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A CRS Review of 10 States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care: Illinois

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Summary

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care for persons with disabilities of all ages have drawn the attention of federal and state policymakers for some time. Spending on long-term care by both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending in 2001 (almost $152 billion of $1.24 trillion). Federal and state governments accounted for almost two-thirds of all spending. By far, the primary payor for long-term care is the federal-state Medicaid program, which paid for almost half of all long-term care spending in 2001.

Many states have devoted significant efforts to respond to the desire for home and community-based care for persons with disabilities and their families. Nevertheless, financing of nursing home care, chiefly by Medicaid, still dominates most states' spending for long-term care today. To assist Congress understand issues that states face in providing long-term care services, the Congressional Research Service (CRS) undertook a study of 10 states in 2002. This report, one of a series of 10 state reports, presents background and analysis about long-term care in Illinois.

Illinois is the fifth largest state in the country with 12.4 million people in 2000; the population increased by almost 9% or about one million people in the past decade. About 12% of the state's population is age 65 and older — 1.5 million people in 2000. By 2025 the Illinois elderly population is expected to increase by over 50% and will be 16.6% of the state's total population.

Illinois is one of the few states in the country that provides older persons and younger adults, who meet the eligibility criteria, with state entitlements to home and community-based long-term care services. Both entitlements resulted from court cases that were brought to eliminate waiting lists for services. The state funds the Community Care Program for older adults and the Home Services Program for persons with physical disabilities with a combination of state general revenue funds and Medicaid Section 1915(c) waiver funds. The Community Care Program uses contracted agencies for the provision of homemaker, adult day care services, and case management services. In contrast, the Home Services Program's relies primarily on personal assistants, whom consumers supervise, to provide services.

According to state officials, in 2002 the state had about 3,000 people with developmental disabilities in state-operated development centers (SODCs), 6,500 people in private intermediate care facilities for the mentally retarded (ICFs/MR) and 8,800 people in Section 1915(c) Medicaid home and community-based services waivers for the developmentally disabled.

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Contents

List of Figures

List of Tables

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Preface

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care for persons with disabilities have drawn the attention of federal and state policymakers for some time. Spending on long-term care by both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (almost $152 billion of $1.24 trillion). Federal and state governments accounted for almost two-thirds of all spending. By far, the primary payor for long-term care is the federal-state Medicaid program, which paid for almost half of all U.S. long-term care spending in 2001.

Federal and state Medicaid spending for long-term care in FY2001 was about $75 billion, representing over one-third of all Medicaid spending. Over 70% of Medicaid long-term care spending was for institutions — nursing homes and intermediate care facilities for the mentally retarded (ICFs/MR). Many believe that the current federal financing system paid through Medicaid is structurally biased in favor of institutional care. State governments face significant challenges in refocusing care systems, given the structure of current federal financing. Many states have devoted significant efforts to change their long-term care systems to expand home and community-based services for persons with disabilities and their families. Nevertheless, financing of nursing home care — primarily through the Medicaid program — still dominates most states' spending on long-term care today.

While some advocates maintain that the federal government should play a larger role in providing support for home and community-based care, Congress has not yet decided on whether or how to change current federal policy. One possibility is that Congress may continue an incremental approach to long-term care, without major federal policy involvement, leaving to state governments the responsibility for developing strategies that support home and community-based care within existing federal funding constraints and program rules.

To help Congress review various policy alternatives and to assist policymakers understand issues that states face in development of long-term care services, the Congressional Research Service (CRS) undertook a study of 10 states in 2002. The research was undertaken to look at state policies on long-term care as well as trends in both institutional and home and community-based care for persons with disabilities (the elderly, persons with mental retardation, and other adults with disabilities). The research included a review of state documents and data on long-term care, as well as national data sources on spending. CRS interviewed state officials responsible for long-term care, a wide range of stakeholders and, in some cases, members or staff of state legislatures.

The 10 states included in the study are: Arizona, Florida, Illinois, Indiana, Louisiana, Maine, Oklahoma, Oregon, Pennsylvania, and Texas. States were chosen according to a number of variables, including geographic distribution, demographic trends, and approaches to financing, administration and delivery of long-term care services.

This report presents background and analysis about long-term care in Illinois. Reports on the other nine states and an overview report will be available during 2003.

A CRS Review of 10 States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care: Illinois

Introduction: Federal Legislative Perspective

States choosing to modify their programs for long-term care face significant challenges. Financing of nursing home care has dominated long-term care spending for decades. The federal financing structure that created incentives to support institutional care reaches back to 1965. A number of converging factors have supported reliance on nursing home spending. Prior to enactment of Medicaid, homes for the aged and other public institutions were financed by a combination of direct payments made by individuals with their Social Security Old Age Assistance (OAA) benefits, and vendor payments made by states with federal matching payments on behalf of individuals. The Kerr-Mills Medical Assistance to the Aged (MAA) program, enacted in 1960, a predecessor to Medicaid, allowed states to provide medical services, including skilled nursing home services, to persons who were not eligible for OAA cash payments, thereby expanding the eligible population.[1]

> *The Social Security Amendments of 1965, which created the Medicaid program, required states to provide skilled nursing facility services under their state Medicaid plans, and gave nursing home care the same level of priority as hospital and physician services.*
>
> *"Section 1902 (a) A State plan for medical assistance must provide for inclusion of some institutional and some noninstitutional care and services, and, effective July 1, 1967, provide (A) for inclusion of at least ... (1) inpatient hospital services ...; (2) outpatient hospital services; (3) other laboratory and X-ray services; (4) skilled nursing home services (other than services in an institution for tuberculosis or mental diseases) for individuals 21 years of age or older; (5) physicians' services ...."*; P.L. 89-97, July 30, 1965.

In 1965, when Kerr-Mills was transformed into the federal-state Medicaid program, Congress created an entitlement to skilled nursing facility care under the expanded program. The Social Security Amendments of 1965 required that states provide skilled nursing facility services and gave nursing home care the same level of priority as hospital and physician services. Amendments in 1967 allowed states to provide care in "intermediate care facilities" (ICFs) for persons who did not need skilled nursing home care, but needed more than room and board. In 1987, Congress

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[1] CRS Report 83-181, *Nursing Home Legislation: Issues and Policies*, by Maureen Baltay (available through CRS authors of this report).

eliminated the distinction between skilled nursing facilities and intermediate care facilities (effective in 1990). As a result of these various amendments, people eligible under the state's Medicaid plan are entitled to nursing home facility care; that is, if a person meets the state's income and asset requirements, as well as the state's functional eligibility requirements for entry into a nursing home, he or she is entitled to the benefit.

These early legislative developments were the basis for the beginnings of the modern day nursing home industry. Significant growth in the number of nursing homes occurred during the 1960s — from 1960 to 1970, the number of homes more than doubled, from 9,582 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than one million.[2] (Today there are about 17,000 nursing homes with 1.8 million beds.[3])

Since its inception, Medicaid has been the predominant payor for nursing home care. In 1970, over $1 billion was spent on nursing home care through Medicaid and Medicare. Federal and state Medicaid payments accounted for almost all of this spending — 87%. Medicaid spending for nursing home care grew by 50% in the three-year period beginning in 1967.

In FY2001, Medicaid spent $53.1 billion on institutional care (for nursing homes and care in intermediate care facilities for the mentally retarded).

During the latter part of the 1960s and the 1970s, nursing home care attracted a great deal of congressional oversight as a result of concern about increasing federal expenditures, and a pattern of instances of fraud and abuse that was becoming evident. Between 1969 and 1976, the Subcommittee on Long-Term Care of the Senate Special Committee on Aging, held 30 hearings on problems in the nursing home industry.[4]

Home care services received some congressional attention in the authorizing statute — home health care services were one of the optional services that states could provide under the 1965 law. Three years later in 1968, Congress amended the law to require states to provide home health care services to persons entitled to skilled nursing facility care as part of their state Medicaid plans (effective in 1970). During the 1970s, the Department of Health, Education and Welfare (now Health and Human Services, DHHS) devoted attention to "alternatives to nursing home care" through a variety of federal research and demonstration efforts. These efforts were undertaken not only to find ways to offset the high costs of nursing facility care, but also to respond to the desires of persons with disabilities to remain in their homes and

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[2] U.S. Congress, Senate Special Committee on Aging, Developments in Aging, 1970, Report 92-46, Feb. 16, 1970, Washington, cited from the *American Nursing Home Association Fact Book, 1969-1970*.

[3] American Health Care Association, *Facts and Trends 2001, The Nursing Facility Sourcebook*, 2001, Washington. The number of nursing homes is for 1999-2000 and number of beds is for 1998. (Hereafter cited as American Health Care Association, *The Nursing Facility Sourcebook*.)

[4] U.S. Congress, Senate Special Committee on Aging, *Nursing Home Care in the United States: Failure of Public Policy*, Washington, 1974, and supporting papers published in succeeding years.

in community settings, rather than in institutions. However, it was not until 1981 that Congress took significant legislative action to expand home and community-based services through Medicaid when it authorized the Medicaid Section 1915(c) home and community-based waiver program.

Under that authority (known then as the Section 2176 waiver program), the Secretary of DHHS may waive certain Medicaid state plan requirements to allow states to cover a wide range of home and community-based services to persons who otherwise meet the state's eligibility requirements for institutional care. The waiver provision was designed to alter the fact that the Medicaid program had emphasized institutional care rather than care in home and community-based settings. Services under the Section 1915(c) waiver include: case management, personal care, homemaker, home health aide, adult day care, habilitation, environmental modifications, among many others.[5] These services are covered as an option of states, and under the law, persons are not entitled to these services as they are to nursing facility care. Moreover, states are allowed to set cost caps and limits on the numbers and types of persons to be served under their wavier programs.

