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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: Florida

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Home and Community-Based Services – States Seek to Change the Face of Long-Term Care: Florida

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 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 long-term care spending. By far, the primary payer for long-term care is the federal-state Medicaid program, which in 2001 paid for almost half of all long-term care spending.

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. 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 in a series of ten state reports, presents background and analysis about long-term care in Florida.

Florida has the largest proportion of elderly in the nation– 2.8 million persons are over age 65, representing 17.6% of its total population. The dramatic rise in the number of persons age 65 and over in Florida over the next 20 years–estimated to total 26.3% of total population–will further stretch the already limited resources of the state. Aware of the pressing demand for long-term care services well into the 21st century, policymakers in Florida have begun seriously to review options for improving financing and delivery of long-term care for the frail elderly and persons with disabilities.

Federal and state Medicaid spending in Florida was $2.6 billion in FY2001, and 30.5% of Medicaid spending was for long-term care. In FY2001, 75.3% of total Medicaid spending was for institutional care. Slightly less than 25% of Medicaid spending was channeled towards home and community-based services. Although institutional care dominated Medicaid spending, there has been slow but steady expansion of home and community-based services funding, both through the use of Medicaid's waiver programs as well as significant support through state sources.

Among the major issues facing long-term care in Florida are: the fragmentation of long-term care services among state and local agencies, an imbalance in financing that favors institutional care rather than home and community based care, shortage of health care workers and well-trained staff throughout the long-term care continuum, and disparities in availability of services across the state.

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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 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 ten 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 Florida. Reports on the other nine states and an overview report will be available during 2003.

Home and Community-Based Services – States Seek to Change the Face of Long-Term Care: Florida

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 eliminated the distinction between skilled nursing facilities and intermediate care facilities (effective in 1990). As a result of these various amendments, people

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

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 in community settings, rather than in institutions. However, it was not until 1981 that

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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 referred to 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.

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 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 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 Florida

With its warm climate and low taxes Florida has attracted growing numbers of elderly. Compared to other states Florida has the highest percentage of elders in its population. Aware of the challenges facing the state, policymakers have started to take a serious look at options for improving the financing and delivery of long-term care services in the state.

Florida's long-term care system is complex. The Long-Term Care Policy Advisory Council succinctly described this complexity in its report to the Governor and the State Legislature: " we have often heard the analogy that Florida's long-term care delivery system is like an onion, having many layers.... The issues are not just layer upon layer but they also have dimension. The mathematical term is "fractal," meaning the closer one looks at a problem the more complex it becomes."[6]

Navigating through this complex web of services, multiple agencies, and numerous waivers is no easy task for an individual or family caregiver looking for long-term care services. Over the past several years Florida has begun to document these challenges and find ways to mitigate these issues and work toward the goal of a seamless long-term care system in the state.

Summary Overview[7]

Demographic Trends

- There are more than 2.8 million people age 65 and older in Florida representing 17.6% of its population. Its population age 85 and over, the group with greatest need for long-term services, numbers over 330,000, ranking it 4th highest in the nation.
- By 2025, Florida's age 65 and over population will exceed one-quarter (26.3%) of its total population compared to 18.5% nationally.

Administration of Long-Term Care Programs

- There are a number of state agencies involved in the delivery of long-term care services in Florida. According to state officials, coordination among these agencies is complex and time consuming. Recent legislation created an Office of Long-Term Care Policy in the

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[6] Report of the Long-Term Care Policy Advisory Council, *Report to Governor Jeb Bush and the 2003 Florida Legislature*, p. 1, Feb. 1, 2003.

[7] Information based on Florida 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 (MR/DD).

Department of Elder Affairs (DOEA) to coordinate the various agencies responsible for the implementation and delivery of long-term care services in the state.
- Florida has no single point of entry into the long-term care system across all populations. However, the Comprehensive Assessment Review and Evaluation System for Long-Term Care Services (CARES) program serves as a entry point for people over 21 years of age applying for Medicaid nursing home services and community-based services.

Trends in Institutional Care

- There are 734 nursing homes with about 84,000 beds in Florida. The state has a lower bed capacity than the nation as a whole. The number of beds per 1,000 persons age 65 and older is about 30 compared to the national average of 53 beds.
- The number of persons with mental retardation and developmental disabilities (MR/DD) residing in large state institutions in Florida has declined over the years partly as a result of litigation. Persons living in large institutions serving 16 or more persons declined from 35% of all persons living with MR/DD in group residencies in 1990 to 27% in 2000.
- Due to a strong and vocal disability advocacy community in the state, Governor Bush has personally devoted a great deal of attention to addressing the issues faced by the developmental disabilities community. The Governor has established a committee to redesign the developmental disabilities program, including plans to develop a single point of entry and a new client assessment tool.

Trends in Home and Community-Based Care

- Florida administers a wide range of home and community-based long-term care services for the frail elderly and for those with MR/DD. The state has 11[8] Medicaid Section 1915(c) waiver programs that target specific populations groups with specific eligibility criteria making it a complicated process for someone applying for services to navigate through the system.
- There are several pilot and demonstration programs such a Social Health Maintenance model (S/HMO), and Program of All-inclusive Care for the Elderly (PACE), among others. These programs are intended to find cost-effective ways of providing care for people in their own homes and communities.

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[8] One of the 11 Medicaid Section 1915(c) home and community-based waiver programs covers children with certain medical conditions; this waiver is outside the scope of this report.

Long-Term Care Spending

- Long-term care comprises a significant portion of Medicaid spending in Florida – almost 31% of all Medicaid spending was devoted to long-term care in FY2001. Nursing home spending represented almost two-thirds of total Medicaid long-term care spending.
- In FY2001, Florida spent $551 million on Medicaid Section 1915(c) home and community-based waiver programs, twelve times the amount spent in 1990 even after adjusting for inflation.
- According to consumer advocates, most of the public spending for long-term care for the elderly has been for nursing homes, and there has been significantly less emphasis on home and community-based services. However, the opposite is true for the developmental disabilities programs, where there has a been a large increase in public funds for supporting home and community-based care. Both state and federal funding for developmental services increased 94% from $502.8 million in 1998 to $975 million in 2002.

Issues in Financing and Delivery of Long-Term Care

- Fragmentation of services at all levels and across all agencies is a significant problem according to state officials. There are many instances where three or four agencies are responsible for portions of a single program. According to state documents, fragmentation in the delivery system creates unnecessary delays in delivery of services.
- Florida has eleven discrete Medicaid waiver programs, each covering discrete populations, which has led to a categorical approach to service delivery to the frail elderly and the disabled, and those with mental retardation and developmental disabilities. While the waiver programs have expanded opportunities for home and community-based services, according to state officials and stake-holders, having several waivers covering different populations with different sets of eligibility criteria has further complicated access to services.
- A recurring theme discussed by state officials is the view that the federal financing system under Medicaid guarantees heavy use of institutional care. This is largely due to the fact that nursing facility care is an entitlement under Medicaid for persons needing such care who meet its eligibility criteria whereas home and community-based services is not.
- According to state officials and consumer advocates, consumers in Florida do not have access to a single source of information about long-term care. Creating a statewide system that is consumer friendly has been challenging to state administrators.

Background

Demographic Trends

With almost 16 million people, Florida has the fourth largest population in the nation. It has the largest proportion of the elderly in the nation. Its population age 65 and older – 2.8 million persons in 2000 – represents 17.6% of its total population **(Table 1)**. Additionally, there are more than 710,000 noninstitutionalized Floridians 65 and older living alone – another group that has a high need for formal long-term care services. According to the 2000 U.S. Census, during the period 1990-2000 Florida's 65 and older population grew by 18.5%, compared to 12% for the rest of the United States. The 85 and over population, those with the greatest need for long-term care services, grew by more than 57% between 1990 and 2000 – from 210,110 to 331,287 **(Table 1)**.

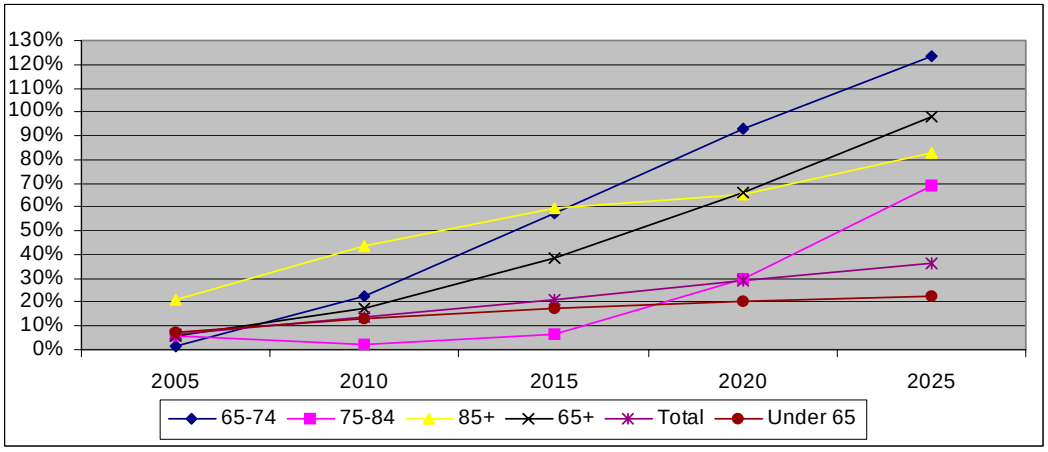
Table 1. Florida Population Age 65 and Older, 1990 and 2000

Age	1990		2000		% change 1990-2000	2000 population rank in U.S. (based on percent)
	Number	% of total population	Number	% of total population		
65+	2,369,431	18.3%	2,807,597	17.6%	18.5%	1
65-74	1,369,652	10.6%	1,452,176	9.1%	6.0%	1
75-84	789,669	6.1%	1,024,134	6.4%	29.7%	1
85+	210,110	1.6%	331,287	2.1%	57.7%	4
Under 65	10,568,495	81.7%	13,174,781	82.4%	24.7%	51
Total	12,937,926	100%	15,982,378	100%	23.5%	4

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

Additionally, the elderly population is predicted to grow significantly in the coming decades, and will considerably outpace the growth of the rest of the population. By 2025, Florida's 65 and over population will exceed one-quarter (26.3%) (**Table 2**) of its total population compared to 18.5% nationally, and its older population (85 and over) will grow to 3%, as compared to 2.2% of the overall U.S. over 85 population (see **Table 2**).

Figure 1. Percentage Population Increase Over 2000 in Florida



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 Populations Projections: Every Fifth Year.

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

Age	Percent of total population, Florida	Percent of total population, United States
65+	26.3%	18.5%
65-74	14.9%	10.5%
75-84	8.4%	5.8%
85+	3.0%	2.2%
Under 65 population	73.7%	81.5%

Source: CRS calculations from Census projections released in 1996. See Appendix 2 for information about the projections, their methodology and their limitations.

Need for Long-Term Care

The number of people needing assistance with Activities of Daily Living (ADL)[9] will have a profound effect on the need for long-term care. According to estimates derived by combining data generated by The Lewin Group, and 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, significant trends emerge concerning the need for long-term care in Florida. Persons age 65 and over with two or more limitations in ADLs are estimated to increase 15% from 2002 to 2010, while those individuals aged 85 and older with two or more limitations in ADLs are estimated to increase by 32% (**Table 3**). Elderly population growth as projected, coupled with increasing need for assistance, will place greater demands on public and private long-term care resources in Florida.

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

	2002			2005			2010		
Percent of Poverty	**Persons with 2+ ADLs by age and income**								
	18-64	**65+**	**85+**	**18-64**	**65+**	**85+**	**18-64**	**65+**	**85+**
Up to 100%	10,982	13,459	2,895	11,577	14,083	3,234	12,417	15,442	3,830
Up to 150%	17,029	33,197	9,301	17,950	34,942	10,391	19,254	38,343	12,306
Up to 200%	22,331	47,585	13,327	23,539	50,084	14,890	25,248	55,002	17,633
All income	45,104	98,210	27,577	47,544	103,386	30,810	50,992	113,247	36,487

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

State Initiatives to Study Florida's Long-Term Care System

Florida has taken many initiatives to study the long-term care system in the state and to find options to remedy perceived deficiencies in the system. To this end, the State Legislature in 1994 established The Commission on Long-Term Care in Florida under the chairmanship of former state Senator Curtis Kiser. Moreover, during the 2000 session, the Legislature created the Task Force on Availability and Affordability of Long-Term Care under the chairmanship of Lieutenant Governor

[9] These include self-care tasks such as bathing, dressing, eating, toileting and transferring from a bed to a chair.

Frank T. Brogan. As a result of the recommendations made by the Brogan Commission, during the 2002 legislative session the State Legislature passed Senate Bill 1276 establishing the Office of Long-Term Care Policy to be situated in the Department of Elder Affairs. This office is intended to play a major role in coordinating all state agencies' policies with regard to long-term care in the state. Below is a brief description of the Kiser Commission, the Brogan Commission, and the Office of Long-Term Care Policy.

The Commission on Long-Term Care in Florida (The Kiser Commission). The Commission was created by Florida's Legislature in the 1994-1995 General Appropriation Act and was active during 1995-1997. The Commission was tasked with studying the programming and financing of long-term care in Florida and developing a framework for long-term care planning for the state.[10] The Kiser Commission called for a "complete redesign"of Florida's long-term care system, including integrating acute and long-term care systems through the use of federal waivers, creating a managed long-term care system, and encouraging individual financing of long-term care, among other things.[11]

As a result of the work of this Commission, significant changes took place in the long-term care system in the state. The State Legislature consolidated parts of the long-term care system, and made uniform many regulations that affect providers of long-term care. For instance, Florida's Legislature passed HB 1675, which resulted in the Department of Elder Affairs (DOEA) gaining responsibility for coordinating long-term care policies among executive branch agencies in the state. Furthermore, in 1995 the Legislature reallocated rule-writing authority to DOEA for assisted living facilities, adult foster homes, and adult day care facilities.

The Task Force on Availability and Affordability of Long-Term Care (The Brogan Commission). The Brogan Commission was established by the State Legislature during the 2000 session. The Commission was tasked with assessing the long-term care system in the state including quality of care, alternatives to nursing homes, impact of lawsuits against nursing homes, and the financial stability of the long-term care industry in the state among other things.[12] The guiding principal of the Task Force that shaped its discussions and recommendations was to provide reasonable access to care in the least restrictive environment, and to provide adequate protection under the law.

When the Task Force convened to make final recommendations to the Legislature prior to the 2001 session, members could not reach a consensus on recommendations and voted not to submit recommendations to the State Legislature as they were originally charged to do. However, in consultation with the Florida Policy Exchange Center on Aging at the University of South Florida, the Task Force published an informational report, which included analysis of the tort reform issue

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[10] The Commission on Long Term Care in Florida, *Managing Florida's Future*, mission statement p. 1, Dec. 15,1995.

