



University of Connecticut Health Center

June 2008

Connecticut Long-Term Care
Needs Assessment

Focused Report IV:

Experiences of People
Using Disability
Programs

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Acknowledgements

We gratefully acknowledge the assistance and support of the Connecticut Commission on Aging, Long-Term Care Planning Committee, and Long-Term Care Advisory Council. We also would like to acknowledge the valuable assistance of numerous people from Connecticut state agencies, providers, and advocacy groups who provided information and guidance in the preparation of this report. Particular thanks go to David Guttchen and Barbara Parks Wolf from the Office of Policy and Management, and Julia Evans Starr and William Eddy from the Connecticut Commission on Aging.



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I. Executive Summary

Connecticut maintains numerous programs for people of all ages with disabilities, including people with physical disabilities, mental illness, and intellectual challenges. These programs include five Medicaid home and community based services (HCBS) waivers as well as four state-funded programs. As part of Connecticut's 2007 state-wide Long-Term Care Needs Assessment (the "Needs Assessment"), state residents who participate in these programs were surveyed on a variety of topics. The overall results were compiled and reported in the 2007 Needs Assessment Report, in which the survey results for people with disabilities were compared to those for a state-wide sample of baby boomer and older adult residents (Robison et al., 2007).

While combining the survey results for all people with disabilities into one group is instructive for many purposes, it masks some significant differences. This report examines key differences by program and takes a more in-depth view of the survey results for people with disabilities. It also takes a close look at the unmet needs of survey respondents as a group and by program.

The programs compared in this report include:

- Connecticut Home Care Program for Elders ("Elder")
- Personal care assistance waiver ("PCA")
- Acquired brain injury waiver ("ABI")
- Katie Beckett waiver ("KatieB")
- Department of Developmental Services waivers combined ("DDS")
- Department of Developmental Services waiting list ("DDS wait")
- Bureau of Rehabilitation Services programs ("BRS")
- Community-based services program ("CBS")
- Department of Mental Health and Addiction Services ("DMHAS")

These programs differ substantially in their target populations, eligibility requirements, and types and levels of assistance. Survey results from the Needs Assessment provide greater insight into the differences in demographics, health status, unmet service need, and need for assistance with daily living activities among beneficiaries of each program. Some key findings from survey responses in these areas include:

Health measures

There are large numbers of people in poor health, with some notable trends in a number of self-reported health measures

- CBS, Elder and PCA participants report the worst overall health. Even the programs with the best self-reported health have a significant percentage of people who report their health as only fair or poor.

- The rate of depressive symptoms is high in most programs, as is the incidence of falls, raising concerns about health complications (e.g., fractures), and potential need for institutionalization or greater care needs.
- Lack of preventive health care in many programs is extreme, with rates of dental cleanings and wellness exams of particular concern.
- Many programs have a high rate of hospitalization and emergency room visits, despite the fact that this population receives a great deal of home-based care, often including nursing.

Employment issues

Employment is a significant issue for respondents in most programs.

- Very few respondents in any program are employed full time, and while part time work is more common, only in two programs (BRS and DDS) are more than half of respondents employed in any capacity.
- Of those not currently working, a significant number of people in many programs do want to have a job, including DMHAS, BRS, ABI, PCA and DDS wait. Of those not working who do want a job, more than half of DMHAS and BRS respondents are actively looking.

Unmet need

By any measure, the rate of unmet need reported by program participants is extremely high. As might be expected, the programs that provide the fewest services (e.g. DDS wait, CBS, and PCA) have the highest overall rate of unmet need. The unmet need identified most often across programs is transportation, which affects every aspect of daily life from health care to employment to socialization. A deeper examination of transportation issues reveals:

- More than half of respondents in most programs consider transportation a top unmet need.
- Programs with the fewest transportation needs are Elder and DDS, while CBS and ABI have the most need.
- Transportation difficulties affect all areas of life, including medical appointments, shopping and socializing and, for those most likely to be working or job seeking (BRS and DMHAS), the ability to get a job or go to work.

An examination of both current use and unmet need for a variety of other community-based services reveals some additional conclusions:

- Elder respondents experience high current use of most community services, but low unmet need, suggesting that the program is meeting a high proportion of the need as defined by program participants.
- By contrast, DDS wait and DMHAS have low current use but relatively high unmet need in many areas, particularly job-related services such as vocational rehabilitation, job coaching and money management, suggesting that these programs may be meeting a smaller percentage of the need.

- Assistive devices in general are lacking most for PCA and KatieB and least by DMHAS and BRS.

Physical accessibility is a larger problem for recreation and shopping than it is for respondents' homes, although home accessibility is still an issue for more than a third of respondents in most programs.

Quality of life

A six-measure variable was created that is designed to combine factors considered most important to quality of life for survey respondents. It examines answers to survey questions concerning transportation, socialization, ability to meet financial needs, presence of unmet long-term care service or assistive technology needs, and self-rated health. By this measure, respondents with the highest quality of life are from DDS, Elder and BRS, with CBS and PCA at the low end.

Policy and program implications

Connecticut's programs to aid people with disabilities are meeting many of the needs of their target populations. However, the forceful message from survey respondents reminds us that numerous gaps remain. Moreover, the various measures of health status as well as unmet needs for long-term care services differ substantially by program. These results reinforce the need for acting in accordance with the guiding principles initially set out in the Needs Assessment:

- Create parity among age groups, across disabilities, and among programs through allocating funds equitably among people based on their level of need rather than on their age or type of disability.
- Break down silos that exist within and among state agencies and programs.

The nine programs examined in detail in the Needs Assessment and in this report, as well as other programs designed to meet the needs of people with disabilities in Connecticut, in many cases purposely differentiate their services based on age and/or type of disability. Moreover, they create silos that are difficult to penetrate, and achieve uneven results for their clients.

Of particular concern are rates of depressive symptoms, incidence of falls, lack of preventive health care, and high rates of hospital admissions and emergency room visits, which may be risk factors for future institutionalization or death. Unmet needs in each program differ substantially, but this report identifies shortfalls in each program that should be examined. The transportation issue is common to most programs and is shared by many in the general population, as evidenced by the results of the Needs Assessment. For people with disabilities, however, the issue is more acute, and is being tackled as a major initiative of Connecticut's Medicaid Infrastructure Grant ("Connect-Ability"). These efforts should be supported. The lack of employment supports and opportunities for those who want to work is also notable. Unmet needs in many programs are standing in the way of employment goals for many. On the positive side, interest in finding employment is high in many programs. Employment efforts for people with disabilities throughout the state are also being supported by Connect-Ability.

It is important that state officials with legislative, administrative and oversight responsibilities for these programs consider the recommendation in the Needs Assessment to strive for a universal waiver with consistent requirements across ages and disabilities. At the program level, administrators and others concerned with the well-being of the population within each program can derive additional insight into the extent of missing services and their effect on quality of life by examining the detailed results contained in this report. Through concerted efforts Connecticut officials, people with disabilities, and their advocates can improve not only program administration and fiscal outcomes, but quality of life for all.



II. Introduction

Connecticut maintains numerous programs for people of all ages with disabilities, including people with physical disabilities, mental illness, and intellectual challenges. These programs include a number of Medicaid home and community based services (HCBS) waivers as well as state-funded programs. As part of Connecticut's 2007 state-wide Long-Term Care Needs Assessment (the "Needs Assessment"), state residents who participate in these programs were surveyed on a variety of topics. The overall results were compiled and reported in the 2007 Needs Assessment Report, in which the survey results for people with disabilities were compared to those for a state-wide sample of baby boomer and older adult residents. (Robison et al., 2007).

While combining the survey results for all people with disabilities into one group is instructive for many purposes, it masks some significant differences. This report examines key differences by program and takes a more in-depth view of the survey results for people with disabilities. It also takes a close look at the unmet needs of survey respondents as a group and by program. It addresses the following questions:

- How do survey results for people with disabilities differ by program?
- What is the overall rate of unmet need for people with disabilities?
- Are there geographical differences in unmet need by region of the state?
- Does the rate of current use and unmet need for particular services differ by program?
- Do quality of life indicators differ by program?
- What are the program and policy implications of the results?

The report does not specifically address differences *within* programs by individual characteristics such as gender, race, or health status. Readers who may have an interest in a deeper analysis of a particular program should contact the authors directly.

III. Background/definitions

There are nine comparison groups of people with disabilities used in this report. Five are categories of Medicaid HCBS waivers, and four are state-funded programs. These nine comparison groups are referred to as “programs” for purposes of this report.

A. Medicaid HCBS waivers in general

Federal law and regulations under Title XIX of the Social Security Act spell out the requirements that a state must meet in operating its Medicaid program. If a state meets these requirements, the federal government will pay a percentage (the Federal Medical Assistance Percentage, or FMAP) of the money the state spends for services to people who are eligible for Medicaid. The FMAP rate varies from a low of 50 percent to a high of 80 percent, depending on income levels in each state. Connecticut’s FMAP is 50 percent.

Under section 1915(c) of the Social Security Act, Medicaid law authorizes the Secretary of the U.S. Department of Health and Human Services to waive certain Medicaid statutory requirements. These waivers enable states to cover a broad array of home and community-based services for targeted populations as an alternative to institutionalization. In general, to be a waiver participant, an individual must:

- Be financially eligible based on income and assets
- Be medically qualified
- Be certified for the waiver’s institutional level of care and
- Choose to enroll in the waiver as an alternative to institutionalization

In addition, the state must demonstrate that providing waiver services to a target population is no more costly than the cost of services these individuals would receive in an institution.

B. Connecticut waiver programs¹

Connecticut has applied for and received a number of Medicaid waivers that provide HCBS for participants who meet their eligibility requirements. Eligibility requirements that are common to the waivers include:

- Individuals (and each member of a couple that is applying for waiver services) may have income of no more than 300 percent of the Supplemental Security Income (SSI) benefit amount (in 2008, \$1,911 per month);
- An individual may have assets of no more than \$1,600;

¹ A major portion of the information in this section is based on program information in McEvoy (2008).

- When one member of a couple is applying for waiver services, spousal protection rules provide that the couple may have assets equal to \$1,600 plus at least the minimum Community Spouse Protected Amount (in 2008, \$20,880);
- When both members of a couple are applying for waiver services, the couple may have assets of no more than \$3,200;
- Assets typically considered exempt for Medicaid eligibility purposes include, but are not limited to, the house in which the applicant resides, a funeral contract, life insurance of up to a certain value, and a car;
- Waiver participants who have monthly income in excess of 200 percent of the Federal Poverty Level (in 2008, \$1,702) must pay “applied income” (cost-sharing) toward the costs of their care plans;
- Applicants to waiver programs who have income or assets in excess of the eligibility requirements may in specified circumstances utilize pooled special needs trusts to gain eligibility; and
- Participants in the Medicaid for the Employed Disabled program may qualify for waiver services despite higher income and assets.

People from the five waiver programs described below were surveyed as part of the Needs Assessment.

Elder waiver (Connecticut Home Care Program for Elders, or CHCPE)

The Connecticut Home Care Program for Elders (CHCPE) consists of two major pieces: a Medicaid waiver and a state-funded program for individuals with higher income and assets than those allowed under the waiver portion of the program. For purposes of the Needs Assessment survey and the analysis contained in this report, both groups of people receiving CHCPE services are combined. Therefore, while this program is listed as a “waiver” program in this report, not all enrollees are in the waiver portion of the program, although the majority are. All references in this report to the Elder program or the CHCPE refer to the combined group.

The Medicaid waiver portion of the CHCPE, first approved in 1987, has an enrollment of over 9000 as of January 2008. There is no waiting list for the waiver. Persons eligible for the Elder waiver must be at least age 65 and must be in need of nursing facility care, evidenced by at least three “critical needs” (critical needs include some of the activities of daily living such as bathing, dressing, toileting, transferring, eating/feeding, and also some of the instrumental activities of daily living such as meal preparation and medication administration.)

The majority of clients receive services via agencies. In addition to home-based care, services can be provided to 1) residents of state-funded congregate housing; 2) residents of assisted living pilot projects; and 3) up to a statewide total of 75 residents in the private managed residential pilot program who spend down to the program limits and require assisted living services. (The 75 slots in this pilot serve both the waiver and state-funded portion of the CHCPE and there has been an extensive wait list since its inception.)

Covered services include adult day programs, care management, chore, companion, home health aide, homemaker, home-delivered meals, laundry service, mental health counseling, minor home modifications, respite, personal emergency response systems, skilled nursing visits and transportation.

The waiver can pay up to 100 percent of the monthly Medicaid nursing facility cost (in 2008, \$5,690.80). Within that cap, the program can pay no more for social services than 60 percent of the monthly Medicaid nursing facility cost. Social services include all services other than skilled nursing visits and home health aide -- the “medical services” covered by Medicaid.

In addition to the Medicaid Elder waiver, the state-funded portion of the CHCPE has an enrollment of nearly 5000 as of January 2008. There is no waiting list for the state-funded portion, although there is a wait list for a state-funded pilot that funds assisted living services in private managed residential communities. There are two levels of the state-funded portion of CHCPE. For Level 1, the person must be at risk of hospitalization or short-term nursing facility placement and must present evidence of one or two “critical needs.” Level 2 participants must be in need of short or long-term nursing facility care and present evidence of three or more “critical needs”. There are no income limits for this program. Asset limits for both Level 1 and Level 2 are \$31,320 for an individual and \$41,760 for couples.

Covered services are the same as the waiver portion of the CHCPE, but the payment amounts are smaller. Level 1 can pay no more than 25 percent of the average monthly Medicaid nursing facility cost (in 2008, \$1,423). Level 2 can pay no more than 50 percent of the average monthly Medicaid nursing facility cost (in 2008, \$2,845). Table III-1 summarizes the provisions of all levels of the CHCPE, including Level 3, which is the waiver portion of the program described above.

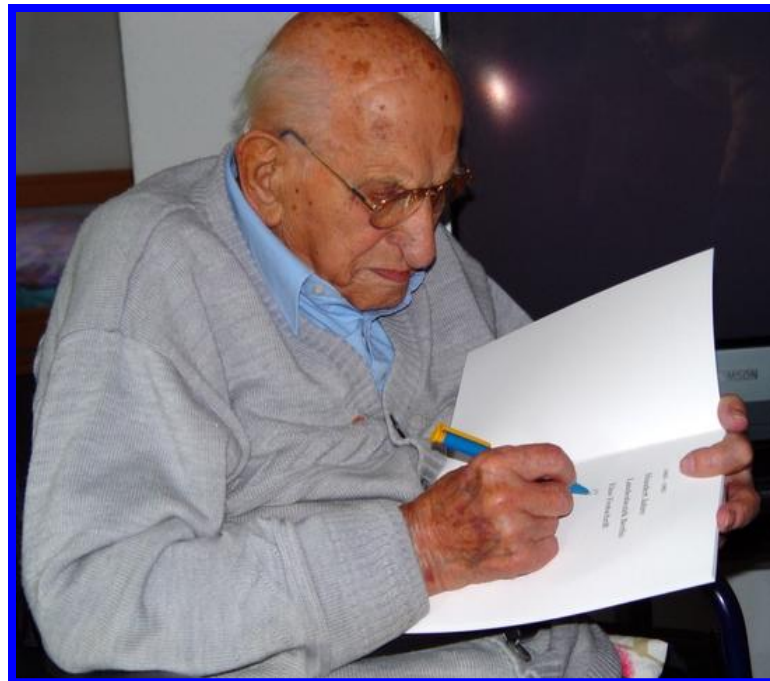


Table III-1. Connecticut Home Care Program for Elders (CHCPE)
As of January 1, 2008

<u>Service Level</u>	<u>Description</u>	<u>Functional Need</u>	<u>Financial Eligibility</u>	<u>Care Plan Limits</u>	<u>Funding Source</u>
Level 1	Limited home care for moderately frail elders	At risk of hospitalization or short term nursing home placement (1 critical need deficit)	Individual Income = no limit Assets: Individual = \$31,320 Couple = \$41,760	<25% NF Cost (\$1,423/mo)	STATE
Level 2	Intermediate home care for very frail elders with some assets above the Medicaid limits	In need of short or long term nursing home care (deficits in 3 critical need areas or ADLs)	Individual Income = no limit Assets: Individual = \$31,320 Couple = \$41,760	<50% NF cost (\$2,845/mo)	STATE
Level 3 (Waiver)	Extensive home care for very frail elders who would otherwise be in a nursing home on Medicaid	In need of long term nursing home care (deficits in 3 critical need areas or ADLs)	Individual Income = \$1,911/month Assets: Individual = \$1,600 Couple (both as clients) = \$3,200 (one as client) = \$22,480	100% NF Cost (\$5,690.80/mo) (Social Services cap = \$3,972.48)	MEDICAID (state/federal)

Personal care assistance waiver (PCA)

The PCA waiver program was first approved in 1996. It has an enrollment capacity of 748 with 703 enrolled as of January 1, 2008. More than 100 people have eligibility pending and there is a waiting list.

The waiver is open to anyone 18 years of age or older. Eligibility requires a functional status that includes chronic, severe or permanent disability resulting from limitations in at least two activities of daily living, (ADLs) including bathing, dressing, eating, transferring, and management of bowel and bladder. Persons with mental illness, mental retardation or dementia do not qualify on the basis of that diagnosis alone. The Department of Social Services will accept the Social Security determination of disability or may perform its own review of the individual's disability status.

The person receiving services must desire to and be able to self-direct his or her own care; it is the only service delivery method offered. The PCA must be 18 years or older and may not be either the spouse or conservator of the client or related in any way to the conservator.

Covered services include bathing, dressing and companion provided by the personal care assistant, as well as a personal emergency response system. The waiver pays up to a percentage of the average monthly Medicaid nursing facility cost depending on the level of ADL impairment. For example, the waiver would pay 60 percent of the cost for those with fewer than three ADL impairments; it would provide 80 percent of the cost for those with impairments in all ADL areas.

Acquired brain injury waiver (ABI)

The ABI waiver program, first approved in 1997, has an enrollment capacity of 369. As of January 1, 2008 there were 343 enrolled in the program with a waiting list of 159 individuals, pending eligibility requirements. Participants must be at least age 18, and must have an acquired brain injury and meet the “level of care” requirement of otherwise needing care in a nursing facility, chronic disease hospital or intermediate care facility (ICF). Persons with developmental and degenerative disorders do not qualify.

The only service delivery method is self-direction. Caregivers must be 18 or older and may not be the spouse, parent (if the client is younger than 21) or conservator of the client, or related to the conservator. Covered services include case management, personal care assistance, homemaker, chore services, companion, home-delivered meals, respite care, vocational supports, housing supports, home and/or vehicle modification, personal emergency response systems, transportation, supported employment, and specialized medical equipment and supplies.

The waiver pays up to 200 percent of the average monthly Medicaid nursing facility cost (in 2008, \$11,381.60) depending on the level of institutional care the individual would otherwise require.

Katie Beckett waiver (KatieB)

The Katie Beckett waiver was first approved in 1983. While the legal capacity as of January 2008 is 200, current funding only supports 180 individuals, and over 100 individuals are currently on a wait list. Although there are no age limits for this waiver, most participants are children with severe health and functional disabilities. Service delivery for this waiver is entirely agency-based. Covered services include case management and home health services. The waiver plan costs cannot exceed the average monthly Medicaid nursing facility cost (in 2008, \$5,690.80).



Department of Developmental Services waivers (DDS)

This program category combines people who are actively receiving services from one of two DDS waivers, which were first approved in 2005. Both generally offer services and supports for individuals age three and above.

- The Individual/Family Support (IFS) waiver, which is for individuals who live in their own or family homes and do not require 24-hour paid supports, has an enrollment as of January 2008 of over 3300. It typically pays no more than \$50,000 per year per care plan.
- The Comprehensive Supports waiver is for individuals who live in licensed settings, including community living arrangements, community training homes, and managed residential communities. It can also be used for individuals who live in their own or family homes and who are in need of a comprehensive level of support. It has an enrollment capacity as of January 2008 of about 6700, although actual enrollment was only 4463. This waiver typically pays far more per care plan than the IFS waiver. Waiver services can be declined if the cost will exceed 150 percent of the cost of an ICF, or approximately \$250,000.

