans), HCCs and DCGs frequently have been found to be more predictive of spending. For example, Ozminkowski, et al. (2000) compared ADGs, ACGs and HCCs in predicting total annual expenditures among 10 sets of chronic condition patients and found HCCs to be most predictive of spending. Sookanan, et al. (2004) compared DCGs and ACGs on Veteran's Administration data and found that DCGs were more predictive of death, use of inpatient rehabilitation facilities, and use of long-term care hospitals.

Table III-5: Comorbidity Status Measurement Tools: Examples from the Literature

Name	Variables Used	Diagnostic Code Grouping	Description	Example References
Charlson Index	Comorbid Conditions and Assigned Weights Myocardial infarct (1) Congestive heart failure (1) Peripheral vascular disease (1) Cerebrovascular disease (1) Dementia (1) Chronic Pulmonary Disease (1) Connective tissue disease (1) Ulcer disease (1) Mild liver disease (1) Diabetes with end organ damage (1) Hemiplegia (2) Moderate or severe renal disease (2) Diabetes with end organ damage (2) Any tumor (2) Leukemia (2) Lymphoma (2) Moderate or severe liver disease (3) Metastatic solid tumor (6) AIDS (6)		A weighted measure of the severity of comorbid disease. The Charlson Index contains 19 categories of comorbidity. Each category has an associated weight, taken from the original Charlson paper, which is based on the adjusted risk of one-year mortality. The Index may be calculated either for a single record (separation) or over a defined period of time prior to an index event. Every diagnosis and procedure code is analyzed to see if it falls within one of the 16 comorbid conditions. If one of these is found, a flag (1) for that condition is set. These flags are weighted appropriately and summed to generate values. The overall comorbidity score reflects the cumulative increased likelihood of one-year mortality; the higher the score, the more severe the burden of comorbidity.	Charlson, et al. (1987) Kramer, et al. (1997b) Kramer, et al. (1997a) Manitoba Centre for Health Policy (2001)
Deyo Index	Comorbid Conditions	ICD-9-CM codes	The Deyo modification of the Charlson index adapts the clinical index for use with an administrative database which records ICD-9-CM diagnoses codes (a few procedure codes are also employed). Deyo assigns ICD-9-CM codes to all 19 diagnoses in the Charlson Index and assesses the index	Deyo, et al. (1992)
	Myocardial infarct	410-410.9, 412		
	Congestive heart failure	428-428.9		
	Peripheral vascular disease	443.9, 441-441.9,		
	Cerebrovascular disease	430-438		
	Dementia	290-290.9		
	Chronic Pulmonary Disease	490-496, 500-505,		
	Connective tissue disease	710, 710.1, 710.4,		
	Ulcer disease	531-534.9, 531.4-		
	Mild liver disease	571.2, 571.5,		
	Diabetes with end organ damage (1)	250-250.3, 250.7		
	Diabetes with end organ damage	250.4-250.6		
	Hemiplegia and paraplegia	344.1, 342-342.9		

Table III-5, cont. Comorbidity Status Measurement Tools: Examples from the Literature

Name	Variables Used	Diagnostic Code Grouping	Description	Example References
Deyo Index Cont.	Moderate or severe renal disease	582-582.9, 583-		
	Any tumor, Leukemia and Lymphoma	140-172.9, 174-		
	Moderate or severe liver disease	572.2-572.8, 456.0		
	Metastatic solid tumor	196-199.1		
	AIDS	042-044.9		
Romano Index	Summary The Romano score is calculated using ICD-9-CM codes derived from all hospital discharges		Romano's index (score) based on the Charlson index adapts the clinical index for use with claims data. Each condition included in the Charlson index corresponds to a set of five-digit ICD-9-CM diagnoses. It has been shown to perform best in adjusting for comorbidity in claims data	Romano, et al. (1993) Schneeweiss, et al. (2001)
Elixhauser Measure	Comorbid Conditions Congestive heart failure Cardiac arrhythmias Valvular disease Pulmonary circulation disorders Peripheral vascular disorders Hypertension Paralysis Other neurological disorders Chronic pulmonary disease Diabetes, uncomplicated Diabetes, complicated Hypothyroidism Renal failure Liver disease Peptic ulcer disease excluding bleeding		A comprehensive set of 30 comorbidity measures for use with large administrative impatient datasets. The comorbidities are associated with substantial increases in length of stay, hospital charges, and mortality. The Elixhauser measure addresses weaknesses of previous works. The Elixhauser system does not combine these conditions into a weighted score; instead the conditions are included as binary indicators in a multivariate model to adjust for confounding.	Elixhauser, et al. (1998) Southern, et al. (2004)

Table III-5, cont. Comorbidity Status Measurement Tools: Examples from the Literature

Name	Variables Used	Diagnostic Code Grouping	Description	Example References
Elixhauser Measure Con't.	Acquired immune deficiency syndrome (AIDS) Lymphoma Metastatic cancer Solid tumor without metastasis Rheumatoid arthritis/collagen vascular diseases Coagulopathy Obesity Weight loss Fluid and electrolyte disorders Blood loss anemia Alcohol abuse Drug abuse Psychoses Depression			
Adjusted Clinical Groups (ACG)	Summary There are 53 main classes of ACGs arranged in order of least severity to most severe. This is carried out through the use of the number of ADGs and age.		ACGs are formed from the ICD-9-CM codes a patient receives in ambulatory and inpatient care settings. ICD-9 codes into 34 diagnostic groups. Every ICD-9 code is individually mapped into a particular diagnosis group, so a person with multiple diagnoses could be assigned to multiple diagnostic groups. For each person, the resulting diagnostic group assignment(s) is combined with age and gender to assign a single ACG. Individuals assigned to the same ACG have similar patterns of morbidity and similar needs for healthcare resources. ACGs are mutually exclusive morbidity categories that have both clinical and administrative meaning. They can be used in a variety of payment, provider profiling, and quality applications.	Reid, et al. (2001)

Table III-5, cont. Comorbidity Status Measurement Tools: Examples from the Literature

Name	Variables Used	Diagnostic Code Grouping	Description	Example References
Hierarchical Coexisting Condition (HCC)	Summary The HHC model has 66 diagnosis categories, 16 categories based on procedure codes and 5 groupings based on principal inpatient diagnosis.		The HCC models are an extension of the DCG risk adjustment methodology. It attempts to improve the model in two ways: the first improvement is to recognize ambulatory diagnosis information in addition to the inpatient diagnosis data and the second significant addition in the HCC model is the ability to recognize multiple conditions for a single person.HHC are based on the inpatient and ambulatory ICD-9 diagnosis information, conditions that are clinically closely related are assigned into hierarchies. Within each hierarchy, a person is assigned to the most serious condition to which he or she belongs. Across hierarchies, a person can be assigned to multiple conditions. The HCC model sums the payment rate for each condition to calculate the total for each member.	Ellis, et al. (1996)
Nursing Severity Index (NSI)	Five diagnostic groups based on 34 nursing Dxs which include: Nutrition and metabolism Urinary and fecal elimination Activity and exercise Underlying management issues Psychosocial issues		Based on 34 admission nursing Dxs that describe functional status, psychosocial factors, and pathophysiologic aspects of disease. Uses clinical observations made during routine care. Scores can range from 0 to 34. Assesses multiple dimensions of illness and predicts risk of in-hospital mortality. MDS limitation: Not based on MDS.	Kramer, et al. (1997a) Rosenthal, et al. (1992)

Table III-5, cont. Comorbidity Status Measurement Tools: Examples from the Literature

Name	Variables Used	Diagnostic Code Grouping	Description	Example References
Patient-in-Patient-Diagnostics Cost Group (PIP-DCG)	Comorbid Conditions	DCG Group	The PIPDCG calculates for each beneficiary a relative risk factor. A risk value of 1.00 equals the national average. Risk factors above 1.00 indicate above average expected costliness; factors below 1.00 indicate lower than average expected cost. There are three steps involved to calcuate the relative risk. Step 1 sum three individual factors (1) age and sex; (2) originally disabled status (for a person who is now over age 65 but was previously entitled to Medicare because of disability); (3) Medicaid status (for a person who was entitled to Medicaid at any time during the base year).Step 2. Select the PIPDCG factor by: (1) assigning each hospital stay of at least 2 days to a PIPDCG category based on the principal medical problem that led to the admission; then (2) identifying the relative risk factor associated with the highest numbered of these PIPDCG categories.Step 3: Add the demographic and PIPDCG factors to achieve a relative risk score. If Medicare is not this person's primary payer, multiply this score by 0.21 to represent the expected part of total health care costs for which CMS is responsible.	Pope, et al. (2000) Shen and Ellis (2002)
	HIV/AIDS, Blood, Lymphatic Cancers/Neoplasms	PIPDCG 29		
	Metastatic Cancer, Brain/Nervous System Cancer	PIPDCG 26		
	Liver/Pancreas/Esophagus Cancer, End Stage Liver Disorders, …	PIPDCG 23		
	Diabetes with Chronic Complications, Coma and Encephalopathy, Aspiration Pneumonia, ..	PIPDCG 20		
	Cancer of Placenta/Ovary/Uterine Adnexa, Blood/Immune Disorders, …	PIPDCG 18		
	Mouth/Pharynx/Larynx/Other Respiratory Cancer, Lung Cancer, Cirrhosis, …	PIPDCG 16		
	Septicemia (Blood Poisoning)/Shock, Adrenal Gland, Metabolic Disorders, …	PIPDCG 14		
	Tuberculosis, Stomach, Small Bowel, Other Digestive Cancer, Rectal Cancer, …	PIPDCG 12		
	Gastrointestinal Obstruction/Perforation, Gastrointestinal Hemorrhage, …	PIPDCG 11		
	Colon Cancer, Schizophrenic Disorders, Post-Myocardial Infarction, Unstable Angina, …	PIPDCG 10		
	Other Cancers, Pancreatitis/Other Pancreatic Disorders, Acute Myocardial Infarction, …	PIPDCG 9		
	Cancer of Uterus/Cervix/Female Genital Organs, Peptic Ulcer, …	PIPDCG 8		
	Central Nervous System Infections, Abdominal Hernia, Complicated,…	PIPDCG 7		
	Cancer of Prostate/Testis/Male Genital Organs	PIPDCG 6		
	Breast Cancer, Ongoing Pregnancy with Complications,…	PIPDCG 5		
	No or Excluded Inpatient Admissions, Ectopic Pregnancy, Miscarriage/Terminated Preg…	PIPDCG 4		

While the Charlson-Deyo method has been available for over a decade and is frequently used in the health services research literature, the developmental population of the Elixhauser system (CHF and other heart conditions) may make it more conceptually appropriate for our cohorts and for long-term care analyses. We will also consider use of a comprehensive system, however, given their explanatory power regarding health expenditures.

Potentially Avoidable Hospitalizations

Hospitalization is a common outcome in studies of nursing facility residents, as well as in the general clinical literature. One aspect of recent research into hospitalization causes and trends has been the identification and monitoring of what are termed “ambulatory-care sensitive” or “potentially avoidable” hospitalizations. ACSCs are a set of roughly 12 conditions for which hospitalization may be potentially avoided if appropriate ambulatory care is received (Table III-6). Adding this type of characterization, as applicable, to hospitalizations identified in our analyses of the cohorts’ care paths may enhance the interpretation of the hospitalizations identified and may improve the utility of the findings.

Table III-6: Conditions Identified as Ambulatory Care Sensitive Conditions

Congestive heart failure
Pneumonia
Cellulitis
Asthma
Kidney infection
Diabetes
Perforated or bleeding ulcer
Ruptured appendix
Malignant hypertension
Hypokalemia (low blood potassium)
Immunizable conditions
Gangrene

Note: Pneumonia often is not considered an ACSC among the elderly (Blustein, et al. 1998).

Source: Kozak, et al.(2001); Weissman, et al. (1992).

Over roughly the last two decades, age-adjusted ACSC discharges as a percentage of all discharges rose substantially among the elderly, from 9.6% in 1980 to 15.9% in 1998 (Kozak, et al. 2001). Actual ACSC discharge rates rose also. The increases were due largely to discharges for CHF, pneumonia, and cellulitis,[26] and occurred mainly in the 1980s. Pappas, et al. (1997) and Culler, et al. (1998) identified several risk factors for ACSC admissions among the elderly, including specific demographic factors (older age, black race, rural residence, core MSA residence) and specific health factors (self-reported poor health, heart disease, diabetes, and needing assistance with 2 or more ADLs).

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[26] Discharge rates declined for three ACSCs (asthma, kidney infection, diabetes) and were basically unchanged for six (perforated or bleeding ulcer, ruptured appendix, malignant hypertension, hypokalemia (low blood potassium), immunizable conditions, and gangrene).

In our review of the literature, one study was found that extends the use of ACSCs to the long-term care population. Carter (2003) examined hospitalizations among nursing facility residents and concluded that the ACSC characterization was a significant factor in explaining hospitalization rates. In addition to that characterization, Carter used a fairly wide range of covariates in the model including patient factors (ADLs, DCG risk-adjustment groups, prescription drug use); facility characteristics (profit status, age, number beds, Medicare and Medicaid volume); and market factors (area income and area supplies of physicians, hospital beds, nursing home beds).

Differentiating admissions based on a set of ACSC conditions may be useful in our cohort studies. Following Blustein, et al. (1998), we would not uniformly label pneumonia discharges as ACSCs. Blustein notes that while the condition is widely considered an ACSC among the non-elderly, it often is a terminal event among the elderly and elderly hospitalizations coded with the diagnosis may not be preventable.

Controlling for 1915(c) Waiver Participation

The combination of federal Medicaid 1915(c) waivers, the 1999 Olmstead Supreme Court decision, and recent federal grant monies has spurred states to provide home and community-based services to elderly who require a nursing facility level of care and otherwise would reside in them. While states and localities can develop programs independent of Medicaid, the waiver mechanism is generally used because it leverages federal matching funds (Fox-Grage 2004). The nature of and participation in states' waiver programs open to the elderly can alter the characteristics and composition of the Medicaid-covered nursing home population in a given state. Thus, it will become increasingly important to control for this participation in analyses of the risks for and determinants of nursing facility use.

To start developing these control variables, we identified participation rates in two waiver categories populated by the elderly— elderly waivers and elderly/disabled waivers. We were not able to isolate the elderly-only participation in elderly/disabled waivers. To develop a more detailed knowledge of waiver programs in states we will likely select for cohort 3, we collected additional waiver program information on 13 states. These are states in which Urban Institute Health Policy Center researchers collectively have thorough Medicaid program knowledge, through site visits and quantitative studies conducted under the Institute's Assessing the New Federalism research program (Alabama, California, Colorado, Florida, Massachusetts, Michigan, Minnesota, Mississippi, New Jersey, New York, Texas, Washington, and Wisconsin.) As control variables in our national-level analyses in cohorts 1 and 2, we would apply participation rates for all 50 states.

Across the 13 states that we researched in detail, 2001 participation rates in elderly and elderly/disabled waiver programs ranged from a low of 0.37 participants per 1,000 persons in California to a high of 5.1 participants per 1,000 in Washington (Table III-7). Washington is one of two states (with Oregon) in which waiver programs are more prevalent than nursing facilities for providing long-term care to the nursing facility-eligible population. Across the 13 states, spending per participant ranged from a low of $1,288 per participant in New York to a high of $11,443 per participant in Texas. These ranges reflect differences across states in the number of waiver programs and in the type and amount of services provided under the waivers. Appendix 4 provides an overview of the section 1915(c) waiver legislation and additional detail on specific waiver programs in the 13 states.

Table III-7: Aged and Aged/Disabled HCBS 1915(c) Waiver Programs, Selected States, 2001

	Participants			Expenditures		
State	**Number**	**Per 1,000 population**	**As a percent of all 1915(c) participants**	**Total (in millions)**	**Per participant**	**As a percent of all 1915(c) expenditures**
Alabama	7,272	1.63	63%	$39.1	$5,376	18%
California	12,712	0.37	25%	$78.5	$6,175	10%
Colorado	14,082	3.19	59%	$72.3	$5,131	24%
Florida	18,019	1.09	36%	$105.3	$5,841	19%
Massachusetts	6,042	0.95	34%	$13.9	$2,301	3%
Michigan	14,364	1.44	66%	$53.1	$3,698	9%
Minnesota	16,433	3.31	53%	$98.5	$5,994	16%
Mississippi	7,281	2.55	89%	$32.0	$4,399	77%
New Jersey	7,260	0.87	46%	$77.8	$10,712	23%
New York	20,367	1.07	31%	$26.2	$1,288	2%
Texas	31,000	1.45	76%	$354.7	$11,443	57%
Washington	9,212	5.10	23%	$221.7	$9,003	45%
Wisconsin	12,510	2.32	57%	$117.4	$9,382	27%

Source: Urban Institute analysis of CMS state waiver data.

It is also useful to have a sense of the relative focus on elderly and elderly/disabled (EED) waiver activity in a state relative to its total 1915 (c) waiver activity. For example, EED waivers in Mississippi account for a large share (89%) of all waiver participants in the state. And a roughly similar, large share of total spending is accounted for by EED waiver activity (77%) in the state. In contrast, EED waiver participants account for 34% of waiver participants in Massachusetts, but EED waiver spending in Massachusetts accounts for only 3% of waiver spending in that state. Overall, we found some substantial differences in the rank orders of states in terms of participation rates and spending rates for EDD waivers, and in terms of participation or spending rates for EDD waivers versus all waivers. This suggests the importance in using participation rates rather than spending rates as a control variable in our analyses, and in using as detailed a program category participation rate as possible in controlling for the proportion of nursing-facility eligible elderly receiving services in the community rather than in facilities.

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CHAPTER IV. COHORT STATISTICAL ANALYSIS PLANS

In this chapter we briefly survey the methodological approaches used in studies of risks facing the elderly. In particular we are interested in how researchers have modeled changes in health and patterns of utilization and costs using longitudinal data. Following this review, we summarize the three cohorts introduced in Chapter III, and for each we suggest multiple research questions of interest that may be addressed in the project and the analytic methods that would be appropriate for these questions.

