Connecticut Long-Term Care Planning Committee

LONG-TERM CARE PLAN

A Report to the General Assembly

January 2004

Balancing the System:

Working Towards Real Choice for Long-Term Care in Connecticut

A Report to the General Assembly
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I. EXECUTIVE SUMMARY

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

Over the coming decades, the capacity of the long-term care system to respond to the needs of increasing numbers of people requiring long-term care assistance will have a profound impact on all of us -- individuals, families, government and society as a whole. If the current structure, rules and public expectations remain unchanged, the anticipated growth in the demand for long-term care services will jeopardize the ability of the system to meet these needs. We will be challenged to address how we will organize, staff, pay for, and deliver, the necessary services and supports for individuals of all ages who need long-term assistance. This challenge must be faced through the spirit of a true public/private partnership, with government at all levels working with the profit and non-profit private sector and supporting the efforts of individuals and families.

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

The Plan centers around two central themes.

A. Long-Term Care Affects Everyone

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

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

Therefore, unless specifically noted, all of the recommendations and action steps outlined in this Plan apply to individuals of all ages and disabilities. While we recognize that certain populations, such as those with behavioral health issues, have not received the equal footing they deserve in terms of attention and resources in long-term care planning and program development, we have deliberately been inclusive in our recommendations and action steps and have not segmented out certain groups of individuals or disabilities.

This strategy is, in fact, designed to break down some of the barriers experienced by individuals with certain disabilities and promote a philosophy that is consumer-centered and focused on the needs of the individual and their family.

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

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

- 'Long-term care' refers to a broad set of paid and unpaid services for persons who need assistance due to chronic illness or mental or physical disability. Long-term care consists largely of personal assistance with the routine tasks of life as well as additional activities necessary for living independently.
- 'Home and community-based care' encompasses home care, adult day care, respite, community housing options, transportation, personal assistants, and employment services.
- 'Institutional care' includes nursing facilities, intermediate care facilities for the mentally retarded (ICF/MRs), psychiatric hospitals, and chronic disease hospitals.

B. The Current System is Out of Balance

Connecticut's long-term care system has many positive elements and has made great strides over the last several years in providing real choices and options for elders and individuals with disabilities. For instance, Connecticut eliminated its waiting list for home care for elders; expanded income eligibility for State-funded home care for elders; introduced subsidized assisted living in State-funded congregate facilities, HUD complexes and private pay assisted living communities; and has begun development of affordable assisted living units (see Appendix E for more details). However, the system is still fundamentally out of balance in two important areas.

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

In order to provide real choices to individuals and families there needs to be equal access to community and institutional care. While there are several sources of payment for long-term care, Medicaid is by far the largest payer and therefore is the focus of this discussion. Traditionally, in Connecticut and nationwide, Medicaid has made access to institutional care easier than to home and community-based care. Largely, this is a result of federal Medicaid rules and regulations. Consequently, the ratio between care and supports provided in individuals' homes and the community and those provided in institutions has consistently been out of balance and skewed towards institutional care. While over the last several years Connecticut has significantly increased its home and community-based options for elders, for the State Fiscal Year ending June 30, 2003 (SFY 2003), Connecticut still spent approximately 70 percent of its Medicaid long-term care funds for institutional care, with 30 percent allocated for home and community-based

care. This contrasts with 52 percent of individuals receiving Medicaid long-term care benefits living in institutions and 48 percent living in the community.

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

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

2. Balancing the Ratio of Public and Private Resources

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

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

Nationally in 2000, Medicaid paid 45 percent of long-term care costs. Individuals covered 23 percent of costs out-of-pocket, with many of those payments made as applied income while on the Medicaid program. Medicare only covered 14 percent of the bill, with private insurance covering 11 percent and the remaining seven percent covered by other public and private sources. These figures only represent paid services and do not include the substantial value of informal care provided by family and friends. In order to develop and sustain a long-term care system that can provide real choice and quality services and supports to those in need, a better balance between public and private resources must be achieved.

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

To these ends, this Plan recommends certain action steps Connecticut can take to move towards a more balanced system of services, supports and resources.

C. Summary of Recommendations and Action Steps

To achieve a more balanced long-term care system in Connecticut that promotes choice and equity for all persons with disabilities, the process of taking action must begin now. Below is a summary of the key action steps needed to move toward this goal (more detailed information on these steps can be found in Section V of this report). Additional action steps that support the major system change recommendations described below also can be found in Section V under six critical focus areas – Community Options, Housing, Employment, Transportation, Access and Quality. Together, these recommendations provide a common vision for long-term care in Connecticut.

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

✍ Currently, Connecticut's Medicaid program provides approximately 48 percent of its long-term care clients with home and community-based care (home care, adult day care and assisted living) and serves 52 percent of its clients in institutional care settings (nursing facilities, ICF/MRs and chronic disease hospitals). ***Connecticut should work to develop a system that provides for more choice, increasing the percentage of Medicaid long-term care clients receiving home and community-based care from 48 to 75 percent by 2025, requiring approximately a one percent increase in the percentage of Medicaid long-term care clients served in the community every year***.

Balancing the Ratio of Public and Private Resources

✍ Currently, private insurance covers approximately 11 percent of the nation's long-term care costs. ***Connecticut should strive over the next 20 years to increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent***.

Home and Community-Based Infrastructure

✍ Examine the possibility of providing greater uniformity among the different Medicaid home and community-based waivers in terms of requirements such as age and income

limits, and of providing maximum flexibility and choice as to how waiver funds can be utilized.

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

Informal and Formal Caregivers

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

- In addition to continuing existing respite care efforts, Connecticut should expand or replicate its successful Alzheimer's Respite Care program to provide respite services for any caregiver of individuals with disabilities of all ages.

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

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

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

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

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

- Connecticut should expand the use of the non-traditional workforce, such as personal care assistants (PCAs), to help address the increased number of individuals desiring home and community-based care. To make the positions competitive and a viable career, these types of jobs will need to provide the necessary worker supports and benefits.

- Connecticut should evaluate the Personal Care Assistance Pilot under the Connecticut Home Care Program for Elders to determine the potential for making personal care assistance a permanent benefit. In addition, explore payment for family members for providing personal care.

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

- Connecticut should increase the capacity of educational institutions to provide training for professional long-term care workers in order to address the current need for and projected growth of these workers in the state.

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

Nursing Facility Transitions

- Connecticut should continue the efforts begun under the State's Nursing Facility Transition Grant (NFTG). Connecticut should build on the successful components of the NFTG and strive to sustain those elements into the future.

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

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

Prescreening Efforts

- Connecticut should expand its present commitment to prescreening all applicants to nursing facilities age 65 and older, regardless of their payer status, to include all nursing facility applicants, regardless of their age or payer source. Similar prescreening for all institutions should be developed for individuals with disabilities. Any expansion of prescreening activities should be performed by State agencies. Prescreening should not prohibit or deny applicants the choice to enter an institution. The overall goal of prescreening should be to assure that individuals have the

knowledge and opportunity to exercise their choice to live in a community or institutional setting. Prescreening activities need to take into account the specific needs of the individual, addressing both cognitive and physical impairments, and ensure that the person receives the appropriate level of care that will protect them and others from any potential harm. Individuals who chose community settings must have safe and adequate living options and sufficient caregiving supports.

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

Reduction in Beds in Institutions

✍ As nursing facilities and other institutions close, or occupancy levels are reduced, Connecticut should continue to conduct a needs analysis to: 1) determine if any of the beds are needed elsewhere in the system; and 2) de-license the remaining beds. As this occurs, there is an opportunity to redirect the appropriate level of resources to enhance home and community-based services and supports.

✍ Connecticut should create incentives for under utilized institutions to convert their facilities to adult day care services, assisted living, residential care homes, independent living communities, or other community housing options. Such incentives could include low-cost financing for conversions and tax credits. Development of any new community housing options should emphasize consumer direction and choice.

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

Federal Reform

✍ Connecticut should continue to advocate for changes to federal Medicaid law that will facilitate an expansion of home and community-based options. Connecticut has submitted a proposal to the federal Centers for Medicare and Medicaid Services (CMS) to expand the medically needy income formula allowing individuals with incomes in excess of 300 percent of Supplemental Security Income to be eligible under the Medicaid portion of the Connecticut Home Care Program for Elders (CHCPE). This will allow individuals the same access to home and community-based care as they have for nursing facility care.

✍ In addition, current Medicaid law prohibits the reimbursement of room and board charges for those living in the community. Connecticut should continue its efforts to

remove this prohibition or expand other federal programs such as Section 8, allowing more aggressive development of community living options.

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

Planning Ahead for Long-Term Care

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

- Connecticut, working with the federal government, should develop incentives for individuals to save for their future long-term care needs. Connecticut should also explore opportunities on the state level to provide tax relief for unreimbursed medical and long-term care expenses.

- Connecticut should continue, and enhance, the efforts of the Connecticut Partnership for Long-Term Care (Partnership), the State's public/private alliance to help educate Connecticut residents about the importance of planning ahead for future long-term care needs through the purchase of high quality private long-term care insurance (LTCI).

- The State should take advantage of any opportunities to enhance the educational capabilities of the Partnership through the use of public and private resources.

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

- Connecticut should continue its efforts on the federal level to enact an "above the line" tax deduction for the purchase of long-term care insurance. Such a tax deduction would also result in a State tax deduction as long as Connecticut's tax system is tied to the federal Adjusted Gross Income. If federal action on this issue is not taken, Connecticut should explore its own tax incentives for long-term care insurance.

- Connecticut should explore and develop other models for private long-term care insurance.

- Connecticut should examine the state and federal reverse annuity mortgage (RAM) programs to see if any enhancements can be made to increase the usage of this program. Connecticut should also monitor the recently announced initiative from the Centers for Medicare and Medicaid Services to increase the usage of RAMs.

D. Development of the 2004 Long-Term Care Plan

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

In 2003, the Long-Term Care Planning Committee embarked on the development of its third long-term care plan in partnership with the Advisory Council. The Advisory Council worked with the Planning Committee in four essential areas: providing data, identifying areas of need, developing priorities and recommendations, and obtaining public input.

The first 6 months of 2003 were focused on data gathering. In the summer of 2003, a work group of the Advisory Council identified areas of need and shared their ideas and priorities for the Long-Term Plan, meeting twice with members of the Planning Committee's State Interagency Work Group.

The Advisory Council assumed responsibility for seeking and gathering broad public input on the draft Plan from diverse organizations and individuals throughout Connecticut with an interest in long-term care. Public comment was solicited in the fall of 2003. Comments were received from over 100 consumers, professionals and advocates, with representation from 23 public and private organizations (*see Appendix I – Sources of Public Comment).*

E. Implementation of the 2004 Long-Term Care Plan

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

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

While this Plan does not prioritize the specific recommendations and action steps, the Governor and General Assembly should consider legislation that will create in statute the following broad philosophical statement to guide future policy and budget decisions: ***Individuals should receive care in the least restrictive setting with institutional care provided as a last resort.*** Such a statement will position Connecticut to make the necessary changes to the laws and regulations that govern the State's long-term care system to make real choices for consumers a reality. Within this framework, Connecticut can begin to prioritize and detail the steps required to realize this goal.

In addition, although extensive data is provided in this Plan describing the potential need and demand for long-term care, what is lacking is a Connecticut specific comprehensive analysis of the need for long-term care and the extent to which these needs are not met. Therefore, ***to assist in the implementation and refinement of recommendations and action steps of this Plan, adequate resources must be allocated to accomplish such a comprehensive assessment and analysis***.

II. VISION, MISSION AND GOVERNING PRINCIPLES

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

A. Vision

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

B. Mission

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

C. Principles Governing the Long-Term Care System

The system must:

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

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

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

4. Be adequately financed and structured to assure that decision-making and service delivery are based on the needs of the individuals and families served and on the needs of employees who provide care and services. It must assure that profits are not made at the expense of delivering necessary care, that informal caregivers receive the support that they need, and that there are a sufficient number of formal caregivers available to provide the necessary care.

5. Assure that consumers have meaningful rights and protections, including access to a strong enforcement authority and the ability to appeal denials and reductions of services and transfers from one service setting to another.

6. Include an information component to educate individuals about available services and financing options.

7. Have an adequate and coordinated regulatory structure to assure that services are provided in a quality and safe manner taking into account the consumer as well as the state perspective of quality and safety.

8. Include a simplified eligibility process

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

10. Include a care management component that, while stressing individual autonomy and self-direction, provides comprehensive assessment, care plan development, coordination and monitoring services to assist individuals and families in providing and securing their necessary care.

11. Have mechanisms for integration with related services and systems including acute medical care, housing and transportation services.

12. Include a prevention component to educate individuals regarding actions that can be taken to reduce the chances of needing long-term care.

