



# University of Connecticut Health Center

June 2007

## Connecticut Long-Term Care Needs Assessment

### Part II: Rebalancing Long- Term Care Systems in Connecticut

and

### Recommendations

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## **Acknowledgments**

We gratefully acknowledge the assistance and support of the Connecticut Commission on Aging, Long-Term Care Planning Committee, and Long-Term Care Advisory Council. We also would like to acknowledge the valuable assistance of numerous people from Connecticut state agencies, providers and advocacy groups who provided information and guidance in the preparation of this report. Particular thanks go to David Guttchen and Barbara Parks Wolf from the Office of Policy and Management, and Julia Evans Starr and William Eddy from the Connecticut Commission on Aging.

This project was funded by the Connecticut General Assembly (Section 38 of Public Act 06-188: An Act Concerning Social Services and Public Health Budget Implementation Provisions).

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## Preface

This case study, “**Rebalancing Long-Term Care Systems in Connecticut**,” (the “Rebalancing Report”) is one of the reports comprising the Connecticut Long-Term Care Needs Assessment (the “Needs Assessment”). The Needs Assessment was commissioned and funded by the Connecticut General Assembly in Section 38 of Public Act 06-188 in consultation with the Connecticut Commission on Aging, the Long-Term Care Advisory Council and Long-Term Care Planning Committee. Two additional reports are being released simultaneously with the Rebalancing Report. First, there is a report on the results from an extensive survey of Connecticut citizens and long-term care providers called Connecticut Long-Term Care Needs Assessment Part I: Survey Results (the “Survey Results”). This Rebalancing Report presents recommendations from both the Survey Results and Rebalancing Report. Second, there is also a free-standing Executive Summary presenting the highlights of both pieces of inter-related work. A related report on the Connecticut Long-Term Care Ombudsman Program, funded by that office, will be released during the summer of 2007. There will also be in-depth follow-up reports on major topics from the Needs Assessment released during the remainder of 2007.

For this Connecticut rebalancing case study, the research team decided to build on the template used for comprehensive baseline case studies in an 8-state project funded by the Centers for Medicare and Medicaid Services (CMS), called “**Research on Program Management Techniques Taken by States to Rebalance Their Long-Term Care System**” (Centers for Medicare and Medicaid Services, 2004b). As a result of a 2003 Congressional mandate for a study in up to 8 states to explore the various management techniques and programmatic features that states have put in place to rebalance their Medicaid long-term care (LTC) systems and their investments in support services towards community care, CMS contracted in the Fall of 2004 with University of Minnesota to conduct a series of qualitative and quantitative studies.

The states of Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington are participating in this 4-year rebalancing study. These particular states were chosen in order to obtain samples of varying progress in the rebalancing process, as well as varied long-term care policies, service delivery models, management approaches, diversity of Medicaid populations, urban and rural populations, and geographic and ethnic diversity. For the study, CMS defined rebalancing as reaching “a more equitable balance between the proportion of total Medicaid support expenditures used for institutional services (i.e., Nursing Facilities [NF] and Intermediate Care Facilities for the Mentally Retarded [ICF/MRs]) and those used for community-based supports under its State Plan and waiver options.” CMS further clarified that a balanced LTC system “offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options.”

Connecticut similarly is interested in shifting its LTC utilization and expenditures towards community care and developing techniques that facilitate managing a system that is largely oriented away from institutions while assuring quality in all components of the system. By opting to use the organization employed in the baseline case studies, comparisons can readily be made between Connecticut and 8 other states. While these 8 states may not all be among those Connecticut would have chosen as the most comparable, the comparisons are nonetheless valuable.

This report is organized into five major sections:

- Section I. The Context for Rebalancing in Connecticut presents background in areas such as demography and economics, history of LTC in the state, LTC programs, the

organization for service delivery at state and local levels for each target population, and the political and advocacy environment;

- Section II. A System Assessment briefly and critically examines dimensions that have been thought important in a rebalanced system, including access to services, array of services, consumer-direction, quality monitoring, information systems, state efforts to downsize the nursing-home sector and reduce incentives for its use, and links between LTC, on the one hand, and housing, mental health services, and acute care;
- Section III. Featured Management Approaches highlights some strategies employed in Connecticut that were deemed helpful in facilitating rebalancing;
- Section IV. Connecticut in a National Context presents quantitative and qualitative comparisons between Connecticut and the 8 states in the CMS-Minnesota Rebalancing Research; and
- Section V. The report ends with conclusions and recommendations from both the Survey Results and the Rebalancing Report.

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## I. Context for Rebalancing in Connecticut

### A. Demographics and economics<sup>1</sup>

Connecticut is a New England state with a population in 2005 of 3.5 million. Over the next 20 years, the total population is projected to grow by over 187,800 people, an increase of 5 percent. Although this increase in population is modest, there are two countervailing trends at work. According to U.S. Census Bureau projections, between 2005 and 2025, the number of children, youth and adults between the ages of 5 and 64 will actually decrease by more than 71,000 people, or close to three percent. In contrast, the number of individuals age 65 and over will increase by 243,880 people, or 51 percent, due to the aging of the Baby Boom generation (Table 1). In all age groups, Connecticut's population is projected to grow more slowly than the national average.

Table 1. Connecticut Population Projections: 2005 – 2025

Age group	2005	2010	2015	2020	2025	Pop. growth 2005-2025	Percent change Connecticut: 2005 - 2025	Percent change U.S. 2005-2025
<b>0 to 4</b>	215,290	217,712	228,547	234,055	230,618	15,328	7%	15%
<b>5 to 20</b>	755,632	739,879	712,195	707,438	716,787	-38,845	-5%	11%
<b>21 to 64</b>	2,052,820	2,104,278	2,117,589	2,091,616	2,020,285	-32,535	-2%	10%
<b>65+</b>	479,443	515,621	577,083	642,541	723,326	243,883	51%	73%
<b>Total</b>	3,503,185	3,577,490	3,635,414	3,675,650	3,691,016	187,831	5%	18%

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

The most significant growth in the proportion of seniors in the population is not expected until after 2011, the year the oldest of the Baby Boom generation (those born between 1946 and 1964) turns 65.

In 2005, the U.S. Census estimated that there were approximately 402,400 individuals age five and over in Connecticut with one or more disabilities (excluding individuals living in institutions). Connecticut's overall rate of people with disabilities is 12.7 percent, lower than the national average of 14.9 percent. In fact, Connecticut had one of the lowest rates of disability in the nation, ranking 41<sup>st</sup> (6.1%) among persons 5 to 20 years old, 48<sup>th</sup> (10.1%) among persons 21 to 64 years old, and last (35.1%) among persons 65 and over. Although the largest proportion of the Connecticut population with a disability is found among those age 65 and over, half the total number of persons with disabilities are younger adults between the ages of 21 and 64.

Between 2005 and 2025, the number of non-institutionalized persons with a disability is expected to grow by 25 percent, or approximately 99,000 people, to an estimated 501,400.<sup>2</sup>

<sup>1</sup> Data in this section taken in part from the Connecticut Long-Term Care Plan, January 2007.

<sup>2</sup> These projections are based on the 2025 Census disability data applied to U.S. Census Bureau Population Projections for 2005 through 2025. The Census does not tabulate disability status for people under age five or individuals in institutions. Disability projections assume a constant rate of non-institutionalized persons with disability over time. It should be noted that with this constant rate the

However, when broken down by age, two dramatically different trends appear that parallel the general population trends. The number of individuals with disabilities age 5 to 64 will increase by only 514 over 20 years, less than a one percent increase. In contrast, the population with disabilities age 65 and over is expected to increase by 98,500 or 63 percent (Table 2).

By some measures, Connecticut’s population as a whole is well-off financially. It is one of the wealthiest states in the U.S., with a 2005 median household income of \$60,941. It ranks 3<sup>rd</sup> in the nation, and compares to the U.S. median household income of \$46,242. The percent of people living below poverty level ranked 49<sup>th</sup> at 8.3 percent, considerably less than the national average of 13.3 percent. The wealth is unevenly distributed, however, with concentrations of poverty in many of the major cities such as Hartford (32%), New Haven (27.2%), Waterbury (18%) and Bridgeport (17.9%).<sup>3</sup>

Table 2. Projection of Non-Institutionalized Persons with Disabilities in Connecticut by Age: 2005 – 2025

	2005	2025	2005 / 2025 increase	Percent increase
<b>5 to 20</b>	44,499	43,767	-732	-2%
<b>21 to 64</b>	202,563	203,809	1,246	1%
<b>65+</b>	155,307	253,825	98,518	63%
<b>Total</b>	<b>402,369</b>	<b>501,401</b>	<b>99,032</b>	<b>25%</b>

Source: Connecticut Office of Policy and Management based on U.S. Census Bureau, Population Division, Interim State Population Projections, 2005 and U.S. Census Bureau, American Community Survey, disability.

Approximately 11 percent of the population in 2006 were receiving Medicaid services or acute-care services, (8.7% in the State Child Health Insurance Program, 1.9% in the Aged, Blind and Disabled program, and 0.6% in nursing home care.)

## B. Geography

Connecticut occupies about 5000 square miles, with a population density of over 700 persons per square mile, far higher than the national average of about 80 persons per square mile.<sup>4</sup> There are eight counties and 169 towns, with a strong tradition of local government and community involvement. There is no government structure at the county level. Three-quarters of the population is concentrated in the central (Hartford County), south central (New Haven County), and southwestern (Fairfield County) portions of the state, with less populous eastern and northwestern regions. Only five cities (Bridgeport, New Haven, Hartford, Stamford and

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number of institutionalized persons would have to grow at the same rate as those non-institutionalized, which is contrary to the goal of the state’s Long-Term Care Plan.

<sup>3</sup> Statistics in this paragraph are based on the U.S. Census Bureau, American Community Survey 2005, and exclude individuals living in institutions.

<sup>4</sup> Geographical information available on the State of Connecticut website, [www.ct.gov](http://www.ct.gov), based on 2000 U.S. Official Census figures.



Waterbury) have a population over 100,000, and 120 towns have a population of less than 20,000.

For illustrative purposes, Table 3 contains comparable data for eight selected states that have recently undergone similar in-depth assessments of their rebalancing efforts. As the table demonstrates, Connecticut has the advantage of a compact geographic area with enough of a population base and per capita income to sustain its programs. It also has a relatively low proportion of the population with a disability (ranking 44<sup>th</sup> on this parameter) but a higher percentage of the population over 65 than many states.

Table 3. Connecticut Comparisons on Relevant Variables to 8 States

State	Size in square miles <sup>5</sup> (US rank)	Population 2005 <sup>6</sup> (US rank)	income 1999 <sup>7</sup>	Percent elderly in population 2005 <sup>8</sup> (US rank)	Percent age 5+ disabled in population 2005 <sup>8</sup> (US rank)
CT	5,543 (48) Small <sup>9</sup>	3,500,701 (29) Medium	\$28,766 (1) High	13.0% (12) High	12.7% (44) Low
AR	53,179 (29) Medium	2,779,154 (32) Medium	\$16,904 (49) Low	13.5% (10) High	21.2% (2) High
FL	65,755 (22) Medium	17,789,864 (4) Large	\$21,557 (19) Medium	16.6% (1) High	15.8% (20) Medium
MN	86,939 (12) Large	5,132,799 (21) Medium	\$23,198 (11) High	11.6% (38) Low	12.2% (48) Low
NM	121,589 (5) Large	1,928,384 (36) Small	\$17,261 (46) Low	12.1% (30) Medium	17.0% (12) High
PA	46,055 (33) Medium	12,429,616 (6) Large	\$20,880 (25) Medium	14.6% (3) High	15.9% (19) Medium
TX	268,581 (2) Large	22,859,968 (2) Large	\$19,617 (33) Medium	9.6% (48) Low	15.8% (20) Medium
VT	9,614 (45) Small	623,050 (49) Small	\$20,625 (26) Medium	12.8% (17) High	16.0% (17) High
WA	71,300 (18) Medium	6,287,759 (14) Large	\$22,973 (13) High	11.1% (45) Low	15.6% (22) Medium
US	3,794,083	296,410,404	\$21,587	12.1%	19.4%

### C. Rebalancing status in brief

Long-term care demand factors in Connecticut overall are somewhat lower than most other states, while its financial resources are greater. It is a wealthy, geographically compact state whose older population is growing more slowly than the nation as a whole, and whose population of people with disabilities is below the national average.

<sup>5</sup> U.S. Census Bureau (2005) Density Using Land Area for States, Counties, Metropolitan Areas, and Places: 2000 At: <http://www.census.gov/population/www/censusdata/density.html> (last updated August 15, 2006).

<sup>6</sup> U.S. Census Bureau Population Division (2005) Table 1: Annual Population Estimates: 2005. At: <http://www.census.gov/popest/states/NST-ann-est.html> (last updated December 21, 2005).

<sup>7</sup> U.S. Census Bureau (2005a) State and Local Government Finances: 1999. At: <http://www.census.gov/govs/www/estimate.html> (last updated May 31, 2006).

<sup>8</sup> U.S. Census Bureau American Community Survey (2005). Fact Sheets. At: [http://factfinder.census.gov/home/saff/main.html?\\_lang=en](http://factfinder.census.gov/home/saff/main.html?_lang=en).

<sup>9</sup> The ratings of high, medium, and low are simply based on whether the state falls, respectively, in the top, middle, or bottom third of all states on the parameter in question.

While Connecticut has made some progress in rebalancing, it remains average among the states for rebalancing expenditures. In a FY 2005 ranking of the states by percent of total Medicaid long-term care expenditures spent on community-based services, Connecticut ranked 26<sup>th</sup> at 37 percent, very close to the U.S. average (Burwell, Sredl, & Eiken, 2006). Top-ranked Oregon spent 70 percent of its Medicaid long-term care dollars on community-based services, while CMS comparison states Vermont, Minnesota and Washington ranked 4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup>, respectively, at between 60 and 57 percent. Nevertheless, Connecticut is an expensive state for long-term care, spending more per capita than most states in many areas. For example, in 2005 Connecticut ranked high in per capita expenditures in the following areas:

- 4<sup>th</sup> in nursing home expenditures
- 9<sup>th</sup> in ICF/MR expenditures
- 9<sup>th</sup> in home and community-based waiver services
- 3<sup>rd</sup> in home health care expenditures (although not all home health expenses are for long-term care)
- 2<sup>nd</sup> in total long-term care expenditures

(Burwell, Sredl & Eiken, 2006). Details of Connecticut's long-term care expenditures follow at the end of this section.

While Connecticut is clearly moving in the right direction in its rebalancing efforts, many other states are moving faster.

#### **D. Political climate**

Long-term care planning efforts in Connecticut have evolved within a political landscape that has reflected ongoing changes in leadership, varying budget circumstances and diverse policy priorities. Currently, there is a Republican governor, while Democrats enjoy veto-proof majorities in both houses of the state's General Assembly. There have been expressions of interest in using the state's nearly \$1 billion budget surplus to increase funding for a variety of social programs, including long-term care. The state climate contrasts somewhat with that at the federal level, where the prospects for increased funding for long-term care initiatives are less likely.

During its 2007 legislative session, the General Assembly continued to explore ways to help older adults and younger people with disabilities remain living independently in the community, and to improve the quality of care provided in institutional settings. However, little substantial progress toward rebalancing was made during the regular session. Bills that died in committee would have expanded the Connecticut Home Care Program for Elders (CHCPE), created a pilot for adults age 18-64 based on the CHCPE model, and increased funding for the assisted living pilot program. The Democratic-controlled General Assembly did override a gubernatorial veto of a bill that will require legislative approval of Department of Social Services applications seeking federal Medicaid waivers. It is likely that some rebalancing proposals may again be raised during the 2007 Special Session.

Many of the state's long-term care efforts have been bipartisan efforts, however, and many, such as state funding for assisted living pilots and liberalization of the Connecticut Home Care Program for Elders (both discussed in more depth below) were proposed by the previous Republican governor through the State Office of Policy and Management.

Further bifurcation of services to older adults and people with disabilities has been the theme in two recent legislative initiatives, both of which go against the national trend to consolidate long-term care services in an umbrella agency. A 2005 law requires the re-establishment of a Department on Aging and the transfer of the functions, powers, duties, and personnel of the Department of Social Services Division of Aging Services to the new department. This Department on Aging initiative has engendered controversy and uncertainty among various constituencies across the state. There has been a proposal to postpone the effective date for the new department until July of 2008. A 2007 legislative proposal would have created an independent Board of Education and Services for Citizens with Autism Spectrum Disorders. While that proposal had not passed by the close of the 2007 regular session, the creation of such a separate agency would also go against the national trend of serving people with mental retardation and other developmental disabilities in the same agency. The proposal was supported by an advertising campaign from the Connecticut State Employees Association/Service Employees International Union Local 2001.

In a bipartisan demonstration of support during the 2006 legislative session, Connecticut lawmakers, in consultation with the Connecticut Commission on Aging, the Long-Term Care Advisory Council and Long-Term Care Planning Committee, authorized and funded the state's first comprehensive long-term care needs assessment in more than 20 years. This report is one result of that effort.

The primary goals of the needs assessment are to:

- Document the public and private inventory of long-term care services and supports currently being provided in Connecticut.
- Assess which segments of the population are receiving services.
- Project the number of persons who will require long-term care services over the next 30 years.
- Document the needs, desires and expectations of Connecticut's residents as they anticipate their need for long-term care services in the future for their families and themselves.
- Make recommendations on qualitative and quantitative changes that should be made to existing programs or service delivery systems, including recommendations on new programs or service delivery systems to better serve persons with long-term care needs.

In conjunction with the state's 2007 Long-Term Care Plan, study findings will help to develop the state's long-term care policy over the coming years.

## **E. Vision and values for long-term care in Connecticut <sup>10</sup>**

In 2005, Connecticut Public Act 05-14 codified into law a broad philosophical statement to guide future policy and budget decisions regarding long-term care. As a result of this legislation, the policy and planning work done through the Long-Term Care Planning Committee is required to "provide that individuals with long-term care needs have the option to choose and receive long-term care and support in the least restrictive, appropriate setting." This statement serves as a guideline to measure progress, and positions Connecticut to make the necessary changes to the laws and regulations that govern the state's long-term care system to make real choices for consumers a reality.

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<sup>10</sup> Discussion taken in part from Connecticut Long-Term Care Plan, January 2007.

In addition, the 2007 Connecticut Long-Term Care Plan summarizes the vision, mission, and principles governing the long-term care system developed by the Long-Term Care Planning Committee.

***Vision***

To assure Connecticut residents access to a full range of high-quality long-term care options that maximize autonomy, choice and dignity.

***Mission***

To develop a comprehensive system of community-based and institutional long-term care options which promotes access to affordable, high-quality, cost-effective services, and other supports, delivered in the most integrated, life-enhancing setting. The components of the long-term care system must be effectively communicated to all those potentially impacted by the need for long-term care.

***Principles governing the long-term care system:***

The system must:

1. Provide access to all necessary supports and services, including a comprehensive range of medical, social, assistive, health promotion, diagnostic, early intervention and other services.
2. Deliver services in a culturally competent manner to meet the needs of a diverse population.
3. Assure that people have control and choice with respect to their own lives.
4. Be adequately financed and structured to assure that decision-making and service delivery are based on the needs of the individuals and families served and on the needs of employees who provide care and services. It must assure that profits are not made at the expense of delivering necessary care, that informal caregivers receive the support that they need, and that there are a sufficient number of formal caregivers available to provide the necessary care.
5. Assure that consumers have meaningful rights and protections, including access to a strong enforcement authority and the ability to appeal denials and reductions of services and transfers from one service setting to another.
6. Include an information component to educate individuals about available services and financing options.
7. Have an adequate and coordinated regulatory structure to assure that services are provided in a quality and safe manner taking into account the consumer as well as the state perspective of quality and safety. This should maintain a reasonable balance between individual choice and individual acceptance of risk.
8. Include a simplified eligibility process.
9. Provide equal access to home and community-based care and institutional care.
10. Include a care management component that, while stressing individual autonomy and self-direction, provides comprehensive assessment, care plan development, coordination and monitoring services to assist individuals and families in providing and securing their necessary care.
11. Have mechanisms for integration with related services and systems including acute medical care, housing and transportation services.
12. Include a prevention component to educate individuals regarding actions that can be taken to reduce the chances of needing long-term care.
13. Have a strong independent advocacy component for those in need.
14. Include meaningful consumer input at all levels of system planning and implementation.

## F. State and local organizations for long-term care

Connecticut has a fractured governance structure for providing administrative and programmatic support to older adults and persons with disabilities. A number of different state departments and agencies are responsible for services and funding for different populations and programs. There are four major agencies responsible for various aspects of long-term care in Connecticut: the Departments of Social Services, Mental Retardation (including the Ombudsman programs associated with those two agencies), Mental Health and Addiction Services, and Public Health. There are many more that play lesser but still significant roles. This organizational complexity poses significant challenges for both consumers and providers of long-term care services. Further uncertainty has been created by a legislative mandate to create a new Department on Aging. The following section of this report describes the major state agencies and their role in the long-term care system, as well as the proposal for a new Department on Aging.<sup>11</sup>

- **Department of Social Services (DSS):** DSS is itself an umbrella agency that provides a broad range of services to older adults and people with disabilities, families and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance, and independent living. The DSS mission statement declares that it provides services to “promote and support the choice to live with dignity in one’s own home and community.” The agency oversees more than 90 programs and is the hub of the majority of long-term care services and supports in Connecticut. By statute, it is the state agency responsible for administering a number of major programs pursuant to federal legislation, including the Social Security Act (which includes Medicaid), and the Older Americans Act. Its Aging Services Division is the state’s identified State Unit on Aging (SUA). Among the SUA’s primary responsibilities is the administration of the Area Agencies on Aging (AAAs) in their regional use of Older Americans Act funds, including funding for social services, elderly nutrition, health promotion and support of family caregivers. Additionally, the SUA oversees the AAAs in regional administration of the CHOICES<sup>12</sup> program, and administers state-funded initiatives including the Statewide Respite Program, Home Share Match Program, and various small volunteer programs such as the Retired & Senior Volunteer Program (RSVP) and Breakthrough to the Aging. Several other programs that serve older adults and persons with disabilities are found in various divisions within DSS, including but not limited to: the Connecticut Home Care Program for Elders (CHCPE), a portion of which is state-funded, Personal Care Assistance (PCA) Waiver Program, the Acquired Brain Injury (ABI) Waiver Program, the Katie Beckett Model Waiver Program, the Department of Mental Retardation Home and Community-based Waiver Program, the Connecticut AIDS Drug Assistance Program, Protective Services for the Elderly, and the Connecticut Pharmaceutical Assistance Contract to the Elderly (ConnPACE). DSS also has administrative oversight responsibility for the independent Long-term Care Ombudsman Program, described more fully below.

DSS administers most of its programs through regional offices located throughout the state. Within the department, the Bureau of Rehabilitation Services (BRS) provides vocational rehabilitation services for eligible individuals with physical and mental disabilities at 23 offices across Connecticut. For the other programs, services are available through 11 offices located in three regions, with central office support located

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<sup>11</sup> Discussion based in part on Connecticut Long-Term Care Plan, January 2007.

