

Staff Briefing

# Planning for Needs of Aging Individuals with Developmental Disabilities

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Legislative Program Review  
& Investigations Committee

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# Introduction

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The Department of Developmental Services (DDS), formerly named the Department of Mental Retardation, is responsible for the comprehensive planning, development, and administration of complete, comprehensive, and integrated statewide services for persons with mental retardation, including the provision of service to persons with Prader-Willi Syndrome<sup>1</sup> and of coordination services to persons with autism. The department also operates the Birth-to-Three program that has a broader service definition.<sup>2</sup>

The department has a long history of providing services to individuals with intellectual disabilities. Up until the late 1980s, most services were provided at Mansfield and Southbury Training School (STS), two large-scale institutions. After a series of lawsuits, resulting in no new admissions being accepted at STS and the closure of Mansfield Training School in the early 1990s, there was a shift to delivering community-based services. Today, the department continues to serve individuals in congregate settings at STS and smaller regional campus settings but most individuals receive services and supports in the community from a network of public and private providers.

The vast majority of DDS services are funded through Medicaid waiver programs approved by the federal Centers for Medicare and Medicaid (CMS). The waivers allow Connecticut to offer a variety of non-medical and supportive services that are not provided through the state Medicaid plan and are critical in allowing persons at risk of institutionalization to remain in the community. Individuals become eligible waiver services if they meet income and asset limits established under the program.

As the single state Medicaid agency, the Department of Social Services (DSS), together with DDS, operates two Home and Community-Based Services Medicaid (HCBS) waivers. One, called the Individual and Family Support (IFS) waiver, provides services and supports for consumers who live in their own homes or their family homes. This waiver is for DDS consumers who do not require 24-hour supports. The other, called the Comprehensive waiver, is typically for people who live in residential settings, have significant needs, and require a comprehensive level of services and supports. The major difference between the two waivers is that the Comprehensive waiver provides for higher funding levels and allows clients to be served in higher cost residential settings. Although neither of the waivers pays for the room and board component if a client lives outside the family home, it does cover staffing and other supports needed by the client to live in a community setting.

A common misconception is that the services and supports provided by the department to individuals deemed eligible for DDS are an entitlement. In actuality, receipt of services is

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<sup>1</sup> A genetic disorder with physical and cognitive problems, including a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.

<sup>2</sup> Children under the age of three who live in Connecticut are eligible for the Birth to Three System when they either are experiencing a significant developmental delay, or have a diagnosed physical or mental condition with a high probability of resulting in a developmental delay. The program does not serve infants and toddlers who are at risk of delay due to environmental causes.

dependent on a number of factors, including system capacity, the amount of resources available, and whether an individual meets the income and asset limits to enroll in one of the HCBS waivers. As a result of these factors, wait lists have been maintained by DDS for many years, particularly for residential services, which includes those provided in the family home, or in another type of residential setting.

DDS began a five-year wait list initiative supported by the governor and General Assembly in 2004. The initiative is now in its final year. Although great strides have been made in reducing the wait list and prioritizing individuals who are offered services and support, future funding is unclear. As a result, it is difficult for the department to predict how many individuals it will be able to serve in the coming years.

### **PRI Study Focus**

In response to advocacy and provider concerns about how the department plans to meet the needs of the growing number of elderly clients that receive or will be seeking services from DDS, the Legislation Program Review and Investigations Committee voted to conduct a study in March 2008. The study, entitled *Planning for Needs of Aging Individuals with Developmental Disabilities*, focuses on DDS efforts to address and plan for the current and future service needs of the aging population with intellectual disabilities in Connecticut. It is important to clarify at the outset that intellectual disabilities are one of a number of developmental disabilities and the two terms are not synonymous. It should also be noted that the term “mental retardation” is accepted as a valid medical diagnosis and continues to exist in the DDS statutes and regulations. As such, the terms are used throughout this report.

*Study target populations.* The study concentrates on two populations: 1) individuals aged 45 or older who are or would be eligible for DDS services and 2) caregivers of DDS clients over the age of 65. The client group aged 45 or older was selected because the literature indicates intellectually disabled people can age prematurely and, therefore, are at risk of developing age-related health conditions at a much younger age than the general population. The designation of the caregiver population age 65 and older reflects the age factor considered by DDS in determining the wait list priority status given individuals living at home with elderly caregivers and seeking a residential placement. It is also the age criteria commonly used for other state elderly services.

It is important to recognize that the target population of this study is a part of the overall DDS client base. The DDS service delivery system is structured and designed for all DDS consumers and is not compartmentalized for the specific age demographic of this study. To understand how services are provided to the aging target population requires an understanding of the overall operations of the department. Therefore, much of the information provided in this report relates to the basic processes and methods the department uses for all its consumers. Whenever possible, committee staff reference statistics and information specific to the study’s target population.

## **Report Organization**

The primary purpose of this report is to describe to the committee the department's methods and processes currently in place to assess the needs and costs of services provided to the aging consumer base. As such, this report is divided into five sections. Section I gives an overview of pertinent population trends and a brief discussion of the effect of aging on intellectually disabled people. In particular, it provides information about the prevalence of intellectual disability within the general population and profiles the active DDS client base aged 45 and older as of June 2008.

Section II describes the framework and structure by which DDS operates and services are delivered. It also examines DDS expenditures, federal revenue receipt for services provided, and staffing information. Section III explains the processes and methods used by DDS to measure need and cost of services including eligibility determination, case management, resource allocation, and appeal processes. Section IV summarizes how DDS is currently planning for needs of the target population through the wait list initiative and other recent efforts. Finally, Section V outlines the issues that will be studied further by the committee staff.

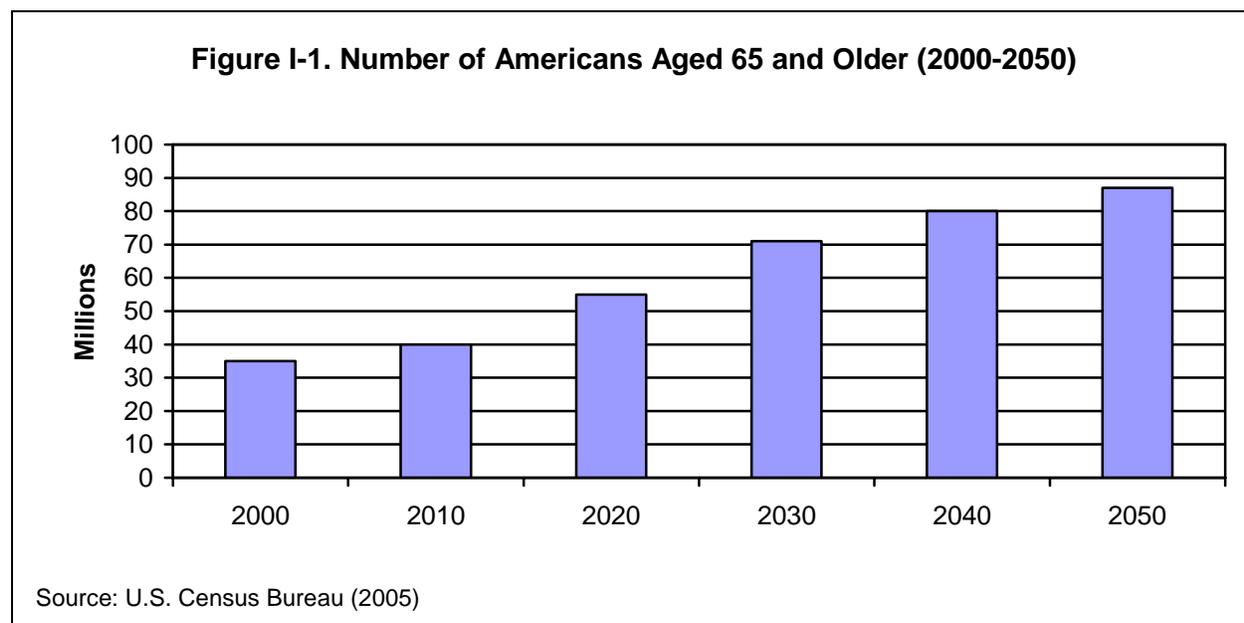
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## Overview

The purpose of the PRI study is to evaluate efforts by the Department of Developmental Services (DDS) to address and plan for the current and future service needs of the aging population with intellectual disabilities in Connecticut. This section describes the projected growth of the number of elderly people both nationally and in Connecticut, and discusses the prevalence of intellectual disability within the population. Finally, a profile of the PRI target population -- individuals who are age 45 years old and older and receiving services from DDS -- is also provided.

## Population Trends

According to national demographic statistics, America is aging rapidly. The growth in the number and proportion of older adults is due in part to the aging of the “baby boom” generation (those born between 1946 and 1964). The most significant growth is expected after 2011, when the first of the baby boomers begin to reach age 65. The U.S. Census Bureau projects the national number of persons aged 65 years and older will reach 40 million in 2010, and 87 million in 2050 (Figure I-1).



In Connecticut, the U.S. Census Bureau projects that between 2005 and 2025, the number of individuals age 65 years old and older will increase by 51 percent, compared to Connecticut’s total population increase of just 5 percent (Table I-1). Current census reports indicate that one million (or almost 30 percent) of Connecticut residents are now 50 years of age or older.

<b>Table I-1. Projections of Connecticut Population 65 and Over.</b>							
	<i>2005</i>	<i>2010</i>	<i>2015</i>	<i>2020</i>	<i>2025</i>	<i>Growth 2005- 2025</i>	<i>Percent Change 2005-2025</i>
<b>Total CT Population</b>	3,503,185	3,577,490	3,635,414	3,675,650	3,691,016	187,831	5%
<b>Population 65 and older</b>	479,443	515,621	577,083	642,541	723,326	243,883	51%
<b>Percent of Total Population 65+</b>	13.6	14.4	15.8	17.4	19.5	--	--

Source: U.S. Census Bureau Interim State Population Projections, 2005.

### **Prevalence of Intellectual Disability in the U.S. and Connecticut Population**

There are widely disparate estimates of the prevalence of intellectual disability in the U.S. population. Different studies report different rates depending on the definitions used, methods of diagnosis, and the particular population studied. Estimates can range from a low of 1 percent of the population to a high of almost 3 percent.

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) is the diagnostic standard for mental health professionals in the United States. The DSM-IV estimates the prevalence of mental retardation at 1 percent. This estimate is similar to that provided by other researchers and organizations, including the Connecticut Department of Developmental Services.

According to the state Department of Developmental Services, there are an estimated 33,500 individuals living in Connecticut who have mental retardation, although only about 15,000 individuals receive services from the department (not including those served by the Birth-to-Three program). State law defines mental retardation as an intellectual functioning level of 70 or below (as measured by standard tests for intelligence quotient) that is well below average (at least two standard deviations below the mean), significant limitations in daily living skills or adaptive functioning, and evidence that the condition existed prior to the age of 18 years old.

**Levels of mental retardation.** A diagnosis of mental retardation varies in severity. The DSM-IV lists different categories of mental disorders and the criteria for diagnosing them, according to the publishing organization, the American Psychiatric Association. According to the manual, there are four levels of mental retardation: mild, moderate, severe, and profound. Table I-2 provides a brief description of each level.

**Active DDS clients.** DDS data shown in Table I-3 indicate the total number of active clients served between 2004 and 2007 grew from 14,936 to 15,148, a 1.4 percent increase.<sup>3</sup> The number of clients 55 years and older increased 11.6 percent during this timeframe, and those who were age 65 or older increased 4.9 percent. The 55 and older group represents 17 percent of the DDS client population.

<b>Table I-2. Levels of Mental Retardation</b>	
<b>Mild</b> IQ between 50-55 to approximately 70	<ul style="list-style-type: none"> <li>- Requires minimal supervision</li> <li>- Often competitively employed (sometimes with supports)</li> <li>- Can live independently or in supported living</li> <li>- May require guidance and support for complex tasks or decisions</li> </ul>
<b>Moderate</b> IQ between 35-40 to 50- 55	<ul style="list-style-type: none"> <li>- Can perform most basic activities of daily living with minimal supports</li> <li>- Usually has good verbal communications skills</li> <li>- Can work with supports and guidance</li> <li>- Requires assistance for complex tasks or decisions</li> </ul>
<b>Severe</b> IQ between 20-25 to 35- 40	<ul style="list-style-type: none"> <li>- Requires assistance with most activities of daily living</li> <li>- Communicates with words, sometimes simple sentences, sometimes gestures</li> <li>- Usually requires supervised work setting</li> <li>- If not living at home usually lives in community training home or group home</li> <li>- Requires substantial support for complex tasks or decisions</li> </ul>
<b>Profound</b> IQ less than 20	<ul style="list-style-type: none"> <li>- Requires comprehensive care and assistance</li> <li>- Usually non-verbal or simple words to communicate</li> <li>- High incidence of secondary disabilities and special health needs</li> <li>- Requires day program with mixed work and activities</li> <li>- Requires substantial support for most tasks and decisions</li> </ul>

Source: DSM-IV and DDS

<b>Table I-3. DDS Population by Age (2004-2007)</b>						
<i>DDS Clients</i>	<i>2004</i>	<i>2005</i>	<i>2006</i>	<i>2007</i>	<i>Population Change</i>	<i>Percent Change</i>
<b>Total All Ages</b>	14,936	14,943	15,018	15,148	+212	1.4%
<b>Aged 0-19</b>	3,815	3,766	3,663	3,625	-190	-5.0%
<b>Aged 20-54</b>	7,859	7,826	7,928	7,945	+86	1.0%
<b>Aged 55+</b>	2,318	2,397	2,470	2,587	+269	11.6%
<b>Aged 65+</b>	944	954	957	991	+47	4.9%

Source: DDS Mortality Annual Report – FY 2007

<sup>3</sup> Active clients include any individual who is eligible for services from the department, even if they are on the wait list or planning list and only receiving case management services from DDS.

**Unknown or un-served population.** As noted previously, the 15,000 persons with intellectual disabilities served by DDS represent less than half of the state's estimated population of 33,500 with mental retardation. It appears a significant number of Connecticut residents with mental retardation are not receiving services from DDS because these individuals:

- have not been identified or diagnosed;
- have enough supports in the community already without seeking support from DDS; or
- are unaware of the services available.

It is also possible current estimates overstate the prevalence in Connecticut's population.

Un-served individuals and their families may be known to the department. In some cases, clients may have used and discontinued services or individuals may have applied and then refused to accept services.