13. Have a strong independent advocacy component for those in need.

14. Include meaningful consumer input at all levels of system planning and implementation.

III. LONG-TERM CARE IN CONNECTICUT

A. Assessment of Need for Long-Term Care

Individuals with long-term care needs comprise a diverse group of children, adults and elders. Whether challenged with limitations due to developmental disabilities, mental illness, chronic health conditions or injuries, they share a common need for assistance with activities necessary to carry out basic functions such as eating, dressing or bathing (activities of daily living or ADLs) or tasks necessary for independent community living, such as shopping, managing finances and house cleaning (instrumental activities of daily living or IADLs). These long-term care needs are being met at home, in congregate residences and in institutional settings.

Currently, there is no universal source of information on the need for long-term care services and supports among individuals with disabling chronic illness and conditions in Connecticut. There is also no one source that looks at needs across the lifespan or across types of disabilities, with the preponderance of information focused on the needs of elders. In order to develop a picture of the need for long-term care in Connecticut, regardless of disability or age, a broad array of sources have been consulted. Where necessary, national findings have been applied to Connecticut. It's important to note that findings vary from study to study depending on how the population in need of long-term care is defined and whether the focus is on individuals with disabilities in general or those with long-term care needs specifically. Disability, which is most commonly defined in terms of limitations in tasks and activities, is used in this Plan as a measure for the need for long-term care services and support, unless otherwise specified, although it is acknowledged that not everyone with a disability will need supports at any given time.

Disabilities affect nearly one in every six non-institutionalized people living in Connecticut. According to estimates from the U.S. Census, in 2000 there were 546,800 individuals living in Connecticut with some type of long-lasting condition or disability, comprising 17.5 percent of the non-institutionalized state population over the age of five.[1] As can be seen in Figure 1a, disability rates rise with age, with the disability rate among individuals age 20 and under at 7.6 percent, adults at 16.8 percent, and elders at 37.0 percent. However, as shown in Figure 1b, in terms of absolute numbers, adults with disabilities comprise the largest group (327,700 or 60 percent of all people with disabilities), followed by elders (162,900 or 30 percent), and then those age 20 and younger (56,200 or 10 percent).[2]

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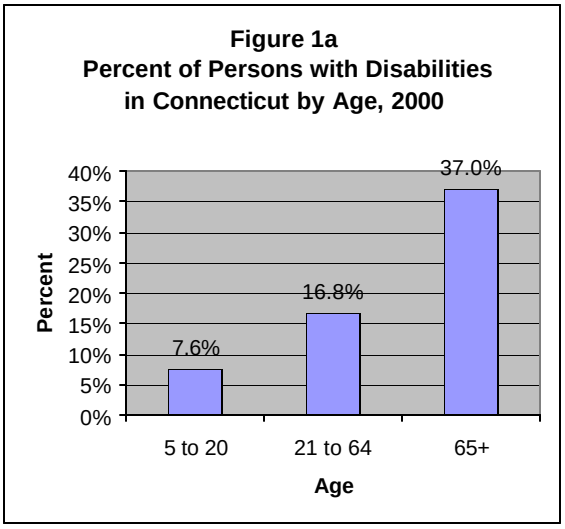
[1] U.S. Census Bureau, Census 2000, Table DP-2. Profile of Selected Social Characteristics: 2000, Connecticut.

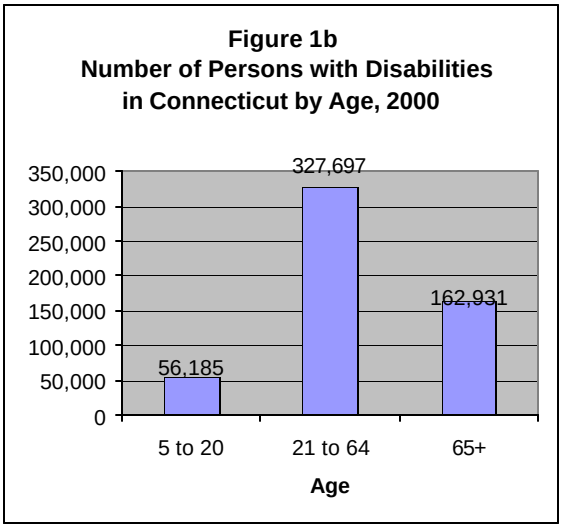
[2] U.S. Census Bureau, Census 2000, defines an individual as having a disability if the following conditions are true:

- Aged 5 or older and responded "yes" to a sensory, physical, mental or self-care disability.
- Aged 16 years or older and responded "yes" to a disability that affects going outside the home.
- Between the ages of 16 and 64 and responded "yes" to an employment disability.

Census 2000 does not include institutionalized populations (nursing facilities, psychiatric inpatient hospitals, Intermediate Care Facilities (ICF/MRs), prisons).

The U.S. Census separately surveys individuals living in group quarters. According to the Census 2000 for Connecticut, there were 32,223 individuals residing in nursing homes, 2,094 individuals in hospitals and hospices for the chronically ill (including hospitals for individuals with substance abuse disorders, psychiatric illness, mental retardation, and physically handicaps). An additional 4,824 were residing in group homes for individuals with substance abuse disorders, mental illness, mental retardation, and physical handicaps. [3]





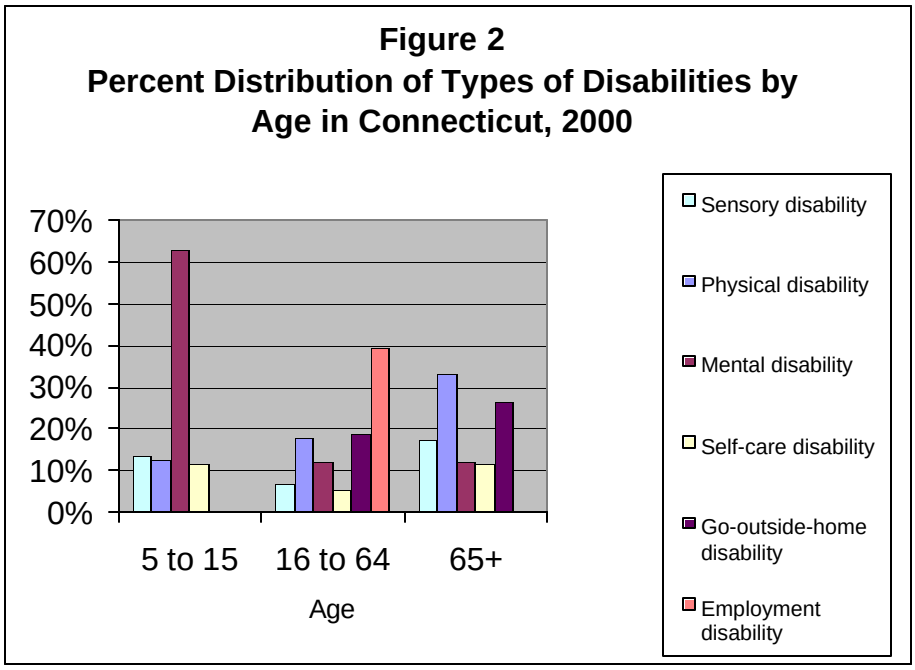
Source: U.S. Census Bureau, Census 2000, Table DP-2. Profile of Selected Social Characteristics: 2000, Connecticut.

An analysis of Census data on persons with disabilities in Connecticut shows that sensory disabilities affect 3.1 percent of the total population, physical disabilities affect 6.9 percent, mental disabilities affect 4.2 percent, and self-care disabilities affect 2.3 percent.[4] The distribution of types of disabilities in the population varies considerably by age (Figure 2). Among individuals with disabilities in the 5 to 15 year old group, an estimated 63 percent had a mental disability, while the prevalence of sensory, physical or self-care disabilities each ranged from 11 to 13 percent. Employment disabilities are the most common limitations among those between the ages of 16 and 64 with disabilities,

[3] U.S. Census Bureau, PCT16. Group Quarters Population by Group Quarters Type, Census 2000 Summary File 1 (SF 1), http://factfinder.census.gov/servlet/DTTable?_ts=86087456746 .

[4] U.S. Census 2000 definitions of types of disabilities:
Sensory: Blindness, deafness or a severe vision or health impairment.
Physical disability: Conditions that substantially limit one or more basic physical activities such as walking, climbing stairs, reaching lifting or carrying.
Mental disability: Difficulty learning, remembering or concentrating.
Self care disability: Difficulty dressing, bathing or getting around inside the home.
Go-outside the home disability: Difficulty going outside the home alone to shop or visit a doctor's office.
Employment disability: Difficulty working at a job or business.

affecting 40 percent. Individuals age 65 and over with disabilities are most affected by physical disabilities and limitations regarding going outside the home, affecting 33 and 26 percent respectively. It should be noted that disability measures from the 2000 Census were not mutually exclusive and nationally, 46.3 percent of people with any disability reported more than one.[5]



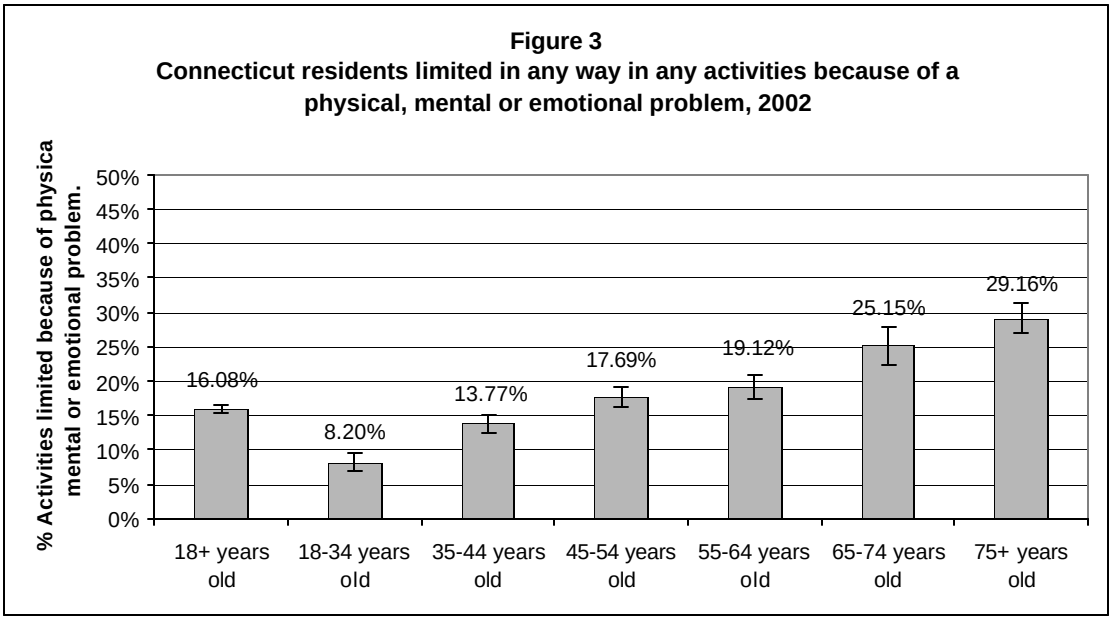
Source: Office of Policy and Management based on the U.S. Census Bureau, Census 2000, Table QT-P21, Disability Status by Sex: 2000, Connecticut (Summary File 3 Sample Data).

A profile of Connecticut residents with disabilities analyzed according to Independent Living Council regions shows that of the 546,813 individuals age five and older with disabilities living in the community, 89,650 were in the Northwest Region, 159,178 were in the North Central Region, 104,831 were in the Southwest Region, 64,236 in the Eastern Region and 128,918 in the South Central Region. This information about individuals with disabilities in Connecticut is based on the U.S. Census 2000 and was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center. Detailed maps with town level data showing individuals with disabilities by gender, age groups, ethnic groups and type of disability is provided in Appendix H.

Another picture of individuals with disabilities in Connecticut is provided by the Connecticut Behavioral Risk Factor Surveillance Survey (BRFSS), conducted by the

[5] U.S. Census Bureau, Disability Status: 2000, Census 2000 Brief, March 2003, p 9. For example, a person with severe asthma may have difficulty climbing stairs and difficulty working at a job.

Department of Public Health.[6] Unlike the Census data on disability, which looks at the population age 5 and over, the BRFSS only surveys adults age 18 and over. Overall, 16.1 percent of respondents reported in 2002 that they are "limited in any way in their activities because of physical, mental or emotional problems," translating into approximately 378,338 Connecticut adults living in the community with some degree of activity limitation. Disability as reported by the BRFSS also increased as people aged, with only 8.20 percent of respondents aged 18 to 34 reporting limitations in activity compared with 29.16 percent of those age 75 and over (Figure 3).[7] The BRFSS estimates there are 261,017 individuals (14 percent) age 18 to 64 and 117,321 individuals (27 percent) age 65 and over with any activity limitations. In contrast, the Census identified 327,697 individuals (17 percent) age 21 to 64 with disabilities and 162,931 individuals (37 percent) age 65 and over.



Source: Connecticut Department of Public Health, Behavioral Risk Factor Surveillance System Survey 2002.

