Connecticut Long-Term Care Planning Committee

LONG-TERM CARE PLAN

A Report to the General Assembly

January 2010

Balancing the System:

Working Toward Real Choice for Long-Term Care in Connecticut

A Report to the General Assembly
January 2010

Table of Contents

Appendices

A. Authorizing Statute for the Long-Term Care Planning Committee and the Long-Term Care Advisory Council

B. Long-Term Care Planning Committee Membership

C. Long-Term Care Advisory Council Membership

D. Sources of Public Comment

E. Long-Term Care Planning Efforts

F. Status Report: 2007 Long-Term Care Plan for Connecticut, October 2009

G. State Long-Term Care Programs and Expenditures – SFY 2008-2009

ACKNOWLEDGEMENTS

Many individuals and organizations provided invaluable assistance in the development of this Plan. Thanks to all the members of the Long-Term Care Planning Committee for their efforts. In addition, appreciation is extended to the Long-Term Care Advisory Council who worked in partnership with the Planning Committee to enhance the quality of this Plan. Thanks also to all the individuals and organizations that took the time to review drafts of the Plan throughout its development and provided helpful recommendations and advice.

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

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 support 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 over the next fifteen years.

It is Connecticut's goal to establish a long-term care system that offers 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 individual 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 2007 Plan, the 2010 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. By balancing the ratio of community-based and institutional services, what is meant is not a system with an equal split between community and institutional services. Instead, a more balanced system in Connecticut would meet the 2025 goal of 75 percent of individuals receiving Medicaid long-term care services and supports in the community and 25 percent receiving long-term care in institutions. 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 informed 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, 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 third Plan developed by the Long-Term Care Planning Committee under the Committee's expanded mandate to go beyond the needs of older adults and address the system as a whole, encompassing all individuals with disabilities and their families.

Therefore, all of the recommendations and action steps put forward in this Plan apply to individuals of all ages and disabilities, unless specifically noted. 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 designed to break down some of the barriers experienced by individuals with certain disabilities and promote a philosophy that is person-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 range of paid and unpaid supportive services for persons who need assistance due to a physical, cognitive or mental disability or condition. 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 where the goal is to cure or control an illness, the goal of long-term care

is to allow an individual to attain and maintain the highest reasonable 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, assistive technology 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 older adults and individuals with disabilities. Despite these gains, 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, regardless of age and disability. 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 the home and the community and those provided in institutions has consistently been out of balance and skewed towards institutional care.

It is important to note that while the Medicaid program provides a critical benchmark for the balancing of the long-term care system, there are other important sources of long-term care funding in Connecticut. For example, the mental health system is substantially funded with state dollars, as are many services for individuals with intellectual disabilities. Also, a number of services for older adults are funded through the federal Older Americans Act. Programs and services funded by other sources are discussed when relevant and appropriate throughout this Plan.

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 system 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 2005, Medicaid paid 49 percent of long-term care costs. Individuals covered 18 percent of costs out-of-pocket, with many of those payments made as applied income while on the Medicaid program. Medicare covered 20 percent of the bill, with private insurance covering 7 percent and the remaining 5 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.

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. What We Know About Long-Term Care

Facts and Trends

- People of all ages and from all walks of life need long-term care supports and services.

- It is estimated that 69 percent of 65 year olds will need long-term care as they age: 79 percent for women and 58 percent for men. On average, they will need three years of long-term care.
- Disabilities affect 10.4 percent of all Connecticut residents – 357,907 individuals in 2008.
- Home and community-based services help people with long-term care needs stay in their homes and communities while reducing long-term care spending. States that have expanded their Medicaid home and community-based services programs require increases in short term spending, followed by a reduction in institutional spending and long-term cost savings.
- Medicaid pays the majority of long-term care expenses. In Connecticut in State Fiscal Year 2009, Medicaid long-term care expenses accounted for 13 percent of the state budget and 53 percent of the Medicaid budget.

Findings from the Long-Term Care Needs Assessment Survey[1]

- People have done little thinking or planning for their long-term care needs.
- People have limited resources set aside for long-term care.
- Many erroneously believe long-term care costs will be paid by Medicare or private health insurance.
- Eighty percent of respondents to the Needs Assessment expressed a desire to remain in their own home with homecare services and/or home modifications.
- People don't know where to go for information and services.
- Over one-third of Needs Assessment respondents report that they cannot get all the services they need to live in the community. Independence, choice, and control are key issues. Finances and lack of knowledge about services are the primary barriers.
- According to long-term care providers in Connecticut, the greatest unmet need for older adults and people with disabilities are increased funding for care, affordable and safe housing, home care and transportation.
- Connecticut residents need improved access to long-term care information and services, and increased coordination among state agencies.
- Unpaid caregiving is common in Connecticut. About one-fourth of caregivers provide care to two or more people.
- The lack of accessible, affordable transportation is cited as an important issue by both residents and providers.
- Compared with other states, Connecticut has a very rigid, highly professionalized model of case management and home care delivery in which both agencies and individual providers are subject to extensive licensing requirements and regulations.

[1] Julie Robison, Ph.D. et al, Connecticut Long-Term Care Needs Assessment, University of Connecticut Center on Aging, June 2007. http://www.uconn-aging.uchc.edu/res_edu/assessment.html

- While there is some shortage of skilled nursing personnel in institutions, there is an even greater shortage of home-based care workers.
- Connecticut provides publicly-financed long-term care services and supports through a somewhat fractured governance structure consisting of a vast array of departments and programs that often operate in silos serving narrowly-defined segments of the population.
- Although Connecticut has made some progress in balancing the long-term care system, the state ranks in the middle among the states in terms of percent of Medicaid home and community-based long-term care expenditures.

C. What's New in Connecticut

Meaningful progress has been made in addressing the goals and recommendation made in the 2007 Long-Term Care Plan. At the same time, the difficult economic climate and state budget deficits have demanded that difficult choices be made. Many of these changes have been documented in the 2007 Long-Term Care Plan Status Report (Appendix F).

Described below are some of the major changes that have been made to the system of long-term care services and support in Connecticut in the last three years. These changes include new and expanded programs as well as areas where there have been reductions in programs and funding. Although significant progress has been made in improving choice, opportunities for self-direction, community inclusion and access to community-based services, many inequities remain in access to services and many individuals have unmet needs for long-term care. More is needed if we are to meet our goals for achieving real choice and truly balancing the long-term care system.

Looking into the future, there is much ongoing activity on the state and federal level with regard to identifying and advancing health care reform. In as much as these efforts address the provision and funding of long-term care services and supports, the recommendations of this Plan may be affected.

Progress in Meeting the Balancing Goals

This Plan advocates that by providing more choices for those with long-term care needs and assuring access to needed services, by 2025 the Connecticut Medicaid program should be serving 75 percent of long-term care clients in home and community-based settings[2], with only 25 percent choosing institutional care[3]. The proportion of Medicaid long-term care clients receiving services in the community has increased from 46 percent in SFY 2003 to 53 percent in SFY 2009 – an increase of over 1 percent a year. Slowly,

[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.

but surely, the Connecticut Medicaid program is moving in the right direction and meeting the Long-Term Care Plan's target of a 1 percent increase a year.

With regard to public spending on long-term care, between SFY 2006 and SFY 2009 the proportion of Medicaid long-term care expenditures received in the community increased by three percent, rising from 32 percent to 35 percent of all Medicaid long-term care expenditures – an increase of one percent per year. Likewise, there was a three percent decrease in expenditures for long-term care provided in institutional settings. Overall, total Medicaid long-term care expenditures increased by 12 percent between SFY 2006 and SFY 2009.

Long-Term Care Services and Supports Website

The Long-Term Care Services and Supports Website has been available to the public since September 2006 (www.ct.gov/longtermcare). This collaborative effort between representatives of the Commission on Aging, Office of Policy and Management (OPM), the Long-Term Care Advisory Council and Infoline was accomplished within existing resources with no specific additional funding. A consumer oriented resource, the website provides information for all individuals and their families in need of long-term care services and supports, regardless of age or disability, and those interested in planning for their future long-term care needs.

In 2008, the Department of Social Services (DSS) CHOICES program was added to the group charged with developing the state's long-term care website. CHOICES provides health insurance counseling, information and assistance and benefits screening to older adults, those with disabilities on Medicare and caregivers. In 2009, DSS partnered with the Commission on Aging and OPM to update the website to provide information about the Aging and Disability Resource Centers (ADRCs) and to adopt the website as the State's ADRC website.

Money Follows the Person Rebalancing Demonstration

The Money Follows the Person (MFP) Rebalancing Demonstration, which began operation in December 2008, is designed to rebalance long-term care services in Connecticut from institutional care to home-based services. The program serves individuals across the age span with physical disabilities, mental illness and intellectual and cognitive disabilities. Under MFP, as of November 30, 2009, 138 individuals have been transitioned from a nursing facility to community living. One hundred persons transitioned to target waivers with the MFP enhanced federal reimbursement rate for services; 38 persons transitioned to community services who are not eligible for the enhanced federal reimbursement rate. Connecticut has established five rebalancing benchmarks that were intentionally aligned with the goals of the 2007 Long-Term Care Plan:

1. Transition 700 people from institutions to the community.
2. Increase dollars to home and community-based services.
3. Increase the percentage of persons receiving long-term care services in the community relative to the number of persons in institutions to 57 percent by 2011.

4. Decrease the hospital discharges to nursing facilities among those requiring care after discharge.
5. Increase the probability of persons returning to the community within the first six months of admission to an institution.

Home and Community-Based Services Programs

- A Connecticut Home Care Option Program for the Elderly (HOPE) and a Connecticut Home Care Trust Fund was established to be administered by the state comptroller. The program and fund must help people plan and save for the costs of certain services for older adults that (1) are either not covered by a long-term care insurance policy or supplement services covered by such a policy or by Medicare and (2) will allow them to remain in their homes or live in a non-institutional setting as they age. Participants are allowed to establish individual saving accounts within the fund and a designated beneficiary is allowed to withdraw funds from an account to pay for qualified home care expenses. It exempts interest earned on fund accounts from the state income tax and makes any unspent funds remaining in an account when a beneficiary dies part of his or her estate.

- The DDS Autism Spectrum Disorder Pilot program, which began in 2006, was expanded from serving 50 to 75 persons on July 1, 2008. In 2008, approximately 30 individuals were served in the greater New Haven area and expansion to the Harford area is anticipated in SFY 2009. The program is designed to study the feasibility of establishing a Medicaid home and community-based program for adults with autism spectrum disorder, but who do not have mental retardation as defined in Connecticut State statutes. In January 2009, the DDS Commissioner provided a report on the pilot's results to the Public Health Committee.

- New funds were appropriated for SFY 2008 and 2009 for the Personal Care Assistance (PCA) Waiver enabling DSS to serve additional people in the program. However, there continues to be a waiting list for this program.

- Funds were appropriated for SFY 2008 and 2009 to fully fund the Katie Beckett waiver, allowing all 200 slots to be filled.

- For SFY 2008 and 2009, funding was appropriated for rate increases to home care providers under the Connecticut Home Care Program for Elders.

- Personal care assistance (PCA) will be added as a service under the Connecticut Home Care Program for Elders beginning July 1, 2010. Currently, DSS provides PCA services through the state-funded PCA pilot program for certain qualifying older adults, the PCA Medicaid waiver program for disabled adults and the Acquired Brain Injury Medicaid waiver program. However, these programs, with the exception of the Connecticut Home Care Program for Elders, have waiting lists.

- In SFY 2010, the cost sharing requirements for the state-funded portion of the Connecticut Home Care Program for Elders will be increased.

- DSS implemented the Connecticut Home Care Program for Disabled Adults in 2008 to provide home care services to individuals with disabilities who require long term home care services. This program expands the state-funded portion of Connecticut Home Care Program for Elders by establishing a state-funded pilot program serving 50 people with disabilities ages 18 to 64 who are either inappropriately institutionalized or at risk of inappropriate institutionalization. In SFY 2009, the asset limits were increased to match the asset limits of the state-funded Connecticut Home Care Program for Elders. The appropriation allowed for approximately 41 people to be serviced. Currently the waiting list exceeds the number of people being serviced.

- The appropriation for the Statewide Respite Program was increased by $1 million beginning in SFY 2008.

- On April 1, 2009, DMHAS began providing services under a Mental Health Medicaid Home and Community-Based Services Waiver Program. This program will help people with serious mental illness avoid being placed in nursing facilities and will help many others with the transition back to a fulfilling life in the community. The Waiver will serve 216 individuals over three years who are currently in nursing facilities or who are at risk for this level of care.

- The Transition Pilot Project, designed to increase opportunities for persons in recovery from serious mental health disorders to transition from Connecticut Valley Hospital (CVH) to the community, generated a 33% increase in the number of people able to return to the community from SFY08 to SFY09.

- The Psychosocial Skill-Building School, a collaboration between DMHAS inpatient and community providers was established to improve the quality of care and help people with serious mental illness remain living in the community.

- HOMEWork, a collaborative project of the Bureau of Rehabilitation Services and DMHAS through the Corporation for Supportive Housing was established to create an infrastructure to help supportive housing tenants pursue their employment goals, move toward self-sufficiency and re-engage with their communities.

Mental Health Transformation Grant

- The Network of Care Website (www.CT.networkofcare.org) is the first one stop web resource providing access to behavioral health information and services for persons of all ages.

- The Advance Directives Initiative developed standardized forms, a toolkit and an outreach effort promoting the self determination of persons served by DMHAS by educating them about their right to execute legal documents setting forth their health care instructions and appointing a health care representative.

- The Quality Improvement Collaborative (QUIC) project was established to ensure that the State's movement to a recovery oriented system of mental health care is driven by the goals of consumers, youth and families and incorporates best practices that support recovery, resiliency and a meaningful life in the community.

- The Public Education Project with Connecticut Public Television entitled "Opening Doors, Opening Minds: Living with Mental Illness", provides a three part series to educate and inform the public about individuals and families dealing with mental illness.

- The Workforce Transformation Project was established to create an infrastructure that supports a sustained effort to address staffing shortages, educates health and human service personnel, fosters the employment of persons in recovery in the behavioral health workforce, and encourages consumer run services.

