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Connecticut Long-Term Care Needs Assessment

Part I: Survey Results

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Note to 2010 Revision:

This 2010 revised report corrects a labeling error at the end of section III (D) of the 2007 report. A revised Table III-9, new Table III 9a, and accompanying discussion may be found on pages 49-51. A more detailed document explaining the corrections, entitled *"Correction to the 2007 Connecticut Long-Term Care Needs Assessment Part I: Survey Results,"* accompanies this revised report.

This project was funded by the Connecticut General Assembly (Section 38 of Public Act 06-188: An Act Concerning Social Services and Public Health Budget Implementation Provisions).

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I. Introduction

Long-term care encompasses a wide range of assistance, services or devices provided over an extended period of time to meet medical, personal, or social needs in a variety of settings and locations (Connecticut Commission on Aging, 2007). Both informal, unpaid care given by family members and care provided by professionals constitutes long-term care (LTC). Long-term care services and supports may be provided in community-based or institutional settings, with the goal of integrating supports and medical care to meet the needs of individuals with functional disabilities. Overarching goals are to maintain health, improve functional capacity, enhance physical, social and emotional well-being, and maximize autonomy.

In recent years, substantial attention in many states, including Connecticut, has been directed at ‘rebalancing’ public resources from institutional to home and community-based long-term care in order to provide people with the services and supports to live in communities of their own choosing. In furtherance of these efforts, and in consultation with the Connecticut Commission on Aging, the Long-Term Care Advisory Council and Long-Term Care Planning Committee, the Connecticut General Assembly during its 2006 session authorized and funded a comprehensive statewide Long-Term Care Needs Assessment. (See Appendix A for a copy of Section 38 of Public Act 06-188.)

Supplementary contributions from the state’s Long-Term Care Ombudsman Program (LCTOP) allow for additional review of that program’s operation, with a goal of optimizing resources in order to best meet consumer needs, quality of care, and quality of life concerns. The LTCOP contribution also funds a survey of nursing home, assisted living, and residential care home residents’ experiences.

This report presents the findings of the Long-Term Care Needs Assessment surveys and includes:

- A comprehensive literature review of national and Connecticut-specific data and trends;
- Detailed results from the Connecticut resident surveys, including an assessment of segments of the population receiving services, a discussion of current long-term care use and unmet need, and projections of future demand;
- Results from the survey of long-term care providers, including an inventory of long-term care services and supports currently being provided in Connecticut and a discussion of present and future workforce issues; and
- Conclusions for consideration by legislators and other policymakers and regulators.

A companion report, Rebalancing Long-Term Care Systems in Connecticut, summarizing Connecticut’s rebalancing efforts and containing recommendations to improve Connecticut’s long-term care system is being released simultaneously with this report. Specific recommendations resulting from the Connecticut resident and provider results are incorporated into these overall project recommendations. A separately bound Executive Summary includes the conclusions and recommendations from both the long-term care needs assessment surveys report and the rebalancing report.

Two supplementary reports regarding the operation of the state’s Long-Term Care Ombudsman Program and the survey results from residents of nursing homes, assisted living, and residential care homes, and the financial planning efforts of the Connecticut population are in progress and will be released in the summer of 2007. In addition, the wealth of information garnered during the course of the Long-Term Care Needs Assessment will allow for additional in-depth studies on topics of particular interest. Two currently planned issue briefs to be released during 2007 will cover:

- A study of long-term care services and need in Connecticut by 12 geographic regions, and
- Detailed results of a survey specifically for Connecticut residents with disabilities broken down by type of disability and participation in Medicaid waiver program(s).

Further issue briefs responding to questions raised by this report are possible and are likely pending future funding.

II. Literature Review

The following background section presents an overview of the long-term care system and provides a foundation for interpreting the Needs Assessment findings. First, the current system of long-term supports and services is defined, including a summary of current federal and state policy efforts to transform the nature of long-term care. Second, individuals who need long-term care and supports, as well as those who provide these supports, are described. Next, the various settings in which long-term care is delivered are noted, including home, community-based and institutional settings. Finally, a review of long-term care financing is provided, with a summary-level federal and state expenditure data to illustrate current public and private contributions to long-term care expenditures.

An exhaustive search of the scientific and policy literature was conducted for this review; an extensive list of additional resources and references is included in Appendix B for readers interested in further detail about a particular topic.

A. Introduction

Definition of long-term care

Long-term care is a response to people who need assistance with the activities of daily living over an extended period due to disability or chronic illness and includes a broad range of medical and non-medical services and supports as well as informal, unpaid care provided by family and friends (Evashwick, 2005; Kane, Kane, & Ladd, 1998; Tsolova & Mortensen, 2006; U. S. Department of Health and Human Services, 2006a). Disability resulting from accidents, conditions occurring at birth or during developmental stages, or significant cognitive impairment, such as Alzheimer's disease, may require long-term care. Individuals with chronic diseases such as diabetes, cerebral palsy, protracted mental illness, or who have experienced traumatic brain injury or paraplegia, may also need assistance. Long-term care services and supports may be provided in community-based or institutional settings, with the goal of integrating supports and medical care to meet the medical, personal and social needs of individuals with functional disabilities (Kane et al., 1998). Overarching goals are to maintain health, improve functional capacity, enhance physical, social and emotional well-being, maximize autonomy, and encourage meaning in life (Kane et al., 1998). Long-term care supports address a number of basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include personal care tasks such as bathing, dressing, feeding, toileting, mobility, and transferring (e.g., from a bed to a chair), and IADLs refer to domestic tasks such as cooking, shopping, doing laundry, cleaning, taking medications, and managing personal affairs (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963; Lawton & Brody, 1969).

The transformation of long-term care

Increasing attention is being devoted to enhancing consumer choice in long-term care, as encouraged by a number of national movements including the disability rights movement, the nursing home culture change movement, and aging of consumer-oriented baby-boomers (Kane, Caplan, Urv-Wong, Aroskar, & Finch, 1997; Hawes, Phillips, Rose, Holan, & Sherman, 2003). Historically, the vast majority of long-term care services have been provided by nursing facilities and intermediate care facilities for the mentally retarded (ICF/MR). However, there is a great deal of variation among states. For example, in 2004, Mississippi spent nearly 95% of long-term care expenditures on institutional care, compared to less than 30% in Oregon (Shirk, 2006). In recent years, substantial attention is being directed at 'rebalancing' the long-term care system to achieve a more equitable balance between the proportion of public funding used for institutional services and that used for community-based supports (Mollica & Reinhard, 2005). Expanding home and community-based services and minimizing institutional care are viewed as central to ensuring that individuals have access to a range of flexible community and institutional supports and services (Kane, Bershadsky, & Bershadsky, 2006). Although a bias remains towards favoring institutional services at the federal level, proponents of rebalancing suggest it will enhance consumer choice, facilitate community integration, enable consumer direction and support civic engagement (Kane et al., 2006).

Primary approaches to rebalancing the long-term care system include: constraining institutional growth through regulation of bed supply and adjustment of payment rates, and reducing institutional services through transitioning residents into community settings and expanding home and community-based programs (Miller, 2005). With significant support from the Centers for Medicare and Medicaid Services (CMS), more than half of the states are implementing nursing home transition programs to help qualified Medicaid beneficiaries and others move from institutional to community-based settings (Reinhard, 2005). In response to requests from states, CMS announced in 2002 that it would allow the use of home and community-based services waivers to pay for relocation costs arising from nursing home transitions. These waivers can subsidize transition costs, including security deposits, essential furniture, moving expenses, and deposits for utility services (Eiken, Holtz & Steigman, 2005). Expansion of non-institutional service options is increasingly accomplished through Medicaid home and community-based services (HCBS) waivers (Reester, Missmar, & Tumlinson, 2004). The HCBS waiver program has become the primary mechanism for funding Medicaid community-based long-term care services, having grown from 37 percent of Medicaid community service expenditures in 1992 to 66 percent in 2001 (Reester et al., 2004). In 2002, a total of 47 states and the District of Columbia had HCBS waivers for older people or waivers for older people and younger persons with physical disabilities (Wiener et al., 2004). Waivers allow states to have greater flexibility over services and more fiscal control over utilization and expenditures.

With support from CMS, recent awards of nearly $20 million in "Real Choice Systems Change Grants for Community Living" have expanded efforts to help states develop programs for people with disabilities or chronic illnesses and to rebalance long-term support programs so that people with disabilities or chronic illnesses can remain in their homes and participate fully in community life (U. S. Department of Health and Human Services, 2006d). The systems transformation grants are intended to: improve access to information about available community-based services, promulgate self-directed service delivery programs, implement comprehensive quality management systems, develop information technology to support community living, offer flexible financing arrangements to promote community living, and coordinate long-term supports with affordable, accessible housing (U. S. Department of Health and Human Services, 2006f).

Programs designed to facilitate long-term care rebalancing include: a) "Money Follows the Person" (MFP) models, b) single point of entry systems (SPOE), c) beneficiary-managed budget programs such as Cash and Counseling, and d) Medicaid managed long-term care programs (MMLTC) (Milligan, 2005: Mollot et al., 2005; Spillman, Black, & Ormond, 2006; Saucier & Fox-Grage, 2005). MFP programs tie funding to specific individuals, allowing flexibility as an individual's needs change, regardless of the setting in which services are delivered (O'Brien, 2005). The model includes a funding stream that allows Medicaid resources budgeted for institutional care to be used for HCBS when a person moves back into the community, and a program that identifies consumers who want to move to the community and enables them in this transition (Mollica, Reinhard, Farnham, & Morris, 2006). States consolidate both institutional and HCBS budgets within the same administrative subdivision. Known as global budgeting or pooled financing, this method sets a cap on total spending, with administrative freedom to manage costs within the spending limit (Hendrickson & Reinhard, 2004). As of January 11, 2007, a total of 17 states have been awarded MFP grants including Connecticut (Centers for Medicare and Medicaid Services, 2007)

Single point-of-entry systems are intended as a consumer-responsive means of more efficiently allocating resources that fund outreach, information, application processing, eligibility determination, enrollment, and case management. Begun in the early 1990s, these systems vary greatly in the nature and scope of integration. They generally involve the development of a single entry point through which consumers in the state are able (and generally required) to access the care they need (Mollot et al., 2005). States that have developed or are developing SPOE systems include Oregon, Minnesota, Indiana and Michigan (Auerbach, Milligan, Zeruld, & Lee, 2003).

Individual budget, participant-directed models such as Cash and Counseling are running in approximately 10 states, with 12 additional states actively planning implementation (Spillman et al., 2006). Medicaid long-term care benefits are translated into a dollar value to establish a beneficiary-managed individual budget that may be used for a broad range of supports and services (Spillman et al., 2006). The models range from increased beneficiary involvement in the care planning process to allowing beneficiaries to choose, hire, and supervise their own workers, including family or friends. Findings suggest that consumer-directed care lowers the cost of services by decreasing administrative expenses (Doty, 1998). The model also allows people to tailor services to meet their individual needs and increase personal empowerment (Cohen, 2002; Cowan & Watson, 2002; Litvak, 1998; Schnur & Holland, 2002). Approximately 13.2 million adults living in the community receive about 31.4 hours each of personal assistance per week (LaPlante, Harrington, & Kang, 2002). While Medicaid personal care services provide only attendant services, programs offered under a HCBS waiver may offer a wider array of services (U.S. Department of Health and Human Services, 2002).

Finally, in Medicaid managed long-term care models, the state makes a single contractor responsible for all long-term care services and supports that a given individual needs, and pays a set monthly fee, regardless of the amount of care delivered. The models range in scope from Medicaid long-term care only, to fully integrated Medicare/Medicaid (such as Program of All-Inclusive Care of the Elderly, or PACE, and Senior Care Options). Presently, seven states are operating state-specific MMLTC programs, and PACE operates in 18 states. There is great variation in MMLTC program structure and scope, for example mandatory versus voluntary enrollment, fee-for-service versus capitated benefits, program eligibility, geographic service areas, payment rates and quality assurance mechanisms (Saucier & Fox-Grage, 2005).

Long-term care rebalancing efforts in Connecticut

An in-depth analysis of Connecticut's efforts to rebalance long-term care is presented in the companion report: Connecticut Long-Term Care Needs Assessment Part II: Rebalancing the Long-Term Care System in Connecticut. The following paragraphs give a brief overview of rebalancing activities to date in Connecticut.

In 1998, the Connecticut legislature mandated the establishment of the Long-Term Care Planning Committee (LTCPC) and the Long-Term Care Advisory Council (LTCAC) (Niesz, 2003). Comprised of representatives from ten state agencies and key legislative committees, the LTCPC's responsibility is to exchange information on long-term care issues, to coordinate long-term care policy development, and to establish a statewide plan for persons of all ages in need of long-term care that is reviewed and revised every three years. The most recent Plan was released in January, 2007. The LTCAC represents an active collaboration among providers, consumers and advocates for older adults and for persons with disabilities. It advises and makes recommendations to the LTCPC, proposes and promotes legislation, and promotes public access to information through a website (http://www.ct.gov/longtermcare) (Connecticut Commission on Aging, 2007).

Under the direction of the LTCPC and the Department of Social Services (DSS), a Community Options Task Force was formed in 2000. This Task Force was a diverse group representing older adults, persons with various disabilities of all ages, family members of persons with disabilities, and the Department of Social Services. The Task Force sought to assure that Connecticut residents with long-term support needs have access to community options that maximize autonomy, freedom of choice, and dignity. This Task Force was charged with developing a plan for community integration, in accordance with the mandates of the U.S. Supreme Court’s Olmstead decision. The plan, entitled “Choices are for Everyone,” defined action steps related to transitions from institutions, housing, supports, and community connections (Community Options Task Force, 2002).

The 2007 Connecticut Long-Term Care Plan (CT Long-Term Care Advisory Council, 2007) calls for a rebalancing of state expenditures between institutional and community-based services and supports. Specific goals include: a) allocating more resources to home and community-based services to achieve rebalancing goals, b) approving increases in appropriations necessary to meet the related current and increasing long-term care needs of Connecticut’s citizens and c) realizing adequate adjustments to the institutional capacity as a result of rebalancing and the evolving constituency (increased acuity levels) (CT Long-Term Care Advisory Council, 2007).

In Connecticut, efforts to rebalance the system are progressing. The proportion of Medicaid long-term care expenses for home and community-based services increased from 23 percent in 1996 to 32 percent in 2006 (CT LTCPC, 2007). However, much of that increase occurred in the late 1990s; since 2002, there has been almost no change due partially to Medicaid reimbursement rate increases to nursing homes (CT LTCPC, 2007). It should be noted that the increase in nursing facility rates affects the ratio but not number of clients. The increase in the proportion of home and community-based services is, in part, a result of efforts to reduce nursing home use by limiting nursing home care through pre-admission screening, a moratorium on new nursing home beds, and constraints on the growth in Medicaid payments with simultaneous expansion of home care through Medicaid (CT LTCPC, 2007). The number of people in Connecticut receiving HCBS between 2002 and 2006 rose from 17,315 to 21,340 (Connecticut State Office of Policy and Management, 2007b). Of everyone in Connecticut receiving Medicaid for long-term care, the percent receiving HCBS went from 46 percent in 2002 to 51 percent in 2006 (Connecticut State Office of Policy and Management, 2007b). The expansion of HCBS in Connecticut has occurred primarily through small pilot programs and by instituting six Medicaid HCBS waivers. Several additional waivers are currently under development.

Connecticut has also received nine federal grants since 2001, aimed at improving the long-term care system. The majority of these grants are CMS systems change grants. The grants include: Medicaid Infrastructure Grant (DSS, 2000), Nursing Facility Transitions to Independent Living Grant (DSS, 2001), Real Choice Systems Change Grant (DSS, 2002), Quality Assurance and Quality Improvement in Home and Community-Based Services (DMR, 2003), Community-Integrated Personal Assistance Services and Supports (DSS, 2003), Mental Health

Transformation State Incentive Grant (DMHAS, 2005), Family-to-Family Health Care Information and Education Centers grant (FAVOR, 2005), and Money Follows the Person (DSS, 2007)

While Connecticut has moved toward the rebalancing goals established in the LTC Plans, it still falls squarely in the middle of states, on a national level. In 2005, Connecticut ranked 26th in the percentage of Medicaid long-term care funding going to HCBS compared to institutional care (Home and Community Based Services, 2005). Connecticut has allowed nursing homes and ICF/MR facilities to close through attrition. The nursing home population in Connecticut has decreased by 641 residents over the past five years; and the ICF/MR population has decreased by two people in the same time period (Connecticut State Office of Policy and Management (2007b). Other states have taken a much more pro-active approach to remove institutional beds and close facilities, and thus have significantly reduced the numbers of residents in long-term care institutions. At the same time, the numbers of Connecticut HCBS users has shown only small increases over recent years, although several of the Medicaid waivers have waiting lists (Connecticut State Office of Policy and Management (2007b).

B. Users of long-term care services and supports

While estimates of the population with functional impairment needing long-term care vary depending on the study and the definitions used, approximately 12 million Americans receive some kind of long-term care; of these, approximately 80 percent are over age 50 and about half are older than 65 (AARP, 2006; Knapp, 2005). Individuals requiring long-term care are diverse in their social setting, individual background, accomplishments, interests, and preferences (Kane et al., 1998). The population using long-term care services is diverse in age, gender, type and degree of disability (Stone, 2000). Risk factors for long-term care include functional and cognitive impairment, mental illness, chronic disease and various socioeconomic factors associated with poorer health and limited access to health care (Houser, Fox-Grage, & Gibson, 2006). There are vast differences in the reasons for disabilities, the age at which they begin, the speed of progression, and the degree of activity limitation that may result; they may be sensory, cognitive, physical, or emotional, and may be observable or unseen (AARP, 2003).

Demographic trends indicate the proportion of the American population that is 65 and older is increasing and will continue to grow as the generation known as the baby boomers, those born between 1946 and 1964, begin to reach age 65 in 2011 (National Center for Health Statistics, 2003). It is estimated that by 2020, 71.5 million people will have reached age 65, and will make up 20 percent of the nation's population (Centers for Disease Control and Prevention, 2003). By 2040, the total population of those 85 and older will more than triple its current size (Moore, 1999). These demographic trends will significantly increase the demand for long-term care services (Johnson, Toohey, & Wiener, 2007). In 2000, almost 10 million Americans needed long-term services and supports; 63 percent of whom were age 65 and older and 37 percent were under age 65 (Kaiser Family Foundation, 2005). In the same year, 83 percent of people with long-term care needs resided in the community (of these 4.5 million or 47% were age 65+, and 3.4 million or 36% were under age 65), and 17 percent resided in nursing homes (of these 1.5 million or 15% were 65+, and .16 million or 2% were under age 65) (Kaiser Family Foundation, 2005).

The association between greater use of long-term care services and older age, chronic illness, and disability is well established (Harahan, Sanders, & Stone, 2006). In the 2000 Census, nearly 14 million people 65 and older reported they have some degree of disability (Wan, Sengupta, Velkoff, & DeBarros, 2005). Disability rates are strongly related to age, increasing from six percent of people 5 to 20 years old, to 10 percent of people 21 to 64 years old, and to 35 percent of those 65 and older (Johnson et al., 2007; U. S. Census Bureau, 2005). In Connecticut, an estimated 13 percent (402,369) of people age 5 and older reported a disability (U. S. Census Bureau, 2005). Disability rates among Connecticut's population who are age 65 and older include those with a disability in one or more of the following areas: physical (26%), mobility (15%), sensory (14%), cognitive/mental (9%), and self-care (8%) (Houser et al., 2006). Thirty-five percent of state residents over age 65 have one or more of the five disabilities listed, and seven percent have a cognitive/mental disability or any other disability (Houser et al., 2006).

There are many factors that may lead to the need for long-term care, including functional and cognitive impairment, mental illness, challenging behaviors, deteriorating health, chronic disease, falls, living alone, and problems with housing or transportation (Houser et al., 2006). Accordingly, services and accommodations must be designed to meet the needs of people with a range of physical (Knapp, 2005) and mental disabilities (National Coalition on Mental Health and Aging, 2005). Finally, attention must also be directed to addressing the needs and preferences of an increasingly racially and ethnically diverse population.

Persons with dementia

An estimated four and a half million people nationwide have been diagnosed with Alzheimer's disease (AD) (Alzheimer's Association, 2006). Although AD can occur in younger people, the incidence is greater in people 65 and older and it increases with age. It is estimated that the rate of moderate to severe dementia is two percent in individuals from age 65 to 69, four percent in those from age 70 to 74, eight percent in individuals from age 75 to 79, and 16 percent in those age 85 and older (Stone, 2000). Alzheimer's disease is the ninth leading cause of death among people aged 65 and older and costs of care have been estimated at $100 billion with individual lifetime costs averaging $174,000 (Family Caregiver Alliance, 2006).

Persons with intellectual disability

An estimated eight million Americans have intellectual disabilities (U. S. Department of Health and Human Services, 2004). Intellectual disability, referred to in the past as mental retardation, is defined in terms of a deficiency model, and uses an intelligence quotient (IQ) of 70 or below, difficulties in adaptive behavior and manifestations of conditions before age 18 (Fredericks & Williams, 1998; Leonard & Wen, 2002). The American Association on Intellectual and Developmental Disabilities currently places greater emphasis on the level of need related to adaptive skills and environmental support requirements (Kellett, Gruman, Robison, Nuss, & Kerins, 2004).

Like other individuals, people with intellectual disabilities experience challenges in economic, educational, and social domains, and need good health and health care systems in their communities (U. S. Department of Health and Human Services, 2002). Common medical conditions among this population requiring long-term care include: hypertension; congenital heart disease; pulmonary and gastrointestinal conditions; musculoskeletal, endocrine, and hematological conditions (Grossman, Richards, Anglin, & Hutson, 2000; Smiley & Cooper, 2003; Bailey & Andrews, 2003; Cowley, Holt, Bouras, Sturmey, Newton, & Costello, 2004; Holden & Gitlesen, 2003). Between 40 and 70 percent of people with intellectual disabilities also experience psychiatric disorders and significant behavioral problems; these are more likely to occur as they grow older (Hurley, Folstein, & Lam, 2003). People with Down Syndrome have a higher incidence of developing Alzheimer's disease in middle age to later years with 25 percent in ages 40 to 49 and 55 percent in ages 50 to 59 being diagnosed (Smith, 2001).

The health status of people with disabilities is negatively affected by multiple disparities; these are viewed as population differences in primary health indicators between people with and without disabilities (U. S. Department of Health and Human Services, 2001). For example, 28 percent of people with disabilities versus 7 percent of people without disabilities report that feelings of sadness, unhappiness, or depression prevent them from participating in activities (U. S. Department of Health and Human Services, 2000). Some people with intellectual disabilities also have higher rates of obesity than those without disabilities (Rimmer & Yamaki, 2006; Weil et al., 2006). Secondary health conditions are also more common among people with disabilities (Krahn, Hammond, & Turner, 2006). These include chronic disability-related pain and fatigue and physical, mental and social disorders that may be preventable (Kinne, Patrick, & Doyle, 2004). National reports indicate that people with intellectual disabilities often receive inappropriate or insufficient treatment, infrequent general health exams, fewer immunizations, and less prophylactic dental health care than their non-disabled counterparts in the general population (Department of Health and Human Services, 2002). They also have poorer health and a higher rate of mortality than people without disabilities (Havercamp, Scandlin, & Roth, 2004; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000).

National service effectiveness trends indicate that both national and state policies are needed to support better long-term care for people with intellectual disabilities, including staff and training development, cross-systems crisis prevention and intervention services, community mental health services, day and vocational services, residential services, and case management (Jacobson, Holburn, & Mulick, 2002). In 1999, The Connecticut Departments of Mental Retardation and Mental Health and Addiction Services partnered to improve services to people in the intellectual disability population. Subsequent to additional staff training over two years on the mental retardation/mental health delivery systems and current treatments, data show a rise in access to community inpatient services and a reduction in state hospital admissions (Beasley & du Pree, 2003).

Persons with mental illness

Mental illness refers to all diagnosable mental disorders and health conditions involving changes in thinking, mood, or behavior that contribute to patient distress, impaired functioning, increased risk of pain, disability, or death (American Psychiatric Association, 2000). There are two groups of people with mental health needs: adults with severe and persistent mental disorders (e.g., schizophrenia, bipolar, and dementia) and children and adolescents with significant emotional disturbances (e.g., schizophrenia, conduct disorder, pervasive developmental disorders) (Lehman, Goldman, Dixon, & Churchill, 2004). Depression is the most common mental illness and people with depressive symptoms tend to also experience more occurrences of physical illness, increased functional disability, and report greater utilization of health care services (Federal Interagency Forum on Aging-Related Statistics, 2006). In people 65 and older, women have higher rates of depressive symptoms than men. Males and females 85 and older had the highest rates of depressive symptoms (19.6%) (Federal Interagency Forum on Aging-Related Statistics, 2006).

Younger people with mental illness are more likely to live in the community, although they often lack adequate support services and receive little more than necessary medications (Bartels, Levine, & Shea, 1999). In addition, an estimated two million people experience traumatic brain injuries (TBI) nationally each year; of these, approximately 75,000 develop a long-term disability with total related expenditures estimated at $38 billion (Wenhui, Sambamoorthi, Crystal, &

Findley, 2006). It is not unusual for people with TBI to experience significant psychiatric problems including major depression or anxiety disorders after reporting an injury (Wenhui et al., 2006).

Persons with behavioral symptoms of underlying impairment

People with behavioral symptoms of underlying impairment also may need long-term care. Such behaviors may be related to functional ability, impaired communication, cognitive and/or physical impairments, physiological pain, dementia, depression, mental illness and psychiatric disorders (Distasio, 1994; Nelson & Cox, 2003; Shinoda-Tagawa, Leonard, Pontikas, McDonough, Allen & Dreyer, 2004; Draper, Brodaty, & Low, 2002; Talerico, Evans, & Strumpf 2002). Challenging behaviors include physical and verbal agitation and aggression, behavioral excesses and deficits, self-destructive behavior and others (Distasio, 1994; Draper et al., 2002; Nelson & Cox, 2003; Shinoda-Tagawa et al., 2004; Talerico et al., 2002). These behaviors are stressful to both caregivers and people needing long-term care services, and may occur in nearly half of nursing home residents (Buhr & White, 2006; Schreiner, 2001).

Persons with chronic conditions

Eighty percent of people age 65 and older currently have at least one chronic condition and half are living with at least two chronic conditions (Centers for Disease Control and Prevention, 2004). Certain chronic health conditions cause functional impairments, which may lead to a need for long-term care. Examples of such conditions include cardiac and respiratory conditions, hearing impairment, weakening vision, declines in cognitive function, mobility limitation, osteoporosis, and urinary problems resulting in incontinence (Knapp, 2005; Kane et al., 1998).

Children with disabilities

Children who have a significant, chronic mental or physical condition may require long-term care supports (Kirk, 1999; Kane et al., 1998). This may include children who are technology-dependent or who have intellectual disabilities, mental illness, or developmental disabilities which result in chronic, substantial functional impairments. Families caring for young people with special needs indicate the stress of caregiving and report experiences of social isolation, exhaustion, marital problems, problematic relationships with professionals, and services that are poorly coordinated (Bradley, Parette, & Van Bierliet, 1995; Diehl, Moffit, & Wade, 1991; Leonard, Brust, & Nelson, 1993; Sloper & Turner, 1992). In addition to children with existing long-term care needs, there are approximately 18 million children who are at increased risk for ongoing health care related to chronic physical, developmental, behavioral, or emotional conditions (Association of Maternal and Child Health Programs, 2003).

C. Providers of long-term care services and supports

Informal caregivers

Informal caregivers are family and friends who provide care without pay, and are the primary source of long-term care (Doty, 2004; Feinberg & Newman, 2004; Harding & Higginson, 2003; Wolff & Kasper, 2006). An estimated 44.4 million caregivers, or 21 percent of the U. S. population, provide unpaid care to family and friends age 18 and older (Pandya, 2005). When measuring informal care as the forgone wages of caregivers, the total estimated annual economic value of informal caregiving in the United States in 1997 was $196 billion, updated to $257 billion in 2002 and to $306 billion in 2004; this figure far exceeds public expenditures for formal home health care ($43.2 billion in 2004) and nursing home care ($115.2 billion in 2004) (Levine, Albert, Hokenstad, Halper, Hart, & Gould, 2006). While estimates may vary when calculating the economic value of informal caregiving this way, it is clear that its worth is significant.

Although family caregivers can be spouses, adult children, or other family and friends, the most common caregiver is female, 46 years old, has some college education, works outside the home, and provides about 20 hours of care weekly to her mother (Pandya, 2005; Stone, 2000; U. S. Department of Health and Human Services, 2003). Twenty percent of informal care is provided to other family members such as grandparents and siblings, and 24 percent of care is given to friends and neighbors (U. S. Department of Health and Human Services, 1998). Greater numbers of informal long-term caregivers are over 65 themselves, and are being challenged by caring for a relative 85 or older (Hobbs & Damon, 1996; Kane et al., 1998).

The importance of the unpaid care provided by family members and friends cannot be overemphasized. Although informal caregivers report some positive aspects of caregiving (Andrén, & Elmståhl, 2005; Haley, et al., 2004; Heru, Ryan, & Iqbal, 2004; Raschick, & Ingersoll-Dayton, 2004; Veltman, Cameron, & Stewart, 2002), the adverse effects experienced by many who provide such care are also well documented (Harding & Higgenson, 2003; Jungbauer & Angermeyer, 2002; Lantz, 2004; Moen, Robison, & Dempster-McClain, 1995; Ohaeri, 2003; Winefield & Harvey, 1994). Caregivers and their families often report high levels of psychological distress and depression, increased rates of physiological illness, and personal, financial, family and social problems (Doornbos, 2002; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Groff, Burns, Swanson, Swartz, Wagner, & Tompson, 2004; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Informal caregivers frequently report that caregiving conflicts with paid employment (Doty, 2004), and two-thirds report having to adjust their work schedule, decrease their hours, or take an unpaid leave in order to care for a family member (U. S. Department of Health and Human Services, 1998). Absenteeism and decreased productivity of employed caregivers contributes to additional employer healthcare expenditures and costs employers approximately $29 billion annually (Centers for Disease Control and Prevention, 2004; U. S. Department of Health and Human Services, 2003).

Informal caregivers need support in order to perform this role (Kane et al., 1998; Pandya, 2005; Wolff & Kasper, 2006; Schulz & Martire, 2004). Since the 1970s, the accessibility, range, and extent of publicly funded community services for caregivers has grown, although funding sources, eligibility requirements, programs and services vary widely among states (Feinberg & Newman, 2004). In addition to the Family and Medical Leave Act, the first national policy to support informal caregivers, the National Family Caregiver Support Program was established by Congress in 2000 (Pandya, 2005). Other caregiver resources are available through the Administration on Aging, Family Caregiver Alliance, National Alliance for Caregiving, National Family Caregivers Association, and FamilyCare America, and respite services are accessible through the National Council on Aging, National Adult Day Services, Interfaith Caregivers Alliance, and other programs (U. S. Department of Health and Human Services, 2003).

Connecticut's informal caregiver support includes programs that provide case management and subsidized home care services to families. These include Connecticut's Medicaid home and community-based waiver program (the Connecticut Home Care Program for Elders); the Older Americans Act-funded Respite and Supplemental Services Programs; and the state-funded Statewide Respite Program for individuals with a diagnosis of dementia. It also includes programs funded by the Older Americans Act that provide training, information, and assistance, support groups and respite opportunities for family caregivers. Finally, the Connecticut Alzheimer's Association provides a small annual respite benefit to families of people diagnosed with Alzheimer's disease (Link, Dize, Folkemer, & Curran, 2006).

Formal caregivers

Formal caregivers, defined as paid direct providers of long-term care services in a home, community-based or institutional setting, constitute a large and growing percentage of the workforce, both nationally and in Connecticut (U.S. Department of Health and Human Services and U.S. Department of Labor, 2003). Although many formal caregiver occupations are among the fastest growing in the country, the demand for such workers is growing at a faster rate than the supply (U.S. Department of Health and Human Services and U.S. Department of Labor, 2003). The emerging gap between the supply of long-term care workers and the needs of older adults and people with disabilities for their services has enormous implications for workforce development and public policy (Seavey, 2006).

The most significant factor affecting demand for paid long-term care services in the first half of the twenty-first century is the aging baby boomer generation. Government estimates suggest that the number of persons needing paid long-term care services, whether in a nursing home, other residential facility, or at home, could substantially double, from 15 million in 2000 to 27 million by 2050 (Friedland, 2004; U.S. Department of Health and Human Services and U.S. Department of Labor, 2003). These projections include children and working age adults with disabilities as well as the elderly. The rate of growth in demand for long-term care services over this period, however, will not be even. Trends in the size of demand indicate that the need for paid institutional and home care will increase significantly after 2020 and even more sharply around 2030 when the baby boomer generation starts to reach age 85 (U.S. Department of Health and Human Services and U.S. Department of Labor, 2003).

Consistent with the growing demand for long-term care workers, the anticipated supply is also increasing with little evidence that there will be enough people to fill the openings. Most paid providers of long-term care services are paraprofessional workers who provide hands-on care and emotional support to older persons and persons with disabilities, helping them to maintain some level of function and quality of life (Stone & Wiener, 2001; Seavey, 2006). The Bureau of Labor Statistics (BLS) has published 2004 data on the number of people currently working in various paraprofessional long-term care-related occupations, as well as the projected number of people who will be needed to fill those jobs in 2014, including both new jobs created and replacements for people leaving the workforce.

The occupation of home health aide is expected to grow by 56% between 2004 and 2014, representing the fastest growing occupation nationwide (Hecker, 2005). The growth rate of nursing aides, orderlies, and attendants (22.3%) and personal and home care aides (41%) will show a significant increase as well (Hecker, 2005).

Despite the actual and projected growth, many long-term care occupations have a negative image due in part to low wages, poor benefits, lack of status and unattractive working conditions, making recruitment and retention difficult (Stone & Wiener, 2001). Little formal training and educational background is required for entry into these three occupational categories with prior work experience and a high school diploma not always required. One study of nurse aides, for example, indicates that those working in long-term care settings are more likely than those in acute care settings to have a high school education or less, be unmarried with children, have incomes below the poverty level, and receive food stamps (Fishman, Barnow, Glosser, & Gardiner, 2004; U.S. General Accounting Office, 2001). Compared to all workers, nurse aides are disproportionately female, African American, less educated, poor, and uninsured (Fishman et al., 2004; U.S. General Accounting Office, 2001).

Wages for these paraprofessional long-term care occupations also lag behind those of other short-term training occupations with 2004 median annual earnings for nurse aides, orderlies and attendants at $21,890, home health aides at $19,200, and personal and home care aides at $17,560 (U.S. Department of Labor, 2004). Many workers do not work full-time year round and have even lower annual incomes. Lack of benefits for these workers affects the attractiveness of the jobs, particularly in home care, with paraprofessionals generally receiving better benefits in a hospital setting or nursing home than in home care. Personal and home care aides and home health aides are less likely to receive benefits at all (Fishman et al., 2004). Employee turnover rates are high, often exceeding 100% (Friedland, 2004; Stone & Wiener, 2001) for reasons related not only to wages but also to lack of professional growth, involvement in work-related decisions, and communication issues between management and employees (Harris-Kojetin, Lipson, Fielding, Kiefer & Stone, 2004).

In order to fill the expanding need for long-term care workers in the coming years, employers and policy makers will need to find ways to overcome the field’s negative image, retain current workers and attract new ones. Strategies could include not only higher wages, but also changes in the culture of the work environment, and in the duties, responsibilities and supervisory structure of the work, advances in labor-saving technology, and the development of new worker pools. It may also require fundamental changes in the way care is organized and delivered (Friedland, 2004).

Policy leaders and employers have begun to address the anticipated demand for long-term care workers in several ways. State and federal workforce development boards, which traditionally have shied away from investing in the development of the long-term care workforce, have begun to support recruitment and training efforts with programs of basic skills and job readiness training, on-the-job training, credentialing and licensing. A number of single-state and multi-state workforce development initiatives have focused on these initiatives in cooperation with local employers (Seavey, 2006; Fishman et al., 2004).

Wage and benefit issues are of paramount importance to recruitment and retention of formal long-term care workers, and a number of initiatives are designed to address them. At the state level, wage pass-through legislation, in which appropriations are earmarked to specific groups of direct care workers, has become a popular policy tool (Stone & Wiener, 2001; Seavey & Salter, 2006). Other wage-enhancement strategies have included rate enhancements linked to provider performance, collective bargaining by direct care workers, reform of reimbursement rates for Medicaid HCBS, and living wage or minimum wage improvements (Seavey & Salter, 2006). On the benefit side, several states have enacted or are exploring methods to expand health coverage for direct care workers or for all low-income workers generally. New York in 2000, for example, authorized establishment of a state-funded health insurance initiative for uninsured home care workers in the New York City/Long Island area. Most initiatives like this are too new to enable analysis of concrete results (Stone & Wiener, 2001; Seavey & Salter, 2006).

Working conditions of long-term care workers have been addressed in various ways designed to increase job satisfaction and reduce turnover. In nursing homes, for example, one recent study involving facilities in Connecticut and New York concluded that the use of special care units for residents with dementia improves working relationships among staff, and improves the morale and retention of the nursing staff (Robison & Pillemer, 2007). Another study, also involving nursing homes in Connecticut and New York, evaluated a promising model designed to reduce employee turnover in nursing homes through the use of a trained, dedicated "retention specialist" (Pillemer et al., 2007). After 12 months, CNA turnover rates had decreased significantly in facilities with the retention specialist, compared to the control facilities (Pillemer et al., 2007). There were also some positive effects on employees' attitudes toward their employer, although not in job satisfaction or levels of stress (Pillemer et al., 2007).

The development of alternate sources of workers is also a high priority for employers and policy makers. States are experimenting with attracting high school students through school-to work programs (Stone & Wiener, 2001), and considering former welfare recipients as candidates for entry-level long-term care positions (Filinson, Cone, & Ray, 2005). These programs have had mixed success, indicating the need for better screening of candidates, and enhanced training and case management (Stone & Wiener, 2001; Filinson et al., 2005).

Technology initiatives hold some promise not only by enhancing recruitment and training (i.e., through on-line job banks and distance learning), but also by changing the nature of some long-term care work through advances in recordkeeping, labor-saving technologies in patient care, and patient monitoring (Friedland, 2004; U.S. Department of Health and Human Services and U.S. Department of Labor, 2003).

D. Locations where long-term care is provided

Long-term care is provided across an array of highly diverse settings, ranging from private homes to supportive environments in the community, to various institutional settings. In addition, some people needing long-term care are incarcerated and live in prisons while other people may live in group homes, special intermediate care facilities or homeless shelters. Typically, people needing long-term care who live in the community depend on a combination of informal and formal care to meet their needs. Community settings can include not only private homes, but also residential care or boarding homes, small group homes, foster homes, retirement homes, congregate housing, or assisted living facilities.

Home and community-based services

Home care includes a variety of services to individuals and families in their homes aimed at increasing independence and decreasing the effects of disability, illness, or terminal sickness (National Center for Health Statistics, 2006; Weissert, Cready, & Pawelak, 2005). Home care is delivered through programs that are regulated by the government and receive reimbursement for care provided to people who experience chronic illness or who have functional limitations (Kane, 1995). The home care industry began its significant growth with the establishment of Medicare in 1965, when the program offered skilled nursing and therapy benefits. In 1973, these services were expanded to include eligible people with disabilities (National Association for Home Care & Hospice, 2004). Between 1967 and 1985, the number of agencies certified to participate in the Medicare program grew from 1,753 to 5,983 (National Association for Home Care & Hospice, 2004). Currently, about 20,000 providers supply home care services to approximately 7.6 million people needing care due to acute illness, long-term care conditions, chronic disability, or illness that is incurable (National Center for Health Statistics, 2006). Since the Balanced Budget Act of 1997 and subsequent changes in Medicare home health reimbursement, there has been a 30.4 percent decline in the number of certified home care agencies (National Association for Home Care & Hospice, 2004).

The Connecticut Home Care Program for Elders (CHCPE) includes both the Medicaid waiver program that makes home care services available to Medicaid-eligible individuals, and state-funded home care services for individuals at slightly higher asset limits. CHCPE is a nursing home diversion program, and eligibility is based on financial and functional criteria. To be eligible for the more expansive supports of the Medicaid waiver, an individual must have a monthly income of no more than 300 percent of the Supplemental Security Income amount (in 2007, $1,869), very limited assets, and must show need for assistance with three or more "critical needs" (bathing, dressing, taking medications) (Connecticut Legal Services, 2006). To qualify for the more modest services available through state funding, an individual must have assets below established amounts and show need for assistance with one or two "critical needs" (Connecticut Department of Social Services, 2006a).

Since home care is funded by both Medicare and Medicaid, it is highly regulated by both federal and state oversight. Medicare requires assessment of all patients receiving home care services. The Outcome and Assessment Information Set (OASIS) was developed as a way to measure improvement or outcomes to specific conditions (Kane & Kane, 2000; Feldman & Kane, 2003). Assessment tools make it possible for either a patient or family member to make informed decisions about which home care agency to contract with. However, it is often not the patient or the family member who makes these decisions, but rather the hospital or nursing home discharge social worker (Mor, 2003). There is a paucity of research measuring consumers' knowledge about home care services, financing options, and how to access care when it is needed (Neal, 2001).

Personal assistance services

Personal assistance services (PAS) are a critical part of the current paraprofessional long-term care workforce (Caro, 2001; Clinco, 1995; Dautel & Frieden, 1999; Kim, Fox, & White, 2006; Stone & Wiener, 2001). PAS provide a range of services including essential hands-on care and support to millions of adult individuals with chronic disabilities who may or may not be employed (Doty, Eustis, & Lindsay, 1994). These supports enable adults with chronic disabilities to sustain a reasonable functional level and quality of life in a community setting (Caro, 2001; Eustis & Fischer, 1992; Given, Given, Stommel, Collins, King, & Franklin, 1992; Stone & Wiener, 2001). During the past decade, a growing interest in the consumer direction of PAS and home and community-based services has been evolving in both the aging and disability population (Kassner & Williams, 1997; Meiners, Mahoney, Shoop, & Squillace, 2002; Simon-Rusinowitz, Bochniak, Mahoney, & Hecht, 2000; Simon-Rusinowitz & Hofland, 1993). Consumer-directed services preserve independence and enhance choice by allowing the consumer, not the service provider, to maintain control over the service plan and providers (Cavallo, 2002; Eustis, 2000; Katz, 1998; Kumar, 1998; Theve-Gibbons, 2001). PAS have been shown to improve functional capacity, productivity and community integration (Prince, Manley, & Whiteneck, 1995; Richmond, Beatty, Tepper, & DeJong, 1997; Dautel & Frieden, 1999; Kim et al., 2006).

While a distinct interest in consumer-directed services and cash allowances for these services is growing, implementing appropriate programs continues to be challenging (Dautel & Frieden, 1999; Stone, 1999). There are also substantial differences between states in the way in which programs are managed and the extent to which program recipients can select and direct services (Dautel & Frieden, 1999). One study comparing four states and their approach to personal assistance services showed that gaps in service exist in each of the states and suggested continued attention to definitions of personal care, eligibility criteria, independent providers and other supports (Mollica, 2001). Additional challenges exist in terms of hiring, training, managing, and paying personal assistants (Simon-Rusinowitz et al., 2000). While consumers want choices in their care and control over who provides it, there is great variation in consumers' capacity and willingness to orchestrate personal services.

Increasing quality, expanding the PAS workforce, and providing adequate compensation and benefits are areas in the forefront of PAS policymaking (Dautel & Freiden, 1999; Kim et al., 2006; Litvak, 1998; Stone & Wiener, 2001). Factors contributing to workforce barriers in the PAS model relate to: a low hourly wage which has been below the national minimum over the past decade; increasing health insurance premiums that limit agencies from offering benefits; labor supply and demand; state-funded systems relying on public policy and economic conditions that are not as responsive as could be to the private sector, and unstable or declining funding levels (American Network of Community Options and Resources, 2002; Center for MassHealth Evaluation and Research, 2002). Related workforce issues including lack of paid sick or vacation time, no workers' compensation coverage, and a weekly cap on the number of working hours per employer, are ongoing areas of concern as well as the lack of worker support and carefully regulated care quality (Kapp, 1996; Marini & Shefcik, 1996; Tilly & Wiener, 2001).

A study conducted in Connecticut to evaluate workforce barriers and problems faced in the Medicaid-funded Personal Assistance Services program reflects national findings mentioned above and found that personal assistants have intrinsic and extrinsic motivations in choosing, maintaining, and leaving employment (Gruman, Kellett, & Porter, 2003). Findings demonstrate that while personal assistants are intrinsically motivated, a certain tension exists for some PAs between these intrinsic and extrinsic motivations. Clearly, those who continue to work as a PA are embedded in a culture of caring, and while dependent on this income to live, accept lower wages with few benefits to do the work they enjoy doing. Twenty-five percent of PA respondents no longer working as a PA reported that low wages, lack of full time work, and absence of health benefits are significant barriers to working in the PAS program (Gruman et al., 2003). Factors reported by employers in recruiting and retaining PAs included: raising the hourly wage cap, providing health insurance benefits, and removing the weekly hour cap (Gruman et al., 2003). Initiatives such as the Personal Assistance Services program and Connecticut's C-PASS program (Community-Integrated Personal Assistance Services and Supports) help address both employee and employer issues and promote better workforce recruitment and retention. C-PASS is a three-year federal grant to the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research and Service in October 2003. The goal of C-PASS is "to develop an infrastructure and create products that will promote the effective recruitment and retention of personal assistants, and ensure that people with disabilities in Connecticut have the knowledge, access, and resources available to maximize choice and control in the use of Personal Assistance Services" (National Clearinghouse, 2003).

Several programs in Connecticut provide opportunities for person-centered planning and supportive services to people needing long-term care. Funded under Medicaid through a HCBS waiver, the Personal Care Assistant (PCA) program offers individuals with significant disabilities the opportunity to hire, train and manage their own personal assistants to provide essential hands-on care and complete household tasks (Gruman et al., 2003). The PCA waiver provides assistance with personal care to anyone 18 and older with chronic, significant, and permanent disabilities (Leslie, 2006). Like the Connecticut Home Care Program for Elders, which allows older adults to have assistance with ADLs and IADLs, this waiver is authorized and available only to people who would otherwise need institutionalization (Cohen, 2003). Other Medicaid waiver programs in Connecticut that allow the use of PCAs include the Acquired Brain Injury (ABI) waiver program, a small pilot program within CHCPE (DSS), and similar Medicaid waiver programs sponsored by the Department of Mental Retardation (DMR) (Connecticut Department of Social Services, 2006b).

Adult day services

Adult day services, also known as adult day care, are community-based group programs with specialized individual plans of care designed to meet the day-time needs of people with functional and/or cognitive impairments. This may include those with Alzheimer's disease, developmental disabilities, traumatic brain injury, mental illness, HIV/AIDS, or vision and hearing impairments (National Adult Day Services Association, 2006; Pandya, 2004). Adult day care has existed in the United States for about 30 years and provides a range of programs addressing participants' physical, social and emotional well-being while allowing respite for the informal caregivers (Day, 2006; Jarrott, Zarit, Berg, & Johansson, 1998; Jennings-Sanders, 2004). There are three models of adult day centers: a) a traditional model that provides social services and activities only; b) a medical model providing skilled nursing, medication management, various forms of therapy, and specialty care; and c) a combined social and medical model, which accounts for 42 percent of all centers nationally (National Study of Adult Day Services, 2001-2002). Although most adult day services offer therapeutic activities, personal assistance, meals and social services, findings from the National Council on Aging (2001) indicate that there is an increasing need for additional programs in adult day centers that target caregiving, chronic disease self-management and health promotion, physical activity, and social support (The National Council on Aging, 2001).

Currently, over 3,500 adult day centers are operating in the United States and provide care for approximately 150,000 older people on a daily basis (National Adult Day Services Association, 2006). One study suggests there is a need for at least 7,000 centers, and by 2050, there will be a need for approximately 30,000 facilities (Moore, 2005). Almost 78 percent of adult day centers are nonprofit and the other 22 percent are for profit; 74 percent of adult day centers are associated with larger organizations, such as home care, skilled nursing facilities, and medical centers (National Adult Day Services Association, 2006). The average consumer age for adult day centers is 72, and two-thirds of participants are female (National Adult Day Services Association, 2006). Twenty-five percent of adult day center participants live by themselves, and 75 percent live with a spouse, adult children, or family and friends (National Adult Day Services Association, 2006). More than half of participants have some level of cognitive impairment, 59 percent need help with two or more ADLs, and 41 percent need assistance in three or more areas (National Adult Day Services Association, 2006). Prolonged use of adult day services increases the benefits to both caregiver and care recipient (Gaugler, Zarit, Townsend, Stephens & Greene, 2003; Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006). Continuous use of adult day care provides the necessary respite that assists caregivers in pursuing activities that have a positive impact on their emotional, as well as psychological, self (Gaugler et al., 2003). Likewise, greater adult day service use was associated with public health benefits including enhanced caregiver well-being (Gitlin et al., 2006).

There are a number of barriers to the expansion of adult day services, including lack of public awareness of the model and regulatory and funding uncertainties. There is a need to develop consistency across agencies responsible for setting rules and regulations, and identifying and addressing problematic regulations is a viable place to start in providing community-based services to older adults (The National Council on Aging, 2001). The majority of adult day services are not covered under Medicare and if this cost is an out-of-pocket one for the caregiver, he/she may be reluctant to put a family member in adult day care and instead take on the burden of caregiving himself/herself (Pandya, 2004). Other barriers preventing the growth of adult day care centers include the inability to expand existing funding sources and identify new ones (The National Council on Aging, 2001).

In Connecticut, adult day centers rely heavily on the CHCPE as a primary source of funding (Siebenaler, O'Keeffe, O'Keeffe, Brown, & Koetse, 2005). The other two sources of public funding for adult day care are the Statewide Respite Program and the Older-Americans Act-funded Respite Services Program. Family caregivers in Connecticut report that stress reduction is the greatest benefit provided by the various community-based services it offers and that funding should be increased to provide these programs to more people who need them (The National Council on Aging, 2001).

Assisted living

Assisted living has grown in popularity and offers extended care options to older adults who may need assistance with ADLs or who have other long-term care needs (Kane & Wilson, 1993; Meyer, 1998). Extensive use of the term assisted living and substantial inconsistency among states in its definition continues to add to the debate about what assisted living is and how it should be regulated (Mollica & Johnson-Lamarche, 2005). Although the name "assisted living" is used in 41 states, a number of different terms are used for the larger residential care settings including: adult care home, assisted living, board and care homes, community-based residential facilities, domiciliary care homes, homes for the aged, personal care homes, and rest homes (Hawes et al., 2003; Mollica & Johnson-Lamarche, 2005). In addition to a substantial difference in the variety of services offered, there is also a range in the amount of privacy and level of services offered by these facilities that varies from "high privacy and high services" to "low privacy and low services" (Hawes et al., 2003, p. 880).

Assisted living may take place in a licensed setting in which services and support are delivered, or in a licensed agency that provides services in different types of settings (Mollica & Johnson-Lamarche, 2005). Connecticut, Maine, Minnesota, and New Jersey describe assisted living services that may be available in two or more settings, but only Connecticut and Minnesota view assisted living as a service, and license the provider of the service, which may be a different unit from the organization that owns and controls the residential building; other states view assisted living as a building or residence in which health and support services are available and provided (Mollica & Johnson-Lamarche, 2005). Different assisted living models that vary in state licensing and regulatory approaches include: the institutional model, housing and services model, service model, and umbrella model; these approaches occur alone or may be combined. In addition, some states require multiple levels of licensing for a single category. For example, Maryland licenses facilities based on residents' characteristics; categories for low-, moderate-, and high-need residents are based on criteria including functional status, health and wellness, medication and treatment, psychological health, and social and recreational needs (Mollica & Johnson-Lamarche, 2005).

In Connecticut, an assisted living facility is a "managed residential community in which supportive services are provided to residents by an entity that is licensed by the Connecticut Department of Public Health as an Assisted Living Services Agency (ALSA)" (Connecticut Department of Social Services, 2000, p.7). In some cases, the managed residential community (MRC) actually holds the license as an ALSA; in other cases the MRC contracts with an ALSA (Connecticut Department of Social Services, 2000). They may provide assistance with ADLs, some nursing services and management of medications (Connecticut Department of Social Services, 2000). ALSAs in Connecticut are required to provide an on-site registered nurse 40 hours a week (on call during other times) (Fortinsky, 2006). MRCs are required to provide services such as laundry, transportation, 24-hour security, maintenance and a variety of activities; the individual resident is responsible for paying a monthly rent that includes all of these services (Connecticut Department of Social Services, 2000).

The substantial variability in assisted living facilities stems from the fact that they are largely unregulated, by either state regulations or federal oversight (Assisted Living Quality Coalition, 1998). In Connecticut, most assisted living facilities are not covered by Medicaid, making it more difficult for a majority of older adults to consider assisted living a viable alternative to nursing home placement (Bridges, 2002). Since aging in place is one of the goals of assisted living, it seems contradictory to assisted living philosophy that once older adults have used up all of their financial resources they must relocate to a nursing home. Nationally, the median rate for assisted living is between $1800 and $2200 per month, however, in Connecticut, the monthly cost can be as high as $5750 (Bridges, 2002). An AARP Assisted Living Survey in Connecticut reports that about half of members are either not at all confident or not very confident that they would be able to afford to live in an assisted living facility for even one year (Bridges, 2002).

Connecticut's affordable assisted living pilots include the moderate and low-income ALSA Demonstration Project (Public Act 98-239 and Public Act 99-279) that allowed for construction of new, stand-alone Managed Residential Communities (MRCs) through which residents who 1) are age 65 and older, 2) are at risk of nursing home placement, and 3) meet CHCPE financial eligibility criteria receive ALSA services. This project is a joint partnership with the Department of Social Services (DSS), the Department of Economic and Community Development (DECD), and the Connecticut Housing Finance Authority (CHFA). In 2000, the Legislature extended the CHCPE to residents of state-funded congregate housing. This project also represents a joint partnership between DSS and DECD. Authorized by Public Act 00-2 and expanded in scope by Public Act 01-2, the State-Assisted Living Demonstration in Federally Funded Elderly Housing provides assisted living services to residents of certain designated buildings. In addition, the Private Assisted Living Pilot assists a limited number of individuals who have spent down resources while living in private MRCs with payment for assisted living services (this excludes payment for room and board). This pilot authorized 50 individuals eligible for the Medicaid waiver, and 25 individuals eligible for the state-funded levels of the CHCPE. More recently, Public Act 04-258 made it available to 75 individuals without respect to which level of care they qualify for. Currently, there is a large wait list. DSS indicates that MRC participation is very changeable and has not issued an updated list since September 2004.

Residential care homes

Residential Care Homes (RCHs), also known as Rest Homes or Homes for the Aged, are facilities for adults whose limitations prevent them from living independently by themselves (State of Connecticut, 2006). Although most residents are still older adults, a large and growing percentage of those currently living in RCHs are younger people with mental illness. People living in these facilities may need some assistance with daily activities, special diets and/or medication management. Residential Care Homes provide a communal living environment and offer private or semi-private rooms, with private or shared bathrooms, but no nursing services are provided. While services differ between facilities, most offer services that include assistance with activities of daily living, dietary and housekeeping services, and social and recreational opportunities. In many homes, transportation is provided and in some homes it is arranged for the resident. Typically, Supplemental Security Income is the funding source for residents of RCHs.

In Connecticut, all Residential Care Homes are licensed by the Connecticut Department of Public Health and offer the following basic services: three meals a day, housekeeping services and laundry services, recreational activities, and 24-hour staff supervision (State of Connecticut, 2006). Staff are helpful in supervising medications that residents take themselves and may assist them with scheduling appointments; some homes have a nurse on site while others help residents arrange for community-based nursing services when they are needed (State of Connecticut, 2006). Age requirements vary according to the home's policy (State of Connecticut, 2006). Residents pay monthly fees that differ by community and by the room provided; in some communities, residents are able to use government assistance to help them pay for care (State of Connecticut, 2006).

Continuing care retirement communities

Continuing care retirement communities (CCRCs) provide a relatively new model of long-term care. While assisted living facilities typically provide an independent living situation preparing an older adult for transition into a more supportive environment, CCRCs are a hybrid institution designed to meet both health and housing requirements as these develop and change over time (Center for Healthy Aging, 2006). For those of retirement age who can afford it, CCRCs provide housing, social support, and health care (Somers, 1993). Also known as life-care facilities or life-care communities, continuing care retirement communities provide access to independent living, assisted living, and skilled nursing facilities within the community (Somers & Spears, 1992). This access provides coordinated and comprehensive care, a primary benefit that older people value in CCRCs (Erikson, Krout, Ewen, & Robison, 2006; Krout, Oggins, & Holmes, 2000).

Unlike assisted living, which is usually financed by a monthly rent, CCRCs have a contractual agreement with their residents that is intended to meet all of their housing and care needs for the rest of their lives (Somers, 1993; Somers & Spears, 1992). This entails substantial up-front financial expenditures that may range anywhere from $20,000 to over half a million dollars, plus monthly maintenance fees ranging from $400 to $2500; the variation in cost is determined by the type of housing chosen and the medical service contract that is signed (Center for Healthy Aging, 2006). It is estimated that CCRCs may only be an option for about 25 percent of the population of those age 75 and older by 2020 (U. S. General Accounting Office, 1997). Thus, the cost of assisted living and CCRCs make it practically unattainable for most low and middle income individuals. It is not so much a matter of choice for some older adults as much as it is a measure of financial resources which determine the type of long-term care they are able to choose and receive.

Accommodations in CCRCs are based on the type of community. For example, some CCRCs are located in high rise buildings which contain all of the facility and housing needs in one location (Center for Healthy Aging, 2006). Other CCRCs are situated on an extensive campus with single family homes, cottages, condominiums or apartments; on these campuses, a skilled nursing facility is located in a separate building (Center for Healthy Aging, 2006).

Reasons for entering a CCRC may not differ substantially from the reasons for locating to an assisted living facility, except for the concept of being able to transition across care settings as needs change and the advantage of being able to design a service plan to meet specific needs and preferences (Somers, 1993). The primary difference between assisted living and CCRC is the payment method, the difference between a contractual agreement and paying monthly rent. As discussed in the assisted living section, an assisted living resident may be required to exit that facility for any reason, including decline in health status or even decline in cognitive ability. It is for this reason that CCRCs more closely approximate the concept of “aging in place,” and, as an all-inclusive setting with amenities, have become an attractive housing option for people in the long-term care system (Krout, Moen, Holmes, Oggins, & Bowen, 2002). It is suggested that relocation to a CCRC is an anticipatory move taken by people who are in good health, are wealthy, and who want to combine services with the assurance of future health care in a community that may be near to family and friends (Erikson et al., 2006; Krout et al., 2002).

Nursing homes

Nursing homes, also known as skilled nursing facilities (SNF), are the principal providers of long-term care for individuals who have significant functional or cognitive disabilities or medical situations that necessitate more formal or 24-hour care (Pandya, 2001). Nursing homes differ from residential care and assisted living in many ways largely because nursing homes are subject to both federal and state regulations, whereas assisted living and other residential care facilities are generally not subject to extensive state or federal mandates (Zimmerman et al., 2003).

As with home health care agencies, nursing homes have their own specific assessment tool to determine whether an individual requires a particular level of care. The Resident Assessment Instrument (RAI) encompasses two separate tools (Kane & Kane, 2000). The Minimum Data Set (MDS) assesses a variety of information from staff, family members and the residents themselves. These domains include physical functioning, medication, communication, cognition, behavior problems, disease diagnosis, overall health, and oral needs such as dental and nutritional. The second part of the RAI is the Resident Assessment Protocols (RAP), which includes delirium, cognitive loss, ADLs in relation to rehabilitation potential, psychosocial well-being, fluid maintenance, pressure ulcers and falls. These assessment instruments are intended to measure not only quantitative treatments and outcomes, but also residents’ perceptions regarding the quality of care; such awareness and insights should always be “the preferred source of information” (Kane & Kane, 2000, p. 683).

More than 1.6 million Americans live in nursing homes (Walshe & Harrington, 2002), and estimates show that 46 percent of those 65 and older will spend some time in a nursing home (Spillman & Lubitz, 2002). In Connecticut, as of September 30, 2006, 27,689 residents were living in nursing homes; this is a 7 percent decrease from September 30, 1999 (Connecticut State Office of Policy and Management, 2007a). Eighty-eight percent of residents were white, 71 percent were female, and 82 percent were widowed; this profile has been constant over time (Connecticut State Office of Policy and Management, 2007a). In addition, 11 percent of residents were less than 65 year of age, 40 percent were between 65 and 84, and 48 percent were age 85 or older (Connecticut State Office of Policy and Management, 2007a). There are three general sets of factors that increase the likelihood of nursing home admission: certain demographic characteristics (i.e., gender, marital status, age, race, and economic status), level of impairment (i.e., physical and/or cognitive), and access to the informal caregiving network (Lee, Kovner, Mezey, & Ko, 2001). Of all residents living in nursing homes, three-quarters require assistance with at least three activities of daily living, including bathing, dressing, eating, and using the toilet; 12 percent had a psychiatric diagnosis (i.e., schizophrenia) (Pandya, 2001) and half (50%) of residents were diagnosed with dementia (Alzheimer’s Association, 2006).

Nursing homes vary in the type of residents they serve. They may focus on special care, rehabilitation, clinically complex behavioral problems, or limited functioning (Fries, Schneider, Foley, Gavazzi, Burke, & Cornelius, 1994). Nationally, there are about 16,000 certified nursing homes with 1.4 million residents on any particular day (Alecxih, 2006). In 2004, approximately 65.9 percent of nursing homes were for-profit, 28 percent were non-profit, and 6.1 percent were government-owned (Harrington, Carrillo, & Mercado-Scott, 2006).

Quality of care in nursing homes has been the focus of considerable attention among policymakers, consumers, advocates and providers for decades. Concerns regarding quality focus on care issues and conditions presenting hazards for residents and workers (Allen, Nelson, Gruman, & Cherry, 2006; Wunderlich & Kohler, 2001; Wright, 2001, 2005). Multiple studies indicate the need for improvement in quality of care in nursing homes (Wunderlich & Kohler, 2001; U. S. General Accounting Office, 2000). Accordingly, the nursing home industry is heavily regulated at the federal and state levels. State survey agencies are required to inspect nursing facilities every 9 to 15 months in categories that include resident rights, quality of care and life, resident assessment, services, dietary, pharmacy, rehabilitation, dental and physician, physical setting, and administration (U. S. Centers for Medicare and Medicaid Services, 2005a; Manard, 2002). There is great variability across states in the rate of citations for deficiencies related to actual harm or jeopardy of residents, ranging from states with fewer than 5% of homes, to Connecticut, the highest in the nation, more than twice the national average at 47% (AARP, 2006). There is also variability in the approach to interpreting and enforcing the regulations during the review and inspection processes. Inadequacies indicated in a recent study included insufficient and inexperienced survey staff, uncertainty about regulations, and unsatisfactory state oversight of the review process (U. S. General Accounting Office, 2004).

Fifty percent of nursing home residents have Alzheimer's or another dementia diagnosis (Alzheimer’s Association, 2006). In response to quality of care issues and in an effort to meet the growing and more complex demand for care for older persons, endeavors to improve the care and health status of people in nursing homes have been made (Kane et al., 1998; Robison & Pillemer, 2005; Robison, 2006). For example, over the past several decades, some nursing homes have created separate units or special care units (SCUs) to care for people with dementia that include an environment favorable to the specific needs of people with dementia and the staff that care for them. Studies indicate when SCUs “meet accepted standards of environmental design, activity programming, and specialized staff training,” positive resident outcomes and benefits to unit staff are realized (Robison & Pillemer, 2007, p. 15). Emphasis on a demand-oriented, integrated care delivery process and engaging residents in home-like activities within nursing homes are additional attempts to replace the traditional provider-oriented, unintegrated care delivery process (Paulus, van Raak, & Keijzer, 2005). SCUs now represent one of the fastest growing areas of the nursing home industry and are a challenge for Alzheimer advocates concerned about the quality of long-term care (Alzheimer’s Association, 2006).

There is increasing interest in efforts to bring about a culture change in long-term care that emphasizes a home-like environment and person-directed care (Klauber & Wright, 2001; Sloane & Zimmerman, 2005). One recent example of culture change is the Green House model (Daitz, 2005). Green Houses differ from assisted living facilities and nursing homes in facility size, architectural design, patterns of staffing and in the way services are delivered; these self-contained residences are designed like a private home for seven to ten people and each person has his or her own bedroom and full bathroom (Hamilton, 2005). The first Green Houses were built in Tupelo, Mississippi and were the subject of a two-year study (Kane 2003).

Early results indicate high levels of satisfaction from residents, family, and staff; fewer complaints than at the state level; less decline in ADLs; staff turnover rates of less than 10 percent; and less depression (Daitz, 2005).

In Connecticut, as of September 30, 2006, 77 percent of 246 nursing facilities were for profit; this was a 3 percent increase from 2004 (Connecticut State Office of Policy and Management, 2007a). Connecticut is one of seven states with the highest percentages of proprietary facilities in the nation (Harrington, Carrillo, & LaCava, 2006). Nursing homes are licensed at two levels of care in Connecticut: Chronic and Convalescent Nursing Homes (CCNH), known as Skilled Nursing Facilities, and Rest Homes with Nursing Supervision (RHNS), or Intermediate Care Facilities. Of the 246 nursing facilities in Connecticut, 211 (86%) are CCNH licensed, 31 (13%) have both licensures, and four (2%) nursing facilities are licensed as a RHNS only (Connecticut State Office of Policy and Management, 2007a). In 2006, nearly all of Connecticut's nursing facilities (99%) were Medicare certified and 96 percent were Medicaid certified (Connecticut State Office of Policy and Management, 2007a).

In Connecticut, the average daily cost for nursing home care rose 8 percent in 2005 to $284 daily or almost $104,000 a year, and ranges from $200 to $350 daily for a semi-private room (Connecticut Partnership for Long-term Care, 2006). With the average length of nursing home stay at two and a half years, the total estimated cost of care is $260,000. Medicaid continues to be the primary source of nursing home payment in Connecticut and covers 69 percent of all residents; Medicare covers 16 percent of residents, 13 percent of people pay privately out-of-pocket, and 2 percent are covered by private medical insurance or long-term care insurance (Connecticut State Office of Policy and Management, 2007a).

Intermediate care facilities for the mentally retarded (ICF/MR)

The ICF/MR program was established in 1971 when legislation was enacted for ICF/MR as an optional Medicaid program (U. S. Department of Health and Human Services, 2006b). Nationally, there are currently 7,400 ICF/MR serving approximately 129,000 people (U. S Department of Health and Human Services, 2006b). Most people receiving services in ICF/MR have other disabilities in addition to MR; these may include seizure disorders, behavior problems, mental illness, visual impairment, or a combination of these (U. S Department of Health and Human Services, 2006b). Institution for persons with mental retardation is mainly for diagnosis, treatment, or rehabilitation and provides ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health and rehabilitative services in a protected residential setting (U. S Department of Health and Human Services, 2006b). To qualify for Medicaid reimbursement, ICF/MR must be certified and be in compliance with Federal standards including management, client protections, facility staffing, active treatment services, client behavior and facility practices, health care services, physical environment and dietetic services (U. S Department of Health and Human Services, 2006b). Although ICF/MR increased in the 1970s, the number of beneficiaries has not increased much since the early 1980s (U. S Department of Health and Human Services, 2006c). In spite of declines in the number of people served, state facilities continue to use a large share of the ICF/MR benefit because most people served by this program still live in large public ICF/MR (U. S Department of Health and Human Services, 2006c). There are major differences among states in their use of the ICF/MR program; for example, New Hampshire, Washington, D.C. and Rhode Island do not have any large public ICF/MR institutions (U. S Department of Health and Human Services, 2006c). In addition to Southbury, there are six state run ICF/MR and a number of private ones in Connecticut. In June, 2006, 1,163 Connecticut residents resided in ICF/MR (Connecticut Long-Term Care Planning Committee, 2007).

Psychiatric hospitals

Psychiatric hospitals are institutions that provide psychiatric services for the diagnosis and treatment of people with mental illness. Some psychiatric hospitals are “forensic hospitals” and primarily serve people in the custody of penal authorities; these institutions are generally excluded from Medicare payment, but payment may be provided to people receiving services who are in the custody of prison authorities (U. S. Department of Health and Human Services, 2006e). Psychiatric hospitals participating in Medicare or JCAHO under hospital accreditation programs must meet the requirements, as specified by Medicare, for hospitals. Psychiatric hospitals may choose to completely participate or may choose a specific part and apply for Medicare participation of that distinct part. Provision for this under the law permits the participation of specific sections of psychiatric hospitals that are appropriately staffed, supervised, and prepared to provide adequate, ongoing treatment (U. S. Department of Health and Human Services, 2006e).

