



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



FOLLOWING AN ADMISSIONS COHORT:

CARE MANAGEMENT, CLAIM EXPERIENCE AND TRANSITIONS AMONG AN ADMISSIONS COHORT OF PRIVATELY INSURED DISABLED ELDERS OVER A 16 MONTH PERIOD

May 2007

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**FOLLOWING AN ADMISSIONS COHORT:
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Transitions among an Admissions Cohort of
Privately Insured Disabled Elders over
a 16 Month Period**

Marc A. Cohen, Ph.D.
Jessica S. Miller, M.S.
Xiaomei Shi, M.A.

LifePlans, Inc.

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TABLE OF CONTENTS

AUTHORS	iv
EXECUTIVE SUMMARY	v
I. BACKGROUND	1
II. PURPOSE.....	1
III. METHOD AND SAMPLE	2
IV. FINDINGS	3
A. Socio-Demographic Characteristics	4
B. Functional Characteristics	6
C. Satisfaction with Service Providers	9
D. Use of Care Management	11
E. Experience with Filing a Claim	13
F. Effect of Having Long-Term Care Insurance	17
G. Movement and Transitions	19
V. SUMMARY.....	24
REFERENCES.....	26

LIST OF FIGURES AND TABLES

FIGURE 1: Service Setting by Wave.....	4
FIGURE 2: Average Number of ADL Limitations by Wave and Service Setting.....	7
FIGURE 3: Average Number of IADL Limitations by Wave and Service Setting.....	8
FIGURE 4: Average Number of IADL Limitations by Wave for NH Residents.....	9
FIGURE 5: Overall Satisfaction with Specific Care Provider by Wave by Service Setting.....	10
FIGURE 6: Current Care Needs Are being Met by Wave by Service Setting.....	10
FIGURE 7: Use of Care Manager by Wave by Service Setting.....	11
FIGURE 8: Proportion of Paid Care Recipients who Found Care Manager Helpful.....	12
FIGURE 9: Proportion of Home Care Recipients who State Care Manager Recommended Changes to Plan of Care and Service Setting	13
FIGURE 10: Proportion of Those Receiving Paid Care at Wave 1 Who Filed a Claim and the Results.....	14
FIGURE 11: Proportion of Approved Claimants Reporting Disagreements with their LTC Insurance Company at Wave 1	15
FIGURE 12: Proportion of Both Approved and Denied Claimants Reporting Disagreements with their LTC Insurance Company at Wave 1.....	15
FIGURE 13: Base and Adjusted Denial Rates for the Cohort of Those Reporting Denied and Pending Claims at Wave 1 Over Time.....	16
FIGURE 14: Costs Covered by LTC Insurance by Wave.....	17
FIGURE 15: Having LTC Insurance Made Obtaining Services Easier by Wave	17
FIGURE 16: Having LTC Insurance Provided Claimant Greater Flexibility with Choice of Service Setting by Wave.....	18
FIGURE 17: Having LTC Insurance Has Limited Provider Choice by Wave	18

FIGURE 18: Without LTC Insurance Claimant Would Receive Less Paid Care by Wave.....	19
FIGURE 19: Percent Remaining in Baseline Service Setting at Each Wave.....	22
FIGURE 20: Transitions Between Waves	22
FIGURE 21: Rate of Transitions for Those Observed at Baseline and All Four Waves.....	23

TABLE 1: Sample Distribution by Wave.....	3
TABLE 2a: Age and Marital Status for Wave 1 Responders by Service Setting	5
TABLE 2b: Age and Marital Status for Wave 2 Responders by Service Setting	5
TABLE 2c: Age and Marital Status for Wave 3 Responders by Service Setting	6
TABLE 2d: Age and Marital Status for Wave 4 Responders by Service Setting	6
TABLE 3: Average ADL Limitations by Wave and Baseline ADL Category and Cumulative Mortality Rate.....	7
TABLE 4a: Movement and Transitions for the Baseline Home Care Recipients.....	19
TABLE 4b: Movement and Transitions for the Baseline Nursing Home Residents	20
TABLE 4c: Movement and Transitions for the Baseline Assisted Living Facility Residents.....	20
TABLE 4d: Movement and Transitions for Those Reporting No Paid Care at Baseline.....	21
TABLE 5: Characteristics Associated with Transitioning.....	23

AUTHORS

Marc A. Cohen, Ph.D.
President, LifePlans, Inc.
Senior Scientist, Center for Health and Long-Term Care Research
51 Sawyer Road, Suite 340
Waltham, MA 02453

Jessica S. Miller, M.S.
Director of Analytic Services, LifePlans, Inc.
President, Center for Health and Long-Term Care Research
51 Sawyer Road, Suite 340
Waltham, MA 02453

Xiaomei Shi, M.A.
Research Analyst, LifePlans, Inc.
51 Sawyer Road, Suite 340
Waltham, MA 02453

EXECUTIVE SUMMARY

This is the second in a series of reports based on longitudinal information collected from a sample of 1,400 individuals with long-term care (LTC) insurance, who notified their insurance company that they are receiving or intend to receive paid services for which they will file or have filed a claim under their LTC policy. These individuals comprise “an admissions cohort” of new LTC service users. This admissions cohort has been tracked over a period of 16 months. The purpose of this report is to present selected findings of data collected from the first four follow-up telephone interviews completed after the initial in-person baseline assessment. These interviews were conducted at four-month intervals and examine key issues related to changes in disability status, the use of care management services, individuals’ experience with the claims filing process, and transitions through the continuum of care. We also report on individuals’ satisfaction with providers and their experiences with their LTC insurance. For a more detailed explanation of the larger study, as well as a discussion of findings from the baseline interviews, please see the report entitled “Service Use and Transitions: Decisions, Choices and Care Management Among an Admissions Cohort of Privately Insured Disabled Elders” located at: <http://aspe.hhs.gov/daltcp/reports/2006/admcohort.htm>. Key findings from the first four follow-up interviews are presented below.

Sample Distribution

- Most of those using paid care throughout the 16 months were residing at home or in assisted living facilities (ALFs).
- The proportion of sample receiving care in any of the service settings does fluctuate over the 16-month period suggesting that there are transitions over the period, although not of a very large magnitude.
- The mortality rate at the first Wave of telephone interviews, four months after baseline is high (11%), which suggests that at least one in ten “new admissions” to the LTC system is very sick, and not likely to be long users of care.

Socio-Demographic Characteristics

- As expected, the age and gender profile of paid care recipients during the follow-up period mirrors that at baseline.
- Those in ALFs remain the oldest and most likely to be widowed, although by Wave 3, there is no significant difference in the age of nursing home (NH) and ALF residents.

Functional Characteristics

- Disability levels remain fairly constant across the Waves and service settings, with those residing in NHs being the most disabled and those in assisted living the least disabled.

- Those who started out at baseline needing help with less than two activities of daily living (ADLs) remain the least disabled over time, increasing to an average of 2.34 ADL limitations by the end of Wave 4.
- For the most part, people are deteriorating over time as is evidenced by the fact that the average number of ADL and instrumental activity of daily living (IADL) limitations increases over time.
- The exception to this general pattern is found for those who are most disabled (had between five and six ADL limitations at baseline). While this group remains the most disabled, the average number of ADL limitations drops slightly by Wave 4, which is most likely due to the fact that the sickest or most disabled in this group are dying and the healthiest (in a relative sense) of this group are remaining in the sample.

Satisfaction with Service Providers

- When looking at satisfaction as a dichotomous variable, satisfaction rates in all service settings across all Waves are very high.
- When focusing on those who reported very high satisfaction levels, however, NH residents are least likely to report that they are very satisfied and this group has the largest decline in satisfaction over time.

Use of Care Management

- While the use of care management was low at baseline (19%, 11% and 7% for home care (HC), NH and ALF respectively), there is a significant increase in the use of care management at Wave 1, which is when individuals are putting specific services in place.
- At Wave 1, 35% of HC recipients, 20% of NH residents and 12% of ALF residents reported using a care manager within the last four months.
- Almost all of those who used a care manager found them helpful, responsive to their needs and felt that the care manager spent enough time with them.

Experience with Filing a Claim

- Ninety-six percent of paid care receivers reported filing a claim by the time of the first follow-up interview.
- The majority for whom a decision was rendered was approved -- 95.7% at Wave 1, with 4.3% reporting they were denied benefits.
- At the end of the 16-month period, the adjusted denial rate (total denials over the period) drops to 2.4%.
- Those who were denied state that they were told they were not disabled enough to qualify for benefits yet. In fact, they only have an average of 0.74 limitations in ADLs at baseline and 1.8 at Wave 1.
- Of all those who submitted claims at Wave 1 (both approved and denied), 94% report having no disagreements with their insurance company or that their disagreements were resolved satisfactorily.

The Effect of Having a LTC Insurance

- At Wave 1, roughly three-quarters of claimants agree that having their insurance made it easier to obtain needed services and that number increases to 83% by the fourth follow-up interview.
- The majority of claimants also agreed that having their LTC insurance policy allowed them greater flexibility with the choice of care setting.
- A majority at all Waves stated that they would have to decrease the amount of paid care they receive if they did not have their policies.

Movement and Transitions

- Those who moved to an ALF at baseline were the most likely to remain there over time and also had the lowest cumulative mortality rate.
- Those who began using paid care at home at baseline were the most likely to stop using paid care over time.
- NH residents had the highest overall mortality rate by Wave 4 -- close to one in three were deceased after 16 months, with 21% of these dying four months after entering the NH.
- The highest rate of transitions occurred at Wave 1 with 37% of the sample either changing care settings or going from paid care to no paid care or vice versa.
- For those who were followed for the entire 16-month period, 41% reported no change in care setting or service use, and 46% reported experiencing one transition.
- The average number of transitions for those observed at all points in time was 0.77.
- For those who do transition, they are most likely to be younger, less disabled (both functionally and cognitively) recipients of paid HC and report being less than satisfied with their initial choice of service provider.

The information gleaned from this random sample of an admissions cohort to the LTC system is extremely informative. This is perhaps the first time a random sample of a cohort of new service users in multiple care settings has been interviewed so close to the time of their decision and then followed for a significant length of time (over two years when the study is completed in 2008). Findings presented here underscore the importance of focusing on phenomena over time, rather than at a point-in-time. In this way it is possible to better understand the dynamic nature of the system and those who are accessing it.

