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**A New Look at U.S. Expenditures for Long-Term Care and
Independent Living Services, Settings, and Technologies
for the Year 2000**

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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Executive Summary

Background

As we age, Americans use an increasingly diverse range of services, residential settings, and technologies to assist in maintaining their functioning and independence. In addition to traditional “long term care,” such as nursing home and home health care services, there is growing use of assisted living residences, adult day care, home modifications, assistive technologies, and other activities.

Individuals and federal, state, and local governments are grappling with the costs of providing these services, settings, and technologies to persons who need them. As a result, it is useful to take stock of the level of expenditures as well as who is paying for them. Given the long-standing focus on health and the costs of health care programs such as Medicare and Medicaid, there are many efforts to track health care spending. However, there have been fewer attempts to estimate spending for the wide range of activities that assist functioning.

Some estimates of spending on long-term care services do exist. For example, one often-cited measure, presented in a General Accounting Office (GAO) report, indicates that long-term care expenditures for persons of all ages totaled about \$137 billion in the year 2000.¹ However, that estimate presents expenditures for only selected long-term care services that are a subset of the health care sector. The estimates presented in this report recognize that long-term care and independent living services, settings and technologies overlap with health care, but are not simply a subset. These estimates incorporate a range of activities that provide long-term care and support independent living, regardless of whether these are considered a subset of health care or not, including expenditures for social services, home-delivered and congregate meals, special needs transportation, and nursing and assistive services provided in assisted living facilities, homes for the elderly, and other types of residences.

However one measures long-term care spending, the total magnitude is great. But a more inclusive and accurate framework for expenditures has several advantages:

- If long-term care spending shifts among various services, settings, and technologies, then these shifts will be revealed. But if some portion of the range is omitted, then shifts may spuriously appear to be either decreases or increases in overall long-term care spending.
- A more accurate picture of what is being spent is more likely to lead to a more accurate picture of need (including unmet need), and of the costs of potential new programs to provide broader public coverage of services, settings and

¹ GAO. *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*. Washington, DC: GAO (GAO-02-544T), March 2002.

technologies designed to meet the long-term care and independent living needs of older persons.

In examining recent history, a more inclusive measure of long-term care and independent living activities would have better captured the changes in spending over time that resulted from the rise in the use of assisted living residences, some of which involved substitution for other community-based services and for nursing home care. Similarly, potential future increases in adult day care services may represent in part a substitution for home care and rehabilitation services that are currently provided in a person's home. A more inclusive measure of long-term care and independent living activities than is currently being used is needed in order to fully capture and track these effects as well.

Purpose

This report presents new estimates of U.S. expenditures on long-term care and independent living activities for the year 2000, both in total and for persons age 65 and over, including breakouts by type of activity and source of payment. To reflect the range of developments in providing assistance in functioning and independence, the estimates presented here incorporate services, settings, and technologies that are both within and outside of the health care sector. This is a departure from most existing estimates, which measure only those long-term care services that are a subset of the health care sector.

Methodology

The estimates presented here are based primarily on the 2000 Service Annual Survey and the 1997 Economic Census, both conducted by the U.S. Census Bureau. These two surveys provide expenditure data by category of provider for non-government providers of services, as well as source-of-payment data. The surveys also form the basis of much of the National Health Accounts produced by the U.S. Centers for Medicare and Medicaid Services (from which are drawn most other estimates of long-term care expenditures). Several additional data sources are also used here to help generate estimates that fill in the following gaps in the expenditure and source of payment data:

- expenditures for government-owned service providers (such as government-owned nursing homes);
- expenditures for the subset of persons age 65 and older;
- sources of payment for the subset of persons age 65 and older; and
- categories that can't be estimated from the two primary data sources.

The additional data sources include the 2000 Medical Expenditures Panel Survey and portions of the National Health Care Survey.

This report provides expenditure and source-of-payment estimates by category for nursing homes, several types of special residential settings, and a range of services and technologies in private homes and other community settings. While the services in

some of these categories overlap, the categories are defined by the characteristics of the service provider, and therefore avoid double-counting. The five source-of-payment categories used here are: Out-of-Pocket; Private Insurance; Medicare; Medicaid; and Other.

Principal Findings

In the year 2000, an estimated \$182 billion was spent for all persons (with breakouts by category shown in the table below), and an estimated \$102 billion for persons age 65 and over, on long-term care and independent living. Even using this more inclusive set of activities, the institutional focus of Medicaid funding is still evident. As the full report shows, Medicaid funded 49.1 percent of spending for services in residential settings and 52.4 percent of spending for nursing facilities specifically, but only 22.8 percent of nonresidential services. Nineteen percent of overall spending on long-term care and independent living was paid for out-of-pocket.

Spending on Long-Term Care and Independent Living, All Persons, 2000

TOTAL SPENDING ON IL/LTC (\$ billions)	\$182.2
NURSING FACILITIES & OTHER RESIDENTIAL SERVICE SETTINGS	\$106.7
Nursing facilities ¹	75.6
Residential mental retardation settings ²	16.3
State mental institutions (long-stayer portion only)	3.7
Residential mental health/substance abuse treatment settings	5.1
Residential settings for older persons with on-site nursing care facilities ³	3.3
Other residential service settings for older persons ⁴	2.7
NONRESIDENTIAL SERVICES	\$75.5
Services of home health care providers	37.7
Physical occupational & speech therapists, audiologists	9.9
Other services for older persons & persons with disabilities	11.6
Home-delivered meals & congregate meals	1.1
Special needs transportation	1.8
Medical equipment, supplies, & home/vehicle modifications ⁵	13.4

¹ Excludes Intermediate Care Facilities for the Mentally Retarded (ICF/MRs).

² Includes ICF/MRs.

³ An estimate of the labor-related assistive and nursing service costs only. Category includes continuing care retirement communities (CCRCs) and some assisted living residences.

⁴ An estimate of the labor-related assistive and nursing service costs only. Category includes assisted living residences *without* on-site nursing care units, homes for the elderly, rest homes, and domiciliary care.

⁵ Includes items such as vision aids, walkers, wheelchairs, hearing devices, artificial limbs, bathroom aids, medical equipment, disposable supplies, ambulance services, and home and vehicle modifications.

The total of \$182 billion is substantially different from the \$137 billion total in the General Accounting Office (GAO) report cited earlier.² Both estimates heavily utilize data series from the U.S. Economic Census and the Service Annual Survey, and expenditure categories in both cases are therefore largely defined by the primary characteristic of the *provider or setting*, not by the specific services actually provided.

The \$137 billion GAO estimate was derived by combining two expenditure categories in the National Health Accounts (NHA), “nursing home care” and “home health care”, with the dollar amount of Medicaid home and community-based waiver spending. So differences from the estimates presented in this report largely result from two sources: 1) additional expenditures included here that fall within the NHA; and 2) expenditures included here that fall outside of the NHA.

The “nursing facilities” category here is not directly comparable to the “nursing home” category in the GAO estimate. That category, from the National Health Accounts, sums up nursing homes, ICF-MRs, and the full level of expenditures for “residential settings primarily for older persons with on-site nursing care facilities” into a single total. But for the estimates in this report, these three settings are presented in three separate categories. Also, the nursing facility category here includes an estimate of expenditures for hospital-based nursing facilities, which are instead included in “hospital care” in the NHA. In addition, only an estimate of the labor-related assistive and nursing service costs is included here for the category “residential settings primarily for older persons with on-site nursing care facilities”, not the entire amount.

