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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: Indiana

December 15, 2003

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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: Indiana

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 in understanding 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 in a series of 10 state reports, presents background and analysis about long-term care in Indiana.

Indiana is the 14th largest state in the country with 6.1 million people in 2000; about 12.4% of its population is aged 65 and older. The state's oldest population grew quite rapidly during the 1990s — those aged 85 and older grew by 27.6% from 1990-2000. By 2025, persons aged 65 and older will represent close to one out of five persons, slightly higher than the U.S. average.

Indiana is one of a few states that house most of its long-term care programs for the frail elderly, younger adults with disabilities and persons with developmental disabilities within the same administrative unit. Indiana makes heavy use of institutional services to serve the first two populations. In FY2001, \$1.1 billion, or more than 27% of all Medicaid spending, was for care in institutions. Nursing home spending accounted for almost two-thirds of Medicaid long-term care spending; services in intermediate care facilities for the mentally retarded accounted for 23%; and home and community-based services accounted for almost 15%.

Slow-moving waiting lists for home and community-based services have been a problem for the state and quality of care issues caused the state to revamp its primary program for persons with developmental disabilities. The state replaced its former program and implemented new quality assurance mechanisms, including use of routine, independent audits.

This study was funded in part by a grant from the Jewish Healthcare Foundation and by a grant from the U.S. Department of Health and Human Services, Office of Rural Health Policy, Health Resources and Services Administration.

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Acknowledgments

CRS wishes to acknowledge the generous time and contributions of the many state officials and stakeholders who provided information on long-term care services in Indiana. Without their generous time and invaluable experience and insight, this report would not be possible. We would particularly like to thank officials from the Indiana Family and Social Services Administration. We would also like to thank the advocates and providers who offered valuable perspectives on the long-term care system in Indiana.

The authors gratefully acknowledge the excellent assistance of Rashelle Butts in the production of this report.

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 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 Indiana.

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

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

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.

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

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

¹ CRS Report 83-181, *Nursing Home Legislation: Issues and Policies*, by Maureen Baltay. (Archived report; available from CRS upon request.)

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 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 (In 2003, there were about 16,400 nursing homes with 1.8 million beds.³)

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 Department of 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

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).

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 Centers for Medicare and Medicaid Services, *Health Care Industry Update, Nursing Facilities*, May 20, 2003.

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.

nursing facility care, but also to respond to the desires of persons with disabilities to remain in their homes and 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 emphasis in the Medicaid program on institutional care. 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 waiver programs.

Notwithstanding wide use of the Section 1915(c) waiver authority by states over the last two 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 two 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

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.

through waiver of federal law, within state-defined eligibility requirements, service availability, and limits on numbers of persons served.

A CRS Review of Ten States: Report on Indiana

Summary Overview

- Indiana has an innovative home and community services system for those adults with disabilities who are able to access it. Funding comes from a Medicaid Section 1915(c) home and community-based services waiver and a generous, non-means-tested state-funded program. The state spends a large proportion of its Medicaid long-term care funds on institutional care.

Demographic Trends

- Indiana is the 14th largest state in the country with 6.1 million people in 2000; the population increased by 9.7% or about half a million people from 1990-2000. About 12.4% of its population is aged 65 and older — 752,831 people in 2000. The state's oldest population is growing quite rapidly; those aged 85 and older grew by 27.6% from 1990-2000.
- Persons aged 85 and over with two or more limitations in activities of daily living (ADLs) in Indiana are estimated to increase 22.8% by 2010 to reach over 11,000 people. The number of persons aged 18 to 64 with the same level of disability is estimated to increase by 3.7% reaching 15,340 or 25.8% of all adults with limitations in two or more ADLs in 2010. Growth in the number of adults of all ages with disabilities will place pressure on public and private long-term care resources.

Administration of Long-Term Care Programs

- Indiana is one of the few states to house most of its home and community-based services programs for the frail elderly, younger adults with disabilities and persons with developmental disabilities within the same administrative unit — the Family and Social Services Administration (FSSA). Within that larger unit, these long-term care functions are spread across two bureaus and one office within FSSA. Indiana's Department of Health regulates nursing homes.
- The state has a single point of entry for these programs and an innovative, electronically-based assessment and case management system.

Trends in Institutional Care

- In 2000, Indiana had 572 nursing facilities with 56,990 beds, with a relatively low occupancy rate of 74.8%. The number of beds per 1,000 persons age 65 and older is 75.7, much higher than the national rate of 52.7; the state's ratio for persons age 85 and over is also much higher than the national rate. The relatively low occupancy rates combined with the high ratio of nursing home beds

to older persons implies that the state has much excess capacity in its nursing home industry.

- Residential care for persons with developmental disabilities has shifted to care in smaller settings over the period from 1990-2000 in Indiana. Persons with developmental disabilities living in large institutions with 16 or more residents declined from 53% of all such persons living in group residences in 1990 to 32% in 2000, while the proportion residing in homes with six persons or fewer persons grew from about one-third in 1990 to 44% in 2000.

Trends in Home and Community-Based Care

- The state uses a combination of Medicaid Section 1915(c) home and community-based services waivers and a large totally state-funded program to provide home and community services to persons with disabilities through the IN-Home Services program. The state-funded program, Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE), funded at \$34.3 million in State Fiscal Year (SFY) 2002, has more generous financial eligibility standards than used under Medicaid and very flexible services.
- In 1992, Indiana started its Medicaid Section 1915(c) home and community-based Intermediate Care Facility for the Mentally Retarded Waiver (ICF/MR Waiver) to provide home and community services for persons with mental retardation. This program was replaced with the Developmental Disabilities Waiver in 2001 as a result of some serious quality problems uncovered by a federal audit. The state also has two other Section 1915(c) waiver programs to help persons with developmental disabilities remain at home.

Long-Term Care Spending

- In FY2001, \$1.1 billion or 27.4% of all Medicaid spending in Indiana was for care in institutions — nursing homes and intermediate care facilities for persons with mental retardation (ICFs/MR). Nursing home spending accounted for almost three-quarters of Medicaid institutional spending and almost two-thirds of Medicaid long-term care spending. In the same year, home and community-based services accounted for almost 15% of all Medicaid spending.
- Spending for Medicaid home and community-based services increased by over 958% from FY1990 to FY2001, while spending for institutional care increased at a slower pace — by 38% over the same period (in constant 2001 dollars).

Issues in Financing and Delivery of Long-Term Care

- Waiting lists for home and community-based services have been a persistent problem in Indiana. The state-funded CHOICE program had a waiting list of over 8,500 persons in SFY2002, a decrease

from almost 12,000 persons in SFY2001. Some state interviewees said that the number of persons on the waiting list may not be a good indication of who needs services, because some people join the list before they really need care. Other interviewees said that the top three ways of getting off the list are, in order, 1) to die, 2) go into a nursing home, or 3) to receive services, generally after a wait of 3.5 to 4 years.

- Indiana has had quality problems in its Section 1915(c) home and community-based services waivers for persons with developmental disabilities. As a result, the state implemented new quality assurance mechanisms, including use of routine, independent audits.

Demographic Trends

Indiana is the 14th largest state in the country with 6.1 million people in 2000; the population increased by 9.7% or about half a million people in the past decade. In 2000, 12.4% of the state's population or 752,831 people were aged 65 and older. The state's oldest populations grew quite rapidly during the 1990s — those aged 75-84 grew by almost 20% and those 85 and older grew by 27.6% from 1990-2000. (See **Table 1**.)