Notwithstanding wide use of the Section 1915(c) waiver authority by states over the last 2 decades, total spending for Medicaid home and community-based services waivers is significantly less than institutional care — about $14.4 billion in 2001, compared to $53.1 billion for nursing facility care services and care for persons with mental retardation in intermediate care facilities (ICFs/MR). Despite this disparity in spending, in many states the Section 1915(c) waiver program is the primary source of financial support for a wide range of home and community-based services, and funding has been increasing steadily. Federal and state Medicaid support for the waiver programs increased by over 807% from FY1990 to FY2001 (in constant 2001 dollars).

The home and community-based waiver program has been a significant source of support to care for persons with mental retardation and developmental disabilities as states have closed large state institutions for these persons over the last 2 decades. Nationally, in FY2001, almost 75% of Section 1915(c) waiver funding was devoted to providing services to these individuals.

States administer their long-term care programs against this backdrop of federal legislative initiatives — first, the entitlement to nursing home care, and requirement to provide home health services to persons entitled to nursing home care, and, second, the option to provide a wide range of home and community-based services through waiver of federal law, within state-defined eligibility requirements, service availability, and limits on numbers of persons served.

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[5] States may waive the following Medicaid requirements: (1) statewideness — states may cover services in only a portion of the state, rather than in all geographic jurisdictions; (2) comparability of services — states may cover state-selected groups of persons, rather than all persons otherwise eligible; and (3) financial eligibility requirements — states may use more liberal income requirements for persons needing home and community-based waiver services than would otherwise apply to persons living in the community. For further information, see CRS Report RL31163, *Long-Term Care: A Profile of Medicaid 1915(c) Home and Community-Based Services Waivers*, by Carol O'Shaughnessy and Rachel Kelly.

A CRS Review of Ten States: Report on Illinois

Summary Overview[6]

Demographic Trends

- Illinois is the fifth largest state in the country with 12.4 million people in 2000; the population increased by almost 9% or about one million people in the past decade. About 12% of the state's population is age 65 and older — 1.5 million people in 2000. The state's older population grew relatively slowly during the 1990s — by 4.4%. However, those most in need of long-term care — the population age 85 and older — grew by 30.1% during the same time period. By 2025, the population age 65 or older is expected to increase by 50.6%

Administration of Long-Term Care Programs

- Administration and operation of long-term care services for the frail elderly population and other adults with disabilities is spread among four state agencies. The *Department of Public Aid (DPA)* is the single state agency for the Medicaid program. The *Department on Aging (DOA)* administers the Community Care Program combining a state-funded entitlement and a Medicaid Section 1915(c) waiver to provide home and community-based services to persons age 60 and older. The *Department of Human Services (DHS)* operates the four Section 1915(c) waivers that serve the adult populations with physical and developmental disabilities. The *Department of Public Health* enforces health and safety standards for long-term care providers.

Trends in Institutional Care

- In 2000, Illinois had 873 nursing facilities with 107,800 beds, with an occupancy rate of 84.5%. The state has undertaken several efforts to decrease its reliance on nursing homes, which include pre-admission screening for nursing home applicants and efforts to return residents to community settings.
- According to state officials, the state has about 3,000 people with developmental disabilities in state-operated developmental centers (SODC), 6,500 people in private intermediate care facilities for the mentally retarded (ICFs/MR), and 8,800 people in Section 1915(c) Medicaid home and community-based services waivers. The costs

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[6] Information based on Illinois data and documents, national data, and interviews with state officials. This report does not discuss programs for persons with mental illness. It also generally excludes discussion of programs for infants and children with disabilities, other than those serving persons with mental retardation and developmental disabilities.

of care for these groups are approximately $300 million, $400 million, and $300 million respectively. The annual average cost for a resident of an SODC is about $90,000 and for a private ICF/MR the cost is about $45,000 for 24-hour care.

Trends in Home and Community-Based Services

- Each population with disabilities (persons age 60 and over, those with physical disabilities and those with developmental disabilities) must access services through a separate screening and assessment process. Illinois does not have a single-point-of-entry for home and community-based services.

- Illinois is one of the few states in the country that provide older persons and younger adults, who meet the eligibility criteria, with a state entitlement to home and community-based services. Both entitlements resulted from court cases that were brought to eliminate waiting lists for services. The state funds the Community Care Program for older adults and Home Services Program for the physically disabled with a combination of Medicaid Section 1915(c) waivers and state funds. State general revenue funds are used to pay for services and then Medicaid reimbursement is claimed for Medicaid eligible individuals.

- The state has a Section 1915(c) Medicaid waiver called the Home and Community-Based Services Waiver for Adults with Developmental Disabilities, which provides care at home or in group residential settings of eight or fewer people.

Long-Term Care Spending

- Long-term care spending represented 31.3% of all Medicaid expenditures ($2.5 billion out of $8.1 billion) in Illinois in FY2001 a substantial decrease from 42.9% in FY1990. Institutional care accounted for about 88 of all long-term care spending in FY2001.

- Spending on institutional care decreased as a percentage of all Medicaid long-term care expenditures from FY1990 to FY2001. This reduction was due, in part, to the state's decreased reliance on intermediate care facilities for the mentally retarded (ICFs/MR). During the same time period, nursing home care as a portion of Medicaid long-term care spending decreased only slightly.

- In FY2001, home and community-based services accounted for 4.5% of all Medicaid spending and 14.4% of all Medicaid long-term care spending. Increases in funding for Medicaid Section 1915(c) waivers were largely responsible for the increase in Medicaid spending on home and community-based services.

Issues in Financing and Delivery of Long-Term Care Services

- Illinois recently began maximizing use of Medicaid under its two entitlement programs — Community Care and Home Services — by requiring applicants and current program beneficiaries to apply for Medicaid. According to interviewees, some people have refused to apply for Medicaid and have dropped out of the programs.

- According to state officials, State Fiscal Year (SFY) 2002 revenue was about $400 million below what had been projected in the summer of 2002. At the time of the site visit in summer of 2002, the state planned no eligibility or service cuts in response to the budget crisis. However, the state planned to reduce payments to most Medicaid providers, except those providing home and community-based waiver services.

- Some interviewees asserted that Medicaid provider payment cuts would exacerbate the state's long-term care labor shortage because providers will have to cut workers' wages and benefits, thus making the jobs less attractive. These interviewees said that quality of care could suffer as a result.

Demographic Trends

Illinois is the fifth largest state in the country with 12.4 million people in 2000; the population increased by 8.6% or about one million people in the past decade. About 12% of the state's population is age 65 and older — 1.5 million people in 2000. The state's older population is growing relatively slowly; it rose 4.4% during the 1990s. Those most in need of long-term care — the population age 85 and older — grew by 30.1% during the same time period (see **Table 1**).

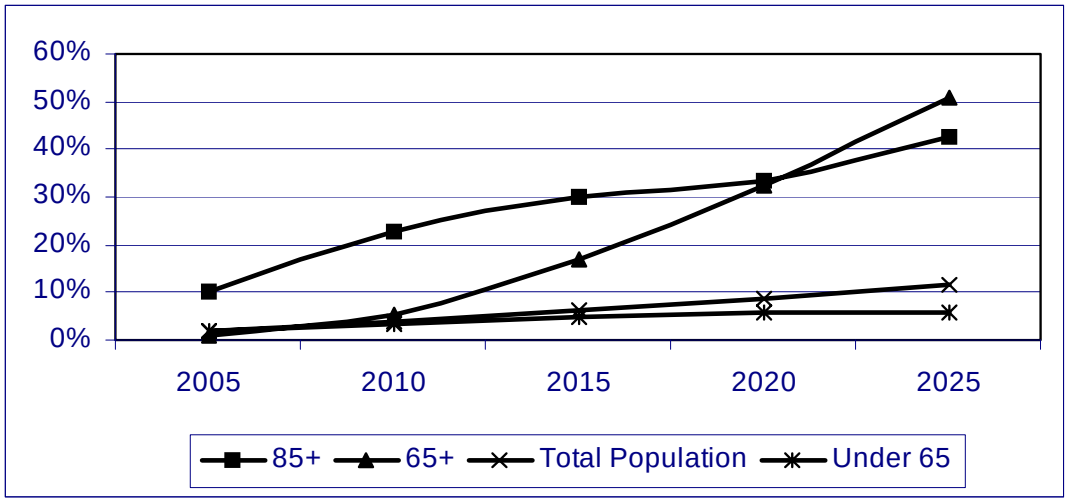
Table 1. Illinois Population Age 65 and Older, 1990 and 2000

Age	1990		2000		Percent change 1990-2000	2000 pop. rank in U.S. (based on percent)
	Number	Percent of total pop.	Number	Percent of total pop.		
65+	1,436,545	12.6%	1,500,025	12.1%	4.4%	32nd
65-74	821,940	7.2%	772,247	6.2%	-6.0%	40th
75-84	467,056	4.1%	535,747	4.3%	14.7%	31st
85+	147,549	1.3%	192,031	1.5%	30.1%	25th
Under 65	9,994,057	87.4%	10,919,268	87.9%	9.3%	18th
Total pop.	11,430,602	100%	12,419,293	100%	8.6%	5th

Source: U.S. Census Bureau, Profile of General Demographics for Illinois: 1990. 2000: [http://www.census.gov/census2000/states/il.html]. Numbers may not sum to 100 due to rounding.

