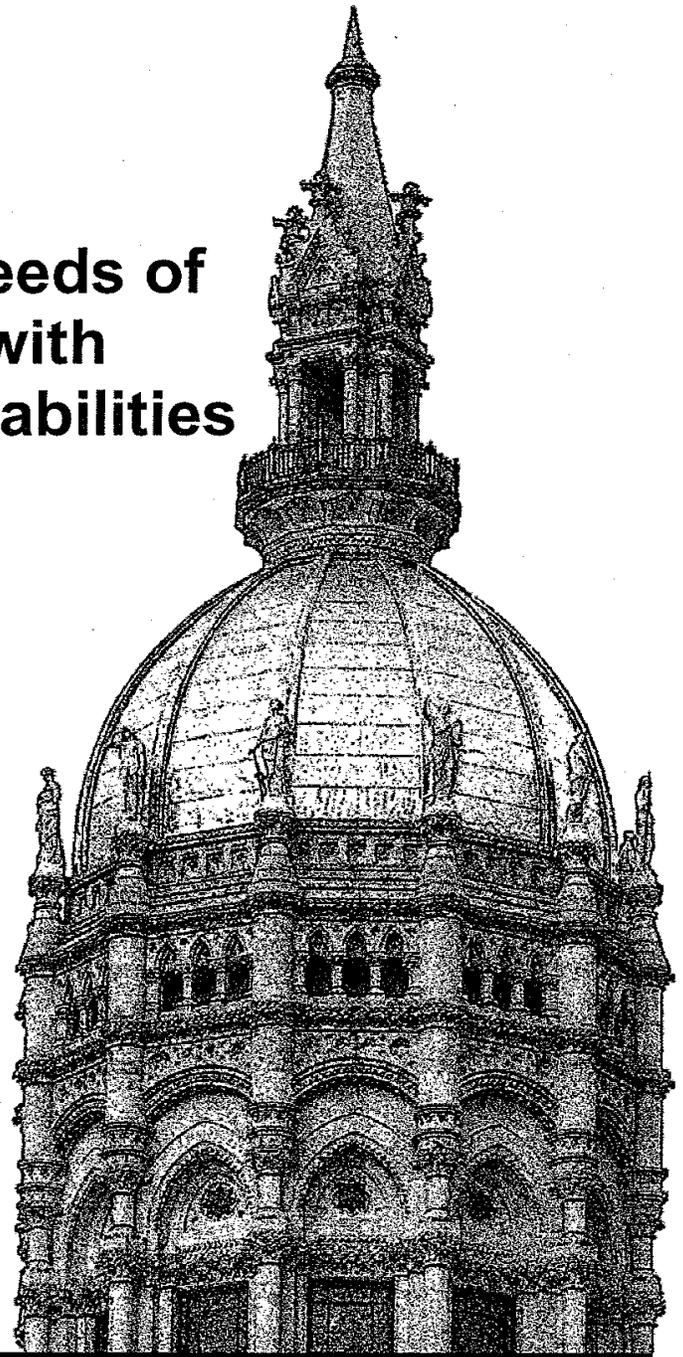


Planning for the Needs of Aging Individuals with Developmental Disabilities

DECEMBER 2008



**Legislative Program Review and
Investigations Committee**

Connecticut General Assembly

**CONNECTICUT GENERAL ASSEMBLY
LEGISLATIVE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE**

The Legislative Program Review and Investigations Committee is a joint, bipartisan, statutory committee of the Connecticut General Assembly. It was established in 1972 to evaluate the efficiency, effectiveness, and statutory compliance of selected state agencies and programs, recommending remedies where needed. In 1975, the General Assembly expanded the committee's function to include investigations, and during the 1977 session added responsibility for "sunset" (automatic program termination) performance reviews. The committee was given authority to raise and report bills in 1985.

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LEGISLATIVE PROGRAM REVIEW
& INVESTIGATIONS COMMITTEE

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Executive Summary

Planning for the Needs of Aging Individuals with Developmental Disabilities

In the past, most persons with an intellectual disability (ID) had a relatively short lifespan and many spent much of their lives in institutions. Consequently, their aging was not of immediate societal concern. Today, increased longevity and the presence of individuals with intellectual disabilities living in the community have heightened awareness of this population's emerging needs.

In Connecticut, the Department of Developmental Services (DDS) is the state agency with the authority and responsibility to provide services to persons with intellectual disabilities. However, the provision of services are not mandated nor entitlements. DDS delivers services and supports through available resources.

The study's focus, approved by the committee, was to examine DDS efforts to address and plan for current and future service needs of the aging population with intellectual disabilities in Connecticut. The study concentrates on two target populations: 1) individuals age 45 or older who are or would be eligible for DDS services, and 2) DDS clients' caregivers over the age of 65.

Based on the PRI review, it is clear DDS has already engaged in a number of efforts to plan for clients' needs as they age:

- preparation of several documents to guide the agency's vision;
- implementation of many recommendations made by the DDS-initiated Focus Team on Aging;
- the creation of a coordinator position for aging services; and
- offering some education and support to aging caregivers.

The report contains the results of the committee examination of the department's efforts, and of other areas pertinent to aging persons who have an intellectual disability. Where relevant, the committee proposes recommendations for improvement.

Given the current fiscal climate, the program review committee tried to be cognizant of potential cost-neutral recommendations in terms of state and/or federal funding, whenever possible. However, certain policy decisions will have to be made with respect to specific aspects of the department's delivery of services – in particular managing the wait list. As such, some of the committee recommendations will require financial investments now or in the future when budgetary conditions improve. Also, some of the committee findings and recommendations address system-wide issues, rather than specific issues related to clients age 45 or older, because the processes around resource allocation and service delivery are the same for all clients.

Prioritizing Financial Resources

Since this study was initiated in April 2008, the financial status of the national and state economy has spiraled downward. Current estimates project state budget deficits over the next two fiscal years will near \$6 billion.¹ Undoubtedly, difficult decisions will have to be made. All agencies are being asked to provide more services and programs with fewer real dollars. There is an urgent need to examine policy and financing issues to find methods of collaboration across service systems and cost-effective strategies.

Confronted with a dramatic growth in the numbers of aging individuals served by DDS, it is timely for policymakers to begin to consider cooperative efforts and rebalancing how care is delivered. The demographics alone are cause for a fundamental re-evaluation of current expenditures as decision-makers weigh the influx of an increasingly aging population on Medicaid budgets. Nationally, states have been moving away from traditional institutional settings, and exploring new ways to reinvest public dollars in order to serve more individuals in cost-effective ways in the community. In many cases, simple supports to an existing situation may mean the difference between continuing to reside at home or having to be institutionalized.

In a time of continuing budget cuts and subsequent decreases in programs or services, setting priorities and planning are paramount. The aging population of individuals with intellectual disabilities is just one segment of the overall aging population in Connecticut. In addition to competing with other aging groups, older individuals with intellectual disabilities face competition for resources even within the agency responsible for their specialized services and supports (e.g. Birth-to-Three, autism, graduates, and age-outs).

Therefore, the development of an effective fiscal plan using solid data to forecast service requirements for persons with intellectual disabilities and their caregivers is crucial. DDS has information about its consumers currently being served in state-sponsored programs. However, some of the information is not centralized or maintained in a useable fashion for planning purposes. In addition, little to no information is available regarding individuals who may need DDS services and supports in the future. These individuals, not presently in the system, may make an impact on the need for future aging services provided through both public and private sectors.

DDS Delivery System

Individuals with intellectual disabilities may require a vast array of supports and services depending on the type and degree of the disability. As such, the DDS delivery system provides for individualized services and support that range from providing minimal assistance to continuous around-the-clock care.

Despite the level of care required, persons who are eligible for DDS services must be assessed and evaluated by regional planning and resource allocation teams (PRAT) to receive funding for services and support. DDS services are not an entitlement and are contingent upon

¹ OFA Projections & Governor's Report (January 2009).

available resources. With limited funding, DDS maintains wait and planning lists based on a priority ranking system to guide allocation decisions and determine who receives services.

Individuals with the most pressing needs (e.g., emergencies) are considered first for services. However, as the limited funding tends to serve the individuals at the “top of the list”, those who continue to hold on at the lower end of the list either never get served or eventually become emergencies themselves creating a continuous cycle. Because crises frequently occur, the department often must use one-time funds in order to close service gaps until more stable resources are available. Thus, PRATs are constantly balancing resources in order to meet demand for services.

In addition, if a person has been found eligible for Medicaid waiver services, the department is required, under federal law, to meet all health and safety needs. This means some individuals receive an extensive amount of services and supports while others may be under-served or receive no services at all.

Current federal funding and the department’s policy are aimed at providing services and support to individuals in the community, preferably in their homes. This approach becomes more difficult as persons with intellectual disabilities and their caregivers age and their needs increase. Age-related changes in an individual’s overall abilities often necessitate increased programmatic and health supports. This may require individuals to transition from a less restrictive setting to one that provides more supports, or, if they are able to age-in-place at home, they may need additional modifications such as accessible doors, entrances, ramps, or bathrooms. In some instances, nursing home care may be the necessary alternative.

Recognizing the growing presence of the aging population, DDS has taken some initiatives to address the challenges of the issue. It has reinstated a Focus Team on Aging and hired an aging services coordinator. However, it has not adopted a formal plan on the types of services or placements that should be developed as its population ages. At the same time, the department faces the end of funding to address its wait and planning lists.

Increasing needs of aging individuals with intellectual disabilities. All people, regardless of their background, feel comfortable in surroundings for which they feel an affinity and which contain things that are familiar. For that reason, most advocates and social service professionals encourage the approach of aging-in-place, which simply means growing older where you are – in your home, with your family, in a group home, or any other place in the community. This approach requires planning to consider the changes that occur as people age. A system of supports that may have been ideal at age 50 may not be at age 70. Therefore, planning must occur to accommodate needs in one year, two years, or even five years out.

Uncounted individuals. Although estimates are not available, most disabilities professionals believe that there are uncounted numbers of families living with a relative who has an intellectual disability. There may be several reasons for these families being unknown to the department. One may be a generational thinking or attitude. Years ago, medical professionals often encouraged institutionalization for families of a child with disabilities. The stigma created around the care of the child may have led families to be reluctant to ask for help, preferring to

keep their needs to themselves. It is also possible the types of services needed were not available when the now-adult child was young and families may have felt they had no options. The adult child may not have been part of any system including educational and simply been cared for in the family home. These families may be unfamiliar with or wary of government services and may be unaware of the advantages. These uncounted families have the potential to overwhelm the system as the parents age, enter nursing homes, or die. By the time DDS discovers these families, it may be a crisis situation requiring emergency intervention. These unknown growing numbers of aging individuals will place even greater demands on a service system that is already stressed and unable to meet current needs.

Aging caregivers. Hundreds of older adults with an intellectual disability still live with their parents or other family caregivers. Many are growing older together and will likely require additional assistance. They may need greater services and supports both in- and out- of the home; legal or financial guidance; and/or preparation for alternative living arrangements. Some families recognize the importance of planning for the future but may feel too overwhelmed by the ongoing caregiver duties to focus on the issue. Others may be reluctant to even think about the implications of when they are no longer able to provide care. In some families, the aging caregiver and the adult child with an intellectual disability may be co-dependent to maintain their home and independence.

Proactive financial planning is also important for families who have a relative with an intellectual disability. If appropriate, they could avail themselves of legal vehicles that allow individuals with intellectual disabilities to receive assets without jeopardizing eligibility for government benefits.

In addition, the need for respite for families becomes more critical as the philosophy is to continue to provide residential services and supports in the family home. The provision of respite for older caregivers is especially vital as their physical energy and stamina may decrease with age.

Without proper planning, emergency situations arise that require crisis intervention (e.g., finding immediate residential placement for an individual with intellectual disabilities because a caregiver is hospitalized or dies). These crises frequently cost more than services provided through long-term planning.

Community supports. Aging adults with intellectual disabilities face many of the same challenges as other aging adults and some may derive benefit from programs and services provided in different service systems. Whenever possible, all aspects of the DDS delivery system must collaborate, coordinate, and leverage federal, state, and municipal resources to develop a full range of services to support aging individuals with intellectual disabilities. This is particularly important in the current financial climate.

The inclusion and integration into existing programs involves networking, planning, awareness, and education in order to be successful. These efforts require a key individual, such as the newly designated DDS aging coordinator, to broker and advocate for change to advance

the interests of older individuals with intellectual disabilities as well as staff to work directly with the persons being integrated and someone to guide and evaluate the integration effort.

Historically, agencies and providers tend to be reluctant to cooperate with each other in order to protect their jurisdiction and funding. However, in these troubling economic times, the need to work together rather than compete against each other may benefit multiple systems with cost-savings and common program options.

For example, senior centers offer a wide range of services geared for the over age 60 population. They provide opportunities to socialize and enjoy recreational or other structured activities. For some older individuals with intellectual disabilities, participation in local aging programs may provide a link to the community, when that is possible and appropriate. There may be need for collaboration and perhaps training with senior center program staff to ensure that older adults with intellectual disabilities can participate. Of course, the opportunities for leveraging resources may be limited. Senior centers do not only offer traditional activities such as bingo or arts and crafts. Today's older demographic and those aging baby boomers seeking to participate in senior centers will be looking for more diversity in activities. The anticipated "senior boom" will mean more of the general population will be in need of these services as well.

Nursing homes. Another area impacted by the growing numbers of aging individuals is long-term care. The need for and appropriateness of admission to long-term care facilities has been a particular issue for advocates for persons with disabilities. When faced with an adult who may appear to need the services of a nursing facility, the preferred practice is to find an alternate living arrangement in the community. The federal Omnibus Budget Reconciliation Act (OBRA) of 1987 instituted procedures for the admission and retention of persons with intellectual disabilities in nursing facilities. The law requires a preadmission screening for mental illness and intellectual disability for every person prior to admission to a nursing facility. It also requires that if an individual is found to have an intellectual disability, the need for specialized services be identified and provided. However, there is a growing concern among advocates for persons with disabilities about the implementation of these requirements.

Finally, as the demand and need for in- and out of home support increases, the pool of workers to provide these supports is dwindling. Furthermore, siblings or other relatives, who are expected to assume a larger role in providing primary care as parents' age or die, may not be prepared for this responsibility. As such, a key strategy is educating and training health professionals, direct-care workers, and new caregivers about challenges of caring for persons with intellectual disabilities.

Committee Recommendations

- 1. Funding for the wait list initiative should continue at current level for another five-year period. In addition, a separate, non-lapsing General Fund account should be established to receive any proceeds from the sale, lease, or transfer of any DDS property. The fund must be used, as appropriated by the General Assembly, to supplement the funding for DDS plans to provide services to individuals on its wait list. Any investment earnings on the fund's balance must be credited to the fund.**

- 2. DDS should analyze the wait and planning lists to identify individuals who will need services within the timeframes established under the priority categories and compare the results to the types of housing available to ensure homes are in similar geographic locations.**
 - 3. DDS should establish minimum criteria for what constitutes a significant change or situation prompting a level of need review.**
 - 4. DDS should increase the minimum frequency of case manager face-to-face contacts for DDS clients residing with aging caregivers as well as for aging individuals receiving DDS case management services in all residential settings.**
 - 5. DDS should request additional funds to provide lower case management ratios after it has examined its case management services.**
 - 6. DDS should evaluate and standardize the PRAT process used in each region to improve consistency.**
 - 7. DDS should reconsider the level of staffing dedicated to aging services when resources are available. At a minimum, a staff person in each region should be delegated to assist the central office aging coordinator in the efforts to develop new service alternatives and to leverage existing elder programs in order to integrate aging DDS consumers whenever possible.**
 - 8. DDS should designate a central office point-of-contact to assist families seeking legal and/or financial guidance regarding planning for the future of their children.**
 - 9. DDS should incorporate an additional component to the individual plan of aging clients that would reflect the individual/family's desired long-term care plan along with alternative contingencies if the desired long-term care plan is not viable.**
 - 10. DDS should consider the expansion of respite services when appropriations become available.**
 - 11. As part of its audit of nursing home records currently conducted by DDS, the following minimum information should be collected on and verified for clients currently living in nursing homes:**
 - a. case managers are assigned and have met the requirement of quarterly contact and annual face-to-face contact;**
 - b. whether or not the nursing home has notified DDS if a client has had a significant change in condition, been hospitalized, or died;**
 - c. health records are complete and accurate; and**
 - d. emergency contact information is contained in the file.**
-

12. The term “significant change in condition” be defined in guidelines, including the process that nursing facilities must follow in notifying DDS, what actions must be taken by DDS upon receipt of such notification, and circumstances that should initiate face-to-face contact between a client and his or her case manager, and/or require an assessment by a DDS nurse consultant. The roles and responsibilities of the case manager supervisor and regional manager-on-call should also be defined, including any actions that must be taken by them when such notification occurs.
13. DDS should establish a centralized data system to capture information on clients residing in nursing homes in order to document:
- a. reason(s) for nursing home admission;
 - b. lengths of stay;
 - c. admitting rates to nursing homes by hospital;
 - d. frequency of case manager contact, with uniform documentation and alerts generated when frequency of contact is not being met; and
 - e. notification of a significant change in a client’s condition, including an identification of the change.
 - f. DDS should randomly audit a sample of cases in the database to ensure its accuracy.
14. DPH shall notify the appropriate Regional OBRA Liaison of the results of its review of the PASSR Level II screens conducted in each nursing home. If DPH finds that the services identified in the Level II screen are not being provided by the nursing home, it should determine the reason why. The Regional OBRA Liaison should forward the results to each client’s case manager who is responsible for following up with the nursing facility to ensure the client has received the services identified in the Level II screen within 30 days of receipt of DPH findings.
15. DDS should partner with the two nursing home associations in Connecticut to provide targeted training around some of the specific issues related to providing care to individuals with intellectual disabilities who reside in nursing homes. Although training efforts could be aimed at a variety of audiences, it should, at a minimum, include:
- Registered Nurse (RN) nursing home directors responsible for client services; and
 - DPH surveyors who conduct nursing home inspections and record reviews.
16. DDS should survey the types of medical care provided in each private provider home and whether or not it is delegated to unlicensed staff. Based on the survey results, the department shall assess what is lacking in services among providers and establish a policy that provides for a comprehensive system of supports which will

encourage providers to provide certain types of care to clients and allow them to age-in-place.

17. DDS should, when revising its five-year plan and internal strategies, incorporate the action plans of the various work group reports it intends to implement and ensure that the goal statements include specific steps and dates of accomplishment for what the department is trying to achieve.
18. DDS should continue to collaborate with groups with similar objectives and report any accomplishments and expected or required DDS commitments to external projects in the department's five-year plan.
19. The Commissioner of Developmental Services, in consultation with the Commissioner of Public Works and the Office of Policy and Management, shall evaluate the feasibility and appropriateness of a continuum of options for Southbury Training School. At a minimum, the range of options shall include property closure and sale, continued or modified use as a DDS residential facility, and alternate uses for other state agency services. Each option considered shall provide:
 - the underlying rationale for the option;
 - the populations affected;
 - associated costs and/or revenue generated; and
 - a specific outline of the required action steps, potential entities involved, and anticipated timeframes for implementing the option.

The DDS commissioner shall hold public hearings to solicit input and opinion of interested stakeholders. The DDS commissioner shall submit a report containing the criteria and standards used to form the basis of the evaluation, transcript of any hearing(s) held, as well as findings and recommendations to the governor and the legislature no later than December 31, 2010.

20. The Department of Developmental Services, in consultation with the Department of Social Services, shall conduct a detailed cost review of per capita, per diem costs of care provided in institutional settings to care provided in the community. The cost methodology should include, but not be limited to the following factors: resident acuity, collective bargaining agreements, Medicaid costs, and the differences in staff costs between public and private providers. The report shall be presented to the legislative committees of cognizance by February 1, 2010.

Introduction

The Department of Developmental Services (DDS), formerly 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 Syndrome² and coordinating services for persons with autism. The department also operates the Birth-to-Three program that has a broader service definition.³

The department has a long history of providing services to individuals with intellectual disabilities.⁴ Up until the late 1980s, most services were provided at the Mansfield and Southbury Training Schools, two large-scale institutions. After a series of lawsuits, resulting in no new admissions being accepted at the Southbury Training School (STS) and the closure of Mansfield 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 DDS 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. There are a limited number of slots available for waiver services and individuals become eligible for waiver services if they meet income and asset limits established under the program and if budgetary resources exist.

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

² A genetic disorder with physical and cognitive problems, including a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.

³ Children under the age of three who live in Connecticut are eligible for the Birth to Three program 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.

⁴ 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, both terms are used throughout this report.

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 are an entitlement. In actuality, receipt of services is 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 and supports, 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, FY 09. Although great strides have been made in serving many individuals who were on 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, including those who are elderly.

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 this study in March 2008. The study 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.

Study target populations. The study concentrates on two populations: 1) individuals age 45 or older who are or would be eligible for DDS services, and 2) DDS client caregivers who are over the age of 65. The client group age 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 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 that is the focus 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, the committee references statistics and information specific to the study's target population.

Study Methodology

The program review committee reviewed national literature as well as Connecticut specific studies conducted on meeting the needs of individuals with intellectual disabilities who are aging and, if they live at home, their caregivers. Federal and state laws and regulations as well as DDS policies and procedures governing services and programs were also examined. The committee held a public hearing in September 2008 to solicit testimony from clients, advocacy groups, DDS, the Office of Protection and Advocacy for Persons with Disabilities (OPA), and others on the impact of the aging population on the provision of DDS services.

The committee, through its staff also conducted numerous on-site interviews with key stakeholders. These included legislators, legislative staff, DDS central office staff, Southbury Training School staff, and DDS regional staff, Department of Social Services central office staff, Commission on Aging staff, the DDS Ombudsman, OPA staff, private provider groups, and advocacy organizations, including family and parent representatives. Committee staff also met with the consultant overseeing the Wait List Settlement Agreement in addition to one of the attorneys involved in the litigation case pending at Southbury Training School.

The program review committee staff analyzed two databases that contained information on current DDS clients, as well as one specifically related to individuals who had been placed on the department's wait list for residential services and were considered not served or underserved. Data were also collected on eligibility determinations and outcomes related to appeals.

Report Organization

The primary purpose of this study was to examine and evaluate the department's methods and processes currently in place to assess the needs and costs of services provided to the aging consumer base. This report is divided into seven chapters. Chapter I gives an overview of pertinent population trends and a brief discussion of the effect of aging on intellectually disabled people. In particular, the prevalence of intellectual disability within the general population is discussed and the active DDS client base age 45 and older as of June 2008 is profiled. Chapter 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.

Chapters III through VII all include study findings and recommendations. Chapter III describes the current and projected status of the DDS wait and planning lists and profiles older DDS clients on those lists. Chapter IV 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. It also discusses DDS policy, procedures, and services as they relate to the aging consumer base. Chapter V examines emerging issues regarding individuals with intellectual disabilities in the nursing home environment. Chapter VI summarizes how DDS is currently planning for the needs of the study target population through the wait list initiative and addresses the need to continue to plan for elderly DDS clients. Finally, Chapter VII presents the challenges of determining cost of client care and planning among various residential settings.

Agency Response

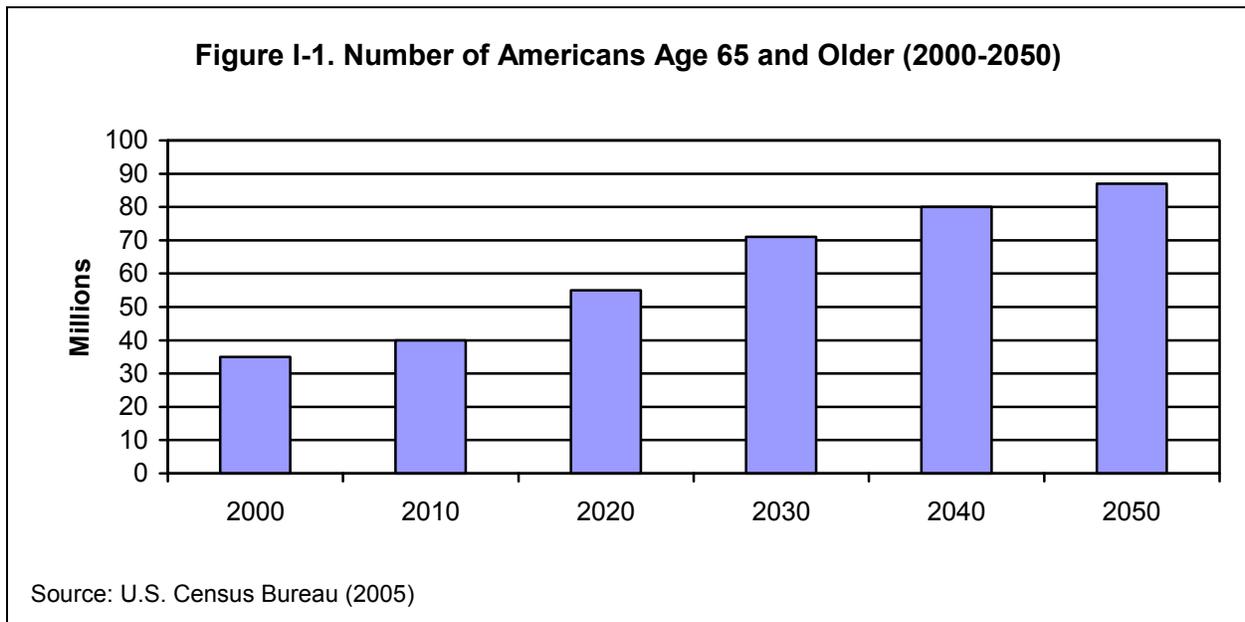
It is the policy of the Legislative Program Review and Investigations Committee to provide agencies subject to a study with an opportunity to review and comment on the recommendations prior to publication for the final report. Appendix F contains the response from the Department of Developmental Services.

Population Overview

The purpose of this study was 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 chapter 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 age 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.

Table I-1. Projections of Connecticut Population 65 and Over							
	<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>
Total CT Population	3,503,185	3,577,490	3,635,414	3,675,650	3,691,016	187,831	5%
Population 65 and older	479,443	515,621	577,083	642,541	723,326	243,883	51%
Percent of Total Population 65+	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 Department of Developmental Services, there are an estimated 33,500 individuals living in Connecticut who have mental retardation (1 percent of the population), 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 15,132, a 1.3 percent increase.⁵ The

⁵ 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.

number of clients 55 to 64 years old increased 14.8 percent during this timeframe, and those who were age 65 or older increased 5 percent. The 45 years old and older group represented 34 percent of the total DDS client population in September 2007.

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

Source: DSM-IV and DDS

Table I-3. DDS Population by Age (2004-2007)*						
<i>DDS Clients</i>	<i>2004</i>	<i>2005</i>	<i>2006</i>	<i>2007</i>	<i>Population Change</i>	<i>Percent Change</i>
Total All Ages	14,936	14,997	15,023	15,132	+196	1.3%
Age 0-21	4,449	4,395	4,312	4,272	-177	-4.0%
Age 22-44	5,806	5,760	5,740	5,746	-60	-1.0%
Age 45 -54	2,368	2,426	2,478	2,520	152	6.4%
Age 55 -64	1,399	1,457	1,523	1,606	207	14.8%
Age 65+	941	959	970	988	47	5.0%

Source: DDS Management Information Report (September 2004 – September 2008).

Unknown or unserved population. As noted previously, the 15,148 persons with intellectual disabilities served by DDS in 2007 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.

Unserved 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 will not 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 unserved 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).⁶

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.⁷ 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.

Demographic Profile of Current DDS Clients

The program review committee obtained a database from DDS containing demographic information on active DDS clients currently receiving services, and who met the study definition of the target DDS population (age 45 or older). The data presented in this chapter 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

⁶ 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.

⁷ *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.

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 that partially reimburses the state for community-based services delivered in a variety of settings to clients who 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 54 years old age group; these percentages diminish fairly rapidly for the older age groups.

