University of Connecticut
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Connecticut Long-Term Care Needs Assessment

Executive Summary

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I. Background

Long-term care services and supports are needed to help people who require assistance over an extended period due to disability or chronic illness. Their needs may include 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 (LTC) needs are being met at home, in the community, in congregate residences and in institutional settings. Most individuals will be recipients of long-term care services at some point.

Connecticut and other states are increasingly confronted with burgeoning Medicaid expenditures, looming demand for long-term care services associated with demographic trends, and growing movements to enhance consumer choice and control. Yet policymakers often lack timely state-specific data to inform planning efforts.

A. Authorization and Funding

To ensure that such data are available for the state's long-term care planning, legislative and other policymaking activities, the Connecticut General Assembly in its 2006 session authorized and funded a comprehensive statewide Long-Term Care Needs Assessment (the "Needs Assessment") - the first in over twenty years (Public Act 06-188, Section 38).

The General Assembly appropriated $200,000 for the project, and subsequent supplementary funding of $80,000 was provided by the Connecticut Long-Term Care Ombudsman Program (LTCOP). The contribution by the LTCOP was earmarked for additional analysis and recommendations to facilitate quality of life for people residing in nursing homes, assisted living and residential care homes.

B. Selection of Researcher and Contract Award

In consultation with the Long-Term Care Advisory Council, the Long-Term Care Planning Committee, and the Connecticut Commission on Aging, the General Assembly selected the University of Connecticut Health Center's Center on Aging to conduct the Needs Assessment. Researchers at the Center on Aging have been awarded numerous related grants, are highly credentialed, and have extensive expertise in the field of aging, persons with disabilities, and long-term care.

C. Project Design and Implementation

The team of researchers from the University of Connecticut Health Center's Center on Aging, led by Dr. Julie Robison and Dr. Cynthia Gruman, co-Principal Investigators, oversaw the design and implementation of the project. In addition to carrying out a comprehensive literature review on both Connecticut-specific and national data, Center on Aging staff conducted statewide mail, telephone and in-person surveys of both Connecticut residents and providers of long-term care services.

Project staff also conducted a full review of Connecticut's existing array of services and long-term care system rebalancing efforts. Rebalancing may be defined as achieving a more equitable balance between the proportion of public expenditures used for institutional services (e.g., nursing facilities and intermediate care facilities for the mentally retarded [ICF/MRs]) and that used for home and community-based services (HCBS). HCBS provide support to people with long-term care needs in their homes and communities.

In order to help identify structural strengths, weaknesses and gaps in the current system, and to compare Connecticut's rebalancing progress to that of other states, the research team hired as consultants Dr. Robert Kane and Dr. Rosalie Kane from the University of Minnesota. The Kanes are national experts in

the field of aging and long-term care. Between them, they have devoted 60 years to the study of aging, written scores of books and hundreds of journal articles about long-term care. For the last three years they have been directors of an in-depth study of long-term care rebalancing in eight states that was funded by the Centers for Medicare and Medicaid Services (CMS).

D. Timeline

The Needs Assessment is a multi-pronged study whose results are presented in several reports. This Executive Summary is a compilation of the results, conclusions and recommendations contained in Part I: Survey Results and Part II: Rebalancing Report, described below. These reports and the others that comprise the entire Needs Assessment are noted below, with anticipated release dates:

Connecticut Long-Term Care Needs Assessment Part I: Survey Results: *June 2007*

- Literature review
- Resident survey results
- Provider survey results
- Conclusions from survey results

Connecticut Long-Term Care Needs Assessment Part II: Rebalancing Report and Recommendations: *June 2007*

- Context for rebalancing
- System assessment
- Featured management approaches
- Connecticut in a national context
- Conclusions from rebalancing study
- Recommendations based on survey results and rebalancing study

Long- Term Care Ombudsman Report: *Summer 2007*

Financial Planning Assessment: *Summer 2007*

Follow-up In-depth Studies: *Periodic releases of issue briefs during 2007 and 2008*

- Study of long-term care services and need in Connecticut by region
- Detailed results of the survey of people with disabilities
- Study of needs, plans, and current services use for people with mental health disabilities
- Other issue briefs as requested, pending additional legislative funding

The Needs Assessment has produced a rich trove of data that can be mined for further specialized studies as needed. The researchers welcome the opportunity for discussion with legislators, policymakers and other stakeholders with specific questions on any topic covered.

II. Needs Assessment: Major Components

A. Literature Review

The review features national and state-specific data and trends as well as a comprehensive inventory of long-term care services and supports. It provides an overview of the delivery system in Connecticut today including who needs long-term care, who provides it, and the settings in which it is delivered. It also examines current public and private contributions to long-term care expenditures. This Executive Summary does not include references; a full list of references can be found in the Connecticut Long-Term Care Needs Assessment Part I: Survey Results.

B. Resident Survey Results

A key element of the Needs Assessment was the gathering of relevant information directly from Connecticut residents. This information included residents' current and future plans, what community-based services they now use, any unmet service needs, how prepared residents are to obtain these services, their preferences and expectations for care, care they provide to family members, and physical and mental health status.

Methodology: The primary method of data collection was a self-administered, written survey mailed directly to a random sample of 15,500 Connecticut residents. The survey was available in both English and Spanish. In order to raise awareness and provide opportunity for additional input from residents across the state, the random survey booklet was augmented by telephone interviews, survey packets distributed to numerous organizations, and a web-based survey. A widespread publicity campaign was conducted, including television appearances, radio interviews, newspaper articles, postings on various web sites, broadcast emails, announcements at multiple events across the state, and word of mouth. In addition, the survey was made available on the University of Connecticut Health Center website.

Response Rate: A total of 6,268 surveys were completed: 5,059 by mail, 34 by phone, and 1,175 online. Response rates from the random surveys were as follows:

	Surveys mailed	Response rate
Older adults (born before 1946)	5,250	34%
Baby boomers (born 1946 to 1964)	5,250	24%
People with disabilities from Medicaid waivers or other state funded programs	5,000	28%

This resulted in 4,700 general surveys and 1,568 surveys from people with disabilities. Seventy of these surveys were completed in Spanish. The number of returned surveys provides a large sample for reliable analysis that can be generalized to the population of Connecticut residents aged 42 and over.

C. Provider Survey Results

Long-term care is provided both by unpaid family members or friends and by professionals in multiple fields. The caregiving perspective of family and friends was gathered as part of the resident survey. Another critical component of a comprehensive needs assessment is the perspective and experience of the professional provider community. The purpose of the provider survey was to characterize the current organization, financing, and delivery of professional long-term care services in the state.

Methodology: A total of 1,211 surveys were mailed to provider and service organizations that provide long-term care services and supports to the state's older adults and residents with disabilities. The sample included a broad mix of both public and private organizations. Fourteen service type categories were designated: home health agency, homemaker agency, assisted living, managed residential care, nursing home, residential care home, hospice, chronic disease hospital, senior center, adult day program, Area Agencies on Aging, Bureau of Rehabilitation Services providers, Department of Mental Retardation providers, and Department of Mental Health and Addiction Services providers. A total of 500 providers responded to the survey for an overall response rate of 46 percent.

D. Progress Toward Rebalancing the Long-Term Care System in Connecticut and Recommendations

Connecticut is interested in shifting its long-term care utilization and expenditures towards community care and developing techniques that facilitate managing a system that is largely oriented away from institutions while assuring quality in all components of the system. The UConn Health Center research

team, in partnership with Drs. Robert and Rosalie Kane, guided a key informant interview process to assist in analyzing Connecticut's rebalancing progress. The team conducted interviews with 43 individuals with experience and knowledge about the Connecticut long-term care system. The group included providers, advocates, policy makers, family members, consumers, and state agency heads. The team also conducted an in-depth programmatic and financial analysis of Connecticut's institutional and home-based care options, and trends in rebalancing.

III. Who Uses Long-Term Care ...Today and Tomorrow?

A. Today: Current Users of Long-Term Care

The population using long-term care services is diverse in age, gender, type and degree of disability. Risk factors for long-term care include functional and cognitive impairment, mental illness, challenging behaviors, chronic disease and falls. They also include various socioeconomic factors associated with poorer health and limited access to health care as well as living alone and problems with transportation. There are vast differences in the reasons for disabilities, the age at which they begin, the speed of progression, and the degree of activity limitation that may result; they may be sensory, cognitive, physical, or emotional, and may be observable or unseen. Individuals using long-term care include persons with dementia, intellectual disability, and mental illness. People with behavioral symptoms of underlying impairment, chronic conditions, and children with disabilities also need long-term care services and supports.

Although estimates differ somewhat, between 10 and 15 million Americans currently need long-term care services and supports. In Connecticut, an estimated 13 percent (402,369) of people age 5 and older reported a disability according to the U.S. Census Bureau's 2005 American Community Survey. Disability rates increase with age from six percent of people 5 to 20 years old, to 10 percent of people 21 to 64 years old, and to 35 percent of those 65 and older. Disability rates among Connecticut's population age 65 and older include those with a disability in one or more of the following areas: physical (26%), mobility (15%), sensory (14%), cognitive/mental (9%), and self-care (8%). Thirty-five percent of people over age 65 have one or more of the five disabilities listed and 7 percent have cognitive/mental disability or any other disability.

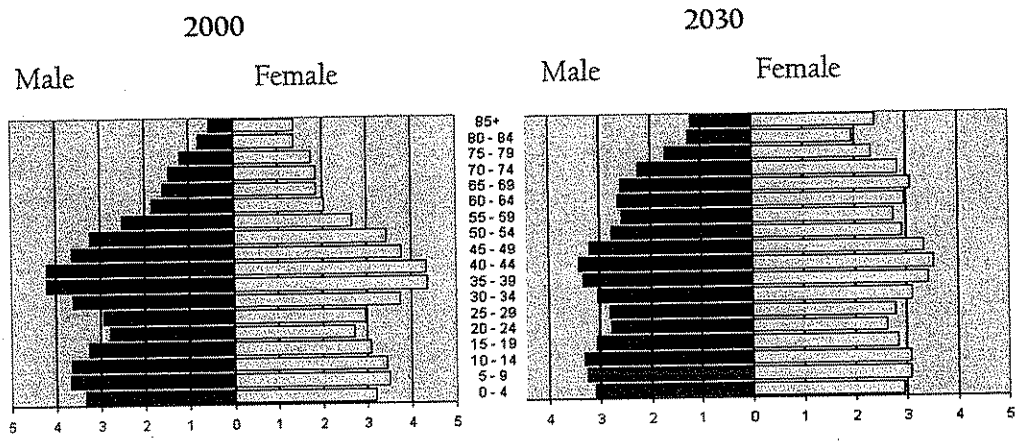
Accordingly, services and accommodations must be designed to meet the needs of people with a range of physical and mental disabilities. Attention must also be directed to addressing the needs and preferences of an increasingly racially and ethnically diverse population.

