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Table of Contents

Executive Summary	4
About the State Profile Tool	4
Efforts to Balance Long-Term Care Services in Florida	4
Demographic and Utilization Profiles of Florida LTC Consumers	4
Foreword	7
Organization of the Profile	9
Section I. Background	
State Demographic Characteristics	
Service Utilization Patterns	
Historical and Political Factors	
Section II. System Administration and Organization	
Section III. Services for the Elderly and Aging	21
Elderly: Programs, Population and Expenditure Trends	
Balancing Indicators for Elder Services	
Consolidated Administrative Structure	
Single Point of Access	27
Continuum of Residential Options	
Participant Direction	
Quality Management	
Nursing Home Transition Capacity	
HCBS Infrastructure Development Capacity	
Major Policy Implications	
Barriers to Rebalanced Care and Services for the Elderly	
Conclusion for Elderly Services Population	
Section IV. Services for the Developmentally and Intellectually Disabled	
DD/ID: Programs, Populations and Expenditures	
Balancing Indicators for DD/ID Services	
Consolidated Administrative Structure	
Single Point of Access	
Participant Direction	
Quality Management	
Major Policy Implications	
Conclusion for DD/ID Services Population	41

Section V. Services for the Chronically III and Physically Disabled			
Disabled Adult Programs Populations and Expenditures			
Balancing Indicators for Chronic Illness and Physical Disability Services			
Single Point of Access			
Continuum of Residential Options			
Increasing HCBS to Chronically III and Physically Disabled Adults			
Participant Direction			
Quality Management			
Conclusion for Chronically III and Physically Disabled Population			
Section VI. Services for Mental Illness and Substance Abuse			
Substance Abuse and Mental Health Programs, Populations and Expenditures			
Balancing Indicators for Mental Health and Substance Abuse Services	53		
Continuum of Residential Options	53		
Quality Management			
Major Policy Implications			
Conclusion for Mental Illness and Substance Abuse Population			
Section VII. Conclusion			
Appendix A	60		

List of Tables

Table 1. Long-Term Care Expenditures and Utilization, Florida and U.S.	17
Table 2. Florida Nursing Home Residents, Age 65+	24
Table 3. Satisfaction Survey Results	39
Table 4. Competitive Employment	39
Table 5. Supported Living	40
Table 6. Mental Health Appropriations 2008-2009	
Table 7a. Aging Programs and Services – Federal Administrative Details	61
Table 7b. Aging Programs and Services – Federal Available Services	62
Table 7b. Aging Programs and Services – Federal Available Services	62
Table 8a. Aging Adult HCBS with Federal and FL Funded Appropriations Administrative Details	64
Table 8b. Aging Adult HCBS with Federal and FL Funded Appropriations Available Services	65
Table 8c. Aging Adult HCBS with Federal and FL Funded Appropriations and Participants	65
Table 9a. Aging Services – FL Funded Administrative Details	
Table 9b. Aging Services – FL Funded Available Services	68
Table 9c. Aging Services – FL Funded Appropriations and Participants	70
Table 10a. Aging Services – Medicaid Administrative Services	73

Table 10b. Aging Services – Medicaid Available Services	. 73
Table 10c. Aging Services – Medicaid Appropriations and Participants	. 76
Table 11a. Disabled Adult Program and Services-Administrative Details	. 77
Table 11b. Disabled Adult Program and Services Appropriations and Participants	. 78
Table 11c. Disabled Adult Program and Services Available Services	. 79
Table 12a. Developmental Disabilities Programs and Services - Administrative Details	. 80
Table 12b. Developmental Disabilities Programs and Services - Available Services	. 81
Table 12c. Developmental Disabilities Programs and Services - Appropriations and Participants	. 83

List of Charts and Figures

Chart 1. Age 65+ Population Fraction	
Chart 2. Age 65+ Fraction of Age 65+ Population	11
Chart 3. Age 85+ Population Fraction	11
Chart 4. Disabled Population Fraction, 2004	12
Chart 5. Developmentally Disabled Population	13
Chart 6. Medicaid Population Fraction	14
Chart 7. Medicaid Participation Among Age 65+ Population	14
Chart 8. Florida Aging and Disabled Long-Term Care Population	15
Chart 9. HCBS Fraction of the Aging and Disabled LTC Population	
Chart 10. ICF/DD Residents Transitioned to Community Setting	
Chart 11. Organization of Florida's LTC Administration Agencies	
Chart 12. Services for Older Adults HCB Services, Participants	24
Chart 13. Services for Older Adults HCB Services, Appropriations	
Figure 1. Network of Services and Recipients	
Chart 14. Wait Lists	
Chart 15. Customer Satisfaction Items by Service	
Chart 16. Waiting List, Persons	
Chart 17. Waiting List, Average Months	
Figure 2. Quality of Life Score by Residential Type for DD/ID	
Chart 18. Adult Residential Treatment, Total Funding 2002-2008	51
Chart 19. Adult Residential Treatment, Ratio of Civil to Forensic Residents 2002-2008	

Executive Summary

About the State Profile Tool

This document describes the factors that have shaped Florida's long-term care system and its rebalancing efforts. This includes the long-term care delivery systems currently in place for the frail elderly population, people with intellectual and developmental disabilities, people with physical disabilities and chronic diseases and people with mental illness and substance abuse problems.

For each population group, this report presents information on the range of available home and community-based services (HCBS) as well as any known gaps in coverage. This profile also presents demographic and utilization trends for each population group and forecasts population increases related to the demand for long term care. Finally, each population is profiled from the perspective of relevant infrastructure components that have been previously identified by researchers as important to a balanced long term support system.

Florida has spent more than 25 years creating a more balanced long-term support system by increasing opportunities for people to live in the community and reducing the demand for institutional long-term care programs. As the state continues to rebalance its long-term care system, it is important to regularly and systematically assess these efforts. This profile of Florida's long-term support system is designed to facilitate current and future assessment of these efforts.

Efforts to Balance Long-Term Care Services in Florida

Nursing home expenditures in Florida grew from \$1.87 billion to \$2.39 billion between 2002 and 2007; however, the number of residents in Florida's nursing homes has remained relatively stable since 2000, indicating the cost of institutional care is rising. Currently, Florida spends about half the national average on HCBS programs. However, Florida expenditures have doubled from 7 percent in 2002 to 14 percent in 2007, which was the second highest increase in the nation. The ratio of Medicaid nursing home residents to HCBS participants declined from 3:1 to 2:1 between 2000 and 2006. The stabilization of the nursing home population can at least partially be attributed to expanding home and community based services (including services available in assisted living facilities). Total funding for HCBS programs has grown from approximately \$200 million in 2000 to over \$400 million in 2008.

In addition to the expansion of HCBS programs, the addition of nursing home beds has been constrained by a legislatively imposed freeze on Certificate of Need (CON) awards since 2001. The CON freeze is believed to have contributed to the steady increase in the nursing home occupancy rate, which is now approaching 90 percent in Florida. Although the CON freeze may have suppressed increases in institutionalized populations, it has also discouraged development of newer, improved facilities, and may constrain the state's ability to meet projected future increases in demand for nursing home beds.

Demographic and Utilization Profiles of Florida LTC Consumers

Florida has a history of innovation in long-term care policy and development of home and communitybased services (HCBS). This profile addresses population and long-term care service use among four distinct long-term care service customer groups. These customer groups are the frail elderly, the intellectually and developmentally disabled, the physically disabled and those with chronic diseases, and persons with mental illness and substance abuse. A summary of the demographic and service utilization issues for each group is provided below.

The Elderly Population

Population forecasts made by the State Data Center on Aging at the University of South Florida indicate a continuing high demand for long-term care by the frail elderly. By 2030, the population over age 85 is forecast to increase to 22.13 percent of the population age 65 and older (3.45 percent of the total state population). The greater percentage of the 85+ population among the aged is expected to be accompanied by a corresponding increase in the demand for long-term care services.

Despite very real funding shortfalls across the state, funding for home and community-based services for elders has received the support of political leaders as evidenced by a net increase in funds for Medicaid waivers. But continued increases in funding remain uncertain. Moreover, tens of thousands of individuals who do not qualify for Medicaid are on waiting lists or are assisted by programs exclusively funded by the state. The cost to provide the increasing need for services exceeds available state funds, and subsequently many participants receive only a few hundred dollars worth of services per year or remain on waitlists. As the population ages and service demand increases, Florida will be challenged to adequately meet this demand.

The Developmentally and Intellectually Disabled Population

The scope of services and the quality of life for persons with developmental and intellectual disabilities have improved substantially over the last 20 years. Florida serves over 70 percent of the developmentally disabled/intellectually disabled (DD/ID) population in the community, in small residential settings, single apartments, and in homes with family members or other relatives.

Adherence to a fundamental philosophy of community integration and person-centered services in conjunction with strong client advocacy has guided the development of DD/ID policy and practice for over two decades and should continue to be valuable in addressing the many challenges confronting the DD/ID community over the next several years as the need for services increases and fiscal resources come under growing pressure.

The Chronically III and Physically Disabled Population

Florida's adult population with chronic physical disabilities is not as comprehensively served as the developmentally disabled/intellectually disabled (DD/ID) or frail elderly populations. During 2008, less than 2 percent of the Medicaid dollars were spent on HCBS for this population. Long-term care support for persons with physical disabilities has largely focused on three subpopulations: persons with Adult Cystic Fibrosis, persons with HIV/AIDS and individuals with Traumatic Brain and Spinal Cord Injuries. Combined, these three populations total to approximately 110,000 people statewide, the bulk of whom are living with HIV/AIDS.

Adult Cystic Fibrosis

The Adult Cystic Fibrosis Program is administered by the Florida Department of Health and serves adults meeting Medicaid eligibility criteria. Program benefits include financial assistance with health insurance, medications, treatments, and support services that are not covered by private health insurance or Medicaid. There are an estimated 600 adults with cystic fibrosis in Florida. The ACF Program may serve up to 150 adults with CF per year and is limited to adults diagnosed with CF in cases where medical and support needs are not currently being met. Participants must meet eligibility as defined by the program, and are admitted on a first come, first served basis determined by the date the application process is completed.

HIV/AIDS

The health and social services for the HIV/AIDS population in Florida is focused on three primary goals: screening for controlling the spread of HIV, managing the services for HIV positive individuals to allow them to live longer and healthier lives, and caring for those who have AIDS. The Patient Care Section of the Department of Health's Bureau of HIV/AIDS provides a continuum of care to those who are HIV positive by ensuring the availability of a variety of health and social services. Medical care, pharmaceuticals, dental services, mental health and substance abuse counseling, medical case management and numerous support services are provided through the Ryan White Part B consortia, patient care networks and county health departments. In addition, the Patient Care Resources Section

administers special programs designed to address specific medical and social needs of HIV/AIDS clients. These programs are funded through a combination of federal and state sources. During 2008, the total allocation for patient care services was \$165 million and the HIV/AIDS housing allocation was \$4.1 million.

Although much has been done to improve service delivery for those who are currently HIV positive or suffering from AIDS, radical intervention is necessary at the education and prevention level. Using the U.S. Center for Disease Control (CDC) methodology, the Bureau of HIV/AIDS calculates approximately 5,550 Floridians were newly infected with HIV in 2006. The new estimate indicates that 36.4 of every 100,000 Floridians age 13 years and older were newly infected with HIV in 2006. This rate is more than 60 percent higher than the national rate.

Traumatic Brain and Spinal Cord Injuries (BSCIP)

The Florida Department of Health's Traumatic Brain and Spinal Cord Injury Medicaid Waiver served 336 individuals in 2007 with moderate-to-severe traumatic brain or spinal cord injuries, with an average annual cost of \$24,925 per consumer. Unlike many programs, the services provided to persons with brain and spinal cord injuries are funded by revenues from fees, fines and legal penalties. For 2007, the total budget authority for the Brain and Spinal Cord Injury Program was \$24.1 million.

The Brain and Spinal Cord Injury Program set a goal to successfully reintegrate 95 percent of their clients back into the community, refer them to the Division of Vocational Rehabilitation (VR), or enroll them in the Medicaid HCBS waiver for more extensive community support services. Of the 968 eligible clients in 2007, 89.3 percent were transferred to another agency or successfully reintegrated, which was 5.7 percent below the targeted goal.

The Mentally III and Substance Abusing Population

Mental illness is the leading cause of disability in the U.S. for people between the ages of 15 and 44 and constitutes a greater disease burden than any other health condition. Mental illness and substance abuse disorders cost the U.S. \$193 billion in lost productivity in 2002. This loss of productivity is projected to reach more than \$300 billion by 2013.

In Florida, access to mental health services expanded for the less impaired segments of the population between 1996 and 2006. However, for the same period, access to services for individuals with serious mental illness remained constant (at 22.5 percent). Fortunately, during this period, out-of-pocket costs remained constant or declined and quality of care continued to improve, especially in the area of pharmacotherapy.

Florida spends relatively little on a per capita basis on mental health, substance abuse prevention, and treatment services. Although the state has promising evidence-based programs, supported employment and housing, peer support services, and self-directed care, these programs have low enrollment and insufficient funding compared with the estimated need. Furthermore, funding for the state's most essential emergency intervention services, the Crisis Intervention and Stabilization Program, has been reduced in recent years, even as the need for crisis services increases annually. With a growing gap between needs and available funding for services, this trend is likely to continue.

Florida also has relatively few state operated psychiatric facilities. More beds will also be needed to increase the capacity of the mental health system to divert persons with serious mental illnesses from unnecessary and counterproductive involvement in the criminal justice system.

Foreword

Florida has been trying to reduce institutionalization and increase the availability of home and communitybased services, that is, "rebalance" the long-term care system, in order to increase opportunities for people to safely remain in the community. In addition to improving individuals' quality of life, rebalancing efforts will result in substantial cost savings.

As Florida continues to rebalance its long-term care system, it is important to regularly monitor and evaluate these efforts. Developing a profile of Florida's existing long-term support system and identifying challenges in service delivery for each subpopulation will strengthen the process of balancing care alternatives in the future.

Potential Benefits of the Profile of Florida's Long-Term Care Rebalancing Efforts

- Provide policymakers and stakeholders with a high-level view of the long-term support system, to ensure a common knowledge base;
- Identify opportunities for improved coordination among long-term support programs and with other health and social services;
- Acknowledge successes that have occurred and identify positive trends;
- Identify opportunities to meet service demand at less cost;
- Identify service gaps and barriers to improved care; and
- Provide a framework for comparing rebalancing efforts that transition residents safely to the community across states.

The Centers for Medicare and Medicaid Services (CMS) have supported state rebalancing efforts in several ways, including policy changes that allow states more Medicaid flexibility to design their long-term care systems and seed money for new initiatives through the Real Choice Systems Change (RCSC) Grants. The creation of this profile was made possible by the RCSC State Profile Tool Grant funded by CMS.

This profile is based in very large part on the "Profile of Florida's Long-Term Care Rebalancing Efforts State Profile Tool and Literature Review" developed under contract for the Florida Department of Elder Affairs in June 2009 by Glenn Mitchell and Larry Polivka of the Florida Policy Exchange Center on Aging at the University of South Florida (USF). Changes to the document developed by USF were made in an effort to comply with CMS' requirements as defined in the technical assistance guide designed by Thomson Medstat and the profile of Pennsylvania's long-term care system, *Profile of Pennsylvania's Long-Term Care System.*¹

The Profile of Florida's Long-Term Care Rebalancing Efforts State Profile Tool and Literature Review drew on a variety of state and federal sources, interviews with many Florida policy makers, and extensive reviews of the scholarship on long-term care and efforts to rebalance from institutional settings to receive care that allows people to safely remain in the community. A stakeholder meeting was held in September 2008 at the Florida Department of Elder Affairs where candidate measures for Florida's state profile were identified and a timeline for submissions by Florida departments and agencies was agreed upon. A second stakeholder meeting was held in May 2009, where a draft of the report was reviewed by the stakeholders and suggested changes were submitted.

¹ Eiken, S., Nadash, P. & Burwell (2006). Profile of Pennsylvania: A model for assessing a state long-term care system. Prepared by Thomson Medstat for U.S. Department of Health and Human Services, Disabled and Elderly Health Programs Group: Baltimore, MD.

The following individuals attended the stakeholder meetings and/or provided information for this report through stakeholder interviews:

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Organization of the Profile

Florida's profile begins with a background section focusing on the factors that have shaped the state's long-term support system and rebalancing efforts. These aspects include demographic indicators of long-term care demand, traditional service utilization patterns and the support system's unique historical, economic and political characteristics.

The next section introduces the government agencies responsible for publicly funded services and describes the roles the legislature, consumers, families, providers, and advocacy groups have typically played in systems change.

This report describes the long-term care delivery systems for groups that account for the majority of adults who use long-term care and may benefit from home and community-based services (HCBS). These groups are: the elderly, intellectually/developmentally disabled people, chronically ill or physically disabled people, and people with mental disorders or substance abuse problems.

This profile presents data and trends for each population group that have been identified as important to a rebalanced long-term support system. Relevant factors for each population group include:

Consolidated state agencies – a single agency for both institutional and community services that coordinates policies and budgets to promote community options;

Single access points – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of available options before receiving more restrictive services;

Institution supply controls – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;

Transition from institutions – outreach to identify and provide assistance to residents who want to move from a nursing home and can safely return to the community;

A continuum of residential options – availability of support services in a range of options from mainstream single family homes and apartments to integrated group settings for people who need 24-hour supervision or support;

HCBS infrastructure development – recruitment and training to develop a sufficient supply of providers with the necessary skills and knowledge to encourage consumer independence;

Participant direction – people who receive HCBS having primary decision making authority over their direct support workers and/or their budget for supports; and

Quality management – an effective system that measures whether the system achieves desired outcomes and meets program requirements and identifies strategies for improvement.

Section I. Background

Relevant Factors Shaping Florida's Long-Term Care System

- High proportion of elders;
- Historical use of service; and
- > Political and organizational structure.

State Demographic Characteristics

Population forecasts for Florida made by USF indicate an increasing demand for long-term care. Analysts at the State Data Center on Aging at the University of South Florida have prepared long-term care population forecasts through 2030 for Florida statewide, by region, and by county.

Elderly

The total population of Florida in 2007 was 18,428,546 persons. Persons age 65+ were 16.7 percent of Florida's general population (3,082,772) individuals. Nationally, persons age 65+ were 12.8 percent of the population in 2007, and have averaged 12-13 percent of the population since 1990.



Chart 1. Age 65+ Population Fraction

Sources: Population Projections Program, Population Division, U.S. Census Bureau State Data Center on Aging, University of South Florida.

There is a downward trend in the proportion of the Florida population that is age 65+. The average age of the population will decrease by 2030, with the population age 65+ dropping from 16.73 percent in 2007 to 15.58 percent in 2030.





Sources: Population Projections Program, Population Division, U.S. Census Bureau State Data Center on Aging, University of South Florida.

In 2007, the age 85+ population was 15.6 percent of the age 65+ population for Florida (480,968 individuals). As a percentage of the general population, the age 85+ population was 2.6 percent of the general population. This is well above the 2007 national population of 1.8 percent for persons age 85+.

Chart 3. Age 85+ Population Fraction



Sources: Population Projections Program, Population Division, U.S. Census Bureau State Data Center on Aging, University of South Florida.

By 2030, the age 85+ population is forecast to increase to 22.13 percent of the age 65+ population (3.45 percent of the general population). The oldest and frailest among the age 65+ population will increase from approximately one in six to a little more than one in five by 2030. The greater preponderance of the 85+ population among the aged is assumed to be accompanied by greater frailty and a corresponding increase in the demand for long-term care. This supports the expectation that the demand for long-term care will grow substantially through 2030.

Intellectual, Developmental and Physical Disabilities

The proportion of disabled Floridians is slightly lower than the U.S. average and is most pronounced among persons age 65+.





In 1994 and 1995, the National Health Interview Survey included a Disability Supplement (NHIS-D). This was used to collect information about disabilities as part of annual census based household interview surveys. The prevalence of intellectual disabilities (ID) in the non-institutionalized population of the United States was estimated to be 7.8 people per thousand (.78 percent). For developmental disabilities (DD), the estimate was 11.3 people per thousand (1.13 percent). The combined prevalence estimate of DD/ID was 14.9 per thousand (1.49 percent) (Larson, Lakin, Anderson & Kwak, 2001).² If the prevalence of 14.9 persons per thousand is applied to the Florida general population, the 2007 estimate for developmentally disabled would be 274,585 individuals. This is projected to grow to 393,778 individuals by 2030.

Source: U.S. Census Bureau, American Community Survey.

² Larson, S. Lakin, K., Anderson, L. & Kwak, N. (2001). Demographic characteristics of persons with MR/DD living in their own homes or with family members: NHIS-D analyses. *MR/DD Data Brief, 2*(2). Minneapolis, MN, University of Minnesota, Research and Training Center on Community Living.



Chart 5. Developmentally Disabled Population

The 1994 and 1995 NHS surveys with the disability supplements identified and compared noninstitutionalized Americans with different types and degrees of disability on a wide range of demographic, health status, functional, socioeconomic, and other factors. Among the more notable demographic differences between children and adults with disabilities and those in the survey who did not have disabilities were the significantly higher prevalence rates among males (18.7 per 1,000) compared to females (11.3 per 1,000); blacks (24.3 per 1,000) compared to whites (13.6 per 1,000); young children (38.4 per 1,000) compared to adults age 18 and older (7.9 per 1,000); and those living below the poverty level (36.1 per 1,000) compared to those living at or above the poverty level (11.3 per 1,000). These predictors are highly correlated with one another, and interaction terms show moderation effects of different factors on prevalence outcomes in some groups. For example, the racial group difference in prevalence rates disappears after controlling for the socioeconomic variables of income and educational status. While socioeconomic status is a key predictor of DD/ID, it is also important because eligibility for Florida Medicaid is the main mechanism through which the disabled receive needed care and services.

