Connecticut Long-Term Care Planning Committee

LONG-TERM CARE PLAN

A Report to the General Assembly

January 2007

Balancing the System:

Working Toward Real Choice for Long-Term Care in Connecticut

A Report to the General Assembly
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This Plan has been informed, in part, by the preliminary findings of the Long-Term Care Needs Assessment conducted by the University of Connecticut Health Center's Center on Aging under contract with the General Assemby's Commission on Aging. Thanks to the Center on Aging for sharing their preliminary findings. A report on the findings and recommendations of the Needs Assessment will be released to the Connecticut General Assembly in the spring of 2007.

I. EXECUTIVE SUMMARY

A. Balancing the System

People of all ages and from all walks of life need long-term care supports and services. They are our parents, siblings, children, co-workers and neighbors. They are us. Whether challenged with limitations due to injuries, developmental disabilities, mental illness, chronic health conditions, or the aging process, they all share a common need for assistance in order to live, work and play.

Long-term care services and supports are needed to help people carry out basic functions such as eating, dressing or bathing or the tasks necessary for independent community living, such as shopping, managing finances and house cleaning. Likewise, needs range from minimal personal assistance with basic activities to virtually total care. These long-term care needs are being met at home, in the community, in congregate residences and in institutional settings.

This Long-Term Care Plan (Plan) addresses the long-term care needs of the citizens of Connecticut. Developed by the Long-Term Care Planning Committee in collaboration with the Long-Term Care Advisory Council, this Plan was produced to educate and provide recommendations to policymakers regarding what steps Connecticut should initiate and continue to take in order to meet the long-term care challenges of the next several decades.

Ideally, Connecticut's long-term care system should offer individuals the services and supports of their choice in the least restrictive and most enhancing setting. This means providing real choices to Connecticut residents regarding the types of supports that they need and requires a system that is consumer focused and driven. To reach this goal, Connecticut must first address the fact that the long-term care system is out of balance.

As in the 2004 Plan, the 2007 Plan is committed to balancing the long-term care system in terms of the ratio of home and community-based and institutional care and the ratio of public and private resources. Inherent in achieving this balance is the promotion of independence and choice for all individuals seeking services and supports. Towards this end, this new Plan continues to address the development and maintenance of a consumer-driven system of long-term services and support across the lifespan and across all disabilities with the focus on choice, least restrictive and most enhancing setting, and community inclusion.

Three years have passed since the last Plan and much has changed to improve Connecticut's long-term care system, yet much remains to be done. Changes in policy and funding on the federal and state level have fostered progress in creating a balanced long-term care system in Connecticut. Despite this progress, the many highlights of which are described later in this Executive Summary (see both the Gains in Connecticut and New Opportunities sections), Connecticut's long-term care system still exists in the

same world with many of the same rules, barriers and challenges that were in place three years ago.

To address these challenges, the Plan centers around two central themes.

1. Long-Term Care Affects Everyone

Long-term care will affect all of us at some point in our lives. Whether it is because we need services and supports ourselves, or we are providing care for someone in need, regardless of age, health or wealth, it is unlikely that we will be able to escape the issue of long-term care.

In keeping with this theme, this Plan is designed to address the current and future needs of all individuals in need of long-term care services and supports, regardless of their age or disability. This is the second Plan developed by the Long-Term Care Planning Committee under the Committee's expanded mandate to go beyond the needs of the elderly and address the system as a whole, encompassing all individuals with disabilities and their families.

Therefore, unless specifically noted, all of the recommendations and action steps outlined in this Plan apply to individuals of all ages and disabilities. While we recognize that certain populations have not received the equal footing they deserve in terms of attention and resources in long-term care planning and program development, we have deliberately been inclusive in our recommendations and action steps and have not segmented out certain groups of individuals or disabilities. This strategy is, in fact, designed to break down some of the barriers experienced by individuals with certain disabilities and promote a philosophy that is consumer-centered and focused on the needs of the individual and their family.

It is important to note that not only will virtually everyone be touched by the long-term care system at some point in their lives, but improvements in the long-term care system also benefits society at large. For example, addressing the shortage of long-term care workers also addresses the need for health professionals in other settings and improving access to public transportation benefits everyone, not only individuals with disabilities.

Accordingly, the critical terms used in this Plan are defined as follows:

- 'Long-term care' refers to a broad set of paid and unpaid services for persons who need assistance due to chronic illness or mental or physical disability. Long-term care consists largely of personal assistance with the routine tasks of life as well as additional activities necessary for living independently. Unlike medical care, the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning in the course of everyday activities and to contribute to independent living.
- 'Home and community-based care' encompasses home care, adult day care, respite, community housing options, transportation, personal assistants, and employment services.

- 'Institutional care' includes nursing facilities, intermediate care facilities for people with mental retardation (ICF/MRs), psychiatric hospitals, and chronic disease hospitals.

2. The Current System is Out of Balance

Connecticut's long-term care system has many positive elements and has made great strides over the last several years in providing real choices and options for elders and individuals with disabilities. However, the system is still fundamentally out of balance in two important areas.

Balancing the Ratio of Home and Community-Based and Institutional Care

In order to provide real choices to individuals and families there needs to be equal access to community and institutional care. While there are several sources of payment for long-term care, Medicaid is by far the largest payer and therefore is the focus of this discussion. Traditionally, in Connecticut and nationwide, Medicaid has made access to institutional care easier than to home and community-based care. Largely, this is a result of federal Medicaid rules and regulations. Consequently, the ratio between care and supports provided in individuals' homes and the community and those provided in institutions has consistently been out of balance and skewed towards institutional care.

In order to realize the Vision and Mission provided in Section II of this Plan, Connecticut must continue its efforts not only to balance the mix between home and community-based and institutional care but must strive for a ratio that provides more options for home and community-based care so that individuals with disabilities and their families can have real choices and control over the care and supports they receive. Institutional care plays a vital role in the continuum of long-term care. However, Connecticut should develop a system whereby individuals enter institutions by choice and not because the necessary and reasonable supports are unavailable for them to live in the community.

Regardless of the ratio of home and community-based care and institutional care, the long-term care system must provide support to the network of informal caregivers and ensure the recruitment and retention of formal caregivers, whose respective roles are essential, complementary and form the backbone of the long-term care system. This will become increasingly critical as the number of individuals receiving home and community-based care increases over the next several decades.

Balancing the Ratio of Public and Private Resources

The second area of imbalance involves the resources spent on long-term care services and supports. Long-term care is one of the most complex and difficult issues for individuals and families to understand and discuss. Many people are under the false impression that Medicare, and other health insurance programs, will cover their long-term care needs. This misunderstanding, coupled with the fact that most individuals understandably would rather not face, or discuss, the possibility of becoming disabled and dependent, leads most people to do little or no planning for their future long-term care costs.

The lack of Medicare and health insurance coverage for long-term care, combined with the lack of planning, has created a long-term care financing system that is overly reliant on the Medicaid program. Medicaid, by default, has become the primary public program for long-term care. However, in order to access Medicaid, individuals must first impoverish themselves. Therefore, we have a system that requires individuals to spend all their savings first in order to receive government support for their ongoing needs.

Nationally in 2004, Medicaid paid 49.3 percent of long-term care costs. Individuals covered 19.0 percent of costs out-of-pocket, with many of those payments made as applied income while on the Medicaid program. Medicare covered 19.2 percent of the bill, with private insurance covering 7.3 percent and the remaining 5.2 percent covered by other public and private sources. These figures only represent paid services and do not include the substantial value of informal care provided by family and friends. In order to develop and sustain a long-term care system that can provide real choice and quality services and supports to those in need, a better balance between public and private resources must be achieved.

The importance of unpaid informal care to the long-term care system cannot be understated. While it is estimated that nationally Medicaid spent $47.3 billion on long-term care for the elderly in 2004, and out-of-pocket spending by older individuals amounted to only slightly less than that amount at $44 billion, unpaid informal care amounted to 76.5 billion. However, many individuals still face a need for long-term care services and support that outstrips their ability to pay for care or are not able to enlist the needed care from family and friends.[1]

If our current system continues unchanged, not only will we experience more and more impoverishment as increasing numbers of Connecticut residents need long-term care, but the Medicaid safety net will start to erode. The financing of our long-term care system must be based on a balanced public/private alliance that stresses personal responsibility for those who can afford it coupled with the necessary obligation of government to provide supports for those who lack the resources to meet their needs.

B. Gains in Connecticut

Meaningful progress has been made in addressing the goals and recommendation made in the 2004 Long-Term Care Plan. Between January 2004 and December 2006, activity has occurred at all levels of government – federal, state and municipal – and in the public and private sectors. Many of these achievements have been documented in the 2004 Long-Term Care Plan Status Report (Appendix F).

Described below are some of the major gains made to address long-term care needs in Connecticut. Although significant progress has been made in improving choice, opportunities for self-direction, community inclusion and access to community-based services, more is needed if we are to meet our goals for achieving real choice and truly balancing the long-term care system.

[1] Douglas Holtz-Eakin, "The Cost and Financing of Long-Term Care Services," CBO Testimony, Congressional Budget Office, April 27, 2005

Policy Statement Formalized into Law

Public Act 05-14 codifies in law a broad philosophical statement to guide future policy and budget decisions. 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 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.

Progress in Meeting the Balancing Goals

For the first time, more individuals are receiving Medicaid long-term care services in the community[2] than are receiving institutional care[3]. This is a significant milestone in achieving one of the primary recommendations in the 2004 Long-Term Care Plan that proposes by 2025, 75 percent of Medicaid long-term care clients are receiving services at home or in the community, with only 25 percent choosing institutional care. To achieve this goal, the Plan recommended a one percent increase a year. Connecticut has exceeded this goal by shifting the balance by five percent over the last three years.

Medicaid 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.
- Likewise, the proportion of Medicaid long-term care clients receiving institutional care decreased nearly two percent a year, from 54 percent in SFY 2003 to 49 percent in SFY 2006.
- 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.

Medicaid 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

[2] The Medicaid long-term care community services include home health services, home and community based waiver programs, and targeted case management for mental health.

[3] The Medicaid long-term care institutional services include nursing facilities, intermediate care facilities for persons with mental retardation, and chronic disease hospitals.

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.
- In SFY 2006, Medicaid long-term care expenditures, both community-based and institutional, represented 14 percent of total state expenditures in Connecticut.

Completion of Long-Term Care Services and Supports Website

The Long-Term Care Services and Supports Website was completed and released to the public in September 2006 (www.ct.gov/longtermcare). This effort represents three-year collaboration between representatives of the Commission on Aging, the Office of Policy and Management, the Long-Term Care Advisory Council and Infoline and was accomplished within existing resources with no specific additional funding. The goal was to develop a consumer oriented 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.

Money Follows the Person Rebalancing Demonstration

In January 2007, Connecticut was awarded a $24.2 million five year grant from the federal Center for Medicare and Medicaid Services (CMS) to participate in the Money Follows the Person 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 federal government will reimburse the state for 75 percent of costs for the first year back in the community, instead of the customary 50 percent. The program will serve 700 individuals across the age span with physical disabilities, mental illness and intellectual disabilities. For eligible individuals, Medicaid funding will cover 24-hour live in assistance, personal management, and home alterations, among other home and community-based services.

New and Expanded Home and Community-Based Services (HCBS) Programs

- For the Connecticut Home Care Program for Elders (CHCP), 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, assets for a single person must not exceed 150 percent of the minimum community spouse protected amount, up from 100 percent, and for couples, assets must not exceed 200 percent of the minimum community spouse protected amount, up from 150 percent. In order to continue the State-funded CHCP 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.

- The Personal Care Assistance Medicaid Waiver for persons age 18 to 64 was renewed in September 2004, increasing the amount of hours a Personal Care Assistant (PCA) may work for a single client from 25 ¾ hours a week to 40 hours. Program capacity was expanded by 200 slots, from 498 to 698. If a PCA works more than 25 ¾ 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.
- The state-funded Personal Care Assistance (PCA) Pilot within the CHCP was expanded from 50 to 100 slots in September 2004 by the Department of Social Services. 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. In addition, 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.
- 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.
- In February 2005, a new Individual and Family Support Medicaid Waiver was awarded to the Departments of Mental Retardation and Social Services by the federal Centers for Medicare and Medicaid Services. The purpose is to strengthen supports to families or individuals and permit the individual who requires long-term support and services to live in the family residence or their own home.
- Effective October 2005, the Department of Mental Retardation received approval from the federal Centers for Medicare and Medicaid Services for a Comprehensive Supports Waiver, the Department's second HCBS waiver.
- Funds were appropriated in SFY 2007 ($1 million) to establish a pilot autism spectrum disorders program for individuals who do not have intellectual disabilities. 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.
- 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.
- 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.
- Section 32 of Public Act 06-188 allows the Department of Social Services, in consultation with the Department of Mental Health and Addiction Services, to seek approval of an amendment to their State Medicaid plan or a waiver from federal law to establish and implement a Medicaid-financed home and community-based program to provide community-based services and, if necessary, housing assistance, to adults

with severe and persistent psychiatric disabilities being discharged or diverted from nursing home residential care. In SFY 2007, $1.7 million was appropriated to begin planning and development of the waiver. It is anticipated the waiver will fund 72 community placements per year.

Expansion of Assisted Living Pilots

- For the Assisted Living Pilot in the four federal financed HUD facilities, $50,000 in additional funds was appropriated in SFY 2005 to allow for continued enrollment, for a total appropriation of over $588,000 for the program.
- For the Private Pay Assisted Living Pilot, the 50 person limit on the Medicaid portion and the 25 person limit on the State funded portion were combined to allow continued enrollment and reduce the likelihood that residents will be tuned away for the program.

Federal System Change Grants

- Since 2002, eight System Change grants have been awarded to Connecticut: the Real Choice Grant, the Community-based Personal Assistance Services (C-PASS) Grant, the Medicaid Infrastructure Grant, the Nursing Facility Transition Grant, the Independence Plus, the Quality Assurance and Improvement Grant, the Mental Health Transformation Grant, and most recently, the Money Follows the Person Rebalancing Demonstration.
- The Nursing Facility Transition grant, a three-year federally funded System Change grant, ended in September 2004. 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.
- In October 2005, Connecticut was one of seven states to be awarded a Mental Health Transformation Grant, receiving $13.5 million over five years. Collaborating on this grant are 14 State agencies and the Judicial Branch, providers and consumers, who are addressing the needs of all individuals with mental health needs across the lifespan. A needs assessment and comprehensive state mental health plan was completed by September 2006 that directs system transformation activities. Grant funds cannot be used for direct services, only for system transformation activities, such as public awareness, information systems, workforce development and quality assurance.
- Also in October 2005, the Bureau of Rehabilitation Services was awarded a five year, $15 million Medicaid Infrastructure Grant (MIG). The MIG is not a new grant, but has renewed funding and expanded purpose. The first grant received in 2000 focused on Medicaid for the employed with disabilities. In this new cycle of funding, received on January 1, 2006, the project has taken a broader view, looking toward a comprehensive employment structure for everyone. The vision is to achieve full participation and increase employment, increase earnings and independence and increase access to long-term care services and supports.

- The directors of the federal System Change Grants awarded to Connecticut have been meeting together on a regular basis to coordinate their efforts, sharing information, ideas and resources. From 2003 to 2006, they have made an annual joint presentation to the Long-Term Care Planning Committee, relating their work and progress to the goals of the 2004 Long-Term Care Plan. They have also provided valuable information and recommendations for this 2007 Plan.

C. New Opportunities

Medicaid Reform

The Federal Deficit Reduction Act (DRA) of 2005 (P.L. 109-171), signed into law on February 8, 2006, made a number of changes to the Medicaid program. Some of these changes provide new long-term care options to states that promote choice, consumer direction, personal responsibility and community living, and reduce the incentives toward institutional care. The DRA also tightened the rules regarding asset transfers and the use of annuities. These changes were designed to encourage individuals to plan ahead for their future long-term care costs without resorting to transferring or sheltering their assets.

Medicaid - Transfer of Assets

- The rules regarding transfer of assets are changed to make it more difficult for individuals to shelter or give away their assets in order to qualify for Medicaid long-term care services. The 'look-back period' for all income and assets disposed of for less than market value by an individual applying for Medicaid benefits is now lengthened from three to five years. The penalty period is changed so that the penalty begins on the date of application or the time of transfer, whichever is later, instead of the date that the transfer was made.
- The treatment of certain annuities when applying for Medicaid are revised, requiring all new applicants to declare all interest in annuities and to name the State as the beneficiary.
- An individual's entrance fee in a continuing care retirement community is now considered as a countable asset in certain circumstances when applying for Medicaid.
- Individuals with equity in their homes that exceed $500,000 are now ineligible for Medicaid nursing facility care or other long-term care services. The DRA gives States the option of electing a greater value not to exceed $750,000. Connecticut has chosen to set the equity threshold at the higher amount of $750,000. Individuals who have a spouse, a child under age 21, or a child who is blind or disabled that resides in their house are not excluded from eligibility based on home equity.
- A hardship waiver is available that sets new State requirements for undue hardship approvals and the appeal process. In order for an application of undue hardship to be approved, the penalty period for the person applying for Medicaid would have to be found to deprive the individual of medical care that would endanger the person's health or life, or deprive the person of food, clothing and other life necessities.

Partnership for Long-Term Care

- Medicaid is amended to allow additional states to develop Long-Term Care Partnership programs. Standards are set for new programs while existing Partnership programs in Connecticut, California, Indiana and New York are allowed to retain their current rules and regulations. Connecticut was the first state to develop a Partnership program, implementing in 1992.

Home and Community-Based Services

- States are now allowed to cover home and community-based services (HCBS) as a Medicaid State plan option for certain individuals with incomes at or below 150 percent of the federal poverty level. Previously, HCBS could only be covered in the context of a Medicaid waiver program. States are permitted to provide this option to individuals without requiring that the person would otherwise require a level of care provided in a hospital, nursing home or an intermediate care facility for persons with mental retardation (ICF-MR). Any service permitted under a HCBS waiver is allowed, but does not include costs for room and board. States may also limit the number of individuals who can participate in this benefit and establish waiting lists.
- States are now allowed to provide a period of presumptive eligibility (not to exceed 60 days) for individuals applying for HCBS. The covered activities include carrying out the independent evaluation, assessment and, if eligible, the specific services the individual will receive.
- In covering this benefit, a State is allowed to waive existing Medicaid requirements related to statewide coverage and the income and resource rules applicable in the community.
- States are required to establish needs-based criteria for determining an individual's eligibility for the HCBS option and the specific services the individual will receive. States may limit the number of persons who are eligible for such services.
- State Medicaid programs may allow individuals to elect to self-direct the purchase and control of State Plan HCBS. Under the self-directed option, the individual's needs, preferences, and capabilities are assessed and a service plan is developed jointly with the individual. The service plan must include activities such as a person-centered planning process and risk management techniques. States may also include an individualized budget that identifies a dollar value for the services and supports under the control and direction of the individual.

Cash and Counseling Services

- States are allowed to provide Medicaid payment for part or all of the cost of self-directed personal assistance services (other than room and board), based on a written plan of care, to individuals who would otherwise require and receive personal care services under the Medicaid State Plan or home and community-based care under a HCBS waiver.

Medicaid Coverage

- Beginning January 2008, a new optional Medicaid eligibility group is established for children with disabilities up to age 18 who meet the disability definition for children under the Supplemental Security Income (SSI) program with family income above the financial standards for SSI but not more than 300 percent of the federal poverty level (FPL). States would be permitted to exceed 300 percent FPL, but federal financial participation would not be available above that level. Medicaid coverage would be phased in depending on a child's age, beginning with qualifying children with disabilities up to age 6 beginning January 1, 2008; up to age 12 in FY 2009, and up to age 18 in FY 2010.

Alternatives to Psychiatric Residential Treatment

- For federal fiscal years 2007-2011, DHHS is authorized to conduct demonstration projects in up to 10 states to test the effectiveness of improving or maintaining a child's functional level, and cost-effectiveness of providing coverage of home and community-based alternatives to psychiatric residential treatment, for children enrolled in Medicaid. Demonstration participants would be required to meet the level of care of a psychiatric residential treatment facility and the average per-person project expenditures cannot exceed the average per person cost of a psychiatric residential treatment facility.

Respite Services

A new federal respite program has been established that will provide $289 million over five years, beginning in 2007. The grants will be directed to statewide respite care service providers and will be available for various purposes, such as training and recruiting workers and volunteers, training family caregivers and providing information about available services.

D. Needs Assessment

Currently, a Needs Assessment on long-term care services and supports in Connecticut is being conducted by the University of Connecticut Health Center's Center on Aging. The General Assembly's Commission on Aging, in consultation with the Long-Term Care Advisory Council and the Long-Term Care Planning Committee, contracted with the Center on Aging to conduct a comprehensive needs assessment of the unmet long-term care needs in the state and projections of the future demand for these services. This Needs Assessment was mandated by Public Act 06-188, Section 38, and funded with a $200,000 appropriation from the Connecticut General Fund and an additional $80,000 from the Connecticut Long-Term Care Ombudsman Program.

In an effort to inform this Plan, preliminary findings have been provided by the Center on Aging and are listed below. These findings are considered preliminary since surveys are still being collected until March 2007 and, therefore, these findings are based on a sample of surveys received to date. In addition, for purposes of these findings, the data has not been stratified and analyzed based on demographic characteristics such as age, gender, income and disability status. Additional findings from the Needs Assessment regarding

providers can be found in Section III under Long-Term Care Services and Supports and data on informal and paid caregivers can be found in Section IV under Caregiver Supply and Demand. A complete report on the Needs Assessment findings and recommendations will be available in the spring of 2007.

Long Term Care Planning

- People have limited resources set aside for long-term care and have done little in the way of long-term care planning.
- Some people continue to erroneously believe long-term care costs will be paid by Medicare or private health insurance.
- Most people would like to stay in their own homes. With regard to other options, assisted living and continuing care retirement communities appeal strongly to Connecticut residents, yet few report having the financial resources to pay for these options.