Long-term care for people with mental illness is provided through a variety of public and private programs. In Connecticut, there are nine psychiatric hospitals. The Department of Mental Health and Addiction Services (DMHAS) operates five inpatient treatment facilities. Connecticut Valley Hospital (CVH), located in Middletown (Region Two), is the only one that provides care for long-term psychiatric residents and currently has 170 beds for mental health, 110 beds for substance abuse, and 248 beds for forensic cases. Four other facilities operated by DHMAS provide acute and intermediate care and include: Cedarcrest Hospital (CRH) in Newington (Region Four); Connecticut Mental Health Center in New Haven (Region Two); Greater Bridgeport Community Mental Health Center in Bridgeport (Region One), and Capitol Region Mental Health Center in Hartford (Region Four). In addition, four other psychiatric facilities located throughout the state also offer acute and intermediate care. In Westport, Hall-Brooke Behavioral Health Services, Inc. provides an integrated continuum of care in behavioral health and addiction services. Natchaug Hospital, in Mansfield, provides inpatient care for emotionally disturbed children and adolescents as well as adults with mental illness and substance abuse problems. In addition to providing acute care, Silver Hill Hospital, in New Canaan, provides transitional living programs for adolescents and adults with addictive disorders, dual disorders, eating disorders, or psychiatric disorders. Yale-New Haven Psychiatric Hospital (YNHPH) provides comprehensive clinical care for people with mental illness and has a psychiatric inpatient facility and intensive outpatient specialty programs. It should be noted that every other general hospital in Connecticut has psychiatric beds for acute care (Connecticut Department of Mental Health and Addiction Services, 2007b).

Local mental health authorities

In addition to offering mental health services through State-Operated Inpatient Facilities, DHMAS operates a number of Local Mental Health Authorities (LMHAs) throughout the state. These provide a broad range of therapeutic programs and crisis intervention services. Private and non-profit agencies can also be accessed through each of the LMHAs. LMHAs are located in each of five regions. Region One includes Southwest Mental Health System in Bridgeport, Greater Bridgeport Community Center in Bridgeport, and the F. S. DuBois Center in Stamford. Region Two includes Birmingham Group Health Services in Ansonia, Bridges…A Community Support System, Inc. in Milford, Connecticut Mental Health Center in New Haven, Harbor Health Services in Branford, River Valley Services in Middletown, and Rushford Center in Meriden. Region Three includes Southeastern Mental Health Authority in Norwich and United Services in Dayville. Region Four includes Capitol Region Mental Health Center in Hartford, Community Mental Health Affiliates, Inc. in New Britain, Inter-Community Mental Health Group in East

Hartford, Community Health resources in Windsor, Genesis Center, Inc. in Manchester, and North Central Counseling Services in Enfield. Region Five comprises the Western Connecticut Mental Health Network and following agencies: Greater Waterbury Mental Health Authority, Greater Danbury Mental Health Authority, and Northwest Mental Health Authority in Torrington (Connecticut Department of Mental Health and Addiction Services, 2007a).

Chronic disease hospitals

By definition, chronic conditions are incurable and while they can often be treated successfully on an outpatient basis, many need special care that is only provided by chronic care hospitals. In the United States, approximately 125 million Americans suffer from at least one chronic condition (i.e., diabetes, asthma, depression); by 2020 this figure is projected to grow to 157 million (Parsons, 2003). This increase is likely to result in demand for more hospitals that specialize in providing care to people with chronic conditions.

There are six chronic care hospitals in Connecticut. Gaylord Hospital, in Wallingford, is licensed as a 109-bed long-term acute care hospital specializing in the care and treatment of medically complex patients, rehabilitation and sleep medicine. The hospital offers over 50 outpatient services and is planning a $20 million expansion program to accommodate a growing number of patients needing special care. The Hospital at Hebrew Health Care is a 45-bed hospital that is part of the Hebrew Health Care campus in West Hartford. It offers specialized inpatient and outpatient care for older adult patients with complex medical or behavioral needs (i.e., anxiety disorders, dementia). The Hospital for Special Care (HSC) in New Britain is a private, not-for-profit 200-bed rehabilitation long-term acute and chronic care that provides physical rehabilitation (including outpatient rehabilitation), respiratory care and medically-complex pediatric services. Masonic Health Care, in Wallingford, is Connecticut's oldest geriatric healthcare facility and provides a full range of services that include acute care, geriatric assessment, rehabilitation, and outpatient mental health. Mount Sinai Rehabilitation Hospital, Inc., in Hartford, is a 60-bed facility that offers a comprehensive range of programs designed to prevent and minimize disability and help people reconstruct their lives after catastrophic illness and injury. The Health Care Facility at the Connecticut Veterans' Home, in Rocky Hill, provides long-term care to veterans with chronic and disabling medical conditions including heart and lung disease, stroke, Parkinson's, Alzheimer's and other dementias. Hospice, palliative and respite care are also provided.

Other community-based care settings and services

In addition to assisted living and residential care homes, other community-based settings that provide housing and certain long-term care services and supports include adult foster homes, group homes, and respite care (Houser et al., 2006).

Adult foster homes

Adult foster homes are similar to small private homes in the community and house between one and five residents; they may also be called family care homes, small group homes, or domiciliary homes (Kane et al., 1998). Adult foster homes are referred to by some as an assisted living facility because they provide help with ADLs and enable people to live as independently as possible for as long as possible. Like assisted living, adult foster homes "bridge the gap between independent living and nursing homes" (Milbank Memorial Fund & Council of Large Public Housing Authorities, 2006, p. viii). Adult foster homes are particularly well-suited for people with dementia and are appropriate for rural areas that are unable to support larger living programs (Kane et al., 1998). In addition, because they emphasize cost containment and quality of life in a home-like setting, they are a positive policy alternative when considering housing costs and quality of life (Reinardy & Kane, 1999). In Connecticut, this initiative is being phased out through attrition and is no longer an available option.

Group homes

Group homes emerged in response to the deinstitutionalization movement and are small, residential, single-family homes located within the community that provide care for dependent populations and are designed to accommodate six or fewer people with chronic disabilities (i.e., frail or disabled elderly, mentally ill, intellectually disabled, developmentally disabled) (Spreat & Conroy, 2001). While there is significant variance in the size, resident mix, programs, services, and costs among these homes (U. S. Department of Health and Human Services, 1993), they share the goal of promoting independence and self-sufficiency (U. S. Department of Health and Human Services, 1993). Group homes are licensed and staffed with trained and certified personnel who are responsible to make sure residents receive the appropriate services including medical care, physical and occupational therapy, and mental health services (U. S. Department of Health and Human Services, 1993).

Respite care programs

Respite care consists of home care, day care, and short-term institutional care and is differentiated from other types of care by its purpose to temporarily relieve caregivers from the stress of caregiving (Kane et al., 1998). Most programs are managed by chapters of national organizations (i.e., Easter Seal Society, United Cerebral Palsy Associations) and have eligibility and licensing requirements. However, of all the available family support programs, respite care is reported to be the most available service (The Arc, 2003). While many respite care programs have focused on younger people, expanding services in the community to include older adults is a cost-containment plan supported by many and has been accomplished successfully in several states (U. S. General Accounting Office, 1994). Most states use Medicaid home and community-based service waivers to expand noninstitutional services such as respite care (Reester et al., 2004).

Long-term care settings and programs in Connecticut

Community-based long-term care settings in Connecticut include: Age-Restricted Communities (i.e., apartments, cooperatives, single-family homes, and condominiums), Continuing Care Retirement Communities, Elderly and Disabled Housing (i.e., Senior Apartment Complexes), Congregate Housing (i.e., private apartments with communal activity areas), Residential Care Homes (also called Homes for the Aged), Assisted Living/Managed Residential Communities, Manufactured/Mobile Homes, Nursing Homes, Rest Homes with nursing supervision, and Chronic and Convalescent Nursing Homes (Connecticut Department of Social Services, 2000; State of Connecticut, 2006).

Programs that are available in Connecticut to help people remain in their homes include: Apartment Conversion for the Elderly (ACE), Connecticut's Program for Health Insurance Assistance, Outreach, Information, and Referral, Counseling, Eligibility, and Screening (CHOICES), Congregate Housing for the Elderly, Energy Assistance Programs (i.e., the Connecticut Energy Assistance Program – CEAP, and the State-Appropriated Fuel Assistance Program – SAFA), Housing for Elderly Persons (i.e., grants/loans for the development of elderly housing), Low Income Public Housing (LIPH) (i.e., federalized subsidized housing), Rental

Assistance Program (RAP) (i.e., state-administered program to assist low-income people in paying rent). Reverse Annuity Mortgage (RAM) (i.e., home equity conversion), Rural Rental Housing Loans (i.e., assist with constructing, purchasing, or repairing apartments), Rental Assistance (Rural Housing Services) (to reduce rent and utility expenses), Property Tax Relief for Homeowners/Renters Rebate Program, Section 202 Housing Assistance (exclusive assistance for the elderly), and Section 8 Rental Assistance (Connecticut Department of Social Services, 2000).

Other home care programs include: Adult Home Share Programs (i.e., matching people as housemates), Companion Services/Friendly Visitor Programs, Connecticut Home Care Program for Elders, ConnPACE (for prescription assistance), Elderly Nutrition Project, Emergency Call System, Home-Health Care, Homemaker/Home Chore Services, and Resident Services Coordinators (Connecticut Department of Social Services, 2000).

E. Housing and transportation supports

Housing is a basic human need that provides shelter and should promote safety and independence (Greenwald & Associates, 2003). Housing trends indicate a crisis in providing decent and affordable housing to people with long-term care needs (O'Hara & Miller, 2000). Since 1998, availability of supportive housing for people with disabilities has declined, coupled with discrimination by real estate owners and federally subsidized housing managers (O'Hara & Miller, 2000). A recent needs assessment conducted by the United Way Community Results Center focused on Bristol, Burlington, Plainville and Plymouth indicated transportation and affordable housing were the top priority issues, citing the need for expanded schedules and service areas for transport services, and additional one-story small homes and senior housing apartments (United Way, 2006). Connecticut's long range strategic housing plan includes encouraging home ownership for low-and moderate income residents, expanding the supply of quality affordable housing, and providing for the shelter, housing, and service needs of the homeless poor and others with special needs (i.e., elderly and frail elderly, people with disabilities, people with HIV/Aids and their families, people with substance abuse issues, and people recently released from prison) (Connecticut Department of Economic and Community Development, 2005).

Transportation is a crucial part of the community infrastructure that enables people to gain access to the goods, programs, services, and social contacts that sustain every day life and promote quality of life (Stowell-Ritter, Straight, & Evans, 2002). Affordable, accessible, flexible transportation alternatives are essential for people who are unable to drive or move around easily (Houser, 2005). About one-fifth of older adults do not drive due to declining health, self-regulation, or lack of transportation and more than 50 percent of non-drivers age 65 and older remain at home on any day of the week due lack of transportation alternatives (Bailey, 2004). People with poor health or disability are less likely to leave their homes more often on a daily/weekly basis (Stowell-Ritter et al., 2002). Between 2000 and 2020, the number of people not driving will rise by 15 percent to 52 percent of older adults, significantly affecting the transportation system specifically and home and community-bases services more generally (Koffman & Weiner, 2004). A number of federal, state and local policy alternatives may be explored in strengthening transportation programs, including consistent funding of existing and improved transportation alternatives, encouraging local control of fiscal decisions related to transportation, and guidance from state agencies in the goal-setting process associated with maintaining and improving transportation systems (Ernst & McCann, 2005).

F. Long-term care costs and financing

Medicare programs, programs funded through the federal Older Americans Act, and state-funded programs for long-term care are substantial and are projected to increase rapidly in the coming decades. In 2004, the total cost of long-term care in the U.S. was $158.4 billion, the majority ($115.2 billion) was spent on nursing home care, and the remainder ($43.2 billion) was spent on home health care (Borger et al., 2006). These costs include both private and public spending on long-term care. Future spending growth will be driven by two factors: aging of the population and increases in per capita medical costs (Congressional Budget Office, 2005). Demographic trends indicate the number of older Americans is growing in size as a result of declining death rates, increasing life expectancy and the aging of the baby boom cohort. These changes are likely to contribute to an increased demand for long-term care. Total costs for nursing home and home health care are projected to increase to $320.5 billion in 2015, with an estimated $216.8 billion for nursing homes and $103.7 billion for home health care (Borger et al., 2006).

There are two broad sources of financing for long-term care: personal resources and public programs. Personal resources include informal care donated by family and friends, out-of-pocket spending and private insurance. Public funding sources include the Medicaid and Medicare programs, and state funded programs such as those administered through the Older Americans Act.

The monetary value of care donated by family and friends ("informal care") was recently estimated to account for approximately 52 percent of total long-term care costs (Congressional Budget Office, 2004). This estimate includes both in-kind care and financial contributions. Approximately half of caregivers who are caring for someone other than their spouse pay out of pocket for a portion of that person's care. This caregiver contribution amounts, on average, to $200 a month (National Alliance for Caregiving & AARP, 2004). Although clearly significant, the financial contribution of informal care providers is difficult to calculate and is not typically included in expenditure estimates. Accordingly, the data presented in this overview of long-term care financing do not include informal care as a source of funding. In 2004, approximately 23 percent of long-term care costs were paid out-of-pocket by individuals, 9 percent were paid by private insurance, 42 percent by Medicaid, 20 percent by Medicare, and 3 percent from other public sources (Heffler, Smith, Keehan, Borger, Clemens, & Truffer, 2005; Office of the Actuary reported in Smith et al., 2006; Kaiser Commission on Medicaid and the Uninsured, 2006b).

Out-of-pocket spending

Individuals paid for nearly one-quarter (23%) of long-term care costs in 2004, including direct payment of services as well as deductibles and co-payments for services primarily paid by another source (Smith et al., 2006). Growth in out-of-pocket payments was expected to decrease sharply in 2006 with the advent of Medicare Part D prescription coverage. Although rising out-of-pocket costs have received a great deal of attention, during the past ten years, out-of-pocket spending increased faster than total private spending only between 1997 and 1998 (Borger et al., 2006).

Private insurance

Types of private insurance include supplements to Medicare coverage (Medigap), traditional health insurance, and policies targeted specifically to long-term care. In 2004, coverage from private insurance represented 9 percent of long-term care expenditures in the U.S. (Smith et al., 2006). Nearly 85 percent of Medicare beneficiaries have some type of supplemental Medigap coverage which typically pays for cost-sharing (deductibles and coinsurance) from Parts A and B, and may pay for additional services not covered (Moon, 2006).

Long-term care insurance covers a wide range of services and supports for individuals who need assistance with ADLs. Policies typically pay for skilled and custodial care provided by nursing homes, assisted living facilities, home care agencies, adult day centers and other providers of services for people with chronic care needs (Cohen, 2003). Private long-term care insurance generally enables policyholders to pay for long-term care services without having to exhaust personal wealth or rely on Medicaid.

Over the past 10 years, the market for long-term care insurance has grown substantially. In 1990, slightly fewer than 2 million policies had been sold to individuals age 55 and older. By 2000, however, this figure had tripled and the number of policies sold either on an individual basis or through employer-sponsored group plans had increased to more than six million (Cohen, 2003).

As states continue to encourage a shift away from reliance on the Medicaid program toward greater private responsibility, various models to make long-term care insurance attractive have been developed, including stimulating market expansion, tax incentives and offering long-term care insurance as a benefit for state employees. Factors inhibiting growth include product cost, on the demand side, and distribution mechanisms on the supply side (Cohen, 2003). Three strategies of governmental intervention to increase the number of people with private long-term care insurance have been contemplated: a) provide individuals with tax incentives that encourage purchase of long-term insurance policies by reducing the net price of such policies, b) encourage employer-based private long-term care insurance through tax incentives and through the federal and state governments serving as role models for private employers by providing governmental employees, retirees, and their dependents the opportunity to purchase insurance and c) waive some or all of the Medicaid asset depletion requirements for purchasers of qualified private long-term care insurance policies, allowing them to retain more of their assets and still qualify for Medicaid (Wiener, Tilly, & Goldenson, 2000).

The Connecticut Partnership for Long-term Care is a program of the State of Connecticut that works in alliance with the private insurance industry (Connecticut Partnership for Long-term Care, 2006). Under the Connecticut Partnership, private insurance companies competitively sell long-term care insurance policies that satisfy specific requirements. These policies offer benefits to pay for long-term care costs, as well as provide dollar-for-dollar protection of assets in the qualification for Medicaid in Connecticut. For individuals who have exhausted (or used at least some of) the benefits of a Partnership policy, the state will disregard some or all of their assets in determining Medicaid eligibility. Approximately 181,600 partnership policies have been sold in the four participating states (CA, CT, IN, & NY) that currently operate Partnership programs. The majority of partnership policies purchased offer comprehensive benefits that include coverage of nursing home stays and home care (Stone-Axelrad, 2005).

Note: In Connecticut, the number of individuals who purchased long-term care insurance in 2005 was 10,476, nearly double the number who purchased policies in 1994. As of December 31, 2005, there were 103,024 Connecticut residents with a private long-term care insurance policy in force. As of December 31, 2005, there were over 40,000 Partnership policies sold in Connecticut. Purchasers of Partnership policies range in age from 20-88 years old, with the average age at purchase being 58 years old; a total of 43,502 policies have been sold (CPLTC Report, 2006).

Medicaid

Medicaid is a joint federal/state insurance program that provides health care coverage for certain individuals and families with low incomes and resources who belong to one of the ‘categorically eligible’ groups (such as children, pregnant women, persons with disabilities, those receiving aid to families with dependent children and persons over age 65). Medicaid is the primary public source of funding for long-term care in the United States. In 2004, total federal and state Medicaid expenditures for nursing home care were $115 billion, representing more than 40 percent of all spending on nursing home care (Sommers, Cohen, & O’Mally, 2006). It is anticipated that Medicaid spending will grow faster than either Medicare or private spending, and by 2015, it is expected that Medicaid will pay for nearly half of all nursing home costs, compared with less than 45 percent in 2004 (Borger et al., 2006).

In 2003, 55 million persons were enrolled in the Medicaid program, three-quarters of whom were poor children and their parents, and pregnant women (Kaiser Commission on Medicaid, and the Uninsured, 2006c). However, most Medicaid beneficiaries incur relatively small average expenditures per person per year, with a small proportion incurring very large costs (Hoffman, Klees, & Curtis, 2006). Medicaid long-term care users accounted for 7 percent of the Medicaid population in 2002 but over half (52 percent) of total Medicaid spending. Among Medicaid enrollees using long-term care services, just over half (55 percent) were elderly, 34 percent were individuals under age 65 classified as disabled, and 11 percent were adults and children who qualified for Medicaid based on income or other eligibility pathways (Sommers et al., 2006). Three quarters of spending went toward long-term care, while the remaining 25 percent was devoted to acute care and other supportive services, such as inpatient hospital, prescription drugs, physician, rehabilitative and therapy services. Medicaid has become the primary payer of mental health services for low-income people and accounted for nearly 40 percent of all spending in the public sector on mental health in 2001 as compared to 21 percent in 1971 (Frank, Goldman, & Hogan, 2003). In 2003, Medicaid expenditures for mental health amounted to 1.8 percent of the long-term care budget, which was 36 percent of the total $266.1 billion Medicaid budget (Kaiser Family Foundation, 2004). Many states are making an effort to contain costs by reimbursement reductions and eligibility, but there is apprehension that these approaches will substantially decrease the resources needed by people with mental illness (Smith, Ramesh, Gifford, Ellis, Rudowitz, & O’Malley, 2004).

The majority of Medicaid funding of long-term care is paid to nursing facilities. The mandatory nursing facility benefit has created what is often characterized as an institutional bias in the Medicaid program. In 2003, Medicaid payments totaled $40.4 billion for 1.7 million beneficiaries using nursing facilities (excluding ICF/MR), for average annual expenditure per person of $23,880. The program paid $4.4 billion for 1.2 million beneficiaries receiving home care (with an average expenditure of $3,725 per home health care beneficiary) (Hoffman et al., 2006). However, in large part due to policy efforts to increase access to HCBS, the allocation of Medicaid funds has shifted in the past decade. For example, in 1992, total Medicaid LTC expenditures amounted to almost $39 billion, only 15 percent of which was for HCBS. By 2005, Medicaid long-term care expenditures had increased to $94.5 billion, and the portion that funded HCBS had increased to 37 percent (Kaiser Commission on Medicaid and the Uninsured, 2006a). The rate of managed care participation is higher in Medicaid than in the Medicare program. In 2005, nearly 63 percent of Medicaid enrollees received benefits through managed care systems, with about 40 percent in HMOs (Centers for Medicare and Medicaid Services, 2005).

States administer their Medicaid programs under broad federal guidelines. Although states must provide coverage for certain minimum services (such as hospital and physician services, nursing facility services, skilled home health care, and laboratory services) to qualified individuals, they also have considerable discretion in defining eligibility criteria and the amount, duration and scope of covered services beyond these federal mandates. States may choose to provide a range of up to 34 optional benefits; there is substantial variation in Medicaid eligibility and coverage across the states. Medicaid provides community-based long-term care services under three different coverage choices: home health care, optional personal care services (provided in 32 states), and home and community-based waiver services (254 waivers) (Elias, 2006). Iowa is the initial state to receive federal approval to add home and community-based services as a permanent feature of its Medicaid plan, eliminating the need for repeated requests for time-limited waivers (U. S. Department of Health and Human Services, 2007). States can provide home and community-based services to people at risk for requiring institutional care and can specify certain groups of people, such as those who are frail and elderly, those who have physical disabilities, or those with HIV/AIDS (Elias, 2006).

In SFY 2006, the Connecticut Medicaid program spent $2.227 billion on long-term care. Of that expenditure, 32 percent was spent on home and community-based services and 68 percent on institutional care. Medicaid long-term care expenses account for 56 percent of all Medicaid spending and 14 percent of total expenditures for the State of Connecticut (Connecticut Long-Term Care Planning Committee, 2007). Resources devoted to long-term care vary widely across states. In 2004, New York spent $833 in Medicaid long-term care costs per state resident, compared to Utah and Nevada, which each spent about $100 per state resident. Medicaid nursing home spending per elderly beneficiary varied from a high of nearly $15,000 in Connecticut to about $2,600 in California and Maine in 2001. Spending on home and personal care ranged from a high of $7,145 per disabled enrollee in Connecticut to less than $250 in the District of Columbia, Hawaii, and Mississippi in 2001 (O'Brien, 2005).

Medicare

Medicare is the federal health insurance program that serves all persons age 65 and over, regardless of income or medical history. The program was created in 1965, and in 1972, was expanded to provide insurance to persons under age 65 with permanent disabilities. Currently, there are nearly 43 million Americans enrolled in Medicare, 15 percent of whom are under age 65 and permanently disabled (Hoffman et al., 2006). By 2030 Medicare is expected to serve 77 million people, or one out of five Americans (Moon, 2006).

Part A, known as Hospital Insurance, covers inpatient hospital services, limited skilled nursing care and hospice. Part B, also called Supplemental Insurance, covers services provided by physicians and other health care providers, outpatient services and certain medical equipment. The Medicare Prescription Drug, Improvement and Modernization Act of 2003 created a voluntary prescription drug benefit through Part D, implemented in 2006.

Medicare coverage for long-term care is extremely limited. The program pays for nursing home or post-acute stays for no more than 100 days for people recently discharged from a hospital. For homebound persons needing part-time skilled nursing care or physical therapy services under a physician's direction, Medicare coverage is focused on rehabilitation, paying for limited home health care, including personal care services provided by home health aides. Medicare spending accounted for slightly over 21 percent of total long-term expenditures in the U.S. in 2004 (Smith et al., 2006).

Medicare accounted for 38 percent of home health spending in 2004, up from 26 percent in 1999. This rapid growth is in part a result of rapid growth in home-based hospice services, which grew an average of 27 percent per year between 2000 and 2004. In 2000, these services accounted for 29 percent of Medicare spending for home health, but by 2004 they had reached 39 percent, or $6.5 billion (Smith et al., 2006).

Medicare beneficiaries who have low incomes and limited resources may also qualify for insurance coverage through the Medicaid program. Individuals enrolled in both the Medicare and Medicaid programs are known as 'dually eligible.' Approximately 18 percent of individuals eligible for Medicare are also eligible for Medicaid (Kaiser Commission on Medicaid and the Uninsured, 2006a). In 2005, almost 7.5 million older Americans and younger persons with disabilities were dually eligible (Holahan & Ghosh, 2005). These individuals represent only 14 percent of Medicaid beneficiaries, yet 40 percent of all Medicaid expenditures are made on their behalf. While Medicare covers basic health services such as physician and hospital care, dually eligible persons rely on Medicaid to pay for Medicare premiums and cost-sharing to cover needed benefits. Additional services might include nursing facility care beyond the 100 days paid for by Medicare, prescription drug costs, eyeglasses and hearing aids.

Other public funding sources

Federal public sources of funding for home and community-based long-term care include the Older Americans Act, which allocates funding to states based on the state's proportion of persons aged 60 and older. These funds support a variety of services and supports, such as personal assistance, information and referral, congregate meals and adult day care (Miller, 2005). Social Services Block Grant funding is awarded to states based on population; roughly 18 percent of funding in 2000 was targeted toward services for older adults and younger persons with disabilities (Miller, 2005). Finally, state-funded home and community-based long-term care programs are generally used to complement Medicaid funded programs, in which states determine functional and financial eligibility criteria as well as service scope and coverage (Wiener, Tilly & Alecxih, 2002; Walker, Bradley, & Wetle, 1998).

The "woodwork effect"

The "woodwork effect" refers to induced demand for services by people living in the community as a result of expanded home and community-based benefits. The theory suggests that paying for supportive services that would otherwise be provided by family or friends will draw people "out of the woodwork," resulting in substantial demand and increasing overall costs to the system. Consequently, any savings realized by providing less-expensive home and community-based care would be more than offset by the increased number of people who would take advantage of the benefits (Desonia, 2003; Doty, Benjamin, Matthias, & Franke, 1999). There is an underlying assumption that the current system does not fully address the community-based long-term care needs of those requiring such services (National Council on Disability, 2004).

Evidence regarding the magnitude of the woodwork effect is mixed and has changed in recent years. Early research on the cost-effectiveness of home and community-based services found that expanding access to these services did not reduce total long-term care spending and in some cases increased total costs (Doty, 2000; Kemper, Applebaum, & Harrigan, 1987; Weissert, Cready, & Pawelak, 1988; Weissert & Cready, 1989). More recent research suggests that home and community-based programs may be cost-effective alternatives to nursing homes, as states have improved targeting services to those at greatest risk of nursing home admission and have developed approaches to manage the woodwork effect (Meng, Friedman, Dick, Wamsley, Eggert, & Mukamel, 2006; Polivka, 2001). Results from a recent national study of the relationship between state-funded HCBS and nursing home admissions indicate that increased availability of HCBS funds does not result in a woodwork effect (Muramatsu, Yin, Campbell. Hoyem, Jacob, & Ross, 2007). Specifically, higher HCBS expenditures related to lower nursing home admission rates *only* among seniors without children, thus implying that adult children are providing unpaid care for their parents regardless of the state's generosity of HCBS funding.

There are a number of ways in which states may minimize the potential for woodworking. Eligibility can be limited to those who meet clear criteria related to need (functional capacities), resources (income and assets), and support network (availability of caregiver) and whose cost of care in the community would not exceed that of nursing home care (Chappel, Havens, Hollanger, Miller, & McWilliam, 2004; Polivka, 2001). The Cash and Counseling Demonstrations have required that the ratio of the number of new clients to the number of current clients is not to exceed an historical average. In an integrated system, funders may be able to obtain efficiencies by substituting community care for residential care, and therefore, limit, or negate, any woodwork effect (Chappel et al., 2004).

G. Conclusion

This review of scientific and policy literature is intended to provide a background for understanding the findings of the Connecticut long-term care needs assessment studies. Major issues examined through the needs assessment were mandated by Public Act 06-188, An Act Concerning Social Services and Public Health Budget Implementation Provisions. This statute required the state to contract for a comprehensive needs assessment of the unmet long-term care needs in the state and project future demand for such services. Major components include surveys of long-term care providers, surveys of Connecticut residents, targeted surveys of Connecticut residents with disabilities and those living in supported living settings, an analysis of the Long-Term Care Ombudsman program, and analysis of long-term care rebalancing in Connecticut.

III. Connecticut Resident Survey

A. Introduction

A critical piece of Connecticut's long-term care needs assessment gathered relevant information directly from people who live in Connecticut. This information includes the community-based long-term care services Connecticut's citizens are currently using, the services they expect to need, how prepared residents are to obtain these services, and their preferences and expectations for care.

B. Methodology and analysis

The primary method of data collection was a self-administered, written survey mailed directly to a sample of Connecticut residents. Mailed surveys allow for the greatest number of potential respondents to be contacted; such a broad reach is necessary when trying to include a large number of respondents from across the state. This was augmented by telephone interviews, survey packets distributed to numerous organizations, and a web-based survey. In order to raise awareness and provide opportunity for input from residents across the state, a widespread publicity campaign was conducted, including television appearances, radio interviews, newspaper articles, postings on various web sites, broadcast emails, announcements at multiple events across the state, and word of mouth.

Instrument development

Survey development was informed by a comprehensive review of the long-term care and disability scientific and policy literature, as well as an examination of surveys used by other states. The Long-Term Care Advisory Council provided significant input in this process, especially regarding areas of focus or concern. Questions were developed using information from all of these sources, along with ongoing input from the Advisory Council and the literature. Emphasis was given to those issues, which would help Connecticut assess the needs of its residents for long-term care services.

A twelve-page survey booklet was developed with the following major topics: current and future plans, health and functional status, long-term care service use and unmet need, social support, employment and transportation, demographics, general information, financial resources, and caregiving (see Appendix C for a complete copy of the general survey). The instrument comprised both quantitative and qualitative questions, with space given so the respondents could fully describe their experiences or views. Below is a brief explanation of the topics covered in each section of the general resident survey:

- Current and future plans addressed current living situation, future living arrangements, services needed to age in place, and questions regarding the provision and payment of long-term care services.
- Health incorporated overall physical and mental health, physical functioning (Activities of Daily Living, Instrumental Activities of Daily Living), use/need of assistive devices, and disability status.
- Employment and transportation focused on employment status and transportation concerns.

- Community long-term care services looked at service use and unmet need for a variety of community-based long-term care services. Questions also addressed difficulties obtaining services, information sources, and satisfaction. Three vignettes explored preferences regarding management of paid services. Finally, an open-ended question asked for suggestions regarding services needed for older adults or people with disabilities.
- Social support focused on a person's immediate support system.
- General information, or demographics, asked for zip code, age, gender, language, race, ethnicity, and education.
- Financial resources focused on income and assets, as well as financial fitness.
- Caregiving explored a person's caregiving responsibilities and the service needs of the care receiver.

The survey included a question asking if the person filled out the survey him/herself, and if not, who assisted in its completion (e.g., spouse, adult child, paid assistant, etc.). It ended with one final open-ended question asking if the person would like to add anything.

People with disabilities survey

To fully address the experiences and needs of people with disabilities, a second survey was designed. Additional questions and responses were developed to further explore issues such as assistive technology, transportation, and accessibility. To make space for these additional questions, the caregiving section was reduced to one question in this survey. The result was a twelve-page survey booklet specific to people with disabilities which addressed the following areas of interest: current and future plans, health, employment and transportation, community long-term care services, social support, general information, and financial resources (see Appendix D for a complete copy of the disability survey).

Research sample

Although often associated with older adults, long-term care services may be needed by anyone, regardless of age. To help plan for the future, as well as report the current status of those who need assistance, middle-aged residents were contacted along with older adults, as well as people with disabilities of all ages. A large sample was chosen for each group so several stratifications could be performed with enough power for accurate analysis. Three distinct groups of residents were identified for the randomized mailing survey: adults age 61 or older, baby boomers (age 42 to 60), and residents with disabilities of all ages. The research design was developed to examine the long-term care needs and plans of all three groups, with a total sample size of 15,500:

- Older adults born in 1945 or earlier (n=5,250)
- Baby boomers born in 1946 – 1964 (n=5,250)
- People with disabilities of any age (n=5,000)

Contact information for the older adult (age 61 or older) and baby boomer (age 42-60) residents was obtained using voter registry and Department of Motor Vehicles (DMV) records, including DMV issued non-license identification cards. Two groups of 5,250 residents each, one born in 1945 or earlier and one born in 1946 to 1964, were randomly chosen from both sources. Using zip codes, the technique of over-sampling was used to increase the number of African American and Latino residents in the sample.

Effort was made to include people with all types of disabilities, including physical, mental illness, and intellectual challenges. Residents with disabilities were identified from participation in one of several state programs. Surveys were mailed to randomly selected participants in one of the six home and community-based Medicaid waivers available in Connecticut: Connecticut Home Care Program for Elders (Elder), Personal Care Assistance (PCA), Acquired Brain Injury (ABI), Katie Beckett (KatieB), Individual/Family Support, and Comprehensive (the last two were combined into one "DMR waiver" group). Individuals were sampled from the DMR waiting list (DMR Wait) as well as those actively receiving services. Surveys were also sent to randomly chosen participants in the state-funded Community Based Services (CBS), Medicaid for the Employed Disabled, and the Bureau of Rehabilitation Services Benefits Counseling program (individuals in these last two groups were combined into one "BRS" group). A random sample of participants was taken from most of the waivers or programs; however, due to their small total numbers, all participants from the ABI, PCA, and KatieB waivers were sent surveys.

In all, 5,000 people with disabilities were chosen from these sources to participate in the mailed survey. Department of Mental Health and Addiction (DMHAS) clients were encouraged to complete a survey by their providers, as their individual contact information was not available. In addition, many individuals with mental health disabilities received a randomly mailed survey because they participate in other Department of Social Services programs.

Recruitment

Each of the 15,500 residents assigned to the mail survey received a personalized introductory letter, a survey booklet, and self-addressed, postage paid return envelope. The introductory letter included an explanation of the reason for the survey, how the information would be used, a guarantee of confidentiality, and a contact name and number for any questions. In addition, a sentence in Spanish gave a number to call to receive the survey in Spanish. An incentive was included in the letter: all participants who sent in a completed survey would have a chance to win one of fifty $25.00 gift certificates. To keep the survey anonymous, a card with an identifying number was sent with the survey to be sent back if the person wanted to be in the drawing. This way no identifiers were put on any survey, and the responses for the mail survey were kept anonymous. Respondents also had the option of checking or leaving blank a separate question on the response card asking if the person was willing to be contacted for further research. Following standard research methodology, after approximately four weeks, a second packet containing a personalized reminder letter, survey, and return envelope was sent to all those for whom a response card had not yet been received. These methods are all well-documented strategies shown to increase the response rate to a mail survey (King, Pealer, & Bernard, 2001; Yammarino, Skinner, & Childers, 1991).

As the information received would inform statewide long-term care policies for the next 30 years, it was important to be able to look at the information received by group. To do so without using individual survey identifiers, the survey booklet was printed in different colors, with each group sent a different colored survey. A green general survey was sent to the 5,250 residents age 61 or older, while the 5,250 baby boomers received a blue general survey, and the 5,000 people with disabilities received a yellow disability survey. Responses from the different waivers and programs used for the yellow survey were tracked using anonymous color-coding on the return envelope. Both of these techniques allow the information to be much more useful for planning purposes without compromising respondents' confidentiality.

In order to reach a greater number of Latino residents, the general survey and letter of introduction were translated into Spanish. Two bilingual Latina research assistants telephoned any nonrespondents they identified as Latino. The researchers offered to complete the survey on the phone or to mail them a survey in either language. In addition, the internet survey was posted in both English and Spanish. For residents with vision difficulties, large print surveys in both languages were also available. Telephone calls were used to reach more African American or Black respondents as well. Using the 2000 U.S. Census report, any non-respondents from the top ten cities or towns with the highest number of African American residents were called. Interviewers offered potential respondents the opportunity to complete the survey with them over the telephone or to mail them another copy. Unfortunately, telephone numbers were not included in the contact information from several of the targeted cities or towns. Still, calls were placed to non-respondents in Hartford, New Haven, and several other towns.

Additional statewide distribution of the survey

In addition to the surveys mailed to the 15,500 randomly chosen respondents, the survey was made available to the public as a general interest survey. Multiple approaches were utilized to reach residents of all ages, diverse ethnic and racial backgrounds, and different geographic regions. All forms of media were used to publicize the survey, including television, radio, newspapers, broadcast emails, and the internet. The web-based survey was easily accessible via a direct link or through several websites, including the Commission on Aging, the University of Connecticut, and the AARP. Announcements at statewide events, newsletters, and word of mouth also helped publicize the survey across Connecticut.

Collaborating with various state departments, agencies, commissions, and organizations, such as Community Action Agencies, African American Affairs Commission, and Area Agencies on Aging, DMHAS, and DMR, helped the survey reach even more residents. Often the parent organization or department sent notices to their member organizations or providers encouraging them to make the survey available to their clients or members. This was followed by sending a packet of multiple surveys to the member organizations. These survey packets were composed of at least 25 survey booklets, each with a self-addressed, postage paid envelope and letter of introduction. The disability survey was sent to organizations that primarily serve people with disabilities, and both English and Spanish survey packets were sent to organizations who serve any Latino members or clients. This technique was used successfully with senior centers, mental health providers, and other provider organizations to reach many state residents who would not have otherwise completed a survey.

To distinguish these surveys from the randomly mailed sample, the general survey was printed on a gray booklet and the disability survey was printed on an ivory booklet. The gray booklet was used for the most widespread distribution. The ivory booklet was sent to organizations or providers that primarily serve people with disabilities.

Response rate

At time of report, 6,268 surveys were completed: 5,059 by mail, 34 by phone, and 1,175 online. This resulted in 4,700 general surveys and 1,568 disability surveys. Seventy of the general surveys were completed in Spanish.

Randomized mail survey response rate

A total of 4,039 surveys were received from the randomized mailing. Older adults had the greatest response (1,607 surveys), followed by people with disabilities (1,278 surveys), and then baby boomers (1,154 surveys). Adjusting for wrong addresses, deceased, non-English/Spanish speaking, or other reasons for ineligibility results in an overall response rate of 29% for all three groups combined. When examined individually, the response rates for each group vary from 24% - 34% (see Table III-1). Although under 33%, the overall response rate is still well within the mail survey range of 10% to 60% (Chiu & Brennan, 1990; Harbaugh, 2002). While considered an important group to include, it was expected that the response rate for baby boomers would not be as high as that for older adults. The rate of response for people with disabilities would be affected in a similar manner given their overall younger age. Still, the sheer number of returned surveys provides a large enough sample for reliable analysis.

Table III-1. Response rates

	Older adults (Green)	**Baby boomers (Blue)**	**People with disabilities (Yellow)**
Surveys mailed	5250	5250	5000
Surveys completed	1607	1154	1278
Wrong address	442	457	346
Ineligible	23	13	16
Deceased	76	2	6
Refused	16	8	18
Response rate	**34%**	**24%**	**28%**

Response rate by waiver or program

Eight programs or waivers were used for the people with disabilities mailed survey. Response rates for each specific waiver or program ranged from 21% to 38% (see Table III-2 below).

Table III-2. Response rates by waiver or program for people with disabilities*

Waiver or program	**Surveys mailed**	**Number wrong address, ineligible, deceased**	**Surveys completed**	**Response rate**
ABI	503	39	129	**28%**
PCA	770	20	211	**28%**
CBS	560	27	156	**29%**
Elder (CHCPE)	1,000	91	256	**28%**
Katie B	163	5	60	**38%**
DMR Active (IFS & Comprehensive)	900	39	181	**21%**
DMR IFS Wait List	100	7	30	**32%**
BRS Combined	1,004	147	236	**28%**

*The waiver or program was not identifiable for 19 people yellow surveys.

Statewide and internet surveys

Well over two thousand surveys were also completed by the general public. The statewide distribution of both the general and disability surveys yielded 764 general surveys and 290 disability surveys. In addition, 1,175 people completed the web-based survey. Overall, of the total surveys received, 4,039 were from the randomized mailing, 1054 surveys from the statewide distribution of surveys, and 1,175 from the internet (total n=6268).

Comparability of research sample

Respondents vs. random sample

To assess generalizability of the survey results, we compared those who returned surveys to the entire sample of those who received surveys in the randomly selected group of Connecticut residents. For older adults, born in 1945 or earlier, respondents did not differ substantially from the random sample population in mean age (71.5 vs. 72.3), gender distribution (46% male vs. 48% male), or geographic distribution throughout the state. For baby boomer respondents (born 1946 or later), geographic distribution also closely tracked that of the random sample, and mean age was similar (52.0 vs. 50.1). However, among the baby boomer respondents, the respondent sample has a higher percentage of women (59%) than the total sample who received the mailed surveys (50%).

For the people with disabilities survey, gender and age of persons in the random sample were not available. However, geographic distribution of respondents is similar to that of the total group who received the randomized mailed survey.

Respondents vs. United States census 2005

For purposes of comparing survey respondents to the Connecticut population as a whole, respondents from both the baby boomer group (age 42-60) and older adult group (age 61+) were compared to United States 2005 census data regarding the Connecticut population of the same age. Table III-3 below compares survey respondents in both groups to similar age cohorts in the general Connecticut population by gender, education, race, disability status, and household income. Overall, respondents do not differ significantly from the Connecticut population. Specifically, survey respondents were a little more likely to be female and Caucasian, with higher educational attainment and rates of disability but slightly lower household incomes.

There was a lower percentage of male respondents in the 42-60 age group compared to the general population (41% vs. 49%), but a slightly higher percentage of male respondents in the 61+ age group (46% vs. 43%). The greatest disparity between respondents and the general population is in educational attainment. Ninety-eight percent of baby boomer respondents and 89 percent of older adults have a high school diploma, compared to 92 percent and 78 percent of the general population in those age categories. Similarly, more baby boomer respondents (58% vs. 39%) and older adults (41% vs. 24%) have a 4-year college degree.

In both age groups, three percent of respondents were Black/ African American, compared to seven percent of the baby boomer census population and six percent of the older adult census population. Hispanic/Latino older adult respondents match the general population at four percent each, but among baby boomers, respondents were five percent Hispanic/Latino compared to eight percent of the population.

There are slightly higher rates of reported disability among survey respondents age 42-60 than among the same age group in the general population. This may in part be due to the definition of disability used in the survey, which differed somewhat from the census definition. Household income was slightly lower for younger respondents than for the general population.

In sum, the survey respondents have higher levels of education the general population in Connecticut, and the sample likely under represents African American or Black respondents. On all other features, the survey respondents closely reflect the larger population of Connecticut in these age groups, and the results may be generalized to Connecticut as a whole.

Table III-3. Comparison of survey respondents to Connecticut population (percentages)*

	Survey respondents 42+	CT population 42+	Survey respondents 42-60	CT population 42-60	Survey respondents 61+	CT population 61+
Male	44	46	41	49	46	43
Female	56	54	59	52	54	57
High school diploma	93	86	98	92	89	78
4-year degree	48	33	58	39	41	24
Caucasian	92	88	91	86	92	91
Black/African American	3	7	3	7	3	6
Hispanic/Latino	4	6	5	8	4	4
With disabilities	22	17	14	10	28	29
Monthly household income less than $3000	31	24	17	14	41	40
Monthly household income $3,000-4,999	22	19	20	17	24	23
Monthly household income $5,000 and above	47	58	63	70	35	38

* CT population estimates based on analysis of the 2005 American Community Survey (ACS) PUMS file by Cornell Disability Statistics RRTC. ACS disability estimates are limited to those reporting Sensory, Physical Mental, and/or Self-care disabilities, which were judged to be the best match for this study's disability definition.

Random vs. nonrandom respondents

To determine the applicability of combining the random general surveys (green and blue) with the nonrandom completed surveys (gray and web), these two groups were compared across age, ethnicity, income, disability, and region. On three of the five variables, the differences were small. For example, rate of disability between the two groups is very similar (do not have a disability: 79% random vs. 78% nonrandom). Income does not vary much on the low end (less than $3,000 monthly: 32% random vs. 30% nonrandom). However, a greater percentage of the random respondents have a higher income (Over $5,000 monthly: 56% random vs. 49% nonrandom). There was also a small increase in the percent of Latino nonrandom participants (3% random vs. 7% nonrandom), although this difference acts to balance out the percentage of Latino participants in the total sample.

The nonrandom respondents are significantly younger than those randomly chosen, with the greatest difference in those under age 42 (0% random vs. 10% nonrandom). This can be expected, given that the random sample was deliberately sent to only those age 42 and over, and the nonrandom sample was open for anyone to complete. A regional difference was noted as well, with significantly more of the nonrandom respondents coming from the Northern region (36% random vs. 53% nonrandom, p<.00). This is probably due to a location effect, given the research team and Connecticut government organizations are located in the Northern region and that word of mouth was strongest in that area. As there were few differences in the results when specifically analyzed by the three regions, this difference is not considered to be as important.

Analysis

All data were entered into Microsoft Access tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) information. After data collection was complete, the data were converted to SPSS version 14.0, a statistical software package designed for both simple and complex analysis. Data were analyzed question by question, with a series of basic tests computed: frequency, average, and percentage.

A three-step statistical strategy was employed in this study. First, a preliminary analysis determined the distribution of the sample across the independent variables (survey items) in the study. The study sample was then further examined by six different groups, using the following dependent variables: disability or activities of daily living (ADL) status, age, income, ethnicity, and geographic region. Next, data were analyzed question by question, with a series of basic tests computed: frequency, average, and percentage. The variables were then simplified by eliminating extraneous variables and by reducing the number of divisions of multi-categorical variables. A comparison of the response distribution both within and between groups was performed. Differences between groups were analyzed using chi-square and one-way ANOVA for categorical and continuous data, respectively.

Several types of data response errors occurred that required transformations prior to analysis. One of the most common errors was encountered in the analysis of skip questions. Individuals who answered “no” to a skip question were theoretically expected to skip to the next designated section. However, several respondents to the mail survey provided quantitative data for questions that should have been skipped. Mirroring analysis conducted in other studies, items embedded within skip questions that were inappropriately answered were usually re-coded to missing values. This process discarded extraneous or clearly inaccurate data which would otherwise skew the results.

Responses to all qualitative or open-ended questions were entered in full into Microsoft Access for systematic analysis. Content from these open-ended questions were analyzed using standard qualitative analysis techniques (McCraken, 1988). Data from each question was transcribed and analyzed line by line in order to identify and interpret each individual’s response. Two researchers independently analyzed the responses for each question, reaching a consensus if interpretations were different. Major concepts or areas of interest supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each. Percentage of response was determined by dividing the number of times any particular theme was mentioned by the total number of responses.

C. Community services: Current use and unmet need

Both the general survey and the disability survey asked respondents to indicate whether they currently use or have a need for any of a list of eight paid, community-based long-term care services that help people live in the community. These services include home health aide, homemaker service, visiting nurse, home-delivered meals, dial-a-ride or other transportation service, friendly visitor service, care management, and adult day program. The disability survey asked about current use of and need for four additional long-term care services: personal care assistance, vocational rehabilitation, job coaching, and money management. It is important to note that these questions concern only formal paid services. They do not cover unpaid services of a similar nature received from family or friends. It is also important to stress that the services are those that allow people to live in the community, and do not include institutional services. (Additional questions concerning handyman services and lawn or snow services were asked in both surveys, but they are not considered long-term care services for purposes of this analysis.)

People who indicate either “using now and receiving enough” or “using now but need more” to at least one of the listed services are grouped together and analyzed as “current users.” People who indicate either “not using now but do need” or “using now but need more” to at least one service are grouped together and analyzed as “people with unmet needs.” There is some overlap between the groups because those who answered “using now but need more” to at least one service are both current users and people with unmet needs.

Results of this analysis reveal that people with disabilities demonstrate both high current usage of long-term care services and high rates of unmet need. The people who answered the general survey have far lower rates of both current usage and need for long-term care services, although at higher ages both are still significant.

Current long-term care users

Seventy-three percent of people who answered the disability survey indicate that they are current users, compared to only eight percent of those who answered the general survey. A breakdown by age (see Table III-4 below) indicates that for people with disabilities, current long-term care service usage increases steadily with age. Current use ranges from a low of 66 percent for people with disabilities under the age of 42, to 96 percent of those 85 and older.

For people who answered the general survey, there is a slightly different age pattern. Whereas ten percent of those under age 42 are current users, only four percent of baby boomers and six percent of those age 61 to 74 are. Current usage then doubles to 13 percent for those age 75 to 84, and nearly triples to a third (33%) of those 85 and over.

It is important to note that the randomly selected group that received the general survey included only people age 42 and above (baby boomers and older adults). The general survey results noted below for people under age 42, therefore, represent a small number (n=210) of people and come only from internet and paper surveys available to the general public of any age. Unlike the results of the general survey for age groups 42 and above, they cannot be generalized to all Connecticut residents in this age group.

Table III-4. Current long-term care use by type of survey and age (percentages)

Age	Disability survey: Currently using LTC (percent)	General survey: Currently using LTC (percent)
<42	66	10*
42-60	69	4
61-74	81	6
75-84	92	13
85+	96	33
All ages	73	8

*This is not a representative sample, as it only includes respondents from the web-based survey.

People with unmet long-term care needs

There is a similar pattern for people with unmet needs, with 57 percent of those who answered the disability survey indicating a need for more long-term care services, compared to nine percent of people who answered the general survey. The age pattern for people with disabilities who have unmet needs is different from people with disabilities currently receiving services (see Table III-5 below). For these people, unmet need decreases somewhat with age, ranging from a high of 63 percent in the under 42 age group to a low of 40 percent of those 75 to 84 (though slightly higher at 42% for those 85 and older). For people who completed the general survey, unmet need is concentrated in the younger and older age groups (12% of under 42, 14% of 75 to 84, and 27% of 85 and over), while only six percent of those 42 to 74 have unmet long-term care needs. In a pattern similar to that for current use, unmet need doubles from age 61-74 to age 75-84, and doubles again for age 85 and over, as more than a quarter of the 85 and over population have unmet needs.

Table III-5. Unmet long-term care need by type of survey and age (percentages)

Age	Disability survey: Percent with unmet LTC needs	General survey: Percent with unmet LTC needs
<42	63	12*
42-60	60	5
61-74	52	7
75-84	40	14
85+	42	27
All ages	57	9

*This is not a representative sample, as it only includes respondents from the web-based survey.

Additional detail concerning current usage and need for long-term care services can be found in Section E below, which analyzes survey results by type of service, income, ethnicity, and region as well as age and disability status.

D. Future demand

Many factors will affect future demand for various long-term care services. Life expectancy is increasing, which could lead to more age-related disabilities. On the other hand, people are living more healthy lives at older ages. Medical science continues to seek treatment for many causes of age-related and other disabilities. A significant breakthrough in the prevention or treatment of Alzheimer's disease, for example, could dramatically decrease the need for many long-term care services. The advent of a previously unknown disease, such as AIDS, could have the opposite effect. Moreover, the trend toward rebalancing institutional and home and community-based services will create greater demand for community services even in the absence of population growth.

Demand for community-based services

Without accounting for unexpected medical developments or predicting the rate at which rebalancing will occur, however, it is possible to project future demand for community long-term care services in the general population. This is accomplished by assuming that for each age group, the same percentage of the population expressing a current demand for services in the general survey will require these services in the coming years. The size and nature of the random sample allows such generalization to the entire Connecticut population. Projections by disability cannot be accomplished in the same manner since the sample used for the disability survey was not random, but consisted of people participating in state programs and Medicaid waivers.

The U.S. Census Bureau has produced population projections by age and gender through the year 2030 for each state, based on the results of the 2000 census. These projections make the general assumption that recent state-specific trends in fertility, mortality, domestic migration, and international migration will continue. Table III-6 below displays population projections for Connecticut in the approximate age groups targeted in the general survey. It is noteworthy that while the overall state population is projected to grow only five percent between 2006 and 2030, there is negative projected growth in the 40 to 59 age group, but greater than 50 percent projected growth in all age groups over 60. Much of this phenomenon is due to the movement of the baby boomer cohort into the older age groups. However, since even the oldest boomers will turn age 84 in 2030, the significant increase in the 85 and older group reflects other factors such as increasing longevity. The State's median age will increase by more than two years over the period 2006 to 2030, from 38.9 to 41.1.

Table III-6. Connecticut population projections for selected age groups and years to 2030

Age Group	Projection 2006	Projection 2010	Projection 2015	Projection 2020	Projection 2025	Projection 2030	Pop. Growth 2006-2030	Percent Change 2006-2030
Total	3,519,930	3,577,490	3,635,414	3,675,650	3,691,016	3,688,630	168,700	5
40 – 59	1,052,235	1,057,286	1,017,539	949,527	905,382	901,639	(150,596)	(14)
60 – 74	393,560	448,837	514,436	576,157	607,589	602,154	208,594	53
75 – 84	176,194	168,674	167,235	193,099	236,880	266,521	90.327	51
85+	82,399	93,698	102,288	105,584	112,044	132,440	50,041	61
Median Age	38.9	39.6	39.6	39.7	40.3	41.1		

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

Using the population figures for 2006 and 2030, future community long-term care service demand can be viewed in three ways (see Tables III-7a,b,c below). Using four age groups, Table III-7a first shows current use of community-based long-term care services reported by respondents to the general survey, expressed as a percentage of all answers to that question. These percentages of service use are then applied to the Connecticut population in 2006 and the projected state population in 2030. The resulting figures compare the number of individuals who use or will use services in those two years. They do not take into account the extent of use, only the number of people who are or will be users. Table III-7b does the same for current and future unmet long-term care need as expressed in the survey results.

Since there is some overlap between the categories of people who indicate they currently use long-term care services and those who have an unmet need for additional services, Table III-7c calculates total demand for long-term care services by including all people who either currently use or have an unmet need for services (or both). The projections in Table III-7c may be the most useful way to view future demand for planning purposes. This table shows total demand for community long-term care services, regardless of whether the need is being met by state programs or paid personal and professional caregivers. The projections in Tables III-7a and b are relevant only to the extent that there is no change in propensity to meet community service needs between 2006 and 2030. Table III-7c indicates that the number of people who need community long-term care services will grow by 28 percent from 2006 to 2030, from approximately 188,000 to 240,000.

Table III-7a. Growth in <u>use</u> of long-term care services for ages 40+, 2006 to 2030

Age	2006 Current LTC Use	2006 CT Population	2006 Current LTC Users	2030 CT Population	2030 Projected LTC Users	Percent increase 2006-2030
40-59	4%	1,052,235	42,089	901,639	36,066	(14)
60-74	6%	393,560	23,614	602,154	36,129	53
75-84	13%	176,194	22,905	266,521	34,648	51
85+	33%	82,399	27,192	132,440	43,705	61
		1,704,388	**115,800**	**1,902,754**	**150,548**	**30**

Table III-7b. Growth in <u>unmet need</u> for long-term care services for ages 40+, 2006 to 2030

Age	2006 Current Unmet Need	2006 CT Population	2006 Current Unmet Need	2030 CT Population	2030 Projected Unmet Need	Percent increase 2006-2030
40-59	5%	1,052,235	52,612	901,639	45,082	(14)
60-74	7%	393,560	27,549	602,154	42,151	53
75-84	14%	176,194	24,667	266,521	37,313	51
85+	27%	82,399	22,248	132,440	35,759	61
		1,704,388	**127,076**	**1,902,754**	**160,304**	**26**

Table III-7c. Growth in <u>total demand</u> for long-term care services for ages 40+, 2006 to 2030

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

Demand for community-based services for people with disabilities

Projections for future demand for services can be made if one has a randomized sample, such as the sample used for the general survey. The survey for people with disabilities, however, was mailed to a purposeful sampling of people with disabilities being served by a state-funded service or waiver program, or on a waiting list for services. This methodology creates results that cannot be generalized to all Connecticut residents with disabilities. As one might expect, the overall rates of service use and service need of this sample were higher than the general population. As a result, their service use or need cannot be used to extrapolate service use or need for other people with disabilities in Connecticut because they are not representative of this group. Respondents from the general survey who self-identified as having a disability create a slightly more random group. However, these results are also very limited in their ability to project future need of all people with disabilities, as this survey was sent only to those age 42 and older, and care was taken so that anyone who was to receive the disability survey was not mailed a general survey.

The U.S. Census numbers can be used as an approximation of the current number of people with disabilities in Connecticut. This number is probably conservative, as the definition of disability used by the U.S. Census does not include people with some types of mental illness. Using the numbers from the Census, one can estimate the future number of people with disabilities living in Connecticut, but without more information these projected numbers cannot be used to predict overall service use or need (see Table III-8).

An issue brief with more detailed information about those who completed the survey for people with disabilities, including differences by waiver or type of disability, will be prepared for release at a future date.

Table III-8. Projection of non-institutionalized persons with disabilities: 2005 – 2025

Age	2005	2025	2005 / 2025 Increase	Percent increase
5 - 20	44,499	43,767	(732)	(2)
21 - 64	202,563	203,809	1,246	1
65+	155, 307	253,825	98,518	63
	402,369	**501,401**	**99,032**	**25**

Source: Office of Policy and Management based on Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005 and U.S. Census Bureau, American Community Survey, disability.

Demand for institutional services

The needs assessment survey for Connecticut citizens focused on current and future use of community or home-based services, rather than institutional long-term care. However, future demand for institutional services may be estimated based on other data gathered by the State and the U.S. Census Bureau.

Connecticut has collected demographic and other data for nursing facility residents from 1997 to the present. The State Annual Nursing Facility Census provides aggregate information on the status of nursing facilities and their residents for September 30th of each year (State of Connecticut, 2006). This data covers residents from both skilled nursing facilities i.e., chronic and convalescent nursing homes) and intermediate care facilities (i.e., rest homes with nursing supervision). As of September 30, 2006, there were a total 27,689 individuals residing in 246 Connecticut nursing facilities. Almost half of all nursing facility residents are age 85 or over (48%), while eleven percent are under age 65 (see Table III-9).

The U.S. Census Bureau population projections discussed in the previous section may be used to estimate the number of future residents who would need care in a nursing facility (U.S. Census Bureau, 2005). Essentially, each discreet age cohort of nursing facility residents is multiplied by the projected U.S. Census percentage change. These rates of changes, however, must be adjusted to take into account the current decline in the nursing facility population. From 1999 to 2006, the number of nursing facility residents has fallen by seven percent. However, this overall trend has not been an even decline, but has varied from year to year. Based on the most recent data available from the Connecticut Annual Nursing Facility Census, in the past two years this decline has averaged 0.4 percent a year. This small decrease may be due to a variety of ongoing factors, including the greater use of home and community-based services (HCBS) due to current rebalancing efforts. Therefore, a compounded 0.4 percent annual structural decrease is factored into both projections of nursing facility service use.

Table III-9 shows the projected increase in residents needing nursing facility care at the current HCBS/institutional care ratio. This would result in an estimated 43 percent increase in Connecticut residents needing nursing facility care within the next 24 years (from 27,689 to 39,635). The greatest percentage increase would be for those age 65 to 74. This age cohort will experience a 67 percent increase in the number of those needing nursing facility care.

This greatly increased need for institutional nursing care would be reduced if the yearly structural decrease in the need for nursing facility beds could be accelerated through more concerted efforts to shift the ratio of institutional/HCBS care, by increasing the use of HCBS and decreasing the need for institutional care. Such rebalancing would allow more people to continue to live at home while receiving long-term care services. The last two columns of Table III-9 illustrate the effect of an *additional* 1 percent yearly structural decrease (i.e. a total 1.4% decrease). In that scenario, the increase in the nursing facility population due to overall population increases from 2006 to 2030 would be limited to 25 percent, compared with the expected 43 percent increase without any further rebalancing efforts.

Table III-9. Projected need for nursing facility care in Connecticut 2006 – 2030*

		With current 0.4% yearly decrease in NF population		Applying additional 1% yearly decrease in NF population	
Age group	**NF 2006 current population**	**NF 2030 population**	**NF percent pop. change 2006-2030**	**NF 2030 population**	**NF percent pop. change 2006-2030**
<65	3178	2737	(14)	2117	(33)
65 - 74	3088	5151	67	4549	47
75 - 84	8062	11,501	43	9881	23
85+	13,361	20,246	51	17,641	32
Total	**27,689**	**39,635**	**43**	**34,188**	**25**

*NOTE: All figures take into account projected overall population increases in each age group.

Given the objective in the state Long Term Care Plan to rebalance the system by decreasing the percentage of persons cared for in institutional settings, it may be useful to explore the hypothetical effect of even greater structural reductions to offset the population increases. Table III-9a provides three additional scenarios, showing the effect of rebalancing efforts that lead to further structural decreases (2%, 4%, and 6%) in the percentage of people living in nursing homes. Due to the large increases in older age groups projected by the US Census Bureau, based on the aging of the baby boom cohort, decreasing the percent of each age group residing in nursing facilities will not result in absolute decreases in the number of people in nursing homes until the annual decrease reaches approximately 4 percent, which is 10 times greater than the structural decrease experienced from 2004-06. At a 4 percent annual decrease, Connecticut could see a 10 percent reduction in the number of nursing home residents by 2030. At a 6 percent annual decrease, the state would see a 25 percent reduction in the number of nursing home residents by 2030.

Table III-9a. Projected need for nursing facility care in Connecticut in 2030 with additional levels of structural decrease

	Applying 2% yearly decrease in NF population		Applying 4% yearly decrease in NF population		Applying 6% yearly decrease in NF population	
Age group	**NF 2030 population**	**NF percent pop. change 2006-2030**	**NF 2030 population**	**NF percent pop. change 2006-2030**	**NF 2030 population**	**NF percent pop. change 2006-2030**
<65	1808	(43)	1044	(67)	570	(82)
65 - 74	4248	38	3506	14	3046	(1)
75 - 84	9100	13	7162	(11)	5962	(26)
85+	16,338	22	13,126	(2)	11,136	(17)
Total	**31,494**	**14**	**24,838**	**(10)**	**20,715**	**(25)**

*NOTE: All figures take into account projected overall population increases in each age group.

Any increase in the number of residents needing nursing facility care does not correspond to current beds available, but instead to the number of beds that would be needed to care for the increased need. In fact, the number of licensed beds has steadily but slowly declined in the past several years. In addition, these projections for institutional care do not include group homes or any other type of long-term residential care other than nursing facilities. This type of projected service use needs further analysis. Nonetheless, even if some rebalancing of institutional and community-based services occurs, there may still be an increased need in the future for institutional nursing facility services. Within the next 25 years, increased demand for nursing facility care may exceed the supply, unless other options, such as affordable assisted living, are assertively put in place.

Other projections for long-term care service use

The above discussion of hypothetical future demand for institutional or community-based services uses data from this survey combined with U.S. Census state population trends. However, projecting future demand for services is an inexact science, and often different methods and populations are employed. Of particular interest is a recent study by the Urban Institute's Retirement Project. This study uses a computer simulation and data from the 2002 Health and Retirement Study to examine future demand for paid long-term care services (Johnson et al., 2007). Looking only at adults age 65 or older with disabilities, these projections indicate that the numbers given above may be an underestimate. According to this study, the number of older adults needing ADL or IADL assistance nationwide will more than double, from 10 million in 2000 to 21 million in 2040. Their data indicates that even the most conservative projected increase in service use by this population is substantial: a three-quarters increase in the use of paid community-based care, with the number of nursing home residents increasing by two-thirds. Although differing methods make it impossible to compare their projections with the ones in this report, it is clear from both studies that Connecticut, as well as the rest of the United States, will experience a marked increase in the need for paid long-term care services of all types in the next 25 years.

E. Detailed results

Results from the Connecticut resident survey are presented in detail in this section. Findings from the Connecticut resident survey are organized by survey topic or section: current and future plans, health, employment and transportation, community long-term care services, social support, general information, financial resources, and caregiving. Within each area, the data are first presented as a whole, with responses from all general and disability surveys analyzed together. Any questions included only in the survey for people with disabilities are discussed within each section, after the common questions are examined.

The survey results are further analyzed and examined by disability status, age category, income status, ethnicity, and geographic region. When applicable, notable differences or similarities are described. These sub-analyses are included at the end of each content area.

Current and future plans

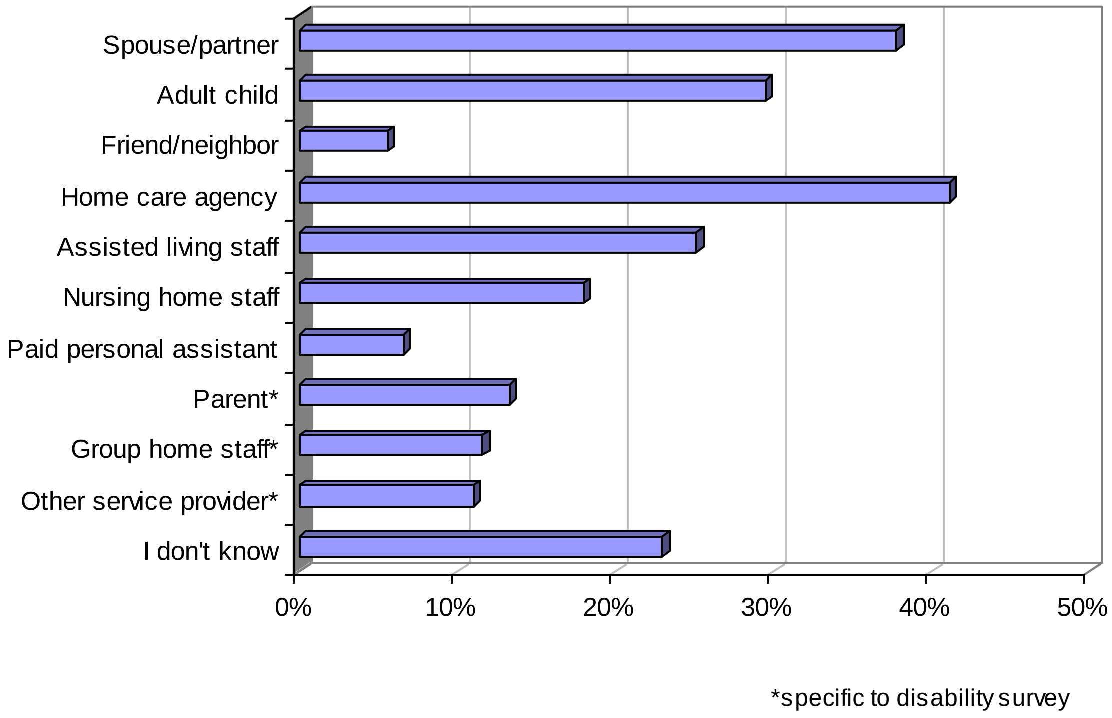
The majority of all respondents (68%) currently live in their own house or condominium, with another eleven percent living in their own apartment. Smaller numbers live in a senior housing complex (6%), with their parents (6%), a retirement community (4%), their adult child's home (4%), or an assisted living facility (4%). Less than one percent of the respondents live in either nursing homes or mental illness/substance abuse institutions, and about the same number live in other situations. Small percentages of people with disabilities indicate living in any of the additional options found in the disability survey: supervised living arrangement (7%), transitional group home or halfway house (3%), group home or community living arrangement (4%), and community training home (<1%).

Asked what type of services they might use as they grow older if they remain in their present residence, a majority of respondents answering the survey mention home maintenance or handyman services (65%) and lawn care/snow shoveling (61%). Less frequent but still significant are homemaker services such as shopping, cleaning, laundry, and bill-paying (56%), transportation (56%), home health care for bathing or other personal care (44%), and meals delivered to the home (38%). A number of respondents (12%) report that they would need personal assistance in the community for things such as getting to doctor appointments, attending church, or going shopping. Six percent of the respondents indicate other types of services would be needed, including companionship or friendly visitors, pet care, emergency response or phone check, home modifications, financial assistance, and 24-hour care. The survey for people with disabilities offered three additional service options: nursing care to give injections or provide other specialized medical treatments (30%), paid staff for monitoring and supervision only (19%), and paid staff for recreation and social activities (27%).

Two-thirds of all respondents (67%) do believe that they will eventually need long-term care services, either at home or in an assisted living or nursing facility, while 25 percent do not believe they will need such services and five percent already receive them.

When asked who would be likely to provide such care in the future, the leading answers for all respondents are home care agency, spouse/partner, adult child, and assisted living staff (see Figure III-1).

