

Balancing the System:

Working Towards Real Choice for Long-Term Care in Connecticut

**A Report to the General Assembly
January 2004**

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APPENDIX A.

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

CONNECTICUT GENERAL STATUTES TITLE 17B. SOCIAL SERVICES CHAPTER 319Y. LONG-TERM CARE

§ 17b-337. Long-term elderly care planning committee. Long-term care plan for elderly persons. Membership

(a) There shall be established a Long-Term Care Planning Committee for the purpose of exchanging information on long-term care issues, coordinating policy development and establishing a long-term care plan for all persons in need of long-term care. Such plan shall integrate the three components of a long-term care system including home and community-based services, supportive housing arrangements and nursing facilities. Such plan shall include: (1) A vision and mission statement for a long-term care system; (2) the current number of persons receiving services; (3) demographic data concerning such persons by service type; (4) the current aggregate cost of such system of services; (5) forecasts of future demand for services; (6) the type of services available and the amount of funds necessary to meet the demand; (7) projected costs for programs associated with such system; (8) strategies to promote the partnership for long-term care program; (9) resources necessary to accomplish goals for the future; (10) funding sources available; and (11) the number and types of providers needed to deliver services. The plan shall address how changes in one component of such long-term care system impact other components of such system.

(b) The Long-Term Care Planning Committee shall, within available appropriations, study issues relative to long-term care including, but not limited to, the case-mix system of Medicaid reimbursement, community-based service options, access to long-term care and geriatric psychiatric services. Such committee shall evaluate issues relative to long-term care in light of the United States Supreme Court decision, *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999), requiring states to place persons with disabilities in community settings rather than in institutions when such placement is appropriate, the transfer to a less restrictive setting is not opposed by such persons and such placement can be reasonably accommodated.

(c) The Long-Term Care Planning Committee shall consist of: (1) The chairpersons and ranking members of the joint standing and select committees of the General Assembly having cognizance of matters relating to human services, public health, elderly services and long-term care; (2) the Commissioner of Social Services, or the commissioner's designee; (3) one member of the Office of Policy and Management appointed by the Secretary of the Office of Policy and Management; (4) one member

from the Department of Social Services appointed by the Commissioner of Social Services; (5) one member from the Department of Public Health appointed by the Commissioner of Public Health; (6) one member from the Department of Economic and Community Development appointed by the Commissioner of Economic and Community Development; (7) one member from the Office of Health Care Access appointed by the Commissioner of Health Care Access; (8) one member from the Department of Mental Retardation appointed by the Commissioner of Mental Retardation; (9) one member from the Department of Mental Health and Addiction Services appointed by the Commissioner of Mental Health and Addiction Services; (10) one member from the Department of Transportation appointed by the Commissioner of Transportation; (11) one member from the Department of Children and Families appointed by the Commissioner of Children and Families; and (12) the executive director of the Office of Protection and Advocacy for Persons with Disabilities or the executive director's designee. The committee shall convene no later than ninety days after June 4, 1998. Any vacancy shall be filled by the appointing authority. The chairperson shall be elected from among the members of the committee. The committee shall seek the advice and participation of any person, organization or state or federal agency it deems necessary to carry out the provisions of this section.

(d) Not later than January 1, 1999, and every three years thereafter, the Long-Term Care Planning Committee shall submit a long-term care plan pursuant to subsection (a) of this section to the joint standing and select committees of the General Assembly having cognizance of matters relating to human services, public health, elderly services and long-term care, in accordance with the provisions of section 11-4a, and such plan shall serve as a guide for the actions of state agencies in developing and modifying programs that serve persons in need of long-term care.

(e) Any state agency, when developing or modifying any program that, in whole or in part, provides assistance or support to persons with long-term care needs, shall, to the maximum extent feasible, include provisions that support care-giving provided by family members and other informal caregivers and promote consumer-directed care.

§ 17b-338. Long-Term Care Advisory Council. Membership. Duties.

(a) There is established a Long-Term Care Advisory Council which shall consist of the following: (1) The executive director of the Commission on Aging, or the executive director's designee; (2) the State Nursing Home Ombudsman, or the ombudsman's designee; (3) the president of the Coalition of Presidents of Resident Councils, or the president's designee; (4) the executive director of the Legal Assistance Resource Center of Connecticut, or the executive director's designee; (5) the state president of AARP, or the president's designee; (6) one representative of a bargaining unit for health care employees, appointed by the president of the bargaining unit; (7) the president of the Connecticut Association of Not-For-Profit Providers for the Aging, or the president's designee; (8) the president of the Connecticut Association of Health Care Facilities, or the president's designee; (9) the president of the Connecticut Association of

Residential Care Homes, or the president's designee; (10) the president of the Connecticut Hospital Association or the president's designee; (11) the executive director of the Connecticut Assisted Living Association or the executive director's designee; (12) the executive director of the Connecticut Association for Homecare or the executive director's designee; (13) the president of Connecticut Community Care, Inc. or the president's designee; (14) one member of the Connecticut Association of Area Agencies on Aging appointed by the agency; (15) the president of the Connecticut chapter of the Connecticut Alzheimer's Association; (16) one member of the Connecticut Association of Adult Day Centers appointed by the association; (17) the president of the Connecticut Chapter of the American College of Health Care Administrators, or the president's designee; (18) the president of the Connecticut Council for Persons with Disabilities, or the president's designee; (19) the president of the Connecticut Association of Community Action Agencies, or the president's designee; (20) a personal care attendant appointed by the speaker of the House of Representatives; (21) the president of the Family Support Council, or the president's designee; (22) a person who, in a home setting, cares for a person with a disability and is appointed by the president pro tempore of the Senate; (23) three persons with a disability appointed one each by the majority leader of the House of Representatives, the majority leader of the Senate and the minority leader of the House of Representatives; (24) a legislator who is a member of the Long-Term Care Planning Committee; and (25) one member who is a nonunion home health aide appointed by the minority leader of the Senate.

(b) The council shall advise and make recommendations to the Long-Term Care Planning Committee established under section 17b-337.

(c) The Long-Term Care Advisory Council shall seek recommendations from persons with disabilities or persons receiving long-term care services who reflect the socio-economic diversity of the state.

APPENDIX B.

Long-Term Care Planning Committee Membership

Legislators

Senator Edith Prague, Co-Chair, Select Committee on Aging
Lydia N. Martinez, Co-Chair, Select Committee on Aging
John A. Kissel, Ranking Member, Select Committee on Aging and Human Services Committee
Alfred Adinolfi, Ranking Member, Select Committee on Aging
Christopher S. Murphy, Co-Chair, Public Health Committee
Art J. Feltman, Co-Chair, Public Health Committee
George L. Gunther, Ranking Member, Public Health Committee
Mary Ann Carson, Ranking Member, Public Health Committee
Mary Ann Handley, Co-Chair, Human Services Committee
Peter F. Villano, Co-Chair, Human Services Committee
Lile R. Gibbons, Ranking Member, Human Services Committee

State Agencies Representatives

David Guttchen, Office of Policy and Management (Chair of Planning Committee)
Tom Ciccalone, Department of Economic and Community Development
Wendy Furniss, Department of Public Health
Pam Giannini, Department of Social Services
Jennifer Glick, Department of Mental Health and Addiction Services
Beth Leslie, Office of Protection and Advocacy for Persons with Disabilities
Dorian Long, Department of Children and Families
Michele Parsons, Department of Social Services
Rick Robbins, Department of Economic and Community Development
Michael Sanders, Department of Transportation
Andrew Wagner, Department of Mental Retardation
Vacant, Office of Health Care Access

Staff Providing Assistance

Barbara Parks Wolf, Office of Policy and Management
Gloria McKenna, Select Committee on Aging
Dennis King, Department of Transportation
Lisa Rivers, Department of Transportation

Former Committee Participants

Sandra Czunas
Stan Kosloski
Chris Lewis
Mary Pettigrew

APPENDIX C.

Long-Term Care Advisory Council Membership

Julia Evans Starr, CT Commission on Aging, Co-Chair
Representative Peter Villano, Co-Chair

Marge Anderson, CT Association of Residential Care Homes
Debbie Barisano, Personal Care Attendant
Bob Board, CT Council for Persons with Disabilities
Cathy Ludlum, CT Council for Persons with Disabilities
Richard C. Brown, CT Association of Health Care Facilities
Joanne Byrne, CT Assoc of Area Agencies on Aging
Christopher Carter, CT Assisted Living Association
Denise Cesareo, Adult Day Care Association
Deborah Chernoff, District 1199 AFL-CIO
Terry Cote, CT Family Support Council
Michelle Duprey, Consumer
William Eddy, AARP -- CT
Brian Ellsworth, CT Association for Home Care, Inc
Maggie Ewald, Long-Term Care Ombudsman Office
Joelen Gates, Legal Assistance Resource Center
Molly Rees Gavin, CT Community Care, Inc.
Kenneth Harrington-Howes, Consumer
Jennifer Jackson, CT Hospital Association
Rolando Marinez, CRT/ CT Association of Community Action Agencies
Joe Ierna, CT Alzheimer's Association
Kathy Freda, CT Alzheimer's Association
Margaret Morelli, CT Association of Non-for-Profit Providers for the Aging
Sue Pedersen, Consumer
Susan Raimondo, Family Caregiver
Lori Santiago, CT Coalition of Presidents of Resident Councils
Stephen T. Surprenant, American College of Health Care Administrators

Friends of the Long-Term Care Advisory Council

Quincy Abbot, ARC/CT
Tom Connors, Citizen Advocate/ Consultant
Mary-Ann Langton, CT Council on Developmental Disabilities
Gloria McKenna, Select Committee on Aging
Helga Niesz, Office of Legislative Research
Barbara Pellett, Home Health Aide
May Terry, Disabilities Network of Eastern CT, Inc.
Andrew Wright, formerly of the Department of Social Services

APPENDIX D.

History of the Long-Term Care Planning Committee and the Long-Term Care Advisory Council

The following summary of the history of the Long-Term Care Planning Committee and the Long-Term Care Advisory Council is the work of the Connecticut Office of Legislative Research, October 16, 2003 (2003-R-0709).



OLR RESEARCH REPORT

October 16, 2003

2003-R-0709

(Revised)

HISTORY OF LONG-TERM CARE PLANNING COMMITTEE AND LONG-TERM CARE ADVISORY COUNCIL

By: Helga Niesz, Principal Analyst

You asked for a legislative history of the Long-Term Care Planning Committee and Long-Term Care Advisory Council.

SUMMARY

In 1998, the legislature created the Long-Term Care Planning Committee, composed of executive agency representatives and chairmen and ranking members of several legislative committees, as a result of a recommendation in a 1996 Program Review and Investigations Committee study. To advise the Planning Committee, it also created the Long-Term Care Advisory Council, composed of a mix of two independent state agencies (the Commission on Aging and the Long-Term Care Ombudsman's Office) and various long-term care industry, labor, and elderly interest groups. Over the years, both entities have added members, so that now the Planning Committee has 23 members and the Advisory Council 27.

The Planning Committee's original charge was to create a long-term care plan for the elderly and study various elderly-related issues, which was later expanded to include all disabled people. The plan must address the three components of the long-term care system: home and community-based services, supportive housing, and nursing facilities. The committee produced a preliminary plan in 1999 and its first formal plan in 2001. The 2001 plan and executive summary are available at: <http://www.cga.state.ct.us/age/LTCPLAN-FINAL2001.pdf> and <http://www.cga.state.ct.us/age/LTCPLAN-FINAL2001.pdf>. The next plan is due in January 2004. The Advisory Council made a number of

recommendations over time to the Planning Committee and has also proposed its own bills to the legislature through its legislative member.

In 2000, the legislature followed the Planning Committee's recommendation and removed the income cap on the state's home care program for people who would otherwise qualify for a nursing home. In 2001, legislation expanded the committee's scope to include younger disabled people, required it to evaluate long-term care issues in light of the *Olmstead v. L. C.* U. S. Supreme Court decision, and required the plan to serve as a guide for state agencies' programs. The Advisory Council's scope and membership was also expanded accordingly.

A chronological history of legislation affecting or derived from the Planning Committee and Advisory Council follows.

LONG-TERM CARE PLANNING

1998

Long-Term Care Planning Committee. New legislation created an inter-agency Long-Term Care Planning Committee to exchange information on long-term care issues, coordinate policy development, and create a state long-term care plan for the elderly. It required the plan to integrate the three components of a long-term care system (home and community-based services, supportive housing arrangements, and nursing facilities) and to address how changes in one component affect the others. It also required the committee to submit the plan to certain legislative committees every two years beginning January 1, 1999 (later changed to every three years). The initial committee members were the chairmen and ranking members of the legislature's Aging, Human Services, and Public Health committees; the social services commissioner or her designee; and one member each from the Office of Policy and Management, the departments of Social Services, Public Health, Economic and Community Development, and the Office of Health Care Access appointed by their respective agency heads. The act requires committee members to elect their chairman (CGS, § [17b-337](#), [PA 98-175](#), [PA 98-239](#)).

Long-Term Care Advisory Council. PA 98-239 also created a Long-Term Care Advisory Council to advise and make recommendations to the Planning Committee. The council consisted of the Commission on Aging director, the state nursing home ombudsman, and representatives of various long-term care industry, labor, and elderly interest groups or in some cases their designees, specifically, the president of the Coalition of Presidents of Resident Councils; the Legal Assistance Resource Center of Connecticut director; one representative of the Connecticut chapter of the American Association of Retired Persons; one representative of a

health care employees bargaining unit; and the presidents of the Connecticut Association of Not-for-Profit Providers for the Aging, the Connecticut Association of Health Care Facilities, and the Connecticut Association of Licensed Homes for the Aged (CGS, § [17b-338](#), [PA 98-239](#)).

1999

Home Care Plan Required. Legislation required the Planning Committee to (1) develop a plan to ensure home care availability under the Connecticut Home Care Program for the Elderly (CHCPE) for seniors who would otherwise qualify for the program except that their income was higher than the established limits, and (2) submit a report on the plan to the Human Services and Aging committees, which the Planning Committee did in February 2000 ([PA 99-279](#), § 39).

Members Added To Planning Committee. PA 99-28 added three new members, one each from the departments of Mental Retardation (DMR), Mental Health and Addiction Services, and Transportation to the Planning Committee ([PA 99-28](#)).

2000

Elimination of Home Care Gross Income Test. Based on the Planning Committee's recommendation for the home care plan in February 2000, new legislation made more seniors eligible for the CHCPE by eliminating the program's gross income limit; now, someone can qualify for state-funded home care benefits if he would otherwise qualify for Medicaid in a nursing home. The new law still requires people to contribute toward their care costs and asset limits did not change. But the income cap removal currently applies only to the program's state-funded portion because federal approval is still needed for the Medicaid waiver portion ([PA 00-2](#), § 10, June Special Session).

Advisory Council Added Members. New legislation added 10 members (or in some cases their designees) to the Advisory Council, including: the Connecticut Hospital Association president, Connecticut Assisted Living Association executive director, Connecticut Homecare Association executive director, Connecticut Community Care Inc. president, a member of the Connecticut Association of Area Agencies on Aging, Connecticut Alzheimer's Association executive director, a member of the Adult Day Care Association, Connecticut Chapter of the American College of Health Care Administrators president, Connecticut Council for Persons with Disabilities president, and the Connecticut Association of Community Action Agencies president ([PA 00-135](#), § 20).

2001

Planning Committee Change of Mission. PA 01-119 broadened the Planning Committee's scope to include all people in need of long-term care, not just the elderly. The act further required the committee to evaluate long-term care issues in light of the U. S. Supreme Court decision in *Olmstead v. L. C.* , which required states to place people with disabilities in community settings rather than in institutions when it is appropriate, the individual does not oppose the transfer, and the community placement can be reasonably accommodated.

In addition, the act required:

1. the committee's long-term care plan to serve as a guide for state agencies' programs that serve people in need of long-term care; and
2. any state agency, when developing or modifying any program that, wholly or partially, assists or supports people with long-term care needs to include, to the extent feasible, features that (a) support care-giving by family members and other informal caregivers and (b) promote consumer-directed care.

The act added two new members to the committee: one Department of Children and Families representative and the Office of Protection and Advocacy for Persons with Disabilities executive director or his designee. And it required the committee to issue its long-term care plan every three years instead of every two ([PA 01-119](#)).

2002

New Duties for Advisory Council. A new law required the Advisory Council to seek recommendations from people with disabilities or people receiving long-term care services who reflect the state's socioeconomic diversity. It also added eight new members to the 19-member council, for a total of 27. The new members were (1) a personal care attendant appointed by the House speaker; (2) the president of the Family Support Council or his designee; (3) someone caring for a person with a disability in a home setting, appointed by the Senate president pro tempore; (4) three people with disabilities, one each appointed by the House and Senate majority leaders and the House minority leader; (5) a legislator who is a member of the Planning Committee; and (6) a nonunion home health aide appointed by the Senate minority leader. The act also makes some minor and technical changes regarding some of the existing council members ([PA 02-100](#)).

Long-Term Care Website. The legislature required the Office of Policy and Management (OPM), within existing budgetary resources, to develop a single, consumer-oriented Internet website that provides comprehensive information on long-term care options in Connecticut. It required that the website include direct links and referral information on long-term care resources, including private and nonprofit organizations offering advice, counseling, and legal services. OPM must consult with the legislature's Aging Committee, the Commission on Aging, and the Advisory Council when developing the site ([PA 02-7](#), § 51, May 9 Special Session).