Long Term Care Service Use

- Finances are the primary barrier to receiving formal services.
- Health care providers and social workers are the most commonly reported sources of information for formal services.
- Users of LTC services report high satisfaction and most of their needs are being met.
- The greatest unmet service need is homemaker services from an agency (for laundry, shopping, cleaning, etc.) followed by transportation services.
- For people with disabilities, additional top unmet needs for long-term care services are vocational rehabilitation services, money management, and job support staff.
- Many providers of long-term care, from across provider types, stated that people with certain behavioral or psychiatric conditions are not eligible for their services.

Informal Caregiving

- Caregiving is common in Connecticut (slightly higher than the national average).
- About one-fourth of caregivers provide care to two or more people.
- Parents are the typical care recipients.
- Moderate/advanced dementia is common among those receiving informal care.

Transportation

- The availability of affordable and accessible transportation was cited as an important issue by both consumers and providers.
- Attending medical appointments, socializing, and shopping or doing errands are the most difficult aspects when relying on formal transportation services.

Housing

- Remaining in one's own home is the primary preference for the vast majority of respondents. However, the majority of the respondents report that home maintenance, handyman service, and lawn/snow care would be essential for independence. This was followed by homemaker services, transportation, home health and personal care.

- Respondents highly endorse the following housing arrangements as likely options for them: Apartment or condominium living, 55+ retirement community, assisted living, and a continuing care retirement community.

E. Recommendations and Action Steps

To fully address the improvement of long-term care services and supports in Connecticut, two types of recommendations have been developed. *Balancing – the Long-Term View* offers recommendations that work to balance the capacity and financing of community-based services with institutional care. Two ratios are addressed: the ratio of home and community-based and institutional services and the ratio of public and private resources. The second type of recommendations provide a broad look at needed long-term services and supports by addressing issues identified under nine *Focus Areas*: Community Options, Informal Caregivers, Long-Term Care Workforce, Housing, Employment, Transportation, Access, Prevention and Quality.

Balancing -- The Long-Term View

1. Balancing the ratio of home and community-based and institutional care

- ***Connecticut should work to develop a system that provides for more choice, increasing the percentage of Medicaid long-term care clients receiving home and community-based care from 51 percent in 2006 to 75 percent by 2025, requiring approximately a one percent increase in the percentage of Medicaid long-term care clients served in the community every year.***

Home and Community-Based Infrastructure

- Examine the possibility of providing greater uniformity among the different Medicaid home and community-based waivers in terms of requirements such as age and income limits, and of providing maximum flexibility and choice as to how waiver funds can be utilized. Within the confines of federal Medicaid law that prohibits combining individuals who are (1) aged and disabled, (2) intellectually disabled or developmentally disabled, or (3) mentally ill into a single waiver, the State should explore any options that may be available, particularly options that do not discriminate against persons with psychiatric disabilities.

- Maximize the involvement of individuals with disabilities and family members of individuals with disabilities in the development and implementation of Connecticut's long-term care system.

- Explore the opportunity to strengthen consumer directed care provided by the Cash and Counseling provision of the federal Deficit Reduction Act of 2005.

- Explore the opportunity to expand home and community-based care provided by the Expanded Access to Home and Community-Based Services (HCBS) and Presumptive Eligibility provision of the Deficit Reduction Act of 2005.

- Explore training opportunities for conservators, guardians, families, probate system staff, medical personnel, social workers, and others about supporting choice, autonomy and dignity and the assistance available for transitioning from institutions to the community and the services available in the community after transition.

- Review Connecticut statutes to identify opportunities to enhance protections of persons with disabilities when there is a conservator involved.

Nursing Facility Transitions

- Connecticut should continue its support of programs to assist individuals in transitioning out of nursing facilities and other institutions. The Nursing Facility Transition Program (NFTP), also called My Community Choices, has shown that with the proper supports and services, individuals with severe disabilities can successfully transition to, and remain in, the community.

- Connecticut should build on the successful components of the NFTP and strive to sustain those elements into the future. For example, the Common Sense Fund, used under the NFTP to provide transition expenses such as security deposits and home modifications should be made a standard benefit. In addition, the State should explore providing reimbursement for peer mentoring and encouraging community activities.

- Connecticut should continue its landmark decision to allocate a number of Section 8 vouchers for individuals transitioning from nursing facilities, developed as part of the Nursing Facility Transition Project.

- Connecticut should work with housing providers, such as Residential Care Homes, Congregate Housing, DMR Residential Services and others to maximize the housing and service and supports opportunities for individuals transitioning from nursing facilities.

Prescreening Efforts

- Connecticut should expand its present commitment to prescreening all applicants to nursing facilities age 65 and older, regardless of their payer status, to include all nursing facility applicants, regardless of their age or payer source. Helping a private pay nursing facility applicant understand their community options and possibly avoid or delay their entrance into a nursing facility is not only advantageous to the individual and family but is a wise investment for the State. Similar prescreening for all institutions should be developed for individuals with disabilities.

- As part of the prescreening efforts, the State, in conjunction with providers and other entities working in the community with individuals with disabilities, should enhance

their existing educational efforts with hospitals, physicians, nursing facilities, and other institutions regarding available community options.

Adjustments to Institutional Capacity

- As nursing facilities and other institutions close, or occupancy levels are reduced, Connecticut should continue to conduct a needs analysis to: 1) determine if any of the beds are needed elsewhere in the system; and 2) de-license or reclassify the remaining beds. As this occurs, there is an opportunity to redirect the appropriate level of resources to enhance home and community-based services and supports. Currently, the general practice is that savings from any reduction in institutional beds goes to the General Fund. In order to allow for a redistribution of resources, at the time the beds are removed from the system, a determination should be made as to the cost to provide services for those institutional beds and the costs to provide services to the same number of individuals in the community. If the redistribution occurs, the result will be an increase in home and community-based service expenditures coupled with an increase in the number of individuals served in the community. The difference between the cost of paying for the institutional beds and the cost for community care could be savings to the General Fund.

- Connecticut should create incentives for under utilized institutions to convert their facilities to adult day care services, assisted living, residential care homes, independent living communities, or other community housing options in order to offer settings that reflect the more home-like features that people generally prefer. Such conversions could help mitigate the large capital expense of building the new housing options that will be needed to help accommodate the increase in individuals receiving services and supports in the community. These conversions can also help institutional operators remain in the long-term care field and utilize their staff as service providers in the community. Such incentives could include low-cost financing for conversions and tax credits. Development of any new community housing options should emphasize consumer direction and choice.

- Connecticut should assess the need for extending the moratorium on construction of new nursing home beds when the enabling legislation sunsets in 2007.

Federal Reform

- Connecticut should continue to advocate for changes to federal Medicaid law that will facilitate an expansion of home and community-based options. In the past, Connecticut submitted a proposal to the federal Centers for Medicare and Medicaid Services (CMS) to expand the medically needy income formula allowing individuals with incomes in excess of 300 percent of Supplemental Security Income to be eligible under the Medicaid portion of the Connecticut Home Care Program for Elders (CHCP). This proposal would have allowed individuals the same access to home and community-based care as they have for nursing facility care. Unfortunately, Connecticut's proposal was rejected by CMS. Connecticut should resubmit this

proposal and continue its efforts in this regard. If successful in its effort to expand the income requirements under the CHCP rules, Connecticut should examine the feasibility of utilizing similar income requirements under its other home and community-based waiver programs, resulting in equal access to home and community-based care and nursing facility care for individuals of all ages and disabilities.

- Current Medicaid law prohibits the reimbursement of room and board charges for those living in the community, including in assisted living communities. Connecticut should continue its efforts to remove this prohibition or expand other federal programs such as Section 8, allowing more aggressive development of community living options.

- Work with Congress and the Centers for Medicare and Medicaid Services to eliminate the "homebound" definition for Medicare home health care or, at a minimum, liberalize this requirement with respect to individuals with long-term disabilities.

2. Balancing the ratio of public and private resources

- ***Connecticut should strive over the next 20 years to increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent. Such an increase in private insurance and other sources of private funding would reduce the burden both on Medicaid and on individuals' out-of-pocket expenses. Nationally, private insurance represented 7 percent of long-term care spending in 2004.***

Planning Ahead for Long-Term Care

- Connecticut should create new options to encourage personal responsibility and planning and identify and maximize existing non-governmental resources.

- Connecticut, working with the federal government, should develop incentives for individuals to save for their future long-term care needs. Preferential tax treatment for dedicated long-term care savings accounts could provide some additional opportunities to infuse private resources into the system without forcing individuals to impoverish themselves. Connecticut should also explore opportunities on the state level to provide tax relief for unreimbursed medical and long-term care expenses.

- Connecticut should continue, and enhance, the efforts of the Connecticut Partnership for Long-Term Care (Partnership), the State's public/private alliance to help educate Connecticut residents about the importance of planning ahead for future long-term care needs through the purchase of high quality private long-term care insurance (LTCI). While the Partnership has had a significant impact on the purchase of private long-term care insurance, with over 40,000 Partnership policies purchased, there is much more that can be done.

The Partnership should continue its strategy of presenting LTCI as an option that can help individuals remain in their homes or communities longer, preventing or delaying the need for nursing home care. If individuals understood that LTCI could actually help them remain at home or in the community it might become a more attractive option.

- The State should pursue possible funding under the federal Long-Term Care Awareness Campaign. This demonstration project sponsored by the U.S. Department of Health and Human Services is designed to help states increase consumer awareness of the need of long-term care and financial planning.

- The State should take advantage of any opportunities to enhance the educational capabilities of the Partnership through the use of public and private resources. Alliances with local communities should be explored to bring the issue of long-term care planning into as many communities as possible. In addition, partnerships with the state's media outlets should be enhanced to enlist the media's support in the efforts to educate Connecticut residents about this important issue.

- Connecticut should explore the development of various products, including a high-risk pool for long-term care insurance to enable individuals who are currently uninsurable to obtain the coverage they need.

- Connecticut should continue its efforts on the federal level to enact an "above the line" tax deduction for the purchase of long-term care insurance. Such a tax deduction would also result in a State tax deduction as long as Connecticut's tax system is tied to an individual's federal Adjusted Gross Income. If federal action on this issue is not taken, Connecticut should explore its own tax incentives for long-term care insurance, such as tax credits or deductions. Any effort to provide tax incentives should be targeted or focused to ensure that the market is truly expanded to include those where the insurance might be unaffordable.

- Connecticut should explore and develop other models for private long-term care insurance. Such models could include a combination disability and long-term care insurance policy or variations on existing combination life insurance and long-term care insurance policy.

- Connecticut should examine the state and federal reverse annuity mortgage (RAM) programs to see if any enhancements can be made to increase the usage of this program. An effective RAM program could allow individuals to use their home equity to remain in their homes longer or even to use the resources to purchase long-term care insurance if that is an affordable and accessible option for them. RAMs may become more popular in light of the DRA provision on home equity and Medicaid eligibility for long-term care services described earlier.

Focus Areas

1. Community Options

- Enhance the capacity of communities to accommodate the needs of individuals with disabilities. Encourage communities to take an active role in planning and supporting long-term care for their residents.

- Encourage communities to provide a more supportive infrastructure including more affordable housing, expanded and coordinated transportation options, and side walks, cross walks and curb cuts.

- Encourage the adoption of actions developed within Model Communities and Interroburst conferences to reduce the isolation felt by individuals with disabilities living in the community and their families.

- Encourage public education on the role all citizens can play within their communities in addressing long-term needs of their friends, neighbors and fellow citizens.

- Connecticut should support additional Interroburst forums to explore the meaning of community and to reduce the isolation of individuals and families.

- Continue support of the monthly series "Able Lives" aired on Connecticut Public Television in 2006 to educate the public on the lives of individuals with disabilities and effect the change needed to create more inclusive communities. This program is sponsored by the Connecticut Council on Developmental Disabilities and other state and private agencies.

- Explore the benefits and potential for adding a service to the Connecticut Home Care Program for Elders that allows payment to Adult Day Care Centers for therapies, making them approved rehabilitation sites. This should include consideration of licensing and Medicaid reimbursement issues.

2. Informal Caregivers

- In order for individuals with disabilities to remain at home or in the community as long as possible, support for family caregivers should take a variety of coordinated forms. These could include information and training, respite services to caregivers, tax benefits and incentives, payment to informal caregivers, transportation alternatives, physical, occupational and speech therapy alternatives, and disability supports.

- In addition to continuing existing respite care efforts, Connecticut should replicate its successful Alzheimer's Respite Care program to provide respite services for any caregiver of individuals with disabilities of all ages. Respite across the lifespan should be available to provide an easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs, and assist with locating training and paying respite providers. As Connecticut begins to increase the amount it spends on home and community-based care while reducing its institutional expenditures, it should allocate resources towards the support of informal caregivers through respite care and caregiver training programs.

- The State should build on and expand current efforts supported under the National Family Caregiver Support Program, enhancing the basic information, training and respite services that are already provided.

- Connecticut should explore the potential for supporting overnight respite care in settings other than institutions. This should include consideration of licensing and Medicaid reimbursement issues.

- Respite training should be considered as part of the curriculum within appropriate programs at state colleges and universities and other educational settings. Such curriculum also should include a component to assist individuals with disabilities and their family members in promoting self-determination.

- Training should be developed for public and private providers to better assist families and other informal caregivers to develop the supports necessary to allow a person with disabilities to live in their community.

- Connecticut should continue its efforts on the federal level to enact a tax credit for those providing informal care.

3. Long-Term Care Workforce

- Connecticut should expand the use of the non-traditional workforce, such as personal care assistants (PCAs) and personal care managers, to help address the increased number of individuals desiring home and community-based care. To make the positions competitive and a viable career, these types of jobs will need to provide the necessary worker benefits and supports. In addition, optional training for PCAs should be considered part of the curriculum within appropriate state colleges and universities and other educational settings.

- Connecticut should work with organizations to continue the efforts of the C-PASS grant as it pertains to training employers how to hire and manage personal care assistants, as well as to continue the Rewarding Work.org website.

- Connecticut should evaluate the Personal Care Assistance Pilot under the Connecticut Home Care Program for Elders to determine the potential for making personal care assistance a permanent benefit.

- Connecticut should develop programs to address the professional workforce shortage. Strategies could include attracting students into the field with scholarships and grants, developing career paths allowing for increases in responsibility, status and wages, enhancing public perception of these jobs, and professionalization of paraprofessional positions. There is also potential for re-training individuals who lose their job in such sectors as manufacturing for a new career in long-term care.

- Connecticut should increase the capacity of educational institutions (i.e. state colleges and universities and high schools) to provide training for professional long-term care workers in order to address the current need for and projected growth of these workers in the state.

- Connecticut should promote the use of distance learning programs to enhance the skills of direct support professionals.

- Home care agencies, nursing homes, and other long-term care providers should consider ways to increase the numbers of direct care workers and provide incentives for recruiting and retaining workers.

- Recruitment of bilingual workers is needed to assure services are accessible and acceptable to individuals whose primary language is not English.

4. Housing

- Over the next biennium, support the efforts of the Accessible Housing Registry to identify accessible units and increase their utilization.

- Expand and preserve the stock of housing for elders and persons with disabilities.

- Enforce current standards in Connecticut regulation and statute, including the Building Code, which require builders of new developments to create a certain percentage of wheelchair accessible units.

- Promote universal design with architects and housing developers.

- Increase outreach to landlords about resources and financing to make their units accessible.

- Increase the utilization of Section 8 Vouchers in communities throughout Connecticut so additional vouchers may be requested from HUD.

- Establish a Resident Services Coordinator in every State-funded Elderly Housing facility. Currently, there is one Resident Services Coordinator in every three facilities. Training is also needed to equip Resident Service Coordinators to serve both older adults and individuals with disabilities.

- Expand assisted living options beyond those available to the elderly.

- Ensure that all State agencies that construct or rehabilitate housing or provide rental assistance report the accessible units to the accessible housing registry.

- Maintain current building codes for type A units and require local building officials to report such units to the Department of Economic and Community Development as part of the building permit process.

5. Employment

- Improve the transition process for young adults moving from school to post-secondary education or employment.

- Increase expectations for people with disabilities in achieving career potential.

- Increase the recruitment, employment and retention of individuals with disabilities into Connecticut businesses.

- Increase access to transportation to and from work for individuals with disabilities.

- Provide technical assistance to support the development of effective strategies for increasing employment of people with disabilities.

6. Transportation

- Whenever new housing resources are being developed for individuals with disabilities or the general public, consideration should be given to the availability of public transportation resources.

- Whenever new supportive employment opportunities are being developed for individuals with disabilities, consideration should be given to the availability of public transportation resources.

- The Department of Transportation, the Office of Policy and Management, State agencies and stakeholders involved in serving or transporting clients and individuals with disabilities should engage a facilitated long-term planning process to evaluate the existing transportation system. The goal of this evaluation should be to improve the existing transportation system to achieve uniform coverage and to better meet the

medical and social needs of Connecticut citizens with disabilities to allow them to participate fully in community life.

- Towns, community service providers and Department of Transportation services should collaborate to increase cost-efficient and flexible transportation. Collaboration will reduce instances when agency or municipal vehicles sit idle for part of the day or when multiple transportation services under a variety of agencies travel to similar destinations.

- Some people with disabilities do not always feel safe as passengers on public transportation. Lack of compliance with safety procedures and improper use of equipment are cited as problems. Drivers, despite mandated reporting requirements, do not always report incidents. Drivers and dispatch workers should be mandated to receive awareness and safety training by using people with disabilities as trainers.

7. Access to Information and Services

- Over time, provide maintenance and ongoing updating of the Long-Term Care Services and Supports Website, which was finalized and released to the public in the fall of 2006. The website provides accessible information to all individuals in need of long-term care services and supports, regardless of age or disability.

- Explore the development of long-term care information resources for those consumers without Internet access.

- Over the next biennium and over time, distribute the *Nursing Facility Transition Project Handbook* to all present and future Nursing Facility residents.

- Over the next biennium and over time, distribute the *Department of Mental Retardation (DMR) Consumer and Family Guide to the DMR Home and Community-based Services Waivers* and *Understanding the DMR Home and Community-based Waivers: An Introduction to Your Hiring Choices Guide* to all present and future DMR consumers.

- Expand existing information and referral resources in order to establish and evaluate a Nursing Facility Transition Project hotline that will serve as an information resource for those interested in transitioning to the community.

- Initiate public/private partnerships to enhance public education regarding all aspects of the long-term care system in Connecticut. This should be done, in part, by building upon existing resources such as CHOICES and Infoline. Include business, government, legislative, and faith-based organizations, and community as well as consumer partners in this campaign to recognize strengths and needs of all individuals and families, to attract more workers to the health care arena, and to increase community concern and commitment to change.

- Support specific programs to disseminate information about transportation resources to both users and human service providers. Tools such as websites, the "Getting on Board" brochures used by case workers facilitating access to jobs for people with disabilities, and Infoline are resources for individuals to access information about transportation services available in their region.

8. Prevention

- Utilize health promotion resources and initiatives outside of State government and attempt to coordinate the various efforts.

- Encourage further development of Visitation Programs for individuals and families in home, community and structured settings.

- Establish a working Fall Prevention partnership between the Department of Social Services (DSS) Aging Services Division and the Department of Public Health (DPH) to expand current DPH fall prevention projects (i.e. home safety assessments, fall prevention seminars, medication safety programs, and fall prevention exercise classes) to serve new populations and geographic areas. Conduct social marketing, distribute public education materials, and utilize the media. Coordinate these activities with other existing Fall Prevention programs in the state. While fall prevention efforts are primarily focused on the elderly, fall prevention programs should be available to individuals of all ages.

- Explore opportunities to prevent the incidence, and delay the progression, of chronic diseases, such as better integration of the delivery of acute and long-term care across settings, use of prescription drugs, increased use of technology such as telemedicine, and increased patient education and self management.

- Explore implementation of Wellness and Nutrition programs and the use of managed health care coordination for individuals served by the Department of Mental Retardation (DMR) who live on their own or with their families as a means to identify and prevent emergent serious health conditions.

- Explore opportunities to work with Connecticut's medical and dental schools and allied professions to increase access to health care screening and preventive and restorative dentistry for individuals with disabilities. For example, establish a DMR Dental Coordinator and possible University of Connecticut dental fellowship to address the lack of community dental care for persons with cognitive disabilities.

- Reduce the incidence of disabilities in newborns by increasing awareness of mercury poisoning and Fetal Alcohol Syndrome.

9. Quality of Care

- Develop improved quality measures for persons with disabilities in the community under person-centered, consumer-directed programs. Such measures must reflect the individuals' own preferences and desires and allow reasonable risks while still avoiding unreasonable risks.

- Connecticut should support the purchase and maintenance of assistive technology. More emphasis should also be placed on the use of robotics in the home to assist with activities of daily living. Expenditures for assistive technology can be minor when compared to the extended cost of human services for personal assistance. This technology can allow an individual to maintain or regain independence and reduce their reliance on paid services.

- Develop a plan to modernize the physical plants of existing nursing facilities.

- Expand the role of the Long-Term Care Ombudsman's Office, which oversees nursing facilities, residential care facilities and assisted living facilities, to include other long-term care settings and include consumer education about the availability of these services. Provide adequate funding for such an expansion.

- Encourage a plan for emergency management supports for people with disabilities and elderly persons. This should include networking with local, state and national organizations, as well as working on information that can be used to encourage personal preparedness.

F. Development of the 2007 Long-Term Care Plan

The Long-Term Care Planning Committee, created under Public Act 98-239, is charged with developing a long-term care plan for Connecticut every three years for the General Assembly. Committee membership is comprised of representatives of ten State agencies and the Chairs and Ranking Members of the General Assembly's Human Services, Public Health and Aging Committees (see Appendix B for a list of Planning Committee members). The Long-Term Care Advisory Council, created under Public Act 98-239, composed of providers, consumers and advocates, provides advice and recommendations to the Planning Committee (see Appendix C for a list of Advisory Council members).