B. Tomorrow: Changing Demographics → Growing Demand

Many factors will affect future demand for various long-term care services. Life expectancy is increasing, which could lead to more age-related disabilities. On the other hand, people are living healthier lives at older ages. Medical science continues to seek treatment for many causes of age-related and other disabilities. A significant breakthrough in the prevention or treatment of Alzheimer's disease, for example, could dramatically decrease the need for many long-term care services. The advent of a previously unknown disease, such as AIDS, could have the opposite effect. Moreover, the trend toward rebalancing institutional and home and community-based services will create greater demand for community services even without the expected population growth.

It is possible, however, to project future demand based on current use and population growth estimates. Demographic trends indicate the proportion of the American population 65 and older is increasing and will continue to grow as the baby boomers begin to reach age 65 in 2011. The population age 85 and older will increase to more than three times its current size by 2040. U.S. Census Bureau population pyramids for Connecticut illustrate the shifting pattern in Figure 1.

Figure 1. Percentage of Total Connecticut Population by Age in 2000 and 2030



The strong association between older age, chronic illness, disability, and greater use of long-term care services will cause the demand for long-term care services to rise significantly in the coming years. Government estimates suggest that the number of persons needing paid long-term care services in the U.S., whether in a nursing home, other residential facility, or at home, could substantially double from 15 million in 2000 to 27 million by 2050. This pattern holds true for Connecticut as well, with major growth occurring for the 85+ population.

Needs assessment survey respondents, particularly persons with disabilities, report high rates of both current use and unmet need for long-term care services. Projections of future demand for long-term care services based on population growth indicate that total demand for ages 40+ will increase by nearly 30 percent by 2030, with far higher percentage increases among the older age groups.

Table 1. Growth in Total Demand for Long-Term Care Services Ages 40+ 2006 to 2030

Age	2006 Current LTC Demand	2006 CT Population	2006 Current LTC Demand	2030 CT Population	2030 Projected LTC Demand	Percent increase 2006-2030
40-59	7%	1,052,235	73,656	901,639	63,115	(14)
60-74	10%	393,560	39,356	602,154	60,215	53
75-84	22%	176,194	38,763	266,521	58,635	51
85+	44%	82,399	36,256	132,440	58,274	61
		1,704,388	188,031	1,902,754	240,238	28

Moreover, future need for nursing facility care, assuming no progress in rebalancing, would rise by 43 percent during the same time period. If Connecticut is able to meet the goal of the state's Long-Term Care Plan to achieve rebalancing of 1 percent per year, demographic trends would still cause the need for nursing facility care to rise by 25 percent by the year 2030.

Table 2. Need for Nursing Facility Care in Connecticut 2006 – 2030*

Age group	NF 2006 current population	With current HCBS/institutional ratio		Applying LTC Plan goal of 1% yearly rebalancing	
		NF 2030 population	NF percent pop. change 2006-2030	NF 2030 population	NF percent pop. change 2006-2030
<65	3178	2737	(14)	2117	(33)
65 - 74	3088	5151	67	4549	47
75 - 84	8062	11,501	43	9881	23
85+	13,361	20,246	51	17,641	32
	27,689	39,635	43	34,188	25

*NOTE: This table takes into account the current 0.4% yearly decrease in NF population.

IV. Who Provides Long-Term Care Services and Supports?

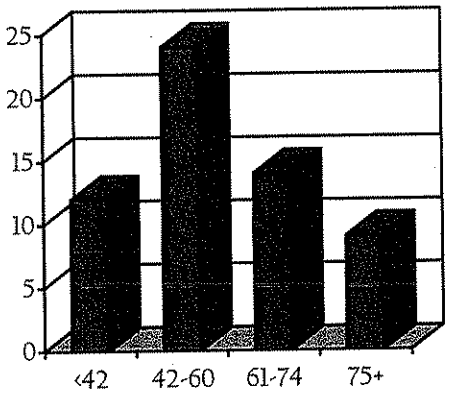
A. Families / Informal Caregivers

Informal caregivers are family and friends who provide care without pay, and are the primary source of long-term care. There are an estimated 44 million informal caregivers in the United States. The importance of unpaid care provided by family and friends cannot be overemphasized, as it constitutes the backbone of the long-term care system. The total estimated annual economic value of unpaid care to people with disabilities age 18 and older in 2004 was $306 billion. This figure exceeds public expenditures for formal home health care ($43 billion in 2004) and nursing home care ($115 billion in 2004).

Although family caregivers can be spouses, adult children, or other family and friends, the most common caregiver is female, 46 years old, has some college education, works outside the home, and provides about 20 hours of care weekly to her mother. Twenty percent of informal care is provided to other family members such as grandparents and siblings, and 24 percent of care is given to friends and neighbors. An increasing number of informal long-term caregivers are over 65 themselves, and are being challenged by caring for a relative 85 or older, a grandchild, or an adult child with disabilities.

Seventeen percent of all Needs Assessment survey respondents report that they provide unpaid care for a relative or friend who lives in Connecticut. Of those who do, 57 percent care for a parent and 31 percent care for a spouse, a child with a disability, or other relative who needs assistance. Over 80 percent of care recipients are age 65 or older, with 39 percent age 85 or older. Almost a third of care recipients have moderate or severe memory problems. Thirty-six percent of respondents report that their care recipient is not getting enough of such services as home health, homemaker services, transportation, adult day services, and care management. The age breakdown of caregivers and top reasons for unmet service needs are indicated in Figure 2 below.

Figure 2. Percent Informal Caregiving in CT by Age



36% had unmet service needs

Reasons:
44% could not afford
32% did not know what was available
21% unreliable/poor service

B. Formal Caregivers

Formal caregivers, defined as paid direct providers of long-term care services in a home, community-based or institutional setting, constitute a large and growing percentage of the workforce, both nationally and in Connecticut. Currently, the most significant factor affecting demand for paid long-term care services is the aging baby boomer generation. By 2050, as many as 27 million persons may need care by formal caregivers. Although many formal caregiver occupations are among the fastest growing in the country, the demand for such workers is growing at a faster rate than the supply.

The Connecticut Labor Department published 2004 data on the numbers of people in various long-term care-related occupations, and projected the numbers of people who will be needed to fill those jobs in 2014 (including both new jobs created and replacements for people leaving the workforce). All of the long-term care occupations will see growth between 2004 and 2014, as shown in Table 3. Efforts to rebalance the institutional bias of the current long-term care system will ideally lead to a greater percentage of people receiving long-term care at home. The impact of this shift on the paid caregiver workforce in Connecticut is reflected in a predicted 25 percent increase in home health aide positions and a 28 percent rise in personal and home care aide positions. These somewhat conservative estimates fall noticeably below the national predictions of greater than 50 percent job growth in these professions.

The emerging gap between the supply of long-term care workers and the needs of older adults and people with disabilities for their services has enormous implications for workforce development and public policy. Concerns related to the long-term care workforce include: low wages, poor benefits, lack of status, unattractive working conditions, recruitment and retention. In order to fill the growing need for long-term care workers in the coming years, employers and policy makers will need to find ways to overcome the field's negative image, retain current workers and attract new ones.

Table 3. Connecticut 2004 and Projected 2014 Selected LTC Occupations

Long-term Care Occupations	2004	2014	Net Change	Percent Change	Total Annual Openings
Home Health Aides	10,240	12,760	2,520	25%	386
Personal and Home Care Aides	5,840	7,480	1,640	28%	258
Personal Care & Service Workers, All Other	680	730	50	7%	20
Nursing Aides, Orderlies, and Attendants	24,410	26,560	2,150	9%	535
Registered Nurses	31,890	36,020	4,130	13%	1,081
Licensed Practical & Licensed Vocational Nurses	7,880	9,100	1,220	16%	294
Physical Therapists	3,120	3,920	800	26%	111
Occupational Therapists	1,550	1,850	300	19%	51
Rehabilitation Counselors	4,080	4,790	710	17%	165
Substance Abuse & Behavioral Disorder Counselors	1,130	1,380	250	22%	51
Mental Health Counselors	1,890	2,390	500	27%	93
Psychiatrists	570	620	50	9%	13
Psychiatric Aides	540	620	80	15%	15
Respiratory Therapists	1,230	1,400	170	14%	58
Mental Health & Substance Abuse Social Workers	2,490	3,010	520	21%	95
Medical and Public Health Social Workers	2,120	2,620	500	24%	86
Social and Human Service Assistants	7,890	9,330	1,440	18%	283

V. Where is Long-Term Care Provided?

Long-term care is provided across an array of highly diverse settings, ranging from private homes to supportive environments in the community, to various institutional settings. In addition, long-term care is provided to persons who live in prisons and homeless shelters. Institutional settings include nursing homes or skilled nursing facilities, intermediate care facilities for the mentally retarded, psychiatric hospitals, and chronic disease hospitals.

A. Home and Community

Home and community care includes a variety of services to individuals and families in their homes or other community settings aimed at increasing independence and decreasing the effects of disability or chronic illness. Community settings can include not only private homes, but also adult day and assisted living facilities, residential care homes, continuing care retirement communities, small group homes, local mental health authorities, and congregate housing.

Typically, people needing long-term care who live in the community depend on a combination of informal and formal care to meet their needs. Medicaid is a primary payer of formal long-term care services, but has historically covered more people with institutional care than with home and community care. Rebalancing efforts in Connecticut and other states have been shifting this balance, with increasing numbers of people covered by home and community services.