Florida's Medicaid population is projected to grow faster than the general population through 2030. The annual growth rate is projected at 6.6 percent, which is more than three times the projected annual growth of Florida's general population (1.89 percent). Medicaid enrollment during 2007 was 1,389,427 persons. As a percentage of the Florida general population, the Medicaid participation rate was 7.54 percent. The population fraction eligible for Medicaid is projected to double to 15.74 percent by 2030. The population fraction age 65+ eligible for Medicaid services will increase to 1 in 4 by 2030 (25.94 percent). The adult disabled Medicaid population is forecast to experience a higher statewide growth rate relative to the aged population: an annual increase of 7.2 percent.

Sources: Population Projections Program, Population Division, U.S. Census Bureau State Data Center on Aging, University of South Florida.





The proportion of Floridians age 65+ participating in Medicaid is expected to increase to 1 in 4 by 2030 (25.94 percent). The adult disabled Medicaid population is forecast to experience a higher statewide growth rate relative to the elderly population: an annual increase of 7.2 percent.

Chart 7. Medicaid Participation Among Age 65+ Population



Source: State Data Center on Aging, University of South Florida.

Like the Medicaid population, the combined aged and disabled LTC population is projected to grow faster than the general population through 2030. There were 195,513 individuals during 2005 participating in aged and disabled LTC subsidized by the state of Florida; 67.52 percent were adults age 65+. Between 2000 and 2030, Florida aging and disabled LTC population growth is projected to grow 4.2 percent annually.



Chart 8. Florida Aging and Disabled Long-Term Care Population

Source: State Data Center on Aging, University of South Florida.

The publicly-funded Long-Term Care (LTC) programs supported by both Medicaid and state revenues include the following:

Long-term nursing home state plan	Consumer Directed Care Plus (CDC+)
Long-term home health state services	Developmental Services Waiver
Hospice state plan service	Family Supported Living
Assistive Care Services	Familial Dysautonomia
Program of All inclusive Care for the Elderly (PACE)	Frail/Elderly Program
Aged and Disabled Adult Waiver	Nursing Home Diversion
AIDS Waiver	Alzheimer's Disease Initiative (ADI)
Alzheimer's Disease Waiver	Community Care for the Elderly (CCE)
Assisted Living for the Frail Elderly Waiver	Contracted Services (CS)
Brain and Spinal Cord Waiver	Home Care for the Elderly (HCE)
Channeling	Local Services Program (LSP)
Adult Health Day Care Waiver	Older Americans Act services (OAA)

Persons enrolled in home and community based services (HCBS) are a subpopulation of the overall longterm care population. In the case of Medicaid waivers and demonstration projects, HCBS participants must meet nursing home Level of Care (LOC) need determinations, and some programs require higher levels of impairment. The HCBS population is distinct from the LTC population through the exclusion of long-term nursing home care and hospice care, and is composed of individuals with a demonstrated ability to be safely served in the community through case management and services offered at home or locations such as adult day care centers.





The HCBS fraction within the LTC population has an upward trend that suggests expanding participation in community alternatives. This is especially the case for the disabled adult population. By 2010, just over 65 percent of the aged LTC population is expected to be served through HCBS programs, a rate that by 2030 is expected to climb to 80 percent of the aged LTC population and to over 85 percent for disabled adults participating in LTC. Statewide growth in HCBS is expected to increase by 6.7 percent annually, and be 200 percent of current participation rates by 2030.

Service Utilization Patterns

Florida's demographic characteristics and service utilization patterns provide important context to Medicaid funding for long-term care. There were 76,520 individuals with Florida Medicaid expenditures for skilled nursing facility (SNF) care during 2006, and 82.83 percent were for individuals age 65+. Among residents of Florida age 65+, 2.09 percent experience one or more days of Medicaid paid nursing home care annually. While the number of Medicaid nursing home residents has dropped in recent years (from 66,476 during 2000 to 58,778 during 2007) and the number of nursing home days has also decreased 1.8 percent between 2005 and 2006, the proportion of Medicaid expenditures for nursing home care has increased 2.11 percent. The increase in the proportion of Medicaid expenditures for nursing home care is the result of an increase in the statewide average per diem nursing facility reimbursement rate. Overall, total Medicaid expenditures by the state of Florida decreased by 4.56 percent from 2005 to 2006.

Florida spends a smaller proportion of its Medicaid expenditures on LTC, compared with the national average. Within the LTC service continuum, Florida spends a much larger share on nursing home care than the national average and, conversely, a smaller share on HCBS alternatives.

Source: State Data Center on Aging, University of South Florida.

	2005		2006	
	Florida	U.S.	Florida	U.S.
Medicaid expenditures, in thousands	\$13,370,794	\$303,608,819	\$12,760,808	\$298,743,621
Proportion of Medicaid budget spent on LTC	26.39 %	33.24 %	30.03 %	31.64 %
Proportion of Medicaid budget spent on nursing facilities	16.67 %	15.64 %	18.78 %	15.97 %
Proportion of Medicaid LTC budget spent on nursing facilities	63.16 %	49.42 %	62.08 %	48.04 %
Per capita Medicaid expenditures	\$752.51	\$1,024.29	\$705.41	\$997.81
Per capita Medicaid expenditures on long-term care	\$198.59	\$340.47	\$211.83	\$315.71
Per capita Medicaid expenditures on HCBS	\$73.16	\$172.21	\$80.33	\$164.04
Per capita Medicaid nursing facility expenditures, per person 65+	\$746.42	\$1,290.68	\$788.91	\$1,282.82
Medicaid nursing facility days, per thousand persons 65+	5707		5505	
Per diem nursing facility reimbursement rates	\$133.03		\$137.87	
Total nursing facility residents, per thousand persons 65+	26		25	

Table 1. Long-Term Care Expenditures and Utilization, Florida and U.S.

Sources: Burwell, Brian; Sredl, Kate; and Eiken, Steve. "Medicaid Long-Term Care Expenditures in SFY 2006." Thomson Medstat.; State Data Center on Aging, University of South Florida.

Florida has had success with transitioning persons with developmental disabilities and intellectual disabilities (DD/ID) from institutional care. Using Florida's population in 2007 and national estimates of prevalence, Florida's DD population estimate for 2007 was 274,585 individuals (18,428,546 * 0.00149 = 274,585). The number of persons resident in a Florida ICF/DD facility was 2,961. This translates into about 1 percent of the estimated DD population was resident in an ICF/DD facility (1.08 percent).

Intermediate Care Facilities for the Developmentally Disabled (ICFDD) are the institutional locus for individuals with profound developmental disabilities, especially those with complex medical needs. There is a strong, downward trend to Medicaid ICFDD residents in Florida. During the ten year period between 1998 and 2008, the number of residents declined from 3,568 to 2,961, which corresponds to a 17 percent decline. This decline is due in part to the implementation of a rigorous eligibility criterion. For the Agency for Persons with Disabilities (APD) to determine that ICFDD services are medically necessary, a recipient must meet the criterion from a uniform assessment of need and must receive a written certification of medical necessity from a doctor of medicine or osteopathy.

Historical and Political Factors

The early development of Florida's LTC support system has had an enduring effect on the current system of HCBS alternatives. Lawsuits by institutional ICFDD residents have had a profound impact on Florida's rebalancing efforts. This section describes three particularly influential historical and political characteristics of Florida's long-term support system: the state's long tradition of state-funded community supports, the complex array of programs developed to target particular circumstances, and lawsuit mandated facility closures. Within this context, the state of Florida has implemented several policies, practices, and programs that have resulted in an extensive infrastructure for the delivery of a wide range of LTC services, including HCBS support services.

History of Innovation in Home and Community-Based Services

Florida has a history of innovation in long-term care policy and program development. Florida was among the first states to implement a statewide in-home long-term care services program, the state funded Community Care for the Elderly (CCE) program and the second state to develop a prototype of consumer directed care, the Home Care for the Elderly (HCE) program, which followed the implementation of the California In-Home Supportive Services (IHSS) by only four years in 1977. Florida was also among the earliest states to develop an Alzheimer's disease specific program, the Alzheimer's Disease Initiative (ADI) program, in 1987. More recently, Florida has been a pioneer in the development of managed care approaches to the financing and delivery of long-term care services through the Long-Term Care

Community Care Diversion Project, known as Nursing Home Diversion Waiver Program, which was initiated in 1999. Florida has made major investments in its largest HCBS Medicaid waiver program (Nursing Home Diversion Waiver Program) since 2002 and has made steady progress in expanding the availability of HCBS support options in recent years. Florida has developed several Medicaid HCBS waivers to serve more individuals and to provide a richer service package. State funded programs still serve tens of thousands of individuals who are on a waiver waiting list or who do not qualify for Medicaid services. In Florida, the increasing need for community supports has outstripped the available state funds. Many participants receive only a few hundred dollars worth of services per year through programs like HCE. The state of Florida will continue be challenged to adequately fund its current array of state funded programs, especially as the population ages and service demands continue to increase.



Chart 10. ICF/DD Residents Transitioned to Community Setting

Source: Florida Medicaid program administrators as a result of directed interviews.

The decline in ICF/DD residency is also the result of efforts by the state of Florida to comply with the lawsuit settlement in the Brown v. Bush lawsuit. Since 2004, the Agency for Persons with Disabilities has transitioned individuals who were class members of the Brown v Bush lawsuit. Items included in this lawsuit settlement agreement included the closing of the Community of Landmark (accomplished 2005) and the closing of Gulf Coast Center (slated to close 2010). APD has requested and has been allocated funding for a specified number of individuals per year to safely transition from the DDCs to the community. Transition of class members from DDCs to the community follows a request from the guardian and the securing of appropriate alternative community living arrangements.

Annually, during the development of the individual support plan, the interdisciplinary team, the consumer and the individual's family or other advocate discuss and plan for present and future living arrangements. If a resident or legal guardian requests community living, and if the interdisciplinary team agrees that community living is appropriate and can be safely provided, a referral is made to APD Area Placement Planning staff. While the state of Florida is still in the implementation phase of the Brown v Bush lawsuit settlement agreement, individuals who requested community living and for whom the interdisciplinary team agreed that community living was appropriate are given the opportunity to transition to the community with special funding granted by the Florida Legislature. Forensic residents who are court ordered into secure facilities are not included as class members of the Brown v Bush lawsuit.

Section II. System Administration and Organization

Florida has a diverse system for LTC support services. Administrative responsibility for long-term care services is distributed among several departments and agencies based on the nature of the disability and the client population. For example, Department of Veterans Affairs handles the medical and long-term care needs for veterans with service related injuries.

Florida Departments and Agencies with Responsibility for LTC Supports

- Florida Agency for Health Care Administration (AHCA)
- Florida Agency for People with Disabilities (APD)
- Florida Department of Children and Families (DCF)
- Florida Department of Elder Affairs (DOEA)
- Florida Department of Health (DOH)
- Florida Department of Veterans Affairs (DVA)

State funded care in Florida is roughly divided into Medicaid and non-Medicaid populations. Non-Medicaid programs include a mix of federal and state funded appropriations. The Agency for Health Care Administration (AHCA) is responsible for Medicaid program development and management. The Department of Children and Families (DCF) determines consumer financial eligibility for Medicaid programs and services. In addition, AHCA contracts with other Florida departments to manage its programs and services. For example, AHCA contracts with Florida Department of Elder Affairs (DOEA) to manage a large number of waivers and demonstration projects the offer services to aging adults. To accomplish this, DCF and DOEA contract with regional resource centers, lead agencies and planning agencies to assist the department(s) with prioritization, case management, care planning, and provider recruitment. In some cases, there are multiple levels of organization (see Figure 1 on the following page). For example, there are eleven Area Agencies on Aging (AAAs) in Florida which function as Aging Resource Centers (ARCs). They contract with a number of Community Lead Agencies for case management and care planning to assist consumers with program enrollment and services from service providers. Aging Resource Centers help ensure that consumers and service recipients are well apprised of their eligibility and choices, and may be the most important determinant of consumer selection into HCBS care and services.



Chart 11. Organization of Florida's LTC Administration Agencies

Section III. Services for the Elderly and Aging

The expansion of home and community based services has become a major public policy priority in many states since the late 1990s. Nationally, HCBS Medicaid expenditures have grown much faster than Medicaid nursing home spending in recent years and total HCBS spending now exceeds 25 percent of all LTC expenditures. Florida, like most states, is now spending considerably more on home and community based LTC services than ten years ago. The major source of this increase is the Nursing Home Diversion Waiver Program, which has grown by more than \$200 million since 2000. The waiver funded Assisted Living Program has also grown during this period to \$31 million, providing 3,300 slots in 2008. These expanded HCBS options have helped increase the percentage of individuals diverted from nursing home placement from 26 percent in 2004, to 30 percent in 2007. Unfortunately, many ALF's still refuse to accept Medicaid clients under the ALE Waiver program.

The SSI/OSS funded Assisted Living Program has also grown since 2000 for the program now receives Medicaid funding through the Assistive Care Services Program (\$160.00 per person per month), which provides a match to the OSS payment (\$180.00 per month). This additional Medicaid funding has made the program more attractive to ALF providers and helped boost the number of residents in the program from about 10,000 in 2000 to over 13,000 in 2008.

Since 2000, the increased funding for nursing home preadmission screening staff has helped the state substantially improve its capacity to provide safe community based long-term care services. The state's major HCBS programs are described below. More detailed information on the funding and scope of each program is available in Appendix 'A' of this report.

Home and Community-Based Service Programs for the Elderly

Alzheimer's Disease Initiative (ADI)- is a Florida state funded program created in 1985 to provide a set of services to help meet the needs of individuals and families affected by Alzheimer's disease and similar memory disorders. \$27.7 million was expended by the state in 2008 on ADI services serving 2,225 aging adults with respite care and 4,745 with memory disorder clinic services. Supportive services include adult day care, counseling, consumable medical supplies, and respite for caregiver relief. Eligible participants include caregivers for adults 18 years and older diagnosed as having probable Alzheimer's disease (or other related memory disorders) and individuals diagnosed or suspected of having a memory loss where mental changes appear and gradually interfere with the activities of daily living.

Alzheimer's Disease Waiver- is a Medicaid HCBS waiver providing specialized services to maintain individuals with Alzheimer's disease in the community. Currently, program services are only available in Broward, Miami-Dade, Palm Beach and Pinellas counties. 406 individuals were served by the Alzheimer's Disease Waiver in 2008 with total funding of \$5.1 million. Available services include case management, adult day health care, respite care, wandering alarm system, wanderer identification and location program, caregiver training, behavioral assessment and intervention, incontinence supplies, personal care, environmental modification, and pharmacy review.

Community Care for the Elderly (CCE)- is a state funded program providing community based services to assist functionally impaired older people to live in the least restrictive environment suitable to their needs. Florida expended \$43.4 million on CCE services during 2008, providing HCBS care to 19,232 individuals. Available HCBS include services like adult day care/health care, case management/aide, escorts, chores, medical supplies, counseling, emergency alert response, emergency home repair, delivered meals, home health aides, companions, homemaker, nursing, legal assistance, material aid, medical therapeutic services, respite, shopping assistance, and transportation. Individuals must be age 60 or older and functionally impaired as determined by an initial comprehensive assessment and annual reassessments.

Contracted Services- is a relatively small state-funded program available in Broward, Palm Beach, and Miami-Dade counties, with \$1.1 million in services during 2006 for 13,349 individuals. Available services include congregate and home delivered meals, recreation, transportation, homemaker services, and nursing and health support services. Participants must be age 60 or older, however, there are no income or co-payment requirements. Instead, emphasis is placed on targeting those with greatest need.

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Home Care for the Elderly (HCE)- a state funded program encouraging the provision of care for elders age 60 and older in family-type living arrangements in private homes as an alternative to institutional or nursing home care. Florida expended \$9.5 million on HCE services during 2008, serving 5,240 aging adults. A basic subsidy is provided for support and maintenance of the elder (\$106 per month), including some medical costs, and a special subsidy may also be provided for services/supplies. Participants must be age 60 or older, have low income, be at risk of nursing home placement, and have an approved adult caregiver living with them.

Local Services Program (LSP)- a state funded program expanding long-term care alternatives to enable elders to maintain an acceptable quality of life in their own homes and avoid or delay nursing home placement. LSP projects are identified each year in the General Appropriations Act, which is the annual budget passed by the Florida Legislature. LSP served 33,634 individuals during 2008 with \$8.8 million in HCBS. Participants in Local Services Programs must be age 60 and older, however there is no income requirement. Instead, emphasis is placed on targeting those with greatest need.

Channeling- the Channeling for Frail Elders waiver provides an array of services for frail elders who need services to prevent or delay placement in a nursing home. Participants must be 65 or older, live in Broward or Miami-Dade counties, have two or more unmet service needs, and meet nursing home level of care requirements. 1,627 individuals were served using the Channeling waiver, with total funding at \$14 million in 2008. Available HCBS include adult day health care, adult companions, case management, chores, , environmental accessibility adaptations, family training, financial education and protection, home health aides, in-home counseling, occupational therapy, personal cares, emergency response systems, physical therapy, respite care, skilled nursing, special drug and nutritional assessments, home delivered meals, medical equipment, medical supplies, and speech therapy.

Consumer Directed Care Plus (CDC+)- a Medicaid HCBS waiver that encourages participants and their families to make choices about purchases from both formal and informal sources of care that best meet their needs. 197 individuals participated in CDC+ with total appropriation of \$2.7 million in 2006. Consumers are given a monthly budget to purchase the amounts and types of long-term care supplies and services they need from providers they choose. Providers may include family members, friends and neighbors, as well as home care agencies and contractors.

Frail/Elderly Program (FEP)- provides, coordinates, and manages LTC support services for the frail and elderly who need services to prevent or delay placement in a nursing home. 2,166 individuals participated in FEP with total funding at \$33.9 million in 2008. Adults age 60 and older are the largest component of FEP (83.3 percent), comprising approximately five out of six participants in the program. This program is offered as an option by Medicaid HMOs. Services include case management, adult day health care, acute care services, adaptive equipment, medical supplies, homemaker/personal care, home health services, caregiver training, financial education, emergency alert response systems, identity bracelets, pharmaceutical management, respite, and nursing home services.

Medicaid Aged and Disabled Adult Waiver (ADA Waiver)- an HCBS program that was implemented statewide on April 1, 1982. The Florida Department of Elder Affairs and the Department of Children and Families have operational responsibility for the A/DA Waiver. To be eligible for the Aged and Disabled Adult Waiver program, an individual must be 60 years old or older or be ages 18 to 59 and determined disabled according to Social Security standards; meet Supplemental Security Income (SSI), or Medicaid waiver assistance income and asset requirements; meet nursing facility level-of-care criteria as determined by CARES; and be in need of waiver services.

Waiver services include 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, 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, and speech therapy. Nursing home services are not included in this program. The elderly adult component for the ADA waiver is a relatively large fraction of the overall ADA waiver population – approximately five out of six participants are elderly adults. Total funding for the 60 and older portion of the ADA waiver in 2008 was \$85.4 million, providing HCBS care services to 10,806 individuals.

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Medicaid Assisted Living for the Elderly (ALE Waiver)- is an HCBS waiver serves clients age 60 and older who are at risk of nursing home placement and meet additional specific functional criteria. 3,186 individuals participated in the ALE HCBS waiver with total funding of \$33.2 million in 2008. Recipients receive services in Assisted Living Facilities (ALFs) with Extended Congregate Care or Limited Nursing Services licenses. Available services include case management, attendant call system, attendant care, behavior management, chores, companions, homemakers, intermittent nursing, medication management, occupational therapy, personal care, physical therapy, specialized medical equipment and supplies, respiratory therapy, speech therapy and therapeutic social and recreational services.

Nursing Home Diversion Waiver Program- also called the Long-Term Care Community Diversion Pilot Project, this is designed to target the frailest individuals who would otherwise qualify for Medicaid nursing home placement, through the provision of long-term care services, including home and community based services, Medicaid covered medical services for persons who are dually eligible (e.g., prescription drugs, Medicare coinsurance and deductibles), and nursing home care. Managed care organizations and other qualified providers receive a 'per member/per month' capitation payment to provide, manage and coordinate the enrollee's full continuum of long-term care. Total funding for 2008 was \$224.3 million, and served 13,024 participants in 32 counties. Available services from the 15 participating providers include adult companionship, adult day health, assisted living services, case management, chore services, consumable medical supplies, environmental accessibility adaptation, escort, family training, financial assessment/risk reduction, home-delivered meals, homemaker, nutritional assessment/risk reduction, personal emergency response systems, respite care, occupational, physical and speech therapies, nursing facility services, prescribed drugs, visual/hearing/dental, and optional transportation.

Program of All Inclusive Care for the Elderly (PACE)- is a project within the Long-Term Care Community Diversion Pilot Project (see separate program listing) targeting individuals who would otherwise qualify for Medicaid nursing home placement and providing them with a comprehensive array of home and community based services at a cost less than nursing home care. It uses a unique service delivery system, with many services being delivered through adult day care centers and case management provided by multidisciplinary teams. In addition to services covered under the Long-Term Care Community Diversion Pilot Project, the PACE project includes all Medicare covered services. Providers receive both Medicare and Medicaid capitated payments and are responsible for providing the full continuum of medical and long-term care services. PACE sites receive an enhanced capitation payment from Medicare, beyond that of a traditional Medicare HMO. 550 individuals participated in PACE in 2008, with total funding of \$7.1 million.

