
The Impact of Reductions to Florida Services on People with Developmental Disabilities and Their Families

December 29, 2008



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All opinions expressed herein are solely those of the authors and do not reflect
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The purpose of this study is to assess the impact of service reductions, enacted by legislation and implemented by the Florida Agency for People with Disabilities (APD) during 2007 and 2008, on individuals with developmental disabilities and their families, and to determine the coping strategies that individuals and families use to compensate or adapt to these service reductions.

As part of this study, 25 Focus Groups were conducted throughout the state. These focus groups involved participation from self-advocates (youth and adults with developmental disabilities), as well as parents/family members of both children and adults with disabilities. The findings emerging from this study provides policy-makers with a better understanding of the effects of service reductions on everyday lives.

This report documents the activities, findings, and conclusions associated with this study, and is organized into the following sections:

- **Background Information** provides a description of the service changes that have occurred in Florida during 2007 and 2008.
- The **Methods** section provides an overview of the methods that were applied to complete the study.
- An analysis of the study is presented in the **Study Findings**. This section includes data analysis prepared by Human Services Research Institute (HSRI), as well as key concepts and discoveries from the statewide focus groups.
- Finally, **Observations and Concluding Remarks** offers summary observations regarding the study findings.

Background Information

In response to budget deficits, the 2007 Florida Legislature mandated the reduction of some services provided through the state's Medicaid Home and Community-Based Services (HCBS) waivers administered by the Agency for Persons with Disabilities (APD). This piece of legislation is often referred to as Senate Bill 1124. The limits imposed in the legislation affected both children and adults receiving services through the State's Developmental Disabilities (DD) waiver, the Consumer Directed Care Plus waiver (CDC+), and the Family and Supported Living (FSL) waiver. Precise tallies of the number of people affected by the service reductions are unavailable, but clearly thousands felt the cutbacks throughout the system.

Specific services targeted for reductions included Support Coordination, Supported Living Coaching, and Personal Care Assistance. These services are described below along with the changes made. Other services that were fully eliminated include Massage Therapy, Chore services, Homemaker services, and Non-Residential Support Services. In addition, Senate Bill 1124 also mandated replacing Florida's existing waivers with four new "Tier Waivers."

Definitions of Services

- *Personal care assistance (PCA)* is a service that assists a person with eating, bathing, dressing, personal hygiene, and other self care activities of daily living. The service also includes activities such as assistance with meal preparation, bed making and vacuuming when these activities are essential to the health, safety and welfare of the recipient and when no one else is available to perform them. This service is provided on a one-on-one basis. PCA may not be used solely for supervision.
- *Support coordination* is the service of advocating, identifying, developing, coordinating and accessing supports and services on behalf of an individual, or assisting the person and his/her family to access services and supports on their own. The support coordinator is responsible for assessing the person's or family's needs, preferences and future goals. With this information, the support coordinator assists the individual/family in developing a support plan and cost plan.

Support coordinators promote the health, safety and well-being of the individual; assist them in identifying and accessing formal and informal support systems; assist them to increase or maintain their capacity to direct formal and informal resources; promote advocacy or informed choice for the recipient; provide information regarding the Medicaid fair hearing process; increase the recipient's involvement in the community; and assist the recipient to achieve personal goals.

- *Supported living coaching* services provide training and assistance, in a variety of activities, to support individuals who live in their own homes or apartments. These services may include assistance with locating appropriate housing; the acquisition, retention or improvement of skills related to activities of daily living such as personal hygiene and grooming; household chores; meal preparation; shopping; personal finances and the social and adaptive skills necessary to enable recipients to reside on their own. Supported living services mean the provision of supports necessary for an adult who has a developmental disability to establish, live in and maintain a household of his or her choosing in the community. This includes supported living coaching and other supports.

Changes to Services

Changes to waiver services were rolled out between August 1 - October 1, 2007. Some adjustments were later made during the 2008 Legislative Session. The reductions to each service were as follows:

Personal Care Assistance

- Personal Care Assistance (PCA) services were reduced to 180 hours per month and do not include rate modifiers for individuals receiving services through the DD waiver. This reduction did not affect anyone receiving intensive rate PCA (effective August 1, 2007).
- Personal Care Assistance services were reduced to 180 hours per month for all adults receiving services through both the DD and CDC+ waivers, including people who receive intensive rate PCA (effective October 1, 2007). In 2008, the Legislature allowed additional hours to be authorized for persons 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.

Supported Living Coaching

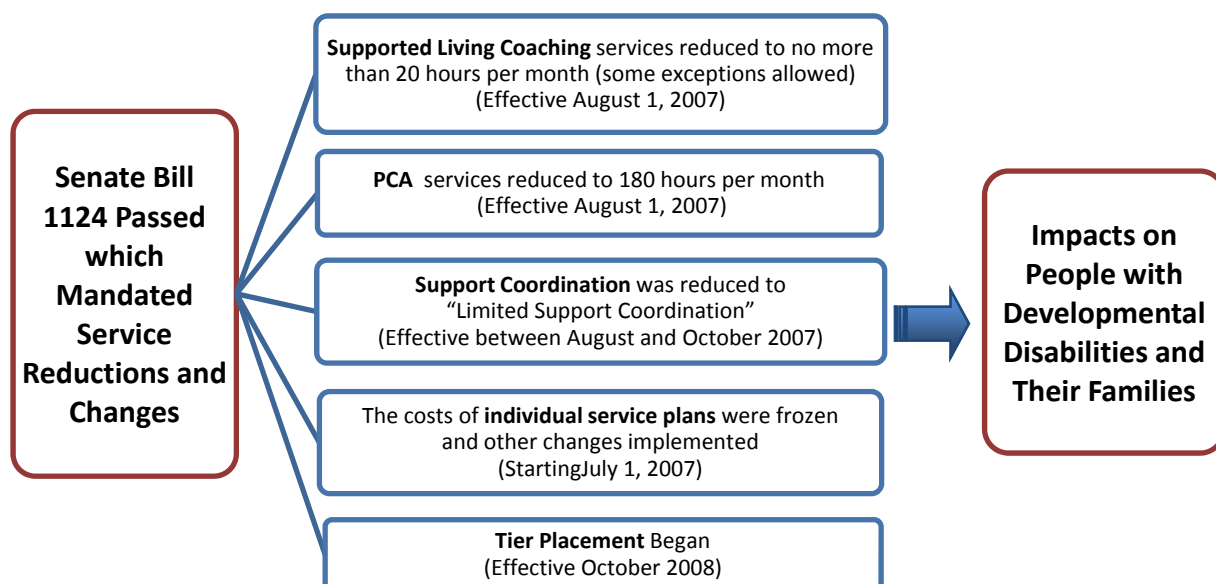
- Supported Living Coaching services were reduced to no more than 20 hours per month for all adults served through the DD waiver, who also receive in-home support services (effective August 1, 2007).