In 2006, the Long-Term Care Planning Committee embarked on the development of its fourth long-term care plan in partnership with the Advisory Council. The Advisory Council worked with the Planning Committee in four essential areas: providing data, identifying areas of need, developing priorities and recommendations, and obtaining public input.

Also in 2006, the Long-Term Care Planning Committee, working with the Commission on Aging and the Long-Term Care Advisory Committee, provided input into the development of a legislatively mandated Long-Term Care Needs Assessment. Some

preliminary findings from the Needs Assessment inform this Plan. The complete Needs Assessment will be released in the spring of 2007.

The Advisory Council 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 was solicited in October and December of 2006 and again in January of 2007. (*see Appendix D – Sources of Public Comment).*

G. Implementation of the 2007 Long-Term Care Plan

To implement the majority of the recommendations and action steps included in this Plan, the Governor and General Assembly will need to make decisions regarding statutory changes and allocation of resources. For those items that the Governor and the General Assembly choose to pursue, the State agencies represented on the Planning Committee, in collaboration with the Long-Term Care Advisory Council, will work together to implement those recommendations and action steps.

For those aspects of the Plan that do not require legislative changes or allocation, or reallocation, of resources, the State agencies represented on the Planning Committee, in collaboration with the Long-Term Care Advisory Council, will work together to address these items and periodically review their progress.

II. VISION, MISSION AND GOVERNING PRINCIPLES

The Long-Term Care Planning Committee developed and continues to refine its Vision, Mission and Governing Principles to guide the development of its Long-Term Care Plan and recommendations for enhancing the long-term care system in Connecticut. They provide a philosophical framework that values choice, consumer-centered care, and a seamless continuum of supports and services for all individuals in need of long-term care, regardless of disability and across the lifespan of fluctuating needs.

A. Vision

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

B. 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.

C. 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.

III. LONG-TERM CARE IN CONNECTICUT

A. The People

People of all ages and from all walks of life need long-term care supports and services. They are our parents, siblings, children, co-workers and neighbors. They are us. Whether challenged with limitations due to injuries, developmental disabilities, mental illness, chronic health conditions, or the aging process, they all share a common need for assistance in order to live, learn, work and play.

Assistance may be needed to carry out basic functions such as eating, dressing or bathing (activities of daily living -- ADLs) or tasks necessary for independent community living, such as shopping, managing finances and house cleaning (instrumental activities of daily living -- IADLs). Likewise, needs range from minimal personal assistance with basic activities to virtually total care. These long-term care needs are being met at home, in the community, in congregate residences and in institutional settings.

It is important to note that long-term care is different and distinct from medical care. The major distinction is that the goal of long-term care is to allow an individual to attain and maintain an optimal level of functioning in every day living. The goal of medical care is to cure or control an illness.

A Word About the Data

Currently, there is no single source of information on the need for long-term care services and supports among individuals with disabling chronic illness and conditions in Connecticut. There is also no one source of information that looks at needs across the lifespan or across types of disabilities. In order to develop a picture of the need for long-term care in Connecticut, regardless of disability, limitation or age, a broad array of sources have been consulted.

Complicating our understanding of who needs long-term care is the fact that there is no single accepted definition of disability or way of defining the need for long-term care. Research findings vary from study to study depending on how the population in need is defined and whether the focus is on individuals with disabilities in general or those with long-term care needs specifically. Disability, which is most commonly defined in terms of long-standing limitations in tasks and activities, is used in this Plan as a measure for the need for long-term care services and support, unless otherwise specified, although it is acknowledged that not everyone with a disability will need supports at any given time.

Much of the data on disability in Connecticut used this report is drawn from the U.S. Census Bureau 2005 American Community Survey (ACS). The Census Bureau defines disability as a long-lasting sensory, physical, mental, or emotional condition. The ACS uses six disability items to determine an individual's disability status: 1) sensory limitations, 2) physical limitations, 3) limitations in cognitive functioning, 4) self-care

limitations, 5) going outside home limitations, and 6) employment limitations. [4] It should be noted that the numbers of individuals with psychiatric disabilities in Connecticut may be undercounted in the ACS.

Who Needs Long-Term Care Services and Supports?

National Perspective

In 2000, 9.5 million people in the U.S. reported needing long-term care when asked if they require another person's help with one or more ADLs or IADLs. Of these individuals, the vast majority (83 percent) live in the community, with 17 percent residing in a nursing home. Younger individuals are more likely to remain in the community. Among those under age 65, 95 percent reside in the community, in contrast to 75 percent of those age 65 and over and 61 percent of those age 85 and older.[5]

For those who have reached the age of 65, the lifetime probability of developing a disability in at least two primary activities of daily living for at least 3 months or becoming cognitively impaired is 44 percent for men and 72 percent for women. This higher probability of disability for women is related to several factors, not least of which is that on average women live longer than men and are therefore more likely to develop a chronic illness. Also among those age 65 and over, the average lifetime service costs associated with ensuring that all individuals who develop a disability can remain in their home for the entire course of their disability total $175,000 in 2002 dollars.[6]

Connecticut

Disabilities affect nearly 12.7 percent of Connecticut residents living in the community -- one in every eight -- lower than the national average of 14.9 percent. According to the U.S. Census, in 2005 there were approximately 402,400 individuals over the age of five living in Connecticut communities with some type of long-lasting condition or

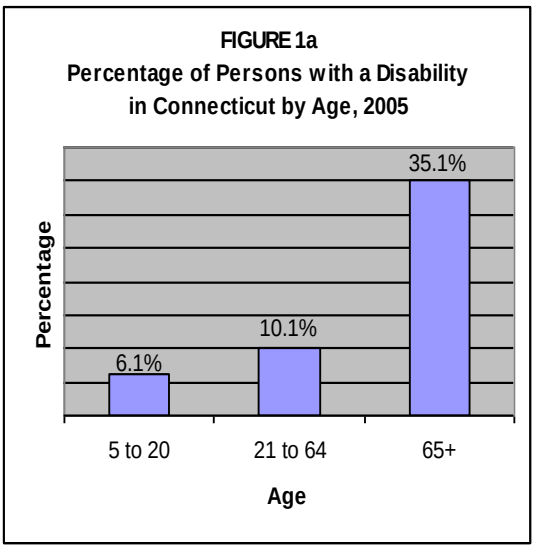
TABLE 1
Number of Persons with Disabilities in Connecticut by Age, 2005

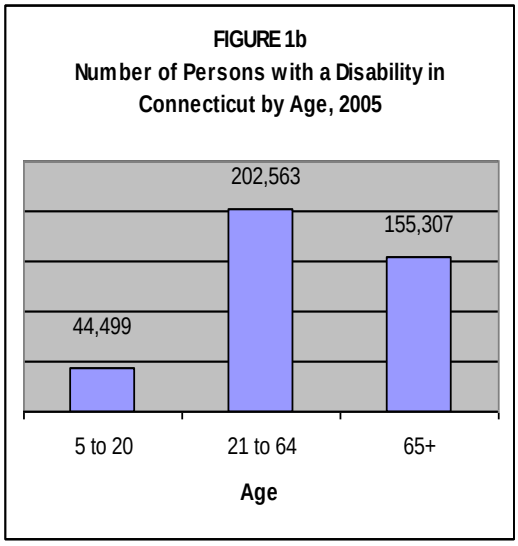
Age	Total Population	Persons with a Disability	Percentage
5 and over	3,179,291	402,369	12.7%
5 to 15	521,274	28,900	5.5%
16 to 20	207,501	15,599	7.5%
21 to 64	2,007,937	202,563	10.1%
64 to 74	211,281	50,307	23.8%
75+	231,298	105,000	45.4%

Source: U.S. Census Bureau, American Community Survey, Custom Table, 2006

[4] Source: U.S. Census Bureau, American Community Survey, 2005 Subject Definitions, page 32 to 35. www.census.gov/acs/www/Downloads/2005/usedata/Subject_Definitions.pdf , pages 31-34.
[5] "Who Needs Long-Term Care?" Long-Term Care Financing Project, Georgetown University, May 2003, based on the 2000 National Health Interview Survey and the 1999 National Nursing Home Survey.
[6] Marc A. Cohen et al, *Becoming Disabled After Age 65: The Expected Lifetime Costs of Independent Living*, AARP, June 2005, page v.

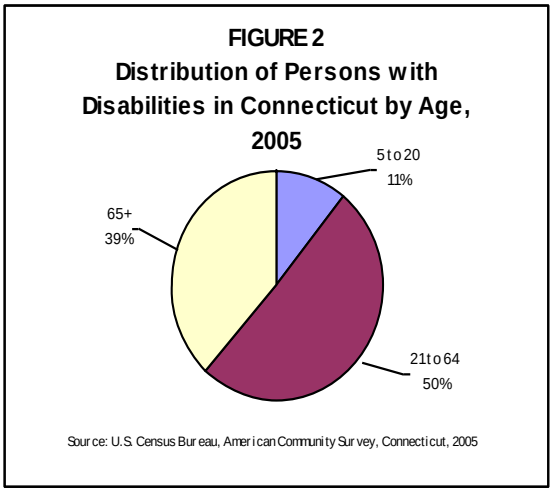
disability (Table 1).[7] Disability rates rise with age, with 5.5 percent of children age 5 to 20 reporting a disability, 10.1 percent of adults age 21 to 64, and 35.1 percent of elders age 65 and over (Figure 1a).





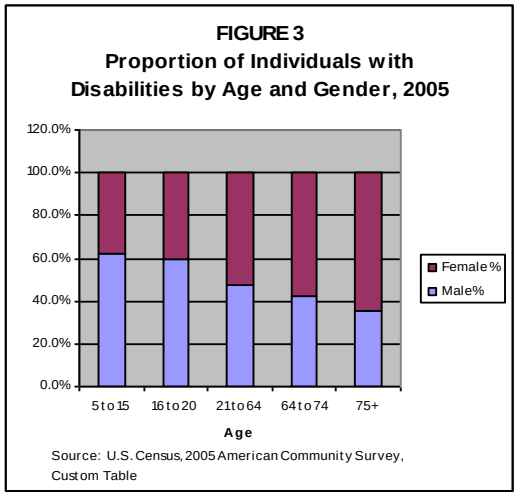
Source: U.S. Census Bureau, American Community Survey, Connecticut, 2005

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 disability are younger adults between the ages of 21 and 64. In 2005, there were 44,499 children and youth age 5 to 20 with a disability in Connecticut, 202,563 individuals age 21 to 64, and 155,307 individuals age 65 and over, representing 11 percent, 50 percent, and 39 percent of those with disabilities, respectively (Figure 1b and Figure 2). Among individuals with disabilities, the ratio of males to females shifts as the population ages, as is the case in the general population. Among children and youth with disabilities, over 60 percent are males. By the senior years, this proportion

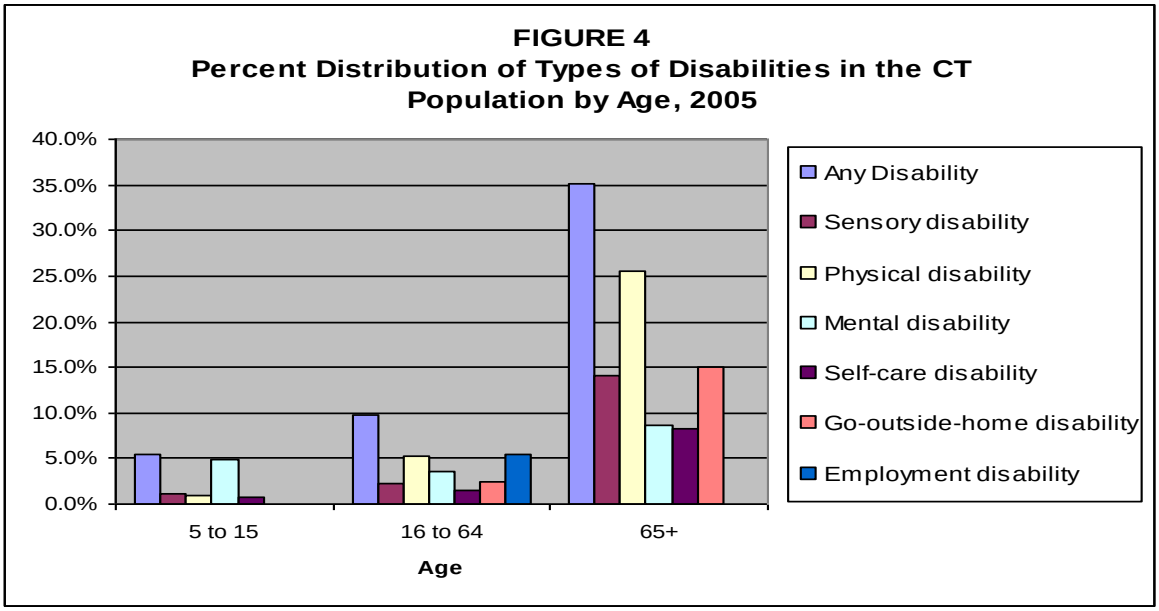


[7] U.S. Census Bureau, 2005 American Community Survey, Connecticut, Selected Social Characteristics. Data are limited to the household population and exclude the population living in institutions, college dormitories, and other group quarters. The American Community Survey, which samples housing units and their occupants, is a relatively new nationwide Census survey that provides Census data every year instead of once in ten years. Note that the number and percent of people with a disability from the 2005 American Community Survey forward is not comparable to the number and percent found in the 2000 decennial census and reported in the 2004 Long-Term Care Plan.

is reversed, with females comprising over 60 percent of those with disabilities (Figure 3).



The distribution of types of disabilities in the population varies considerably by age (Figure 4).[8] Among individuals in the 5 to 15 year old group, almost 5 percent had a mental disability, while the prevalence of sensory, physical or self-care disabilities was one percent. Employment and physical disabilities are the most common limitations among those between the ages of 16 and 64 with a disability, affecting approximately 5 percent of the population in each case. Individuals age 65 and over are most affected by physical disabilities and limitations regarding going outside the home, affecting 26 and 15 percent respectively. It should be noted that an individual may have one or more disabilities, so the percentages in any particular age group could exceed 100 percent.[9]



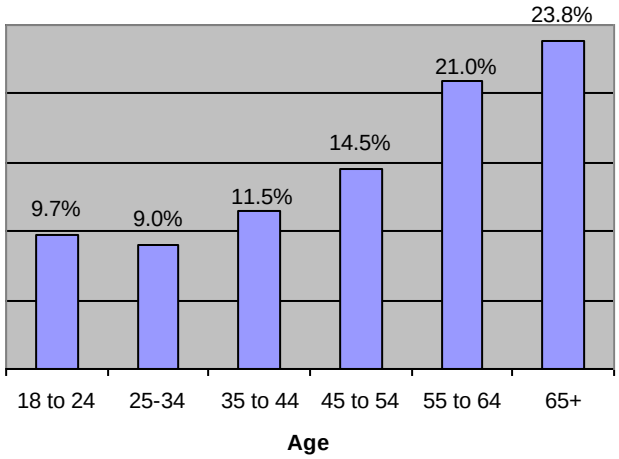
Source: U.S. Census, 2005 American Community Survey, Table S1801: Disability Characteristic

[8] U.S. Census Bureau, 2004 American Community Survey, uses six disability items to determine an individual's disability status: 1) sensory limitations, 2) physical limitations, 3) limitations in cognitive functioning, 4) self-care limitations, 5) going outside home limitations, and 6) employment limitations. Source: U.S. Census Bureau, American Community Survey, 2004 Subject Definitions, page 32 to 35. www.census.gov/acs/www/Downloads/2004/usedata/Subject_Definitions.pdf

[9] For example, a person with severe asthma may have difficulty climbing stairs and difficulty working at a job.

Another picture of individuals with disabilities is provided by the Connecticut Behavioral Risk Factor Surveillance System (BRFSS), which surveys adults age 18 and over living in the community. Overall, in 2005, 15 percent of Connecticut adults answered yes when asked if they are "limited in any way in any activities because of physical, mental or emotional problems." This translates into approximately 393,078 Connecticut adults living in the community with some degree of activity limitation (Figure 5). This compares to the 2005 Connecticut Census estimate of 402,369 individuals with disabilities. Compared to the Census findings, the BRFSS survey found a higher proportion of younger individuals in Connecticut with disabilities (13.1 percent for ages 18 to 64 versus 9.8 percent for ages 16-64, but a lower proportion of individuals with disabilities age 65 and older (23.8 percent versus 35.1).

FIGURE 5
Connecticut Residents Limited Due to a Physical, Mental or Emotional Problem by Age, 2005



Source: Centers for Disease Control, Behavioral Risk Factor Surveillance System, 2005 Core Variables Report, Jan. 18, 2006.

B. Long-Term Care Services and Supports

Home and community-based services

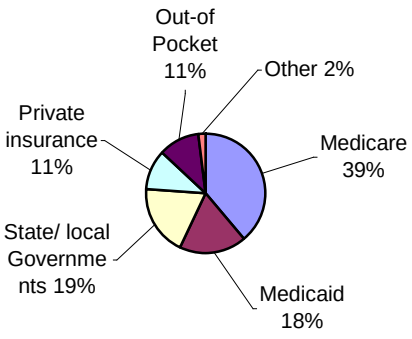
Traditionally, long-term care has been associated with nursing homes or other institutions. In fact, the vast majority of long-term care is provided at home by informal and formal caregivers. Over the last decade, opportunities to live and obtain supports in community settings have increased significantly, with a growing emphasis on independent living and consumer choice. Increased availability of home and personal care supports have allowed increasing numbers of individuals to remain in their homes and avoid or delay moving to an institutional setting.

Home and community-based care includes a range of varied services and supports provided either formally, by paid individuals, or informally, by family and friends. Typically, the level of formal support used increases with age, functional impairment and income.

Home Care

The number of home care agencies in the U.S. has grown rapidly over the last 30 years, from 1,100 in 1963 to approximately 20,000 in 2004. The term 'home care' includes home health agencies, home care aide agencies and hospices. Collectively, the 20,000 home care agencies in the U.S. delivered care to 7.6 million individuals who required

FIGURE 6
Sources of Payment for Home Health Care in the U.S., 2005



Source: CMS, Office of the Actuary, National Health Care Expenditures Projections: 2005-2015, Table 10.

services due to acute illness, long-term health conditions, permanent disability, or terminal illness at a cost of about $38.3 billion. Of these agencies, 8,224 were Medicare certified in 2005.[10]

Nationally, all levels of government – federal, state and local - covered 76 percent of home care costs in 2005. Medicare paid the largest share of skilled home care costs, covering 39 percent of the total payments. Private sources, including private insurance and out-of-pocket payment, represented 22 percent of payments (Figure 6).

Preliminary Needs Assessment Findings – Home Health Care Agencies [11]

In Connecticut, the majority of formal home care services are provided by home health care agencies. As of June 30, 2006, there were 89 agencies licensed by the Department of Public Health to provide home health care services in Connecticut.[12] Among the 29 home health care agencies responding to the Needs Assessment survey, the top five services provided include visiting nursing services (90 percent), home health aide services (90 percent), physical, speech, respiratory, and occupational therapies (76 percent), homemaker services (55 percent), and care/case management (52 percent). The smallest agency currently serves 29 clients, while the largest agency serves 1,288 clients. The average number of clients currently being served is approximately 250.

The largest proportion of clients being served by home health care agencies falls within the age range 65 to 84 (37 percent), followed closely by the age range 85 to 99 (35 percent). Individuals age 19 to 59 make up 14 percent of clients and those ages 18 and under account for 8 percent. The majority of home care clients are White/Caucasian (80 percent), followed by African American (9 percent). Five percent of the population was reported to be of Hispanic or Latino origin. Well over half (62 percent) of clients served by the home care system are female.

With regard to method of payment, over half (62 percent) of home health care clients use Medicare to at least partly pay for their home care services. Medicaid is used by 28 percent of individuals, private health insurance provides coverage for 15 percent and 11

[10] National Association for Home Care and Hospice, *Basic Statistics About Home Care*, Updated 2004 and pre-published data for the 2006 edition.
[11] University of Connecticut Center on Aging, Long-Term Care Needs Assessment, Preliminary data, January 2006.
[12] Connecticut Department of Public Health, 2006.

percent pay out-of-pocket. Clients relying on private long-term care insurance account for less than one percent.

Eight out of ten (80 percent) of all home health care agencies have eligibility requirements. The most commonly endorsed eligibility category was targeted geographic areas (78 percent), followed by the exclusion of individuals with certain behavioral or psychiatric conditions (22 percent). Other eligibility categories, endorsed 31 percent of the time, included living independently, only with a safe and appropriate environment, terminal prognosis, and requirement of a physician order.

Only 10 percent of home health care agencies have a waiting list. Over the course of the past year, almost half (48 percent) either declined services or added the person to the waiting list due to lack of available staff. An almost equal number (44 percent) declined services because the person did not meet the eligibility requirements, and over one-third (37 percent) could not provide services because of lack of staff in a particular region or town. Less than ten percent could not provide services because of lack of a payment source (7 percent) or because agency staff did not speak the client's language (7 percent). Twelve percent of agencies cited the following reasons: client required extended IVs, do not accept clients with a primary diagnosis of mental illness, or lack of Medicare reimbursement.

Thirteen percent of clients served by home health care agencies have a diagnosis of mental illness (excluding dementia), while an equal number (13 percent) exhibited challenging behaviors in the past six months. Almost three-quarters (72 percent) of all staff members have received specialized training to work with challenging behaviors. Agency directors were asked to rate their employees overall level of training and skill working with clients who have challenging behaviors. Almost two-thirds (61 percent) of agencies rated their employees as being either quite or extremely skilled in working with clients who have challenging behaviors.

Forty-one percent of home health care agencies have employees who do not show up or call out sick at the last minute at least once a month, and one-fifth (20 percent) report using temporary employees because they do not have enough staff for the day. Over one-third (39 percent) of agencies indicate they have problems with transportation for clients at least once a month, and seventeen percent have difficulty finding health care services for their clients at least once a month. For the majority of the home health agencies, most of the employee and client situations asked about seem to be not a great concern.

