



# A Strategic Path Forward:

## Responding to the Needs of People with Developmental Disabilities in Florida

### *Planning Context*

September 2009

Human Services Research Institute

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7420 SW Bridgeport Road Suite #210  
Portland, OR 97224  
Voice: 503-924-3783 • Fax: 503-924-3789  
[www.hsri.org](http://www.hsri.org)



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Administration on Developmental Disabilities and the Florida Developmental  
Disabilities Council, Inc.

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**Prepared for:**

Florida Developmental Disabilities Council, Inc.  
124 Marriott Drive, Suite 203  
Tallahassee, FL 32301-2981  
850-488-4180  
[www.fddc.org](http://www.fddc.org)

**Prepared By:**

John Agosta, Ph.D., Drew Smith, B.A., Jaime Daignault, M.S.,  
Jon Fortune, Ed. D., and Robert Gettings, M.P.A.

Human Services Research Institute  
7420 SW Bridgeport Road, Suite 210  
Portland, OR 97224  
503-924-3783  
[www.hsri.org](http://www.hsri.org)

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| <p>All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Florida Developmental Disabilities Council, Inc.</p> |
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## About the Authors

Human Services Research Institute (HSRI), a non-profit, tax-exempt corporation, was founded in 1976 to improve the availability and quality of supports for children and adults with special needs and other vulnerable populations. Working in the fields of developmental disabilities, mental health, physical disabilities, and child welfare, HSRI staff strongly support efforts to improve community-centered responses to human needs, leading to service approaches that are family and person driven and most apt to result in increased independence and self sufficiency. HSRI has assembled a five-person team to complete this work.

This report was prepared by the following staff:

**John Agosta, Ph.D.** is an HSRI Vice President. He completed his doctorate in Rehabilitation Research at the University of Oregon, specializing in research methods and community supports for people with disabilities, and has worked with people with disabilities for over 30 years. Employed at HSRI since 1983, he has been involved with nearly all efforts at HSRI surrounding family support issues, facilitated development of strategic plans, conducted analyses of state systems for people with developmental disabilities (e.g., Arkansas, Idaho, Oregon, Hawaii), and has studied specific facets of the field (e.g., trends in supported employment, managed care, self-determination). He is a nationally recognized expert in topic areas such as family support, self-directed supports, and community systems regarding policies that affect individuals with developmental disabilities.

**Drew Smith, B.A.** is a Policy Assistant at HSRI. He is a graduate of Portland State University in Business Administration, and currently works on several HSRI projects tied to: developing person-centered funding strategies, assessing the impacts of service changes and reductions, and supporting self-advocacy through the national e-Newsletter, *The Riot!*. He has worked on waiver reimbursement projects in Colorado, Florida, Oregon, Rhode Island, and Virginia.

**Jaime Daignault, M.S.** is a Policy Associate at HSRI. With a graduate degree in Special Education and an undergraduate degree in Family and Human Services, she has worked in the field for several years in both direct service and research capacities. Her primary responsibilities at HSRI presently involve project management. For example, she managed implementation of a Family Support Cooperative in Arkansas County, Arkansas, and coordinated systems change projects to promote self determination in Idaho and Alabama, as well as a three-year Project of National Significance funded by the U.S. Administration on Developmental Disabilities.

**Jon Fortune, Ed.D.** is a Senior Policy Specialist at HSRI. Dr. Fortune has solid research skills as well as hands-on experience as a state administrator. In 1990, he joined the Wyoming Department of Health, Developmental Disabilities Division, where he has held senior management positions. He was instrumental in designing and implementing Wyoming's system of community services for individuals with developmental disabilities and acquired brain injury, including developing Medicaid waivers for both populations. During his tenure in Wyoming, the state substantially reduced the number of people served in its large state facility and built an especially strong system of quality community supports. Dr. Fortune was also the chief architect of the precedent-setting Wyoming DOORS model through which people with

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disabilities are assigned individual budgets based on their assessed needs and other factors. Prior to joining the Wyoming Department of Health, Dr. Fortune managed a community agency in Wyoming and held other positions in Colorado and Illinois. He is currently working on financial architecture in statewide developmental disability service systems in ten states.

In addition, HSRI staff were assisted by Robert Gettings.

**Robert Gettings, M.P.A** is the former Executive Director of the National Association of State Directors of Developmental Disabilities Services and will serve as a Senior Policy Advisor. Recently retired, Mr. Gettings served as NASDDDS's chief executive officer for nearly 37 years. In this capacity, he was responsible for representing the interests of the fifty state developmental disabilities agencies in Washington, D.C., and facilitating communication among the states concerning the most effective means of serving citizens with lifelong disabilities. Before joining the Association, Mr. Gettings was on the staff of the President's Committee on Mental Retardation and the National Association for Retarded Children. Over a period spanning four decades, Mr. Gettings participated in the development and passage of numerous pieces of landmark federal legislation. Collectively, these statutes revolutionized national disability policy. He also has written and lectured extensively on the impact federal legislative and administrative policies have had on the delivery of state and local services to individuals with intellectual and other developmental disabilities. Mr. Gettings is widely recognized as a leading expert on federal Medicaid policy. Having helped many states to solve a variety of service delivery problems over the years, he is well versed in program developments and service delivery trends across the nation. A Life Member of the American Association on Intellectual and Developmental Disabilities, Mr. Gettings was recognized in 2000 by the National Historic Trust on Mental Retardation as one of 36 major contributors to the field during the 20th Century.

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# Table of Contents

|  |           |
|--|-----------|
| <b>Introduction</b> .....  | <b>1</b>  |
| <i>Analysis Framework</i> .....  | 1         |
| <i>Three Performance Benchmarks</i> .....                                    | 2         |
| <i>Data Sources</i> .....  | 3         |
| <i>Legislative Updates</i> .....   | 5         |
| <br>   |           |
| <b>Benchmark 1: Serving Individuals with Reasonable Promptness</b> .....     | <b>8</b>  |
| <i>Background</i> .....  | 8         |
| <i>Florida Status and Service Utilization Patterns</i> .....                 | 9         |
| <i>Waitlist for Services</i> .....   | 10        |
| <i>Time Spent Waiting for Services</i> .....                                 | 13        |
| <i>Conclusion</i> .....  | 14        |
| <br>   |           |
| <b>Benchmark 2: Serving Individuals in the Most Integrated Setting</b> ..... | <b>15</b> |
| <i>Background</i> .....  | 15        |
| <i>Florida Status</i> .....  | 16        |
| <i>Reliance on Families to Provide In-Home Supports</i> .....                | 17        |
| <i>Continued Use of Large Congregate Care Facilities</i> .....               | 23        |
| <i>Conclusion</i> .....  | 26        |
| <br>   |           |
| <b>Benchmark 3: Economy and Efficiency</b> .....                             | <b>27</b> |
| <i>Background</i> .....  | 27        |
| <i>Florida Status</i> .....  | 29        |
| <i>Insufficient Spending</i> .....   | 29        |
| <i>Utilization of Medicaid Financing</i> .....                               | 31        |
| <i>Waiver and Related Service Reductions</i> .....                           | 32        |
| <i>Conclusion</i> .....  | 35        |

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## Tables and Charts

|   |    |
|---|----|
| Table 1: Waiver Enrollment and Payments .....   | 10 |
| Table 2: Number of Individuals with Developmental Disabilities Added to Service per Year from 2001-2007 ..... | 11 |
| Table 3: Length of Wait for Any Waiver Services .....   | 14 |
| Table 4: States with No Institutions or 150 or Fewer People in Institutions.....                              | 16 |
| Table 5: Residential Out-of-Home Option Service Vacancies.....  | 22 |
| Table 6: Fiscal Effort .....  | 29 |
| Table 7: Impacts on Service Reductions on Individuals by Tier (2009-2010) .....                               | 35 |
|   |    |
| Chart 1: People Receiving Medicaid Services Per 100,000.....  | 10 |
| Chart 2: Projected Unmet Service Demand in Florida from 2007-2020.....  | 13 |
| Chart 3: Percentage of Individuals Receiving Residential Services by Living Arrangements .....                | 17 |
| Chart 4: People Served in Out-of-Home Residential Settings Per 100k State Population...                       | 21 |
| Chart 5: Estimated Number of People with Developmental Disabilities Living at Home by Age of Caregivers.....  | 23 |
| Chart 6: Percentage of Individuals Living in 16+ Bed State-Run Residential Facilities .....                   | 23 |
| Chart 7: Per Diem Rates for State-Run Institutions in Florida.....  | 24 |
| Chart 8: Trends of Individuals with Developmental Disabilities Residing in Nursing Homes .....                | 26 |
| Chart 9: Developmental Disabilities Spending Per Citizen in 2006.....   | 30 |
| Chart 10: Percentage of Individuals Receiving In-Home Family Supports and Spending per Person .....           | 31 |
| Chart 11: Percentage of Medicaid Recipients Receiving HCBS .....  | 31 |

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# Introduction

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The Florida Developmental Disabilities Council (FDDC) in collaboration with the Strategic Path *Work Group* stakeholders engaged the Human Services Research Institute (HSRI) to develop *A Strategic Path Forward* for Florida's system for serving people with developmental disabilities. This is the first of two reports prepared by HSRI for the FDDC. Here, we provide an analysis of the *Planning Context* within which policy makers must act in Florida. A second report<sup>1</sup> offers a series of *Action Steps* for implementing the plan.

## Analysis Framework

The Agency for Persons with Disabilities (APD) has primary responsibility for establishing and maintaining a system of services for people with developmental disabilities whose mission is to support these individuals "in living, learning, and working in their community." This includes operation of state institution programs and programmatic management of the Medicaid HCBS waivers established to fund services, and other services not funded through Medicaid.

In a December, 2008 presentation to the Florida Senate Health and Human Services Appropriations Committee, APD reported that:

- Its FY 2008-09 appropriations will total \$1.06 billion to serve about 35,000 people. Of this amount, 79% is related to HCBS waivers, 13% to operation of Developmental Disability Centers, 3% to non-waiver services, 3% to Area Offices, and 2% to the Central Office.
- The agency had experienced a funding deficit exceeding \$150 million going into the 2007 session. APD reduced this deficit to \$12 million for FY 2007-2008 through a combination of increased funding and cost reduction measures implemented through Senate Bill 1124.
- Additional budget and service reduction steps are being taken to maintain the fiscal discipline needed to stay within appropriated limits (e.g. eliminating vacant staff positions at Developmental Centers, hiring and travel freezes, restructuring of the Central Office, review of contractual obligations).

Prior to making a series of policy choices aimed at re-positioning the Florida developmental disabilities service system, it is essential to gain a perspective on the present issues confronting the system. After all, the system is not being designed from scratch. Rather, its current status results from past decisions made over many years which have resulted in current policy preferences, funding patterns, and service arrays. Taken together, these system factors comprise the planning context or platform upon which the *Strategic Path Forward* must be built.

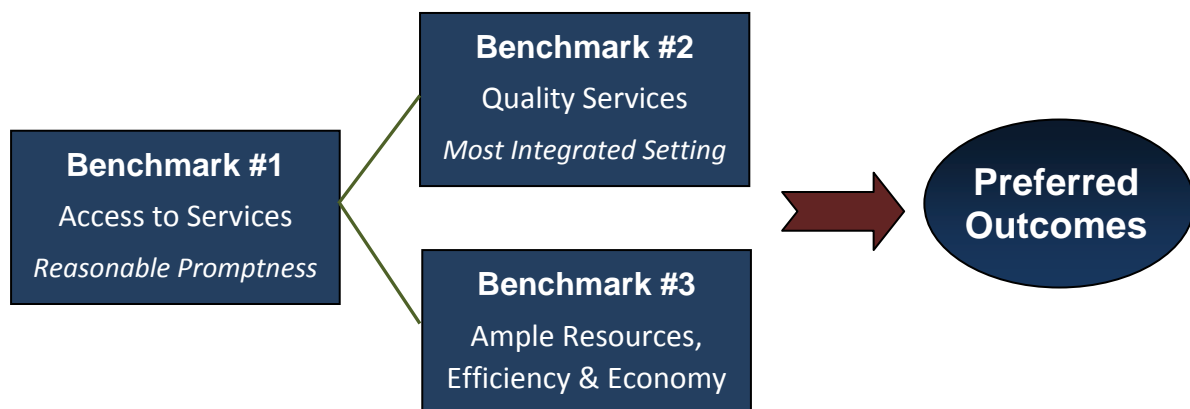
To gain a better understanding of the planning context, we conducted a gap analysis during which the performance of Florida's current service system was assessed against three key

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<sup>1</sup> *A Strategic Path Forward: Responding to the Needs of People with Developmental Disabilities in Florida; Action Steps*. Agosta, J. (et al.). August 2009. Florida Developmental Disabilities Council. Tallahassee, FL.

benchmarks. A *gap analysis* compares an enterprise's actual, to its potential, or desired, performance. It is an assessment of the distance between what an enterprise is currently doing and what it seeks to do in the future. A gap analysis flows from benchmarking the level of performance achieved and other assessments of requirements as well as current system capabilities.