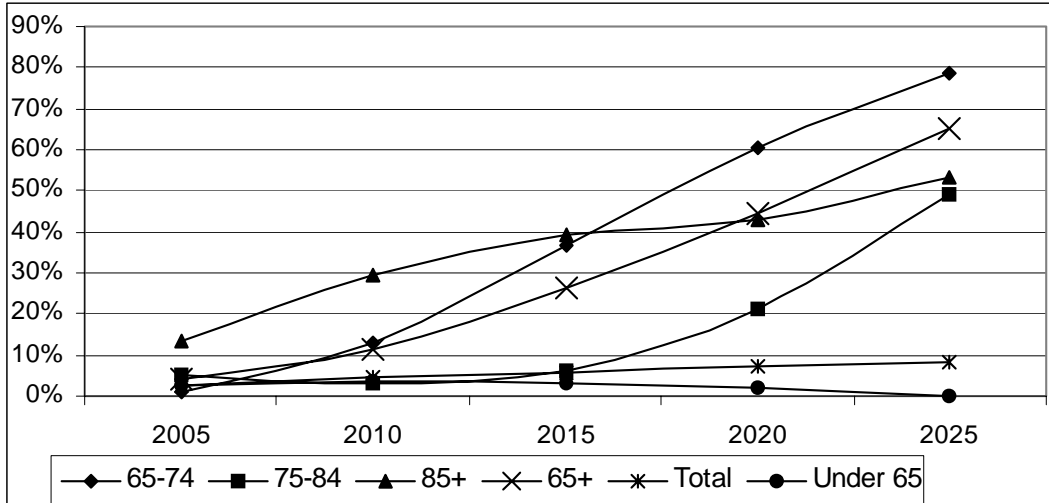
Table 1. Indiana Population Age 65 and Older, 1990 and 2000

Age	1990		2000		Percent change 1990-2000	2000 population rank in U.S. (based on percent)
	Number	Percent of total population	Number	Percent of total population		
65+	696,196	12.6%	752,831	12.4%	8.1%	28 th
65-74	(402,041)	(7.3%)	395,393	(6.5%)	-1.7%	32 nd
75-84	(222,404)	(4.0%)	265,880	(4.4%)	19.5%	27 th
85+	(71,751)	(1.3%)	91,558	(1.5%)	27.6%	28 th
Under 65	4,847,963	87.4%	5,327,654	87.6%	9.9%	24 th
Total pop.	5,544,159	100.0%	6,080,485	100%	9.7%	14 th

Source: U.S. Census Bureau, Profile of General Demographics for Indiana: 1990; 2000: [<http://www.census.gov/census2000/states/me.html>]. Percentages may not sum to 100% due to rounding.

Indiana, along with the rest of the country, will experience large increases in its older population over the next 25 years. In 2025, 19.2% of Indiana's population will be aged 65 years or older, compared to 18.5% for the nation (See **Table 2**).

Figure 1. Percentage Population Increase Over 2000 in Indiana



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, Indiana and the United States, 2025

Age	Proportion of total population in 2025 in Indiana	Proportion of total population in 2025 in U.S.
65-74	11.0%	10.5%
75-84	6.1%	5.8%
85+	2.2%	2.2%
65+	19.2%	18.5%
Under 65 pop.	80.8%	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.

Need for Long-Term Care

Table 3 presents estimates of the number of persons aged 18 and over in Indiana who have limitations in two or more activities of daily living (ADLs) and thus may need long-term care. These estimates were derived from data generated by The Lewin Group and combine national level data on persons with disabilities with state-level data from the U.S. Census Bureau on age, income, and broad measures of disability. Persons aged 65 and over with two or more limitations in ADLs in Indiana are estimated to increase by 11% to reach nearly 33,000 persons. The fastest growth will be for those aged 85 and over with two or more limitations in ADLs who are estimated to increase 23% by 2010 to reach over 11,000 persons. The number of persons aged 18 to 64 with the same level of disability will increase by almost 4% reaching over 15 thousand persons. Growth in the number of adults of all ages with disabilities will place pressure on public and private long-term care resources.

Table 3. Estimated Number of Persons with Two or More Limitations in Activities of Daily Living (ADLs), by Poverty Status, in Indiana

Percent of poverty	2002			2005			2010		
	Persons with 2+ ADLs by age and income								
	18-64	65+	85+	18-64	65+	85+	18-64	65+	85+
Up to 100%	2,795	3,968	1,033	2,852	4,110	1,114	2,898	4,372	1,269
Up to 150%	4,682	10,426	3,775	4,776	10,863	4,068	4,855	11,640	4,635
Up to 200%	6,346	15,404	5,384	6,473	16,039	5,802	6,580	17,140	6,611
All income	14,797	29,747	9,082	15,090	30,897	9,788	15,340	32,933	11,151

Source: CRS analysis based on projections generated by The Lewin Group through the HCBS State-by-State Population Tool available online from [<http://www.lewin.com/cltc>]. *The Lewin Group Center on Long Term Care HCBS Population Tool*, by Lisa M.B. Alexih, and Ryan Foreman (2002).

Administration of Long-Term Care Programs

Indiana is one of the few states to house most of its home and community services programs for the frail elderly, younger adults with disabilities and persons with developmental disabilities within the same administrative unit — the Family and Social Services Administration (FSSA). The long-term care functions are spread across two bureaus and one office within FSSA. The Indiana Department of Health regulates nursing homes.

The Bureau of Aging and In-Home Services (BAIHS) oversees the IN-Home Services program for older persons and younger adults with disabilities who are at risk of institutionalization. IN-Home Services encompasses the state-funded CHOICE program; seven⁶ Medicaid Section 1915(c) home and community-based waivers; and funding from the Older Americans Act, the Social Services Block Grant, and state and local sources.

The BAIHS contracts with the statewide network of 16 area agencies on aging (AAAs) which are the single point of entry for most community-based long-term care services for older adults and persons of all ages with disabilities. Area agencies administer IN-home Services for adults with disabilities at the local level.

⁶ Six of the state's Medicaid Section 1915(c) waivers are described in this report. A seventh waiver, the Medically Fragile Children Waiver, serves children under age 18 who are in need of significant medical services, including those who are technologically dependent. Recipients of these services must meet either skilled nursing facility level of care or hospital level of care. This waiver is outside the scope of this report.

The state uses a data system called InSite to manage the IN-Home Services Program. Case managers conduct home visits to assess applicants' needs and eligibility for services as well as to monitor quality; the resulting data go into a state-maintained data base, which is used to produce care plans and data about service use and quality.

In 1983, Indiana began pre-admission screening of all nursing home applicants to ensure that they know about care options in the community. Area agencies on aging perform, and are reimbursed for, the screenings; they performed 31,063 screenings in SFY2002 at a cost of \$2.8 million.⁷ In addition, the Pre-Admission Screening Resident Review (PASRR) program, enacted into federal law in 1987, reviews the health and supportive care needs of persons who have a mental illness or a developmental disability and who are applying to, or are residents of, Medicaid certified nursing facilities to determine if their needs can be, or are being, met. The PASRR program served over 9,000 persons in Indiana in SFY2002; expenditures for PASRR were \$3.3 million in SFY2002.

The FSSA Bureau of Developmental Disability Services (BDDS) administers all institutional services for people with mental retardation and developmental disabilities and controls all admissions to ICFs/MR. In 2002, administration of the Medicaid Section 1915(c) Developmentally Disabled Waiver was transferred to BDDS. Local BDDS units provide assessment and case management services to persons with developmental disabilities.