Review of Statistical Analysis Methods in the Literature

Health Dynamics

A variety of approaches have been used in the health services research literature to model changes in health. At one end of the spectrum, changes in health status that can be measured discretely (e.g., death, onset of a new functional limitation within a fixed followup period, increased severity of a limitation) are often treated as a binary outcome. In these cases, either linear or logistic regression can be used to identify factors that increase or decrease the relative risk of that outcome. Examples of this type of analysis abound, but a recent example can be seen in Bundorf, et al. (2004). When longitudinal data are collected with a single followup survey where dates of events or transitions are not be identified, this approach is likely the only choice. If exact dates are available, however, this simple binary variable approach discards potentially useful variation. If, for example, one identifiable set of patients (group a) dies within weeks of hospital discharge while another identifiable group (b) faces an expected survival of 10 months, grouping all deaths within a year as equivalent will miss the protective effect of being a member of group b. In these cases, standard survival time (hazard) models are more appropriate (e.g., Iwashyna, et al. 2002a,b). Alternatively, if exact dates of events or functional transitions are not available, but multiple followup observations are available for each subject (e.g., in quarterly assessments or an annual survey of ADL disability status), discrete time hazard models can differentiate transitions that occur in early follow-ups from those that occur later or not at all (e.g., Chernew, et al. 2001). These models estimate the parameters that maximize the likelihood that events occur within date ranges, rather than at specific points in time. A variant on these methods based on repeated observations, are Markov models of transition between states (e.g., Albert and Waclawiw, 1998).

When outcomes are not binary, but polychotomous, more complex, but related models are typical. The simplest of these models use a multinomial logistic specification to model transitions from one state to several others (Mor, et al. 1994, Anderson, et al. 1998, Beland and Zunzunegui 1999). These models can be thought of as generalizations of the binary logistic models where several outcomes are competing with independent risks, often not a tenable assumption. Multistate life table methods not assuming independence of competing risks are less common in the literature on disability among the elderly, but examples do exist (Lynch, et al. 2003). When these methods are applied to changes in functional status, dates of transitions are not usually observable. Hence continuous time models, while theoretically available (Wolf 1988), are not often used in these cases. A simpler approach employs linear models with random coefficients (sometimes referred to as hierarchical linear modeling, or HLM) to summarize group trends in prevalence of health states over time (Frytak, et al. 2001).

Continuous measures of health status are less common. With the exception of specific clinical measures like body mass index, and serum lipid levels, most measures available to researchers using administrative and survey data to obtain summary measures of health must rely on discrete indicators. A variety of methods have been developed to summarize multiple categorical data items by constructing scales. Several of these were discussed in the previous chapter, notably ADL scales and claims-based risk adjusters. Changes in ADL scales have been used as a continuous variable in linear models (e.g., Hadley, et al. 2000). Two other types of summary measures have been developed for measuring health status as well as health dynamics. Both rely on the creation of an index from a set of categorical and continuous variables, allowing the data to determine appropriate weighting of individual items making up the index. In these models, health is treated as either a single latent variable (e.g., Bound, et al. 1999) or several latent variables capturing multiple dimensions (e.g., Manton and Woodbury 1991, Larsen 2004) of health. Applying these models to longitudinal data is less straightforward, but the method has been used (Reboussin, et al. 1999). A particularly thorough effort to combine multi-dimensional health data in a continuous time hazard framework measuring transitions between multiple health states and mortality hazards was made by Manton and Land (2000).

Utilization and Cost Dynamics

Many of the same methods used in modeling health dynamics have been used in measuring utilization and cost dynamics. In contrast to the health dynamics literature, however, there are more observable continuous outcomes (costs) that lend themselves to more traditional linear (or log-linear) modeling methods. Following Duan , et al. (1983) health services utilization is often analyzed with two-part models (e.g., Pezzin and Kasper 2002; Anderson, et al. 2003). The analysis of costs often establishes a fixed period of observation over which to observe costs following an event or particular treatment (e.g., Subramanian, et al. 2003; Weiner, et al. 2003), though some retrospective studies look at a variable period between a treatment or diagnosis event and death (e.g., Earle, et al. 2004). The HLM variation on the linear model is sometimes used when there are both individual and aggregate level variables (Iwashyna, et al. 2002a,b). Controlling for case mix is essential in these analyses, and a variety of approaches have been used. When the objective is to examine the expenditure effect of potentially endogenous treatment choices, analysts have relied on instrumental variable techniques (e.g., Ettner, et al. 1999).

Finally, the treatment of discretely measured utilization outcomes such as nursing home entry, hospitalization span a spectrum similar to the health dynamics literature: from simple logistic regression models of hospitalization in a fixed followup period (Barker, et al. 1994) to hazard models with competing risks of post-acute care use in alternative settings (Cagney and Agree 1999). Entry into long-term care is typically analyzed with hazard models (Cohen, et al.1986, 1988; Tomiak, et al. 2000).

Proposed Cohort Statistical Analysis Plans

Cohort 1: Elderly Hospitalized for Congestive Heart Failure

The first cohort analysis we propose is a forward-looking study of beneficiaries hospitalized with a prevalent condition likely to lead to the use of long-term care. Congestive heart failure (CHF) is the most common discharge diagnosis for Medicare beneficiaries and has been shown to be a strong risk factor for death, rehospitalization, and functional decline (Wolinsky, et al. 1997; Krumholz, et al. 1997; Philbin and DiSalvo 1999). The analyses described below examine the course of CHF patients through the acute, post-acute and long-term care systems, and seek to identify the factors associated with the various trajectories (health, utilization, and cost) through those systems.

Cohort Definition

The principal diagnosis field of Part A inpatient claims will be searched for a set of 14 ICD codes listed in Table IV-1, indicating congestive heart failure (CHF) as the primary reason for hospitalization. All beneficiaries with such claims during the calendar year 1999 who did not also have such a claim in the five years prior are eligible for inclusion. To assure a comparable lookback period for all selected beneficiaries, we will restrict our attention to persons who were age-eligible for Medicare in January 1994. If an individual has more than one CHF hospitalization in the year, we will use the first such hospitalization to mark the beginning of the longitudinal record for prospective analysis. Finally, we will exclude hospitalizations of persons already residing in long-term care facilities (as determined by the presence of non-SNF MDS assessment records for the year prior to hospitalization. Thus, the analytic file will consist of one set of records per person with an eligible CHF discharge in the year, containing the relevant utilization, cost, health and longevity variables described below.

Table IV-1: Diagnosis codes (ICD-9-CM) indicating CHF on Hospital Claim

398.91	Rheumatic Heart Failure (Congestive)
402.01	Malignant Hypertensive Heart Disease with CHF
402.11	Benign Hypertensive Heart Disease with CHF
402.91	Hypertensive Heart Disease with CHF
404.01	Hypertensive Heart and Renal Disease, Malignant, with CHF
404.03	Hypertensive Heart and Renal Disease, Malignant, with CHF and RF
404.11	Hypertensive Heart and Renal Disease, Benign, with CHF
404.13	Hypertensive Heart and Renal Disease, Benign, with CHF and RF
404.91	Hypertensive Heart and Renal Disease, Unspecified, with CHF
404.93	Hypertensive Heart and Renal Disease, Unspecified, with CHF and RF
428.0	Congestive Heart Failure
428.1	Left Heart Failure
428.9	Heart Failure, Unspecified
785.51	Cardiogenic Shock

Outcomes of Interest

Several outcome measures will be collected for analysis. The methods of analysis will differ depending on the nature of the measure and are described here.

Utilization and Costs

Medicare claims files for the cohort members will be used to quantify the types of services used and the public costs incurred by CHF patients. Part A claims will be aggregated by care setting (inpatient acute care hospital, SNF, IRF, hospice, etc.). Part B claims will be aggregated by broad BETOS categories so that we can distinguish between major and minor procedures, tests and office visits. Use of institutional long-term care services other than post-acute care will be identified from MDS assessments.

We are interested in the variety of services used as well as the intensity of use. While CHF (DRG 127) accounts for the largest number of Medicare discharges, less than 20 percent of those patients are discharged to Medicare post-acute care. To understand the determinants of post-acute care use, we will estimate a discharge destination model where destination is modeled as a polychotomous choice. A common model in which the choice is determined by individual level factors is the multinomial logit model,

$$
\begin{aligned}
P(D_i = k) &= \frac{\exp\left(\alpha_k + X_i{}'\beta_k\right)}{1 + \exp\left(\sum_{j=1}^{4} \alpha_j + X_i{}'\beta_j\right)} \quad for\ k = 1,...K \\
P(D_i = 0) &= \frac{1}{1 + \exp\left(\sum_{j=1}^{4} \alpha_j + X_i{}'\beta_j\right)}
\end{aligned}
\qquad (1)
$$

where D_i is the variable indicating type of discharge (home/no PAC (k=0), hospital-based SNF, freestanding SNF, inpatient rehabilitation facility, long-term care hospital, Medicare home health, and death). Explanatory variables, X_i, described more fully below, will include basic demographic information, a claims-based risk adjuster, and market characteristics including accessibility of post-acute care facilities.

Analysis of service utilization and costs, by type, will use standard two-part models (Duan, et al. 1983) to estimate frequency and intensity for various types (j) of service use. Claims files for 1999 through 2003 (if available) will used to construct utilization variables for the period following discharge.

$$
P(U_{ji} > 0) = \frac{\exp\left(\alpha_j + X_i{}'\beta_j\right)}{1 + \exp\left(\alpha_j + X_i{}'\beta_j\right)}
$$

$$
\ln(U_{ji}) = X_i'\delta_j + \varepsilon_i \quad if \quad U_j > 0 \qquad (2)
$$

For the purposes of this cohort, we are interested in nationally representative data. Using Medicaid claims for all states would entail more resources than are available under this project, so to the extent that we analyze non-Medicare payments, we will rely on imputation. Most notably, costs of long-term care services will be imputed using the MDS records to establish dates of services and state payment rates to establish per diem payments to nursing homes. Imputing drug expenditures would be more difficult in this analysis, since payment methods under Medicaid differ substantively across states (Harrington, et al., 2000). We will examine drug expenditures using survey data in the second cohort study and using claims data in the third study.

Time to Formal Long-Term Care Use

While many in this cohort will use formal long-term care services, it is useful to distinguish between those who need those services within a short period of time and those who will use them farther into the future. Identifying the factors that are associated with prolonged independence among the chronically ill is important for policy makers interested in controlling future long-term care costs. To estimate the timing of LTC use, survival analysis is the most appropriate method to study effectiveness in prolonging independence (measured by no entry into long-term care). We will estimate the parameters of a continuous time hazard function of the form:

$$h\ (t; X_{it}) = \lim_{\Delta \to 0} \frac{\Pr(t < T_i \leq t + \Delta \mid T_i \geq t, X_{it})}{\Delta} \tag{3}$$

where $h\ (t; X_{it})$ represents the instantaneous probability that person *i* will experience a failure (residential transition to a nursing home) at time *t* given that she has survived without a failure before *t*, and given individual characteristics at time *t*, X_{it}. Maximum likelihood estimation techniques are used to estimate the parameters of this function. Estimation of the hazard function requires the specification of a functional form to explain how the hazard varies with time and explanatory variables. We will specify the hazard as proportional to a baseline hazard. Thus,

$$h(t; X_i) = h_0(t) g(X_{it}). \tag{4}$$

Both parametric (e.g., Weibull, Gompertz) and non-parametric (Cox) specifications for the baseline hazard, $h_0(t)$, will be estimated. In the Weibull and Gompertz models, respectively

$$\begin{aligned} h_w(t) &= \lambda \gamma (\lambda t)^{\gamma - 1} \\ h_g(t) &= \lambda \exp(\gamma t) \end{aligned}, \tag{5}$$

while in the Cox model, $h_0(t)$ is an arbitrary unspecified function. In maximum likelihood estimation of the Cox model, timing enters only to create a rank ordering of events, and parameters are chosen to best reproduce the ordering rather than to fit a pre-established survival curve described by equation (5). While the parametric model can provide tighter estimates, estimating the Cox model as well serves as a sensitivity analysis on the assumptions made by our choice of a baseline hazard function.

The effect of the covariates is to multiplicatively shift the baseline hazard up or down, respectively reducing or prolonging the expected time to failure, and is often parameterized as

$$g(X_{it}) = \exp(X_{it}'\beta). \tag{6}$$

The data element necessary for estimating these models is the elapsed time between the date of discharge and the date of nursing home admission (as indicated on the MDS record). Medicare claims records will be used to distinguish MDS records for short term SNF stays from those pertaining to long-term nursing stays.

An important complication in this model is that we will not observe a time to nursing home admission for all CHF discharges. Some will remain out of a nursing home beyond the observation period, and others will die during the observation period while residing in the community. Typically in hazard models, these two types of cases are treated as distinct and "competing" failure types. The problem of competing risk is often summarized as the estimation of the risk of certain types of failure given the absence of some or all other failure types. It is relatively straightforward to estimate these multiple-failure-type models if we assume the risks of each type of failure are independent of one another. Each failure type hazard is estimated treating failures of every other type as "right-censored." If failure of one type increases (or decreases) the risk of another type of failure, then the independence assumption is clearly false and the estimates produced by simply estimating individual cause-specific models do not represent the true cause-eliminated hazard desired. The presence of time-dependent covariates, however, allows us to relax the assumption of independence and estimate true cause-eliminated risks (Kalbfleisch and Prentice 2002). Thus, in this example, it seems likely that the risk of institutionalization is not independent of the risk of re-hospitalization for CHF (or other causes). For the purposes of policy makers, knowing whether the risks are independent is important in predicting long-term care use based on the recurrence of hospitalization or the use of other services. By including data from Medicare claims after discharge we can directly test the assumption of independence as well as estimate the appropriate measures of risk for long-term care use.

Stratifying and Control Variables

Predisposing and Enabling Characteristics

Using the terminology of Andersen and Newman's (1973) model, the predisposing and enabling characteristics that influence health care utilization, are largely absent from the data available for this cohort analysis. Income, education, insurance coverage, and availability of family support have all been shown to affect utilization, but Medicare administrative data lack these elements. The Medicare enrollment database does, however, identify age, gender, race, some geographic data, and Medicaid enrollment status. Medicaid status provides both an indicator of the economic resources available to a patient and the presence of an additional payer for health care costs, complicating interpretation. Nevertheless, it is important to control for it in the models we estimate. Additional controls for socioeconomic status can be obtained from Census SF-3 (long-form) data, aggregated by zip code, allowing merge with the Medicare EDB.

Information on local area poverty rates and median income can be used as a proxy for patient level income.[27]

Need Characteristics

The principal means of including health status controls in the models is a constructed risk-adjustment factor, described above. To the extent that health status factors can be captured by patterns of health care utilization, the models we estimate will be able to control for much of the variation in need in this cohort. These calculations will be made at baseline (using the year prior to the index hospitalization) and at annual intervals during the observation period, giving us a time-varying measure of health status for the failure models. We will also use principal diagnosis (within the set of ICD-9 codes) to stratify patients.

Market Characteristics

Variables necessary to correct for the endogeneity of post-acute care setting were discussed above. In general, variables that reflect conditions of the health care market can be constructed by merging geographic identifiers in the Medicare EDB and data from HRSA's Area Resource File (ARF). These will include measures of physician and hospital availability, and HMO penetration.

Policy Characteristics

Several state and federal policy issues can be examined in this cohort. At the state level, the availability of state-financed alternatives to institutional nursing care (e.g., 1915(c) and 1915(d) waiver programs) is expected to reduce the risk of nursing home admissions. We will also include income and asset cutoffs for Medicaid eligibility, which are expected to affect decisions to enter formal long-term care.

Of interest for Medicare policy is the use of post-acute services, especially if a particular post-acute setting can be shown to be effective at reducing the risk of long term institutionalization. The central problem with including indicators of SNF and LTCH utilization is that placement in these settings is not random. The multinomial logit model described above will measure the extent to which individuals are selectively assigned to each of the post-acute settings. It is likely that correlation exists between setting and key observable characteristics (namely health). If, however, there are unobservable components of health (or other factors) that are affect both short term and long term placements, there may well be cause to worry that comparisons in outcomes by treatment setting will be biased. Instrumental variable techniques can be used to correct for this bias. Various possibilities exist for the choice of instrumental variables, but we will focus, in general, on supply-related variables, since demand-related variables tend to be associated with both selection and outcomes. We will use proximity to the various types of post-acute care settings. This would be a particularly useful correction here, given the small number of IRFs and LTCHs relative to the number of SNFs and home health

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[27] Since Medicare administrative data do not contain information on individual socioeconomic status, neighborhood characteristics will be used as proxies. Any inferences based on these variables, however, will have to account for clustering effects in calculations of standard errors.

agencies. OSCAR data can be used to establish distance between a beneficiary's zip code and that of the nearest facility of each type. AHA data can be used to determine if the hospital in which acute care is delivered owns a SNF or inpatient rehabilitation unit. We will also investigate supply of specific types of post-acute care providers in market areas defined, for example, by Health Services Market Areas (HSMAs) or by counties. In other studies, we are currently analyzing changes in Medicare home health use across such market areas. Supply variables for the various post-acute care providers can be constructed from difference sources, including OSCAR and the Area Resource File.

Cohort 2: Elderly with Heart Disease (MCBS Respondents)

Questions of Interest

While the first study seeks to identify as homogeneous a cohort as possible, starting at a similar point in a disease and health care trajectory, the data available to the researcher are limited in scope. As shown in the literature review section above, health services research has demonstrated the importance of individual level factors that are not available from administrative data sources. The second cohort study we suggest complements the first, sacrificing sample size and clinical homogeneity of cases for a richer set of contextual variables. In addition this cohort represents a broader slice of the Medicare population, and thus it may be more generally relevant for policy discussions. With this pair of studies, we hope to shed light on the potential value for planners and policy makers of collecting other types of data on a larger scale.