I. BACKGROUND

The long-term care (LTC) system is often characterized by fragmented service delivery, complicated financing, and complex interrelationships between paid (formal) care providers and unpaid (family) caregivers. Most data about individuals' use of services is cross-sectional in nature. That is, we know a great deal about how disabled individuals who need LTC services use them at a point-in-time. We have less precise information about how individuals actually use services over time; that is, we do not know how the disability status and service use patterns of individuals change over time, thus making it difficult to predict how and where people will actually receive care and under what circumstances. Moreover, despite the tremendous amount of research devoted to identifying the factors related to the need for LTC services -- be they paid or unpaid -- we still do not have a good understanding of what influences consumers to choose a particular service modality. Again most of the national data on the prevalence of disability and service use is cross-sectional in nature. While such data does enable one to uncover the factors related to **observing** someone in a particular state of disability or service modality, it does not facilitate an understanding of the factors behind the decision to **begin using** a particular service. Nor can we adequately understand the reasons behind various transitions across alternate service modalities. Thus, without a better understanding of consumers' decision-making process when they perceive they need care and engage providers, it is difficult to make predictions about patterns of service use.

II. PURPOSE

This is the second in a series of reports based on longitudinal information collected from a sample of 1,400 individuals with LTC insurance, who notified their insurance company that they are receiving or intend to receive paid services for which they will file or have filed a claim under their LTC policy. This admissions cohort has been tracked over a period of 16 months. The purpose of this report is to analyze data collected from four follow-up telephone interviews conducted at four month intervals and examine key issues related to disability level, use of care management services, claims experience and transitions through the continuum of care. We also report on their satisfaction with providers and experiences with their LTC insurance.¹ This report focuses on answering four key research questions. These include:

- How do functional and cognitive disability status change over time and does this vary by service modality?

¹ For a more detailed explanation of the larger study, as well as a discussion of findings from the baseline interviews, please see the report entitled "Service Use and Transitions: Decisions, Choices and Care Management among an Admissions Cohort of Privately Insured Disabled Elders" located at: <http://aspe.hhs.gov/daltcp/reports/2006/admcohort.htm>.

- Are individuals satisfied with their service providers and does this level of satisfaction persist over time?
- Do individuals using formal paid care use care management services and do they find it beneficial over time?
- What is the aggregate and adjusted claim approval and denial rates over time?
- How does having LTC insurance affect care patterns?
- How do individuals transition across service settings over time?

III. METHOD AND SAMPLE

A detailed in-person baseline interview was conducted with each of the 1,474 participating individuals. This interview collected basic demographic information (i.e., age, gender, marital status, education, income level, presence of children near household, etc.); service use data (i.e., type, intensity, duration, and start date of formal and family care); use of care management (i.e., was it offered, was it used, is there a care plan, developed, etc.); and health and disability data (i.e., activities of daily living (ADLs), instrumental activities of daily living (IADLs), Short Portable Mental Status Questionnaire, behavioral assessment, information on number of medications, etc.), as well as information regarding the decision-making process, service use, family support, and insurance coverage. The sample was collected from ten of the largest LTC insurance companies accounting for diverse market segments and policy designs that employ differing underwriting and claims management strategies. In order to be included in the baseline interview, the insured had to meet the following criteria:

1. An individual had to have begun using paid services in their current service setting within the last 120 days or had to anticipate beginning paid service use within 60 days; and,
2. They had to have an LTC policy that covered care in all three service modalities, that is, nursing home (NH), home care (HC), and assisted living; and,
3. They intended to file a claim or had already filed a claim with their LTC insurance company.

After the initial in-person assessment was completed, we began a period of follow-up that consisted of a telephonic interview conducted every four months. The follow-up period will last at least two years, that is, seven additional phone interviews will be completed after the baseline interview. The purpose of these interviews is to track the functional, service setting and attitudinal characteristics of the participant, as well as their experiences with their insurance and insurer. In this way, we gain a “real-time” understanding of the factors behind various transitions, in cases where they occur. This report focuses on the findings from the first four of these interviews, which began in October 2003 (Wave 1) and ended in September 2006 (Wave 4).

It is important to note that the findings below are based on weighted data. Once all of the responses were collected, we developed a standard weight based on the in-force market share of each of the participating companies. These market share numbers were obtained from the 2003 and 2004 National Association of Insurance Commissioners experience exhibits, as well as the 2003 and 2004 Top Writers Survey conducted by LifePlans.² In this manner, we assure that we are not giving too much weight to companies with smaller market shares that contributed larger samples to the survey and alternatively, too little weight to companies with larger market shares, but smaller samples. All of the tables and charts that follow are based on analyses done with the weighted sample unless otherwise noted.

IV. FINDINGS

Table 1 below shows the distribution of the sample in terms of completed interviews, rate of refusal, mortality rate and drop-off rate for all four Waves of the follow-up interviews. Keeping in mind that the first Wave of telephone interviews took place four months after the baseline, the mortality rate for the first Wave is very high. This suggests that at least one in ten “new admissions” to the LTC system is very sick, and not likely to be long users of care. In fact, on a cumulative basis, roughly 18% of the original admissions cohort had died within one year of the baseline interview.

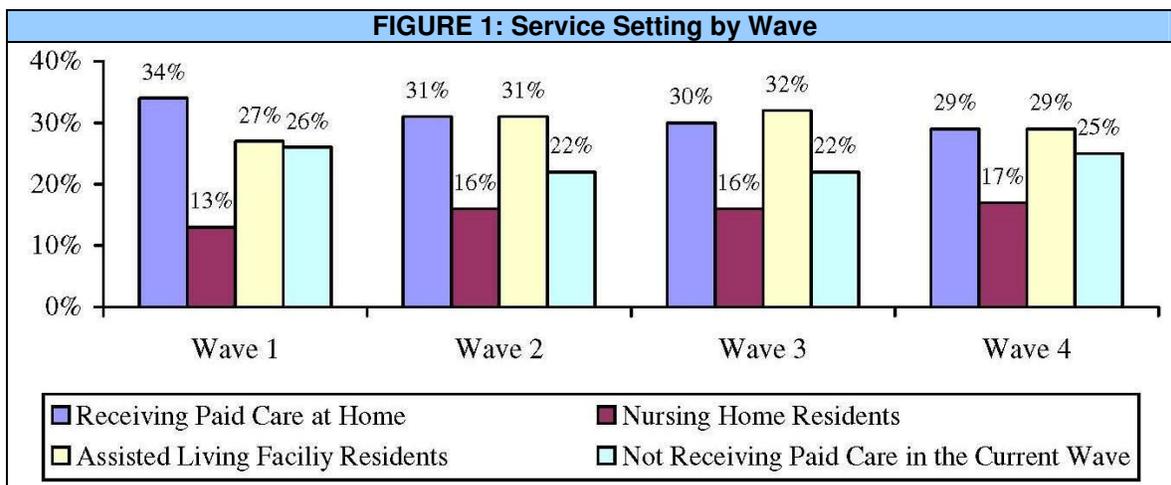
As shown, the refusal rate remains fairly low throughout all four Waves, perhaps due to the affinity that these participants have with their insurance carriers. Where possible, the insurance companies were contacted to convert wrong numbers or assist in finding policyholders that we were unable to contact at their previously given information. Thus, we were able to keep our drop-off rate (those we were not able to locate for subsequent Waves) fairly low.

TABLE 1: Sample Distribution by Wave				
	Wave 1	Wave 2	Wave 3	Wave 4
Completed Interviews	1,118	884	735	602
Refused	8%	7%	8%	9%
Deceased ^a	11%	6%	7%	6%
Unable to locate	4%	4%	3%	4%
<p>NOTES: Wave 1 occurred 4 months after the baseline interview. Wave 2 occurred 8 months after the baseline interview. Wave 3 occurred 12 months after the baseline interview. Wave 4 occurred 16 months after the baseline interview.</p> <p>a. When calculating mortality rates, we removed those policyholders who we were unable to locate.</p>				

Figure 1 shows the overall distribution of all four Waves by service status in each Wave. It is important to note that this figure does not take into account individual

² These years correspond to the years in which the baseline interviews took place.

transitions. In other words, the 34% of participants who were receiving HC in Wave 1 are not necessarily the same participants that comprise the 31% who were receiving HC in Wave 2 and so forth. Roughly one-third of the sample at any given time over the 16-month period was receiving paid care at home, while the lowest proportion (13%-17%) were receiving care in a NH. The proportion of sample receiving care in any of the service settings does fluctuate over the 16-month period suggesting that there are transitions over the period, although not of a very large magnitude. Of particular note is the fact that roughly one-quarter of the sample at any given time does not receive paid care. Not receiving paid care is defined as those participants who were not receiving any paid care at the time they were interviewed, but may have received paid care during a prior study interview, that is, within the time period between the baseline interview and the time they were observed at a particular Wave. In order to remain a study participant, one must have used paid care by Wave 2. If an individual indicated that they were not receiving paid care in Wave 2 and they had not received paid care at the time of the baseline and Wave 1 interview, they were dropped from the study. This pattern suggests that at various points throughout the time period a meaningful proportion of individuals stop using paid services.



A. Socio-Demographic Characteristics

One would not expect the socio-demographic profile of the participants to change drastically over the follow-up period. When viewing the tables that follow, note that the largest drop-off in an age group occurs in the 85 and above at Wave 4. It is also true that the proportion in each service setting reporting they are widowed increases over the 16-month period -- most notably among the NH residents. At Wave 1, 40% report being widowed and by Wave 4 that figure climbs to 52%. The highest proportion of widowers is found in the assisted living facility (ALF) -- they are also the oldest, which is consistent with baseline findings as well.

For Table 2a, Table 2b, Table 2c and Table 2d, each service setting is labeled with a different letter. For example, individuals receiving paid HC are in column (A), whereas those who are in an ALF are labeled as column (C). These letters are assigned so that

we can analyze the extent to which there are statistical differences between findings across service settings. If a finding has the letters (BC) by it, this suggests that it is statistically **greater/higher** than the findings in columns B and C. If a finding has a letter (B) by it, this means that it is statistically **greater/higher**, than the finding in column B. We report differences that are significant at the 0.05 level.