There may be many reasons why individuals and families do not seek or accept services. Some professionals in the field find some families believe there is a stigma associated with intellectual disabilities or families fear or mistrust government and won't accept services. These beliefs may be due to generational and/or cultural differences. Some advocacy groups believe the DDS system will witness an influx of families with service needs as caregivers of individuals previously un-served or unknown to DDS begin to age. Conversely, others believe that the local school systems are better at identifying potential clients of the department, making it easier to anticipate the future needs of the younger population.

**Changes with age.** As with the general population, a combination of medical and scientific advances and improved access to health care has increased longevity of the intellectually disabled population. However, life expectancy for individuals with intellectual disabilities is still much lower at 66 years (58 years if diagnosed with Down Syndrome), compared to the general Connecticut population (75 years) and the U.S. population (78 years).<sup>4</sup>

Although great strides have been made in increasing the average life expectancy of people with intellectual disabilities, some factors like genetic disorders, certain neurological conditions, and more severe intellectual disabilities accelerate the aging process. For example, research indicates that Down Syndrome is known to result in premature aging, a heightened risk for Alzheimer's disease, and the co-occurrence of select organ dysfunctions.<sup>5</sup> Based on data from DDS, 63 percent of DDS consumers with Down Syndrome had Alzheimer's disease prior to their deaths. Thus, the onset of age-related health conditions, in conjunction with an intellectual disability, creates a complex health outlook and an indication of the scope of services that may be needed in the future.

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<sup>4</sup> Department of Developmental Services, Aging Focus Team, October 2003, p. 15, and Findings and Recommendations Department of Developmental Services, Mortality Annual Report, FY 2007, p. 5.

<sup>5</sup> *State of the Science in Aging with Developmental Disabilities* (2008), The Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, p. 4

## Demographic Profile of Current DDS Clients

Program review committee staff obtained a database from DDS containing demographic information on active DDS clients currently receiving services, and who meet the study definition of the target DDS population (aged 45 or older). The data presented in this section is based on 5,187 clients who were 45 years old or older as of June 12, 2008. (An additional 10,098 clients were also receiving DDS services on that date but were age 44 years old or younger, and therefore, not part of the study target population.) Overall, the data show for the target population:

- there are more males than females, with males representing 54 percent of the target population;
- 87 percent are White;
- the majority were diagnosed with a mild (37 percent) or moderate (28 percent) level of mental retardation;
- about 65 percent receive services under the Medicaid waiver programs which partially reimburses the state for community-based services delivered to clients that are at risk of institutionalization; and
- 2,125 individuals (41 percent) live in community living arrangements (i.e., group homes), while the next largest group (17 percent) live at home with family.

**Age of target DDS population.** Table I-4 shows a breakout by age categories of the target population (45 years old and older). The largest percentage of clients fall in the 45 to 55 years old age group; these percentages diminish fairly rapidly for the older age groups.

<i>Age Group</i>	<i>Number</i>	<i>Percent</i>
45 – 54 years old	2,570	50%
55 – 64 years old	1,614	31%
65 - 74 years old	657	13%
75 - 84 years old	275	5%
85 and older	71	1%
Total	5,187	100%

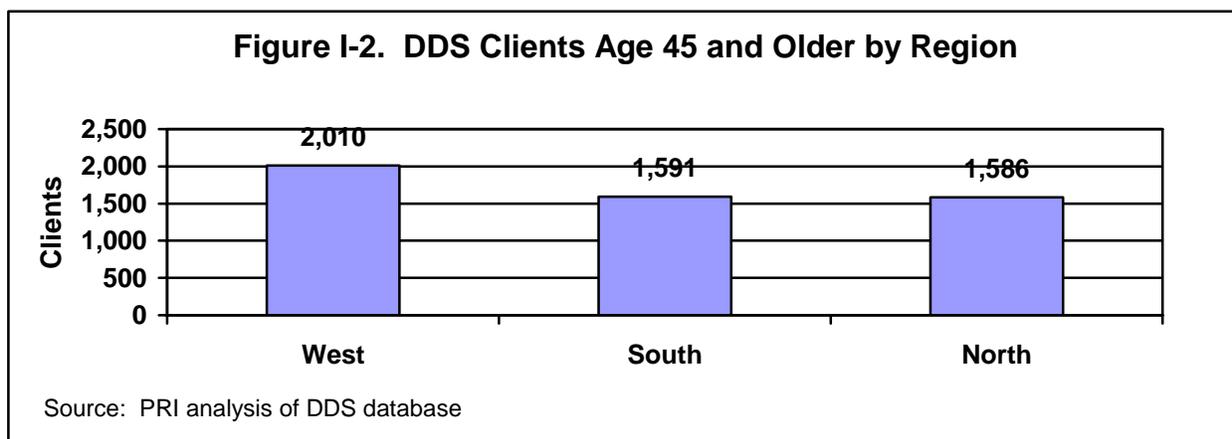
Source: PRI analysis of DDS database.

Individuals who were age 45 years old or older comprise about one-third of total department consumers (15,285 total clients on June 12, 2008), while clients who were age 65 or older make up only 7 percent.

Given that the average life expectancy for persons with intellectual disabilities has increased significantly since the 1970s, more medically fragile clients most likely will need higher levels of services and supports in the future. Thus, the 45 to 54 year old age group may already be experiencing age-related health conditions and illnesses, and therefore the level of services and supports needed is expected to increase as clients age. This has serious implications

for DDS, in terms of planning to address these growing needs, as well as whether enough system capacity exists to provide such services.

**Geographic location.** The department is organized into three regions – West, South, and North -- which serve a similar number of towns and individuals. The figure below shows the number of target population DDS clients residing in each region. The West Region has almost 30 percent more older DDS consumers than the other two regions. The reason for this is that Southbury Training School (STS), with about 500 residents, is located in this region and the average STS resident age is 59 years old. When the STS clients are subtracted from the West Region’s client count, the three regions have comparable numbers of clients.



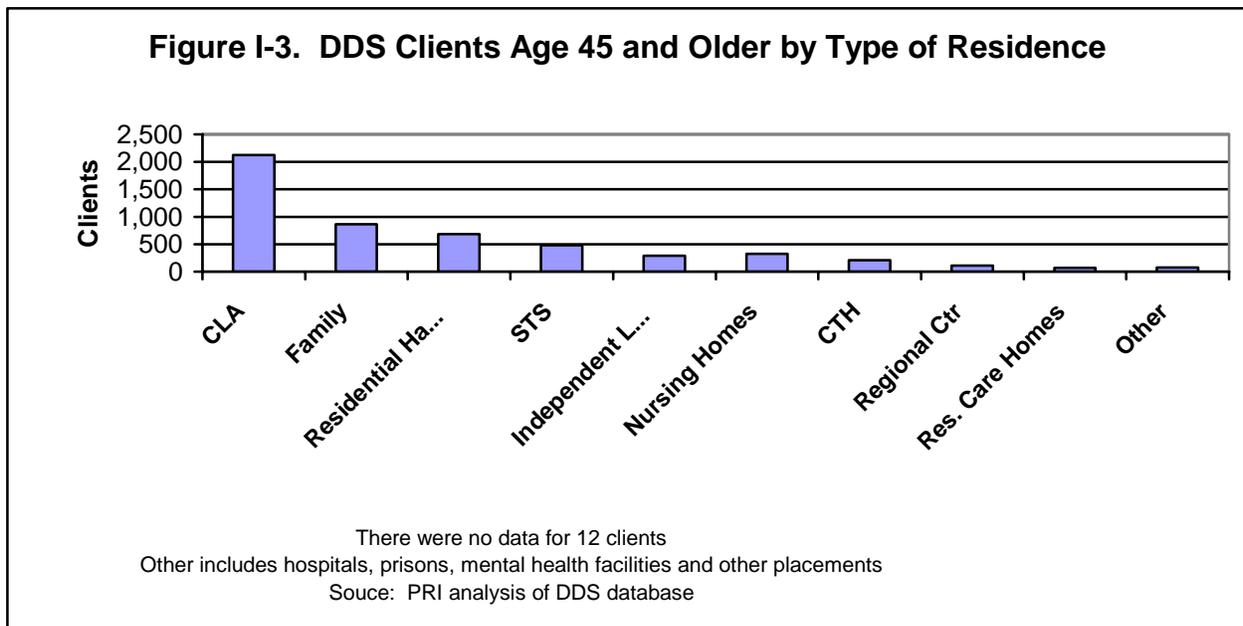
**Type of residence.** About 17 percent of DDS consumers age 45 and older live with their families. There are also a variety of other residential settings that DDS operates and/or funds. They include:

- *Community Living Arrangements (CLAs)* - operated by both DDS and private providers, and clients can either live in single family group homes or apartments with 24-hour staffing;
- *Residential Habilitation (formerly called Supported Living)* – persons live in their own apartments or with others and receive less than 24-hour staff services. Supports can range from a few hours a day to a few hours a month and include assistance with such things as managing a household budget, shopping, and taking prescription medication;
- *Southbury Training School* – individuals live in large congregate living residences in a campus setting;
- *Independent Living* – persons live independently needing no staff support to manage a household on their own. The types of residences range from apartments, condominiums and houses;

- *Community Training Homes (CTH)* – clients live with individuals or families, similar to foster care home arrangements provided under the Department of Children and Families; and
- *Regional Centers* – campus type settings located in each region.

DDS consumers can also reside in two other types of settings including residential care homes and long-term care facilities (i.e., nursing homes), both of which are licensed by the Department of Public Health.

Figure I-3 shows the number of DDS consumers meeting the PRI target population definition by the type of residence they live in. As noted above, the majority of older DDS consumers reside in a community living arrangement (i.e., group homes), with the next largest group living with their families. There were 322 DDS clients age 45 years or older living in a nursing home (6 percent), compared to about 27,000 total nursing home residents statewide. Therefore, DDS clients account for a very small percent of total nursing home residents in the state.



*Where older versus younger DDS clients reside.* Program review committee staff compared the type of residential setting that DDS clients who were 45 years old and older live, to clients who were under age 45 years. Table I-5 shows that while about 41 percent of DDS consumers age 45 years old and older live in CLAs, only 16 percent of younger (age 44 years or less) clients reside in this type of setting. The majority of younger clients (68 percent) live with their families compared to only 17 percent of clients age 45 or older. There are several reasons for this, including:

- a philosophy shift that seeks to keep clients at home with family by providing in-home services and supports;
- the services and supports needed by the younger population may be less intensive and therefore, easier to provide in family settings;
- parents of younger adults are more likely to still be alive, in good health, and thus, capable of providing care in the family home; and
- funding for residential placements is unavailable, so younger clients are more likely to be on the Wait or Planning List for such a placement.

<i>Residence Type</i>	<i>45 Years old and Older<sup>1</sup></i>		<i>Under Age 45<sup>2</sup></i>	
Community Living Arrangement	2,125	41%	1,587	16%
Family Home	864	17%	6,839	68%
Supported Living	682	13%	515	5%
Southbury Training School	479	9%	19	-
Independent Living	292	6%	442	4%
Nursing Home (SNF/ICF)	322	6%	28	-
Community Training Home	209	4%	190	2%
Regional Center	112	2%	152	2%
Residential Care Home	64	1%	5	-
Other	26	1%	294	3%
<b>Total</b>	<b>5,175</b>	<b>100%</b>	<b>10,071</b>	<b>100%</b>

<sup>1</sup> There were no data for 12 DDS consumers age 45 and older  
<sup>2</sup> There were no data for 27 DDS consumers age 44 and younger  
Source: PRI analysis of DDS database

**Older consumers living with family.** Program review committee staff examined the demographics of those clients who were age 45 or older and live at home with their families. Table I-6 shows the number of clients living with family by age group. Most individuals (93 percent) living in family homes were under 65 years old. This has important implications for DDS, given it is likely many of these clients will eventually need a residential placement, and therefore, become more costly to serve. By the time clients have reached the 65 to 74 year-old age group, 82 percent live in other non-family types of residential settings, and 97 percent of the 75 to 84 age group do so.

<i>Age Group</i>	<i>Number of Clients Living with Family Members</i>	<i>Percent</i>
45 – 54 years old	576	67
55 – 64 years old	225	26
65 – 74 years old	54	6
75 – 84 years old	8	1
85 and older	1	--
<b>Total</b>	<b>864</b>	<b>100%</b>

Source: PRI analysis of DDS database

*Level of mental retardation.* Program review committee staff also examined the diagnosed level of mental retardation for the 864 clients living with family. Almost half (410 clients) were diagnosed with mild retardation; 308 clients (36 percent) were diagnosed with moderate; 11 clients (1 percent) with profound and 89 clients, slightly more than 10 percent of the total number living with family, with severe retardation.

*Primary responsible person.* Data were available identifying the primary responsible person for 407 clients that live at home with family, and were not available for 457 clients because it had not been entered into the DDS database by case managers. For those with data, mothers are listed as the primary responsible person for 319 clients and fathers are listed for 88 clients.

*Day programs.* Of the 864 clients living at home with family, 842 had information about whether or not they were involved in a day program. The largest numbers (230) were involved in group-supported employment, followed by 167 clients enrolled in day service options, which include activities like leisure activities and recreational programs. Most of those employed were in either the 45 to 54 age group or the 55 to 64 age group. There were 61 individuals age 45 and older that did not have a day program, either because they only receive case management services from DDS, refused to participate in a program, or were transitioning from one program to another.

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### Department Organization and Resources

Originally established in 1950 as a division within the Department of Health, the department became an independent state agency in 1975. This section provides information on the organizational structure in place to carry out the department's mission. It also discusses the financial and staffing resources allocated to the department over time, and identifies federal Medicaid revenue received for services delivered to DDS clients overall.

The state has a long history of providing services to individuals with intellectual disabilities. Mansfield Training School provided services to individuals as early as 1917 and Southbury Training School was opened in the 1940s. Although DDS continues to operate STS, since the 1980s, there has been a major shift to provide community-based services and supports.

As discussed in the previous section, the DDS statewide system provides an array of supports and services to persons with intellectual disabilities who live in a range of residential settings. Services and supports are provided by the department either directly or through a network of private providers. Depending on the needs of the individual and the availability of funding, services and supports can include: case management; respite care; early intervention; family grants; family support services; in-home supports; residential services; employment services; and adult day programs. However, not everyone who is eligible for services actually receives them, because services are not considered an entitlement. For example, individuals who live with family and are seeking a residential placement are often placed on a Wait or a Planning list, and priority on the list depends on a number of factors (not just first come, first served).

