

Findings
and Recommendations

Planning for Needs of Aging
Individuals with
Developmental Disabilities

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Legislative Program Review
& Investigations Committee

CONNECTICUT GENERAL ASSEMBLY

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Introduction

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, is to examine DDS efforts to address and plan for current and future service needs of the aging population with intellectual disabilities in Connecticut.¹ 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.

This report contains the result 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 at a time 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.

¹ The study concentrates on two target populations: 1) individuals age 45 or older who are or would be eligible for DDS services, and 2) caregivers of DDS clients over the age of 65.

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.² 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. As noted above, 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, the older individuals with intellectual disabilities face competition for resources even within the agency responsible for its 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 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

² OFA Projections & Governor's Report

available resources. With limited funding, DDS maintains wait 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 list.

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.

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 lead 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 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 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. As noted in the briefing report, 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 prepare 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 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 the 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 person 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.

Report 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 the 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 also conducted a multitude of on-site interviews with key stakeholders. These included legislators, legislative staff, DDS central office staff, Southbury Training School staff, and 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. The committee 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 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 Format

This report contains five sections. Section I describes the current and projected status of the DDS wait and planning lists. Section II discusses DDS policy, procedures, and services as they relate to the aging consumer base. Section III examines emerging issues of individuals with intellectual disabilities in the nursing home environment. The need for continued planning efforts is evaluated in Section IV. Finally, Section V presents the challenges of determining cost of care and planning.

DDS Wait and Planning Lists

As discussed in the committee briefing, 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 (DMR) and the Department of Social Services. The suit alleged among other things that the agencies' failure to provide services with reasonable promptness to all persons eligible under Connecticut's Home and Community-Based Services waiver (HCBS) was a violation of Medicaid law. The federal court allowed the lawsuit to proceed as a class action, which included over 1,000 individuals on the DMR wait list.

The parties negotiated and eventually entered into 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.

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-based 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 and planning lists and how priority was assigned to more accurately reflect those with the greatest need for services (shown in Table I-1). The department reconfigured its *wait list* to only include individuals who had an emergency (E) or required residential supports within one year (Priority 1 status). All other individuals with non-emergency needs would be placed on a *planning list* as underserved or undersupported.

Table I-1. DDS Priority Status Categories for Wait and Planning List		
Status		Definition
Wait List	Emergency	An <i>immediate</i> need for residential placement, support or services.
	Priority 1	A need for residential placement, support or services <i>within one year</i> .
Planning List	Priority 2	A potential need for residential placement, support or services <i>within two to five years</i> .
	Priority 3	A potential need for residential placement, support or services <i>more than five years</i> in the future.
Source: <i>ARC/Connecticut et al. v. O'Meara et al.</i> Settlement Agreement Section II		

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 will 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.³

Profile of Older DDS Clients or Those with Older Caregivers on 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 lists who meet 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 meeting 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 list either:

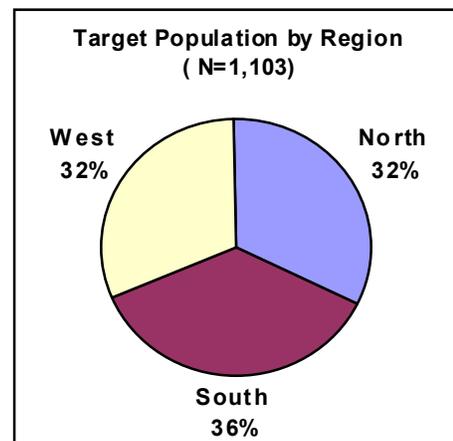
- reside at home with family or live independently, and
 - receive only case management; or
 - receive limited DDS services funded through state enhanced family support grants; or
- live at home with family or in a residential setting, such as a community living arrangement or supported living, and receive DDS residential services and supports under the Home and Community-Based Services (HCBS) Medicaid waiver, but are considered underserved or expected to be 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 I-1 to I-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. Additional analysis and information on the target population is provided in Appendix A.

Figure. I-1. Regional Distribution of Target Population.

- 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.



³ 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.

Figure I-2. Primary Reasons Why Target Population on List.

- 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

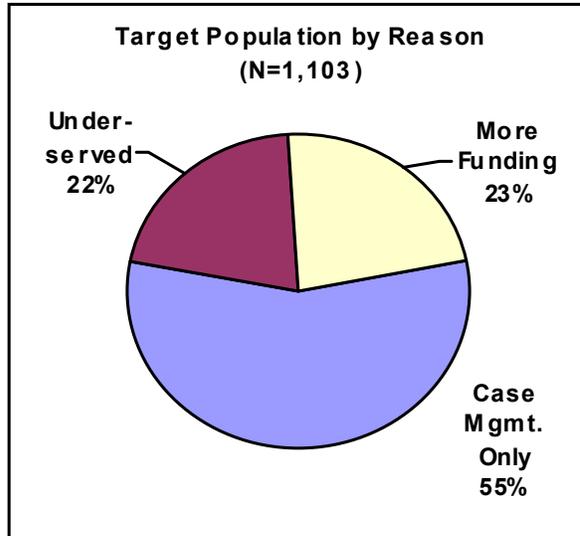


Figure I-3. Priority Status of Target Population.

- The largest numbers of the target population have been identified as Priority 1 (45%) 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.

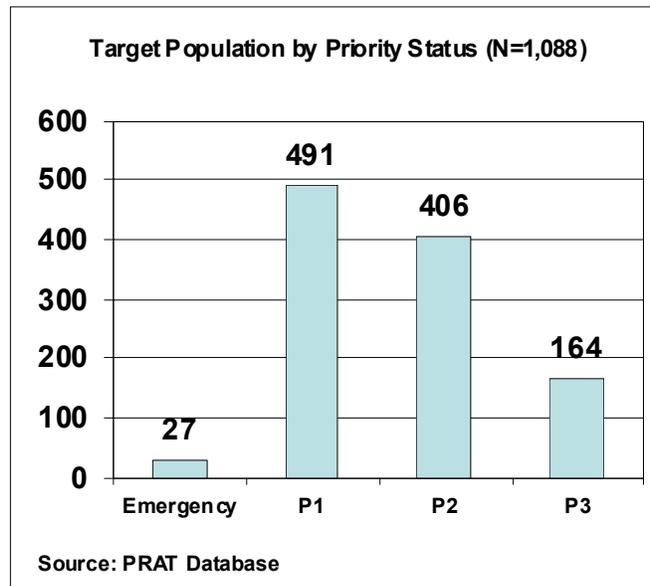


Figure I-4. Primary Residence of Target Population.