TABLE 2a: Age and Marital Status for Wave 1 Responders by Service Setting			
Socio-Demographic Characteristics	Receiving Paid Care at Home (A)	Nursing Home (B)	Assisted Living (C)
Age			
Average Age	78	79	82 AB
Below 65	7% C	4%	2%
65-74	20% C	18% C	8%
75-79	24%	24%	18%
80-84	27%	33%	36%
85 or above	22%	22%	36% AB
Marital Status			
Married	48% C	42% C	24%
Widowed	42%	40%	65% AB
Unmarried	10%	18% A	11%

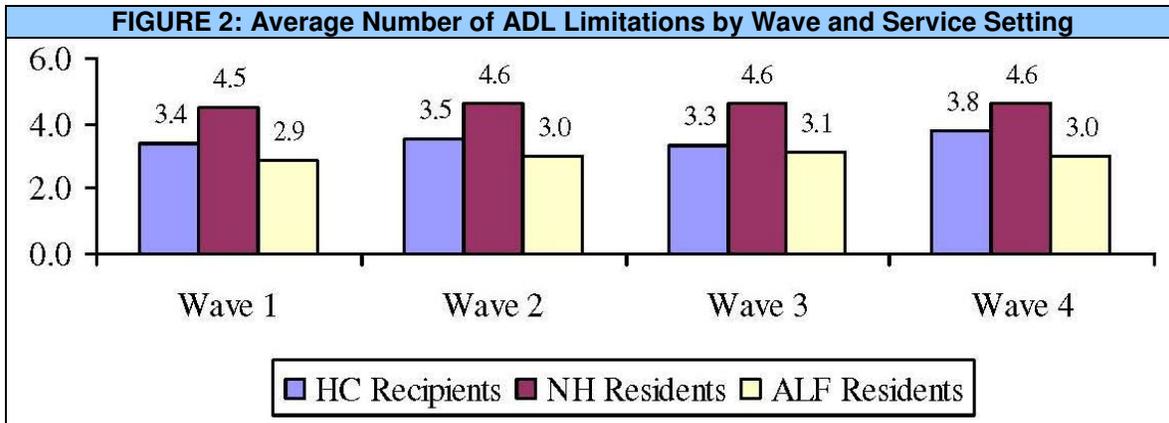
TABLE 2b: Age and Marital Status for Wave 2 Responders by Service Setting			
Socio-Demographic Characteristics	Receiving Paid Care at Home (A)	Nursing Home (B)	Assisted Living (C)
Age			
Average Age	80	80	83 AB
Below 65	6% C	2%	1%
65-74	22% C	16% C	7%
75-79	20%	23%	18%
80-84	22%	32%	32%
85 or above	30%	27%	32% AB
Marital Status			
Married	49% C	40% C	20%
Widowed	40%	44%	70% AB
Unmarried	11%	16%	10%

TABLE 2c: Age and Marital Status for Wave 3 Responders by Service Setting			
Socio-Demographic Characteristics	Receiving Paid Care at Home (A)	Nursing Home (B)	Assisted Living (C)
Age			
Average Age	80	81	83 A
Below 65	3%	2%	1%
65-74	20% C	17%	9%
75-79	20%	21%	15%
80-84	26%	28%	32%
85 or above	31%	32%	43%
Marital Status			
Married	51% BC	31%	21%
Widowed	39%	49%	69% AB
Unmarried	10%	20% AC	10%

TABLE 2d: Age and Marital Status for Wave 4 Responders by Service Setting			
Socio-Demographic Characteristics	Receiving Paid Care at Home (A)	Nursing Home (B)	Assisted Living (C)
Age			
Average Age	79	81	83 A
Below 65	6%	3%	2%
65-74	21% C	12%	9%
75-79	20%	15%	13%
80-84	26%	35%	33%
85 or above	27%	35%	43% A
Marital Status			
Married	52% BC	34%	23%
Widowed	39%	52%	66% A
Unmarried	9%	14% A	11%

B. Functional Characteristics

As part of the baseline interview, the trained nurses assessed the functional status of the claimants by asking questions regarding Katz's ADLs scale and Lawton's scale of IADLs. ADLs include bathing, dressing, toileting, transferring, eating and continence. IADLs include doing housework, doing laundry, meal preparation, shopping for groceries, managing money, using the telephone, transportation and medication management. For the follow-up interviews, participants were asked whether someone is currently helping them with a particular activity. Help was defined as someone needing to be near when the activity is being performed (stand-by assistance) or someone physically helping with the activity (hands-on assistance). Figure 2 below shows the average number of ADL limitations by Wave for individuals in each service setting.



Disability level remains fairly constant across the Waves and service settings, with those residing in NHs being the most disabled (4.5 or 4.6 limitations out of six) and those in assisted living reporting help with the least amount of ADLs on average -- between 2.9 and 3.1 over the follow-up period. These findings mirror those reported in the baseline interviews. This data does not track individual transitions, but aggregate point-in-time statistics regarding disability status of individuals by service setting.

We were also interested in following the disability level of respondents on a longitudinal basis. Are people who are classified in a certain ADL category at baseline getting better, worse, staying the same or dying? We expected that the highest mortality would be those that were the most disabled at baseline. We also anticipated that those who had fewer ADL limitations at baseline, would become more disabled over time, but less so than those with higher levels of disability. We calculated the average number of ADL limitations and cumulative mortality rate for those who fell into different ADL categories at baseline. At the time of the baseline interview, about one-quarter of the sample had less than two ADL limitations (26%), about one in six had exactly two ADL limitations (16%), 29% of the sample had 3-4 limitations and another 29% had 5-6 ADL limitations. Overall, 41% of the baseline sample was cognitively impaired. Table 3 shows the average ADL transition results by Wave.

TABLE 3: Average ADL Limitations by Wave and Baseline ADL Category and Cumulative Mortality Rate

Baseline ADL Category	Baseline	Wave 1	Wave 2	Wave 3	Wave 4	Deceased
<2 ADL limitations	0.51	1.43	1.86	2.17	2.34	11%
2 ADL limitations	2.00	2.18	3.09	2.89	2.82	16%
3-4 ADL limitations	3.64	2.83	3.47	3.51	3.85	21%
5-6 ADL limitations	5.31	4.64	4.63	4.49	4.81	33%
Cognitively Impaired	3.43	3.47	3.55	3.67	3.76	25%

NOTES: The percentages that appear in the deceased column above are cumulative, that is they represent the total proportion of people in each category that were deceased by Wave 4. While the ADL categories are mutually exclusive among themselves, those who were determined to be cognitively impaired at baseline could fall in to any of the baseline ADL categories.

In terms of mortality patterns, the results show that the least disabled individuals at baseline are also the least likely to die by Wave 4 -- only 11% of those who had less

than two ADL limitations at baseline had died by Wave 4. Alternatively, about one-third of those who reported between five and six ADL limitations at baseline were deceased by Wave 4. In terms of average ADL limitations, the overall pattern is also not surprising. For those who started out with less than two ADL limitations -- an average of 0.51 at baseline -- by the end of the 16-month period they had an average of 2.3 ADL limitations. For the most part, people are deteriorating over time and this is evidenced by the fact the average number of limitations increases over the time period. The exception to this general pattern is found for those who had between five and six ADL limitations at baseline. While this group remains the most disabled, the average number of ADL limitations drops slightly by Wave 4 from what it was at baseline. This is most likely due to the fact that the sickest or most disabled in this group are dying and the healthiest (in a relative sense) of this group are remaining in the sample through Wave 4. What is not shown is that the mortality rate for all groups is highest at Wave 1, meaning that most deaths occur four months after the baseline interview and is highest for those in the 5-6 limitation category (20% deceased at Wave 1) and the 3-4 limitation category (9% deceased at Wave 1). It seems that there are factors aside from intrinsic disability levels that are related to relatively high mortality rates at the outset of new service use, primarily in NH settings. This could account for the decline in the average limitations at Wave 1 for these two groups.

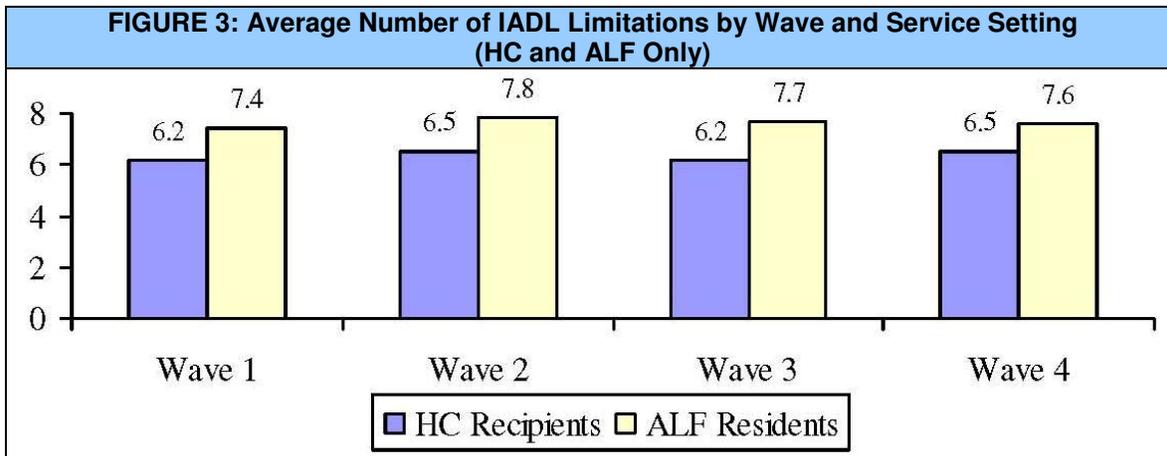
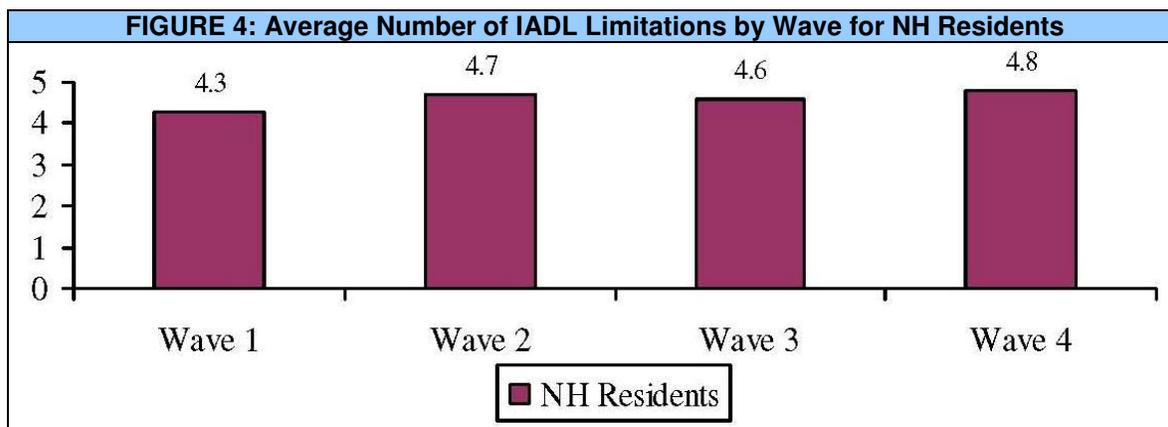


Figure 3 summarizes the IADL profile of HC and ALF residents throughout the follow-up period. NH residents were asked a simplified set of questions relating to IADLs and their profile is represented in Figure 4. HC and ALF residents were asked whether someone helped with each of the eight IADLs (listed above) separately, while those in the NH were asked if someone helped them with the following five activities: (1) caring for personal possessions such as clothing, toiletries, etc.; (2) securing personal items such as newspapers; (3) using the telephone; (4) managing money; and (5) managing and taking medications.³ We assumed that IADLs related to housework, laundry, meal preparation and shopping for groceries were all services that were provided to NH residents (whether they are able to do them or not). Therefore asking

³ It is often the case that facility policy requires medication be given to all residents, regardless of their level of dependence with medication management.