People on the waiting list for both DDS waivers (a total of 634 people as of January 2008) are described and included as a separate state-funded program in the analysis below.

Eligibility for both waivers requires a medical diagnosis of mental retardation or Prader-Willi Syndrome. In addition, it requires a level of need that can be met by waiver services to avoid placement in a nursing home or ICF. There are several service delivery methods for the waivers, including use of agency-based services provided by qualified vendors, the “agency + choice” model offering a choice of providers, and self-directed care. The waivers also permit a blend of the aforementioned options.

Licensed residential services are available only in the Comprehensive Supports waiver. Other services common to both waivers include:

- residential and family supports (supported living, personal support, adult companion, respite, personal emergency response systems and home and vehicle modifications)
- vocational and day services (supported employment, group day activities, and individualized day activities),
- specialized and support services (behavior and nutritional consultation, specialized equipment and supplies, interpreters, transportation and family consultation and support).

Both waivers set specific dollar limits of services and supports that can be offered based on an individual's assessed level of support needs. Certain services, such as specialized equipment and physical modifications to the home, come with specific annual cost caps, and services cannot replace services already being provided by family members.

C. State-funded programs

In addition to the five Medicaid waiver programs described above, people with disabilities in Connecticut may be eligible for a number of state-funded programs. The state-funded programs under which individuals were surveyed as part of the Needs Assessment include the following four.

Department of Developmental Services waiting list (DDS wait)

DDS is in the process of implementing a five-year waiting list initiative designed to reduce the number of people waiting for services and to resolve prior litigation. As of January 1, 2008, there were 634 people on the waiting list seeking residential or support services under one of the DDS Medicaid waivers. These individuals currently live at home with their families and receive very few services. All waiting list individuals receive case management services, and some also receive state-funded day programs, respite services, family grants, and small amounts of family support. Persons on the waiting list were surveyed as a separate category in the Needs Assessment.

Bureau of Rehabilitation Services programs (BRS)

The Connecticut Bureau of Rehabilitation Services (BRS) is a division of the state Department of Social Services. It provides numerous services designed to allow people with disabilities to live and work independently. For purposes of the Needs Assessment, clients of four BRS programs were combined into one category:

- Vocational rehabilitation (VR), a program for people with physical disabilities, mental illness, and intellectual challenges (except legal blindness) that pose a substantial barrier to employment, who require services in order to prepare for, find and succeed in employment. Supports include counseling, medical and psychological services, job training, and assistive technology;
- Benefits counseling, a program that may help individuals retain benefits while working;
- Medicaid for the Employed Disabled (MED), a state-run medical assistance program that allows people with disabilities to be employed and remain eligible for medical insurance; and
- Other Medicaid recipients who are working but have lower incomes than those receiving MED.

Community-based services (CBS)

CBS is a program of the Social Work Division of the state Department of Social Services (DSS). It is designed to assist persons with disabilities to remain in the community and avoid institutional placement. It provides services for individuals who need help with activities such as cleaning, laundry, shopping, errands, meal preparation, chores, and companion services, but who are not eligible for the PCA waiver. It can also cover the cost associated with a personal emergency response system.

The age range of clients is 18 to 64. Persons 65 and older are referred to the CHCPE. To be eligible, an individual must be at risk in the community and in danger of being institutionalized without the provision of services from the CBS program. Clients are assessed by a DSS social worker as not only medically, but also financially and socially eligible. The social worker matches the client with individual services offered by various community agencies.

The program is funded by federal block grant dollars, and the amount of money available for each individual is currently capped at \$650 per month. The current active caseload is about 1700.

Department of Mental Health and Addiction Services (DMHAS)

Clients of the Department of Mental Health and Addiction Services (DMHAS) were not included in the original Needs Assessment survey of people with disabilities because their individual contact information was not available. However, surveys were widely distributed to Local Mental Health Authorities (LMHAs), and these clients were encouraged by their providers to complete a survey.

DMHAS serves low-income adults age 18 and over with psychiatric or substance abuse disorders, or both, who lack the financial means to obtain such services on their own. Most clients who have a mental illness and receive treatment through DMHAS become Medicaid-eligible. They may also be eligible for state general assistance, with medical benefits covered by the Department of Social Services (DSS).

In conjunction with 15 LMHAs, DMHAS promotes and administers recovery-oriented services in the areas of mental health treatment and substance abuse. Most are treated in community settings, with inpatient treatment as needed. In conjunction with DSS, DMHAS helps individuals move from psychiatric hospitals into the community. It also provides supportive housing for over 2500 individuals.



Mental health services include inpatient hospitalization, outpatient clinical services, emergency care, day treatment, psychosocial and vocational rehabilitation, restoration to competency and forensic services (including jail diversion programs), outreach services for persons with serious mental illness who are homeless, and comprehensive, community-based mental health treatment and support services. Substance abuse services include ambulatory care, residential detoxification, long-term care, long-term rehabilitation, intensive and intermediate residential services, methadone or chemical maintenance, outpatient, partial hospitalization, and aftercare. Services for HIV-infected clients include counseling, testing, support and coping therapies, alternative therapies and case management.

IV. Methodology

Five thousand people with disabilities were chosen from the waiver programs and from three of the four state-funded programs described above to participate in a mailed survey as part of the Connecticut Long-Term Care Needs Assessment. (See the Needs Assessment Report for details of overall methodology.) Individual contact information was not available for DMHAS clients to be included in the mailed survey, but DMHAS clients were encouraged by their providers to complete and return a survey. Surveys were mailed randomly to selected participants in most of the other programs. However, because of their small total numbers, all participants from the ABI, PCA, and KatieB waivers were sent surveys.

The survey instrument was a 12-page booklet with the following major topics:

- Current and future LTC plans
- Health and functional status
- Community LTC services and unmet need
- Social supports
- Employment and transportation
- Demographic information
- Financial resources

Most questions were identical to those on the survey used for the random sample of older adults and baby boomers in Connecticut. However, additional questions were developed and added to the survey for people with disabilities. These additional questions were designed to further explore issues such as assistive technology, transportation and accessibility.

Return envelopes for each survey were color coded in order to identify the program with which the respondent was associated. A total of 1354 surveys were completed by persons who could be identified by program, including 95 from DMHAS clients who were not included in the original mailing. Response rates by program ranged from 21 to 38 percent, as noted in Table IV-1. Since DMHAS clients were not included in the original mailed survey, a response rate could not be calculated for that program. The respondent's program was not identifiable for 19 originally mailed surveys or for 195 disability surveys completed by the general public. The results from these unidentifiable surveys were included in the Needs Assessment report, but could not be included in this report since the associated program is unknown.

Table IV-1. Response rates by program

Waiver or program	Surveys mailed	Number wrong address, ineligible, deceased	Surveys completed	Response rate
Elder (CHCPE)	1,000	91	256	28%
PCA	770	20	211	28%
ABI	503	39	129	28%
Katie B	163	5	60	38%
DDS Active	900	39	181	21%
DDS Wait List	100	7	30	32%
BRS Combined	1,004	147	236	28%
CBS	560	27	156	29%
DMHAS	N/A	N/A	95	N/A
Total	5,000	375	1,354	

As with any self-administered survey, there is some subjectivity and the possibility of data response errors if respondents (or those helping them fill out the survey) did not understand certain questions or terminology.

V. Results

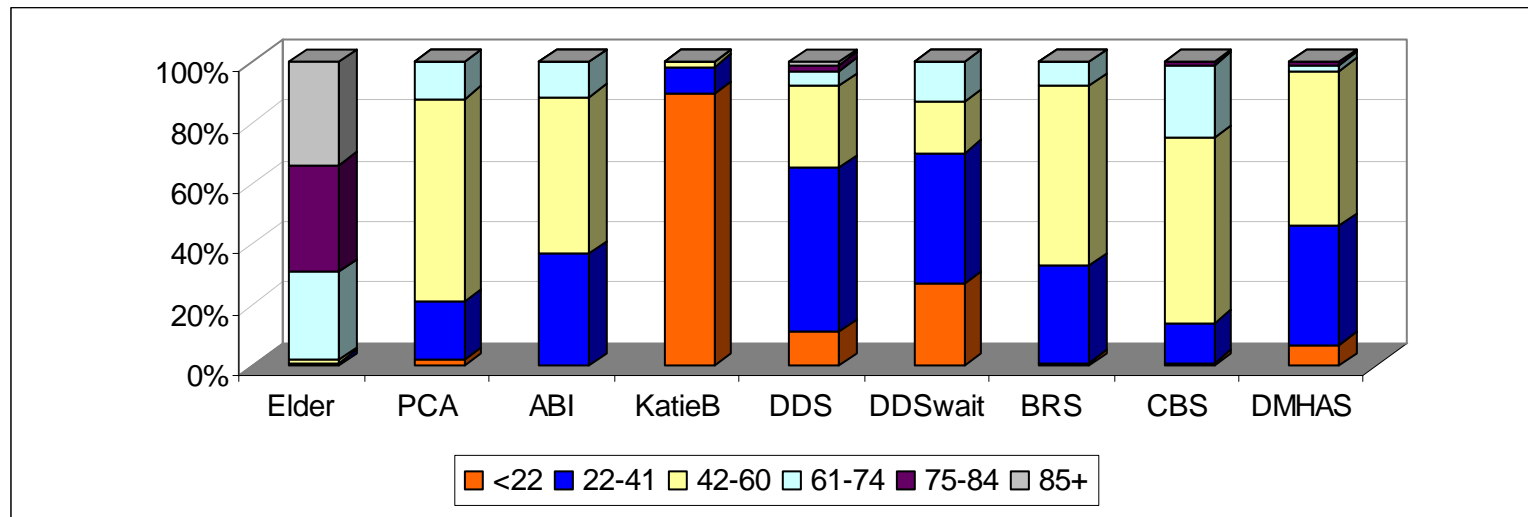
A. Differences in survey results by program

Demographic information

Age distribution

As would be expected, the age distribution among programs differs considerably, with Elder respondents in the oldest three age groups and KatieB respondents primarily 21 and under. Within the other programs, the vast majority of respondents are between 22 and 60, with more DDS and DDS wait respondents in the 22-41 category, and more respondents from the other programs in the 42 to 60 category. CBS has a substantial number (25%) in the 61-74 category, all of whom are likely to be 61 to 64, since program eligibility ends at 64. Figure V-1 displays the age distribution among programs.

Figure V-1. Age distribution by program

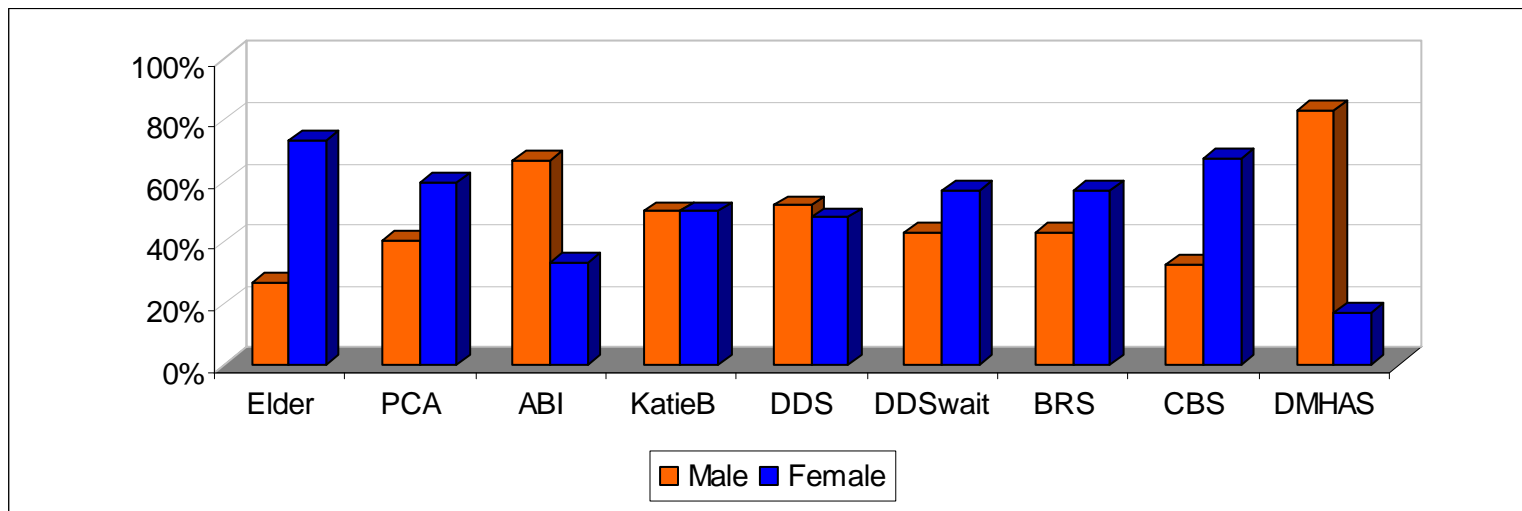


Gender distribution



The gender distribution among programs also differs somewhat, with females constituting nearly three-quarters (73%) of elder respondents, and a majority of most others. Only three programs have a majority of male respondents: DMHAS (83%), ABI (67%), and DDS (52%). Figure V-2 demonstrates the gender distribution among respondents of the nine programs.

Figure V-2. Gender distribution by program

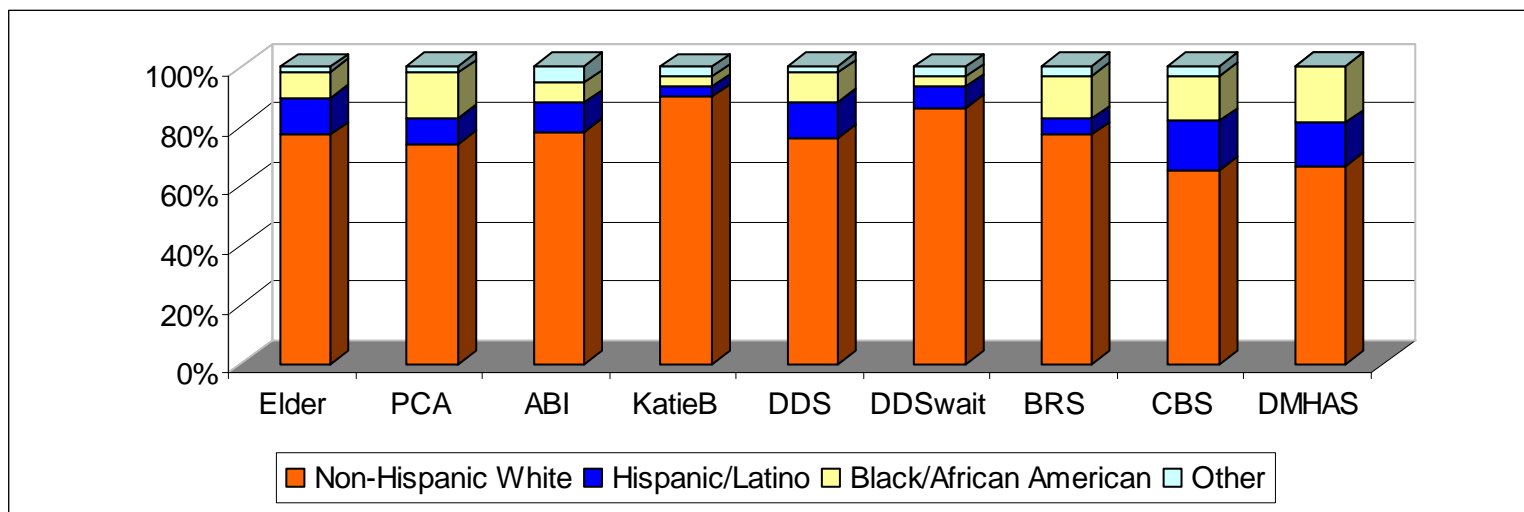


Race/ethnicity



A large majority of respondents from each program are non-Hispanic white, ranging from 65 percent (CBS) to 90 percent (KatieB). Programs with the largest percentage of Hispanic/Latino respondents include CBS (16%), DMHAS (15%), DDS and Elder (12% each). Programs with the highest percentage of Black/African American respondents are DMHAS (19%), PCA, CBS, and BRS (15% each). Only a small percent from each program listed another race/ethnicity. Figure V-3 summarizes the race/ethnicity of respondents.

Figure V-3. Race/ethnicity by program

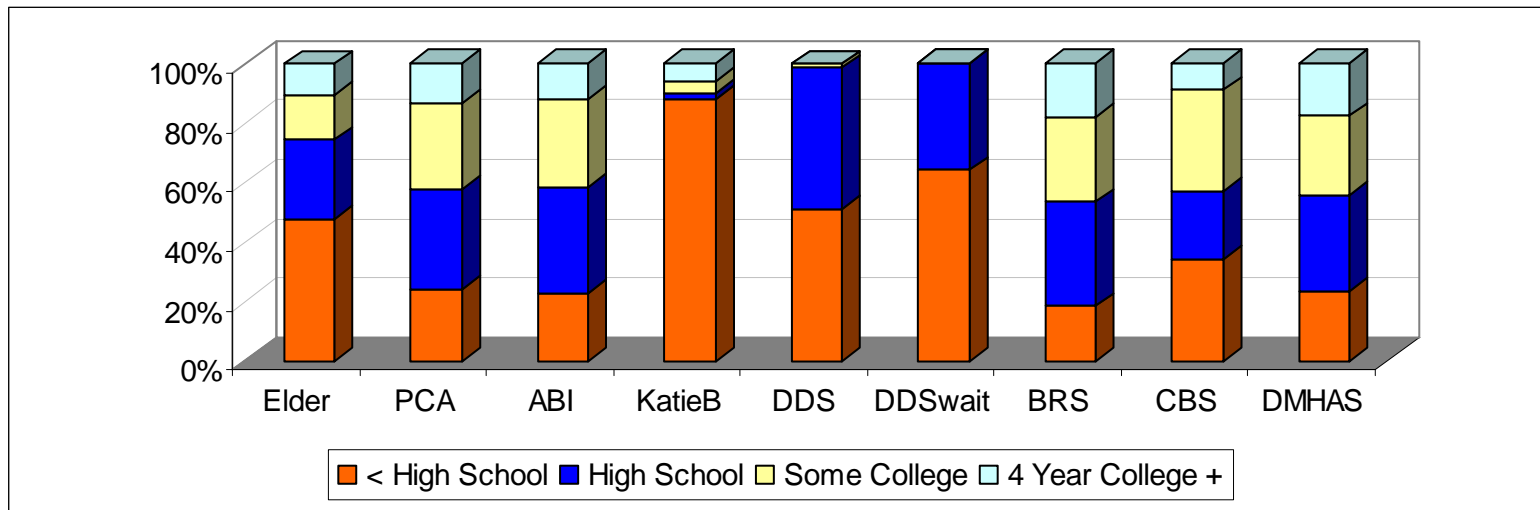


Education level



Educational attainment level differs in several expected ways, with very few KatieB respondents, most of whom are children, having completed high school. In five programs, close to half of respondents attended at least some college: BRS (47%), DMHAS (44%), CBS (43%), PCA and ABI (42% each). Figure V-4 summarizes reported education levels among programs.