- The majority of the target population 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).

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 I-5. Target Population Living with Family

- Of the 680 target population individuals living with family, 149 (22%) had caregivers age 80 years old or older.
- 83% of the target population 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

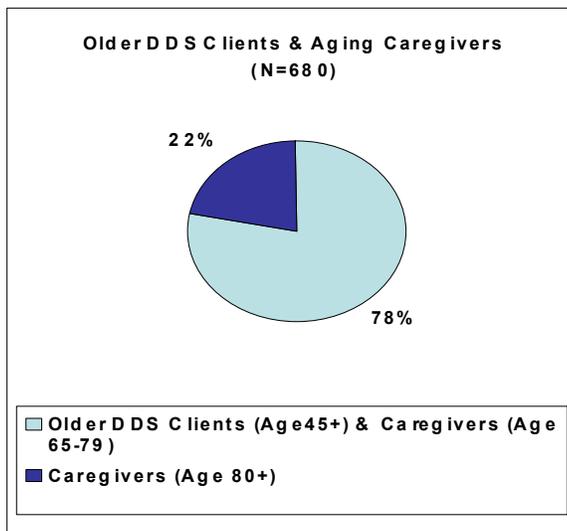


Figure I-6. Target Population Living with Elderly Caregivers (Age 80+).

- The majority of those living with elderly caregivers 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 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

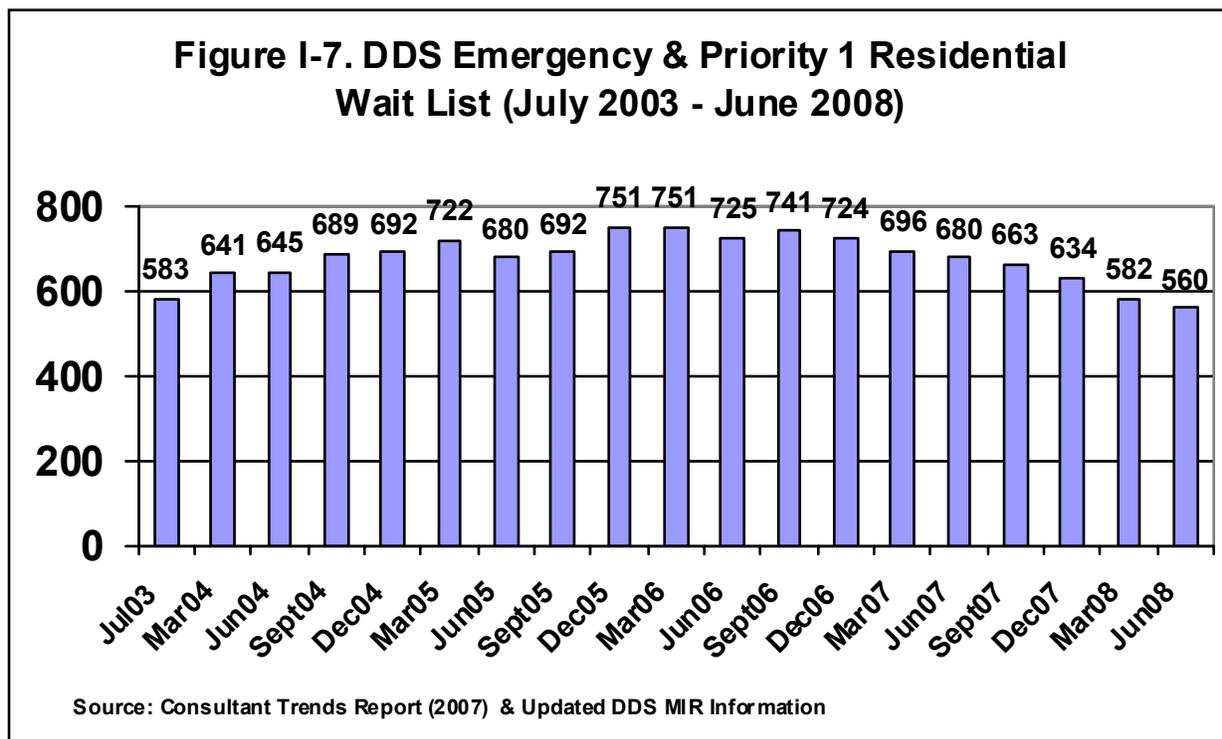
Implications. One of the stated objectives of the priority categories, according to the settlement agreement, was to serve individuals with older caregivers. The program review data analysis indicates that a large number (149) of DDS clients have elderly caregivers over the age of 80. Without proper 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 Section II, 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 list. 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 on the wait and planning list database serves as the foundation to evaluate current needs and project estimates of future needs.

Wait List Projections and Trends

In 2007, trend analysis on the number of individuals seeking residential services and supports was conducted by an independent consultant selected by the settlement agreement parties. In 2008, the parties requested an update of the 2007 report.

Figure I-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 updated consultant's 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."⁴ In addition, the department

⁴ 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.

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

Among the points made by the updated consultant's report:

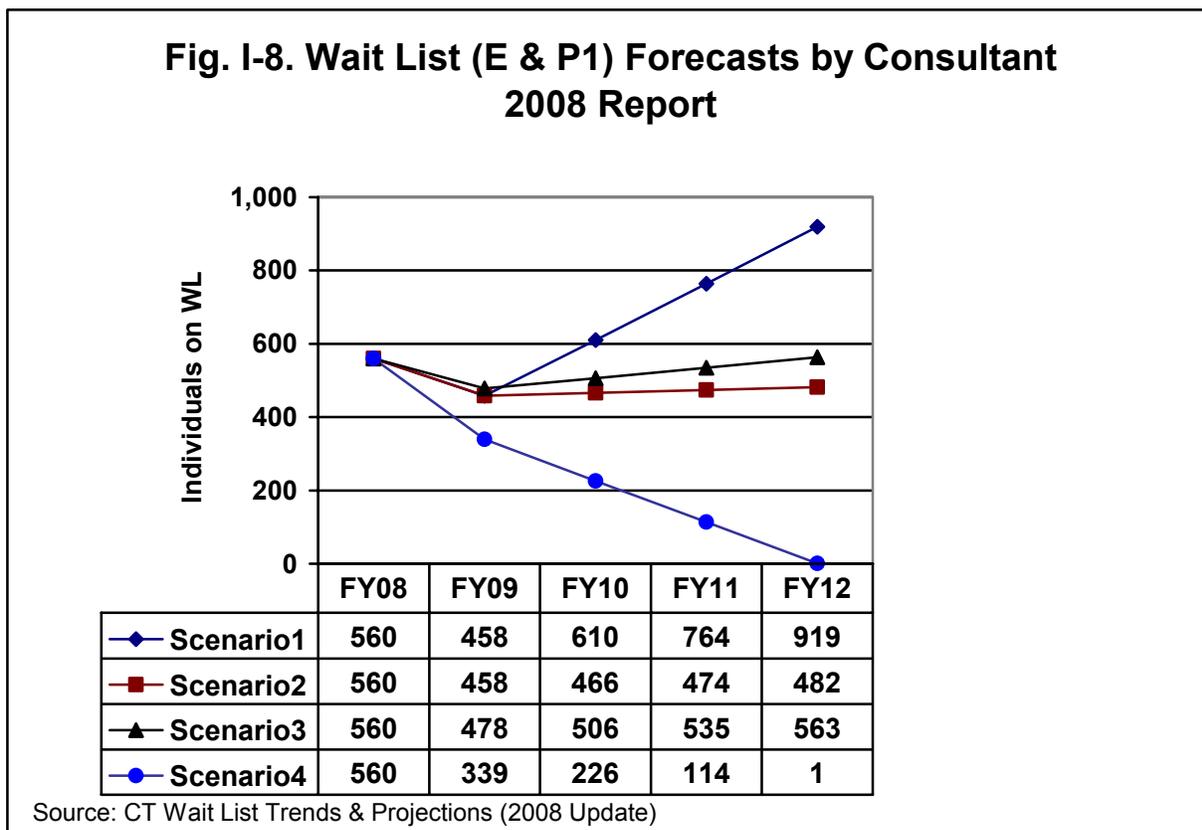
- The number of people on the residential wait list declined in part due to a higher than expected number of opportune openings. The number of opportune openings in 2008 was 12.5 percent higher than in 2007 and about 36 percent higher than the average over the last four years. The report indicates that 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."⁵ 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 Section II, 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 off 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 that projected a 3.5 percent increase each year and a 13.9 increase over the same time period.

⁵ *Connecticut Waiting List Trends & Projections*, September 23, 2008, p.3

Nevertheless, the recent consultant’s report concurs with the previous report’s conclusion that individuals eventually shift upwards in the priority rankings over time as they and their care-givers age. As such, “holding the wait list constant will require year-over-year expansion of services to keep pace with demand.”⁶

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 report depicts four alternative scenarios to forecast the future of the DDS wait list. All the scenarios assume: the settlement funding will continue to create 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 I-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 following the expiration of the settlement agreement in FY 09 to continue the growth in system capacity, the wait list will rapidly grow by 2012 to 919 individuals.

⁶ Connecticut Waiting List Trends & Projections, September 23, 2008, p.5

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) 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 will 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 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.⁷

At the program review committee's request, the committee was also asked to determine if the housing bond funds that had been already released for assisted housing could be used for DDS clients. The committee identified bond funds that were authorized and released last year to supplement funding for the supportive housing pilots initiative.⁸ 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 staff, bond funds once allocated and released cannot be used for another purpose.

Provider Capacity and People on the Waiting List

In response to questions raised at the September briefing, the committee examined residential community living arrangements 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 945 Community Living Arrangements (CLAs) in the state with a total licensed capacity of 3,871 beds.

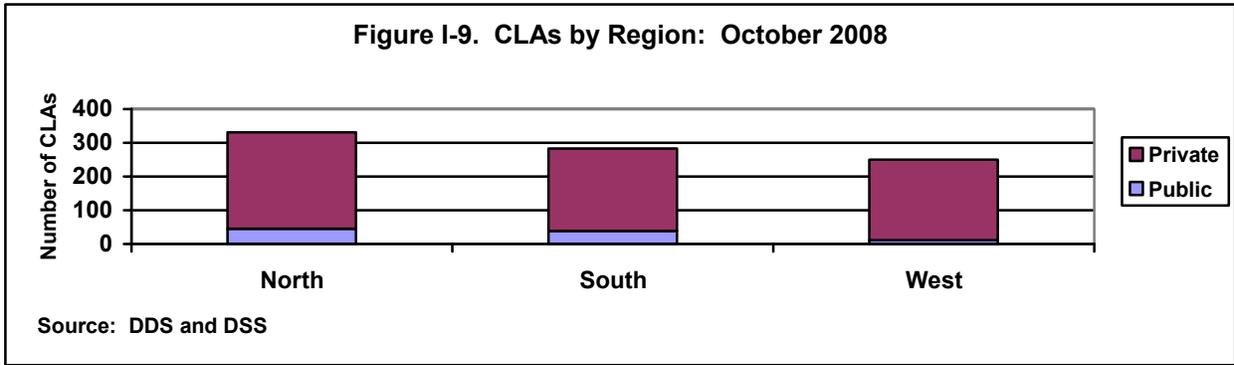
The program review committee found that there was almost no excess capacity in the system. When a permanent vacancy occurs, there is already so much pent-up demand for residential services, that an unfilled bed quickly becomes an opportune placement and is filled. An individual without resources or someone 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 family, DDS staff noted that 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, although an individual may be on the wait list when a placement is found, often the caregiver is not yet ready to have the individual move out of the family home.

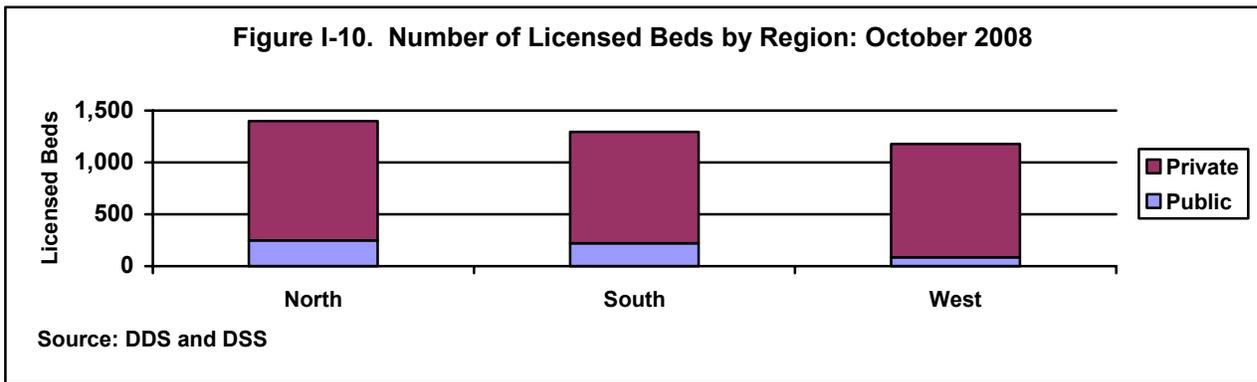
Figure I-9 shows the number of CLAs in each region and whether they are privately or publicly owned and operated. The North and West Regions each had a total of 331 homes, while the South Region has 283 homes. In addition, the North Region has the greatest number of publicly-operated homes (45) and the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

⁷ 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.

