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Connecticut Long-Term Care Needs Assessment

Focused Report II: Identifying the Long-Term Care Needs of People with Mental Illness

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Artwork included in this report was created by people in recovery from a mental illness.

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Identifying the Long-Term Care Needs of People with Mental Illness in Connecticut

I. Executive Summary

- Mental illness strikes all age groups, genders, nationalities, and economic backgrounds and is a serious public health issue in the United States (Keyes, 2005).
- Mental illness refers to all diagnosable medical conditions that impair a person's thinking, mood, ability to relate to others, and daily functioning (American Psychological Association, 2000; Gazzaniga & Heatherton, 2006).
- Nearly 58 million Americans are affected by mental disorders and these disorders are the primary cause of disability in the United States (National Institute of Mental Health, 2007).
- Current estimates of prevalence suggest that 26 percent, or one in every four, American adults suffer from some diagnosable form of mental illness annually with about six percent, or one in seventeen, who experience serious mental illness (Kessler, Chiu, Demler, & Walters, 2005b).
- Mental health disorders have substantial economic and social costs and also relate to chronic conditions that need long-term care (World Health Organization, 2007).
- This focused report explores the long-term care needs of people with mental illness as identified in the 2007 Connecticut Long-Term Care Needs Assessment. Compared to people with other disabilities, the proportion of people with mental health disabilities is smaller in this sample than it would be in a representative sample of people with disabilities.
- The primary method of data collection was a self-administered survey mailed directly to a sample of Connecticut residents. This method was augmented by telephone interviews, survey packets distributed to organizations, and a web-based survey.

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Summary of Key Findings

Key findings of the 2007 Connecticut Long-Term Care Needs Assessment are organized under the following sections:

- Demographics
- Health and Functioning
- Long-Term Care Plans, Service Use and Needs
- Social and Financial Support Needs

Demographics

- Nine percent of respondents (n=542) have a mental illness disability.
- People with mental illness were most likely to be in the 42-60 age category.
- There were higher rates of ethnic minorities in the disability groups than the no disability group.
- People with a mental illness disability had less education than those without.
- People with mental illness were most likely to be unemployed or working part time.

Health and Functioning

- Most people with a mental illness disability or other disability report only good or fair health.
- People with a disability other than mental illness reported a higher level of activities of daily living (ADL) impairment, but the two disability groups have almost the same impairment on instrumental activities of daily living (IADLs).
- People with mental illness disability reported most impairment in managing money and in taking medications correctly.

Long-Term Care Plans, Service Use and Needs

- The majority of respondents with mental illness are very likely or somewhat likely to continue to live at home, most likely with physical modifications or home health care services. Living in an apartment for people with a disability is also likely.
- Most people with a mental illness disability reported no plans to pay for long-term care.
- In order to remain in their current home, people with a mental illness disability reported the most need for transportation and homemaker services.
- Fifty-nine percent of people with a mental illness disability report using community long-term care services.
- More than half of respondents with mental illness reported needing more services.
- Not being able to afford services was the main reason people with a mental illness disability didn't get them.

Summary of Key Findings (continued)

Social Support Needs

- Forty-one percent of people with a mental illness disability report they could not count on anyone for social support.
- Only fifty-six percent of people with a mental health disability report they currently receive support from family and friends for help with daily tasks at least once a week.
- Twenty-one percent of respondents with a mental illness disability report not receiving any emotional support.

Financial Support Needs

- People with mental illness disabilities had significant financial difficulties.
- Forty-six percent of people with mental illness disability report not having enough money to make ends meet at the end of the month.
- Seventy-five percent of people with a mental illness disability report that over the past twelve months they experienced inadequate financial resources to meet basic needs.
- Sixty-three percent of respondents with mental illness disability reported that they could not expect financial help from anyone.

Recommendations

Needs assessment is an essential part of mental health planning. The following recommendations are offered for consideration in helping the state and mental health care providers plan for the needs of people with mental illnesses in Connecticut and are based on the results of the 2007 Connecticut Long-Term Care Needs Assessment.

1. Provide access to and financing for comprehensive community-based mental health care services

People with mental illnesses plan to and prefer to live and receive long-term support and treatment in the community rather than in institutional settings. Other studies have consistently demonstrated that community-based care for people with disabilities, including mental health disabilities, is cost-effective.

State agencies and community providers need to increase the availability and financing of community-based mental health service options to meet the multiple long-term care needs of people managing mental illness disabilities. The state should support ongoing efforts demonstrating such collaboration: for example, the Mental Health Systems Change Grant, the Money Follows the Person Rebalancing Demonstration, and Connect-Ability (Connecticut's Medicaid Infrastructure Grant).

2. Provide assistance with long-term care planning for people with mental illness disabilities

More than half of respondents with mental illness disability acknowledge that they will need long-term care; however, like people in other groups, the majority have done little

planning for their future long-term care needs. Most respondents with mental illnesses plan to live at home, with the help of physical modifications as necessary, and want to avoid living in a nursing home, with an adult child, or in an apartment for seniors or people with disabilities. Very few have purchased long-term care insurance or could afford to pay anything substantial toward their future long-term care costs.

Regardless of where they live and receive long-term care in the future, most people with mental illness disabilities have no plans for paying for long-term care and will rely on Medicare and Medicaid to pay for the care they need. Mental health disabilities often require lifelong management for persons in recovery. It is critical for mental health treatment programs to include assistance with long-term care planning of symptom management as well as financing.

3. Increase access to specific long-term care services with high rates of unmet need

People with mental illness disabilities report high levels of service use particularly for care management and homemaker services. In comparison to other groups, people with mental illness disabilities report higher rates of unmet need for many services. The greatest reported unmet needs include transportation, homemaker, handyman, friendly visitor, and care management services, home delivered meals, and adult day programs. As providers and individuals in recovery from a mental illness devise their long-term care treatment plans, they should consider how individuals will access and finance these services that are needed and often lacking. Access to these specific services should be increased for people with mental illness disabilities through opportunities like the Medicaid Mental Illness HCBS waiver that is under development.

4. Provide opportunities for self-direction as well as agency-directed mental health care

Most people with mental illness disabilities expressed preference for a balanced partnership model between a provider agency and themselves in deciding on and implementing services, rather than pure self-direction or total agency direction. But large numbers also endorsed complete self-direction and complete agency-direction. Long-term care models for people with mental illnesses should provide flexibility to allow self-direction when desired, but also to provide support and direction from provider agencies. Further, these models must be adaptable to change over time as mental illness symptoms fluctuate and people gain confidence with directing their own care.

5. Address mental health needs for residents of all ages and ethnicities

Mental illness disabilities were reported by respondents in every age group, with the majority in the 42 to 60 age group. Hispanic, Black, and other non-white participants reported higher rates of mental illness than of other types of disabilities. Nineteen percent of people with a mental illness disability reported sometimes having problems communicating with providers because they spoke different languages. Effective mental health care must be culturally competent and actively work to eliminate ethnic, cultural, and linguistic barriers. Providers of long-term care to people with mental illness

disabilities should tailor their programs to acknowledge and respect these demographic and cultural differentials. Access to mental health diagnostic and treatment programs must be made available to residents of all ages and ethnicities.

6. Increase educational opportunities for people with mental illness disabilities

People with mental illness disabilities report considerably lower levels of education than people with other types of disabilities or no disabilities. Despite efforts during the 1960s and 1970s to provide supportive education opportunities for people with mental illnesses, educational gaps persist. Concrete support is essential in assisting students with admissions, enrollment, and financial aid for those planning to attend post secondary school. More comprehensive programs and services that support educational endeavors are needed to provide emotional, psychological, and administrative support and ensure success for those who want to complete and continue their education.

7. Improve and expand vocational rehabilitation for people with mental illness disabilities

Compared to other groups, more people with a mental illness disability are unemployed or working only part time. Job coaches or support staff and vocational rehabilitation services are used more by people with mental illness disability than those with another disability. People with mental illness report frequent use and unmet need for money management, job coaches, and vocational rehabilitation services. Connecticut has focused efforts to address vocational rehabilitation needs through Connect-Ability (the Medicaid Infrastructure Grant). Continued efforts are needed to assist individuals to obtain employment and live more independently through the provision of supports, such as counseling, medical and psychological services, job training, and other individualized services and supports.

8. Improve access to health care for people with mental illness disabilities

In comparison to people with other disabilities or no disabilities, people with mental illness were more likely to rate their health as only fair or poor. Studies of people with various physical health conditions routinely report worse health-related outcomes when patients also have mental illnesses. People with mental illnesses experienced nearly as many difficulties with IADLs such as managing money, taking medications correctly, getting to places out of walking distance, and doing household chores, as those with other disabilities. Connecticut should work to improve access to health care and provide support for daily functioning needs across clinical and rehabilitative programs.

9. Improve and expand transportation services

People with mental illness disabilities report that transportation is necessary in order for them to remain in their current living place and that it is one of the greatest unmet needs they experience. Transportation is important in supporting autonomy and lack of transportation can be a barrier to receiving needed services. Participants reported that it

is difficult to do errands or go to medical appointments because they lack transportation. Problems related to cost as well as availability and accessibility of public transportation need to be addressed to improve mobility for people with mental illness disabilities.

10. Increase options for affordable housing alternatives

In addition to better health care services, transportation, and home and community-based services, people with mental illness disabilities need better options for affordable housing alternatives. Through public and private partnerships, Connecticut has begun to develop successful approaches to providing alternative housing that includes services for those who need them. Continued efforts to supply a broader range of options in both housing and services will enable individuals with mental illness disabilities to live and participate in the community.

11. Increase opportunities for social support and community integration

Many more respondents with mental illness disabilities reported that they did not have anyone in their lives to provide emotional support, assistance with daily activities, or financial help than did people with other disabilities or no disabilities. People with mental illnesses expressed the need for companionship or friendly visitor services, as well as social and recreational activities. Community integration is a key part of the recovery process for many people with mental illnesses. The lack of individual support from family and friends in this population must be recognized and addressed in long-term care treatment planning through supplementing with service programs such as friendly visiting or through skill-building education in topics such as developing relationships.

In summary, in order to meet the long-term care needs of Connecticut residents with mental illness disabilities, the state should place greater emphasis on cost-effective community-based care and encourage collaboration among state agencies and consumer and advocacy organizations. Basing program and policy design on the views and experiences of consumers as described in this report is essential for improving the network of long-term care for this population.

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II. Background

Mental illness strikes all age groups, genders, nationalities, and economic backgrounds and is a serious public health issue in the United States (Keyes, 2005). Nearly 58 million Americans are affected by mental disorders and these disorders are the primary cause of disability in the United States (National Institute of Mental Health, 2007). Current estimates of prevalence suggest that 26 percent, or one in every four, American adults suffer from some diagnosable form of mental illness annually with about six percent, or one in seventeen, who experience serious mental illness; this includes disorders such as schizophrenia, bipolar disorder, major depressive disorder and other dangerously disabling psychiatric conditions (Kessler, Chiu, Demler, & Walters, 2005b). Within this population, about half of the individuals have two or more mental disorders (Kessler et al., 2005a; National Institutes of Health 2006; Satcher, 2000). In the population of individuals aged 55 years and older, nearly 20 percent experience specific mental disorders that are not part of the normal aging process (U. S. Department of Health and Human Services, 1999). The annual prevalence of mental illness in children and adolescents is not as well documented as that for adults, but estimates of prevalence suggest that 20 percent, or one in every five American children and adolescents suffer from a mental illness requiring treatment (Satcher, 2000).

Mental illness refers to all diagnosable mental disorders and health conditions involving changes in thinking, mood, or behavior that contribute to personal distress, impaired functioning, increased risk of pain, disability, or death (American Psychiatric Association, 2000; Gazzaniga & Heatherton, 2006). Mental disorders usually have complex etiologies that involve interactions among many different genetic and environmental risk factors, and gender is characteristically related to risk with males having higher rates of attention deficit disorder, autism, and substance abuse and females having higher rates of major depression, anxiety disorders, and eating disorders (Hyman, 2000). Symptoms of mental illness vary widely and are dependent on the disorder, but may include anxiety, depression, emotional dysregulation, problems with attention, loss of cognitive abilities or the presence of delusions or hallucinations (American Psychiatric Association, 2000). High risk health behaviors associated with mental illness include alcohol and other substance abuse, smoking, poor diet, and lack of exercise (Leas & McCabe, 2007). It should also be noted that individuals age 65 and over (12 percent of the U.S. population) are disproportionately at risk for death by suicide; in 2004, this age group accounted for 16 percent of all suicide deaths (Centers for Disease Control and Prevention, 2007). Of all people who commit suicide, more than 90 percent have a diagnosable mental disorder, usually a depressive or a substance abuse disorder (National Institute of Mental Health, 2007).

The United States is experiencing a mental health crisis on two fronts: in childhood and later life. Results from the National Comorbidity Survey suggest that half of all serious adult psychiatric illnesses including major depression, anxiety disorders, and substance abuse, begin by 14 years of age and 75 percent of them are present by 25 years of age (Kessler et al., 2005b). However, most mental illness in youth and young adults is unrecognized and untreated, leaving them at risk for emotional, social and academic impairments during a significant developmental period in their lives. With the exponential growth in the number and proportion of Americans older than 65 years of age, it is anticipated that those over age 65 with psychiatric disorders will quadruple from approximately 4 million in 1970 to 15 million in 2030 (Jeste et al., 1999). Estimates suggest that two-thirds of adults and one-third of children and adolescents requiring mental health services don't receive them, and it is less likely that racial and ethnic minorities needing mental health care receive the help they need (Alliance Health Reform, 2007). Although significant changes are taking place in the structure and financing of

long-term care and managed care, a general inattentiveness to older adults with mental illness exists and they are more likely to receive less adequate and appropriate mental health care than younger adults with mental illness (Bartels, Levine, & Shea, 1999; Bartels et al., 2005). Core deficits identified by the Older Adult Subcommittee of the President's New Freedom Commission on Mental Health still exist and draw attention to major gaps in poor quality of services and a provider workforce that lacks adequate geriatric assessment and treatment capability (Bartels et al., 2005).

While mental illness has traditionally been viewed as somewhat separate from the rest of the health care delivery system and is largely unfamiliar to general health care because it includes housing, employment, income support, and social services (Satcher, 2000), its costs have been underestimated and it has a significant impact on society and the long-term health care system (National Institute of Mental Health, 2007). National statistics show that mental illness comprises 15 percent of the burden of disease in established market economies and exceeds the combined disease burden caused by all cancers (National Institute of Mental Health, 2007). Not only do mental health disorders result in elevated economic and social costs, they also affect and are impacted by chronic conditions that need long-term care, such as cancer, cardiovascular diseases, diabetes, and HIV/AIDS (World Health Organization, 2007). The facts make a strong case that mental illness and mental health are not areas that can afford to be neglected.