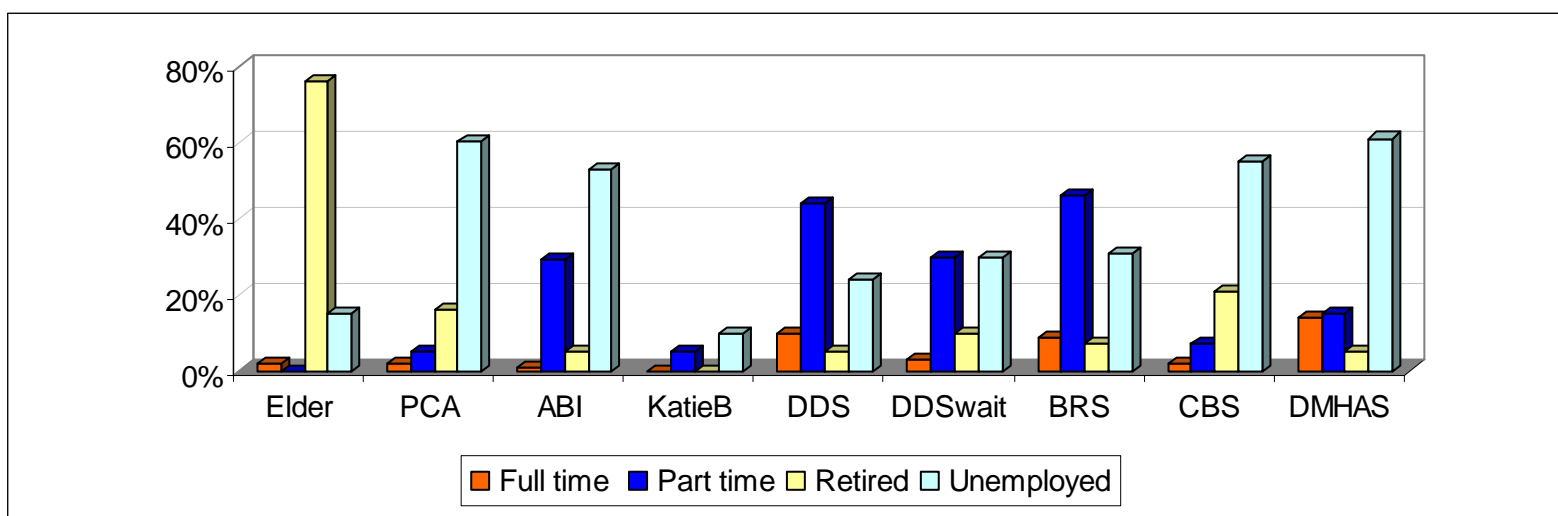
Figure V-4. Educational attainment level by program



Employment status

The employment status of respondents shows dramatic differences by program. As might be expected, the great majority of Elder respondents are retired, while only a small percentage of those from KatieB are employed. The incidence of full time work in all programs is small, with DMHAS at 14 percent being the highest. Part time work is more common, with nearly half of BRS and DDS and almost a third of ABI and DDS wait employed part time. Unemployment affects more than half of DMHAS, PCA, CBS and ABI respondents. Figure V-5 summarizes employment results by program.

Figure V-5. Employment status by program



Delving further into employment issues, the survey asked those who are not currently working for pay if they want to have a job, and if so, if they are actively hunting. Results of those questions are summarized in Figures V-6a and V-6b. Of those not currently working, DMHAS (70%) and BRS respondents (61%) have the greatest desire to obtain a job. Likewise, of those not currently working who want a job, DMHAS (62%) and BRS (55%) respondents have the highest percentage of respondents who are actively job hunting.

Figure V-6a. Percent not currently working who want a job, by program

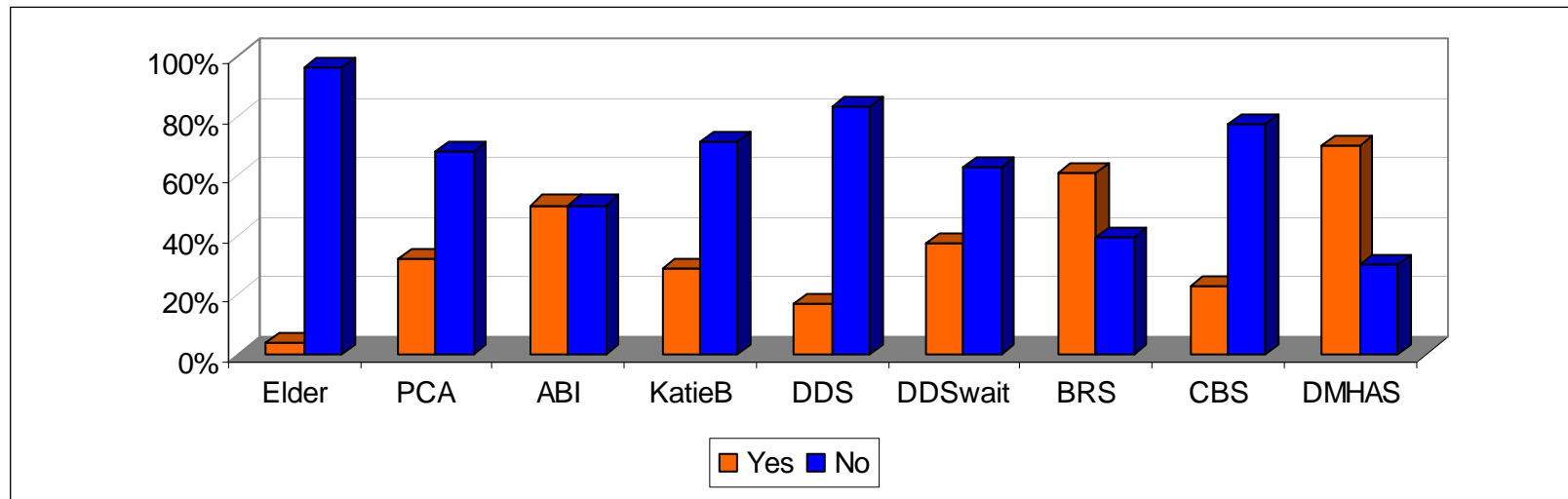
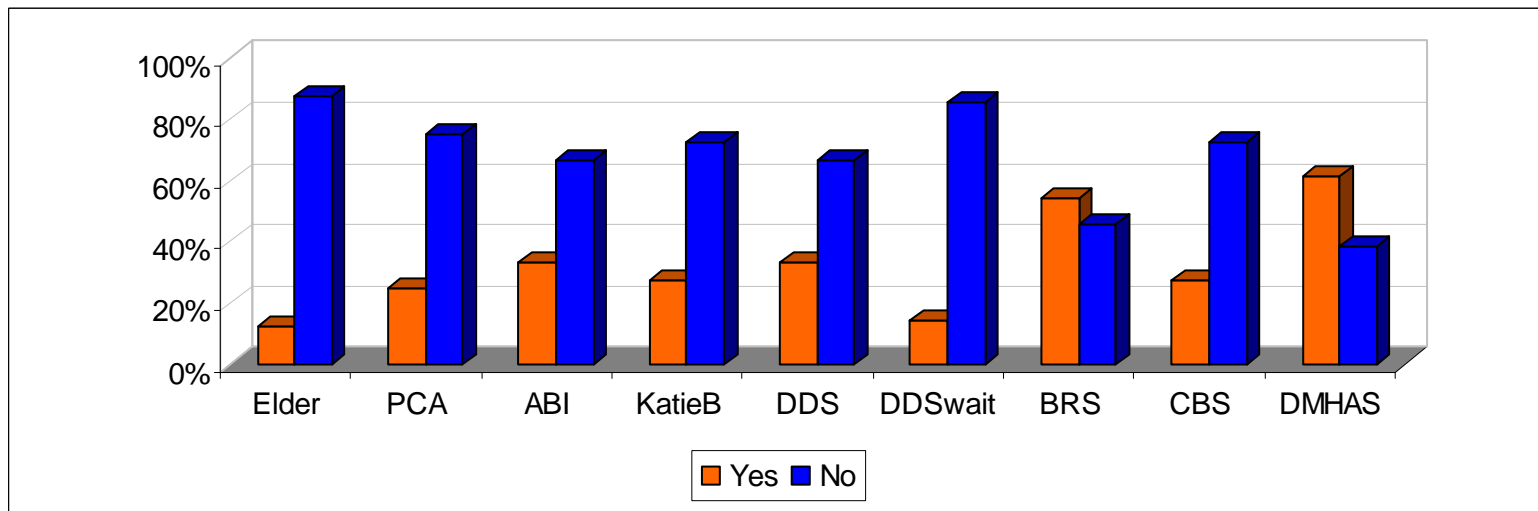


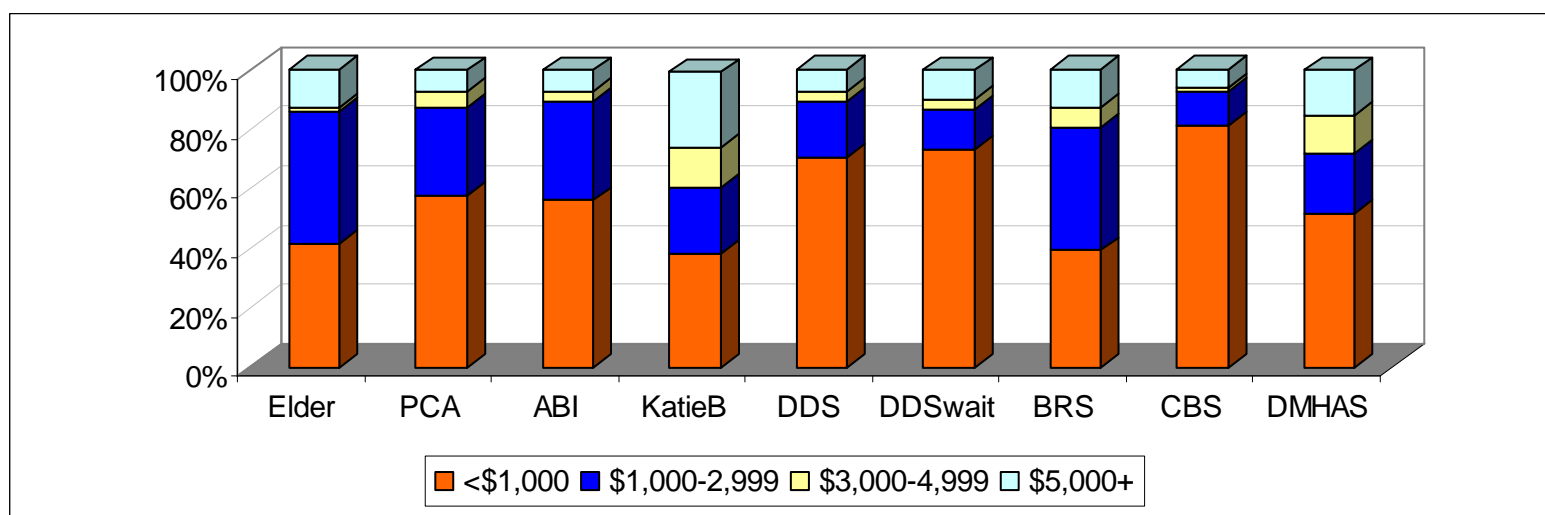
Figure V-6b. Percent who want a job who are actively job hunting, by program



Financial status

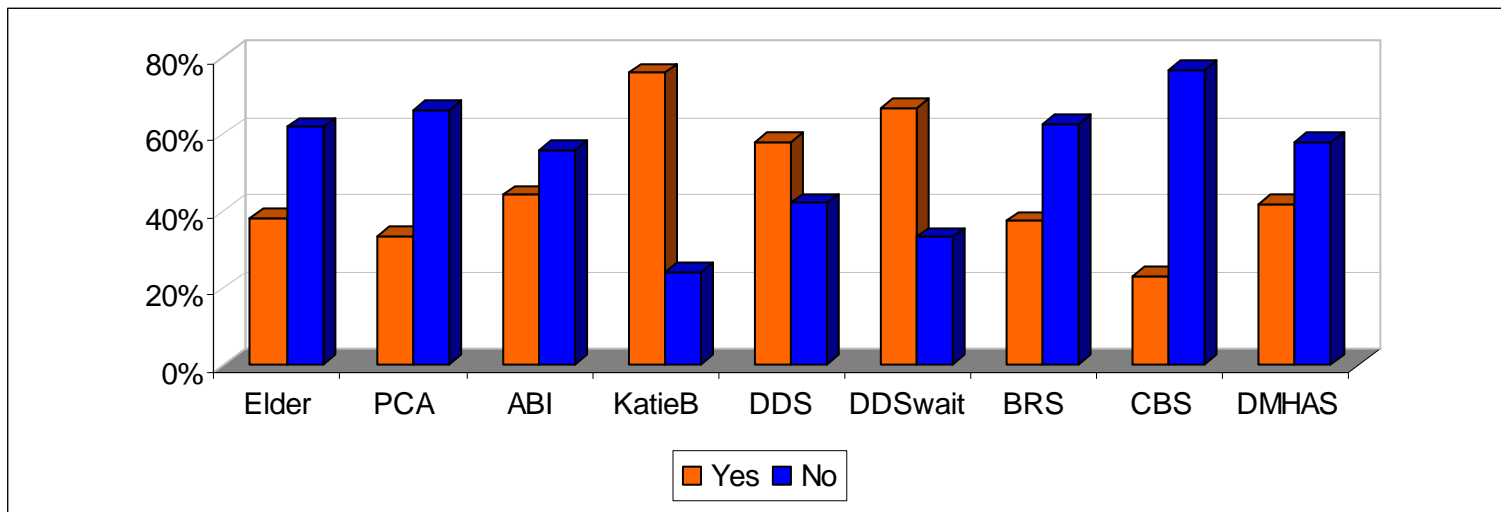
As the programs in question frequently have income and asset limits for program eligibility, respondents by and large report low incomes, with more than half of all respondents (55%) having monthly household income of less than \$1,000. Even among programs, however, there are considerable differences. The percent of respondents with monthly household income of less than \$1,000 ranges from a high of 81 percent (CBS) to a low of 39 percent (KatieB and BRS). At the high end, 25 percent of KatieB respondents, and more than ten percent of respondents from DMHAS, BRS and Elder report monthly household incomes in excess of \$5,000. Figure V-7 summarizes monthly household income distribution by program.

Figure V-7. Monthly household income by program



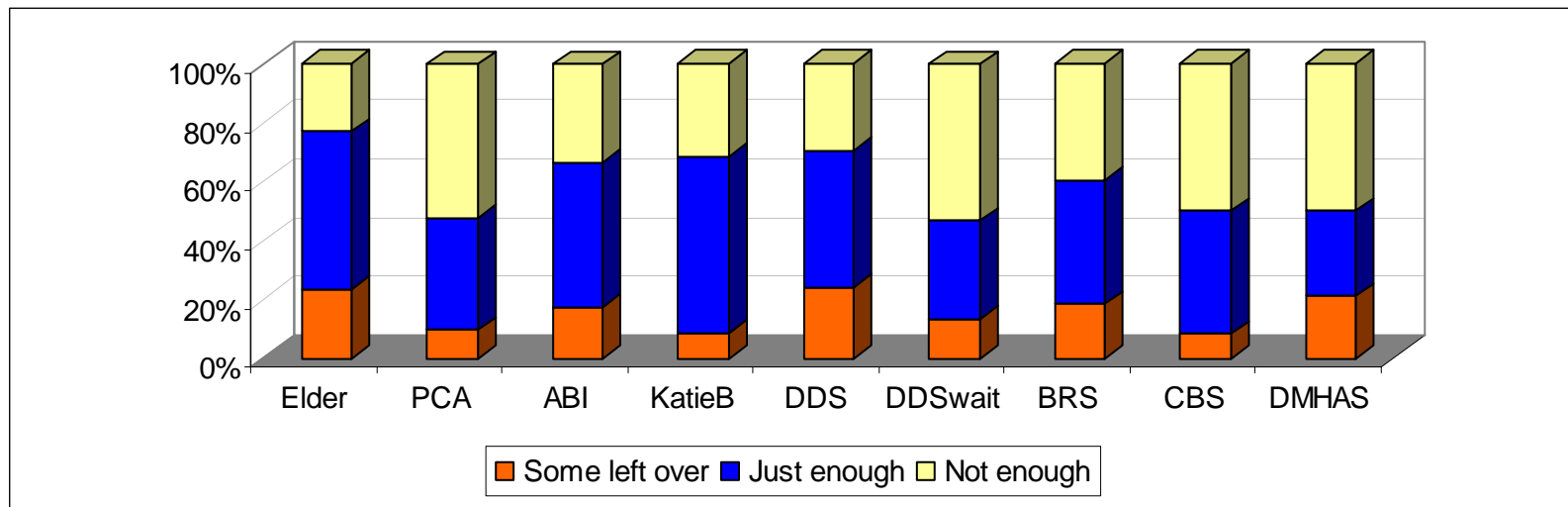
Factors other than monthly household income affect a person's financial well-being. Survey respondents were also asked to indicate whether they could count on anyone to help them pay bills, housing or medical costs, or food or clothing if they needed extra financial help. Programs where more than half of respondents indicate they can count on others for such financial help are KatieB (76%), DDS wait (67%) and DDS (58%). Those with the least ability to call on others for financial help are CBS (23%) and PCA (34%). These results are summarized in Figure V-8.

Figure V-8. Percent who could count on extra financial help by program



Respondents were also asked how their finances usually work out at the end of the month: whether they have enough money, just enough, or not enough to make ends meet. Fifty percent or more of respondents from four programs indicate that they do not have enough money to make ends meet: DDS wait (53%), PCA (52%), CBS and DMHAS (50% each). Programs with the highest percentage of people who make ends meet or have money left over each month are Elder (77%), DDS (71%), and KatieB (69%). Figure V-9 indicates financial results by program.

Figure V-9. How finances work out at end of month by program

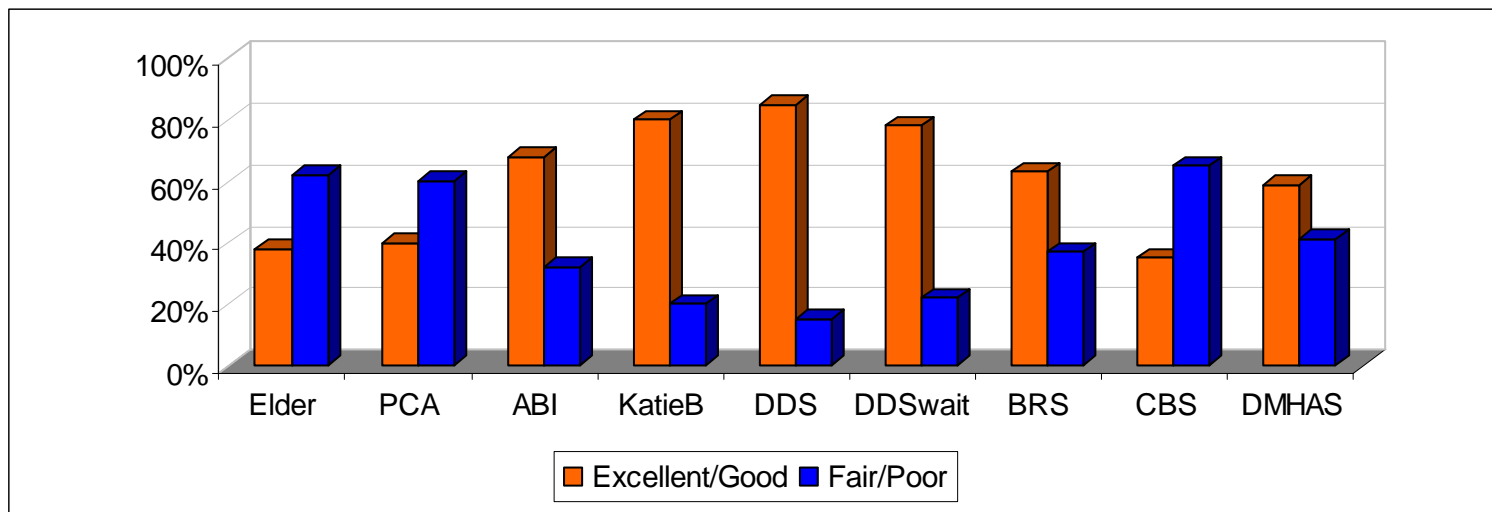


Health issues

Current health status

As noted in Part I of the Needs Assessment report, people with disabilities as a group report substantial differences on various measures of health status as compared to people with no reported disabilities. Among disability programs, there are also some striking differences. While overall, 56 percent of people with disabilities report their current health to be excellent or good (compared to 93 percent of people with no reported disabilities) there is a wide variation among programs, ranging from a low of 35 percent to a high of 85 percent. People with the best reported current health are in DDS, DDS wait, and KatieB, while those with the worst reported current health are in CBS, Elder, and PCA. Figure V-10 indicates the wide range of responses to current health ratings.