FSSA's Office of Medicaid Policy and Planning determines financial eligibility for all Medicaid applicants. The Bureau of Quality Improvement Services monitors the quality of Medicaid waiver programs and the Bureau of Fiscal Services administers Medicaid waiver funding.

Indiana's Long-Term Care Services for the Elderly and Persons with Disabilities

Trends in Institutional Care

In 2000, Indiana had 572 nursing facilities with 56,990 beds, with a relatively low occupancy rate of 74.8% (see **Table 4**). The number of beds per 1,000 persons aged 65 and older is 75.7, much higher than the national rate of 52.7. The state's ratio is 622.4 beds per 1,000 persons age 85 and over, a figure also much higher than the national rate of 434.8. The relatively low occupancy rates combined with the high ratio of nursing home beds to older persons implies that the state has significant excess capacity in its nursing home industry. There is no certificate of need process in Indiana.

⁷ Indiana Family and Social Services Administration, *Statewide IN-Home Services 2002 Annual Report, July 1, 2001-June 20, 2002*, Indianapolis, IN, 2002.

Table 4. Nursing Home Characteristics in Indiana and the United States

(Data are for 1999-2000)

Characteristics	Indiana	United States
Number of facilities	572	17,023
Number of residents	42,621	1,490,155
Number of beds	56,990	1,843,522
Number of Medicaid beds	18,357	841,458
Number of beds per 1,000 pop aged 65 and older	75.7	52.7
Number of beds per 1,000 pop aged 75 and older	159.4	111.1
Number of beds per 1,000 pop aged 85 and older	622.4	434.8
Occupancy rate	74.80%	80.8%

Source: American Health Care Association, *Facts and Trends: The Nursing Facility Source Book*.

Perhaps because of excess capacity, nursing homes across the state are closing, according to state officials, regardless of the homes' level of quality. Indiana has implemented the Senior Security Plan to address the problems residents face when their facilities close. The Plan involves Senior Care Teams that assist Medicaid-eligible residents of closing nursing facilities to find another facility, or to transition to home or community settings. The state plans to use former residents' Medicaid funding to pay for their services under the Medicaid Aged and Disabled Waiver. The state expected to fund up to 1,000 of the state's 10,000 unused Medicaid Aged and Disabled waiver slots in this way in SFY2002. According to state officials, Indiana did not have the expected number of persons leaving nursing facilities and therefore did not obtain the funding for most of the unused slots. As a result, the waiver was amended in October 2002 to decrease the maximum number of waiver slots to 6,000.

Indiana is addressing excess nursing home capacity in a number of ways. The state received a nursing facility transition grant of \$770,000 in 2001 from the U.S. Department of Health and Human Services (DHHS) to move persons from nursing homes into the community, and to divert persons who live in the community and are at risk of nursing home placement from these facilities.⁸ Use of grant funds allows area agencies on aging and nursing home ombudsmen to identify nursing home residents with relatively low care needs and inform them about opportunities to move into the community using waiver funding.

In addition, the state has established a nursing home occupancy standard to address excess capacity. The state has stipulated that if any nursing facility has less than a 75% occupancy level, then its Medicaid reimbursement amount would be reduced. Some homes have decertified beds as a result of this rule.

⁸ [http://www.hcbs.org/compendium/web/indiana_nft.htm] accessed on Apr. 5, 2003.

Trends in Home and Community-Based Care

Indiana uses a combination of Medicaid Section 1915(c) home and community-based services waivers and state funds to provide home and community services to older persons and younger adults with disabilities through its IN-Home Services program. Three waiver programs — the Aged and Disabled Waiver, the Traumatic Brain Injury Waiver, and the Assisted Living Waiver — served 3,307 persons in SFY2002; the state-funded CHOICE program, which uses more liberal functional and financial eligibility tests than used by Medicaid waiver programs, served almost four times that number.

Medicaid Section 1915(c) Waivers. All waiver participants must require assistance with three or more of 14 activities of daily living (ADLs). The state's financial eligibility standards require that in order to be eligible for the waiver programs, persons must have incomes at or below the Supplemental Security Income (SSI) benefit standard (\$552 per month in 2003) and have countable financial assets of less than \$1,500.⁹

Indiana has three Medicaid Section 1915(c) waivers serving older persons and younger adults with disabilities. The *Aged and Disabled Waiver* is the largest and served 3,154 persons in SFY2002. Services covered include adult day care, case management, meals, home modifications, and respite care, among others. The average monthly Medicaid expenditure under this waiver in SFY2002 was \$644.

The state has had DHHS approval for many more slots than persons served for a number of years; state funding constraints have not allowed the state to serve persons up to the approved slot level.¹⁰ At the same time, its state-funded home and community-based program (described below) has had an extensive waiting list.

The *Traumatic Brain Injury Waiver* targets persons who have suffered brain injuries. The waiver had 200 slots in 2002. The number of slots has increased dramatically since 2000, when the state had only 100 slots. The number of persons served has also increased rather dramatically from 25 persons in SFY2000 to 146 persons in SFY2002. A wide range of services is available including case management, therapies, companion, habilitation and residential services. The average monthly Medicaid expenditure under this waiver in SFY2002 was \$1,589.

The *Assisted Living Facility Waiver* began in July 2001; Indiana received approval from DHHS in 2001 to cover 350 persons in assisted living in the first year,

⁹ Medicaid law provides for certain excluded assets, including an individual's home; up to \$2,000 of household goods and personal effects; life insurance policies with a face value of \$1,500 or less; an automobile with value up to \$4,500; and burial funds up to \$1,500, among other things.

¹⁰ Olmstead Real Choices Narrative downloaded from [<http://www.in.gov/fssa/servicedisabl/olmstead/realnar.html>] on Feb. 1, 2002.

1,050 in the second and 2,250 in the third year of the waiver.¹¹ In FY2002, seven persons were served under the waiver. ALFs must give each resident his or her own room with a lockable door, bathroom, and food preparation area. The average monthly Medicaid expenditure under this waiver in SFY2002 was \$1,177.

State Programs. There are a number of pathways that establish Medicaid eligibility for home and community-based long-term care services. These include coverage of persons whose income is 300% of the federal SSI payment level (\$1,656 a month in 2003), as allowed under the Section 1915(c) waiver program. Despite the availability of this more liberal standard, many people may need community care but cannot meet Medicaid's income limits or resource tests. Many of these persons cannot establish eligibility until they spend-down almost all of their resources and income, and, by that time, may be in danger of entering an institution. One of the issues many states have confronted is how to serve these people.

Indiana has addressed this issue in part through its Community and Home Options to Institutional Care for Elderly and Individuals with Disabilities (CHOICE) program which is totally state-funded. There are no income and asset tests under the CHOICE program, but persons with incomes at or above 150% of the federal poverty level are required to contribute toward the costs of services, based on a sliding fee scale. Persons with incomes at or above 351% of poverty are required to pay the full cost of services.

CHOICE beneficiaries must have a long-term disability or be age 60 or older and unable to perform two of 14 ADLs or Instrumental Activities of Daily Living (IADLs);¹² this standard is more liberal than the functional eligibility standard for the Medicaid Section 1915(c) Aged and Disabled Waiver. The program provides all the services provided by the Aged and Disabled Waiver in addition to other authorized services that a person may need to remain at home. Examples of these services include language translation and pest control services. The program was funded at \$34.3 million in SFY2002.

Many persons served by the CHOICE program are of advanced age; of 12,702 persons served in SFY2002, more than one-quarter were age 85 and over and one-third were age 75-84 years old.