[11] Report of the Long-Term Care Policy Advisory Council, *Report to Governor Jeb Bush and the 2003 Florida Legislature*, p. 1, Feb. 1, 2003.

[12] The Florida Senate, *Interim Project Report 2002-025*, p. 5, Feb. 2001.

relating to limiting lawsuits and punitive damages against nursing homes, as well as the availability of liability insurance for the industry. As a result of this informational report, the State Legislature passed legislation that implemented improvement of nursing home staffing standards, increased sanctions for regulatory violations by nursing homes, and enhanced nursing home staff training programs.

Florida Office of Long-Term Care Policy. The Office of Long-Term Care Policy grew out of the need to have a coordinated planning structure for the long-term care system in the state. In 2002, the Florida State Legislature established by statute (SB 1276) an Office of Long-Term Care Policy within the Department of Elder Affairs. The major function of the office is to ensure close communication and coordination among state agencies that develop and administer long-term care services in order to ensure a more efficient and coordinated long-term-care service delivery system. Additionally, the office is charged with identifying duplication and unnecessary services in the long-term-care system, making recommendations to eliminate inappropriate service provision, and developing strategies for promoting and implementing cost-effective home and community–based services as an alternative to institutional care.

In September 2002, the Long-Term Care Policy Advisory Council in the Office of Long-Term Care Policy commenced its work. The Council met several times, heard presentations by experts, held public hearings, and discussed the long-term care system in Florida. On February 1, 2003, the Council issued a report to the Governor and State Legislature on these deliberations and proposed an outline for the future work of the Council. The Long-Term Care Policy Advisory Council decided to focus on four broad policy areas. These are: access, coordination/integration of services, quality/evaluation of services, and financing/resources.[13]

Administration of Long-Term Care Programs

State Administration

At the state level planning and administration of long-term care services for the elderly and persons with disabilities are shared among many agencies. **Figure 2** displays an organization chart of state and local agencies with responsibilities for administration of long-term care.

Department of Elder Affairs (DOEA). The Department was established in 1991 in response to a 1988 general election constitutional referendum calling for the creation of a state agency focused on the needs of the elderly.[14] It is the primary agency for administering home and community-based service programs for the elderly, and it has responsibility for overseeing both federal and state funds appropriated for aging programs. The Department implements a wide range of programs for the elderly including: Medicaid Section 1915(c) home and community-

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[13] Report of the Long-Term Care Policy Advisory Council, *Report to Governor Jeb Bush and the 2003 Florida Legislature*, p. 1, Feb. 1, 2003.

[14] The Florida Senate, *Interim Project Report 2001-005*, Nov. 2000.

based waivers, Assisted Living for the Elderly, Aged and Disabled Adult waivers, a Consumer-Directed Care Project, and Older Americans Act programs, among others. Moreover, the Department has rulemaking authority for the Ombudsman program which has oversight for assisted living facilities, adult family care homes, and hospice programs.

Additionally, the Department staff is responsible for administering the Comprehensive Assessment Review and Evaluation System for Long-Term Care Services (CARES) tool.[15] The program staff is tasked with determining functional eligibility of persons who need nursing home and community-based services. The Department also oversees the eleven area agencies on aging established by the Older Americans Act (OAA). The area agencies administer funds locally and contract with a variety of provider agencies to offer a wide array of services designed to meet the needs of their senior constituencies.

Agency for Health Care Administration (AHCA). The Agency was created by the Florida Legislature as part of the Health Care Reform Act of 1992. It is the chief health policy entity for the state. The Agency is primarily responsible for administering Florida's Medicaid program and also determines the state's need for nursing homes (Certificate of Need for nursing homes). Before determining if there is a need for a new bed, AHCA must determine that the need cannot be met through provision, enhancement or expansion of home and community-based services. AHCA is also responsible for licensure and regulation of hospitals, medical clinics, and home health agencies, and nursing facilities. AHCA has financial and policy oversight for Medicaid's Section 1915(c) home and community-based waivers and is entrusted with the authority for reimbursing Medicaid service providers.

Department of Children and Families (DCF). The Department is responsible for determining financial eligibility for all Medicaid applicants. Additionally, DCF is responsible for the determination of functional eligibility for all participants in the Developmental Services [Section 1915 (c)] waiver regardless of age. The Department administers several programs for persons with developmental disabilities, through offices in 13 service districts and one region.

Department of Health (DOH). Established in 1889, Florida's Department of Health is one of the oldest state agencies. The Department is responsible for administering the AIDS waiver, and the Traumatic Brain and Spinal Cord Injury program (described elsewhere in this report). Additionally, DOH administers the Children's Medical Services Program, which provides home and community – based services for children who have chronic and life threatening diseases or who are

[15] CARES provides on-site assessment for all individuals age 21 and older applying for Medicaid nursing facility services and certain home and community-based services (further information provided in the next section).

fragile and have medical complications. DOH is also responsible for licensure of medical professionals.

State Administration of Long-Term Care at A Glance

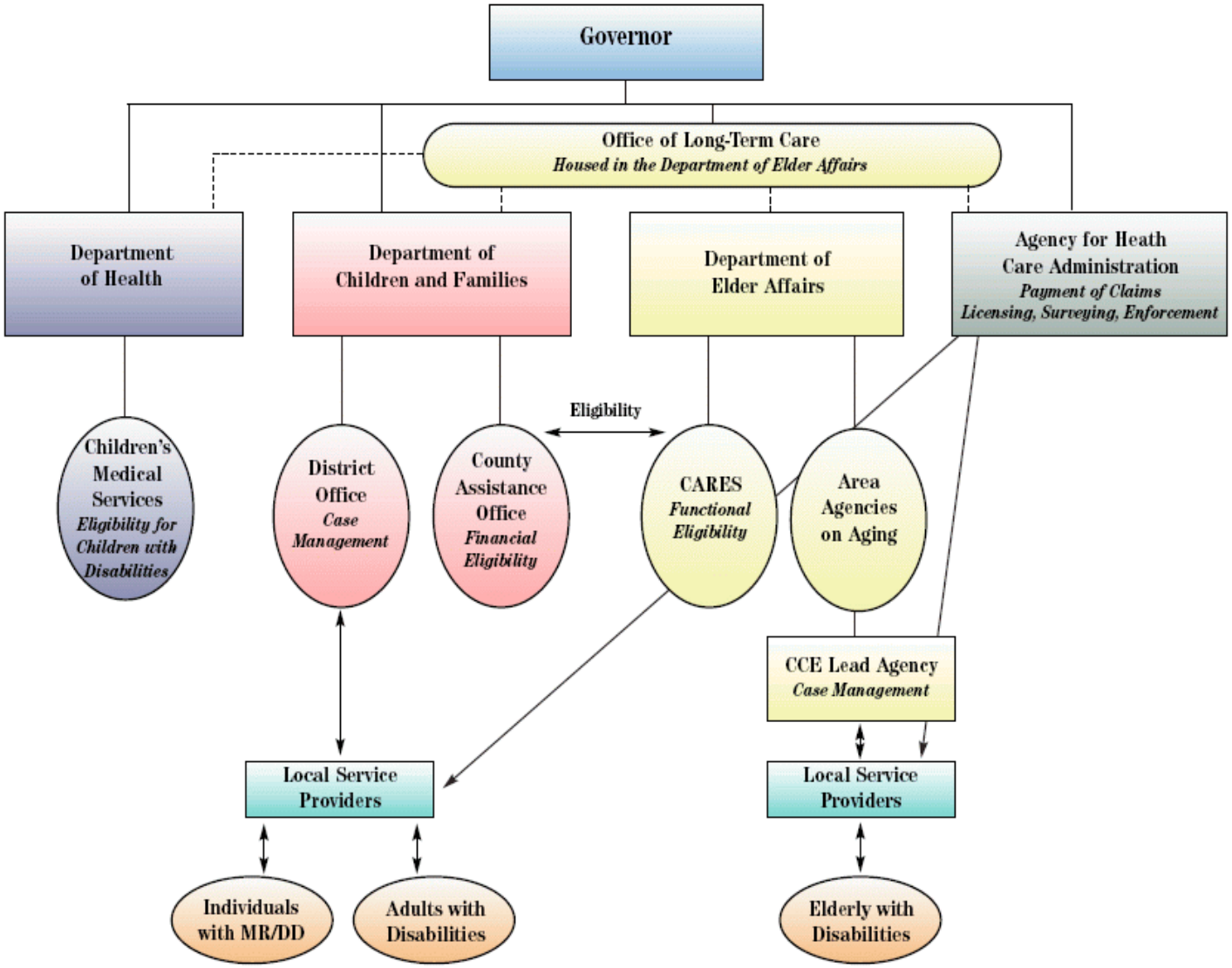
- ***Department of Elder Affairs (DOEA)*** – Administers the nursing home pre-admission screening (CARES) program, contracts out services and monitors home and community-based services for the elderly. Trains Assisted Living Facility and Adult Family Care Home administrators and staff. Has rule writing authority for assisted living facilities, adult day care and adult family care homes. Serves as Ombudsman for assisted living facilities, nursing homes, and family care homes.

- ***Agency for Health Care Administration (AHCA)*** – Administers the state Medicaid program. Issues licences and regulates nursing facilities, assisted living facilities, and family care homes. Pays Medicaid claims to service providers. Administers the Certificate of Need (CON) program for nursing homes among other things.

- ***Department of Children and Families (DCF)*** – Determines financial eligibility for all Medicaid services. Administers the Developmental Disabilities (DD) waiver, and determines functional eligibility for DD waiver services.

- ***Department of Health (DOH)*** – Administers the Traumatic and Spinal Cord Injury program, and the AIDS waiver, that provides home and community-based services for people with HIV or AIDS. DOH also regulates medical equipment, and issues medical licenses to service providers.

Figure 2. Florida Long-Term Care System



Source: Prepared by CRS based on Florida documents.

Responsibility for Functional and Financial Eligibility Determinations

Functional eligibility for those applying for long-term care services is determined by Department of Elder Affairs (DOEA) staff. Assessment staff are housed in the Comprehensive Assessment Review and Evaluation System for Long-Term Care Services (CARES) assessment units spread throughout the state.

The CARES program was initiated by the Florida Legislature in 1980. The intent in creating the program was to verify that those applying for Medicaid nursing home assistance actually required nursing home care rather than less expensive community-based care.[16] The first CARES program was a pilot begun in March 1982 in the Jacksonville, St. Petersburg, and Miami areas.[17] By 1986 the State Legislature determined that CARES had demonstrated its cost effectiveness and approved its expansion statewide. Prior to the creation of the Department of Elder Affairs (DOEA) in 1992, the CARES program was housed in the Department of Health and Rehabilitative Services.[18] In 1995, the CARES program was transferred to DOEA to better coordinate the pre-admission screening program. Over the years the role of CARES has been expanded beyond the pre-admission certification for nursing homes.[19] DOEA has day-to day operational responsibility for the program through an interagency agreement with the Agency for Health Care Administration(ACHA). AHCA monitors statewide CARES activities through annual programmatic and administrative reviews.

There are 17 CARES units in district offices throughout Florida. The program conducts a significant number of assessments of Medicaid eligible persons at risk for nursing home care and makes referrals to alternative care in a community-based setting. CARES provides on-site assessment of nursing facility applicants by a registered nurse and/or a social worker. The assessment evaluates the emotional, medical, psychosocial condition as well as limitations in activities of daily living (ADLs) of the individual. The goal of CARES is to place the applicant in the least restrictive, most appropriate setting with emphasis on community placement. Following the assessment, interdisciplinary staff including a physician determine the placement level of care (LOC) needed. All individuals aged 21 and older applying for Medicaid nursing facility services and home and community-based services must receive CARES assessment. All nursing facility residents converting to Medicaid from Medicare, private pay or Veterans Administration benefits must apply for the Medicaid Institutional Care Program (ICP) and undergo a CARES assessment.[20] During SFY2001-2002, 69,482 applicants at risk for nursing homes placement were

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[16] *Comprehensive Assessment & Review for Long Term Care Services (CARES): A Report to the Florida Legislature,* Dec. 31, 2002, p. 4.

[17] Ibid, p. 4.

[18] The Florida Senate, *Interim Project Report 2002-136,* Nov. 2001, p. 8.

[19] Ibid. p. 8.

[20] Department of Elder Affairs *2002 Resource Manual,* Jan. 2002, p. 75.

assessed by CARES staff and of those 23.5% of applicants were referred for waiver services.

The Department of Economic Affairs in the Department of Children and Families (DCF) does the financial eligibility determination for both the elderly and those individuals with mental retardation and developmental disabilities in the state. Additionally, DCF is responsible for determining functional eligibility of all adults with developmental disabilities. The Children's Medical Services Unit located in the Department of Health determines functional eligibility for children requiring nursing home care.

Local Administration

At the local level, long-term care is administered by three different entities: area agencies on aging, Community Care for the Elderly (CCE) lead agencies, and local providers. The area agencies are ultimately responsible for administration of long-term care at the local level. In Florida there are 11 area agencies on aging and 53 CCE lead agencies. A brief description of each of the local administrative entities is given below.

Area Agencies on Aging. Authorized under Title III of the Older American Act, area agencies are quasi-governmental entities mandated to serve as focal points to which elders, caregivers, and the public can turn for information, referral, and assistance. These agencies facilitate the coordination of long-term care at the local level. Florida has 11 planning and service areas (PSAs) throughout the state. These geographic areas are designated based on factors that include the distribution of elders, the need for services with emphasis on the needs of low- income minorities, and existing boundary areas for the delivery of social services.[21] There is an area agency on aging in each of the 11 PSAs. Area agencies conduct assessment, and develop area plans on aging based on the needs of older persons in the PSA. Area agencies administer home and community-based waiver services as well as other federal, state, local, and private funds through contracts with lead agencies and other local providers that deliver direct services programs. These programs include: the Aged and Disabled Waiver, Assisted Living for the Elderly, Home Care for the Elderly, Alzheimer Disease Initiative, and Emergency Home Energy Assistance for the Elderly Program.[22]

Community Care for the Elderly (CCE) Lead Agencies. These agencies were set up by state statute and are contracted by the area agencies on aging to provide direct consumer services. These service provider agencies are not-for-profit corporations administered by a single governing board, or county or local government agencies. There are 53 lead agencies in the state, of which 44 are non-for-profit corporations and nine are county or local government agencies. Lead agencies are responsible for coordinating a community service system, and

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[21] Justification Review Services to Elders Program Department of Elder Affairs Report No. 01-66 Dec. 2001, available at [http://www.oppaga.state.fl.us/reports/pdf/0166rpt.pdf].