Figure V-10 Current health status



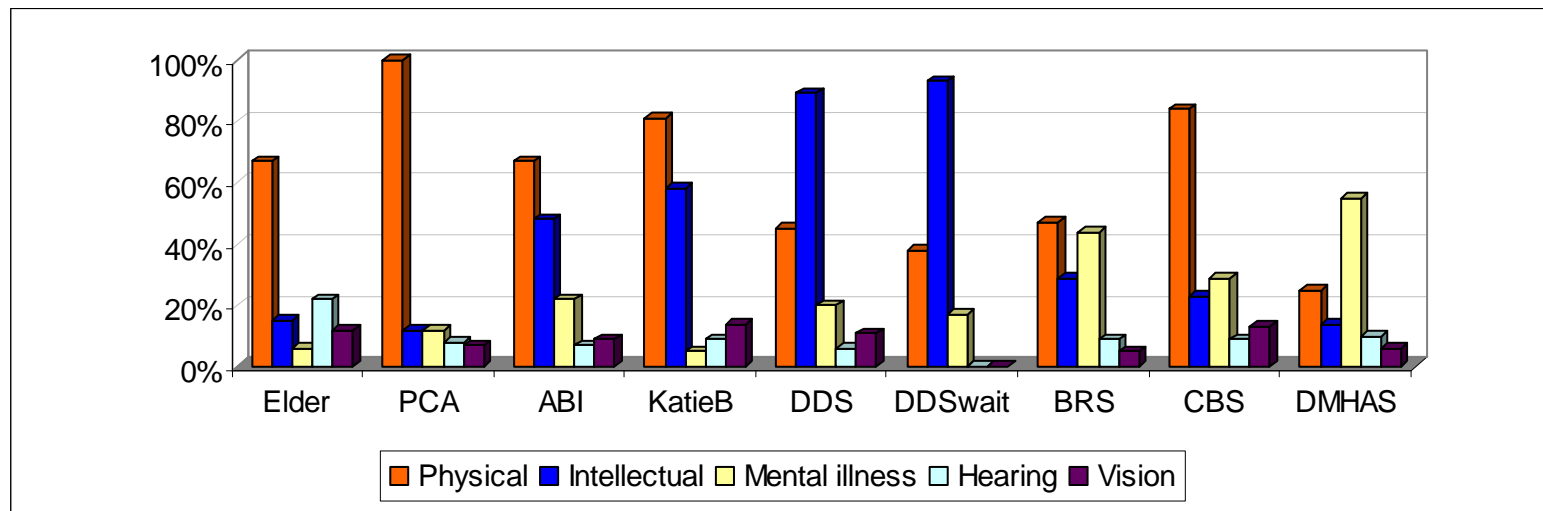
Type of disability

Respondents were asked to indicate whether they have one or more of five types of disability:

- Physical disability or chronic illness
- Intellectual or cognitive disability
- Mental illness or psychiatric disability
- Deafness or severe hearing impairment
- Blindness or legal blindness

Differences among programs were substantial in several expected ways given the nature and purpose of the programs. Physical disability is most common in PCA (100%), CBS (84%) and KatieB (81%), but also affects two-thirds of ABI and Elder. DDS and DDS wait have the highest levels of intellectual disability, with high levels also appearing in KatieB (58%) and ABI (48%). Mental illness is most prevalent with DMHAS (55%), BRS (44%) and CBS (29%). Vision and hearing impairments are the least frequent overall. Hearing disabilities occur in nearly a quarter (22%) of Elder respondents, but less than ten percent in other programs. Vision impairments affect more than ten percent of KatieB, CBS, Elder and DDS, and less than ten percent in other programs. Figure V-11 shows type of disability by program.

Figure V-11. Type of disability by program

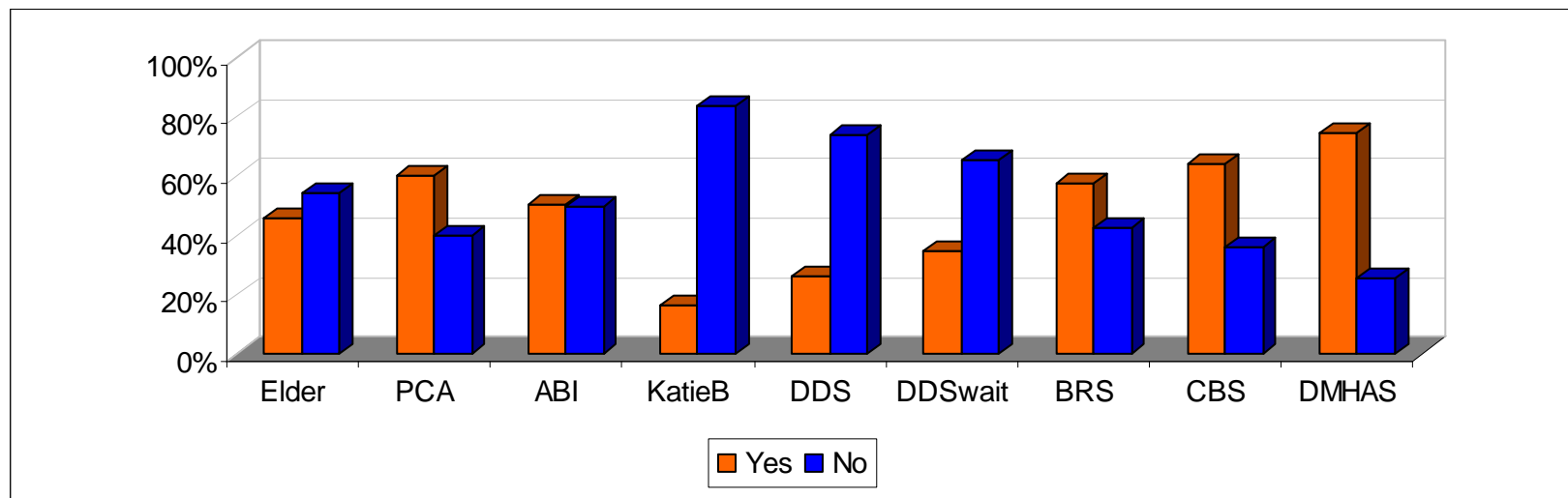


Depressive symptoms



There are major differences among the programs in reported symptoms of depression, such as feeling down, depressed or hopeless, or having little interest in doing things, ranging from a high of 75 percent to a low of 16 percent. Respondents from DMHAS (75%), CBS (64%) and PCA (60%) report the highest rate of depressive symptoms, with those from KatieB (16%), DDS (26%) and DDS wait (35%) reporting the lowest. Figure V-12 summarizes the differences among programs in reported symptoms of depression.

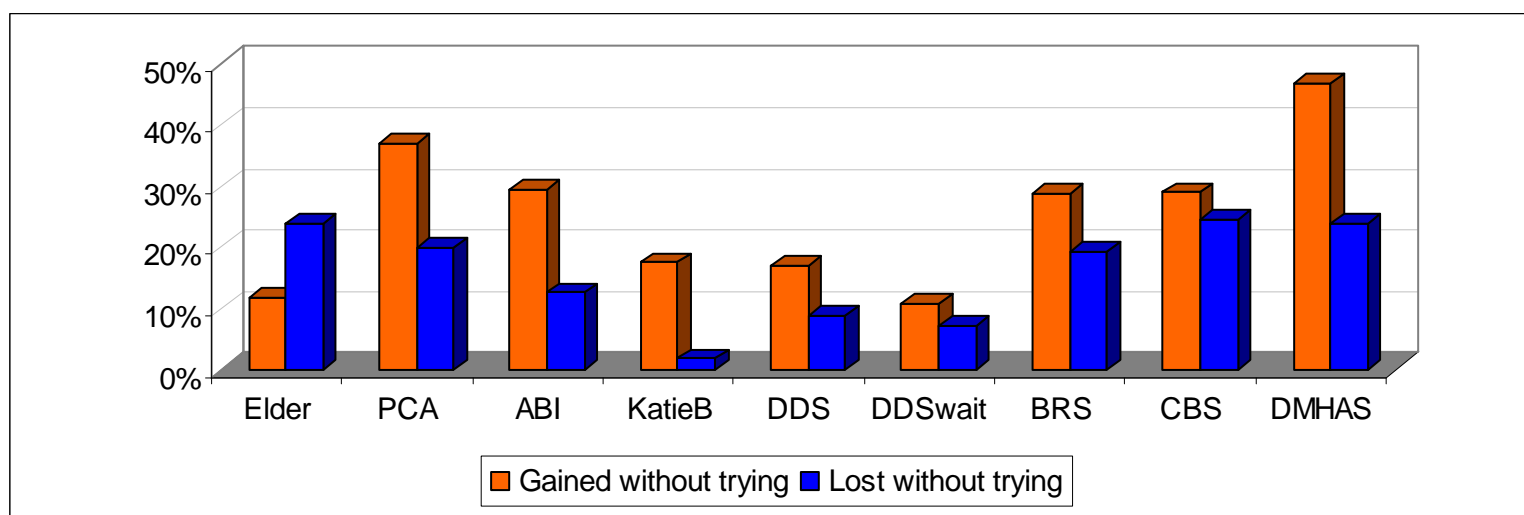
Figure V-12. Reported symptoms of depression



Unplanned weight gain or loss

Another potential indicator of health status is unplanned weight gain or loss. A significant unplanned weight gain or loss can have serious implications for overall health. Asked if they had gained or lost at least ten pounds without trying over the last 12 months, 44 percent of respondents in disability programs indicate that they did gain or lose at least that amount without trying (compared to only 18 percent of persons with no reported disabilities.) There are also major differences on this measure among the groups. At the high end, 71 percent of DMHAS respondents gained or lost at least ten pounds without trying, while at the low end only 18 percent of those on the DDS wait list did. Respondents from the Elder waiver were the only ones to experience more weight loss than weight gain. All other groups experienced more weight gain than loss. Figure V-13 illustrates differences among the nine programs.

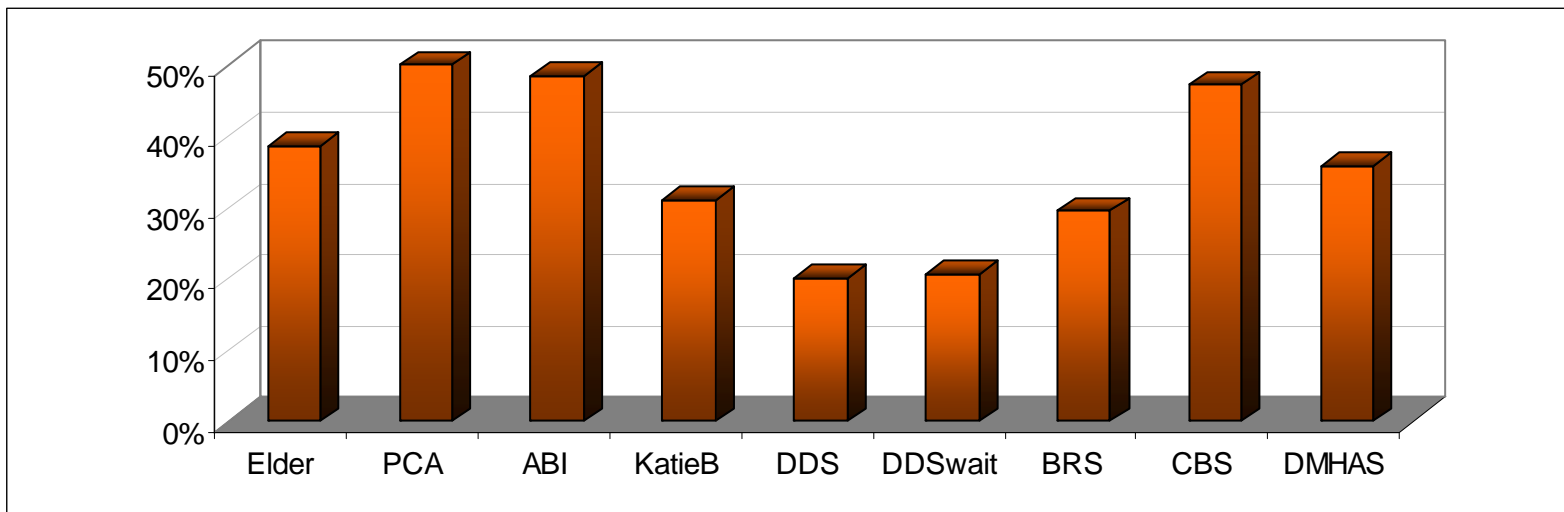
Figure V-13. Percent who gained or lost ten lbs. in past year without trying



Incidence of falls

The incidence of falls is another important indicator not only of health but also of the probability of needing an increased level of care. Falls often lead to serious complications, institutionalization, or the need for greater long-term care at home. Whereas only 14 percent of people with no reported disabilities indicated that they had fallen in the past year, that percent is much higher (37%) for people with disabilities. Within programs, there is also a wide variation in the incidence of falls over the past year, ranging from about one in five for DDS and DDS wait to nearly half for PCA, ABI and CBS. These results are summarized in Figure V-14.

Figure V-14. Incidence of falls in past year by program



Health exams and screenings

Another important indicator of health is the regular receipt of important health exams and screenings. The survey asked respondents to indicate whether they had received certain exams and vaccines in the last year, and a wellness checkup within the last two years. While large majorities in all programs (at least 77%) had received a blood pressure check, rates of cholesterol screening were far lower. Although the low rate for KatieB (14%) is understandable in light of their young age, screening rates are also below 60 percent for DDS, PCA, DDS wait, ABI and BRS. The rate of dental cleanings is particularly low in many programs, with only 24 percent of Elder respondents and less than 50 percent of DMHAS, CBS, PCA and ABI having received one. Flu vaccines were received by between 40 percent and 70 percent of respondents, with DDS wait on the low end and Elder on the high end. Rates of

pneumonia vaccination were uniformly low. Wellness exams were received by about two-thirds or more of KatieB, DDS and DDS wait, but by less than half of CBS and PCA. These results appear in Figures V-15a and V-15b.

Figure V-15a. Percent receiving health exams by program

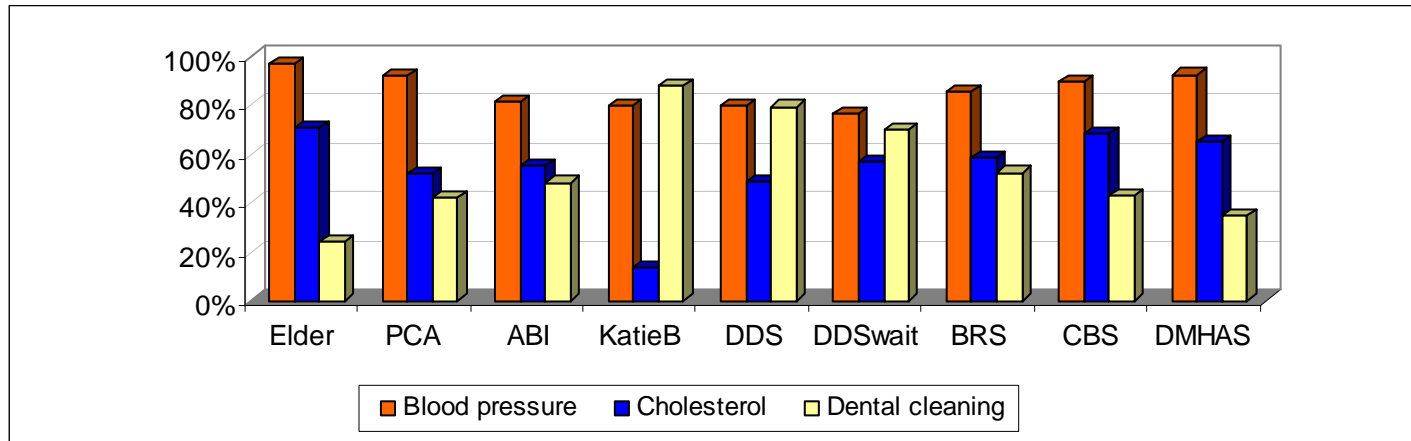
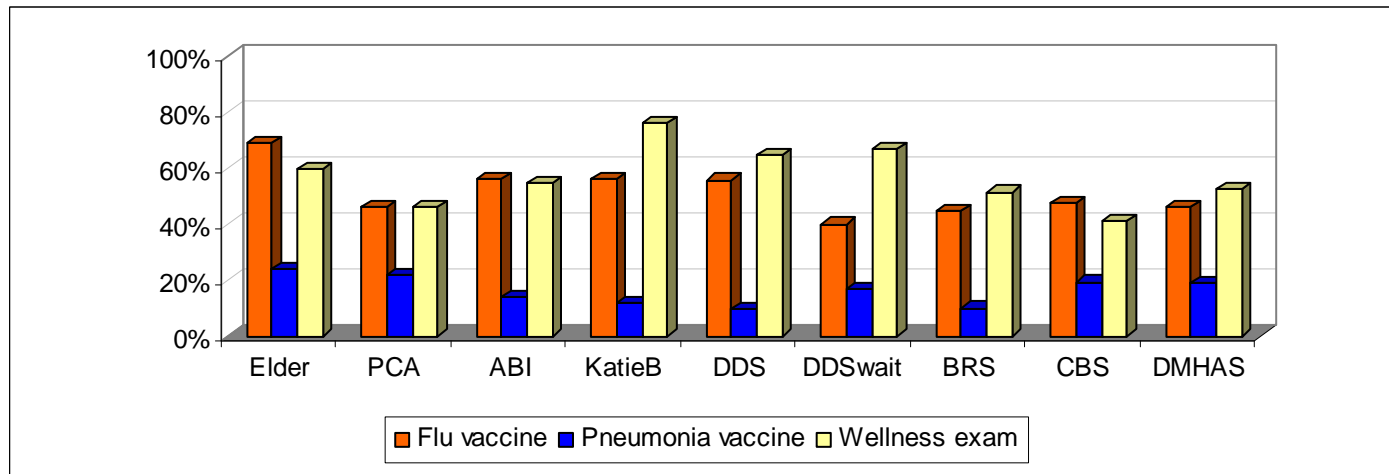


Figure V-15b. Percent receiving health exams by program

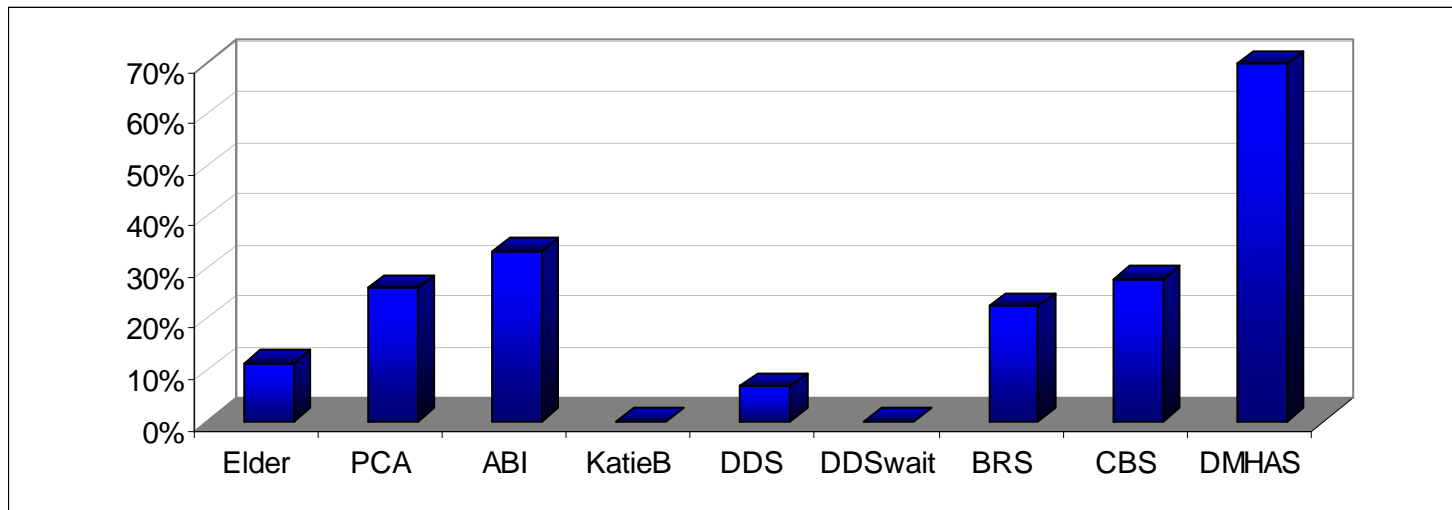


Smoking



The incidence of smoking is another indicator of potentially compromised health. As shown in Figure V-16, the program with the most smokers by far is DMHAS (70%), while KatieB and DDS wait have no admitted smokers. After DMHAS, the programs with the most smokers are ABI (33%), CBS (28%), PCA (26%) and BRS (23%).