The expenditure estimates presented here also incorporate estimates of the following sub-sets of health expenditures, which are not included in the \$137 billion estimate:

- long-stay patients in state mental institutions
- residential mental health/substance abuse treatment settings
- home health service providers that are hospital-based (which are instead included in “hospital care” in the NHA)
- physical, occupational, and speech therapists and audiologists.

In addition, the estimates for long-term care and independent living services, settings, and technologies presented here include the following categories that are outside of the National Health Accounts:

- residential mental retardation settings other than ICF/MRs.
- other residential service settings primarily for older persons
- other services for older persons and persons with disabilities
- home-delivered meals and congregate meals
- special needs transportation

² Ibid.

Finally, the category in the present estimates labeled “equipment, supplies, and home modifications” includes both some spending that is counted in the NHA and some that is not.

Conclusions

The nonmedical nature of many activities that assist individuals in functioning and maintaining independence indicates that a broad approach should be taken in measuring expenditures for long-term care and independent living activities. The estimates presented here demonstrate that substantial activity is omitted by focusing solely on a subset of the health care sector.

Even though the estimates presented here cover a more complete set of categories of long-term care and independent living services, settings, and technologies than those that were previously available, they do embody the limitations of the available data. For example, most of the categories consist of *all* of the services delivered by a specific type of provider. But for some of these categories, it may be argued that while the large portion of the activity constitutes long-term care or support of independent living, another portion is too short-term in nature to be viewed as such. For example, the estimate provided here (and the GAO estimate discussed earlier as well) include the four days’ worth of home health care a person may receive after an inpatient surgery and before resuming independent living without services or other supports.

For categories that represent residential settings, it is not clear-cut whether one should exclude the portion of these settings’ costs that represent room and board, or how to calculate the plant and equipment costs that are associated with the services and technologies that are provided. Even when a decision is made, data sufficient to make an actual estimate can be lacking. For both of these reasons, decisions about how to estimate the costs to be included in this report were made on a setting by setting basis.

Several specific long term care and independent living activities are not included in the expenditure estimates presented here. The most important of these are the following:

- some services provided directly by state and local government employees;
- educational and vocational programs for children and young adults, which have not been included in the analysis presented here that focus on adults, and on older adults in particular;
- services and products that are considered "medical", but that help persons function with chronic disease (for example, some prescription drugs) or have a primary purpose of restoring functioning (for example, surgical procedures such as hip replacement); and
- the substantial level of unpaid home care, which is excluded from the estimates presented here that measure activities involving monetary transactions.

While higher than previous estimates, the estimates presented here should not obscure the fact that numerous other studies indicate that notable unmet need remains. Estimates for future years using the same definitions will be able to capture not only overall growth but also expenditure shifts within the diverse range of services, settings, and technologies.

TABLE OF CONTENTS

Introduction.....	1
What Do We Mean When We Talk about Long-Term Care and Activities that Maintain or Restore Independent Living?.....	3
Brief Description of Data Sources	5
Service and Payment Categories Used in This Report.....	6
Overall Spending on Long-Term Care and Independent Living	10
Sources of Payment for Expenditures on Long-Term Care and Independent Living.....	12
Spending on Long-Term Care and Independent Living for Persons Age 65 and Older. 15	
Sources of Payment for Expenditures on Long-Term Care and Independent Living for Persons Age 65 and Older	16
Limitations of This Accounting	19
Summing Up	21

List of Tables

TABLE 1: Spending on Long-Term Care and Independent Living, All Persons, 2000	11
TABLE 2: Sources of Payment for Expenditures on Long-Term Care and Independent Living, All Persons, 2000	13
TABLE 3: Expenditures on Long-Term Care and Independent Living, Persons Age 65 and Older, 2000	17
TABLE 4: Sources of Payment for Expenditures on Long-Term Care and Independent Living, Persons Age 65 and Older, 2000	18

A New Look at U.S. Expenditures for Long-Term Care and Independent Living Services for the Year 2000

Introduction

As the U.S. population ages, we increasingly confront the problems of maintaining the health and functioning of individuals. While there is a long-standing and strong interest in the health of older persons, there is an increasing focus on functioning as well—that is, the ability of individuals to interact effectively with their environment, with as much control and in as much of a community setting as is feasible.

Some services, such as nursing home services and some types of home care, have traditionally been called “long-term care.” In addition, however, an increasingly diverse range of services, residential settings, and technologies are available to assist in maintaining functioning and independence—including, for example, home-delivered meals, home modifications, and assisted living residences.

Individuals and federal, state, and local governments are grappling with the costs of providing these services, settings, and technologies to persons who need them. As a result, it is useful to take stock of the level of expenditures for these activities as well as who is paying for them. Given the long-standing focus on health and the costs of government health care programs such as Medicare and Medicaid, there are many efforts to track health care spending. However, there have been fewer attempts to estimate spending on the wide range of long-term care and independent living services, settings, and technologies that assist functioning.

Some estimates of spending on long-term care services do exist. For example, one often-cited measure, presented in a General Accounting Office (GAO) report, indicates that long-term care expenditures for persons of all ages totaled about \$137 billion in the year 2000.³ However, that estimate presents expenditures for only selected long-term care services that are a subset of the health care sector. The estimates presented in this report recognize that long-term care and independent living services, settings and technologies overlap with health care, but are not simply a subset. The estimates incorporate a range of activities that provide long-term care and support independent living, regardless of whether these are considered health care or not, including expenditures for social services, home-delivered and congregate meals, special needs transportation, and nursing and assistive services provided in assisted living facilities, homes for the elderly, and other types of residences.

However one measures long-term care spending, the total magnitude is great. But a more inclusive and accurate framework for expenditures has several advantages:

³ GAO. *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*. Washington, DC: GAO (GAO-02-544T), March 2002.

- If long-term care spending shifts among various services, settings, and technologies, then these shifts will be revealed. But if some portion of the range is omitted, then shifts may spuriously appear to be either decreases or increases in overall long-term care spending.
- A more accurate picture of what is being spent is more likely to lead to a more accurate picture of need (including unmet need), and of the costs of potential new programs to provide broader public coverage of services, settings and technologies designed to meet the long-term care and independent living needs of older persons.
- Discussions of long-term care policy that are motivated by the presentation of spending estimates that cover only a subset of services, settings, and technologies may yield inefficient policy options that ignore the potential of the omitted activities.

A more inclusive measure of long-term care and independent living activities would have better captured the overall effects of the increase in expenditures for assisted living residences, some of which involved substitution for other community-based services and for nursing home care. Similarly, potential future increases in adult day care services may represent in part a substitution for home care and rehabilitation services currently provided in a person's home. A more inclusive measure of long-term care and independent living activities than is currently being used is needed in order to fully capture these effects as well.

This report presents new estimates for the year 2000 of U.S. expenditures on long-term care and independent living services, settings, and technologies, including data on sources of payment for these expenditures. The estimates are provided both in total and for persons age 65 and over. A relatively broad definition of included activities is used, reflecting recent developments in ways to provide assistance in functioning. Consequently, estimates for future years using the same definition will be able to capture not only overall growth but also spending shifts within the diverse range of services, settings, and technologies.

Some of the activities included here, such as rehabilitation and nursing home services, overlap with health care measures, while other services, such as domestic chore services, are largely separate from health care. As a result, these estimates differ from estimates sometimes cited elsewhere, which are generated as a subset of the expenditures in the National Health Accounts (NHA) maintained by the Centers for Medicare and Medicaid Services (CMS).⁴ By design, the NHA excludes a range of non-medical social and residential services.