The gap analysis begins with defining key expectations for desired system performance. These expectations serve as the basis for appraising current performance. We recognize that a primary and overarching goal in Florida, as in other states, is that everyone supported by the system receives high quality services and supports. In addition, and for the purpose of this gap analysis, we identified three fundamental, top-level performance benchmarks against which to gauge the provision of publicly-funded services and supports for people with developmental disabilities in Florida. These benchmarks were derived from HSRI's nationally recognized work in developing quality assurance indicators (i.e., the "Quality Framework" for the Centers for Medicare and Medicaid Services, and the National Core Indicators utilized by nearly 30 states). As illustrated by the graphic below, the benchmarks are related to service access, service delivery, system efficiency, and associated outcomes.



### Three Performance Benchmarks

- 1. People with intellectual or developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.** Publicly-funded systems should be capable of ensuring that those needing services receive them within a reasonable period of time. This requires sound system infrastructure in order to ensure a diverse and agile service delivery capacity. When services are not furnished promptly, individuals and families experience negative life outcomes
- 2. Services and supports are provided in the most integrated setting appropriate to the needs of the individual.** The U.S. Supreme Court's *Olmstead* decision has established the clear benchmark that publicly-funded services must be furnished in the most integrated setting possible given the individual's needs. The decision mandates that states operate services so that individuals are not unnecessarily institutionalized or otherwise served in overly restrictive programs or settings.

- 3. The system must have ample resources and promote economy and efficiency in the delivery of services and supports.** This means that the state must seek out the most cost effective services and supports, building on the supports that families and communities provide, and effectively utilize federal funding. Systems that do not stress economy and efficiency are not sustainable.

These three essential benchmarks serve as the framework for the following analysis. In this regard, however, it should be noted that we understand that many other aspects of the Florida developmental disabilities service system might have been reviewed but fell outside the scope of this report. For instance, we did not review Florida's performance in relation to benchmarks keyed to preferred individual outcomes (e.g., employment) or quality assurance and oversight, including protections for health and well-being. Likewise, our analysis did not focus deeply on specific service types (e.g., family support, supported employment). This report focuses solely on the three benchmarks outlined above.

### Data Sources

To complete this work, we:

- **Participated in meetings of a Strategic Path Work Group convened by the FDDC.** The FDDC convened a work group composed of self-advocates, parents, APD staff, service providers and advocates. This group met on three occasions to provide feedback and guidance to our work.
- **Reviewed state and national literature relevant to the Florida long-term care service system.** Project staff researched and compiled various materials dated 2001 to 2008 regarding the Florida long-term care service system for people with developmental disabilities. Our search identified analyses, papers, correspondence, administrative rules, legislation and other documentation pertaining to the Florida disabilities services system. These sources were carefully reviewed and contributed to our understanding and overall impressions of the Florida service system, its strengths and weaknesses, and the political and social context within which it operates.
- **Compiled available state and national data.** HSRI worked with national experts and Florida state staff to gather data from 2001 to 2007 relevant to the Florida developmental disabilities services system. We gathered information from the following sources:
  - Data available from the Research and Training Center on Community Living, Institute on Community Integration/UCEDD at the University of Minnesota. The research team at RTCCL/UMN collect information by state on the numbers served and related expenditures associated with Medicaid-funded developmental disability programs, including Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) and Home and Community-Based Services (HCBS) waivers. This resource provided us with data through 2007<sup>2</sup>.

<sup>2</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential Services for People with Developmental Disabilities: Status and Trends Through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

- Data available from the University of Colorado’s Coleman Institute for Cognitive Disabilities tracking longitudinally the level of spending, service delivery practices and numbers served across all states. This resource provided us with data through 2006.<sup>3</sup>
- **Reviewed the status of the Florida system against three fundamental performance benchmarks.** These markers pertain to: (a) the promptness with which people needing supports are enrolled in services, (b) whether individuals are served in the most integrated setting, and (c) the degree to which available fiscal resources are adequate and the level of efficiency in how they are applied.

To assess performance against these markers, we often compared Florida to other states and the national average. Comparison states were selected using two main criteria: (a) states within the same federal Medicaid region as Florida (Region 4<sup>4</sup>); and (b) states with large populations (8 million or more). Florida’s 2007 state population = 18,199, 526.<sup>5</sup> The states selected for this comparison include:

| <b>CMS Region</b> | <b>2007 Population</b> | <b>8 million +</b> | <b>2007 Population</b> |
|-------------------|------------------------|--------------------|------------------------|
| Alabama           | 4,627,851              | California         | 36,553,215             |
| Georgia           | 9,544,750              | Illinois           | 12,852,548             |
| Kentucky          | 4,241,474              | New Jersey         | 8,685,920              |
| Mississippi       | 2,918,785              | New York           | 19,297,729             |
| North Carolina    | 9,061,032              | Ohio               | 11,466,917             |
| South Carolina    | 4,407,709              | Pennsylvania       | 12,432,792             |
| Tennessee         | 6,156,719              | Texas              | 23,904,380             |

The following three sections provide analysis regarding circumstances in Florida pertaining to each of the three benchmarks.

It should be noted that this report was largely compiled just prior to and during the 2009 Legislative Session. As a result, outcomes stemming from the session are not precisely reflected throughout the report. On the following pages, however, we present a summary of major legislative actions, primarily tied to Senate Bills 1660 and 2600. Readers should take these actions into account as they review the report. A more complete summary of legislative actions compiled by the Office of Legislative Affairs is found at: [http://apd.myflorida.com/legislative/2009-  
legislative/2009-legislative-wrap-up.pdf](http://apd.myflorida.com/legislative/2009-legislative/2009-legislative-wrap-up.pdf)



<sup>3</sup> Braddock, D. et al. (2008). *The State of the States in Developmental Disabilities: 2008*. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

<sup>4</sup> Two states, Georgia and North Carolina fall under both categories, CMS Region 4 and large population.

<sup>5</sup> Michigan, while having a 2007 population over 8,000,000, was not included as a comparison state for this analysis. Michigan’s developmental disability service system operates under a managed care framework, making direct comparisons problematic.

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## ***Legislative Session 2009 Updates***

### ***Updates Relative to SB 1660***

In the 2009 legislative session, SB 1660 amended statutory language by:

- Establishing a prescribed order for the Agency to address the waitlist for waiver services. Beginning July 1, 2010, the agency shall assign and provide priority to clients waiting for waiver services in the following order:

Category 1: includes clients deemed to be in crisis as described by agency rule.

Category 2: includes children on the wait list who are from the child welfare system with an open case in the Department of Children and Family Services' statewide automated child welfare information system.

Category 3: includes, but is not required to be limited to, clients:

- Whose caregiver has a documented condition that is expected to render the caregiver unable to provide care within the next 12 months and for whom a caregiver is required but no alternate caregiver is available;
- At substantial risk of incarceration or court commitment without supports;
- Whose documented behaviors or physical needs place them or their caregiver at risk of serious harm and other supports are not currently available to alleviate the situation; or
- Who are identified as ready for discharge within the next year from a state mental health hospital or skilled nursing facility and who require a caregiver but for whom no caregiver is available.

Category 4: includes, but is not required to be limited to, clients whose caregivers are 70 years of age or older and for whom a caregiver is required but no alternate caregiver is available.

Category 5: includes, but is not required to be limited to, clients who are expected to graduate within the next 12 months from secondary school and need support to obtain or maintain competitive employment, or to pursue an accredited program of postsecondary education to which they have been accepted.

Category 6: includes clients 21 years of age or older who do not meet the criteria for category 1, category 2, category 3, category 4, or category 5.

Category 7: includes clients younger than 21 years of age who do not meet the criteria for category 1, category 2, category 3, or category 4.

- Requiring that within categories 3, 4, 5, 6, and 7, the agency shall maintain a wait list of clients placed in the order of the date that the client is determined eligible for waiver

services. The client, the client's guardian, or the client's family must ensure that accurate, up-to-date contact information is provided to the agency at all times. The agency shall remove from the wait list any individual who cannot be located using the contact information provided to the agency, fails to meet eligibility requirements, or becomes domiciled outside the state.

- Granting rule making authority to promulgate rules addressing waitlist categories and procedures.

In the 2009 legislative session, SB 1660 amended statutory language by:

- Deleting the requirement that all services covered under the current developmental disabilities waiver shall be available to all clients in all tiers where appropriate, except as otherwise provided in this subsection or in the General Appropriations Act.
- Eliminating medication review as a service provided through the waiver.
- Requiring the Agency to develop a plan to eliminate redundancies and duplications between in-home support services, companion services, personal care services, and supported living coaching by limiting or consolidating such services.
- Requiring the Agency to develop a plan to reduce the intensity and frequency of supported employment services to clients in stable employment situations who have a documented history of at least 3 years' employment with the same company or in the same industry.
- Reenacting the cost plan re-basing as implemented during fiscal year 2008-2009 for fiscal year 2009-2010, requiring the Agency, beginning January 1, 2010, to adjust cost plans to reflect the amount of expenditures for the previous state fiscal year plus 5 percent if such amount is less than the existing cost plan.
- The agency may not rebase the cost plan of any client who experiences a significant change in recipient condition or circumstance which results in a change of more than 5 percent to his or her cost plan between July 1 and the date that a rebased cost plan would take effect pursuant to this subsection.

#### ***Updates Relative to SB 2600***

SB 2600 resulted in the following funding decisions:

- Funding for Home and Community Services increased by \$8,632,371.
- Funding for Developmental Disabilities Public Facilities increased by \$803,957.
- APD was authorized to add up to 2,500 individuals to the Consumer Directed Care Plus Program. Any savings generated are to be used to enroll individuals from the waitlist.
- Medication review services are eliminated effective October 1, 2009. This resulted in a budget reduction of \$301,907.

- The Agency is required to consolidate the purchasing of durable and consumable medical supplies effective January 1, 2010. This resulted in a budget reduction of \$932,093.
- The Agency, in coordination with the Agency for Health Care Administration must seek federal approval to implement a flexible benefit service to each Home and Community Based Waiver provided by the Agency.
- The Agency, in consultation with the Agency for Health Care Administration, must develop a plan to establish individual budgets for individuals enrolled in the home and community based services waivers.
  - The plan shall provide for the following:
    - An equitable distribution of available resources among individuals based on an assessment process that includes client characteristics and a valid formal assessment instrument;
    - Client choice of services and providers once the individual budget is determined;
    - Any formula necessary to predict resource needs and establish individual budgets;
    - A recommended role for providers and support coordinators during the assessment process to avoid any potential conflicts of interest;
    - A proposed schedule for implementation; and
    - Any suggested statutory revisions necessary to implement individual budgets.

The agency must consider input from stakeholder groups, including self-advocates, family members, service providers, waiver support coordinators, and advocacy organizations in developing the plan.

The plan shall be delivered to the Governor, the chair of the Senate Policy and Steering Committee on Ways and Means, and the chair of the House Full Appropriations Council on General Government & Health Care no later than February 1, 2010.

*Source: Office of Legislative Affairs, APD. 2009 Session Legislative Wrap-Up Report*

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# Benchmark #1: Serving Individuals with Reasonable Promptness

*Assessment: Given its state population, Florida approaches the national average with respect to the number of people served, but still has a significant waitlist. Further, existing methods of gathering, compiling and analyzing waitlist data are inadequate for forecasting purposes.*

## Background

Most of the 5 million people with developmental disabilities in the United States are supported by their families, live independently with only intermittent publicly-funded support, or get along without any specialized, publicly-funded developmental disabilities services. Public developmental disabilities service systems provide services and supports to a relatively small percentage (about 20-25 percent) of all individuals with developmental disabilities. Public systems focus principally on people who have significant functional limitations and require services over and above the supports that their families are able to provide or that they can obtain through generic human services programs.

Demand for publicly-funded developmental disabilities services is growing nationwide. Generally, demand has been increasing at a rate greater than population growth alone. This increase in demand is the product of several factors. One of the most important factors is the increased longevity of people with developmental disabilities. The life span of people with developmental disabilities has increased dramatically as the result of better health care and is approaching the average lifespan of the general population. This increased longevity has two ramifications for developmental disabilities service systems: (a) turnover among individuals receiving services is reduced (consequently, there is less capacity to absorb new demand); and (b) there is a growing cohort of individuals who live in households with aging primary caregiver(s) who are less able to perform essential caretaking duties. About 25 percent of people with developmental disabilities reside in households in which the primary caregiver is age 60 or older. As caregivers grow older, their capacity to continue to support individuals with developmental disabilities diminishes. Increased demand also is the result of other factors, including the development of community services and supports that better meet the needs of individuals and families.

The demand for developmental disabilities services is dynamic. Each year, significant numbers of youth with developmental disabilities exit special education systems and need ongoing services and supports as young adults. Other people seek services because their families cannot continue to support them or they need extra assistance. Based on work completed elsewhere and national comparisons by the University of Minnesota Research and Training

Center on Community Living, it is not uncommon to observe year-over-year increases in the expressed demand for developmental disabilities of 4 percent<sup>6</sup> or more.