[22] Florida Department of Elder Affairs, *Aging in Florida: Program and Funding Matrix 2001*.

performing ongoing case management activities of eligible clients.[23] In this role they perform intake and client assessments and develop client care plans. The lead agencies are also tasked with providing direct services to clients pursuant to their care plans. Case management consists of a number of activities intended to assist elders to remain in the community and avoid the costs of nursing home care. Case management includes assessing need, determining eligibility for services, assisting the elder client in obtaining community resources, and monitoring the client's progress.[24] The CCE lead agencies have the option of subcontracting selected services.

Local Service Providers. Providers are selected through a local competitive bidding process, and are funded by the area agencies on aging or by the CCE lead agencies or both. These service providers translate funding into direct services. They also play a visible role as community elder advocates.[25] As of June 2001, over 1,100 local service providers had contracts with lead agencies to meet the needs of the elders in their communities.[26]

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[23] Ibid.

[24] *Elder Affairs Takes Steps to Separate Case Management from Other Services*, OPPAGA Report No. 98-83, June 1999, available at [http://www.oppaga.state.fl.us/reports/pdf/9883rpt.pdf].

[25] Florida Department of Elder Affairs, *Aging in Florida: Program and Funding Matrix 2001*.

[26] Justification Review Services to Elders Program Department of Elder Affairs Report No. 01-66 Dec. 2001, available at [http://www.oppaga.state.fl.us/reports/pdf/0166rpt.pdf].

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

Trends in Institutional Care

Florida has 734 nursing homes with about 84,000 beds. The number of beds per 1,000 persons age 65 and older is about 30 compared to the national average of 53 beds. There are about 253 beds per 1,000 elderly persons age 85 and older compared to about 435 beds nationally (**Table 4**). The occupancy rate in Florida is approximately 82.6%, only slightly higher than the national average of 80.8%.

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

(data are for 1999-2000)

Characteristic	Florida	United States
Number of facilities	734	17,023
Number of residents	69,122	1,490,155
Number of beds	83,639	1,843,522
Number of Medicaid beds	36,217	841,458
Number of beds per 1,000 pop. age 65 and older	29.8	52.7
Number of beds per 1,000 pop age 75 and older	61.7	111.1
Number of beds per 1,000 pop age 85 and older	252.5	434.8
Occupancy rate	82.6%	80.8%

Source: Data came from the following sources: U.S. Census Bureau, Census 2000 Demographic Profile 1. American Health Care Association (AHCA), Facts and Trends: The Nursing Facility Sourcebook. *For the U.S.*, American Health Care Association.

As in most states, long-term care in Florida is dominated by spending for nursing home care. In FY2001, almost two-thirds of total Medicaid long-term care spending was for nursing home care. According to state officials and consumer advocates, the financing incentives built into the Medicaid program cause a bias toward spending for institutional care.

Certificate of Need. Given the growing expenditures associated with institutional care, the state has taken a number of initiatives to regulate the growth of nursing homes in the state. The Certificate-of-Need (CON) program is a regulatory program that determines the need for additional nursing home beds.[27] Under the program, health care providers must obtain prior state approval before opening new facilities or expanding services. The factors considered in the CON

[27] The Florida Senate *Interim Project Report 2002-136*, Nov. 2001, p. 3.

formula are number of elderly population in the area, existing beds per elder population, and the existing occupancy rate in 33 separate market areas.[28]

In 2001, the State Legislature passed into law SB 1202 placing a moratorium on issuance of new CONs for nursing home beds (other than non-Medicaid beds in Continuing Care Facilities) until July 1, 2006.[29] The intention of the Legislature was to limit the number of beds and to channel more funds to home and community-based care in keeping with the wishes of Florida's elderly and those with disabilities. As of October 2001, 2,285 nursing home beds were approved for construction under previous certificate of need approvals.[30]

Quality of Care. Senate Bill 1202 implemented sweeping changes that will increase direct care staff in nursing homes, as well as implement an internal risk-management and quality assurance program. The program will assess patient care practices, review facility quality indicators and develop plans of action to correct and respond quickly to identified quality deficiencies. Additionally, the bill increases the requirements and training period for nursing home staff, and gives the state agencies increased powers to penalize nursing homes and assisted living facilities for deficiencies in quality care.

Implementation of Medicaid 1915 (c) Waiver Program. In 1982, Florida implemented its first waiver for the elderly and persons with disabilities. The home and community-based waivers authorized under Section 1915(c) of the Social Security Act provide states the option of caring for individuals in their own homes and communities rather than in institutions. When the intensive services of a nursing home are not medically required, this option preserves the individual's independence and ties to family and friends at a lower cost than institutional care.

Trends in Home and Community-Based Care

Home and community-based services for the elderly and persons with disabilities are mainly provided through a series of Medicaid Section 1915(c) waiver programs and a Medicaid Section 1115 waiver as a demonstration program. The state has also experimented with some programs that provide home and community-based services as an alternative to nursing home care, expand consumer choice, and contain costs. These waiver and non-waiver programs cater to a targeted group of individuals who meet specific eligibility criteria.

Medicaid 1915(c) Waivers. Florida operates 11 waiver[31] programs for the elderly and persons with disabilities. Certain general eligibility criteria apply to each

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[28] Ibid, p. 3.

[29] Department of Elder Affairs Home and Community-Based Services Program, on the web at [http://www.oppaga.state.fl.us/profiles/5025/right.asp?programnum=5025].

[30] The Florida Senate *Interim Project Report 2002-136*, Nov. 2001, p. 4.

[31] One of the 11 Medicaid Section 1915(c) home and community-based waiver programs covers children with certain medical conditions; this waiver is outside the scope of this report.

of the waivers for the aged and those with disabilities. First, in order to be eligible for services, persons must have income that does not exceed 300% of the Supplemental Security Income (SSI) level ($1,656/month in 2003) and must meet SSI's resources limit of $2,000 (for an individual).[32] Second, except for two waiver programs (Nursing Home Diversion Waiver, and Channeling Waiver), all are operated on a statewide basis.

The following section describes Medicaid Section1915(c) waiver services, demonstration programs and state supported home and community-based programs (for more detailed information, see **Appendix 1**; waiver programs for persons with mental retardation/developmental disabilities are presented in the next section).

Aged/Disabled Adult Waiver Program. The program was implemented statewide on April 1, 1982. The waiver is administered by the Department of Elder Affairs, and the Agency for Health Care Administration is responsible for the program's financial and policy oversight. At least one Medicaid waiver specialist is employed at each area agency on aging to enroll clients and monitor provider operations and service quality.

Recipients of services must be age 60 or older, or age 18 to 59 and meet the Social Security definition of disability. Clients must also meet nursing facility level of care as determined by the Comprehensive Assessment Review and Evaluation System for Long-Term Care Services (CARES) program. Among the most utilized services are: adult companion, attendant care, case aid, chore services, homemaker and personal care services, case management, respite care, and home-delivered meals.[33]

During State Fiscal Year (SFY) 2002[34], 16,400 clients were served by this waiver, and the maximum allowable number of clients approved under the Aged/Disabled Adult Waiver program is 35,652.[35] Services are provided on a fee-for-service basis within a given budget and caseload. Medicaid reimburses at the maximum allowable Medicaid fee for a specific service, or the providers fee, whichever is lower. The annual cost per client is $5,272.[36]

Nursing Home Diversion Waiver Program (Long-Term Care Community Diversion Project). This waiver was implemented on March 25, 1997. The Department of Elder Affairs administers the program and the Agency for Health Care Administration is responsible for financial and policy oversight.

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[32] Certain items are excluded, such as 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.

[33] Florida Agency for Health Care Administration, *Florida Medicaid Summary of Services*, Jan. 2002.

[34] State Fiscal Year (SFY) is from July, 1, 2001 through June 30, 2002.

[35] *Florida's Medicaid Long-Term Care System*, A Presentation for the Congressional Research Service. May 14, 2002.

[36] Agency for Health Care Administration, SFY2002 Data.

Clients must be at least age 65 and over, and meet nursing home eligibility criteria. Those who are eligible for both Medicare and Medicaid (i.e., "dual eligibles") receive long-term care and acute care services under the waiver. To receive services, clients must reside in one of the following counties: Orange, Osceola, Seminole, Brevard, Palm Beach, Martin, Okeechobee, St. Lucie, or Indian River. The most utilized services include: adult companion, assisted living, family training, home-delivered meals, case management, homemaker, personal care, respite and home health care.[37]

Services are provided by managed care providers under contract with the Department of Elder Affairs. Providers are reimbursed at a capitated rate, on a per member, per month basis. In SFY2002, 1,177 clients were served under the program, and the maximum allowable number of clients approved under the waiver is 2,300. The annual cost per client is $28,104.[38] The high unit cost is due to a monthly capitation payment of $2342 per member per month, which is the highest reimbursement rate of all the waivers that serve elders. The state has undertaken an actuarial study to determine a new rate structure for managed long term care programs, and the results are expected to be released in the fall of 2003.

Channeling Waiver Program. The waiver was implemented on July 1, 1985 in Dade and Broward counties.[39] In order to qualify for services persons must be age 65 or older and reside in Dade and Broward counties. Services include the following: adult day health care, case management, chore services, companion services, counseling, family training, home health aide services, occupational therapy, personal care services, personal emergency response systems, physical therapy, respite care, skilled nursing, special home delivered meals, special drug and nutritional assessments, special medical supplies, and speech therapy among others. During SFY2002, 1,721 individuals were served under this waiver, and a total of 1,804 slots have been approved. The annual cost per client is $8,307.[40]

Project AIDS Care Waiver Program (PAC). The program was implemented statewide on November 1, 1989, and is administered by the Agency for Health Care Administration. In order to qualify, persons must meet the following criteria: have a diagnosis of AIDS; meet Social Security Administration's definition of disability; not be enrolled in a Medicaid HMO or hospice program; have a Level of Care determination for risk of hospitalization or placement in a nursing facility; be able to remain safely at home; and have completed PAC waiver enrollment application.

The case manager must complete a Needs Assessment and a Plan of Care before authorizing any of the following services: day health care, education and support,

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[37] Florida Agency for Health Care Administration, *Florida Medicaid Summary of Services*, Jan. 2002, p. 104.

[38] Agency for Health Care Administration, SFY2002 Data.

[39] This waiver provides services to persons who were served under the federal Long-Term Care Channeling project during the 1980's.

[40] Agency for Health Care Administration, SFY2002 Data.

personal care, skilled nursing, specialized medical equipment and supplies, specialized personal care for foster care children and therapeutic massage.[41] Recipients receive physician services, home health, therapy, prescribed drugs and other state plan services in addition to waiver services. The PAC waiver is the payer of last resort after services are paid by other funding sources such as Medicare, private insurance, other third parties and the Medicaid state plan.

During SFY2002, 6,658 persons were served under the waiver. The maximum allowable number of clients approved under the waiver program is 10,000.[42] Case management is reimbursed as a flat-fee per recipient per month. All other waiver services are reimbursed at a fee-for-service rate for the units of service provided. The annual cost per client is $3,719.[43]

Assisted Living for the Elderly Waiver Program.[44] The waiver was implemented statewide on February 1, 1995. Under the waiver clients in qualified Assisted Living Facilities (ALFs) receive home and community-based services in lieu of receiving services in an institution. The program includes three services: case management, assisted living and, if needed, incontinence supplies. Through an interagency agreement with the Agency for Health Care Administration, the Department of Elder Affairs administers the program. The Agency for Health Care Administration has financial and policy oversight for the program. The Department of Elder Affairs contracts with each area agency on aging for the employment of a Medicaid Waiver Specialist to enroll, train and monitor providers.[45]

To qualify for this waiver, individuals must be at least age 60, must meet Social Security Administration's definition of disability, and must meet one or more of the following criteria: require assistance with four or more activities of daily living (ADLs); require assistance with three activities of daily living plus the supervision or administration of medication; require total assistance with one or more ADLs; have a diagnosis of Alzheimer's disease or another type of dementia and require assistance with two or more ADLs; have a diagnosed degenerative or chronic medical condition requiring nursing services that cannot be provided in a standard ALF, but

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[41] Florida Agency for Health Care Administration, *Florida Medicaid Summary of Services*, Jan. 2002, p. 105.

[42] *Florida's Medicaid Long-Term Care System*, A Presentation for the Congressional Research Service. by the Agency for Health Care Administration, May 14, 2002, slide 46.

[43] Agency for Health Care Administration, SFY2002 Data.

[44] Florida is one of the few states that attempts to define the philosophy underlying an assisted living facility (ALF) in state statute. In Florida Statute Chapter 400, Part 3 (which creates a distinct category for the licencing of assisted living facilities in Florida), it states that the purpose of an ALF is "to promote availability of appropriate services for elderly and disabled persons in the least restrictive and most home-like environment, to encourage the development of facilities which promote the dignity, individuality, privacy and decision-making ability...." This statute also directs state agencies to regulate ALFs as "residential environments and not as medical or nursing facilities."

[45] Department of Elder Affairs *2002 Resource Manual*, Jan. 2002, p. 89.

are available in an ALF that is licensed for limited nursing or extended congregate care, or be a Medicaid eligible person who meets ALF criteria.[46]

Services most often used include: attendant care, chore services, companion services, homemaker, intermittent nursing, medication administration (within the ALF license), personal care, physical therapy, specialized medical equipment and supplies, and therapeutic social and recreational services. During SFY2002, 3,993 clients were served, the total number of clients approved under the waiver is 3,196.[47] The annual cost per client is $7,673.[48]

Traumatic Brain Injury/Spinal Cord Injury Waiver Program. The waiver provides persons with brain or spinal cord injuries with an option to receive services in a home and community-based setting. The Department of Health has administrative oversight for the waiver. The Agency for Health Care Administration is responsible for the financial and policy oversight of the program. In order to receive services individuals must be clients of the Brain and Spinal Cord Injury Program and at least age 18.

Waiver services include: adult day training, chore services, companion services, environmental modification, homemaker, in-home supports, non-residential support services, occupational therapy, personal care assistance, personal emergency response systems, physical therapy, private duty nursing, psychological services, respiratory therapy, residential habilitation, residential nursing, respite care, skilled nursing services, special medical equipment and supplies, special medical home care, specialized mental health services, support coordination, supported employment, supported living coaching, therapeutic massage, and transportation among others. During SFY2002, 147 persons were served and 200 slots were approved. The annual cost per client $13,556.

Adult Cystic Fibrosis Waiver Program. The waiver was approved on September 25, 2002, and is implemented statewide. The Department of Children and Families, Adult Services Program Office, operates the Adult Cystic Fibrosis (CF) Waiver Program.