This report first discusses the range of long-term care and independent living services, settings, and technologies, and describes the categories used in the estimates. It then

⁴ For example, *ibid.*

presents the expenditure and source-of-payment estimates and concludes with a discussion and summary.

This report frequently uses the phrase, “older persons and persons with disabilities,” to describe recipients of the activities discussed here. However, use of this phrase is not meant to imply that these two groups are mutually exclusive, or that formal disability determinations have been made in all cases. Some older persons may meet specific disability criteria, other older recipients of the services reported here may not be considered to have a disability by certain specific criteria, and some persons who are not older and who might not be considered to have a disability may also be recipients of the services included here.

What Do We Mean When We Talk about Long-Term Care and Activities that Maintain or Restore Independent Living?

From the broadest perspective, any service, setting, or technology that preserves or restores functioning or assists a person with limited functioning might be considered a long-term care service or an activity that contributes to independent living. Therefore, a wide range of activities can contribute to functional independence, including both health-related and other services.

Take, for example, a person who has had a stroke. Immediately following the event there might be an acute inpatient hospital stay. During this stay, rehabilitation services will probably begin, and rehabilitation may continue for some period in a subacute or community-based setting. In addition, other services and technologies may begin to be provided on a long-term basis. These may be medical in nature, such as medications to lower the probability of subsequent strokes. Services may also include assistance with activities of daily living (ADLs), such as bathing or using the toilet, or with other basic activities such as shopping or housekeeping. At the same time, the person may make modifications to his or her home and may adopt any number of assistive technologies to accommodate functional limitations. Alternatively, a person may move to another residential setting, such as an assisted living residence or a nursing home, where technological accommodations and/or service provision are more readily available.

There is no consensus on which portion of the above activities should be considered long-term care and independent living services, settings, and technologies. Expenditures for long-term care/independent living activities may be made in several domains:

- medical care and health services;
- social services, such as assistance with ADLs and homemaker activities;
- personal assistive technologies (for example, wheelchairs, prosthetics and orthotics, hearing aids and communication devices) and other technological adaptations such as home modifications;

- living arrangements that are designed to accommodate difficulties in functioning and/or to facilitate provision of services to residents; and
- transportation services that accommodate difficulties in functioning.

Most measures of independent living/long-term care expenditures exclude payments for services that are considered medical in nature (that is, delivered in physicians' offices or in hospitals). For example, while a hip replacement operation is usually performed to improve functioning, the inpatient hospital stay and the physician services associated with the procedure are not generally categorized as independent living/long-term care services. However, rehabilitation therapy provided in the home or an outpatient setting is generally included in measures of independent living/long-term care (though such therapy is usually delivered under a plan of care supervised by a physician).

To be considered as long-term care and/or supporting independent living, an activity need not be required for a recipient's *entire* remaining lifetime. In particular, some activities are usually of limited duration, such as various types of rehabilitation therapy, which may be viewed as investments in a future lifetime of independent living. In much the same way as medical care can be viewed as an investment in human capital, we can consider such nonmedical therapies as investments in "long-term independence" from a human capital perspective as well. Similarly, home modifications and the purchase of wheelchairs are examples of investments in physical capital for long-term independence.

The specific activities included in the expenditure estimates presented here are described in some detail below. The best simple description of what is included is: all of the services/settings/technologies of the types discussed above, *except* for services provided directly *by* physicians or provided in physicians' offices or in hospitals.⁵

It may be useful to relate this specified set of activities to the "System of Health Accounts" created by the Organisation for Economic Co-operation and Development (OECD).⁶ In its functional classification, the OECD specifies three basic types of health care: curative, rehabilitative, and long-term care. It also defines an additional set of "health-*related* functions" that are excluded when measuring health care for OECD accounts, one of which is social services "to assist living with disease and impairment." In essence, the accounting presented in this report focuses on the three OECD categories/functions of rehabilitative care, long-term care, and social services that assist in living with disease and impairment, and also adds a category for assistive technologies. Long-term care and independent living activities therefore overlap with health care but are not solely a subset of it.

⁵ Neither the estimates presented here nor estimates of long-term care expenditures presented elsewhere attempt to unbundle the components delivered in hospitals, nursing homes, or doctor's offices. For example, care in a hospital may include some rehabilitation services, but these services are not included in the long-term care estimates. And care in a nursing home may include some prescription drugs, but these drugs are not *excluded* from the long-term care estimates.

⁶ OECD. *A System of Health Accounts, Version 1.0*. Paris: OECD Publications, 2000.

To be more specific, for the purposes of this report the costs of skilled nursing and personal care services provided in the home are included, as are rehabilitation services provided outside of in-patient hospital stays and doctor visits. Other types of social services and both residential and personal technological adaptations are included as well. Finally, the cost of nursing home care is also included, as is the cost of assistive, nursing, and social services provided in assisted living and other types of special residential settings. Thus, the estimates include some health care categories that may be *supervised* by a physician but are largely provided by nonphysician practitioners. Service categories that are highly medical in nature, such as physician and inpatient hospital services, are excluded. Prescription drugs, almost exclusively prescribed by physicians, are also excluded, even though over the past decades prescription medicines for conditions such as heart disease, high blood pressure, and depression have become increasingly important elements in maintaining the quality of life for many older persons with chronic conditions that might otherwise have resulted in increased disability, institutionalization, or death.

Brief Description of Data Sources

While there generally are good measures of health care spending, data are less complete for expenditures on nonmedical services, settings, and technologies that are used to maintain or assist with functioning and independence. As a result, while the majority of the estimates presented here are derived directly from empirical sources, some of them required assumptions to be made in order to generate estimates of expenditure levels or the distribution of sources of payment. In addition, as described below, some of the categories presented here contain only a partial accounting of all expenditures in that category.

The estimates presented here are based primarily on the 2000 Service Annual Survey (SAS) and the 1997 Economic Census, both conducted by the U.S. Census Bureau.⁷ (These efforts also form the basis of portions of the National Health Accounts.) Both the Service Annual Survey and the Economic Census collect data directly from private sector service providers, both for-profit and not-for-profit, and the Economic Census covers the entire range of economic activity in the private sector. The economic activity recorded in these surveys is categorized according to the North American Industry Classification System.

Several other data sources are used to complete the results presented here, by providing one or more of the following types of data:

- adjustments to the private sector data to expand the estimates to incorporate public sector service providers;
- breakouts of expenditures for persons age 65 and older;

⁷ The Economic Census profiles the U.S. economy every five years, and the most recent year for which complete data are available is 1997. Data reports from the 2002 Economic Census are now being produced.

- data on the distribution of sources of payment;
- data on the proportions of the revenues of continuing care retirement communities (CCRCs), assisted living residences, and other related settings that go toward the costs of assisted living and nursing services; and
- the spending levels for categories that cannot be obtained from the SAS or the Economic Census.

Most important of these additional data sources is the 2000 Medical Expenditures Panel Survey (MEPS), which surveys the civilian noninstitutionalized U.S. population for a variety of measures, including health care use and expenditures and sources of payment for these expenditures that can be broken out by age groups. Also used here is the National Health Care Survey of the National Center for Health Statistics, which includes the 2000 National Home and Hospice Care Survey and the 1999 National Nursing Home Survey. The data sources other than those from the year 2000 are used primarily to provide ratio adjustments for services not included in 2000 data and to generate percentage allocations among sources of payment, not to estimate absolute levels of spending.