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III. Purpose

This focused report explores the long-term care needs of people with mental illness as identified in the 2007 Connecticut Long-Term Care Needs Assessment and focuses on interrelationships between mental health and 4 areas: 1) demographics, 2) health and functioning, 3) long-term care plans, service use and needs, and 4) social and financial support.

Research questions addressing these areas are:

1. How do the demographics of people with mental illness in Connecticut differ from people who reported other disability or no disability?

2. How do the health and functioning of people with mental illness in Connecticut vary from people who reported other disability or no disability?

3. What long-term care plans, service use and needs do people with mental illness in Connecticut have compared to people reporting other disability or no disability?

4. How do the social and financial support needs of people with mental illness in Connecticut differ from people reporting other disability or no disability?

IV. Methodology

Data for this report are from the 2007 Connecticut Long-Term Care Needs Assessment. For complete details about the methodology see the Connecticut Long-Term Care Needs Assessment Part 1: Survey Results at http://www.uconn-aging.uchc.edu/res_edu/assessment.html. The main method of data collection was a self-administered, written survey mailed directly to a sample of Connecticut residents. This was augmented by telephone interviews, survey packets distributed to numerous organizations, and a web-based survey. In order to provide greater opportunities 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

Development of the survey instrument was informed by a comprehensive review of the long-term care and disability scientific and policy literature, a review of surveys used by other states, and input from the Long-Term Care Advisory Council. Using information from these sources, questions were developed which would enable Connecticut to assess residents' needs for long-term care services.

- A twelve-page survey booklet included 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. The instrument included both quantitative and qualitative questions and provided space for respondents to more fully express their experiences and perspectives.

- In addition to the general survey, a second twelve-page survey was designed for people with disabilities. Additional questions and responses were developed to further explore issues pertinent to this population including assistive technology, transportation, and accessibility. In order to make space for these additional questions in this survey, the caregiving section was reduced to one question. Major topical areas were identical to the general survey (Appendix A).

Research sample

Three 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 total target sample was 15,500.

- Older adults born in 1945 or earlier (n=5,250)
- Baby boomers born between 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 between 1946 and 1964, were randomly chosen from both sources. Communities with larger proportions of African American and Latino residents were oversampled.

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 who were not actively receiving services were also sampled from the DMR waiting list (DMR Wait). In addition, surveys were 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. Due to the small number of participants in the ABI, PCA, and KatieB waivers, all people in those programs were mailed surveys.
From these sources, a total of 5,000 people with disabilities were selected to participate in the mailed survey. In addition, Department of Mental Health and Addiction (DMHAS) providers encouraged clients to complete a survey. Individuals with mental health disabilities participating in other Department of Social Services programs were also randomly chosen to receive a mailed survey.

Survey response

A total of 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.

A total of 4,039 surveys were received from the randomized mailing. Older adults returned 1,607 surveys. People with disabilities returned 1,278 surveys, and baby boomers returned

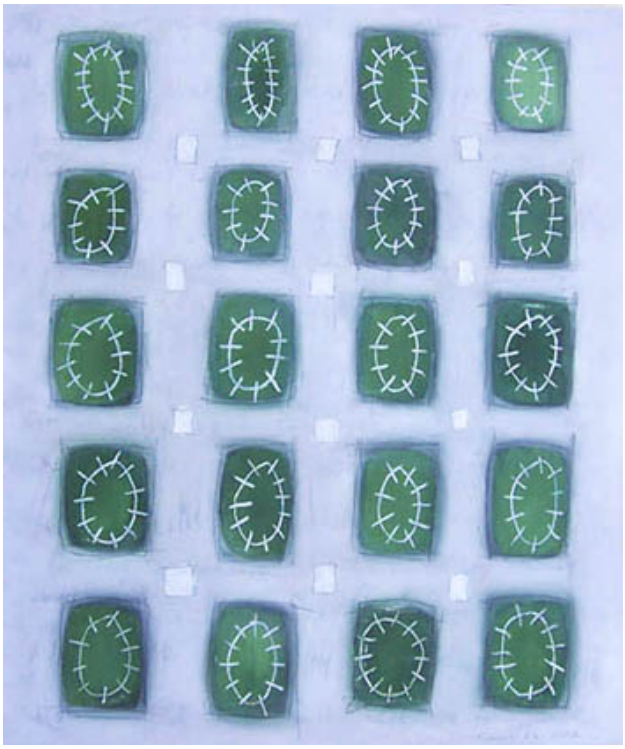
1,154 surveys. Adjusting for wrong addresses, deceased, non-English/Spanish speaking, or other reasons for ineligibility results in an overall response rate of 29% for all three groups combined. When examined individually, the response rates for each group vary from 24% for baby boomers to 28% for people with disabilities, and 34% for older adults.

For this study, of the 6,268 respondents, 5,809 provided information on whether they had a specific disability or not. A subset of respondents reporting mental illness disability (n=542) were compared to people with other disabilities (n=1,706), and people who reported no disability (n=3,561). Of the 542 who reported having a mental illness, 80 percent (n=434) answered the disability survey, 15 percent (n=83) answered the general survey, and 5 percent (n=25) answered the web survey. A disability was defined as a physical or mental impairment that substantially limits one or more major life activities, such as walking, self-care, thinking, or working. A "mental illness disability" was defined as mental illness or other psychiatric disability such as schizophrenia or bipolar disorder. In this study, people with mental illness disability were all those who specified having a mental illness. Those in the "other disability" group included: 1) Physical disability or chronic illness disability that makes it difficult for a person to walk, move, or get around, 2) Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment, 3) Deafness or other severe hearing impairment, and 4) Blindness or legal blindness. If a respondent reported having both a mental illness disability and another type of disability, he/she was included in the mental disability group. People who did not endorse any disability category comprised the third group. This sample is not representative of all people with disabilities. Compared to people with other disabilities, the proportion of people with mental health disabilities is smaller in this sample than it would be in a representative sample of people with disabilities.

V. Analysis

Descriptive statistical methods using SPSS 15.0 were used to analyze and summarize data. Bivariate analyses were also used to identify patterns, note trends, and draw conclusions. Data were analyzed question by question, with a series of basic tests computed: frequency, average, and percentage. A comparison of the response distribution both within the mental illness disability group and among the three groups (mental illness disability, other disability, and no disability) was also performed. Differences between groups were analyzed using chi-square tests. While it is unusual, all differences shown are statistically significant at the $p<.05$ level unless specifically noted.

Qualitative or open-ended questions were entered verbatim into Microsoft Access for systematic analysis, and content were analyzed using standard qualitative analysis techniques (McCraken, 1988). Data from each question were 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. Similar statements were explored and compared to refine each theme and ensure a greater understanding of each. Percentage of response for qualitative items was calculated by dividing the number of times any particular theme was mentioned by the total number of responses.



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VI. Results

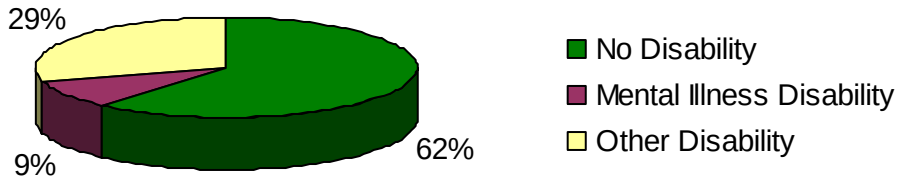
Demographics

Demographics are useful as part of any scientific study to better understand a population and can help draw out economic and policy implications, both explaining the past and looking toward the future. In this study, demographic characteristics include: disability type, age, gender, marital status, ethnicity, education, and employment.

Disability Type

The total sample consisted of 6,268 respondents. Of all those answering the disability type question, 9 percent (n=542) reported having a mental illness disability. This compares to 29 percent (n=1,706) who reported a physical, intellectual/cognitive, or sensory disability, but no mental illness, and 62 percent (n=3,561) who reported no disability (Figure 1).

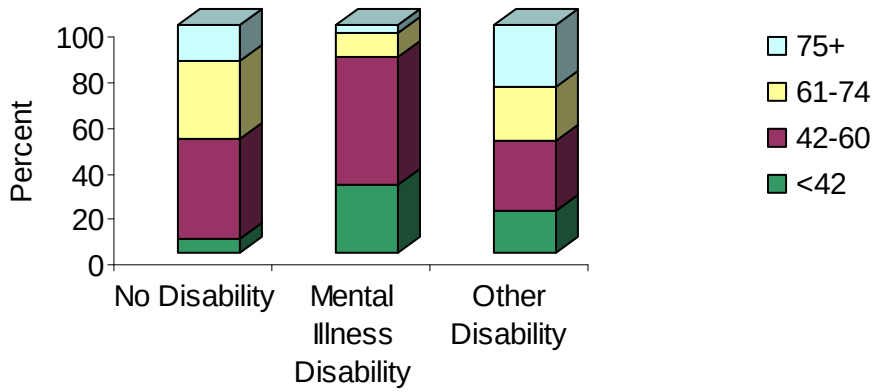
Figure 1. Disability Type



Age

Of the 5,647 respondents who reported their age, people with mental illness were most likely to be in the 42-60 age category (n=289) followed by the less than 42 age category (n=153). In comparison, those reporting no disability were most likely to be in the 42-60 (n=1,506) or 61-74 (n=1,146) age categories while people with another disability were more evenly distributed across the four age groups (Figure 2).

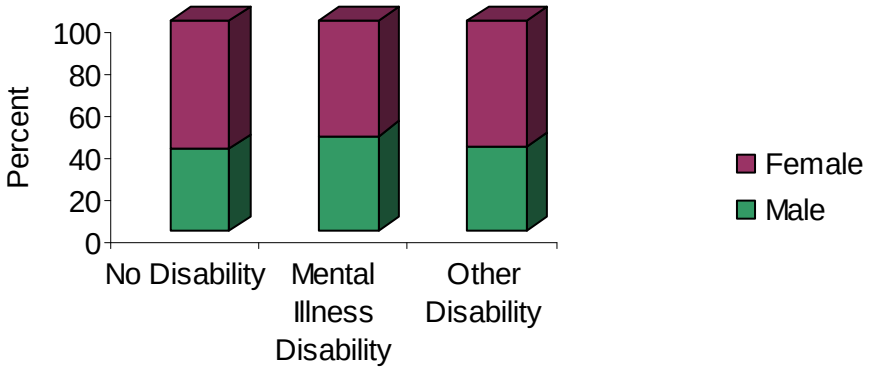
Figure 2. Age Categories



Gender

There were no significant differences between the number of females and males that participated in the survey (Figure 3).

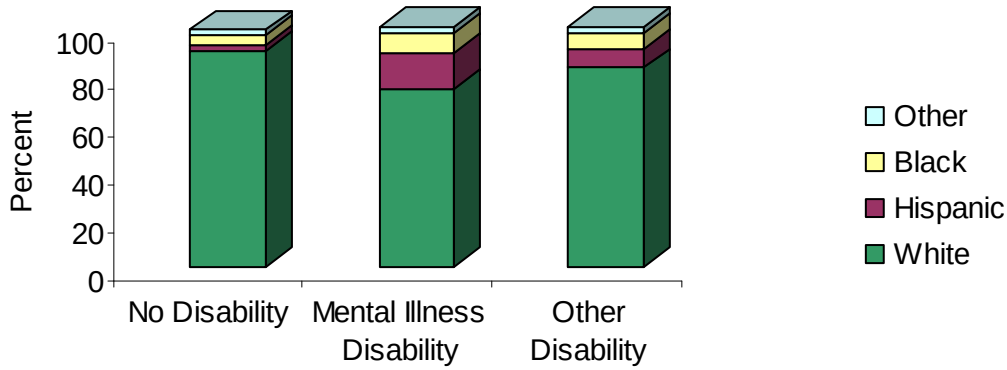
Figure 3. Gender



Ethnicity

There were higher rates of ethnic minorities in the disability groups than the no disability group. Fifteen percent (n=77) of people in the mental illness disability group were Hispanic. Eight percent (n=136) of people in the other disability group were Hispanic, and only 4 percent (n=152) of the no disability group were Hispanic. In comparison, 9 percent (n=45) of people in the mental illness disability group were Black as were 7 percent (n=122) in the other disability group and only 4 percent who reported no disability (Figure 4).

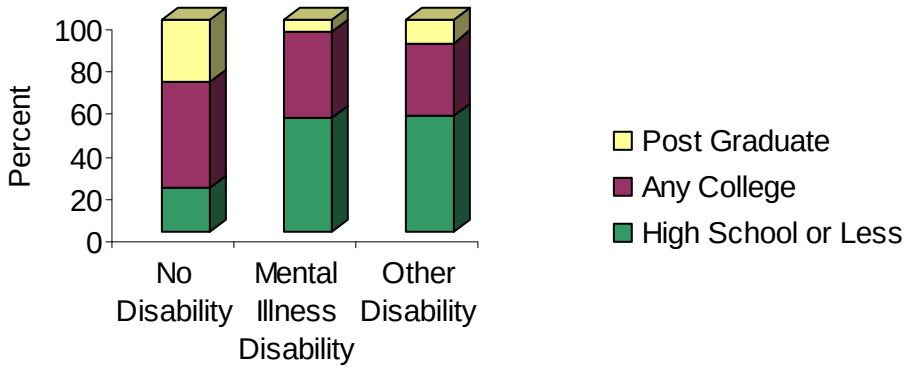
Figure 4. Ethnicity



Education

Considerably more people with a mental illness disability (54%, n=273) and people in the other disability group (55%, n=907) have a high school education or less compared to 21 percent (n=729) of those with no disability. Six percent of people with mental illness (n=30) have post graduate education. This compares to 11 percent of people with another disability (n=184) and 29 percent of people with no disability (n=990) (Figure 5).

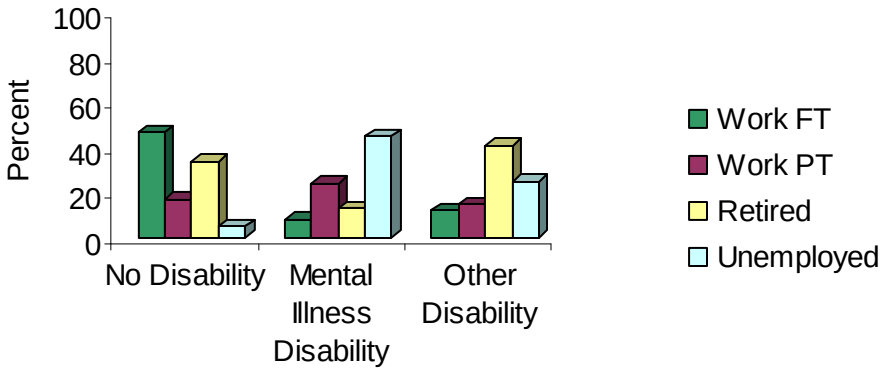
Figure 5. Education



Employment

People with mental illness were most likely to be unemployed (45%, n=241) or working part time (24%, n=129). This compares to people with another disability who were most likely to be retired (34%, n=724) or unemployed (25%, n=447) and those with no disability who were most likely to be working full time (47%, n=1,675) or to have retired (34%, n=1,213) (Figure 6).

