



C.H.A.I.N 2012-2 BRIEF REPORT

Home Care Service Need and Utilization

Yoav Vardy

María Cabán

Peter Messeri

Columbia University
Mailman School of Public Health
In collaboration with the NYC Department of Health and Mental Hygiene,
the Westchester Department of Health,
the HIV Health & Human Services Planning Council of New York,
and Public Health Solutions

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Background

Dramatic improvement in health among PLWHA as a result of widespread access to antiretroviral therapy has substantially reduced the need for home care. However, the reduced need for home care related to improved HIV health outcomes may be partially offset by increasing disabilities related to both HIV and non-HIV chronic health conditions in an aging HIV population. This brief report summarizes trends in home care service utilization for CHAIN's New York City 2002 and Tri-County 2001 cohorts. The tables present detailed information on what types of services are received at home, the characteristics of users of home care, and whether home care is targeted at those most in need as measured by physical disability or perceived need.

Study Variables

Home care utilization. CHAIN participants were considered to have received home care at each round of interview if they answered yes to *in the past six months, have you received any help or assistance at home? This help could be for medical problems, for help with personal care or housekeeping, or other services that you might need at home.* Those responding "yes" were then asked to list each organization providing home care, the number of days visited by providers from each organization, the type of help received (medical care, personal care, light housekeeping, counseling, meals, help with children, other) and the occupation of the home care provider (MD, nurse, nurse's aide, social worker, case manager, physical therapist, home health aide, mental healthcare provider). Multiple responses are possible for answers to each of these questions.

Satisfaction with home care services. Respondents who reported having received home-based services were also asked, *Overall how satisfied were you with the care and service that you received from this person who helped you...* and the care and service *"..that you get from this agency?"*. The possible responses are very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied.

Need for home care. In the absence of a generally accepted standard for measuring the need for home care, we investigated two alternative approaches to measuring need.

Perceived Need: Please tell me if, in the last six months... you had a problem or needed assistance for home care.

Physical Functioning Measures: We also approached need for home care based on various measures in the CHAIN dataset that tap into limitations on physical functioning. These include the 12-item physical component summary scale (PCS) and two subscales: a 2-item physical functioning subscale (Physical Functioning subscale) and a 2-item role limitations

subscale (Physical Limitations subscale). See appendix for the wording of the items forming the subscales. The subscales are normed on a scale of 0 to 100, in which 50 represents the average value of these scales for national samples of the general population. A literature review failed to find application of these scales for home-bound populations that might serve as norms for home care need. In the absence of an external standard or cut point for defining home care need, we followed an empirically driven strategy. First we combined all observations for these scales for both NYC and Tri-County cohorts, and then selected two cut points for each scale that were closest to the lowest 15% and 25% of all observations. We assumed that need for home care services should increase with lower values on these scales. The cut points and percentiles for each scale are reported below:

<u>Scale</u>	<u>Cut point</u>	<u>Percentile</u>
Physical limitations	12.5	15 %
	25	25 %
Physical functioning	0	17 %
	25	29 %
PCS	30	15 %
	34	25 %

In the tables below, we examine how well each of the six cut points and the perceived need variable create “need for home care” classifications that distinguish rates of use of home care services between individuals who do and do not “need” home care. We compared the seven need variables with respect to targeting and coverage. Targeting is operationally measured as the percentage of *people receiving home care* who meet the criteria for need. Coverage is the percentage of people *in need* who receive home care. There is a tradeoff between targeting and coverage, which we explore below.

The following tables and figures are introduced by brief summaries of key findings.

New York City

I. Table 1 shows that during the nine years of the observation period, CHAIN NYC cohort members' use of home care rose from 10% at baseline to 13% by Round 6 interviews. The refresher sample has a substantially lower rate of home care use, at 8%.

Table 1: Home care services utilization, 6 months prior to interview, NYC.