With respect to children, findings from a national survey show that 120,300 or 14 percent of Connecticut children under the age of 18 have a special health care need. Almost four percent, or 32,000, of children in the state have an emotional, developmental or behavioral problem that has lasted more than a year. Not all children with special health care needs require long-term care services or supports. A smaller proportion of

[6] The Behavioral Risk Factor Surveillance System is a state-based, ongoing data collection program designed to measure behavioral risk factors in the adult, non-institutionalized population 18 years of age or older. Every month, states select a random sample of adults for a telephone interview.

[7] In the BRFSS, information on functional impairment is self-reported. Therefore, individuals with disabilities that prevent them from responding to a phone survey would not be represented in the responses. Many national surveys look at households rather than individuals and can use other household members to answer for persons who are not able to respond themselves.

Connecticut children, just over three percent or 27,500, are limited in their ability to do things due to a medical, behavioral or other health condition that has lasted or is expected to last for a year or more.[8]

Without the resources necessary to perform a comprehensive assessment of unmet long-term care needs in Connecticut, we must rely on the existing data sources noted below. Based on this data, the unmet need among Connecticut residents with long-term care needs may be as great as 20 percent.

National perspective

In the U.S., compared with the general population, persons who need long-term care are disproportionably low-income, very old, and living alone or with relatives other than a spouse. They also incur substantial costs for acute care services. Results from a 1994 national survey indicate that many individuals in need of long-term care often do not get the care they require or prefer, with approximately one in five adults with long-term care needs and living in the community unable to receive needed care, such as assistance in toileting or eating. These unmet needs are attributed to the cost of services, difficulty finding help, or lack of income or medical eligibility for services.[9]

Elders

According to the *Connecticut State Plan on Aging*,[10] only four percent of individuals age 60 and over living in the community need the help of another person to assist with personal care activities such as eating, bathing, dressing or getting around the house (ADLs). Eleven percent need the help of another person with more routine activities such as everyday household chores, shopping, or getting around because of any impairment or health problem (IADLs). Overall, 13 percent of elders reported needing the help of another person with either personal care or routine activities, translating to an estimated 78,240 individuals. Elders reporting a need for help with either personal care or routine activities were more likely to be female, over 75 or a member of a minority group. They reported lower incomes and more were renters or residents of specialized housing for the elderly. They were also more likely to rate their health and emotional well being as fair or poor, although in both cases the majority rated these conditions as good or better.

Among elders reporting a need for personal care assistance in the *State Plan on Aging*, 40 percent receive it from a family member, 28 percent receive it from a paid employee or home health service, and only one percent receive assistance from an unpaid volunteer. Six percent reported that they do not receive the help they need. Of those in need of help

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[8] National Survey of Children with Special Health Care Needs, conducted by the National Center for Health Care Statistics from October 2000 to April 2002. Connecticut survey results provided by the Connecticut Department of Public Health, 2003.

[9] Judith Feder et al., Long-Term Care in the United States: An Overview, *Health Affairs*, May/June 2000, pp 40-56.

[10] Department of Social Services Elderly Services Division, *Connecticut State Plan on Aging*, October 1, 2002 to September 30, 2005, pp 41–44. The findings are from the *Elderly Needs Assessment Survey*, a telephone survey of 1,008 Connecticut residents age 60 or older conducted from November 2001 through January 2002 by the University of Connecticut Center for Survey Research and Analysis.

handling routine activities, 66 percent rely on family, 13 percent rely on paid help, six percent rely on help from a friend or neighbor, three percent receive help from a combination of family, friends and paid help, and five percent do not receive help.

With regard for the need for transportation by individuals over the age of 60 in Connecticut, the *State Plan on Aging* indicates that five percent of respondents reported that they almost always had problems with transportation and four percent indicated that it is sometimes a problem. The nine percent of elders who reported that they sometimes or always have a problem obtaining transportation are generally older, more likely to be minority group members and living alone than those without such problems. Rural residence and gender did not have a significant impact. Persons reporting transportation difficulties also were in fair or poor health and indicated a need for assistance with personal care or routine activities. Respondents reporting transportation difficulties were more likely to live in private apartments than their own homes or specialized housing for the elderly.

B. Long-Term Care Services and Supports

Constructing an accurate picture of persons receiving long-term care services in Connecticut is a complex exercise bearing fragmented results. Without the resources to conduct a statewide survey of public and private long-term care in the state, data must be pieced together from disparate, overlapping and often incompatible sources. Ideally, a picture of long-term care service utilization in Connecticut would cover services in all types of settings, whether formally or informally provided or publicly or privately financed. With adequate resources, this data could be provided through a statewide utilization survey and needs assessment. Short of this, our understanding of who obtains long-term care in the state is based upon data on state programs, piecemeal information regarding utilization of private resources and limited information on services received from informal caregivers.

Home and community-based services

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

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

Nationally, with regard to adult long-term care users in the community, nearly equal proportions are age 18 to 64 (47 percent) and age 65 and over (53 percent). Compared with elderly long-term care users in the community, long-term care users age 18 to 64 are

more likely to receive assistance with instrumental activities of daily living (IADLs) only, more likely to have mental impairments, and less likely to receive any formal care.[11]

Home Health Care

The majority of formal home care services are provided by home health care agencies. In 2003, there were 87 agencies licensed to provide home health care services in Connecticut.[12] Services offered by these agencies include nursing, physical therapy, speech therapy, homemaker/ home health aide services, occupational therapy and medical social services. Home health care agencies vary in size from as few as 20 patients to several thousand and are non-profit, for-profit or local pubic health agencies.

In 2002, home health agencies in Connecticut provided care to 47,500 Medicare beneficiaries. In addition, approximately 15,500 people received home health care services through the Medicaid and State-funded portions of the Connecticut Home Care Program for Elders (CHCPE). Commercial insurance and self-pay account for about 13 percent of the typical home health agency's revenue in Connecticut. Payment for home care by HMOs has been declining in recent years as Medicare HMOs have left the Connecticut market. Of the estimated $405 million in revenue to home health care agencies in Connecticut, Medicare and Medicaid provided the greatest share, at 44 percent and 41 percent respectively. The remaining revenue is from State-only funds (2 percent) and insurance and self-pay (13 percent).[13]

Adult Day Care

Adult day services are an option for frail elders who want to remain in their homes. They provide respite to family caregivers as well as therapeutic care for cognitive and physically impaired older adults. Individuals receive professional services ranging from social activities and therapeutic recreation to nursing care and rehabilitation services, representing a blend of traditional health and social services.[14] In SFY 2002, slightly over one-half of all adult day care clients were funded through the Connecticut Home Care Program for Elders, with 47 percent of clients paying out of pocket and two percent covered by private insurance. Approximately 33 percent of participants were over the age of 85 and women out numbered men two to one.

Medicaid Waivers

Most State funding for long-term care is through the Medicaid program. Medicaid home and community-based service waivers are the primary means by which states provide non-institutional long-term care. In an effort to provide needed long-term support services and avoid the need for services in institutional settings, five Medicaid Home and Community-Based Waivers are offered in Connecticut to individuals in specific populations. The Connecticut Department of Social Services (DSS) currently administers

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[11] William D. Spector et al, *The Characteristics of Long-Term Care Users, Agency for Healthcare Research and Quality*, Public Health Service (AHRQ Publication No. 00-0049), September 2000, Table 10.
[12] Connecticut Department of Public Health, 2003.
[13] Connecticut Association for Home Care, 2003.
[14] The Connecticut Association of Adult Day Centers, 2003, www.canpfa.org.

four of the five home and community-based services waivers under Medicaid, which are summarized below. The Department of Mental Retardation (DMR) administers the fifth waiver. Of the five waivers, one serves elders age 65 and over, the Personal Care and Acquired Brain Injury Waivers serve adults between the ages of 18 and 64, the Model Waiver serves all ages, but primarily children, and the DMR waiver has no age limit.[15]

1. Elder Waiver: This waiver constitutes the Medicaid portion of the Connecticut Home Care Program for Elders (CHCPE). On June 30, 2003, it provided community-based services to approximately 9,148 elders aged 65 and older, who would otherwise be institutionalized. Available services include adult day care, homemaker, companion, chore, home delivered meals, emergency response systems, care management, home health, skilled nursing, respite, assisted living and minor home modifications.

   The State-Funded Home Care Program, the other portion of the Connecticut Home Care Program for Elders (CHCPE), is supported solely by State funds and provides the same services as the Medicaid Elder Waiver. On June 30, 2003, the program served over 3,928 elders age 65 and older who are at risk of institutionalization and have assets greater than the Medicaid limit.

   Enrollment in the CHCPE (both waiver and State-funded) more than doubled between 1994 and 2003, increasing the number of participants from 6,024 to 13,076 partly as a result of a 'no waiting list policy' established in 1997.

   Only July 1, 2000, Connecticut implemented a 50-person Personal Assistance (PCA) pilot project to make self-directed personal care services available to persons transitioning from the Medicaid Personal Care Assistance Services (PCA) Waiver to the State-funded portion of the CHCPE, as well as for others on the CHCPE who do not have access to formal services in their community. This program allows a seamless transition for waiver clients when they turn 65 and become eligible for the CHCPE. On June 30, 2003, there were 35 individuals enrolled in the pilot program.

2. Personal Care Assistance Services Waiver: This waiver provides personal care services to persons with physical disabilities who are between the ages of 18 and 64. On June 30, 2003, 463 persons were receiving services under the program.

3. Acquired Brain Injury Waiver: This waiver provides 21 specific behavioral and support services to persons between the ages of 18 and 64 with acquired brain injury. The program is capped at 500 persons. On June 30, 2003, 152 people were enrolled in the program and many other individuals are in the process of applying.

[15] Connecticut Department of Social Services and the Connecticut Department of Mental Retardation, 2003.

4. Model Waiver: This waiver offers case management and home health services primarily to disabled children who would normally only qualify for Medicaid in an institution under the institutional "deeming" rules. In June of 2003, the program served 125 people, which is the maximum allowed under State law.

5. Department of Mental Retardation Waiver: This waiver offers a variety of services, including residential habilitation, day habilitation, respite, family support, and environmental modifications. On June 30, 2003, the program served 5,991 persons with mental retardation who would otherwise be institutionalized. Approximately 430 (7 percent) of the clients served were children.

State Long-Term Care Programs

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

Municipal, non-profit, private sector and volunteer services

In addition to the State programs, a wide array of statewide, regional and local long-term care supports and services exist throughout Connecticut that are administered by government agencies, non-profit and for-profit organizations, as well as volunteer groups. Each city and town provides services and accommodations to address the needs of elders and people with disabilities. Connecticut has five regional Centers for Independent Living, five Area Agencies on Aging, and a number of statewide and local mental health councils and advisory councils for persons with disabilities. There is also the Corporation for Independent Living and Co-op Initiatives, which are non-profit partners focused on new housing initiatives for person with disabilities. Also indispensable to the system of care are the myriad of volunteer organizations that address the needs of individuals with specific chronic illnesses and conditions, providing support and companionship that foster “sustainable” independent living.

Community Housing Options

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

Congregate Housing

Congregate housing provides frail elders with private living arrangements, moderate supportive services, and common areas of dining, socialization and other activities. These facilities furnish at least one daily meal, which is usually included in the monthly fee, housekeeping services and a variety of social and recreational activities. They are

generally meant for individuals who are basically self-sufficient but need a few services to help them to live independently.

As of June 30, 2003, 971 people age 62 and over lived in State-funded congregate housing in Connecticut. Residents were all low-income and predominantly white (96 percent). Of the 24 congregate housing facilities operating at this time, 16 offer assisted living services, serving 147 individuals.[16]

Assisted Living Services/ Managed Residential Communities

Assisted living is an alternative for seniors who need more assistance than may be available at home, but who do not require the intensive medical and nursing care provided in a nursing facility. In Connecticut, assisted living service agencies (ALSAs) are licensed to provide assisted living services in managed residential communities (MRC). Assisted living services can be provided in a number of different settings, such as continuing care retirement communities or elderly housing, as long as the facility provides the services to qualify as a MRC. Services include laundry, transportation, housekeeping services, meals, recreational activities, and assistance with activities of daily living. Primarily, assisted living is available to individuals age 55 and older who do not need full nursing home services, but require some health care, nursing, or assistance with activities of daily living.

In 2003, there were 64 ALSAs licensed in Connecticut providing services in 104 managed residential facilities.[17] There were 5,977 assisted living units in Connecticut as of January 2003, with an additional 88 under construction. The Connecticut Assisted Living Association estimates that there are approximately 4,700 individuals living in assisted living apartments. Assisted living residents are typically older, with 75 percent of residents over the age of 85. Approximately two-thirds of residents are female and almost all are white (98 percent).[18]

Since the cost of assisted living is virtually all paid out of pocket, these community living arrangements are available to individuals who can afford the cost of both room and board and services. Through a collaborative effort of the Department of Economic and Community Development, Department of Public Health, the Office of Policy and Management and the Department of Social Services, Connecticut is making assisted living services available to lower-income individuals through the Assisted Living Demonstration Project, State-funded congregate housing, HUD complexes and the Private Pay Assisted Living Pilot (a description of these new initiatives is provided in Appendix E – Long-Term Care Planning and Program Implementation Efforts).