Comprehensive Needs Assessment. The legislature, on the Advisory Council's recommendation, required OPM to conduct a comprehensive needs assessment of the unmet long-term care needs in the state and project future demand for such services. The assessment must include a review of the DMR's waiting list. The original 1998 legislation had required the Planning Committee to do a needs assessment, but had not provided funding for it ([SA 02-7](#)).

Olmstead Plan. In addition, the Planning Committee, a Community Options Task Force composed of people with disabilities and representatives from the Department of Social Services (DSS), and DSS finished two years of work in March 2002 by publishing [Choices Are For Everyone](#). This is a plan for how the state can integrate people with disabilities into the community as required by the *Olmstead* decision instead of having to live in institutions.

2003

In 2003, the legislature enacted no legislation that affected the Planning Committee or Advisory Council.

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APPENDIX E.

LONG-TERM CARE PLANNING AND PROGRAM IMPLEMENTATION EFFORTS

A. Long-Term Care Planning Committee Efforts

Establishment of the Long-Term Care Planning Committee

The Long-Term Care Planning Committee (Planning Committee), created in 1998 under Public Act 98-239, was established for the purpose of exchanging information on long-term care issues, coordinating policy development and establishing a long-term care plan. The Planning Committee is comprised of representatives from ten State agencies and the Chairs and Ranking Members of the General Assembly's Aging, Human Services, and Public Health Committees. (See Appendix A for the authorizing statute and Appendix B for a listing of Planning Committee members.)

The Planning Committee grew out of the recommendations of a December 1996 report issued by the Legislative Program Review and Investigations Committee. The study concluded that the State's structure for planning, funding and overseeing long-term care services needed reinforcement and coordination. The Legislative Program Review and Investigations Committee recommended the creation of an interagency committee to "exchange information on long-term care issues, ensure coordinated policy development, and establish a long-term care plan."

In addition to the Long-Term Care Planning Committee, Public Act 98-239 also established the Long-Term Care Advisory Council (Advisory Council) to advise and make recommendations to the Planning Committee. The Advisory Council members include a balance of consumers, providers and advocates representing a wide range of interests. (See Appendix C for a listing of Advisory Council members.)

Originally, the Planning Committee was required to establish a long-term care plan for the elderly that integrates the three components of a long-term care system including home and community based services, supportive housing arrangements and nursing facilities. Subsequently, Public Act 01-119 broadened the Planning Committee's purview by requiring a plan for all persons in need of long-term care.

In addition, the Planning Committee was directed by P.A. 98-239 to conduct several studies, subject to appropriation: the case-mix system of Medicaid reimbursement; community-based service options; access to long-term care; and geriatric psychiatric services. However, to date, the General Assembly has not appropriated any funds for these studies and, therefore, they have not been undertaken.

Long-Term Care Planning Committee Products

Preliminary Long-Term Care Plan – 1999

As noted above, the Planning Committee was created by statute in 1998 and held its initial meeting in August 1998. The Planning Committee's authorizing statute required the Planning Committee to produce its first Long-Term Care Plan by January 1999. The Planning Committee felt that given the short timeframe, it would not be possible to develop a comprehensive Plan and rather produced a Preliminary Long-Term Care that provided a description of Connecticut's long-term care system in order to develop a baseline for future Plans. In addition, the Preliminary Plan was focused on long-term care for elderly persons in keeping with the original statutory charge for the Planning Committee. The Planning Committee then began the work to develop a comprehensive Long-Term Care Plan due to the General Assembly by January 2001 (the original statute required a Long-Term Care Plan every two years – this requirement was later changed, through Public Act 01-119, to mandate a Plan be developed every three years).

Home Care Report – 2000

In 1999, the General Assembly enacted Public Act 99-279 that required the Planning Committee to develop, by February 2000, a plan that ensures the availability of home care services for elderly persons under the Connecticut Home Care Program for Elders (CHCPE) who would otherwise qualify for the program except their income exceeds the program's established income limits. The impetus for this legislation was the fact that the CHCPE had a strict income eligibility requirement that resulted in individuals with as little as one dollar above the income level being ineligible for home care services. This contrasted with the income requirements for nursing home coverage through Medicaid that allows individuals with incomes that are not sufficient to pay for their care to be eligible while contributing most of their income towards their care.

To meet this requirement, the Planning Committee produced a report titled "Home Care for Older Adults - A Plan for Increasing Eligibility Under the Connecticut Home Care Program for Elders." that was delivered to the General Assembly in February 2000. The report concluded that the only mechanism to assure the availability of home care services under the CHCPE was to revise the income eligibility cap to mirror the income requirements utilized for nursing home care eligibility, thus allowing individuals to buy into the CHCPE.

During the 2000 legislative session, Governor Rowland requested, and the General Assembly approved, that the income requirements for both the State-funded and Medicaid components of the CHCPE be revised to allow individuals with incomes in excess of the income eligibility cap to become eligible for the CHCPE by buying into the program. The expanded income level was implemented for the State-funded portion of the CHCPE in October 2000. However, to implement a similar revision for the Medicaid portion of the CHCPE, federal approval was needed. The Department of Social Services (DSS) submitted a revision to their CHCPE Medicaid waiver in 2001 but, to date, DSS has not received approval for the revised income eligibility level.

Long-Term Care Plan - 2001

After the completion of its Preliminary Long-Term Care Plan in 1999, the next Plan from the Planning Committee was due by January 2001. Beginning in early 1999, the Planning Committee undertook an ambitious effort to solicit public input regarding what was needed for a comprehensive Long-Term Care Plan.

In March 1999, the Planning Committee, in conjunction with the Advisory Council, held a public hearing at the Legislative Office Building where over 50 individuals provided testimony regarding Connecticut's long-term care system. The Planning Committee then embarked on a series of meetings with a variety of groups and organizations involved with the long-term care system. Most of the groups were members of the Advisory Council. All told, Planning Committee and Advisory Council members held 24 forums throughout 1999 and 2000. In addition, the Planning Committee and Advisory Council held five public hearings throughout the state in 2000 to garner additional feedback and input for the Long-Term Care Plan.

The input gathered through the forums and public hearings helped develop the framework for the Planning Committee's Long-Term Care Plan that was submitted to the General Assembly in January 2001.

Ongoing Activities

Long-Term Care Website

In 2002, the General Assembly passed Public Act 02-7 (May 9 Special Session) that required the Office of Policy and Management (OPM), within existing budgetary resources and in consultation with the Select Committee on Aging, the Commission on Aging and the Long-Term Care Advisory Council, develop a consumer-oriented website that provides comprehensive information on long-term care options that are available in Connecticut.

Since the passage of Public Act 02-7, OPM staff have been working with a Steering Committee comprised of representatives from the Commission on Aging and Long-Term Care Advisory Council to develop the long-term care website. A survey was widely distributed to solicit feedback as to what individuals and organizations would like to see be included in the website and over 500 responses were received. Members of the Steering Committee have been working with staff from InfoLine regarding the sharing of data to be used for the website. Initial components for the site are in the process of being developed and reviewed with the goal of having the site functioning sometime in early 2004.

B. Olmstead Planning Efforts

On June 22, 1999, the United States Supreme Court decided the *Olmstead v. L.C.* case, holding that unjustified isolation, caused by unjustified placement or retention of persons with disabilities in institutions, should be regarded as discrimination based on disability, in violation of the Americans with Disabilities Act (ADA).

Federal regulation requires public entities to make “reasonable modifications” to their policies, practices, or procedures in order to avoid discrimination on the basis of disability, unless the modifications would “fundamentally alter” the nature of the service or program. As part of the Olmstead decision, four Justices stated that one of the ways the reasonable modification standard could be met is if the State had a comprehensive, effectively working plan of placing qualified persons with disabilities in less restrictive settings.

In 2000, Governor Rowland asked the Department of Social Services to develop an Olmstead Plan. The Governor instructed that the Long-Term Care Planning Committee provide oversight and leadership for the development of the Olmstead Plan. In order to assure that individuals with disabilities and family members of persons with disabilities were active participants in the development of the Olmstead Plan, a Community Options Task Force was created to take the lead in the development of the Plan. The men and women of this advisory group, made up of adults of all ages with various disabilities, family members of persons with disabilities, and representatives from the elder community, worked hard on Connecticut’s Community Options Plan, entitled “Choices are for Everyone,” for two years.

On March 25, 2002, the “Choices are for Everyone” Plan was submitted to Governor Rowland and the Connecticut General Assembly as a collaboration between the Department of Social Services, the Long-Term Care Planning Committee and the Community Options Task Force.

A number of activities are ongoing in Connecticut that support the goals outlined in the “Choices are for Everyone” Plan. These activities are described below.

“Choices are for Everyone” Plan -- Action Steps Update

“Choices are for Everyone” included a series of Action Steps. The Long-Term Care Planning Committee committed to the implementation of these Action Steps over the next several years. Appendix F provides a status report on the Action Steps.

Systems Change Grants

Over the last three years, five Systems Change for Community Living grants were awarded to Connecticut by the Centers for Medicare and Medicaid Services (CMS) as part of the federal New Freedom Initiative: These grants were designed to assist states in their efforts to remove barriers to equality for individuals living with disabilities or long-term illnesses, enabling them to live in the most integrated setting suited to their needs, exercise meaningful choices about their living arrangements and exercise more control over the providers of the services they receive.

Nursing Facility Transition Grant

In September 2001, the Department of Social Services received a three-year Nursing Facility Transition grant of \$800,000 to help transition individuals with disabilities out of nursing homes and back to the community. The project goal for Connecticut is to develop an effective system of transition for individuals residing in nursing facilities who

want to return to independent community living, transitioning 150 people out of nursing facilities over the course of the grant. The Connecticut Association of Centers for Independent Living is responsible for the overall management and administration of the grant activities. Activities under the grant include: 1) designing and implementing an outreach campaign with materials that inform nursing facility residents and their families about long-term care alternatives and 2) developing and implementing a volunteer peer support network to provide technical assistance to people who are making the transition to the community.

As of September 30, 2003, 34 individuals have made the transition from residing in a nursing home to living in the community, with 50 other people in the process of making this transition. By moving to the community, the first 30 people to make the transition resulted in an estimated savings to the State Medicaid program of \$900,000.

Real Choice Systems Change Grant

On October 1, 2002, a three-year \$1.385 million Real Choice Systems Change grant was awarded to the Department of Social Services (DSS) to design and implement effective and enduring improvements in community long-term support systems that will enable children and adults with disabilities or long term illnesses to live and participate in their communities. DSS has contracted with the University of Connecticut's Center for Disabilities to implement this initiative. Addressing individuals across the lifespan, the primary goals of the Real Choice grant are twofold: to build the capacity within Connecticut to support informed decision-making, independent living, and a meaningful quality of life for persons with disabilities; and to assist three communities in Connecticut to become models of support for opportunities and choices for persons with disabilities.

In the spring of 2003, three Connecticut towns, Bridgeport, Groton, and New Haven, were awarded model community inclusion grants. Over three years, each community will receive \$75,000 to support activities to enhance inclusion efforts for persons with disabilities and their families. Three other towns received honorable mention: Manchester, Old Lyme and Hamden. During the summer of 2003, a survey was conducted by the Real Choice grant to learn if Connecticut citizens with disabilities are able to participate in all desired aspects of community life. The resulting information will identify gaps in the integration of persons with disabilities into community life and identify changes necessary to make communities more supportive and inclusive. Results of the survey are expected in early 2004. Workforce development activities have focused on establishing a central point of recruitment for direct support personnel and their employees and the development of recruitment materials.

Community-integrated Personal Assistance Services and Supports (C-PASS) Grant

On October 1, 2003, a three-year, \$585,000, C-PASS grant was awarded to the Department of Social Services (DSS) to 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. As with the Real Choice Grant, DSS has contracted with the University of Connecticut's Center for Disabilities to implement this initiative.

The grant has three main objectives: (1) develop a single statewide tool to recruit personal assistants for permanent and backup employment; (2) create a strategic marketing plan to recruit personal assistants; and (3) provide training for employers of personal assistants.

Independence Plus Waiver Initiative

On October 1, 2003, a three-year \$175,000 Independence Plus Waiver Initiative was awarded to the Department of Mental Retardation (DMR) that will help consumers and their families develop and manage individual budgets for their services and supports.

Quality Assurance and Improvement in Home and Community-Based Services

On October 1, 2003, a three-year \$499,000 Quality Assurance and Improvement in Home and Community-Based Services initiative was awarded to DMR to implement its comprehensive quality improvement review system.

Work Incentives

The Connect to Work Center

In 2001, the Department of Social Services' Bureau of Rehabilitation Services applied for and received two federal grants to establish the Connect to Work Center: the Medicaid Infrastructure Grant and the Benefits Planning, Assistance and Outreach Grant.

Combining the resources of these two grants with funding from the Bureau of Rehabilitation Services, this Center provides benefits information to individuals, families, advocates, agencies, and others to encourage and support the full participation of persons with disabilities in the competitive workforce. The Connect to Work Center provides benefits counseling, training, public education and outreach about state and federal benefits and services for persons with disabilities.

- *The Medicaid Infrastructure Grant* was awarded by the Centers for Medicare and Medicaid Services in 2000. This grant provides a minimum of \$500,000 annually to make infrastructure changes that support the competitive employment of individuals with disabilities. The two major focus areas are Personal Assistance Services and the Medicaid Buy-In program, known in Connecticut as the Medicaid for the Employed Disabled Program. For personal assistance services, the grant has focused on workforce issues through such activities as a personal assistance conference, two focus groups, and a mail survey. For the Medicaid for the Employed Disabled program, the grant has focused on education, outreach, benefits counseling and research.
- *The Benefits Planning, Assistance, and Outreach Grant* was awarded by the Social Security Administration in 2000. This grant provides approximately \$200,000 annually to provide individualized benefits planning and assistance to persons with disabilities who want to work. Benefits counselors provide information on the impact of work on cash and medical benefits to approximately 1,000 Connecticut citizens with disabilities each year.

Federal Ticket to Work/Work Incentives Improvement Act of 1999

This federal program is designed to support competitive employment for individuals with disabilities. Below are examples of what has been implemented in Connecticut.

- *Ticket to Work Program:* This program is designed to provide the supports necessary for Supplemental Security Income (SSI) recipients and Social Security Disability Insurance (SSDI) beneficiaries to go to work. When it was implemented in November 2002, approximately 85,000 SSI and SSDI beneficiaries were eligible to receive a “ticket” to obtain vocational rehabilitation, employment services and other support services.
- *Medicaid for the Employed Disabled Program:* Implemented in October 2002, the program allows persons with a disability to engage in employment without jeopardizing needed medical services through the Medicaid program. Individuals with disabilities may earn up to \$75,000 per year, and retain access to Medicaid coverage. In addition, certain individuals are allowed to retain other necessary services enabling them to remain actively employed. The Personal Care Assistance Services Waiver program also is available to these individuals if they meet program requirements. As of June 30, 2003, there were 2,718 individuals receiving benefits under this program.
- *Expedited Reinstatement:* Another fear of individuals with disabilities considering work is loss of eligibility for Social Security benefits. Expedited Reinstatement provides a five-year window after an individual’s entitlement stops because of work. During this window, an individual can go back onto temporary benefits for a period of six months while Social Security reviews their medical status. In Connecticut, 96 percent of those who have applied for Expedited Reinstatement have been approved.

Connecticut Community KidCare

Implemented in 2002, this innovative reform and restructuring of the state’s behavioral health care system for children places families at the center of all treatment planning. Led by the Departments of Children and Families and Social Services, the program works to promote the healthy functioning of children with behavioral health problems and their families in their natural community settings rather than in out-of-home or out-of-state care. KidCare is enhancing and developing community-based and residential services for children. Services include emergency mobile psychiatric services, care coordinators, child guidance clinics, extended day treatment programs, in-home care and substance abuse treatment programs for youth.

C. Recent Long-Term Care Initiatives

Since the last Long-Term Care Planning Committee’s Long-Term Care Plan, issued in January 2001, progress has been made in Connecticut in the development and expansion of home and community-based services. These services assure that elders and individuals with disabilities have choices that allow them to reside in their communities and avoid institutional care.

Expanding Home Care Eligibility

As reported earlier, the Department of Social Services began implementing the “medically needy” component to the Connecticut Home Care Program for Elders (CHCPE) on October 1, 2000. This change allows individuals with incomes over 300 percent of the Supplemental Security Income (SSI) level to be eligible for the program as long as they apply some of their income toward their care and their income does not exceed the cost for nursing home care. Individuals are allowed to retain income up to 200 percent of the federal poverty level (approximately \$1,500 per month). All other income is applied to their care. Prior to October 1, 2000, an individual’s income could not exceed 300 percent of the SSI threshold. As noted earlier, if an individual was as little as one dollar over the income limit, even if they met other CHCPE eligibility criteria, they were ineligible to receive CHCPE services.

Currently, this expansion only applies to the State-funded component of the CHCPE. A phased approach is being used due to the fact that federal approval is needed to implement this change in the Medicaid waiver portion of the program. Although the federal government historically has not supported this buy-in approach for home care, through the federal New Freedom Initiative, it is anticipated that federal Medicaid regulations will be implemented that will support this program change. The Department of Social Services applied for federal approval in 2001 and as soon as federal approval can be secured, Connecticut will implement a similar expansion for the Medicaid waiver portion of the CHCPE.

Expanding Assisted Living Options

Over the past several years, the Department of Economic and Community Development (DECD), the Department of Social Services (DSS), the Office of Policy and Management (OPM), and the Connecticut Housing Finance Authority have been developing the Assisted Living Demonstration Project, which, when fully operational, will provide up to 300 subsidized assisted living units in both urban and rural settings. Four projects have been approved in the cities of Glastonbury, Hartford, Middletown, and Seymour. The first units are expected to open in 2004.