Assistive Care Services (ACS)- is a Medicaid state plan service that provides care to eligible participants who require an integrated set of services on a 24-hour-per-day basis. 15,021 individuals participated in ACS in 2006, with total funding of \$31.9 million. To participate in ACS an individual must be at least 18 years of age, be Medicaid eligible, be assessed by a physician or other health care practitioner as needing at least two of the four ACS components below, and be a resident of an ACS enrolled assisted living facility (ALF) or adult family care home (AFCH). ACS participants must demonstrate functional deterioration that makes it medically necessary for them to live in a supportive setting and receive integrated services. ACS includes assistance with four main service components: activities of daily living (bathing, walking, toileting), instrumental activities of daily living (shopping or making a telephone call, self-administered medications), and health support (observing the recipient's state of health and well-being on a daily basis and reporting changes to the health care provider, as appropriate).

Elderly: Programs, Population and Expenditure Trends

The number of aging adults resident in a Florida nursing home has increased slightly between 2000 and 2008, with a 0.6 percent average annual growth. In comparison, the Medicaid nursing home population decreased on average by 1.6 percent annually, a slight but steady decline. Florida Medicaid purchases or finances the nursing home care for approximately one-quarter of all nursing home residents. The total nursing home census includes both long-term and short term residents. Short term residents are mostly post acute rehabilitation, largely subsidized by Medicare. Long-term nursing home stays are not covered by Medicare.

Table 2. Florida Nursing Home Residents, Age 65+

	2000-2001	2007-2008
Florida NH Population	215,861	227,646
Florida Medicaid NH Population	66,476	58,778
Medicaid NH Fraction (short term stays)	30.8 %	25.8 %

Note: NH residents include any person with a stay of one day or longer in a Florida nursing home. **Source:** Florida Medicaid MIS Database and Florida Minimum Data Set (MDS II).

The ratio of nursing home residents to home and community based service (HCBS) participants is one potential measure of rebalancing. Among the Florida general population age 65 or older, there are 1.6 nursing home residents for each participant in subsidized HCBS long-term care. Subsidized HCBS long-term care includes federal programs such as Older Americans Act services, Florida state funded programs for the elderly, and Florida Medicaid services. This ratio worsened slightly between 2000 and 2008. During 2000, there were approximately three Medicaid participants resident in a nursing home for each participant in HCBS waivers and demonstration projects. This ratio decreased to just under 2:1 by 2008. The increase in participation in the last seven years has averaged about 24 percent a year. Corresponding with this increase is an expanded appropriation for aging adult HCBS, which increased 27.7 percent annually, amounting to a 193.6 percent increase between 2000 and 2008.

Chart 12. Services for Older Adults HCB Services, Participants



Source: Florida DOEA Client Information and Registration Tracking System (CIRTS) Database Florida Medicaid (FMMIS) Database

The proportion of HCBS dollars provided by the state has decreased between 2000 and 2008. At the beginning of the decade, state funds were the predominant appropriation source. Federal appropriations (including the Medicaid match) now comprise slightly more than half of the total appropriations for Florida HCBS for the elderly.



Chart 13. Services for Older Adults HCB Services, Appropriations



Approximately one-half of the Floridians age 60 and older who receive publicly-funded home and community based services (HCBS) participate in programs funded entirely by the federal government. Programs funded entirely by the state serve approximately one-sixth of the aging adult HCBS population. Medicaid's role in the financing of HCBS has been increasing. In 2000, HCBS for older adults financed through Florida Medicaid were 57.2 percent of all Florida and federal public funding sources. By 2008, Florida Medicaid services increased to 70.4 percent of publicly funded HCBS.

Staffing level requirements have resulted in the growth of Medicaid nursing home reimbursement from an average per diem payment in 1999 of \$102.38 to the 2008 level of \$177.06 per diem. Within the reimbursement rate, the fastest growing component is direct patient care costs. The Florida legislature funded mandatory increases in staffing levels for direct care staff (certified nurse aides and licensed practical nurses), and subsequently has one of the highest staffing levels for direct care staff in the nation. Given the dramatic required growth in staffing, direct patient costs have increased 95 percent from \$66.94 to \$129.68 per Medicaid day since 1999.

Balancing Indicators for Elder Services

Consolidated Administrative Structure

Although a consolidated state long-term care agency is purported to be the most important single factor in facilitating the development of balanced long-term care systems, only two states (Oregon and Washington) have fully integrated control over all long-term care programs and funds, including the Medicaid Nursing Home Program. In Florida, the management of long-term care programs is divided among multiple agencies.

Beginning in July 2009, division of responsibilities for the 60+ population will become less fragmented as the DOEA will receive the funding for, and become the administrators of, all Medicaid waivers serving elders. The Agency for Health Care Administration (AHCA) has lead responsibility for administrative oversight of the programs funded through Medicaid state plan services. Additionally, financial eligibility for Medicaid-funded services is determined by staff with the Department of Children and Families (DCF).

In Florida, eleven Area Agencies on Aging and a number of Community Care Lead Agencies handle care planning and case management at the local level. Florida's elder services network components include the following:

<u>U.S. Department of Health and Human Services</u>, Administration on Aging, led by the Assistant Secretary for Aging, funds home and community-based services for millions of older persons through Older Americans Act (OAA) allotments to the states and competitive grants.

<u>Florida Department of Elder Affairs</u> is the designated state unit on aging in accordance with the Older Americans Act and Chapter 430, Florida Statutes. The Department's role is to administer Florida's OAA allotment and grants and to advocate, coordinate and plan services to elders provided by the state. The Older Americans Act requires the Department to fund a service delivery system through designated Area Agencies on Aging in each of the state's 11 Planning and Service Areas. In addition, Chapter 430, Florida Statutes requires that the Department fund service delivery lead agencies that coordinate and deliver care at the consumer level in the counties comprising each Planning and Service Area.

<u>Area Agencies on Aging (AAA)</u> are the designated private not-for-profit entities that advocate, plan, coordinate and fund a system of elder support services in their respective Planning and Service Areas. The designation of AAA is in keeping with the Older Americans Act. Area Agencies on Aging operate Aging and Disability Resource Centers (ADRCs) or Aging Resource Centers (ARCs).

<u>Lead Agencies</u> provide and coordinate services for elders in the state's 11 Planning and Service Areas. There are 58 lead agencies serving all of Florida's 67 counties. Some lead agencies provide services in more than one county due to the scarcity of providers in some rural counties. Lead agency providers are either non-profit corporations or county government agencies. Among the non-profit corporations are senior centers and councils on aging. Lead agencies are the only entities that can provide fee-for-service case management on an ongoing basis.

<u>Local service providers</u> include non-profit and for-profit corporations. Among non-profits are senior centers, county organizations, community action agencies, faith-based organizations and Alzheimer's clinics. Among for-profit entities are assisted living facilities, in-home service agencies and managed care organizations.



Figure 1. Network of Services and Recipients

Source: Florida Department of Elder Affairs, Summary of Programs and Services (SOPS), April 2009

Single Point of Access

Florida has implemented a statewide single entry point system of Aging Resource Centers and Aging and Disability Resource Centers to streamline access to long-term care information and services. These centers are designed to integrate, streamline and customize intake, assessment and referral services for anyone who may need long-term care assistance, regardless of service payment source (public or private source). The centers began with federal funding (AOA) but are now funded from state, federal, and local sources and operate statewide. When the Aging Resource Center/Aging and Disability Resource Center initiative reaches maturity, the state will have a fully operational single-entry system for accessing long-term care services, which is generally recognized as an essential resource for creating a balanced long-term care system featuring an extensive array of HCBS programs. Eight Area Agencies on Aging have transitioned to Aging Resource Centers (ARCs) and three have been designated as Aging and Disability Resource Centers (ADRCs). As single entry points, they provide information and referral services, centralized screening, eligibility determination, and enrollment for home and community-based services.

The DOEA Comprehensive Assessment and Review for Long-Term Care Services (CARES) program staff is responsible for determining the functional eligibility for individuals applying for nursing facility care or Medicaid waiver services. Through either physical or virtual collocation at the Aging and Disability Resource Center (ADRC) or Aging Resource Center (ARC), CARES is a partner in Florida's ADRC/ARCs throughout the state and functions as part of the ADRC/ARC. Also collocated with the ADRC/ARC, either physically or virtually, are staff from the Department of Children and Family Services ACCESS Program, who perform the financial and technical eligibility determination for individuals applying for public assistance programs, such as Medicaid and Food Stamps.

CARES is Florida's federally mandated pre-admission screening program for nursing home applicants. A registered nurse and/or assessor perform client assessments, and a physician or registered nurse reviews each assessment to determine the level of care needed. The purpose of the assessment is to identify long-term care needs, establish level of care (medical and functional eligibility for nursing facility care and Medicaid waivers), and recommend the least restrictive, most appropriate placement. Emphasis is placed on enabling people to remain safely in their homes or return to the community after a nursing home stay, through provision of home based services or with alternative community placements such as assisted living facilities. Federal law mandates the CARES Program perform an assessment of each individual anticipating Medicaid reimbursement for nursing facility placement to determine medical eligibility and conduct pre-admission Screening for Serious Mental Illness of Mental retardation. CARES also determines medical and functional eligibility for the Medicaid waiver programs. Any person or family member can initiate a CARES assessment to identify their long-term care options. During 2008, CARES operated with 251 full-time equivalent (FTE) positions and 51 Other Personnel Service (OPS) positions for a total of 302 positions throughout Florida. The staff includes a multidisciplinary team of assessors, nurses, doctors, supervisors, administrative support and management.

To improve entry into the system and facilitate the "no wrong door" concept, each ADRC/ARC has executed agreements with a number of designated access points, including local service providers, senior centers, lead agencies, health care providers, and other community organizations. These agreements outline the access point's responsibilities to provide accurate and consistent information about resources available to assist individuals and to refer anyone seeking publicly funded long-term care services to the ADRC/ARC. Additionally, individuals can access ADRC/ARC services by telephone or through the Internet. To ensure consistent access to aging and other long-term care resources, the ADRC/ARCs are using a common centralized and web based information and referral (I&R) software system, designed for I&R networks with multiple members. Following the development of an Internet accessible statewide database, accurate information on long-term care resources will be available to consumers regardless of access location.

At the ADRC/ARC, staff completes the authorized prioritization instrument (DOEA Form 701A) to collect information about individuals applying for services funded by the Department. The resulting information allows applicants to be assessed based on their need for home and community based services. Based on a priority score and funding availability, the applicant is either referred to a Lead Agency case manager for a comprehensive assessment (DOEA Form 701B) or placed on a waitlist. When funding is available, individuals are removed from the waitlist based on their priority ranking.

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Before an individual is placed on the waitlist, the ADRC/ARC staff explores resources to address immediate needs as well as service options including private pay, sliding scale, or other alternatives. While an individual is waiting on the waitlist, the Department's policy requires routine rescreening to determine continuing priority for services; during these rescreening calls, ADRC/ARC staff again explores community resources and alternate service options for meeting the individual's immediate needs.

As depicted in Chart 14, the ratio of persons on one of the waiting lists to persons enrolled in the respective programs range from nearly 1:1 for CCE (where the 17,713 persons were on the waiting list and 19,232 were enrolled) to approximately 1:5 for Older Americans Act programs (14,530 on the waiting list and 80,326 enrollees).





Source: Florida DOEA Client Information and registration Tracking System (CIRTS) Database

Several barriers exist to individuals interested in being diverted from initial placements in nursing facilities or transitioned out of nursing facilities and back to community living, including waitlists, proper documentation for Medicaid, and individual risk factors that can't be adequately served in a home-based setting. In addition, many people who apply for services are not eligible due to financial reasons. The Department of Children and Families (DCF) requires documentation to verify financial eligibility for Medicaid. It may take over 30 days in some areas of the state for DCF to determine that a person does not have assets or income above the eligibility requirements. Waiting for clients and/or their representatives to return required medical information to CARES, or financial information to DCF can cause a significant delay in the eligibility process which in turn may impact the client's ability to remain in the community through Medicaid waivers. A second factor is related to the appropriateness of community services when an individual's health and/or functioning have declined to a level that makes it unsafe for them to remain in or return to the community. For many individuals, home and community based services may have delayed nursing facility placements for months or years; however, facility services may be intermittently or ultimately required when community services are unable to adequately meet individual needs for health care, supervision or safety. Families or caregivers are frequently in crisis by the time

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CARES is contacted. They are sometimes less receptive to exploring community placements. A lack of familiarity with the various home and community based services, feeling that a nursing facility best meets their needs or the reluctance to wait for home and community based services to be arranged may result in caregivers refusing alternatives to nursing facility placement. Some areas, especially rural counties in Florida, do not have enough assisted living facilities to meet nursing home alternative demands. In addition, Florida has a limited number of licensed adult family care homes, which also serve as residential alternatives to nursing facilities.

DOEA assesses applicants into one of five priority levels based on their need for home and community based services. Level 1 is assigned to those least in need for services, level 5 assigned to those most at need. In addition, consumers may be placed in one of three special high risk categories if they were determined by DCF's Adult Protective Services (APS) to be at high risk of further abuse, neglect or exploitation; are at imminent risk of nursing home placement or are currently in a nursing home and can safely be transitioned to the community; or are turning 60 years of age and receiving HCBS services by DCF (aging out). DOEA's prioritization policy requires service agencies to provide services in the following order of priority: referred by APS, at imminent risk, aging out, priority level 5, priority level 4, priority level 3, priority level 2, and priority level 1.

Continuum of Residential Options

Florida has implemented several policies, practices, and programs that now constitute an extensive infrastructure for the delivery of a wide range of long-term care services, including in-home and community residential services.

The relatively modest growth, however, of the Medicaid waiver and SSI/OSS/ACS funded assisted living programs, including the Adult Family Care Home (5 or fewer beds) portion may have limited Florida's effort to develop a cost-effective HCBS long-term care system. Community residential care includes a wide range of congregate living arrangements and service packages, from small family care homes (1 to 4 residents) to large assisted living facilities (50 plus residents), and many variations on these arrangements in between.

For many frail elderly persons with inadequate caregiver networks, assisted living may also be an appropriate option. Although ALF's are very popular and well proven to maintain a high level of care, the availability of publicly supported assisted living is still very limited in Florida. However, this limitation is predicted to change in the next ten years, as market demand for ALF's increases with the aging of the next cohort. As noted by Polivka and Salmon, in 2008:

"The demographic characteristics (fewer children and spouses) and life style preferences (independence and autonomy) are likely to make assisted living a highly preferred option for the baby boomers, regardless of their individual financial resources."

Participant Direction

Almost 2 million Americans receive publicly funded personal care services such as bathing, dressing, grooming, transferring, housekeeping, and shopping, each year. Over 40 states now have some version of 'participant', 'recipient' or 'consumer' directed care, but the percentage of publicly supported long-term care recipients in individual locus of control programs is still very small (probably less than 5 percent). Within the traditional system, a provider or agency (typically a home health or personal care agency) hires, trains, and manages employees to provide these home services as well as performing employment and payroll tasks such as payment and reporting of state and federal taxes, unemployment insurance, and workers compensation. Conversely, in a consumer directed model, such as CDC+ in Florida, independent workers including family and friends are hired by the individual. Employment and payroll tasks are completed by a support entity, which is referred to as a Financial Management Service provider and serves as the "agent" for employment taxes. Counseling is provided to assist individuals to understand their risks and responsibilities and provides guidance and advice with the self-directed experience. More expanded versions of the model allow participants to use a flexible individual budget to purchase items or goods that promote their personal care and might include home modifications, assistive devices, transportation, and personal care supplies. The highly individualized opportunities for recipients to receive services from friends and family could improve the quality of life of LTC consumers in Florida, and may also be able to help ameliorate the emerging state shortage of professional long-term care workers.

The Cash and Counseling Program is an example of a flexible consumer directed model that has been very successful in Florida. It gives the consumer control of funds which can be used to organize the needed and preferred kinds of long-term care assistance, which is usually by paying a relative or friend to be a caregiver. Consumer choice programs have been extensively evaluated and hailed by researchers for their flexibility and highly personalized approach to care, and a recent study of cash and counseling demonstration projects in Arkansas, New Jersey, and Florida found that the projects were generally cost effective in comparison to agency directed programs, especially in terms of caregiver and consumer satisfaction levels and reduced nursing home use (Dale & Brown, 2007).³

The consumer directed model of service provision consistently receives high marks for client satisfaction with services, empowerment, and quality of life. With the additional efficiency and cost effectiveness of consumer directed long-term care programs, they have the potential be increasingly employed in efforts to help LTC recipients remain in their community.

Quality Management

The Department of Elder Affairs' Monitoring and Quality Assurance team is responsible for monitoring each Area Agency on Aging (AAA) once a year to ensure adherence to federal and state rules, standards of good practice within the industry, contract requirements and legislatively-mandated performance outcome measures. Programs for which the AAAs had administrative and fiscal oversight responsibilities totaled approximately \$288 million in 2007 contract awards. The Department of Elder Affairs manages quality through several efforts, such as on-going program monitoring, evaluations and consumer satisfaction surveys for many of the programs they administer.

Some of the surveys recently conducted by the Department of Elder Affairs' Bureau of Planning and Evaluation are described below.

CARES Choice Counseling Survey

In 2007, Nursing Home Diversion Waiver (NHD) clients were surveyed about the choice counseling they received and their satisfaction with the program. Choice counseling informs clients of their options in choosing a service provider. The survey was intended to determine the effectiveness of the choice counseling and to identify the basis on which consumers selected their service providers. Significant positive correlations emerged between consumers having enough information at the outset and both satisfaction with the services they received and their perception of the helpfulness of services in allowing them to remain in their homes. Approximately 85 percent of the clients felt they received enough information to help them make a decision. Eighty-nine percent reported satisfaction with their services. When asked what could be changed to make this program better, about half of the clients responded with one or more suggestion. Forty-four percent of the suggestions related to quality and reliability of provider services, 31 percent related to the need for additional services and 15 percent related to program and program implementation.

Caregiver Surveys

A caregiver survey was conducted in 2005 to determine program effectiveness and consumer satisfaction of caregiver services offered by the following programs: Community Care for Elderly, Home Care for the Elderly, Alzheimer's Disease Initiative, RELIEF, Older Americans Act and the Medicaid Aged and Disabled Adult Waiver. Eighty-four percent of the caregivers surveyed had been providing care for over two years. Survey results indicated that respite, help or information that connects them to other types of caregiver support services, and other supplemental or support services were the services caregivers found most helpful. Seventy-five percent of the caregiver services enabled them to provide care for a longer time than would have been possible without these services, 50 percent said "yes, definitely" and 28.2 percent said, "yes, I think so." A caregiver survey was also conducted in 2008, which showed caregiver services were rated as "excellent" or "good" by 76.8 percent of the respondents. In addition, a high level of satisfaction was demonstrated by the 97 percent of those surveyed who responded "yes" when asked if they would recommend the services to others who might need them.

³ Dale, S. & Brown, R. (2007, Aug.). Reducing nursing home use through consumer directed personal care services. *Medicare Care, 44*, 760-767.

Client Satisfaction Survey

During 2007, DOEA surveyed 512 clients who had received case management, personal care, homemaker and/or home delivered meals. The overall average satisfaction score across all four services was 83.8 percent. The survey showed satisfaction highest among clients who received personal care (86.6 percent) and lowest among clients who received homemaker services (81.3 percent). The client satisfaction results as shown in Chart 15 were slightly higher compared to a similar survey conducted in four years earlier.

QUALITY	QUANTITY/ CHOICE	FRIENDLINESS	RELIABILITY	Overall
93.9 %	65.4 %	90.2 %	95.1 %	84.2 %
94.2 %	69.0 %	91.6 %	80.6 %	86.6 %
88.6 %	66.0 %	83.3 %	88.4 %	81.3 %
75.8 %	80.9 %	N/A	91.4 %	82.9 %
88.1 %	70.3 %	88.4 %	88.9 %	83.8 %
	93.9 % 94.2 % 88.6 % 75.8 % 88.1 %	QUALITY CHOICE 93.9 % 65.4 % 94.2 % 69.0 % 88.6 % 66.0 % 75.8 % 80.9 %	QUALITY CHOICE FRIENDLINESS 93.9 % 65.4 % 90.2 % 94.2 % 69.0 % 91.6 % 88.6 % 66.0 % 83.3 % 75.8 % 80.9 % N/A 88.1 % 70.3 % 88.4 %	QUALITY CHOICE FRIENDLINESS RELIABILITY 93.9 % 65.4 % 90.2 % 95.1 % 94.2 % 69.0 % 91.6 % 80.6 % 88.6 % 66.0 % 83.3 % 88.4 % 75.8 % 80.9 % N/A 91.4 % 88.1 % 70.3 % 88.4 % 88.9 %

Chart 15. Customer Satisfaction Items by Service

Source: DOEA client satisfaction survey, 2007

HCBS Programs Cost-Effectiveness Evaluations

The DOEA in collaboration with the Agency for Health Care Administration has developed a unique capacity to evaluate all HCBS programs in terms of relative cost-effectiveness on an annual basis. This capacity was created through contractual relationships with the Florida Policy Exchange Center on Aging since 1999, which now provides DOEA and AHCA with a wide range of consumer, services, outcomes, and cost data each year. This program evaluation and policy analysis partnership was expanded in 2004 through a contractual relationship with the University of North Florida.

Under this agreement, the University of North Florida has conducted three evaluative studies of the state's five Medicaid waiver funded HCBS programs since 2003. Each of these studies found that all five programs are relatively cost-effective compared to nursing home care. These studies also raise important policy questions about the differential growth rates of programs over the past several years and challenge whether a greater percentage of the need for care could be met through increased funding for two waiver programs (Aged and Disabled Adult Medicaid Waiver and Assisted Living for the Frail Elderly Medicaid Waiver).