To be eligible for the CF waiver services, an individual must be between ages 18 through 59 years, and diagnosed with cystic fibrosis. Additionally, the client must be determined to be at risk of hospitalization, and meet the Supplemental Security Income (SSI)-related Medicaid or the Institutional Care Program (ICP) income and asset requirements.

Waiver services include: acupuncture, adult companion, adult day health, chore service, counseling (individual and family), durable medical equipment, exercise

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[46] The recipient should be awaiting discharge from nursing facility placement and be unable to return to a private residence because of a need for supervision, personal care, periodic nursing services or a combination of the three.

[47] Agency for Health Care Administration, SFY2002 Data.

[48] Ibid.

therapy, massage therapy, occupational therapy, personal care, personal emergency response service, physical therapy, prescribed drugs, respiratory therapy, respite care, skilled nursing, specialized medical equipment and supplies, transportation, and vitamins and nutritional supplements.

Enrollment of individuals for the waiver is scheduled to begin on January 1, 2004 and the approved number of clients for the first, second, and third year of enrollment are 75, 115, and 150 respectively.

Adult Day Health Waiver Program. The waiver was approved in March 2003. The program plans to serve approximately 130 individuals in each of the three years it will be in operation. To receive services participants must be age 75 or older, meet nursing facility level of care, be a resident of Lee or Palm Beach county, and reside with a caregiver. One provider will be chosen through a competitive procurement process to serve individuals in Palm Beach County, and one will be chosen to serve Lee County. There is one service to be provided under this waiver, comprehensive adult day health care. The project is designed to test whether this service alone is enough to prevent or delay nursing home placement of frail, elderly individuals.

Section 1115 Waivers. Florida is one of the states in the country that applied for a demonstration waiver from the Centers for Medicare and Medicaid Services (CMS) to implement a Consumer Directed Care project. Section 1115 of the Social Security Act authorizes the Secretary of Health and Human Services(DHHS) to conduct research and demonstration projects under several programs authorized by the Social Security Act, including Medicaid and the State Children's Health Insurance Program (SCHIP).

Specifically, Section 1115 authorizes the Secretary to waive certain statutory requirements for conducting these projects. For this reason, the research and demonstration projects are often referred to as Section1115 "waiver" projects. Under the waiver authority, states may modify virtually all aspects of their programs without Congressional review. Requirements that may be waived include:

- "freedom of choice" - The requirement that Medicaid beneficiaries have the freedom to choose their own medical care providers;
- "comparability" - The requirement that services be comparable in amount, duration, and scope for all persons in each eligibility group; and
- "state wideness" - The requirement that states provide services on a state-wide basis, rather than only in a portion of the state. Furthermore, the experimental program cannot be conducted together with more limited waivers such as Section 1915 (c) waivers.[49]

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[49] For further information see CRS Report RL30813 *Federal and State Initiatives to Integrate Acute and Long-Term Care: Issues & Profiles* by Edward A. Miller, Jan. 22, 2001.

Consumer Directed Care. The Centers for Medicare and Medicaid Services (CMS) approved Florida's Cash and Counseling Demonstration project in October 1998 and it was implemented on March 1, 2000. Cash and Counseling is a self-directed program that is designed to ensure that consumers have a direct voice in making decisions with regard to the care they will receive. This project supports the Olmstead Decision[50] by promoting community-based services for persons with disabilities who otherwise would be placed in an institutional setting.

Persons eligible to receive services include the frail elderly, and adults and children with disabilities. To receive benefits, eligible individuals are randomly placed into two groups: a treatment group that receives a monthly cash benefit used to purchase needed services under the personal care benefit, and a control group that receives services under the traditional (agency provided) method. The demonstration project is voluntary and the participants may leave the program at any time.

Consumer Directed Care is available to adults who receive services from the Aged and Disabled Waiver and the Traumatic Brain Injury/Spinal Cord Injury waiver and residing in selected counties.[51,52] Additionally, adults who receive services under the Developmental Services waiver (described later in the report) are eligible for Consumer Directed Care if they reside in one of selected counties.[53] However, it is available to children receiving services from the Developmental Services Waiver on a statewide basis.[54] Participants will be involuntarily disenrolled from the treatment group if there is a misuse of the cash grant, if the individual's ability to manage their

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[50] In its 1999 opinion, in *Olmstead v. L.C.*, the U.S. Supreme Court held that the Americans with Disabilities Act (ADA) requires states to transfer individuals with mental disabilities from institutions to less confining community settings when a state treatment professional has determined the latter are appropriate, the community setting is not opposed by the individual with a disability, and the placement can be reasonably accommodated by the state [for further information see CRS Report RS20588 *Olmstead v. L.C.: Implications and Subsequent Judicial, Administrative, and Legislative Actions* by Melinda De Atley, Nancy Lee Jones, May 31, 2000.

[51] The counties are: Brevard, Broward, Charlotte, Collier, Dade, Hillsborough, Lee, Manatee, Martin, Okeechobee, Orange, Osceola, Palm Beach, Pasco, Pinellas, Polk, Sarasota, Seminole and St. Lucie.

[52] During the initial phase of the Section 1115 demonstration, individuals from these waivers wishing to participate in Consumer Directed Care program were enrolled. They were randomly place in either an experimental group where they "cashed out" their traditional Section 1915(c) waiver services and were able to manage a budget and hire their own care staff or they were placed into the control group where they continued to receive services through the traditional Section 1915(c) waiver structure.

[53] The counties are : Calhoun, Franklin, Jefferson, Liberty, Madison, Taylor, Holmes, Jackson, Washington, Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union, DeSoto, Glades, Hendry, Flagler, Volusia, Citrus, Hernando, Lake, Sumter, Marion, Hardee, Highlands, Indian River and Monroe. Brevard, Broward, Charlotte, Collier, Dade, Hillsborough, Lee, Manatee, Martin, Okeechobee, Orange, Osceola, Palm Beach, Pasco, Pinellas, Polk, Sarasota, Seminole and St. Lucie.

[54] Florida Agency for Health Care Administration, *Florida Medicaid Summary of Services*, Jan. 2002, p. 95.

cash grant declines and there is no client representative available, or if the participant fails to provide documentation of use of the cash benefit. Those persons assigned to the control group continue to receive services through Medicaid waiver providers. Personal care services are provided to consumers enrolled in the treatment group by providers of their choosing. Treatment group consumers determine the services they need, and from whom they would like to receive them.

Services available to consumers include: personal care, homemaking, consumable medical and personal care supplies, home repairs and maintenance, and adaptive services such as wheelchair ramps and grab bars among other things. The consumers pay their workers from accounts set up for them through a fiscal intermediary. There is no cost sharing associated with this demonstration project. Total participation is limited to 6,000 (3,000 experimental group members and 3,000 control group members).[55] Enrollment for the program ended on June 30, 2002, and the total number of participants was 2,080.[56] The Florida Legislature enacted the Consumer Directed Care Act on July 1, 2002, authorizing it to be a statewide program.

Managed Care Programs. Florida has experimented with several managed long-term care models. These models range from: putting a Medicaid HMO at risk for all Medicaid services including nursing home care for up to a year, to making participating HMOs liable for unlimited nursing home payments for as long as the person remains enrolled. These programs create strong incentives to reduce nursing home usage in order to reduce costs. Apart from these programs, as of February 1, 2003 the state has implemented a Program of All Inclusive Care for the Elderly (PACE) and has been developing a second-generation social HMO (S/HMO) model.[57]

The Program of All-Inclusive Care for the Elderly (PACE).[58,59] The PACE program is based on the On Lok Senior Health Services program, which was founded in the Chinatown section of San Francisco in the 1970s. The purpose of the PACE program is to provide the frail elderly, and Medicaid-eligible elderly a continuum of acute care and long-term care in their own homes and communities and avoid institutionalization.[60] At its inception the program was operated as a federal demonstration project, and the Balanced Budget Act (BBA) of 1997 made it a permanent benefit under Medicare and an optional benefit states can offer under

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[55] Ibid.

[56] Personal communication with the staff of the Department of Elder Affairs.

[57] Ibid.

[58] Department of Elder Affairs, *2002 Resource Manual*, Jan. 2002, p. 75-76.

[59] For further information see CRS Report RL30813 *Federal and State Initiatives to Integrate Acute and Long-Term Care: Issues & Profiles* by Edward A. Miller, Jan. 22, 2001.

[60] *Managed Care for the Elderly and The Role of the Aging Network* by Larry Polivka, Ph.D. and Randa Robinson-Anderson, M.A. June 1999.

Medicaid.[61] As a result of this federal law, states now have the freedom to implement PACE projects without applying for waiver status from CMS. In 1998, the Florida Legislature authorized financing for the program.

The program targets individuals who would otherwise be placed in a nursing home under Medicaid and provides them with a comprehensive range of services. PACE providers receive both Medicare and Medicaid capitated payments, and they are responsible for providing a full continuum of medical and long-term care services within the capitated amounts they receive. To be eligible for the program applicants must be 55 years of age or older; be certified eligible for nursing home care; and live in the program's service area.[62] The program is administered by the Department of Elder Affairs in consultation with the Agency for Health Care Administration, and services are delivered through adult day care centers. The program was implemented on February 1, 2003, and as of August 2003, 12 individuals are enrolled in the program. At present only one provider is available. Medicaid's monthly capitation rates vary according to the type of individual Medicare coverage. If the individual has coverage under Medicare Parts A and B then the monthly capitation rate is $1,944, if the individual has only Medicare Part B then the monthly capitation rate is $2,677, if the individual has no Medicare coverage then the monthly capitation rate is $3,169.

Frail Elderly Program. This is a state administered, capitated, managed long-term care program contracted to an HMO. At present, the program is implemented in Dade and Broward counties. The purpose of the program is to provide and manage services for the frail elderly and to prevent or delay nursing home placement.

To be eligible for the Frail Elderly program, recipients must be 21 years of age or older, meet the state's requirements for nursing home level of care, and be in need of services as determined by CARES. The program provides comprehensive and medically necessary services. A case manager is assigned to each enrollee and is responsible for coordinating all program services and implementing services according to the plan of care. The Frail Elderly program is responsible for provision of all covered services the member needs which are not included in the nursing home rate.

Services provided under this program include: adult day health care, adaptive equipment, homemaker or personal care, and caregiver training among others. During SFY2002, 3,099 recipients were being served by the Frail Elderly program. The average monthly reimbursement rate is $1,275 per recipient.

Social Health Maintenance Organizations(S/HMO). Similar to Medicare HMOs, S/HMOs provide coverage for acute care services. However, S/HMOs provide expanded benefits to include limited nursing home benefits and a

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[61] For further information on the PACE Program see CRS Report RL30813 *Federal and State Initiatives to Integrate Acute and Long-Term Care: Issues & Profiles* by Edward A. Miller, Jan. 22, 2001, p. 40-42.

[62] It is only available in part of Miami-Dade county.

wide array of home and community-based services such as homemaker services, adult day care, personal care, and medical transportation among other things.[63]

In 1998, the Department of Elder Affairs received a grant to develop several S/HMO demonstrations in the state for those who have long-term care needs and are dually eligible for Medicare and Medicaid. The S/HMO model will integrate Medicare and Medicaid services to respond to the needs of the dually eligible population including the very frail and chronically ill. Both Medicare and Medicaid eligible clients receive long-term care services including home and community-based care through one managed care organization. It is expected that the S/HMO program will be administered by the Department of Elder Affairs in consultation with the Agency for Health Care Administration.[64] As of June 2003, this program is still in the planning stages.

Real Choice System Change Grant (Florida's Olmstead Grant). In addition to managed care programs, Florida has implemented a program that would provide those with disabilities meaningful choices in selecting their living environments and the types of services they need. In May 2001, the Centers for Medicare and Medicaid Services (CMS) invited proposals from states to design and implement effective and long-lasting improvements in community long-term support systems. The major purpose of the system change grants is to assist states make systematic changes in their programs to enable children and adults of any age who have a disability or long-term illness live in the most integrated community setting appropriate to their individual requirements and their preferences.

Florida received $2 million for the 3-year period beginning October 1, 2001 through October 1, 2004. The Real Choice Partnership (RCP) Project was implemented in January 2002. The project works with a variety of Olmstead related activities but there is no enrollment of individuals in the program. The grant was funded by CMS in order to help states and territories comply with the Olmstead decision.

The focus of the project is to examine all state and federal policies related to community services while enhancing local resources that will improve the opportunity for individuals with disabilities to live in the most integrated setting appropriate to their need as required by Title II of the Americans with Disabilities Act. The RCP Project is being administered by the Americans with Disabilities Act Working Group housed in the Department of Management Services.

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[63] Ibid p. 43-45.

[64] Department of Elder Affairs, *2002 Resource Manual*, Jan. 2002, pp. 76-79.

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

Overview

Services to persons with mental retardation and other developmental disabilities have 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 (Supplemental Security Income) and SSDI (Social Security Disability Insurance) and to service providers through the Medicaid program, and significant litigation brought on behalf of persons with mental retardation.[65]

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 to almost 200,000 individuals nationwide in 165 free-standing state-operated mental retardation institutional facilities.[66] Today, some states are still faced with the legacy of large state-operated institutions. In the nation as a whole and in Florida, over the last several decades, large state-operated institutions have been closed or downsized, a development that has been prompted by litigation.

The majority of the state's initiatives for providing non institutional services for persons with developmental disabilities and mental retardation have been driven by class action law suits filed against the state of Florida to prevent the state from unnecessary institutionalzation of these individuals. In a major law suit, Wolf Prado-Steinman et al., v. Bush et al.,[67] advocates within the developmentally disabled community argued that individuals who participated in Florida's Section 1915(c) home and community-based waiver program did not receive the "full range of services" authorized under the individual's service plan. In May 2000, all parties to the lawsuit signed an 18-point settlement agreement, which required Florida to: provide the full range of waiver services to recipients; improve the quality of services under the home and community-based waiver; improve the workload ratios of support coordinators; and complete a study of waiver payment rates.[68] In March 1998, the 11th U.S. Circuit Court of Appeals ruled in *Does v. Chiles* (now *John/Jane*

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

[66] Ibid.

[67] 221 F.3d 1266 (Eleventh Circuit. 2000).

[68] Further information about this settlement agreement is available at [http://www.advocacycenter.org/news/sep1100a.htm].