Waiting lists for home and community-based services have been a persistent problem. In SFY2002, CHOICE had a waiting list of over 8,500 persons, a decrease from almost 12,000 persons in SFY2001. State interviewees said that the top three ways of getting off the list are, in order, 1) to die, 2) go into a nursing home, or 3) receive services, generally after a wait of 3.5 to 4 years. However, some interviewees said that the number of persons on the waiting list may not be a good indication of need for services, because some people join the list before they really need care.

¹¹ Bureau of Aging and In Home Services Annual Report 2001, Indianapolis, IN, 2001.

¹² IADLs refer to activities necessary for independent community living, such as meal preparation, shopping, light housework, telephoning, and money management.

Indiana is undertaking efforts to maximize Medicaid funding for home and community-based services. First, the state is converting some CHOICE beneficiaries to the Medicaid Aged and Disabled waiver to take advantage of the federal Medicaid matching funds. The Centers for Medicare and Medicaid Services (CMS) has allowed this as long as the additional federal funds are devoted to the waiver. In addition, the state had plans to close a 30-year old, state-funded room and board assistance program to new participants because the state is encouraging providers to become assisted living facilities and participate in the Medicaid assisted living facility waiver. The state had plans to use the program's state funding to draw down federal Medicaid matching funds.

Medicaid Policy Affecting Consumers of Long-Term Care. Two aspects of Medicaid policy in Indiana affect consumers of long-term care. The first is the state's initiative to participate in a long-term care partnership program; the second relates to the definition of disability for adults under age 65.

Long-Term Care Partnership Program. With funding from the Robert Wood Johnson Foundation, Indiana established the Indiana Long Term Care Insurance Program (ILTCIP) in 1993. The Long-Term Care Partnership program was initiated by the Robert Wood Johnson (RWJ) Foundation in 1988. The purpose of the program is to encourage the purchase of long-term care insurance and to blend public financing (Medicaid) with private insurance. Indiana is one of four states that implemented the program with funding from RWJ (the other states are California, Connecticut and New York). Under the program, persons who purchase a certified private long term care insurance policy may qualify for Medicaid once they exhaust their insurance benefits. In return for purchasing insurance coverage, they may qualify for Medicaid assistance without being required to meet Medicaid assets tests and thereby protect some of their assets. The amount of assets protection is dependent upon the amount of insurance coverage purchased. Applicants must, however, meet Medicaid income and categorical eligibility requirements (age or disability criteria).

In Indiana, insurance purchasers can receive "dollar for dollar" protection of their assets, or protection of all of their assets, depending upon the amount of long-term care insurance benefits they purchase. Purchasers can choose between nursing home-only policies and those that cover home, community, and facility services. All policies include inflation protection. In Indiana, as of April 2003, 22,285 insurance policies were in effect; seven persons had qualified for Medicaid. Thirteen insurance companies participate in the program.¹³

Definition of Disability. Before 2001, people under 65 could not qualify for Medicaid on the basis of their disabilities, if their disabilities could improve with proper medical treatment. In September 2000, the Indiana Court of Appeals ordered the state to stop denying disability benefits on this basis. In June 2001, the Indiana Supreme Court declined to hear the state's appeal of the Court of Appeals decision.¹⁴

¹³ Data collected by CRS, summer 2003.

¹⁴ *Petricia Day v. Indiana*, Ind. Ct. App., No. 49A02-0001-CV-30, Sept. 29, 2000.

The state Supreme Court's decision extended Medicaid coverage to those whose disability is expected to last four years if left untreated.¹⁵ The previous standard had required that a person have a permanent, untreatable disability; therefore, for example, people with conditions such as cancer or kidney failure could not obtain Medicaid coverage.¹⁶ The state had originally estimated the cost of compliance with the decision to be \$850 million; that figure declined to \$130 million because just 3,665 of 17,559 persons who were contacted and expected to be eligible for Medicaid actually applied, and were found eligible, for the program. The state contacted people who were denied coverage between December 20, 1993 and December 2001.

Indiana's Long-Term Care Services for Persons with Mental Retardation and Developmental Disabilities

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 a number of converging factors. These include the advocacy efforts of families and organized constituency groups, various changes to the Social Security law that provided payments to individuals through SSI and social security disability insurance (SSDI) and to service providers through the Medicaid program, and significant litigation brought on behalf of persons with mental retardation.¹⁷

Trends in Institutional Care

The early history of services to persons with developmental disabilities and 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 free-standing, state-operated mental retardation institutional facilities.¹⁸ Today, some states are still faced with the legacy of large state-operated institutions.

Indiana, like many other states, has eliminated some of its large state facilities for persons with mental retardation and developmental disabilities. The state closed five

¹⁵ Corcoran Kevin, "Medicaid Costs Under Budget," *Indianapolis Star*, Aug. 2, 2002, downloaded from [<http://www.indystar.com/article.php?day02.html>] on Aug. 15, 2002.

¹⁶ The old standard was stricter than SSI disability requirements. Under SSI, a person is considered to be disabled if he or she is unable to engage in substantial gainful activity because of a medically-determined physical or mental impairment.

¹⁷ 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, 1988, Washington, D.C. (Hereafter cited as Braddock, et al., *The State of the States in Developmental Disabilities*.)

¹⁸ *Ibid.*

of its 11 facilities between 1979 and 1998 and was scheduled to close another in 2003. Four of the five remaining facilities are more than 100 years old; the youngest remaining facility opened in 1910. (See **Appendix Table 2** for a list of the institutions that have been closed and those in operation and their 2000 census.)

The nationwide trend in care for persons with developmental disabilities has been to provide care in smaller community-based facilities. In Indiana, persons living in large institutions with 16 or more residents declined from 53.1% of all persons living in group residences in 1990 to 31.5% in 2000 (**Table 5**). The number of persons living in group residences with 7-15 persons more than doubled between 1990 and 2000 to reach 2,754 in 2000, while the number of persons with developmental disabilities in homes with six persons or fewer grew from 3,200 in 1990 to 4,958 in 2000.

Table 5. Persons with Mental Retardation and Development Disabilities Served in Residential Settings, by Size of Setting, 1990, 1995, and 2000

Persons served by setting			
Setting by size	1990	1995	2000
		9,659 (100%)	10,152 (100%)
16+ persons	5,132 (53.1%)	4,507 (44%)	3,550 (31.5%)
Nursing facilities	2,370	2,057	1,933
State institutions	1,983	1,299	782
Private ICF/MR	779	1,151	835
Other residential	0	0	0
7-15 persons	1,327 (13.7%)	2,767 (27.3%)	2,754 (24.5%)
Public ICF/MR	0	0	0
Private ICF/MR	1,327	2,767	2,754
Other residential	0	0	0
≤6 persons	3,200 (33.1%)	2,878 (28.3%)	4,958 (44%)
Public ICF/MR	0	0	0
Private ICF/MR	2,000	1,028	1,037
Other residential	1,200	1,850	3,921

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

Trends in Home and Community-Based Care

Indiana has three Medicaid Section 1915(c) waivers for persons with developmental disabilities: the *Home and Community-Based Waiver for Persons with Developmental Disabilities* (DD Waiver); the *Support Services Waiver*; and the *Autism Waiver*, serving a total of 4,161 persons in SFY2002. In order to be eligible for waiver services, persons must meet the level of care requirements provided in an ICF/MR.