Illinois, along with the rest of the country, will experience large increases in its older population over the next 25 years. By 2025, its elderly population will have increased by 50.6% (**Figure 1**). In 2025, 16.6% of Illinois' population will be age 65 years or older, compared to 18.5% for the nation (**Table 2**). Illinois will have to address the long-term care needs of 2.2 million elderly in that year, 267,947 of whom will be age 85 or older.

Figure 1. Percent Population Increase in Illinois, 2000-2025



Source: CRS calculations based on data from the U.S. Census Bureau. Projections: [http://www.census.gov/population/www/projections/st_yrby5.html]; analyzed data from *State Population Projections: Every Fifth Year*.

Table 2. Elderly Population as a Percent of Total Population, Illinois and the United States, 2025

Age	Proportion of total pop. in 2025 in Illinois	Proportion of total pop. in 2025 in US
65+	16.6%	18.5%
65-74	9.4%	10.5%
75-84	5.2%	5.8%
85+	2.0%	2.2%
Under 65 pop.	83.4%	81.5%

Source: CRS calculations based on data from the U.S. Census Bureau. Projections [http://www.census.gov/population/www/projections/st_yrby5]; analyzed data from *State Populations Projections: Every Fifth Year*.

Administration of Long-Term Care Programs

Four state agencies share responsibility for oversight and operation of long-term care services for the frail elderly population and other adults with disabilities. The *Department of Public Aid (DPA)* is the single state agency for the Medicaid program. DPA has interagency agreements with: *the Department on Aging (DOA)*, which operates the Section 1915(c) home and community-based waiver serving older persons, and the *Department of Human Services (DHS)*, which operates the four Section 1915(c) waivers that serve the adult populations with physical and developmental disabilities. The *Department of Public Health (DPH)* enforces health and safety standards for long-term care providers.

Within DPA, the Bureau of Interagency Coordination monitors DOA and DHS' program operations related to the waivers. The Bureau of Program Reimbursement and Analysis monitors these Departments' financial performance. Through its Bureau of Long Term Care, DPA also operates the Supportive Living Program waiver, which funds assisted living services.

The DOA has a Division of Long-Term Care that administers the Community Care Program, which combines a state-funded entitlement and a Medicaid Section 1915(c) waiver to provide home and community-based services to persons age 60 and older. DOA also conducts universal pre-admission screening (PAS) for all persons age 60 and older applying to enter nursing homes. Universal PAS began in 1996; it screened approximately 65,000 individuals in FY2001, according to state officials.

The Community Care Program contracts with approximately 50 Case Coordination Units that DOA identifies in conjunction with 13 local Area Agencies on Aging (AAAs). Case Coordination Units' case managers evaluate the need for long term care services using a standardized needs assessment instrument — the Determination of Need. Community referrals and all nursing facility applicants are evaluated prior to admission and, if eligible, are offered the option of using in-home and other community-based services. In addition to initial intake and assessment responsibilities, case coordination unit case managers write plans of care, arrange for the implementation of Community Care Program services, perform re-determinations of need (at least annually), and provide ongoing case management to program beneficiaries. Case Coordination Units are typically not-for-profit agencies or a governmental entity, such as a local public health department. These units cannot deliver services in the same areas in which they provide assessment and case management services.

The Department of Human Services (DHS) has two offices involved in long-term care. DHS' Office of Rehabilitation Services administers three Section 1915(c) waivers for persons with physical disabilities, brain injury, and HIV/AIDS. This Office also administers the Home Services Program, which incorporates state entitlement funds and a Section 1915(c) waiver to serve younger adults (i.e., age 18-59) with physical disabilities. DHS' Office of Developmental Services manages the Section 1915(c) waiver for adults with mental retardation or developmental disabilities (MR/DD).

The Home Services Program is a consumer-directed program where most beneficiaries hire, supervise, and fire their own personal assistants. While the beneficiary is the personal assistant's employer, DHS is the fiscal agent with responsibility for issuing checks to workers, as well as withholding FICA and other deductions for the personal assistants. DHS' local field offices determine financial eligibility for the Home Services Program. Centers for Independent Living (CILs),[7] which are staffed by persons with disabilities, recruit and train personal assistants and provide training to beneficiaries on how to manage their assistants. The Centers also perform some case management when people leave institutions, through a pilot project that allows consumers to move from nursing homes to community integrated settings. The Centers take applications from residents of institutions, determine eligibility for the Home Services Program, and arrange services until the former residents can handle these tasks on their own.

DHS' Office of Developmental Disabilities contracts with 354 community service providers and operates 11 state-operated developmental centers (SODCs).[8] The Office also contracts with 18 pre-admission screening organizations to conduct screening for people with developmental disabilities seeking access to home and community-based services, or to Medicaid-funded residential settings, including ICFs/MR, SODCs, and nursing facilities. Pre-admission screening organizations conduct assessments in persons' homes, make eligibility determinations, facilitate choice of services and providers, make referrals to providers, and monitor services for the first month beneficiaries receive them.

The Office of Developmental Disabilities also administers a Medicaid Section 1915(c) waiver for persons with developmental disabilities. The Office recently merged its state-funded Home-Based Support Services program with the waiver to draw down federal Medicaid matching funds. Each waiver beneficiary receives Individual Service and Support Advocacy, which involves quarterly monitoring visits to beneficiaries, participation in service plan development, education about individual rights, and problem resolution.

The Illinois Department of Public Health administers the state and federal regulations governing the quality of long term care facilities, residential health care facilities for the mentally retarded, and assisted living facilities (ALFs). The majority of the Department of Public Health's workload involves the state and federal surveys and investigations mandated by the state Nursing Home Care Act and the federal Social Security Act under Title XVIII/Medicare and Title XIX/Medicaid. According to state officials, in 2003, Illinois had 873 nursing facilities, about 300 ICFs/MR, 10 skilled nursing facilities for children and 70 assisted living facilities. Together, these facilities represent over 128,000 state-licensed or federally-certified beds in Illinois. Supportive living facilities that participate in a Medicaid Section 1915(c) assisted living waiver are certified by the DPA.

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[7] Centers for Independent Living were established by Title VII of The Rehabilitation Act in 1978. They are consumer-directed centers serving persons with disabilities that promote the concept of independent living.

[8] [http://www.state.il.us/agency/dhs/mhddfsnp.html] accessed on Feb. 19, 2002.

Illinois Long-Term Care Services for the Elderly and Persons with Disabilities

Trends in Institutional Care

In 2000, Illinois had 873 nursing facilities with 107,800 beds, with an occupancy rate of 84.5% (**Table 3**). The state has a high supply of nursing home beds compared to the U.S. as a whole. In 2003, the state had about 72 beds per 1,000 persons age 65 and older. In comparison, in 2000 the U.S. as a whole had 53 beds per 1,000 persons age 65 and older.

The state has undertaken three programs to decrease its reliance on nursing homes. In FY1995, DOA began the first deinstitutionalization program which has helped about 300 to 400 people a year return to the community, after they have been in a nursing facility 90 or more days.[9] In FY1998, the Home Services Program began the second program under which four Centers on Independent Living (CILs) visit nursing facilities and help willing residents in those facilities return to their homes and communities. In FY1998, six persons left nursing facilities for the community; in FY2002, 20 CILs projected that they would help 225 persons leave facilities.[10] This program uses Home Services Program funding to pay for such things as deposits on utilities, appliances, furniture, clothing, and groceries. Since 1998, the program has deinstitutionalized 400 people.

In 2000, the Home Services Program started a third program which involves screening patients being discharged from hospital to nursing homes or their homes and providing information on available services and alternatives to nursing facilities. In FY 2001, the program screened 2,787 persons up to age 59.[11]

Table 3. Nursing Home Characteristics in Illinois and the United States

Characteristics	Illinois (2003)	United States (1999-2000)
Number of facilities	873	17,023
Number of residents (average)	59,000	1,490,155
Number of beds	107,800	1,843,522
Number of Medicaid beds	104,564	841,458
Number of beds per 1,000 pop. aged 65 and older	71.9	52.7

[9] Renee Baker, et al., *Community Living and Disabilities Plan*, Office of the Governor, Springfield, Illinois, May 2002. (Hereafter cited as Baker, et al., *Community Living and Disabilities Plan*.)

[10] Ibid.

[11] Ibid.

Characteristics	Illinois (2003)	United States (1999-2000)
Number of beds per 1,000 pop. aged 75 and older	148.1	111.1
Number of beds per 1,000 pop. aged 85 and older	561.4	434.8
Occupancy rate	84.5%	80.8%

Source: For Illinois figures, data are for 2003 from the Department of Public Aid, Bureau of Rate Development and Analysis. U.S. figures are from the American Health Care Association (ACHA), *Facts & Trends: The Nursing Facility Sourcebook*. Number of beds per 1,000 population in 2000.

Trends in Home and Community-Based Care

Two of Illinois' home and community-based services programs are unique in the Nation because they provide older persons and younger adults who meet nursing home functional eligibility requirements with a state entitlement to home and community-based services. The state funds the *Community Care Program* for older adults and *Home Services Program* for younger adults with physical disabilities with a combination of Medicaid Section 1915(c) waiver and state funds.

Entitlements for both groups resulted from court cases that were brought against the state to eliminate waiting lists for services. In 1982, the Department on Aging received an order from the U.S. District Court regarding the *Benson vs. Blaser* case. This class action suit focused on the lengthening waiting list for community-based services for the elderly. The court ruled that persons on the waiting list were as entitled to timely determination of eligibility and receipt of services as beneficiaries who applied earlier, when no waiting list existed. The order required the department to resolve the waiting list immediately, in effect changing the *Community Care Program* into an entitlement. The final court order mandated the following: 1) determination of eligibility within 30 days; 2) mailing of a notice of eligibility to each applicant within 15 days of the date of eligibility determination; and 3) provision of services within 15 days of when the notice was sent.