### DDS Mission and Organizational Structure

The department's mission, adopted in 1986, is "to join with others to create the conditions under which all the people we serve experience:

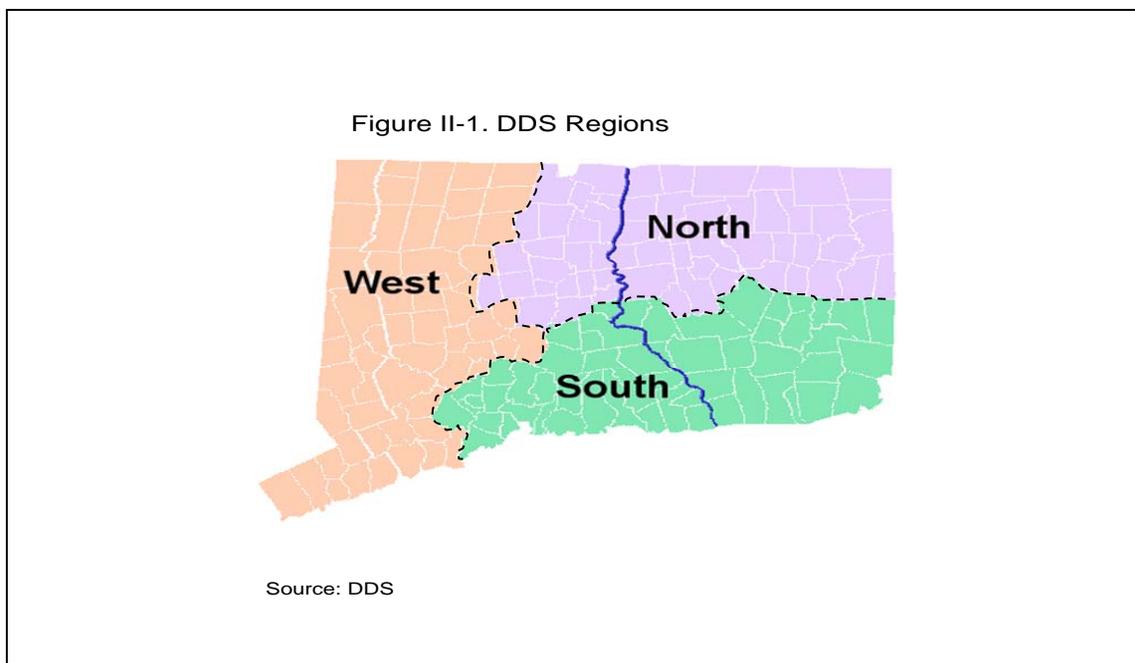
- Presence and participation in Connecticut town life
- Opportunities to develop and exercise competence
- Opportunities to make choices in the pursuit of a personal future
- Good relationships with family members and friends
- Respect and dignity."

**Central office.** The department operates with a central office located in Hartford and three regions, which include several regional campuses, and Southbury Training School. The primary responsibilities of the central office revolve around financial and oversight functions, while services for clients are handled through the three regional offices or at Southbury Training School.

A statutorily mandated Council on Developmental Services advises the commissioner on the planning and development of services for people with intellectual disabilities. The 13-member council also makes recommendations to the governor and the General Assembly on legislation to improve services. The commissioner of DDS serves as a non-voting ex-officio member and attends the monthly meetings.

Attached to the department, for administrative purposes only, is the DDS Ombudsman's Office. The Ombudsman works on behalf of consumers and their families to address complaints or problems regarding access to services or equity in treatment. To assist consumers and their families, the Ombudsperson's Office may provide information to help them solve particular problems. The Ombudsperson also provides families with policies and procedures related to how to appeal specific decisions made at the regional level.

**Regional offices.** Figure II-1 shows the location of the three regional offices. Each region has a main office and three satellite offices. Services are delivered at the regional level by both public and private providers. Regional directors also oversee the eight regional campuses, which provide day services and some provide residential services.



*Structure of regional offices.* The three regional offices share the same type of organizational structure and are each managed by a regional director. Each region has three assistant regional directors who oversee client services, with case management structured according to whether a client is receiving:

- *Public Services* – the clients live in DDS public group homes and receive services from state employees;

- *Private Administration* – clients live in private group homes and receive services from private providers; and
- *Individual Family Support* – clients live alone or with their family and receive services from private providers, or clients “self direct” and purchase their own support while case managers provide service coordination.

Each region also has a Human Resource Division and a Quality Improvement Division, headed by directors. There is also a director for the Self Determination Division, responsible for overseeing self-advocacy coordinators for clients who direct and purchase their own services.

*Regional councils.* Each region has a Regional Advisory and Planning Council. The councils are responsible for consulting with and advising the regional director on the needs of persons with mental retardation within the region. The councils also provide education and advocacy, and promote communication between advisory groups, individuals, family members, local citizens, and organizations.

### **Southbury Training School**

Southbury Training School opened in the 1940s as a home for individuals with mental retardation. Today, almost 500 individuals reside at STS, and 60 percent of the residents have lived here for the past thirty years. The school is geographically located in the West Region, but is headed by a separate director.

The school is located on over 1,600 acres and is comprised of 125 buildings. The school independently operates its own power, heat, sewage treatment and water plants, and has a separate fire and ambulance departments and an on-site Connecticut State Police Resident Trooper.

### **Budget Resources and Staffing**

**Overview.** As of June 2008, the Department of Developmental Services provided services to about 15,200 clients (excluding those in the Birth-to-Three program) and had almost 3,600 permanent full-time and 1,120 part-time staff positions. The department’s expenditures for FY 08 are estimated at almost \$940 million of which \$342.7 million has been reimbursed to date under the federal Medicaid program for certain services provided to DDS clients.

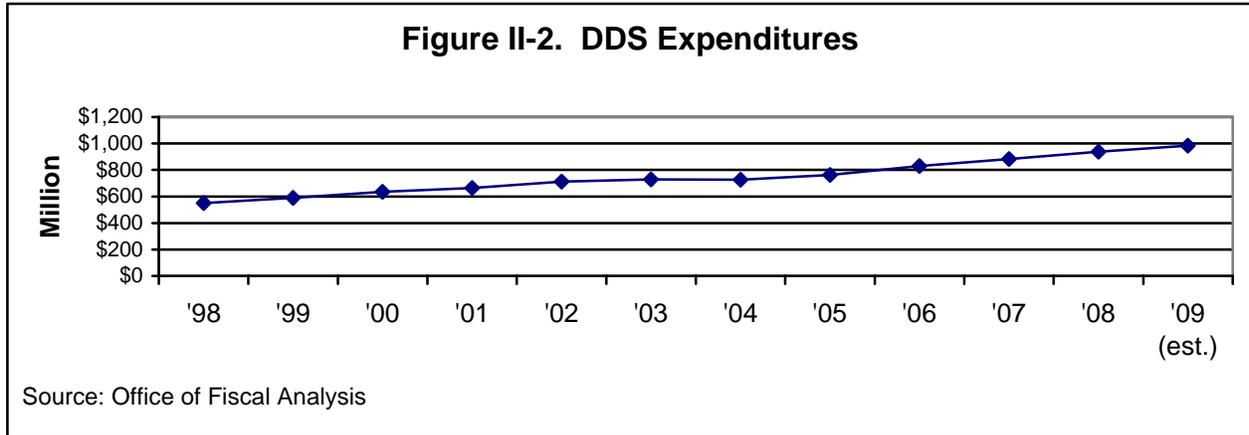
For the current fiscal year, the department’s FY 09 budget reflects the biennial budget passed for FY 08 and FY 09 in June 2007. Although the mid-term budget proposed during the 2008 legislative session included a 1 percent cost-of-living increase (COLA) for private providers and funding for six new case managers, it was not adopted.

The program review committee staff examined DDS expenditure trends, the amount of federal revenue received under the Medicaid program, and staffing trends. It is important to note, that for budgetary purposes, DDS expenditures are allocated by account number (i.e.,

personnel, equipment, employment opportunities and day services, etc.), rather than based on the ages of clients being served.

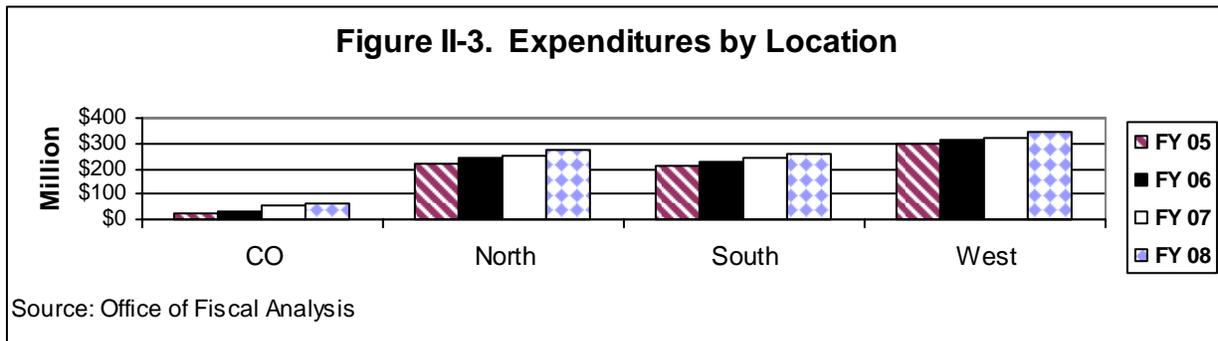
## Expenditures and Revenue

**Total expenditures.** Figure II-2 shows DDS expenditures grew from \$549.5 million in FY 98 to estimated expenditures of \$983.2 million in FY 09, an increase of 79 percent. The department’s expenditures actually decreased between FY 03 and FY 04 by about \$1 million, primarily because of personnel reductions as a result of layoffs and early retirements.

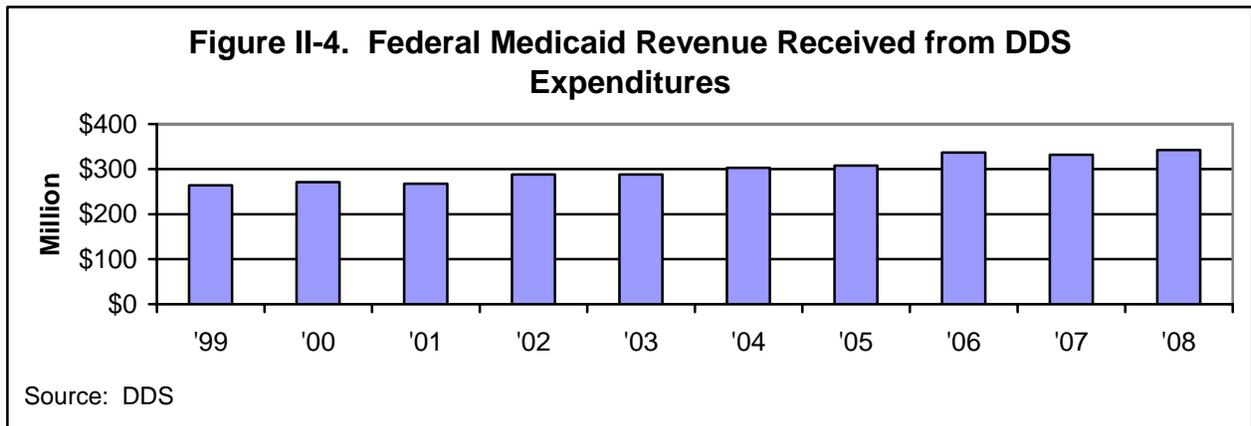


**Expenditures by geographic location.** DDS expenditures are examined by geographic location in Figure II-3, which shows the amount expended by the central office and in each of the three DDS regions. Expenditures for Southbury Training School are included as part of the West Region’s expenditures, which accounts for that region having the largest expenditures of the three.

The figure shows, over the four years examined, central office expenditures increased the most (174 percent), on a percentage basis, while the West region’s increased the least at 16 percent. Although about 40 percent of the increase in the central office can be attributed to increases in personnel services, the reason for the largest percentage increase (240 percent) is, according to DDS, because of technical changes in how the Birth-to-Three program was accounted for – with those expenditures being transferred from the regions to the central office.



Many services provided to DDS clients receive federal reimbursement if they are services identified in the state’s Medicaid State Plan or provided under Medicaid waiver programs, which are approved by the Centers for Medicare and Medicaid Services under the U.S. Department of Health and Human Services. Connecticut receives 50 percent federal reimbursement. Depending on the type of service provided, federal reimbursement is either credited to expenditures paid for by the Department of Social Services (such as medical services provided under the state Medicaid Plan) or those paid for by DDS. Figure II-4 shows the amount of federal revenue received for services provided to DDS clients since FY 99, which has increased by almost \$140 million over the nine-year period examined.



Although the Department of Social Services pays for the bulk of traditional (non-waiver) Medicaid services provided to DDS clients if they are Medicaid recipients, it is accounted for in the DDS budget in four specific areas: care provided to clients in intermediate care facilities for people with mental retardation (ICFs/MR), services received under the Medicaid Individual Family Support and Comprehensive waivers, provision of targeted case management, and services under the Birth-to-Three program.<sup>6</sup>

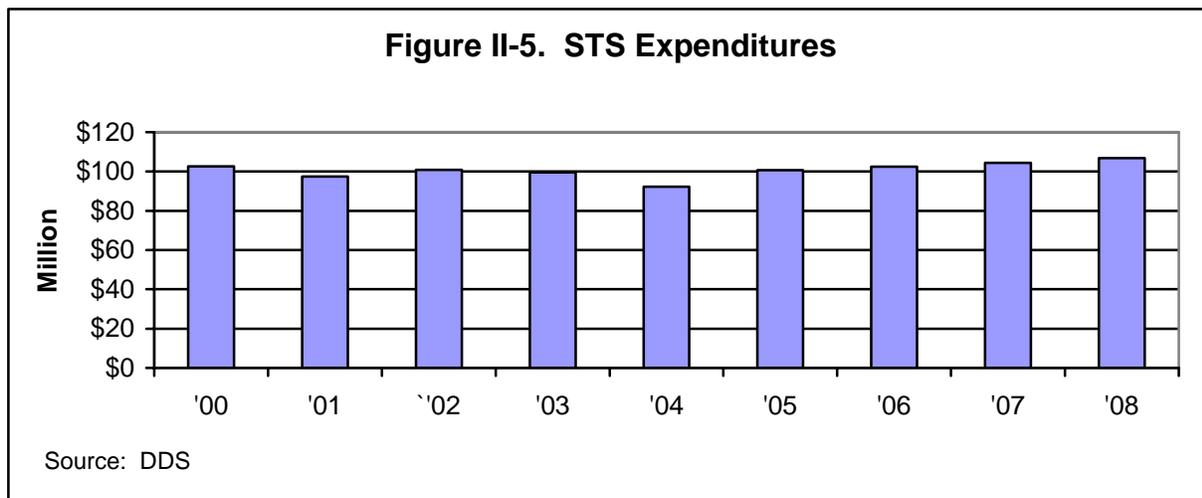
Most of the federal Medicaid revenue received is for services provided by DDS under the IFS or Comprehensive Waivers, accounting for 68 percent of total federal revenue in FY 07, compared to 27 percent for ICFs/MR in FY 07. Revenue for the other two areas - targeted case management and the Birth-to-Three program -- accounted for less than 4 percent each of federal revenue in FY 07.