<sup>12</sup> Connecticut program for Health insurance assistance, Outreach, Information and referral, Counseling, and Eligibility Screening.

in Hartford. In addition, many services funded by the agency are available through community-based agencies.

- **Department of Mental Retardation (DMR):** DMR provides, either directly or through contracts with private community agencies, case management, residential habilitation, individualized supports, campus settings, day habilitation, prevocational services, supported employment, respite care, family support and Birth to Three services to more than 16,000 persons with mental retardation and their families. Its stated mission is to join with others to create the conditions under which all people with mental retardation experience: presence and participation in Connecticut town life, opportunities to develop and exercise competence, opportunities to make choices in the pursuit of a personal future, good relationships with family members and friends, respect and dignity. As of June 2005, 62 percent of those receiving services from DMR were served in their own homes, 5.6 percent lived in campus settings, 24 percent lived in public or private community living arrangements, three percent lived in community training homes, and 2.8 percent were in skilled nursing facilities. DMR is organized into three geographic regions and administered out of a central office located in Hartford.

Unlike all but one other state, Connecticut's DMR serves only people with a mental retardation diagnosis. People with other developmental disabilities are served primarily through other state agencies, when eligible. Generally, DMR serves people with autism spectrum disorders (ASD) only if they have a co-occurring diagnosis of mental retardation. DMR also houses a small pilot program created by the state General Assembly for up to 50 adults who have ASD, who do not have a diagnosis of mental retardation, and are not receiving services from DMR.

There was a proposal during the 2007 legislative session that would create a new Board of Education and Services for Citizens with Autism Spectrum Disorders to address the lack of services for people with ASD. It would be an independent board residing for administrative purposes only within DMR. The bill received widespread support but did not pass by the time the regular session adjourned. Its future is uncertain.

Legislation passed in 2007 will change the name of the DMR to the Department of Developmental Services, effective October 2007.

- **Ombudsman Programs:** The Long-Term Care Ombudsman Program (LTCOP), an independent office under the umbrella of the DSS, provides complaint investigation, educational, and advocacy services to residents of nursing facilities, residential care homes and assisted living facilities. The mission of the Connecticut LTCOP is to protect the health, safety, and rights of long-term care consumers by supporting clients' rights to self-determination. This is accomplished by providing prompt and timely investigation of complaints, supporting resident and family councils in long-term care facilities, disseminating pertinent information and resources regarding options for long-term care, and representing resident interests in shaping legislative agendas.<sup>13</sup>

The 2007 state Long-Term Care Plan recommends that the Long-Term Care Ombudsman's jurisdiction be expanded to include other long-term care settings and include consumer education about the availability of these services.

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<sup>13</sup> From the Connecticut Long-Term Care Ombudsman website at [www.ltcop.state.ct.us](http://www.ltcop.state.ct.us).

In addition, the Independent Office of the Ombudsperson for Mental Retardation, created in 2001, works on behalf of consumers and their families. The office addresses complaints or problems regarding access to services or equity in treatment. The results and nature of complaints and concerns are communicated to the DMR commissioner, the General Assembly, and the Council on Mental Retardation.<sup>14</sup>

- **Department of Mental Health and Addiction Services (DMHAS):** DMHAS has 15 Local Mental Health Authorities that provide a vast array of comprehensive, recovery-oriented services in the areas of mental health treatment and substance abuse prevention and treatment throughout Connecticut. While the Department's prevention services serve all Connecticut citizens, its mandate is to serve adults (over 18 years of age) with psychiatric or substance use disorders, or both, who lack the financial means to obtain such services on their own. DMHAS operates five inpatient hospitals and facilities for persons with severe addiction and/or psychiatric problems. In SFY 2005, DMHAS served 45,480 persons with mental illness in the community and 2,112 persons with mental illness in inpatient facilities.

DMHAS also provides collaborative programs for individuals with special needs, such as persons with HIV/AIDS infection, people in the criminal justice system, those with problem gambling disorders, substance abusing pregnant women, persons with traumatic brain injury or hearing impairment, those with co-occurring substance abuse and mental illness, and special populations transitioning out of the Department of Children and Families.

- **The Department of Public Health (DPH):** The mission of DPH is to protect and improve the health and safety of the people of Connecticut. DPH is the state's leader in public health policy and advocacy. The Department is a partner to local health departments for which it provides advocacy, training and certification, technical assistance, consultation, and specialty services such as risk assessment that are not available on the local level. Additionally, DPH establishes health priorities and evaluates the effectiveness of health initiatives. The agency also has regulatory functions which focus on the quality of services provided by licensed professionals, health care institutions such as nursing homes, residential care homes and ICF/MRs, laboratories, ambulances, and environmental health entities. Regulation of ICF/MRs is shared by DMR, which does licensing, and DPH, which regulates health and safety. Resources are also dedicated to epidemiology, vital statistics, health education, and surveillance.
- **Proposal for New Department on Aging:** PA 05-280 requires the re-establishment of a Department on Aging and the transfer of the functions, powers, duties, and personnel of the DSS Division of Aging Services to the new department. That law also created a task force to study the department's re-establishment. In 2006, the General Assembly adopted the task force's recommendations to postpone the new department's start date from January 1, 2007 to July 1, 2007 and to analyze the service needs of Connecticut's older adults by conducting a long-term care needs assessment. There has been a proposal to further postpone the effective date to July 2008.

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<sup>14</sup> From the Mission Statement of the Independent Office of the Ombudsperson for Mental Retardation.



Other agencies that play roles with respect to long-term care include:

- **Office of Policy and Management (OPM):** OPM coordinates the long-term care planning efforts of state agencies. It also collects data and maintains the annual nursing facility census, which provides aggregate information on the state of nursing facilities and their residents each year. In addition, OPM administers the Connecticut Partnership for Long-Term Care, a unique alliance between state government and the private insurance industry. The Partnership is explored in more detail in Section III.
- **The Connecticut Commission on Aging (COA):** The COA, created by the Connecticut General Assembly in 1993, leads public/private-sector efforts to promote and improve public policy on older adult issues including health care, long-term care, and many others. The independent Commission is guided by a Board composed of citizens with expertise in aging issues who represent the voting members, as well as the chairs and ranking members of several legislative committees, and representatives of various departments of state government. In order to strengthen its independence, it became a part of the Legislative Branch through legislative action in 2005, and is now located at the State Capitol.
- **Department of Economic and Community Development (DECD):** DECD oversees all state statutes related to accessible housing. In addition to being a key partner in the assisted living demonstrations, it administers capital grants for the conversion of adaptable living units to accessible units for persons with disabilities. The agency is also responsible for a statewide registry of accessible housing.
- **Department of Transportation (DOT):** DOT provides about \$80 million a year in subsidies to bus and paratransit systems throughout the state. The fixed route bus system provides discounted (half-fare) rides to seniors and people with disabilities. Out of a total of 37 million riders annually on the fixed-route system, about 2 million rides are provided to seniors and customers with disabilities. DOT administers the Federal Section 5310 program, which provides over 100 vehicle grants to municipalities and non-profit organizations in the state. In addition, the federal Americans with Disabilities Act (ADA) requires that demand-responsive paratransit services be provided to pre-qualified individuals who are not able, due to their disability, to utilize the local fixed-route bus system. ADA paratransit services are available to origins and destinations within 3/4 mile of the local bus route and are operated during the same days and hours as the local bus service. The state currently spends over \$10 million annually to support ADA services, and provides over 500,000 rides annually. The DOT-subsidized bus and paratransit operations serve 107 towns in the state.
- **Department of Children and Families (DCF):** DCF provides a variety of community-based and institutional services for children and adolescents with disabilities and their parents. DCF's mandates include prevention, child protection, juvenile justice services and behavioral health. Services are provided through contracted providers as well as state-operated facilities. DCF and DSS have formed the Behavioral Health Partnership to provide enhanced access to and coordination of a more complete and effective system of community-based behavioral health services and supports and to improve individual outcomes.
- **Office of Protection and Advocacy for Persons with Disabilities (P&A):** P&A is an independent state agency created to safeguard and advance the civil and human rights of people with disabilities. By providing various types and levels of advocacy assistance, P&A seeks to leave people with disabilities and their families better informed, equipped, and supported to advocate for themselves and others. In SFY 2005, the P&A provided information, referral, or short-term assistance to 5,967 people, while 1,046 individuals

received a more intensive level of advocacy representation. P&A also investigated or monitored 1,029 investigations into reports of suspected abuse or neglect of adults with intellectual disabilities, and provided training to over 2,000 individuals on disability rights topics.

- **Board of Education and Services for the Blind (BESB):** BESB offers a comprehensive array of services to improve the independent living skills of adults and children who are legally blind or visually impaired. Services are customized to each consumer's specific situation and include vocational counseling, technology training, teaching to improve activities of daily living, training in use of devices for safe travel, provision of low vision evaluations and aides, and self-advocacy training. Rehabilitation professionals are available to come to the homes, schools and places of employment of consumers, delivering specialized independent living, educational and vocational training. In addition, the agency Business Enterprises Program offers a unique opportunity for people who are blind to become entrepreneurs.
- **Commission on the Deaf and Hearing Impaired (CDHI):** CDHI works to advocate, strengthen and implement state policies affecting deaf and hard of hearing individuals. Services and supports include: interpreting services for deaf and hard of hearing persons interacting with the public; counseling and assistance regarding many types of job-related concerns; individual, marital, family and group counseling services to deaf and hard of hearing persons and hearing family members; and orientation seminars on deafness and deaf culture. Based on 2000 census numbers, CDHI estimates that there are slightly more than 200,000 people in Connecticut with hearing disabilities.
- **Department of Veterans' Affairs (DVA):** DVA provides health care, residential and rehabilitative services for veterans honorably discharged from the Armed Forces. Its health care facility is licensed by the DPH as a chronic disease hospital and provides general medical care, physical therapy, occupational therapy, respiratory therapy, an Alzheimer's unit, and hospice care. A new replacement health care facility, serving 125 beds in total, is currently under construction with an anticipated completion date of January 2008. DVA's residential facility is certified for 488 beds by the Federal Department of Veterans Affairs. In SFY05 the average monthly residential census was 324. Veterans receive substance abuse treatment, social work services, educational and vocational rehabilitation, job skills development, self-enhancement workshops, employment assistance and transitional living opportunities.
- **Other Organizations:** In addition to the state agencies and programs, a wide array of statewide, regional and local long-term care supports and services exist throughout Connecticut that are administered by government agencies, non-profit and for-profit organizations, as well as volunteer groups. Each city and town provides services and accommodations to address the needs of older adults and people with disabilities. Connecticut has five regional Centers for Independent Living, five Area Agencies on Aging (AAAs), and a number of statewide and local mental health councils and advisory councils for persons with disabilities. There is also the Corporation for Independent Living, which is a non-profit partner focused on new housing initiatives for person with disabilities. Also indispensable to the system of care are the myriad volunteer organizations that address the needs of individuals with specific chronic illnesses and conditions, providing support and companionship that foster sustainable independent living.<sup>15</sup>

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<sup>15</sup> Connecticut Long-Term Care Plan, January 2007.

## **G. History of policy implementation efforts regarding rebalancing<sup>16</sup>**

### ***Introduction to Olmstead plans***

Many of the policy implementation efforts regarding rebalancing were strongly influenced by the U.S. Supreme Court's 1999 decision in the case *Olmstead v. L.C.*, 527 U.S. 581 (1999). The case was brought against the Georgia State Commissioner of Human Resources (Tommy Olmstead) on behalf of two women with developmental disabilities (known as L.C. and E.W.) who were diagnosed with mental illness (schizophrenia and personality disorder respectively). They were voluntarily admitted to Georgia Regional Hospital for treatment in a psychiatric unit. After some time, they requested discharge and the professionals working with them assessed that they were ready to move into a community setting with appropriate support.

However, they were not successfully discharged from the hospital and in 1995 the Atlanta Legal Aid Society brought this lawsuit which was eventually heard by the Supreme Court. The Supreme Court ruled that under Title II of the Americans with Disabilities Act (ADA, 1990) the women had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA.

The *Olmstead* ruling stimulated lawsuits raising similar issues in other states on behalf of people who are institutionalized or at risk of institutionalization because of a lack of community-based services. However, numerous barriers exist to implementing Olmstead plans and promoting the inclusion of people with disabilities in the community including, financial constraints on Medicaid, the lack of affordable and accessible housing, labor shortage of home care workers and political pressure of institutional care facilities.

In response to the Olmstead decision, Connecticut began development of its "Olmstead Plan." A Community Options Task Force, including adults of all ages with various disabilities, family members of persons with disabilities, and representatives from the elder community, completed the "Choices are for Everyone" plan in 2002, in collaboration with the Long-Term Care Planning Committee and DSS. A number of activities have occurred or are ongoing in Connecticut that support the goals outlined in the "Choices are for Everyone" Plan.

### ***Systems Change Grants and Mental Health Transformation Grant***

The rebalancing goals of Connecticut's long-term care plan have been furthered through the work accomplished with the funding of seven *Systems Change for Community Living* grants awarded to Connecticut by the Centers for Medicare and Medicaid Services (CMS) as part of the federal New Freedom Initiative, and one grant from the Substance Abuse and Mental Health Services Administration (SAMSA). (See Table 4 below). These grants were designed to assist states in their efforts to remove barriers to equality for individuals living with disabilities or illnesses, enabling them to live in the most integrated setting suited to their needs, exercise meaningful choices about their living arrangements and exercise more control over the providers of the services they receive.

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<sup>16</sup> A portion of the following discussion is based on the Connecticut Long-Term Care Plan, January 2007.

Table 4. Summary of Grants

<p><b>2001-2004</b></p>	<p><b>Nursing Facility Transition Grant</b></p>	<p><b>To:</b> BRS  <b>From:</b> CMS  <b>Amount:</b> \$800,000  <b>Duration:</b> 3 years  <b>Purpose:</b> To help transition individuals with disabilities out of nursing homes and back to the community.  <b>Goals:</b> To develop an effective system of transition for individuals residing in nursing facilities who want to return to independent community living, transitioning 150 people out of nursing facilities over the course of the grant.  <b>Result:</b> 101 people were transitioned from residing in a nursing home to the community over the course of the three year federal grant period. The project was estimated to save nearly \$2.8 million annually in Medicaid nursing home expenditures. To continue the work begun with this grant, \$267,000 in state funds were appropriated for SFY 2006 and a total of \$375,000 are available in SFY 2007 to support the transition of individuals wishing to move from a nursing home to the community.</p>
<p><b>2002-2005</b></p>	<p><b>Real Choice Systems Change Grant</b></p>	<p><b>To:</b> DSS  <b>From:</b> CMS  <b>Amount:</b> \$1.4 million  <b>Duration:</b> 3 years  <b>Purpose:</b> To design and implement effective and enduring improvements in community long-term support systems enabling children and adults with disabilities or long-term illness to live and participate in their communities.  <b>Goals:</b> To build the capacity within Connecticut to support informed decision-making, independent living and a meaningful quality of life for persons with disabilities and to assist three communities in Connecticut to become models of support for opportunities and choices for persons with disabilities.  <b>Result:</b> Three Connecticut towns, Bridgeport, Groton, and New Haven were awarded model community inclusion grants of \$75,000 over the three years to support activities that enhance inclusion efforts for persons with disabilities and their families. The remainder of the grant money was used primarily for training, grant management and research. The three model communities provided a learning environment for local change, but with varying levels of success. Beyond the model communities themselves, the project held eight regional forums throughout the state, and found that these forums were a valuable tool for promoting local change. A compendium of Ideas was developed to chronicle the learning from the communities, the forums, and the project's statewide conference.</p>

<p><b>2003-2006</b></p>	<p><b>Independence Plus Waiver Initiative</b></p>	<p><b>To:</b> Department of Mental Retardation (DMR)  <b>From:</b> CMS  <b>Amount:</b> \$175,000  <b>Duration:</b> 3 years  <b>Purpose:</b> To help consumers and their families develop and manage individual budgets for their services and supports.  <b>Result:</b> DMR developed a new Level of Need Assessment tool and individual budget methodology that improved its ability to equitably disperse resources. It also supported the submission of a new Independence Plus Waiver effective Feb 2005 that introduced extensive consumer-directed care options in the DMR service system under waiver funding. A second waiver, the Comprehensive Services Waiver also included the same consumer-directed options in Oct. 2005.</p>
<p><b>2003-2006</b></p>	<p><b>Quality Assurance and Improvement in Home and Community-Based Services</b></p>	<p><b>To:</b> DMR  <b>From:</b> CMS  <b>Amount:</b> \$499,000  <b>Duration:</b> 3 years  <b>Purpose:</b> To implement its comprehensive quality improvement review system  <b>Result:</b> The development of a web-based data application to support the department's new Quality Service Review System, which evaluates all waiver service types and providers. The grant also supported the development of numerous consumer friendly publications regarding the department's new waiver, consumer direction, and training materials for support staff who are hired directly by consumers and families.</p>
<p><b>2003-2007</b></p>	<p><b>Community-integrated Personal Assistance Services and Supports (C-PASS) Grant</b></p>	<p><b>To:</b> DSS  <b>From:</b> CMS  <b>Amount:</b> \$585,000  <b>Duration:</b> 3 years  <b>Purpose:</b> To address the development of a personal assistance workforce by building an infrastructure that will allow for the effective recruitment and retention of direct support personnel.  <b>Goals:</b> To develop a single statewide tool to recruit personal assistants for permanent and backup employment, to create a strategic marketing plan to recruit personal assistants and to provide training for employers of personal assistants.  <b>Result:</b> A statewide registry tool has been developed (<a href="http://www.rewardingwork.org">http://www.rewardingwork.org</a>), as well as an extensive training curriculum and marketing efforts. A study is currently underway to assess the training efforts.</p>

<p><b>2005-2010</b></p>	<p><b>Mental Health Transformation Grant</b></p>	<p><b>To:</b> Connecticut (14 key state agencies and Judicial Branch)  <b>From:</b> Substance Abuse and Mental Health Services Administration (SAMHSA)  <b>Amount:</b> \$13.5 million  <b>Duration:</b> 5 years  <b>Purpose:</b> Collaborating on this grant are 15 state agencies, providers and consumers, who are addressing the needs of all individuals with mental health needs across the lifespan.  <b>Result:</b> A needs assessment and comprehensive state mental health plan was completed by September 2006 that directs system transformation activities.</p>
<p><b>2006-2011</b></p>	<p><b>Medicaid Infrastructure Grant (MIG)</b></p>	<p><b>To:</b> BRS  <b>From:</b> CMS  <b>Amount:</b> \$15 million  <b>Duration:</b> 6 years  <b>Purpose:</b> This grant is a continuation of a 2000 grant. Its renewed funding and expanded purpose is to achieve full participation and increase employment, increase earnings and independence and increase access to long-term care services and supports.  <b>Goal:</b> In this new cycle of funding, the project has taken a broader view, looking toward a comprehensive employment structure for everyone.  <b>Results:</b> The first grant received in 2000 focused on establishing a Medicaid Buy-In program for the employed with disabilities, which allows people to earn up to \$70,000 and retain \$10,000 in assets while retaining Medicaid coverage.</p>
<p><b>2007-2011</b></p>	<p><b>Money Follows the Person Rebalancing Demonstration</b></p>	<p><b>To:</b> Connecticut  <b>From:</b> CMS  <b>Amount:</b> \$24.2 million  <b>Duration:</b> 5 years  <b>Purpose:</b> Under this program, Medicaid funding is allowed to follow Medicaid eligible individuals living in a nursing home or other institution as they move out to live in the community and receive community-based services.  <b>Goals:</b> The program will serve 700 individuals across the age span with physical disabilities, mental illness and mental retardation. For eligible individuals, Medicaid funding will cover 24-hour live in assistance, personal management and home alterations, among other home and community-based services.</p>

## **Connecticut Behavioral Health Partnership**

In addition to the systems change grants and mental health transformation grant summarized above that furthered the state's rebalancing efforts, in 2006 the Department of Children and Families and DSS formed the Behavioral Health Partnership to plan and implement an integrated public behavioral health service system for children with special behavioral health needs and their families. The primary goal is to provide enhanced access to and coordination of a more complete and effective system of community-based behavioral health services and supports and to improve member outcomes. Secondary goals include better management of state resources and increased federal financial participation in the funding of behavioral health services.

The Behavioral Health Partnership is designed to eliminate the major gaps and barriers that exist in the current children's behavioral health delivery system. As such, both Departments are committing resources to develop a full continuum of behavioral health services for children that include evidenced-based programs, non-traditional support services, and community-based alternatives to restrictive institutional levels of care. Through collaboration with family members, providers and social support systems, the Behavioral Health Partnership promotes a strengths-based treatment approach that focuses on client success. Particular attention is given to the cultural needs and preferences of the child and family and treatment planning reflects this focus on cultural competency.

### **H. History of the state long-term care planning process<sup>17</sup>**

Over the last decade, Connecticut has been engaged in a comprehensive planning process for the organization, financing and delivery of long-term care. This process has gained significant momentum and is receiving increased attention across the state and nationally. The process in Connecticut pre-dated *Olmstead*, but was significantly affected by that decision. The following synopsis highlights the progress of long-term care planning efforts to date:

- **1996:** Report issued by Legislative Program Review and Investigations Committee concluded that the state's structure for planning, funding and overseeing long-term care services needed reinforcement and coordination. The Committee recommended the creation of an interagency committee to exchange information on long-term care issues, ensure coordinated policy development, and establish a long-term care plan.
- **1998:** Public Act 98-239 created the Long-Term Care Planning Committee (LTCPC) for the purpose of exchanging information on long-term care issues, coordinating policy development and establishing a long-term care plan. Public Act 98-239 also established the Long-Term Care Advisory Council (LTCAC) to advise and make recommendations to the Planning Committee. The LTCAC members include a balance of consumers, providers and advocates representing a wide range of interests.
- **1999:** Supreme Court *Olmstead* decision.
- **1999:** The LTCPC produced a Preliminary Long-Term Care Plan that provided a description of Connecticut's long-term care system in order to develop a baseline for future Plans. This preliminary plan for older adults integrated the three components of a long-term care system including home and community-based services, supportive housing arrangements and nursing facilities.

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<sup>17</sup> The following highlights are based in part on the Connecticut Long-Term Care Plan, January 2007.