An entitlement to the *Home Services Program* was created as a result of a judicial decision emerging from the *McMillan vs. McCrimon* case in 1992. The state was refusing to accept and process applications for the Home Services program as a method to contain costs. The U.S. District Court held that the state could not refuse to process applications for the program because federal Medicaid requirements state that all individuals have the opportunity to apply for medical assistance. The court also stated that it was not clear where the public interest lay because forcing Home Services Applicants into nursing homes had the potential to increase the state budget more than receiving care under the Home Services Program. The practical result of this court holding was that the state must offer those eligible for nursing facility services the opportunity to enter the Home Services Program if they choose to do so.

The Community Care Program for Persons Age 60 and Over: State Entitlement and Medicaid 1915(c) Waiver. The state finances the Community Care entitlement through a combination of state general revenue funds and Medicaid Section 1915(c) home and community-based waiver reimbursement funds. The state

funds the entire cost of those who do not qualify for Medicaid but do meet the Community Care program's eligibility requirements.

To be eligible for the Community Care Program, an individual must be: 1) age 60 years or older; 2) a U.S. citizen or resident alien; 3) have non-exempt assets of $10,000 or less; 4) an Illinois resident; and 5) assessed as needing long-term care (minimum score of 29 on the Determination of Need, the state's method for determining level of care for services).

Also, as of July 1, 2002, people who apply for Community Care must apply for Medicaid, which will cover them if their countable incomes are at or below 100% of the federal poverty level. Those who do not qualify for Medicaid, but who meet the above eligibility criteria will be eligible for Community Care; their costs will be covered entirely by state funds. According to some stakeholders, some beneficiaries are dropping out of the Community Care program because they do not want to apply for Medicaid.

Although Community Care does not have an income test, beneficiary income levels are determined to establish their co-payment amounts. The average beneficiary co-payment is approximately $10 a month, according to state officials, and participants generally pay no more than 50% of the cost of their care plans.

Case Coordination Unit case managers visit applicants in their homes to determine whether they meet the program's eligibility requirements. Case managers assess applicants' level of impairment in 15 activities of daily living (ADLs, e.g., bathing, dressing) and instrumental activities of daily living (IADLs, e.g., housework, meal preparation). The case manager also assesses the applicants' unmet need for services. Applicants must have 29 total points to receive services, with at least 15 of these points due to functional and cognitive impairment. The case manager also does a mini-mental status examination that can add up to 20 points to the applicant's score if he or she has cognitive impairment.

The Community Care Program provides: 1) case management; 2) homemaker services, which are non-medical support by supervised and trained homemakers and include assistance with personal care tasks and performance of environmental tasks such as meal preparation, laundry, housekeeping, and shopping; and 3) adult day care. Some interviewees argued that Community Care should include medication management, assistive technology such as Hoyer lifts, and transportation, services which they said would make it easier for beneficiaries to remain in the community. According to state officials, the program covered 39,354 persons on average each month in FY2002 and approximately 43% of beneficiaries were on Medicaid. In FY2002, the average monthly spending per program beneficiary was $445.00, according to state officials.

Home Services Program and Other Services for Younger Adults with Disabilities: State Entitlement and 1915(c) Waiver. The Home Services program serves persons under age 60, although persons who reach age 60 after having joined the program can remain in it. People must score 29 points on their determination of need; this is the same eligibility standard as the Community Care Program for the frail elderly population. In addition, the beneficiary must have

a disability that will last 12 months or more. If an individual has cognitive impairment, he or she receives ten extra points on the assessment, similar to the Community Care Program. People must apply for Medicaid to receive services and, according to state officials, 60% of program participants are Medicaid beneficiaries. Unlike the Community Care Program, the Home Services Program has no cost sharing requirements.

Program services include homemaker, personal care, adult day care, home health, and environmental adaptations among others. Service cost maximums are based on the level of impairment. Beneficiaries can hire and manage individual personal care assistants who provide these services. About three-fourths of the program's spending went for personal assistant services in SFY2002.[12]

Other Medicaid Section 1915(c) Waivers. *Supportive Living*. Illinois began its Supportive Living Facilities Waiver in July 1999 as a pilot program to test use of assisted living facilities for people with disabilities aged 22-64 or frail older persons age 65 and older who meet a nursing facility level of care. The financial eligibility standards for an applicant's assets are the same as for nursing facilities. In order to qualify, persons must have countable income at or below the SSI benefit amount, and have countable assets of no more than $2,000. Residents are allowed to keep a $90 monthly personal needs allowance. Services available to participants include nursing, personal care, transportation to community events, and assistance with IADLs. The Department on Aging determines functional eligibility for the program.

The pilot test was designed to deflect nursing facility admissions and to determine if providing supportive living to persons with lighter care needs might delay admission to a nursing facility. According to state officials, as of spring 2003, the state had 23 supportive living facilities serving about 340 Medicaid residents, and an additional 45 facilities had been approved or are under development. The waiver was renewed for another 5 years in 2002.

Medicaid Waivers for Persons with Brain Injuries and HIV/AIDS. Illinois has two additional Medicaid Section 1915(c) home and community-based services waivers that target specific populations.

- The Brain Injury waiver contracts with community-based organizations that have experience with beneficiaries with brain-injury or cognitive impairment to provide case management for a variety of services, including rehabilitation.

- The HIV/AIDs waiver provides the same set of services as the Home Services Program and DHS' Office of Rehabilitative Services contracts with community organizations to provide assessment and case management services.

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[12] Ibid.

Illinois Long-Term Care Services for Persons with Mental Retardation and Developmental Disabilities

Overview

Services to persons with mental retardation and other developmental disabilities in the United States changed dramatically over the last half of the 20th century as a result of several factors including: 1) advocacy efforts of families and organized constituency groups, 2) various changes to the Social Security law that provided payments to individuals through SSI and SSDI and to service providers through the Medicaid program, and 3) significant litigation brought on behalf of persons with mental retardation.[13]

According to state officials, Illinois has about 3000 people in SODCs, 6,500 people in private ICFs/MR, and 8,800 in Medicaid Section 1915(c) home and community-based services waivers. The costs of care for these groups are approximately $300 million, $400 million, and $300 million respectively. The average annual cost for a resident of an SODC is approximately $90,000; for a private ICF/MR the cost is about $45,000 for 24-hour care.

Trends in Institutional Care

The early history of services to persons with mental retardation is characterized by the development of large state institutions or training schools begun during the latter part of the 19th century and continuing through the first part of the 20th century. Between 1920 and 1967, institutions quadrupled in size and peaked at almost 200,000 individuals nationwide in 165 freestanding, state-operated mental retardation institutional facilities.[14] Today, some states are still faced with the legacy of large state-operated institutions.

As in most states, Illinois has closed a number of its large state institutions. Since 1960, the state has closed six of its 17 large state facilities. Some of these facilities dated back to the late 19th century or the early part of the 20th century. Some of the facilities that remain open are just as old and they contained 3,151 residents with developmental disabilities on June 30, 2001. (See **Appendix Table 2** for a list of the institutions that have been closed and those in operation and their 2000 census.)

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[13] For a detailed history of the development of services for persons with developmental disabilities, see David Braddock, Richard Hemp, Susan Parish, and James Westrich, *The State of the States in Developmental Disabilities*, University of Illinois at Chicago, American Association on Mental Retardation, Washington, D.C. 1998. (Hereafter cited as Braddock, et al., *The State of the States in Developmental Disabilities*.)

[14] Braddock, et al., *The State of the States in Developmental Disabilities*.

The number of residents in SODCs declined from 4,209 in 1992 to an estimated 2,928 in 2002, a 30.4% decrease.[15] Interviewees mentioned that some parents' organizations have allied with unions to keep SODCs open. For example, the state has tried to close the Lincoln Developmental Center because of quality problems and the facility's age. Despite concerns about quality of care provided by the Center, a court order has prevented the state from closing the Center so residents only leave voluntarily. The state has put together a small working group to assess the future of the SODCs; in the future, these facilities may focus on serving developmentally disabled persons with significant medical or behavioral problems and those with criminal convictions.

In addition to closure of state-operated facilities, the state shifted care to smaller facilities during the 1990s. Persons with developmental disabilities living in large institutions with 16 or more residents declined from 76.4% of all persons living in group residences in 1990 to 44.5% in 2000. During the same period, the percentage of persons with developmental disabilities living in group residences with 1 to 6 beds increased from none to 39.8%. In 2000, 15.7% of persons with developmental disabilities who lived in group residences lived in homes with 7 to 15 beds (**Table 4**).

Table 4. Persons with Mental Retardation and Developmental Disabilities Served in Residential Settings, by Size of Setting, 1990, 1995, and 2000

Persons served by setting			
Setting by size	**1990**	**1995**	**2000**
Total	18,303 (100%)	20,031 (100%)	20,405 (100%)
16+ persons	13,985 (76.4%)	11,836 (59.1%)	9,073 (45.5%)
7-15 persons	4,318 (23.6%)	2,729 (13.6%)	3,208 (15.7%)
≤6 persons	0 (0%)	5,466 (27.3%)	8,124 (39.8)

Source: David Braddock, editor, with Richard Hemp, Mary C. Rizzolo, Susan Parish, and Amy Pomeranz, *Disability at the Dawn of the 21st Century and the State of the States*, American Association on Mental Retardation, Washington, D.C., 2002.