Table I-4. DDS Consumers Age 45 and Older by Age Range		
<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%

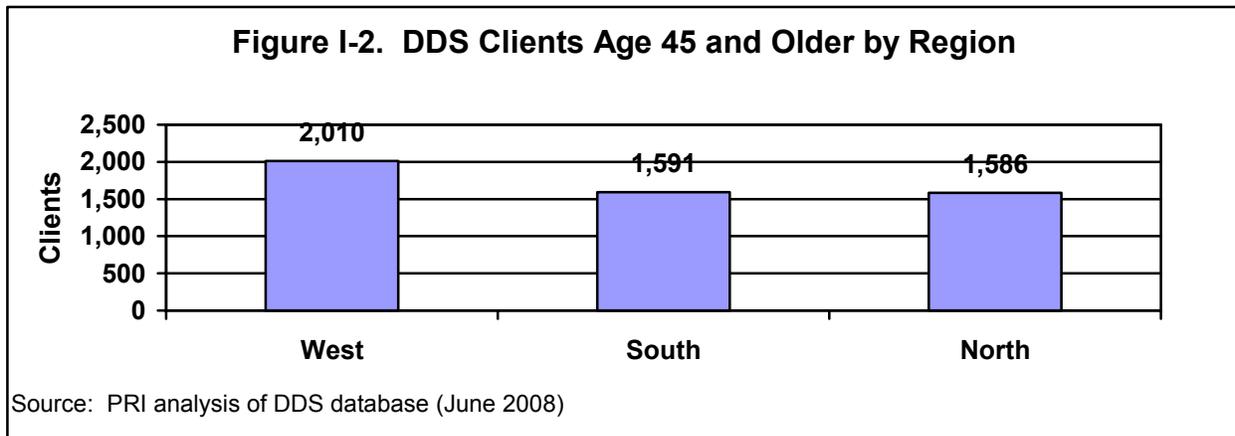
Source: PRI analysis of DDS database (June 2008).

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. Figure I-2 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.

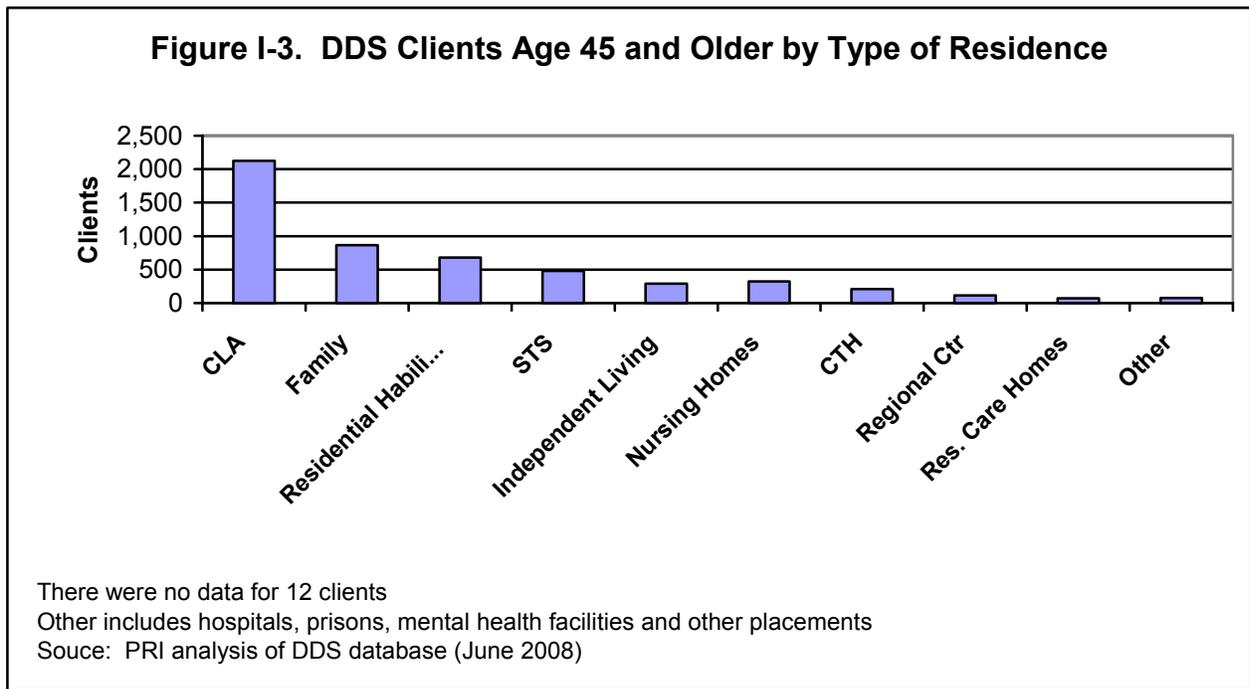


Type of residence. About 17 percent of DDS consumers age 45 and older live with their families. There are also a variety of other residential settings that DDS operates and/or funds. They include:

- *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 with 24-hour staffing;
- *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 with 24-hour staffing.

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. The program review committee compared the type of residential setting that DDS clients who were 45 years old and older lived, to where clients who were under age 45 years lived. 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 Older¹</i>		<i>Under Age 45²</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%
Total	5,175	100%	10,071	100%

¹ There were no data for 12 DDS consumers age 45 and older
² There were no data for 27 DDS consumers age 44 and younger
Source: PRI analysis of DDS database (June 2008)

Older consumers living with family. The program review committee examined the demographics of those clients who were age 45 or older and lived 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	--
Total	864	100%

Source: PRI analysis of DDS database

Level of mental retardation. The program review committee 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.

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 chapter 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 chapter, 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:

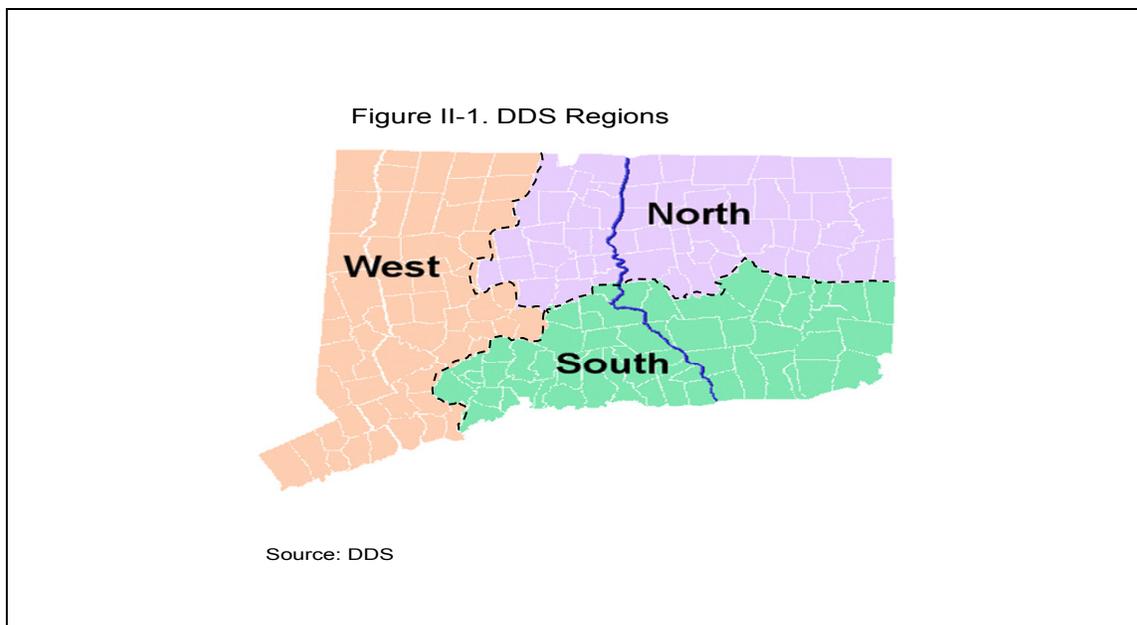
- Presence and participation in Connecticut town life
- Opportunities to develop and exercise competence
- Opportunities to make choices in the pursuit of a personal future
- Good relationships with family members and friends
- Respect and dignity."

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 DDS 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 DDS commissioner 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 Ombudsman's Office may provide information to help them solve particular problems. The Ombudsman 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 DDS regions in Connecticut. 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, all of which provide day services, with five providing residential services also.



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* – 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; or

- *Individual Family Support* – clients live alone or with their families 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. Each region also has a 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 there 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 with 125 buildings. The school independently operates its own power, heat, sewage treatment and water plants, and has separate fire and ambulance departments and an on-site Connecticut State Police Resident Trooper.

Budget Resources and Staffing

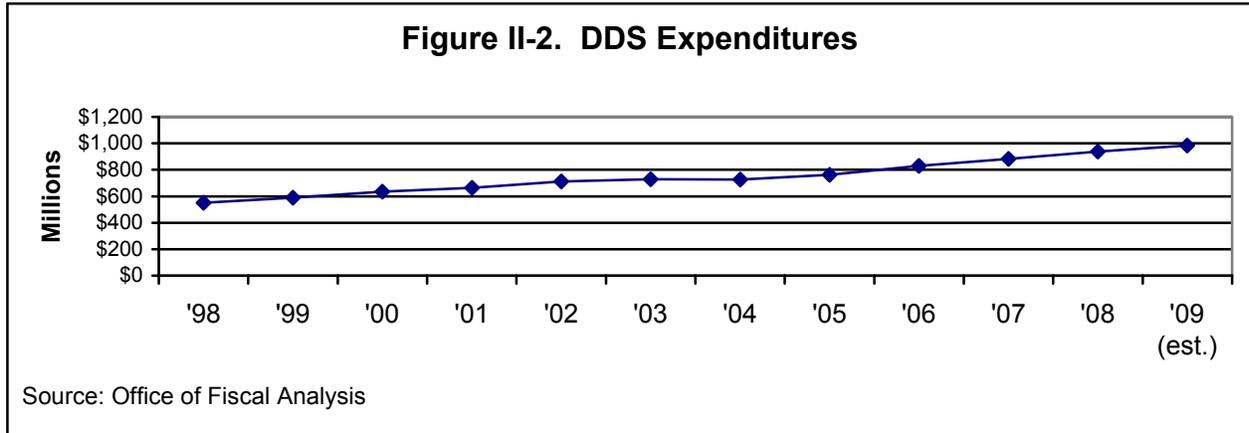
Overview. As of June 2008, the Department of Developmental Services provided services to about 15,200 clients (excluding those in the Birth-to-Three program) and had almost 3,600 permanent full-time and 1,120 part-time staff positions. The department’s expenditures for FY 08 are estimated at almost \$940 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, FY 09, the department’s budget reflects the biennial budget adopted 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 DDS case managers, it was not adopted.

The program review committee 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, like all state agencies, 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.

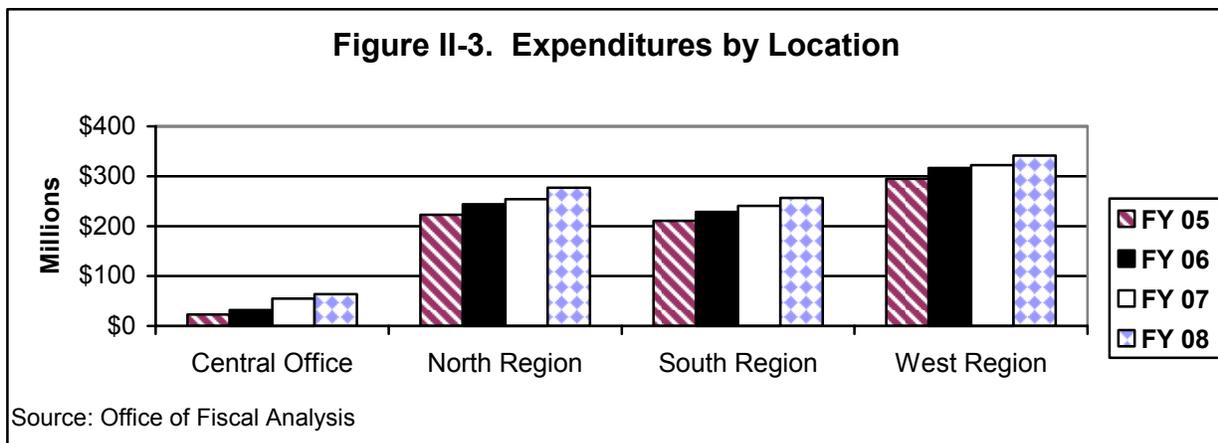
Expenditures and Revenue

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.

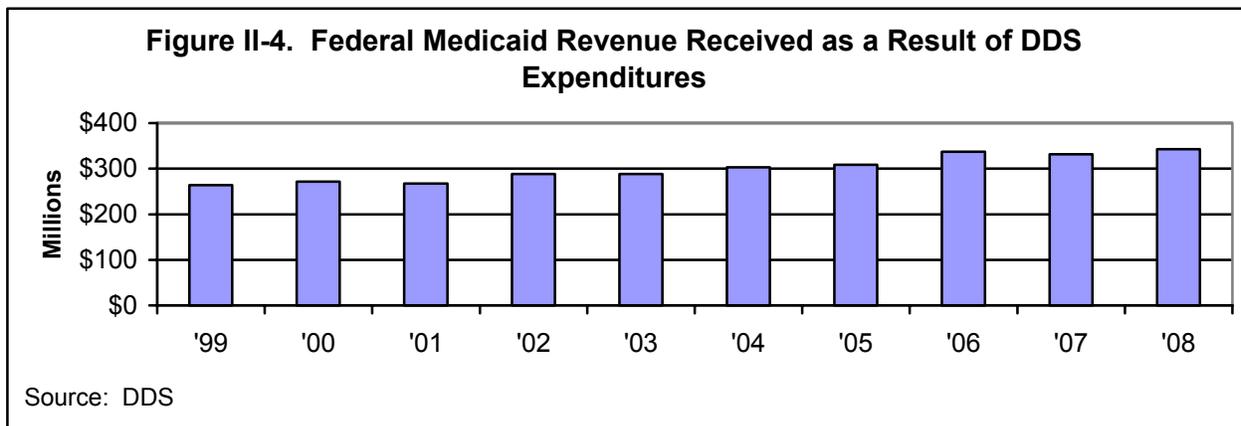


Expenditures by geographic location. DDS expenditures are examined by geographic location in Figure II-3, which shows the amount expended by the central office and in each of the three DDS regions. Expenditures for Southbury Training School are included as part of the West Region's expenditures, which 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 for covered services. 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 accredited only for services provided to DDS clients since FY 99 (not those paid for by DSS), 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.⁸

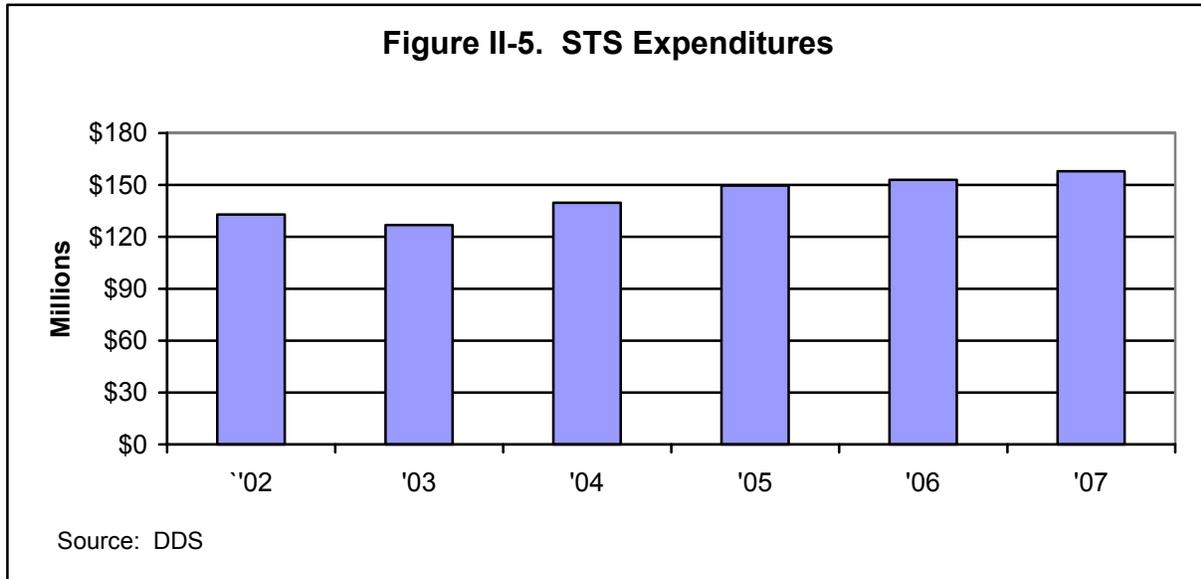
Most of the federal Medicaid revenue received is for services provided by DDS under the IFS or Comprehensive waivers, accounting for 68 percent of total federal revenue in FY 07, compared to 27 percent for ICFs/MR in FY 07. Revenue for the other two areas - targeted case management and the Birth-to-Three 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 02. Although the number of DDS consumers at STS has declined from 654 clients in June 2002 to about 500 in June 2008, expenditures increased almost 19 percent.

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

⁸ 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.

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.



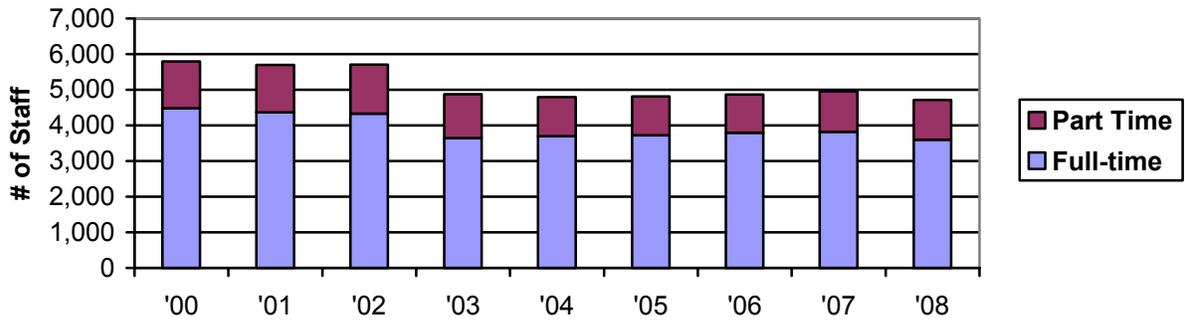
DDS Staff Resources

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 age 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.

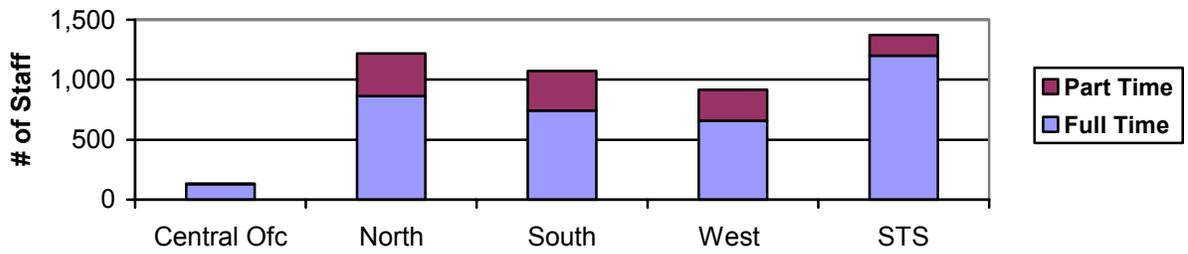
Staff by geographic location. Figure II-7 shows the number of filled positions by location. Southbury Training School had the most staff with 1,199 full-time filled positions compared to the North Region, which had 862 full-time staff. It is not surprising that Southbury has the greatest number of filled 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. Filled Positions (as of June 30th each fiscal year).



Source: Office of Fiscal Analysis

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



Source: Office of Fiscal Analysis

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DDS Wait and Planning Lists and Recent Planning Efforts

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 that existed at that time.

The parties negotiated and eventually agreed to a five-year settlement agreement (FYs 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, FY 2009.

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 newly created planning list as underserved or undersupported.

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.⁹

One critical settlement agreement requirement was that DDS and DSS apply for a new federal Medicaid waiver with an emphasis on self-directed supports and services tailored to meet individual and family needs as well as another new waiver with higher monetary thresholds to provide services and supports to individuals who need and require services on a comprehensive basis.

⁹ 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 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 stated that the consultant reports should be structured and viewed as progress reports, not compliance reports.

Two independent consultants were hired in July 2005. The consultants have conducted numerous activities including facilitating quarterly meetings with the parties, and holding 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, which are referred to as opportune vacancies. 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.

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 believed DDS was aware of the issues and was actively working to address the problems.

Profile of Older DDS Clients or Those with Older Caregivers on Wait or Planning List

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

Table III-1. DDS Priority Status Categories for Wait and Planning List as of June 2008				
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
	Total		560	195
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
	Total		1450	32
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 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.

The program review committee obtained a database from DDS containing information related to active DDS clients on the wait or planning lists who met the definition of the study's target population – DDS clients who are age 45 or older or have a caregiver who is age 65 or older. The data presented below are based on 1,103 clients who met this definition as of October 2008. It provides a snapshot of individuals currently active on the wait or planning list seeking residential services and supports. The clients who are on the wait or planning lists either:

- reside at home with family or live independently, and
 - receive only case management; or
 - receive limited DDS services funded through state enhanced family support grants; or
- live at home with family or in a residential setting, such as a group home or supported living, and receive DDS residential services and supports under the

Home and Community-Based Services (HCBS) Medicaid waiver, but are considered underserved and need more resources or a different placement now or in the future.

Of the 1,103 individuals meeting the study's target population definition, 762 individuals were age 45 or older and 341 were under age 45, but had an elderly caregiver who was age 65 years old or older.

The following set of figures (Figures III-1 to III-6) provides a brief summary of the staff data analysis. It should be noted that due to missing information in the database, the N=counts in each of the figures vary, which can impact other figure numbers. Additional analysis and information on the target population is provided in Appendix A.

Figure. III-1. Regional Distribution of Target Population on Wait and Planning Lists

- The South Region had the highest percentage on the wait and planning lists but there was not a large variation in the number of target clients among the three regions.

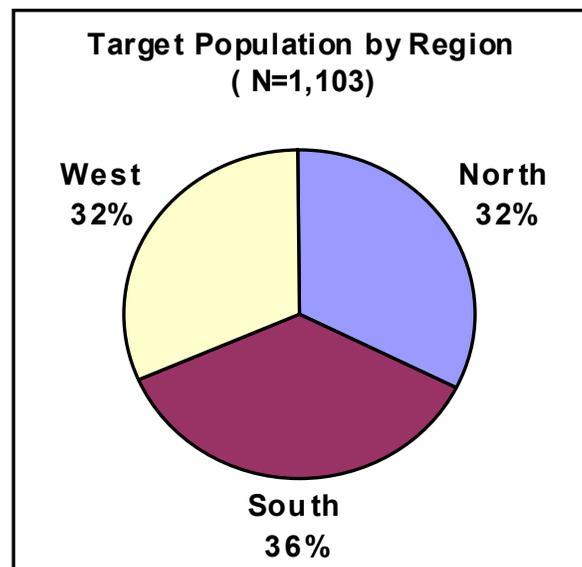


Figure III-2. Primary Reasons Why Target Population on Wait and Planning Lists

- Most of the target population were receiving only case management (55%) and many were underserved (22%). The remaining individuals (23%) needed additional funding, particularly to move from one DDS residence to another for a more appropriate placement.

Source: PRAT Database

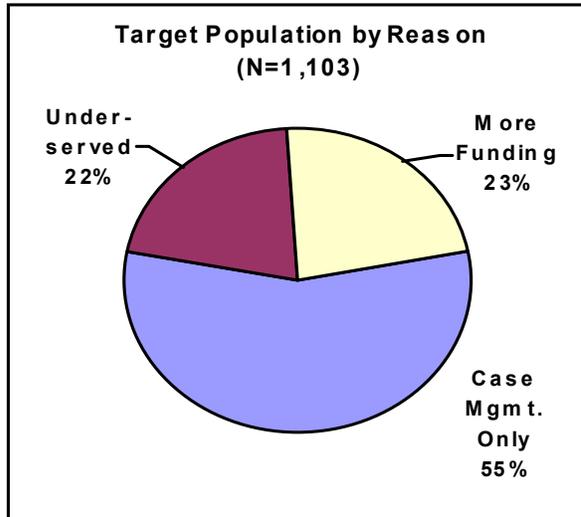
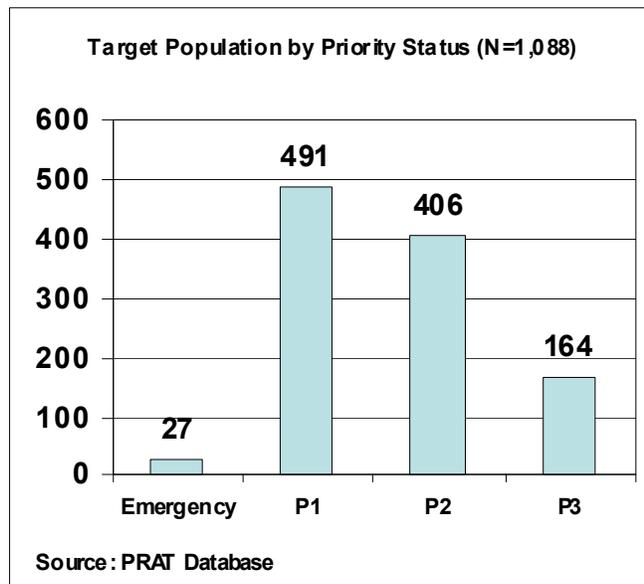


Figure III-3. Priority Status of Target Population on Wait and Planning Lists

- 45% of the target population have been identified as Priority 1 or needing services within a year.
- Only 27 individuals in the target population need emergency placement as of October 2008. However, they represent 40% of all emergencies on the wait list.



Source: PRAT Database

Figure III-4. Primary Residence of Target Population on Wait or Planning Lists

- The majority of clients age 45 or older considered an emergency are living with family, while those identified as a Priority 1 live in a variety of settings, but primarily reside either with their family or in a community living arrangement (i.e., group home).

Where Clients are Living by Priority Status (N=1,081)				
Residence	Emergency	P1	P2	P3
Family	19	185	318	141
CLA	1	172	35	6
SNF	-	47	1	4
Sup. Living	2	4	13	42
Ind. Living	1	24	22	3
Reg. Center	-	6	5	2
CTH	-	3	4	1
Other	2	5	10	3
Total	25	446	408	202

Source: DDS

Figure III-5. Target Population Living with Family on Wait or Planning Lists

- Of the 680 age 45 or older individuals living with family, 149 (22%) had caregivers age 80 years old or older.
- 83% of the clients age 45 or older living with family were not receiving any residential services or supports beyond case management, while others were receiving a small state grant or were considered to be underserved.

Source: PRAT Database

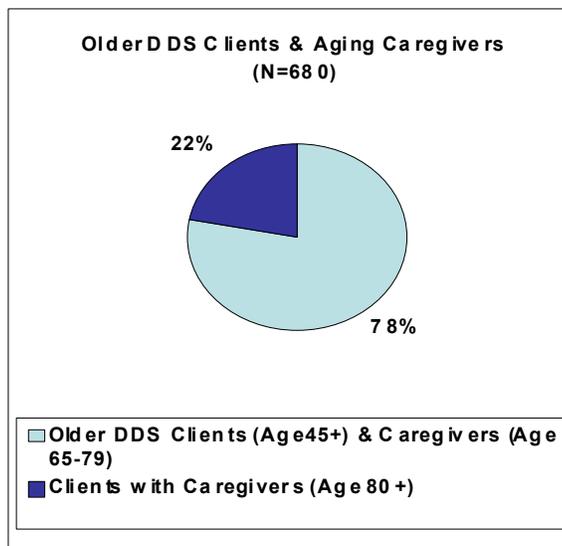


Figure III-6. Target Population on Wait and Planning Lists Living with Elderly Caregivers (Age 80+)

- The majority of those living with elderly caregivers age 80 or older were identified as P1 or P2 (77%) indicating residential services and supports would be needed within a year (P1) or within two to five years (P2).
- 115 clients (77%) living with elderly caregivers who were age 80 or older were not receiving any services except case management.