- **1999:** General Assembly enacted Public Act 99-279 requiring the LTCPC to develop, by February 2000, a plan to ensure the availability of home care services for persons under the CHCPE who meet all qualifications for the program except established income limits. The impetus for this legislation was the fact that the CHCPE had a strict income eligibility requirement that resulted in individuals with as little as one dollar above the income level being found ineligible for home care services. This contrasted with the income requirements for Medicaid nursing home coverage that allow individuals with incomes that are not sufficient to pay for their care to become eligible for Medicaid as long as they contribute most of their income towards their care.
- **1999-2000:** The LTCPC and LTCAC embarked on a series of meetings with a variety of groups and organizations involved with the long-term care system, including 24 forums and five public hearings throughout the state to gather additional feedback and input for the Long-Term Care Plan from a wide range of constituencies.
- **1999-2000:** In 1999, legislation established a 10-person pilot program to permit those whose monthly income exceeded income eligibility limits for the Medicaid waiver component of the CHCPE by no more than \$100 to continue accessing the program. During the 2000 session, the General Assembly approved legislation that revised the income requirements for both the state-funded and Medicaid components of the CHCPE to allow individuals with incomes in excess of the income eligibility cap to become eligible for the CHCPE by buying into the program. The expanded income level was implemented for the state-funded portion of the CHCPE in October 2000. However, to implement a similar revision for the Medicaid portion of the CHCPE, federal approval was needed.
- **2000:** The LTCPC produced and delivered to the General Assembly a report titled "Home Care for Older Adults - A Plan for Increasing Eligibility under the Connecticut Home Care Program for Elders." The report concluded that the only mechanism to assure the availability of home care services under the CHCPE was to revise the income eligibility cap to mirror the income requirements utilized for nursing home care eligibility, thus allowing individuals to buy into the CHCPE.
- **2001:** DSS submitted a proposed revision to the CHCPE Medicaid waiver in 2001, but the DSS proposal was not approved by CMS. The state attempted to negotiate the buy-in, but CMS determined it was not consistent with Medicaid regulations and therefore not reimbursable. The state remained committed to the change in income limits regardless of the CMS ruling, and the eligibility revisions remained intact in the state-funded portion of CHCPE.
- **2001:** Long-Term Care Plan submitted to the General Assembly in January.
- **2001:** Public Act 01-119 broadened the LTCPC's purview by requiring a plan for all persons in need of long-term care, including persons with disability of any age. It also required the LTCPC to issue its long-term care plan every three years instead of every two.
- **2002:** Connecticut's Olmstead Plan, entitled "Choices are for Everyone," was completed as a collaboration among DSS, the LTCPC, and the Community Options Task Force.
- **2003:** LTCAC assumed responsibility for seeking and gathering broad public input on the draft Plan from diverse organizations and individuals throughout Connecticut with an interest in long-term care. Public comment solicited for next triennial long-term care plan. Comments were received from over 100 consumers, professionals and advocates, with representation from 23 public and private organizations.
- **2004:** LTCPC's third plan was issued in January. The 2004 plan for the first time established specific goals for HCBS services.
- **2005-2006:** Status updates issued on 2004 plan.



- **2007:** Using a similar process, the state's 2007 long-term care plan was developed and presented to the Connecticut General Assembly in January of 2007. The Plan contains recommendations for continuing to rebalance the state's long-term care system by shifting from a system reliant primarily on institutional care to one that supports care in a variety of home and community-based settings.

## **I. Advocacy environment**

The advocacy environment in Connecticut is rich with committed, active and fully engaged advocates participating in many aspects of state planning for long-term care, including many self-advocates and direct consumers of services. They are, however, often fragmented across disability groups and between disability and aging issues, which has lessened their overall effectiveness. While Connecticut historically has had a weak advocacy presence (with some notable exceptions), there has been some progress in recent years in the level of collaboration among groups on long-term care issues, particularly with respect to strengthening advocacy for the poor in various Medicaid programs and waivers. An organized voice for long-term care consumer advocates is still lacking. However, there is a foundation for such a voice as well as a growing need and will to move advocacy in that direction.

Advocacy groups for issues concerning those with developmental disabilities have a long history in Connecticut. In the 1950s, for example, The Arc of Connecticut lobbied to obtain a Special Education law long before federal legislation. In the 1960s, it encouraged the state to develop small regional centers as an alternative to its two big institutions for people with intellectual disabilities. This was followed by settlement of litigation in 1983 that developed a community system of group homes and individual apartments and resulted in the closure of Mansfield Training School, a 2000-bed institution, as well as some of the small regional institutions. Litigation settled in 2002 resulted in a five-year plan to increase the proportion of students with disabilities included in regular classrooms. Additional litigation settled in 2005 led to a settlement that will reduce the Department of Mental Retardation's waiting list by 750 individuals over a 5 year period.

Numerous advocacy groups are also involved in issues concerning mental health and substance abuse. The Connecticut Legal Rights Project and the Connecticut affiliate of the National Alliance on Mental Illness have been most active in rebalancing efforts for their constituency. Citizen involvement is encouraged through regional mental health boards and catchment area councils.

In the past decade, cross-disability advocacy groups have been evolving and becoming increasingly effective. The LTCAC, comprising consumers, providers and advocates, collaborates with the LTCPC on several initiatives, including the state's long-term care plan. In 2002, representatives of numerous disability advocacy groups joined the LTCAC bringing together AARP, the COA, and other advocates for older adults with those advocating for younger people with disabilities. Since that time, they advocated successfully to codify into law the statement of principle guiding future policy and budget decisions regarding long-term care (discussed in Section I (E) above), to create the state's long-term care website, and to secure funding for this Long-Term Care Needs Assessment. Moreover, cross-disability groups also joined together to support Connecticut's efforts to obtain federal grants for Nursing Facility Transitions, Medicaid Infrastructure and Money Follows the Person, described more fully below.

For the last two years, disability advocates have been involved in the organization of a cross-disability network called the Connecticut Disability Advocacy Collaborative.<sup>18</sup> The purpose of the Collaborative is to draw from the collective strength and energy of individuals with disabilities and families, as well as the dozens of advocacy organizations that exist in the state, in order to have a meaningful impact on the way services and supports are provided to people with disabilities in Connecticut. As a part of the organizing effort of the project, regional advocacy networks are being formed in nine different areas of the state.

## **J. Litigation related to rebalancing**

Connecticut has a history of litigation concerning rebalancing issues. Two cases from the 1970s and 1980s involved clients of the Department of Mental Retardation and resulted in consent decrees. Two more recent cases involve issues raised in the Supreme Court's *Olmstead* decision and its progeny.

### ***Department of Mental Retardation consent decrees***<sup>19</sup>

Two consent decrees from the 1980s made community placement a top priority at DMR. The most far-reaching was the result of a federal class action suit filed in 1978 by the Connecticut Association of Retarded Citizens (CARC) against DMR and its Commissioner. In *CARC v. Thorne*, CARC represented clients at Mansfield Training School, contending that the care provided by DMR to these clients at Mansfield and clients transferred from there to other long-term care facilities violated the U. S. Constitution and other federal protection laws.

The case was settled in 1984 through a consent decree. The settlement applied to about 1300 individuals meeting certain criteria, primarily residing at Mansfield on a particular date or at risk of placement there at a particular time. These "class members" for lawsuit purposes retained their status as such even after placement in the community. Provisions of the Consent Decree directed DMR to reduce the client population at Mansfield Training School and skilled nursing facilities by making available "suitable facilities and services that will assure an opportunity for every class member to live in a community residential setting." Each class member was to be evaluated by an interdisciplinary team to determine his or her needs and suitability for community placement. Any decision on placement had to be made with the knowledge, input and agreement of the client and his or her parents, guardian, or advocate. In addition, Mansfield had to improve its facilities and its care of clients who remained residents of the school. The consent decree ultimately contributed to the closing of Mansfield in 1993.

A second significant court case involving DMR was *U.S.A. v. State of Connecticut*, which concerned Southbury Training School. Plaintiffs in this case alleged civil rights violations based on conditions at the school. The suit was initiated by the Department of Justice in 1984 and resolved in 1986 through a consent decree. The *U.S.A.* case only applies to individuals while they are in residence at Southbury. The Consent Decree required DMR to develop an implementation plan addressing conditions that led to the lawsuit. The plan addressed: (1) assuring sufficient staffing to protect and enhance the life of residents; (2) providing periodic, professional evaluation of residents and communication about their care, training and medical

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<sup>18</sup> See organization's website at [www.ct-dac.org](http://www.ct-dac.org).

<sup>19</sup> Information in this section is from the Central Connecticut State University library website at <http://library.ccsu.edu/oneill/> and the Department of Mental Retardation website at <http://www.dmr.state.ct.us/wrstsabout.htm>.

needs; (3) creating more community-based opportunities for residents; and (4) improving the physical environment of the facility to eliminate fire and safety risks. Admission to Southbury closed in 1986. The Decree authorized meeting staff ratios and other standards through increased staffing and/or planned reduction of the resident population. In 1997 the state was held in contempt of Consent Decree provisions and a Special Master was appointed. In March of 2006 the Court held that the state had purged itself of contempt. Today, Southbury remains open with a population of 533, compared with 1200 residents in 1986, the year the state entered into the Consent Decree with the U.S. Justice Department. The average age of the individuals who live at Southbury Training School is currently 59.

### ***Olmstead lawsuits***

Even though community-based services have grown in the wake of *Olmstead*, most states have not kept pace with the huge demand, resulting in waiting lists. As a result, over 100 lawsuits have been initiated across the country (Smith, 2007; Kitchner, Willmont, Wong, and Harrington 2006).

- In many cases, the lawsuit involves individuals who receive no services at all and are seeking HCBS waiver services (e.g., KY, TN, UT);
- Other lawsuits involve persons who already participate in a waiver program but have been wait-listed for or denied some services offered in the program, most often residential services (e.g., CT, MA, WA);
- In a few lawsuits, the plaintiffs seek ICF/MR services in small community group homes as opposed to HCBS (e.g., CO); and,
- In other lawsuits, plaintiffs also include individuals who reside in ICF/MRs or large public institutions who are seeking HCBS instead as well as persons in the community waiting for services (e.g., NM, TX)

Two cases in Connecticut that address rebalancing have been brought since the *Olmstead* decision, the first of which is settled.

#### Arc/Connecticut et al. v. O'Meara and Wilson-Coker

This complaint (01-cv-1871) was filed in October 2001 in U.S. District Court for the District of Connecticut by Arc/Connecticut against the Commissioners of DMR and DSS (the state's Medicaid agency) on behalf of persons with intellectual disabilities wait-listed for Medicaid waiver services. The plaintiffs included persons who received some waiver services but were wait-listed principally for residential services and persons who did not receive any waiver services at all.

The lawsuit challenged several state policies. A central issue was plaintiffs' allegation that Connecticut restricted waiver services to available funding. The plaintiffs argued that this practice violated federal policy which requires that waiver participants receive the full range of services offered in a state's program that are necessary to meet their needs. The state was alleged to have wait-listed individuals who receive day and other supports for waiver residential services.

In January 2003, the court granted class certification, thereby expanding the lawsuit's scope to the then 1,700 individuals on the state's waiting list. The class included all persons eligible for

DMR services who have applied for and are eligible for the waiver program or would be eligible if they had the opportunity to apply.

In late 2004, the parties arrived at a settlement agreement. In February 2005, the Connecticut General Assembly agreed to underwrite the costs of the settlement. In March 2005, the parties submitted the agreement to the court. The court approved the agreement and dismissed the lawsuit in May 2005. The agreement provides for the following:

- The class includes persons who have been found eligible for DMR services and (a) have applied for and been found eligible for waiver services or (b) would be eligible for services had they had a reasonable opportunity to apply;
- Over the five-year period commencing in FY 2005 year and ending in FY 2009, the state committed to expand its HCBS waiver to accommodate an additional 150 persons each year at an average annual cost of \$50,000 per person and furnish family support services to another 100 persons per year at an average cost of \$5,000 per person. Over the five-year settlement period, Connecticut committed to spend an additional \$41 million in state funds to underwrite the settlement. Persons with urgent or high priority immediate needs will have priority for waiver services;
- The state also agreed to create a new Individual and Family Support HCBS waiver that offers flexible supports, incorporate self-direction, and complement the “comprehensive services” offered under the state’s existing waiver. The state also agreed to revamp its current waiver, including providing for independent service brokers; and,
- The state agreed to revise its procedures to ensure that individuals have the opportunity to apply for waiver services, are provided information about such services, and receive a prompt determination of their eligibility for such services.

The settlement agreement is currently being implemented. While the number of persons receiving services has increased as per the agreement, the waiting list for services has continued to grow. The state redesigned its comprehensive services waiver and secured federal approval to launch the individual and family support waiver.

#### Office of Protection and Advocacy v. State of Connecticut (DSS, DPH, DMHAS)

In February of 2006, in reaction to the increasing number of nursing home placements for individuals with mental illness, the Connecticut Office of Protection and Advocacy (OPA) filed a complaint (06-00179)<sup>20</sup> against the Connecticut Departments of Social Services, Public Health, and Mental Health and Addiction Services in the U.S. District Court for the District of Connecticut. The suit alleges that individuals with mental illnesses are needlessly unnecessarily isolated and segregated in nursing home facilities in violation of the ADA and the Rehabilitation Services Act. The complaint centers on 200 individuals with mental illnesses who are served in three nursing facilities in Hartford, Manchester and New Haven. The complaint charges that individuals served in these nursing facilities are housed in locked units. The complaint alleges that the annual costs of nursing facility services is between \$50,000 and \$80,000 per year and these individuals could be served more appropriately and economically in community mental health settings, including supportive housing living arrangements.

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<sup>20</sup> The complaint is located at:  
[ct.gov/opapd/lib/opapd/documents/adobe/complaint\\_ opa v. state of ct.pdf](http://ct.gov/opapd/lib/opapd/documents/adobe/complaint_opa_v_state_of_ct.pdf).

In part, a 2004 report of the Lieutenant Governor's Mental Health Cabinet<sup>21</sup> provides the basis of this lawsuit. Based on the report, the lawsuit notes that there are more than 2,700 individuals with psychiatric disabilities housed in Connecticut nursing facilities and that the number is growing at a rate of between 5 and 10 percent annually. Many of these persons are placed in nursing homes solely to obtain mental health care that could easily be provided in an integrated, community-based setting. The high rate of placement to nursing facilities is attributed to the state's failure to expand community services in the wake of its shrinking state mental health hospital services. The lawsuit contends that Connecticut has no comprehensive working plan to meet the needs of these individuals in the community, as required by the *Olmstead* decision.

In May 2006, the state agencies filed motions to dismiss. These motions challenged the legal standing of OPA to bring a lawsuit of this nature. In September, the parties informed the court that they are making progress in arriving at a settlement. As a result, the court has put further proceedings on hold.

#### **K. Service provider environment<sup>22</sup>**

The providers of direct care and other related services represent another key piece of Connecticut's long-term care context. Connecticut has a wide variety of long-term care service providers in community and institutional settings, as noted in Table 5.

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<sup>21</sup> Located at: [ct.gov/ltgovksullivan/lib/ltgovksullivan/Connecticut\\_Mental\\_HealthKBS2\\_-\\_FINAL.pdf](http://ct.gov/ltgovksullivan/lib/ltgovksullivan/Connecticut_Mental_HealthKBS2_-_FINAL.pdf).

<sup>22</sup> A portion of the following discussion is from the Connecticut Long-Term Care Plan, January, 2007.

Table 5. Connecticut Facilities Providing Long-Term Care<sup>23</sup>

	<b>Approximate number of persons served<sup>24</sup></b>
Home Health Care Agencies	32,000
Adult Day Centers	3,200
Senior Centers <sup>25</sup>	*
Assisted Living Services Agencies <sup>26</sup>	4,700
Managed Residential Communities <sup>26</sup>	6,500
Residential Care Homes	2,800
Nursing Facilities	27,700
Chronic Disease Hospitals	800
Continuing Care Retirement Communities	3,200
State-funded Congregate Housing	950
Supported Living Arrangements/DMR	1,300
Community Living Arrangements/DMR	3,600
Community Training Homes/DMR	400
Residential Setting/DMR	800
Group Homes/DMHAS	325
Supervised Housing/DMHAS	1,000
Supported Housing/DMHAS	2,500
Residential Setting/DMHAS <sup>27</sup>	700

### ***Home health care agencies***

In Connecticut, the majority of formal home care services are provided by home health care agencies. These agencies provide professional nursing services and other related services that help people stay in the community including: homemaker-home health services, physical, occupational or speech therapy, and medical social services. As of June 30, 2006, there were 89 agencies licensed by the Department of Public Health to provide home health care services in Connecticut.<sup>28</sup> Approximately one-third of the services provided by home health agencies are paid for by Medicaid under the state plan.<sup>29</sup> In Connecticut, there is a second type of home health agency defined as homemaker-home health aide agency. These agencies provide assistance with activities of daily living to ‘chronic and stable’ private pay clients in their home or similar environment. Types of supportive services include assistance with personal hygiene,

<sup>23</sup> The table does not include family homes where many people receive services funded through waivers or state funds, e.g. the DMR Individual and Family Support waiver and Elder waiver.

<sup>24</sup> Number of persons served for the first two categories estimated from provider responses to the 2007 Connecticut Long-Term Care Needs Assessment Part I: Survey Results. Estimates for the remaining 15 categories taken from the Connecticut Long-Term Care Plan, January, 2007.

<sup>25</sup> Estimates for Senior Centers could not be reasonably determined as responses were inconsistent among daily, weekly, monthly and yearly census.

<sup>26</sup> See discussion of assisted living/managed residential communities below.

<sup>27</sup> Of this number, some are women with addiction who are pregnant or have children and are pursuing employment and educational goals.

<sup>28</sup> Connecticut Department of Public Health, 2006.

<sup>29</sup> Connecticut Long-Term Care Needs Assessment Part I: Survey Results, 2007.

dressing, feeding and incidental household tasks essential to achieving adequate household and family management. These services must be provided under the supervision of a registered nurse and various specialists as determined by the nurse (such as social worker, physical therapist, speech therapist or occupational therapist). Supervision may be provided directly or through contract. (Connecticut Department of Public Health, 2006d).

### ***Adult day centers***

Adult day services are an option for frail older adults who want to remain in their homes. The 51 licensed adult day centers in Connecticut provide respite to family caregivers as well as therapeutic care for cognitive and physically impaired older adults. Individuals receive professional services ranging from social activities and therapeutic recreation to nursing care and rehabilitation services, representing a blend of traditional health and social services.<sup>30</sup> The average cost to care for an individual in an adult day center is \$69 per day,<sup>31</sup> and approximately 40 percent of services provided are paid for by Medicaid as a waiver service under the CHCPE.<sup>32</sup> Adult day care centers are not regulated by the Department of Public Health. Instead, the Connecticut Association of Adult Day Centers (CAADC) is authorized by DSS to provide a program of peer review and certification, which is required in order for an adult day center to receive state funds.

### ***Senior centers***

Senior centers are not providers of long-term care services in the traditional sense, as many center clients and members are in good health and use the centers primarily for social and educational purposes. However many centers assist frail older adults to remain in their home by providing services such as recreation, information and referral, health screenings, transportation, and congregate meals. Connecticut's 155 senior centers provide services to nearly every town, although they range in size from small centers with limited hours and volunteer staff to large full-service centers.

### ***Assisted living services/Managed residential communities***

Assisted Living Services Agencies (ALSAs) are an alternative for older adults who need assistance with activities of daily living (e.g. bathing, dressing), but who do not require the intensive medical and nursing care provided in a nursing facility. In Connecticut, ALSAs are licensed to provide assisted living services in managed residential communities (MRC). Assisted living services can be provided in a number of different settings, such as continuing care retirement communities or elderly housing, as long as the facility provides the services to qualify as a MRC. Services provided by the MRC include laundry, transportation, housekeeping services, meals, and recreational activities. Individuals choosing to live in an MRC may purchase long-term care services from the ALSA allowing them to live in their own apartment. Medicaid payment for assisted living services is quite limited. Except in the pilot programs, coverage does not include room and board, and slightly less than ten percent of the total cost of services is paid for by Medicaid as a waiver service through the CHCPE.<sup>33</sup>

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<sup>30</sup> The Connecticut Association of Adult Day Centers, [www.canpfa.org](http://www.canpfa.org), October 2006.

<sup>31</sup> Connecticut Partnership for Long-Term Care, *Cost of Care in Connecticut*, April 2006.

<sup>32</sup> Connecticut Long-Term Care Needs Assessment Part I: Survey Results, 2007.

<sup>33</sup> Connecticut Long-Term Care Needs Assessment Part I: Survey Results, 2007.

As of September 2006, there were 68 ALSAs licensed in Connecticut providing services in 109 managed residential facilities.<sup>34</sup> There were 5,977 assisted living units in Connecticut as of January 2003, with an additional 88 under construction. The Connecticut Assisted Living Association estimates that there are approximately 4,700 individuals living in assisted living apartments. Assisted living residents are typically older adults, with 75 percent of residents over the age of 85. Approximately two-thirds of residents are female and almost all are white (98 percent).<sup>35</sup>

Since the cost of living in the MRC and the assisted living services purchased are virtually all paid out of pocket, these community living arrangements are available to individuals who can afford the cost of both room and board and services. Through a collaborative effort of the DECD, DPH, OPM and DSS, Connecticut is making assisted living services available to lower-income individuals through the Assisted Living Demonstration Project, state-funded congregate housing, HUD complexes and the Private Pay Assisted Living Pilot, discussed in more detail in Section III below.

### ***Residential care homes***

Residential care homes are facilities that provide a room, meals and supervision, but no nursing services, for individuals whose limitations prevent them from living alone. Services vary from facility to facility but may include dietary and housekeeping services, monitoring of prescription medication, social and recreational opportunities, transportation, and assistance with activities of daily living. One hundred and two residential care homes in Connecticut are licensed by the Department of Public Health, with a total of 2,826 beds. The majority of people residing in a residential care home are supported through the State Supplement to the Aged, Blind and Disabled.

### ***Continuing care retirement communities***

Continuing care retirement communities (CCRC), sometimes called life care communities, offer lifetime living accommodations and a wide variety of services, including a specified package of health and nursing services for older adults. People usually enter these living arrangements while living independently, but are able to receive services at every level of care as they age. These living arrangements are paid for privately and usually require a substantial monetary investment. Each CCRC is mandated to register with DSS. Although CCRCs are not licensed, various components of their health care packages, such as residential care beds, assisted living services, and nursing facility care are licensed by the Department of Public Health.

As of June 30, 2006 there were 17 CCRCs operating in Connecticut, offering a total of approximately 3,200 units. All CCRCs offer personal care services, assisted living services, and skilled nursing care. Only 3 CCRCs offer intermediate care beds and three offer residential care beds.<sup>36</sup>

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<sup>34</sup> Connecticut Department of Public Health, 2006.

<sup>35</sup> The Connecticut Assisted Living Association, 2003.

<sup>36</sup> Connecticut Department of Social Services, 2006.



### ***Nursing facilities***

Nursing facilities provide personal and skilled nursing care 24 hours a day. This level of care is often used when an individual has a condition that requires 24-hour supervision, substantial needs based on activities of daily living (ADL) or cognitive status, inadequate informal support, or insufficient financial resources to pay for home and community-based services. There are two types of nursing facilities licensed in Connecticut: Chronic and convalescent nursing homes and rest homes with nursing supervision

On September 30, 2006, there were 27,689 individuals residing in 246 Connecticut nursing homes and a total of 29,657 licensed nursing facility beds. Since 1991, efforts have been made to reduce the number of residents in Connecticut's nursing facilities by placing a moratorium on additional beds. From 1991 to 1994, the total number of licensed beds increased from 29,391 to 32,149, due to the addition of beds that had been approved before the moratorium went into effect. From 1994 to 2006, the total number of licensed beds decreased by 2,492, or 7.8 percent. Approximately 69 percent of nursing home residents are covered by Medicaid.<sup>37</sup>

### ***Chronic disease hospitals***

On June 30, 2006, there were six chronic disease hospitals in Connecticut with a total of 804 beds. Medicaid covered a monthly average of 722 individuals in SFY 2005. Medicare provides coverage using the same criteria used for nursing facilities. These hospitals provide diagnosis, care and treatment of a wide range of chronic diseases.