Expenditure estimates are in year 2000 dollars. For most categories of service, data were available from which to directly estimate source-of-payment shares. However, for several categories, other sources and methods had to be incorporated. These included allocations of known program spending amounts among appropriate service categories, non-quantitative information about funding sources, and consultation with experts. For more technical details about the construction of these estimates, including the steps and assumptions needed to generate them, see Marc Freiman, "Methodology for A New Look at U.S. Expenditures for Long-Term Care and Independent Living Services, Settings, and Technologies for the Year 2000: Technical Documentation" (April 2004), available from the author.

Service and Payment Categories Used in This Report

The specific service categories for long-term care and independent living used in this report are presented below. Most are derived from the North American Industry Classification System (NAICS) used by the Census Bureau, so they correspond directly to categories for which data are available in their Service Annual Survey. In such cases, the descriptions are derived from the NAICS codebook, with paraphrases where necessary to ensure standard use of terms in this report.

NURSING FACILITIES AND OTHER RESIDENTIAL SERVICE SETTINGS:

Nursing facilities (excluding Intermediate Care Facilities for the Mentally Retarded [ICF/MRs]): These facilities are establishments primarily engaged in providing inpatient nursing and rehabilitative services, generally for an extended period of

time. Includes skilled nursing facilities (SNFs) and Medicaid nursing facilities (NFs), including inpatient care hospices.

Residential mental retardation settings: These settings consist of group homes, hospitals, and ICF/MRs primarily engaged in providing residential care services for persons diagnosed with mental retardation or developmental disabilities (MR/DD).

State mental institutions (long-stayer portion): Most inpatient psychiatric care, like most medical/surgical inpatient stays in general hospitals, consists of acute care for relatively short lengths of stay. However, as providers of last resort, state and county mental institutions provide treatment and custodial care to some patients on a longer-term basis. The estimates presented here use data on lengths of stay to estimate the portion of expenditures for state mental hospitals accounted for by long-stay patients (longer than three months).

Residential mental health/substance abuse treatment settings: These settings are establishments primarily engaged in providing residential care and treatment for patients with mental health and substance abuse illnesses. Although medical services may be available, they are incidental to the counseling, mental rehabilitation, and support services offered.

Residential settings primarily for older persons with on-site nursing care facilities (an estimate of only the labor-related assistive and nursing costs): These settings include continuing care retirement communities (CCRCs) and those assisted living residences with on-site nursing care facilities.

Other residential service settings primarily for older persons (an estimate of the labor-related assistive and nursing costs only): This category consists of homes for the elderly, rest homes, and assisted living residences that provide residential and personal care services but without on-site nursing care units or facilities. Veterans Health Administration domiciliary care is also included here.

By the very nature of their settings, residential service providers create both conceptual and measurement issues with regard to what portion, if any, of the room and board component of their total services should be included in a measure of long-term care and independent living services. This report includes estimates of the entire costs for nursing facilities, residential MR/DD settings, long-term state mental hospital care, and residential mental health/substance abuse treatment settings, as is done in the NHA. Therefore, the estimates for these settings incorporate all activities in these settings, regardless of whether they are considered by this report as long-term care or in support of independent living. However, for assisted living residences, CCRCs, homes for the elderly, and related residential service settings, estimates of only the labor costs of assistive and nursing services are included, with the assumption that the room, board, and other components represent more of a voluntary residential choice that is less directly related to service needs. While this subset of costs is closer to an appropriate measure of only those services that assist in functioning than would be the entire costs

of such settings, they are an *underestimate* in that they do not include nonlabor costs related to maintaining a nursing unit or to providing assistive services. The issues that these decisions entail are discussed further at the end of this report.

NONRESIDENTIAL SERVICES:

The categories for nonresidential services are defined by the primary characteristic of the *provider*, not by the specific services actually provided. For example, physical therapy services may be provided in both the home health care provider category and in the physical therapist category. But there is no double-counting of any specific service that was delivered, and each individual provider is counted in only one category.

Services of home health care providers: These providers are establishments and persons who provide skilled nursing services in the home, along with a range of other services, such as physical, occupational, and speech therapy, personal care, and homemaker and companion services. This category also includes in-home hospice care. As a result, it includes instances where a home health provider may provide home health care services only, personal care services in addition to home health care, or even possibly personal care services only. Regardless, all the services in this category are delivered by providers who have the capability to provide skilled nursing care and who have defined themselves as home health care providers in terms of NAICS codes.

Physical, occupational, and speech therapists and audiologists: These practitioners consist of independent establishments and persons who engage in educational, recreational, and social activities designed to help individuals with disabilities regain function or adapt to their disabilities and/or to administer medically prescribed physical therapy treatment. These practitioners operate private or group practices from their own offices or in facilities such as hospitals or HMO medical centers. To the degree that there are reporting independent hospital-based practices that provide care to inpatients, some of the therapy delivered to hospitalized patients may be unavoidably included in the estimates presented here.

Other services for older persons and persons with disabilities: This category consists of establishments and persons who provide nonresidential social assistance services to improve the quality of life for older persons, persons diagnosed with mental retardation, or persons with disabilities. These services include day care, nonmedical home care or homemaker services, social activities, group support, and companionship.

Home-delivered meals and congregate meals: In the absence of a broader usable data source, for this category we use spending for these types of meals from all sources reported through State Units on Aging.

Special needs transportation: Establishments and persons in this category provide special needs transportation (*except* to and from school or work) to those who are infirm, older persons, or persons with disabilities. These providers may use specially equipped vehicles to provide transportation. This category explicitly excludes establishments that primarily provide ambulance services for emergency and medical purposes.

Equipment, supplies, and home modifications: This category includes expenditures for the purchase or use of:

- vision aids, including eyeglasses;
- orthopedic items (includes canes, walkers, wheelchairs, etc.);
- hearing aids and other hearing devices;
- artificial limbs;
- bathroom aids (includes raised toilet seats, handrails, etc.);
- medical equipment (includes hospital beds, lifts, special chairs, oxygen, etc.);
- disposable supplies (includes bandages, dressings, diapers, IV supplies, etc.);
- ambulance services;
- alterations/modifications (includes ramps, handrails, elevators, car modifications, etc.); and
- other miscellaneous items or services.

Some of these items, such as ambulance services, disposable supplies, and some portion of medical equipment, ideally might be excluded from the estimates presented here. However, such exclusion would require extensive new analysis at a level of detail that may not be possible using publicly available data sets.

SOURCES OF PAYMENT. The five source-of-payment categories we use here (most of which are self-explanatory) are:

- **Out-of-Pocket.** These payments can occur for several reasons: persons without private or public health coverage, as well as persons with coverage who are paying for deductibles, copayments, or portions of charges above those covered by insurance or government programs.
- **Private Insurance.** This category includes health insurance, Medigap insurance, and long-term care insurance, paid for by insurance premiums from individuals, employers, etc.
- **Medicare**
- **Medicaid**
- **Other.** This final “catchall” category includes federal and state government programs other than Medicaid and Medicare (such as Older Americans Act funding), local government programs, Veterans Administration programs, and Workers Compensation. It also includes private sector funding through gifts, grants, and nonservice related revenues. Finally, it includes a few instances

where data on sources of payment were available, but in which some portion of spending was reported as coming from unknown sources.