Priority Status for DDS Clients living with Caregiver Age 80 or Older. (N=149)		
Status	Number of Clients	Percent of Total
Emergency	8	5.4
P1	48	32.2
P2	67	45.0
P3	26	17.4
Total	149	100%

Source: PRAT Database

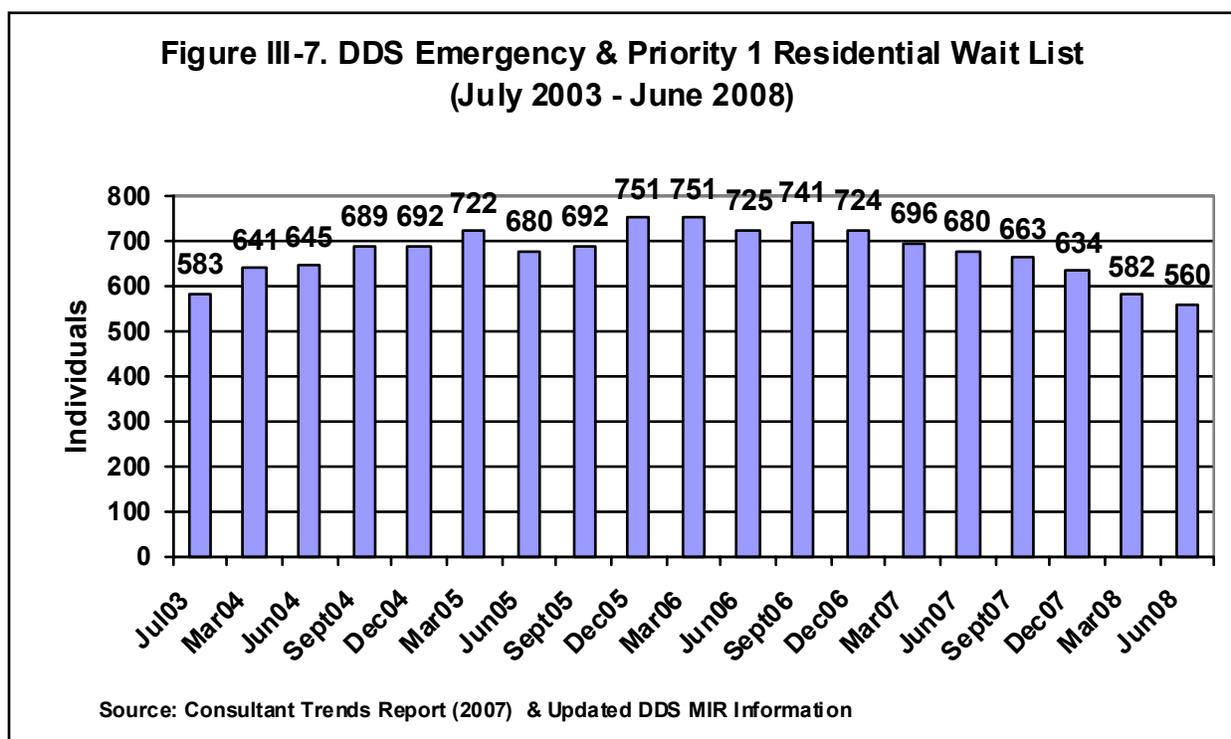
Implications. One of the stated objectives of the priority categories, according to the settlement agreement, was to serve individuals with older caregivers. The program review data analysis indicates that 149 DDS clients have elderly caregivers over the age of 80. While not a large number compared to the 15,000 active DDS clients, these individual’s situations could become a potential source of emergencies as they could change quickly. Without proper planning, this could become a potential source of emergencies. DDS may want to consider developing contingency plans for individuals who live with parents who are aged 80 and over. (This issue is discussed further in Chapter Four, which covers DDS policy, procedure, and services.)

In order for the department to adequately plan for the needs of individuals who will be seeking services either almost immediately or within one year, it is critical that this data be better maintained by case managers and tracked by the department. The program review analysis shows that DDS gathers a significant amount of data on the individuals placed on the wait and planning lists. However, some of the information is not maintained in a consistent manner. For example, the type of residence needed was not identified in 130 cases contained in the database. Data are an essential tool in the planning process. Information contained in the wait and planning list database serves as the foundation to evaluate current needs and project estimates of future needs.

Wait List Trends and Projections

In 2007, an independent consultant selected by the settlement agreement parties conducted a trend analysis on the number of individuals seeking residential services and supports. This analysis was updated in 2008 at the parties request and is summarized here.

Residential wait list for Emergency and Priority 1 status. Figure III-7 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 number of individuals waiting for residential services as of June 2008 is 13 percent lower than it was in June 2004 and is the lowest count since before the settlement agreement went into effect. One reason for this is because the legislature, as part of the settlement agreement, appropriated \$33.8 million over a five-year period targeted at providing services to individuals on the wait list. Another reason is that the department changed its methodology on how individuals are prioritized on the wait list, as explained below.



The consultant's 2008 report specifically notes changes in DDS fiscal and contract management as impacting the wait list. The report cites DDS' ability to reuse annualized funds when clients leave the system and recapture money from client allocations that are not completely used as better management of "opportune openings."¹⁰ In addition, the department made changes in the wait list priority assignments by placing more emphasis on the individual's level of need and situational factors and less on the family/individual's request for services

¹⁰ Opportune opening(s) arise when a person leaves DDS-funded residential services, or funds allocated can be used for more than one person and the vacancy is filled with someone from the waiting list.

within 12 months. According to the consultant, the combination of these changes has resulted in additional placements and a decrease in demand.

Among the points made in the consultant's 2008 report:

- The number of people on the residential wait list declined in part due to a higher than expected number of opportune openings. The number of opportune openings in 2008 was 12.5 percent higher than in 2007 and about 36 percent higher than the average over the last four years. The report indicates that approximately 422 wait-listed individuals received residential service by virtue of opportune openings in the last three years.
- Although there has been an almost 18 percent drop in the number of individuals waiting for services in the Emergency and Priority 1 categories (560 individuals in June 2008 compared to 680 in June 2007), there has also been a 23.4 percent *increase* in the number of persons waiting in the Priority 2 status. The consultant suggests this increase is partially due to DDS "refinements in the assessment and categorizations criteria for Priorities 1 and 2."¹¹ According to the consultant's report, DDS now applies a more stringent test for Priority 1. In the past, Priority 1 was assigned to families/individuals that indicated they wanted residential services within 12 months. Now, the department focuses on other factors such as the individual level of need (LON) scores, which is described in Chapter IV, along with situational and environmental factors including the age of the caregiver and current level of supports and services. Furthermore, to infuse fairness and consistency, these factors are considered by the regional planning and resource allocation (PRAT) teams rather than the case managers.
- Despite the progress made in moving people out of the top two (Emergency and Priority 1) categories of the wait list, the overall wait list including individuals in Priority 2 and Priority 3 continues to grow (approximately one percent from 1,986 in 2007 to 2,010 in 2008).

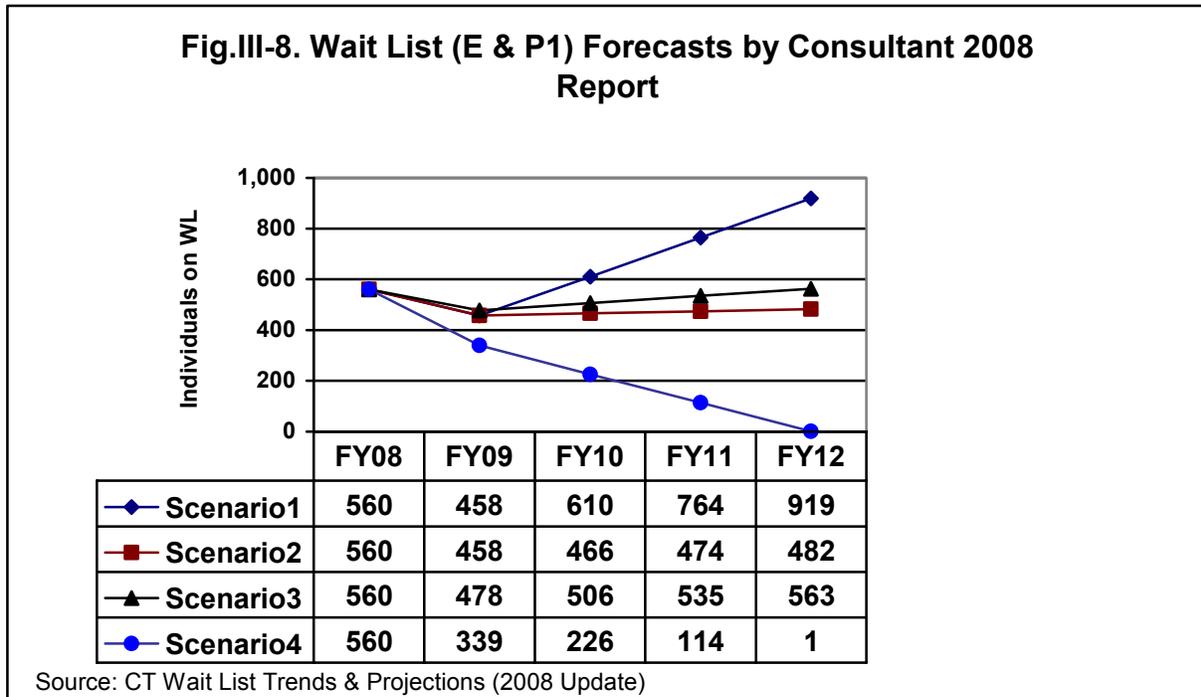
In projecting the future service demands of the wait list, the 2008 consultant report assumes these new trends (more opportune openings, more effective use of new funding, and a smaller number of people on the Emergency and Priority 1 wait list) will continue to hold. As a result, the consultant's report projects a lower rate of demand compared to the rate predicted in the 2007 report. Under the updated consultant's analysis, the total residential services demand would increase approximately 2.46 percent per year or 9.9 percent from the year 2008 to 2012 as opposed to the 2007 consultant report, which projected a 3.5 percent increase each year, or a 13.9 increase over the same time period.

Nevertheless, the consultant continues to concur with his previous conclusion that individuals eventually shift upwards in the priority rankings over time as they and their care-

¹¹ *Connecticut Wait List Trends & Projections*, September 23, 2008, p.3

givers age. As such, “holding the wait list constant will require year-over-year expansion of services to keep pace with demand.”¹²

Looking ahead to the next four years, the number of people on the wait list will depend on the extent the state is willing to fund services. The consultant’s 2008 report depicts four alternative scenarios to forecast the future of the DDS wait list. All the scenarios assume: continued settlement funding creating new openings (except Scenario 1); ongoing opportune openings and same turnover rate; and separate funding to manage youth who age-out of residential services. Figure III-8 illustrates the four scenarios described below.



Scenario 1 shows that the use of the remaining settlement agreement funding through FY 09 will expand and provide residential services and supports that would initially decrease the wait list numbers. However, with no further additional funds allocated following the expiration of the settlement agreement in FY 09 to continue the growth in system capacity, the wait list would rapidly grow by the year 2012 to 919 individuals.

Scenario 2 reflects continued funding for each year after the expiration of the settlement agreement funding. By maintaining new residential funding at the same rate (an estimated 120 clients at an average cost of \$50,000 per client) as previously provided, a modest decline would occur in the wait list. Under Scenario 3, funding for slightly fewer individuals (103 new clients) than currently provided for under the settlement agreement would result in essentially no change in the wait list.

Finally, Scenario 4 presents the elimination of the wait list by 2012. To do this, the state would have to provide new funding for 262 persons a year beginning in FY 09. This would

¹² Connecticut Wait List Trends & Projections, September 23,2008, p.5

decrease the current wait list to half by 2010 and end it by 2012 assuming funding continues to prevent the wait list from reappearing.

Conclusions. The trend analysis shows that the five-year wait list initiative has been successful in reducing the number of individuals seeking residential services including many eligible DDS consumers who had previously not been served or were underserved. Part of the success in the reduction of the wait list has also been to reclassify individuals by shifting them into a lower priority category. However, the trends indicate that demand greatly exceeds current funding. The aging of the population will continue to increase demand for residential services as the individuals served and their caregivers age and most likely need more supports.

Based on PRI analysis and a review of the consultant report findings, the committee finds that *the five-year initiative has moved many individuals off the DDS wait list, including many over the age of 45.* Wait list funding ends this fiscal year and the impact, as cited in the consultant's projections, will be dramatic if no new funds are appropriated. *The end of wait list funding will stop the momentum made in serving persons on the wait list and create another definite backlog and possible risk of further litigation.* Already operating as a crisis-driven system, the elimination of wait list funding will exacerbate this system given the finite resources and anticipated demand. Therefore, the program review committee recommends:

Funding for the wait list initiative should continue at the current level for another five-year period. In addition, a separate, non-lapsing General Fund account should be established to receive any proceeds from the sale, lease, or transfer of any DDS property. The fund must be used, as appropriated by the General Assembly, to supplement the funding for DDS plans to provide services to individuals on its wait list. Any investment earnings on the fund's balance must be credited to the fund.

The current economic climate is much worse than when the wait list initiative began five years ago. However, it is clear that without a continued infusion of funding for the DDS wait list, the progress made through the wait list initiative investment of \$33.8 million will be diminished. These financial times, coupled with the competing needs of various groups, require different ways of securing funding. One method would be to earmark funds for specific purposes. For example, in 2001 the legislature created a non-lapsing General Fund account to hold the proceeds from the sale, lease, or transfer of all or any part of the Fairfield Hills and Norwich hospitals and any regional center. The fund could only be used, as appropriated by the General Assembly, for site acquisition, capital development, and infrastructure costs needed to provide services to persons with psychiatric disabilities and mental retardation. One recent example of a potential sale of DDS property would be the Seaside Regional Center located in Waterford. If the state had authorized the sale proposed by the Department of Public Works in late 2007, approximately \$7.1 million dollars would have been available for the account.¹³

Use of housing bond funds. A question arose during the study about whether certain housing bond funds that had been already released for assisted housing could be used for DDS

¹³ In 2008, Governor Rell directed the Department of Public Works not to sell the Seaside property in Waterford. Instead, the governor indicated her decision to preserve the 36 acre parcel.

clients, specifically bond funds authorized and released in 2007 to supplement funding for the supportive housing pilots initiative.¹⁴ This initiative would provide up to 650 units of affordable housing and support services for persons or families who are affected by psychiatric disabilities or chemical dependency, or both, and who are homeless or at risk of homelessness. According to the Office of Fiscal Analysis, bond funds once allocated and released cannot be used for another purpose.

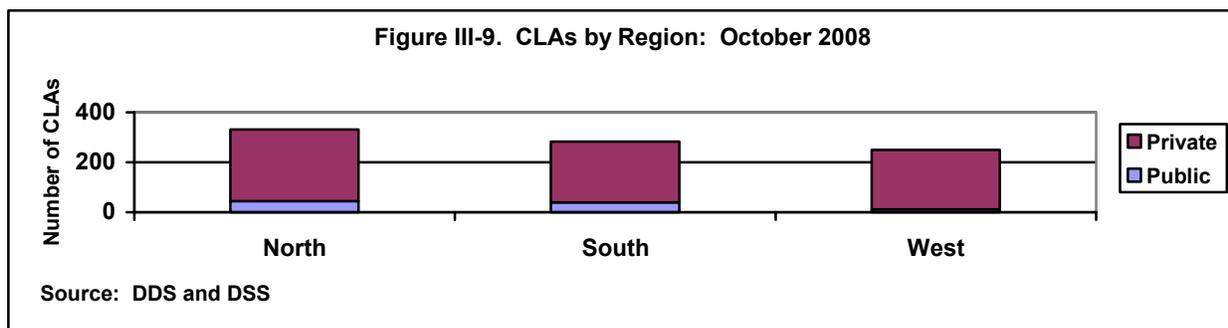
Provider Capacity and People on the Wait List

The committee also examined residential community living arrangements (CLAs), or group home, capacity to determine: any regional variation in the number of homes and/or beds; the average number of beds by type of provider; and any excess capacity in towns where individuals on the wait list for residential services were residing. As of October 2008, there were 864 CLAs in the state with a total licensed capacity of 3,872 beds – 559 public (i.e., owned and staffed by DDS) and 3,313 private beds.

The committee found that there was almost no excess capacity in the system. When a permanent vacancy occurs, an unfilled bed quickly becomes an opportune placement and is filled. An individual without resources or who is inappropriately placed will be moved into the vacancy as determined through the Planning and Resource Allocation Team (PRAT) process.

Although the department does try to place individuals close to their families, it can be difficult to predict when or where beds will become available, and whether the level of care provided in a specific CLA matches the needs of the individual being placed. In addition, when a placement is found, often the caregiver is not yet ready to have the individual move out of the family home.

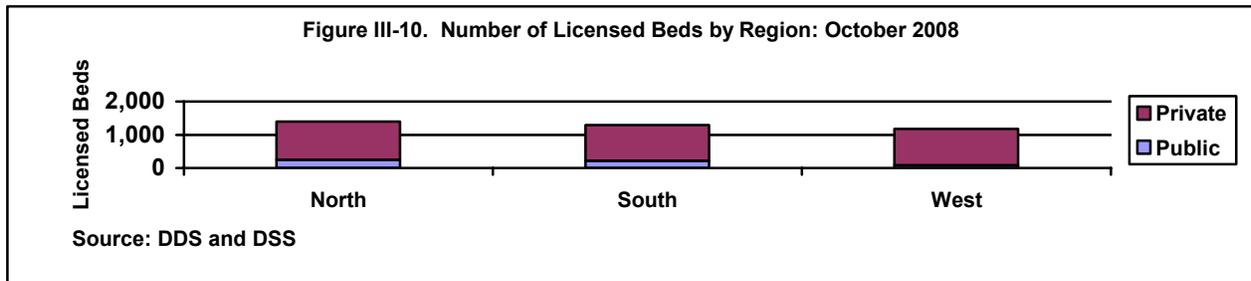
Figure III-9 shows the number of CLAs in each region and whether they are privately or publicly owned and operated. The North Region had a total of 331 homes, the South Region had 283, and the West Region had 250 homes. In addition, the North Region has the greatest number of publicly-operated homes (45) and the West Region the least (11).



The vast majority of licensed beds are owned and operated by private providers. Figure III-10 identifies the number of beds in each region by type of provider. The North Region has

¹⁴ Bond Commission Agenda (January 26, 2007), Item Number 29, Department of Economic and Community Development for various housing projects and programs as authorized under S.A. 04-2 (Sec. 9)

the most beds with 1,150 private and 250 public beds and the West Region the least with 1,091 private and 87 public beds.



According to the Department of Social Services, as of October 2008 there were 2,896 licensed private CLA beds (see Table III-11), although DDS indicated to DSS that it could potentially expand capacity to 2,924 beds. Table III-11 shows the number of licensed private beds by region and whether any of those homes could add new beds to increase capacity. According to DDS, most homes are at capacity and very few homes could increase the number of licensed beds. This means that either opportune vacancies need to occur or additional homes would have to be developed to serve a greater number of individuals in terms of residential placement.

	<i>North Region</i>	<i>South Region</i>	<i>West Region</i>	<i>TOTAL*</i>
Current Licensed	1,041	958	897	2,896
Maximum Capacity	1,052	963	909	2,924
Available Growth	11	5	12	28

Source: DSS
 *The total number of 2,896 in the DSS database is different from the DDS total number of 3,313 private beds because DDS includes 385 licensed CLA ICF/MR private beds and 30 beds that are filled by children and teenagers and funded by DCF.

The trend over the years has been to reduce the size of group homes to make them more like a family home. Under the Money Follows the Person federal grant initiative, if an individual moves out of an institutional setting, he or she can only live in a home that has four or fewer beds. Table III-12 compares bed size among CLAs and found that homes operated by private providers are smaller, with an average size of four licensed beds, although they range from one to ten licensed beds.

Region	Public	Private
North	5.6	4.0
South	5.7	4.4
West	7.9	4.6

Source: DDS

Table III-13 shows there were 683 individuals who were on the wait or planning lists who were age 45 or older or living with a caretaker age 65 or older by priority status. The table

identifies the wait list priority status by region. The majority of these individuals (83 percent) are not receiving any services beyond case management. Of the 683 individuals, 274 were waiting for a CLA placement (110 in the North Region, 60 in the South, and 104 in the West).

Table III-13. Wait and Planning Lists Status for Individuals Age 45 or Older or Caregiver is Age 65 and Older by Region				
<i>Priority Status</i>	<i>North Region</i>	<i>South Region</i>	<i>West Region</i>	<i>Total</i>
Emergency	8	3	8	19
1	64	58	65	187
2	116	113	99	328
3	45	51	53	149
Total	233	225	225	683

Source: PRI analysis of PRAT database

As noted earlier, the wait and planning lists provide the department with a valuable tool by helping to identify the clients who will require residential services and supports within the next year, the types of residential service that will be needed, and the level of care the department will have to provide to the client. Even for clients who want services and supports provided at home with their caregivers, many older individuals and those with older caregivers will ultimately need a residential placement. The program review committee believes that the department could use the wait and planning lists to plan for older clients coming into the system by determining where need exists and whether a complementary number of homes with the services that will be needed are available in similar geographic locations. Therefore, the committee recommends:

DDS should analyze the wait and planning lists to identify individuals who will need services within the timeframes established under the priority categories and compare the results to the types of housing available to ensure homes are in similar geographic locations.

By using the wait and planning lists as a strategic planning tool to identify the types and locations of residential services, the department will better meet the future needs of its wait and planning lists population.

DDS Eligibility, Case Management, and Sources of Funding

This chapter 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 chapter identifies the sources of funding that are used to provide services to clients.

DDS Eligibility

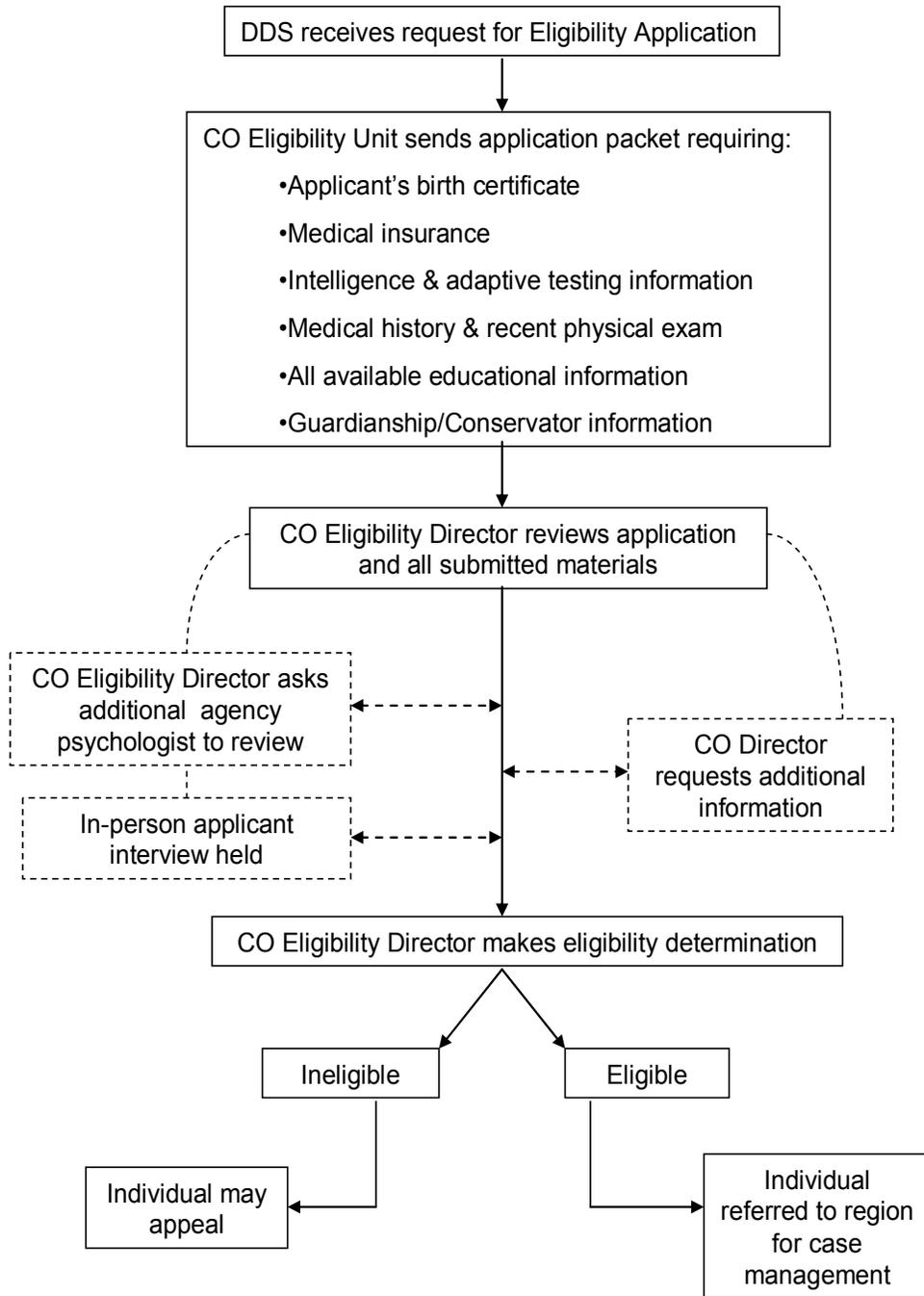
As noted in Chapter I, in order to be eligible for supports or services from the Department of Developmental Services, an individual must: be a Connecticut resident, and have a diagnosis of mental retardation as defined in C.G.S. § 1-1g or present a medical diagnosis of Prader-Willi Syndrome.

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 IV-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 provided 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.

Figure IV-1. DDS Eligibility Process



Source: PRI

Applications are available in Spanish and interpreters and assistance are 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 applicants 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 chapter.)

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 annual 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 IV-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 eligible for DDS services 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.

Table IV-1. Number and Age of Persons Found DDS Eligible (as of YTD June)					
Age	2004	2005	2006	2007	2008
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 provided 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 IV-2 outlines the general case management process.