**Expenditures for Southbury Training School.** Figure II-5 shows expenditures for Southbury Training School since FY 00. Although the number of DDS consumers at STS has declined from 683 in June 2000 to about 500 in June 08, expenditures have fluctuated only slightly from year-to-year.

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<sup>6</sup> Intermediate care facilities for people with mental retardation (ICF/MR) services are an optional Medicaid benefit. It allows states to receive federal matching funds for institutional services. Section 1905(d) of the Social Security Act created this benefit to fund “institutions” (four or more beds) for people with mental retardation and specifies that “active treatment” must be provided.

Since all of the beds at STS are licensed as ICFs/MR, the state receives 50 percent federal reimbursement under the Medicaid program. The vast majority of expenditures are for personnel services. It is important to note that the average age of STS residents is 59 years making it likely that higher staffing is needed because the residents are experiencing more age-related health and medical conditions.



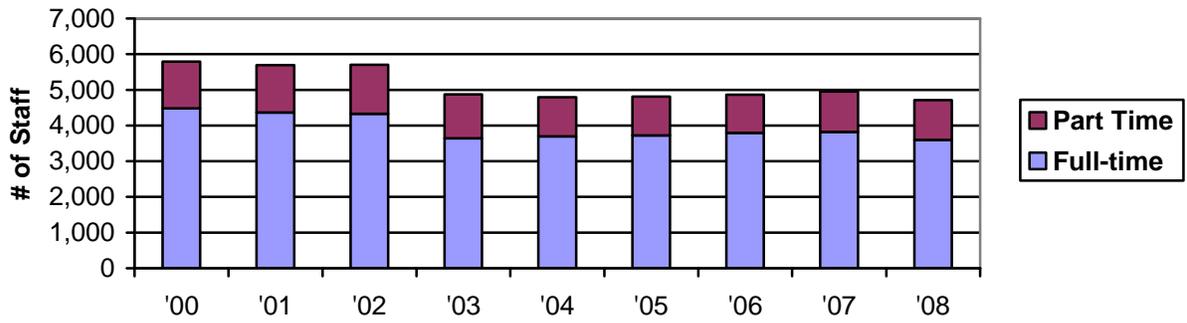
### DDS Staff Resources

**Total DDS staff.** As of June 30, 2008, the department had almost 3,600 permanent full-time filled positions and 1,120 part-time filled positions – the lowest number of staff in the nine years examined. Figure II-6 shows full-time staff has decreased about 20 percent since FY 00.

In 2007, DDS examined its internal workforce employment patterns with regard to individuals eligible for retirement in the near and distant future, with the assistance of the Department of Administrative Services. It found that almost 58 percent of its management workforce was over aged 50, while over 71 percent of its senior managers were over 50 years old. The analysis indicated that almost 44 percent of DDS managers could retire within two years, raising potential issues for continuity of operations.

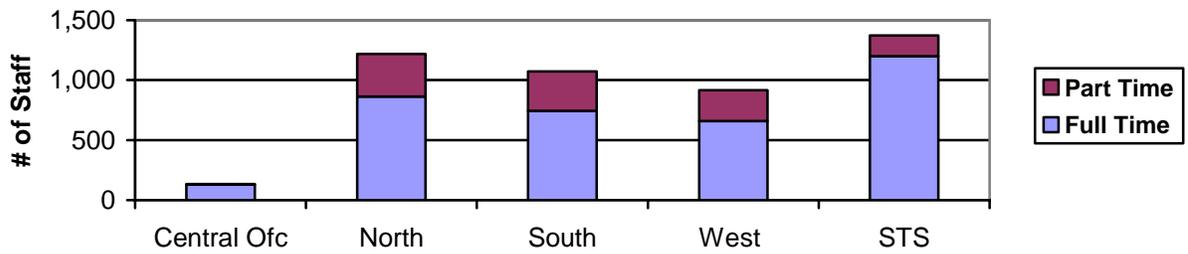
**Staff by geographic location.** Figure II-7 shows the number of general fund filled positions by location. Southbury Training School had the most staff with 1,199 full-time filled positions compared to the North Region, which had 862 full-time staff. It is not surprising that Southbury has the greatest number of filled positions, since it provides direct care to residents. In addition, STS is located on extensive grounds and operates its own fire department, and physical plant.

**Figure II-6. GF Filled Positions (as of June 30th each fiscal year).**



Source: Office of Fiscal Analysis

**Figure II-7. GF Filled Positions by Location as of June 30 2008.**



Source: OFA

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### DDS Eligibility, Case Management & Sources of Funding

This section provides a general overview of the processes and methods used by DDS to measure consumer need and cost of services. These include: the process used to determine who is eligible for DDS services; the individual level of need prepared through case management; the resource allocation decisions made by the regional teams; and exceptions and reconsideration decisions made through the utilization review and appeals processes. In addition, the section identifies the sources of funding that are used to provide services to clients.

#### DDS Eligibility

In order to be eligible for supports or services from the Department of Developmental Services, an individual must: be a Connecticut resident, and have a diagnosis of mental retardation as defined in C.G.S. 1-1g (see below) or present a medical diagnosis of Prader-Willi Syndrome.

**Statutory definition.** Connecticut General Statutes § 1-1g defines mental retardation as “significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.” State law requires that three basic criteria be present before an individual can be determined eligible for DDS services:

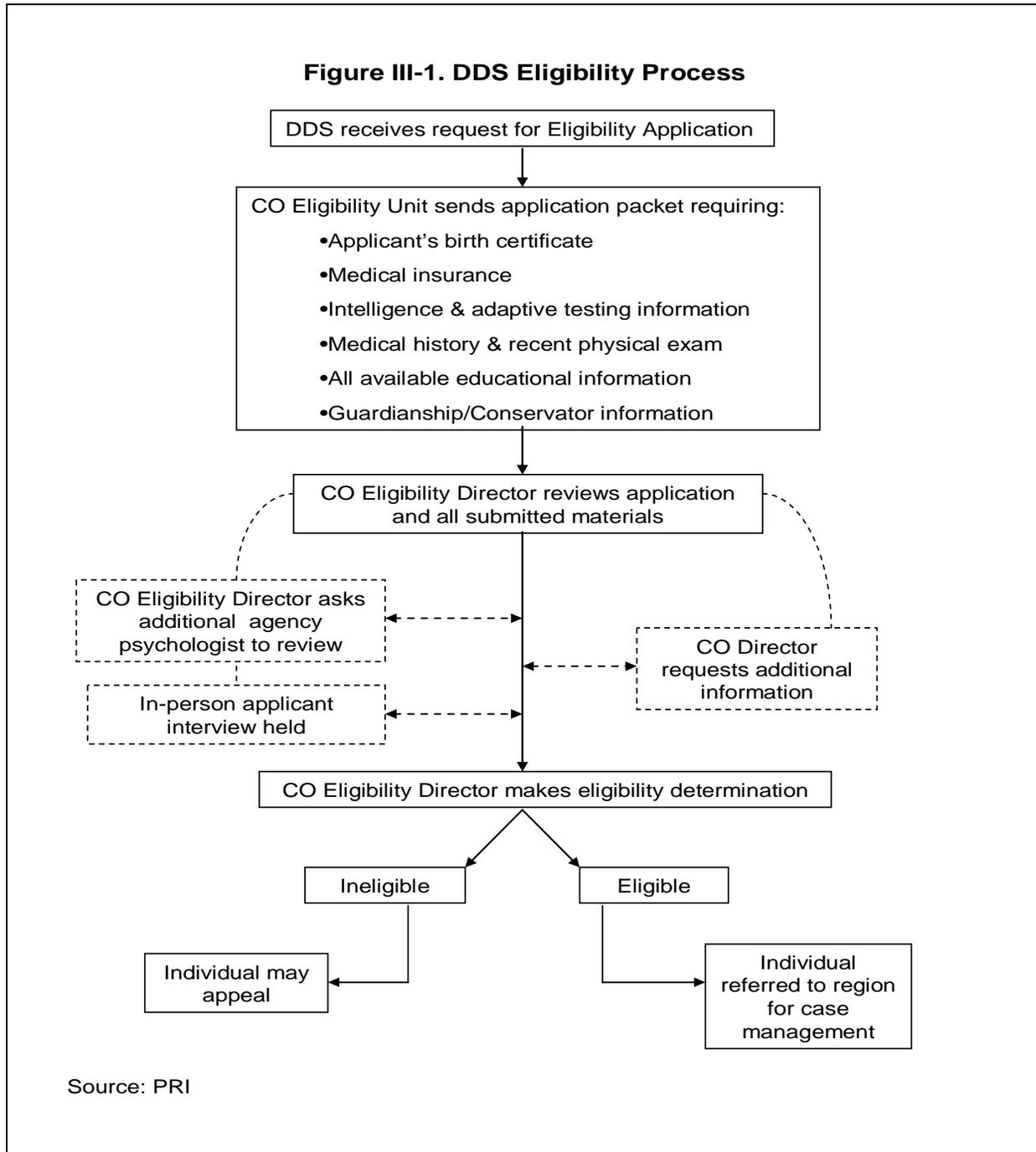
- formal intelligence test results that indicate performance at least two standard deviations below the mean – typically meaning a score of 69 or below;
- evidence of deficits in adaptive behavior through tests measuring any special assistance needed in communications or activities of daily living such as dressing and grooming, and in social activities and relationships; and
- documentation that both of these were manifested before the age of 18.

**Eligibility process.** The Eligibility Unit within the DDS central office is the single point of entry for all individuals seeking eligibility for services. This approach is meant to streamline the application process and assure statewide consistency in reviewing and determining eligibility. Figure III-1 outlines the basic eligibility process.

An individual may seek eligibility for DDS services at any age. The application for eligibility determination may be submitted by the individual seeking services or by someone on the person's behalf. Upon request, an eligibility packet is mailed that requires basic information be completed and certain documentation submitted including:

- a written formal request for DDS services;
- birth certificate for the individual seeking services;

- the applicant’s medical insurance cards including private insurance, Medicaid, and/or Medicare;
- psychological testing - both intelligence (IQ) and adaptive testing which can usually be obtained from schools, other agencies or private psychologists;
- medical history and the most recent physical examination report;
- all available educational information; and
- Guardianship or Conservator forms from the probate court, if applicable.



Applications are available in Spanish and interpreters and assistance is provided if an applicant consents to release of his or her information allowing DDS staff to discuss the application with others. However, all records submitted are kept confidential. The eligibility director, a licensed psychologist within the DDS central office, reviews all eligibility applications and documentation. If necessary, the director will request additional information. Eligibility determinations are usually made by the unit's director within a few days. According to DDS, approximately 85 percent of applications are deemed eligible upon a file review. About 15 percent are reviewed by a second or even third agency psychologist. Rarely, but on occasion there is an in-person interview/assessment.

If an individual is found ineligible, the reasons for this decision are provided in a notification letter. Individuals found ineligible may request a hearing within 60 days of receiving the notification. (The appeals process is described later in this section.)

If an individual is determined eligible, a case manager from the DDS region where the applicant resides is assigned to help access services and supports. However, an eligibility determination does not guarantee that requests for services will be met right away. DDS services are provided on a priority basis and within available appropriations. In order to receive most DDS services, an individual must be eligible for one of the agency's Medicaid Home and Community Based Services waivers. The policy and procedures related to waiver services are described in further detail below.

**Eligibility statistics.** The number of requests for eligibility applications has been just over 1,100 for the last few years with a slight increase in 2007 and 2008. From June 2007 to June 2008, the department received about 1,600 requests for eligibility applications. According to the department, much fewer applications are submitted than requested for a variety of reasons. Sometimes families will request applications multiple times or delay for extended periods of time before deciding to actually submit one. DDS staff believes this may be due to concerns over the perception of stigma of applying for state services or needing disability supports. At times, eligibility files may become inactive after being determined eligible. However, the regional staff can reactivate eligibility status if needed.

Table III-1 provides a breakdown by age of the persons deemed eligible for DDS services. As the table shows, the total number of persons found to be DDS eligible annually has slightly increased in the last five years with the exception of a modest decline in 2005. The vast majority of individuals determined eligible are under age 45 (96 percent in 2008) with less than two percent being 55 or older.

<b>Table III-1. Number of Persons DDS Eligible (as of YTD June)</b>					
<b>Age</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>
Under 45	522	436	530	549	510
45-54	14	16	12	15	14
55 and older	8	7	4	12	10
Total	544	459	546	576	534
Source: DDS Management Information Reports					

## DDS Case Management

As noted previously, eligibility for DDS services does not guarantee that any service requested can be met immediately or at all. Department services are provided on a priority basis and within available appropriations. Once an eligibility determination is made by the Eligibility Unit within the DDS Central Office, the client is referred to case management in the DDS region where the client resides.

The case manager is the primary contact for DDS services and assists clients to identify needs through the level of need assessment and planning process, prepares requests for supports and services to address those needs, and monitors progress and evaluates the quality of supports and services. Figure III-2 outlines the general case management process.

