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Validity of proxy reported service utilization for the cognitively impaired elderly

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Validity of Proxy Reported Service Utilization
for the Cognitively Impaired Elderly

by

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Affectionately dedicated to my parents

Stella and Jerry Donatoni

My heartfelt thanks for your encouragement and love.

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Validity of Proxy Reported Service Utilization

for the Cognitively Impaired Elderly

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ABSTRACT

This study verified caregiver reported utilization data for 2,745 clients enrolled in the Medicare Alzheimer's Disease Demonstration Evaluation. Researchers substitute proxy respondents for nonparticipating subjects to increase survey response rates, minimize sampling error, and reduce data collection costs. Although proxy respondents provide most survey data on Alzheimer's patients, researchers have not systematically evaluated reporting by "primary" caregivers of these subjects.

The verification used direct record check methods to compare reported adult day care and a package of in-home services against demonstration claims history data at baseline and 6 months. The analysis used crosstabulations and multiple regression modeling to evaluate reports of service use, service funding source, and service units.

Caregivers were adept at recalling service use, but they underestimated the extent of funding that the demonstration provided. Respondents achieved 93 percent sensitivity for all reported service use at baseline and 6 months. Reports had low error rates, with net positive biases. Respondents significantly reduced rates of nonmatching reports over time. They failed to identify demonstration funding for at least half the service reports having TAPE claims. Logistic modeling found that caregivers living with clients had significantly better chances of correctly reporting the use or absence of day care services, and significantly lower chances of reporting day care services without TAPE claims than

caregivers not living with clients. Increasing levels of caregiver depression significantly reduced the odds of accurately reporting the use or absence of day care, and significantly heightened the odds of reporting day care services without TAPE claims. There were no significant predictors of in-home service use reporting.

Reported day care and in-home services units exceeded TAPE units. With practice, respondents significantly increased rates of matching reports and reduced rates of reports exceeding TAPE units. Least squares modeling found that caregiver living arrangement, caregiver relationship, and depression were significant predictors of day care and in-home services residual units. Regression findings for caregiver living arrangement, caregiver relationship, and depression were weakly significant. The findings suggest that the level of resulting bias arising from these factors would not substantially affect proxy reported services or units for Alzheimer's patients.

Approved: Robert J. Newcomer 12-22-97

Robert J. Newcomer, Committee Chair Date

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I. INTRODUCTION TO THE STUDY

Alzheimer's disease has become a prominent issue in social health policy and research in the twenty years since Katzman identified the disease as a cause of senile dementia and one of the top five causes of death in the United States (Fox, 1989; Katzman, 1976; U. S. House of Representatives Select Committee on Aging, 1990). Demographers estimate that the elderly aged 65 and above will explode from 12.6 percent of the American population in 1992 to 20.6 percent in 2050 (U. S. Bureau of the Census, 1992).[1] The prevalence of dementing illness increases with age (Bachman et al., 1992), becoming most prevalent among the very old (Fichter, Meller, Schroppel & Steinkirchner, 1995; Heeren, Lagaay, Hijmans & Rooymans, 1991; Ritchie & Kildea, 1995).[2] Alzheimer's disease is the primary cause of cognitive impairment among the elderly (Evans et al., 1990).[3] Nearly 4 million Americans have the disease; nearly 14 million will be affected in the next half century (Khachaturian, Phelps & Buckholtz, 1994).

Alzheimer's disease causes progressive global impairment. The course of the disease is highly variable, but survival generally averages 8 to 10 years from onset (Larson, Kukull & Katzman, 1992). Patients notice that they are becoming forgetful, but

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[1]These rates represent 32 million and 79 million people, respectively.

[2]Recent studies confirm that the prevalence of dementia (DSM-III criteria) increases with age, reaching high rates at 85 years and above (Fichter et al., 1995; Heeren et al., 1991; Ritchie & Kildea, 1995). Evidence from a meta-analysis of 9 epidemiological studies found that the rate of increase falls at ages 80-84, suggesting that the risk of developing dementia diminishes for the very old (Ritchie & Kildea, 1995). A study reporting an overall prevalence rate of 23 percent among old old Dutch community residents found age-related prevalences were 19 percent in ages 85-89, 32 percent in ages 90-94, and 41 percent in ages 95 and above. Mild impairment was present in 12 percent of cases, moderate impairment in 7 percent, and severe impairment in 4 percent (Heeren et al., 1991). The incidence of dementia in south-western France (DSM-III-R criteria) increased from 2/1000 in ages 65-69 to 74/1000 in ages 90 and above. The incidence of Alzheimer's disease (NINCDS-ADRDA criteria) increased from 0.7/1000 in ages 65-69 to 66/1000 in ages 90 and above (Letenneur, Commenger, Dartigues & Barberger-Gateau, 1994).

[3]Alzheimer's disease and vascular dementia are the main causes of dementia in developed countries (Brayne et al., 1995; Hebert & Brayne, 1995). The population-based Rotterdam study of 7,528 people aged 55-106 reported an overall prevalence of dementia of 6.3 percent. The prevalence rates for specific dementing illnesses were: 72 percent Alzheimer's disease, 16 percent vascular dementia, 6 percent Parkinson's type, and 5 percent other dementia (Ott et al., 1995).

the onset of symptoms is insidious. Language impairment and other cognitive deficits gradually appear. In time, symptoms become severe enough to interfere with work and everyday activities (Berg & Morris, 1994). Individuals may develop other noncognitive symptoms or disruptive behaviors as the disease progresses (Folstein & Bylsma, 1994; Swearer, Drachman, O'Donnell & Michell, 1988).[4] Patients eventually need complete in-home or institutional care (Coughlin & Liu, 1989; Gaitz & Wilson, 1987).[5]

Many researchers have studied Alzheimer's patients and their caregivers (Bracco et al., 1994; Chenoweth & Spencer, 1986; Fitting, Rabins, Lucas & Eastham, 1986; Fox, Lindeman & Benjamin, 1987; George & Gwyther, 1986; Iacopino, Cinotti & Biber, 1989; Rice et al., 1992; Zarit, Reever & Bach-Peterson, 1980). Longitudinal studies have gained prominence in recent years (LaRue, 1987). Some of these projects have been developing patient registries and tracking participants (Godard et al., 1994; Kukull et al., 1995; Morris et al., 1993; Severson et al., 1994). Policy-relevant research still lags behind newer developing models of patient care, namely, the explosion of Alzheimer's special care units in nursing homes and residential care facilities (Lindeman, Beitler & Lombardo, 1994).

Much of what researchers learn about Alzheimer's patients and their caregivers comes from survey data. Few patients can report on themselves. Most rely on caregivers to act as proxy respondents (Caserta, Lund, Wright & Redburn, 1987; Lawton, Brody & Saperstein, 1989; Rice et al., 1992). Although proxy respondents provide most survey data on Alzheimer's patients, researchers have not systematically evaluated reporting by "primary" caregivers of these subjects.

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[4]These include angry outbursts, aggression, depression, delusions or hallucinations, paranoia, phobia, sleep disturbances, incontinence, altered dietary babits, and altered sexual habits (Folstein & Bylsma, 1994; Swearer, Drachman, O'Donnell & Michell, 1988).

[5]The average duration of symptoms lasts 8 to 10 years from onset or 4 to 5 years from diagnosis (Larson et al., 1992). Alzheimer's disease cost Americans $67.3 billion in caregiver costs, medical care, institutional and community care, and lost lifetime earnings during 1991 (Ernst & Hay, 1994). A recent outpatient study found a "positive and significant" correlation between disease severity and costs (Soutre et al., 1995).

Health researchers depend heavily on self-reported data even though many would prefer records data (Cornoni-Huntley et al., 1993; Harris & Kovar, 1992). Records data are the closest to a "gold standard" in health research (Branch, 1992; Mathiowetz, 1989; Verbrugge, 1989), but self-reported data are usually more accessible and affordable than clinical or administrative data (Richardson & Freeman, 1972). The ability to maintain adequate response rates presents a major difficulty to health service researchers who collect survey data. Commentators on the National Medical Care Expenditure Survey, one of the most comprehensive federally-sponsored health surveys, wrote that achieving a high response rate on the Physicians' Practice Survey was time consuming and costly (Berk, Wilensky & Cohen, 1984). Investigators want to obtain the best quality data for a given project budget. Many commonly substitute proxy respondents for sampled cases or households to increase response rates (Herzog & Rodgers, 1988), minimize sampling error (Mathiowetz & Groves, 1985; Mathiowetz & Groves, 1987), and reduce survey costs (Mathiowetz & Groves, 1985; Rodgers & Herzog, 1989).

Proxy respondents answer questions for subjects who do not personally participate in surveys. Subjects may be unavailable when the interviewer calls. Sometimes subjects refuse to participate in the study, or refuse to answer specific questions (Augustsson, Eriksson, Rosenhall, Warne & Steen, 1994; Berk et al., 1984; Ferber, 1966). Nonparticipants in the National Medical Expenditure Survey offered many reasons why subjects may not cooperate. Some were too busy, concerned about their privacy, or disinterested. Others were against surveys in general or the survey sponsor (Meyers & Oliver, 1978). Many subjects do not participate in surveys because they cannot capably respond for themselves.

Numerous factors may prevent subjects from capably responding. Subjects may lack fluency in the interviewer's language (Burnam et al., 1985). Very young children cannot answer questions (Smith & McElwee, 1989). Neither can subjects who have health conditions that impede their ability to give information. Such conditions may include

communication impairments (e.g., stroke), writing impairments (e.g., arthritis, nutritional deficiencies) (Penland, 1994; Tennstedt, Dettling & McKinlay, 1992), psychiatric disorders (e.g., schizophrenia and psychosis) (Nelson, Longstreth, Koepseu & vanBelle, 1990), cognitive impairments (e.g., mental retardation, Alzheimer's disease, and other dementing illnesses) (Stephens, 1982; Weinberger et al., 1993; Welch, Walsh & Larson, 1992), and rapidly progressive terminal illnesses (e.g., cancer) (Lerchen & Samet, 1986). Finally, proxy respondents commonly provide epidemiologic and health service data on deceased cases (Burnam et al., 1985; Grigoletto et al., 1994; Lerchen & Samet, 1986; Nelson et al., 1990; Tepper, Connally, Haltmeier, Smith & Sweeney, 1993).

Aging and advancing disability increase people's need for proxy respondents (Burnam et al., 1985; Magaziner, 1992; Tennstedt et al., 1992). About 20 percent of the elderly living in the community may be reluctant or incapable of responding in health studies (Burnam et al., 1985; Cornoni-Huntley, Brock, Ostfeld, Taylor & Wallace, 1986). A substantially lower rate of women 80 and older completed the Health and Nutrition Examination III pilot study than women under 70 (Rodgers & Herzog, 1989). Proxies responded for 3 percent of cases 65 and older in the 1982-1983 wave of the East Boston Study of EPESE (Adams et al., 1990).[6] By comparison, 14.5 percent of frail elders 70 and above had proxy respondents for the 1984-1985 baseline interview of the Massachusetts Elder Health Project (Tennstedt et al., 1992). The 1984 Supplement on Aging to the National Health Interview used proxy respondents for 8.5 percent of cases over 70 and 26.6 percent of cases 85 and older (Fitti & Kovar, 1987). Proxies assisted 4 percent of subjects aged 75-84 and 15 percent of subjects 85 and above in a validity of reported health services utilization (Carsjo, Thorslund & Warneryd, 1994).

Numerous surveys have demonstrated that adults aged 65 and above are less likely to respond in first time surveys than younger adults. Adults 85 and above have the lowest response rates (Fitti & Kovar, 1987; Herzog & Rodgers, 1988; Kingery, 1989). National

[6]Established Populations for Epidemiologic Studies of the Elderly

surveys from the Survey Research Center found declining response rates with increasing age. Several national election and attitude polls reported response rates ranging from 62.6 to 79.8 percent for ages 18-64, from 68.0 to 68.8 percent for ages 65-74, from 62 to 66.9 percent for ages 75-84, and from 48.8 to 53.9 percent for ages 85 and above (Herzog & Rodgers, 1988).

The elderly have low response rates partly because they refuse to participate in surveys. Several epidemiologic and health utilization studies of the elderly have reported refusal rates from 13 to 17 percent (Adams et al., 1990; Bracco et al., 1994; Norris, 1985; West et al., 1995). Many studies reported higher refusal rates for elderly persons than for younger individuals (Hawkins, 1975; Lowe & McCormick, 1955; Sharp & Feldt, 1959; Stephan & McCarthy, 1958), while other studies found statistically significant increases in refusals during the middle years that declined to very low rates in the mid-80's and above (Herzog & Rodgers, 1988). Refusals by the frail elderly increase with age, but low refusal rates are not unheard of among the very old. Only 2.7 percent of subjects refused to answer one health utilization survey of persons 85 and older (Carsjo et al., 1994). Tennstedt and associates found a tendency for respondents 85 and above to refuse more often than ages 70-84, but the difference between groups was not statistically significant (Tennstedt et al., 1992). Differences in refusal rates between men and women have not been consistent across studies (De Maio, 1980; Jay, Liang, Liu & Sugisawa, 1993; Tennstedt et al., 1992).

Apparent discrepancies in refusal rates across studies may partly stem from the fact that researchers do not uniformly distinguish outright refusals from other reasons for nonresponse, or give added attention to older respondents. Researchers have reported that interviewers who are sensitive to the needs and concerns of older respondents can reduce refusal rates by as much as 50 percent (Norton, Breitner, Welsh & Wyse, 1994; Tennstedt et al., 1992).

While many elders do participate in surveys, the number of items they leave unanswered increases with age (Colsher & Wallace, 1989; Ferber, 1966; Slymen, Drew, Wright, Elder & Williams, 1994). Studies have shown that elders living in the community tend to have lower average rates of nonresponse across items than nursing home residents (0-4 percent versus 0-8 percent) (Colsher & Wallace, 1989; Garrard, Skay, Ratner, Kane & Chan, 1989). Noninstitutionalized respondents over 84 have significantly higher numbers of missing items than respondents 65-74 and 75-84 (Colsher & Wallace, 1989). Women are more likely to have missing data than men, but this finding has not been a significant finding across all studies (Colsher & Wallace, 1989; Ferber, 1966; Slymen et al., 1994).