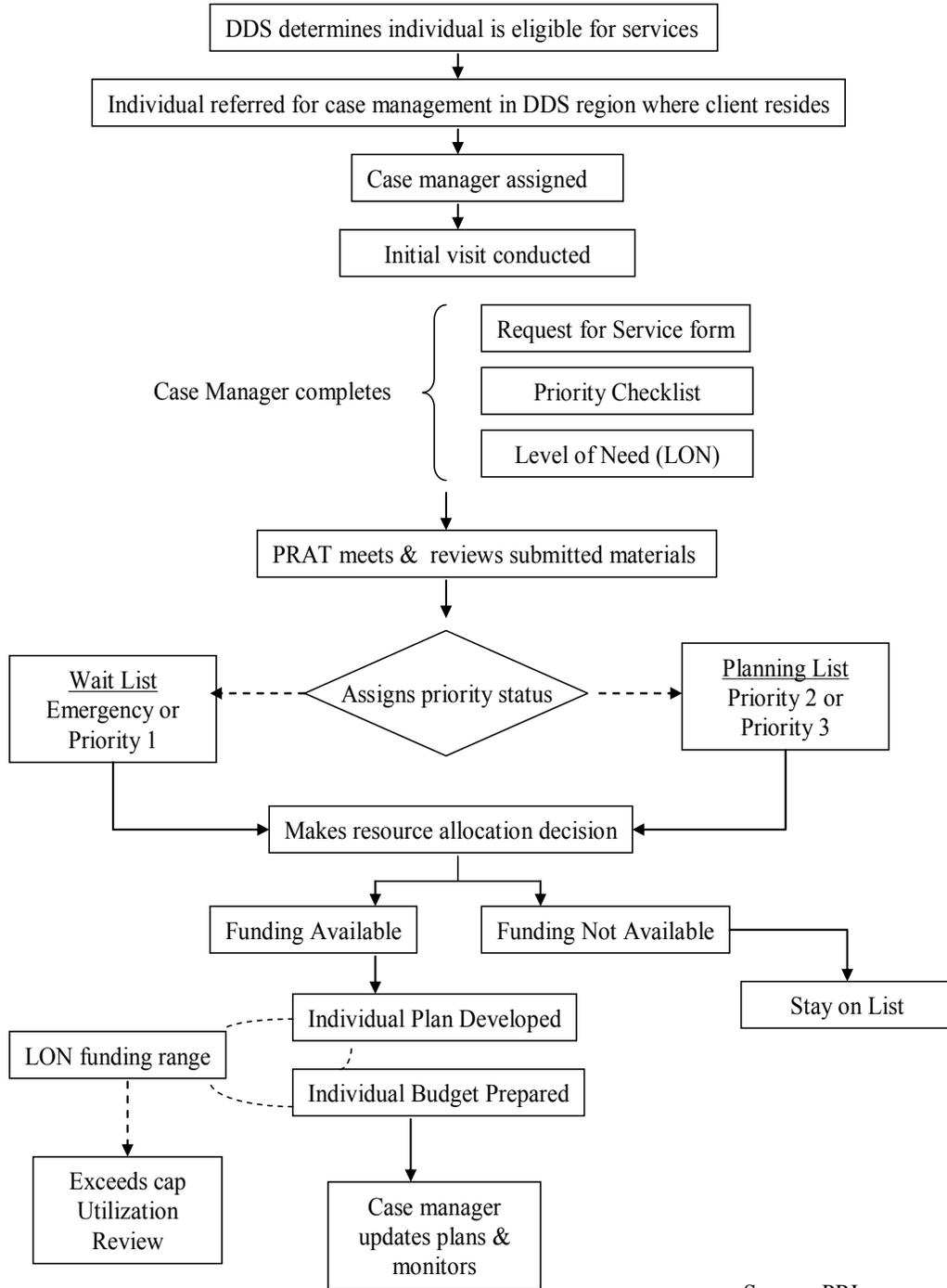
Case manager assignment and initial meeting. New clients are typically notified of their case manager assignment within two weeks of being determined eligible for DDS services. According to the department, case management resources may not always be immediately available except for those clients already 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 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, and Minimum. (The level of need funding ranges are explained in more detail below.)

Figure IV-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.¹⁵ 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 desired 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 may vary

¹⁵ 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. PRATs meet on a regular schedule and on-need basis for emergencies.

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

- 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 its 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 and planning 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 Southbury Training School beds are certified as ICF/MR, as well as beds of DDS regional campuses. In addition, there are a total of 69 private CLAs with ICF/MR certified beds. Room and board is reimbursable under the ICF/MR state Medicaid plan option.

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 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*: 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. As of September 30, 2008, CMS had approved 4,018 slots to be funded under this waiver although only 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, of which 4,471 were filled because of funding.

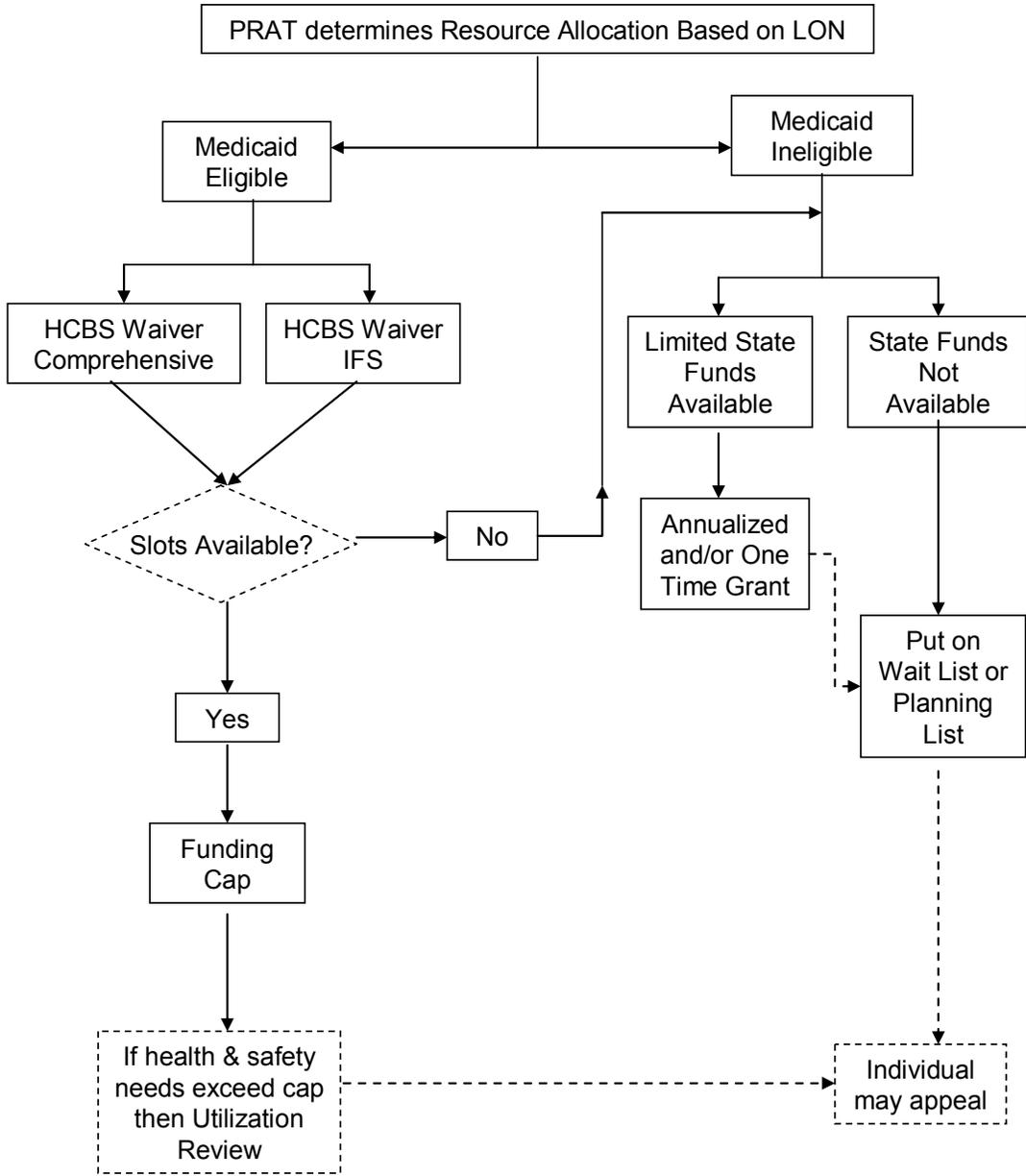
Services available. The types of services that can be provided under each waiver program are shown in Table IV-2. Although many of the services are similar under the two waivers, the major difference is that the Comprehensive waiver includes a licensed residential component, and the intensity of services provided is much greater, both of which account for the higher cost ceilings allowed for individuals enrolled in this waiver. It is important to note, however, no room and board component is reimbursed. This is paid for by the Department of Social Services under a separate program.

Table IV-2. Medicaid IFS and Comprehensive Waiver Services	
<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 IV-3 shows the process used by PRAT teams to allocate resources, once the case manager has provided the information shown in Figure IV-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 eligible for the Medicaid waiver, actually receives waiver services and supports. Rather, the individual will be placed on the Wait or Planning lists until resources become available to provide services to the client.

If no waiver slot is available, the individual and his or her family will be offered limited state funds and/or case management services. The individual may also be placed on the Wait or Planning lists, 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 IV-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 IV-3 and Table IV-4 show the funding ranges and caps under each waiver.

Table IV-3. FY 08 Level of Need Funding Ranges – IFS Waiver for Adults		
<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		

Table IV-4. FY 08 Level of Need Funding Ranges – Comprehensive Waiver			
<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 IV-4). In these cases, PRAT only has discretion to recommend funding be exceeded by a certain level (shown in Table IV-4 in the third column), even if the services and supports needed are higher. If this occurs, the regional director has three choices:

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

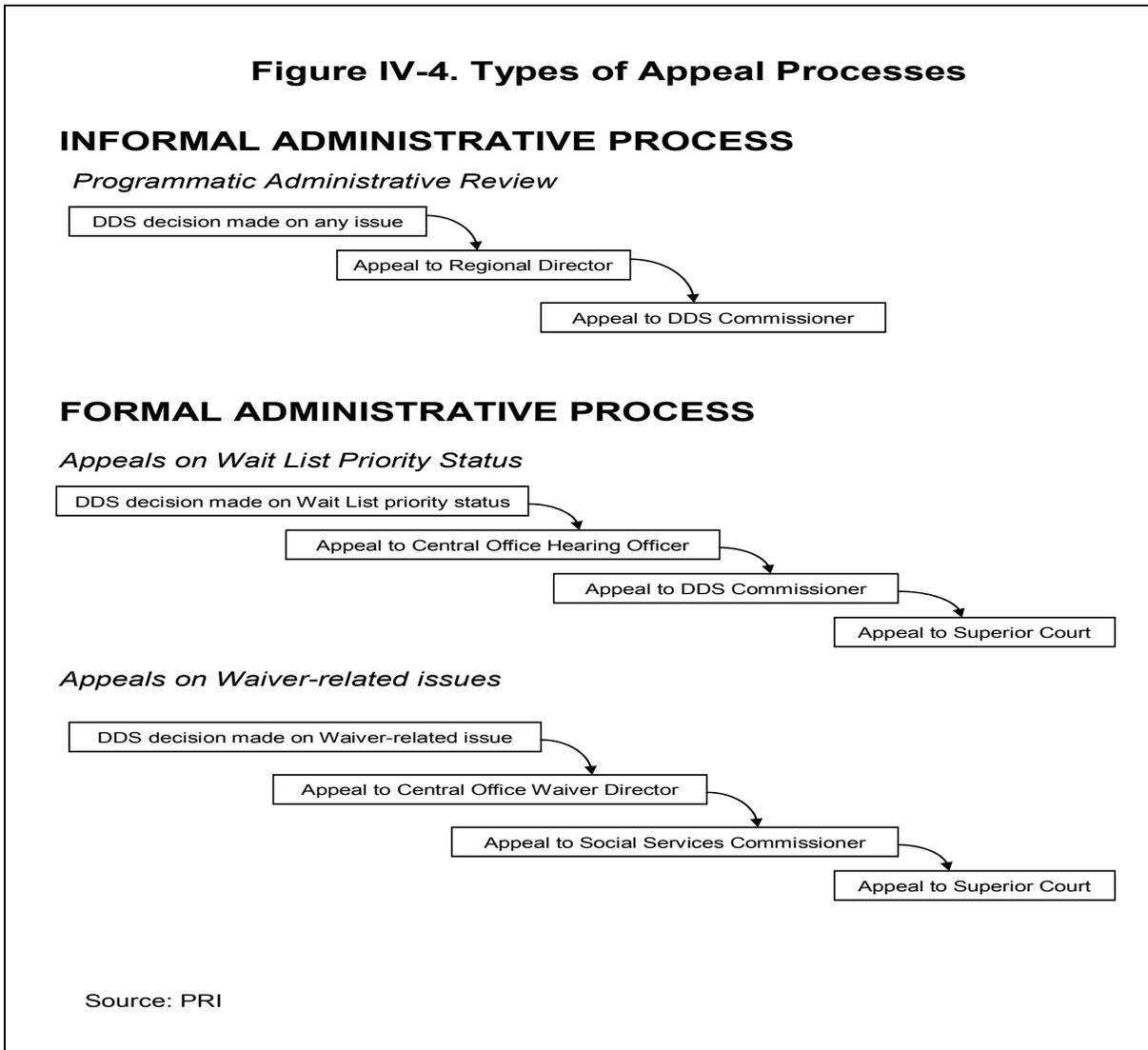
State Funded Supports

Many individuals 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 IV-5).

Table IV-5. State-Funded Supports Available to Non-Waiver Individuals and Families	
<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 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>	Consultation 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 IV-4 provides a basic overview of the appeal processes.



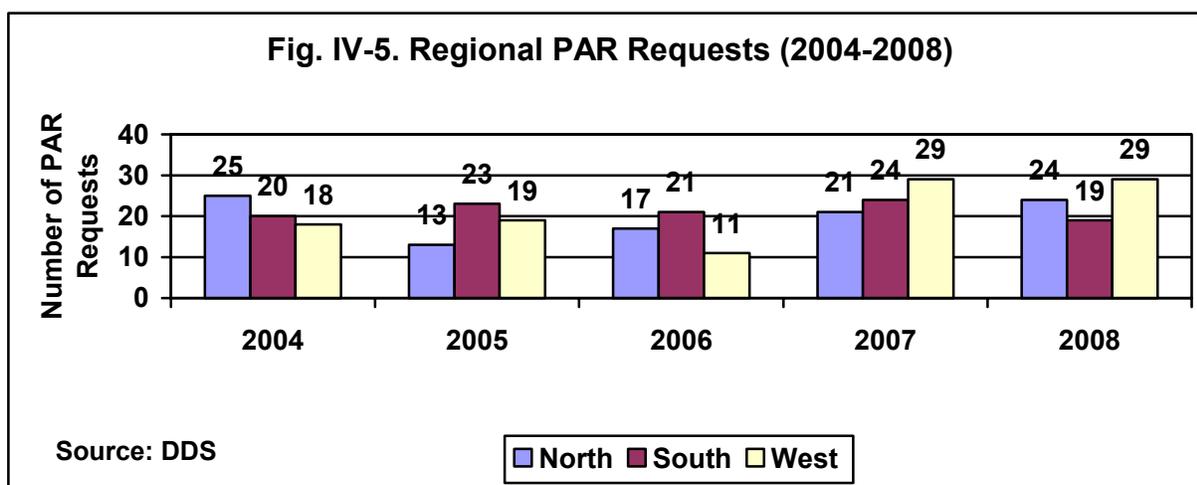
Programmatic administrative review (PAR). A programmatic administrative review (PAR) is available for any decision related to:

- 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 IV-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.



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 waiver services may request a DSS hearing.

Wait list priority assignments may be contested at any time. Persons seeking to contest a priority assignment may request an administrative hearing through the DDS Division of Legal and Government Affairs. 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 denying eligibility for services under the HCBS waiver;
- DDS denying provision of certain relevant waiver services; or
- DDS determining a level 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.

DDS Policy, Procedure, and Services

The scope of this study was not intended to include the overall operations of the Department of Developmental Services. However, certain agency functions, such as case management services and regional decision-making processes, have an impact on the delivery of services and support provided to all DDS clients, including the aging DDS consumer. The following discusses certain aspects of DDS policy and procedure that affect the entire DDS population, including older individuals. Recent DDS efforts made specifically to improve service delivery to older clients and their caregivers are also described, along with suggested improvements.

Case management. The LON tool produces a composite score by examining 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 assessment is updated annually or upon a change in the client's life or situation.

The DDS policy and procedures manual provides no guidance or directives for what would constitute a change in situation that would prompt a new LON assessment. Interviews with various DDS staff indicate a change of situation is determined by the case manager. It would appear that the underlying policy objective is to provide case managers discretion for when to prepare an updated LON assessment. Recognizing that the circumstances and factors involved in each client's life may be unique, the program review committee supports the concept of case-by-case discretion for case managers. However, individual interpretation and discretionary authority should be balanced with the need for systemic consistency. Therefore, the program review committee recommends:

DDS should establish minimum criteria for what constitutes a significant change or situation prompting a level of need review.

One purpose of the LON tool is to determine an individual's need for supports in an equitable and consistent manner for the allocation of DDS resources. This intention to infuse fairness into the decision-making process could be undermined if broad interpretation by case managers results in inconsistent application of the tools designed to assist the distribution of resources.

Another purpose of the needs assessment is to identify potential risks that could affect the health and safety of the individual. The case manager is responsible for developing an individual plan to mitigate those risks by monitoring the client's situation. The frequency of case manager contact is based on the individual's residential setting. The DDS policy and procedure manual clearly states that "in no circumstance will an individual receiving case management services be contacted less often than annually."¹⁶ A review of the DDS policy and procedures documents indicates that the minimum frequency of case manager visits and contacts increases if the individual receives waiver services and/or day supports. Non-waiver clients residing in their own or family home and individuals residing in private ICFs/MR or nursing homes have a once-a-year face-to-face minimum contact. It is important to note that even though the DDS manual references only the minimum level of contact required, case managers may actually be making contact more often than the minimum requirement. However, the committee believes a better system must be established that systematically tracks case manager contact and alerts supervisors when requirements are not being met.

Client contact is a crucial foundation of case management services. In particular, face-to-face contacts provide an opportunity to monitor and accurately assess a client's situation. Anecdotally, case managers state that families, especially those with older caregivers, are reluctant to share information or even allow entry to their homes. Considering that an aging individual's health and medical status can change fairly quickly, families with older caregivers and those with limited or little supports may be more vulnerable and potentially at risk for crisis. As a measure to prevent a situation requiring DDS crisis or emergency intervention, the committee believes that *older individuals residing in their own or family home with few or no supports and perhaps with an aging caregiver should be monitored on a more frequent schedule.*

¹⁶ DDS Manual, Procedure No. I.C.1PR.001.c (June 2003) p.2.

In addition, a person receiving care in a long-term care facility does not necessarily merit less case supervision. In fact, there have been long standing concerns about the level and type of care provided to individuals with intellectual disabilities at long-term facilities. This issue is currently being reviewed by the DDS central office and the Office of the DDS Ombudsman. (Further discussion on DDS clients residing in nursing homes is provided Chapter V.) Therefore, the program review committee recommends:

DDS should increase the minimum frequency of case manager face-to-face contacts for DDS clients residing with aging caregivers as well as for aging individuals receiving DDS case management services in all residential settings.

This recommendation will likely increase case manager workload at a time when additional resources may be unavailable. Although an examination of the department's overall caseload was outside the scope of this study, the committee believes *a comprehensive look at the demands of DDS case management services should be considered.*

In 2007, the consultant hired as a result of the DDS wait list settlement agreement issued a report also suggesting DDS evaluate its case management services. The consultant's 2008 report applauded DDS steps to address case management ratios but stressed the importance of the settlement parties to seek additional funds to provide effective ongoing monitoring to ensure health and safety needs and increase face-to-face time with DDS clients. The program review committee concurs with the consultant's conclusion and recommends:

DDS should request additional funds to provide lower case management ratios after it has examined its case management services.

PRAT decisions. At the core of all key decisions regarding DDS client services including requests for residential and day supports is the regional planning and resource allocation team (PRAT). The PRAT team examines available resources and matches them to individuals on the wait list. To gain a better understanding of the PRAT decision-making process, the program review committee staff attended regional PRAT meetings and interviewed DDS staff about the process. *The committee interviews and observation of the meetings revealed some examples of regional difference.*

First, the number of PRAT meeting participants depends on the type of request or nature of the agenda. One regional PRAT meeting had over 20 participants with a consensus building approach while another region limited involvement to six or seven higher-level staff. Second, each region handled the notification of residential vacancies differently. One region closely controlled the release of vacancy notifications while another shared vacancy information freely with case managers. Another regional difference is the administration of the wait list. Each region has its own method of tracking movement among the priority categories. Finally, one region has adopted an informal method of prioritizing within a wait list priority category.

These examples are presented as potential areas of inconsistency among regions. An in-depth evaluation of the PRAT process was not possible under the time constraints of this study. Therefore, it is difficult to conclude whether one region's methods or process yields better

results. The committee staff interviews indicate some regional differences are due in part to a lack of a coordinated database among the regions. As a result, each region has developed its own internal datasheets and methods used at the PRAT meetings. This is an issue the department is in the process of remedying through an updated centralized computer system. This will resolve some of the differences noted among the regions.

It must be noted that the department's policy and procedures manual does outline the process for the resource allocation process. For instance, the DDS manual allows the composition of PRAT to vary. However, as the examples mentioned above indicate the number of individuals involved in PRAT decision-making can range from six up to 20 staff. While the program review committee was not able to determine whether the variation in composition yields different regional results, it does raise the possibility.

The DDS manual also requires the central office Waiver Unit to annually audit the regions' prioritization and resource allocation processes for adherence to DDS procedure.¹⁷ However, discussion with the Waiver Unit director indicates that the audit is actually a quarterly review of the regional data submitted to prepare the department's Management Information Report. The review is primarily to resolve any discrepancies (mainly coding errors) and is not an audit of individual decisions.

As part of its review, the program review committee examined the number and type of recent appeals made by individuals age 45 and older through either the formal or informal DDS grievance process. Individuals disputing waiver-related issues may seek a formal DDS administrative hearing and, if necessary, appeal to DSS as the state's Medicaid administrator. Since 2006, only six of the 41 waiver-related formal appeals involved clients age 45 and older.

An internal programmatic administrative review (PAR) is also available as an informal dispute resolution process. PARs allow clients or their advocates to meet with the regional directors to discuss concerns and, if necessary, to seek a review by the commissioner or his delegates. In 2008, only seven of the 42 requests for an informal programmatic administrative review were made by individuals age 45 and older. Appendix B provides the results of the committee's limited review, which did not reveal any impact from regional differences.

To maintain a fair and equitable system, there must be a good and reliable data system with accurate assessments of client situations made by case managers. Finally, there must be consistent application of resources tools, such as the LON, and consistent decision-making among regions. Therefore, the program review committee recommends:

DDS should evaluate and standardize the PRAT process used in each region to improve consistency.

DDS Aging Services and Caregiver Support

As mentioned previously, 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 include: representatives from families; service providers; state agencies on housing;

¹⁷ DDS Manual, Procedure No.: I.B.1.PR.001.

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 its proposals.

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 the DDS central office.

Aging coordinator. In conducting its study, the program review committee worked extensively with the newly assigned DDS aging coordinator. The coordinator's overall role is to ensure the individuals served by DDS have access to the supports and services they need as they age. *The scope and multitude of duties associated with the aging coordinator position are immense.* 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. The coordinator also acts as an internal liaison between the central office and DDS regions including Southbury Training School for all age-related issues ranging from health care, end-of-life planning, housing, recreational services, transportation, public awareness, and education and training. In addition, the coordinator serves as liaison with external groups including other state agencies, private providers, associations, and advocacy groups.

Recently, the responsibilities for this position were expanded to include the Money Follows the Person (MFP) initiative (a DSS-led effort to move individuals out of institutions and back into the community) and the development of statewide forums for aging caregivers. The volume of individuals and entities that the coordinator position must interact with to satisfy the required duties are vast. For example, one of the coordinator's primary responsibilities is to contact municipalities to tap into existing local services such as senior centers. The communications and activity required for this, as well as all the other coordinator tasks, are time-consuming. Given the current scope of duties and the recognition that aging services will become increasingly vital as the DDS population continues to age, the program review committee recommends:

DDS should reconsider the level of staffing dedicated to aging services when resources are available.

At a minimum, a staff person in each region should be delegated to assist the central office aging coordinator in the efforts to develop new service alternatives and to leverage existing elder programs in order to integrate aging DDS consumers whenever possible.

Caregiver support. Most of the services DDS provides directly benefit the individual with intellectual disabilities and indirectly support the individual's caregiver. DDS has recognized the need to provide more direct support for caregivers and families through certain

services such as respite. In addition, the department has recently started to hold forums across the state to offer caregiver education, support, and awareness of relevant issues.

Caregiver forums. In the fall of 2008, the DDS aging services coordinator, in conjunction with the North Central Area Agency on Aging, began a six-week presentation series to provide caregivers with residential, legal, and financial information. The program was provided at no cost to parents, siblings, and guardians of individuals with intellectual disabilities.

Despite various attempts to encourage participation, attendance at the first series of caregiver forums was low. According to DDS, this is not unexpected based on some of the generational and cultural attitudes of older caregivers regarding government involvement and privacy concerns frequently encountered by case managers. By promoting the series through the DDS website, flyers, e-mail, newsletters, support groups, providers, and direct invitations, the department plans to hold two forums in each DDS region with a goal to implement the caregiver forum in at least twelve different sites within the next two years.

Planning for the future. One topic discussed at the caregiver forums is the importance of planning for the future. For families dealing with the day-to-day caregiver challenges, taking the steps to make sure their child is cared for after they die is not necessarily a concern or they “just aren’t ready yet” to let go of the care-giving duties. Unfortunately, families may not realize that certain traditional estate planning methods such as a will may not produce their desired outcome. For example, a direct inheritance may be considered an asset and jeopardize an individual’s eligibility for government services such as Medicaid or could possibly be taken to repay public cost-of-care charges such as publicly funded residential costs.

There are different ways a family may safeguard a child’s eligibility for services while providing for additional needs not covered by government programs. One approach is the preparation of a special needs trust. Special needs trusts, sometimes referred to as supplemental needs trusts, allow a person with intellectual disabilities to receive certain funds, yet those funds are not considered to belong to the individual in determining eligibility for public benefits.

Special needs trusts may not provide or replace the basic support or necessities usually covered by government assistance, but rather, as the name implies, these funds can be used to supplement government benefits. These funds may cover quality of life items, such as wheelchairs, handicap-accessible vans, mechanical beds, and personal attendants as well as recreational and cultural experiences. Some families may want their loved one to continue to live in the same house. Through certain legal arrangements, the house can be managed for the benefit of the person, or perhaps expanded into a group home setting.

The exact language and provisions contained in a legal document are critical. DDS cannot provide legal advice to families on private estate planning issues. Currently, families seeking guidance from DDS will be referred to the Office of the Attorney General, the Department of Social Services, and/or the Department of Administrative Services.¹⁸ However,

¹⁸ As the lead Medicaid agency, DSS reviews the impact of assets on eligibility. DAS determines if the state is owed any cost-of-care charges while the Office of the Attorney General reviews any legal implications in the state’s interests.

there is no direct central point-of-contact person assigned at DDS to handle basic estate planning inquiries. The program review committee recommends:

DDS should designate a central office point-of-contact to assist families seeking legal and/or financial guidance regarding planning for the future of their children.

In addition to legal and financial matters, planning for the future also involves other major areas of a person's life such as living arrangements and the array of services, supports, and personal needs of the person with intellectual disabilities. This is particularly critical for individuals with intellectual disabilities who live at home with aging caregivers. According to DDS, many families fail to make plans for their loved one's future living arrangement when the primary caregiver can no longer provide at-home care. As a result, many times individuals arrive at DDS as a crisis or emergency situation. Anecdotes shared by case managers with program review committee staff reveal several reasons families fail to plan. Parents may assume siblings will continue the care-giving duties even though they have not discussed or confirmed this with them. Aging caregivers may not be ready to accept their own mortality or give up their responsibility for fear that no one else can provide care as they do. Some families believe that government services and supports will be available whenever they need or want them.

DDS has provided awareness and training for case managers and families to address these issues. However, *case managers can only suggest future planning to families who are under no obligation to consider it.* Currently, DDS clients eligible to receive services must have an individual plan that guides the current services and supports to be provided. The plan is generally updated on an annual basis or upon a change in circumstances. The committee recommends:

DDS should incorporate an additional component to the individual plan of aging clients that would reflect the individual/family's desired long-term care plan along with alternative contingencies if the desired long-term care plan is not viable.

This recommendation is not intended to be viewed in any way as a mandatory or binding component of the individual plan. Rather, it is proposed as ongoing encouragement to the individual and/or family to consider addressing future needs in periodic manner.

DDS Respite Services

Respite services provide families temporary relief from ongoing caregiver responsibilities. Respite care may be provided in- or out-of-home. Families enrolled in the HCBS waiver program may obtain in-home respite care from community providers or purchase respite services from others selected by the family. Non-waiver individuals may request a DDS Individual and Family Support grant to purchase their own respite services. Centralized information regarding the use and cost of in-home or private source respite services by DDS clients was not readily available for analysis by the committee. Therefore, the focus of the following discussion is on out-of-home respite care provided by DDS.