In addition to the Assisted Living Demonstration Project, assisted living options have been extended to State-funded congregate housing, federally financed Housing and Urban Development (HUD) complexes and private pay assisted living facilities, described below.

Congregate Housing

Beginning in 2001, DECD and DSS introduced assisted living services within State-funded congregate housing facilities. Sixteen of the 24 congregate facilities are participating in this service expansion. As of June 30, 2003, 147 congregate housing residents were actively enrolled in the assisted living program. From when the program was implemented in May 2001, to June 30, 2003, a total of 269 residents have received assisted living services through the program.

The development by DECD of 95 new congregate units with enhanced core services and the option to provide assisted living services is currently underway. These new units, which are expected to be completed within the next two years, will be build in Bridgeport, Danbury and New Haven.

HUD Complexes

In addition to congregate settings, assisted living services are also being offered in three federally financed HUD complexes. As of June 30, 2003, 103 residents in two HUD facilities in New Haven and Hartford were actively receiving assisted living services, with implementation beginning for the third HUD complex in Storrs. From when the program was implemented in May 2001, to June 30, 2003, a total of 150 residents have received assisted living services in federally financed HUD complexes.

Private Pay Assisted Living Pilot

In August of 2002 the General Assembly authorized the development of two private pay assisted living pilot programs to help residents in private pay assisted living facilities avoid entrance to a nursing home once they have exhausted their personal resources.

One pilot is Medicaid-funded and will allow up to 50 persons residing in private pay assisted living facilities to receive support from Medicaid, through the CHCPE, for their assisted living services once they have exhausted their resources. While the pilot will not pay for any room and board charges, it will help subsidize the costs for services, which often can be the reason the individual can no longer afford to live in the facility.

Similar to the Medicaid-funded pilot, the State-funded pilot will allow up to 25 individuals residing in private pay assisted living facilities to receive support for their assisted living services under the State-funded component of the CHCPE.

The pilots began implementation in January 2003. As of June 30, 2003, 11 individuals were receiving services under the pilots, with an additional 71 individuals having applied for the program.

Moratorium on Construction of Nursing Facility Beds

In 1991, Connecticut established a moratorium on the construction of new nursing facility beds with limited exceptions. Since 1997, the average monthly number of nursing facility days for Medicaid residents has dropped even though the moratorium allowed the addition of new beds that were approved prior to the moratorium. In 2001, the General Assembly extended the moratorium to 2007 because nursing facility occupancy rates have not reached capacity and have continued to drop over the years.

APPENDIX F.

“Choices are for Everyone” Plan -- Action Step Updates

Included in this appendix are the following three items related to the "Choices are for Everyone" Plan that was produced in March 2002.

- Status Report on the Plan's Action Steps.
- Guardianship and Conservatorship Report.
- Housing Report.

Status Report
“CHOICES ARE FOR EVERYONE” PLAN – ACTION STEPS

The Long-Term Care Planning Committee will oversee the implementation of these action steps, including developing a timetable for completion of the action steps and assignment of who will be responsible for each step. In addition, the Planning Committee will review this Plan on a regular basis and revise it as necessary.

ACTION STEPS	LEAD PERSON	COMPLETION
Transition		
1. Develop a system to identify individuals who are residing in institutional care (restrictive environments) and want to live in the community.	Michele Parsons – <i>will be done through NF Transition Grant. Will also coordinate with DMR & DMHAS.</i>	June 2004
2. Review guardianship and conservatorship laws, regulations, and training to determine what revisions would be necessary to make them consistent with the independent living model.	Chris Lewis – <i>will coordinate with DMR, which is charged with conducting a study on guardianship for persons with mental retardation. Report is due to the General Assembly by Jan. 2003.</i>	June 2003 – See Guardianship Report.
3. Educate people with disabilities who are in institutions and who will be transitioning out, about the importance of working with a peer who has made a successful transition to the community. The peer can provide practical advice about how to prepare for and deal with many of the difficulties of living in the community and provide assistance once the person gets out. For example, when people first transition out of an institution, they may have no friends or relatives to help them in the community and/or they may have little to do. This can be depressing. In addition, in order to successfully work with personal assistants who are not available 24-hours per day, people may need to train their bodies to be able to cope with the time periods between the personal assistance visits.	Michele Parsons – <i>will be done through NF Transition Grant.</i>	April 2004
4. Explore the possibility of developing a peer support network for people transitioning from living in institutions to living in the community. This is important because adjustment to living in the community is more than getting the physical care or mental health services from a paid provider.	Michele Parsons – <i>will be done through NF Transition Grant</i>	June 2004

ACTION STEPS	LEAD PERSON	COMPLETION
5. Educate people with disabilities that relying on paid support staff for 100 percent of their support needs will still leave them vulnerable. It is crucial to build on existing relationships where appropriate, and to develop strong new relationships with neighbors and members of the community.	Michele Parsons – <i>will be done through NF Transition Grant.</i>	June 2004
Housing		
1. Investigate how to improve the reporting of accessible housing units to the Connecticut Accessible Housing Registry. The current voluntary system has not produced the number of reported accessible units that are necessary for a successful registry.	Mickey Regan -- <i>responsible for the accessibility registry at DECD, will explore ways to improve reporting.</i>	December 2002 – <i>See Housing Report.</i>
2. Educate architects, housing authorities, builders, and local boards, such as planning and zoning commissions, about accessibility.	Rick Robbins & Stan Kosloski – <i>will identify the appropriate parties to participate in an initial meeting to identify next steps. Will be combined with Housing Action Step #3 below</i>	October 2002 for initial meeting. - <i>See Housing Report.</i>
3. Convene a Task Force to review safety codes such as fire and building codes and recommend revisions designed to assure safety for individuals with functional limitations. Methods to follow-up and enforce these codes also needs to be reviewed.	Rick Robbins & Stan Kosloski – <i>see Housing Action Step #2 above.</i>	October 2002 for initial meeting. - <i>See Housing Report.</i>
4. Explore the possibility of providing tax or other incentives to encourage new homes or substantial renovations to meet minimum accessibility standards. This would apply to private homes as well as to public or private condominiums or apartments.	Jim Heckman, <i>legislative liaison for DECD, is working with CHFA to explore existing tax incentives as a starting point.</i>	December 2002 - <i>See Housing Report.</i>
5. Strongly encourage every housing authority in the State to seek Section 8 certificates for people with disabilities when they are available.	Rick Robbins – <i>work already underway for this Action Step. Rick will provide a status report. Will be combined with Housing Action Step #6 below.</i>	Ongoing - <i>See Housing Report.</i>
6. Ensure that available Section 8 certificates are distributed to eligible families and individuals.	Rick Robbins – <i>see Housing Action Step #5 above.</i>	Ongoing – <i>See Housing Report.</i>

ACTION STEPS	LEAD PERSON	COMPLETION
Supports		
1. Increase the paraprofessional support workforce through the creation and implementation of a strategic marketing plan to recruit personal assistants and personal managers for permanent and backup employment.	David Guttchen – <i>will contact Debbie Barisano from the PCA Assoc. – work would have been done under PCA Grant CT didn't receive – might be included in new Real Choice Grant. Andy Wagner will also contact Labor Dept. (see Supports Action Step #4 below.)</i>	Summer 2002 for initial contact. – <i>Initial Contact Made.</i>
2. Develop and implement coordinated information source for backup personal assistants utilizing existing waiver program registries.	Michele Parsons – <i>will coordinate with the fiscal intermediary and DMR to establish emergency back-up registry.</i>	January 2004
3. Encourage the “community team” (the team that comes together to assist the individual who is moving into the community) to continue to be involved with that individual for up to a year, if necessary, to deal with issues that could arise and increase the risk of re-institutionalization.	Michele Parsons – <i>tie to work under the NF Transition Grant.</i>	June 2004
4. Work with Department of Labor to develop programs for displaced workers, clients of the Bureau of Rehabilitation Services, etc. to learn about personal assistance as a career.	David Guttchen – <i>will contact Labor Dept. – also will discuss Supports Action Step #1 (see above).</i>	Summer 2002 for initial contact. – <i>Initial Contact Made.</i>
5. Develop and make available optional training programs for individuals who want to support people with disabilities. Topics would include items such as meeting individual preferences of people with physical disabilities, meeting the special needs of individuals with mental health and mental retardation issues, communication with people who rely on non-verbal methods, and values associated with independent living.	David Guttchen – <i>will contact Debbie Barisano of the PCA Association (see Supports Action Step #1 above). Would have been covered under PCA Grant CT didn't get – might be in new Real Choice Grant.</i>	Summer 2002 for initial contact. – <i>Initial Contact Made.</i>

ACTION STEPS	LEAD PERSON	COMPLETION
6. Develop and implement training for people with disabilities who employ personal assistants regarding management of their employees. Management of employees includes hiring, coordinating personal assistants and their schedules, training personal assistants, completing the paperwork related to being an employer, working with a fiscal intermediary, developing and using effective relationship and communication skills, and terminating the employment of personal assistants when necessary.	Michele Parsons – <i>will be done through NF Transition Grant.</i>	April 2004
7. Educate the public about the availability of services provided by the Department of Transportation and specifically how to access those services.	Michele Parsons – <i>tie into NF Transition Grant – pull in DOT to provide necessary transportation info.</i>	June 2004
8. Analyze the fiscal impact of providing a Connecticut income tax deduction for medical expenses that are deductible under the federal income tax.	David Guttchen	Fall 2002 – <i>Estimates range from \$11-15 million per year in lost revenue based on current federal medical expense deductibility rules.</i>
Community Connections		
1. Distribute materials developed by the Nursing Facility Transition Grant to the general public, current residents of institutions, and providers of supports such as physicians and their office staffs, pharmacists and their support staffs, hospital personnel, builders, and plumbers.	Michele Parsons – <i>will be done through NF Transition Grant.</i>	January 2004
2. Develop and implement training for people to become bridge builders, introducing people with disabilities to fellow community members who may become friends and support people.	Michele Parsons – <i>will be done through NF Transition Grant – should also be a component of the model communities being developed under the new Real Choice Grant.</i>	April 2004
3. Assure that translators, interpreters for the deaf, and those skilled in interpreting for individuals with cognitive or communication issues are available to provide information and assistance.	Michele Parsons – <i>should be a component of the model communities being developed under the new Real Choice Grant.</i>	April 2004

**Report Prepared for the
Connecticut Long-Term Care Planning Committee:**

**Olmstead Plan Action Step –
Review of Guardianship and Conservatorship Laws,
Regulations, and Training**

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I. Introduction

On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The Court ruled that the Americans with Disabilities Act may require states to provide community-based services for people with disabilities, who would otherwise be entitled to institutional services, when:

- The state's treatment professionals reasonably determine that such placement is appropriate;
- The affected person does not oppose such placement; and
- The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving services.

The Court's decision in that case clearly challenged Federal, state, and local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. This means that states have the obligation to:

- Divert people from going into institutional placements in the first place if they can be served in a community setting;
- Review those already in institutions to decide how many could be served in the home or community-based setting and how many want to be served in the community; and
- Respond to individual requests by institutionalized people to leave the institutional setting for a home or community-based setting.

In order to develop this report, the following steps were taken:

- Researched the Connecticut General Statute sections concerning guardianship and conservatorship laws in Connecticut;
- Reviewed conservatorship resources and pilot volunteer programs;
- Interviewed advocates who have been involved in the judicial, counseling, and volunteer processes; and
- Researched and reviewed other states' statutes, conservator/guardian programs, *Olmstead* plans, and literature on related issues.

From this research, it became apparent that in order to meet the requirements set forth in the *Olmstead* decision, the Connecticut plan must address ways to *enable/enhance a consumer's capacity to make his or her own choices and become as independent as possible*, and *provide consumers, families and providers with the information, education, and assistance to make this possible*. Accordingly, the recommendations included herein are directed toward these objectives. This appears to be in consonance with

Connecticut's final draft of its community integration plan, *Choices Are for Everyone*, in March 2002.

II. Guardianship and Conservatorship Laws in Connecticut

By the very nature of guardianships and conservatorships, they are inconsistent with promoting "independence" in Connecticut. The statutes do, however, provide degrees of both guardianship and conservatorship that allow for more or less control over a ward according to one's capacity as determined by a Probate Court.

A. Probate Courts

In Connecticut, Probate Courts have jurisdiction over a variety of matters including Guardians, Conservators and Civil Commitment:

- Appointing guardians for persons with mental retardation;
- Approving sterilizations of persons with mental retardation;
- Approving placements of persons with mental retardation;
- Approving the involuntary placement of persons with mental retardation to the Department of Mental Retardation;
- Appointing a guardian of the estate or person for a child;
- Appointing conservators of the person and the estate for persons with mental illness and/or for persons who are incapable of managing or administering their own affairs; and
- Committing those suffering from severe mental illness to an appropriate facility.

The probate courts have often been called "the people's courts" because they offer simple, direct access to legal proceedings. They have also been described as "neighborhood courts" because there is a probate court in almost every town in the state. 130 of 169 towns have a probate court. In most cases, the probate courtroom will be a conference room in the probate court offices. The atmosphere at the hearing is informal; the judge does not preside from a bench or wear a black robe. Probate judges are elected officials who are not required to be attorneys.

In addition to the probate judges, there exists an office of the probate court administrator. The administrator is appointed by, and serves at the pleasure of, the Chief Justice of the Connecticut Supreme Court. The probate court administrator has the power to issue rules and regulations concerning the procedures of the several courts. In addition, the administrator may make recommendations to the General Assembly regarding possible changes to the statutory law of the state, as may be necessary or advisable, to improve the administration of the courts of probate.

B. Protective Oversight

There are, in particular, three categories of protected persons statutorily provided for within the responsibilities of the probate court: minors, persons with mental retardation,

and other “incapable” persons. The term “guardianship” in Connecticut is specifically used relative to minors and persons with mental retardation. The term “conservator” is used relative to supervision of the financial or personal affairs of other persons deemed “incapable.” The populations of adults affected by *Olmstead* are those described in sections 2 and 3, below –persons with mental retardation and other “incapable” persons.

1. Minors

In The Connecticut Uniform Transfers to Minors Act, a “guardian” is “a person appointed or qualified by a court to act as guardian of a minor’s estate.” (C.G.S. Sec. 45a-557) “Guardianship” as used to refer to minors, provides for the greatest degree of control by a guardian: “(A) The obligation of care and control; and (B) the authority to make major decisions affecting the minor’s welfare, including, but not limited to, consent determinations regarding marriage, enlistment in the armed forces and major medical, psychiatric or surgical treatment.” (C.G.S. Sec. 45a-604)

2. Persons with Mental Retardation

The Guardians of Mentally Retarded Persons Act, found in C.G.S. Sec. 45a-668 to 45a-684, provides for two levels of guardianship -- plenary and limited. Mental retardation is defined as a “significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.” (C.G.S. Sec. 1-1(g))

A “plenary guardian” supervises “all aspects of the care of an adult person...who by reason of the severity of his mental retardation, has been determined to be **totally unable** to meet essential requirements for his physical health or safety and **totally unable** to make informed decisions about matters related to his care.” (C.G.S. Sec. 45a-669(a)) A “limited guardian” supervises only “certain specified aspects of the care of an adult person...who by reason of the severity of his mental retardation, has been determined to be able to **do some, but not all**, of the tasks necessary to meet essential requirements for his physical health or safety or to **make some, but not all**, informed decisions about matters related to his care.” (C.G.S. Sec. 45a-669(c))

Of particular note is the statutory requirement (C.G.S. Sec. 45a-677(d)) that a guardian assumes duties and powers in order to “assist a ward in achieving self-reliance.” Further language prevents a guardian from exercising power or authority under certain circumstances, either by providing consent or causing an event to happen -- such as placement in a training facility when in conflict with the ward’s wishes -- without complying with due process procedures. (C.G.S. Sec. 45a-677(e))

However, CGS 45a-677(i), the newest provision enacted in 2001, stipulates that the primary decision maker is the guardian and the guardian must consult with the ward and appropriate members of the ward’s family "where possible". There is no provision in the statute for situations where the ward and guardian conflict on the types of programs needed by the ward after the ward has been consulted. The statute seems to imply that

deference will be given to the guardian. If the ward wants to live in a particular independent living situation and the guardian opposes it because he or she thinks that living independently will impact negatively on the ward's well being, the guardian's position will likely prevail. Similarly, the ward may oppose the particular independent living program proposed, while the guardian may support the placement.

In addition, the term "where possible" is not defined. Thus a lot of discretion is placed in the hands of the guardian to decide whether or not a particular situation requires consulting with the ward and/or appropriate members of the ward's family.

3. *Other "Incapable" Persons*

A conservator may be appointed by the Probate Court to supervise "the financial affairs of a person found to be incapable of managing his or her own affairs" (Conservator of the estate, C.G.S. Sec. 45a-644) and/or "the personal affairs of a person found to be incapable of caring for himself or herself" (Conservator of the person, C.G.S. Sec. 45a-644). This incapacity can be a result of mental illness or disability, chronic use of drugs or alcohol, or confinement, which results in the person's "inability to provide (as to the person) medical care for physical and mental health needs, nutritious meals, clothing, safe and adequately heated and ventilated shelter, personal hygiene and protection from physical abuse or harm and which results in endangerment to such person's health." For example, within this category, the person could be a 23 year-old physically disabled woman, an elderly gentleman with Alzheimer's disease, a 55 year-old veteran with schizophrenia, or a 42 year-old homeless person.