Residential Care Homes

Residential Care Homes are facilities that provide a room, meals and supervision, but no nursing services, for individuals whose limitations prevent them from living alone. Services vary from facility to facility but may include dietary and housekeeping services,

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[16] Connecticut Department of Economic and Community Development, 2003.
[17] Connecticut Department of Public Health, 2003.
[18] The Connecticut Assisted Living Association, 2003.

monitoring of prescription medication, social and recreational opportunities, and assistance with activities of daily living. Residential Care Homes in Connecticut are licensed by the Department of Public Health.

In 2002, there were 108 Residential Care Homes in Connecticut, serving a total of 3,674 individuals. With regard to age, 20 percent are adults under the age of 55, 25 percent are 55 to 64, and 55 percent are age 65 and over. Fifty-seven percent of these individuals are female, 88 percent are white, seven percent are African American and three percent are Hispanic. On September 30, 2002, there were 2,951 Residential Care Home units in Connecticut, 2,830 of which were occupied, with 209 people waiting for available units. The majority of people residing in Residential Care Homes (84 percent) are supported through State Supplement/Aid to the Aged, Blind and Disabled (AABD) funds. In SFY 2003, $40.2 million in State Supplement funds helped cover the cost of living in a Residential Care Home, serving a monthly average of 2,301 individuals. Those who pay privately tend to be older than those receiving State Supplement funds, with 84 percent over the age of 65.[19]

Continuing Care Retirement Communities

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

As of June 30, 2002 there were 16 CCRCs operating in Connecticut, offering a total of 3,034 units. An additional CCRC with 166 units was under development. All CCRCs offer personal care services, assisted living services, and skilled nursing care. Only 3 CCRCs offer intermediate care beds and three offer residential care beds.[20]

Supportive Housing

The Connecticut Supportive Housing Demonstration Program, initiated in 1996, provides affordable, independent housing with a social service component, for tenants who need and want such services. Unlike more restrictive, treatment-based settings, tenants of supportive housing choose to live in the housing, hold the lease, and cannot be evicted for non-compliance with social services treatment plans. As of January 2001, there were nine projects, located in six Connecticut sites, with a total of 281 units of supportive housing. At least 70 percent of the units are reserved for occupancy by individuals who were formerly homeless or at risk of homelessness, and approximately 50 percent are

[19] Connecticut Association of Residential Care Homes, 2003.
[20] Connecticut Department of Social Services, 2003.

reserved for individuals with special needs (HIV/AIDS, mental illness, or a history of chronic substance abuse).[21]

The Department of Mental Health and Addiction Services funds several types of residential settings for individuals age 18 and older with psychiatric or addiction disorders.[22]

- *Group Homes* – A community-based residence with on-site staffing 24 hours per day, seven days a week. In SFY 2002, 325 individuals lived in these group home settings.

- *Supervised Housing* – Services are provided in intensively managed housing where individuals live in private or shared apartments with staff co-located 24 hours per day, seven days a week. In SFY 2002, 986 individuals lived in supervised housing.

- *Supported Housing* – Community-based private or shared apartments with weekly visits and support services. Staff is on call 24 hours per day, seven days a week, although they are not necessarily located on site. In SFY 2002, 1,852 individuals resided in supported housing.

- *Long-Term Treatment* – A 24 hour per day, seven days a week staffed residence with a highly structured recovery environment. The length of stay is typically three to six months. In SFY 2002, 2,256 individuals participated in this program.

- *Long-Term Care* – A 24 hour per day, seven days a week staffed residence with a structured recovery environment. In SFY 2002, 141 individuals participated in this program.

- *Transitional Care/ Halfway House* – A 24 hour per day, seven days a week staffed residence in a minimally structured environment. In SFY 2002, 822 individuals participated in this program.

Institutional Care Settings

Nursing Facilities

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

In SFY 2003, a total of 64,686 people received care in a Connecticut nursing facility. Residents were disproportionately female (67 percent). Although 89 percent of residents

[21] Arthur Andersen, LLP et al, *Connecticut Supportive Housing Demonstration Program*, Corporation for Supportive Housing, January 2001.
[22] Connecticut Department of Mental Health and Addiction Services, 2003.

were age 65 and older, among younger adults, 64 were under the age of 25, 1,902 were between the ages of 25 and 49, and 5,470 were between the age of 50 and 64. Ninety-one percent of residents were white, six percent were African American, and three percent were Hispanic.[23] About half of those who are cared for at home through the Connecticut Home Care Program for Elders eventually enter a nursing facility.[24]

Connecticut had a total of 30,857 licensed nursing facility beds in SFY 2003. Since 1991, efforts have been made to reduce the number of residents in Connecticut's nursing facilities by placing a moratorium on additional beds. Despite the moratorium, from 1991 to 1994, the total number of licensed beds increased from 29,391 to 32,149. This was due to the addition of beds that had been provided before the moratorium went into effect. From 1994 to 2003, the total number of licensed beds decreased by 1,292.[25]

Medicaid was the source of payment for 69 percent of individuals residing in a Connecticut nursing facility as of September 30, 2001, with private pay covering 18 percent and Medicare covering 12 percent (Table 2). Between 1995 and 2001, the percentage relying on Medicaid and Medicare increased by 2.3 percent and one percent respectively, and the percent paying out of pocket and relying on insurance decreased by 2.4 percent and 0.8 percent (Table 3).[26] The average annual private pay rate for a semi-private nursing home room in Connecticut is $89,100.[27]

Table 2
Residents in Connecticut Nursing Facilities by Payment Source, September 30, 2001

Payment Source	Number	Percent
Medicaid -- Connecticut	19,941	68.5 %
Private Pay	5,197	17.8 %
Medicare	3409	11.7 %
Insurance	246	0.8 %
Medicaid – Out of State	161	0.6 %
Other	152	0.5 %
Total	**29,106**	**100.0 %**

Note: Total excludes 186 residents for whom payment source was not reported.
Source: State of Connecticut Nursing Facility Registry, Office of Policy and Management, Policy Development and Planning Division.

In Connecticut, nursing home expenditures over the last decade have increased from approximately $500 million in SFY 1990 to over $1.032 billion by SFY 2002, an increase

[23] Connecticut Department of Public Health, 2003.
[24] Connecticut Department of Social Services, 2001.
[25] Connecticut Department of Public Health, 2003.
[26] State of Connecticut Nursing Facility Registry, Office of Policy and Management, Policy Development and Planning Division.
[27] Connecticut Department of Social Services, September 30, 2002.

of 107 percent.[28] When compared to the rest of the nation, the fraction of Connecticut health care spending going to nursing home (15 percent) is the largest in the U.S.[29]

Table 3
Percent Distribution of Residents in Connecticut Nursing Facilities by Payment Source on September 30, 1995 and 2001

Payment Source	1995	2001
Medicaid -- Connecticut	66.2	68.5
Private Pay	20.2	17.8
Medicare	10.7	11.7
Insurance	1.6	0.8
Medicaid – Out of State	0.5	0.6
Other	0.8	0.5

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

Intermediate Care Facilities for the Mentally Retarded – ICF/MR
On June 30, 2003, a total of 1,175 people over the age of 18 in Connecticut resided in an ICF/MR. Of these individuals, 850 people resided in an ICF/MR operated by the Department of Mental Retardation in one of seven locations throughout the state. Another 325 individuals resided in 63 group homes at an ICF/MR level of care. In June 2002, of the 871 residents of the publicly operated programs, 63 percent were between the age of 19 and 54, 21 percent were between the ages of 55 and 64, and 16 percent were age 65 and over. At this level of care, residents received residential and day habilitation services, prevocational services and supported employment services. All services are financed through the State Medicaid Program.[30]

Chronic Disease Hospitals
On June 30, 2003, there were six chronic disease hospitals in Connecticut with a total of 772 beds. Medicaid covered a monthly average of 299 individuals in 2003. These long-term hospitals provide diagnosis, care and treatment of a wide range of chronic diseases.

C. Long-Term Care Financing

Nationally, over 60 percent of expenditures for long-term care services are paid for through public programs, primarily Medicaid and Medicare. Individuals finance almost one-fourth of these expenditures out-of–pocket. Private insurance, both traditional and long-term care, pays for slightly over 10 percent. (See Figure 4). In addition to these

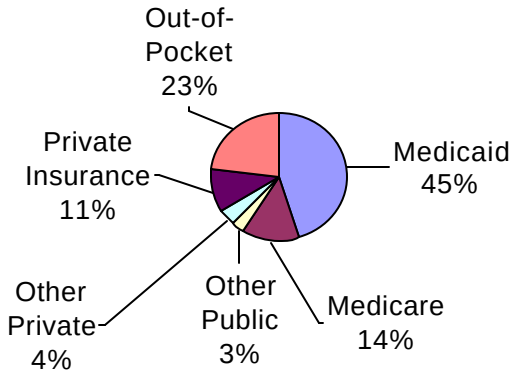
[28] Office of Policy and Management (Marc Ryan's slide presentation at the April 11, 2002 Long-Term Care Conference, Hartford, Connecticut).
[29] Dennis Heffley, Health Care Spending, Connecticut Style, *The Connecticut Economy*, Winter 2003, pp 6&7.
[30] Connecticut Department of Mental Retardation, 2003.

expenditures is the unpaid long-term care provided by family members and other informal caregivers.

Medicaid

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

Figure 4
Funding Sources for Long-Term Care, U.S., FY 2000



Source: U.S. General Accounting Office, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, No. GAO-02-544T, March 21, 2002, p 3.

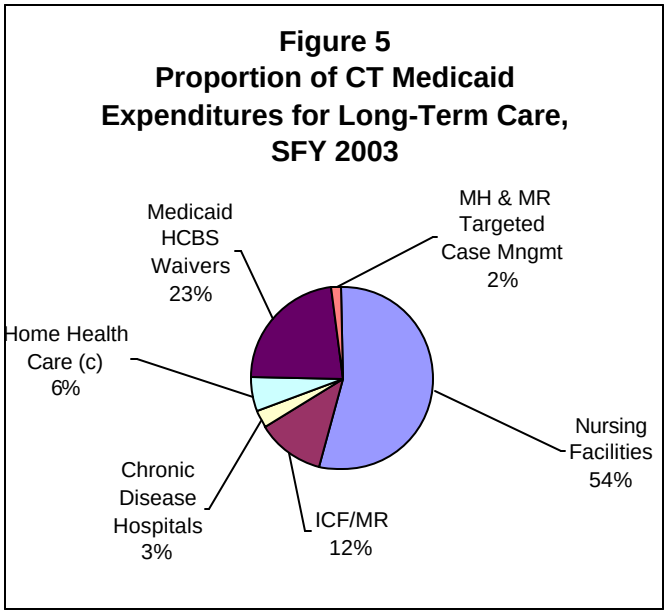
Note: Does not include unpaid care provided by family or other informal caregivers or expenditures for nursing home and home health services provided by hospital-based services.

Total national Medicaid spending for long-term care increased from $33.8 billion in federal fiscal year (FFY) 1991 to $75.3 billion in FFY 2001.[31] Historically, Medicaid long-term care spending was almost exclusively for institutional services. In FY 1990, more than 90 percent of Medicaid long-term care expenditures went to institutional care

[31] United States General Accounting Office, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened*, June 2003, GAO-03-567, p 3.

(nursing homes and intermediate care facilities for the mentally retarded (ICF/MR) facilities) and only 10 percent were spent on home and community-based care programs. By 2001, the percentage shifted to 71 percent of Medicaid long-term care dollars for institutional care and 29 percent for home and community-based services. [32]

Nationally, the elderly and people with disabilities comprise 25 percent of all Medicaid beneficiaries (9 and 16 percent respectively) but account for 70 percent of Medicaid acute and long-term care spending (27 and 43 percent respectively).[33] In Connecticut in 2000, the elderly and people with disabilities comprised 27 percent of Medicaid beneficiaries (13 and 14 percent respectively) but account for 82 percent of Medicaid spending (43 and 39 percent respectively).[34]



Source: Office of Policy and Management, Policy and Planning Division, 2003.

In SFY 2003, the Connecticut Medicaid program spent $1.9 billion on long-term care. Of that expenditure, 69 percent was spent on institutional care and 31 percent on home and community care. Medicaid long-term care expenses account for 56 percent of all Medicaid spending and 15 percent of total expenditures for the State of Connecticut.[35]

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[32] Barbara Coleman et al, State Long-Term Care: *Recent Developments and Policy Directions*, National Conference of State Legislatures, 2002, p 4.
[33] Kaiser Commission on Medicaid and the Uninsured, *Medicaid: Fiscal Challenges to Coverage*, May 2003.
[34] Joan Alker et al, *Federal Proposals to Restructure Medicaid: What Could They Mean for Connecticut?* Health Policy Institute, George Washington University, Commissioned by Anthem Foundation of Connecticut, Inc., Children's Health Council and the Connecticut Health Foundation, June 20, 2003.
[35] Office of Policy and Management, Policy Development and Planning Division, 2003.