States generally operate their developmental disabilities service systems under fixed capacity limits. Only a handful of states (e.g., AZ and CA) provide for automatic annual caseload increases to accommodate additional eligible individuals. System capacity is managed by capping dollars or “slots” (service openings), or a combination of both. Likewise, capacity is regulated by changes in funding from year to year.

Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto “waitlists.” The number of people on a waitlist measures the gap between current system capacity and expressed service demand. This gap grows when the expansion of system capacity does not keep pace with growth in service demand. The waitlist queue will lengthen even though there may have been some growth in system capacity.

**... people who have critical near-term needs should be able to count on receiving services within 6-9 months.**

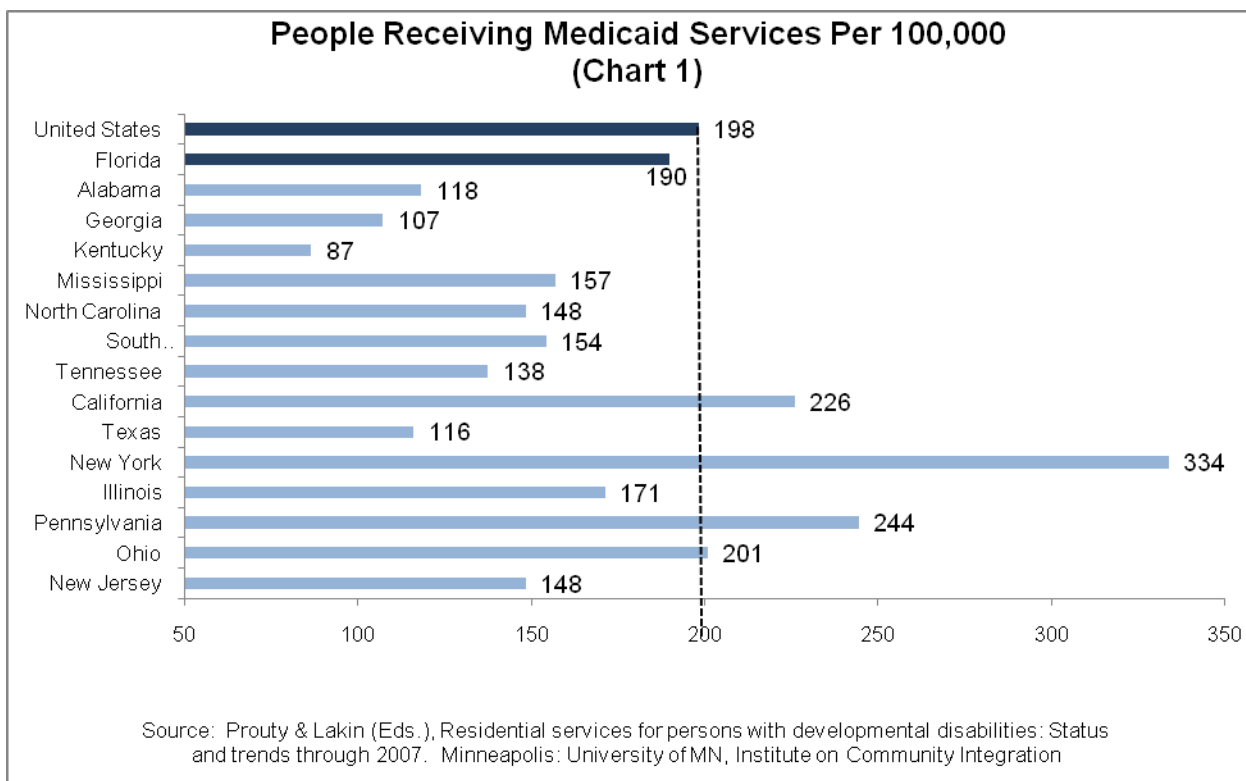
Federal court decisions have clearly indicated that responding to service needs with reasonable promptness means that individuals enrolled in Medicaid who have emergency or crisis needs must receive Medicaid-funded services within 90 days. It follows then that people who have critical unmet needs should be able to count on receiving services within 6-9 months (Federal Medicaid Act 42 C.F.R. § 435.930(a)). If they do not receive the services required, their needs can rapidly turn into an emergency or crisis situation.

### **Florida Status and Service Utilization Patterns**

Our review of the Florida developmental disabilities service system finds that the state serves close to the national average of individuals with developmental disabilities per 100,000 (i.e., 100K) in the general state population. However, Florida does have a waitlist for services that continues to grow.

Service utilization patterns can be used to benchmark a state in terms of how many individuals receive services. Florida furnishes Medicaid-funded services (Home and Community Based Service (HCBS)) waivers and Intermediate Care Facilities for the Developmentally Disabled (ICF/DD)) at a rate that is 4 percent below the nationwide average (190 per 100K population in Florida versus 198 per 100K population nationwide as can be seen in Chart 1). Florida’s utilization of Medicaid-funded services allowed the State to offer services to 34,630 individuals in 2007. For Florida to have served the national average of people per 100K population in 2007, the state would have had to provide services to roughly 1,560 more people in that year.

<sup>6</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential Services for People with Developmental Disabilities: Status and Trends Through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.



When providing services, Florida primarily utilizes the HCBS waiver authority as the funding source. As illustrated below, a report submitted by APD in February 2008 shows that the vast majority of those served receive HCBS<sup>7</sup>. The remainder, fewer than 3,500, receives ICF/DD services.

| <b>Waiver Enrollment and Payments</b> |                           |                              |                         |                              |                         |                              |
|---------------------------------------|---------------------------|------------------------------|-------------------------|------------------------------|-------------------------|------------------------------|
| <b>Table 1</b>                        |                           |                              |                         |                              |                         |                              |
|                                       | <b>DD/HCBS Waiver*</b>    |                              | <b>FSL Waiver</b>       |                              | <b>Both Waivers</b>     |                              |
| <b>Month</b>                          | <b>Enrolled Clients**</b> | <b>Total Waiver Payments</b> | <b>Enrolled Clients</b> | <b>Total Waiver Payments</b> | <b>Total Enrollment</b> | <b>Total Waiver Payments</b> |
| Oct-07                                | 25,152                    | \$77,649,109                 | 6,059                   | \$3,879,212                  | 31,211                  | \$81,528,321                 |
| Nov-07                                | 25,147                    | \$72,845,890                 | 6,053                   | \$3,566,912                  | 31,200                  | \$76,412,802                 |
| Dec-07                                | 25,118                    | \$65,631,905                 | 6,060                   | \$3,358,649                  | 31,178                  | \$68,990,555                 |

\*CDC+ Waiver enrollment is included.      \*\*as of the first day of the month

### Waitlist for Services

Since 2001, Florida has worked to expand its system capacity. From 2001-2007 Florida enrolled an additional 10,064 people with developmental disabilities in services (1,438 people per year on average). Table 2 on the following page depicts the year over year system change.

<sup>7</sup> Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs. Second Quarter Fiscal Year 2007/2008 (October, November, December 2007). Submitted February 2008

| Number of Individuals with Developmental Disabilities Added to Service per Year from 2001-2007   |       |        |      |       |       |      |        |
|--|-------|--------|------|-------|-------|------|--------|
| Table 2  |       |        |      |       |       |      |        |
| 2001   | 2002  | 2003   | 2004 | 2005  | 2006  | 2007 | Total  |
| 3,654  | 1,039 | -1,651 | -167 | 1,932 | 5,219 | 38   | 10,064 |
| Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2007. Minneapolis: University of MN, Institute on Community Integration |       |        |      |       |       |      |        |

Despite such growth, the state has been unable to keep up with the increased demand for services. By comparison, note that during this same period New York, a state with a total population similar to Florida, added 18,187 people. Likewise, Pennsylvania and Ohio, with much lower populations added 8,617 and 9,714 people respectively.

While Florida has added significant capacity in recent years and presently serves nearly the national average per 100K/population, like other states, a waitlist has accumulated. Based on information provided by APD, a recent study by the University of Florida found that there are currently 17,000 plus individuals on the waiting list for specialized developmental disabilities services in Florida.<sup>8</sup> This survey began the process to explore the types of needs individuals with developmental disabilities have who are waiting for services.

This number, however, is not so easily interpreted, largely due to the absence of information related to the urgency of need for services which can greatly alter one's understanding of projected service need. Of the 17,000 individuals on the waitlist, it is not known how many need services urgently, in the near term or some, unspecified time in the future. Some individuals may be on the list simply because they want to be in the queue so that they will not be bypassed later. Further, the present waitlist data offers little understanding of *what* services individuals are waiting for. Some may prefer out-of-home residential services or in-home support. Others may seek a day service only, or a particular type of day service (e.g., supported employment). Without such clarifying information it is difficult to make use of the available waitlist data for forecasting purposes.

**The number of people with developmental disabilities on the APD Waitlist cannot be easily interpreted.**

The Office of Program Policy Analysis and Government Accountability (OPPAGA), for example, notes: "The waiting list is not a valid indicator of need for waiver services. Approximately 28 percent of the 10,488 individuals who were offered waiver services for Fiscal Year 2005-06 did not enroll. Many of these individuals were already receiving related services through other sources such as the Family and Supported Living Waiver, other state-funded programs, school district programs, or the Medicaid state plan. Also, information on individuals on the waiting list is often out of date and inaccurately reflects their current or potential service needs. This

<sup>8</sup> Andresen, Elena (et. al.) (2008). Waiver Program Waitlist Survey. Tallahassee: Agency for Persons with Disabilities (APD).

hinders the Legislature's ability to determine the level of funding needed to serve eligible persons."<sup>9</sup>

We understand that APD is taking steps to correct these problems. Beginning in March, 2009, for example, the agency began canvassing those on the waitlist using the *Questionnaire for Situational Information* (QSI). This effort will likely shed light on the needs of those on the waitlist, but may not offer a sense of the urgency of the identified needs. As previously noted, during the 2009 Legislative session, legislation was passed to prioritize individuals on the waitlist in Florida.

Given these circumstances, we utilized an alternative method for estimating Florida's potential waitlist. Based on our work elsewhere and a review of national data bases (i.e., Prouty et al., 2008), we surmise that states serving closer to 250 people per 100K/general population tend to have small to no waitlists for services. This estimate is not a guaranteed number. In any particular state, waitlist numbers may be higher or lower, and may fluctuate with time. Still, serving 250 people per 100K is a reasonable goal.

Using this marker, to project the extent of unmet service needs in Florida, we considered the state's population (about 18.2 million) in relation to the number served in 2007 (34,630 people) to calculate the additional number the state would have to serve in order to reach a service use rate of 250 per 100K/population. Complicating matters, however, we note that in most states, waitlists grow at a rate greater than population growth alone.

According to the US Census Bureau, the Florida population is growing faster than the national population. Between 2000 and 2007, the Florida population grew by 13.4 percent, from 16 million to 18.2 million. In comparison, during this same period, the United States population increased by only 7 percent, from 282 million to 301 million.

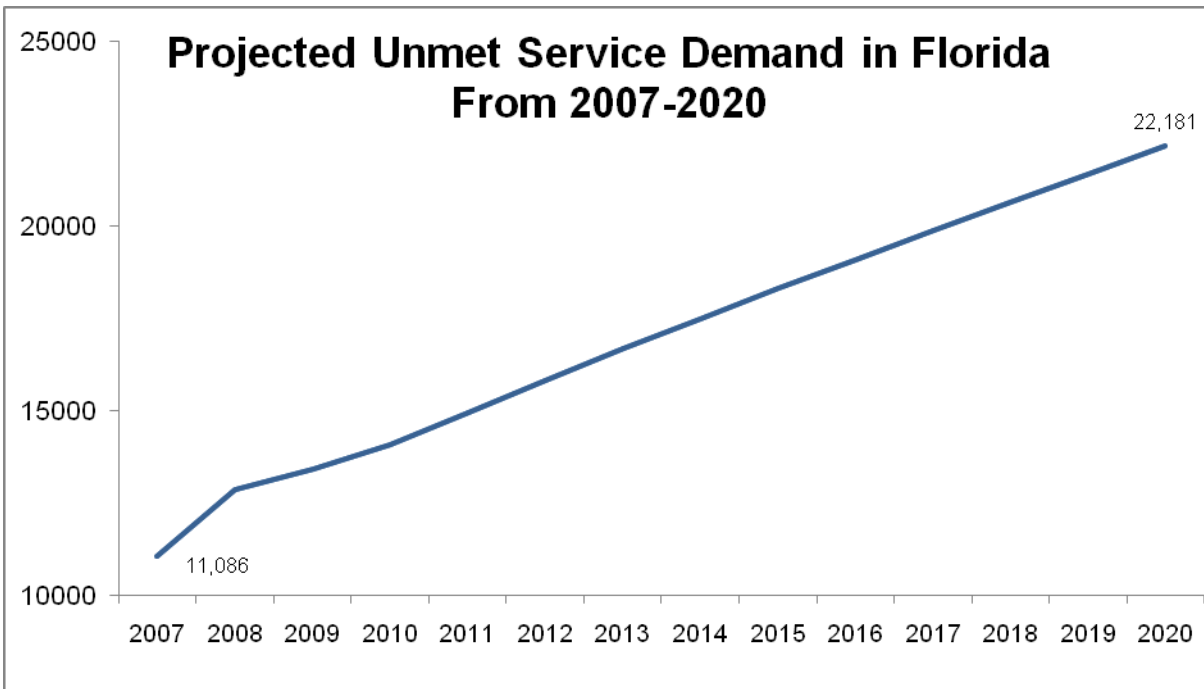
Noteworthy, the University of Florida published a recent study stating that population growth in Florida is projected to be roughly 209,000 people per year from 2007-2010. This is nearly half of the population growth the state typically sees year over year. This slower growth rate is due to a troubled Florida economy and will likely have strong implications for the state's tax revenues over the time frame. Moreover, the University reports that the state should reach a more stabilized growth rate from 2010-2020 of approximately 318,000 people per year<sup>10</sup>.