### ***Congregate housing***

Congregate housing provides frail older adults with private living arrangements, moderate supportive services, and common areas of dining, socialization and other activities. These facilities furnish at least one daily meal, which is usually included in the monthly fee, housekeeping services and a variety of social and recreational activities. They are generally meant for individuals who are basically self-sufficient but need a few services to help them to live independently. Most are federal or state-funded.

As of June 30, 2006, 951 people age 62 and over lived in state-funded congregate housing in Connecticut. Residents were all low-income and had a minimum of one ADL limitation. Beginning in 2001, DECD and DSS introduced assisted living services within state-funded congregate housing facilities. Fifteen of the 23 congregate facilities are participating in this service expansion. As of February 2007, 165 congregate housing residents were actively enrolled in the assisted living program.

### ***Residential settings for individuals with intellectual disabilities***

The Department of Mental Retardation administers or contracts for residential services from independent living, supported living arrangements, community living arrangements, community training homes, and residential center settings. The majority of people served by DMR live at home with their families.<sup>38</sup>

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<sup>37</sup> State of Connecticut Nursing Facility Registry, September 1995 and Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2006.

<sup>38</sup> Department of Mental Retardation website, Residential Services: [www.dmr.state.ct.us/ssdesc.htm#res-cla](http://www.dmr.state.ct.us/ssdesc.htm#res-cla).

- *Independent Living* -- Some people with intellectual disabilities need no staff support to manage a household on their own. They live in apartments, houses, and condominiums and manage their residential life just like any person without intellectual disabilities. On September 30, 2006, 278 individuals lived independently and an additional 300 individuals lived independently with some minimal individualized supports.
- *Supported Living Arrangements (SLA)* -- Some people need minimal hours of support to live in their own place. This staff support may be in the form of assistance with budgets, shopping and/or leisure activities. People living in SLAs get staff support from a few hours a day to only a few hours a month, depending on the needs of the person. On September 30, 2006, 1,272 individuals lived in SLAs.
- *Community Living Arrangements* -- People who need 24 hour support are provided with staff in group home settings. Usually, two to six people will share an apartment or house and will have staff available to them 24 hours a day. On September 30, 2006, 3,634 individuals lived in Community Living Arrangements.
- *Community Training Homes* -- People with intellectual disabilities live in a family setting that is not within their own family. People in these settings live with a family that has received training and licensing from DMR. On September 30, 2006, 408 individuals lived in Community Training Homes.
- *Residential Center Settings* -- Residential centers are facilities with over 16 people. Connecticut has eight residential centers that provide 24 hour staffing for the people who live there. Usually, a person living in a residential center also receives their day services at the same facility. On September 30, 2006, 269 individuals lived in Residential Center Settings and 541 individuals reside at the Southbury Training School, one of the three largest such facilities in the country.

The Medicaid state plan funds DMR Residential Centers, Southbury Training School, and community living arrangements (private ICF/MR group homes). Waiver funding covers the direct support costs for staffing in all other settings. DSS state supplemental payments cover room and board costs for community living arrangements and community training homes. Personal income, and for some individuals some DMR state funds called rent subsidy, covers the costs of other independent living situations' room and board.

### ***Residential settings for individuals with psychiatric or addiction disorders***

The Department of Mental Health and Addiction Services funds several types of residential settings for individuals age 18 and older with psychiatric or addiction disorders.<sup>39</sup>

#### Psychiatric disorders

- *Group Homes* – A community-based residence with on-site staffing 24 hours per day, seven days a week. In SFY 2005, 327 individuals lived in these group home settings.
- *Supervised Housing* – Services are provided in intensively managed housing where individuals live in private or shared apartments with staff co-located 24 hours per day, seven days a week. In SFY 2005, 1,008 individuals lived in supervised housing.

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<sup>39</sup> Connecticut Department of Mental Health and Addiction Services, 2006.

- *Supported Housing* – Community-based private or shared apartments with weekly visits and support services. Staff is on call 24 hours per day, seven days a week, although they are not necessarily located on site. In SFY 2005, 2,480 individuals resided in supported housing

#### Addiction disorders

- *Long-term care* – A 24 hour per day, seven days a week staffed residence with a structured recovery environment providing substance abuse intermediate and long-term residential treatment or care. In SFY 2005, 199 individuals participated in this program.
- *Short and long-term residential treatment for women with alcohol and/ or drug addiction who are pregnant and/ or have children* -- The program allows women to continue treatment in a gender-specific program while pursuing employment and educational goals. Since October 2004, 491 women have been admitted to the residential programs.

#### **Provider advocacy**

Well-organized unions representing workers in nursing facilities, as well as state employee unions in areas including the Department of Mental Retardation, also exert significant efforts in their role as advocates. The former have been strong advocates on issues concerning the displacement of individuals in nursing homes or leaving residents without care. Strike threats have often been effective in obtaining enhancements to nursing home reimbursement rates. Similarly, the nursing facility industry groups have been a vocal influence on rebalancing issues, often supporting increasing home and community-based service funds while not decreasing funds for nursing homes.

#### **L. Nursing home rate setting**

While all states set rates for Medicaid nursing home services, they use different approaches such as case mix, cost-based, fixed rates and various forms of incentives. Under Connecticut's Medicaid program, payment rates for nursing homes are cost-based, that is, based on the "allowable" (defined by the state) cost of providing care, and are specific to each facility (this is in contrast to the acuity-based case mix system used by most states). Rates are set on a prospective basis and are determined annually. The rate setting formula is defined in state statute (CGS 17b-340), and requires rates to be recalculated (also known as 'rebasings') every 2 to 4 years.

Nursing home costs are categorized into five major components: direct resident care, indirect care, administration, capital, and property. Direct resident care includes nursing staff salaries, wages and benefits. Indirect care includes dietary, medical supplies, laundry, social services and other professional fees. Administration includes administrative salaries and expenses, maintenance and plant operations. Capital costs are taxes, insurance and equipment expenses. Property costs represent a fair rent value yielding a constant amount each year. Rates are based on costs in the direct care, indirect care and administrative categories, and are capped by statute, not to exceed a specified percentage of median costs. It should be noted that the nursing home providers report that allowable costs defined through this process frequently do not reflect the *actual* costs of care. The last partial rebasing was done on July 1, 2005, and in 2006 there was a fixed 3% increase in rates.

The payment method incorporates incentives to encourage homes to target spending toward direct resident care and to be as efficient as possible. For example, the direct resident care ceiling is set at 135 percent of the median direct resident care costs, while the ceiling for indirect care is 115 percent and the administrative ceiling is set at 100 percent. Rate increase adjustments are given to facilities with lower costs in the indirect and administrative categories; rates are increased by 25% of the difference between the facility's cost and the statewide median cost. It is important to note that nursing home providers report that incentives are not generally included in rates.

Like most states, Connecticut classifies homes into peer groups, or categories, based on characteristics such as location, and sets separate cost-center ceilings for each peer group. Connecticut's peer groups include two geographic regions (Fairfield county and the rest of the state, reflecting the higher wages in that area) and two license types (Chronic and convalescent nursing homes and rest homes with nursing supervision) (Program Review and Investigations Committee, 2001). Since the early 1990s, a number of cost containment features have been in place, such as the cost categories and caps described above. Other notable provisions include a year to year increase limit (also known as "stop gain/stop loss") that caps how much a rate can increase each year, and the use of an occupancy standard of 95% to set rates. Nursing home providers indicate that these cost-containment features, particularly the year-to-year increase limit implemented in 1995, are the primary reason for Medicaid underpayments to providers.

There are statutory provisions for the DSS Commissioner to issue interim rates and make special adjustments for facilities that incur extraordinary or unanticipated costs, change ownership, or change licensed bed capacity. Nearly half (45 percent) of facilities in the state have received such individual adjustments since 1998, and it is typical for the Department to issue 30 to 50 interim rates annually related to major capital projects, ownership changes and hardship situations (DSS, 2006). Problems with the interim rate-setting process include: a lack of criteria for requesting, or granting these rates; inequities in reimbursement that result from interim reviews; and substantial administrative costs associated with case by case rather systematic, statewide rate setting (Ad Hoc Task Force, 2002).

In an effort to increase federal funding for the state's Medicaid program, Connecticut passed legislation establishing a nursing facility user fee ("provider tax") effective July 1, 2005. The user fee is a tax and reimbursement system designed to redistribute funds to nursing homes and other providers in the Medicaid system, such as community-based programs and services. As a result of the federal formula, there was a substantial range in the net increases in funding, with some nursing homes receiving no increase, and others receiving a net increase of up to 8%. The return of money to the nursing homes is not guaranteed, and the industry association reports that while some facilities received additional funds, many did not recover their actual or allowable costs. It is anticipated that some nursing homes will find it necessary to increase their charges for private-pay residents in order to compensate for these losses. In 2005, the average cost of a semi-private room was \$284 a day, an eight percent increase over the average daily rate of \$263 in 2004. The annual percentage change over the last five years was five percent for private pay rates (OPM, 2006).

### ***Current rates***

Connecticut's Medicaid average nursing home per diem rates are fifth highest in the nation and second highest in the Northeast. In the rate period, July 1, 2006 through June 30, 2007, the average Medicaid rate is \$209.23 per day and rates range from \$121.01 to \$255.13 per day

(DSS, 2006). However, while these rates are high, the average Medicaid per diem rate is substantially less than the other primary payers (Medicare and private pay). The Medicaid rate is nearly \$100 a day less than Medicare and \$75 less than the average private pay rate (Medicare rates for sub-acute short stays are significantly higher than the Medicaid rate for long-term care). In addition, there is great variability in the Medicaid rates paid across facilities. This variation is related to profit status (average rates in non-profit facilities are \$15.72 higher than for-profit), and union status (unionized homes received \$8.15 a day more than non-unionized homes; non-profit, unionized received \$24.49 more per day for each Medicaid resident than for-profit, unionized homes) (Program Review and Investigations Committee, 2002).

Despite the fact that Connecticut's average per diem rates are higher than in most states, shortfalls in Medicaid funding for nursing home care persist. An analysis done for the American Health Care Association found that, in 2003, Connecticut experienced a \$14.30 per patient day shortfall in Medicaid funding. This shortfall occurred despite many states implementing or expanding the use of provider tax programs to help improve nursing facility reimbursement (BDO Seidman, 2006).

### ***Policy implications***

Connecticut's nursing home rate system has received a great deal of attention in recent years (Program Review and Investigations Committee, 2001; Ad Hoc Task Force, 2002; U.S. General Accounting Office, 2003). A number of recommendations for improvement have been offered. The need for an overarching, coordinated framework for long-term care financing has been stressed, as the current reimbursement system does not "adequately reflect the actual costs of wages, benefits and staffing" (Ad Hoc Task Force, 2002). The cumulative effect of stop-gain/stop-loss ceilings, infrequent rebasing and a high discretionary interim rate process has limited the effectiveness of Connecticut's rate setting system (Ad Hoc Task Force, 2002). Consequences have been greatest for those facilities that serve primarily Medicaid-pay residents. These nursing homes are less able to shift un-reimbursed Medicaid costs onto other sources (Medicare and private payers) due to increasing numbers of Medicaid-only residents, lower Medicare reimbursement rates, and declining numbers of private pay residents associated with increased community-based long-term care alternatives (BDO Seidman, 2003). It has been recommended that nursing homes caring for primarily Medicaid-pay residents receive supplemental disproportionate share payments to address the additional costs of taking care of low-income persons and the fact that Medicaid rates are lower than that of any other payor (Ad Hoc Task Force, 2002).

## **M. Programs for long-term care in Connecticut**

### ***Medicaid institutional and HCBS programs and services***

It is well documented that at the national level most Medicaid long-term care expenditures pay for institutional services in nursing facilities, intermediate care facilities for the mentally retarded (ICF/MRs) and other institutional settings. Federal Medicaid law (Title XIX of the Social Security Act) requires that every state cover nursing facility services in its Medicaid program. States also have the option to offer ICF/MR services.

Despite the fact that institutional spending dominates Medicaid services, spending for home and community-based services has been growing rapidly. For more than a decade, national HCBS spending has risen more rapidly than institutional services. Between 1996 and 2005, HCBS

waiver expenditures grew nearly four-fold, reaching \$22.7 billion. In 2005, the share of Medicaid services expenditures devoted to HCBS reached 37% compared to a little over 10% in 1990.<sup>40</sup>

Medicaid home and community-based services include home health care, personal care/assistance provided as a Medicaid state plan benefit, and home and community-based services (HCBS) furnished under federal waivers. All states must cover home health in their Medicaid programs. States may elect to provide personal care/assistance and/or operate HCBS waivers. States may provide community services as an alternative to institutional services under the HCBS waiver.

### ***Connecticut state plan and state-funded services<sup>41</sup>***

Connecticut's Medicaid state plan covers the cost of institutional services including nursing homes, ICF/MRs, and chronic disease hospitals. There are also a limited number of home and community-based services funded through state sources, including home health care, durable medical equipment, and rehabilitation options for adults and children. The majority of the formal home care services are provided by home health care agencies. Services offered include skilled nursing, physical therapy, speech therapy, occupational therapy, homemaker/home health aide service and medical social services.

Durable Medical Equipment (DME) is equipment that can be used repeatedly for medical purposes. Medicaid will only pay for equipment that meets the definition of DME and is medically necessary. Although DSS has a list of DME for which it routinely pays, additional items may be approved for coverage and are considered on an individual need basis.

Rehabilitation Option for Psychiatric Rehabilitation Services:

*Adults:* Connecticut currently covers rehabilitation services provided in mental health group homes of 16 or fewer beds as well as targeted case management services to individuals with chronic mental illness. Services help clients to access medical, social, educational and other benefits to ameliorate their symptoms and improve personal functioning.

*Children:* Through the Behavioral Health Partnership, Connecticut provides case management and rehabilitation services through Early Periodic, Screening, Diagnosis and Treatment (EPSDT) authority when medically necessary to link medical, social, educational, and other services. Services include a variety of psychiatric home-based rehabilitation and emergency mobile benefits.

### ***Connecticut Medicaid waivers<sup>42</sup>***

Home and community-based waiver programs in Connecticut are administered by two different agencies, DSS and DMR, with DSS being the lead Medicaid agency. A brief description of each of the HCBS waivers is noted in Table 6:

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<sup>40</sup> For information concerning Medicaid services spending nationwide and by state, see [hcbs.org/moreInfo.php/type\\_tool/129/ofS/40/doc/1637/](http://hcbs.org/moreInfo.php/type_tool/129/ofS/40/doc/1637/).

<sup>41</sup> Money Follows the Person Rebalancing Demonstration Proposal submitted to the Center for Medicare and Medicaid Services by the Connecticut Department of Social Services, November 1, 2006.

<sup>42</sup> Money Follows the Person Rebalancing Demonstration Proposal submitted to the Center for Medicare and Medicaid Services by the Connecticut Department of Social Services, November 1, 2006; Connecticut Long-Term Care Plan, January 2007.

Table 6. Connecticut's System of Medicaid Home and Community-Based Service Waivers as of April 2007

**CT Home Care Program for Elders**

Participants:	Serves approximately 14,000 Older adults age 65+ with a minimum of three critical needs (the same criteria as required for nursing homes). Includes both Medicaid waiver clients (9,000) and state-funded clients who do not meet either the financial or functional qualification for the waiver. No wait list for waiver or state-funded PCA pilot; wait list for state-funded pilot that funds ALSA services in private MRCs.
Settings:	Personal residences, adult day care centers, congregate housing, elderly housing, residential care homes, CCRC and MRC assisted living, Alzheimer's facilities with private assisted living.
Services:	Adult day programs, adult day health care, assistive devices, assisted living services, care management, chore services, companion services, home health aide services, home delivered meals, homemaker services, hospice services, information & referral, mental health counseling, nursing services, nutritional services, PCA services, personal emergency response, physical, speech, respiratory & occupational therapy, respite care, transportation

**Personal Care Assistance Waiver**

Participants:	Serves up to 698 adults with physical disabilities, self-direction. Waiting list begun in February 2007 when maximum number of slots reached.
Settings:	Personal residences
Services:	Personal assistance services, personal emergency response

**Acquired Brain Injury Waiver**

Participants:	Serves up to 369 adults with acquired brain injury. Currently at or near capacity on financial cap and number of slots
Settings:	Personal residences, group residences
Services:	Case-management, chore, cognitive behavioral program, community living supports, companion, day habilitation, durable medical equipment, family training, homemaker services, home delivered meals, independent living training, personal care assistance, personal emergency response, pre-vocational services, respite care, substance abuse, supported employment, transportation and vehicle modification

**Katie Beckett Model Waiver**

Participants:	Serves up to 180 individuals (primarily children) with physical disabilities. Waiting list of over 100.
Settings:	Personal residences
Services:	Assistive devices, care management, durable medical equipment, home health aide services, information & referral, mental health counseling, nursing services, physical, speech, respiratory, occupational therapy, prescription drug assistance, transportation

**DMR Individual/Family Support Waiver**

Participants:	Serves 3,245 individuals with intellectual disabilities. (Current waiting list because budget cap reached.)
Settings:	Personal residences
Services:	Supported living, personal support, individual habilitation, adult companion, respite care, personal emergency response, home and vehicle modifications, supported employment, group day programs, individual day programs, behavior/nutritional consultation, specialized equipment and supplies, transportation, family consultation/support, individual consultation/support

**DMR Comprehensive Waiver**

Participants:	Serves 4370 individuals with intellectual disabilities. (Current waiting list because budget cap reached.)
Settings:	Personal residences, community living arrangement, community training home, assisted living

Services: Supported living, personal support, individual habilitation, adult companion, respite care, personal emergency response, home and vehicle modifications, supported employment, group day programs, individual day programs, behavior/nutritional consultation, specialized equipment and supplies, transportation, family consultation/support, individual consultation/support

### Connecticut Home Care Program for Elders (CHCPE)

The CHCPE is the state's largest HCBS waiver program. For the CHCPE, funding was increased by \$2.1 million in SFY 2005 in recognition of the continued growth of the program. For SFY 2007, \$900,000 was appropriated to increase the asset limit. As of April 1, 2007, asset limits for the state-funded components of the program were expanded such that a single person may now have assets of up to 150 percent of the Community Spouse Protected Amount (CSPA) (amount established annually by DSS), and a couple may have assets of up to 200 percent of the CSPA. In order to continue the state-funded CHCPE program, including maintaining the no-waiting list policy and continuing the new Personal Care Assistance Pilot initiative begun in SFY 2005, funding was increased by \$4.6 million in SFY 2006 and \$9.7 million in 2007, for a total appropriation of \$43.8 million in SFY 2006 and \$50.2 million in SFY 2007.

### State-funded Personal Care Assistance (PCA) Pilot

The state-funded PCA Pilot within the CHCPE was expanded from 50 to 100 slots in September 2004 by DSS. In SFY 2006, the program was repealed and replaced by a less restrictive pilot program that allows recipients' relatives, other than a spouse, to act as a PCA. The number of people who may participate in the PCA Pilot was increased from 100 to 150 in SFY 2006 and from 150 to 250 in SFY 2007. In SFY 2007, \$2.1 million was appropriated for the program expansion to 250 slots. During the 2007 legislative session, the cap was eliminated.

### Personal Care Assistance Waiver

The Personal Care Assistance Waiver for persons age 18 to 64 was renewed in September 2004, increasing the amount of hours a PCA may work for a single client from 25  $\frac{3}{4}$  hours a week to 40 hours. Program capacity was expanded by 200 slots, from 498 to 698. If a PCA works more than 25  $\frac{3}{4}$  hours for one client then the client (the employer) is required to purchase Workers Compensation insurance. In SFY 2007, the program extended eligibility to include individuals age 65 and older. As of April 2007, there were approximately 90 people on a waiting list with about 200 in the process of being assessed for eligibility.

### Acquired Brain Injury (ABI) Waiver

The Acquired Brain Injury waiver was implemented effective in January, 1999 to address the needs of persons disabled by acquired brain injuries who currently receive, or would otherwise receive, services in an institutional setting. The waiver serves people between the ages of 18 and 64 who meet all other home and community-based Medicaid eligibility requirements. The waiver applies the principles of person-centered planning to develop an adequate, appropriate and cost-effective plan of care from a menu of twenty-one home and community-based services to meet the person's needs in the community. The program is capped at 369 persons. The number of participants as of December 1, 2006 was 290, but in early 2007, the program was fast approaching its cap and the need for a waiting list.



### Katie Beckett Medicaid Waiver

The Katie Beckett Medicaid Waiver was expanded from 125 to 180 slots. The program offers case management and home health services primarily to disabled children who would normally only qualify for Medicaid in an institution. An appropriation of \$1.5 million was made in both SFY 2006 and 2007 to support the expansion.

### DMR Individual and Family Support (IFS) Waiver

This waiver provides in home, day, vocational and family supports services for people who live in their own or family home. In SFY 2006, the monthly average number of participants was 2,383.

### DMR Comprehensive Supports Waiver

This waiver provides for the vocational and in-home services needed for people who need a more intensive level of support to remain in the community. These services are delivered primarily in licensed settings (community living arrangements, community training homes and assisted living) and include residential and family support services, vocational and day services and specialized and support services. In SFY 2006, the monthly average number of participants was 4,890.

### Additional HCBS efforts

In addition to the existing waivers, legislative activity reflects a continued commitment to explore other home and community-based options within the state. There are four population-specific pilots under discussion or development, which include individuals with autism, with mental illness, with multiple sclerosis and with HIV:

- ***Autism Spectrum Disorders Pilot Program***  
Funds were appropriated by the General Assembly in SFY 2007 (\$1 million) to establish a pilot autism spectrum disorders program for individuals who do not have a diagnosis of mental retardation. The pilot program, which began in October 2006 and will run through October 2008, will serve a maximum of 50 people and provide a coordinated system of supports and services.
- ***Program for Adults with Severe and Persistent Psychiatric Disabilities***  
In SFY 2007, \$1,725,000 was appropriated to support the development and implementation of a Medicaid HCBS Program for Adults with Severe and Persistent Psychiatric Disabilities who are discharged or diverted from nursing home residential care.
- ***Program for People with AIDS and People with Multiple Sclerosis***  
In SFY 2007, \$400,000 was appropriated for the development of two HCBS Medicaid waiver programs for people with AIDS and people with multiple sclerosis.

## **N. Progress toward rebalancing goals**

For the first time in Connecticut, more individuals are receiving Medicaid long-term care services in the community<sup>43</sup> than are receiving institutional care<sup>44</sup>. This is a significant milestone in achieving one of the primary recommendations first stated in Connecticut's 2004 Long-Term Care Plan. That plan proposed that by 2025, 75 percent of Medicaid long-term care clients will be receiving services at home or in the community, with only 25 percent receiving institutional care. To achieve this goal, the 2004 Plan recommended a one percent increase per year. Connecticut has exceeded this goal by shifting the balance by five percent over the last three years.