The issues raised by these evaluations are noteworthy, however, they should be considered in the context of the state's continuing effort over the last 25 years to construct a better balanced, consumeroriented long-term care system based on the expansion of HCBS programs and improved quality of nursing home care. All of Florida's HCBS waiver programs are relatively cost-effective alternatives to nursing home care for several thousand poor and frail elderly persons, especially those without caregivers. Even the most expensive program, the Nursing Home Diversion Waiver Program, is about \$2,500 less expensive per month than Medicaid-funded nursing home care.

Nursing Home Transition Capacity

A comprehensive initiative to create and maintain a balanced long-term care system should include a nursing home relocation or transition program designed to identify nursing home residents that want to move to a community-based program as long as their medical and long-term care needs can safely be met outside of institutional settings. According to MDS data, almost 25 percent of nursing home residents have indicated a desire to return to the community. Florida has received \$3.8 million in CMS system change grant funding to support nursing home residents transition to the community in areas where appropriate housing and support services are available. As of April 2009, the Governor and the Legislature provided additional funding to transition appropriate Medicaid eligible beneficiaries from skilled nursing facilities to community-based alternatives in order to maximize the reduction in Medicaid nursing home occupancy. As of June 2009, DOEA's CARES staff identified 977 individuals as potential candidates for nursing home transition. Of these 977 individuals, over 800 have been assessed and approximately 174 have successfully transitioned to the community.

HCBS Infrastructure Development Capacity

The growing need for LTC services is creating a national shortage of LTC workers which is likely to reach crisis proportions by 2015. The need for LTC workers of all kinds from registered nurses to assisted living administrators to direct care workers will increase 50 percent or more by 2015 (Institute of Medicine, 2008).⁴ This percentage is likely to be even higher in much of Florida where the older impaired population is projected to grow faster than in the U.S. as a whole. The Consumer Directed Care (CDC+) program model described earlier could help address the LTC labor shortage by pulling more family and friends into the formal LTC system. However, even a greatly expanded CDC system cannot resolve the LTC labor crisis. A more comprehensive labor force strategy will be required, that should be a fully integrated part of any proposal for systemic reform of LTC at the state and federal levels (Stone and Dawson, 2008).⁵

The growth in the need for LTC services over the next 40 years will increase the demand for LTC workers from 1.9 million in 2010 to over 4 million in 2050. This will require a 2 percent annual increase in the LTC workforce over a 40-year period. The working age population, however, will grow by only 0.3 percent over this period (Stone, 2001).⁶ Addressing this discrepancy effectively will require a multifaceted labor force strategy, including initiatives to ramp-up productivity with a more expansive use of technology, as well as improved worker wages, benefits, training, and working conditions designed to increase existing worker retention and new worker recruitment. As Florida expands HCBS programs, it will need to help providers address the growing shortage of frontline long-term care workers by recruiting and training workers with the skills and knowledge to help consumers achieve the quality of life they desire.

Major Policy Implications

Even though Florida is among the top five states for state spending on long-term care services, Florida is well below the national average for per capita spending on home and community based services. The nursing home budget has doubled since 2000 and the Nursing Home Diversion Waiver Program budget has grown from \$22 million to over \$200 million. These increases have helped the state improve its HCBS status among the states since 2002; however, Florida is still much closer to the national average in nursing home per person spending than in HCBS spending.

With a notable exception in the Nursing Home Diversion Waiver, there have been no substantial increases in HCBS funding limiting the expansion of Florida's overall program capacity and contributing to the growth of waiting lists for services. The following programs will require substantial and sustained increases in funding to properly expand HCBS in Florida:

State funded programs- Overall, the state funded programs, which provide essential services to non-Medicaid eligible persons with few assets and low-to-modest incomes, have remained stagnant for a decade as waiting lists for their services grew. Funding for both the Community Care for the Elderly (CCE) and Home Care for the Elderly (HCE) programs has declined since 2000—from \$46.9 million to \$43.3 million for CCE and from \$13.4 to \$9.5 million for HCE. These losses have been offset by increases in the local services program, which is very similar to the CCE program (\$3.8 million to \$8.7 million in 2008), and the Alzheimer's Disease Initiative (ADI) in-home services program (\$7.8 million in 2000 to \$10.3 million in 2008). Funding for the Memory Disorder Clinic part of the ADI program, however, declined from \$4.2 million to \$3.3 million over this period.

Older Americans Act (OOA) Program- Funding for this federally funded program has followed a pattern of flat funding for several years followed by major increases and then several more years of flat funding, resulting in approximately a 30 percent decline in the program's purchasing power since 1990. Consistent with this pattern, OAA funding for Florida increased by only \$3.4 million from 2003 (\$72.3 million) to 2008 (\$75.7 million).

⁴ Institute of Medicine (2008). *Retooling for an aging America: Building the health care workforce*. Executive Summary, National Academy of Sciences. <u>http://www.nap.edu/ctaalog/12089.html</u>. (accessed Aug. 21, 2008).

 ⁵ Stone, R. & Dawson, (2008). The origins of better jobs better care. *The Gerontologist, 48*(Special Issue 1), 5-13.
⁶ Stone, R. (2001, Oct.). *Long-term care workforce shortages: Impact on Families*. Policy Brief No. 3, Family Caregiver Alliance: San Francisco, CA.

Florida's State Profile Tool

HCBS Medicaid-Waiver Programs- As the Nursing Home Diversion Waiver Program grew by over \$200 million from 2000 to 2008 (\$22 million to \$224 million), the other major HCBS waiver programs have grown by relatively small amounts (Assisted Living for Frail Elderly Waiver) or actually declined (Aging and Disabled Adult and Frail/Elderly Program). The Assisted Living for the Frail/Elderly Program grew from \$5.6 million in 1997-98 to \$30.6 million in 2002/03, but then increased by only about \$2.5 million over the next five years (\$33.2 million in 2008). The Aged and Disabled Adult in-home services waiver grew from \$42.5 million in 1997/98 to \$87.6 million in 2003/04, but then declined to \$86.5 million by 2008. Channeling, which has been administered by Miami Jewish Home and Hospital since 1985, has grown by a small amount from 1,480 persons in 1998 to 1,627 in 2008. It should be noted, however, that the home now operates a Medicare and Medicaid funded Program of All inclusive Care for the Elderly (PACE) program which received \$19 million in 2008.

Barriers to Rebalanced Care and Services for the Elderly

Many of slow progress states, like Florida, are characterized by growing levels of need for longterm care services and below national average fiscal resources available to meet these needs. Although fiscal shortages are the major cited reason for the relatively slow progress in expanding home and community based services in recent years, there are other contributing factors to contend with as well. An often mentioned reason for the relatively slow growth of HCBS programs is the perception that community-based care is not cost-effective because it lacks the capacity to substitute for institutional care for the seriously impaired and frail elderly. An additional common concern is that HCBS programs are so much more appealing than nursing home care, their expansion will flood the systems with too many new consumers and the sheer volume of service demand will eventually make the long-term care budget unsustainable.

Despite the concerns of financing and staffing HCBS, the experiences of other states and recent research have shown that LTC expenditures are reduced by using HCBS as an alternative to institutional care. For example, in their research across the states, Kaye et al. found that the expansion of HCBS program capacity helps states contain the costs of their LTC systems (Kaye, LaPlante & Harrington, 2009)⁷, and recent studies of Medicaid funded HCBS programs in Florida covering a five-year period from 2000 to 2005 found that all of them were cost-effective alternatives to nursing home care (Mitchell, Salmon & Polivka, 2006;⁸ Mitchell, Polivka & Wang, 2007).⁹

The experience in the few states with relatively balanced long-term care systems should assure Florida policy makers that the costs of HCBS-oriented long-term care systems can be effectively contained through uniform and rigorous needs assessment, service planning, care management, and the expansion of community-based services that cost less than nursing home care. With sustained and well managed efforts to expand HCBS programs, the current levels of nursing home residence of those over the age of 65 can be reduced very substantially over the next several years. If proven policies are broadly implemented, the projected tripling of the nursing home population by 2050 can be avoided. Preventing a huge growth of the nursing home population in Florida may depend on increased investments in several HCBS programs.

Conclusion for Elderly Services Population

Florida has made significant progress toward constructing a more balanced long-term care system over the last ten years through the expansion of the Medicaid funded Nursing Home Diversion Waiver Program, Florida's managed long-term care program, and the much more limited expansion of the Medicaidsupported assisted living programs (ALE and ACS). Florida has also improved access to services through the implementation of the Aging and Disability Resource Centers/Aging Resource Centers (ADRCs/ARCs) and elevated the quality of nursing home care by increasing direct care staffing levels.

⁷ Kaye, S., LaPlante, M. & Harrington, C. (2009). Do noninstitutional long-term care services reduce Medicaid spending? *Health Affairs*, 28(1), 262-271.

⁸ Mitchell, G., Salmon, J.R., & Polivka, L. (2006). The relative benefits and cost of Medicaid home- and communitybased services in Florida. *The Gerontologist, 46*(4), 483-494.

⁹ Mitchell, G., Polivka, L. & Wang, S. (2007). *Florida Medicaid HCBS waivers: A comparison of outcomes and cost-effectiveness.* Unpublished report produced for the Agency for Health Care Administration.

Florida's State Profile Tool

Many other states, however, serve a higher proportion of their LTC population in home and community settings. Florida needs to continue to improve the balance between nursing home services and HCBS well in advance of the peak demand for long-term care services, which is expected to occur sometime around 2030. The following initiatives have been proposed by advocates and researchers to enhance the long-term care system for the elderly:

- Accelerate the expansion of the Assisted Living for the Frail Elderly (ALE) Waiver program, and the Aged and Disabled Adult (ADA) Waiver program. The Assisted Living for the Frail Elderly and Aged and Disabled Adult Waiver programs are administered through the Aging Network, which the state has historically relied on to provide publicly funded HCBS. It is imperative that the state strengthen the Aging Network in anticipation of the projected increase in the need for long-term care. With 30 years of experience, this network has the potential to administer the entire publicly funded long-term care system.
- The major state-funded HCBS programs (CCE, HCE, ADI) should also be expanded in order to increase the state's capacity to assist the non-Medicaid population of frail elders and disabled adults with low-incomes, few assets, and substantial long-term care needs. These programs are critical for early intervention and crisis stabilization.
- The research findings from the consumer directed care literature indicate that as a HCBS program, CDC+ is cost-effective and deserves to be a larger part of the state's HCBS system over the next several years.
- Expand existing nursing home transition programs to identify nursing home residents appropriate for community placement and provide the services required to make the transition achievable and safe. Several states have received large Money Follows the Person (MFP) grants to establish transition programs, which appear to be providing an effective bridge back into the community for many nursing home residents.
- Conduct an assessment of the HCBS labor pool and employers in preparation for addressing changing demands of the long-term care work force. Prepare now to prevent shortages of trained direct care workers.
- The financing and delivery of long-term care services should be critically examined in terms of administrative efficiency and organizational capacity to expand home and community based services. Methods for more flexible allocation of resources across programs should be evaluated.
- Codify the state's commitment to providing long-term care services supporting consumer choice by providing an expansive array of home and community-based services and progressively reduce reliance on institutional care.

In conclusion, even with the demonstrated quality of care and relative cost-effectiveness of HCBS programs, balanced long-term systems face tremendous fiscal and political challenges. The care reform necessary to balance institutional and alternative services requires resources, sustained advocacy and political leadership. It may well be that balance of long-term care services cannot be achieved until reaching a level of HCBS program capacity that is sufficient to break a state's dependence on nursing home care as the principal site for long-term care services. This has occurred in several other states already, but for Florida to reach this transformation tipping point, it will need both strong political support as well as adequate fiscal resources to develop the structures necessary for a community based long-term care system.

Section IV. Services for the Developmentally and Intellectually Disabled

The nature of services provided to the developmentally and intellectually disabled (DD/ID) community has changed fundamentally over the last 30 years. Until the early 1990s most DD/ID persons received services in institutional settings. Today, however, the vast majority of the DD/ID population in the U.S. lives and receives services in the community, either in small congregate facilities or in their own homes.

Home and Community Based Programs for the DD/ID

In Florida, as in most states, services are typically provided through private sector organizations and have historically occurred through community organizations such as local Associations of Retarded Citizens, United Cerebral Palsy, Center(s) for Independent Living, and local affiliates of the Florida Association of Rehabilitation Facilities. However, across time there has been a growth in small, independent providers consistent with growth in a person-centered service delivery system. Within the Consumer Directed Care Plus (CDC+) Program, for example, people receiving services and their legal representatives are able to choose who will provide needed services.

Throughout the APD service system there has been a shift in recent years to person-centered direction and in provider solicitation and development. Support coordinators are directed to assist people in finding supports and services that meet their individual expectations. This direction means support coordinators would solicit and tailor small providers that match expectations of individuals receiving services when traditional services are either unavailable or inconsistent with those expectations. APD received a threeyear Real Choice Systems Change Grant in 2007 for "Person-Centered Planning and Implementation" which is being used to retrain and underscore the need for support planning and service development focused on meeting person-directed choice and expectations.

During years when the APD service system received an influx of new funding to serve a large number of people from the waiting list, it has proven difficult to conduct provider development in a person-centered fashion. Within these limited resources, however, APD has an ongoing initiative in place at both the state and local levels to recruit providers specific to service types where there is a demonstrated need and specific to local level need.

Medicaid HCBS Waivers for Developmentally Disabled Adults

The supports and services provided through the Medicaid waiver for the DD/ID population are generally intended as long-term supports. The overarching expectation is that people who have intellectual and other developmental disabilities will need long-term care throughout the course of their lifetime. The type and level of these services may rise and fall in intensity in cycles across a person's life, but the duration of supports and services are expected to be needed across a person's life.

Beginning in October 2008, APD began implementation of a four-tier Medicaid waiver system to help the Agency manage resources more efficiently. Consumer assignment within Tiers is determined by assessed level of need and other criteria with those in Tier 1 requiring the most assistance. Annual expenditures per person are capped at \$14,972 for Tier 4, \$35,000 for Tier 3, and \$55,000 for Tier 2. Tier 1 has no annual spending cap. The number of individuals served in Tier 1, 2, and 3 has remained stable since 2000, increasing from 23,314 to 23,906. The appropriation has more than doubled during the same period of time, from \$334.8 million to \$858.7 million. Family Support Living (FSL), Tier 4, has grown dramatically since 2000 when 33 individuals were served and the appropriation was \$85,645. In 2007-08, enrollment reached 5,944 and the appropriation was \$45.4 million. During 2000, FSL claims were a very tiny fraction of DD/ID HCBS waiver claims (less than 0.03 percent). This increased to 5.3 percent by 2007-08, serving nearly one in five among DD/ID HCBS participants (19.9 percent).

Waiting Lists for DD/ID HCBS Support Services

There are many people on the waiting list for services through APD and the services funded under the Medicaid HCBS waivers. In 2008, the waiting list for developmental services had in excess of 16,000 people on it, and the number is expected to continue to climb.
Chart 16. Waiting List, Persons



Source: Survey of agency managers by analysts at the State Data Center on Aging, University of South Florida.

In addition to the long lists of people waiting for services, the length of time people spend waiting is also increasing. The wait for developmental services in 2008 is about five months longer than in 2007, but this increase is much slower for clients waiting for Family and Supported Living services. The length of wait time for family and supported living assistance is longer higher than two years and has doubled each year since 2004.



Chart 17. Waiting List, Average Months

Source: Survey of agency managers by analysts at the State Data Center on Aging, University of South Florida.

APD is actively working with other agencies to reduce wait list rosters and waiting times. For example, to more rapidly respond to the needs of individuals, DCF and APD implemented procedures in 2009 that include the following actions:

- Training APD staff in the Medicaid application process and web application screens so they can better assist families;
- Identification of pending crisis applications so that Medicaid eligibility issues can be resolved prior to APD crisis committee review;

- Assignment of a Medicaid eligibility expert to consult with the APD crisis committee to troubleshoot any complex eligibility issues; and
- Encourage families to apply for regular Medicaid before enrollment in the waiver. If eligible, they can be immediately enrolled in the waiver when funding becomes available. If not eligible for regular Medicaid, relevant information and documentation, including that related to the disability can be collected early and be available to complete the Medicaid eligibility approval as soon as the individual is accepted on the waiver.

APD has developed a number of cooperative agreements with other agencies that fund services that may cross populations with people eligible to receive services funded by Medicaid waiver programs. It may be that someone may need services through Children's Medical Services, Vocational Rehabilitation, linkages with school systems, need for access to funding under the state Medicaid programs through AHCA, etc. Referral and collaboration arrangements among a variety of state agencies have been developed to ensure timely access to services, regardless of where an individual's process begins.

Despite these efforts, the average wait times are increasing, and some people may be waiting for services for several years. Subsequently, APD has constructed options to help people receive urgently needed services as soon as possible. The most common of the options APD uses to help people receive services as soon as possible is the "Crisis Process." Priority for services beyond the crisis process is strictly based on the date each person was enrolled on the waiting list. The crisis process addresses the immediate critical needs of individuals through short-term approval of General Revenue or Social Services Block Grant funded services. APD can immediately authorize services funded by these sources to address emergency situations. In addition to meeting emergency needs through alternative funding, the crisis procedures also allow people with critical needs (meeting specific crisis criteria) to request waiver funded services through a crisis application. There is a standing APD crisis committee that meets monthly and reviews all crisis applications for approval or denial. Per legislative direction, crisis enrollment into waiver funded services is available through attrition from the waiver. An average of 32 APD applications for Medicaid waiver eligibility are received and processed each month. The federal standard for timely processing of Medicaid eligibility is 45 to 90 days, but applications that take so long are rare.

DD/ID: Programs, Populations and Expenditures

Total national spending on DD/ID services was \$43.84 billion in 2006 and 81 percent was spent on HCBS programs. The remaining 19 percent was spent on public (15 percent) and private (4 percent) institutions. During the same year, 75 percent of all DD/ID spending went to settings of six persons or fewer. Between 2003 and 2006, annual increases in spending on HCBS programs declined to lower levels than any time since 1978 (with a 3.1 percent increase in 2003, 2.3 percent increases in 2004 and 2005, and only a 0.8 percent increase in 2006). The current recession is likely to keep increases small for at least the next few years. The capacity of states to meet the projected growth in need for services is threatened by fiscal constraints on state and federal budgets and labor force deficits in service workers for the DD/ID population. As of 2008, community based programs received over 80 percent of all public funds spent on services for the LTC DD/ID population. The changes that made this possible for the DD/ID population occurred over a relatively short period of time and at a far faster pace than changes in long-term care (LTC) services for other populations. The pace of change has remained steady since the 1990s; however, this advancement has not been uniform in all states.

The majority of states have made substantial progress toward constructing extensive home and community-based LTC systems for DD/ID populations, which allows them to serve more persons in the community than in institutional environments. However, there is still considerable variation. Four states serve more than 2,000 persons in institutions and three states have no institutional programs at all. Mississippi was the only state serving more persons in institutions than in the community by 2006. Florida tended to lag behind most of the other states during the 1990s in the development of HCBS alternatives to institutional care. Since 2000, however, the state has made substantial progress in the development of its HCBS programs and is now serving a comparably high percentage of service recipients in the community and in small facilities or family settings as most other states.

Determining functional eligibility for HCBS programs is an operational responsibility of Agency for Persons with Disabilities (APD) staff in local area offices. Chapter 393.065, F.S., instructs APD to "review each

Florida's State Profile Tool

applicant for eligibility within 45 days after the date the application is signed for children under six (6) years of age, and within 60 days after the date the application is signed for all other applicants." The assessment process, which is based on the Questionnaire for Situational Information (QSI), is mandated by the Florida Legislature and is one of the requirements for receiving waiver funded services. The assessment provides information for developing a support plan, a cost plan, and authorization of service delivery consistent with the person's support needs. The QSI is reviewed annually between the person and his/her support coordinator and conducted in preparation of that meeting if there are major life changes such as a change in health status or someone moving to a new home. Typically, however, the assessment will be performed every three years.

Residential Options

The Florida Agency for Persons with Disabilities (APD) offers a variety of residential options and accompanying supports. Residential options available through APD include independent/supported living, family homes, foster homes, small group homes, adult living facilities and large group homes. Rather than describing them as a "continuum," inferring people that move along "less restrictive settings" as their skills and capacities increase, Florida is consistent with the philosophy of "participant direction so that all residential options are open to the choice of each individual with supports provided at greater or lesser intensity in the setting, depending on the needs of the individual. These options include independent and supported living arrangements, residence in a family member's home, placement in a licensed foster home or small group home, and referred to an adult living facility or large group home. Annual cost of care per person varies greatly by residential setting. For example, Supported living coupled with personal assistance services is much less costly than ICF/DD residency.

According to APD, more than one-half of 2006 funding (\$35.6 billion) for DD/ID home and community based support services came from federal sources (52 percent). Medicaid provides 68 percent of that funding (with 60 percent from Medicaid HCBS; and 8 percent from other Medicaid sources and SSI). Income maintenance payments constitute 19 percent of the federal funding. Thirteen percent comes from other federal sources. State revenues provided \$15.52 billion (44 percent), most being the state's share of Medicaid funding. Local contributions were \$1.6 billion in 2006.