Many factors lead to survey nonresponse by elderly subjects. Nonrespondents in two longitudinal studies cited disinterest and illness or frailty as the primary reasons for refusal. These factors were 88.0 and 96.5 percent of the total refusal rates for the two studies (Norris, 1985; Tennstedt et al., 1992) . Studies have indicated that subjects who are women, unmarried, living alone, cognitively impaired, less educated, poorer, and less healthy are more likely to become nonrespondents than respondents (Jay et al., 1993; Launer, Wind & Deeg, 1994; Norton et al., 1994; Thomas, 1989). Participants in longitudinal studies have higher odds of leaving during the study when they are male, very sick, and older when they die than continuing respondents and respondents who choose to quit the study (Thomas, 1989). Death and disability comprise increasing proportions of attrition over time, and rates of death and disability differ by gender. A study tracking respondents over five waves reported that with passing time, women's disability rates exceeded men's rates and men's mortality rates exceeded women's rates (Norris, 1985).

Factors associated with partial or item nonresponse are related to characteristics of respondents and the questions. Studies have shown that respondents leave missing items for many of the reasons that respondents refuse to answer any questions. Elderly subjects likely to leave unanswered questions have lower incomes, no spouse, diminished recall,

poorer health, and lower functional status (Colsher & Wallace, 1989; Guadagnoli & Cleary, 1992; Slymen et al., 1994). The type of question is also a significant predictor of item nonresponse (Colsher & Wallace, 1989). Respondents are more prone to skip questions they perceive as burdensome. These include questions on threatening topics (Sudman & Bradburn, 1973), evaluative questions, questions requiring detailed responses, and lengthly surveys (Ferber, 1966; Pickle, Brown & Blot, 1983; West et al., 1995). A Consumers Union survey that requested detailed factual and evaluative information about household purchases and planned purchases reported that half the questionnaires returned by respondents 35 and under had no missing items. Only 5 percent of questionnaires from respondents 65 and above were complete; 49 percent had 6 or more missing items (Ferber, 1966). Group Health Cooperative enrollees 50 and older could not give accurate, complete reports of the dates, dosages, and names of medications prescribed during a 12-year period (West et al., 1995).

Survey nonresponse among the elderly is a concern for researchers. Nonrespondents generally have worse health, poorer cognition, and fewer resources than self-respondents. This selective nonresponse may seriously bias some data. There is evidence that selective nonresponse is a greater problem for cognitively impaired subjects than unimpaired subjects. We have seen that moderately and severely demented subjects do not participate in cross-sectional studies. The progressive trajectory of dementing illness increases the likelihood of high morbidity- and mortality- related attrition in longitudinal studies. Selective attrition of cognitively impaired subjects has a larger impact in studies that compare cognitively impaired and unimpaired subjects over time (LaRue, 1987).

Comparisons between longitudinal studies drawn from elderly populations and demented elderly populations reveal higher morbidity and mortality rates for studies of demented subjects. Two longitudinal studies of the elderly show relatively modest attrition from mortality and disability. The first, a 3.5 year study of Medicare enrollees reported a

2 percent average attrition on each 6 month wave, and another 3-4 percent of the original sample dying between any two waves (Thomas, 1989). At the end of another 2 year study, 3.2 percent of the original sample had died, 5.4 percent were unlocatable, 5.7 percent were too disabled to respond, 15.3 percent were disinterested, and 9.0 percent left the study for other reasons (Norris, 1985).

Studies of subjects having Alzheimer's disease and related dementias show high rates of mortality and institutionalization. One year after leaving an Alzheimer's dementia unit, 13.9 percent of subjects with probable Alzheimer's disease had died, and 34 percent were institutionalized (Bianchetti et al., 1995). Thirty-four percent of patients died and 25.5 percent were lost to follow-up by the end of another year-long study (Kaszniak, Huckman & Ramsey, 1978). The Consortium to Establish a Registry for Alzheimer's Disease reported that 0.83 percent of the original sample died after the first year, then 5.4 percent every year for the next 3 years. About 2.5 percent of the sample refused or moved each year (Morris et al., 1993). By the fifth year of another survival study, 83 percent of late onset Alzheimer's patients and 61 percent of early onset patients had died (Bracco et al., 1994). The Mayo Clinic Alzheimer's Disease Patient Registry reported that 9 percent of patients refused to participate and 8 percent withdrew due to death, illness, or relocation 1.5 years after initial evaluation. Patient institutionalization rose from 39 to 63 percent at 1.5 to 3.9 years, respectively. Rates for matched controls remained at 4 percent (Severson et al., 1994). During a 2.5 year Kungsholmen project study, 31 percent of demented cases entered institutions compared with 4 percent of undemented controls (Grafstrom & Winblad, 1995). The large variance in mortality rates across Alzheimer's studies may be partly attributed to the highly variable course of the illness. Another consideration is that some of the studies cited were not representative of the Alzheimer's population because subjects came from hospitals and clinics.

These studies indicate that compared to the elderly subjects in general, a larger proportion of demented subjects who do not participate in studies are disabled,

institutionalized, or deceased. Most Alzheimer's patients are community residents. They use chronic care services including adult day care, in-home health, personal care, and homemaker services (Eisdorfer, 1994). One study reported that 46 percent of community-dwelling dementia patients were using formal services and 29 percent were using daily informal care at 1.5 years after their initial evaluation. Only 4 percent of matched controls were using formal services and 5 percent were using daily informal care at 3.9 years after intake (Severson et al., 1994). Functional decline -- independent of patient age, level of cognitive decline, duration of dementia, and number of comorbidities -- is the most important predictor of short-term mortality in Alzheimer's disease (Bianchetti et al., 1995).

People who respond for Alzheimer's patients in surveys do not necessarily become proxies by chance. Women generally act as proxies more often than men. Specific groups of people also tend to respond for subjects having certain characteristics. Proxy respondents may represent one or more cases in a study. In surveys using sampling frames that take individuals as the sampling unit, single proxy respondents usually respond for single cases. Many surveys use sampling designs that take households or other groupings as the sampling unit. In such designs, proxy respondents typically provide information about themselves and other members of the sampling unit (Cannell, Marquis & Laurent, 1977; Mathiowetz & Groves, 1987; Mathiowetz, 1989; Mosely & Wolinsky, 1986). Large household surveys, such as the National Medical Expenditure Survey and the National Health Interview Survey, sample households and select respondents by established respondent rules (Mathiowetz & Groves, 1985).

The living arrangements and age of the subject may determine the availability of a proxy and who ultimately serves as a proxy. Adult children and spouses typically act as proxy respondents for the elderly. They may or may not live with the elderly person. Adult children usually provide information for their institutionalized parents, and spouses report for elderly partners still living at home (Rodgers & Herzog, 1989). In the Sicilian Neuroepidemiologic Study, mothers most often responded for subjects 40 and younger,

wives for subjects 40-69, and children for subjects 70 and older. Among deceased and unreachable subjects, men and subjects under 50 had the largest proportions of available proxy respondents (Grigoletto et al., 1994). In a study that compared elderly respondents and nonrespondents, Adams and others found that respondents by proxy were older and significantly more likely to be living with others than self-respondents (Adams et al., 1990).

Women are proxy respondents more often than men. Women are more willing to grant interviews and complete mail surveys than men (Briscoe, 1984; Kaldenberg, Koenig & Becker, 1994). Nonresponse is significantly higher among men than women; men are more likely to refuse or be away from home (Jay et al., 1993). Why women are easier to reach at home is not entirely clear. Researchers traditionally assumed that men are away from home because they are working, but comparisons made while controlling for employment status show diminished differences in the availability between men and employed women and substantial differences between employed and unemployed women (Sudman, 1967).

Women customarily report health information for themselves and their families. Most caregivers are women, and household members usually identify a woman as the person most knowledgeable about everyone's health (Clarridge & Massagli, 1989; U. S. Congress Office of Technology Assessment, 1987). Women monitor the health of the household through their daily activities and act as the household's link to the health care system by making appointments, consulting with providers, and managing medical insurance and bills. Women comprised 91 percent of proxy respondents in the 1972 National Health Interview Survey (Kovar & Wright, 1973). According to Kovar (Kovar, 1989), women "protect" men from giving interviews, especially telephone interviews. Men 70 and older living in spousal households were 1.5 times as likely as women to have proxy respondents in the household interview of the 1984 Supplement on Aging to the

Longitudinal Study on Aging. They were 2.1 times as likely as women to have a proxy respondent in the 1986 telephone interview.

These studies suggest a tendency, if not a weak bias, towards particular proxy-subject pairings. Self-selection bias is often an additional factor in Alzheimer's studies (Rice et al., 1992). The use of proxy respondents for Alzheimer's subjects therefore presents a dilemma to researchers. Researchers may rightly argue that proxy respondents provide most survey data on Alzheimer's subjects. There are also opposing concerns that some individuals are more inclined than others to become proxy respondents, and that certain types of proxies are likely to respond for certain types of subjects. Whether proxy reported data would benefit or weaken a given study depends on many factors. For example, if proxy report data are biased, then the probability of overall bias is higher in studies primarily using proxy report data than studies using proxy report data and self-report data (Rodgers & Herzog, 1989). This study provides additional information to questions researchers must answer for their specific studies. Are proxy reported data accurate? Are proxy reported data biased? Does respondent type significantly affect data quality?

Purpose of the Study

This study verified proxy reported utilization data for 2,745 enrollees of the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE). The project had two goals. The foremost goal was to quantitatively evaluate the quality of proxy reported data. The evaluation of data quality comprised four interrelated tasks: verify reported data against an objective standard, determine reporting variability over time, detect and characterize systematic biases, and identify significant correlates of reporting behavior. The first objective is summarized in the main research questions of the study.

Did respondents accurately report demonstration service use?

Did respondents distinguish between service payment sources?

Did respondents accurately report the level of demonstration utilization?

The second goal of the study was to develop an alternate plan for verifying reported data. Rossi and Freeman state the obvious when they advise researchers that monitoring social processes requires flexibility. The researcher's workplan has to accomodate changes in the social environment that evolve during the project evaluation (Rossi & Freeman, 1993). Clients enrolled in MADDE used services funded within and outside the demonstration. The originally proposed verification would have confirmed all reported use, but a reference "standard" was only available for demonstration data.[7] It was impossible to construct a reliable reference standard for utilization funded outside the demonstration because a large number of providers did not provide billing data to the evaluation. A substitute design was developed to verifiy only reports of demonstration services and payment sources against billing claims. The new plan would be workable only if demonstration and nondemonstration data could be separated in the proxy data file. The second goal of the study was to test an exploratory method of distinguishing service payment sources in the reported data.

Significance of the Study

This study is for health service researchers who study the Alzheimer's population. The American population is growing older while the major causes of morbidity are shifting from acute illnesses to chronic conditions (Eldemire, LaGrenade & Longsworth, 1995). Between 1970-1990, the relative health care costs of persons 65 and above rose faster than the health care costs of younger persons (Mendelson & Schwartz, 1993). Elders with chronic care needs normally need both health and social health services (Topinkova´,

[7]We requested billing claims from nondemonstration providers, but their responses were unsatisfactory. Response rates are reported in the Methods chapter.

1994). It is important for researchers to monitor the functional status and service use of the elderly to design services in the future. Alzheimer's patients represent a sizable, rapidly growing segment of the elderly population whose need for chronic care is increasing. They are surviving much longer than in previous decades (Gruenberg, 1978), but remain largely inaccessible to researchers. A verification study of chronic care service reporting by caregivers of Alzheimer's patients develops a neglected area of the literature.

Proxy validity studies have examined epidemiological data more thoroughly than service utilization data. The literature comprises studies of reported functionality, symptomatology, medical history, occupational exposure, and smoking, drinking, and dietary habits. Studies of health service reporting have predominantly evaluated reports of acute care services. These include hospitalizations, physician visits, and ambulatory care services. Studies of community-based chronic care service reporting are largely absent from the literature. Verbrugge has recognized that the verification of reported services over the past several decades paralleled the expansion of public funding for those services (Verbrugge, 1989). Public funding of community-based chronic care services has not been generous. Medicare provides short-term funding for post-hospitalization home nursing services, but it does not cover most community-based long-term services (Medicare and Medicaid Guide, 1989). Now that providers are developing care models that support a continuum of acute and long-term care services (Anderson, 1993; Frederickson & Cannon, 1995; Glista, 1994; Montague, 1996), it makes sense to include studies of chronic care service reporting in the proxy literature.

In effect, a continuum of care services manages the growing need for chronic care through cost-containment measures that blur distinctions between acute and long-term care services, and between formal and informal spheres of care. Corporations are using financial incentives to promote the integration of acute and long-term care services into a "seamless continuum" (Leutz, Greenlick & Capitman, 1994; Lumsdon, 1993; Phillips-Harris & Fanale, 1995). Unpaid caregivers in the home perform tasks that formal

providers formerly supplied exclusively (Glazer, 1988; Glazer, 1990). In practice, services along a continuum of services would probably overlap considerably. If proxy reporting of acute and chronic care services can be shown to be of equivalent quality, the implication for health service research is that proxy reporting of any service along the service continuum should be equally reliable or accurate. The present literature cannot demonstrate if reporting is equivalent across acute and chronic care services. Existing studies do not present a consistent body of findings, and there is a lack of chronic care studies available for comparison.

Methodological weaknesses in many health reporting studies contribute to disparities among findings (Mosely & Wolinsky, 1986). One problem is the choice of an inadequate verifying criterion. First, researchers widely regard clinical and hospital records as the best reference criterion (Branch, 1992; Mathiowetz, 1989). The problem is that all medical providers do not necessarily have the same or the best knowledge of a subject (Mosely & Wolinsky, 1986; Verbrugge, 1989). Second, many records lack data to verify both positive and negative reports. Without this capability, the study cannot estimate false negative and false positive biases (Marquis, 1978). Third, the unproven generality that self-respondents are more accurate than proxy respondents (Mathiowetz & Groves, 1985) has led many researchers to compare proxy respondents against self-respondents instead of an objective standard.