### ***Medicaid long-term care clients***

- The proportion of Medicaid long-term care clients receiving services in the community has increased from 46 percent in SFY 2003 to 51 percent in SFY 2006 – an increase of almost two percent a year. Table 7 and Figure 1 provide a breakdown by program. (Note that Connecticut does not have a personal care option in the state Medicaid plan, so all the HCBS services shown in the table are financed through various HCBS waivers.) During that three-year period, all community care programs showed an increase in percent of Medicaid clients served. The largest decrease was in nursing facilities, which declined from 51 percent to 45 percent.
- The total number of people receiving long-term care services through Medicaid has increased by 10 percent between SFY 2003 and SFY 2006, increasing from 37,969 to 41,773 individuals (Table 7; see also Figure 1).
- Rebalancing has occurred primarily through a 23% increase in the number of individuals served by home and community-based care, with only a slight 1% decrease in the number of those receiving institutional care.

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<sup>43</sup> Medicaid long-term care community services include home health services, home and community-based waiver programs, and targeted case management for mental health.

<sup>44</sup> Medicaid long-term care institutional services include nursing facilities, intermediate care facilities for persons with mental retardation, and chronic disease hospitals.

Table 7. Proportion of CT Medicaid LTC Clients: Monthly Average SFY 2003 and 2006<sup>45</sup>

	SFY 2003 Medicaid LTC clients	Percent distribution	SFY 2006 Medicaid LTC clients	Percent distribution	Percent change 2003-2006
<b>Home and Community Care</b>					
CT Home Care Program for Elders	8,794	23.16%	10,326	24.72%	17%
Personal Care Assistance Waiver	410	1.08%	555	1.33%	35%
Katie Becket Model Waiver	125	0.33%	160	0.38%	28%
Acquired Brain Injury Waiver	144	.038%	261	0.62%	81%
Mental Retardation Waivers <sup>46</sup>	5,857	15.43%	7,273	17.41%	24%
Targeted Case Management/ Mental Health	1,985	5.23%	2,765	6.62%	39%
<b>Home and Community Care Subtotal</b>	<b>17,315</b>	<b>45.60%</b>	<b>21,340</b>	<b>51.09%</b>	<b>23%</b>
<b>Institutional Care</b>					
Nursing Facility	19,373	51.02%	18,732	44.84%	(3%)
ICF/MR	981	2.58%	979	2.34%	0%
Chronic Disease Hospital	300	0.79%	722	1.73%	141%
<b>Institutional Subtotal</b>	<b>20,654</b>	<b>54.40%</b>	<b>20,433</b>	<b>48.91%</b>	<b>(1%)</b>
<b>Total LTC Clients</b>	<b>37,969</b>	<b>100%</b>	<b>41,773</b>	<b>100%</b>	<b>10%</b>

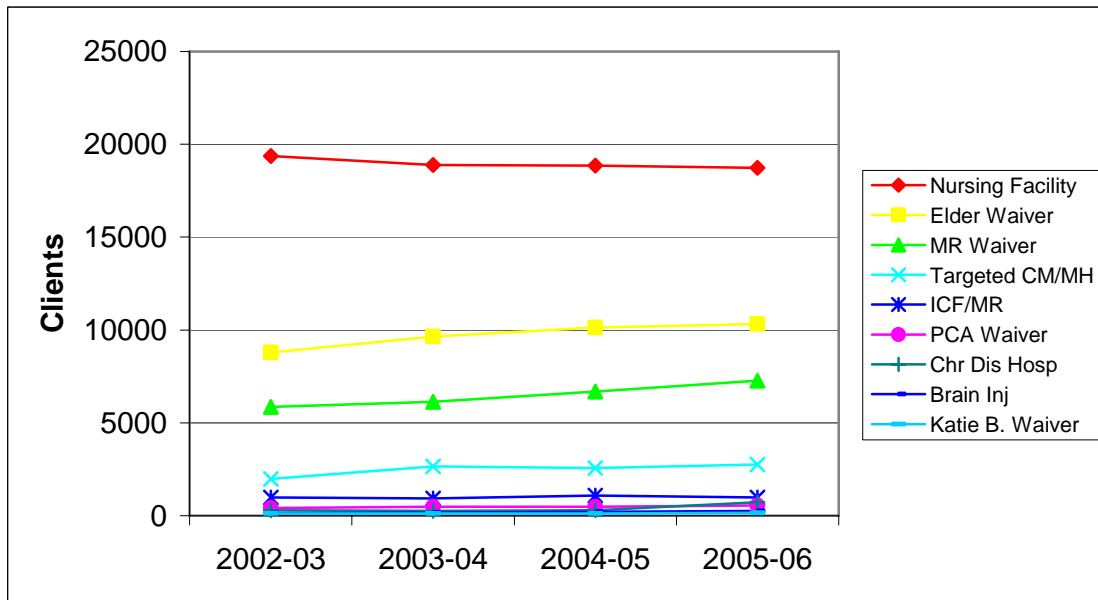
Source: Connecticut Office of Policy and Management

Figure 1 reflects the numbers of clients served in institutions including nursing homes, chronic disease hospitals and ICF/MRs, as well as those served under various waiver programs in Connecticut between 2002 and 2006. The number of individuals receiving services in nursing homes dropped over this time frame, while those served under the Elder, MR and targeted CM/MH waivers increased. The number of clients in ICF/MR and other settings remained relatively stable.

<sup>45</sup> Long-term care beds in the state psychiatric hospital are not included.

<sup>46</sup> In SFY 2006, this number comprises both the Comprehensive Waiver for Mental Retardation (4,890) and the Individual/Family Support Waiver for Mental Retardation (2,383).

Figure 1. CT Medicaid Long-term Care Clients 2002-2006



Breaking down Medicaid long-term care clients by age, Table 8 indicates that while about three-quarters of recipients are age 65 or older, that age group receives community-based services at a far lower rate than younger age groups. More than half of persons 65 and over receive institutional services, compared to a third of adults 22 to 64 and only six percent of those 21 and under.

Table 8. Type of Medicaid LTC Service by Age, 2006

	Number of recipients	Percent of people with HCBS services	Percent of people with institutional services
<b>Birth to 21</b>	548	94%	6%
<b>Age 22 to 64</b>	9,914	68%	32%
<b>Age 65+</b>	30,764	46%	54%

Source: Connecticut Department of Social Services, based on claims paid as of December 2006.

### Medicaid long-term care expenditures

- Between SFY 2003 and SFY 2005 the proportion of Medicaid long-term care expenditures received in the community increased by four percent, rising from 31 percent to 35 percent of all Medicaid long-term care expenditures.
- In SFY 2006, the proportion of Medicaid funds spent on community-based care dropped to 32 percent – a decrease primarily due to a significant Medicaid rate increase to

- nursing home providers in the fall of 2005. (It should be noted that the rate increase reflected the cost of the nursing facility provider tax that was imposed at the same time and used to finance a four percent rate increase for community providers.)
- Overall, total Medicaid long-term care expenditures increased by 16 percent between SFY 2003 and SFY 2006, from \$1.9B to \$2.2B (Table 9, Figure 2).
- In SFY 2006, Medicaid long-term care expenditures, both community-based and institutional, represented 14 percent of total state expenditures in Connecticut and 56 percent of total Medicaid expenditures.

Table 9. Proportion of CT Medicaid LTC Expenditures: Yearly Average SFY 2003 and 2006<sup>47</sup>

	SFY 2003 Medicaid LTC expenditures	Percent distribution	SFY 2006 Medicaid LTC expenditures	Percent distribution	Percent change 2003-2006
<b>Home and Community Care</b>					
Home Health Care <sup>48</sup>	\$108,824,193	5.68%	\$116,236,565	5.22%	7%
CT Home Care Program for Elders	\$75,790,031	3.96%	\$96,951,560	4.35%	28%
Personal Care Assistance Waiver	\$8,716,194	0.46%	\$13,539,732	0.61%	55%
Katie Becket Model Waiver	\$9,680	0.00%	\$14,297	0.00%	48%
Acquired Brain Injury Waiver	\$11,501,481	0.60%	\$24,182,363	1.09%	110%
Mental Retardation Waivers <sup>49</sup>	\$367,302,861	19.19%	\$420,338,318	18.87%	14%
Targeted Case Management	\$29,194,592	1.53%	\$30,906,934	1.39%	6%
<b>Home and Community Care Subtotal</b>	<b>\$601,339,032</b>	<b>31.41%</b>	<b>702,169,769</b>	<b>31.53%</b>	<b>17%</b>
<b>Institutional Care</b>					
Nursing Facility	\$1,023,182,228	53.45%	\$1,174,641,952	52.74%	15%
ICF/MR	\$227,496,382	11.88%	\$281,766,774	12.65%	24%
Chronic Disease Hospital	\$62,256,089	3.25%	\$68,658,647	3.08%	10%
<b>Institutional Subtotal</b>	<b>\$1,312,934,699</b>	<b>68.59%</b>	<b>\$1,525,067,373</b>	<b>68.47%</b>	<b>16%</b>
<b>Total LTC Expenditures</b>	<b>\$1,914,273,731</b>	<b>100%</b>	<b>\$2,227,237,142</b>	<b>100%</b>	<b>16%</b>

Source: Connecticut Office of Policy and Management

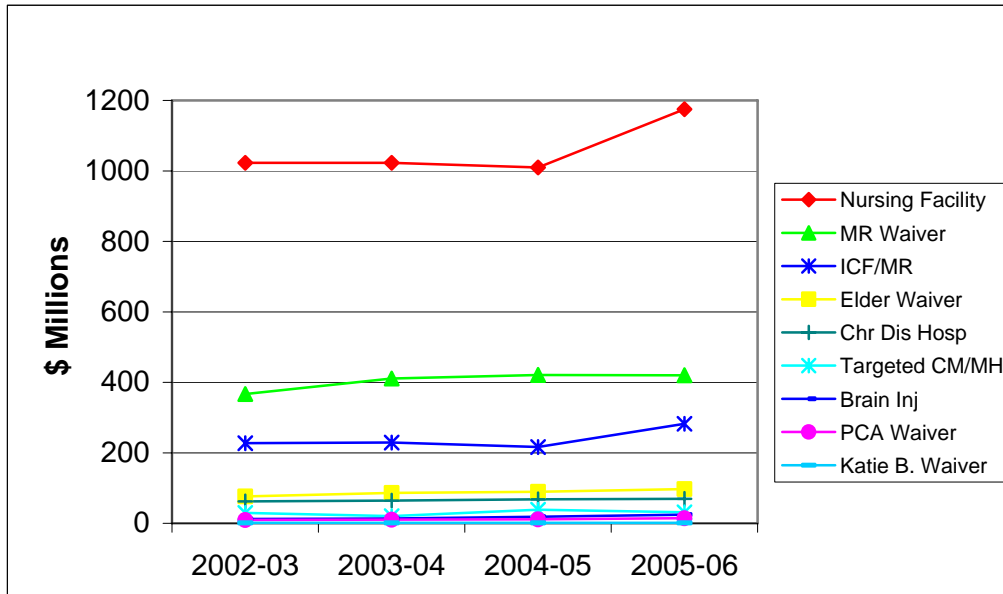
Figure 2 indicates the change in total long-term care expenditures during the time frame 2002-2006. ICF/MR expenditures rose substantially (24%) between 2002 and 2006, while nursing home expenditures grew by 15 percent. The biggest percentage increases in expenditures among the large home and community-based waiver programs were the elder waiver (28%) and the mental retardation waivers (14%). The smaller programs grew by greater amounts.

<sup>47</sup> The cost of long-term care beds in the state's psychiatric hospital is not included.

<sup>48</sup> Home health care expenditures are based on an estimate of the percentage of Medicaid recipients receiving long-term home health care as opposed to short-term care. It is estimated that long-term home health care services comprise 60% of total Medicaid home health care costs.

<sup>49</sup> In SFY 2006, this number comprises the State Waiver for Mental Retardation (\$345,452,683), the Comprehensive DMR Waiver (\$48,794,421) and the Individual/Family Support Waiver for Mental Retardation (\$26,091,214).

Figure 2. CT Medicaid LTC Expenditures 2002-2006



A breakdown of Medicaid long-term care expenditures by age (see Table 10) reveals significant differences by age. Roughly half of Medicaid long-term care expenditures for those 21 and under, and nearly two-thirds of expenditures for adults age 22 to 64 are for community-based services. By contrast, less than 20 percent of Medicaid long-term care expenditures for adults 65 and over are for community services. For all age groups, the average per client cost of community services is less than for institutional services. The difference is most pronounced for the youngest age group and least pronounced for adults 22 to 64. Part of the reason for the disparity is that Medicaid does not pay for items such as food, laundry, housekeeping and rent for HCBS clients, while those are generally covered for institutional clients.

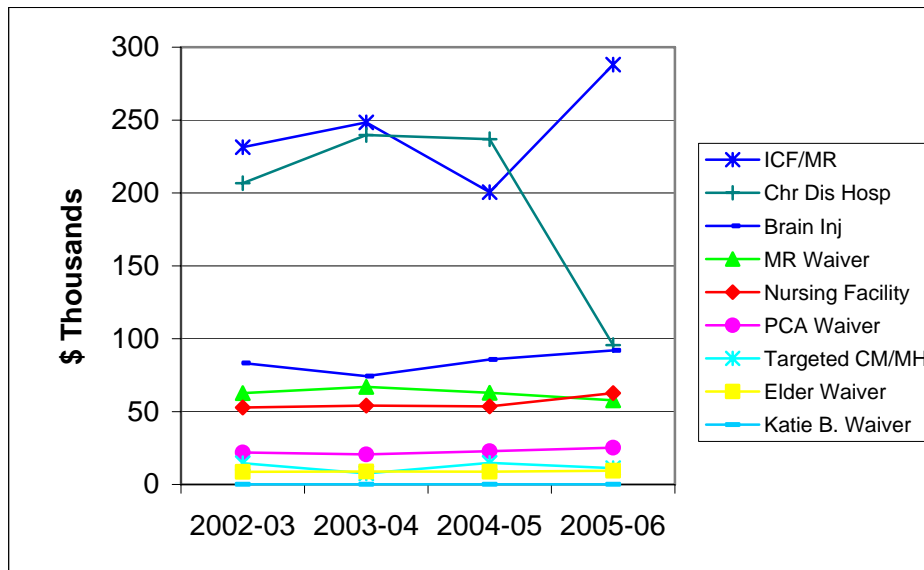
Table 10. Medicaid LTC Expenditures by Age, 2006

	Number of recipients	Percent of expenditures for HCBS services	Average monthly HCBS cost per client	Percent of expenditures for institutional services	Average monthly institutional cost per client
<b>Birth to 21</b>	548	52%	\$1,754	48%	\$27,247
<b>Age 22 to 64</b>	9,914	62%	\$5,551	38%	\$7,172
<b>Age 65+</b>	30,764	18%	\$1,352	82%	\$5,112

Source: Connecticut Department of Social Services, based on claims paid as of December 2006.

Figure 3 demonstrates the change in Medicaid cost per client for various institutions and waiver programs in Connecticut during the time frame 2002-2006. The cost per client for ICF/MR care is the most expensive, in part because it offers a more extensive array of services such as vocational supports, and it is trending higher. The per client expenditures for the Elder waiver are substantially less than those for the MR waiver (greater than a ten-fold difference).

Figure 3. CT Medicaid LTC Cost per Client Served, 2002-2006





## **II. System Assessment**

This section briefly profiles selected system functions, including access to long-term care services, the range of services available, the regulatory and quality assurance approaches, aspects of consumer direction, and data capacity.

### **A. Access to services<sup>50</sup>**

Connecticut was one of the earlier states to incorporate a comprehensive assessment model into the CHCPE program, and it was and remains demonstrably successful in diverting many older adults into supported community-based care. The current screening method for the CHCPE is a two-step process, with a “quick screen” at the DSS Alternate Care Unit, followed by referral to access agencies for a comprehensive in-home assessment. There are several problematic issues, however, with the screening process as it is currently conducted. There is no universal screening of all individuals regardless of age or payor source. Furthermore, the assessment is unique to nursing home admissions and does not apply to other care settings. Some people may be inappropriately turned away at the initial quick screen since it relies on self-reported functional deficits, which is a potentially faulty measure of actual deficits. In addition, the value of a two-step process is unclear.

Another issue related to effective screening concerns the role and duties of conservators. Until two years ago, Connecticut law did not require conservators to consider less restrictive settings when placing a ward in a nursing facility. In many cases people may have been inappropriately placed for reasons of expedience, ignorance, or over-concern for safety. There is currently a legislative effort to enhance conservator obligations in this area. Effective screening requires conservators and Probate Court judges to be fully conversant in home and community-based service options.

Even where people have the means, private or public, to pay for services, they still may struggle to receive them because of inadequate staffing. There is widespread inability of home care providers to staff care plans as ordered because of unfilled home health aide/homemaker positions and high staff turnover rates. Staff recruitment and retention have been significantly affected by 1) higher wage opportunities and vacancies in other service fields; 2) lack of health insurance and other employee benefits; 3) the physical and emotional challenges of the job; and 4) low social valuation of this essential work.

Also of relevance with respect to access are barriers faced by members of minority groups. Despite significant growth in the Hispanic population in Connecticut, many programs do not have the capacity to respond effectively to a person whose first language is Spanish, either through primary staff contact or through written material.

Most states have an Aging Disability Resource Center (ADRC), which provides information and referral regarding long-term care issues. Connecticut is one of the few states without an ADRC. While there are multiple models of ADRCs, one particularly appealing model that exists in some states provides an integrated, one-stop point of entry into the long-term care system, often called a “single point of entry” (SPE). A similar model is known as “no wrong door” (NWD). The vision of NWD is to have resource centers in every community serving as highly visible and

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<sup>50</sup> Discussion taken in part from Money Follows the Person Rebalancing Demonstration Proposal submitted to the Center for Medicare and Medicaid Services by the Connecticut Department of Social Services, November 1, 2006; and the Connecticut Long-Term Care Plan, January 2007.

trusted places where individuals can turn for information on the full range of long-term support options and entry to public long-term support programs and benefits. Connecticut has nothing comparable to the SPE or NWD. However, the state DSS, in partnership with the AAAs, operates the CHOICES<sup>51</sup> Program, which provides a “one-stop shopping” information source for services available to persons age 60 and older. The program makes referrals to appropriate agencies, which enables individuals to access needed services. The five AAAs provide direction to local service providers who can specifically address numerous problems or concerns that older persons and their families may be encountering.

In the absence of a formal ADRC with an SPE/NWD model, the CHOICES program could potentially be expanded to perform the role of a one-stop access center. It is already established statewide, serves older adults on a wide range of issues, and also assists younger adults with disabilities with issues related to Medicare. Such a model would require new expertise in responding to the needs of people with disabilities under age 60, perhaps with input from the current Independent Living Centers (ILCs). One difficulty to overcome is the common misperception in many state departments and legislative offices that CHOICES is limited to its original charge (Medicare counseling), rather than the expansive range of information and referral for older people that it has become.

The state’s recent “Money Follows the Person” (MFP) grant from the Center for Medicare and Medicaid Services also presents an opportunity to improve coordination and capacity between the AAAs and the ILCs as entry points. Both community-based organizations receive federal funding to provide information and referral regarding the long-term care system. The MFP will fund full time transition coordinators, provide technical assistance and support monthly collaborative sessions. The plan will create a stronger entry point with dedicated staff providing systems navigation to aid people in making their choice to move to the community through successful implementation of a care plan. Though this increased access is limited to those who are interested in transitioning out of a nursing home, the increased capacity and coordination between ILCs and AAAs has a broader application for the future development of a comprehensive SPE or NWD model.

At the Department of Mental Retardation, a new Single Point of Entry provides a centralized intake and eligibility determination process that gives Connecticut residents a consumer-oriented entry point to access DMR services. This ensures timely and consistent response to families. Regional case managers who previously performed this function have returned to case management providing more service coordination for people at home. The system offers English and Spanish speaking capacity.

In addition, for consumers and family members with access to the Internet, Connecticut offers a wide range of information on long-term care. DSS, the Connecticut Commission on Aging, and the five AAAs, among others, maintain websites with information about long-term care or links to other sites. In particular, the Connecticut Long-Term Care Services and Supports website was completed and released to the public in 2006 ([www.ct.gov/longtermcare](http://www.ct.gov/longtermcare)). The goal was to develop a website that provides easy access to comprehensive information on private and public long-term care services and supports in Connecticut, including home care, community care, housing and institutional/ nursing home care. The website provides information to all individuals in need of long-term care services and supports, regardless of age or disability. It is the lack of such information that was cited by respondents to the Connecticut Long-Term Care

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<sup>51</sup> Connecticut’s program for Health insurance assistance, Outreach, Information and referral, Counseling, and Eligibility screening.

Needs Assessment as the number two reason for not getting the services they need, and this is an area in need of improvement.

## **B. Array of services**

Connecticut has a wide array of long-term care services available for those who can afford them, but it is quite constrained for low-income clientele. For those who cannot afford to purchase services, Medicaid and its state waiver programs provide some assistance. However, the waivers are limited and not well coordinated to serve the entire population in need. Many potential clients are currently experiencing waiting lists for some waiver programs.

The state's case management model for long-term care services under the CHCPE has strengths and weaknesses. Many consider a major strength to be that case management is performed by neutral access agencies and not by potentially self-interested home care agencies.<sup>52</sup> Case management obligations are strictly regulated by DSS, providing safeguards for clients that support consumer preference. In addition, access agencies can take a global look at a complete care plan that includes not only home health services but meals, transportation, emergency response, etc. On the other hand, home health agencies have argued that it would save money and recognize what they do for their clients to pay them directly for care management.

While the state's case management model for the CHCPE is rich and professionally oriented, combined with professionally oriented home health care it is a very expensive model. Home health services in Connecticut in general are dominated by nursing services and supervision. Even homemaker services must be under the supervision of a registered nurse. Though case management is not the preferred model for younger adults with disabilities, there remains some demand for such services among this population. For example, the Multiple Sclerosis Society has led efforts in recent legislative sessions to create a pilot for people ages 18-64 so that they can receive services that mirror the CHCPE, primarily due to the benefits of case management.

## **C. Consumer direction<sup>53</sup>**

The terminology regarding "consumer self-direction" in Connecticut encompasses two distinct concepts. The first is the commonly-understood definition employed in other states, whereby consumers truly direct their own services and supports. Connecticut's HCBS waiver programs provide a number of opportunities for this type of self-direction. A brief description of these opportunities follows:

- **PCA Waiver:** Participants hire and manage their own PCA staff with a fiscal intermediary who administers the PCA's payroll; the consumer establishes salary within budget caps. Training on managing PCAs is available for consumers.
- **ABI Waiver:** Participants or their conservators hire and manage their own PCA staff just as in the PCA program. Participants are responsible for managing up to 20 additional home

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<sup>52</sup> For those self-directing care with DMR funding, there is little or no case management oversight by a neutral access agency.

<sup>53</sup> A portion of this discussion taken from the Money Follows the Person Rebalancing Demonstration Proposal submitted to the Center for Medicare and Medicaid Services by the Connecticut Department of Social Services, November 1, 2006.

and community supports, depending on their level of need. Services are determined with the individual, a neuropsychologist, social worker and consumer-designated circle of support.

- **DMR Waivers:** Waivers permit consumers to hire people directly for many services, such as supported living and employment, respite, personal care, etc. Participants are provided with a fiscal limit where they can choose services in their customized package. DMR does not tell participants what services they can have and in what amounts as long as it stays within the budget limit and basic health and welfare needs are met. The DMR self-direction process and quality system are highlighted in more detail in Section III below.