The state was relatively slow to set up its first waiver for persons with developmental disabilities. It was not until 1992 that Indiana began its *Intermediate Care Facility for the Mentally Retarded Waiver* (ICF/MR Waiver) (11 years after enactment of the federal law). Use of the waiver program has affected the type of care for persons with developmental disabilities in that care has been shifted to small community-based settings. The ICF/MR waiver was replaced with the DD Waiver in 2001. The replacement occurred because of serious quality problems that a routine CMS regional office audit uncovered. The regional audit found that the state had failed to insure a safe environment in the community-based waiver settings and that case management and quality assurance systems were inadequate. Interviewees indicated that safety problems occurred because three ICFs/MR with 40 beds each closed and the state was forced to find placements for the residents quickly and therefore placed residents in community-based waiver settings that turned out to be unsafe.

The state reacted to the waiver audit in a number of ways. It moved administration of the waiver from BAIHS to the Bureau of Developmental Disabilities Services (BDDS) in 2001. In addition, the DD Waiver was modified to give the state more flexibility to pay for beneficiary participation in community activities, vocational skills training and transportation to community activities to improve the quality of services. The state has also applied for a targeted case management waiver to provide intensive case management to some persons and began requiring 18 months of training for case managers. Persons with developmental disabilities can choose between area agency on aging (AAA) case managers and service coordinators from the BDDS field offices for intake activities; they can choose between AAA case managers and private case managers for on-going case management activities. To address quality, the state hired Electronic Data Systems, Inc. (EDS) to audit at least 10% of developmental disability service providers annually; this system was expanded to the aged and disabled waiver in 2002.

The average monthly Medicaid waiver expenditure in SFY2002 was \$3,677.¹⁹

The *Support Services Waiver*, which began in April 2002, is designed to help persons remain in their own homes by providing such services as caregiver support, respite, adult day care, and a wide range of therapies. In SFY2002, 486 persons were

¹⁹ Telephone interview with Indiana Bureau of Developmental Disabilities Services staff.

served. The average monthly Medicaid waiver expenditure in SFY2002 was \$1,125.²⁰

The *Autism Waiver* provides a broad array of services similar to those of the Support Services Waiver; 267 persons were served under this waiver in SFY2002. The average monthly Medicaid waiver expenditure in SFY2002 was \$2,788.²¹

Financing of Long-Term Care

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 of their own to long-term care. In Indiana, the Medicaid program accounted for \$1.3 billion in long-term care spending in FY2001; long-term care spending represented almost one-third of all Medicaid spending.

Medicaid Spending in Indiana

Medicaid is a significant part of state budgets, representing the single largest spending category in almost half the states. 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 19.6% of state budgets for the United States as a whole in 2001 (see **Table 6**).

In Indiana, Medicaid is the second largest category of federal and state spending (after spending for elementary and secondary education), representing 18.7% of the state's \$17.8 billion budget in 2001 (see **Table 6**). State spending for Medicaid services in Indiana contributed from state funds only (excluding federal funds),²² as a percent of total state spending, remained relatively stable during the 1990s. State Medicaid spending as a percent of spending for all categories of state spending was 9.9% in 2001, compared to 8.1% in FY1990 (see **Table 7**).

²⁰ Ibid.

²¹ Ibid.

²² Federal and state governments share the costs of Medicaid spending according to a statutory formula based on a states' relative per capita income (federal medical assistance percentage or FMAP). In FY2001, the federal share for Medicaid in Indiana was 62.04%.

Table 6. Share of State Spending by Category, Indiana and the United States, 1990-2001

	Indiana				U.S. total
	1990	1995	2000	2001	2001
<i>Total expenditure (in millions)</i>	<i>\$9,011</i>	<i>\$12,778</i>	<i>\$16,563</i>	<i>\$17,767</i>	<i>\$1,024,439</i>
<i>Medicaid</i>	<i>16.0%</i>	<i>18.0%</i>	<i>17.9%</i>	<i>18.7%</i>	<i>19.6%</i>
Elementary & Secondary Education	28.3%	26.1%	26.2%	26.1%	22.2%
Higher Education	12.0%	8.0%	9.6%	8.6%	11.3%
Public Assistance	1.6%	1.6%	0.5%	0.7%	2.2%
Corrections	2.8%	2.9%	3.7%	3.5%	3.7%
Transportation	11.5%	8.8%	13.8%	13.8%	8.9%
All other expenses	27.8%	34.5%	28.3%	28.6%	32.1%

Source: CRS calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1992, 1997 and 2001. Data reported are for state fiscal years and include federal funds that are spent by states. Percentages may not sum to 100% due to rounding.

Table 7. State Spending for Medicaid as a Percent of Total State Spending, Indiana and the United States, 1990-2001

State spending	Indiana				All states
	1990	1995	2000	2001	2001
Total state spending (in millions)^a	\$6,813	\$9,392	\$12,241	\$12,822	\$760,419
State Medicaid spending (millions) ^b	\$552	\$861	\$1,118	\$1,271	\$85,141
State Medicaid spending as a percent of total state spending	8.1%	9.2%	9.1%	9.9%	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.

- Total state spending for all spending categories, *excluding* federal funds.
- State spending for Medicaid, *exclusive* of federal funds. For FY1995, includes \$4 million in community residential facilities for the developmentally disabled (CRF/DD) for nursing facilities, and disproportionate share hospital (DSH) payments of \$38.8 million. These funds represented 0.5% and 4.5% of total state funded Medicaid expenditures.

Medicaid Long-Term Care Spending in Indiana

Long-term care spending represented almost one-third of all Medicaid spending in Indiana in FY2001, a decrease from 43.8% in 1990 (see **Table 8**). Institutional care is a significant share of these expenditures at 85.3%.

From 1990-2001, spending for home and community-based services as a proportion of total long-term care spending grew 958.1% (in constant 2001 dollars) to reach 14.7% of long-term care spending in FY2001 (see **Table 9**). The fast rate of growth in Medicaid home and community-based services largely occurred because Indiana did not rely on Medicaid to support these services in 1990. Its use of Medicaid Section 1915(c) home and community-based services waivers is the primary reason for the increase; spending for waiver programs increased by over 700% over the 11 year period. In contrast, institutional care spending grew at a much slower pace — by 38% over the same period (see **Table 9**).

In FY2001, \$1.1 billion, or 27.4% of all Medicaid spending, was for care in institutions; and nursing home spending accounted for almost three-quarters of total institutional spending. In the same year, home and community-based services accounted for 4.7% of all Medicaid spending (see **Table 9**).

Medicaid long-term care financing in Indiana at a glance:

Spending for nursing homes represented 20.1% of total Medicaid spending in FY2001.

Spending for nursing home care grew by 37.8% from FY1990-FY2001, less than the 114.8% increase in total Medicaid spending.

Spending for nursing home care decreased as a percentage of long-term care spending — from 72% in FY1990 to 63% in FY2001. During the same period, the portion spent on ICFs/MR decreased only slightly (from 26% to 23%) of long-term care spending.

In FY2001, 14.7% of Medicaid dollars spent on long-term care was for home and community-based services. Spending increased dramatically from FY1990-FY2001, by 958% (in constant 2001 dollars), primarily due to expanded use of the home and community-based waiver program.