Another problem is the way researchers select proxy respondents. Proxy selection is often nonrandom (Moore, 1988). Some respondent rule studies designate the proxy respondent as whoever is home for the interview (Mathiowetz & Groves, 1985). Self-selection bias is common in studies of married couples.

A final problem is the choice of study material. The proxy literature is contaminated by a large "pseudo proxy" literature. Pseudo proxy studies superficially look like legitimate proxy studies, but their subject matter is not appropriate for proxy reporting. Legitimate studies verify reported information that refers specifically to an individual, such

as the number of physician visits or hours of personal care services. Questions about family income, planned household purchases, or marital relations are inappropriate because they evaluate respondents' perceptions of shared activities (Moore, 1988).

It was beyond the scope of this study to correct methodological problems in earlier studies. This study attempted to avoid problems shown to compromise validity studies. Proxy respondents were randomly assigned into the treatment group. Reported services pertained to individual clients. Most importantly, the two data sources were not compared in aggregate. All positive and negative reports of service use were individually compared against matched records. This comparison method allowed estimation of false positive and false negative reporting biases.

This study of chronic care service reporting furthered the proxy literature in two ways. First, by contributing substantively to the area of service reporting. Second, by evaluating differential reporting among respondent types. Previous research has demonstrated that the meanings respondents give to events affects how accurately they report those events. Self-respondents are more likely to report events they find salient, enjoyable, or socially desirable (Bowman, Redman, Dickinson, Gibberd & Sanson-Fisher, 1991; Chu et al., 1992; Suarez, Goldman & Weiss, 1985; Sudman & Bradburn, 1974; Sudman & Bradburn, 1982) than events they find mundane, threatening, or embarrassing (Anderson, Katus, Puur & Silver, 1994; Cannell, Fisher & Bakker, 1965; Sudman & Bradburn, 1973; Sudman & Bradburn, 1974; Sudman & Bradburn, 1982; Wyner, 1980). How such factors affect chronic care service reporting is unknown. There is some evidence that saliency and threat do not affect proxy reports of behavioral items (Sudman & Bradburn, 1974). It may be that direct involvement with services increases saliency for respondents. Caregiver respondents prepared clients for transportation to day care, monitored home IV therapy, and performed home dialysis. The high cost of ongoing chronic care may have had tremendous economic impact for some caregivers. Some respondents may have given less saliency to community-based chronic care once clients

were institutionalized. Earlier studies have indicated that respondents tend to overestimate frequent non-salient events, and underestimate occassional non-salient events (Sudman & Bradburn, 1973; Sudman & Bradburn, 1974).

Relatively few studies have examined reporting by respondent type. With some exceptions, most studies evaluated proxy reports of epidemiological data or assessments of subject functioning. More studies of reporting by nonspouse proxies of elderly subjects are needed (Kalton, 1989). Findings from several respondent rule studies suggested that no respondent type is inherently more or less accurate than another (Mathiowetz & Groves, 1985). Other studies have concluded that some proxies are better respondents than others (Fultz & Herzog, 1995; Graham & Jackson, 1993; Grigoletto et al., 1994; Tepper et al., 1993). The amount of shared information between household members varies (Mathiowetz & Groves, 1987) because family composition and interrelationships between members has changed with the increase in separate households and varied lifestyles within households (Arditti, 1992; Smith & McElwee, 1989; Winn & Walden, 1989). Proxy respondents living with subjects are better to provide information than respondents living in separate households (Pickle et al., 1983).

Overview of Methodology

This study used data from the Medicare Alzheimer's Disease Demonstration Evaluation. The 2-year longitudinal study gave noninstitutionalized dementia patients and their caregivers coverage for over 20 community-based chronic care services. The analysis verified caregiver reports of day care services and a package of in-home services for 2,745 demonstration enrollees. The verification compared respondent reports against demonstration billing claims at baseline and 6 months. The study answered three main questions. Did respondents know whether clients used demonstration services? Did they recall which services were funded through the demonstration or purchased outside the demonstration? Did they accurately report the level of demonstration use?

The study verified reported utilization and units of service in separate analyses. The first analysis checked reports of utilization and source of payment. Percent agreement for reported utilization and source of payment were initially estimated from simple crosstabulations. Demonstration and nondemonstration sources of payment in the reported data could not be positively identified through reference standards; therefore, source of payment was recoded on each reported service using a formula based on demonstration benefit cap amounts and the clients' total demonstration reimbursement. Revised estimates of false reporting error and weighted net bias were then calculated from crosstabulations of the recoded data. The revised estimates attempt to distinguish service reporting error from funding source error. McNemar's tests were performed to determine if the proportions of false utilization reports changed significantly over time. Finally, logistic regression models of the recoded data were used to predict matching and nonmatching reports of demonstration service utilization.

The second analysis verified reported units from confirmed reports of demonstration utilization. Crosstabulations were examined to evaluate absolute differences between reported and claims units. Matched pairs *t* tests were performed to determine if matches within unit intervals changed significantly over time. Reporting variance was then predicted using staged multiple regressions. The first model regressed reported units on claims units, and the residuals were output as a SAS data set. The residuals served as the dependent variable in subsequent models. Demonstration and nondemonstration payment sources in the reported data could not be separated using reference standards. To compensate for the effects of nondemonstration sources in the reported data, separate regressions were run to model unaltered reported and claims units, reported units trimmed to the maximum allowable demonstration benefit, and log-transformed claims units. The three regressions were compared to determine the best explanatory model.

Generalizability of Study

This study is generalizable to primary caregivers of elderly dementia patients who are willing to seek formal assistance and serve as proxy respondents. It is true that the sample has limited generalizability, but a probability sample of Alzheimer's patients and their caregivers cannot be drawn from any sample frame (Caserta et al., 1987; Rice et al., 1992). Writing in 1987, La Rue conceded that most longitudinal studies of the time may not have been following subjects who were representative of the Alzheimer's patient population (LaRue, 1987). The difficulty then, as is now, is identifying early dementing illness in the population and finding a sample of representative caregiver respondents.

Because there is no gold standard for diagnosing dementia, researchers must tailor their identification strategy to the purpose of the study (Brayne, Day & Gill, 1992). The population at highest risk for developing Alzheimer's dementia is likely to have multiple chronic health problems (Minaker & Rowe, 1985; Verbrugge, Lepkowski & Imanaka, 1989). Epidemiologists and clinicians recognize that identifying cases from this population is complicated because dementing illness, chronic illness, and normal aging processes may be indistinguishable from each other (Jorm, 1990; Kitwood, 1990; Minaker & Rowe, 1985). Epidemiological methods are unsuitable for distinguishing chronic illness in a population because the techniques were developed to study infectious diseases (Jorm, 1990). Clinical examination is an option, but the recommended diagnostic workup for Alzheimer's disease is too extensive (Horowitz, 1988) and expensive (Ernst & Hay, 1994) to efficiently screen large numbers of individuals. Many find cognitive screens simple, quick, and accurate enough to identify early deficits. But investigators have few guidelines to select instruments and set cut off scores (Ritchie & Fuhrer, 1992). Screening instruments have limitations (Christensen, 1989; Gagnon et al., 1990; Summers, DeBoynton, Marsh & Majovski, 1990) and are often misused by uninformed individuals. Gerontologists themselves do not know what cognitive deficits are a part of "normal" aging processes (Gruenberg, 1978).

Given the technical limitations of cognitive screening, the demonstration adopted a strategy for confirming cases that would minimize the number of misclassified cases. Potential demonstration enrollees had to present a physician's certification of irreversible dementing illness at the time of application and interviewers administered the Mini-Mental Status Examination (MMSE) (Folstein, Folstein & McHugh, 1975) at the intake interview. The MMSE has high reliability, validity, and positive predictive value in clinical work (Folstein, Folstein & McHugh, 1975; Kane & Kane, 1981). Many say the MMSE is the best short cognitive screen currently used in diagnostic evaluations (Roth et al., 1986). The longitudinal design of the study provided an additional mechanism for identifying cases of reversible dementia. Several reversible cases were subsequently deleted from the analysis.

It is likely that some caregiver self-selection bias was present in the sample. Researchers have reported that they often have trouble locating and securing willing proxy respondents because potential respondents find dementing illness stigmatizing (Rice et al., 1992). La Rue had also noted that researchers usually recruit Alzheimer's patients from university-affiliated health centers. We do not know how these subjects differ from individuals who obtain care from other sources (LaRue, 1987). There was evidence that some respondents felt stigmatized by the client's diagnosis of dementia, and it must be assumed that the most uncomfortable individuals never applied to the study. Some caregivers did not want outsiders to know of their participation in MADDE. Others did not even want the client to know of their own diagnosis. MADDE actively recruited participants from the general community through an outreach program and from current agency clients. Applicants submitted referrals from university-affiliated providers, private physicians, and HMOs. Although a random sample was not brought into the study, every effort was made to enroll a large sample of clients and caregivers from varied geographical areas, having a wide range of sociodemographic characteristics.

Definitions of Key Terms

This report includes terminology developed for the study and commonplace terms that had specific meanings within the context of the study. The terms are briefly defined in the glossary below.

caregiver: the client's self-identified primary formal or informal caregiver. The respondents who reported for clients in the study. The same respondent must have reported in each of the two interviews selected for verification.

claims history data or billing claims data: service transaction records comprising the TAPE data file.

client: a demonstration enrollee who was eligible to receive demonstration benefits.

funding source code: code distinguishing service payment sources in the UE data file. Respondents reported whether services were funded through demonstration sources, nondemonstration sources, or both sources.

service transaction: a single entry on a transaction record. Service use transactions report the use of day care and personal care/housekeeping/companion services. Zero-use transactions report the absence of service use. UE and TAPE service transactions contain client identifiers, service identifiers, service dates, units, and cost information. UE service use transactions also contain funding source codes.

transaction record: a client's listing of all service transactions during a given time period. Transaction records may be of any length. Clients have one UE and one TAPE transaction record per 6 month reporting period.

UE data file: the file containing caregiver and client data for the intake, baseline, and follow-up reporting periods. This study verified caregiver reported utilization data from the baseline and 6 month follow-up periods.

TAPE data file: the file containing site-generated claims history data. The TAPE data file was the verifying criterion for this study.

The chapters that follow report on the dissertation analysis and findings. Chapter II presents the research questions and study methodology. Chapter III reports the study findings. This section presents the evaluation of reported service utilization first, followed by the findings on reported units. Chapter IV discusses the verification findings and reports the study conclusions. The discussion locates the results within the literature and demonstrates how the findings have extended the literature. The chapter closes with recommendations for further study.

II. RESEARCH QUESTIONS AND METHODOLOGY

This study of day care and in-home services reporting by primary informal caregivers of cognitively impaired elderly persons came from the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE) project. The Health Care Financing Administration (HCFA) implemented MADDE to address the lack of adequately funded long-term care options for the demented elderly (Section 9342 of the Omnibus Reconciliation Act of 1986). The Institute for Health and Aging (IHA) at the University of California, San Francisco, under contract with HCFA, provided technical training and assistance to the project sites and evaluated demonstration outcomes.

Medicare does not usually cover most community-based long-term services (Medicare and Medicaid Guide, 1989). People needing such assistance must either seek out subsidized services or pay the full costs themselves. The annual costs of caring for an Alzheimer's patient are considerable: in 1991 the paid and unpaid costs of community care for a single patient were $3,150 and $20,900, respectively (Ernst & Hay, 1994). Costs are also measured in terms of the psychological, health, and social, consequences of caregiving. Many studies have documented caregiver burden among caregivers of demented patients (Barusch & Spaid, 1989; Chenoweth & Spencer, 1986; Fitting, Rabins, Lucas & Eastham, 1986; George & Gwyther, 1986; Rice et al., 1992; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). Compared to matched controls, caregivers of moderately to severely demented individuals have significantly higher numbers of physician visits and prescription medications, lower church attendance, and fewer vacations and activities with friends (Haley, Levine, Brown, Berry & Hughes, 1987).

Families expressing dissatisfaction with medical care have reported that providers did not give them sufficient information about dementia or enough referrals for supportive services (Haley, Clair & Saulsberry, 1992). MADDE sought to develop a network of cost-

effective, community-based services appropriate for Alzheimer's patients and their caregivers. In theory, the project increased opportunities for clients to receive care in home-like settings, and offered caregivers avenues to improve their caretaking skills and reduce caregiving stress. MADDE offered participating clients and their caregivers over 20 social health services plus medical supplies, equipment, and consumable care goods in exchange for a 20 percent copayment (MADDE assumed all service costs if the client was covered under Medicaid) (Appendix A). The demonstration extended contracts to a broad network of area providers; however, case managers were expected to finance services through public or private funds before seeking demonstration reimbursements. Clients could purchase extra services on their own, but they could not carry over unused MADDE benefits from one month to another.

Case management formed the basis of the demonstration intervention. Case managers identified appropriate services, authorized and monitored benefits, and provided information to caregivers. They also arranged Medicare reimbursements to caregivers and obtained funding for services bought outside the demonstration. The demonstration compared two service models. Each offered the same range of services, but varied by case manager to client ratio and by the level of monthly expenditures available to each client. The two models are contrasted in Appendix B.

General Questions and Hypotheses

This study hypothesized that respondents' caregiving experiences affects their ability to recall clients' service use, and reporting accuracy varies among respondents having dissimilar experiences. Three broad questions guided the verification.

Did respondents accurately report demonstration service use?

Did respondents distinguish between service payment sources?

Did respondents accurately report the level of demonstration utilization?

Six hypotheses directed the analysis of the main research questions. The first two hypotheses tested the assumption that caregivers' differential emphasis on caregiving tasks and service use patterns affects their ability to recall service use.

H_1: Reports from caregivers living with clients are more likely to agree with claims records than reports from caregivers not living with clients.

H_2: Reports from spouses, daughters, and sons are more likely to agree with claims records than reports from other relatives and nonrelative caregivers.