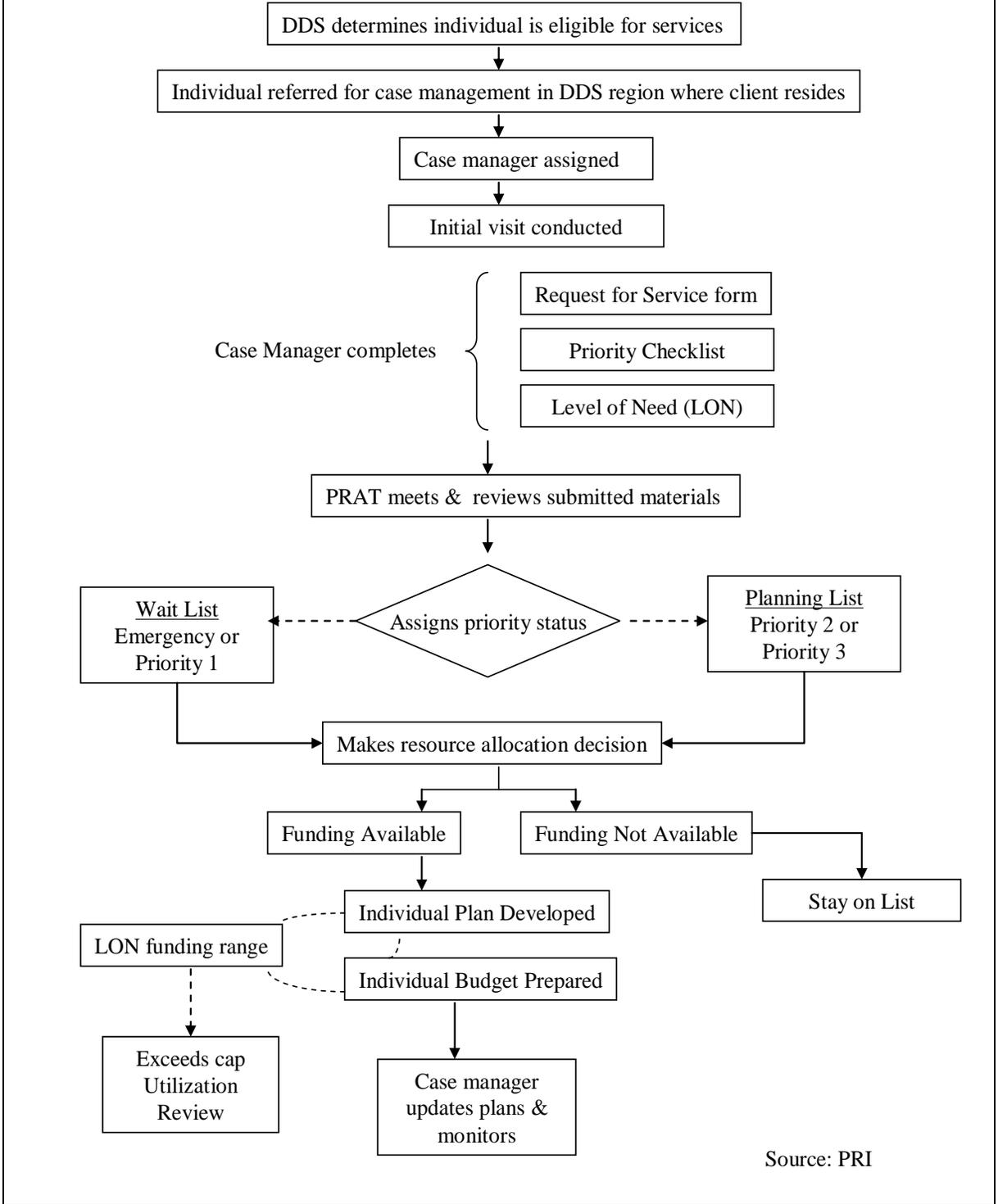
**Case manager assignment and initial meeting.** New clients are typically notified of their case manager assignment within two weeks of being determined eligible for DDS services. According to the department, case management resources may not always be immediately available except for those clients already receiving Medicaid benefits. Case management services for non-Medicaid clients are subject to caseload demands. However, each region has an intake liaison who is accessible to unassigned clients if they require immediate assistance. Case managers are assigned to clients in the order in which they became eligible for DDS supports and services. As of September 10, 2008, 86 eligible individuals statewide did not have case manager assignments. All were under the age of 44 with the majority being 18 or younger.

After the assignment is made, the case manager schedules an initial meeting with the client and/or family or guardian. At the initial meeting, the case manager provides information about DDS supports and services, DDS privacy practices, and family member's rights. The case manager gathers information for a brief history of past and current services, if any, and about the type of services currently being sought from the department. The case manager is then responsible for completing a Level of Need (LON) assessment tool.

**Level of need (LON) assessment.** Each person expected to receive DDS-funded services must have a level of need assessment. The case manager uses a standardized assessment and screening tool to determine each client's level of need for supports and services. The LON tool examines a number of areas including: health and medical; personal care activities; daily living activities; behavioral and mental health; safety; support for waking hours; overnight support; comprehension and understanding; communication; transportation; social life, recreation, and community activities; and unpaid caregiver support. The LON is a web-based data application that produces a composite LON score based on the various assessment areas. The LON assessment is updated annually or upon a change in the client's life or situation.

The LON is a new assessment tool that was implemented in 2006 in order to better link a client's health and safety needs to the services and supports that will be required. A client's LON results assists in the allocation of resources by corresponding funding limits to level of need ranges: Comprehensive, Moderate, Minimum. (The level of need funding ranges are explained in more detail below.)

**Figure III-2. Case Management Process**



Source: PRI

**Priority checklist.** In addition to the LON assessment, the case manager must complete a priority checklist that determines how soon residential services must be addressed. The priority system is the result of a settlement agreement of a federal lawsuit against DDS. There are four categories of priority status – Emergency, Priority 1, Priority 2, and Priority 3. A client’s priority status is determined by a group of regional staff, known as the planning and resource allocation team (PRAT), who review the priority checklist. The priority checklist indicates that an individual’s needs are deemed an emergency if:

- The individual may have frequent and severe self-injurious behavior that requires intervention and cannot be managed.
- The individual’s behavior may place others at imminent risk of significant harm, either intentional or unintentional.
- The individual is homeless or in a temporary setting (i.e., hospital) and he or she cannot return home.
- The caregiver or individual is so physically or mentally ill that the individual cannot remain at home without DDS support.
- The home environment is unstable and/or deteriorating to the point where the person or family is at significant risk.

Persons coded as Emergency or Priority 1 (those requiring services or support within a year) are considered first when allocating resources. The needs of individuals with Priority 2 or 3 codes are not considered urgent or critical because residential services are not required for two or more years. The priority status is re-evaluated each year or upon request as a client’s needs/situation changes. Individuals may appeal their priority status through a formal hearing process.

**Individual plans.** Each individual eligible to receive DDS services must have a plan guiding the services and supports to be provided.<sup>7</sup> The plan must reflect the individual’s current situation and include specific action steps and timeframes to meet desired identified outcomes. The plan must note how to monitor progress and how to evaluate whether the provided supports are helping the individual reach his or her outcomes. It also indicates the frequency of case manager contact that is required based on the individual’s residential setting. At a minimum, case managers are required to have quarterly contact and at least one annual face-to-face contact with each client. The case manager is responsible for monitoring plan implementation and progress as well as updating it at least annually or upon a change in the individual’s life or situation that prompts a new needs assessment.

**Request for service and supports.** Each region has a planning and resource allocation team (PRAT) that makes all key decisions regarding DDS client services including requests for residential and day supports, the designation of priority status, the allocation of regional resources, and HCBS waiver eligibility. The members on each regional PRAT team may vary

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<sup>7</sup> All clients receiving HCBS waiver services or receiving DDS funded in-home supports as well as all children in Voluntary Services must have an Individual Plan. Individuals who reside in private ICFs-MR or live at home with families or in their home without DSS funded supports have an Individual Plan Short Form that is less detailed.

depending on the type of request or nature of the agenda. PRAT teams meet on a regular schedule and on-need basis for emergencies.

For any request for service, the case manager must submit to the PRAT team:

- request for services form;
- level of need (LON) assessment;
- priority checklist; and
- the individual's current plan.

The PRAT team may request additional information or the participation of other individuals to assist with their decision making. The PRAT team considers the priority checklist in relation to any reports or assessments submitted with the request for services. The team then assigns the client a priority status that determines whether the individual is assigned to the wait list (Emergency or Priority 1) or the planning list (Priority 2 or 3).

The PRAT team examines available resources and matches them to individuals on the wait list. As noted earlier, emergencies are considered first, followed by those with a Priority 1 status. Individuals who refuse repeated offers of appropriate resources or resources that can substantially meet the person's need may result in a downgrade of priority status. According to DDS, this rarely occurs.

**Individual budget.** The PRAT team informs the case manager when a request for service and related resource allocation decision is made for either residential or day supports reflecting the client's level of need. Based on the PRAT team decision, the case manager refines the individual plan and develops an individual budget, which must be approved by the region. The individual budget outlines the type, cost, and frequency of support to be provided to the client. Specifically, the individual budget shows any funds for the current budget period that DDS has authorized through the PRAT process including one-time funds or annualized funds. All DDS clients are required to apply for Medicaid and enroll in one of the department's Home and Community Based Services (HCBS) waivers if they are eligible. The majority of services offered by DDS are part of the department's federal Medicaid HCBS waiver. The state receives reimbursement from the federal government for half of the service cost.

**Utilization resource review (UR).** Each DDS region has a utilization resource review committee made up of the region's three assistant directors, the regional PRAT manager, and the directors of clinical services, health services, and quality improvement. If an individual consumer's health and safety needs exceed the LON approved funding range, a request for additional services and support may be submitted for regional utilization resource review. The committee reviews all requests for intensive staffing in DDS funded, operated, or licensed services and monitors intensive staffing situations that are medically required.

If the consumer's need for intensive staffing support is for behavioral reasons and is expected to continue for more than six months, the request must be presented to a statewide utilization resource review committee. The statewide committee is made up of various DDS staff representing health, clinical services, quality improvement, financial and administrative

functions. The statewide committee also conducts random sample reviews of the regional PRAT resource allocations that are above the funding limits to ensure process consistency across regions. If the region and/or the consumer disagree with the statewide committee's decision, they may appeal to the department's deputy commissioner. If the aggrieved issue is waiver-related, the consumer may seek a formal Medicaid appeal through DSS.

### **Sources of Funding for Client Services and Supports**

Funding for services and supports provided to clients of DDS primarily comes from a combination of federal Medicaid and state funds. Under the Medicaid program, Connecticut receives 50 percent reimbursement from the federal government for clients residing in ICFs-MR. This is an optional service that Connecticut provides under its state Medicaid plan. All of Southbury Training School beds are certified as ICF/MR, as well as beds on regional campuses. In addition, there are a total of 69 private CLAs with ICF/MR certified beds.

For care provided to clients living in the community, Connecticut operates two Medicaid Home and Community Based Services waiver programs. The intent of the waivers is to provide services in the community to prevent the institutionalization of individuals that require that level of care. Although states can provide services as an optional service under regular Medicaid, Connecticut does not cover home-based services under its regular Medicaid program but provides it to persons that are enrolled in the Medicaid waiver program. The federal government provides 50 percent reimbursement for the cost of services provided.

The two waivers are:

- *Individual and Family Support (IFS) Waiver:* provide services and supports for consumers who live in their own homes or their family homes. This waiver is for consumers of DDS that do not require 24-hour supports. As of September 30, CMS had approved 4,018 slots to be funded under this waiver although 3,434 were filled because of funding constraints.
- *Comprehensive Waiver:* typically for people in residential settings with significant needs and in need of comprehensive level of supports, but they also may reside with family or in supported living arrangements. As of September 30, 2008, CMS had approved 5,117 waiver slots and 4,471 were filled because of funding.

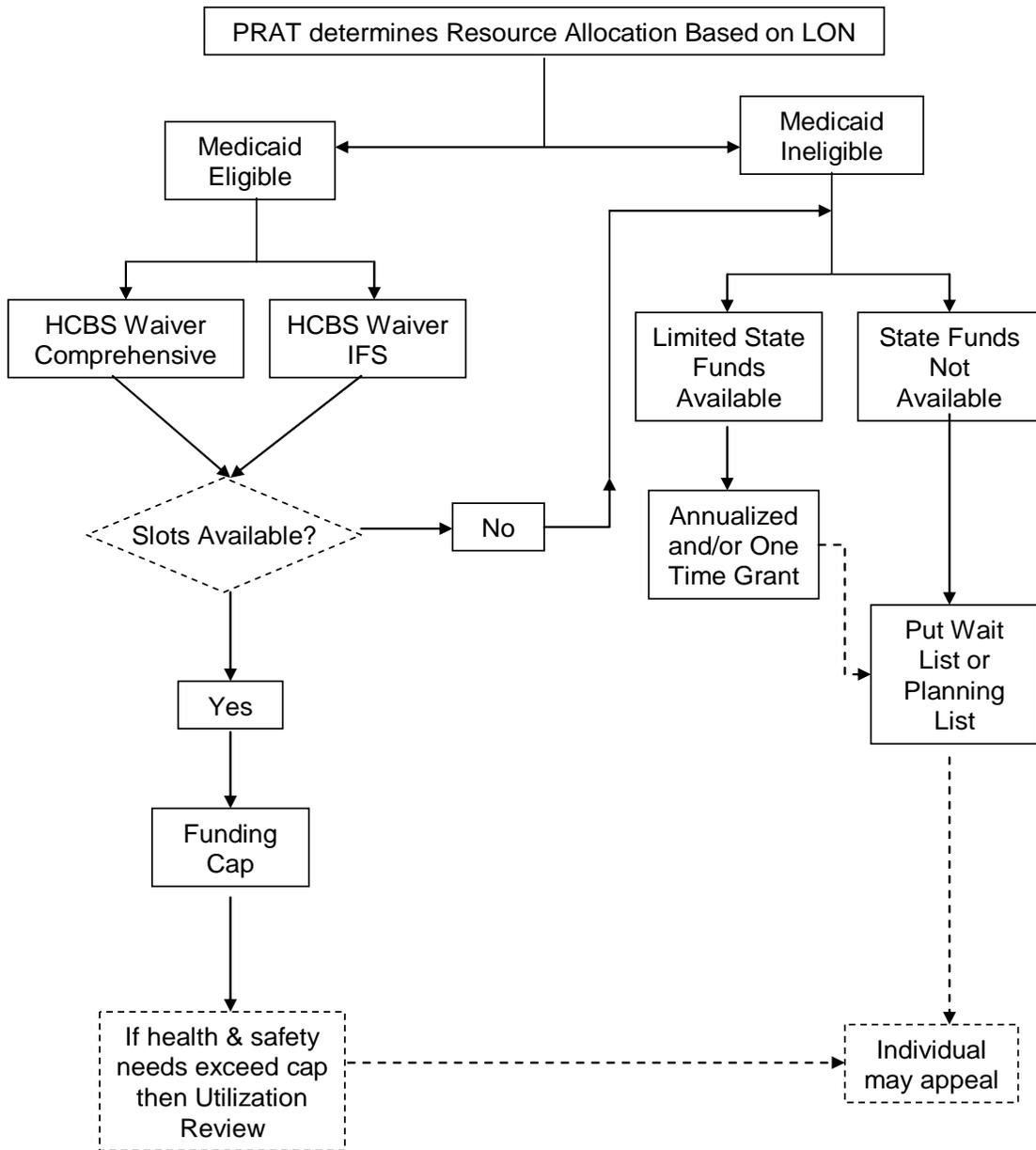
**Services available.** The types of services that can be provided under each waiver program are shown in Table III-2. Although many of the services are similar under the two waivers, the major difference is that the Comprehensive waiver includes a licensed residential component, and the intensity of services provided is much greater, both of which account for the higher cost ceilings allowed for individuals enrolled in this waiver.