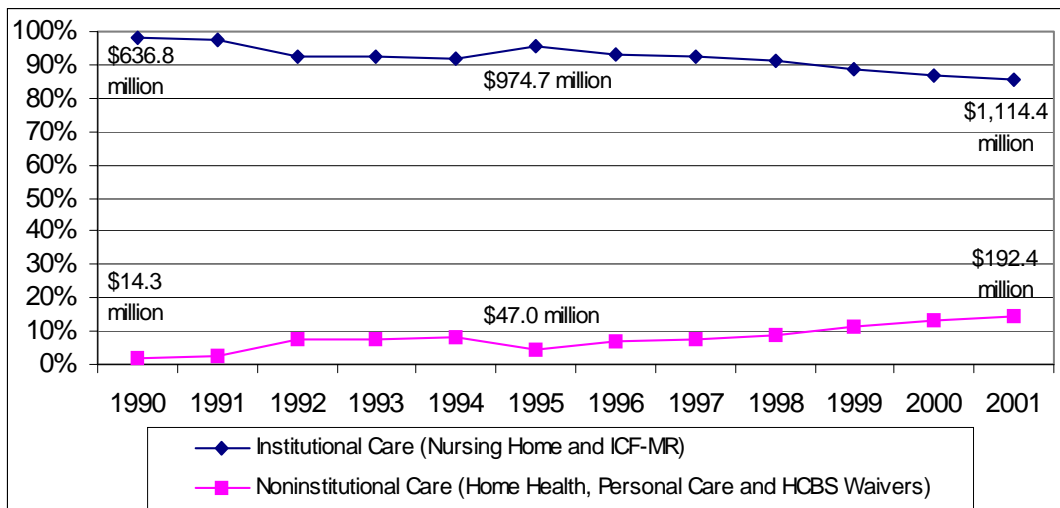
Table 8. Medicaid Long-Term Care Spending in Indiana, FY1990-FY2001

Indiana	1990	1995	2000	2001
Long-term care spending as a percentage of Medicaid spending	43.8%	40.4%	33.9%	32.2%
Institutional care spending as a percentage of long-term care spending	97.8%	95.4%	86.8%	85.3%
Nursing home spending as a percentage of long-term care spending	71.7%	66.9%	65.0%	62.6%
ICF/MR ^a spending as a percentage of long-term care spending	26.2%	28.5%	21.8%	22.7%
Total home and community-based services spending as a percentage of long-term care spending	2.2%	4.6%	13.2%	14.7%
HCBS waivers spending as a percentage of long-term care spending ^b	0	1.4%	9.0%	10.7%

Source: CRS calculations based on CMS/HCFA 64 data provide 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, Jan. 10, 1992. (Hereafter cited as Burwell, *Medicaid Expenditures FY1991-FY2001*.) Total Medicaid spending in 1990 based on HCFA 64 data provided by The Urban Institute, Washington, D.C. Numbers may not sum to 100% due to rounding.

- a. Intermediate care facilities for persons with mental retardation.
- b. For FY1990, amount is less than 0.005%.

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



Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*. Total Medicaid spending for 1990 based on HCFA 64 data provided by Urban Institute, Washington, D.C.

Table 9. Medicaid Spending in Indiana, Total Spending and Long-Term Care Spending by Category and Percent Change, FY1990-FY2001

(dollars in millions)

	1990	1995	2000	2001	Percent change 1990-2001 (in constant 2001 dollars)
Total Medicaid	\$1,486.9	\$2,528.7	\$3,489.9	\$4,061.8	114.8%
Total long term care*	\$651.1	\$1,021.7	\$1,184.5	\$1,306.7	57.9%
Total institutional care	\$636.8	\$974.7	\$1,028.5	\$1,114.4	37.6%
Nursing home services	\$466.5	\$683.5	\$770.0	\$817.5	37.8%
ICF-MR**	\$170.3	\$291.2	\$258.5	\$296.8	37.1%
Total home and community-based services	\$14.3	\$47.0	\$156.0	\$192.4	958.1%
Home health	\$14.1	\$33.0	\$48.7	\$51.9	189.8%
Personal care	\$0.0	\$0.0	\$0.3	\$0.0***	—
HCBS waivers	\$0.2	\$14.0	\$107.0	\$140.5	701.5%

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

Note: Actual dollars in millions. Percent change calculated using constant dollars.

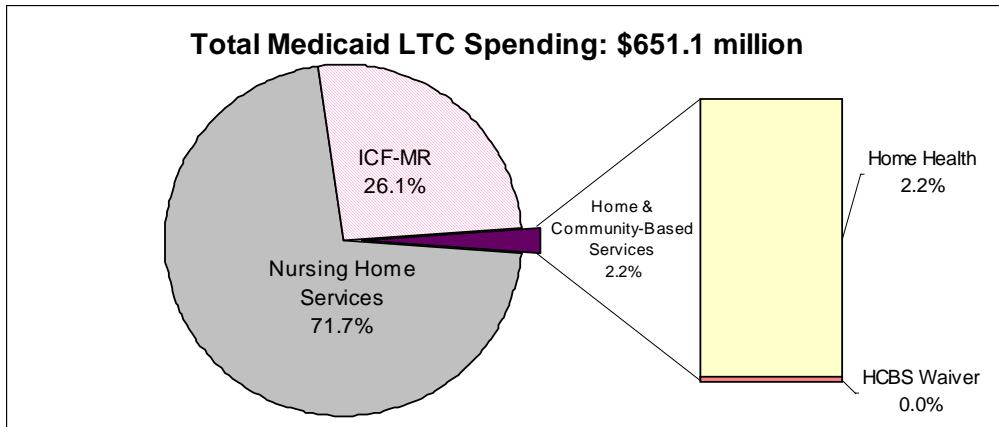
* Long Term Care includes only Medicaid LTC spending — neither private pay, Medicare, nor state programs are included.

**ICF-MR stands for Intermediate Care Facility for the Mentally Retarded.

***Actual expenditure is \$12,175.

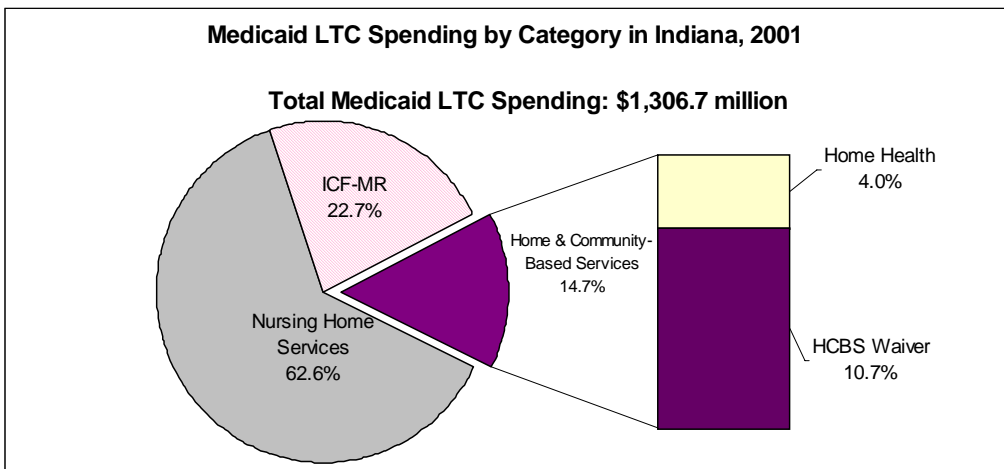
Figures 3 and 4 depict changes in long-term care spending patterns from FY1990-FY2001. In FY1990, over one-quarter of Medicaid long-term care spending was devoted to care for persons with developmental disabilities in ICFs/MR; the figure decreased only slightly to 22.7% in FY2001. The proportion of spending on nursing home services declined during that time period from 71.7% to 62.6%. Spending on home and community services increased from 2.2% to 14.7% of long-term care expenditures, primarily due to the expansion of Section 1915(c) waivers. Not included in these amounts, however, is funding for the state-funded CHOICE program, which accounted for \$38.8 million in SFY2001 (and \$34.3 million in SFY2002).