Figure V-16. Incidence of smoking by program



Use of hospitals, emergency rooms and counseling services

In the survey for people with disabilities, respondents were asked how many times in the prior twelve months they had:

- Been admitted as a patient in a hospital and stayed at least overnight;
- Used an emergency room at a hospital; or
- Used any type of mental health, behavioral health, or substance abuse counseling

The results for hospital and emergency room use are similar for each program, with emergency room use exceeding hospital use for every program except KatieB. For both types of medical care, DMHAS respondents indicated the highest percentage of usage, at 70 percent or more. Relatively high rates of hospital admission were also experienced by PCA (53%), Elder (46%), and CBS (44%). The lowest rates were experienced by DDS and DDS wait (15% and 17%). Emergency room use was also high for PCA and CBS (63% each), Elder (57%) and ABI (51%). DDS wait and KatieB experienced the lowest rate of emergency room use (21% and 25%, respectively).

With respect to counseling services, DMHAS respondents use these services most frequently as may be expected (85%). The next most frequent users are BRS (48%) and ABI (43%). Programs with the lowest rate of usage for counseling services are Elder (12%) and KatieB (15%). These results are summarized in Figures V-17a and V-17b.



Figure V-17a. Percent using hospital or emergency room by program

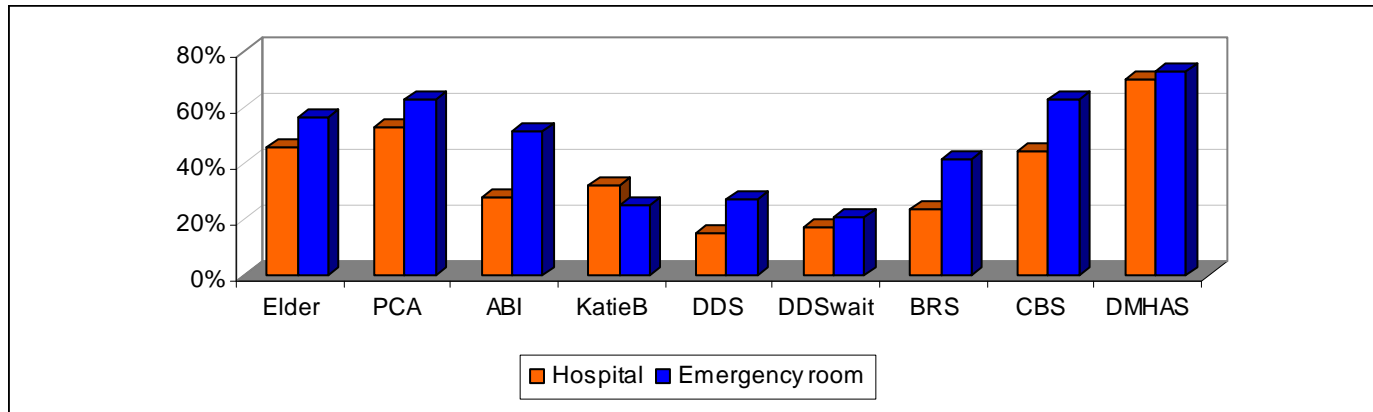
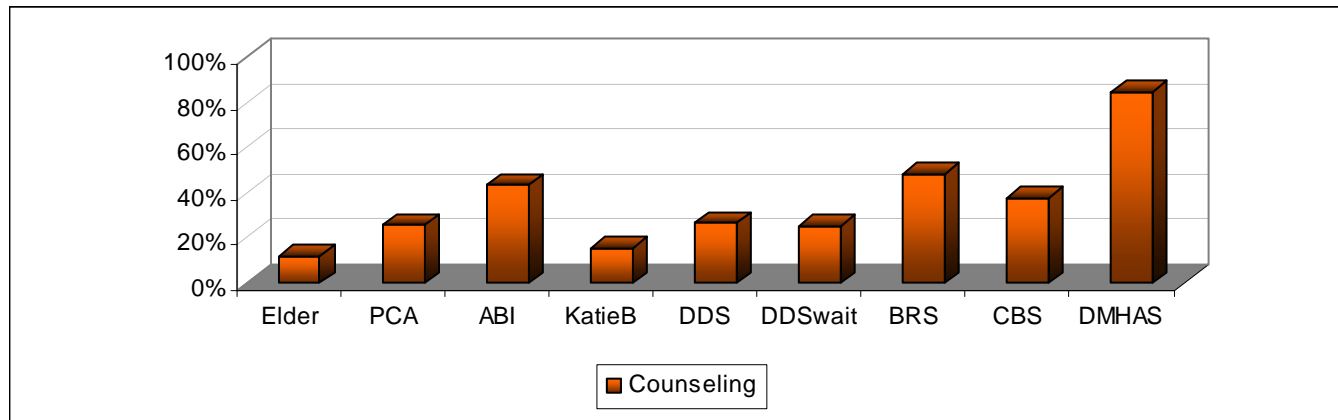


Figure V-17b. Percent using counseling service by program



Daily living activities

Measuring a person's ability to perform daily or habitual tasks is a vital part of evaluating their need for services. The survey asked respondents about their need for help with a number of basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The ADLs include personal care activities such as bathing, dressing, eating, toileting, mobility, and transferring (e.g., from a bed to a chair), and IADLs refer to more complex and habitually performed tasks such as cooking, shopping, doing laundry, cleaning, taking medications, and managing personal affairs.

Overall, about 60 percent of respondents indicate a need for help with at least one ADL. That figure varies widely, however, with nearly all PCA and 90 percent of KatieB respondents requiring some help. At the low end, only 18 percent of DMHAS and 27 percent of BRS respondents require such help. Moreover, the number of ADL impairments by program shows a wide range, with nearly two-thirds of KatieB and PCA respondents indicating a need for help with 5 or more ADLs. See Figures V-18a and V-18b.

Figure V-18a. Percent needing help with at least one ADL by program

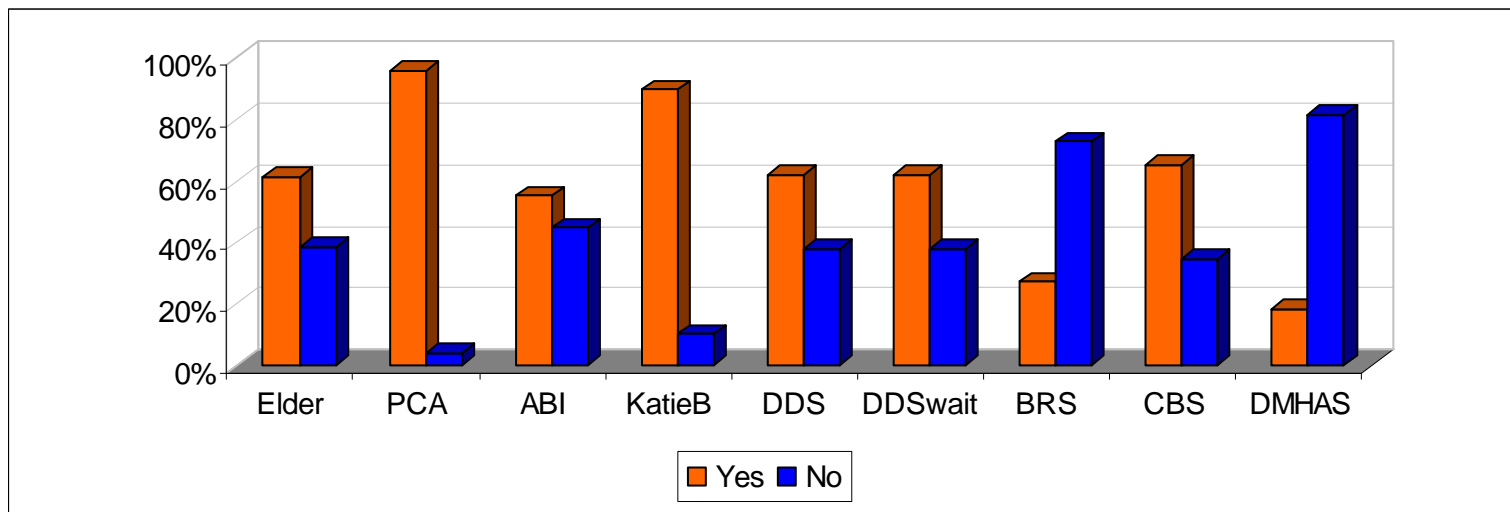
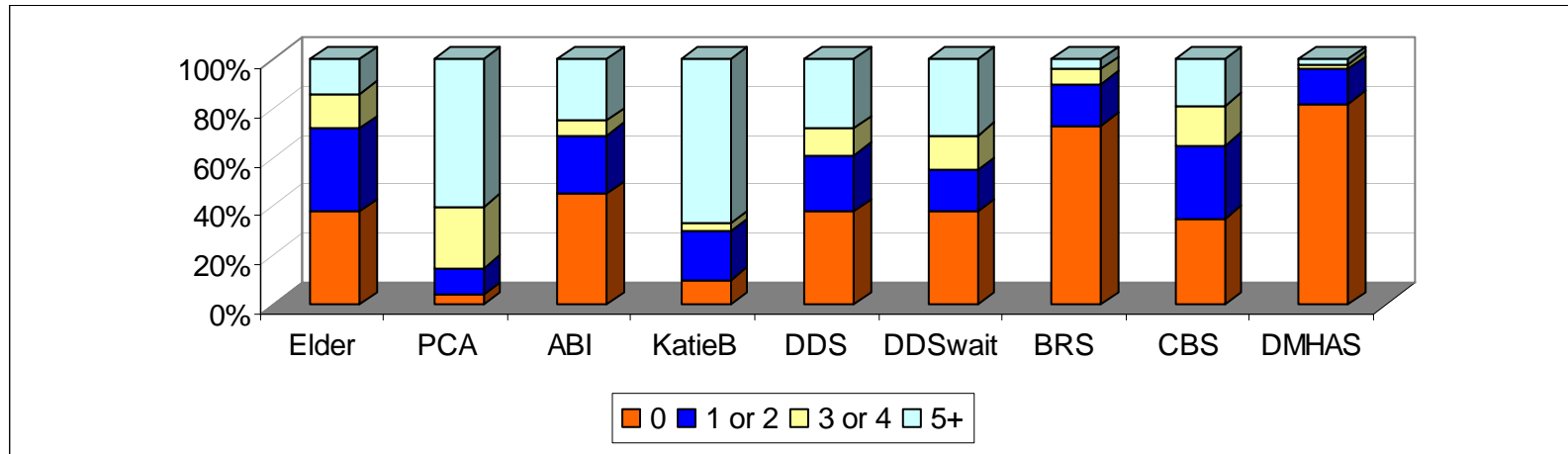


Figure V-18b. Number of ADL impairments by program



The reported need for assistance with IADLs is even higher than the need for help with ADLs. Overall, about 87 percent of respondents indicate a need for help with at least one IADL. In seven of the nine programs, the proportion needing help exceeds 90 percent. Only BRS (71%) and DMHAS (54%) respondents were at somewhat lower levels. The number of IADL impairments by program is also higher than the number of ADL impairments. Two-thirds or more of respondents from PCA, ABI, KatieB, DDS and DDS wait have five or more IADL impairments, with KatieB the highest at 90 percent. Almost 60 percent of Elder and CBS respondents need help with five or more IADLs. For BRS and DMHAS respondents, those numbers are far lower, at 26 percent and 12 percent, respectively. Figures V-19a and V-19b summarize these results.

Figure V-19a. Percent needing help with at least one IADL by program

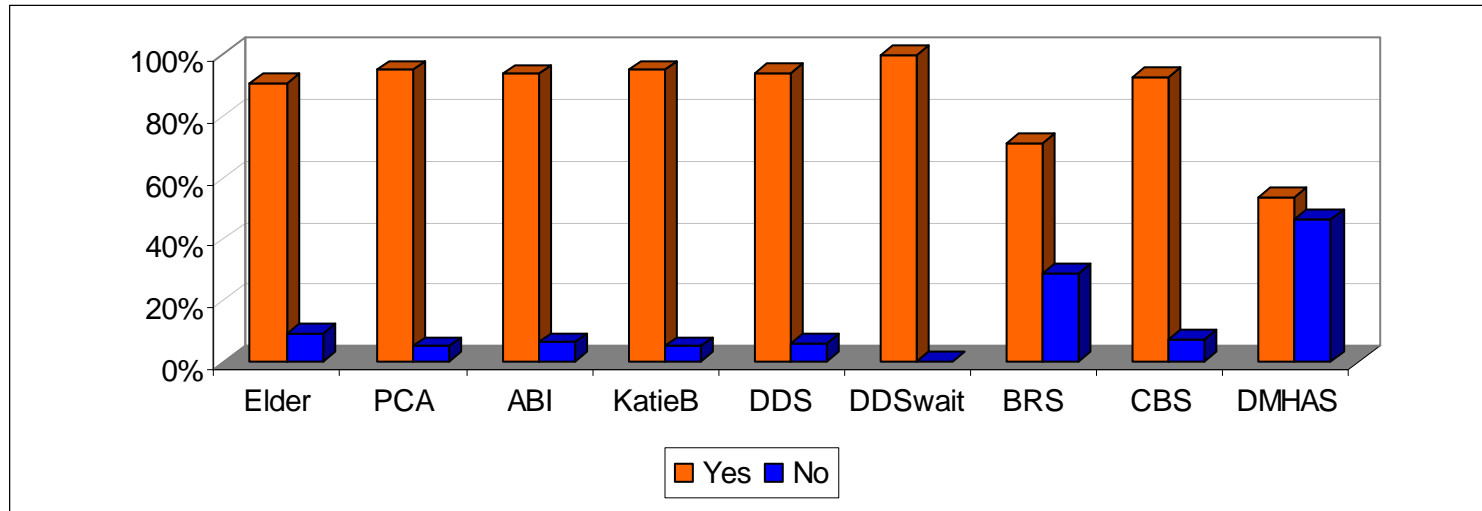


Figure V-19b. Number of IADL impairments by program

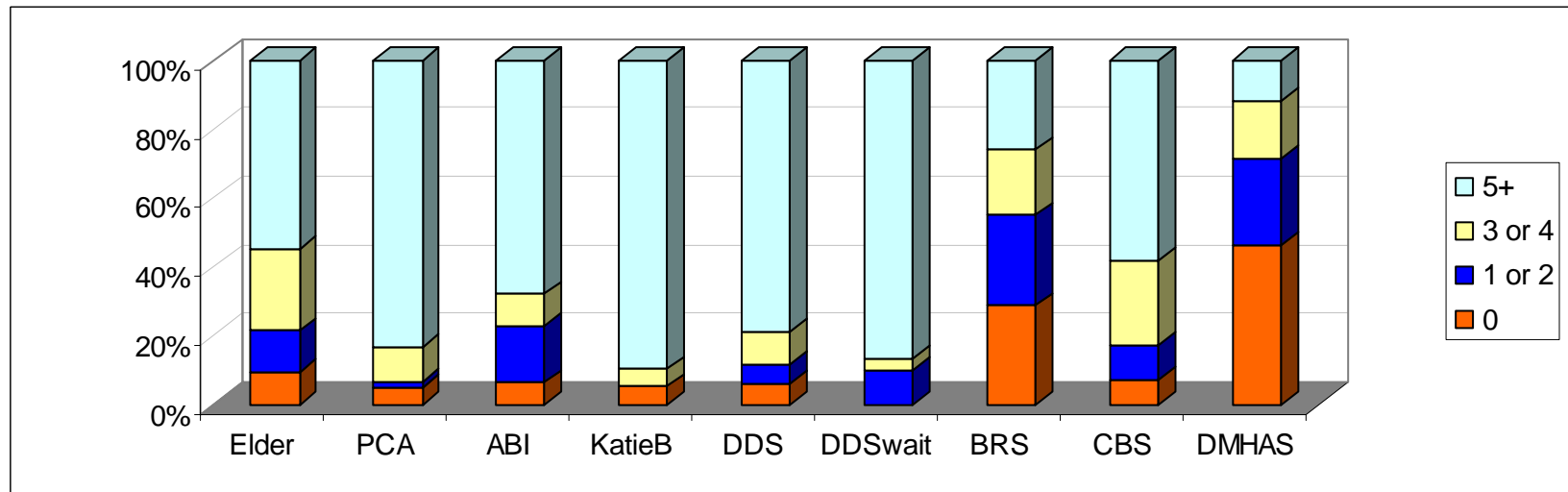


Table V-1 summarizes the reported need for help with each ADL by program. For each ADL, PCA and KatieB have the highest percent of people needing help (bold italics), while BRS and DMHAS have the lowest percent of people needing help (bold),

Table V-1. Percent needing help with ADLs

Activity	Elder	PCA	ABI	KatieB	DDS	DDS wait	BRS	CBS	DMHAS
Take bath or shower	50	<i>93</i>	44	<i>83</i>	56	62	12	44	5
Get dressed	29	<i>88</i>	33	<i>73</i>	48	48	11	33	5
Get in and out of a bed or chair	25	<i>75</i>	32	<i>56</i>	25	25	11	31	7
Use the toilet	13	<i>61</i>	22	<i>71</i>	32	41	5	20	3
Eat	10	<i>42</i>	20	<i>61</i>	27	31	4	12	5
Maintain control of bowel or bladder	28	<i>55</i>	27	<i>66</i>	35	35	11	32	9
Get around inside the house	22	<i>62</i>	25	<i>61</i>	25	24	9	30	3

The results for IADLs are similar, and are summarized in Table V-2. BRS and DMHAS still have the lowest percentage of people needing help with most IADLs (bold). While PCA and KatieB are still among the highest in percent of people needing help with IADLs, DDS wait also has very high levels of need for most IADLs (bold italics).

Table V-2. Percent needing help with IADLs

Activity	Elder	PCA	ABI	KatieB	DDS	DDS wait	BRS	CBS	DMHAS
Prepare meals	60	92	70	95	86	89	35	69	14
Shop for groceries	82	98	78	93	88	96	41	85	20
Do routine household chores	84	98	75	95	82	89	44	86	17
Manage money/bills	51	56	81	90	93	100	44	41	37
Do laundry	78	97	69	95	80	86	34	81	16
Take medications correctly	44	60	63	88	79	90	27	36	25
Get to places out of walking distance	82	92	84	93	83	97	45	85	32
Use the telephone	26	34	34	74	62	76	9	19	7

B. Analysis of unmet needs

Several questions on the Needs Assessment survey identified a variety of services that help people remain in the community. These questions then asked respondents to state whether they had a need for any of these services, and whether these needs were currently being met. Three broad categories of services were included: Community long-term care services, assistive devices, and transportation. Although transportation is listed among the community long-term care services, a separate section of the survey delved deeper into the causes and ramifications of transportation difficulties.

For each category, unmet need as indicated by survey respondents is analyzed by program. It is important to note, however, that respondents who do not report an unmet need in a particular area fall into two groups:

- Those whose disabilities do not require the need for a particular service; and
- Those who do have needs for the service, but whose needs are being fulfilled by the program or in some other manner.