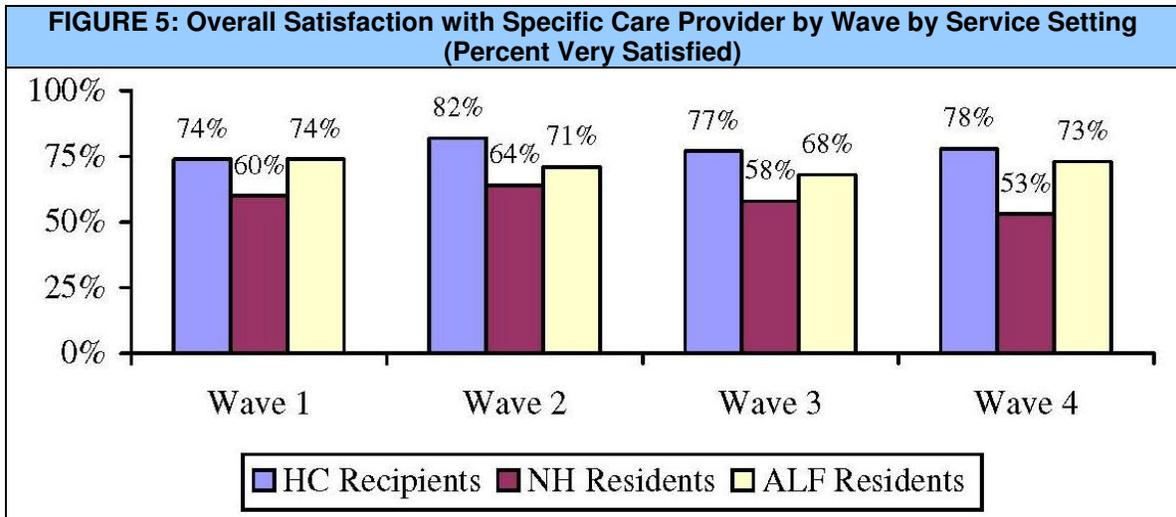
about them would not give a true sense of whether those in NHs get help with the types of activities that need to be done on a daily basis and are comparable to IADLs.



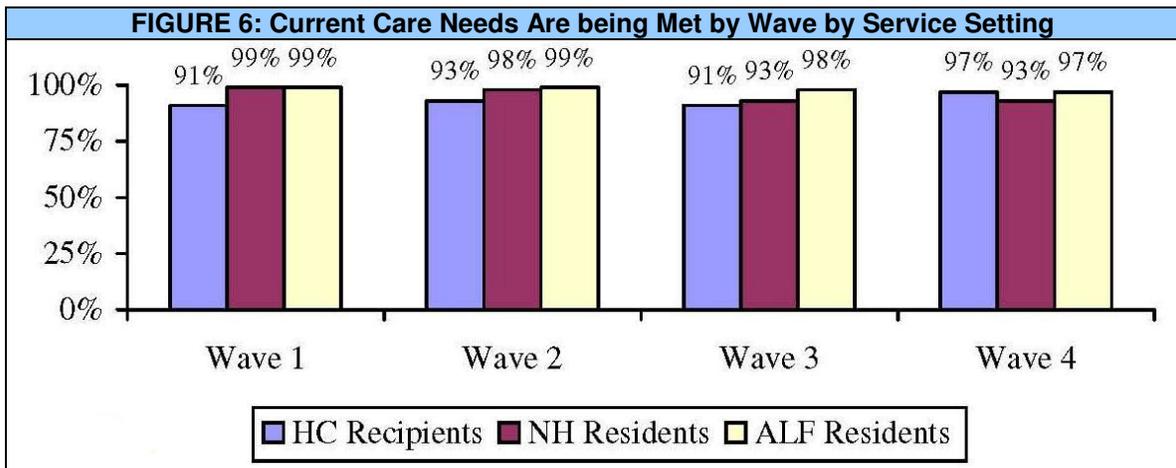
Over time and across all service settings, individuals receive help with a growing number of IADLs. Although ALF residents have fewer ADL limitations on average than HC recipients, they receive assistance with more IADLs. This may also be related to the fact that some of these services are provided to them by virtue of their residing in an ALF. As expected, NH residents require help with more than four of the five IADLs, and they appear to require more help over time. This is born out by the fact that 57% of NH residents required assistance with all five IADLs at Wave 1(not shown) and by Wave 4, this figure had risen to 79%.

C. Satisfaction with Service Providers

An important focus of our study was to assess the level of overall satisfaction with the current service provider -- agency or caregiver for HC recipients, specific ALF or specific NH. We asked whether participants were very satisfied, somewhat satisfied, not very satisfied or not at all satisfied with their current service provider. Figure 5 shows the proportion reporting that they were very satisfied with their provider. When looking at satisfaction as a dichotomous variable, (satisfied versus not satisfied) satisfaction rates in all service settings across all Waves are very high (between 96%-99% for HC, 88%-97% for NH and 96%-98% for ALF). When focusing on the proportion reporting they are very satisfied, it is possible to observe difference with greater sensitivity.



The majority of people in all three service settings report that they are satisfied with their current provider and remain that way over time. However, as noted in Figure 5, NH residents are the least likely to report that they are very satisfied with the NH and this group has the largest decline in satisfaction over time -- dropping from a high in Wave 2 of 64% to a low at Wave 4 of 53%. We know from the baseline interviews that many of those residing in NHs choose that care setting because of an acute incident or moved there from a hospital. Perhaps they expected their health to improve over time and viewed the NH as a temporary residence. Not shown is the fact that NH residents are also consistently more likely to say that they do not have enough privacy and that the staff do not spend enough time with them.



We also asked participants whether the care they are receiving is meeting their needs. We assumed that the level of unmet need would be related to overall satisfaction -- the more unmet need, the lower the overall satisfaction. However, as shown in Figure 6, this is not necessarily the case. Almost all participants -- including those in NHs -- report that their care needs are being met. This finding suggests that there are other factors associated with lower reported satisfaction levels in these service

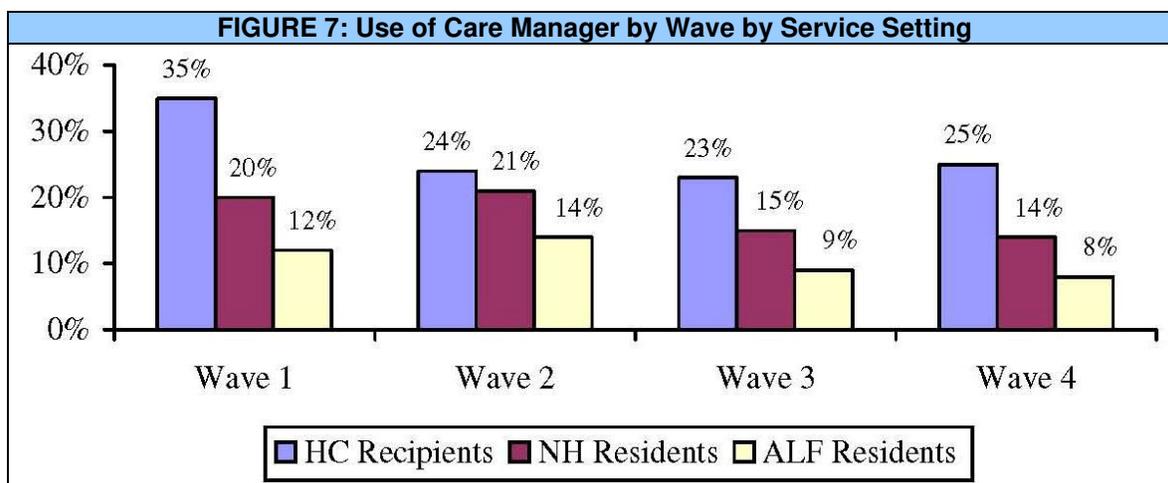
settings. These can include such things as physical plan, control over time and schedule, privacy, and the like.

D. Use of Care Management

We learned prior to beginning the fieldwork for this study that while all of the participating companies claim that they provide care management, each defines this service differently. Therefore, we provided participants with the most broad and inclusive definition of a care manager that was read to them at baseline and all subsequent telephone interviews. The definition is as follows:

Sometimes when people need to find paid care and make arrangements for care, they work with a person called a care manager or care coordinator. This person is generally a nurse or health professional and is either someone you can hire privately or someone your LTC insurance company provides to you. He or she may visit with you in your home or talk to you over the telephone. This person is different from a doctor or a hospital discharge planner.

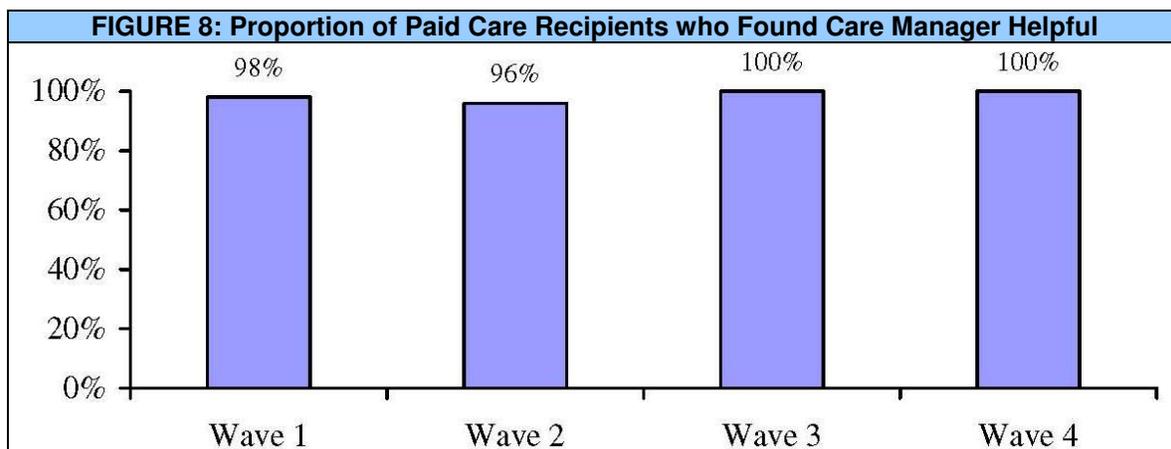
We found that only a small percentage of participants at baseline had used care management services -- 19%, 11% and 7% for HC, NH and ALF respectively. This was perhaps due to the fact that the baseline interview occurred very close to the time that they were making their decision to use paid care. It is possible that at baseline, participants were focused on the process of deciding to use paid care, where and from whom to receive it, and thought little about someone who could help them do it. At each Wave, we asked participants if they had been in contact with a care manager in the past four months (since the last interview). Figure 7 below shows the proportion of participants who used care managers over the 16 months after the baseline interview.