Several studies have documented different caregiving preferences and service use patterns among caregiver types. Women caregivers were most likely to care for an individual's personal care needs, such as laundry, cooking, and emotional support (Aronson, 1992; Stone, Cafferata & Sangl, 1987; Young & Kahana, 1989). Daughters managed personal care needs as well as transportation. In contrast, men were more likely to perform nonpersonal work, such as house repairs. Spouses took greater responsibility for housekeeping and nutritional planning than others (Young & Kahana, 1989).

Formal service use among the elderly has not been widespread. The Informal Caregivers Survey of the 1982 National Long-Term Care Survey reported that only 10 percent of the frail community-dwelling elderly used formal services (Stone et al., 1987). Others have shown that service use varied by caregiver gender and age (Barusch & Spaid, 1989; Wenger, 1990), although the level of use was about the same for husbands, wives, and daughters (Enright, 1991). Nonrelative caregivers used formal services more than other relatives (Tennstedt, McKinlay & Sullivan, 1989). Caregivers who provided care and purchased additional services were slightly more likely not to live with the impaired person than other caregiver types (Stone et al., 1987).

Some studies have concluded that certain proxy respondents are more effective than others (Fultz & Herzog, 1995; Graham & Jackson, 1993; Grigoletto et al., 1994; Tepper, Connally, Haltmeier, Smith & Sweeney, 1993). A case-control study of proxy

respondents' ability to provide medical history data reported total proxy nonresponse rates from 5 to 17 percent across 8 health conditions. Rates varied widely by respondent type. Spouses provided physician names for 60 percent of reported conditions, compared with 40 percent of reported conditions by children and parents, 36 percent for other proxies, and 18 percent for siblings. The chances of matching reported conditions to medical records were highest for life-threatening conditions (Tepper et al., 1993). Another study found that wives were more accurate reporters of drinking frequency than nonspouse proxies. The findings revealed no systematic biases for any proxy type. Reports of drinking amounts showed high standard deviations for individual agreement, particularly for male self-respondents (Graham & Jackson, 1993).

Reporting accuracy is often improved if respondents have increased opportunities to observe subjects' functioning and witness health events. Studies have measured increased contact between respondents and subjects in terms of living arrangements and frequencies of visits. A study of older women and their respondents found varying correlations between mental health scale scores and proxy ratings. Case MMSE scores and proxy ratings were more highly correlated for proxies who lived with cases than for proxies who did not live with cases. Case scores on the MMSE and CES-D showed higher correlation with proxies who visited cases five or more times a month than with proxies who saw the case person less than five times a month (Bassett, Magaziner & Hebel, 1990). Proxy respondents in three case-control studies had the lowest nonresponse rates for events that occurred while they shared a household with self-respondents (Pickle, Brown & Blot, 1983). Living with cases does not necessarily ensure accurate reporting. A recall study of known pediatric poisoning events found significantly lowered chances of an event being reported by someone who did not initially report the poisoning to the poison control center (Smith & McElwee, 1989). The likely reason that some household members were unaware of incidents is that individuals share different information among themselves (Mathiowetz & Groves, 1987).

The third hypothesis tested the assumption that respondents would become more proficient with reporting practice.

H3: The level of agreement between reported data and claims data increases over time.

A study of nonresponse and inconsistent responses in a population-based health survey of respondents 65 and older found that the number of "don't know" responses were much lower at the 3-year follow-up than at baseline. The investigators speculated that respondents may have acquired more information since the baseline interview, that trust increased between respondents and interviewers, and that interviewers developed experience (Colsher & Wallace, 1989). Admittedly, factors outside of the study, including natural history and Hawthorne effects, may affect study outcomes (Bouchet, Guillemin, & Briancon, 1996). Subjects often respond to please interviewers when the two have close rapport or similarity (i.e., ethnically, socioeconomically) (Dohrenwend, Colombotos, & Dohrenwend, 1968; Weiss, 1968-1969). There are reasons to discount the influence of interfering effects in this study. MADDE interviewers followed the same individuals throughout the study. We would expect some reporting improvement as respondents gained experience, interviewers became more adept, and trust developed between parties. Respondents probably did not consider social desirability when reporting utilization. It is possible that some respondents found the questions threatening. Panel studies, such as MADDE, routinize events through repetition. For this reason, panel designs reduce respondent threat over time (Sudman & Bradburn, 1982).

The fourth hypothesis tested the assumption that respondents having higher depression scale scores would have difficulty recalling information.

H4: Caregiver depression increases the likelihood of reporting error.

Clinical depression and dysphoria are prevalent among Alzheimer's caregivers.[1] Depression is a problem regardless of whether the Alzheimer's patient resides in the community or in a nursing home (Bergman-Evans, 1994; Fiore, 1983). Depressed caregivers have been more likely to perceive a lack of control over their situation than nondepressed caregivers (Cohen & Eisdorfer, 1988). As many as 87 percent of Alzheimer's caregivers reported that they usually felt depressed, angry, or tired (Rabins, Mace & Lucas, 1982). One study found that 46 percent of Alzheimer's caregivers who requested assistance were clinically depressed, and another 22 percent had depressive symptoms. Clinical depression and depressive symptoms were also evident among 18 percent of caregivers who did not request help (Gallagher, Rose & Rivera, 1989). While all Alzheimer's caregivers are not clinically depressed, some are significantly more dysphoric than healthy controls (Wright, 1994).

Wife caregivers are more depressed than husbands. Husbands of Alzheimer's patients are less depressed than home-bound wife caregivers who have no social support. Husbands usually work, which probably provides some caregiving respite. However, having a network of non-familial support reduces depression among wives more than husbands (Morrissey, Becker, & Rubert, 1990). The quality of couples' relationships prior to Alzheimer's disease, and caregivers' desire to meet others' needs and to have their needs met also affects caregiver depression. The most depressed caregivers had little desire to respond to others and have others meet their needs. Of these, caregiving husbands who had distant prior relationships with their wives were more depressed than caregiving wives who had distant prior relationships with their husbands. Caregiving wives were more depressed than caregiving husbands if they had close prior relationships with their husbands (Williamson & Schulz,1990).

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[1]Depression is a psychiatric syndrome that includes low mood, psychomotor impairment, weight loss, insomnia, and other symptoms. Dysphoria is a state of agitation or uneasiness (Dorland's Illustrated Medical Dictionary, 1974).

The association between memory impairment and depression is not well-defined (Burt, Zembar & Niederehe, 1995). According to Brown and others, cognitive impairment is a significant component of depression. They found that depressed individuals showed significant deficits in areas of language, attention, behavioral regulation, recall, and recognition, compared with nondepressed controls (Brown, Scott, Bench & Dolan, 1994). La Rue and colleagues found a significant association between several scale variables on the Center for Epidemiologic Studies Depression Scale and measures of cognitive status, memory, and psychomotor speed when controlling for demographic variables, subjective measures of health, and objective measures of health (LaRue, Swan & Carmelli, 1995). Supporting studies have reported similar findings among subjects having major depression (Ilsley, Moffoot & O'Carroll, 1995). Others demonstrated that depression impedes performance on complex tasks (Levy & Maxwell, 1968; Tarbuck & Paykel, 1995). Among normal elderly subjects, higher scores for dysphoria have been associated with significantly greater cognitive impairment (Rabbitt, Donlan, Watson, McInness & Bent, 1995). Cognitive functioning improves after recovery from major depression (Tarbuck & Paykel, 1995).

The fifth hypothesis tested the assumption that overlapping between home care services or service packages confused caregivers.

> **H5**: The level of agreement between reported and claims units is higher for day care services, which provides a standard set of services at each encounter, than for home care services, which groups interrelated or overlapping sets of services into flexible service packages.

Respondents use several kinds of cognitive processes to determine how often events occur over time. They may estimate the frequency directly from an intuitive perception of how often the event happens (automatic encoding) (Hasher & Zachs, 1979; Hasher & Zachs, 1984), estimate frequencies by how easily they recall the event

(availability heuristic) (Tversky & Kahneman, 1974), recall separate events and add them together (episode enumeration), apply an occurrence rule to the time period, or combine methods (Burton & Blair, 1991). Estimation errors result when respondents misdefine the event, telescope events forwards or backwards in time, or report what is socially desirable (Burton & Blair, 1991). Tversky and Kahneman have noted that people typically do not know when their estimates are biased (Tversky & Kahneman, 1974).

Presumably, respondents needed more effort to estimate home care units than day care units. Day care units, measured in days, equaled the number of times clients attended day care per period. Home care units, measured in hours, equaled the number of home care visits times the number of hours per visit. The lack of distinction between home care services may have increased the likelihood that respondents misidentified services, leading to erroneous omissions or inclusions. Caregivers probably did not use episodic enumeration to estimate units; respondents tend to use other methods when the recall period is long (Blair & Burton, 1987). Preliminary findings by Burton and Blair suggest that episodic enumeration increases the likelihood of omitted events and rule-based estimation increases the likelihood of overreported events (Burton & Blair, 1991).

The sixth hypothesis tested the assumption that respondents had better knowledge of service use than of service funding sources.

H_6: Reports are more accurate for service use than for source of payment.

Many studies confirm that respondents report general information about an event more accurately than specific details, regardless of the study topic. Proxy respondents in one epidemiological survey had better knowledge of how much case subjects drank alcohol than of how much the subjects drank (Graham & Jackson, 1993). Consumer studies have shown that people have less trouble remembering that they purchased a product or service than they do recalling details about the purchase (Sudman & Bradburn, 1982). Enrollees in

a group health plan provided more accurate information on their use of prescription medicines than on prescription dates, dosages, and medication names (West et al., 1995).

Experimental psychologists have repeatedly demonstrated that older subjects do not recall sources of information as well as younger subjects (Cohen & Faulkner, 1989; Dywan & Jacoby, 1990; Hashtroudi, Johnson, & Chrosniak, 1989; Rabinowitz, 1989). Under experimental conditions, elderly subjects reported factual information familiar to them as well as, or better than, younger subjects; but younger subjects were better at reporting sources of new information (McIntyre & Craik, 1987). In another study, subjects reviewed a list of nonfamous people before identifying famous people from a list containing people from the original list and famous people. Older subjects were less likely to realize that they recognized nonfamous names from the original list and more likely to misidentify them as famous people (Dywan & Jacoby, 1990). Older individuals are also more easily swayed by conflicting information. Young and old respondents accurately accounted an event they had seen after they read accurate information about the event. Older respondents who read a misleading account of the event they had witnessed were more likely to provide erroneous accounts (Cohen & Faulkner, 1989). These studies suggest that demonstration caregivers would have had trouble deciding if they recalled service information from billing claims or contacts within the demonstration or outside the demonstration.

Health service researchers do not usually verify reports of service payment sources, but one study asked respondents about their source of health care. Researchers asked low-income black women who reported having a regular source of health care to characterize the place of care and provide additional information on the provider. Respondents underreported care from private physician's offices by 26 percent. They overreported care from hospital outpatient departments, health department clinics, and other clinics from 5 to 12 percent across providers (Perloff & Morris, 1989). The authors reminded health survey

researchers to ask questions that are within respondents' knowledge of the health care system.

Subjects and Methods

This section presents the study sample and research design. It is conceptually divided into two sections. The beginning section describes the sample, interview instruments, analytic measures, and data sources. The second section describes the research design and analytical methods.

Study Sample

The dissertation sample was drawn from caregivers and clients enrolled in MADDE. Demonstration sites actively recruited participants from the general community through an outreach program and from current agency customers. The project targeted primary informal caregivers, but accepted formal caregivers when clients had no primary informal caregivers. Eligible clients were living in the site's catchment area, presented a physician's diagnosis of irreversible dementia, needed case management and / or service assistance because of their cognitive or functional impairments, and were covered under Medicare Parts A and B. Clients for this analysis began enrolling into the demonstration on December 1, 1989 and continued to enroll through April 30, 1991. Initially, 6,040 caregiver-client pairs were randomized into treatment (N=3,079) and comparison (N=2,961) groups. Ineligible cases were removed from the sample, leaving 5,833 (2,977 treatment, 2,856 comparison) participant partners in the demonstration.[2]

[2]A client became ineligible if the individual either died or entered a nursing home within 30 days of randomization into the evaluation, or if found to have reversible dementia.

A subsample of treatment group cases has been used to examine the study questions. The sample comprised 2,745 cases at 6 months following randomization and 2,077 cases at 12 months following randomization.[3] The respective periods ending at 6- and 12 months after randomization were the first and second exposure periods to the demonstration intervention. In this study, these periods are called the baseline and 6 month reporting periods. The respondents were original caregivers whose client partners survived at least halfway through the first reporting period.[4] Practical and theoretical criteria were used to select the sample. First, treatment group clients had a readily accessible criterion for verifying reported services. Comparable external records were not available for those in the control group.[5] Second, clients had to have survived at least halfway through the reporting period to ensure there would be paired UE and claims TAPE data for the verified periods. Sites submitted billing claims for every month that clients used services, but interviewers did not contact caregivers for follow-up or close-out interviews if clients died within the first 3 months of a reporting period. Finally, new caregivers who reported in

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[3]Cases remaining after adjustment for sample attrition and new caregivers were as follows. Cases lost by 6 months following randomization: 56 deaths within first 3 months of intake period, 61 moved, 34 refusals, 1 unreplaced lost caregiver, 1 for unspecified reasons, and 85 new caregivers. Cases lost by 12 months following randomization: 108 deaths during last 3 months of intake period, 118 deaths within first 3 months of baseline period, 37 moved, 25 refusals, 334 permanent nursing home placements, and 98 new caregivers. Categories are not mutually exclusive.

[4]The ability to identify and study caregivers is complicated by the fact that there is no standardized definition of caregiver across studies. Some researchers classify caregivers by their relationship to the patient, the patients' characteristics, and caregiving dimensions such as time spent caregiving and type of caregiving (Dillehay & Sandys, 1990; Stone, 1991). Caregivers do not always see themselves in a dichotomous caregiver-dependent relationship, as when an impaired couple tends to each other (Pollitt, O'Connor & Anderson, 1989; Wenger, 1987; Wenger, 1990). While our caregiver respondents identified themselves as the primary caregiver, the distinction is somewhat artificial in cases where more than one caregiver shared caregiving responsibilities. In these situations it cannot be determined whether the study respondent or someone else was most knowledgeable about the client's service history.