Out-of-home respite care is available on a limited basis through visits to the DDS respite centers. DDS respite centers are aimed at DDS-eligible individuals who reside in their family home but do not receive in-home supports. There is no charge for using DDS respite centers.

As Table IV-6 shows, respite centers are available in each of the DDS regions. The North Region has an 18-bed capacity among three centers located in Putnam, Windsor, and Newington. The South Region has a total of 19 respite beds available in Meriden, New Haven, and Waterford. The West Region has the largest number of beds (26) in respite centers in Torrington, Stratford, Trumbull, Norwalk, and Southbury. With a total 63-bed capacity statewide, all eleven centers provide both overnight and hourly respite by trained DDS staff and most of the centers have nursing available on-site or access to nursing for medications and treatments.

Respite centers are open every weekend during the year, though each center may vary slightly in terms of their hours of operation. In addition to long weekends, each center is open for eight weeks throughout the year including weeks during the summer and some school vacations. Specific dates may vary depending on the respite center.

DDS respite centers are generally able to accommodate individuals with various abilities and needs, as well as persons who may have behavioral or medical challenges. A wait list for each center is maintained by the regional respite coordinator. Priority is given to families who are not receiving other in-home supports, personal supports, or other services from DDS.

Scheduling respite. Families are limited to the use of respite centers in the DDS regions in which they reside. By exception, a region may consider requests from families in other regions. Case managers provide the necessary information and help with the process of applying and scheduling a visit to one or more of the respite centers.

Table IV-6. Respite Bed Capacity and Nursing Availability			
	REGION	CAPACITY	Nursing Availability
NORTH	Newington	6	Yes (On-site)
	Putnam	6	No
	Windsor	6	Yes (On-site)
	Sub-total	18	
SOUTH	New Haven Area (Hamden)	4	No
	Meriden	6	Yes (Access)
	Waterford		
	Rope Ferry	3	Yes (Access)
	George Street	6	Yes (On-site)
	Sub-total	19	
WEST	Ella Grasso (Stratford)	2	Yes (On-site)
	Lower Fairfield (Norwalk)	6	Yes (On-site)
	Spruce Brook (Southbury)	6	Yes (Access)
	Torrington	6	Yes (On-site)
	White Plains (Trumbull)	6	Yes (Access)
	Sub-total	26	
	TOTAL STATEWIDE	63	
Source: DDS			

After a pre-visit, the case manager requests respite for the family’s preferred date(s). Each region has a regional review committee to review, approve, modify, and schedule all respite visits. Regional committee members include, at a minimum, representatives from the regional respite coordinator, a respite program supervisor, and a respite nurse. Scheduling is based upon: the availability of space given the number of requests for a particular time period, attempts to group individuals into compatible peer clusters, the safety concerns of particular individuals, and the number of previous individual visits compared to other individuals. If possible, individuals with the most challenging needs are given first priority.

The respite committee attempts to accommodate families’ plans and specific dates by scheduling respite visits in advance. However, the centers cannot guarantee specific dates given the large number of requests. If a family cannot use the available dates, the respite staff will offer the opening to alternate families. The centers try to provide families with multiple weekends of respite per year; however, resources are very limited. According to DDS staff, most families are allotted about two visits a year.

According to DDS, about 50 percent of families request “any available openings.” The regions are able to accommodate dates for special events about 80 percent of the time. In the North Region, requests can be made up to six months in advance. The South Region considers respite requests on a quarterly basis. The West Region will consider respite requests up to six months in advance for families without residential supports and two months in advance for all others. On occasion, there are administrative exceptions based on family and regional needs.

Table IV-7 shows the use of DDS respite centers during FYs 2007 and 2008 as well as the FY 08 respite center wait list. As the table indicates, the total number served in the respite centers grew in the North and South Regions while the West Region had an unexplained decrease.¹⁹ However, all regions experienced an increase of visits by individuals age 45 and older. In FY 08, the North Region was the only region to have a formal wait list, although the committee was told that demand for respite services far exceed availability.

Region	Total Served in Respite Centers		Total Number Served age 45 yrs. +		Total Respite Center visits for age 45 yrs. +		Wait List for Respite Centers FY 08	
	FY 07	FY 08	FY 07	FY 08	FY 07	FY 08	All Ages	Age 45+
North	278	310	20	21	46	53	48	4
South	370	397	34	38	100	118	0	-
West	466	402	32	48	80	114	0	-
Totals	1,114	1,109	86	107	226	285	48	4

Source: DDS

¹⁹ DDS reports the decrease may be due to the relocation of a respite center last year. Initially, there was a reduced number of guests while making the necessary preparations to bring the center up to full capacity.

According to DDS, the West and South Regions were able to accommodate all families who requested respite stays during the 2008 fiscal year. The department reports that since July 1, 2008, the 48 people on the North Region wait list have either: received respite; had their pre-visits completed or scheduled; are a low priority because they already receive more than \$20,000 in other supports; or were no longer interested.

It appears that DDS has provided respite services within available resources whenever possible. However, the large number of persons on the North Region wait list suggests that *the funding for and access to respite services have been limited.* At one point, the department had hoped to open two additional respite centers, one each in the North and South Regions. Budget and staffing constraints have put those plans on hold for the time being. Recognizing the fiscal crisis, the program review committee recommends:

DDS should consider the expansion of respite services when appropriations become available.

The need for respite services becomes more important as the state policy approach is to continue to serve individuals at home. It is widely acknowledged that caregivers with long-standing responsibilities benefit from the occasional relief of the physical and emotional requirements of their care-giving duties. This is particularly true for older caregivers whose physical energy and stamina may decrease as they age. Planned respite allows caregivers to take time off from care giving activities and provides an opportunity to do other things such as attend a special event, take a short vacation, spend time with other family members, or just relax. Respite allows families time to re-energize, deal with emergency situations, or engage in personal, social, or routine activities and tasks that otherwise may be neglected, postponed, or curtailed due to the demands of caring for a person who has intellectual disabilities.

Long-Term Care Provided in Nursing Facilities

During the course of this study, several concerns were raised by advocacy groups regarding the care provided to individuals with intellectual disabilities (ID) who reside in nursing homes. There were three specific areas of concern: (1) whether there were many individuals with ID that had never been identified as such and were living in nursing homes; (2) whether nursing home staff were trained to provide care for some of the unique needs that individuals with ID have; and (3) the limited contact that DDS clients have with DDS case managers. As of November 2008, there were 362 DDS clients residing in nursing homes.

A broader, more philosophical issue was also raised regarding how long-term care, in general, should be provided to individuals with intellectual disabilities. Many advocates believe that these individuals should be allowed to age-in-place in the community and services can and should be provided there. Recent efforts, such as the federal Money Follows the Person (MFP) Demonstration grant, spearheaded by the Department of Social Services, support this position and are aimed at moving people out of institutions and into the community in an effort to rebalance the long-term care system. Other advocates think that long-term care for persons with intellectual disabilities should be provided in specialized nursing homes that only admit individuals with an intellectual disability, so that any unique needs can be met. This group advocates that as the population ages and dwindles at Southbury Training School, STS could be transitioned into this type of specialized facility.

A final issue area identified by the program review committee was the lack of a comprehensive policy that encourages community providers to provide certain medically-related services so that clients can return home following a hospital admission. For example, some DDS clients that live in group homes or private ICFs/MR are admitted to nursing homes upon hospital discharge, while others, with the same medical needs, may be discharged back to their group homes or ICFs/MR.

Based on a review of case files for the Fatalities Review Board, staff from the Office of Protection and Advocacy for Persons with Disabilities, in a 2008 draft report, indicated that some group home providers can meet certain medical needs of clients (such as gastric feeding tube use and oxygen supports), while others can not. Thus, provider capacity or lack thereof, in terms of having the expertise to provide a higher level of care may result in one person being admitted to a nursing home and another returning home. As the DDS population ages, the department will have to meet the medical needs of more and more clients. To address this, the department must determine how to build provider capacity and encourage providers to support clients as they age in place.

Preadmission Screening for Nursing Homes and Eligibility

The federal Omnibus Budget Reconciliation Act of 1987 (OBRA '87) mandated preadmission screening of individuals for serious mental illness and/or mental retardation

(MI/MR) prior to nursing home admission. The purpose of the screening is to ensure that individuals with MI/MR are not inappropriately placed and:

- require the level of care provided by nursing homes;
- are evaluated on whether any specialized services are needed; and
- receive any specialized services that were identified during the preadmission screening.

A description of the two-part screening process is provided below.

Level I Screen. In Connecticut, the responsibility for coordinating the federally-required preadmission screening and resident review (PASRR) process for new nursing home admissions rests with the Department of Social Services, Alternate Care Unit. When an individual is seeking admission to a nursing home, a health care professional must complete two DSS-developed forms and submit them to the Alternative Care Unit for review before an individual can be admitted to the home. This is known as a Level I PASRR screen and consists of two parts -- a health screen and a MI/MR screen. All individuals are screened for this regardless of payer source. However, in reality the information entered on the form depends on the diligence of the health professional completing it, and borderline cases may be difficult to detect. Thus, individuals with an intellectual disability may be admitted to a nursing home without being identified.

The unit reviews the submitted forms and if an individual is thought to have an intellectual disability or mental illness, or has already been identified as a client of either DDS or the Department of Mental Health and Addiction Services, the Alternative Care Unit forwards the information to the applicable state agency for a Level II PASSR screen.

According to the Alternative Care Unit staff, the majority of Level I screens are completed by hospital discharge planners, although community providers and physicians may also complete the forms. In June 2008, the Alternative Care Unit received more than 3,650 Level I screens and passed 402 of those on to DDS for additional screening. Of the 402 screens referred, 271 (67 percent) of those indicated MR was either suspected or the individual was already a client of DDS, and 131 screens indicated a dual diagnosis of MI/MR was suspected or the person had already been identified. Although the unit forwards the Level I screen to both DMHAS and DDS, DDS is considered the lead agency when a dual diagnosis is suspected or indicated. Data were not readily available on the number of Level II screens conducted on individuals who already were clients of DDS and those that had never been identified.

Level II PASSR screen. The purpose of the Level II screen is to confirm that the applicant has an intellectual disability or mental illness, needs a nursing home level of care, and determine if specialized services are necessary. In DDS, it is the responsibility of the Regional OBRA Liaisons in each of the three regions (called OBRA nursing home coordinators) to determine whether a Level II preadmissions screening report needs to be completed. In practice, DDS may already be aware that a client is in a hospital and may need nursing home care upon discharge because the client's provider has notified his or her case manager.

Under certain circumstances, a Level II screen does not have to be completed for already identified DDS clients if:

- the stay is expected to be less than 30 days;
- the client has a terminal illness or severe medical condition; or
- admission is for a short-term respite stay.

The federal law provides for an extension for another 30 days, but after 60 days, the regional OBRA nurse coordinator must complete a Level II screen for clients who were initially admitted for a short-term stay. In addition, if a person has a related condition (e.g., cerebral palsy or epilepsy prior to age 22) or unsubstantiated mental retardation, as defined by federal law, DDS does not conduct a Level II screen unless the nursing home or the Alternative Care Unit notifies DDS in writing that the person will/has exceeded 60 days and requires a Level II PASSR assessment.

The screening report includes health information, developmental history, functional profile, behavioral needs, therapy services and/or adaptive equipment use, and vocational needs. If the individual is already a client of DDS, once the Level II screen is completed the regional OBRA nurse coordinator determines if additional services are necessary.

For individuals that are not DDS clients (i.e., have never been identified) but, as part of this screening review, are determined to have an intellectual disability, eligibility for DDS services is not automatic. In addition, if an intellectual disability cannot be substantiated because records are not available documenting its presence prior to age 22, the individual or guardian is provided with information to pursue DDS eligibility if desired.

Once the need for nursing home care is verified, a notification letter, signed by the regional director, is sent to the individual or his or her guardian, nursing facility, DSS Alternative Care Unit, and DDS case manager. Without such a notification letter, the nursing home will not be reimbursed by the state for any care provided. After an individual is admitted to a nursing home, the regional OBRA nurse coordinator sends a copy of the Level II report within 30 days to the nursing home and to the individual/family/guardian if requested.

At the time of notification, the regional OBRA nurse coordinator provides the nursing facility with a copy of a DDS Contact Sheet with the individual's case manager, case manager supervisor, and the manager-on-call phone numbers, and a form that specifies that the facility must promptly notify DDS of any significant changes to an individual's status.

Specialized services. Under federal law, specialized services should be provided to a client so that the client has a continuous active treatment program that, when combined with services provided by the nursing facility:

- develop the behaviors necessary for the client to function with as much self-determination and independence as possible; and
- prevent or decelerate regression or loss of current functional status.

It is the responsibility of DDS to provide or arrange for the provision of specialized services that are identified as the result of the Level II PASSR screen. There are six types of specialized services including:

- behavior modification/management;
- out of facility recreational opportunities beyond that provided by nursing facilities;
- vocational and day programming services;
- adaptive equipment not otherwise obtainable;
- habilitation services; and/or
- other - to be determined by an individual's case manager.

If specialized services are not recommended, the Level II screen must identify any specific services of lesser intensity that are required to meet the individual's mental retardation needs. The nursing facility must provide these and Medicaid does not separately reimburse for their cost.

According to DDS, of the 362 clients in nursing homes in November 2008, 185 clients received some type of day program services that were being paid for by DDS. An additional 177 individuals did not receive any day program, with 138 clients refusing a program or not wanting a program because they were retired, 14 clients in need of a day program, and no information available for 25 clients. The department was unable to provide information to the committee on any other types of specialized services being provided.

Reviews of Level I and Level 2 Screens by DSS. In February 2008, the DSS Alternative Care Unit examined every patient chart (271 records) in one nursing home to ensure that all clients had been screened for MI/MR because of concerns related to this specific nursing home provider. The unit found evidence that there were potentially many individuals with an intellectual disability residing in nursing homes that have never been DDS clients.

- 71 out of the 271 residents had no MI/MR screen contained in the patient's chart maintained by the nursing home:
 - DSS had evidence (in its own data system) of a Level I screen for 21 residents and no evidence of one for 50 residents; and
- There were 22 residents with a diagnosis of MR and for 8 of these residents, there was no evidence of a Level II screen by DDS.

At this time, the scale of the problem and what steps the department intends to take to determine the scope of this issue is unknown.

Significant change in condition. Although federal law requires all nursing home residents in Medicaid/Medicare certified facilities be assessed if they have a significant change in condition, it requires no state action be taken on their behalf. However, federal law does give

guidance to nursing homes that identifies the types of resident decline or improvement that would trigger the requirement that a new assessment be completed.

For nursing home residents that are DDS clients, federal and state law requires a client review if there is a significant change in a nursing home resident's physical or mental condition. Under state law, nursing homes are required to notify a client's case manager, case manager supervisor, or DDS regional on-call manager (if after hours or on weekends) when a client experiences a significant change in condition, is hospitalized, or dies. This prompts another Level II review to examine the appropriateness of an individual's placement and whether specialized services are needed. This review is conducted by the client's case manager. Documentation of this review must be contained in the individual's DDS file.

Draft Findings of Office of Protection and Advocacy for Persons with Disabilities Review of Nursing Home Clients for the Fatality Review Board

During the course of this study, PRI committee staff met with staff from the Office of Protection and Advocacy for Persons with Disabilities (OPA) concerning two reviews that the office recently conducted in 2008 as part of its responsibilities supporting the Fatality Review Board for Persons with Disabilities (FRB). The Fatality Review board examines all deaths of DDS clients and operates independently of the DDS review structure. The first review focused on DDS nursing home clients by examining such factors as why clients were placed in nursing homes, the length of nursing home stay, and frequency of case manager contact. The parameters for the review were developed in conjunction with the Director of Nursing at Quinnipiac University. A nurse intern enrolled in the forensic nursing program at the university assisted OPA staff in reviewing a sample of records for 71 out of 357 DDS clients that had died between January 1, 2002, and December 31, 2007, while residing in a nursing home.

Among the draft report findings were:

- 40 percent of DDS clients (27 of 69 clients for which there was data) had lived in a nursing home for more than 5 years, with 9 clients there for 10 or more years;
- the most common reason for being admitted to a home was because of a hospitalization (19 clients), an event occurring, such as the death of a primary caregiver or a fall resulting in an injury (13 clients), onset of Alzheimer's Disease or dementia (12 clients), or at risk of falling or injury to a client (5 clients);
- the most common reasons clients were not discharged from the home included lack of improvement (24 clients), lack of advocacy (9 clients), hospice care needed (8 clients), aspiration pneumonia (6 clients), Alzheimer's Disease (5 clients), and at family request (5 clients); and
- although case manager involvement was regular (defined as occurring at least once a year and frequently more often) for 41 clients, it was sporadic (defined as less than once a year) for 9 clients, there were no notes found in nine client's files but some indication that a DDS case manager was involved, and

missing information for 12 clients with large gaps in the files and very little information on the person.

The review identified several issues including the “discovery of significant and multiple lapses in the quality of nursing home care, faulty communication of important information between health care and service providers, a lack of alternatives to nursing home placement and a lack of effective case management and advocacy services when DDS clients are admitted to nursing homes.” The draft report puts forth several recommendations including:

- requesting DDS avoid nursing home placements and where possible, establish a network of preferred nursing home providers to meet short-term rehabilitative needs;
- encouraging nursing homes to keep DDS informed of significant changes in client conditions and DDS clarify case manager, regional health service directors, regional directors and central office personnel responsibilities with respect to information received indicating a change in client condition; and
- recommending DDS procedures specify who is responsible for acting on information concerning whether a DDS client requires the level of services provided by a nursing home or requires specialized services and for taking appropriate action with respect to Do Not Resuscitate orders and other major medical care issues.

The second review conducted by OPA staff for the FRB involved an examination of 61 cases for inclusion in the board's next annual report. The review covered the period between July 1, 2006, and June 30, 2008. During that timeframe, DDS reported a total of 416 deaths to FRB, of which an "in-depth" review of 222 cases was completed. Sixty-one of those cases involved DDS clients who were living in nursing homes at the time of their deaths.

The review resulted in an array of issues being identified for DDS nursing home clients, many of which mirrored the findings of the first review. Areas of concern included: infrequent case management contact, lack of notification regarding significant changes in client condition, incomplete medical histories for individuals moving from a community-based setting to a nursing home, reasons why people are placed in nursing homes, and people being placed far away from friends and family.

Committee Findings

The committee found it difficult to determine the effectiveness of the Preadmission Screening and Resident Review process because of the lack of any aggregated data related to DDS clients residing in nursing homes. Although DDS policy requires the regional OBRA nurse coordinator and the client’s case manager maintain documentation of all clients residing in a nursing home, there does not appear to be a comprehensive quality assurance process that ensures case managers are meeting DDS policy requirements, or that clients are being re-evaluated if they experience a significant change in condition.

Adequate monitoring of DDS clients in nursing homes entails having the ability to have a variety of information available on the population residing there. *The program review committee found no formal quality assurance system in place to systematically oversee that the requirements for DDS clients in nursing homes are being fulfilled.* The committee requested detailed information about DDS clients living in nursing homes but the department was unable to provide it because it is kept at the regional level. Furthermore, each region maintains it differently and only some of the regions had a database that would include some of the elements requested. An example of some of the basic information requested by the committee included:

- DDS clients admitted to a nursing home for 30 days or less but the time was extended so a Level II screen was needed;
- number of DDS clients at nursing homes receiving specialized services that were funded by DDS;
- types of specialized services being received;
- number of times DDS has been notified of a “significant change in client condition,” the reasons for the notification, and what resulted (change in services, case manager face-to-face contact, etc.); and
- frequency of case manager contact with clients living in nursing homes.

Because of the lack of aggregated data collected by the department and inconsistent tracking systems at the regional level, the committee relied on multiple interviews with a variety of different parties to identify issue areas regarding clients residing in nursing homes. Based on these interviews, the committee identified many of the same issues outlined in the two reviews conducted by OPA for the fatality review board.

While the PRI study was underway, DDS hired a nurse located in central office to work with the Ombudsmen to visit DDS clients in nursing homes and review their records. The program review committee encourages the department to continue this process and identify areas for improvement and develop recommendations based on the information obtained. In addition, the committee recommends:

- 1. As part of its audit of nursing home records currently conducted by DDS, the following minimum information should be collected on and verified for clients currently living in nursing homes:**
 - a. case managers are assigned and have met the requirement of quarterly contact and annual face-to-face contact;**
 - b. whether or not the nursing home has notified DDS if a client has had a significant change in condition, been hospitalized, or died;**
 - c. health records are complete and accurate; and**
 - d. emergency contact information is contained in the file.**

- 2. The term “significant change in condition” be defined in guidelines, including the process that nursing facilities must follow in notifying DDS, what actions must be taken by DDS upon receipt of such notification, and circumstances that should initiate face-to-face contact between a client and his or her case manager, and/or require an assessment by a DDS nurse consultant. The roles and responsibilities of the case manager supervisor and regional manager-on-call should also be defined, including any actions that must be taken by them when such notification occurs.**

- 3. DDS should establish a centralized data system to capture information on clients residing in nursing homes in order to document:**
 - a. reason(s) for nursing home admission;**
 - b. lengths of stay;**
 - c. admitting rates to nursing homes by hospital;**
 - d. frequency of case manager contact, with uniform documentation and alerts generated when frequency of contact is not being met; and**
 - e. notification of a significant change in a client’s condition, including an identification of the change.**

DDS should randomly audit a sample of cases in the database to ensure its accuracy.

Individuals with intellectual disabilities living in nursing homes tend to be fragile and vulnerable, and many may have communication disorders, making it important for clients to have contact with their case managers. The committee found that clients placed in nursing homes are at risk of “falling through the system cracks” since there is no adequate quality assurance check in place that tracks them. In interviews, committee staff were told that at times clients die in nursing homes and unless the nursing home notifies the department, the department remains unaware of the death until the client’s case manager visits the home.

Once a DDS client enters a nursing home, the Department of Social Services, under the Medicaid program, pays for the care provided in nursing homes. Any DDS resources allocated to the individual become available for DDS to use to pay for services for someone else. Therefore, if a client is living in a group home but is placed in a nursing home, there are a limited number of days that DDS will save the bed before someone else who is on the wait list and is a high priority will be offered the vacancy. This can become an issue if the individual in a nursing home wants to return to the community, as he or she may have lost DDS funding and now must be placed back on the wait or planning list. Since nursing homes are meeting the health and safety needs of the individual, the individual is not typically considered a high priority and thus could wait for years to be offered another DDS residential placement.

Department of Public Health

Licensing, inspections, and review of Level II PASSR screens. The Department of Public Health (DPH) primarily relies on DMHAS and DDS to monitor their respective clients that reside in nursing homes, except in its role in licensing nursing homes and certifying them eligible for Medicare and Medicaid reimbursement. The department inspects all nursing homes in the state and part of the inspection includes examining a sample of nursing home client records to ensure appropriate care is being provided. The random sample may or may not include DDS clients with intellectual disabilities, given that they compose a very small percent of overall nursing home residents.

The role of DPH was broadened during the last legislative session with the passage of P.A. 08-184. The act requires DPH to examine all PASSR Level II screens completed for nursing home residents, as part of their inspection process, and compare the services required in the screen to the services actually received. Because the department only began implementing this requirement on October 1, 2008, little data were available.

Although DPH must determine whether any required services outlined in the PASSR Level II screen were being received, the public act did not require DDS case managers be notified of DPH findings once the review was completed. To maximize the benefit of these new DPH reviews, it would seem logical that DDS be informed of the outcome of the DPH reviews, since it should trigger follow-up by the client's case manager if gaps were identified. Therefore, the program review committee recommends:

DPH shall notify the appropriate Regional OBRA Liaison of the results of its review of the PASSR Level II screens conducted in each nursing home. If DPH finds that the services identified in the Level II screen are not being provided by the nursing home, it should determine the reason why. The Regional OBRA Liaison should forward the results to each client's case manager who is responsible for following up with the nursing facility to ensure the client has received the services identified in the Level II screen within 30 days of receipt of DPH findings.

Training of certified nurse aides. Another area of concern to advocates for persons with intellectual disabilities residing in nursing homes was whether nursing home staff were trained to provide the appropriate level and type of care to meet some of the unique needs of this population.

Certified nurse aide (CNA) programs and the curriculum taught in them are approved by DPH. Certified nurse aides are required to complete at least 100 hours of a training program in order to become certified. In Connecticut, at least 25 of those hours must include specialized training in understanding and responding to challenging behaviors related to physical, psychiatric, psychosocial, and cognitive disorders.

In addition, Public Act 08-184 increased the requirement that Alzheimer's special care units or programs annually provide Alzheimer's and dementia-specific training to all licensed and registered direct care staff and nurse aides who provide direct patient care to residents

enrolled in those units or programs from three to eight hours.²⁰ It also required that a minimum of one hour of Alzheimer's and dementia-specific training be provided to all unlicensed and unregistered staff that provide services and care to residents enrolled in an Alzheimer's special care unit or program.

According to DPH staff, it is the responsibility of licensed nurses within nursing facilities to train CNAs on how to handle specific issues related to specific clients, including those with intellectual disabilities. Given that the training curriculum includes a cognitive disability component and was recently expanded to include Alzheimer- and dementia-specific training, the program review committee does not recommend expanding any regulatory requirements related to licensed and certified staff training at this time. However, the committee does believe that training could be enhanced on specific medical and behavioral issues related to individuals with intellectual disabilities and such training would be beneficial. To accomplish this the committee recommends:

DDS should partner with the two nursing home associations in Connecticut to provide targeted training around some of the specific issues related to providing care to individuals with intellectual disabilities who reside in nursing homes. Although training efforts could be aimed at a variety of audiences, it should, at a minimum, include:

- **Registered Nurse (RN) nursing home directors responsible for client services; and**
- **DPH surveyors who conduct nursing home inspections and record reviews.**

Creating an informal mechanism to provide training would be low cost but beneficial on two levels. First, training RN nursing home directors who are responsible for managing and overseeing the nursing care provided in nursing homes would provide them with additional knowledge of specific techniques and interventions. With this new knowledge, they may better instruct direct-care staff on specific client needs.

Such training could also be provided to DPH staff that are responsible for conducting surveys related to licensing and certifying nursing homes. This training would give them additional insight in order to better review records of cases that involve an individual with an intellectual disability, if one is included in its samples of records, as well as in its reviews of PASSR Level II screens.

Money Follows the Person Demonstration Grant

The Money Follows the Person Demonstration Grant (MFP), offered through the Centers for Medicare and Medicaid Services (CMS), was created as part of the Deficit Reduction Act of 2005. The purpose of the demonstration is to promote “rebalancing” efforts to reduce or

²⁰ Research indicates that Down Syndrome is known to result in a heightened risk for Alzheimer’s disease. Based on DDS data, 63 percent of DDS clients with Down Syndrome had Alzheimer’s disease prior to their deaths.

eliminate barriers to receiving long-term care services in home and community settings, rather than in institutional settings.

Connecticut received a \$24.2 million grant funded by CMS, which will help rebalance Connecticut's long-term care system. The Department of Social Services is the lead agency for the initiative with the goal of transitioning 700 Medicaid-eligible elderly and individuals with disabilities who are living in a nursing facility or another type of institution (including an ICF/MR, or a DDS regional center) back into the community to receive support and services at home. The targeted population groups are individuals with mental illness, physical disabilities including acquired brain injury, and intellectual disabilities, and the elderly.

DSS was required to submit a protocol to CMS and approval was received in summer 2008. The protocol identifies five rebalancing benchmarks for the state:

- transition 700 people to the community;
- increase funding to home- and community-based services;
- increase the percentage of persons receiving long-term care services in the community relative to the number of persons in institutions;
- decrease the hospital discharges to nursing facilities among those requiring care after discharge; and
- increase the probability of persons returning to the community within the first six months of admission to an institution.