Does v. Bush et al.,)[69] that no state can place an individual on a waiting list for Intermediate Care Facility for the Mentally Retarded (ICFs/MR) services indefinitely. The court ruled that Florida's attempt to restrict the availability of ICFs/MR and home and community-based waiver services to eligible applicants was a violation of federal Medicaid law. The decision stated that individuals had the same entitlement to ICF/MR services as other non-waiver Medicaid services, and as an entitlement, ICF/MR services must be provided with "reasonable promptness to eligible applicants."[70]

In *Brown et al., v. Bush et al.*, a 1998 class action lawsuit, the plaintiffs maintained that the institutionalization of those with developmental disabilities is a violation of the Americans with Disabilities Act's (ADA) integration mandate, Section 504 of the Rehabilitation Act, federal Medicaid law, and the U.S. Constitution. The plaintiffs in this case sought a permanent injunction against the state from unnecessarily placing individuals with developmental disabilities in institutions. The injunction was not granted, [71, 72] and the parties involved went in to a lengthy arbitration process. The case is scheduled for trial again in early 2004.

Since taking office, Governor Bush has committed the state to improve resources and services for those with mental retardation and developmental disabilities. Governor Bush has proposed increased funding for the Developmental Disabilities program every year since 1994 and has put forward a plan to redesign the Developmental Disabilities program. The primary goal of the redesign is to refine the current system so that it is more responsive to individuals, families, and other stakeholders, while enhancing consumer choice and control over services used. The Florida Department of Children and Families, and the Agency for Health Care

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[69] 136 F.3d 709 (Eleventh Circuit. 2000).

[70] United States Court of Appeals, Eleventh Circuit. *Does v. Chiles* (case # No. 96-5144) available at [http://laws.findlaw.com/11th/965144man.html].

[71] In March 1999, the U.S. District Court for the Southern District of Florida, adopted the Plaintiffs' definition of class and certified the class as: "all persons who on or after January 11998, have resided, are residing, or will reside in DSIs (Developmental Services Institutions) including all persons who have been transferred from institutions to other settings, such as ICF, group homes, or SNF's but remain defendant's responsibility; and all persons at risk of being sent to DSIs." The state appealed the class certification to the U.S. Court of Appeals for the Eleventh Circuit. In an unpublished opinion, the Eleventh Circuit Court agreed that the definition of class was too broad and remanded the case to the District Court with the following definition of class: "all individuals with developmental disabilities who were residing in a Florida DSI as of Mar. 25,1998, and/or are currently residing in a Florida DSI who are Medicaid eligible and presently receiving Medicaid benefits, who have properly and formally requested a community-based placement, and who have been recommended by a state-qualified treatment professional or habilitation team for a less restrictive placement that would be medically and otherwise appropriate, given each individual's particular needs and circumstances." However, the state did not agree with the second definition of class and the parties involved sought to negotiate the reduction of number of individuals served in institutions [Case Number 99-11544 JJ].

[72] *Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilitie*s by Gary A. Smith, Jan.16, 2003, p. 20, available at [http://www.hsri.org/index.asp?id=news].

Administration have jointly initiated the redesign by establishing stakeholder work groups made up of designated stakeholder representatives who have been charged with providing consultation.[73] The Department of Children and Families has held several public hearings and has awarded a contract to Mercer Human Resources Consulting to help with the redesign effort. Mercer has a toll-free number and a website that will be used to provide information about the redesign. The complete system redesign is scheduled for delivery during 2003.

In addition to litigation, Florida's system of services for persons with developmental disabilities and mental retardation has been influenced by a number of other significant factors. These include:

- enactment of the Developmental Disabilities Prevention and Community Service Act in 1982. With this legislation, the Legislature declared that the greatest priority should be given to community-based residential placements and services;[74]
- implementation of the Medicaid Section 1915 (c) waiver in 1982;
- addition of the definition of "supported living" to the Developmental Disabilities and Community Act in 1991, giving official recognition to this service as a residential service option;
- 1992 expansion and amendment of Florida's Home and Community-Based Services Waiver to add a broad array of services;[75]
- development of a strategic planning process by the Developmental Services Program Office in 1994, to enable individuals with developmental disabilities to "live everyday lives," including meaningful employment, and full inclusion in community activities;[76]
- development of a "Cash and Counseling Program" with a grant from the Robert Wood Johnson Foundation to demonstrate that traditional case management services can be replaced with less costly counseling services for some clients with mental retardation and developmental disabilities.[77]

There are an estimated 288,534 persons of all ages with developmental disabilities and mental retardation in Florida.[78] As of June 30, 2002 the Department

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[73] Florida Department of Children and Families, Developmental Disabilities Program Office-E-Bulletin, Aug. 16, 2002, available at [http://www.myflorida.com/cf_web/myflorida2/healthhuman/ddp/ebulletins/081602ebulletin.pdf].

[74] Developmental Services Program *Florida's Evolution to Participant-Driven Managed Care 1980-2000.* p. 1. (Communication from the Developmental Disabilities Program office in the Department of Children and Families).

[75] Ibid. p. 2.

[76] Ibid. p. 3.

[77] Ibid. p. 9.

[78] Communication from the Developmental Disabilities Program office in the Department (continued...)

of Children and Families was serving 30,902 Floridians with developmental disabilities.[79] The State Fiscal Year (SFY) 2002-2003 budget for persons with developmental disabilities program is $975 million, representing a 94% increase over the last 4 years.[80] The funds are projected to serve about 1,546 individuals in 2002-2003 who need waiver services and continue to provide all medically necessary services to the approximately 25,000 individuals currently enrolled in the Developmental Services Waiver.[81]

The Developmental Disabilities Program in the Department of Children and Families has operational responsibility for the Developmental Services home and community-based waiver. The program receives funding from state General Revenue (GR) funds and the federal Medicaid waiver funds. A small proportion of the GR funds are set aside for some support services for those who do not qualify for Medicaid waivers.[82]

Trends in Institutional Care

The number of persons residing in large state institutions in Florida has declined over the years partly as a result of litigation. Persons living in large institutions with 16 or more persons declined from 35% of all persons living in group residences in 1995 to 27% in 2000 (**Table 5**). The Medicaid home and community-based services wavier option (discussed below) has allowed Florida to focus on development of small congregate care options. In 2000, 12,618 persons with mental retardation were living in group residential settings, with 50% living in residences of 6 or fewer persons. This is an increase since 1995 when 40% of the total in group residences were in small facilities (see **Table 5**).

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[78] (...continued)
of Children and Families, Apr. 16, 2003.

[79] Ibid.

[80] Department of Children and Families, Developmental Disabilities Program Office, *E-Bulletin,* May 24, 2002. p. 2. available at [http://www.state.fl.us/cf_web/].

[81] Notice to Individuals Who Have Become a Client of Developmental Disabilities or Submitted an Application to Become a Client of Developmental Disabilities since July 1, 1999, available at
[http://www5.myflorida.com/cf_web/myflorida2/healthhuman/ddp/about_us/0203spendplan.pdf].

[82] Department of Children and Families, Developmental Disabilities Program Office, *E-Bulletin ,* Apr. 26,2002. p. 1., available at [http://www.state.fl.us/cf_web/].

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

Persons served by residential setting			
	1990	**1995**	**2000**
TOTAL	**N/A**	**11,340 (100%)**	**12,618 (100%)**
16+ PERSONS	**N/A**	**3,961 (35%)**	**3,378 (27%)**
Nursing facilities	N/A	234	191
State institutions	1,992	1,619	1,534
Private ICFs/MR	1,335	1,339	1,274
Other residential	724	769	379
7 - 15 PERSONS	**5,252**	**2,849 (25.1%)**	**2,937 (23.3%)**
Public ICFs/MR	0	0	0
Private ICFs/MR	600	600	574
Other residential	4.652	2,249	2,363
≤6 PERSONS	**N/A**	**4,531 (40%)**	**6,303 (50%)**
Public ICFs/MR	0	0	0
Private ICFs/MR	0	159	194
Other residential	N/A	4,372	6,109

Source: *The State of the States in Developmental Disabilities: 2002 Study Summary*, by David Braddock, Richard Hemp, Mary C. Rizzolo, Susan Parish, and Amy Pomeranz. Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado, June 2002.

N/A= Not available.

Trends in Home and Community-Based Care

In Florida, as in many other states in the nation, the Medicaid Section 1915(c) waiver has played an important role in providing revenue for home and community-based services for those with developmental disabilities and mental retardation. As stated before, Governor Bush has committed additional resources to the Developmental Disabilities program in the state, especially to address the waiting list for home and community-based services. State and federal funding for developmental services increased 94% from $502.8 million in 1998 to $975 million in 2002.

Medicaid 1915(c) Waivers: Developmental Services Waiver Program. There are two Medicaid Section 1915(c) waivers for persons with developmental disabilities. The waiver was originally implemented on April 1, 1982 as a combined waiver together with the Aged/ Disabled Adult Services. However, in 1985 the waiver was split into two separate waiver programs in order to accommodate the growing needs of the two diverse populations. The Developmental Services Program Office in the Department of Children and Families has day-to-day operational responsibility, and the Agency for Health Care Administration has financial and policy oversight of the program.

To be eligible, clients must be 3 years of age or older and meet the level-of-care criteria for intermediate care facilities for those with developmental disabilities (ICFs/DD).[83] Financial eligibility of service recipients is assessed by the Department of Children and Families. The waiver includes a wide range of services: adult day training, adult dental, behavioral services, chore services, companion services, dietitian, environmental modification, homemaker, in-home supports, non-residential support services, occupational therapy, personal care assistance, personal emergency response systems, physical therapy, private duty nursing, psychological services, respiratory therapy, residential habilitation, residential nursing, respite, skilled nursing services, special medical equipment and supplies, special medical home care, speech, specialized mental health services, support coordination, supported employment, supported living coaching, therapeutic massage, and transportation.

The allowable number of clients that may be served under the waiver is 25,352, and during SFY2002, 24,418 persons were served. Medicaid reimburses service providers based on rates approved by the Department of Children and Families, and the Agency for Health Care Administration. The annual cost per client is $18,417.

Supported Living Waiver. The waiver was implemented statewide on October 1, 1995. This waiver replaced the Medicaid Community Supported Living Arrangement program. The Developmental Disabilities Office in the Department of Children and Families has operational responsibility for the Supported Living Waiver Program. The Agency for Health Care Administration is responsible for the financial and policy oversight of the program. In order to receive services under the waiver, individuals must be age 18 or older, meet the level of care for ICFs/MR, and be able to direct their own support in all but limited areas. In addition, they must participate in the planning and implementation of support necessary to manage their households.

The waiver services include: adult day training, in-home support services, supported employment, and transportation among other things. The allowable number of clients that may be served under the waiver is 200 and during SFY2002, 6 persons were served. The annual cost per client is $5,477.

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[83] For further information on level-of-care criteria see Department of Children and Families, See *Developmental Services Home and Community-Based Services Waiver, Services Directory 2001*. p. 4-5, available at [http://www5.myflorida.com/cf_web/myflorida2/healthhuman/ddp/publications/].

Financing Long-Term Care

In most states, the federal-state Medicaid program is the chief source of funding for long-term care. In Florida the Medicaid program accounted for $2.6 billion in long-term care spending in FY2001. In addition, state resources through General Revenue (GR), state's share of tobacco settlement funds, cigarette taxes, and drug rebates among others, contributed toward the state Medicaid budget.

Medicaid Spending in Florida

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), Medicaid represented 19.6% of state budgets for the United States as a whole in 2001.

In Florida, Medicaid is the second largest single category of *federal and state* spending second only to elementary and secondary education as a single spending category. Of the state's $52.4 billion budget in 2001, federal and state Medicaid spending represented 17% **(Table 6)**. Federal and state spending for Medicaid increased from 10.6% in 1990 to 17% in 2001.

State spending for Medicaid services in Florida contributed from state *only* funds (excluding federal funds)[84] also increased during the 1990s. As a percent of spending for all categories of state spending, state Medicaid spending increased from 5.6% in 1990 to 9.4% in 2001–almost 1 of every 10 dollars **(Table 7).**

[84] 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 Florida was 56.62%.

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

Expenditure category	Florida				All states
	1990	1995	2000	2001	2001
Total expenditures (in millions)	**$22,812**	**$37,559**	**$47,517**	**$52,390**	**$1,024,439**
Medicaid	**10.6%**	**15.8%**	**16.1%**	**17.0%**	**19.6%**
Elementary and secondary education	28.2%	17.9%	19.8%	18.5%	22.2%
Higher education	10.2%	7.1%	9.0%	9.0%	11.3%
Public assistance	1.8%	2.2%	0.5%	0.4%	2.2%
Corrections	3.8%	3.9%	3.5%	3.2%	3.7%
Transportation	7.1%	12.4%	12.0%	12.7%	8.9%
All other expenses	38.3%	40.6%	39.1%	39.2%	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. Numbers may not sum to 100% due to rounding.

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

State spending	Florida				All states
	1990	1995	2000	2001	2001
Total state spending (in millions)[a]	**$18,875**	**$29,142**	**$36,876**	**$40,910**	**$760,419**
State Medicaid spending (millions)[b]	$1,049	$2,580	$3,344	$3,857	$85,141
State Medicaid spending as a percent of total state spending	5.6%	8.9%	9.1%	9.4%	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 categories, excluding federal funds.

[b] Fiscal 1995 includes $443.7 million in provider assessments, $46.8 million in pharmacy rebates and $88.0 million in local funds. In 1995 these funds represented 12.4%, 1.8%, and 3.4% of total state funded Medicaid expenditures, respectively. Fiscal 2000 includes $380 million in provider assessments, $114 million in pharmacy rebates, and disproportionate share of local county funds of $94 million. These funds represented 11.4%, 3.4%, and 2.8% of total state funded Medicaid expenditures, respectively. Fiscal 2001 includes $368 million in provider assessments, pharmacy rebates of $112 million, and $171 million in disproportionate share of local county funds. These funds represented 9.5%, 2.9%, and 4.4%, respectively of total state funded Medicaid expenditures in 2001.

Medicaid Long-Term Care Spending in Florida[85]

Long-term care spending represented almost 31% of all Medicaid spending in Florida in FY2001,[86] declining slightly from 33.7% in FY1990 (**Table 8**). Long-term care spending exceeded $2.6 billion in FY2001. Institutional care dominates long-term care spending at almost $2 billion in FY2001, and is a significant share of all Medicaid spending. However, over the period FY1990-FY2001, institutional care spending (including care in nursing homes and ICFs/MR) decreased significantly as a share of total long-term care spending, while spending for home and community-based services increased. According to state officials these trends are due to a number of factors and programs implemented during the 1990's. These include the implementation of eleven Medicaid 1915(c) waivers, Medicaid managed care programs, and increased spending on services for persons with disabilities as a result of settlement of litigation against the state among other things. In FY2001, 75.3% of Medicaid long-term care spending was channeled towards home and community-based services **(Table 8)**.

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

Medicaid long-term care spending in Florida was $2.6 billion in FY2001, and represented almost 31% of all Medicaid spending in FY2001.