For our purposes, we base our estimates on information made available by the Economic and Demographic Research for the Florida Legislature in 2009. This source estimates that from 2007 to 2020 the state's population will grow by about 4.35 million to 22,550,452, a 24 percent increase. Given these estimates, we can project unmet service demand from 2007-2020 based on the gap between Florida's current service utilization rate (190 per 100K) and a service utilization rate of 250 per 100K, amounting to a gap of 60 people per 100K in population.

<sup>9</sup> OPPAGA, (2006, July). APD Waiting List Should Be Improved for Agency's Planning and Budgeting Purposes, Report No. 06-54, July 2006. from <http://www.oppaga.state.fl.us/reports/health/r06-54s.html>

<sup>10</sup> Keen, Cathy (2008, March 27). Economy slows Florida population growth to lowest level in 30 years. Retrieved January 15, 2009, from <http://news.ufl.edu/2008/03/27/florida-population-2/>

Chart 2 offers a forecast of unmet service demand in Florida if nothing more was done to address the need. The scenario is based on a consistent gap in service use of 60 people per year (190 vs 250 people served per 100K<sup>11</sup>.) but shows growth in unmet service demand based on demand that grows 2% over population growth year over year. As mentioned earlier, based on the work HSRI has done in other states, and national comparisons, it is not uncommon to observe year-to-year increases in expressed demand of four percent or more. Thinking more conservatively, if unmet need were to grow by two percent per year (over population growth), projected unmet service demand would grow to 22,181 by 2020, or by an average of 2,218 new people per year.



### Time Spent Waiting for Services

Ideally, once an individual applies for Medicaid-funded services and is deemed eligible, he or she will start receiving services with reasonable promptness (i.e., 90 days or sooner for Individuals with emergency or crisis needs or within 6-9 months for those with critical unmet needs).

As of January 2008, the APD reported that 63.2 percent of people on the wait list for Medicaid-funded services have been waiting for 2-5(+) years for services, with 16.9 percent waiting for 5(+) years. Table 3 shows the distribution of individuals waiting for Medicaid-funded developmental disabilities services in Florida.

<sup>11</sup> A growth in waitlists is calculated by reviewing year-to-year growth in the list over the past five years and then projecting the growth forward, given the anticipated increase in population according to the Florida Legislature.

**Length of Wait for Any Waiver Services  
as of January 1, 2008**

**Table 3**

| Length of Wait          | Date Placed on Wait List            | Wait List Clients |               |
|-------------------------|-------------------------------------|-------------------|---------------|
|                         |                                     | #                 | %             |
| Less than 6 Months      | Later than June 30, 2007            | 1,347             | 8.2%          |
| 6 to 12 Months          | January 1, 2007- June 30, 2007      | 1,600             | 9.8%          |
| 12+ to 18 Months        | July 1, 2006 - December 31, 2006    | 1,602             | 9.8%          |
| 18+ to 24 Months        | January 1, 2006 - June 30, 2006     | 1,443             | 8.8%          |
| 24+ to 30 Months        | July 1, 2005 - December 31, 2005    | 1,259             | 7.7%          |
| 30+ to 36 Months        | January 1, 2005 - June 30, 2005     | 1,200             | 7.3%          |
| 36+ to 42 Months        | July 1, 2004- December 31, 2004     | 1,104             | 6.7%          |
| 42+ to 48 Months        | January 1, 2004 - June 30, 2004     | 1,423             | 8.7%          |
| 4+ to 5 Years           | January 1, 2003 - December 31, 2003 | 2,608             | 15.9%         |
| More than 5 Years       | Earlier than January 1, 2003        | 2,771             | 16.9%         |
| <b>Total Wait List*</b> |                                     | <b>16,357</b>     | <b>100.0%</b> |

\*Excluding Family and Supported Living Waiver enrollees.

Source: Wait List Database as of January 1, 2008.

Note: Persons on the wait list 40.6 months or longer as of July 1, 2006 received a waiver enrollment offer.

## Conclusion

Over the past 7-8 years, Florida has done much to expand its service capacity for people with developmental disabilities. Due to high population growth and other factors, however, the state still maintains a stubborn waiting list that leaves some individuals waiting for extended periods with little or no service. If nothing more is done to respond more aggressively to the growing unmet needs within the developmental disabilities service system, these numbers will grow larger due to the expected growth in the state population and inescapable demographics of an aging population that will accelerate demand over the next several years.

Further, we understand that the state has and is taking steps to improve the data collected on its waitlist and use it to forecast demand and make policy decisions. These data, however, as presently compiled, are difficult to interpret. Additional markers are needed to illustrate the urgency of service need among prospective service recipients and the types of services they require.

Florida has, for the most part, ramped up the number of people served at a reasonably steady pace over the past several years. By continuing on this course, it is not out of reach for the state to significantly minimize or eliminate the waitlist while providing services to some of Florida's most vulnerable citizens.

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## Benchmark #2: Serving Individuals in the Most Integrated Setting

**Assessment:** *Since 2001, Florida has re-shaped its system to rely most heavily on “in-home” supports where individuals receive services while living with a family member; but the state has not developed an adequate infrastructure to manage and oversee the effectiveness of such supports. Regarding out-of-home services, the state relies more on smaller community residences than on ICF/DD options, though more can be done to phase out congregate care options, including the use of nursing facilities.*

### Background

In its landmark *Olmstead v. LC & EW* decision, the United States Supreme Court affirmed that, under Title II of the Americans with Disabilities Act, states are obliged to operate their programs for people with disabilities in a manner that ensures that individuals receive services in the *most integrated setting* appropriate to their needs. The *Olmstead* decision established a clear benchmark for the operation of publicly-financed programs for people with disabilities.

As a practical matter, “most integrated setting” means that individuals are supported in community settings that are as similar as possible to typical living arrangements for people without disabilities. The *Olmstead* decision sent the strong message that people should not be unnecessarily institutionalized or otherwise served in segregated environments. The decision also established affirmative expectations for the transition of people from institutional settings to the community.

Twenty years ago in the developmental disabilities field, the majority of individuals were served in large congregate settings (i.e., settings where seven or more people reside). According to RTCCL in 1987, only 27.3 percent of all people who received residential services were supported in living arrangements for six or fewer people. About one-half of all individuals were served in very large settings accommodating sixteen or more individuals, including 95,000 people who resided in state-operated public institutions.

Since then, the nation has significantly reduced its reliance on large, congregate care options in favor of smaller, more personalized residences and supported living arrangements. In fact, at present, nine states plus the District of Columbia have no large, publicly-operated residential institutions serving people with developmental disabilities. Noteworthy, in March of 2009 California completed the closure of Agnews Developmental Center, which was opened in 1888. The state worked diligently to relocate individuals into the community prior to closing the campus permanently. Table 4, below, shows the nine states without institutions, as well as 10 states that have decreased the number of individuals in remaining state-run institutions to 150 or fewer people.<sup>12</sup>

<sup>12</sup> In 2007, Michigan had 183 individuals residing in state run institutions. However, in 2009, the state will complete steps for closing this remaining institution, and will become the most populous state *without* an institution.

In a complementing vein, nationally about 70 percent of those receiving residential services live in homes of fewer than six people, with the average home size now under three individuals per setting. More recently, states are emphasizing “in-home” support options where individuals receive services while living with a family member (e.g., parents, sibling). In 2007, 55.8 percent of those receiving developmental disability services lived at home with a family member. Another eleven percent lived in their own homes<sup>13</sup>.

While most people with developmental disabilities have always lived with their families, states have not always been inclined to provide in-home supports. Given growing service demands and finite resources to meet such demands, however, policy makers increasingly realize that they cannot afford to accommodate all those needing sheltered living setting through out-of-home options. As a result, states are steadily investing in less expensive in-home support services.

### Florida Status

In 2007, Florida served 34,630 individuals with developmental disabilities through Medicaid-funded Home and Community Based Services (HCBS) waivers as well as in Intermediate Care Facilities for people with developmental disabilities (ICFs/DD). This amounts to 190 individuals per 100K in the general population. It is important to note that system capacity was expanded significantly from 2001-2007. During that period, 10,064 individuals were added to the system, or an average of 1,677 per year.

Data presented by the Prouty et al. (2008) shows that in 2007:

- Florida provided residential services to 3,205 people in ICFs/DD and another 31,425 through HCBS waiver funding.
- 72% of those receiving services lived at home with a family member.
- The number living in ICFs/DD amounted to 9 percent of the total, compared to 16 percent nationally.
- 1,186 individuals resided in state-run institutions, or 6.5 individuals per 100K compared to 12.2 nationally.
- About 69 percent of the 14,067 people receiving residential services in Florida lived in homes of 1-6 people, compared to the national average of 70 percent.

| States With No Institutions or 150 or Fewer People in Institutions<br>Table 4 |   |          |
|---|---|----------|
| States With No Institutions<br>State  | States with 150 or Fewer People in Institutions |          |
|   | States  | # Served |
| Alaska  | Minnesota                                       | 41       |
| District of Columbia  | Oregon  | 41       |
| Hawaii  | Nevada  | 66       |
| Maine   | Montana   | 67       |
| New Hampshire   | Delaware  | 81       |
| New Mexico  | Idaho   | 93       |
| Rhode Island  | Wyoming   | 94       |
| Vermont   | Colorado  | 104      |
| West Virginia   | North Dakota                                    | 127      |
|   | Arizona   | 133      |
| Lakin, et al., (2008)   |   |          |

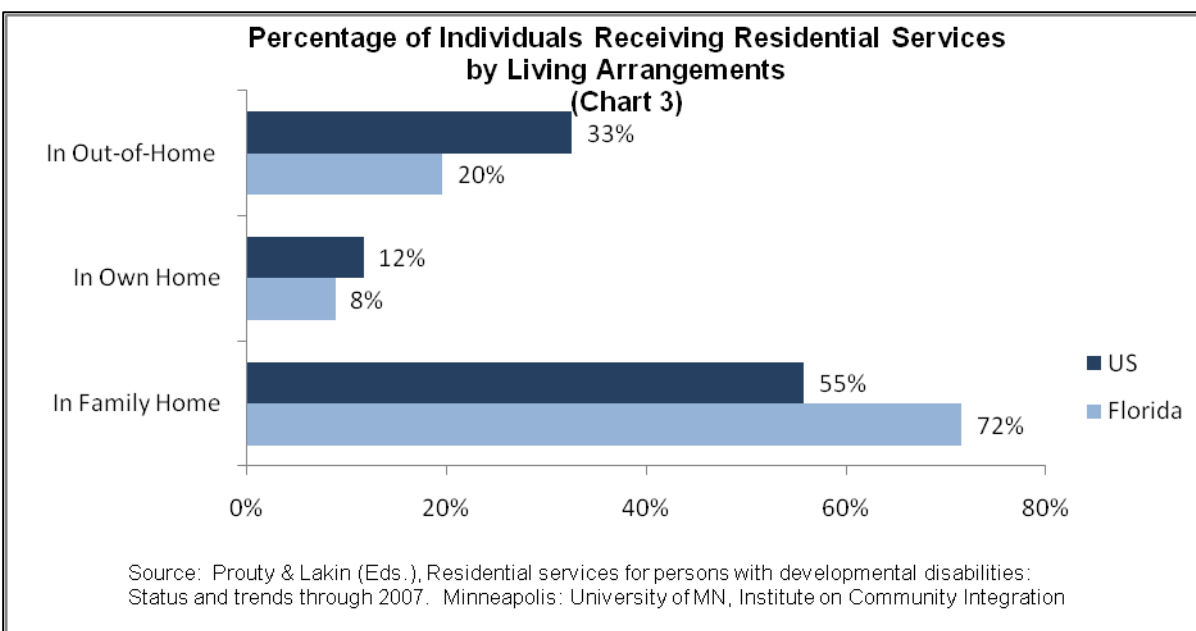
<sup>13</sup> The majority of individuals included in this data point do not own their own home, but are leasing apartments.