Community long-term care services

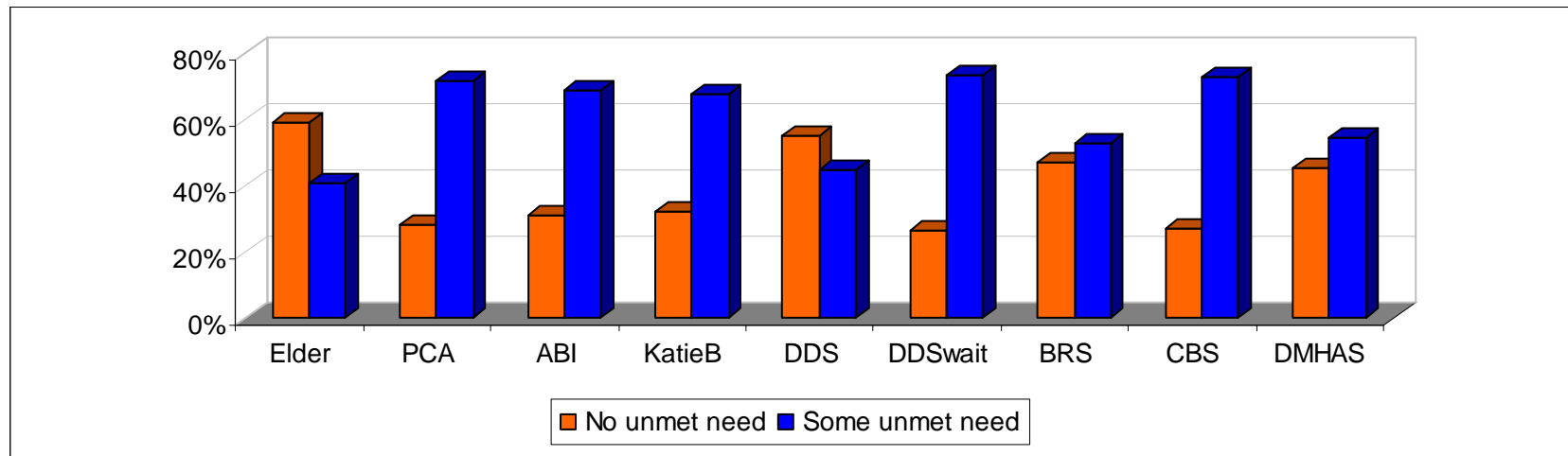
The Needs Assessment survey asked respondents to indicate whether they currently use or have a need for any of a list of twelve paid, community-based long-term care services. These services include home health aide, homemaker service, visiting nurse, home-delivered meals, dial-a-ride or other transportation service, friendly visitor service, care management, adult day program, personal care assistance, vocational rehabilitation, job coaching, and money management. It is important to note that these questions concern only formal paid services. They do not cover unpaid services of a similar nature received from family or friends. (Additional questions concerning handyman services and lawn or snow services were asked, but they are not considered long-term care services for purposes of this analysis.)

For each of the twelve listed services, respondents noted whether they were:

- Not using now and do not need
- Not using now but do need
- Using now and receiving enough, or
- Using now but need more

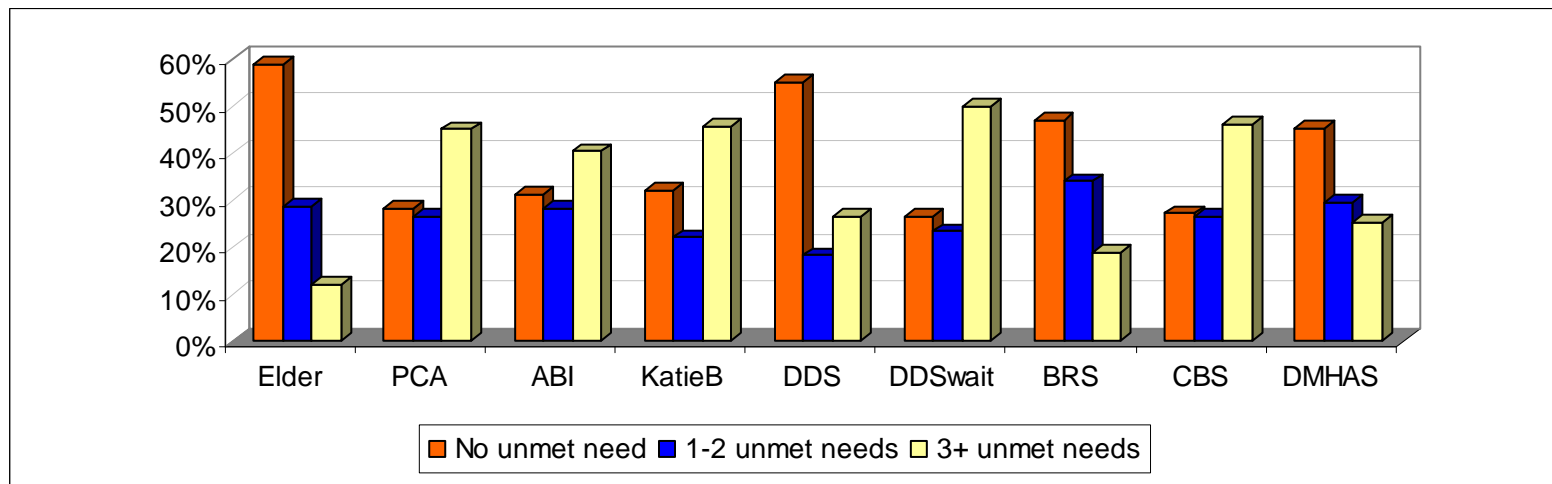
“Unmet need” for this category of services is defined as a deficit in one or more of the enumerated services. People who indicated either “not using now but do need” or “using now but need more” for at least one service are considered to be people with unmet needs. The rate of any unmet need by program differed substantially. While more than half of Elder and DDS respondents reported that they have no unmet need in any of the twelve categories, more than two-thirds of DDS wait, CBS, PCA, ABI and KatieB respondents reported at least one unmet need. Figure V-20 summarizes these results.

Figure V-20. Rate of unmet need by program



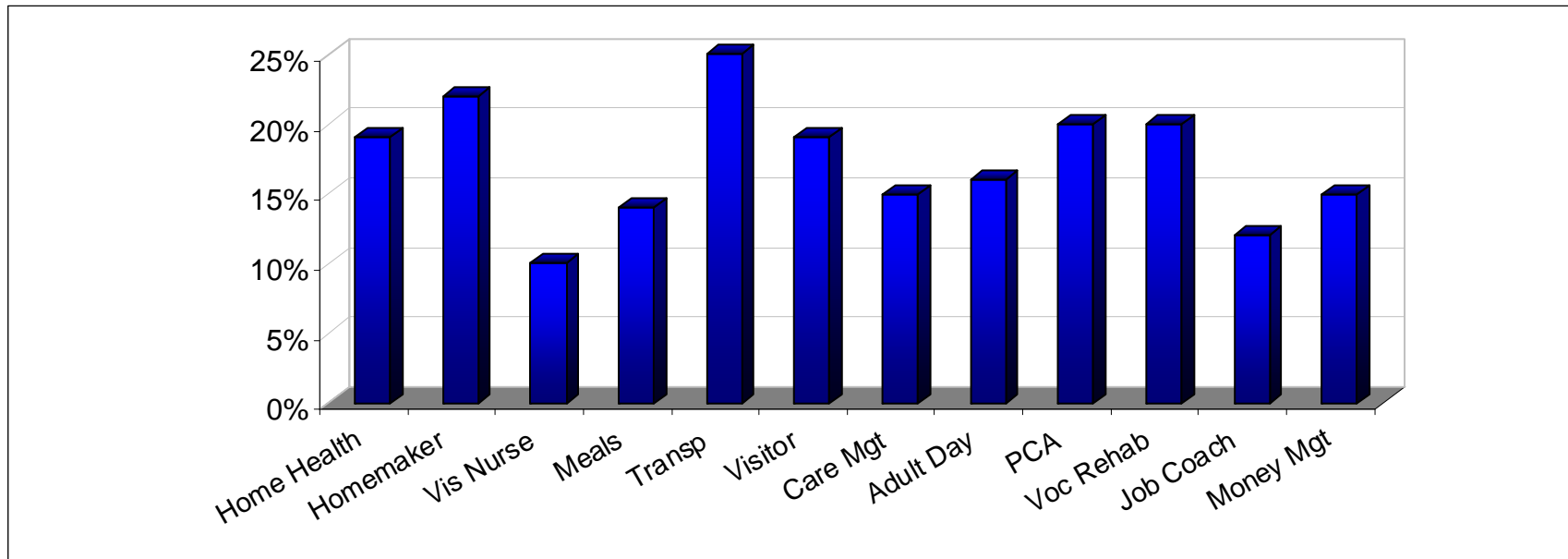
Moreover, the total number of unmet needs differs by program, as indicated in Figure V-21. Programs having the most people with 3 or more unmet needs include DDS wait, CBS, KatieB and PCA.

Figure V-21. Number of unmet needs by program



The rate of unmet need by type of community service ranged from a high of 25 percent for transportation services such as dial-a-ride or van service to a low of ten percent for visiting nurse services. Other services for which the rate of unmet need is at least 20 percent include homemaker services, personal care assistants, and vocational rehabilitation. Figure V-22 demonstrates the overall rate of unmet need for each of the 12 services.

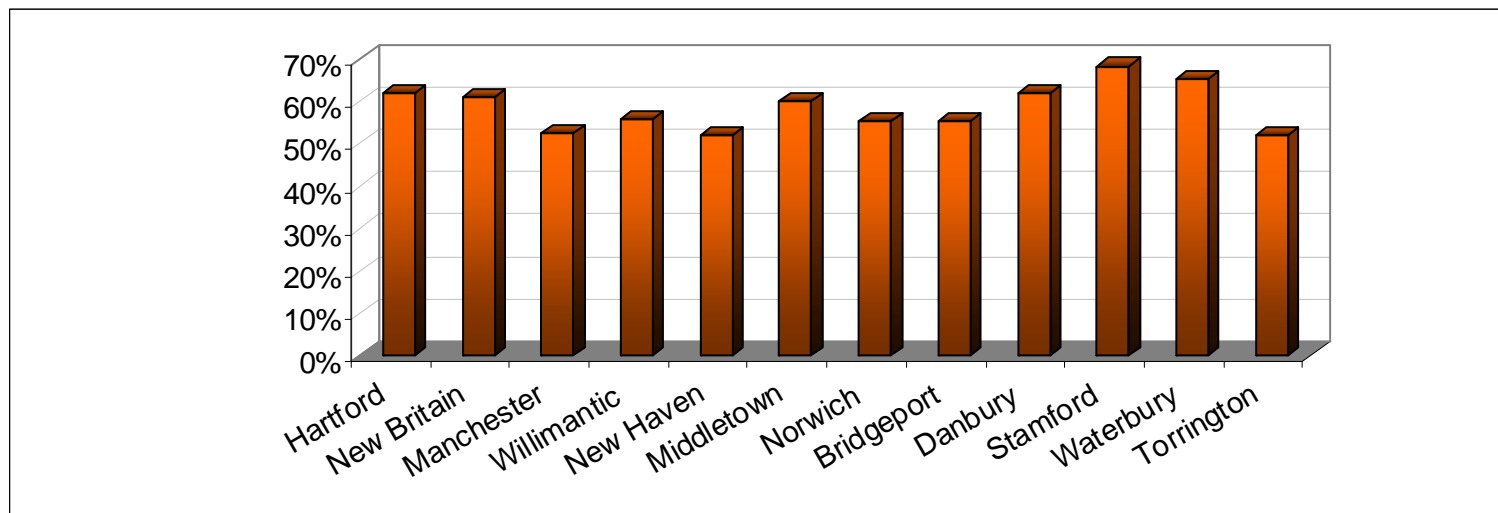
Figure V-22. Overall rate of unmet need by type of service



The rate of unmet need (defined as a deficit in one or more of the enumerated services) can also be analyzed for geographic differences. The Department of Social Services (DSS) maintains 12 regional offices in order to allow for services to be specifically targeted and delivered at a local level. (For a more detailed description, see Needs Assessment Focused Report III: An Analysis by Region.)

When analyzed by DSS region, unmet need for people with disabilities does differ somewhat by area of the state, but not to a large extent. It ranges from a low of 52 percent in the New Haven and Torrington regions to a high of 68 percent in the Stamford region. Other regions at the high end include Waterbury (65%), Hartford and Danbury (62% each). Other regions at the lower end include Manchester (53%), Norwich and Bridgeport (55 percent each). Figure V-23 summarizes these results.

Figure V-23. Unmet need by region of the state



An analysis of specific unmet needs by program also shows significant variation. In conjunction with the analysis of unmet need in the area of specific community long-term services, it is also instructive to compare the rate of current use of each service with the reported unmet need for that service. “Current users” of each service are those who answered either “using now and receiving enough” or “using now but need more.” Figures V-24a through V-24h detail both the reported current use and the reported unmet needs by program for each of the 12 community-based services enumerated in the survey.

A number of observations about home health, homemaker and visiting nurse services are salient:

- These three services are currently used most frequently by Elder, PCA, and CBS.
- They are used least frequently by BRS and DMHAS.
- Whereas Elder respondents have high current use, they have relatively low unmet need.
- PCA and CBS respondents have both high current use and relatively high unmet need for these services, particularly for homemaker services in the case of CBS.
- DDS wait has low current use but high unmet need, particularly for home health and homemaker services.
- Home health services are needed most by KatieB (38%) and PCA (34%), and least by BRS (7%) and DMHAS (9%).
- Homemaker services are needed most by CBS (44%) and DDS wait (37%) and least by Elder (11%) and DMHAS (14%).
- Visiting nurse services, while having the lowest overall rate of unmet need, are needed most by PCA and CBS (18% each) and least by DMHAS (1%) and BRS (3%).

Figure V-24a. Current use of home health, homemaker, and visiting nurse services

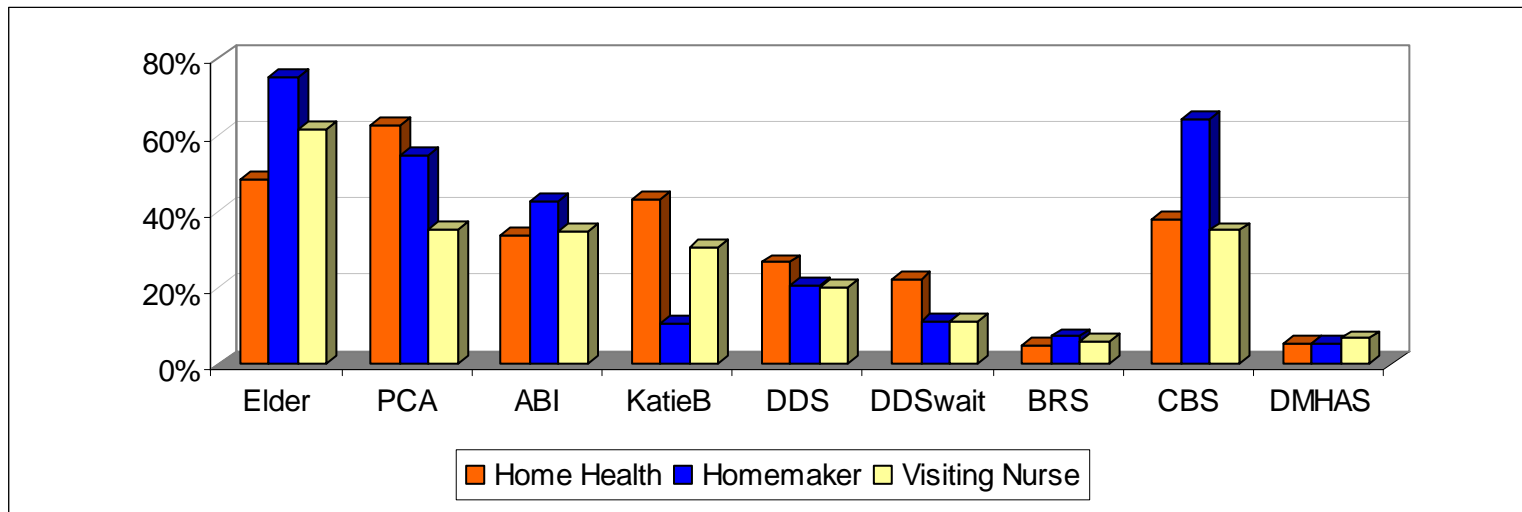
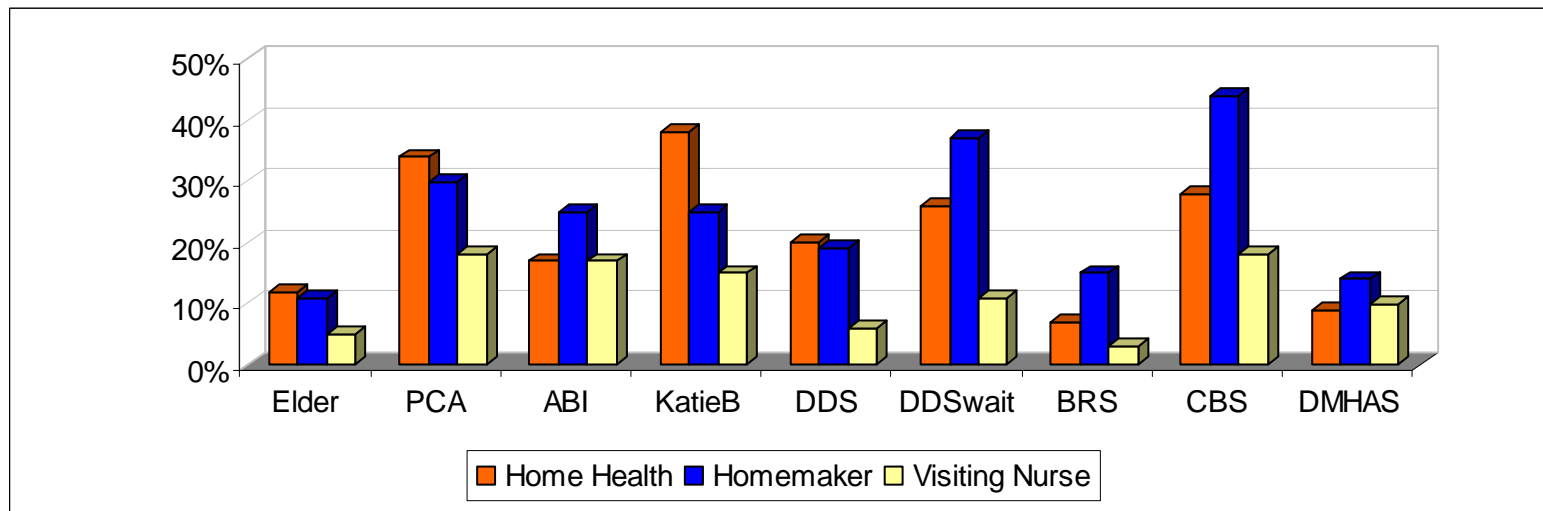


Figure V-24b. Unmet need for home health, homemaker, and visiting nurse services



Current use and unmet need for home delivered meals, transportation, and friendly visitors show a similar pattern.

- Again, Elder, PCA and CBS are among the most frequent users of these services, especially for transportation.
- Elder respondents report high current use and low unmet need for home delivered meals and transportation.
- There is very low usage of these services by KatieB, DDS wait, BRS and DMHAS while unmet need is higher, particularly for DDS wait.
- Friendly visitor services have the lowest overall current use.
- About one-fifth of CBS and DMHAS respondents identify home-delivered meals as an unmet need, compared to only seven percent of KatieB and nine percent of Elder and BRS respondents.
- Transportation, which is the highest identified unmet need overall, is a particularly high need for CBS (44%), DDS wait (36%) and ABI (35%). Even at the low end, between 15 and 20 percent of Elder, KatieB and DDS respondents identify it as an unmet need.
- Friendly visitor services are identified most often as an unmet need by CBS and ABI (32% and 27%, respectively) and least often by BRS (10%) and KatieB (11%).