Spending for nursing home care as a percent of Medicaid long-term care spending decreased slightly from 76% to 64% from FY1990 - FY2001. Spending for ICF/MR also decreased from 18.4% to 11%.

Spending for home and community-based services as a share of long-term care services increased from 6% to 25% from FY1990-FY2001.

Spending for home and community-based waiver services as share of total Medicaid long-term care spending increased dramatically from almost 4% in FY1990 to almost 21% in FY2001. This was twelve times the amount spent in 1990, even after adjusting for inflation.

Institutional care is still a major factor in Medicaid long-term care spending. Institutional care represented 94.2% of total long-term care spending in FY1990, declining to 75.3% in FY2001 (**Table 8**). Moreover, *total* home and community-based spending increased by almost tenfold from FY1990 to FY2001 (in constant 2001 dollars) (**Table 9**), as compared to institutional care, which increased by 94.8%. Furthermore, Medicaid spending for home and community-based waivers *increased* twelve times the amount spent in 1990, even after adjusting for inflation.

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

[86] Total Medicaid spending using NASBO data differ from data shown in this table due to differences in data collection methods.

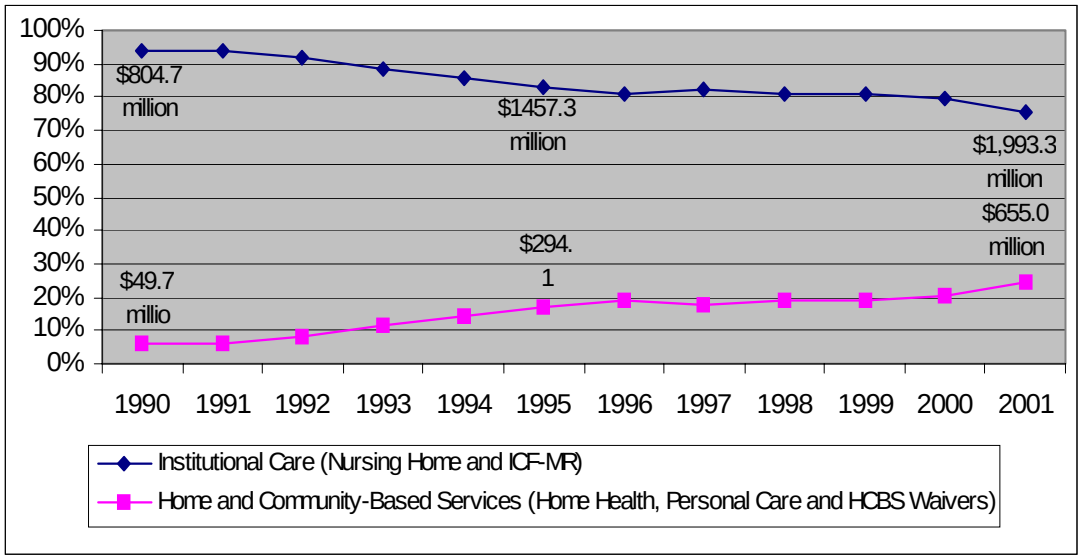
Table 8. Medicaid Long-Term Care Spending In Florida, FY1990-FY2001

	FY1990	FY1995	FY2000	FY2001
Long-term care spending as a % of Medicaid spending	33.7%	28.6%	30.9%	30.5%
Institutional care spending as % of long-term care spending	94.2%	83.2%	79.8%	75.3%
Nursing home spending as a % of long-term care spending	75.8%	69.1%	67.8%	64.3%
ICFs/MR* spending as a % of long-term care spending	18.4%	14.1%	12.0%	11.0%
Total home and community-based services spending as a % of long-term care spending	5.8%	16.8%	20.2%	24.7%
HCBS waivers spending as a % of long-term care spending	3.8%	8.6%	16.4%	20.8%

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

* Intermediate care facilities for the mentally retarded.

Figure 3. Institutional and Home and Community-Based Services as a Percent of Medicaid Long-Term Spending in Florida, 1990-2001



Source: CRS calculations based on Burwell, Medicaid Expenditures FY1991-FY2001. 1990 total Medicaid spending, based on HCFA 64 data provided by Urban Institute , Washington, DC.

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

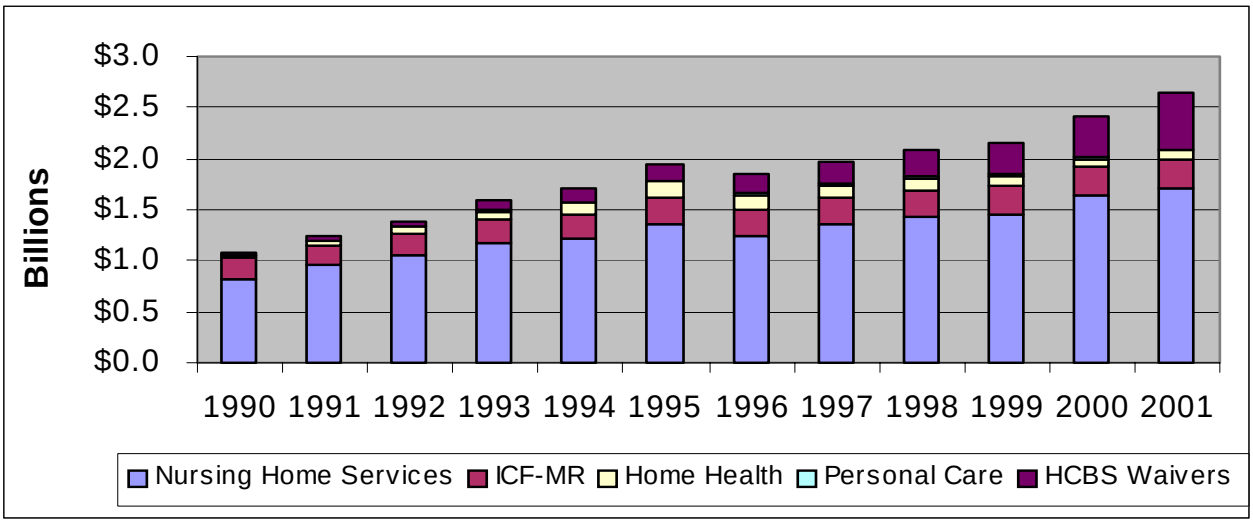
(dollars in millions)

Spending category	FY1990 (current dollars)	FY1995 (current dollars)	FY2000 (current dollars)	FY2001 (current dollars)	Percent change FY1990-FY2001 (in **constant** 2001 dollars)
Total Medicaid	$2,534.8	$6,134.1	$7,599.3	$8,683.5	169.4%
Total long term care*	$854.5	$1,751.4	$2,346.3	$2,648.3	143.8%
Total institutional care	**$804.7**	**$1,457.3**	**$1,871.8**	**$1,993.3**	**94.8%**
Nursing homes	$647.6	$1,210.6	$1,590.7	$1,702.8	106.8%
ICFs/MR**	$157.1	$246.7	$281.1	$290.5	45.4%
Total home and community based services	**$49.7**	**$294.1**	**$474.5**	**$655.0**	**936.3%**
Home health	$16.9	$139.0	$74.2	$86.0	301.5%
Personal care	$0.0	$3.7	$16.1	$17.6	-
HCBS waivers	$32.9	$151.4	$384.2	$551.3	1219.8%

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

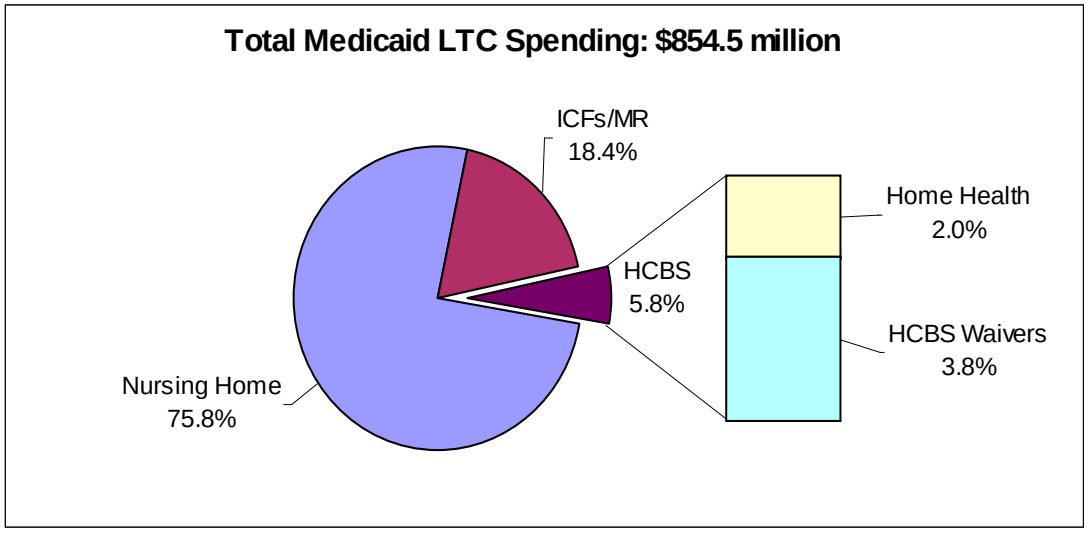
* Long Term Care includes only Medicaid LTC spending–neither private pay, Medicare, nor state programs are included.
**ICFs/MR stands for Intermediate Care Facility for the Mentally Retarded.

Figure 4. Medicaid Long-Term Care Spending by Category in Florida 1990-2001 (in constant 2001 dollars)



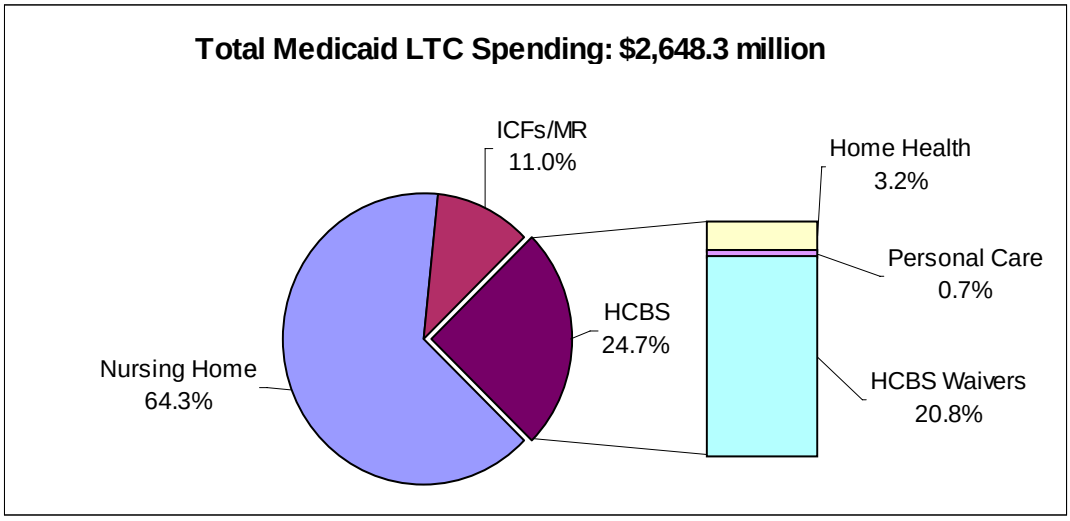
Source: CRS Calculations based on Burwell *Medicaid Expenditures FY1991-FY2001*.

Figure 5a. Medicaid Long-Term Care Spending in Florida by Category, FY1990



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

Figure 5b. Medicaid Long-Term Care Spending in Florida by Category, FY2001

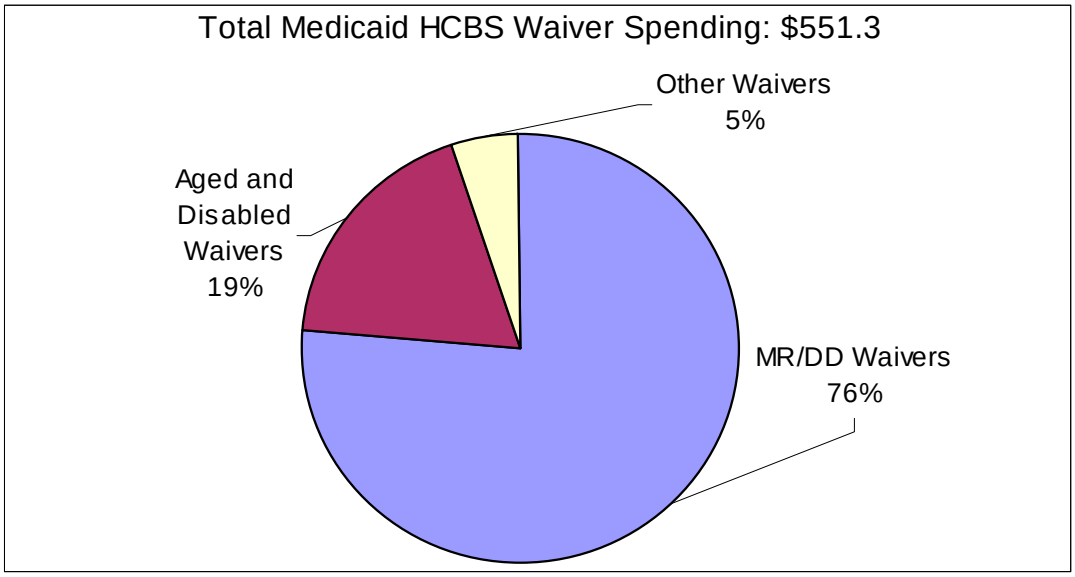


Source: CRS calculations based on Burwell, *Medicaid Expenditures* FY1991-FY2001.

Figures 5a. and **5b**. show changes in long-term care spending patterns from FY1990 to FY2001. In FY1990, 18.4% of Medicaid long-term care spending was devoted to care for persons with mental retardation in ICFs/MR; by FY2001 this spending had decreased to 11%. Additionally, nursing home spending decreased from approximately 76% in FY1990 to 64.3% in FY2001. One of the most significant changes is the increase in home and community-based services. In FY1990, of total Medicaid spending for long-term care in Florida, only 5.8% was for home and community-based services. This number has increased dramatically to almost a quarter of total spending in FY2001.

The state also increased spending for home and community-based waiver services. In FY1990, of the spending for home and community based services only 3.8% went into home and community-based waiver services. By FY2001, 20.8% of such spending was devoted to waiver services.

Figure 6. Medicaid Home and Community-Based Services Waiver Spending by Target Population in Florida, FY2001



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

Increased funding for waiver services, however, does not affect all populations equally. By far, the majority of Medicaid waiver spending is for persons with mental retardation and developmental disabilities. In FY2001, approximately 76% of waiver spending was for these individuals, with the balance allocated to other disability groups.