Figure 6. Employment

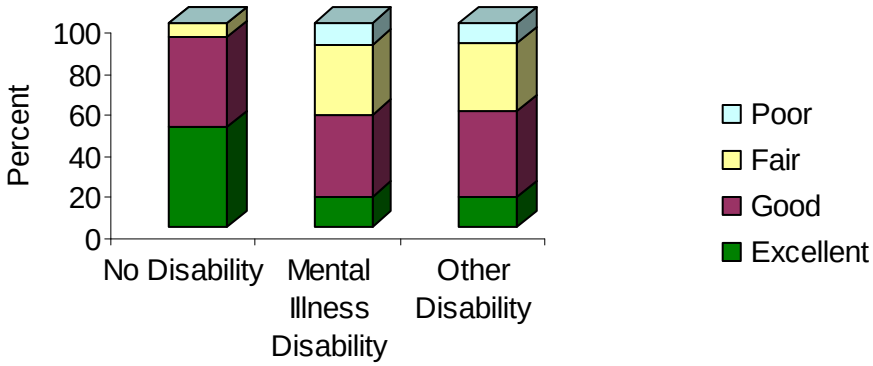


Health and Functioning

In ensuring long-term care, health and functioning must be taken into account. Health and functioning including self-reported health, mental health, and being able to perform daily living skills that enable a person to live adequately in the community are reported below.

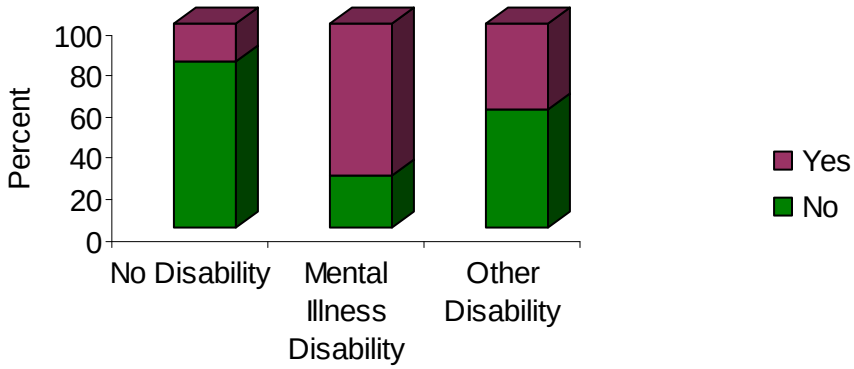
As would be expected, most people without disabilities report their current health to be either excellent or good, while most of those with mental illness disability or other disability report good or fair health. Compared to the other two groups, more people with mental illness disability reported fair (34%, n=182) or poor (11%, n=57) health (Figure 7).

Figure 7. Overall Self-Reported Health



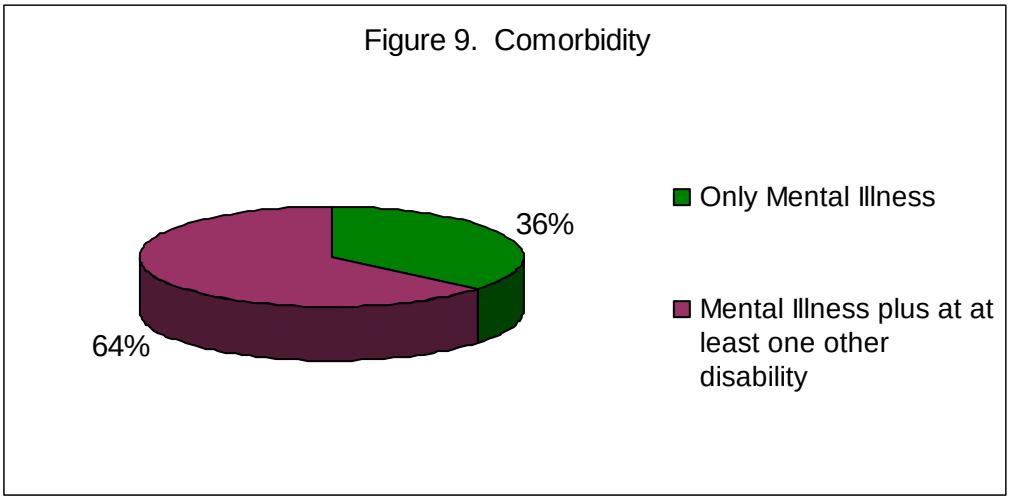
A substantially larger percent of people with mental illness disability (74%, n=389) report symptoms of depression such as feeling down, depressed or hopeless or having little interest in doing things, compared to those in the other two groups (Figure 8).

Figure 8. Depression



Comorbidity is common among people experiencing mental illness disability, and individuals with co-occurring disorders are more likely to experience a chronic course and to utilize services than are those with either type of disorder alone. Thirty-six percent (n=189) of people with mental illness disability reported mental illness only, while 64 percent (n=333) reported mental illness and at least one other disability (Figure 9).

Figure 9. Comorbidity



Of the 333 people with mental illness who reported comorbid conditions, most (75%) have a physical disability or chronic illness and half have an intellectual or cognitive disability. Less than 15 percent reported deafness or severe hearing impairment and blindness or legal blindness as comorbid conditions. These categories are not mutually exclusive (Table 1).

Table I. Mental Illness Disability and Comorbid Conditions

Disability	Frequency	Percent
Physical disability or chronic illness that makes it difficult to walk, reach, or carry	**245**	**75**
Intellectual or cognitive disability, such as mental retardation, Alzheimer's disease, or other severe thinking impairment	**162**	**50**
Deafness or other severe hearing impairment	**45**	**14**
Blindness or legal blindness	**38**	**12**

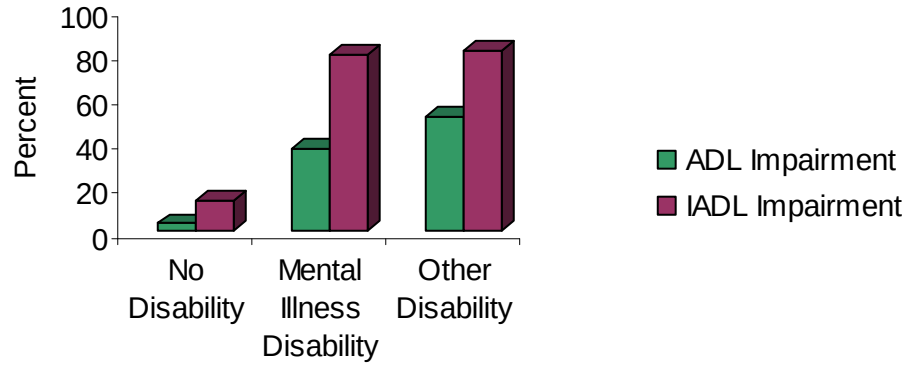
Specific comorbid mental illnesses reported by respondents included but were not limited to:

- Bipolar/schizophrenia/ADD
- Bipolar disorder/severe back problems
- Bipolar disorder/brain damage/adrenal insufficiency
- Bipolar disorder/arthritis
- Bipolar disorder/stroke
- Depression/chronic fatigue syndrome
- Depression/anxiety/high cholesterol/obesity
- Major depression/schizoaffective/herniated discs
- Polio/depression/diabetes
- PTSD/depressive disorder/anxiety disorder/degenerative disc-joint disease
- TBI/MR
- TBI/schizoaffective disorder/ADHD/bipolar/multiple sclerosis

Health professionals consider the ability to perform ADLs and IADLs in assessing a person's ability to function. This measurement is useful for assessing the elderly, people with a mental illness disability, those with chronic diseases, and others, in order to assess what type of long-term care services an individual may need. In this sample, people were considered to be impaired if they had difficulty with one or more ADL or IADL. ADLs include any daily self-care activity, such as showering, dressing, transferring from bed to chair, eating, maintaining bowel/bladder function, and getting around inside the house. IADLs include preparing meals, shopping for groceries, managing money, doing laundry, taking medications correctly, using the telephone, and getting to places out of walking distance.

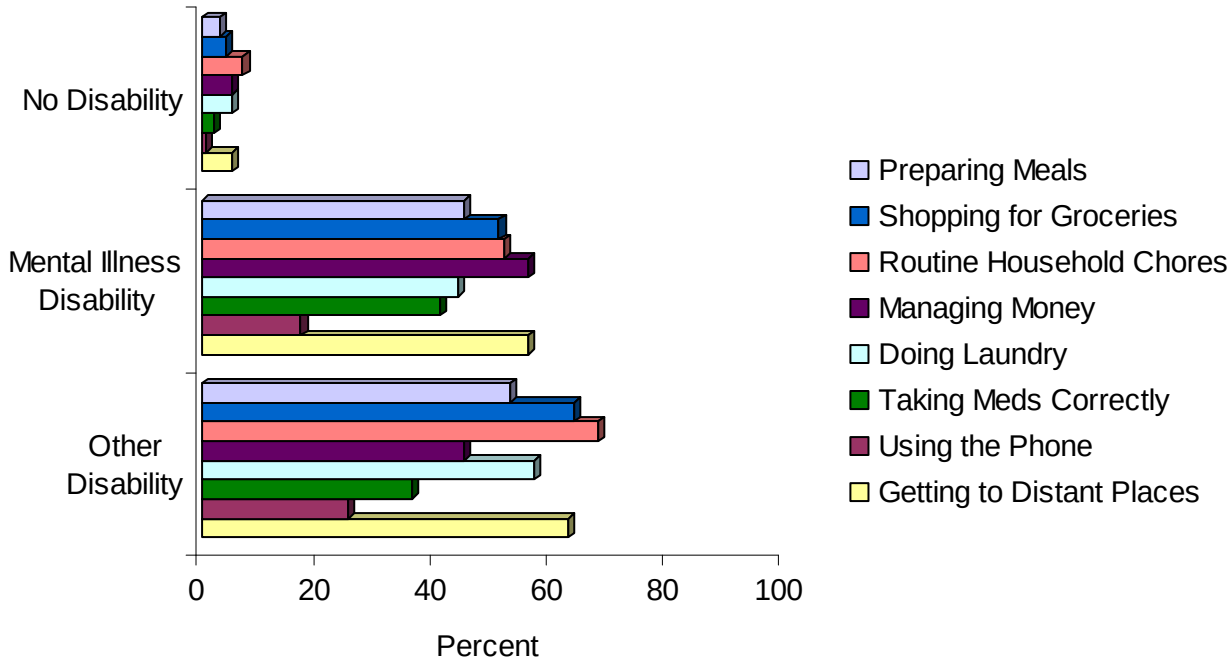
A significant relationship was found between disability groups and ADLs and IADLs. Not surprisingly, people with a disability other than a mental illness disability reported a higher level of ADL and IADL impairment, but the two disability groups have almost the same level of impairment on IADLs (Figure 10).

Figure 10. Any ADL and IADL



The IADL categories are not mutually exclusive. Some people have impairments in more than one category. Fifty-six percent of people with mental illness disability (n=295) reported impairment in managing money; this includes keeping track of bills. In comparison, 45 percent of people with another disability (n=776) and only 5 percent of people with no disability (n=158) reported difficulties managing money. People with a mental illness disability also report more impairment in taking medications correctly (46%, n=213) than people with another disability (36%, n=625) and those with no disability (2%, n=74). Although people in the other disability group consistently reported more impairment in most of the IADLs, more than half of respondents with mental illness report impairment in four out of eight IADLs (Figure 11).

Figure 11. IADL Impairments



Long-Term Care Plans, Service Use and Needs

An important part of Connecticut's long-term care needs assessment gathered pertinent information about the long-term care preferences people have, current service use, the services they expect to need, and how prepared they are to obtain these services.

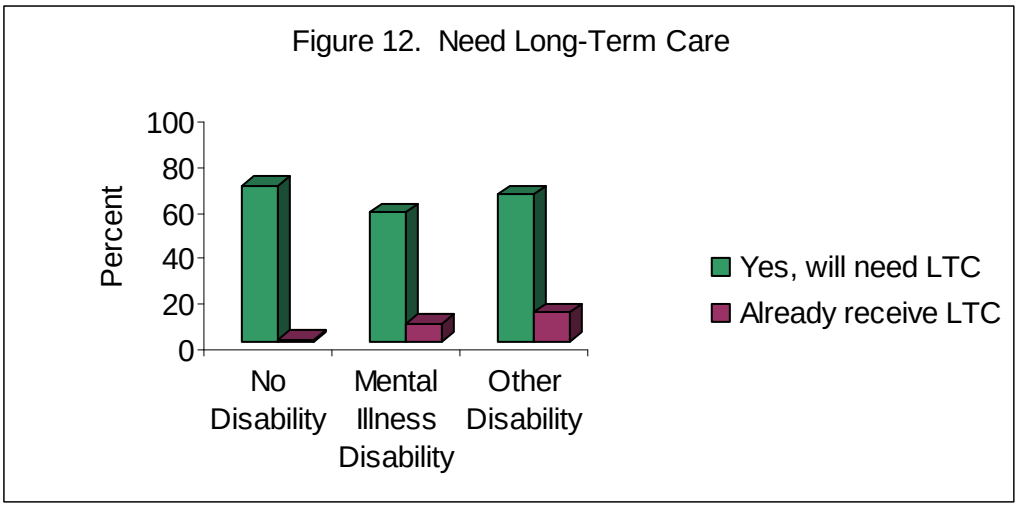
Long-term care plans

Long-term care plans include the arrangements people have for the provision of care including who will provide this care, where they will live and receive long-term care services and supports, and how it will be paid for.