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



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

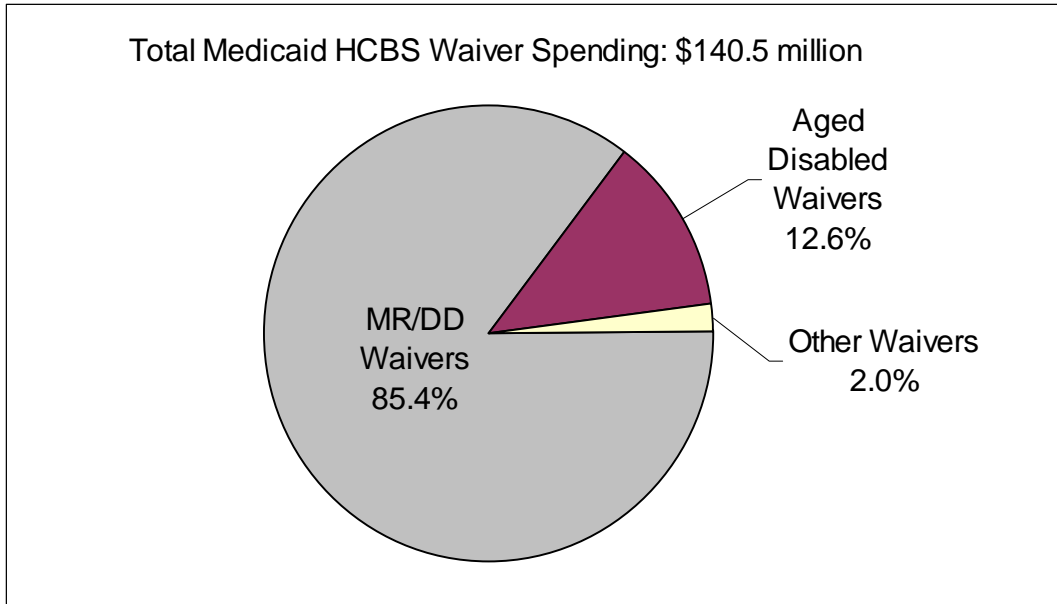
Figure 4. Medicaid Long-Term Care Spending in Indiana by Category, FY2001



Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*. Percentages may not sum due to rounding.

Increased funding for Section 1915(c) waiver services does not affect all populations equally. In FY2001, 12.6% of waiver spending in Indiana was devoted to services for the elderly and other adults with physical disabilities; services for persons with mental retardation and developmental disabilities accounted for 85.4% of waiver spending in FY2001 (see **Figure 5**).

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



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

Issues in Long-Term Care in Indiana

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

Institutional Bias. Most interviewees indicated their belief that the state has an institutional bias toward care in nursing facilities for frail older persons and younger adults with disabilities. In response, the state has taken several steps to increase use of home and community-based services. The state has expanded the number of slots in several Medicaid Section 1915(c) waivers. In addition, in 2002, Governor O'Bannon's administration received a Systems Change grant from the Department of Health and Human Services to create the Governor's Commission on Home and Community Based Care to increase opportunities for persons with disabilities to live in the community. Methods to be examined include increased housing and transportation options, initiation of projects to allow persons to direct their own care, and ways to train and retain caregivers.

Labor Issues. Most interviewees agreed that all long-term care providers face a labor shortage that is affecting quality of care — some people do not receive services in the community and continuity of care is affected in nursing homes. The shortage involves licensed nurses in addition to paraprofessional workers. The labor shortage appears to be worse in rural areas. A labor shortage of a different sort occurs among state and local officials. As in other states, programs have grown in scope without concomitant increases in funding for the staff needed to administer them.

Consumer Direction. The state has established pilot programs under the state-funded CHOICE program to test consumer-directed personal assistance services but the programs faltered because only a few area agencies on aging participated. Interviewees attributed this reluctance to confusion about who is considered the employer of the personal assistant and how taxes should be withheld.²³ In 2001, the legislature enacted a provision to provide CHOICE and waiver beneficiaries the opportunity to recruit, hire, pay, supervise, and dismiss a personal services attendant.

Housing and Transportation. Interviewees view lack of affordable housing and convenient transportation as major barriers to assist persons with disabilities to remain in the community. Housing issues include (1) able-bodied people occupying accessible housing that is designed for persons with disabilities and (2) the CHOICE program limiting its home adaptations to one home with a \$5,000 lifetime limit. Transportation problems are exemplified by the situation in Indianapolis where accessible buses cover only part of the city or some routes operate only once a day, making going to work difficult, if not impossible, for persons with disabilities.

Quality Assurance Issues. Indiana has had quality problems in its Section 1915(c) home and community-based services waivers for persons with developmental disabilities. As a result, the state replaced its former waiver with a new one and implemented new quality assurance mechanisms, including use of routine, independent audits.

Licensure standards for assisted living facilities have been a source of controversy. Draft regulations were controversial because they would have required discharge of residents if they had certain medical conditions or needed regular assistance with two or more ADLs. At the time of the site visit (summer 2002), the Department of Health was rewriting regulations to require facilities that provide services themselves to obtain licensure but this would not be necessary if the facilities hired an agency to deliver services in the facility.

Waiting Lists. The state-funded CHOICE program had a waiting list of 8,577 people in SFY2002, a decrease from 11,922 in SFY2001.²⁴ Some interviewees said that the number of persons on the waiting list may not be a good indication of who needs services, because some people join the list before they really need care. Other

²³ For further information on consumer direction in long-term care, see CRS Report RL32219, *Long-Term Care: Consumer-Directed Services Under Medicaid*, by Karen Tritz.

²⁴ Indiana Family and Social Services Administration. *Statewide IN-Home Services 2002 Annual Report, July 1, 2001-June 20, 2002*. Indianapolis, IN, 2002.

interviewees said that the top three ways of getting off the list are, in order, to die, go into a nursing home, or to receive services, generally after a wait of 3.5 to 4 years. The state also had a long waiting list for its Aged and Disabled Waiver, despite the fact that it has many available waiver slots. Slots remain unused because the state has not appropriated sufficient funds to fill them.

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

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons served/slots approved, SFY2002	Annual cost cap (aggregate/individual) SFY2002	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/resource limits	Determined by					
Aged and Disabled Waiver Medicaid 1915 (c) waiver Began in 1990 and was preceded by another waiver in 1984	Persons aged 65 years and older and adults with disabilities	Nursing facility level of care People must have difficulty with 3 of 14 ADLs.	Area agencies on aging	100% of SSI income limit/ \$1,500 asset limit for an individual	FSSA county offices	Adaptive aids & devices; adult day services; attendant care; case management; home-delivered meals; home modifications; homemaker; respite care	3,154 persons served/3,300 slots approved \$117 a day aggregate cap Average cost per month, \$644 (weighted monthly average based on participation and length of service)	Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning	

Sources: Bureau of Aging and In Home Services Annual Report 2002, Indianapolis, IN, 2002.

