



APD Waiting List Should Be Improved for Agency's Planning and Budgeting Purposes

at a glance

The Agency for Persons with Disabilities maintains a waiting list of individuals requesting services under its Developmental Disabilities Home and Community-Based Services Waiver. As of May 3, 2006, the agency reported having 17,467 individuals on its waiting list, of which 5,798 were receiving services from the Family and Supported Living Waiver.

The waiting list is not a valid indicator of need for waiver services. Approximately 28% 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 Also, information on individuals on the waiting list is often out of date and inaccurately reflects their current or potential service needs.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 hinders the Legislature's ability to determine the level of funding needed to serve eligible persons.

The agency should regularly review its waiting list to determine the number of individuals who are receiving services under related programs and/or who have declined waiver services, as well as the length of time such individuals have been on the waiting list. The agency also should develop a multi-year plan for addressing the waiting list for waiver services that considers the length of time individuals have been on the waiting list, how soon the individuals are expected to need waiver services, the expected level of services to be provided, and whether the individuals are receiving services from other waivers or programs.

Scope

As requested by the Legislature, this report examines the Agency for Persons with Disabilities' waiting list for waiver services. Specifically, the report addresses four questions.

- How is the waiting list developed?
- What are the characteristics of individuals on the waiting list?
- Is the waiting list a valid indicator of individuals' need for waiver services?
- How could the waiting list be modified to provide more useful information for agency planning and budgeting purposes?

Background

The Agency for Persons with Disabilities supports persons with developmental disabilities to help ensure their safety, self-sufficiency, and well-being. Persons with developmental disabilities include individuals who have or are at risk of having mental retardation, autism, cerebral palsy, spina bifida, or Prader-Willi syndrome. Many agency clients receive services in community settings, which include the person's home, a family home, a supported living situation, or a group home.

The agency administers three Medicaid waivers that allow the state to receive federal Medicaid matching payments for services provided to developmentally disabled persons in the community:

- the Developmental Disabilities Home and Community-Based Services Waiver (DD/HCBS), which funds services such as personal care, nursing, residential habilitation, and training; there is no per-client total dollar cap limit on these services;
- the Family and Supported Living Waiver which funds services to eligible persons living in their own home or family home; this waiver provides 11 services and is limited to a total per-client dollar cap of \$14,282 per year; and
- the Consumer Directed Care Plus Waiver which allows consumers to direct their own care and develop a purchasing plan to manage their allocated monthly budgets in order to meet their long-term care needs. ¹

¹ Clients must have their cost plans approved before they can receive services through the Consumer Directed Care Plus Waiver. There is no per-client total dollar cap limit on these services.

Each individual who is enrolled in a waiver program chooses a Medicaid-funded private waiver support coordinator who acts as the client’s advocate and develops a support and cost plan that describes the client’s needs and service requests.

As of May 1, 2006, the agency served 25,289 clients under the Developmental Disabilities Home and Community-Based Services Waiver, of whom 992 were also enrolled in the Consumer Directed Care Plus Waiver. It also served 5,944 other clients under the Family and Supported Living Waiver.

As shown in Exhibit 1, Fiscal Year 2006-07 appropriations for the three waiver programs total \$851.5 million.

The agency administers the three waivers through its central office in Tallahassee and 14 area offices located throughout the state. The area offices are responsible for the day-to-day operation of the programs and report to the central office. Area office staff guides clients through the process of applying for services, enrolling in the waivers, and being placed on the waiting list.

**Exhibit 1
Most Waiver Funding Comes From Federal Sources**

| Waiver Program | General Revenue | Operations and Maintenance Trust Fund | Tobacco Settlement Fund | Total |
|---|----------------------|---------------------------------------|-------------------------|----------------------|
| DD/Home and Community-Based Services ¹ | \$293,811,354 | \$460,417,023 | \$22,609,461 | \$776,837,838 |
| Family and Supported Living | 30,740,048 | 43,971,686 | 0 | 74,711,734 |
| Total | \$324,551,402 | \$504,388,709 | \$22,609,461 | \$851,549,572 |

¹ Includes Consumer Directed Care Plus Waiver funds.
Source: General Appropriations Act, Fiscal Year 2006-07.

Questions and Answers

How is the waiting list developed?