- 293 individuals with developmental disabilities resided in nursing home facilities, roughly 1.6 people per 100K compared to 8.6 nationally.

These data suggest that Florida has taken steps to re-shape its developmental disabilities service system. It relies heavily on in-home supports as a mainstay of the system. And it has decreased its reliance on large congregate care options. These outcomes were plainly the result of purposeful policy to promote community and person-centered responses to serving individuals with developmental disabilities. At issue is the status of these outcomes presently. What follows is a more detailed presentation of closely related findings, along with complementing observations.

### Reliance on Families to Provide In-Home Supports

Chart 3 shows that in 2007 Florida served 72 percent of service recipients through in-home family supports. This compares to 55 percent nationally. Further, the state furnished only about 20 percent of its services to people in out-of-home placement options, compared to 33 percent nationally.



The heavier reliance on in-home supports depicted in Chart 3 does not suggest that the state's investment in in-home supports is undesirable. However, there are three key questions to consider regarding funding, infrastructure, and the availability of alternatives to in-home supports. Summary observations pertaining to each of these questions follow.

- 1. Is current funding for in-home supports adequate given the needs of the individuals being served and their families?** Put in other ways, are the budget allocations per person and the amount of services allocated to each individual sufficient? Likewise, are providers of in-home support services being adequately compensated?

While developing a system of in-home supports may be cost efficient and preferable for many recipients, it is essential that the state provide the resources necessary to meet the support needs of individuals being served in home settings. In 2007, the state's in-home support system for individuals with developmental disabilities endured a series of funding reductions (see pages 29-30). These cuts greatly concerned many Florida stakeholders. Soon after the first (2007) round of cuts the state announced a new "four tier" system of HCBS waiver programs, which further alarmed individuals and families. Individuals receiving services at home would generally be placed into Tier Four, limiting such individuals to relatively few services, with overall funding capped at \$14,792 per annum (see pages 30-31). HSRI conducted a statewide study<sup>14</sup> in the fall of 2008 involving 24 focus group meetings held across the state to examine the impacts of the service reductions and perceptions about the new tier waiver system. We found that there is a widespread belief in Florida that the amounts presently allocated to individuals living at home are insufficient. In response to the changes made by the state, families told us that some family members quit their jobs, sold their houses or assumed a full role as a support coordinator or caretaker. Some meeting participants said that they could not continue to provide support at home and were planning to seek an out-of-home placement. In anticipation of the tiered waiver system, focus group participants often expressed apprehension and thought the amounts allocated would be insufficient.

## 2. Is the infrastructure to support an effective in-home support network in place?

Infrastructure can be defined as the underpinning physical and organizational structures needed for the operation or enterprise to succeed. Human services infrastructure may include system administration, rules or regulations, paperwork requirements, service coordination, training for system participants, technical assistance, crisis response capacity, information management, quality monitoring and assurance, and other supportive functions.

Our study of Florida's system infrastructure regarding in-home supports is not exhaustive, but focuses on a few key areas:

- Support coordination. In Florida support coordinators play various roles related to ensuring that individuals receive the supports they need. They facilitate service planning, may help individuals and families acquire supports, mediate between service providers and service recipients, and follow-up with individuals to ensure their well being. This service is financed through Medicaid, and in Florida each support coordinator is an independent contractor to the family/individuals they are serving, though some support coordinators do work for an agency.

Over the past 5 years, support coordination in Florida has grown more cumbersome, given increased demands placed on support coordinators, including those that require movement away from direct contact with service recipients. Some members of the *Strategic Path Planning Group* described the following difficulties:

<sup>14</sup> Melda, K., Smith, D., Agosta, J. (2008). *The impact of reductions to Florida services on people with developmental disabilities and their families*. Tallahassee, FL: Florida Council on Developmental Disabilities.

- *A lack of cooperative networking among support coordinators.* To date, there is not a defined and developed network for support coordinators. While all are dependent on APD for direction, each coordinator is more like an island of one trying to keep pace with copious amounts of work with little mutual support or collaboration with his or her peers.
- *A lack of standardization in record keeping and support planning.* Currently, A lack of standardization in record keeping and support planning. Currently, the expectations of the system for support coordinators' recording and tracking of information about individuals is not consistent across the state. Support coordinators utilize various methods, making it difficult to establish statewide standards or practices. This approach promotes inefficiency and undercuts development of a learning community among coordinators.
- *Large case loads.* Under APD policies, a support coordinator is not permitted to serve more than 43 adult recipients of services. However, two children count as one adult. As a result, several support coordinators develop large and unmanageable case loads. At issue is that a support coordinator serving at full capacity, and serving solely children, could have up to 86 cases. This large number of cases makes it difficult for individuals to get the full support they need, or leads to a push on support coordinators to work longer hours.
- *Overwhelming amounts of paperwork.* A key role of a support coordinator is to hold face-to-face meetings with individual service recipients and their families. Paperwork demands, however, leave support coordinators with little time to check in with individuals each month.
- *Low wages.* On top of the numerous issues outlined above, support coordination, like other services, has experienced reductions in reimbursement rates. While no systematic study has been completed, members of the *Work Group* familiar with service coordination argue that increased work demands, modest wages and benefits earned by support coordinators contribute to an increased turnover rate among coordinators.
- In-home Supports. The mainstay of the Florida system is in-home supports. In turn, a lynchpin component to the approach is support coordination. To be most effective, however, support coordinators must be intimately familiar with the individuals and families they support. Taken together, the issues noted above detract from this essential relationship between coordinators and services recipients. Some *Work Group* members noted that, in turn, the quality and consistency of in-home support furnished to Floridians with developmental disabilities is compromised.

Some families experience difficulties with recruiting and retaining staff, especially in rural areas. Some members of the *Strategic Planning Group* also noted that low wages reduce further the labor pool that can be drawn from to secure staff. The inability to find support workers leads families to settle for workers they would not

ordinarily hire, which may lead to difficulties later. Added to this concern is the high turnover among workers which disrupts service delivery and undercuts quality.

- Responding to individuals with complex support needs. Some families are well suited to addressing the needs of an individual with complex needs. Others, however, find it extraordinarily challenging.
  - For people with complex medical needs, these challenges may include the acquisition of specialized medical knowledge, and the ability to closely monitor the individual's health status and respond quickly when emergencies arise. Home caretakers also may be called upon to perform routine medical procedures and coordinate the work of various physicians and nurses who are involved in providing health care to the person.
  - For people with extraordinary behavioral challenges, these challenges may include coping with excessive tantrums, breaking or destroying things, running away, harming others or one's self, eating inappropriate or dangerous things or some other significant behavior. The caretaker may be required to closely monitor the individual, assertively re-direct, restrain or otherwise intervene when the individual engages in inappropriate or dangerous behaviors. The individual may also require mental health services or medical review to determine whether or not the behavior is caused by an underlying health condition.

Moreover, the needs of individuals can fluctuate and, consequently, the care giving capacity of the family must be sufficiently flexible to address the individual's changing needs.

Some members of the *Strategic Path Work Group* stated that families providing support at home to individuals with complex medical or behavioral needs are not provided sufficient training, technical assistance or crisis backup. They felt that this was especially the case with respect to individuals with significant behavioral needs. They note that families often complain about insufficient funding to retain specialized service providers due to low reimbursement rates and a lack of needed family training. In such instances, challenging behavior could go unchecked and grow more troublesome until the family's capacity to cope is exceeded.

- Community through association. Families are the mainstay of the Florida developmental disabilities system. Little, however, is done to link these families together so that they provide each other with mutual support, share information or tie their resources together to achieve common goals. Indeed, during HSRI's aforementioned study on the impact of service reductions on families and individuals, several families indicated that they felt alone and unsupported. Others commented that they felt as though they were

**Florida's in-home support system, while appreciated by many, establishes thousands of free-standing, albeit disconnected, support-giving family households.**

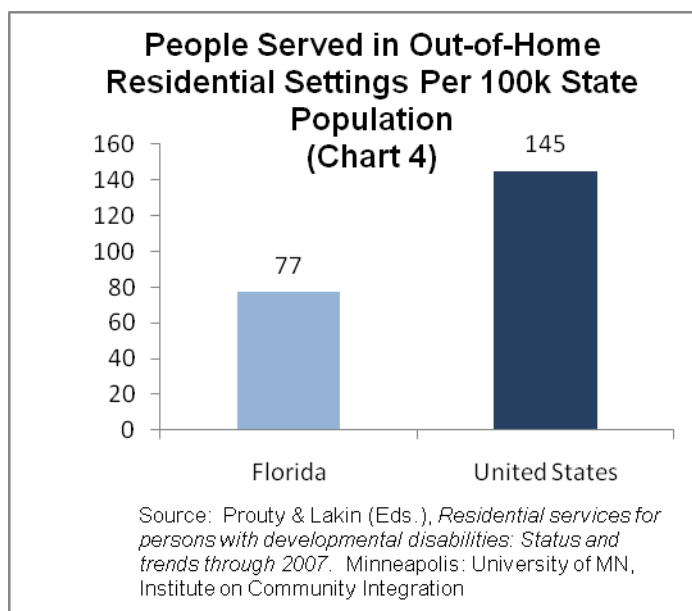
continually “reinventing the wheel.” In essence, each family is left on an island largely to fend for itself.

In-home support systems could be made most effective if steps were to be taken to establish an intentional community among families supporting individuals with developmental disabilities at home. Through association, families could work together in a variety of ways to sustain and enhance the supports each offers. This may include offering each other mutual support, recruiting staff together, offering worker’s compensation plans, purchasing services as an “alliance” at a reduced price, or otherwise working collaboratively as a network or cooperative.

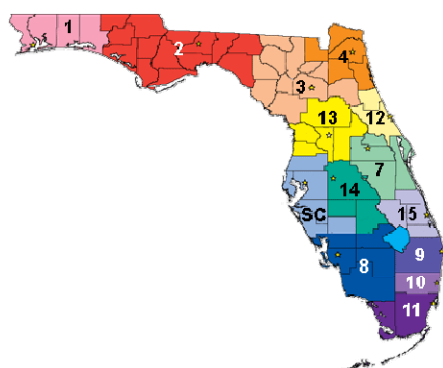
- 3. Are there sufficient options available to adults with disabilities** who seek to leave their family home to begin their own life or whose parents prefer an alternative residence for their son or daughter? It should be noted that this topic was discussed at length by the *Work Group*. Some felt that there are ample options already available and favor a continued policy emphasis on in-home support tied to families. Others, while valuing family-centered approaches, felt that more alternative options must become available. What follows is a discussion of the topic based on the opinions of the authors.

To begin, consider that:

- Nationally, as shown by Chart 4, 145 individuals per 100K of general population are receiving out-of-home residential placement options, compared to 77 people per 100K in Florida, or 47 percent below the national average;
- In 2007, Florida had 1,579 licensed residences of any kind. Whereas, New York, with a similar state population, had 5,855 licensed residences available. Pennsylvania had 3,575. In Florida, this amounted to 87 residences per 100K while the national average was 182 or 48 percent more; and
- As of Septmebr 15,2009 APD estimates 1,843 vacancies of 8,958 licensed community beds in various types of living options spread across the state (<http://apd.myflorida.com/planning-resources/>). Given fluctuations in supply, however, this estimate may not be up to date. Table 5 displays vacancies by service area.



- As shown, some service areas have more openings than others. Also, further review of these data reveal that some openings are within specialty homes (e.g., for behavior) or have gender specific requirements (e.g., men or women only). In each service area, such restrictions reduce the prospect of availability to individuals seeking residence. Add in too that individuals may not want to move far from their families or particular homes may not offer a good match of residents. Some individuals may, for example, be capable of and prefer less expensive living options, such as supervised apartments that offer greater freedom. As a result, while vacancies totaling close to 2,000 may seem ample to some, in a state as large and populous as Florida, individuals and families may not draw the same conclusion.



**Total Vacancies by Service Area \***

**Table 5**

|        |     |           |     |
|--------|-----|-----------|-----|
| Area 1 | 19  | Area 10   | 224 |
| Area 2 | 23  | Area 11   | 441 |
| Area 3 | 129 | Area 12   | 96  |
| Area 4 | 49  | Area 13   | 243 |
| Area 7 | 83  | Area 14   | 35  |
| Area 8 | 69  | Area 15   | 116 |
| Area 9 | 45  | Sun Coast | 271 |

**Total 1,843**

\* Areas 5 & 6 are subsumed within Sun Coast Region

Source: APD website: <http://apd.myflorida.com/planning-resources/>

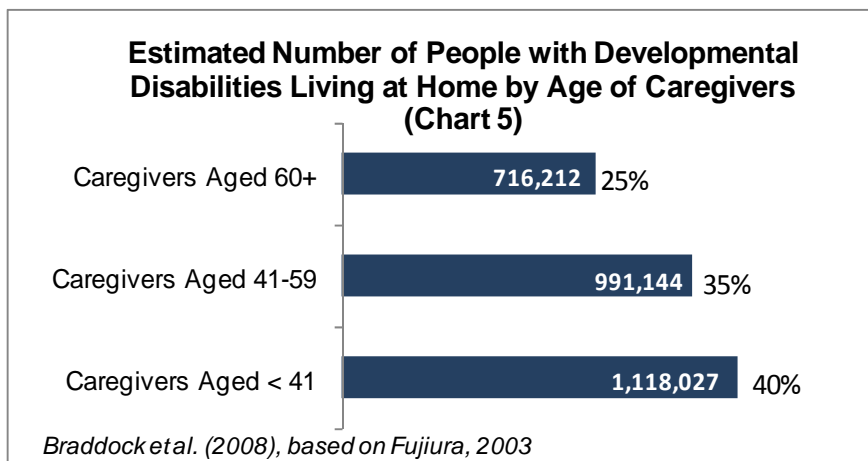
Certainly, Florida need not seek to pattern its system precisely after other states. Florida's high reliance on families and in-home support may be a policy option preferred by self-advocates, families and others.