Support Coordination

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

Other Changes

- The costs of individual service plans were frozen as of July 1, 2007. Plans with certain services are now subject to special review and reauthorization.
- Residential habilitation services were limited to 8 hours per day. Additional hours could be authorized for people with intensive medical or adaptive needs if such hours are essential for avoiding institutionalization, or for people with behavioral problems exceptional in intensity, duration, or frequency and present a substantial risk for harming themselves or others. This restriction was in effect until the four-tiered waiver system is fully implemented.
- Chore service, nonresidential support services, and homemaker services were eliminated. The agency expanded the definition of in-home support services to enable the provider of the service to include activities previously provided in the eliminated services.
- Massage therapy and psychological assessment services were eliminated.



Tier Waivers

Senate Bill 1124 also mandated replacing Florida's existing waivers (Developmental Disabilities (DD) waiver, the Consumer Directed Care Plus waiver (CDC+), and the Family and Supported Living (FSL) waiver) with four new "Tier Waivers". Below, is a working definition of people who qualify for each of the four tier waivers, as well as the dollar amount associated with each tier:

TIER ONE is limited to individuals who have intensive medical or adaptive support needs that are essential for avoiding institutionalization, or who possess 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 in residential habilitation services or clients in supported living who receive more than 6 hours a day of in-home support services. Total annual expenditures under Tier Two may not exceed \$55,000 per individual.

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

TIER FOUR replaces the Family and Supported Living Waiver. Tier Four includes individuals not eligible for Tiers One, Two or Three. Generally, this 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. 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 year.

These tiered waivers are meant as a systematic approach to placing people into a "tier" that matches their support needs to a dollar amount to pay for those supports. Service coordinators were instructed by APD to follow a pre-struck protocol for assigning individuals into a tier. Subsequently, APD assigned individuals to tiers using both the information gathered from support coordinators, as well as support plans that had been used in the prior year. People and families were notified of their tier placement in October 2008. If families felt that the tier placement had been assigned incorrectly, the family was allotted 10 business days to file an appeal and request a re-assessment.

Methods

Information related to this study was collected by: (a) completing a review of printed materials regarding the Florida service system for people with developmental disabilities, (b) preparing a protocol to guide local focus groups, (c) recruiting and training focus group facilitators, (d) conducting statewide focus groups, and (e) compilation and analysis of information generated during the focus groups.

Review of Printed Materials

Information related to this project was collected from the following sources:

- **Florida’s Agency for Persons with Disabilities (APD)**

Information regarding services offered, service definitions, agency policy and procedures, Medicaid waivers and relevant legislation were gathered from APD for use in this report.

“APD works in partnership with local communities and private providers to assist people who have developmental disabilities and their families. APD also provides assistance in identifying the needs of people with developmental disabilities for supports and services.” (APD website: www.apd.myflorida.com)

- **Family Care Council Florida (FCCF)**

Information regarding services offered, Medicaid waivers, relevant legislation, and FCCF positions in response to service changes were also reviewed.

“The mission of the Family Care Council Florida is to advocate, educate and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring quality services to individuals for dignity and choice.” (FCCF website: www.fccflorida.org)

- **Florida Developmental Disabilities Council (FDDC)**

Information regarding services, definitions, APD actions, legal actions in response to APD implementation of service reductions and new tier waivers, and analyses of Medicaid claims data and APD expenditures were gathered from FDDC for review.

“The...FDDC is a non-profit organization funded through federal assistance from the Department of Health and Human Services Administration on Developmental Disabilities. The Council accomplishes its mission by supporting innovative initiatives that demonstrate new approaches to enhance the independence, productivity, inclusion and self-determination of individuals with developmental disabilities in all facets of community life.” (FDDC website: www.fddc.org)

- **The Advocacy Center for Persons with Disabilities, Inc.**

Information regarding Florida statutes, rules and regulations, legal reactions to implementation of APD service reductions and tier waivers were also gathered and reviewed.

“The Advocacy Center for Persons with Disabilities, Inc., is a non-profit organization providing Protection and Advocacy ("P & A") services in the State of Florida. The Advocacy Center’s mission is to advance the quality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities through collaboration, education, advocacy, as well as legal and legislative strategies.” (Advocacy Center website: www.advocacycenter.org)

- **Research and Training Center on Community Living (RTC) at the University of Minnesota**

Annually, RTC conducts a comprehensive nationwide survey of state developmental disabilities agencies to obtain comparative information and data on residential and other services and supports for people with developmental disabilities. All states, including Florida, participate in this survey. In general, RTC survey data serve as the source of information that compares Florida’s performance to the national average as well as selected other states. (RTC website: www.rtc.umn.edu)

- **Coleman Institute on Cognitive Disabilities at the University of Colorado**

Data is also compiled by the Coleman Institute on Cognitive Disabilities at the University of Colorado. The Coleman Institute collects annual developmental disabilities service data primarily related to financial and programmatic information from states on a yearly basis. The Coleman Institute now has a 30-year trend for each state spanning back to 1977. The data collected is done in cooperation with state agency officials to ensure accuracy within the information presented (Coleman Institute website: www.colemaninstitute.org).

Recruitment and Training of Group Facilitators

In Spring/Summer of 2008, fifteen (15) Partners in Policymaking graduates were identified and contracted (by the Florida Developmental Disabilities Council, Inc (FDDC)) to conduct focus groups throughout the state. Partners is a training program sponsored by FDDC primarily for people with developmental disabilities and their families. Participants generally attend a series of two day training sessions over a year covering a variety of topics on disability policy and practice (e.g., disability history, early intervention, public education services, adult services, family support).

In July, this group came together for a full day of training provided by HSRI. In advance of the training HSRI had prepared a 60 page manual to help guide focus group facilitators through the process of advertising, preparing for and managing focus groups¹. The manual went hand in hand with the training HSRI provided. The training covered:

- Background information (Senate Bill 1124, service changes/cuts, Tier Waivers);
- The plan for statewide focus groups (composition of groups, locations, assignments to areas, facilitation and note-taking responsibilities, materials needed);
- Informing and inviting participants (methods, local resources);

¹ Melda, Kerri and Smith, Drew. *Training Manual for Focus Groups*. July, 2008. For copies or more information regarding this training manual, please contact the Florida Council for Developmental Disabilities at (850) 488-4180.

- Role of the facilitator;
- Role of the note-taker;
- Focus group agendas;
- Strategies for productive focus groups; and
- Administrative information so that they could coordinate with HSRI staff.