<b>Table III-2. Medicaid Comprehensive and IFS Waiver Services</b>	
<i>IFS Waiver</i>	<i>Comprehensive Waiver</i>
<i>Similar Services</i>	
Adult Companion	Adult Companion
Consultative Services (Behavior and Nutrition)	Consultative Services (Behavior and Nutrition)
Family and Individual Consultation and Support (FICS)	Family and Individual Consultation and Support (FICS)
Group Day Services	Group Day Services
Health-care Coordination	Health-care Coordination
Individualized Day Services	Individualized Day Services
Individualized Home Supports (formerly Independent Habilitation or Supported Living)	Individualized Home Supports (formerly Independent Habilitation or Supported Living)
Interpreter Services	Interpreter Services
Live-in Caregiver	Live-in Caregiver
Personal Emergency System (PERS)	Personal Emergency Systems (PERS)
Personal Support	Personal Support
Respite	Respite
Supported Employment Services	Supported Employment Services
Specialized Medical/Adaptive Equipment	Specialized Medical/Adaptive Equipment
Transportation	Transportation
Vehicle Adaptations	Vehicle Adaptations
<i>Different Services</i>	
Environmental Adaptations	Assisted Living
Family Training	Individual Directed Goals and Services
	Residential Habilitation (CLA and CTH)
Source: DDS	

Figure III-3 shows the process used by PRAT to allocate resources, once the case manager has provided the information shown in Figure III-2. Once an individual's Medicaid eligibility is determined, PRAT calculates the level of resources needed by the client. If the client is eligible for Medicaid, and funding is available, the client will be enrolled in the applicable waiver. However, since there are a limited number of resources available to the department, not every DDS client that is eligible for the Medicaid waiver, actually receives waiver services and supports. Rather, the individual will be placed on a Wait or Planning list until resources become available to provide services to the client.

If no waiver slot is available, the individual and their family will be offered limited state funds and/or case management services. The individual may also be placed on the Wait or Planning list, depending on how quickly residential placement is needed. State funds, in the form of small grants, may also occasionally be given to individuals and their families who are ineligible for Medicaid.

**Figure III-3. Resource Allocation**



Source: PRI

**Funding caps.** Once PRAT calculates the funding necessary to meet the needs of the client, the individual's needs are classified as minimum, moderate, or comprehensive. Table III-3 and Table III-4 show the funding ranges and caps under each waiver.

<b>Table III-3. FY 08 Level of Need Funding Ranges – IFS Waiver for Adults</b>		
<i>Level of Need</i>	<i>Combined Residential, Community and Day/Voc Supports</i>	<i>Home and Vehicle Modifications</i>
Minimum	<= \$25,000	Up to \$15,000 for environmental modifications over a 5-year period Up to \$10,000 for vehicle modifications over a 5-year period
Moderate	<=\$40,000	
Comprehensive	<=\$58,000	
Source: DDS.		

<b>Table III-4. FY 08 Level of Need Funding Ranges – Comprehensive Waiver</b>			
<i>Level of Need</i>	<i>Range</i>	<i>PRAT upper ceiling</i>	<i>Regional Director Upper Ceiling</i>
Minimum	\$6,427 - \$21,852	\$27,316	\$32,779
Moderate	\$21,852 - \$49,168	\$60,094	\$68,647
Comprehensive	\$49,186 - \$81,942	\$92,336	\$98,336
Source: DDS.			

Sometimes PRAT's resource allocation calculation shows an individual needs even greater services (due to intensive medical, physical and/or behavioral conditions and/or insufficient availability or natural supports are unavailable and a residential placement is needed) than the initial range (shown in the second column of Table III-4). In these cases, PRAT only has discretion to recommend funding be exceeded by a certain level (shown in Table III-4 in the third column), even if the services and supports needed are higher. If this occurs, the regional director has three choices:

- he or she can approve the PRAT recommendation; or
- using their discretion, he or she can exceed the PRAT recommendation slightly although their authority is still limited (fourth column); or
- if they believe the need exists, and the health and safety of the client would be compromised, forward a recommendation to the Utilization Review Team at the DDS Central Office for approval of a higher funding level.

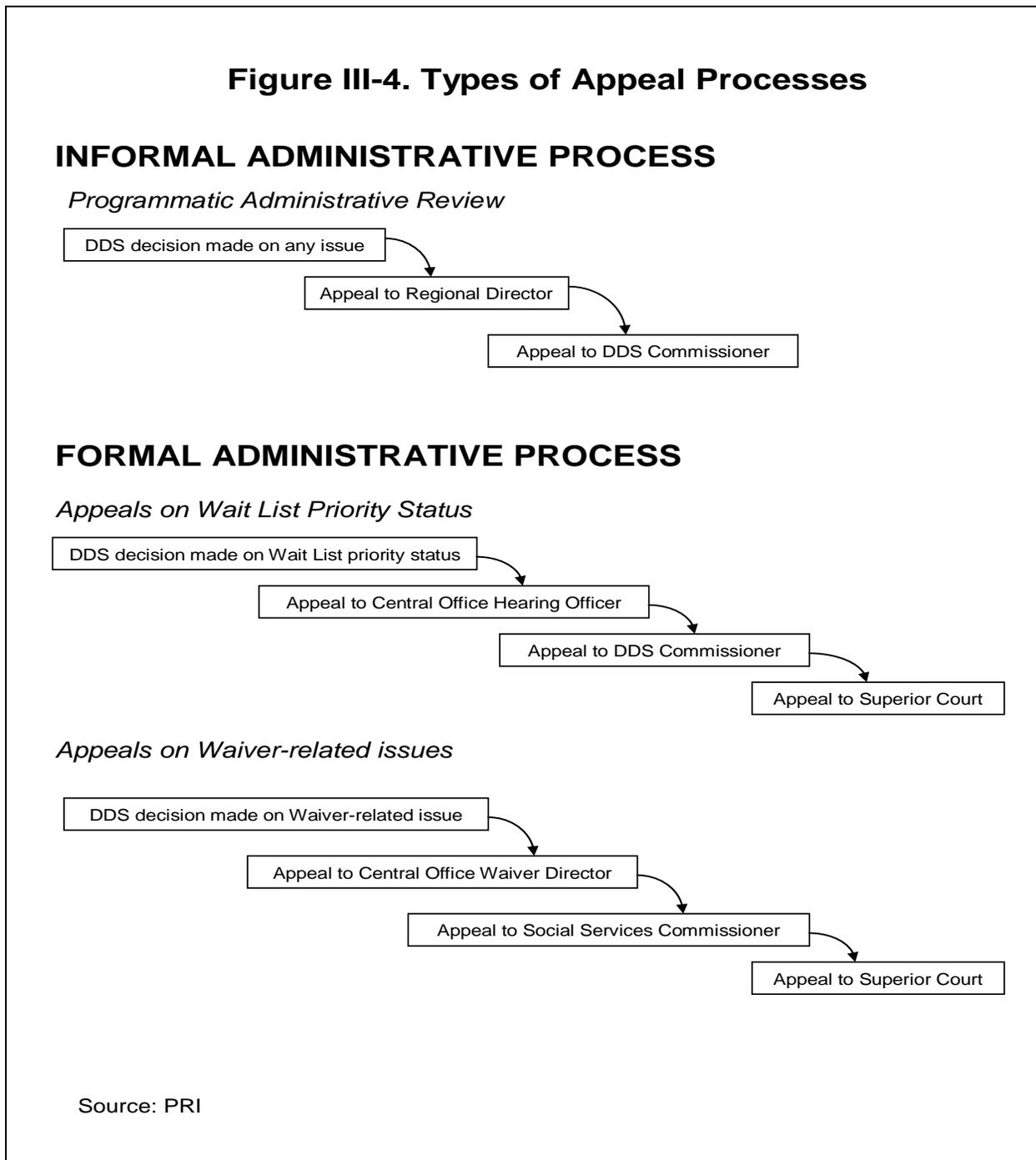
### **State Funded Supports**

Many individuals that have been found eligible by DDS currently live at home with their families and receive very limited services from the department. Since the number of clients that can be served under either of the waiver programs is limited, wait lists are maintained for residential services and for respite services. While all individuals on the Wait and Planning lists receive some case management services, only some may receive respite services, family grants, and other family supports, and the scope and intensity can be very limited (shown in Table III-5).

<b>Table III-5. State-Funded Supports Available to Non-Waiver Individuals and Families</b>	
<i>Type of Support</i>	<i>Description</i>
<i>Case Management</i>	Help individuals and families identify and acquire the supports, services and resources needed
<i>Individual and family resource teams</i>	Teams work with case managers to provide needed services to someone living at home alone or with their family. Supports can include small cash grants, overnight respite, and short-term temporary family assistance.
<i>Individual and family support grants</i>	Annualized grants to help caregivers pay for respite and other needs. Additional one-time grants can also be requested.
<i>Nursing consultation</i>	Evaluation, assessment, or family/individual training due to a medical condition affecting an individual
<i>Psychological/behavioral consultation</i>	Consult or evaluation of the presentation of psychological or behavioral issues
<i>Temporary family assistance</i>	For individuals living at home who are in need of temporary in-or out-of-home respite due to family or individual need (limited to 90 days)
<i>In-home respite supports</i>	Planned respite services in an individual's own home or in the family home (not an overnight service).
<i>Community respite supports</i>	Hourly out-of-home respite services with trained DDS family support workers for individuals who are having difficulty accessing community resources and/or integrating into existing programs
<i>Leisure/recreation consult</i>	Available to individuals and families who are looking to access existing community based resources
<i>DDS Respite Centers</i>	Short-term planned overnight respite
Supports for families with young and school-age children are not included in the table.	
Source: DDS	

## Reconsideration or Appeals of DDS Decisions

Any individual or legal representative aggrieved by a DDS decision may seek a reconsideration or appeal. The process used and individuals involved depends on the issue to be appealed. Figure III-4 provides a basic overview of the appeal processes.

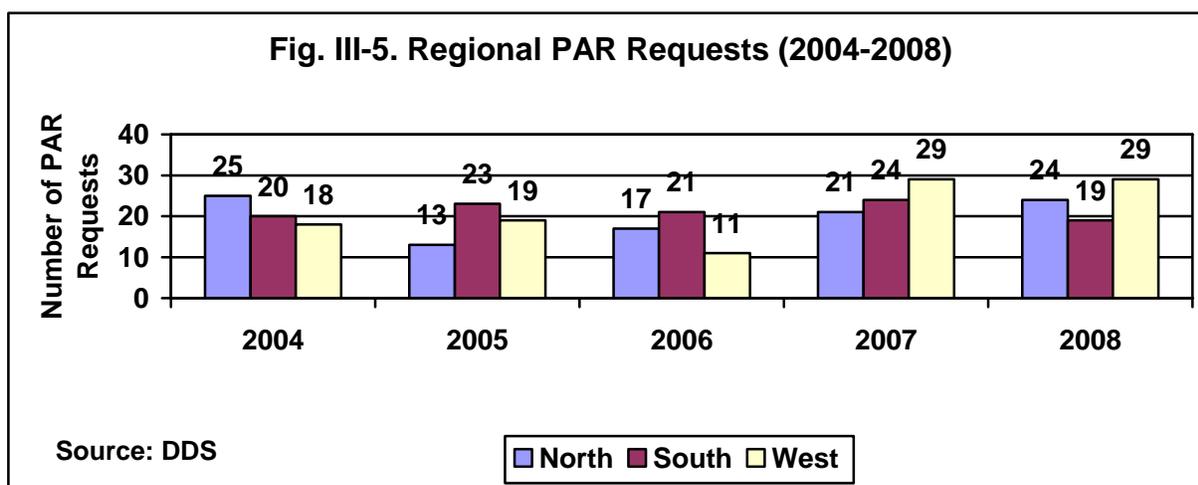


**Programmatic administrative review (PAR).** A programmatic administrative review (PAR) is available for any decision related to:

- eligibility, admission, placement, and assignment of programs and services;
- any changes in, termination of, or discharge from, a service; or
- any element of the client’s individual plan.

The PAR is an informal dispute resolution process that may be requested at any time. It allows a client, family, guardian, or legal representative to meet with the regional director to discuss concerns. The regional director will review all pertinent information and make a written determination within ten days of the PAR request. Individuals unsatisfied with any PAR determination may seek reconsideration by the DDS commissioner. The commissioner or his designee will review any supporting information and materials submitted by the aggrieved party and issue a written decision within 20 working days of the reconsideration request. The commissioner’s decision is deemed final except for disputes over wait list priority assignments and denials of waiver enrollment or waiver services. Waiver-related appeals must be heard by DSS, the single state agency for Medicaid.

**PAR statistics.** Figure III-5 presents the 313 PAR requests by region from 2004 to 2008. The graph shows that the number of PAR requests in the South region have remained somewhat consistent during this time period while the PAR requests in the other two regions have fluctuated. In 2007, the West region experienced a substantial increase in the number of PAR requests that continued into 2008 while the number of PAR requests in the North region has steadily increased in recent years. Program review staff will further examine PAR results and outcomes in the findings and recommendations phase of the study.



**Wait list and waiver-related appeals process.** Individuals disputing their wait list priority status may seek a formal DDS administrative hearing while persons denied waiver enrollment or involving waiver services may request a DSS hearing.

Wait list priority assignments may be contested at any time. Persons seeking to contest a DDS priority assignment may request an administrative hearing through the DDS Division of Legal and Government Affairs. The division will schedule the hearing in the DDS central office and make reasonable efforts to accommodate client schedules. A DDS hearing officer manages the hearing and reviews all information presented by the participants. Participants may include the client, client attorneys, DDS attorneys, regional representatives, or anyone else the parties believe can provide information regarding the claim. The hearing officer must make and provide a written decision to the client and the DDS commissioner within 60 days after the hearing. The client may submit additional written comments to the DDS commissioner within ten days of the hearing officer's decision. The commissioner makes the final determination on the hearing officer's decision. Any appeal of the commissioner's final decision must proceed to Superior Court.

As the state's single Medicaid agency, the Department of Social Services (DSS) has oversight of the DDS waiver operations. Therefore, an individual seeking an appeal regarding waiver eligibility or waiver services may also request a DSS administrative hearing for one of the following reasons:

- DDS decision denying eligibility for services under the HCBS waiver;
- DDS decision denying provision of certain relevant waiver services ; or
- DDS decision determining a level or amount of funds allocated to meet waiver services.

Prior to the DSS hearing, the client or legal representative must appeal the decision to the DDS Waiver Unit within the central office. The unit director will re-examine the PRAT decision along with any additional requested information. If waiver eligibility or service is denied, the central office waiver unit will provide a written notice to the client along with an explanation of appeal rights and include a request form for a DSS administrative hearing. The individual has 60 days from the date of notice to request a hearing. The DSS legal division will schedule and conduct the hearing in accordance with the Uniform Administrative Procedures Act.