SSI — Supplemental Security Income

FSSA — Family and Social Services Administration

ADLs — Activities of Daily Living

MR — Mental Retardation

DD — Developmental Disabilities

IFC — Intermediate Care Facilities

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved, SFY2002	Annual cost cap (aggregate individual) SFY2002	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Traumatic Brain Injury Waiver Medicaid 1915(c) waiver Initiated in March 2000	People who have suffered injuries to the brain	Nursing facility level of care	Office of Medicaid Policy and Planning	100% of SSI income limit/ \$1,500 asset limit for an individual	FSSA county offices	Adult companion services; case management; environmental modifications; occupational therapy; personal care; personal emergency response systems; physical therapy; residential care/community residential services; respite care; speech/hearing/language therapy; habilitation including behavior counseling and training independent living skills training; pre-vocational services; structured day program; supported employment	146 persons served/200 slots approved	Aggregate \$112 a day Average cost per month, \$1,589 (weighted monthly average based on participation and length of service)	Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning

Sources: Bureau of Aging and In Home Services Annual Report 2002, Indianapolis IN, 2002.

SSI — Supplemental Security Income
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FSSA — Family and Social Services Administration
 DD — Developmental Disabilities

ADL — Activities of Daily Living
 IFC — Intermediate Care Facilities

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved in SFY2002	Annual cost cap (aggregate individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/resource limits	Determined by					
Assisted Living Waiver Medicaid 1915(c) waiver Approved in 2001	Persons with disabilities aged 18 and over	Nursing facility level of care	Office of Medicaid Policy and Planning	100% of SSI income limit/\$1,500 asset limit for an individual	FSSA county offices	Case management; assisted living	Seven persons served Approved slots: 350 in first year; 1,050 in second year; and 2,250 in the third year	Average cost per month, \$1,177 (weighted monthly average based on participation and length of service)	Office of Medicaid Policy Planning	Office of Medicaid Policy and Planning

Sources: Bureau of Aging and In Home Services Annual Report 2002, Indianapolis, IN, 2002.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved in SFY2002	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Community and Home Options to Institutional Care for Elderly and Individuals with Disabilities (CHOICE) State-funded. CHOICE is funding of last resort after Medicaid Began in 1987	Persons age 60 and over, or of any age with disabilities	People must be unable to perform two of 14 ADLs and IADLs	Area agencies on aging	None but persons with incomes above 150% of the federal poverty level pay cost sharing on a sliding scale Persons with incomes at or above 351% of poverty to pay the full cost of services	Area agencies on aging	Case management; home health supplies and services; attendant care; homemaker; respite; meals; adult day care; transportation; other necessary services	12,728 persons served	Not applicable Spending was \$34.3 million in SFY2002	Bureau of Aging and IN-home services	Bureau of Aging and IN-home services

Sources: Bureau of Aging and In Home Services Annual Report 2002, Indianapolis Indiana, 2002.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved in SFY2002	Annual cost cap (aggregate individual)	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/resource limits	Determined by					
Residential Care Assistance Program (RCAP) State funded Began in 1975	Persons aged 65 and older or younger persons with disabilities	Persons who cannot live independently but who do not need care in a nursing facility	FSSA County offices	Income must be less than the residential care facility rate	FSSA county office	Pays for facility charges exceeding residents' income; provides residents a personal needs allowance	1,411 residents served	Not applicable. State spending was \$9.6 million	FSSA	FSSA

Sources: Bureau of Aging and In Home Services Annual Report 2002, Indianapolis Indiana, 2002.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved, SFY2002	Annual cost cap (aggregate individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Developmental Disabilities Waiver Medicaid 1915(c) waiver Initiated in 2001 (formerly the Intermediate Care Facility for the Mentally Retarded Waiver, which began in 1992)	Persons with mental retardation/ developmental disabilities	ICF/MR level of care	Office of Medicaid Policy and Planning and Bureau of Developmental Disabilities Services	300% of SSI income/ \$1,500 asset limit for an individual	FSSA County Offices	Residential habilitation and support; community habilitation and participation; respite care; adult day services; pre-vocational services; supported employment services; health care coordination; family & caregiver training; physical therapy; occupational therapy; speech/language therapy; recreational therapy; music therapy; psychological therapy; nutritional counseling; enhanced dental services; behavior management/crisis intervention; environmental modifications; specialized medical equipment & supplies; personal emergency response systems; transportation; rent & food expenses of an unrelated live-in caregiver	3,432 served/4,816 slots approved	Average monthly Medicaid waiver cost, \$3,677 SFY2002	Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning

Sources: Bureau of Aging and In Home Services Annual Report 2001, Indianapolis, IN, 2001 and telephone interviews.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved, SFY2002	Cost cap (aggregate individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/resource limits	Determined by					
Support Services Waiver 1915 (c) Initiated in April 2002	Persons with developmental disabilities	ICF/MR level of care	Office of Medicaid Policy and Planning and Bureau of Developmental Disabilities Services	300% of SSI/\$1,500 asset limit for an individual	FSSA county offices	Provides an annual allowances for services. Rent & food;community habilitation & participation; respite care; adult day services; pre-vocational services; supported employment; health care coordination; family and caregiver training; physical therapy; occupational therapy; speech/language therapy; recreational therapy; music therapy; psychological therapy; nutritional counseling; enhanced dental services; behavioral management/crisis intervention; specialized medical equipment & supplies; personal emergency response systems; transportation	486 persons served/2,333 slots approved	Average cost per month, \$1,125 SFY2002	Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning

Sources: Olmstead Real Choices Narrative downloaded from [<http://www.in.gov/fssa/servicedisabl/olmstead/realnar.html>] on Feb. 1, 2002.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved, SFY2002	Cost cap (aggregate individual)	Admin. Oversight	Financial oversight
		Criteria	Determined by	Income/resource limits	Determined by					
Autism Waiver Medicaid 1915(c) waiver Initiated in 1990	Persons with a diagnosis of autism	ICF/MR level of care	Office of Medicaid Policy and Planning and Bureau of Developmental Disabilities Services	300% of SSI/\$1,500 asset limit for an individual	FSSA county offices	Personal assistance, residential-based habilitation, respite care, adult day services, pre-vocational services, supported employment services, family & caregiver training, adult day habilitation, physical therapy, occupational therapy, speech/language therapy, behavioral management/crisis intervention, applied behavior analysis, environmental modifications, assistive technology, personal emergency response systems, supported living services, transportation	243 persons served/400 slots approved	Average cost per month per individual, \$2,788 SFY2002	Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning

Sources: Bureau of Aging and In Home Services Annual Report 2001, Indianapolis, IN, 2001.

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

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 (\$)
Central State Hospital (Indianapolis)	1848	1995	—	—
Evansville State Hospital (Evansville)	1890	—	41 ^a	216.14 ^a
Fort Wayne Developmental Center (Fort Wayne)	1890	—	324	338.76
Logansport State Hospital (Logansport)	1888	—	46	287.11
Madison State Hospital (Madison)	1910	—	78	268.10
(Butlerville)	1920	2003	258	380.00
New Castle Ctr. (New Castle)	1907	1998	—	—
Norman Beatty Memorial Hospital (Westville)	1951	1979	—	—
Northern Indiana Ctr. (South Bend)	1961	1998	—	—
Richmond State Hospital (Richmond)	1890	—	35	268.00
Silvercrest State Hospital (New Albany)	1974	1995	—	—

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.

a. FY2000 data.

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, Population Projections for States by Age, Sex, Race, and Hispanic Origin: 1995 to 2025, 1996, U.S. Bureau of the Census, Population Division, PPL-47. For detailed explanation of the methodology, see [<http://www.census.gov/population/www/projections/ppl47.html>].

Additional Reading

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