Appointment of a conservator can be made upon the ward's request (voluntary) or petition of another (involuntary). It is important to note that even when the court finds by clear and convincing evidence that a person is incapable of managing his or her affairs and/or caring for himself or herself, the court need not appoint a conservator if it appears that the person is being cared for properly and/or that his or her affairs are being managed properly without the appointment of a conservator (C.G.S. Sec. 45a-650(c)). The person, while still competent, could have executed a durable power of attorney authorizing another to act on his or her behalf.

The Probate Court has discretion to limit the powers and duties of a conservator when deemed in the "best interests of the ward" as supported by specific findings to justify such limitations. The court can consider such factors as abilities of the ward, prior appointments of fiduciaries, trustees, or attorneys-in-fact, and available support services. (C.G.S. 45a-650(g)) The court can subsequently make modifications to its decree provided a change in circumstances occurs.

Unlike the guardian of a person with mental retardation, a conservator has no statutory obligation to "assist a ward in achieving self-reliance." The language limits any sense of enabling a ward's independence in referring to the conservator's "power" to establish a place of abode and to give consent for medical and professional care, counsel, treatment or service. And further, only the power and authority to cause the ward to be committed

to a mental institution is prohibited, requiring compliance with statutory due process provisions.

III. Education and Training

A. 1988 Task Force

In 1988, Probate Courts identified conservatorship as the area of greatest human services concern to the courts. The primary reason listed was the difficulty experienced in locating a qualified person or agency to be appointed as conservator of the estate or conservator of the person for an individual found to be incapable. This was particularly true for frail elderly persons without close family and persons impaired by long-term substance abuse or mental illness. In March, The Office of Probate Administration created an interagency Task Force to study the issues, assess current and project future need for conservators, explore issues of concern, and to formulate specific recommendations which might be implemented. Recommendations included the following:

- Explore expanded resources, with a priority given to establishing local municipal programs;
- Establish qualifications and coordinate training of appointees;
- Channel funding into local programs, established by local government and private agencies; and
- Provide better training and support to family members to encourage participation where appropriate.

B. Volunteer Court Visitor / Conservator of the Person Program

In the early 1990's, Sage Services, Inc. of New Haven began an innovative voluntary court visitor program for indigent wards without families living in nursing homes in the New Haven area. A Board consisting of professionals knowledgeable in legal, health care, social, and other geriatric issues assisted with the development of a training program and programmatic evaluation and modification. These court visitors served as liaisons between their ward and court appointed conservator, who traditionally had little time to visit the ward or develop any kind of meaningful relationship. Eventually the program was expanded with qualified visitors receiving appointments as volunteer conservators from participating area probate judges.

A large grant from the Robert Wood Johnson Foundation and other regional foundations allowed the program to expand to include the southwest, western, and north central regions with varying results. It was difficult to match volunteers with community wards suffering from mental illnesses. Probate Judge enthusiasm and cooperation was a factor in linking up with potential wards and receiving appointments. Some regional social services offices felt threatened by the availability of alternative conservator resources. In general, however, the program was a success and has been used as a national model worthy of replication. The program in Western CT was a notable success story. The

Probate Judge provided the agency with a court computer for the program supervisor to directly communicate with area courts and personnel. Over 31 volunteers were recruited and matched with wards. When the grant money was depleted, however, and other fundraising efforts failed, the Area Agencies on Aging eventually were no longer able to bear the financial affects of administering the programs within their regions. To this day, however, many of the placed volunteers in Western CT still maintain contact with the Agency.

C. Current Status

Connecticut has no statutory requirements for certification of guardians or conservators, nor any educational requirements or established programs. In practice, Probate Courts rely on the pro bono services of attorneys when appointing a conservator for an indigent ward, in return for a more lucrative appointment when a ward can afford to pay for services. Probate Courts also heavily utilize the Commissioner of Social Services as the conservator of estate and/or person in cases of last resort. On numerous occasions the Commissioner has had to close intake of additional cases for the Conservator of the Estate program due to limited personnel available to handle the caseload.

Although individual Probate Courts (i.e. Glastonbury) have, in the past, provided training sessions to develop a pool of knowledgeable volunteers or other appointees, this is the exception rather than the rule.

IV. Comments

A. Probate Court

Because of their relative independence and the differing education and experience levels of probate judges, rulings are inconsistent among the 130 courts throughout the state. This can be particularly problematic when dealing with any limitation in guardian or conservator duties.

The Probate court system is facing reorganization due to the pending financial crisis foreseen by the phasing out of their major source of income – state succession and federal estate taxes. Probate courts rely almost exclusively on statutory probate fees to pay judicial salaries, clerks and staff, and the bulk of these fees come from the administration of decedents' estates. The amount of funding received from estate work is disproportionate to the time spent on estate work. This trend is likely to make funding of the probate courts even more problematic. The majority of work is spent on the other areas of jurisdiction including juvenile, guardianship, and conservatorship issues, which do not generate financially lucrative fees. Members of the probate assembly (judges) have been involved in the CT Bar Association Task Force that recently released its report (June 2002) with recommendations for legislative action in the upcoming session. Further, members have also been working on statutory revisions to the Uniform Trust Code, that will, if enacted in Connecticut this year as anticipated, further affect probate practice by creating a "First of its Kind" comprehensive and modern codification of the

laws of trust in Connecticut Accordingly, this has not been an opportune time to pursue study or support of additional statutory revisions.

Although there are provisions for limited guardianship and conservatorship, in practice, few are ordered. The laws make it more difficult for a judge to award limitations since each limitation must be supported in a finding of fact. Accordingly, rather than enabling a person to make the choices she or he is able to do, the law has the opposite affect by discouraging judges from taking that extra step.

It appears that not only laws, training, and regulations need review, but the actual PRACTICE impacts as well, in order to move to a supportive independent model.

B. Mental Retardation

In 2001, with Public Act 01-140, the legislature required DMR to conduct a study specifically relating to the guardianship of persons with mental retardation. Although this study could have been helpful to the broader disabled population, DMR was proceeding according to the statutory guidelines. Members of the collaborative group include representatives from the Office of the Probate Court Administrator, Office of Protection and Advocacy for Persons with Disabilities, ARC-CT, and FORConn. This study, including findings and recommendations, was submitted to the General Assembly in January 2003. Since DSS was not a party, it was impractical to pursue a separate, parallel study.

Concerns related by advocates that have impacted practice in this area include current guardianship by DMR standards, suggesting that rather than giving credence to a ward's wishes, deferential treatment is being given to the guardian's wishes. Although statutes admirably provide that a guardian assumes duties and powers in order to "assist a ward in achieving self-reliance," and must solicit the ward's wishes and desires to the maximum extend possible, concerns have been raised that this is not always the case. Advocates suggest that wards have faced "emotional blackmail" by relative guardians when they wish to pursue life with some modicum of independence. When faced with losing the emotional support of the family, a ward usually retreats. Advocates also suggest that more has to be done to determine which issues wards can be assisted in understanding, and thus capable to make decisions about – including medical treatment, and risk.

C. Other "Incapable" Persons

The population included within this category ranges from persons with developmental disabilities, to physical disabilities, to mental illnesses, to dementia and related maladies. Severity can range from mildly dysfunctional to severely incapacitated. Age, as well, ranges from those persons who have just attained the age of majority to the very old.

Although the statutes specify the factors that can and should be considered in appointing a limited conservator, language suggests a full conservatorship "unless"... and practice follows.

Current statutory language is silent as to the decision making guidelines for a conservator's actions. There are two standards that could be considered – in the ward's best interest or as a substitute decision maker (one who would make the decision the ward would make if "capable"). Currently, under most circumstances, a conservator is considered held to the "best interest" standard. Virginia requires that the conservator (of financial affairs) "exercise reasonable care, diligence, and prudence, and shall act in the best interest of the incapacitated person. To the extent known to him or her, the conservator shall consider the expressed desires and personal values of the incapacitated person." As to a guardian, who makes decisions about how the person lives, he or she "applies the values of the incapacitated person in making these living decisions."

The CT statutes have no provision for a duty to encourage a ward to participate in decisions, to act on his or her own behalf when able, and to develop or regain the capacity to manage his or her own personal affairs or manage the estate and his or her financial affairs. These provisions are modeled in the Guardianship and Conservatorship Proceeding Regarding Incapacitated Adults of Virginia and are recommended by the Wingspan Conference and the National Probate Court Standards. In practice, conserved psychiatric patients have been denied the opportunity to execute Health Care Planning Documents, despite being able to understand the ramifications when explained to them by knowledgeable counselors. This has similarly been an issue with conserved elders under the cognizance of the Department of Social Services. With the appropriate information and assistance, certain conserved individuals can be capable of making medication and treatment decisions, as well.

D. Education and Training

The major challenge, as was evident in the Pilot Programs operated by Sage Services and the Area Agencies on Aging, to providing adequate education and support for volunteer or family guardians and conservators has historically been funding.

All major studies have recommended a training and support component to conservatorship at all levels. This component should include, at a much earlier stage, alternatives to guardianship or conservatorship. Alternatives include caregivers, Powers-of-Attorney, Health Care Planning Directives, Trusts, and Representative Payees.

Practice reveals that some petitions for involuntary conservatorship are mired with conflicts in the family. And this conflict extends well beyond the initial petition. Conflicts continue between wards and their families as evidenced among individuals with mental retardation and developmental disabilities and their family caregivers. Another system which should be considered and made available is mediation as a means of resolving conservator issues. Other CT courts have utilized "ordered" mediation in custody disputes. These circumstances are no less compelling.

The issues raised in the 1988 Probate Task Force study still remain – lack of conservator resources available for poor community or institutionalized wards. This may be a major

impediment to de-institutionalization since conservators will need to spend more time with wards to provide the assistance necessary for wards to be able to become as independent as possible.

Standards for Conservators and Guardians need to be in place and further personnel resources available to Probate Courts to be able to adequately monitor an increasing population residing in the community under Court jurisdiction. The National Guardianship Association has developed model standards, developed a system of certification, and provides training programs and other services.

Education and Training cannot stop with consumers, their caregivers, and those appointed as guardians and conservators. Probate judges need continuing legal education, as well as training about medical and social issues inherent in ordering limited conservatorships and guardianships.

V. Recommendations

This limited review and study is by no means a final answer as to measures to take to “right” the Probate Court, CT statutes about Guardianship and Conservatorship, and the lack of resources available for appropriate Education and Training to support *Olmstead* implementation. It does, however, lay a foundation upon which more detailed and comprehensive work can be based.

A. Guardianship and Conservatorship Laws:

1. In CT, Guardianship refers to adults with mental retardation; Conservatorship refers to “incapable” adults. Use of this terminology is not consistent with the majority of states that use the term “guardian” to relate to the person, and “conservator” to refer to fiscal management. Consistency in terms and provisions, as appropriate, is needed.
2. CT laws provide for the appointment of both limited guardianship and conservatorship. The conservatorship laws, however, make such an appointment the exception rather than the rule by requiring a probate judge to justify anything less than full conservatorship. The law needs to focus on enabling a ward to utilize what capacity he or she has. (Is the glass half full or half empty? Wingspan Conference recommends use of the term “diminished capacity” rather than “incapable” or “incapacitated” for this very reason.) This is particularly important when it comes to making medical, health care planning, and other quality of life decisions.
3. Current conservator laws provide no incentive to encourage a ward to develop or regain the capacity to manage his or her own personal affairs or manage his or her financial affairs. CT statutes define as one of a guardian’s duties to “assist a ward in achieving self-reliance.” This provision should be uniform among all adult wards.

4. CT statutes need to provide for a "substitute decision maker" standard -- a standard that requires that the guardian or conservator make certain decisions based upon what the ward would have decided if "capable" -- in appropriate situations. As examples, this standard could be applicable for certain health care or living determinations, rather than always requiring that a guardian or conservator make determinations based on "the best interests of the ward."

B. Education and Training:

1. In order to provide wards with the assistance necessary to increase capacity, **more** guardians and conservators are needed who will spend adequate time with a ward. This involves the creation of programming to support alternative sources of conservators/guardians such as volunteer and paid regional/municipal programs. The traditional "lawyer" conservator is no longer adequate to meet this increasing role.
2. Guardians and conservators need a source of initial and continuing training and support as to their responsibilities and duties, as well as an understanding of other issues including physical and mental capacity, fiduciary responsibilities, and health care decision making. Currently no system of certification is required or available within the state. More statutory scrutiny is provided to a hairdresser than these important persons responsible for the lives of adults with diminished capacity.
3. Education and training also must be directed to those persons at-risk of conservatorship and family caregivers. Such topics should include alternatives to conservatorship.
4. Although laws throughout CT are uniform, practice in the Probate Court is not. The level of education (a judge need not be or ever have been an attorney) and experience may result in significantly different findings of capacity among the 130 courts. Continuing education, even in matters outside the law relating to the physical and mental status and capabilities of wards, must be available and required.
5. CT needs to seriously explore "mediation" as a means of resolving conservator issues. Mediation is increasingly being utilized in other states to resolve conflicts within families as to home and personal care issues. This system can be particularly helpful in addressing conflicts among wards and their families which can already be seen in CT, especially in populations with mental retardation, developmental disabilities, and mental illness who will be most impacted in *Olmstead* transitions.

C. Other:

1. The DMR study, submitted to the General Assembly in January 2003, needs to be reviewed for inclusion of recommendations as applicable.
2. The Wingspan Guardianship Conference and the Commission on National Probate Court Standards recommendations address a number of the concerns raised in this study. Both recommend the less intrusive alternatives to conservatorship and limitations of the scope of the order by virtue of particular needs and functional capabilities. Both also recommend educational components. The recently released report of the Task Force on the Future of the Connecticut Probate Courts also raises concerns about the Probate Court that have been noted here that will impact *Olmstead* implementation. All should serve as “core” resources in future study.
3. Finally, it is essential to pursue these perceived roadblocks to *Olmstead* implementation through the further research, study, and recommendations of a Task Force, such as that put together under the authority of the Probate Administration in 1988 or recently by the CBA. Appropriate parties to work on these issues as a long-term committed project should necessarily include representatives from the CT Supreme Court, CBA, Elder Law and Estates and Probate Sections, Probate Assembly, P & A, DMR, and Connecticut Legal Rights Project. Such a Task Force should pursue the development of specific legislative recommendations relative to Guardianship and Conservatorship laws, Mediation implementation, and Education and Training certification and requirements.

VI. Resources and References

Advocacy Unlimited, Inc., Building a Grassworks Network of Mental Health Advocates Across Connecticut from the Inside Out, Connecticut Legal Rights Project, Inc. (CLRP), <http://www.mindlink.org/clrp.html>

Americans with Disabilities Act/ *Olmstead* Decision, Centers for Medicare & Medicaid Services, <http://cms.hhs.gov/olmstead/default.asp>

Connecticut General Statutes, Secs.45a-593-700

“Connecticut Probate Court System,” an article by Paul A. Hudson

“Consumer Choice in Home- and Community –Based Long-Term Care: Policy Implications for Decisionally Incapacitated Consumers,” by Marshall B. Kapp, JD, MPH, Wright State University of Medicine.

Conversation with Atty. Tom Behrendt, Legal Director, Connecticut Legal Rights Project, August – September, 2002

Evaluating Mediation as a Means of Resolving Adult Guardianship Cases, a report submitted by The Center for Social Gerontology

Final Report of the Task Force on Appointment of Conservators in Connecticut, December, 1988

“Guardianship and Conservatorship Proceedings Regarding Incapacitated Adults,” Commonwealth of Virginia

Guidelines for Conservators, © 2002 Probate Court Administrator, State of Connecticut

Meeting with Atty. Marilyn N. Toland, Chair of the Probate Practice standing committee of the CBA Elder Law Section and member of the CBA Estates and Probate Section, September 17, 2002. Section missions:

Estates and Probate Section: To focus on Connecticut practice affecting wills, estates, trusts, guardianship, conservatorship, property interest of spouses, transfers of property, powers of attorneys, living wills, as well as the impact of gift, inheritance, estate and income taxes.

Elder Law Section: To discuss and consider issues in elder law, promote the continuing education of CBA members and the general community, monitor and develop positions with respect to proposed legislation and regulatory action involving the elderly and to foster relationships between attorneys and private, public and governmental organizations dealing with the elderly.

Meeting with Office of Protection & Advocacy for Persons with Disabilities Staff, July 2, 2002 and follow-up conversations

Memorandum of April 7, 1998 re: Court Visitor / Conservator of the Person Programs

National Guardianship Association, www.guardianship.org.

The main goal of this website is "to provide educational, training, and networking opportunities for guardians; to promote the highest levels of values, standards and ethics; and to ensure a nationally recognized standard of excellence" for guardians. Although this site is for guardians, it does describe guardianship, what a guardian does and general guidelines for choosing a guardian. It also discusses training and certification for guardians.

National Probate Court Standard, A Project of the National College of Probate Judges and the National Center for State Courts - <http://www.ncpj.org/standard.html>

Pilot Program for Court Visitor and Volunteer Conservator, Sage Services Inc., December 4, 1992

Presentation by CBA President Atty. Deb Tedford, September 17, 2002, on CBA Probate Court Task Force Report concerning the severe financial crisis faced by the Probate Courts. Deb emphasized the two functions of the Probate Courts, namely: (1) to provide orderly wealth transfers under Estates and Trusts; and, (2) to provide protection for the elderly, disabled and minors. Although the wealth transfers provide revenue for the Courts, the Court's functioning is shifting more and more toward dealing with the less-profitable incapacity protection issues. The "five pillars of probate court reform" as set forth on page 20 of the Report of the CBA's Task Force on the Future of Connecticut Probate Courts as delivered to the House of Delegate on June 2, 2002, namely: to provide statewide fiscal control of probate courts, including budgeting, consolidation and economic efficiency; to work for increased professionalism and increased compensation for judges and clerks, as well as increased revenue for those courts in need; to continue the trend of increasing the jurisdiction and powers of the probate courts; to recommend limited campaign finance reform; and for the state to assume responsibility for certain mandated costs of judicial operation, such as indigency fees, and ultimately to bear the responsibility for maintaining a viable probate system.