Aging and Disability Resource Centers (ADRCs)

In 2007, DSS was awarded a Nursing Home Diversion and Modernization Grant from the federal Administration on Aging (AoA) designed to divert older adults from entering nursing facilities by providing alternate services which enable them to stay in their homes. Under this 18 month, $500,000 grant, an Aging and Disability Resource Center (ADRC) has been established in the south central region of the state, called 'Community Choices.' The purpose is to offer a coordinated one-stop-shop single-entry-point system of assistance, information and referral services related to long-term care options and planning that includes comprehensive assessment, advocacy and application assistance, for individuals aged 18 and over regardless of income or disability..

In the fall of 2008, DSS received a second Nursing Home Diversion grant that has extended the ADRC program to the western part of the state, allowing for the pilots to operate in a rural and an urban setting. The Western Connecticut 'Community Choices' began May 2009 and the Cash and Counseling component started in July 2009. The Diversion grant also expands caregiving options by offering Cash and Counseling to participants in the Connecticut Statewide Respite Care Program and the National Family Caregiver Support Program, allowing individuals to choose and hire their own caregivers. Another component of the second Diversion Grant addresses the needs of veterans at risk of a nursing facility admission. The pilot will serve approximately 25 veterans of the Iraq war with mental health problems and will be using the new Medicaid Mental Health Waiver administered by DMHAS.

Nursing Facilities

- The moratorium on new nursing facility beds was extended from June 30, 2007 to June 30, 2012. DSS continues to analyze and monitor the need for beds. Several methods are used to reduce unneeded capacity such as de-licensing or reclassifying beds.

- In 2008, DSS was mandated to establish a pilot program, within existing resources, to support the development of up to 10 small house nursing facilities in the state. The

goals of the pilot are to improve the quality of life for nursing facility residents and provide nursing facility care in home-like, rather than institutionalized, settings. In consultation with the Long-Term Care Planning Committee, DSS must evaluate and approve up to 10 small house nursing home proposals. In 2009, the legislature modified the pilot program, limiting it to one project with a maximum of 280 beds through June 30, 2011.

State Government

- The establishment of the Department on Aging was postponed until July 1, 2010. In 2005, the legislature reestablished the department effective January 1, 2007, and has delayed the implementation for the last three years.

- The Department of Mental Retardation was renamed as the Department of Developmental Services. (DDS) on October 1, 2008. The name change did not affect the criteria for determining eligibility for the department's services.

- In SFY 2009, $1,000,000 was appropriated to establish an Autism Division within DDS to serve individuals with autism, regardless of age.

- DMHAS has established an Older Adult Services Unit and, in collaboration with DSS, is assisting nursing facility residents with mental illness to transition out of nursing facilities back to the community with supports. Additionally, Medicaid Home and Community-Based Services Waiver staff have been hired, as well as staff that will focus on diverting persons with mental illness away from nursing facilities to the least restrictive residential setting.

Federal Stimulus Funds

The American Recovery and Reinvestment Act (ARRA) of 2009 provided stimulus spending to the States in the spring of 2009. These are one time funds and must be spent over two years. The purpose of the AARA is to make supplemental appropriations for job preservation and creation, infrastructure investment, energy efficiency and science, assistance to the unemployed, and State and local fiscal stabilization. Stimulus funds were received in Connecticut to support the following programs that will benefit individuals in need of long-term care:

- Money Follows the Person: an enhanced federal match, from 75% to 80%, adding $9 to $11 million over 5 years.
- Elderly Nutrition Program: $1.2 million, funding congregate meals ($775,759) and home delivered meals ($381,912). Funds are allocated to the five Area Agencies on Aging.
- Supplemental Nutrition Assistance Program (formerly the Food Stamp Program): As of April 1, 2009, all participants received an increase in the benefit. Connecticut received $1.2 million to administer the program.

- Homeless Prevention and Rapid Re-Housing: Formula Grants provide $10.8 million to the State and $6.1 million to five cities. The purpose is to provide financial assistance and services to prevent individuals and families from becoming homeless and help those who are homeless to be quickly re-housed and stabilized. At least 60% of funds must be spent within two years and all funds must be spent within three years (2012). The types of services that are intended to be supported from these dollars are short term and medium term rental assistance, back rent, security deposits for apartments or utilities, back utility payments, mediation services, legal services, credit repair, relocation assistance, moving expenses (not furniture replacement), case management, counseling and budgeting. These services are targeted to those 'but for these services' would be homeless and those in institutions qualify for assistance. 211 will complete initial screenings and referrals for these services.
- Senior Community Services Employment Program (SCSEP): Of $1.3 million, $259,468 is allocated to DSS, $483,503 to Easter Seals, and $536,101 to The Workplace, Inc. SCSEP enhances employment opportunities for older Americans and promotes them as a solution for businesses seeking trained, qualified and reliable employees.
- Weatherization: Over $64 million has been allocated to Connecticut to assist low – income people in weatherizing their homes to reduce energy consumption and energy related bills, a portion of these dollars is targeted to older adults in State-financed housing. Over 2,800 houses belonging to older adults and people with disabilities will be weatherized in Connecticut under the plan that was approved by the U.S. Department of Energy.

D. Goals, Recommendations and Action Steps

The goals, 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.

In 2005, a broad philosophical statement was enacted in Connecticut statute to guide policy and budget decisions. 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, designed to make real choices for individuals a reality, provides a larger framework for Connecticut upon which the Plan goals, recommendations and action steps rest.

The 2010 Long-Term Care Plan is informed by the findings of the Connecticut Long-Term Care Needs Assessment (Center on Aging at the University of Connecticut School of Medicine, June 2007) and many of the recommendations made in the Needs Assessment have been adopted in this Plan. Overall, the recommendations are primarily focused on initiatives State government can undertake. 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 addition to two rebalancing goals, this Plan puts forward 16 recommendations. Although these recommendations are not prioritized, they were chosen from a much longer list of recommendations and therefore represent the priorities for this Plan. The recommendations are reflective of a system of care, and as such, must be viewed as both interrelated and interdependent. Each recommendation is followed by a series of action steps providing more detailed guidance. As Connecticut continues its work to balance its long-term care system, progress must be made on multiple fronts. Chapter V provides a description of the Plan goals and presents the actions steps for each of the recommendations.

Goals

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

Develop a system that provides for more choice and opportunities for community integration as alternatives to all institutional settings, and increases the proportion of individuals receiving Medicaid long-term care home and community-based care from 54 percent in 2009 to 75 percent by 2025, requiring approximately a one percent increase in the proportion of individuals receiving Medicaid long-term care in the community every year.

2. Balance the ratio of public and private resources:

Increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent by 2025. 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 2005.

Summary of Recommendations

Structural

1. Create greater integration of State level long-term care administration and functions serving both older adults and people with disabilities and their families.
2. Simplify Connecticut's Medicaid structure.
3. Address access and reimbursement for key Medicaid services.
4. Further reform and coordinate the nursing facility/ institutional admission prescreening process.

Information/ Access

5. Provide true individual choice and self-direction to all users of long-term care.
6. Address education and information needs of the Connecticut public.
7. Develop and implement a statewide system of Aging and Disability Resource Centers for providing information, referral, assistance and long-term care support options.

Workforce

8. Address the long-term care workforce shortage.
9. Provide support to informal caregivers.

Quality

10. Promote efforts to enhance quality of life in various settings.
11. Address the scope and quality of institutional care.

Programs and Services

12. Provide a broader range of community-based choices for long-term care supports, foster flexibility in home care delivery, and promote independence, aging in place and other community solutions.
13. Increase availability of readily accessible, affordable, and inclusive transportation.
14. Preserve and expand affordable and accessible housing for older adults and individuals with disabilities.
15. Support programs that divert or transition individuals from nursing facilities or other institutions.
16. Expand and improve employment opportunities and vocational rehabilitation for persons with disabilities and older adults.

E. Development and Implementation of the Plan

Development

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 nine 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 2009, the Long-Term Care Planning Committee embarked on the development of its fifth 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 recommendations, and obtaining public input.

The Advisory Council assisted the Planning Committee with 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 July and August of 2009. (*see Appendix D – Sources of Public Comment).*

Implementation

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, individual-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

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

B. Mission

To provide guidance for the development of a comprehensive system of community-based and institutional long-term care options. Such a system should promote access to affordable, high-quality, cost-effective services and supports that are delivered in the most integrated, life-enhancing setting.

C. Principles Governing the Long-Term Care System

The system must:

1. Provide equal access to home and community-based care and institutional care.

2. Provide access to all necessary supports and services, including a comprehensive range of medical, social, assistive technology, health promotion, diagnostic, early intervention and other services.

3. Deliver services in a culturally competent manner to meet the needs of a diverse population.

4. Assure that people have control and choice with respect to their own lives.

5. 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.

6. Assure that individuals 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.

7. Include an information component to educate individuals about available services and financing options. The components of the long-term care system must be effectively communicated to all those potentially impacted by the need for long-term care.

8. 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.

9. Include a simplified eligibility process.

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, at work, in congregate residences and in institutional settings.

It is important to note that long-term care is different 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 has 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 in this Plan is drawn from the U.S. Census Bureau 2008 American Community Survey (ACS). The Census Bureau defines disability as a long-lasting sensory, physical, mental, or emotional condition that makes it difficult for a person to do functional or participatory activities such as seeing, hearing, walking, climbing stairs, learning, remembering, concentrating, dressing, bathing, going outside the home, or working at a job. 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

Of the 10 million people in the U.S. in need of long-term care in 2005, the vast majority (86 percent) lived in the community, with 14 percent residing in a nursing facility. Among those living in the community, 48 percent were under 65 and 52 percent were age 65 or older. Among nursing facility residents, the vast majority of individuals were over age 65 (86 percent).[5]

Among older adults, it is estimated that 69 percent of 65 year olds will need long-term care as they age: 79 percent for women and 58 percent for men. On average, they will need three years of long-term care. Although over 30 percent of people age 65 will not need long-term care, 17 percent will need up to one year; 12 percent will need from one to two years; 20 percent will need from two to five years; and 20 percent will need 5 years or more.[6]

Connecticut

Disabilities affect 10.4 percent of Connecticut residents, lower than the national average of 12.1 percent. In 2008, there were 357,907 individuals living in Connecticut with some type of long-lasting condition or disability (Table 1).[7] Disability rates rise with age, with 3.6 percent of children and youth under age 18 reporting a disability, 8.2 percent of adults age 18 to 64, and 33.0 percent of older adults age 65 and over (Figure 1a).

TABLE 1

Number of Persons with Disabilities in Connecticut by Age, 2008

Age	Total Population	Persons with a Disability	Percentage
<5	210,653	1,895	0.9%
5 to 17	599,314	27,563	4.6%
18 to 34	713,787	33,947	4.8%
35 to 64	1,466,406	145,773	9.9%
65 to 74	232,787	46,728	20.1%
75+	217,897	102,001	46.8%
Total	3,440,844	357,907	10.4%

Source: U.S. Census Bureau, 2008 American Community Survey, One Year Estimates, Custom Table

[4] U.S. Census Bureau, American Community Survey, 2007 Subject Definitions, page 35 to 38. http://www.census.gov/acs/www/Downloads/2008/usedata/Subject_Definitions.pdf

[5] Judith Feder et al, *Long-Term Care Financing: Policy Options for the Future*, Long-Term Care Financing Project, Georgetown University, June 2007, Figure 2, page 7, based on the 2005 National Health Interview Survey and the 2004 National Nursing Home Survey.

[6] Peter Kemper et al, "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?, *Inquiry* 42, no. 2 (Winter 2005/2006): 335-350.

[7] U.S. Census Bureau, 2008 American Community Survey, Connecticut, Selected Social Characteristics. Data includes individuals living in households and group quarters and exclude the population living in institutions. The American Community Survey, which samples housing units and their occupants, provides Census data every year instead of once in ten years.

FIGURE 1a
Percentage of Persons with a Disability in Connecticut by Age, 2008

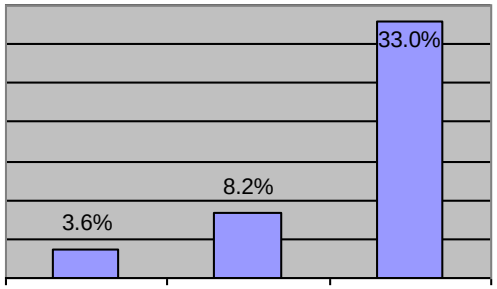


FIGURE 1b
Number of Persons with a Disability in Connecticut by Age, 2008

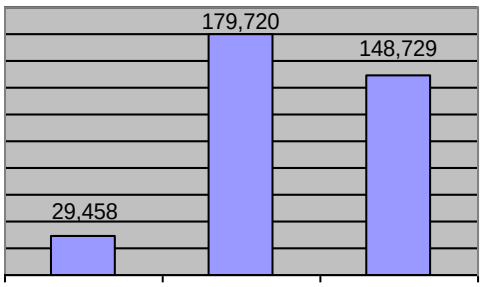


FIGURE 2
Distribution of Persons with Disabilities in Connecticut by Age, 2008

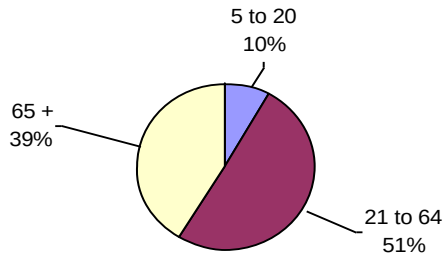
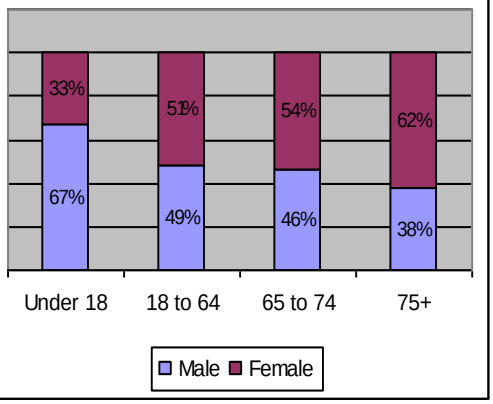


FIGURE 3
Proportion of Individuals with Disabilities by Age and Gender, 2008



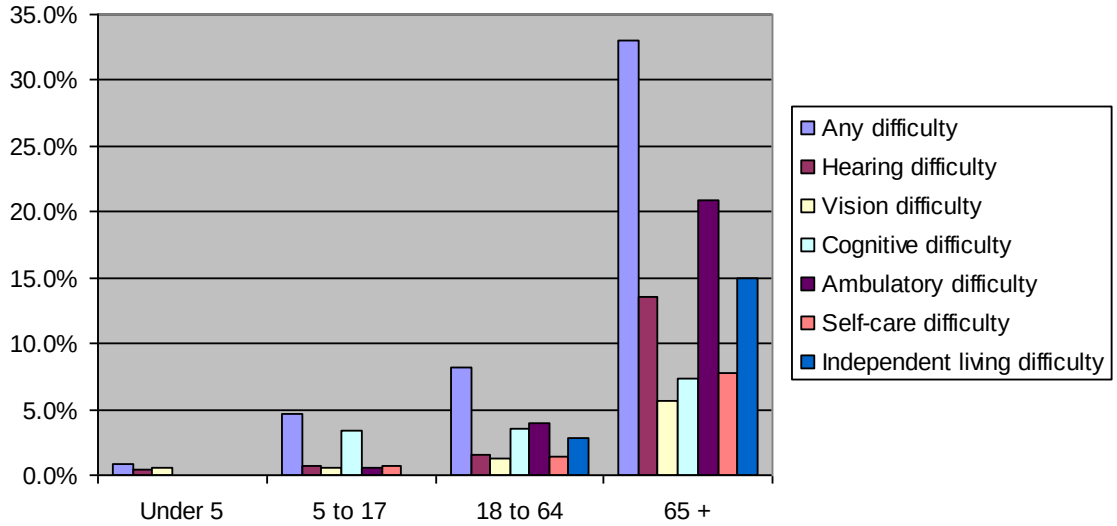
Source: U.S. Census Bureau, American Community Survey, Connecticut, 2008

Although the largest proportion of the Connecticut population with a disability is found among those ages 65 and over (Figure 1a), 51 percent of the total numbers of persons with a disability are adults between the ages of 21 and 64 (Figure 1b and 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, 67 percent are males. By the senior years, this proportion is reversed, with females comprising 62 percent of those with disabilities age 75 and older (Figure 3).