A variety of paid or formal long-term care services can assist people living in the community with age-related problems, injuries, or disabilities. When asked if they ever think they will need long-term care, including care at home, assisted living, or nursing home care, people with mental illness disabilities are least likely to expect to need long-term care and have done little planning for long-term care needs in the future. Fifty-seven percent of people with a mental illness disability (n=301) think they will need long-term care, including care at home, assisted living, or nursing home care. This compares to 65 percent of people with another disability (n=1,107) and 69 percent of people with no disability (n=2,407). Eight percent of people with mental illness disability (n=43) reported already receiving long-term care services. This compares to 13

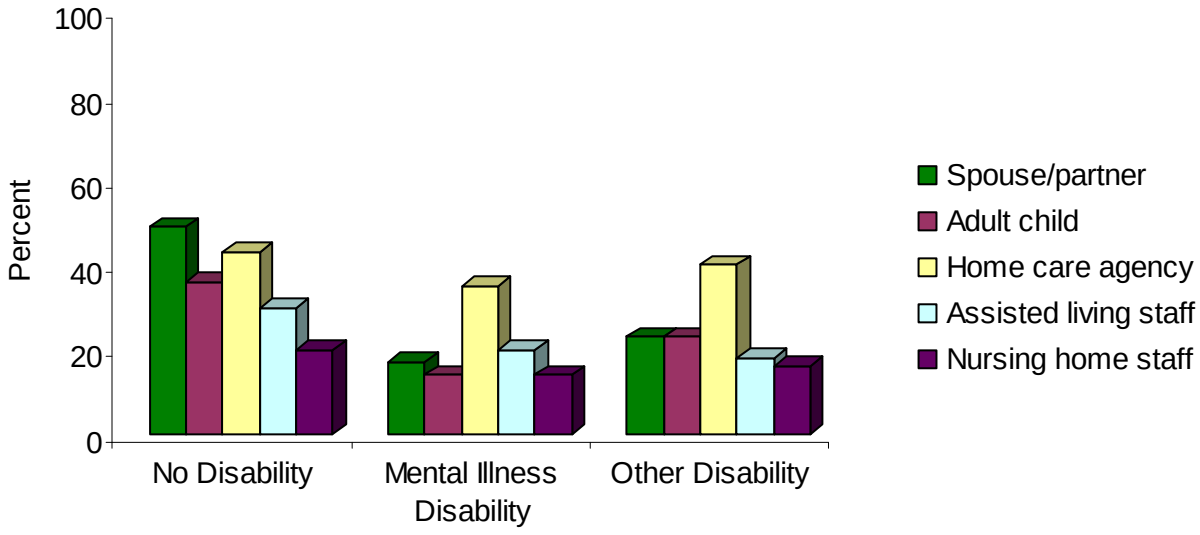
percent of people with another disability (n=223) and less than 1 percent of those with no disability (n=26) (Figure 12).

Figure 12. Need Long-Term Care



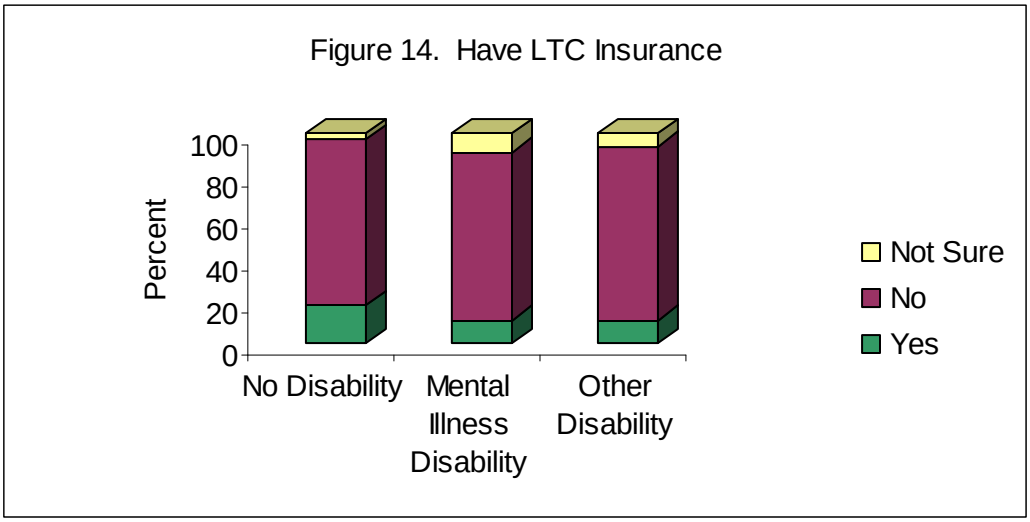
Most people with a mental illness disability think that a home care agency (35%, n=188) will provide long-term care in the future if needed. This expectation is less than those with another disability (40%, n=693) and those with no disability (43%, n=1,552) who think a home care agency will provide LTC, but it is the most common plan for this group (Figure 13).

Figure 13. Future LTC Provider



In this sample, few people, regardless of disability status, do not currently have long-term care insurance compared to those who do. A small percentage of people in each group reported not being sure whether or not they have long-term care insurance. Based on current trends and reports that people often confuse employer-sponsored health insurance or Medicaid with LTC insurance, the percentage of those who reported they have long-term care insurance may be higher than actuality (Figure 14).

Figure 14. Have LTC Insurance



Respondents were asked how likely they were to move to or live in a number of housing arrangements as they grow older (Table II). When comparing the three groups, 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: no disability - 79% and 81%, respectively; mental illness - 60% and 68% respectively; other disability - 69% and 76% respectively). The least liked options are nursing homes (not at all likely: disability - 70%, mental illness - 69%, other disability - 68%), living with an adult child (no disability - 64%, mental illness - 62%, other disability - 63%), and living in an apartment for seniors or people with disabilities with no special services (no disability - 58%, mental illness - 39%, other disability - 54%).

Over one-third of people with mental illness (38%) from the disability survey indicate it is at least somewhat likely they will live in a group home, and another six percent report they already live there. Contrarily, people with mental illness do not see either living with their parents or with another relative in his/her home as likely options (74% and 70%, respectively).

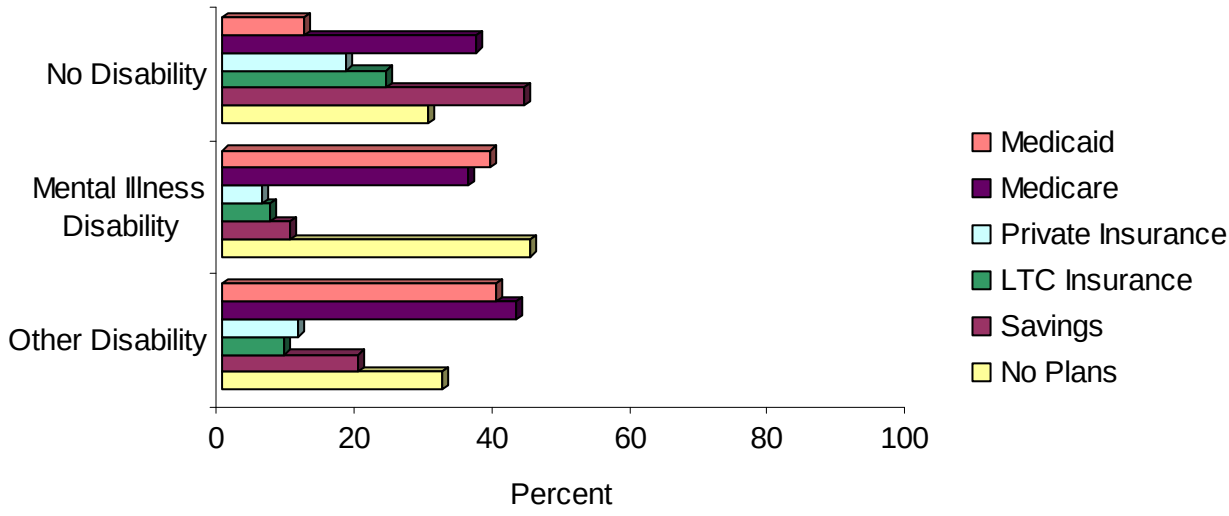
Table II. Anticipated future housing arrangements (percentages)*

		Very likely	Somewhat likely	Not at all likely	Already made this change
Remain in your own home with some modifications to adjust for physical problems	ND	29	50	19	2
	MI	29	31	37	4
	OD	34	35	21	11
Remain in your own home with home health care or homemaker services provided at home	ND	29	52	18	1
	MI	33	35	27	5
	OD	42	34	16	8
Live in a nursing home	ND	4	25	70	1
	MI	7	21	69	3
	OD	8	22	68	2
Live with my adult child in his/her home**	ND	6	28	64	3
	MI	13	23	62	3
	OD	9	25	63	3
Live in apartment for seniors or people with disabilities with no special services	ND	9	31	58	2
	MI	21	29	39	12
	OD	13	23	54	9
Live in a group home or community living arrangement***	MI	16	22	55	6
	OD	14	19	60	7
Live with my parents in their home***	MI	9	11	74	6
	OD	16	8	68	8
Live with another relative in his/her home***	MI	6	20	70	4
	OD	10	20	66	4

*Rows may not sum to 100% due to rounding
**Specific to general survey
***Specific to disability survey
ND=No Disability; MI=Mental Illness Disability; OD=Other Disability

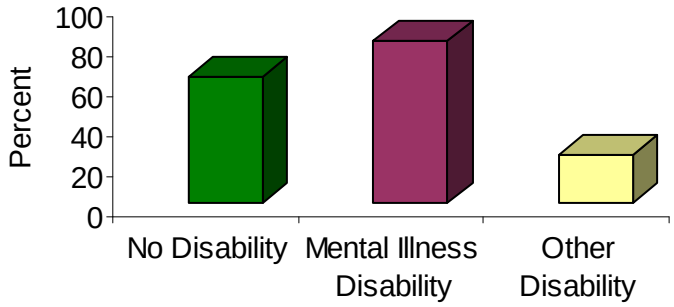
When asked how they plan to pay or how they currently pay for LTC services, most people with a mental illness disability reported that they have no plans to pay for long-term care (45%, n=243) or expect to have Medicaid (39%, n=209) or Medicare (36%, n=195) pay for services. In contrast, fewer people with another disability have no plans to pay for long-term care services (32%, n=566), but similarly expect Medicare (43%, n=763) or Medicaid (40%, n=716) to pay for services. People with no disability report they are more likely to use savings (44%, 1,561) as a primary source to pay for long-term care services followed by Medicare (37%, n=1,326), and 30 percent of people with no disability (n=1,055) report no plans to pay for long-term care services. Categories are not mutually exclusive (Figure 15).

Figure 15. Pay for LTC Services



Eighty-one percent of people with a mental illness disability (n=413) responded that if they or a family member needed long-term care for a 5-year period, they could not afford to pay anything each year for this care. This compares to 63 percent of people with another disability (n=1,013) and 24 percent of people with no disability (n=776) (Figure 16).

Figure 16. Could Pay Nothing for LTC Each Year for 5 Year Period

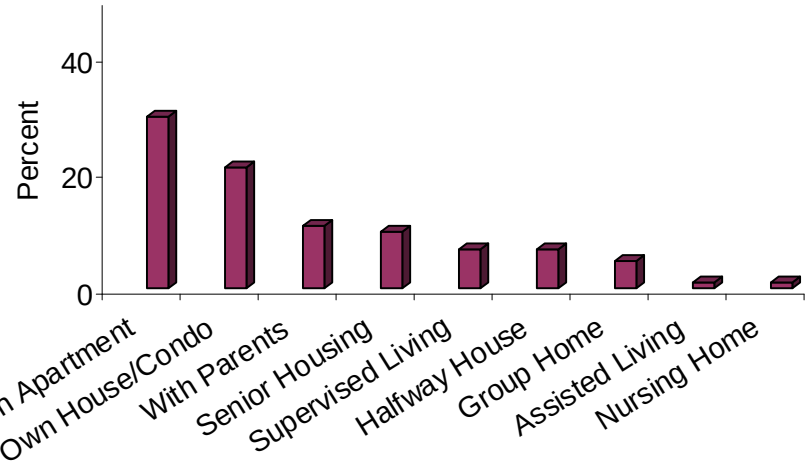


Service use and need

As the population ages, many people face a diminished ability to care for personal needs and long-term care use and the need for services is rapidly escalating. Of particular concern is the ability to address the needs of certain groups of the aging population including people with mental illness disabilities. While community-based services may represent a more desirable alternative to institutionalization, there is a lack of evidence on service use and need. Compounding the health vulnerability of this group are circumstances, such as low education and income, and poor access to affordable housing, medical services and other services and supports, that often make it difficult to meet their needs.

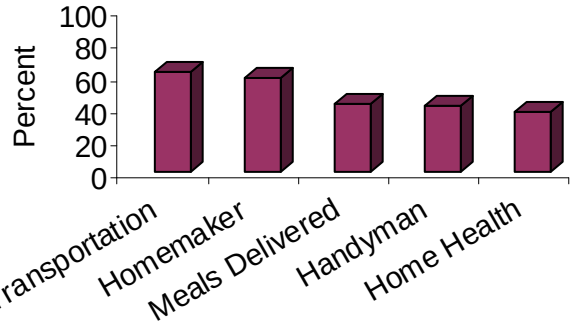
In the mental illness disability literature, a key question that has been unexplored is, "Where do people with mental illness live and where do they want to live?" (Carling, 1990). In this sample, most people with mental illness disability reported living in their own apartment (30%, n=161) or in their own house or condominium (21%, n=111). Another 11 percent (n=61) reported living with their parents in their parents' home and 10 percent (n=56) reported living in senior housing. Other reported living arrangements included: halfway houses, group homes, assisted living, and nursing homes (Figure 17).

Figure 17. Current Living Arrangements:
People with Mental Illness Disabilities



In order to remain in their current living place, people with mental illness disability reported the most need for: transportation services (62%, n=335), homemaker services (58%, n=314), meals delivered (42%, n=225), handyman services (41%, n=224), and home health services (37%, n=200) (Figure 18).

Figure 18. Services Most Needed to Remain
in Present Residence:
People with Mental Illness Disabilities*

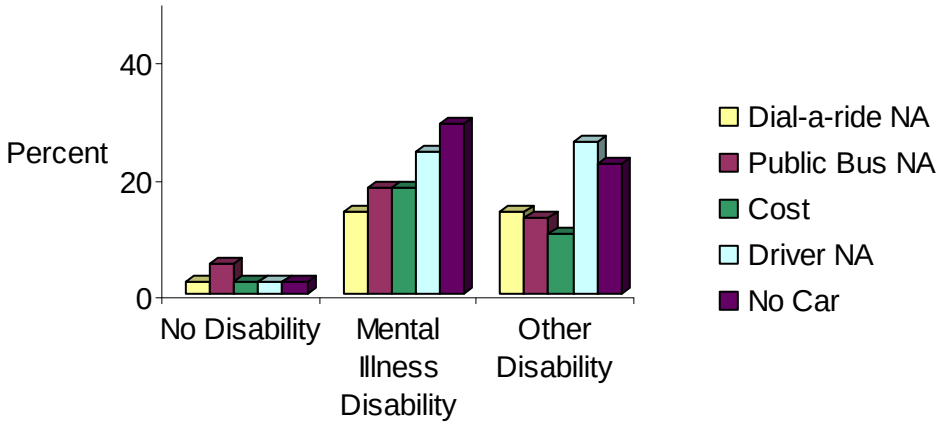


*Categories are not mutually exclusive

Transportation is one important long-term care community support that helps people maintain their independence and can also be a barrier to needed services. People with a mental illness disability were more likely to not drive or have a car available to them (29%, n=159) than people with another disability (22%, n=390) or no disability (3%, n=104). Cost and the unavailability or

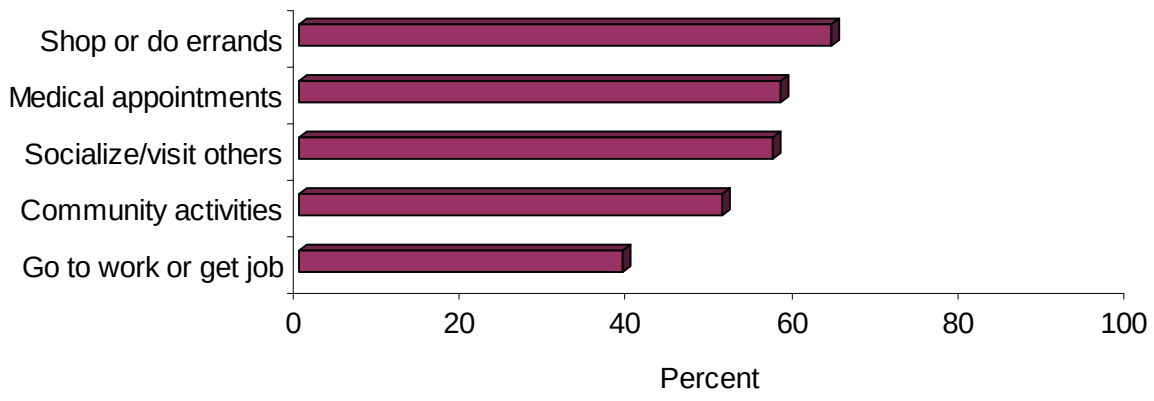
dependability of public buses, dial-a-ride, and van/bus services were also reported as significant barriers to transportation for people with a mental illness disability and those with other disabilities (Figure 19).