Figure III-1. Anticipated future providers of long-term care

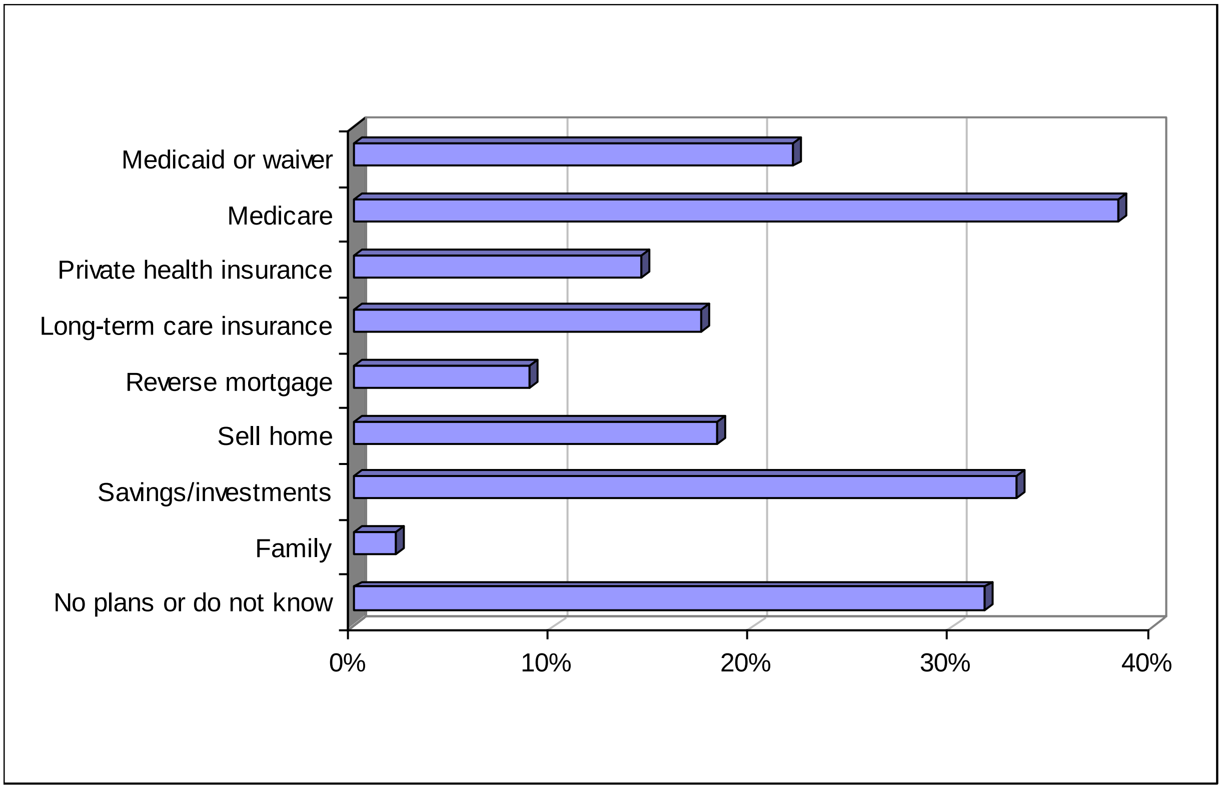


In addition, of the over 100 respondents who wrote in a response not on the list, about one quarter list other unpaid help such as from other family members or religious group members. Comments written in indicate a range of expectations and preferences for long-term care.

> *If my spouse passes away, then hopefully my children will take care of me.*
>
> *I will NEVER go into long-term care.*
>
> *Financially, I will have to move into subsidized housing.*
>
> *I regret not making plans.*

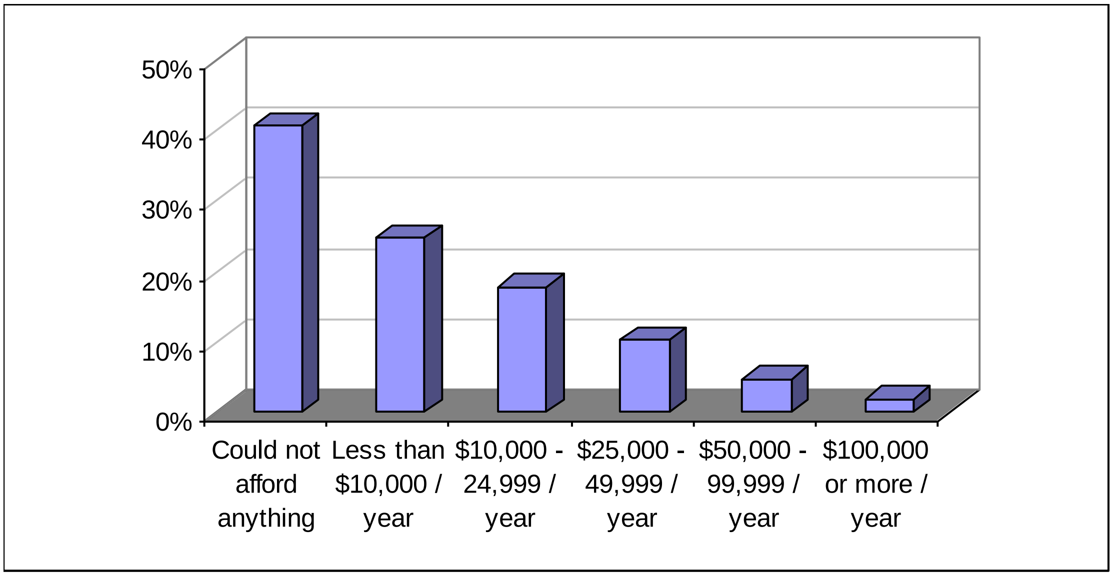
Only 15 percent of all respondents report that they currently have long-term care insurance that may cover such services, with another four percent not sure. When asked how they plan to pay for needed services (check all that apply), over one-third (38%) of all respondents indicate Medicare, another third (33%) indicate savings or investments, and an almost equal figure (32%) report no plans or do not know (see Figure III-2). This high response for Medicare may indicate some lack of understanding of what Medicare will cover. Other methods chosen by approximately one-fifth of respondents include Medicaid (22%), long-term care insurance (17%), and selling my home (18%).

Figure III-2. Plans to pay for long-term care services



Even though savings and investments are often the initial payment source for long-term care, respondents' resources may be inadequate to cover the costs. As shown in Figure III-3, over four out of ten respondents indicate they cannot afford to pay anything, and another quarter can pay less than $10,000 per year. Less than 20 percent report being able to pay between $10,000 and $25,000 per year, or more than $25,000 per year for long-term care services.

Figure III-3. How much could you afford to pay for long-term care each year?



A hypothetical question asked, “If you were living by yourself and had to enter a nursing home, what do you think should happen with your home or other property once you could no longer pay for your care?” The three options were selling all your property before receiving government assistance, being able to keep some of your property and receive government assistance, or not sure. The largest percentage (42%) report they are not sure. One-third of respondents chose the second option, “I should be able to keep some of my property for my relatives, even if this means more tax money goes to pay for my care.” The remaining one-quarter feel they should have to sell all of their property before getting government assistance.

Respondents were also asked how likely they were to move to or live in a number of housing arrangements as they grow older (see Table III-10). As might be expected, the majority of respondents anticipate they will continue to live at home, most likely with physical modifications or home health care services (very or somewhat likely: 74% and 78%, respectively). The least liked options are nursing homes, living with an adult child, and housing for seniors or people with disabilities with no special services (not at all likely: 69%, 63%, and 55%, respectively). One-third of respondents from the disability survey indicate it is at least somewhat likely they will live in a group home, and another seven percent report they already live there. On the other hand, people with disabilities do not see either living with their parents or with another relative in his/her home as likely options. Other options or comments written in by respondents include:

> *Add onto my home for someone to live on the premises.*
>
> *Depends on what Medicare and Medicaid will allow because my life has not allowed me to have savings.*
>
> *Live in communal arrangement with friends where we contract for services. care for me, I hope to transition to a group home.*
>
> *There is no one to care for me when my parents die. As they grow too old to*
>
> *Move to smaller house with no stairs.*

Table III-10. Anticipated future housing arrangements (percentages)*

	Very likely	**Somewhat likely**	**Not at all likely**	**Already made this change**
Remain in your own home without modifications	34	**36**	31	**
Remain in your own home with some modifications to adjust for physical problems	30	**44**	21	5
Remain in your own home with home health care or homemaker services provided at home	33	**45**	18	4
Sell your house and move to an apartment or condominium	15	30	**46**	10
Live in apartments for seniors or people with disabilities with no special services	11	29	**55**	5
Live in a retirement community that provides some meals, housekeeping, transportation, and social activities for age 55+ only***	14	**45**	40	2
Live in an assisted living facility that provides meals, housekeeping, transportation, and limited nursing care	13	**42**	44	1
Live in a nursing home	5	24	**69**	2
Live in a continuing care retirement community that provides independent living units, assisted living, and nursing home care***	13	**46**	40	1
Live with my adult child in his/her home***	7	27	**63**	3
Live in a group home or community living arrangement****	14	20	**59**	7
Live with my parent's in their home****	13	9	**71**	7
Live with another relative in his/her home****	9	20	**67**	4

*Rows may not sum to 100% due to rounding

**Not given as an answer choice for this item

***Specific to general survey

****Specific to disability survey

Differences by disability status

Answers to all survey questions were analyzed by disability status by dividing the responses into three categories, which will be used throughout this report when reporting differences by disability status. These categories are defined below:

- No Disability (hereafter **"Group ND"**) – this category includes persons who answered the Connecticut resident survey and indicated that they do not have a disability and do not require assistance with any activities of daily living (ADL) (n=3664).

- Disability ADL/Self-reported (hereafter **"Group DAS"**) – this category includes persons who answered the Connecticut resident survey and reported that they do have a disability (of any type) and/or that they require assistance with at least one activity of daily living, including taking a bath or shower, getting dressed, getting in and out of a bed or chair, using the toilet, eating, or getting around inside the house (n=1037).

- Disability Waiver/DSS (hereafter **"Group DWD"**) - this category includes persons who received and answered the survey specific to persons with disabilities, because they are on a Medicaid waiver or otherwise receiving services from DSS, DMR, DMHAS, or received the survey at an event or through word of mouth (n=1525).

Table III-11 shows the relative percents of each disability status group.

Table III-11. Disability status

Category	Number of respondents	Percent of respondents
Group ND (no disabilities)	3664	59
Group DAS (ADL/self reported)	1037	17
Group DWD (disability waiver)	1525	24

The three groups were also rated on a disability scale that ranks the severity of ADL impairment. On a scale from zero to 18, with 18 being the most severely disabled, the mean rank of Group ND by definition was zero. The mean for Group DAS was 1.3 and for Group DWD it was 3.1, indicating that on average, Group DWD had more severe functional impairments.

Current and future plans concerning long-term care do show some significant differences by disability status. The question concerning where respondents currently live reveals that those in Group DWD have significantly different living arrangements from Groups DAS and ND. Whereas most of the latter two groups live in their own house or condominium, only 17 percent of Group DWD do. They are more likely to live in an apartment (27%), with their parents (20%), or in a supervised living, group home, community living arrangement, or transitional group home (15%).

When asked how they plan to pay for long-term care services, more members of Group ND anticipate using multiple sources of payment than either Group DAS or DWD (see Table III-12). Interestingly, over one-third of respondents in each of the three groups make the (probably erroneous) assumption that Medicare will pay for their long-term care needs. Group DWD, however, is far more likely to pick Medicaid as the anticipated payer, possibly because of existing experience with that program.

Table III-12. Anticipated payers of long-term care services by disability status (percentages)

	Group ND	**Group DAS**	**Group DWD**
Savings/investments	**45**	36	4
Sell my home	**25**	20	2
Long-term care insurance	**24**	15	3
Private health insurance	**18**	15	5
Medicare	37	**47**	36
Medicaid	11	21	**51**

The anticipated providers of future long-term care also differ by disability status. While all three groups name home care agency as one of the top three likely providers, Groups ND and DAS round out the top three with spouse/partner and adult child. For Group DWD, however, the other two top choices are paid personal assistant and assisted living staff.

Asked what type of services they might use as they grow older if they remain in their present residence, the three groups give similar answers, with two exceptions. Groups ND and DAS are twice as likely to name handyman/home maintenance and lawn and snow services (most likely since so many more currently live in their own homes), and members of Group DWD are far more likely than the other groups (38% to <3%) to name personal assistance in the community as something they might need.

Another striking though understandable difference among these three groups lies in the amounts they could afford to pay for long-term care each year. Almost all of Group DWD (85%) can afford to pay nothing, compared to only 22 percent of Group ND and 41 percent of Group DAS. By contrast, four out of ten respondents from Group ND, and 26 percent of Group DAS, can afford more than $10,000 per year.

Differences by age

The survey data was also examined by age, using six different age groups. This type of analysis allows for an exploration of any differences that correlate with age. All respondents who reported their age were divided into six consecutive age categories:

Table III-13. Age categories

Category	Age range	Percent of respondents*
Youngest	1 – 21	2
Young adults	22 – 41	10
Baby boomers	42 – 60	41
Young old	61 – 74	29
Older adults	75 – 84	14
Oldest	85+	5

*Rows may not sum to 100% due to rounding

Differences in living situation fall along expected age category lines. For example, the greatest percentage of the youngest live with their parents (69%). Young adults, on the other hand, are split between living with their parents (30%) or in their own home or condominium (29%). This age group also represents the greatest percentage of apartment dwellers (21%). In comparison, the majority of baby boomers, young old, and older adults live in their own home or condominium (range 72% - 78%), while only half of those 85 or older do so.

When asked about what services they might use to remain in their home as they grow older, it is the homeowners (baby boomers, young old, and older adults) who would most like either home maintenance (70%, 70%, 58%) or lawn/snow services (67%, 64%, 55%). The greatest percentage of the oldest, however, feel that homemaker (65%), home health care (56%), or meal services (42%) would help them stay at home. About equal percentages of the two youngest age groups (65% and 63%) as well as the oldest age group (60%), indicate that transportation would be necessary, while over half of the youngest would also like personal assistance services or home care.

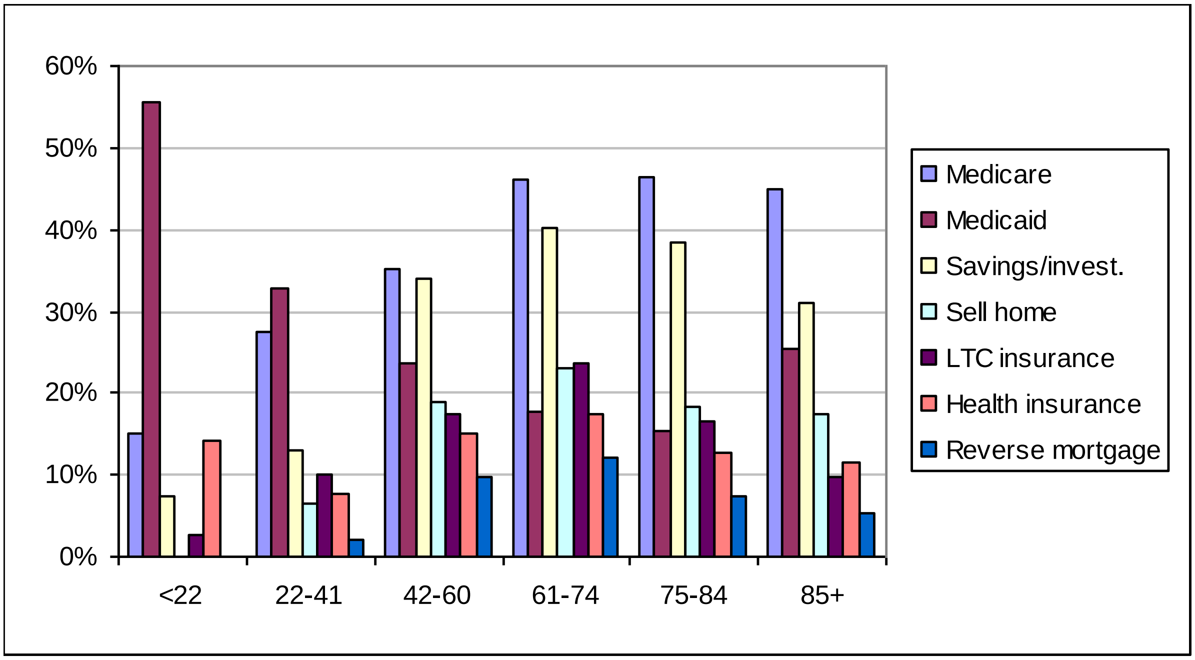
The majority of each age group believes they will need long-term care (ranges from 59% of young adults to 69% percent of baby boomers). As one might expect, more of the oldest respondents (18%) currently receive this care than any other age group. Interestingly, more than any other age group, baby boomers and the young old expect this care will be provided by diverse types of caregivers. Compared with the other age groups, a greater percentage of baby boomers or young old feel this care might be given by their spouse/partner (43% each), adult child (31%, 33%), home care agency (44%, 45%), assisted living staff (30%, 26%), or nursing home staff (19%, 20%). Similar to these two age groups, 42 percent of the youngest group predict that they will use a home care agency for services. Assisted living also appeals to one-quarter of the young adults (25%), while almost one-third of the oldest (31%) expect their adult child to provide this care. Receiving care from a paid personal assistant basically only interested the youngest (25%) or the young adults (20%), with only one to ten percent of any other age group predicting using this service. Finally, very few of any age group think a friend or neighbor will provide this care for them (ranges from 3% - 7%).

When asked how they will pay for any needed long-term care (check all that apply), a significant number of respondents of any age erroneously expect Medicare to pay for at least some of their care. Medicare is the most frequently chosen method of payment for respondents age 42 or older, and this is especially true for those age 61 and older. Almost half of the respondents in each of the three oldest age groups think that Medicare will cover some or all of their care, along with over one-third of baby boomers and over one-quarter of young adults (see Figure III-4).

A number of respondents are also counting on state or federally funded Medicaid to pay for their long-term care expenses. Medicaid is the payer of choice for the youngest respondents, chosen by over half (56%) of this age group, as well as for the young adults (33%). This might be expected, given that many of the younger survey respondents received a survey because of their participation in a Medicaid-funded waiver or program. One-quarter of both baby boomers and of those 85 plus also plan to rely on Medicaid to help pay for their long-term care. In addition, many baby boomers (40%) indicate that they can pay nothing for long-term care, as do half of those 85+. While it is expected that the majority of the youngest or even young adults can not afford to pay anything, that 40 percent of baby boomers report this is troubling. This may also indicate a greater reliance on State or federal aid in the future to pay for such care, especially given that almost 70 percent of this age cohort believes they will need long-term care in the future.

From 31 to 40 percent of those age 42 and older do plan to use savings and investments to help pay for their care. Overall, the young old (age 61 to 74) indicate they plan to use more private, or non-publicly funded, options. Compared with the other age groups, a greater percentage of those age 61 to 74 report they could use long-term care insurance (24%), savings or investments (40%), sale of their home (23%), reverse mortgage (12%), or private health insurance (18%) to pay for their care. However, even including this age group, only a small proportion of respondents from any age category have plans to use any of these private methods to pay for their care. In addition, while the greatest percentage of the young old report having long-term care insurance, this still represents only one-quarter of this age group.

Figure III-4. How do you plan to pay for any long-term care services?



Differences by income

Answers to all survey questions were also analyzed by income level. Respondents were divided into five income categories based on total monthly household income before taxes. Total monthly income was defined as including wages, salaries, Social Security, retirement benefits, veterans' benefits, public assistance, investment income, and any other income. The following income categories are used throughout this report when discussing differences by income status.

Table III-14. Income categories

Category	Reported monthly household income	Percent of total
Low	Less than $1,000	19
Low/medium	$1,000 to $2,999	25
Medium	$3,000 to $4,999	18
Medium/high	$5,000 to $8,999	24
High	$9,000 and above	14

There is substantial overlap between the low income group and persons with disabilities or self-reported ADL impairments disabilities (Groups DWD and DAS, respectively). The differences by income noted below, therefore, are highly correlated with differences by disability status.

As might be expected, the living situation for the low income group differs substantially from the others. Whereas more than 85 percent of the top three income groups and 60 percent of those with low/medium income live in their own home or condominium, only 17 percent of those with low income do. They are more likely to live in an apartment (30%), and as likely to live in senior housing (17%) or with their parents (16%). Another 13 percent of the low income group report living in an arrangement that was only an option for those answering the survey for persons with disabilities: a supervised living arrangement, group home or transitional group home, community living arrangement, community training home, or mental illness or substance abuse supportive living arrangement.

There are few differences among the income groups concerning services they might need as they grow older, with two exceptions. Given their higher rates of home ownership, the higher income groups are understandably far more likely to need home maintenance and handyman services as well as lawn care and snow removal, while the low income group names community or personal assistance as an anticipated need more often than the highest three income groups (29% to <5%).

More of the two lower income groups already receive long-term care than the three highest income groups (13% of low income, 6% of low/medium income, and 2% or less for the other three groups). Predictions about who will provide future long-term care services differ somewhat by income level, with the highest three income groups naming spouse/partner, adult child, and assisted living staff as likely care providers two to four times as often as the low income group. The two lowest income groups are somewhat more likely to name paid personal assistant or do not know who will pay for their care.

Asked how they will pay for future long-term care services, the three higher income groups are predictably more likely to name savings/investments or sell my house, while the two lower income groups are more likely to name Medicaid. All groups are equally misinformed about the likelihood of Medicare paying for their long-term care, with over a third of every group naming it as a likely source of payment. Ability to pay out-of pocket for long-term care follows income level in a predictable pattern.

Differences by ethnicity

Answers to all survey questions were also analyzed by ethnicity. Respondents were divided into four groups based on answers to the questions about race and Hispanic or Latino origin. Respondents were asked to check one of five categories of race: White or Caucasian; Black or African-American, or Caribbean Black; American Indian or Alaska Native; Asian, including Asian Indian, Chinese, Filipino, Korean, or other Asian; or other. An additional question asked if they were of Spanish, Latino or Hispanic origin. Based on the responses, respondents were grouped into four categories, White, Black, Latino and Other. White and Black races are exclusively represented by those who checked those categories and did not check “yes” to Spanish or Latino origin. The other race category includes those who checked either Asian or Native American, those who may have checked more than one race category, and those who checked other. The other race category also excludes those who checked “yes” to Spanish or Latino origin. These categories are used throughout the report when discussing differences by ethnicity.

Table III-15. Race and ethnicity categories

Category	Description	Percent of total
White	Non-Hispanic White or Caucasian	87
Black	Non-Hispanic African-American or Caribbean Black	5
Latino	Anyone of Spanish, Latino or Hispanic origin	6
Other race	Any non-Hispanic who checked any of the other racial categories, (including Asian, Native American), who checked more than one racial category, or who checked “other” for race	2

Current and future plans concerning long-term care do show some significant differences by ethnicity. The question concerning where respondents currently live reveals that the White group is more likely to own their own homes (72%) than the other ethnic groups. The other race group indicates home ownership at 56%; however, both Black and Latino indicate home ownership as far less (34% and 37% respectively). Over one-fourth of both Blacks (31%) and Latinos (27%) live in apartments, compared with less than ten percent of Whites. Given their higher rates of home ownership, Whites are understandably far more likely to need home maintenance and handyman services as well as lawn care and snow removal.

More of the Blacks and Latinos are currently receiving long-term care services with nine percent of the Blacks and seven percent of Latinos receiving these services compared to only four percent of each of the other two groups. Whites are more likely to count on a spouse to provide care (40%) than either Latinos (24%) or Blacks (20%). However, Latinos are twice as likely to select another family member as the provider of these services than the other three groups, while Blacks and the other race group are almost twice as likely to select a paid personal assistant to provide services.

Asked how they will pay for future long-term care services, Whites were significantly more likely to name savings/investments or sell my house, while the three other ethnic groups are more likely to name Medicaid. Once again, all four groups are equally misinformed about the likelihood of Medicare paying for their long-term care, with over a third of every group naming it as a likely source of payment.

Nearly three-quarters of the Black and Latino groups and almost two-thirds of the other race group indicate that they could not afford to pay anything for long-term care. Only about one third of the White group says that they cannot afford to pay anything at all for long-term care.

Differences by region

Survey respondent results are analyzed by region of residence in the State (Northern, Southern, Western), as defined by the Department of Social Services. An issue brief is forthcoming that will examine differences across 12 regions.

Table III-16. Regional categories

Region	Number of Respondents*	Percent of total
Northern (N)	2,382	41
Southern (S)	1,831	32
Western (W)	1,547	27

*506 individuals left the zip code question blank

Modest differences exist by region with respect to living situation. Respondents in the Northern region are slightly more likely to report home ownership. There is very little variation among the regions in terms of living in a 55+ retirement community or living with a parent.

There are no significant differences among the regions with respect to anticipated future service use. There is only a slight variation in the responses for services such as home maintenance and handyman services, homemaker services, home health care, transportation, home delivered meals, and lawn/snow care. The slight differences tend to correspond to the higher rates of home ownership.

Almost three-fourths of individuals in all three regions anticipate needing long-term care. Likely providers of services are fairly similar when comparing the three groups. Home care agency is the first choice, followed by spouse/partner, adult child, assisted living staff and nursing home staff. About one-quarter of the respondents from each region have no idea who will provide future long-term care.

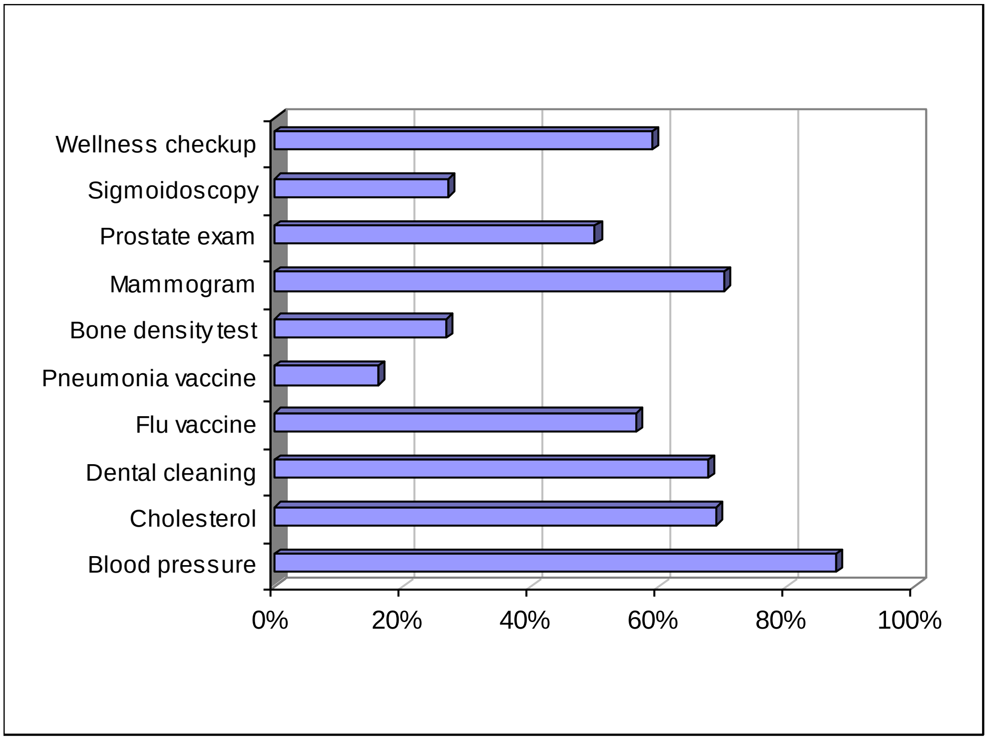
With respect to paying for any long-term care services, about one-third of all respondents in each region “have no plans or do not know.” Consistent with other findings, many believe that private health insurance and Medicare will cover expenses. One point of interest is that a slightly greater proportion of respondents from the Northern region report having long-term care insurance (19%-N; 17%-S; 16%-W).

Health

The majority of survey respondents report themselves to be in generally good health, with 78 percent rating their health as good or excellent in the last month. Still, one-fifth of respondents (22%) indicate their health is either fair or poor. Moreover, 28 percent of all respondents have gained or lost at least 10 pounds without trying over the last year. It is also significant that almost one-quarter (23%) of all respondents have experienced a fall in the past 12 months, given that falls often lead to institutionalization or need for long-term care at home. When asked about the quality of care from all health providers over the last year, a strong majority (89%) rate their quality of care to be excellent or good. Only a small number (4%) have not seen a health provider in the last year. A significant number report signs of depression, with over one-quarter (27%) often bothered by feeling down, depressed or hopeless, and 23 percent often bothered by little interest or pleasure in doing things.

Respondents report varying compliance with recommended health screenings and preventive measures over the last one to two years. As evident in Figure III-5 below, they indicate high rates of blood pressure checks, mammograms (women only), cholesterol screenings, and dental cleanings, but low levels of pneumonia vaccines, bone density tests, and sigmoid/colonoscopy screenings. Half of male respondents (50%) have had a prostate exam, while over half of all respondents (59%) indicate they have had a wellness check up in the past two years.

Figure III-5. Health exams



The Medicare Part D prescription drug plan has not yet been a significant issue for many respondents from either survey. About two-thirds of respondents who are eligible for Part D (65%) report that they have never used it. Fifteen percent of those who have used Medicare Part D say that they have experienced a problem with it to date; however, 85 percent report having experienced no problems at all. The difficulties encountered include issues such as the plan is too complicated, costly “doughnut” hole before coverage resumes, current prescriptions not on plan list, and expensive co-pays.

> *I can’t get a prescription because it’s not on the list.*
>
> *The… doughnut hole. This is a ridiculous plan for seniors on a fixed income. My wife and I pay dearly because of this.*

> *It's beyond comprehension and difficult to compare with other plans. How about less complicated explanations?*
>
> *I can't find anyone to explain it to me. No prescription coverage as of this date.*
>
> *"Donut hole" comes too soon… is too long and too expensive.*

Overall, respondents indicate little need for help with most daily living activities. Slightly more help is needed for activities such as routine household chores, getting to places out of walking distance, grocery shopping, doing laundry, managing money, and preparing meals, as noted in Table III-17 below. Lifting heavy objects, dealing with stairs, doing outside yard work, and driving at night are some of the other problems that respondents report for which they require some additional help.

Table III-17. Assistance needed for daily living activities (percentages)*

	No help	**A little help**	**A lot of help**	**Cannot do it at all**
Preparing meals	**79**	9	6	7
Shopping for groceries	**74**	10	8	8
Doing routine household chores	**71**	14	10	6
Managing money, including keeping track of bills	**79**	8	6	7
Doing laundry	**76**	9	7	8
Taking medications correctly	**84**	7	4	5
Getting to places out of walking distance	**73**	8	10	9
Using the telephone	**91**	4	2	3
Taking a bath or shower	**85**	6	5	4
Getting dressed	**88**	6	3	3
Getting in and out of a bed or chair	**90**	5	2	3
Using the toilet	**93**	3	2	2
Eating	**94**	3	2	1
Maintaining control of your bowel/bladder function	**89**	6	3	2
Getting around inside the house	**91**	6	2	1
Other ______________________	**71**	10	12	6

*Rows may not sum to 100 due to rounding

Consistent with the reported high levels of independence with respect to daily living activities, only a small percentage of respondents indicate a need for, or current use of, building modifications (13%), mobility aids such as wheelchairs or stair lifts (12%), transportation aids such as lift vans (10%), and computer access aids such as touch screens (8%). Many of those who responded indicate that they need other types of assistive devices including minor building modifications, such as grab bars in the bathroom, and items such as canes and walkers for mobility, or hearing aids or regular wheelchairs. A few of the respondents report that they would like some other kind of assistive devices. Notable among the write-ins included an alert or response system, like Life Line, in order to remain in their current situation.

The disability survey included some additional categories of assistive devices or technology to cover communication aids and devices for people with hearing or vision disabilities. Ten percent of these respondents indicate that they do need some kind of communication aid, while another six percent currently use such devices. Smaller percentages currently need or use assistive technology for people with either hearing or vision disabilities. Only five percent indicate a need for either type of support, while two percent are current users of either of these types of assistive technology (see Table III-18).

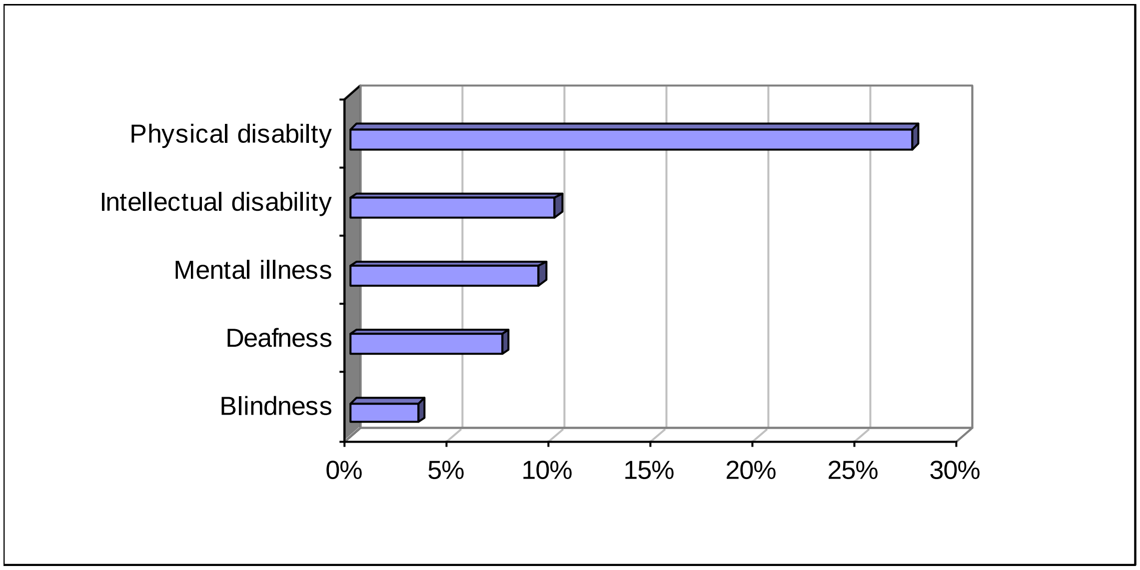
Table III-18. Assistive devices needed (percentages)

	I do not need it	**I currently use it**	**I do need it, but do not have it**
Building modifications (entrance ramps, expanded doorways, accessible space, etc.)	**87**	8	5
Mobility aids (electric wheelchair, stair lift, etc.)	**88**	8	4
Transportation aids (lift van, adaptive driving controls, etc.)	**90**	5	5
Computer access aids (touch screens, keyless entry, voice to text software, etc.)	**92**	2	6
Communication aids (communication boards, voice activated telephone, etc.)*	**84**	6	10
Devices for people who are deaf (TDD, TTY, phone relay services, etc.)*	**93**	2	5
Devices for people who are blind or legally blind (Braille translation software, etc.)*	**93**	2	5
Other ___________________________	**78**	18	4

*Specific to disability survey

Respondents were asked if they have any of five different categories of disabilities: physical or chronic illness, intellectual, mental illness, hearing, or vision disability (check all that apply). Over one-quarter of all respondents report a physical or chronic illness disability (28%). About one in ten respondents report they have a mental illness or psychiatric disability (9%), with a nearly equal number reporting an intellectual or cognitive disability (10%). Smaller numbers indicate either a hearing (7%) or vision (3%) disability. When asked to describe their disability, the most frequently mentioned disability is arthritis (4%), which includes both rheumatoid and osteoarthritis. Depression and bi-polar disorder are listed almost as frequently (3%). Conditions listed by respondents less frequently include mental retardation or Down syndrome, chronic obstructive pulmonary disease (COPD), spinal injuries, or strokes. Among those who indicate they do have a disability, they report an extremely wide variation in the age when the disability started. The minimum is zero, or at birth, and the maximum is 98, with a mean age of 37.

Figure III-6. Rate of disabilities



Additional questions regarding hospitalizations, emergency room visits, and utilization of mental or behavioral health services were included in the survey for people with disabilities. Overall responses indicate a high rate of use for hospital and emergency room services. Over one-third (37%) of respondents were admitted and stayed overnight in a hospital in the past year. One out of ten (11%) were even more frequent hospital patients, reporting three or more admittances with an overnight stay in the past year. At least one visit to an emergency room in the past year is reported by one-half (49%) of respondents, with 15 percent using emergency room services three or more times in this time period. An overall smaller percentage indicate use of mental, behavioral, or substance abuse services in the past year, with 60 percent reporting no visits, and eight percent one or two visits in the past year. Still, almost one third (31%) have used some type of mental or behavioral health services three or more times in the past year, with one-fifth (21%) indicating they have used these services six or more times.

Issues related to accessibility in a person’s home, workplace, where he/she shops or does errands, and for any community-based recreation or leisure activities were asked on the survey for people with disabilities. Over half (59%) of respondents indicate that their home is totally accessible; however one-third (33%) report that their home is only somewhat accessible. Another eight percent of those who responded say that their home is not at all accessible.

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

> *I became disabled after I was living here and [the] landlord will not make changes.*

Of those who responded to the question, almost two-thirds (61%) are not employed. Of those who do work, nearly three-quarters (72%) indicate that their workplace is totally accessible, and just about one-quarter (23%) say that their workspace is only somewhat accessible. A much smaller percentage (5%) report that their workplace is not physically accessible at all. Over half of the respondents (53%) state that where they shop or do errands is either somewhat accessible (41%) or not at all physically accessible (12%). The other half of the respondents (47%), indicate that where they shop or do errands is totally accessible.

> *I don't know directions.*

> *Not enough handicap parking.*

> *I need transportation and someone to shop for me.*

Nearly two-thirds of responders indicate some sort of difficulty with regard to recreational or leisure activities they might want to do in the community. Sixty-three percent of the respondents say that access to any recreation is either not at all accessible or only somewhat accessible. Only 37 percent report that access to recreation and leisure activities in the community is totally accessible.

Differences by disability status

As would be expected, there are a number of major differences in how respondents answered the health questions on the survey, depending on their disability status. While nearly all of those without disabilities (Group ND, 93%) report their current health to be either excellent or good, 42% of both those respondents completing the survey for people with disabilities (Group DWD) and those with self-reported impairments (Group DAS) report theirs to be only fair or poor. Moreover, a substantially larger percent of both Groups DAS and DWD report signs of depression such as feeling down, depressed or hopeless or having little interest in doing things. More than one third of those two groups report such signs, compared to only 13 percent for Group ND. Falling in the past year is also reported significantly more often by Groups DAS and DWD (36% each), while only 14 percent of those in Group ND have fallen in the past year.

While the three groups report having most medical exams and screenings in roughly equal proportions, Group DWD is far less likely than Group ND to have had a dental cleaning, bone density test, mammogram or prostate exam, with Group DAS in between.

Group DWD is also far more likely to have experience with Medicare Part D (only 36% have never used it compared to 79% of Group ND and 58% of Group DAS). Most have not experienced problems with Part D, but of those who do, concerns include switching plans, important medications not covered, and confusion about its provisions.

> *They've taken my most expensive med off the formulary.*

> *They mixed my plan up with someone else's. I take 35 medicines and couldn't get them for a while.*

> *Program is confusing and difficult to decipher. Call centers give conflicting responses to same questions. No one knows how the program is supposed to work.*

While respondents in general require very little help with most daily living activities, there are substantial differences by disability status. For every activity listed in the survey, more than 95 percent of Group ND require no help. For Groups DAS and DWD, however, a large proportion requires at least some help on many activities, as noted in Table III-19.

Table III-19. Percent requiring at least some help with daily living activities

	Group DAS	**Group DWD**
Preparing meals	31	61
Shopping for groceries	42	70
Doing routine household chores	53	69
Managing money, including keeping track of bills	38	59
Doing laundry	36	64
Taking medications correctly	19	48
Getting to places out of walking distance	43	71
Using the telephone	12	28
Taking a bath or shower	21	43
Getting dressed	16	35
Getting in and out of a bed or chair	16	28
Using the toilet	9	23
Eating	8	18
Maintaining control of your bowel/bladder function	18	28
Getting around inside the house	15	25

Likewise, whereas more than 98 percent of Group ND do not use or need any assistive devices either at home or at work, significant percentages of the other two groups do use or need such devices, as indicated in Table III-20

Table III-20. Percent using or needing various assistive devices

	Group DAS	Group DWD
Building modifications (e.g. entrance ramps, expanded doorways, accessible space, etc.)	21	35
Mobility aids (e.g. electric wheelchair, stair lift, etc.)	19	33
Transportation aids (e.g. lift van, adaptive driving controls, etc.)	12	29
Computer access aids (e.g. touch screens, keyless entry, voice to text software, etc.)	11	22

Finally, whereas by definition no member of Group ND reports having any type of disability, the rate of various disabilities reported in the other two groups is substantial, as shown in Table III-21.

Table III-21. Percent reporting disability

	Group DAS	Group DWD
Physical disability or chronic illness disability that makes it difficult for you to walk, reach, lift, or carry	71	61
Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	11	33
Mental illness or psychiatric disability, such as schizophrenia or bipolar disorder	12	30
Deafness or other severe hearing impairment	29	10
Blindness or legal blindness	7	9

Differences by age

Even when examined by age, the majority of respondents in each category are in either good or excellent health, although the oldest show a greater percentage of those in fair or poor health. Baby boomers show the greatest number of those in excellent health (43%), even when compared with young adults or the youngest (39% and 29%, respectively). This finding is probably influenced by the overall younger age of people who filled out the survey for people with disabilities (mean age disability survey 49.5, range 2-99; mean age general survey 62.5, range 16-100; p<.0).

Depression is considerably more prevalent in young adults than all other age groups, while the young old are the least affected overall (young adults 37%, young old 18%). Young adults are also the least satisfied with the quality of their health care and most frequently report an unintentional weight gain of at least ten pounds in the past year. However, it is the oldest who report the largest percentage of unintended weight loss of ten pounds or more; almost twice as many of the oldest experienced such a loss in weight compared with any other age group (22% versus 6%-12%). This is significant, as such a weight loss can have implications for overall health. Also important to note is that four out of ten of the oldest report falling in the past year, which can lead to serious complications or the need for long-term assistance.

When compared to the other age groups, the young old seem to take the best care of themselves regarding preventative health screenings. With the exception of wellness exams, this age group consistently reports the highest, or one of the highest, use of any of the listed screenings, especially cholesterol, bone density, sigmoid/colonoscopies, mammograms, or prostate exams. Still, only about one-third of those age 61 to 84 have had either a bone density or sigmoid/colonoscopy in the past two years. Three-quarters of those age 75 and over had a flu vaccine, but the pneumonia vaccine is much less utilized by any age group. In addition, while the flu vaccine is also recommended for children, less than half of the youngest received it in the past year. Data by age also show that by the time one reaches age 85, some preventative procedures or screenings are not given as frequently, including dental cleanings, cholesterol screenings, sigmoid/colonoscopies, and bone density tests. If our life expectancy continues to increase, use of these screenings or exams at older ages will need to increase as well.

Differences in assistance needed for daily living activities are pronounced. The youngest group by far require the most assistance for both activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and either currently use or need the most assistive devices at home or work. Once again, this finding confirms the overall disability status of the youngest group. Still, assistance with several IADLs is needed for a notable number of both older and younger adults. Over one-quarter to one-half of older adults either cannot do at all or need a lot of help with laundry, meals, chores, shopping, money management, or getting to places out of walking distance (range 28% - 48%). Young adults also need a significant amount of assistance with these same activities (range 26% - 37%).

The youngest also show the highest rates of disability for intellectual (61%), physical (62%), or vision disabilities (15%), and the second highest rate for mental illness disabilities (18%). Almost one-third of the oldest are deaf, and they also have the second highest rate of physical disabilities (52%), while young adults have the highest rates of mental illness disability rates. This last finding may relate to their higher rates of depression as well.

<u>Differences by income</u>

Members of the top three income categories give substantially similar responses to most of the health-related questions. There are some stark differences between the top three groups and the low income group, however, with the low/medium income group in between. Because of the substantial overlap between the low income group and persons with disabilities from Groups DAS and DWD, many health results are similar.

While more than 86 percent of the top three income groups rate their current health as excellent or good, 45 percent of the low income group rate theirs as fair or poor. Nearly three times as many of the low income group have been bothered by feelings of depression or hopelessness over the last month (48% compared to about 17% for the three highest income groups). Compared to the three highest income groups, the low income group reports that they gained or lost weight without trying twice as often, fell twice as often, and are less likely to have gotten certain medical exams such as cholesterol screenings, dental cleanings, bone density tests and prostate exams. For every daily living activity mentioned in the survey, the low income group requires substantially more help than the three high income groups, with the low/medium income group in between. Finally, the incidence of disability differs by income as noted in Table III-22 below.

Table III-22. Percent reporting disability

	Low income	Low/medium income	Top three income groups
Physical disability or chronic illness disability that makes it difficult for you to walk, reach, lift, or carry	55	36	14
Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	31	10	3
Mental illness or psychiatric disability, such as schizophrenia or bipolar disorder	29	9	3
Deafness or other severe hearing impairment	9	12	5
Blindness or legal blindness	9	4	1

Differences by ethnicity

The majority of the respondents in all categories rate their health as either excellent or good however, there are some significant differences for the Latino group and the Black group. Nearly one-half of the Latino group (45%) rates their health as either fair or poor. The same is true for almost one-third (32%) of the Black group. Far more of the respondents in the Latino group say that they are bothered by feeling down, depressed or hopeless during the past month (43%). Nearly one-third of the other race group and exactly one-third of the Black group indicate feelings of depression as well, compared to only one-quarter of the White group.

Blacks, Latinos and the other race group were twice as likely as the White group to rate the quality of their health care as either fair or poor. Significant also is the fact that Black and other race males are less likely to get prostate exams with only 29 percent of Blacks and 24 percent of the other race group receiving prostate exams within the last two years compared to 52 percent of the Whites and 41 percent of the Latinos. In addition, Blacks had fewer wellness checkups during the past two years with over half (54%) indicating that they had not received one. Latinos followed close behind with 47% indicating that they had not had a wellness checkup in the past two years. Almost two-thirds of the White group (62%) and more than two-thirds of the other race group (67%) indicate that they had received a wellness checkup within the past two years.

For almost every daily living activity mentioned in the survey, the Black and the Latino groups seem to require substantially more assistance than the other two groups. Blacks and Latinos are almost twice as likely to require at least some help with many of the activities of daily living as compared to the White group. The other race group falls somewhere in between, sometimes requiring only a little help with some of the activities of daily living. The same is true regarding use of any kind of assistive devices. Nearly twice as many of the Black, Latino and other race groups do need some sort of assistive devices, but do not have them, compared to the White group. Finally, the incidence of disability differs by race and ethnicity, as noted in Table III-23 below.

Table III-23. Percent reporting disability by race/ethnicity

	White	**Latino**	**Black**	**Other**
Physical disability or chronic illness disability that makes it difficult for you to walk, reach, lift, or carry	26	40	42	29
Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	9	20	15	13
Mental illness or psychiatric disability, such as schizophrenia or bipolar disorder	8	22	16	9
Deafness or other severe hearing impairment	8	10	7	7
Blindness or legal blindness	3	9	5	7

Differences by region

Self-reported health is similar across regions as are rates of depression. A small but noticeable trend can be found for some preventative health exams. Individuals in the Northern region are more likely to report cholesterol screening, dental cleaning, flu vaccine, bone density test, mammogram, and wellness check up (see Table III-24 below).

Table III-24. Percent reporting health exams

	Northern	Southern	Western
Blood pressure check	90	90	89
Cholesterol screening	73	71	67
Dental cleaning	71	67	69
Flu vaccine	59	57	56
Pneumonia vaccine	16	17	17
Bone density test	29	27	26
Mammogram	46	40	41
Prostate exam	19	20	21
Sigmoidoscopy or colonoscopy	27	29	28
Wellness check up	62	60	60

Problems with Medicare Part D are similar across regions, about 30% for each group. ADL and IADL limitations are similar across regions, with the typical respondent in each region reporting one ADL limitation.

Reported physical or mental health impairments are greater in the Southern region. This finding holds true for physical, intellectual, mental illness, and hearing deficits (see Table III-25 below). Age of disability onset is also slightly higher for individuals in the Southern Region (36 years-N; 39 years-S; 37 years-W).

Table III-25. Percent reporting physical or mental impairment

	Northern	Southern	Western
Physical disability	26	30	27
Intellectual disability	9	11	10
Mental illness	8	11	9
Deafness/hearing impairment	7	9	7
Blindness	4	4	3

Community long-term care services

A variety of paid or formal long-term care services can assist people living in the community with age-related problems, injuries, or disabilities. As might be expected, given the overall lack of need for assistance reported by most respondents, a majority indicate they do not currently need or use any formal community-based services (see Table III-26 below). Current use or need for these services can be determined by combining the last three columns in this table: not using now but do need, using now and receiving enough, and using now but need more. Using this method, less than twenty percent of respondents currently use or need homemaker services (18%), dial-a-ride or other van service (17%), or care management (16%). Less than 15 percent of all respondents indicate current use or need for home health aide (14%), visiting nurse (12%), home delivered meals (9%), friendly visitor (10%) and adult day programs (10%). Not surprisingly, the services showing the greatest use or need are handyman services (24%) and lawn/snow care (24%).

Several additional types of formal long-term care services were included as options for people with disabilities that were not on the general survey. These included personal care assistance, vocational rehabilitation services, job support staff, and money management. One quarter to one third of respondents who answered this survey indicate a current use or need for assistance with money management (35%), vocational rehabilitation services (32%), or support staff on the job (27%). Slightly more respondents (39%) indicate current use or need for personal assistance for daily living needs.

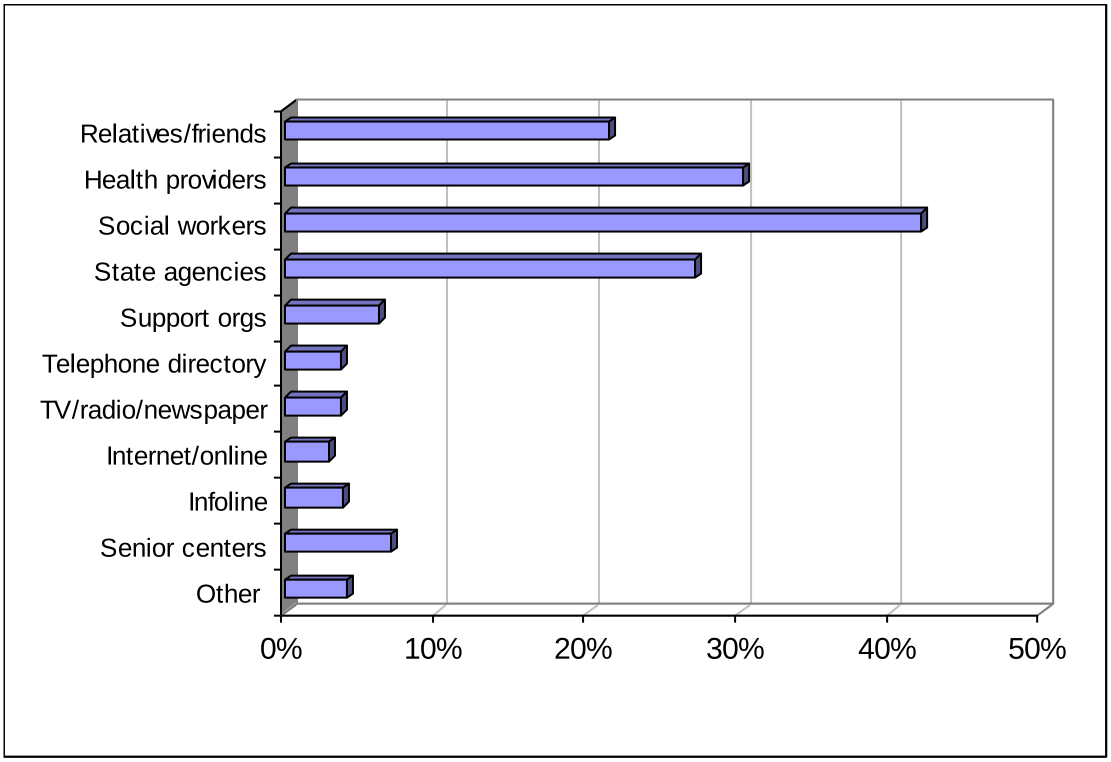
Table III-26. Need for long-term care services (percentages)*

	Not using now and Do not need	Not using now but Do need	Using now and receiving Enough	Using now but Need more
Home health aide from an agency or personal care assistant (for bathing, dressing, daily living needs, etc.)	**87**	4	7	3
Homemaker services from an agency (for laundry, shopping, cleaning, etc.)	**82**	7	9	2
Visiting nurse (to change bandages, give injections, etc.)	**88**	3	8	1
Home delivered meals (Meals-On-Wheels, etc.)	**91**	5	4	<1
Dial-a-ride or van service (transportation for shopping, medical appointments, etc.)	**84**	8	7	2
Friendly visitor services (social visits from volunteers)	**91**	7	2	1
Care management (assessment, coordination, and monitoring of services by a social worker, nurse, etc.)	**84**	4	11	1
Adult day program (activities and health services provided at care centers)	**90**	5	4	1
Handyman services (home maintenance, minor repairs)	**76**	13	10	1
Lawn or snow services (lawn care, snow removal)	**75**	10	13	1
Personal care assistance (for daily living needs, paid for privately or with a waiver)**	**60**	12	21	7
Vocational rehabilitation services**	**68**	17	12	4
Job coach or support staff at your job**	**73**	10	14	3
Money management, paying bills**	**65**	14	18	2

*Rows may not sum to 100% due to rounding
**Specific to disability survey

In a separate question, all of the respondents were asked if they are able to receive all of the above long-term care services. Nearly two-thirds (62%) of those who responded report that they are able to obtain any of the services that they may require. Of those who indicate that they do need paid long-term care services, 38 percent report that they are unable to get all the services they need. Leading reasons for their inability to get services include affordability (53%), lack of knowledge about available services (42%), can't find someone to hire (22%), unreliable or poor care (17%), services not available in their area (15%), and services not accessible for people with disabilities (10%). Asked how they find out about long-term care services, the most frequent answers are social workers or care managers (42%), health providers (30%), state agencies (27%), and relatives or friends (21%).

Figure III-7. Sources of information for long-term care services



For those currently receiving formal long-term care services, respondents report that these services meet their needs very (57%) or somewhat (37%) well, with only six percent reporting that their needs are not met well at all. Communication problems with workers providing these services due to language or cultural differences occur for some respondents. Just under one-quarter experience communication problems at least sometimes (23%), while over three-quarters experience this either rarely (20%) or never (57%).

All respondents, whether or not they had ever used any formal or informal long-term care services, were asked their preference regarding arranging and managing long-term care services, including finding, training, managing, and paying their workers. Three approaches described the management of services either primarily by an agency, together with an agency, or independently by oneself. A slight majority (60%) selected the second scenario, preferring to work jointly with an agency to find, schedule, and coordinate services, with the agency taking care of the financial paperwork such as paychecks, tax forms, etc. Over one-quarter (29%) would prefer to manage their own care independently of an agency, including the processing any financial paperwork, while only 11 percent would like the agency to primarily handle all aspects of their care for them.

Senior centers may see an increase of new members, as over half of respondents report that they are somewhat or very likely (55%) to use a senior center in the future. In addition, one out of ten already goes to a senior center.

Differences by disability status

With the exception of handyman and lawn/snow services, less than three percent of Group ND currently need or use any of the long-term care services listed in Table III-26 above. Persons in the other two groups, however, report significant need and/or current use of such services. Between 15 and 25 percent of those with self-reported impairments (Group DAS) need or use each of these services, while 25 to 50 percent of respondents from the disability survey (Group DWD) need or use each listed service. The most frequently used or needed service for Group DAS is homemaker services from an agency, while for Group DWD it is care management.

Interestingly, although Group DAS needs fewer services than Group DWD, they are more likely (by 48% to 40%) to say that they are not able to get all of the long-term care services they need. This could reflect the fact that Group DWD is already receiving substantial support from State agencies. Lack of affordability and lack of knowledge about what services are available are cited by all groups as the primary reasons they are unable to get all the service they need.

The way in which each group receives information about available services differs somewhat. The top three sources of information for Group DWD are social workers, health providers and state agencies, while for Group DAS they are relatives or friends, followed by health providers and social workers.

When asked about their preferred way of arranging for long-term care services, Group DWD is far more likely than Group ND (by 24% to 5%) to want an agency alone to find and arrange services and far less likely (16% to 33%) to want to make decisions and arrange services by themselves. Group DAS falls in between.

Differences by age

The greatest percentage of those in the youngest group (under 22) need help from a home health aid or homemaker services. The youngest as well as young adults (22-41) tend to need dial-a-ride or van service more than the other groups also, with almost as many of the oldest group (85+) requiring these services. Again, the youngest and the young adults along with the oldest group would like to have more in the way of friendly visitor services, nearly twice as many as each of the other three groups. In addition, twenty-five percent of the youngest group indicate a need for either some or more care management.

For the youngest group and the young adults, being able to afford services is a consideration. Seventeen percent of the youngest group and 13 percent of the young adults indicate that they cannot afford the services they need. Twice as many of the youngest group and the young adults feel that these services are not available in their area, and, for the youngest group, nearly twice as many as the other groups say that they cannot find anyone to hire. Once again, the youngest group, the young adults and the oldest group all represent the largest percentages of respondents who say that they do not know what services are available.

More often, relatives, friends or neighbors are cited as sources of information about long-term care services for the youngest group, the young adults and the oldest group. These same three groups also say that they found out about long-term care services through health providers, and social workers and state agencies. Logically, more of the older adults find their information about long-term care from a senior center, and more of the younger two groups find this information from their schools. A greater percentage of the younger two groups indicate that the long-term care services they receive do not meet their needs adequately.

While a majority of all groups want to work with either a provider agency or have a provider agency make decisions for them, it is interesting that a greater percentage of the older respondents clearly want to make their own decisions and arrangements regarding hiring and managing personal assistants. Thirty-two percent of the young old group, 44 percent of the older adults, and 37 percent of the oldest group report that they want to hire and manage their own paid long-term care services without assistance from an agency. Only 26 percent of the baby boomers, and even fewer of those under age 42, want to have this responsibility all to themselves (see Table III-27 below). At the same time, another quarter of those age 85 or older (23%) would like to have the agency alone manage their paid services, compared with only 12 percent of those age 75 to 84.

Table III-27. Preferences for self-directed care by age category (percentages)*

	<22	**22-41**	**42-60**	**61-74**	**75-84**	**85+**	**Overall**
Agency alone hires and manages paid services	14	17	9	8	12	23	11
Both agency and consumer work together to hire and manage paid services	76	65	65	60	44	40	60
Consumer alone hires and manages paid services	10	18	26	32	44	37	29

*Columns may not sum to 100 due to rounding

<u>Differences by income</u>

Responses by income level follow a pattern similar to responses by disability category. With the exception of handyman/home maintenance and lawn/snow care services, less than seven percent of the top three income categories require assistance with any of the long-term care services listed in Table III-26 above. By contrast, one-quarter to one-half of the low income group currently use or need each of these services, with the low/medium income group in between. The low income group names lack of affordability and lack of knowledge as the primary reasons for not getting needed services.

<u>Differences by ethnicity</u>

For Blacks and Latinos, the need for long-term care services is more than twice as high as that of the White group. For services such as visiting nurse, homes delivered meals, dial-a-ride or van service, friendly visitor service, and adult day programs, Blacks, Latinos and the other race group indicate a need for these services that they currently do not have. Compared to the White group, more than twice as many of these same three groups indicate that cost is prohibitive as far as affording any services. In addition, twice as many of the same three groups do not know what services are available as compared to the White group. Thirty-eight percent of the Latino group say that they do have problems communicating with someone who provides long-term care services because they speak a different language. Latinos reported that these problems occur either sometimes (22%) or always (16%).

Differences by Region

Service use is similar across the three groups, with approximately one-quarter of respondents in each region reporting use of paid long-term care services. Need for services or need for additional services is reported slightly more frequently by respondents in the Southern and Western regions (20%-N; 22%-S; 22%-W). Inability to afford services and lack of knowledge about services are cited most frequently as reasons for lack of service use. Both of these barriers are a slightly greater issues for the Southern and Western regions than for the Northern region.

When asked about future senior center use, somewhat more respondents from the Northern region report they are "very likely" to go to a senior center in the future, compared to respondents from the other two regions (17%-N; 15%-S; 14%-W).

Additional Services Wanted for Older Adults or People with Disabilities

Residents in Connecticut who completed either a general or a disability survey were asked an open-ended question about what services the state should provide older adults or people with disabilities. A total of 1,755 people responded to this question: 1,172 responses from the general survey and 583 from the survey for people with disabilities. The responses were compared and contrasted, and then grouped under eight distinct themes which arose from this analysis:

- Transportation
- Healthcare services
- Home and community-based services
- Financial assistance
- Programs and services
- Housing
- Recreation/social activities
- Other comments

Results for both groups are similar, and show that transportation is by far the most important service wanted for older adults or people with disabilities. Healthcare services and financial assistance are mentioned more frequently by general survey respondents than by those in the disability group, and housing and recreation/social activities are mentioned more often by disability survey respondents than general survey respondents. Both groups suggest home and community-based services, such as home care and personal assistance services, and improved programs and services for older adults and people with disabilities. Separate response rates for each theme are compared by group and displayed in the Figure III-8, while the combined results for all respondents is shown in Figure III-9. Each theme is then discussed in detail, with supporting quotes provided.

Figure III-8. Themes by respondent group

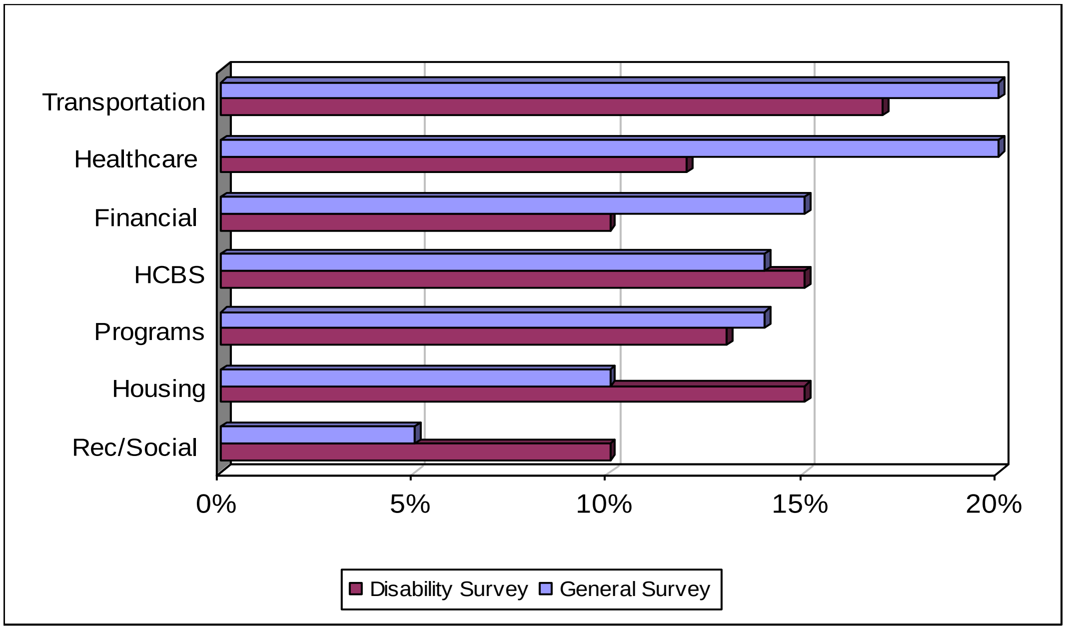
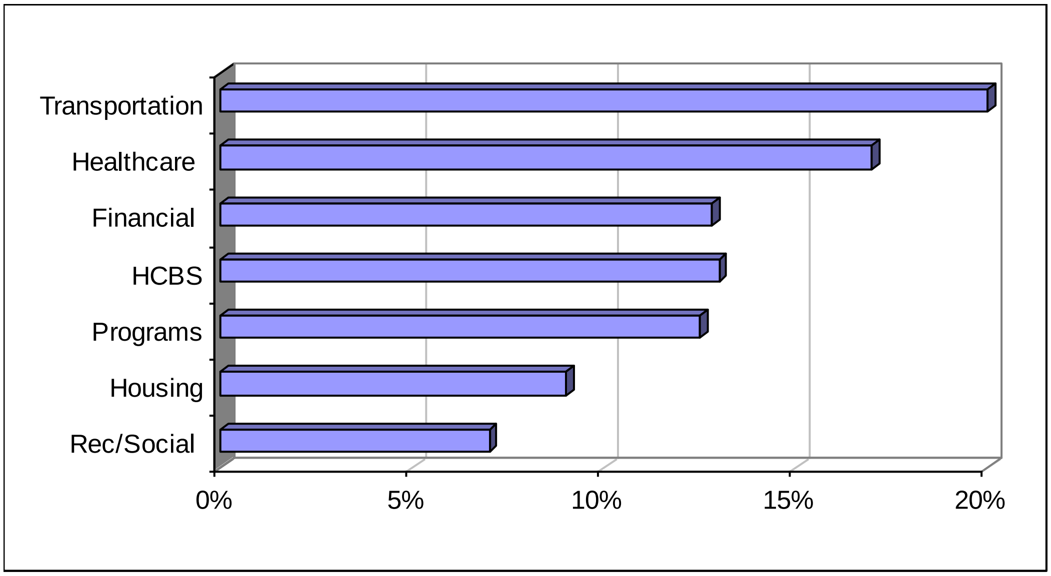


Figure III-9. Combined themes for all respondents



Transportation

One-fifth of responses to the question about what services Connecticut should provide to older adults or people with disabilities indicate that transportation services are one of the most important services that should be provided. In general, respondents report that access to transportation services is important for independent living. Transportation programs make it possible for any older adults or people with disabilities who do not drive and cannot use public transportation to obtain rides for necessary trips. These include medical appointments, errands, shopping, and other activities.

Respondents indicate that Connecticut should provide more comprehensive public transportation services for older adults or people with disabilities. This includes services that are available to residents throughout the week and weekend with expanded hours that include evenings. Respondents suggest that a wider range of transportation options would be helpful to older adults or people with disabilities who cannot drive or who may choose not to drive under certain conditions (i.e., at night).

> *Statewide public transportation services seven days a week, plus evenings.*
>
> *Early evening bus service 6-8.*

Respondents mention that town to town transportation should be provided for older adults or people with disabilities who need rides to medical appointments or who may need special transportation services for appointments with specialists who are beyond the local area (i.e., 50-80 miles away).

> *I feel the transportation system should be upgraded. You should be able to go between towns for your medical needs.*
>
> *Occasional out of town transportation to medical appointments that Senior Center transportation does not provide.*

Some respondents indicate that transportation services are also needed in rural and suburban areas where services are limited or non-existent.

> *We have very little help in this area (Windham County).*
>
> *Better transportation for isolated adults.*
>
> *Transportation is badly needed in Northeastern CT – particularly door to door. There is a fixed route bus service, but I do not live near a stop.*

In addition, respondents mention that transportation services are needed for older adults or people with disabilities to get to work, attend social engagements, visit with friends, go shopping, or to religious services.

> *More transportation for people that want to work, but have a very hard time finding ways to get there.*

> *I have a lot of friends for years but we can't together because there is no place to meet and no transportation to get there. My friends and I would like a van or some other form of transportation to bring us out to get a bite to eat together.*

Respondents indicate that wheelchair accessible vans and dial-a-ride services should be more available and that transportation overall should be more accessible, affordable and reliable. Some respondents suggest there should be discounted prices for transportation or free bus transportation for older adults or for people with disabilities as occurs in various other countries.

> *More van service schedules.*
>
> *People I know who are receiving services say transportation is their major concern – cost and availability.*
>
> *Transportation that is more readily available (i.e., without having to prearrange two or more days ahead of time for an appt. that comes up quickly).*

Healthcare services

Both medical and social models of healthcare are important in preventing, treating and managing illness, in preserving mental health and physical well-being, in providing services by the medical, nursing, and allied health professions, and enabling people to make lifestyle changes that contribute to making the population healthier.

Almost one-fifth (17%) of responses indicate that healthcare services are extremely important and should be better provided to older adults or people with disabilities. For many respondents, providing better healthcare includes offering more affordable comprehensive health insurance for low and middle income people or universal healthcare.

> *Better insurance and cheap monthly payments.*
>
> *Some form of low cost health insurance or supplemental coverage to Medicare.*
>
> *Better healthcare insurance system. Currently it costs my husband and myself $1861.31 a month for insurance – then there are co-pays for meds, doctors, etc.*
>
> *The state needs to provide a program for universal healthcare insurance coverage. 400,000 people without medical insurance in Connecticut is a disgrace.*

Many respondents mention that more comprehensive healthcare should include making long-term care healthcare insurance available at a reasonable cost to all older adults or people with disabilities who want coverage. This includes people with conditions that might disqualify them. Some respondents indicate that information and help should be provided to assist people with choosing a long-term care insurance company.

> *Affordable long-term care insurance, even with pre-existing conditions. More liberal underwriting requirements.*
>
> *Allow the premium for long-term care health insurance to be tax deductible.*

In addition, many respondents suggest the need for improved pharmacy plans that include prescription discounts and help with paying for the high cost of prescriptions. Some respondents mention that there should be no cost prescriptions for those who are age 65 and older.

> *No elderly person should have to worry about whether they eat or take medications.*
>
> *Free prescriptions or a $10.00 co-pay only.*
>
> *Expand limits of ConnPace.*

Respondents indicate that healthcare services should include dental insurance and better dental services as well as affordable, high-quality vision and audiology care for the hearing impaired including evaluations, diagnostic testing and coverage for eyeglasses and hearing aids.

> *Dental services – most seniors over 65 do not have any dental insurance.*
>
> *I bought two hearing aids in September 2006. The bill was between 3 and 4 thousand dollars. I'm paying it in 18 installments.*

A number of respondents indicate that the needs of those with behavioral health are underserved and that more mental health counseling services, group therapy, and detoxification programs for people with addiction issues should be provided.

> *Integrated mental health services in primary care settings.*
>
> *Supportive services and counseling.*

Respondents mention that a wider range of services should be provided and include greater access to and coverage for geriatric assessment, health education and rehabilitative services including chiropractic and naturopathic services that emphasize a holistic approach to health and healing.