The Agency for Persons with Disabilities maintains a waiting list of individuals who have requested services under the Developmental Disabilities Home and Community-Based Services Waiver because there are not enough funded slots in this program to serve all eligible persons. Individuals are placed on the waiting list in order of the date they were determined eligible for services. However, individuals determined to be in crisis or who are dependent foster care children will receive priority for enrollment in a waiver program.^{2,3}

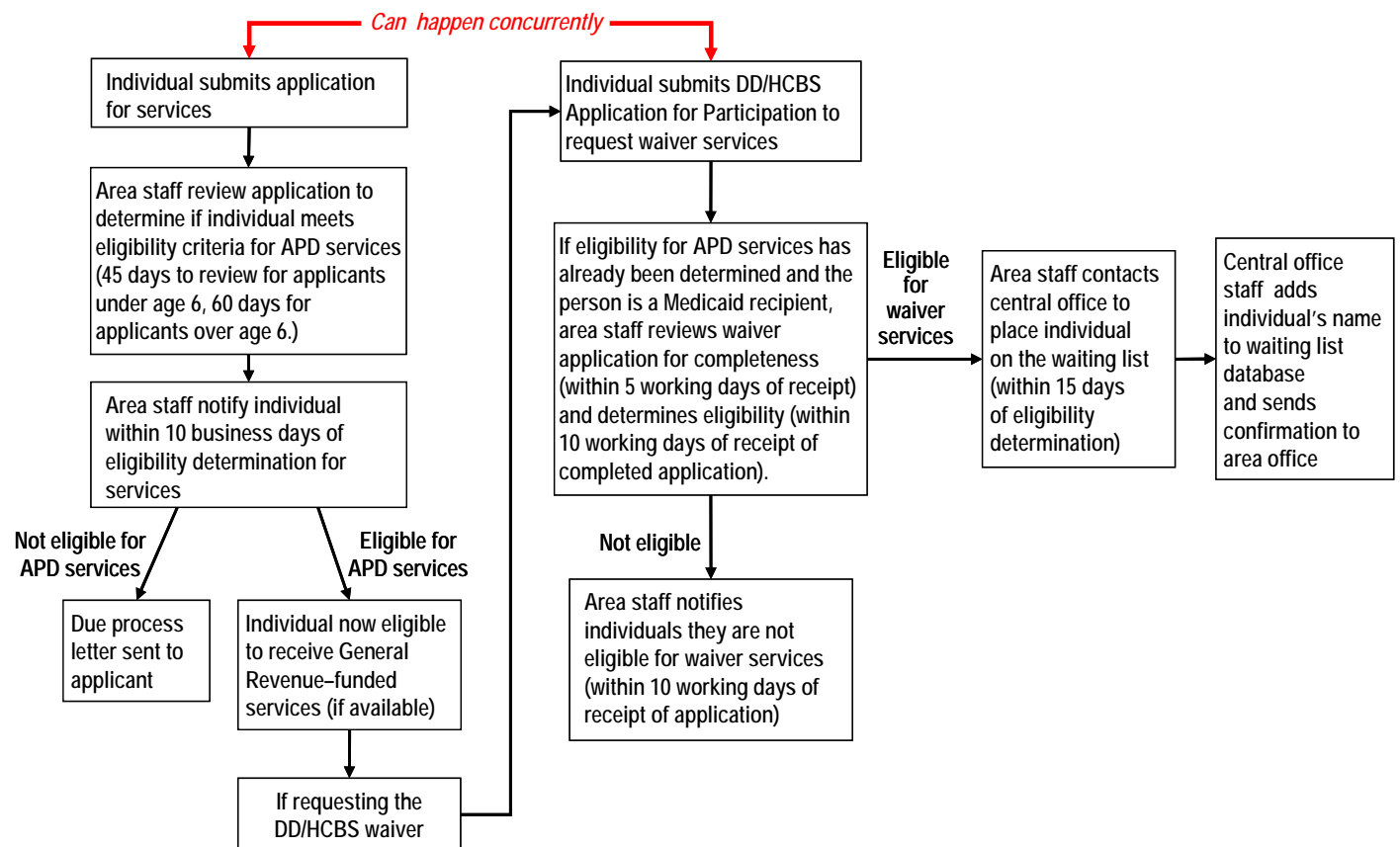
² To be eligible for crisis enrollment, an individual must meet certain criteria, such as be a danger to themselves or others, be homeless, or have a caregiver unable to further care for them.

As of May 3, 2006, the agency reported having 17,467 individuals on its waiting list for waiver services, of which 5,798 were receiving services from the Family and Supported Living Waiver but were waiting for DD/HCBS Waiver services.