For those choosing to receiving home health care, Connecticut regulations can make it difficult to achieve true consumer direction. Public Health Code regulations concerning homemaker home health aide agencies require supervision by a registered nurse or other professional as determined by the nurse (Connecticut Department of Public Health, 2006d). This prohibition on delegated activities contributes to a highly professionalized and licensed workforce, but inhibits consumer direction.

A second, less-common notion of consumer direction is used in connection with the CHCPE. In this instance, consumer direction refers to care without a care manager but still in the hands of an agency provider. This usage is a distortion of the usual meaning and has added some confusion in discussions of self-direction.

- **CHCPE:** The elder participant undergoes a holistic assessment conducted by a professional to identify unmet needs and recommend supports. Whenever possible, the person is regarded as “self-directed” and is empowered to make adjustments in the frequency, duration and intensity of their services without prior approval. However, care is still delivered via agency staff. Connecticut has also offered a small group of 250 older adults the option of self-directing personal care assistance which mirrors the PCA and ABI Waivers. During the 2007 legislative session, the cap of 250 was eliminated.

#### **D. Regulation and quality approaches**

##### ***Regulatory oversight: system components***

Most long-term care providers are regulated, including nursing homes, home health agencies, and assisted living service agencies. The regulatory programs are administered by the Health Care Systems Branch within DPH, in accordance with federal standards issued by CMS. The DPH Health Care Systems branch regulates access to the health care professions and provides regulatory oversight of health care facilities and services. There are three major sections: facility licensing and investigations, practitioner licensing and investigations and a legal office. The DPH has authority to investigate complaints and take disciplinary action against providers found to have violated the law or otherwise pose a risk to public health and safety. The regulation of intermediate care facilities for persons with a diagnosis of mental retardation is shared between DPH (which carries out the federal certification for ICF/MR facilities) and the Department of Mental Retardation (which administers the licensure program).

## Nursing homes

Nursing homes participating in the Medicare or Medicaid programs are inspected approximately once a year. A standard inspection involves a team of state surveyors spending several days on site in the nursing home to evaluate compliance with federal long-term care facility requirements defined by CMS. Surveyors determine whether adequate care and services are being provided to meet residents' needs and whether the home is providing adequate quality care (GAO, 2003). Though CMS establishes specific protocols, states have the primary responsibility for conducting the on-site inspections and recommending plans of correction for nursing homes providing a poor quality of care.

The DPH licenses two categories of nursing facilities in Connecticut -- (1) chronic and convalescent nursing homes (CCNH) for skilled or rehabilitative care, and (2) rest homes with nursing supervision (RHNS) for custodial care. DPH surveyors are highly trained and develop expertise in these categories: nursing homes, home health/assisted living and residential care. The nursing home unit is the largest and most active, with 42 nurses and 6 supervisors. The majority of surveyors (71%) have more than 2 years of experience, and for RN surveyors a minimum of 4 years of nursing experience is required, which is higher than most states (GAO, 2003). Predictability of individual facility surveys is addressed in federal regulations. In Connecticut, in 2002, about 30 percent had predictable surveys, and 16 percent were surveyed within 15 days of prior year anniversary (GAO, 2003).

Waivers to the regulations are granted on a case by case basis by a committee established within DPH. The nursing home submits a request for a waiver, presenting the rationale and any alternatives in place to protect the resident's health, welfare and safety. Most requests have to do with the physical plant and its operations. Most requests are granted, and the review process typically takes four to six weeks (University of Minnesota School of Public Health, 2007; Connecticut Department of Public Health, 2006b).

## Assisted living

Connecticut has had licensed assisted living services agencies (ALSAs) since 1994, in accordance with regulations administered by DPH. The regulations address service agencies rather than licensing both a building and services as a single entity. Managed residential communities (MRCs) may offer assisted living through ALSAs. MRCs are not regulated by DPH, though they must meet local zoning ordinances and building codes. (Mollica, 2002). Residents receiving ALSA services must have chronic and stable conditions as determined by a physician or health care practitioner at least on an annual basis and as needed. Chronic and stable conditions are not limited to medical or physical conditions, but also include chronic and stable mental health and cognitive conditions. Each ALSA agency develops its own admission criteria but the regulations do not allow the ALSAs to impose unreasonable restrictions and screen out people whose needs may be met by the ALSA.

As is the case nationally, one major challenge in assisted living in Connecticut is balancing the residents' preference to remain living in their home even in the face of declining physical or cognitive functioning that may threaten their own health and safety or that of other residents. Increasingly, residents in assisted living have more complex needs that may be difficult to meet adequately with available services and supports. Connecticut regulations do not provide guidance on how best to balance resident autonomy with protecting the well-being of other residents. A related area of concern is the great variability in the types of residency agreements between the ALSA and the resident. A resident agreement is developed on admission and

includes: basic and additional services provided, costs to the resident for these services, provisions for payment and rate changes, criteria for admission, resident's rights to participate in service planning; and aging in place policies including circumstances for discharge. Despite the requirement for such agreements, admission and continued stay criteria are often not clear to residents, presenting further challenges to negotiating transitions when they may need to occur (Mollica, 2002).

Regulations for ALSAs specify minimum numbers of nursing and aide staff (at least one RN in addition to an on-site supervisor whose hours are determined by the number of nurses or assisted living aides providing services). All aides must be certified nurse aides or home health aides and must complete 10 hours of orientation and one hour of in-service training every two months. An RN must be available on-call, 24-hours a day. ALSAs are required to establish a quality assurance committee to conduct ongoing review of the agency's policies including assessment and referral criteria, data systems, evaluation of client satisfaction, standards of care, and professional issues relating to the delivery of services. The committee submits annual reports to the ALSA summarizing findings and recommendations. The report and actions taken to implement recommendations are made available to the state Department of Public Health. Agencies are inspected biennially. Penalties include revocation, suspension, or censure; letter of reprimand; probation; a restriction on acquisition of other entities; a consent order compelling compliance; and civil monetary penalties. (Connecticut Department of Public Health, 2006a).

### Residential care homes

Adult Residential Care Homes are also known as Rest Homes or Homes for the Aged in Connecticut. The Connecticut Department of Public Health licenses all residential care homes in Connecticut, pursuant to Public Health Code section 19-13-D6. (Connecticut Department of Public Health, 2006e). State law requires that residential care homes provide three meals per day, housekeeping and laundry services, recreational activities, 24 hour supervision and emergency services. Some homes, which are part of extended care facilities, may have a nurse available; other facilities may assist residents in arranging for community-based nursing services when necessary. The regulations address: a) physical plant specifications for resident rooms, baths, common areas, dietary and laundry facilities, b) administrator licensure requirements, c) mandatory services such as physician services in case of illness, d) attendant/resident staff ratio (minimum of one attendant for each 25 residents), e) staff training regarding resident rights, behavioral management, personal care, nutrition, safety, and f) medication administration requirements for non-prescription topical medications, with additional requirements for administration of all other types of medication.

### Adult day centers

The Connecticut Association of Adult Day Centers is authorized by DSS to conduct and administer a program of peer review and certification. This certification is required for programs to qualify to receive state funding under the Connecticut Home Care Program (centers not receiving any state funding are not required to be certified). Requirements for certification are specified in DSS agency regulations (Regulations of Connecticut State Agencies, 2006). The Connecticut Association of Adult Day Centers, Inc. is a statewide organization of proprietary and not-for-profit adult day providers. CAADC is a non-profit corporation, and represents nearly all the adult day centers in Connecticut.

The regulations address the following: a) physical space requirements for zoning, licensing, sanitation, fire and safety; b) mandatory personnel to provide administration, nursing and social work consultation services, dietary services, personal care services, recreational therapy, and transportation services; c) direct care staff/client ratio (a minimum of one staff member for every seven clients); and d) specifications for staff training and recordkeeping. Programs seeking to qualify as a medical model of adult day health must meet additional requirements, such as nursing services for medication administration, advanced training for direct care staff individual therapeutic and rehabilitation services such as physical therapy, occupational therapy and speech therapy.

### Intermediate care facilities for people with mental retardation

Regulation of the intermediate care facilities for people with mental retardation is complex and is shared between DPH and DMR. There are seven ICF/MR locations across the state (including Southbury Training School) and sixty-nine privately owned and operated group homes serving approximately 1,163 people over the age of 18. The licensing of group homes is administered by DMR, while DPH oversees the regulations contained in the Code of Federal Regulations, section 483.400 – 483.480, Conditions of Participation for Intermediate Care Facilities for the Mentally Retarded. These regulations establish the minimum health and safety requirements that ICF/MR providers must meet in order to participate in the Medicare and Medicaid programs. The health and safety requirements address topics such as the provider's governing body, client protections, facility staffing, facility environment, and services provided.

### Home health care agencies

Home health care agencies are also regulated by the DPH. These agencies provide professional nursing services and other related services including: homemaker-home health services, physical, occupational or speech therapy, or medical social services. Agencies are required to be available to enroll new clients and to provide services seven days a week, twenty-four hours per day in the client's home or similar setting. The DPH surveyor team is very active, monitoring home care as well as assisted living services. There are 5 staff nurses and a nursing supervisor.

In addition, CMS develops conditions of participation and coverage that agencies must meet in order to begin and continue participating in the Medicare and Medicaid programs. These minimum health and safety standards are the foundation for improving quality and protecting the health and safety of beneficiaries. The conditions address a wide range of organizational and programmatic components, for example, client rights, comprehensive assessment, types of services and personnel qualifications, records and reporting through OASIS and compliance with state and local laws (Connecticut Department of Public Health, 2006c).

### ***Quality of care issues***

There is no single agency or set of regulations or guidelines that define overarching quality of care for individuals using long-term care services, regardless of care setting. Rather, quality assurance is idiosyncratic in nature, developed within the context of a specific care setting. The nursing home industry is far more heavily regulated than most home and community-based services, and there is no similar level of oversight designed to ensure that home care recipients are getting high quality care. Quality measures are not explicitly tied to individual outcomes and preferences across settings. The following section describes various quality initiatives within the

range of care settings; some are supported and coordinated through state agencies (such as DPH) and others through ombudsman offices.

Nursing home quality of care is evaluated and monitored through systems developed by CMS and implemented by DPH. Results of DPH inspections are compiled and reported through the On-Line Survey, Certification, and Reporting system (OSCAR). Pursuant to CMS guidelines, quality is also measured and tracked using national chronic and post acute care quality indicators such as decline in activities of daily living, pressure sores, infections, and rehospitalization rates. These quality indicators are based on nursing home resident assessment information (data on each resident that homes are required to report periodically to CMS). Quality indicators are derived from nursing homes' assessments of residents and are used to rank a facility in 24 areas compared with other nursing homes in the state. Connecticut nursing homes are included in CMS' Nursing Home Compare website intended to make standard quality information available to the general public. There is no quality improvement section within DPH, such as exists in Washington or Florida, to assist nursing homes with quality improvement initiatives.

Complaints regarding quality of care in nursing homes may be filed by nursing home residents, family members or nursing home employees. The proportion of nursing homes cited for actual harm or immediate jeopardy has declined nationally from 29 percent to 20 percent since mid-2000. However, in 2002, Connecticut had the highest rate of nursing homes with deficiencies for actual harm or immediate jeopardy of residents in 2002, at 49% as compared to a rate of 7% in Wisconsin (GAO, 2003). It is not clear whether these significant variations are due to actual higher rates of substandard care, more active enforcement by certain states' surveyors, or inconsistencies in the definition of "actual harm" and "immediate jeopardy." Connecticut officials said that the growing volume of complaints, combined with limited resources, is a concern. Connecticut indicated that 90 percent of the complaints it receives allege actual harm and require investigation within 10 days, but that with fairly stagnant budget allocations from CMS, its ability to initiate investigations of so many complaints within 10 days was limited. In 2001, CMS's state performance review found that Connecticut did not investigate about 30 percent of actual harm complaints in a timely manner (GAO, 2003).

#### Enhancing quality through culture change in nursing homes

Culture change in nursing homes refers to the process of transforming a traditionally institutional approach to nursing home care into one that is home-like and person-directed. There are a number of national and state level culture change initiatives underway, including the "green house" model, the Eden alternative and others.

Early evaluations of these models show positive outcomes being self-reported in staff turnover, resident and family satisfaction, census, and clinical outcomes. While providers and advocates often report that state nursing home regulations impede progress in culture change, there is no evidence to show whether and how regulations either impede or may in fact serve to foster desirable nursing home culture change (University of Minnesota School of Public Health, 2007). Advocates and experts include coalitions such as the Nursing Home Pioneer Network, the National Citizen's Coalition for Nursing Home Reform and the Connecticut Breaking the Bonds Coalition. CMS is supportive of many aspects of culture change, and recently issued a lengthy memorandum intended to clarify interpretations of regulatory compliance in the context of a wide range of culture change practices (CMS, 2007). In Connecticut, DPH reports that there appears to be growing interest among nursing home providers in culture change efforts. They have had an increase in requests for waivers, for example a recent request to waive the



requirement for three feet surrounding a resident's bed. They indicate that the Public Health Code does have flexibility within it, and the DPH can exercise discretion to enable change efforts provided they do not pose a risk to residents.

### Long-Term Care Ombudsman Program (LTCOP)

The Connecticut LTCOP is an independent program structurally located under the umbrella of DSS, with the state Ombudsman reporting directly to the Commissioner of DSS. The state Ombudsman has complete responsibility over the program's administration, operation, budget, and oversees all employees associated with the program. It was established by Congress by the Older Americans Act (OAA) of 1965 with a federal mandate requiring all states to create and develop ombudsman programs in order to address the poor quality of care found within long-term care settings and to address specific shortcomings of the nursing home regulatory system. The 1992 amendments to the OAA facilitated an important shift in philosophy and focus, calling for the LTCOP to become a more resident-centered program, to provide advocacy services, and to become a community presence within long-term care settings. Currently the OAA stipulates that the LTCOP must identify, investigate, and resolve individual and systems-level grievances of those residing in long-term care facilities including residential care homes, skilled nursing and assisted living facilities. Though primary responsibilities include investigating and resolving complaints made by constituents, ombudsmen are also responsible for educating residents and families about their rights, providing information and resources regarding various long-term care services, as well as lobbying for program initiatives in state and federal government forums.

Ombudsman responsibilities include: 1) receiving, investigating, and resolving complaints made by or on behalf of residents in long-term care facilities (Chelimsky 1991; Netting, Paton, and Huber 1992), 2) bringing residents to the forefront to voice their concerns directly to public officials on issues affecting their lives and 3) supporting residents in shaping their own legislative agenda. In Connecticut the LTCOP also administers the Volunteer Resident Advocate Program in which community volunteers are trained by Ombudsman staff in resident's rights, problem solving, interviewing skills, negotiating, working with nursing home staff, and the health care system (Connecticut LTC Ombudsman program, 2007).

### Independent Office of the Ombudsperson for Persons with Mental Retardation

The Independent Office of the Ombudsperson for Mental Retardation works on behalf of consumers and their families. The office addresses complaints or problems regarding access to services or equity in treatment and provides information regarding rights and methods of dispute resolution concerning consumers and/or their families. Concerns include dissatisfaction with placement, waiting list issues, comprehensive waivers, and other quality of care and access issues. The nature and resolution of complaints are communicated to the Mental Retardation Council, the state General Assembly and the DMR Commissioner in order to better direct the resources of the department and to improve service to our consumers and/or their families. The Office of the Ombudsperson addressed over 520 issues involving complaints or concerns regarding the DMR for calendar year 2005, an increase of 17% from 2004 (Independent Office of the Ombudsperson, 2007).

## Quality issues for Medicaid waivers<sup>54</sup>

The DSS Medical Care Administration is responsible to assure that the waivers meet the federal requirements and expectations for the quality operation of the HCBS waivers in the state. DSS has had in place a long-standing system of quality assurance to address service planning, service delivery, health and welfare, participant rights and safeguards and financial accountability for service delivered by providers. The waiver programs are at varying levels of transition between the traditional quality system and the newer quality framework. With the current expansion of multiple waiver programs in the state, DSS is in the process of reassessing all waiver programs with respect to the quality framework.

All waiver programs reflect a values-driven approach to quality designed to assure that individual participants achieve meaningful personal outcomes, have the supports necessary to make choices, informed decisions, experience community opportunities and individual relationships, benefit from system safeguards and experience satisfaction with their services, supports and desired lifestyle.

### **E. Data capacity**

Information technology is inextricably linked to quality management and to improving access to services and streamlining eligibility. Connecticut considers it essential to develop state of the art information technology, with an automated system to collect, warehouse, analyze, and report information to guide program development and monitor quality.

DSS houses the Information Technology Services (ITS) Division. The ITS Division has two distinct sections, Information Technology Technical Services and Support Services. ITS manages two major mainframe computer systems—the Eligibility Management System (EMS) and the Connecticut Child Support Enforcement System (CCSES). The EMS system provides fully integrated data processing support for the determination of client eligibility, benefit calculation and issuance, financial accounting, and management reporting. EMS supports many of the agency’s major programs such as Temporary Family Assistance (TFA), Medical Assistance (Medicaid and State Medical Assistance), Food Stamp, State Supplement to the Aged, Blind, and Disabled, and the State Administered General Assistance (SAGA) and Refugee Assistance Cash and Medical assistance programs. EMS also supports the Managed Care Program and the TFA Diversion Program. A separate Medicaid Management Information System (MMIS) is also located within DSS, and requests for MMIS data must be submitted to DSS.

Many other agencies, bureaus and departments have developed elaborate database systems that operate separate and removed from DSS. Further, many private providers have invested heavily in platforms that allow for sophisticated data collection techniques. However, the autonomous development of these myriad systems has resulted in extremely limited cross-fertilization of data within and between agencies.

Web-based technology for the purpose of collecting information relating to plan of care, service delivery, and case information is currently used in a very limited fashion in the state system. One extremely promising endeavor, funded through a CMS QA/QI grant is the Department of

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<sup>54</sup> Money Follows the Person Rebalancing Demonstration Proposal submitted to the Center for Medicare and Medicaid Services by the Connecticut Department of Social Services, November 1, 2006.

Mental Retardation’s quality management system which systemically addresses all outcomes identified in the HCBS Quality Framework. Key areas of interest include: access, service planning and delivery, safeguards, rights, outcomes and satisfaction, and system performance. The goal is to have a flow of information between DMR, providers, case managers, clients, and families. See discussion in Section III below.

Another promising initiative is a data capacity-building and systems integration initiative currently being funded under Connecticut’s Medicaid Infrastructure Grant. Though still in the analysis stage, it appears that the primary change would be the development of a federated data network that can draw from several different agency databases without compromising individual privacy/confidentiality and without disrupting existing agency business practices. Numerous state agencies, including DSS, DMHAS, DMR, DCF, and DOL, in conjunction with the state’s Office of Workforce Competitiveness, are currently discussing methods of data sharing that will allow analysis of client demographics, service patterns, and outcome data to determine program effectiveness, aid in policy analysis, and support continuous improvement. Proposed data sharing would also enhance direct service provision, and could include the sharing of client characteristic and case histories, as well as information on past and current service provision to the client.

Once legal and confidentiality hurdles have been overcome, the major task for the planned implementation stage will be to design and build the kind of system that can provide both the data needed for frontline case managers and other staff who deal with clients, and the insight needed for policymakers and planners.

**F. Links to and availability of housing**

***Community housing options<sup>55</sup>***

A number of housing options with long-term care supports are available in Connecticut, allowing individuals with long-term care needs the opportunity to avoid entering an institution. The community housing options in table 11 provide some common meals, housekeeping, and some degree of personal services, but vary with respect to the extent and range of services and staffing provided, the types of accommodations available, and requirements for residency.

Table 11. Community Housing Options in Connecticut, June 30, 2006

	<b>Facilities</b>	<b>Units, beds, or residents</b>	<b>Age</b>
State-funded congregate housing	23	951 residents	62 and older
Assisted living	109	(not available)	Adults
Residential care homes	102	2,826 units	Adults
Continuing care retirement communities	17	3,200 units	Older adults

<sup>55</sup> Based in part on Connecticut Long-Term Care Plan, January 2007.

Housing options for those transitioning from or wishing to avoiding institutional placement, however, can be limited, particularly for those with few financial resources. Some waiver options are capped. Connecticut does have a number of innovative pilots and means of providing assistance outside of institutional settings. These are described more fully in Section III.

## **G. Links to mental health care**

Long-term care for people with mental illness is provided through a variety of public and private programs. Historically, the state provided psychiatric inpatient services at three state hospitals with more than 9,000 beds. During the 1960s and 1970s, improved medications, federal court rulings acknowledging rights to less restrictive settings, and changing Medicaid policies resulted in the transition of most people from institutional settings to community-based care.

Two of the three state psychiatric hospitals closed in the mid-1990s, and today only Connecticut Valley Hospital (CVH), operated by DMHAS, provides care for long-term psychiatric residents. CVH currently has 170 beds for mental health in addition to beds designated for substance abuse and forensic cases. Four other facilities operated by DMHAS and four private psychiatric facilities located throughout the state provide only acute and intermediate care. Every other general hospital in Connecticut also has psychiatric beds for acute care.

DMHAS provides community psychiatric rehabilitation services, including case management and vocational services, through 15 Local Mental Health Authorities (LMHAs) throughout the state. These provide a broad range of therapeutic programs and crisis intervention services. Private and non-profit agencies can also be accessed through each of the LMHAs, which are located in each of five regions. DMHAS operates under the principle that people with mental illness should receive services in community settings, and that inpatient treatment should be used only when absolutely necessary to meet a person's best interests.<sup>56</sup> Approximately 5,000 people with mental illness receive psychiatric visiting nurse services, primarily for medication management, under the state's Medicaid plan, at a cost of about \$60 million per year.<sup>57</sup>

Private mental health services have also undergone a transformation with changes in managed care, provider incentives, and mental health coverage. Connecticut passed a law in 1999 requiring private health insurance plans to cover mental health disorders in the same manner as physical disorders, with some exceptions.

Through its Mental Health Transformation Grant, Connecticut completed a needs assessment and comprehensive state mental health plan in September 2006.<sup>58</sup> The plan aims to transform mental health services to a recovery-oriented system of care that will offer citizens meaningful choices from an array of services.

A new Medicaid waiver is under development for this population, the Medicaid Home and Community-based Services (HCBS) Program for Adults with Severe and Persistent Psychiatric

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<sup>56</sup> A Comprehensive Mental Health Plan for the State of Connecticut, September 2006, available at <http://www.ct.gov/DMHAS/site/default.asp>.

<sup>57</sup> Source: Connecticut Association for Home Care, Inc.

<sup>58</sup> A Comprehensive Mental Health Plan for the State of Connecticut, September 2006, available at <http://www.ct.gov/DMHAS/site/default.asp>.

Disabilities who are discharged or diverted from nursing home residential care. This waiver is expected to be operational in 2008.

To eliminate the major gaps and barriers that exist in the behavioral health delivery system for children, adolescents and families with behavioral health challenges who rely on public funding, DCF and DSS in 2006 formed the Behavioral Health Partnership (BHP). The BHP is designed to provide enhanced access to and coordination of a more complete and effective system of community-based behavioral health services and supports and to improve individual outcomes. It links medical, social, educational and other services with a variety of psychiatric home-based rehabilitation and emergency benefits.