FIGURE 4
Percent Distribution of Types of Disabilities in CT by Age, 2008



Source: U.S. Census, 2007 American Community Survey, Table S1801: Disability Characteristics

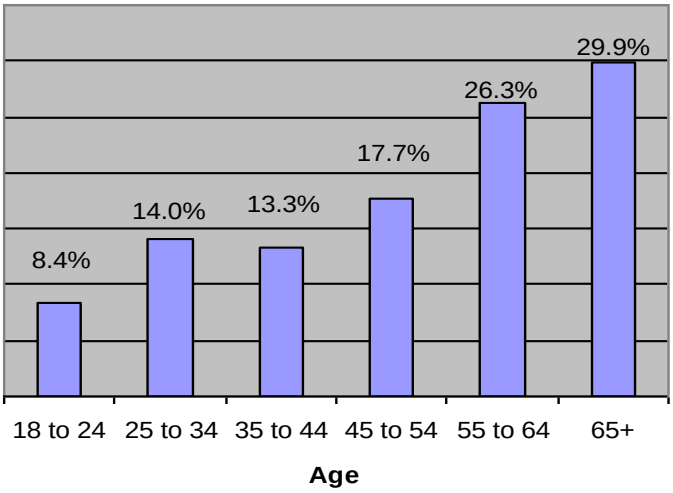
The distribution of types of disabilities in the population varies considerably by age (Figure 4). The proportion of individuals with disabilities increases with age, affecting nearly one percent of children under age five and steadily rising to 33 percent of adults age 65 and older. Among individuals in the 5 to 17 year old group, the greatest reported difficulty is cognitive (3.4 percent). Among adults age 18 to 64, the greatest difficulty is ambulatory (4.0 percent) followed by cognitive (3.5 percent). Among individuals age 65 and older, ambulatory difficulties are most prevalent (20.9 percent) followed by independent living difficulties (14.9 percent). Cognitive difficulties were experienced by the same proportion of individuals in the 5 to 17 and the 18 to 65 age groups (3.4 and 3.5 percent respectively) and doubled in the over 65 age group (7.4 percent). The 2008 American Community Survey determined those with cognitive difficulty by asking individuals if due to a physical, mental or emotional condition, they had 'serious difficulty concentrating, remembering or making decisions'.[8] [9]

[8] U.S. Census Bureau, 2008 American Community Survey, uses six items to determine an individual's disability status: 1) hearing difficulty, 2) vision difficulty, 3) cognitive difficulty, 4) ambulatory difficulty, 5) self-care difficulty, and 6) independent living difficulty. The questions defining disability were changed substantially for the 2008 survey and therefore disability data for 2008 cannot be compared to past years. Source: U.S. Census Bureau, American Community Survey, 2008 Subject Definitions, page 38 to 41. http://www.census.gov/acs/www/Downloads/2008/usedata/Subject_Definitions.pdf

[9] 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. 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 (Figure 5). Overall, in 2008, 18.8 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." [10] This translates into approximately 494,605 Connecticut adults age 18 and older living in the community with some degree of activity limitation. This compares to the 2008 Connecticut Census estimate of 328,449 individuals with disabilities age 18 and over.

FIGURE 5
Connecticut Residents Limited Due to a Physical, Mental or Emotional Problems by Age, 2008



Source: Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System Survey, 2009

B. Long-Term Care Services and Supports

Home and community-based services

Although long-term care traditionally has been associated with nursing facilities or other institutions, the fact is that the vast majority of long-term care is provided at home and in the community 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 individual choice. Increased availability of home and personal care supports have allowed greater numbers of individuals to remain in their homes and avoid or delay moving to an institutional setting.

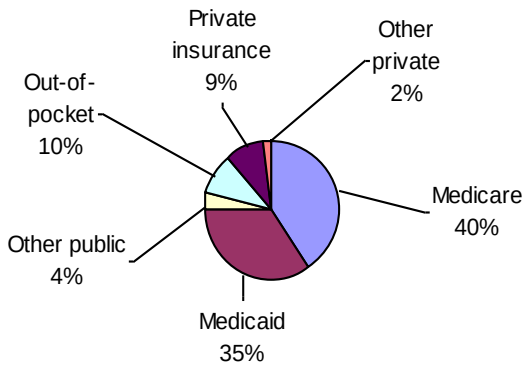
Home and community-based care includes a range of varied services and supports provided either formally by paid individuals or informally by family and friends. Typically, the level of formal support used increases with age, functional impairment and income. In addition to private homes, community settings can include adult day care, assisted living, residential care homes continuing care retirement communities, small group homes and congregate housing.

[10] Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2007.

Home Care Services

In the U.S., approximately 83,000 home care providers delivered care to 7.6 million individuals who required services due to acute illness, long-term health conditions, permanent disability, or terminal illness. Of these agencies, 9,284 are Medicare certified. In 2007, annual expeditors for home health care were projected at $57.6 billion.[11]

FIGURE 6
Sources of Payment for Home Health Care in the U.S., 2007



Source: CMS, Office of the Actuary, National Health Care Expenditures Projections: 2008-2018, Table 10.

Nationally, 79 percent of home health care costs incurred in 2007 were covered by government payers (federal, state and local). Medicare paid the largest share of skilled home care costs, covering 40 percent of the total payments. Private sources, including private insurance and out-of-pocket payment, represented 21 percent of payments (Figure 6). It is important to note that home health care represents only a portion of home care services and generally addresses more medically oriented needs.

In Connecticut, paid home care services are provided by homemaker-companion agencies, homemaker-home health aide agencies and home health care agencies.

- *Homemaker-companion agencies* provide non-medical assistance to persons with disabilities and older adults and must be registered with the Department of Consumer Protection. Tasks generally include grocery shopping, meal preparation, laundry, light housekeeping and transportation to appointments. As of June 30, 2009, there were 236 registered Homemaker-companion agencies.[12]

- *Homemaker-home health aide agencies*, which are licensed by DPH, are similar to homemaker-companion agencies in that they provide non-medical assistance to individuals. In addition, they have the authority to provide training programs and competency evaluations for home health aides. As of June 30, 2009, there were 7 licensed agencies in Connecticut.[13]

- *Home health care agencies*, which are licensed by DPH, provide care in the home that is typically prescribed by an individual's physician as part of a written plan of

[11] National Association for Home Care and Hospice, *Basic Statistics About Home Care*, Updated 2008.
[12] Connecticut Department of Consumer Protection, 2009.
[13] Connecticut Department of Public Health, 2009.

care. These agencies offer skilled nursing, home health aide services, physical therapy, occupational therapy, speech therapy, and hospice services. Non-medical services include helping individuals with activities of daily living such as bathing, dressing and eating; assistance with cooking, cleaning, and other housekeeping jobs; and managing medications. Although home health care may include some non-medical home care services such as homemakers and companions, home health care is more medically oriented, helping individuals recover from an illness or injury. Home health care agencies, unlike homemaker-home health aide agencies and homemaker-companion agencies, may be eligible for Medicare reimbursement. As of June 30, 2009, there were 94 agencies licensed by the DPH to provide home health care services in Connecticut.[14]

According to the Connecticut Long-Term Care Needs Assessment Survey: [15]

- Among the 47 home health care agencies responding to the Needs Assessment survey, the top five services provided by home health care agencies include visiting nursing services (92 percent), home health aide services (92 percent), physical, speech, respiratory, and occupational therapies (79 percent), homemaker services (60 percent), and care/case management (43 percent).

- The largest proportion of individuals being served by home health care agencies falls within the age range 65 to 84 (46 percent), followed closely by the age range 85 to 99 (29 percent). The majority of individuals receiving home care are White/Caucasian (77 percent), followed by African American (9 percent). Five percent of the population was reported to be of Hispanic or Latino origin. Almost two-thirds (63 percent) of people served by the home care system are female.

- With regard to method of payment, almost half (43 percent) of home health care clients use Medicare to at least partly pay for their home care services. Medicaid is used by 34 percent of clients, private health insurance provides coverage for 14 percent, and 3 percent pay out-of-pocket. Individuals relying on private long-term care insurance account for less than one percent.

Adult Day Care

Adult day services are an option for frail older adults 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. Health, personal care and social services are provided to adults who do not need the continuous services of a nursing facility or institutional setting and are able to leave their homes. 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.[16]

[14] Connecticut Department of Public Health, 2009.
[15] Julie Robison et al, *Connecticut Long-Term Care Needs Assessment - Part I: Survey Results*, June 2007, page 131-134.
[16] The Connecticut Association of Adult Day Centers, www.canpfa.org, March 2009.

Adult day care centers are not regulated by DPH. Instead, the Connecticut Association of Adult Day Centers (CAADC) is authorized by the DSS to provide a program of peer review and certification, which is required in order for an adult day center to receive State funds. As of June 30, 2009, there were 49 adult day centers certified by CAADC serving people who receive State assistance.[17]

According to the Connecticut Long-Term Care Needs Assessment Survey: [18]

- Among the 41 adult day agencies responding to the Needs Assessment Survey, the most frequently provided service was adult day care medical model (85 percent). Transportation (66 percent), recreational services (61 percent), specialized dementia care (51 percent), independent living skills training (55 percent), as well as nutritional services, information and referral and various therapies (49 percent each) comprise the services in most demand.

- The average number of people served by adult day providers is 66, and ranges from eight to 430. The largest proportion of people are age 65 to 84 (57 percent), with 36 percent age 85 or older. The majority of adult day clients are White/Caucasian (78 percent), with 17 percent African American, and eight percent of Latino origin. Almost two-thirds of adult day clients are female (65 percent).

- Individuals participating in adult day care programs have multiple payment sources. Close to half of day care clients are covered by Medicaid (44 percent) and one-quarter (25 percent) pay out-of-pocket. Another 28 percent use other payment sources such as funding though an agency or private grant. Long-term care insurance covers about one percent.

Public Home and Community-Based Programs - Medicaid Waivers and State-Funded Programs

An array of Medicaid and State-funded programs has been developed in Connecticut to address the need for long-term care supports for those living at home or in other community settings. Medicaid, through its home and community-based waiver programs, is the major public financing mechanism for providing long-term care in community settings. Under both Medicaid and State-funded programs, individuals who would otherwise require the level of care provided in an institutional setting are served in the community. 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.[19]

[17] The Connecticut Association of Adult Day Centers, www.canpfa.org, October 2009.
[18] Julie Robison et al, *Connecticut Long-Term Care Needs Assessment - Part I: Survey Results*, June 2007, page 139-141.
[19] Cynthia Shirk, *Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program*, National Health Policy Forum, March 3, 2006.

- **For Ages 65 and Older**

Connecticut Home Care Program for Elders (CHCPE): provides home and community-based services to frail older adults age 65 and over as an alternative to nursing facility admission. The program has a Medicaid waiver as well as state-funded component. A no waiting list policy was established in 1997.

1. *Medicaid Elder Waiver*: constitutes the Medicaid portion of the CHCPE. On June 30, 2009, it provided community-based services to 9,387 older adults age 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 2009 was 9,400.

2. *State-Funded CHCPE Program*: constitutes the State-funded portion of the CHCPE and provides the same services as the Medicaid Elder Waiver except that plans of care are capped at lower levels. The program serves older adults age 65 and older with slightly higher income and asset levels than permitted under the Waiver portion. Also, the program will also cover individuals with less needs than under the Medicaid Elder Waiver. The monthly average number of participants for SFY 2009 was 5,356.

State-Funded Personal Care Assistance (PCA) Pilot, a component of the CHCPE, enables participants to hire and manage the schedules of their own personal care assistants. PCA services may be provided by non-spousal family members. On June 30, 2009, there were 242 people enrolled in the PCA pilot program.

- **For Ages 18 and Older**

Medicaid Personal Care Assistance Services (PCA) Waiver: provides personal care services to persons with physical disabilities who are age 18 and older. In this person directed program, participants hire and direct their own care. The program is capped at 748 people. The monthly average number of participants during SFY 2009 was 739.

- **For Ages 18 to 64**

Connecticut Home Care Program for Disabled Adults (CHCPDA): is a state-funded pilot program that provides services based upon the CHCPE model. The program serves up to 50 individuals age 18 to 64 with degenerative, neurological conditions who are not eligible for other programs and who need case management and other supportive services. On June 30, 2009, there were 42 people enrolled.

DDS 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 2009, the monthly average number of participants was 3,771.

DDS 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 2009, the monthly average number of participants was 4,571.

Medicaid Acquired Brain Injury 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 people. The monthly average number of participants during SFY 2009 was 369.