Cohort Definition

The Medicare Current Beneficiary Survey (MCBS) interviews approximately 12,000 persons a year representing the entire Medicare beneficiary population. In addition to asking about respondents' health care use and out of pocket spending, it collects data on health and functioning, demographic and socioeconomic characteristics, family structure and health insurance coverage. Data from each of these areas can be used to supplement the any of the claims-derived data used in the first cohort study, albeit on a smaller sample. One goal of this study is to examine a population similar to that from the first cohort. Identifying CHF patients in the survey data is possible through assessing their claims, but this would result in a very small sample if it were done. However, several conditions that have been identified as precursors to CHF are identifiable in the survey itself, and allows for a broader cohort definition. From the 1999 MCBS we will select community-dwelling persons age 70 and older who report being told by a doctor that they had one of the following conditions: diabetes, hypertension, myocardial infarction, angina pectoris, coronary heart disease, or other heart conditions.[28] Because of their unique patterns of utilization and health status, we will exclude ESRD patients.

Outcomes of Interest

The outcomes to be studied for this cohort are chosen to be similar to those studied in the first. A key difference however is the lack of a clearly defined starting point (i.e., date of hospital discharge). Thus, the beginning of calendar year 1999 will be chosen as the start date. The health

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[28] As discussed above, as a sensitivity test, patients reporting only diabetes will be excluded from some analyses.

data for the 1999 MCBS release were collected in the last months of 1998, so individuals are assured of having been diagnosed prior to the start of the observation period.

Utilization and Costs

Cost and utilization variables will be defined similarly to those in the first cohort, and will be measured using Medicare claims beginning on 1/1/1999. The difference in this cohort is that no separate (multinomial logit) analysis will be done on post-acute care setting. Any analysis of SNF or other post-acute care utilization will be done with 2-part models as described in (2) above.

Survey data on prescription drug use will allow us to supplement the findings of the hospital cohort. An advantage of this data source is that drug information will be available for the entire sample, rather than being limited to Medicaid beneficiaries. Drug expenditure and use analysis will also be done with 2-part models.

Time to Formal Long-Term Care Use

Hazard models similar to those described above (3-6) will be used to analyze the risk factors for NF entry. Failure time will be measured uniformly from 1/1/1999. As above, the presence of MDS admission assessment without an accompanying SNF claim will be use to establish the long-term NF admission date.

Stratifying and Control Variables

As this cohort is intended as a replication of the claims-based cohort, we will create the same set of independent variables that are created for the two cohorts. For this cohort, however, we will also develop several other types of variables that are not available from administrative data.

Social and Financial Support

The MCBS collects data on marital status and number of living children. From these, we will construct variables indicating whether the person has a living spouse, living children or both. The survey also asks about income and health insurance. Several specifications of income variables will be used in the analyses. The battery of health insurance questions will allow us to characterize the breadth and depth of the respondent’s health coverage from up to five plans. Of particular interest are questions related to coverage of long-term care and prescription drugs.

Self-Reported Health

In addition to the utilization-related measures of health available from claims, in the period respondents are followed by the MCBS (up to 4 years), we will also construct measures of health based on self-rated health and functioning. Measures we can construct on an annual basis include a general rating of health (excellent-poor), body mass index (BMI), self-ratings of vision and hearing (no trouble – lot of trouble), a self-reported diagnostic history, five Nagi difficulty items indicating limited physical function, six IADL measures, and six ADL measures. Several specifications of self-reported health measures will be used, consistent with the health services literature.

Cohort 3: Elderly Admitted to Nursing Facilities

The final cohort analysis proposed examines the characteristics of beneficiaries who use formal long-term care services. This cohort can be seen as complementary to the two others that follow persons with one set of identified risk factors for long-term care use but who are not yet using those services. This cohort looks at a cohort of long-term care users to describe the variety of antecedent care used and the factors influencing quality outcomes for nursing home patients. Because this cohort will make explicit use of Medicaid claims data, it will be restricted to approximately four states chosen, in part, for data quality and availability.

Questions of Interest

Medicare claims data alone can tell us what types of hospitalizations are most likely to precede the use of post-acute care, but answering the same question for long-term care users requires a merged longitudinal file of claims and assessment data. This is one of several descriptive analyses of pre-admission utilization and costs we will undertake. Looking forward from nursing facility admission, this cohort can also be used to better understand the impact of policy and individual and facility characteristics on individual-level indicators of quality of care. This cohort will also allow us to examine factors affecting Medicaid spend-down among residents who begin their nursing care stay as private pay patients.

Cohort Definition

The cohort is defined as all nursing facility admissions in the target states during calendar year 1999. Subjects will be identified using MDS admission assessments and Medicare claims to exclude post-acute stays from the sample. Using the Medicare enrollment database, will exclude ESRD patients.

Outcomes of Interest

Prior Year Utilization and Diagnoses

The set of retrospective measures we will generate are intended to give a profile of health service utilization prior to nursing facility admission. Because we do not use a control group, we cannot assert a causal relationship between the use of formal long-term care and pre-admission service patterns. These analyses are intended to be descriptive. Data from the pre-admission period will also be used in the prospective analyses described below.

Using both Medicare and Medicaid claims, we will construct a variety of service counts and cost measures by service type. Two part models, as described above, will be used in these analyses. What we get from Medicaid claims in this analysis is the ability to fully describe public expenditures on behalf of beneficiaries and the ability to include the cost and use of prescription drugs for low-income beneficiaries. Most other services will have Medicare as the primary payer, and will be observed for the entire cohort. Of particular interest in the retrospective analysis will be hospitalization, post-acute care, and physician visits.

Physician visit and hospitalization claims will be scanned for diagnosis codes. One analysis will tabulate the most frequent DRGs used for hospitalization in the year prior to NF entry. This tabulation can be compared with the overall DRG prevalence to give an indication of the diagnoses that are disproportionately represented among nursing facility admissions. More generally, diagnostic codes will be used to create a health profile of a cohort of new admissions.

Medicare and Medicaid Spending Over Time

The prospective portions of this analysis will focus on the period two years after admission. We will use two-part models to describe the observable factors that affect public expenditures by type of service.

Hospitalizations Over Time

Of particular interest in this cohort is the use of hospital services by nursing facility residents. Hospitalization for ambulatory care sensitive conditions (ACSC) is seen as an adverse quality outcome. Hospitalization that results in a Medicare post-acute stay at the same nursing facility raises concerns that the facility is gaming the payment system to maximize reimbursement. This analysis will scan Medicare claims for both inpatient and outpatient (e.g., emergency department) hospitalizations for dates and diagnoses. Initial analyses will be logistic regression models of (1) any ACSC hospitalization in the followup period and (2) any inpatient hospital stay followed by a readmission to the nursing facility for a Medicare SNF stay. Separate analyses will be done using a 1-year followup and a 2-year followup. If these results warrant further investigation, continuous failure time analyses can be conducted on the same data.

MDS-Based Indicators of Quality and Functional Decline

A variety of individual level indicators of quality of care will be created from the MDS assessments. As part of CMS's Multistate Nursing Home Case Mix and Quality Demonstration, the Center for Health Systems Research and Analysis (2001) defined 24 quality indicators over 11 domains using the MDS 2.0 quarterly assessment form. For each member of the cohort we will create a longitudinal record of these indicators. At the individual level, several of these indicators (e.g., decline in ADLs) can be viewed as a natural part of the progression to end of life. Others (e.g., prevalence of pressure ulcers) are more clearly markers of deficient care. We will consult with our clinical team in making these distinctions for the final report. These indicators will be modeled initially with logit regression analysis. For those indicators that can be seen as markers of natural decline in function, we will distinguish between short (1-year) and long (2-year) term onset.

Time to Medicaid Enrollment

The final outcome we will model is the time until Medicaid enrollment. For persons who enter the nursing facility as private payers, we are interested in the expected duration of the spend-down period and the factors that influence the speed of spend-down. We will estimate these relationships with a hazard model (see above), treating death as a competing failure type.

Stratifying and Control variables

Demographic Information

While this study relies solely on administrative data, the MDS provides additional demographic and social support data that can be used to control for patient characteristics. The admission assessment collects information on marital status, living arrangement prior to admission, and education.

Health Status

As with the other cohort analyses, it is important to control for variations in health among cohort members. Since we are limited to administrative data, we will rely largely on the claims based risk adjustment methods used in the first cohort. However, because an MDS admission assessment should exist for every nursing facility admission, we can also use the detailed information provided there as an alternative control variable. The availability of both measures will also allow us to compare the predictive power of the two data sources. For the spend-down model, the quarterly assessment records will also provide a set of time-varying health covariates.

Payer Status at Admission

The full MDS assessment form administered at admission indicates all current payment sources for the patient. Indicators for each source of payment will be created. In addition to using this information to define the sample for the spend-down analysis, these variables are also of interest as factors influencing other outcome measures. Of particular interest for the hospital readmission analysis is the distinction between Medicaid, self-pay, and private insurance patients in the incentives to use the Medicare post-acute benefit to pay for services. In the general utilization models, we will investigate the impact of payment sources (especially private insurance) on the types and amount of services used.

Nursing Facility Characteristics

Annual OSCAR data and CMS data on quality measures used for nursing home comparisons will be merged to the cohort member record to create facility-level indicators of staffing levels and patient population characteristics. However, a finding that patient outcomes vary with facility characteristics may reflect geographic patterns in patient populations and market characteristics. To isolate the effects of facility-related factors, we can include data on the alternative choice set for nursing home residents by creating county-level aggregate measures from OSCAR and quality measure data.

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CHAPTER V. COHORT FILE DEVELOPMENT APPROACH AND NEXT STEPS

In the prior two chapters we defined three study cohorts, proposed several research questions of interest, and formulated statistical analysis plans for addressing the questions. Implementing these research plans requires substantial and intensive file construction efforts involving multiple data years, multiple data file types, and complex variable creation. This chapter summarizes the file types, file years, and variable needs for the cohorts and discusses the overall approach to building and documenting these files, which is the phase 2 activity of this project. The files we develop can be used for studying several other questions of interest (not addressed in this project) on the elderly's use of Medicare and long-term care. Further, the computer programs used to generate these files can be modified to create other data extracts and analytic files (e.g., for studying other hospitalization cohorts, nursing facility entrants in different states, etc).

Developing Cross-Cohort Analytic Files of Control Variables

Some right-side variables are needed in nearly all of our analyses are either constant or extremely similar in construction across all of our analyses, such as area variables (e.g., nursing facility beds, waiver participation rates, poverty rates); provider characteristics (e.g., profit/ownership status, number of beds, case-mix adjusted quality measure); and cohort members' demographic characteristics (e.g., gender, date of birth, date of death, zip code of community residence, monthly dual-eligibility status). Thus we will create a set of files (area file, provider file, beneficiary file) that will be generally applicable across our analyses in this project.

Variables in our area analytic files will draw mainly from HRSA's Area Resource File (ARF) for 1999 data. The county-level fields of interest to us in this file include information on health professions and facility supply and population characteristics and economic data. We will create state elderly and elderly/disabled waiver participation rates from CMS data. We may construct additional area variables on the zip-code level that affect individuals' socioeconomic status from Census SF-3 (long-form) data. Variables in our provider analytic files will draw mainly from CMS's Online Survey and Certification Reporting System (OSCAR) file for 1999. Information of interest in this file includes, for example, profit status and ownership (and for nursing facilities, deficiencies cited during the survey process). In addition, we will select quality measures from the CMS data used to create its Nursing Home Compare website. We will merge these facility variables for those particular providers used by the elderly in our cohorts. Our beneficiary analytic file will consist of selected demographic and enrollment characteristics, constructed from Medicare enrollment files, for the elderly in our cohorts. Medicaid eligibility files also may be used for the dually eligible. Finally, the programming code necessary for creating BETOS groupings on Part B claims and creating comorbidity controls (e.g., code for the Elixhauser system or software for ADGs, DCGs, or HCCs) will be applied in most of our analyses as well.

Cohort 1 (CHF Hospitalization) Analytic Files

Implementing the research plans as described for cohort 1 requires the use of up to 9 years of Medicare claims data (1994 through 2002); 4 ½ years of MDS assessment data (July 1998 through 2002); about 3 ½ years of OASIS assessment data (August 1999 through 2002); 4 years of Medicare eligibility data; 4 years of state waiver participation rate data (1999 through 2002); and use of the common analytic files described above. This range of files is needed for the combined activities of cohort delineation, outcome variable construction, and model covariate construction.

To initially create the cohort, 5 years of hospital claims will be scanned prior to the baseline year (1999) to isolate index hospitalizations for CHF, and 6 months of MDS assessments will be scanned (in combination with SNF claims) prior to index hospitalization to isolate community-residing individuals.

The four research questions of interest on cohort 1 encompass analyses on: 1) utilization; 2) expenditures; 3) post-acute care choice; and 4) time-to-long-term-care entry. The outcome variables include Part A stays and their associated payments, monthly Part B expenditures by BETOS category, and entry to non-Medicare nursing facility and entry to non-Medicare home health. To create the utilization and spending outcome variables, up to 4 years of claims will be analyzed. For each individual in this cohort, variable construction and analyses will cease at the time of non-Medicare nursing facility entry, death, or end of available data (i.e., neither of the prior events as of December 2002). The “time to” variables are calculated from the index hospital claim to, as applicable, the first non-Medicare MDS assessment (identified by lack of SNF claims), the death date on Medicare eligibility files, or the end of our data file.

Constructing the model covariates requires the use of Medicare eligibility, Medicare claims, and MDS and OASIS assessment data for up to 4 years (1999 through 2002) to create time-varying variables for dual-eligibility status, comorbidity status, functional status, and cognitive status. As noted above, extant software or computer code will be needed for constructing the comorbidity variables. In addition, one year of Part A or Parts A and B claims would be scanned prior to the baseline year to create a baseline risk, or comorbidity, control variable for each cohort individual. Right-side variables on area, provider, and beneficiary demographic characteristics will be extracted and further refined as needed from our common analytic files. Two additional provider variables important to this cohort’s analyses include hospital ownership of post-acute care units (from AHA files) and distance measures between beneficiary residence and post-acute care providers.

Cohort 2 (MCBS Cohort) Analytic Files

Implementing the research plans for cohort 2 requires the use of up to 3 years (1999 through 2001) of MCBS survey data and associated Medicare claims, eligibility files, MDS assessments, and OASIS assessments. Unlike cohort 1, file years prior to the baseline year are not needed to construct the cohort; and the number of file years analyzed after the baseline year are limited by the survey’s availability.

By design, our research questions of interest replicate most of those for cohort 1. Thus they encompass analyses on: 1) utilization; 2) expenditures; 3) time to long-term care entry. (multivariate post-acute care choice analyses cannot be conducted because of sample size limitations.) With the survey data, we can expand the expenditure questions on this cohort to include out-of-pocket expenditures and prescription drug expenditures.

Thus, the outcome variables constructed for this cohort's analyses include several expenditure measures (out-of-pocket, prescription drug, Part A stays and their associated payments, monthly Part B expenditures by BETOS category), as well as entry to non-Medicare nursing facility and entry to non-Medicare home health. To create the utilization and spending outcome variables, up to 4 years of claims will be analyzed. For each individual in this cohort, variable construction and analyses will cease at the time of non-Medicare nursing facility entry, death, or end of available data (i.e., neither of the prior events as of December 2002). The "time to" variables are calculated from the index hospital claim to, as applicable, the first non-Medicare MDS assessment (identified by lack of SNF claims), the death date on Medicare eligibility files, or the end of our data file.

Right-side variables on area, provider, and beneficiary demographic characteristics will be extracted and further refined as needed from our common analytic files. Additional right-side variables, drawn from the survey, include measures on social and financial support, functional status, cognitive status, and self-reported health.

Cohort 3 (Nursing Facility Entrants) Analytic Files

Constructing the research plans for cohort 3 requires the use of 2 years (1999 and 2000) of Medicaid claims and eligibility files, almost three years (1998 through 2000) of MDS assessments, Medicare claims, and Medicare eligibility files; and our common analytic files described above. As mentioned, up to four states (or four sets of Medicaid claims analyses) are tentatively proposed for this cohort. (Although the computer programs used to create these files could be easily modified to replicate these cohorts or analyses on other states.) We have had input from CMS staff and MSIS technical assistance contracting staff regarding latest availability of Medicaid Analytic eXtract (MAX) files and regarding data quality or data lag problems regarding particular states. Final state selection is one of the immediate next steps in this project.

To initially create the cohort, up to 12 months of MDS assessments will be scanned (in combination with SNF claims) prior to entry in the base year (1999), to isolate first-time non-Medicare nursing facility entrants (recognizing the start-date limitations of MDS data availability).

The research questions on cohort 3 encompasses backward-looking analyses in the 12 months prior to nursing facility entry as well analyses on the remaining portion of 1999 and in 2000. Specifically, the 5 research questions include: 1) prior year utilization and spending of Medicare and any Medicaid use, and specific identification of Medicare principal diagnoses and DRGs; 2) post-entry spending for Medicare and any Medicaid services; 3) post-entry utilization of Medicare services (particularly hospitalizations and post-acute care use); 4) post-entry resident quality of care indicators, constructed from MDS items on functional status, resident condition, etc; and 5) post-entry time to Medicaid conversion. For a given individual in the cohort, file construction and analyses will cease at the time of death or the end of available data (using Medicaid availability as the end point – likely December 2000).

Similar to the other two cohorts, the basic utilization and spending variables will consist of Medicare Part A stays and their associated payments, monthly Medicare Part B expenditures by BETOS category, and measures of Medicaid spending by type of provider. Medicare claims and MDS assessment data will be used to create time-varying variables for dual-eligibility status, comorbidity status, functional status, cognitive status, and nursing facility resident quality indicators. Our common analytic files will be used to create the area, provider, and beneficiary demographics measures. Of particular interest in this cohort is the use of CMS's data on nursing facility quality measures.

Overall File Development Approach

In addition to the common analytic files, developing a given cohort and it research plan involves writing computer programs for and processing several initial extracts, intermediate files, and final analytic files of large files of claims data and assessment data. All of these efforts— initial extracts, intermediate files, final analytic files, and accompanying code— may be valuable for future research on these data.