Presentation by CBA President Atty. Deb Tedford, November 19, 2002 on Uniform Trust Code legislative proposal developed in cooperation with Probate Assembly

Probate Court Procedures Involving Persons with Mental Retardation, ©2002 Probate Court Administrator, State of Connecticut

PROBATE COURTS AND PRIVATE PROFESSIONAL GUARDIANS/
CONSERVATORS, Edited by Terry W. Hammond, President of the National
Guardianship Association [http://www.hammondlaw.net/professional_guardians.htm]

Proposal for the Expansion and Replication of the Court Visitor / Conservator of the Person Program, Sage Services, Inc., September, 1996

REPORT OF THE TASK FORCE ON THE FUTURE OF THE CONNECTICUT
PROBATE COURTS, © 1997-2002 Connecticut Bar Association

- (a) THE STATES' RESPONSE TO THE *OLMSTEAD* DECISION: A WORK IN PROGRESS By Wendy Fox-Grage, Donna Folkemer, Tara Straw, Allison Hansen, January 2002,
<http://www.ncsl.org/programs/health/forum/olmsreport.htm>

Wingspan – The Second National Guardianship Conference, Recommendations,
December 2, 2001

VII. Other Resources:

Lori A. Stiegel, J.D., Alternatives to Guardianship: Substantive Training Materials for Professionals Working With the Elderly and Persons With Disabilities, Part I (1992).

This book is primarily a collection of training materials but it also describes guardianship and its implications, durable powers of attorney, trusts, joint property arrangements, living wills and health care powers of attorney. Hypothetical situations and possible solutions to these situations are also presented as examples and possible guidance.

Paula L. Hannaford and Thomas L. Hafemeister, *The National Probate Court Standards: The Role of the Courts in Guardianship and Conservatorship Proceedings*, 2 *Elder L.J.* 147 (1994).

This article describes guardianship and conservatorship and tells what the court is likely to do. It also talks about having court visitors or guardian ad litem as less intrusive ways to care for those who are incapacitated. Temporary guardianship is also discussed as an alternative to a plenary guardianship.

“Choices are for Everyone” Plan Action Steps - Housing

1. Investigate how to improve the reporting of accessible housing units in the Connecticut Accessible Housing Registry. The current voluntary system has not produced the number of reported accessible units that are necessary for a successful registry.

The accessible housing registry is based on the Massachusetts model known as Mass Access. The Mass Access registry legislation requires property owners to not only list their units but to hold them open for 15 days for people with disabilities. In addition, the Mass Access program is administered by and available only through the Independent Living Centers. In Connecticut, the information is available on the Internet in the form of a searchable database. In both Connecticut and Massachusetts, the registry coordinator is responsible for maintaining current vacancy listings and pursuing new listings.

Co-Op Initiatives, Inc administers the current contract for the accessible housing registry. Co-Op Initiatives has held the contracts since this program began in June of 1999. The Registry utilizes software developed by New England Index the same organization that developed the Massachusetts database. New England Index currently hosts the site.

To date Co-Op Initiatives has focused on identifying developments, property owners, property managers and landlord associations throughout the state and have contacted them in a variety of ways to obtain data on their units. Co-Op Initiatives has undertaken several direct mailing initiatives targeted to a list of over 2000 developments and property owners. These mailings have met with very limited response. Co-Op Initiatives followed all mailings with targeted phone calls and site visits. With the assistance of DECD, they sent a stronger request to properties in the DECD's portfolio.

To date approximately 60 individual properties have been entered in the registry and are available for searching on the Internet. Co-Op Initiatives is working with public housing entities to further spread the word about the registry and use their contacts to expand the registry's information base. Since the registry is an Internet site, we can tell how many persons visited the site (1964 hits) but not the number of successes.

Co-Op Initiatives has reported that they have had difficulty in populating the database and that the data that they do have has been difficult to keep up to date, as the owners and managers of the properties do not routinely provide updated vacancy or unit information. It is Co-Op Initiatives belief that the tight real estate market provides no tangible incentive for property owners to use the registry. Co-Op Initiatives feels that short of the mandate to list, the low response rate is unlikely to change until such time as the market changes.

For the last ten years all multi family developments have had to make each and every unit on an accessible level accessible (no grab bars or cut outs under sinks/lavatories, but

everything else accessible). For example, if there is a building with 100 units but no elevator, then all 50 units on the first floor must be accessible. If there is an elevator, then all 100 units must be accessible.

In Connecticut, Type A units set a very high standard for accessibility, and they are the type of unit currently mandated since 1992. The registry could be expanded if someone could identify all multi family developments constructed since 1992 by development name, street address and phone number of the development, since any vacant unit should be accessible. Older units would have had to provide one in twenty five fully accessible units, so the registry would have to have the specific number of accessible units that become vacant.

Note: R-2 dwelling units are those units located in a building constructed as a multi-family building where the units share a common means of access and egress. R-3 units are also multi-family, but each unit has its own means of access and egress. In R-2 buildings, 100% of the units on accessible levels must be accessible (i.e., Type A) units, while 10% must be accessible in R-3 developments.

Possible ways “to improve the reporting of accessible housing units in the Connecticut Accessible Housing Registry”:

- Mandate that property owners doing business with DECD, CHFA, DMR and DSS list their vacant units with the Registry.
- Mandate that property owners list their vacant units and hold those accessible units available for a period of 15 days for people with disabilities.
- Undertake more extensive and sustained public relations/advertising/marketing campaign that would involve more high-profile support.
- Expand the focus of the registry beyond accessible units, marketing it as a free service to property owners who wish to list all of their units. This expanded database would continue to benefit people with disabilities through its data and search features and may provide property owners with the incentive they need to list their accessible units. Populating the database with more broad-based and updated information that can serve all of the citizens in the state would also serve the target population of people with disabilities. As part of the listing process property owners would be required to provide accessibility information. Over time, if this strategy proved successful, it may be possible to charge a nominal listing fee that can be used to offset the costs of administering and marketing the registry.

Co-Op Initiatives estimates that the cost associated with an adequate administration of this program is approximately \$64,000. The annual contract for the registry was originally budgeted at approximately \$75,000. Due to recent budget constraints the amount of the contract has been reduced to \$33,000.

Recommendations

- *Mandate through legislation that property owners doing business with DECD, CHFA, DMR and DSS list their vacant units with the Accessible Housing Registry.*
- *Figure out a way to get local building officials to report to a central source information about R-2 and R-3 housing units that are constructed in their towns - the objective here is to make the Accessible Housing Registry work for people.*

2. Educate architects, housing authorities, builders, and local boards, such as planning and zoning commissions, about accessibility.

Met with Chris Laux, State Building Inspection, John Blaschik, Deputy State Fire Marshal and Wayne Maheu, Director of the Office of Education and Data Management. They indicated willingness over the next 12-18 months to develop specific training about accessibility. They noted difficulty in reaching design professionals, builders/developers and planning and zoning commissions/boards.

Recommendations

- *Work with the Department of Public Safety's Office of Education and Data Management over the next 12-18 months to do workshops for (local) building officials about Type A standards, with an emphasis on kitchens and bathrooms.*
- *Meet with the AIA CT to do workshops for architects on the same topics.*
- *Reach out to developers and make them aware of access needs in housing.*

3. Convene a Task Force to review safety codes such as fire and building codes and recommend revisions designed to assure safety for individuals with functional limitations. Methods to follow-up and enforce these codes also needs to be reviewed.

During our meeting at the Department of Public Safety, they indicated that the process to revise to the state's building code is about to begin under the direction of the Codes & Standards Committee. It was suggested that we send a letter to Code Amendment Subcommittee asking that we be added to the mailing list to receive notices of meetings. We determined that to convene a formal task force involving key staff from the Department of Public Safety is infeasible now.

Recommendations

- *Make sure the Codes and Standards Committee does not weaken the present state Building Code and restrict the requirement for Type A units. Request the Governor and all State agencies on the Long-Term Care Planning Committee send letters to Codes & Standards Committee.*

- *Organize our own focus group with individuals who have lots of experience with their own accessible housing needs to discuss the code review process and determine best way to provide input into this process.*
- *Meet with State Fire Marshal to discuss emergency egress issues. Additionally, we are unsure exactly what the original concerns were and need some guidance.*

4. Explore the possibility of providing tax or other incentives to encourage new homes or substantial renovations to meet minimum accessibility standards. This would apply to private homes as well as to public or private condominiums or apartments.

The Connecticut Housing Finance Authority (CHFA) administers the Housing Tax Credit Contribution Program; Connecticut General Statute section 8-395. This program generates equity for housing initiatives undertaken by non-profit organizations. A non-profit that is developing, sponsoring or managing housing for very low-, low- and moderate-income individuals and families can apply to CHFA for an allocation of up to \$400,000 in state tax credits. The non-profit then offers the credits to businesses that make cash contributions to support the development. Business firms receive a dollar-for-dollar reduction in their state tax liability in exchange for their financial support of the affordable housing program.

CHFA allocates \$5 million in HTCC credits annually. Each year, non-profit applicants are rated and ranked, and then credits are reserved for the highest-scoring proposals. Successful applicants must secure commitments for cash contributions from business firms. The business firms then receive tax credits in exchange for their contributions. There is no limit to the amount of a cash contribution made by an eligible business firm. The State of Connecticut provides tax credits to the businesses. Each eligible firm receives a dollar-for-dollar reduction in its corporate business tax in exchange for its contribution.

As presently written, stand-alone accessibility modifications are not eligible.

Recommendations

- *Mandate legislative change to allow stand-alone accessibility modifications done through non-profit organizations to be eligible for assistance under the Housing Tax Credit Contribution Program.*
- *If unsuccessful, seek sufficient funding to assist individuals who need to modify housing units to make them meet their unique access needs through organizations such as the Corporation for Independent Living and/or CACIL.*

5. Strongly encourage every housing authority in the State to seek Section 8 certificates for people with disabilities when they are available.

DSS is considered a public housing authority (PHA) under HUD rules, however, owing to its utilization rate, DSS was unable to apply for vouchers for people with disabilities last year. As a result, CACIL and the Hamden HA applied for vouchers but were unsuccessful. Limited efforts have been made to encourage all eligible entities to apply for Section 8 vouchers for people with disabilities.

DSS and other PHAs can establish and change its selection preferences for Housing Choice Vouchers. Public notice and comment is required for any changes to the PHA Administrative Plan. Changes in the plan do not require approval for implementation. HUD requires that they receive a copy of PHA Administrative Plan (or revised plan) but they do not need to approve it before it can be implemented.

Existing unused vouchers that are not targeted for special purposes or specific categories of applicants may be available immediately for individuals who are eligible under an identified selection preference. For example, if DSS or other local PHAs choose to establish a selection preference for individuals with disabilities living in institutional facilities (in their administrative plan) unused vouchers could be available immediately after the revised plan is adopted and sent to HUD.

Recommendations

- *Ask DSS and other local housing authorities (PHAs) to amend their administrative plans to prioritize individuals coming out of "facilities". This approach has already been utilized in some states..*
- *Encourage PHAs, especially those near their full utilization rate, to work with the community integration initiative of the state to reach their % goal and apply for more certificates.*
- *Meet with HUD Hartford Office to better understand the administrative requirements that PHAs must follow in order to ensure units for individuals with disabilities are not lost in the process of creating "elderly only" units within federal housing; and the monitoring efforts done by HUD.*

6. Ensure that available Section 8 certificates are distributed to eligible families and individuals.

The Department of Social Services administers Section 8 vouchers statewide and distributes vouchers to eligible families and individuals. DSS must meet a certain utilization rate in order to apply for the vouchers.

APPENDIX G.

State Long-Term Care Programs

This appendix is comprised of the following four sections:

- I. Overview of State Agencies Providing Long-Term Care Services and Supports
- II. State Long-Term Care Programs in Connecticut – SFY 2002
- III. State Long-Term Care Program Expenditures in Connecticut – SFY 2002
- IV. Proportion of Connecticut Medicaid Expenditures for Long-Term Care -- SFY 2003
- V. Connecticut Medicaid Long-Term Care Clients, Monthly Average -- SFY 2003
- VI. Older Americans Act Service Units and Expenditures in Connecticut

I. Overview of State Agencies Providing Long-Term Care Services and Supports

Department of Social Services (DSS): DSS provides a broad range of services to people who are elderly or have disabilities, families and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance, and independent living. It administers over 90 programs. By statute, it is the State agency responsible for administering a number of programs under federal legislation, including the Social Security Act (which includes Medicaid), the Rehabilitation Act, the Food Stamp Act and the Older American Act. DSS administers the Connecticut Home Care Program for Elders (CHCPE), a portion of which is State-funded, and other programs such as the Connecticut AIDS Drug Assistance Program and the Connecticut Pharmaceutical Assistance Contract to the Elderly and the Disabled Program (ConnPACE).

Department of Mental Retardation (DMR): DMR provides case management, residential habilitation, individualized supports, campus settings, day habilitation, prevocational services, supported employment, respite care, family support and birth to three services to more than 18,500 persons with mental retardation and their families. As of June 2003, 60 percent of those receiving services from DMR were served in their own homes, six percent lived in campus settings, 24 percent lived in public or private community living arrangements and four percent lived in community training homes, and two percent were in skilled nursing facilities.

Department of Mental Health and Addiction Services (DMHAS): DMHAS has 18 Local Mental Health Authorities that provide a vast array of community mental health services for persons with mental illness. In addition, DMHAS operates inpatient hospitals and facilities for persons with severe addiction and/or psychiatric problems. In SFY 2003, DMHAS served 63,379 persons in the community and 3,938 persons in inpatient facilities.

Department of Children and Families (DCF): DCF provides a variety of community-based and institutional services for children and adolescents with disabilities and their parents. The department's mandates include Prevention, Child Protection, Juvenile Justice Services and Behavioral Health. Services are provided through contracted providers as well as state operated facilities. DCF, in collaboration with the Department of Social Services, is currently developing a significant initiative to reorganize behavioral health services for children in the community, called CT Community KidCare.

Department of Economic and Community Development (DECD): DECD oversees all State statutes related to accessible housing. In addition to being a key partner in the assisted living demonstrations mentioned above, it administers capital grants for the conversion of adaptable living units to accessible units for persons with disabilities. The agency also has developed a statewide registry of accessible housing, which is administered by Co-op Initiatives, Inc.

Department of Transportation (DOT): (DOT) provides about \$80 million a year in subsidies to bus and paratransit systems throughout the state. The fixed route bus system provides discounted (half-fare) rides to seniors and people with disabilities. Out of a total of 37 million riders annually on the fixed-route system, about 2 million rides are provided annually to elderly and disabled customers. DOT administers the Federal Section 5310 program, which provides vehicle grants to municipalities and non-profit organizations. Over 100 vehicles funded by this grant program are operating around the state. In addition, the federal Americans with Disabilities Act (ADA) requires that demand-responsive paratransit services be provided to pre-qualified individuals who are not able, due to their disability, to utilize the local fixed-route bus system. ADA paratransit services are available to origins and destinations within 3/4 mile of the local bus route and are operated during the same days and hours as the local bus service. The State currently spends over \$10 million annually to support ADA services, and provides over 500,000 rides annually. The DOT-subsidized bus and paratransit operations serve 107 towns in the state.

Office of Protection and Advocacy for Persons with Disabilities (P&A): P&A is an independent State agency created to safeguard and advance the civil and human rights of people with disabilities. By providing various types and levels of advocacy assistance, P&A seeks to leave people with disabilities and their families better informed, equipped, and supported to advocate for themselves and others. In SFY 2002, the P&A provided information and referrals to over 7,000 people, monitored over 1,200 abuse and neglect investigations, and provided advocacy representation to over 900 individuals and families.

Board of Education and Services for the Blind (BESB): BESB provides a comprehensive array of services to improve the independent living skills of adults and children who are legally blind or visually impaired. The agency served approximately 4,250 clients in SFY 2003. Services include vocational counseling, technology training, teaching to improve activities of daily living, training in use of devices for safe travel, provision of low vision evaluations and aides, and self-advocacy training.

Commission on the Deaf and Hearing Impaired (CDHI) – CDHI works to advocate, strengthen and implement state policies affecting deaf and hard of hearing individuals. Services and supports include: interpreting services for deaf and hard of hearing persons interacting with the public; counseling and assistance regarding many types of job related concerns; individual, marital, family and group counseling services to deaf and hard of hearing persons and hearing family members; and orientation seminars on deafness and deaf culture. There are approximately 204,334 hearing impaired people in Connecticut.