Clearly, Figure 7 shows that across all service settings, there is a significant increase in the use of care management, particularly at Wave 1, which is when individuals are putting specific services in place. The proportion using care managers

almost doubled for all service settings from the baseline interview to Wave 1, although the percentage is still relatively small for those who moved into an ALF. One would expect the use of a care manager to be highest in the home, where people are more likely to need help finding (licensed) care providers, investigating all of the costs involved and coordinating different care providers -- perhaps from different agencies. For Wave 2, the use of a care manager dropped somewhat, but then seemed to level off or only decline slightly in subsequent Waves. It is not surprising that 16 months after the decision was made to use paid care, the use of a care manager would decline, given that most often care managers were used to develop care plans, assure appropriate services were provided and to help find local providers if needed.

We also asked those who used a care manager if they found the care manager helpful. There was little variation by service setting; therefore, Figure 8 shows the proportion that found the care manager helpful for all service settings combined. As shown, almost all of those who used a care manager found them to be helpful.



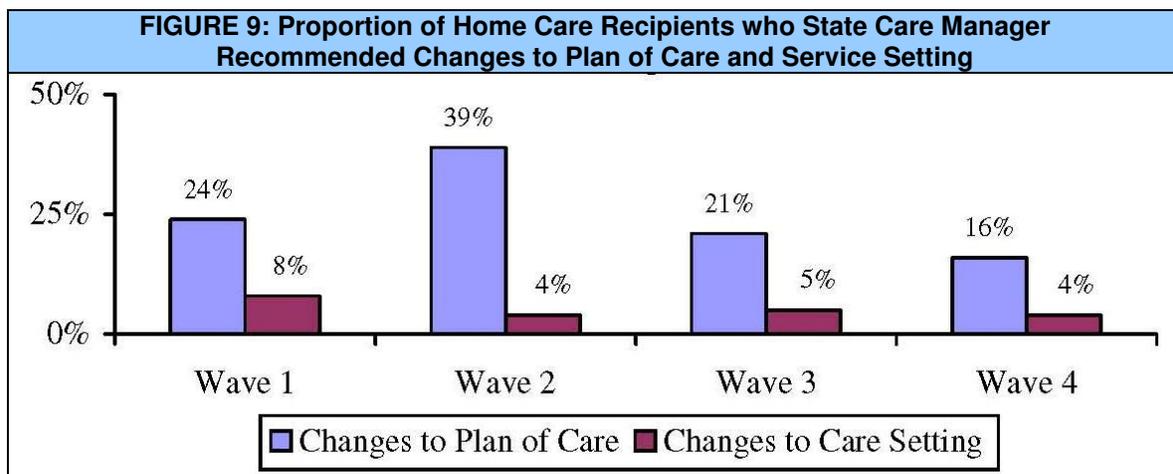
For the group of participants at each Wave who reported they had been in contact with a care manager for the first time (they had not used a care manager in the past), we asked a series of questions about the duties performed by the care manager. Although not shown in graph form, the highest proportion of new users reported that the care manager made sure they were receiving the appropriate services -- roughly five out of every six participants using a care manager for the first time stated that the care manager was making sure they were receiving appropriate services; this finding was consistent across service settings and across Waves. The next highest proportion of new users reported that the care manager helped in the development of a plan of care -- roughly three out of every four participants using a care manager stated this.

Although the proportion of paid care recipients using a care manager increased after baseline, it is important to note that the overall number of people remains relatively small. We did ask a number of questions about the care manager and the types of services that they provided; however, due to the small sample sizes in the NH and ALF

settings, we will report results related to the care management questions only for the largest group -- HC recipients.⁴

We first wanted to know if the care manager was responsive to the insured’s needs. It appears that with the exception of a decline at Wave 2 (87%), all those (100%) who used a care manager felt they were responsive. We also asked if participants felt that the care manager spent enough time with them and/or their family (if they were involved). Between 80% and 100% of HC recipients across the four Waves felt that their care manager had spent enough time with them when they contacted them.

Finally, we asked specifically if the care manager recommended any changes to the HC recipient’s existing plan of care or if perhaps they recommended a change in the service setting. Not surprisingly, few individuals receiving care at home said that the care manager recommended they move to a facility. A higher proportion -- between 18% and 39% -- stated that the care manager recommended changes to a plan of care over the 16-month period.



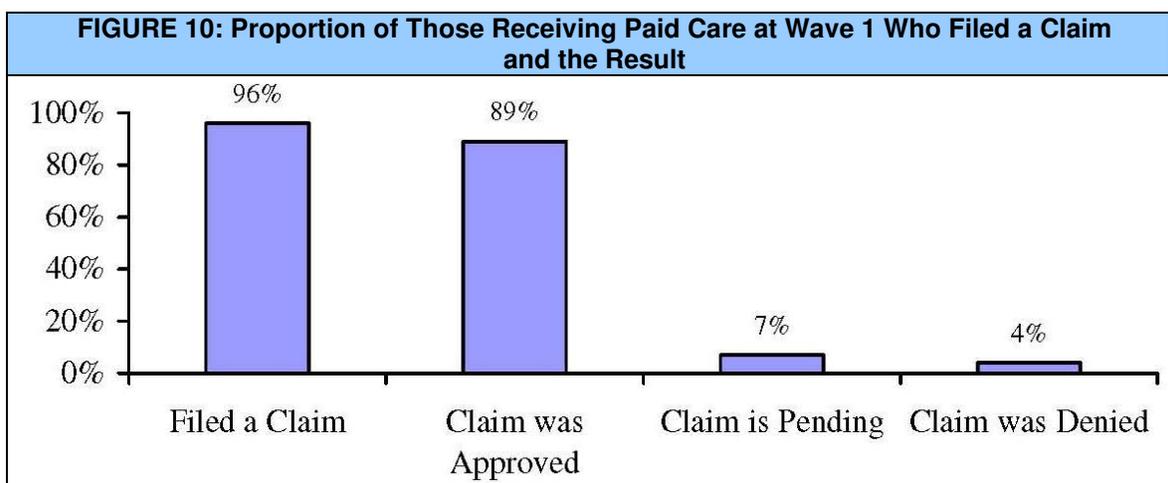
E. Experience with Filing a Claim

A primary focus of the baseline interviews was to ask questions related to the decision-making process of policyholders as close to the time that they began using paid care as possible. The questions asked at baseline focused mainly on the demographic, functional, cognitive and service use profile, the decision-making process regarding specific providers, as well as satisfaction with their providers. At that time, we intentionally left out questions related to the insurance company claims process as we believed these questions would be more appropriate during the follow-up period, particularly relevant at the time of the first interview (Wave 1) directly following the baseline, which occurred after four months. At the time of the Wave 1 interview, we asked all participants who were receiving paid care whether they had filed a claim and if

⁴ Sample sizes for HC recipients who reported using a care manager are 121 in Wave 1, 58 in Wave 2, 47 in Wave 3 and 39 in Wave 4.

so, whether it was approved, denied or still pending. Results reported in this section will not be segmented by service setting, but simply reported for the entire sample.

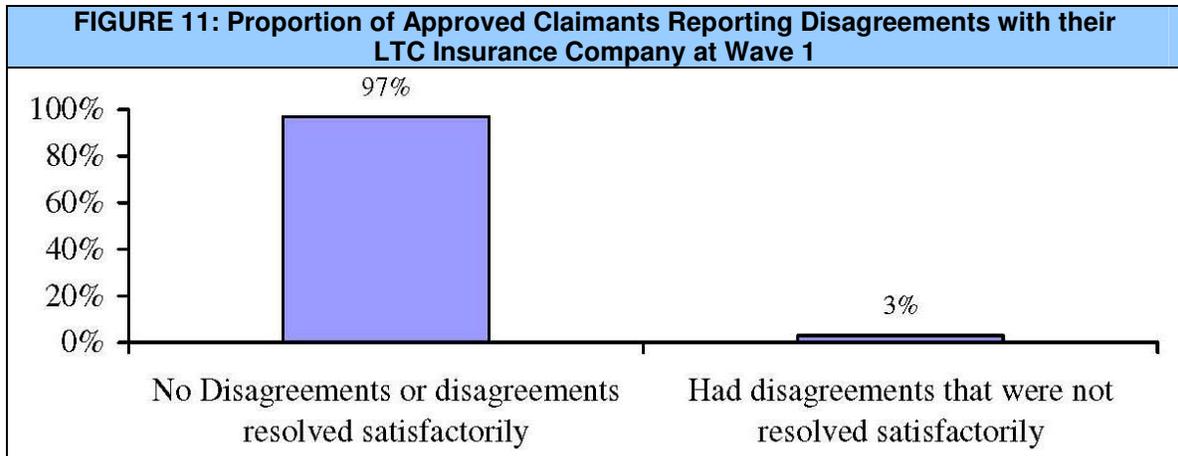
Figure 10 shows that 96% of paid care receivers reported filing a claim by the time of the first follow-up interview.⁵ The majority of those filing claims reported that they were approved and had become “claimants” -- 89%, while 7% reported that they were still waiting for a decision. Only 4% reported that their claims were denied. Thus, at Wave 1, for those for whom a decision had been made (not including those who said their claim was pending), 4.3% were denied benefits under their LTC insurance policy and 95.7% had been approved for claims payment.