Using cohort 1's definition and analysis plans as an example, a set of programs and claims file sweeps will be necessary to construct the cohort. While many other analyses could be conducted on this group (CHF index admissions), the code could be easily modified to construct a different diagnosis cohort. In addition, we will need to create a set of intermediate health care event files, or claims and assessment data extracts, for cohort 1 where each event in one file is, for example, a Part A stay for a cohort individual. A Part B event file will include monthly sums of Part B activity for a cohort; an MDS event file will include non-Medicare nursing facility stays (as indicated by a lack of a coinciding Medicare SNF claim); and an OASIS event file will include non-Medicare home care episodes. These specific claims extracts could be used for a wealth of other analyses on individuals with CHF. Or, the cohort code and claims extract code could be modified to construct another hospitalized population and to extract their claims and assessments.

We note that, given the cohort analysis goal of the project, the project efforts will not result in the production of a single, final analytic file of Medicare and long-term care episodes of all beneficiaries (or all in a set of states). Episodes files of beneficiaries included in our cohort populations would be constructed and documented, as they are one of several intermediate files necessary to create the final files needed for each research question. This is consistent with the analytic orientation of the project and the phase 1 (development) and phase 3 (cohort analysis and reporting) requirements of the project.

Documentation for a given cohort's files will consist of several components, including text summaries and details of the cohort populations and research questions (to help provide context for the reader); text summaries of the initial extracts, intermediate files, and final files created; diagrams of key file creation steps; the names, definitions, descriptions, coding, and source files of variables extracted or created for our cohorts and models; tables indicating results of initial matches and merges; tables of descriptive information (means, percents, etc) on key variables in the final analytic files; pointers to source documentation (e.g., OASIS survey, MDS survey, CMS claims data layouts); and computer programs with commented code.

Next Steps

This Analytic Framework and Analysis Plan Report is a culmination of several phase 1 activities, all with the aim of developing policy relevant and clinically appropriate study cohorts, research questions, and statistical analysis plans. The activities included discussions with our clinical consultants, policy experts from CMS and the private sector, and Medicaid data experts from CMS and its technical assistance contractors. We also reviewed and synthesized the literature (and its application for this project) on several topics, including conceptual models of disability and long-term care use, public expenditure statistics on health and long-term care, determinants of long-term care use, measurement issues regarding health and function, and multivariate methods in modeling health outcomes.

The results of this activity are the cohorts and analysis plans presented here. The proposed plans address fundamental long-term care questions, using comprehensive models and complex modeling methods. The findings from this research would advance the literature, and the resulting data files and file construction programs could be used in many other studies by CMS or its research contractors. Implementing all of these research plans implies a substantial amount of analytic file construction effort that involves multiple data years, multiple data file types, complex variable creation, and detailed documentation requirements, followed by an equally substantial level of effort in statistical analysis, data interpretation, and report and manuscript preparation. As the next steps in this project, ultimate selection of cohorts, research questions, and number of states will be finalized in conjunction with CMS staff, and file development will begin.

Appendix 1. Highlights of Clinician Consultant Comments on Cohort Development and Analysis Issues

Our clinical consultants included three geriatrician/researchers, who provided critical input during the phase 1 tasks of selecting populations or conditions on which to focus and research questions to address. They also provided valuable insight regarding specific outcomes to consider (and others to avoid). The consultants' clinical insight and perspective regarding acute care use and progression of disability and long-term care use will be valuable in during phases 2 and 3 of this project as well, particularly regarding the construction and use of potential clinically-related control variables (in phase 2 file development), and in cohort analysis and data interpretation (in phase 3).

The clinical consultants provide a breadth and depth of clinical and research experience in the geriatric and long term care population, across the disability continuum, and regarding medical and functional assessment issues. One consultant is a physician/researcher at the Johns Hopkins Medical Institutions and the project director on studies developing and evaluating home health and other community-based alternatives to institutional care. Another consultant is a physician/researcher at Brigham and Women's Hospital and the Massachusetts General Hospital Institute for Health Policy; his research focus is on chronic respiratory disease epidemiology and care patterns among the elderly, and he is PI of studies examining outcomes and care patterns of elderly with prolonged mechanical ventilation. The third consultant is an occupational therapist/researcher at the University of Pittsburgh School of Health and Rehabilitation Sciences. Her research focuses on analyses of functional status and outcomes following medical and rehabilitation interventions, and on comparisons of functional status assessment tools.

In this appendix, we highlight comments from the consultants regarding cohort and research issue design, specific conditions, and selected measurement issues.

Cohort Selection Issues

Survey-Based Populations

One consultant encouraged use of a survey (such as our proposed MCBS or AHEAD survey cohorts) in order to access information on social support. The consultant's research and clinical experience suggests that patients with similar clinical presentations are in different placements (NF versus community) primarily because of social support and keen desire to remain in the community.

Epidemiological Look-Back Populations

The consultant also encouraged selection of a cohort(s) where we select LTC users (e.g., nursing home entrants), look back through their data history (claims and assessments) over several years, and identify summary spending patterns and spending determinants. A key point is that these cohorts look back over several years of data, while most longitudinal studies of, for example, determinants of nursing home entry use only a couple years' worth of data and do not identify expenditure or other patterns prior to entry. Another consultant encouraged this type of analysis as well, and hypothesized about the paths of stroke, hip fracture, CHF, pneumonia, and COPD patients (see below).

Waiver Participant Populations

One consultant acknowledged the variation in waiver program services and eligibility across states, and the need to address this variation if they are analyzed. For example, perhaps waiver analyses should occur within states and not across states.

The consultant commented that very little analyses of waiver participants have occurred, and thus, despite problems of state variation, there was merit in analyzing a waiver population in the cohorts.

Based on one consultant's experience with a state Medicaid waiver program, the key differences between waiver participants and NF residents are a) their social support and attitude regarding NF entry, and b) their functional and health status fitting a pattern of a relatively slow decline without major acute episodes (e.g., fitting the "frail" path rather than the "organ failure" path).

Racial and Ethnic Minority Populations

Two consultants noted that minority populations use informal support more than other populations.

Condition-Specific Populations

All the consultants suggested that useful conditions to study include stroke, joint replacement, and hip fracture. They further suggested that condition-based populations be analyzed separately (i.e., conduct separate analyses rather than using the conditions as control variables in a single analysis, and tabulate and assess expenditure patterns for the conditions separately). The consultants explained that the conditions proposed (stroke, joint replacement, hip fracture, CHF) have very different sequelae, and analyzing them together would muddy the identification of otherwise fairly distinct expenditure and utilization patterns.

Congestive Heart Failure

One consultant commented that persons with CHF would be harder to process, data-wise, because it is more prevalent in the overall elderly than the other conditions he mentioned above. Thus, the share of CHF patients using LTC likely will be smaller that the share of the other conditions using LTC. CHF patients have a 25% to 30% chance of readmission within 30 days of hospitalization. Another consultant commented that CHF patients will generally exhibit a pattern of functional decline after the acute episode is resolved (rather than a decline followed by improvement, such as with stroke patients). Relatedly, a potential functional status-related QI for CHF patients would be evidence of a marked change in the rate of decline over time. Another stated that CHF (and also pneumonia and COPD) patients often do not regain the level of function they held prior to an acute event, and added that the interval between acute events generally becomes shorter and LOS increases.

Pneumonia

One consultant stated that comorbidities and previous history are particularly important in analyzing pneumonia patients.

Stroke

Based on one consultant's research and clinical experience, stroke hospital stays are often very short (e.g., 5 days); rehab often ceases at 3 months; but function can continue to improve for up to 12 months post stroke. Declining function could be an indication of poor quality. Another considered stroke patients a good potential cohort in part because of the variations in outcomes from stroke and thus the likely variation in care paths.

Joint Replacement

One consultant suggested that the functional status of joint replacement patients should improve following the event (surgery), but cognitive status could be a likely explanatory variable if functional decline is seen following the replacement.

Hip Fracture

One consultant noted that common conditions among individuals who have hip fractures are osteoporosis and cognitive limitations. Another noted that hip fracture is highly associated with morbidity and mortality, and that there may be somewhat less variation in outcomes among this cohort and thus perhaps less variation in the care path.

Mechanical Ventilation

One noted that for patients on ventilators, functional status at the outset (prior to the acute event) is a good predictor for eventual functional status (after the event).

Other Analyses

Post-Acute Care Choice

One consultant stated that under the PPS, SNF admissions coordinators screen hospital patients to identify/admit the lighter cases. Based on experience with hospitals treating stroke patients, SNFs (and rehabilitation, generally) are often underused and patients are discharged to home as long as there is social support.

Another indicated that PAC choice is affected by several non-clinical factors including hospital incentives to discharge patient, PAC bed availability, patient/family expectation regarding outcome, hospital and physician relationships with PAC providers.

Quality, Outcome, and ACSC-related analyses

One consultant suggested that any ACSC-related analyses should focus on facility characteristics rather than beneficiary (health, diagnostic, functional) characteristics.

Measurement Issues

Functional Status

One consultant recommended that we be sure to include the early loss ADLs in functional status assessments. Focusing on late-loss ADLs will mask much of the process of decline. Relatedly, the RUGs ADLs scale is not recommended as a measure (at least as the sole functional measure), because it uses only late-loss items. The bathing ADL should not be used for NF or SNF patients, because of the facility-related issues (liability, FN policies, etc).

Another consultant recommended obtaining functional status data prior to major events; this is key to interpreting functional status measures in a post-event period. At a minimum, knowing admission source (NF or community) is important.

One also noted that an artifact and consequence of frequent staff turnover is a (false) appearance of excess disability among residents. That is, new staff are unfamiliar with each resident's abilities and generally assist more with ADLs.

Diagnoses and Comorbidities

One consultant had concerns about the MDS diagnoses section, and suggested using claims data when possible (e.g., using qualifying hospital claims for identifying diagnoses of SNF users and other PAC users who enter following hospitalization.)

Cognitive Status

One consultant noted that cognitive function should improve among delirium residents, and often is related to conditions such as infection and septicemia. Cognitive decline typically will be seen over a period of years, rather than months among dementia patients.

Quality and Outcome Analyses

One recommended using the following NF QIs from the MDS, in large part they are distinct from the natural course of decline (which can be confused with some of the other QIs):

- catheter use (very few should be used);
- pressure sores (should not exist with adequate turning of patients);
- feeding tube use (are used for a very short time when used); and
- walking improvement.

Items suggested to avoid using:

- UTIs (too correlated with catheters);
- infection; and
- weight loss (a very complex issue).

One consultant recommended using OSCAR deficiency data as a NF quality measure, with perhaps a weighted ranking of the deficiencies as a measure.

Another recommended using decreased function over a stay and decreased cognitive function in those with delirium as potential QI markers.

Another made the following comments regarding ACSC-like conditions identified as important in the frail elderly population:

- UTIs – associated with catheter use;
- septicemia – associated with central IV lines;
- cellulitis – associated with pressure sores; and
- dehydration – should see low prevalence of this (it has a slow development period; is easy for NF to identify and correct).

Summary Comments on Specific Factors

The feedback provided by the clinical consultants influenced both the choice of CHF as an important and analytically interesting disease cohort and the set of measures to be included in future analyses. In particular, the following factors were identified as clinically relevant:

- social support -- critical factor re: NF entry and SNF entry;
- hospitalization -- clear, negative impact on function;
- functional decline -- potential indicator of poor QI for stroke patients;
- catheters, pressure sores, feeding tubes, walking improvement -- good QIs to use for NF residents;
- increase in the rate of functional decline -- potential indicator of poor QI for CHF patients;
- functional status prior to acute event – key to interpreting post-event function; and
- admission source– helpful for interpreting post-even function.

Appendix 2. Overview of Conditions Considered for Cohort 1: Stroke, Hip Fracture, and Congestive Heart Failure

Our first proposed cohort is comprised of all community-dwelling elderly who are hospitalized for congestive heart failure in 1999. The primary focus of this cohort is to follow a clinically similar population through the course of their acute, post-acute, and long-term care encounters throughout and after 1999, and enable analyses related to the risk of long-term care and the relationships between long-term care entry and Medicare use. We selected CHF based on its leading prevalence in the community-dwelling and nursing home elderly population, the high level of interest in CHF among the disease management community, and on the confirmatory advice of our clinical consultants. An additional, logistical consideration was to select a condition with a relative short “tail” of long-term care use so that our episodes would not be subject to right-censor data problems. As additional years of MDS and OASIS assessment data and Medicaid analytic files become available, conditions with longer average long-term care utilization will not be as subject to this problem.

While CHF was selected due to these issues, we also gave serious consideration to stroke and hip fracture. Each condition is prevalent among the elderly, is generally associated with eventual long-term care use, and would be good cohort candidates, particularly as additional years of assessment data and Medicaid analytic files become available. This appendix includes summary information about the prevalence, burden, and risk factors for the three conditions.[29]

Stroke

A stroke, or cerebro-vascular accident (CVA), is a disruption in the blood supply to the brain. A temporary disruption in the blood supply is termed a transient ischemic attack or TIA (or, commonly, a mini-stroke). If disruption in the blood supply results in permanent damage to the brain tissue, a full stroke is said to have occurred. Stroke is a major cause of long-term disability. The American Heart Association estimates that $51 billion of health care spending was owed to stroke in 2003, with $12 billion of the total spent for nursing facility care. Taylor, et al. (1996) estimated that acute care spending incurred in the 2 years following a first stroke account for about 45% of the lifetime costs of stroke; long-term ambulatory care and nursing facility care account for about 35% and 18%, respectively, of lifetime costs.

Between 1988 and 1997, the (age-adjusted) hospitalization rate for stroke rose 18.6%, from 560 to 664 per 100,000. The total number of stroke hospitalization days fell during this time, due partly to a decline in in-hospital mortality. Hospitalization rates vary by area—higher rates occur in the south, and lower rates occur in the west (Fang and Alderman 2001).

Mortality due to stroke is associated with age, number of neurological deficits at onset of initial stroke, and the presence of myocardial infarction, cardiac arrhythmia, and diabetes mellitus. Hazard ratios associated with these three conditions are 1.7, 1.5, and 1.4, respectively

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[29] These summaries are intended to give a general impression of the literature. A detailed analysis of the findings based on comparability of measures used was beyond the scope of the current project.

(Lai, et al. 1995). Lai, et al. found that hypertension and transient ischemic attacks are not associated with death. The cumulative survival rates for stroke at one through four years are, respectively, an estimated 87%, 79%, 73%, and 72% (Lai, et al.1995; Bravata 2003).

Davis, et al. (2003) found that about 50% of Medicare beneficiaries hospitalized for stroke are discharged home. About 20% are discharged to skilled nursing facilities; 20% to other facilities, and about 10% die in the hospital. This is consistent with the findings by Fang and Alderman (2001). Rundek, et al. (2000) found that age and cognitive impairment increase the likelihood of long-term nursing facility placement following hospitalization for stroke by a factor of three. These risk factors, in addition to living alone prior to hospitalization, are associated with short-term SNF placement for rehabilitation.

Hip Fracture

A hip fracture is a fracture of the neck of the femur. The femoral neck is the area between the shaft of the bone and the head of the femur (or, the ball that fits into the socket of the hip). The health care costs of hip fracture are estimated at about $9 billion annually.

More than 250,000 hospitalizations occur each year for hip fractures; about 86% of those occur among the elderly (Braithwaite, et al. 2003). Three-fourths of elderly with hip fractures are women, and white women are twice as likely to suffer hip fractures than black and Hispanic women. Other risk factors include transferring, age 75 or older and cognitive impairment. The odds ratios associated with these three risks are 2.0, 1.6, and 3.0, respectively (Walter, et al. 2003).

Hip fractures among the elderly are associated with high mortality rates and short survival rates. Mortality is highest in the two months following fracture (Jacobsen 1992). This is consistent with Braithwaite, et al. (2003), who found that 56% of the decrease in average life occur in the 6 months following the fracture. Jacobsen (1992) found higher mortality rates among men than women, and among black women than white women.

Hip fracture also is associated with post-acute care use and long-term nursing facility use (Finsen, et al. 1995; Sloan, et al. 1995). In a recent study, Chen, Kane, and Finch (2000) argue that home health care is a more cost-effective setting for post-acute rehabilitation of most hip fracture patients.

Congestive Heart Failure

Congestive heart failure (CHF) is a clinical condition resulting from failure of the heart to maintain adequate circulation. It is manifested by pulmonary edema, which is the result of excessive, diffuse accumulation of fluid in the alveoli and interstitial tissue of the lung. The inability of the heart to contract and relax normally causes pulmonary edema. This inability may be due to an underlying condition such as cardiac arrhythmia, long-standing hypertension, amyloidosis, hemachromatosis, chronic pericarditis, myocardial disease, or valvular disease. CHF can affect the right, left, or both chambers of the heart. Annual hospital costs for CHF exceed $8 billion, and annual outpatient costs for CHF are about $3 billion. On average, a hospital stay costs $10,000. Overall management of CHF patients costs an estimated $18 billion annually (Haldeman, et al. 1999).

Roughly five million individuals in the US have CHF; over 75% are elderly. About 500,000 cases are diagnosed each year. The average mortality rate is 10% at one year after diagnosis and 50% at five years after diagnosis (Wilkes, et al. 1999). CHF mortality rates increase exponentially with age (Rich 1997) CHF is the most common cause of hospitalizations among the elderly (CMS 2003). Post-hospital survival rates are fairly low-- less than 25% of elderly survive 6 years after initial hospitalization for CHF; post-hospital survival rates are somewhat higher among women (25% to 30% among women; 20% among men). Rehospitalization rates are generally high, but rates vary substantially across the literature. Rich, et al. (1995) reported that studies of rehospitalization rates within 3 months and within 6 months after initial CHF hospitalization discharge were roughly 30% and roughly 47%, respectively. In the last six months of life, CHF patients' function declines substantially and hospitalizations occur more frequently (Levenson, et al. 2000; English and Mastrean 1995). CHF also is a risk factor for death in the long-term care setting. In Flacker and Kiely's (2003) study of one-year mortality among nursing facility residents, those with CHF were roughly 60% more likely to die within the year than other residents.