Mental Health Home and Community-Based Waiver: administered by the Department of Mental Health and Addictions Services, this program diverts people with serious mental illness from nursing facilities and works to discharge those who no longer need to live in a nursing facility. The program began on April 1, 2009. As of June 30, 2009, there were six individuals enrolled and using Waiver services.

- **For Children**

Medicaid Model 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. The program is capped at 200 persons. The number of participants as of June 30, 2009 was 192 and the average monthly number of participants for SFY 2009 was 187.

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 older adults 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, enabling individuals with long-term care needs the opportunity to avoid entering an institution. Residential housing is considered community living, where the goal is to provide an environment where people can live with maximum independence and minimum restrictions.

TABLE 2
Community Housing Options in Connecticut, June 30, 2009

	# Facilities	# Units/ Beds/ Residents	Age
State Funded Congregate Housing	23	951 residents	62 and older
Managed Residential Communities (Assisted Living)	107	5,508 units	Adults and older adults
Residential Care Homes	100	2,765 beds	Adults and older adults
Continuing Care Retirement Communities	18	3,200 units	Older adults
Nursing Facilities	242	28,981 beds	All ages

Source: Office of Policy and Management, 2009

In fostering choice, self-determination, independence and community integration, it is important to assure that residential housing is community-based and not institutional. In distinguishing between residential and institutional settings, five aspects can be considered: 1) residential scale and characteristics; 2) privacy; 3) autonomy, choice and control within the residential settings; 4) integration with the greater community; and 5) resident control over moving to, remaining in, or leaving the setting.[20]

[20] Rosalie A. Kane et al, *Community-Based Residential Care Settings as Rebalancing Vehicles: State Strategies to Make Them More like Home than like Institutions*, Submitted to the Division of Advocacy and Special Programs, Centers for Medicare and Medicaid Services, August 2008, page 7.

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.

Congregate Housing

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

As of June 30, 2009, 951 people age 62 and over lived in 23 State-funded congregate housing facilities 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 June 30, 2009, 89 congregate housing residents were actively enrolled in the assisted living program. Throughout the year, more than 103 residents were served under this program.[21]

Assisted Living Services/ Managed Residential Communities

Assisted Living Services Agencies (ALSAs) are an alternative for older adults who need assistance with activities of daily living (e.g. bathing, dressing), but who do not require the intensive medical and nursing care provided in a nursing facility. In Connecticut, assisted living service agencies (ALSAs) are licensed to provide assisted living services in managed residential communities (MRCs). Assisted living services can be provided in a number of different settings, such as continuing care retirement communities or elderly housing, as long as the facility provides the services to qualify as a MRC. Services provided by the MRC include laundry, transportation, housekeeping services, meals, and recreational activities. Individuals choosing to live in an MRC may purchase long-term care services from the ALSA allowing them to live in their own apartment. Primarily, assisted living services in the MRC are available to individuals age 55 and older.

As of June 30, 2009, there were 83 ALSAs licensed in Connecticut providing services in 107 managed residential facilities.[22] The Connecticut Assisted Living Association estimates that there are approximately 5,508 assisted living units, with an additional 60 under construction.[23]

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

[21] Connecticut Department of Economic and Community Development, 2009.
[22] Connecticut Department of Public Health, 2009.
[23] The Connecticut Assisted Living Association, 2009.
http://www.ctassistedliving.com/pdfs/connecticut_assisted_living_fact_sheet.pdf

collaborative effort of the Department of Economic and Community Development (DECD), DPH, OPM and DSS, Connecticut is making assisted living services available to lower-income individuals through the Assisted Living Demonstration Project, State-funded congregate housing, HUD complexes and the Private Pay Assisted Living Pilot.

According to the Connecticut Long-Term Care Needs Assessment Survey:[24]

- A total of 56 ALSAs and MRCs responded to the Needs Assessment Survey (ALSA and MRC results were combined due to overlap). The most frequently offered services include assisted living services (96 percent), recreational services (61 percent), transportation (52 percent), and congregate meals (62 percent).

- On average, there are 102 residents served in facility, with a range from 9 to 400. The largest percentage of clients being served are age 85 to 99 (60 percent), with another 38 percent age 65 to 84. Almost three quarters (74 percent) of clients are female. Ninety-two percent are White/Caucasian, and almost all clients (98 percent) are of non-Hispanic origin.

- More than half (60 percent) of clients pay for their services out of pocket, and only 14 percent use more than one payment source to pay for their care.

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 DPH. As of June 30, 2009, there were 100 residential care homes in Connecticut with a total of 2,765 beds.[25]

According to the Connecticut Long-Term Care Needs Assessment Survey:[26]

- A total of 42 residential care homes from across the state answered the Needs Assessment Survey. The top five services provided by residential care homes include recreational services (52 percent), transportation (48 percent), personal care assistant services (43 percent), assisted living services and congregate meals (41 percent each).

- The smallest residential care home serves five clients, while the largest serves 86 clients. The average number of clients currently being served is 26. There is a wide age distribution, with 22 percent of clients age 19 to 59, 30 percent 65 to 84 and 27 percent of clients 85 to 99 years old. In addition, one quarter of residential care home

[24] Julie Robison et al, *Connecticut Long-Term Care Needs Assessment - Part I: Survey Results*, June 2007, page 161-164.
[25] Connecticut Department of Public Health, 2009.
[26] Julie Robison et al, *Connecticut Long-Term Care Needs Assessment - Part I: Survey Results*, June 2007, page 154-156.

clients (25 percent) are age 85 to 99 years old. In addition, 15 percent of clients are 100 years old or older. The majority of clients are White/Caucasian (91 percent) and of non-Hispanic origin (98 percent), while nearly two-thirds (64 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 categories were: only certain ages accepted (60 percent), must have certain functional or cognitive abilities (60 percent), and certain behavioral or psychiatric diagnoses not accepted (57 percent).

- With regard to source of payment, typically, Supplemental Security Income is the funding source for RCH residents.

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 DSS 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 DPH.

As of June 30, 2009 there were 18 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.[27]

Supportive Housing

Designed to enable individuals and families to live independently in the community, supportive housing provides permanent, affordable rental housing with access to individualized health, support and employment services. People living in supportive housing usually hold their own leases and have all the rights and responsibilities of tenants. In addition, they have the option to use a range of training and support services such as case management, budgeting and independent living skills, health care and recovery services, and employment services.

Residential Settings for Individuals with Intellectual Disabilities

DDS administers or contracts for residential services from independent living, individualized home supports, community living arrangements, community training homes, and residential center settings. The majority of people served by DDS live at home with their family. [28]

[27] Connecticut Department of Social Services, 2009.
[28] Department of Developmental Services, 2009

- *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, 2009, 263 individuals lived independently.

- *Individualized Home Supports* -- 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 receiving Individualized Home Supports 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, 2009, 1,682 individuals received Individualized Home Supports.

- *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 DDS. On June 30, 2009, 413 individuals lived in Community Training Homes.

- *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, 2009, 3,781 individuals lived in Community Living Arrangements.

- *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. On June 30, 2009, 243 individuals lived in Residential Center Settings and 480 individuals reside at the Southbury Training School.

Residential Settings for Individuals with Psychiatric or Addiction Disorders

DMHAS funds several types of residential settings for individuals age 18 and older with psychiatric or addiction disorders. In SFY 2009, a total of 57,095 individuals received mental health services in the community and 3,851 received services in inpatient settings. Also in SFY 2009, a total of 69,083 individuals received substance abuse services in the community and 8,402 received inpatient services.[29]

Psychiatric disorders

- *Group Homes* – A community-based residence with on-site staffing 24 hours per day, seven days a week. In SFY 2009, 371 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 2009, 1044 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,

[29] Connecticut Department of Mental Health and Addiction Services, 2009.

although they are not necessarily located on site. In SFY 2009, 1879 individuals resided in supported housing.

- *Inpatient Psychiatric Care* - Inpatient psychiatric facilities are State hospital-level-of care services for individuals experiencing an exacerbation of symptoms/behaviors related to serious mental illness. In SFY 2009, 1548 individuals received acute and general inpatient psychiatric care.

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 2009, 7,412 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. In SFY 2009, 240 women were 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. Not all nursing facility residents receive long-term care. In addition to serving long-term care needs, nursing facilities are also relied upon for short term post-acute rehabilitation services. There are two types of nursing facilities licensed in Connecticut: chronic and convalescent nursing facilities (skilled nursing facilities) and rest homes with nursing supervision (intermediate care facilities).

On September 30, 2009, there were 26,325 individuals residing in Connecticut nursing facilities. The majority of residents were white (87 percent), female (71 percent), and without a spouse (81 percent), a profile that has remained consistent over the years. Twelve percent of the residents were under age 65, 39 percent were between age 65 and 84 and 49 percent were age 85 or older.[30]

Connecticut had a total of 29,317 licensed nursing facility beds as of September 30, 2008. 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.

[30] State of Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2009.

This was due to the addition of beds that had been approved before the moratorium went into effect. From 1994 to 2008, the total number of licensed beds decreased by 2,832, or nine percent. [31]

In 2008, a nursing facility resident in Connecticut paid on average $327 a day for a semi-private room, or $120,000 a year. Medicaid was the primary source of payment for 69 percent of individuals residing in a Connecticut nursing facility as of September 30, 2008, with private pay covering 12 percent and Medicare covering 16 percent. Between 1995 and 2005, the percentage relying on Medicaid and Medicare increased by four percent and 47 percent respectively, and the percent paying out of pocket (private pay) and relying on insurance decreased by 41 percent and 11 percent (Table 3). [32]

TABLE 3

Percent Distribution of Residents in Connecticut Nursing Facilities by Payment Source on September 30, 1995 and 2008

Payment Source	1995	2008
Medicaid	66.7	69.3
Medicare	10.7	15.7
Private Pay	20.2	12.0
Insurance	1.6	1.4
Other	< 1	1.5

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, 2009, a total of 1,080 people over the age of 18 in Connecticut resided in an ICF/MR. Of these individuals, 723 people resided in an ICF/MR operated by DDS in one of seven locations throughout the state. Another 357 individuals resided in 67 group homes operated at an ICF/MR level of care by private agencies. Of all of the people living in ICF/MRs 586 (31 percent) were between the age of 18 and 54, 307 (28 percent) were between the ages of 55 and 64, and 185 (17 percent) were age 65 and over. At this level of care, individuals received residential and day habilitation services, prevocational

[31] State of Connecticut Nursing Facility Registry and Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division.
[32] State of Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, September 2008.

services and supported employment services. All services are financed through the State Medicaid Program.[33]

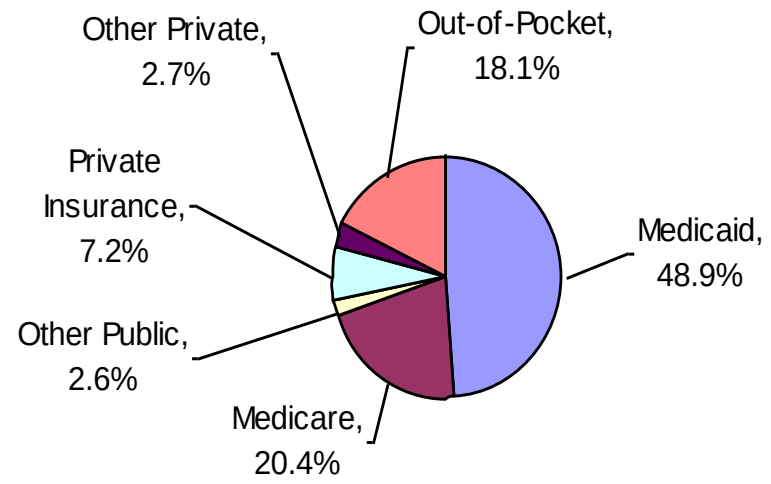
Chronic Disease Hospitals

On June 30, 2009, there were six chronic disease hospitals in Connecticut with a total of 832 beds.[34] Medicaid covered a monthly average of 369 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 72 percent of expenditures for long-term care services are paid for through public programs, primarily Medicaid (49%). 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 7). 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.

FIGURE 7
National Spending for LTC, by Payer, 2005



National Spending for Long-Term Care, Fact Sheet, Georgetown University Long-Term Care Financing Project, February 2007.

[33] Connecticut Department of Developmental Services, 2009.
[34] Connecticut Department of Developmental Services, 2009.

TABLE 4
Source of Payment for Long-Term Care Services

Long-Term Care Service	Medicare	Private Medigap Insurance	Medicaid	You Pay on Your Own
Nursing Facility Care	Pays in full for days 0-20 if you are in a Skilled Nursing Facility following a recent hospital stay. If your need for skilled care continues, may pay for days 21 through 100 after you pay a $128/day co-payment.	May cover the $128/day co-payment if your nursing facility stay meets all other Medicare requirements.	May pay for care in a Medicaid-certified nursing facility if you meet functional and financial eligibility criteria.	If you need only personal or supervisory care in a nursing facility and/or have not had a prior hospital stay, or if you choose a nursing facility that does not participate in Medicaid or is not Medicare-certified.
Assisted Living Facility (and similar facility options)	Does not pay	Does not pay	In some states, may pay care-related costs, but not room and board	You pay on your own except as noted under Medicaid if eligible.
Continuing Care Retirement Community	Does not pay	Does not pay	Does not pay	You pay on your own
Adult Day Services	Not covered	Not covered	Varies by state, financial and functional eligibility required	You pay on your own [except as noted under Medicaid if eligible.]
Home Health Care	Limited to reasonable, necessary part-time or intermittent skilled nursing care and home health aide services, and some therapies that are ordered by your doctor and provided by Medicare-certified home health agency. Does not pay for on-going personal care or custodial care needs only (help with activities of daily living).	Not covered	Pay for, but states have option to limit some services, such as therapy	You pay on your own for personal or custodial care, except as noted under Medicaid, if you are eligible.