Adult Day Care

Adult day services are an option for frail elders who want to remain in their homes. They 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.[13] The average cost to care for an individual in an adult day center is $69 per day.[14] 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 the Connecticut Department of Social Services to provide a program of peer review and certification, which is required in order for an adult day center to receive state funds.

Preliminary Needs Assessment Findings – Adult Day Centers [15]

In 2006, there were 51 adult day centers certified by CAADC serving clients who receive state assistance.[16] Among the 33 adult day agencies responding to the Needs Assessment, the most frequently provided service was adult day care medical model (82 percent). Transportation (70 percent), recreational services (67 percent), nutritional services (58 percent), specialized dementia care (55 percent), independent living skills training (55 percent), and various therapies (55 percent) comprise the top services offered.

The average number of clients currently being served by adult day providers is 71, and ranges from eight to 430. The largest proportion of clients are age 65 to 84 (47 percent), with 41 percent age 85 or older. The majority of adult day clients are White/Caucasian (76 percent), with 17 percent African American, and only six percent of Latino origin. Almost two-thirds of adult day clients are female (63 percent).

Clients of adult day care programs have multiple payment sources. One-third of clients (33 percent) pay out-of-pocket, with slightly fewer (31 percent) using Medicaid to pay for these services and only eight percent uses Medicare. Long-term care insurance covers about one percent. Another third (34 percent) use other payment sources such as funding from a waiver program, through an agency, or from a private grant.

The vast majority of adult day programs (85 percent) have eligibility requirements. The most commonly endorsed eligibility category was geographic area (77 percent), followed by the exclusion of individuals with certain behavioral or psychiatric conditions (45 percent), the requirement of certain functional or cognitive abilities (45 percent) and an age requirement (44 percent). Other eligibility requirements included the ability to function appropriately in a group setting and a need for socialization or supervision.

Only nine percent of adult day agencies report currently having a waiting list for services. Commonly reported reasons for declining services to a client or placing a client on a waiting list in the past year were no source of payment (33 percent), person did not meet eligibility requirements (31 percent), and no program or staff in a particular region or town (15 percent). For adult day agencies, lack of transportation was most frequently

[13] The Connecticut Association of Adult Day Centers, www.canpfa.org, October 2006.
[14] Connecticut Partnership for Long-Term Care, *Cost of Care in Connecticut*, April 2006
[15] University of Connecticut Health Center's Center on Aging, Long-Term Care Needs Assessment, Preliminary data, January 2006.
[16] The Connecticut Association of Adult Day Centers, www.canpfa.org, October 2006

mentioned as the other reason for declining services to an individual, for reasons such as no bus service or current van service will not cross town lines.

Of the reporting adult day agencies, 15 percent of clients served have a diagnosis of mental illness (excluding dementia), with a slightly greater percentage of clients exhibiting challenging behaviors in the past six months (19 percent). All adult day staff members (100 percent) in this sample have received specialized training to work with clients who have challenging behaviors. When asked to rate their employees overall level of training and skill working with clients who have challenging behaviors, a great majority of agencies (82 percent) rate their employees as either quite or extremely skilled.

Adult day providers report only two significant employee concerns: having employees not showing up or calling out sick at the last minute (30 percent report this happens once a month or more) and the presence of language differences between clients and employees (24 percent report this happens once a month or more). Clients concerns were reported more frequently. Almost half of adult day providers (48 percent) report problems with client transportation once a month or more, while nearly one-third (31 percent) indicate that finding health care services for their clients is an issue at least once a month.

Medicaid Waivers

Medicaid, through its home and community-based waiver programs, is the major public financing mechanism for providing long-term care in community settings. Under the waiver programs, individuals are served in the community who would otherwise require the level of care provided in an institutional setting. Most people express a strong preference for home and community-based services over institutional care since it allows them to live in their own homes, participate in community life and exert more control over their own affairs.[17] In 2005, there were equal numbers of Medicaid long-term care clients receiving home and community based care as there were residing in institutions and in 2006 the ratio tipped to 51 percent of individuals receiving home and community-based care.

Six Medicaid Home and Community-Based Waivers are offered in Connecticut to individuals in specific populations. The Connecticut Department of Social Services (DSS) currently administers four of the home and community-based services waivers and the Department of Mental Retardation (DMR) administers the other two waivers, which are summarized below. Of the six waivers, the Elder Waiver serves individuals age 65 and over, the Personal Care waiver serves individuals age 18 and older, the Acquired Brain Injury Waiver serve adults between the ages of 18 and 64, the Model Waiver serves all ages, but primarily children, and the DMR waivers have no age limit.[18]

[17] Cynthia Shirk, *Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program*, National Health Policy Forum, March 3, 2006.
[18] Connecticut Department of Social Services and the Connecticut Department of Mental Retardation, 2006.

1. Elder Waiver: This waiver constitutes the Medicaid portion of the Connecticut Home Care Program for Elders (CHCP). On June 30, 2006, it provided community-based services to 10,333 elders aged 65 and older, who would otherwise be institutionalized. Available services include adult day care, homemaker, companion, chore, home delivered meals, emergency response systems, care management, home health, skilled nursing, respite, assisted living and minor home modifications. The monthly average number of participants for SFY 2006 was 10,124.

   The State-Funded Home Care Program, the other portion of the Connecticut Home Care Program for Elders (CHCP), is supported solely by State funds and provides the same services as the Medicaid Elder Waiver. On June 30, 2006, the program served over 5,085 elders age 65 and older who are at risk of institutionalization and have income and/or assets greater than the Medicaid limit.

   Enrollment in the CHCP (both waiver and State-funded) grew by almost 150 percent between 1994 and 2006, increasing the number of participants from 6,024 to 15,418, partly as a result of a 'no waiting list policy' established in 1997.

   Within the CHCP there is a state-funded Personal Care Assistance (PCA) Pilot Program that serves individuals who are 65 years old and over and qualify for CHCP. The program capacity increased from 150 to 250 in SFY 2007. PCA services may be provided by non-spousal family members. This program, implemented in 2005, replaces the PCA pilot implemented in 2000 and serves participants of the original pilot, CHCP participants and waiver clients who turn 65 and become eligible for the CHCP. On June 30, 2006, there were 150 people enrolled in the pilot PCA program.

2. Personal Care Assistance Services Waiver: This waiver provides personal care services to persons with physical disabilities who age 18 and older. In this consumer directed program, participants hire and direct their own care. The program is capped at 698 people. The monthly average number of participants during SFY 2006 was 576.

3. Acquired Brain Injury Waiver: This waiver provides 19 specific behavioral and support services to persons between the ages of 18 and 64 with acquired brain injury. The program is capped at 369 persons. The number of participants as of December 1, 2006 was 290.

4. Model Waiver: This waiver, sometimes referred to as the Katie Beckett Waiver, offers case management and home health services primarily to disabled children who would normally only qualify for Medicaid in an institution. The waiver itself offers only case management services, but the families have access to full Medicaid benefits, including home health and physical therapy. As a result of Public Act 05-251, the program was expanded to serve a maximum of 180

individuals, an increase from the previous limit of 125. The monthly average number of participants for SFY 2006 was 160.

5. Department of Mental Retardation Individual and Family Support (IFS) 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.

6. Department of Mental Retardation Comprehensive Supports Waiver: Provides for the vocational and in-home services needed for people who need a more intensive level of support to remain in their own family home. These services are delivered 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.

State Long-Term Care Programs

In addition to the programs listed above, there are a wide range of long-term care services that support individuals with disabilities and chronic health conditions that are funded or operated by State agencies. A description of these State agencies can be found in Appendix G as well as charts describing State long-term care programs, their eligibility requirements and participants and program expenditures.

Municipal, Non-Profit, Private Sector and Volunteer Services

In addition to the State 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 elders and people with disabilities. Connecticut has five regional Centers for Independent Living, five Area Agencies on Aging, 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 of volunteer organizations that address the needs of individuals with specific chronic illnesses and conditions, providing support and companionship that foster "sustainable" independent living.

Community Housing Options

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 described below all 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 2
Community Housing Options in Connecticut, June 30, 2006

	Facilities	Units/ Beds	Residents	Age
State Funded Congregate Housing	23		951	62 and older
Assisted Living	109			Adults and elders
Residential Care Homes	102	2,826 units		Adults and elders
Continuing Care Retirement Communities	17	3,200 units		Elders
Nursing Facilities	246	29,671 beds		All ages

Congregate Housing

Congregate housing provides frail elders 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.

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 November 2006, 168 congregate housing residents were actively enrolled in the assisted living program. From when the program was implemented in May 2001, to November 2006, a total of 512 residents have received assisted living services through the program. [19]

Assisted Living Services/ Managed Residential Communities

Assisted Living Services Agencies (ALSAs) are an alternative for seniors 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, assisted living service agencies (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

[19] Connecticut Department of Economic and Community Development, 2006.

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. Primarily, assisted living services in the MRC are available to individuals age 55 and older.

As of September 2006, there were 68 ALSAs licensed in Connecticut providing services in 109 managed residential facilities.[20] 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).[21]

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 Department of Economic and Community Development, Department of Public Health, the Office of Policy and Management and the Department of Social Services, 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 (a description of these new initiatives is provided in Appendix E – Long-Term Care Planning and Program Implementation Efforts).

Preliminary Needs Assessment Findings - MRCs[22]

A total of 26 MRCs responded to the Needs Assessment survey. The most frequently offered services include assisted living services (89 percent), recreational services (65 percent), congregate meals (62 percent), and specialized dementia care (50 percent).

The MRCs report serving an average of 122 clients, with a range from 25 to 400. The largest percentage of clients being served are age 85 or older (48 percent), with another 39 percent age 65 to 84. Almost three quarters (71 percent) of MRC clients are female. Three-quarters (77 percent) are White/Caucasian, and almost all clients (96 percent) are of non-Hispanic origin.

Three-quarters (76 percent) of MRC clients pay for their services out of pocket, and only 11 percent use more than one payment source to pay for their care.

About half (52 percent) of these MRCs report any eligibility requirements. The most commonly endorsed eligibility category is an age requirement (77 percent), followed by only certain payment sources accepted (39 percent), and must have certain functional or

[20] Connecticut Department of Public Health, 2006.
[21] The Connecticut Assisted Living Association, 2003.
[22] University of Connecticut Health Center's Center on Aging, Long-Term Care Needs Assessment, Preliminary data, January 2006

cognitive abilities (39 percent). Other eligibility requirements include cannot be danger to oneself and ability to live independently.

Most MRCs (89 percent) report the presence of a waiting list for services. Over the course of the past year, over one-half of MRCs had a waiting list or declined services due to lack of available beds (58 percent) or because the eligibility requirements were not met (54 percent), while another third (31 percent) report lack of payment source as the cause for declining services.

These MRCs report a low percentage of clients with either mental illness (4 percent) or challenging behaviors (14 percent). Still, three quarters of the staff members (73 percent) have received specialized training to work with challenging behaviors, and these organizations report that most of their employees (72 percent) are either extremely or quite skilled in working with clients who have challenging behaviors.

When asked about certain issues over the past year, overall, MRC providers report few employee or client concerns. One exception would be employees not showing up or calling out sick at the last minute. Forty percent of these respondents indicate this happens once a month or more. One out of five respondents (20 percent) report that clients complain about employees once a month or more, and client transportation is a problem once a month or more for over one quarter (28 percent) of MRCs.

Preliminary Needs Assessment Findings - ALSAs[23]

Fourteen assisted living services agencies (ALSAs) from across the state responded to the survey. The top five services provided by ALSAs include assisted living services (100 percent), transportation (71 percent), recreational services (64 percent), personal emergency response system (57 percent), and physical, speech, respiratory, or occupational therapy (57 percent).

These ALSAs currently have an average of 104 clients, with the smallest agency serving 13 clients, and the largest agency serving 385 clients. Almost all (99 percent) of ALSA clients are over age 64, with the majority age 85 or older (61 percent). About three quarters (71 percent) are female. The great majority of these clients are also White/ Caucasian (96 percent) and of non-Hispanic origin (99 percent).

As with the MRC providers, three-quarters of clients (76 percent) pay out-of-pocket for these services. One fifth (22 percent) of these clients use Medicare as one of their payment sources and an equal number (23 percent) of clients use multiple payment sources. Just over half of ALSAs report an age requirement (54 percent), and 39 percent have a payment source requirement.

One question on the survey collected information pertaining to eligibility requirements for agency services followed by an optional brief explanation. Just over half of these respondents report an age requirement (54 percent), and 39 percent have a payment

[23] University of Connecticut Health Center's Center on Aging, Long-Term Care Needs Assessment, Preliminary data, January 2006

source requirement. The most common eligibility requirement written in by respondents was having a stable medical condition which did not require intensive nursing care.

Currently, just over one third (38 percent) of reporting agencies have a waiting list. Over the course of the past year, 43 percent of agencies had a waiting list or declined services due to lack of available beds or units, 21 percent could not provide services because the client did not meet eligibility requirements, 14 percent reported a lack of payment source, and 14 percent reported a lack of available spaces or slots.

As with the MRC organizations, assisted living services agencies report relatively low percentages of clients with either mental illness (10 percent) or challenging behaviors (12 percent). Almost all (93 percent) of ALSA staff members receive specialized training to work with challenging behaviors, and these providers report that half of their employees (50 percent) are either extremely or quite skilled in working with clients who have challenging behaviors.

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, and assistance with activities of daily living. Residential care homes in Connecticut are licensed by the Department of Public Health.

Preliminary Needs Assessment Findings – Residential Care Homes[24]

As of June 30, 2006, there were 102 residential care homes in Connecticut with a total of 2,826 beds.[25] A total of 30 residential care homes from across the state answered the Needs Assessment survey. The top five services provided by residential care homes include recreational services (53 percent), transportation (47 percent), personal care assistant services (40 percent), assisted living services (37 percent), and congregate meals (37 percent).

The smallest residential care home serves only five clients, while the largest serves 130 clients. The average number of clients currently being served is 30. There is a wide age distribution, with one third of clients being 19 to 59 (34 percent), 12 percent 60 to 64, and one-third 65 to 84 (33 percent) years old. In addition, one quarter of residential care home clients (25 percent) are age 85 to 99 years old. The majority of clients are White/Caucasian (82 percent) and of non-Hispanic origin (98 percent), while over half (60 percent) are female.

The vast majority (90 percent) of all residential care homes have some type of eligibility requirements. The three most commonly endorsed eligibility category were only certain

[24] University of Connecticut Health Center's Center on Aging, Long-Term Care Needs Assessment, Preliminary data, January 2006.
[25] Connecticut Department of Public Health, 2006.

ages accepted (60 percent), must have certain functional or cognitive abilities (60 percent), and certain behavioral or psychiatric diagnoses not accepted (57 percent).

Currently, over half (61 percent) of residential care homes report that they have a waiting list for services. Over the course of the past year, over almost two-thirds had a waiting list or declined services due to a lack of available beds, over one third (40 percent) because the person did not meet eligibility requirements, and one quarter (28 percent) because of no payment source.

Almost half (46 percent) of the clients being served by these residential care homes have a diagnosis of mental illness (excluding dementia). In addition, over one-quarter (28 percent) of all clients exhibited challenging behaviors in the past six months. Over three-quarters (82 percent) of all staff members have received specialized training to work with challenging behaviors. Residential care homes were asked to rate their employees overall level of training and skill working with clients who have challenging behaviors; none rated their employees as extremely skilled, although two thirds (62 percent) rated their employees as quite skilled.

Residential care home providers report few employee or client concerns. One third (30 percent) do report difficulty finding health care services for their clients at least once a month, and one quarter (26 percent) indicate that problems with client transportation occur at least once a month.

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 long-term 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 usually require a substantial monetary investment. Each CCRC is mandated to register with the Department of Social Services by filing an annual disclosure statement. 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.[26]

Supportive Housing

Designed to assist individuals and families to live independently in the community, supportive housing combines affordable rental housing with individualized health, support and employment services. People living in supportive housing have all the

[26] Connecticut Department of Social Services, 2006.

responsibilities of tenants. In addition, they have the option to access support services such as case management, developing independent living skills, and pursuing mental health treatment and employment services.

Since 1993, over 1,000 supportive housing units have been created in Connecticut through the Supportive Housing Demonstration Project and the Pilots Initiative. In 2005, to address the need for additional supportive housing in the state, the Next Steps Initiative has proposed that another 1,000 units of affordable, service-supported rental housing be created over the next three years: 350 apartments for families and 650 for single adults, including 50 for young adults.

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 family. [27]

- *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 June 30, 2006, 286 individuals lived independently and an additional 304 individuals lived independently with some minimal individualized supports.

- *Supported Living Arrangements* -- 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 June 30, 2006, 1,269 individuals lived in Supportive Living Arrangements.

- *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 June 30, 2006, 3,614 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 June 30, 2006, 412 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

[27] Department of Mental Retardation website, Residential Services: www.dmr.state.ct.us/ssdesc.htm#res-cla

services at the same facility. On June 30, 2006, 266 individuals lived in Residential Center Settings and 550 individuals reside at the Southbury Training School.

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.[28]

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.

- *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.

Institutional Care Settings

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

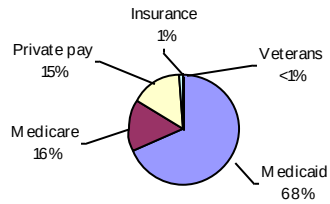
[28] Connecticut Department of Mental Health and Addiction Services, 2006.

and convalescent nursing homes (skilled nursing facilities) and rest homes with nursing supervision (intermediate care facilities).

On September 30, 2005, there were 27,840 individuals residing in Connecticut nursing homes. The majority of residents were white (89 percent), female (71 percent), and without a spouse (83 percent), a profile that has remained consistent over the years. Ten percent of the residents were under age 65, 42 percent were between age 65 and 84 and 48 percent were age 85 or older.[29]

Connecticut had a total of 29,643 licensed nursing facility beds as of September 30, 2005. Since 1991, efforts have been made to reduce the number of residents in Connecticut's nursing facilities by placing a moratorium on additional beds. Despite the moratorium, from 1991 to 1994, the total number of licensed beds increased from 29,391 to 32,149. This was due to the addition of beds that had been provided before the moratorium went into effect. From 1994 to 2005, the total number of licensed beds decreased by 2,506, or 7.8 percent. [30]

FIGURE 7
Percent Distribution of CT Nursing Facility Residents by Payment Source, 2005



Source: CT Annual Nursing Facility Survey, Office of Policy and Management, 2005

In 2005, the average annual cost for residing in a semi-private nursing home room in Connecticut was $104,000. Medicaid was the primary source of payment for 68 percent of individuals residing in a Connecticut nursing facility as of September 30, 2005, with private pay covering 15 percent and Medicare covering 16 percent (Figure 7). Between 1995 and 2005, the percentage relying on Medicaid and Medicare increased by 1.5 percent and 4.0 percent respectively, and the percent paying out of pocket and relying on insurance decreased by 4.6 percent and 0.3 percent (Table 3). [31]

In Connecticut, Medicaid expenditures for nursing home care have increased from approximately $500 million in SFY 1990 to over $1.175 billion by SFY 2006, an increase of 135 percent.[32] When compared to the rest of the nation, the fraction of Connecticut health care spending going to nursing home (15 percent) is the largest in the U.S.[33]

[29] State of Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2005.
[30] State of Connecticut Nursing Facility Registry, September 1995 and Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2005.
[31] State of Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2005.
[32] Office of Policy and Management, 2006.
[33] Dennis Heffley, Health Care Spending, Connecticut Style, *The Connecticut Economy*, Winter 2003, pp 6&7.

TABLE 3
Percent Distribution of Residents in Connecticut Nursing Facilities by Payment Source on September 30, 1995 and 2005

Payment Source	1995	2005
Medicaid	66.7	68.2
Medicare	10.7	14.7
Private Pay	20.2	15.6
Insurance	1.6	1.3
Other	< 1	< 1

Source: State of Connecticut Nursing Facility Registry and Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division.

Intermediate Care Facilities for Persons with Mental Retardation – ICF/MR

On June 30, 2006, a total of 1,163 people over the age of 18 in Connecticut resided in an ICF/MR. Of these individuals, 811 people resided in an ICF/MR operated by the Department of Mental Retardation in one of seven locations throughout the state. Another 352 individuals resided in 67 group homes at an ICF/MR level of care operated by private providers. Of the 811 residents of the publicly operated programs, 54 percent were between the age of 19 and 54, 29 percent were between the ages of 55 and 64, and 17 percent were age 65 and over. At this level of care, residents received residential and day habilitation services, prevocational services and supported employment services. All services are financed through the State Medicaid Program.[34]

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. These long-term hospitals provide diagnosis, care and treatment of a wide range of chronic diseases.

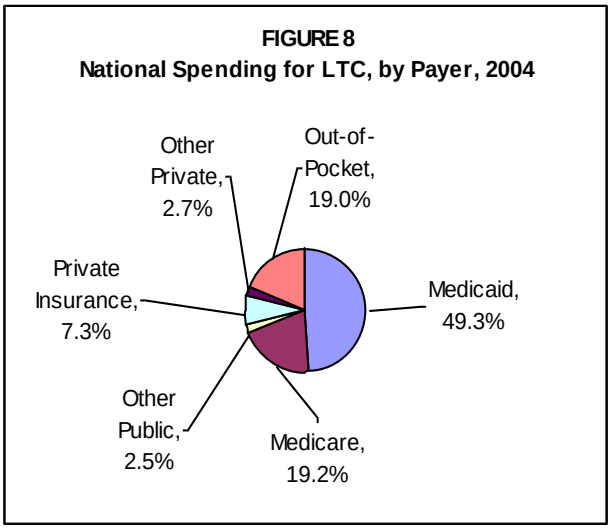
C. Long-Term Care Financing

Nationally, approximately 71 percent of expenditures for long-term care services are paid for through public programs, primarily Medicaid and Medicare. Individuals finance almost one-fifth of these expenditures out-of–pocket. Private insurance, both traditional and long-term care, pays for only 7 percent (Figure 8). In addition to these expenditures is the unpaid care provided by family members and other informal caregivers. Unpaid care represents the largest share of financing for long-term care costs.