The Connecticut Home Care Program for Elders (CHCPE) is a major example of attempts to increase the number of people receiving home and community-based care, and decrease the number receiving institutional care. CHCPE is a nursing home diversion program, and eligibility is based on financial and functional criteria. It includes both a Medicaid waiver program that makes home care services available to Medicaid-eligible individuals, and state-funded home care services for individuals at slightly higher

asset limits. Its major drawback is its limitation to people age 65 and older. A younger person with Alzheimer's, multiple sclerosis, or other condition requiring long-term care would not be eligible.

In state fiscal year 2006 (SFY06) for the first time, more than half (51%) of Connecticut Medicaid long-term care clients received home and community-based care (see Table 4). Their eligibility for home and community services stems from their participation in the CHCPE and other Medicaid waiver programs, which are described in more detail in Section VII.

B. Institutions

In SFY06, 49 percent of Connecticut Medicaid long-term care clients resided in institutions. The vast majority were in nursing facilities, with smaller numbers in ICF/MRs and chronic disease hospitals (see Table 4).

Table 4. Proportion of CT Medicaid LTC Clients: Monthly Average SFY 2003 and 2006

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

Source: Connecticut Office of Policy and Management. Long-term care beds in the state psychiatric hospital are not included. In SFY 2006, this number comprises both the Comprehensive Waiver for Mental Retardation (4,890) and the Individual/Family Support Waiver for Mental Retardation (2,383).

VI. How is Long-Term Care Being Transformed Across the Country?

Increasing attention is being devoted to enhancing consumer choice and self-direction in long-term care, encouraged by a number of national movements including the disability rights movement, the nursing home culture change movement, the growing strength of advocacy groups and self-advocacy, and the aging of consumer-oriented baby boomers.

The New Freedom Initiative (NFI) was announced by President Bush on February 1, 2001, followed up by the Executive Order 13217 on June 18, 2001. The NFI is a nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illnesses. It represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life.

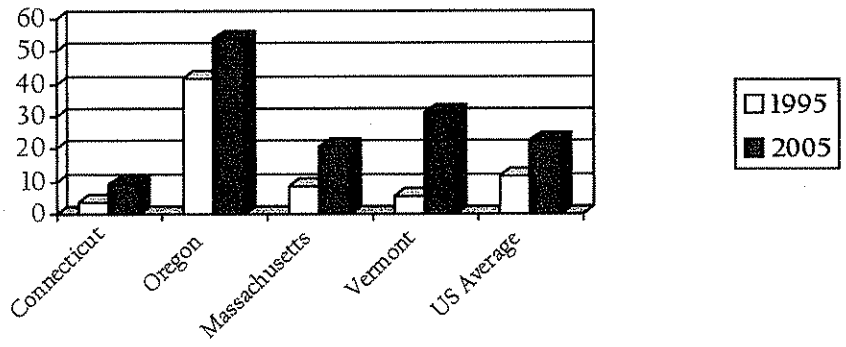
There is also increasing interest in efforts to bring about a culture change in long-term care that emphasizes a home-like environment and person-directed care. One recent example of culture change is the Green House model. Green Houses differ from assisted living facilities and nursing homes in facility size, architectural design, patterns of staffing, and the way services are delivered. These self-contained residences are designed like a private home for seven to ten people, with each person having his or her own bedroom and full bathroom.

Connecticut's residents echoed these preferences throughout this assessment process. Independence, choice, and control are key factors for Connecticut residents, especially when using any type of long-term care services. For example, most respondents would like to work jointly with an agency in managing their community-based services, while over one-quarter expressed a desire for self-directed care independent of an agency.

VII. What is Connecticut Doing to Rebalance?

In Connecticut, efforts to rebalance the system are progressing, though more slowly than in some of the leading states.

Figure 3. Percent Increase in Medicaid Spending for Home and Community-Based Services



The proportion of Medicaid long-term care expenses for home and community-based services increased from 23 percent in 1996 to 32 percent in 2006. However, much of that increase occurred in the late 1990s; since 2002, there has been almost no change.

This increase in the proportion of home and community-based services is in part a result of efforts to reduce nursing home use by limiting nursing home care through pre-admission screening, a moratorium on new nursing home beds, and constraints on the growth in Medicaid payments with simultaneous

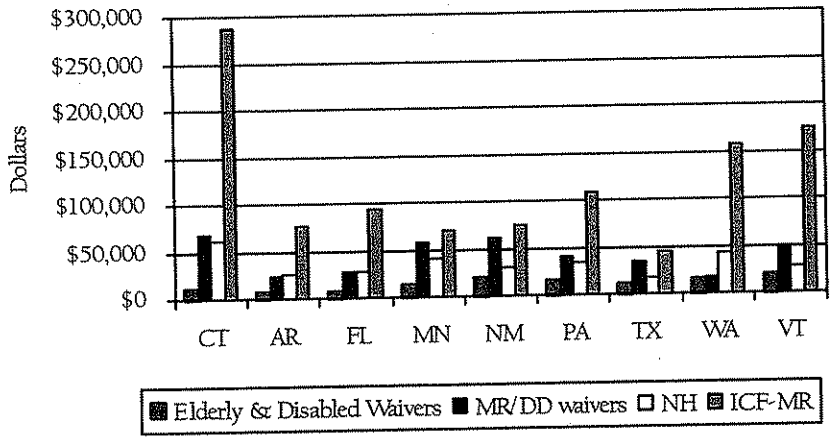
expansion of home care through Medicaid. The expansion of HCBS in Connecticut has occurred primarily through several small pilot programs and Medicaid home and community-based waivers explained in more detail in Section VII (A) below. These include the CHCPE, the Personal Assistance Waiver (PCA), the Acquired Brain Injury Waiver (ABI), the Katie Beckett Waiver, and two waivers for individuals with intellectual disabilities that are managed by the Department of Mental Retardation. Also in process are waivers to support individuals with HIV/AIDS and serious psychiatric disabilities. Connecticut has also received eight federal grants since 2000, aimed at improving the long-term care system.[1] The majority of these grants are CMS systems change grants.

While Connecticut has made some progress in rebalancing, it ranks in the middle among the states for rebalancing expenditures. In a FY 2005 ranking of the states, Connecticut ranked 26th with only about a third of its total Medicaid long-term care expenditures spent on community-based services, very close to the U.S. average. Top-ranked Oregon spent 70 percent of its Medicaid long-term care dollars on community-based services. Nevertheless, Connecticut is an expensive state for long-term care, spending more per capita than most states in many areas. For example, in 2005 Connecticut ranked high in per capita expenditures in the following areas:

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

Connecticut's per capita expenditures in various waivers and institutions can be compared to that in eight other states that have recently undergone a CMS-funded comprehensive review of their rebalancing efforts (see Figure 4).

Figure 4. State Comparisons of Costs per Client Served, 2005



Connecticut has allowed nursing homes and ICF/MRs to close through attrition and has a moratorium on any new nursing facility beds. The nursing home population in Connecticut has decreased by 641 residents between 2003 and 2006, and the ICF/MR population has decreased by two people in the same time period. At the same time, several of the Medicaid waivers have waiting lists. Other states have

[1] The grants include: Medicaid Infrastructure Grant (2000), Nursing Facility Transitions to Independent Living Grant (2001), Real Choice Systems Change Grant (2002), Independence Plus Waiver Initiative (2003), Quality Assurance and Improvement in Home and Community-based Services (2003), Community-Integrated Personal Assistance Services and Supports (2003), Mental Health Transformation State Incentive Grant (2005), and Money Follows the Person Rebalancing Demonstration (2007).

taken a much more proactive approach to remove institutional beds and close facilities, and thus have significantly decreased the numbers of residents in long-term care institutions. However, reducing the number of institutional beds is only part of the equation, especially given the future increase in the number of people needing long-term assistance. This approach only works well if money saved through nursing home bed reduction is reinvested into home and community-based services, and the state commits to expanding community options. While Connecticut is clearly moving in the right direction in its rebalancing efforts, many other states are moving faster.

A. What are the Major Home and Community-Based Services and Supports in Connecticut?

Connecticut's HCBS system is fragmented, with many programs, pilots and waivers. The six Medicaid waiver programs are summarized in Table 5.

Table 5. Connecticut's Medicaid Home and Community-Based Service Waivers as of April 2007

CT Home Care Program for Elders

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

Personal Care Assistance Waiver

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

Acquired Brain Injury Waiver

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

Katie Beckett Model Waiver

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

DMR Individual/Family Support Waiver

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

DMR Comprehensive Waiver

Participants:	Serves 4,370 individuals with intellectual disabilities. (Current waiting list because budget cap reached.)
Settings:	Personal residences, community living arrangement, community training home, assisted living
Services:	Supported living, personal support, individual habilitation, adult companion, respite care, personal emergency response, home and vehicle modifications, supported employment, group day programs, individual day programs, behavior/nutritional consultation, specialized equipment and supplies, transportation, family consultation/support, individual consultation/ support

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

B. Who Pays for Long-Term Care and How Much?

There are two broad sources of financing for long-term care: public programs and personal resources. Public funding sources include the Medicaid and Medicare programs, programs administered through the Older Americans Act, and state-funded programs. Personal resources include informal care donated by family and friends, out-of-pocket spending and private insurance. Although clearly significant, the financial contribution of informal care providers is difficult to calculate and is not typically included in expenditure estimates. Without including the cost of informal care, in 2004, approximately 23 percent of long-term care costs were paid out-of-pocket by individuals, 9 percent were paid by private insurance, 42 percent by Medicaid, 20 percent by Medicare, and 3 percent from other public sources.