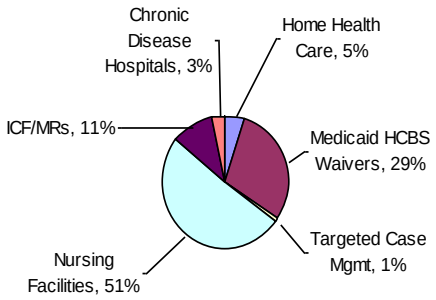
Source: U.S. Department of Health and Human Services, National Clearinghouse for Long-Term Care Information, Who Pays for Long-Term Care? Chart, Accessed on April 8, 2009, http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx#Who

At the individual level, those who have sufficient income and assets are likely to pay for their long-term care needs on their own, out of their own personal resources. Medicaid will pay for those who meet the financial eligibility criteria and have limited financial resources, or deplete them paying for their care. Medicare may pay for individuals who are eligible and require primarily skilled or recuperative care for a short time, but do not cover individuals with stable chronic conditions. The Older Americans Act is another Federal program that helps pay for long-term care services. As financial circumstances and the need for care changes, a variety of payment sources may be used.[35]

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 facility care, accounting for almost half of all long-term care spending in 2005 (Figure 7). 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 older adults become eligible for Medicaid as a result of depleting their assets to pay for nursing facility care that Medicare does not cover.

FIGURE 8
Proportion of CT Medicaid LTC Expenditures, SFY 2009



Source: Office of Policy and Management, 2009

In SFY 2009, the Connecticut Medicaid program spent $2.497 billion on long-term care. These Medicaid long-term care expenses account for 53 percent of all Medicaid spending and 13 percent of total expenditures for the State of Connecticut. [36]

Looking at Connecticut's Medicaid long-term care expenses in more detail, 35 percent was spent on home and community-based services and 65 percent on institutional care. Nursing facility care represents 51 percent of total Medicaid long-term care expenses and Medicaid home and community-based waiver services represent 29 percent (Figure 8). Breaking down Medicaid home and community-based waiver services further, we see that services for the developmentally disabled account for 22 percent of long-term care expenses, in contrast to 7 percent for the Elder, Personal Care Attendant, Katie Beckett, and Acquired Brain Injury waivers combined.

[35] U.S. Department of Health and Human Services, National Clearinghouse for Long-Term Care Information, Who Pays for Long-Term Care? http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx#Who

[36] Office of Policy and Management, Policy Development and Planning Division, 2009.

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 35 percent in SFY 2009. This 52 percent increase in the proportion of home and community-based services is, in part, a result of efforts to reduce nursing facility use by limiting nursing facility care through pre-admission screening, a moratorium on new nursing facility beds, and constraints on the growth in Medicaid payments on the one hand and expanding home care primarily through Medicaid waivers on the other.

Experience from other states has shown that home and community-based services help people with disabilities stay in their homes while reducing long-term care spending. Researchers at the Institute for Health and Aging at the University of California, San Francisco, found that the growth in spending was greater for states offering limited community-based services than for states with large, well-established home and community-based programs. They conclude that while expansion of home and community-based services requires a short-term increase in spending, it is followed by a reduction in institutional spending and long-term cost savings.[37]

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 older adults 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 facility 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 about 20 percent (about $42.2 billion) of total long-term expenditures in the U.S. in 2005 (see Figure 7).

Out-Of-Pocket Spending / Private Pay

Nationally, approximately 18 percent of long-term care spending in 2005 was paid directly by individuals (about $37.4 billion), rendering out-of-pocket payments as the third largest source of long-term care financing (Figure 7). 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.

[37] H. Stephen Kaye et al, *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?* Health Affairs, Vol. 28, No. 1, January/February, 2009, pgs 262-272.

Private Insurance Spending

In 2005, coverage from private insurance represented over seven percent of long-term care expenditures in the U.S. (Figure 7). Sources of private insurance include supplemental Medicare coverage (Medigap), traditional health insurance, and private long-term care insurance.

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).[38]

In Connecticut, the number of individuals who purchased long-term care insurance in 2008 was 8,571. As of December 31, 2008, there were 112,791 Connecticut residents with a private long-term care insurance policy in force.[39]

Connecticut Partnership for Long-Term Care[40]

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;
- 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.

As of December 31, 2008, there were over 50,000 Partnership policies sold in Connecticut. Purchasers of Partnership policies range in age from 20 to 88 years old, with the average age at purchase being 58 years old. Over 1,000 Partnership

[38] Connecticut Partnership for Long-Term Care, *Frequently Asked Questions*, April 2009
[39] Office of Policy and Management, Policy Development and Planning Division, 2009.
[40] Connecticut Partnership for Long-Term Care, 2009

policyholders have utilized benefits under their policies, with over $60 million in benefits paid. Only 64 Partnership policyholders have accessed Medicaid utilizing the Asset Protection earned under their policies. This has helped the Partnership save the State over $8 million in Medicaid long-term care funds with larger savings projected for the future.

Connecticut was the first state to implement a Partnership. From 1992, when the Partnership was first launched, through 2006, New York, Illinois, Indiana and California developed similar Partnership programs. Due to changes in federal law (Deficit Reduction Act of 2005) making it easier for states to establish Partnership programs, 30 new states have developed Partnership programs.

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 and although means testing is not allowed 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 employment services programs for older adults.

The federal Administration on Aging provided $17.2 million in FFY 2009 to the DSS Aging Services Division. Of these funds, $16 million were distributed by formula to the Area Agencies on Aging who in turn contract with community-based organizations to provide social and nutritional services. $1.2 million of these funds were special grants received by Aging Services, including Nursing Home Diversion and Modernization (Community Living Project), Model Approaches to Statewide Legal Assistance, Empowering Older People to Take Control of Their Health (Evidence-Based Health Promotion), and CT CHOICES project. Both federal and state funds for Aging Services provided a multitude of services to 79,244 seniors.

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 older adults 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.

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, adults age 65 and older accounted for less than 5 percent of the total U.S. population. A century later, the proportion of older adults in the U.S. population has grown to over 12 percent or 33 million.[41] By 2025, the older adult population is expected to have grown to almost 18 percent of the U.S. population, or 64 million.[42]

In Connecticut over the next 15 years (2010 to 2025), the total population is projected to grow by 113,526 people, an increase of 3 percent. Although this increase in population is modest, there are two extraordinary trends at work. Firstly, the number of adults between the ages of 18 and 64 will actually decrease by 107,092. In contrast, the number of individuals age 65 and over will increase by 207,705, or 40 percent, due to the aging of the Baby Boom generation (Table 5).

TABLE 5
Connecticut Population Projections: 2010 – 2025

Age Group	2010	2015	2020	2025	Pop. Growth 2010-2025	Percent Change: 2010 - 2025
Under 18	814,008	806,875	816,345	826,921	12,913	2%
18 to 64	2,247,861	2,251,456	2,216,764	2,140,769	-107,092	-5%
65+	515,621	577,083	642,541	723,326	207,705	40%
Total	3,577,490	3,635,414	3,675,650	3,691,016	113,526	3%

Source: File 3. Interim State Projections of Population by Single Year of Age: July 1, 2004 to 2030, U.S. Census Bureau, Population Division, Interim State Population Projections, 2005.

According to Census projections, a significant growth in the proportion of older adults in the population will occur after 2011, the year the oldest of the Baby Boom generation (those born between 1946 and 1964) turn 65. In Connecticut, the proportion of older

[41] 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.
[42] Table 2. Projections of the Population by Selected Age Groups and Sex for the U.S.: 2010 to 2050, U.S. Census Bureau, Population Division, August 14, 2008.

adults in the population is expected to increase steadily between 2010 and 2025, growing from 14 percent in 2010 to 20 percent in 2025 (Table 6).

TABLE 6
Connecticut Population Projections,
Percent Distribution of Population by Age: 2010 – 2025

Age	2010	2015	2020	2025
Under 18	23%	22%	22%	22%
18 to 64	63%	62%	60%	58%
65+	14%	16%	17%	20%

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

In 2008, the U.S. Census estimated that there were approximately 357,907 individuals in Connecticut with one or more disabilities (excluding individuals living in institutions). Between 2008 and 2025, this number is expected to grow by 7.25 percent, or approximately 25,959 people, to an estimated 383,866.[43] However, when broken down by age, dramatically different trends appear that parallel the general population trends. The number of individuals with disabilities under age 18 is projected to increase by only one percent (311) over 15 years and the number of individuals with disabilities age 18 to 64 is projected to decline by 2.32 percent (4,177). In contrast, the population with disabilities age 65 and older is expected to increase by 89,969 or 60 percent (Table 7).

Although the projections provided in Table 7 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 older adults 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.[44] Furthermore, the annual decline in chronic disability among older adults has been accelerating over time. In 1982 approximately 26.5 percent of individuals age 65 and over had a chronic disability compared to 19.0 percent in 2004/2005 – representing a 1.52 percent annual decline. If chronic disability continues to decline at 1.5 percent annually, there could be significant improvements in the future fiscal stability of Social Security and Medicare.[45] In contrast,

[43] These projections are based on the 2008 Census disability data applied to U.S. Census Bureau Population Projections through 2025. The Census does not tabulate disability status for individuals in institutions. Disability projections assume a constant rate of disability over time.
[44] 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.
[45] Kenneth G. Manton et al, *Change in Chronic Disability from 1982 to 204/2005 as Measured by Long-Term Changes in Function and Health in the U./S. Elderly Population*, Proceedings of the National

a 2009 study concluded that people aged 60 to 69, the youngest group of older adults, appear to be more disabled than in prior generations, mostly as a result of being overweight and diabetes. Between 1988-1994 and 1999-2004, disability increased among 60 to 69 year olds: 60 percent for basic ADLs, 60 percent for IADLs, 30 percent for mobility and 20 percent for functional limitations.[46]

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.[47]

TABLE 7
Projection of Non-Institutionalized Persons with Disabilities in Connecticut by Age: 2008 – 2025

	2008	2025	2005 / 2025 Increase	Percent Increase
Under 18	29,458	29,769	311	1.06%
18 to 64	179,720	175,543	-4,177	-2.32%
65+	148,729	238,698	89,969	60.49%
Total	**357,907**	383,866	25,959	7.25%

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 data for Connecticut, 2005.

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.[48] [49] AARP predicts that due to declines in disability the future demand for support services among the elderly will

Academy of Sciences (PNAS), November 28, 2006, Volume 103, No. 48, www.pnas.org/cgi/doi/10.1073/pnas.0608483103

[46] Theresa E. Seeman, et al, "Disability Trends Among Older Americans: National Health and Nutrition Examination Surveys, 1988-1994 and 1999-2004." American Journal of Public Health, November 12, 2009.

[47] Darius N. Lakdawalla et al, *Are the Young Becoming More Disabled?* Health Affairs, January/ February 2004.

[48] 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.

[49] 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).

grow very slightly."[50] Other experts maintain that the sheer numbers of aging baby boomers are expected to overwhelm the positive benefits of the decreased prevalence of disability.[51] [52]

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.

By focusing on Medicaid, what is not accounted for is the demand for long-term care services among individuals who either depend upon unpaid caregivers and family, those with private long-term care insurance, those who pay out of pocket and those who depend upon other sources of federal and state funds. For example, this analysis does not include the long-term care services and supports for adults with psychiatric disabilities funded by the State Department of Mental Health and Addiction Services.

TABLE 8
Connecticut Medicaid Long-Term Care Clients and Expenditures: SFY 2009

	SFY 2009 Medicaid LTC Clients, Monthly Average	SFY 2009 Medicaid LTC Expenditures
Community-based Care	**21,275**	**$886 million**
Institutional Care	**18,822**	**$1,612 million**
Total	**40,097**	**$2,498 million**

Source: Office of Policy and Management, 2009.

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 40,097 Medicaid clients who received long-term care services and supports in Connecticut each month in SFY 2009, 53 percent received services in the community and 47 percent received care in an

[50] AARP, *Before the Boom: Trends in Long-Term Support Services for Older American with Disabilities*, October 2002, pp 41-42.
[51] Congressional Budget Office Memorandum, *Projections of Expenditures for Long-Term Care Services for the Elderly*, March 1999.
[52] 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.

institutional setting (Table 8). 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 7.5 percent increase in individuals receiving Medicaid services: an additional 1,542 Medicaid clients receiving long-term care in the community and an additional 1,365 receiving care in institutions (Table 10). To meet this additional demand for long-term care, Medicaid expenditures are expected to grow from $2.5 billion in SFY 2009 to $5.8 billion in 2025, assuming current ratios of institutional and community care and a five percent annual inflation rate (Table 11).

TABLE 9
Percent of Medicaid Long-Term Care Spending for Home and Community-Based Services, FY 2007[53]

State	Percent	U.S. Rank
U.S.	41.7	
New Mexico	72.9	1
Oregon	72.7	2
Arizona	64.0	3
Maine	51.4	11
Rhode Island	45.6	14
Massachusetts	38.7	28
Connecticut	35.5	34
New Hampshire	39.6	25
Pennsylvania	28.3	48
North Dakota	25.6	49
Mississippi	12.7	50

Source: Brian Burwell et al; *Medicaid Long Term Care Expenditures FY 2007*; September 2008; http://www.hcbs.org/files/145/7233/FY2007InstComm-Updated.xls

In the U.S., Medicaid spending for community-based long-term care services amounted to 42 percent of all Medicaid long-term care costs and 58 percent were spent on institutional care. Over the years, the percentage spent for community-based care has increased by one to three percentage points a year, reflecting increased investment by states in offering their residents opportunities to live in the least restrictive settings possible. A comparison of states provided in Table 9 shows New Mexico to have the highest proportion of Medicaid long-term spending for home and community-based services (72.9 percent) and Mississippi to be the lowest (12.7 percent). Among the states,

[53] Community-based services include home and community-based waiver services, personal care, home health, and home and community-based services authorized under Section 115 waivers and under section 1929. Institutional services include facility services and ICF-MR services.

Connecticut ranks 34th, with 35.5 percent Medicaid long-term care expenditures for home and community-based services. 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. If Connecticut is to reach the ratios of community-based care sooner than 2025, balancing efforts will need to be more aggressive.

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 53 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 10,978 clients receiving community-based services and supports, and a decrease of 8,071 individuals receiving care in institutions when compared to 2009 levels (Table 10). By holding the number of 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 $4.9 billion, instead of $5.8 billion; $904 million less than the State might otherwise have spent (Table 11).

TABLE 10
Projections of Connecticut Medicaid Long-Term Care Clients by Current and Optimal Ratios of Community and Institutional Care SFY 2009 and SFY 2025

	Current Ratio	2025 clients/ monthly average	Increase from 2009 to 2025	Optimal Client Ratio	2025 Optimal clients/ monthly Average	Increase from 2009 to 2025
Community-based Care	**53%**	22,817	1,542	**75%**	32,253	10,978
Institutional Care	**47%**	20,187	1,365	**25%**	10,751	-8,071
Total		43,004	2,907		43,004	2,907

Source: Office of Policy and Management, Policy and Planning Division, 2009 based on: (1) Department of Social Services Medicaid data for SFY 2009; (2) U.S. Census Bureau, Population Division, Interim State Population Projections, 2005; (3) U.S. Census Bureau, American Community Survey, 2008 disability data for Connecticut.