Medicaid reimbursement under MFP. For the first year in which an MFP participant receives services in the community, Connecticut will receive an enhanced reimbursement rate from the federal government. Currently, Connecticut receives a 50 percent match rate on Medicaid services. Under MFP, Connecticut will receive a 75 percent match rate on the community-based services for each participating individual for up to one year after the individual moves into the community. After the first year, the Medicaid reimbursement rate will return to 50 percent. Additional funds received from the federal government under the enhanced reimbursement must be used for long-term care rebalancing efforts.

MFP for DDS clients. The Department of Developmental Services, as one of the MFP participants, has been allotted 70 slots over the next three and one-half year time period and its goal is to transition 70 individuals from nursing facilities or other institutional settings into community placements. There is no age restriction or limit but eligible individuals must:

- have resided in a nursing home, ICF/MR, or regional center for six months or longer; and
- be eligible for Medicaid, including one of the two Home and Community-Based Service (HCBS) waivers administered by DDS.

Eligible DDS clients will receive assistance in transitioning into the community and, after one year, will be transitioned into one of DDS' home and community-based Medicaid waivers. There will be a broad range of services available under Money Follows the Person. Transition Coordinators will provide one-to-one assistance with coordinating the move to the community.

They will be responsible for assisting with directing community supports, navigating the systems, and accessing resources. If people transitioning need housing, Housing Coordinators will help participants by locating acceptable apartments or other living arrangements. To the maximum degree possible, MFP participants will direct the transition process. Rental assistance will also be available for those who qualify.

Under the MFP demonstration, the state has the opportunity to expand services provided in community-based settings. However, as noted at the beginning of this chapter, private providers differ in their capacity to treat certain conditions that prevent nursing home care placement in the first place, with some providers unable or unwilling to allow clients to return to their homes following hospital discharge. *Since clients leaving nursing homes under MFP funds will eventually need to transfer to one of the two home-and-community based Medicaid waivers, the committee believes that DDS needs to set a clear policy direction on the types of services that should be provided in the community with the goal of reducing nursing home placements.* To begin this process, the program review committee recommends:

DDS should survey the types of medical care provided in each private provider home and whether or not it is delegated to unlicensed staff. Based on the survey results, the department shall assess what is lacking in services among providers and establish a policy that provides for a comprehensive system of supports which will encourage providers to provide certain types of care to clients and allow them to age in place.

Although the committee recognizes that a continuum of care needs to be available in the community, there also needs to be a recognition that individuals with intellectual disabilities live longer and develop medical issues at a younger age, as well as the higher incidence of Alzheimer's disease in individuals with Down Syndrome. The department needs to plan on how those needs can be met and allow people, as much as possible, to age in place.

Other Recent Planning Efforts for Aging Population

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 chapter discusses the department's primary planning tool – the DDS Wait List -- and other recent planning efforts aimed at the aging DDS 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".²¹ 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.

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:

²¹ State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012), p.5.

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.²²

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). 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 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 C outlines the proposed DDS action plan.

One of the focus team recommendations was that 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

²² State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012) p.9.

2005, another workgroup was established to analyze the Supported Living service model. The recommendations resulting from the two workgroups are provided in Appendix D.

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.²³ 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.²⁴

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.

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.

DDS planning documents. As noted earlier, the current plan's primary and only stated goal for the aging population is to "develop a continuum of care plan for DDS consumers as they age."²⁵ One accomplishment noted in the plan is the re-establishment of the department's Focus Team on Aging. Other than this statement, there is no other mention specific to the aging population.

It is important to note that many of the agency's goals for system-wide improvements will benefit all DDS populations including the aging group. However, the department has initiated a few other planning efforts aimed specifically at the aging DDS population. Among these are a report and recommendations compiled by the 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 work contained in these other reports, which were developed to provide focus for the department's activities with respect to the aging community, is not reflected in the five-year plan.

²³ United States v. Connecticut, 931 F. Supp. 974 (D. Conn. 1986).

²⁴ Messier v. Southbury Training School, 562 F. Supp. 2d 294 (D. Conn. 2008).

²⁵ State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012) p.33.

The program review committee acknowledges that the five-year plan's stated goal to develop a continuum of care plan is a critical component of the department's delivery service. In addition, the committee recognizes the department's commitment to this population through its support and implementation of several proposals made by the various work groups on aging. However, *more specific objectives are needed in the agency's overall five-year plan to convey a clear vision or at least an anticipated picture of where the department wants to be in the future.* Therefore, the program review committee recommends:

DDS should, when revising its five-year plan and internal strategies, incorporate the action plans of the various work group reports it intends to implement and ensure that the goal statements include specific steps and dates of accomplishment for what the department is trying to achieve.

The five-year plan should be a unified goals document that communicates the status of the agency's objectives and the results of its performance to stakeholders and interested parties.

Another aspect of producing a unified goals document is to reveal collaborations with other entities with similar goals. The basic service needs of aging DDS consumers frequently overlap with the needs of the general population such as long-term care options, shortage of medical and personal care attendants, and transportation needs. Interviews with various state agency staff indicate *DDS is involved in multiple initiatives such as the Connecticut Long-Term Care Needs Assessment and others by the Departments of Social Services and Public Health.* The program review committee commends the efforts of DDS to provide input into many of these initiatives. Continued collaboration eliminates duplication of efforts, reduces conflicts for competing needs, and provides opportunity to leverage resources. As such:

DDS should continue to collaborate with groups with similar objectives and report any accomplishments and expected or required DDS commitments to external projects in the department's five-year plan.

DDS Eligibility and Planning for the Unidentified Population

A part of the planning process is anticipating need through certain indicators such as population growth. 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. This suggests 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 DDS support; or
- are unaware of the services available.

It is also possible current estimates overstate the prevalence of intellectual disabilities in Connecticut's population. As part of the study, the program review committee examined the DDS eligibility process focusing on the number of referrals age 45 and older. The results are summarized below and further detail is provided in Appendix E.

Eligibility referrals. The Eligibility Unit within the DDS central office is the single point of entry for all individuals seeking eligibility for services. 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. The eligibility director, a licensed psychologist within the DDS central office, reviews all eligibility applications and required documentation. If necessary, the director will request additional information.

Table VI-1 provides a summary of the eligibility referrals made within the last three years. Since 2006, over 3,293 referrals for all ages were made to DDS with approximately eight percent or 266 referrals made for individuals age 45 and older. As the table shows, each year a large portion of referrals are withdrawn by the applicants or are deemed inactive by DDS when there is no further communication after a six-month period. Currently, there are 475 referrals considered by DDS as pending or active because they are still within the six-month timeframe.

Table VI-1. Summary of Eligibility Referrals Made between 2006 and 2008.*									
	2008*			2007			2006		
	All Ages	Age <45	Age 45+	All Ages	Age <45	Age 45+	All Ages	Age <45	Age 45+
No. of individual referrals	1,125	1,035	90	1,107	1,013	94	1,061	979	82
No. found Eligible	227	213	14	403	382	21	466	441	25
No. found Ineligible	85	81	4	104	96	8	77	71	6
No. Withdrawn/Inactive	438	403	35	600	535	65	518	467	51
Pending (last 6 months)	475	438	37						
*As of November 5, 2008									
Source: LPR&IC analysis									

The number of eligibility approvals and denials has been relatively consistent since 2006. A slight increase in the number of denials is seen in 2007. According to DDS, many of the denials were due to persons mistakenly seeking services after the department changed its name.

Appendix E provides a demographic profile and basic statistics regarding the eligibility referrals made for individuals aged 45 and older. Overall, the program review committee's limited analysis of the eligibility process found no significant deficiencies or differences in the eligibility process for the older population. On average, the eligibility process takes three to five months to complete. Most referrals (62 percent) are submitted by family members. Almost an equal percentage of the individuals age 45 and older resided with family members (48 percent) and in the community (47 percent) at time of referral. The majority (78 percent) did not specify what types of services they were seeking. The most common reason for the applicants to be deemed ineligible is due to test scores not meeting the statutory requirement and/or not occurring during the developmental period. Few of those deemed ineligible appeal the decision. Many applicants withdraw their requests before an appeal hearing occurs. Frequently, a determination is made when the applicant provides additional or necessary documentation prior to the hearing.

Conclusions. Based on its analysis, the committee concludes that the DDS eligibility process is operating according to agency policy and practice. Interestingly, *a significant number of individuals (approximately 50 percent) initially seek DDS services but for unknown reasons either withdraw their applications or simply discontinue contact with the department.* Without

following up with these individuals, it is impossible to know or project whether they would be eligible for DDS services and support now or in the future.

This raises a larger policy consideration -- to what extent should the state actively seek additional applicants or invest staff resources in projecting potential client populations. Although estimates are not available, most disabilities professionals believe that there are uncounted numbers of families living with a relative with intellectual disabilities. As noted in the introduction, there may be several reasons for these families being unknown. Some advocacy groups believe the DDS system will witness an influx of families with service needs as caregivers of individuals previously unserved or unknown to DDS continue to age.

However, the supports provided by DDS are not mandated entitlements. They are provided within available appropriations and resources. DDS is struggling to meet the needs of its current consumer base and faces continuing challenges managing the existing wait list.

Future of Southbury Training School

Up until about 25 years ago, many persons with intellectual disabilities were relegated to living their adult lives in large institutional settings. However, much has changed over the past quarter century as federal and state initiatives to enhance opportunities for community living have affected the lifestyles of most of these adults. In Connecticut, the last state-operated institution for persons with intellectual disabilities is Southbury Training School (STS). Currently, Southbury has a resident population of 499 with an average age of 59.

Southbury admissions were halted by federal court order in 1986 amid concerns of the U.S. Department of Justice over the care and conditions for residents.²⁶ In 1997, the legislature statutorily prohibited the DDS commissioner from accepting new admissions. At the same time, the federal court appointed a Special Master to find out why the state's efforts were not improving conditions. In 1998, a remedial plan was established with specific outcomes and criteria to be met as conditions for compliance. The federal court found in 2006 that the state had met all requirements of the consent decree.

Following years of litigation, the federal judge issued a decision in June 2008 on another related case concluding that although the state had satisfied the consent decree requirements it had not done enough to relocate Southbury residents voluntarily into the community.²⁷ Hearings to determine the next steps are expected to be scheduled in early 2009. According to a variety of interested parties, it is unlikely the federal judge will make any decision regarding the future of Southbury. Assuming this is true, Southbury is likely to remain operational while the remaining residents either age in place or voluntarily leave. Going forward, it is apparent that Southbury's future is unclear or unstated. To date, DDS has not made public any plans for the future of Southbury.

Almost every interested stakeholder interviewed by the committee mentioned concern over the future of Southbury. Opinions on the topic range considerably. Many advocates, private providers, and field professionals believe the concept of institutional care is outdated and

²⁶ United States v. Connecticut, 931 F. Supp. 974 (D. Conn. 1986).

²⁷ Messier v. Southbury Training School, 562 F. Supp. 2d 294 (D. Conn. 2008).

unnecessarily expensive. They contend individuals could and should be integrated into the community at a lower cost than in an institutional setting. On the other side, families involved in some long-standing advocacy groups support the continued use of Southbury, which has evolved significantly since the court-ordered consent decree required changes. Some have suggested modifying Southbury to provide congregate living for persons with disabilities as they age or as a specialized nursing home exclusively for individuals with intellectual disabilities.

The issues of institutional care are not unique to Connecticut. Massachusetts is currently involved in a decades-old controversy surrounding the Fernald Developmental Center, a 186-acre residential facility for the mentally and developmentally disabled.²⁸ In the 1970s, a federal class action suit was filed to upgrade conditions at Fernald and several other state institutions. The judge disengaged from the case in 1993 declaring that the improvements in the care and conditions at the facilities had improved. In February 2003, Massachusetts announced its plan to close the institution and have its residents moved to other state-run facilities or into homes in the community. A coalition of family advocates and state employee unions began a campaign to save Fernald and asked the judge who oversaw Fernald's operations from 1972 to 1993 to resume his oversight of the class action lawsuit and keep the institution open indefinitely.

The federal judge ruled in 2007 that the state must give the residents with intellectual disabilities the option of staying at the facility. In September 2007, Massachusetts reiterated it would close the facility and transfer residents to other state-run institutions and homes in the community. State officials insisted that continuing to operate the institution goes against the national trend toward community living and noted it would be too expensive to keep the facility open for the few people (approximately 163) still housed there and that equal or better care could be provided in private, community-based settings for the remaining residents.

The state of Massachusetts appealed the judge's ruling arguing that he does not have the legal power to order the state to keep the institution operating. The state reported that it makes little financial sense to keep the institution open, noting that it costs more than \$239,000 to house a person there each year. It would cost between \$14 to \$20 million in capital improvements to keep the buildings operational. At the same time, the state estimates that it costs an annual average of \$102,000 to support each person with the same level of needs in the community. On October 1, 2008, the federal appeals courts ruled that the federal district court judge lacked the jurisdiction to order Fernald to remain as an option for its current residents.

Similar to Connecticut, Massachusetts has advocates on both sides. The coalition of families claim that in the community system, services and supports are subject to little effective government oversight and are characterized by high turnover of direct-care staff and low salaries. The Fernald families argue that those who remain at Fernald are more profoundly retarded and have more complex medical issues than those in community settings. They believe individuals would not receive the same level of care if they were moved to other facilities and would be separated from those who know them. They also are concerned that the facility is slowly suffering by attrition as the administration cuts the budget, lays off the staff, and continues to prohibit new admissions. They propose a "postage stamp" approach whereby the state would sell off much of the property to support a small section used for the current residents.

²⁸ Ricci v. Okin, 499 F. Supp. 2d 89 (D. Mass. 2007).

The advocacy groups that support Massachusetts's position consider the institutionalization of even the severely impaired to be antiquated. Their concern is that any investment of long-term capital expenditures would force the state to continue to place clients there. These arguments are similar to the comments heard by the committee throughout the study. While this report does not make any conclusions regarding the future of Southbury, the study focus was to examine DDS plans for aging clients. As such, this includes the aging population residing at Southbury.

The committee finds that Southbury Training School is a significant state asset. Built in the late 1930s, STS is located on over 1,600 acres. It has approximately 125 buildings including apartments, cottages, and its own medical health care unit. STS also operates its own power, heat, sewage treatment and water plants as well as a fire and ambulance department it shares with the town. The property continues to be maintained despite decreasing numbers of residents. At some point, a cost-analysis decision must be made regarding the on-going property maintenance for limited use. The committee believes *a comprehensive cost-analysis decision for Southbury Training School is critical and overdue*. Therefore, the committee recommends:

The Commissioner of Developmental Services, in consultation with the Commissioner of Public Works and the Office of Policy and Management, shall evaluate the feasibility and appropriateness of a continuum of options for Southbury Training School. At a minimum, the range of options shall include property closure and sale, continued or modified use as a DDS residential facility, and alternate uses for other state agency services. Each option considered shall provide:

- **the underlying rationale for the option;**
- **the populations affected;**
- **associated costs and/or revenue generated; and**
- **a specific outline of the required action steps, potential entities involved, and anticipated timeframes for implementing the option.**

The DDS commissioner shall hold public hearings to solicit input and opinions of interested stakeholders. The DDS commissioner shall submit a report containing the criteria and standards used to form the basis of the evaluation, transcript of any hearing(s) held, as well as findings and recommendations to the governor and the legislature no later than December 31, 2010.

Regardless of the alternatives considered for the ultimate use for Southbury, a comprehensive cost analysis must be made to guide the state's decision. In the current economy, all potential cost-saving measures must be examined. Attempts have been made by some groups to measure the cost of care in various settings but the comparison presents several obstacles. The difficulties in conducting such a cost analysis are discussed in further detail in Chapter VII.

Cost of Client Care and Planning

During the course of this study, the committee met with community provider associations and advocacy groups that contend that care in the community is provided at a much lower cost than in institutional settings (i.e., ICFs/MR).²⁹ The program review committee examined DDS data related to the per capita, per diem client costs of care provided at Southbury Training School and the state-operated regional centers to costs of private providers caring for clients in the community.

In Connecticut, allocating resources for one component of the DDS system obviously impacts the availability and funding of each of the other components. Since services are not an entitlement, many families providing care to family members with an intellectual disability receive no services beyond case management, while other DDS clients receive very intensive and costly services and supports. The program review committee believes that a discussion needs to occur around the factors that influence the costs of care delivered in various settings and whether rebalancing the system would allow for more individuals with intellectual disabilities to be served, while still ensuring the health and safety of all individuals receiving DDS services.

Alternatively, many individuals have lived at STS for over 30 years. For those who want to remain and age in place, to make them leave what has been home to many clients for decades, could be unnecessarily disruptive, and it has not yet been proven that it would be less costly to provide services in the community. However, STS is a large property with widespread services and the state should consider whether the entire property is still needed for DDS purposes or whether it could be used for alternative purposes.

Before such a discussion can occur, however, more analysis needs to be performed in order for valid comparisons to be made regarding the costs of providing care in one setting versus another. Although the committee provides some gross measures of per capita, per diem cost information, the committee recommends:

The Department of Developmental Services, in consultation with the Department of Social Services, shall conduct a detailed cost review of per capita, per diem costs of care provided in institutional settings to care provided in the community. The cost methodology should include, but not be limited to, the following factors: resident acuity, collective bargaining agreements, Medicaid costs, and the differences in staff costs between public and private providers. The report shall be presented to the legislative committees of cognizance by February 1, 2010.

²⁹ 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. Connecticut receives 50 percent reimbursement from the federal government for services provided.

Cost Comparisons Calculated by DDS

Both DDS and the Office of the State Comptroller (OSC) calculate per diem, per capita costs annually. During the period of 2002-2009, the state used interim rates to bill the federal government and claim 50 percent reimbursement for state costs for public ICFs/MR, such as Southbury Training School and the five Regional Centers, and public group homes referred to as Community Living Arrangements (CLAs). It was expected that actual rates would be set at a future date and a cost settlement would occur. While a cost settlement was delayed for a number of years because of a lack of data, the Department of Social Services and DDS set revised rates in November 2008, which are retroactive to 2002. Additional revenue based on the revised rates was estimated at \$157 million and will be used to fill the FY 09 budget gap. The data presented in this chapter reflects the revised rates that were recently calculated by DDS under the cost settlement agreement.

Based on analysis of DDS per capita, per diem cost calculations, the committee finds while this analysis can be used to compare costs within specific settings with similar services and reimbursement methodologies, it is more problematic to compare costs across settings for a number of reasons.

The reasons why comparisons should not be drawn with existing data about residential care provided in ICF/MR settings to community-based settings are numerous. First, and of fundamental importance, is that Medicaid reimburses under different rules for the cost of care provided to individuals in institutional beds than for care provided in the community. All beds at STS and the five regional centers are licensed and certified as ICF/MR beds. In addition, a small number of private providers also have ICF/MR beds. For clients residing in these types of beds, Medicaid reimburses 50 percent of the total cost of care -- including the room and board component -- provided to DDS clients.

For clients living in the community, Connecticut operates two Medicaid Home and Community-Based Services waiver programs, which provide residential services and supports but does not reimburse for the room and board component of care. That component is typically paid for separately by clients eligible for Supplemental Security Income (SSI), Social Security Disability benefit, and/or the State Supplement for the Aged, Blind and Disabled. Although the data provided by DDS do include the room and board component paid for by the Department of Social Services in its per capita, per diem calculations, the federal Medicaid rules governing the number of billable days can vary between the two settings if a client is hospitalized, needs nursing home care, or stays with family overnight.

Another difficulty in comparing costs of care provided between the two types of settings is that ICFs/MR, particularly at STS and the regional centers, have a more medically-oriented model, with certain medical and nursing services provided within the facility. For example, STS has a hospital and nursing facility, along with an on-site doctor and nursing staff available 24 hours-per-day, seven-days-per-week. These services are covered under the Medicaid ICF/MR optional benefit and thus are included in the per capita, per diem calculations done by DDS. Conversely, although nursing consultation services are often available for clients living in a

group home, if they need to visit a doctor or go to an emergency room, those costs are not reimbursed under the Medicaid waiver programs. If this occurs, the cost is reimbursed through the traditional Medicaid program and is paid for separately by the Department of Social Services; it is not included as part of a provider's cost, and therefore, would not be included in the per diem costs calculated annually by DDS or the Office of the State Comptroller, since the OSC calculations are based on DDS data.

Several other factors also should be considered when comparing costs of care between the two types of setting. These include: how development of new homes and renovation of existing homes are accounted for; the acuity of residents and its impact on costs; the average length of time staff has been employed; and the effect of public versus private employment, including the variation in wages and fringe benefits between the two.

For these reasons, the information provided in this chapter is not to compare the costs across settings but to explain how per diem costs are currently calculated by DDS and caution against comparing per diems without further review. Although an in-depth cost examination needs to be performed before a comparison between these two types of settings should be made, the committee believes this discussion would be timely given the state's budgetary forecasts. Pent-up demand for DDS services already exists, and given that this is the last year of wait list funding, a direction on how best and most cost effectively clients can be provided care is practical during these difficult fiscal times.

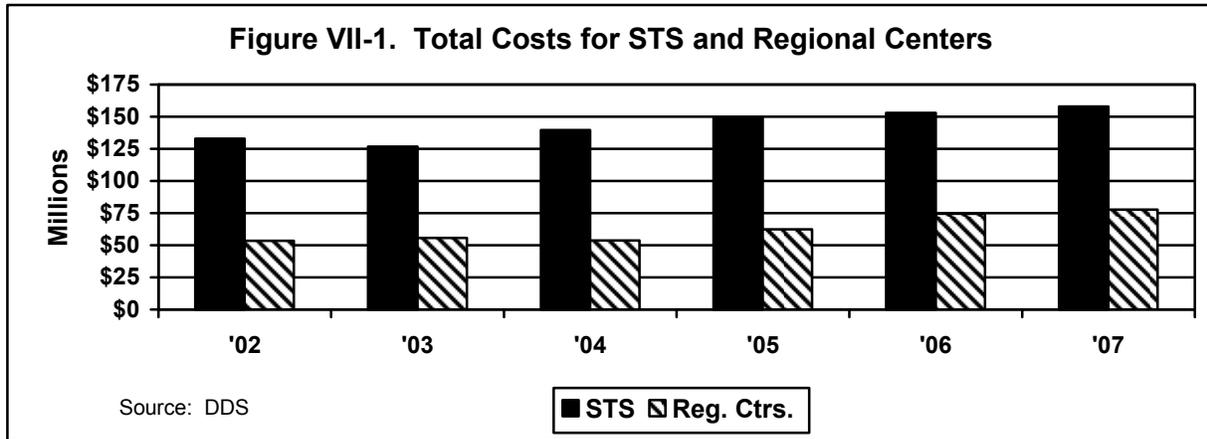
Residential Costs at Southbury Training School and the Regional Centers

State "inpatient" costs that are used to calculate the per capita, per diem cost of STS and the regional centers are quite comprehensive. They include all direct costs of providing services (employee salaries, fringe benefits, and other direct expenditures for the facilities, such as food, maintenance, and care of residents), operating expenses, and statewide allocation costs, and other allowable costs. The cost calculation for STS, the regional centers, and publicly supported group homes and supported living, also includes a portion of administrative and overhead costs of DDS' Central Office allocated to each facility, as well as building and equipment depreciation costs.

Statewide Cost Allocation Plan (SWCAP). The per capita, per diem cost for publicly supported settings (STS, the regional centers, public CLAs, and public supported living arrangements), also include an allocation of central state agency administrative support for DDS programs and services. This amount, known as the Statewide Cost Allocation Plan (SWCAP allocation), is approved each year by the federal government. The SWCAP calculates the cost of central agency services (i.e., administrative support) furnished by, but not billed to other state agencies like DDS. Examples of SWCAP allocations include services provided by the comptroller's office for accounting, payroll, and employee benefit support; the Office of Policy and Management for budget and financial support; the Department of Information Technology for IT support; the Office of the Attorney General for legal services; the Department of Administrative Services for human resource and procurement assistance; and the Auditors of Public Accounts for auditing services.

Total cost calculation. Once the total costs are allocated to DDS facilities, the amounts are divided by the number of inpatient days of service to determine the average per capita, per diem cost. Inpatient days means the number of days of care provided to clients.

Southbury Training School and the Regional Centers residential expenditures. Figure VII-1 shows total residential costs for Southbury Training School and the regional centers since FY 02. Over the six years presented, costs increased 19 percent for STS and 45 percent for the regional centers.



In terms of the population, Figure VII-2 shows the number of individuals served between FY 02 and FY 07. At STS, the population has declined from a high of 627 in FY 02 to a low of 494 clients in September 2008, a reduction of 27 percent. The population at the regional centers has remained steady over the years. The reason for this is that new admissions to STS have not been allowed since 1986, while the regional centers are able to fill beds if a vacancy occurs.