⁸ 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 vast majority of licensed beds are owned and operated by private providers. Figure I-10 identifies the number of beds in each region by type of provider. The North Region has the most beds and the West Region the least. In terms of licensed capacity, publicly operated homes, on average, have more beds than privately operated homes.



As of October, 2008 there were 2,896 licensed CLA beds, although the department could potentially expand capacity to 2,924 beds. Table I-11 shows the number of licensed 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>
Current Licensed	1,041	958	897
Maximum Capacity	1,052	963	909
Available Growth	11	5	12

Source: Department of Social Services

The trend over the years has been to reduce the size of group homes to make them 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 three or fewer

beds. Table I-12 compares bed size among CLAs and found that homes operated by private providers have smaller group homes, with an average size of four licensed beds, although they range from one to ten licensed beds.

Table I-12. Average Size of Group Home by Provider Type and Region: October 2008		
Region	Public	Private
North	5.6	4.0
South	5.7	4.4
West	7.9	4.6

Source: Department of Developmental Services

Table I-13 shows there were 683 individuals that were on the wait list 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 I-13. Wait List Status for Individuals Age 45 or Older or Caregiver is Age 65 and Older by Region				
Priority Status	North Region	South Region	West Region	Total
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 list provides the department with a valuable tool by helping to identify the clients that 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 list 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 list 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 list population.

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 consumer base. The following section provides a discussion of certain aspects of DDS policy and procedure that affect the entire DDS population, including older individuals. It also includes a description of recent DDS efforts made specifically to improve service delivery to older clients and their caregivers, and suggested improvements.

Case management. The case manager is the primary contact for DDS services and assists clients to identify and secure services through the level of need (LON) assessment and planning process. Recently, DDS implemented a new LON assessment tool to better link a client's health and safety needs to the services and supports that will be required.

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."⁹ 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.*

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 in Section III.) 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 June 2008 consultant report applauds DDS steps to address case management ratios but stresses the importance of the

⁹ DDS Manual, Procedure No. I.C.1PR.001.c (June 2003) p.2

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 attended regional PRAT meetings and interviewed DDS staff on 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 limits involvement to six or seven higher-level staff. Second, each region handles the notification of residential vacancies differently. One region closely controls the release of vacancy notifications while another shares 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 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.¹⁰ 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

¹⁰ DDS Manual, Procedure No.: I.B.1.PR.001

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 committee examined the number and types of recent appeals made by individuals aged 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 aged 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 regional director 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 aged 45 and older. Appendix B provides the results of the committee's limited review, which did not reveal any impact of 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 includes representatives from families, service providers, state agencies on housing, aging, transportation, and mental health and addiction services, as well as 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 is 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 extent of 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 (discussed in further detail below). 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 of the topics 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 forefront 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.¹¹ However, *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 mentioned by case managers to program review committee reveals 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

¹¹ As the lead Medicaid agency, DSS reviews the impact of assets on eligibility. DAS determines if state is owed any cost-of-care charges while the Office of the Attorney General reviews any legal implications in the state’s interests.

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 program review 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 PRI. 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 II-1 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 types of services from the department.

Table II-1. 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			

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. Case managers also help schedule a pre-visit meeting with that center’s supervisor.

The pre-visit meeting allows the family to tour the center and meet with respite center staff to discuss the individual’s level of need and any information that will help the respite staff become familiar with the client such as medications, types of food eaten, special activities, and any types of adaptive devices used.

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 II-2 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.¹² However, all regions experienced an increase of visits by individuals aged 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

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*

¹² 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.

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 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 clients have with DDS case managers. As of November 2008, there were 362 DDS clients residing in a nursing home.

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, it could be transitioned into this type of specialized facility.

A final issue area identified by 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 a group home or a private ICF/MR are admitted to a nursing home upon hospital discharge, while others, with the same medical needs, may be discharged back to their group home or ICF/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 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 described 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 border-line 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 the presence of it prior to age 22, the individual or guardian is provided with information to pursue DDS eligibility if they desire.

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 clients 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, there were a total of 362 clients in a nursing home in November 2008 and 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 the 138 clients refusing a program or did not want a program because they were retired, 14 clients were in need of a day program, and no information was 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 the 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 be conducted 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 met with staff from the Office of Protection and Advocacy for Persons with Disabilities (OPA) concerning two reviews that the office recently conducted as part of its responsibilities supporting the Fatality Review Board for Persons with Disabilities (FRB). The fatality review board reviews 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 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 to the client (13 clients), or Alzheimer's Disease or dementia (12 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);
- 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;
- Encourage 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
- DDS procedures should 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 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 meetings, the committee identified many of the same issues outlined in the two reviews conducted by OPA for the fatality review board.

During the course of this study, DDS hired a nurse located in central office to work with the Ombudsmen to visit DDS clients in nursing homes and review their records. Program review 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, the committee were told that at times clients die in nursing homes and unless the nursing home notifies the department, the department remains unaware of it until the client’s case manager visits the home.

Once a DDS client enters a nursing home, the Department of Social Services, under its Medicaid program, pays for the care provided in nursing homes. Any DDS resources allocated to the individual becomes 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, he or she may have lost DDS funding and now must be placed back on the wait 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 DPH's reviews, since it should trigger follow-up by the client's case manager if gaps were identified. Therefore, 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.¹³ 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 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 of RN nursing home directors who are responsible for managing and overseeing the nursing care provided in nursing homes provides them with additional knowledge of specific techniques and interventions so that 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 record, 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

¹³ 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, intellectual disabilities, and 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 section, 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 as 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.

Continued Planning Efforts for the Aging Population

As noted in the briefing report, DDS has already engaged in a number of efforts to plan for its aging consumer base. Among these efforts are the preparation of several documents to guide the agency's vision and the implementation of many recommendations made by the DDS-initiated Focus Team on Aging. This section discusses the department's current five-year plan (2007-2012) and the need for continued planning efforts.

DDS planning documents. The primary guidance document for the department is the agency's statutorily required five-year plan. The plan is required to:

- 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.

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 and analyzing health and safety risk data to implement system improvements). However, it also includes targeted goals for certain DDS populations such as Birth-to-Three, Autism, and aging.

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."¹⁴ 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.