Figure 19. Transportation



People with mental illness disabilities reported that problems with transportation make it most difficult for them to shop or do errands (64%, n=171) and go to medical appointments (58%, n=156). In addition, transportation problems make it difficult for them to socialize or visit family and friends (57%, n=153), take part in community activities (51%, n=137), and go to work or get a job (39%, n=105) (Figure 20).

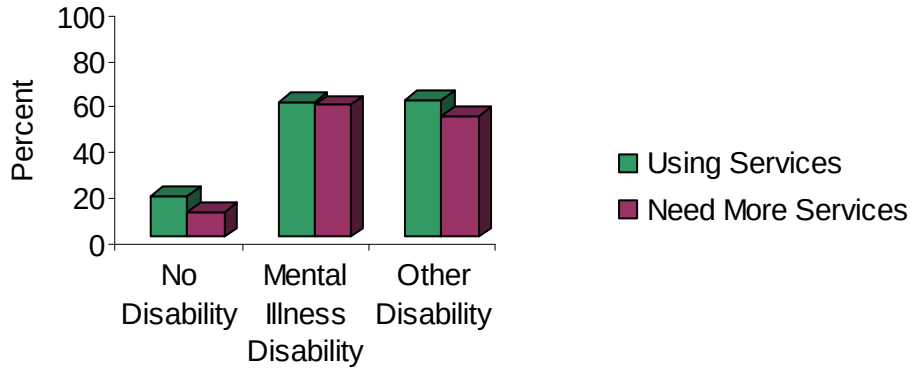
Figure 20. Difficulties Associated with Transportation Problems: People with Mental Illness Disabilities



Long-term care services can be used when people need ongoing assistance because of disabilities or chronic illness. In this sample, there is a significant difference between disability type in both service use and service need. Fifty-nine percent of people with a mental illness

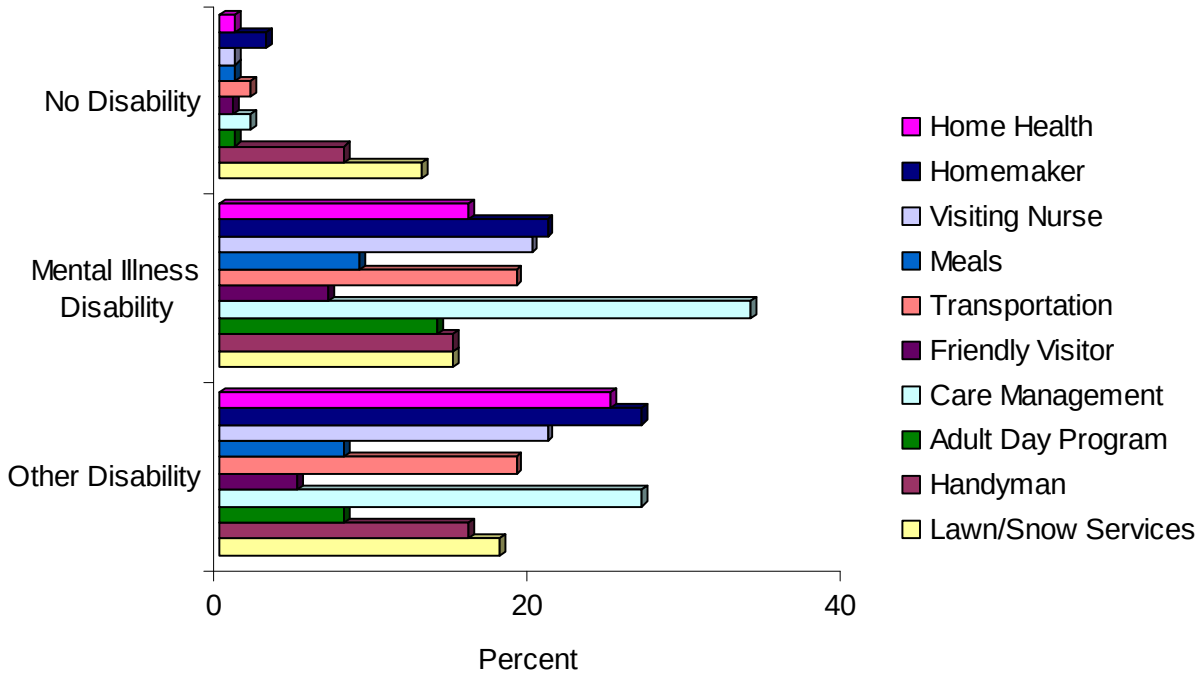
disability (n= 317) report using services. This compares to 60 percent of people with other disabilities (n=1,054) and 18 percent of people with no disability (n=623) who report using services. More than half of people with mental illness in this sample reported needing more services (58%; n=310). In comparison, 53 percent of people with another disability (n=931) and 11 percent of people with no disability (n=396) report needing more services (Figure 21).

Figure 21. Community LTC Services



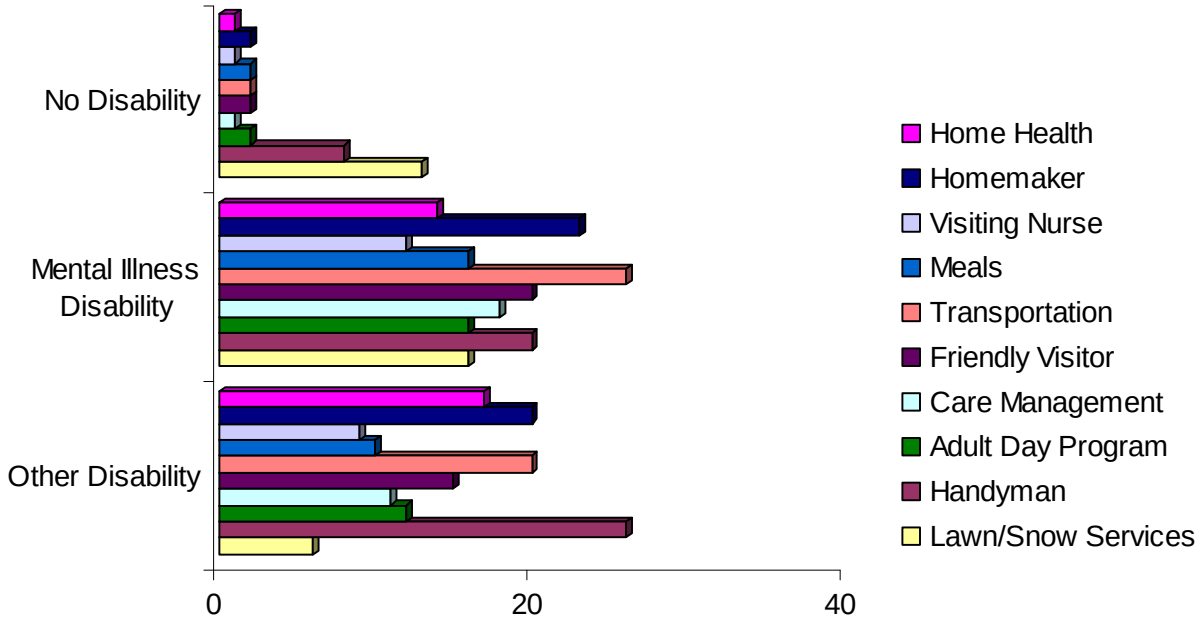
People with disabilities have high rates of service use in many LTC service areas. The highest service use reported by people with mental illness disability is care management (34%, n=169). This compares to 27 percent of people with another disability (n=445) and only 2 percent of those with no disability (n=57). The second highest service use reported by people with mental illness disability is homemaker services from an agency (for laundry, shopping, cleaning) (21%, n=109). This compares to 27 percent of people with other disability (n=446) and 3 percent of people with no disability (n=88). People with mental illness disability and those with another disability both use transportation services (19%, n=98 and 19%, n=307, respectively) (Figure 22).

Figure 22. Community LTC Service Use



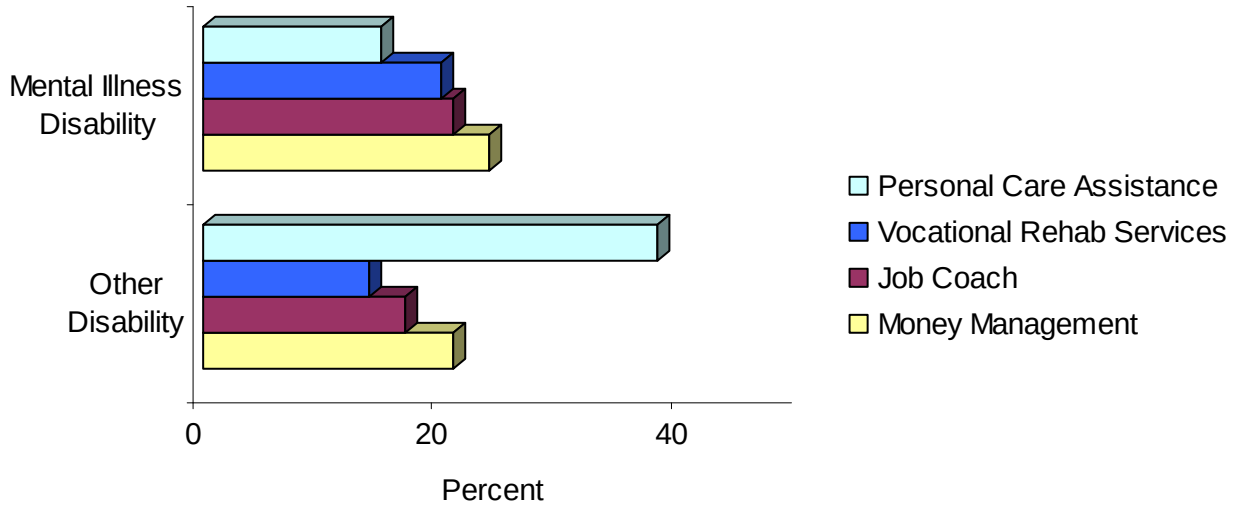
People with disabilities report high rates of unmet need in many LTC services, but people with a mental illness disability report higher rates of unmet need across services. The greatest need reported by people with mental illness is transportation (26%, n=133). This compares to 20 percent (n=325) of people with another disability. The second greatest need reported by people with mental illness disabilities is for homemaker services from an agency (23%, n=117). This compares to 20% (n=326) of people with another disability. Other unmet needs reported by people with mental illness disabilities include handyman services (20%, n=102), friendly visitor services (20%, n=99), and care management services (18%, n=91), home delivered meals (16%, n=81), adult day program (16%, n=81), and lawn or snow services (16%, n=78) (Figure 23).

Figure 23. Community LTC Service Need



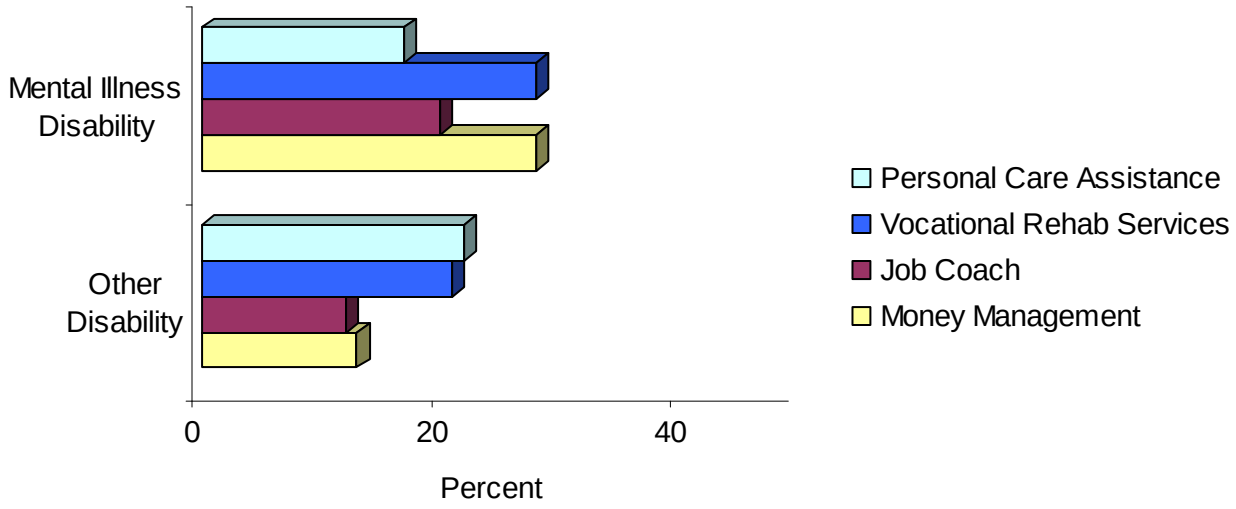
Four additional community long-term care services were included in the disability survey only. The highest service use reported by people with a mental illness disability is money management (24%, n=97). This compares to 21 percent (n=184) of people with another disability. Job coach or support staff and vocational rehabilitation services are also used more by people with mental illness disabilities (21%, n=84 and 20%, n=81). As might be expected, people with another disability report greater use of personal care assistance services than people with a mental illness disability (38%, n=319 and 15%, n=61 respectively) (Figure 24).