In a study of hospital discharge destinations, Haldeman, et al. (1999) found that roughly two-thirds of individuals hospitalized for CHF were discharged home, about 8% died in the hospital, and the remaining were discharged to other care settings. Women were more likely to be discharged to long-term care facilities and SNFs than men.[30]

The primary risk factor for CHF is coronary heart disease. He, et al. (2001) estimated that 62% of all CHF cases are accounted for by the condition. Other risk factors include male gender, high school education, low physical activity, smoking, and the presence of obesity, hypertension, diabetes, valvular heart disease, as well as coronary heart disease (He, et al. 2001). Chen, et al. (1999) studied risk factors for CHF among those without prior diagnosis of coronary heart disease, conditional on suffering myocardial infarction after CHF. Only the odds ratio associated with age differed significantly by those with and without later occurance of myocardial infaraction.

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[30] Haldeman, et al. found that 67% and 57% of men and women, respectively, were discharged home; 12% and 21% of men and women, respectively, were discharged to a LTC facility or SNF; 6% of both men and women were discharged to another acute care hospital, 8% and 7% of men and women, respectively, died in the hospital. The remaining 7% to 8% of discharge destinations were unidentified.

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Appendix 3. Survey Data Sources Considered for Cohort 2

Despite the richness of the project's core data of Medicare and Medicaid claims and patient assessments, other factors important in explaining long-term care entry include, for example, individuals' level of social and economic support. Because of the importance of this additional information, we propose to use survey-based information as the basis for one of our three proposed project cohorts.

We considered three surveys, the Medicare Current Beneficiary Survey (MCBS)**,** the National Long Term Care Survey (NLTCS), and the Health and Retirement Study/Study of Assets and Health Dynamics Among the Oldest Old (AHEAD). Each of these would add to the value of the project's core data (claims and assessments) and could be linked by beneficiary identifier to the core data. The survey data also will be useful because of the availability of universal and uniformly collected functional and cognitive status data on the participants. The project's core data includes this information only on users of nursing facilities, home health agencies and IRFs at the time of their utilization, and this information is not collected in a uniform manner (in terms of question structure) across the settings.

This appendix describes the NLTCS and AHEAD surveys, which we considered but did not choose for linking with the project's core claims and assessment data. (For convenience, the MCBS summary from Chapter III is repeated in this appendix as well.) Overall, each of these surveys in combination with the project's core data would provide uniquely valuable information, and would accommodate somewhat different types of analyses and research questions on the progression and use of long-term care. Incorporating all three surveys at the outset would be somewhat redundant for the conduct of initial analyses in this project. However each survey alone would add valuable functional status and

Medicare Current Beneficiary Survey

Westat, Inc. annually conducts for CMS the Medicare Current Beneficiary Survey (MCBS), which collects information on a nationally representative sample of Medicare beneficiaries residing in the community or facilities. Key advantages of potentially using the MCBS with this project include the ease of merging the survey data with other administrative data, the common survey items among both community and facility residing respondents, as well as its functional status and contextual information regarding respondents. The main weakness is its somewhat small sample size regarding beneficiaries identified as disabled or using long-term care.

The MCBS is a rotating longitudinal panel survey that follows representative samples of Medicare beneficiaries over a four-year period. The annual sample is about 12,000 persons, including an over-sample of those age 85 or older (Adler 1994; Laschober and Olin 1996; CMS 2002). A supplemental sample is drawn and interviewed in the fall of each year (September through December) to replace participants being retired from the sample, to replenish cells depleted by refusals and death, and to correct for coverage errors in the initial sampling frame (CMS 2002). Since 1994, the supplemental sample has been representative of beneficiaries alive and eligible on January 1 of the survey year. The full sample represents all beneficiaries who were enrolled in Medicare during the calendar year. Weights are constructed to be used for full-year and round estimates.

The "Cost and Use" component of the MCBS contains a wide range of information on the survey participants, including data regarding health status, supplemental insurance information, income, prescription drug expenditures, out-of-pocket expenditures, social support, as well as health care use and Medicare program payments. For beneficiaries in fee-for-service Medicare, the health care encounter and payment data from the survey are reconciled with participants' actual Medicare claims. For each respondent, an initial baseline interview elicits information on non-changing characteristics (such as date of birth, gender) and the core survey questionnaire, administered each fall between September and December, provides information on personal and health characteristics that change over time (such as income, living arrangement, and health and functional status).

The health related survey questions include items on overall health status (such as self reported health status, presence of selected medical conditions), service use (such as counts of admissions or health system encounters, by type of provider), and functional status. Functional status is measured using ADL and IADL items. ADL items capture limitations in personal care, while IADLs (such as housework, meal preparation, financial management) capture limitations more related to the ability to live independently (Lawton and Brody, 1969). The MCBS asks individuals whether they receive any personal assistance or supervision in conducting the activities. Five ADLs (bathing, dressing, toileting, transferring, and eating) and three IADLs (telephoning, shopping, and money management) are used in facility interviews. As noted below, additional ADL questions were added in the 1997 survey round.

The MCBS also tracks respondents' changing residence, or institutional status. Initial interviews, whether conducted in the community or in a facility, are conducted and for each year a time line noting changes of residence is constructed for each person. This tracking is useful in conducting analyses of long-term care lengths of stay, episodes, and overall pathways. For respondents in institutions at the time of the survey, the MCBS also collects information about facility characteristics (such as number of beds, ownership) and types of services routinely furnished by the facility (such as nursing or medical care, supervision of self-administered medications, assistance with ADLs, or 24 hour supervision or nursing).[31] In the 1997 and later survey rounds, the survey timeline also specifies Medicare-covered or skilled stays in facilities, in addition to residential or long-term care stays in facilities. In prior years, SNF stays were not identified or incorporated in the timeline (although they can be identified by merging survey data with the respondents' SNF claims).

Also in 1997 and later survey rounds, the MCBS modified the medical condition, ADL, and IADL questions for participants residing in facilities so as to be more consistent with the

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[31] The MCBS defines a facility as having three or more beds and providing long-term care services throughout the facility or in a separate unit (CMS 2002). In addition to nursing homes, long-term care facility types identified in the MCBS facility data are retirement home, domiciliary/personal care, mental health facility, institution for the mentally retarded/developmentally disabled, mental health center, life care/continuing care, assisted living facility, rehab facility, and "other place".

MDS assessments required on all patients in Medicare-certified or Medicaid-certified nursing facilities. Information was taken from the most recent MDS assessment, if available, and otherwise from the admission assessment. Regarding medical conditions, the list of conditions was changed to correspond to the medical conditions section of the MDS instrument. Regarding ADLs, before 1997 respondents were asked whether the individual had difficulty performing each ADL "by himself/herself and without special equipment" because of health or did not do the activity because of health, and if health-related difficulty was reported, whether help or supervision was received for the activity. As of 1997, facility respondents were also asked to provide levels of dependency for each ADL, from independent to totally dependent (or the activity did not occur). There is no direct determination of health reasons if the activity did not occur. Regarding IADLs, before 1997 respondents were asked whether the individual had difficulty doing each IADL without help because of health or did not do the activity because of health. There was no follow-up question regarding whether help was received. The two changes would have a tendency to increase the number of persons reported to be dependent in IADLs or ADLs, but it is not clear that the difference would be large within the population living in long-term care facilities.

Health and Retirement Study/Study of Assets and Health Dynamics Among the Oldest Old

The AHEAD survey is a nationally representative longitudinal household survey of persons born before 1924, conducted by the University of Michigan for the National Institute on Aging. Individuals were first interviewed in 1993, and every two years after that. The survey is a sub-sample of the overall HRS study. The HRS study is comprised of four sub-samples (the HRS, AHEAD, Children of the Depression, and War Babies sub-samples). The first three sub-samples are comprised of individuals who are *now* elderly, and thus would allow for cross-sectional analyses of the elderly and long-term care. The sampling frame of the AHEAD sub-sample makes it the only longitudinal sample of the elderly.

The key strengths of using the AHEAD survey is its longitudinal framework and its uniquely and extremely detailed information on the socioeconomic status of the elderly, in addition to questions regarding health and functional status. The main limitations of the study are its small sample size (relative to the MCBS and NLTCS), its lack of facility-residing respondents, and the presence of some difficulty in currently obtaining permission to link the survey data to our core Medicare and Medicaid data. The survey leaders indicate that these linking opportunities will be finalized in the near future.

The AHEAD interview consists of several detailed questions regarding demographics (including education and parents' education), family structure and support (including details regarding children and distance to them), medical and life insurance coverage, type and value of housing, employment status and history, financial and retirement expectations (including likelihood of entering a nursing home or moving to be nearer to children), income, net worth, and health.

The health questions include items regarding 12 medical conditions (as addition to assessment of height, weight, vision, hearing, smoking, drinking, depression, and pain), cognition, health care utilization, and payments (including long-term care use and payments), out-of-pocket costs, limitations regarding six ADLs, limitations regarding five IADLs, and the extent of any ADL/IADL assistance and out-of-pocket costs associated with that assistance. The interview questions regarding the other sub-samples are extremely similar, but not identical to the AHEAD questions.

HRS Sub-Samples

The HRS sub-sample consists of people who were born in 1931 through 1941 and were household (community) residents in spring 1992, and of their spouses or partners at the time of the 1992 or subsequent interviews. In the 2002 interviews, these respondents were mainly 61 to 71 years old. This sub-sample was interviewed in 1992 and every two years after.

The AHEAD sub-sample consists of people who were born before 1924, were household residents in spring 1992, and were still household residents at the time of their 1993-94 interview, and their spouses or partners at the time of the initial or subsequent interviews. In the 2002 interviews, these respondents were mainly age 79 or older. The sub-sample was interviewed in 1993-94, 1995-96, 1998 and every two years after.

The Children of the Depression sub-sample consists of people who were born in 1924 through 1930, were household residents when first interviewed in 1998, and who at that time did not have a spouse or partner born in the AHEAD or HRS sampling frames (i.e., born before 1924 or between 1931 and 1947), and their spouses or partners at the time of the initial or subsequent interviews. In the 2002 interviews, these respondents were mainly 72 to 78 years old. This sub-sample was interviewed in 1998 and every two years after

The War Babies sub-sample consists of people who currently are near-elderly—they were born in 1942 through 1947, were household residents in spring 1992, who at that time did not have a spouse or partner born in the AHEAD or HRS sampling frames (i.e., born before 1924 or between 1931 and 1941), and were still household residents at the time of the first interview in 1998, and their spouses or partners at the time of the initial or subsequent interviews. In the 2002 interviews, these respondents were mainly 55 to 60 years old. The sub-sample was interviewed in 1998 and every two years after.

The National Long Term Care Survey

The NLTCS is a nationally representative survey of elderly Medicare beneficiaries conducted by the Census Bureau under the direction of Duke University Center for Demographic Studies. It is funded manly by the National Institutes on Aging. It is a longitudinal survey designed to assess changes in the health and functional status, track expenditures and Medicare service use, and identify the availability of personal, family, and community resources for caregiving. Four supplemental surveys on primary informal caregivers have been conducted (1982, 1989, 1999, 2004). Three decedent followback surveys have been conducted (1984, 1999, 2004). The survey is designed to identify elderly who are chronically disabled in one or more ADLs or IADLs. Key advantages of potentially using the NLTCS with this project include its large sample of disabled respondents (roughly 1,000 facility-residing and 3,000 community-residing respondents per survey wave, with another 2,000 nondisabled also administered the detailed questionnaire in 1994 and since). Medicare claims and enrollment data from 1982 on are merged to the survey data. The potential for merges of additional data (e.g., MDS assessment data) is not known. The main limitations of the NLTCS are that it is a periodic survey, and many key survey items are not consistent between community and institutional respondents or are omitted for institutional respondents.

The survey began in 1982 as a survey of the community disabled population, with individuals drawn from the 1982 Medicare enrollment files. Beginning in 1984, additional waves of the survey have been conducted at five-year intervals (1984, 1989, 1994, and 1999), and a fifth wave is being fielded in 2004. About 5,000 people die between waves and are replaced by a sample of about that size of people who have become age 65 since the prior wave. In 1994 and 1999, supplemental samples of those age 95 or older were added to increase precision of estimates for the very old, where erosion of sample size due to mortality was most severe. Beginning in 1984, all waves have included those living in institutions as well as community residents. At each wave, a screener questionnaire is administered to the complete longitudinal sample from the previous waves and new entrants, so that in addition to the longitudinal component, the survey produces a representative cross-section of the elderly in each survey year. The screener collects basic demographic information on all respondents and divides the sample into three groups: the non-disabled (or “screen-outs”), the chronically disabled living in the community, and the chronically disabled living in an institution. Chronically disability is defined as reporting difficulty with at least one ADL or inability to perform at least one IADL lasting or expected to last at least 3 months. All chronically disabled respondents, as well as a sample of the “screened-out” population in the 1994 survey and subsequent waves, then receive a detailed questionnaire.

The total number of respondents (including screen-outs) is about 21,000 in 1984, 16,000 in 1989, 17,000 in 1994, and 17,000 in 1999. The subset with detailed interview information includes about 7,600 detailed respondents in the 1984 wave and about 6,000 detailed respondents in the later waves. Of that subset, the institutional sample ranges from 1,690 (1984) to 1,025 (1999). Medicare enrollment and claims data from 1982 on have been merged to all survey respondents (i.e., those with just screening interview information as well as those with the detailed disability interview information) in all years. (Claims since 1991 are in Standard Analytic File format, Version I.)

The survey collects information on a variety of socio-economic and support measures, including age, gender, ethnicity, education, income, living arrangement, neighborhood, residence, and community characteristics, family support, insurance, military service, and use of unpaid and paid caregivers (and payments to caregivers). Health and functional status information includes self-reported medical conditions, ADL limitations, IADL limitations, type, source and amount of help received, use of assistive devices, and cognitive status. Through the survey and its linked Medicare claims files, information is available about facilities and medical providers, Medicare expenditures, and Medicare service utilization.

Some changes have been made in the information collected over the waves of the survey. For example, in 1984 and 1989 (the first waves to include the facility-residing population), the detailed questionnaire was administered only to those identified as chronically disabled or living in an institution on the screener interview and to those who had received a detailed interview in a previous wave. Beginning in 1994, a subsample of the nondisabled identified on the screener also have received the detailed questionnaire, so that detailed information is available on a representative cross-section of all Medicare elderly. Some survey questions differ depending on a respondent’s residence (community or facility), and questions about medical conditions and informal support are collected only on community respondents.   The 2004 wave is collecting medical condition information on facility respondents.

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Appendix 4. Home and Community-Based Services 1915(c) Waivers

Most of the recent growth in states' home and community-based services (HCBS) spending has been due to the growth in their section 1915(c) waiver programs.[32] In some states, particularly Washington and Oregon, these waiver programs have even replaced nursing facilities as the dominant means of providing long-term care to nursing facility-eligible elderly (GAO 2003). As of June 2002, states operated a total of 263 1915(c) waivers, with 77 serving the elderly. Familiarity with state-specific waiver program activity is useful for this project in terms of potential analyses focusing on waiver program participants, and in terms of constructing variables to control for state-specific elderly participation in our long-term care analyses.

In this appendix, we briefly describe the 1915(c) waiver program and then summarize recent waiver activity in the 13 states that are the focus of the Urban Institute's Assessing the New Federalism research program on state-level health and social programs and policies (Alabama, California, Colorado, Florida, Massachusetts, Michigan, Minnesota, Mississippi, New Jersey, New York, Texas, Washington, and Wisconsin). Our state summaries draw mainly from three sources: 1) the CMS website page, "Overview of State Home and Community-based Services Waivers," and its numerous links; 2) states' Medicaid websites; and 3) a detailed report by Kitchener, et al. (2003), "Medicaid Home and Community-Based Services: Program Data, 1992-2001".[33]

Authorizing Legislation

Congress established the Medicaid Home and Community-Based Services (HCBS) 1915 (c) Waiver Program through section 2176 of the Omnibus Budget Reconciliation Act of 1981. Before this legislation, long-term care benefits under traditional Medicaid were limited to personal care and home health services and to care in institutional facilities (hospitals, nursing facilities, and intermediate care facilities for people with mental retardation or ICF/MRs). Currently, all states have at least one HCBS 1915 (c) waiver program except Arizona, which provides long-term care services through an 1115 waiver.

The two founding concepts of the HCBS waiver legislation were to slow the growth in Medicaid spending; and to offer better quality care, quality of life, and increased choice in care provision to participants than what, in many instances, could be furnished for them in institutional settings. The waiver program would meet these twin goals, Congress reasoned, by allowing care to be provided to individuals in the presumably less expensive home and community setting. To help achieve the desired cost savings and ensure that the waiver program did not effectively expand the Medicaid program's eligibility criteria, the legislation limited the

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[32] "HCBS waiver" or "waiver" refers here to the HCBS 1915(c) waiver program.

[33] Note that formal waiver program evaluations generally have not been completed. A large part of the waiver literature consists of summaries of state-level waiver expenditures and participation rates (eg, Kitchener 2003), individual program descriptions (eg, from state and CMS websites), and tracking efforts about new waivers and other HCBS initiatives among states (eg, National Conference of Legislators tracking activities; State Health Policy Forum tracking activities).

scope of waivers to only those individuals who, absent the waiver, would be cared for in institutions. Further, states must ensure that on average, the per capita costs of providing care under the waiver do not exceed the costs of care for an identical population in institutional settings. Another key feature of the HCBS waiver program is that it allows individual states the flexibility to tailor programs and services to the particular needs of their local populations, rather than requiring them to implement a uniform or federally-mandated program or set of benefits. States can target both specific populations and specific geographical areas for waiver services, by waiving, respectively, the “comparability” and “statewideness” requirements in the federal Medicaid legislation. States also have more flexibility with waiver programs in that they can limit the amount of services and supports per individual and serve more people than would be required under traditional Medicaid.

As specified in the 1981 legislation, states are allowed to request and provide (with approval from the Secretary) a range of long-term care services under a waiver program including: 1) case management services; 2) homemaker services; 3) home health aide services; 4) personal care services; 5) adult day health care services; 6) habilitation services; and 7) respite care services (Duckett, 2000). Other services may be approved and provided as well, including other in-home support services, transportation, meal services, minor home modifications, adult day care, and special communication services. Specifically forbidden from the waiver program are payments for room and board (excluding institutional respite care and live-in personal caregivers) (Weiner, 2000).