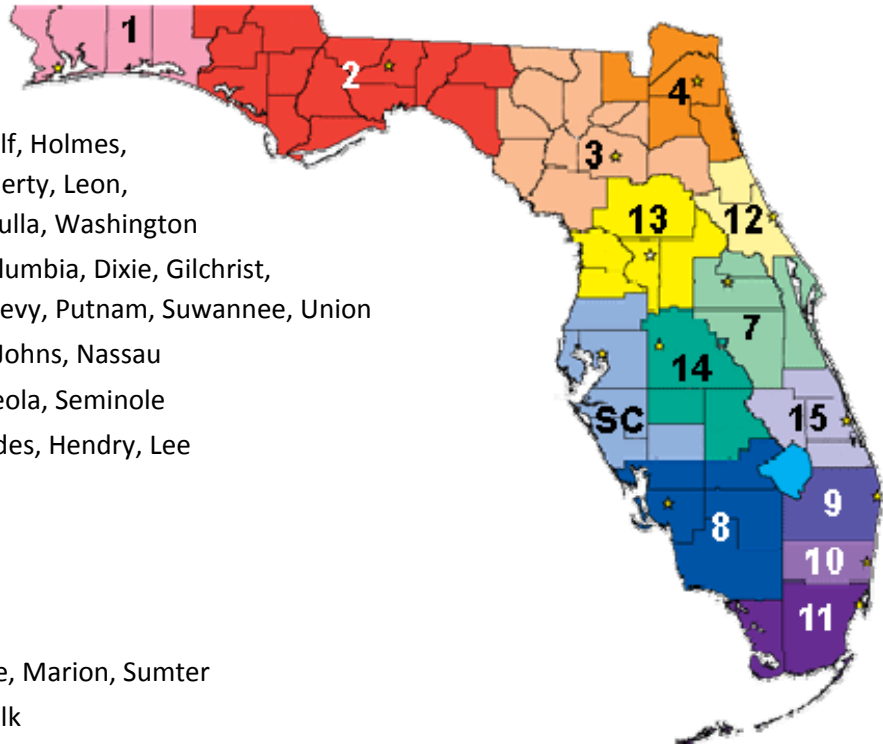
In addition, during the session, participants were given the opportunity to sharpen their facilitation and note taking skills. They also received materials electronically (e.g., a sample flyer to publicize the event and a sample agenda) that they could tailor to their local needs. Finally, they were given instructions so that they could forward the information generated from the focus group to HSRI staff.

Conduct of Focus Groups

Our goal for the focus groups was to assure that all parts of the state are represented, and that all relevant populations were included. Thirty-six (36) focus groups were planned, to allow for two to five focus groups in each of Florida's fourteen Service Areas (see map below).

APD's Statewide Map of Area Offices

<u>Area 1</u>	Escambia, Okaloosa, Santa Rosa, Walton
<u>Area 2</u>	Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Liberty, Leon, Madison, Taylor, Wakulla, Washington
<u>Area 3</u>	Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union
<u>Area 4</u>	Baker, Clay, Duval, St Johns, Nassau
<u>Area 7</u>	Brevard, Orange, Osceola, Seminole
<u>Area 8</u>	Charlotte, Collier, Glades, Hendry, Lee
<u>Area 9</u>	Palm Beach
<u>Area 10</u>	Broward
<u>Area 11</u>	Dade, Monroe
<u>Area 12</u>	Flagler, Volusia
<u>Area 13</u>	Citrus, Hernando, Lake, Marion, Sumter
<u>Area 14</u>	Hardee, Highlands, Polk
<u>Area 15</u>	Indian River, Martin, Okeechobee, St Lucie
<u>SunCoast</u>	De Soto, Hillsborough, Manatee, Pasco, Pinellas, Sarasota



In total, twenty-five (25) focus groups took place between July 15th and September 30th, 2008, with 273 attendees representing thirteen (13) of Florida's Service Areas (all except Areas 4 and 14). In 15 of these focus groups, two facilitators were present.

These focus groups were conducted with four distinct populations of people:

- *Self-advocates (youth and adults with developmental disabilities):* Four (4) focus groups were conducted with self-advocates, each in areas with existing self-advocacy groups. These groups consisted of all youth, all adults, or a combination of youth and adults with developmental disabilities who have personally experienced (or anticipate experiencing) changes/cuts to their services or budget.
- *Families of adults with developmental disabilities:* Seven (7) focus groups were conducted with families of adults with developmental disabilities whose family members experienced cuts to PCA or Supported Living Coaching services, or anticipate cuts due to their new Tier Waiver assignment.
- *Families of children with developmental disabilities:* Five (5) focus groups were conducted with families of children with developmental disabilities who have experienced, or anticipate, service cuts.
- *Combined group of families:* Nine (9) focus groups were conducted with a combination of families who have children or adults with developmental disabilities. This occurred in areas with smaller population bases.

Focus groups ranged in size from two (2) to twenty-five (25) participants, and included individuals with developmental disabilities and/or family members who have: (a) already experienced changes/cuts to their developmental disabilities services or budgets, (b) received notification of upcoming changes/cuts, or (c) who anticipate changes/cuts to their services/budgets in the future.

Recognizing that some self-advocates and family members would like to participate in a focus group, but may be unable to attend, they were also given the opportunity to contact HSRI directly and share (via e-mail or phone) their contributions to the study. Likewise, participants who did attend, but felt they had more to share, were also afforded the opportunity to submit additional information by phone or e-mail. Approximately ten (10) individuals participated in this fashion.

The 25 focus groups were each approximately one and one-half (1 ½) to two (2) hours in length and covered the following topics, as appropriate to the specific population in attendance:

- Personal Care Assistance (PCA)
- Supported Living Coaching
- Support Coordination
- Tier Waivers
- Other Waiver changes

For each of these areas, participants were asked:

1. What changes have you experienced/do you anticipate experiencing?
2. How have/do you anticipate these changes affecting you/your family?
3. How are you/do you anticipate coping/dealing with it?

Study Findings

In advance of talking directly with families, HSRI examined several contextual factors that should be taken into account when assessing the impacts of the service reductions. Information on various contextual themes emerged from review of printed materials, including data to compare Florida with other states. These findings were complemented by the personal circumstances that families and self-advocates shared with us. What follows are findings resulting from our inquiries, including: (a) a presentation of Florida’s developmental disabilities service context; (b) an articulation of the challenges that many families of individuals with developmental disabilities face; (c) information generated from the focus groups on the impacts of service reductions and coping strategies.

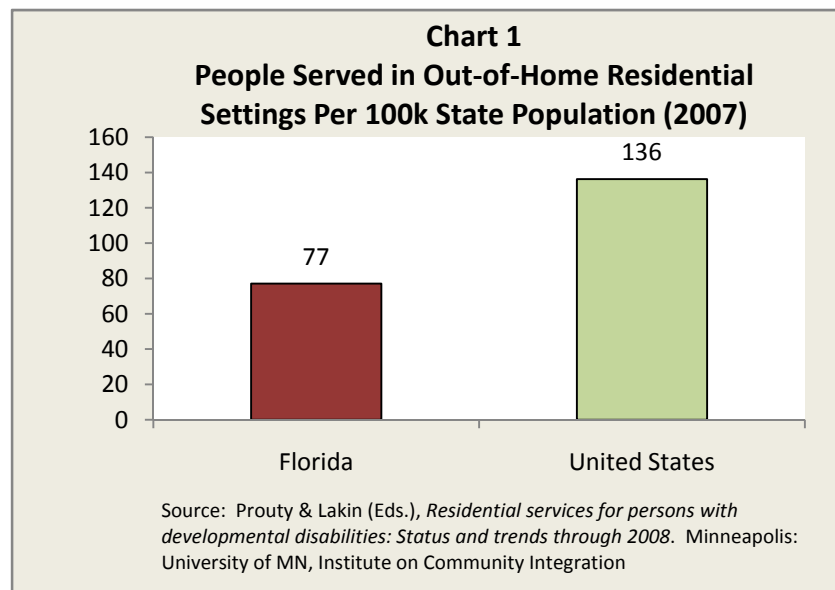
The Services Context

The cuts to services made over the past year were imposed within a scarcely funded system that relies heavily on families to provide continued support at home to adult sons and daughters. Consider that:

- **Florida relies on families to provide support at home to people with developmental disabilities.**

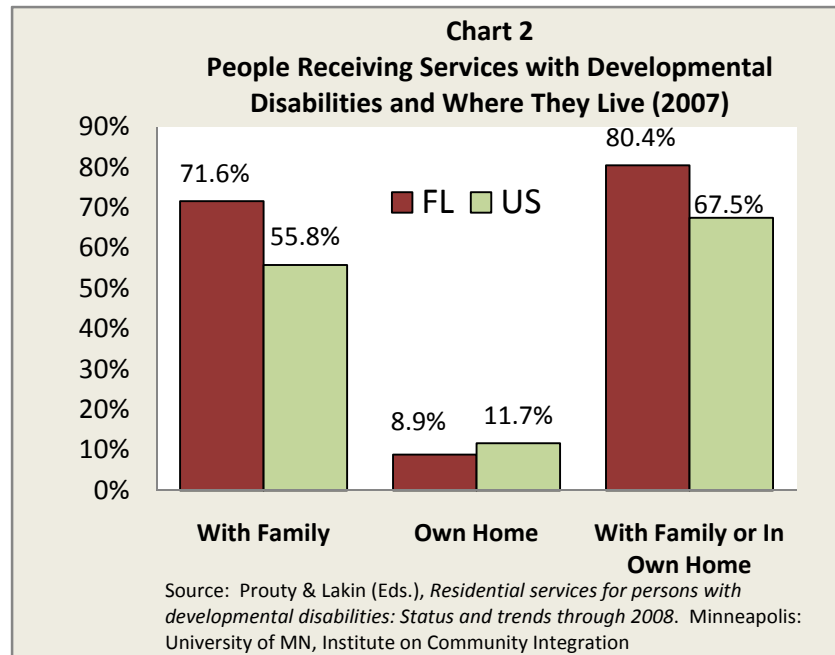
In 2007, Florida served 190 people per 100,000 in state population. This compares to the national average of 198 people or about 4% fewer than the national average. Florida would have had to serve roughly 1,420 more people with developmental disabilities (in 2007) to reach the national average in 2007. While the state serves near the national average per 100K population, it is important to note that a recent report documents that the state maintains a considerable waiting list for services of roughly 17,000 people².

Yet, at the core of Florida’s service response are families. While Florida is near the national average in service utilization, most other states have better developed out-of-home residential options available. Chart 1 shows that Florida serves 77 people in out-of-home residential options per 100,000 in state population, compared to a national average of 136. In fact, as



² Florida Office on Disability and Health Department of Epidemiology and Biostatistics, (2008). *Agency for Persons with Disabilities (APD) Waiver Program Waitlist Survey*.

illustrated by Chart 2, 80.4% of those served by APD live with family (71.6%) or on their own (8.9%). Aside from the heavy reliance on families this illustrates, it also suggests that Florida lacks in available residential options for people with disabilities seeking to leave their family home or for families who can no longer provide in-home support.



- **Florida Spends Less than the National Average on Developmental Disability Services.**

To begin, we note the US Census Bureau ranks Florida 4th in total population and 20th in personal income per capita for 2007 (99 percent of the national personal income rate). Further, Florida is ranked 47th among states in state tax burden to its citizens.

In this context, the Coleman Institute³ tracks expenditure patterns for developmental disability services nationally. One method used to compare expenditures across states appraises a state’s level of financial effort by measuring its overall spending for developmental disabilities services relative to state personal income. By this measure of fiscal effort, Florida ranked 47th among the states in 2006,

Alternatively, the Coleman Institute also measures a state’s financial effort by its expenditures per citizen – that is, total developmental disabilities expenditures divided by the state’s population. By this method, in 2006, Florida spent \$78 per citizen for developmental disabilities services. The nationwide average of \$144 per citizen was 85% higher.

By either method, it is apparent that Florida lags most other states in spending for its system of services for people with developmental disabilities. As a result, a reliance on families as a mainstay supports resource coupled with relatively scarce fiscal resources to begin with, places the mandated service reductions within an extraordinary service context that directly challenges families.

³ 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.

Challenges Faced by Individuals and Their Families

In Florida, nearly seventy-two percent (72%) of those receiving developmental disability services through the APD live at home with their families, and no two of these people with disabilities or families are exactly alike. Some individuals (adults or children) live in what's conventionally thought of as a family – with two parents and brothers and sisters. Others live in households headed by siblings, grandparents, or other extended family. And still others have their own homes; where they live either alone, or with a spouse or roommate. In fact, people living in their own homes make up another eight percent (8%) of service recipients in Florida.

Individuals and families have varying ethnic origins and speak varying languages. Some are difficult to reach, living in rural areas or hard-to-penetrate urban areas. The age of support-givers ranges from young adult to past retirement age. And still other families have unique circumstances such as families where a parent is serving in the military, or where the support-givers themselves have disabilities.

Each family has unique needs, strengths, capabilities, and preferences. Yet many families find that the “ordinary” challenges faced by others can become “extraordinary” when providing support to an individual with disabilities at home.

Contemporary family life already poses significant day-to-day obstacles. Having a family member with a disability, however, often complicates matters. The difficulties experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of challenging behavior, family characteristics, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community supports. As a result, though not all families who provide support at home have extraordinary problems, all are more "at risk" for having more difficulties than families without members with disabilities. For instance, research shows that families may experience one or more of the following challenges:

- *Natural reactions* to the discovery that a family member has a disability, including a sense of shock or numbness, denial, grief, shame, guilt or depression. These natural feelings are also sometimes accompanied by social isolation brought on by negative or stigmatizing reactions of neighbors, extended family or other community members.
- *Chronic stress* that can affect family interactions and functioning. Such stress may be felt within the parental marital relationship, given a need for both parents to adjust to their child's disability and to take on new roles. Likewise, siblings of children with disabilities may also experience a variety of stressors.
- *Changes in lifestyle* often affecting established social relationships within the family or with others, which may result in isolation from their personal or larger communities.
- *Difficulty in undertaking family routines* such as shopping and house cleaning, or in finding ample time for recreation.
- *Difficulty managing relationships between brothers and sisters and the individual with disabilities.* Certainly, brothers and sisters can be a great source of support within a family. Sometimes, however, families have difficulty reconciling between disability related support demands and the needs of other family members.

- *Financial costs, or lost opportunities for employment or education.* Families frequently report that there are numerous out-of-pocket expenses associated with providing care at home for a child with disabilities. The costs can be relatively low, yet persistent and ultimately significant (e.g., for diapers), or quite high (e.g., home barrier removal).

Added to the out-of-pocket expenses are the various *opportunity costs*, most often tied to lost chances for a job or advancement. Very often, someone must stay at home to provide support. Inevitably, the lost opportunities translate into reduced family income.