Overall Spending on Long-Term Care and Independent Living

Table 1 presents estimates of expenditures for the year 2000 for the long-term care and independent living services, settings, and technologies measured here. The combined total for these spending categories was \$182 billion. Fifty-nine percent of this total was spent in residential service settings. By far the largest segment of this residential portion (\$75.6 billion) was for the services of nursing facilities—either freestanding or hospital-based, but excluding intermediate care facilities for the mentally retarded (ICF/MRs) and nursing units in CCRCs and assisted living residences. Expenditures for residential service settings for mental retardation and developmental disabilities amounted to \$16.3 billion (including Medicaid ICF/MRs). Almost \$4 billion was spent on long-term stays in state mental institutions, and an additional \$5.1 billion was spent in residential mental health/substance abuse settings.

An estimated \$3.3 billion was spent on the labor portion of assistive and nursing services in settings such as continuing care retirement communities and assisted living residences that included on-site nursing facilities. (This \$3.3 billion total includes a portion of the amount spent on these on-site nursing facilities.) An additional \$2.7 billion was spent on the labor portion of assistive and nursing services in other residential service settings, such as assisted living residences without nursing units and board and care homes.

Nonresidential services amounted to \$75.5 billion in 2000. The largest component (\$37.7 billion) of this category was services delivered by home health care providers. The specific services provided consist primarily of skilled nursing services but also include some therapies, personal care, homemaker, and companion services. They also include in-home hospice. An additional \$9.9 billion was spent on practitioners who provided a range of therapies, including physical, occupational, and speech. Also, \$11.6 billion was spent on nonmedical social services (day care, homemaker services, companionship, etc.) for older persons and persons with disabilities delivered by entities other than home health care providers.

Transportation assistance can take many forms, some of which are more difficult to measure than others. One large portion of such assistance consists of establishments primarily engaged in providing special needs transportation for older persons and persons with disabilities, but not including transportation to and from school or work. This category of service providers received \$1.8 billion in 2000. Similarly, it is difficult to measure all expenditures on programs providing meal assistance to older persons and disabled persons. But we can measure one important portion: State Units on Aging and local Area Administrations on Aging reported that in 2000 their expenditures included \$563 million for congregate meals and \$534 million for home delivered meals, totaling \$1.1 billion.

**TABLE 1: Spending on Long-Term Care and Independent Living,
All Persons, 2000**

TOTAL SPENDING ON IL/LTC (\$ billions)	\$182.2
NURSING FACILITIES & OTHER RESIDENTIAL SERVICE SETTINGS	\$106.7
Nursing facilities (excluding ICF/MRs) ¹	75.6
Residential mental retardation settings ²	16.3
State mental institutions (long-term portion) ³	3.7
Residential mental health/substance abuse settings ⁴	5.1
Residential settings with on-site nursing care facilities ⁵	3.3
Other residential service settings ⁵	2.7
NONRESIDENTIAL SERVICES	\$75.5
Services of home health care providers ⁶	37.7
Physical occupational & speech therapists, audiologists ⁴	9.9
Other services for older persons & persons with disabilities ⁷	11.6
Home-delivered meals & congregate meals ⁸	1.1
Special needs transportation ⁹	1.8
Medical supplies, equipment & home modifications ¹⁰	13.4

¹PPI calculations based on 2000 U.S. Service Annual Survey, 1997 Economic Census, and 1999 National Nursing Home Survey.

²PPI calculations based on 2000 U.S. Service Annual Survey and 2001 National Residential Information Systems Project on Residential Services Survey.

³PPI calculations based on FY2001 data from National Association of State Mental Health Program Directors.

⁴2000 U.S. Service Annual Survey.

⁵PPI calculations based on 2000 U.S. Service Annual Survey; includes only the labor-portion of assistive and nursing services out of total costs (27.6 percent of \$12.1 billion for "residential settings with on-site nursing care facilities," and 25.8 percent of \$9.1 billion, plus \$.4 billion for VA domiciliary care, for "other residential service settings.")

⁶PPI calculations based on 2000 U.S. Service Annual Survey, 2000 Medical Expenditure Panel Survey, and 2000 National Home and Hospice Care Survey.

⁷PPI calculations based on 2000 U.S. Service Annual Survey.

⁸2000 Administration on Aging data.

⁹PPI calculations based on 1997 U.S. Economic Census.

¹⁰2000 Medical Expenditure Panel Survey.

Expenditures on a range of medical equipment, supplies, and home modifications amounted to \$13.4 billion in 2000. As noted above, this category includes expenditures for the purchase, installation, or use of such items as eyeglasses and other vision aids (which total roughly half of this category), walkers, wheelchairs, hearing devices, raised toilet seats, handrails, hospital beds, lifts, oxygen, home ramps, and car modifications (plus disposable supplies and ambulances).

Sources of Payment for Expenditures on Long-Term Care and Independent Living

No single program, public or private, pays for all long-term care and independent living activities, and sources of payment vary according to a person's age, income, work status, and disability characteristics. Table 2 presents sources of payment for expenditures on independent living/long-term care services, settings, and technologies, both overall and by category. Due to data limitations, source of payment data are combined for the two categories "Residential settings with on-site nursing care facilities" and "Other residential service settings."

Medicaid funded over half of nursing home care (52.4 percent). Medicaid is a federal-state-funded entitlement program that provides medical assistance to low-income persons with limited assets who are aged, blind, disabled, or members of families with dependent children, and in a majority of states to certain individuals with large medical care costs who are "medically needy." With respect to long-term care services, most of the services provided by Medicaid fall into four categories: (1) nursing facility services (mandatory coverage for states) and other institutional (optional) services; (2) home health services (mandatory); (3) personal care services (optional and covered in about half the states); and (4) home and community-based services waiver programs that exist in all states.

Out-of-pocket sources paid for roughly 19 percent of nursing home care, and Medicare paid for 16.5 percent. While Medicare is a federal entitlement program that provides care to older persons and persons with disabilities, payment for nursing facility care is limited by the requirements of a preceding hospital stay of at least three days and a continuing need for skilled care, and by the limitation on the number of covered days of care for a given episode.

Using data from several sources and additional assumptions, this report estimates that Medicaid funded two-thirds of expenditures for residential mental retardation settings, mostly through payments to ICF-MRs but also through waivers for home and community-based services. The remaining portion is allocated primarily to other government programs. This report assumes that the long stays in state mental institutions are funded primarily through state budget appropriations. Residential mental health/substance abuse settings display a range of funding sources, although our estimates assign the majority of them to the range of funding sources represented by the "Other" category.

TABLE 2: Sources of Payment for Expenditures on Long-Term Care and Independent Living, All Persons, 2000

	Out-of-Pocket	Private Ins.	Medi-care	Medi-caid	Other
ALL SPENDING ON IL/LTC	19.0%	10.6%	15.8%	38.2%	16.5%
NURSING FACILITIES & OTHER RESIDENTIAL SERVICE SETTINGS	18.6	6.2	12.6	49.1	13.5
Nursing facilities (excluding ICF/MRs) ¹	19.0	7.8	16.5	52.4	4.3
Residential mental retardation settings ²	3.8	0.0	4.0	66.7	25.6
State mental institutions (long-term portion)	0.0	0.0	0.0	0.0	100.0
Residential mental health/substance abuse settings ³	14.3	10.7	0.0	18.8	56.2
Residential settings with on-site nursing care facilities ⁴	69.1	3.0	5.8	15.1	7.0
Other residential service settings ⁴					
NONRESIDENTIAL SERVICES	19.4	16.8	20.2	22.8	20.7
Services of home health care providers ⁵	8.7	18.1	35.1	25.1	13.0
Physical, occupational & speech therapists, audiologists ⁵	9.8	35.1	16.7	6.3	32.1
Other services for older persons and persons with disabilities ⁶	5.0	2.3	0.0	50.0	42.7
Home-delivered meals & congregate meals ⁷	10.0	0.0	0.0	5.0	85.0
Special needs transportation	10.0	0.0	0.0	20.0	70.0
Medical supplies, equipment & home modifications ⁸	71.3	16.0	3.0	6.7	3.0

¹PPI calculations based on 2000 U.S. Service Annual Survey, 1997 Economic Census, and 1999 National Nursing Home Survey.