[5]The random assignment of caregiver-client pairs into treatment and comparison groups eliminated self-selection into groups, and the distribution of spouses, daughters, sons, and others into groups was comparable. It may be assumed that no significant differences in reporting error exist between treatment and comparison groups.

The demonstration evaluators initially planned to verify reported services against provider billing claims. We requested data in 1989 and 1990. The plan was abandonned for this study after two mailings and intensive follow-up telephoning failed to produce adequate response rates. Response rates varied widely by provider type. N requests sent=19,794. Response percentages: usable data, 38.8; no response, 42.5; refusals 3.3; misc (no record of client, wrong or no information sent, no services identified); 15.4.

either the baseline or 6 month interviews were omitted from the study to ensure that all respondents had the same practice effect on their reporting. According to Magaziner (Magaziner, 1992), variability may be introduced into data whenever respondents change or leave a longitudinal study. Bias may have been compounded over time if new carergivers were allowed to remain in the sample.

Instrumentation

Standardized interviews provided all caregiver reported data. Intake data collection began on December 1, 1989. Caregivers of potential demonstration beneficiaries completed intake forms and interviews prior to randomization into treatment and comparison groups. Appendix C identifies the data collected during the application, intake, and follow-up process. The family application and physician referral forms contain client demographic information, Medicare coverage status, and a physician's diagnosis of irreversible dementing illness and other medical conditions. Specially trained nurses and social workers collected in-home intake interviews. These intake workers were employed by the demonstration sites, trained and supervised by IHA. HCFA staff members attended the interviewer group training sessions conducted in Baltimore, MD by Berkeley Planning Associates of Oakland, CA (Wilkinson, 1994).

Caregivers responded for clients and themselves in the intake interview. The interview contains data on client and caregiver characteristics, and service utilization during the 6 months prior to enrollment into the demonstration. Appendix C shows that caregivers were requested to supply information on client demographics and health insurance coverage, client living arrangements, and relationship to caregiver. Caregivers gave their assessments of clients' dementia, behavioral problems, and functional impairments. They identified the reasons for clients' functional impairments and stated their unmet needs with ADL and IADL tasks. Clients also took a Mini-Mental Status Examination (MMSE) (Folstein, Folstein & McHugh, 1975) during the intake session.

Informal caregivers gave demographic, employment, and caregiving information on themselves. They provided a self-assessment of their physical health and completed inventories of caregiver depression and caregiver burden. Caregivers were also asked to recall prior service use and to state their unmet service needs.[6] They responded to a list of client medical and social health services, and caregiver support services. For each service used, they supplied provider information, their satisfaction with the service, and estimates of either units of service or expenditures over the previous 6 months. Lastly, caregivers told interviewers why they did not use particular services. A comprehensive, systematic account of service use was made because these services were tracked for the evaluation of demonstration outcomes.

Follow-up interviewing of treatment and comparison group caregivers continued every 6 months following the date of randomization into the evaluation.[7] Treatment group clients repeated the MMSE once a year. Community-based nurses and social workers collected follow-up data by telephone. IHA hired, trained, and supervised these interviewers. Most had some experience working with aged and demented populations. IHA held interviewer training sessions in Oakland, CA (Wilkinson, 1994).

The follow-up instrument, shown in Appendix D, contains separate sections for caregiver and client data. All caregivers were asked to recall clients' service use during the 6 months preceding the interview, and to update their assessments of clients' behavioral,

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[6]Data on caregiver demographics, use of caregiver support services, functionality, and caregiver well-being were only collected for informal caregivers because the demonstration intervention was designed to assist primary informal caregivers. Formal caregivers did not receive demonstration benefits.

[7]An important aspect of the interviewing process was the decision to give interviewers individually assigned caseloads which they followed throughout the evaluation. While having particular interviewers repeatedly contact the same caregivers increased the possibility of introducing interviewer bias into the UE data, the strategy also maximized the likelihood of successfully tracking caregivers and maintaining caregivers' interest to participate. Our interviewers lived in their catchment areas and were acutely aware of major events which could affect caregivers' immediate priorities and ability to respond in follow-up interviews; Hurricane Andrew at the Florida in 1992 site is a striking example.

Interviewers maintained a high response rate and completed the majority of follow-up interviews on time. Ninety-five percent of baseline interviews were obtained within 2 weeks of the scheduled due date. Long delays meant that an unlocatable case was lost to follow-up, but this was relatively uncommon (Yordi, 1994). Only 0.2% of cases were lost to follow-up 6 months after intake.

dementia, and functional problems. Informal caregivers reported their use of support services during prior 6 months, their current physical and emotional status, and other attributes. Section I of the instrument supplies client demographic data, health insurance or HMO coverage, and Medicaid status. Sections II and III supply caregiver-rated measures of client functional status. Section IV supplies the weekly total of informal caregiving hours given to the client. Section V supplies the caregiver's assessment of the client's dementia and behavioral problems. Section VI supplies caregiver demographic data, health insurance or HMO coverage, and employment hours. Section VII reports measures of caregiver burden and caregiver depression. Section VIII supplies caregivers' self-rated functional and health status. Service use appears in Section IX of the instrument. Interviewers asked caregivers to respond to the identical list of services inventoried at intake. Respondents told if each service was used, estimated either total units or the 6 month costs of each service used, and identified the source(s) of payment.

Measures

The use of established measures in the MADDE study builds on the literature and facilitates comparisons between the evaluation and others containing similar assessments. The verification used sociodemographic information on clients and caregivers, and measures of client service utilization, client functional status, caregiver well-being, and caregiver involvement.

Sociodemographic information on clients included age, gender, ethnicity, education, and income. Sociodemographic information on caregivers included age, gender, caregiver type, relationship to client, living arrangement with client, education, and income.

The verification used service information for day care services and in-home services including personal care, housekeeping, and companion services. The presence or absence of service use was established by asking caregivers if clients used each service during the 6

months prior to the interview. The level of use was quantified using the cost and units of service for the period. All costs were measured in whole dollars. Day care units were measured in days. In-home service units were measured in hours.

The caregiver well-being measure was caregiver depression. Depression was quantified using the Geriatric Depression Scale (short form) (Sheikh & Yesavage, 1986). The instrument minimizes fatigue and other problems that prevent some elderly respondents from completing long scales. Depression was measured by summing the affirmative responses given for 15 statements. The level of caregiver involvement was estimated by the number of hours per week the caregiver spent helping and supervising the client.

Data Sources

The analysis used two main data sources: demonstration claims history records (claims TAPE file) and caregiver reported utilization data (UE data file). The claims TAPE contains site reimbursement data for all follow-up reporting periods.[8] By definition, the demonstration provided case management to all clients. Each site submitted monthly claims to the Health Care Financing Administration (HCFA) for recipients who used at least one additional demonstration service during an eligible month.[9] Sites did not prepare claims for clients who used case management only.

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[8]The decision to verify survey data against demonstration billing claims records built on the existing verification literature. While there are no "gold standards" in health research, health survey researchers strongly prefer profession-based instruments as the criterion for validity studies (Verbrugge, 1989). Administrative records are the recommended referent for utilization verifications (Branch, 1992). Because administrative systems generate claims continuously, these data provide a "comprehensive and representative" record of services as provided at comparatively low cost (Fowles, 1994). Researchers consider these data more accurate than survey data because records are free of the kinds of error found in survey data, such as recall error and interviewer error (Mathiowetz, 1989). However, records are themselves liable to certain inaccuracies. The completeness and accuracy of administrative databases are quite variable (Fowles, 1994). Billing records used for provider reimbursement purposes could potentially yield falsely high service utilization estimates because paid providers might be more likely to correct underreported services than overreported services. Quality control records may give erroneously low service estimates if service gatekeepers are more careful to identify erroneous additions to their records (Branch, 1992).

[9]Office of Research and Demonstrations, Division of Research and Demonstration Systems Support. HCFA supplied claims information to IHA on 9-track 6250 BPI SL tapes. IHA stored the files either on tape or on 44 megabyte Bernoulli cartridges (Iomega Corporation, 1821 West 4000 South, Roy, UT 84067).

The record specification for the TAPE file is shown in Appendix E. Site claims documented actual service dates (rather than billing dates) for each service received (Kundert, 1994). HCFA aggregated clients' service transactions into monthly transaction records by service and service dates. An individual's monthly TAPE record is therefore an accurate record of the services actually used during a particular month (Johnston, 1994). A transaction entry appears for every demonstration service, regardless of utilization. If the client used the service, the entry shows the total units of service and the site reimbursement amounts (80% of total cost) for the month. If the client did not use the service, zeros appear in the units and reimbursement fields (Kundert, 1994). HCFA generated TAPE records only for clients who presented claims (i.e., HCFA did not generate records showing zero units and reimbursements for all services).

The UE data file contains all reported utilization, demographic, and scale data collected at enrollment and follow-up periods. Project staff at IHA processed instruments and coded utilization data for keypunching.[10] Coders prepared a service utilization code sheet for each interview submitted, regardless of whether the client used any services. Appendices F through H contain sample coding materials and the list of cleaning checks for reported utilization data.

The structures of the UE and TAPE files differ, and some adjustments were made to match the files for comparison.[11] These modifications are fully described in Appendix A. First, all service categories are not comparable across data sets. Service codes for in-home services in the Service Use and Transaction Codebook (Appendix G) correspond to 3 UE and 6 TAPE service categories. Service categories in each data file were collapsed into a single code for personal care/housekeeping/companion services. No adjustments were needed to match day care services across data sets. Second, the UE file contains

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[10]Keypunched data were stored as mainframe computer files and entered into Paradox version 4.0 (1992)(Borland International, Scotts Valley, CA).

[11]TAPE and UE data files were converted into SAS data files for this analysis. All data preparation, storage, and analysis were performed using SAS version 6.06 (1989)(The SAS Institute, Carey, NC).

transaction records for all eligible clients, regardless of utilization. The TAPE contains records only for clients who claimed reimbursement from the demonstration. Zero-use transaction records were inserted into the TAPE data base for clients who claimed no reimbursements during an eligible month. Third, UE transaction records show utilization during a 6 month period. TAPE transaction records show utilization during a single month. Service periods on the claims TAPE were aggregated into 6 month periods to align with UE reporting periods. Fourth, UE transactions show either costs or units of service, and TAPE transactions show both costs and units. UE transactions with costs data were converted into equivalent units using the median cost per unit rate by site.

The UE and TAPE data bases differ in one other way. The UE file contains transaction data on all services paid through demonstration and nondemonstration sources. The TAPE "standard" contains transaction data on services funded exclusively through the demonstration. Nondemonstration sources in the UE file cannot be positively verified because a standard does not exist for nondemonstration sources. Exploratory methods for provisionally identifying UE service transactions that were funded outside the demonstration were integrated into the verification.[12]

Analytical Methods

Direct record check methods were used to compare caregiver reports against demonstration claims data at baseline and 6 months. In a direct record check, respondent interviews are completed and subsequently matched against records in the reference criterion (Jabine, 1987). The verification contained two complementary analyses. One analysis evaluated reports of service use, and the other evaluated reports of service units. Each of the two verification checks contained descriptive and predictive components.

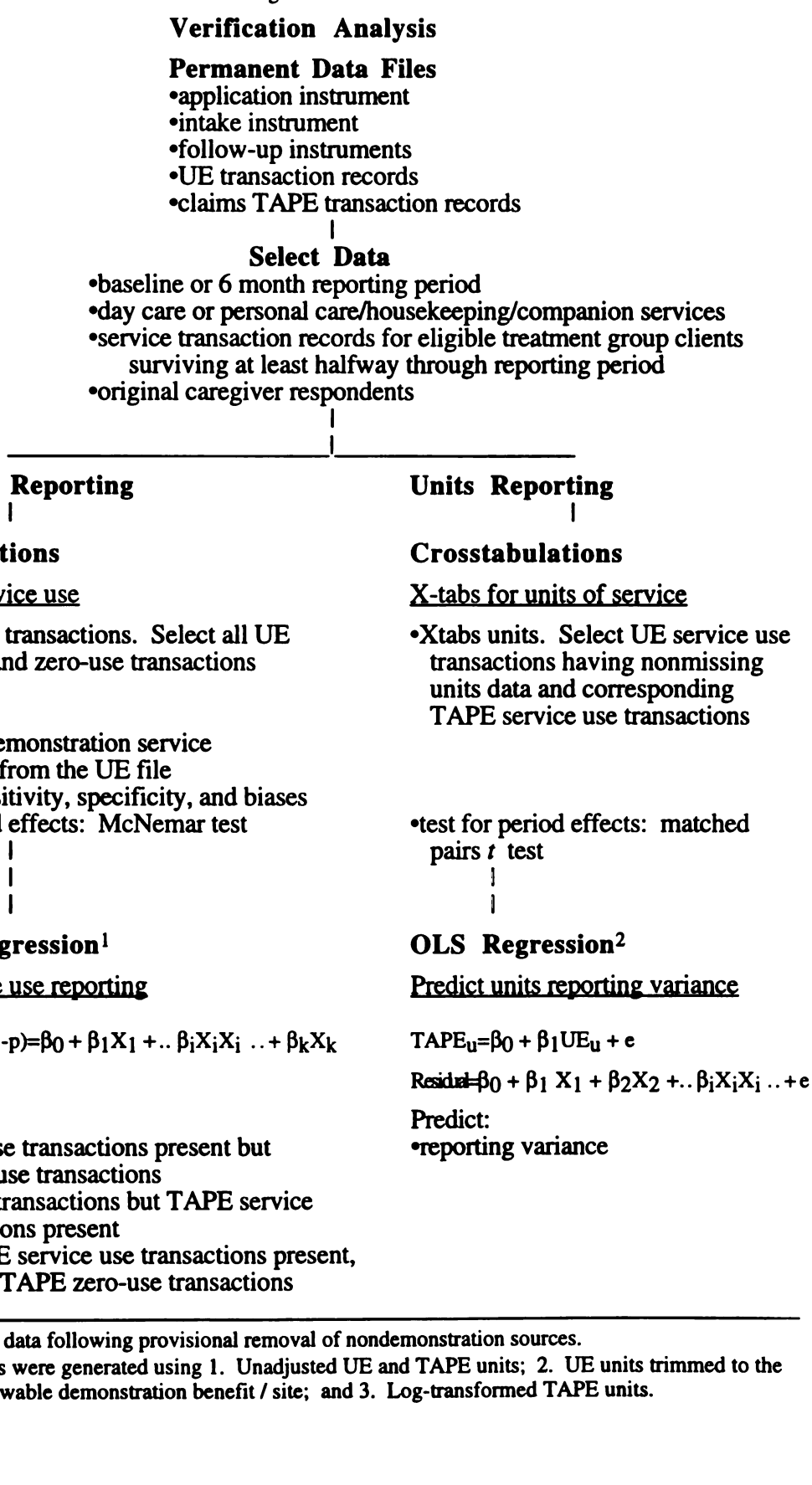
The verification is outlined in Figure 1. The analysis of service use reporting compared UE and TAPE service transactions using a "full design" direct record check. A

[12]Adjustment methods are presented in the findings chapter.

full design check validates reports of service use (service use transactions) and service nonuse (zero-use transactions). This is the only design that allows estimation of both false positive and false negative reporting biases (Marquis, 1978). The analysis of units reporting determined if UE service use transactions having corresponding TAPE service use transactions matched, underreported, or overreported units of service relative to claims. Nondemonstration funding sources in the UE file complicated the verification of reported demonstration service use and units, and the analysis tested several approaches of distinguishing funding sources in the UE file.