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,[54] is significantly lower than serving them in institutions.

With regard to institutional services, it is projected that in 2025 an estimated 10,751 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 9,436 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.

TABLE 11
Projections of Connecticut Medicaid Long-Term Care Expenditures by Current and Optimal Client Ratios of Community and Institutional Care SFY 2009 and SFY 2025, in millions of dollars

	Current Client Ratio	2025 Expenditures with Current Client Ratio	Increase from 2009 to 2025	Optimal Client Ratio	2025 Expenditures with Optimal Client Ratio	Increase from 2009 to 2025
Community-based Care	**53%**	$2,073,145,970	$1,187,614,916	**75%**	2,930,441,990	$2,044,910,936
Institutional Care	**47%**	$3,774,168,135	$2,162,056,332	**25%**	2,010,050,810	$397,939,007
Total		$5,847,314,105	$3,349,671,248		$4,940,492,800	$2,442,849,943

Note: Expenditure projections include a 5 percent annual compound rate increase.
Source: Office of Policy and Management, Policy and Planning Division, 2009 based on: (1) Department of Social Services Medicaid data for SFY 2009; (2) U.S. Census Bureau, Population Division, Interim State Population Projections, 2005; (3) U.S. Census Bureau, American Community Survey, 2008 disability data for Connecticut.

[54] 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.

C. Caregiver Supply and Demand

Currently, long-term care providers report large numbers of vacancies and turnover rates for paraprofessional workers. 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 older adults 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.

Informal Caregivers

Relatives, friends and other unpaid caregivers account for the vast majority of individuals providing long-term care supports to individuals across the lifespan. In 2007, there were 34 million caregivers at any one time and 52 million throughout the year, representing 19 percent of the U.S. adult population. Over this time, the estimated economic value of unpaid contributions from informal caregivers was approximately $375 billion, up from an estimated $350 billion in 2006. In fact, the economic value of caregiving exceeded total Medical spending in the U.S. for both medical and long-term care. In Connecticut in 2007, there were an estimated 370,000 caregivers at only one time, accounting for an estimated $4.9 billion in unpaid contributions.[55]

Long-Term Care Needs Assessment Survey Findings[56]

In Connecticut, one in six people report being a caregiver for another Connecticut resident. Most of this care goes to parents (57 percent) or another relative (14 percent). Ten percent provide care for their spouse and another 10 percent provides care for a friend. Seven percent provide care for a child with a disability. Typically, it is older individuals that receive assistance from an informal caregiver. Of the 81 percent of individuals receiving care age 65 and older, 42 percent are between the ages of 65 and 84, and 39 percent are 85 and older.

Most caregivers live near those they care for. Sixty-two percent live with in the same town or a nearby community and another 27 percent live with the person they are caring for. In contrast, 11 percent live more than 45 minutes away. 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 (54 percent) have had to miss some work due to these responsibilities.

[55] Ari Houser et al, *Valuing the Invaluable: The Economic Value of Family Caregiving*, AARP Public Policy Institute 2008 Update.

[56] Julie Robison, Ph.D. et al, *Connecticut Long-Term Care Needs Assessment, Part I: Survey Results*, University of Connecticut Center on Aging, June 2007, pages 109-110.

Paid Direct Caregivers

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.

Long-term care related occupations are expected to be among the fastest growing in the nation. The federal Bureau of Labor Statistics has published 2006 data on the numbers of people in various long-term care-related occupations and has projected the numbers of people who will be needed to fill those jobs in 2016, which include both new jobs created and replacements for people leaving the workforce (Table 12). The occupation of personal and home care aide is expected to grow by 51 percent between 2006 and 2016, representing one of the fastest growing occupations nationwide. Not far behind is home health aide, which is expected to grow by 49 percent. Two other occupations related to long-term care will show significant growth as well: registered nurses are projected to grow by 24 percent and nursing aides, orderlies, and attendants by 18 percent.

For Connecticut, similar data on long-term care occupations are available from the Connecticut Department of Labor. Table 13 displays the number of people working in each occupation in 2006, the number of positions projected to be available in 2016, and the net and percent change.

TABLE 12
Occupations in the U.S. 2006 and Projected 2016

Occupation	Employment (in thousands) 2006	2016	Change Number	Percent
Home health aides	787	1171	384	48
Nursing aides, orderlies, attendants	1447	1711	264	18
Personal and home care aides	767	1156	389	51
Registered nurses	2394	3096	703	29

Source: U.S. Bureau of Labor Statistics Office of Occupational Statistics and Employment Projections, Table 5. The 30 occupations with the largest employment growth, 2006-2016, http://data.bls.gov/cgi-bin/print.pl/news.release/ecopro.t05.htm

Long-term care occupations in Connecticut will see growth between 2006 and 2016, with most of this growth expressed in double-digit figures. Efforts to balance 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 33 percent rise in personal and home care aide positions and a 25 percent increase in home health aide positions. These somewhat conservative estimates fall noticeably below the national predictions. 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 12 percent.

Table 13
Connecticut 2006 and Projected 2016 Occupations

Occupational Title	Employment		Change	
	2006	2016	Number	Percent
Personal and Home Care Aides	6,340	8,450	2,110	33%
Home Health Aides	10,590	13,280	2,690	25%
Registered Nurses	32,840	38,560	5,720	17%
Licensed Practical and Licensed Vocational Nurses	8,020	9,070	1,050	13%
Nursing Aides, Orderlies, and Attendants	24,660	27,590	2,930	12%
Occupational Therapists	1,590	1,830	240	15%
Occupational Therapist Assistants	420	470	50	12%
Physical Therapists	3,200	3,780	580	18%
Physical Therapist Aides	430	520	90	21%
Physical Therapist Assistants	670	820	150	22%
Respiratory Therapists	1,250	1,470	220	18%
Speech-Language Pathologists	1,520	1,600	80	5%
Rehabilitation Counselors	4,370	5,220	850	20%
Mental Health and Substance Abuse Social Workers	2,640	3,280	640	24%
Substance Abuse and Behavioral Disorder Counselors	1,210	1,640	430	36%
Mental Health Counselors	2,010	2,600	590	29%

Source: Office of Policy and Management, from Connecticut Department of Labor, *Connecticut Statewide Forecast: 2006 – 2016*, http://www.ctdol.state.ct.us/lmi/misc/fc2016_statewide.htm#hpract

V. GOALS and RECOMMENDATIONS

A. Introduction

The goals, 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 and their families. While this Plan maps out the need for long-term care through 2025, the recommendations address current needs as well as future demands.

In addition to two rebalancing goals, this Plan puts forward 16 recommendations. Although these recommendations are not prioritized, they were chosen from a much longer list of recommendations and therefore represent the priorities for this Plan. These recommendations are reflective of a system of care, and as such, they must be viewed as both interrelated and interdependent. As Connecticut continues its work to balance its long-term care system, progress must be made on multiple fronts. 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.

The 2010 Long-Term Care Plan is informed by the findings of the Connecticut Long-Term Care Needs Assessment (Center on Aging at the University of Connecticut School of Medicine, June 2007) and many of the recommendations made in the Needs Assessment have been included in this Plan. Each recommendation is followed by a series of action steps providing more detailed guidance. Overall, the recommendations are primarily focused on initiatives State government can undertake. 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 enacted in Connecticut statute to guide policy and budget decisions. 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 people a reality.

B. Goals

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

> ***GOAL #1: Develop a system that provides for more choice and opportunities for community integration as alternatives to all institutional settings, and increases the proportion of individuals receiving Medicaid home and community-based care from 53 percent in 2009 to 75 percent by 2025, requiring approximately a one percent increase in the proportion of individuals receiving Medicaid long-term care 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; developed a long-term care services and supports website and established the Money Follows the Person Rebalancing Initiative.

In the six years since the establishment of the Plan's goal of improving the balance between home and community-based services and institutional care (SFY 2003 – 2009), this goal has been met, with an increase in the proportion of Medicaid long-term care clients served in the community of over one percent a year, from 46 percent to 53 percent (Table 14). However, the increase in the proportion of Medicaid long-term care clients receiving community-based care has slowed in the last three years, increasing from 51 percent in SFY 2006 to 53 percent in SFY 2009 – a two percent gain in three years.

The shift toward community-based care can also be seen in terms of Medicaid long-term care expenditures. Between SFY 2006 and SFY 2009 the proportion of Medicaid long-term care dollars spent on care delivered in the community also increased by three percent, rising from 32 percent to 35 percent (Table 15).

Although Connecticut is making progress, we rank only 34th among all the states in the proportion of Medicaid long-term care dollars spent on home and community-based services according to an annual national study of Medicaid long-term care expenditures.[57] Many states have achieved significantly higher ratios of Medicaid long-term care

[57] Brian Burwell et al; Medicaid Long Term Care Expenditures FY 2007; September 2008; http://www.hcbs.org/files/145/7233/FY2007InstComm-Updated.xls . Community-based services include home and community-based waiver services, personal care services, and home health services and institutional services include nursing facility services and ICF-MR. This methodology differs from that used in this Plan to estimate the ratio of Medicaid long-term care expenses.

expenditures on community-based care than has Connecticut, such as New Mexico (73 percent), Oregon (73 percent), Arizona (64 percent) and Minnesota (63 percent), with the U.S. average at 42 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 14
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
2006-07	52%	48%	41,335
2007-08	52%	48%	40,057
2008-09	53%	47%	40,097

Source: Office of Policy and Management, Policy Development and Planning Division, 2009

TABLE 15
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
2006-07	33%	67%	$2,299,133,950
2007-08	33%	67%	$2,403,524,813
2008-09	35%	65%	$2,497,642,857

Source: Office of Policy and Management, Policy Development and Planning Division, 2009

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. Additionally, Connecticut would be offering more choice to its residents. 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 25,959 or 7.25 percent. However, this increase is concentrated among older adults, with a 60 percent increase among individuals age 65 and older. For individuals with disabilities under age 18, only a one percent increase is projected between 2009 and 2025 and for those ages 18 to 64, the number is expected to decline by over two percent. Assuming current ratios of community-based to institutional care, a five percent per year inflation rate and a 7.25 percent increase in the number of individuals with disabilities, Medicaid expenditures for long-term care are anticipated to grow from $2.5 billion in SFY 2006 to $5.8 billion by SFY 2025 to meet the expected increase in demand for long-term care.

However, with 75 percent of individuals receiving community care in 2025, these long-term care expenditures are only expected to be $4.9 billion, which is just shy of $1 billion ($904 million) less than the State might otherwise have spent that year. In addition, approximately 59 percent, up from 35 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 fifteen years by holding the percentage of persons with disabilities constant over time. As described in Chapter IV, the percentage of older adults 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.

2. Balancing the ratio of public and private resources

> ***GOAL #2: Increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent by 2025. 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 7.2 percent of long-term care spending in 2005.***

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 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.

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 (7.2 percent) and other dedicated sources of private funds (2.7 percent) successfully reached 25 percent (See Figure 7). 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 7.5 percent. Using today's dollars, and a Medicaid long-term care budget of approximately $2.5 billion, that would equate to $188 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 has 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.

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. 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.

C. Recommendations and Action Steps

STRUCTURAL

1. **Create greater integration of State level long-term care administration and functions serving both older adults and people with disabilities and their families.**

   According to the Long-Term Care Needs Assessment, the governance structure for providing administration and programmatic support to older adults and persons with disabilities is splintered and not well coordinated. The goal should be to break down silos that exist within and among State agencies and programs. A number of State agencies have service, funding and oversight responsibilities and are represented on the Long-Term Care Planning Committee: DSS, DDS, DMHAS, DPH, the Department of Children and Families (DCF), DECD, the Department of Transportation (DOT) as well as the Office of Protection and Advocacy, and OPM.

   Action Steps

   a. Establish a consolidated, efficient all-ages human services approach to long-term care in Connecticut that maximizes the impact of Medicaid, Older Americans Act and Veterans Administration funds rather than divides them.

   b. Ensure linkages between the Long-Term Care Services and Supports and ADRC Website and other websites that include specific long-term care service information.

   c. Provide for global budgeting with flexibility and authority to fund an array of long-term care services and supports, to be adjusted annually based on the projected needs of the population and for inflation.

d. Simplify administration through a reduction in duplication and the development of standardized contracting, a unified application and assessment instrument for services and efficient application procedures.

e. Ensure linkages with the CHOICES Program, ADRCs, Centers for Independent Living, and providers of mental health services for all ages.

f. Develop systems and technology to share long-term care data.

- Improve technology in state systems to implement electronic records and make valuable data readily retrievable.

- Assist all health care providers with the implementation of electronic records and the implementation of the statewide electronic data exchange.

- Build data capacity and systems integration that facilitates more efficient care management for people receiving services.

2. Simplify Connecticut's Medicaid structure.

The Medicaid program is particularly complex, especially with regard to the separate long-term care pilot programs and home and community-based waivers that vary in terms of eligibility, services provided and types of disabilities that are addressed. Ideally, eligibility for long-term care services and supports should address functional needs and not exclude individuals due to age or particular disability. Policy and program changes should create parity among age groups, across disabilities, and among programs through allocating funds equitably among people based on their level of need rather than on their age or type of disability.

Action Steps

a. If the federal government revises their rules to allow it, establish a universal Medicaid home and community-based services waiver based on function, not age or diagnosis. Allow for flexibility to address a variety of specific needs.

b. If it is determined that a universal Medicaid waiver is not feasible, every effort should be made to ensure that eligibility criteria and level of need reporting forms are consistent across waivers.

c. As an alternative to a universal Medicaid home and community-based services waiver, include home and community-based services, such as personal care assistance, in the State Medicaid Plan. Include programs for adults with developmental disabilities who do not have intellectual disabilities.

d. Make pilot programs that are proven successful a permanent feature of the Medicaid program. Require evaluation of all pilot programs after three years, including cost-effectiveness.

e. Streamline Medicaid eligibility procedures, reduce response time to individuals and develop a web-based on-line application process for Medicaid services.

f. Ensure interagency accessibility to eligibility application information to streamline the application process for many state programs.

g. Explore locating DSS eligibility service workers with ADRCs to reduce Medicaid eligibility determination response time.