II. State Long-Term Care Programs in Connecticut – SFY 2002

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	Connecticut Home Care Program (CHCP)	Adult day care Adult day health care Adult foster care Assertive devices Assisted living services Care management Chore services Companion services Home health aide services Home delivered meals Homemaker services Hospice services Info & referral MH counseling Nursing services Nutritional services PCA services Personal emerg response system Physical, speech, respiratory & occupational therapy Respite care Transportation	Personal residences Adult day care centers Congregate housing Elderly housing Residential care homes CCRC - Assisted living MRC - Assisted living Alzheimer's facilities with private assisted living	Age 65 and over. Must have at least one critical need (bathing, dressing, toileting, transferring, eating/feeding, meal preparation, medication administration). Medicaid income limit = \$1,656 /month. Medicaid asset limit = Indiv \$1,600/ couple \$3,200. State funded income limit = no limit. State funded asset limit = Indiv \$18,132/ couple \$27,198 (one or both receiving services)	<u>Total Participants</u> Total- 14,939 Waiver- 10,348 State - 4,591 <u>Age</u> 65-84: 69.1% 85+: 30.7 % <u>Gender</u> male: 25.1% female: 74.9% <u>Race/Ethnicity</u> W = 74.9% AA = 13.8% Hisp = 9.9% Asian = 0.6% Am Ind = 0.1%
DSS	Personal Care Assistance Waiver	Personal care assistance services	Personal Residences	Age 18-64. Chronic severe and permanent disabilities. Would otherwise require nursing facility care. Capable of self-	<u>Total Participants</u> 421 (SFY 2003) <u>Age</u> N/A <u>Gender</u> N/A

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
				<p>direction.</p> <p>Medicaid income limit = \$1,500 /month. Income in excess of 200% FPL applied to care.</p>	<p><u>Race/Ethnicity</u> N/A</p>
DSS	Acquired Brain Injury Waiver (ABI)	<p>Case-management Chore Cognitive behavioral program Community living supports Companion Day Habilitation Durable medical equipment Family training Homemaker services Home delivered meals Independent living skill training Information and referral Personal care assistance Personal emergency response system Pre-vocational services Respite care Substance abuse Supported employment Transportation Vehicle modification Transitional living</p>	<p>Personal care residence Group residence</p>	<p>Age 18-64.</p> <p>Brain injury that is not a result of a developmental disability or degenerative condition. Dysfunction is not primarily the result of a mental illness. Would otherwise be institutionalized.</p> <p>Medicaid income limit = Less than 200% FPL. Medicaid asset limit = Indiv \$1,600</p>	<p><u>Total Participants</u> 169 (SFY 2003)</p> <p><u>Age</u> 18-39: 60% 40+: 40%</p> <p><u>Gender</u> Male: 127 Female: 42</p> <p><u>Race/Ethnicity</u> N/A</p>

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	Katie Beckett Model Waiver	Assistive devices Care management Durable medical equipment Home health aide services Information & referral Mental health counseling Nursing services Physical, speech, respiratory and occupational therapy Prescription drug assistance Transportation Recipients also receive all traditional Medicaid benefits.	Personal Residences.	No age restriction. Would otherwise require care in a nursing home or ICF/MR. Medicaid income limit = \$1,656. Medicaid asset limit = \$1,000. Income of parent or spouse not counted. Medicaid clients only.	<u>Total Participants</u> 139 <u>Age</u> 0-18: 137 19-54: 1 55-64: 1 <u>Gender</u> Female: 42 <u>Race/Ethnicity</u> N/A
DSS	Breakthrough to the Aging	Companion Transportation Grocery Shopping	Personal Residences Congregate Housing Elderly Housing	Age 60 and over. Clients must be homebound and request services.	<u>Total Participants</u> 594 volunteers 151 new clients <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	CT's National Family Caregiver Support Program	Adult day care Adult day health care Assistive devices Care management Chore services Home health aide services Homemaker services Info & referral Personal emergency response system Respite Care Transportation Grandparents support	Personal residences Adult day care centers Elderly housing Nursing facilities (for short term respite only)	Age 60 and over. Two or more ADL limitations. Priority is given to persons with disabilities for respite/ supplemental services.	<u>Total Participants</u> 389 (respite and supplemental services only) <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DSS	CHOICES	Health insurance counseling Information & referral	Personal residences Adult day care centers Congregate housing Elderly housing CCRC - Assisted living MRC - Assisted living Hospice facilities Nursing facilities Area Agencies on Aging	Age 60 and over. Medicare eligible.	<u>Total Participants</u> 59,747 <u>Age</u> <65: 796 65-84: 2,662 85+ not recorded 50,983 <u>Gender</u> male: 3,107 female: 6,021 not recorded 50,619 <u>Race/Ethnicity</u> W = 4,760 AA = 630 Hisp = 284 Asian = 31 Am Ind = 13 not recorded 54,029

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	MediSave	Information & referral Train the trainer	Congregate housing Elderly housing CCRC - Assisted living MRC - Assisted living Senior centers	N/A	<u>Total Participants</u> 225 volunteers 3,862 beneficiaries who attended training 38,111 reached by community educ. events. <u>Age</u> Not collected <u>Gender</u> Not collected <u>Race/Ethnicity</u> Not collected
DSS	CT Partnership for LTC - Information & Education Program	Information & referral	Personal residences	Age 18-89	<u>Total Participants</u> 2,722 calls for information; 693 individuals counseled; 1,392 attended group presentations; 608 attended public forums. <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	Statewide Respite Care Program (for persons with Alzheimer's or related dementia)	Adult day care Adult day health care Assisted living services Care management Chore services Companion services Health Insurance Counseling Home health aide services Home delivered meals Homemaker services Info & referral MH counseling Nursing services Nutritional services PCA services Personal emerg response system Respite care Transportation	Personal residences Adult day care centers Congregate housing Elderly housing Residential care homes CCRC - Assisted living MRC - Assisted living Alzheimer's facilities with private assisted living Hospice facilities Nursing facilities Alzheimer's facilities	No age requirement. Alzheimer's or a related dementia. \$30,000 income \$80,000 assets	<u>Total Participants</u> 491 <u>Age</u> Not collected <u>Gender</u> Not collected <u>Race/Ethnicity</u> Not collected
DSS	Retired Senior and Volunteer Program	Information & referral Recreational services	Adult day care centers Congregate housing Elderly housing Nursing facilities Schools, airports, state institutions, community social agencies, police depts.	Age 55 and over. Some programs provide volunteer opportunities for people with disabilities who are under age 55.	<u>Total Participants</u> 5,994 volunteers <u>Age</u> <60: 104 60-74: 2,930 75+: 2,960 <u>Gender</u> Not collected <u>Race/Ethnicity</u> Not collected

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	Area Agency on Aging	Adult day care Adult day health care Adult foster care Care management Chore services Companion services Health insurance counseling Home health aide services Home delivered meals Homemaker services Hospice services Info & referral MH counseling Nursing services Nutritional services PCA services Personal emerg response system Physical, speech, respiratory & occupational therapy Prescription drug assistance Recreation services Respite care Transportation Medication monitoring	Personal residences Adult day care centers Congregate housing Elderly housing	Age 60 and over.	<u>Total Participants</u> 57,304 <u>Age</u> 19-54: 995 55-64: 5,202 65-84: 38,031 85+: 13,076 <u>Gender</u> male: 17,290 female: 40,011 not recorded: 5 <u>Race/Ethnicity</u> W = 47,109 AA = 5,341 Hisp = 4,118 Asian = 409 Am Ind = 293
DSS	Congregate Housing Services	Adult day care Care management Chore services Companion services Home health aide services Information & referral Nutritional services Personal care attendant services Personal emergency response system	Congregate housing	Age 60 and over. Frail with temporary or permanent disabilities.	<u>Total Participants</u> 203 <u>Age</u> 18-61: 6 62-95: 197 <u>Gender</u> male: 23 female: 90

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
		Transportation Medication monitoring Foot care			<u>Race/Ethnicity</u> W = 95 AA = 12 Hisp = 5 Asian = 0 Am Ind = 1
DSS	Senior Community Service Employment Program	Information & referral Employment & training	Community (AAA, Community Action Agencies, municipalities, community-based orgs.)	Age 55 and over. Income not exceeding 125% of the federal poverty level. 25% of social security income excluded.	<u>Total Participants</u> 113 <u>Age</u> 55-64: 51 65-84: 59 85+: 3 <u>Gender</u> male: 28 female: 176 <u>Race/Ethnicity</u> W = 201 AA = 2 Hisp = 0 Asian = 0 Am Ind = 1
DSS	Medicare Legal and Education Assistance Project	Health insurance counseling Information & referral Legal representation for Medicare appeals	Not setting specific	Medicare eligible by virtue of age or disability.	<u>Total Participants</u> 6,600 direct client assistance <u>Age</u> Not collected <u>Gender</u> Not collected <u>Race/Ethnicity</u> Not collected

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DSS	Elderly Health Screening Program	Mental health counseling Nutritional services Physical health screenings	Personal Residences Congregate Housing Elderly Housing Any community setting	Age 60 and over.	<u>Total Participants</u> 18,550 <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DECD	Congregate Operating Subsidy Program	Assisted living services Care management Chore services Companion services Health insurance counseling Info & referral Nutritional services PCA services Recreation services Transportation	Congregate housing	Age 62 and over and frail. One ADL minimum. Annual income cannot exceed the "Low Income" for the area adjusted for family size as defined by HUD.	<u>Total Participants</u> 971 residents <u>Age</u> 65+: 971 <u>Gender - N/A</u> <u>Race/Ethnicity</u> W = 928 AA = 22 Hisp = 9 Asian = 9 Am Ind = 0 Other = 3

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DECD	Elderly Rental Registry and Counseling	Funds provided to hire a Resident Service Coordinator to assist residents of state-funded elderly facilities.	Elderly Housing	N/A	<u>Total Participants</u> 2,942 units in 36 facilities <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DECD	Elderly Rental Assistance Program	Financial Assistance to make rents affordable to low/ moderate income elderly.	Personal residences	Age 62 and over or disabled. Certified disabled by Social Security Board or other federal board or agency as being totally disabled. Annual income cannot exceed the "Low Income" for the area adjusted for family size as defined by HUD.	<u>Total Participants</u> 1,112 <u>Age</u> 0-64: 398 65+: 714 <u>Gender</u> N/A <u>Race/Ethnicity</u> W = 1,013 AA = 38 Hisp = 38 Asian = 6 Am Ind = 0 Other = 17

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DECD	Housing Assistance and Counseling	Assisted living services Info and referral	Elderly Housing (federal 202 or 236)	Age 62 and over. Requires assisted living services (at least 1 ADL) as determined by Care Plan.	<u>Total Participants</u> 46 <u>Age</u> 65+: 46 <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DMHAS	Case management- Mental Health	Info & Referral Transportation Case management	Personal Residences RCH NF Shelters	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Requires assistance in obtaining and coordinating treatment, rehabilitation, and social services without which the individual would likely require a more intensive level of care. No private insurance to pay for comparable services.	<u>Total Participants</u> 10,856 <u>Age</u> 0-18: 191 19-54: 9,080 55-64: 1,113 65-84: 429 85+: 43 <u>Gender</u> male: 5,382 female: 5,394 <u>Race/Ethnicity</u> W = 5,884 AA = 2,260 Hisp = 1,739 Asian = 242 Am Ind = 53

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMHAS	Assertive Community Treatment (ACT)	A set of clinical, medical & psychosocial services, provided on a one-to-one basis, essential to maintaining an individual's ability to function in community settings. Services available 24/7.	Personal residences Community settings	<p>Adults age 18 and over.</p> <p>Primary diagnosis of a psychiatric disorder; Would otherwise require more intensive and restrictive services.</p> <p>No private insurance to pay for comparable services.</p>	<p><u>Total Participants</u> 2,446</p> <p><u>Age</u> 0-18: 19 19-54: 2,108 55-64: 237 65-84: 81 85+: 1</p> <p><u>Gender</u> male: 1,451 female: 981</p> <p><u>Race/Ethnicity</u> W = 1,331 AA = 637 Hisp = 346 Asian = 39 Am Ind = 6</p>

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMHAS	MH Intensive Outpatient Services	Individual, group or family psychotherapy; Psycho-educational groups; Classes on ADLs; Recovery oriented services.	Non-residential services provided in a general hospital, private free-standing psychiatric hospital, psychiatric outpatient clinic for adults, or a state-operated facility.	<p>Adults age 18 and over.</p> <p>Primary diagnosis of a psychiatric disorder; Behavior does not pose an imminent risk of harm to self and other; Living environment can assure a reasonable degree of safety; Symptomology/behavior warrants an increase in frequency and/ or intensity of clinical contact in an effort to stabilize the individual.</p> <p>No private insurance to pay for comparable services.</p>	<p><u>Total Participants</u> 173</p> <p><u>Age</u> 0-18: 3 19-54: 155 55-64: 14 65-84: 1 85+: 0</p> <p><u>Gender</u> male: 68 female: 105</p> <p><u>Race/Ethnicity</u> W = 107 AA = 8 Hisp = 49 Asian = 0 Am Ind = 0</p>

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMHAS	MH Outpatient Therapy Services	Individual, group or family counseling; Education to client and family; Support with connecting to/referral to natural community supports; Assistance with obtaining/maintaining employment.	Non-residential services provided in a general hospital, private free-standing psychiatric hospital, a state-operated facility, a facility licensed by DPH to offer "outpatient treatment," or by a private independent psychiatrist or psychologist or private group practice.	Adults age 18 and over. Primary diagnosis of a psychiatric disorder. No private insurance to pay for comparable services.	<u>Total Participants</u> 20,024 <u>Age</u> 0-18: 371 19-54: 15,859 55-64: 2,295 65-84: 1,130 85+: 369 <u>Gender</u> male: 8,762 female: 10,930 <u>Race/Ethnicity</u> W = 11,891 AA = 2,483 Hisp = 3,003 Asian = 268 Am Ind = 171
DMHAS	MH Residential - Group Home	Rehabilitative support focusing on areas of self-care and independent living skills.	Group home	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Significant skill deficits in the area of self-care and independent living as a result of the psychiatric disability. No private insurance to pay for comparable services.	<u>Total Participants</u> 325 <u>Age</u> 0-18: 19 19-54: 279 55-64: 21 65-84: 5 85+: 1 <u>Gender</u> male: 204 female: 120 <u>Race/Ethnicity</u> W = 219 AA = 55

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
					Hisp = 32 Asian = 2 Am Ind = 0
DMHAS	MH Residential - Supervised Housing	Supportive counseling directed at solving day to day problems with community living; Psycho-education groups; Assistance with employment; Rehabilitative support.	Supervised housing	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Significant skill deficits in the area of independent living as a result of severe and persistent mental illness. No private insurance to pay for comparable services.	<u>Total Participants</u> 986 <u>Age</u> 0-18: 16 19-54: 845 55-64: 91 65-84: 31 85+: 3 <u>Gender</u> male: 591 female: 391 <u>Race/Ethnicity</u> W = 633 AA = 169 Hisp = 83 Asian = 32 Am Ind = 8

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMHAS	MH Residential - Supported Housing	Supportive counseling directed at solving day to day problems with community living; Psycho-education groups; Assistance with employment; Teaching/ coaching of daily life skills.	Supportive housing	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Moderate skill deficits in the area of independent living as a result of the psychiatric disability. No private insurance to pay for comparable services.	<u>Total Participants</u> 1,852 <u>Age</u> 0-18: 17 19-54: 1,622 55-64: 164 65-84: 40 85+: 4 <u>Gender</u> male: 960 female: 876 <u>Race/Ethnicity</u> W = 1,172 AA = 341 Hisp = 173 Asian = 17 Am Ind = 4
DMHAS	Psychosocial Rehabilitation	Independent living and community reintegration skill development.	Community setting	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Moderate impairment in vocational, educational and/or social functioning; Needs assistance with at least 2 ADLs. No private insurance to pay for comparable services.	<u>Total Participants</u> 6,562 <u>Age</u> 0-18: 65 19-54: 5,513 55-64: 725 65-84: 230 85+: 29 <u>Gender</u> male: 3,700 female: 2,818 <u>Race/Ethnicity</u> W = 4,101 AA = 1,120

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
					Hisp = 518 Asian = 241 Am Ind = 49
DMHAS	Crisis Stabilization Beds (respite)	Short-term residential services to help stabilize a rapidly deteriorating behavioral health condition and avert hospitalization.	A facility of not more than 15 beds staffed 24/7.	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Increased exacerbation of symptoms within the past 24 hours; Does not present as an imminent safety risk to self or others consistent with criteria for inpatient psychiatric care. No private insurance to pay for comparable services.	<u>Total Participants</u> 213 <u>Age</u> 0-18: 3 19-54: 192 55-64: 12 65-84: 6 85+: 0 <u>Gender</u> male: 113 female: 99 <u>Race/Ethnicity</u> W = 143 AA = 48 Hisp = 13 Asian = 0 Am Ind = 2

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMHAS	Mobile Crisis Services	Psychiatric evaluation; Psychiatric stabilization; Brief clinical treatment; Medication evaluation; Hospital pre-screening.	Personal residences Congregate housing Elderly housing Residential care homes Nursing facilities Shelters On the streets	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Presentation of symptoms/ behaviors that place the individual at risk to self or others. No private insurance to pay for comparable services.	<u>Total Participants</u> 5,488 <u>Age</u> 0-18: 212 19-54: 4,687 55-64: 372 65-84: 199 85+: 18 <u>Gender</u> male: 2,944 female: 2,418 <u>Race/Ethnicity</u> W = 3,045 AA = 990 Hisp = 1,046 Asian = 73 Am Ind = 24
DMHAS	Long-Term Psychiatric Hospitalization	Medication evaluation; Individual/ group counseling; Specialized treatment services.	Psychiatric hospital	Adults age 18 and over. Primary diagnosis of a psychiatric disorder; Chronic risk of being a danger to self or to others or chronic grave disability as a result of the psychiatric disorder. No private insurance to pay for comparable services.	<u>Total Participants</u> 1,550 <u>Age</u> 0-18: 62 19-54: 1,404 55-64: 75 65-84: 7 85+: 2 <u>Gender</u> male: 963 female: 580 <u>Race/Ethnicity</u> W = 830 AA = 345