Figure V-24c. Current use of home-delivered meals, transportation and friendly visitor

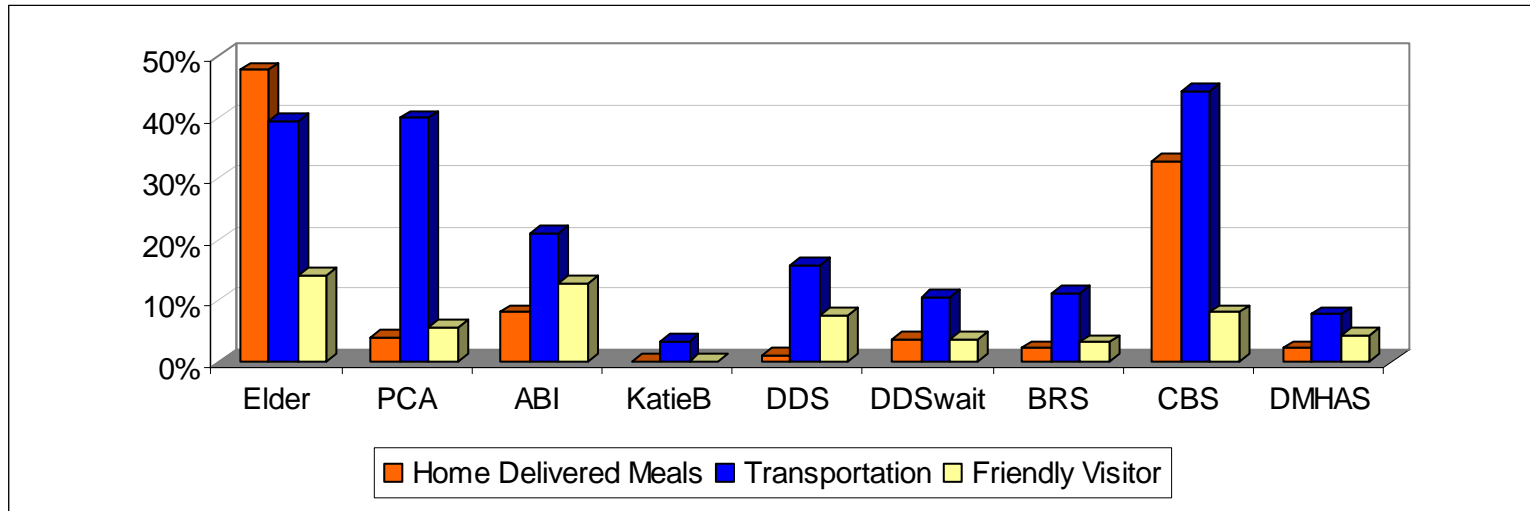
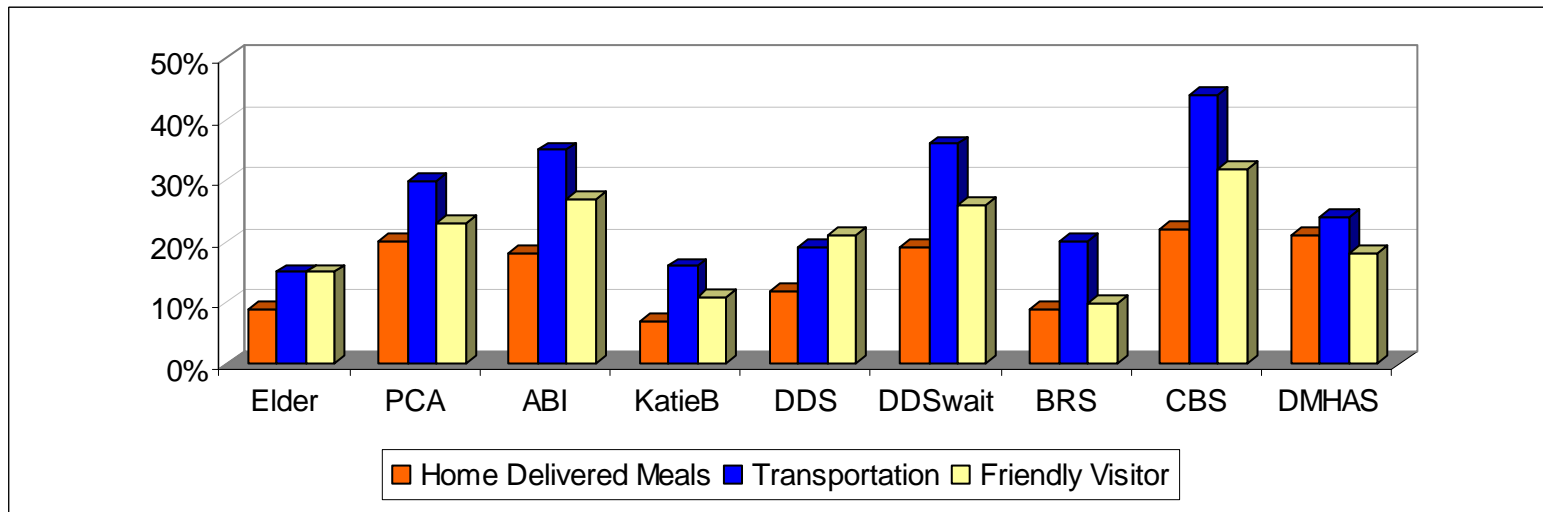


Figure V-24d. Unmet need for home-delivered meals, transportation and friendly visitor



The areas of care management, adult day programs and PCA services show some interesting contrasts.

- For care management services, Elder respondents have high current usage (67%) but low unmet need (5%).
- In addition to Elder, care management services are currently used most by ABI and Katie B (greater than 50%) and by CBS and DDS (greater than 40%).
- Care management services are nevertheless a high unmet need for DDS wait and ABI (29% and 26%, respectively), but far less so for Elder (5%), BRS (11%) and DDS (12%).
- Adult day programs are currently used most by DDS and DDS wait (35% and 27%, respectively) and by only 14% of Elder respondents.
- Adult day programs are most needed for DDS wait (35%) and ABI (29%), and least needed by BRS (6%) and Elder respondents (10%).
- Current use of PCA services is, as expected, highest among PCA respondents (83%). While that percent might be expected to be even higher for those receiving PCA waiver services, there may be instances where respondents may not currently have a PCA if, for example, they are in the process of hiring or otherwise transitioning between PCAs.
- PCA services are a particular unmet need for ABI (37%), DDS wait (36%), and, despite the fact that they are already receiving PCA waiver services, PCA respondents (35%). These services were identified as an unmet need the least by Elder and BRS respondents (9%).

Figure V-24e. Current use of care management, adult day program and PCA services

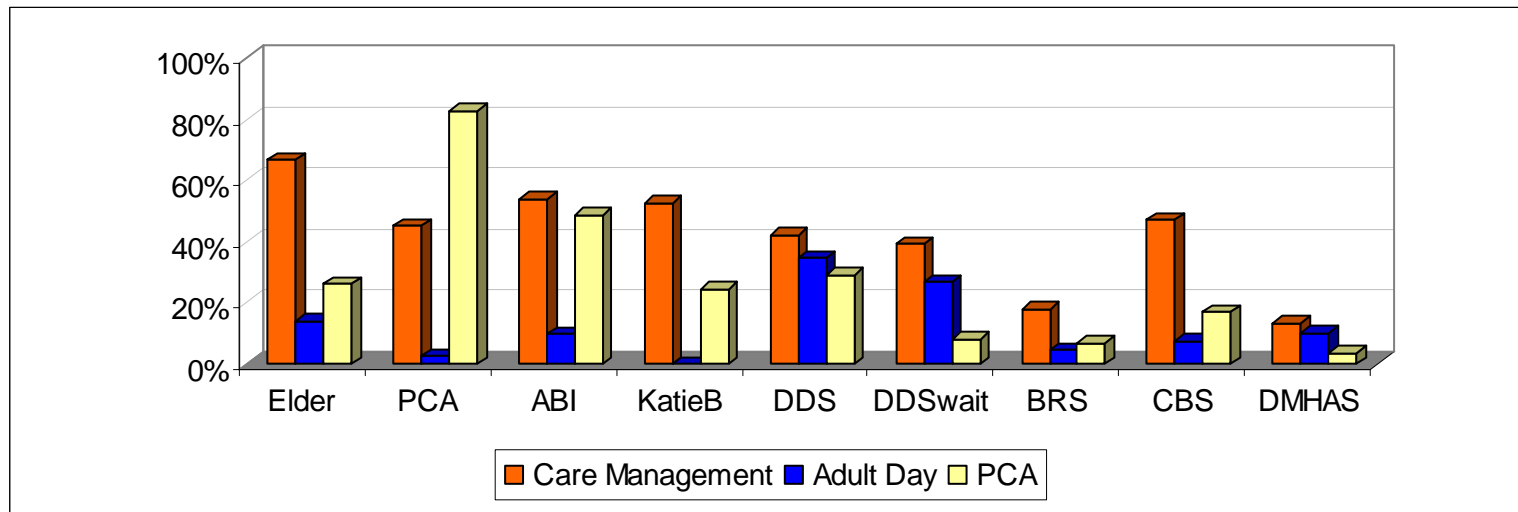
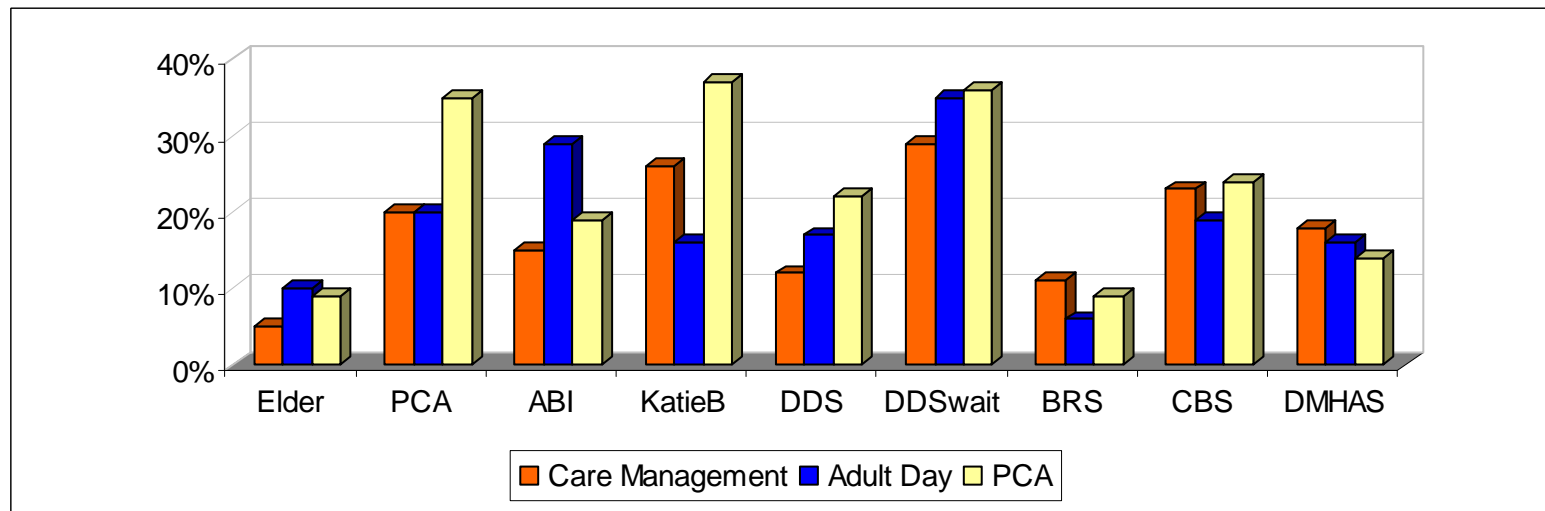


Figure V-24f. Unmet need for care management, adult day program and PCA services





Regarding vocational rehabilitation, job coaching and money management:

- The highest current users of all three services are ABI and DDS.
- Yet while ABI has among the highest unmet need for these services, DDS has among the lowest.
- Vocational rehabilitation services are needed most by ABI and PCA respondents (34% and 31%, respectively), and least by Elder (5%) and DDS (11%).
- Job coaching was identified as an unmet need most often by DDS wait (27%), and by ABI and KatieB (21% each). At the low end, only one percent of Elder and eight percent of CBS respondents identified job coaching as an unmet need.
- Money management services showed a wide range of responses, with 35 percent of DDS wait and 32 percent of DMHAS respondents reporting an unmet need. By contrast, only three percent of Elder respondents reported such a need.

Figure V-24g. Current use of vocational rehabilitation, job coach and money management

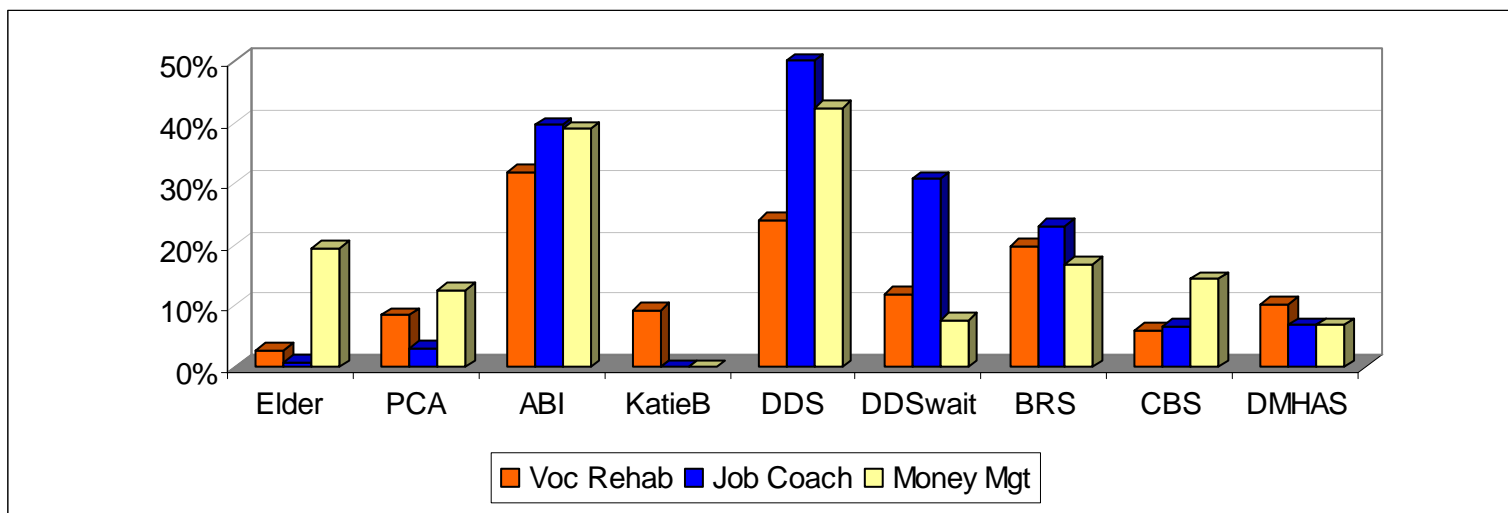
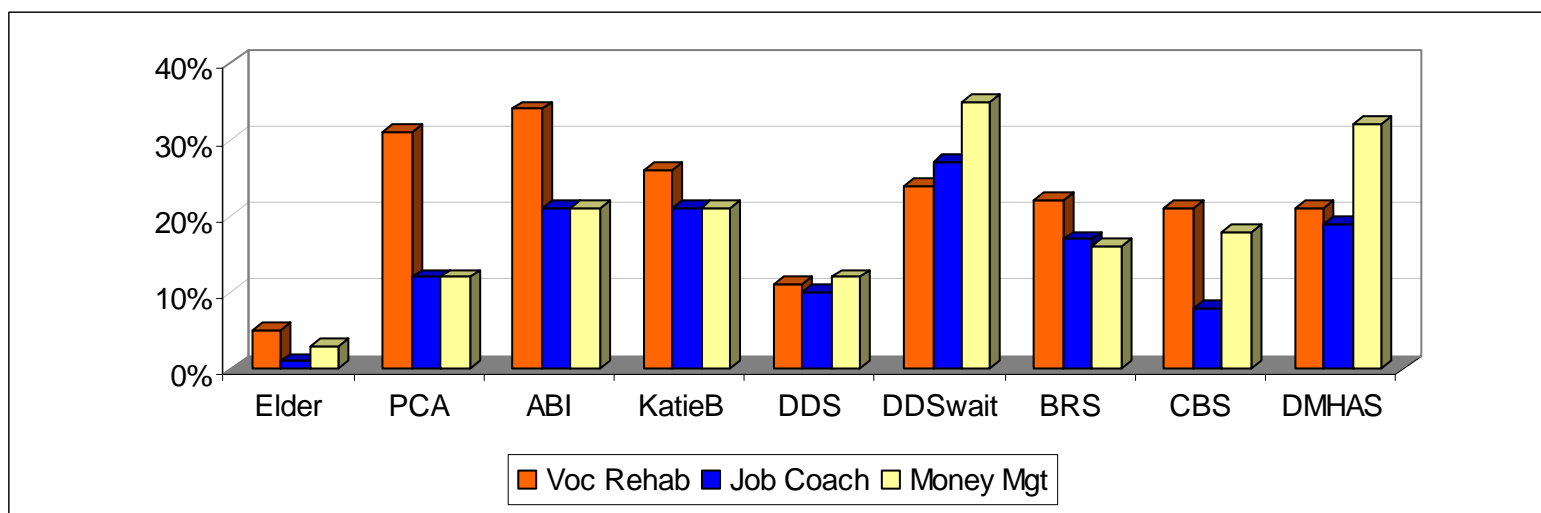


Figure V-24h. Unmet need for vocational rehabilitation, job coach and money management



Assistive devices

Many people with disabilities need and use various assistive devices to help them at home, at work, or both. The survey enumerated seven categories of assistive devices, as follows:

- 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.)

The survey then asked respondents to indicate, for each of the seven listed categories, whether they:

- Do not need it;
- Currently use it; or
- Do need it but do not have it

Unmet need for assistive devices is calculated as the percentage of people from each program who indicate for any assistive device that they “do need it but do not have it.”

Overall:

- The programs with the most unmet need for assistive devices are PCA and KatieB, followed by CBS and ABI.
- The programs with the least overall unmet need for assistive devices include DMHAS, BRS and Elder, although Elder respondents are among those with the most unmet need for devices for those who are deaf, blind, or legally blind.
- While DDS and DDS wait fall in between, DDS wait respondents exhibit more unmet need than those from DDS in most categories.
- The categories of assistive devices with the most unmet need are computer access and transportation aids
- The categories with the lowest unmet need are devices for those who are deaf, blind or legally blind.

These results are summarized in Table V-3. (Bold italicized numbers indicate highest need for each device and bold numbers indicate lowest need.)

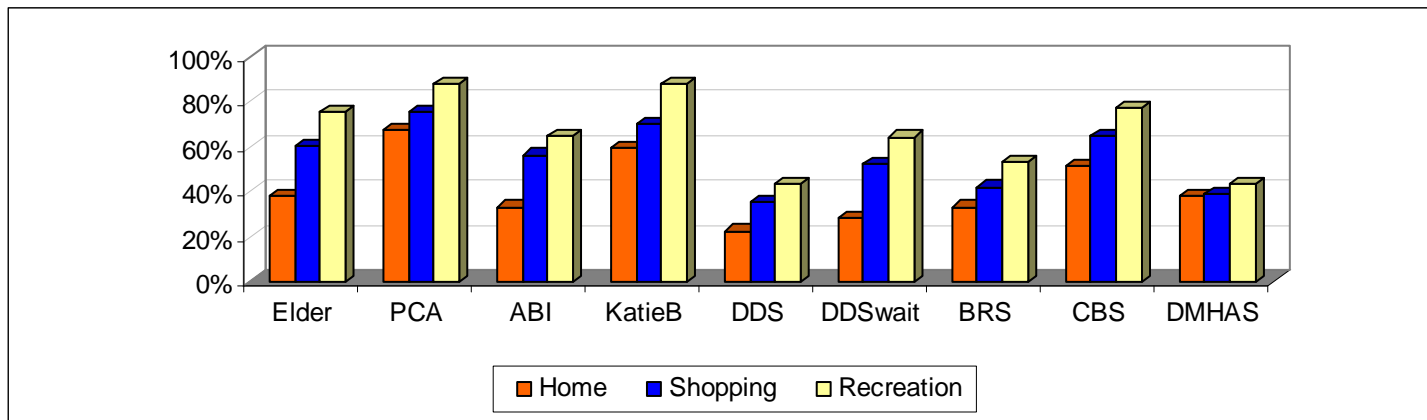
Table V-3. Percent who need assistive device but do not have it

Assistive device	Elder	PCA	ABI	KatieB	DDS	DDS wait	BRS	CBS	DMHAS
Building modifications	7	26	14	25	9	10	7	23	1
Mobility aids	10	16	11	12	5	10	6	17	1
Transportation aids	9	27	22	28	6	17	6	15	6
Computer access aids	10	30	23	33	12	29	8	19	9
Communications aids	8	20	13	23	12	18	5	9	5
Devices for people who are deaf	7	7	8	3	4	3	4	4	4
Devices for people who are blind or legally blind	8	8	9	5	4	0	3	3	1



As a follow-up to the questions concerning assistive devices, respondents were asked about the physical accessibility of their homes, the places where they shop or do errands, and the places for recreational or leisure activity in their community. They were asked for each category to check whether the place was “totally,” “somewhat,” or “not at all” accessible. The percent of respondents who indicate that each place is only “somewhat” or “not at all” accessible is summarized in Figure V-25. In each case, places of recreation have the most problems with accessibility, followed by shopping areas. Homes have the least problems with accessibility. Respondents from PCA and KatieB have the most problems with accessibility, while respondents from DDS and DMHAS have the least.