- Medicaid is the primary payer of LTC nationally and in Connecticut.
- In Connecticut, in SFY 2006, Medicaid expenses for long-term care comprised approximately 14 percent of total state expenditures or 2.23 billion. Of that total, 32 percent was spent on HCBS, representing 51% of LTC clients, and 68 percent on institutional care, representing 49% of LTC clients.
- Historically, Medicaid did not pay for long-term care in the community except by waiver, hence it is "institutionally biased".
- Medicare does not generally pay for long-term care, with minor exceptions - it will pay for 100 days post-hospital discharge in a nursing home and for very limited home care services. Medicare coverage is focused on rehabilitation.
- Individuals paid for nearly one-quarter of long-term care costs in 2004, including direct payment of services as well as deductibles and co-payments for services primarily paid by another source. Growth in out-of-pocket payments was expected to decrease sharply in 2006 with the advent of Medicare Part D prescription coverage.
- Types of private insurance include supplements to Medicare coverage (Medigap), traditional health insurance, and policies targeted specifically to long-term care.
- Nearly 85 percent of Medicare beneficiaries have some type of supplemental Medigap coverage which typically pays for cost-sharing (deductibles and coinsurance) from Parts A and B, and may pay for additional services not covered. Medigap insurance typically does not cover most long-term care expenses.
- Over the past 10 years, the market for long-term care insurance has grown substantially. In 1990, slightly fewer than 2 million policies had been sold in the U.S. to individuals age 55 and older. By 2000, however, this figure had tripled and the number of policies sold either on an individual basis or through employer-sponsored group plans had increased to more than six million.

The average private-pay daily cost for nursing home care in Connecticut rose 5 percent in 2006 to $299 daily or $109,000 a year, according to the Connecticut Partnership for Long-Term Care. With the average length of nursing home stay at two and a half years, the total estimated cost of care is $272,000. Medicaid continues to be the primary source of nursing home payment in Connecticut and covers 69 percent of all residents. Sixteen percent is paid by Medicare (primarily for the first 100 days post-hospital discharge), 13 percent is paid out-of-pocket, and 2 percent by private or long-term care insurance.

Connecticut's overall Medicaid long-term care expenditures continue to grow, with nursing facilities constituting the greatest total expenditures and ICF/MRs the greatest per client cost. Figure 5 indicates the change in total long-term care expenditures during the time frame 2002-2006. ICF/MR expenditures rose substantially (24%) between 2002 and 2006, while nursing home expenditures grew by 15 percent. The biggest percentage increases in expenditures among the large home and community-based waiver programs were the elder waiver (28%) and the mental retardation waivers (14%).

Figure 5. CT Medicaid LTC Expenditures 2002-2006

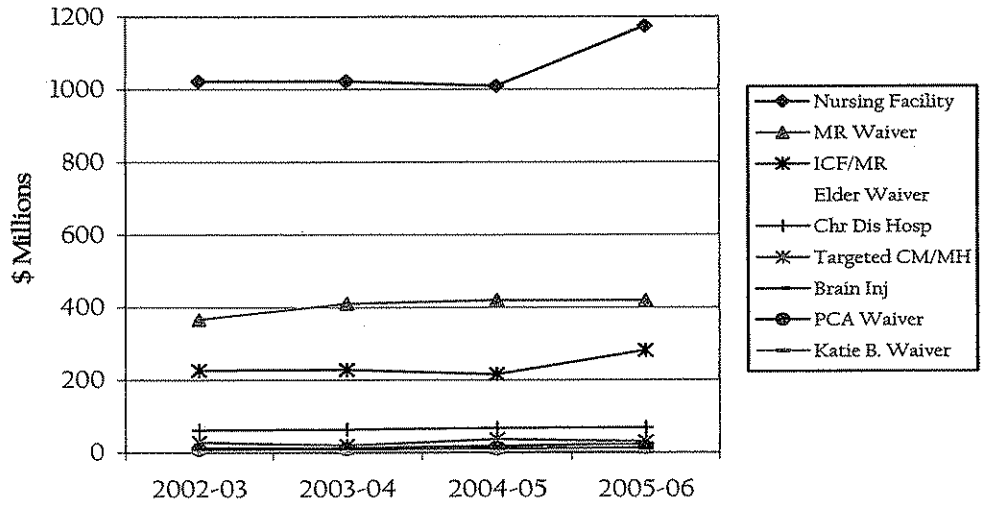
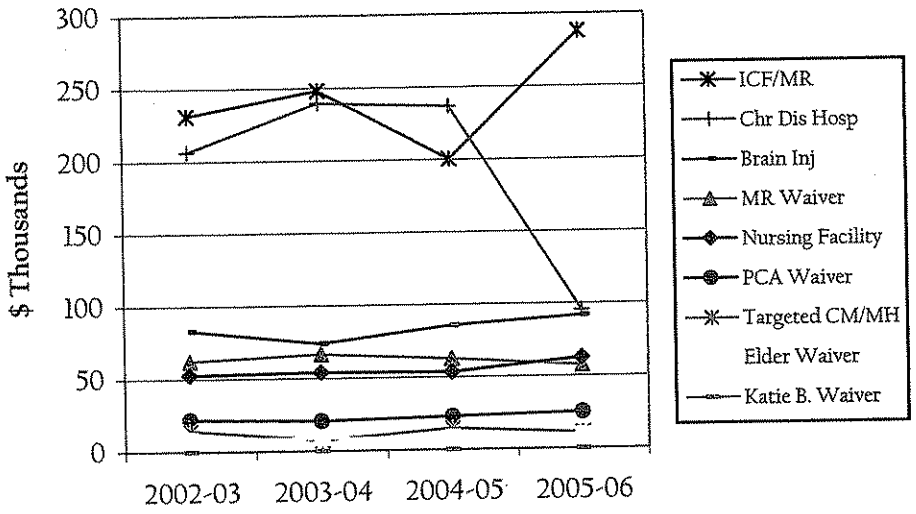


Figure 6 demonstrates the change in Medicaid cost per client for various institutions and waiver programs in Connecticut during the time frame 2002-2006. The cost per client for ICF/MR care is the most expensive, in part because it offers a more extensive array of services such as vocational supports, and it is trending higher. The per client expenditures for the Elder waiver are substantially less than those for the MR waiver (greater than a ten-fold difference).

Figure 6. CT Medicaid LTC Cost per Client Served, 2002-2006



VIII. What is Connecticut's Capacity to Meet the Growing Demand?

Government estimates suggest that the number of persons needing paid long-term care services in the U.S., whether in a nursing home, other residential facility, or at home, could substantially double from 15 million in 2000 to 27 million by 2050. Consistent with the growing demand for long-term care workers, the anticipated supply is increasing slowly with little evidence that there will be enough people to fill the openings.

Workforce Shortages: Diminishing general workforce with younger people fleeing the state, combined with a negative image of long-term care occupations, plus a burgeoning aging population = looming (or growing) crisis!

- Paraprofessionals: Most paid providers of long-term care services are paraprofessional workers who provide hands-on care and support to older persons and persons with disabilities, helping them to maintain their highest possible level of function and quality of life.

- Occupational growth: In the U.S., the occupation of home health aide is expected to grow by 56% between 2004 and 2014, representing the fastest growing occupation nationwide. The growth rate of nursing aides, orderlies, and attendants (22%) and personal and home care aides (41%) will show a significant increase as well. Projected growth rates of these occupations in Connecticut are somewhat lower than nationally, but still among the fastest growing occupations.

- Negative images: Many long-term care occupations have a negative image due in part to low wages, poor benefits, lack of status, and unattractive working conditions, making recruitment and retention difficult.

Strategies for Recruitment & Retention

In order to fill the expanding need for long-term care workers in the coming years, employers and policymakers will need to find ways to overcome the field's negative image, retain current workers and attract new ones.

Strategies could include not only higher wages, but also changes in the culture of the work environment, and in the duties, responsibilities and supervisory structure of the work, advances in labor-saving technology, and the development of new worker pools. It may also require fundamental changes in the way care is organized and delivered.

- **Little formal training and educational background** is required for entry into these occupations, with prior work experience and a high school diploma not always required.

- **Home and community-based paraprofessionals at a disadvantage**: Paraprofessionals generally receive better benefits in a hospital setting or nursing home than in home care. Personal and home care aides and home health aides are less likely to receive benefits at all.

- **Turnover rates are high**, often exceeding 100% for reasons related not only to wages but also to lack of professional growth, lack of involvement in work-related decisions, and communication issues between management and employees.

- **A recent unanimous U.S. Supreme Court decision** could exacerbate the staffing shortage problem already affecting the long-term care industry. The case, *Long Island Care at Home, Ltd. v. Coke*, No. 06-593, 551 U.S. (2007), was brought by a home care aide who sued her employer for failing to pay minimum wages and overtime wages, even when she worked 24-hour shifts. The Court held that the minimum wage and overtime pay laws do not apply to home care aides.

When asked how they plan to handle the anticipated future workforce shortage in Connecticut, for the vast majority of providers the answer is some form of **recruitment and retention.** About three-quarters (76%) say they will extend their efforts not only to recruit new employees but also to retain the employees they already have. This would be achieved in a variety of ways, including offering competitive wages and good benefits packages, maintaining a pleasant working environment, and offering flexible work schedules.

What did CT providers say regarding how they plan to deal with the workforce shortage in Connecticut in the future?

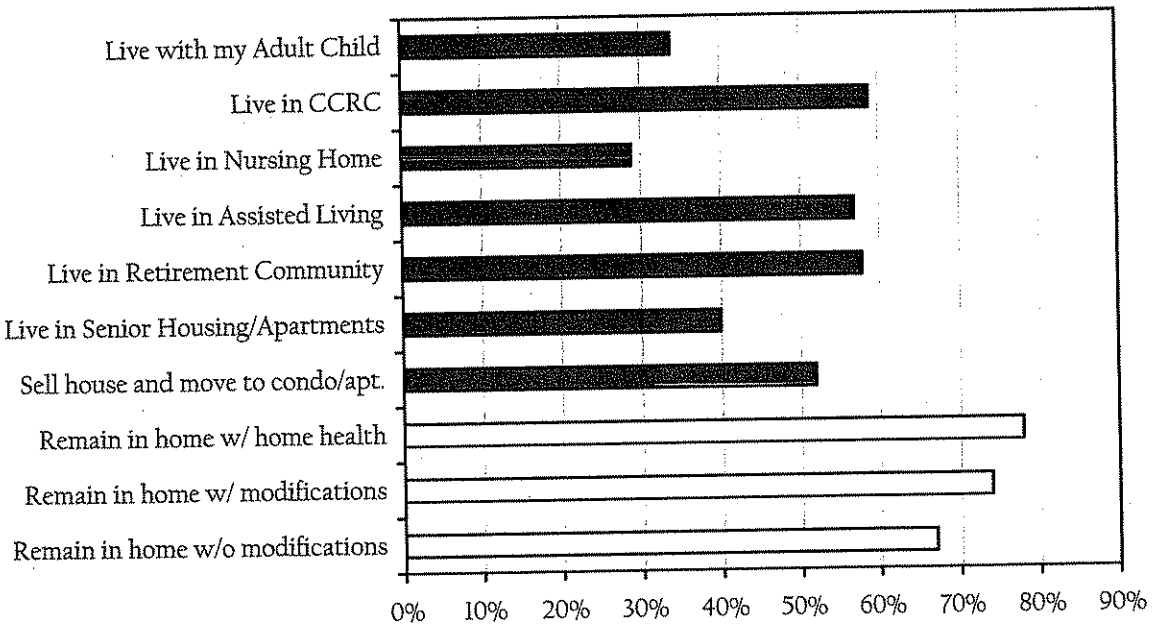
- Streamlining...many processes electronically.
- Using foreign born, licensed staff.
- I plan to close our doors.
- We promote education here and provide tuition assistance for staff.
- We don't know.
- Pray.
- Increase salaries to compete with the market.