State Spending on Home and Community-Based Services for the Elderly

Medicaid funding represents only part of the total funding for home and community-based services. Apart from Medicaid, Florida has used different sources to fund its support services to persons age 60 and older. The following table shows the Florida Department of Elder Affairs budget for State Fiscal Year (SFY) 2002-2003. Approximately 40.8% of the total budget comes from the General Revenue and Tobacco Settlement Trust Funds. Almost 94% of funds from all sources are allocated for home and community-based services.

Table 10. Florida Department of Elder Affairs Budget, SFY2002-2003

(in millions)

Service Entity	General Revenue Fund	Tobacco Settlement Trust Fund	Federal Funds	Other Funds	Total	Percent of Total
Home and Community-Based Services*	$102.2	$24.3	$179.3	$1.4	$307.2	93.3%
Comprehensive Eligibility Services**	3.0	0.2	8.1	0.0	11.3	3.4%
Consumer Advocate Services***	2.4	0.3	1.3	0.0	4.0	1.2%
Executive Direction and Support Services****	2.0	0.0	4.9	0.0	6.9	2.1%
Total	**$109.6**	**$24.8**	**$193.6**	**$1.4**	**329.4**	**100.0%**
Percent of Total	**33.3%**	**7.5%**	**58.8%**	**0.4%**	**100.0%**	

Source: General Appropriations Act enrolled also HB29E second engrossed, also *Governor's Budget Veto List* SFY2002-2003 (figures provided by the Department of Elder Affairs budget office).

*****This includes homes and community-based waiver services, Older Americans Act programs, Alzheimer's Disease Initiative, Home Energy Assistance program, and other contracted services such as Adult Food program.
****** Florida's federally mandated Comprehensive Assessment & Review for Long-Term Care Services (CARES).
******* Long-term care Ombudsman and Public Guardian programs.
******** Administrative expenses.

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

State and federal spending for persons with mental retardation and developmental disabilities was $726 million in 2000 (**Table 11**). This represented almost a 64% increase (in constant 2000 dollars) since 1990. Florida has devoted considerable efforts to increase home and community-based services to persons with developmental disabilities and mental retardation.

In 2000, almost 67% of total spending was for home and community-based services. Of the total spending for home and community-based services in 2000, 18.5% was from federal funding for the waivers and 23.3% was from state funds. Federal spending for waivers increased by a factor 10 (in constant 2000 dollars) since 1990 (**Table 11**).

Table 11. Federal and State Spending for Institutional and Community Services for Persons with Mental Retardation/Developmental Disabilities in Florida, 1990 and 2000

(in millions of dollars)

	1990 (current dollars)	2000 (current dollars)	Percent of FY2000 total	% change in constant 2000 dollars
Services	**$357.6**	**$726.1**	**100.0%**	**63.6%**
Congregate/institutional services	**$195.1**	**$240.8**	**33.2%**	**-0.5%**
Federal Funds	$67.9	$115.2	15.9%	36.6%
State Funds	$127.2	$125.6	17.3%	-20.4%
Home and community-based services	**$162.5**	**$485.3**	**66.8%**	**140.7%**
Federal funds	$53.0	$316.2	43.5%	381.1%
ICFs/MR funds	$19.1	$44.1	6.1%	86.3%
HCBS waiver	$9.5	$134.7	18.5%	1042.5%
Title XX/SSBG funds	$11.8	$11.7	1.6%	-20.7%
Other	$12.5	$125.7	17.3%	707.4%
State funds	$109.5	$169.1	23.3%	24.4%

Source: CRS calculations based on data presented in *The State of the States in Developmental Disabilities* (Fifth Edition), by David Braddock et al. (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).

*Intermediate care facilities for the mentally retarded.
**Home and community-based waiver (Section 1915(c) of the Medicaid statute.
***Social Services Block Grant (Title XX of the Social Security Act).

Issues Facing Florida's Long-Term Care System

Florida's current publicly funded system of long-term care services has evolved over time incorporating federal, state, and local initiatives and has emerged as a loosely connected set of programs. Florida is faced with many challenges in the implementation and delivery of long-term care services. The following discussion highlights the key issues identified in state reports, and task forces, as well as issues that surfaced during CRS interviews with state officials, providers, consumers, and advocacy groups.

Institutional Bias. A recurring theme in discussions of long-term care with state officials is the view that the federal financing system guarantees heavy use of institutional care. This is largely due to the fact that nursing facility care is an entitlement under Medicaid for persons who need such care and meet the eligibility criteria. Financing of institutional care is a federal mandate; home and community-based care is not. Although states may choose to provide home and community-based services under various Medicaid options, state officials indicate that state funding constraints and the provider system that was created as a result of the institutional entitlement make it difficult to reorient the system. According to state officials, the majority of public funding for long-term care is Medicaid spending for institutional care, which leaves little funding to promote care in the community which many prefer.

Officials noted that while the rhetoric regarding changing the institutional bias has intensified over the years, actually accomplishing this objective is difficult and moving very slowly. They indicated that the impetus for heavy reliance on institutional care is built into the incentive structure for providers resulting in vast funding disparities between institutional care and home and community-based care. State officials and stakeholders stated that the institutional bias has resulted in a provider culture that is often counter to the desires of the population needing long-term care services and supports.

Another major impediment for states in planning an effective and efficient long-term care system is the difficulty of managing the interrelationship of incentives between the Medicare and Medicaid financing systems, and the effect that care of acute illnesses has on the eventual need for long-term care. Additionally, states have little control over the admission of a patient into a nursing home since the initial portion of a nursing home stay is financed by Medicare (if a person needs skilled care) or through a person's own income and assets. Once a person no longer needs skilled care or a person's income and resources are exhausted, Medicaid may finance nursing home stays.

One method to address the perceived the institutional bias is to control or downsize institutional capacity. According to the Interim Project Report by the Florida Senate, the state regulates the number of nursing home beds via the Certificate of Need (CON) program. The program requires that health care providers obtain state approval before offering new or expanded nursing home services. It is designed to ensure that the supply of beds does not greatly exceed demand, and slows

the expansion of nursing homes.[87] Senate Bill 1202 enacted on May 15, 2001, a comprehensive long-term care reform bill, placed a moratorium on the construction of nursing homes, with the intent to limit the increase in Medicaid nursing home expenditures and invest the saved funds in community-based care (see earlier description of the CON program under Trends in Institutional Care).

State officials and stakeholders indicated that the system should be changed so that nursing homes are an exception rather than the rule. From their perspective, home and community-based care should be considered first, and then, if services are judged to be inappropriate or unavailable, the alternative would be an institutional placement. In addition, state officials note the need to have in place methods to divert people from nursing homes who in are danger of spending down their income and assets and thereby establishing Medicaid eligibility. For instance, Florida has implemented the Nursing Home Diversion Waiver program in selected counties to provide home and community based services to persons who otherwise may seek nursing home care.

Lack of Statewide Home and Community-Based Services System. While Florida has made significant strides in developing initiatives to improve its long-term care services, it still lacks a strong home and community-based system. According to state officials and consumer advocates, consumers in Florida do not have access to a single source of information about long-term care. Creating a statewide system that is consumer friendly has been challenging. At present, the state is experimenting with creating an eligibility access system that is integrated with an information and referral system. The 211 pilot project[88] is being implemented by AHCA and DCF in Duval County where the eligibility determination process will be merged with an information and referral system sponsored by the United Way of North East Florida.

According to state officials and stakeholders, having several waivers to cover different populations with different sets of eligibility criteria has further complicated access to services. For instance, Florida has eleven discrete Medicaid waiver programs each covering discrete populations leading to a categorical approach to service delivery to the frail elderly and persons with disabilities.

They indicated that provider participation has been complicated by excessive bureaucratic requirements such as separate enrollment in each waiver program and a complex set of rules governing each waiver. The procedures for locating the appropriate waiver or other service program and the administering agency, and trying to fit needs into the prescribed waiver requirements, can be burdensome for clients.

According to a recent report presented to the State Legislature by the CARES program, physicians know very little about community based long-term care, and

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[87] Florida Senate *Interim Project Report 2002-136,* Nov. 2001, p. 3.

[88] The Federal Communication Commission (FCC) on July 21, 2000,designated the 3-digit telephone number 2-1-1 for easy access to community human service information. Florida is one of the states in the nation that has implemented a 2-1-1 program.

often recommend nursing home placement.[89] Additionally, at the time long-term care decisions are made, families are often in crisis and do not know that there may be alternatives to institutional care.[90]

Fragmentation of Responsibilities for Long-Term Care. According to state officials and stakeholders there is still too much fragmentation and duplication in the administration of long-term care in the state. This fragmentation stems from the multiple agencies that are responsible for administration and implementation of long-term care at the state and local levels. While one agency is responsible for determining functional eligibility, another agency is responsible for determining financial eligibility. This makes coordination of services very paper–and staff–intensive. According to a report published by the Office of Program Policy Analysis and Government Accountability (OPPAGA) (an office of the Florida Legislature), the "Medicaid waiver financial eligibility process can be labor-intensive and time-consuming which may make it difficult for some frail elders to complete." The report further stated that 1,274 clients who had applied for Medicaid waiver program financial eligibility in August 2001, had to wait an average of 5.9 months for their eligibility to be determined.[91] Moreover, according to the CARES report, due to the time it takes for financial eligibility determination, "families are more willing to place family members in nursing facilities from an acute care setting knowing Medicare will pay the bills for the short term."[92]

Most of the challenges are attributable to a lack of understanding or agreement among the parties involved with respect to final administrative authority and financing of coordinated programs. The report found that, given the complicated administrative structure and many bureaucratic layers, the Department of Elder Affairs had not been able to provide CCE lead agencies, area agencies on aging, and local service providers with "clear guidelines and timely technical assistance to enable them to effectively implement policy changes"[93] of the long-term care system in the state.

To address coordination issues, the Legislature established an Office of Long-Term Care Policy housed in the Department of Elder Affairs as part of SB1276 signed into law on May 1, 2002. This office is charged with ensuring coordination among agencies responsible for the long-term care continuum, and making

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[89] *Comprehensive Assessment & Review for Long Term Care Services (CARES): A Report to the Florida Legislature,* Dec. 31, 2002, p. 20.

[90] Ibid. p. 20.

[91] Office of Program Analysis and Government Accountability, *Justification Review Services to Elders Program, Department of Elder Affairs.* Report No.01-66, Dec. 2001, p. 22.
[http://www.oppaga.state.fl.us/reports/pdf/0166rpt.pdf].

[92] *Comprehensive Assessment & Review for Long-Term Care Services (CARES): A Report to the Florida Legislature,* Dec. 31, 2002, p. 20.

[93] Office of Program Analysis and Government Accountability, *Justification Review Services to Elders Program, Department of Elder Affairs.* Report No.01-66, Dec. 2001, p. 30. [http://www.oppaga.state.fl.us/reports/pdf/0166rpt.pdf].

recommendations to the executive agencies and the Legislature to increase quality of care and use of non-institutional settings to provide care to the elderly. The Long-Term Policy Advisory Council in the Office of Long-Term Care Policy presented its first report to the Governor and the State Legislature in February 2003. According to the report "fragmentation of services at all levels and among agencies creates unnecessary delays for clients and duplicative functions for agencies."[94]

As with long-term care services for the elderly, several agencies share responsibilities for providing services for the disabled. There are 5 different agencies that handle disability issues in Florida. Medicaid Services are handled by the Agency for Health Care Administration; the Department of Health is responsible for the licensing of healthcare workers; the state Department of Education provides vocational rehabilitation and blind services; the Department of Elder Affairs is responsible for disability issues with regard to elderly citizens in Florida; and the Department of Children and Families (DCF) is responsible for administering the Developmental Disabilities program for both children and adults.

Quality of Long-Term Care. Like many states, Florida has grappled with issues related to the quality of care provided by nursing homes and assisted living facilities. Quality of care was the basis for a large number of law suits filed against nursing homes. The State Legislature accepted suggestions from the Task Force on the Availability and Affordability of Long-Term Care, and during its 2002 session passed Senate Bill 1276 which was signed in to law on May 1, 2002. Among its provisions was the creation of a Managed Integrated Long-Term Care Pilot Program. This program will test the feasibility of having a single entity coordinate the continuum of state-funded programs for the elderly. In addition, the law provided for establishing a Consumer Directed Care Program to provide elders with choices in their long-term care, and a more direct role for the Department of Elder Affairs in the Long-Term Care Ombudsman program. Another key piece of legislation was Senate Bill 1202, a comprehensive long-term care reform bill. This bill significantly affected the funding, operation, regulation, liability coverage requirements, and litigation aspects of nursing homes and assisted living facilities (ALFs).

Long-Term Care Staffing. Perhaps the most notable provision of SB 1202 is the requirement for new staffing ratios in nursing homes and assisted living facilities. The legislation directed the Agency for Health Care Administration to adopt rules specifying a minimum staffing standard for certified nursing assistants of 2.3 hours of direct care per resident per day beginning January 1, 2002; 2.6 hours beginning January 1, 2003; 2.8 hours beginning January 1, 2004; and increasing to 2.9 hours beginning January 1, 2005. The nursing assistant staff ratio is never to fall below one certified nursing assistant per 20 residents. A minimum licensed nursing standard of 1.0 hour of direct resident care per resident per day is also established. The licensed nursing staff ratio is never to fall below one licensed nurse per 40 residents. Each nursing home is required to document compliance with these staffing standards and post the names of staff on duty daily.

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[94] Report of the Long-Term Care Policy Advisory Council, *Report to Governor Jeb Bush and the 2003 Florida Legislature*, Feb. 1, 2003, p. 6.

The bill increases the minimum amount of civil penalties for all classes of deficiencies. Penalties for class I deficiencies (deficiencies which present an imminent danger to residents or guests or a substantial probability of death or physical harm) are set at no less than $10,000, but cannot exceed $25,000 (previous fines for these type of deficiencies were from $5,000 to $25,000). The agency must levy such fines "notwithstanding the correction of the deficiency." Penalties for class II deficiencies (those that have a direct or immediate relationship to health, safety or security of residents) are set at an amount no less than $5,000, not to exceed $10,000. The penalty for a class III deficiency (an indirect or potential relationship to health, safety, or security of residents) is set at no less than $1,000 not to exceed $2,500 for each deficiency.