Most states implement multiple waiver programs. Many have separate programs targeting different categories of individuals, including the elderly, the elderly and/or people with physical disabilities, people (of any age) with physical disabilities, people with developmental disabilities, and people with behavioral health conditions. States also may have waiver programs designed for individuals with a specific illness, such as AIDS.[34]

Selected State Summaries

Each of the 13 state segments below includes a summary of 1915(c) waiver program activity as of 2001 as well as updates on any post-2001 waiver developments, a summary table of waiver participation and spending in 2001, and a list of the state’s current aged waiver programs and age/disabled waiver programs. The waiver participation and spending data are broken out by all 1915(c) programs and by those serving the aged and the aged/disabled. (Data specifically on the aged in programs serving both the aged and disabled are not available.) Descriptions of the current waiver programs provide useful context whether considering specific analyses on the waiver population, or for simply using participation rates as covariates in our

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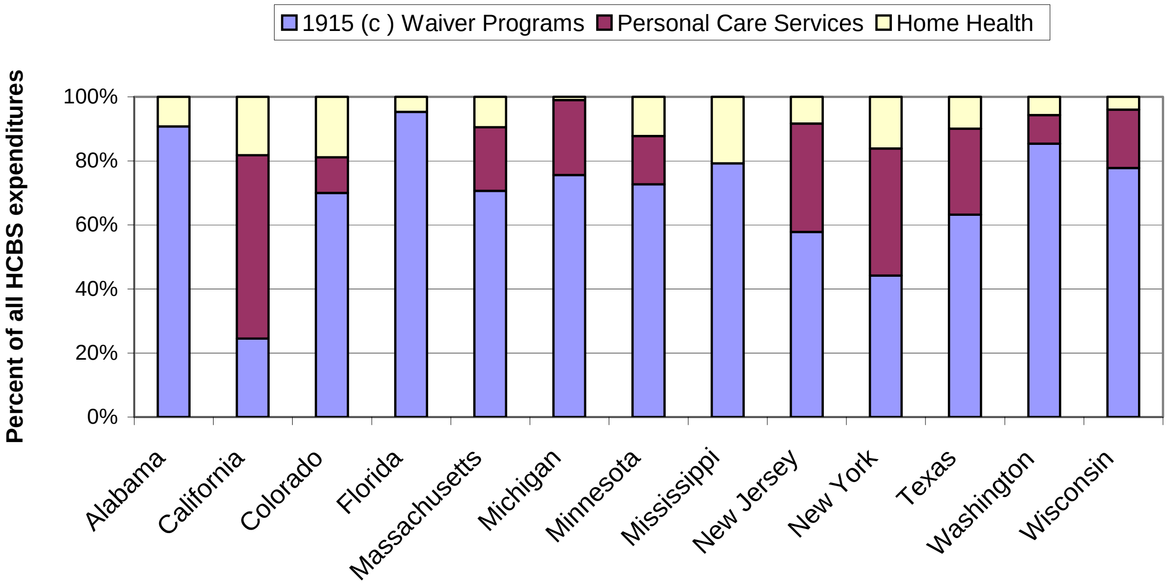
[34] Congress amended the waiver program several times since the authorizing legislation in order to incorporate changes. These amendments are less relevant to the elderly population, but are included here for completeness. The amendments: 1) expanded coverage to individuals who, absent the waiver, would necessitate a hospital level of care; 2) added (with exceptions), pre-vocational, educational and supported employment to the list of allowable habilitation services; 3) extended the waiver renewal period from three years to five years; and 4) included day treatment and other partial hospitalization services, psychosocial rehabilitation services and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.

analyses. The post-2001 waiver activities are useful when considering future analyses and future data years. More detailed tables following the summaries include the waiver data in the context of states' other HCBS activities (Tables A4-1 through A4-3). We focused on 13 states in order to develop a more thorough knowledge of waiver programs, but as a control variable in our analyses we would apply participation rates for all 50 states.

Across the 13 states explored below, waiver spending in 2001 accounted for over 50% of states' Medicaid HCBS spending except in California and New York (Figure A4-1). California spending is mostly on personal care service programs and New York spending is split roughly evenly between waiver programs and personal care services.

Figure A4-1: Distribution of HCBS Expenditures for Selected States, by Type of Program, 2001



Alabama

Alabama has two HCBS waiver programs serving the aged and/or physically disabled. The "Independent Living Waiver" serves adults (age 18 and over) with severe and chronic physical disabilities. This waiver provides a broad spectrum of services including personal care, environmental adaptations, assistive technology and repairs, medical services and case management. The "Homebound Waiver" serves elderly and/or disabled individuals and provides personal care, adult day health, case management, companion services, respite services, and homemaker services.

In early 2003, Alabama approved a new HCBS waiver (0398) that provides services to individuals who are disabled due to Alzheimer's disease or dementia. Services include assisted living, medical supplies, attendant call system, adult residential care, and case management.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
Alabama, 2001		**(#)**	**(%)**
Participants	11,564	7,272	63%
Change from 2000	12.9%	1,067	17.2%
Participants per 1,000 Population	2.59	1.63	63%
Change from 2000	12.6%	0.24	17.3%
Expenditures	$217,638,481	$39,092,333	18%
Change from 2000	60.5%	-$1,338,100	-3.3%
Expenditures per Participant	$18,820	$5,376	29%
Change from 2000	42.2%	-$1,140	-17%

Alabama HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
AL 0068	Independent Living Waiver
AL 0241	Homebound Waiver
AL 0398	Alzheimer's or Dementia

Sources:
http://www.hcbs.org/files/7/348/Alabama_AD.pdf
http://www.cms.hhs.gov/medicaid/waivers/alwaiver.asp
http://www.cms.hhs.gov/medicaid/services/regular.pdf

California

California has four Medicaid HCBS waiver programs for aged and/or physically disabled adults. One waiver serves the aged only (0141), and three waivers (0139, 0348, 0384) serve the aged or disabled. These three focus on different levels of care needs. All of the waivers, however, offer a wide range of services including respite care, case management, environmental modifications, personal emergency response systems, family counseling, habilitation, personal care, assistive technology, chore/home maintenance, and therapy services. All of the waivers serve either a moderate (500 - 5000) or large (>5000) population.

One of the service types that MediCal (California's Medicaid program) is interested in improving in its HCBS waivers is providing back-up assistance when a person's attendant is absent. In response to demand for more participant control and choice, some California programs are addressing the issue of locating back-up support when a participant needs a new provider or a substitute provider when an attendant is unavailable. Alameda County and San Francisco County are two of several California counties that offer temporary back-up services to individuals with disabilities that direct their own care. In a comprehensive evaluation of the original Alameda County program, participants reported that back-up services are important, easy to obtain, and available upon short notice. The San Francisco County program has not been evaluated, but provides similar services.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
California, 2001		**(#)**	**(%)**
Participants	50,537	12,712	25%
Change from 2000	13.5%	1,289	11.3%
Participants per 1,000 Population	1.46	0.37	25%
Change from 2000	11.8%	0.03	8.8%
Expenditures	$765,624,295	$78,493,194	10%
Change from 2000	31.7%	$4,351,742	5.9%
Expenditures per Participant	$15,150	$6,175	41%
Change from 2000	16.1%	-$316	-5%

California HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
CA 0139	Nursing Facility Waiver (NF/AB)
CA 0141	Multi-purpose Senior Services Program Waiver (MSSP)
CA 0348	Nursing Facility Waiver (NF Subacute)
CA 0384	In-home Medical Care Waiver (IHMC)

Sources: http://www.cahsah.org/statebudget/waiveroverview.pdf
http://www.cms.hhs.gov/medicaid/waivers/cawaiver.asp

Colorado

Colorado has one HCBS waiver program for aged and disabled (0006). The waiver serves over 5000 participants and offers residential care, personal care, and respite care services.

In the 1990s, Colorado conducted a study that found that roughly 40% of Medicaid recipients admitted to nursing facilities were admitted from a hospital stay and that one-third of the nursing facility entrants were eligible for waiver services. As a result of the findings, Colorado implemented the "Fast Track" program, which determines HCBS eligibility more quickly in efforts to reduce the number of preventable nursing facility admissions. Under the program, a Medicaid HCBS case manager and financial eligibility staff work at a major urban hospital (Denver Medical Health Center) to quickly determine eligibility for hospital patients needing long-term care following discharge. Between March 1999 and June 2001, 149 people were placed into HCBS care and "avoided likely nursing facility residency."

Colorado also has begun a 5-year demonstration project in which participants can use money to buy in-home services from attendants they personally select, hire, and train. These services substitute for Medicaid state plan home health and personal care services. Colorado also has established single entry point agencies that function to inform elderly and disabled persons about long-term care options and coordinate easier access for individuals interested in long-term care programs. Over the five years that agencies have served the entire state, enrollment in HCBS waiver programs doubled. The number of nursing facility residents remained stable over the period.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
Colorado, 2001		**(#)**	**(%)**
Participants	23,925	14,082	59%
Change from 2000	7.8%	1,076	8.3%
Participants per 1,000 Population	5.42	3.19	59%
Change from 2000	5.6%	0.18	6.0%
Expenditures	$304,367,003	$72,256,809	24%
Change from 2000	9.7%	$7,051,974	10.8%
Expenditures per Participant	$12,722	$5,131	40%
Change from 2000	1.8%	$118	2%

Colorado HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
CO 0006	Aged and Disabled

Sources: http://www.cms.hhs.gov/medicaid/waivers/cowaiver.asp
http://www.cms.hhs.gov/promisingpractices/cocopdh.pdf

Florida

Currently, Florida operates four HCBS waiver programs serving the aged and/or disabled. Three of the four waivers (1090, 0116, 0315) are more general, offering the same core services that include personal care, case management, respite, adult day health, chore, personal emergency response system, companion, family training, home delivered meals, financial assessment and risk reduction, nutritional assessment, physical therapy, occupational therapy, and speech therapy. In addition to these services, the “Aged and Disabled Adult Services” (1090) waiver offers homemaker services, skilled nursing, special medical equipment and supplies, counseling, pest control, escort, and respiratory therapy. The “Home and Community-Based Channeling Services Waiver for Frail-Elders” (0116) offers skilled nursing, special medical equipment and supplies, counseling, and environmental modifications. The “Nursing Home Diversion” waiver offers homemaker, attendant care, escort, and environmental adaptations. A fourth waiver, the “Assisted Living for the Frail Elderly” waiver (0280), focuses on the frail elderly and aged/disabled individuals aged 60 or older living in assisted living facilities. This waiver offers case management and incontinence supplies. The population sizes of these four programs range from small (<500) to large (>5000).

CMS recently approved two new Florida waivers. Waiver 0406 (approved in early 2003) is a combination of the 1915(c) and 1915(b) waivers and will provide adult day health to individuals aged 75 and older in Lee and Palm Beach counties. Waiver 0392 (approved in late 2002), targets adults who are disabled with cystic fibrosis and offers several types of services including case management, homemaker, personal care, respite, adult day health, skilled nursing, transportation, specialized equipment, chore, companion, in-home care supplies, nutritional and vitamin supplements, acupuncture, massage therapy, exercise therapy, respiratory therapy, and individual and family counseling.

Florida is waiting for approval of another 1915b/c waiver, which targets elderly with Alzheimer’s disease or dementia. The program is expected to serve 350 participants and will offer services including case management, adult day health care, respite care, wanderer alarm system, wanderer identification and location programs, family training, behavioral assessment and intervention, incontinence supplies, personal care, environmental modification, and pharmacy review.

Florida also participated in a two-year HHS demonstration program testing the substitution of cash allowances for Medicaid services from providers. The program was run under an 1115 waiver, “Consumer Directed Care”, as part of the Cash and Counseling Demonstration project funded by HHS and the Robert Wood Johnson Foundation. The case group participates received a monthly cash allowance and services to help them effectively use the allowance. Initial findings from the evaluation indicate high satisfaction with the project, and the program has begun to expand across the state with some modifications.

Florida, 2001	1915 (c) Waiver Programs Total	Aged/Disabled (#)	 (%)
Participants	50,689	18,019	36%
Change from 2000	16.2%	78	0.4%
Participants per 1,000 Population	3.09	1.09	35%
Change from 2000	13.8%	-0.03	-2.7%
Expenditures	$560,185,338	$105,250,110	19%
Change from 2000	63.7%	$14,897,109	16.5%
Expenditures per Participant	$11,051	$5,841	53%
Change from 2000	40.8%	$805	16%

Florida HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
FL 0116	Home and Community Based Channeling Services Waiver for Frail-Elders
FL 0280	Assisted Living for the Frail Elderly
FL 0315	Nursing Home Diversion
FL 0392	Cystic Fibrosis
FL 1090	Aged and Disabled Adult Services
FL 0406	Florida Comprehensive Adult Day Health Care Program (Lee and Palm Beach)
FL pending	Florida Alzheimer's 1915b/c Waiver (pending)

Sources: http://www.cms.hhs.gov/medicaid/1915c/fl0116extltr5203.pdf
http://www.state.fl.us/audgen/pages/pdf_files/2004-032.pdf
http://www.cms.hhs.gov/medicaid/waivers/flwaiver.asp

Massachusetts

Massachusetts has one HCBS waiver program that serves a large (>5000) population of the near-elderly and elderly (aged 60 or older). Services included under the waiver are adult day health, homemaker, home delivered meals, companion services, and residential habilitation.

In a recent initiative to help disabled persons of any age obtain housing, Massachusetts has created a central registry for accessible housing that includes public housing, privately operated subsidized housing, and private market-rate developments. People with disabilities can access the registry on the Internet and by contacting the state's Centers for Independent Living.

Massachusetts, 2001	1915 (c) Waiver Programs Total	 Aged/Disabled (#)	 (%)
Participants	17,968	6,042	34%
Change from 2000	2.2%	-11	-0.2%
Participants per 1,000 Population	2.82	0.95	34%
Change from 2000	1.9%	0.00	0.0%
Expenditures	$506,934,671	$13,902,859	3%
Change from 2000	7.9%	$731,889	5.6%
Expenditures per Participant	$28,213	$2,301	8%
Change from 2000	5.6%	$125	6%

Massachusetts HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
MA 0059	Aged and Disabled 60 and Older

Source: http://www.cms.hhs.gov/medicaid/waivers/mawaiver.asp

Michigan

Michigan operates one HCBS waiver program serving a large (>5000) population of aged or disabled adults. The waiver services includes meals, adult day health care, transportation, training, respite care, nursing, accessibility modifications, specialized medical equipment, and in-home services.

Michigan, 2001	1915 (c) Waiver Programs Total	 Aged/Disabled (#)	 (%)
Participants	21,774	14,364	66%
Change from 2000	11.5%	3,023	26.7%
Participants per 1,000 Population	2.18	1.44	66%
Change from 2000	11.1%	0.30	26.3%
Expenditures	$593,216,397	$53,118,351	9%
Change from 2000	19.1%	$19,950,692	60.2%
Expenditures per Participant	$27,244	$3,698	14%
Change from 2000	6.8%	$773	26%

Michigan HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
MI 0233	Aged/Disabled

Source: http://www.cms.hhs.gov/medicaid/waivers/miwaiver.asp

Minnesota

Minnesota operates three HCBS waiver programs serving aged or disabled individuals. One waiver serves a large (>5000) elderly population (0025) and offers services including meals, adult day health care, in-home services, assisted living, family training, transportation, supplies and equipment, respite care, extended home health, and adult foster care. Another waiver (0166) serves a moderately-sized (500 - 5000) non-elderly disabled population and offers child foster care, independent living skills training, and vocational services, in addition to the services furnished under the elderly waiver program. A third waiver (4128) serves a small (<500) non-elderly chronically ill population and provides private duty nursing, family counseling and training, environmental modifications, respite, homemaker, and case management.

New waivers are not pending in Minnesota, but some areas of the state are refining their provider licensing/quality assurance process. Specifically, in five southeastern counties the state's licensing process for providers of services to the developmentally disabled is being replaced by a quality assurance review process. Services for a participant are evaluated by a volunteer reviewer, who works with the individual and his/her caretaker(s) to identify necessary improvements.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
Minnesota, 2001		**(#)**	**(%)**
Participants	30,767	16,433	53%
Change from 2000	34.2%	2,211	15.5%
Participants per 1,000 Population	6.19	3.31	53%
Change from 2000	33.2%	0.42	14.5%
Expenditures	$622,718,294	$98,499,653	16%
Change from 2000	24.4%	$22,236,494	29.2%
Expenditures per Participant	$20,240	$5,994	30%
Change from 2000	-7.4%	$773	9%

Minnesota HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
MN 0025	Elderly Waiver (EW)
MN 0166	Community Alternatives for Disabled Individuals (CADI)
MN 4128	Community Alternatives for Chronically Ill Individuals (CAC)

Sources: http://www.dhs.state.mn.us/Contcare/waivers/current_programs.htm
http://www.cms.hhs.gov/medicaid/waivers/mnwaiver.asp

Mississippi

Mississippi has three HCBS waiver programs serving the aged and/or disabled populations. The "Elderly and Disabled Waiver" (0272) is a large (>5000) program and provides case management, respite care, homemaker services, transportation, and home delivered meals. The "Independent Living Waiver" (0255) serves a smaller (<500) population of non-elderly adults, and provides case management and personal care services. The "Assisted Living Waiver" (0355) offers assisted living and case management to a moderate (500 – 5000) number of aged and disabled adults.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
Mississippi, 2001		**(#)**	**(%)**
Participants	8,159	7,281	89%
Change from 2000	75.8%	3,157	76.6%
Participants per 1,000 Population	2.85	2.55	89%
Change from 2000	75.3%	1.10	75.9%
Expenditures	$41,519,123	$32,029,294	77%
Change from 2000	63.4%	$10,270,869	47.2%
Expenditures per Participant	$5,089	$4,399	86%
Change from 2000	-7.1%	-$877	-17%

Mississippi HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
MS 0255	Independent Living Waiver
MS 0272	Elderly and Disabled Waiver
MS 0355	Assisted Living Waiver
MS 0388	Aged/Disabled (pending)

Sources: http://www.dom.state.ms.us/
http://www.cms.hhs.gov/medicaid/waivers/mswaiver.asp
http://www.cms.hhs.gov/medicaid/services/regular.pdf

New Jersey

New Jersey has three HCBS waiver serving aged and/or disabled adults. The "Community Care Program for Elderly and Disabled" waiver (0032) serves a moderate (500 – 5000) number of elderly and of disabled of any age. The waiver provides respite care, case management, homemaker, and social adult day care. Another waiver (4133) serves the disabled population and offers private duty nursing and case management to a small (<500) population. The "Enhanced Community Options" (0285) focuses on transitioning the elderly or disabled from nursing facilities to community settings. The waiver services include environmental modifications, home-based supportive care, personal emergency response systems, attendant care, social adult day care, and home delivered meals.