Past 6 months	Round 1 2002- 2004	Round 2 2004- 2005	Round 3 2005- 2007	Round 4 2007- 2008	Round 5 2008- 2009	Round 6 2009- 2011	Refresher 2009-2010
Total N	693	548	481	400	383	357	489
Any home care	10%	12%	13%	13%	13%	13%	8%
Frequency*							
<i>Frequent Home Care Use</i>	4%	6%	7%	6%	3%	4%	3%
<i>Episodic Home Care Use</i>	5%	5%	5%	6%	3%	4%	3%
<i>Missing</i>	1%	1%	1%	1%	7%	5%	2%

*Frequency of Home Care Services

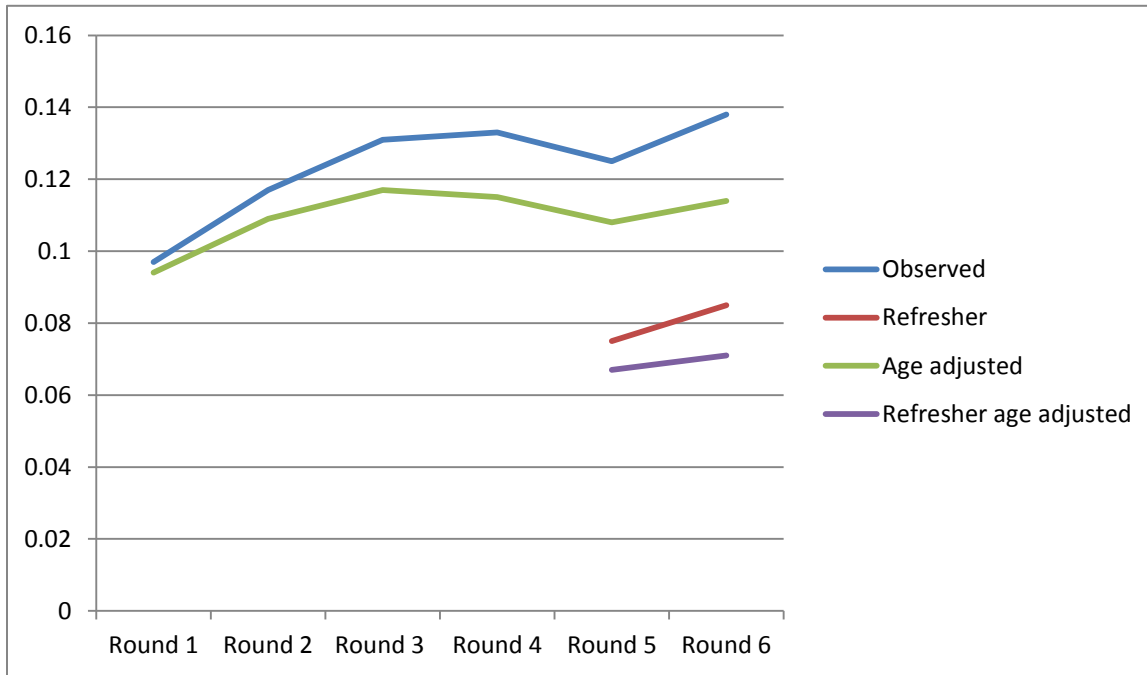
Frequent Use- report being visited by a provider for 24 days or more during the past 6 months (≥ 24)

Episodic Use- report being visited by a provider fewer than 24 days during the past 6 months (< 24)

Missing- no information on frequency available

II. The increase in home care use is mainly a consequence of the aging of the 2002 cohort. This can be seen in Figure 1, which displays observed trends in home care with a trend line in which the effects of aging are removed. Age differences, however, do not account for the falloff in home care for the refresher sample. This difference remains to be explained.

Figure 1: Secular trends in home care use before and after adjusting for cohort aging, NYC.