3. Address access and reimbursement for key Medicaid services.

The Medicaid program is the primary payer for long-term care services. Nationally, approximately 49 percent of expenditures for long-term care services are paid for by Medicaid. In SFY 2009, the Connecticut Medicaid program spent $2.498 billion on long-term care. Medicaid long-term care expenses accounted for 53 percent of all Medicaid spending and 13 percent of total expenditures for the State of Connecticut.

Action Steps

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

b. DSS should assess the feasibility of increasing Medicaid reimbursement rates to attract providers willing to serve individuals with disabilities. Psychiatric, dental, and podiatric services were identified in the Long-Term Care Needs Assessment as a particular problem for those receiving services through the Medicaid program. Difficulties involving access and financing persist, as well as finding medical personnel who are sensitive and respectful to the needs of people with disabilities.

c. Reinvest the federal Medicaid match obtained through the Money Follows the Person demonstration into long-term care initiatives such as statewide ADRCs, expanded home and community-based programs, nursing facility transition and diversion programs, workforce development, support for informal caregivers, assistive technologies and prevention and wellness programs.

d. Maximize reimbursement of state long-term care expenditures through an ongoing review process.

e. Consider setting Medicaid rates based on objective quality measures.

4. Further reform and coordinate the nursing facility/ institutional admission prescreening process.

In order to make more progress in meeting the goals of balancing the long-term care system in Connecticut, assuring individual choice and maximizing independent living, comprehensive, coordinated pre-admission screening is needed to assess and educate individuals before they are admitted to a nursing facility or similar institution. Helping private pay nursing facility applicants 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. 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 should not prohibit or deny applicants the choice to enter an institution. Prescreening activities need to take into account the specific needs of the individual, addressing both intellectual, cognitive and physical disabilities, and ensure that the person receives the appropriate level of care that will protect them and others from any potential harm.

Action Steps

a. Expand the current State commitment to prescreen all applicants to nursing facilities age 65 and older, regardless of their payer status, to include all nursing facility applicants, regardless of age or payer source. Similar prescreening for applicants of all institutions for individuals with disabilities should be developed.

b. Implement a systematic, web-based, comprehensive prescreening program for persons seeking admission in a nursing facility or other institution, regardless of age or payer source. As part of this system, track length of stay in the institution.

c. Enhance existing educational efforts with hospitals, physicians, nursing facilities, and other institutions regarding prescreening and available community options in collaboration with providers and other entities working in the community with individuals with disabilities.

d. Identify people who have housing to return to and preserve its availability as part of the prescreening process.

INFORMATION/ ACCESS

5. Provide true individual choice and self-direction to all users of long-term care.

According to the Long-Term Care Needs Assessment, Connecticut has only achieved partial success implementing a self-directed model of service delivery. The defining characteristic of a self-directed model is that it empowers people to take control and make choices that embody recovery, independence, and personal choice over which services they receive, how they receive supportive services and from whom. Some self-directed programs go further by providing a cash benefit (often called Cash and Counseling), with which the individual can purchase services or pay caregivers, including family members. Examples of self-directed programs in Connecticut are found in the DDS Medicaid waiver programs, the Medicaid Personal Care Assistance (PCA) waiver program, and the Nursing Home Diversion Grant at DSS.

Action Steps

a. Expand self-directed care options under home and community-based services programs.

   - Allow individuals and family members to choose their own care providers, including individuals from within their own informal care network, particularly family members, and allow individuals to control their own budgets.

   - Operate programs with as much flexibility as possible, including the ability to arrange for as many care provider hours as necessary, in whatever configuration across providers as is appropriate and preferred by the person. (See Recommendation #12)

   - Ensure that self-directed programs are an option, not a requirement or condition, for receiving home care services.

b. Offer where feasible a self-directed care option for programs, including but not limited to the DSS National Family Caregiver Support Program (for those caring for relatives age 60 and older) and the Connecticut State Respite Care Program (for individuals with Alzheimer's disease) using the existing model being piloted under the Nursing Home Diversion Modernization Grants. Also, investigate funding options to support Fiscal Intermediary Services under these and other programs to allow individuals the flexibility to choose and hire their own personal care workers and control their budgets, similar to what are allowed under the current DDS Medicaid waivers.

c. Implement Cash and Counseling as a tool to increase program flexibility and choice. Consider options available under Section 1915 of the federal Deficit

Reduction Act to implement Cash and Counseling. Make case management available to those who wish to use it but optional for individuals who are able to manage their own care.

d. Increase public and professional understanding of individual choice, recovery, independence and self-determination.

e. Identify appropriate funding and provide training opportunities about choice, autonomy and dignity and the assistance available for transitioning from institutions to the community and the services available in the community after transition.

- Training should be available for people with disabilities, conservators, guardians, families, probate system staff, medical personnel, social workers, clergy, attorneys and others. Training of people with disabilities, families and professionals should include recognizing signs of abuse and neglect.

- Training should be updated to include recent revisions to the conservatorship statutes which promote self-determination.

- There should be training on Social Roles Valorization that would help human service workers better understand the value of social roles and the do's and don'ts of supporting people in the community. Social role valorization starts with the assumption that it is important for people who need long-term care to live in valued residential situations and take on valued roles in the community. This relates both to a person's individual competencies and social image in the community.

6. Address education and information needs of the Connecticut public.

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 admissions are their only options. Information and education is also needed to help people plan ahead for paying for long-term care needs in case they arise due to illness, injury or disability.

Connecticut has a number of sources of public information on long-term care, including the Long-Term Care Services and Supports and ADRC Website, Infoline (2-1-1), the CHOICES Program, ADRCs in the south central and western regions of the state, the Connecticut Partnership for Long-Term Care, as well as through a number of specific State agency programs. Despite the availability of these

resources, access to information, resources and options regarding long-term care is still elusive for many people seeking information on state and local resources and programs.

Action Steps

a. 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). 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 facility care.

b. Coordinate efforts of the Connecticut Partnership for Long-Term Care with the long-term care support options counseling efforts of the ADRCs.

c. Develop targeted information campaigns about long-term care services and supports in collaboration with high-visibility, convenient community partners, such as hospital discharge planning offices, community and senior centers, Area Agencies on Aging (AAAs), ADRCs, public libraries, mental health agencies, advocacy groups, physicians, clergy and teachers. These campaigns should integrate existing internet resources such as the Long-Term Care Website. Additional training and resources should be provided to those who are the most frequent sources of long-term care information and advice, such as social workers and heath care providers, as well as Probate Court officials and conservators.

d. Initiate a campaign of cultural change around long-term care, especially targeting health care professionals (physicians, nurses, social workers, occupational therapists, physical therapists, etc.). These professions often influence consumer choices.

7. **Develop and implement a statewide system of Aging and Disability Resource Centers for providing information, referral,** assistance and long-term care support options**.**

Although there are a number of resources in Connecticut to assist individuals in need of long-term care services and supports, there is no statewide initiative providing standardized information, referral and screening. However, two regional ADRCs have been established in Connecticut, one in the south central region of the state and the other in the western region, both known as "Community Choices."

Connecticut's two ADRCs are designed to provide a cadre of services to anyone age 18 and over regardless of income or ability including: comprehensive information and assistance, screening, assessment, options counseling (employment, benefits and

long-term care), long-term care planning and advocacy. They were established with funding from the federal Administration on Aging. Additional funding is required to sustain the existing programs as well as to expand to the remaining regions of Connecticut. Services to people with all disabilities will be strengthened by also seeking funding from the National Institute of Mental Health, the Substance Abuse and Mental Health Services Administration (SAMHSA), and other disability grant funders.

Action Steps

a. Use the existing model from the DSS State Unit on Aging, through leveraging of available funding sources including the federal Administration on Aging, to enhance ADRC services in south central and western Connecticut.

b. Implement new ADRCs in the remaining three areas of the state: eastern, southwestern, and north central. Base further development of the model upon evaluation of the existing ADRCs and tracking of their quality and efficiency.

c. Build on the existing model with Area Agencies on Aging (AAAs) and Centers for Independent Living (CILs) as the core regional partners providing comprehensive information and assistance and explore other disability and mental health models and regional partners to maximize the variety and creativity of approaches. Continue to integrate disability specific agencies in the ADRC network, including mental health agencies and advocacy organizations.

d. Train ADRC staff, utilize a comprehensive resource database, create management information system (MIS) database tracking, and enhance the Long-Term Care Website to include interactive features.

e. Build on the connection with the CHOICES program, the widely recognized information and assistance program operating out of the AAAs.

WORKFORCE

8. Address the long-term care workforce shortage.

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. Examples of formal caregivers include personal care assistants, home health aides, companions, homemakers, care managers, and nurses. 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. Without an adequate trained workforce that is paid appropriately for services, many of the long-term care

community support programs will fall short of their goals. Special programs and Medicaid waivers will fail if there are not enough willing and qualified workers to support the disabled and aging populations.

Action Steps

a. Enhance public perception of long-term care jobs and professionalize paraprofessional positions.

b. Promote flexibility of workplace employment policies and practices. Flexibility is important not only for older workers who may need to work longer than planned, but also for caregivers.

c. Develop career paths allowing for increases in responsibility, status and wages.

d. Create loan forgiveness programs for students graduating into professions where there is a shortage of workers, requiring employment within long-term care settings that have the greatest need.

e. Develop, coordinate and expand education and training programs targeted to areas of workforce shortages.

   - Attract students into the field with scholarships and grants. Education and training curricula should be considered beginning in high school.

   - Provide re-training for individuals who lose their job in such sectors as manufacturing and institutional care for new careers in long-term care, especially home and community-based care.

   - Expand efforts at collaboration among the Connecticut Department of Labor, the Workforce Investment Boards and the Older Workers program to address the needs of workers who have lost their jobs and need to be retrained in order to support themselves.

   - Promote distance learning as an option for workforce shortage areas.

   - Provide opportunities for college students seeking internships or community service. College students are often interested in a year of community service after college, but before entering the work world.

f. Inventory existing direct care workforce initiatives to identify duplication and gaps.

g. Review the current licensing certification statutes for formal caregivers to be sure that appropriate skills, training and roles are required as the system of formal caregiving evolves.

h. Engage Workforce Investment Boards to develop approaches to increase the size of the formal long-term care workforce, including training, education and incentives. The wage gaps, including benefits, between public and private frontline workers and across those workers who care for different populations should be addressed. Transportation issues must also be addressed.

i. Allow individuals to choose their own care-providers and increase flexibility in Connecticut's self-direction model to increase availability of workers and help to address the workforce shortage. (See Recommendation #5)

j. 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 must provide the necessary worker benefits and supports, including health insurance. Low cost opportunities for health insurance for PCAs should also be explored.

k. Support the creation and availability of PCA registries such as *rewardingwork.com*.

l. Recruit bilingual multicultural individuals to long-term care positions.

9. Provide support to 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. According to the Long-Term Care Needs Assessment, some researchers estimate the total economic value of informal caregiving at twice the public expenditures of formal home health care and nursing facility care combined. 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

a. Provide support for informal caregivers and family members in a variety of coordinated forms, such as information and training, respite services, tax benefits and incentives, payment to informal caregivers, transportation alternatives,

physical, occupational and speech therapy alternatives, and mental health and disability supports such as peer support, mobile crisis information, psychoeducation, disability education, wellness and recovery planning, and counseling. Assessment and periodic reassessments of the capabilities and needs of family caregivers should also be provided, especially when there may be specific caregiving challenges such as caring for individuals with dementia and Alzheimer's disease.

b. Increase availability of and access to respite and adult day programs statewide without age and specified disability restrictions. Inventory existing programs and coordinate easier access to respite services by individuals of all ages and disabilities. For example, replicate the Alzheimer's Respite Care program to provide respite services for any caregiver of individuals with disabilities of all ages. Such expanded respite care services would need to be flexible enough to accommodate any unique caregiving challenges for individuals with specific disabilities, such as Alzheimer's disease.

c. Explore the potential for supporting overnight respite care in settings other than institutions, such as evening or overnight adult day care. This should include consideration of licensing and Medicaid reimbursement issues.

d. 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.

e. Support partnerships across State agencies to share information on age and disease specific programming for caregivers and develop coordinated sources for caregivers to obtain information on available respite services, utilizing ADRCs.

f. Expand and support caregiver respite service options through the availability of flexible respite services, including respite services provided in an individual's or caregiver's home. (See Recommendation # 5)

g. Explore informal peer support training as a means to meeting needs without increasing the cost associated with licensed or other professional personnel.

QUALITY

10. Promote efforts to enhance quality of life in various settings.

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 can enjoy.

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 self-direction and control so that individuals can have a voice in how services and supports are provided to them.

Integral to quality of life is the ability to be a productive and welcomed member of the community. 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 with disabilities have gifts and assets to share with their communities.

Action Steps

a. Include a structure and process to ensure quality oversight throughout the system.

b. Develop improved quality measures for persons with long-term care needs in the community under person-centered, self-directed programs. Such measures must reflect the individuals' own preferences and desires and allow reasonable risks while still avoiding unreasonable risks. The individual's right to "Dignity of Risk" should be honored. An individual must be able to give "informed consent" to undertaking a risk that might otherwise be considered a compromise of quality of care.

c. Increase the quality of care in the various long-term care settings by including educational programs, identification of mechanisms that encourage longevity of employment, team building concepts and education of the public regarding the continuum of care. Include education about evidenced-based programs such as fall prevention, Gatekeeper Program, Healthy IDEAS (Identify Depression, Empowering Activities for Seniors), and Chronic Disease Self-Management.

d. Incorporate the needs of older adults and persons with disabilities in all state emergency planning.

e. Employ a state disability coordinator who can organize and coordinate emergency preparedness trainings with people with disabilities for fire responders, emergency medical technicians (EMT), police and community teams.

f. 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.

g. Utilize federal and state health promotion resources through adoption of Evidence-Based Programs.

h. Establish a working Fall Prevention partnership between the DSS Aging Services Division and the 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 older adults, fall prevention programs should be available to individuals of all ages.

i. In addition to family guardians and conservators, investigate establishing a public guardian/ conservator in Connecticut and require that all guardian/conservators be trained (www.guardianship.org).

j. Address the isolation and segregation of older adults and people with disabilities by emphasizing connection to natural supports and community as well as social and recreational opportunities. This should include strategies to link individuals with informal, non-paid networks. Support for transportation options to aid and encourage participation is also important.