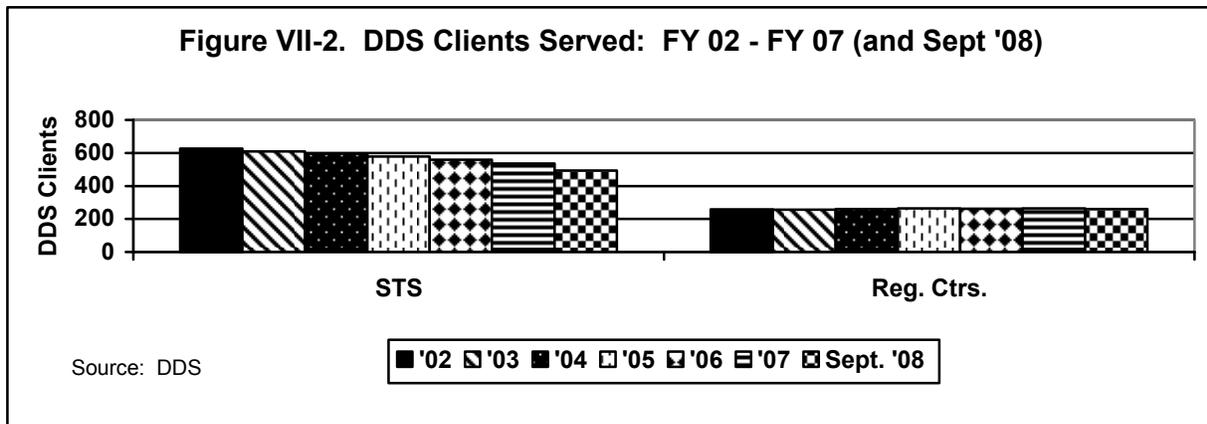
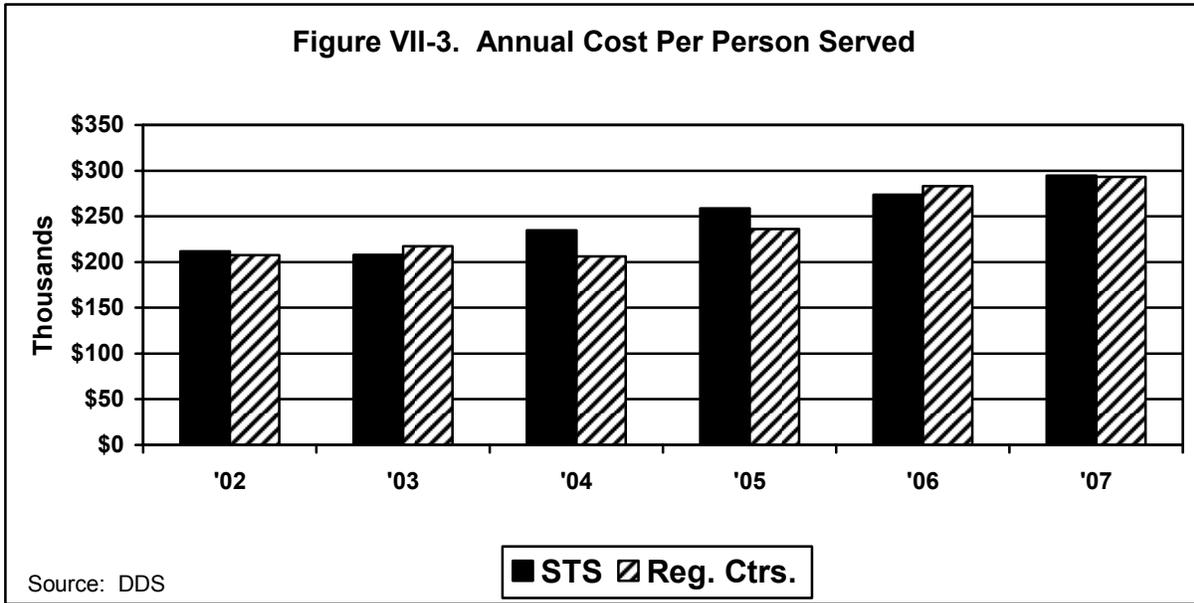
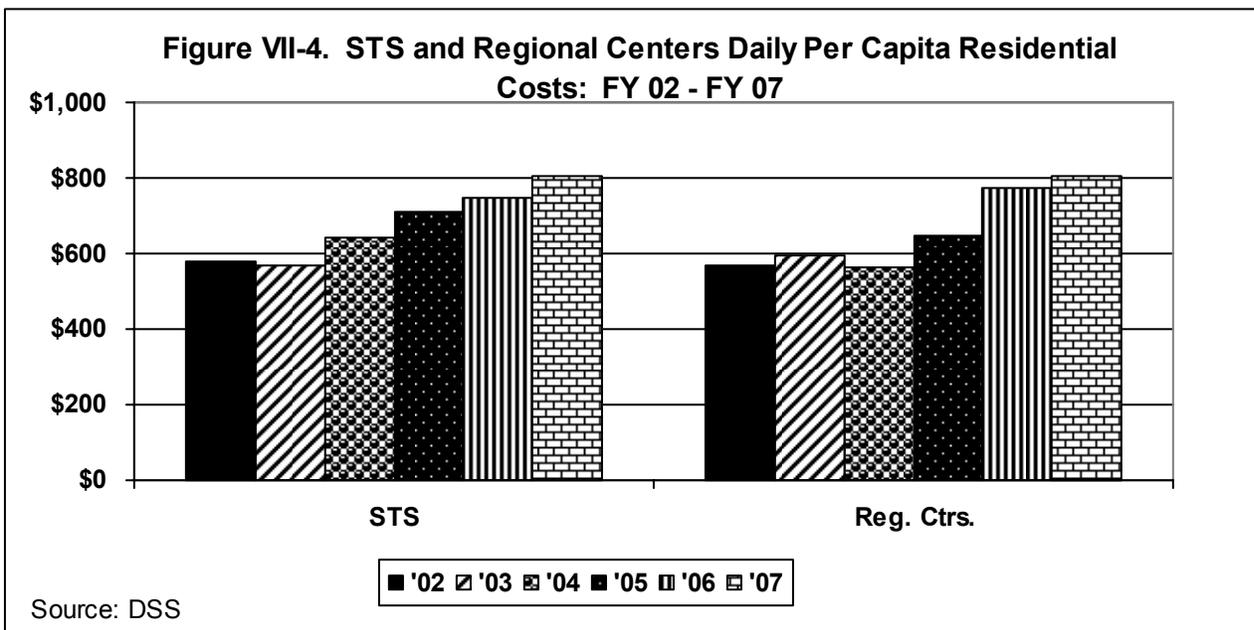


Figure VII-3 presents the annual residential cost per person served for FY 02 to FY 07. Annual per person costs at STS have grown steadily from year-to-year, increasing 39 percent over the six years examined. The regional centers experienced a decline in annual cost per person served between FY 03 and FY 04, but over the six years examined, costs increased 41 percent.

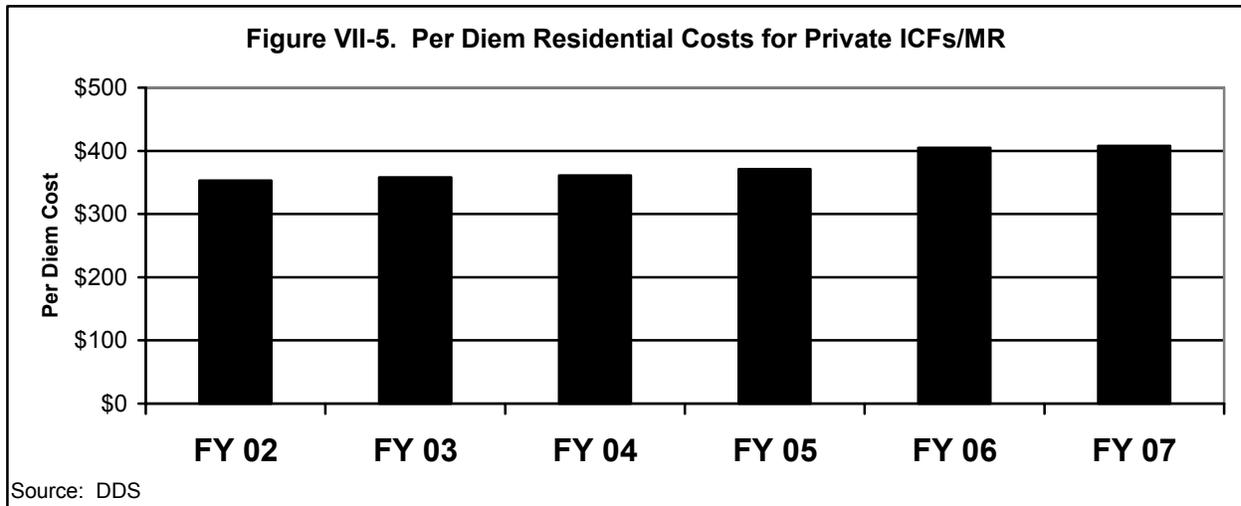


The Department of Developmental Services annually calculates the per capita, per diem cost at STS and the regional centers, excluding any day program that is attended by a client. As Figure VII-4 shows, costs have increased at both STS and the regional centers by 39 percent and 41 percent respectively, over the five years examined. The number of people served decreased by 91 individuals at STS and increased by 7 people at the regional centers during the same time period.



Private ICF/MR costs. There were also 379 clients being served by ICFs/MR operated by private providers in FY 07. The program review committee examined costs of residential care provided by private providers since FY 02 (see Figure VII-5). Per diem costs of ICF/MR

private providers increased by 16 percent since FY 02, although private ICF/MR per diem costs were about half the cost of STS and the regional centers in FY 07. The most likely reason for this is because of the wage and fringe benefit variation that exists between public and private employees. However, resident acuity may also be a factor.

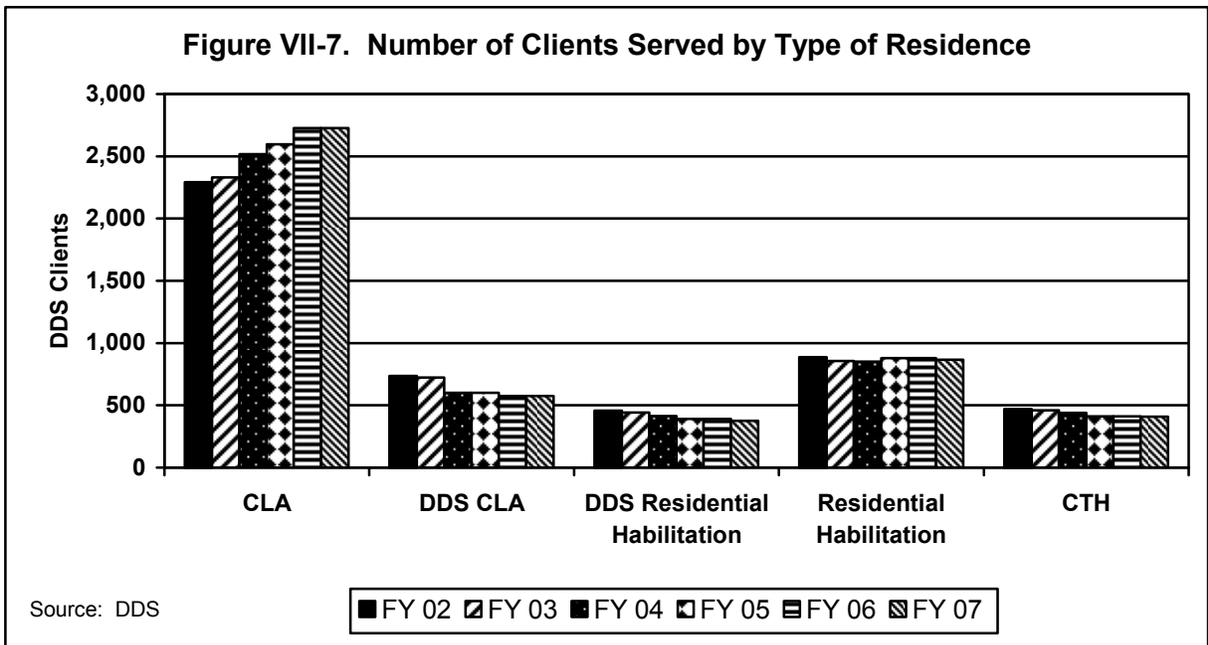
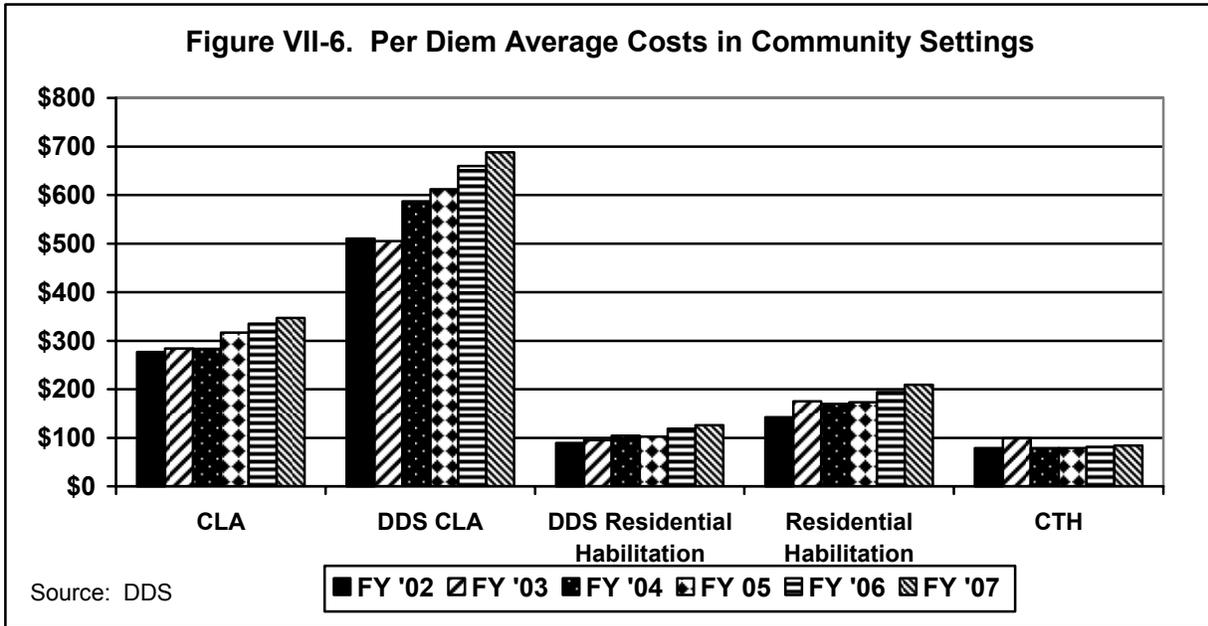


Costs of Community Care

The Department of Developmental Services also calculates the cost of care provided in various community-based settings, including community living arrangements, residential habilitation (formerly called supported living), and community training homes. Like ICF/MR per capita, per diem costs, they include all direct costs of providing services (employee salaries, fringe benefits, and other direct expenditures for the care of patients, operating expenses, administrative costs, and other allowable costs). The cost calculations prepared by DDS includes the room and board costs paid for by the Department of Social Services.

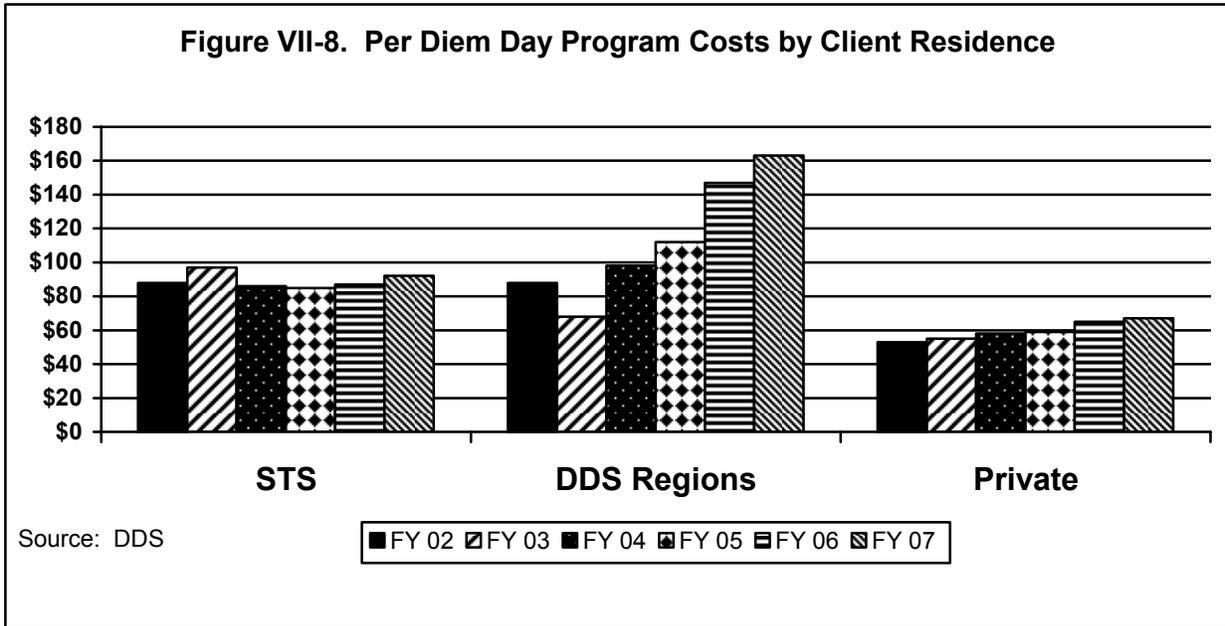
Figure VII-6 compares per capita, per diem costs by type of community setting and Figure VII-7 shows the number of clients living in each setting. The cost of publicly operated group homes is the highest – more than two times the cost of CLAs operated by private providers. Reasons for this include that higher wages and fringe benefits are paid to employees of public CLAs, and that these homes may serve more challenging clients, which would require higher staff ratios. Costs for residential habilitation are for support services provided to clients.³⁰ As shown in Figure VII-6, publicly-supported residential habilitation living arrangements cost less than those served by private providers. The least expensive option is for residential services and supports provided in a Community Training Home (CTH) setting, where clients live with individuals or families, similar to foster care arrangements provided under the Department of Children and Families.

³⁰ Residential habilitation services are for clients who 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 medicine.



Day Program Per Diem Costs

In FY 07, total day program costs were slightly more than \$209 million, and served almost 8,000 clients. By far, the largest providers of day program services are private, serving 91 percent of the clients enrolled. Figure VII-8 shows the per capita, per diem day program costs. Regional centers served 310 clients in FY 07 and had the highest costs -- almost two-and-one-half times the cost of private provider programs.



Summary

Since the deinstitutionalization of clients living at Mansfield Training Center in the 1980s, the shift has been away from providing care in large-scale institutions to providing it in the community. This trend continues under the new Money Follows the Person demonstration project, and with the addition of a new service that would allow the state to receive Medicaid waiver reimbursement for residential services and supports (but not the room and board component) for clients who live in assisted living settings.

The Money Follows the Person (MFP) Demonstration grant, as noted in Chapter V, is the latest federal initiative that creates an incentive for states to reduce their reliance on institutional care for people residing in long-term care facilities, by expanding options for elderly people and individuals with disabilities to receive care in the community. States use the funds to develop systems and services to help people living in nursing facilities and ICFs/MR who want to move back to home or community-based settings. The federal government, through the MFP grant and by allowing Medicaid home and community-based waivers, is encouraging states to shift Medicaid long-term care spending permanently toward community-based care and services.

Appendices

APPENDIX A: Profile of Target Population on DDS Wait or Planning List

The program review committee obtained a database from DDS containing information related to active DDS clients on the wait or planning list and meet definition of the study's target population – DDS clients that are age 45 or older or have a caregiver who is age 65 or older. The data presented below is based on 1,103 clients meeting this definition as of October 2008. It provides a snapshot of currently active individuals on the wait or planning list seeking residential services and supports. It is important to note that clients on the wait or planning list include those who:

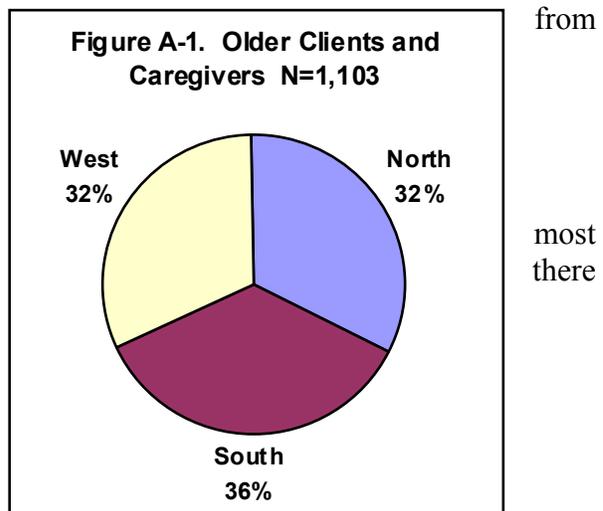
- reside at home with family or live independently, and
 - receive no DDS services except for case management; or
 - receive limited DDS services funded through state Enhanced Family Service grants; or
- live at home with family or in a residential setting, such as a community living arrangement or supported living, and receive substantial DDS residential services and supports under the Home and Community-Based Services (HCBS) Medicaid waiver, but are considered underserved.

DDS-funded residential services and supports are provided in a variety of settings including in a family home, in a community training home, or in a client's own apartment or condo. The state receives 50 percent federal reimbursement under the HCBS Medicaid waivers for residential services and supports that are provided in a community setting. Reimbursable services do not cover the cost of a client's room and board, but do pay for services that allow the individual to live in the community.

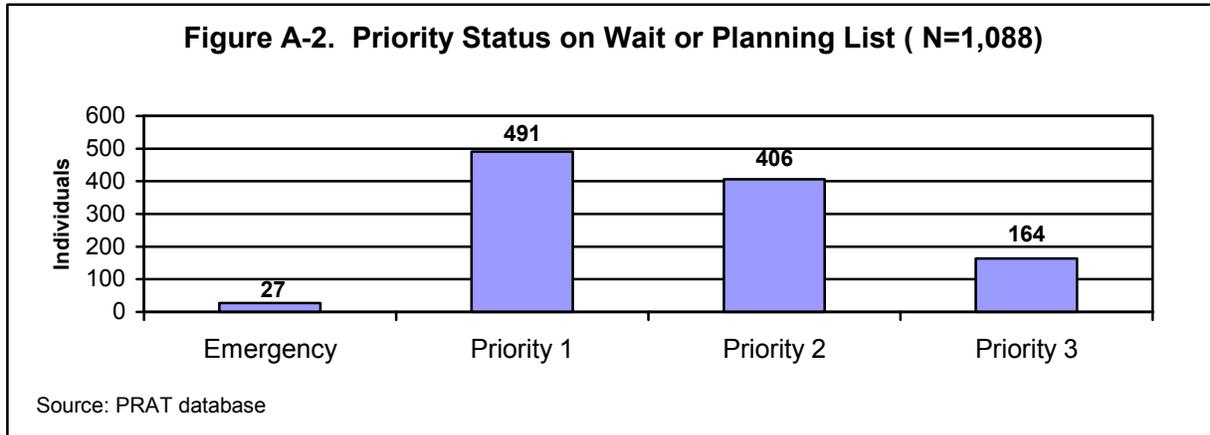
Based on the target population definition stated above, as of October 2008, there were 1,103 active clients on the wait and planning lists who were in need of some type of residential services and supports. Of this total, 762 individuals were age 45 or older and 341 were under age 45, but had an elderly caregiver who was age 65 years old or older. Data were available for 1,088 clients indicating the reason they were on the wait or planning list – most were not receiving any services (604) and many were underserved (234). The remaining individuals needed additional funding, particularly to move one DDS residence to another for a more appropriate placement.

Figure A-1 shows the number of active clients waiting for residential services and supports by region. The South Region had the clients on the wait and planning lists, although was not a large variation in the number of clients among the three regions.

A priority status was indicated for 1,088 clients (Figure A-2). The largest numbers of clients have been identified as Priority 1 (45



percent). Although there were 68 cases that were considered an Emergency in October 2008, only 27 of those involved a client that was 45 or older or a caregiver over the age of 65 years old. Of the 27 cases, 16 involved a client age 45 or older while in 11 cases the caregiver was older with a younger client.



Priority status and primary residence. As shown above, 27 individuals on the wait list were classified as an Emergency and 491 individuals categorized as a Priority 1. Table A-1 lists where clients were living while they waited for residential services and supports. The majority of individuals considered an Emergency are living with family, while those identified as a Priority 1 live in a variety of settings, but primarily reside either with their family or in a community living arrangement (i.e., group home).

Table A-1. Where Clients are Living by Priority Status (N=1,081)

<i>Residence</i>	<i>Emergency</i>	<i>Priority 1</i>	<i>Priority 2</i>	<i>Priority 3</i>
Community Living Arrangement	1	172	35	6
Community Training Home	0	3	4	1
Family Home	19	185	318	141
Hospital	1	0	0	0
Intensive Care Facility	0	3	0	0
Independent Living	1	24	22	3
Mental Health	0	0	1	0
OR	1	1	4	1
Regional Center	0	6	5	2
Res. Care Home	0	0	5	2
Supported Living	2	4	13	42
Skilled Nursing Facility	0	47	1	4
Southbury Training School	0	1	0	0
Total	25	446	408	202

Source: DDS PRAT database

The program review committee also examined the type of residential services and supports sought for older clients and/or those living with older caregivers that were identified as either an Emergency or a Priority 1 (Table A-2). Although there were a total of 27 Emergency

and 491 Priority 1 cases, the type of residence needed was not identified in 130 cases contained in the database. In order for the department to plan for the needs of individuals who will be needing services either almost immediately or within one year, it is critical that this data be better maintained by case managers and tracked by the department.

Table A-2. Type of Residence Needed (N=410)		
<i>Type of Residence</i>	<i>Emergency</i>	<i>Priority One</i>
Community Living Arrangement	13	260
Community Training Home	1	19
Family	4	34
Independent Living	2	9
Supported Living	2	66
Total	22	388
Source: PRAT database		

Living with family. There were 680 active individuals living with family who were on the wait or planning list and were 45 years old or older, and/or had a caregiver that was 65 and older. The data show:

- distribution is even across three regions;
- 83 percent of the families were not receiving any residential services or supports beyond case management, while others were receiving a small state grant or were considered to be underserved;
- mothers and fathers were listed as the caregiver for 83 percent of the clients, with sisters, grandparents, brothers, aunts and friends making up the remaining percentage. Fifty-four individuals did not have a caregiver listed in the database.

Caregivers age 80 and older. There were 149 caregivers age 80 years old or older and had their adult child residing at home. Based on data contained in the database:

- the caregivers ranged from 80 to 96 years old, with an average age of 84;
- the client ages ranged from 11 to 82 years old, with an average age of 48 years old;
- the South region had the most caregivers age 80 or older (61 caregivers), compared to 40 caregivers in the West region;
- a caregiver was identified for all 149 clients, with mothers or fathers providing care in 89 percent of the cases; and
- 115 clients living with caregivers age 80 or older were not receiving any services beyond case management; 15 were underserved; 14 were receiving EFS funding but were requesting more; four received residential services and supports but wanted to move; and one was a 16-year old child aging out of the Voluntary Services Program.

Priority status for clients living with age 80 or older caregivers. Table A-3 shows the priority status for the 149 clients living with an elderly caregiver. The majority of clients (62 percent) were identified as Priority 2 or Priority 3 indicating the need for residential services and supports would be needed in two to five years for Priority 2 or more than five years in the future for Priority 3.

Table A-3. Priority Status for Clients Living with Caregiver Age 80 or Older		
<i>Status</i>	<i>Number of Clients</i>	<i>Percent of Total</i>
Emergency	8	5.4
Priority 1	48	32.2
Priority 2	67	45.0
Priority 3	26	17.4
Total	149	100%
Source: PRI analysis of PRAT database		

APPENDIX B. Informal & Formal Appeals of Persons Age 45 and Older

Programmatic Administrative Reviews (PARs)

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. A programmatic administrative review (PAR) is an internal informal DDS 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.

Within the last year, seven programmatic administrative reviews (PARs) were requested by individuals age 45 and older. This represents 17 percent of the total 42 that were requested. To discover the types of services and issues aggrieved by older DDS consumers, the program review committee staff examined the PAR requests made by individuals age 45 and older within the last year. The results are provided in Table B-1.

Region	Regional Level Par	Commissioner Level Par	Total
North	11 (none 45+)	3 (two 45+)	14
South	12 (three 45+)	3 (none 45+)	15
West	12 (two 45+)	1 (none 45+)	13

Source: DDS

As the table shows, the number of PAR requests was evenly distributed among the regions. Only seven of the 42 PAR requests were made by individuals age 45 and older. The oldest individual requesting a referral was 62 years old but most were under the age of 55. Five of the referrals were resolved at the regional level while two continued to a commissioner level review.

All of the requests were asking for either increased funding for support services and/or a change of residential placement. Most wanted to increase in-home staff support. In two cases, the individual was seeking additional supports to return home from a nursing home. One wanted to relocate to a CLA with a more age appropriate setting. Three were seeking placement closer to their families.

All the PARs were resolved within a week to a month of the request. In all cases, the department offered proposals to mitigate the issue. Typically, the agency response was to state that annualized funding was not available and to provide one-time funding while the PRAT reconsidered the individual's request. One-time funding is frequently used as a mechanism to pay providers for service costs. Annualized funding is allocated based on PRAT and Utilization Review, depending on the individual's needs and on the availability of funding. One-time funding is often the only option available to pay for services.

Waiver-related appeals. Waiver-related appeals must be heard by DSS, the single state agency for Medicaid. Prior to the DSS hearing, the client or legal

representative must appeal the decision to the DDS Waiver Unit within the central office. Since 2006, the central office Waiver Unit director has made decisions on 41 waiver related appeals. Six of the 41 waiver service appeals involved clients age 45 and older. The program review committee staff examination of the six appeals revealed the following:

- All but one came from the DDS North Region. One was from the West region.
- Four of the individuals were female and two were male.
- The client ages ranged from 46 to 84 years old with three individuals under 55 and three individuals over 55.
- Four were asking for an increase of staff support while two of the four were requesting additional staff supports to return home from rehabilitating in long-term care facilities. One was seeking placement in a community living arrangement and one was appealing a denial of waiver enrollment.
- None required a formal DSS hearing because all six decisions were made in favor of the client prior to a hearing.

