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

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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***.