Interestingly, most respondents who emphasize recruitment speak of hiring new graduates or attracting employees from other organizations. Very few address the creation of a larger overall long-term care workforce, although a few mention the need to increase the number of students in nursing schools and note that the lack of nursing teachers is an issue.

IX. What Do Connecticut Residents and Providers Say?

A. Where do Connecticut's Residents Prefer to live?

Figure 7. Future Living Arrangements
(percent reporting very likely or somewhat likely)



IN THEIR HOMES AND COMMUNITIES

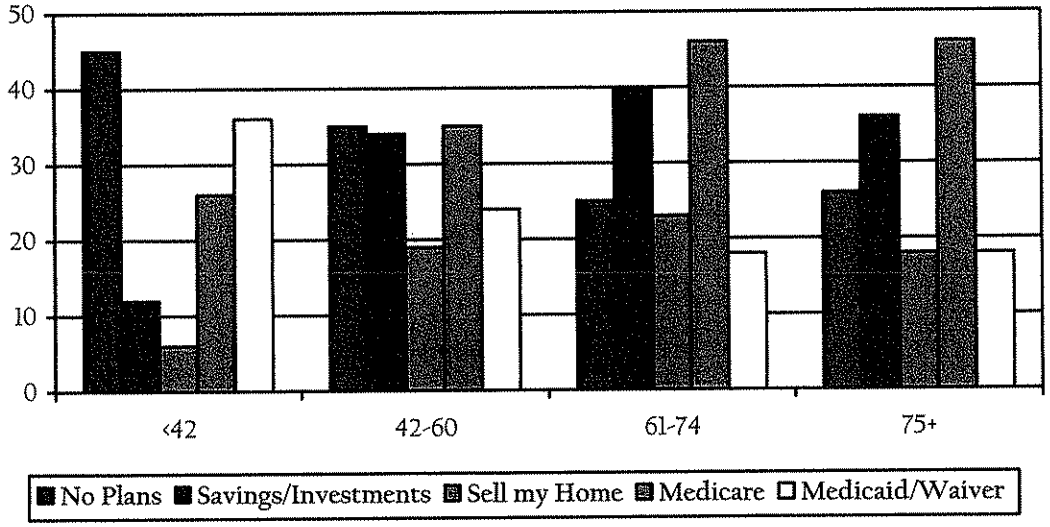
The majority of respondents express a strong desire to remain in their own homes with homecare services and supports as necessary, as shown by the yellow bars in Figure 7 above. Almost 80% of respondents would like to continue living in their homes with home health or homemaker services provided at home. Almost as many respondents recognize that home modifications, such as a wheelchair ramp or a full first floor bathroom, would let them stay in their homes and age in place. Less well-liked are any future living arrangements that require moving to a type of institutional or congregate living, represented by the red bars in the above figure. Of these, assisted living, continuing care retirement communities, and limited service retirement communities are the most popular, yet few report having the financial resources to pay for these housing options. Interestingly, living with an adult child is just slightly more appealing than moving to a nursing home.

> I will NEVER go into long-term care.
>
> There is no one to care for me when my parents die. As they grow too old to care for me, I hope to transition to a group home.

Most report that home maintenance, handyman service, and lawn/snow care would be essential for independence as they grow older. This was followed by homemaker services, transportation, and home health or personal care. Additional community-based services wanted by people with disabilities include money management, vocational rehabilitation services, and on the job support.

B. How do Connecticut's Residents Think They Will Pay for Their Long-Term Care?

Figure 8. Anticipated Long-Term Care Payment Sources by Age



MEDICARE AND MEDICAID

Overall, over one-third (38%) of respondents plan on Medicare funding to pay for at least part of their long-term care. **In addition, almost half of those age over age 60 (46%) think that Medicare will pay for their care,** while Medicaid is the primary payer of choice for respondents under age 21. In addition, one-quarter of all baby boomers and one-third of all young adults expect to rely on Medicaid to help pay for their long-term care.

> Depends on what Medicare and Medicaid will allow because my life has not allowed me to have savings.

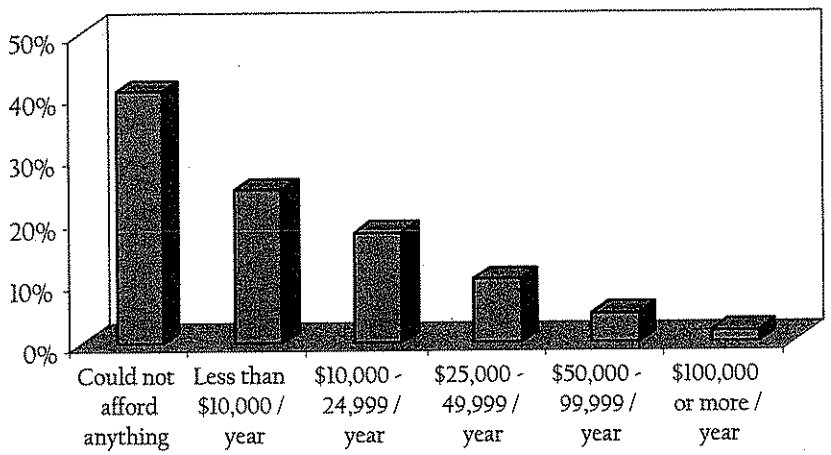
Clearly it is not well known by many Connecticut residents that Medicare actually pays very little for either long-term nursing home or home and community-based care. In addition, Medicaid, the anticipated long-term care funding source for over one-fifth of respondents, does not support the vast majority of people in their homes. This creates a dissonance between residents' strong desire to continue living in the community with supports and how they plan to pay for such care. Currently, Connecticut does have six Medicaid waivers administered by various agencies which may pay for some community-based services for people with certain disabilities or other eligibility requirements. However, in addition to specific eligibility criteria, many of these waivers presently have waiting lists, with capped enrollments and funding.

C. How Much Do Residents Think They Can Afford to Pay for Long-Term Care Each Year?

While the majority of respondents of any age believe they will need long-term care, few have the financial resources to pay for it, as shown in Figure 9. In general, over four out of ten respondents indicate they cannot afford to pay anything, and another quarter can pay less than $10,000 per year. Less than 20 percent of all respondents report being able to pay $25,000 or more a year for this care. Many baby boomers (40%) indicate that they could pay nothing for long-term care, as do half of those 85+. While it can be expected that the majority of the youngest, or the very old, could not afford to pay anything, that 40 percent of baby boomers report this is troubling, and may indicate a greater reliance on state or federal aid in the future to pay for such care.

Respondents' limited financial resources are in stark contrast to the cost in Connecticut for these services. In 2006, the average cost of nursing home care in Connecticut for the average length of stay (2 ½ years) is $272,000.

Figure 9. Amount Residents Could Pay Each Year for Long-Term Care



There is a strong need for education of the general population about long-term care – what it is, who may need it, how much it costs, what choices exist, etc. Furthermore, the study findings suggest that Connecticut residents have limited resources set aside for long-term care and have done little in the way of long-term care planning. Erroneous perceptions about the role of Medicare or private health insurance in covering typical long-term care costs persist.

D. Obstacles to Receiving Needed Community-Based Services

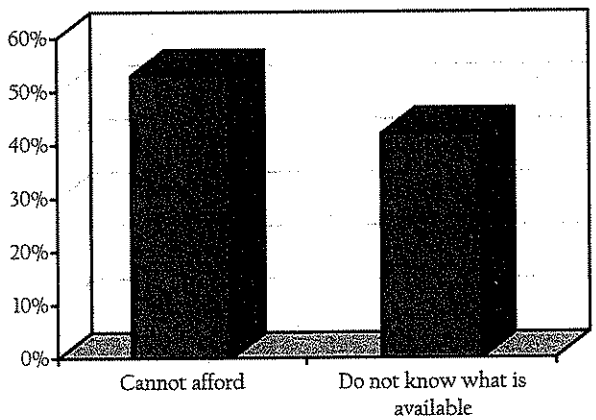
FINANCES AND LACK OF KNOWLEDGE ABOUT SERVICES

Over one-third (38%) of those who currently need paid long-term care services report that they are unable to get all the services they need. This number is greatest for residents who self-identified as having a disability or an activities of daily living (ADL) deficit (48%), compared with 40 percent of the residents who completed the disability survey, most of whom already receive state or Medicaid-funded long-term care.

Figure 10. Why Cannot Get Services Needed

Inability to afford services and lack of knowledge about services top the list of barriers to getting this care.

Other reasons reported less frequently include inability to find help, unreliable or poor care, services not available, and services not accessible for people with disabilities.



Financial assistance is mentioned most frequently by residents when asked what services Connecticut should offer to older adults or people with disabilities. Specifically, respondents need assistance with paying for home care or homemakers services, home modifications, adult day programs, and respite care in order to continue living in the community.

> If people have the strong desire, the physical ability, and mental capacity to remain in their home in the community where they have family and friends, it should behoove the state to help provide and pay for services to keep people in their homes...[as] hospitals and nursing homes ...[are] much more expensive.