The proportion of Medicaid long-term care expenses for home and community-based care in Connecticut has increased from 23 percent in SFY 1996 to 31 percent in SFY 2003. This is, in part, a result of efforts to reduce nursing home use by limiting nursing home care through pre-admission screening, moratorium on new nursing home beds, and constraints on the growth in Medicaid payments on the one hand and expanding home care primarily through Medicaid waivers on the other.

Medicare

Medicare provides health care coverage for people age 65 and older. Individuals under age 65 with disabilities are also covered, however, only after they have received Social Security disability benefits for two years. Medicare only covers 33 percent of individuals living at home with long-term care needs between the ages of 18 and 64.[36] Medicare spending accounted for only 14 percent (about $19 billion) of total long-term expenditures in 2000.[37]

Although Medicare is the major health insurance program for the elderly and certain persons with disabilities, it does not cover most long-term care costs. Primarily, acute care is covered, with limited long-term care coverage available. Medicare covers nursing home stays for no more than 100 days following a hospital stay of at least three days. Assisted living costs are not covered. With regard to home health care, coverage is limited by type and duration, focusing on rehabilitation rather than long-term care. For homebound persons needing part-time skilled nursing care or physical therapy services, Medicare pays for home health care, including personal care services provided by home health aides.

Older Americans Act

Another major source of federal long-term care funds is the Older Americans Act (OAA), enacted in 1965 to promote the well being of older persons and help them remain independent in their communities. All persons age 60 and older are eligible to receive services, but states are required to target assistance to persons with the greatest social or economic need. In FY 2001, the total federal appropriation for the OAA was $1.1 billion. In Connecticut, the OAA provides the largest source of community service funding, approximately $14.4 million in FFY 2003. This funding is distributed by formula to the Area Agencies on Aging who in turn contract with community-based organizations to provide social and nutritional services.

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

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

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[36] Judith Feder et al., Long-Term Care in the United States: An Overview, *Health Affairs*, May/June 2000, p 42.

[37] U.S. General Accounting Office, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, No. GAO-02-544T, March 21, 2002, p 5.

of settings, including their own apartments, housing for the elderly or persons with disabilities, or residential care homes.

Rental Subsidies

Many individuals with disabilities need assistance with covering their rental costs if they are going to be able to live in the community. While federal Medicaid law prohibits home and community-based waiver programs from covering the costs of room and board (room and board expenses are only covered in institutional settings under Medicaid), there are both state and federal sources of rental support in the form of Section 8 vouchers, rental subsidies in State-funded congregate facilities, the State's rental assistance program, State Supplement funds and other sources.

Private Pay

Nationally, almost a quarter of long-term care costs were paid directly by individuals in 2000 (about $31 billion), rendering out-of-pocket payments as the second largest source of long-term care financing. The vast majority of these payments were used for nursing home care[38] (Figure 4)

Private Long-Term Care Insurance

Nationally, private insurance paid for 11 percent (about $15 billion) of long-term care expenditures in 2000 (Figure 4). Both traditional health and long-term care insurance are included. With respect to long-term care insurance policies, less than 10 percent of the elderly and an even lower percentage of those between the ages of 55 to 64 have purchased them. [39] In Connecticut, the number of individuals purchasing long-term care insurance in 2002 was more than double the number who purchased policies in 1994. As of December 31, 2002, there were over 88,000 Connecticut residents with private long-term care insurance policies in force.[40]

[38] U.S. General Accounting Office, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, No. GAO-02-544T, March 21, 2002. P 5.
[39] U.S. General Accounting Office, Long-Term Care: *Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, No. GAO-02-544T, March 21, 2002. P 5.
[40] Office of Policy and Management, Policy Development and Planning Division, 2003.

IV. FUTURE DEMAND FOR LONG-TERM CARE

A. Population and Disability Trends

Although long-term care services and supports are needed by a diverse number of individuals with disabilities or chronic illnesses of all ages, and not solely the elderly, it is important to recognize the significant impact the aging of our society will have on the future demand for long-term care. In 1900, seniors accounted for less than 5 percent of the total U.S. population. A century later, the proportion of seniors in the U.S. population has grown to 12.4 percent or 33 million. By 2030, the senior population is expected to more than double to an estimated 71 million, or 20 percent of the U.S. population.[41]

Over the next 25 years, the population in Connecticut is projected to grow by over 450,000 people, an increase of 14 percent.[42] According to U.S. Census Bureau projections, between 2000 and 2025, the number of children, youth and adults will increase about 9 percent or 244,000. In contrast, the number of those age 65 and over will increase by 46 percent or 210,000, due to the aging of the Baby Boom generation (Table 4).

Table 4
Connecticut Population Projections: 2000 – 2025

	2000	2005	2010	2015	2020	2025	Pop. growth: 2000 – 2025	Percent change: 2000 – 2025
0 to 20	915,606	908,964	910,118	921,160	952,880	993,471	77,865	9%
21 to 64	1,906,936	1,952,180	2,012,411	2,058,829	2,079,499	2,073,146	166,210	9%
65 +	461,600	455,785	476,977	525,709	588,899	671,922	210,322	46%
Total	**3,284,142**	**3,316,929**	**3,399,506**	**3,505,698**	**3,621,278**	**3,738,539**	**454,397**	**14%**

Source: 1995 U.S. Census Bureau population projections (1995 – 2025).

Significant growth in the proportion of seniors in the population is not expected until the Baby Boom generation reaches retirement age. In Connecticut between 2000 and 2010 the proportion of elderly in the population is expected to remain relatively level. As the Baby Boom generation (those born between 1946 and 1964) reaches retirement age after 2010, the growth of the elderly population is expected to accelerate rapidly. By the year 2025, the survivors of the Baby Boom will be between the ages of 61 and 79. The

[41] Centers for Disease Control and Prevention, Public Health and Aging: Trends in Aging -- United States and Worldwide, *MMWR Weekly*, February 14, 2003, 52(06); pp 101-106.
[42] The data presented is from the U.S. Census Bureau Population Projections for 1995 through 2025, based on the 1990 Census. Population projections based on the 2000 Census are not anticipated until early 2004.

proportion of people age 65 and over is expected to increase from 14 percent in 2000 to 18 percent in 2025 (Table 5). [43]

Table 5
Connecticut Population Projections,
Percent Distribution of Population by Age: 2000 -- 2025

	2000	2005	2010	2015	2020	2025
0 to 20	28%	27%	27%	26%	26%	27%
21 to 64	58%	59%	59%	59%	57%	55%
65 +	14%	14%	14%	15%	16%	18%
	100%	100%	100%	100%	100%	100%

Source: 1995 U.S. Census Bureau population projections (1995 – 2025).

In 2000, the U.S. Census estimated that there were over 546,000 individuals age five and over in Connecticut with one or more disabilities (excluding individuals living in institutions). Between 2000 and 2025, this number is expected to grow by 20 percent, or 109,000 people, to an estimated 655,000.[44] As illustrated in Table 6, the percentage increase in persons with disabilities varies by age group, with the number of children and youth increasing by six percent, adults by nine percent and elders by 46 percent.

Table 6
Persons with Disabilities in Connecticut by Age: 2000 – 2025

	2000 Population with a Disability	2025 Population with a Disability	2000/ 2025 Increase	Percent Increase
5 to 20	54,000	57,000	3,000	6%
21 to 64	321,000	349,000	28,000	9%
65+	171,000	249,000	78,000	46%
Total	**546,000**	**655,000**	**109,000**	**20%**

Source: Office of Policy and Management based on 1995 U.S. Census Bureau population projections for Connecticut (1995 – 2025). To estimate the 2000 population with a disability, the 1995 population estimates for Connecticut were used, applying the percentage distribution of persons with disabilities from the Census 2000 estimates for Connecticut.

Although the projections provided in Table 6 assume that the proportion of people in the population with disabilities will remain constant, there is evidence that the prevalence of disability maybe diminishing over time. For the past two decades, the number of elderly

[43] U.S. Census Bureau, Population Division, Population Paper Listing #47, Population Electronic Product #45.
[44] These projections are based on the 2000 Census disability data applied to U.S. Census Bureau Population Projections for 1995 through 2025. The Census does not tabulate disability status for people under age five or individuals in institutions. Disability projections assume a constant rate of disability over time.

persons has remained fairly constant while the percentage of those with disabilities has fallen between one and two percent a year. Whether these declines also apply to populations other than the elderly has not been established.[45] Possible factors contributing to this decrease in the prevalence of disability include improved health care, improved socioeconomic status and educational attainment, and better health behaviors. Also, the proportion of persons with disabilities in the community who use assistive technology but do no require human assistance has increased dramatically since the mid-1980s.[46] [47]

There is disagreement regarding the future course of the decline in disability. One position holds that it is unclear at this point whether these trends will continue or how this decline will affect future demand for care.[48] AARP predicts that due to declines in disability the future demand for support services among the elderly will grow very slightly."[49] Other experts maintain that the sheer numbers of aging baby boomers are expected to overwhelm the positive benefits of the decreased prevalence of disability.[50] [51]

B. Demand for Long-Term Care

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

As discussed in Section III, Medicaid is the largest and most significant payer of long-term care services at both the state and national level. Of the nearly 40,000 Medicaid clients who received long-term care services and supports in Connecticut each month in SFY 2003, 48 percent received services in the community and 52 percent received care in an institutional setting (Table 7). If these ratios remain steady over the next two decades and disability rates do not rise or fall, U.S. Census Bureau disability data and population projections for Connecticut suggest that in the year 2025 there will be a 20 percent increase in individuals receiving Medicaid services: an additional 3,819 Medicaid clients receiving long-term care in the community and an additional 4,131 receiving care in

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[45] Vicki A. Freedman, PhD., et al, Recent Trends in Disability and Functioning Among Older Adults in the United States, *Journal of the American Medical Association*, December 25, 2002, Vol. 288, No. 24, p 3137.
[46] AARP, *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, 2003, p 8.
[47] David M. Cutler, Declining Disability Among the Elderly, *Health Affairs*, November/ December 2001, pp 17-21.
[48] Vicki A. Freedman, PhD., et al, Recent Trends in Disability and Functioning Among Older Adults in the United States, *Journal of the American Medical Association*, December 25, 2002, Vol. 288, No. 24, pp 3145-3146.
[49] AARP, *Before the Boom: Trends in Long-Term Support Services for Older American with Disabilities*, October 2002, pp 41-42.
[50] Congressional Budget Office Memorandum, *Projections of Expenditures for Long-Term Care Services for the Elderly*, March 1999.
[51] General Accounting Office, Long-Term Care: *Aging Baby Boom Generation will Increase Demand and Burden on Federal and State Budgets*, GAO-02-544T, March 21, 2002, p 10.

institutions (Table 8). To meet this additional demand for long-term care, Medicaid expenditures are expected to grow from $1.9 billion in SFY 2003 to $6.4 billion in 2025, assuming current ratios of institutional and community care and a five percent annual inflation rate (Table 9).

Table 7
Connecticut Medicaid Long-Term Care Clients and Expenditures: SFY 2003

	SFY 2003 Medicaid LTC Clients, Monthly Average	SFY 2003 Medicaid LTC Expenditures
Community-based Care	**19,095**	**$601 million**
Institutional Care	**20,654**	**$1,313 million**
Total	**39,749**	**$1,914 million**

Source: Connecticut Department of Social Services, 2003.

In Oregon and Maine, both model states in terms of long-term care, state policies have been implemented to offer individuals with long-term care needs the opportunity to live in the least restrictive setting possible. If current ratios of Medicaid community and institutional long-term care services were to evolve over time to reflect the greater emphasis on home and community-based services achieved in these two states, Connecticut could develop a long-term care system that provides community-based care to 75 percent instead of 48 percent of its Medicaid long-term care clients. If the number of Medicaid clients receiving long-term care in 2025 reflected this optimal ratio, Connecticut could expect an additional 16,679 clients receiving community-based services and supports, but see a decrease of 8,729 in individuals receiving care in institutions (Table 8). By holding the number of individuals served in 2025 constant, and increasing the proportion of individuals receiving community-based care to 75 percent, Medicaid long-term care expenditures are projected to be $5.2 billion, instead of $6.4 billion; $1.2 billion less than the State might otherwise have spent (Table 9).

Total Medicaid long-term care expenditures in 2025 are projected to be lower under the optimal ratios because in general, although the same numbers of people are served, the cost of serving people at home and in the community, on average,[52] is significantly lower than serving them in institutions. For instance, under the Medicaid program, nursing home care is approximately 3.5 times more costly than assisted living services and 4.4 times more costly than home care services (Figure 6).