11. Address the scope and quality of institutional care.

Although the majority of individuals responding to the Long-Term Care Needs Assessment expressed a preference to remain in their homes and live as independently as possible with homecare supports, there are those who prefer or need the care provided in a nursing facility or similar institution. Additionally, the Needs Assessment predicts that as a result of the aging of Connecticut's population, by the year 2030 the need for institutions will increase by 43 percent. If Connecticut is able to meet the Plan's goal of increasing the proportion of Medicaid long-term care clients receiving home and community-based care by one percent per year, demographic trends would still cause the need for nursing facility care to rise by 25 percent by the year 2030.[58]

Ensuring a vibrant long-term care system in Connecticut will mean developing incentives to encourage the redistribution, redesign or downsizing of public and private institutions and, at the same time, assuring that high quality care is provided at remaining institutions. As nursing facilities and institutions that serve adults and children with psychiatric and developmental disabilities close, or as occupancy levels are reduced, these reductions should be used as opportunities for real community

[58] Julie Robison, Ph.D. et al, *Connecticut Long-Term Care Needs Assessment, Executive Summary*, University of Connecticut Health Center, June 2007, page 5.

integration for older adults and persons with disabilities and should not be used to recreate institutions under another name.

Action Steps

a. Develop a plan to modernize the physical plants of existing nursing facilities when feasible and appropriate. Modernized and high quality skilled nursing facilities are needed as an available option for consumers of long-term care.

b. Explore the concept of the small nursing home and compare to the current nursing facility model in terms of reducing acute care hospital admissions, complications and declines in health and function and assessing overall costs.

c. As nursing facilities and other institutions close, or occupancy levels are reduced, Connecticut should continually conduct a needs analysis to: 1) determine if any of the beds are needed elsewhere in the system; and 2) de-license, reclassify, or hold in abeyance the remaining beds. Distinctions should be made between beds serving long-term care needs and beds serving post-acute rehabilitation needs. Data and analysis is needed to guide both providers and policy makers. As this occurs, there is an opportunity to redirect the appropriate level of resources to enhance home and community-based services and supports.

PROGRAM AND SERVICES

12. Provide a broader range of community-based choices for long-term care supports, foster flexibility in home care delivery, and promote independence, aging in place and other community solutions.

As Connecticut works to balance its long-term care system and improve access to a full range of long-term care services, from aging in place at home to residing in institutions, the amount and types of community-based choices will need to be sufficient to meet the demand. A comprehensive system of public and private services and supports address both physical and mental health needs across the lifespan without exclusion of specific populations. The demand for home and community-based services will only grow as the baby boomer generation ages and the number of older adults in need of long-term care increases over time. By the year 2011, baby boomers will begin to enter retirement age. Meeting these demands will require flexibility and creativity in our approaches to service delivery.

Action Steps

a. Develop increased flexibility in Connecticut's highly professionalized model of home care delivery without sacrificing quality of care and health and safety concerns. In the current model, both agencies and individual providers are

sometimes subject to extensive and inflexible licensing requirements and regulations.

- Reduce restrictions on who can provide home and community-based services to foster personal choice and independence, flexibility, aging in place, and the needs of caregivers. States such as Oregon and Washington can serve as useful models.

- Study, and implement where appropriate, scope of practice issues, such as delegation of specific tasks in specific settings, and use of lower cost alternatives (e.g. homemaker vs. home health care) while not compromising the quality of care.

- Review the current scope of practice definitions for the nursing professions, and develop options for refinement in order to promote flexibility.

- Consider allowing under Medicaid waivers and public funding an independent provider model in which providers are not required to work for an agency, a model that is more cost-effective and flexible. DDS currently employs such a model.

b. Provide incentives to existing, experienced providers to transition or expand their services to provide more community-based options.

c. Break down the barriers to community integration, such as the "not in my backyard" syndrome.

d. Expand the Veterans directed home and community-based program being developed and piloted in the south central region of the state through the DSS State Unit on Aging, Area Agency of South Central Connecticut and the Veterans Administration Connecticut Health Care System, West Haven Office. Enhance partnerships between the aging and disability networks and the Veterans Administration to better serve veterans of all ages and disabilities.

e. Enhance the availability of and access to community mental health services to support individuals at home. This includes improving access to Local Mental Health Authorities in addition to advocating for investment in the creation of a comprehensive system of community mental health services. Through collaboration with the Local Mental Health Authorities and other service providers, expand the capacity of the DMHAS Older Adult Services to educate the system about the aging process and develop services that meet the behavioral health needs of older adults, particularly services that provide interventions in homes and communities to promote aging in place over institutionalization.

f. Expand the number of slots, funding and case management in the various community-based State-funded and Medicaid waiver programs, including the

Connecticut Home Care Program for Elders, Connecticut Home Care Program for People with Disabilities, Personal Care Assistance, Acquired Brain Injury, Katie Becket, Mental Health Waiver, the DDS Comprehensive Supports Waiver and the DDS Individual and Family Support Waiver. Some of these programs have a waiting list and this impedes the ability of persons with disabilities from transitioning into or remaining in the community.

g. 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 (CHCPE). 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 CHCPE rules, Connecticut should also examine the feasibility of utilizing similar income requirements under its other Medicaid home and community-based services waiver programs, resulting in equal access to home and community-based care and nursing facility care for individuals of all ages and disabilities.

h. 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 State and federal programs such as Section 8 housing vouchers, allowing more aggressive development of community living options.

i. Enhance rates and grants to home and community-based service providers in order to develop and maintain an adequate network of services.

j. Allow reimbursement for adult day care for residents of subsidized assisted living facilities.

k. Enhance interagency efforts to offer community-based service options to dually diagnosed individuals.

l. Explore Aging in Place models of community living, such as the Beacon Hill Village in Massachusetts (www.beaconhillvillage.org), that are designed to enable people to stay in their neighborhoods as they age, by organizing and delivering programs and services that allow them to lead safe, healthy productive lives in their own homes.

13. Increase availability of readily accessible, affordable and inclusive transportation.

In order to facilitate true choice in care and support alternatives, there is a need to improve transportation options at the state and local levels for persons who require additional assistance due to disability or other declines in physical or mental functioning. Individuals with decreased driving capabilities report the lack of transportation alternatives as the principle reason they continue to drive.

Action Steps

a. Increase the availability and affordability of transportation options available to aging individuals and those with disabilities that provide transport not only for medically-related purposes, but also employment, social and recreational activities through utilization of models such as the Independent Transportation Network (ITN - http://itnamerica.org), expansion of the Municipal Matching Grant program funded through DOT, and volunteer programs such as Interfaith Caregivers and RSVP.

b. Encourage municipalities to work together to form regional plans that meet local and regional needs.

c. Consider the formation of a broadly representative task force, led by a state-wide liaison from DOT, to fully investigate alternative approaches and resource needs to improve transportation options. Coordinate with the Medicaid Infrastructure Grant (Connect-Ability) team which has identified transportation as a priority area.

d. Give priority to the availability of public transportation resources whenever new housing resources are being developed for individuals with disabilities or the general public.

e. Provide transportation options beyond the limitations of the existing Medicaid medical transportation contracts to participants of Medicaid home and community-based services waiver programs. A recurring problem is the lack of same day transportation to unanticipated medical appointments. Another obstacle is that social service provider organizations willing to provide transportation to their customers receive no specific reimbursement for this expense.

f. Persons with disabilities who want to access public transportation may not be able to get to and from the public transportation lines. Explore solutions to this barrier to transportation, such as reconfiguring vans funded under the federal Capital Assistance Program for Elderly Persons and Persons with Disabilities (Section 5310C) into a feeder-system so these vans can take people with disabilities to and from public transportation lines. Also address the need for para-transit services in rural areas due to the limited availability of public transportation.

g. Provide adequate funding for the Dial-a-Ride Program (municipal match for demand-responsive transportation).

h. Enhance sidewalks, cross-signals, crosswalks, and curb cuts to ensure pedestrian access.

14. Preserve and expand affordable and accessible housing for older adults and individuals with disabilities.

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 long-term care needs. Many people with long-term care needs remain in public institutions or nursing facilities or in housing that consumes the greater portion of their income. Finding a home can be twice as difficult for people with long-term care needs because it must be physically and financially accessible. Although significant progress has been made in making public buildings accessible, the same is not true for residential housing.

Action Steps

a. Promote universal design and "Visit-ability" in new building projects and with architects and housing developers. Require Visit-ability standards as part of tax credits to builders for affordable housing.

b. Increase outreach to landlords and homeowners about resources and financing to make their units and homes accessible.

c. Provide funding for home modifications that would either allow individuals to remain in their own homes or return to their own home following institutionalization.

d. Encourage all State agencies, cities, and towns to update their ADA Transition Plans to ensure that necessary accessibility modifications are made when rehabilitating or updating public facilities, including public housing, or their programs, policies, and services.

e. Preserve and expand the stock of affordable housing and link residents with existing community-based services. Explore a range of different housing options to maximize the number of units available with supports, including Supportive Housing, with an emphasis on truly integrated community housing. Make alternative low income housing and rental assistance available for older adults and people with disabilities. Models of community living used by DDS, generally no larger than one to four people per single dwelling, should serve as a model of true community integration.

f. Increase the utilization of housing vouchers in communities throughout Connecticut so additional vouchers may be requested from HUD.

g. Over the next biennium, support the efforts of DECD regarding the *CTHousingSearch.org* website to identify accessible units and increase their utilization. Ensure that all State agencies that construct or rehabilitate housing or provide rental assistance, report the accessible units to the website.

h. Ensure that persons with disabilities and older adults are accessing foreclosure assistance programs when needed including special assistance if forced to move.

i. Expand affordable assisted living options. Strategies could include making assisted living available to individuals under the age of 55 and combining HUD and other housing programs to cover housing costs for those whose assisted living services are covered by Medicaid. Direct systematic attention toward expanding available slots in pilot programs for assisted living and other supportive community-based residence settings, and making these programs permanent. Remove obstacles in state laws that prevent full maximization of federal funds under the Assisted Living Conversion Program.

j. 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 people with disabilities.

k. 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.

l. Develop new housing alternatives for persons with persistent mental illness who do not need nursing facility level of care. Consider Supportive Housing as one strategy to pursue.

m. Raise public awareness about reverse mortgage options.

15. Support programs that divert or transition individuals from nursing facilities or other institutions.

The Connecticut Long-Term Care Needs Assessment indicates that most individuals prefer living in their own home, with supports if necessary. Connecticut should strive to allow this to be the rule rather than the exception by maximizing choice supporting stability and recovery, and promoting community integration and independent living opportunities for all older adults and persons with disabilities through a

comprehensive community-based system. For individuals at risk of admission to a nursing facility or institution that serves people with psychiatric or developmental disabilities, and for those residing in these institutions that prefer to live in the community, diversion and transition strategies are a critical component for maximizing opportunities for individual choice and rebalancing the long-term care system.

Action Steps

a. Support current nursing facility diversion and transition programs, such as Money Follows the Person (MFP), the home and community-based Medicaid waiver programs, the Pre-Admission Screening Resident Review (PASRR), Aging and Disability Resource Centers (ADRCs), cash and counseling options under existing respite programs, and the DMHAS Nursing Home Diversion and Transition Program.

b. Identify individuals at risk of institutionalization, including people determined to be ineligible for Medicaid, and develop a long-term care service system that is able to sustain community living and significantly delay or avoid institutionalization.

- Establish and fund ADRCs statewide. (See Recommendation #7)

- Refer identified individuals who are at risk of spend-down to Medicaid and at risk of institutionalization to the ADRC for comprehensive long-term care needs assessments so that a home and community-based services plan can be developed.

- Emphasize diversion at the point of hospital admission and discharge. Information on the availability of community services and Medicaid home and community-based waivers should be provided to discharge nurses and updated periodically.

- For people residing in institutions, provide additional transition discussions after three months, six months and annually thereafter. Discharge planning should be an active part of every person's plan of care.

- Support and expand the DMHAS Nursing Home Diversion and Transition program to avoid continued institutionalization of individuals with mental illness at the point of hospital discharge.

- Expand the number of Medicaid eligibility service workers stationed at ADRCs, hospitals, community health centers and local mental health authorities to expedite the Medicaid eligibility screening process.

- Simplify the Medicaid application process and develop a web-based on-line application system, making both a paper-based and computer based application process equally available. Also, develop and implement an expedited eligibility process for state programs that support services in the community such as the Connecticut Home Care Program for Elders (CHCPE) and other Medicaid home and community-based services waiver programs. (See Recommendation #2)

- Support and promote the availability and development of adequate housing such as Supportive Housing, services and in-home respite in efforts to divert people from initial institutionalization.

16. Expand and improve employment opportunities and vocational rehabilitation for persons with disabilities and older adults.

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 balancing effort within a long-term care system.

The Connect-Ability initiative is designed to strengthen the employment infrastructure for job seekers with disabilities. Funded through the Centers for Medicare and Medicaid Services (CMS), Connect-Ability has created a technical assistance center designed to meet the needs of job seekers with disabilities, employers, State agencies, and other interested stakeholders throughout Connecticut. A comprehensive website and a toll free number provide a single point of entry to a multi-faceted system, and the Connect-Ability staff help navigate this system.

Many older adults are redefining retirement; many need or want to work, but often on a reduced or alternative work schedule. Private companies who have offered flexible schedules for their workers have seen lower turnover, less use of sick leave, increased employee productivity and improved morale, and significant cost savings.

Action Steps

a. Increase expectations and opportunities for people with disabilities in achieving career potential. Educate the public and professionals about career potential for persons with disabilities.

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

c. Increase the recruitment, employment and retention of individuals with disabilities and older adults into Connecticut businesses.

d. Increase access to transportation to and from work for individuals with disabilities and older adults. (See Recommendation #13)

e. Create a statewide technical assistance center for job seekers with disabilities and employers.

f. State government, as the largest employer in Connecticut should adopt older worker friendly initiatives that provide flexibility for workers, while ensuring that their work is completed on time and with high quality. Options include: voluntary schedule reductions, flexible work hours, phased-in retirement programs and telecommuting options.

VI. CONCLUSIONS

Over the next 15 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. There are no guarantees. However, we do know that Connecticut residents want a system that maximizes the opportunity for all persons, regardless of age or disability, to live in the community as independently as possible. We also know 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 balance 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.