III. Table 2 displays a round-by-round breakdown of types of services received for frequent and episodic home care, and Table 3 highlights the types of services (by frequent or episodic use) for Round 6 alone, combining the NYC 2002 and refresher cohorts. Medical care and light housekeeping are the two most common types of home care. (Note: the sum of percentages for multiple response categories can exceed 100%.) While housekeeping support has always been reported by over 50% of home care recipients, medical care has become a greater proportion of home care services in recent years. The most frequent providers of home care at the current round of interviews were visiting nurses and home health aides. Among cohort members receiving home care at Round 6 interviews, 39 reported an average of 38 visits from a nurse in the last six months, and 52 received an average of 94 visits by home health aides in the last six months (data not shown).

Table 2: Type and frequency of home care services received in the past 6 months, NYC.

	Round 1 2002-2004		Round 2 2004-2005		Round 3 2005-2007		Round 4 2007-2008		Round 5 2008-2009		Round 6 2009-2011		Refresher 2009-2010	
Total N	67		64		63		53		49		48		39	
Frequency*	F	E	F	E	F	E	F	E	F	E	F	E	F	E
N	27	40	32	32	33	30	24	29	11	38	13	35	13	26
Service Type														
<i>Medical Care</i>	19%	27%	56%	34%	36%	37%	17%	66%	100%	29%	85%	40%	92%	54%
<i>Counseling</i>	0%	2%	3%	9%	3%	7%	0%	10%	0%	0%	31%	9%	8%	4%
<i>Personal Care</i>	22%	22%	37%	31%	42%	17%	50%	34%	54%	24%	46%	37%	62%	50%
<i>Light Housekeeping</i>	85%	50%	72%	75%	82%	57%	92%	66%	64%	76%	70%	80%	92%	77%
<i>Delivered Meals</i>	7%	2%	6%	3%	9%	0%	8%	3%	0%	8%	0%	0%	0%	0%
<i>Help with Children</i>	19%	7%	16%	16%	6%	17%	25%	3%	0%	13%	0%	3%	0%	8%
<i>Other</i>	26%	15%	25%	22%	18%	10%	12%	21%	9%	21%	0%	26%	8%	12%

* F= Frequent Use E=Episodic Use and missing frequency data

Table 3: Type and frequency of home care services received from formal providers at Round 6 interviews in the past 6 months, NYC.

	Current* (2009-2011)	
Total N	87	
	Frequent Use	Episodic Use**
N	26	61
Service Type		
<i>Medical Care</i>	88%	46%
<i>Counseling</i>	19%	7%
<i>Personal Care</i>	54%	43%
<i>Light Housekeeping</i>	81%	79%
<i>Delivered Meals</i>	0%	0%
<i>Help with Children</i>	0%	5%
<i>Other</i>	4%	20%

*Includes Round 6 & Refresher

**Includes missing

IV. At most rounds of interviews, over two-thirds of the CHAIN cohort members were very satisfied with both the specific people providing their home care and the home care agency in general.

Table 4: Satisfaction with home care provider service and agency in the past 6 months, NYC.

	Round 1 2002-2004		Round 2 2004-2005		Round 3 2005-2007		Round 4 2007-2008		Round 5 2008-2009		Round 6 2009-2011		Refresher 2009-2010	
Total N	67		64		63		53		49		48		39	
Frequency*	F	E	F	E	F	E	F	E	F	E	F	E	F	E
N	27	40	32	32	33	30	24	29	11	38	13	35	13	26
Very Satisfied														
Home Care Provider	74%	65%	66%	69%	70%	47%	62%	45%	55%	63%	85%	74%	85%	77%
Home Care Agency	81%	57%	75%	75%	67%	47%	58%	59%	82%	61%	85%	71%	85%	73%

* F= Frequent Use E=Episodic Use (includes missing)

V. Table 5 presents rates of targeting and coverage of home care services for each of the operational measures of home care need. Higher cut points necessarily improve targeting while reducing coverage. Examination of the results for the current interviews indicates that the three most discriminating need measures (relatively high levels of targeting without a sharp reduction in coverage) were PCS less than or equal to 34 (N=140 of 643 interviewed at Round 6); physical functioning less than or equal to 25 (N=179); and a physical functioning score of 0 (N=125). Because it retains good discrimination while defining a relatively small group in need, (less than 20% of the cohort interviewed at Round 6) we have chosen to use physical functioning=0 to define need in the rest of the tables presented below. Physical functioning of 0 is the lowest possible value on this scale and corresponds to physical health that “limits a lot... moderate activities, like moving a table, carrying groceries, or pushing a vacuum cleaner” and “climbing several flights of stairs.” See appendix for complete wording of scale questions.