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

¹⁴ State of Connecticut Department of Mental Retardation, Five Year Plan (2007-2012) p.33

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. As noted in the briefing report, 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 seeking support from DDS; 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 aged 45 and older. The results are summarized below and further detail is provided in Appendix C.

Eligibility referrals. State law requires that three basic criteria be present before an individual can be determined eligible for DDS services:

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

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 IV-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 aged 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.

	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 for all ages 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 primarily due to persons mistakenly seeking services after the department changed its name.

Appendix C provides a demographic profile and basic statistics regarding the eligibility process for the 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%) are submitted by family members. Almost an equal percentage of the individuals age 45 and older resided with family members (48%) and in the community (47%) at time of referral. The majority (78%) 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 program review 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 begin to age.

However, the benefits and 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. In any case, what is known is that Connecticut, along with the nation, is aging rapidly and policy and services will have to adapt to this changing need.

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 lifestyle 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.¹⁵ 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

¹⁵ United States v. Connecticut, 931 F. Supp. 974 (D. Conn. 1986)

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.¹⁶ 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 program review 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 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.¹⁷ 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 re-iterated 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.

¹⁶ *Messier v. Southbury Training School*, 562 F. Supp. 2d 294 (D. Conn. 2008)

¹⁷ *Ricci v. Okin*, 499 F. Supp. 2d 89 (D. Mass. 2007)

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 dollars 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, the Massachusetts issue of institutional care has advocates on both sides. The coalition of families claims 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 elderly parents and staff 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.

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 or long-term capital expenditures would force the state to continue to place clients there. These arguments are similar to the comments heard by the program review 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 program review 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 ongoing property maintenance for limited use. The program review 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 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.

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 Section V.

Cost of Client Care and Planning

During the course of this study, the committee met with community provider associations and advocacy groups who contend that care in the community is provided at a much lower cost than in institutional settings (i.e., ICFs/MR).¹⁸ 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. During these difficult economic times, when funding is limited or being reduced, it is important to examine resources to see if they can be rebalanced so that more clients can receive services.

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

¹⁸ 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.

and private providers. The report shall be presented to the legislative committees of cognizance by February 1, 2010.

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 08 budget gap. The data presented in this section 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, costs are reimbursed through the traditional Medicaid program and are 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 office's calculations are based on DDS data.

Several other factors also should be considered when comparing costs of cares 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 section 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

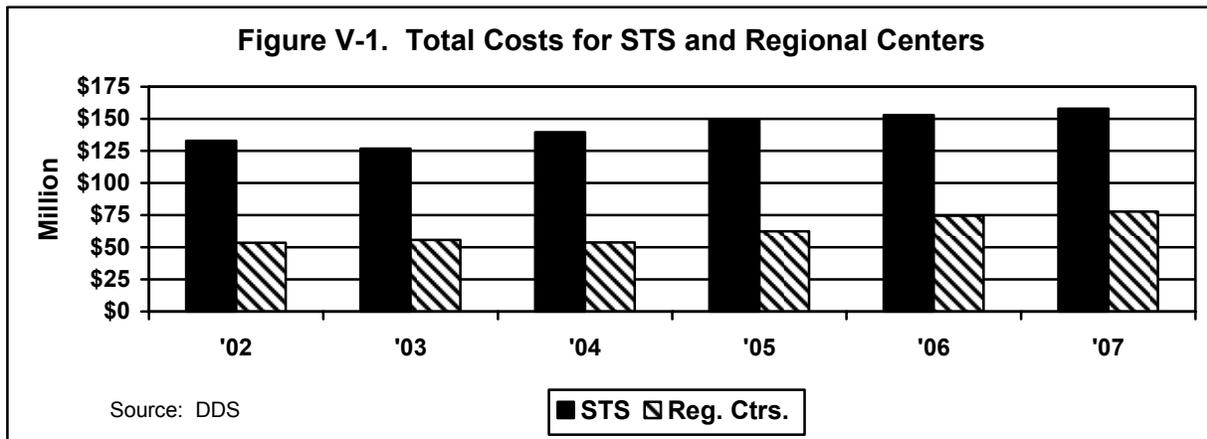
State "inpatient" costs that are used to calculate the per capita, per diem cost of STS and the regional centers are quite comprehensive. They include all direct costs of providing services (employee salaries, fringe benefits, and other direct expenditures for the facilities, such as food, maintenance, and care of residents), operating expenses, and state wide 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, and public CLAs and 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 comptrollers 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 V -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 V-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.