Between 1990 and 2004, two notable national trends in financing long-term care occurred. The proportion of long-term care expenditures paid for by public sources grew from 55 percent in 1990 to 71 percent in 2004. At the same time, home and community-

[34] Connecticut Department of Mental Retardation, 2006.

based services, including home care and personal care services, increased from 22 percent to 37 percent of all long-term care spending.[35]



Source: Karen Tritz et al, Long-Term Care: Trends in Public and Private Spending, Congressional Research Service, April 11, 2006

Medicaid

The Medicaid program, jointly funded by the state and federal governments, is the primary payer for long-term care services in the U.S. and the major public program providing coverage for nursing home care, accounting for almost half of all long-term care spending in 2004 (Figure 8). Medicaid provides coverage for people who are poor and disabled. It also provides long-term care services for individuals who qualify for Medicaid because they have 'spent down' their assets due to the high costs of such care and have become nearly impoverished. For example, many elderly persons become eligible for Medicaid as a result of depleting their assets to pay for nursing home care that Medicare does not cover.

Total national Medicaid spending for long-term care increased from $30.5 billion in 1990 to $95.7 billion in 2004.[36] Historically, Medicaid long-term care spending in the U.S. was almost exclusively for institutional services. In FY 1990, 86 percent of expenditures were for institutional care and only 14 percent of Medicaid long-term care expenditures went to home and community-based care programs. By 2004, the percentage shifted to 59 percent for institutional care and 41 percent for home and community-based services.[37]

In SFY 2006, the Connecticut Medicaid program spent $2.227 billion on long-term care. Of that expenditure, 32 percent was spent on home and community-based services and 68 percent on institutional care. Looking in more detail, nursing facility care represents 53percent of total Medicaid expenses and Medicaid home and community-based waiver services represent 25 percent (Figure 9). Medicaid long-term care expenses account for 56 percent of all Medicaid spending and 14 percent of total expenditures for the State of Connecticut. [38]

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[35] Karen Tritz, *Long-Term Care: Trends in Public and Private Spending*, Congressional Research Service, Report for Congress, April 11, 2006, page 2-3.
[36] Karen Tritz, *Long-Term Care: Trends in Public and Private Spending*, Congressional Research Service, Report for Congress, April 11, 2006, Table 4, page 22.
[37] IBID, Tables 1 and 2, pages 10-11.
[38] Office of Policy and Management, Policy Development and Planning Division, 2006.

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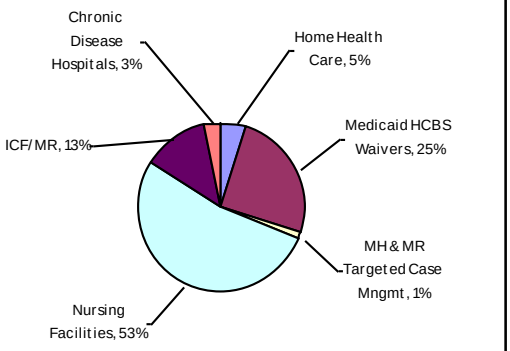
FIGURE 9
Proportion of CT Medicaid LTC Expenditures, SFY 2006



Source: Office of Policy and Management, Policy and Planning Division, 2006.

Over time, the proportion of Medicaid long-term care expenses for home and community-based services has increased from 23 percent in SFY 1996 to 32 percent in SFY 2006. This 40 percent increase in the proportion of home and community-based services is, in part, a result of efforts to reduce nursing home use by limiting nursing home care through pre-admission screening, a moratorium on new nursing home beds, and constraints on the growth in Medicaid payments on the one hand and expanding home care primarily through Medicaid waivers on the other.

It is worth noting that between SFY 2005 and SFY 2006, the percent of Medicaid long-term care expenditures for institutional care increased, from 65 to 68 percent, reversing a the trend toward shifting expenses toward community-based care. The increase was not due to an increase in the use of institutional care or a shift away from home and community-based care, but rather reflects the significant Medicaid rate increase provided specifically to nursing homes in the fall of 2005.

Medicare

The federal Medicare program provides health care coverage for people age 65 and older. Individuals under age 65 with disabilities are also covered, however, only after they have received Social Security disability benefits for two years. Although Medicare is the major health insurance program for the elderly and certain persons with disabilities, it does not cover most long-term care costs. Primarily, acute care is covered, with limited long-term care coverage available. Medicare covers nursing home stays for no more than 100 days following a hospital stay of at least three days, paying for all of the first 20 days and a portion of the next 80 days. Assisted living costs are not covered. With regard to home health care, coverage is limited by type and duration, focusing on rehabilitation rather than long-term care. For homebound persons needing part-time skilled nursing care or physical therapy services, Medicare pays for home health care, including personal care services provided by home health aides. Medicare spending accounted for slightly over 19 percent (about $37.4 billion) of total long-term expenditures in the U.S. in 2004 (see Figure 8).

Out-Of-Pocket Spending / Private Pay

Nationally, 19 percent of long-term care spending in 2004 was paid directly by individuals (about $36.9 billion), rendering out-of-pocket payments as the third largest source of long-term care financing (Figure 8). This includes direct payment of services as well as deductibles and co-payments for services primarily paid by another source, but does not include the uncompensated costs of informal caregivers. Over the years, out-of-pocket spending has decreased as a proportion of long-term care expenditures, moving from 30 percent in 1990 to 19 percent in 2004.[39]

Private Insurance Spending

In 2004, coverage from private insurance represented 7.3 percent of long-term care expenditures in the U.S. (Figure 8). Sources of private insurance include supplemental Medicare coverage (Medigap), traditional health insurance, and private long-term care insurance. The percent of long-term care expenditures covered by private insurance has fluctuated over the years, paying 8.2 percent in 1990, up to 10.9 percent in 1998, and down to 7.3 percent in 2004.[40]

Private Long-Term Care Insurance

Long-term care insurance covers services needed by people who cannot perform every day activities on their own due to a chronic condition, limited ability to function or deterioration in mental capacity. It covers a wide range of services that include bathing, dressing, eating, using the toilet, continence, and transferring from a bed to a chair. Since individuals in need of long-term care do not usually require skilled help, the services are not generally covered by private health insurance or Medicare. Depending upon the policy, care can be provided in a variety of places, including: a person's home, a nursing facility, through community-based services (i.e., adult day care) and in a variety of assisted living settings (i.e., continuing care retirement communities, residential care homes, assisted living facilities).[41]

In Connecticut, the number of individuals who purchased long-term care insurance in 2005 was 10,476, nearly double the number who purchased policies in 1994. As of December 31, 2005, there were 103,024 Connecticut residents with a private long-term care insurance policy in force.[42]

Connecticut Partnership for Long-Term Care[43]

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;
- enhance the standards of private long-term care insurance;

[39] Karen Tritz, *Long-Term Care: Trends in Public and Private Spending*, Congressional Research Service, Report for Congress, April 11, 2006, page 15.
[40] IBID, page 16.
[41] Connecticut Partnership for Long-Term Care, *Frequently Asked Questions*, April 2006
[42] Office of Policy and Management, Policy Development and Planning Division, 2006.
[43] Connecticut Partnership for Long-Term Care, 2006

- provide public education about long-term care; and
- conserve State Medicaid funds.

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 a policy holder has up to the amount the Partnership insurance policy paid in benefits will be disregarded. The Partnership Medicaid Asset Protection feature is not available under non-Partnership policies.

Connecticut was the first state to implement a Partnership. Since 1992, when the Partnership was first launched, New York, Illinois, Indiana and California have developed similar Partnership programs. As of December 31, 2005, there were over 40,000 Partnership policies sold in Connecticut. Purchasers of Partnership policies range in age from 18 to 86 years old, with the average age at purchase being 58 years old.

Older Americans Act

Another major source of federal long-term care funds is the Older Americans Act (OAA), enacted in 1965 to promote the well being of older persons and help them remain independent in their communities. All persons age 60 and older are eligible to receive services, but states are required to target assistance to persons with the greatest social or economic need. Services funded under this Act include information and referral, counseling, outreach, congregate meal sites and home-delivered meals, transportation, long-term care ombudsman services, legal services, elderly protective services, and senior employment services programs.

In Connecticut, the OAA provided approximately $15.4 million in FFY 2005 to the Department of Social Services Elderly Services Unit, serving an estimated 112,000 seniors across the state. This funding is distributed by formula to the Area Agencies on Aging who in turn contract with community-based organizations to provide social and nutritional services.

State Supplement Program/ Aid to the Aged, Blind and Disabled (AABD)

The State Supplement Program provides a monthly cash benefit for basic living expenses to low-income individuals who are age 65 and over, individuals who are disabled and between the ages of 18 and 64, or individuals who are blind. Benefit amounts vary based on an individual's needs and expenses. Those eligible for State Supplement benefits are also eligible for Medicaid. Those receiving a State Supplement benefit live in a variety of settings, including their own apartments, housing for the elderly or persons with disabilities, or residential care homes.

Rental Subsidies

Many individuals with disabilities need assistance with covering their rental costs if they are going to be able to live in the community. While federal Medicaid law prohibits

home and community-based waiver programs from covering the costs of room and board (room and board expenses are only covered in institutional settings under Medicaid), there are both state and federal sources of rental support in the form of Section 8 vouchers, rental subsidies in State-funded congregate facilities, the State's rental assistance program, State Supplement funds and other sources.

D. Financing of Prescription Drugs

Although prescription drugs are traditionally considered a medical product and not a long-term care service or support, many individuals in need of long-term care rely on prescription drugs. There are a number of sources of coverage for prescription drugs for Connecticut residents:

Medicare Part D Prescription Drug Program (Medicare Rx)

As of January 1, 2006, Medicare began to offer insurance coverage for prescription drugs. Insurance companies and other private companies work with Medicare to offer these plans. The Prescription Drug Program (Medicare Rx), provided under Medicare Part D, is open to all Medicare beneficiaries and is voluntary.

A subsidy is available for low-income individuals who want to participate in Medicare Rx. A full drug subsidy with low co-payments is provided to Medicare beneficiaries with incomes up to 135 percent of the federal poverty limit (FPL) and limited resources. A partial subsidy of the premium, deductible and co-insurance is provided to Medicare beneficiaries with incomes up to 150 percent of the FPL and limited (but higher than allowed for full subsidy) resources.[44]

Seniors and individuals with disabilities who participate in both the Medicare and Medicaid programs formerly had their prescription drugs covered under Medicaid. Now these individuals, called 'dual eligibles,' have their prescription drugs covered under the Medicare Rx program. Although Medicaid no longer covers drugs that the new Medicare Part D program will pay, it continues to cover prescriptions it previously paid for that are not covered by Part D. Unlike other Medicare beneficiaries, 'dual eligibles' do not pay a premium or deductible or the gap in coverage known as the "Doughnut Hole". Also, the Connecticut Medicaid program will cover co-pays and continue to cover certain drugs which are not available from the individual's Medicare Part D Plan.

Connecticut Pharmaceutical Assistance Contract to the Elderly and Disabled (ConnPACE)

ConnPACE, established in 1986, is a state-funded program designed to assist low-income individuals aged 65 and older and people with disabilities aged 18 to 64 pay for prescription medicines and insulin supplies. To qualify, an individual must be age 65 or older or determined to be disabled for Social Security purposes and have income below 226 percent of the federal poverty level. As of January 1, 2006, an individual must have an income below $22,300 and couples must have incomes below $30,100. The DSS

[44] Center for Medicare Advocacy, Inc., www.medicareadvocacy.org/FAQ_PartD.htm , April 2006.

Commissioner is required to adjust the income limits each year by inflationary increases in the Social Security program.

Participants must pay an annual enrollment fee of $30 and a co-payment of $16.25 for each prescription. There is no yearly dollar limit on the amount of prescriptions purchased, but there is a limit on the quantity dispensed. Generic drugs must be substituted for brand name drugs unless the prescribing physician specifies brand name drug only and obtains prior authorization from DSS to dispense the brand name drug. During SFY 2005, the ConnPACE program paid for 991,923 prescriptions and expended $94,095,619 on these prescriptions for an average of 49,411 program enrollees. As of June 30, 2005, there were 49,396 individuals in the program.

As of January 2006, individuals participating in ConnPACE who are eligible for Medicare must also enroll in the Medicare Prescription Drug Program (see above). The ConnPACE benefit supplements or "wraps around" the Medicare prescription drug benefit at no additional cost to the ConnPACE member, providing federal cost sharing for the State, and lower costs for certain low-income ConnPACE members. ConnPACE will cover the cost of most drugs that are unavailable under the Medicare Part D plan, co-payments in excess of $16.25, and the full costs of drugs during the time when the consumer is in the Medicare 'doughnut hole.'

Connecticut AIDS Drug Assistance Program (CADAP)

This program pays for drugs determined by the U.S. Food and Drug Administration to prolong the life of people with AIDS, or HIV infection. To be eligible for the program in Connecticut, an individual must have a physician certification that the individual has HIV infection, HIV disease or AIDS, must not be a recipient of Medicaid, and must have net countable income within 400 percent of the federal poverty level. In addition, the individual must apply for Medicaid within two weeks of approval for this program. The Department of Social Services receives federal funding for the program under Ryan White Title II grants that are awarded to the Department of Public Health. In addition, there are General Fund appropriations that continue the program when the annual federal grant funds awarded to the Department of Social Services are exhausted.

Other Sources of Pharmacy Coverage in Connecticut

Below are state sponsored programs that provide pharmacy coverage as part of their benefit package:

- Medicaid Fee-For-Service (excluding individuals eligible for both Medicare and Medicaid or "dual eligibles")
- HUSKY A and B
- State Administered General Assistance
- Refugee Medical Assistance
- State Employees' Workers' Compensation Program
- State Employee and Retiree Health Plans

IV. FUTURE DEMAND FOR LONG-TERM CARE

A. Population and Disability Trends

Although long-term care services and supports are needed by people of all ages and may be required as a result of a diverse array of disabilities or chronic illnesses, it is important to recognize the significant impact the aging of our society will have on the future demand for long-term care. In 1900, seniors accounted for less than 5 percent of the total U.S. population. A century later, the proportion of seniors in the U.S. population has grown to over 12 percent or 33 million. By 2030, the senior population is expected to more than double to an estimated 71 million, or 22 percent of the U.S. population.[45]

In Connecticut 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 extraordinary 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 56,050 people. 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 4).

TABLE 4
Connecticut Population Projections: 2005 – 2025

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

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

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 Connecticut, between 2005 and 2010, the proportion of elderly in the population is expected to increase by about 7.5 percent and continue to increase steadily until 2025, when the survivors of the Baby Boom will be between the ages of 61 and 79 (Figure 10). The proportion of people age 65 and over is expected to increase from 14 percent in 2005 to 20 percent in 2025 (Table 5).

[45] Centers for Disease Control and Prevention, Public Health and Aging: Trends in Aging -- United States and Worldwide, *MMWR Weekly*, February 14, 2003, 52(06); pp 101-106.

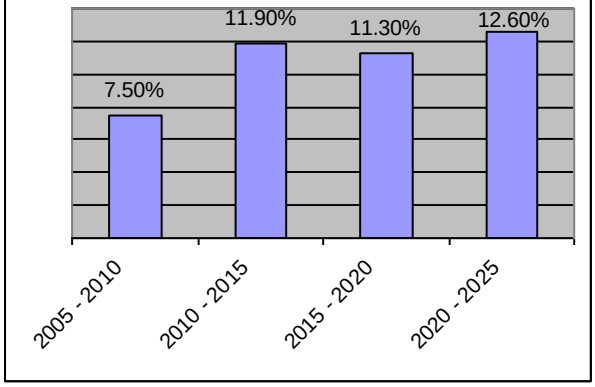
TABLE 5
Connecticut Population Projections,
Percent Distribution of Population by Age: 2005 – 2025

Age	2005	2010	2015	2020	2025
0 to 4	6%	6%	6%	6%	6%
5 to 20	22%	21%	20%	19%	19%
21 to 64	59%	59%	58%	57%	55%
65+	14%	14%	16%	17%	20%

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

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). Between 2005 and 2025, this number is expected to grow by 25 percent, or approximately 99,000 people, to an estimated 501,400.[46] 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 older is expected to increase by 98,500 or 63 percent (Table 6).

FIGURE 10
Rate of Increase in the Connecticut Population 65+



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

Although the projections provided in Table 6 assume that the proportion of people in the population with disabilities will remain constant over time, there are several trends occurring in the population with regard to changes in disability status. Among the elderly there is evidence that the prevalence of disability is declining. For the past two decades, the number of individuals age 65 and older has remained fairly constant while the percentage of those with disabilities has fallen between one and two

[46] These projections are based on the 2005 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 disability over time.

percent a year.[47] Possible factors contributing to this decrease include improved health care, improved socioeconomic status and educational attainment, and better health behaviors. [48] [49]

At the same time that disability rates are declining among older adults, rates of disability appear to be growing among individuals between the ages of 18 and 59. Possible explanations for this trend are the increase in obesity and related illnesses, technological advances in medicine and changing disability insurance laws.[50]

TABLE 6
Projection of Non-Institutionalized Persons with Disabilities in Connecticut by Age: 2005 – 2025

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

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

There is disagreement regarding the future course of the decline in disability among older adults. One position holds that it is unclear at this point whether these trends will continue or how this decline will affect future demand for care.[51] [52] AARP predicts that due to declines in disability the future demand for support services among the elderly will grow very slightly."[53] Other experts maintain that the sheer numbers of aging baby

[47] Vicki A. Freedman, PhD., et al, Recent Trends in Disability and Functioning Among Older Adults in the United States, *Journal of the American Medical Association*, December 25, 2002, Vol. 288, No. 24, p 3137.
[48] AARP, *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, 2003, p 8.
[49] David M. Cutler, Declining Disability Among the Elderly, *Health Affairs*, November/ December 2001, pp 17-21.
[50] Darius N. Lakdawalla et al, *Are the Young Becoming More Disabled?* Health Affairs, January/ February 2004.
[51] Vicki A. Freedman, PhD., et al, Recent Trends in Disability and Functioning Among Older Adults in the United States, *Journal of the American Medical Association*, December 25, 2002, Vol. 288, No. 24, pp 3145-3146.
[52] Douglas A. Wolf et al, *Perspectives on the Recent Decline in Disability at Older Ages*, The Milbank Quarterly, Vol. 83, No. 3, 2005 (pp. 365-396).
[53] AARP, *Before the Boom: Trends in Long-Term Support Services for Older American with Disabilities*, October 2002, pp 41-42.

boomers are expected to overwhelm the positive benefits of the decreased prevalence of disability.[54] [55]

B. Demand for Long-Term Care

Ideally, an estimate of the future demand for long-term care in Connecticut would include all aspects of the system in a single picture, including publicly and privately financed services and formal and informal care. However, creating such a comprehensive picture is not possible without more complete data on privately financed services and the use of informal care. Short of this, what is critical in terms of public policy is an understanding of the impact of future demand on the Medicaid financed long-term care community and institutional services once the baby boom generation ages.

As discussed in Section III, Medicaid is the largest and most significant payer of long-term care services at both the state and national level. Of the nearly 42,000 Medicaid clients who received long-term care services and supports in Connecticut each month in SFY 2006, 51 percent received services in the community and 49 percent received care in an institutional setting (Table 7). If these ratios remain steady over the next two decades and disability rates do not rise or fall, U.S. Census Bureau disability data and population projections for Connecticut suggest that in the year 2025 there will be a 25 percent increase in individuals receiving Medicaid services: an additional 5,335 Medicaid clients receiving long-term care in the community and an additional 5,108 receiving care in institutions (Table 9). To meet this additional demand for long-term care, Medicaid expenditures are expected to grow from $2.2 billion in SFY 2006 to $7.0 billion in 2025, assuming current ratios of institutional and community care and a five percent annual inflation rate (Table 10).

TABLE 7
Connecticut Medicaid Long-Term Care Clients and Expenditures: SFY 2006

	SFY 2006 Medicaid LTC Clients, Monthly Average	SFY 2006 Medicaid LTC Expenditures
Community-based Care	**21,340**	**$702 million**
Institutional Care	**20,433**	**$1,525 million**
Total	**41,773**	**$2,227 million**

Source: Connecticut Department of Social Services, 2006.

[54] Congressional Budget Office Memorandum, *Projections of Expenditures for Long-Term Care Services for the Elderly*, March 1999.
[55] General Accounting Office, Long-Term Care: *Aging Baby Boom Generation will Increase Demand and Burden on Federal and State Budgets*, GAO-02-544T, March 21, 2002, p 10.

A number of other states have made a commitment to balancing their long-term care systems by offering their residents opportunities to live in the least restrictive settings possible. A comparison of states provided in Table 8 shows that among the New England states in 2005, Connecticut (37 percent) and New Hampshire (34 percent) had the lowest proportion of Medicaid spending for home and community-based long-term care services. In contrast, Vermont spent 60 percent of Medicaid long-term care dollars on community-based care and Maine spent 49 percent. Among the western states, Oregon has achieved a Medicaid spending ratio of 70 percent of long-term care dollars on community-based care and Washington expended 58 percent. Although no one other state's model can be totally replicated in Connecticut, spending patterns in other states illustrate that greater ratios of home and community-based care are achievable.