As shown in Exhibit 2, there are several steps an individual must take to be placed on the waiting list for waiver services.

³ Language in Ch. 2006-227, *Laws of Florida*, and a proviso in the Fiscal Year 2006-07 General Appropriations Act (Ch. 2006-26, *Laws of Florida*) states that with the exception of clients deemed to be in crisis, the agency shall place at the top of the waitlist for waiver services children on the waitlist who are from the child welfare system with open cases in the Department of Children and Family Services' State Automated Child Welfare Information System.

Exhibit 2 The Waitlist Enrollment Process Has Several Steps



Source: Agency for Persons with Disabilities.

The process begins when an individual or his or her guardian completes an application form for agency services. This application includes demographic and disability information. At the same time, an individual may express interest in receiving waiver services by completing a separate waiver application. Once these forms are completed, agency area office staff determines the individual’s eligibility for services by collecting and reviewing information such as psychological evaluations or other assessments of disability, education plans, and medical records.⁴ Agency staff works with individuals who are eligible for waiver services to complete a short support plan. This plan includes information on the potential client’s background and lists the support and services he or she may need.

Individuals who are eligible for Developmental Disabilities Home and Community-Based Services Waiver services are added to the waiting list maintained by the agency’s central office in Tallahassee. As slots for waiver services become available through attrition or increased funding, the agency contacts individuals who have been on the waiting list the longest period of time to offer them the first opportunity to enroll in the waiver. If these persons cannot be contacted or refuse services, the agency then contacts the individuals who are next on the list.

What are the characteristics of individuals on the waiting list?

Primary disability. As shown in Exhibit 3, the majority of the 17,476 clients on the waiting list have a primary disability of mental retardation (67.6%). Mental retardation refers to significant limitations in functioning in areas such as communication, self-care, work, and functional academics because of lower than average intelligence. Other primary disabilities of individuals on the waiting list include cerebral palsy (14.9%), which refers to a group of motor disabilities that can lead to significant motor

impairment, and autism (14.6%), which is a condition characterized by impairment in social interactions and communication abilities. Other individuals on the waiting list have primary disabilities of spina bifida and Prader Willi syndrome.

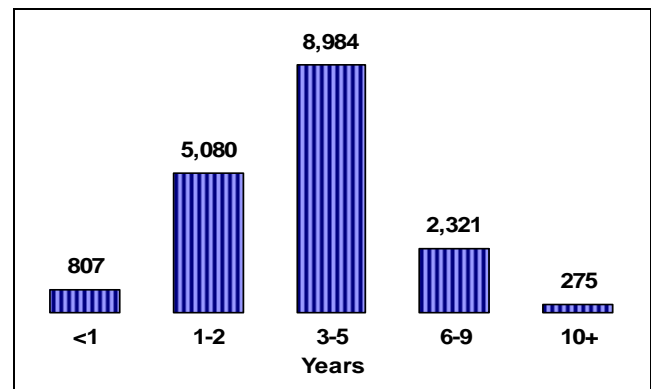
**Exhibit 3
Most Individuals on the Waiting List Have a Primary Diagnosis of Mental Retardation**

| Primary Disability | Number | Percentage |
|-----------------------|---------------|---------------|
| Mental Retardation | 11,810 | 67.6% |
| Cerebral Palsy | 2,603 | 14.9% |
| Autism | 2,555 | 14.6% |
| Spina Bifida | 391 | 2.2% |
| Prader Willi Syndrome | 60 | 0.3% |
| High Risk | 48 | 0.3% |
| Total | 17,467 | 100.0% |

Source: Agency for Persons with Disabilities.

Lengths of time individuals waiting for services. As shown in Exhibit 4, most individuals on the waiting list have been waiting for waiver services for 5 years or less (14,871, or 85.1%). Of those individuals who have been waiting for services 10 years or more, the agency reports that over 90% did not enroll when offered waiver services for various reasons, such as not needing services at that time. In addition, some individuals on the waiting list are residents of institutions and were determined to be unable to transition to community placement at the time they were offered waiver services.