> *Therapists, counselors, psychiatrists to help those with physical disability or those with terminal illness to cope with depression.*
>
> *The state should provide access to integrative medical services, such as craniosacral therapy, massage therapy, acupuncture and Reiki.*
>
> *We need agencies to realize that there are people who need to have chiropractic services and herbal needs. Some can't take prescription drugs so chiropractic and naturopathic are needed.*

In addition, respondents suggest that there should be better nursing home care including improved patient/aid ratio and more pleasant nursing home environments.

> *Transform nursing homes into community like settings.*

Home and community-based services

Thirteen percent of responses indicate there is a significant need to offer a greater spectrum of home and community-based services to older adults and people with disabilities in all areas of Connecticut. This includes alternatives to nursing home care, such as adult day services.

> *Adult Day Care is helpful and cost effective. Unfortunately, the best (i.e., the smallest) are in terrible financial trouble because Medicaid does not begin to cover the cost of care. Large programs are more fiscally viable, but not as helpful for meeting elder's perceived needs. Small Adult Care programs should be subsidized more generously. I believe much expensive nursing home care could be deferred if day care was available.*
>
> *More adult day care centers (Eastern CT).*

More home services, such as Personal Care Assistant services, Personal Assistant services or compensation for family members who provide care to older people with disabilities are needed to help people remain in their homes for as long as possible.

> *Home care should be provided when trying to avoid a nursing home – family cannot provide 100% care at all times and need help in order to continue with aspects of their life (i.e., work, etc.).*
>
> *Provide an alternative to nursing home care such as the state of Vermont does. Pay family members /friends to provide home care assistance.*
>
> *Family should be involved/responsible as much as possible for care of elderly/disabled. Family need support services as they need to maintain their own lives/families.*

In order to retain quality homecare workers, respondents suggest that these workers should receive better pay for their services and that home health and homemaker services should be more affordable so people can receive the care they need within their community.

> *If people have the strong desire, the physical ability, and mental capacity to remain in their home in the community where they have family and friends, it should behoove the state to help provide and pay for services to keep people in their homes because the cycle of being shuffled between hospitals and nursing homes is inhumane and deprives a person of dignity and compassionate care, creates unnecessary stress, and is much more expensive.*

Respondents mention that more residential group homes in local neighborhoods are also needed for older adults and people with disabilities in order to keep them out of nursing homes and in a more home-like environment. In addition, respondents suggest that waiver services are needed for people with acquired brain injury who don't need assistance with two or more activities of daily living. Other services that are suggested include home psychiatric services and informational services to let people know what services currently exist within the community.

Financial assistance

Thirteen percent of responses are from people who indicate that financial assistance is needed for older adults and people with disabilities. This includes tax breaks or tax reductions as well as tax incentives.

> *Tax relief. I'm 85 years old and paying $10,000 per year for the house alone.*
>
> *Reduce property taxes! In a few years I may have to sell my home and move into senior housing because I will not be able to afford property tax and the cost of fuel and electricity any longer.*
>
> *Exempt all social security and pension income for income tax! This tax is a killer which drives people out of Connecticut.*

Respondents mention that financial assistance is needed to help older adults and people with disabilities pay for the rising cost of utilities, which are basic life expenses.

> *Financial assistance with heat and electric.*
>
> *I work every day but can't earn enough to pay my bills.*

Some respondents indicate that financial assistance is needed for food, medication, dentures, hearing aids, home care, and transportation. Some people indicate that financial support for home modifications, such as stair lifts, would be beneficial so older adults and people with disabilities can age in place.

> *Today everything keeps increasing except for your income. Food, gas, taxes, insurances, shopping – everything.*
>
> *Financial help with repairs/maintenance, and household services in the form of sliding scale rates and very low or no-interest loans.*

In addition, respondents suggest that financial management assistance or money management services (i.e., for bill paying), estate planning assistance, real estate and asset counseling, and legal advice should be available to older adults and people with disabilities.

> *Older adults and people with disabilities need affordable legal advice.*

Programs and services

Thirteen percent of responses indicate a need for better provider programs and services for older adults or people with disabilities. Respondents suggest that social services should be expanded and that more care coordinators and social workers are needed to provide support and make it easier to access services and navigate the healthcare network.

> *Case management is an essential role and piece to keeping the elderly individuals in their home.*

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

Respondents mention that it should be easier to know what services are available and how to access them. An effective information network that links services for people would begin to meet this need. Some respondents suggest that the state should provide a wider range of supportive services for older adults and people with disabilities through Connecticut's Area Agencies on Aging and programs such as the CHOICES Program.

> *A central coordinating agency that is familiar with all the programs and overall basic information. They can point you in the right direction and make referrals from there.*
>
> *A directory of services and providers should be published and made available. Also, there are programs and aid out there you only find out about if someone is willing to share the information or if you ask the right question.*

Respondents indicate that the state should provide better quality food and nutrition services, such as Meals-on-Wheels, to better sustain older adult or people with disabilities who live in their homes but are unable to prepare their meals.

> *Provide meals on wheels for those who need it.*
>
> *Vegetarian options for food services.*

Many respondents suggest that respite services are needed to support caregivers and should be provided to those who care for older adults or people with disabilities. Some respondents indicate a need for financial support for these services.

> *As I get older and can no longer care for a disabled daughter, will need more respite time (i.e. weekends, night time, occasionally weekend care).*
>
> *Respite care for those who look after the sick [family member].*
>
> *We need more respite money to get a break (parents). We do not get enough funding.*

Some respondents report that they are dissatisfied with the quality of services offered by the state and that the service system needs to be revamped for easier usage. In addition, respondents mention that more competent and reliable people are needed to help people find the services they need.

> *Our citizens that need these services can not get them. The paperwork and what the agency's put you through is humiliating.*
>
> *The agencies are not reliable. My family and I could probably do better on our own for getting services. DMR needs to be better funded so the waiting list is reduced.*

Housing

Nine percent of responses mention a need for more affordable housing and a broader range of housing alternatives for older adults or people with disabilities including more assisted living options, senior housing projects or apartments in local communities. Some respondents mention concern about the need to control rent increases in senior complexes and for rental assistance, financial aid or subsidized housing.

> *Lots of housing options at a reasonable cost.*
>
> *Many of us cannot afford homes or condos over $100,000 or apartments over $900/month in a 55 or older complex or even something like Avery Heights.*
>
> *Great need for good quality assisted living.*
>
> *Rental assistance for physically handicap should be readily available. Section 8 housing is in limited supply for physically handicap (not over age 65).*

Other suggestions for housing options include building cluster housing and planned, intergenerational communities. In addition, some respondents mention that older adults or people with disabilities should have help in planning for future housing needs if they want it.

> *Help people consider various options for where they can live and how to finance it well before they actually have to make such a decision so there is time to think and prepare!*

A small percent of the responses related to housing mention that those with homes would like more available and affordable handyman services, such as painting, repairs and maintenance of grounds so that they can continue to remain in their homes.

> *There should be a list of dependable handymen, as well as individuals who do snow removal and lawn care along with the price of said service available in each Senior Center. It is very hard to find reliable people to do these things in a timely manner…and at reasonable prices.*
>
> *Handyman services would help me stay in my home longer.*

Recreation and social activities

Seven percent of responses mention that older adults or people with disabilities need affordable recreation and social activities including exercise groups, outside activities (i.e., day trips) and entertainment.

> *Give them more things to look forward to.*
>
> *More variety of activities free for those who don’t have the money or funds to work with.*

Some respondents suggest that companions or friendly visiting is an important part of life that is lacking for many people who live alone and who are more isolated than others.

> *Older people are lonely. It would be nice to have trustworthy people visit with the elderly who can no longer drive and get out of the house.*
>
> *I really think volunteers paying friendly visits would be great. As far as I know this service is not provided in my area.*

<u>Other comments</u>

A small number of responses did not fit into any of the categories mentioned above. Of these responses, some respondents indicate that they do not know what services should be provided for older adults or people with disabilities in Connecticut. Other respondents mention that they don't currently need any services or that the current services offered are adequate.

> *Don't know exactly what's available.*
>
> *In case of my disability, the state has been amazing! The people have been extremely helpful and accommodating, caring, patient, and very efficient! I am truly grateful. The state is currently helping me return to work.*

Social support

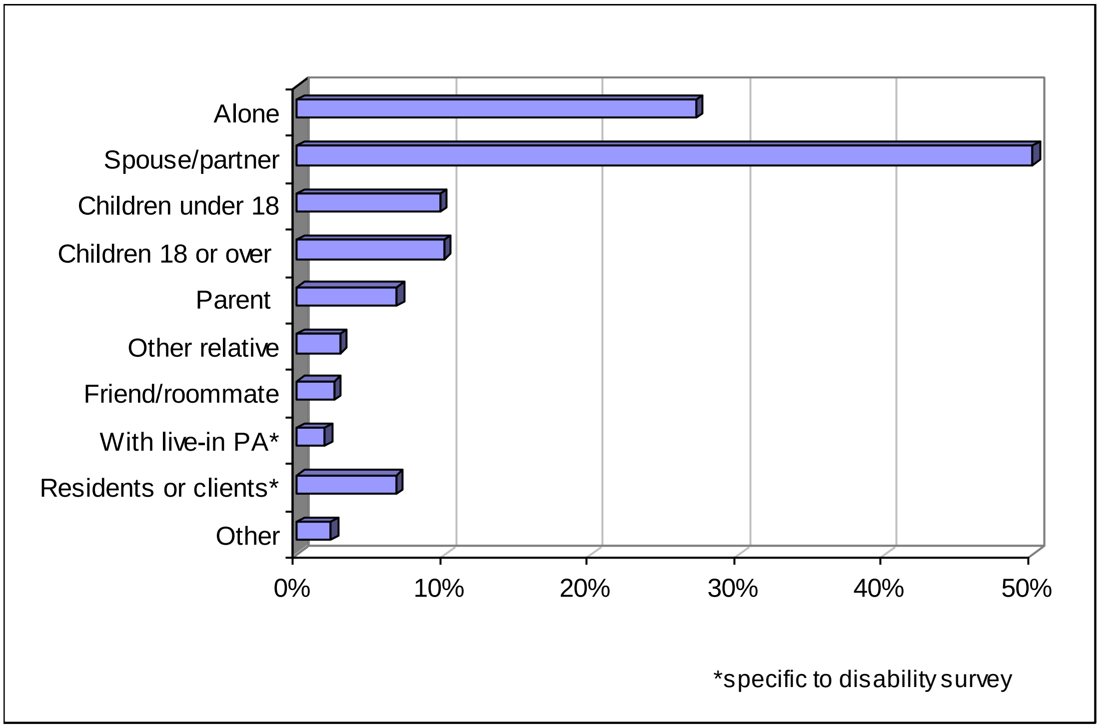
Social support encompasses any emotional or physical help or assistance we receive from our family, friends, co-workers, community members, or others. These relationships provide us with social contact as well as a network of people who might help us in a variety of ways, including emotional support or more tangible assistance, such as help with our daily lives or financial support. This informal assistance may take the place of, or supplement, paid services. A majority of respondents (76%) report that they may count on family or friends if they needed help with daily tasks such shopping, cooking, or transportation. Almost one-quarter of all respondents said that they do currently receive this type of unpaid assistance from family or friends at least once a week. An even larger number (87%) can count on someone to provide emotional support for problems or difficult decisions. As for financial support, forty-two percent report that if they need some extra help financially, they can count on someone to help them by paying any bills, housing costs, medical costs or even providing them with food or clothes.

Table III-28. Social support from family and friends (percentages)

	Yes	**No**
Can count on family or friends for help with daily tasks if needed	76	24
Currently receive this assistance at least once a week	23	77
Can count on someone for extra financial help if needed	87	13

With whom we live is important, as physical or other support is often provided by family or friends who live close by. Current living arrangements vary, with the largest number (50%) living with a spouse or partner, followed by those who live alone (27%), and those who live with children of any age (20%). Only seven percent live with a parent, and very small numbers live with another relative, friend or roommate. The survey for people with disabilities included two additional options: living with a live-in paid personal assistant (2%) and other living arrangements (2%). A new category, living with other resident or clients, was carved out of the responses written in on the survey for people with disabilities. In all, seven percent of respondents to this survey wrote in that they live with others in a group home, mental health institution, nursing home, or other facility.

Figure III-10. Living situation

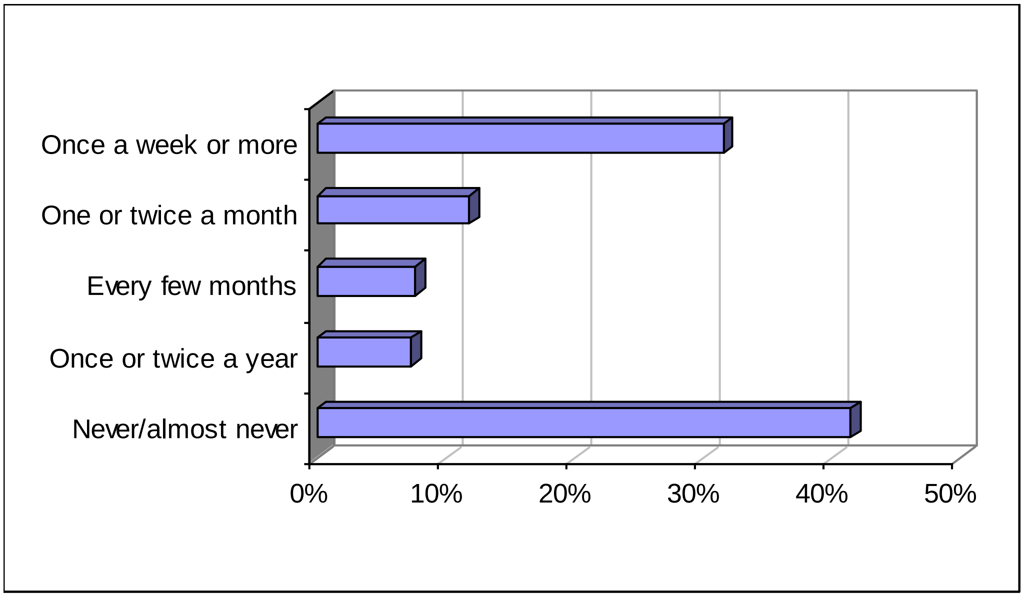


The general survey included a question regarding children who are living. Most respondents to this survey (84%) have at least one child, the majority of whom are age 18 or older. A minority of the sample (16%) report no living children. For those with children, over three-quarters live within 45 minutes of at least one of their children.

Almost half (54%) of all respondents leave home for some reason every day, while 25 percent leave home four to six days per week, and 13 percent leave home three days per week or less. Eight percent of respondents leave their homes much less frequently, only one day a week or less or only for medical appointments. Most respondents (84%) are happy with how often they leave their home, while 12 percent wish to go out more often and four percent less often.

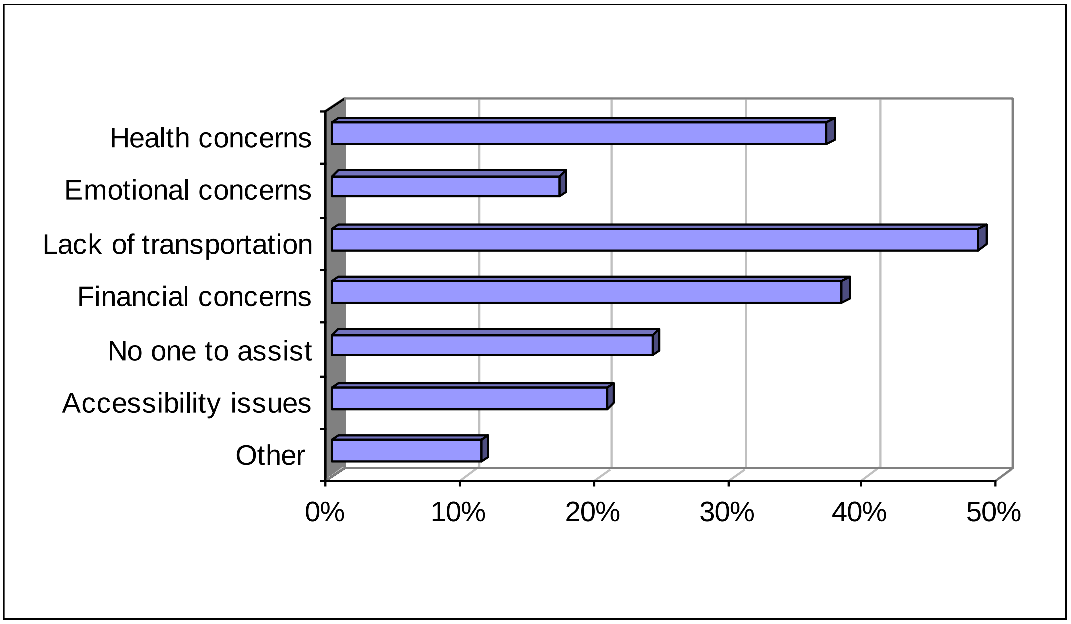
Two additional questions regarding social support were included on the survey for people with disabilities: participation in the community and barriers to going out. Community activities or groups is widely defined in the survey as “a community center, social group, advocacy group, religious group, support group, sports group, or any other community group. etc., or any other community group.” Still, 42 percent indicate they never or almost never participate in such activities, with an additional seven percent participating only once or twice a year. On the other hand, one-third of respondents (32%) are much more active in community groups, participating once a week or more.

Figure III-11. Rate of participation in community activities for persons with disabilities



When asked what keeps them from going out more often (check all that apply), the number one barrier is transportation, which affects almost half (48%) of those completing a disability survey. Financial and health concerns affect more than one-third of these respondents (38% and 37%, respectively). Nearly one-fourth of respondents (24%) report that there is no person available to assist them, while slightly fewer respondents indicate accessibility issues (21%) or emotional concerns (17%) prevent them from leaving their home and going out more often.

Figure III-12. Reasons that keep people with disabilities from going out more often



Differences by disability status

Questions concerning help from family and friends generated an interesting contrast. While both Groups DWD (disability survey) and DAS (ADL/self-reported) are slightly less likely to say that they can count on family or friends for help with daily tasks than Group ND (71% vs. 80%), in fact they are currently receiving substantially more of such help, perhaps because of their greater current need. Fifty-five percent of Group DWD currently receives help from family or friends at least once a week, compared to 37 percent of Group DAS and only six percent of Group ND.

There are also substantial differences in living situation among the three groups. Whereas 67 percent of Group ND live with a spouse or partner, only 48 percent of Group DAS and a mere 13 percent of Group DWD do. Persons in Group DWD are far more likely than the other groups to live alone or with a parent, friend or roommate, and less likely to live with their children of any age.

Propensity to leave home also differs among the groups. Although nearly all of Group ND leave home four days a week or more, only about half of Group DWD and two-thirds of Group DAS do. However, a large number (a third of Group DWD and 20% of Group DAS) want to go out more.

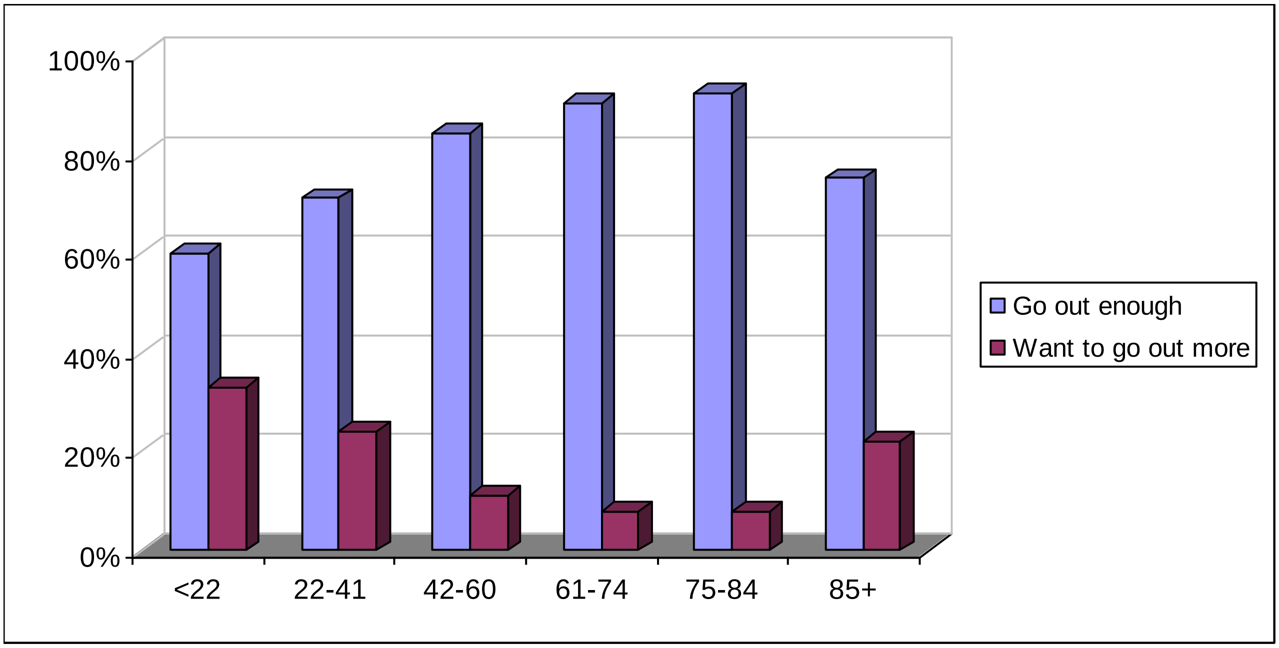
Differences by age

Most respondents, no matter what their age category, can rely on someone to help with either emotional support or daily tasks. As can be expected, a greater percentage of the youngest (75%) and the oldest (55%) currently receive assistance with daily tasks like shopping, cooking, or driving. It is also not surprising that more of the youngest group (75%) feel that they could count on family or friends for financial assistance to pay bills or other costs, while about half of both the older adults (45%) and the oldest (52%) indicate this is true for them. On the other hand, such financial assistance is not available for the majority of the baby boomers (63%) or the young old (60%).

Although differences in living arrangements are great, there are no unexpected results. For example, more of the oldest (55%) as well as older adults (43%) live alone, compared to only two percent of the youngest. Baby boomers and the young old are also most likely to live with a spouse, while a much higher percentage of the youngest live with a parent. In addition to having the greatest percentage who live alone, the greatest percentage of the oldest also live with an adult child (17%), followed by baby boomers (14%). Young adults are the most likely to have a child under age 18, while over 80 percent of the young old, older adults, and the oldest have at least one living adult child.

Over one-quarter of those age 85 and over (28%) are effectively homebound, leaving their house only for medical appointments or less than one day a week. This number represents a huge increase over the older adults, of whom only eight percent go out of their homes less than once a week. At the same time, three-quarters of the oldest respondents report they are satisfied with how often they go out. This is in comparison with 60 percent of the youngest who are satisfied. In addition, one-third of the youngest would also like to go out more, compared with just about one-quarter of young adults (24%) and one-fifth of those age 85 or older (22%).

Figure III-13. Preference for going out by age



Differences by income

Survey results by income status track results by disability status fairly closely, due in part to the large overlap between Group DWD and the low income category. The low income group is less likely to report the ability to count on others for help with daily tasks than the higher income groups (67% vs. 79%), yet is currently receiving far more of such help (52% vs. 10%).

Current living situation also varies greatly by income group. Nearly 80 percent of the two highest income groups live with a spouse or partner, compared to only ten percent of the low income group. The two lowest income groups are more likely to live alone. Results for all income categories are presented in Table III-29 below.

Table III-29. Living arrangement by income category (percentages)*

	Low	Low/ medium	Medium	Medium/ high	High
Alone	**46**	**42**	22	13	13
Spouse or partner	10	34	**67**	**79**	**78**
Children under 18	3	5	10	18	16
Children 18 or over	6	12	13	11	11
Parent	18	6	4	4	3
Other relative	7	4	2	1	1
Friend or roommate	6	3	2	1	2

*Columns may not sum to 100% due to rounding

Income groups also differ in how often they leave their homes each week. Over ninety percent of the three highest income groups leave home at least four times per week, compared to three-quarters of the low/medium income group and only half of the low income group. One-third of the low income group wants to go out more often, compared to 14 percent of the low/medium income group and less than five percent of the three highest income groups.

Differences by ethnicity

The Black group and the Latino group both currently receive more help with things like grocery shopping, cooking, and getting rides from either friends or family. Forty-two percent of the Latino group and 41 percent of the Black group currently receive this type of assistance, compared to 21 percent of the White group and 29 percent of the other race group. This need for assistance with things like getting rides may be related to their responses to the question as to whether they go out enough. Nearly twice as many of the Latinos, Blacks, and the other race group say that they do want to go out more as compared to the White group.

Living situations vary by ethnicity as indicated in Table III-30. The largest percentage of Latino and Black groups live alone, while the largest percentage of the White and other race group live with a spouse or partner. Latino respondents are only slightly more likely than Whites or Blacks to live with an adult child.

Table III-30. Living arrangement by ethnicity (percentages)*

	White	**Latino**	**Black**	**Other race**
Alone	28	**36**	**40**	28
Spouse or partner	**56**	32	21	**53**
Children under 18	10	13	7	22
Children 18 or over	10	13	11	5
Parent	7	8	9	16
Other relative	3	5	7	2
Friend or roommate	3	2	5	2

*Columns may not sum to 100% due to rounding

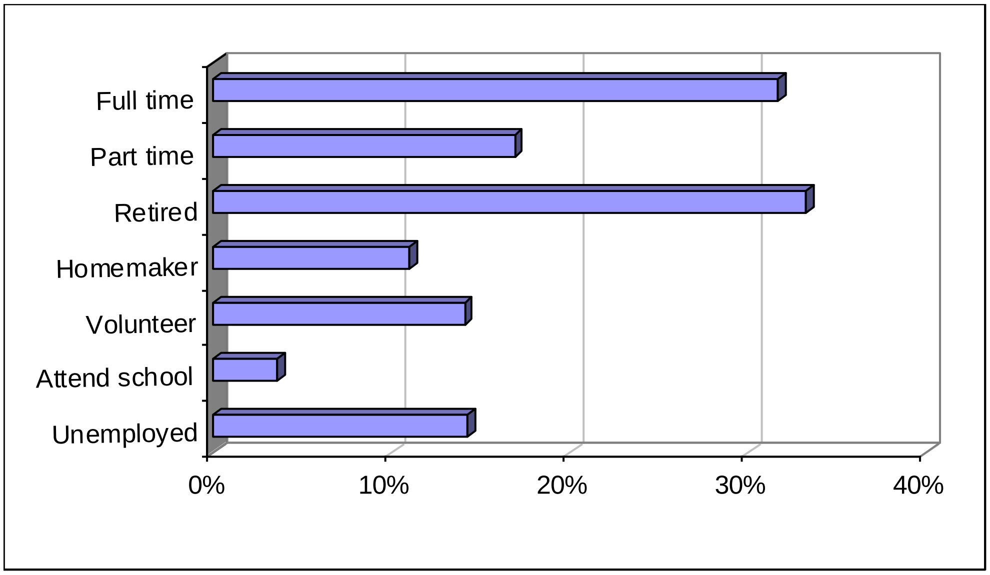
Differences by region

There are no significant differences among the three regions regarding social support. About three-quarters of respondents in each of the regions can count on family or friends for help with daily tasks, and many respondents are currently receiving the help. The vast majority of all respondents have family or friends available for emotional support. Slightly less than half of respondents from each of the three regions can count on another individual for financial help. Very little difference exists with respect to living arrangements, with the majority of respondents in each region reporting that they live with a spouse or a partner. Most respondents in each region have living children, and most of these children live with 45 minutes.

Employment and transportation

Nearly half of all respondents are currently employed, either full or part time, and one-third are retired. Fourteen percent list themselves as unemployed. Smaller numbers are homemakers, volunteers, or full or part time students.

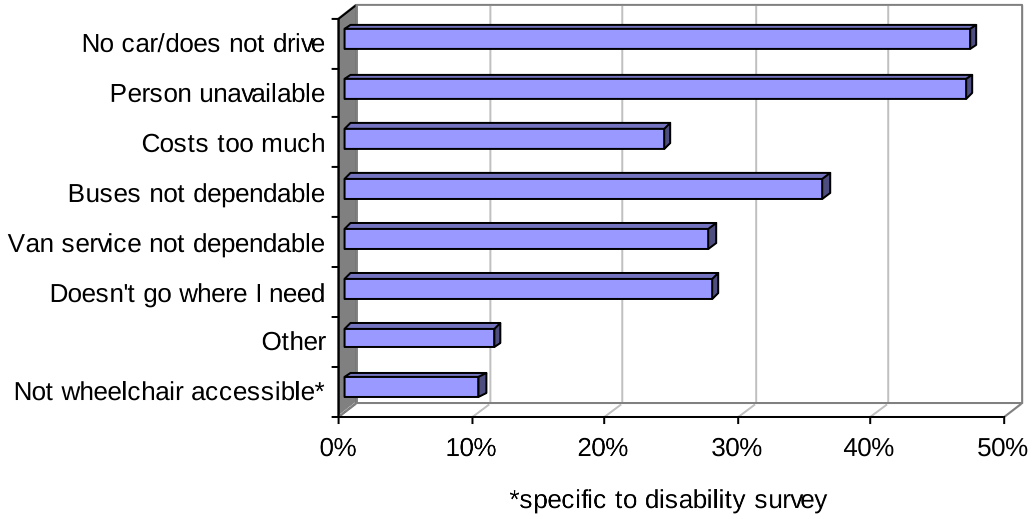
Figure III-14. Employment status



Over one-fifth (21%) of those not currently working do want to have a job. Of those respondents who would like a job, over one-third (38%) are actively job hunting. Twenty-five percent of those not currently in school would like to get more schooling or education. Mean age when respondents plan to retire is 65, and ranges from age 18 to 100.

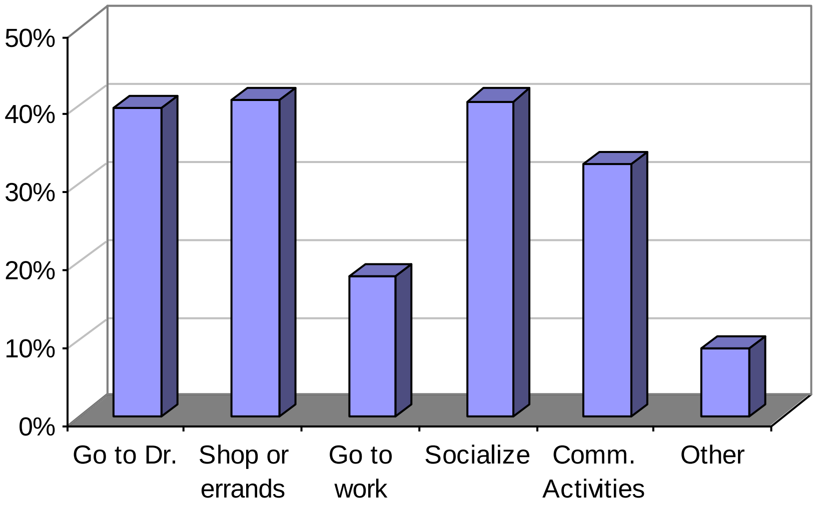
Over three-quarters (77%) of all respondents report no problems with transportation. For all of those who indicate that they have problems with transportation, 47 percent say that they do not own a car and/or do not drive. Another 47 percent of those who have difficulties with transportation report the lack of a person to assist or drive, while for over one-third (36%) public buses are unavailable or undependable. Other transportation problems include van or bus will not take me where I want to go (28%), dial-a-ride or other van services are unavailable or undependable (27%), and cost (24%). For people with disabilities another option was offered. Among the respondents to the disability survey who indicate difficulties with transportation, ten percent checked this other option: that the car, bus or van is not wheelchair or scooter accessible.

Figure III-15. Reasons for transportation problems among those who have difficulties



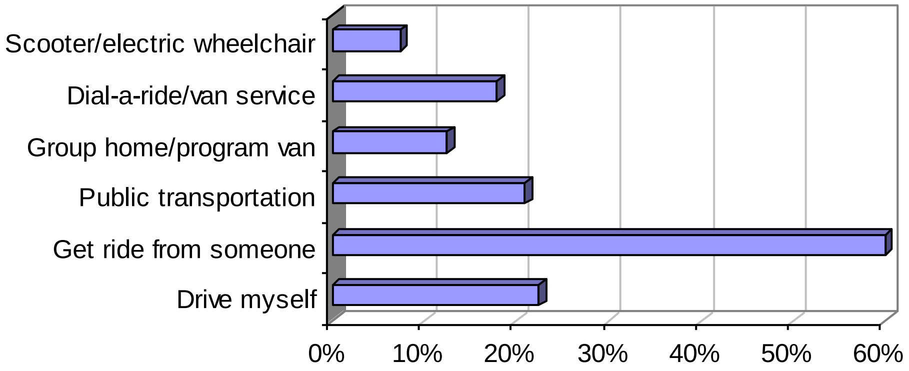
Problems with transportation do make it difficult for some people (about 40%) to socialize, go to medical appointments, shop or do errands. Other reported difficulties include taking part in community activities (33%) and going to work (18%).

Figure III-16. Impact of transportation problems among those who have difficulties



An additional transportation question was included in the survey for people with disabilities, "How do you usually get to places out of walking distance? (Check all that apply)." The majority of these respondents (61%) indicate that they usually get a ride from someone else, either a family member, friend or paid assistant, while one-quarter of respondents (22%) drive themselves. Twenty-one percent of the respondents use public transportation, 18 percent utilize dial-a-ride or other van service, and another 12 percent rely on the group home or day program van. Only seven percent of respondents use a scooter or electric wheelchair.

Figure III-17. How do you usually get to places out of walking distance?



Differences by disability status

The employment status of the three groups differs considerably. Group ND, respondents with no disabilities, is most likely to work full time (46%) or be retired (33%). Group DAS (ADL/self-reported), perhaps related to their higher mean age, reverses the order of those two categories, with 54 percent retired and 20 percent working full time. For those who completed the disability survey (Group DWD), however, the most likely employment status is unemployed (39%) followed by working part time (20%). For those not currently working, members of Group DWD are far more likely to want a job (33%) than the other two groups (14%).

For people with disabilities, there are also some striking differences in responses concerning transportation. For example, while only eight percent of Group ND have problems with transportation, 35 percent of Group DAS and more than half (55%) of Group DWD experience transportation problems. While reasons for the transportation difficulties are ranked the same for the three groups (e.g. inability to drive and having no one available to assist are the top reasons cited by all groups), Group DWD has trouble ten to fifteen times as often as Group ND, with Group DAS about halfway between.

Moreover, while the impact of transportation problems occurs in the same areas for all groups, with medical appointments, errands and socializing being the most adversely affected, Group DWD once again experiences these problems ten to fifteen times as often as Group ND, with Group DAS in between.

Differences by age

More than half of the baby boomers are working full time, compared to about only one-third (31%) of the young adults and one-fifth (21%) of the young old group. As would be expected, more than three-fourths of the older adults and oldest adults are retired (81% and 82% respectively). Twenty percent each of the young old group and the older adult group are involved with volunteer work. Unemployment figures are higher for those in the two youngest groups with 24 percent of the youngest group and 30 percent of the young adults reporting that they are unemployed. About 40 percent of the youngest group and the same percentage of baby boomers say that they would like to have a job, however only about one-fourth of the youngest group who would like to have a job are currently job hunting. Whether or not the respondents want to go to school or get more education is inversely proportional to age.

Transportation is problematic for the two youngest groups and the oldest group. Nearly one-fourth of these groups indicate that they do not have a car or do not drive. Almost the same number of these groups also say that no one is available to assist or to drive them. Nearly twice as many of the young adults, as compared to the other groups, say that transportation costs too much or that public buses are either not available or not dependable. Nearly twice as many of the young adults and the oldest group indicate that dial-a-ride or other van services are not always available, compared to all of the other groups, and that the van or bus does not always go to the places they need to go. Also nearly twice as many of the young adults and the oldest group say that transportation problems make it difficult to go to medical appointments, shop or do errands, or socialize. Transportation makes it difficult to take part in community activities for the youngest group and the young adults both. Nearly twice as many of the respondents in these groups have problems as compared to all the other groups.

Differences by income

There are two stark contrasts in employment among the groups by income level. Over half (51%) of the top three income groups work full time, compared to18 percent of the low/medium income group and only 3 percent of the low income group. As might be expected, a far higher percent (42%) of the low income group are unemployed than the low/medium group (16%) or the three top income groups (5%).

Difficulties with transportation paint a similar picture. Over half of the low income group (57%) experience difficulties with transportation, compared with 28 percent of the low/medium income group and 12 percent of the highest three income groups. While medical appointments, socializing and doing errands are the areas most affected by transportation problems for all groups, the low income group experiences those problems more than twice as often as the low/medium income group, and about six times as often as the top three income groups.

Differences by ethnicity

Over half of the Whites (51%) and the other race group (59%) are either working full time or part time, whereas only 37 percent of each the Black group and Latino group are working full or part time. Nearly twice as many Latinos and Blacks are unemployed (28% and 33% respectively). Significantly more of the Black group and the other race group indicate that they want more schooling or education (37% and 45% respectively). Only about one-fourth of the other two groups say that they want more education.

Eighty-two percent of the White group indicate that they do not have any problems with transportation; however, over one-third of the other three groups say that they do have some difficulties with transportation (Latino 40%; Black 36%; other race 38%). More than twice as many of these three groups compared to the White group indicate either no car available or do not drive. They are almost twice as likely as the White group to have no person available to assist or drive them. Problems with getting to medical appointments, shopping and doing errands, getting to work or finding a job and socializing are more than twice as likely to affect Latinos, Blacks and other race group when compared to the Whites.

Differences by Region

Rates of full time employment are slightly lower in the Southern region, while at the same time, rates of retirement are higher. Rates of attending school full or part time are slightly higher in the Western region. There is very little variation between the regions in terms of the number of individuals who are not working for pay, but want to have a job; however, individuals in the Southern region who want employment are most actively job hunting (36%-N; 43%-S; 34%-W).

Table III-31. Percent employment status*

	Northern	**Southern**	**Western**
Work full time	35	30	31
Work part time	17	18	18
Retired	34	36	32
Homemaker	11	12	12
Volunteer	16	15	13
Attend school full or part time	3	3	5
Unemployed	14	16	15

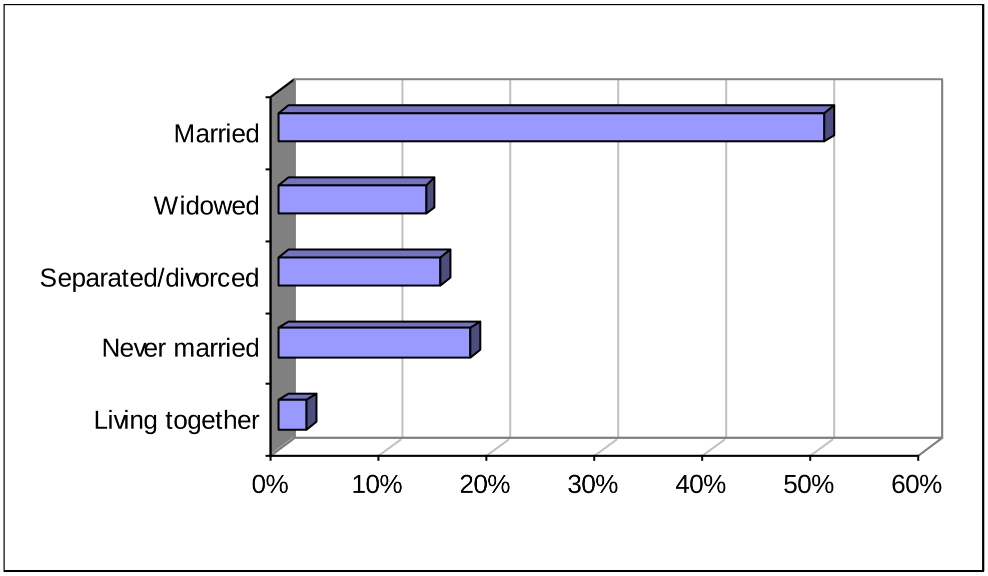
*Columns may not sum to 100% due to rounding

Transportation problems are fairly equal across regions. However, respondents in the Southern and Western regions report some transportation difficulties more frequently than respondents from the Northern region. Although the individual differences are small, when taken together they point to a trend of greater transportation concerns in these regions. Individuals in the Southern region are somewhat more likely than either the Northern or Western regions to report that cost makes transportation difficult or that the current van or bus routes do not take them to the places they need to get to. Moreover, slightly more respondents in either the Southern or Western regions report that transportation issues make it difficult for them to work or find employment, compared with respondents from the Northern region.

F. General information

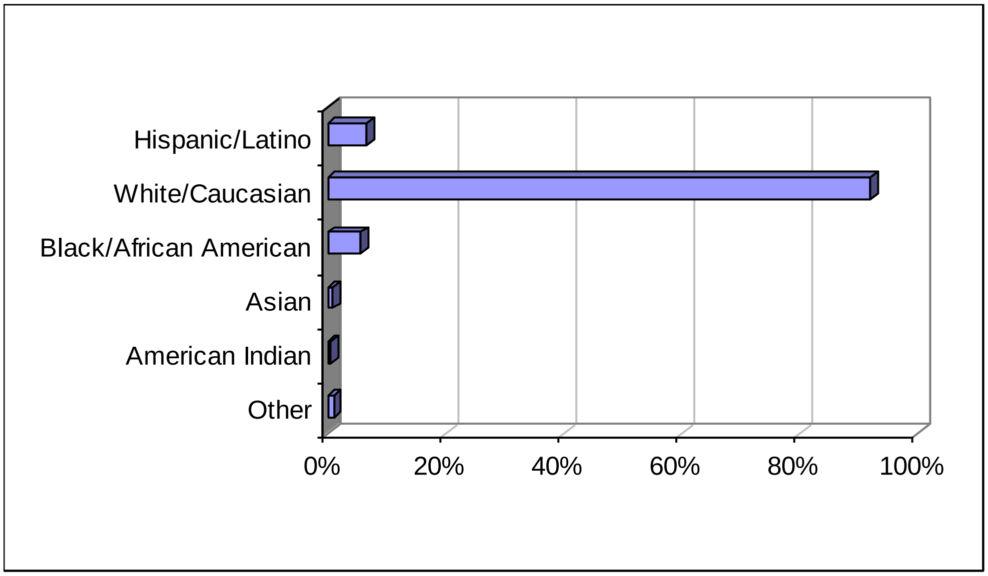
Demographic information includes zip code, age, gender, marital status, language, race/ethnicity, and education. Respondents come from all over the state. All eight counties are represented, with the greatest percentage from Hartford and New Haven counties (32% and 22%, respectively). Over half of the respondents are female (60%), with 40 percent male. Mean age is 59, with an age range of 3 to 100 years old. Half are married (51%), with an additional four percent living together as though married (see Figure III-18 below):

Figure III-18. Marital status



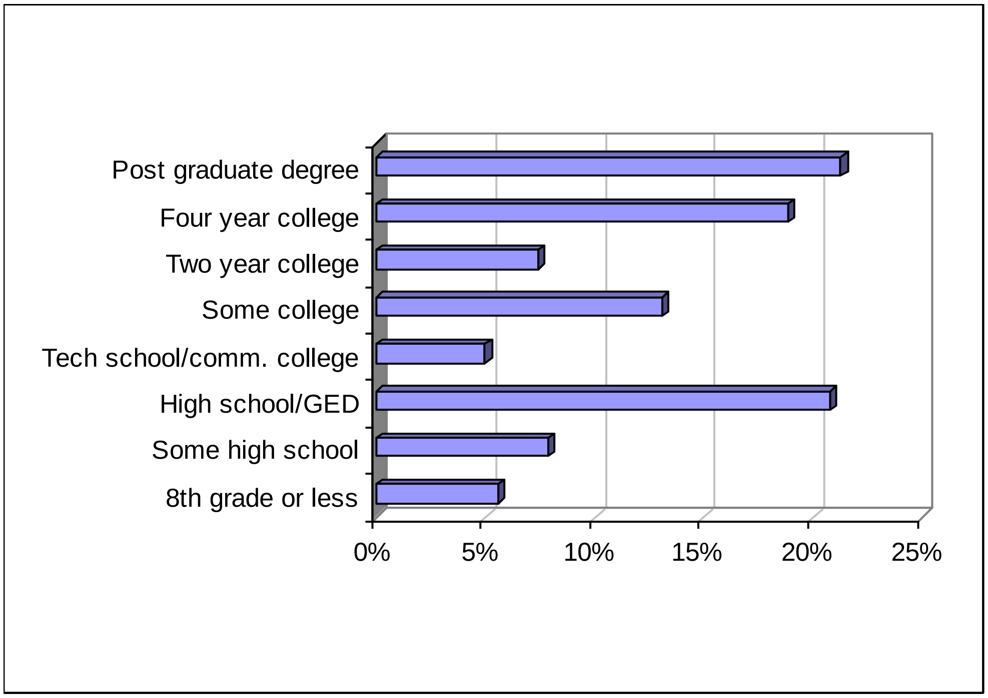
The vast majority of respondents (95%) speak English, with only small percentages speaking primarily Spanish (3%) or some other language (2%) at home. Most respondents are non-Hispanic white (92%), with less than ten percent either Hispanic/Latino (7%), or Black/African American (6%).

Figure III-19. Race/ethnicity



The education level of respondents is somewhat divided. About 40 percent received a four-year college or post-graduate degree, while 35 percent earned a high school diploma or less.

Figure III-20. Highest grade finished in school



Over three-quarters of respondents filled out the survey by themselves (77%). Correspondingly, only two to four percent of respondents report assistance in completing the survey from each of the following: spouse/partner, adult child, parent, or paid assistant (choices were not mutually exclusive).

Differences by disability status

Demographic data vary considerably by disability status. The mean age of respondents completing the disability survey (Group DWD) is 50, compared to 67 for Group DAS and 60 for Group ND. Sixty-eight percent of Group DAS members are over age 60, compared to half of Group ND and only 25 percent of Group DWD. Members of Group DWD are also far less likely to be married than the other groups (only 13% compared to 48% for Group DAS and 68% for Group ND). Over half of Group DWD have never married. Groups DAS and DWD are more likely to speak Spanish at home than Group ND (5% vs. only 1%). Groups DWD and DAS are also more likely to be of Hispanic/Latino origin (11% and 9% respectively), compared to Group ND (4%). Members of Group DWD are also more likely to be Black/African American than the other two groups (12% vs. 3-4%). Finally, educational attainment differs substantially among the groups. More than half of Group ND have a four-year college degree or more compared to only 12 percent of Group DWD. Sixty-six percent of Group DWD attained a high school diploma or less, compared to only 20 percent of Group ND and 40 percent of Group DAS.

Differences by age

Demographic data for the various age groups vary significantly. The majority of both the youngest group and the young adults have never been married (91% and 63% respectively). As would be expected the majority of the oldest group are widowed (65%). A larger percentage of Latinos are represented in the two youngest groups, between 10 and 15 percent each. The largest percent of the youngest group (78%) have either an 8th grade education or less or only some high school, whereas the great majority of young adults (84%), baby boomers (92%), young old (88%), older adults (84%) have at least a high school diploma or GED. Two-thirds of those age 85 or older also have at least a high school degree. Almost half of the baby boomers (47%) and the young old group (43%) have either a four-year college degree or post-graduate degree.

Differences by income

Similarly, demographic data vary substantially by income level. The low income group has a mean age of 53, compared to 64 for the low/medium income group and 59 for the three highest income groups. Income is highly correlated with marital status: the higher the income the more likely one is to be currently married, with a range of 10 percent for the low income group and 76 percent for the high income group. Similarly, 48 percent of the low income group never married, ranging down to seven percent for the high income group. Divorce rates also decrease with income, ranging from 21 percent of the low income group to six percent of those with high income.

More than 97 percent of the top four income groups speak primarily English at home, while of the low income group, ten percent speak primarily Spanish and four percent speak primarily another language. The low income group is more likely to be Black/African American than the top three income groups (15% vs. 2%) or of Latino/Hispanic origin (17% vs. 3-5%). Attained educational level correlates with income: 36 percent of the low income group has less than a high school diploma compared to 18 percent of the low/medium income group and only four percent of the three highest income groups. More than two-thirds of the top two income groups attained at least a four-year college degree compared to 45 percent of the medium group, 23 percent of the low/medium group, and only nine percent of the low income group.

Income level is also related to the likelihood that respondents filled out the survey by themselves. Whereas 90 percent or more of the top three income groups filled it out themselves, only half of the low income group and three-quarters of the low/medium income group did.

Differences by ethnicity

Age also varies by ethnicity. The mean age for Whites is 60, compared to 54 for both Latinos and Blacks and 49 for the other race group. Half of the White group and the other race group are married (53% and 49% respectively) however a slightly higher percentage of Blacks and Latinos are divorced (19% and 22% respectively) compared to only 13% of Whites and 10% of the other race group. Also, over one-fourth of those in the Black, Latino and other race group have never been married, as opposed to only 16 percent of Whites. The majority of Whites, Blacks and the other race group indicate that they speak English mainly at home. Forty-two percent of the Latinos say that their main language is Spanish, and 20 percent of the other race group indicate another language besides English as their main language spoken at home. A larger percentage of the Black group and the Latino group have only a high school education or less (58% and 55% respectively). Furthermore, 31 percent of the Black group and 39% of the Latino group do not have a high school diploma or GED. A greater percent of the White group (62%) have either attended some college or have completed college or post-graduate degrees, and 70 percent of the other race group report that they too have either attended some college or have received either college or post-graduate degrees.

Differences by region

Women in the Northern region are slightly more likely to respond to the survey than women in the other two regions (63%-N; 58%-S; 59%-W). Marital status is virtually identical between the three regions, as is race, and age (mean age 59-N; 60-S; 59-W). Approximately six percent of respondents in any region are of Latino origin (7%-N; 6%-S; 6%-W), and the Northern region has only slightly more Spanish speaking respondents than the other two regions (3%-N; 2%-S; 3%-W).

Some regional differences in education do exist. More respondents in the Southern and Western regions have a high school diploma or less (31%-N; 36%-S; 35%-W), while more individuals from the Northern region have greater than a high school diploma than the other two regions (69%-N; 64%-S; 65%-W).

Financial information

Respondents report a wide range of monthly household incomes and total value of assets. Nearly half have monthly incomes of $4,000 or more, while 19 percent have incomes of less than $1,000 per month. The number of people supported by this monthly income is anywhere from one to nine with a mean of 1.97 (standard deviation=1.109). Nearly one-quarter have total assets of $350,000 or more, while over 30% have total assets of less than $5,000 (assets do not include a home or car).

Figure III-21. Total monthly household income

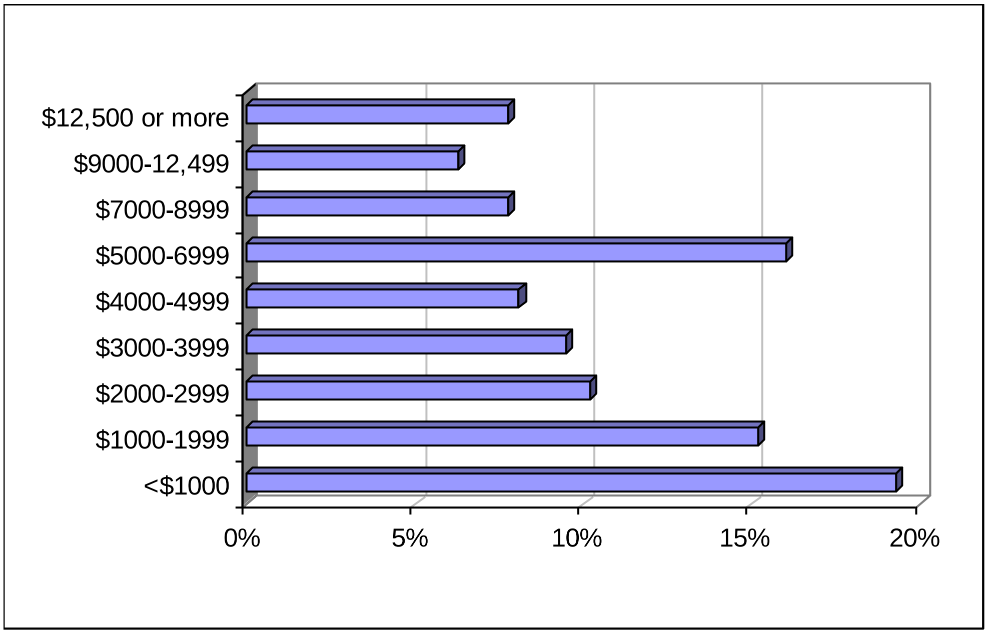
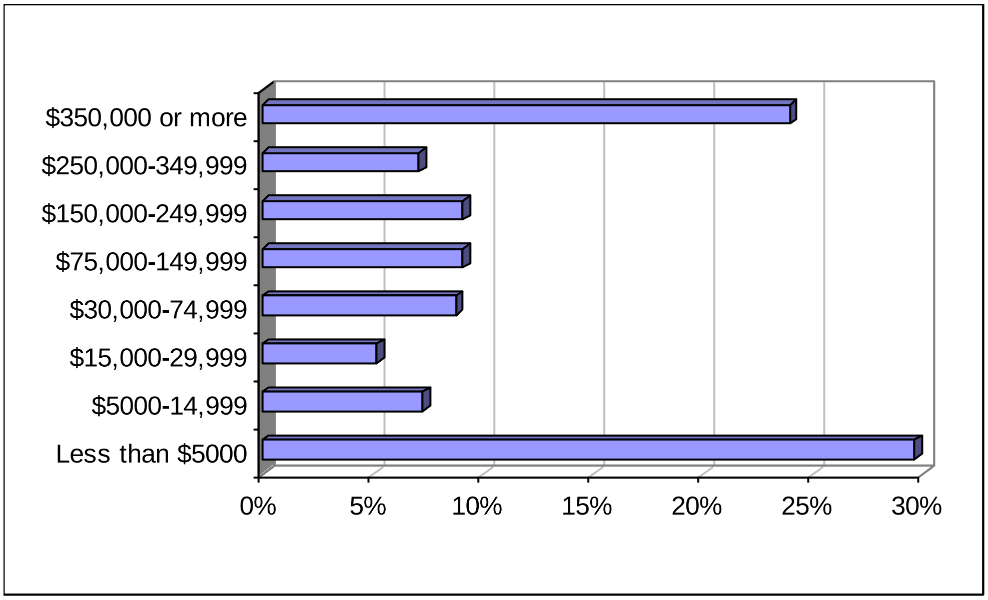


Figure III-22. Total value of assets



Homeownership is relatively common as two-thirds of respondents report owning their own home. In addition, about half of respondents report that they have money left over at the end of the month. However, one-third are just making ends meet, and 16 percent are in worse financial shape, not having enough money to pay for all their needs.

For those respondents who do not have enough money to make ends meet, eight percent said that they have difficulty paying the rent, mortgage or real estate taxes; 12 percent have problems paying utility bills; 11 percent said it is difficult to either own a car or pay for necessary repairs; nine percent finds it difficult to pay for needed food; seven percent have difficulty in filling prescriptions; 10 percent cannot afford dental care; nine percent cannot afford to obtain eyeglasses or hearing aids; six percent cannot obtain other medical care; five percent cannot pay for any home modifications to adjust for physical needs; four percent cannot pay for any assistive devices or technology needed; 11 percent cannot pay any more than the minimum balance on their credit card; ten percent cannot afford to pay into a retirement account; and two percent find difficulty in paying for the care of a parent or child with disabilities (respondents told to check all that apply).

Differences by disability status

As expected, there are significant differences in financial status among respondents by disability status, with the most significant differences between those with no disabilities (Group ND) and respondents from the disability survey (Group DWD). Once again, respondents with self-reported impairments (Group DAS) are in the middle. Over half of Group DWD have a monthly household income of less than $1000, compared to only four percent of Group ND. The asset picture is even more stark. Eighty-two percent of Group DWD have less than $5000 in total assets (compared to 4% of Group ND) while 58 percent of Group ND (and only 3% of Group DWD) have in excess of $150,000 in total assets.

Homeownership status produces similar results, with 86 percent of Group ND owning their own homes or condominiums, versus 65 percent of Group DAS and only 13 percent of Group DWD.

Only 19 percent of Group DWD have money left over at the end of the month (vs. 44% for Group DAS and 65% for Group ND.) While lack of money causes a variety of problems for Group DWD, the most common are the inability to pay for utility bills and food.

Differences by age

Income varies considerably among the five age groups. Half of the youngest and nearly half of the young adults (45%) earn less than $1000 per month. This is probably reflective of the fact that more of the younger groups are people with disabilities. Nearly one-third of the baby boomers earn anywhere from $5000 to $8000 per month, whereas most of the older adults and the oldest group (42% and 49% respectively) earn between $1000 and $3000 per month. At the same time, the two younger groups and the two older groups indicate that this income is only used to support themselves, with about 70 percent of the oldest group in this situation and about half of the other three groups. More than half (59%) of the young old group and almost half (45%) of the older adults use their income to support not only themselves but another person as well, such as a spouse.

Assets follow income with regard to age. The majority of the youngest and the young adults indicate that they have less than $5000 in total assets. This includes 86 percent of the youngest group and 65 percent of the young adults. Once again this may be a reflection of a disability status, especially since the disability status limits the amount a person may have in their savings. Nearly one-fourth of the baby boomers (24%) and the older adults (23%) have assets of $350,000 or more, and one-third of the young old (34%) also have assets of over $350,000.

With regard to home ownership, over three-fourths of the youngest group (86%) and the young adults (75%) do not own their own home or condominium/townhouse. Well over three-fourths of the young old own their own homes (78%) and over two-thirds of the baby boomers (68%) and the older adults (69%) also own their own home or condominium. The oldest group is split almost in half, with 46 percent owning their own home.

About half of each group over the age of 42 indicate that they have money left over at the end of each month, however about one-third of the two youngest groups say that there is not enough money to make ends meet. Over three times as many of the youngest groups and over twice as many of the baby boomer group say that they didn't have enough money to pay their rent, mortgage or real estate taxes as compared to the oldest three groups. The respondents in the three youngest groups (including the baby boomers) consistently have more difficulty in paying most of their bills, including utility bills, owning or repairing a car, paying more than the minimum balance on their credit card, or even buying needed food. Approximately one-fifth of the respondents in the youngest group say that they cannot afford to pay for home modifications to adjust for physical needs (19%) and of that same group, nearly the same number (17%) indicate their inability to pay for any assistive devices or technology that they may need.

Differences by income

The income groups, as would be expected, are highly correlated with asset levels and likelihood of having enough money to make ends meet. Eighty-five percent of the low income group have total assets of less than $5,000, while one-quarter to one-half of the highest three income groups have assets exceeding $350,000. Forty-three percent of the low income group does not have enough money to make ends meet at the end of the month, compared to 19 percent of the low/medium income group and about seven percent of the three highest income groups.

Differences by ethnicity

Monthly income varies substantially by ethnicity. Nearly half of all of the Latinos and Blacks earn less than $1,000 per month (49% and 50% respectively). Only one-third (32%) of the other race group earn under $1,000 per month, and 15 percent of the White group earn under that amount. Forty percent of the White and 38 percent of the other race group earn over $5,000 per month compared to only 23 percent of the Latino group and 14 percent of the Black group. Earnings are reflected in the total value of assets held by each group. For 60 percent of both the Black group and the Latino group, total assets are estimated at less than $5,000, and 45 percent of the other race group also have minimal assets of less than $5,000. This compares to only 25 percent of those in the White group who have assets of less than $5,000. Another 26 percent of those in the White group indicate assets of over $350,000 compared to only 10 percent of the Latino group and three percent of the Black group.

Due to income levels, it is not surprising that nearly two-thirds (68%) of the White group own their own home or condominium. Only about one-third of the Latinos (34%) and Blacks (30%) own their own home. Fifty percent of those in the other race group also own their own home or condominium. The same would hold true as far as how one's finances usually work out at the end of the month. Compared to the White group, over twice as many of the Black, Latino and other race group indicate that there is not enough money at the end of the month to make ends meet. Over twice as many of the Black, Latino and other race group have difficulty paying their mortgage or real estate taxes and utility bills as compared to the White group. Three times as many of the Black, Latino and other race group do not have enough money to buy needed food as compared to the White group.

Differences by region

Reported total monthly household income by region has complex variations. The Western region has not only the greatest percentage in the lowest reported monthly income category (less than $500 each month), but also the greatest percentage in the highest income category ($12,500 or more each month) relative to region (see Table III-32).

Table III-32. Percent reporting income

	Northern	**Southern**	**Western**
Less than $500 each month	4	5	6
$500-$999	14	15	14
$1,000-$1,999	15	16	14
$2,000-$2,999	11	11	9
$3,000-$3,999	11	9	8
$4,000-$4,999	8	8	10
$5,000-$6,999	18	16	13
$7,000-$8,999	9	7	7
$9,000-$12,499	5	7	8
$12,500 or more each month	7	7	11

Like income, total assets show modest variation by region as well. More than a quarter of all respondents in each of the regions report assets to be less than $5,000 (see Table III-33).

Table III-33. Percent reporting assets

	Northern	**Southern**	**Western**
Less than $5,000	27	31	29
$5,000-$14,999	7	7	7
$15,000-$29,999	5	6	5
$30,000-$74,999	10	8	9
$75,000-$149,999	10	10	8
$150,000-$249,999	9	11	8
$250,000-$349,999	8	6	7
$350,000 or more	23	21	28

There is very little variation among regions for homeownership. Slightly more individuals from the South and West regions report running short of money each month, with difficulty paying utility bills or credit card payments mentioned most frequently.

Caregiving

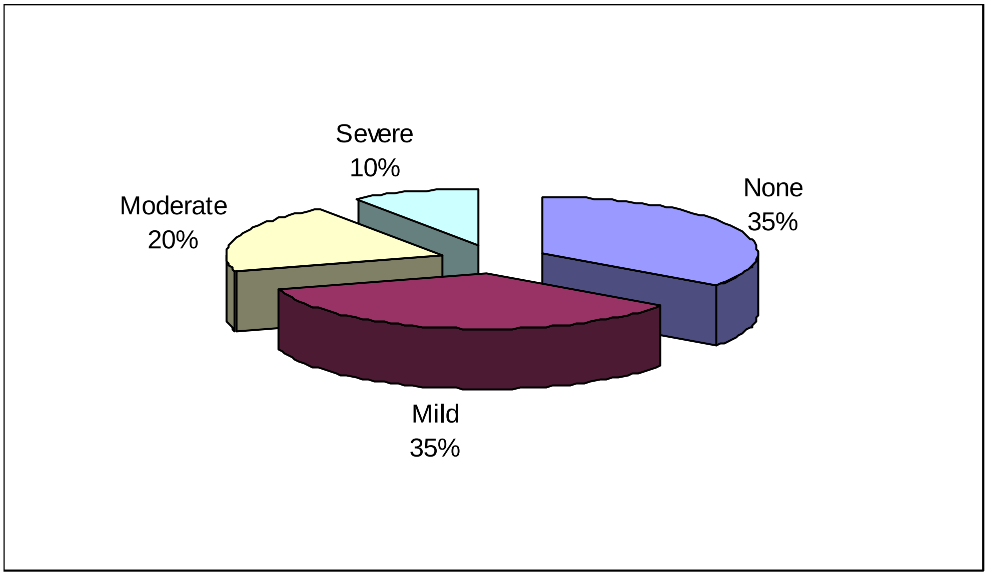
All of the respondents were asked the question "Do you provide unpaid care and assistance for a relative or friend who lives in Connecticut?" Seventeen percent of all respondents indicate that they do provide care and assistance without pay to at least one Connecticut resident because of old age or disabilities.

Additional questions regarding caregiving were asked only of those who had filled out the general survey. The additional questions were not asked of those completing the survey for people with disabilities. In most instances, the care is provided for a parent (57%) or another relative (14%). Ten percent provide care for their spouse and the same number provides care for a friend. Seven percent provide care for a child with a disability. The number of relatives or friends for whom care is provided ranges from one to five with a mean average of 1.3 (standard deviation=.610).

The age of the person receiving assistance is typically older: eighty-one percent of those receiving assistance are sixty-five or older. Forty-two percent are between the ages of 65 and 84, and 39 percent are 85 or older. About 16 percent of the caregivers provide assistance to people under 59 years old. The greatest percent (62%) of caregivers live in close proximity to those they care for, either in their own town or a nearby community. Another 27 percent report that the care recipient is living with them, while 11 percent say that the person they care for lives more than 45 minutes away.

About 30 percent of caregivers indicate that the person they care for has either moderate or severe memory problems, while others report mild memory problems or no memory problems at all.

Figure III-23. Does this person have any memory problems?



Only a small percentage of caregivers (6%) missed 11 or more days of work because of caregiving responsibilities. Forty-six percent of the group lost no work time. However, another 48 percent missed anywhere between one and ten days of work as a result of their caregiving.

Twenty-two percent of the caregivers report that their care recipient is not getting any of the home health aid help he or she needs, or needs more help from a home health aid (see Table III-34). The remainder say that they do not need help or are already receiving enough. A slightly larger percent (29%) say that the person they care for is not getting all the homemaker services he or she needs. Almost 90 percent of caregivers indicate that the person cared for either does not need or is receiving enough help from a visiting nurse; 85 percent are either not in need of or are receiving enough home delivered meals. One-fourth want more Dial-a-ride or van service for shopping or medical appointments, and some caregivers (20%) confirm that more case management is required for their loved one. Finally, 18 percent of those responding said that they need more adult day programs for the person they care for. Over one-quarter (29%) of those who responded indicate that their relative or friend needs some other long-term care service, such as companionship, escorts for dial-a-ride, or handyman services.

Table III-34. Long-term care services (percentages)

	Not using now & Does not need	**Not using now but Does need**	**Using now & receiving Enough**	**Using now but Needs more**
Home health aide from an agency or personal care assistant (for bathing, dressing, daily living needs, etc.)	**62**	14	16	8
Homemaker services from an agency (for laundry, shopping, cleaning, etc.)	**56**	24	15	5
Visiting nurse (to change bandages, give injections, etc.)	**72**	7	17	3
Home delivered meals (Meals-On-Wheels)	**78**	14	7	1
Dial-a-ride or van service (transportation for shopping, medical appointments, etc.)	**65**	21	10	4
Care management (assessment, coordination, and monitoring of services by a social worker, nurse, etc.)	**64**	16	16	4
Adult day program (activities and health services provided at care centers)	**75**	15	8	3
Other ____________________________	34	17	**38**	12

About 23 percent of those responding say that language is an issue. They report that problems with communication between the care recipient and the provider occur either sometimes or always because they either speak different languages or are from a different cultural background. Seventy-seven percent of those responding say that problems with communication occur either rarely or never.

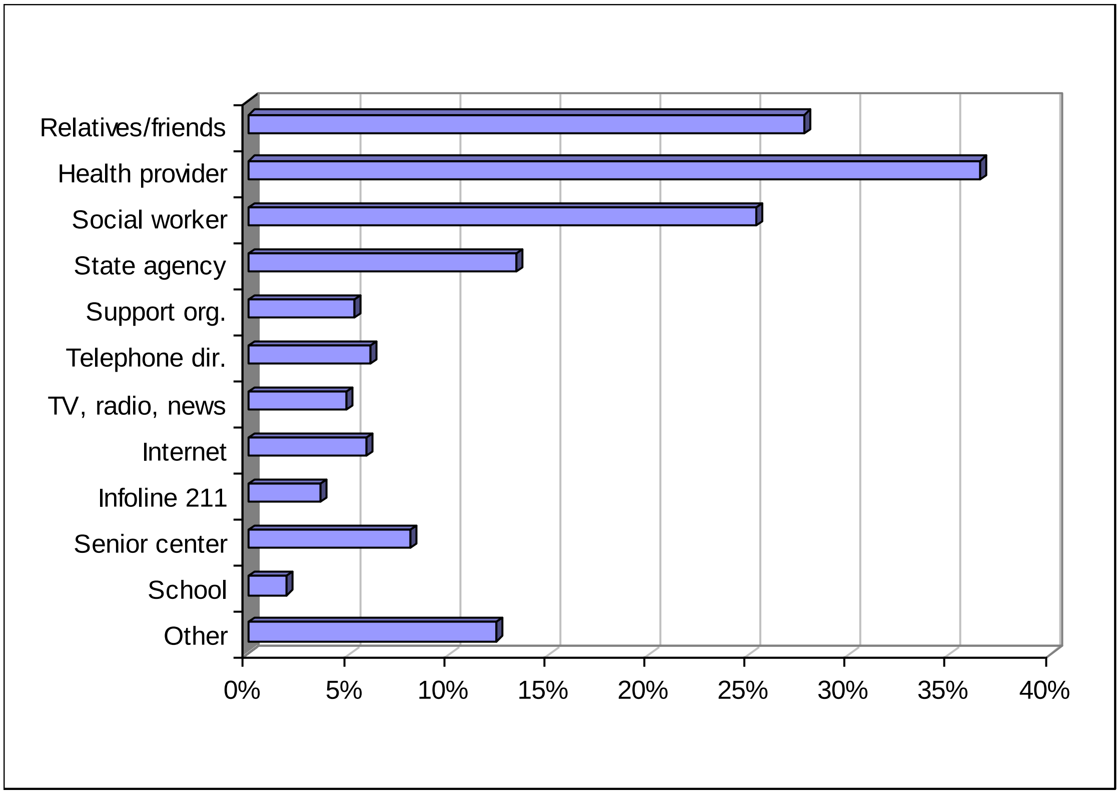
Of those who report difficulties in obtaining services, 44 percent of those responding report that lack of funds is an issue for obtaining services. Other difficulties in obtaining services include lacking services available in their area (15%), inability to find someone to hire (15%), services unreliable or give poor care (21%), services not accessible to people with disabilities (7%), or services not available in his or her language (3%). Thirty-two percent of those who responded, who also had difficulties in finding services, said that they did not know what services or help are available.