Another issue that faces the state is the Medicaid and Medicare reimbursement methodologies that do not provide adequate incentives for staff retention. House Bill 1971 passed by the State Legislature in 1999 created a Panel on Medicaid Reimbursement to make recommendations for Florida's Medicaid reimbursement plan. The Panel determined that quality of care for nursing home residents is likely to be affected due to the difficulty providers are experiencing in hiring and retaining staff, and improving the physical facilities.[95]

Waiting Lists for Home and Community-Based Care . *Waiting List for Frail Elderly and Disabled.* According to the Office of Program Policy Analysis and Government Accountability (OPPAGA) report, significant barriers to home and community-based services have resulted in waiting lists for services. During SFY 2002, 69,482 applicants at risk for nursing homes placement were assessed by CARES staff, and of those 23.5% of applicants were referred for waiver services. According to the CARES Barrier Report for SFY2001, 2,232 clients who were recommended for home or community-based placement could not receive such services and were placed in nursing homes. Among the reasons attributed for this situation include the following:

- many clients did not have caregivers to help them stay in the community. Of the 2,232 clients for whom home and community-based services were recommended, three-quarters did not have caregivers and were subsequently placed in nursing homes;
- some persons were placed in nursing homes before home and community-based services started. In FY2001, 8.7% of clients were on waiting lists for waiver services, when they were placed in nursing homes; and
- some individuals who applied for community based care needed specialized services such as assisted living facilities that offer mental health services. Of the 2,232 clients placed in nursing homes, 5.9% were placed in such institutions because there was lack of specialized community services.[96]

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[95] The Florida Senate, *Interim Project Report 2001-025*, Feb. 2001.

[96] Office of Program Policy Analysis and Government Accountability *Justification Review, Services to Elders Program, Department of Elder Affairs*, Report No. 01-66, Dec. 2001, p. (continued...)

Waiting List for Persons with Mental Retardation and Developmental Disabilities. The state has strongly committed itself to improving community-based alternatives for those with mental retardation and developmental disabilities. Disability advocates stated that when Governor Jeb Bush took office there was a large number of pending law suits regarding waiting lists for services for those with developmental disabilities. The number of Floridians with developmental disabilities who were being fully served was less than 10,000. Instead of contesting these law suits, the Governor proposed more funding to eliminate the waiting list. From 1999-2002, state funding for developmental services increased by 94% to a total of $975 million.

However, the waiting list issue still remains. When more people came into the program, there were not enough providers to meet the demand. The Legislature was not pleased that the increase in funds was not eliminating the waiting lists. After the events of September 11th 2001, and the economic recession, Governor Jeb Bush requested all state agencies to cut back on spending due to a decline in state tax revenue. The Developmental Disabilities program cut back by broadly defining medical necessity and publishing a new service directory. Due to the vocal advocacy of consumers, family members and advocacy organizations, the Governor expressed his desire for a system redesign to address the issues facing the Developmental Disabilities program. The Department of Children and Families is working with the Agency for Health Care Administration on a viable long-term redesign of the service delivery system that is consumer-directed and choice-based. The long-term redesign also seeks to increase efficiency and flexibility in both administrative and programmatic areas. The completed system redesign was scheduled for delivery during July 2003.[97]

For the State Fiscal Year 2002-2003, Governor Bush has requested a large amount of funds to reduce the waiting list for developmental disability services. The Governor had requested a $90 million increase in funding for the Developmental Disabilities program and the State Legislature appropriated $60 million. However, according to consumer advocates, the waiting lists do not include people currently residing in Intermediate Care Facilities (ICFs/MR) or state institutions who would like to move out. Additionally, individuals who would like to move out of these institutions are now at the bottom of the waiting list, and the general revenue funding is not available to assist them.

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[96] (...continued)
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[97] Department of Children and Families, Developmental Disabilities Program Office, *E-Bulletin* , May 10, 2002. p. 1.
[http://www.myflorida.com/cf_web/myflorida2/healthhuman/ddp/].

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

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Aged/Disabled Adult Waiver [1915 (c)] Implemented statewide on April 1, 1982	Persons age 60 or older, or age18 to 59 and determined disabled according to Social Security standards.	Meet nursing facility level-of-care criteria as determined by CARES	DOEA, CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Adult companion, adult day health care, attendant care, case aide, case management, chore services, consumable medical supplies, counseling, environmental accessibility adaptation, escort, family training, financial risk reduction, health support, home-delivered meals,	During State Fiscal Year (SFY)2002, 16,400 clients were served by the waiver. The Maximum allowable number of clients approved for the waiver is 35,652.	Annual cost per client $5,272	DOEA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
						homemaker and personal care services, nutrition, personal emergency response systems, pest control, physical risk reduction, physical therapy, respite care, skilled nursing, specialized medical equipment and supplies				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

AHCA- Agency for Health Care Administration
CARES- Comprehensive Assessment and Review of Long-Term Care Services
DCF- Department of Children and Families
DOEA– Department of Elder Affairs

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Nursing Home Diversion Waiver [1915(c)] The waiver was first implemented on March 25, 1997.	Age 65 and over	Dual Eligible for Medicaid (institutional care level) and Medicare. Live in the pilot project areas of: Orange, Osceola, Seminole and Brevard, Palm Beach, Martin, Okeechobee, Saint Lucie and Indian River counties	DOEA-CARES assessment units	300% of the federal SSI level ($1,656 in 2003/ $2,000 for an individual[a]	DCF	Adult companion, adult day health, assisted living, case management, environmental accessibility and adaptation, escort, family training, financial assessment and risk reduction, home delivered meals, homemaker, nutritional assessment and risk reduction, personal care, personal emergency response systems, respite care, occupational, physical and	During SFY2002, 1,177 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 2,300	Annual cost per client $28,104	DOEA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
						speech therapies, home health and nursing facility services.				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

AHCA- Agency for Health Care Administration
CARES- Comprehensive Assessment and Review of Long-Term Care Services
DCF- Department of Children and Families
DOEA– Department of Elder Affairs

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Channeling Waiver [1915(c)] The waiver was first implemented in July 1, 1985 in Dade and Broward counties.	Age 65 or older	Meet the nursing facility level-of-care criteria as determined by CARES. Have two or more unmet long term care service needs	DOEA-CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Adult day health care, case management, chore services, companion services, counseling, environmental accessibility adaptations, family training, financial education and protection services, home health aide services, occupational therapy, personal care services, personal emergency response systems, physical therapy, respite care, skilled	During SFY2002, 1,721 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 1,804.	Annual cost per client $8,307	DOEA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
						nursing, special home delivered meals, special drug and nutritional assessments, special medical supplies, and speech therapy				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

AHCA- Agency for Health Care Administration
CARES- Comprehensive Assessment and Review of Long-Term Care Services
DCF- Department of Children and Families
DOEA– Department of Elder Affairs

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Projects AIDS Care Waiver [1915(c)] The waiver was first implemented statewide on November 1, 1989.	Those with a medical diagnosis of AIDS	Diagnosed with AIDS; determined disabled according to Social Security administration standards; need and receive case management and have an enrolled PAC waiver case manager; not be enrolled in a Medicaid HMO or Hospice program; have a Level of Care determination for risk of hospitalization or placement in a nursing facility; be able to	DOEA/ CARES assessment units.	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DOEA/ CARES units determines level of care. Projects AIDS Care case manager completes a needs assessment.	Case management, chore services, companion, day health care, education and support, health assessment, substance-abuse treatment, home-delivered meals, homemaker, home modification, massage therapy, personal care, personal emergency response system, pest control, physical therapy,	During SFY2002, 6,658 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 10,000.	Annual cost per client $3,719	AHCA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
		remain safely at home; and have completed PAC waiver enrollment application.				respiratory therapy, respite care, skilled care, specialized medical equipment and supplies, and specialized personal care for foster children				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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CARES- Comprehensive Assessment and Review of Long-Term Care Services
DCF- Department of Children and Families
DOEA– Department of Elder Affairs

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved,	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ resource limits	Determined by					
Assisted Living for the Elderly Waiver [1915(c)] The waiver was implemented statewide on February 1, 1995.	Age 60 and older	Nursing facility level-of-care and Meet one or more of the following: 1. require assistance with four or more activities of daily living (ADLs). 2. require assistance with three ADLs plus supervision or administration of medication. 3. require total help with one or more ADLs. 4. have a diagnosis of Alzheimer's disease or another type of dementia and require assistance with two or more ADLs. 5. have a diagnosed degenerative or	DOEA, CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Case management, assisted living, and if needed, incontinence supplies. The components of assisted living include: attendant call system, attendant care, behavior management, chore, companion services, homemaker, intermittent nursing, medication administration (within the ALF license), occupational therapy, personal care, physical therapy, specialized medical	During SFY2002, 3,993 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 3,196.	Annual cost per client $7,673	DOEA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved,	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ resource limits	Determined by					
		chronic medical condition requiring nursing services that cannot be provided in a standard ALF(Assisted Living Facility), but are available in an ALF licensed for limited nursing or extended congregate care.				equipment and supplies, speech therapy				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

ACHA- Agency for Health Care Administration
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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Traumatic Brain Injury/spinal cord Injury Waiver [1915(c)]	Those with brain or spinal cord injuries ages 18 and over.	Be a client of the Brain and Spinal Cord Injury Program; meet at least level II care criteria for nursing facilities	DOEA CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Assistive technologies, attendant care, behavioral programming, case management companion services, community support coordination, environmental accessibility adaptations, life skills training, personal adjustment counseling, personal care, and rehabilitation engineering evaluation	During SFY2002, 147 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 200.	Annual cost per client $13,556	DOEA	AHCA

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Adult Cystic Fibrosis Waiver [1915(c)] Approved on September 20, 2002	Those diagnosed with Cystic Fibrosis between ages 18-59 years.	Meet the nursing facility level-of-care criteria as determined by CARES	DOEA CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	acupuncture, adult companion, adult day health, chore service, counseling (individual and family), durable medical equipment, exercise therapy, massage therapy, occupational therapy, personal care, personal emergency response service, physical therapy, prescribed drugs, respiratory therapy,	Enrollment of individuals for the waiver is scheduled to begin January 1, 2004, and the approved number of clients for the first, second and third year of enrollment are 75,115, and 150 respectively,	Not Applicable	DCF	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
						respite care, skilled nursing, specialized medical equipment and supplies, transportation, and vitamins and nutritional supplements.				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Adult Day Health Waiver [1915(c)]	Those age 75 and older	Meet the nursing facility level-of-care criteria as determined by CARES, reside in Lee or Palm Beach county, and reside with a caregiver.	DOEA CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Compre-hensive adult day health care	The program plans to serve approximately 130 clients in each of the three years it will be operational.	Not applicable	DOEA/ AHCA	AHCA

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Consumer Directed Care [Section 1115 waiver under a US Department of Health and Human Services demonstration]	Those receiving services under the Aged/Disabled waiver, or Traumatic Brain Injury/Spinal Cord Injury (TBI/SCI) waiver, or Develop-mental Services waiver.	Adults enrolled in the ***Aged/ Disabled Waiver and TBI/SCI Waiver*** residing in the following counties: Brevard, Broward, Charlotte, Collier, Dade, Hillsborough, Lee, Manatee, Martin, Okeechobee, Orange, Osceola, Palm Beach, Pasco, Pinellas, Polk, Sarasota, Seminole and St. Lucie. Adults enrolled in the ***Develop-mental***	DOEA CARES assessment units	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Clients are given the oppor-tunity to exchange their traditional waiver services for a cash option to purchase services directly from a provider of their choice.	Total participation was limited to 6,000: 3,000 experimental group members and 3,000 control group members. Enrollment for the program ended on June 30, 2002 and the total number of participants was 2,080	Annual cost per client $15,099	DOEA/ AHCA	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
		Services must reside in the above mentioned counties as well as: Calhoun, Franklin, Jefferson, Liberty, Madison, Taylor, Holmes, Jackson, Washington, Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union, DeSoto, Glades, Hendry, Flagler, Volusia, Citrus,								

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
		Hernando, Lake, Sumter, Marion, Hardee, Highlands, Indian River and Monroe.								

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved,	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
The Developmental Services (DS) Waiver Implemented on April 1, 1982, as a combined waiver with Aged/Disabled Adult Services. In order to meet the needs of these two diverse client populations, the waiver was split into separate waiver programs on June 14, 1985.	Those with Develop-mental Disabilities	Age 3 years and older. Meet the level-of-care criteria for intermediated care facilities for the mentally retarded (ICF/MR); and be enrolled in the Develop-mental Services Waiver	DCF	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Adult day training, adult dental, behavioral services, chore services, companion services, dietitian, environmental modification, homemaker, in-home supports, non- residential support services, occupational therapy, personal care assistance, personal emergency response systems, physical therapy, private duty nursing, psychological services, respiratory therapy,	During SFY2002, 24,418 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 25,352	Annual cost per client $18,417	DCF	AHCA

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved,	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
						residential habilitation, residential nursing, respite, skilled nursing services, special medical equipment and supplies, special medical home care, speech, specialized mental health services, support coordination, supported employment, supported living coaching, therapeutic massage, and transportation				

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things.

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/ slots approved,	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Monthly income limit/ annual resource limits	Determined by					
Supported Living Waiver Implemented on October 1, 1995.	Those with Developmental Disabilities	Age 18 or older, be able to direct their own support in all but limited areas, participate in the planning and implementation of support necessary to manage their households, and participate in community life, meet the level of care for intermediate care facilities for the Mentally Retarded (ICF/MR).	DCF	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual[a]	DCF	Adult day training, in-home support services, coaching, supported employment, and transportation	During SFY2002, 6 clients were served under the waiver. The Maximum allowable number of clients approved for the waiver is 200.	Annual Cost per client $5,477	DCF	AHCA

a. Certain items are excluded, such as an individual's home; up to $2,000 of house hold goods and personal effects; life insurance policies with a face value of $1,500 or less; and automobile with value up to$4,500; and burial funds up to $1,500 among other things

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Appendix 2. Population in Large State Facilities

Table A-1. Population in Large State Facilities for Persons with Mental Retardation/ Developmental Disabilities, Closure Date, and Per Diem Expenditures

Large state MR/DD or units operating 1960-2001	Year facility opened	Year closed	Residents with MR/DD on 6/30/01	Average per diem expenditures FY01($)
Florida State Hospital 1) Unit 29(MR Defendant Program	1977		95	225.25
2) Unit 27(Dually Diagnosed)	1976		29	289.43
Gulf Coast Center (Fort Meyers)	1960		309	260.13
Community of Landmark (Miami)	1966	2004/ 2005	213	322.00
North East Florida State Hospital (Mac Clenny)	1981	2000		
Seguin Unit-Alachua Retarded Defendant Center (Gainesville)	1989		32	274.93
Sunland Center (Marianna)	1961		319	222.20
Sunland Training Center (Orlando)	1960	1984		
Sunland Training Center (Tallahassee)	1968	1983		
Tacachale Community of Excellence (Formerly Sunland of Gainesville)	1921		468	312.46

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: Campbell, Paul R., 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].