- *Extraordinary time demands* involved with providing personal support to the family member with disabilities, finding needed specialized professionals, or negotiating bureaucratic systems.
- *Difficulty with physical management* (e.g., lifting, carrying). As the child ages, so do parents. The combination can result in increasing difficulty with providing needed care.
- *Lack of skills needed to cope* with potential medical emergencies and/or to teach necessary adaptive skills.

Within this family context is the individual with developmental disabilities. Typically, these individuals want a full and rewarding life just like any other person. Young children attend school, seek playmates and enjoy participating in their communities. Teens seek separation from their parents, look forward to the transition to adulthood, and along the way, also create anxieties for their parents. Adults want to go to school or find a good job and make decisions for themselves. Many eventually want to live away from parents and even build their own families. All want to live their life in the community with the support they need. Still, these individuals often have needs in one or more of the domains listed below.

- *Assistance with life threatening health impairments:* Several types of disabilities require frequent monitoring of medical conditions and require that caretakers be knowledgeable and adept in coping with chronic medical needs.
- *Help with learning adaptive skills:* Individuals with intellectual disabilities may have trouble learning new skills, while others with physical disabilities and no intellectual disabilities may acquire skills at a slower pace due to their physical condition.
- *Help with undertaking various activities of daily living:* Individuals with disabilities may have difficulty with completing a variety of everyday activities such as toileting, eating, bathing or communicating.
- *Help with developing a life outside the family,* such as making friends with others his/her age or getting to participate in typical community activities. This issue may intensify as the child grows into an adult, brothers and sisters leave home, and parents age.
- *A need for specialized support:* Individuals with disabilities may require specialized therapies (e.g., communication training or physical therapy, prosthetics).
- *Support and treatment for behavioral health problems:* The inability to grasp concepts quickly, diminished capacity to communicate or the frustrations of having a disability can result in challenging behavior. An individual may disrupt household routines, inflict harm on others or self, destroy objects or surroundings, or otherwise pose a behavioral threat.

Information Generated From the Focus Groups

Individuals and families attending focus groups either already have been affected by service reductions mandated in 2007 (e.g., PCA, chore, supported living coaching, massage therapy), or expect to be greatly affected by budget reductions (and therefore additional service reductions across the full service array) as a result of the new Tiered HCBS waivers.

As mentioned earlier, twenty-five (25) focus groups took place across the state between July 15th and September 30th, 2008, with 273 attendees. These focus groups ranged in size from two to twenty-five participants, and included individuals with developmental disabilities and/or family members who have: (a) already experienced changes/cuts to their DD services or budgets, (b) received notification of upcoming changes/cuts, or (c) who anticipate changes/cuts to their services/budgets in the future.

From these meetings, six (6) major themes emerged. Individuals with developmental disabilities and their families are being affected by increasing:

1. stress;
2. difficulty in accessing services;
3. concerns for individual/family safety;
4. concern for individual/family health;
5. financial difficulties (e.g., job loss, housing concerns); and
6. willingness to consider out-of-home placement to obtain needed services.

Hanging like a dark cloud over all of these themes is a sense of anxiety, uncertainty/insecurity and hopelessness. Others continue to wait, and now feel hopeless that the wait will result in services that are inadequate to meet their or their family member's needs. Individuals and families seek access to services, adequacy of services, and consistency in their services so they can plan for the future. Minus these key components, many feel forced (often for the first time) to consider out-of-home options.

Many families lingered for years on waiting lists, finally received services, only to learn later they would be taken away.

Below, more details are provided about each of the six emergent themes:

1. Families Feel Additional Stress Due to Service and Budget Cuts.

Families are struggling to adjust their lives as services are reduced or removed, services providers become harder to find, and the future becomes uncertain. Feelings of tension, anxiety, stress and hopelessness were common across all twenty-five of the focus groups. The increased stress is felt across the entire family. Individuals with developmental disabilities, who used to worry about leading more independent and self-directed lives, now worry about getting their basic needs met. Parents, who used to worry about what would happen to their child after they're gone, worry how they will manage now. Further, siblings (young and old) find themselves making sacrifices in their own lives to become unpaid caregivers and support providers.

During the focus groups, many stories were shared about families' emotional, relationship, and financial stresses. Service and budget reductions are having devastating impacts on the quality of life, health and well-being of individuals with developmental disabilities, and reductions are taking their toll on marriages, jobs, and finances of parents and siblings. Added to this is the stress that uncertainty brings. Might things get better? Will it get worse? What are our options? How will we make it? For many families, these questions are proving to be overwhelming.

Here are some selected focus group comments from individuals with developmental disabilities and their families related to this topic:

- One man, taking care of both of his parents, shared that his mother is in a wheelchair, has a heart condition and developmental disabilities. APD placed his mother in Tier 4 because she lives at home with him. She is unable to work due to a lack of transportation providers, so he is the sole provider. He works two jobs and provides care and transportation for his parents to support his family.
- One family tells that their child's siblings have been a natural support, but the siblings are getting tired of helping because of the sacrifices they have to make, and feeling that their life (childhood) is not typical.
- One parent states that the rest of her children are suffering because she is physically unable to be there for them (she spends so much time providing care to her child with disabilities). Also, because her other kids have to assist with care giving, they miss out on time with their friends and to complete homework.
- One family says that their marriage is ending. The struggles and stress have just been too much.
- One family says, "The cuts are emotionally devastating for the whole family."
- Several families commented that they feel completely unsure of what the future holds.
- One family that recently lost respite and companion services says, "Respite is invaluable!" There will be more stress in their family without it.
- Many families feel they are being penalized for keeping their children at home.
- One parent states, "This is a path to failure."
- Many focus group attendees noted that they or someone they knew had considered divorce due to the stress placed on the marriage because of these reductions.
- Some families shared that they are constantly sleep-deprived since getting reductions to their PCA services. Now they need to be up much of the night attending to their family member's (with disabilities) needs.
- Several families indicated that the overwhelming stress is leading them to consider or pursue out-of-home care in lieu of in-home supports.

Many families feel they are being penalized for keeping their children at home.

2. Families Find it Increasingly Difficult to Access Adequate or Appropriate Services.

As several changes have occurred in Florida over the past few years, access to qualified service providers has diminished greatly. With reductions to provider payment rates, a weakening economy and changes to individuals' service budgets, some providers are closing down, shortening hours or facing higher turnover rates. These issues directly affect the families that rely on them, and cause further stress to the family.

Families expressed great difficulties in obtaining, retaining and trusting service providers. Some were frustrated with unqualified or unresponsive support coordinators. Others described a severe lack of services available where they live. Still others had trained and qualified providers quit, due to pay decreases and job insecurity.

Of special note here, and of special concern to several who attended the focus groups, is the fact that new Tier waiver assignments and budgets will be based on historical use of services. These individuals and families typically had approved service/support plans that included specialized behavioral services or therapies (e.g., speech, OT, PT), but due to a lack of provider availability in their area, were unable to access or obtain these vital services. With the new "use it or lose it" rules for budget development, families feel they are unjustly being stripped of badly needed services solely because the community service infrastructure is unfit.