Respondents were asked to describe any other problems their care recipient has experienced with his or her paid services. Of those who responded, half report problems with the poor quality of services. This poor quality of work includes unreliability of healthcare assistants, for example, not showing up when they are scheduled, absences, theft, and inconsistency. Several of the comments also emphasize the high cost of these services.

> *Sometimes home health aides are unreliable in keeping to their schedule or don't show up or call to say they're not coming.*
>
> *Money stolen, medication stolen, workers quit, replacements are not sent.*
>
> *Poor quality, inconsistent, unprofessional, too expensive, not available.*

Caregivers find services in a variety of ways as indicated in Figure III-24 below. The leading sources of information are health providers, relatives/friends, and social workers.

Figure III-24. How did you find out about the services this person uses?



Of those respondents who indicate that they are currently involved in caregiving, two-thirds are female (67%). The age of the caregivers ranges from 20 to 95, with a mean of 57.05 (standard deviation=12.46). The majority of caregivers are married or living with a partner (67%). Twelve percent of caregivers are either divorced or separated. Thirteen percent of caregivers never married, and seven percent of caregivers are widowed. The racial background of the caregiver is predominantly white or Caucasian (94%). Almost half of the caregivers have a four-year college degree or a post-graduate degree (48%), while nearly one-fourth (24%) received at least some college or a two-year college degree. Sixteen percent of caregivers have a high school diploma, and fewer than ten percent never completed high school.

Total monthly income for all caregivers varies widely. Nearly one-half of all caregivers earn a monthly income of over $5,000. Eleven percent of caregivers report monthly incomes of under $1,000. The largest single category is represented by those who earn between $5,000 and $6,000 per month (21%). When asked how many people are supported by this income, sixty-two percent report that only one or two people are supported by this income. One-fourth of the respondents say that their monthly income supported three or four persons. Total assets for this group of caregivers also is quite varied, however almost half (46%) have assets upwards of $150,000 (total assets do not include home or car). Still, 19 percent have assets of less than $5,000.

The majority of caregivers rate their own health as either excellent or good (84%). Only two percent rate their health as poor. Over one-fourth (27%) of the caregivers indicate that they have been bothered by feeling down, depressed or hopeless during the past month, and almost as many (23%) have been bothered by little interest or pleasure in doing things.

Almost half of the caregivers work full time (45%), and another 19 percent work part time. Others indicate that they are: retired (26%), a homemaker (15%), volunteer (19%) or attend school either full or part time (4%).

The majority of caregivers have either family or friends they can count on if they need extra help (75%), but only 17 percent say that they are currently receiving this type of extra help from family or friends at least once a week. An even larger percent (87%) say that they can count on someone to provide them with emotional support such as someone to talk over problems with or help in making difficult decisions.

Differences by disability status

There is a noticeable difference among the three groups in likelihood of being a caregiver for a relative or friend living in Connecticut. Twenty percent of Group ND are currently caregivers, compared to 16 percent of Group DAS and 11 percent of Group DWD. As noted above, the more detailed questions about caregiving were only asked of Groups DAS and ND, and there are two interesting differences between them. Group DAS is more likely than Group ND to care for a spouse or partner (19% to 8%) while Group ND is more likely to care for a parent (61% to 43%). Group ND is also more likely (41% to 29%) to have missed work or used sick or vacation time on account of their caregiving duties. Questions about other aspects of caregiving did not differ substantially between the groups.

Differences by age

Almost one-fourth of all of the baby boomers are caregivers for someone else. The young old group also has the responsibility of caregiving (14%), however the baby boomers are twice as likely to have this responsibility for more than one person, usually a parent or other relative. For those over 75 years of age, the caregiving responsibility is extended more often to a spouse. For almost every age group, the majority of caregiving is given to people over the age of 65. For the baby boomers, 38 percent of the respondents indicate that they missed anywhere between one and five days of work in the past year because of this responsibility, compared with 21 percent of those age 22-41, and 11 percent of those age 61-74. Another 18 percent of the baby boomers say that they have missed more than 6 days of work in order to take care of their loved ones, compared to 10 percent of those age 22-41 and six percent of those age 61-74. Other questions about caregiving did not differ substantially between the groups.

Differences by income

Likelihood of being a caregiver does differ somewhat by income category. Ten percent of the low income group provides care for a relative or friend in Connecticut, compared with 16 percent of the low/medium income group and 20 percent of the three highest income groups. Almost two-thirds of the three highest income groups care for a parent, compared to only 21 percent of the low income group and 44 percent of the low/medium income group. The two lower income groups care for persons with a wider variety of relationships, with ten percent or more of each caring for a friend, other relative, spouse/partner, or child with disabilities.

Care recipients are older for the higher income groups. For the four highest income groups, a large majority of care recipients (82%) are age 65 or over, compared to only 45 percent of care recipients in the low income group. Other aspects of caregiving do not differ substantially by income group.

Differences by ethnicity

The percentage of caregivers for each group does not differ significantly. Sixty percent of the White group care for a parent as compared to only 40 to 45 percent of the other three groups. The Latino group is more than two times as likely to care for a child with a disability (15%) than the other three ethnic groups. Also, the Black and Latino groups are two times as likely to provide care for a friend as compared to the White group.

Communication problems for the care recipient are similar to communication problems for the Latino group in general. Over two times as many care recipients of the Latino group have difficulty with communication, either always or sometimes, as compared to the other three groups.

Differences by region

The rate of caregiving is slightly higher in the North region (19%-N; 17%-S; 16%-W). A parent is the most common care recipient in each of the three regions and the typical age of the care recipient is between 65 and 84 years. A large proportion of caregivers in all three regions report needing more services. Homemaker services are listed first, followed by transportation, home delivered meals, adult day, home health, care management and visiting nurse services.

IV. Provider Survey

A. Introduction

A critical component of a comprehensive needs assessment is the perspective and experience of the provider community. The purpose of the provider survey was to characterize the current organization, financing, and delivery of long-term care services in the state. Providers included a broad range of agencies and organizations that provide long-term care services and supports to the State's older adults and residents with disabilities. Though the list of provider groups is not exhaustive in nature, the comprehensive inventory provides an overview of the delivery system in Connecticut today.

B. Methodology and analysis

Instrument development

A seven-page survey was developed incorporating issues raised in the literature or in previous surveys of long-term care providers with input from the Long-Term Care Advisory Council. Emphasis was placed on ascertaining an overview of services provided, unmet needs of clients and other consumers in Connecticut and how to resolve these concerns, client demographics, eligibility requirements, reasons for declining services, employee training and concerns, workforce and service capacity issues, and interactions with State agencies, (please see Appendix E for a complete copy of the survey). Specifically, questions address the following areas:

- Services provided or made available by the agency. This included a diverse array of potential services, with room for the respondent to write in additional services provided. Examples of services listed include homecare services, transportation, health screenings, mental health services, and physical, speech, respiratory or occupational therapy.
- Total clients currently being served
- Demographic profile of clients being served (age, gender, ethnicity)
- Payment method of clients (e.g., Medicaid, Medicare, private insurance)
- Any eligibility requirements needed to receive services (e.g., certain diagnosis, certain payment methods)
- Capacity with current funding levels and presence of a waiting list
- If provider declined services to anyone in the past year, and if so, why service declined
- Percentage of clients with a diagnosis of mental illness
- Percentage of clients who exhibited challenging behaviors in the past six months
- Employee issues or concerns
- Specific service or situational concerns
- Specialized training for employees regarding working with clients who have challenging behaviors
- Experiences working with state agencies (i.e., regulatory environment, issues or concerns)
- Plans for coping with future workforce shortages
- Plans to meet future long-term care service needs
- Unmet service needs of current clients
- Unmet services needs of consumers in general
- Suggestions for addressing these unmet needs

The instrument comprised both quantitative and qualitative questions. The open-ended format of these questions gave the interviewees the freedom to fully describe their experiences or views.

Recruitment and response

A total of 1,211 surveys were initially mailed to provider and service organizations from across the State. The sample included a broad mix of both public and private agencies. Fourteen service type categories were designated, based on agency licensing defined by the Department of Public Health: home health agency, home health agency, homemaker agency, assisted living, managed residential care, nursing home, residential care home, hospice, chronic disease hospital, senior center, adult day program, Area Agencies on Aging, Bureau of Rehabilitation Services providers, Department of Mental Retardation providers, and Department of Mental Health and Addiction Services providers.

All organizations within each service type provided by the Department of Public Health licensing division were contacted for the survey. In addition, providers from three state agencies were selected for inclusion in the survey based on the often complex and unique needs of the populations they serve (Bureau of Rehabilitation Services, Department of Mental Retardation, and Department of Mental Health and Addiction Services). It is important to note that many private provider organizations, home health agencies for instance, provide services to individuals with intellectual disabilities in addition to other populations, but it is unusual for a provider organization under the DMR umbrella to serve an individual from the general population.

All providers on the combined list (n=1,211) were sent an initial mailing which included a letter of introduction and the seven-page survey. The letter of invitation was sent on the University of Connecticut's Center on Aging letterhead and signed by the two project investigators. Confidentiality was assured, and postage-paid, self-addressed return envelopes were included with each survey.

Feedback received after the initial mailing indicated that some of the addresses were duplicates. For example, some providers supply services to more than one state agency (e.g. Bureau of Rehabilitation Services, Department of Mental Retardation, and/or Department of Mental Health and Addiction Services) and had been included on more than one source list. In those cases, the provider's primary agency relationship was determined through discussions with state agency staff, and the provider was removed from the other provider lists. In addition, many managed residential care organizations are also assisted living service agencies and had initially been included as both provider types. In all, 115 duplicates were noted and redistributed to the most appropriate service type category.

Following standard research methodology, four weeks after the initial mailing a reminder mailing was sent to all nonresponders. This second mailing included a reminder letter, a second copy of the survey, and a postage-paid return envelope. Those who had already completed their survey, called in to refuse, or had a wrong address were not sent a second survey.

Ten weeks after the second mailing, another reminder was sent to all nonresponders. This third mailing included a letter encouraging providers to respond even if some questions did not apply to their organization, as well as another copy of the survey and a postage-paid return envelope. Again, those who had already completed their interview, called in to refuse (n=6), and any wrong addresses (n=9) were not sent the third survey.

Surveys that were returned at all stages were opened and examined for completeness. Those with conflicting answers or missing data received follow-up calls to amend answers if necessary. Given the wide range of provider types, some questions were not applicable.

In addition, five weeks after the second mailing, follow-up telephone calls were initiated to nonresponders and continued until approximately four weeks after the third mailing. The follow-up calls were targeted to providers from adult day programs, assisted living service agencies (ALSAs), managed residential care agencies (MRCs), home health care agencies, homemaker agencies, and chronic disease hospitals. At least three messages were left for each provider called. This effort resulted in 16 additional surveys completed by telephone as well as numerous additional written surveys returned.

A total of 500 providers responded to the survey for an overall response rate of 46 percent. Table IV-1 below displays the number of unduplicated agencies contacted, the number of agencies that responded to the survey, and the response rate by type. The response rate by provider type ranges from zero percent (hospice agency) to 100 percent (Area Agencies on Aging). Most of the surveys (n=484) were completed by mail, with sixteen completed by telephone.

Table IV-1. Agencies contacted, agencies responding, and response rate

Service Type	Agencies contacted	Agencies responding to survey	Response rate by service type
Home health care agency	87	47	54%
Homemaker agency	8	2	25%
Assisted living	54	28	52%
Managed residential care	54	28	52%
Nursing home	242	96	40%
Residential care home	101	42	42%
Hospice	1	0	0%
Chronic disease hospital	6	3	50%
Senior center	150	77	51%
Adult day program	48	41	85%
Area Agency on Aging	5	5	100%
Bureau of Rehabilitation Services providers	49	19	39%
Dept. of Mental Retardation providers	130	61	47%
Dept. of Mental Health and Addiction Services providers	152	51	34%
Total	**1087***	**500**	**46%**

*Wrong addresses (n=9) and duplicates (n=115) were excluded.

Analysis

All data were entered into Microsoft Access tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) information. After data collection was complete, the data were converted to SPSS version 14.0, a statistical software package designed for both simple and complex analysis. Descriptive data were generated for each question within each provider type including frequencies and percentages or mean, range and standard deviation. The variables were then simplified by eliminating extraneous variables and by reducing the number of divisions of multi-categorical variables.

Responses to all qualitative or open-ended questions were entered in full into a Microsoft Access database. Content from these open-ended questions were analyzed using standard qualitative analysis techniques (McCraken, 1988). Data from each question was transcribed and analyzed line by line in order to identify and interpret each individual's response. Two researchers independently analyzed the responses for each question, reaching a consensus if interpretations were different. Major concepts or areas of interest supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each. Percentage of response was determined by dividing the number of times any particular theme was mentioned by the total number of responses.

C. Detailed results

The results are presented in two parts. The first section presents a cumulative overview of responses from all providers to the survey's open-ended questions. It depicts their experiences with Connecticut's regulatory environment, state agencies, workforce shortages, and suggested future legislation, and is presented with all providers combined into one group.[1]

The second section provides a detailed overview for each of the provider categories that contain ten or more respondents and summary level data for the rest. All tables are subject to rounding error and may not always add to 100 percent.

General provider responses

There was a particular interest among Advisory Council members in understanding how the current regulatory environment facilitates or constrains the provision of long-term care services in Connecticut. To gather this information, two survey questions focused on provider interactions with state agencies, each with an additional open-ended question allowing for respondents to describe their experiences or opinions:

1. Does the State regulatory environment affect your ability to provide services to your clients? If yes, please describe.
2. Have you experienced any issues or difficulties working with any specific State agencies or departments in the past year? If yes, please describe

Slightly less than one-half of all respondents (44%) indicate that the regulatory environment affects their ability to provide services to clients, and 30 percent experienced difficulties with specific state agencies or departments in the past year (see Figure IV-1 below).

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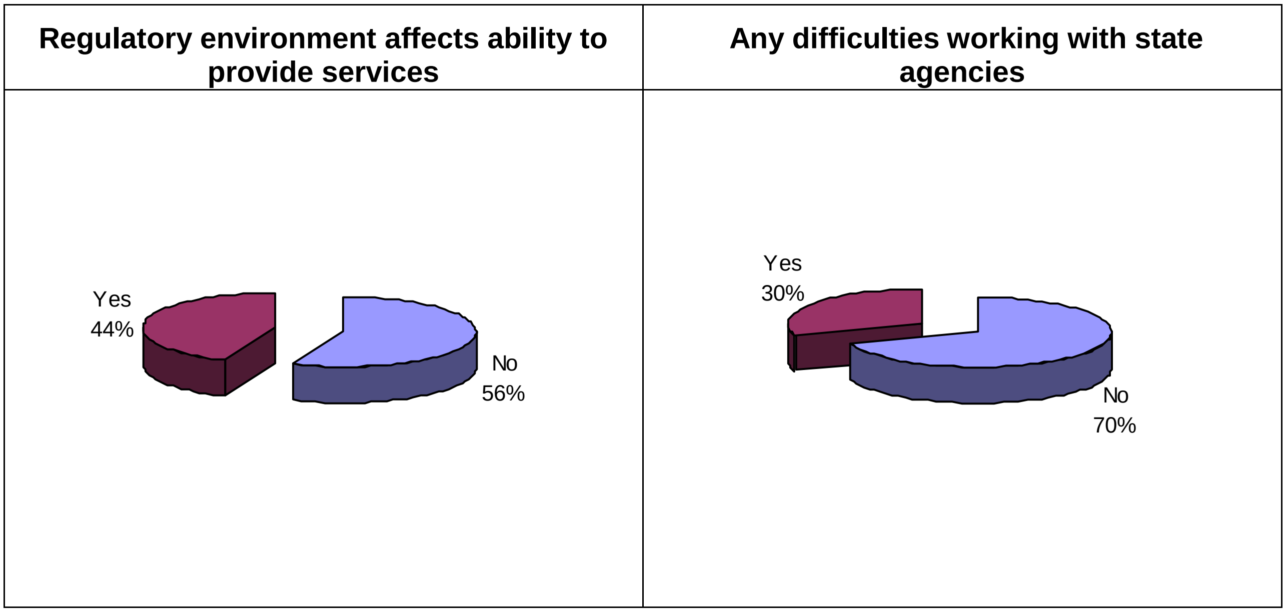
[1] The impact of the regulatory environment is included in this report only from the provider perspective. The report on the Long-Term Care Ombudsman Program will include the resident/consumer perspective (to be released July, 2007).

Figure IV-1. Experiences with agencies and regulatory environment



1. Impact of state regulatory environment

A number of themes that emerged from the responses of 189 providers to this question. Providers report issues with state and federal funding, regulations, limited services, documentation, interpretation, and response time.

State and federal funding

Although state and federal long-term care funding has increased over the past two decades, primarily through Medicaid waiver programs, 36 percent of the responses identify state and federal funding, reimbursement, and cost issues as factors that affect the scope and extent of patient services. This includes limited funding to cover services required by regulations well as income/asset guidelines for certain state programs and waivers.

> *Reimbursement rates are so far below costs that we are forced to subsidize a significant percentage of care we provide to the Medicaid population.*
>
> *Sometimes people apply for RCH and do not qualify for AABD…, but cannot afford to pay privately. They should change the monthly income guidelines.*

Regulations

State and federal agencies dictate or guide the services offered by providers, which continues to be a thorny issue in many areas of long-term care. Twenty-one percent of responses indicate that the increasing number of regulations has a negative impact on the provision of services, and inhibits the use of new methods of care. Providers also indicate that state required inspections are time consuming and complex, and enforce state policies that are not always evidence-based.

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

> *The regulatory environment is a major obstacle to innovation in health care.*

Limited services

Respondents indicate that regulations and licensure determine or restrict patient care and services. Fourteen percent of responses suggest that it is difficult to serve clients with changing needs effectively when guidelines and eligibility requirements are so specific.

> *At this time [we] have to do things to meet state regulations, but not necessarily what is best for patient or resident.*
>
> *Some of the regulations are too restrictive and inappropriate for an inpatient psychiatric unit.*

Documentation

A nearly equivalent percent of responses suggest that documentation is both time consuming and labor intensive. Thirteen percent of the responses indicate that because documentation takes so much time, it has a direct negative affect on the amount of time that can be spent providing care to residents.

> *Our nurses spend more time on documentation than "hands on" patient care.*
>
> *I discourage taking medically complex patients due to the additional paperwork and cost involved.*

Interpretation

Interpretation of regulations is a concern for respondents as well, as eight percent of responses indicate concern about the dissimilar perspectives of inspectors and differences in compliance interpretation among state and local officials.

> *State regulations are applied inconsistently. We are driven to avoid unfair assessments.*

Response time

A small number of responses (7%) reflect concern about the delayed response time from state agencies, such as a protracted wait for Title 19 approval for nursing home clients. Other concerns mentioned include the lack of returned phone calls and the application process.

> *The application process for applying for a grant to replace [our] bus is too long and restrictive.*

Other responses

Slightly more than ten percent of responses detail other concerns, including oversight by multiple state agencies, state agency staffing concerns, and clients getting lost in the system.

> *We work with five state agencies for funding and oversight.*
>
> *Sometimes clients are lost in the system, and it is hard for us to help them with entitlement programs.*

Although providers were asked only for their concerns, or negative impressions, a few providers (3%) express having positive experiences stating, for example, that the State regulatory environment is helpful in affecting their ability to provide client services.

2. Issues or difficulties working with State agencies or departments

Approximately 30 percent of responding agencies (N=129) indicate having difficulties with state agencies or departments in the past year. Respondents report problems with administration, funding, the inspection and survey process, client services, and conflicting interpretation of policies and procedures.

Administration

For many providers (37%), the most difficult challenges in working with State agencies involve administrative issues. Challenges faced by providers include difficulty arranging services, difficulty working with case managers, lack of a person-centered approach, poor response time, and a shortage of staff to process applications or otherwise assist providers in offering services to clients. Providers also indicate that there is too much paperwork or unreasonable requests for information. These and other administration difficulties often thwart the provider's ability to provide optimal service to clients.

> *[They] question all expenses. Audits have become investigations.*
>
> *Red tape with the waiver takes a lot of time away from other duties.*
>
> *Excessive paperwork that restricts our ability to enhance services.*
>
> *Some agencies are overwhelmed and understaffed, and it takes weeks for them to be able to assist you.*
>
> *It is extremely difficult to check on the status of an application or to communicate in any fashion. Submitted materials sometimes cannot be found.*

Funding

Providers are concerned about the level of funding, delays in reimbursements, denial of payment for services, and insufficient repayments. Twenty-one percent of responses suggest that there is not enough money to provide adequate services and that there is a high number of people who need assistance but are not receiving it.

> *We have been having difficulty being reimbursed through one time amendments in a timely fashion.*
>
> *There is not enough money to provide adequate [mental health] services.*
>
> *If you're handing in reports, they don't give you money. They will slash the rate 20 to 30 percent if you are late in handing in reports.*

Inspection and survey process

Nearly 15 percent of the responses focus on state inspections and some of the difficulties experienced by providers when interacting with inspectors or surveyors. These concerns include conflicting perspectives of different inspectors and their inability to recognize the current realities of providing care. In addition, providers indicate that the surveyors are often reluctant to work with the provider or jump to conclusions before gathering all of the facts.

> *They seem to put a new spin on existing regs, and all of a sudden what was acceptable before is now grounds for sanction.*
>
> *[The surveyor] mishandled paperwork and accused our staff of the problems. They have tunnel vision and are out of touch with the realities of providing care today.*
>
> *Just the usual – being dependent on the personal leanings and moods of the individual surveyors which affect survey outcome.*
>
> *[They have] been over focused on health and safety and [have] no vision of degree of risk or person-centered supports.*

Client services

Providers express concern about the inadequate quality of client services. Nearly 12 percent of responses indicate that State agencies are often too specific about "critical needs," which can be an encumbrance. Providers are also concerned about the unreasonable amount of paperwork that's required to process service requests for clients.

> *Some agencies are overly prescriptive in mandating a treatment/care model. Other agencies are slow and inefficient.*
>
> *Finding enough critical needs to qualify a needy client can be an issue. Isolation should be a critical need.*
>
> *The State eliminated RN visits to all clients.*

Conflicting interpretation of policies and procedures

Respondents report that another difficult issue in working with State agencies is the conflicting interpretation of policies and procedures between agencies, departments, or even the city and State. Nine percent of the responses suggest that different departments put their own spin on existing regulations, which causes confusion. Other issues include an inconsistent application of regulations even within agencies, such as changing licensing regulations without notice, and a rigid adherence to regulations without regard for the individual's circumstances,

> *The challenge sometimes comes with building code/building safety issues where state and local officials may have different interpretations of compliance.*
>
> *The different departments don't go by the same regulations. Some actually contradict each other.*

It is important to note that the majority of respondents (70%) answering this question did not report any regulatory or agency specific concerns. These providers experience State agencies as responsive and helpful.

> *The state is very responsive and thorough. They do a great job digging in during a survey. That helps us aim for excellence.*

The last five questions in the survey were also qualitative and more exploratory in nature. These open-ended questions allowed respondents to fully share their thoughts, experiences, and suggestions regarding the future need for long-term care in Connecticut and how the State can address these needs:

- The workforce shortage in Connecticut is expected to <u>increase</u> in the future. How do you plan to deal with this?
- Connecticut is also experiencing a dramatic increase in the number of older adults, which will continue for the next 30 years. How do you plan to meet the long-term care service needs of this growing segment of the population?
- What services are missing for your clients that you cannot either provide or subcontract?
- In your opinion, what is the greatest <u>unmet</u> long-term care service or need for older adults or people with disabilities in Connecticut?
- How should the State address this unmet need?

<u>Anticipated future workforce shortage</u>

When asked how the provider plans to handle the anticipated future workforce shortage in Connecticut, for the vast majority the answer is some form of **recruitment and retention.** Out of 361 respondents who answered this question, about three-quarters (76%) say they will extend their efforts not only to recruit new employees but also to retain the employees they already have. This would be achieved in a variety of ways. A substantial number of respondents (35%) indicate that having competitive wages and good benefits packages for their employees is the best way to attract new employees and hold on to existing employees. In many cases, this also includes having a pleasant working environment (12%), while for others it involves offering flexible work schedules (6%).

> *Focus on creating a dynamic work environment where staff are motivated to continue to make a difference in-patient [care] and they are recognized for their contributions.*

Six percent of those for whom recruitment and retention are primary report that they will actively work with colleges and nursing schools to attract new employees, and another six percent indicate that they are already recruiting from other states or foreign countries. Other respondents indicate that they will offer some sort of training (13%) or tuition assistance (6%) for their existing staff. For example, tuition reimbursement for certified nursing assistants (CNAs) who go on to become nurses is mentioned a number of times along with in-house training of CNAs.

> *We promote education here and provide tuition assistance for staff looking to further their education, either within their field or for promotion (i.e., CNAs or recreation [staff] going to LPN school). Also we provide housing for traveling and/or foreign nurses.*

A smaller number of respondents mention incorporating more volunteers and retirees, increased use of technology, staff sharing, and using pool employees. Many respondents point to the use of multiple simultaneous approaches.

> *We are employing "retention" strategies for our staff including high salaries, high benefits, performance rewards. We are investigating new creative strategies for recruitment, inclusive of summer internships, partnering with universities; increased use of technology to make clinical documentation more easy and efficient.*

> *1) Increase our participation in area job fairs; 2) nurture our relationships with educators in the community (community college, certification programs, CT Nurses Association, etc.; 3) promote (ongoing) employee referral incentive program.*

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

> *Our workforce challenges are specifically related to licensed staff (RNs & LPNs). Connecticut is making no effort to increase graduating numbers*

Meeting the long-term care needs of an increasingly older population

The two most common responses to this question (total responses=359) are expanding services and continuing to provide good care to as many people as possible. For example, nearly half of those who responded (43%) report they have **intentions of expanding**, either their physical space or their programs.

> *Our facility has recently been renovated to meet the needs of our community. We will continue to make modifications as necessary.*

Some of those who express an interest in expanding are clearly frustrated by current barriers, not only in terms of financial concerns but also a frustration with the State moratorium on nursing home beds.

> *We would be able to expand a little, but that is regulated through the State. We have added new programs to better suit the changing population. Need more dollars!*

> *Expansion of our skilled nursing services if the moratorium on beds is lifted.*

Another large segment of those who responded to the question (25%) are not flexible in their ability to expand. They stress their intentions to **continue to provide excellent services** in the manner that they are currently providing.

> *We are not a community capable of physical expansion, but plan to continue to provide a warm, compassionate and safe environment that allows our residents to age in place with appropriate services.*

Slightly less than ten percent cite **financial concerns** as the main obstacle to meeting the needs of the increasing older population. A smaller number of respondents mention the need to create alternative types of housing for older adults, to utilize existing home care services to the fullest extent, and to explore ways of coping with the increasing older population through their strategic planning process.

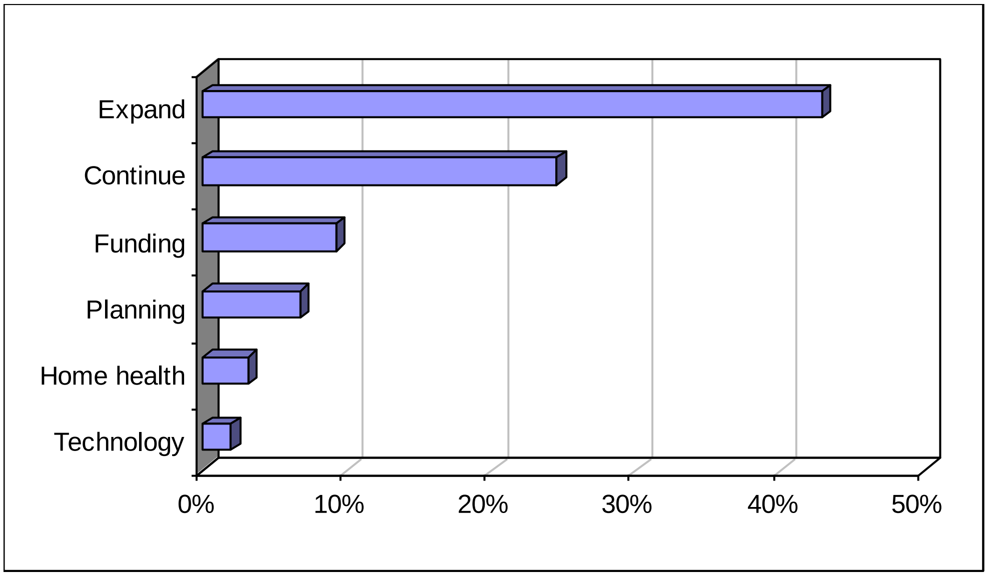
> *Unless the rates provided to community providers substantially increase to cover the cost of doing business and to increase wages and benefits, new development is unlikely.*
>
> *Alternatives to long-term care facilities. More affordable state subsidized assisted living or home care.*

Other comments note that the number of older adults will not only increase in numbers but also experience changes in the type of services they will expect. Still others point out that prevention tactics can alleviate the growing service need.

> *I think these adults will want more sophisticated care, including computers with DSL – things that today's elderly have no clue about. Also, they'll want private bathrooms, whereas today's elderly lived through the depression. They are not so picky. We are mostly state funded and will not be able to provide too much.*
>
> *We are also emphasizing wellness and preventive care - including exercise, nutrition, socialization. We are trying to promote "program without walls." People do not want institutionalized settings. They can be cost prohibitive as well.*

Figure IV-2 below illustrates the most common responses to the question concerning plans for meeting future long-term care service needs. It is noteworthy that very few responses mention technology as one avenue for meeting the growing need.

Figure IV-2. How do you plan to meet future long-term care service needs?



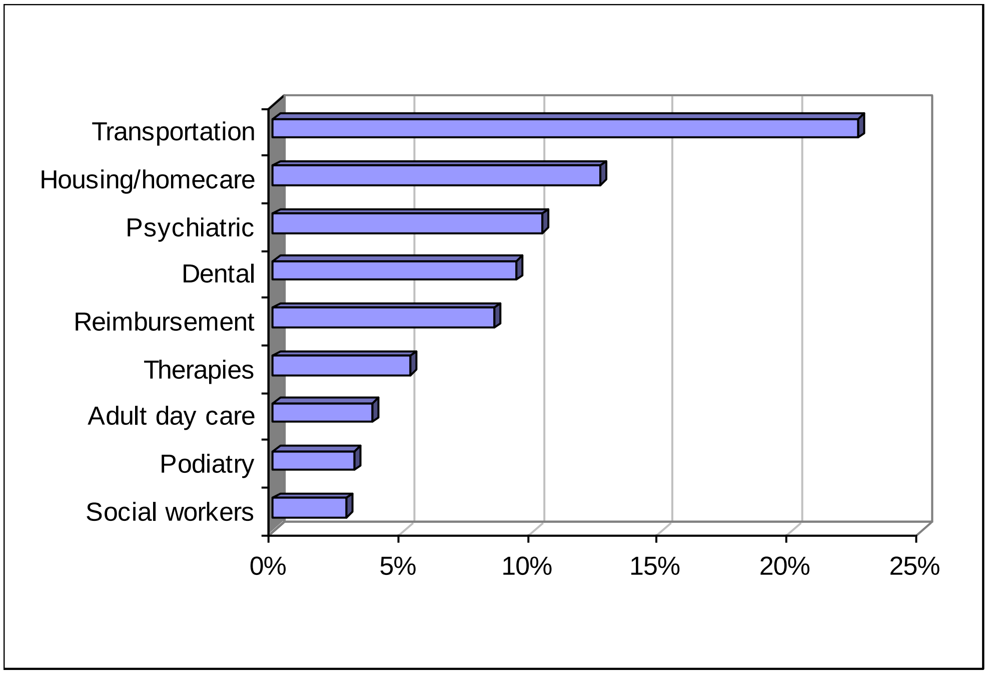
Missing services providers cannot offer

An examination of the 318 responses to this question reveals that transportation is the most frequently reported service providers cannot offer. Of all respondents, 23 percent indicate that **transportation problems are paramount** for a wide variety of reasons, from medical appointments to social needs.

> *We provide transportation; however this is a constant struggle and growing need for the senior population. What we provide does not begin to touch what is actually needed.*
>
> *Transportation is an ongoing challenge. We subcontract transportation at this time, which is costly. We could service more if we could expand our transportation capability. At this time it's cost prohibitive.*
>
> *Transportation is only available in this town, so those who have doctors in another town have to find alternative transportation.*
>
> *Transportation - many of my clients not only need transportation but assistance in/out of their homes and with packages, etc.*

Providers also mentioned a wide variety of other missing services. To a certain degree, the answers are representative of the type of provider. For example, the services currently provided by a senior center differ significantly from those provided by a nursing home. Thirteen percent of respondents indicate that supportive housing and homecare services are missing, and ten percent lack mental health or behavioral services. Another nine percent note that timely dental services are lacking for their clients who are on Medicaid. Other missing services mentioned less frequently include physical, speech and respiratory therapy, podiatry and dermatology services, social workers and case management, hospice services, physicians willing to make house calls, dialysis, and vocational services.

Figure IV-3. Services missing that cannot be provided



Illustrative responses include the following:

> *It is hard to find experienced psychiatrists/psychologists to work with the developmentally disabled.*
>
> *Long-term care for the disabled and elderly when there are no skilled needs and chronic care is needed by home health aides.*
>
> *Affordable housing; affordable medical specialists who are willing to work with an indigent aging population. Affordable housing alternatives beyond independent housing, i.e., assisted living communities and community agencies that have the expertise in working with an aging population.*
>
> *Vocational - no funding available. Current vocational programs don't want to serve people with mental health/substance abuse histories because it negatively impacts their outcomes and then potentially their funding.*

Greatest unmet long-term care service need for older adults and people with disabilities

A total of 404 providers offered suggestions on a wide variety of currently unmet needs for older adults or people with disabilities. The top category of unmet needs concerns **funding and reimbursement issues**, mentioned by 24 percent of respondents. Apprehension about the rising costs of a variety of services and inadequate reimbursement is the predominant theme. A sub-theme of those who are concerned with funding issues is that that funding will not be available for homecare or other appropriate services, resulting in more frequent institutional placement.

> *Many people who could stay home for want of home care and related homemaker services are institutionalized instead due to lack of homecare coverage*

Respondents identify **affordable and safe housing** as the number two unmet need for older adults and people with disabilities in Connecticut overall. One quarter (23%) of the responses to this question indicate that the lack of appropriate housing is paramount for this population. Associated with this comment is the desire to have individuals living in their homes as a viable alternative to nursing home placement.

> *Adequate housing that is affordable.*
>
> *Lack of adequate, flexible, individualized community services, and HOUSING!*

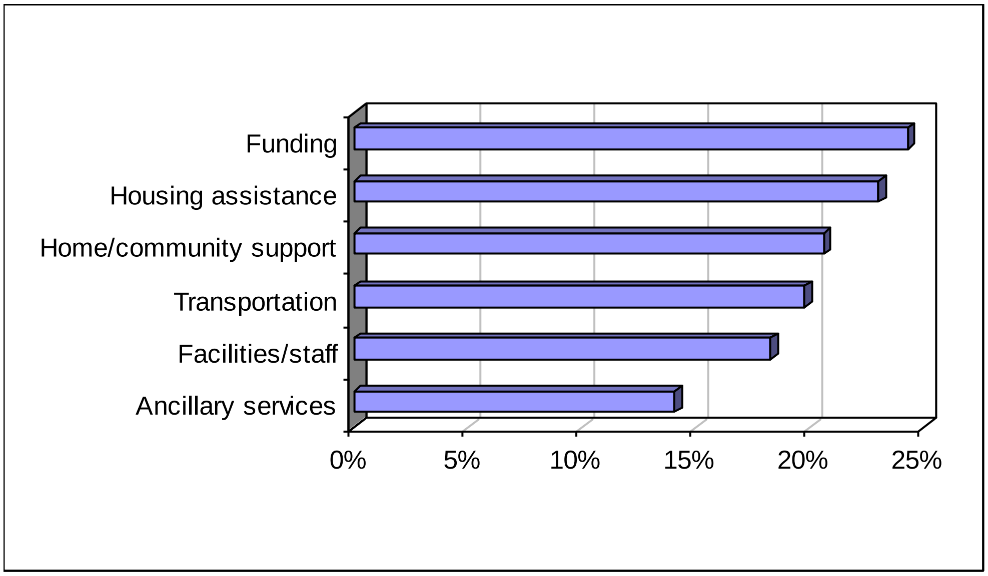
Homecare and other community supports such as adult day programs are mentioned almost as frequently (21%) as the first two concerns. Many of these respondents note that by allowing individuals to continue to live in their homes, these community-based alternatives to nursing homes would be one answer to Connecticut's long-term care service need.

> *Community support services. These services are holistic, recovery focused, assist people to stay in the community in a quality way and it will cost less.*
>
> *The greatest unmet need is support for the kind of services… that will allow people to remain at home. There is no payment for most of them, and payment for home health aides (the greatest need) is woefully inadequate.*

Improved transportation is seen as very important as well, with 20 percent of respondents indicating that transportation is the greatest unmet service need. Others (18%) stress institutional needs such as improved facilities and increased staffing to address the shortage of direct caregivers. Fewer respondents (14%) report that there is a need to address ancillary services such as dental, podiatric, mental health, and social work services. Other responses include the need for better prescription drug coverage, respite care, dementia units, hospice, and case management. Figure IV-4 summarizes responses to the question about greatest unmet need.

> *Seniors want to get out and about but they stay home because they don't want to put people out and make them go out of their way [to give the person a ride]. Giving up your independence is painful.*
>
> *Shortage of RNs will create a significant future problem for nursing homes. Also an apparent shortage of psychiatric facilities to accept urgent admissions from nursing homes, and shortage of dentists willing to accept low Medicaid reimbursement for that population.*

Figure IV-4. Greatest unmet long-term care service need



How the State can address these unmet needs

For those who answered this question (n=336), by far the number one answer was **increased funding**, including funding for improved transportation, affordable assisted living, training of home health aides and nurses, and assistance with home care. Over two-thirds (68%) of the responses had to do with increased funding levels for different programs, as well as increased reimbursement rates.

> *The biggest challenges are not the residents themselves, but the reimbursement system. The allowable costs and the use of ancient cost reports make it extremely difficult to run a business.*
>
> *Community-based care - more slots in ALSA pilot. Why is it still limited to only 75 people?*

Others point out that increased funding for home care, assisted living, or adult day programs would make these care settings a more viable alternative to nursing home placement. The emphasis on where the increased funding should be applied was largely determined by the type of provider.

> *Provide reimbursement incentives to support people in their current housing; develop incentives for people to go into this field of practice; consider supplemental payments for agencies who provide these services to these individuals; provide funding incentives, especially for the infrastructure for those agencies who want to convert to working with an aging population.*
>
> *Increase benefits to caretakers and those attempting to take care of a loved one on their own.*

> *Expand Medicaid coverage - need to see assisted living as an integrated program of housing and wellness, not as two separate entities.*

Other responses address areas such as workforce training and regulatory changes.

> *Offer incentives to schools and RN candidates to choose that profession. It is a CRIME that interested persons are on wait list of up to 3 years to enter RN programs in Connecticut!!! We are losing our future because of the lack of programs.*
>
> *Connecticut is one of the most regulated states. In many cases this impedes or limits the delivery of support. Do statistics show that this increased regulation improves outcomes? Could Connecticut make better use of its limited resources - i.e. LPNs, RNs, MDs, PTs – compared to other states?*

In summary, in order to meet the growing needs of an increasing older population, providers report a desire to expand their service capacity and an intention to continue to provide excellent services. However, providers also find that transportation is most often the service missing for their consumers which they cannot provide. Overall, providers feel that increased affordable, appropriate housing, as well as an increase in affordable home care and other community-based services, are the greatest barriers facing older adults and people with disabilities in Connecticut, and that increased funding would allow many of these barriers to be addressed.

Detailed results by provider type

This section provides an in-depth analysis of responses by provider type. Following the discussion of each provider type is a map indicating the geographic distribution of those organizations throughout the State.

Home health care agencies

A total of 47 home health care agencies from across the State answered the survey (54% response rate). Table IV-2 provides a breakdown of all services offered by these agencies. The top five services provided include: visiting nursing services (92%), home health aide services (92%), physical/speech/respiratory/occupational therapy (79%), homemaker services (60%), and care/case management (43%). Services mentioned under the category “other” include energy assistance, spiritual counseling, and telemonitoring.

The smallest home health agency currently serves 15 clients, while the largest serves 2,200 clients. The average number of clients currently being served is 368 (SD=473).

Table IV-2. Home health care agencies by services provided
(n=47)

Service	**Percent providing service**
Adult day care-social model	2
Assistive devices	11
Case/care management	**43**
Companion services	30
Durable medical equipment	11
Employment services	4
Handyman services	2
Health insurance counseling	2
Health screenings	34
Home delivered meals	6
Home health aid services	**92**
Homemaker services	**60**
Hospice services	32
Independent living skills training	2
Information and referral	28
Mental health counseling	17
Nutritional services	23
Other nursing services	40
Personal case assistant services	21
Personal emergency response system	26
Physical/speech/respiratory/occupational therapy	**79**
Prescription drug assistance	4
Respite care	26
Specialized dementia care	4
Transportation	6
Visiting nursing services	**92**
Other	17

Figures IV-5a,b,c,d below provide a demographic profile of home health clients currently being served. The largest proportion of clients falls within the age range 65 to 84 (46%), followed by the age range 85 to 99 (29%). The majority are White/Caucasian (77%), with less than ten percent (9%) African American. Five percent of the population is reported to be of Hispanic or Latino origin. Almost two-thirds (63%) of clients served by the home health care system are female.

Figure IV-5a. Home health care agency age distribution

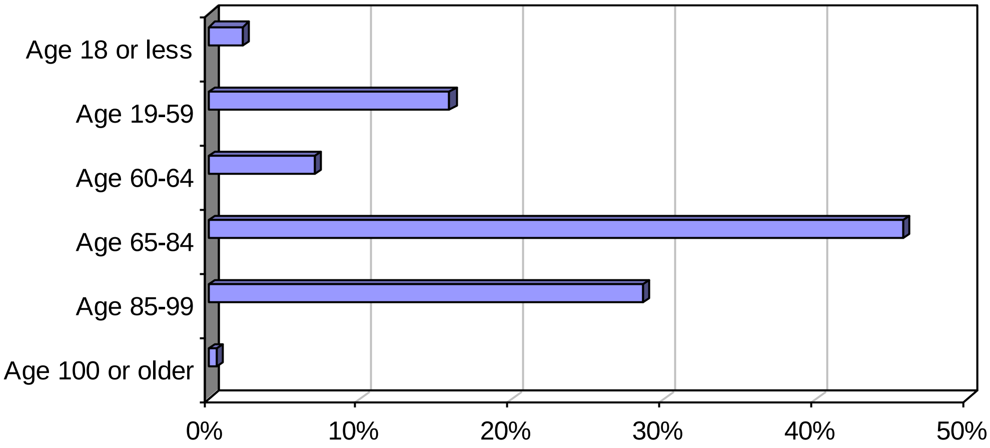


Figure IV-5b. Home health care agency by ethnic distribution

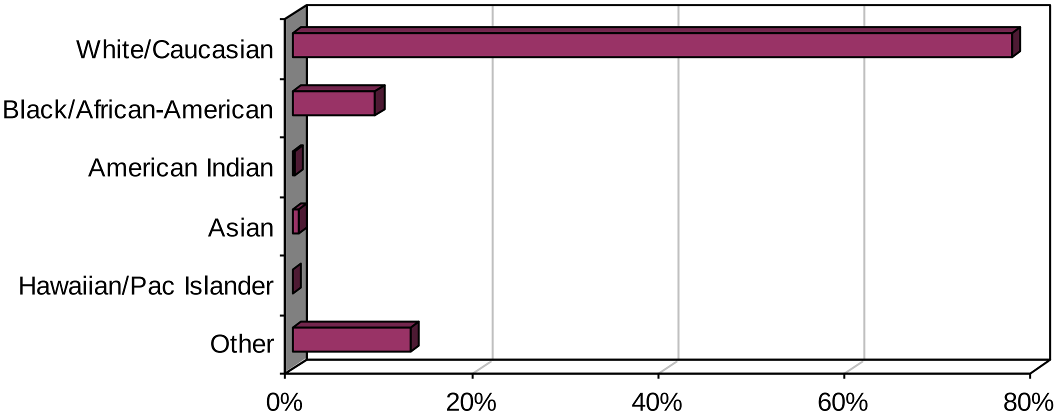


Figure IV-5c. Home health care agency by Hispanic origin distribution

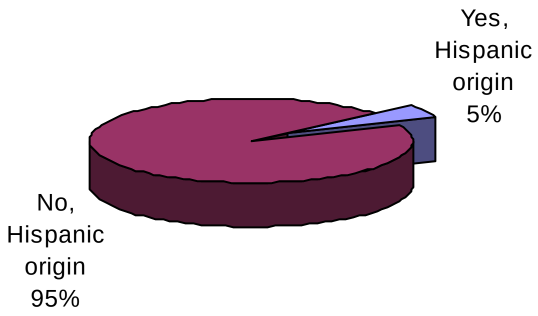
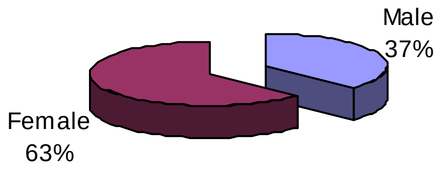


Figure IV-5d. Home health care agency by gender distribution



The method of payment for clients currently in service is summarized in Table IV-3 below. Data indicate that 16 percent have multiple payment sources. Almost half (43%) of these clients use Medicare to pay at least a portion of their home health services, and another third (34%) rely on Medicaid.

Table IV-3. Home health care agency by method of payment*
(n=47)

Method of payment	**Percent using**
Medicaid	34
Medicare	43
Out of Pocket (self pay)	3
Private Health Insurance	14
Private Long-Term Care Insurance	<1
Veteran's Administration	<1
Other	5

*Responses not mutually exclusive as consumers may have multiple payment sources

One question on the survey pertained to eligibility requirements for agency services, followed by an optional brief explanation (see Table IV-4 below). Nine out of ten (89%) of all home health care agencies have eligibility requirements. The most commonly endorsed eligibility category is targeted geographic areas (75%), followed by the exclusion of individuals with certain behavioral or psychiatric conditions and the acceptance of only certain payment sources (26% each). The category "other" is endorsed 36 percent of the time, and typical responses include living independently, living in a safe and appropriate environment, terminal prognosis, and requirement of a physician order.

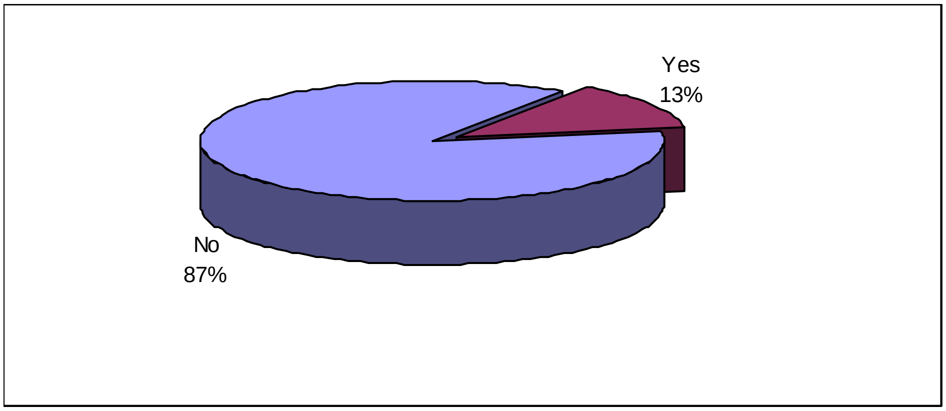
Table IV-4. Home health care agencies by eligibility requirements
(n=47)

Eligibility requirement	**Percent requiring**
Only certain diagnoses accepted	13
Only certain ages	17
Only certain payment sources accepted	26
Only certain geographic areas accepted	75
Certain behavioral or psychiatric diagnosis NOT accepted	26
Must have a certain number of impairments	0
Must have certain functional or cognitive abilities	4
Other	36
No eligibility requirements	11

* Responses not mutually exclusive

A key area of interest was a review of the current waiting list status for each agency. Data was gathered on the presence of a waiting list during the prior year and any reason for the wait. Currently, only 13 percent of reporting agencies have a waiting list (see Figure IV-6 below). Over the course of the past year, over half (55%) either declined services or added individuals to the waiting list due to lack of available staff. Forty percent declined clients because eligibility requirements were not met, and over one-third (36%) could not provide services because of lack of staff in a particular region or town. A smaller number could not provide services because of lack of a payment source (11%) or because agency staff did not speak the client's language (13%). Eleven percent of respondents listed other reasons, including medical reasons such as "client too medically complex."

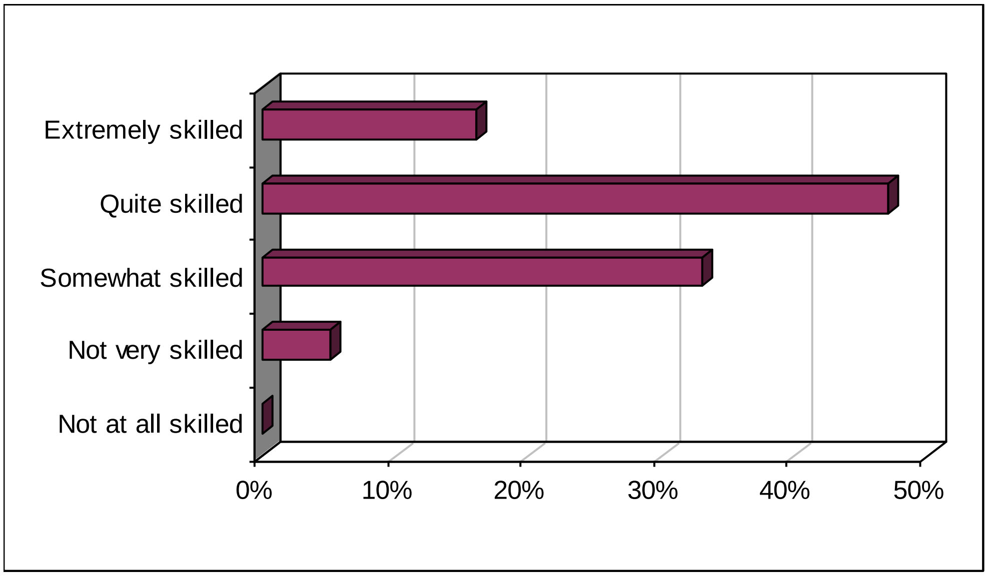
Figure IV-6. Home health care agencies by waiting list
(n=47)



Four questions explored services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients exhibiting challenging behaviors. Of the reporting agencies, eight percent of clients served have a diagnosis of mental illness (excluding dementia), while ten percent exhibited challenging behaviors in the past six months.

Almost three-quarters (73%) of all staff members have received specialized training to work with challenging behaviors. Agency directors were asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors. As Figure IV-7 demonstrates, almost two-thirds (63%) of providers rate their employees as being either quite or extremely skilled in working with clients who have challenging behaviors.

Figure IV-7. Home health care agencies by training and skill level (n=47)



Home health care providers responded to a series of questions about the frequency with which different situations have occurred. These questions focused on both employee and client concerns, and the results are presented in Table IV-5 below.

Table IV-5. Home health care employee and client concerns in the past year (percentages)*

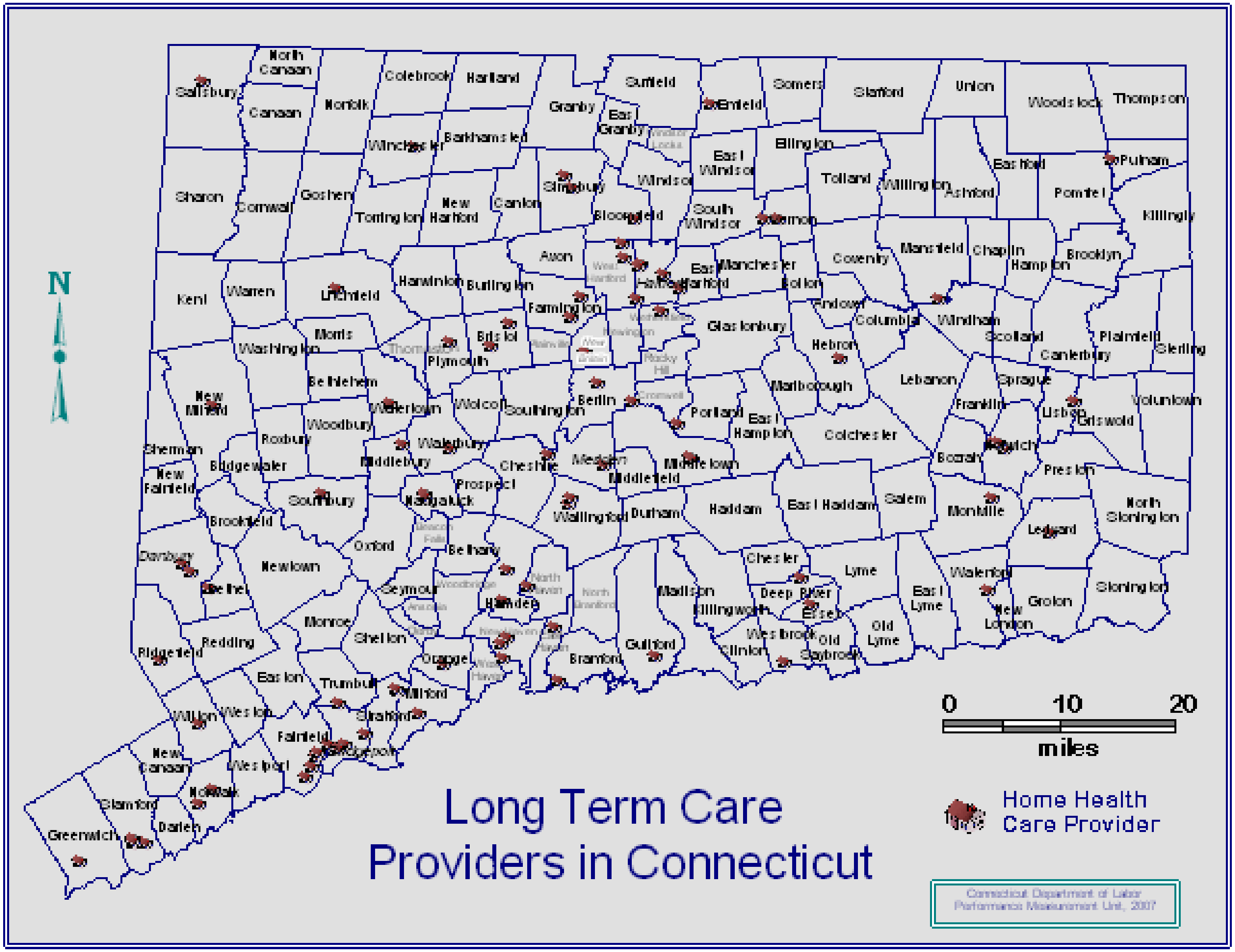
	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	11	**35**	17	23	13
Employees having difficulties with transportation to or from work	30	**43**	11	13	4
Clients complaining about employees	30	**52**	9	9	0
Language differences between clients and employees	36	**44**	4	9	7
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**66**	28	2	4	0
Issues or difficulties with employee unions	**87**	13	0	0	0
Using temporary or pool employees because it makes sense financially	**85**	4	0	4	7
Using temporary or pool employees because you do not have enough staff for the day	**72**	6	4	6	11
Problems with transportation for your clients	**33**	23	18	15	13
Difficulty finding health care services or providers for your clients	**41**	34	9	11	5
Transferring a client to another provider or ending services because of challenging behaviors	38	**60**	2	0	0
Transferring a client to another provider or ending services because of issues related to mental illness	**57**	41	2	0	0
Any other issues with employees or clients	**44**	33	11	0	11

*Rows may not sum to 100% due to rounding.

Fifty-three percent of respondents indicate that employees do not show up or call out sick at the last minute at least once a month, and more than one-fifth (21%) report using temporary employees because they do not have enough staff for the day. Nearly half (46%) of home care agencies indicate they have problems with transportation for clients at least once a month, and 25 percent have difficulty finding health care services for their clients at least once a month. Other issues mentioned by respondents include problematic dynamics with the client’s family and poor patient compliance.

The following map indicates the locations of home health agencies throughout the State. Many, of course, provide services covering a wide geographic area.

Home Health Care Providers



Connecticut Department of Labor
Performance Measurement Unit, 2007

Adult day programs

Forty-one adult day agencies from across the State answered the survey (85% response rate). Table IV-6 provides a breakdown of all services offered. As might be expected with this type of provider, the most frequently provided service was adult day care-medical model, chosen by 85 percent of these respondents. Transportation (66%), recreational services (61%), and specialized dementia care (51%), as well as nutritional services, information and referral, and various therapies (49% each) complete the top services provided by these respondents.

Table IV-6. Adult day agencies by services provided

Service	**Percent providing service**
Adult day care-medical model	**85**
Adult day care-social model	15
Adult foster care	2
Assistive devices	10
Case/care management	27
Companion services	10
Congregate meals	20
Durable medical equipment	2
Group home/supported living services	7
Handyman services	2
Health insurance counseling	7
Health screenings	34
Home delivered meals	15
Home health aid services	15
Homemaker services	15
Hospice services	7
Independent living skills training	10
Information and referral	**49**
Mental health counseling	20
Nutritional services	**49**
Other nursing services	34
Personal care assistant services	26
Personal emergency response system	10
Physical/speech/respiratory/occupational therapy	**49**
Prescription drug assistance	15
Recreational services	**61**
Respite care	44
Specialized dementia care	**51**
Transportation	**66**
Visiting nursing services	12
Other	15

The average number of clients currently being served by adult day providers is 66 (range 8-430, SD=69). The demographic profile of clients currently served by adult day agencies is shown in Figures IV-8a,b,c,d below. As with home health agencies, the largest proportion of clients is between the ages of 65 and 84 (57%), with thirty-six percent age 85 or older. The majority of adult day clients are White/Caucasian (78%), with 17 percent African American, and only eight percent were reported to be of Latino origin. Almost two-thirds of the adult day clients are female (65%).

Figure IV-8a. Adult day agency age distribution

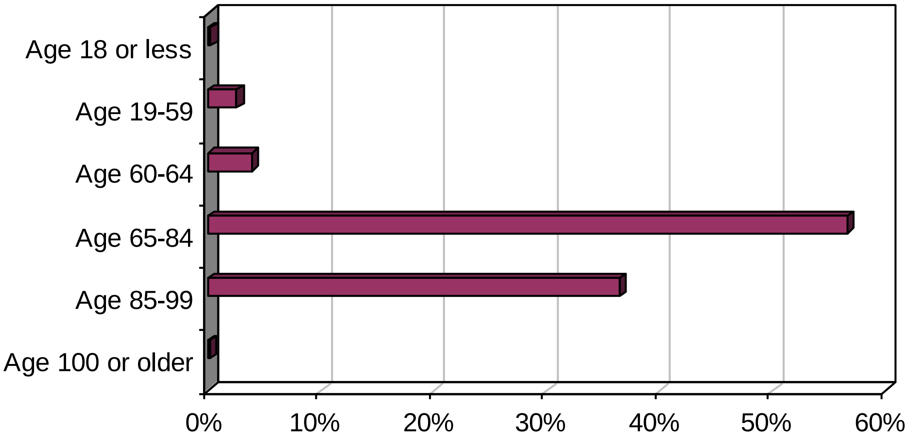


Figure IV-8b. Adult day agency by ethnic distribution

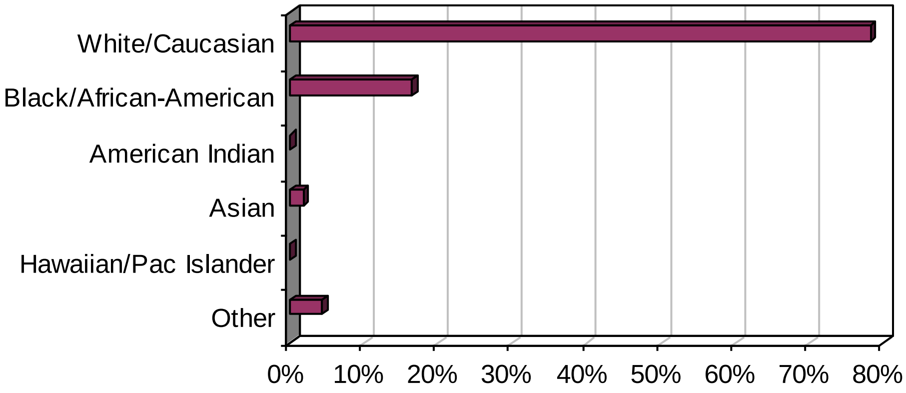
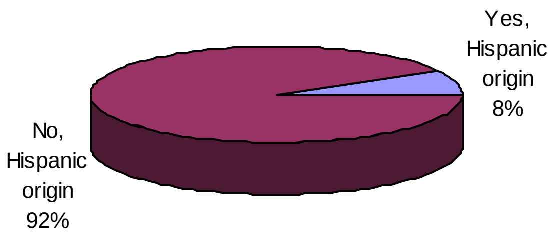
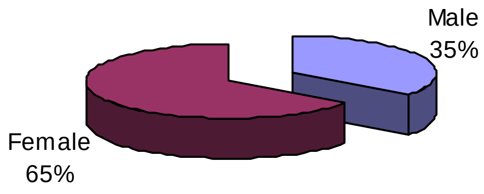


Figure IV-8c. Adult day agency by Hispanic origin distribution	Figure IV-8d. Adult day agency by gender distribution
	

The method of payment for clients currently in service is noted in Table IV-7 below. Data indicate that only six percent of adult day clients have multiple payment sources. Adult day agencies report that close to half (44%) of their clients pay for their services using Medicaid while one quarter (25%) pay out of pocket. Another 28 percent use other payment sources such as funding through an agency or from a private grant.

Table IV-7. Adult day agency by method of payment*
(n=41)

Method of payment	**Percent using**
Medicaid	44
Medicare	4
Private Health Insurance	<1
Private Long-Term Care Insurance	1
Veteran's Administration	<1
Out of Pocket (self pay)	25
Other	28

*Responses not mutually exclusive

One question on the survey pertained to eligibility requirements for agency services, followed by an optional brief explanation (see Table IV-8 below). The vast majority (90%) of all adult day agencies have eligibility requirements. The most commonly endorsed eligibility category was geographic area (68%), followed by an age requirement (46%), the exclusion of individuals with certain behavioral or psychiatric conditions (42%), and the requirement of certain functional or cognitive abilities (39%). Other eligibility requirements include the ability to function appropriately in a group setting without being threatening or disruptive, and a need for socialization or supervision.

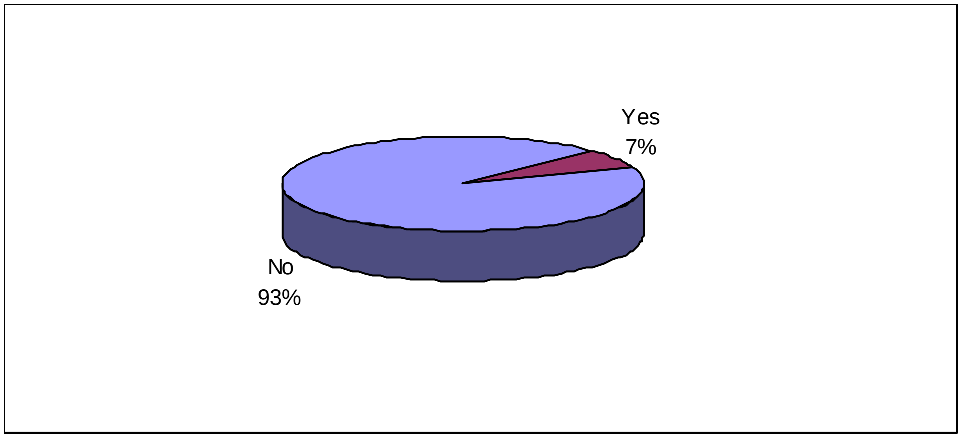
Table IV-8. Adult day agency by eligibility requirements*

Eligibility requirement	Percent requiring
Only certain diagnoses accepted	7
Only certain ages	46
Only certain payment sources accepted	7
Only certain geographic areas accepted	68
Certain behavioral or psychiatric diagnosis NOT accepted	42
Must have a certain number of impairments	5
Must have certain functional or cognitive abilities	39
Other	27
No eligibility requirements	10

* Responses not mutually exclusive

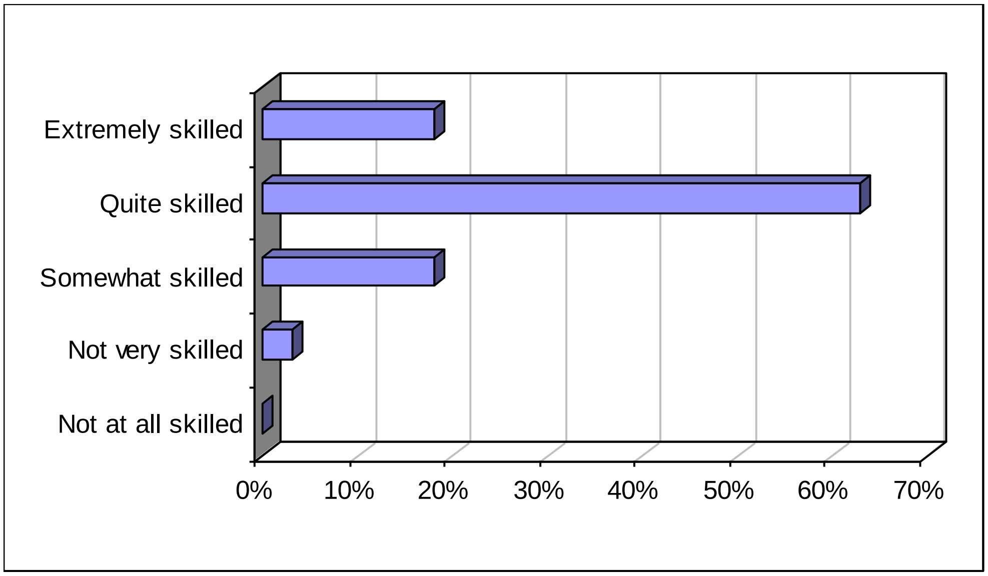
Only seven percent of adult day agencies report having a current waiting list for services. The most commonly reported reasons for declining services to a client or placing a client on a waiting list in the past year are: no source of payment (24%), person did not meet eligibility requirements (24%), and no staff in a particular region or town (10%). For adult day providers, lack of transportation is most frequently mentioned as another reason for declining services to an individual, with answers such as no bus service available or current van service will not cross town lines.

Figure IV-9. Adult day agencies by waiting list



Four survey questions sought to understand services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients who have challenging behaviors. Of the reporting adult day agencies, 13 percent of clients served are reported to have a diagnosis of mental illness (excluding dementia), with a slightly greater percentage of clients exhibiting challenging behaviors in the past six months (16%). All adult day staff members (100%) in this sample have received specialized training to work with clients who exhibit challenging behaviors. When asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors, a great majority of agencies (81%) rate their employees as either quite or extremely skilled. See results in Figure IV-10 below.

Figure IV-10. Adult day agencies by training and skill level



Adult day providers were also asked about the frequency of certain employee and client issues in the past year (see Table IV-9 below). Overall, adult day providers report that few employee concerns happen with any regularity. The two exceptions are employees not showing up or calling out sick at the last minute (32% report this happens once a month or more), and presence of language differences between clients and employees (22% report this happens once a month or more). Client concerns were reported more frequently. Almost half of adult day providers (47%) report problems with client transportation once a month or more, while more than a quarter (28%) indicate that finding health care services for their clients is an issue at least once a month.