TABLE 8
Percent of Medicaid Long-Term Care Spending for Home and Community-Based Services, FY 2005[56]

State	Percent	U.S. Rank
Oregon	70%	1
Washington	58	6
Vermont	60	4
Maine	49	10
Rhode Island	43	13
New York	43	15
Massachusetts	38	22
Connecticut	37 [57]	26
New Hampshire	34	30

Source: HCBS Clearinghouse for the Community Living Exchange Collaborative. Brian Burwell et al, *Medicaid Long Term Care Expenditures FY 2005* www.hcbs.org/files/94/4693/FY2005InstComm.xls

If current ratios of Medicaid community and institutional long-term care services were to evolve over time to reflect the greater emphasis on home and community-based services achieved in other states, Connecticut could develop a long-term care system that provides community-based care to 75 percent instead of 51 percent of its Medicaid long-term care clients. If the number of Medicaid clients receiving long-term care in 2025 reflected this optimal ratio, Connecticut could expect an additional 17,822 clients receiving community-based services and supports, and a decrease of 7,379 individuals receiving care in institutions when compared to 2006 levels (Table 9). By holding the number of

[56] Community-based services include home and community-based waiver services, personal care services, and home health services. Institutional services include nursing home services and ICF-MR.
[57] As a result of methodological differences in calculating Medicaid spending, the percentage of Medicaid spending for home and community-based services in Connecticut provided in this chart (37 percent) differs from the percentage calculated for this Plan (35 percent).

TABLE 9
Projections of Connecticut Medicaid Long-Term Care Clients by Current and Optimal Ratios of Community and Institutional Care SFY 2006 and SFY 2025

	Current Ratio	2025 clients/ monthly average	Increase from 2006 to 2025	Optimal Client Ratio	2025 Optimal clients/ monthly Average	Increase from 2006 to 2025
Community-based Care	**51%**	26,675	5,335	**75%**	39,162	17,822
Institutional Care	**49%**	25,541	5,108	**25%**	13,054	(7,379)
Total		52,216	10,443		52,216	10,443

Source: Office of Policy and Management, Policy and Planning Division, 2006 based on: (1) Department of Social Services Medicaid data for SFY 2006; (2) U.S. Census Bureau, Population Division, Interim State Population Projections, 2005; (3) U.S. Census Bureau, American Community Survey, 2005 disability data for Connecticut.

TABLE 10
Projections of Connecticut Medicaid Long-Term Care Expenditures by Current and Optimal Client Ratios of Community and Institutional Care SFY 2006 and SFY 2025, in millions of dollars

	Current Client Ratio	2025 Expenditures with Current Client Ratio	Increase from 2006 to 2025	Optimal Client Ratio	2025 Expenditures with Optimal Client Ratio	Increase from 2006 to 2025
Community-based Care	**51%**	$2,217,935,044	$1,515,765,275	***75%***	3,256,201,989	2,554,032,220
Institutional Care	**49%**	$4,817,211,620	$3,292,144,247	***25%***	2,462,063,586	936,996,213
Total		$7,035,146,664	$4,807,909,522		5,718,265,575	3,491,028,433

Note: Expenditure projections include a 5 percent annual rate increase.
Source: Office of Policy and Management, Policy and Planning Division, 2006 based on: (1) Department of Social Services Medicaid data for SFY 2006; (2) U.S. Census Bureau, Population Division, Interim State Population Projections, 2005; (3) U.S. Census Bureau, American Community Survey, 2005 disability data for Connecticut.

individuals served in 2025 constant, and increasing the proportion of individuals receiving community-based care to 75 percent, Medicaid long-term care expenditures are projected to be $5.7 billion, instead of $7.0 billion; $1.3 billion less than the State might otherwise have spent (Table 10).

Total Medicaid long-term care expenditures in 2025 are projected to be lower under the optimal ratios because in general, although the same numbers of people are served, the cost of serving people at home and in the community, on average,[58] is significantly lower than serving them in institutions.

With regard to institutional services, it is projected that in 2025 an estimated 13,054 Medicaid long-term care clients would receive these services under the optimal ratio scenario. Compared to the amount of people that would be expected to receive services under current service ratios in 2025, this would represent 12,487 fewer people receiving care in an institution.

In forecasting future demand for long-term care in Connecticut, it is important to note that there are many variables that will affect these estimates, whether related to changes in public policy, demographics, medical advances, or health status. On an individual level, not all people with a disability, whether it is physical, developmental, or psychiatric, will require long-term care support services. Those who do need long-term care supports often have needs that fluctuate over time, depending on their health, the nature of their disability and personal circumstances. Individuals vary in the level of supports they need, with the majority of people requiring support with instrumental activities of daily living (IADLs), and others requiring more intense support. Furthermore, the amount and type of informal care available from family and friends will influence the amount of paid care that is required.

C. Caregiver Supply and Demand

Currently, long-term care providers report large numbers of vacancies and turnover rates for paraprofessional workers. Moving into the 21st century, as the demand for long-term care services and supports grow, the traditional supply of both paid and unpaid caregivers is expected to decline. Both these trends are based to some extent on the impact of the aging of the baby boom generation. Increasing numbers of elders in the population will increase the demand for services and supports while low labor force growth and a substantially smaller pool of middle-aged women who have traditionally provided care will dampen supply.

[58] Although the average cost of serving people in the community is less expensive than care in institutions, this is not the case in all circumstances, such as the cost of caring at home for a person with Alzheimer's Disease or other severe disabilities.

Informal Caregivers

Preliminary Needs Assessment Findings[59]

Relatives, friends and other unpaid caregivers account for the vast majority of individuals providing long-term care supports to individuals across the lifespan. In Connecticut, one in five people report being a caregiver for another Connecticut resident. Further, a significant number (24%) currently care for more than one person. Most of this care goes to parents and to other older people. A quarter of caregivers live with their care receiver, reflecting an intensive ongoing type of care, and most of the remaining care receivers live close by. Almost two-thirds of care recipients have some degree of memory impairment, which also translates into a more intensive level of caregiving requiring significant supervision in addition to hands-on assistance. Over half of the working caregivers have had to miss some work due to these responsibilities.

Although informal caregivers provide the bulk of long term care in Connecticut and nationally, many people receive a combination of informal and formal long term care supports. The formal services used most include home health aides or personal care assistants, homemakers, visiting nurses and care management. According to caregivers, services their care recipients need, most but do not get, are homemakers and transportation. While most people do get the services they need, about one-third do not. Cost and lack of information represent the primary barriers to receiving services. Further, about one-third of caregivers had observed communication problems between their relatives and formal care providers. Caregivers also encounter problems with reliability and quality of service providers and transportation, and inflexible agency rules and regulations. Information about services most commonly comes from personal contacts with health care providers or relatives and friends.

Paid Direct Caregivers

Preliminary Needs Assessment Findings[60]

While the majority of long-term care services are provided by unpaid family members or other informal caregivers, paid direct caregivers form a large and growing percentage of the workforce, both in Connecticut and nationally.

The federal Bureau of Labor Statistics has published 2004 data on the numbers of people in various long-term care-related occupations. They have then projected the numbers of people who will be needed to fill those jobs in 2014 which include both new jobs created and replacements for people leaving the workforce (Table 11)

The occupation of home health aide is expected to grow by 56 percent between 2004 and 2014, representing the fastest growing occupation nationwide.[61] Three other occupations related to long-term care will show significant growth as well: nursing aides, orderlies,

[59] University of Connecticut Center on Aging, Preliminary findings of the Long-Term Care Needs Assessment, January 2006.
[60] University of Connecticut Center on Aging, Preliminary findings of the Long-Term Care Needs Assessment, January 2006.
[61] Hecker, Daniel E. (2005). Occupational employment projections to 2014. Monthly Labor Review, 70-101.

and attendants are expected to grow by 22 percent, personal and home care aides by 41 percent, and registered nurses by 29.4 percent.

TABLE 11
Occupations in the U.S. 2004 and Projected 2014

Occupation	Employment (in thousands)		Change	
	2004	2014	number	percent
Home health aides	624	974	350	56.0
Nursing aides, orderlies, attendants	1455	1781	325	22.3
Personal and home care aides	701	988	287	41.0
Registered nurses	2394	3096	703	29.4

Source: University of Connecticut Center on Aging, from Hecker, Daniel E., *Occupational Employment Projections to 2014*, Monthly Labor Review, 70-101, 2005.

Similar data, for Connecticut specifically, are available from the Connecticut Department of Labor for many occupations related to long term care as well as other health occupations. Table 12 displays the number of people working in each occupation in 2004, the number of positions projected to be available in 2014, the net and percent change, and the annual openings during this ten year period. Similar to the national data, annual openings include both new jobs and replacements for people retiring or leaving the occupation for other reasons.

All of the long term care and other health occupations will see growth between 2004 and 2014 with the exception of orthodontists. Efforts to rebalance the institutional bias of the current long-term care system will ideally lead to a greater percentage of people receiving long-term care at home. The impact of this shift on the paid caregiver workforce in Connecticut is reflected in a predicted 25 percent increase in home health aide positions and a 28 percent rise in personal and home care aide positions. These somewhat conservative estimates fall noticeably below the national predictions. However, the Allied Health occupations are expected to have double the growth of Connecticut's other occupational groups.

In addition to these community-based occupations, the sheer increase in numbers of people who will need long-term care will also increase the demand in Connecticut for nursing aides, orderlies and attendants by almost eight percent. One important caveat to consider when reviewing long-term estimates is the potential impact of policy changes pertaining to self-directed care that could occur over the next decade. For example, an absolute increase in per client expenditures in the Connecticut Home Care Program for Elders would definitely increase the demand for direct service providers. Further, a decrease in any number of waiting lists (i.e., DMR) would increase the need for home and personal care providers.

Most of the long-term care and other health occupations in Table 12 show double-digit increases in demand over these 10 years. Among the long-term care jobs, projected increases of over 20 percent are also expected for physical therapy occupations, mental health and substance abuse counselors and social workers, and medical and public health social workers.

Table 12
Connecticut 2004 and Projected 2014 Occupations

Occupational Title	2004	2014	Net Change	Percent Change	Total Annual Openings
Long Term Care Occupations					
Home Health Aides	10,240	12,760	2,520	24.6%	386
Personal and Home Care Aides	5,840	7,480	1,640	28.1%	258
Personal Care and Service Workers, All Other	680	730	50	7.4%	20
Nursing Aides, Orderlies, and Attendants	24,410	26,560	2,150	8.8%	535
Registered Nurses	31,890	36,020	4,130	13.0%	1,081
Licensed Practical and Licensed Vocational Nurses	7,880	9,100	1,220	15.5%	294
Physical Therapists	3,120	3,920	800	25.6%	111
Physical Therapist Assistants	650	840	190	29.2%	30
Physical Therapist Aides	420	520	100	23.8%	17
Occupational Therapists	1,550	1,850	300	19.4%	51
Occupational Therapist Assistants	410	470	60	14.6%	12
Occupational Health and Safety Specialists	610	640	30	4.9%	16
Speech-Language Pathologists	1,480	1,630	150	10.1%	52
Rehabilitation Counselors	4080	4,790	710	17.4%	165
Recreational Therapists	930	950	20	2.2%	25
Massage Therapists	690	790	100	14.5%	23
Substance Abuse and Behavioral Disorder Counselors	1,130	1,380	250	22.1%	51
Mental Health Counselors	1,890	2,390	500	26.5%	93
Psychiatric Technicians	1,110	1,170	60	5.4%	20
Psychiatric Aides	540	620	80	14.8%	15
Mental Health and Substance Abuse Social Workers	2,490	3010	520	20.9%	95
Child, Family, and School Social Workers	5,000	5560	560	11.2%	141
Medical and Public Health Social Workers	2,120	2620	500	23.6%	86
Social and Human Service Assistants	7,890	9330	1440	18.3%	283
Dietitians and Nutritionists	570	620	50	8.8%	20
Dietetic Technicians	360	410	50	13.9%	10
Medical Equipment Preparers	440	480	40	9.1%	12
Other Health Occupations					
Internists, General	1,700	1,990	290	17.1%	52
Family and General Practitioners	2,010	2,340	330	16.4%	60
Psychiatrists	570	620	50	8.8%	13
Obstetricians and Gynecologists	700	820	120	17.1%	21

Occupational Title	2004	2014	Net Change	Percent Change	Total Annual Openings
Pediatricians, General	660	760	100	15.2%	19
Surgeons	1,230	1,440	210	17.1%	38
Anesthesiologists	1,140	1,340	200	17.5%	35
Optometrists	670	750	80	11.9%	26
Physician Assistants	930	1,100	170	18.3%	31
Medical Assistants	4,860	6,490	1,630	33.5%	253
Dentists, General	2,880	3,010	130	4.5%	37
Dental Hygienists	3,120	3,850	730	23.4%	100
Dental Assistants	3,350	4,140	790	23.6%	172
Orthodontists	190	190	0	0.0%	3
Pharmacists	2,750	3,190	440	16.0%	97
Pharmacy Technicians	2,880	3,320	440	15.3%	81
Pharmacy Aides	690	780	90	13.0%	22
Emergency Medical Technicians and Paramedics	2,860	3,160	300	10.5%	63
Medical and Clinical Laboratory Technologists	2,090	2,430	340	16.3%	90
Surgical Technologists	1,040	1,080	40	3.8%	17
Medical Records and Health Information Technicians	1,540	1,820	280	18.2%	50
Medical and Clinical Laboratory Technicians	1,490	1,680	190	12.8%	59
Respiratory Therapists	1,230	1,400	170	13.8%	58
Respiratory Therapy Technicians	210	250	40	19.0%	7
Nuclear Medicine Technologists	340	390	50	14.7%	12
Medical Transcriptionists	1,080	1,310	230	21.3%	43
Opticians, Dispensing	870	910	40	4.6%	19
Radiation Therapists	760	950	190	25.0%	36
Radiologic Technologists and Technicians	2,910	3,430	520	17.9%	107
Cardiovascular Technologists and Technicians	670	840	170	25.4%	29
Diagnostic Medical Sonographers	680	840	160	23.5%	29
Chiropractors	510	580	70	13.7%	17
Podiatrists	240	250	10	4.2%	7
Orthotists and Prosthetists	180	220	40	22.2%	7
Audiologists	140	150	10	7.1%	5

Source: University of Connecticut Center on Aging, from Connecticut Department of Labor, *Forecast 2014: Connecticut's Employment Projections*, Summer 2006, www.ctdol.state.ct.us/lmi/misc/forecast2014.pdf

V. RECOMMENDATIONS AND ACTION STEPS

The recommendations and action steps provided in this Plan are put forward to improve the balance of the long-term care system in Connecticut for individuals of all ages and across all types of disabilities. While this Plan maps out the need for long-term care over the next 25 years, the recommendations address current needs as well as future demands.

To fully address the improvement of long-term care services and supports in Connecticut, two types of recommendations have been developed. *Balancing – the Long-Term View* offers recommendations that work to balance the capacity and financing of community-based services with institutional care. Two ratios are addressed: the ratio of home and community-based and institutional services and the ratio of public and private resources. The second type of recommendations provide a broad look at needed long-term services and supports by addressing issues identified under nine *Focus Areas*: Community Options, Informal Caregivers, Long-Term Care Workforce, Housing, Employment, Transportation, Access, Prevention and Quality.

Overall, the recommendations are primarily focused on initiatives State government can undertake. In addition, much of the emphasis is on the Medicaid program since it is the largest payer of long-term care, public or private. While the focus of this Plan is on State government, it is important to recognize the vital role that cities, towns, the private sector and individuals and families play in the long-term care system. Government at all levels must work in partnership with individuals, families and the private sector in order to develop a quality and effective system.

In 2005, a broad philosophical statement was created in statute to guide policy and budget decisions with the passage of Public Act 05-14: An Act Concerning the State's Long-Term Care Policy. It states *that Connecticut's long-term care plan and policy must 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 simple statement provides a larger framework for 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. Within this framework, Connecticut can prioritize and detail the steps required to realize this goal.

A. Balancing – the Long-Term View

A balanced long-term care system is one where policies, incentives and services are aligned to allow individuals with long-term care needs to live fulfilling and productive lives. Balancing the mix of home and community-based and institutional care as well as the mix of public and private resources is needed if Connecticut hopes to provide real long-term care choices for its residents and to achieve the long-standing Vision, Mission and Governing Principles put forth by this Plan and previous Long-Term Care Plans. Over the years, Connecticut has made notable progress towards this goal, but more must be done to meet needs today as well as to anticipate the demands on the long-term care system that will be made by the aging of the baby boom generation.

1. Balancing the ratio of home and community-based and institutional care

Connecticut should work to develop a system that provides for more choice, increasing the percentage of Medicaid long-term care clients receiving home and community-based care from 51 percent in 2006 to 75 percent by 2025, requiring approximately a one percent increase in the percentage of Medicaid long-term care clients served in the community every year.

Over the last decade, Connecticut has made significant progress in developing home and community-based and residential alternatives to institutional care. Examples abound. Connecticut eliminated its waiting list for home care for elders; expanded income eligibility for State-funded home care for elders; introduced subsidized assisted living in State-funded congregate facilities, HUD complexes and private pay assisted living communities; developed affordable assisted living units; increased funding and capacity for various Medicaid home and community-based waiver programs; expanded access to personal care services for individuals eligible for Medicaid; and developed a long-term care services and supports website. In addition, there has been a four-fold increase in the number of elderly State-funded and Medicaid home care clients since 1996.

In the three years since the last Long-Term Care Plan was issued, Connecticut has exceeded the Plan's goal of improving the balance between home and community-based services and institutional care by one percent a year. The proportion of Medicaid long-term care clients receiving community-based care has increased from 46 percent in SFY 2003 to 51 percent in SFY 2006 – a five percent gain in three years (Table 11). For the first time in Connecticut, there are more individuals receiving Medicaid long-term care services in the community than are receiving institutional care.

The shift toward community-based care can also be seen in terms of Medicaid long-term care expenditures. Between SFY 2003 and SFY 2005 the proportion of Medicaid long-term care dollars spent on care delivered in the community increased by 4 percent, rising from 31 percent to 35 percent (Table 12). 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.

If Connecticut is able to meet the goal of serving three out of every four Medicaid long-term care clients in the community, the impact on future long-term care expenditures will be significant. Based on U.S. Census Bureau disability data and population projections, and assuming the proportion of individuals with disabilities remains the same, it is estimated that by 2025 the number of persons with disabilities in Connecticut will grow by 99,000 or 25 percent. However, for individuals with disabilities below age 64, barely any increase is projected by 2025: less than one percent among those ages 5 to 64. For those 65 years of age and older, the number of individuals with disabilities is expected to increase by 63 percent. Assuming current ratios of community-based to institutional care, a five percent per year inflation rate and a 25 percent increase in the number of individuals with disabilities, Medicaid expenditures for long-term care are anticipated to

grow from $2.2 billion in SFY 2006 to $5.5 billion by SFY 2025 to meet the expected increase in demand for long-term care.

TABLE 11
Proportion of Connecticut Medicaid Long-Term Care Clients over Time

SFY	Home & Community Care	Institutional Care	Total Monthly Average LTC Medicaid Clients
2002-03	46%	54%	37,969
2003-04	49%	51%	39,305
2004-05	50%	50%	40,417
2005-06	51%	49%	41,773

Source: Office of Policy and Management, Policy Development and Planning Division, 2006

TABLE 12
Proportion of Connecticut Medicaid Long-Term Care Expenditures over Time

SFY	Home & Community Care	Institutional Care	Total LTC Medicaid Expenditures
2002-03	31%	69%	$1,914,273,731
2003-04	33%	67%	$1,955,406,395
2004-05	35%	65%	$1,977,418,433
2005-06	32%	68%	$2,227,237,142

Source: Office of Policy and Management, Policy Development and Planning Division, 2006

However, with 75 percent of individuals receiving community care in 2025, these long-term care expenditures are only expected to be $4.5 billion, which is $1 billion less than the State might otherwise have spent that year. In addition, approximately 56 percent, up from 32 percent, of Medicaid long-term care expenditures would go toward the cost of care in the community. This cost avoidance over time not only allows Connecticut to provide relief to the Medicaid budget but also allows Connecticut to meet the needs of a larger group of individuals.

This Plan takes a conservative approach to projecting the numbers of individuals with disabilities over the next twenty-five years by holding the percentage of persons with disabilities constant over time. As described in Chapter IV, the percentage of elderly with disabilities has fallen over the last two decades. Experts disagree whether this

decline in the rate of disability will continue or whether the expected demographic changes will overwhelm these gains. Fluctuations in either direction in the rate of disability will have an impact on the cost of providing long-term care services and supports.

The following action steps can assist Connecticut in its efforts to balance its long-term care service mix:

Home and Community-Based Infrastructure

Action Steps

- Examine the possibility of providing greater uniformity among the different Medicaid home and community-based waivers in terms of requirements such as age and income limits, and of providing maximum flexibility and choice as to how waiver funds can be utilized. Within the confines of federal Medicaid law that prohibits combining individuals who are (1) aged and disabled, (2) intellectually disabled or developmentally disabled, or (3) mentally ill into a single waiver, the State should explore any options that may be available, particularly options that do not discriminate against persons with psychiatric disabilities.

- Maximize the involvement of individuals with disabilities and family members of individuals with disabilities in the development and implementation of Connecticut's long-term care system.

- Explore the opportunity to strengthen consumer directed care provided by the Cash and Counseling provision of the federal Deficit Reduction Act of 2005. States are allowed to provide Medicaid payment for part or all of the cost of self-directed personal assistance services (other than room and board) based on a written plan of care to individuals who would otherwise require and receive personal care services under the Medicaid State Plan or home and community-based care under a HCBS waiver.

- Explore the opportunity to expand home and community based care provided by the Expanded Access to Home and Community-Based Services (HCBS) and Presumptive Eligibility provision of the Deficit Reduction Act of 2005. The HCBS provision allows states to cover HCBS as a Medicaid State plan option for individuals with incomes at or below 150 percent of the federal poverty level. Previously, HCBS could only be covered in the context of a Medicaid waiver program. States are permitted to provide this option to individuals without requiring that the person would otherwise require a level of care provided in a hospital, nursing home or ICF-MR. Any service permitted under a HCBS waiver is allowed, but does not include costs for room and board. States may also limit the number of individuals who can participate in this benefit and establish waiting lists. The Presumptive Eligibility provision allows States to provide a period of presumptive eligibility (not to exceed 60 days) for individuals applying for HCBS.