DHS' Office of Developmental Disabilities has a number of processes or programs designed to minimize long-term use of large facilities. The first practice involves pre-admission screening of all applicants for institutional care to determine if they can be served in the community. The Network Service and Support Program

[15] *Community Living and Disabilities Plan*.

uses SODC services and staff to provide planning and services designed to prevent admission to SODCs for people at risk. Another program — Short-Term Assistance — admits applicants to SODCs for a maximum of 45 days to deal with a behavioral crisis or medical condition that cannot be addressed in the community. These programs have evolved to the point where every new admission to a SODC is considered a short-term admission. Under another process, an interdisciplinary team conducts a personal preference assessment, which is part of the larger assessment of SODC residents, to determine whether the residents want to transfer to a community program. Essentially, the discharge planning process begins at admission. Each individual has a goal to move to a less restrictive setting. If the resident is capable of living in the community, then the team develops a transfer plan for the resident.

In June 1993, Illinois signed a consent decree in the case of *Bogard v. Bradley*.[16] The case concerned adults with developmental disabilities who were in nursing facilities between 1986 and 1994 for more than 120 days. The decree provides these persons with service coordination, and a choice between remaining in a nursing facility with specialized services or moving to another residential setting. The state has provided specialized services in nursing homes and has made 1,000 new Section 1915(c) home and community-based services waiver slots available to Bogard class members since 1993.

Trends in Home and Community-Based Care

The major program the Office of Developmental Disabilities (ODD) offers is one Medicaid Section 1915(c) waiver called the Home and Community-Based Services Waiver for Adults with Developmental Disabilities. The covered services include case management, direct support workers, respite, nursing, transportation, day program services, residential habilitation, therapies, adaptive equipment, and minor home modifications. Participants in this waiver receive individual service and support advocacy, which is a form of case management designed to monitor the beneficiary's well-being and service implementation. The case management is performed by an independent service coordinator agency under contract with the state. The state does not have a separate waiver for children with developmental disabilities; they are served under the state's waiver for technology dependent, medically fragile children under 21.

The Home and Community-Based Services Waiver for Adults with Developmental Disabilities has two parts — residential and home-based. The most popular residential setting is community integrated living arrangements (CILAs). CILAs allow participants to live in group residential settings of eight or fewer people. Priority populations for the residential part of the waiver include people in crisis situations, such as those who have lost a caregiver, wards of the state approaching age 22, people living in SODCs, and Bogard class members. Participants who live in their own homes receive home-based support services (HBSS). Priority populations for the HBSS services are those who are not currently receiving services, people with a caregiver age 60 and older, people who left special education within the last 5 years and those living with only one caregiver.

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[16] Ibid.

On July 1, 2002, Illinois terminated its state-funded HBSS program, which provided services to help people remain at home regardless of whether they were eligible for Medicaid. The state instead used the state program funding to expand the home-based portion of the Medicaid waiver for persons with developmental disabilities. HBSS participants are able to hire and fire their workers and adult parents and siblings can be workers. Participants or guardians have the option of deeming direct support workers qualified and of hiring and firing these workers.

Financing of Long-Term Care in Illinois

In most states, Medicaid is the chief source of financing for long-term care. In addition to state matching of federal Medicaid funds, many states also devote significant resources to long-term care, as Illinois does through its Community Care and Home Services state entitlement programs. In Illinois, federal and state spending for long-term care under the Medicaid program was $2.5 billion in FY2001.

Medicaid Spending in Illinois

Medicaid is a significant part of state budgets. After elementary, secondary and higher education spending, Medicaid spending was the largest share of state budgets in 2001. According to data compiled by the National Association of State Budget Officers (NASBO), *federal and state* Medicaid spending represented almost 20% of state budgets for the United States as a whole in 2001.

In Illinois, Medicaid is the largest single category of *federal and state spending combined*. Of the state's $37.7 billion budget in 2001, federal and state Medicaid spending represented slightly more than one of every five dollars. Spending for Medicaid about doubled as a proportion of the state's spending from 1990 to 2001 (**Table 5**).

State spending for Medicaid services in Illinois contributed from state funds *only* (excluding federal funds)[17] also increased during the 1990s. As a percent of spending for all categories of state spending, state Medicaid spending increased from 7.9% in 1990 to 14.5% in 2001. (**Table 6**).

[17] Federal and state governments share the costs of Medicaid spending according to a statutory formula based on a state's relative per capita income (Federal Medical Assistance Percentage, or FMAP). In FY2001, the federal share for Medicaid in Illinois was 50.0%.

Table 5. Share of Total Spending by Category, Illinois and the United States, 1990-2001

	Illinois				U.S. total
	1990	1995	2000	2001	2001
Total expenditure (in millions)	**$18,845**	**$26,486**	**$35,086**	**$37,657**	**$1,024,439**
Medicaid	**11.9%**	**24.0%**	**21.5%**	**22.5%**	**19.6%**
Elementary and Secondary Education	20.4%	17.1%	20.9%	19.7%	22.2%
Higher Education	11.0%	9.5%	7.4%	7.6%	11.3%
Public Assistance	5.6%	4.0%	1.0%	0.6%	2.2%
Corrections	3.0%	3.1%	3.8%	3.8%	3.7%
Transportation	12.0%	10.5%	9.3%	9.4%	8.9%
All other expenses	36.1%	31.7%	36.2%	36.4%	32.1%

Source: CRS calculations based on National Association of State Budget Officers (NASBO), State Expenditure Reports, 1990-2001.

Table 6. State Spending for Medicaid from State Funds as a Percent of State Spending, Illinois and the United States, 1990-2001

State spending	Illinois				All states
	1990	1995	2000	2001	2001
Total state spending (in millions)[a]	**$15,887**	**$20,349**	**$27,681**	**$29,469**	**$760,419**
State Medicaid spending (millions)[b] — state only funds	$1,252	$3,295	$3,924	$4,261	$85,141
State Medicaid spending as a percent of total state spending — state only funds[c]	7.9%	16.2%	14.2%	14.5%	11.2%

Source: CRS calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1991, 1997 and 2001. Data reported are for state fiscal years. Percentages may not sum to 100% due to rounding.

a. Total state spending for all spending categories, excluding federal funds.
b. State spending for Medicaid, exclusive of federal funds.
c. Includes assessments of $817.3 million and $10.4 million in local funds in FY1995. These funds represent 24.8% and 0.3% of total state-funded Medicaid expenditures.

Medicaid Long-Term Care Spending in Illinois[18]

Long-term care spending represented 31.3% of all Medicaid expenditures in Illinois in FY2001 ($2.5 billion of $8.1 billion), a large decrease from 42.9% of all expenditures in FY1990 ($1.1 billion of $2.5 billion) (**Tables 7 and 8**). This reduction was due, in part, to the state's decreased reliance on ICFs/MR; its spending decreased from 32.6% of Medicaid long-term care spending in FY1990 to 26.4% in 2001. During the same time period, nursing home care as a portion of Medicaid long-term care spending decreased only slightly from 61.1% to 59.2%. Despite these decreases in the proportion of spending devoted to institutions, institutional care still accounted for 85.6% of Medicaid long-term care spending in 2001.

Expenditures for home and community-based services as a proportion of total long-term care spending more than doubled to reach 14.4% of long-term care spending in FY2001. Increases in funding for Medicaid Section 1915(c) home and community-based waivers were largely responsible for the increase in Medicaid spending on home and community-based services (**Table 7**).

Spending for home and community-based services grew by 332.1% from FY1990 to FY2001 (in constant 2001 dollars). However, nominal spending for this form of long-term care was only $364.4 billion compared to $2.2 billion for institutional care (**Table 8**).

Medicaid long-term care financing at a glance:

In FY2001, $2.2 billion or more than one of four Medicaid dollars was for care in institutions; nursing home spending accounted for more than two-thirds of total institutional spending (Table 8). Spending for nursing homes represented 18.5% of total Medicaid spending in FY2001. In the same year, home and community-based services accounted for 4.5% of all Medicaid spending.

Spending for nursing home care grew 81.4% from FY1990 to FY2001, much less than the 157.1% increase in total Medicaid spending during the same time period.

Spending for nursing home care decreased slightly as a percentage of long-term care spending from 61.1% in FY1990 to 59.2% in FY2001. During the same period, the portion spent on ICFs/MR decreased from 32.6% to 26.4%.

About 14.4% of Medicaid dollars spent on long-term care is for home and community-based services, primarily for Section 1915(c) home and community-based services waivers. Spending on this form of waiver increased by 355.2% from FY1990-FY2001.

[18] This section discusses total Medicaid spending, both federal and state.