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
					<p>Hisp = 256 Asian = 37 Am Ind = 6</p>
DMHAS	Substance Abuse Residential - Long-Term Treatment	Clinical/ therapeutic services.	Residence with a highly structured recovery environment	<p>Adults age 18 and over.</p> <p>Meets criteria for substance dependence, but not for sustained full remission.</p> <p>No private insurance to pay for comparable services.</p>	<p><u>Total Participants</u> 2,256</p> <p><u>Age</u> 0-18: 34 19-54: 2,166 55-64: 33 65-84: 1 85+: 22</p> <p><u>Gender</u> male: 1,798 female: 454</p> <p><u>Race/Ethnicity</u> W = 889 AA = 698 Hisp = 604 Asian = 10 Am Ind = 8</p>
DMHAS	Substance Abuse Residential - Long-Term Care	Clinical/ therapeutic services.	Residence with a highly structured recovery environment	<p>Adults age 18 and over.</p> <p>Meets criteria for substance dependence, but not for sustained full remission.</p> <p>No private insurance to pay for comparable services.</p>	<p><u>Total Participants</u> 141</p> <p><u>Age</u> 0-18: 0 19-54: 132 55-64: 8 65-84: 1 85+: 0</p> <p><u>Gender</u> male: 114</p>

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
					female: 27 <u>Race/Ethnicity</u> W = 100 AA = 13 Hisp = 25 Asian = 0 Am Ind =
DMHAS	Substance Abuse Residential - Transitional/ Halfway House	Individual/ group counseling Family therapy Employment skill development	Residence with a minimally structured environment	Adults age 18 and over. Meets criteria for substance dependence, but not for sustained full remission. No private insurance to pay for comparable services.	<u>Total Participants</u> 822 <u>Age</u> 0-18: 6 19-54: 792 55-64: 18 65-84: 0 85+: 6 <u>Gender</u> male: 500 female: 322 <u>Race/Ethnicity</u> W = 483 AA = 191 Hisp = 123 Asian = 3 Am Ind = 4

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DMR	Home and Community-Based Services Waiver	Respite care Residential habilitation Day habilitation Prevocational services Supported employment services Environmental accessibility adaptations	Personal residences Community living arrangement Community training home Community day program site Community employment	No age limit. Person with mental retardation needing ICF/MR level of care. Medicaid program: Income less than 300% of SSI and assets less than \$1600.	<u>Total Participants</u> 6,098 <u>Age</u> 0-18: 511 19-54: 4,503 55-64: 654 65-84: 404 85+: 26 <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DMR	Intermediate Care Facility for the Mentally Retarded (ICF/MR)	Residential habilitation Day habilitation Prevocational services Supported employment services	ICF/MR	No age limit. Person with mental retardation needing ICF/MR level of care. Medicaid program: Income less than 300% of SSI and assets less than \$1600.	<u>Total Participants</u> 871 <u>Age</u> 0-18: 0 19-54: 549 55-64: 184 65+: 138 <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DCF	Voluntary Services	Care management Mental health counseling Nursing services (residential treatment setting) Recreational services Respite care	Personal residences Foster homes Residential treatment facilities/ group homes	Age 18 and under (Until 21 if still enrolled in school). Serious emotional, behavioral or substance abuse disorder. Families are assessed for financial contribution but not eligibility.	<u>Total Participants</u> 705 with LTC needs <u>Age</u> 0-18: 705 <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A
DOT	Local Bus Services	Transportation (Local bus at half fare)	Community	All ages Seniors and people with a qualifying disability.	<u>Total Participants</u> 1,866,000 (of 35,375,000 passenger trips) <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A

State Agency	Long-Term Care Program	Services	Settings	Eligibility	Demographics July 1, 2001 – June 30, 2002
DOT	ADA Paratransit Van Services	Transportation	Community (within 3/4 mile of local public bus routes)	All ages Any person with a disability who is unable, due to physical or mental impairment, and without the assistance of another individual, to board, ride or disembark from any public local bus. Also for those with a specific impairment-related condition that prevents them from traveling to or from a bus stop.	Total Participants 15,877 registered users <u>Age</u> N/A <u>Gender</u> N/A <u>Race/Ethnicity</u> N/A

III. State Long-Term Care Program Expenditures in Connecticut – SFY 2002

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DSS	Connecticut Home Care Program (CHCP)	\$137,595,416	\$23,009,540	\$114,585,876			
DSS	Personal Care Assistance Waiver (2003 data)	\$7,560,630		\$7,560,630			
DSS	Acquired Brain Injury Waiver (ABI) (2003 data)	\$10,763,368		\$10,763,368			
DSS	Katie Beckett Model Waiver (1/1/02 - 12/31/02)	\$2,538,108		\$2,538,108			
DSS	Breakthrough to the Aging	\$110,382	\$75,519	\$0	\$34,863		
DSS	CT's National Family Caregiver Support Program	\$1,709,384			\$1,606,775		
DSS	CHOICES	\$439,550			\$260,034	\$179,516 (DHHS/CMS)	

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DSS	MediSave	\$160,000				\$160,000 (DHHS/AoA)	
DSS	CT Partnership for LTC - Information & Education Program	\$10,000	\$10,000				
DSS	Statewide Respite Care Program (for persons with Alzheimer's or related dementia)	\$1,120,000	\$1,120,000				
DSS	Retired Senior and Volunteer Program	\$1,173,773	\$89,568			\$576,568 (federal Corporation for National Services and State DECD)	\$508,072 (United Way, Local sponsors, Community fundraising)
DSS	Area Agency on Aging	\$19,676,477	\$3,167,111		\$13,019,327		\$3,490,039
DSS	Congregate Housing Services	\$734,155			\$33,000	\$60,797 (SSBG) \$265,587 (HUD)	\$75,334 (client contributions) \$299,437 (municipalities and other funding sources)

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DSS	Senior Community Service Employment Program	\$969,103					
DSS	Medicare Legal and Education Assistance Project	\$131,541	\$130,541			\$1,000	
DSS	Elderly Health Screening Program	\$507,372	\$507,372				
DECD	Congregate Operating Subsidy Program	\$4,709,790	\$4,709,790				
DECD	Elderly Rental Registry and Counseling	\$589,495	\$589,495				
DECD	Elderly Rental Assistance Program	\$886,721	\$886,721				
DECD	Housing Assistance and Counseling	\$221,000	\$221,000				

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DMHAS	Case management-Mental Health	\$26,164,777	\$23,819,213	\$102,503		\$1,573,755 (DHHS)	\$669,306
DMHAS	Assertive Community Treatment (ACT)	\$16,724,844	\$15,718,141	\$104,298		\$396,464 (DHHS)	\$505,942
DMHAS	MH Intensive Outpatient Services	\$361,041	\$97,830	\$87,890		\$177,044 (DHHS)	\$58,277
DMHAS	MH Outpatient Therapy Services	\$41,298,176	\$26,806,567	\$2,840,725		\$3,678,287 (DHHS)	\$7,972,597
DMHAS	MH Residential - Group Home	\$12,217,462	\$10,467,842			\$58,501 (DHHS)	\$1,691,119
DMHAS	MH Residential - Supervised Housing	\$30,209,837	\$27,802,104	\$198		\$721,276 (DHHS)	\$1,686,259
DMHAS	MH Residential - Supported Housing	\$14,452,468	\$13,417,627			\$91,541 (DHHS)	\$943,300

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DMHAS	Psychosocial Rehabilitation	\$14,569,351	\$13,446,545			\$243,008 (DHHS)	\$879,798
DMHAS	Crisis Stabilization Beds (respite)	\$3,602,794	\$3,602,794				
DMHAS	Mobile Crisis Services	\$23,729,531	\$18,415,064	\$329,090		\$2,028,016 (DHHS)	\$2,957,361
DMHAS	Long-Term Psychiatric Hospitalization	\$66,932,756	\$61,768,170			\$2,036 (DHHS)	\$5,162,550
DMHAS	Substance Abuse Residential - Long-Term Treatment	\$22,780,806	\$16,416,551	\$28,337		\$3,528,185 (DHHS)	\$2,807,733
DMHAS	Substance Abuse Residential - Long-Term Care	\$2,043,174	\$1,495,658			\$362,158 (DHHS)	\$185,358
DMHAS	Substance Abuse Residential - Transitional/ Halfway House	\$2,795,893	\$2,188,007			\$284,951 (DHHS)	\$322,935

State Agency	Long-Term Care Program	Total Expenditures	State Expenditures	Medicaid Expenditures	OAA Title III Expenditures	Other Federal Expenditures	Other Expenditures
DMR	Home and Community Based Services Waiver	\$376,755,900		\$376,755,900			
DMR	Intermediate Care Facility for the Mentally Retarded (ICF/MR)	\$178,780,010		\$178,780,010			
DCF	Voluntary Services						
DOT	Local Bus Services	\$95,350,000	\$61,356,000			\$1,025,000	\$2,599,000 (local) \$30,370,000 (passenger fares)
DOT	ADA Paratransit Van Services	\$13,045,000	\$10,566,000			\$490,000 (Sec 5307)	\$585,000 (local) \$1,404,000 (passenger fares)

**IV. PROPORTION OF CONNECTICUT MEDICAID EXPENDITURES
FOR LONG-TERM CARE
SFY 2003^(a)**

Type of Service	Medicaid LTC Expenditures	Percentage of Medicaid LTC Expenditures ^(b)	Percentage of Total Medicaid Expenditures ^(b)
Home and Community Care			
Home Health Care ^(c)	\$108,824,193	6%	3%
Home & Community Based Waiver	\$75,137,482	4%	2%
Personal Care Attendant Waiver	\$8,716,194	<1%	0%
Model Waiver	\$9,680	<1%	0%
Acquired Brain Injury Waiver	\$11,501,481	<1%	0%
State Waiver for Mental Retardation	\$367,302,861	19%	11%
Targeted Case Management (MH & MR)	\$29,194,592	2%	1%
Subtotal	\$600,686,483	31%	18%
Institutional Care			
Chronic & Convalescent Nursing Facility	\$982,409,503	52%	29%
Rest Home with Nursing Supervision	\$40,772,725	2%	1%
Intermediate Care for Mental Retardation	\$227,496,382	12%	7%
Chronic Disease Hospitals	\$62,256,089	3%	2%
Subtotal	\$1,312,934,699	69%	39%
Total Long-Term Care Expenditures	\$1,913,621,182	100.00%	56%

(a) Includes long-term care expenditures for individuals of all ages.

(b) Individual percentages may not add to totals due to rounding.

(c) Home health care expenditures are based on an estimate of the percentage of Medicaid recipients receiving long-term home health care as opposed to short-term care such as post-natal care. It is estimated that long-term home health care services comprise 60% of the total Medicaid home health care costs.

Source: Office of Policy and Management.

**V. CONNECTICUT MEDICAID LONG-TERM CARE CLIENTS
MONTHLY AVERAGE -- SFY 2003**

	Medicaid LTC Clients Monthly Average	Medicaid LTC Clients Percent Distribution
COMMUNITY	19,095	48.04%
<i>Home Health Care</i>	<i>N/A</i>	<i>N/A</i>
<i>Home & Community-Based Waiver</i>	<i>8,794</i>	<i>22.12%</i>
<i>Personal Care Attendant Waiver</i>	<i>410</i>	<i>1.03%</i>
<i>Model Waiver</i>	<i>125</i>	<i>0.31%</i>
<i>Acquired Brain Injury Waiver</i>	<i>144</i>	<i>0.36%</i>
<i>State Waiver for Mental Retardation</i>	<i>4,521</i>	<i>11.38%</i>
<i>Targeted Case Management - MH</i>	<i>N/A</i>	<i>N/A</i>
<i>Targeted Case Management - MR</i>	<i>5,101</i>	<i>12.83%</i>
INSTITUTION	20,654	51.96%
<i>Nursing Facility</i>	<i>19,373</i>	<i>48.74%</i>
<i>Intermediate Care Facility for Mental Retardation</i>	<i>981</i>	<i>2.47%</i>
<i>Chronic Disease Hospital</i>	<i>300</i>	<i>0.76%</i>
TOTAL	39,749	100.00%

Source: Connecticut Department of Social Services, 2003

**VI. OLDER AMERICANS ACT
SERVICE UNITS AND SERVICE EXPENDITURES
CONNECTICUT
OCTOBER 1, 2001 TO SEPTEMBER 30, 2002**

Selected Services	Service Units	Service Expenditures
Personal Care	62,064	\$137,066
Homemaker	106,108	\$319,737
Chore	28,392	\$259,105
Home Delivered Meals	2,221,508	\$3,040,695
Day Care	512,870	\$479,296
Case Management	1,621	\$47,122
Congregate Meals	1,106,004	\$3,761,229
Nutrition Counseling	350	\$19,999
Assisted Transportation	967	\$14,983
Transportation	249,357	\$756,679
Legal Assistance	7,836	\$253,437
Nutrition Education	8,257	\$37,992
Information and Assistance	114,477	\$189,270
Outreach	26,705	\$136,236
All Other Services	N/A	\$1,487,794

Source: Connecticut State Program Report for 10/1/01 to 9/30/02 to U.S. Department of Health and Human Services.

APPENDIX H. Supplementary Census Data

Number and Percentage of Individuals with Disabilities, U.S. and Connecticut, 2000

	CT	%	U.S.	%
Total population	3,405,565		281,421,906	
Total population age 5+	3,182,221		262,285,216	
5-20 years old	735,594		64,689,357	
With a disability	56,185	7.6%	5,214,334	8.1%
21-64 years old	1,945,424		159,131,544	
With a disability	327,697	16.8%	30,553,796	19.2%
▪ Percent employed	63.1%		56.6%	
Without a disability	1,617,727		128,577,748	
▪ Percent employed	80.3%		77.2%	
65+ year old	439,935		33,346,626	
With a disability	162,931	37.0%	13,978,118	41.9%
Total with disabilities	546,813	17.2%	49,746,248	19.3%

Note: Census data does not include institutionalized individuals. Disability data does not include individuals under the age of five.

Source: U.S. Census Bureau, 2000 Census.

Connecticut Population Projections: 2000 – 2025

	2000	2005	2010	2015	2020	2025	Population growth 2000 - 2025	2000 - 2025 percent change
0 to 20	915,606	908,964	910,118	921,160	952,880	993,471	77,865	8.50%
21 to 64	1,906,936	1,952,180	2,012,411	2,058,829	2,079,499	2,073,146	166,210	8.71%
65 +	461,600	455,785	476,977	525,709	588,899	671,922	210,322	45.56%
Total	3,284,142	3,316,929	3,399,506	3,505,698	3,621,278	3,738,539	454,397	13.84%

Source: U.S. Census Bureau Population Projections, 1995

Connection 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: U.S. Census Bureau Population Projections, 1995

Projections of the U.S. Population Ages 65 and Older, by Disability Status (in millions)

	2000	2010	2020	2030
Total Age 65+	35.7	40.6	53.9	71.0
Non Disabled	26.9	31.3	43.5	58.6
Disabled *	8.8	9.2	10.4	12.3
Disabled as a Percentage of Total	24.6 %	22.7%	19.3%	17.4%

* People unable to perform one or more activities of daily living.

Source: Congressional Budget Office calculation based on data from the Lewin Group and the Center for Demographic Studies at Duke University. From the Congressional Budget Office Memorandum, Projections of Expenditures for Long-Term Care Services for the Elderly, March 1999.

Individuals with Disabilities in Connecticut By Independent Living Council Region and Town

The following table and maps provide region and town level data regarding individuals with disabilities in the community age five and older by gender, ethnic groups, age groups and type of disability. This data, based on the U.S. Census 2000, was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center.