Selected focus group comments related to this topic are detailed below:

- One focus group raised the point that people with developmental disabilities need stable and consistent services. However, currently, due to issues such as limited hours at day habilitation programs, high turnover, and limited transportation, their family members are unable to receive constant support and are having occasional service, which is feared to cause regression in behavior.
- A personal care assistant (PCA) accompanied a young woman with disabilities to the focus group. She was informed about the rate reductions recently and chose to continue PCA services, in this case, because she cares very much for the young lady and her family. But, she also mentioned that the price of gas was extremely high and strongly affecting her ability to continue services at the lower pay rate. She had decided not to provide PCA services for anyone new at this time. "It is a hard time economically for those of us who make less money. My client...is only allowed to have five hours two times a week of PCA as it is now. Lower wages are making it harder for me to live, and I have to look at finding a better way to support my family. I would be sad to stop this work because my heart is with my consumers. I am concerned for their well being."
- A single mother of three, whose oldest daughter has profound cerebral palsy and medical involvement, shared: "The cut that limits support coordination for children living at home has affected [my daughter's] care. Our support coordinator is less willing to make calls on her behalf, stating that she doesn't get paid enough. I'm planning to switch support coordinators, but I always had a hard time finding a good support coordinator before the cuts. I'm concerned

that it will be hard to find a support coordinator that will help us when we need it, under the limited support coordination model, but I am keeping my fingers crossed.”

- Several families noted that their Personal Care Assistants are quitting due to pay cuts.
- Other families raised concerns that there is a possibility of scarcity of services. That is, providers will be forced into providing fewer choices due to staffing shortfalls. A direct consequence of this will be that self-determination will be much more difficult in the new system.
- Many families indicate that services are getting harder to find locally. Some families travel hours (each way) to get specialized behavioral services or therapies.
- One parent states, “Many service agencies I have used have gone out of business. It is difficult enough to care for a child with special needs. The stress of all this is ongoing, and aggravated by constant Medicaid waiver cuts, changes, and issues finding appropriate service providers.”

Several families noted that their Personal Care Assistants are quitting due to pay cuts.

3. Families have Increased Concern for their Family Member’s Safety.

As service allocations and provider availability are reduced, concerns for safety are on the rise. These safety concerns are not limited to personal safety for individuals with disabilities, but also include safety for family members of the individual as well. Concerns included fear that children or adults with disabilities who are at home without supervision risk hurting themselves, hurting others, feeling isolated, and being more vulnerable to harm from others (e.g., burglary, assault or harassment). Several parents commented that an increase in self-injury had become apparent with the reduction and/or elimination of behavioral therapy. Further, as programs are cut, and individuals are spending more time at the house, siblings are being asked to become caretakers. As this happens, safety risks arise around an individual’s size, strength and proneness to violence, and the siblings’ chance for being injured.

Below are selected focus group comments from individuals with developmental disabilities and their families related to this topic:

- One highly concerned parent shared that, due to reductions to services, her child had to be dropped off and was to stay at the house alone. Upon being dropped off, the transportation provider did not notice glass broken by the front door. The child entered the home in the middle of a burglary. Luckily, the child was not harmed, but this issue brings forward significant issues related to safety risk tied to the cuts.
- The dangers of staying home alone are frightening. Many individuals and families are having to choose fewer hours or days for rehabilitation services.
- One family worries that without supervision, her son will have huge safety issues. He will leave the house with anyone, say inappropriate things to people, and get into

Parents have to work, so family members with disabilities are left at home alone. These parents expressed great fear for their child’s safety.

all kinds of trouble.

- One mother, whose son experiences significant behavior challenges, fears for the safety of her other children should her son get violent.

4. Families Have Increased Concern for Their Health and Their Family Member's Health.

Service cuts and anticipated budget cuts (leading to additional service cuts) have families deeply worried about regressions in health and quality of life, as well as behavioral setbacks for their family member with developmental disabilities. Across the state, numerous families expressed concern that, because family members are losing the services and supports they rely upon, they are in jeopardy of having complicated health and behavioral issues return. Other families, some elderly or with their own health issues, worry that by increasing their own care giving hours, they will be putting their own health in jeopardy.

Families know the hard work that has gone into getting their family member with disabilities feeling healthy, happy, independent, and/or behaviorally appropriate, and they fear that it will quickly disintegrate without service stability. The fear is real, that as services and budget reductions take effect, either a caregiver or family member's health deterioration will lead the family to consider out-of-home placement.

Here are some selected focus group comments from individuals with developmental disabilities and their families related to this topic:

- A 23-year-old self advocate who attended a focus group described her situation. She lives in an apartment by herself, receives in-home support services, supported living coaching, transportation, and works at an adult day training facility five days a week. She said that all of these services are important to her because she has limited support from her family. Her support coordinator, who accompanied her to the focus group, indicated that they were anticipating a loss of two days of work and some in-home supports. The Support Coordinator expressed concern that, "Without supervision and/or caregivers, she has dietary problems. She will eat until she is sick. Loss of in-home support services would put her health at great risk."
- One parent stated, "[My daughter with cerebral palsy] had her massage therapy services eliminated in the cuts. I can't afford to privately pay for the services, and so she has gone without. She has been negatively affected by the cut in services in a physical way. Without the massage therapy, her muscles are tighter, she has more muscle pain and she needs to take Valium for the spasms."
- One mother reports that both she and her daughter have medical issues. If they aren't assigned to Tier 1, she is afraid they will both die.
- Another parent states she they cannot lift her daughter by herself. It takes two people to move her from her wheelchair to the bed, toilet, bath, and table. Without the proper services, she is uncertain about how this will affect them.
- Several parents stated a real fear about an increase in behavioral problems due to the deterioration of services and qualified staff.

- Several parents said their children have an increase in self-injury when behavioral therapies are reduced.
- One family receiving PCA cuts commented about their struggles. The PCA helps their adult child with toileting and other supports. Their child can't limit their toileting needs until the PCA comes for support.
- One parent experiencing service cuts said, "They are condemning our loved one to a slow death."

Several parents said their children have an increase in self-injury when behavioral therapies are reduced.

5. Families are Losing Jobs, Health Insurance & Housing.

Families face extraordinary challenges when attempting to meet both the family's typical (e.g., food, housing, health insurance) and disability-related (e.g., specialized equipment, home modifications) financial needs, *and* the family member with a disability's support or care giving needs. Families experience numerous out-of-pocket expenses associated with providing care at home for a family member with disabilities. The costs can be relatively low, yet persistent and ultimately significant (e.g., for diapers), or quite high (e.g., home barrier removal). There are also extraordinary time demands involved with providing personal support to a family member with disabilities, finding needed specialized professionals, or negotiating bureaucratic systems. Added to these out-of-pocket expenses are the various *opportunity costs*, often tied to lost chances for a job or advancement. Very often, someone must stay at home to provide support. Inevitably, the lost opportunities translate into reduced family income.