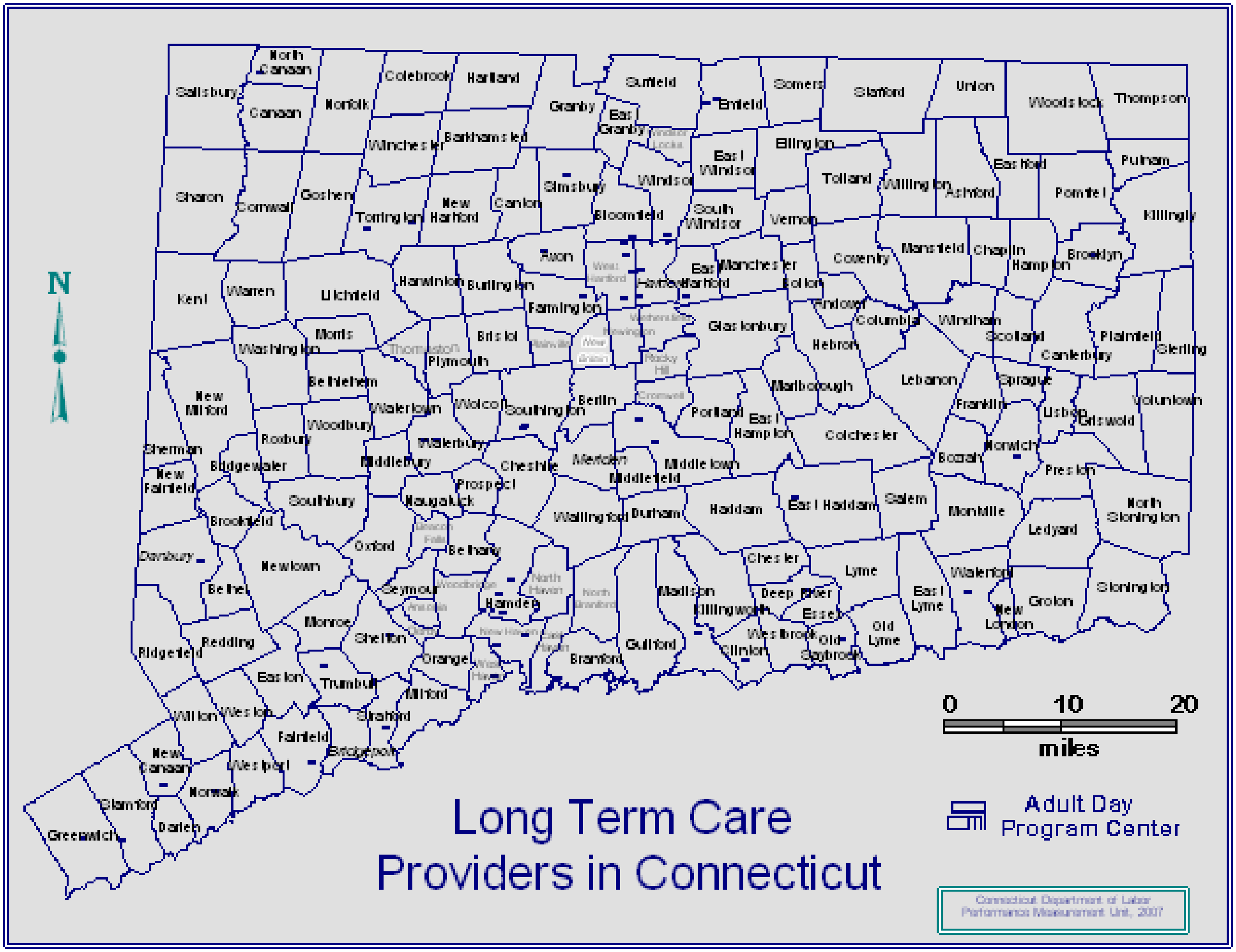
Table IV-9. Adult day employee and client concerns in the past year (percentages)*

	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	24	**44**	22	10	0
Employees having difficulties with transportation to or from work	**59**	22	7	10	2
Clients complaining about employees	**59**	32	10	0	0
Language differences between clients and employees	**61**	17	5	2	15
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**85**	15	0	0	0
Issues or difficulties with employee unions	**89**	3	3	3	3
Using temporary or pool employees <u>because it makes sense financially</u>	**100**	0	0	0	0
Using temporary or pool employees <u>because you do not have enough staff for the day</u>	**80**	10	8	3	0
Problems with transportation for your clients	22	**32**	12	20	15
Difficulty finding health care services or providers for your clients	**40**	33	20	3	5
Transferring a client to another provider or ending services because of challenging behaviors	33	**65**	3	0	0
Transferring a client to another provider or ending services because of issues related to mental illness	**61**	37	2	0	0
Any other issues with employees or clients:	**60**	40	0	0	0

*Rows may not sum to 100% due to rounding.

The following map shows the locations of the adult day centers in Connecticut.

Adult Day Program Centers



Nursing homes

The nursing home provider category includes both types of nursing homes licensed in Connecticut: chronic and convalescent nursing homes (also known as skilled nursing facilities) and rest homes with nursing supervision (also called intermediate care facilities). The two together are hereafter collectively referred to as "nursing homes." Ninety-six nursing homes from across the State answered the survey (40% response rate). Table IV-10 provides a breakdown of all services offered by nursing homes. The most frequently offered services include physical, speech, respiratory, or occupational therapy (88%); recreational services (80%); respite services (74%); hospice services and other nursing services (72% each); and nutritional services (60%).

Table IV-10. Nursing homes by services provided

Service	**Percent providing service**
Adult day care-medical model	8
Adult day care-social model	3
Assisted living services	10
Assistive devices	43
Case/care management	44
Companion services	5
Congregate meals	23
Durable medical equipment	34
Employment services	2
Fiscal intermediary	7
Group home/supported living services	2
Handyman services	8
Health insurance counseling	6
Health screenings	13
Home delivered meals	2
Home health aid services	4
Homemaker services	5
Hospice services	**72**
Independent living skills training	20
Information and referral	44
Mental health counseling	27
Nutritional services	60
Other nursing services	**72**
Personal case assistant services	24
Personal emergency response system	15
Physical/speech/respiratory/occupational therapy	**88**
Prescription drug assistance	25
Recreational services	**80**
Respite care	**74**
Specialized dementia care	33
Transportation	26
Visiting nursing services	9
Other	37

The average number of clients served by the respondent nursing homes is 118 (SD 73), with a range of 9 to 500 clients. A demographic profile of nursing home clients is found in Figures IV-11a,b,c,d. As might be expected, nursing homes serve an older population, with over half of clients (51%) age 85 or older, and another 39 percent in the 65 to 84 age range. The great majority of these nursing home residents are Caucasian (88%), female (70%), and of non-Hispanic origin (96%).

Figure IV-11a. Nursing home age distribution

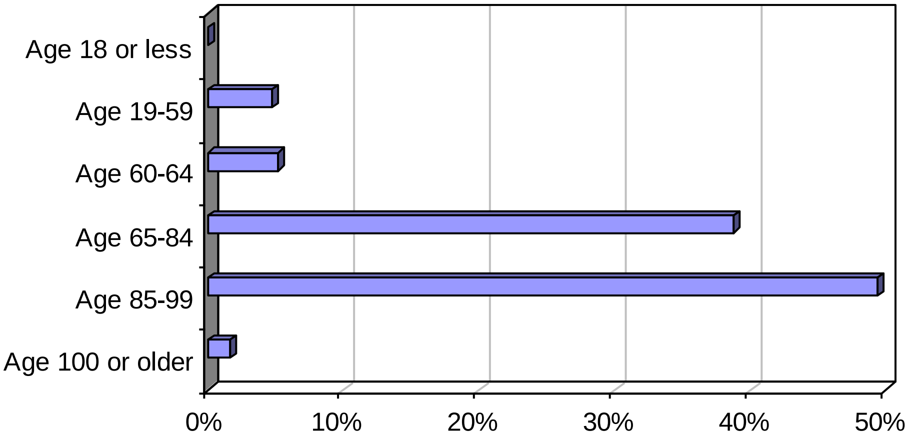


Figure IV-11b. Nursing home ethnic distribution

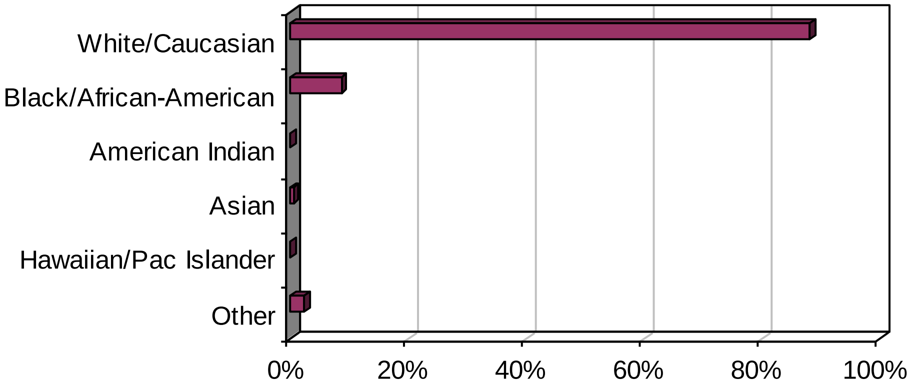


Figure IV-11c. Nursing home Hispanic origin distribution

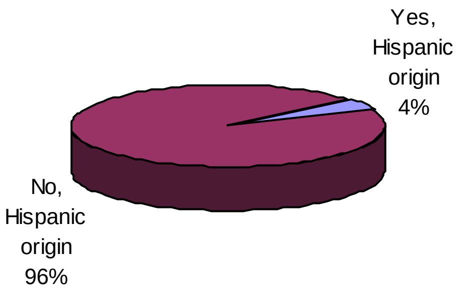


Figure IV-11d. Nursing home gender distribution

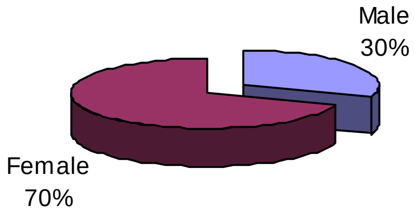


Table IV-11 shows the method of payment for current nursing home clients. Almost two-thirds (65%) use Medicaid to pay for at least part of their services, and over one-quarter (27%) use two or more methods to pay for their services.

Table IV-11. Nursing home method of payment*
(n=96)

Method of payment	**Percent using**
Medicaid	65
Medicare	19
Private Health Insurance	4
Private Long-Term Care Insurance	1
Veteran's Administration	<1
Out of Pocket (self pay)	14
Other	4

*Responses not mutually exclusive

Most nursing homes in the sample (86%) have eligibility requirements for services (see Table IV-12). Over half (55%) report that certain behavioral or psychiatric conditions are not accepted, and 35 percent have an age requirement.

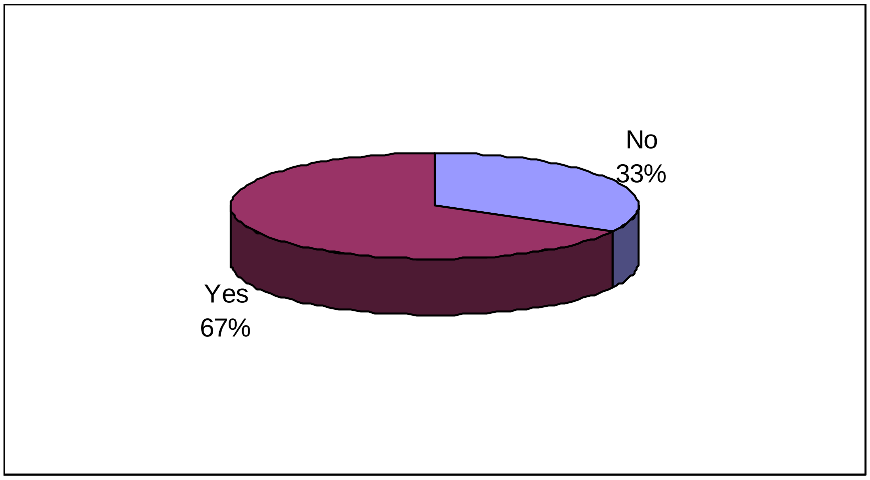
Table IV-12. Nursing homes eligibility requirements*
(n=96)

Eligibility requirement	**Percent requiring**
Only certain diagnoses accepted	15
Only certain ages	35
Only certain payment sources accepted	17
Only certain geographic areas accepted	1
Certain behavioral or psychiatric diagnosis NOT accepted	55
Must have a certain number of impairments	2
Must have certain functional or cognitive abilities	3
Other	25
No eligibility requirements	14

*Responses not mutually exclusive

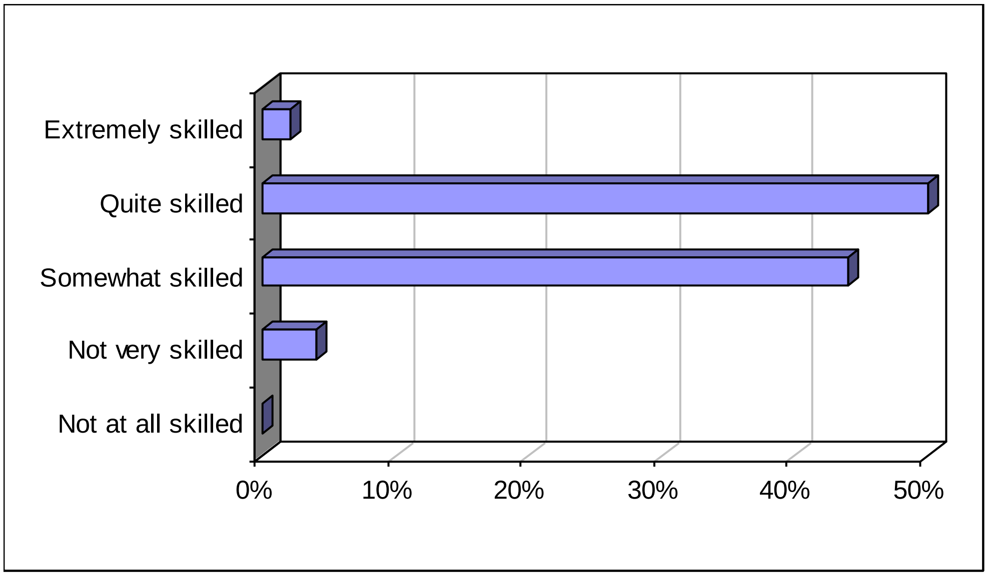
Two-thirds of nursing home respondents (67%) have a waiting list for services (Figure IV-12). More than two-thirds of nursing home respondents (68%) report a lack of beds as one reason for declining services or putting a person on a waiting list. Over one-third endorse either no source of payment (39%) or not meeting the eligibility criteria (35%) as reasons for declining services over the past year. Other reasons were written in by 13 percent of respondents, and include responses such as the person being too medically complex or exhibiting unsafe behaviors.

Figure IV-12. Nursing homes with a waiting list for services



Four survey questions concern services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients who have challenging behaviors. Of the reporting nursing homes, only 11 percent of clients served were reported to have a diagnosis of mental illness (excluding dementia), and in the past six months, nearly one-fifth (17%) of all clients exhibited challenging behaviors. A great majority (85%) of all staff members have received specialized training to work with challenging behaviors. However, when asked to rate the overall level of training and skill of their staff when working with clients with challenging behaviors, only half (52%) of nursing homes indicate that that their staff are either quite or extremely skilled at caring for these residents (Figure IV-13).

Figure IV-13. Nursing homes training and skill level
(n=96)



Nursing home providers were also asked about the frequency of certain employee and client issues in the past year (see Table IV-13 below). For employee concerns, most notable is that three-quarters (76%) of nursing home providers report problems with employees not showing up or calling out sick at the last minute at least once a month, while over half (55%) report using temporary employees because of staff shortages at least once a month. Client concerns that occur at least once a month include problems with transportation (41%), clients complaining about employees (32%), and difficulty finding health care services or providers for clients (31%). The health care service most frequently mentioned as difficult to find is dental service for Medicaid clients.

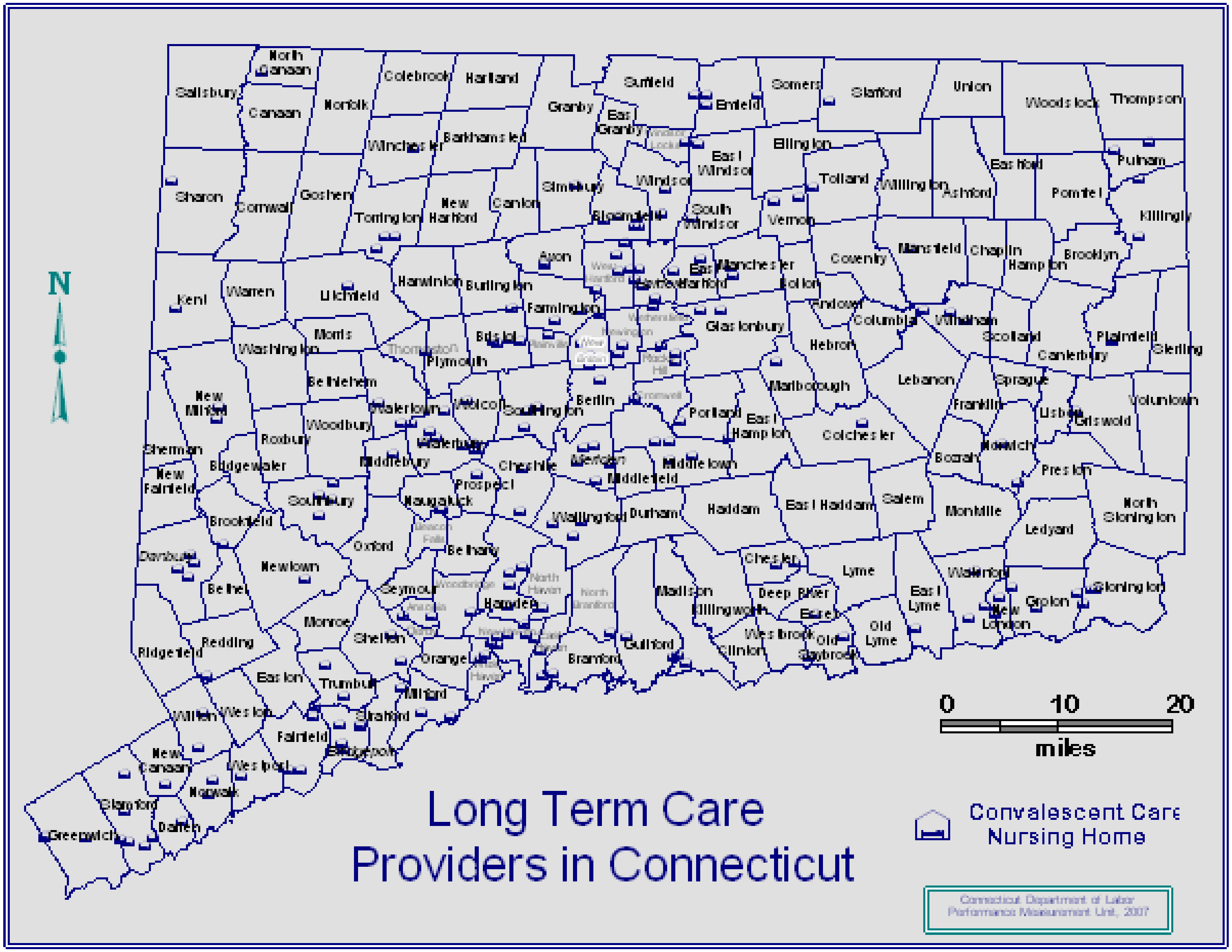
Table IV-13. Nursing home employee and client concerns in the past year (percentages)*

	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	1	23	25	**33**	18
Employees having difficulties with transportation to or from work	11	**47**	23	17	2
Clients complaining about employees	15	**53**	21	9	2
Language differences between clients and employees	33	**44**	13	5	5
Problems or issues related to cultural, ethnic or racial differences between clients and employees	37	**49**	9	3	2
Issues or difficulties with employee unions	**76**	13	8	1	2
Using temporary or pool employees because it makes sense financially	**92**	4	1	1	2
Using temporary or pool employees because you do not have enough staff for the day	**34**	10	7	21	27
Problems with transportation for your clients	**34**	25	20	16	5
Difficulty finding health care services or providers for your clients	33	**36**	21	5	5
Transferring a client to another provider or ending services because of challenging behaviors	27	**65**	7	1	0
Transferring a client to another provider or ending services because of issues related to mental illness	33	**61**	5	1	0
Any other issues with employees or clients:	**50**	29	0	8	13

* Rows may not sum to 100% due to rounding.

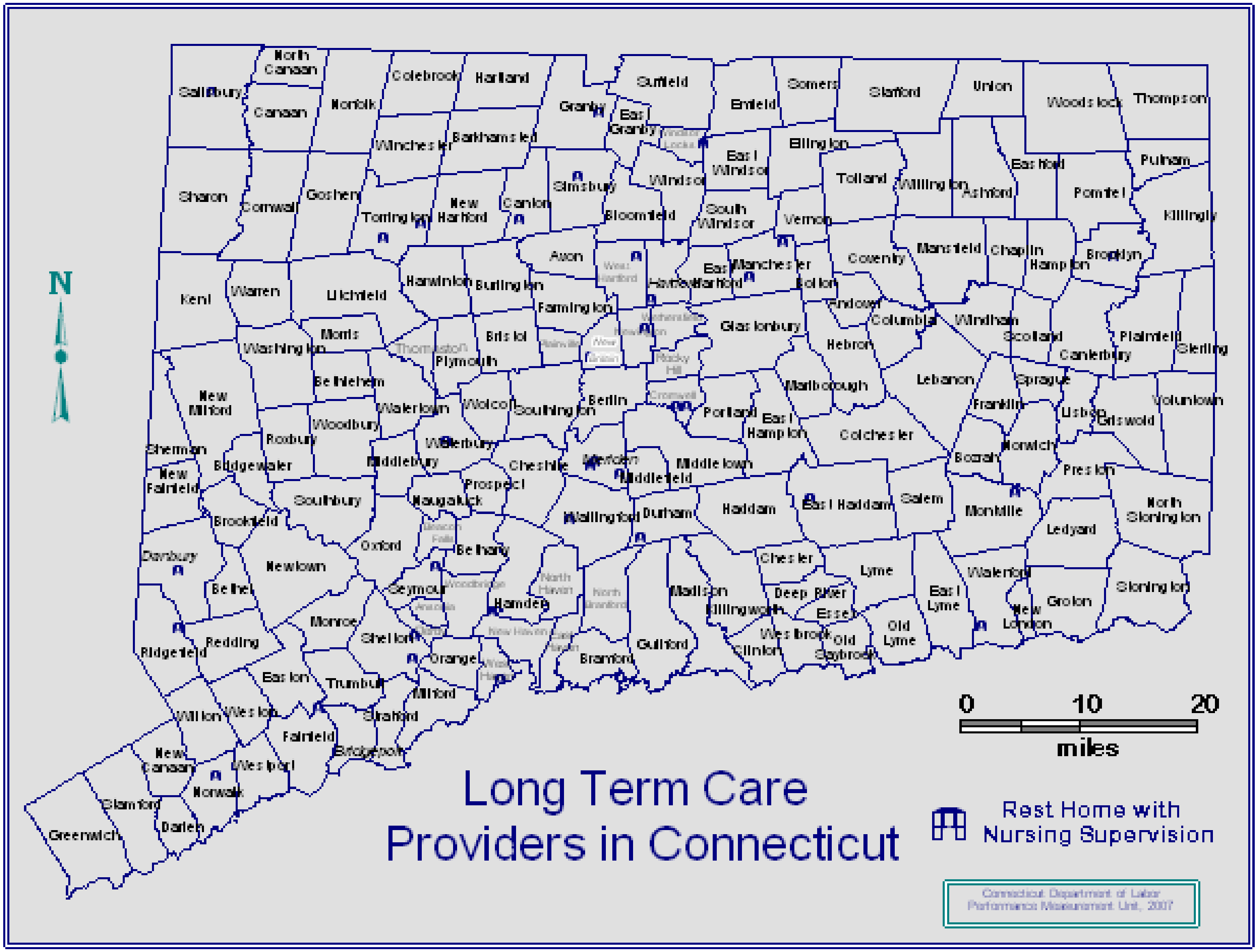
The two maps below indicate the locations of both types of nursing homes licensed in Connecticut.

Convalescent Care Nursing Homes



Connecticut Department of Labor
Performance Measurement Unit, 2007

Rest Home with Nursing Supervision



Residential care homes

A total of 42 residential care homes from across the State answered the survey (42% response rate). Table IV-14 provides a breakdown of all services offered. The services most frequently provided by residential care homes include recreational services (52%), transportation (48%), and personal care assistant services (43%), assisted living services and congregate meals (41% each).

Table IV-14. Residential care homes by services provided
(n=42)

Service	**Percent providing service**
Adult day care-medical model	5
Assisted living services	**41**
Assistive devices	12
Case/care management	17
Companion services	14
Congregate meals	**41**
Durable medical equipment	7
Employment services	2
Group home/supported living services	36
Handyman services	24
Health screenings	17
Home delivered meals	2
Home health aid services	19
Homemaker services	21
Hospice services	12
Independent living skills training	2
Information and referral	29
Mental health counseling	21
Nutritional services	17
Other nursing services	19
Personal care assistant services	**43**
Personal emergency response system	24
Physical/speech/respiratory/occupational therapy	21
Prescription drug assistance	24
Recreational services	**52**
Respite care	24
Specialized dementia care	2
Transportation	**48**
Visiting nursing services	31
Other	29

The smallest residential care home serves only five clients, while the largest serves 86 clients. The average number of clients currently being served is 26 (SD=17). Figures IV-14a,b,c,d below provide a demographic profile of residential care home clients currently in service. There is a wide age distribution, with roughly one-fifth of clients (22%) being 19 to 59, almost a third of clients (30%) 65 to 84 years old, and a quarter of clients (27%) 85 to 99 years old. In addition, 15 percent of residential care home clients are 100 years old or older. Once again, the majority of clients are White/Caucasian (91%) and of non-Hispanic origin (98%), while nearly two-thirds (64%) are female.

Figure IV-14a. Residential care homes age distribution

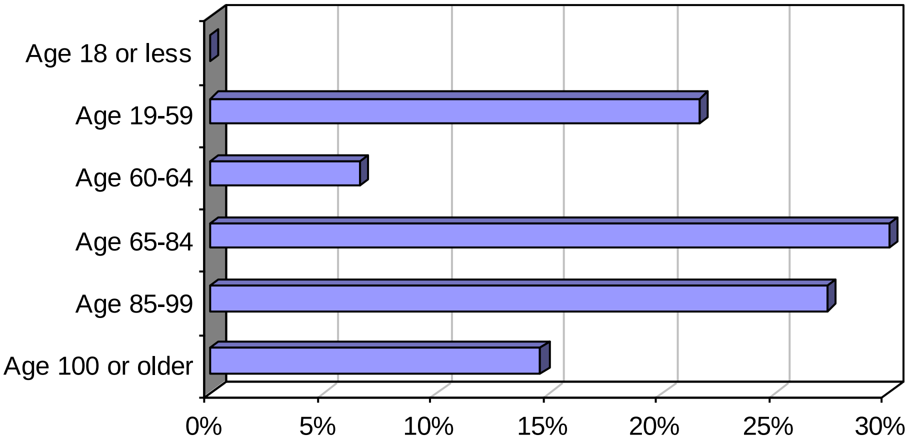


Figure IV-14b. Residential care homes ethnic distribution

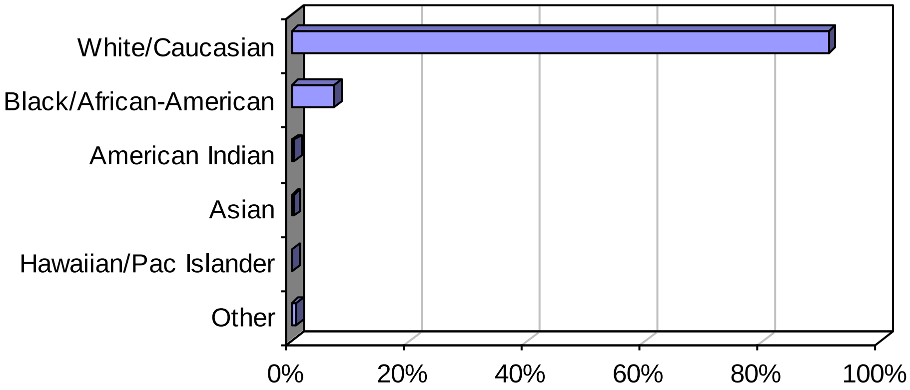


Figure IV-14c. Residential care homes Hispanic origin distribution

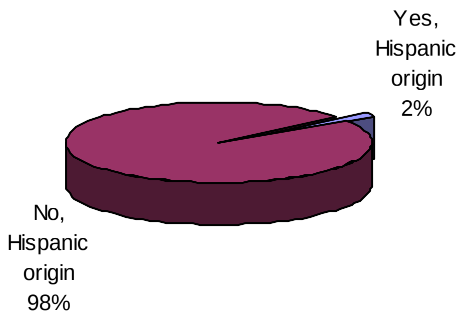
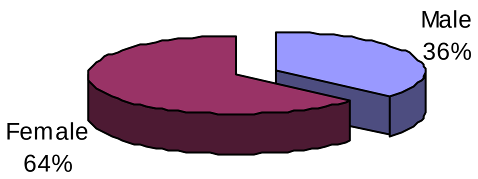


Figure IV-14d. Residential care homes gender distribution



The method of payment for clients currently in service is noted in Table IV-15 below. Two-thirds of clients (67%) use Medicaid as one source of payment, while one-quarter (26%) pay out of pocket for these services. Data indicate that 33 percent have multiple payment sources.

Table IV-15. Residential care homes by method of payment*
(n=42)

Method of Payment	**Percent using**
Medicaid	67
Medicare	13
Private Health Insurance	1
Private Long-Term Care Insurance	0
Veteran’s Administration	1
Out of Pocket (self pay)	26
Other	12

*Responses not mutually exclusive

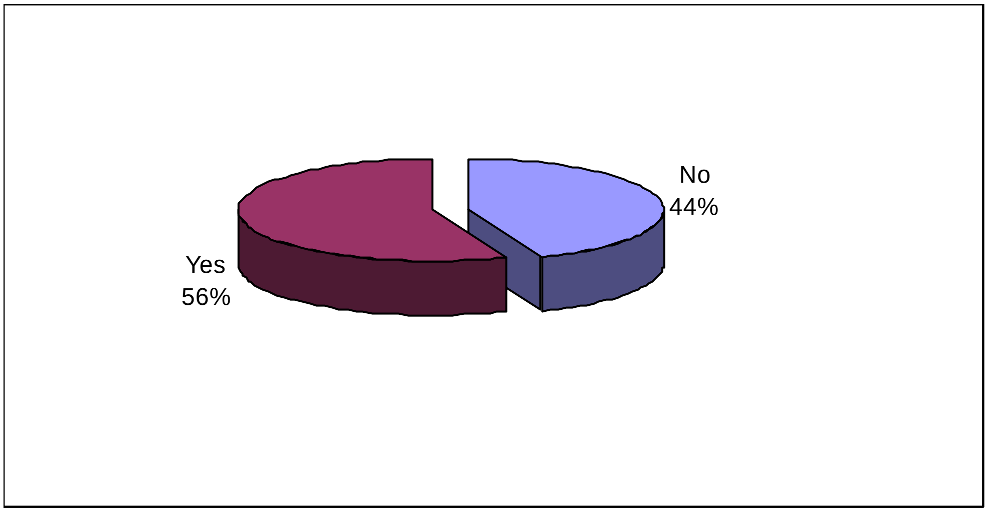
One survey question pertained to eligibility requirements for agency services, followed by an optional brief explanation (see Table IV-16 below). The vast majority (95%) of all residential care homes have some type of eligibility requirement. The three most common eligibility categories are must have certain functional or cognitive abilities (60%), only certain ages accepted (57%), and certain behavioral or psychiatric diagnoses not accepted (52%).

Table IV-16. Residential care homes by eligibility requirements (n=42)

Eligibility requirement	**Percent requiring**
Only certain diagnoses accepted	14
Only certain ages	57
Only certain payment sources accepted	24
Only certain geographic areas accepted	2
Certain behavioral or psychiatric diagnosis NOT accepted	52
Must have a certain number of impairments	2
Must have certain functional or cognitive abilities	60
Other	33
No eligibility requirements	5

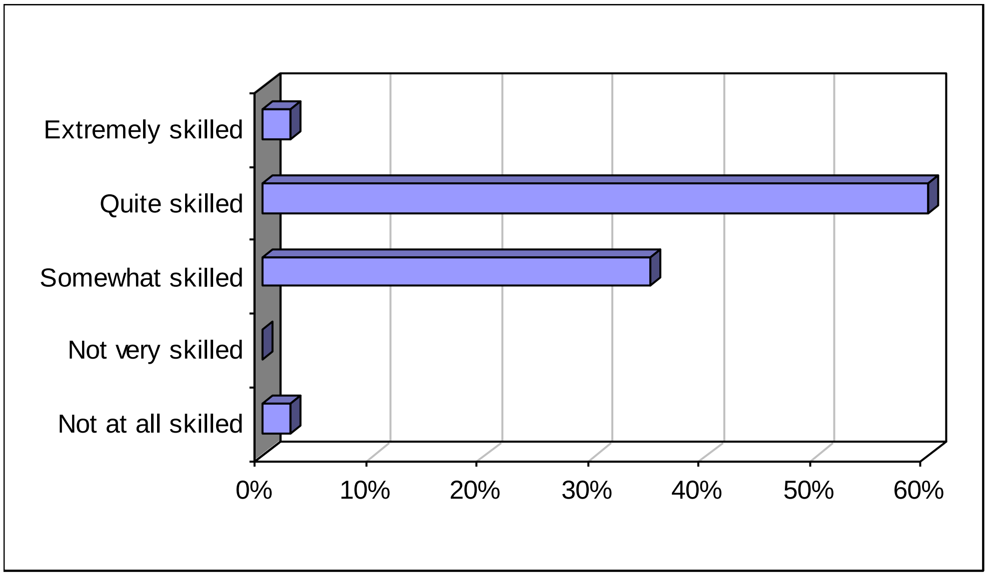
Currently, over half (56%) of residential care homes report that they have a waiting list for services (Figure IV-15). Over the course of the past year, over two-thirds (69%) declined services or had a waiting list due to a lack of available beds, over one-third (38%) because the person did not meet eligibility requirements, and one-fifth (21%) because of no payment source.

Figure IV-15. Residential care homes presence of a waiting list for services



Four questions cover services to clients with mental illness and/or challenging behaviors, and staff training for employees who work with clients who exhibit challenging behaviors. Almost half (46%) of the clients being served by these residential care homes are reported to have a diagnosis of mental illness (excluding dementia). In addition, one-quarter (24%) of all clients exhibited challenging behaviors in the past six months. Three-quarters (76%) of all staff members have received specialized training to work with challenging behaviors. Residential care homes were asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors. While very few rate their employees as extremely skilled, over half (60%) rate their employees as quite skilled, as shown in Figure IV-16 below.

Figure IV-16. Residential care homes by training and skill level (n=42)



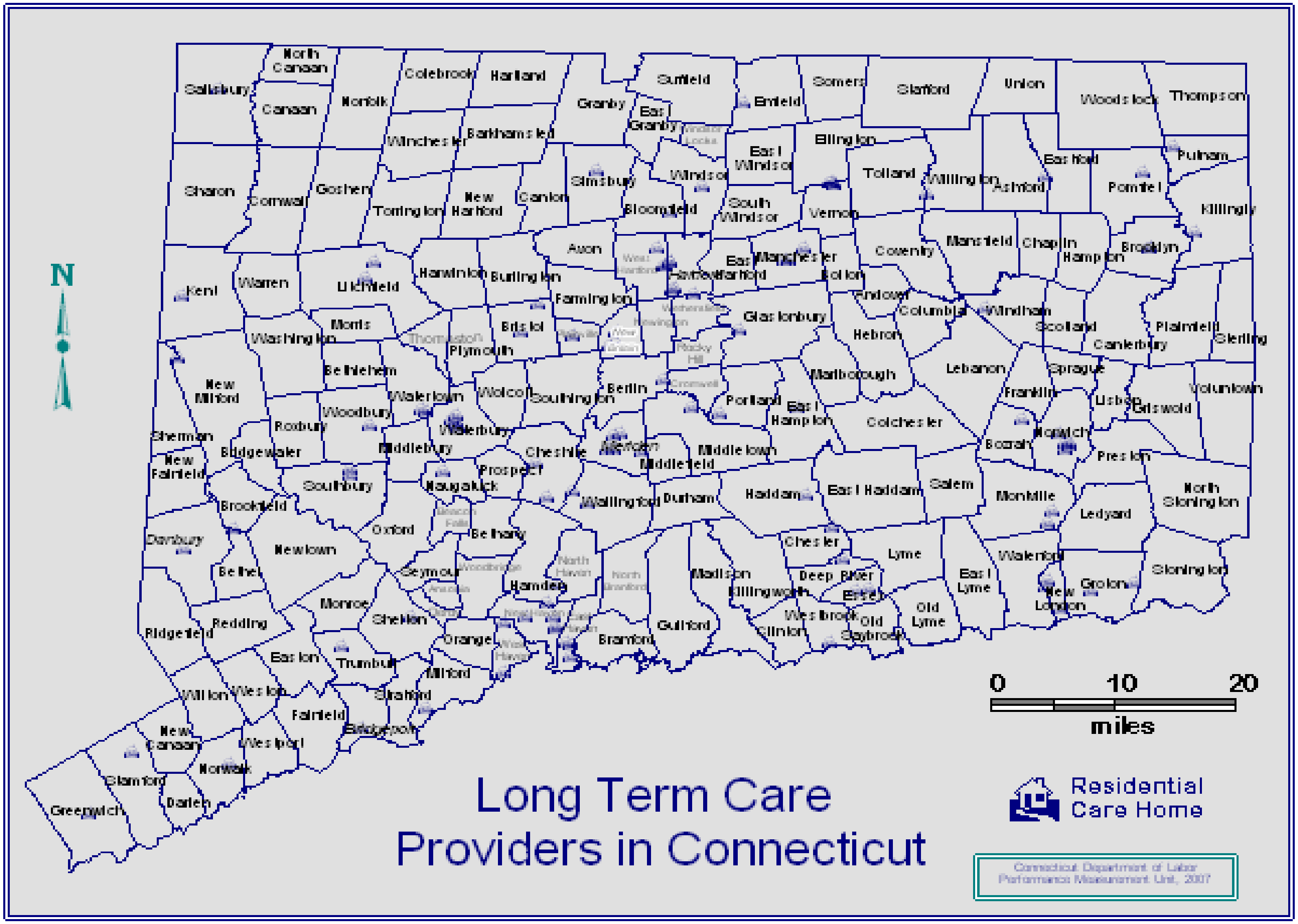
Residential care home providers responded to a series of questions about the frequency of different issues or concerns in the past year. These providers report few employee or client concerns (see Table IV-17 below). About one-quarter do report difficulty at least once a month in three areas: finding health care services for their clients (26%), problems with client transportation (24%), and employees not showing up or calling out sick at the last minute (22%). As with nursing homes, the most frequently mentioned missing health care service for clients is dental care for Medicaid recipients.

Table IV-17. Residential care homes employee and client concerns in the past year (percentages)*

	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	22	**56**	15	5	2
Employees having difficulties with transportation to or from work	**50**	41	7	2	0
Clients complaining about employees	33	**62**	2	2	0
Language differences between clients and employees	**81**	15	5	0	0
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**83**	14	2	0	0
Issues or difficulties with employee unions	**98**	2	0	0	0
Using temporary or pool employees because it makes sense financially	**100**	0	0	0	0
Using temporary or pool employees because you do not have enough staff for the day	**85**	7	5	0	2
Problems with transportation for your clients	29	**46**	10	12	2
Difficulty finding health care services or providers for your clients	36	**38**	19	5	2
Transferring a client to another provider or ending services because of challenging behaviors	**48**	**48**	3	3	0
Transferring a client to another provider or ending services because of issues related to mental illness	**63**	35	0	3	0
Any other issues with employees or clients:	**77**	18	0	0	6

*Rows may not sum to 100 due to rounding.

Residential Care Homes



Assisted living service agencies and managed residential care organizations

Although assisted living service agencies and managed residential care organizations were initially surveyed as separate provider classes, their results are combined for reporting purposes because of the substantial overlap. In Connecticut, assisted living service agencies are licensed to provide assisted living services in managed residential care organizations. Assisted living services can be provided in a number of different settings, such as continuing care retirement communities or housing for older adults, as long as the facility provides the services to qualify as a managed residential care organization.

A total of 56 assisted living service agencies and managed residential care organizations (ALSA/MRCs) from across the state answered the survey (52% response rate). Table IV-18 provides a breakdown of all services offered. The most frequently offered services include assisted living services (96%), recreational services (61%), transportation (52%), and congregate meals (50%).

Table IV-18. ALSA/MRCs by services provided

Services	**Percent providing service**
Adult day care-medical model	7
Adult day care-social model	9
Assistive devices	14
Assistive living services	**96**
Case/care management	29
Companion services	20
Congregate meals	**50**
Durable medical equipment	9
Group home/supported living services	4
Handyman services	21
Health insurance counseling	7
Health screenings	20
Home delivered meals	13
Home health aid services	23
Homemaker services	23
Hospice services	34
Independent living skills training	4
Information and referral	32
Mental health counseling	14
Nutritional services	27
Other nursing services	30
Personal care assistant services	45
Personal emergency response system	**48**
Physical/speech/respiratory/occupational therapy	34
Prescription drug assistance	29
Recreational services	**61**
Respite care	41
Specialized dementia care	39
Transportation	**52**
Visiting nursing services	30
Other	16

The ALSA/MRCs report serving an average of 102 clients (SD 90), with a range from nine to 400. Other client demographics are provided in Figures IV-17a,b,c,d below. The largest percentage of clients being served are age 85 to 99 (60%), with another 38 percent age 65 to 84. Almost three-quarters (74%) of ALSA/MRC clients are female. Ninety-two percent are White or Caucasian, and almost all clients (98%) are of non-Hispanic origin.

Figure IV-17a. ALSA/MRCs by age distribution

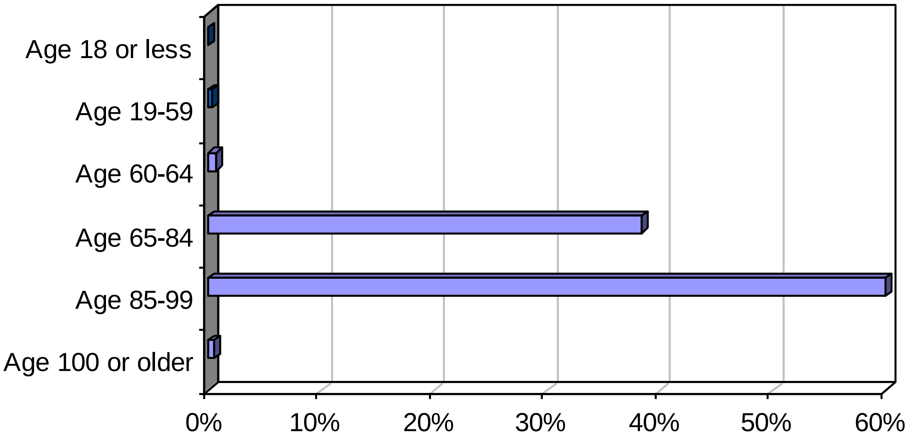


Figure IV-17b. ALSA/MRCs by Ethnic Distribution

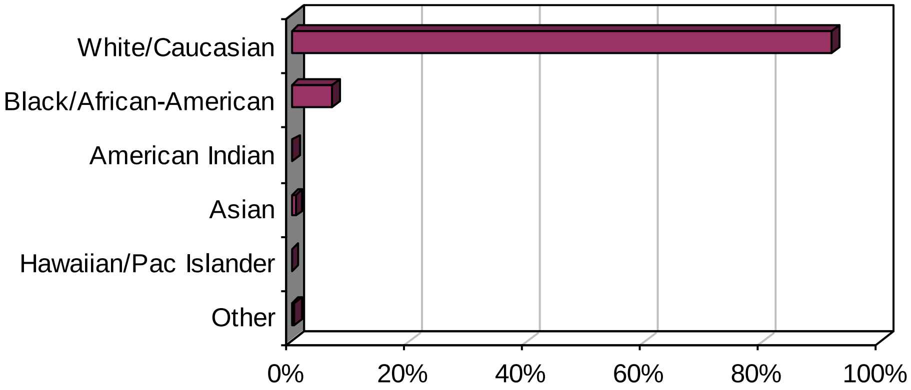
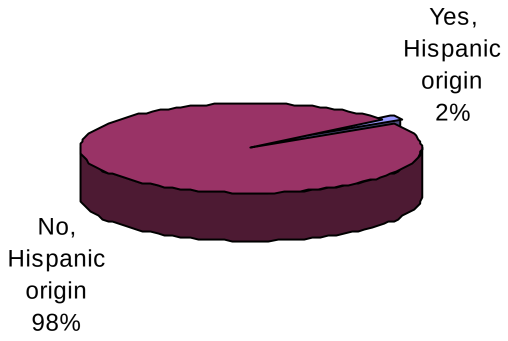
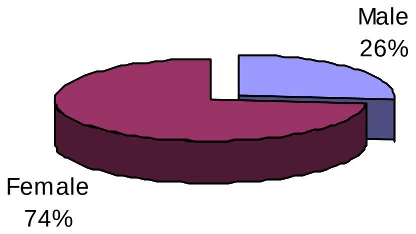


Figure IV-17c. ALSA/MRCs by Hispanic origin distribution	Figure IV-17d. ALSA/MRCs by gender distribution
 	

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

Table IV-19. ALSA/MRC's by method of payment*
(n=56)

Method pf payment	**Percent using**
Medicaid	9
Medicare	22
Private Health Insurance	11
Private Long-Term Care Insurance	3
Veteran's Administration	1
Out of Pocket (self pay)	60
Other	5

*Responses not mutually exclusive

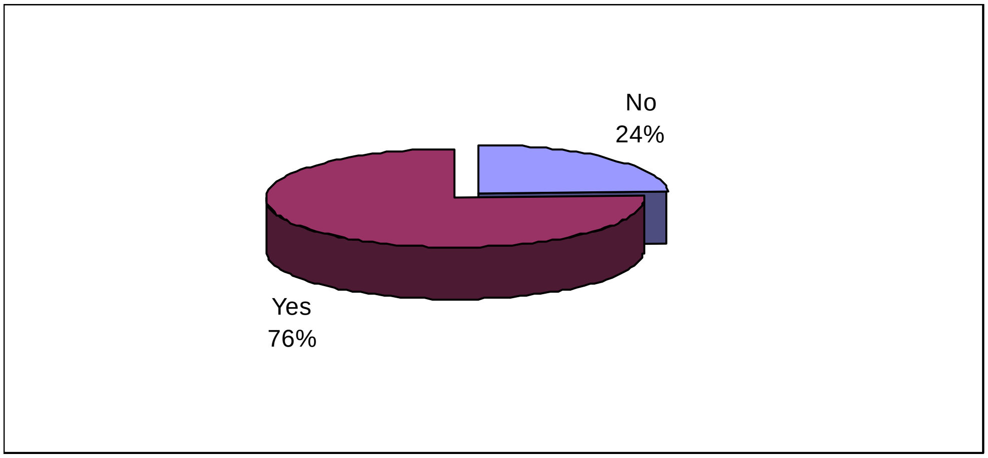
As shown in Table IV-20, nearly all (96%) of ALSA/MRCs report at least one eligibility requirement. The most commonly endorsed eligibility category is an age requirement (68%), followed by only certain payment sources accepted (50%), and must have certain functional or cognitive abilities (38%). Other eligibility requirements written in include cannot be danger to oneself or others, stable medical condition without need for intensive nursing care, and ability to live independently.

Table IV-20. ALSA/MRCs by eligibility requirements
(n=56)

Eligibility requirement	Percent requiring
Only certain diagnoses accepted	19
Only certain ages	68
Only certain payment sources accepted	50
Only certain geographic areas accepted	2
Certain behavioral or psychiatric diagnosis NOT accepted	29
Must have a certain number of impairments	5
Must have certain functional or cognitive abilities	38
Other	38
No eligibility requirements	4

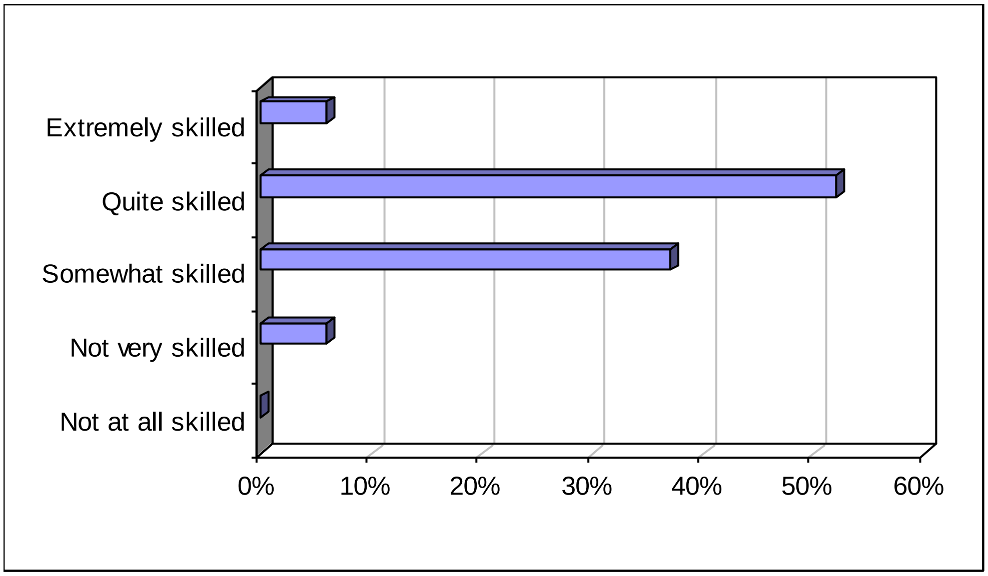
Three-quarters of ALSA/MRCs (76%) report the presence of a waiting list for services (Figure IV-18). Over the course of the past year, approximately one half of ALSA/MRCs declined services or had a waiting list because eligibility requirements were not met (54%), lack of available beds or units (46%), or lack of payment source (23%).

Figure IV-18. ALSA/MRC presence of a waiting list



These ALSA/MRCs report a fairly low percentage of clients with either mental illness (11%) or challenging behaviors (9%). Still, more than three-quarters of the staff members (79%) have received specialized training to work with challenging behaviors, and these organizations report that over half of their employees (58%) are either extremely or quite skilled in working with clients who exhibit challenging behaviors. See results in Figure IV-19 below.

Figure IV-19. ALSA/MRC's by training and skill level
(n=56)



When asked about certain issues over the past year, ALSA/MRC providers report few employee or client concerns (see Table IV-21). One exception is employees not showing up or calling out sick at the last minute. Forty-three percent of respondents indicate this happens once a month or more, while nearly one-quarter of respondents (23%) report that clients complain about employees once a month or more. Respondents also indicate that transportation is a problem once a month or more for both employees (19%) and clients (24%).

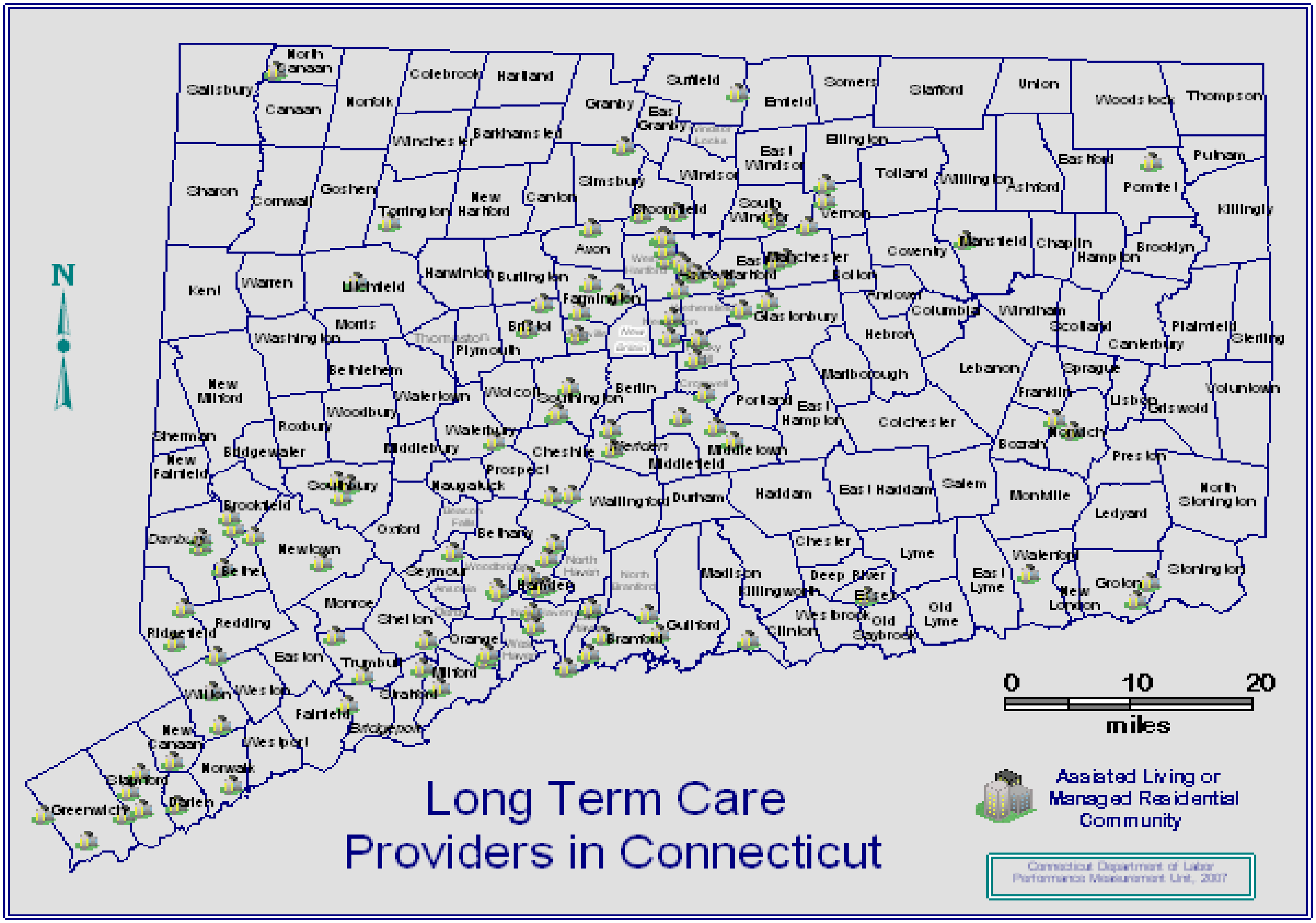
Table IV-21. ALSA/MRC employee and client concerns in the past year (percentages)*

	Never	Less than once a month	Once a month	Once a week	Almost every day
Employees not showing up or calling out sick at the last minute	15	**43**	20	17	6
Employees having difficulties with transportation to or from work	39	**43**	4	11	4
Clients complaining about employees	18	**63**	15	4	4
Language differences between clients and employees	**50**	30	13	5	2
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**49**	35	11	6	0
Issues or difficulties with employee unions	**96**	4	0	0	0
Using temporary or pool employees because it makes sense financially	**96**	4	0	0	0
Using temporary or pool employees because you do not have enough staff for the day	**66**	22	4	6	4
Problems with transportation for your clients	**38**	**38**	16	4	4
Difficulty finding health care services or providers for your clients	**67**	22	9	2	0
Transferring a client to another provider or ending services because of challenging behaviors	31	**67**	2	0	0
Transferring a client to another provider or ending services because of issues related to mental illness	**51**	45	4	0	0
Any other issues with employees or clients:	38	**50**	0	13	0

*Rows may not sum to 100% due to rounding.

The map below indicates the location of ALSA/MRCs in Connecticut.

Assisted Living or Managed Residential Community



Senior centers

Seventy-seven senior centers from across the State completed a provider survey (51% response rate). Of the myriad services provided, six services are provided by two-thirds or more of the responding senior centers: recreational services (88%), information and referral (87%), health screenings (82%), transportation (78%), health insurance counseling (70%), and congregate meals (69%).

Table IV-22. Senior centers by services provided
(n=77)

Service	**Percent providing service**
Adult day care-medical model	1
Adult day care-social model	14
Assistive devices	14
Assistive living services	3
Case/care management	21
Companion services	7
Congregate meals	69
Durable medical equipment	20
Employment services	12
Fiscal intermediary	5
Group home/supported living services	1
Handyman services	13
Health insurance counseling	**70**
Health screenings	**82**
Home delivered meals	48
Home health aid services	4
Homemaker services	7
Hospice services	3
Independent living skills training	5
Information and referral	**87**
Mental health counseling	9
Nutritional services	47
Other nursing services	23
Personal care assistant services	1
Personal emergency response system	4
Prescription drug assistance	57
Recreational services	**88**
Respite care	4
Transportation	**78**
Visiting nursing services	31
Other	33

The reported number of clients served by the senior centers is highly variable. Some centers report the total number of people on their membership list, while others provide a count of the actual clients being served on a daily, weekly, or monthly basis. Numbers range from a low of 20 to a high of 7,000 (average=902; SD 1,160).

Two-thirds (69%) of senior center clients are female, and two-thirds are age 65 to 84 (see Figures IV-20a,b,c,d). The majority are White/Caucasian (93%), while only a small percentage are African American (4%) or of Hispanic origin (3%).

Figure IV-20a. Senior center age distribution

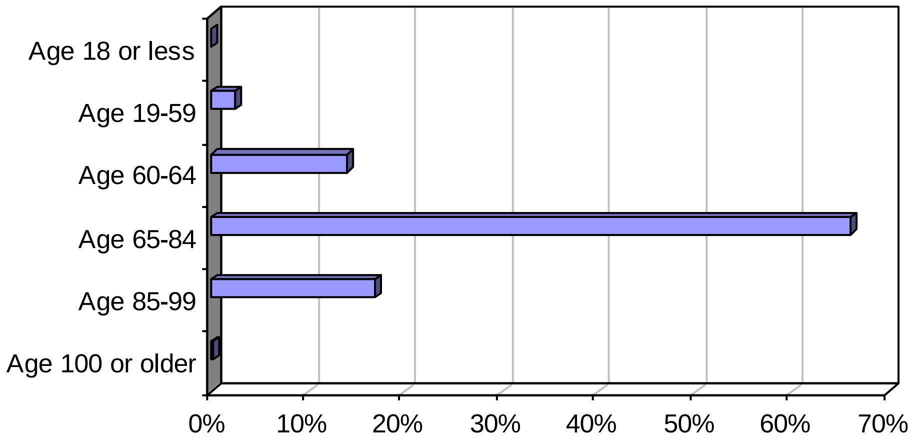


Figure IV-20b. Senior center by ethnic distribution

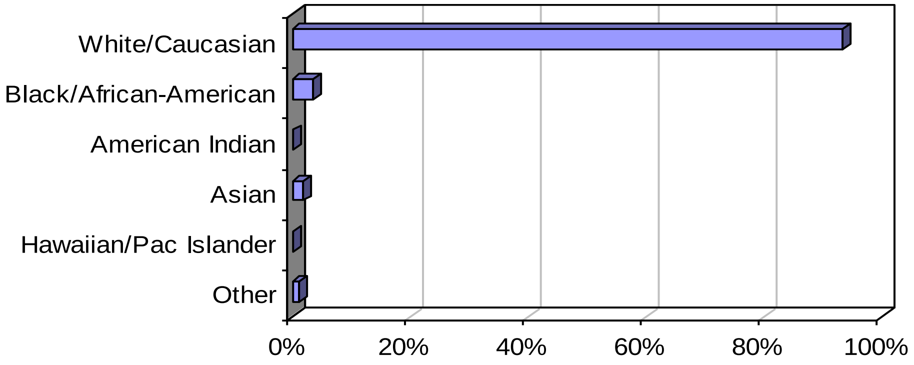


Figure IV-20c. Senior center by Hispanic origin distribution

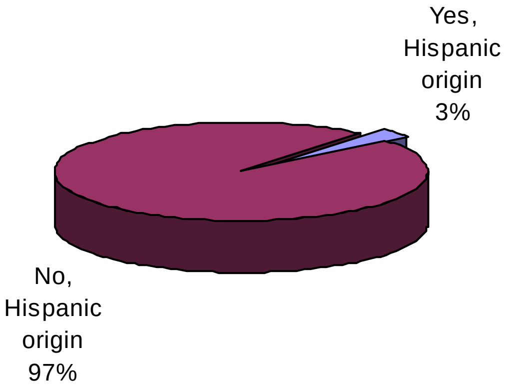
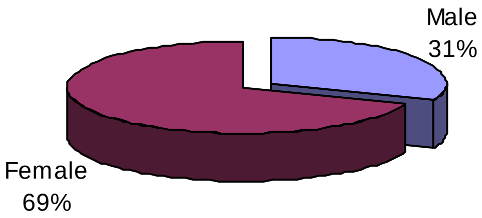


Figure IV-20d. Senior center by gender distribution



Reported methods of payment for senior center clients receiving paid services are shown in Table IV-23 below. Many respondents indicate that all or most services are free. For those services that require a payment, one-quarter of clients (26%) pay out of pocket. Medicare is used by about one in ten (11%) clients as a payment source, while private health insurance is used by seven percent. Only ten percent of clients use more than one source of payment for services.

Table IV-23. Senior centers by method of payment*

Method of payment	**Percent using**
Medicaid	2
Medicare	11
Private Health Insurance	7
Private Long-Term Care Insurance	1
Veteran’s Administration	2
Out of Pocket (self pay)	26
Other	4

*Responses not mutually exclusive

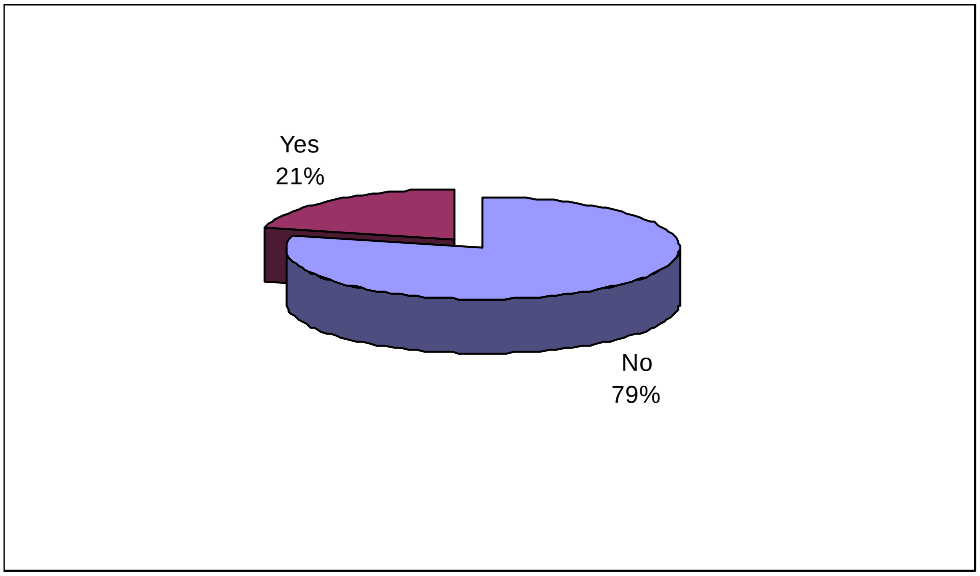
More than four in five (83%) senior centers report eligibility requirements for their services (see Table IV-24). By far the most frequently mentioned is an age requirement, reported by 74 percent. Nearly one-third (29%) indicate a geographic eligibility requirement, and about one-quarter (23%) report that their members must have certain cognitive or functional abilities to receive services.

Table IV-24. Senior centers by eligibility requirements

Eligibility requirement	**Percent requiring**
Only certain diagnoses accepted	1
Only certain ages	74
Only certain payment sources accepted	3
Only certain geographic areas accepted	29
Certain behavioral or psychiatric diagnosis NOT accepted	9
Must have a certain number of impairments	0
Must have certain functional or cognitive abilities	23
Other	10
No eligibility requirements	17

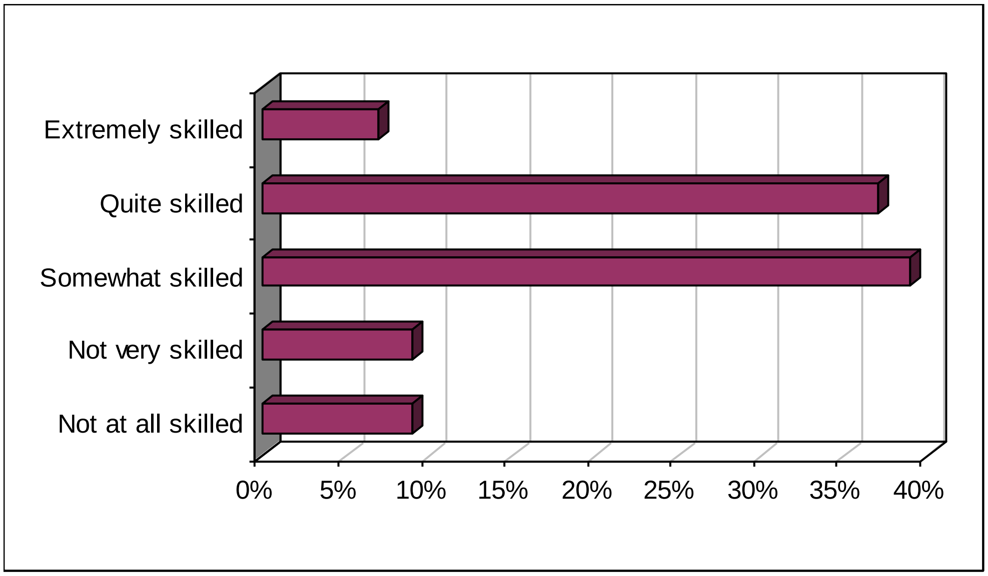
Currently, only one out of five (21%) senior centers indicates that they have a waiting list for at least one of their services. The most frequently mentioned services that have a waiting list are transportation, social trips, and other recreation services. Over the course of the past year, senior centers declined services or had a waiting list due to lack of available staff (13%) or not meeting eligibility requirements (10%). Services were declined or waiting lists created for other reasons 21 percent of the time. Lack of transportation or lack of activity space were the two other reasons mentioned most frequently.

Figure IV-21. Senior centers presence of waiting list



Senior centers report small numbers of clients with either a mental illness diagnosis (1%) or challenging behaviors (6%). Less than one-third (29%) of senior center staff members have received specialized training to work with challenging behaviors. Agency directors were asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors. See results in Figure IV-22 below.

Figure IV-22. Senior centers by training and skill level



Senior centers were also asked the frequency of certain employee and client issues in the past year (see Table IV-25 below). Overall, senior centers report few employee concerns. Many note that the center has only one or two employees and is run primarily by volunteer staff. The most frequent client issue is difficulty finding transportation for clients, reported by 41 percent of senior centers as happening once a month or more. One quarter (24%) also report difficulty finding health care services for their members at least once a month.

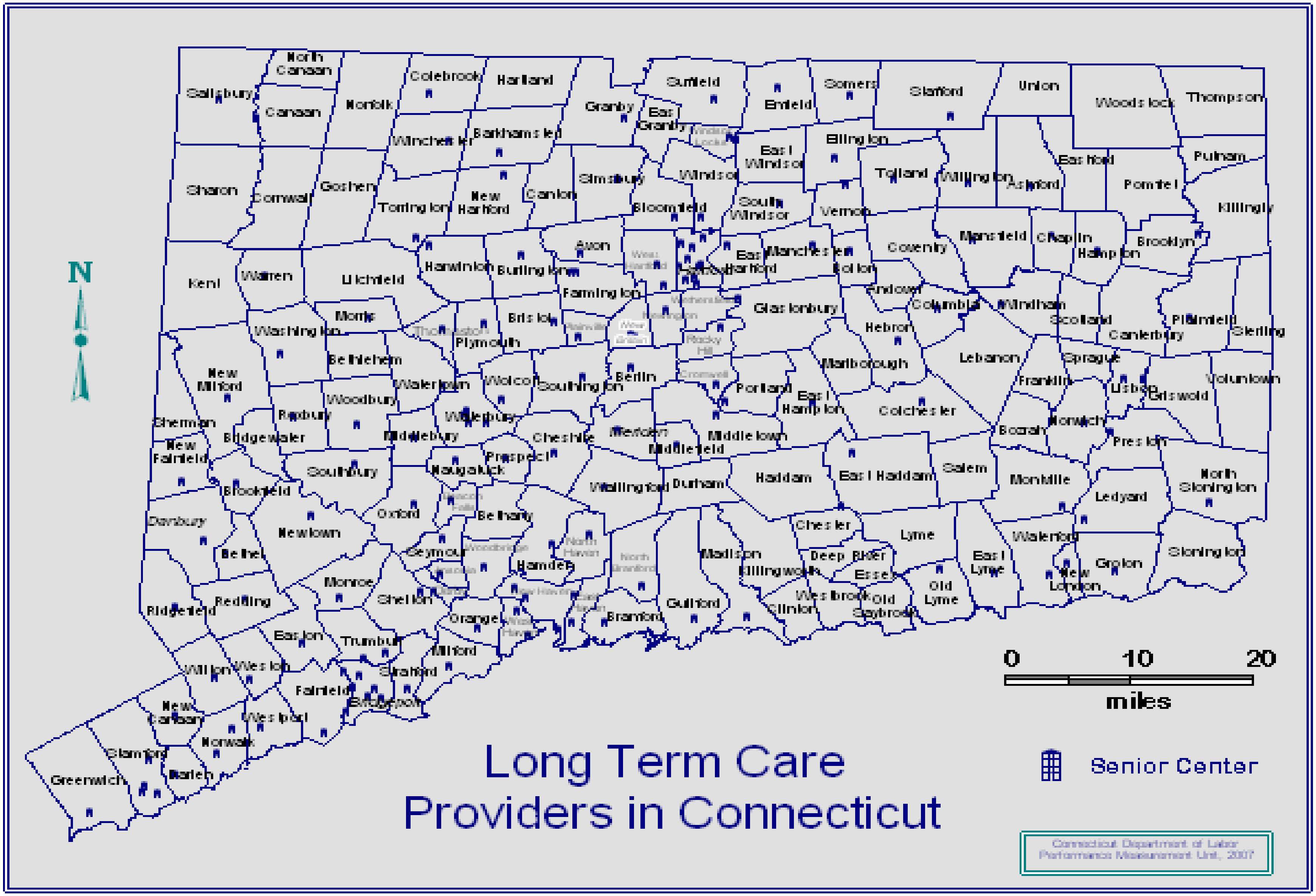
Table IV-25. Senior Center employee or client concerns in the past year (percentages)*

	Never	Less than once a month	Once a month	Once a week	Almost every day
Employees not showing up or calling out sick at the last minute	**56**	27	14	3	0
Employees having difficulties with transportation to or from work	**87**	10	2	2	0
Clients complaining about employees	**47**	44	6	2	2
Language differences between clients and employees	**70**	21	6	2	2
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**81**	15	3	2	0
Issues or difficulties with employee unions	**86**	12	0	0	2
Using temporary or pool employees because it makes sense financially	**89**	8	2	0	2
Using temporary or pool employees because you do not have enough staff for the day	**85**	5	8	0	3
Problems with transportation for your clients	23	**35**	15	15	11
Difficulty finding health care services or providers for your clients	**41**	34	19	5	0
Transferring a client to another provider or ending services because of challenging behaviors	**66**	29	5	0	0
Transferring a client to another provider or ending services because of issues related to mental illness	**71**	29	0	0	0
Any other issues with employees or clients:	**82**	12	0	6	0

*Rows may not sum to 100% due to rounding

The locations of senior centers throughout the State are indicated on the map below.