Reports of service use and service units were evaluated using crosstabulations and multiple regression techniques. The complete verification was run separately for day care and for personal care/housekeeping/companion services, by period. These two service packages seem very different because they employ different delivery systems, but both provide similar assistance with tasks of daily living, personal hygiene, medications, nutrition, and client supervision. The study verified both of these service groupings because little is known about proxy reporting of chronic care services and because the method of service delivery may have affected respondent recall (Appendix A).

Figure 1



[1]modeled on UE data following provisional removal of nondemonstration sources.

[2]Separate models were generated using 1. Unadjusted UE and TAPE units; 2. UE units trimmed to the maximum allowable demonstration benefit / site; and 3. Log-transformed TAPE units.

Service Use Reporting

The analysis of service use reporting addressed two main research questions.

1. Did respondents accurately report demonstration service use?
2. Did respondents distinguish between service payment sources?

The analysis proceeded in three stages. The first stage evaluated the second main research question and assessed the impact of nondemonstration sources on the verification of reported demonstration use. UE and TAPE service transactions were matched using simple crosstabulations (Figure 2). Service transactions were tabulated in aggregate and by reported funding source codes. Crosstabulations were then compared to derive two estimates. One was an estimate of respondents' misidentification of service payment sources, or source code reporting error. The other was an assessment of the confounding effects of nondemonstration sources on the verification of reported demonstration use. The presence of nondemonstration sources in the UE file confounds the measurement of reporting error: both false reports of demonstration use and true reports of nondemonstration use appear as UE service transactions having zero-use TAPE transactions. Services funded through nondemonstration sources were removed from the UE file in the next part of the analysis.

The second analytic stage considered the first main research question. First, nondemonstration transactions were provisionally removed from the UE file to produce more reliable estimates of reporting bias. To assess percent agreement between UE and

Figure 2

CROSSTABULATIONS FOR SERVICE USE

Match Category	UE-TAPE Service Transactions
Match	UE Service Use Transaction & TAPE Service Use Transaction present
Match	UE Zero-Use Transaction & TAPE Zero-Use Transaction present
Mismatch	UE Zero-Use Transaction but TAPE Service Use Transaction present
Mismatch	UE Service Use Transaction present but TAPE Zero-Use Transaction

TAPE transactions, crosstabulations were generated for transactions in aggregate, by caregiver relationship, and by living arrangement using the UE file that was adjusted for nondemonstration funding sources. Sensitivity and specificity values are reported for these crosstabulations. These respective measures are the probabilities that any given service use or zero-use TAPE transaction had a corresponding UE transaction report. Rates of false negative and false positive reports were also computed from crosstabulations and compared against expected error rates. The McNemar test statistic was calculated to determine if differences between the proportions of mismatched transactions at baseline and 6 months were significant.

The source-adjusted UE data were then modeled using logistic multiple regression techniques. The basic logistic model is

$$\text{logit}(p)=\log_e(p/1-p)=\beta_0 + \beta_1X_1 + \beta_2X_2 + \ldots\ \beta_iX_iX_i\ \ldots +\beta_kX_k,$$

where p=the probability of an event occurring, 1-p=the probability of an event not occurring, β_0=the intercept term, β_i=the slope, X_i=individual independent variables, and X_iX_i=an interaction term between two independent variables. The independent variables used in this analysis describe caregiver status at the time of interview. A list of all regression variables is given in Table 1. Separate models were run to predict the likelihood of three outcome events: 1. UE and TAPE service use transactions present, and UE and TAPE zero-use transactions present; 2. UE zero-use transactions but TAPE service use transactions present; and 3. UE service use transactions present but TAPE zero-use transactions.

The logistic models were run as nested regressions. Nesting regressions allows stepwise addition of several variables or variable block(s) into the model at once. Inspection of the goodness of fit Chi-square statistic for each regression shows if the overall model is significant, that is, how well the model explains the data. A simple calculation using the Chi-square statistic and the appropriate degrees of freedom reveals if the variables added in each step were themselves significant.

The nested model was created by running the model twice, once as the full model including all independent variables, and again, excluding some terms (the smaller model is nested within the full model). Variables for caregiver education, caregiver income, caregiver depression, living arrangement, caregiver relationship, and an interaction term for caregiver relationship * living arrangement were added together in the first step. The model was run again without the interaction term. Main effects measures were compared before and after adding the interaction term.

Table 1

List of Regression Variables[13]

I. Dependent Variables

Logistic Regression

UE and TAPE service use transactions present & UE and TAPE zero-use transactions present. UE service use transactions had corresponding TAPE billing records. TAPE billing records were not present for UE records showing no service use.

UE zero-use transactions but TAPE service use transactions present. Billing records on claims TAPE had no corresponding service use transactions in the UE file.

UE service use transactions present but TAPE zero-use transactions. UE service use transactions had no corresponding TAPE billing records.

Ordinary Least Squares Regression

Claims Units. Number of service units shown on claims TAPE for period, coded as a continuous variable. Day care units were in days. Personal care/housekeeping/companion units were in hours.

Residuals. Units of variance generated when UE units were regressed on claims TAPE units.

II. Independent Variables

Logistic and Ordinary Least Squares Regressions

UE Units. Number of service units shown in the UE file for period, coded as a continuous variable. Reported units were taken directly from caregiver reports. Service use reported in cost amounts were converted into equivalent units using the median cost per unit rate for the site.

Caregiver Education. Years of education, coded as a continuous variable. Taken from intake instrument.

Caregiver Income. Annual household income, coded as a continuous variable. Taken from intake instrument.

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[13]A correlation matrix was constructed for all analytical variables. Colinear variables were not found among these variables (Pearson's product moment correlation 0.5).

Caregiver Depression. Scale score for depression, coded as a continuous variable. Scores >5 reflect probable depression. Taken from baseline and 6 month instruments.

Living Arrangement. Indicated if caregiver lived with client during reporting period. Coded 1 if live with, 0 if not live with. Taken from baseline and 6 month instruments.

Caregiver Relationship. Caregiver's relationship to client. Spouse, daughter, son, and others were coded as dummy variables, with spouse as the reference group. Taken from baseline and 6 month instruments.

Caregiver Relationship * Living Arrangement. Interaction term between caregiver relationship and living arrangement. Interaction term between caregiver relationship and living arrangement. Spouse * live with, daughter * live with, son * live with, and others * live with were coded as dummy variables, with spouse * live with as the reference group. Taken from baseline and 6 month instruments.

Units Reporting

The analysis of units reporting concentrated on the subset of caregiver reports that correctly identified demonstration service use. The analysis verified units from UE service use transactions having TAPE service use transactions to answer the final main research question. Did respondents accurately report the level of demonstration utilization? The verification compared UE and TAPE units using ordinary least squares regressions and crosstabulations.

Multiple regression modeling was used to predict reporting error from covariates of reporting behavior. The basic model is

$$Y=\beta_0 + \beta_1 X_1 + \beta_2 X_2 + \ldots \beta_i X_i X_i \ \ldots + e,$$

where Y=the dependent variable, β_0=the intercept term, β_i=the slope, X_i=individual independent variables, $X_i X_i$=interaction terms between two independent variables, and e=the error term. The regression variables are listed in Table 1.

A single regression analysis used two regression equations. Regression analysis may be used to model change and stability over time (Kessler & Greenberg, 1981). In this application, TAPE units represented units at time 1 and UE units represented units at time 2. In the first equation,

$$TAPE_u=\beta_0 + \beta_1 UE_u + e,$$

UE units were regressed on TAPE units. The residuals that were generated were output as a SAS data set. The residuals are interpreted as prediction error or variance. The residuals created in the first regression became the dependent variable in the second regression. In this equation,

$$Residual=\beta_0 + \beta_1 X_1 + \beta_2 X_2 + \ldots \beta_i X_i X_i \ \ldots + e,$$

variables for caregiver education, caregiver income, caregiver depression, living arrangement, caregiver relationship, and an interaction term for caregiver relationship * living arrangement were regressed on the residuals. The interaction term was introduced in

nested models, as in the logistic analysis. Several models were tested to determine the best explanatory model.

All the UE records sampled for these regressions had verified demonstration funding. Some of the records contained additional transaction units funded through other sources. The presence of nondemonstration sources increased differences between UE and predicted TAPE units, resulting in spuriously high residual units. UE and TAPE units were modified to minimize the effects of nondemonstration sources. Multiple regressions were initially modeled with unaltered UE and TAPE units. These models were compared against models using UE units trimmed to the maximum allowable demonstration benefit / site and models using log-transformed TAPE units.

A weakness of these regressions is that we could not directly examine reported units against the TAPE standard. Crosstabulations were generated between UE and TAPE units to show differences between reported and claims units. UE and TAPE units were compared using units aggregated across reported funding sources, by reported funding source, and by caregiver relationship. Units were divided into intervals to facilitate interpretability (Figure 3). Day care units were divided into intervals of 14 units and personal care/housekeeping/companion units were divided into intervals of 53 units.

Crosstabulations were evaluated for units agreement and for source code error. Crosstabulations by caregiver relationship were inspected for differences between

Figure 3

CROSSTABULATIONS FOR UNITS

UE Units Relative to TAPE	UE Units-TAPE Units
Match	UE unit interval equals TAPE unit interval
Underreport Units	UE unit interval less than TAPE unit interval
Overreport Units	UE unit interval greater than TAPE unit interval

respondent groups. Crosstabulations by aggregated UE units were inspected for matching intervals, overreported intervals, and extreme outliers to determine cut off levels for UE units in ordinary least squares regressions. Crosstabulations by reported funding source code were evaluated for source code error. Matched pairs *t* tests were calculated to determine if differences between baseline and 6 month unit intervals were statistically significant.

III. FINDINGS

This chapter reports what the MADDE verification revealed about caregiver reporting for the cognitively impaired elderly. The chapter is divided into two main sections. The first section reports descriptive statistics for clients and their caregivers at baseline and 6 months. The section also summarizes and compares transaction data contained in the UE and TAPE data files. UE and TAPE service transactions are shown in aggregate, by reported funding source, and by demonstration case management model. The second section reports the analytic findings. The opening narration briefly summarizes the key verification findings. Presentation of the complete analysis follows. The analysis of service use reporting and the analysis of units reporting are discussed in order. Each set of results is arranged to show the progression of the investigation, from crosstabulations of the full data sets through source code reassignment and either logistic or ordinary least squares modeling of the source-adjusted UE data. Data recodes, statistical tests, and side analyses are highlighted where relevant.

Statistical Description of Sample and Data Sources

Sample Descriptives

Tables 2 through 5 display descriptive statistics for the sample at the baseline and 6 month interviews. Caregiver demographics are displayed in Table 2. Nearly three-fourths of respondents were women. Two-thirds of respondents were living with clients at baseline and at 6 months. The percent distributions for caregiver relationship remained virtually unchanged over time, with spouses and daughters comprising the two largest groups. Caregivers' years of education were fairly evenly distributed across all educational levels. The majority of caregivers had annual household incomes between $10,000-$29,999.

Nearly all caregivers in the sample were informal caregivers, caregivers who are not paid or otherwise compensated for their work. Formal caregivers comprised less then 2 percent of the sample. Formal caregivers provide services in exchange for payment or other compensation, such as room or board. They include live-in caregivers and staff from assisted living facilities, board and care homes, sheltered care residences, adult foster care programs, and nursing homes.

Table 3 shows caregivers' ages, time spent caregiving, and emotional responses to caregiving. Most caregivers were in their early 60's, although the range of ages extended from 16 years through the 90th decade. Primary caregivers spent slightly less time helping and supervising clients at 6 months than at baseline, but they still provided as much as 87 percent of clients' total care. Caregivers were not depressed, but showed moderate stress and burden at baseline and 6 months.

Client demographics, functional health, and cognitive status are given in Tables 4 and 5. Clients were mostly female and primarily white. Most were in their late 70's; a handful were aged 29-40. On average, clients had less formal schooling and were less well-off financially than their caregivers.[1] Mean MMSE, ADL, and IADL impairment scores decreased slightly from baseline to 6 months. The mean number of behavioral problems also dropped minimally. The decrease in client impairments and caregiving hours over time suggests that caregivers provided less hands-on care over time because the most impaired and / or behaviorally disruptive clients had either died or moved into institutional care during the period between the baseline and 6 month interviews.

[1]Higher annual household incomes for caregivers was attributed to nonspouse caregivers. At baseline, 46.1% of nonspouse caregivers had incomes $30,000 compared to 33.0% of all caregivers. At 6 months, 47.0% of nonspouse caregivers had incomes $30,000 compared to 33.6% of all caregivers.