**Exhibit 4
The Majority of Individuals Have Been Waiting for Waiver Services for Five Years or Less**

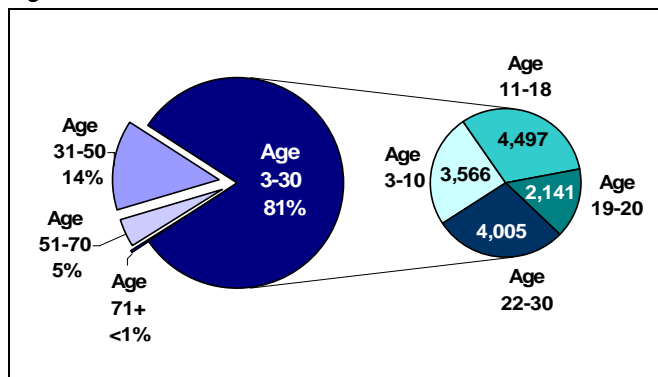


Source: Agency for Persons with Disabilities.

⁴ To be eligible for waiver services, individuals must meet both the criteria for developmental disability as defined in Ch. 393.063, F.S., and other criteria (an IQ of 59 or less an IQ 60-69 and a secondary handicapping condition, or a primary disability of autism, cerebral palsy, spina bifida, or Prader-Willi syndrome that results in substantial functional limitations).

Age. The ages of individuals on the waiting list range from 3 to 83 years. As shown in Exhibit 5, most individuals (14,209, or 81%) on the waiting list are age 30 and under.

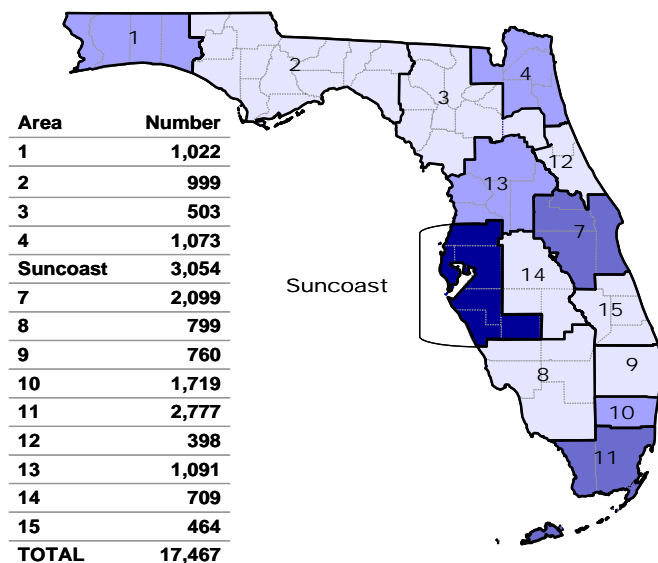
Exhibit 5
81% of the Individuals on the Waiting List Are Age 30 Years and Under



Source: Agency for Persons with Disabilities.

Location. As shown in Exhibit 6, most of the individuals on the waiting list are concentrated in area office regions that include the state’s major population centers. Thus, the Suncoast area office, which includes the Tampa Bay area, and area office 11, which includes Miami-Dade County, have the largest number of persons on the waiting list.

Exhibit 6
The Number of Individuals on the Waiting List by Area Office Corresponds to State Population Centers



Source: Agency for Persons with Disabilities.

Is the waiting list a valid indicator of individuals’ need for waiver services?

The waiting list is not a valid indicator of individuals’ need for services from the Developmental Disabilities Home and Community-Based Services Waiver. Many individuals on the list do not enroll when offered waiver services or are already receiving some services through the Family and Supported Living Waiver or other programs.

A recent agency analysis of 10,488 individuals who were sent letters offering them waiver services during the period from May 31, 2005, to April 12, 2006, determined that 3,002 individuals (28.6%) did not enroll in the waiver. Exhibit 7 shows that of these individuals, 22.3% specifically declined the offer, while 9% were determined to not meet Medicaid eligibility and 11.1% did not enroll for other reasons.⁵ As shown in Exhibit 7, over half of these clients (1,729 or 57.6%) did not respond to an agency letter offering waiver services.⁶ Agency staff report that very few of these letters were returned to the agency due to incorrect contact information, and that, in addition to sending letters, area staff attempted to contact these individuals by telephone.⁷

⁵ The agency does not assess individuals for Medicaid eligibility when it places these persons on the waiting list. The other reasons for not enrolling in services included moving out of state, dying, residing in a nursing home, assisted living facility, jail, or other institution, and problems with legal status and guardianship.