Still, all family care ends eventually. For many, such care ends as a normal transition from adolescence to adult life. For people with developmental disabilities, however, this transition is often delayed. In fact, across the nation most adults live in the household of a family member far beyond adolescence.

Florida's emphasis on in-home supports is consistent with this reality. Still, it is reasonable to wonder whether or not the state has sufficient alternative out-of-home options available and the extent to which the State should encourage greater private sector investment to expand these options. After all, not all adults with disabilities *want* to live with their families. Instead they want to move out on their own to make their own way. Likewise, not all families want their adult son or daughter to stay at home. Some parents may want their child, as he or she becomes an adult, to experience a typical separation from their parents. Likewise, older parents may want the freedom to live out their lives free of day-to-day support responsibilities and knowing that their loved one is well supported elsewhere.

Further, circumstances in any household can change. The death or illness of a parent, siblings moving away, a change in jobs, or a change in the needs of the family member can significantly alter any family's capacity to provide in-home support.

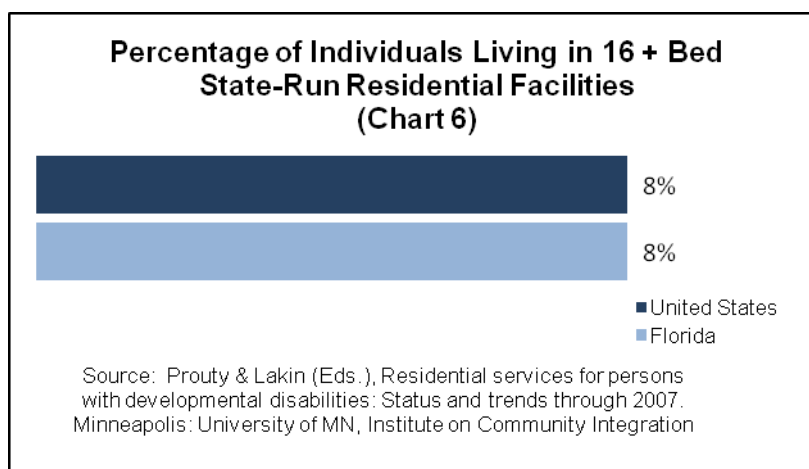
In addition, simple demographics of an aging population suggest that baby-boomers with disabilities have aging parents who will soon be unable to continue providing support at home. As these life-long support-givers stand aside, who will provide support to their loved ones and where? As illustrated by Chart 5, about 25 percent of care-givers nationally are over 60 years of age.



Consistent with these factors, an emerging demand for services may press policymakers to offer increased opportunities for out-of-home alternatives, such as, supported living or shared living accommodations in apartments or small homes. If such options are unavailable or unsatisfactory, families may be thrown into crisis or seek other less preferable placements, such as in nursing homes or ICFs/DD.

### Continued Use of Large Congregate Care Facilities

Florida, like many other states, has reduced its reliance on state-run institutions. From 1977-2007, Florida cut its institutional population nearly in half from 2,061 to 1,186 individuals. In addition, Florida is in the process of closing the Gulf Coast Center in Ft. Myers. As can be seen from Chart 6, Florida is on par with the national average regarding the percentage of individuals served who live in state-run institutions.



Aside from Gulf Coast, APD operates two other residential centers, including the Sunland Centers in Marianna and Tacachale in Gainesville. All of these facilities are licensed and certified as ICFs/DD. Operation of facilities such as these is inconsistent with a vision of having all individuals with developmental disabilities live self-directed lives in their communities and falls short of the standard held by the present benchmark of having individuals live in the most integrated setting.

Certainly, there are individuals residing in these facilities with extraordinarily challenging behaviors as well as individuals committed by the courts. Such individuals may pose a great threat to others or the community at large, and so are justifiably segregated from the community. Other individuals, however, have no such behaviors and pose no threat.

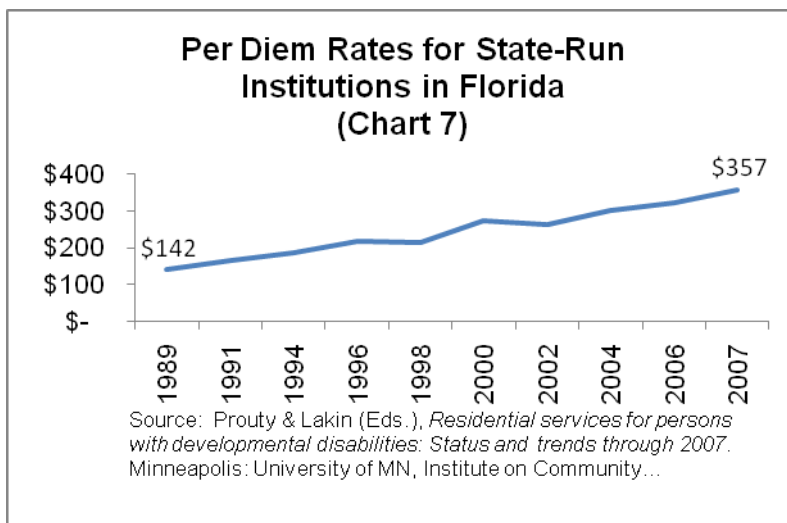
Tacachale, Florida's oldest facility, houses 468 individuals, including 55 male residents in one of the court ordered forensic programs. There is the presumption that the remaining 413 people require services in a large, segregated, congregate care facility such as Tacachale. Note that, as stated on a facility fact sheet, "most residents are in semi-private rooms with one or two roommates, and about one-half of [the] residents are able to work and want to work - 248 on payroll from work done in specialized settings." (<http://apd.myflorida.com/tacachale/facts.htm>). Similar words could be used to describe life for others with disabilities living in the community. Overall, reasonable questions should be raised over why Florida continues to maintain such facilities. Given experiences in other states, however, this presumption is arguable at best. Recall that several states have no institutions at all.

After all, consider that:

- As illustrated by Chart 7, the average per diem cost to serve an individual in a Florida institution is steadily rising. In 2007 it was \$357 per day or \$130,305 annually.

There is reason to believe that many of the individuals currently served in these centers could be supported as

well or better in alternative community settings. It is important to note that a formal study of individual level of need was not conducted for this project. Such a study is outside the scope of this project. However, it would be a valuable study for state staff to consider. Given experiences elsewhere (e.g., TX, NE), it would not be surprising to find that the great majority of individuals served in Florida's institutions have "twin" with similar support needs who are being served in the community.



An example of this pattern was found in a report conducted by HSRI in the state of Texas<sup>15</sup>. Data available in Texas found that there was a modest tendency to support people with more significant disabilities in ICFs/DD settings (referred to as ICF/MR in Texas). The trending, however, was not absolute. The percentage of people with a “Limited Level-of-Need” served in either ICFs/DD or waivers was roughly equivalent (44.8 percent ICFs/DD to 42.9 percent in waivers). However, 2,768 individuals or 24.8 percent of all those served in community waivers have extensive support needs compared to 38.36 percent or 1,085 people in ICFs/DD. Meanwhile, 13.5 percent or 1,573 of those with intermittent needs were served in ICFs/DD settings, compared to 32.31 percent or 3,605 served through the waivers. These data raised issues over why so many people with intermittent (low level) needs are in ICFs/DD. Likewise the data show that community-based waivers serve significant numbers of people with extensive (moderate to high) levels of need.

- We note that the average cost of serving an individual in a community ICFs/DD in Florida is \$86,027. Likewise, the average cost of serving an individual on the HCBS waiver in Florida is \$28,912. We understand that the latter figure reflects the fact that a large percentage of HCBS waiver participants receive in-home support services instead of residential services in an out-of-home setting. Still, the national experience suggests that on average community centered approaches are less expensive than institutional services (See Prouty et al., 2008).

In addition to large state-run institutions, in 2007 Florida also funded 87 non-state, privately run, community ICFs/DDs. Note that:

- Though 38 residences are licensed for 6 or fewer individuals, 47 facilities, or 54 percent, are licensed for 16-plus residents. Nationally, of the 6,075 licensed ICFs/DD, 6.4 percent serve 16-plus residents.
- These 47 facilities in Florida served 1,770 people in 2007, or 88 percent of the 2,019 served in ICF/DD-certified facilities. Nationally, 59,243 people were served in ICFs/DD, with 20,432 or 21.2 percent served in larger 16 plus facilities.

These findings suggest that compared to national markers Florida makes relatively greater use of large ICFs/DD. We understand that some in Florida defend this service approach and distinguish between smaller (i.e., six bed) and larger ICFs/DD. Yet, on balance, policy makers across the nation are de-emphasizing use of ICFs/DD in favor of HCBS waiver approaches.

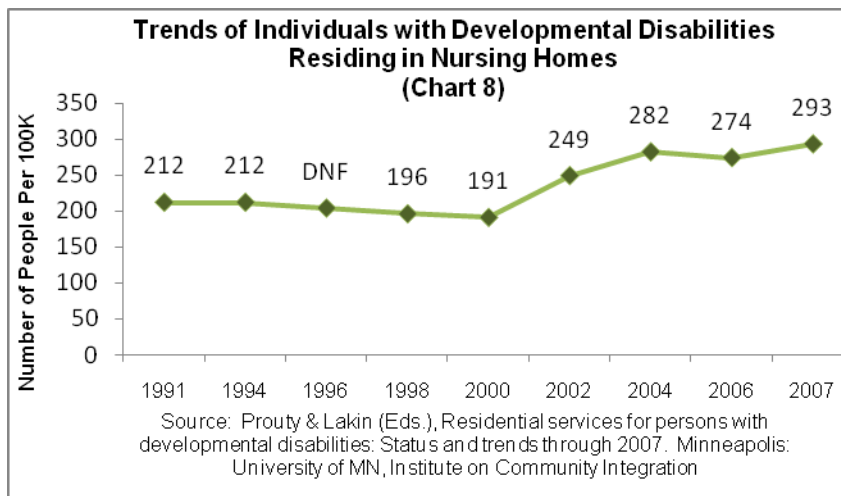
Overall, states increasingly seek a unified approach to financing a full range of community supports required by people with developmental disabilities. This ranges from periodic home and community-based supports to highly intense, round-the-clock medical and social supports provide at home or in small, community living arrangements. Under present circumstances, the HCBS waiver authority is the only available vehicle for achieving a unified funding approach while maximizing federal financial participation. This objective can be accomplished without

<sup>15</sup> Agosta, J., Fortune, J., Smith, D., Melda, K., Gettings, R., and Bradley, V. *Closing the Gap in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. October 2008. HSRI. Portland, OR 97224.

undermining the financial integrity of existing agencies that operate private ICFs/DD facilities, as the experiences of other states (e.g., CO, IN, PA and MA) have illustrated.

Of further concern is the state's use of nursing home facilities for individuals with developmental disabilities. Nationally, the trend over the past 15 years has been to decrease the number of such individuals served in nursing facilities.

Chart 8 shows the number of nursing facility residents with developmental disabilities in Florida. As the chart depicts, since 2000, Florida has shown a steady increase in the numbers of people with developmental disabilities served in nursing homes. The number has grown from 212 in 2000 to 293 in 2007, a 53 percent increase. Noteworthy, the state is below the national



average; however, the national average has not shown an increase such as the increase in Florida. When considering this finding, the *Strategic Planning Group* could not easily explain the rise. Some remarked that it may simply reflect better reporting or changes in demographics. Others, however, warned that it could indicate that families are increasingly unable to provide support at home and APD does not offer adequate residential alternatives. As a result, nursing homes become a reasonable alternative by default especially since APD need not be an integral part of the placement process.

### Conclusion

Florida serves nearly as many people with developmental disabilities per 100K in the general population as the national average. To do so, the state established a service system in which families act as the mainstay of the system. Seventy-two percent of those served by APD live at home with a family member. Yet, as Florida built out this system, it neglected to develop a strong supportive infrastructure to underpin this approach. Further, it may well have overinvested in the approach, leaving too few opportunities for individuals to live their own lives in the community as do the great majority of adults without disabilities.