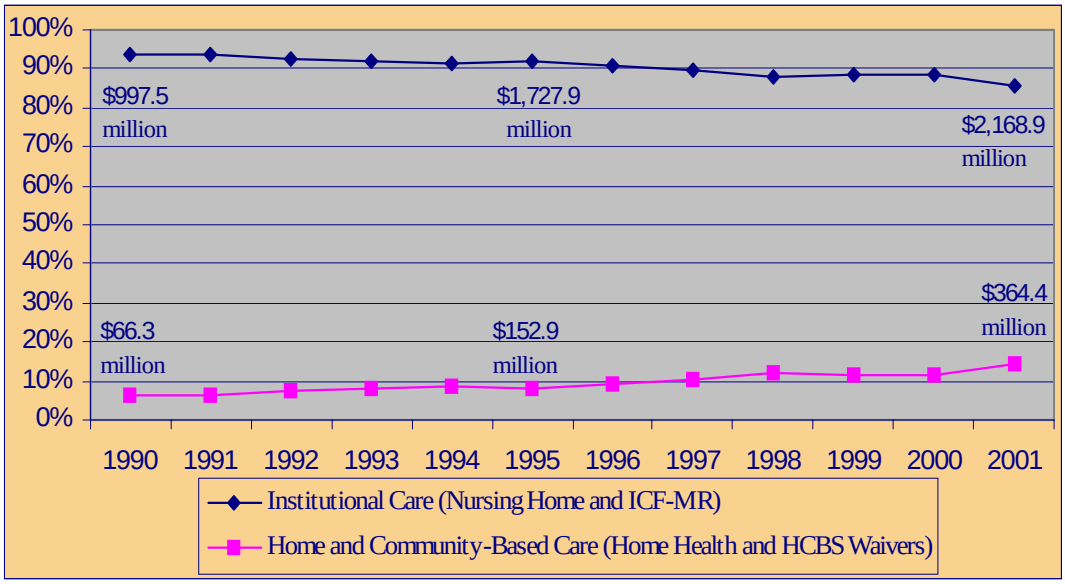
Table 7. Medicaid Long-Term Care Spending in Illinois, FY1990-FY2001

(Numbers may not sum to 100% due to rounding)

	1990	1995	2000	2001
Long-term care spending as a % of Medicaid spending	**42.9%**	**31.4%**	**31.7%**	**31.3%**
Institutional care spending as a % of long-term care spending	**93.8%**	**91.9%**	**88.3%**	**85.6%**
Nursing home spending as a percentage of long-term care spending	61.1%	63.8%	61.8%	59.2%
ICF/MR*spending as a percentage of long-term care spending	32.6%	28.0%	26.5%	26.4%
Total home and community-based services spending as a percentage of long-term care spending	**6.2%**	**8.1%**	**11.7%**	**14.4%**
HCBS waivers spending as a % of long-term care spending	5.7%	7.8%	11.3%	13.8%

Source: CRS calculations based on CMS/HCFA 64 data provided by The Medstat Group, Inc. For 2000 and 2001, Brian Burwell et al., *Medicaid Long-Term Care Expenditures in FY2001*, May 10, 2002. For 1995, Brian Burwell, *Medicaid Long-Term Care Expenditures in FY2000*, May 7, 2001. For 1990, Brian Burwell, *Medicaid Expenditures for FY1991*, Systemetrics/McGraw-Hill Healthcare Management Group, January 10, 1992. (Hereafter cited as Burwell, *Medicaid Expenditures FY1991-FY2001*.) The 1990 total Medicaid spending based on HCFA 64 data provided by The Urban Institute, Washington, D.C.
*Intermediate care facilities for the mentally retarded.

Figure 2. Institutional and Home and Community-Based Services as a Percent of Medicaid Long-Term Care Spending in Illinois, 1990-2001



Source: CRS calculations based on Burwell, Medicaid Expenditures FY1991-FY2001.

Table 8. Medicaid Spending in Illinois, Total Spending and Long-Term Care Spending, by Category, and Percent Change, FY1990-FY2001 in Constant 2001 Dollars

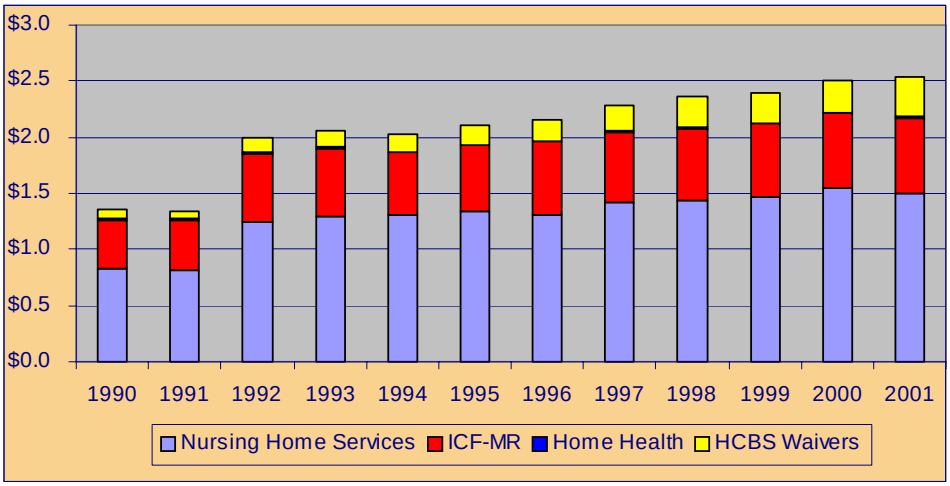
(in millions of current dollars)

	1990	1995	2000	2001	Percent change 1990-2001
Total Medicaid	**$2,479.3**	**$5,986.5**	**$7,738.4**	**$8,103.0**	**157.1%**
Total Long-Term Care	**$1,063.8**	**$1,880.8**	**$2,450.3**	**$2,533.3**	**87.3%**
Total Institutional Care	**$997.5**	**$1,727.9**	**$2,164.5**	**$2,168.9**	**71.0%**
Nursing Home Services	$650.5	$1,200.8	$1,515.3	$1,499.9	81.4%
ICFs/MR	$347.0	$527.1	$649.2	$669.0	51.6%
Total Home and Community-Based Services	**$66.3**	**$152.9**	**$285.8**	**$364.4**	**332.1%**
Home Health	$6.1	$7.1	$8.1	$15.9	104.3%
Personal Care	$0.0	$0.0	$0.0	$0.0	0.0%
HCBS Waivers	$60.2	$145.9	$277.6	$348.6	355.2%

Source: CRS calculations based on Brian Burwell, Medicaid Expenditures FY1991-FY2000. FY1990 total Medicaid spending is based on CMS/HCFA 64 data provided by The Urban Institute, Washington, D.C.

Figure 3. Medicaid Long-Term Care Spending by Category in Illinois, FY1990-FY2001

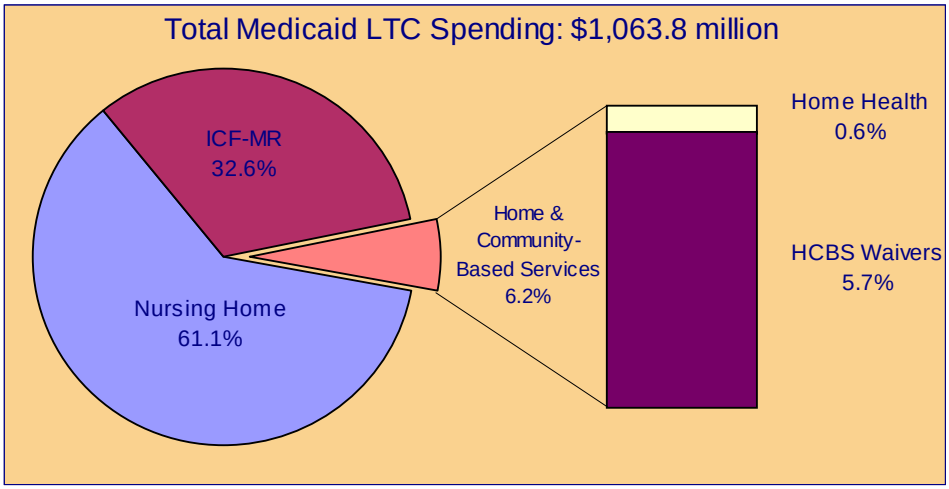
(in constant 2001 dollars)



Source: CRS calculations based on Burwell, Medicaid Expenditures FY1991-2001.

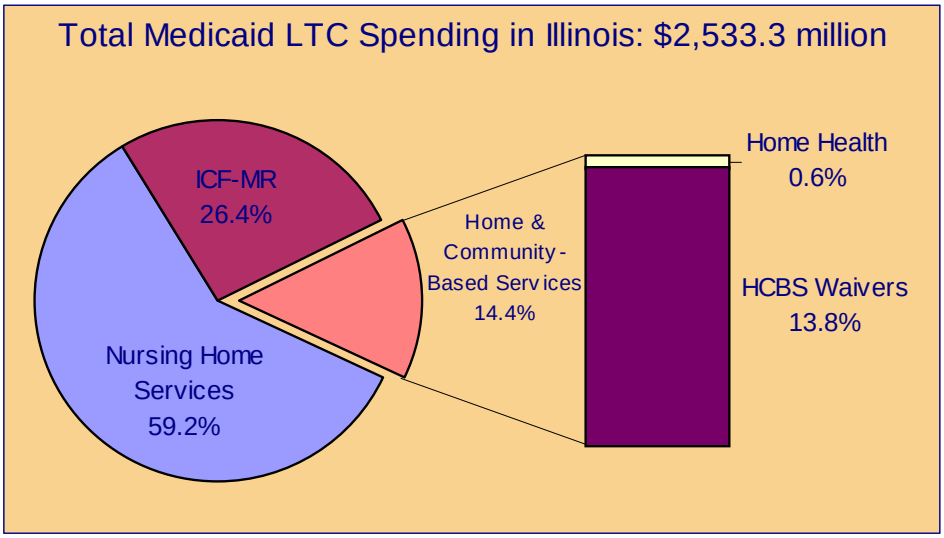
Figures 4a and 4b depict changes in long-term care spending patterns from FY1990 to FY2001, showing a small shift in Medicaid spending for home and community-based care.

Figure 4a. Medicaid Long-Term Care Spending in Illinois, by Category, FY1990



Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991 -FY2001*.