The second greatest obstacle to obtaining needed community-based services is lack of knowledge. Respondents state that it should be easier to know what services are available and how to access them. Without comprehensive information about existing community-based options, people may see nursing homes or other residential care as their only option.

An effective information network that links services for people would begin to meet this need. Some respondents suggest that the state should provide a wider range of supportive services for older adults and persons with disabilities through Connecticut's Area Agencies on Aging and programs such as the CHOICES Program. Linking consumers with appropriate services would help them take advantage of programs or services that are already in place.

> A contact person to talk with to help through all of the forms and phone calls that need to be made for the assistance that is out there. Finding the help is the toughest part of being disabled.

Most states have an Aging Disability Resource Center (ADRC) to meet this type of need. An ADRC provides information and referral regarding the complete spectrum of long-term care options available for older adults or people with disabilities, and acts an integrated point of entry into the long-term care system. Connecticut is one of the few states without an ADRC, which can be designed to address many of the frustrations consumers and their families experience when trying to access needed information, services, and supports.

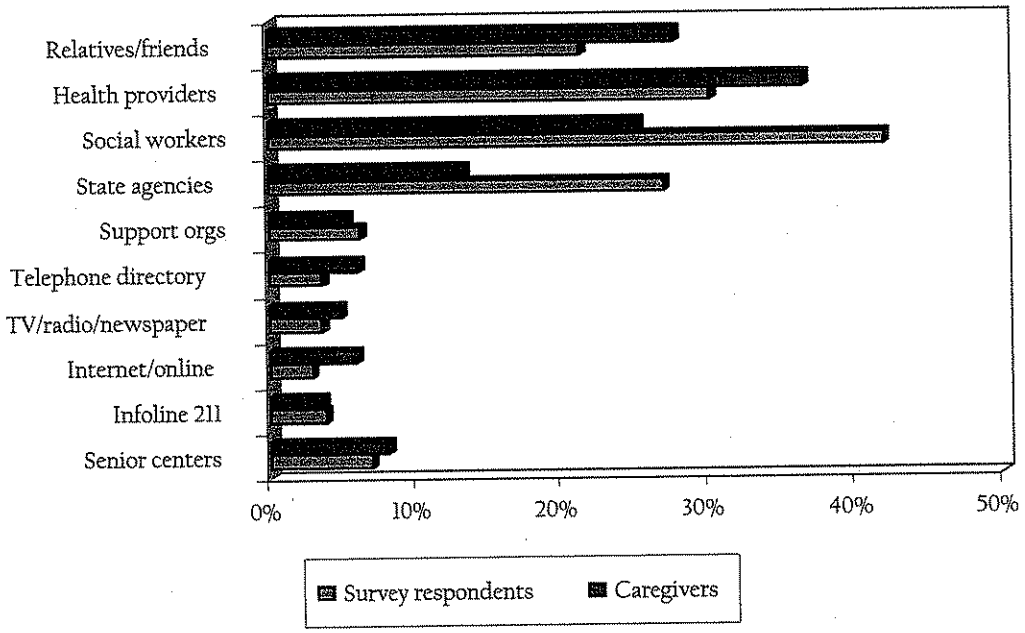
E. Who do Residents Turn to for Information About Services and Supports?

SOCIAL WORKERS, HEALTH PROVIDERS, STATE AGENCIES, RELATIVES, AND FRIENDS

Asked how they find out about their current long-term care services, the most frequent answers are social workers or care managers (42%), health providers (30%), state agencies (27%), and relatives or friends (21%). Caregivers also utilize these same sources, although they *most* often turn to health providers, relatives and friends, and social workers for information about long-term care services for the person they are caring for. Senior centers, support organizations, telephone directories, internet, Infoline, and all media outlets are each used to access this information by less than ten percent of either residents or caregivers.

Increased awareness on the part of health providers and social workers of existing supports, or even where to refer people, may help people find the services they or their loved one needs. Increased coordination across state agencies and a single point of entry system, or "no wrong door," f or people of all ages or disabilities would make it easier for everyone to find this information – health professionals, family members, and consumers alike.

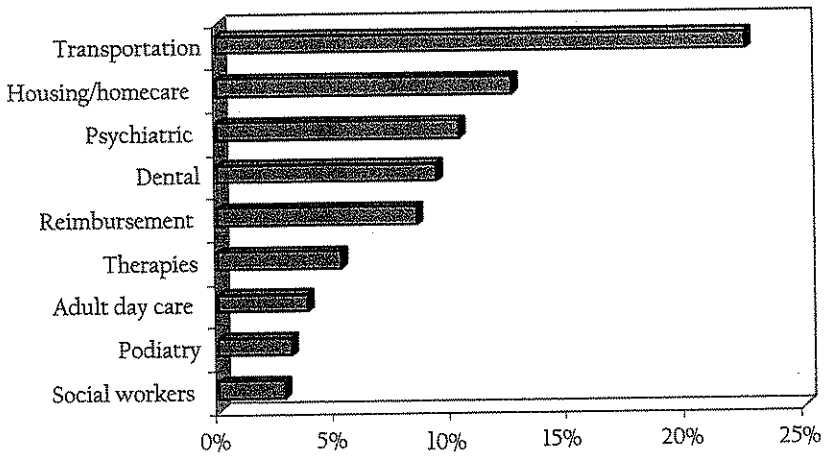
Figure 11. Sources of Information for Long-Term Care Services



F. What are the Major Gaps in Long-Term Care Services in Connecticut According to Residents and Providers?

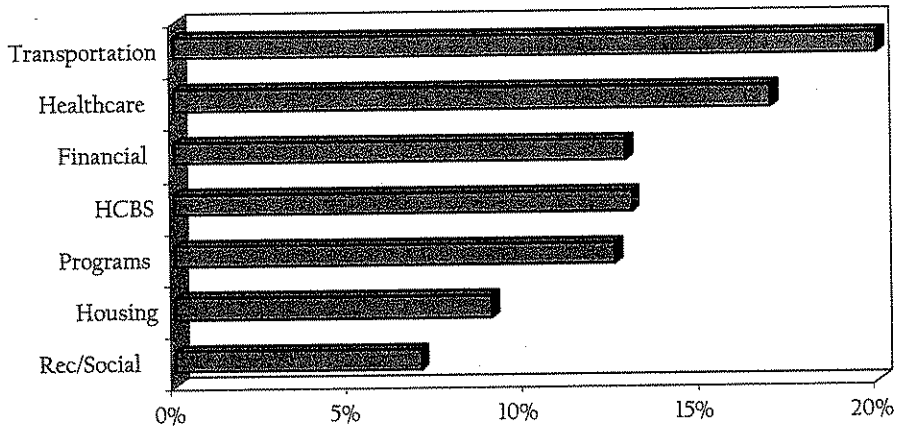
Providers in Connecticut recognize that they are not able to meet all the needs of the growing population who have any impairments or disabilities which make community living difficult. These missing services which are difficult for providers to fulfill create gaps in service for community-living consumers. From the provider perspective, the major missing services or gaps include transportation, supportive housing or homecare, health care such as psychiatric and dental services, and inadequate rates of reimbursement.

Figure 12. Gaps in Services According to Providers



Connecticut residents also identified missing services or programs which create barriers to living in the community. For residents, the missing services or programs most needed by older adults or people with disabilities living in the community are transportation, health care, community-based services/homecare, and financial resources.

Figure 13. Missing Services Identified by Connecticut Residents



TRANSPORTATION

The availability of affordable and accessible transportation is cited as the most important concern by both residents and providers. Just about one-quarter of providers indicate transportation problems are paramount for a wide variety of reasons, from medical appointments to social needs.

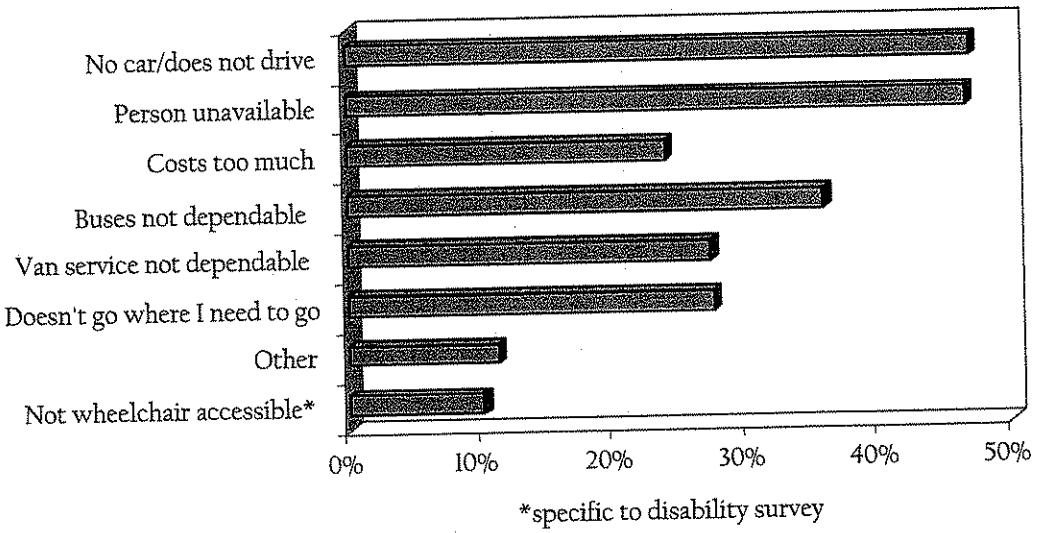
> We provide transportation; however, this is a constant struggle and growing need for the senior population. What we provide does not begin to touch what is actually needed. (provider)

Just under one-quarter of all residents report transportation difficulties. When examined further by disability status, it becomes clear that problems with transportation occur much more frequently for respondents with either ADL impairments or disabilities: over half of respondents from the disability survey and over one-third of respondents with ADL impairments from the general survey indicate at least one difficulty with transportation. Inability to drive or having no car, lack of personal assistance, undependable van or bus transportation, and limited van or bus route are the top transportation problems listed by all respondents. Shopping, doing errands, socializing, and attending medical appointments are the activities most affected when relying on formal transportation services.