#### **H. Links to primary/acute care**

Connecticut currently has no state-wide integrated program for delivery of acute and long-term care. It lacks a PACE program (Program of All-Inclusive Care for the Elderly), which in many states serves as a comprehensive service delivery system of acute and long-term care services. There are, however, two demonstration projects that have been in place since 2004 that allow chronic disease hospitals to operate long-term acute care hospitals (LTACHs) or satellite facilities. The purpose of these demonstration projects is to enable a study of service quality, patient outcomes and cost effectiveness for medically complex patients in need of long-term hospitalization within an acute care setting. (Office of Health Care Access, 2007). A preliminary evaluation in 2007 concluded that while there was insufficient data to measure acute care discharges and intensive care days, there were significant savings associated with transferring eligible patients to LTACHs, and varying levels of improved clinical outcomes. (Office of Health Care Access, 2007).

In Connecticut, as in many states, one issue for Medicaid recipients is the difficulty of finding access to primary care because many providers decline to accept new Medicaid patients due to low reimbursement rates. The issue is particularly acute with respect to behavioral health, dental care, and podiatry.

### **III. Featured Management Approaches**

This section highlights three strategies employed in Connecticut that are deemed helpful in facilitating rebalancing between institutional and home and community-based care. It also describes the Connecticut Partnership for Long-Term Care, an innovative means of encouraging citizens to protect their assets through long-term care insurance while saving the state Medicaid long-term care costs.

#### **A. Nursing home transition/Money follows the person**

Connecticut received a 3-year \$800,000 Nursing Facility Transition Grant from CMS in 2001 to help transition individuals out of nursing homes and back to the community. Through the efforts of the grant staff, 101 people were transitioned from residing in a nursing home to the community between 2002 and 2005. The project was estimated to save nearly \$2.8 million annually in Medicaid nursing home expenditures, and the average daily saving per person after transition was \$95.90 per day. These results were so compelling that after the grant ended, the governor requested state funds to continue the project. The General Assembly appropriated \$267,000 in state funds for SFY 2006 and \$375,000 in SFY 2007 to support the transition of individuals wishing to move from a nursing home to the community. These appropriations funded transition coordinators and a project manager, as well as additional PCA waiver slots for home and community-based services.

Two keys to the project's success were: a governing committee and infrastructure with the proper knowledge, authority and robust stakeholder communication; and an independent evaluation process. The project involved key policy and budget decision makers in both the design and implementation phases. The evaluation aided project staff in understanding both how consumer characteristics affected the transition process and the amount of time and assistance required to help people make successful transitions. The evaluation also measured consumer satisfaction and tracked the progress of transitioned persons over time. It identified characteristics of consumers that either facilitated or delayed successful transitions.

Partly as a result of the success of the nursing facility transition program under the CMS waiver and as a state-funded project, in January 2007, Connecticut was awarded a \$24.2 million five-year grant from CMS to participate in the Money Follows the Person (MFP) Rebalancing Demonstration. Under this program, Medicaid funding is allowed to follow Medicaid eligible individuals living in a nursing home or other institution as they move out to live in the community and receive community-based services. The MFP grant aims to assist states in rebalancing their long-term care systems. A primary goal is to transition 700 individuals over the five-year period.

The lead agency for Connecticut's MFP will be DSS. The state plans to operate the MFP through a team approach involving nearly all units of the DSS reflecting the high level of coordination and collaboration needed for successful implementation. Connecticut has essential components in place to implement the MFP demonstration including a strong transition program, flexible funding, a rebalancing goal, quality management, strong involvement of stakeholders and an excellent foundation of HCBS. Building on this strong foundation, Connecticut plans to enhance what already exists. Connecticut will address service gaps such as housing, assistive technology and information, and provide broader choices for persons who would like to receive long-term care in the community.

## **B. Housing/Assisted living pilot programs**

Connecticut has developed a number of innovative housing options for persons with various long-term care needs.

### ***Expanded assisted living options***

Over the past several years, DECD, DSS, OPM, and the Connecticut Housing Finance Authority have been developing the Assisted Living Demonstration Project, which, when fully operational, will provide 224 subsidized assisted living units in four communities. The first units became available in Glastonbury in 2004. Since then, the projects in Hartford, Middletown and Seymour have all been completed and are being occupied by clients of the CHCPE.

In addition to the Assisted Living Demonstration Project, assisted living options have been extended to state-funded congregate housing, federally-financed Housing and Urban Development (HUD) complexes and private pay assisted living facilities, described below.

### ***Congregate housing***

Beginning in 2001, DECD and DSS introduced assisted living services within state-funded congregate housing facilities. Fifteen of the 23 congregate facilities are participating in this service expansion. As of February 2007, 165 congregate housing residents were actively enrolled in the assisted living program. From when the program was implemented in May 2001, to February 2007, a total of 526 residents have received assisted living services through the program.

The development by DECD of 95 new congregate units with enhanced core services and the option to provide assisted living services is currently underway. These new units, which are expected to be completed within the next three years, will be built in Bridgeport, Waterbury and New Haven.

### ***HUD complexes***

In addition to congregate settings, assisted living services are also being offered in four federally financed HUD complexes in Hartford, New Haven and Mansfield. As of February 2007, 203 residents in the four HUD facilities were actively receiving assisted living services. From when the program was implemented in May 2001, to February 2007, a total of 395 residents have received assisted living services in federally financed HUD complexes.

### ***Private pay assisted living pilot***

In August of 2002 the General Assembly authorized the development of two private pay assisted living pilot programs to help residents in private pay assisted living facilities avoid entrance to a nursing home once they have exhausted their personal resources. There was a 50-person Medicaid pilot and a 25-person state-funded pilot through the CHCPE. Subsequent to the program beginning implementation, the General Assembly combined the two pilots so that there is one pilot that can accommodate up to 75 clients of the CHCPE, regardless of whether they are Medicaid or state-funded.

The pilot allows persons residing in private pay assisted living facilities to receive support from Medicaid or the state-funded component of the CHCPE, for their assisted living services once

they have exhausted their resources. While the pilot will not pay for any room and board charges, it will help subsidize the costs for services, which may help residents to meet the overall cost of staying in their assisted living apartments. From time to time there have been legislative proposals addressing the issue that Medicaid funds cannot be used to pay for room and board. One solution would allow SSI funds to be used for these costs, but there has been no change to date.

The pilots began implementation in January 2003. As of February 2007, 67 individuals were receiving services under the pilots, with an additional 90 individuals having applied for the program.

### **C. DMR quality system<sup>59</sup>**

DMR has had in place a long-standing system of quality assurance to address service planning, service delivery, health and welfare, participant rights and safeguards, and financial accountability for services delivered by licensed residential providers, and contracted supported living, facility day services, and supported employment services to all individuals supported by DMR. With the expansion of the DMR service system to include periodic support and in-home services, DMR re-assessed its quality system, prepared a quality improvement plan and completed a number of initiatives designed to address weaknesses in the traditional quality system.

DMR has structured its quality management system to systematically address all outcomes identified in the Home and Community-based Services (HCBS) Quality Framework promulgated by CMS in 2003. Through the HCBS Quality Framework, which outlines the major focus areas in the design of an HCBS program and the quality management functions used to assess its goals, CMS encourages states to change from a look-back method of managing quality to designing quality throughout the system. DMR regional offices have assumed the responsibility for substantial elements of the quality system through the provision of Targeted Case Management, and the maintenance of state administrative functions. Specifically, focus areas addressed by the quality management system include: access, service planning and delivery, safeguards, rights, system performance, and outcomes and satisfaction.

Quality activities and processes evaluate and monitor case management and regional administrative roles in each focus area. Additional system monitoring, enhancement and analysis is carried out by the central office through licensing inspections, provider certification reviews, state and independent Mortality Review Boards, independent analysis of data, audits, and contracting with outside consultants to complete special studies.

### **D. Connecticut Partnership for Long-Term Care**

The Connecticut Partnership for Long-Term care (the "Partnership") is a unique alliance between state government and the private insurance industry developed to provide individuals with a way to plan for their long-term care needs without the risk of impoverishment. It also enhances the standards of private long-term care insurance, provides public education about long-term care, and conserves state Medicaid funds. Connecticut was the first state to implement a Partnership. Since 1992, when the Partnership was first launched, New York,

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<sup>59</sup> A portion of this discussion is from the Connecticut DMR 2006 Quality Management Plan.



Indiana and California have developed similar Partnership programs. Recently, the federal government has allowed additional states to develop Partnership programs and a number of states have taken advantage of this opportunity and have received approval to implement a Partnership program.

The most unique aspect of a Connecticut Partnership policy is the Medicaid asset protection feature. This feature provides dollar-for-dollar asset protection: for every dollar that a Partnership policy pays out in benefits, a dollar of assets can be protected from Medicaid spend down rules. When determining Medicaid eligibility, any assets held by the policyholder up to the amount the Partnership insurance policy paid in benefits will be disregarded. For example, if the policyholder receives \$200,000 in policy benefits, he/she may then apply to Connecticut's Medicaid program for assistance and still keep \$200,000 in assets (in addition to the small amount everyone is allowed to keep and any other asset allowances under Medicaid, including any assets a spouse may be allowed to keep). The Partnership Medicaid asset protection feature is **not** available under non-Partnership policies.

As of March 31, 2007, over 54,000 Partnership applications had been submitted, and more than 44,000 policies purchased.<sup>60</sup> Active in-force policies as of that date numbered approximately 35,000. To date, 654 Partnership policyholders qualified to receive benefit payments, of who 36 accessed Medicaid. The total amount of asset protection earned by all policyholders totaled nearly \$35 million, and the Partnership has saved the Connecticut Medicaid program more than \$4 million in long-term care costs since inception.

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<sup>60</sup> Extensive evaluation statistics concerning the Partnership since its 1992 inception can be found at <http://www.opm.state.ct.us/pdpd4/ltc/consumer/stats.htm>.

#### IV. Connecticut in a National Context

When comparing Connecticut to the eight states whose rebalancing efforts were studied in depth by the University of Minnesota in its Rebalancing Research Project<sup>61</sup>, the following factors should be considered:

- All eight states were actively working to shift their utilization and expenditures for long-term care further towards the community. CMS invited the states to participate in part because they collectively demonstrate wide variation in circumstances, programs, and baseline rebalancing accomplishments.
- The programmatic data for the eight state studies were gathered more than two years before the data collected for Connecticut. Each state continues to make improvements and experiment with models for change.
- The comparisons are instructive. While Connecticut compares favorably on some measures, it lags on many others, and policymakers can learn from the success of other states.

The figures below present a quantitative comparison of Connecticut over time and with the other eight states on many rebalancing measures. Figure 4 reports comparisons between Connecticut and the eight selected states in terms of the numbers of clients served in various programs. Connecticut is similar to most of these states with regard to the proportion of clients supported in various settings. In all but two states (WA and MN), the number of individuals receiving care in nursing homes is far greater than the number of those enrolled in HCBS waivers. In most of the selected states, the number of nursing home clients is double the number being served through waivers, and in Florida and Texas, for example, the number of nursing home residents is more than three times as large as the number of clients living in the community.

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<sup>61</sup> Abbreviated versions of the 8 case studies and an executive summary can be found on the CMS New Freedom Website at [http://www.cms.hhs.gov/NewFreedomInitiative/035\\_Rebalancing.asp#TopOfPage](http://www.cms.hhs.gov/NewFreedomInitiative/035_Rebalancing.asp#TopOfPage). Six of the long reports following the format described are found on the website of the University of Minnesota's LTC Resource Center at [http://www.hpm.umn.edu/ltrcresourcecenter/on\\_going\\_research/Rebalancing\\_state\\_ltc\\_systems\\_case\\_studies.htm](http://www.hpm.umn.edu/ltrcresourcecenter/on_going_research/Rebalancing_state_ltc_systems_case_studies.htm).

Figure 4. State Comparisons re Number of Clients Served, 2005

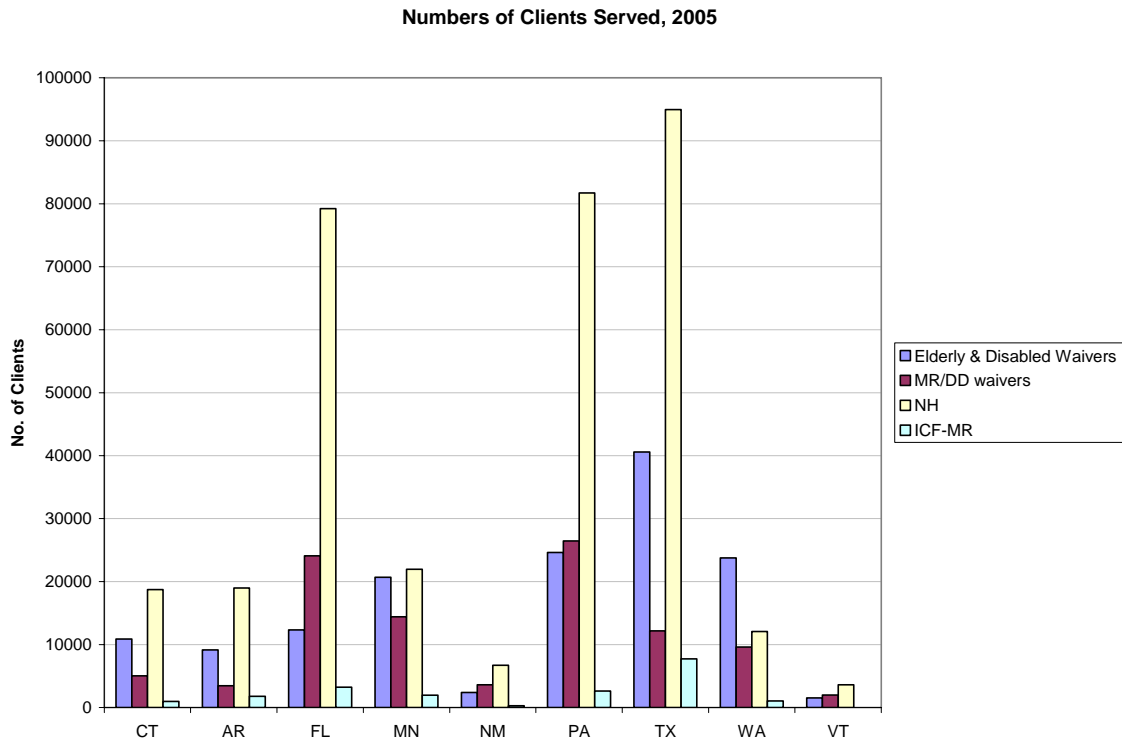


Figure 5 compares Connecticut to other selected states in terms of their long-term care expenditures. In all states except New Mexico, the majority of expenditures are for nursing home care. Connecticut is similar in expenditure patterns to Arkansas, Florida, Pennsylvania and Texas, where nursing home costs are more than four times as high as costs for waiver programs.

Figure 5. State Comparisons re LTC Expenditures, 2005

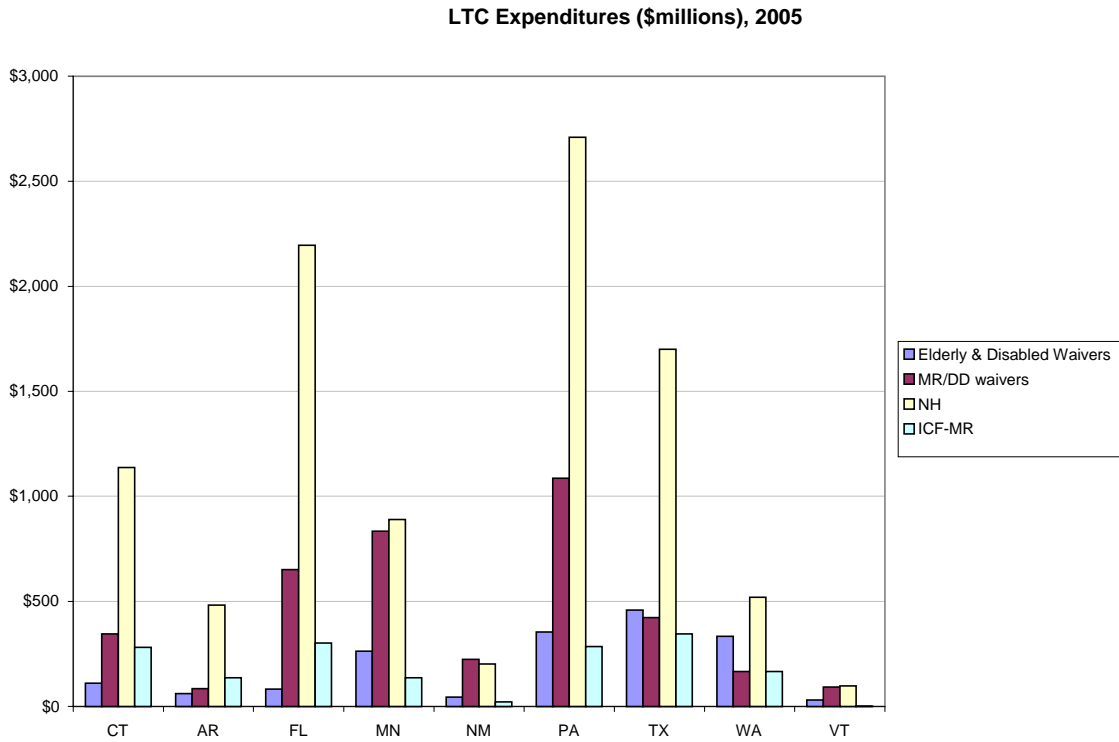
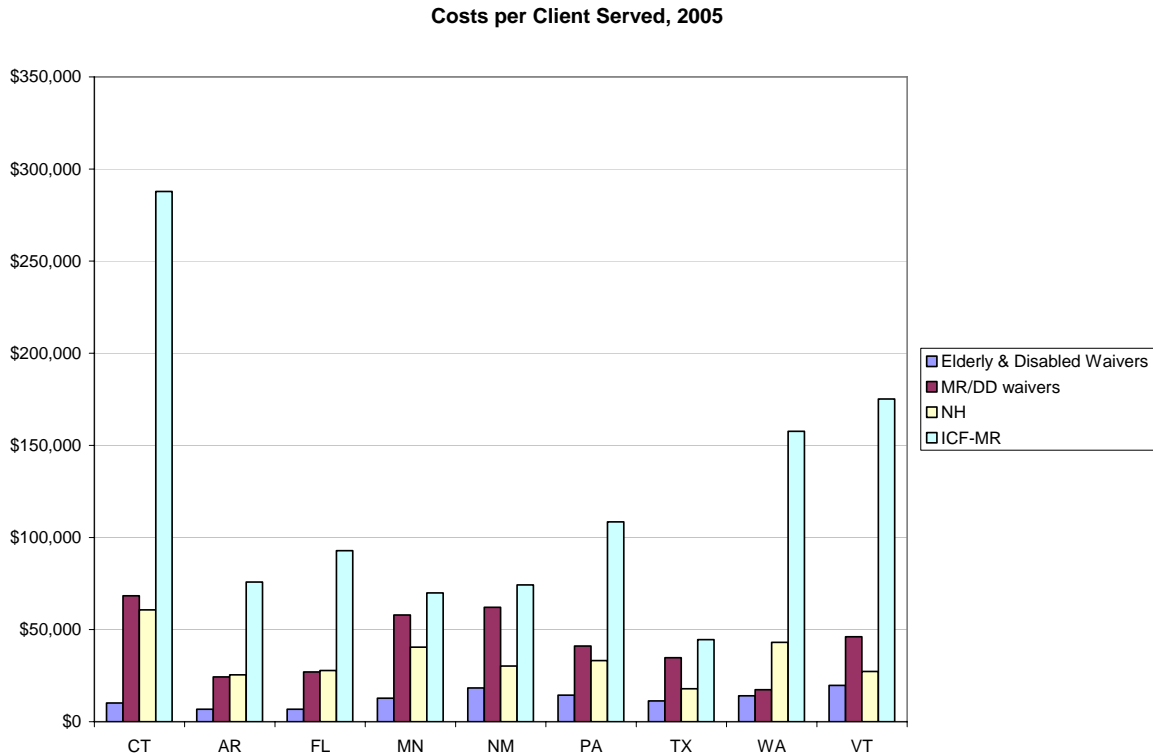


Figure 6 reports comparisons among selected states in terms of the costs per client served in various programs. As is the case in all of the selected states, ICF/MR costs per client are the highest. In terms of MR/DD clients, Connecticut's per client costs are roughly equal to those found in New Mexico and Minnesota. For nursing home clients, Connecticut's per client cost is the highest among these selected states. The per client cost for elderly and disabled waiver programs are fairly equivalent across these states.

Figure 6. State Comparisons re Costs per Client Served, 2005



Other measures of rebalancing progress cannot be captured as easily in charts and figures, but are more qualitative and policy-driven.

**State organization**

In six of the eight states, there has been a noted a trend towards consolidating and integrating government functions across target disability populations, including aging, across functions (budgeting and planning, service delivery, and quality assurance) and across community care and institutional care. Connecticut has not followed this trend towards consolidation.

States with the greatest success in rebalancing -- Texas, Vermont, and Washington -- have moved to a substantial amount of cross-age, cross-disability consolidation at the state level. New Mexico created a new cabinet level Department of Aging and Long-Term Services. Two other cabinet level agencies (Health and Human Services) are also involved with long-term care, but these three agencies coordinate frequently and closely. Consideration is being given

to move MR/DD (currently in the state Health Department) to the new department. Minnesota also has substantial consolidation among all programs for people under age 65, though aging is administered separately. In contrast to Minnesota, Arkansas has achieved considerable consolidation in aging and physical disability, but MR/DD tends to be viewed separately. Florida and Pennsylvania are fragmented and poorly coordinated. Both have responsibility for aging matters separately at the cabinet level.

Only two of the eight states, Florida and Pennsylvania, have a cabinet level agency dedicated to aging, and this organizational structure has tended to isolate aging programs. If Connecticut proceeds with its legislatively-mandated plan to create a separate department for aging, it will “buck” the trend seen in these states and others.

Certainly, the experience of these eight states show that great strides towards community care for seniors can be made when the State Unit on Aging, the repository of Older Americans Act Programs, is housed within an umbrella agency.

### ***Developmental disability***

Compared to some states, Connecticut has made good inroads into reducing institutional care for persons with developmental disabilities. Still, other states are models for further improvement. For example, of the eight states, Minnesota, New Mexico, and Vermont have eliminated all of their state institutions for persons with mental and developmental disabilities. They also tend to have very small ICF/MRs. Vermont stands out with an average population of 1.3 in its group homes, meaning that many house one person in a companion model.

Florida and Washington are trying to close their state facilities but like Connecticut still maintain some. Washington is finding it difficult to downsize about 1,000 beds because of family member and union concerns. Arkansas and Texas face similar, even more pronounced challenges. Furthermore, Arkansas, Florida, and Texas still have numerous ICF/MRs with well over 16 beds.