⁶ Proviso language in the Fiscal Year 2005-06 General Appropriations Act specified that clients must be in need of certain services in order to enroll in the Developmental Disabilities Home and Community-Based Services Waiver. These services include nursing services not available through the Medicaid state plan, residential waiver services in a licensed facility, or supported living services not available through the Family and Supported Living Waiver.

⁷ The agency contacted all individuals on the waiting list in 2005 to update contact information in preparation for offering waiver services.

**Exhibit 7
Many Individuals on the Waiting List Did Not Enroll After Being Offered Waiver Services**

| Client Reasons for Not Enrolling for Waiver Services | Number | Percentage |
|--|--------------|---------------|
| No response to letter offering waiver services | 1,729 | 57.6% |
| Declined services | 669 | 22.3% |
| Other (moved out of state, deceased, etc.) | 334 | 11.1% |
| Not Medicaid-eligible | 270 | 9.0% |
| Total | 3,002 | 100.0% |

Source: Agency for Persons with Disabilities.

Agency managers indicated that some individuals on the waiting list may have declined the waiver enrollment offer because they were already receiving services through other programs. (See Exhibit 8.) Individuals who do not accept an offer to enroll in the Developmental Disabilities Home and Community-Based Services Waiver can remain on the waiting list and maintain their ranking. They may decide to remain on the list because they do not currently need Developmental Disabilities Home and Community-Based Services Waiver services but believe they may need these services in the future. For example, an individual on the waiting list may be currently receiving services from a school district, but may need waiver services when they reach the age of 21 and are no longer served by the district. Similarly, a client currently served by the Family and Supported Living Waiver may want to stay on the waiting list for services under the Developmental Disabilities Home and Community-Based Services Waiver in case they need more extensive services in the future.

The agency could improve the usefulness of the waiting list by identifying the services already being received by individuals on the waiting list and whether these persons have previously declined offers of waiver services. This would provide the agency and the Legislature with more valid information on expected future service needs.

**Exhibit 8
Many of the 17,467 Individuals on the Waiting List Receive Services From Other Waivers and Government Programs^{1,2}**

| Source of Services Received by Individuals on the Waitlist | Number of Individuals |
|--|--------------------------|
| Agency for Persons with Disabilities Services | |
| Family and Supported Living Waiver | 5,798 |
| Individual and Family Supports | 1,240 |
| Room and Board | 19 |
| Developmental Services Institutions | 70 |
| Medicaid State Plan | 6,771³ |
| School districts | 6,569⁴ |

¹ Individuals may be receiving services from more than one source or through privately funded community providers.

² Data in the exhibit are from March-April 2006.

³ This number represents the number of individuals on the waiting list as of March 1, 2006, who had Medicaid service claims during Fiscal Year 2005-06.

⁴ This number represents all individuals on the waiting list ages 3-21 who received exceptional education services from a school district during the 2005-06 school year.

Source: Agency for Persons with Disabilities and Department of Education.

How could the waiting list be modified to provide more useful information for agency planning and budgeting purposes?

Two primary factors limit the Agency for Persons with Disabilities’ ability to use its waiting list for planning and budgeting purposes.

- Area office staff collects limited information on individuals on the waiting list. The short support plan that area office staff completes depicts an individual’s service requests, but does not necessarily include information on the intensity, frequency, duration, or medical necessity of these services. In addition, the waiting list database does not include information on whether persons are currently receiving services through other sources such as Medicaid or school district programs. This limited information makes it difficult for the agency to estimate an individual’s future service needs and associated costs.

- The agency does not have a statewide policy governing how frequently information on persons on the waiting list is to be updated. Consequently, this data can be out of date and no longer accurately reflect current conditions or potential service needs. Area offices vary substantially in how often they attempt to update client information. For example, one area office contacts families twice a year, while other offices only update information if the client contacts the office.

Some other states collect more complete information on persons on their waiver waiting lists, which enable them to develop support plans and budgets. For example, Georgia assesses individuals requesting waiver services and categorizes them based on their level of need. Based on this assessment, department staff place individuals on either a short- or long-term waiting list. The short-term waiting list is designed to identify individuals who will need services in the next six months. Most individuals on this list have recently lost a caregiver or their caregiver's health is declining. The long-term waiting list identifies individuals who will need services in the next two years, such as individuals who will be leaving the school system or will need care in the future due to the age of their caregiver. Georgia has used this data to develop a five-year plan for eliminating its waiting list. This plan projects annual enrollment and cost levels and the level of state funding needed to increase the number of individuals served each year. For the past two years, the Georgia Legislature has used this plan to fund services at the level needed to eliminate the waiting list.