State Facility Closures

Lawsuits initiated by ICF/DD residents and their families have compelled the state of Florida to close two public institutions and to phase out a third by 2010. Florida has averaged 67 transfers annually from DD/ID facilities to community waivers in recent years (back to 2003). During the last three years, the state has transferred funds in the amount of \$85,000 per person to the Developmental Services Waiver. The most recent analysis shows that for all persons discharged since the initiation of the Landmark closure, (2005) the claims average under \$80,000. This is 23.6 percent below the \$104,676 average claim per resident in a state facility since the closure of the Landmark Community in 2005. The dynamic in the institutional facilities is changing, as the overall institutional population of Florida declines, but the number needing a forensic placement grows.

Balancing Indicators for DD/ID Services

Consolidated Administrative Structure

The state of Florida does not have a single state agency that administers and coordinates long-term supports for the DD/ID population. Florida divides DD/ID program administration between the Agency for Health Care Administration (AHCA) and the Agency for Persons with Disabilities (APD). The two agencies collaborate closely in the administration of the Medicaid waiver funded HCBS programs and APD is responsible for administering the institutional programs.

Single Point of Access

The Agency for Persons with Disabilities has lead responsibility for the operational implementation of all programs (HCBS and institutional) and services for Florida's citizens with developmental disabilities. The Agency for Health Care Administration (AHCA) has lead responsibility for administrative oversight of the programs funded through Medicaid and the Medicaid waiver for this population. Financial eligibility for Medicaid funded services is determined by staff with the Department of Children and Families (DCF). The agencies work in collaboration on all related issues.

Participant Direction

Participant directed service is the primary focus in the Consumer Directed Care (CDC+) Medicaid waiver programs. To the extent possible, participant direction is also afforded within both the Developmental Services (DS) and FSL waivers. The quality assurance system is deployed in a fashion to determine the extent to which self-direction is promoted as part of the service delivery system ranging from the extent to which people are involved in choice and control over service planning at all levels, are able to choose and direct such attributes as type, time, place and intensity of specific services, and whether personal quality of life expectations are met.

Participants in CDC+ are allowed to employ their own worker(s) to provide services, to manage their service budget and purchase goods and services outside the standard service package, and to choose a representative to assist with participant direction responsibilities. Extensive support is available for participant direction within the CDC+ program, including independent or agency based consultant support services; financial management services provided by APD; toll free customer service line with program specialists to provide assistance as needed; independent parent support groups; and a consumer handbook.

Quality Management

The quality assurance process for APD includes interviews with people receiving services to determine whether quality of life outcomes are being achieved. The interview uses the *Personal Outcome Measures*, a tool developed by the Council on Quality and Leadership (CQL). Two of the 25 quality of life measures focus on satisfaction with services received and satisfaction with personal life situations. The protocol for these measures has the interviewer consider a number of factors and considerations from the entire interview in determining whether the measure is met. As a result, the findings from the *Personal Outcome Measures* percentage of satisfaction scores are lower than many other instruments but provide a rich source of information for person-centered planning and recommendations for an improved quality of life. The following data is a presentation of annual data collected for these measures of satisfaction with life in general and services received as well as other factors associated with life satisfaction like employment and residential arrangement.

Year	Satisfied with Services	Satisfied with Life
2002 -2003	61.6 %	71.7 %
2003 -2004	47.5 %	73.0 %
2004 -2005	53.8 %	70.9 %
2005 -2006	60.8 %	75.7 %
2006 -2007	63.1 %	75.3 %
2007 -2008	73.7 %	80.5 %

Table 3. Satisfaction Survey Results

Source: APD Personal Outcome Measures

Employment

The APD is currently in the final year of a five-year initiative to increase the number of people who are supported in competitive employment. The chart below displays the number of people APD supported in competitive employment and the percentage of people that number represents among all people APD was supporting in all forms of meaningful daily activities (employment, Adult Day Training Programs, volunteering in the community, job explorations, etc.).

Table 4. Competitive Employment

Year	Number	Percentage
2003 -2004	2,428	20.8 %
2004 -2005	2,827	24.2 %
2005 -2006	3,636	31.1 %
2006 -2007	4,490	38.4 %
2007 -2008	4,936	42.2 %

Source: APD Personal Outcome Measures

Housing

In 2006, Florida was well below the national utilization rate for housing settings with 1-6 people. For the U.S. generally, the rate was 126 per 1,000 of the DD/ID population. The rate in Florida was 80 per 1,000 (41st among the states). Eight states were above 200 per 1,000. Approximately 26 percent (115,589) of persons receiving DD/ID residential services nationally live in their "own homes" which they own or lease. From 1993 to 2007, this number increased by 241 percent in response to the advocacy movement for consumer-controlled housing and supported living. As shown in Figure 2 below, the data from ADP quality assurance process consistently demonstrates people who live in homes of their own through supported living services typically have significantly higher overall quality of life scores than people living in alternative residential settings. This is particularly true in the difference between supported living and licensed facilities such as group homes, Adult Congregate Living Facilities, or even foster care.



Figure 2. Quality of Life Score by Residential Type for DD/ID

Source: APD Personal Outcome Measures

As a result of consumer satisfaction rates, one of the measures under the APD Long Range Program Plan is to increase the number of people supported in homes of their own. The Table 5 presents the number of people living in supported living situations and the percentage among all residential options (both Medicaid waiver and Florida state-funded).

Table 5. Supported Living

Year	Number	Approximate Percentage
2003 -2004	3,652	11.9 %
2004 -2005	3,892	12.6 %
2005 -2006	4,571	14.8 %
2006 -2007	4,028	13.1 %
2007 -2008	5,072	16.5 %

*using 30,814 as the average number of persons served by APD

Major Policy Implications

The quantity and quality of services and the quality of life for persons with developmental and intellectual disabilities has improved at a steady, virtually uninterrupted pace for almost 20 years. Most states, including Florida, now serve over 70 percent of service recipients in the community, in small residential settings, including single apartments, or in homes recipients share with family members or other relatives. States vary considerably in terms of HCBS program design and funding, per capita spending on services, and the extent to which they have adopted innovative service models like consumer directed care. Overall, however, the DD/ID community (advocates, service providers, state program administrators, consumers and their families, and other) has achieved a far more balanced system of LTC services than has been achieved for any other LTC population.

To offset likely increases in demand, Florida will need major policy initiatives to look to the programs it can quickly expand and efficiently monitor to support greater numbers of people. Even under conditions of fiscal stress, the following policy issues should receive high priority as the state prepares for substantial increases in the need for DD/ID services over the next several years:

- 1. Continued and enhanced focus on the development of the consumer-directed services program, expansion of the family support and independent living programs, and the continued displacement of larger facilities by small (6 persons or fewer) living environments.
- 2. Plan to increase the number (and percentage of total persons served) of DD/ID persons employed, especially in regular, mainstream jobs as the economy begins to recover.
- 3. Long-term initiatives are needed to recruit and retain competent long-term care workers. Better compensation with improve wages, benefits and working conditions will help develop this field.
- 4. The recently developed APD/AHCA/Delmarva quality measurement and monitoring program should be institutionalized through a permanent funding arrangement.

Conclusion for DD/ID Services Population

Until the early 2000's, Florida tended to lag behind most other states in the development of home and community based programs for persons with developmental and intellectual disabilities. Since then, however, the state and broader DD/ID community have made substantial progress in creating a more balanced system of services and reducing the number of persons receiving services in state institutions and large (16+ residents) privately operated ICF/DD facilities. This shift has been accompanied by a focus on providing the kinds of supportive services needed to nurture consumer choice, independence, and self-sufficiency. Florida has experienced growth of HCBS programs, a decline in institutional care, and the emergence of an increasingly person-centered approach to service provision. However, the state has also experienced a steady growth of waiting lists for services, is still under-employing disabled adults, and is facing intense fiscal pressures that are certain to adversely affect the DD/ID population.

The progress that has been achieved was made possible through a huge increase in Medicaid waiver funding for HCBS programs and a vigorous effort on the part of the APD staff, providers, and advocates to create and expand programs on an accelerated basis. These efforts have not always been carried out in the most administratively efficient and fiscally sound manner, but the effect of these efforts is nonetheless impressive. The recently implemented Tiers Initiative that sets expenditure limits based on assessed levels of needs should improve also help improve efficiency and overall program cost-effectiveness. Increased administrative efficiency may also help the APD reduce, or at least contain, the growth of the waiting lists for APD services, which have increased even as HCBS programs have expanded. In the face of severe fiscal shortfalls, the state will need to be as efficient as possible simply to avoid major reductions in services.

Section V. Services for the Chronically III and Physically Disabled

Florida's adult population with chronic illnesses and physical disabilities is not as comprehensively served as the developmentally disabled/intellectually disabled or aging adult populations. This is true for both state and Medicaid funded programming.

Disabled Adult Programs Populations and Expenditures

During 2008, there were 339,537 disabled adults between the ages of 18-64 participating in Florida Medicaid totaling \$4.9 billion in paid claims. In the same year, long-term HCBS supports for this population totaled \$46.8 million, accounting for less than 2 percent of the funds spent on Medicaid claims for disabled adults. The disabled adult population in this report is grouped into the following subpopulations: Adult Cystic Fibrosis, HIV/AIDS and Traumatic Brain and Spinal Cord Injuries (TBI/SCI).

Adult Cystic Fibrosis

Cystic fibrosis is a genetic disease that affects a person's lungs and digestive system. It is chronic, progressive, and terminal. Medical advances have increased the life expectancy of persons with cystic fibrosis, and what was once a childhood disease has become an adult disease as well. Median life expectancy of persons with the disease in the 1960s was only five years, however by 2000, cystic fibrosis patients had an average life expectancy of 35 years.

Individuals with cystic fibrosis often need to take medications to prevent and treat infections and typically experience frequent hospitalizations. Many receive respiratory therapy multiple times each day to maintain lung function. Individuals with cystic fibrosis burn up to half of their calories breathing, and subsequently have high caloric needs. To meet these needs, an estimated 40 percent of adults with cystic fibrosis need nutritional supplements as well as special foods.

The Adult Cystic Fibrosis Program at Florida Department of Health (DOH) provides services that help an estimated 600 adults with cystic fibrosis in the state cover the cost of health insurance, medications, treatments, and support services that are not covered by private health insurance, Medicaid, or personal income. The program is administered by Abilities, Inc., of Florida under a contract with the Department of Health's Bureau of Brain and Spinal Cord Injury. Abilities, Inc. received \$990,000 in state funds to determine program eligibility, provide case management, coordinate service provision, and process payments for services and goods.

HIV/AIDS

In August 2008, the US Center for Disease Control (CDC) released a new method of estimating the incidence of HIV infections that revealed an estimated 56,300 people were infected with HIV in the United States. Using CDC's methodology, the Bureau of HIV/AIDS calculates approximately 5,550 Floridians were newly infected with HIV in 2006, and the statewide total is over 110,000 HIV positive. The new estimate indicates that 36.4 of every 100,000 Floridians age 13 years and older were newly infected with HIV annually. This rate is more than 60 percent higher than the national rate of 22.8 per 100,000 in the population, making Florida the second highest state in the number of reported acquired immune deficiency syndrome (AIDS) cases.

The Patient Care Section of the Bureau of HIV/AIDS provides a continuum of care to those who are HIV positive by ensuring the availability of a variety of health and social services including medical care, pharmaceuticals, dental services, mental health and substance abuse counseling, medical case management and numerous support services. The programs that provide services to meet the medical and social needs of HIV/AIDS clients include: Ryan White Part B Consortia, AIDS Insurance Continuation Program (AICP), AIDS Drug Assistance Program (ADAP), General Revenue Patient Care Networks, County Health Departments General Revenue Direct Patient Care, and Housing Opportunities for Persons with AIDS Program (HOPWA), and Special Contracts. These programs are funded through a combination of federal and state sources. For the 2009 service period, the total allocation for patient care services was \$165 million and HOPWA's allocation was \$4.1 million.

During the 2006-2007 program year, the following Bureau of HIV/AIDS programs are providing patient care services with both federal and state funding:

• The AIDS Insurance Continuation Program (AICP), with over \$11.1 million in funding, is now serving over 1,700 persons in Florida. The AICP is a program in which the state continues to pay private insurance premiums, co-payments, and deductibles for persons living with AIDS who cannot afford to pay on their own. The program provides \$5 in medical care services for every dollar spent and prevents the client from having to access costly public healthcare.

• Fourteen regional HIV Care Consortia Programs, seven patient care networks and 32 county health departments provide medical care, pharmaceuticals, laboratory services, dental services, mental health and substance-abuse counseling, case management and many other support services to persons living with HIV disease. In addition, transitional assistance is provided to HIV positive inmates scheduled for release in Florida's correctional system.

• The AIDS Drug Assistance Program (ADAP) is providing approximately \$100 million in prescription drugs to over 10,000 low-income and uninsured persons living with AIDS in Florida. All antiretrovirals and many other drugs to prevent opportunistic infection and side effects are available through this program. This program operates through the 67 county health departments to provide maximum access to all populations infected with HIV. The expansion of the program brings the total number of drugs and agents now available through ADAP to 85.

• The bureau provides transitional and emergency housing assistance statewide to eligible persons living with HIV disease through the Housing Opportunities for Persons with AIDS (HOPWA) Program. The HOPWA Program provides temporary mortgage, rent, and utility assistance to eligible individuals with HIV/AIDS. Funding of \$4.5 million will provide housing for approximately 2,800 households.

• Patient care staff developed a HIV/AIDS Patient Care Resource Directory, in an agreement with the Florida HIV/AIDS Hotline, to provide a comprehensive listing of providers for patient care services by county for the entire state of Florida. This directory is available online and is downloadable for printing. It is also accessible through an on-line searchable database.

• The Ryan White program funds the Emerging Communities Program and the Minority AIDS Initiative and provides care and support services and outreach and linkage services for the minority populations that are greatly affected by HIV/AIDS.

Traumatic Brain and Spinal Cord Injuries

The Medicaid HCBS Waiver Program served 336 individuals with moderate-to-severe traumatic brain or spinal cord injuries, with the average annual cost per consumer being \$24,925. (Waiver services are provided to those who may otherwise be placed in skilled nursing facilities/nursing homes.) Unlike many programs, the services provided to persons with brain and spinal cord injuries are funded by revenues from fees, fines and legal penalties. These funds provide an operating budget of \$24.1 million for the Brain and Spinal Cord Injury Program (BSCIP) to provide community reintegration services. BSCIP has set a goal to successfully reintegrate 95 percent of all program-eligible clients back into the community. A successful community reintegration closure is a case that was closed from the program with no further need for BSCIP services, referred to the Division of Vocational Rehabilitation (VR), referred to another community agency, or referred to the Medicaid HCBS Waiver for more extensive community support services. In 2008, 3,440 cases were closed by the program, and of the 968 program eligible cases closed during the year, 864 individuals (89.3 percent) were successfully reintegrated back into the community after completing a plan of care. This was only 5.7 percent below the ambitious target goal.

Balancing Indicators for Chronic Illness and Physical Disability Services

Single Point of Access

Access to long-term care supports for disabled adults occurs through multiple access points, but there is no "wrong door". For example, access to services for Florida's Brain and Spinal Cord Injury Program (BSCIP) requires referral through the BSCIP Central Registry, which is driven by reports from trauma centers. HIV/AIDS has a large number of access points, including physicians, hospital emergency rooms, hospital discharge counseling, and patient organizations.

Although the Florida Department of Health (DOH) has lead responsibility for the operational implementation of most programs related to adult chronic diseases and services for Florida adults with physical disabilities, this role is supported by the Agency for Health Care Administration (AHCA) who has lead responsibility for administrative oversight of the programs funded through Medicaid state plan services and Medicaid waivers for this population. Additionally, financial eligibility for Medicaid funded services is determined by staff with the Department of Children and Families (DCF). These three agencies work in collaboration on all disabled adult related issues, but remain functionally distinct from one another.

Continuum of Residential Options

The primary barriers to successfully serving this population in the community are affordable/accessible housing, waiting lists for in-home paid supports through the Medicaid Home and Community-Based Waiver and the lack of identified family and friends available to provide support. Additional funding and improvement is needed statewide for affordable housing for adults with chronic and debilitating health conditions. The major state housing programs also serve other populations, such as the homeless, young families with children, or the elderly. There are limited housing assistance programs available for persons with HIV/AIDS and TBI/SCI within the state.

HIV/AIDS: *Ryan White Waiver Program*- Individuals with AIDS who enter into an institutional setting are often times in the final stages of life and generally do not return to the community. Although the PAC waiver does not provide funds for housing, funding for housing assistance is provided by the Department of Health, through the Ryan White Waiver program. In this program, an HIV/AIDS positive individual uses their case management organization to assist them with transition from an institutional setting to a community setting. There is limited funding through the local community for the expenses of this transition process.

TBI/SCI: *Institutional Transition Initiative* (ITI)- for persons with traumatic brain and spinal cord injuries was established in 2003 to move individuals with moderate to severe traumatic brain and spinal cord injuries from nursing homes to community-based settings. The ITI is administered by the Florida Alliance for Assistive Services and Technology (FAAST), through a contract with the BSCIP. Under this contract, FAAST conducts an annual survey of all licensed nursing homes in Florida to identify individuals with traumatic brain and/or spinal cord injuries who are currently living in a Florida nursing home. Once identified, these individuals are contacted and interviewed to determine their readiness and capacity to live safely and independently in the community. If it is determined that these individuals have the potential to be reintegrated into a community-based setting, they are enrolled in the ITI program.

During 2007, a total of 229 individuals residing in nursing homes were identified and 11 percent were subsequently enrolled in the ITI and transitioned to the community. Of the 20 individuals that were reintegrated back to the community from skilled nursing facilities in 2007, they cost an average \$21,000 each. The total cost for the ITI program for 2007 was \$420,420. Since the Institutional Transition Initiative was established in 2003, the ITI has successfully transitioned 91 individuals from a nursing home setting into the community. When calculating the average cost of \$21,021 per transition against the average annual cost for skilled nursing home services (\$170 X 365/days = \$62,050/year), the state of Florida recoups the ITI transition costs in approximately five months from the date the individual leaves the nursing home.

Increasing HCBS to Chronically III and Physically Disabled Adults

Florida has developed programs in recent years to balance long-term care for adults with physical disabilities with extensive reliance upon Medicaid waiver use. There are four chronic disease Medicaid waivers and a Medicaid state plan service supporting low-income disabled adults who reside in Medicaid enrolled assisted living facilities, qualified residential treatment facilities or adult family care homes. These are the Adult Cystic Fibrosis Waiver, Project AIDS Care Waiver, the Traumatic Brain and Spinal Cord Injury Waiver, the Aged and Disabled Adult Waiver and the Assistive Care Services state plan service. In addition, the Frail/Elderly Program is an optional service offered by HMOs.

Adult Cystic Fibrosis Medicaid Waiver Program (ACF Waiver)- is available statewide for 150 slots. This program is operated by the Florida Department of Health. To be eligible for ACF Waiver services, an individual must be 18 years of age or older, be diagnosed with cystic fibrosis, 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, case management chore service, counseling (individual and family), dental services, durable medical equipment, exercise therapy, homemaker, massage therapy, nutritional services, 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. Nursing home services are not included in this program.

Project AIDS Care Medicaid Waiver Program (PAC Waiver)- was implemented statewide in 1989, and is administered by the Agency for Health Care Administration. PAC Waiver services include case management, chore services, day health care, education and support, environmental accessibility adaptations, home delivered meals, homemaker, personal care, restorative massage, skilled nursing, RN and LPN, specialized medical equipment and supplies, specialized personal care for foster care children, and therapeutic management of substance abuse. Nursing home services are not included in this program. In order to participate in the Project AIDS Care Waiver, one must meet the following criteria:

- have a diagnosis of AIDS documented by a physician;
- have the presence of AIDS-related opportunistic infections;
- > be determined eligible for Supplemental Security Income (SSI) or Institutional Care Program (ICP);
- > be determined by CARES to be at risk of hospitalization or placement in a skilled nursing facility;
- be determined disabled according to Social Security Administration standards;
- > not be enrolled in a Medicaid HMO, unless contracted as part of 1915(b) HIV/AIDS Specialty Waiver;
- be capable of remaining safely in the home and community;
- > need and receive PAC Waiver case management services; and
- > have completed, signed, and dated a PAC Waiver enrollment application.

During 2008, there were 5,703 individuals enrolled in the PAC Waiver, with aggregate claims of \$10 million. However, the caseload and claims experience for the PAC Waiver has varied over time. As many as 6,907 individuals have participated in a year (2003) and aggregate claims have been as high as \$25,791,519 (2000). The Project AIDS Care Waiver does not have a waiting list, nor has there ever been one in the history of the waiver. However, some areas of the state do not have providers available for the services covered by this waiver.

Traumatic Brain and Spinal Cord Injury Medicaid Waiver Program (TBI/SCI Waiver)- is available statewide and is operated by the Department of Health. To be eligible for TBI/SCI Waiver services, an individual must be considered medically stable meaning the absence of an active, life threatening condition. Waiver services include adaptive health and wellness, assistive technologies, attendant care, behavioral programming, case management, companion services, community support coordination, consumable medical supplies, environmental accessibility adaptations, life skills training, personal adjustment counseling, personal care, and rehabilitation engineering evaluation. Nursing home services are not included in this program.

TBI/SCI Waiver program had 336 participating individuals in 2008, with \$8.4 million in Medicaid claims. Settlement of the lawsuit, Dubois v. Calamas, requires that DOH shall make it a priority to seek funding sufficient to expand the TBI/SCI Waiver Program by a minimum of 50 slots for 2007, 75 slots for 2008, and 75 slots for 2008. To the extent that the expansion of the TBI/SCI Waiver Program depends upon federal funding or is subject to approval by CMS, AHCA is required to use its best efforts to obtain such funding or approvals.