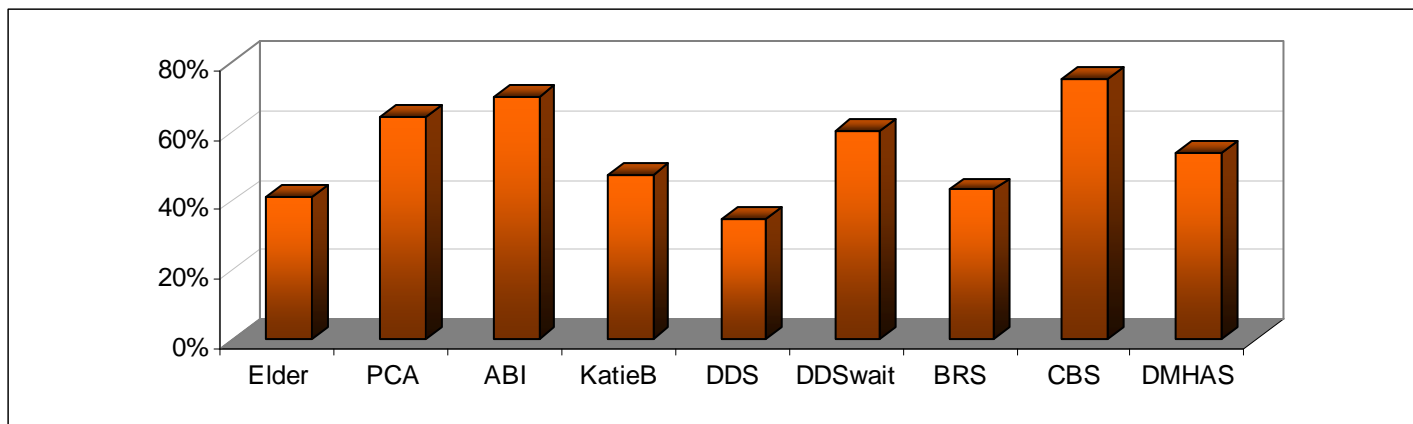
Figure V-25. Percent indicating place is “somewhat” or “not at all” accessible by program



Transportation

Transportation is identified as the greatest unmet need in the Needs Assessment overall, and among people with disabilities in particular. A more detailed examination of transportation issues reveals the magnitude of the problem, some details about transportation difficulties, and the consequences of its absence. In the Needs Assessment survey, respondents were asked to indicate what types of difficulties they have in getting the transportation they need. They could respond that they have no difficulties, or check one or more of seven enumerated transportation problems. The percentage of people in each program who indicate that they do have at least one transportation problem is summarized in Figure V-26. Programs with the highest percent of people with a transportation problem are CBS (76%), ABI (70%), and PCA (64%). Those with the lowest percent are DDS (35%) and Elder (41%).

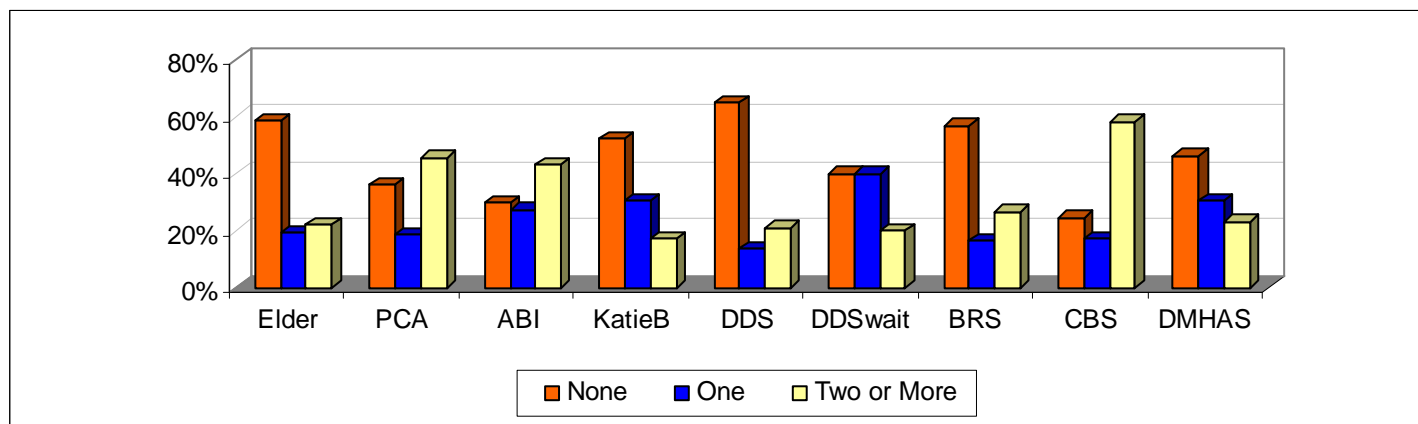
Figure V-26. Percent with at least one transportation problem by program





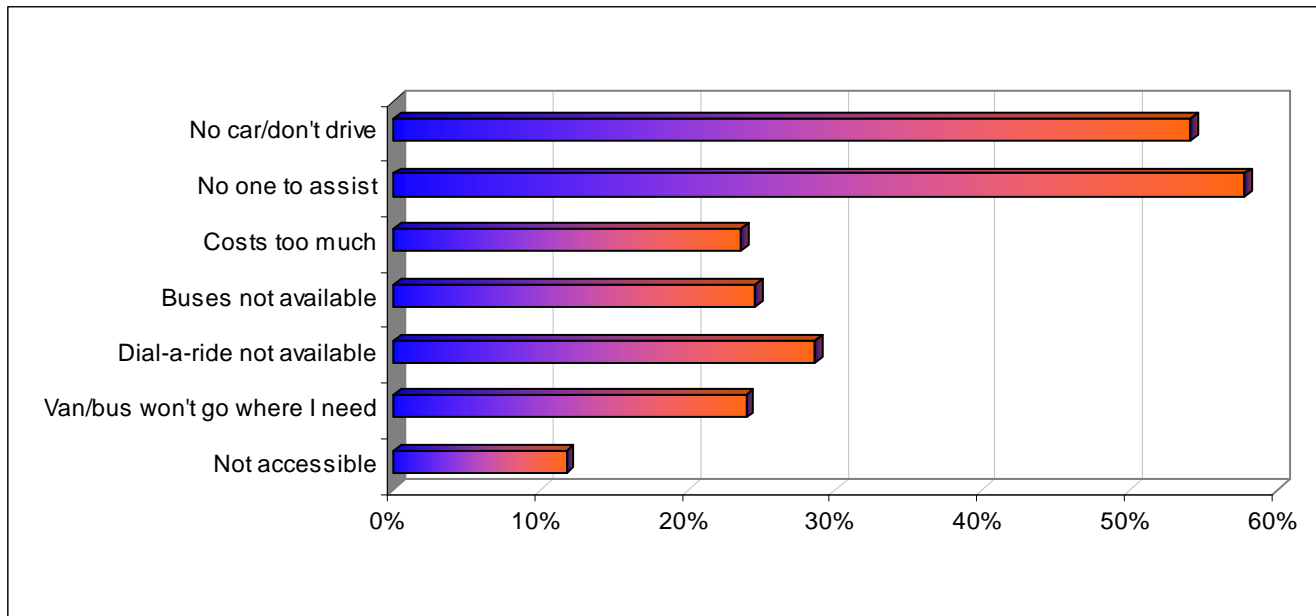
The extent of transportation problems can also be gauged by the number of problems checked by respondents, as indicated in Figure V-27 below. Programs with the highest percentage of respondents naming two or more problems include CBS (58%), PCA (46%), and ABI (43%).

Figure V-27. Number of transportation problems by program



The most frequently-named transportation problems, cited by more than half of respondents, include “no one to assist or drive me” (58%) and “no car/I do not drive” (54%). The percent of people naming each enumerated transportation problem is summarized in Figure V-28.

Figure V-28. Percent of people naming each transportation problem



Another way to measure transportation difficulty is to explore major life activities that are affected by, or made more difficult by, transportation issues. Table V-4 summarizes, for people who indicated that they do have at least one transportation problem, the percent for whom each life activity is affected by transportation problems. The activities most affected overall are shopping/errands and socializing, while going to work or job seeking is least affected overall. However, for those respondents most likely to be employed, including BRS and DMHAS, work and job seeking is affected by transportation difficulties for nearly half. DMHAS, PCA and BRS respondents have the most life activities affect by transportation difficulty (bold italics), while KatieB, DDS and Elder have the fewest (bold).

Table V-4. Percent with transportation issues for whom life activity is difficult

Activity	Elder	PCA	ABI	KatieB	DDS	DDS wait	BRS	CBS	DMHAS
Go to medical appointments	49	54	40	11	25	28	48	47	53
Shop or do errands	49	61	48	21	29	33	54	54	63
Go to work or get a job	2	20	22	14	19	22	41	17	49
Socialize or visit friends/family	34	61	56	29	43	39	50	54	49
Take part in community activities	21	46	37	32	37	39	37	39	45

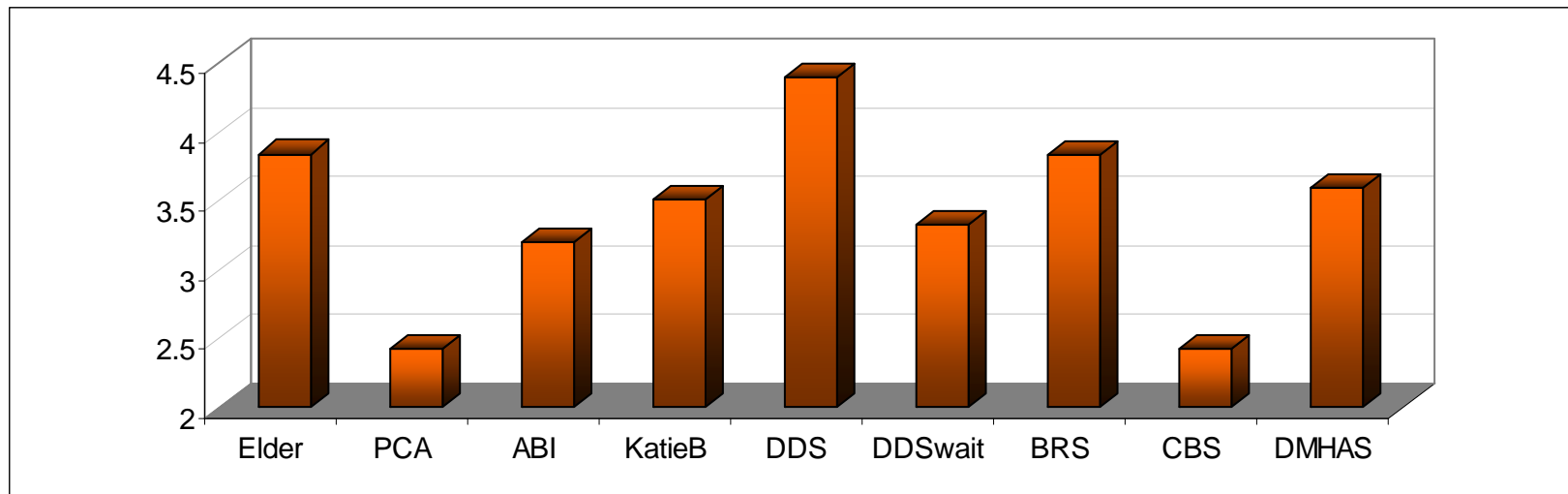
C. Quality of life indicators by program

In order to gauge the extent to which various measures of unmet need and health-related factors affect the quality of life of program participants, a new six-factor variable was created. The six factors from the Needs Assessment survey considered most important to quality of life include:

- No transportation difficulty
- Happy with amount of socialization
- Enough money to make ends meet
- No unmet long-term care services needs
- No unmet assistive device needs
- Self-rated health excellent or good

One point was given for each factor, with zero as the lowest/worst quality of life score and six as the highest/best quality of life score. By this measure, the programs whose respondents experience the highest quality of life are DDS, Elder and BRS, all with scores above 3.8. Those with the lowest quality of life score include CBS and PCA, both with scores below 2.5

Figure V-29. Quality of life score (out of 6) by program



VI. Conclusions and Program Implications

Connecticut programs that support the long-term care needs of people with disabilities, either funded or operated by state agencies, differ substantially in their target populations, eligibility requirements, and types and levels of assistance. Survey results from the Connecticut Long-Term Care Needs Assessment provide greater insight into the differences in demographics, health status, unmet service need, and need for assistance with daily living activities among beneficiaries of each program. Some key findings from survey responses in these areas include:

Health measures

There are large numbers of people in poor health, with some notable trends in a number of self-reported health measures

- CBS, Elder and PCA participants report the worst overall health. Even the programs with the best self-reported health have a significant percentage of people who report their health as only fair or poor.
- The rate of depressive symptoms is high in most programs, and seems to be related to levels of unmet need and poor overall health.
- The incidence of falls in many programs is also notably high, raising concerns about health complications (e.g., fractures), and potential need for institutionalization or greater care needs.
- Lack of preventive health care in many programs is extreme. The populations in these programs are vulnerable, many are frail, and yet many are missing basic health care. Rates of dental cleanings and wellness exams are of particular concern, with vaccinations and cholesterol screenings also lacking.
- Smoking is a significant issue for the health of the DMHAS population, which also has the highest rates of both depressive symptoms and unplanned weight gain or loss.
- Many programs have a high rate of hospitalization and emergency room visits, despite the fact that this population receives a great deal of home-based care, often including nursing.

Employment issues

Employment is a significant issue for respondents in most programs.

- Very few respondents in any program are employed full time, and while part time work is more common, only in two programs (BRS and DDS) are more than half of respondents employed in any capacity.
- Of those not currently working, a significant number of people in many programs do want to have a job, including DMHAS, BRS, ABI, PCA and DDS wait. Of those not working who do want a job, more than half of DMHAS and BRS respondents are actively looking.
- Respondents from several programs, including BRS, DMHAS, CBS, PCA and ABI, report fairly high educational levels, with more than 40% having at least some college.

Unmet need

In addition, a major focus of this report is to identify, and to the extent possible quantify, the unmet long-term care needs of respondents from each program. In analyzing unmet need it is important to bear in mind that it is unrealistic to expect to reach a level of zero unmet need. No federal or state-funded program purports to meet every need of every client in every category. While there is no “acceptable” level of unmet need to use as a benchmark, it is nevertheless instructive to gauge the rate of unmet need, to compare it by program, to identify the most serious omissions, and to make judgments about the effects of unmet need on the lives and well-being of program participants.

By any measure, the rate of unmet need reported by program participants is extremely high. As might be expected, the programs that provide the fewest services (e.g. DDS wait, CBS, and PCA) have the highest overall rate of unmet need. The unmet need identified most often across programs is transportation, which affects every aspect of daily life from health care to employment to socialization. A deeper examination of transportation issues reveals:

- More than half of respondents in most programs consider transportation a top unmet need.
- Programs with the fewest transportation needs are Elder and DDS, while CBS and ABI have the most need.
- The top reasons for transportation problems are the lack of a car/driving ability and no one available to assist.
- Transportation difficulties affect all areas of life, including medical appointments, shopping and socializing and, for those most likely to be working or job seeking (BRS and DMHAS), the ability to get a job or go to work.

An examination of both current use and unmet need for a variety of other community-based services reveals some additional conclusions:

- Elder respondents experience high current use of most community services, but low unmet need, suggesting that the program is meeting a high proportion of the need as defined by program participants.
- By contrast, DDS wait and DMHAS have low current use but relatively high unmet need in many areas, particularly job-related services such as vocational rehabilitation, job coaching and money management, suggesting that these programs may be meeting a smaller percentage of the need.
- No program indicates high current use of friendly visitor programs, though many consider it an unmet need, indicating that socialization is an important area not being addressed well.
- Visiting nurse services have the lowest overall rate of unmet need.
- Assistive devices in general are lacking most for PCA and KatieB and least by DMHAS and BRS.
- For most programs, the assistive devices with the highest unmet need are computer access and transportation aids.

Physical accessibility is a larger problem for recreation and shopping than it is for respondents’ homes, although home accessibility is still an issue for more than a third of respondents in most programs.

Quality of life

A six-measure variable was created that is designed to combine factors considered most important to quality of life for survey respondents. It examines answers to survey questions concerning transportation, socialization, ability to meet financial needs, presence of unmet long-term care service or assistive technology needs, and self-rated health. By this measure, respondents with the highest quality of life are from DDS, Elder and BRS, with CBS and PCA at the low end.

Policy and program implications

Connecticut's programs to aid people with disabilities are meeting many of the needs of their target populations. However, the forceful message from survey respondents reminds us that numerous gaps remain. Moreover, the various measures of health status as well as unmet needs for long-term care services differ substantially by program. These results reinforce the need for acting in accordance with the guiding principles initially set out in the Needs Assessment:

- Create parity among age groups, across disabilities, and among programs through allocating funds equitably among people based on their level of need rather than on their age or type of disability.
- Break down silos that exist within and among state agencies and programs.

The nine programs examined in detail in the Needs Assessment and in this report, as well as other programs designed to meet the needs of people with disabilities in Connecticut, in many cases purposely differentiate their services based on age and/or type of disability. Moreover, they create silos that are difficult to penetrate, and achieve uneven results for their clients.

Of particular concern are rates of depressive symptoms, incidence of falls, lack of preventive health care, and high rates of hospital admissions and emergency room visits, which may be risk factors for future institutionalization or death. Unmet needs in each program differ substantially, but this report identifies shortfalls in each program that should be examined. The transportation issue is common to most programs and is shared by many in the general population, as evidenced by the results of the Needs Assessment. For people with disabilities, however, the issue is more acute, and is being tackled as a major initiative of Connecticut's Medicaid Infrastructure Grant ("Connect-Ability"). These efforts should be supported. The lack of employment supports and opportunities for those who want to work is also notable. Unmet needs in many programs are standing in the way of employment goals for many. On the positive side, interest in finding employment is high in many programs. Employment efforts for people with disabilities throughout the state are also being supported by Connect-Ability.

It is important that state officials with legislative, administrative and oversight responsibilities for these programs consider the recommendation in the Needs Assessment to strive for a universal waiver with consistent requirements across ages and disabilities. At the program level, administrators and others concerned with the well-being of the population within each program can derive additional insight into the extent of missing services and their effect on quality of life by examining the detailed results contained in

this report. Through concerted efforts Connecticut officials, people with disabilities, and their advocates can improve not only program administration and fiscal outcomes, but quality of life for all.



VII. References

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- Robison, J., Gruman, C., Curry, L., Shugrue, N., Kellett, K., Porter, M. et al (2007). *Connecticut long-term care needs assessment*. Hartford, CT: University of Connecticut Health Center. Access at: http://www.uconn-aging.uchc.edu/res_edu/assessment.html.