Connecticut has a problem similar to Pennsylvania’s because its HCBS waiver is for mental retardation only, and people with developmental disabilities without accompanying mental retardation (such as people with cerebral palsy without MR) are not covered. Several of the states also emphasize the development of community programs under Medicaid or other funding for autism spectrum disorders, and strengthening advocacy networks for persons with autism. Connecticut’s activities are consistent with this trend.

### ***Aging***

Programs for older adults tend to have a heavier case management presence than do programs for younger persons. Connecticut has a very strong tradition of case management. In fact in some ways, Connecticut Community Care, Inc provides models for case management to the rest of the country. Connecticut’s programs appear to reflect a higher degree of case management professionalization than do many states. This is especially true since home care providers with whom case management agencies contract also mandate high requirements for professional personnel.

In aging services, a “front door” approach to community care involves preventing use of nursing homes and a “back door” approach involves active transitions from nursing homes. Of the eight states, Washington has the longest history of active assistance to move individuals out of

nursing homes. In the last five years, Texas has also mounted a vigorous effort to move people from nursing homes to the community. Texas actually pioneered the concept of Money Follows the Person and utilized state contracts with independent living centers as a vehicle for transition counseling. Pennsylvania, a state that resembles Connecticut in terms of a longstanding and highly professional case management capability, is energetic in its work to help consumers leave nursing homes, provides roles for Area Agencies on Aging (AAAs), and has identified a need to re-educate AAAs and traditional case managers on the possibilities for community care. Connecticut similarly has been energetic in modeling a nursing home transition program, which is an important building block for its Money Follows the Person demonstration.

Another approach is to downsize the supply of nursing homes. Looking at states that serve as models of systemic efforts to downsize the nursing home sector, Minnesota was the most active (and also the most highly bedded with nursing homes), followed by Pennsylvania.

The role of assisted living and other group residential care as a vehicle for community supports for seniors is also of interest. The challenge here is to ensure that assisted living does not become another institution, albeit with slightly better amenities. Minnesota tries to prevent this from occurring with its “housing-with-service” model of assisted living apartments. Connecticut seems progressive in this regard with the same feature that allows elders in assisted living to maintain a great deal of control.

Each state is challenged to allocate HCBS services to older people in a way in which people with nursing-home levels of need truly have options for community care, including assisted living. They all battle fixed (erroneous) attitudes that community care can substitute only for very light nursing home care. In this area, Pennsylvania has encountered a real catch-22 situation. The waivers cover residential care services for nursing home-certifiable people, but state licensing does not allow nursing home-certifiable people to live in personal care homes (Pennsylvania’s version of assisted living). Connecticut is similarly challenged to develop ways to refrain from pre-empting the decision by enforcing professional preferences for consumer safety.

### ***Consumer direction***

Consumer-directed models of care and flexible consumer controlled services appear to be at the heart of how many of these states have enabled increased community care for all populations. Connecticut has room for significant improvement in this area. For example, Connecticut has a program called “self-directed care,” which would not be recognized as self-directed care in any other state because it merely moves waiver dollars to a provider agency rather than to a case manager. In a state with a great deal of flexibility in care arrangement such as Washington, case management is stronger because many clients receive services from independent providers rather than agencies.

As non-agency models develop, states also decide how (or if) they will pay family members for services. Washington, Texas, Vermont and New Mexico all have well-developed consumer-directed programs. All allow the consumer to choose a family member as paid care provider within certain parameters. In Washington, such family members must join the union. Arkansas has extremely innovative programs in consumer direction, beginning with its original cash and counseling demonstration. Minnesota offers consumer-directed options for all populations, but at the time of the case studies, seniors’ participation was low, as is true in many states.

Many states have revised their nurse practice acts to enhance flexible in-home services to specify that certain nurse functions can be delegated by a nurse to unlicensed assistive personnel, or that certain programs can be exempted from nurse practice entirely. Arkansas, Washington, and Texas have all been active in this regard.

***Other areas***

Finally, Washington is viewed as a model in two additional areas. Its excellent data system drives assessment and quality assurance and is superior in this area to other states. Washington is also a leader in ease of access to services, avoidance of roadblocks and delays for financial aid and functional disability because of its presumptive eligibility. Pennsylvania established a similar system in several counties but has not taken it statewide.



## V. Conclusions and Recommendations for Connecticut

### A. Conclusions

**While major progress has been made nationally in rebalancing the long-term care system, through the expansion of home and community-based services and a reduction in the number of people living in long-term care institutions, Connecticut has not achieved its full potential.** Numerous opportunities and incentives for states to achieve their rebalancing goals have been provided by federal developments including the Olmstead Supreme Court decision (1999), the New Freedom Initiative (2000), and the Deficit Reduction Act (2006). Many states have responded to these opportunities and have made comprehensive changes to the way they provide and finance long-term care.

**Over the last 15 years, Connecticut has made a number of important strides in improving and rebalancing long-term care services and supports.** The state developed a number of Medicaid home and community-based waivers, and eliminated the waiting list for the CHCPE. While progress has been made on other waiver waiting lists, such as DMR and Katie Beckett, long waiting lists remain for both. State policymakers and agencies developed assisted living demonstration projects, placed a moratorium on nursing home beds, and assumed funding for the Nursing Home Transition Program when federal funds ran out. The state also codified into law the broad philosophical statement that “individuals with long-term care needs have the option to choose and receive long-term care and support in the least restrictive, appropriate setting.” Connecticut has instituted a comprehensive Long-Term Care Planning process that sets and tracks progress against ambitious goals. For the first time, more Connecticut residents are receiving long-term care services in the community than in institutions, although more than two-thirds of Medicaid long-term care dollars are still spent on institutional care.

**However, the state is not a leader of systems change in terms of long-term care rebalancing.** Though important progress has been made, a number of reforms to long-term care organization, financing and delivery are warranted in order to achieve rebalancing goals. At this time, Connecticut:

- Serves 49 percent of its Medicaid long-term care clients in institutional settings;
- Spends 68 percent of its Medicaid long-term care dollars on institutional care;
- Is one of 18 states that do not have a personal care option in their Medicaid state plan;
- Is one of 2 states with no program for adults with developmental disabilities who are not mentally retarded;
- Is one of 10 states without an Aging and Disability Resource Center (ADRC) or other mechanism to provide a “single point of entry” or “no wrong door” model of entry into the long-term care support system.

**Connecticut provides publicly-financed long-term care services and supports through a somewhat fractured governance structure consisting of a vast array of departments and programs that often operate in silos serving narrowly-defined segments of the population.** This organizational complexity poses significant challenges for both consumers and providers of long-term care services. By contrast, the most progressive states in terms of long-term care rebalancing have restructured their state governments by consolidating most or all of their long-term care programs into a single agency within an umbrella organization, creating an efficient all-ages human services approach specifically linking long-term care and Medicaid. Some leading examples of states with these government structures are Vermont,

Washington, Oregon, and Wisconsin; many other states are also moving in this direction. Connecticut appears to be moving in the opposite direction, having voted to create a cabinet-level Department on Aging that would split responsibilities even further.

**The Connecticut Long-Term Care Needs Assessment demonstrates that residents need improved access to long-term care information and services, and increased coordination among state agencies.** The proposal to establish a cabinet-level Department on Aging has generated concerns regarding further splitting of responsibilities and lack of coordination between Medicaid waivers and Older Americans Act (OAA) programs. Separating OAA money from other Medicaid programs in a cabinet-level Department on Aging is likely to make the system more complex and confusing and thus be counter-productive for older people. Generally, the interests of older people are not served well when they are isolated from other groups and from the primary funding source, Medicaid.

**Once a pioneer in case management, Connecticut lacks a single point of entry into its long-term care system that would serve to standardize information, referral and screening.** The state's CHOICES program does have some of the desirable features of a single point of entry, although it is run out of five separate Area Agencies on Aging. It provides information and referral services to adults age 60 and over and assistance on Medicare issues to younger persons with disabilities, and performs at least some of the functions of a single point of entry for certain segments of the population. The CHCPE performs an assessment and screening function that diverts many older adults into community-based care. However, it is unique to nursing home admissions, does not conduct universal screening regardless of age or payor source, and its two-step process can be cumbersome.

**Connecticut has achieved only partial success in implementing a self-direction model, which involves the development and implementation of methods of consumer-directed care.** Evidence from consumer-directed care programs in other states indicates this model can be highly effective, particularly when the formal caregiving labor force is limited, as it is in Connecticut. In such models, beneficiary autonomy and control serves as the guiding programmatic priority; consumers hire, train, supervise, and pay workers of their choice. The option to hire PCAs is an important aspect of self-direction in long-term care. In Connecticut, self-direction and access to PCA services are currently permitted only for participants in the Acquired Brain Injury waiver (369 people), the Personal Care Attendant waiver (698 people), and the Department of Mental Retardation's Comprehensive and Family Support waivers (approximately 7,500 people). People enrolled in these waivers can all self-direct, although all DMR clients have a case manager. By contrast, while participants of the CHCPE can, if they wish, opt for what is called "self-direct" status, this is operationalized as only allowing consumers to choose their agency providers and determine the service schedule and service options. Consumers in the CHCPE do not control their individual budget and are required to use a provider agency. The exception within the CHCPE is the state-funded PCA pilot which has allowed true self-direction of PCAs for a maximum of 250 people. That cap was recently eliminated.

Connecticut has a highly diverse population in terms of economic resources with concomitantly wide variation in access to health care. Though individuals with private resources can access care in whatever setting they choose, persons of every socioeconomic status often lack good advice and education about existing options. Long-term care services are not always equally available to all, or of similar high quality. Many potential clients are experiencing waiting lists for some of the state's Medicaid waiver programs, including Department of Mental Retardation

waivers, the Katie Beckett waiver, and the Personal Care Assistance Waiver. The Acquired Brain Injury waiver is also nearing full capacity.

**The state's numerous consumer advocacy organizations are highly engaged and committed, though often fragmented between aging and disability issues and across disability groups.** They are not always unified on issues concerning long-term care. Many represent primarily older adults or primarily persons with particular disabilities, though there has been a recent trend to join efforts on many long-term care issues. An organized voice for consumer advocates is still lacking. There is, however, an organized voice for provider issues, as the state's nursing home industry and state employee unions are strong and well-organized.

**There is a significant lack of knowledge regarding long-term care services, planning and financing, among the general public as well as among those who currently need or use services.** People currently receiving or needing services often lack knowledge regarding available choices, services and funding sources. Those who most frequently advise people seeking services, such as medical personnel, social workers, and hospital discharge planners, are not themselves aware of all the choices that exist. Connecticut residents of all ages have not adequately planned for their future long-term care needs, and have limited understanding about the likelihood of requiring long-term care services and potential sources of payment.

**Connecticut has procedures in place for establishing and revising nursing home reimbursement rates.** The state's Medicaid average per diem rates are fifth highest in the nation. Yet the Medicaid rate is nearly \$100 a day less than Medicare and \$75 less than the average private pay rate (Medicare rates for sub-acute short stays are significantly higher than the Medicaid rate for long-term care), and has no quality incentives. Connecticut's Medicaid reimbursement rates for nursing homes are cost-based, in contrast to the acuity-based case mix system used by many states (4 of the 6 New England states use a case mix approach). A report by the Connecticut Legislative Program Review and Investigations Committee noted that although the adoption of a case mixed rate setting approach has been opposed by the nursing home industry and the New England Health Care Employees Union District 1199, the disparity between resident acuity and Medicaid reimbursement results in substantial inequities across the system. The current rate setting model lacks effective incentives for quality improvement and has been generally ineffective, with greater adverse consequences for facilities that serve primarily Medicaid residents.

**Compared with other states, Connecticut has a very rigid, highly professionalized model of case management and home care delivery in which both agencies and individual providers are subject to extensive licensing requirements and regulations.** Case management is performed by access agencies, which brings the advantages of neutrality and global planning, but also high cost. Home health services in Connecticut in general are dominated by nursing services and supervision, such that even homemaker services must be under the supervision of a registered nurse. Such requirements make home care expensive and limit access.

**While there is some shortage of skilled nursing personnel in institutions, in Connecticut there is a greater shortage of home-based care workers,** including home health aides, personal care assistants and homemaker assistants. Projections indicate continuing and increasing shortages in the coming years.

**Connecticut lacks a robust data capacity and systems integration capability to manage clients served by multiple programs.** Agencies, bureaus and departments have each developed elaborate database systems that operate separate and removed from each other. Further, many private providers have invested heavily in platforms that allow for sophisticated data collection techniques. However, the autonomous development of these myriad systems has resulted in extremely limited cross-fertilization of data within and between agencies. The issue has begun to be addressed in limited areas.

## **B. Recommendations for Connecticut**

The following recommendations are offered for consideration by Connecticut lawmakers and policymakers. They are based on:

- Analysis of the results of the long-term care needs assessment surveys of Connecticut residents and service providers;
- A comprehensive review of the current system of organization, financing and delivery of long-term care in Connecticut; and
- A comparison of Connecticut's long-term care services, organization and financing with those of other states, several of whom are leaders in this field.

The recommendations are also based on two guiding principles, which should be considered in connection with any policy or program changes developed to implement the recommendations:

- Create parity among age groups, across disabilities, and among programs through allocating funds equitably among people based on their level of need rather than on their age or type of disability.
- Break down silos that exist within and among state agencies and programs. Use the model of systems change grants such as the Money Follows the Person Grant and the Medicaid Infrastructure Grant to foster integration of services and supports.

### **1. Create a statewide Single-Point of Entry (SPE) or No Wrong Door (NWD) long-term care information and referral program across all ages and disabilities.**

Survey respondents, providers and state agency staff all reported that it is difficult for Connecticut residents who need long-term care to find basic information about the types of care that are available to them and who will provide this care. An expert team comprised, for example, of State Unit on Aging staff, members of the Long-Term Care Planning Committee and Advisory Council, consumers and providers should develop a plan to implement a centralized SPE/NWD in Connecticut. The SPE/NWD should encourage equity in allocation of services and supports across ages and across disabilities. Many of the 43 jurisdictions throughout the U.S. with existing Aging and Disability Resource Centers (ADRCs) present models for doing so. The SPE/NWD should also inform the hospital discharge planning process to avoid unnecessary institutionalization, and should consider the creation of common applications for program eligibility to avoid the necessity of giving the same information multiple times.

Another promising avenue would be to consider modeling a Connecticut SPE/NWD on certain features of the existing CHOICES program, which currently provides referral services through each of the five AAAs. If CHOICES is used as the most appropriate model for Connecticut, it would require centralization of at least the initial point of contact, an increase in the capacity to include Centers for Independent Living or other community-based organizations, additional staff training on all long-term care options across ages, disabilities and income, across all entry point agencies, and increased visibility of its services. Whatever method is chosen, provide a wide

range of access (e.g. face-to-face, telephone, and web) that will help individuals and their families: first, identify the most appropriate type of long-term care services and supports and second, select specific providers that will meet their needs. Utilize standard assessments and programmatic coordination to increase equity in access, enhance residents' knowledge of options, enable better decision-making, and encourage better discharge planning.

**2. Provide a broader range of community-based choices for long-term care supports.**

Major policy and financing efforts should be undertaken to develop a broadly integrated infrastructure for community-based services including home health, homemaker and adult day services. Reduce restrictions on who can provide this care. States such as Oregon and Washington can serve as useful models. Both diversion and transition strategies must be improved in order to maximize opportunities for individual choice. Comprehensive, coordinated pre-admission screening for need and eligibility is necessary in order for these strategies to work. In addition, systematic attention must be directed toward expanding available slots in pilot programs for assisted living and other supportive community-based residence settings, and making these programs permanent. Combine HUD and other housing programs to cover housing costs for those whose assisted living services are covered by Medicaid.

**3. Foster flexibility in homecare delivery.**

Develop increased flexibility in Connecticut's rigid, highly professionalized model of home care delivery. In the current model, both agencies and individual providers are subject to extensive and sometimes inflexible licensing requirements and regulations. Increase in-home delivery with more cost-effective models. Study, and implement where appropriate, initiatives such as nurse delegation of specific tasks in specific settings, and using lower cost alternatives (e.g. homemaker vs. home health care) while not compromising the quality of care. Review the current scope of practice definitions for the nursing professions, and develop options for refinement in order to promote flexibility. Consider allowing an independent provider model in which providers are not required to work for an agency, a model that is more cost-effective and flexible.

**4. Address scope and quality of institutional care.**

Explore and establish effective incentives to encourage the downsizing of public and private institutions while at the same time improving quality in remaining institutions. Examples include single rooms, report cards, and creation of a reimbursement system for all institutional settings based on quality improvement indicators. Other alternatives should be sought when additional institutions are proposed. Facilitating national efforts to change the culture and quality of life in nursing homes, the Department of Public Health, in collaboration with Centers for Medicare and Medicaid Services, should assess and amend existing regulations to allow for continued development of individualized care and culture change models within this care setting. The long-term care Ombudsman Program and coalitions such as the long-standing Breaking the Bonds Coalition should be engaged in this process.

**5. Provide true consumer choice and self-direction to all long-term care users.**

Develop policies and programs to: a) allow consumers/family members to choose their own care providers, including from within their own informal care network, particularly family members, b) allow consumers to control their own budgets, c) make case management optional for individuals who are able to manage their own care, d) use the DMR waivers as a model for self-directed care, and e) make these options available across all ages and disabilities. Programs should operate with as much flexibility as possible, including the ability to arrange for as many care provider hours as necessary, in whatever configuration across providers is appropriate and preferred by the consumer. Since many consumers/family members come into a long-term care

situation without prior knowledge or experience, it is important that they have assistance in making choices and self-direction, and that the assistance be comprehensive and unbiased.

#### **6. Simplify Connecticut's Medicaid structure.**

Strive for simplification in Connecticut's Medicaid structure, which is based heavily on waivers and pilot programs. Add essential community-based services such as personal care assistance options to the state Medicaid plan. Strive for a universal waiver with consistent requirements across ages and disabilities, or include HCBS services in the state plan, as was recently done in Iowa. Include programs for adults with developmental disabilities who are not mentally retarded. If it is determined that one waiver is not feasible, every effort should be made to ensure that consistent eligibility and level of need reporting forms are consistent across waivers. In addition, pilot programs that have proven successful should be made a permanent feature of the Medicaid program.

#### **7. Create greater integration of functions at the state level, and consider alternative configurations of state government structure in order to best meet the long-term care needs of Connecticut's residents.**

Establish a consolidated, efficient all-ages human services approach to long-term care in Connecticut that maximizes the impact of Medicaid dollars and Older Americans Act funds rather than dividing them. Reconsider the establishment of a separate cabinet-level State Department on Aging. Address the needs of persons with autism without the creation of a separate Board of Education and Services for Citizens with Autism Spectrum disorders. Study recent trends in states with successful long-term care and other programs that serve all age and disability groups. As appropriate, individual departments could function with some level of autonomy under one umbrella agency in order to maximize expertise about specific conditions.

#### **8. Address education and information needs of the Connecticut public.**

In addition to establishing a highly visible SPE/NWD for people needing long-term care (as described in Recommendation #1), targeted information campaigns concerning long-term care services and supports should be developed in collaboration with high-visibility, convenient community partners, such as hospital discharge planning offices, community and senior centers, AAAs, and public libraries. These campaigns should integrate existing internet resources such as the long-term care website. Additional training and resources should be provided to those who are the most frequent sources of long-term care information and advice, such as social workers and health care providers, as well as Probate Court officials and conservators.

More broadly, the state should consider investing in a public information and education campaign directed at educating the public about long-term care. All educational efforts should emphasize a broad public understanding of long-term care that combats misperceptions created by the traditional definition that relates solely to medical facilities. Connecticut should investigate the joint federal-state "Own Your Future" long-term care Awareness Campaign designed to increase consumer awareness about, and planning ahead for, long-term care needs. Another model for a public education campaign is the "Able Lives" series produced by Connecticut Public Television.

#### **9. Increase availability of readily accessible, affordable transportation.**

In order to facilitate true choice in care and support alternatives, improve transportation options at the state and local level for persons who require additional assistance due to disability or other decline in physical or mental functioning. Encourage municipalities to work together to form regional plans that meet local and regional needs. Consider the formation of a broadly

representative task force, led by a state-wide liaison from the Department of Transportation, to fully investigate alternative approaches and resource needs to accomplish this goal. Coordinate with the Medicaid Infrastructure Grant (Connect-Ability) team which has identified transportation as a priority area.

**10. Address long-term care needs of persons with mental health disabilities.**

It is noteworthy that approximately 25 percent of the Needs Assessment survey respondents reported symptoms of depression, and that persons with psychiatric disabilities stressed the difficulty in accessing mental health services. Therefore, it is imperative that, under the Mental Health Transformation Grant, and in the development of the Medicaid Home and Community-based Services Program for Adults with Severe and Persistent Psychiatric Disabilities, state agencies work together to increase the financing and availability of comprehensive mental health services, including community-based care options, to meet the needs of Connecticut residents.

**11. Address access and reimbursement for key Medicaid services.**

Psychiatric, dental, and podiatric services were identified in the Long-Term Care Needs Assessment survey as a particular problem for those receiving services through the Medicaid program. Difficulties involving access and financing persist. The Department of Social Services should assess the feasibility of increasing reimbursement rates to attract providers willing to serve this population. Several states, including Washington and Oregon, have already accomplished this critical component.

**12. Expand and improve vocational rehabilitation for persons with disabilities.**

Connecticut has begun to address this identified need through its Medicaid Infrastructure Grant (Connect-Ability). The Connect-Ability project coordinators should review the findings from the Long-Term Care Needs Assessment. To the extent feasible, targeted analyses of relevant data should be conducted, based on needs identified by project coordinators.

**13. Address the long-term care workforce shortage.**

Workforce Investment Boards should be engaged to develop approaches to increase the size of the formal long-term care workforce, including training, education and incentives. The wage gaps, including benefits, between public and private frontline workers and across those workers who care for different populations should be addressed. Increased flexibility in Connecticut's self-direction model, allowing consumers to choose their own care providers, will also help to address the workforce shortage.

**14. Provide support to informal caregivers.**

Provide assistance with training, financing (including incentives) and information for informal caregivers, including family members. Respite and adult day programs should be available statewide without age and specified disability restrictions. Caregivers should be a target group for education about long-term care services availability and financing.

**15. Continue and expand efforts to build data capacity and systems integration in the service of better management and client service.**

Build upon the web technology and systems integration efforts of DMR and the Medicaid Infrastructure Grant to enhance access to data for providers and policymakers.

***This Long-Term Care Needs Assessment was charged with providing a broad overview of the existing long-term care system in Connecticut and projecting long-term care needs***

***in the coming decades. These recommendations focus on the major areas where Connecticut's long-term care system must be improved in order to meet these needs.***

***In implementing these recommendations, systematic review of successful models being used in other states is essential. As a result of federal developments such as the Olmstead Supreme Court decision, the New Freedom Initiative and the Deficit Reduction Act, a number of states have implemented innovative programs designed to achieve rebalancing goals. Whenever feasible, the successes, accomplishments and lessons learned from these states should be used to inform policy and planning efforts in Connecticut. Connecticut's lawmakers and policy-makers are well-positioned, with the assistance of expert advisors and the examples of leading states, to bring these recommendations to fruition.***

***A planned series of in-depth issue briefs from the long-term care needs assessment survey data, which will address specific long-term care topics, will assist in this continuing endeavor.***



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