Frail/Elderly Program (FEP)- provides, coordinates, and manages LTC support services for the frail and elderly who need services to prevent or delay placement in a nursing home. Individuals must be 21 years of age or older. Additional information about this program is provided in the Home and Community Based Service Programs section above in Section III.

Medicaid Aged and Disabled Adult Waiver (ADA Waiver)- is a home and community based services program that was implemented statewide on April 1, 1982. The Florida Department of Elder Affairs and the Department of Children and Families have operational responsibility for the A/DA Waiver. To be eligible for the Aged and Disabled Adult Waiver services, an individual must be 60 years old or older or be ages 18 to 59 and determined disabled according to Social Security standards; meet Supplemental Security Income (SSI), or Medicaid waiver assistance income and asset requirements; meet nursing facility level-of-care criteria as determined by CARES; and be enrolled in the waiver. Waiver services include 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, 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, and speech therapy. Nursing home services are not included in this program.

Assistive Care Services (ACS)- is a Medicaid state plan service that provides care to eligible participants who require an integrated set of services on a 24-hour-per-day basis. ACS participants must demonstrate functional deterioration that makes it medically necessary for them to live in a supportive setting and received integrated services, whether scheduled or unscheduled. To participate in ACS, an individual must be at least 18 years of age, be Medicaid-eligible, be assessed by a physician or other health care practitioner as needing at least two of the four ACS components, and be a resident of an ACS-enrolled assisted living facility (ALF) or adult family care home (AFCH). ACS includes assistance with activities of daily living (ADLs) such as bathing, walking, toileting, etc.; assistance with instrumental activities of daily living such as shopping or making a telephone call; assistance with self-administered medications; and health support (observing the recipient's state of health and well-being on a daily basis and reporting changes to the health care provider, as appropriate).

Participant Direction

HIV/AIDS- There are 14 regional Ryan White Part B HIV/AIDS Care Consortia that are responsible for planning and prioritizing the delivery of HIV/AIDS services in their respective geographic areas around Florida. Health care, housing, mental health and substance abuse providers participate in the planning process, as well as homeless coalitions. Client involvement in the HIV/AIDS planning process is a successful client-centered model of planning and care. The HIV/AIDS community conducted 860 planning meetings during the past year. On average, there were 11.5 consortia meetings conducted throughout the state in any given month, with a minimum of 361 participants, of which 103 were persons living with HIV/AIDS.

Traumatic Brain and Spinal Cord Injury- The Brain Injury Association of Florida, Inc. (BIAF) is the only non-profit organization in the state that is dedicated to helping individuals understand and live with the long-term effects of traumatic brain injury (TBI). Through a statewide network of eight Family/Community Support offices, BIAF provides practical solutions to the difficult problems faced by individuals and families when living with the long-term consequences of a TBI. Family/Community Support services are designed to assist individuals with TBI and their families with identifying and accessing community resources and needed services. These services keep TBI patients in their most integrated settings, strengthen their ability to live with the life- long consequences of TBI, and remain out of institutional settings.

Quality Management

HIV/AIDS- Each year AHCA Area Office staff must complete reviews of all Project AIDS Care (PAC) Wavier case management provider agencies. In preparation for the review, they review the previous monitoring reports, all follow-up corrective action reports, any correspondence identifying technical assistance needs of the agency, status of required reports (quality improvement reports, progress reports, etc.) and any other pertinent information. Information about current services received is gathered during the case record reviews and compared to the beneficiary's responses concerning services during the Beneficiary Survey. The purpose of the Beneficiary Survey is to validate the delivery and quality of services authorized and delivered by the PAC Waiver case manager along with determining the beneficiary's satisfaction with other services provided. Beneficiary Surveys must be completed preferably during a home visit on 1 percent of the caseload or a minimum of five PAC Waiver beneficiaries per case management agency. The review ends with the completion of the quality assurance documents which provide a summary of findings. The objective of the quality assurance review is to assess the agencies that provide services and support under the PAC Waiver.

TBI/SCI - The Brain and Spinal Cord Injury Program (BSCIP) contracts with the Brain Injury Association of Florida and the Florida Spinal Cord Injury Resource Center to conduct customer satisfaction surveys. Eligible clients, one month post closure, ranked their satisfaction with the quality of service provided to them. Overall, the program averaged 4.6 on a possible 5-point rating scale during 2007 for individuals who had sustained a brain injury and 4.3 for individuals who had sustained a spinal cord injury.

Conclusion for Chronically III and Physically Disabled Population

With extensive reliance upon Medicaid waiver use, Florida has developed programs in recent years to balance long-term care for adults with chronic illnesses and physical disabilities. However, relative to the other long term care populations, state and Medicaid funded programming for subpopulations with cystic fibrosis, HIV/AIDS and TBI/SCI remains quite low. Of the current expenditures on these disabled adults, long-term HCBS supports accounted for less than 2 percent of paid claims. In both HIVAIDS and cystic fibrosis populations, there are more frequent short-term hospital and nursing home stays due to higher demand for intense medical attention with these illnesses. It is unlikely these will be well-met by expanding basic home and community services, however some services from skilled home health aides and home nursing programs could help delay these institutional placements longer. It remains imperative that the institutional transitions for HIV/AIDS and cystic fibrosis remain fluid and easily traversed back into community settings for as long as possible. To accomplish this, the numbers of waiver program slots need to be drastically increased for both the TBI/SCI and the Adult Cystic Fibrosis Waiver, and HIV/AIDS service providers need to be recruited to the currently underserved areas.

Section VI. Services for Mental Illness and Substance Abuse

Mental illness is the leading cause of disability in the U.S. for people between the ages of 15 and 44.¹⁰ Mental illness and substance abuse disorders cost the U.S. \$193 billion in lost productivity in 2002; this loss of productivity is projected to reach more than \$300 billion by 2013.¹¹

According to Glied and Frank (2009),¹² national rates of access to care expanded for the less impaired segments of the population needing mental health services between 1996 and 2006, out-of-pocket costs remained constant or declined and quality of care continued to improve, especially in the area of pharmacotherapy. However, with shrinking budgets and increasing need, serious problems face the states in providing care and services for the mentally ill and substance abusive.

Despite the highest mental illness prevalence estimates in history, the provision of treatment and services is stagnant or declining for some segments of the population. For example, between 1996 and 2006 treatment rates for adults seriously impaired by mental health issues remain unchanged and these rates decline for the population of adults over 60 during this time span. This illustrates a national problem of mental health service provision that is especially salient to states like Florida with a rapidly growing population of elderly. The Report of the Surgeon General (1999)¹³ notes that mental disorders and problems are as common among older adults as those under age 55 or 65, but they continue to experience significantly less access to services in many communities.

Although mental illness prevalence rates are about the same for younger and older adults, the latter are often exposed to stressful life events (illness and loss of mate and friends) that may precipitate treatable mental conditions, especially depression. The mental health needs of this population will become a major public health challenge with the doubling of the 65+ population by 2040. If the large gap between the needs and services available to older persons is not reduced in the years ahead, the increased medical costs and unnecessary suffering will be substantial. Effectively treating older persons with mental disorders and problems has been shown to improve medical care outcomes (taking medications appropriately) and reduce the use of expensive long term care services, especially nursing home care (Bartels, Miles, Dums & Levine, 2003).¹⁴

Two possibly related negative trends over the last several years have been the persistent loss of funding for mental health/substance abuse treatment programs, and the growing incarceration of people with serious mental illness. Without early detection and treatment intervention, persons suffering with mental illness have high probability of encounters with law enforcement, rates that are reflected in the number of prison inmates with a mental illness increasing from 8,000 to 17,000 since 2000. This number is projected to reach 32,000 within 10 years. This trend is requires new policies to increase funding for mental health screening and treatment services, and reduce the flow of mentally ill people into the criminal justice system.

Florida estimates that 784,558 adults have serious mental illnesses (schizophrenia, bipolar disorder, chronic depression) (about 5.4 percent of the adult population) and 331,496 adolescents suffer from serious emotional disturbance. Even as these numbers have increased, funding for mental health programs has been reduced each year since 2006 and residential capacity in crisis stabilization,

¹⁰Bazelon Center for Mental Health Law (2008, Nov.). *Integrating Mental Health in Health Care: Overview*. Healthcare Reform Issue Brief: Washington, DC.

¹¹lbid.

¹² Glied, S. & Frank, R. (2009). Better but not best: Recent trends in the well-being of the mentally ill. *Health Affairs, 28*(3), 637-448.

¹³ U.S. Department of Health and Human Services (1999). *Mental health: A report of the Surgeon General— Executive summary*. Rockville, MD. Substance Abuse and Mental health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

¹⁴ Bartels, S., Miles, K, Dums, A. & Levine, K. (2003). Are nursing homes appropriate for older adults with severe mental illness? Conflicting consumer and clinician views and implications for the Olmstead Decision. *Journal of the American Geriatrics Society*, *51*, 1571-1579.

short-term residential treatment, and civil commitment beds has decreased with this lack of funding. Furthermore, funding for the state's most essential emergency intervention services, the Crisis Intervention and Stabilization Program, has been reduced in recent years, even as the need for crisis services increases annually. Florida is serving only 22.5 percent of the estimated population of persons with serious mental illness and that most of the states' most promising evidence-based programs, like Assertive Community Treatment (ACT), supported employment and housing, peer support services, and self-directed care are still quite small and far from fully funded.

Mental Health Appropriations 2008-2009									
Budget Entity	State Funds	Trust Funds	Total Appropriations						
Program Management and Compliance	\$6,779,495	\$32,298,424	\$39,077,919						
Adult Community Mental Health	\$228,293,239	\$65,893,795	\$294,197,034						
Children's Mental Health	\$73,165,979	\$20,169,939	\$93,335,918						
Adult Mental Health Treatment Facilities	\$265,064,160	\$72,055,292	\$337,119,452						
Violent Sexual Predator Program	\$25,740,534	\$5,940,369	\$31,680,903						
Total	\$599,043,407	\$196,357,819	\$795,401,226						

Table 6. Mental Health Appropriations 2008-2009

Source: APD Long Rang Plan, 2008

Substance Abuse and Mental Health Programs, Populations and Expenditures

Florida has shifted the focus of mental health services from large hospitals to a range of community based programs including crisis stabilization centers, counseling and medication management services, supported housing and employment programs, peer support, and consumer directed services. Like most states, the three major support components to Florida's services for treatment of adult mental illness include substance abuse treatment, community mental health services, and mental health treatment facilities. The effectiveness of assertive community treatment and psychosocial rehabilitative services has been demonstrated, and significant improvements in medications for a wide range of mental disorders have been gained.

Adult Substance Abuse Treatment

The Substance Abuse Program contracts with licensed community based agencies to provide emergency, acute care and detoxification services, residential, outpatient, recovery support, and housing support services. Funding for services is equally provided by the Substance Abuse Prevention and Treatment Block Grant (SAPT) and from Florida state funds. Funding for adult substance abuse treatment has remained relatively flat since 2000, averaging \$116 million per year. Likewise, the number of persons treated has also remained stable, averaging 109,000 annually. Eligibility criteria for the Substance Abuse Program services are primarily focused on persons at or below 150 percent of federal poverty level <u>and</u> are either intravenous drug users, women with children, parents putting children at risk, dually diagnosed with substance abuse / mental health (SA/MH), or involved in the criminal justice system.

Adult Community Mental Health

Mental health programs comprise a statewide system of community-based outpatient and residential services that work in combination with local hospitals and state mental health treatment facilities. Community-based services are provided in each of the Department's service areas (circuit/regions) through contracts with providers. The kinds and amounts of publicly funded mental health services available in an area are limited by the amount of funding available in that area.

The following list shows the variety and purpose of services that can be provided to people who meet the adult mental health priority population criteria:

- Treatment: a systematic approach to relieving, lessening or remove the symptoms of mental illnesses, usually involves medications, individual therapy and when necessary, psychiatric hospitalization.
- Rehabilitation: used to help individuals recover from episodic problems, and assist in preventing reoccurrence or worsening of symptoms.
- Support services: to help individuals cope with symptoms when medications and other treatments are only partially successful and provide crisis intervention.

To be eligible for mental health state services, an individual must meet one of the following three criteria:

1) **Adults in mental health crisis** - This group includes people who are 18 or older who meet criteria under the Baker Act for admission to a mental health receiving facility or show evidence of a recent stressful event and significant problems coping with that event.

2) Adults with severe psychiatric disabilities - This group includes people 18 or older who have a diagnosis or diagnostic impression of a mental disorder meeting DSM-III-R Axis I (Primary Psychiatric Diagnosis) or Axis II (Secondary Psychiatric Diagnosis) and meet any of the following criteria:

- Receive Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) or Disabled Veteran Income or other type of disability income due to a psychiatric disability; or
- Receive Social Security Income (SSI) for reasons other than a psychiatric disability and has a serious and persistent mental illness; or
- Have documented evidence of a long-term psychiatric disability, and does not need, is unable to apply or refuses to apply for disability benefits; or
- Does not receive disability income, has applied for disability income that is in process, or has received such income in the past five (5) years.

3) Adults with a serious mental illness and forensic (court) involvement - This group includes people over 18 (as well as juveniles who have been adjudicated adults) who meet any of the following: Have an "incompetent to proceed (ITP)" due to mental illness court order; <u>or</u> have a "not guilty by reason of insanity (NGI)" court order; <u>or</u> an order of conditional release due to a mental illness.

The number of persons with severe and persistent mental illness treated through community mental health supports has doubled between 2000 and 2007, with nearly all of the increase occurring by 2005. Community mental health supports are a critical community based alternative to residential facility treatment in the state. It is critical to understand that many adults with severe and persistent mental illness oscillate between community mental health services and residential facility treatment. It is not uncommon for individuals receiving treatment through community mental health services to be committed, voluntarily or involuntarily, to a residential facility briefly and then safely released back to the community for continuing treatment.

Adult Mental Health Treatment Facilities

In Florida, there are seven mental health treatment facilities (also known as state hospitals) operated by the Department of Children and Families or managed by DCF via contract with a private provider. Total funding for residential treatment has been increasing since 2002 by an average of 5.3 percent each year. Over the same period, total funding averaged \$287.4 million to treat 4,105 individuals at an average annual cost of \$69,365.



Chart 18. Adult Residential Treatment, Total Funding 2002-2008

To be admitted for treatment in a state mental health treatment facility, an individual must meet the criteria contained in Chapter 394, Florida Statutes (civil commitment) or Chapter 916, Florida Statutes (forensic commitment). Individuals admitted under Chapter 394, Florida Statutes, have been determined to have a major mental illness and be at substantial risk for living in the community due to possible dangerousness to themselves or others. These individuals may be admitted on a voluntary or involuntary basis. People committed under the forensic statute have been adjudicated either Incompetent to Proceed through the judicial system or Not Guilty by Reason of Insanity (NGI). All of these individuals are committed involuntarily by the court. As depicted in Chart 19, forensic admittance was approximately double the rate of civil admittance in 2008.



Chart 19. Adult Residential Treatment, Ratio of Civil to Forensic Residents 2002-2008

Florida has one facility that serves civilly committed persons exclusively, two facilities serve civilly committed persons and forensic step-down persons, three serve forensically committed persons only, and one serves persons committed through both processes. An additional facility operated under contract with a private vendor is reserved for persons who are civilly committed as sexually violent predators and for persons being detained while awaiting trial to determine whether they will be committed as sexually violent predators. For children's residential services, DCF and Medicaid co-fund contracted providers located in each of DCF's six regions. Civil and forensic mental health treatment facilities provide the following services:

Basic Support Services - includes provision of the basic requirements for survival such as shelter, food, clothing, and a sense of personal safety.

Healthcare Services - are intended to identify and treat physical and mental illness and promote good health. The priorities of health services include routine physical and mental health assessment, evidence-based treatment, and health education; rapid response to acute illness or injury; ongoing management of chronic health conditions; and provision of pharmacotherapy with clinical pharmacology oversight.

Recovery Services - consists of psychiatric evaluation, diagnosis, holistic recovery planning with the individual and interdisciplinary team, stabilization of the symptoms of mental illness through psychotherapeutic medication and recovery therapies, restoration of optimum level of functioning, and transition to community placement with the appropriate support services in place.

Continuity of Care Services - include internal case management services and community linkages designed to ensure that essential services are being provided consistent with the individual's recovery plan. The state mental health treatment facilities work in partnership with the community providers and circuits to facilitate continuous services and supports for people transitioning from the facility back into the community.

Competency Restoration Training and Evaluation Services for forensic cases - The focus of training is on helping individuals to understand the judicial process, the role of the court, the nature of their charges, the possible penalties, and their personal legal rights. Competency evaluations are completed, as needed, and competency evaluation reports are prepared for the courts indicating the individual's progress, as required.

Balancing Indicators for Mental Health and Substance Abuse Services

The Report of the Surgeon General (1999)¹⁵ notes that "The U.S. mental health service system is complex and connects many sectors (public–private, specialty–general health, health–social welfare, housing, criminal justice, and education). As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given sometimes competing incentives between funding sources." (p.xvii). To correct this trend, a recent national initiative by the President's New Freedom Commission on Mental Health (2003)¹⁶ has produced several ambitious goals for qualitatively improving mental health services. As stated in a progress report on six of the major goals by the National Association of State Mental Health Program Directors Research Institute (2006)¹⁷, most state mental health agencies were successfully collaborating with Medicaid and state health departments in the following efforts:

- > Promoting diagnosis and treatment of mental health needs in primary care setting,
- > Attempting to reduce inefficiencies between state agencies providing mental health services,
- > Working to develop recovery oriented services, providing prevention and early intervention services,
- Implementing at least one evidence based service, and
- Investing heavily in technology to enhance quality and accountability

Availability of Hospital Beds for the Mentally Disordered

The National Association of State Mental Health Program Directors (NASMHPD) also publishes reports on the efforts, challenges and failures of the state mental health and substance abuse treatment systems. In their 2006 report on state psychiatric hospitals¹⁸ they found that half the states were reorganizing their hospital systems, continuing to close hospitals, and spending 29 percent of total mental health funds on hospital care, which was about half the percentage spent on hospital care in the mid-1980s. Although this trend would suggest a decrease in reliance upon institutions and an increase in HCBS, the services available in the community have not been expanded in Florida to meet the rise in demand, and deinstitutionalization has subsequently created yet another barrier to access: availability of beds.

In 2006, most states also reported a shortage of needed hospital beds, but like Florida, they have remained committed to shifting spending from hospitals to community based programs. A vast majority of states (40) use community services to perform gate keeping functions to control admissions to hospitals and primarily use their hospitals to provide services to forensic patients. These national trends have been consistently present in Florida's rebalancing efforts in providing treatment and services for mental disorders and substance abuse. The seven civil and forensic mental health facilities in Florida, they only have a combined capacity of 2,698 beds. Of these, there are 1,021 beds to serve people committed under the civil statute who have been determined to be a danger to self or others due to their mental illness and 1,677 beds to serve individuals committed under the forensic statute as either Incompetent to Proceed to Trial or Not Guilty by Reason of Insanity. All other mental disorder and substance abuse issues are treated in temporary emergency hospitalization, through home and community based services, or not treated at all.

Continuum of Residential Options

Individuals admitted to Florida mental health treatment facilities will receive clinical and rehabilitative services focused on reducing severity of psychiatric symptoms, early return to the community or other appropriate placement, and continuing recovery in order for each individual to resume meaningful life roles. According to the Florida Substance Abuse and Mental Health (SAMH) Services Plan for 2009,¹⁹ the state mental health program: "continues to focus on a system that is person and family-centered and

¹⁵U.S. Department of Health and Human Services (1999), supra, 62.

¹⁶President's New Freedom Commission on Mental Health (2003). Achieving the promise: transforming mental health care in America. Final Report: Washington, DC.

 ¹⁷National Association of State Mental Health Program Directors Research Institute (2006). State mental health agency implementation of the six New Freedom Commission goals: 2006. State Profile Highlights, No. 06-1: Alexandria, VA.

¹⁸National Association of State Mental Health Program Directors Research Institute (2006). State psychiatric hospital: 2006. State Profile Highlights, No. 06-4: Alexandria, VA.

¹⁹ Florida Department of Children & Families (2009). Substance abuse and mental health annual plan update. January 2009: Tallahassee, FL.

directed, promotes individual and family choice in mental health services and supports, and assures that those services reflect the best practices available." Community based services are provided in each of the Department's service areas (regions) through contracts with providers. The statewide system of mental health programs combines intermittent community-based outpatient and residential services with state mental health treatment facilities on as needed basis. Transitions in and out of facilities and communities are fluid, and ongoing efforts support these transitions to reduce the likelihood of relapse and support independence and functioning. However, these efforts to retain individuals in community settings are not without challenges. In the NASMHPD 2005 report on housing,²⁰ despite the extensive activity at the state level to address growing demand, there is a shortage of subsidized housing for persons with mental illnesses. Without subsidy for housing assistance, individuals with mental disorders and substance abuse problems are at a far greater risk of homelessness and the subsequent injuries, negative social interactions and more severe symptom experience from their disorders.