When this criterion is used to measure home care need, home care is received by 33% of those in “need” of these services, compared to 6% not in need.

Table 5: Use and need for home care services: targeting and coverage.

	Rounds 1 to 5 (2002-2009)		Round 6 (2009-2011)	
	Targeting (N=310 Used H.C.)	Coverage	Targeting (N=73 Used H.C.)	Coverage
Perceived Need for Home Care	35%	76%	18%	93%
PCS<=34	51%	24%	60%	31%
PCS<=30	36%	27%	44%	35%
Physical Functioning<=25	62%	26%	70%	28%
Physical Functioning=0	44%	33%	58%	34%
Physical Limitations<=25	49%	19%	51%	28%
Physical Limitations<=12.5	30%	20%	30%	37%

VI. Table 6 shows group differences in need and use of home care, and the results of a multiple regression analysis that simultaneously measured the effects of all subgroups. Findings indicate that subgroups with greatest need for home care were those 50 and older, and those with CD4 counts below 200. Use of home care services was highest among women, whites, and those over 50.

Table 6: Need for home care services: selected characteristics, NYC.

	Past (2002-2009)		Current (2009-2011)	
	Need	Utilization	Need	Utilization
Total	325	310	125	73
%	16%	12%	22%	11%
Gender				
<i>Male</i>	13%	8%	18%	9%
<i>Female</i>	20%*	17%*	22%	14%*
Race/ Ethnicity				
<i>White</i>	19%	14%	24%	22%
<i>Black</i>	14%	11%	17%	9%
<i>Latino</i>	18%*	12%	23%	11%*
Age Group				
<i>Age 19-39</i>	8%	10%	10%	4%
<i>Age 40-49</i>	14%	9%	17%	9%
<i>Age 50+</i>	20%*	14%*	23%*	15%*
CD4				
<i>0-199</i>	21%	11%	26%	13%
<i>200-349</i>	15%	13%	14%	14%
<i>350-499</i>	15%	10%	21%	13%
<i>500+</i>	14%*	12%	15%*	8%
Borough of Residence				
<i>Bronx</i>	16%	11%	22%	10%
<i>Brooklyn</i>	16%	11%	17%	11%
<i>Manhattan</i>	14%	12%	18%	11%
<i>Queens</i>	16%	14%	25%	15%
<i>Staten Island</i>	26%	7%	26%	13%
Place of Birth				
<i>U.S.</i>	17%	12%	19%	8%
<i>Puerto Rico (P.R.)</i>	17%	11%	30%	17%
<i>Outside U.S. & P.R.</i>	11%*	11%	16%	15%
Homeless				
<i>Yes</i>	16%	5%	18	3%
<i>No</i>	16%	13%	31%*	12%*
Mental Health				
<i>Poor (MCS<37)</i>	12%	9%	12%	9%
<i>Good (MCS>=37)</i>	18%*	12%*	22%*	12%
Substance Use				
<i>Never Used</i>	16%	14%	21%	14%
<i>Past User</i>	16%	13%	18%	12%
<i>Current User</i>	15%	6%*	20%	5%*
HIV Medical Care Setting				
<i>HHC</i>	15%	8%	15%	8%
<i>Voluntary Hospital</i>	18%	14%	18%	15%
<i>Community Health Centers/Clinic</i>	21%	11%	21%	8%
<i>Drug Treatment</i>	22%	5%	22%	6%
<i>Social Service</i>	24	3%	27%	4%

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	Past (2002-2009)		Current (2009-2011)	
	Need	Utilization	Need	Utilization
<i>Private MD</i>	13%*	7%*	28%	3%*

*p<.05

Tri-County

I. Use of home care in Tri-County has increased from 9% to 13% during the first three rounds of interviews and has declined in recent years, notably in rounds 5 and 6 that corresponds to the change in design to a repeated cohort study. In contrast to NYC, the trend over time is not strongly related to aging of the cohort. Home Care in Tri-County is mainly episodic in nature.