With the recent budget and service reductions in Florida, many families are discovering that they will need to reduce their work hours, or quit their jobs completely to meet their family member's care needs. This, however, means that they will have to sacrifice the income they have relied upon to meet the whole family's financial needs. Families express that they feel stuck between a rock and a hard place. Quitting a job, losing a job, reducing work hours, losing health insurance, moving to a smaller house, selling the house, facing foreclosure, moving to a less safe neighborhood, choosing to eat fewer meals in a day, jeopardizing your own health to protect your family member's health; these are all real possibilities for families now experiencing service reductions in Florida.

Many stories were heard throughout the state of work-related uncertainties, financial hardships, and other difficult decisions forced by these changes. The following stories highlight these areas of concern and fears faced by families throughout the state:

- A parent of a child with developmental disabilities almost lost her job last year during the time of the crisis. At that time, she was forced to take a 25% reduction in her schedule and began working 3 days a week, 10 hour days. At the same time, she increased the household health insurance and lost retirement benefits. The mother visits her son's school every other Thursday to insure implementation of his Individualized Education Plan (IEP). She also works another job on nights and weekends.

- One mother described recent reductions in her adult son’s companion services. Fearful of leaving her son alone, the mother claimed that she would have to quit her job again to care for her 35-year-old son. She continues by stating, “[Before companion services], his quality of life was not good at the workshop. He didn’t really have job opportunities. He was not talking while at the workshop. Now he is talking. He is in the community having lunch together with friends and he is happy. If he will go back to the way things were, it will really affect his daily life. He likes bowling, Special Olympics, being with friends” but with the cutback, the parents will have to do it all. Her husband added, that in the past they had time to care for other things in their life knowing that their son was working, and having a good time, and now all of that will be taken away after these cuts.
- Another woman shared that as a working single mother she has had to pass up promotions because she cannot take on any added responsibilities in a better job due to the amount of time her son requires.
- One family says that without adequate PCA services, they will not be able to hold a full-time job, which means they will likely have their house foreclosed on.
- Several parents of children with severe disabilities indicate that they will need to give up their jobs when PCA services are reduced.
- In one family, both parents commented they will likely lose their jobs without PCA services for their adult son.
- Parents who are lucky enough to maintain adequate and constant employment are afraid that their income will keep their case from being heard seriously by a court.
- Several families are trying to significantly modify household budgets to supplement money from APD. This has caused stress on family budgets and many are concerned about foreclosure. By losing PCA services, they feel they will be unable to work, and therefore unable to support the household.
- Several families said that paying for lost services out of their own pocket would cause a financial burden on the family.
- One set of parents shared that both had quit their jobs and moved to a lower income area to help pay for lost services.
- One mom has twin boys with autism. She often has to leave work early to assist the boys after school. With PCA reductions, the father will lose many hours at work, due to the importance of having supervision for the children, and the family income is going to greatly decrease.

Several parents of children with severe disabilities indicate that they will need to give up their jobs when PCA services are reduced.

6. Families are Taking a Serious Look at Out of Home Options for their Family Members.

Across the state and across focus groups, real concern was expressed that people with developmental disabilities might not be able to continue either living with their families or on their own with the service and support reductions they knew about or anticipated. Many families took

the one-two punch, losing PCA services in 2007 and then finding out they would also face budget reductions with their new waiver assignment. Should they hold out as long as possible with the hand they've been dealt, and watch their lives deteriorate? Or should they start pursuing placement into group homes or other residential options? Many families feel these are desperate times. Faced with so much uncertainty, the relative security of a group home starts to make sense for many families. Individuals with disabilities and families who used to think they would grow old together under the same roof, are now having conversations weighing the pros and cons of in-home vs. out-of-home services, and some have already begun the process of seeking group home or institutional services.

Here are some selected focus group comments from individuals with developmental disabilities and their families related to this topic:

- One mom provides PCA services herself, and says that no staff is willing to stay very long due to her son's significant behaviors. Her son is non-verbal, punches himself in the face, intimidates others, bangs his head on the car windows and doors, has a feeding tube and sleep apnea.
- Some parents feel that their adult children will be better off in group homes, because there, they will get more money and services allocated to them than if the parents decide to keep their child at home.
- One parent of a son with autism has been told that she will experience a \$60,000 budget reduction when placed in Tier 3. She has gone in to fill out the paperwork for an institution, but was told they are full.
- Many families simply cannot imagine how they will make it with the budget cuts proposed. At this point, they feel that an appeal is the only option. If denied during the appeal process, they may be forced to look at out-of-home options.
- One parent says that she feels that kids are being forced into institutional care. She feels that the state does not want independence for her loved one.
- One parent states, "If being a minor puts him on the lowest tier, he will not receive the medical and behavioral services he desperately needs to live at home and be part of the community. It will be a disaster."

One mother states that, due to her son's need for constant care, with reductions, she will either need to leave the state or seek facility-based services for her son.

How Individuals and Families Are Coping Across the State

In each focus group conducted, individuals with developmental disabilities and families were asked to describe what they have done, or plan to do, to cope with the reductions faced. Many families were unable to identify specific actions they had taken to cope. Most conveyed that they were too overwhelmed and stressed to truly cope. Instead, families shared that they are simply trying to survive.

Overall, however, focus group discussions revealed that families are generally: (a) relying more on immediate family members to make up for lost services, (b) utilizing other available natural supports, (c) having difficulty utilizing supports that may be available from community serving organizations and businesses, and (d) seeking to push back at the service system by filing appeals to the reductions or tier assignments.

- Families are relying more on themselves . Many families indicated that they no longer feel that they can rely on the state to help them support their family members with developmental disabilities, and so are relying, largely, on their immediate family. The majority of focus groups found that immediate family, in most cases those living in the family home, have felt extreme stress and have been forced to fill the void left by service reductions and changes. Some immediate family members, including brothers and sisters, have begun working additional hours to support the family financially, while others have stepped in to act as the primary care taker for their loved ones.

In any case, this study showed that families have had to over-extend themselves in hopes of surviving these reductions. Countless family members discussed the hardships this has placed on the family, yet, feel that this is their only true option, at the time, to cope with these changes.

- Families are relying more on natural supports outside of their immediate family. Natural supports have historically been, and continue to be, families' first line of support. When service cuts were made in 2007, many asked family members, neighbors, and friends to step in and help. These individuals offered to provide supervision or care. In many cases, an increased reliance on natural supports has been the sole coping strategy. Yet, many families have already seen these supports dwindle over time, and wonder if it is a feasible long-term solution. Some families also believe that they are simply expanding their financial or care giving stress to a wider array of family and friends.

As an example, one couple explained that to continue supporting their child at home, they have been forced to sell their home and move in with their aging parents. This has allowed them to compensate for some of the lost services by paying out of their own pocket, but it has also taken away other opportunities and caused family-wide stress.

- Families are struggling to develop supports from community serving organizations. Even while families have experienced increased stress, many have worked to build stronger community ties and gather in help from churches, community centers, or other community serving organizations. This task has proven extremely difficult though, because families do not have the time to maintain community relationships, nor the ability to get to community meetings. Families often do not have time to search and develop such help, or simply cannot find the support they need. This struggle has become more difficult as families are finding their day program facilities going out of business, community centers being financially stressed, and in many cases the inability to care for someone with an intellectual or developmental disability.