Table 2

CAREGIVER GENDER, RELATIONSHIP TO CLIENT, LIVING ARRANGEMENTS, EDUCATION, AND INCOME

	Baseline		6 Months	
Characteristics[1]	N	%	N	%
Total	2745	100.00	2077	100.00
Gender				
Male	758	27.7	569	27.4
Female	1983	72.3	1506	72.6
Caregiver Type				
Informal	2695	98.2	2040	98.2
Formal	50	1.8	37	1.8
Relationship to Client				
Spouse	1350	49.2	1011	48.7
Daughter	797	29.0	629	30.3
Son	220	8.0	158	7.6
Other[2]	377	13.7	278	13.4
Living Arrangement[3]				
Lives with client	1809	66.4	1360	65.9
Education[3]				
Less than high school	591	22.0	433	21.3
High school	822	30.6	622	30.6
Some college	638	23.7	478	23.5
College and post-graduate	636	23.7	499	24.6
Income[3,4]				
$0-9,999	321	12.2	231	11.6
$10,000-19,999	892	33.8	672	33.7
$20,000-29,999	556	21.1	421	21.1
$30,000-39,999	363	13.8	274	13.7
$40,000-49,999	217	8.2	173	8.7
$50,000 and over	290	11.0	223	11.2

[1]Data on baseline living arrangement taken from baseline instrument. Data on 6 month living arrangement taken from 6 month instrument. All other measures taken from intake instrument.
[2]Other category includes formal caregivers, friends, former spouses, siblings, parents, step-children, grandchildren, step-grandchildren, in-laws, nieces, nephews, cousins, and unspecified relatives.
[3]Does not include formal caregivers.
[4]Annual household income for all spouse and nonspouse caregivers.

Table 3

CAREGIVER AGE, CAREGIVING HOURS, STRESS & BURDEN, AND DEPRESSION

Measures[1]	Baseline		6 Months	
	Mean (SD)	Median	Mean (SD)	Median
Age	63.5 (14.3)	65.6	63.1 (14.2)	65
Primary caregiving hours[2]	61.7 (52.1)	56	61.2 (53.7)	51.5
Primary caregiving hours as % of total hours	88.0%		87.2%	
Stress & Burden[3,5]	14.2 (8.0)	14	13.8 (8.1)	13
Depression[4,5]	4.3 (3.4)	3	4.2 (3.54)	4

[1]Age taken from intake instrument. All other baseline measures taken from baseline instrument. All other 6 month measures taken from 6 month instrument.

[2]hours spent helping and supervising client per week

[3]Adapted from "The Burden Interview" (Zarit, Reever & Bach-Peterson, 1980). Scores of 0-8 indicate low stress & burden, 9-16 moderate, 17 severe. Range 0-32.

[4]Geriatric Depression Scale (short form) (Sheikh & Yesavage, 1986). Scores >5 reflect probable depression.

[5]Informal caregivers' response to caregiving

Table 4

CLIENT GENDER, ETHNICITY, EDUCATION, AND INCOME

	Baseline		6 Months	
Characteristics[1]	**N**	**%**	**N**	**%**
Total	2744	100.00	2076	100.00
Gender				
Male	1083	39.5	800	38.5
Female	1661	60.5	1276	61.5
Ethnicity				
Caucasian (non-Hispanic)	2416	88.0	1814	87.4
Black (non-Hispanic)	222	8.1	180	8.7
Other[2]	106	3.9	82	3.9
Education				
Less than high school	1185	43.2	871	42.0
High school	756	27.6	578	27.8
Some college	412	15.0	319	15.4
College and post-graduate	391	14.2	308	14.8
Income[3]				
$0-9,999	944	34.4	702	33.8
$10,000-19,999	1043	38.0	801	38.6
$20,000-29,999	410	14.9	306	14.7
$30,000-39,999	162	5.9	122	5.9
$40,000-49,999	95	3.5	74	3.6
$50,000 and over	89	3.2	70	3.4

[1]All measures taken from intake instrument.

[2]Other category includes American Indian, Asian, Pacific Islander, Filipino, Hispanic, and other.

[3]Annual household income. Includes combined incomes of clients, spouse caregivers, and spouse non-caregivers.

Table 5

CLIENT AGE, MMSE SCORE, AND FUNCTIONAL IMPAIRMENTS

Measures	Baseline		6 Months	
	Mean (SD)	Median	Mean (SD)	Median
Age[1]	78.6 (7.8)	79	78.3 (7.9)	79
MMSE Score[2]	14.2 (8.7)	15	13.6 (7.4)	14.4
ADL Impairments[3]	12.3 (62.9)	6.3	8.7 (6.1)	7.5
IADL Impairments[4]	16.8 (49.8)	15	13.9 (3.0)	15
Behavioral Problems[5]	7.8 (4.0)	8	7.3 (3.9)	7

[1]Age taken from intake instrument.

[2]Mini-Mental Status Examination (Folstein, Folstein & McHugh, 1975) Normal 24-30, mild-mod cognitive impairment 10-23, severe impairment <10. Range 0-30.
Scale score for baseline MMSE taken from intake instrument.
Scale score for 6 month MMSE taken from 6 month instrument.

[3]Activities of daily living (Katz, Ford, Moskowitz, Jackson & Jaffee, 1963). Sum of scores. Range 0-20. Scale scores taken from baseline and 6 month instruments.

[4]Instrumental activities of daily living (Lawton & Brody, 1969). Sum of scores. Range 0-16. Scale scores taken from baseline and 6 month instruments.

[5]Adapted from the "Memory and Behavior Problem Checklist" (Zarit & Zarit, 1982). Sum of scores. Range 0-19. Scale scores taken from baseline and 6 month instruments.

Service Transaction Records

The UE and claims TAPE files contain all the service transaction records used in the verification. Each client has paired UE and claims TAPE transaction records for every eligible reporting period. Summaries of UE and claims TAPE service transactions appear in Tables 6 and 7. Table 6 displays all day care and personal care/housekeeping/companion transactions at baseline and 6 months. The table columns list TAPE and UE records. UE transactions are entered with funding source codes aggregated across individual cases and disaggregated by reported funding source codes. Table rows report descriptive information about the records in each file. This information includes the numbers of zero-use transactions and service use transactions, the subset of service use transactions that have units data, the mean and median units of service for service recipients, and the maximum units of service recorded for the highest user(s).

The first two rows of Table 6 describe zero-use transactions and service use transactions, the transaction records used to analyze service use reporting. The UE and TAPE files each had 2,745 baseline transactions and 2,077-6 month transactions available for the analysis. There were more day care and personal care/housekeeping/companion service use transactions in the UE file than in the TAPE file. This is expected because the UE file contains reports of services funded through both demonstration and nondemonstration sources. Within data files, the ratio of zero-use transactions to service use transactions varied by service type. No more than 33.5 percent of either TAPE or UE records showed day care use in any period. In contrast, nearly 55 percent of TAPE records and over 70 percent of UE records showed personal care/housekeeping/companion services in both service periods. During the period between baseline and 6 month follow-up interviews, the numbers of service use transactions decreased for both service types; however, the mean and median units of service increased among service recipients.

Table 6

TAPE and UE Service Transaction Records for Clients Surviving at Least Three Months into Period

Day Care Records

Baseline (6 months following randomization)

			UE by Reported Funding Source		
Record Type	**TAPE**	**UE[1]**	**Demo only**	**Nondemo only**	**Both**
N Zero-Use Transaction Records (% of 2745)	1998 (72.8)	1826 (66.5)	----	----	----
N Service Use Transaction Records (% of 2745)	747 (27.2)	919 (33.5)	369 ----	519 ----	31 ----
N Transactions with Use and Units Data (% with service use)	747 (100.0)	881 (95.9)	350 ----	501 ----	30 ----
Mean Units for Service Recipients (SD)	31.6 (23.3)	53.6 (40.2)	49.9 (36.3)	53.7 (41.2)	95.6 (43.3)
Median Units for Service Recipients	27	48	48	48	100
Max Units used by any Recipient	132.5	182	182	182	180

6 Months (12 months following randomization)

			UE by Reported Funding Source		
Record Type	**TAPE**	**UE[1]**	**Demo only**	**Nondemo only**	**Both**
N Zero-Use Transaction Records (% of 2077)	1539 (74.1)	1422 (68.5)	----	----	----
N Service Use Transaction Records (% of 2077)	538 (25.9)	655 (31.5)	237 ----	399 ----	19 ----
N Transactions with Use and Units Data (% with service use)	538 (100.0)	639 (97.6)	233 ----	387 ----	19 ----
Mean Units for Service Recipients (SD)	39.2 (26.4)	61.3 (41.0)	57.3 (36.5)	62.2 (42.3)	91.9 (51.9)
Median Units for Service Recipients	37	52	52	52	104
Max Units used by any Recipient	127	182	182	182	182

[1]Funding source codes aggregated across cases.

Table 6 (continued)

TAPE and UE Service Transaction Records for Clients Surviving at Least Three Months into Period

Personal Care / Housekeeping / Companion Records

Baseline
(6 months following randomization)

			UE by Reported Funding Source		
Record Type	**TAPE**	**UE[1]**	**Demo only**	**Nondemo only**	**Both**
N Zero-Use Transaction Records (% of 2745)	1257 (45.8)	812 (29.6)	----	----	----
N Service Use Transaction Records (% of 2745)	1488 (54.2)	1933 (70.4)	498 ----	1066 ----	369 ----
N Transactions with Use and Units Data (% with service use)	1488 (100.0)	1783 (92.2)	468 ----	968 ----	347 ----
Mean Units for Service Recipients (SD)	89.7 (87.5)	279.4 (534.1)	130.3 (212.8)	317.4 (624.0)	374.4 (525.9)
Median Units for Service Recipients	69	108	78	104	208
Max Units used by any Recipient	958.5	4368	2520	4368	4358

6 Months
(12 months following randomization)

			UE by Reported Funding Source		
Record Type	**TAPE**	**UE[1]**	**Demo only**	**Nondemo only**	**Both**
N Zero-Use Transaction Records (% of 2077)	946 (45.5)	602 (29.0)	----	----	----
N Service Use Transaction Records (% of 2077)	1131 (54.5)	1475 (71.0)	358 ----	840 ----	277 ----
N Transactions with Use and Units Data (% with service use)	1131 (100.0)	1391 (94.3)	335 ----	787 ----	269 ----
Mean Units for Service Recipients (SD)	111.6 (97.0)	346 (612.0)	183.1 (311.6)	364.8 (683.0)	493.8 (630.9)
Median Units for Service Recipients	90	150	112	128	288
Max Units used by any Recipient	758	4368	4368	4368	4368

[1]Funding source codes aggregated across cases.

The third row of Table 6 describes service use transactions having units data. This subset of service use transactions provided data for the analysis of units reporting. All TAPE service use transactions were available for units analysis; HCFA provided full utilization information on all reimbursed services. The UE service use transactions that were available for units analysis had either reported units, or expenditures that could be converted into equivalent units as described in Appendix A. The table shows that well over 90 percent of day care and personal care/housekeeping/companion service use transactions presented units data suitable for analysis at baseline and 6 months.

The key finding in Table 6 is evidence of funding source code error in the UE data file. Respondents reported that the demonstration financed less than half of service use, regardless of service type or reporting period. If demonstration source code reporting was accurate, the total number of UE service use transactions having "demo only" and "both" funding source codes would equal the number of TAPE service use transactions, and UE demonstration units would equal the number of TAPE units. Instead, TAPE service use transactions substantially exceeded UE "demo only" and "both" transactions, suggesting that respondents either failed to report any service (shows as a zero-use transaction), or reported a service that was wholly or partially funded through the demonstration as "nondemo only". In addition, mean unit values from UE "demo only" transactions, though higher than mean TAPE units, were closer to mean TAPE units than UE "nondemo only" transactions. This suggests that demonstration services reported as "nondemo only" were probably funded through "both" (demonstration and nondemonstration) sources rather than solely through the demonstration.

Table 7 displays TAPE and UE service use transactions by case management model. The table shows service use transactions, service use transactions with units, and unit descriptives. Model A had fewer service use transactions than Model B: expected, because Model A allotted $200 per month less for each client than Model B. Service use transactions decreased over time, and the decline was greater for Model B than for Model

A. Model differences in the rates of decline were pronounced for day care services, but strong differences were not seen for personal care/housekeeping/companion services. The percentages of UE day care transactions having units data suitable for analysis also demonstrated model differences over time. In each reporting period, over 4 percent more Model B transactions contained units data than Model A transactions. Personal care/housekeeping/companion service use transactions did not show consistent model differences over time.

Table 7

TAPE and UE Transaction Records by Case Management Model[1]

Day Care Records for Service Recipients Surviving at Least 3 Months into Period

Baseline
(6 months following randomization)

Record Type	N Records with Service Use	N Records with Use & Units Data (% of users)	Mean Units for Recipients (SD)	Median Units for Recipients	Max Units for any Recipient
Tape A	237	237 (100.0)	24.6 (17.7)	20	77
Tape B	510	510 (100.0)	34.9 (24.8)	32	132.5
UE A[2]	311	289 (92.9)	48.4 (40.6)	39	182
UE A demo only	123	114 (92.7)	45.4 (38.4)	37.5	182
UE A nondemo only	182	169 (92.8)	49.2 (41.7)	38	132
UE A both	6	6 (100.0)	83 (41.7)	68	136
UE B[2]	608	592 (97.4)	56.2 (39.7)	50	182
UE B demo only	246	236 (95.9)	52.1 (35.1)	50	144
UE B nondemo only	337	332 (98.5)	56.0 (40.9)	48	182
UE B both	25	24 (96.0)	98.7 (44.0)	104	180

6 Months
(12 months following randomization)

Record Type	N Records with Service Use	N Records with Use & Units Data (% of users)	Mean Units for Recipients (SD)	Median Units for Recipients	Max Units for any Recipient
Tape A	190	190 (100.0)	28.9 (19.6)	26.2	78
Tape B	348	348 (100.1)	44.8 (28.0)	45	127
UE A[2]	234	222 (94.9)	51.8 (38.6)	48	132
UE A demo only	91	88 (96.7)	45.2 (30.7)	41	132
UE A nondemo only	139	130 (93.5)	56.1 (43.0)	51.5	130
UE A both	4	4 (100.0)	60 (29.6)	48	104
UE B[2]	421	417 (99.0)	66.4 (41.3)	60	182
UE B demo only	146	145 (99.3)	64.6 (37.9)	52	182
UE B nondemo only	260	257 (98.8)	65.4 (41.7)	62	182
UE B both	15	15 (100.0)	100.5 (53.9)	104	182

[1]Model A Sites: NY, IL, TN, OR. Model B Sites: OH, WV, MN, FL.