Quality Management

The evaluation research and policy analysis literature on mental health is not as extensive or as focused as the available literature on long-term care for the elderly or the developmentally disabled. The literature is sufficient, however, to support the efficacy of a number of community-based treatment interventions, especially for chronic depression and other serious disorders. Although the research from academics and clinicians have historically focused on patient outcomes from treatment, the mechanisms to evaluate the treatment providers, programs and facilities themselves are still being developed and tested against these patient outcomes. Few quality indicators related to mental health services have been generated and these indicators have not been employed extensively yet. Despite the slowness with which these measures have been put in place statewide, there is significant recent progress in developing these quality management programs for different disorders and treatment types, and preliminary results have been well-regarded. According to Patel in 2006:

"Programs that have addressed providers' competencies and prescribing practices represent critical steps forward. Newer initiatives such as Enhancing Quality Utilization in Psychosis (EQUIP-2) aim to improve a broader range of treatment domains for clients with schizophrenia, and in particular, systems of care. EQUIP-2 offers great promise in the field of quality improvement in treatment of psychotic disorders... (Patel, 2006, p. 681)²¹

"Evidence-based service delivery programs, including Assertive Community Treatment (ACT) for SPMI and Multi-Systemic Therapy for youth with conduct disorders, add scope to the programs that are available for improving outcomes by practices and systems... (Patel, 2006, p. 683)²²

"Toolkits such as those developed by the Implementing Evidence Based Practices for SMI Project, which includes ACT as well as resources on family psychoeducation and supported employment, share many features with quality improvement programs, and evaluations are forthcoming. Linking these types of resources to process and outcome measures is an important ongoing research agenda." (Patel, 2006, p. 685)²³

Despite these recent advancements and their promising preliminary results, a great deal of work remains to be done in addressing barriers to improving the quality of mental health care in Florida. The emerging quality management tools need to be continuously improved and deployed statewide. Systematic evaluation of facilities should be conducted on an ongoing basis in such a way to take patient outcomes, recidivism and type of treatment into account. The analysis of source of services with patient long-term outcomes is necessary for performance measures to capture the true rate of successful reintegration in community settings.

²⁰ National Association of State Mental Health Program Directors Research Institute (2005). Housing for persons with mental illnesses: 2004. State Profile Highlights, No. 05-4: Alexandria, VA.

²¹Patel, K. Butler, B. & Wells, K. (2006). What is necessary to transform the quality of mental health care. *Health Affairs*, *25*(3), 681-693.

²²Ibid.

²³lbid.

The Florida Substance Abuse and Mental Health Program office is required by the legislature to track 25 performance measures at the state, district/circuit, and service provider levels. Federal legislation requires recipients of federal block grants or performance partnership grants to report on National Outcome Measures (NOWS), which cover ten domains, including employment, education, housing, and cost-effectiveness. The performance data for 2008 indicates that the mental health program was able to meet most of the standards for each of the major measures including the following:

- 1. Among adults with serious and persistent mental illness (SPMI), the average number of days spent in the community (not in institutions or other facilities) was 349.10 (meets the goal of 350 days minimum).
- 2. Median length of time in CSO/inpatient services was kept to two days (exceeds the goal of five days maximum).
- 3. Average annual days worked were 43.88(four days below the goal of 49 days minimum).
- 4. For forensic patients, the percent of persons who violate the conditional release and were recommitted was 0.67 percent (exceeds the goal of 2 percent maximum).
- 5. The annual average days spent in community for adults with forensic involvement were 287.4 days (exceeds the goal of 260 days minimum).
- 6. The percent of adults in a civil mental health treatment facility who show improvement in functional level was 67 percent (6 percent below goal of 73 percent).
- 7. The number of adults in forensic commitment per Chapter 916 F.S was 3,031 (exceeded the 2,300 goal).
- 8. The percentage of forensic patients not guilty by reason of insanity who showed an improvement in functional level was 42 percent (substantially below the 63 percent minimum improvement goal).
- 9. The average number of days to restore competency for forensic patients was 134 (exceeded goal of 143 day maximum).

These outcomes represent a considerable achievement in the Mental Health Program's efforts to serve the civil patient population in 2007-08, especially in light of chronic funding constraints. The Program's efforts in serving the forensic population were not as successful. This population is difficult to serve effectively and has been a long-standing challenge for the state Mental Health Program, the courts, the police, and local and state corrections programs. All of these agencies have been collaborating to develop a comprehensive strategy for addressing this challenge and are now prepared to present the legislature with a plan for implementation over the next few years.

The Substance Abuse Mental Health (SAMH) Program is also using several, somewhat more programspecific measures, mostly the required national outcome measures, to generate state performance data, including the following for adults with serious and persistent mental illness in 2008:

- 1. 24 percent are competitively employed.
- 2. 1,749 received supported employment services (exceeds goal of 1,500).
- 3. 2,048 received housing services (exceeds goal of 2,000).
- 4. 3,300 received assertive community treatment services (exceeds goal of 3,000).
- 5. 94 percent reported that they are satisfied with their treatment, based on the client satisfaction survey of 780 surveyed clients, 736 of whom responded (exceeds goal of 90 percent satisfaction).
- 6. 1 percent (4 out of 598 discharged persons) have been readmitted to civil state psychiatric hospital within 30 days of discharge from services (exceeds goal of no more than 2 percent).
- 7. 6 percent (35 of 598 persons discharged) have been readmitted to civil state psychiatric hospitals within 180 days of discharge from services (exceeds goal of no more than 10 percent).
- 8. 6 percent (7,753 of 146,149 persons) have been involved in the criminal justice system (meets goal of no more than 6 percent)
- 9. 93 percent (706 of the 766 surveyed) have reported that they feel positively about social connectedness (exceeds goal of at least 90 percent).
- 10. 92 percent (704 of the 766 surveyed) have reported feeling positive about their functional status (exceeds goal of 90 percent).
- 11. 6 percent (9,026 of 159,387) of homeless have received state funded services (exceed goal of at least 5 percent).
- 12. 8 percent (13,323) living in rural areas have received state services (meets goal of 8 percent).

Florida's State Profile Tool

Although only 22.5 percent of those who need services are receiving them, Florida is meeting or exceeding most outcomes for the quality of service delivery to persons with SPMI for 2008. However, the National Alliance on Mental Illness (NAMI) reports on America's health care system for adults with serious mental illness grades the states to provide a baseline for measuring progress toward the transformation of the U.S. mental health system. In the 2009 NAMI report, the states earned an average grade of "D". Although fourteen states improved their grades from 2006 to 2009, 12 fell back a grade and 23 stayed the same.

The report grades states on 64 measures divided into four categories, each of which receives a letter grade. Of these 64 measures, Florida scored above the national average on 34 items, below the national average on 24 items, and at the national average on 6 items. The categories and the grades given to Florida for each category are: Health promotion and measurement 'D'; Financing and core treatment/recovery services 'C'; Consumer and family empowerment 'C'; Community integration and social inclusion 'C'. Florida earned an overall grade of a 'C' in 2006, which dropped to a 'D' in 2009.

The report found that Florida has too few total psychiatric beds, including local, state, and federally funded beds and not-for-profit invested owned private sector beds. Florida had 6.8 beds per 1,000 adults with serious mental illness in 2007, which was next to last among the states and four beds below the national average of 10.8 beds.

The report notes that the state's relatively scarce in-patient beds are disproportionately used to restore competency for people facing criminal charges and that many people who receive little or no mental health services enter the criminal justice system when their needs reach a crisis point. The NAMI report also recognizes Florida's efforts underway to address these challenges:

"Florida Partners in Crisis," a non-profit collaboration between public officials in the criminal justice system and mental health advocates, has taken bold steps to respond to the crisis in Florida's jails and prisons. It has advocated for the Criminal Justice, Mental Health, and Substance Abuse Reinvestment Grant program, which provides state matching grants to counties for police Crisis Intervention Teams (CIT), mental health courts, and other programs to reduce the criminalization of people with mental illnesses. In addition, the state's Supreme Court justices have taken the lead drafting a plan for targeting intensive mental health services to people who are at the greatest risk of criminal justice system involvement." (p.27)

The report also notes other areas of progress in the Florida mental health system, including efforts to involve consumers and families in planning and providing services, integration of mental health and substance abuse treatment, and the implementation of 30 Assertive Community Treatment (ACT) teams that strive to meet national standards.

Major Policy Implications

Most states have implemented relatively extensive Medicaid managed mental health programs in an effort to overcome some of the barriers to access caused by organizational divisions, service gaps, and multiple funding streams. The Report of the Surgeon General (1999) notes that there is little direct evidence of quality deficiencies in "well-implemented" managed care programs. Florida began a mental health managed care program several years ago, beginning with demonstration projects which have evolved into a full scale program over the last two years.

These two demonstration projects and the regular Medicaid waiver funded program have been evaluated at several intervals by researchers in The Louie de la Parte Florida Mental Health Institute. The report finds that the implementation of managed care has changed both the kinds of services delivered to enrollees and their relative frequency. For example, ambulatory care tended to shift toward more traditional office visits and away from community mental health services and supports.

However, the change in the mix of ambulatory services did not negatively affect short term outcomes. During the first six months, the performance of many of the managed care plans in providing follow up care to enrollees discharged from inpatient care within 30 days was inadequate, however, significant improvement was observed in the second six month period.

The patterns evident in recent research are not consistent across all areas in the state, and vary between providers. Increases in the use of inpatient psychiatric care that occurred in the post implementation period with a number of plans may cause future problems, but it is too early to make judgments about the impacts of the shift to managed care overall, (Constantine, Murrin, Guo & Wang, 2007;²⁴ Boothroyd, Constantine, Robinson & Sharrock, 2007;²⁵ Murrin & Constantine, 2008;²⁶ and Boothroyd, 2007;²⁷ Murrin & Constantine, 2008, p. 23-24).²⁸

These inconsistencies in findings indicate that Medicaid funded mental health managed care in Florida is in its early stages of implementation and increased experience should lead to improved outcomes and greater cost-effectiveness over time. Two immediate concerns, however, are the diminished involvement of the community mental health centers in the provision of services for the managed care organization members and the failure to reduce inpatient care in most of the areas included in the evaluation. The first issue concerns the role of the CMHCs in the public mental health system and the potential emergence of duplicative service systems. This issue may also indicate a growing quality gap between services for Medicaid supported consumers and those supported by private insurance and other sources of financing.

Florida continues to monitor and evaluate the Medicaid managed mental health program. It is not yet clear that this is the most cost-effective method for organizing the financing and delivery of mental health services and the state should not prematurely close off other policy options. The relationship between the managed care system and the community mental health centers needs to be monitored with any eye toward preventing the emergence of duplicative service systems that may be inefficient. If it can be determined that the current design of the Florida mental health system is not the most optimal for meeting the anticipated needs in the next several decades, then policy makers and advocates should consider alternative models for service provision.

Some proposed alternatives include prevention and early intervention services that could increase the state's capacity to provide more cost-effective care as the need for services increases. One model might be to develop a network of relatively small (50-100 beds) treatment centers in each or most of the districts/circuits, which would be designed to serve those with SPMI requiring sustained support and treatment for up to 90-100 days. These centers would be an integrated part of the district mental health system providing a readily available backup for the community based services programs, a residential program designed to keep residents in their home communities and in touch with their family, friends, and community-based providers. The current state psychiatric hospitals could be reserved for longer-stay residents and their beds gradually reduced as the network of smaller district-based facilities come on line.

Conclusion for Mental Illness and Substance Abuse Population

Compared to other states, Florida spends very little on a per capita basis on mental health, substance abuse prevention, and treatment services. The Florida Mental Health program, like those in many other states, needs a major increase in funding each year for several years to come to meet expected demand for services. This funding is needed to build a solid infrastructure of home and community-based programs, including housing, employment, and education. The state is also likely to need additional psychiatric beds over the next several years.

Florida has relatively few state-operated psychiatric beds which is creating a hardship in some areas of the state in meeting the needs of some persons who need more sustained support and attention than can currently be provided. More beds will also be needed to increase the capacity of the mental health system to divert persons with serious mental illnesses from unnecessary and counter-productive involvement in the

²⁴Constantine, R., Murrin, M., Guo, J. & Wang (2007). Evaluation of Florida's Medicaid managed mental health plans years 10 report: Administrative data component. The Louis de la Parte Florida Mental Health Institute, University of South Florida: Tampa, FL.

²⁵Boothroyd, R. Constantine, R., Robinson, P. & Sharrock, P. (2007). Evaluation of Florida's Medicaid managed mental health Plans: Integrated summary. The Louis de la Parte Florida Mental Health Institute, University of South Florida: Tampa, FL.

²⁶Murrin, M. & Constantine, R. (2008). The administrative data component of the pre-paid managed care evaluation: Year III. The Louis de la Parte Florida Mental Health Institute, University of South Florida: Tampa, FL.

²⁷Boothroyd, R. (2007). Evaluation of Florida's Medicaid managed mental health plans: Mail survey component. The Louis de la Parte Florida Mental Health Institute, University of South Florida: Tampa, FL.

²⁸Murrin & Constantine, supra, note 89.

criminal justice system. To do this, the state needs to expand its community based mental health system and intervene before people reach a crisis point. Unfortunately, the fundamental facts about mental health and substance abuse services in Florida are the state has an underdeveloped system of services, funding for the expansion of this system has been losing ground intermittently for several years, and the system is likely to lose even more ground in the foreseeable future with a growing gap between needs and resources.

The available program performance and outcome data would seem to indicate that Florida's mental health system provides effective services, even given the state's relatively low level of per capita spending on mental health care. However, the state is serving only 22.5 percent of those estimated to need mental health treatment and some of the most cost-effective interventions (i.e., assertive community treatment) are underfunded. The availability of mental health care will not be substantially increased nor the full potential of cost-effective intervention achieved until the state is able to make major new investments in its community mental health system on a sustained basis for several years.

Section VII. Conclusion

This document described the factors that have shaped Florida's long-term care system and its rebalancing efforts for four populations: the frail elderly, people with intellectual and developmental disabilities, people with physical disabilities and chronic diseases and people with mental disorders and substance abuse problems.

Through the expansion of the Medicaid Nursing Home Diversion Waiver Program and the expansion of the Medicaid supported assisted living programs (ALE and ACS), Florida has made significant progress toward constructing a more balanced long-term care system for elders over the last ten years. Florida has also improved access to services through the implementation of the Aging and Disability Resource Centers/Aging Resource Centers and elevated the quality of nursing home care by increasing direct care staffing levels. Despite this ongoing effort, Florida's funding of HCBS alternatives has historically been lower than most other states, and despite recent improvements, state per capita expenditures remain approximately half that of the national average. In addition, many other states serve a higher proportion of their LTC population in home and community settings. As Florida's waiting lists for HCBS grow and the peak demand for services is still two decades into the future, Florida needs to continue to find ways to address current and future unmet need.

Florida has also made significant progress in developing a balanced system for people with intellectual and developmental disabilities. Florida has experienced growth in their HCBS programs, a decline in institutional care, and the emergence of an increasingly person-centered approach to service provision. However, the state has also experienced a steady growth of waiting lists for services, is still under-employing disabled adults, and is facing intense fiscal pressures that may impede additional short-term progress.

Florida has also made gains in recent years with balancing the LTC system for people with physical disabilities and chronic illnesses mainly through the use of extensive Medicaid waivers. However, relative to the other long term care populations, state and Medicaid funded programming for subpopulations with cystic fibrosis, HIV/AIDS and Traumatic Brain and Spinal Cord Injuries remains quite low. It is recommended that the numbers of slots be drastically increased for both the Traumatic Brain and Spinal Cord Injury Medicaid Waiver Program and the Adult Cystic Fibrosis Waiver. In addition, recruiting efforts are needed to increase the availability of HIV/AIDS service providers.

Program performance and outcome data indicate that Florida's mental health system provides effective treatment, however, state programs are estimated to reach less than a quarter of those who need these services. The capacity to meet this need will not be adequately increased until the state is able to make large sustained investments in its community mental health system. To do this, the state will need to increase availability of early intervention services and enhance home and community-based programs, especially housing, employment, and education services. Although seemingly contrary to HCBS, projections indicate that the state needs additional institutional psychiatric beds. However, with expanded facilities, it will become easier to divert persons with serious mental illnesses from the criminal justice system. These facilities should be used only for the intermittent care of those who will return to community settings.

As with many states, the further shifting of funding from institutional care to home and community based programs faces fiscal challenges amidst difficult economic times. However, Florida will continue to advocate for increased funding for HCBS for these populations for whom HCBS have been shown to be cost effective alternatives to institutionalization. Home and community based service programs have been shown to be cost effective and deliver improved quality of care in comparison to institutional care program. However, the reforms necessary to balance institutional and alternative long-term care services to Florida's growing consumer populations will require significant additional resources, sustained advocacy and political leadership.

Appendix A

Appendix A: Florida HCBS Programs

The appendix presents summary tables for Florida HCBS programs. These include programs funded through federal sources, Florida state- funded, and Medicaid.

There are three tables for each category of program.

- Administrative Details include eligibility criteria, funding source, statutory authority, and Florida department(s) responsible for program administration.
- > Available Services include a large number of HCBS.
- Appropriations and Participants include comparative baseline data for 2000 and information from the most recent year (2008).

Table 7a. Aging Programs and Services – Federal Administrative Details

Long-Term Care Service Programs									
	OAA Title III	OAA Title V	OAA Title VII Emergency Home Energy Assistance Program (EHEAP)		OAA Title V OAA Title VII Assistance Program Incentive Program		Serving Health Insurance Needs of Seniors (SHINE)		
Eligibility Requirements									
Age	60	55	None	60	60	None			
Region Served	Entire State	Entire State	Entire State	Entire State	Entire State	Entire State			
Income Limitation	Targeted at low income	Low Income		Household income less than 150 percent of federal poverty level					
Other Limitation				Heating or cooling emergency.	Receiving home delivered meals or congregate meals under OAA.	Medicare recipients, their family members, and caregivers			
Co-Pay Required	None	None	None						
Funding Sources									
Federal	V	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark			
Program Administration	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA			
Statutory Authority	Older Americans Act, 42 United States Code 3001 et.seq. as amended by Public Law 106-501; Section 20.41 and Chapter 430, Florida Statutes.	Title V of the Older Americans Act, 42 United States Code 3001 et seq. as amended by Public Law 109-365.	Older Americans Act, 42 United States Code 3001 et. seq. as amended by Public Law 106-501; Section 430.101, Florida Statutes	Low-Income Home Energy Assistance Act of 1981, 42 United States Code 8621 et. seq.; Title XXVI of Public Law 97-35, as amended; 45 Code of Federal Regulations 96; Section 409.508, Florida Statutes; Chapter 91-115, Laws of Florida, Section 10.	Sections 430.07- 430.071, Florida Statutes; Public Law 93-113, Domestic Volunteer Service Act.	Omnibus Budget Reconciliation Act of 1990, Section 4360; Section 430.07, Florida Statutes.			

Table 7b. Aging Programs and Services – Federal Available Services

	OAA Title III	OAA Title V	OAA Title VII	Emergency Home Energy Assistance Program (EHEAP)	Nutrition Services Incentive Program (NSIP)	Serving Health Insurance Needs of Seniors (SHINE)
Services						
Case Management	V					
Chores	V					
Congregate Meals					\checkmark	
Environmental Adaptations	$\mathbf{\nabla}$					
Escort	\mathbf{N}					
Health Education	\square					
Home Delivered Meals	V				\checkmark	
Home Health Aide						
Homemaker Services	N					
Information and Referral						Ø
Legal Services	V					
Nutrition Education						
Outreach						V
Transportation						
Other		Senior Community Service Employment Program (SCSEP)	Elder Abuse Prevention	Heating and cooling equipment, such as blankets, fans, and space heaters. Limited to \$400 per season.		

	OAA Title III	OAA Title V	OAA Title VII	Emergency Home Energy Assistance Program (EHEAP)	Nutrition Services Incentive Program (NSIP)	Serving Health Insurance Needs of Seniors (SHINE)
2000-01						
Appropriation (Federal)	\$49,299,486	n/a	\$172,259	\$1,013,152	\$6,768,177	\$989,837
Enrollees	89,058	3,547		7,183		94,315
2007-08						
Appropriation (Federal)	\$75,785,098	\$5,661,826	\$382,298	\$1,761,778	\$7,632,469	\$2,267,337
Enrollees	80,326	3,497		n/a		n/a

Table 7c. Aging Programs and Services – Federal Appropriations and Participants

	Long-Term Care Service Programs									
	AmeriCorps	Elder Farmers' Market Nutrition Program	Long-Term Care Ombudsman	Senior Companion Program						
Eligibility Requirements										
Age	60	60		60						
Region Served	Entire State	Entire State	Entire State	Entire State						
Frailty Requirement				At risk of nursing home placement						
Income Limitation		Less than 185 percent of federal poverty level								
Co-Payment	Co-Payment None		None	None						
Funding Sources										
Federal	☑	$\overline{\mathbf{A}}$	\checkmark	N						
Florida State Funded	Ø	Ø	\checkmark	\checkmark						
Program Administration	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA						
Program AdministrationFibrida DOEAStatutory AuthorityCitizens Service Act of 2002, which amends the National AmeriCorps and Community Service Act of 1990; Domestic Volunteer Service Act of 1973; Section 430.07(8), Florida Statutes.		Section 5(e) of the Commodity Credit Corporation Charter Act, 15 United States Code 714c(e).	Title VII of the Older Americans Act, 42 United States Code 3001 et. seq. as amended by Public Law 106-501; Part I, Chapter 400 Florida Statutes.	Sections 430.07- 430.071, Florida Statutes; Public Law 93-113, Domestic Volunteer Service Act.						