> People I know who are receiving services say transportation is their major concern - cost and availability. (resident)

Between 2000 and 2020, the number of people not driving in the U.S. is estimated to rise by 15 percent to 52 percent of older adults, significantly affecting the transportation system specifically, and home and community-based services more generally.

Figure 14. Reasons for Transportation Problems for Residents



SUPPORTIVE HOUSING

The overall lack of affordable and safe housing in Connecticut is also a concern for both providers and residents. Equally important is housing which is accessible by those who use wheelchairs or have difficulty walking. Providers report a need for more affordable housing as well as a broader range of housing alternatives which provide some support, including more assisted living options, senior housing complexes, or apartments in local communities. Respondents also mention concern about the need to control rent increases in housing for older adults or people with disabilities, and the need for rental assistance, financial aid, or subsidized housing.

The lack of affordable, accessible, and safe housing makes it difficult for people who develop impairments to continue living in the community. It is also a prominent barrier for people living in institutions such as nursing homes to transition back into the community. This issue is a problem for other states as well, as trends nationally indicate a crisis in providing decent and affordable housing to people with long-term care needs.

> All the cupboards are too high. I am wheel-chair-bound. The tub is too high, old fashioned. (resident)

> Affordable housing; affordable medical specialists who are willing to work with an indigent aging population. Affordable housing alternatives beyond independent housing, i.e., assisted living communities and community agencies that have the expertise in working with an aging population. (provider)

COMMUNITY-BASED PROGRAMS AND SERVICES

Community-based services such as homecare are identified by both providers and residents as inadequate to meet the needs of Connecticut's older adults or people with disabilities. **Overall, over one-third of respondents cannot get all the services they need to live in the community.** This number is greatest for residents who identified themselves as having a disability or ADL deficit (48%), compared with 40 percent of the residents who completed the disability survey. For residents, one of the

greatest unmet community-based service need is for homemaker services for assistance with tasks such as laundry, shopping, cleaning, etc.

> Home care should be provided when trying to avoid a nursing home - family cannot provide 100% care at all times and need help in order to continue with aspects of their life (i.e., work, etc.). (resident)

MENTAL HEALTH

Mental or behavioral health issues are also a notable concern mentioned by both groups of survey respondents. For providers, ten percent report a lack of psychiatric, mental health or behavioral services, especially for clients who rely on Medicaid for their mental health care.

> It is hard to find experienced psychiatrists/psychologists to work with the developmentally disabled. (provider)

Significant mental health issues are also reported by respondents. Using a standardized two question depression screen, approximately one-quarter of respondents screened positive for depression, such as feeling down, depressed, hopeless, or having little interest in doing things. In addition, nine percent of all respondents self-identify as having a mental illness disability.

Mental health issues seem to be highly correlated with the presence or absence of a disability. Whereas only 13 percent of respondents with no disabilities show signs of depression, more than one-third of respondents with either disabilities or ADL impairments screen positive for depression. Mental illness disability is also a major concern for those who completed the disabilities survey; almost one-third report they have a mental illness disability (alone, or in addition to, other disabilities).

DENTAL CARE

Affordable dental care is another concern focused on by both residents and providers. Nine percent of providers indicate this as a missing service, and point out that it is difficult to find dental services for their clients on Medicaid. One out of ten residents report that they are unable to pay for needed dental care.

> Dental services - most seniors over 65 do not have any dental insurance. (resident)

OTHER HEALTH CARE ISSUES

Both providers and residents also point out that other missing or inadequate health care services also make it difficult to live in the community. Concerns of residents include affordability, improved prescription coverage, and expanded health care benefits covering services such as hearing aides or medical specialists.

> No elderly person should have to worry about whether they eat or take medications. (resident)

Personal health concerns are reported by respondents, with notable differences between those with and without disabilities. While nearly all of those without disabilities report their current health to be either excellent or good, 42 percent of respondents completing the survey for people with disabilities and those with self-reported impairments report theirs to be only fair or poor. Emergency room and hospital visits in the past year were also included in the survey for people with disabilities. Of these, 37 percent were admitted or stayed overnight in a hospital, while half of respondents to the disability survey report at least one visit to an emergency room.

Age is also significantly correlated with overall health. Fair or poor health is reported by one-third of respondents age 75 or older, while less than 20 percent of those younger than 75 report fair or poor health. Notable differences by age in the number of respondents who experienced a fall are also shown, as just under one-third of those over age 74 fell in the past year, compared with 22 percent of all younger respondents.

G. What do providers report as their primary obstacles?

Providers report issues with state and federal funding, regulations, limited services, documentation, interpretation, and response time.

FUNDING AND REIMBURSEMENT

One frequently mentioned concern for providers focuses on funding and reimbursement issues. Approximately 25 percent of providers find this to be an issue affecting their ability to adequately provide needed client services. Apprehension about the rising costs of a variety of services and inadequate reimbursement is the predominant theme. Increased funding is especially needed to pay for services not fully covered by Medicaid. Increased funding would also help address the shortage of direct caregivers, improve client services, and allow for greater training of home health aides and nurses. A sub-theme of those who are concerned with funding issues is that available funding is not going to the preferred or most appropriate community-based services, resulting in more frequent institutional placement.

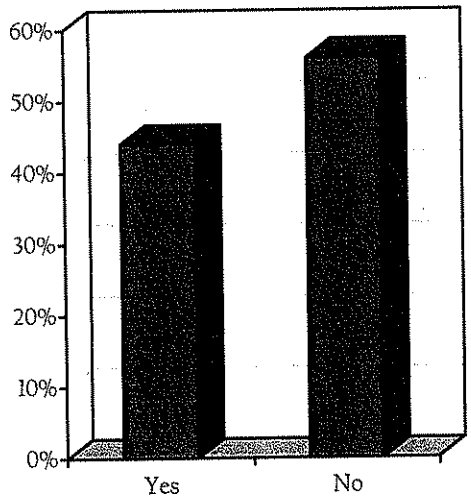
> Reimbursement rates are so far below costs that we are forced to subsidize a significant percentage of care we provide to the Medicaid population.

> There is not enough money to provide adequate mental health services.

REGULATORY ENVIRONMENT

Over 40 percent of responding providers indicate that the regulatory environment affects their ability to provide services to clients. Providers report issues with state and federal funding, regulations, limited services, documentation, interpretation, and response time.

Figure 15. Regulatory Environment Affects Ability to Provide Services



- Regulations inhibit individualized or new approaches to care
- Excessive documentation takes away from client care
- Regulations require MD visits; most doctors will not accept Medicaid
- Extremely long wait for Title 19 approval
- Inspectors place emphasis on paper compliance, not client care

Excessive regulatory compliance related to bureaucracy restrains key staff from integrating or enhancing support services.

Some of the regulations are too restrictive and inappropriate for an inpatient psychiatric unit.

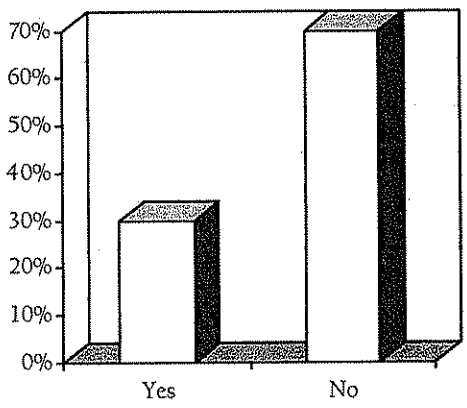
I discourage taking medically complex patients due to the additional paperwork and cost involved.

Sometimes clients are lost in the system, and it is hard for us to help them with entitlement programs.

DIFFICULTIES WORKING WITH STATE AGENCIES

Approximately 30 percent of responding agencies indicate having difficulties with state agencies or departments in the past year. Respondents report problems with administration, funding, the inspection and survey process, client services, and conflicting interpretation of policies and procedures.

Figure 16. Experienced Difficulties Working with State Agencies



- Issues working with state workers and case managers – being unresponsive or difficult to work with
- Late payments for service reimbursements or one time amendments
- Conflicting interpretations of rules and regulations by different departments
- Excessive red tape and paperwork
- State restrictions on client services

They seem to put a new spin on existing regs, and all of a sudden what was acceptable before is now grounds for sanction.

Red tape with the waiver takes a lot of time away from other duties.

The State eliminated RN visits to all clients.

We work with five state agencies for funding and oversight.

X. Conclusions

A. Connecticut Resident Survey

Due primarily to the large number of aging baby boomers, as well as overall increased longevity, the number of Connecticut residents age 75 and over is expected to increase by 54 percent within the next 24 years. This statistic is especially striking when compared with the five percent projected increase of the state's total population. Combining U.S. Census information with the current use and unmet need for services from the Long-Term Care Needs Assessment survey data, we project a 28 percent increase in the need for community long-term care services by 2030. Meanwhile, demand for nursing home services in the State is expected to rise by 43 percent, with a 67 percent increase in the number of residents age 65 to 74 who need this care. This considerable increase in demand for institutional services can be reduced if the current Long-Term Care Plan goals for rebalancing institutional and community-based services are met. However, efforts to divert and transition people out of institutional settings must be met with a substantial increase in the supply of community-based services. Clearly, this significant increase in demand for long-term institutional and community-based services over the next 25 years will greatly exceed the supply, unless we systematically address existing barriers, such as the workforce and affordable housing shortages.

There is a critical need to educate the general population about long-term care – what it is, who may need it, how much it costs, what choices exist, and so on. Connecticut residents of all ages have not adequately planned for their future care needs, and have limited understanding about the likelihood of requiring long-term care services and potential sources of payment. The study findings suggest that most Connecticut residents have inadequate resources set aside for long-term care and have done little in the way of long-term care planning. Erroneous perceptions about the role of Medicare or private health insurance in covering typical long-term care costs persist.

The majority of respondents express a strong desire to remain in their own homes with homecare services and supports as necessary. Assisted living and continuing care retirement communities are also popular, yet few report having the financial resources to pay for these housing options. Other potentially more widely affordable housing settings include apartments, condominiums, or 55+ retirement communities. Interestingly, living with an adult child is just slightly more appealing than moving to a nursing home. Most report that home maintenance, handyman service, and lawn/snow care would be essential for independence as they grow older. This was followed by homemaker services, transportation, and home health or personal care. Additional community-based services wanted by people with disabilities include money management, vocational rehabilitation services, and on the job support.