Figure 24. Disability Specific Community LTC Service Use



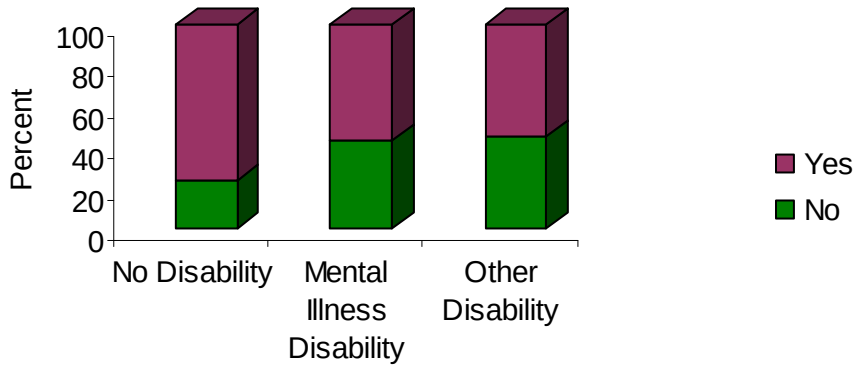
Of the four additional community long-term care services included in the disability survey only, the greatest reported need reported for with mental illness was for money management (28%, n=114). This compares to 13 percent of people with another disability (n=108). This was followed by need for vocational rehabilitation and job coach or support staff services (28%, n=111 and 20%, n=81 respectively). As with service use, service need for personal care assistance was greater among people with another disability than those reporting mental illness disability (22%, n=186 and 17%, n=70 respectively) (Figure 25).

Figure 25. Disability Specific Community LTC Service Need



When asked if they were able to get all the LTC services they needed, 43 (n=158) percent of people with mental illness disability responded they could not. This compares to 45 percent (n=492) of people with another disability and 24 percent (n=135) of people with no disability (Figure 26).

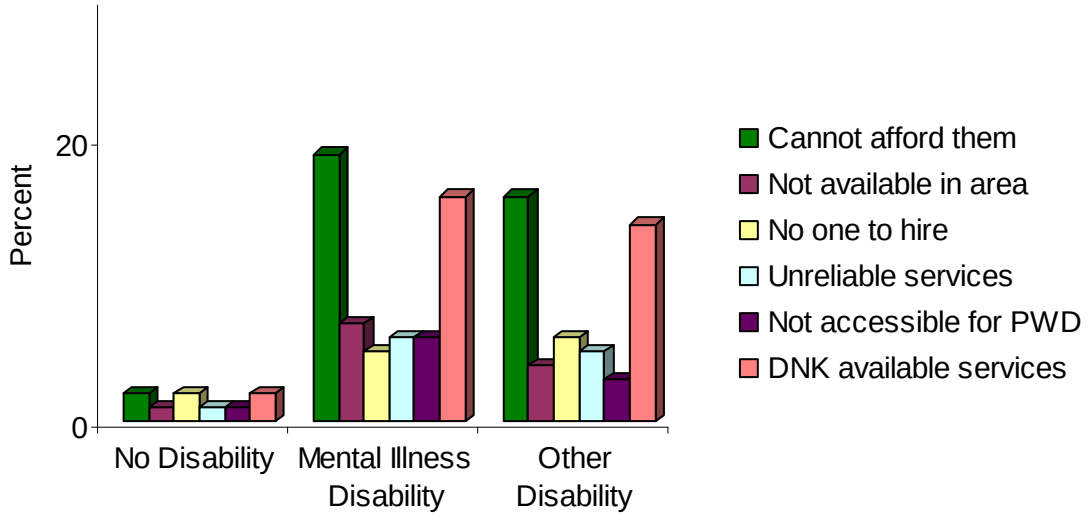
Figure 26. Able to Get Needed LTC Services



People with a mental illness disability (19%, n=105) reported that not being able to afford services was the main reason they didn't get them. This compares to 16 percent (n=281) of people with another disability and 2 percent (n=81) of people with no disability. Not knowing what services or help are available was another important reason people with mental illness

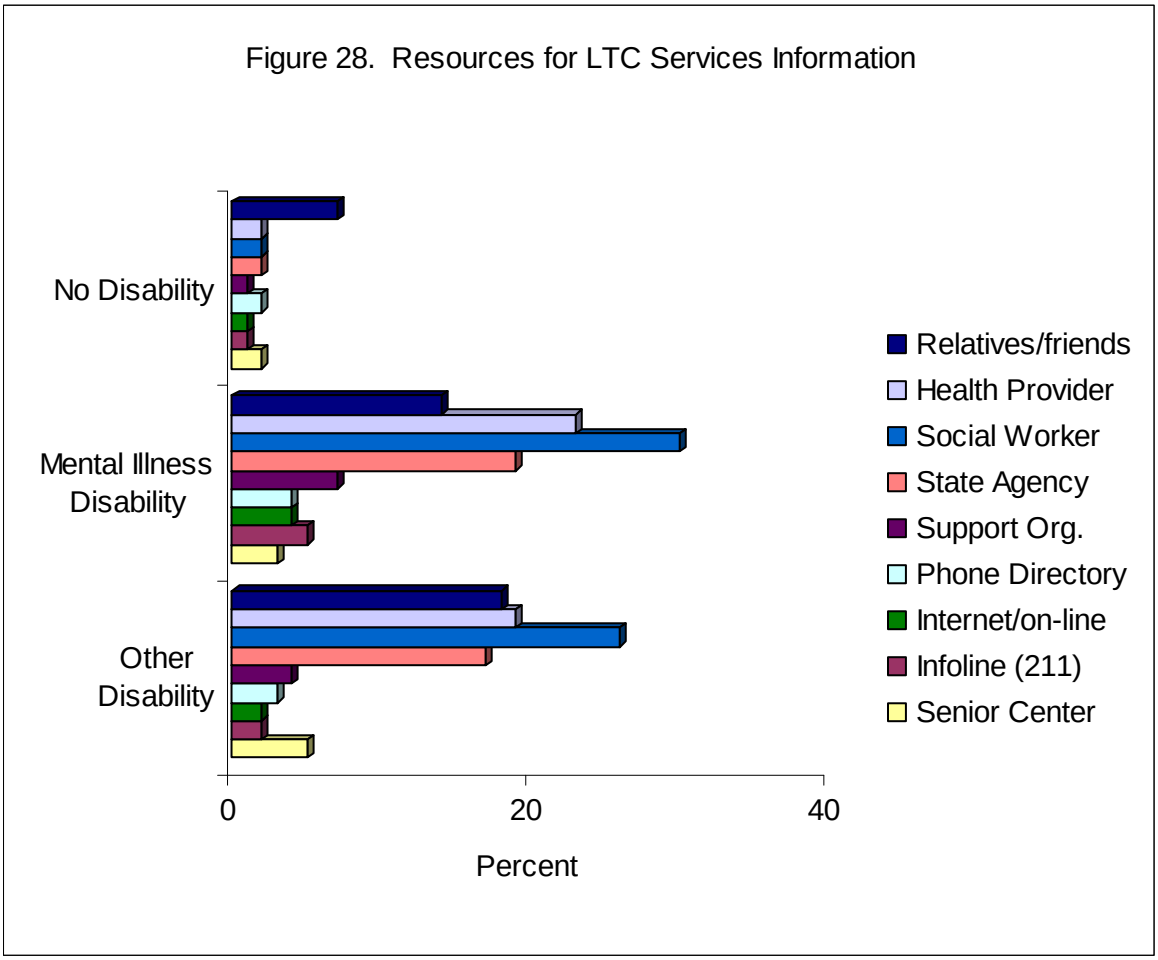
disabilities and those with another disability did not get the services they needed (16%, n=88 and 14%, n=254 respectively) (Figure 27).

Figure 27. Reasons for not Getting Services



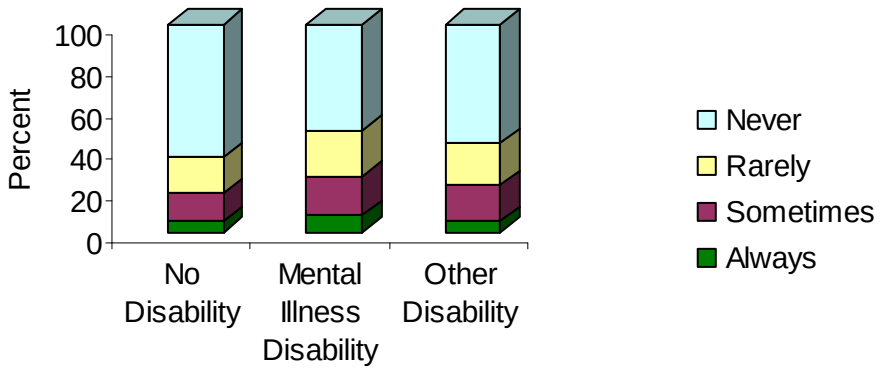
Most people with mental illness disabilities found out about the LTC services they use through social workers, health care providers, or a state agency (30%, n=164; 23%, n=123; 19%, n=104 respectively). Social workers, health care providers, and relatives/friends were the most common LTC service resources for people with another disability (26%, n=465; 19%, n=309; 17%, n=302 respectively), and relatives/friends were the best resource for people with no disability (7%, n=227) (Figure 28).

Figure 28. Resources for LTC Services Information



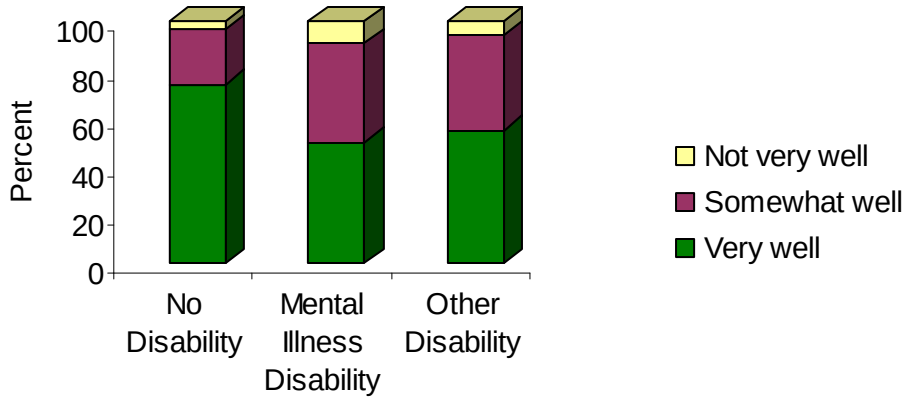
Sometimes people have problems communicating with LTC providers because they speak a different language or are from a different culture. While most respondents in this sample report never having these problems, people with a mental illness disability are slightly more likely to always, sometimes, or rarely (8%, n=30; 19%, n=66; 22%, n=77 respectively) have communication problems with LTC providers than those with another disability or those with no disability (Figure 29).

Figure 29. Communication Problems with LTC Service Providers



When asked how well the LTC services they receive meet their needs, half of people with mental illness disabilities (n=143) reported "very well." More people with a mental illness disability than those with another disability or no disability reported that their needs are met only "somewhat well" or "not very well" (Figure 30).

Figure 30. Overall Satisfaction with LTC Services Received



There are different ways for people to arrange and manage their paid services. Managing paid services can include finding someone, training them, deciding on a work schedule, and paying them. Alternatively, an agency can provide these management services. Respondents were given three approaches from which to choose the one they like best.

First approach

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.

Second approach

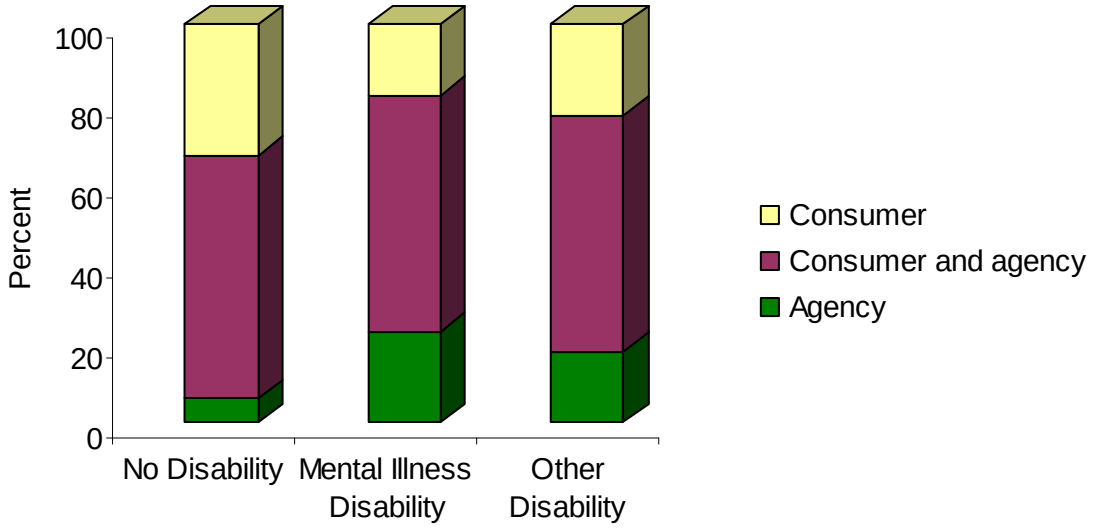
Together with the agency or provider of your choice, you decide the services and schedule for the services you want. You and the agency work together to find and arrange these services. The agency processes the paychecks and handles any tax forms or financial paperwork.

Third approach

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.

More than half of respondents across groups clearly favor the second approach in which the consumer and the agency work together to decide the services and schedule for services that are preferred. Compared to people with another disability (18%, n=257) and those with no disability (6%, n=172), more respondents with a mental illness disability (23%, n=99) prefer the first approach in which the agency or provider decides on the services and schedule (Figure 31).

Figure 31. Care Management Approaches



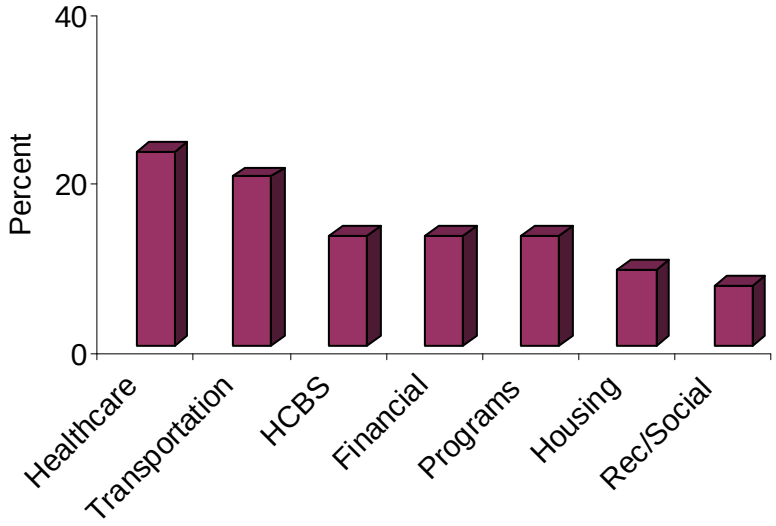
Additional Services Wanted for People with Mental Illness Disability

People 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 223 people with a mental illness disability responded to this question. The responses were compared and contrasted and then grouped under eight distinct themes which arose from this analysis:

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

Health care services and transportation are the most important services wanted by people with mental illness disabilities. 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 are also services that are important to people with a mental illness disability. Separate response rates for each theme are displayed in Figure 32. Each theme is then discussed in detail, with supporting quotes provided.