Like Florida, New Jersey also participated in a two-year HHS demonstration program testing the substitution of cash allowances for Medicaid services from providers. The program was run under an 1115 waiver as part of the Cash and Counseling Demonstration project funded by HHS and the Robert Wood Johnson Foundation. The case group participates received a monthly cash allowance and services to help them effectively use the allowance. An early study indicated that 97% of participants in New Jersey would recommend the allowance to others.

New Jersey also offers a permanent nursing facility transitions program, "Community Choice." The program has a staff of 40 counselors who provide information and assistance to nursing facility residents. Between 1998 and 2001, the Community Choice program assisted over 3,400 participants in leaving nursing facilities. The state also established a transition expense fund that helps pay for expenses for which no other funding is available (e.g. furniture, housing deposits).

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
New Jersey, 2001		**(#)**	**(%)**
Participants	15,764	7,260	46%
Change from 2000	10.0%	1,442	24.8%
Participants per 1,000 Population	1.86	0.87	47%
Change from 2000	9.4%	0.18	26.1%
Expenditures	$341,064,337	$77,767,763	23%
Change from 2000	9.4%	$14,760,498	23.4%
Expenditures per Participant	$21,636	$10,712	50%
Change from 2000	-0.6%	-$118	-1%

New Jersey HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
NJ 0032	Community Care Program for Elderly and Disabled Waiver
NJ 0285.90.R1A	Enhanced Community Options Waiver
NJ 0285.90.R1B	Assisted Living Waiver
NJ 4133	Community Resources for People with Disabilities (subsumed waivers 40104 and 40123 in 2002)

Sources: http://www.cms.hhs.gov/medicaid/waivers/njwaiver.asp
http://www.state.nj.us/health/consumer/alfact.shtml

New York

New York has one HCBS waiver program serving the aged and/or disabled; it serves over 20,000 participants. The program services include nutritional counseling, home repair, social day care, moving assistance, personal emergency response system, home delivered meals, medical social work, and chore/home maintenance.

While not a waiver program, New York's Visiting Nurse Service (VNS) operates a home care program (VNS Choice) for dually-eligible beneficiaries who meet nursing facility requirements for care. The program in oriented to long-term care – recipients must qualify for long-term care services for at least four months. Using teams composed of a nurse practitioner, rehabilitation therapist, social worker, and registered nurse, the program provides home health services and case management to help arrange for and coordinate Medicaid and Medicare services.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
New York, 2001		**(#)**	**(%)**
Participants	65,258	20,367	31%
Change from 2000	4.6%	84	0.4%
Participants per 1,000 Population	3.43	1.07	31%
Change from 2000	4.6%	0.00	0.0%
Expenditures	$1,748,152,379	$26,222,889	2%
Change from 2000	-4.7%	$1,798,264	7.4%
Expenditures per Participant	$26,788	$1,288	5%
Change from 2000	-8.9%	$83	7%

New York HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
NY 0034	Aged and Disabled

Source: http://www.cms.hhs.gov/medicaid/waivers/nywaiver.asp

Texas

Texas has three HCBS waiver programs serving the aged and/or disabled adult population. The "Consolidated Waiver Program" serves a small (<500) population; the "STAR+PLUS Community Based Alternatives Waiver" serves a moderate (500 - 5000) sized population; the "Community Based Alternatives Waiver" serves a large (>5000) population. All three waivers provide services including skilled nursing care, physical therapy, speech/language pathology services, nutritional counseling, social worker services, residential care, case management, supplies and equipment, companion services, environmental modifications, supported living, habilitation, foster care, dental care, respite care and psychologist services.

Texas increases the funding for and participation in its HCBS waiver programs through a biennial state budget transfer mechanism. The transfer essentially allows a nursing facility resident's facility payments to follow the individual into a waiver program. This provides funding as needed for new participants, but does not permanently increase the size of Texas' waiver program. The mechanism is known as the Rider 37 to the fiscal year 2001/02 budget, and as Rider 27 to the fiscal year 2003/04 budget. Since September 2001, over 1,900 nursing facility residents have transitioned to a waiver through the rider.

	1915 (c) Waiver Programs		
	Total	**Aged/Disabled**	
Texas, 2001		**(#)**	**(%)**
Participants	40,922	31,000	76%
Change from 2000	80.0%	-1,718	-5.3%
Participants per 1,000 Population	1.92	1.45	76%
Change from 2000	-90.0%	-0.11	-7.1%
Expenditures	$625,828,309	$354,723,046	57%
Change from 2000	880.0%	$52,627,305	17.4%
Expenditures per Participant	$15,293	$11,443	75%
Change from 2000	790.0%	$2,209	24%

Texas HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
TX 0266	Community Based Alternatives Waiver
TX 0281	(note: CMS defines this as MR/DD, Kitchener defines as A/D)
TX 0325	STAR+PLUS Community Based Alternatives Waiver
TX 0373	Consolidated Waiver Program: Age/Disabled and Medically Dependent Children

Sources: http://www.cms.hhs.gov/medicaid/waivers/txwaiver.asp
http://www.hhsc.state.tx.us/pubs/LTC_Plan_MHMR_02-03.pdf

Washington

Washington has three HCBS waiver programs serving the aged and disabled population. The waivers are in the moderate (500 – 5000) to large (>5000) size range and provide adult day care, skilled nursing, assisted living, personal care, and home delivered meals.

Washington provides case management services and an array of other resources for helping nursing facility residents transition to home and community-based settings. For example, the state also has four funding sources for transitional services people may require when leaving nursing facilities. Over a five-year period the state's nursing facility population has decreased 16%.

Washington, 2001	1915 (c) Waiver Programs Total	 Aged/Disabled (#)	 (%)
Participants	39,731	9,212	23%
Change from 2000	3.9%	1,341	4.6%
Participants per 1,000 Population	6.64	5.10	77%
Change from 2000	2.6%	0.16	3.2%
Expenditures	$496,477,521	$221,720,632	45%
Change from 2000	13.7%	$33,647,919	14.0%
Expenditures per Participant	$12,496	$9,003	72%
Change from 2000	9.4%	$739	9%

Washington HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
WA 0049	Community Options Program Entry System (COPES)
WA 0389	New waiver for individuals living at home, approved May 1, 2002, and expected to serve 300 participants
WA 0390	New waiver for individuals living in the community, approved May 1, 2002, and expected to serve 1467 participants

Sources: http://www.hcbs.org/files/8/381/Washington_AD.doc
http://www.cms.hhs.gov/medicaid/waivers/wawaiver.asp

Wisconsin

Wisconsin has two HCBS waivers serving the aged and/or disabled population. The "Community Options Program" waiver serves a large (>5000) number of aged or disabled participants; the "Family Care" waiver operates in selected counties and serves a more moderate (500 – 5000) number of aged and disabled.

Wisconsin helps nursing facility residents transition to home and community-based settings using a combination of a waiver program (the "Community Options Program Waiver") and a state program for those not qualifying for the waiver (the "Community Options Program"). In 2001, over 150 nursing facility residents received funding for transitioning to community-based care. Wisconsin recently appropriated funding over a two-year period for one-time transition costs of individuals from nursing facilities into waiver programs.

Wisconsin also has developed "Age and Disability Resource Centers" to coordinate information about long-term care options. These centers were developed as part of the Wisconsin Family Care initiative (a component of the state's HCBS 1915(c) Family Care Waiver). The centers offer advice on a variety of long-term care concerns and offer a single entry point for people seeking HCBS programs.

Wisconsin, 2001	1915 (c) Waiver Programs Total	Aged/Disabled (#)	 (%)
Participants	22,091	12,510	57%
Change from 2000	-6.1%	-1,374	-9.9%
Participants per 1,000 Population	4.09	2.32	57%
Change from 2000	-6.5%	-0.26	-10.1%
Expenditures	$430,262,587	$117,371,991	27%
Change from 2000	4.3%	-$2,967,689	-2.5%
Expenditures per Participant	$19,477	$9,382	48%
Change from 2000	11.0%	$715	8%

Wisconsin HCBS 1915(c) Waivers Serving the Aged and/or Disabled

Waiver No.	Name
WI 0154	Community Options Program Waiver
WI 0367	Family Care Waiver

Sources: http://www.cms.hhs.gov/medicaid/waivers/wiwaiver.asp
http://www.hcbs.org/files/8/386/HCBSWisconsin.rtf

Table A4-1: HCB Service and 1915(c) Waiver Program Participation and Expenditures, Selected States, 2001

	Home Health	Personal Care Services	1915 (c) Waiver Programs Total	Aged/Disabled Number	Aged/Disabled Percent	All HCBS	waivers % of total	aged/disabled % of total
Alabama								
Participants	7,924	N/A	11,564	7,272	63%	19,488	59%	37%
Change from 2000	4.8%	N/A	12.9%	1,067	17.2%	9.5%		
Participants per 1,000 Population	1.77	N/A	2.59	1.63	63%	4.37	59%	37%
Change from 2000	4.5%	N/A	12.6%	0.24	17.3%	9.1%		
Expenditures	$22,111,550	N/A	$217,638,481	$39,092,333	18%	$239,750,031	91%	16%
Change from 2000	2.3%	N/A	60.5%	-$1,338,100	-3.3%	52.5%		
Expenditures per Participant	$2,790	N/A	$18,820	$5,376	29%	$12,302	153%	44%
Change from 2000	-2.3%	N/A	42.2%	-$1,140	-17%	39.4%		
California								
Participants	70,666	203,345	50,537	12,712	25%	324,548	16%	4%
Change from 2000	40.9%	-3.9%	13.5%	1,289	11.3%	6.0%		
Participants per 1,000 Population	2.05	5.89	1.46	0.37	25%	9.41	16%	4%
Change from 2000	38.9%	-5.3%	11.8%	0.03	8.8%	4.4%		
Expenditures	$569,623,735	$1,792,437,265	$765,624,295	$78,493,194	10%	$3,127,685,295	24%	3%
Change from 2000	47.3%	20.6%	31.7%	$4,351,742	5.9%	27.4%		
Expenditures per Participant	$8,061	$8,815	$15,150	$6,175	41%	$9,637	157%	64%
Change from 2000	4.5%	25.5%	16.1%	-$316	-5%	20.3%		
Colorado								
Participants	8,551	7,598	23,925	14,082	59%	40,074	60%	35%
Change from 2000	26.9%	6.7%	7.8%	1,076	8.3%	11.1%		
Participants per 1,000 Population	1.94	1.72	5.42	3.19	59%	9.07	60%	35%
Change from 2000	24.2%	4.5%	5.6%	0.18	6.0%	8.9%		
Expenditures	$81,976,321	$48,128,227	$304,367,003	$72,256,809	24%	$434,471,551	70%	17%
Change from 2000	21.7%	7.8%	9.7%	$7,051,974	10.8%	11.6%		
Expenditures per Participant	$9,587	$6,334	$12,722	$5,131	40%	$10,842	117%	47%
Change from 2000	-4.0%	1.1%	1.8%	$118	2%	0.4%		
Florida								
Participants	14,324	N/A	50,689	18,019	36%	65,013	78%	28%
Change from 2000	0.9%	N/A	16.2%	78	0.4%	12.5%		
Participants per 1,000 Population	0.87	N/A	3.09	1.09	35%	3.97	78%	27%
Change from 2000	-1.2%	N/A	13.8%	-0.03	-2.7%	10.1%		
Expenditures	$27,649,025	N/A	$560,185,338	$105,250,110	19%	$587,834,363	95%	18%
Change from 2000	19.9%	N/A	63.7%	$14,897,109	16.5%	60.9%		
Expenditures per Participant	$1,930	N/A	$11,051	$5,841	53%	$9,042	122%	65%
Change from 2000	18.8%	N/A	40.8%	$805	16%	43.1%		

Table A4-1 (2 of 4). Medicaid Home and Community-Based Services Participation and Expenditures, by State, 2001

			1915 (c) Waiver Programs				All HCBS	
	Home Health	Personal Care Services	Total	Aged/Disabled			waivers %	aged/disabled
Massachusetts				Number	Percent		of total	% of total
Participants	25,000	6,938	17,968	6,042	34%	49,906	36%	12%
Change from 2000	0.0%	22.4%	2.2%	-11	-0.2%	3.4%		
Participants per 1,000 Population	3.92	1.09	2.82	0.95	34%	7.82	36%	12%
Change from 2000	-0.3%	22.1%	1.9%	0.00	0.0%	3.2%		
Expenditures	$67,955,350	$142,697,517	$506,934,671	$13,902,859	3%	$717,587,578	71%	2%
Change from 2000	0.0%	23.0%	7.9%	$731,889	5.6%	9.8%		
Expenditures per Participant	$2,718	$20,568	$28,213	$2,301	8%	$14,379	196%	16%
Change from 2000	0.0%	0.5%	5.6%	$125	6%	39.4%		
Michigan								
Participants	4,772	55,046	21,774	14,364	66%	81,592	27%	18%
Change from 2000	15.1%	0.0%	11.5%	3,023	26.7%	3.6%		
Participants per 1,000 Population	0.48	5.51	2.18	1.44	66%	8.17	27%	18%
Change from 2000	14.7%	-0.3%	11.1%	0.30	26.3%	3.3%		
Expenditures	$7,945,699	$183,363,404	$593,216,397	$53,118,351	9%	$784,525,500	76%	7%
Change from 2000	1.2%	-3.5%	19.1%	$19,950,692	60.2%	12.7%		
Expenditures per Participant	$1,665	$331	$27,244	$3,698	14%	$9,615	283%	38%
Change from 2000	-12.1%	-3.5%	6.8%	$773	26%	8.7%		
Minnesota								
Participants	60,479	7,773	30,767	16,433	53%	99,019	31%	17%
Change from 2000	0.4%	6.2%	34.2%	2,211	15.5%	9.5%		
Participants per 1,000 Population	12.16	1.56	6.19	3.31	53%	19.91	31%	17%
Change from 2000	-0.3%	5.4%	33.2%	0.42	14.5%	8.6%		
Expenditures	$104,831,663	$129,754,550	$622,718,294	$98,499,653	16%	$857,304,507	73%	11%
Change from 2000	5.7%	10.7%	24.4%	$22,236,494	29.2%	19.6%		
Expenditures per Participant	$1,733	$16,693	$20,240	$5,994	30%	$8,658	234%	69%
Change from 2000	5.3%	4.2%	-7.4%	$773	9%	9.2%		
Mississippi								
Participants	7,812	N/A	8,159	7,281	89%	15,971	51%	46%
Change from 2000	38.5%	N/A	75.8%	3,157	76.6%	55.4%		
Participants per 1,000 Population	2.73	N/A	2.85	2.55	89%	5.59	51%	46%
Change from 2000	38.1%	N/A	75.3%	1.10	75.9%	54.9%		
Expenditures	$10,915,766	N/A	$41,519,123	$32,029,294	77%	$52,434,889	79%	61%
Change from 2000	53.4%	N/A	63.4%	$10,270,869	47.2%	61.2%		
Expenditures per Participant	$1,397	N/A	$5,089	$4,399	86%	$3,283	155%	134%
Change from 2000	10.7%	N/A	-7.1%	-$877	-17%	37.0%		

Table A4-1 (3 of 4). Medicaid Home and Community-Based Services Participation and Expenditures for Selected States, by Type of Program, 2001

			1915 (c) Waiver Programs				All HCBS	
	Home Health	Personal Care Services	Total	Aged/Disabled			waivers %	aged/disabled
New Jersey				Number	Percent		of total	% of total
Participants	4,541	15,369	15,764	7,260	46%	35,674	44%	20%
Change from 2000	-64.8%	-25.4%	10.0%	1,442	24.8%	-25.4%		
Participants per 1,000 Population	0.54	1.81	1.86	0.87	47%	4.2	44%	21%
Change from 2000	-65.0%	-25.8%	9.4%	0.18	26.1%	-25.9%		
Expenditures	$49,068,815	$199,241,618	$341,064,337	$77,767,763	23%	$589,374,770	58%	13%
Change from 2000	-12.0%	4.4%	9.4%	$14,760,498	23.4%	5.6%		
Expenditures per Participant	$10,806	$12,964	$21,636	$10,712	50%	$16,521	131%	65%
Change from 2000	150.3%	39.9%	-0.6%	-$118	-1%	41.6%		
New York								
Participants	93,517	88,370	65,258	20,367	31%	247,145	26%	8%
Change from 2000	-9.6%	-0.5%	4.6%	84	0.4%	-2.9%		
Participants per 1,000 Population	4.92	4.65	3.43	1.07	31%	13	26%	8%
Change from 2000	-9.6%	-0.5%	4.6%	0.00	0.0%	-3.0%		
Expenditures	$634,792,137	$1,571,618,449	$1,748,152,379	$26,222,889	2%	$3,954,562,965	44%	1%
Change from 2000	4.5%	3.4%	-4.7%	$1,798,264	7.4%	-0.2%		
Expenditures per Participant	$6,788	$17,785	$26,788	$1,288	5%	$16,001	167%	8%
Change from 2000	15.5%	3.8%	-8.9%	$83	7%	2.8%		
Texas								
Participants	116,552	42,863	40,922	31,000	76%	200,337	20%	15%
Change from 2000	0.0%	590.0%	80.0%	-1,718	-5.3%	140.0%		
Participants per 1,000 Population	5.47	2.01	1.92	1.45	76%	9.39	20%	15%
Change from 2000	-170.0%	400.0%	-90.0%	-0.11	-7.1%	-40.0%		
Expenditures	$97,941,162	$266,072,715	$625,828,309	$354,723,046	57%	$989,842,186	63%	36%
Change from 2000	1290.0%	1080.0%	880.0%	$52,627,305	17.4%	970.0%		
Expenditures per Participant	$840	$6,208	$15,293	$11,443	75%	$4,941	310%	232%
Change from 2000	1290.0%	470.0%	790.0%	$2,209	24%	820.0%		
Washington								
Participants	6,480	7,208	39,731	9,212	23%	53,419	74%	17%
Change from 2000	2.7%	10.7%	3.9%	1,341	4.6%	4.6%		
Participants per 1,000 Population	1.08	1.20	6.64	5.10	77%	8.92	74%	57%
Change from 2000	1.4%	9.2%	2.6%	0.16	3.2%	3.3%		
Expenditures	$32,971,631	$51,600,000	$496,477,521	$221,720,632	45%	$581,049,152	85%	38%
Change from 2000	2.9%	30.6%	13.7%	$33,647,919	14.0%	14.3%		
Expenditures per Participant	$5,088	$7,159	$12,496	$9,003	72%	$10,877	115%	83%
Change from 2000	0.2%	18.1%	9.4%	$739	9%	9.3%		