Under the optimal ratio scenario in 2025, there would be 35,774 Medicaid clients receiving care in the community. Based on data from Oregon[53], a state that served 79

[52] Although the average cost of serving people in the community is less expensive than care in institutions, this is not the case in all circumstances, such as the cost of caring at home for a person with Alzheimer's Disease or other severe disabilities.
[53] Oregon Department of Human Services, Seniors and People with Disabilities, SFY 2001.

percent of their Medicaid long-term care clients in the community in SFY 2001, it can be projected that 19,676 of these Connecticut Medicaid clients (55 percent) would be residing in their own homes and 16,098 (45 percent) would be living in assisted living, congregate, or residential care settings.

Table 8
Projections of Connecticut Medicaid Long-Term Care Clients by Current and Optimal Ratios of Community and Institutional Care SFY 2025

	Current Client Ratio	Current Ratio -- clients/ monthly average	Increase from 2003 to 2025	Optimal Client Ratio	Optimal Ratio-- clients/ monthly Average	Increase from 2003 to 2025
Community-based Care	48%	22,914	3,819	75%	35,774	16,679
Institutional Care	52%	24,785	4,131	25%	11,925	-8,729
Total		47,699	7,950		47,699	7,950

Source: Office of Policy and Management, Policy and Planning Division, 2003. Based on: (1) Department of Social Services Medicaid data for SFY 2003; (2) U.S. Census Bureau 1995 population projections for Connecticut (1995-2025); (3) U.S. Census Bureau, 2000 disability data for Connecticut.

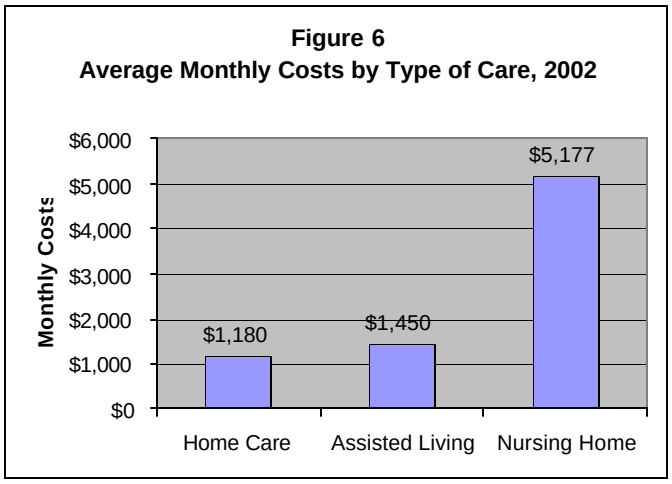
Table 9
Projections of Connecticut Medicaid Long-Term Care Expenditures by Current and Optimal Client Ratios of Community and Institutional Care SFY 2025, in millions of dollars

	Current Client Ratio	2025 Expenditures with Current Client Ratio	Increase from 2003 to 2025	Optimal Client Ratio	2025 Expenditures with Optimal Client Ratio	Increase from 2003 to 2025
Community-based Care	48%	$2,009	$1,408	75%	$3,135	$2,534
Institutional care	52%	$4,389	$3,076	25%	$2,112	$799
Total		$6,398	$4,484		$5,247	$3,333

Note: Expenditure projections include a 5 percent annual rate increase.
Source: Office of Policy and Management, Policy and Planning Division, 2003. Based on: (1) Department of Social Services Medicaid data for SFY 2003; (2) U.S. Census Bureau 1995 population projections for Connecticut (1995-2025); (3) U.S. Census Bureau, 2000 disability data for Connecticut.

With regard to institutional services, it is projected that in 2025 an estimated 11,925 Medicaid long-term care clients would receive these services under the optimal ratio

scenario. Compared to the amount of people that would be expected to receive services under current service ratios, this would represent 8,188 fewer people in nursing facilities, 415 people less in ICF/MRs, and 127 less in a Chronic Disease Hospital.



Source: State of Connecticut, Governor's Budget Summary FY 2003-FY2005, February 2003, p 73.

Looking beyond Medicaid, estimates can be made of the numbers of people in need of long-term care services and supports in 2025 if optimal ratios of community and institutional services are achieved. Seventy-five percent or 491,250 individuals with long-term care needs would be receiving supports in the community, with 270,188 (55 percent) receiving care at home and 221,062 (45 percent) residing in assisted living, congregate or residential care settings. Twenty-five percent, or 163,750 would be receiving institutional care.

Table 10
Projections of Persons with Disabilities in Connecticut by Care Setting, 2025

Setting	Persons with Disabilities
Community-based Care	491,250
Home Care	*270,188*
Residential Care Settings	*221,062*
Institutional Care	163,750
Total	655,000

Source: Office of Policy and Management, Policy Development and Planning Division, 2003. Based on: (1) U.S. Census Bureau 1995 population projections for Connecticut (1995-2025); (2) U.S. Census Bureau, 2000 disability data for Connecticut.

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

C. Caregiver Supply and Demand

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

Informal Caregivers

Relatives, friends and other unpaid caregivers account for the vast majority of individuals providing long-term care supports to individuals across the lifespan in the U.S. Estimates ranges from 76 percent[54] to 80 percent, and upwards to 92 percent[55]. Many individuals who require and use long-term care in the community do not get counted because they rely on informal caregivers and voluntary organizations. According to national estimates, in 2000, there were 22 million unpaid informal caregivers aiding 14 million elderly persons in the U.S. These numbers are projected to rise to approximately 40 million individuals caring for approximately 28 million Americans in 2050 (Figure 7).

An estimate of the dollar value of paid and unpaid personal assistance provided to adults age 18 and over living at home found that of the almost $200 billion worth of care provided, only 16 percent of this was for formal paid care, representing $32 billion in home health services. Unpaid care provided had an economic value of approximately $168 billion. Older persons were more likely to receive paid personal assistance, while working-age people rely to a greater extent on unpaid help.[56]

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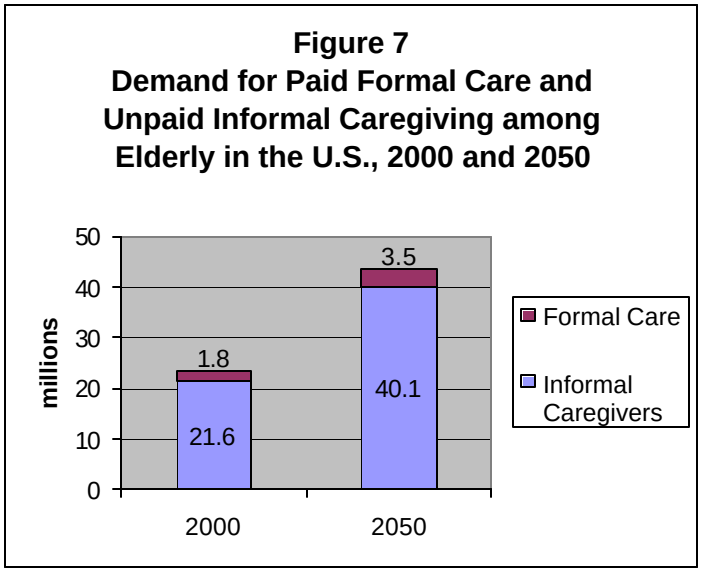
[54] Nora Super, *Who Will Be There To Care? The Growing Gap Between Caregiver Supply and Demand*, National Health Policy Forum, The George Washington University, January 23, 2003, p 3.
[55] Department of Health and Human Services, *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation*: Report to Congress, May 14, 2003, p 7.
[56] Mitchell P. LaPlante et al, Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home," *Health Services Research*, Vol. 37, No. 2, April 2002.

Despite this reliance on informal care, many factors are working against the availability of informal caregivers. Informal care is adversely affected by a number of factors, including the geographic dispersion of families, smaller family size, and the increasing participation of women in the workforce. In coming decades, fewer and fewer individuals may have the option of unpaid care because a smaller proportion may have a spouse, adult child, or sibling to provide it. By 2020, the number of elderly throughout the country who will be living alone with no living children or siblings is estimated to reach 1.2 million, almost twice the number without family support in 1990.[57] According to the National Family Caregivers Association, the number of potential family caregivers for each person needing care will decrease from 11 in 1990 to 4 by 2050.[58]



Source: Department of Health and Human Services, *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress*, May 14, 2003, page 7. Estimates are based on data from the National Long-Term Care Survey, 1989 Caregiver Supplement and National Health Interview Survey, 1994.

Paid Direct Caregivers

Nationally, the Bureau of Labor Statistics estimates that there were 1.9 million jobs for direct care workers in long-term care settings in 2000. Types of workers include nurse practitioners, registered nurses, licensed practical nurses, certified nursing assistants, nurse aides, orderlies, home health workers, home health aides, home care aides, personal care attendants, personal care aides, geriatric aides, and caregivers. Most paid caregivers are paraprofessionals, delivering the largest share of the primarily low-tech personal care needed by those with long-term care needs. Registered nurses and licensed practical nurses made up approximately 28 percent of this workforce and paraprofessional workers

[57] Urban Institute, *Long Term-Care: Consumers, Providers, and Financing, A Chart Book*, Washington, D.C., March 2001.
[58] Family Caregiving Statistics, National Family Caregivers Association, www.nfcacares.org/NFC2002_stats.html

represent 72 percent. Of the total number of direct care worker jobs in long-term care, 56 percent were in nursing facilities, 17 percent in assisted living and other residential care settings, and the remaining 27 percent in home health care services.[59]

Currently, the demand for long-term care workers exceeds the supply, whether in home care, assisted living and other residential settings or in institutional settings. Nationally, annual turnover rates among nurse aides approach 100 percent in nursing homes. In home health care, turnover rates are 21 percent nationwide for nurses and 28 percent for home health aides.[60] These shortages of long-term care workers in Connecticut have increased pressure on state and federal governments to provide incentives to attract and retain workers. There is a need to consider ways to increase the numbers of direct care workers and provide incentives to home care agencies, nursing homes, and other long-term care providers for recruiting and retaining workers.

With the aging of the population and corresponding increase in potential long-term care users, the demand for long-term care workers is expected to sharply increase. In addition to changes in the composition of the population, changes in the health care system have also added to this demand. Expansions in community-based care have increased the demand for workers. With advances in medical care and technology, individuals with chronic illnesses and disabilities are living longer.

According to the federal Department of Labor, labor force growth is expected to slow dramatically in the future, reflecting the large impact of retiring baby boomers. The labor force is expected to grow by only 1.1 percent between 2000 and 2010 and by 0.4 percent between 2010 and 2025. However, the Bureau of Labor Statistics estimates that between 2000 and 2010, employment for direct care workers such as registered nurses, licensed practical nurses and aides will grow annually by 5.5 percent in community-based services, 5.2 in residential care, and 2.3 percent in nursing homes. These growth rates will be difficult to achieve or sustain in an environment of slowing labor force growth.[61]

By 2020 it is predicted that the number of registered nurses will be about the same as it is today, a nearly 20 percent shortfall in the estimated number of RNs required to respond to the need. The reasons cited for this include the aging of the nursing workforce, lower nursing salaries relative to other professions, smaller nursing school graduating classes, and an increase in the size of the elderly population needing care.[62]

Connecticut is systematically losing both its younger and older workers. Since 1980, Connecticut's population grew at less than half the national rate during the last two decades. In contrast, Colorado, a similar state in terms of weather and population size, grew twice as fast as the national rate. As experienced baby boom workers age and leave

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[59] Department of Health and Human Services, *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress*, May 14, 2003, p 10.
[60] Carol Raphael, Long-Term Care: Confronting Today's Challenges, *AcademyHealth*, June 2003, page 1.
[61] Department of Health and Human Services, *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress*, May 14, 2003, pp 14 - 15.
[62] Peter I. Buerhaus, PhD., RN et al, Implications of an Aging Registered Nurse Workforce, *Journal of the American Medical Association*, June 14, 2000, Vol. 283, No. 22.

the workforce, younger workers may not be available to replace them in sufficient numbers. [63]

In Connecticut, the Department of Labor shows significant increases in creation of jobs for the professional and paraprofessional long-term care workforce between 2000 and 2010 (Table 11). While the largest growth in terms of absolute numbers over these 10 years is projected among registered nurses (6,180) and nursing aides (4,250), the greatest percent increase is among home health aides (28 percent) and personal and home care aides (40.7 percent).

Table 11
Connecticut Occupational Forecast

Job Title	2000 Empl.	2010 Empl.	Net Change	Percent Change	Total Annual Openings
Registered nurses	30,560	36,740	6,180	20.2%	1,235
Licensed Practical and Vocational Nurses	7,010	7,990	980	14%	278
Nursing Aides, orderlies and Attendants	23,640	27,890	4,250	18%	727
Home Health Aides	8,410	10,760	2,350	28%	342
Personal and Home Care Aides	4,470	6,280	1,820	40.7%	250

Source: Connecticut Department of Labor, Office of Research, Labor Market Information, www.ctdol.state.ct.us/lmi/misc/occsindemand.htm

[63] James R. Moor, Connecticut's Workforce Drain, *The Connecticut Economy*, Summer 2002, p 6.