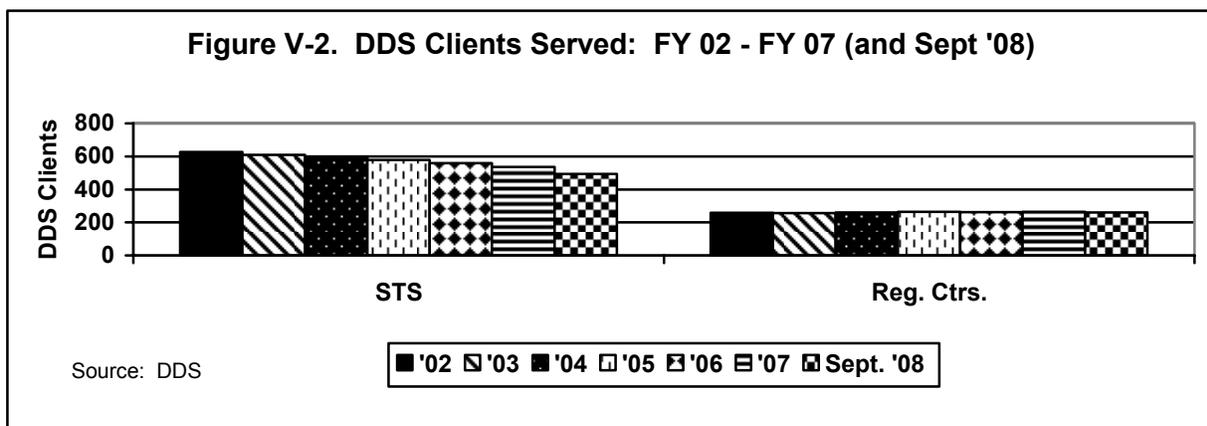
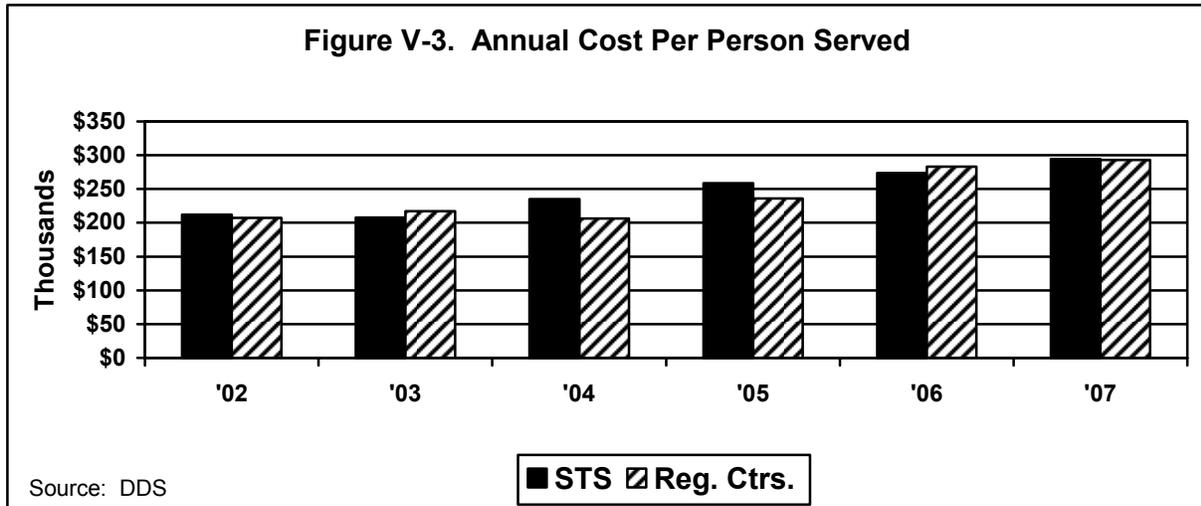
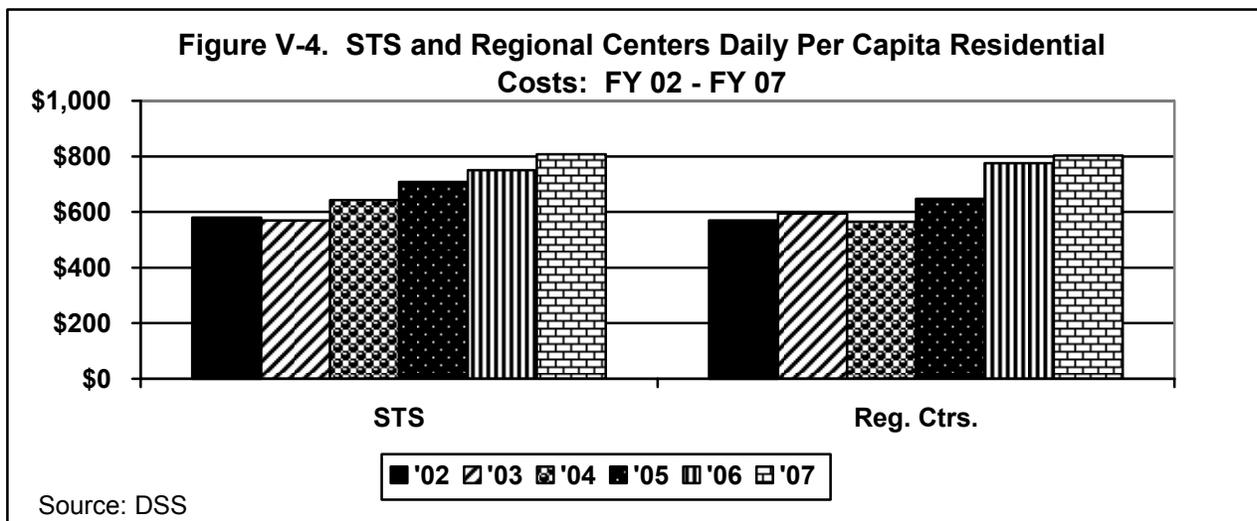


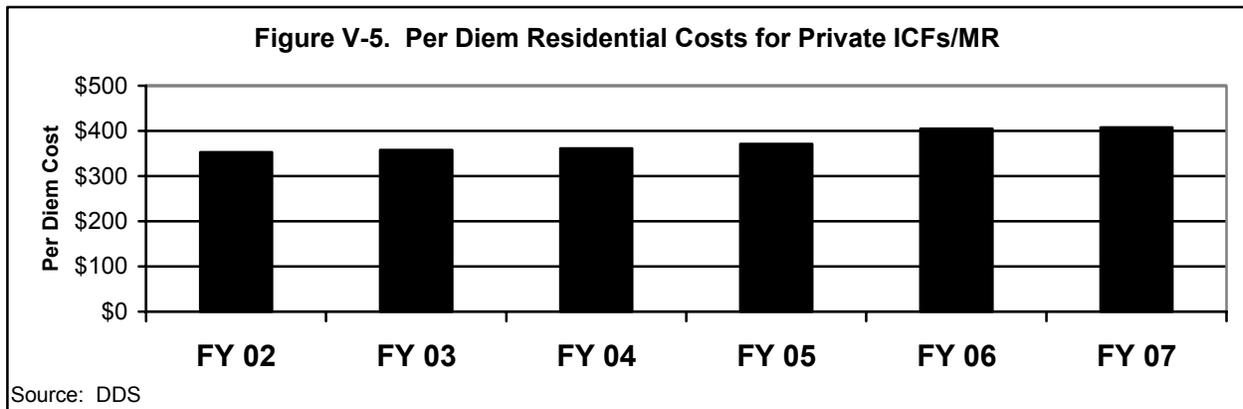
Figure V-3 presents the annual residential cost per person served for FY 02 to FY 07. Annual per person costs at STS have grown steadily from year-to-year, increasing 39 percent over the six years examined. The Regional Centers experienced a decline in annual cost per person served between FY 03 and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