Figure 32. Additional Services: People with Mental Illness Disabilities



Health Care Services

Health care services are essential in preventing, treating and managing illness, in maintaining mental health and physical well-being, in offering services by the medical, nursing, and allied health professions, and enabling people to make lifestyle changes that contribute to making the population healthier.

Almost 25 percent (23%) of responses indicate that health care services are very important and should be better provided to people with mental illness disabilities. For many respondents, providing improved health care includes access to more affordable comprehensive health insurance that includes supplemental coverage and coverage for those who are considered high-risk.

Some form of low cost health insurance or supplemental coverage to Medicare.

AFFORDABLE long-term care insurance for individuals who are high-risk.

Some respondents mention that more comprehensive health care should include coverage for people with conditions that might disqualify them. Others indicate that the spend down policy is burdensome and should be eliminated. In addition, a number of respondents suggest the need

for better pharmacy plans that include prescription discounts and help with paying for the high cost of prescriptions.

Long-term care insurance for people with some conditions (breast cancer, depression, etc) that might disqualify them.

Get rid of the spend down policy so that you can utilize your medical coverage to your advantage.

Lower costing medical and pharmaceutical service.

Many respondents indicate a need for improved psychiatric services including more telephone crisis support, counseling, and better access to outpatient programs for people with a mental illness disability.

More telephone support (crisis lines) for those who are depressed. There are too few services for the depressed at every age group.

More counseling substance abuse treatment program (outpatient).

Respondents suggest that health care services should include dental insurance and improved dental services as well as affordable, high-quality audiology and vision care including evaluations, diagnostic testing and coverage for eyeglasses and hearing aids.

Dental care/assistance, services for health impairment, hearing aids.

Dental coverage would be nice.

Some respondents indicate that a broader range of services should be provided and include greater access to and coverage of rehabilitative services including chiropractic and naturopathic services that emphasize a holistic approach to health and healing.

> ***Homeopathy-alternative medicine-naturopathic.***
>
> ***Massage for pain and stress, acupuncture for pain.***

Transportation

Transportation programs and reliable, accessible public transportation make it possible for people who do not drive and cannot use public transportation to obtain rides for necessary trips. These include medical appointments, errands, shopping, and other activities. Twenty percent of people with a mental illness disability indicated that transportation services are one of the most important services that should be provided.

Respondents indicate that more affordable and accessible public transportation services for older adults or people with disabilities should be provided. This includes more comprehensive transportation for people 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). Some respondents indicate that transportation services are especially important in rural and suburban areas where services are limited or don't exist.

> ***Better transportation is a must especially in rural areas.***
>
> ***We really need public transportation in downtown Thompsonville, Enfield. These days it costs too much to own, register, maintain and insure a vehicle.***

In addition, people with a mental illness disability indicate that transportation services are needed for older adults or people with disabilities to participate in social functions, visit with friends, go shopping, or to religious services.

> ***Transportation to and from social/ recreation/ support groups.***

Home and Community-Based Services

As an increasing number of older adults and people with disabilities age in place, community-based services are becoming more important so people can receive the care they need within their communities.

Thirteen percent of respondents with a mental illness disability indicate that a broader range of services in the community are essential so that they can remain at home. This includes affordable services that provide quality home care workers and substitutes when they are needed. Services, such as Personal Assistant services or compensation for family members who provide care to people with disabilities are also needed to help them remain in their homes for as long as possible.

> ***Long-term home care to stay out of nursing home.***
>
> ***Dependable, good help with someone to substitute when the regular people can't make it!***
>
> ***More homecare/ personal assistance services with longer hours; option of home-maker services for younger people with disabilities who don't need "hands on" assistance.***

In order to retain quality homecare workers, respondents suggest that these workers should receive better wages including payment for transportation time. In addition, respondents suggest that waiver services should be expanded to include more people and higher incomes.

> ***You can't pay minimum wage and get responsible caregivers. Pay transportation time so I do not need to sacrifice service time for their transportation.***
>
> ***Expansion of personal care asst. waivers program for more people and higher incomes. Include companionship as activity of daily living.***

Volunteering has the potential to rebuild communities and enhances social support networks. Some respondents indicate that it would be helpful to use volunteer services to provide friendly visits and much-needed companionship.

> ***Volunteer services to check on them, make periodic visits, discuss circumstances as they change. Some stay secluded and are afraid for some reason about change and opportunities to help themselves.***
>
> ***I really think volunteers paying friendly visits would be great. As far as I know this service is not provided in my area.***

Financial Assistance

Another thirteen percent of responses from people with a mental illness disability indicate that financial assistance is needed for older adults and people with disabilities. This includes financial assistance for the rising costs of basic life expenses, such as utilities, as well as property taxes.

> ***Heating and electric bills assistance.***
>
> ***Property tax relief.***

Some respondents indicate that financial assistance is needed for basic necessities, such as food and medication. Others indicate that financial support for home modifications, such as low-interest loans, would be beneficial so older adults and people with disabilities can continue to live in their homes within the community.

> ***More money for food stamps.***
>
> ***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 help with money management would be useful and should be available to older adults and people with disabilities. This includes legal assistance with previous debts and financial management classes to help avoid future debt.

> ***Legal help with past debt money management.***
>
> ***Budgeting classes - I have more than 10K in credit card debt.***

Programs and Services

Thirteen percent of responses suggest that better provider programs and services are needed for older adults or people with disabilities. Respondents indicate that social services should be expanded to inform people about available services and to assist them in getting the support they need.

> ***Have someone to tell me about any discounts the town offers their seniors, such as tax breaks on their housing.***
>
> ***An older person and/or people with disabilities Hot Line to seek out advice and direction.***
>
> ***I believe you should let us try it by ourselves but if we need someone's help they'll be there to help.***

Respondents mention that a centralized information network that links services for people would make it easier to know what services are available and how to access them. In addition, respondents suggest that bilingual services would be helpful to older adults and people with disabilities.

> ***There should be a centralized system to let people know which services are available.***
>
> ***More personnel to aid w/ services i.e. transportation who are bilingual.***

Some respondents indicate that respite services are needed to support caregivers and should be provided to those who care for older adults or people with disabilities. In addition, people with mental illness disabilities report that they are disappointed with the quality of services offered by the state and the way in which they are often treated.

Long overnight weekend respite stays at a facility.

Better social services department that won't treat a person like a number, faster paper work for people with disabilities.

Housing

Nine percent of responses indicate a need for more affordable housing and more options for housing alternatives for older adults or people with disabilities. This includes more assisted living options, senior housing apartments, and Section 8 housing within communities. Some respondents indicate they would like more subsidized housing. Other alternative suggestions for housing include group homes.

Affordable housing in local communities.

More subsidized housing.

Community group homes with all needed services.

A small number of respondents indicate a need for affordable handyman services or for volunteers to assist with painting, repairs and maintenance of grounds so that they can continue to live in the community.

Handyman Services.

Try to enlist volunteers to help seniors and the disabled to have ramps built. Help repair scooters and other things that we need done, such as tightening loose cabinet door.

Recreation and Social Activities

Seven percent of people with mental illness disabilities indicate that older adults or people with disabilities need a greater variety of affordable recreation and social activities to give them something meaningful to look forward to. This includes educational programs offered in senior centers and other activities, such as entertainment and affordable trips. In addition, some respondents indicate that socialization is an essential part of life that many who live alone or who are isolated don't experience.

PM activities in senior center. Provide additional lectures; low cost trips.

Some kind of entertainment.

More social and leisure activities to be available for people with disabilities.

Other Comments

A small percentage of responses did not fit into any of the above mentioned categories. Of these responses, some people indicate that they are satisfied with current services or don't need any services at the moment. Other respondents indicate that they are unsure about what services exist or what services should be made available for older adults or people with disabilities in Connecticut.

Services are good.

Cannot assess this as I have family support at the current time. If this were to change my needs would change drastically.

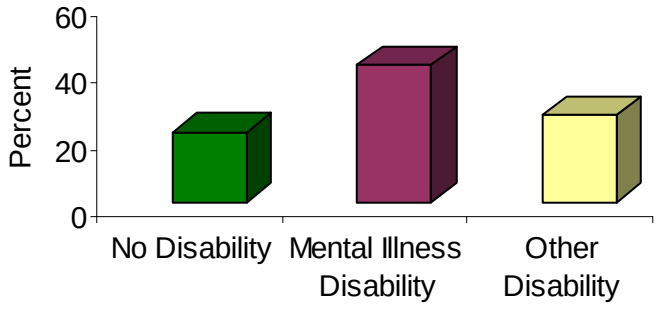
Social and Financial Support Needs

Social support needs

Social support impacts health and the quality of life. Viewed generally, older people with stronger social ties are more likely to experience better physical and mental health than older people who do not sustain close relationships with other people (Krause, 2006). Research also demonstrates an association between the size of a person's social network and cognitive functioning and indicates that network size is associated with the onset of disability among older adults (Moren-Cross & Lin, 2006).

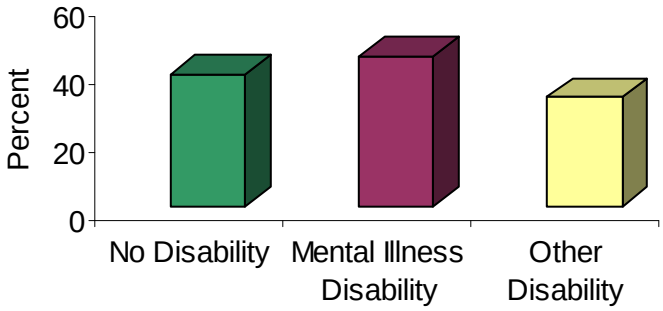
When asked about the level of social support that could be expected from family and friends if help was needed with daily tasks like grocery shopping, cooking, or providing a ride, 41 percent of people with a mental illness disability (n=211) report they could not count on anyone. This compares to 26 percent of people with another disability (n=433) and 21 percent of people with no disability (n=715) (Figure 33).

Figure 33. Could not Count on Extra Support for Daily Tasks from Family/Friends



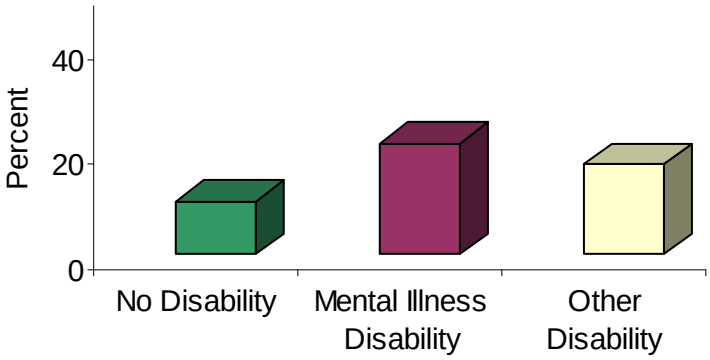
People were also asked if they currently receive support from family and friends for extra help with daily tasks at least once a week. Forty-four percent of people with mental health disabilities (n=229) report they do not currently receive such assistance. In comparison, 32 percent of people with other disabilities (n=535) and 38 percent of people with no disabilities (n=1,340) report not receiving help from family and friends at least once a week (Figure 34). People without any disabilities may not currently need help from anyone while people with a mental illness disability are less likely to have the availability of social support from family and friends.

Figure 34. Do not Currently Receive Weekly Support from Family/Friends



In this sample, 21 percent of people with a mental illness disability (n=109) do not receive any emotional support, such as someone to talk over problems with or help make a difficult decision. This compares to 17 percent of people with another disability (n=277) and 10 percent of people with no disability (n=349) (Figure 35).

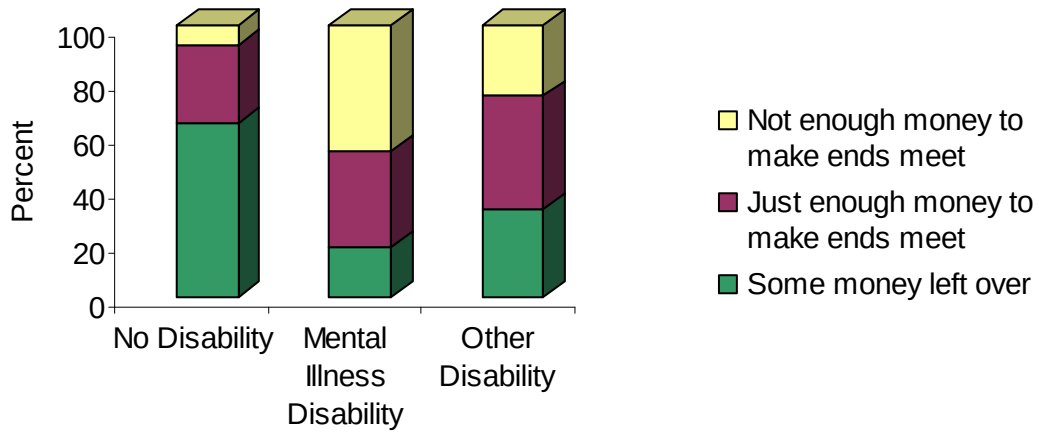
Figure 35. Lack of Emotional Support



Financial support needs

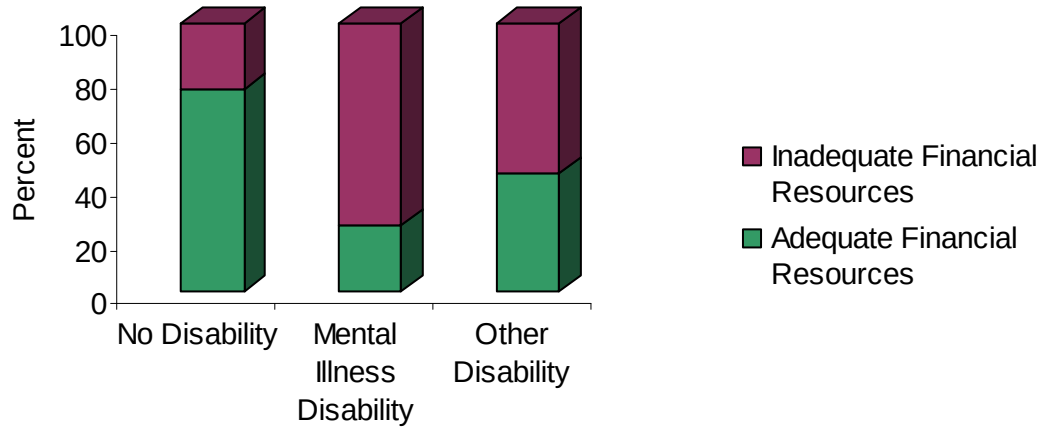
People with mental illness disabilities had the most financial difficulties. Forty-six percent in this disability group (n=232) report not having enough money to make ends meet at the end of the month. This compares to 26 percent of people with other disabilities (n=423) and 8 percent of people with no disability (n=253) (Figure 36).