Independence, choice, and control are key for Connecticut citizens, especially when using any type of long-term care services. Most respondents would like to work jointly with an agency in managing their community-based services; in addition, over one-quarter of all respondents expressed a desire for self-directed care independent of an agency.

Users of long-term care services report high satisfaction with their care, and most of their needs are being met. The greatest unmet service need is for homemaker services from an agency (for laundry, shopping, cleaning, etc.), followed by transportation services. For people with disabilities, additional top unmet needs for long-term care services are vocational rehabilitation services, money management, and job support staff.

Overall, over one-third of respondents cannot get all the services they need to live in the community.[2] This number is greatest for respondents from the general survey who identified themselves as having a disability or ADL deficit (48%). A slightly smaller percentage of respondents to the survey for people

[2] Institutional care is addressed in the literature review, the Rebalancing report, and the Ombudsman report.

with disabilities (40%) also cannot get the community-based services they need. Finances and lack of knowledge about services are the primary barriers to receiving assistance. Lack of coordination across agencies and lack of a single point of entry system for people of all ages or disabilities also make it difficult for residents to access the programs and services they need. Social workers and heath care providers are the most commonly reported source of information for formal services.

The lack of accessible, affordable transportation is cited as an important issue by both residents and providers. Overall, one-quarter of all respondents indicate they have difficulties with transportation, while over half of people with disabilities report this problem. Problems identified most frequently are lack of car or do not drive, lack of person for assistance, public buses not available or dependable, van or bus route too limited, and dial-a-ride/van service not available or dependable. Shopping or doing errands, socializing, and attending medical appointments are the activities most affected when relying on formal transportation services.

Significant mental health issues are reported by respondents. Using a standardized two question depression screen (see Appendix E, Health section), approximately one-quarter of respondents screened positive for depression, such as feeling down, depressed, hopeless, or having little interest in doing things. In addition, nine percent of all respondents self-identify as having a mental illness disability.

Mental health issues are highly correlated with the presence or absence of a disability. Whereas only 13 percent of respondents with no disabilities show signs of depression, more than one-third of respondents with either disabilities or ADL impairments screen positive for depression. Mental illness disability is also a major concern for those who completed the survey for people with disabilities; almost one-third self-report they have a mental illness disability (alone, or in addition to, other disabilities).

Unpaid caregiving is common in Connecticut and is on par with the national average. Seventeen percent of respondents reported being a caregiver to a Connecticut resident because of old age, disabilities, or other care needs. About one-fourth of caregivers provide care to two or more people. Older parents are the most common care recipients. Moderate or advanced dementia is frequent. Over one-third of caregivers report unmet service needs for the people they care for, primarily because of finances, lack of knowledge about what is available, and poor quality care. Information about services comes from disparate sources, and is somewhat different for caregivers than the rest of the population. Over one-third found out about services from their doctor or nurse, followed by relatives/friends and then social workers. Senior centers are a source of information concerning services for less than one out of ten caregivers.

B. Provider Survey

The number of older adults in Connecticut is on the rise and will continue to increase for the next 30 years. Unfortunately, in Connecticut a workforce shortage is expected to accompany this increase in demand for services. To meet this growing need for care, providers plan to expand their services, while others without the flexibility to expand plan to continue to provide good care to as many people as possible. The vast majority of providers surveyed plan to use some form of increased recruitment or retention to handle this decrease in available staff. Respondents suggested strategies to do so include offering competitive wages, inclusive benefits packages, and a good working environment. Other respondents do not know how they will address this issue, and express concern that it may affect their ability to continue providing care.

Increased funding for care, affordable and safe housing, homecare, and transportation are reported by providers as the greatest unmet long-term care needs for Connecticut's older adults or people with disabilities. Providers often express the desire to have individuals living in their homes as a viable alternative to nursing home placement, with an emphasis on community supports services. Other issues mentioned include the need for more auxiliary services such as psychiatric, dental, and respite services, as well as the need to address the shortage of direct caregivers. For providers, transportation is the missing

service that is by far the most difficult for them to offer. Other missing services respondents mention as difficult to provide include housing, homecare, dental care, and psychiatric services.

As can be expected, the number one suggestion from providers is increased funding for services such as improved transportation, affordable assisted living, and increased home care. Providers also report the need for increasing the funding levels for different programs, higher reimbursement rates, reducing the wage gap between State and private employees, and increasing the recruitment and training of home health aides and nurses.

The current regulatory environment affects the ability of over half of respondents to provide services. Providers voiced concerns such as an emphasis on paper compliance, contradictory regulations, excessive paperwork, and long waiting periods for Medicaid approval. Difficulties with specific state agencies or departments in the past year are reported as well, including problems with case managers, late payments, and difficulty reaching agency employees, problems with arranging transportation to a state run clinic, and receiving conflicting advice from different departments.

C. Rebalancing Long-Term Care Systems in Connecticut

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

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

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

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

Connecticut provides publicly financed long-term care services and supports through a somewhat fractured governance structure consisting of a vast array of departments and programs that often operate in silos serving narrowly-defined segments of the population. This organizational complexity poses significant challenges for both consumers and providers of long-term care services. By contrast, the most progressive states in terms of long-term care rebalancing have restructured their state governments by consolidating most or all of their long-term care programs into a single agency within an umbrella organization, creating an efficient all-ages human services approach specifically linking long-term care and Medicaid. Some leading examples of states with these government structures are Vermont, Washington, Oregon, and Wisconsin; many other states are also moving in this direction. Connecticut appears to be moving in the opposite direction, having voted to create a cabinet-level Department on Aging that would split responsibilities even further.

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

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

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

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

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

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

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

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

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

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

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

XI. Recommendations for Connecticut

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

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

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

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

1. **Create a statewide Single-Point of Entry (SPE) or No Wrong Door (NWD) Long-term Care Information and Referral program across all ages and disabilities.** Survey respondents, providers and state agency staff all reported that it is difficult for Connecticut residents who need long-term care to find basic information about the types of care that are available to them and who will provide this care. An expert team comprised, for example, of State Unit on Aging staff, members of the Long-Term Care Planning Committee and Advisory Council, consumers and providers should develop a plan to implement a centralized SPE/NWD in Connecticut. The SPE/NWD should encourage equity in allocation of services and supports across ages and across disabilities. Many of the 43 jurisdictions throughout the U.S. with existing Aging and Disability Resource Centers (ADRCs) present models for doing so. The SPE/NWD should also inform the hospital discharge planning process to avoid unnecessary institutionalization, and should consider the creation of common applications for program eligibility to avoid the necessity of giving the same information multiple times.

Another promising avenue would be to consider modeling a Connecticut SPE/NWD on certain features of the existing CHOICES program, which currently provides referral services through each of the five AAAs. If CHOICES is used as the most appropriate model for Connecticut, it would require centralization of at least the initial point of contact, an increase in the capacity to include Centers for Independent Living or other community-based organizations, additional staff training on all long-term care options across ages, disabilities and income, across all entry point agencies, and increased visibility of its services. Whatever method is chosen, provide a wide range of access (e.g. face-to-face, telephone, and web) that will help individuals and their families: first, identify the most appropriate type of long-term care services and supports and second, select specific providers that will meet their needs. Utilize standard assessments and programmatic coordination to increase equity in access, enhance residents' knowledge of options, enable better decision-making, and encourage better discharge planning.

2. **Provide a broader range of community-based choices for long-term care supports.** Major policy and financing efforts should be undertaken to develop a broadly integrated infrastructure for community-based services including home health, homemaker and adult day services. Reduce restrictions on who can provide this care. States such as Oregon and Washington can serve as useful models. Both diversion and transition strategies must be improved in order to maximize opportunities for individual choice. Comprehensive, coordinated pre-admission screening for need and eligibility is necessary in order for these strategies to work. In addition, systematic attention must be directed toward expanding available slots in pilot programs for assisted living and other supportive community-

based residence settings, and making these programs permanent. Combine HUD and other housing programs to cover housing costs for those whose assisted living services are covered by Medicaid.

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

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

5. **Provide true consumer choice and self-direction to all long-term care users.** Develop policies and programs to: a) allow consumers/family members to choose their own care providers, including from within their own informal care network, particularly family members, b) allow consumers to control their own budgets, c) make case management optional for individuals who are able to manage their own care, d) use the DMR waivers as a model for self-directed care, and e) make these options available across all ages and disabilities. Programs should operate with as much flexibility as possible, including the ability to arrange for as many care provider hours as necessary, in whatever configuration across providers is appropriate and preferred by the consumer. Since many consumers/family members come into a long-term care situation without prior knowledge or experience, it is important that they have assistance in making choices and self-direction, and that the assistance be comprehensive and unbiased.

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

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

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

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

9. **Increase availability of readily accessible, affordable transportation.** In order to facilitate true choice in care and support alternatives, improve transportation options at the state and local level for persons who require additional assistance due to disability or other decline in physical or mental functioning. Encourage municipalities to work together to form regional plans that meet local and regional needs. Consider the formation of a broadly representative task force, led by a state-wide liaison from the Department of Transportation, to fully investigate alternative approaches and resource needs to accomplish this goal. Coordinate with the Medicaid Infrastructure Grant (Connect-Ability) team which has identified transportation as a priority area.

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

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

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

13. **Address the long-term care workforce shortage.** Workforce Investment Boards should be engaged to develop approaches to increase the size of the formal long-term care workforce, including training, education and incentives. The wage gaps, including benefits, between public and private frontline

workers and across those workers who care for different populations should be addressed. Increased flexibility in Connecticut's self-direction model, allowing consumers to choose their own care providers, will also help to address the workforce shortage.

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

15. **Continue and expand efforts to build data capacity and systems integration in the service of better management and client service.** Build upon the web technology and systems integration efforts of DMR and the Medicaid Infrastructure Grant to enhance access to data for providers and policymakers.

This Long-Term Care Needs Assessment was charged with providing a broad overview of the existing long-term care system in Connecticut and projecting long-term care needs in the coming decades. These recommendations focus on the major areas where Connecticut's long-term care system must be improved in order to meet these needs.

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

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