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

Category	Recommendations
Person Centered Plan	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
Health	Develop screening and evaluation tools, advisories for all individuals served
	Evaluate recruitment and retention strategies for nurses
	Develop health resource center of excellence
Housing	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
Transportation	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
Retirement	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
Leisure	Ensure access to leisure and recreation services
	Ensure individual’s plans include recreation and leisure activities
Supports to Families	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
Education and Training	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
Legislation	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
Grants and Research	Expand effort to increase access and participation in grants and research
End of Life Planning	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

APPENDIX D. Community Training Homes (CTH) Aging Population Report: Issues and Recommendations	
<i>Issues</i>	<i>Recommendations</i>
Aging population and future planning	
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.	
Regional staffing and practice	
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.
Regulations and funding	
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.
Training	
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)	

APPENDIX D. Supported Living Services Aging Population Report: Issues and Recommendations	
<i>Issues</i>	<i>Recommendations</i>
	Aging population and future planning
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 in 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.
	Impact of new waiver
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 be reviewed and revised as necessary.
	Education and training
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)	

APPENDIX E. DDS Eligibility Referrals of Persons Age 45 and Older

Table E-1 provides a demographic profile of the eligibility referrals since 2006 for persons age 45 and older. As the table shows, the majority of referrals are for individuals between the ages of 45 and 64. Only eight percent of the eligibility referrals were made for persons age 65 and older. The referrals came from all three regions with 40 percent in the North Region, 33 percent in the South Region, and 26 percent in the West Region.

		2006	2007	2008	Total
Age	Between 45-54	44	53	52	149
	Between 55-64	30	30	34	94
	65 and older	7	11	4	22
Region	South	26	28	34	88
	West	19	30	21	70
	North	36	36	35	107
Source: LPR&IC analysis					

In terms of the DDS eligibility process for the referrals made for persons age 45 and older since 2006, the program review committee found:

- The process time has ranged between one and 25 months. On average, the eligibility process takes approximately three to five months to complete.
- About a quarter of the referrals were reviewed by a second agency psychologist.
- The most common reason for the applicants to be deemed ineligible is due to test scores not meeting the statutory requirement and/or disability not occurring during the developmental period.
- Of the applicants in this group who were found eligible, the majority were determined to have the following level of mental retardation: 70 percent were “mild”, 21 percent “moderate”, 7 percent “severe”, and 2 percent “profound”.

Further analysis of the 90 eligibility referrals made in 2008 for individuals age 45 and older found:

- The referral source varied among this group. The majority of referrals were submitted by family members (62 percent) followed by social workers/community providers (22 percent), non-family conservators/guardians (6 percent), nursing homes (3 percent), and other advocates or friends (3 percent) as well as the individual themselves (3 percent).
- Almost an equal percentage of the individuals age 45 and older resided with family members (48 percent) and in the community (47 percent) at time of

referral. The remaining individuals resided with a non-family conservator/guardian (2 percent) or in a long term care facility (3 percent).

- While 78 percent of the applicants did not specify what services they were seeking, the 22 percent that did indicated they wanted case management (17 percent), residential placement (10 percent), in-home family supports (7 percent), vocational services (6 percent), day program (3 percent), and recreational services (3 percent).

Eligibility appeals. 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 committee reviewed the 20 eligibility appeals of persons age 45 and older made since 2005 (Table E-2). As of November 2008, two appeals for individuals age 45 and older are pending. In eight of the 20 cases (40 percent), applicants withdrew their requests before the hearing occurs. Ten had hearings with six determined eligible and four found ineligible. Frequently, a determination is made when the applicant provides additional or necessary documentation prior to the hearing. In all four cases of ineligibility, the department found that the individual's IQ scores did not meet the statutory level and deficits did not occur during the developmental period.

Table E-2. Summary of Eligibility Appeals for Individuals Age 45 and Older (2005-2008)					
	2005	2006	2007	2008	Total
Requests for Hearing	9	2	8	1	20
Withdrew Request	5	1	2	-	8
Determined Eligible on Appeal	2	1	3	-	6
Determined Not Eligible on Appeal	2	-	2	-	4
Pending	-	-	1	1	2
Source: DDS					



M. Jodi Reil
Governor

Appendix F
State of Connecticut
Department of Developmental Services

DDS

Peter H. O'Meara
Commissioner

Kathryn du Pree
Deputy Commissioner

February 10, 2009

Carrie E. Vibert, Director
Legislative Program Review and Investigations Committee
State Capitol Room 506
Hartford, CT 06106

Dear Ms. Vibert:

Thank you for the opportunity to review and comment on your committee findings and recommendations related to *Planning for the Needs of Aging Individuals with Developmental Disabilities*. I appreciate the time and effort that has gone into studying this important issue that impacts many individuals in our service system.

We understand that the focus of this study was to evaluate the Department of Developmental Services' (DDS's) efforts to address and plan for the current and future service needs of the aging population with intellectual disabilities in Connecticut. With the recognition of this issue, DDS has taken steps over the past several years to evaluate future needs and to put systems in place to address these needs. We have outlined these steps in previous testimony before your committee related to this study.

Regarding the specific recommendations that have been supported by committee members, we will address the recommendations in the order presented.

Section 1: DDS Wait and Planning Lists

1. **Funding for the wait list initiative should continue at current level for another five-year period. In addition, a separate, non-lapsing General Fund account should be established to receive any proceeds from the sale, lease, or transfer of any DDS property. The fund must be used, as appropriated by the General Assembly, to supplement the funding for DDS plans to provide services to individuals on its wait list. Any investment earnings on the fund's balance must be credited to the fund.**
- DDS has made significant strides in addressing the needs of individuals on the waiting list over the past several years with financial support of Governor M. Jodi Reil and the legislature through the state budget process. Although the Waiting List Settlement Agreement expires on June 30, 2009,

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and it is unlikely there will be additional resources added for this purpose in the next biennium based on the current economy, the Governor has continued to propose new resources for high school graduates and individuals who are aging out, individuals who ultimately would have added to Waiting List numbers. In addition, the Waiting List Settlement Agreement and initiative has substantially expanded the funded capacity of the department over the past five years. The resource commitments set forth in the Settlement Agreement have been fully realized and the department has sought, and will continue to seek, new resources targeted to the Waiting List while efficiently managing the enhanced capacity established during the term of the Settlement Agreement.

- Regarding the establishment of a nonlapsing fund for the proceeds from the sale, lease or transfer of any DDS property, please note two relevant statutes: CGS Section 17a-451d and CGS 17a-283a. Conn. Gen. Stat. Section 17a-451d established a Non Lapsing Fund for site acquisition, capital development and infrastructure costs to provide services to persons with mental retardation or psychiatric disabilities. This statute was related to the sale of Norwich Hospital or any regional center after January 1, 2001. In addition, Sec. 17a-283a, as amended, placed a moratorium on the sale, lease or transfer of state property used for residential purposes by persons with mental retardation through June 30, 2009. The moratorium was extended once already for a two year period and there has been interest expressed by some to extend it even further. Although there are no current plans by the department to sell, lease or transfer any DDS property, any such extension of the moratorium would prohibit the department from doing so. It is important to note that any resources obtained through the sale of property would be a one-time amount. However, individuals in our service system usually require a lifetime of services and an annualization of service dollars would be required.

2. DDS should analyze the wait and planning lists to identify individuals who will need services within the timeframes established under the priority categories and compare the results to the types of housing available to ensure homes are in similar geographic locations.

- The current Waiting List initiative is based upon the provision of individual supports either in ones' own or family home. This initiative was not designed or funded to include the development of new community living arrangements (CLAs). In part, this was because of the significant expense of group home development and because DDS can and does offer appropriate CLA vacancies to individuals on the Waiting List as they become available. Each region maintains a list of vacancies in CLAs and other settings. The regions' Planning Resource and Allocation Teams (PRAT) are responsible for making referrals from either the Emergency or Priority 1 lists. In making these referrals, families' wishes for geographic proximity are taken into consideration, but distance may be unavoidable particularly when addressing an emergency situation. Some families have also chosen to work collaboratively to pool the resources assigned to their children to create out-of-home group living options.

Section II: DDS Policy, Procedure, and Services

3. DDS should establish minimum criteria for what constitutes a significant change or situation prompting a level of need review.

- The Level of Need Assessment (LON) should be completed before the consumer's initial individual plan is developed and updated annually, or more often as needed, to reflect significant changes in the person's life or to identify and document concerns or issues that may pose a health and safety risk to the individual. An updated LON for an individual is

required when there are changes in any of the domains included in the assessment that would necessitate a change in the level or type of support/supervision required by the individual. These domains are: Health and Medical, PICA, Behavior, Psychiatric, Criminal/ Sexual Issues, Seizure, Mobility, Safety, Comprehension and Understanding, Social Life, Communication, Personal Care, and Daily Living. Reasons for updating the LON might include (but are not limited to), transition planning to a different work or residential environment, new medical diagnosis, change in level of support required for previously prescribed medical treatment, new Physical and/or Occupational Therapy evaluations, behavioral/psychiatric changes, or change in supervision protocols for dining, bathing, mobility, or behavior. An updated LON is required whether the situation prompting the change in supports and services is short or long term.

4. DDS should increase the minimum frequency of case manager face-to-face contacts for DDS clients residing with aging caregivers as well as for aging individuals receiving DDS case management services in all residential settings.

- While the department agrees with the recommendation to focus additional case management time and resources on the aging individuals we serve and aging caregivers, any increases to the number of visits would require additional case management resources. As the department receives new case management positions or is able to reallocate resources to case management, the caseloads for case managers who serve aging individuals and individuals with aging caregivers will be considered a priority.
- In the meantime, the Aging Services Coordinator will provide guidance and information to case managers regarding the potential vulnerabilities of and risks to our department's aging population and the early identification of concerns and increased needs.

5. DDS should request additional funds to provide lower case management ratios after it has examined its case management services.

- During fiscal years 2007 and 2008, the department conducted a thorough review of case management tasks and, as a result, made a number of improvements and increased efficiencies. Additional technology efficiencies are in development or in the planning stage.
- Each year, the department assesses its case management resources and when necessary, requests case management resources in an effort to keep pace with the numbers of individuals served and the demand of various case manager caseloads. As mentioned above, as additional case management resources are identified, the caseloads for case managers who serve aging individuals and individuals with aging caregivers will be considered a priority.

6. DDS should evaluate and standardize the PRAT process used in each region to improve consistency.

- The department's goal is to have consistency in its resources allocation function. DDS policies and procedures have been developed and issued in conjunction with the use of the waiver manual to guide the work of the regional Planning Resource and Allocation Teams (PRAT). The core membership of these teams has been defined, but Regional Directors do have the authority to expand the team's membership beyond the core group if that works well for a particular region. The director of Waiver Policy meets regularly with PRAT Coordinators to review practices, clarify policy and interpret procedures. During the next six

months, the director of Waiver Policy will attend PRAT meetings in each region and will make recommendations to improve consistency.

7. DDS should reconsider the level of staffing dedicated to aging services when resources are available. At a minimum, a staff person in each region should be delegated to assist the central office aging coordinator in the efforts to develop new service alternatives and to leverage existing elder programs in order to integrate aging DDS consumers whenever possible.

- The department is sensitive to the growing needs of both its elderly population and aging caregivers. We have given priority to this need over other important enhancement functions when redeploying personnel resources. In FY07, DDS established the position of Coordinator for Aging Services. In addition to this position, we have asked the DDS Ombudsperson to visit every DDS consumer who resides in a nursing home to assess their general quality of life and to make recommendations for systems improvement. We have also hired a full time nurse to monitor the health care and medical conditions of individuals in nursing homes as a compliment to the role of the 3 OBRA Coordinators who work in the regions.

Currently, DDS does not have the personnel resources to add an aging services liaison in each region. We will review this recommendation again in the future if additional personnel resources become available to the department.

8. DDS should designate a central office point-of-contact to assist families seeking legal and/or financial guidance regarding planning for the future of their children.

- While DDS cannot provide legal assistance to consumers and families concerning trust and estate planning, the department is willing to establish a process in which trusts and estate planning issues can be identified by the DDS Case Manager and questions referred to the DDS Medicaid Operations Unit. The DDS Legal Director is planning to consult with the appropriate section(s) of the Connecticut Bar Association to examine whether there is a fair and ethical approach for the department to direct consumers and families to legal services.

9. DDS should incorporate an additional component to the individual plan of aging clients that would reflect the individual/family's desired long-term care plan along with alternative contingencies if the desired long-term care plan is not viable.

- The DDS Individual Plan form currently includes a section for identifying an individual's future plans. We expect our case managers to discuss future planning and long term care needs with families whose children are older or in cases when the caregiver is elderly. Families differ in their willingness and comfort in discussing this in detail. We will use our case manager newsletter and upcoming meetings with case manager supervisors to reinforce this expectation and determine if additional training is needed.

10. DDS should consider the expansion of respite services when appropriations become available.

- The department is very committed to the provision of respite to families and knows that the DDS Respite Centers are an important component of support for many families who have kept their children at home. We have created 11 Respite Centers through the redeployment of staff. An additional respite center had been planned for both the North and South Regions to

equalize capacity across the department's three regions. At this time, these plans have been put on hold because of the state's current financial situation. If possible, we will resume respite expansion in the future.

Section III: Long-Term Care Provided in Nursing Homes

11. As part of its audit of nursing home records currently conducted by DDS, the following minimum information should be collected on and verified for clients currently living in nursing homes:

- a. case managers are assigned and have met the requirement of quarterly contact and annual face-to-face contact;** Case managers will be instructed to sign the DDS contact information form located in the clinical record of all DDS consumers residing in licensed nursing facilities. The DDS Utilization Review Nurse and DDS Ombudsman will audit consumer records at all facilities to ensure that case managers are documenting on the DDS contact sheet when they visit the consumer(s). As part of their ongoing supervision of case managers, case management supervisors ensure that visits are scheduled and conducted as required.
- b. whether or not the nursing home has notified DDS if a client has had a significant change in condition, been hospitalized, or died;** Through the existing DDS critical incident/death reporting system, the department routinely receives information regarding the timely reporting of all deaths of DDS consumers who reside in licensed nursing facilities. In October 2008, DDS, jointly with the Departments of Public Health and Mental Health and Addiction Services, issued a letter reminding licensed nursing facilities of their state and federal notification requirements. Specifically, DDS is to be notified "when a resident who has mental retardation undergoes a change in condition or when a resident who has not previously been diagnosed as having mental retardation undergoes a significant change in condition which may require specialized services." Conn. Gen. Stat., Section 17b-360(d). The Social Security Act includes an analogous notification requirement, specifically: "In addition, a nursing facility shall notify the mental health authority (DMHAS) or state mental retardation or developmental disability authority (DDS), as applicable, promptly after a significant change in physical or mental condition of a resident who is mentally ill or mentally retarded." 42 U.S.C. 1396r(b)(3)(E). If the DDS Utilization Review Nurse, DDS Ombudsperson, or case manager discovers a delay or failure on the part of the facility to report a death, they will notify the DDS Regional Health Services Director and the DDS Director of Health and Clinical Services.
- c. health records are complete and accurate;** Federal regulations, state regulations and nursing home licensing requirements require that certain minimum standards are met with respect to maintenance of health/clinical related documentation/records. Complete and accurate health records are the responsibility of the nursing facility. Nursing homes that receive federal funds must comply with federal legislation that calls for a high quality of care. Though all states must comply, at a minimum, with the federal regulations, some states have adopted more stringent laws. A nursing home "must provide services and activities to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident in accordance with a written plan of care..." as prescribed in the U.S. Code of Federal Regulations (42 CFR Part 483) and "Maintain accurate, complete and easily accessible clinical records on each resident" (42 CFR 483.75). On an annual basis, the DDS Utilization Review Registered Nurse assigned to monitor licensed nursing facilities will evaluate the quality of health records maintained by the nursing facility.; **and**
- d. emergency contact information is contained in the file.** On an annual basis, the DDS Utilization Review Nurse will audit the licensed nursing facility record/chart of DDS consumers to ensure that the emergency DDS contact sheet includes emergency contact information and is present in the consumer's file. Additionally, new Long Term Care guidelines for staff are being developed that will standardize the information that case managers need to gather and/or update during visits to long term care facilities.

12. The term "significant change in condition" be defined in guidelines, including the process that nursing facilities must follow in notifying DDS, what actions must be taken by DDS upon receipt of such notification, and circumstances that should initiate face-to-face contact between a client and his or her case manager, and/or require an assessment by a DDS nurse consultant. The roles and responsibilities of the case manager supervisor and regional manager-on-call should also be defined, including any actions that must be taken by them when such notification occurs.

- It is the responsibility of the Registered Nurse employed by the licensed nursing facility to assess an individual's health status to determine whether the resident's symptoms or change in condition constitute a significant change in condition (Conn. Gen. Stat. Sections 17b-359(d); and 17b-360(d)).
- Under Conn.Gen. Stat. 17b-360(d), nursing facilities are required to notify the Department of Developmental Services when the resident who has mental retardation undergoes a significant change in condition. The DDS contact sheet in each DDS consumer's file states that the facility must notify DDS of a significant change in the person's condition or the death of the consumer. Deaths are defined as a critical incident/significant change in condition in DDS Procedure (I.D.PR.009).
- This notification requirement is also found in the Social Security Act 42 U.S.C. 1396r(b)(3)(E).
- Significant changes in condition are reported to DDS via the established DDS business and after hours reporting system.
- DDS will review its existing processes and procedures to clarify expectations, roles and responsibilities of the case manager, case management supervisor and regional manager-on-call, including actions that must be taken when such notification of death or change in condition occurs. The new long term care guidelines currently under development will outline and standardize this information and will be reviewed with DDS and licensed nursing facility staff as needed.
- At any time, on a case-by-case basis, DDS case managers may request consultation and/or technical assistance from a DDS Nurse Consultant to review the health status of DDS consumers living in licensed nursing facilities.

13. DDS should establish a centralized data system to capture information on clients residing in nursing homes in order to document:

- a. reason(s) for nursing home admission;
- b. lengths of stay;
- c. admitting rates to nursing homes by hospital;
- d. frequency of case manager contact, with uniform documentation and alerts generated when frequency of contact is not being met; and
- e. notification of a significant change in a client's condition, including an identification of the change.
- f. **DDS should randomly audit a sample of cases in the database to ensure its accuracy.**

- A standardized DDS database for maintaining the above data elements is in the development phase and is expected to be finalized by April 2009. However, completion of this database is dependent on the availability of departmental resources and workload demands. This new data base will address data elements recommended in #13 a, b, & c above. Additionally, the state's Money Follows the Person (MFP) grant will track the number of admissions to nursing homes and work with discharge planners to decrease long term care admissions so as to better understand the barriers to returning to the community following hospitalizations. DDS, as a MFP partner, will work on this issue as resources permit.

- d. frequency of case manager contact, with uniform documentation and alerts generated when frequency of contact is not being met;

The department is not able to address the collection of this information in an electronic database at this time, but will consider it in the development of any future data applications. This information is available in the consumer's individual record. Case management supervisors ensure that visits are scheduled and conducted as required as part of their ongoing supervision of case managers. Expectations for uniform documentation will be addressed in the new Long Term Care guidelines and procedures.

e. notification of a significant change in a client's condition, including an identification of the change.

DDS maintains death report data, and all deaths are reported to DDS per federal and state regulations. In addition, when a change in a consumer's condition, who is placed or treated under the direction of the commissioner of DDS, warrants the need for a properly executed medical order to withhold cardiopulmonary resuscitation the nursing facility shall report this change of condition to DDS for review pursuant to Public Act 93-303. Requests by nursing facilities' medical practitioners to withhold cardiopulmonary resuscitation are maintained by DDS.

f. DDS should randomly audit a sample of cases in the database to ensure its accuracy.

On an annual basis, the DDS Utilization Review Nurse will audit a sample of consumer information in the DDS' standardized data base against the facility records/charts of DDS consumers.

14. DPH shall notify the appropriate Regional OBRA Liaison of the results of its review of the PASSR Level II screens conducted in each nursing home. If DPH finds that the services identified in the Level II screen are not being provided by the nursing home, it should determine the reason why. The Regional OBRA Liaison should forward the results to each client's case manager who is responsible for following up with the nursing facility to ensure the client has received the services identified in the Level II screen within 30 days of receipt of DPH findings.

- The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) mandated preadmission screening for individuals suspected of having serious mental illness and mental retardation to ensure that; (1) nursing facilities admit only individuals needing nursing facility care, (2) these individual's needs for specialized services are determined, and (3) these individuals obtain the services identified through the preadmission screening. The Preadmission Screening and Resident Review (PASRR) is the primary mechanism to meet these objectives. All individuals who apply or reside in Medicaid nursing facilities are required to receive a Level I PASRR screen to identify suspected mental retardation. Those suspected of having mental retardation must receive a Level II PASRR evaluation to confirm that they have mental retardation, to determine whether they require nursing facility services, and to determine whether they require specialized services.
- DDS case managers routinely audit the level of services identified in the Level II screen, ensure that there is a plan for the identified services and follow up with the nursing facility to ensure the consumer has received the services identified in the plan. It is really not the responsibility of DPH to determine the reason why services identified in a Level II screen are not being provided by a nursing home.

15. DDS should partner with the two nursing home associations in Connecticut to provide targeted training around some of the specific issues related to providing care to individuals with intellectual disabilities who reside in nursing homes. Although training efforts could be aimed at a variety of audiences, it should, at a minimum, include:

- Registered Nurse (RN) nursing home directors responsible for client services; and

- **DPH surveyors who conduct nursing home inspections and record reviews.**
 - The DDS Aging Services Coordinator and Focus Team on Aging have developed a number of training presentations on issues related to aging and intellectual disabilities, and delivered these to a variety of audiences. The Aging Services team will work with DDS Educational Support and Staff Development to develop a web-based training curriculum based on these existing training materials. This training can be made available to nursing home directors and staff through either the University of Connecticut Health Center - Video Communications Department, the DDS website, or a combination of the two. DDS will work with Connecticut's two nursing home associations to make this training available to RN nursing home directors, DPH surveyors and other audiences as appropriate.

16. DDS should survey the types of medical care provided in each private provider home and whether or not it is delegated to unlicensed staff. Based on the survey results, the department shall assess what is lacking in services among providers and establish a policy that provides for a comprehensive system of supports which will encourage providers to provide certain types of care to clients and allow them to age-in-place.

- DDS conducted a nursing supports survey of private agencies in early 2008. An additional survey would not be warranted at this time. DDS is aware that there are several agencies that have implemented policies that limit the number of consumers who may return home after an acute or chronic illness. These agency decisions are frequently driven by the availability of skilled nursing resources. The Connecticut Board of Examiners for Nursing's Memorandum of Decision, Re: Declaratory Ruling - Delegation By Licensed Nurses to Unlicensed Assistive Personnel (April 5, 1995) and DDS Nursing Standard (97.1) define the parameters for delegation of tasks to unlicensed personnel. Therefore, within the DDS service system, licensed registered nurses have established a process that allows health related procedures to be delegated to non-licensed personnel.
- While hospitals prefer to discharge consumers back to their original place of residence, they are sometimes pressed to discharge individuals to licensed nursing facilities when the support services at their residence can not meet the individual's health needs. The DDS service system is designed to allow and support agencies to provide services for individuals so that they can remain in their own homes. Typically, the additional services that are required by an individual occur acutely and are able to be addressed by the person's individual planning team through the department's existing resource allocation system. As a result, the majority of individuals are able to be supported in their home until the time of their death.

Section IV: Continued Planning Efforts for the Aging Population

17. DDS should, when revising its five-year plan and internal strategies, incorporate the action plans of the various work group reports it intends to implement and ensure that the goal statements include specific steps and dates of accomplishment for what the department is trying to achieve.

- The department's current Five Year Plan was written in 2006 and issued in early 2007. The next Plan will be issued in early 2012. In the interim, the department engages in an annual business planning process. While aging issues were not prominently featured in the 2007-2012 Plan, there have been specific aging goals in the annual business plan since then and especially once the department hired the Aging Services Coordinator. An update of activities mentioned in the Legislative Program Review and Investigation Committee's report will be

reflected in the 2012 Plan as well as new aging specific goals. Until then, the annual business plan will serve as the vehicle for capturing aging goals and activities.

18. DDS should continue to collaborate with groups with similar objectives and report any accomplishments and expected or required DDS commitments to external projects in the department's five-year plan.

- DDS will continue to collaborate with groups with similar objectives and report any accomplishments and expected or required DDS commitments to external projects in the department's five-year plan as well as in any documents associated with the collaborative groups. The groups that DDS currently collaborates with include Money Follows the Person (MFP), The Long Term Care Planning Committee, Aging and Disability Resource Center (ADRC), Commission on Aging, Connecticut Coalition on Aging and Developmental Disabilities (CCADD) and American Association on Intellectual and Developmental Disabilities (AAIDD).

19. The Commissioner of Developmental Services, in consultation with the Commissioner of Public Works and the Office of Policy and Management, shall evaluate the feasibility and appropriateness of a continuum of options for Southbury Training School. At a minimum, the range of options shall include property closure and sale, continued or modified use as a DDS residential facility, and alternate uses for other state agency services. Each option considered shall provide:

- the underlying rationale for the option;
- the populations affected;
- associated costs and/or revenue generated; and
- a specific outline of the required action steps, potential entities involved, and anticipated timeframes for implementing the option.

The DDS commissioner shall hold public hearings to solicit input and opinion of interested stakeholders. The DDS commissioner shall submit a report containing the criteria and standards used to form the basis of the evaluation, transcript of any hearing(s) held, as well as findings and recommendations to the governor and the legislature no later than December 31, 2010.

- At this time, there are close to 500 DDS consumers living at Southbury Training School (STS) and admissions are currently closed pursuant to state statute Conn. Gen. Stat. 17a-218a(b) and binding federal court commitments. There are significant legal issues involved in the operation of STS including two major lawsuits that are still ongoing. DDS currently has agreements with multiple entities involving use of the parts of the campus currently unused by the department. These include use by the Department of Agriculture (farm and crop land), the Department of Emergency Management and Homeland Security (district office), Special Olympics, Connecticut State Employee credit union (CSECU), a summer camp, and the Town of Southbury. In addition, use by the Department of Environmental protection (passive recreation and open space preservation) is being explored. Also, STS employs a Fire Department/ EMS that provides mutual aid to the Towns of Southbury and Roxbury in addition to addressing the needs of STS residents.
- A study of this magnitude would require a significant amount of time and administrative resources. Decisions regarding the future use of the campus must take into account the legal and contractual obligations currently in existence regarding individuals who live and work at STS. Although the discussion about continued operation of STS is entrenched in a philosophical debate, the feasibility and appropriateness of a continuum of options for

Southbury Training School is an administrative policy decision that should be based on the current and potential future needs of the state and of course, DDS consumers. DDS will continue to discuss options with the Office of Policy and Management regarding future use, but with the current state of Connecticut's economy, DDS does not believe that this study would be the best use of increasingly limited time or resources.

Section V: Cost of Client Care and Planning

20. The Department of Developmental Services, in consultation with the Department of Social Services, shall conduct a detailed cost review of per capita, per diem costs of care provided in institutional settings to care provided in the community. The cost methodology should include, but not be limited to the following factors: resident acuity, collective bargaining agreements, Medicaid costs, and the differences in staff costs between public and private providers. The report shall be presented to the legislative committees of cognizance by February 1, 2010.

- The Department of Developmental Services (DDS) will be able to conduct a detailed cost review which will produce average per capita cost for individuals living in campus settings and individuals residing in the community. The cost methodology (rate structures), which are computed within DDS and reviewed and agreed upon with the Department of Social Services, will include all direct and indirect costs that will demonstrate the differences in per diem costs between public and private providers.

Again, thank you for the opportunity to respond to the committee's final report. In recent years, DDS has integrated many of the recommendations of the Aging Focus Team into our overall systems improvements including portability of resources, restructuring of the waiting list with an emphasis on aging caregivers, updating our waiting list priority checklist, assessing individual's needs with a comprehensive Level of Need (LON) tool, adding services to our Home and Community Based Services (HCBS) Waivers including assisted living and health care coordination, developing 15 health related fact sheets for individuals and families, and working with a doctor who specializes in medical care for aging individuals who have disabilities.

As a result of our efforts, we are able to help individuals age in place, and we have seen the number of individuals going into nursing homes decrease. We have offered day programs, which provide a variety of stimulating activities during the day, for more individuals living in Long Term Care Facilities (LTC). Quality of care has improved immensely through the years. Individuals with intellectual disabilities are living longer than in previous decades. The Department will continue to ensure the continued health and safety of our consumers who are aging while providing services that promote quality of life.

Sincerely,



Peter H. O'Meara
Commissioner