Individuals may bring their own attorney or advocates. The DDS legal division presents the department's position and provides any necessary documentation and testimony for the hearing. The hearings are conducted at the local DSS regional office. A DSS final decision must be made within 60 days of the hearing. If the applicant/waiver participant prevails at the DSS hearing, the DDS regional office will be notified and DDS must implement the hearing decision as soon as possible. Any further appeals must proceed in Superior Court.

Since 2006, the central office Waiver Unit director has made decisions on 41 waiver related appeals. From these, 13 requests were made for a DSS administrative hearing and one was appealed to Superior Court. The program committee staff will further review the appeal information in the findings and recommendations report.

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### DDS Wait List & Recent Planning Efforts

The Department of Developmental Services is statutorily charged with planning and developing comprehensive services for persons with mental retardation. However, as noted throughout this report, DDS services are not an entitlement program and are provided within available resources. As such, the department is obliged to explore ways to ensure there is a fair and equitable distribution of available resources while providing individualized supports and services to the maximum number of eligible persons as possible. This balance requires the department to periodically examine its service delivery and set the future direction of the department through strategic planning. This section discusses the department's primary planning tool – the DDS Wait List -- and other recent planning efforts aimed at the aging DDS population.

#### DDS Wait List

In October 2001, the Association for Retarded Citizens of Connecticut (ARC/Connecticut) filed a federal lawsuit on behalf of individuals waiting for residential supports and/or day services from the then Department of Mental Retardation and the Department of Social Services. The suit alleged among other things that the agencies' failure to provide services with reasonable promptness to all persons eligible under Connecticut's Home and Community Based Services waiver (HCBS) was a violation of Medicaid law. The federal court allowed the lawsuit to proceed as a class action, which included over 1,000 individuals on the DMR wait list.

The parties negotiated and eventually agreed to a five-year settlement agreement (FY 2005-2009), which was reviewed by the Attorney General's Office and approved by the General Assembly during the 2004 legislative session. The settlement agreement is now in its last year.

**Settlement agreement and five-year initiative.** The primary goal of the settlement agreement has been to implement various strategies to serve as many individuals with intellectual disabilities as possible on the DDS wait list with community services and supports. The settlement agreement resulted in a five-year wait list initiative that began in 2005.

Part of the strategy for the five-year initiative was for the department to revise its definition of who should be placed on the wait list and how priority was assigned to more accurately reflect those with the greatest need for services. The department reconfigured its wait list to only include individuals who had an emergency (E) or required residential supports within one year (Priority 1 status). All other individuals with non-emergency needs would be placed on a planning list as under-served or under-supported.

The legislature has supported the initiative with five years of funding (FY 05 - FY 09) to annually serve approximately 150 individuals on the wait list at an average of \$50,000 per person and to provide an additional 100 families on the planning list with enhanced family support at an average of \$5,000 annually for each of the five years. The initiative's final outcome would be

serving and removing 750 persons from the wait list and providing services to an additional 500 individuals on the planning list over the five year period.<sup>8</sup>

One critical settlement agreement requirement was that DDS and DSS apply for federal Medicaid waivers that emphasize the self-directed supports and services tailored to meet individual and family needs as well as a new waiver to provide services and supports to individuals who need and require services on a comprehensive basis.

The settlement agreement also required that the state retain an independent consultant to review progress, facilitate implementation, and report to the parties during the last quarter of each year during the five-year term of the settlement agreement. The agreement explicitly states that the consultant reports should be structured and viewed as progress reports and not compliance reports.

Two independent consultants were hired in July 2005. The consultants have conducted numerous activities including facilitating quarterly meetings with the parties, separate meetings and conference calls with state staff, class members, and community service providers, as well as an on-going document review.

**Consultant progress reports.** When it was originally planned, DDS was to accomplish the wait list initiative by using new funding at a level averaging \$50,000 per individual for residential supports and reusing residential vacancies as they occurred. The first consultant progress report issued in 2006 found the wait list turnover rate was proceeding at the pace prescribed by the parties in the settlement agreement. The report also found that DDS had made progress on HCBS waiver development including communications, training, and related policies and procedures. The consultant made a number of recommendations in these areas including that DDS evaluate its case management services to determine the extent of time and effort devoted directly to consumer/family contact.

The primary focus of the consultant's second progress report was on health and safety issues for class members receiving HCBS waiver services. The consultant made several recommendations regarding psychiatric, behavior, and dental services. As part of their activities for the second annual progress report, the consultants were also asked by the settlement agreement parties to develop and conduct a quantitative analysis of the DDS wait list trends. A report was prepared and presented during the summer of 2007.

The analysis of the wait list trends indicated that the demand for residential and family support services was growing at a faster rate than anticipated even though the department was serving the number of individuals prescribed in the settlement agreement. The consultant's conclusion was that an increase in resources would be needed to achieve the long term goal of eliminating the wait list. Furthermore, it was unlikely that existing FY 09 funding approvals would change this trend.

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<sup>8</sup> The total five year settlement agreement costs (including litigation and expert consultant fees) are \$33.8 million with federal reimbursement under Medicaid's HCBS waiver at 50 percent or \$16.4 million in waiver-eligible costs. The federal revenue is deposited into the General Fund and is not retained by DDS.

The most recent consultant progress report was issued June 30, 2008. The report's focus, as requested by the settlement parties, was on self-directed services. Self-directed services are part of the DDS principle that individuals and families who receive DDS services and supports should have the maximum amount of choice and control. Under this approach, individuals and/or their families hire and manage personnel to provide specific services, goods, or equipment with the assistance of a fiscal intermediary and case management or support broker services. The consultant's report found overall self-directed services to be successful despite some operational problems such as multiple revisions to the individual budgeting process. The consultant believes DDS is aware of the issues and is actively working to address the problems.

### Wait List Trends and Projections

As noted earlier, the settlement agreement directs DDS to assign individuals seeking services to one of four priority status (shown in Table IV-1). It is important to note that individuals on the Wait or Planning list may already receive varying levels of DDS service while they wait for additional services.

Status		Definition	Current Number on List as of June 2008	
			Residential Services	Day Services
Wait List	Emergency	An <i>immediate</i> need for residential placement, support or services.	35	2
	Priority 1	A need for residential placement, support or services <i>within one year</i> .	525	193
Planning List	Priority 2	A potential need for residential placement, support or services <i>within two to five years</i> .	965	29
	Priority 3	A potential need for residential placement, support or services <i>more than five years</i> in the future.	485	3

Source: ARC/Connecticut et al. v. O'Meara et al. Settlement Agreement Section II and DDS Management Information Report (June 2008)

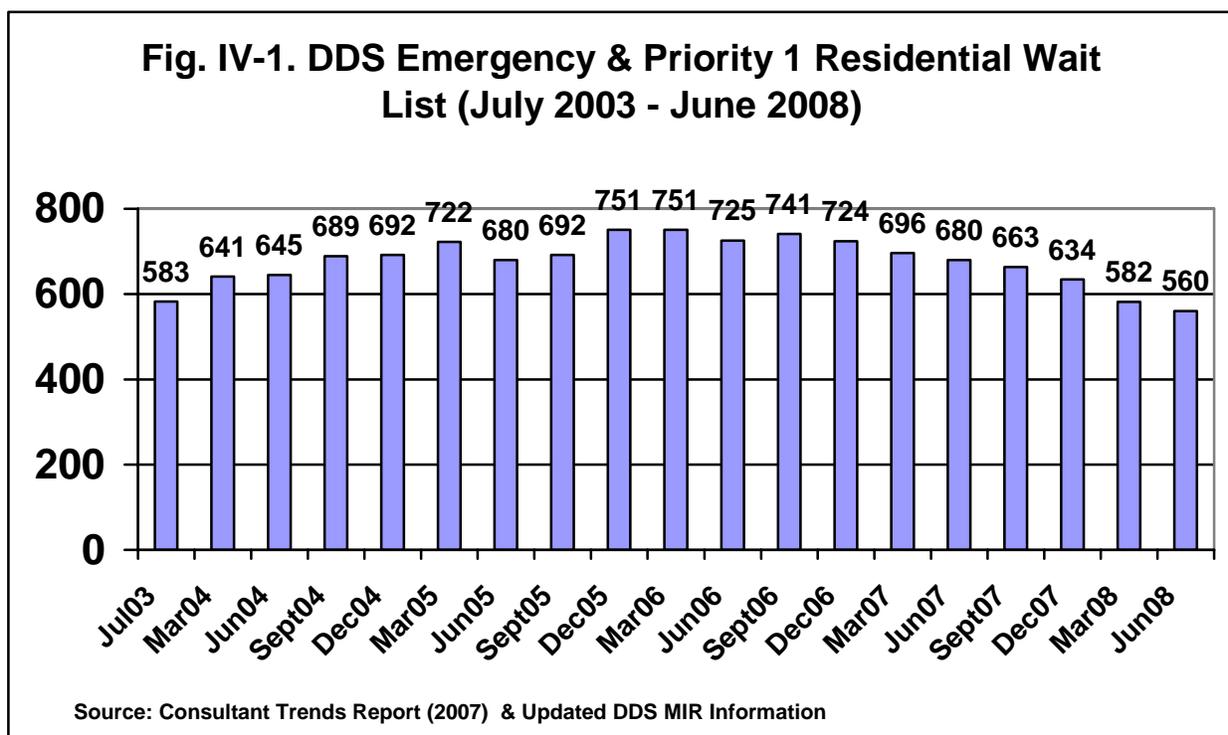
As of June 2008, there were 560 individuals seeking residential services on the DDS wait list and 1,450 people on the planning list. Since the legislature approved funding for the wait list initiative in FY 2005, the new development funds were used to serve 172 persons on wait list in 2005; 166 people during 2006; 190 individuals in 2007; and 228 served in 2008. Trend analysis on the number of individuals seeking residential services and supports was conducted by the independent consultants selected by the settlement agreement parties. The following is a summary of the consultant's findings.

**Residential wait list for Emergency and Priority 1 status.** Pursuant to the settlement agreement, priority designation for residential services must be given to individuals on the wait

list with an Emergency or Priority 1 status. As noted earlier, factors considered in determining the priority designation include:

- the age of the caregiver and individual;
- the physical and mental health of the caregiver and individual;
- other sources of support;
- support needs of other members of the household; and
- risk of harm to the individual and other members of the household.

Figure IV-1 shows the number of persons with an Emergency or Priority 1 status on the DDS wait list for residential services between July 2003 and June 2008. The wait list peaked in late 2005 and early 2006 when 751 individuals were seeking residential services. Since that time, the wait list has declined approximately 25 percent to 560 individuals in June 2008. The wait list is 13 percent lower in June 2008 than it was in June 2004 before the settlement agreement went into effect.



According to the consultant, “the expansion in residential services since the first year of the settlement agreement has not been sufficient to offset the new urgent demand for residential services.”<sup>9</sup> One reason the number of individuals in the Emergency and Priority 1 categories may not have significantly decreased is that people shift upwards in the priority rankings over time –

<sup>9</sup> Connecticut Waiting List Trends & Projections, August 28, 2007 p.3

individual status changes from Priority 3 to Priority 2 to Priority 1. The consultant concluded that the recent decline in wait list numbers is due in part to an unexplained higher than expected level of opportune residential openings that occur when a client leaves a DDS residential service and the vacancy is filled with a wait list individual.

Based on the demand growth rates observed between March 2004 and June 2007 and an assumption that the turnover rate among persons receiving DDS residential services will remain stable or about the same as it has been over the past three years, the consultant's report forecasts that going forward the DDS residential service demand will grow at a rate of approximately 300 persons a year with about 90 individuals absorbed through opportune opening placements. Consequently, the net year-over-year increase in service demand is projected to be 210 individuals per year. By FY 2012, the wait list is expected to be 13.9 percent over the current level or 638 individuals. It is important to note that since the consultant's report in mid -2007 the wait list numbers have continued to decline. Further analysis of the wait list will be provided in the program review findings and recommendations report.

**Summary.** The five-year funding initiative has provided services to many eligible DDS consumers who had previously not been served or were under-served but the trends indicate that great need still exists. As life expectancy ages have increased for persons with intellectual disabilities, the number of individuals seeking services and supports can be expected to grow.

### **Other Recent Planning Efforts for Aging Population**

In recent years, DDS has prepared a number of planning documents to direct the department's service system. The primary guidance document for the department is the agency's statutorily required five-year plan. In addition, the department has initiated a few planning documents aimed at the aging DDS population. Among these are a report and recommendations compiled by a Focus Team on Aging, two additional reports stemming from that original focus team report, and a document resulting from litigation related to Southbury Training School. The following is a brief synopsis of these efforts.

**DDS five-year plan.** According to DDS, the department's five-year plan is a strategic statement of direction and an outline of priorities. It is to serve as "a compass to guide the direction of the current and future service system".<sup>10</sup> Since 1991, the department has been required to develop a five-year plan, hold public hearings, and submit the plan and a transcript of the hearings to the legislature. Specifically, the plan must:

- set priorities;
- identify goals and objectives and strategies for meeting them;
- define the criteria for evaluating the department's progress;
- identify changes in goals, objectives, and strategies from the prior plan;
- document the progress made; and
- estimate the type and number of staff and services needed to meet the plan.

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<sup>10</sup> State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012), p.5

To produce the five-year plan, the department conducts an annual internal business planning process, includes outside stakeholders in meetings, and participates in advisory groups and various initiatives. The most recent five-year plan (2007-2012) recognizes the need to assess current economic conditions and future demographics, and the costs of developing new programs, as well as examining trends in state and federal funding. The plan also acknowledges the challenges confronting the department's future service delivery:

“The department is also faced with the changing needs of people who are already receiving funded services from the agency but whose needs for support have increased. The population we serve continues to age and our service providers experience the challenges and increased need for support brought on by changes in individuals' physical and health status”.<sup>11</sup>

Most of the goals and objectives listed in the five-year plan are aimed at the department's overall general service delivery to benefit all DDS consumers (e.g., increasing family support options, analyzing health and safety risk data to implement system improvements, and continuing implementation of the wait list settlement). However, it also includes targeted goals for certain DDS populations such as Birth-to-Three, Autism, and aging. The plan's primary goal for the aging population is to develop a continuum of care plan for DDS consumers as they age. One accomplishment noted in the plan is the re-establishment of the department's Focus Team on Aging.

**Focus Team on Aging.** In 2003, the DDS commissioner established a Focus Team on Aging to assist the department to develop a vision and action plan to serve older adults. The focus team included representatives from families, service providers, state agencies on housing, aging, transportation, and mental health and addiction services, and DDS case management staff, nurses, and residential and day staff. The team made specific recommendations and developed an action plan to address the recommendations.