Complementing the strong commitment to in-home supports, Florida serves relatively few people in state-run institutions. Of concern, however, is the state's continued reliance on state institutions, even though the state's total institutional population is under 1,200. Further, of those served in community ICFs/DD, Florida providers operate a large proportion of these facilities for 16 plus residents. Likewise, the recent increase of placements in nursing facilities bears watching and further study.

## Benchmark #3: Economy and Efficiency

*Assessment: Florida's Medicaid spending on developmental disability services lags significantly behind the national average. This circumstance is not explained by the state's reliance on less costly in-home supports. More recently, service reductions within HCBS services have undercut further the system's capacity to provide quality community services.*

### Background

There is no doubt that appropriately supporting people with developmental disabilities requires a substantial financial commitment on the part of a state. Developmental disabilities are life-long. People with developmental disabilities have significant functional impairments and many require day-to-day services and supports throughout their lives. Developmental disabilities services are among the most costly long-term services. Therefore, it is important that a state: (a) invest ample resources in financing services to this population, and (b) employ effective financial management practices that promote economy and efficiency in the delivery of services.

There is significant variability among the states with respect to their level of financial effort in supporting services for people with developmental disabilities. State fiscal capacity varies due to underlying economic and other differences. However, all other things being equal, states where there is a relatively low level of financial effort in support of developmental disabilities services usually have large waitlists for services. Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and stabilizing in the disability services workforce.

Effective financial management of developmental disabilities services is complex and multi-faceted. Key facets include:

- **Managing the use of federal Medicaid dollars.** To the extent that a state can qualify services for federal Medicaid cost sharing, it can stretch its own dollars to serve more people with developmental disabilities. Medicaid financing can play a major role in underwriting the expansion of system capacity to meet service demand. It presents states with alternative pathways to securing federal dollars to pay for services. As a consequence, there are major differences among the states in their utilization of Medicaid dollars to finance services.
- **Promoting economical service delivery.** It is in a state's best interest to channel service demand into less expensive, more economical service alternatives. Some models of developmental disabilities service delivery are extremely costly due to regulatory and other requirements. In an environment of limited budgets, reliance on high cost service models obviously will foreshorten a state's ability to meet current and future service demand.
- **Purchasing of services.** Government is the principal – indeed, virtually the only -- purchaser of developmental disabilities services. Consequently, state purchase-of-

service policies and practices have major marketplace ramifications. The rates that a state pays for services affect the viability, quality and availability of services. To the extent that state payments are not based on a realistic appraisal of legitimate provider costs, quality will suffer and there will be an insufficient supply of providers to support individuals.

How a state addresses these system management issues has major consequences for the state's ability to support its citizens with developmental disabilities. Among the states, there have been several noteworthy national trends and developments pertaining to the financing and management of developmental disabilities services. With respect to Medicaid financing, the trend for more than 20 years has been for states to concentrate on expanding HCBS waiver services to people with developmental disabilities while concurrently reducing the utilization of more costly ICF/DD services.

Between 2000 and 2006, states increased the overall number of individuals with developmental disabilities enrolled in Medicaid-funded long-term services by a little over one-third. In most states, this expansion was fueled by more aggressive leveraging of community developmental disabilities services through the Medicaid home and community-based waiver authority. Leveraging, including converting community-based ICFs/DD to waiver funding helped states to capture partial reimbursement for their expenditures, an attractive outcome for states. In turn, this allows states to weather downturns in state revenue and/or expand services. The HCBS waiver program now is the principal source of federal financial assistance to states to underwrite the costs of specialized developmental disabilities services. In terms of expenditures, in 2006 federal/state spending on HCBS waiver services accounted for 59.5 percent of the \$30.8 billion in Medicaid spending nationwide for specialized developmental disabilities long-term services.

Another important development has been the emergence of new approaches to purchasing services. Several states have implemented or are designing relatively sophisticated rate-setting systems. These systems are designed to ensure that payments for services match up with their underlying service needs of each individual along with provider agency costs. For example, Arizona has implemented a rate system that takes into account market wages, difficulty of care, geographic differences as well as other factors that affect provider costs. Likewise, Colorado, Georgia, Oregon, Louisiana, Rhode Island, Virginia have all sought to reform their resource allocation methods.

States also are abandoning their conventional purchase of service systems in favor of umbrella service authorization limits that are based on the usual and customary costs of serving people with developmental disabilities who have similar support needs and life circumstances. For example, Connecticut has designed a system that establishes cost limits based on statistically significant factors that affect the overall costs of supporting individuals. States are moving toward greater standardization of payment rates based on market factors and standardized assessments of individual needs. Matching dollars to the support needs of each individuals and using standardized methodologies and tools promotes efficiency and encourages the entry of new providers into the market place.

## Florida Status

In comparison to other states, as well as the nation as a whole, Florida spends considerably less on furnishing services to individuals with developmental disabilities. Though the state has taken steps in a positive direction by investing heavily in in-home supports and de-emphasizing the use of more costly residential settings, funding is inadequate. Florida nearly matches the national average in the number of people served per 100K in the general population (190 to 198 per 100K). Yet, due to scarce resources, the investment per individual is relatively modest and the community system itself lacks the needed infrastructure. Put another way, it can be said that the Florida system runs wide, but shallow.

**Put another way, it can be said that the Florida system runs wide, but shallow.**

## Insufficient Spending

There are two ways to measure a state’s overall level of financial effort in supporting its citizens with developmental disabilities:

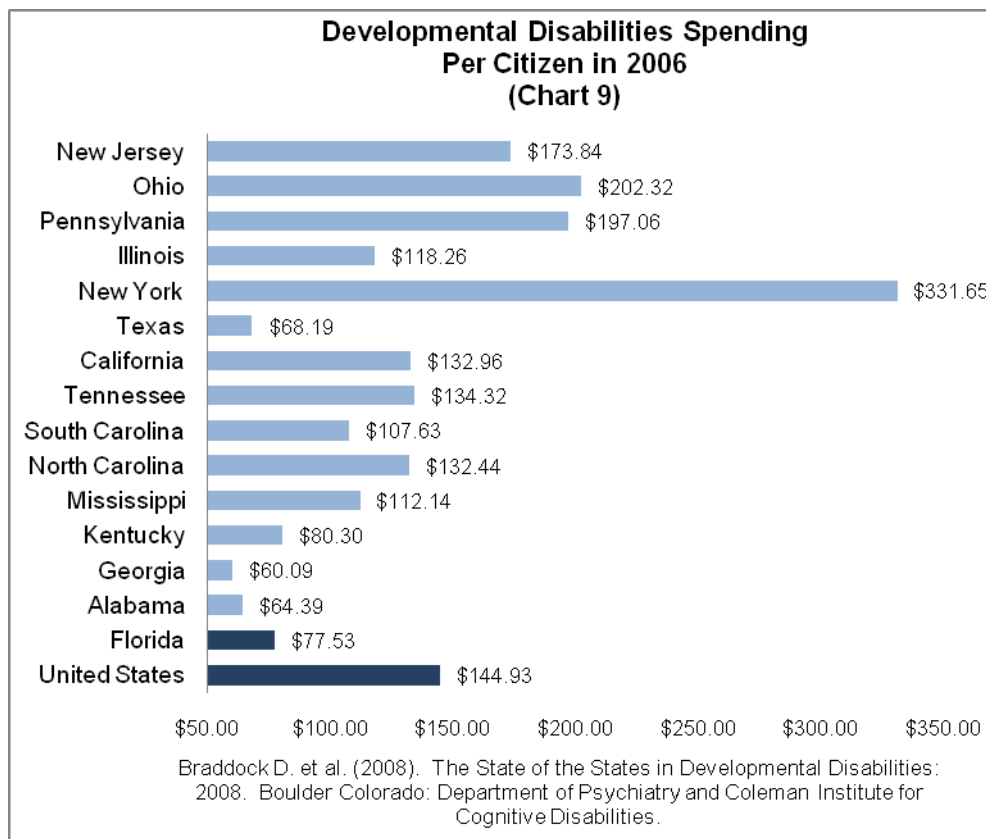
- Fiscal effort.** This method appraises a state’s level of financial effort by measuring its overall spending on developmental disabilities services relative to state personal income. This method takes into account underlying differences in the relative strength of state economies and, therefore, a state’s capacity to fund developmental disabilities services. Under this model, the operating assumption is that the higher a state’s personal income, the greater its capability to fund developmental disabilities services. Using this measure, the Coleman Institute for Cognitive Disabilities at the University of Colorado/Boulder ranked Florida 47<sup>th</sup> among the states in its overall level of fiscal effort on behalf of individuals with developmental disabilities during fiscal year 2006. Among the 15 comparison states, Alabama, Georgia and Texas were the only states to rank lower than Florida.
- Expenditures per citizen.** Another way to measure a state’s level of financial effort is to compare its expenditures per citizen with other states – that is, total developmental disabilities expenditures divided by the state’s population. Chart 9 compares Florida’s expenditures per citizen to the nation as a whole and to other selected states. In 2006, Florida spent \$77.53 per citizen for developmental disabilities services. The nationwide average (\$144.93 per citizen) was nearly double that figure. Florida’s 2006 spending for developmental disabilities services would have had to have been \$1.21 billion higher in

|                |           |
|----------------|-----------|
| <b>Florida</b> | <b>47</b> |
| Alabama        | 48        |
| Georgia        | 50        |
| Kentucky       | 44        |
| Mississippi    | 27        |
| North Carolina | 25        |
| South Carolina | 32        |
| Tennessee      | 26        |
| California     | 37        |
| Texas          | 49        |
| New York       | 2         |
| Illinois       | 40        |
| Pennsylvania   | 14        |
| Ohio           | 9         |
| New Jersey     | 31        |

Braddock D. et al. (2008). The State of the States in Developmental Disabilities: 2008. Boulder Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

2006 to match the nationwide average. As also can be seen, nearly all the other selected states exhibited a stronger level of financial effort than Florida.

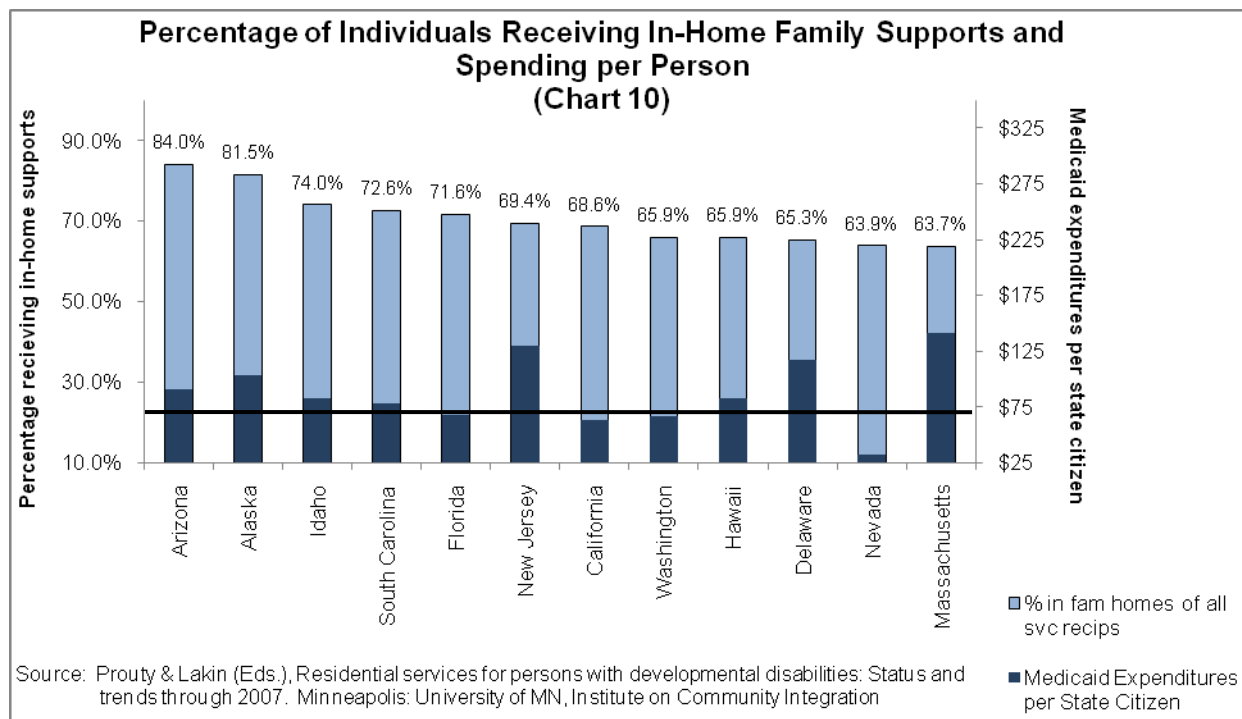
Measured in either fashion, Florida's current spending is not sufficient to support those in need of services. As it is reasonable to expect, states (like Florida) who invest heavily on in-home supports will likely have lower per person expenditures. Often this is the case because out-of-home residential placements are one of the most expensive types of services offered under state HCBS waiver programs.