²PPI calculations based on 2000 U.S. Service Annual Survey, 2001 and 2000 National Residential Information Systems Project on Residential Services Surveys, and Medicaid administrative data.

³PPI calculations based on 2000 U.S. Service Annual Survey.

⁴2000 U.S. Service Annual Survey; data were available only for these two categories combined.

⁵2000 U.S. Service Annual Survey.

⁶PPI calculations based on Medicaid administrative data.

⁷2000 Administration on Aging data.

⁸PPI calculations based on 2000 Medical Expenditure Panel Survey.

Assistive and nursing services in residential service settings primarily for older persons (with and without on-site nursing care) were overwhelmingly paid for out-of-pocket (69 percent). However, small portions of the costs of these settings were also estimated to be paid for by other sources.

Turning to nonresidential services, Medicare paid for just over a third of the services of home health care providers (35.1 percent) in 2000. Medicare-covered home health care can include a range of nursing and personal care services as long as skilled care is required, but skilled care cannot be needed on a full-time basis. These limitations mean that coverage of these services under Medicare is rarely long term. Also included in this service category are in-home hospice services provided under Medicare. Private insurance paid for roughly 18 percent of the services of home health care providers; as with Medicare, most likely for shorter terms of service.

Medicaid paid for roughly one-quarter of the services of home health care providers. In addition to the home health services provided under Medicaid, this category includes a portion of the personal care services covered under Medicaid—home health providers can and do provide some personal care services, and as noted, the service categories used here are defined by the primary nature of the provider, not by the specific services provided. This category also includes skilled nursing services provided to some persons with disabilities under some Medicaid home and community-based services waivers.

The “Other” category accounted for 13 percent of payments to home health care providers. Few of the services of these providers were paid for out-of-pocket (only 8.7 percent).

Therapists present a different picture, with private insurance the largest source (35.1 percent) of payments, and an additional 32 percent funded by “Other” (including Workers Compensation and the Veterans Administration) and almost 17 percent by Medicare.

This analysis used a process of allocating Medicaid funds among service categories that results in Medicaid accounting for half of spending on “other services for older persons and persons with disabilities.” The large “Other” payment category (42.7 percent) consists to a great degree of government programs other than Medicaid and Medicare (including grant programs), and also includes grants and donations from the private sector.

Almost all (90 percent) of the expenditures on home-delivered meals and congregate meals that State Units on Aging and local Area Administrations on Aging reported were estimated to be funded by the federal government through the Older Americans Act, other government programs (including grant programs), and grants and donations from the private sector.

The majority of the funding for special needs transportation services has been assigned to the “Other” category. Finally, 71 percent of expenditures for medical equipment, supplies, and home modifications were funded out-of-pocket, and private insurance paid for 16 percent.

Looking at all spending on long-term care and independent living services, settings and technologies combined, Medicaid was the largest single source of funding, accounting for almost 40 percent. Medicare funded 16 percent of independent living/long-term care activities. Given Medicaid and Medicare’s various qualification requirements and service coverage limitations, it is not surprising that out-of-pocket sources accounted for a large percentage of payments for long-term care/independent living activities—almost 20 percent of overall spending was estimated to be paid for out-of-pocket.

Although private insurance is a major source of funding for health care, it played a limited role with regard to long term care and independent living services, settings, and technologies, paying for only about 11 percent of the total. And more than one type of insurance is involved. Private health insurance can pay for noncustodial use of skilled nursing homes and home health care and some related social services; Medigap policies can pay for some portions of the costs of long-term care services not covered by Medicare; and long-term care insurance (as opposed to health insurance) focuses more directly on paying for these services, but only a small portion of persons have such policies.

Spending on Long-Term Care and Independent Living for Persons Age 65 and Older

It is more difficult to estimate expenditures and sources of payment for persons age 65 and older than it is for all persons, because the primary data sources (the Economic Census and the Service Annual Survey) do not provide age breakouts. Therefore, to present estimates for persons 65 and older, this report incorporates data from additional sources (or, in some cases, additional assumptions).

Given the definitions of the service providers included, several service categories provide services almost exclusively to older persons. For example, “residential settings with on-site nursing care facilities” and “other residential service settings” comprise places such as continuing care retirement communities and homes for the elderly, residential settings that focus almost exclusively on older persons. For these two categories, as well as meal service expenditures derived from Administration on Aging data, expenditures for all persons and for persons age 65 and older are assumed to be the same, based on the limited relevant data available. Therefore, these figures are the same as those in Table 1, and the sources of payment that will be presented in Table 4 are the same as those in Table 2 for these categories.

Table 3 presents estimates of expenditures on long-term care and independent living services, settings, and technologies for persons age 65 and older. The overall expenditure estimate for 2000 is \$102 billion. Three-quarters of this total (74.7 percent) is for some type of residential service setting, with nursing homes accounting for two-thirds of total expenditures (66.8 percent). Given the small proportion of persons who receive services in state mental institutions and residential mental health/substance abuse settings who are age 65 and over, the level of expenditures in these two categories is low.

Nonresidential services accounted for \$25.9 billion, or one-quarter (25.3 percent) of total expenditures on long-term care and independent living services for persons age 65 and older. Most of these nonresidential service expenditures consisted of the range of services delivered by home health providers (16.4 percent of total age 65+ spending). Other social services for older persons amounted to \$2.7 billion, and spending for medical supplies, equipment, and home modifications amounted to \$3.4 billion.

Sources of Payment for Expenditures on Long-Term Care and Independent Living for Persons Age 65 and Older

Table 4 presents the estimates of sources of payment for persons age 65 and older for expenditures on independent living/long-term care services, settings, and technologies, both overall and by category. For several categories, the source of payment distribution is the same as that presented in Table 2 for all persons. This is either because the providers in a category almost exclusively serve persons 65 and over, and/or or because no data are available that indicate that the distribution of sources of payment differs significantly for the over 65 population compared to all persons.

For all spending for older persons, Medicaid accounts for roughly 40 percent. The next largest source, accounting for just over 20 percent of payments, is out of the consumer's pocket (22.0 percent). Medicare also funds roughly 20 percent (20.5 percent) of spending on long-term care and independent living, while private insurance funds only 8.7 percent of these expenditures for persons age 65 and over. Other government sources account for 8.3 percent.

Medicare pays for 35.9 percent of expenditures for persons 65 and over for nonresidential services and technologies. This is a much larger proportion than the 20.2 percent for nonresidential services for all persons in Table 2, and this difference is due to the near-universal Medicare coverage of persons 65 and over, and the fact that many of these nonresidential services, such as home health care, rehabilitation services, and some medical equipment and supplies, are covered at least partially by this program.