 Table 8a. Aging Adult HCBS with Federal and Florida State Funded Appropriations Administrative Details

Table 8b. Aging Adult HCBS with Federal and Florida State Funded Appropriations Available Services

Services	AmeriCorps	Elder Farmers' Market Nutrition Program	Long-Term Care Ombudsman	Senior Companion Program
Companionship				$\mathbf{\nabla}$
Education/Training	$\mathbf{\nabla}$			
Legal Services			\checkmark	
Nutrition Education		N		
Outreach	$\mathbf{\nabla}$			
Respite Care	$\mathbf{\Sigma}$			
Other	Provides education award in exchange for one year of service.	Coupon books for discounts on fresh fruits and vegetables		

Table 8c. Aging Adult HCBS with Federal and Florida State Funded Appropriations and Participants

	AmeriCorps	Elder Farmers' Market Nutrition Program	Long-Term Care Ombudsman	Senior Companion Program
2000-01				
Appropriation (Federal)	\$695,765		\$1,011,559	\$301,106
Appropriation (Florida)	\$130,000		\$339,634	\$80,076
Enrollees	2,653			725
2007-08				
Appropriation (Federal)	\$137,813	\$94,903	\$1,115,096	\$277,928
Appropriation (Florida)	\$41,940	\$31,335	\$1,401,870	\$117,764
Enrollees	120	3,274		n/a

Table 9a. Aging Services – Florida State Funded Administrative Details

				Long-Te	rm Care Ser	vice Progra	ms			
Eligibility Requirements	Alzheimer's Disease and Related Disorders Training Provider and Curriculum Approval (ADRD)	Alzheimer's Disease Initiative (ADI)	Community Care for the Elderly (CCE)	Contracted Services	Home Care for the Elderly (HCE)	Local Services Program	Osteoporosis Screening and Education	Respite for Elders Living in Everyday Families (RELIEF)	Statewide Public Guardianship Office	Sunshine for Seniors Prescription Assistance Program
Age		Caregivers for adults 18 years and older, diagnosed as having probable Alzheimer's disease or other related disorders.	60 and older	60 and older	60 and older	60 and older	60 and older	60 and older		60 and older
Region Served	Entire State	Entire State	Entire State	Palm Beach, Broward, and Miami-Dade counties	Entire State	All Planning and Service Areas (PSAs) except PSA 1	Entire State	Entire State	Entire State	Entire State
Frailty Requirement			Functionally impaired		At risk of nursing home placement			Must be frail		
Disease-Specific		Alzheimer's disease or other related memory disorders.								
Caregiver Requirement					Living with full-time caregiver			Living with full-time caregiver		
Asset Limitation					ICP or lower					
Income Limitation					ICP or lower	None, targeted by need.	Economically Needy			
Other Limitation							Medically Underserved			Need assistance with prescriptions

	Alzheimer's Disease and Related Disorders Training Provider and Curriculum Approval (ADRD)	Alzheimer's Disease initiative (ADI)	Community Care for the Elderly (CCE)	Contracted Services	Home Care for the Elderly (HCE)	Local Services Program	Osteoporosis Screening and Education	Respite for Elders Living in Everyday Families (RELIEF)	Statewide Public Guardianship Office	Sunshine for Seniors Prescription Assistance Program
Co-Payment			V							For some medications.
Funding Source: Florida State Funded	Ø	V	Ø	Ø	Ø	Ø	Ø	Ŋ	Ø	Ø
Program Administration	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA	Florida DOEA
Statutory Authority	Sections 400.1755, 429.178, 400.6045, 429.917, and 400.4785, Florida Statutes.	Sections 430.501 - 430.504, Florida Statutes.	Sections 430.201- 430.207, Florida Statutes.	General Appropriation s Act, State of Florida.	Sections 430.601 - 430.608, Florida Statutes.	General Appropriatio ns Act, State of Florida.	General Appropriations Act, State of Florida; Section 430.07(8), Florida Statutes.	Section 430.071, Florida Statutes.	Chapter 744, Florida Statutes.	Section 430.83, Florida Statutes.

Table 9b. Aging Services – Florida State Funded Available Services

Services	Alzheimer's Disease and Related Disorders Training Provider and Curriculum Approval (ADRD)	Alzheimer's Disease initiative (ADI)	Community Care for the Elderly (CCE)	Contracted Services	Home Care for the Elderly (HCE)	Local Services Program	Osteoporosis Screening and Education	Respite for Elders Living in Everyday Families (RELIEF)	Statewide Public Guardianship Office	Sunshine for Seniors Prescription Assistance Program
Adult Day Care			\square			V				
Adult Day Health Services			M							
Caregiver Support Services		V								
Case Aide			\square			$\mathbf{\nabla}$				
Case Management						M				
Chores			V			M				
Companionship			M			M				
Congregate Meals			Ŋ	Ŋ						
Counseling			Ŋ			Ŋ				
Durable Medical Equipment						V				
Education/Training						\square				
Emergency Alert Response			V			M				
Emergency Home Repairs			Ø							
Escort			Ø							
Health Support Services										
Home Delivered Meals			Ø	V						
Home Health Aide			V							
Home Nursing			Ø	M		M				
Homemaker Services			Ø	V		V				
Housing Improvement						M				
Information and Referral			Ø			M				
Legal Services			Ø			M				

Services	Alzheimer's Disease and Related Disorders Training Provider and Curriculum Approval (ADRD)	Alzheimer's Disease initiative (ADI)	Community Care for the Elderly (CCE)	Contracted Services	Home Care for the Elderly (HCE)	Local Services Program	Osteoporosis Screening and Education	Respite for Elders Living in Everyday Families (RELIEF)	Statewide Public Guardianship Office	Sunshine for Seniors Prescription Assistance Program
Material Aid			Ø			M				
Medical Therapeutic Services			Ø							
Nutrition Education						M				
Outreach						V				
Physical Education						V				
Recreation				Ø		V				
Respite Care		V				V		V		
Screening and Assessment						V				
Shopping Assistance			\square							
Transportation			Ø	$\mathbf{\nabla}$		N				
Other	Approves training providers and training curricula for long-term care employees	Memory Disorder Clinics (MDCs), Model Day Care			A basic subsidy averaging \$106 per month. Additional subsidies in special circumstanc es.		Osteoporosis screening and education services.			Prescription assistance and counseling.

Table 9c. Aging Services – Florida State Funded Appropriations and Participants

	Alzheimer's Disease and Related Disorders Training Provider and Curriculum Approval (ADRD)	Alzheimer's Disease initiative (ADI)	Community Care for the Elderly (CCE)	Contracted Services	Home Care for the Elderly (HCE)	Local Services Program	Osteoporosis Screening and Education	Respite for Elders Living in Everyday Families (RELIEF)	Statewide Public Guardianship Office	Sunshine for Seniors Prescription Assistance Program
2000-01										
Appropriation (Florida)		\$12,155,902	\$46,933,055	\$398,424	\$13,458,403	\$3,828,443	\$45,485	\$1,330,044	\$1,252,858	
Enrollees			40,804	837	8,813	5,570	1,400	449	1,098	
2007-08										
Appropriation (Florida)	\$77,826	\$27,714,674	\$43,364,370	\$1,075,924	\$9,529,461	\$8,764,833	\$200,000	\$1,044,530	\$2,279,718	\$158,000
Enrollees			19,232	n/a	5,240	33,634	n/a	n/a	2,544	2,063

Table 10a. Aging Services – Medicaid Administrative Details

	Long-Term Care Service Programs										
	Aged and Disabled Adult Waiver (MedWaiver)	Alzheimer's Disease Waiver	Assisted Living for the Elderly (ALE)	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/ Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)	
Eligibility Requirements											
Age	60 for aged, 18 for disabled	60	55	18	65	75	No limit	21	60	55	
Region Served	Entire State	Entire State	Broward, Miami-Dade, Palm Beach, and Pinellas counties	Entire State	Broward and Miami-Dade counties	Lee and Palm Beach counties	Entire State	Miami- Dade County	32 Florida counties	Duval, Lee, Martin, Miami Dade, and St. Lucie counties	
Frailty Requirement	Meets ICP Level of Care (LOC)	Meets ICP Level of Care (LOC)	Meets ICP Level of Care (LOC) with additional frailty criteria	ACS participants must demonstrate functional deterioration that makes it medically necessary for them to live in assisted living	Meets ICP Level of Care (LOC) with additional frailty criteria	Meets ICP Level of Care (LOC)	Meets ICP Level of Care (LOC)	Meets ICP Level of Care (LOC)	Meets ICP Level of Care (LOC) with additional frailty criteria	Meets ICP Level of Care (LOC)	
Disease- Specific		Have a confirmed diagnosis of Alzheimer's Disease									
Caregiver Requirement		Living with a caregiver				Living with a caregiver					
Asset Limitation	Medicaid eligibility	ICP or lower	Medicaid eligibility	Medicaid eligibility	ICP or lower	Medicaid eligibility	Medicaid eligibility	Medicaid eligibility	Medicaid eligibility	ICP or lower	
Income Limitation	Medicaid eligibility	ICP or lower	Medicaid eligibility	Medicaid eligibility	ICP or lower	Medicaid eligibility	Medicaid eligibility	Medicaid eligibility	Medicaid eligibility	ICP or lower	
	Aged and Disabled Adult Waiver (Medicaid Waiver)	Alzheimer's Disease Medicaid Waiver	Assisted Living for the Elderly (ALE) Medicaid Waiver	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/ Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)	
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Other Limitation			Qualify for SSI; be a resident of an ALE-enrolled assisted living facility (ALF).	Qualify for SSI; be a resident of an ACS- enrolled assisted living facility (ALF), or adult family care home (AFCH), or residential treatment facility.			Be enrolled in one of the following Section 1915(c) waivers: Aged and Disabled Adult, Brain and Spinal Cord Injury, Developmental Services.	Qualify for SSI	Be dually enrolled in Medicaid and Medicare	Be dually enrolled in Medicaid and Medicare	
Co-Payment		None	Participants are responsible for room and board payments.		Sliding scale, not to exceed 85 percent of the Medicaid nursing home payment in Broward or Miami-Dade County						
Funding											
Medicaid		V	V	Ø	V		V		\square	Ø	
Demonstration Project						1115 Demonstration ended 2/29/08				M	
State Plan Service				Ø							
Waiver	Section 1915(c)	Sections 1915(b) and (c)	Section 1915(c)		Section 1915(b)	Effective 03/01/2008, Section 1915(j) State Plan Amendment.	Independence Plus 1115 waiver amendment	Section 1915(b)	Section 1915(c)		
Program Administration	Florida DOEA via interagency agreement with AHCA	Florida DOEA via interagency agreement with AHCA	Florida DOEA via interagency agreement with AHCA	Florida Medicaid (AHCA)	Florida Medicaid (AHCA)	Florida Medicaid (AHCA)	Florida DOEA via interagency agreement with AHCA	Florida Medicaid (AHCA)	Florida DOEA via interagency agreement with AHCA	Florida DOEA via interagency agreement with AHCA	

Table 10b. Aging Services – Medicaid Available Services

	Aged and Disabled Adult Waiver (MedWaiver)	Alzheimer's Disease Waiver	Assisted Living for the Elderly (ALE)	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/ Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)
Services										
Adult Day Health Services	V	V			Ø		V	Ø		
Assisted Living Services			V	Ŋ					V	
Attendant Care	M		V				N		A	
Behavior Management			V							
Caregiver Support Services		M								
Case Aide	Ø						V			
Case Management	Ø	V	V		Ø		$\mathbf{\nabla}$	Ø	V	
Chores	Ø				Ø		V		M	
Companionship	Ø				Ø		V		V	
Consumable Medical Supplies	V	V	V				V		V	
Counseling	Ø				V		Ø			
Durable Medical Equipment	Ø		V		Ø		Ŋ			
Emergency Alert Response	V						V		V	
Environmental Adaptations	Ø	V			Ø		Ŋ	V	V	
Escort	Ø						Ø		V	
Family Training and Support	V				Ø		\mathbf{N}			
Health Support Services							\square			

	Aged and Disabled Adult Waiver (MedWaiver)	Alzheimer's Disease Waiver	Assisted Living for the Elderly (ALE)	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/ Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)
Home Delivered Meals	V				M		V		V	
Home Health Aide										
Home Nursing							V		\square	
Homemaker Services	V		\blacksquare				Ø	V	V	
Medical Therapeutic Services	M		V		M		Ø	M	Ø	
Nutrition Education							Ø	V	V	M
Personal Care Services	Ø	V	\square	Ø	V		M	Ø	V	M
Pest Control	Ø						$\overline{\mathbf{V}}$		Ø	
Recreation					Ø					
Respite Care	Ø	Ø					$\overline{\mathbf{A}}$	Ø	Ø	M
Risk Reduction	Ø						\square	Ø	V	
Shopping Assistance			V	Ø			Ø			
Skilled Nursing Facility					Ŋ				Ø	M
Transportation						V	Ø		Ø	Ø
Other		Wandering alarm, identification and location program, behavioral assessment intervention, and pharmacy needs			Financial education		Consumers are given a monthly budget to purchase the amounts and types of long-term care supplies and services from whomever they choose.	Caregiver training, financial education, home health services	Financial education, all acute medical care services	All acute medical care services, including (but not limited to) home health, inpatient, outpatient, and physician services

	Aged and Disabled Adult Waiver (MedWaiver)	Alzheimer's Disease Waiver	Assisted Living for the Elderly (ALE)	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/ Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)
Statutory Authority	Section 1915(c)(1) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; Section 409.906(13), Florida Statutes.	Sections 1915(b) and (c) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; Section 409.906 (13), Florida Statutes.	Section 1915(c) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; General Appropriations Act, State of Florida; Section 409.906(13), Florida Statutes.		Section 1915(b) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; Section 409.906 (13), Florida Statutes.	Sections 1915(b) and (c) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; Section 409.906 (13), Florida Statutes.	Section 1915(c) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; General Appropriations Act, State of Florida; Section 409.906(13), Florida Statutes.	Section 1915(b) of the Social Security Act of 1965; 42 Code of Federal Regulations 441.302; Section 409.906 (13), Florida Statutes.	Section 1915(c), Social Security Act; Sections 430.701- 430.709, Florida Statutes; Section 409.912, Florida Statutes.	42 Code of Federal Regulations 460; Balanced Budget Act of 1997; Sections 430.701 - 430.709 Florida Statutes; Section 409.912 Florida Statutes; Laws of Florida 2004-270.

Table 10c. Aging Services – Medicaid Appropriations and Participants

	Aged and Disabled Adult Waiver (MedWaiver)	Alzheimer's Disease Waiver	Assisted Living for the Elderly (ALE)	Assistive Care Services	Channeling for Frail Elders	Comprehensive Adult Day Care	Consumer Directed Care Plus (CDC+)	Frail/Elderly Program (FEP, ElderCare)	Long-Term Care Community Diversion Pilot Project (Nursing Home Diversion)	Program of All Inclusive Care for the Elderly (Pace)
2000-01										
Appropriation (Medicaid)	\$61,976,956		\$21,482,532	\$14,444,203	\$10,126,507	n/a	\$175,930	\$55,572,542	\$22,907,907	
Enrollees	12,068		3,017	7,458	1,473	n/a	41	4,925	1,074	
2007-08										
Appropriation (Medicaid)	\$85,485,333	\$5,057,409	\$33,186,632	\$32,871,249	\$14,027,202	\$1,946,858	\$2,722,190	\$33,904,000	\$224,335,496	\$9,055,012
Enrollees	10,808	406	3,186	12,386	1,627	53	192	2,166	13,024	191

	Long-	Term Care Service Program	S	
	AIDS Drug Assistance Program (ADAP)	Housing Opportunities for Persons with AIDS (HOPWA)	Project AIDS Care (PAC)	Traumatic Brain and Spinal Cord Injury (TBI/SCI)
Eligibility Requirements				
Disease-Specific	Documented diagnosis of AIDS, current viral load and CD4 results.	Documented diagnosis of AIDS, current viral load and CD4 results.	Documented diagnosis of AIDS	Sustained a traumatic brain or spinal cord injury.
Asset Limitation			Medicaid eligibility	Medicaid eligibility
Income Limitation	Income at or below 400 percent of Federal Poverty Level (FPL).	Income at or below 400 percent of Federal Poverty Level (FPL).	Medicaid eligibility	Medicaid eligibility
Other Limitation	Living at home or in the community, cannot be receiving same service in another program, have a prescription for at least one drug on the formulary.	Living at home or in the community, cannot be receiving same service in another program, have a prescription for at least one drug on the formulary.	Living at home or in the community.	Living at home or in the community.
Co-Pay Required	None	None	None	None
Funding Sources				
Federal	\square	$\overline{\mathbf{A}}$		
Florida State Funded	\checkmark	\checkmark		
Medicaid Waiver			Section 1915(c)	Section 1915(c)

Table 11a. Disabled Adults Program and Services-Administrative Details

	AIDS Drug Assistance Program (ADAP)	Housing Opportunities for Persons with AIDS (HOPWA)	Project AIDS Care (PAC)	Traumatic Brain and Spinal Cord Injury (TBI/SCI)
Program Administration	Florida Department of Health administers the ADAP program and contracts with project sponsors in 10 Ryan White Part B consortium and planning body areas throughout the state.	The Agency for Persons with Disabilities has lead responsibility for operational implementation	The PAC Waiver Program is administered by the Agency for Health Care Administration (AHCA), Division of Medicaid, Department of Elder Affairs (DOEA) and the Department of Children and Families (DCF).	The Florida Department of Health has lead responsibility for care of TBI/SCI persons. The Agency for Health Care Administration (AHCA) has lead responsibility for programs funded through Medicaid and the Medicaid waiver.
Statutory Authority	Sections 393, Florida Statutes.	Sections 393, Florida Statutes.	Sections 409.919, Florida Statutes.	Sections 393, Florida Statutes.

Table 11b. Disabled Adults Program and Services Appropriations and Participants

	AIDS Drug Assistance Program (ADAP)	Housing Opportunities for Persons with AIDS (HOPWA)	Project AIDS Care (PAC)	Traumatic Brain and Spinal Cord Injury (TBI/SCI)
2000-01				
Appropriation (Federal)	n/a	n/a	\$23,808,041	\$1,283,746
Enrollees	n/a	n/a	6,712	116
2007-08				
Appropriation (Federal)	\$89,361,659	\$4,425,116	\$10,041,771	\$8,374,645
Enrollees	13,336	1,956	5,703	336

Table 11c. Disabled Adults Program and Services Available Services

	AIDS Drug Assistance Program (ADAP)	Housing Opportunities for Persons with AIDS (HOPWA)	Project AIDS Care (PAC)	Traumatic Brain and Spinal Cord Injury (TBI/SCI)
Services				
Adult Day Health Services			\checkmark	
Attendant Care				\checkmark
Behavior Management				\checkmark
Case Management			☑	\checkmark
Chores			☑	
Companionship				\checkmark
Consumable Medical Supplies				\checkmark
Durable Medical Equipment			V	
Education/Training			V	
Environmental Adaptations			V	\checkmark
Home Delivered Meals			☑	
Home Nursing			V	
Homemaker Services			V	
Medical Therapeutic Services			\checkmark	
Personal Care Services				\checkmark
Pest Control				
Other	Prescription drugs from established formulary.	The State HOPWA program provides short-term, temporary housing assistance and long- term housing in specified areas to qualified individuals.	Specialized personal care for children in foster care, therapeutic services for substance abuse	Adaptive health and wellness, assistive technology, life skills training, personal adjustment counseling, rehabilitative engineering adaptations.

Table 12a. Developmental Disabilities Programs and Services- Administrative Details

	Developmental Services (Tiers I, II, III)	Family Supported Living (Tiers IV)		
Eligibility Requirements				
Age	3 years or older	3 years or older		
Region Served	Entire State	Entire State		
Frailty Requirement				
Disease-Specific	Have a developmental disability that occurred before the age of 18	Have a developmental disability that occurred before the age of 18		
Caregiver Requirement				
Asset Limitation				
Income Limitation				
Other Limitation				
Co-Pay Required	None	None		
Funding Sources				
Federal				
Medicaid				
Florida State Funded				
Medicaid				
Demonstration Project				
State Plan Service				
Waiver	Section 1915(c)	Section 1915(c)		
Administration				
Program Administration	The Agency for Persons with Disabilities has lead responsibility for operational implementation	The Agency for Persons with Disabilities has lead responsibility for operational implementation		
Statutory Authority	Sections 393, Florida Statutes.	Sections 393, Florida Statutes.		

	Developmental Services	(Tiers I, II, III)	Family Supported Living (Tiers IV)
Services			
Adult Day Care			
Adult Day Health Services			\checkmark
Assisted Living Services			
Attendant Care	\checkmark		
Behavior Management	\checkmark		
Caregiver Support Services			
Case Aide			
Case Management	\checkmark		
Chores	\checkmark		
Companionship	\checkmark		
Congregate Meals			
Consumable Medical Supplies			
Counseling	\checkmark		
Durable Medical Equipment	\checkmark		
Education/Training			
Emergency Alert Response	\checkmark		
Emergency Home Repairs			
Environmental Adaptations	V		
Escort			
Family Training and Support			

Table 12b. Developmental Disabilities Programs and Services - Available Services

	Developmental Services (Tiers I, II, III)	Family Supported Living (Tiers IV)
Health Education		
Health Support Services		
Home Delivered Meals		
Home Health Aide		
Home Nursing		
Homemaker Services		
Housing Improvements		
Information and Referral		
Legal Services		
Material Aid		
Medical Therapeutic Services		
Personal Care Services		
Pest Control		
Physical Education		
Recreation		
Respite Care		
Risk Reduction		
Screening and Assessment		
Shopping Assistance		
Skilled Nursing Facility		
Transportation		
Other	Adult Day Training, adult dental services , behavior analysis services, behavior assistant services, mental health counseling, supported living coaching	Adult Day Training, behavior analysis services, behavior assistant services, supported employment

Table 12c. Developmental Disabilities Programs and Services - Appropriations and Participants

	Developmental Services (Tiers I, II, III)	Family Supported Living (Tiers IV)
2000-01		
Appropriation (Federal)	\$344,770,800	\$85,645
Enrollees	23,314	33
2007-08		
Appropriation (Federal)	\$858,660,849	\$45,473,971
Enrollees	23,906	5,944