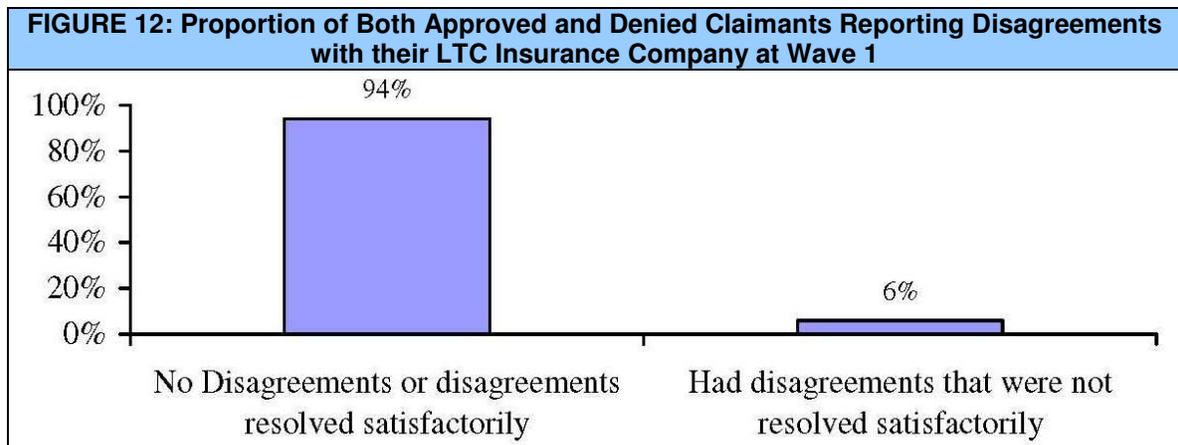
For those claimants receiving paid care at Wave 1, we also asked how easy or difficult it was to file their claim. About three-quarters said that it was either easy or neither easy nor difficult, and one-quarter found filing the claim difficult. When looked at by service setting, a higher percentage of NH residents found filing a claim difficult (31%), than those receiving care at home (22%) or in an ALF (21%). The most common reasons given for why it was difficult to file a claim was that it took longer than expected to obtain benefits and that there were problems understanding and filling out the claim forms.

We also asked these approved claimants if they had any disagreements with their insurance company over coverage or eligibility for benefits and if so, were they resolved to their satisfaction. Figure 11 shows that an overwhelming majority -- 97% either reported no disagreements or that their disagreements were resolved satisfactorily.

⁵ Of the 4% who had not filed claims, the most common reasons given were that they were still in their elimination period, they did not believe they yet met the benefit eligibility requirements, they had not filled out the paperwork or they were covered under Medicare.



Of the 4% who said their claim was denied (27 people) at Wave 1, the majority stated that the reason they were denied was that they were not disabled enough to meet policy definitions. In fact these denials had an average of only 0.74 limitations in ADLs at baseline and 1.8 ADL limitations by Wave 1 and close to three-quarters (71%) were residing in ALFs at Wave 1. A small number of those reporting denied claims said they were using services or providers not covered under their policy or that they had not yet met their policy elimination period. We also asked this small sample of individuals who had their claims denied if they had any disagreements with their insurance company that were not resolved to their satisfaction. Not surprisingly, 60% reported having disagreements with their insurer over coverage or eligibility that were not resolved to their satisfaction. Of all those who submitted claims at Wave 1 (including those reporting their claim approved and those reporting that their claims had been denied), 94% reported having no disagreements with their insurance company or that their disagreements were resolved satisfactorily.



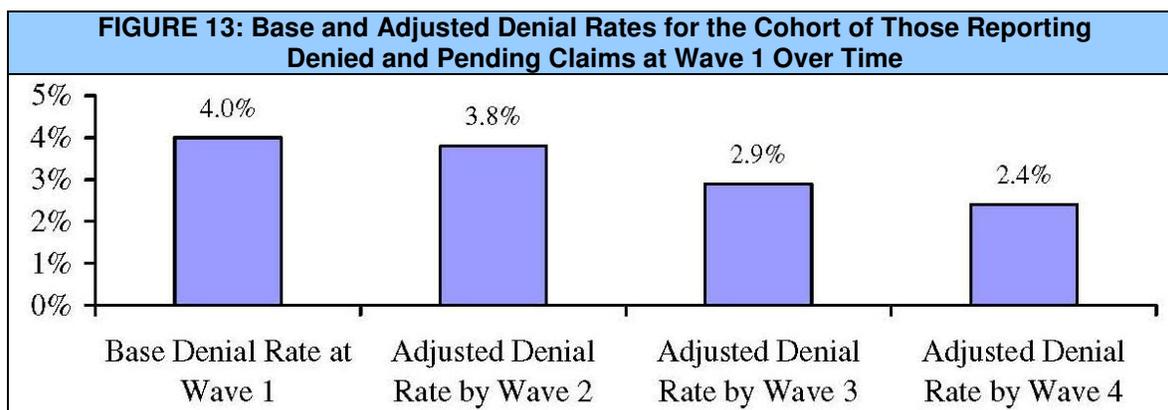
Because we are following a cohort (the same group of people over time), we are able to uncover what happens to different subsets of participants over the 16 month period. We were interested to know if the original group of 27 people (4%) who stated that their claims had been denied at Wave 1 reported that they had been approved at a subsequent Wave. This allows us to calculate an adjusted denial rate over the course

of paid care use. This adjusted denial rate is based only on those who reported that their claims were denied at Wave 1 and for whom we have information for at each of the subsequent waves -- we do not include or impute denials for those that were dropped from the sample (refused, deceased, unable to locate, etc.).⁶

We found that of the people who stated their claims were denied at Wave 1, 4 stated that the insurance company was paying for their care or that they had filed a claim that was approved 4 months later at Wave 2. At Wave 3, eight months after their initial response of a denied claim, an additional three participants stated that their insurance company was paying for care or that they had filed a claim that was approved. Finally, at Wave 4 -- 12 months after their initial response at Wave 1, an additional four participants now report that their insurance company is paying for benefits or that they had filed a claim that was approved.

We also looked at responses for those who stated they were still waiting for a response to their claim submission at Wave 1. Responses to subsequent claim related questions over the following Waves for this group show that the vast majority of these convert to approved claims (76% of those remaining in the sample at Waves 2 and 3) and that only three respondents whose claim submission was pending at Wave 1 are subsequently denied (these were denied at Wave 2).

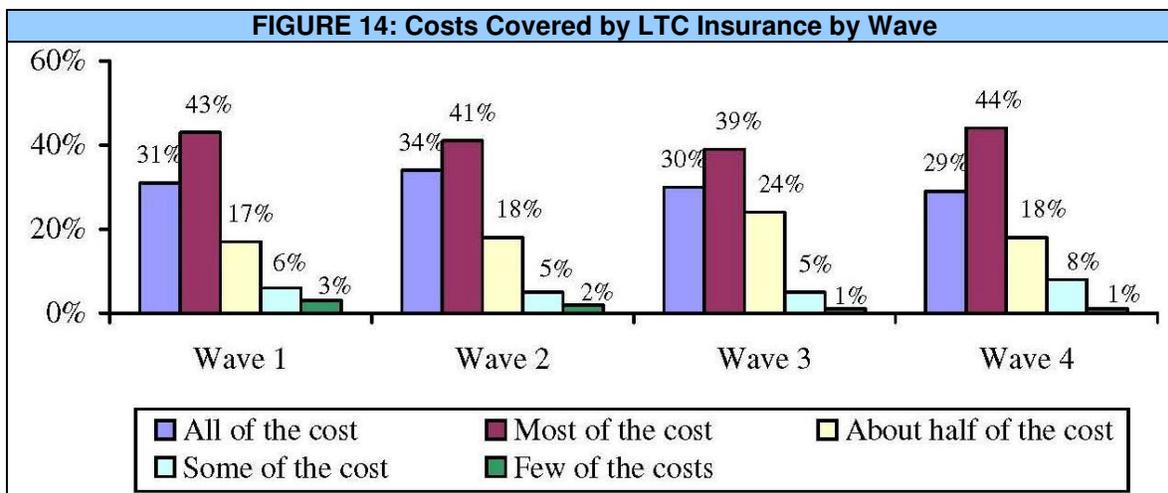
Based on the responses of those who reported their claims were denied or pending at Wave 1, we calculated an adjusted denial rate for each of the subsequent Waves. Figure 13 tracks the adjusted denial rate over the Waves -- showing that the rate goes down to 2.4% after a one year period.



For those who were receiving paid care that was reimbursed by their LTC insurance company (in other words -- claimants), we were interested in knowing how

⁶ It is important to note that these estimates are perhaps conservative as the adjusted denial rates shown here are calculated using the original sample of 27 as the denominator throughout the Waves. We do know that at Wave 2, only 20 of the original 27 responded to questions (five refused to participate at Wave 2, one was deceased and one was not locatable). Similarly, at Wave 3, 13 respondents remained (two refused to participate at Wave 3, one was deceased, we were unable to locate two respondents and two respondents did not answer the questions used to calculate the denial rate) and at Wave 4, nine of the original 27 remained (an additional two refused to participate at Wave 4, one more was deceased and one did not answer the question).

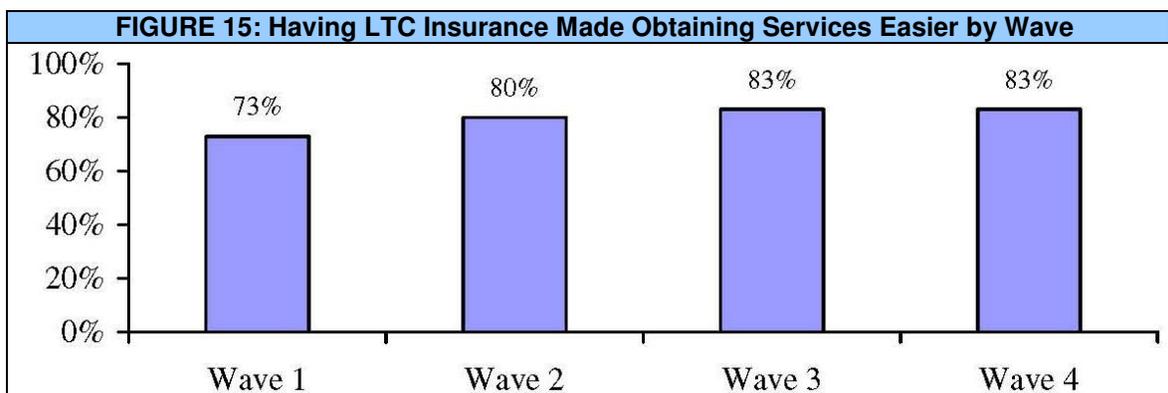
much of that care was covered by their insurance and did it change over time? The question was asked simply, “do your LTC insurance benefits pay for all, most, half, some or few of the costs of your paid care?” Figure 14 shows the proportion of those responding that their policies were paying for at least half of their care.



As shown, the vast majority report that their policies are paying for at least half of the paid care they are receiving. In fact, between 69% and 75% reported that their policies were paying for at least most of their care at any given time.