One woman attending a focus group shared how she has tried to stay connected with others and develop resources for them as well. She has started a website called “Bobby’s World” to help parents and self-advocates find the resources they need to live their lives. In establishing the site, she has compiled resources so individuals and their families do not have to struggle to find them as she did. Her hope is that families can use these materials to cope and survive.

- Thousands of individuals with developmental disabilities and families are appealing tier placements. With drastic changes to funding levels and services, many families noted that the only way they feel they can cope is to appeal their tier placement. Several families shared that they either had already filed an appeal, intended to file an appeal or were in the process. This coping strategy has developed an “us against them” between families and APD.

Families feel they have been backed into a corner. Over 5,000 families and self-advocates filed an appeal against their tier placement because they either feel the process or their budget allocation is unjust. This defensive coping strategy suggests that the APD’s process for assessing support needs, and allocating individual budgets may be either inadequate, inequitable or both. To date, roughly one quarter of the appeals have been approved, while the rest have been denied based on their lack of merit or due to missed appeal deadlines.

Faced with constant changes and uncertainty, families feel they are trying to survive more than cope. Families fear that as their natural supports diminish, their situations, both financially and emotionally, will only get worse.

... most families do not feel that they are coping. ... Family fears are outweighing their coping strategies.

As has been described in other parts of this report, many families have already experienced losing their jobs, taking on second jobs, down-sizing their homes, or putting their lives on hold in hopes of “coping” with this added stress. Many families simply struggle, day to day, to get through, and make sure that all family members are healthy, safe and have food and shelter.

Observations and Concluding Remarks

In 2007, the Florida Legislature mandated reductions in some services provided through the state’s HCBS waivers administered by APD. Senate Bill 1124 affected children and adults receiving services through several waivers with targeted cuts to support coordination, supported living coaching, and personal care assistance, and other services (i.e., massage therapy, chore services, homemaker services, and non-residential support services). The legislature also required that Florida’s existing waivers be replaced with four new “Tier Waivers.”

The present study is meant to assess the impacts of these reductions primarily from the perspective of the individuals affected, including people with developmental disabilities and their families. The cuts targeted services received by these individuals, lessening APD’s service role in their lives but shifting increased support-giving responsibility to their families.

Review of the service context within which these cuts occurred and discussions held at 25 focus groups show that:

- **Spending cuts were imposed on a developmental disabilities service system that already lags behind nearly all other states in spending while relying heavily on families to provide support.**

The findings, based on statistical data collected in 2007, show that Florida spends far less than the national average on developmental disability services. In 2007, per person ICF/DD expenditures were about 18 percent lower in Florida than the nationwide average for comparable facilities. Florida's HCBS costs were also appreciably below (34%) the nationwide average. Also, while Florida serves about the same number of people per 100,000 state population as other states, it maintains a lengthy waitlist for services of approximately 17,000 individuals.

The spending pattern reflects a significant reliance on family members to provide supports to children and adults with developmental disabilities living at home. In Florida, seventy-two percent (72%) of those receiving developmental disability services through APD live at home with their families and another eight percent (8%) live in their own homes. Combined, this amounts to four out of every five people being supported in "their home." The concern, however, is whether they are being adequately supported. In a service system that relies heavily on family and natural supports, it is important that the state afford resources to support the responsibilities they bear.

- **Service reductions in Florida are taking a destructive toll on individuals with developmental disabilities and their families.** While no two individuals and families are the same, many families face significant challenges to providing support at home to children or adults with developmental disabilities. It should not be surprising then, that individuals and families in Florida would have common concerns where needed services and supports are put in jeopardy by severe service and budget cuts. The primary concern expressed by participants at the focus groups included: additional stress; increased difficulty in accessing services; rising concerns for both the individuals with disability and other family members' health and safety; devastating financial difficulties such as job loss, housing foreclosures and loss of health insurance; and an increased willingness to pursue out-of-home placements as a last ditch effort to get needed services. The level of stress that individuals with developmental disabilities and their families were feeling about implemented and impending services cuts was palpable in each of the sessions.

In addition, with pay reductions for providers and less service demand due to budget reductions, individuals and families feel this struggle getting worse day by day. Fewer hours of service and less qualified providers lead to greater concerns for the health and safety of everyone in the household. Ultimately, families are faced with difficult decisions about how to balance family finances, employment options, housing needs and support needs for their family member with disabilities. Families, who in the past, may have sacrificed a better job or living in a better neighborhood, are now worried about keeping their job and having a roof over their heads.

Overall, after years on waiting lists, followed by months or years of frustration in accessing services or attempting to find service stability, several families are now questioning whether the State's pattern of offering too little, too late is, in fact, encouraging them to seek alternative residential

settings for their loved ones. Put plainly, the belief for many families - that their family member would live at home as long as they needed, or that they would live as normal a life as possible in the community – is fading due to the dire circumstances that individuals with disabilities and their families find themselves in. More than any time in the past few decades, families are starting to consider and pursue out-of-home placements for their family members with disabilities. Out of home placements, a discussion topic previously “off the table” for many families is now a consuming focus of conversation. Family coping strategies have become family survival strategies. Quite simply, many feel depressed and defeated, unsure and insecure about their child’s and family’s future.

- **Families are doing their best to cope, but their capacity to cope seems overwhelmed by the challenges they face.** Families are coping by changing their own daily life patterns to devote increased time to support-giving responsibilities. They are also utilizing natural supports more often, including extended family, neighbors and friends. In addition, they are utilizing other resources available in the community, such as supports available through churches, community serving organizations, civic clubs, and others.

Yet, families are also beginning to push back at the Legislature’s decisions. Thousands, for instance, have filed appeals against their tier placement. Moreover, the families attending the focus groups generally felt that they were not coping successfully. Families indicate that they are trying to survive rather than cope. They understand that if the natural and extended community supports presently available were to lessen, their already challenging situations, both financially and emotionally, will worsen.

Overall, this examination of information regarding the impact of senate Bill 1124 suggests the following observation:

Given the present fiscal investment in services for people with developmental disabilities and recent reductions to these services, the state has jeopardized the well-being of these individuals and their families.

Family-caregivers are the mainstay of the Florida system of supports for children and adults with developmental disabilities. In part due to resulting cost efficiencies, it is in the best interest of the state to keep this network strong and vibrant.

Families are spread across the state and not particularly linked to one another in any formal way. The network is, by its very nature, maximally decentralized so that each individual and family are greatly on their own and dependent on the support offered them through APD. As a result, even small service cuts can have a significant effect on these independent units. Moreover, because these individuals and families are independent of one another, they cannot easily absorb the cuts themselves or work together to offset the impacts, as service providers might who serve hundreds of people.

As a result, the service reductions brought on by SB 1124, however well intended by the Legislature as a means of reining in APD spending, have had significant negative consequences on people with

developmental disabilities and their families. In essence, the state has undercut the mainstay of its service approach, putting in jeopardy many individuals and families while inadvertently generating demand for more expensive out-of-home living options. If the state is to maintain and strengthen its reliance on family support-givers throughout the state, study findings reveal that the Legislature will need to reconsider SB 1124 and begin reinvesting in its in-home support system.