Recommendations ---

To make its waiting list more useful for planning and budgeting purposes, the Agency for Persons with Disabilities should take the actions discussed below.

- The agency should obtain more current information on the location and status of individuals on its waiting list. To help keep this information current, the agency should add a feature to its website to enable individuals on the waiting list or their guardians to update contact information. It also should inform clients about the importance of updating contact information via the website in the letter it sends to individuals informing them of their placement on the waiting list. In addition, the agency should adopt a policy to contact individuals on the waiting list at the beginning of each fiscal year who are most likely to be offered services during the year to ensure that contact and support plan information are correct.
- The agency should maintain better information on the expected need for waiver services. To do so, the agency should regularly determine the number of individuals who have declined a previous offer of waiver services but remain on the waiting list and the number of individuals on the waiting list who are currently receiving services from other programs such as the Family and Supported Living Waiver and school district programs. Chapter 2006-15, *Laws of Florida*, requires the agency to report such information on a quarterly basis. In addition, the agency should determine the level of services received from these other sources and the estimated time when individuals may need services from the Developmental Disabilities Home and Community-Based Services Waiver.

- Once this information is available, the agency should develop a multi-year plan for addressing the state’s waiting list for waiver services. This plan should consider the length of time individuals have been on the waiting list, how soon the individuals are expected to need waiver services, the level of expected services to be provided, and whether the individuals are receiving services from other waivers or programs.

Agency Response ---

In accordance with the provisions of s. 11.51(5), *Florida Statutes*, a draft of our report was submitted to the director of the Agency for Persons with Disabilities for her review and response.

The director’s written response is reproduced in its entirety in Appendix A.

Appendix A



June 30, 2006

Jeb Bush,
Governor

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..
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Dear Mr. VanLandingham:

..
(850) 488-4257
Fax:
(850) 922-6456

Thank you for the opportunity to respond to the June 2006 OPPAGA report, "APD Waiting List Should Be Improved for Agency's Planning and Budgeting Purposes." We appreciate your team's thorough outline of the wait list, an often misunderstood tool. This may help partners, stakeholders and other interested parties better understand the complexities of the wait list and those waiting for services from the Agency.

At the time of your reporting, there were 17,467 individuals determined eligible and currently waiting for services. You noted that 5,798 of these individuals are served through the Family and Supported Living Waiver and remain on the wait list should their needs change. This translates to 11,669 persons with disabilities on the wait list and not currently receiving any waiver services. Further, your report is accurate in reflecting that many of those individuals are not in immediate need of services. As you point out, this is evidenced by the refusal of offer rate.

The administration of the wait list for waiver services is defined in administrative rule. This Agency has taken the position of erring on the side of individuals by only removing a person from the wait list if we receive a specific request in writing to do so. An individual may also be removed from the wait list if we receive notification that the person no longer resides in Florida or has died.

At the time the wait list was created, there was tremendous need in the state with no accurate reflection of the number of individuals requesting services through the developmental disabilities program. Enrollment efforts under the leadership of Governor Bush, and with the support of the Florida Legislature, have made significant strides in addressing the needs of many individuals that had been waiting years for services. During the last eight years, the number of persons with disabilities fully served through our Waiver programs has increased by 340 percent since the Governor took office, with more than 40,000 individuals anticipated to be enrolled in a Waiver

Mr. Gary R. VanLandingham
June 27, 2006
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program by the close of this fiscal year. Further, funding for persons with developmental disabilities has increased by nearly \$800 million, or 159 percent.

After undertaking such a significant enrollment effort in the 2005-2006 fiscal year, we now have a better sense of actual need. While since its creation the wait list has been widely considered an assessment of Floridians with developmental disabilities needing services, we now have data to indicate that it is far more complex.

Again, thank you for your review of this very important tool. With your insights, we can work with partners and stakeholders to better assess need. Some of your recommendations may require upgrades to systems or additional funding to implement. We will take your recommendations under consideration as we appropriately revise state rule, policies and procedures.

If further information concerning our response is needed, please call Chuck Faircloth, Inspector General or Karen Glymph, Director of Auditing, at (850) 488-4257.

Sincerely,

[original on file]

Shelly Brantley
Director

cc: Chuck Faircloth, Inspector General
Karen Glymph, Director of Auditing

The Florida Legislature

Office of Program Policy Analysis and Government Accountability



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