Table 7: Home care services utilization, 6 months prior to interview, Tri-County.

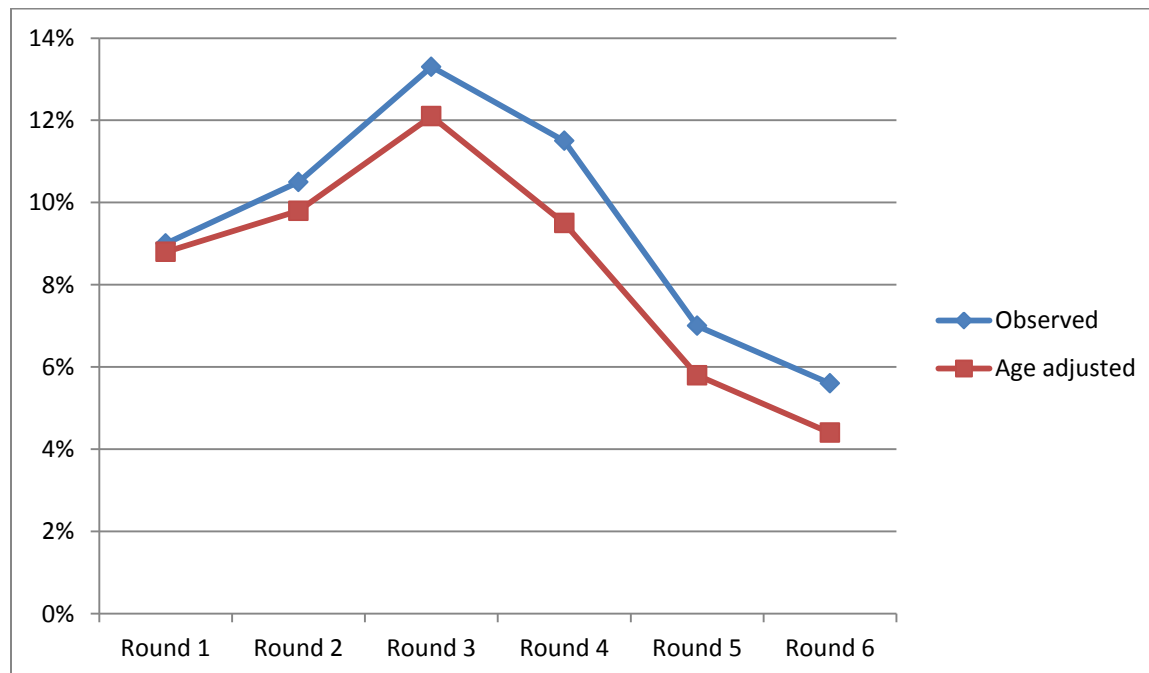
Past 6 months	Round 1 2001- 2003	Round 2 2003- 2004	Round 3 2004- 2007	Round 4 2005- 2007	Round 5 2008- 2010	Round 6 2010-2012
Total N	398	315	338	234	302	251
Any home care	9%	10%	13%	12%	7%	6%
Frequency*						
Frequent Home Care Use	~0%	~0%	4%	4%	6%	~0%
Episodic Home Care Use	8%	9%	8%	6%	1%	3%
Missing	1%	1%	1%	2%	~0%	3%

*Frequency of Home Care Services

Frequent Use-report being visited by a provider for 24 days or more during the past 6 months (≥ 24)

Episodic Use report being visited by a provider less than 24 days during the past 6 months (< 24)

Figure 2: Secular trend in home care use before and after adjusting for cohort aging, Tri-County.