- Explore training opportunities for conservators, guardians, families, probate system staff, medical personnel, social workers, and others about supporting choice, autonomy and dignity and the assistance available for transitioning from institutions to the community and the services available in the community after transition.

- Review Connecticut statutes to identify opportunities to enhance protections of persons with disabilities when there is a conservator involved.

Nursing Facility Transitions

Action Steps

- Connecticut should continue its support of programs to assist individuals in transitioning out of nursing facilities and other institutions. The Nursing Facility Transition Program (NFTP), also called My Community Choices, has shown that with the proper supports and services, individuals with severe disabilities can successfully transition to, and remain in, the community.

- Connecticut should build on the successful components of the NFTP and strive to sustain those elements into the future. For example, the Common Sense Fund, used under the NFTP to provide transition expenses such as security deposits and home modifications should be made a standard benefit. In addition, the State should explore providing reimbursement for peer mentoring and encouraging community activities.

- Connecticut should continue its landmark decision to allocate a number of Section 8 vouchers for individuals transitioning from nursing facilities, developed as part of the Nursing Facility Transition Project.

- Connecticut should work with housing providers, such as Residential Care Homes, Congregate Housing, DMR Residential Services and others to maximize the housing and service and supports opportunities for individuals transitioning from nursing facilities.

Prescreening Efforts

Action Steps

- Connecticut should expand its present commitment to prescreening all applicants to nursing facilities age 65 and older, regardless of their payer status, to include all nursing facility applicants, regardless of their age or payer source. Helping a private pay nursing facility applicant understand their community options and possibly avoid or delay their entrance into a nursing facility is not only advantageous to the individual and family but is a wise investment for the State. Similar prescreening for all institutions should be developed for individuals with disabilities.

Any expansion of prescreening activities should be performed by State agencies. Prescreening should not prohibit or deny applicants the choice to enter an institution. The overall goal of prescreening should be to assure that individuals have the knowledge and opportunity to exercise their choice to live in a community or institutional setting. Prescreening activities need to take into account the specific needs of the individual, addressing both cognitive and physical impairments, and ensure that the person receives the appropriate level of care that will protect them and others from any potential harm. Individuals who chose community settings must have safe and adequate living options and sufficient care giving supports.

- As part of the prescreening efforts, the State, in conjunction with providers and other entities working in the community with individuals with disabilities, should enhance their existing educational efforts with hospitals, physicians, nursing facilities, and other institutions regarding available community options.

Adjustments to Institutional Capacity

Action Steps

- As nursing facilities and other institutions close, or occupancy levels are reduced, Connecticut should continue to conduct a needs analysis to: 1) determine if any of the beds are needed elsewhere in the system; and 2) de-license or reclassify the remaining beds. As this occurs, there is an opportunity to redirect the appropriate level of resources to enhance home and community-based services and supports. Currently, the general practice is that savings from any reduction in institutional beds goes to the General Fund. In order to allow for a redistribution of resources, at the time the beds are removed from the system, a determination should be made as to the cost to provide services for those institutional beds and the costs to provide services to the same number of individuals in the community. If the redistribution occurs, the result will be an increase in home and community-based service expenditures coupled with an increase in the number of individuals served in the community. The difference between the cost of paying for the institutional beds and the cost for community care could be savings to the General Fund.

- Connecticut should create incentives for under utilized institutions to convert their facilities to adult day care services, assisted living, residential care homes, independent living communities, or other community housing options in order to offer settings that reflect the more home-like features that people generally prefer. . Such conversions could help mitigate the large capital expense of building the new housing options that will be needed to help accommodate the increase in individuals receiving services and supports in the community. These conversions can also help institutional operators remain in the long-term care field and utilize their staff as service providers in the community. Such incentives could include low-cost financing for conversions and tax credits. Development of any new community housing options should emphasize consumer direction and choice.

- Connecticut should assess the need for extending the moratorium on construction of new nursing home beds when the enabling legislation sunsets in 2007.

Federal Reform

Action Steps

- Connecticut should continue to advocate for changes to federal Medicaid law that will facilitate an expansion of home and community-based options. In the past, Connecticut submitted a proposal to the federal Centers for Medicare and Medicaid Services (CMS) to expand the medically needy income formula allowing individuals with incomes in excess of 300 percent of Supplemental Security Income to be eligible under the Medicaid portion of the Connecticut Home Care Program for Elders (CHCP). This proposal would have allowed individuals the same access to home and community-based care as they have for nursing facility care. Unfortunately, Connecticut's proposal was rejected by CMS. Connecticut should resubmit this proposal and continue its efforts in this regard. If successful in its effort to expand the income requirements under the CHCP rules, Connecticut should examine the feasibility of utilizing similar income requirements under its other home and community-based waiver programs, resulting in equal access to home and community-based care and nursing facility care for individuals of all ages and disabilities.

- Current Medicaid law prohibits the reimbursement of room and board charges for those living in the community, including in assisted living communities. Connecticut should continue its efforts to remove this prohibition or expand other federal programs such as Section 8, allowing more aggressive development of community living options.

- Work with Congress and the Centers for Medicare and Medicaid Services to eliminate the "homebound" definition for Medicare home health care or, at a minimum, liberalize this requirement with respect to individuals with long-term disabilities.

2. Balancing the ratio of public and private resources

- ***Connecticut should strive over the next 20 years to increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent. Such an increase in private insurance and other sources of private funding would reduce the burden both on Medicaid and on individuals' out-of-pocket expenses. Nationally, private insurance represented 7 percent of long-term care spending in 2004.***

Long-term care is one of the most complex and difficult issues for individuals and families to understand and discuss. Many people are under the false impression that Medicare, and other health insurance programs, will cover their long-term care needs.

This misunderstanding, coupled with the fact that most individuals understandably would rather not face, or discuss, the possibility of becoming disabled and dependent, leads most people to do little or no planning for their future long-term care costs.

The lack of Medicare and health insurance coverage for long-term care, combined with the lack of planning, has created a long-term care financing system that is overly reliant on the Medicaid program. Medicaid, by default, has become the primary public program for long-term care. However, in order to access Medicaid, individuals must first impoverish themselves. Therefore, we have a system that requires individuals to spend all their savings first in order to receive government support for their ongoing needs.

The private resources paying for long-term care primarily are in the form of individuals and families spending their own funds with only a small percentage of the costs being paid for by private insurance or other private sources. The usage of private savings to pay for long-term care would not be a hardship if those savings had been dedicated in advance for long-term care. However, in most cases that is not the case and the funds being utilized had been targeted to meet other needs, such as retirement income.

In order for Connecticut residents to have real choices about what type of long-term care services and supports they receive and where those services are provided, there needs to be a better balance between public and private resources. An over reliance on the Medicaid program as the primary source for long-term care financing threatens to reduce choices as budget pressures will only mount as the need for long-term care increases. Resources such as insurance benefits and other dedicated sources of private long-term care funding (i.e. reverse annuity mortgages) are needed to help balance the ratio of public and private funds in the system.

If enough individuals would plan for their long-term care needs through long-term care insurance or dedicated savings, there would be more Medicaid funding for community-based care and people would not have to deplete their assets if they required prolonged long-term care services. For example, the burden on both the state Medicaid program and individuals paying out-of-pocket for long-term care would be significantly reduced if the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds successfully reached 25 percent. If these reductions in expenses were evenly divided between Medicaid and out-of-pocket costs for individuals, then Medicaid's share of the costs could be reduced by 7 percent. Using today's dollars, and a Medicaid long-term care budget of approximately $2.2 billion, that would equate to $154 million in annual savings. These savings could be partially allocated to the General Fund and partially used to help fund enhancements to the long-term care system, such as infrastructure and service improvements, leading to more choices for individuals and their families.

Private long-term care insurance is one possible option to help balance the long-term care financing system. Long-term care insurance was developed to help fill the gap left by the lack of long-term care coverage under traditional health insurance plans and Medicare. Both health insurance and Medicare are designed to pay for acute care and will only pay

for a very limited amount of long-term care as long as it is rehabilitative or restorative in nature. Private long-term care insurance emerged to specifically cover the personal and custodial care services and supports that comprise most of what is referred to as long-term care, including both home-based and institutional services.

However, private long-term care insurance (LTCI) has its limitations. The premium for LTCI is priced based on the purchaser's age. The older someone is the more expensive the policy. Therefore, for many individuals who wait too long to plan for their long-term care, LTCI may not be affordable. Also, there will always be a portion of the population where LTCI is not affordable at any age.

In addition, in order to purchase LTCI an individual must generally pass a medical underwriting screen (there are some exceptions to this in large group/employer offerings). Individuals who are already in need of long-term care, or have conditions, such as Multiple Sclerosis or Parkinson's Disease, that, even if there are no symptoms at the time the individual applies for coverage, will very likely lead to needing long-term care, aren't able to purchase the coverage. This medical screening will likely continue until such time as more individuals purchase LTCI since insurance companies are not willing to take on the additional risk of covering what they perceive to be high-risk applicants.

Given its limitations, private LTCI is not a panacea. However, it can play a more significant role than it does today in financing long-term care. While, as noted above, there are individuals where LTCI is not affordable or accessible, there is a segment of the population where LTCI can be a viable option if these individuals are educated about long-term care and are motivated to do some personal planning to avoid impoverishment. In Connecticut, the presence of the Partnership for Long-Term Care program makes LTCI more affordable for many since they need only purchase an amount of coverage equal to the amount of assets they wish to protect.

In addition to LTCI as a planning tool, Connecticut needs to be creative in the development of other financing options that can help to balance the ratio of public and private resources in the system.

In order to affect such a shift in the balance of public and private resources, individuals and families must be educated as to what long-term care is and the risks and costs they face if they do nothing to plan for their future long-term care needs. The following action steps are designed to facilitate such a change:

Planning Ahead for Long-Term Care

Action Steps

- Connecticut should create new options to encourage personal responsibility and planning and identify and maximize existing non-governmental resources.

- Connecticut, working with the federal government, should develop incentives for individuals to save for their future long-term care needs. Preferential tax treatment for dedicated long-term care savings accounts could provide some additional opportunities to infuse private resources into the system without forcing individuals to impoverish themselves. Connecticut should also explore opportunities on the state level to provide tax relief for unreimbursed medical and long-term care expenses.

- Connecticut should continue, and enhance, the efforts of the Connecticut Partnership for Long-Term Care (Partnership), the State's public/private alliance to help educate Connecticut residents about the importance of planning ahead for future long-term care needs through the purchase of high quality private long-term care insurance (LTCI). While the Partnership has had a significant impact on the purchase of private long-term care insurance, with over 40,000 Partnership policies purchased, there is much more that can be done.

  The Partnership should continue its strategy of presenting LTCI as an option that can help individuals remain in their homes or communities longer, preventing or delaying the need for nursing home care. If individuals understood that LTCI could actually help them remain at home or in the community it might become a more attractive option.

- The State should pursue possible funding under the federal Long-Term Care Awareness Campaign. This demonstration project sponsored by the U.S. Department of Health and Human Services is designed to help states increase consumer awareness of the need of long-term care and financial planning.

- The State should take advantage of any opportunities to enhance the educational capabilities of the Partnership through the use of public and private resources. Alliances with local communities should be explored to bring the issue of long-term care planning into as many communities as possible. In addition, partnerships with the state's media outlets should be enhanced to enlist the media's support in the efforts to educate Connecticut residents about this important issue.

- Connecticut should explore the development of various products, including a high-risk pool for long-term care insurance to enable individuals who are currently uninsurable to obtain the coverage they need.

- Connecticut should continue its efforts on the federal level to enact an "above the line" tax deduction for the purchase of long-term care insurance. Such a tax deduction would also result in a State tax deduction as long as Connecticut's tax system is tied to an individual's federal Adjusted Gross Income. If federal action on this issue is not taken, Connecticut should explore its own tax incentives for long-term care insurance, such as tax credits or deductions. Any effort to provide tax incentives should be targeted or focused to ensure that the market is truly expanded to include those where the insurance might be unaffordable.

- Connecticut should explore and develop other models for private long-term care insurance. Such models could include a combination disability and long-term care insurance policy or variations on existing combination life insurance and long-term care insurance policies.

- Connecticut should examine the state and federal reverse annuity mortgage (RAM) programs to see if any enhancements can be made to increase the usage of this program. An effective RAM program could allow individuals to use their home equity to remain in their homes longer or even to use the resources to purchase long-term care insurance if that is an affordable and accessible option for them. RAMs may be more popular with the Deficit Reduction Act provision on home equity and Medicaid eligibility for long-term care services described in the Executive Summary.

B. Focus Areas

Balancing the system to promote real choices for all persons with disabilities requires not only a common vision for providing long-term care, but to succeed, this task must be approached on multiple fronts. Below are recommendations for action steps in nine Focus Areas that support the major system change recommendations described above. For each Focus Area, there is a brief description of the issue followed by recommended action steps.

1. Community Options

People with disabilities, like everyone in society, want to live full and satisfying lives. They want to be productive, be welcomed into and participate in community life, and have control over where and how they live. However, those who have disabilities face losing control over their lives and their care because they often must depend on others to help them with essential daily activities.

One of the consequences of having a disability is that it tends to increase isolation and reduce community participation. Often overlooked is the fact that all individuals have gifts and assets, and those individuals limited due to any type of disability have much to share with their communities. A 2000 Harris poll of Americans with and without disabilities found that those with disabilities feel significantly more isolated and left out of community life. People without any disabilities say that the main reason for not being as involved as much as they would like in their community is lack of time. In contrast, those with disabilities give different reasons: they do not feel encouraged by community organizations to participate (54 percent), they don't have the income necessary to participate (53 percent), or they are not aware of what activities exist (46 percent).[62]

Efforts to address issues of social isolation and community inclusion were undertaken at the state level from 2002 through 2006 through the federal Real Choice Systems Change grant, funded by the Centers for Medicare and Medicaid Services (CMS). As part of this grant, three towns – Bridgeport, Groton and New Haven – were awarded funding to establish themselves as Model Communities for inclusion of persons with disabilities and their families in the life of their communities.

Community inclusion was also the topic of the Interroburst Conference, sponsored by the Office of Protection and Advocacy in October 2003. The purpose of the conference was to explore feelings of isolation many people with disabilities and their families experience living in their communities. Two basic types of barriers were identified: structural barriers (lack of personal care assistance, architectural barriers and difficulty with transportation) and barriers related to community acceptance and inclusion. A video

[62] Humphry Taylor, "Many People with Disabilities Feel Isolated, Left Out of their Communities and Would Like to Participate More", *The Harris Poll*, #34, July 5, 2000, www.harrisinteractive.com/harris_poll/index.asp?PID=97

of the conference has been used across the state as tool to generate discussion and thinking on community inclusion.

In order to improve home and community-based services for people with disabilities, states are increasingly incorporating consumer-directed services into their Medicaid programs to give individuals more control and independence over the services and supports they receive. In Connecticut, consumer- directed personal care assistance (PCA) is provided by the Department of Social Services through the Medicaid Personal Care Assistance Services Waiver to eligible individuals with disabilities age 18 and older who need help with their activities of daily living. Established in 1997, the program allows people to hire, train, and supervise their own personal care assistants. In addition, there is a state-funded Personal Care Assistance Pilot Program for 250 people within the Connecticut Home Care Program for Elders that allows relatives, other than a spouse, to act as a PCA.

The Department of Mental Retardation also offers a self-determination approach to service delivery that helps people, their families and friends design their own support plans, choose the assistance they need to live full lives and control a personal budget for their supports. Individuals may use their individual budgets to hire their own staff, to purchase supports from an agency, or may select a combination of these approaches.

Action Steps

- Enhance the capacity of communities to accommodate the needs of individuals with disabilities. Encourage communities to take an active role in planning and supporting long-term care for their residents.

- Encourage communities to provide a more supportive infrastructure including more affordable housing, expanded and coordinated transportation options, and side walks, cross walks and curb cuts.

- Encourage the adoption of actions developed within Model Communities and Interroburst conferences to reduce the isolation felt by individuals with disabilities living in the community and their families.

- Encourage public education on the role all citizens can play within their communities in addressing long-term needs of their friends, neighbors and fellow citizens.

- Connecticut should support additional Interroburst forums to explore the meaning of community and to reduce the isolation of individuals and families.

- Continue support of the monthly series “Able Lives” aired on Connecticut Public Television in 2006 to educate the public on the lives of individuals with disabilities and effect the change needed to create more inclusive communities. This program is sponsored by the Connecticut Council on Developmental Disabilities and other state and private agencies.

- Explore the benefits and potential for adding a service to the Connecticut Home Care Program for Elders that allows payment to Adult Day Care Centers for therapies, making them approved rehabilitation sites. This should include consideration of licensing and Medicaid reimbursement issues.

2. Informal Caregivers

Connecticut should do whatever it can to support and enhance the selfless efforts of caregivers who, with some support, will continue to provide the informal care that provides the backbone of the long-term care system. While the focus of the long-term care system tends to be on the dollars spent from public and private sources, most services and supports are still provided by family and friends on an informal basis. This informal support is absolutely critical and any opportunities Connecticut has to support this informal caregiving network should be explored. Any support for informal caregivers is an investment. A primary caregiver at home who is provided adequate respite will be able to maintain their caregiving responsibilities for a much longer period of time, possibly delaying or avoiding the cost for formal care and admission into an institutional setting.

Action Steps

- In order for individuals with disabilities to remain at home or in the community as long as possible, support for family caregivers should take a variety of coordinated forms. These could include information and training, respite services to caregivers, tax benefits and incentives, payment to informal caregivers, transportation alternatives, physical, occupational and speech therapy alternatives, and disability supports.

- In addition to continuing existing respite care efforts, Connecticut should replicate its successful Alzheimer's Respite Care program to provide respite services for any caregiver of individuals with disabilities of all ages. Respite across the lifespan should be available to provide an easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs, and assist with locating training and paying respite providers. As Connecticut begins to increase the amount it spends on home and community-based care while reducing its institutional expenditures, it should allocate resources towards the support of informal caregivers through respite care and caregiver training programs.

- The State should build on and expand current efforts supported under the National Family Caregiver Support Program, enhancing the basic information, training and respite services that are already provided.

- Connecticut should explore the potential for supporting overnight respite care in settings other than institutions. This should include consideration of licensing and Medicaid reimbursement issues.

- Respite training should be considered as part of the curriculum within appropriate programs at state colleges and universities and other educational settings. Such curriculum also should include a component to assist individuals with disabilities and their family members in promoting self-determination.

- Training should be developed for public and private providers to better assist families and other informal caregivers to develop the supports necessary to allow a person with disabilities to live in their community.

- Connecticut should continue its efforts on the federal level to enact a tax credit for those providing informal care.

3. Long-Term Care Workforce

> *"The paraprofessional long-term care workforce – nursing assistants, home health and homecare aides, personal care attendants and personal services workers – form the centerpiece of the formal long-term care system. These frontline workers provide hands-on care, supervision and emotional support to millions of elderly and younger people with chronic illnesses and disabilities. After informal care givers, these workers are the most important in helping older and younger people with disabilities maintain some level of function and quality of life."* -- Robyn I. Stone[63]

The current supply of formal caregivers in the community and institutions, both professional and non-traditional, is not meeting the need for long-term care services. As the population ages and the numbers of those in need of long-term care supports grows, the demand for workers is expected to sharply increase. Attention must be given to attracting individuals to work in long-term care by enhancing the compensation and benefits, status, career ladders and training associated with these jobs.

In particular, the shortage of nursing assistants and home care aides that began in the late 1990s is driving the current concern about the adequacy of the long-term care workforce. High turnover rates mean additional costs for recruiting, training and lost productivity. There is concern that difficulties attracting and retaining direct care workers may translate into poorer quality or unsafe care, major disruptions in the continuity of care and reduced access to care. For the workers, inadequate staffing imposes additional demands on those with jobs, limits the workers' ability to respond to the needs of those in their care, and may increase the rate of accident or injuries.[64]

[63] Robyn I. Stone, *Linking Services to Housing: Who Will Provide the Care?* Generations, Winter 2005-2006, page 44.
[64] Ibid, page 46.

Gains have been made to promote the effective recruitment and retention of personal assistants and ensure that people with disabilities in Connecticut have the knowledge, access and resources available to maximize choice and control in the use of Personal Assistance Services. Connecticut was awarded a three-year federal Community-integrated Personal Assistance Services and Supports (C-PASS) grant that ended in September 2006, and with the approval of a no cost extension, will be continued through September 2007. The grant addresses the development of a personal assistance workforce by building an infrastructure that allows for the effective recruitment and retention of direct support personnel through the following efforts:

- *Rewarding Work Website* -- gives older people and individuals with disabilities the choice of hiring staff directly and allows them control of the process of hiring personal assistants. The site also provides private agencies a resource to assist in recruitment of direct support professionals and other staff. www.rewardingwork.org

- *Personal Care Assistants Recruitment Video and Employer Training Manual* – A video has been produced by staff from the UConn Center on Disabilities, with assistance from consumers and personal care assistants participating in various home and community-based waiver programs. Included are perspectives from individuals and family members representing various disabilities and ages, explaining why personal assistants are important parts of their daily lives, and why being a personal assistant can be a challenging and rewarding career. In addition, a training manual and program have been developed to assist individuals with disabilities to acquire the skills to be an employer and hire and manage their own personal care assistants.

A number of strategic plans have been developed in the last few years to address the workforce shortage.