As mentioned earlier, Florida serves roughly 72 percent of service recipients in in-home supports. Compared to out-of-home residential options, this approach is far less costly. It follows then that states, such as Florida, that invest heavily in this approach should require fewer resources. Such reasoning is used sometimes in Florida to justify the state's comparatively modest investment in developmental disability services.

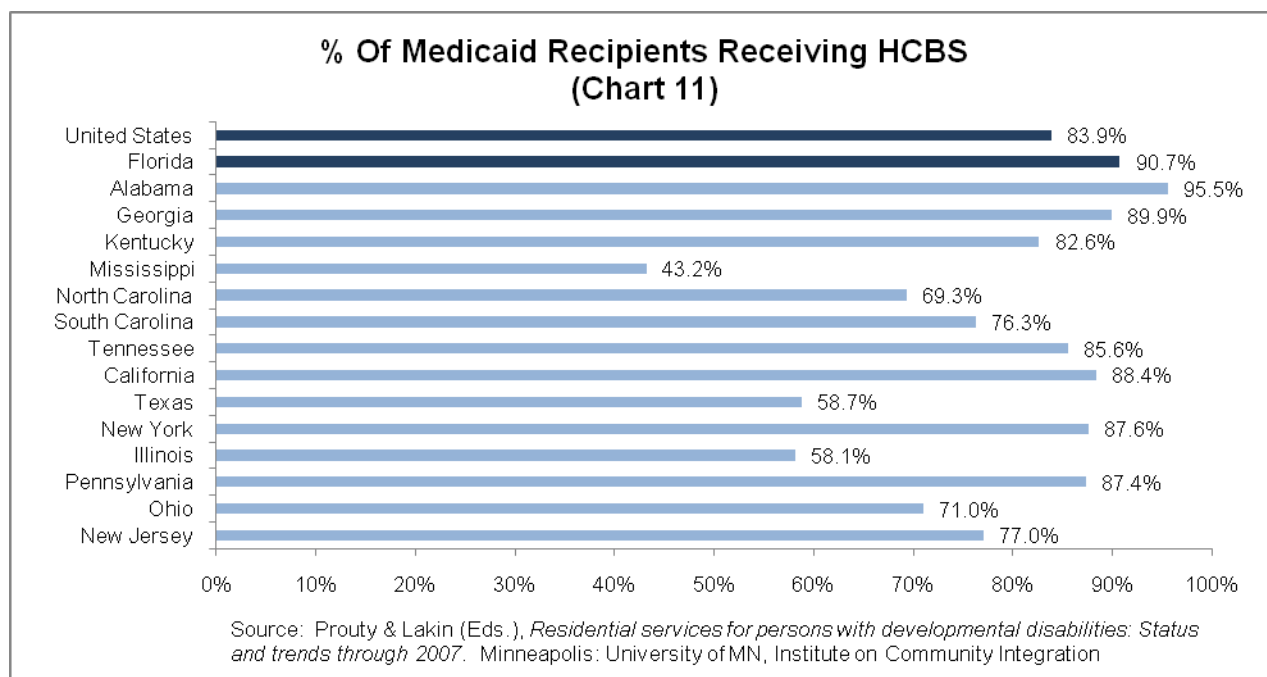
We examined the validity of this proposition in two ways. First, we studied the relationship between state investment in services and the percent of people served who live in the home of a family member. We found nearly no correlation between these two variables ( $r=.032$ ).

Second, we developed a list of 12 states that served 63.5 percent or more of the individuals they serve through in-home supports during 2007. Subsequently, as shown by Chart 10, we compared these states in terms of the percentage of service recipients served at home and overall Medicaid expenditures per state citizen. Within this group of 12 states, Florida ranks 5<sup>th</sup> in the percentage of individuals served through in-home supports, but 9<sup>th</sup> in expenditures per state citizen. In fact, all of the four states with a higher percent of people served at home spent more per citizen than Florida.



### Utilization of Medicaid Financing

In 1996, 81 percent of state developmental disability funding was tied to Medicaid with the proportion growing to 89 percent in 2006. This increase was achieved principally by shifting state-only funded services to the HCBS waiver program. With respect to the utilization of Medicaid financing of developmental disabilities services, Florida is noteworthy in one main respect. As can be seen by Chart 11, Florida serves a higher percentage of individuals through

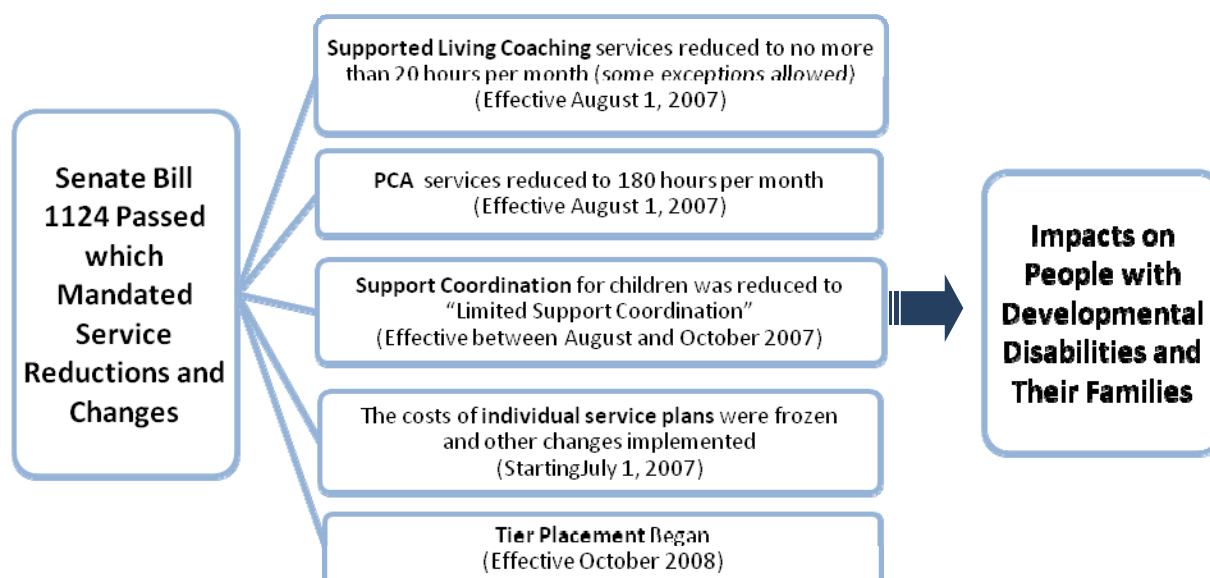


HCBS waiver services than almost all of the comparison states, as well as the national average.

### Waiver and Related Service Reductions

Coupled with already modest spending on behalf of individuals with developmental disabilities, the Florida Legislature recently implemented several service reductions and also directed APD to initiate a four-tiered home and community based waiver system.

The state's new waiver configuration was mandated by the Legislature in 2007. Senate Bill 1124 mandated several cuts in services and also replaced two of Florida's existing waiver programs (e.g., the Developmental Disabilities (DD) waiver and the Family and Supported Living (FSL) waiver) with four new "tier waiver" programs.



Below, is a list of service reductions imposed by the Florida Legislature as well as the working definitions of waiver eligibility for the four tiered waiver programs:

- **Service Reductions.** The mandated spending cuts affected a variety of services:

#### *Personal Care Assistance*

- Personal Care Assistance (PCA) services were reduced to 180 hours per month, a step which does not include rate modifiers for individuals receiving services through the Developmental Disabilities waiver program. This reduction did not affect anyone receiving intensive rate PCA services (effective August 1, 2007). In 2008, the Legislature allowed additional hours to be authorized for people who have intensive physical, medical, or adaptive needs if such hours are essential for avoiding institutionalization.

- For children, effective October 1, 2007, Personal Care Assistance services must be provided through a Medicaid provider rather than a waiver provider through the state plan.

#### *Supported Living Coaching*

- Supported Living Coaching services for individuals also receiving in-home support services were reduced to no more than 20 hours per month for all adults served through the DD waiver program (effective August 1, 2007).

#### *Support Coordination*

- Support Coordination was reduced to “Limited Support Coordination” for children under age 18 receiving services through the DD waiver program (effective August 1, 2007).
- Support Coordination was reduced to “Limited Support Coordination” for children under age 18 receiving services through the CDC+ waiver program and the FSL waiver program (effective October 1, 2007).

#### *Other Changes*

- The costs of individual service plans were frozen at the July 1, 2007 level. Plans with certain services are now subject to special review and reauthorization.
- Residential habilitation services were limited to 8 hours per day. Additional hours may be authorized for people with intensive medical or adaptive needs if such hours are essential to avoiding institutionalization, or for people with behavioral problems exceptional in intensity, duration, or frequency and who present a substantial risk of harm to themselves or others. This restriction is to be in effect until the four-tiered waiver system is fully implemented.
- The coverage of chore service, nonresidential support services, and homemaker services were eliminated from the waiver programs. To partially offset the effect of this rollback in coverage, APD expanded the definition of in-home support services to enable the provider of the service to include activities previously furnished under the eliminated service categories.
- Massage therapy and psychological assessment services were eliminated.

When these cuts were implemented, thousands of families were affected. As described earlier, HSRI’s study of these impacts, involving 24 focus group meetings statewide, revealed that many families are being hard pressed to provide support to their loved ones.<sup>16</sup>

<sup>16</sup> Melda, K., Smith, D., Agosta, J. (2008). *The impact of reductions to Florida services on people with developmental disabilities and their families*. Tallahassee, FL: Florida Council on Developmental Disabilities.

- **Tiered Waiver Programs.** The four waiver program tiers include:

**TIER ONE** is limited to individuals who have intensive medical or adaptive support needs that are essential to avoid institutionalization, or who exhibit behavioral problems that are exceptional in intensity, duration, or frequency and present a substantial risk of harm to themselves or others. These service needs cannot be met in tiers two, three, or four. No annual expenditure limit is legislated for participants assigned to Tier One.

**TIER TWO** is limited to individuals whose service needs include a licensed residential facility and more than 5 hours per day of residential habilitation service, or clients in supported living who need and receive more than 6 hours a day of in-home support services. Total annual expenditures under Tier Two may not exceed \$55,000 per annum, per individual.

**TIER THREE** includes individuals in residential placements, independent or supported living situations, and/or in their family homes who require moderate levels of PCA services, skilled or private duty nursing, or behavioral, occupational, physical, speech or respiratory therapies. Individuals under 22, in general, must receive more than 60 hours per month of behavioral services to qualify for Tier Three eligibility. Total annual expenditures for Tier Three recipients may not exceed \$35,000 per annum, per individual.

**TIER FOUR** replaces the Family and Supported Living Waiver program. Tier Four includes individuals not eligible for Tiers One, Two or Three. Generally, the target population includes children (under 22) living in their own home or the family home, dependent children living in residential facilities, and those of all ages who were previously served through the Family and Supported Living Waiver program. Tier Four services are limited to: adult day training, behavior analysis, behavior assistance, consumable medical supplies, durable medical equipment, environmental accessibility adaptations, in-home support service, personal emergency response system, respite care, support coordination, supported employment, supported living coaching, and transportation. Total annual expenditures under Tier Four may not exceed \$14,792 per participant, per year.

As APD has moved to implement the new tiered waiver structure, there has been widespread concern, with many individuals/families appealing the tier assignment and service allocation. Indeed, as illustrated by Table 7, 30% of the 29,582 service recipients are scheduled for service reductions in FY 09-10, yielding about \$91 million in cost savings.

Some members of the *Strategic Planning Group* shared in the concerns expressed by families during the focus groups conducted by HSRI staff. Two significant issues that were voice are: (a) the way in which individuals are assigned to a tier and the perceived inequity in such assignments, and (b) the lack of flexibility in service choice within tiers.

**Impacts of Service Reductions on Individuals by Tier (FY 2009-2010)**

**Table 7**

|                                  | <b>Tier 1</b><br>(unlimited) | <b>Tier 2</b><br>(\$55,000 limit) | <b>Tier 3</b><br>(\$35,000 limit) | <b>Tier 4</b><br>(\$14,792 limit) | <b>Totals</b> |
|----------------------------------|------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|---------------|
| # in Tier                        | 3,426                        | 4,643                             | 7,053                             | 14,460                            | 29,582        |
| Percent in the Tier              | 12%                          | 16%                               | 24%                               | 49%                               | 100%          |
| Number over budget limits        | NA                           | 2,340                             | 3,058                             | 3,424                             | 8,822         |
| Percentage receiving a reduction | NA                           | 50%                               | 43%                               | 24%                               | 30%           |
| Projected savings                | NA                           | \$20,967,218                      | \$35,528,685                      | \$35,235,217                      | \$91,731,120  |

*APD. Tier Waiver Implementation Update. (2009)*

### **Conclusion**

The state's overall investment in developmental disability services lags behind nearly all other states. Overall, in 2007, Florida's Medicaid spending per citizen for developmental disability services was 52 percent below the nationwide average. Over time, inadequate resources undercuts the quality of the supports offered individuals and families and results in growing waitlists for services.