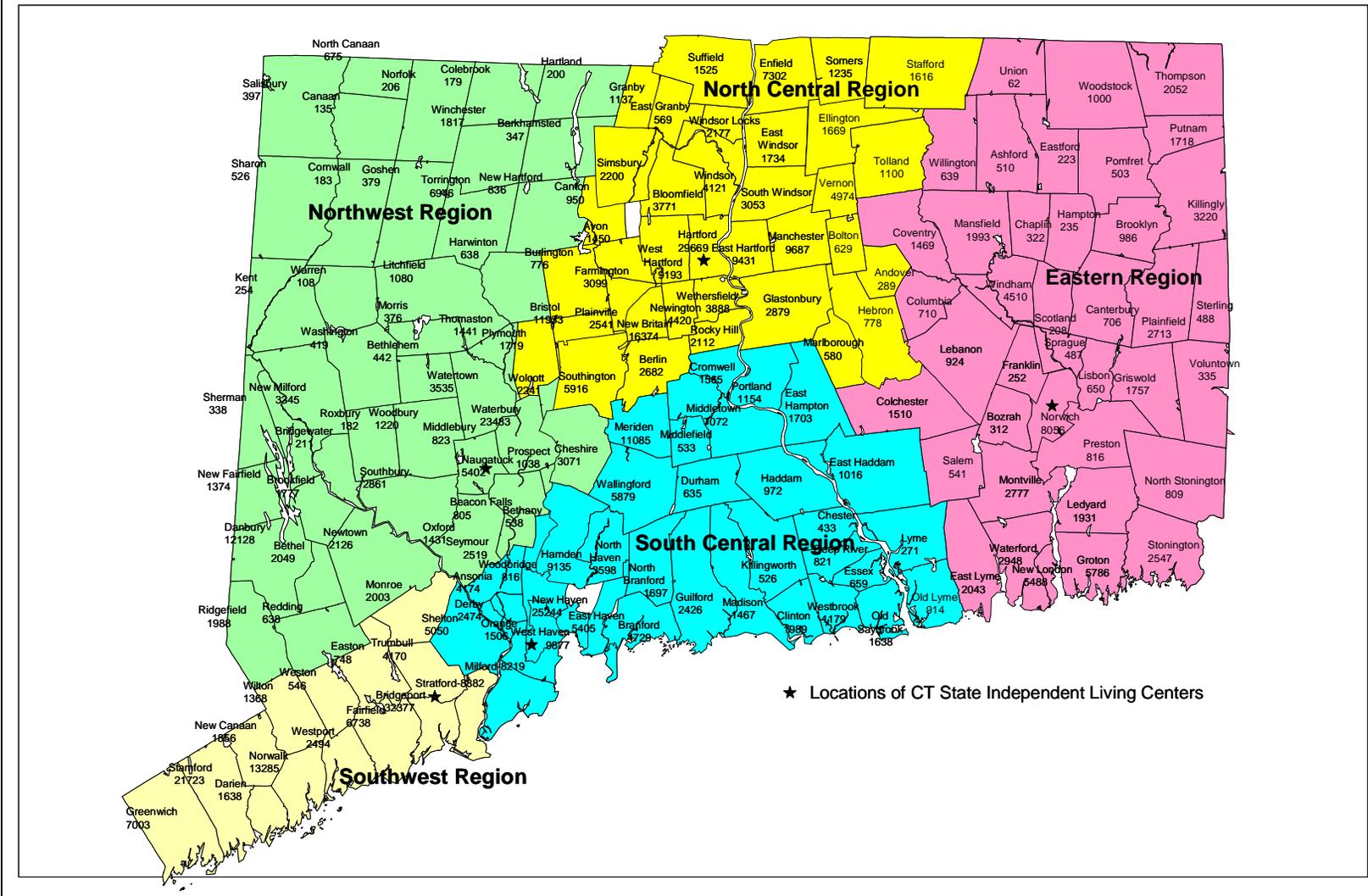
**Number of Persons Aged 5 and Older with Disabilities in Connecticut,
by Independent Living Council Region and Selected Population Characteristics, 2000***

	Northwest	North Central	Southwest	Eastern	South Central	State Totals
Total Number	89,650	159,178	104,831	64,236	128,918	546,813
Gender						
Males	43,678 (49%)	75,155 (47%)	49,965 (48%)	32,383 (51%)	61,405 (48%)	262,586 (48%)
Females	45,972 (51%)	84,023 (53%)	54,866 (52%)	31,853 (49%)	67,513 (52%)	284,227 (52%)
Ethnic Groups						
White	72,521 (81%)	111,716 (70%)	65,747 (63%)	54,869 (85%)	96,635 (75%)	401,488 (73%)
African-American	5,249 (6%)	19,794 (12%)	15,743 (15%)	2,750 (4%)	16,074 (12%)	59,610 (11%)
Hispanic/Latino	8,441 (9%)	21,788 (14%)	18,433 (18%)	4,164 (6%)	11,706 (9%)	64,532 (12%)
Age Group						
Ages 5-15	5,053 (6%)	8,271 (5%)	5,378 (5%)	4,298 (7%)	6,698 (5%)	29,698 (5%)
Ages 16-20	4,196 (5%)	8,175 (5%)	4,856 (5%)	3,875 (6%)	6,079 (5%)	27,181 (5%)
Ages 21-64	53,251 (59%)	95,115 (60%)	63,903 (60%)	38,044 (59%)	76,600 (59%)	326,913 (60%)
Ages 65-74	9,600 (11%)	17,843 (11%)	11,500 (11%)	7,441 (12%)	14,064 (11%)	60,448 (11%)
Ages 75 & over	16,775 (19%)	29,765 (19%)	19,494 (19%)	10,578 (16%)	25,871 (20%)	102,483 (19%)
Type of Disability						
Sensory	16,678 (19%)	27,642 (17%)	16,354 (16%)	12,989 (20%)	28,458 (22%)	102,121 (19%)
Mental	23,178 (26%)	38,012 (24%)	21,711 (21%)	17,457 (27%)	31,122 (24%)	131,480 (24%)
Physical	36,469 (41%)	62,137 (39%)	36,512 (35%)	27,363 (43%)	52,866 (41%)	215,347 (39%)

*Source: Based on data collected from The United States Census 2000 "Long" Form Questionnaire and from data files of the Census 2000 Summary File 3 (SF 3) [<http://factfinder.census.gov/servlet/BasicFactsServlet>].

This information about individuals with disabilities in Connecticut was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center.

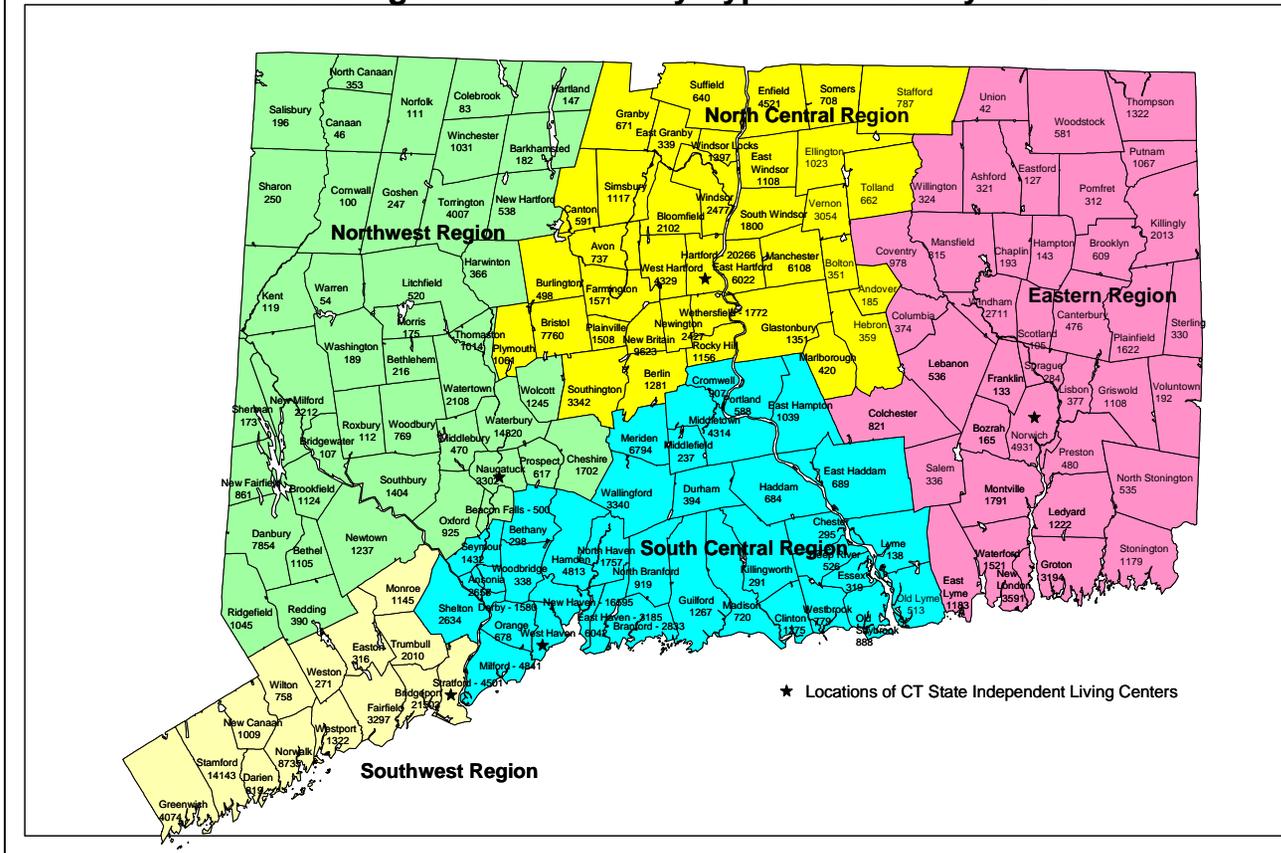
Individuals with Any Type of Disability by Connecticut Towns



Note: Data represents individuals ages five and older in the civilian non-institutional population. Data Set Source: Census 2000 Summary File 3 (SF 3) - Sample Data. This map does not include the 48 individuals from two CT Reservations: (Mashantucket Pequot Reservation, n=38) and the Paucatuck Eastern Pequot Reservation (n=10). Census Data was not available for the Mohegan Reservation, Golden Hill Reservation, and the Schaghticoke Reservation.

This information about individuals with disabilities in Connecticut was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center.

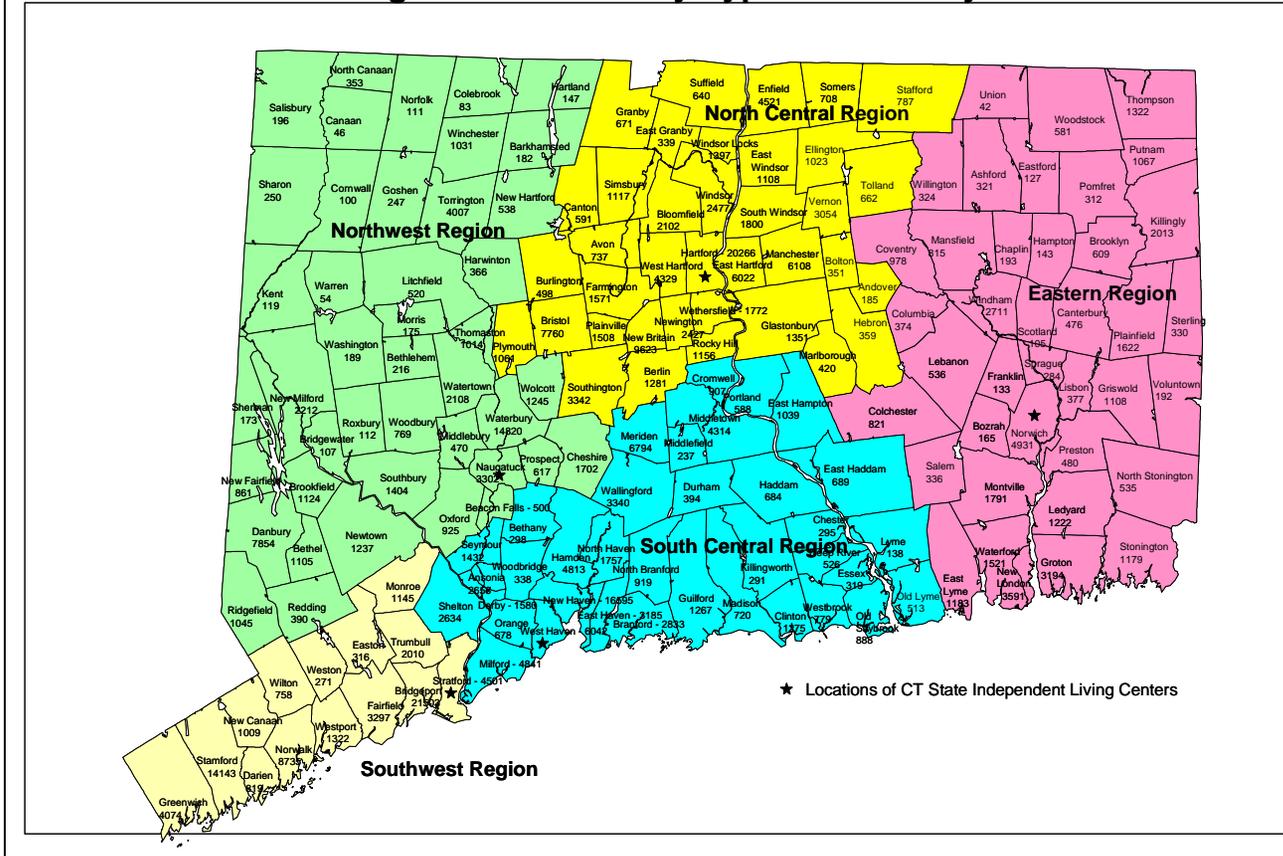
Individuals Ages 21-64 with Any Type of Disability in Connecticut



Note: Civilian non-institutionalized population 21 - 64 years with a disability
 Source for Data Set: Census 2000 Summary File 3 (SF 3) - Sample Data

This information about individuals with disabilities in Connecticut was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center.

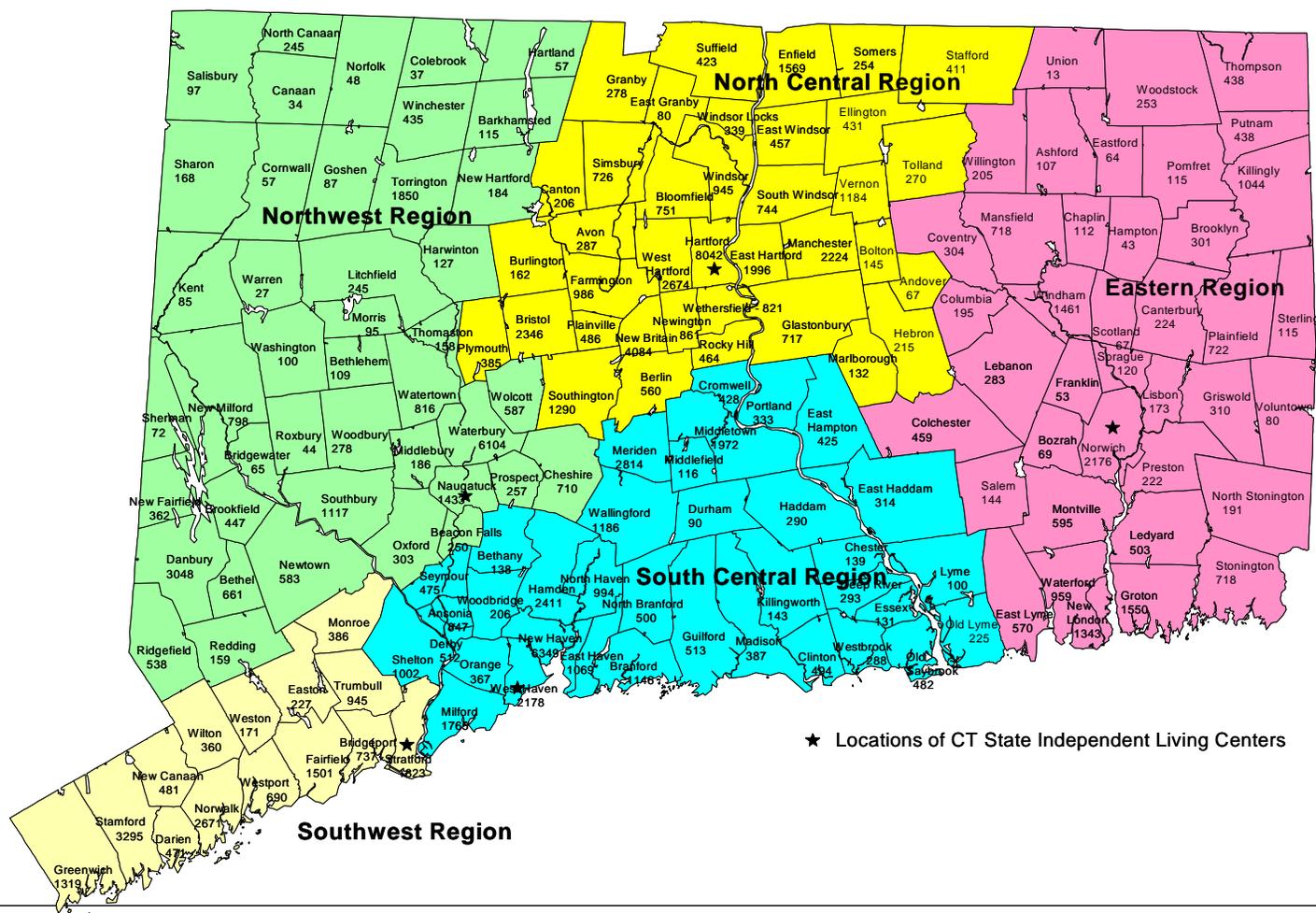
Individuals Ages 21-64 with Any Type of Disability in Connecticut



Note: Civilian non-institutionalized population 65-74 years with a disability
 Source for Data Set: Census 2000 Summary File 3 (SF 3) - Sample Data

This information about individuals with disabilities in Connecticut was commissioned by the Connecticut State Independent Living Council and compiled by the Center on Aging, University of Connecticut Health Center.

Individuals with a Mental Disability in Connecticut



APPENDIX I.

Sources of Public Comment

The Long-Term Care Advisory Council assumed responsibility for seeking and gathering broad public input on the 2004 Long-Term Care Plan. In the fall of 2003, a draft of the Plan was distributed to diverse organizations and individuals throughout Connecticut with an interest in long-term care. Comments were received from over 100 consumers, advocates and professionals, with representation from 23 public and private organizations.¹

Consumers, Advocates and Professionals

Organizations:

Alzheimer's Association
American College of Health Care Administrators
AARP – National
AARP – Connecticut
Breakthrough to the Aging
Coalition on Aging, Inc.
Connecticut Association of Area Agencies on Aging
Connecticut Association of Adult Day Care Centers
Connecticut Association of Home Care, Inc.
Connecticut Association of Personal Assistants
Connecticut Association of Residential Care Homes
Connecticut Coalition of Presidents of Resident Councils
Connecticut Commission on Aging
Connecticut Council for Persons with Disabilities
Connecticut Legal Rights Project
Connecticut Long-Term Care Advisory Council
Department of Social Services, Bureau of Rehabilitative Services
Department of Social Services, Elderly Services Department
Essex Meadows Health Center
Nursing Facilities Transition Grant
Office of the Ombudsperson for Mental Retardation, State of Connecticut
University of Connecticut Center of Excellence in Developmental Disabilities
Westview Nursing Care and Rehabilitation Center

¹ Copies of the public comments are available through the Long-Term Care Advisory Council. Contact Co-Chair Julie Evans Starr at the CT Commission on Aging office at 860-424-5360 or at commission.aging@po.state.ct.us .