Senior Centers



Connecticut Department of Labor
Performance Measurement Unit, 2007

Bureau of Rehabilitation Services providers

A total of 19 Bureau of Rehabilitation Services (BRS) providers from across the State answered the survey (39% response rate). Table IV-26 provides a breakdown of all services offered. The top five services provided by BRS providers include: employment services (84%), group home/supportive living services (53%), independent living skills training and recreation (47% each), and mental health counseling and transportation (32% each). Services mentioned under the category "other" include school-to-career and other educational services, and supportive housing.

The smallest agency currently serves three clients, while the largest agency serves 1,465 clients. The average number of clients currently being served is 487 (SD=459).

Table IV-26. BRS providers by services provided
(n=19)

Service	**Percent providing service**
Adult day care-social model	11
Assistive devices	5
Case/care management	21
Companion services	11
Congregate meals	16
Durable medical equipment	5
Employment services	**84**
Group Home/supportive living services	**53**
Health insurance counseling	5
Health screenings	5
Home delivered meals	5
Homemaker services	11
Independent living skills training	**47**
Information and referral	21
Mental health counseling	**32**
Nutritional services	5
Personal care assistant services	5
Physical/speech/respiratory/occupational therapy	21
Recreation	**47**
Respite care	11
Transportation	**32**
Other	26

Figures IV-23a,b,c,d below provide a demographic profile of clients currently in service. The largest proportion of clients being served by BRS providers falls within the age range 19 to 59 (75%), followed by clients age 18 or less (13%). Over half (56%) of clients served by BRS providers are male. The majority are White/Caucasian (72%), followed by African American (16%). Nine percent of the population are reported to be of Hispanic or Latino origin.

Figure IV-23a. BRS providers by age distribution

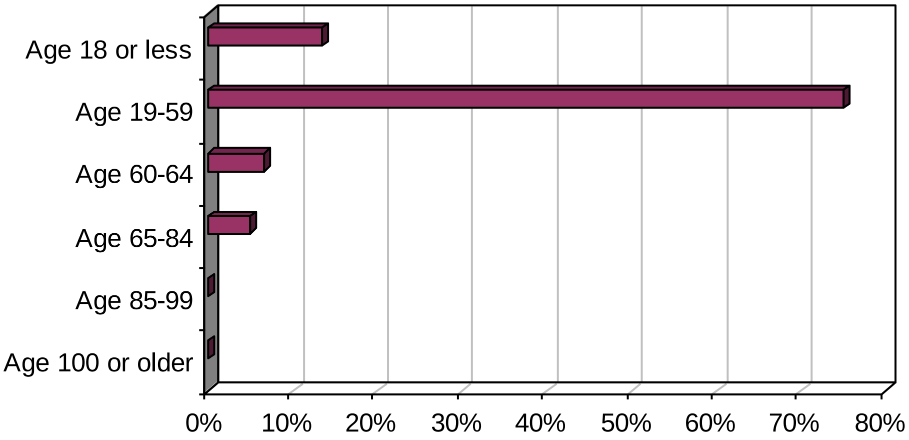


Figure IV-23b. BRS providers by ethnic distribution

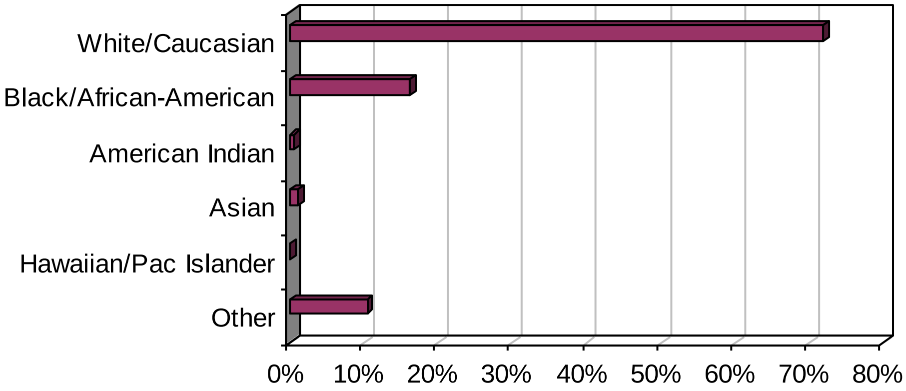


Figure IV-23c. BRS providers by Hispanic origin distribution

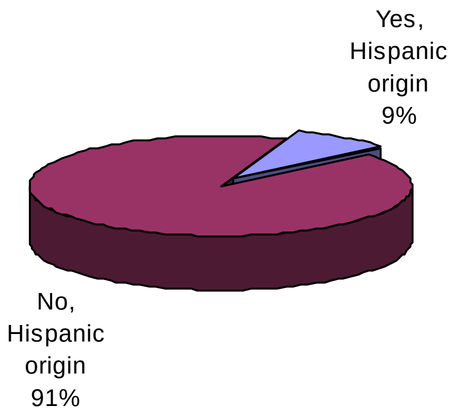
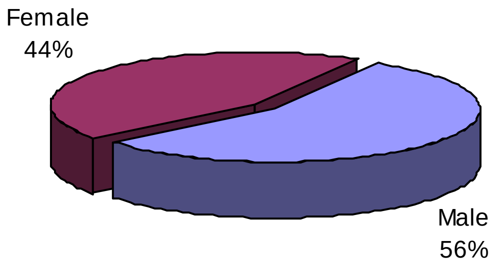


Figure IV-23d. BRS providers by gender distribution



The method of payment for clients currently in service is noted in Table IV-27 below. Data indicate that only seven percent have multiple payment sources. About one-quarter (27%) of clients use Medicaid to at least partly pay for their services. The large category of other payment sources includes SAGA/welfare, school districts, other state funding, and BRS itself.

Table IV-27. BRS providers by method of payment*
(n=19)

Method of payment	**Percent using**
Medicaid	27
Medicare	10
Private Health Insurance	3
Private Long-Term Care Insurance	0
Veteran’s Administration	<1
Out of Pocket (self pay)	4
Other	32

*Responses not mutually exclusive

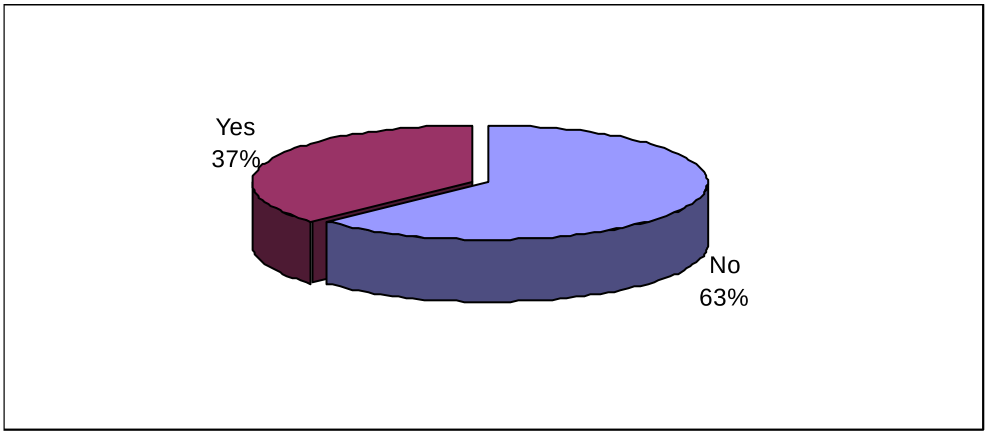
Nearly all (95%) of BRS providers have eligibility requirements (see Table IV-28 below). The most frequently chosen eligibility criteria is the acceptance of only certain diagnoses (74%), followed by targeted geographic areas (58%), and the acceptance of only certain ages (53%).

Table IV-28. BRS providers by eligibility requirements
(n=19)

Eligibility requirement	Percent requiring
Only certain diagnoses accepted	74
Only certain ages	53
Only certain payment sources accepted	16
Only certain geographic areas accepted	58
Certain behavioral or psychiatric diagnosis NOT accepted	21
Must have a certain number of impairments	0
Must have certain functional or cognitive abilities	26
Other	11
No eligibility requirements	5

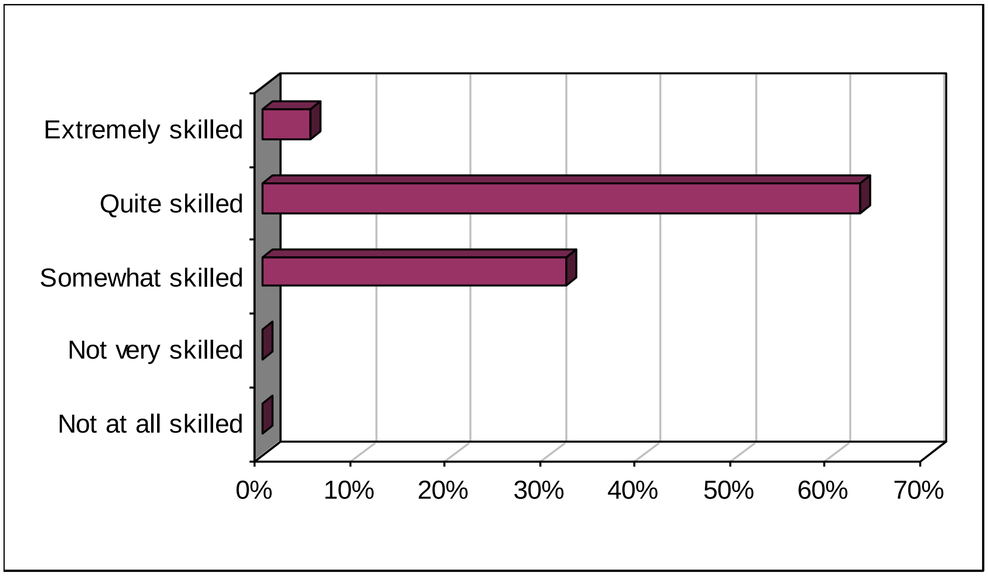
A key area of interest was a review of the current waiting list status for each agency. Data was gathered on the presence of a waiting list during the prior year and reasons for the wait. Currently, 37 percent of reporting BRS agencies have a waiting list (see Figure IV-24 below). Over the course of the past year, one-third (32%) either declined services or added people to a waiting list due to lack of available beds/housing units or failure to meet the agency's eligibility requirements. Twenty-one percent declined services because of lack of a payment source.

Figure IV-24. BRS providers by waiting list
(n=19)



Four survey questions sought to understand services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients who have challenging behaviors. Of the reporting agencies, 57 percent of clients served are reported to have a diagnosis of mental illness (excluding dementia), while 21 percent exhibit challenging behaviors in the past six months. Nearly all staff members (95%) have received specialized training to work with challenging behaviors. BRS providers were asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors. As Figure IV-25 shows, over two-thirds (68%) of providers rate their employees as being either quite or extremely skilled in working with clients who have challenging behaviors.

Figure IV-25. BRS providers by training and skill level
(n=19)



BRS providers responded to a series of questions about the frequency of certain employee and clients concerns in the past year. The results are presented in Table IV-29 below.

Table IV-29. BRS providers employee and client concerns in the past year (percentages)*

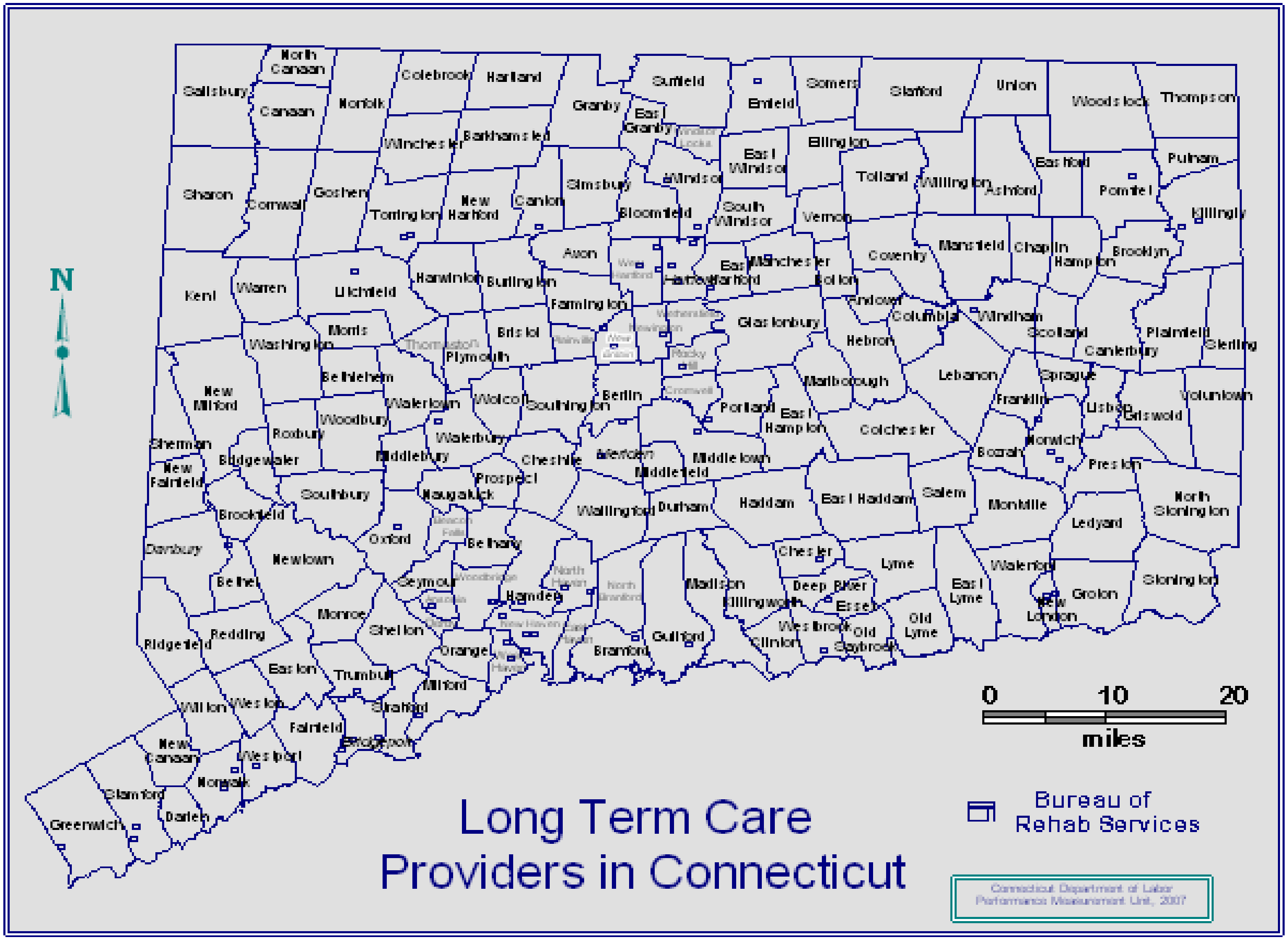
	Never	Less than once a month	Once a month	Once a week	Almost every day
Employees not showing up or calling out sick at the last minute	6	18	18	**41**	18
Employees having difficulties with transportation to or from work	28	28	**44**	0	0
Clients complaining about employees	22	**56**	17	6	0
Language differences between clients and employees	32	**37**	16	0	16
Problems or issues related to cultural, ethnic or racial differences between clients and employees	37	**53**	0	0	11
Issues or difficulties with employee unions	**78**	11	11	0	0
Using temporary or pool employees <u>because it makes sense financially</u>	**72**	11	0	11	6
Using temporary or pool employees <u>because you do not have enough staff for the day</u>	**67**	6	11	6	11
Problems with transportation for your clients	26	5	16	21	**32**
Difficulty finding health care services or providers for your clients	11	0	**50**	22	17
Transferring a client to another provider or ending services because of challenging behaviors	**41**	**41**	12	0	6
Transferring a client to another provider or ending services because of issues related to mental illness	**53**	35	12	0	0
Any other issues with employees or clients	25	25	**50**	0	0

*Rows may not sum to 100% due to rounding.

Nearly all (89%) BRS respondents indicate that they have difficulty finding health care services or providers for their clients at least once a month, and more than three-quarters (76%) report that employees do not show up or call out sick at the last minute at least once a month. Two-thirds (69%) of BRS providers indicate they have problems with transportation for their clients at least once a month, with a third (32%) experiencing that problem on a daily basis.

A map of BRS provider locations is included below.

Bureau of Rehabilitation Services Providers



Long Term Care Providers in Connecticut

Connecticut Department of Labor Performance Measurement Unit, 2007

Department of Mental Retardation providers

Sixty-one Department of Mental Retardation (DMR) providers from across the state answered the survey (47% response rate). Table IV-30 provides a breakdown of all services offered. The services most commonly offered by DMR providers include: group home/supportive living services (72%), recreation (48%), independent living skills training (46%), transportation (41%) and employment services (38%). Services mentioned under the category "other" include medication management, education, and advocacy.

The smallest agency currently serves one client, while the largest agency serves 4,985 clients. The average number of clients currently being served is 242 (SD=796).

Table IV-30. DMR providers by services provided
(n=61)

Service	**Percent providing service**
Adult day care-social model	34
Adult day care-medical model	13
Assistive devices	8
Assisted living services	20
Case/care management	23
Companion services	16
Congregate meals	7
Durable medical equipment	3
Employment services	**38**
Group Home/supportive living services	**72**
Health screenings	7
Home health aid services	8
Independent living skills training	**46**
Information and referral	25
Mental health counseling	13
Other nursing services	20
Nutritional services	10
Personal care assistant services	20
Physical/speech/respiratory/occupational therapy	13
Recreation	**48**
Respite care	36
Transportation	**41**
Other	20

Figures IV-26 a,b,c,d below provide a demographic profile of clients currently in service. The largest proportion of clients being served by DMR providers falls within the age range 19 to 59 (71%) followed by the age range 18 or less (18%), and the majority are White/Caucasian (71%), followed by African American (20%). Nearly two-thirds (61%) of clients served by DMR providers are male. Twelve percent of the population are reported to be of Hispanic or Latino origin.

Figure IV-26a. DMR providers by age distribution

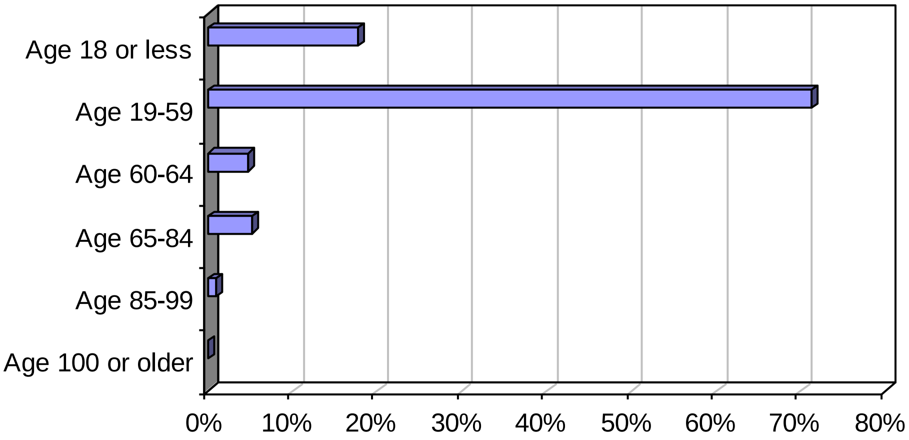


Figure IV-26b. DMR providers by ethnic distribution

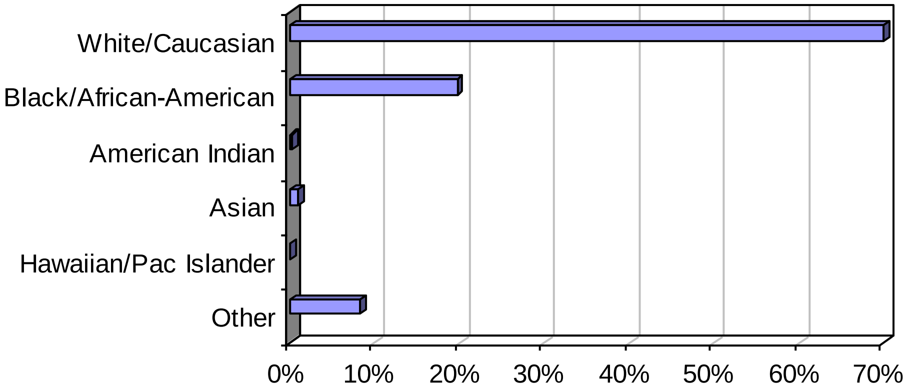


Figure IV-26c. DMR providers by Hispanic origin distribution

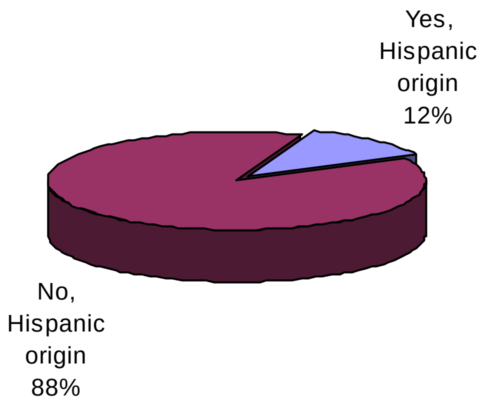
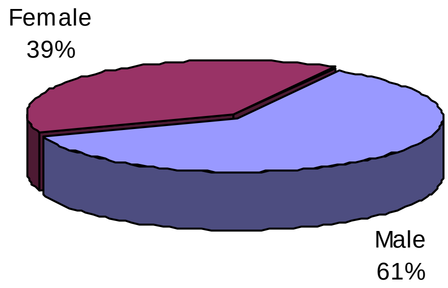


Figure IV-26d. DMR providers by gender distribution



The method of payment for clients currently in service is noted in Table IV-31 below. Data indicate that 22 percent have multiple payment sources. Nearly one-third (32%) of clients use Medicaid to partly pay for their services while one-quarter (24%) use Medicare. The large category of other includes a wide variety of other governmental funding sources including DMR, Department of Social Services, Bureau of Rehabilitation Services, and Social Security.

Table IV-31. DMR providers by method of payment*
(n=61)

Method of Payment	**Percent using**
Medicaid	32
Medicare	24
Private Health Insurance	3
Private Long-Term Care Insurance	0
Veteran's Administration	0
Out of Pocket (self pay)	7
Other	16

*Not mutually exclusive

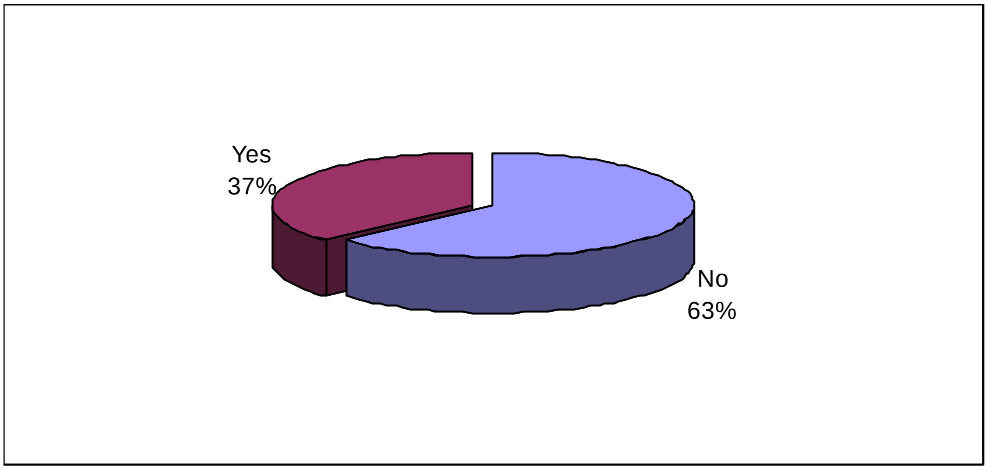
One question on the survey collected information pertaining to eligibility requirements for agency services, followed by an optional brief explanation (see Table IV-32 below). Most (82%) of DMR providers have eligibility requirements. The most commonly endorsed eligibility category is the acceptance of only certain diagnoses (57%), followed by targeted geographic areas (33%), and the acceptance of only certain ages (26%).

Table IV-32. DMR providers by eligibility requirements
(n=61)

Eligibility requirement	Percent requiring
Only certain diagnoses accepted	57
Only certain ages	26
Only certain payment sources accepted	15
Only certain geographic areas accepted	33
Certain behavioral or psychiatric diagnosis NOT accepted	15
Must have a certain number of impairments	0
Must have certain functional or cognitive abilities	13
Other	25
No eligibility requirements	18

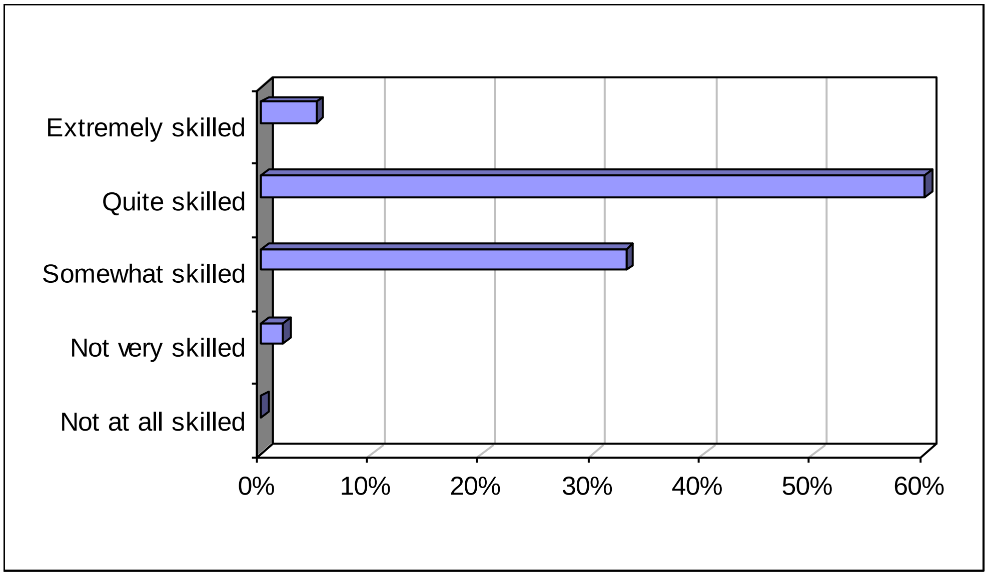
A key area of interest was a review of the current waiting list status for each agency. Data was gathered on the presence of a waiting list during the prior year and reasons for the wait. Currently, 37 percent of reporting agencies have a waiting list (see Figure IV-27 below). Over the course of the past year, nearly one-third (30%) declined services due to no source of payment, and one-quarter (25%) declined services or added the person to the waiting list due to lack of available beds/housing units. Roughly one in five declined services due to lack of available staff (20%) or no staff in a particular region or town (18%). Other reasons mentioned for declining services were behavioral issues and inability to meet complex medical needs.

Figure IV-27. DMR providers by waiting list
(n=61)



Four survey questions were dedicated to understanding services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients who have challenging behaviors. Of the reporting agencies,38 percent of clients served are reported to have a diagnosis of mental illness (excluding dementia), while 43 percent exhibited challenging behaviors in the past six months. Nearly all staff members (94%) have received specialized training to work with challenging behaviors. Agency directors were asked to rate their employees' overall level of training and skill working with clients who have challenging behaviors. As Figure IV-28 shows, about two-thirds (65%) of providers rate their employees as being either quite or extremely skilled in working with clients who have challenging behaviors.

Figure IV-28. DMR providers by training and skill level
(n=61)



DMR providers responded to a series of questions about the frequency that different situations have come up in the past year for their organizations. These questions focused on both employee and client concerns. The results are presented in Table IV-33 below.

Table IV-33. DMR providers employee and client concerns in the past year (percentages)*

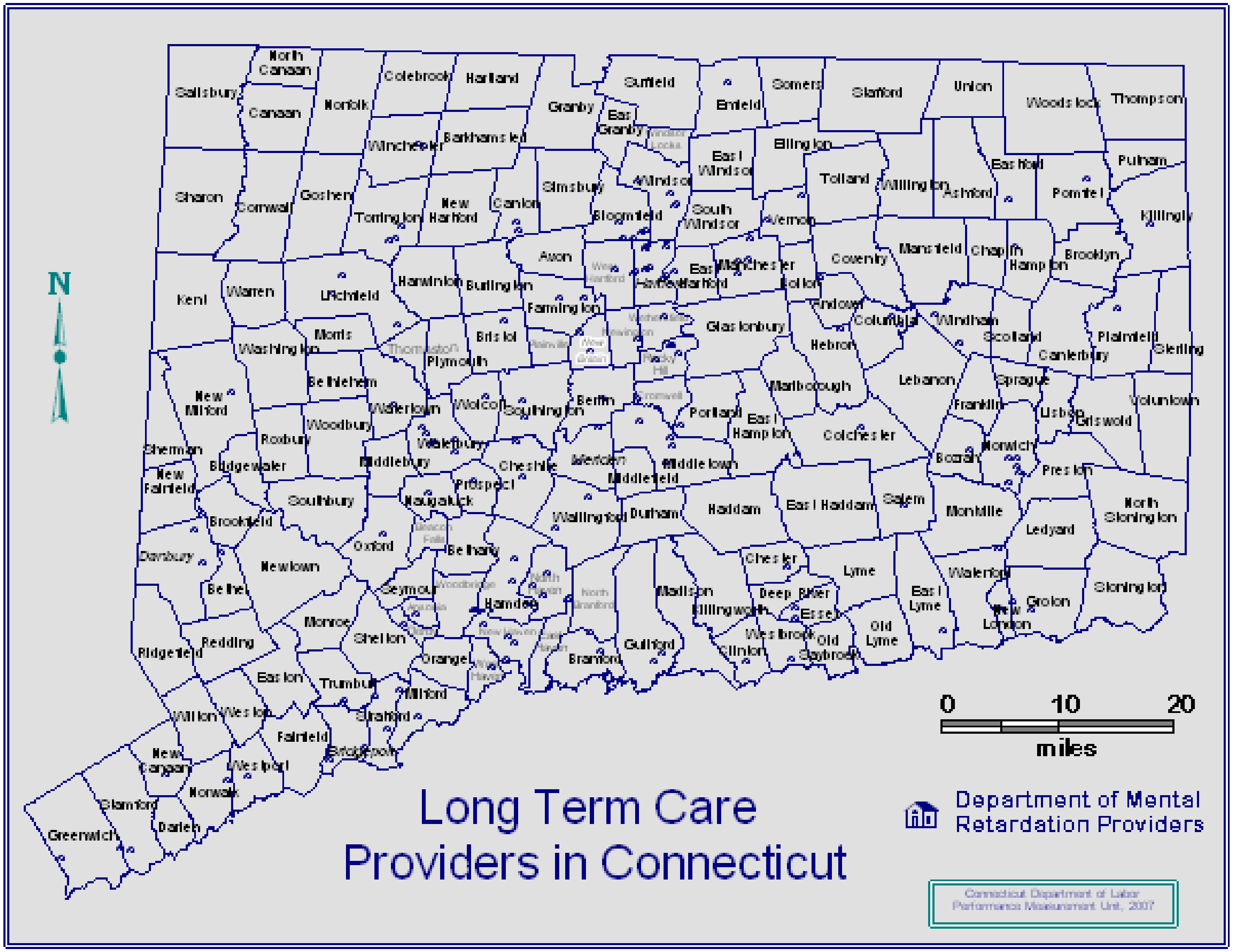
	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	7	**30**	27	22	15
Employees having difficulties with transportation to or from work	19	**36**	22	20	3
Clients complaining about employees	20	**59**	12	7	2
Language differences between clients and employees	**53**	31	7	5	5
Problems or issues related to cultural, ethnic or racial differences between clients and employees	**52**	42	3	2	2
Issues or difficulties with employee unions	**80**	10	5	0	5
Using temporary or pool employees because it makes sense financially	**79**	7	7	3	3
Using temporary or pool employees because you do not have enough staff for the day	**62**	9	7	14	9
Problems with transportation for your clients	28	**33**	17	14	9
Difficulty finding health care services or providers for your clients	20	**31**	29	15	6
Transferring a client to another provider or ending services because of challenging behaviors	**56**	39	2	2	2
Transferring a client to another provider or ending services because of issues related to mental illness	**73**	22	2	2	2
Any other issues with employees or clients	**71**	18	**0**	0	12

*Rows may sum to over 100% due to rounding.

Nearly two-thirds of DMR providers (64%) report that employees do not show up or call out sick at the last minute at least once a month. Half (50%) of all respondents indicate that they have difficulty finding health care services or providers for their clients at least once a month. DMR providers also indicate they have problems with transportation at least once a month, for both their employees (45%) and their clients (40%).

DMR provider locations are indicated in the map below.

Department of Mental Retardation Providers



Department of Mental Health and Addiction Services providers

A total of 51 Department of Mental Health and Addiction Services (DMHAS) providers from across the state answered the survey (34% response rate). Table IV-34 provides a breakdown of all services offered. The top five services provided by DMHAS providers include: mental health counseling (59%), case/care management (47%), information and referral (43%), independent living skills training (28%), and employment services (22%). Services mentioned under the large "other" category include substance abuse prevention, treatment and counseling services, psychiatric evaluation, medication management, and education.

With the exception of three large agencies whose educational services reach more than 25,000 persons each, the smallest agency currently serves 14 clients, and the largest agency serves 2,958 clients. The average number of clients currently being served is 654 (SD=839).

Table IV-34. DMHAS providers by services provided
(n=51)

Service	**Percent providing service**
Case/care management	**47**
Congregate meals	6
Employment services	**22**
Group Home/supportive living services	20
Health insurance counseling	6
Health screenings	12
Independent living skills training	**28**
Information and referral	**43**
Mental health counseling	**59**
Nutritional services	8
Other nursing services	12
Personal emergency response system	4
Prescription drug assistance	6
Recreation	14
Respite care	4
Transportation	8
Other	**51**

Figures IV-29 a,b,c,d below provide a demographic profile of clients currently in service. The largest proportion of clients being served by DMHAS providers falls within the age range 19 to 59 (47%) followed by the age range 18 or less (27%), and the majority are White/Caucasian (54%), followed by African American (35%). Over half (55%) of clients served by DMHAS providers are female and 40 percent of the population are reported to be of Hispanic or Latino origin.

Figure IV-29a. DMHAS providers by age distribution

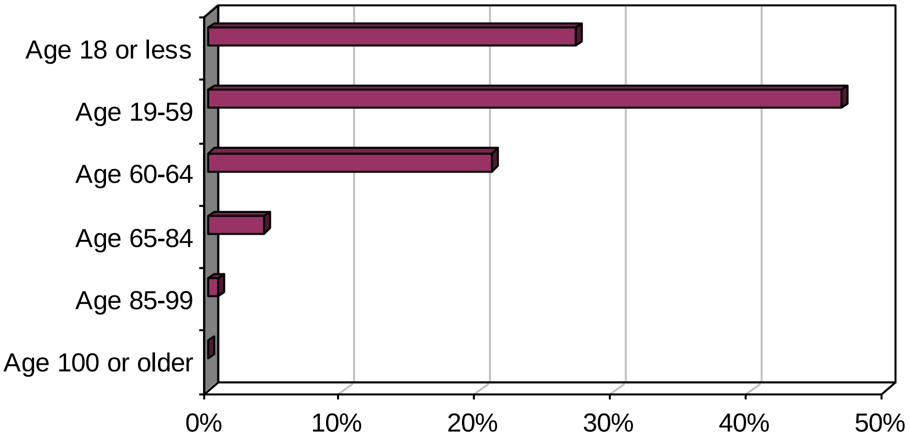


Figure IV-29b. DMHAS providers by ethnic distribution

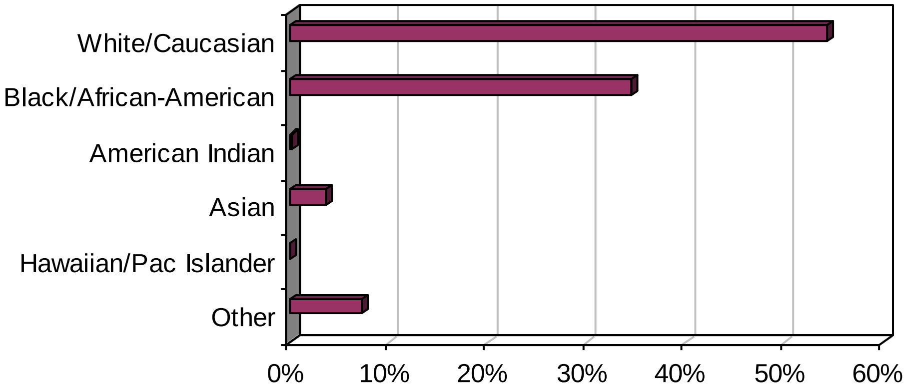


Figure IV-29c. DMHAS providers by Hispanic origin distribution

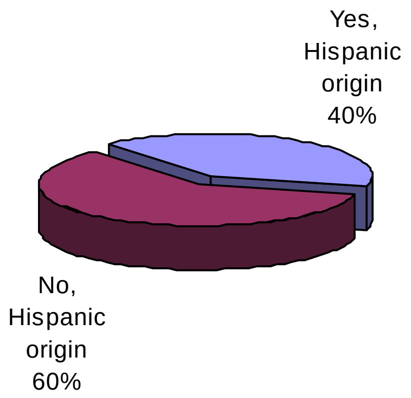
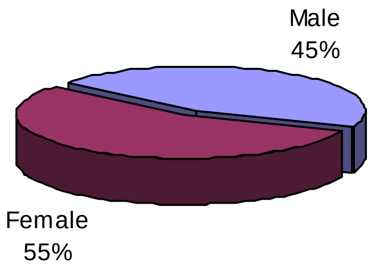


Figure IV-29d. DMHAS providers by gender distribution



The method of payment for clients currently in service is shown in Table IV-35 below. Data indicate that 11 percent have multiple payment sources. Half (50%) of these clients use Medicaid to at least partly pay for their services while one more than one in five (22%) pay for services out of pocket. The category of other includes state general assistance and other government or private grants.

Table IV-35. DMHAS providers by method of payment*
(n=51)

Method of Payment	**Percent using**
Medicaid	50
Medicare	10
Private Health Insurance	8
Private Long-Term Care Insurance	0
Veteran's Administration	<1
Out of Pocket (self pay)	22
Other	10

*Not mutually exclusive

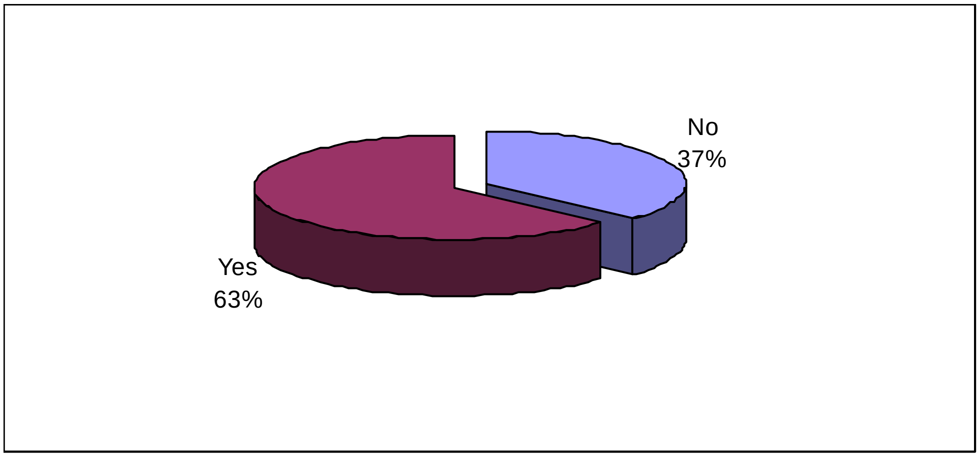
One question on the survey collected information pertaining to eligibility requirements for agency services, followed by an optional brief explanation (see Table IV-36 below). Most (86%) of DMHAS providers have eligibility requirements. The most commonly endorsed eligibility category was the acceptance of only certain ages (59%) followed by the acceptance of only certain diagnoses or targeted geographic areas (47% each).

Table IV-36. DMHAS providers by eligibility requirements
(n=51)

Eligibility requirement	Percent requiring
Only certain diagnoses accepted	47
Only certain ages	59
Only certain payment sources accepted	14
Only certain geographic areas accepted	47
Certain behavioral or psychiatric diagnosis NOT accepted	20
Must have a certain number of impairments	0
Must have certain functional or cognitive abilities	10
Other	28
No eligibility requirements	14

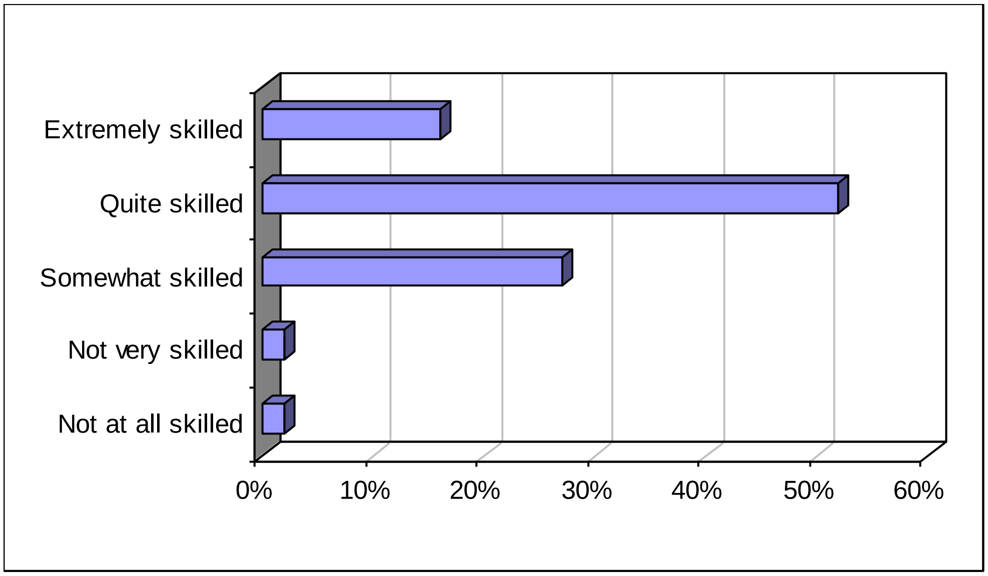
A key area of interest was a review of the current waiting list status for each agency. Data was gathered on the presence of a waiting list during the prior year and reasons for the wait. Currently, nearly two-thirds (63%) of reporting DMHAS providers have a waiting list (see Figure IV-30 below). Over the course of the past year, more than four in ten (41%) declined services due to no available beds/housing units, and one-third (33%) declined services due to failure to meet eligibility requirements, Another quarter (26%) declined services or added the person to the waiting list due to lack of available staff.

Figure IV-30. DMHAS providers by waiting list
(n=51)



Four questions covered services to clients with mental illness and/or challenging behaviors, as well as staff training for employees who work with clients who have challenging behaviors. Of the reporting agencies, 35 percent of clients served are reported to have a diagnosis of mental illness (excluding dementia), while 11 percent exhibited challenging behaviors in the past six months. Although the percentage of mental illness diagnoses may seem low for this provider group, many of their clients have substance abuse disorders without mental illness. Nearly all staff members (88%) have received specialized training to work with challenging behaviors. Agency directors were asked to rate their employees’ overall level of training and skill working with clients who have challenging behaviors. As Figure IV-31 shows, over two-thirds (68%) of DMHAS providers rate their employees as being either quite or extremely skilled in working with clients who have challenging behaviors.

Figure IV-31. DMHAS providers by training and skill level
(n=51)



DMHAS providers responded to a series of questions about how often different situations have come up in the past year for their organizations. These questions focus on both employee and client concerns. The results are presented in Table IV-37 below.

Table IV-37. DMHAS providers employee and client concerns in the past year (percentages)*

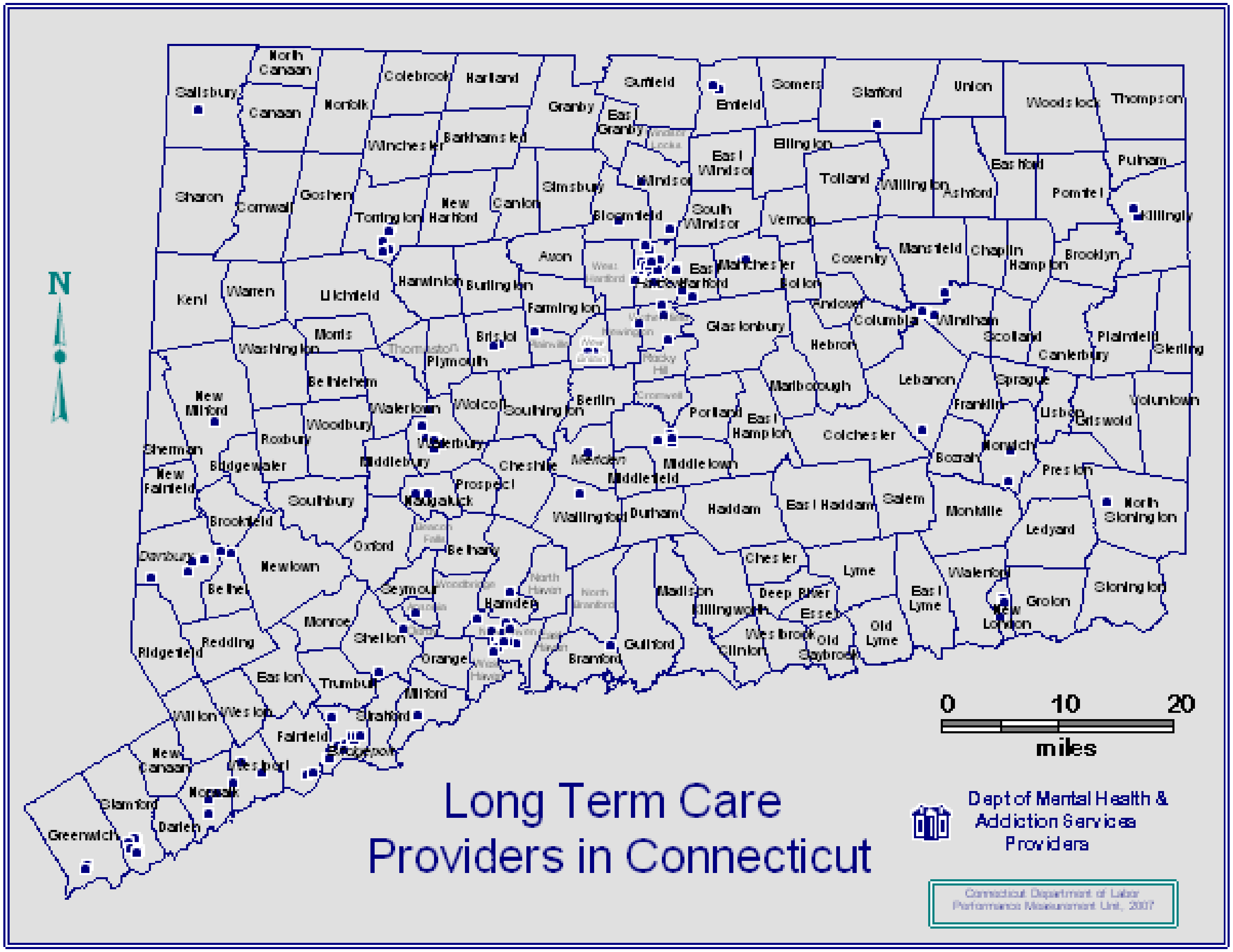
	Never	**Less than once a month**	**Once a month**	**Once a week**	**Almost every day**
Employees not showing up or calling out sick at the last minute	22	**49**	9	18	2
Employees having difficulties with transportation to or from work	30	**59**	11	0	0
Clients complaining about employees	14	**68**	9	9	0
Language differences between clients and employees	16	**53**	20	7	4
Problems or issues related to cultural, ethnic or racial differences between clients and employees	30	**61**	7	2	0
Issues or difficulties with employee unions	**67**	12	14	0	7
Using temporary or pool employees because it makes sense financially	**68**	22	0	7	2
Using temporary or pool employees because you do not have enough staff for the day	**49**	34	5	5	7
Problems with transportation for your clients	9	27	11	23	**30**
Difficulty finding health care services or providers for your clients	16	16	23	**32**	14
Transferring a client to another provider or ending services because of challenging behaviors	26	**57**	12	5	0
Transferring a client to another provider or ending services because of issues related to mental illness	39	**44**	15	2	0
Any other issues with employees or clients	**36**	**36**	27	0	0

*Rows may sum to over 100% due to rounding.

By far the biggest issues facing DMHAS providers with respect to their clients are problems with client transportation (experienced by 64% at least once a month and by 30% every day) and difficulty finding health care services or providers for clients (experienced by 69% at least once a month). Issues experienced with employees at least once a month include language differences between clients and employees (31%), and employees not showing up or calling out sick at the last minute (29%).

A map of DMHAS provider locations is included below.

Department of Mental Health and Addiction Services Providers



Overview of other providers

As noted above, there are three service categories that contain only small numbers of providers, for which a detailed analysis of results is infeasible. Responses from these providers are presented at a summary level.

Homemaker agencies

Although there are numerous homemaker agencies throughout Connecticut, only eight are registered with the Department of Public Health as homemaker-home health aide agencies, from which the mailing list was derived. Two responded to the survey, and it is difficult to generalize the results to other such agencies. As expected, homemaker and companion services are the most prevalent. In this small sample clients were primarily older (with a heavy concentration in the 85-99 age range), and mostly female and Caucasian. A high number pay for homemaker services out of pocket. Small numbers are reported to have mental illness or challenging behaviors, and there is generally an assessment made whether the client can be safely cared for at home or in assisted living. Although few employee or client issues were noted, some providers commented on the inability of the State to provide enough services for clients to remain in their homes, and the need for more funding to allow home-based services.

Chronic disease hospitals

Three of six chronic disease hospitals responded to the survey. All offer a wide variety of medical and supportive services including nursing, therapy and nutrition. Clients are from a wide range of ages, though not all hospitals shared data on racial background. More than half pay for services through Medicare, although Medicaid and private health insurance are significant payment sources as well. All have age restrictions and other eligibility requirements concerning medical condition. There are few problems experienced with either employees or clients, although one hospital has employees not showing up or calling out sick at the last minute on a daily basis, and one has problems finding health care services for its clients at discharge at least weekly. All provide specialized training for employees on how to work with clients who have challenging behaviors.

Area Agencies on Aging

All five of Connecticut’s Area Agencies on Aging (AAAs) responded to the survey. All provide (or make available through referral or grant funding) most of the long-term care services listed on the survey. Each serves thousands of clients through a variety of programs in its respective geographic area. As with most providers of services to older adults, more women than men are served. Although the majority are Caucasian, there are a significant number of African-American (10-15%) and Latino (10-30%) clients, depending on region of the state.

Because of the vast array of services provided, and because the AAAs do not use one data system for logging client information, much of the data provided differs by program. All have some type of age restriction, for example, but the minimum age for Title III (Older Americans Act) grants is 60, while the minimum age for the Home Care Program for Elders is 65, and participants in Grandparents Raising Grandkids must be 55. Clients served through Medicare counseling, congregate meals, and through the Home Care Program for Elders number in the thousands, while clients for the Alzheimer’s Association Respite Care Program, money management program, and others, may only be in the hundreds or less. Many of the services are free, and where mandatory co-pays exist they are paid out of pocket.

The AAAs do not mention waiting lists for most services, although they occasionally exist for such services as the Congregate Housing Services Program, the Alzheimer's respite grant, and home-delivered meals in certain towns. The only client issues mentioned as occurring at least weekly are transportation problems for clients and difficulty finding health care services or providers for clients.

Summary of major differences by provider type

Client demographics

The demographics of clients served by each provider type do differ in some respects. Most provider types serve primarily older adults (mostly age 60 and older), the majority of whom are also white (85 to 90%), non-Hispanic (more than 95%) and female (65 to75%). Three provider types, however, have a very different client profile. DMR, DMHAS and BRS providers serve a much younger clientele, three-quarters or more of whom are under age 60. These providers also have a higher percentage of male clients (45 to 61%) and a lower percentage of white clients (55 to 75%). Clients of DMHAS providers are 35 percent Black/African American and 40 percent Hispanic/Latino, while clients of DMR providers are 20 percent Black/African American and 12 percent Hispanic/Latino.

Payment source

Medicaid is a primary payment source for residential care homes (67%), nursing homes (65 %), DMHAS providers (50%), and adult day centers (44%). Medicare is a primary payment source for chronic disease hospitals (67%) and home health agencies (43%), although the latter also receive a large portion of their payments from Medicaid, at 34 percent. The major payment source for ALSA/MRCs is private pay (60%).

Other client and employee issues

The reported incidence of mental illness is highest at BRS providers (57%), residential care homes (46%), DMR providers (38%) and DMHAS providers (35%) and lowest at senior centers (1%), home health agencies (8%) and ALSA/MRCs and nursing homes (11% each.) The prevalence of challenging behaviors follows a similar pattern. Provider types most likely to have a waiting list include ALSA/MRCs (75%), nursing homes (67%), DMHAS providers (63%), and residential care homes (56%). Organizations least likely to have a waiting list are adult day centers (7%), home health agencies (13%), and senior centers (21%). The waiting lists at senior centers are frequently for specific programs or classes, not for all services.

Major employee and client issues differ somewhat by provider type. Employees not showing up or calling out sick at the last minute is a particular problem for BRS providers, nursing homes, home health agencies, DMR providers, and ALSA/MRCs. Client transportation problems are the top concern of DMHAS providers, adult day centers, and senior centers. Other top concerns include hiring temporary or pool employees due to lack of staff (experienced most by nursing homes and home health agencies) and finding health care services for clients (noted most by DMHAS, DMR, and BRS providers). Only adult day centers include language differences between clients and employees among their top concerns.

D. Employment projections for Connecticut's paid caregivers

While the majority of long-term care is provided by unpaid family members or other informal caregivers, paid direct caregivers form a large and growing percentage of the workforce, both in Connecticut and nationally.

The federal Bureau of Labor Statistics published 2004 data on the numbers of people in various long-term care-related occupations. It then projected the numbers of people who will be needed to fill those jobs in 2014, which include both new jobs created and replacements for people leaving the workforce (Table IV-38).

Table IV-38. National 2004 and projected 2014 occupations

	Employment (in thousands)		Change 2004 - 2014	
Occupation	**2004**	**2014**	**Number**	**Percent**
Home health aides	624	974	350	56%
Nursing aides, orderlies, attendants	1455	1781	325	22%
Personal and home care aides	701	988	287	41%
Registered nurses	2394	3096	703	29%

The occupation of home health aide is expected to grow by 56 percent between 2004 and 2014, representing the fastest growing occupation nationwide (Hecker, 2005). Three other occupations related to long-term care will show significant growth as well: nursing aides, orderlies, and attendants are expected to grow by 22 percent, personal and home care aides by 41 percent, and registered nurses by 29 percent.

Similar data, for Connecticut specifically, are available from the Connecticut Department of Labor for many occupations related to long-term care. Table IV-39 displays the number of people working in each occupation in 2004, the number of positions projected to be available in 2014, the net and percent change, and the annual openings during this ten-year period. Similar to the national data, annual openings include both new jobs and replacements for people retiring or leaving the occupation for other reasons.

All of the long-term care occupations will see growth between 2004 and 2014. Efforts to rebalance the institutional bias of the current long-term care system will ideally lead to a greater percentage of people receiving long-term care at home. The impact of this shift on the paid caregiver workforce in Connecticut is reflected in a predicted 25 percent increase in home health aide positions and a 28 percent rise in personal and home care aide positions. These somewhat conservative estimates fall noticeably below the national predictions. However, the Allied Health occupations are expected to have double the growth of Connecticut's other occupational groups.

In addition to these community-based occupations, the sheer increase in numbers of people who will need long-term care will also increase the demand in Connecticut for nursing aides, orderlies and attendants by almost eight percent. One important caveat to consider when reviewing long-term estimates is the potential impact of policy changes pertaining to self-directed care that could occur over the next decade. For example, an absolute increase in per client expenditures in the Connecticut Home Care Program for Elders would definitely increase the demand for direct service providers. Further, a decrease in any number of waiting lists (e.g. DMR) would increase the need for home and personal care providers.

Most of the long-term care occupations in Table IV-39 show double-digit increases in demand over these ten years. Among the long-term care jobs, projected increases of over 20 percent are also expected for physical therapy occupations, mental health and substance abuse counselors and social workers, and medical and public health social workers.

Table IV-39. Connecticut 2004 and projected 2014 occupations.

Long-term Care Occupations	**2004**	**2014**	**Net Change**	**Percent Change**	**Total Annual Openings**
Home Health Aides	10,240	12,760	2,520	**25%**	386
Personal and Home Care Aides	5840	7480	1640	**28%**	258
Personal Care and Service Workers, All Other	680	730	50	7%	20
Nursing Aides, Orderlies, and Attendants	24,410	26,560	2,150	9%	535
Registered Nurses	31,890	36,020	4,130	13%	1,081
Licensed Practical and Licensed Vocational Nurses	7,880	9,100	1,220	16%	294
Physical Therapists	3,120	3,920	800	**26%**	111
Physical Therapist Assistants	650	840	190	**29%**	30
Physical Therapist Aides	420	520	100	**24%**	17
Occupational Therapists	1,550	1,850	300	19%	51
Occupational Therapist Assistants	410	470	60	15%	12
Occupational Health and Safety Specialists	610	640	30	5%	16
Speech-Language Pathologists	1,480	1,630	150	10%	52
Rehabilitation Counselors	4080	4790	710	17%	165
Recreational Therapists	930	950	20	2%	25
Substance Abuse and Behavioral Disorder Counselors	1130	1380	250	**22%**	51
Mental Health Counselors	1890	2390	500	**27%**	93
Psychiatrists	570	620	50	9%	13
Psychiatric Technicians	1,110	1,170	60	5%	20
Psychiatric Aides	540	620	80	15%	15
Respiratory Therapists	1,230	1,400	170	14%	58
Respiratory Therapy Technicians	210	250	40	19%	7
Mental Health and Substance Abuse Social Workers	2490	3010	520	**21%**	95
Child, Family, and School Social Workers	5000	5560	560	11%	141
Medical and Public Health Social Workers	2120	2620	500	**24%**	86
Social and Human Service Assistants	7890	9330	1440	18%	283
Dietitians and Nutritionists	570	620	50	9%	20
Dietetic Technicians	360	410	50	14%	10
Medical Equipment Preparers	440	480	40	9%	12

V. Conclusions

A. Connecticut resident survey

Future demand for services

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

Long-term care planning and future needs

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

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

Community long-term care service use

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

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

Overall, over one-third of respondents cannot get all the services they need to live in the community.[2] This number is greatest for respondents from the general survey who identified themselves as having a disability or ADL deficit (48%). A slightly smaller percentage of respondents to the survey for people with disabilities (40%) also cannot get the community-based services they need. Finances and lack of knowledge about services are the primary barriers to receiving assistance. Lack of coordination across agencies and lack of a single point of entry or "no wrong door" system for people of all ages or disabilities also make it difficult for residents to access the programs and services they need. Social workers and heath care providers are the most commonly reported source of information for formal services.

Transportation

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

Mental health

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

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

Informal caregiving

Unpaid caregiving is common in Connecticut and is on par with the national average. Seventeen percent of respondents reported being a caregiver to a Connecticut resident

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[2] Institutional care is addressed in the literature review, the report Rebalancing Long-Term Care Systems in Connecticut (June, 2007), and the Connecticut Long-Term Care Ombudsman Program report (July, 2007).

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

B. Provider survey

Workforce shortage and increase in demand for services

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

Greatest unmet need for older adults and people with disabilities

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

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

How the State can address these missing services

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

Impact of the regulatory environment

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

Recommendations based on the survey results reported in this document, as well as those from an examination of the long-term care rebalancing efforts in Connecticut, appear together at the end of the concurrently released reports: "Long-Term Care Needs Assessment Executive Summary" and "Long-Term Care Needs Assessment Part II: Rebalancing Long-Term Care Systems in Connecticut."

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VII. Appendices

Appendix A: Legislation

Appendix B: Additional Reference and Resource List

Appendix C: Maps of Connecticut Towns by Age Groups

Appendix D: Connecticut Resident General Survey

Appendix E: Connecticut Resident People with Disabilities Survey

Appendix F: Provider Survey

Appendix A

Senate Bill No. 703

Public Act No. 06-188

AN ACT CONCERNING SOCIAL SERVICES AND PUBLIC HEALTH BUDGET IMPLEMENTATION PROVISIONS.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Sec. 38. Section 1 of special act 02-7 is amended to read as follows (*Effective July 1, 2006*):

[The Office of Policy and Management shall conduct**]** The General Assembly, after consultation with the Commission on Aging, the Long-Term Care Advisory Council and the Long-Term Care Planning Committee, shall contract for a comprehensive needs assessment of the unmet long-term care needs in the state and project future demand for **[**such**]** services. Such assessment shall include, **[**a review of the Department of Mental Retardation's waiting list**]** but not be limited to, a review and evaluation of: (1) The number of persons presently at risk for having unmet long-term care needs, (2) the number of persons potentially at risk for having long-term care needs over the course of the next thirty years, (3) both costs and public and private resources available to meet long-term care needs, including the adequacy of current resources, projected costs and the projected resources needed to address long-term care needs over the next thirty years, (4) the existing array of services available to persons with long-term care needs, (5) existing and potential future models of public and private service delivery systems for persons with long-term care needs, (6) state government's programmatic structure in meeting the needs of persons requiring long-term care, (7) strategies that may assist families in making provisions for their own long-term care needs at reasonable costs, and (8) the service needs of the state's elderly population with long-term care needs with emphasis on healthcare, housing, transportation, nutrition, employment, prevention and recreation services. Such assessment shall also include recommendations on qualitative and quantitative changes that should be made to existing programs or service delivery systems, including recommendations on new programs or service delivery systems to better serve persons with long-term care needs.