II. Medical care, personal care, and light housekeeping were the most commonly reported home care services.

Table 8: Type and frequency of home care services received in the past 6 months, Tri-County.

	Round 1 2001-2003		Round 2 2003-2004		Round 3 2004-2007		Round 4 2005-2007		Round 5 2008-2010		Round 6 2010-2012	
Total N	36		33		45		27		21		14	
Frequency*	F	L	F	L	F	L	F	L	F	L	F	L
N	0	36	1	32	14	31	10	17	17	4	1	13
Service Type												
<i>Medical Care</i>	N/A	44%	N/A	31%	36%	39%	10%	47%	29%	25%	NA	31%
<i>Counseling</i>	N/A	6%	N/A	0%	7%	3%	0%	6%	0%	0%	N/A	8%
<i>Personal Care</i>	N/A	39%	N/A	59%	36%	45%	70%	41%	29%	25%	N/A	62%
<i>Light Housekeeping</i>	N/A	64%	N/A	72%	93%	71%	100%	59%	76%	50%	N/A	77%
<i>Delivered Meals</i>	N/A	11%	N/A	12%	7%	10%	0%	6%	0%	0%	N/A	8%
<i>Help with Children</i>	N/A	6%	N/A	9%	0%	0%	10%	0%	6%	0%	N/A	15%
<i>Other</i>	N/A	8%	N/A	19%	21%	29%	30%	12%	24%	0%	N/A	8%

* F= Frequent Use L=Light Use (includes missing)

III. In general, large majorities of recipients were very satisfied with the particular home care services they received, as well as the agencies involved as a whole.

Table 9: Satisfaction with service from formal home care provider and from agency in the past 6 months, Tri-County.

	Round 1 2001-2003		Round 2 2003-2004		Round 3 2004-2007		Round 4 2005-2007		Round 5 2008-2010		Round 6 2010-2012	
Total N	36		33		45		27		21		14	
Frequency*	F	E	F	E	F	E	F	E	F	E	F	E
N	0	36	1	32	14	31	10	17	17	4	1	13
Very Satisfied												
<i>Home Care Provider</i>	N/A	56%	N/A	72%	57%	55%	100%	65%	59%	75%	N/A	69%
<i>Home Care Agency</i>	N/A	53%	N/A	66%	64%	77%	70%	71%	59%	50%	N/A	69%

* F= Frequent Use E=Episodic Use

IV. Small sample sizes make the comparison of home care need measures difficult. Consequently we chose the physical functioning = 0 to be consistent with NYC although its discrimination properties are not as strong in Tri-County compared to other measures. Nonetheless, 46% of the 35 Tri-County participants who received home care fell into this relatively strict definition of need. Although only 18% of those needing home care received these services, this was considerably higher than the 4% at higher levels of physical functioning.

Table 10: Use and need for home care services: targeted and coverage.

	Rounds 1 to 4(2002-2009)		Rounds 5 & 6 (2010-2012)	
	Targeted (N=141 used H.C.)	Coverage	Targeted (N=35 Used H.C.)	Coverage
Perceived Need for Home Care	24%	43%	9%	50%
PCS<=34	53%	23%	49%	12%
PCS<=30	39%	27%	34%	13%
Physical functioning<=25	51%	19%	69%	15%
Physical Functioning=0	32%	22%	46%	18%
Physical Limitations<=25	41%	27%	54%	14%
Physical Limitations<=12.5	28%	30%	34%	19%

V. The findings of Table 11 combined with a multiple regression analysis indicate that the groups with the highest need for home care were those over 50 and those with CD4 counts below 200. The groups with the highest use of home care were women, older cohort members, and those with low CD4 counts.

Table 11: Need for home care services: selected characteristics, Tri-County.