After the focus team issued its report, a position was created at the DDS central office to develop policy and coordinate initiatives in elder services. These responsibilities were subsequently merged into another position due to a staff retirement. However, in February 2008, the department restored and filled the aging coordinator position at central office.

The coordinator role's is to ensure the individuals served by DDS have access to the supports and services they need as they age. The coordinator collaborates with various stakeholders to develop a full range of available community service options. Among the coordinator's responsibilities is to monitor and assist in the development and implementation of the recommendations of the Focus Team on Aging.

**Recommendations of the Focus Team on Aging Report.** The Focus Team on Aging report identified a number of key issues and made specific recommendations to assist the department in developing priorities for older DDS consumers. Generally, the focus team report concluded that significant system and policy changes are required to meet increasing demands for additional and different types of services and supports within the context of limited fiscal

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<sup>11</sup> State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012) p.9

resources. As a result, an evaluation and revision of current systems were needed to meet the anticipated needs of the aging population. The department produced an action plan for the recommendations which the Focus Team continues to refine and monitor. Appendix A outlines the proposed DDS action plan.

One of the focus team recommendations was that the DDS analyze two of the department's residential service models with the needs of aging persons in mind. In 2004, the commissioner formed a workgroup to review the future needs of the Community Training Home program. In 2005, another workgroup was established to analyze the Supported Living service model. The issues and recommendations resulting from the two workgroups are provided in Appendix B.

**Southbury Training School litigation.** In 1984, the U.S. Department of Justice initiated a lawsuit concerning alleged civil rights violations based on the conditions at the Southbury Training School.<sup>12</sup> The suit was initially resolved in 1986 through a consent decree that required the state to prepare and implement a plan to address the school conditions. Among other things, the plan would: assure sufficient staffing; provide periodic professional evaluation of the school residents; create additional community-based opportunities for residents; and improve the school's physical fire and safety environment. Admission to Southbury was closed in 1986 with a planned reduction of the resident population. In 1994, another related class action lawsuit was initiated by three advocacy organizations and Southbury residents.<sup>13</sup>

In 1997, the state was found in contempt of the consent decree provisions and a Special Master was appointed. In March 2006, the court found the state was no longer in contempt and all requirements of the Southbury consent decree were met. In June 2008, the federal judge issued a decision related to the second lawsuit (Messier) that the state has not done enough to relocate Southbury residents voluntarily into the community. Hearings to determine the next steps are scheduled for September 2008. Currently, Southbury has a resident population of 499 with an average age of 59.

In 1998, the department established a Committee on Aging to prepare a plan addressing the issues related to the growing elderly population at Southbury. The plan was to assure the federal court that Southbury compliance would continue. The 17-member committee included various Southbury officials and staff as well as client representatives. The committee was divided into six sub-committees relating to: medical and clinical services; day programming; recreation and community integration; environmental modifications; residential programming; and staff training. The committee prepared a first draft of an aging plan containing a number of objectives and action steps.

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<sup>12</sup> United States v. Connecticut, 931 F. Supp. 974 (D. Conn. 1986)

<sup>13</sup> Messier v. Southbury Training School

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### Issues for Further Review

The Department of Developmental Services, with almost \$1 billion in expenditures and over 4,700 staff in FY 08, is responsible for managing, overseeing, and delivering a complex set of services and supports for individuals with intellectual disabilities. With the exception of Southbury Training School and the regional centers, services and supports are delivered in the community through a regional organizational structure. The range, intensity, and cost of services provided to clients by the department vary widely, with some clients receiving only case management services while others receive residential care with 24-hour staffing. Because resources are limited, however, individuals who meet statutory eligibility criteria do not automatically receive services. Rather, the department maintains wait and planning lists of individuals, for both residential and day services, and services and supports are only offered when funding is available.

As noted throughout the briefing report, the subject of aging within the intellectual disabilities population is a multifaceted topic that encompasses a broad range of issues. While the PRI study scope was targeted only at aging DDS clients and, if they are living at home, their elderly caregivers, the entire delivery system was examined, since allocation of services is based on client needs, not the age of the client.

This section briefly describes some of the framework surrounding these issues and identifies the areas, particularly as they relate to the PRI target population, that program review staff will review in further detail in the staff findings and recommendations phase of the study.

### Context of Issues

Issues surrounding the planning efforts for an aging population are not just a concern for the intellectually disabled population. The impact of aging affects all demographics. Increased demand for accessible and affordable health care along with a shortage of medical professionals, particularly nurses, continues to be a problem for everyone. Economic realities along with fiscal constraints require all entities to find ways to do more with less. Similar to other state agencies, DDS is struggling to manage existing demands without the resources to dedicate to projected or unknown potential demand. Opportunities must be found, whenever possible, to coordinate and leverage existing resources with other entities with similar goals and objectives.

There must also be a recognition that an equitable distribution of limited resources may mean making resource allocation decisions that rebalances the service system so more individuals can be served. At the same time, every effort must be made to ensure supports and services provided are appropriate to the individual's health and safety needs.

Ideally, most people would like to "age in place" or remain in their own homes until they die. However, in order for this to happen, sometimes an extensive support system is required. This may include natural supports such as family who are willing and able to provide continuing care, sufficient publicly funded services and programs, and private organizations that provide

home care. As the statistics show, the majority of persons with intellectual disabilities live in the community – many with their families who are their primary caregivers.

Increased life expectancy for persons with intellectual disabilities has extended caregiver responsibilities for many who are aging themselves. Sometimes as the parent ages the household becomes a two-part case, one for the adult child and one for the aging parent. Furthermore, a mutual interdependence may arise when the adult child with disabilities is providing physical, emotional, or financial support to the aging caregiver. These family dynamics are sometimes further complicated by generational and/or cultural attitudes about accepting government services.

As with the general population, many parents of children with intellectual disabilities delay or avoid discussions about death or making contingency plans for their loved ones. Some rely, sometimes erroneously, on the belief that other relatives are willing to or capable of taking over the primary caregiver role. At times, caregivers are reluctant to recognize their own diminishing capacity to provide care. Assisting families with many of these challenges is one of the roles DDS, in conjunction with other service providers, can fulfill to avoid crisis situations and alleviate transitions as caregivers and individuals with intellectual disabilities age. To do this, DDS must strategically prioritize its resources and outline the steps required to plan for its population's needs.

### **Potential Areas for Further Review**

Some of the issues discussed above that relate to the planning for the needs of an aging population have broader implications than the scope of this particular study can address. While there must be an acknowledgement of these issues as potential obstacles and challenges to planning, there are limitations in what can be reasonably explored given the time and resource constraints of this study. However, one basic foundation of any evaluation or planning process is solid data. Therefore, the committee staff provides the following questions to be answered during the findings and recommendations phase of this study.

#### **Eligibility for DDS Services**

- How were individuals age 45 and older who were identified and determined eligible for DDS services for the first time within the last three years discovered and what type of services were needed?

#### **Wait and Planning List**

- Have all individuals who have an elderly caregiver and were on the wait list been offered services, since this was a major factor in establishing priority status under the wait list initiative? If services were refused, what was the reason and how did it impact the client's priority status on the wait list?
- What types of services are being requested and received by individuals age 45 and older who are on the wait or planning lists (i.e, how many are enrolled in

one of the Medicaid waiver programs, or are they only receiving state-funded services)?

- How often do individuals age 45 and older file appeals based on PRAT decisions denying increased services?
- Does the department's data system adequately track DDS clients living with elderly caregivers?
- How will demands of the Wait list be addressed without additional funding after the Wait list initiative ends?

#### **DDS Clients Living in Nursing Homes:**

- Are additional efforts necessary to ensure admissions and placements to nursing homes are appropriate?
- What is the process to identify persons living in nursing homes who want to move to the community under the new Money Follows the Person (MFP) Medicaid Waiver?

#### **Evaluation of Agency Planning Efforts**

- Are the roles and responsibilities for Aging Services with DDS well-defined? Are the resources to fulfill roles and responsibilities adequate?
- What have been DDS efforts in terms of education, awareness, and training for aging caregivers? Are current caregiver services (i.e., respite) adequate to meet demand?
- Does the State have contingency plans for the final disposition of litigation related to Southbury Training School?
- What steps have been or should be taken to obtain better estimates of the future needs of the aging population?

## **APPENDICES**

**Appendix A. Summary of Action Plan for the Focus on Aging Report Recommendations**

Category	Recommendations
<b>Person Centered Plan</b>	Annually assess individual’s changing support interests, preferences and support needs as they relate to aging
	Develop system to analyze and track individual needs
	Develop database to track individuals’ abilities and support needs
<b>Health</b>	Develop screening and evaluation tools, advisories for all individuals served
	Evaluate recruitment and retention strategies for nurses
	Develop health resource center of excellence
<b>Housing</b>	Offer continuum of residential service models including assisted living
	Standardize Community Living Arrangement home profile – incorporate Americans with Disabilities Act checklist and database
	Address future needs of individuals in Community Training Homes
	Analyze future needs of individuals in Supported Living
	Continue participation in statewide interagency groups to address housing concerns of elderly
	Continue to review homes for possible need to vacate inappropriate placements
	Develop browser-based resource lists for information on home renovations and modification programs
<b>Transportation</b>	Continue work with other agencies to facilitate transportation collaborative
	New development to consider individuals’ transportation needs
	Ensure transportation training as appropriate
	Develop system to replace vehicles per individuals’ changing needs
<b>Retirement</b>	Identify resource point for all services relating to retirement options
	Work with other agencies to establish common eligibility requirements
	Investigate feasibility of retirement savings
	Address portability of funds to move work funds to residential, transportation, recreation, or other supports
<b>Leisure</b>	Ensure access to leisure and recreation services
	Ensure individual’s plans include recreation and leisure activities
<b>Supports to Families</b>	Establish high level position to oversee aging services
	Develop wide range of support services for individuals and families
	Explore needs of older individuals, families, and prioritize services and support needs
	Ensure circles of support are maintained throughout person’s life
<b>Education and Training</b>	Coordinate effort to gather data for training needs of individuals, families and others for older adults
	Develop and provide training for Long Term Care staff
	Work with other agencies and provide education as needed
<b>Legislation</b>	Continue to participate in Long Term Planning committee
	Convene group to review federal waivers and make recommendations for changes as identified
	Work to expand range of residential service models including assisted living communities
	Convene group to review guardianship law for possible legislative changes
	Expand collaboration with others to ensure knowledge of and support for legislation impacting older adults
<b>Grants and Research</b>	Expand effort to increase access and participation in grants and research
<b>End of Life Planning</b>	Ensure individual’s plan addresses end of life decisions when appropriate
	Expand education and training for individuals, families and others
	Support increased participation on hospital ethics committees

Source: DDS Action Plan for Recommendations of Focus Team on Aging Report

<b>APPENDIX B. Community Training Homes (CTH) Aging Population Report: Issues and Recommendations</b>	
<i>Issues</i>	<i>Recommendations</i>
<b>Aging population and future planning</b>	
Individuals living in CTHs are aging and have increasing health, support and transportation needs.	DMR should clearly articulate its position on the future direction and growth of the CTH service model.
CTH providers are aging, have increased health issues, need increased supports to continue providing services, and eventually may become too ill to continue providing services.	DMR should assign additional resources to regional CTH teams, dedicated to recruitment and pre-licensing or develop a central office unit to perform this function.
DMR has not detailed a future plan for the CTH residential model.	
Recruitment efforts and follow-up with potential providers are limited due to lack of staffing resources.	
<b>Regional staffing and practice</b>	
CTH staff resource and practices differ by region.	DMR should continue to standardize procedures to ensure consistent practices statewide.
	DMR should continue to address regional staffing differences.
<b>Regulations and funding</b>	
CTH regulations have not been reviewed or revised in several years.	DMR should convene a group to review current licensing regulations for possible revision.
There has been no increase in the DMR funding portion for many years.	DMR should request an increase in CTH funding in the next legislative session.
<b>Training</b>	
There is a lack of knowledge regarding the CTH model by individuals, families, and staff.	DMR should develop and implement training for individuals, families and staff to ensure that people are knowledgeable and that the CTH model is presented as a residential option.
	DMR should revise the CTH handbook and continue to develop fact sheets and other written materials for individuals and families.
Source: Community Training Homes Aging Population Report and Recommendations (June 2005)	

<b>APPENDIX B. Supported Living Services Aging population Report: Issues and Recommendations</b>	
<i>Issues</i>	<i>Recommendations</i>
<b>Aging population and future planning</b>	
Individuals receiving Supported Living services are aging and have increasing health, support and transportation needs.	DMR should ensure that the needs of individuals receiving supported living services are assessed and addressed in the person's individual plan
As people age, their health needs increase. Additional consultation and coordination of health care individuals need is often not available.	DMR should convene a group to identify issues, needed supports and best practice standards for health services for people receiving Supported Living supports.
As people age, their homes/apartments may no longer be suitable due to changes in mobility and other health issues.	DMR should explore a variety of residential options for individuals and develop a plan to meet future needs of older individuals.
Individuals' transportation needs may change due to changes I health, mobility, vision or other similar factors.	The department should complete the Focus Team on Aging recommendation to identify accessible housing (CLAs) and develop a database documenting pertinent data relating to accessibility.
	Identify accessible apartments and apartment complexes and ensure the information is available to individuals, families and teams.
	DMR should continue to build networks/natural supports.
<b>Impact of new waiver</b>	
Individuals currently receiving residential habilitation (Supported Living) will continue to receive that support under the existing waiver unless they exercise portability and enroll in the new waiver for individual habilitation.	DMR should complete the procedures for transferring individuals to IFS waiver.
	DMR should continue to work with service providers on waiver changes affecting people over age 55.
	DMR should develop guidelines and fact sheets for individuals and families regarding new waiver.
	SL regulations should b reviewed and revised as necessary.
<b>Education and training</b>	
There is no plan for educating individuals, families, staff, and community providers on issues around aging and people with mental retardation.	DMR together with other stake holders should identify topics for educating individuals and families on aging issues, and develop and implement a standardized training curriculum.
	The department should continue development of fact sheets and other similar educational materials.
	DMR should revise new employment training to include issues related to aging.
	DMR should develop and implement standardize on-going training for staff including information on aging issues, attitudes on aging in various cultural and ethnic groups, entitlements, other federal waivers, retirement planning, end-of-life planning and other topics.
	DMR should develop a plan to further interact with and educate community providers including hospitals, nursing homes, elder service providers and others.
Source: Supported Living Services Aging Population Report and Recommendations (June 2005)	