Figure 4b. Medicaid Long-Term Care Spending in Illinois, by Category, FY2001



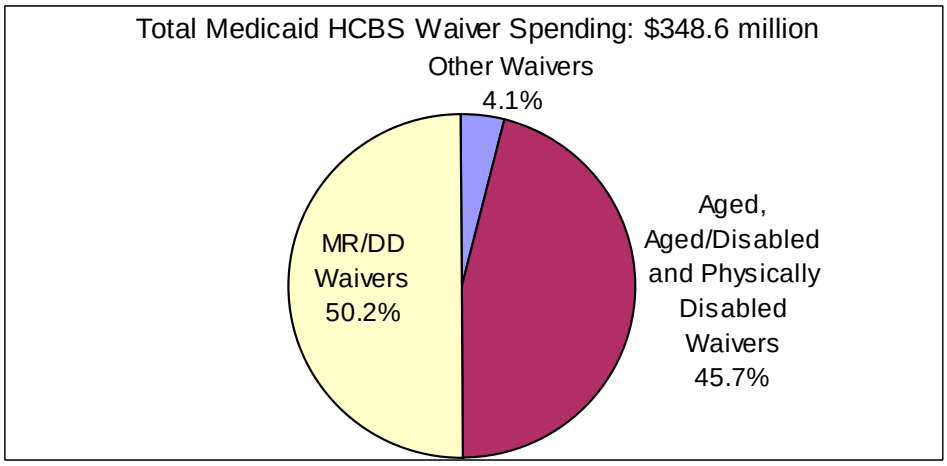
Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991 -FY2001*.

Medicaid and State Spending on Services for Persons with Mental Retardation or Developmental Disabilities

Federal and state spending for persons with mental retardation and developmental disabilities (MR/DD) was $1.2 billion in 2000 (**Table 9**). This represented an increase of 63.1% (in constant 2000 dollars) since 1990. Of total 2000 spending, 60.2% came from state resources. Section 1915(c) waiver funding increased from $9.8 million in 1990 to $74.4 million in 2000.

In Illinois, there is about an equal use of Medicaid waiver spending for persons with MR/DD and other persons with disabilities. The MR/DD population accounted for about half of spending in FY2001 (**Figure 5**).

Figure 5. Medicaid Home and Community-Based Services Waiver Spending by Target Population in Illinois, FY2001



Source: CRS calculations based on Steve Eiken and Brian Burwell, *Medicaid HCBS Waivers Expenditures*, FY1995-FY2001, by The Medstat Group, Inc., May 13, 2002.

In 2000, 56.6% of total spending on persons with developmental disabilities or $673.5 million was for home and community-based services. The Medicaid Section 1915(c) waiver program is one component of spending for these services, representing 11.0%. Waiver spending increased by 661.6% in constant 2000 dollars since 1990. The state has used waivers to maximize federal Medicaid reimbursement for home and community-based services. Federal spending for congregate and institutional services increased by 26.0% in constant dollars from 1990 to 2000 (**Table 9**).

Table 9. Federal and State Spending for Institutional and Community Services for Persons with Mental Retardation/Developmental Disabilities in Illinois, 1990 and 2000
(in millions of current dollars)

	1990	2000	Percent of FY2000 total	Percent change in constant 2000 dollars
Total funds	**$729.2**	**$1,189.5**	**100%**	**63.1%**
Congregate/Institutional services	**$435.3**	**$516.0**	**43.4%**	**18.5%**
Federal funds	$195.1	$245.9	20.7%	26.0%
State funds	$240.2	$270.1	22.7%	12.5%
Community services	**$293.9**	**$673.5**	**56.6%**	**129.1%**
Federal funds	$64.1	$226.9	19.1%	254.1%
ICF/MR funds	$21.2	$65.0	5.5%	207.5%
HCBS Waiver	$9.8	$74.4	6.3%	661.6%
Title XX/SSBG Funds	$0.0	$0.0	0.0%	—
Other	$33.1	$87.5	7.4%	163.9%
State funds	$229.8	$446.6	37.5%	94.3%

Source: CRS calculations based on data presented in David Braddock, et al., *The State of the States in Developmental Disabilities* (Fifth Edition), 1998, Washington, D.C., American Association on Mental Retardation, p. 404 (for 1990 data). Unpublished data furnished by Richard Hemp, University of Colorado (for 2000 data).

Issues in Long-Term Care in Illinois

The following discussion highlights the issues raised in state reports collected for the project and the interviews with state officials and key stakeholders conducted during the site visit to Illinois in the summer of 2002.

State Entitlement and Maximization of Federal Medicaid Dollars. Illinois has a unique approach to long-term care, compared to other states, because it has programs that provide an entitlement to home and community-based services for frail older persons and younger adults with physical disabilities – Community Care and the Home Services Program, respectively. These entitlements result from two court cases during the early 1980s and 1990s, which were designed to eliminate delays in receipt of services for which people qualified. The state programs do not have income eligibility requirements, but do have a maximum level of non-exempt assets. The Community Care Program uses a cost-sharing system for those non-Medicaid individuals whose income exceeds 100% of the federal poverty level.

Before 2002, Illinois did not require Community Care and Home Services program beneficiaries to apply for Medicaid; the state covered the program costs of some beneficiaries who might have qualified for Medicaid entirely from state funds. In 2002, the state began requiring applicants for, and current beneficiaries of, both programs to apply for Medicaid. This action is part of the state's efforts to maximize Medicaid funding by using this program's options to the fullest extent possible. This Medicaid maximization has occurred, at least in part, because of the budgetary crisis Illinois has been facing.

According to persons interviewed for this study, some people have refused to apply for Medicaid and have dropped out of the state entitlement program. Interviewees assume that people do not apply for Medicaid because they object to being "welfare recipients" and want to avoid potential estate recovery. (Under Medicaid, states are required to recover from the estate of an individual age 55 or older reimbursement for amounts paid by Medicaid for nursing facility services, home and community-based services, and related hospital and prescription drugs.)[19]

Budget Cuts. Illinois, like many states, is facing a revenue shortfall; according to state officials, State Fiscal Year (SFY) 2002 revenue was about $400 million below what had been projected. At the time of the site visit, the state planned no eligibility or service cuts in response to the budget crisis. Rather, most Medicaid providers, including home health agencies and nursing facilities, received a 5.9% rate decrease for SFY2003; however, waiver providers did not receive any cuts. Generally low payment rates are affecting some providers; for example, interviewees asserted that some adult day care sites are closing because payments are too low.

The DPA has also slowed its payments to providers to address the budget shortfall; payment can be delayed by up to 90 days. DPA can do this because it is the only department of state government that is able to pay the prior's year's bills with current appropriations. According to interviewees, slow payments do not hit large for-profits as hard as smaller, non-profit providers who do not have existing relationships with creditors. Payments to providers from other departments are not delayed.

Certification and Licensing of Facilities. Interviewees mentioned a number of issues related to certification and licensing of long-term care facilities.

The first issue relates to nursing facility certification for participation in Medicare and Medicaid. The federal survey process treats every nursing facility the same and some interviewees would like surveyors to spend more time on the facilities with poor performance. Interviewee suggested that surveyors examine a facility's core conditions and if they find that the facility is out of compliance in one of these areas, they then go into more depth in that area without having to do a full survey.

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[19] Section 1917 of the Medicaid statute. The law specifies that recovery may be made only after the death of the individual and his or her surviving spouse and only at a time when there is no surviving child under age 21 or a child with disabilities.

The second issue relates to licensure for assisted living facilities (ALFs), which began in December 2001. According to state officials, 17 licenses have been issued, and 105 facilities have applied for licensure, half of which are located in the Chicago area. State officials estimate that 300-500 ALFs may seek licensure and state officials may face an upsurge in applications as a result increasing the supply of facilities but also increasing the workload of licensing staff.

Labor Issues. Most interviewees agreed that the labor shortage may be affecting the quality of long-term care. With the recent economic problems and the resulting rise in unemployment, facilities had found it easier to hire direct care workers. However, Medicaid payment cuts for facilities may lead to reductions in staff salary and benefits and additional problems hiring workers. Facilities that have trouble hiring staff tend to rely on temporary staffing agencies. The results can be lack of continuity of care, which can negatively affect residents' quality of life because the temporary staff are not familiar with residents' needs. Rural areas tend to have less trouble hiring and keeping long-term care staff because facilities may be the only major employers in an area.

One of the ways in which providers have dealt with the labor shortage is to bring in nationally recognized experts to provide facilities with information about how to make facilities more home-like and a better environment for long-term care workers.

Labor shortages do not appear to be as much of a problem for facilities serving those with developmental disabilities. Three reasons were given for this: (1) these facilities pay staff more than nursing facilities; (2) developmental disability workers are generally in smaller facilities with long staying residents where relationships between staff and residents have a chance to develop over time; and (3) these workers also do not have to deal with as much incontinence as nursing facility workers do. However, retention of workers is still a challenge.

The state implemented an early retirement initiative for state employees in 2002. This initiative has reduced the number of veteran employees just as a new Governor came into office. The state has also attempted to lay off employees but a court decision halted these actions. The Home Services Program is an example of how a limited number of state workers can affect a program. The program is serving 200 new beneficiaries a month, up from 70 a month several years ago. However, the number of state staff has not kept pace with the growth in the number of beneficiaries.

Consumer Direction. Although consumer direction is incorporated into the basic structure of the Home Services Program for younger adults with physical disabilities, older persons have not had that option. A concern is that older adults, many with cognitive impairments, would not want to manage their own services and might be vulnerable to exploitation by their workers.

Some interviewees recommended that the federal government bring together policymakers who have instituted consumer-direction for persons with developmental disabilities to determine if some of the techniques are transferable to persons with cognitive impairment.