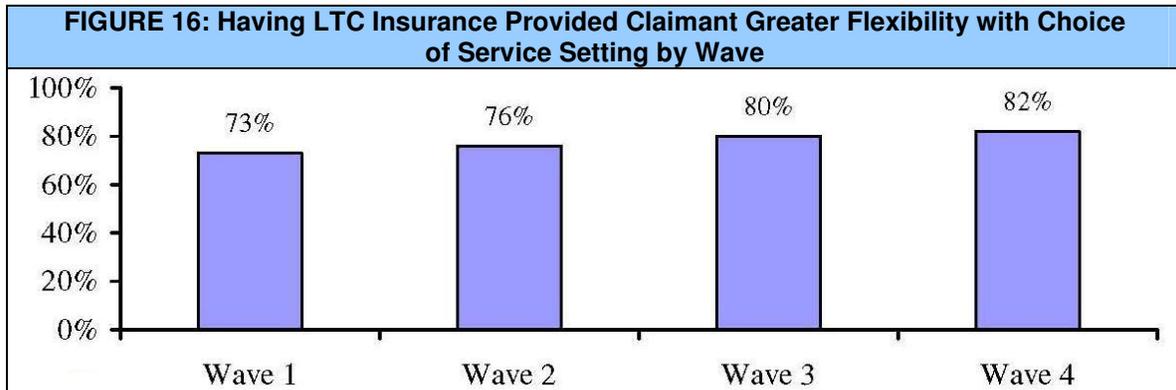
F. Effect of Having Long-Term Care Insurance

We were interested in knowing what perceived effect having a LTC policy had on claimants’ service use and claim experience. Also examined were peoples’ thoughts about what they would do in the absence of their insurance policy. As shown in Figure 15, in Wave 1, roughly three-quarters of claimants agreed that having their insurance made it easier to obtain needed services and that number increased to 83% by the fourth follow-up interview.

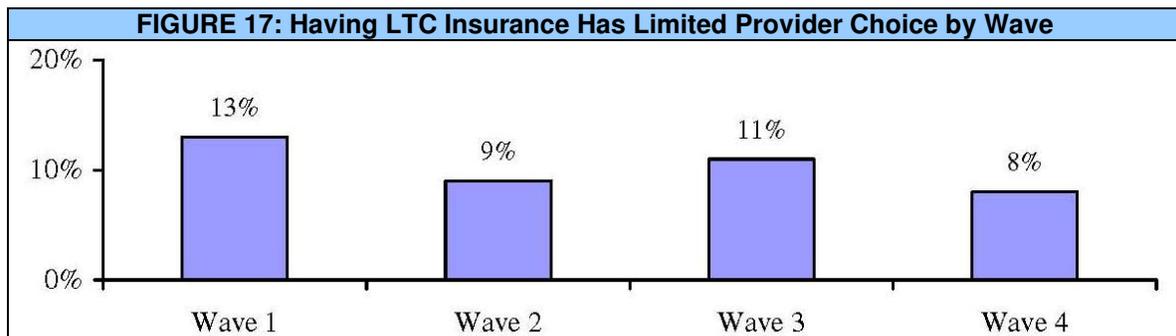


We also asked if having the policy allowed claimants greater flexibility with choosing where they could receive care (e.g., at home instead of in a NH). It is

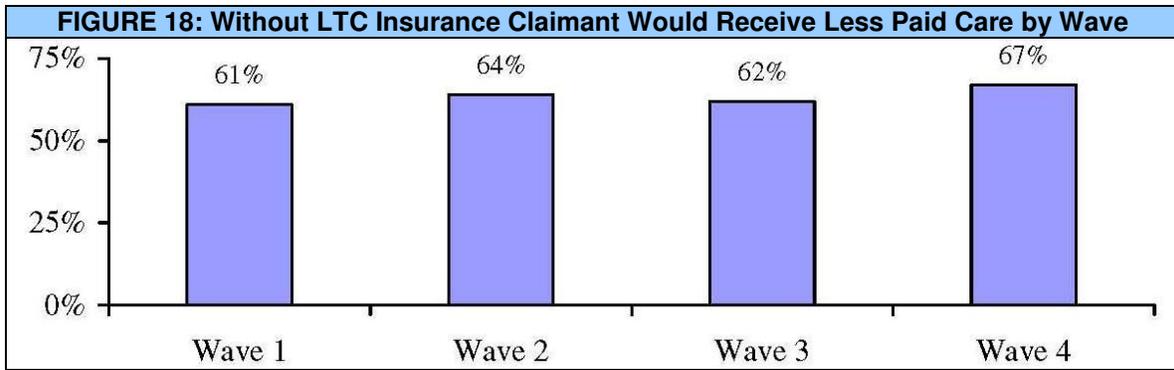
important to note that all participants have policies that pay benefits for all service settings (HC, NH and ALF), thereby mitigating the effect of insurance policy design on their choice of service setting. Again, the majority of claimants agreed that their policy did allow them greater flexibility and this perception increased over the 16 month follow-up period (see Figure 16).



Some LTC insurance policies have contract language that compels service providers chosen by the insured to meet certain requirements -- for example some policies require that paid caregivers in the home be licensed. We asked claimants if their policies limited their choice of care providers in any way. Figure 17 shows that the majority does not believe that their policy definitions restricted their choice of provider, with only 8% reporting that it did in Wave 4. Most of the individuals who indicated that they felt that the policy restricted their use of specific providers were in the HC setting (62% at Wave 1 and roughly 48% at all other Waves).



Lastly, we were interested in knowing how claimants perceived the impact of not having their LTC insurance policy on the use of paid care. We asked if claimants believed that they would receive less paid care if they did not have their insurance policy. In fact, the majority of claimants agreed that they would have to decrease the amount of paid care they receive if they did not have their insurance. This is not surprising given that most of the claimants report that the policy pays for most, if not all of the paid care they receive.



G. Movement and Transitions

The tables below show transitions through care settings for the baseline samples. A transition is defined as a change in service setting (moving from a NH to an ALF for instance) or a change from a status of no paid service use to paid service use or vice versa. We were interested in knowing whether and how people moved between care settings over the 16-month period. We also track those who filed a claim at baseline, but were not yet using paid services.

Findings are discussed separately for each baseline group. It is important to note that for all of the following tables, the percentages reported for those who died, refused to participate, or were not locatable, are cumulative; that is, they are the rates for the 16 month period, not the proportion that applies to the current Wave.

TABLE 4a: Movement and Transitions for the Baseline Home Care Recipients

Care Setting	Wave 1	Wave 2	Wave 3	Wave 4
HC	43%	30%	24%	18%
NH	3%	3%	3%	2%
ALF	2%	3%	3%	4%
No Paid Care	26%	23%	20%	19%
Deceased	11%	15%	18%	20%
Refusal	10%	18%	22%	24%
Unable to locate	5%	8%	10%	13%
	100%	100%	100%	100%

NOTE: Percentages above the dotted line apply only to that Wave. Those below the dotted line are cumulative.

At the baseline interview, 37% of the sample reported using HC (not shown). Table 4a shows that at Wave 1 (four months after the initial interview) the majority was either still receiving HC or had stopped using paid care (43% and 26% respectively). Only a small proportion entered NHs or ALFs. This pattern continues to hold true over the 16-month period. Also shown is that 20% of the original HC sample is deceased 16 months after their initial baseline interview. We also know from the baseline report that those using paid care at home at baseline were the among the less disabled in terms of their ADL and IADL profile. Therefore, it is not surprising that a high percentage of them move from paid care to no paid care.

TABLE 4b: Movement and Transitions for the Baseline Nursing Home Residents				
Care Setting	Wave 1	Wave 2	Wave 3	Wave 4
HC	5%	3%	3%	3%
NH	51%	40%	32%	26%
ALF	5%	7%	8%	6%
No Paid Care	9%	11%	8%	7%
Deceased	21%	24%	29%	32%
Refusal	7%	11%	13%	17%
Unable to locate	2%	4%	7%	9%
	100%	100%	100%	100%
NOTE: Percentages above the dotted line apply only to that Wave. Those below the dotted line are cumulative.				

At the baseline interview, 14% of the sample reported moving into a NH. Of that original sample, only 51% remained in the NH at Wave 1; about one in five died within the first four months of NH use. Very few NH residents transitioned to the HC setting or assisted living, although slightly more seemed to have gone to assisted living than HC. By Wave 4, almost one-third of the original sample was deceased, much higher than the 20% of the original HC sample.

TABLE 4c: Movement and Transitions for the Baseline Assisted Living Facility Residents				
Care Setting	Wave 1	Wave 2	Wave 3	Wave 4
HC	1%	1%	2%	1%
NH	5%	7%	9%	8%
ALF	70%	56%	46%	32%
No Paid Care	8%	6%	5%	5%
Deceased	7%	12%	13%	18%
Refusal	5%	10%	16%	21%
Unable to locate	4%	8%	9%	15%
	100%	100%	100%	100%
NOTE: Percentages above the dotted line apply only to that Wave. Those below the dotted line are cumulative.				

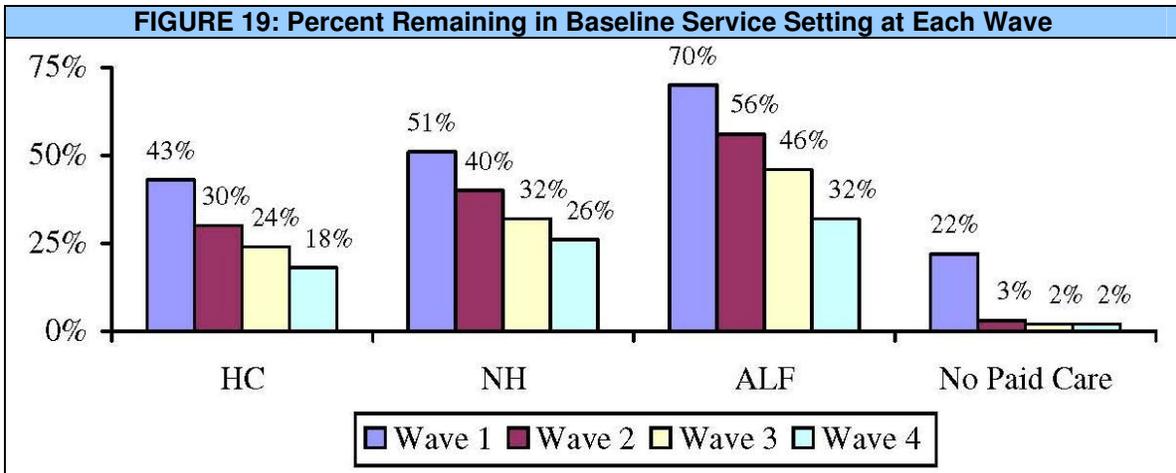
At baseline, 23% of the sample reported living in an ALF. Although this sample had the highest average age, they have a much lower rate of death than those living at home or in NHs, reflecting their superior functional status. At Wave 1, only 7% of the sample was deceased and this proportion grew to 18% by Wave 4. This group also seems to have the lowest rate of movement among the three groups discussed so far, with almost one-third still residing in ALFs 16 months after the initial interview. They also report the lowest rate of transition to no paid care, which is not surprising since a move to an ALF is typically a permanent lifestyle change.