Figure 36. End of the Month Finances



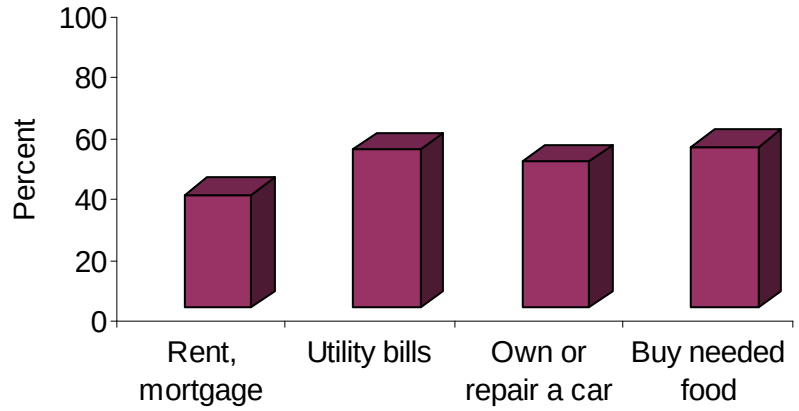
Seventy-five percent of people with a mental illness disability (n=341) report that over the past twelve months they experienced inadequate financial resources to meet basic needs. This compares to 56 percent of people with other disability (n=809) and 25 percent of people with no disability (n=755) who also reported not having adequate funds to meet their needs (Figure 37).

Figure 37. Finances Over the Past Twelve Months



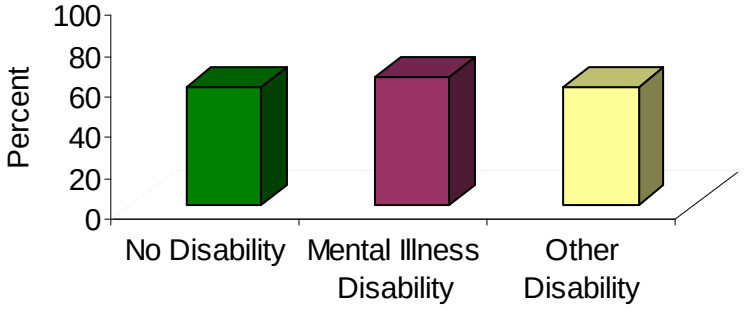
Of the 341 people (75%) with a mental illness disability who reported inadequate resources over the past twelve months, 53 percent (n=181) did not have enough financial resources to purchase needed food, 52 percent did not have enough money to pay for utility bills, 48 percent lacked enough money to pay for or repair a car (n=164), and 37 percent did not have financial resources to pay for rent or a mortgage (n= 125) (Figure 38).

Figure 38. Inadequate Financial Resources: People with Mental Illness Disabilities



In addition, when asked the question, “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?” 63 percent of people with a mental illness disability (n=318) reported that they could not expect financial help from anyone, but this was not a significant difference compared to the other two groups (Figure 39).

Figure 39. No Extra Financial Help



VII. Recommendations

Needs assessment is an essential part of mental health planning. The following recommendations are offered for consideration in helping the state and mental health care providers plan for the needs of people with mental illnesses in Connecticut and are based on the results of the 2007 Connecticut Long-Term Care Needs Assessment.

1. Provide access to and financing for comprehensive community-based mental health care services

People with mental illnesses plan to and prefer to live and receive long-term support and treatment in the community rather than in institutional settings. Other studies have consistently demonstrated that community-based care for people with disabilities, including mental health disabilities, is cost-effective.

State agencies and community providers need to increase the availability and financing of community-based mental health service options to meet the multiple long-term care needs of people managing mental illness disabilities. The state should support ongoing efforts demonstrating such collaboration: for example, the Mental Health Systems Change Grant, the Money Follows the Person Rebalancing Demonstration, and Connect-Ability (Connecticut's Medicaid Infrastructure Grant).

2. Provide assistance with long-term care planning for people with mental illness disabilities

More than half of respondents with mental illness disability acknowledge that they will need long-term care; however, like people in other groups, the majority have done little planning for their future long-term care needs. Most respondents with mental illnesses plan to live at home, with the help of physical modifications as necessary, and want to avoid living in a nursing home, with an adult child, or in an apartment for seniors or people with disabilities. Very few have purchased long-term care insurance or could afford to pay anything substantial toward their future long-term care costs.

Regardless of where they live and receive long-term care in the future, most people with mental illness disabilities have no plans for paying for long-term care and will rely on Medicare and Medicaid to pay for the care they need. Mental health disabilities often require lifelong management for persons in recovery. It is critical for mental health treatment programs to include assistance with long-term care planning of symptom management as well as financing.

3. Increase access to specific long-term care services with high rates of unmet need

People with mental illness disabilities report high levels of service use particularly for care management and homemaker services. In comparison to other groups, people with mental illness disabilities report higher rates of unmet need for many services. The greatest reported unmet needs include transportation, homemaker, handyman, friendly visitor, and care management services, home delivered meals, and adult day programs. As providers and individuals in recovery from a mental illness devise their long-term care treatment plans, they should consider how individuals will access and finance these services that are needed and

often lacking. Access to these specific services should be increased for people with mental illness disabilities through opportunities like the Medicaid Mental Illness HCBS waiver that is under development.

4. Provide opportunities for self-direction as well as agency-directed mental health care

Most people with mental illness disabilities expressed preference for a balanced partnership model between a provider agency and themselves in deciding on and implementing services, rather than pure self-direction or total agency direction. But large numbers also endorsed complete self-direction and complete agency-direction. Long-term care models for people with mental illnesses should provide flexibility to allow self-direction when desired, but also to provide support and direction from provider agencies. Further, these models must be adaptable to change over time as mental illness symptoms fluctuate and people gain confidence with directing their own care.

5. Address mental health needs for residents of all ages and ethnicities

Mental illness disabilities were reported by respondents in every age group, with the majority in the 42 to 60 age group. Hispanic, Black, and other non-white participants reported higher rates of mental illness than of other types of disabilities. Nineteen percent of people with a mental illness disability reported sometimes having problems communicating with providers because they spoke different languages. Effective mental health care must be culturally competent and actively work to eliminate ethnic, cultural, and linguistic barriers. Providers of long-term care to people with mental illness disabilities should tailor their programs to acknowledge and respect these demographic and cultural differentials. Access to mental health diagnostic and treatment programs must be made available to residents of all ages and ethnicities.

6. Increase educational opportunities for people with mental illness disabilities

People with mental illness disabilities report considerably lower levels of education than people with other types of disabilities or no disabilities. Despite efforts during the 1960s and 1970s to provide supportive education opportunities for people with mental illnesses, educational gaps persist. Concrete support is essential in assisting students with admissions, enrollment, and financial aid for those planning to attend post secondary school. More comprehensive programs and services that support educational endeavors are needed to provide emotional, psychological, and administrative support and ensure success for those who want to complete and continue their education.

7. Improve and expand vocational rehabilitation for people with mental illness disabilities

Compared to other groups, more people with a mental illness disability are unemployed or working only part time. Job coaches or support staff and vocational rehabilitation services are used more by people with mental illness disability than those with another disability. People with mental illness report frequent use and unmet need for money management, job coaches, and vocational rehabilitation services. Connecticut has focused efforts to address vocational

rehabilitation needs through Connect-Ability (the Medicaid Infrastructure Grant). Continued efforts are needed to assist individuals to obtain employment and live more independently through the provision of supports, such as counseling, medical and psychological services, job training, and other individualized services and supports.

8. Improve access to health care for people with mental illness disabilities

In comparison to people with other disabilities or no disabilities, people with mental illness were more likely to rate their health as only fair or poor. Studies of people with various physical health conditions routinely report worse health-related outcomes when patients also have mental illnesses. People with mental illnesses experienced nearly as many difficulties with IADLs such as managing money, taking medications correctly, getting to places out of walking distance, and doing household chores, as those with other disabilities. Connecticut should work to improve access to health care and provide support for daily functioning needs across clinical and rehabilitative programs.

9. Improve and expand transportation services

People with mental illness disabilities report that transportation is necessary in order for them to remain in their current living place and that it is one of the greatest unmet needs they experience. Transportation is important in supporting autonomy and lack of transportation can be a barrier to receiving needed services. Participants reported that it is difficult to do errands or go to medical appointments because they lack transportation. Problems related to cost as well as availability and accessibility of public transportation need to be addressed to improve mobility for people with mental illness disabilities.

10. Increase options for affordable housing alternatives

In addition to better health care services, transportation, and home and community-based services, people with mental illness disabilities need better options for affordable housing alternatives. Through public and private partnerships, Connecticut has begun to develop successful approaches to providing alternative housing that includes services for those who need them. Continued efforts to supply a broader range of options in both housing and services will enable individuals with mental illness disabilities to live and participate in the community.

11. Increase opportunities for social support and community integration

Many more respondents with mental illness disabilities reported that they did not have anyone in their lives to provide emotional support, assistance with daily activities, or financial help than did people with other disabilities or no disabilities. People with mental illnesses expressed the need for companionship or friendly visitor services, as well as social and recreational activities. Community integration is a key part of the recovery process for many people with mental illnesses. The lack of individual support from family and friends in this population must be recognized and addressed in long-term care treatment planning through supplementing with service programs such as friendly visiting or through skill-building education in topics such as developing relationships.

In summary, in order to meet the long-term care needs of Connecticut residents with mental illness disabilities, the state should place greater emphasis on cost-effective community-based care and encourage collaboration among state agencies and consumer and advocacy organizations. Basing program and policy design on the views and experiences of consumers as described in this report is essential for improving the network of long-term care for this population.

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IX. Appendices

Appendix A: Connecticut Resident People with Disabilities Survey

Appendix B: Artists and Artwork

Appendix A
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 ☐ 3 – 5 times
☐ 1 or 2 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 ☐ 3 – 5 times
☐ 1 or 2 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 ☐ 3 – 5 times
☐ 1 or 2 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 ☐ I did not see a doctor or other health
☐ Good provider in the past 12 months
☐ Fair
☐ Poor

18. Have you gained or lost at least 10 pounds without trying in the last 12 months?

☐ Yes, I gained at least 10 pounds ☐ No, my weight stayed the same
☐ Yes, I lost at least 10 pounds ☐ 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: In past two years:

☐ Blood pressure check ☐ Bone density test
☐ Cholesterol screening ☐ Mammogram
☐ Dental cleaning ☐ Prostate exam
☐ Flu vaccine ☐ Sigmoidoscopy or colonoscopy
☐ Pneumonia vaccine ☐ 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 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 or bladder function	☐	☐	☐	☐
Getting around inside the house	☐	☐	☐	☐
Other _____	☐	☐	☐	☐

24. 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	☐	☐

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 <u>at home or at work</u>. 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 <u>not need it</u>	**I currently <u>use it</u>**	**I do need it, but <u>do not have it</u>**
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 <u>for you</u> is your home, your workplace, or other places you want to go? Check <u>one</u> 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	☐	☐	☐	☐
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 month
☐ Once or twice a year ☐ Once a week or more
☐ Every few months

41. How many days per week, on average, do you leave home for any reason?
☐ Only for medical appointments ☐ 4-6 days per week
☐ Less than one day per week ☐ Every day
☐ 1-3 days per week

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 ☐ Financial concerns
☐ Health concerns ☐ No person to assist me
☐ Emotional concerns ☐ Accessibility issues
☐ Lack of transportation ☐ 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 ☐ Homemaker ☐ Attend school full or part time
☐ Work part time ☐ Volunteer ☐ Unemployed
☐ Retired

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 <u>not</u> 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 <u>all</u> 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 <u>all</u> that apply.

☐ I have no difficulties – the transportation I use is fine
☐ I have no car available to me <u>or</u> 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 <u>all</u> 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
☐ Separated
☐ Never married
☐ Widowed
☐ Divorced
☐ Living together as though married

56. What language do you mainly speak at home?

☐ English ☐ Polish ☐ Other _____
☐ Spanish ☐ Russian

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?

_____

_____

_____

_____

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 B
Artists and Artwork

1. Mikey Welsh is a self-taught artist based in Burlington, VT. His style is somewhat akin to Art Brut and the Cobra movement of the 1940's. Mikey's mother, who is a classically-trained painter, immersed him in art from a young age. Starting with watercolors and collage, Mikey continued to work on art until the age of 19, at which point he started his music career. At the age of 30, after suffering a nervous breakdown, he dedicated himself to painting full-time. Since 2001, Mikey has had several successful solo exhibitions, selling his work to collectors and working private commissions.

   Untitled (pink and yellow), 4 x 4 feet, acrylic on canvas, © 2004

   Retrieved February 19, 2008, from http://www.mikeywelsh.com/

2. Carol Es is a self-taught artist and native of Los Angeles. Her dichotomous, artistic nature formed early at age six, drawing cartoons underneath tables in bowling alleys. Since then, she has come to express herself completely in her art after surviving childhood sexual abuse, and disability. She uses past experience as the fuel for subject matter, transforming a broken past into a positive and hopeful present and future.

   Recycle, 20 x 16 inches, oil, acrylic & trash on canvas, 2001

   Retrieved February 19, 2008, from http://www.outsiderart.info/es.htm

3. Louis Wane

   Louis Wane was born in London's Clerkenwell district in 1860 and was diagnosed with schizophrenia in 1917 at the age of 57. In 1924, he was certified "insane" and committed to the pauper's wing of a mental hospital in Tooting, England. Years later a foundation was set up for him by his peers (including the famous H.G. Wells), which enabled Wain to spend the last years of his life in comfort in private asylums in Southwark and Napsbury, where he continued to paint and draw his cats.

   Untitled (cat)

   Retrieved February 19, 2008, from
   http://instruct1.cit.cornell.edu/courses/nbb421/student2003/epl8/

4. Louis Wane

Untitled (cat)

Retrieved February 19, 2008, from http://instruct1.cit.cornell.edu/courses/nbb421/student2003/epl8/

5. Mickey Welsh

Sunday morning, 2 x 2 feet, enamel and acrylic on fiberboard © 2004

Retrieved February 19, 2008, from http://www.mikeywelsh.com/

6. Carol Es

Intrinsic Esjp, 30 x 30 inches, oil on canvas, 1999

Retrieved February 19, 2008, from http://www.outsiderart.info/es.htm

7. Carol Es

The Germs, 24 x 21 inches, oil & graphite on canvas, 2002

Retrieved February 19, 2008, from http://www.outsiderart.info/es.htm

8. Mikey Welsh

Boy with flowers, 5 x 4 feet, acrylic, newspaper transfer and collage on canvas, © 2004

Retrieved February 19, 2008, from http://www.mikeywelsh.com

9. Mikey Welsh

Untitled (rain), 4 x 4 feet, acrylic on canvas, © 2004

Retrieved January 19, 2008, from http://www.mikeywelsh.com/

10. Mikey Welsh

Sunspots, 4 x 4 feet, acrylic on canvas, © 2004

Retrieved January 19, 2008, from http://www.mikeywelsh.com/