Table A4-1 (4 of 4). Medicaid Home and Community-Based Services Participation and Expenditures for Selected States, by Type of Program, 2001

Wisconsin	Home Health	Personal Care Services	1915 (c) Waiver Programs			All HCBS		
			Total	Aged/Disabled			waivers % of total	aged/disabled % of total
				Number	Percent			
Participants	6,765	10,587	22,091	12,510	57%	39,443	56%	32%
Change from 2000	-11.7%	0.8%	-6.1%	-1,374	-9.9%	-5.4%		
Participants per 1,000 Population	1.25	1.96	4.09	2.32	57%	7.3	56%	32%
Change from 2000	-12.2%	0.2%	-6.5%	-0.26	-10.1%	-5.9%		
Expenditures	$22,155,252	$100,696,997	$430,262,587	$117,371,991	27%	$553,114,836	78%	21%
Change from 2000	-8.2%	35.4%	4.3%	-$2,967,689	-2.5%	8.2%		
Expenditures per Participant	$3,275	$9,511	$19,477	$9,382	48%	$14,023	139%	67%
Change from 2000	3.9%	34.4%	11.0%	$715	8%	14.4%		

Table A4-2: List of All 1915(c) Waiver Programs and Participation Counts for Selected States, 2001

	Medicaid 1915(c) Waivers Participants, by Waiver			
	Waiver No.	***Participant Category***	***2001***	
Alabama	AL 00001	MR/DD	4,292	
	AL 00068	Aged/Disabled	6,881	
	AL 00241	Disabled/Physically Disabled	391	
	Total Waiver Participants		11,564	
	Aged and/or Physically Disabled		7,272	
	Percent of Total Waivers		63%	

	Medicaid 1915(c) Waivers Expenditures, by Waiver			
	Waiver No.	***Participant Category***	***2001***	
Alabama	AL 00001	MR/DD	108,546,150	
	AL 00068	Aged/Disabled	106,798,116	
	AL 00241	Disabled/Physically Disabled	2,294,215	
	Total Waiver Expenditures		217,638,481	
	Aged and/or Physically Disabled Expenditures		109,092,331	
	Percent of Total Waivers Expenditures		50%	

	Medicaid 1915(c) Waivers Participants, by Waiver			
	Waiver No.	***Participant Category***	***2001***	
California	CA 00139	Disabled/Physically Disabled	449	*
	CA 00141	Aged/Disabled	12,070	
	CA 00183	AIDS/ARC	2,453	
	CA 00348	MR/DD	35,372	
	CA 40136	Aged/Disabled	193	*
	Total Waiver Participants		50,537	*
	Aged and/or Physically Disabled		12,712	*
	Percent of Total Waivers		25%	*

	Medicaid 1915(c) Waivers Expenditures, by Waiver			
	Waiver No.	***Participant Category***	***2001***	
California	CA 00139	Disabled/Physically Disabled	43,871,715	*
	CA 00141	Aged/Disabled	32,926,380	
	CA 00183	AIDS/ARC	8,278,700	
	CA 00348	MR/DD	678,852,401	
	CA 40136	Aged/Disabled	1,695,099	*
	Total Waiver Expenditures		765,624,295	*
	Aged and/or Physically Disabled Expenditures		78,493,194	*
	Percent of Total Waivers Expenditures		10%	*

	Medicaid 1915(c) Waivers Participants, by Waiver		
	Waiver No.	***Participant Category***	***2001***
Colorado	CO 00006	Aged/Disabled	14,082
	CO 00007	MR/DD	3,648
	CO 00211	AIDS/ARC	90
	CO 00268	Mental Health	1,717
	CO 00288	TBI/Head Injury	310
	CO 00293	MR/DD	2,975
	CO 00305	MR/DD	264
	CO 40157	Children (Special Care)	645
	CO 40180	MR/DD	194
	Total Waiver Participants		23,925
	Aged and/or Physically Disabled		14,082
	Percent of Total Waivers		59%

	Medicaid 1915(c) Waivers Expenditures, by Waiver		
	Waiver No.	***Participant Category***	***2001***
Colorado	CO 00006	Aged/Disabled	72,256,809
	CO 00007	MR/DD	172,671,423
	CO 00211	AIDS/ARC	122,164
	CO 00268	Mental Health	9,418,635
	CO 00288	TBI/Head Injury	4,983,007
	CO 00293	MR/DD	34,389,423
	CO 00305	MR/DD	7,945,270
	CO 40157	Children (Special Care)	263,407
	CO 40180	MR/DD	2,316,865
	Total Waiver Expenditures		304,367,003
	Aged and/or Physically Disabled Expenditures		72,256,809
	Percent of Total Waivers Expenditures		24%

Florida

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
FL 00116	Aged/Disabled	1,473
FL 00194	AIDS/ARC	6,757
FL 00280	Aged/Disabled	3,188
FL 00294	MR/DD	18
FL 00315	MR/DD	1,059
FL 01090	Aged/Disabled	13,358
FL 01091	MR/DD	24,712
FL 01879	TBI/Head Injury	119
FL 40166	Children (Special Care)	5
Total Waiver Participants		50,689
Aged and/or Physically Disabled		18,019
Percent of Total Waivers		36%

Florida

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
FL 00116	Aged/Disabled	10,126,507
FL 00194	AIDS/ARC	25,126,172
FL 00280	Aged/Disabled	21,825,254
FL 00294	MR/DD	66,870
FL 00315	MR/DD	21,943,695
FL 01090	Aged/Disabled	73,298,349
FL 01091	MR/DD	406,449,501
FL 01879	TBI/Head Injury	1,289,818
FL 40166	Children (Special Care)	59,172
Total Waiver Expenditures		560,185,338
Aged and/or Physically Disabled Expenditures		105,250,110
Percent of Total Waivers Expenditures		19%

Massachusetts

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
MA 00059	Aged	6,042
MA 00064	MR/DD	11,926
Total Waiver Participants		17,968
Aged and/or Physically Disabled		6,042
Percent of Total Waivers		34%

Massachusetts

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
MA 00059	Aged	13,902,859
MA 00064	MR/DD	493,031,812
Total Waiver Expenditures		506,934,671
Aged and/or Physically Disabled Expenditures		13,902,859
Percent of Total Waivers Expenditures		3%

Michigan

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
MI 00167	MR/DD	7,002
MI 00233	Aged/Disabled	14,364
MI 40119	MR/DD	408
Total Waiver Participants		21,774
Aged and/or Physically Disabled		14,364
Percent of Total Waivers		66%

Michigan

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
MI 00167	MR/DD	531,243,158
MI 00233	Aged/Disabled	53,118,351
MI 40119	MR/DD	8,854,888
Total Waiver Expenditures		593,216,397
Aged and/or Physically Disabled Expenditures		53,118,351
Percent of Total Waivers Expenditures		9%

Medicaid 1915(c) Waivers Participants, by Waiver

	Waiver No.	Participant Category	2001
Minnesota	MN 00025	Aged	11,333
	MN 00061	MR/DD	13,888
	MN 00166	Disabled/Physically Disabled	4,971
	MN 40128	Disabled/Physically Disabled	129
	MN 40169	TBI/Head Injury	446
	Total Waiver Participants		30,767
	Aged and/or Physically Disabled		16,433
	Percent of Total Waivers		53%

Medicaid 1915(c) Waivers Expenditures, by Waiver

	Waiver No.	Participant Category	2001
Minnesota	MN 00025	Aged	61,546,361
	MN 00061	MR/DD	507,730,208
	MN 00166	Disabled/Physically Disabled	31,958,168
	MN 40128	Disabled/Physically Disabled	4,995,124
	MN 40169	TBI/Head Injury	16,488,433
	Total Waiver Expenditures		622,718,294
	Aged and/or Physically Disabled Expenditures		98,499,653
	Percent of Total Waivers Expenditures		16%

Medicaid 1915(c) Waivers Participants, by Waiver

	Waiver No.	Participant Category	2001
Mississippi	MS 00255	Disabled/Physically Disabled	330
	MS 00272	Aged/Disabled	6,951
	MS 00282	MR/DD	878
	Total Waiver Participants		8,159
	Aged and/or Physically Disabled		7,281
	Percent of Total Waivers		89%

Medicaid 1915(c) Waivers Expenditures, by Waiver

	Waiver No.	Participant Category	2001
Mississippi	MS 00255	Disabled/Physically Disabled	2,739,901
	MS 00272	Aged/Disabled	29,289,393
	MS 00282	MR/DD	9,489,829
	Total Waiver Expenditures		41,519,123
	Aged and/or Physically Disabled Expenditures		32,029,294
	Percent of Total Waivers Expenditures		77%

Medicaid 1915(c) Waivers Participants, by Waiver

	Waiver No.	Participant Category	2001
New Jersey	NJ 00031	MR/DD	7,348
	NJ 00032	Aged/Disabled	4,431
	NJ 00160	AIDS/ARC	705
	NJ 00244	Children (Special Care)	196
	NJ 00285	Aged/Disabled	2,520
	NJ 40104	Disabled/Physically Disabled	44
	NJ 40123	Disabled/Physically Disabled	43
	NJ 40133	Disabled/Physically Disabled	222
	NJ 40174	TBI/Head Injury	255
	Total Waiver Participants		15,764
	Aged and/or Physically Disabled		7,260
	Percent of Total Waivers		46%

Medicaid 1915(c) Waivers Expenditures, by Waiver

	Waiver No.	Participant Category	2001
New Jersey	NJ 00031	MR/DD	245,193,696
	NJ 00032	Aged/Disabled	37,465,312
	NJ 00160	AIDS/ARC	4,709,087
	NJ 00244	Children (Special Care)	394,189
	NJ 00285	Aged/Disabled	22,832,167
	NJ 40104	Disabled/Physically Disabled	50,925
	NJ 40123	Disabled/Physically Disabled	42,460
	NJ 40133	Disabled/Physically Disabled	17,376,899
	NJ 40174	TBI/Head Injury	12,999,602
	Total Waiver Expenditures		341,064,337
	Aged and/or Physically Disabled Expenditures		77,767,763
	Percent of Total Waivers Expenditures		23%

New York

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
NY 00034	Aged/Disabled	20,367
NY 00238	MR/DD	42,641
NY 00269	TBI/Head Injury	789
NY 00296	Children (Special Care)	374 *
NY 40125	Children (Special Care)	564
NY 40163	MR/DD	210
NY 40176	MR/DD	208
NY 40200	TBI/Head Injury	105
Total Waiver Participants		65,258
Aged and/or Physically Disabled		20,367
Percent of Total Waivers		31%

New York

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
NY 00034	Aged/Disabled	26,222,889
NY 00238	MR/DD	1,679,148,226
NY 00269	TBI/Head Injury	32,588,546
NY 00296	Children (Special Care)	5,614,327 *
NY 40125	Children (Special Care)	2,085,085
NY 40163	MR/DD	1,074,159
NY 40176	MR/DD	942,223
NY 40200	TBI/Head Injury	476,924
Total Waiver Expenditures		1,748,152,379 *
Aged and/or Physically Disabled Expenditures		26,222,889 *
Percent of Total Waivers Expenditures		2% *

Texas

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
TX 00110	MR/DD	5,023
TX 00181	Children (Special Care)	1,147
TX 00221	MR/DD	1,508
TX 00240	MR/DD	122
TX 00266	Aged/Disabled	30,895
TX 00281	Disabled/Physically Disabled	105
TX 00330	MR/DD	2,122
Total Waiver Participants		40,922
Aged and/or Physically Disabled		31,000
Percent of Total Waivers		76%

Texas

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
TX 00110	MR/DD	161,244,944
TX 00181	Children (Special Care)	17,551,366
TX 00221	MR/DD	39,945,664
TX 00240	MR/DD	4,271,041
TX 00266	Aged/Disabled	350,783,471
TX 00281	Disabled/Physically Disabled	3,939,575
TX 00330	MR/DD	48,092,248
Total Waiver Expenditures		625,828,309
Aged and/or Physically Disabled Expenditures		354,723,046
Percent of Total Waivers Expenditures		57%

Washington

Medicaid 1915(c) Waivers Participants, by Waiver

Waiver No.	***Participant Category***	***2001***
WA 00049	MR/DD	30,519
WA 00050	Aged/Disabled	9,212
Total Waiver Participants		39,731
Aged and/or Physically Disabled		9,212
Percent of Total Waivers		23%

Washington

Medicaid 1915(c) Waivers Expenditures, by Waiver

Waiver No.	***Participant Category***	***2001***
WA 00049	MR/DD	274,756,889
WA 00050	Aged/Disabled	221,720,632
Total Waiver Expenditures		496,477,521
Aged and/or Physically Disabled Expenditures		221,720,632
Percent of Total Waivers Expenditures		45%

Medicaid 1915(c) Waivers Participants, by Waiver

	Waiver No.	***Participant Category***	***2001***
Wisconsin	WI 00154	Aged/Disabled	12,510
	WI 00229	MR/DD	9,120
	WI 00275	TBI/Head Injury	244
	WI 00297	MR/DD	217

Total Waiver Participants	22,091
Aged and/or Physically Disabled	12,510
Percent of Total Waivers	57%

Medicaid 1915(c) Waivers Expenditures, by Waiver

	Waiver No.	***Participant Category***	***2001***
Wisconsin	WI 00154	Aged/Disabled	117,371,991
	WI 00229	MR/DD	297,824,314
	WI 00275	TBI/Head Injury	13,720,189
	WI 00297	MR/DD	1,346,093

Total Waiver Expenditures	430,262,587
Aged and/or Physically Disabled Expenditures	117,371,991
Percent of Total Waivers Expenditures	27%

souce: "Medicaid Home and Community-Based Services: Program Data, 1992-2001" Kitchener, Ng, and Harrington
* estimate for missing data

Table A4-3: Medicaid Long-Term Care Expenditures, by Service Type and by State, FY 2001

(sorted by HCBS waiver share of spending)

		Percent of expenditures by service or setting				
State	Medicaid LTC expenditures (in millions)	Nursing Facilities	HCBS Waivers	Personal Care	Home Health	ICF/MR
Vermont	191	44	49	2	3	1
Alaska	156	46	48	5	0	0
Wyoming	113	35	48	0	4	13
Oregon	1,058	51	45	3	0	1
Colorado	768	47	42	0	10	2
Rhode Island	420	58	39	0	1	2
New Mexico	410	40	39	16	0	4
New Hampshire	358	59	38	1	1	1
Maine	411	49	37	1	2	11
Utah	241	38	37	0	1	23
Washington	1,427	43	36	11	1	9
Kansas	887	54	34	1	3	8
Minnesota	1,916	47	32	7	3	11
Oklahoma	811	53	29	5	0	14
Virginia	1,010	52	29	0	0	19
West Virginia	531	55	28	5	4	9
South Carolina	789	47	28	0	3	21
Wisconsin	1,813	53	27	6	3	11
Montana	215	52	27	11	0	10
Hawaii	210	71	25	0	1	4
South Dakota	237	66	25	0	1	8
Delaware	195	57	24	0	3	16
Nebraska	579	64	23	1	3	8
Connecticut	1,842	56	23	0	8	13
Idaho	258	46	23	5	3	24
North Carolina	2,037	43	22	11	4	20
Florida	2,648	64	21	1	3	11
Massachusetts	2,450	58	21	10	3	9
Texas	3,288	49	21	8	0	22
Maryland	1,061	66	20	3	6	6
North Dakota	251	60	20	0	1	19
Missouri	1,677	62	18	9	0	11
Alabama	927	73	17	0	4	7
Michigan	2,385	73	17	8	1	1
Pennsylvania	5,114	72	17	0	1	10
Kentucky	935	60	17	0	13	10
Nevada	162	57	17	4	4	18
Iowa	756	49	17	0	6	27
Georgia	1,099	69	16	0	4	10
Tennessee	1,203	65	15	0	0	19
Arkansas	647	57	15	10	4	15
New York	13,469	47	15	14	8	16
Illinois	2,533	59	14	0	1	26
Ohio	3,643	64	13	0	2	22
Indiana	1,307	63	11	0	4	23
New Jersey	3,192	69	10	6	2	13
California	5,066	51	10	27	3	8
Louisiana	1,677	69	8	0	1	21
Mississippi	646	64	8	0	2	26
District of Columbia	253	63	1	0	6	31
Arizona	15	n.a.	n.a.	n.a.	n.a.	n.a.
U.S. Total	75,288	14	19	7	3	57

Source: GAO analysis of HCFA Form 64 data as reported by Brian Burwell, Steve Eiken, and Kate Sredl in Medicaid Long Term Care Expenditures in FY 2001, The MEDSTAT Group, May 10, 2002.

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