Care Setting	Wave 1	Wave 2	Wave 3	Wave 4
HC	28%	21%	18%	13%
NH	1%	2%	1%	1%
ALF	6%	7%	7%	5%
No Paid Care - - - -	22% - - - -	3% - - - -	2% - - - -	2% - - - -
Deceased	10%	14%	17%	19%
Refusal	14%	16%	17%	20%
Unable to locate	4%	7%	8%	10%
	100%	100%	100%	100%
NOTE: Percentages above the dotted line apply only to that Wave. Those below the dotted line are cumulative.				

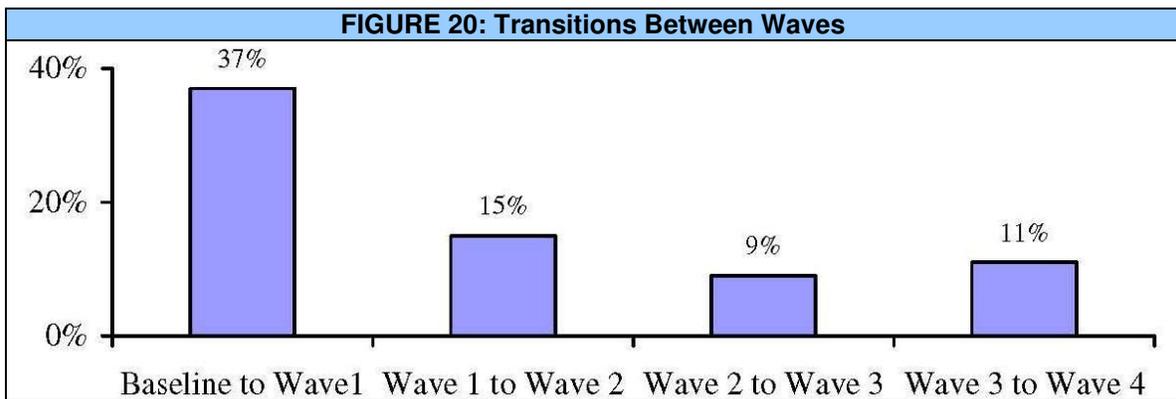
Slightly more than one-quarter (26%) of the original sample report that they had not begun using paid care at baseline. Since we were only interested in following those people who used paid care at some point in the study period, we asked a question at each Wave pertaining to their current or intended paid care use. In order to be included in the study sample, a participant had to either be using paid care or intend to begin paid care in the next four months. Those who were not receiving paid care at the baseline interview were asked again at Wave1 if they were receiving paid care. If they said no, they were then asked if they intended to begin using paid care in the next four months. If they answered no again, they were considered ineligible and removed from the sample. If they answered in the affirmative, they were kept in the sample for an interview at Wave 2. The same set of questions was repeated at Wave 2 for this group; however, if they were not yet receiving paid care at Wave 2, regardless of whether they intended to begin in the next four months, they were dropped from the study. Table 4d shows that 30% of insureds who notified their company of an intention to file a claim and begin using paid care never actually began using paid services. The percentages for the ineligible category are cumulative -- the same as the proportions in the deceased, refused and unable to locate categories. In other words, at Wave 1, 15% were ineligible and at Wave 2 another 15% became ineligible -- for a total of 30% of the original baseline sample of those not receiving paid care dropped after Wave 2. These 30% were removed from the sample and no longer interviewed after Wave 2.

Not surprisingly, the highest proportion of those who did go on to use paid care ended up using paid care at home. By Wave 4, 19% of the original sample is deceased, which is comparable to the rates for the assisted living and HC recipients. This was somewhat surprising given that this group seemed to be the youngest and healthiest. This could imply that mortality rates seem to “even out” somewhat over the 16-month period, although those starting out in NHs die at a much higher rate than all of the other groups.

Figure 19 represents in graph form the percent of participants remaining in their baseline service setting at each Wave. This clearly shows that those who moved to an ALF at or near the baseline interview were the most likely to remain there over the 16 month period.



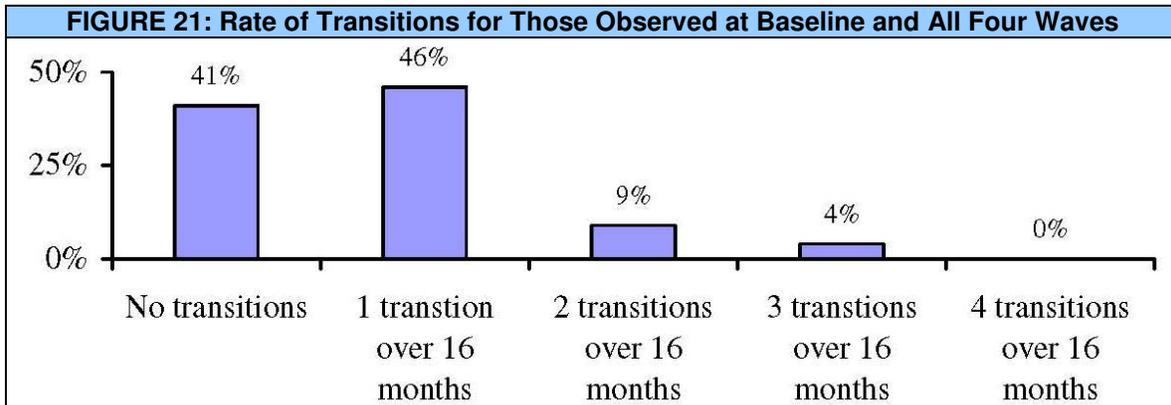
We were also interested in overall transition rates for the entire sample, both from Wave to Wave and for those that remained in the study from baseline to Wave 4. Figure 20 below shows the transition rate between Waves. We looked at all of those whose location changed from the previous Wave. This could have been a transition from one care setting to another, from paid care to no paid care or from no paid care to paid care.



The proportion of the sample that changed location or status between baseline and Wave one is greater than one in three. This means that 37% of participants either changed their care setting or went from paid to unpaid or unpaid to paid care four months after the baseline interview. This rate declines dramatically over time and levels off somewhat. This implies that after four months, there is much more “settling-in” to a care setting or service use status.

Figure 21 characterizes the number of transitions over a 16 month period for participants who were observed at all five points in time (at baseline and then for all four telephone Waves). The minimum number of transitions is zero, meaning that a participant did not move at all over the period, and the maximum number is four. As shown, 41% of those who we observed at all points in time over the 16 month period reported no transitions and another 46% reported changing care settings or going from paid care to no paid care or vice versa only once. A small proportion (9%) transitioned

twice, while 4% transitioned three times. No one changed settings the maximum number of times over the 16-month period. Not shown is that the average number of transitions for people observed throughout the 16-month period was 0.77 -- a relatively low rate indicating stability of service setting use among those who remain in the sample over the 16 months.



There are many characteristics that one could hypothesize are associated with a higher likelihood of transitioning across service settings. We looked at age, marital status, gender, baseline disability level, cognitive impairment, baseline service setting, baseline satisfaction level with specific service provider, whether or not the insured reported unmet need at baseline, whether their baseline service setting was the first choice and what factor had the most influence on baseline care setting choice. Table 5 shows the results of only those characteristics that had statistically significant differences at the 0.05 level.

TABLE 5: Characteristics Associated with Transitioning

Characteristic	Had at Least One Transition	Had No Transitions
Average Age	78 years	80 years
Average ADL limitations	2.8	3.2
Average IADL limitations	6.2	6.7
Cognitively Impaired		
Yes	39%	61%
No	56%	44%
Receiving Paid Care at Home	56%	44%
Receiving Care in NH	36%	64%
Receiving Paid Care in an ALF	31%	69%
Satisfaction with Specific Service Provider (at Baseline)		
Very Satisfied	39%	61%
Other than Very Satisfied	56%	44%

We found that older individuals and those with higher levels of disability are less likely to experience a transition -- that is those who had at least one transition were significantly younger (78 years old with 2.8 ADL limitations and 6.2 IADL limitations) than those who did not transition over the 16-month period (80 years old with 3.2 ADL limitations and 6.7 IADL limitations). Those who are cognitively impaired are also more

likely to stay in one place (have no transitions) for the entire 16 months. Those receiving paid care at home at baseline were more likely to experience a transition, which seems surprising. However, this is likely due to the high proportion of HC recipients who stopped using paid care (also counted as a transition), especially since previous tables show a low rate of transition to NH and ALF among this sample. Beginning paid care use in a NH or ALF also means that you are more likely to remain there (only 36% of those in NHs at baseline experienced at least one transition) than transition to another care setting or stop using paid care. NH and ALF residents were also significantly less likely than baseline HC residents to have experienced a transition over time. Lastly, we found that those who stated they were less than very satisfied with their choice of provider were more likely than not to experience a transition (56% versus 44% respectively). Marital status, gender, unmet need and whether or not the baseline care setting was the first choice had no influence on the likelihood of experiencing a transition.

V. SUMMARY

The information gleaned from this random sample of an admissions cohort to the LTC system is extremely informative. This is perhaps the first time a random sample of a cohort of new service users in multiple care settings has been interviewed so close to the time of their decision and then followed for a significant length of time (over two years when the study is completed in 2008). Findings presented here suggest that there is a high mortality rate, particularly in the first four months after initiating paid service use (11%), with 18% dying after one year. Over the course of the study period (16 months), roughly one-quarter of the sample is not receiving any paid care at a given time, which suggests that a meaningful proportion of individuals exit the LTC service system within a year or so of initial use.

Findings also show that claims denial rates are low -- with only 2.4% of the remaining sample reporting that their claims were ultimately denied by the end of the 16 month period. The rate of disagreement with the insurance company over coverage or benefit eligibility is also low -- only 6% of those who file a claim (both approved and denied) report that they had disagreements that were not resolved satisfactorily. Furthermore, those who are denied benefits are the least disabled, with an average of less than one ADL limitation at the time they were interviewed at baseline (0.74 ADL limitations) and that average is still less than two ADL limitations four months later (1.8 ADL limitations).

Data on transitions show that 41% of individuals observed over the study period have no transitions at all. The average rate of transitions for the entire sample is 0.77. For those who do transition, they are most likely to be younger, less disabled (both functionally and cognitively) recipients of paid HC and report being less than satisfied with their initial choice of service provider. The highest rate of transition occurs within four months after the baseline interview, and then declines dramatically over time and

levels off. ALF residents are least likely to transition, whereas users of home health care transition more frequently.

Findings presented here underscore the importance of focusing on phenomena over time, rather than at a point-in-time. In this way it is possible to better understand the dynamic nature of the system and those who are accessing it.

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