Lack of Adequate Supported Housing. Another issue raised relates to lack of affordable housing. This is a significant barrier to receipt of long-term care in the community, according to interviewees. People who have resided in nursing homes and lost their community residence may have difficulty going back to the community without access to affordable housing. Also, since Medicaid pays for room and board in nursing facilities and not in assisted or supportive living facilities, people may be forced into nursing facilities.

Appendix 1. Major Home and Community-Based Long-Term Care Programs for the Elderly and Persons with Disabilities in Illinois

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Community Care Program Program is funded by state general revenue funds. Medicaid reimbursement is received for Medicaid eligible beneficiaries who are claimed through the Home & Community-Based Services Waiver for the Elderly.	Persons age 60 and over This program is an entitlement for those meeting the eligibility criteria.	Nursing facility level of care	Case Coordination Units	Non-exempt assets of $10,000 or less No income test	Case Coordination Units determine financial eligibility for Community Care Programs and the Department of Human Services local offices determine financial eligibility for Medicaid.	Homemaker, adult day service, various demonstration project services Services are available in persons' homes or adult day service sites.	FY2002 average monthly caseload — 39,354 FY2002 general revenue fund spending - $210.3 million	Service cost maximums are based on assessment scores.	Department on Aging Case Coordination Units provide case management services to beneficiaries. Department of Public Aid oversees waiver services with periodic reviews of a sample of CCP case files.	Department on Aging and Department of Public Aid (for waiver only)

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Home and Community-Based Services Waiver for Supportive Living Facilities Section 1915(c) waiver was initially approved in July 1999.	People with disabilities aged 22-64 or frail elderly, age 65 and over	Nursing facility level of care	Care Coordination Units	Non-exempt assets of $2,000 or less Annual income is dependent on geographic area: Chicago – $28,140 S. Suburb – $27,108 Northwest – $25,212 Central – $24,168 W. Central – $22,884 St. Louis – $24,060 South – 22,152	Department of Human Services	Intermittent nursing, personal care, medication oversight and assistance with self-administration, laundry, housekeeping, maintenance, social/ recreational programming, ancillary services such as transportation to community events, 24 hour response/ security staff, health promotion and exercise programming, emergency call system Services available in certified	2,750 is the total number of slots approved at the time of the waiver renewal beginning July 1, 2002.	There are seven geographic areas each with their own annual cap for provisions of services. Chicago – $22,608 S. Suburb – $21,575 Northwest– $19,674 Central – 18,633 W. Central – $17,352 St. Louis – $18,524 South – $16,622	Department of Public Aid, Bureau of Long Term Care	Department of Public Aid

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
						supportive living facilities. These facilities offer private apartments and all meals.				

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Home Services Program Program is funded by the Home and Community-Based Services Waiver for Persons with Disabilities and state funds. Initial approval date of the Section 1915(c) waiver was in 1983.	People with physical disabilities ages 0–59. People who turn 60 after entering the program may remain in it. This program is an entitlement to people who meet the eligibility criteria.	Nursing Facility level of care and severe disability lasting at least 12 months	Department of Human Services, Office of Rehabilitation Services	For those 18 or over, individuals can have no more than $10,000 in non-exempt assets. For those under 18, family assets cannot exceed $30,000. People on SSI because of DD must have countable incomes at or below 200% of SSI to receive Medicaid.	Department of Human Services	Homemaker, personal care, adult day care, maintenance home health, personal emergency response system, environmental accessibility adaptations, home-delivered meals Services are available in individual homes or adult day care sites.	Waiver year 2001 – 19,198. Unduplicated recipients in FY2001 – 15,860 $320.3 million in FY2001	Service cost maximums are based on assessment scores.	Department of Human Services, Office of Rehabilitation Services	Department of Public Aid

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Home Services Program Home and Community-Based Services Waiver for Persons with Brain Injury Initial Section 1915(c) waiver approval date July 1999	Persons with brain injury of any age This program is an entitlement for those meeting the eligibility criteria.	Nursing facility level of care	Department of Human Services, Office of Rehabilitation Services	For those 18 or over, individuals can have no more than $10,000 in non-exempt assets. For those under 18, family assets cannot exceed $30,000. People on SSI because of developmental disabilities must have countable incomes at or below 200% of SSI to receive Medicaid.	Department of Human Services	Homemaker, personal care, adult day care, habilitation, day habilitation, prevocational services, supported employment services, environmental accessibility adaptations, personal emergency response systems, behavioral services, maintenance home health, occupational therapy, speech hearing and language services, physical therapy, specialized medical equipment and	800 slots, 614 unduplicated recipients in FY 2001 $15.6 million in FY2001	Service cost maximums are based on assessment scores.	Department of Human Services, Office of Rehabilitation Services	Department of Public Aid

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
						supplies, skilled nursing, home delivered meals Services are available in individual homes				

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Home Services Program Home and Community-Based Services Waiver for Persons with HIV or AIDS Initially approved in October 1990	Persons diagnosed with HIV or AIDS of any age who would otherwise be institutionalized in a hospital setting. This program is an entitlement for people who meet the eligibility criteria.	Hospital level of care	Department of Human Services	For those 18 or over, individuals can have no more than $10,000 in non-exempt assets. For those under 18, family assets cannot exceed $30,000. People on SSI because of DD must have countable incomes at or below 200% of SSI to receive Medicaid.	Department of Human Services	Homemaker, personal care, maintenance home health, personal emergency response system, home delivered meals, environmental accessibility adaptations Services are available in individual homes.	Waiver slots: 1,575 in waiver year (WY) 2001; 1,294 unduplicated waiver recipients in WY2001 General revenue fund expenditures in SFY2001 $17,903,502. State expenditures $9,937,168 in WY2001. Federal reimbursement $4,968,584 in WY2001	Service cost maximums are based on assessment scores.	Department of Human Services, Office of Rehabilitation Services	Department of Public Aid

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
Home and Community-Based Services Waiver for Adults with Develop-mental Disabilities Initial approval in Dec. 1983	People with MR/DD, 18 years or older	ICF/MR level of care	PAS agencies	Aged, blind, or disabled in 209(b) States. Optional State supplement recipients. Optional categorically needy aged and disabled who have income at 100% of federal poverty level. Medically needy persons.	Department of Human Services	Residential habilitation, including Community Integrated Living Arrangements or Community Living Facility for 16 or fewer persons; day habilitation including developmental training and supported employment; supported living services including team leader, direct support, respite, nursing, behavioral services, physical therapy, occupational therapy, speech therapy and	8250 slots in WY2001; 8,037 unduplicated waiver recipients State expenditures in WY2001 $201,616,853 Federal reimbursement $94,766,934 in WY2001	For Supported Living Services, $1500 a month. Beneficiaries in this program have access to funding for adaptive equipment or minor home or vehicle modifications of up to $15,000 over 5 years. SLS, now called Home-Based Support Services (HBS), provides services based on the individual service plan up to a maximum determined by DHS.	Department of Human Services, Office of Developmental Disabilities	Department of Public Aid

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource limits	Determined by					
						transportation; professional therapies including behavioral, physical, occupational and speech; adaptive equipment and minor home modifications Services are available in people's homes, community residential sites, and day programs.				

Source: Illinois Home and Community-Based Services 1915(c) Waivers Fact Sheets, Aug. 5, 2002, Department of Public Aid, Bureau of Interagency Coordination.

Appendix 2. Large State MR/DD Facilities, 1960-2001, Including Facility Population, Per Diem Expenditure, and Closures (IL)

Large state MR/DD facilities or units operating 1960-2001	Year facility opened	Year closed	Residents with MR/DD on June 30, 2001	Average per diem expenditures FY2001 ($)
Alton Mental Health & Dev. Ctr. (Alton)	1914	1994	—	—
Bowen Ctr. (Harrisburg)	1966	1982	—	—
Choate Dev. Ctr. (Anna)	1873		191	429.74
Dixon Ctr. (Dixon)	1918	1987	—	—
Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994	—	—
Fox Dev. Ctr. (Dwight)	1965	—	158	325.52
Galesburg Ctr. (Galesburg)	1959	1985	—	—
Howe Dev. Ctr. (Tinley Park)	1973	—	387	364.65
Jacksonville Dev. Ctr. (Jacksonville)	1851	—	227	377.36
Kiley Dev. Ctr. (Waukegan)	1975	—	269	303.56
Lincoln Dev. Ctr. (Lincoln)	1866	—	379	317.00
Ludeman Dev. Ctr. (Park Forest)	1972	—	408	309.01
Mabley Dev. Ctr. (Dixon)	1987	—	100	298.96
Meyer Mental Health Ctr. (Decatur)	1967	1993	—	—
Murray Dev. Ctr. (Centralia)	1964	—	323	318.28
Shaprio Dev. Ctr. (Kankakee)	1879	—	662	328.05
Singer Mental Health & Dev. Ctr. (Rockford)	1966	—	47	456.05

Source: Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001, Research and Training Center on Community Living, Institute on Community Integration/UCEED, University of Minnesota, June 2002.

Appendix 3. About the Census Population Projections

The projections use the cohort-component method. The cohort-component method requires separate assumptions for each component of population change: births, deaths, internal migration (Internal migration refers to state-to-state migration, domestic migration, or interstate migration), and international migration ... The projection's starting date is July 1, 1994. The national population total is consistent with the middle series of the Census Bureau's national population projections for the years 1996 to 2025." Source: Paul R.,Campbell, 1996, Population Projections for States by Age, Sex, Race, and Hispanic Origin: 1995 to 2025, U.S. Bureau of the Census, Population Division, PPL-47. For detailed explanation of the methodology, see same available at:

[http://www.census.gov/population/www/projections/ppl47.html].

Additional Reading

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