V. RECOMMENDATIONS AND ACTION STEPS

A. Balancing – the Long-Term View

As noted earlier, balancing Connecticut's long-term care system is a central theme of this Plan. Balancing the mix of home and community-based and institutional care as well as the mix of public and private resources is needed if Connecticut hopes to provide real long-term care choices for its residents and to achieve the long-standing Vision, Mission and Governing Principles put forth by this Plan.

The following recommendations and action steps are designed to facilitate the balancing of the system in these two important areas. While this Plan maps out the need for long-term care over the next 20 years, the recommendations are designed, if implemented, to take action that will address current needs as well as future demands. These recommendations are primarily focused on initiatives State government can undertake. In this regard, "Connecticut" and 'the State" are used interchangeably to refer to State government unless the reference is to Connecticut as a whole. The State agencies represented on the State Interagency Work Group of the Long-Term Care Planning Committee will work together, in collaboration with the Long-Term Care Advisory Council, to address those recommendations that do not require legislative action or reallocated or new resources.

In addition, much of the emphasis is on the Medicaid program since it is the largest of any payer, public or private, of long-term care. While the focus of this Plan is on State government, we recognize the vital role that cities, towns, the private sector and individuals and families play in the long-term care system. As discussed earlier, government at all levels needs to work in partnership with individuals, families and the private sector in order to develop a quality and effective system.

While this Plan does not prioritize the specific recommendations and action steps, the Governor and General Assembly should consider legislation that will create in statute the following broad philosophical statement to guide future policy and budget decisions: ***Individuals should receive care in the least restrictive setting with institutional care provided as a last resort.*** Such a statement will position Connecticut to make the necessary changes to the laws and regulations that govern the State's long-term care system to make real choices for consumers a reality. Within this framework, Connecticut can begin to prioritize and detail the steps required to realize this goal.

In addition, although extensive data is provided in this Plan describing the potential need and demand for long-term care, what is lacking is a Connecticut specific comprehensive analysis of the need for long-term care and the extent to which these needs are not met. Therefore, ***to assist in the implementation and refinement of recommendations and action steps of this Plan, adequate resources must be allocated to accomplish such a comprehensive assessment and analysis***.

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

Over the last several years, Connecticut has made significant progress in developing home and community-based and residential alternatives to institutional care. For instance, Connecticut eliminated its waiting list for home care for elders; expanded income eligibility for State-funded home care for elders; introduced subsidized assisted living in State-funded congregate facilities, HUD complexes and private pay assisted living communities; and has begun development of affordable assisted living units (see Appendix E for more details). In addition, there has been more than a doubling of the number of elderly State-funded and Medicaid home care clients since 1994. However, while progress has been made in shifting the balance between home and community-based and institutional care, Connecticut's publicly financed long-term care system still, largely due to federal Medicaid rules, provides easier access to care in institutional settings.

Currently, Connecticut's Medicaid program provides approximately 48 percent of its long-term care clients with home and community-based care (home care, adult day care and assisted living) and serves 52 percent of its clients in institutional care settings (nursing facilities, ICF/MRs and chronic disease hospitals).[64] Consequently, because of the high cost for institutional care, the Medicaid program spends approximately 70 percent of its long-term care dollars on institutional care, with only 30 percent devoted to home and community-based care. Connecticut should strive to shift these ratios so that real choices are available for home and community-based care.

In order to achieve such a change, ***Connecticut should work to develop a system that provides for more choice, increasing the percentage of Medicaid long-term care clients receiving home and community-based care from 48 to 75 percent by 2025, requiring approximately a one percent increase in the percentage of Medicaid long-term care clients served in the community every year.*** This type of change is within our reach and similar accomplishments have already been realized in other states such as Oregon and Maine.

If Connecticut is able to meet this goal of serving three out of every four Medicaid long-term care clients in the community, the impact on future long-term care expenditures will be significant. Based on U.S. Census Bureau disability data and population projections, it is estimated that by 2025 the number of persons with disabilities in Connecticut is expected to grow by 109,000 or 20 percent. The percentage increase in persons with disabilities varies by age, with the number of children and youth increasing by six percent, adults by nine percent and elders by 46 percent. Assuming current ratios of community-based to institutional care, a five percent per year inflation rate and a 20 percent increase in the number of individuals with disabilities, Medicaid expenditures for long-term care are anticipated to grow from $1.9 billion in SFY 2003 to almost $6.4 billion by SFY 2025 to meet the expected increase in demand for long-term care.

[64] Home and community-based services and institutional care are more narrowly defined with respect to the Connecticut Medicaid program than they are generally in this Plan.

However, with 75 percent of individuals receiving community care in 2025, these long-term care expenditures are only expected to be $5.2 billion, $1.2 billion less than the State might otherwise have spent that year. In addition, approximately 60 percent, up from 30 percent, of Medicaid long-term care expenditures would go toward the cost of care in the community. This cost avoidance over time not only allows Connecticut to provide relief to the Medicaid budget but also allows Connecticut to meet the needs of a larger group of individuals.

This Plan takes a conservative approach to projecting the numbers of individuals with disabilities over the next twenty years by holding the percentage of persons with disabilities constant over time. As described in Chapter IV, the percentage of elderly with disabilities has fallen over the last two decades. Experts disagree whether this decline in the rate of disability will continue or whether the expected demographic changes will overwhelm these gains. Fluctuations in either direction in the rate of disability will have an impact on the cost of providing long-term care services and supports. For example, even as little as a five percent change in the overall rate of disability in 2025 would mean the addition or reduction of 32,750 people with disabilities, and a change up or down in 2025 of approximately $320 million in Medicaid long-term care expenses (in 2025 dollars).

A number of other states, notably Oregon and Maine, have made a commitment to balancing their long-term care systems by offering their residents opportunities to live in the least restrictive settings possible.[65] Oregon, a state with a population size and demographic profile similar to Connecticut, has a third as many individuals in nursing homes as does Connecticut while they have nearly 150 percent more individuals in their Medicaid home care program. Moreover, three-quarters of Oregon's Medicaid clients are covered in their own homes or assisted living settings. At the same time, total long-term care spending in 2001 in Oregon amounted to $1.1 billion, compared to $1.9 billion spent by Connecticut. While Oregon differs from Connecticut both economically and geographically, it does provide an example of how a commitment to home and community-based care can result in increased choices for its residents.

A sister New England state, Maine, also has made significant progress in rebalancing their long-term care system. Beginning in 1994, Maine began to implement a series of policy changes that included tightening Medicaid nursing home admission standards, adopting universal, statewide pre-admission screening for all nursing home placements, expanding home and community-based care and revising regulations for all public long-term care programs to promote choice, equity and cost-effectiveness. Between 1995 and 2002, Maine reduced the number of individuals in nursing homes by 18 percent and doubled the number receiving home and community-based care. Furthermore, 2,000 nursing home beds were de-licensed. Over this time period, the number of people receiving long-term care increased 30 percent with only a modest increase in total

[65] Connecticut has its unique characteristics and challenges that must be addressed and no one other state's model can be totally replicated and expected to work. Maine and Oregon are illustrated here only to show that different ratios of home and community-based and institutional care are achievable.

spending. Total long-term care spending rose by 2.5 percent annually over this time span, well below the rate of health care inflation.

Oregon and Maine, as well as many other states, have faced difficult decisions in the face of large state budget deficits over the last several years that have eroded gains in the development of their home and community-based long-term care options. It is important to note that reference to these states in this Plan is only used to show that it is possible to make such a commitment and rebalance a state's long-term care system. The budgetary problems faced by these states highlight the importance of maintaining an established commitment to a system that provides real choices.

In order to affect this type of change, Connecticut will need to expand home and community-based care as the reliance on institutional care is incrementally reduced. In addition, Connecticut will need to be aggressive in its efforts to prescreen those individuals being admitted to long-term care institutions to ensure that they have a clear understanding of all their service and support options and to help transition institutionalized residents back into the community.

As the long-term care system moves closer to optimal ratios and home and community-based resources and options increase, the infrastructure to provide the quality services and necessary supports needs to be enhanced. There also needs to be recognition that an increase in the number of those in need and a shift to home and community-based services will require a larger long-term care workforce within the state. Affordable and accessible quality home care cannot be achieved in the private or public sector with the present workforce shortage.

Whatever the ratio between home and community-based care and institutional care, the long-term care system must provide adequate support to both informal (unpaid) and formal (paid) caregivers whose respective roles are essential, complementary and often interdependent. Shortages in both informal and formal caregivers are projected to grow as the number of persons with disabilities increase over the next two decades.

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

In addition, the current supply of formal caregivers in the community and institutions, both professional and non-traditional, is not meeting the need for long-term care services.

As the population ages and the numbers of those in need of long-term care supports grows, the demand for workers is expected to sharply increase. Attention must be given to attracting individuals to work in long-term care by enhancing the status, compensation and career tracks associated with these jobs.

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

Home and Community-Based Infrastructure

Action Steps

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

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

Informal and Formal Caregivers

Action Steps

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

- In addition to continuing existing respite care efforts, Connecticut should expand or replicate its successful Alzheimer's Respite Care program to provide respite services for any caregiver of individuals with disabilities of all ages. As Connecticut begins to increase the amount it spends on home and community-based care while reducing its institutional expenditures, it should allocate resources towards the support of informal caregivers through respite care and caregiver training programs.

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

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

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

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

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

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

  Connecticut has been awarded two federal grants, Real Choice (2002-2005) and Community-integrated Personal Assistance Services and Supports (C-PASS) that address the development of a personal assistance workforce by building an infrastructure that will allow for the effective recruitment and retention of direct support personnel. The gains produced by these efforts should be maintained and enhanced over time.

- Connecticut should evaluate the Personal Care Assistance Pilot under the Connecticut Home Care Program for Elders to determine the potential for making personal care assistance a permanent benefit. In addition, explore payment for family members for providing personal care.

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

- Connecticut should increase the capacity of educational institutions (i.e. state colleges and universities and high schools) to provide training for professional long-term care

workers in order to address the current need for and projected growth of these workers in the state.

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

Nursing Facility Transitions

Action Steps

- Connecticut should continue the efforts begun under the State's Nursing Facility Transition Grant (NFTG). The NFTG has shown that with the proper supports and services, individuals with severe disabilities can successfully transition to, and remain in, the community. Connecticut should build on the successful components of the NFTG and strive to sustain those elements into the future. For example, the Common Sense Fund, used under the NFTG to provide transition expenses such as security deposits and home modifications should be made a standard benefit. In addition, the State should explore providing reimbursement for peer mentoring and engagement activities.

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

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

Prescreening Efforts

Action Steps

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

  Any expansion of prescreening activities should be performed by State agencies. Prescreening should not prohibit or deny applicants the choice to enter an institution. The overall goal of prescreening should be to assure that individuals have the knowledge and opportunity to exercise their choice to live in a community or institutional setting. Prescreening activities need to take into account the specific

needs of the individual, addressing both cognitive and physical impairments, and ensure that the person receives the appropriate level of care that will protect them and others from any potential harm. Individuals who chose community settings must have safe and adequate living options and sufficient caregiving supports.

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

Reduction in Beds in Institutions

Action Steps

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

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

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

Federal Reform

Action Steps

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

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

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

Balancing the ratio of public and private resources

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

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

The private resources paying for long-term care primarily are in the form of individuals and families spending their own funds with only a small percentage of the costs being paid for by private insurance or other private sources. The usage of private savings to

pay for long-term care would not be a hardship if those savings had been dedicated in advance for long-term care. However, in most cases that is not the case and the funds being utilized had been targeted to meet other needs, such as retirement income.

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

Private long-term care insurance is one possible option to help balance the long-term care financing system. Long-term care insurance was developed to help fill the gap left by the lack of long-term care coverage under traditional health insurance plans and Medicare. Both health insurance and Medicare are designed to pay for acute care and will only pay for a very limited amount of long-term care as long as it is rehabilitative or restorative in nature. Private long-term care insurance emerged to specifically cover the personal and custodial care services and supports that comprise most of what we refer to as long-term care, including both home-based and institutional services.

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

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

Given its limitations, private LTCI is not a panacea. However, it can play a more significant role than it does today in financing long-term care. While, as noted above, there are individuals where LTCI is not affordable or accessible, there is a segment of the population where LTCI can be a viable option if these individuals are educated about long-term care and are motivated to do some personal planning to avoid impoverishment.

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

Currently, private insurance covers approximately 11 percent of the nation's long-term care costs. While Connecticut specific data is not available, we will assume that private insurance plays a similar role in Connecticut. ***Connecticut should strive over the next 20 years to increase the proportion of long-term care costs covered by private insurance and other dedicated sources of private funds to 25 percent.*** Such an increase in private insurance and other private sources of funding would reduce the burden both on Medicaid and individuals' out-of-pocket expenses. If these reductions were evenly divided between Medicaid and individuals' costs, then Medicaid's share of the costs could be reduced by seven percent. Using today's dollars, and a Medicaid long-term care budget of approximately $2 billion, that would equate to $140 million in annual savings. These savings could be partially allocated to the General Fund and partially used to help fund enhancements to the long-term care system, such as infrastructure and service improvements, leading to more choices for individuals and their families.