Appendix B
Additional Reference and Resource List

Adult Day Care

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Appendix C: Maps of Connecticut Towns by Age Group

Map 1: Residents by median age

Map 2: Residents age 26 to 44

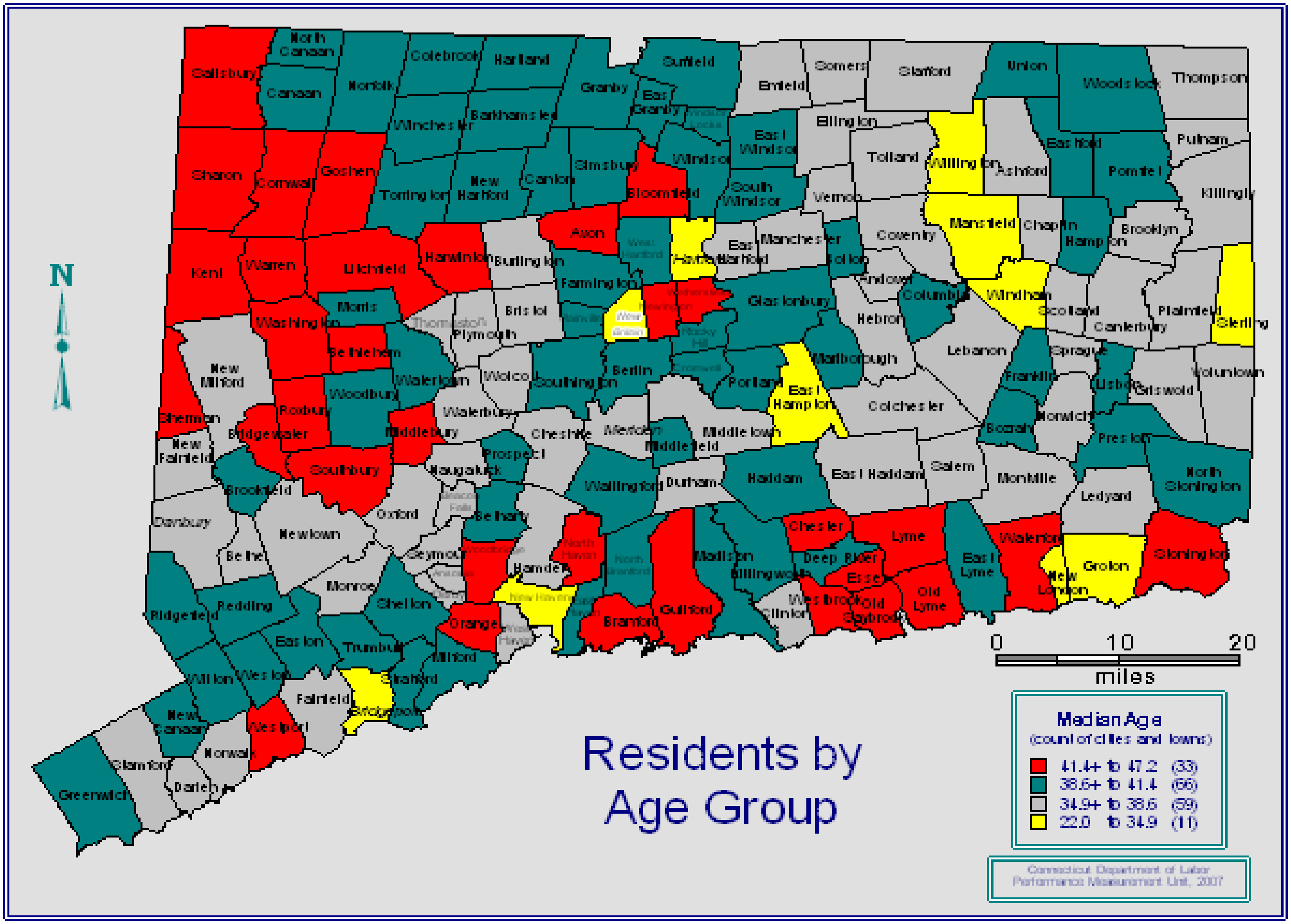
Map 3: Residents age 45 to 64

Map 3: Residents age 65 to 74

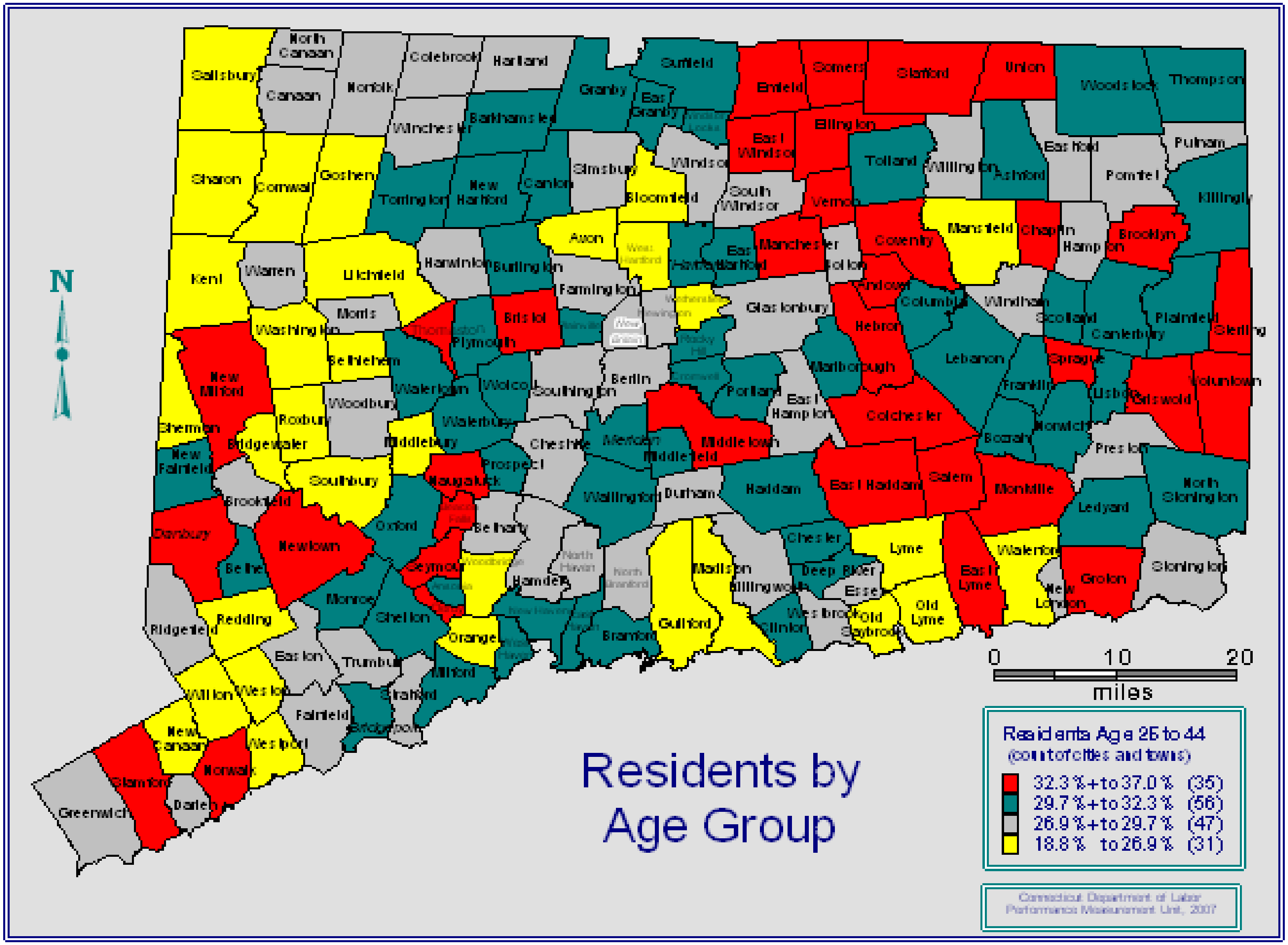
Map 4: Residents age 75 to 84

Map 5: Residents age 85 and over

Map 1: Residents by median age

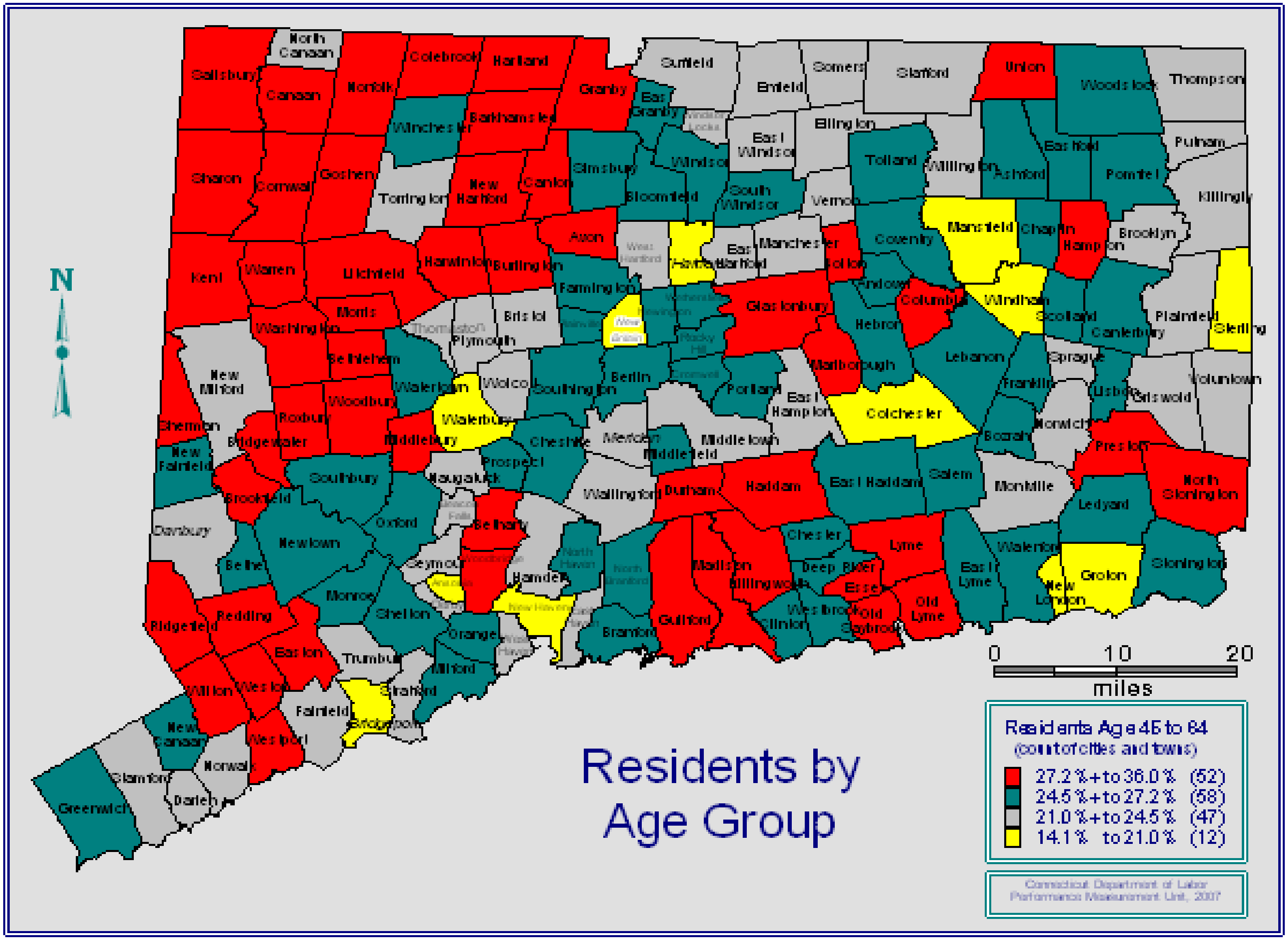


Map 2: Residents age 26 to 44

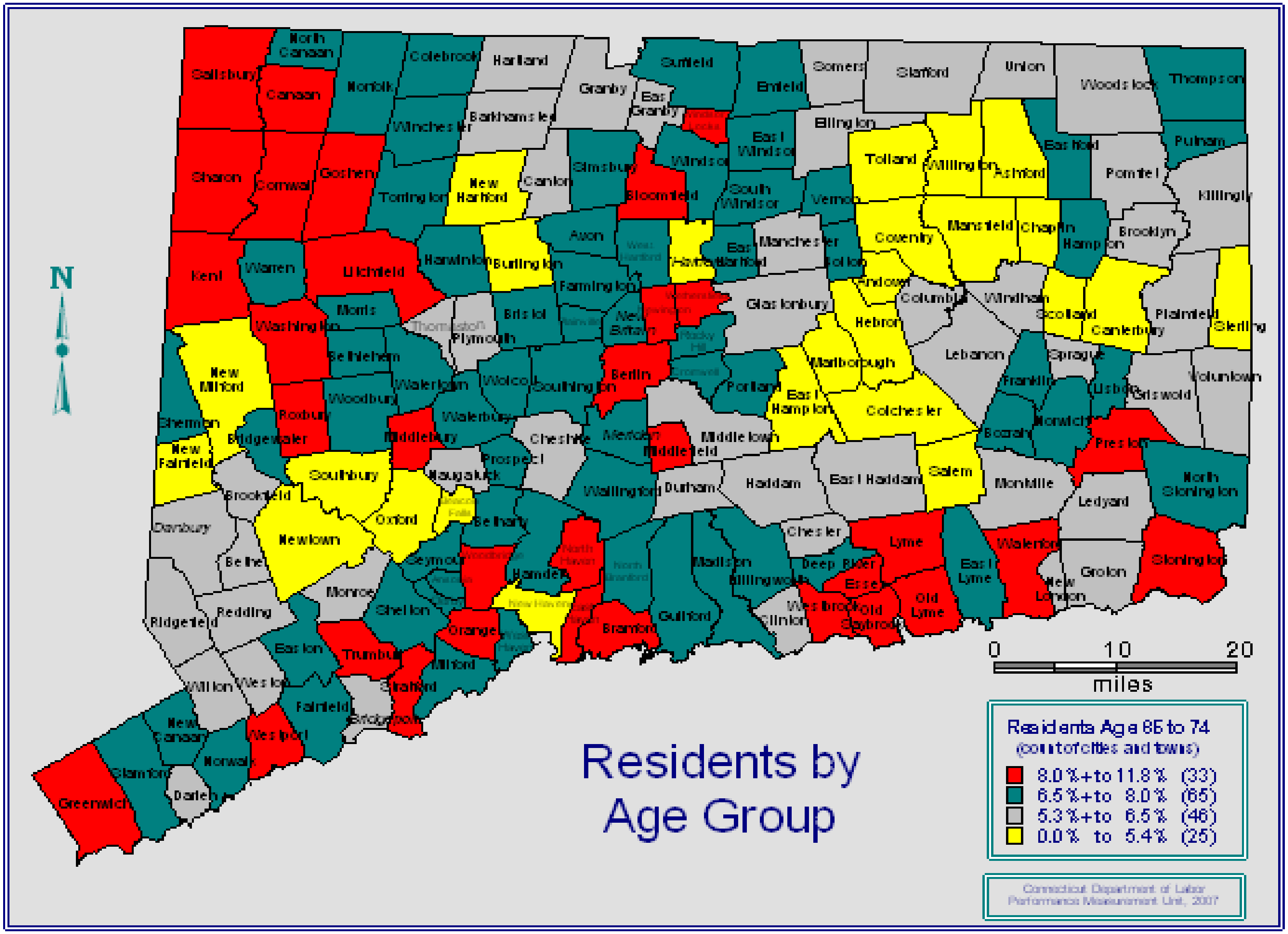


Connecticut Department of Labor
Performance Measurement Unit, 2007

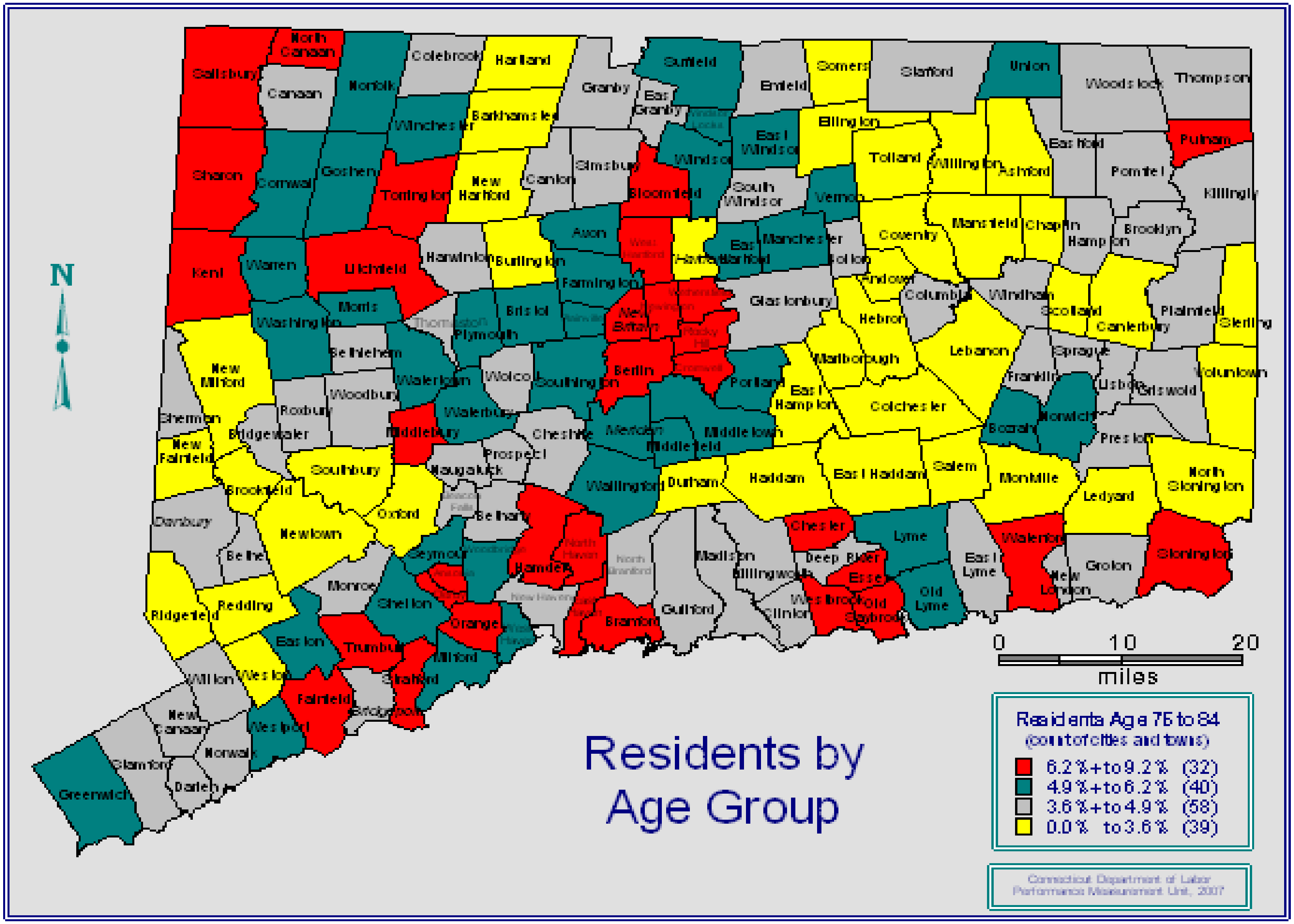
Map 3: Residents age 45 to 64



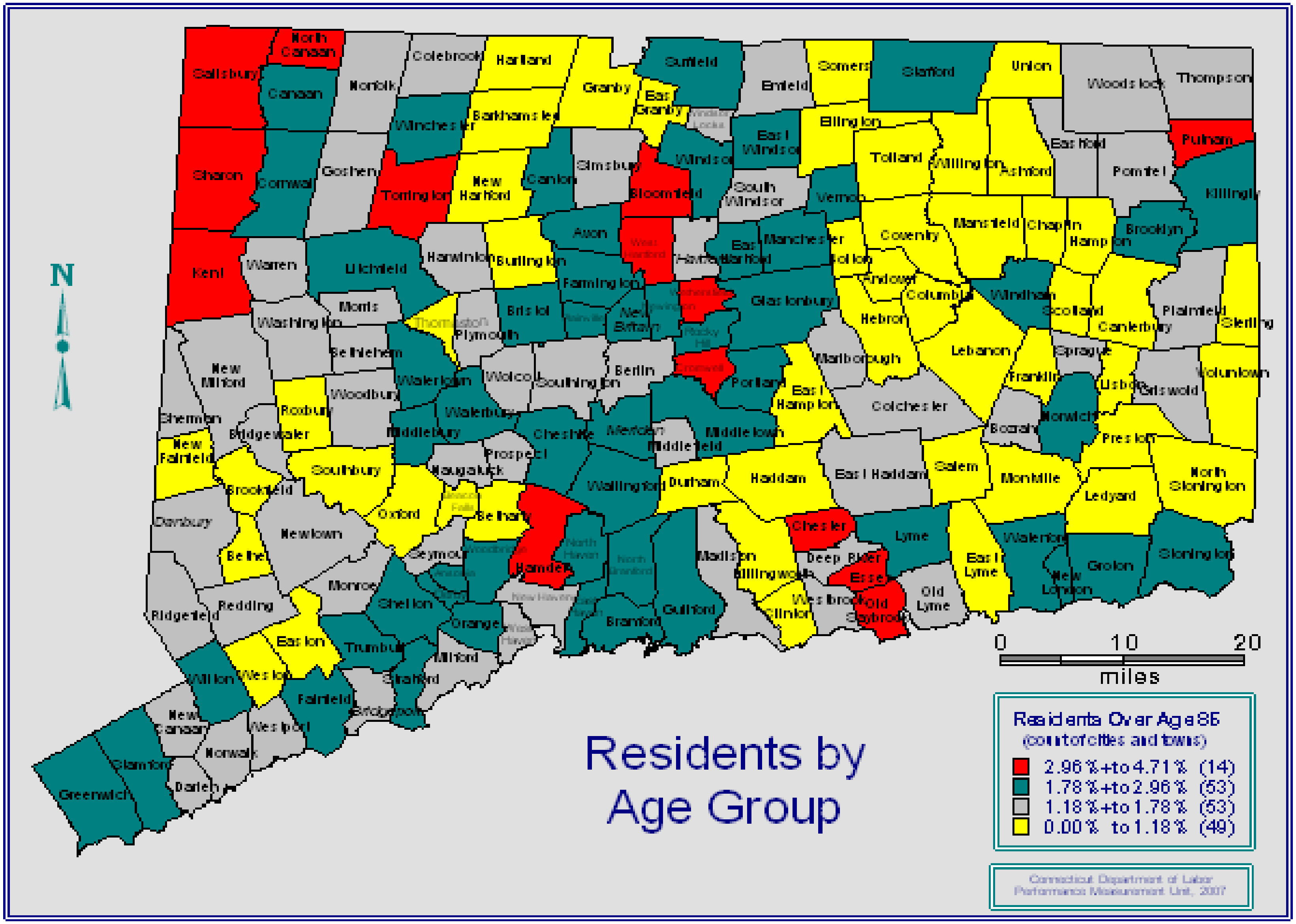
Map 4: Residents age 65 to 74



Map 5: Residents 75 to 84



Map 6: Residents age 85 and over



Appendix D

Connecticut Resident General Survey

Shaping Our Future: A Survey of Connecticut's Citizens

The State of Connecticut will make decisions about future programs and policies based on the responses to this survey! Please share your experiences and future plans.

ALL RESPONSES ARE CONFIDENTIAL AND ANONYMOUS.

Please check only one box per question, unless instructed to do otherwise.

Current and Future Plans

1. I am currently living in: (Check only one.)

☐ My own house
☐ My own apartment
☐ Condominium/Townhouse
☐ Senior housing complex
☐ Assisted living facility
☐ Retirement community (age 55+ only)
☐ With my child in his/her home
☐ With my parent/s in their home
☐ Other _________________

2. If you were to remain in your present residence, what services do you think you might use as you grow older? Check all that you think might be helpful for you.

☐ Home maintenance or handyman services
☐ Homemaker services for shopping, cleaning, laundry, paying bills, etc.
☐ Home health care for bathing or other personal care
☐ Transportation
☐ Meals delivered
☐ Lawn care, snow shoveling, or taking garbage to the curb
☐ Other ______________________

3. Do you think you will ever need long-term care, including care at home, assisted living, or nursing home care?

☐ No
☐ Yes
☐ I already receive long-term care

4. If you needed long-term care in the future, who do you think will provide this care? Or, if you already receive long-term care, who provides this care? Check all that apply.

☐ Spouse/partner
☐ Adult child
☐ Friend or neighbor
☐ Home care agency
☐ Assisted living staff
☐ Nursing home staff
☐ Other __________________
☐ I don't know

5. Do you currently have long-term care insurance for nursing home or home health care? This does **not** include life insurance, medical or other health insurance, Medicare, Medicaid or Title 19.

☐ No
☐ Yes
☐ Not sure

6. As you grow older, how likely are you to move to, or live in, each of the following arrangements? Please check <u>one</u> box for each statement indicating if each one is very likely, somewhat likely, not at all likely, or if you have already made this change.

	Very <u>likely</u>	**Somewhat <u>likely</u>**	**Not at all <u>likely</u>**	**Already made this <u>change</u>**
Remain in your own home <u>without</u> modifications	☐	☐	☐	
Remain in your own home <u>with</u> some modifications to adjust for physical problems	☐	☐	☐	☐
Remain in your own home with home health care or homemaker services provided at home	☐	☐	☐	☐
Sell your house and move to an apartment or condominium	☐	☐	☐	☐
Live in senior housing – apartments for seniors and people with disabilities with no special services	☐	☐	☐	☐
Live in a retirement community that provides some meals, housekeeping, transportation, and social activities for age 55+ only	☐	☐	☐	☐
Live in an assisted living facility that provides meals, housekeeping, transportation, and limited nursing care	☐	☐	☐	☐
Live in a nursing home	☐	☐	☐	☐
Live in a continuing care retirement community that provides independent living units, assisted living, and nursing home care	☐	☐	☐	☐
Live with my adult child in his/her home	☐	☐	☐	☐
Other _________________________	☐	☐	☐	☐

7. How do you plan to pay (or how do you currently pay) for any long-term care services? This can include care at home, assisted living, or nursing home care. Check <u>all</u> that apply.

☐ No plans or do not know
☐ My family will pay for it
☐ Savings or investments
☐ Sell my home
☐ Reverse mortgage
☐ Long-term care insurance
☐ Private health insurance
☐ Medicare
☐ Medicaid or Medicaid waiver
☐ Other __________________

8. If you or a family member needed long-term care for a 5 year period, how much could you afford to pay <u>each year</u> for this care?

☐ I could not afford to pay anything
☐ Less than $10,000 each year
☐ $10,000 - $24,999 each year
☐ $25,000 - $49,999 each year
☐ $50,000 - $99,999 each year
☐ $100,000 or more each year

9. If you were living by yourself and had to enter a nursing home, what do you think should happen with your home and other property once you could no longer pay for your care?

- ☐ I should sell all my property before getting government assistance
- ☐ I should be able to keep some of my property for my relatives, even if this means more tax money goes to pay for my care
- ☐ I'm not sure

Health

10. Overall, how would you rate your health during the past month?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

11. During the past month, have you often been bothered by feeling down, depressed, or hopeless?

☐ No ☐ Yes

12. During the past month, have you often been bothered by little interest or pleasure in doing things?

☐ No ☐ Yes

13. Overall, how would you rate the quality of care given to you from all your doctors, nurses, and other health providers in the last 12 months?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ I did not see a doctor or other health provider in the last 12 months

14. Have you gained or lost at least 10 pounds without trying in the last 12 months?

- ☐ Yes, I gained at least 10 pounds
- ☐ Yes, I lost at least 10 pounds
- ☐ No, my weight stayed the same
- ☐ No, I lost or gained weight on purpose

15. A fall is when your body goes to the ground without being pushed. Did you fall in the last 12 months?

☐ No ☐ Yes

16. Have you had any of the following health exams? Check all that you have had…

In the past year:

- ☐ Blood pressure check
- ☐ Cholesterol screening
- ☐ Dental cleaning
- ☐ Flu vaccine
- ☐ Pneumonia vaccine

In past two years:

- ☐ Bone density test
- ☐ Mammogram
- ☐ Prostate exam
- ☐ Sigmoidoscopy or colonoscopy
- ☐ Wellness check up

17. Have you had any problems with Medicare Part D – Medicare's new prescription drug plan?

- ☐ I have never used it
- ☐ No
- ☐ Yes → **If Yes,** Please describe the difficulties you have experienced:

____

18. Do you need help from another person for any of the following activities because of a disability or health problem? Check one box to show how much help you need with each activity: no help, a little help, a lot of help, or you cannot do the activity at all.

	No help	**A little help**	**A lot of help**	**Cannot do it at all**
Preparing meals	☐	☐	☐	☐
Shopping for groceries	☐	☐	☐	☐
Doing routine household chores	☐	☐	☐	☐
Managing money, including keeping track of bills	☐	☐	☐	☐
Doing laundry	☐	☐	☐	☐
Taking medications correctly	☐	☐	☐	☐
Getting to places out of walking distance	☐	☐	☐	☐
Using the telephone	☐	☐	☐	☐
Taking a bath or shower	☐	☐	☐	☐
Getting dressed	☐	☐	☐	☐
Getting in and out of a bed or chair	☐	☐	☐	☐
Using the toilet	☐	☐	☐	☐
Eating	☐	☐	☐	☐
Maintaining control of your bowel/bladder function	☐	☐	☐	☐
Getting around inside the house	☐	☐	☐	☐
Other ______________________	☐	☐	☐	☐

19. Some people use assistive devices to help them at home or at work. Please mark one box for each statement to indicate if you do not need it, currently use it, or do need it but do not have the assistive device.

	I do not need it	**I currently use it**	**I do need it, but do not have it**
Building modifications (entrance ramps, expanded doorways, accessible space, etc.)	☐	☐	☐
Mobility aids (electric wheelchair, stair lift, etc.)	☐	☐	☐
Transportation aids (lift van, adaptive driving controls, etc.)	☐	☐	☐
Computer access aids (touch screens, keyless entry, voice to text software, etc.)	☐	☐	☐
Other ___________________________	☐	☐	☐

20. A disability is defined as a physical or mental impairment that substantially limits one or more major life activities, such as walking, self-care, thinking, or working. Please check No or Yes for each one to indicate if you have any of the following disabilities.

	No	**Yes**
Physical disability or chronic illness disability that makes it difficult for you to walk, reach, lift, or carry	☐	☐
Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	☐	☐
Mental illness or psychiatric disability, such as schizophrenia or bipolar disorder	☐	☐
Deafness or other severe hearing impairment	☐	☐
Blindness or legal blindness	☐	☐

21. If you have a disability, what is your primary disability? ________________________

22. If you have a disability, how old were you when your disability started? _____ years

Employment and Transportation

23. Are you currently employed, volunteering, or going to school? Check all that apply.

☐ Work full time
☐ Work part time
☐ Retired
☐ Homemaker
☐ Volunteer
☐ Attend school full or part time
☐ Unemployed

24. If you are not currently working for pay, do you want to have a job?

☐ I am working for pay
☐ No
☐ Yes → **If Yes,** Are you actively job hunting at this time? ☐ No ☐ Yes

25. At what age do you plan to retire or work fewer than 20 hours a week?

_____ age when I plan to retire or work fewer than 20 hours/week

☐ I am already retired, working fewer than 20 hours/week, or not working

26. If you are not in school at this time, do you want to get more schooling or education?

☐ No
☐ Yes → **If Yes,** What education are you interested in? _______________________

27. What kinds of difficulties do you have in getting the transportation that you need? Check all that apply.

☐ I have no difficulties – the transportation I use is fine
☐ I have no car available to me or I do not drive
☐ A person is not always available to assist or to drive me
☐ It costs too much
☐ Public buses are not available or not dependable
☐ Dial-a-ride or other van service is not always available, not dependable, or too slow
☐ The van or bus will not take me to all the places I need to go
☐ Other ___________________

28. Do problems with transportation make it difficult for you to do any of the following? Check all that apply.

☐ Go to medical appointments
☐ Shop or do errands
☐ Go to work or get a job
☐ Socialize or visit friends and family
☐ Take part in community activities
☐ Other ______________

Community Long Term Care Services

29. Long-term care services can be used when people need ongoing assistance because of age-related problems, serious injury, disabilities, or other difficulties. The following is a list of paid long-term care services which can help people live in the community. Please tell us if **you use or need** any of these services for yourself. Check one box for each service.

	Not using now and Do not need	**Not using now but Do need**	**Using now and receiving Enough**	**Using now but Need more**
Home health aide from an agency or personal care assistant (for bathing, dressing, daily living needs, etc.)	☐	☐	☐	☐
Homemaker services from an agency (for laundry, shopping, cleaning, etc.)	☐	☐	☐	☐
Visiting nurse (to change bandages, give injections, etc.)	☐	☐	☐	☐
Home delivered meals (Meals-On-Wheels, etc.)	☐	☐	☐	☐
Dial-a-ride or van service (transportation for shopping, medical appointments, etc.)	☐	☐	☐	☐
Friendly visitor services (social visits from volunteers)	☐	☐	☐	☐
Care management (assessment, coordination, and monitoring of services by a social worker, nurse, etc.)	☐	☐	☐	☐
Adult day program (activities and health services provided at care centers)	☐	☐	☐	☐
Handyman services (home maintenance, minor repairs)	☐	☐	☐	☐
Lawn or snow services (lawn care, snow removal)	☐	☐	☐	☐

30. Are you able to get all the above long-term care services that you need?

☐ I do not need any services
☐ Yes
☐ No → **If No,** Why can't you get the services you need? Check all that apply.
  ☐ Cannot afford services
  ☐ Services are not available in my area
  ☐ Cannot find someone to hire
  ☐ Services are unreliable or give poor care
  ☐ Services are not accessible for people with disabilities
  ☐ Services are not available in my language
  ☐ Do not know what services or help are available
  ☐ Other ___________________

31. How did you find out about the long-term care services you use? Check all that apply.

☐ I do not use any services
☐ Relatives, friends, or neighbors
☐ Doctor, nurse, or other health provider
☐ Social worker or care manager
☐ State agency
☐ Support organization (e.g., Easter Seals, Alzheimer's Association, etc.)
☐ Telephone directory
☐ Television, radio, or newspaper
☐ Internet or on-line
☐ Infoline (211)
☐ Senior center
☐ School
☐ Other _______________

32. How often do you have problems communicating with someone who provides long-term care services to you because they speak a different language or are from a different cultural background?

☐ Always
☐ Sometimes
☐ Rarely
☐ Never
☐ I do not use any services

33. Overall, how well do the long-term care services you receive meet your needs?

☐ I do not use any services
☐ Very well
☐ Somewhat well
☐ Not very well → Please describe your experiences:

____

34. How likely is it that you will go to a senior center in the future?

☐ Not at all likely ☐ Somewhat likely ☐ Very likely ☐ I already go

35. There are different ways for people to arrange and manage their paid services. Managing your paid services can include finding someone, training them, deciding on a work schedule, and paying them. If you had a choice, how would you like to manage your paid services, including any you use now or might use in the future? Please check the one approach you would like best.

☐ You and an agency or provider talk about what services you want. The agency then decides on the services and schedule. The agency finds and arranges the services for you. The agency processes the paychecks and handles any tax forms or financial paperwork.

☐ Together with the agency or provider of your choice, you decide the services and schedule for the services you want. You and the agency work together to find and arrange these services. The agency processes the paychecks and handles any tax forms or financial paperwork.

☐ You make the decisions about, find, and arrange your own services without the help of an agency or provider. You can get advice and training to learn how to hire and fire, train, pay, and manage your workers. You process the paychecks and handle any tax forms or financial paperwork.

36. What additional services should Connecticut offer to older adults or people with disabilities?

____

____

____

Social Support

37. If you needed some extra help, could you count on any family or friends to help you with daily tasks like grocery shopping, cooking, or giving you a ride?
☐ No ☐ Yes

38. Do you currently receive this type of extra help from family or friends at least once a week?
☐ No ☐ Yes ☐ I do not need this help

39. Can you count on anyone to provide you with emotional support, such as someone to talk over problems with or help you make a difficult decision?
☐ No ☐ Yes

40. Who do you currently live with? Check all that apply.
☐ No one - I live alone
☐ With a spouse or partner
☐ With my child/ren under age 18
☐ With my child/ren age 18 or over
☐ With a parent
☐ With another relative
☐ With a friend or roommate

41. Do you have any children who are living? Check all that apply.
☐ No, I do not have any living children
☐ Yes, at least one child age 17 or younger
☐ Yes, at least one child age 18 or older

42. Do any of these children live within 45 minutes of you (this includes those who live with you)?
☐ No ☐ Yes ☐ I do not have any living children

43. How many days per week, on average, do you leave home for any reason?
☐ Only for medical appointments
☐ Less than one day per week
☐ 1-3 days per week
☐ 4-6 days per week
☐ Every day

44. Is the number of days you leave home each week the right amount for you?
☐ Yes, I go out enough
☐ No, I want to go out more
☐ No, I want to go out less

General Information

45. What is the zip code or name of the town you live in? ____________

46. What is your age? _____

47. What is your gender? ☐ Male ☐ Female

48. What is your marital status?
☐ Married
☐ Widowed
☐ Separated
☐ Divorced
☐ Never married
☐ Living together as though married

49. What language do you mainly speak at home?
☐ English
☐ Spanish
☐ Polish
☐ Russian
☐ Other ________________

50. Which category best describes your race? Check only one.

- ☐ White or Caucasian
- ☐ Black, African-American, or Caribbean Black
- ☐ Asian, including Asian Indian, Chinese, Filipino, Korean, or other Asian
- ☐ American Indian or Alaska Native
- ☐ Other ______________________

51. Are you of Spanish, Latino, or Hispanic origin?

☐ No ☐ Yes

52. What is the highest grade or year you finished in school?

- ☐ 8th grade or less
- ☐ Some high school
- ☐ High school diploma or GED
- ☐ Technical school/community college
- ☐ Some college
- ☐ Two-year college degree
- ☐ Four-year college degree
- ☐ Post graduate degree (masters/doctorate)

Financial

53. What category best describes your total monthly household income from all sources before taxes? Include income such as wages, salaries, Social Security, retirement benefits, veteran's benefits, public assistance, investment income, or any other income.

- ☐ Less than $500 each month
- ☐ $500 - $999
- ☐ $1,000 - $1,999
- ☐ $2,000 - $2,999
- ☐ $3,000 - $3,999
- ☐ $4,000 - $4,999
- ☐ $5,000 - $6,999
- ☐ $7,000 - $8,999
- ☐ $9,000 - $12,499
- ☐ $12,500 or more each month

54. How many people are supported by this income (including you)? ______

55. What category best describes the total value of your assets? Do not include your home or your car. Assets include bank accounts, stocks, bonds, investment or business property, and the cash value of any life insurance.

- ☐ Less than $5,000
- ☐ $5,000 - $14,999
- ☐ $15,000 - $29,999
- ☐ $30,000 - $74,999
- ☐ $75,000 - $149,999
- ☐ $150,000 - $249,000
- ☐ $250,000 - 349,999
- ☐ $350,000 or more

56. Do you own your own home or condominium/townhouse?

☐ No ☐ Yes

57. If you needed some extra help financially, could you count on anyone to help you, that is, by paying any bills, housing costs, medical costs, or providing you with food or clothes?

☐ No ☐ Yes

58. In general, how do your finances usually work out at the end of the month? Do you find that you usually end up with… (Check only one.)

- ☐ Some money left over
- ☐ Just enough to make ends meet
- ☐ Not enough money to make ends meet

59. Were there any times in the past 12 months when you did not have enough money to: (Check all that apply.)

- ☐ Pay rent, mortgage, or real estate taxes
- ☐ Pay utility bills (heat, electricity, phone)
- ☐ Own or repair a car
- ☐ Buy needed food
- ☐ Fill a prescription for medicine
- ☐ Obtain dental care
- ☐ Obtain eyeglasses or hearing aids
- ☐ Obtain other medical care
- ☐ Pay for home modifications to adjust for physical needs
- ☐ Pay for the assistive devices or technology that I need
- ☐ Pay more than the minimum balance due on a credit card
- ☐ Pay into a retirement account
- ☐ Pay for the care of a parent or child with disabilities
- ☐ I have always had enough money

Caregiving

60. Do you provide unpaid care and assistance for a relative or friend who lives in Connecticut because of old age, disabilities, or other problems?

- ☐ No → **If No,** Skip to question 72, page 12
- ☐ Yes → **If Yes,** Continue to question 61

61. How many relatives or friends do you provide this care for? Do not include children without disabilities.

_______ number of relative/s or friend/s you provide care for

62. Think of the person you provide the greatest amount of care for. Do not include children without disabilities. How is this person related to you? Check only one.

- ☐ Spouse or partner
- ☐ Child with disabilities under age 18
- ☐ Child with disabilities age 18 or older
- ☐ Parent
- ☐ Other relative – specify relationship: _______________
- ☐ Friend

63. How old is this person?

- ☐ Less than 18
- ☐ 18 - 59
- ☐ 60 - 64
- ☐ 65 - 84
- ☐ 85 - 99
- ☐ 100 or older

64. How close to you does this person live?

- ☐ Lives with me
- ☐ Lives in my town or a nearby community
- ☐ Lives more than 45 minutes away

65. Does this person have any memory problems?

- ☐ None
- ☐ Mild
- ☐ Moderate
- ☐ Severe

66. In the past year, how often have you missed work or used sick or vacation time to care for this person?

☐ I do not work
☐ None
☐ 1-5 days
☐ 6-10 days
☐ 11 days or more

67. The following is a list of paid long-term care services which can help people live in the community. Please tell us if the <u>person you provide care for</u> uses or needs any of these services. Check <u>one</u> box for each service.

	Not using now and <u>Does not need</u>	**Not using now but <u>Does need</u>**	**Using now and receiving <u>Enough</u>**	**Using now but <u>Needs more</u>**
Home health aide from an agency <u>or</u> personal care assistant (for bathing, dressing, daily living needs, etc.)	☐	☐	☐	☐
Homemaker services from an agency (for laundry, shopping, cleaning, etc.)	☐	☐	☐	☐
Visiting nurse (to change bandages, give injections, etc.)	☐	☐	☐	☐
Home delivered meals (Meals-On-Wheels)	☐	☐	☐	☐
Dial-a-ride or van service (transportation for shopping, medical appointments, etc.)	☐	☐	☐	☐
Care management (assessment, coordination, and monitoring of services by a social worker, nurse, etc.)	☐	☐	☐	☐
Adult day program (activities and health services provided at care centers)	☐	☐	☐	☐
Other ___________________________	☐	☐	☐	☐

68. Is this person able to get all the services that he/she needs?

☐ He/she does not need services
☐ Yes
☐ No → **If No,** Why can't this person get the services that he/she needs? Check <u>all</u> that apply.
  ☐ Cannot afford services
  ☐ Services are not available in his/her area
  ☐ Cannot find someone to hire
  ☐ Services are unreliable or give poor care
  ☐ Services are not accessible for people with disabilities
  ☐ Services are not available in his/her language
  ☐ Do not know what services or help are available
  ☐ Other ___________________

69. How often does this person have problems communicating with someone who provides care to him/her because they speak different languages or are from a different cultural background?

☐ Always
☐ Sometimes
☐ Rarely
☐ Never
☐ I am the only caregiver

70. Please describe any other problems this person has experienced with his/her paid services.

____

71. How did you find out about the services this person uses? Check all that apply.

☐ He/she does not use any services
☐ Relatives, friends, or neighbors
☐ Doctor, nurse, or other health provider
☐ Social worker or care manager
☐ State agency
☐ Support organization (e.g., Easter Seals, Alzheimer's Association, etc.)
☐ Telephone directory
☐ Television, radio, or newspaper
☐ Internet or on-line
☐ Infoline (211)
☐ Senior center
☐ School
☐ Other ______________

---

72. Did anyone help you fill out this survey? Check all that apply.

☐ No, I filled it out myself
☐ My spouse/partner
☐ My adult child
☐ My parent
☐ My paid assistant or helper
☐ Other _______________

73. Is there anything else you would like to add?

____

____

____

____

____

____

____

Thank you for taking the time to participate in this survey.
Please mail your completed survey in the envelope provided, or mail to:

Martha Porter, University of Connecticut Health Center
263 Farmington Avenue, Building 7, Farmington, CT 06030- 6147

Appendix E

Connecticut Resident People with Disabilities Survey

Shaping Our Future: A Survey of Connecticut's Citizens

The State of Connecticut will make decisions about future programs and policies based on the responses to this survey! Please share your experiences and future plans.

ALL RESPONSES ARE CONFIDENTIAL AND ANONYMOUS.

Please check only one box per question, unless instructed to do otherwise.

Current and Future Plans

1. I am currently living in: (Check only one.)
   - ☐ My own house or condominium/townhouse
   - ☐ My own apartment
   - ☐ Supervised living apartment or program
   - ☐ Group home or community living arrangement
   - ☐ Transitional group home or halfway house
   - ☐ Community training home
   - ☐ With my parent/s in their home
   - ☐ With my child in his/her home
   - ☐ Housing complex for seniors or people with disabilities
   - ☐ Assisted living
   - ☐ Retirement community (age 55+ only)
   - ☐ Other _________________

2. Who do you currently live with? Check all that apply.
   - ☐ No one - I live alone
   - ☐ With a spouse or partner
   - ☐ With a parent
   - ☐ With another relative
   - ☐ With a friend or roommate
   - ☐ With a live-in paid assistant
   - ☐ With my child/ren under age 18
   - ☐ With my child/ren age 18 or over
   - ☐ Other _________________

3. If you were to remain in your present residence, what services do you think you might use as you grow older? Check all that you think might be helpful for you.
   - ☐ Home maintenance or handyman services
   - ☐ Homemaker services for shopping, cleaning, laundry, paying bills, etc.
   - ☐ Home health care for bathing or other personal care
   - ☐ Personal care assistance for daily living needs, paid for privately or with a waiver
   - ☐ Nursing care to give injections or provide other specialized medical treatments
   - ☐ Paid staff for monitoring or supervision only
   - ☐ Paid staff for recreation and social activities
   - ☐ Transportation
   - ☐ Meals delivered or made for you
   - ☐ Lawn care, snow shoveling, or taking garbage to the curb
   - ☐ Other ______________________

4. As you grow older, how likely are you to move to, or live in, each of the following arrangements? Please check one box for each statement indicating if each one is very likely, somewhat likely, not at all likely, or if you already live there or made this change.

	Very likely	**Somewhat likely**	**Not at all likely**	**Already live there or made this change**
Remain in your own home or apartment without modifications	☐	☐	☐	☐
Remain in your own home or apartment with some modifications to adjust for physical problems	☐	☐	☐	☐
Remain in your own home or apartment with home health care, homemaker, or other paid services	☐	☐	☐	☐
Sell your house and move to an apartment or condominium	☐	☐	☐	☐
Live in a group home or community living arrangement	☐	☐	☐	☐
Live in housing for seniors or people with disabilities – apartments for seniors and people with disabilities with no special services	☐	☐	☐	☐
Live in an assisted living facility that provides meals, housekeeping, transportation, and limited nursing care	☐	☐	☐	☐
Live in a nursing home	☐	☐	☐	☐
Live with my parent/s in their home	☐	☐	☐	☐
Live with another relative in his/her home	☐	☐	☐	☐
Other ________________________	☐	☐	☐	☐

5. Do you think you will ever need long-term care, including care at home, in another community living arrangement, assisted living, or nursing home care?

☐ No
☐ Yes
☐ I already receive long-term care

6. If you needed long-term care in the future, who do you think will provide this care? Or, if you already receive long-term care, who provides this care? Check all that apply.

☐ Spouse or partner
☐ Adult child
☐ Parent
☐ Friend or neighbor
☐ Paid personal assistant
☐ Home care agency
☐ Group home staff
☐ Assisted living staff
☐ Nursing home staff
☐ Other service provider
☐ Other ________________
☐ I don’t know

7. Do you currently have long-term care insurance for nursing home or home health care? This does **not** include life insurance, medical or other health insurance, Medicare, Medicaid, or Title 19.
   - ☐ No
   - ☐ Yes
   - ☐ Not sure

8. How do you plan to pay (or how do you currently pay) for any long-term care services? This can include care at home, in another community living arrangement, assisted living, or nursing home care. Check all that apply.
   - ☐ No plans or do not know
   - ☐ My family will pay for it
   - ☐ Savings or investments
   - ☐ Sell my home
   - ☐ Reverse mortgage
   - ☐ Long-term care insurance
   - ☐ Private health insurance
   - ☐ Medicare
   - ☐ Medicaid or Medicaid waiver
   - ☐ Other _______________

9. If you or a family member needed long-term care for a 5 year period, how much could you afford to pay each year for this care?
   - ☐ I could not afford to pay anything
   - ☐ Less than $10,000 each year
   - ☐ $10,000 - $24,999 each year
   - ☐ $25,000 - $49,999 each year
   - ☐ $50,000 - $99,999 each year
   - ☐ $100,000 or more each year

10. If you were living by yourself and had to enter a nursing home, what do you think should happen with your home and other property once you could no longer pay for your care?
    - ☐ I should sell all my property before getting government assistance
    - ☐ I should be able to keep some of my property for my relatives, even if this means more tax money goes to pay for my care
    - ☐ I'm not sure

Health

11. Overall, how would you rate your health during the past month?
    - ☐ Excellent
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

12. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
    - ☐ No
    - ☐ Yes

13. During the past month, have you often been bothered by little interest or pleasure in doing things?
    - ☐ No
    - ☐ Yes

14. During the past 12 months, how many times were you admitted as a patient in a hospital and stayed at least overnight?

☐ No visits
☐ 1 or 2 times
☐ 3 – 5 times
☐ 6 or more times

15. During the past 12 months, how many times did you use an emergency room at a hospital?

☐ No visits
☐ 1 or 2 times
☐ 3 – 5 times
☐ 6 or more times

16. During the past 12 months, how many times did you use any type of mental health, behavioral health, or substance abuse counseling or services?

☐ No visits
☐ 1 or 2 times
☐ 3 – 5 times
☐ 6 or more times

17. Overall, how would you rate the quality of care given to you from all your doctors, nurses, and other health providers in the last 12 months?

☐ Excellent
☐ Good
☐ Fair
☐ Poor
☐ I did not see a doctor or other health provider in the past 12 months

18. Have you gained or lost at least 10 pounds without trying in the last 12 months?

☐ Yes, I gained at least 10 pounds
☐ Yes, I lost at least 10 pounds
☐ No, my weight stayed the same
☐ No, I lost or gained weight on purpose

19. A fall is when your body goes to the ground without being pushed. Did you fall in the last 12 months?

☐ No
☐ Yes

20. Do you smoke?

☐ No
☐ Yes

21. Have you had any of the following health exams? Check all that you have had…

In the past year:
☐ Blood pressure check
☐ Cholesterol screening
☐ Dental cleaning
☐ Flu vaccine
☐ Pneumonia vaccine

In past two years:
☐ Bone density test
☐ Mammogram
☐ Prostate exam
☐ Sigmoidoscopy or colonoscopy
☐ Wellness check up

22. Have you had any problems with Medicare Part D – Medicare's new prescription drug plan?

☐ I have never used it
☐ No
☐ Yes → **If Yes,** Please describe the difficulties you have experienced:

____

23. Do you need help from another person for any of the following activities because of a disability or health problem? Check <u>one</u> box to show how much help you need with each activity: no help, a little help, a lot of help, or you cannot do the activity at all.

	No help	**A little help**	**A lot of help**	**Cannot do it at all**
Preparing meals	☐	☐	☐	☐
Shopping for groceries	☐	☐	☐	☐
Doing routine household chores	☐	☐	☐	☐
Managing money, including keeping track of bills	☐	☐	☐	☐
Doing laundry	☐	☐	☐	☐
Taking medications correctly	☐	☐	☐	☐
Getting to places out of walking distance	☐	☐	☐	☐
Using the telephone	☐	☐	☐	☐
Taking a bath or shower	☐	☐	☐	☐
Getting dressed	☐	☐	☐	☐
Getting in and out of a bed or chair	☐	☐	☐	☐
Using the toilet	☐	☐	☐	☐
Eating	☐	☐	☐	☐
Maintaining control of your bowel or bladder function	☐	☐	☐	☐
Getting around inside the house	☐	☐	☐	☐
Other ______________________	☐	☐	☐	☐

24. A disability is defined as a physical or mental impairment that <u>substantially limits one or more major life activities</u>, such as walking, self-care, thinking, or working. Please check No or Yes for each one to indicate if <u>you</u> have any of the following disabilities.

	No	**Yes**
<u>Physical</u> disability or chronic illness disability that makes it difficult for you to walk, reach, lift, or carry	☐	☐
<u>Intellectual</u> or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	☐	☐
<u>Mental illness</u> or psychiatric disability, such as schizophrenia or bipolar disorder	☐	☐
<u>Deafness</u> or other severe hearing impairment	☐	☐
<u>Blindness</u> or legal blindness	☐	☐

25. How old were you when your disability started? _____ years

26. What is your primary disability? _______________________

27. Some people use assistive devices to help them at home or at work. Please mark one box for each statement to indicate if you do not need it, currently use it, or do need it but do not have the assistive device.

	I do not need it	**I currently use it**	**I do need it, but do not have it**
Building modifications (entrance ramps, expanded doorways, accessible space, etc.)	☐	☐	☐
Mobility aids (electric wheelchair, stair lift, etc.)	☐	☐	☐
Transportation aids (lift van, adaptive driving controls, etc.)	☐	☐	☐
Computer access aids (touch screens, keyless entry, voice to text software, etc.)	☐	☐	☐
Communication aids (communication boards, voice activated telephone, etc.)	☐	☐	☐
Devices for people who are deaf (TDD, TTY, phone relay services, etc.)	☐	☐	☐
Devices for people who are blind or legally blind (Braille translation software, etc.)	☐	☐	☐
Other ___________________________	☐	☐	☐

28. How physically accessible for you is your home, your workplace, or other places you want to go? Check one box for each to indicate how accessible each one is for you overall.

a. Your home or residence:
- ☐ Totally
- ☐ Somewhat
- ☐ Not at all → Please explain: _______________________

b. Your place of work:
- ☐ Totally
- ☐ Somewhat
- ☐ Not at all → Please explain: ________________________
- ☐ I do not work

c. Where you want to shop or do errands:
- ☐ Totally
- ☐ Somewhat
- ☐ Not at all → Please explain: ________________________

d. Any recreation or leisure activities you want to do in the community:
- ☐ Totally
- ☐ Somewhat
- ☐ Not at all → Please explain: ________________________

Community Long Term Care Services

29. Long-term care services can be used when people need ongoing assistance because of age-related problems, disabilities, serious injury, or other difficulties. The following is a list of paid long-term care services which can help people live in the community. Please tell us if **you** use or need any of these services for yourself. Check one box for each service.

	Not using now and Do not need	**Not using now but Do need**	**Using now and receiving Enough**	**Using now but Need more**
Home health aide from an agency (for bathing, dressing, daily living needs, etc.)	☐	☐	☐	☐
Homemaker services from an agency (for laundry, shopping, cleaning, etc.)	☐	☐	☐	☐
Personal care assistance (for daily living needs, paid for privately or with a waiver)	☐	☐	☐	☐
Visiting nurse (to give injections, provide specialized medical treatment, etc.)	☐	☐	☐	☐
Care management (assessment, coordination, and monitoring of services by a social worker, nurse, etc.)	☐	☐	☐	☐
Home delivered meals (Meals-On-Wheels, etc.)	☐	☐	☐	☐
Dial-a-ride or van service (transportation for shopping, medical appointments, etc.)	☐	☐	☐	☐
Friendly visitor services (social visits from volunteers)	☐	☐	☐	☐
Adult day program (activities and health services provided at care centers)	☐	☐	☐	☐
Handyman services (home maintenance, minor repairs)	☐	☐	☐	☐
Lawn care or snow removal	☐	☐	☐	☐
Vocational rehabilitation services	☐	☐	☐	☐
Job coach or support staff at your job	☐	☐	☐	☐
Money management, paying bills	☐	☐	☐	☐

30. Are you able to get all the above long-term care services that you need?
    - ☐ I do not need any services
    - ☐ Yes
    - ☐ No → **If No,** Why can't you get the services that you need? Check all that apply.
        - ☐ Cannot afford services
        - ☐ Services are not available in my area
        - ☐ Cannot find someone to hire
        - ☐ Services are unreliable or give poor care
        - ☐ Services are not accessible for people with disabilities
        - ☐ Services are not available in my language
        - ☐ Do not know what services or help is available
        - ☐ Other ___________________

31. How did you find out about the long-term care services you use? Check all that apply.

☐ I do not use any services
☐ Relatives, friends, or neighbors
☐ Doctor, nurse, or other health provider
☐ Social worker or care manager
☐ State agency
☐ Support organization (e.g., Easter Seals, Alzheimer's Association, etc.)
☐ Telephone directory
☐ Television, radio, or newspaper
☐ Internet or on-line
☐ Infoline (211)
☐ Senior center
☐ School
☐ Other _______________

32. How often do you have problems communicating with someone who provides services to you because they speak a different language or are from a different cultural background?

☐ Always
☐ Sometimes
☐ Rarely
☐ Never
☐ I do not use any services

33. Overall, how well do the long-term care services you receive meet your needs?

☐ I do not use any services
☐ Very well
☐ Somewhat well
☐ Not very well → Please describe your experiences:

____

34. How likely is it that you will go to a community center for seniors and people with disabilities in the future?

☐ Not at all likely ☐ Somewhat likely ☐ Very likely ☐ I already go

35. There are different ways for people to arrange and manage their paid services. Managing your paid services can include finding someone, training them, deciding on a work schedule, and paying them. If you had a choice, how would you like to manage your paid services, including any you use now or might use in the future? Please check the one approach you would like best.

☐ You and an agency or provider talk about what services you want. The agency then decides on the services and schedule. The agency finds and arranges the services for you. The agency processes the paychecks and handles any tax forms or financial paperwork.

☐ Together with the agency or provider of your choice, you decide the services and schedule for the services you want. You and the agency work together to find and arrange these services. The agency processes the paychecks and handles any tax forms or financial paperwork.

☐ You make the decisions about, find, and arrange your own services without the help of an agency or provider. You can get advice and training to learn how to hire and fire, train, pay, and manage your workers. You process the paychecks and handle any tax forms or financial paperwork.

36. What additional services should Connecticut offer to older adults or people with disabilities?

____

____

____

Social Support

37. If you needed some extra help, could you count on any family or friends to help you with daily tasks like grocery shopping, cooking, or giving you a ride?

☐ No ☐ Yes

38. Do you currently receive this type of extra help from family or friends at least once a week?

☐ No ☐ Yes ☐ I do not need this help

39. Can you count on anyone to provide you with emotional support, such as someone to talk over problems with or help you make a difficult decision?

☐ No ☐ Yes

40. How often do you participate in any community activities or groups, such as a community center, social group, advocacy group, religious group, support group, sports group, or any other community group?

☐ Never or almost never
☐ Once or twice a year
☐ Every few months
☐ Once or twice a month
☐ Once a week or more

41. How many days per week, on average, do you leave home for any reason?

☐ Only for medical appointments
☐ Less than one day per week
☐ 1-3 days per week
☐ 4-6 days per week
☐ Every day

42. Is the number of days you leave home each week the right amount for you?

☐ Yes, I go out enough
☐ No, I want to go out more
☐ No, I want to go out less

43. What keeps you from going out more often? Check all that apply.

☐ Nothing, I go out as much as I want
☐ Health concerns
☐ Emotional concerns
☐ Lack of transportation
☐ Financial concerns
☐ No person to assist me
☐ Accessibility issues
☐ Other _______________

44. Do you provide unpaid care and assistance for a relative or friend who lives in Connecticut because of old age, disabilities, or other problems?

☐ No ☐ Yes

Employment and Transportation

45. Are you currently employed, volunteering, or going to school? Check all that apply.

☐ Work full time
☐ Work part time
☐ Retired
☐ Homemaker
☐ Volunteer
☐ Attend school full or part time
☐ Unemployed

46. If you are not currently working for pay, do you want to have a job?

☐ I am currently working for pay
☐ No
☐ Yes → **If Yes,** Are you actively job hunting at this time? ☐ No ☐ Yes

47. At what age do you plan to retire or work fewer than 20 hours a week?

_____ age when I plan to retire or work fewer than 20 hours/week

☐ I am already retired, working fewer than 20 hours/week, or not working

48. If you are not in school at this time, do you want to get more schooling or education?

☐ No
☐ Yes → **If Yes,** What education are you interested in? ______________________

49. How do you usually get to places out of walking distance? Check all that apply.

☐ Drive myself
☐ Get a ride from someone else (family member, friend, paid assistant)
☐ Public transportation, such as the bus or train
☐ Group home or day program van
☐ Dial-a-ride or other van service for people with disabilities
☐ Scooter or electric wheelchair
☐ Other (describe): _____________________

50. What kinds of difficulties do you have in getting the transportation that you need? Check all that apply.

☐ I have no difficulties – the transportation I use is fine
☐ I have no car available to me or I do not drive
☐ A person is not always available to assist or to drive me
☐ It costs too much
☐ Public buses are not available or not dependable
☐ Dial-a-ride or van service is not always available, not dependable, or too slow
☐ The van or bus will not take me to all the places I need to go
☐ The car, bus, or van is not wheelchair or scooter accessible
☐ Other __________________

51. Do problems with transportation make it difficult for you to do any of the following? Check all that apply.

☐ Go to medical appointments
☐ Shop or do errands
☐ Go to work or get a job
☐ Socialize or visit friends and family
☐ Take part in community activities
☐ Other ______________

General Information

52. What is the zip code or name of the town you live in? ____________

53. What is your age? _____

54. What is your gender? ☐ Male ☐ Female

55. What is your marital status?

☐ Married
☐ Widowed
☐ Separated
☐ Divorced
☐ Never married
☐ Living together as though married

56. What language do you mainly speak at home?

☐ English
☐ Spanish
☐ Polish
☐ Russian
☐ Other ________________

57. Which category best describes your race? Check only one.

☐ White or Caucasian
☐ Black, African-American, or Caribbean Black
☐ Asian, including Asian Indian, Chinese, Filipino, Korean, or other Asian
☐ American Indian or Alaska Native
☐ Other ______________________

58. Are you of Spanish, Latino, or Hispanic origin?

☐ No ☐ Yes

59. What is the highest grade or year you finished in school?

☐ 8th grade or less
☐ Some high school
☐ High school diploma or GED
☐ Technical school/community college
☐ Some college
☐ Two-year college degree
☐ Four-year college degree
☐ Post graduate degree (masters/doctorate)

Financial

60. What category best describes your total monthly household income from all sources before taxes? Include income such as wages, salaries, Social Security, retirement benefits, veteran's benefits, public assistance, investment income, or any other income.

☐ Less than $500 each month
☐ $500 - $999
☐ $1,000 - $1,999
☐ $2,000 - $2,999
☐ $3,000 - $3,999
☐ $4,000 - $4,999
☐ $5,000 - $6,999
☐ $7,000 - $8,999
☐ $9,000 - $12,499
☐ $12,500 or more each month

61. How many people are supported by this income (including you)? ______

62. What category best describes the total value of your assets? Do not include your home or your car. Assets include bank accounts, stocks, bonds, investment or business property, and the cash value of any life insurance.

☐ Less than $5,000
☐ $5,000 - $14,999
☐ $15,000 - $29,999
☐ $30,000 - $74,999
☐ $75,000 - $149,999
☐ $150,000 - $249,000
☐ $250,000 - 349,999
☐ $350,000 or more

63. Do you own your own home or condominium/townhouse?

☐ No ☐ Yes

64. If you needed some extra help financially, could you count on anyone to help you, that is, by paying any bills, housing costs, medical costs, or providing you with food or clothes?

☐ No ☐ Yes

65. In general, how do your finances usually work out at the end of the month? Do you find that you usually end up with… (Check only one.)

☐ Some money left over
☐ Just enough to make ends meet
☐ Not enough money to make ends meet

66. Were there any times in the past 12 months when you did not have enough money to: Check all that apply.

☐ Pay rent, mortgage, or real estate taxes
☐ Pay utility bills (heat, electricity, phone)
☐ Own or repair a car
☐ Buy needed food
☐ Fill a prescription for medicine
☐ Obtain dental care
☐ Obtain eyeglasses or hearing aids
☐ Obtain other medical care
☐ Pay for home modifications to adjust for physical needs
☐ Pay for the assistive devices or technology that I need
☐ Pay more than the minimum balance due on a credit card
☐ Pay into a retirement account
☐ Pay for the care of a parent or child with disabilities
☐ I have always had enough money

67. Did anyone help you fill out this survey? Check all that apply.

☐ No, I filled it out myself
☐ My spouse/partner
☐ My adult child
☐ My parent
☐ My paid assistant or helper
☐ Other ________________

68. Is there anything else you would like to add?

____

____

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Thank you for taking the time to participate in this survey.
Please mail your completed survey in the envelope provided, or mail to:

Martha Porter, University of Connecticut Health Center
263 Farmington Avenue, Building 7, Farmington, CT 06030- 6147

Appendix F

Provider Survey

Long-Term Care Services Survey

As a provider of long-term care services, your experiences and opinions are vital for the accurate assessment of current and future long-term care services for Connecticut's residents. Please share with us your experiences and future plans.

ALL RESPONSES ARE CONFIDENTIAL.

Please check only one box per question, unless instructed to do otherwise.

ID: _________ Date: _________

Name of organization: ____

Respondent name: ____

Respondent title: ____

Respondent phone number: ____

Respondent e-mail: ____

1. Which of the following long-term care services do you provide or make available? Check all that apply.

   - ☐ Adult Day Care (social model)
   - ☐ Adult Day Health Care (medical model)
   - ☐ Adult Foster Care
   - ☐ Assistive Devices
   - ☐ Assisted Living Services
   - ☐ Case/Care Management
   - ☐ Companion Services
   - ☐ Congregate Meals
   - ☐ Durable Medical Equipment
   - ☐ Employment Services
   - ☐ Fiscal Intermediary
   - ☐ Group Home/Supportive Living Services
   - ☐ Handyman Services
   - ☐ Health Insurance Counseling
   - ☐ Health Screenings
   - ☐ Home Delivered Meals
   - ☐ Home Health Aid Services
   - ☐ Homemaker Services
   - ☐ Hospice Services
   - ☐ Independent Living Skills Training
   - ☐ Information and Referral
   - ☐ Mental Health Counseling
   - ☐ Visiting Nursing Services
   - ☐ Other Nursing Services
   - ☐ Nutritional Services
   - ☐ Personal Care Assistant Services
   - ☐ Personal Emergency Response System
   - ☐ Physical, Speech, Respiratory, or Occupational Therapy
   - ☐ Prescription Drug Assistance
   - ☐ Recreational Services
   - ☐ Respite Care
   - ☐ Specialized Dementia Care
   - ☐ Transportation
   - ☐ Other (specify): ____________________ ________________________________

We would like to know some basic information about the clients you serve.

2. How many clients are you serving at this time?

_________ **total <u>current</u> clients**

3a. For what age ranges do you provide services at this time? Please indicate **<u>the number or the percentage</u>** of your current clients in each age range. How many of your current clients are:

Age 18 or less .... number_____ *or* ______ %

Age 19 – 59 …………. number_____ *or* ______ %

Age 60 – 64 …………. number_____ *or* ______ %

Age 65 - 84 ………… number_____ *or* ______ %

Age 85 - 99 ………… number_____ *or* ______ %

Age 100 or older ……. number_____ *or* ______ %

3b. How many, or what percentage, of your current clients are:

Male……….................number_____ *or* ______ %

Female…………………number_____ *or* ______ %

3c. What are the racial backgrounds of your current clients? How many, or what percentage, of your current clients are:

White or Caucasian …………………………………………………...number_____ *or* ______ %

Black, African-American, or Caribbean Black ……………………….. number_____ *or* ______ %

American Indian or Alaska Native …………………………………….. number_____ *or* ______ %

Asian, including Asian Indian, Chinese, Filipino,
Japanese, Vietnamese, or other Asian ………………………….. number_____ *or* ______ %

Native Hawaiian, Samoan and other Pacific Islander ………………. number_____ *or* ______ %

Other (describe): ____________________________ ……………… number_____ *or* ______ %

3d. How many, or what percentage, of your current clients are of Spanish, Latino, or Hispanic origin?

Clients of Spanish, Latino, or Hispanic origin …………………………number_____ *or* ______ %

4. How many, or what percentage, of your clients use the following methods of payment at this time? *If a client uses two or more forms of payment, please include them on all applicable lines.*

Medicaid ………………………………………………………….. number ____ *or* ____ %

Medicare …………………………………………………………..number ____ *or* ____ %

Private health insurance (includes Medigap) …………………… number ____ *or* ____ %

Private long-term care insurance ………………………………….number ____ *or* ____ %

Veteran's Administration ……………………………………………number ____ *or* ____ %

Out of pocket (self-pay) …………………………………………… number ____ *or* ____ %

Other (describe): _________________________ …………….. number ____ *or* ____ %

5. How many, or what percentage, of your clients use **more than one payment source** at this time?

Clients who use more than one payment source………………number_____ *or* ______ %

6. What are the eligibility requirements for services from your organization? Please check all that apply, and briefly describe the requirement for each.

☐ Only certain diagnoses accepted (specify): ____
☐ Only certain ages accepted (specify): ____
☐ Only certain payment sources accepted (specify): __________________________________
☐ Only certain geographic areas accepted (specify): __________________________________
☐ Certain behavioral or psychiatric diagnoses not accepted (specify):____________________
☐ Must have a certain number of impairments (specify): ______________________________
☐ Must have certain functional or cognitive abilities (specify): ___________________________
☐ Other (describe): ____
☐ No eligibility requirements

7. We are interested in your organization's current **capacity** to provide services at this time. With current funding sources or levels, what is the total number of clients for whom you could provide services at this time?

_________ total number of clients could provide services for with current funding levels

8. Is there a waiting list for any of your services?

☐ No

☐ Yes → Please list the service/s which have a waiting list and the total number of people on the waiting list for each service:

____

____

____

9. In the past year, did your organization decline services to anyone, or place anyone on a waiting list, for any of the following reasons? Check all that apply.

☐ Not enough available staff
☐ No staff in particular region or town
☐ No source of payment
☐ No available beds or housing units
☐ If government waiver program, no available slots
☐ If private program, no available spaces or slots
☐ No staff available who spoke the client's language
☐ Person did not meet our eligibility requirements
☐ Other (describe): ________________________________

10. How many, or what percentage, of your current clients have a mental illness diagnosis at this time (<u>excluding</u> diagnosis of Alzheimer's disease or other dementia)?

Clients with a mental illness diagnosis ...…..………………… number_____ *or* ______ %

11. In your best estimate, how many, or what percentage, of your current clients have exhibited challenging behaviors in the past six months? This can include clients with <u>any</u> type of diagnosis.

Clients with challenging behaviors ……………..……………number_____ *or* ______ %

12. How often have you experienced the following situations in the past year? Please check <u>one</u> box for each statement.

	<u>Never</u>	**Less than once a <u>month</u>**	**Once a <u>month</u>**	**Once a <u>week</u>**	**Almost <u>every day</u>**
Employees not showing up or calling out sick at the last minute	☐	☐	☐	☐	☐
Employees having difficulties with transportation to or from work	☐	☐	☐	☐	☐
Clients complaining about employees	☐	☐	☐	☐	☐
Language differences between clients and employees	☐	☐	☐	☐	☐
Problems or issues related to cultural, ethnic or racial differences between clients and employees	☐	☐	☐	☐	☐
Issues or difficulties with employee unions	☐	☐	☐	☐	☐
Using temporary or pool employees <u>because it makes sense financially</u>	☐	☐	☐	☐	☐
Using temporary or pool employees <u>because you do not have enough staff for the day</u>	☐	☐	☐	☐	☐
Problems with transportation for your clients	☐	☐	☐	☐	☐
Difficulty finding health care services or providers for your clients	☐	☐	☐	☐	☐
Transferring a client to another provider or ending services because of challenging behaviors	☐	☐	☐	☐	☐
Transferring a client to another provider or ending services because of issues related to mental illness	☐	☐	☐	☐	☐
Any other issues with employees or clients: ______________________	☐	☐	☐	☐	☐

13. Please elaborate on any issues or concerns from Question 12.

____

____

____

14. Do you provide specialized training for your employees on how to work with clients who have challenging behaviors?

☐ No

☐ Yes → Please describe the training:

____

____

15. Please rate your employees' overall level of training and skill working with clients who have challenging behaviors by circling <u>one</u> number on the following scale:

0	1	2	3	4
not at all skilled	not very skilled	somewhat skilled	quite skilled	extremely skilled

We'd also like to ask you about your interactions with state agencies.

16. Does the State regulatory environment affect your ability to provide services to your clients?

☐ No

☐ Yes → Please describe your experiences:

____

____

17. Have you experienced any issues or difficulties working with any specific State agencies or departments in the past year?

☐ No

☐ Yes → Please describe your experiences:

____

____

Finally, we would like to ask you about the future need for long-term care in Connecticut.

18. The workforce shortage in Connecticut is expected to <u>increase</u> in the future. How do you plan to deal with this?

____

____

____

19. Connecticut is also experiencing a dramatic increase in the number of older adults, which will continue for the next 30 years. How do you plan to meet the long-term care service needs of this growing segment of the population?

____

____

____

20. What services are missing for your clients that you cannot either provide or subcontract?

____

____

____

The State legislature is looking for your input and creative ideas.

21. In your opinion, what is the greatest unmet long-term care service or need for older adults or people with disabilities in Connecticut?

____

____

____

____

22. How should the State address this unmet need?

____

____

____

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Thank you for taking the time to complete this survey.
Please mail your completed survey in the postage paid,
self-addressed envelope provided.

Or mail to: Irene Reed, University of Connecticut Health Center
263 Farmington Avenue, Building 7, Farmington, CT 06030 – 6147