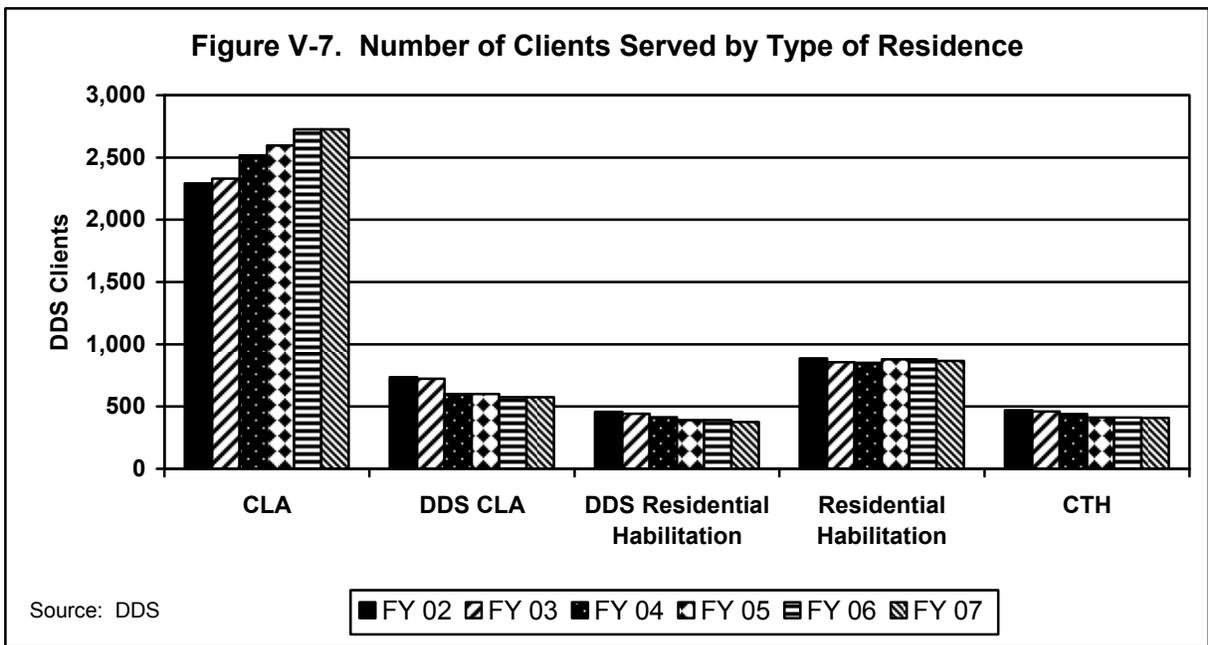
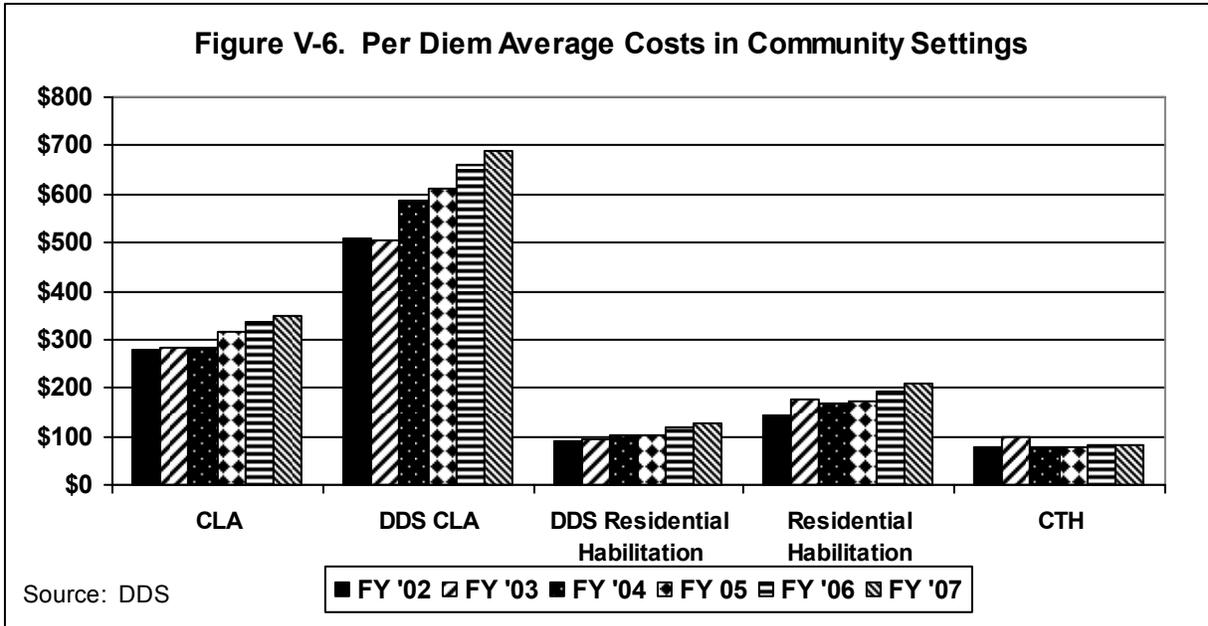


Costs of Community Care

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 prepaid by DDS includes the room and board costs paid for by the Department of Social Services.

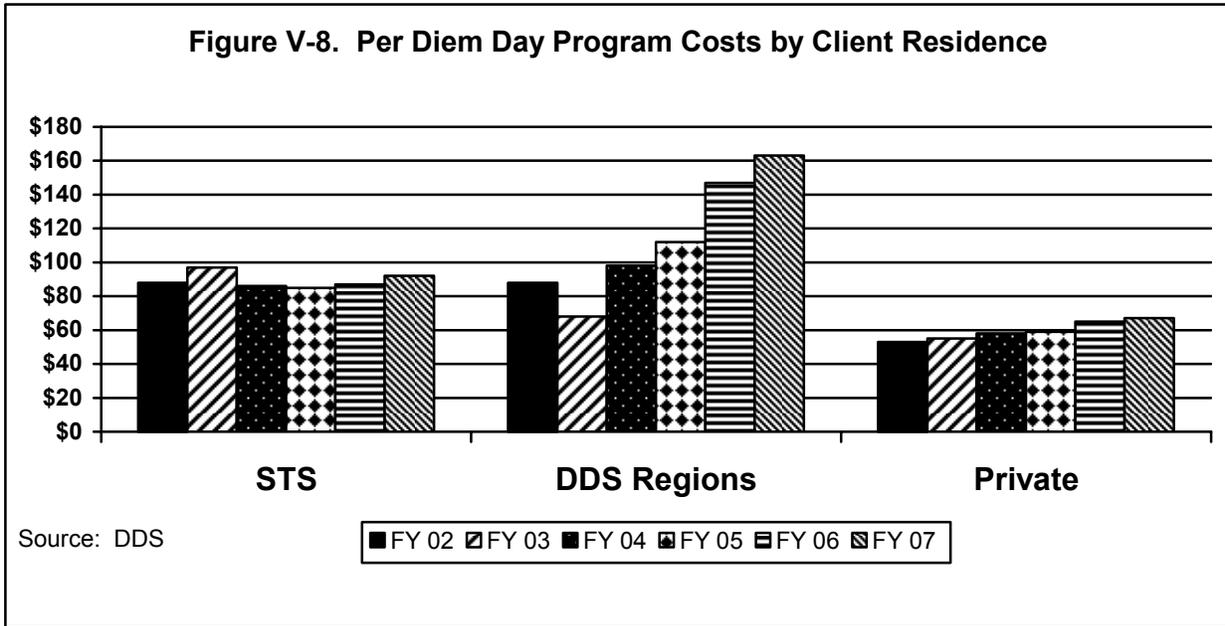
Figure V-6 compares per capital, per diem costs by type of community setting and Figure V-7 shows the number of clients living in each setting. The cost of publicly operated group homes is the highest – more than two times the cost provided in CLAs operated by private providers. Reasons for this include higher wages and fringe benefits are paid to employees of public CLAs, and these homes may serve more challenging clients, which would require higher staff ratios. Costs for residential habilitation are for support services provided to clients.¹⁹ As shown in the figure, 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.