TABLE 3: Expenditures on Long-Term Care and Independent Living, Persons Age 65 and Older, 2000

TOTAL SPENDING ON IL/LTC, Age 65 and Older	\$102.1	100%
NURSING FACILITIES & OTHER RESIDENTIAL SERVICE SETTINGS	76.3	74.7
Nursing facilities (excluding ICF/MRs) ¹	68.2	66.8
Residential mental retardation settings ²	1.3	1.3
State mental institutions (long-term portion) ³	.4	.4
Residential mental health/substance abuse settings ⁴	.2	.2
Residential settings with on-site nursing facilities ⁵	3.3	3.3
Other residential service settings ⁵	2.7	2.7
NONRESIDENTIAL SERVICES	25.9	25.3
Services of home health care providers ⁶	16.7	16.4
Physical, occupational & speech therapists, audiologists ⁷	1.5	1.5
Other services for older persons ⁸	2.7	2.7
Home-delivered meals & congregate meals ⁹	1.1	1.1
Special needs transportation ¹⁰	.4	.4
Medical supplies, equipment & home modifications ¹¹	3.4	3.3

¹PPI calculations based on 2000 U.S. Service Annual Survey, 1997 Economic Census, and 1999 National Nursing Home Survey.

²PPI calculations based on 2000 U.S. Service Annual Survey and 2000-2001 National Residential Information Systems Project on Residential Services Surveys.

³PPI calculations based on FY2001 data from National Association of State Mental Health Program Directors and 1997 Client/Patient Sample Survey, Substance Abuse and Mental Health Services Administration.

⁴ PPI calculations based on 2000 U.S. Service Annual Survey and 1997 Client/Patient Sample Survey, Substance Abuse and Mental Health Services Administration.

⁵PPI calculations based on 2000 U.S. Service Annual Survey; includes only the labor portion of assistive and nursing services out of total costs (27.6 percent of \$12.1 billion for “residential settings w/ on-site nursing care facilities,” and 25.8 percent of \$9.1 billion, plus \$.4 billion for VA domiciliary care, for “other residential service settings”).

⁶PPI calculations based on 2000 U.S. Service Annual Survey, 2000 Medical Expenditure Panel Survey, and 2000 National Home and Hospice Care Survey; includes assistive and nursing services only.

⁷PPI calculations based on 2000 U.S. Service Annual Survey and 2000 Medical Expenditure Panel Survey.

⁸PPI calculations based on 2000 U.S. Service Annual Survey and Weiner et al. (2002).⁸

⁹2000 Administration on Aging data; it is assumed that all of the reported spending from this source is for persons age 65 and older.

¹⁰PPI calculations based on 1997 U.S. Economic Census and Weiner et al. (2002).⁸

¹¹PPI calculations based on 2000 Medical Expenditure Panel Survey.

⁸ Weiner, Joshua M., Jane Tilly, and Lisa Maria Alecxih. “Home and Community-Based Services in Seven States”, *Health Care Financing Review*, Spring 2002 (23:3), 89-114.

TABLE 4: Sources of Payment for Expenditures on Long-Term Care and Independent Living, Persons Age 65 and Older, 2000

	Out-of-Pocket	Private Ins.	Medi-care	Medi-caid	Other
ALL SPENDING ON IL/LTC	22.0%	8.7%	20.5%	40.5%	8.3%
NURSING FACILITIES & OTHER RESIDENTIAL SERVICE SETTINGS	22.6	7.2	15.3	49.3	5.6
Nursing facilities (excluding ICF/MRs) ¹	19.0	7.8	16.5	52.4	4.3
Residential mental retardation settings ²	3.8	0.0	4.0	66.7	25.6
State mental institutions (long-term portion)	0.0	0.0	0.0	0.0	100.0
Residential mental health/substance abuse settings ³	17.8	0.0	0.0	22.4	59.8
Residential settings with on-site nursing care facilities ⁴	69.1	3.0	5.8	15.1	7.0
Other residential service settings ⁴					
NONRESIDENTIAL SERVICES	20.1	13.2	35.9	14.7	16.0
Services of home health care providers ⁵	14.0	16.9	47.8	12.2	9.0
Physical, occupational & speech therapists, audiologists ⁶	10.5	15.7	63.5	6.5	3.9
Other services for older persons ⁷	5.0	2.3	0.0	50.0	42.7
Home-delivered meals & congregate meals ⁸	10.0	0.0	0.0	5.0	85.0
Special needs transportation	10.0	0.0	0.0	20.0	70.0
Medical supplies, equipment & home modifications ⁹	71.6	8.1	10.3	4.7	5.3

¹PPI calculations based on 2000 U.S. Service Annual Survey, 1997 Economic Census, and 1999 National Nursing Home Survey.

²PPI calculations based on 2000 U.S. Service Annual Survey, 2001 and 2000 National Residential Information Systems Project on Residential Services Surveys, and Medicaid administrative data. In the absence of better data, the Medicaid funding percentage is assumed to be the same for all persons and for persons 65+.

³PPI calculations based on 2000 U.S. Service Annual Survey. In the absence of better data, the Medicaid funding percentage is assumed to be the same for all persons and for persons 65+.

⁴2000 Service Annual Survey; data were available only for these two categories combined.

⁵2000 Service Annual Survey and 2000 Medical Expenditure Panel Survey (MEPS).

⁶PPI calculations based on 2000 Service Annual Survey and 2000 MEPS.

⁷PPI calculations based on Medicaid administrative data.

⁸2000 Administration on Aging data.

⁹PPI calculations based on 2000 Medical Expenditure Panel Survey.

Limitations of This Accounting

Even though the estimates presented here cover a more complete set of categories of long-term care and independent living services, settings, and technologies than those that were previously available, they do embody the limitations of the available data, many of which are described below.

Most of the categories consist of *all* of the services delivered by a specific type of provider. For some of these categories, it may be argued that while the large portion of the activity constitutes long-term care or support of independent living, another portion is too short-term in nature to be viewed as such. For example, the estimate provided here (and the GAO estimate discussed earlier as well) include the four days' worth of home health care a person may receive after an inpatient surgery and before resuming independent living without services or other supports.

There is a range of issues regarding which costs to include for residential service settings. People need to eat and need somewhere to stay, regardless of abilities or disabilities. But the largest of the four residential categories presented here, both in dollar terms and in terms of days of residential service delivery, is the nursing home category, and the entirety of expenditures for this category is included in CMS's National Health Accounts (NHA) without any adjustments for room and board, as are the entire costs of Medicaid ICF/MRs included in the NHA. This inclusion may be justified by computational ease and by the possibility that the residents might well have difficulties in preparing and consuming meals. Also, some nursing home residents may still maintain a private residence, either inhabited by a spouse or for a hoped-for return to the community—in either instance, the nursing home room is a real additional service delivery cost. We therefore kept our estimates comparable to the NHA by also including the full costs of these service settings.

However, residents of assisted living residences, CCRCs, homes for the elderly, and related settings are likely to have lower levels of disability on average than are persons who reside in nursing homes. We therefore estimate and only include the labor costs of assistive and nursing services provided in these less institutional settings. But one might argue that for some persons in these settings, providing meals may appropriately be considered an assistive service given their level of functioning. And for those settings with a nursing unit or other facilities set aside for assistive service provision, there are likely substantial additional nonlabor costs as well that ideally should be included. Finally, places such as assisted living residences may provide safeguards and other features greater than those available in an individual's private residence and may impose greater restrictions on a resident's behavior, privacy, and rights of tenancy. For these reasons, including in this report only the labor costs of assistive and nursing services for these residences is likely to result in an underestimate.