	Past (2002-2009)		Current (2010-2012)	
	Need	Utilization	Need	Utilization
Total	144	141	87	35
%	12%	11%	16%	6%
Gender				
<i>Male</i>	9%	9%	14%	3%
<i>Female</i>	15%*	13%*	17%	9%*
Race/ Ethnicity				
<i>White</i>	11%	14%	24%	5%
<i>Black</i>	13%	12%	15%	7%
<i>Latino</i>	10%	7%*	11%*	6%
Age Group				
<i>Age 19-39</i>	7%	4%	8%	2%
<i>Age 40-49</i>	12%	12%	13%	7%
<i>Age 50+</i>	16%*	13%*	21%*	7%*
CD4				
<i>0-200</i>	15%	15%	23%	13%
<i>201-350</i>	13%	11%	18%	4%
<i>351-500</i>	10%	10%	15%	7%
<i>500+</i>	10%*	9%	12%	6%
County of Residence				
<i>Putnam</i>	0%	16%	NA	NA
<i>Rockland</i>	10%	9%	15%	10
<i>Westchester</i>	13%*	11%	16%	6%
Place of Birth				
<i>U.S.</i>	12%	12%	16%	7%
<i>Puerto Rico</i>	9%	4%	14%	10%
<i>Foreign Born</i>	13%	9%	16%	6%
Homeless				
<i>Yes</i>	10%	4%	13%	2%
<i>No</i>	12%	11%	16%	7%
Mental Health				
<i>Poor (MCS<37)</i>	10%	9%	11%	5%
<i>Good (MCS>=37)</i>	13%*	12%	18%*	7*
Substance Use				
<i>Never Used</i>	10%	12%	16%	8%
<i>Past User</i>	14%	12%	15%	6%
<i>Current User</i>	8%*	7%	17%	4%
HIV Medical Care Setting				
<i>Voluntary Hospital</i>	12%	13%	18%	7%
<i>CHC/Clinic</i>	8%	6%	11%	6%
<i>Social Service</i>	43%	12%	NA	NA
<i>Private MD</i>	10%*	11%*	8%*	4%

*p<.05

Appendix 1: CHAIN questionnaire items utilized in home care need and utilization analyses.

Home Health Care (Section J, Q.10, pg.66, W6 Follow-up)

In the past six months, have you received any help or assistance at home? This help could be for medical problems, for help with personal care or housekeeping, or for other services you might need at home.

Formal Provider Only:

- Number of home care providers visited respondent in the last 6 months.
- Type of Assistance from Formal Provider: 1. Medical care, 2. Personal care, 3. Light housekeeping, 4. Counseling, 5. Meals delivered, 6. Help with children, 7. Other
- Number of days respondent was visited by provider in the last 6 months.

2 Qs on Satisfaction (*Formal Provider Only*):

Satisfaction with care received from provider and Satisfaction with service from agency.

Home Care (Section L, Q.25, pg.105, W6 Follow-up)

Need: Did you need help or assistance with home care (help with activities of daily living) in the last six months?

Received: In the last six months, have you received any services for home care (help with activities of daily living)?

Physical Functioning (2 items: Section B, Q.18, pg.8, W6 Follow-up)

Does your health now limit you in these activities? If so, how much?

1. Moderate activities, like moving a table, carrying groceries, or pushing a vacuum cleaner
 1. Limited a lot
 2. Limited a little
 3. Not limited at all
2. Climbing several flights of stairs
 1. Limited a lot
 2. Limited a little
 3. Not limited at all

Role limitations due to physical health (2 items: Section B, Q.19, pg.8, W6 Follow-up)

Now I would like to find out if your health has interfered with your regular daily activities, including work. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

1. Accomplished less than you would like
 1. All of the time
 2. Most of the time
 3. Some of the time
 4. A little of the time
 5. None of the time
2. Been limited in the kind of work or other activities you could do
 1. All of the time
 2. Most of the time
 3. Some of the time
 4. A little of the time
 5. None of the time