¹⁹ 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 V-8 shows the per capita, per diem day program costs. Regional centers served 310 clients in FY 07 and had 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 which 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 Section III, 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 Lists

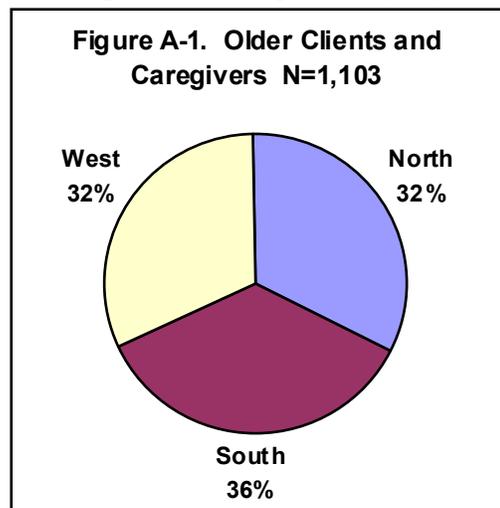
Program review staff obtained a database from DDS containing information related to active DDS clients on the wait or planning lists and meets the definition of the study's target population – DDS clients who are age 45 or older or have a caregiver who is age 65 or older. The data presented below are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

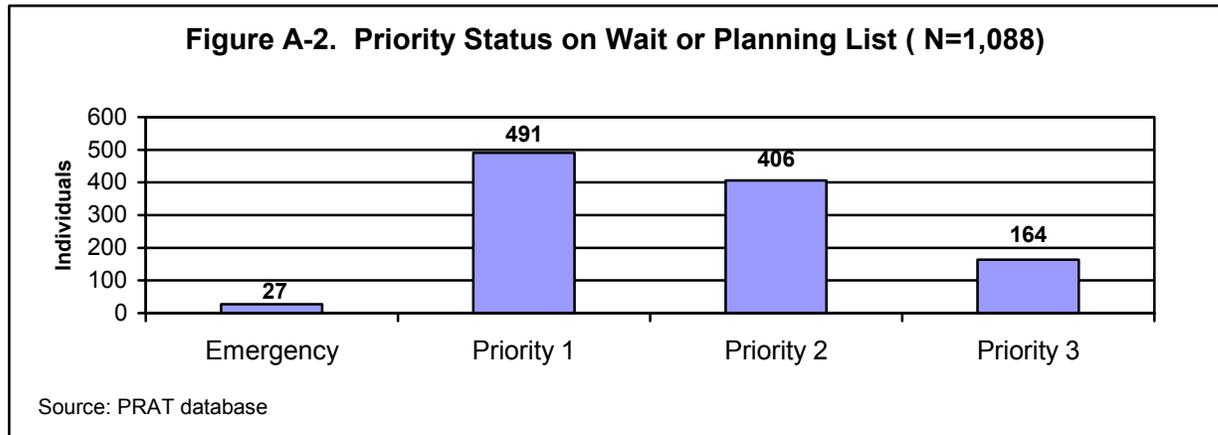
As described in the briefing, DDS-funded residential services and supports are provided in a variety of settings including in a family home, a community training home, or a client's own apartment or condo. The state receives 50 percent federal reimbursement under the HCBS Medicaid waivers for residential 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 except case management (604) and many were underserved (234). The remaining individuals needed additional funding, particularly to move from 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 most clients on the wait and planning lists, although there was not a large variation in the number of clients among the three regions.



A priority status (see p.7 of report) was indicated for 1,088 clients (Figure A-2). The largest numbers of clients have been identified as Priority 1 (45%). Although there were 68 cases that were considered an Emergency in October 2008, only 27 of those involved a client age 45 or older or a caregiver over the age of 65 years. Of the 27 cases, 16 involved a client aged 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 are classified as an Emergency and 491 individuals categorized as a Priority 1. Table A-1 lists where clients are living while they wait 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).

<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

Program review committee staff 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 Home	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 are on the wait or planning list and are 45 years old or older, and/or have a caregiver 65 years old and older. The data show:

- distribution is even across three regions;
- 83 percent of the families are not receiving any residential services or supports beyond case management, while others are receiving a small state grant or are considered to be underserved;
- Mothers and fathers are 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 do not have a caregiver listed in the database.

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

- the caregivers range from 80 to 96 years old, with an average age of 84;
- the client ages range from 11 to 82 years old, with an average age of 48 years old;
- the South region has the most caregivers age 80 or older (61 caregivers), compared to 40 caregivers in the West region;
- a caregiver is identified for all 149 clients, with mothers or fathers providing care in 89 percent of the cases;

- 115 clients living with caregivers age 80 or older are not receiving any services beyond case management; 15 are underserved; 14 are receiving EFS funding but are requesting more; four receive residential services and supports but want to move; and one is 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) are 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 a 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.

Table B-1. DDS Programmatic Administrative Reviews (2008).			
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 aged 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 increased in-home staff support. In two cases, the individuals were 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. DDS Eligibility Referrals of Persons Age 45 and Older

Table C-1 provides a demographic profile 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 aged 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.

Table C-1. Demographic Profile of Eligibility Referrals for Persons Age 45 and Older (2006-2008).					
		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%) followed by social workers/community providers (22%), non-family conservators/guardians (6%), nursing homes (3%), and other advocates or friends (3%) as well as the individual themselves (3%).
- Almost an equal percentage of the individuals age 45 and older resided with family members (48%) and in the community (47%) at time of referral. The remaining individuals resided with a non-family conservator/guardian (2%) or in a long term care facility (3%).
- 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%), residential placement (10%), in-home family supports (7%), vocational services (6%), day program (3%), and recreational services (3%).

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. As of November 2008, two appeals for individuals age 45 and older are pending. In eight of the 20 cases (40%), 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 C-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					