- *Connecticut Career Ladder Advisory Committee Three Year Strategic Plan (February 2004)* – The Connecticut Career Ladder Advisory Committee was established by Public Act 03-142 to promote the creation of new career ladder programs and the enhancement of existing career ladder programs for occupations with projected workforce shortages, including health care. www.cwealf.org/pdf/careerladrpt.pdf

- *Career Ladder Advisory Committee Legislative Update, February 2006* – Provides an update on activities related to the recommendations of the Connecticut Career Ladder Advisory Committee Three Year Strategic Plan. www.cwealf.org/resources/careerladders.pdf

- *Allied Health Workforce Policy Board, Legislative Report, February 2006* – Established by Public Act 04-220: An Act Concerning Allied Health Workforce Needs, the Board is charged with monitoring data and trends and developing recommendations addressing the recruitment and retention of individuals in the

allied health fields. www.cwealf.org/resources/allied_health_2006_final.pdf#search=%22%22Allied%20Health%20Workforce%20Policy%20Board%22%20%22Legislative%20Report%22%22

- *A Comprehensive Mental Health Plan for the State of Connecticut, September 2006* -- Includes information related to the behavioral health workforce and recommendations for recruitment, retention and training. www.dmhas.state.ct.us/transformation/MHTfinalreport.pdf

Action Steps

- Connecticut should expand the use of the non-traditional workforce, such as personal care assistants (PCAs) and personal managers, to help address the increased number of individuals desiring home and community-based care. To make the positions competitive and a viable career, these types of jobs will need to provide the necessary worker benefits and supports. In addition, optional training for PCAs should be considered part of the curriculum within appropriate state colleges and universities and other educational settings.

- Connecticut should work with organizations to continue the efforts of the C-PASS grant as it pertains to training employers how to hire and manage personal care assistants, as well as to continue the Rewarding Work.org website.

- Connecticut should evaluate the Personal Care Assistance Pilot under the Connecticut Home Care Program for Elders to determine the potential for making personal care assistance a permanent benefit.

- Connecticut should develop programs to address the professional workforce shortage. Strategies could include attracting students into the field with scholarships and grants, developing career paths allowing for increases in responsibility, status and wages, enhancing public perception of these jobs, and professionalization of paraprofessional positions. There is also potential for re-training individuals who lose their job in such sectors as manufacturing for a new career in long-term care.

- Connecticut should increase the capacity of educational institutions (i.e. state colleges and universities and high schools) to provide training for professional long-term care workers in order to address the current need for and projected growth of these workers in the state.

- Connecticut should promote the use of distance learning programs to enhance the skills of direct support professionals.

- Home care agencies, nursing homes, and other long-term care providers should consider ways to increase the numbers of direct care workers and provide incentives for recruiting and retaining workers.

- Recruitment of bilingual workers is needed to assure services are accessible and acceptable to individuals whose primary language is not English.

4. Housing

Everyone needs a place to call home. To live in a community and participate in community life, people need affordable, safe and accessible housing. However, this is out of reach for many individuals with disabilities. Many people with long-term disabilities remain in public institutions or nursing homes or in housing that costs the greater portion of their income.

In terms of affordability, in 2004, the average national rent for a one-bedroom housing unit was greater than the amount of income received by people with disabilities from the Supplemental Security Income (SSI) program. In Connecticut, where the average SSI monthly payment was $747.00 in 2004, people paid an average of 102.5 percent of their monthly SSI check for one-bedroom units at fair market rent.[65]

Finding a home can be twice as difficult for people with disabilities because it must be within reach physically as well as financially. Although significant progress has been made in making public buildings accessible to the physically disabled, the same is not true for residential housing.

The Department of Economic and Community Development (DECD), in partnership with other state agencies, has developed two State Plans that address the housing needs of seniors and individuals with disabilities:

- *Connecticut 2005 – 2009 Long Range Housing Plan*. This State Plan was prepared by DECD in consultation with the Connecticut Housing Finance Authority and was developed in tandem with the Connecticut Consolidated Plan for Housing and Community Development. The focus of the Plan is on the administration of state funded housing development and subsidy programs. One of the six goals identified in the Plan addresses special needs, specifically the elderly and frail elderly, persons with disabilities, persons with HIV/AIDS and their families, persons with substance abuse issues and persons recently de-incarcerated. (www.ct.gov/ecd/lib/ecd/2005-2009_slrhp.pdf)

- *Connecticut 2005-2009 Consolidated Plan for Housing and Community Development*. This Plan was prepared by DECD and was developed in tandem with the Connecticut Long Range Housing Plan. It focuses on the state's administration of four federal housing and community development block grant programs: Community Development Block Grant (CDBG), HOME Investment Partnership Program

[65] Ann O'Hara et al, *Priced Out in 2004: The Housing Crisis for People with Disabilities*, Technical Assistance Collaborative, Inc and the Consortium for Citizens with Disabilities Housing Task Force, September 2005.

(HOME), Emergency Shelter Grant (ESG), and Housing Opportunities for Persons with AIDS (HOPWA). (www.ct.gov/ecd/lib/ecd/decd_consolidated_plan_for_housing_and_community_development.pdf)

To ensure affordable supportive housing for individuals who are homeless and for those with substance abuse or psychiatric disabilities, the *Interagency Council on Supportive Housing and Homelessness* was established in 2004 through Executive Order #34 and charged with the development of a plan that will create 900-1,000 additional units of supportive housing over the next 10 years. Supportive housing combines affordable rental housing with individualized health support and employment services. The Council issued its first report in January 2005 (www.opm.state.ct.us/secr/Reports/Report2005HousingHomeless.doc). Through the Next Step Supportive Housing Initiative, the Council set out an approach to create 1,000 units of affordable, service-supported rental housing over the next three years: 350 apartments for families and 650 for single adults, including 50 for young adults.

Action Steps

- Over the next biennium, support the efforts of the Accessible Housing Registry to identify accessible units and increase their utilization.
- Expand and preserve the stock of housing for elders and persons with disabilities.
- Enforce current standards in Connecticut regulation and statute, including the Building Code, which require builders of new developments to create a certain percentage of wheelchair accessible units.
- Promote universal design with architects and housing developers.
- Increase outreach to landlords about resources and financing to make their units accessible.
- Increase the utilization of Section 8 Vouchers in communities throughout Connecticut so additional vouchers may be requested from HUD.
- Establish a Resident Services Coordinator in every State-funded Elderly Housing facility. Currently, there is one Resident Services Coordinator in every three facilities. Training is also needed to equip Resident Service Coordinators to serve both older adults and individuals with disabilities.
- Expand assisted living options beyond those available to the elderly.
- Ensure that all State agencies that construct or rehabilitate housing or provide rental assistance report the accessible units to the accessible housing registry.

- Maintain current building codes for type A units and require local building officials to report such units to the Department of Economic and Community Development as part of the building permit process.

5. Employment

Full participation in the community means the opportunity to live, work and play in accordance with personal choice. The same supports that are necessary for an individual to live successfully in their community often translate into needed supports for the workplace. Community integration efforts should provide individuals with opportunities to increase employment outcomes and earnings. This, in turn, becomes a critical component of any rebalancing effort within a long-term care system.

In 2006, Connecticut embarked on a comprehensive strategic planning process. This process resulted in the development of Connecticut's Strategic Employment Plan.

The plan begins with the needs of our key stakeholders: individuals with disabilities and employers. It will serve as a guiding force for Connecticut's efforts to maximize opportunities for self-sufficiency and full participation for its residents with disabilities. The priority areas resulting from the planning process include 1) school to work transition, 2) stakeholder education, 3) recruitment, employment and retention, 4) transportation, and 5) technical assistance. Each of the priority areas will be approached in a way that meets system needs, but also attends to the nuances of individual community needs.

Action Steps

- Improve the transition process for young adults moving from school to post-secondary education or employment.

- Increase expectations for people with disabilities in achieving career potential.

- Increase the recruitment, employment and retention of individuals with disabilities into Connecticut businesses.

- Increase access to transportation to and from work for individuals with disabilities.

- Provide technical assistance to support the development of effective strategies for increasing employment of people with disabilities.

6. Transportation

Transportation is inadequate or inaccessible for some people with disabilities living in the community. According to the National Organization on Disability/ Harris 2000 Survey

of Americans with Disabilities, 30 percent of Americans with disabilities have a problem with transportation, compared to only 10 percent of those without disabilities. In addition, otherwise healthy individuals may lose their ability to drive as they age and the loss of the ability to drive may deprive an individual of many of the supports that are needed to maintain self-sufficiency. Transportation is fundamental to independence, affecting access to employment, medical care, friends and family, shopping, entertainment, community events, and religious activities. [66]

In Connecticut, elders and people with disabilities have access to the same modes of transportation as the general public, including fixed route public buses which are fitted with wheelchair lifts or have low floors, railways and private taxis. Paratransit services and dial-a-ride programs are offered to elders and those with disabilities that cannot use these methods of transportation. The Americans with Disabilities Act (ADA) requires that every entity receiving public funds for fixed-route bus transit must offer equivalent paratransit services to ADA-eligible people in the service area and during the service hours of the fixed-route operation. Dial-a-ride services are available in many areas of the state and may be sponsored by towns, non-profit agencies, senior centers and regional transit districts. Some of these services have eligibility restrictions and/or limited hours and days of services or limited services areas.

The Connecticut Department of Transportation (DOT) has received federal funds through the United We Ride program to develop a State Action Plan to define issues that may limit comprehensive and coordinated human service transportation and to develop solutions that will enhance cross-agency collaboration. DOT is also embarking on an effort called LOCHSTP (Locally Coordinated Public Transit Human Service Transportation Plan). The long-term vision of the federal mandate is to develop a unified comprehensive strategy for public transportation service planning and delivery. In the near term it is to develop this process for three specific Federal Transit Administration-funded programs that serve individuals with disabilities, older adults, and individuals with limited income. The process is to use regional, multi-disciplinary colloboratives to identify the service gaps for the target populations, lay out strategies for meeting these needs, and prioritize the services within a region. A LOCHSTP plan is expected to be in place by the spring of 2007. Combined with the United We Ride effort described above, there is an opportunity for a much more inclusive, high level view of the transportation system for the target populations.

In 2005 a series of forums on transportation were conducted to help shape the United We Ride State Action Plan. Consumers with disabilities who use transportation services participated, representing individuals with a wide variety of disabilities from all areas of the state. This effort was conducted by the UConn A.J. Pappanikou Center for Excellence in Developmental Disabilities and was supported with a grant from the

[66] National Organization on Disabilities, www.nod.org/content.cfm?id=798

Connecticut Council on Developmental Disabilities. Five priorities for action were identified: community access, collaboration, education, training and safety.[67]

In SFY 2007, the DOT provided funding through a new Municipal Matching Grant program, distributing up to $5 million annually to towns to deliver additional transportation services to seniors and persons with disabilities. Coordination with existing transportation providers or creation of new transportation coordination entities was encouraged. One hundred and thirty-six (136) towns and cities were awarded grants either individually or through coordinated transportation entities.

Actions Steps

- Whenever new housing resources are being developed for individuals with disabilities or the general public, consideration should be given to the availability of public transportation resources.

- Whenever new supportive employment opportunities are being developed for individuals with disabilities, consideration should be given to the availability of public transportation resources.

- The Department of Transportation, the Office of Policy and Management, State agencies and stakeholders involved in serving or transporting clients and individuals with disabilities should engage a facilitated long-term planning process to evaluate the existing transportation system. The goal of this evaluation should be to improve the existing transportation system to achieve uniform coverage and to better meet the medical and social needs of Connecticut citizens with disabilities to allow them to participate fully in community life.

- Towns, community service providers and Department of Transportation services should collaborate to increase cost-efficient and flexible transportation. Collaboration will reduce instances when agency or municipal vehicles sit idle for part of the day or when multiple transportation services under a variety of agencies travel to similar destinations.

- Some people with disabilities do not always feel safe as passengers on public transportation. Lack of compliance with safety procedures and improper use of equipment are cited as problems. Drivers, despite mandated reporting requirements, do not always report incidents. Drivers and dispatch workers should be mandated to receive awareness and safety training by using people with disabilities as trainers.

[67] University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities; *Consolidated Findings from Regional Forums on Transportation;* www.uconnucedd.org/Projects/paths/publications.html

7. Access to Information and Services

Individuals often do not seek information about long-term care until they are in a crisis situation and need immediate help. At that point it is difficult to navigate the complex system to get needed information so that supports can be secured quickly. Minority families are even less likely to have information about available supports due to cultural assumptions that such supports should be provided by families. Often this lack of information leads individuals to assume that institutional placements are their only option.

The State has a number of sources for information on long-term care services and supports:

- Infoline (2-1-1) provides a single statewide information resource about all types of social services and programs serving people of all ages.
- The Long-Term Care Services and Supports Website provides easy access to comprehensive information on private and public long-term care (LTC) services and supports in Connecticut, including home care, community care, housing and institutional/nursing home care (www.ct.gov/longtermcare).
- The Department of Social Services Aging Services Division will continue to enhance and expand its ListServ (e-mail list) of aging network professionals who receive up-to-date information about aging services and training available. In addition, Aging Services will build on its new website to ensure that information about long-term care services and supports is current and that the link to the Long-Term Care Services and Supports Website is easily accessible (www.ct.gov/agingservices).
- The CHOICES Program provides a resource for individuals requesting information regarding Medicare, Medicare Part D, Medicare Supplemental Insurance, Medicaid and long-term care insurance.
- The Department of Social Services distributes booklets that provide comprehensive information about long-term care services and supports.
- Through the Nursing Facility Transition project, materials have been developed to inform nursing facility residents and their families about long-term care alternatives.
- The Departments of Mental Retardation, Mental Health and Addiction Services, and Children and Families provide information on the programs and supports they provide and fund.
- Municipal agents in each town and city provide a valuable resource to seniors and individuals with disabilities.
- The five Connecticut Area Agencies on Aging serving elders and five Independent Living Centers serving people with disabilities provide toll-free phone numbers and information and assistance programs for their respective audiences.

Despite the availability of these resources, access to information, resources and options regarding long-term care is still elusive for many people looking for information.

Action Steps

- Over time, provide maintenance and ongoing updating of the Long-Term Care Services and Supports Website, which was finalized and released to the public in the fall of 2006. The website provides accessible information to all individuals in need of long-term care services and supports, regardless of age or disability.

- Explore the development of long-term care information resources for those consumers without Internet access.

- Over the next biennium and over time, distribute the *Nursing Facility Transition Project Handbook* to all present and future Nursing Facility residents.

- Over the next biennium and over time, distribute the *DMR Consumer and Family Guide to the DMR Home and Community-based Services Waivers* and *Understanding the DMR Home and Community-based Waivers: An Introduction to Your Hiring Choices Guide* to all present and future DMR consumers.

- Expand existing information and referral resources in order to establish and evaluate a Nursing Facility Transition Project hotline that will serve as an information resource for those interested in transitioning to the community.

- Initiate public/private partnerships to enhance public education regarding all aspects of the long-term care system in Connecticut. This should be done, in part, by building upon existing resources such as CHOICES and Infoline. Include business, government, legislative, and faith-based organizations, and community as well as consumer partners in this campaign to recognize strengths and needs of all individuals and families, to attract more workers to the health care arena, and to increase community concern and commitment to change.

- Support specific programs to disseminate information about transportation resources to both users and human service providers. Tools such as websites, the "Getting on Board" brochures used by case workers facilitating access to jobs for people with disabilities, and Infoline are resources for individuals to access information about transportation services available in their region.

8. Prevention

Choice and independence are aspects of life that everyone values, regardless of health status or disability. Prevention efforts serve as a tool to help assure that a person remain as healthy and independent as possible, for as long as possible. This means that an

individual's health is maintained, problems are identified early and falls and injuries are avoided. The goal is to remain as active and independent as possible and remain in the community as long as possible with supports. Connecticut programs that contribute to this goal include CHOICES, friendly visitor programs, fall prevention programs, and medication management programs.

Fall-related injuries are a particular threat to older adults. In fact, 30 to 40 percent of persons age 65 and over fall each year. Falls may lead to hospitalizations beginning the downward spiral that can result in long-term disability or death. Common injuries as a result of a fall include brain injuries, and fractures of the hip, vertebrae, and pelvis. Over 60% of falls that lead to hospitalizations occur in the home. Findings from a recent study show that fall prevention efforts have a higher impact than either physical activity or depression screening and treatment on reducing disability later in life.[68]

Health maintenance and illness prevention is important for everyone, yet individuals with disabilities have more difficulty obtaining preventive health and dental care. To address the issue of dental care among older adults, the Department of Public Health established a Task Force on Oral Health for the Elderly in the fall of 2006 to increase the awareness of the importance of oral health and its impact on the overall health of older adults and to explore strategies to increase access to dental care, particularly for individuals in residential care, in the areas of financing, community advocacy, education services and training.

Action Steps

- Utilize health promotion resources and initiatives outside of State government and attempt to coordinate the various efforts.

- Encourage further development of Visitation Programs for individuals and families in home, community and structured settings.

- Establish a working Fall Prevention partnership between the Department of Social Services (DSS) Aging Services Division and the Department of Public Health (DPH) to expand current DPH fall prevention projects (i.e. home safety assessments, fall prevention seminars, medication safety programs, and fall prevention exercise classes) to serve new populations and geographic areas. Conduct social marketing, distribute public education materials, and utilize the media. Coordinate these activities with other existing Fall Prevention programs in the state. While fall prevention efforts are primarily focused on the elderly, fall prevention programs should be available to individuals of all ages.

- Explore opportunities to prevent the incidence, and delay the progression, of chronic diseases, such as better integration of the delivery of acute and long-term care across

[68] Vicki A. Freedman et al, "Promoting Declines in the Prevalence of Later-Life Disability: Comparisons of Three Potentially High-Impact Interventions," The Milbank Quarterly, Vol. 84, No. 3, 2006, page 493.

settings, use of prescription drugs, increased use of technology such as telemedicine and increased patient education and self management.

- Explore implementation of Wellness and Nutrition programs and the use of managed health care coordination for individuals served by the Department of Mental Retardation (DMR) who live on their own or with their families as a means to identify and prevent emergent serious health conditions.

- Explore opportunities to work with Connecticut's medical and dental schools and allied professions to increase access to health care screening and preventive and restorative dentistry for individuals with disabilities. For example, establish a DMR Dental Coordinator and possible University of Connecticut dental fellowship to address the lack of community dental care for persons with cognitive disabilities.

- Reduce the incidence of disabilities in newborns by increasing awareness of mercury poisoning and Fetal Alcohol Syndrome.

9. Quality of Care

To assure a high quality of living for individuals with long-term care needs, real choices must be provided regarding the type of services and supports they need and in what setting they live. In many cases, the quality of a person's life is measured by the level of control and independence an individual with a disability can enjoy.

Assistive technology often makes a critical difference in daily living for individuals with disabilities and chronic illnesses, allowing them the independence to live in their communities and work, learn and play. Assistive technology is any item or piece of equipment that is used to increase, maintain, or improve functional capabilities of individuals with physical, sensory or cognitive impairments. Examples include hearing aids, motorized wheelchairs, environmental control, electric door openers, voice-activated telephones and telemonitoring. The majority of assistive technology devices needed by individuals to improve their level of independence are not considered medically necessary and therefore are not often covered by private insurance and public medical assistance programs. [69]

Low-interest loans are available through the Connecticut Assistive Technology Loan Program, sponsored by the Department of Social Services (DSS), Bureau of Rehabilitation Services, in partnership with People's Bank. In addition, the Connecticut Tech Act Project provides information and advocacy services regarding assistive

[69] Therese Willkomm, Ph.D., Achieving Independence and Interdependence Through Assistive Technology Applications, *Community Living Briefs*, Vol. 1, Issue 2, 2003 (Community Living Technical Assistance Exchange at Independent Living Research Utilization, Houston, Texas)

technology. The project's goal is to make sure that Connecticut residents with disabilities of all ages get access to assistive technology.[70]

Quality of care is a broad issue that encompasses the range of care settings and services, both institutional and community-based. It is measured objectively as well as subjectively, with physical as well as psychological and social components. Assuring quality of care not only involves adequate training and oversight of providers but also consumer direction and control so that individuals can have a voice in how services and supports are provided to them. With regard to the State Medicaid program, each HCBS waiver program has a quality management system in place that addresses service planning and delivery, health and welfare, participant rights and safeguards and financial accountability for service delivered by providers. With the implementation of the Money Follows the Person, a quality coordinating committee will be established in 2007 to ensure coordination, communication and data sharing to enhance quality improvement across all the waiver programs

Actions Steps

- Develop improved quality measures for persons with disabilities in the community under person-centered, consumer-directed programs. Such measures must reflect the individuals' own preferences and desires and allow reasonable risks while still avoiding unreasonable risks.

- Connecticut should support the purchase and maintenance of assistive technology. More emphasis should also be placed on the use of robotics in the home to assist with activities of daily living and the use of telemonitoring to support individuals in managing their own home care. Expenditures for assistive technology can be minor when compared to the extended cost of human services for personal assistance. This technology can allow an individual to maintain or regain independence and reduce their reliance on paid services.

- Develop a plan to modernize the physical plants of existing nursing facilities.

- Expand the role of the Long-Term Care Ombudsman's Office, which oversees nursing facilities, residential care facilities and assisted living facilities, to include other long-term care settings and include consumer education about the availability of these services. Provide adequate funding for such an expansion.

- Encourage a plan for emergency management supports for people with disabilities and elderly persons. This should include networking with local, state and national organizations, as well as working on information that can be used to encourage personal preparedness.

[70] Connecticut Tech Act Project – Achievement Through Technology, www.techactproject.com/Default.htm.

VI. CONCLUSIONS

Over the next 25 years Connecticut will be challenged to develop a long-term care system that is consumer focused and directed and provides real choices for individuals with disabilities and their families. Many uncertainties could affect the level of demand for long-term care in Connecticut. Disability rates may decline, medical technologies may reduce the incidence of certain chronic diseases, or new conditions may arise that increase the demand for long-term care. However, there are no guarantees. What is known is that current levels of Medicaid long-term care expenditures for institutional care and the significant reliance on public funds for long-term care will not allow Connecticut to reach its goal of real long-term care choices and to adequately meet a possibly growing demand for services and supports. The time to take steps to rebalance the system is now. As outlined in this Plan, the shifting of the ratio of home and community-based and institutional care, coupled with a larger role for private funds in the system, will position Connecticut to be responsive to the potential long-term care needs of our citizens in the short and long-term and will help realize its goal of a system driven by choice and consumer control.