Several specific long term care and independent living activities are not included in the expenditure estimates presented here. These exclusions result from several sources:

the criteria adopted for defining long-term care and independent living services; inadequate data; and unpaid activities. The most important of these are the following:

Social services provided directly by state and local government employees. Many of the data presented here are collected directly from private sector service providers. In several instances, these data have been expanded to include estimates of spending on government service providers by incorporating data from other sources. For example, the data for private sector nursing home care have been expanded to include an estimate for government-owned nursing homes by incorporating data from a national nursing home survey. Similar adjustments have been made for the services of home health care providers, and some specific public-sector service providers, such as Veterans Administration domiciliary facilities and state mental institutions, are explicitly incorporated into these estimates as well.

However, in some areas such adjustments have not been possible. To the degree that governments directly provide social services and residential settings (for example, home and personal care services, transportation assistance, old age homes), this portion of spending is not captured, and the figures presented here represent underestimates. This caveat may be particularly relevant for the category, “other services for older persons and persons with disabilities.” If such services provided by state and local governments could be measured more accurately, then not only would the size of this category be increased, but the percentage of funding derived from Medicaid for this category would decrease. It should be emphasized that this caveat does *not* apply to services *funded* by government where the actual services are provided by persons working for private for-profit or not-for-profit employers or by persons who are independent contractors providing these services. Such services funded by government but provided by others *are* captured here.

Educational and vocational programs for children and young adults. There is a range of services that is provided primarily to children and younger adults that consists of education, habilitation, and vocational training. While these may be considered as assisting in functioning and in independent living, especially in the larger social and financial sense, we have not attempted to include them in the measures presented here, which focus on adults, and on older adults in particular.

Services and products considered "medical" in nature. As discussed briefly early in this report, many medical services provided to persons are important in maintaining functioning, slowing functional decline, and/or preserving independent living in the community, and many of these medical services are provided on a long-term basis. The most prominent of these is probably prescription drugs. Such drugs are often taken regularly for the remainder of one’s life to deal with chronic conditions—a description that mirrors services that are usually considered “long-term care.” Nevertheless, prescription drugs, repeated medical treatments, and checkups for chronic conditions; procedures that restore physical functioning (for example, hip replacements); and other medical services are excluded from the estimates presented here.

Unpaid home care and services. The estimates presented here focus solely on activities involving monetary transactions. However, in addition to “marketplace” services to preserve independent living and provide long-term care, family members, friends, and others provide a substantial volume of unpaid care. One study has estimated that 18.7 billion hours of “informal” personal assistance services were provided to adults living in the community in 1996, with 5.8 billion of these hours provided to persons 65 and over.⁹ Other studies have yielded estimates for all adults that are higher¹⁰ and lower¹¹. While the precise measurement and accurate monetary valuation of these unpaid services remains difficult, the magnitude of these estimates indicates that, at plausible levels of valuation for these hours of informal care, the total value of unpaid care is roughly comparable to the \$182 billion estimate for paid long-term care and independent living services.

Summing Up

This report presents estimates of spending on long-term care and independent living services, settings, and technologies in 2000 that total \$182 billion for all persons and \$102 billion for persons age 65 and over. These totals are higher than some amounts reported elsewhere. For example, one often-cited measure, presented in a General Accounting Office (GAO) report, indicates that long-term care expenditures for persons of all ages totaled about \$137 billion in the year 2000.¹²

There are two primary sources of the substantial difference between these two estimates. One is that the estimates presented here are designed to measure a broad range of activities that support functioning, while excluding those that are on the more medical end of the services spectrum. In other words, as measured here, long-term care and independent living activities overlap with health care services but are not simply a subset of the health care sector. As a result, these estimates incorporate a range of activities that provide long-term care and support independent living, regardless of whether these are considered health care or not, including expenditures for social services, home-delivered and congregate meals, special needs transportation, home modifications, and nursing and assistive services provided in assisted living facilities, homes for the elderly, and other types of residences. On the other hand, the \$137 billion estimate only incorporates a few selected subsets of health care from the National Health Accounts (NHA) maintained by the Centers for Medicare and Medicaid Services.

⁹ LaPlante, Mitchell P., Charlene Harrington, and Taewoon Kang. “Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home.” *HSR: Health Services Research* 37 (2) (April 2002): 397-416.

¹⁰ Arno, P.S., C. Levine, and M. M. Memmott. “The Economic Value of Informal Caregiving.” *Health Affairs* 18 (2) (1999): 182-88.

¹¹ Liu, K., K. G. Manton, and C. Aragon. “Changes in Home Care Use by Disabled Elderly Persons: 1982-1994.” *Journal of Gerontology: Social Sciences* 55B (4) (2000): S245-53.

¹² GAO. *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*. Washington, DC: GAO (GAO-02-544T), March 2002.

The other important difference is that, even within health expenditures as defined by the NHA, the GAO estimate includes a smaller subset of services than the estimates presented here. In particular, the estimate cited in the GAO report sums up spending for only two NHA categories of health care services (nursing home services and home health care services), plus spending on one specific Medicaid program (Medicaid home and community-based services waivers). In contrast, the estimates in this report go beyond these three categories within the health care sector to include: residential mental retardation settings; the long-stayer portion of state mental institutions; residential mental health/substance abuse treatment settings; physical, occupational, and speech therapists and audiologists; and medical equipment.

There are also other differences between the estimates presented here and those based on the NHA, some of which reflect the logical NHA focus on measuring health care expenditures rather than long-term care expenditures per se. For example, the NHA-based estimate of long-term care services largely excludes both nursing home and home health services that are delivered by hospital-based providers. These services are included instead as part of hospital spending in the NHA.

There is one area where the estimates presented here include only a subset of those included in the NHA, and in long-term care estimates based on it. The NHA incorporates into its estimate for the nursing home category the entire amount of expenditures for continuing care retirement communities and other similar residences that include on-site nursing facilities. In contrast, the estimates presented here present these residences as a separate category, and the expenditure amount includes only the portion of the total spending for this type of residence that is estimated to represent labor-related assistive and nursing costs.

So the “nursing facilities” category in this report includes hospital-based nursing facilities that are excluded from the “nursing home care” category in the NHA, and excludes (counts in other separate categories) both expenditures for ICF-MRs and continuing care retirement communities and other similar residences that include on-site nursing facilities that are included in the NHA nursing home category. Given these substantial differences in what is included in the nursing home category, it is not surprising that the estimates for sources of payment for the “nursing facilities” category presented here are different from those in the NHA for nursing home care, and simple direct comparisons for this category cannot be made in isolation.

Society is increasingly focused on shifting long-term care expenditures under the Medicaid program toward services in the home and community. The estimates presented here incorporate several residential service settings that are largely privately funded, but in spite of this, the institutional focus of Medicaid funding for long-term care and independent living services is still evident. As shown in Table 2, Medicaid funds 49.1 percent of spending for services in residential settings, and 52.4 percent of the spending for nursing facilities in particular, but only 22.8 percent of nonresidential activities.

Finally, it is important to reiterate that the figures presented here are estimates, not a highly precise set of figures. In particular, the estimates for a few specific smaller categories, some allocations among specific sources of payment, and spending levels in some instances for the subset of persons age 65 and over involve a greater level of uncertainty than the majority of the estimates presented in this report.

Updates to these estimates. These estimates use as their primary data sources the Service Annual Survey and the Economic Census, both conducted by the U.S. Census Bureau. The Economic Census is conducted every five years; the 2002 Census was recently completed, and the Census Bureau has begun to release reports based on it. We expect to be able to present estimates for 2002 after all of the detailed health and social services sector data from this most recent census become available.