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

Planning Ahead for Long-Term Care

Action Steps

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

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

- Connecticut should continue, and enhance, the efforts of the Connecticut Partnership for Long-Term Care (Partnership), the State's public/private alliance to help educate Connecticut residents about the importance of planning ahead for future long-term care needs through the purchase of high quality private long-term care insurance (LTCI). While the Partnership has had a significant impact on the purchase of private long-term care insurance, with over 30,000 Partnership policies purchased, there is much more that can be done.

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

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

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

- Connecticut should continue its efforts on the federal level to enact an "above the line" tax deduction for the purchase of long-term care insurance. Such a tax deduction would also result in a State tax deduction as long as Connecticut's tax system is tied to the federal Adjusted Gross Income. If federal action on this issue is not taken, Connecticut should explore its own tax incentives for long-term care insurance.

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

- Connecticut should examine the state and federal reverse annuity mortgage (RAM) programs to see if any enhancements can be made to increase the usage of this program. Connecticut should also monitor the recently announced initiative from the Centers for Medicare and Medicaid Services to increase the usage of RAMs. An effective RAM program could allow individuals to use their home equity to remain in their homes longer or even to use the resources to purchase long-term care insurance if that is an affordable and accessible option for them.

B. Focus Areas

Balancing the system to promote real choices for all persons with disabilities requires not only a common vision for providing long-term care, but to succeed, this task must be approached on multiple fronts. Below are recommendations for action steps in six focus areas – Community Options, Housing, Employment, Transportation, Access and Quality -- that support the major system change recommendations described above. For each Focus Area, there will be a brief description of the issue followed by recommended action steps.

Community Options

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

One of the consequences of having a disability is that it tends to increase isolation and reduce community participation. A 2000 Harris poll of Americans with and without disabilities found that those with disabilities feel significantly more isolated and left out of community life. Those without disabilities cite lack of time as the main reason for not being as involved as much as they would like in their community. For those with disabilities, the reasons are that they do not feel encouraged by community organizations to participate (54 percent), they don't have the income necessary to participate (53 percent), or they are not aware of what activities exist (46 percent).[66]

To address social isolation and community inclusion, Connecticut applied for and was awarded a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS) in October 2002 (see Appendix E – Long-Term Care Planning and Implementation Efforts). Through this grant, three towns – Bridgeport, Groton and New Haven – were awarded funding to establish themselves as Model Communities for inclusion of persons with disabilities and their families in the life of their communities. Also through the Real Choice grant, a survey was conducted by the University of Connecticut's Center for Disabilities to learn if Connecticut citizens with disabilities are able to participate in all desired aspects of community life. The results of the survey, expected in early 2004, will identify gaps in the integration of persons with disabilities into community life and identify changes necessary to make communities more supportive and inclusive.

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

In order to improve home and community-based services for people with disabilities, states are increasingly incorporating consumer-directed services into their Medicaid programs to give individuals more control and independence over the services and supports they receive. Examples of consumer directed initiatives include Cash and Counseling and Person Centered Planning.

In Connecticut, consumer- directed personal care assistance (PCA) is provided by the Department of Social Services through the Medicaid Personal Care Assistance Services Waiver to eligible individuals with disabilities between the ages of 18 and 64 who need help with their activities of daily living. Established in 1997, the program allows people to hire, train, and supervise their own personal care assistants. In 2000, the legislature approved a purely State-funded pilot PCA program for up to 50 people age 65 and over who have either aged out of the disabled PCA waiver or otherwise cannot find appropriate home care.

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

Action Steps

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

- Expand efforts to promote community inclusion of individuals with disabilities. Build upon the work currently being done with support from Connecticut's Real Choice Grant in three Model Communities -- Bridgeport, Groton and New Haven.

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

- Explore opportunities to strengthen consumer directed care. Examples of promising programs currently being piloted across the country are Money Follows the Person, Cash and Counseling, and Person Centered Planning.

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

Housing

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

In terms of affordability, in 2002, the average national rent was greater than the amount of income received by people with disabilities from the Supplemental Security Income (SSI) program.[67] In Connecticut, people paid an average of 97.8 percent of their monthly SSI check for one-bedroom units at fair market rent. People with long-term disabilities received $545 per month in 2002. Connecticut is one of 24 states that adds a supplement, bringing the assistance to $747 per month.[68]

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

Action Steps

- Over the next biennium, support the efforts of the Accessible Housing Registry to identify accessible units and increase their utilization.
- Expand and preserve the stock of housing for elders and persons with disabilities.
- Enforce current standards in Connecticut regulation and statute, including the Building Code, which require builders of new developments to create a certain percentage of wheelchair accessible units.
- Increase outreach to landlords about resources and financing to make their units accessible.
- Increase the utilization of Section 8 Vouchers in communities throughout Connecticut so additional vouchers may be requested from HUD.
- Establish a Resident Services Coordinator in every State-funded Elderly Housing facility. Currently, there is one Resident Services Coordinator in every three facilities.
- Expand assisted living options beyond those available to the elderly.

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[67] Emily Cooper et al, *Priced Out in 2002: Housing Crisis Worsens for People with Disabilities*, Opening Doors, Issue 21, May 2003, www.c-c-d.org/od-May03.htm

[68] Angela Carter, Disabled 'Priced Out' of Rental Market, *New Haven Register*, May, 31, 2003.

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

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

Employment

Individuals with significant disabilities who live in the community often have difficulty obtaining the supports they need for employment. The age limits for the Medicaid for the Employed Disabled Program (MEDP), adults between ages 18 to 65, present barriers for young people who want to work while they are in school or individuals who want to work after age 65. Some individuals will need to work after this age because of Social Security changes for retirement eligibility. The increased income and asset levels for the MEDP provide the kind of supports that allow individuals to have significant work, contribute to the tax base and reduce reliance on benefits.

Individuals who are under age 18 and over age 65 are also not able to access the Medicaid Personal Care Assistance Waiver at the income and asset levels that would be available to them under the MEDP. The result of these inconsistencies in eligibility requirements is that some older individuals will not be able to retain the supports they need to continue to live in the community and work until they are eligible for Social Security retirement benefits.

Employers have few incentives for hiring individuals who have significant personal assistance needs on the job as well as at home. At this time, few employers are willing to provide personal assistance as an Americans with Disabilities Act (ADA) accommodation. This means that individuals who need this kind of support often severely restrict the number of hours they work, if they try to work at all.

Action Steps

- Explore the development of ongoing tax credits or other incentives for employers to provide support services or assistive technology so that individuals with significant disabilities can both obtain and maintain higher levels of employment for longer periods of time. The current tax credits for employers are short-term or one time credits.

Transportation

Transportation is often inadequate or inaccessible for people with disabilities living in the community. According to the National Organization on Disability/ Harris 2000 Survey of Americans with Disabilities, 30 percent of Americans with disabilities have a problem

with transportation, compared to only 10 percent of those without disabilities. Transportation is fundamental to independence, affecting access to employment, medical care, friends and family, shopping, entertainment, community events, and religious activities. [69]

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

Actions Steps

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

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

- Working collaboratively with individuals with disabilities, families, and providers, Connecticut should evaluate the existing transportation system and identify the gaps in services needed for persons with disabilities. The goal of this evaluation should be to improve the existing transportation system to achieve uniform coverage and to better meet the medical and social needs of Connecticut citizens with disabilities to allow them to participate fully in community life.

Access to Information and Services

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

The State has a number of sources for information on long-term care services and supports. Infoline (2-1-1) is designed to provide a single statewide information resource

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

about all types of social services and programs serving people of all ages. The CHOICES Program provides a resource for individuals requesting information regarding Medicare, Medicare Supplemental Insurance, Medicaid and long-term care insurance. The Department of Social Services also distributes booklets that provide comprehensive information about long-term care services and supports. The Departments of Mental Retardation, Mental Health and Addiction Services, and Children and Families provide information on the programs and supports they provide and fund. Municipal agents in each town and city provide a valuable resource to seniors and individuals with disabilities. In addition, the five Connecticut Area Agencies on Aging serving elders and five Independent Living Centers serving people with disabilities provide toll-free phone numbers and information and assistance programs for their respective audiences.

Despite the availability of these resources, much of the information is program specific and only provided upon request. To address this issue, in 2002 the General Assembly required the Office of Policy and Management, within existing budgetary resources and in consultation with the Select Committee on Aging, the Commission on Aging and the Long-Term Care Advisory Council, to develop a consumer-oriented website that provides comprehensive information on long-term care options available in Connecticut. Initial components of the website are in the process of being developed and reviewed with the goal of having the site functioning in early 2004 (see Appendix E – Long-Term Care Planning and Implementation Efforts).

Information on community long-term care options is also being provided through the Nursing Facility Transition Grant. This three-year grant awarded by the federal Centers for Medicare and Medicaid Services (CMS) in September of 2001 helps transition individuals with disabilities out of nursing homes and back to the community. Through the efforts of this grant, materials have been developed to inform nursing facility residents and their families about long-term care alternatives (see Appendix E – Long-Term Care Planning and Implementation Efforts).

Action Steps

- Complete construction of the Long-Term Care Website providing accessible information to all individuals in need of long-term care services and supports, regardless of age or disability. Over time, provide maintenance and ongoing updating of the Long-Term Care Website.

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

- Over the next biennium and over time, distribute the Nursing Facility Transition Grant handbook to all present and future Nursing Facility residents.

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

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

Quality of Life and Quality of Care

To assure a high quality of life for individuals with long-term care needs, real choices must be provided regarding the type of services and supports they need and in what setting they live. In many cases, quality of life is measured by the level of control and independence an individual with a disability can enjoy. One aspect of ensuring a high quality of life focuses on efforts to prevent entrance to a long-term care institution. Connecticut programs that contribute to this goal include CHOICES, friendly visitor programs, fall prevention programs, and medication management programs.

Assistive technology often makes a critical difference in the quality of life for individuals with disabilities and chronic illnesses, allowing them the independence to live in their communities and work, learn and play. Assistive technology is any item or piece of equipment that is used to increase, maintain, or improve functional capabilities of individuals with physical, sensory or cognitive impairments. Examples include hearing aids, motorized wheelchairs, environmental control, electric door openers, and voice-activated telephones. The majority of assistive technology devices needed by individuals to improve their level of independence are not considered medically necessary and therefore are not often covered by private insurance and public medical assistance programs. [70]

Low-interest loans are available through the Connecticut Assistive Technology Loan Program, sponsored by the Department of Social Services (DSS), Bureau of Rehabilitation Services, in partnership with People's Bank. In addition, the Connecticut Tech Act Project provides information and advocacy services regarding assistive technology. The project's goal is to make sure that Connecticut residents with disabilities of all ages get access to assistive technology. [71]

Quality of Care is a broad issue that encompasses the range of care settings and services, both institutional and community-based. It is measured objectively as well as subjectively, with physical as well as psychological and social components. Assuring

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[70] Therese Willkomm, Ph.D., Achieving Independence and Interdependence Through Assistive Technology Applications, *Community Living Briefs*, Vol. 1, Issue 2, 2003 (Community Living Technical Assistance Exchange at Independent Living Research Utilization, Houston, Texas)
[71] Connecticut Tech Act Project – Achievement Through Technology, http://www.techactproject.com/Default.htm

quality of care not only involves adequate training and oversight of providers but also consumer direction and control so that individuals can have a voice in how services and supports are provided to them.

Actions Steps

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

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

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

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

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

- Connecticut should support the purchase of assistive technology. Expenditures for assistive technology can be minor when compared to the extended cost of human services for personal assistance. This technology can allow an individual to maintain or regain independence and reduce their reliance on paid services.

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

- Expand the role of the Long-Term Care Ombudsman's Office to include other long-term care settings, such as assisted living facilities. Provide adequate funding for such an expansion.

VI. CONCLUSION

Over the next 20 to 25 years Connecticut will be challenged to develop a long-term care system that is consumer focused and directed and provides real choices for individuals with disabilities and their families. Many uncertainties could affect the level of demand for long-term care in Connecticut. Disability rates may decline, medical technologies may reduce the incidence of certain chronic diseases, or new conditions may arise that increase the demand for long-term care. However, there are no guarantees. What is known is that current levels of Medicaid long-term care expenditures for institutional care and the significant reliance on public funds for long-term care will not allow Connecticut to reach its goal of real long-term care choices and to adequately meet a possibly growing demand for services and supports. The time to take steps to rebalance the system is now. As outlined in this Plan, the shifting of the ratio of home and community-based and institutional care, coupled with a larger role for private funds in the system, will position Connecticut to be responsive to the potential long-term care needs of our citizens in the short and long-term and will help realize its goal of a system driven by choice and consumer control.