[2]Funding source codes aggregated across cases.

Table 7 (continued)

TAPE and UE Transaction Records by Case Management Model[1]

Personal Care / Housekeeping / Companion Records for Service Recipients Surviving at Least 3 Months into Period

Baseline (6 months following randomization)

Record Type	N Records with Service Use	N Records with Use & Units Data (% of users)	Mean Units for Recipients (SD)	Median Units for Recipients	Max Units for any Recipient
Tape A	684	684 (100.0)	66.1 (48.8)	61.6	288
Tape B	804	804 (100.0)	109.7 (106.2)	83	958.5
UE A[2]	910	844 (92.7)	277.6 (564.8)	104	4368
UE A demo only	243	221 (90.9)	98.7 (209.9)	56	2520
UE A nondemo only	512	477 (93.2)	329.0 (647.1)	104	4368
UE A both	155	146 (94.2)	380.4 (587.3)	168.5	4358
UE B[2]	1023	939 (91.8)	281 (505.2)	128	4368
UE B demo only	255	247 (96.9)	158.6 (211.9)	96	1872
UE B nondemo only	554	491 (88.6)	306.2 (601.2)	104	4368
UE B both	214	201 (93.9)	370.1 (477.8)	226	4116

6 Months (12 months following randomization)

Record Type	N Records with Service Use	N Records with Use & Units Data (% of users)	Mean Units for Recipients (SD)	Median Units for Recipients	Max Units for any Recipient
Tape A	523	523 (100.0)	80.3 (56.8)	76	292.5
Tape B	608	608 (100.0)	138.5 (114.8)	121.5	758
UE A[2]	712	684 (96.1)	347.6 (670.5)	130	4368
UE A demo only	153	142 (92.8)	119.0 (142.6)	96	1248
UE A nondemo only	446	432 (96.9)	407 (782.5)	130	4368
UE A both	113	110 (97.3)	406.7 (532.5)	224	4368
UE B[2]	763	707 (92.7)	344.5 (550.3)	168	4368
UE B demo only	205	193 (94.1)	230.3 (385.6)	156	4368
UE B nondemo only	394	355 (90.1)	312.6 (534.2)	128	4368
UE B both	164	159 (96.9)	554.1 (686.0)	336	4200

[1]Model A Sites: NY, IL, TN, OR. Model B Sites: OH, WV, MN, FL.

[2]Funding source codes aggregated across cases.

Verification Findings

Summary of Key Findings

This study of proxy reported utilization found that primary caregivers of Alzheimer's patients are effective respondents for patients. This section summarizes the major study findings. Subsequent sections of the chapter present the complete results.

Service Use Reporting

- Caregiver living arrangement is a significant predictor of day care service reporting, but not of personal care/housekeeping/companion service reporting. Caregivers living with clients had significantly higher chances of reporting matching service use and zero-use transactions for baseline day care services than caregivers not living with clients. Caregivers living with clients were also significantly less likely to report baseline service use transactions having TAPE zero-use transactions than caregivers not living with clients.

- Neither caregiver relationship nor the interaction between caregiver relationship and living arrangement is a reliable predictor of either day care or personal care/housekeeping/companion service reporting.

- Caregivers significantly reduced rates of nonmatching service use and zero-use transaction reports over time. Weighted total error for day care reporting dropped from 10 percent to 8.4 percent, and from 23.8 percent to 22.5 percent for personal care/housekeeping/companion reporting. Rates of false negative service reporting, the most reliable measure of reporting error, was 7 percent for both services in each period.

- Caregiver depression is predictive of day care service reporting, but not of of personal care/housekeeping/companion service reporting. Increasing caregiver depression significantly reduced caregivers' chances of reporting matching service use and zero-use transactions for day care at baseline. Depressed respondents were significantly more likely to report service use transactions having TAPE zero-use transactions.

- Reported service use shows better agreement with the reference standard than reported funding sources. TAPE claims records for day care services matched 75.6 percent of baseline reports and 76.3 percent of 6 month service use reports. Of these, caregivers

accurately assigned demonstration funding sources to 49.9 percent of the matching baseline and 54.4 percent of the matching 6 month reports. TAPE claims records for personal care/housekeeping/companion services matched 71.5 percent of baseline reports and 71.7 percent of 6 month service use reports. Of these, caregivers accurately assigned demonstration funding sources to 54.7 percent of the matching baseline and 53.5 percent of the matching 6 month reports.

Units Reporting

- Caregiver living arrangement is a reliable predictor of day care and personal care/housekeeping/companion residual units. Caregivers living with clients had significantly higher residual units for baseline and 6 month day care services, and for baseline personal care/housekeeping/companion services than caregivers not living with clients.

- Caregiver relationship is a significant predictor of residual units for day care at 6 months and for personal care/housekeeping/companion services at baseline and 6 months. Differences between respondents varied by service and reporting period.

- Rates of agreement between reported and TAPE units increased significantly over time. Although reporting for both services showed net positive biases, the rates of UE units exceeding TAPE units decreased.

- Caregiver depression is a significant predictor of personal care/housekeeping/companion residual units, but not of day care residual units.

Service Use Reporting

This section reports on the analysis of service use reporting. It presents the results of the verification, and of an exploratory method for distinguishing services funded from within or outside the demonstration. The full verification studies of day care and personal care/housekeeping/companion transactions are presented separately. Each presentation begins with crosstabulations between TAPE and unadjusted UE data. A procedure for separating reported services by funding source is introduced, and the adequacy of source code reassignment documented by comparing mismatch rates from post-adjustment crosstabulations against expected error rates. The section is completed with findings of logistic multiple regressions generated from the recoded UE data.

Day Care Services

Table 8 displays crosstabulations of TAPE and UE service transaction records for day care services.[2] These comparisons did not attempt to distinguish services funded through the demonstration from services funded through other sources. Table 8 provides two kinds of information. One is a measure of the agreement between TAPE and UE service use reports. This study reports percent agreement, but other measures of correspondence or agreement are seen in the literature.[3] The other is the balance between

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[2]Reports from formal and informal caregivers were included in all service use and units crosstabulations.

[3]Cohen's kappa, κ, is frequently reported with percent agreement. This brief discussion and critique of kappa is given to aquaint the reader with a measure increasingly encountered in the verification literature; however, κ was disregarded in this study in favor of statistical tests more suited to the data. The Kappa statistic corrects percent agreement for agreement happening by chance by calculating the proportion of chance agreement from the marginals and then using that factor to discount the observed agreement (Carsjo, Thorslund & Warneryd, 1994; Feinstein & Cicchetti, 1990; Fleiss, 1981). Responses must be statistically independent (Graham, 1995). Perfect agreement exists when $\kappa=1$. By comparison, large values of other correlation coefficients such as chi-square and Pearson's r could mean either high agreement or disagreement (Nelson, Longstreth, Koepseu & vanBelle, 1990). Kappa is dependent on the prevalence of the event. It is not informative when the prevalence is low (Herjanic & Reich, 1982). In this situation kappa can be low even if there is high agreement. The marginal distributions also affect kappa. When the marginal values are extreme, kappa can be higher than if the marginals are more balanced (Cicchetti & Feinstein, 1990; Feinstein & Cicchetti, 1990).

Kappa is often used as a measure of validity or of reliability. Kappa agreements are often calculated for multicategorical data. Yet the statistic was originally meant to evaluate the agreement of two raters giving binary responses. Maclure & Willett (Maclure & Willett, 1987) convincingly argue that deviations from

reporting sensitivity and specificity in the data.[4] Reporting sensitivity is a measure of the probability that caregivers correctly reported service use, or the probability that any one TAPE service use transaction record had a matching UE service use transaction record. Reporting specificity is a measure of the probability that caregivers correctly reported zero-use transactions, or the probability that any one TAPE zero-use transaction record had a corresponding UE zero-use transaction record (Last, 1983; Verbrugge, 1989).

The crosstabulations in Table 8 indicate that 89.68 percent of all baseline and 90.70 percent of all 6 month day care transactions matched across data files. The majority of matching transactions showed no service use (zero-use transactions). Baseline reporting specificity was also high and improved with practice. There were fewer UE service use transactions with corresponding TAPE service use transactions because utilization was low; the associated sensitivities were quite high, indicating a 0.93 probability that any one baseline or 6 month TAPE service use transaction had a matching UE service use transaction.

Cohen's original model have often been inappropriate. For instance, researchers often convert continuous data into intervals and calculate kappas for the intervals. This is inappropriate because κ is a measure of exact agreement: κ varies as the number of categories is increased or reduced. With ordinal data, kappa agreements are lower in intermediate intervals than in the extreme intervals simply because there is only one direction to deviate away from an extreme interval. The authors recommend statistics other than kappa for validity studies such as this dissertation, when one data set is verified against a reference. Sensitivity and specificity, or positive/negative predictive values are preferred for dichotomous data (Sackett, Haynes & Tugwell, 1985) (cited in (Maclure & Willett, 1987). The mean and SD of the difference (Bland & Altman, 1986)(cited in (Maclure & Willett, 1987) or the product-moment correlation (Fisher, 1973)(cited in (Maclure & Willett, 1987) are preferred for continuous data.

[4]Sensitivity and specificity balance each other within in the same data set. An increase in one will be offset by a decrease in the other. Sensitivity and specificity are calculated rather than observable measures. The epidemiologic calculations adapted for this study are given below (Formulas adapted from Verbrugge, 1989).

Sensitivity=

$$\frac{\text{UE service use transaction and TAPE service use transaction present}}{\text{UE service use transaction and TAPE service use transaction present} + \text{UE zero-use transaction but TAPE service use transaction present}}$$

Specificity=

$$\frac{\text{UE zero-use transaction and TAPE zero-use transaction present}}{\text{UE zero-use transaction and TAPE zero-use transaction present} + \text{UE service use transaction present but TAPE zero-use transaction}}$$

Table 8

Crosstabulations of Claims TAPE and UE Transaction Records for Day Care Services

Unadjusted UE Data File

Baseline
(6 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	695 (25.97) (75.62) (0.930)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	1705 (63.71) (0.884)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	52 (1.94)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	224 (8.37)

N Reporting=2676

6 Months
(12 months following randomiztion)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	500 (24.10) (76.34) (0.929)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	1382 (66.60) (0.899)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	38 (1.83)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	155 (7.47)

N Reporting=2075

Compared to the high correspondence rates for service use and zero-use transactions, mismatch rates were relatively low. The best measure of service reporting error is the percentage of UE transactions that failed to report service use in the presence of TAPE service use transactions. Less than 2 percent of either baseline or 6 month UE records reported zero-use transactions when TAPE service use transactions were present. The percentages of UE transactions reporting service use in the presence of TAPE zero-use transactions were higher: 8.37 percent at baseline and 7.47 percent at 6 months. These latter rates are misleading because they include *all* UE service use transactions having TAPE zero-use transactions. Analysis of the table shown below finds that nondemonstration funding sources accounted for 76.78 percent of baseline and 81.93 percent of 6 month UE service use transactions having TAPE zero-use transactions. Revised estimates of reporting error were less than 2 percent in either period.

Table 9 shows the distribution of UE service use transaction records by reported funding source code. Caregivers who reported services as funded either wholly or partly through the demonstration accurately assigned the demonstration funding source code to 87.00 percent of baseline and 89.10 percent of 6 month UE service use transactions.[5] However, respondents also failed to identify the demonstration funding source in a large proportion of UE service use transactions having corresponding TAPE service use transactions. Caregivers said that 49.92 percent of baseline services and 54.40 percent of 6 month services were paid through nondemonstration sources alone.[6] We know these "nondemo only" sources were either "demo only" or "both" because the reported transactions had matching TAPE service use transactions. Of UE service use transactions having TAPE zero-use transactions, respondents reported that all funding for 76.78 percent of baseline and 81.93 percent of 6 month transactions came from nondemonstration

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[5]87.00% reports verified on baseline TAPE=348 of 400 "demo only" and "both" service use transactions
89.10% reports verified on 6 month TAPE=228 of 256 "demo only" and "both" service use transactions

[6]49.93%=347 of 695 baseline service use transactions
54.40%=272 of 500 6 month service use transactions

sources.[7] We cannot verify these "nondemo only" sources, but the absence of TAPE service use transactions confirms that caregivers correctly did not assign demonstration funding sources to the transactions. UE "demo only" and "both" service use transactions having TAPE zero-use transactions were false reports of demonstration funding sources. These rates were 1.94 percent at baseline and 1.35 percent at 6 months.[8]

Table 9

UE Transaction Records for Day Care Services by Funding Source Code

Unadjusted UE Data File

Baseline (6 months following randomization)

		all sources[1]	demo only	nondemo only	both
UE service use transaction and TAPE service use transaction present	N (%)	695 (100.00)	320 (46.04)	347 (49.92)	28 (4.03)
UE service use transaction present but TAPE zero-use transaction	N (%)	224 (100.00)	49 (21.87)	172 (76.78)	3 (1.34)

Total N reporting=2676

6 Months (12 months following randomization)

		all sources	demo only	nondemo only	both
UE service use transaction and TAPE service use transaction present	N (%)	500 (100.00)	211 (42.20)	272 (54.4)	17 (3.40)
UE service use transaction present but TAPE zero-use transaction	N (%)	155 (100.00)	26 (16.77)	127 (81.93)	2 (1.29)

Total N reporting=2075

[1]All funding source codes aggregated across individual cases.

This check of source code reporting demonstrates that respondents did not reliably distinguish service funding sources in the UE file. We want to delete nondemonstration

[7]76.78%=172 of 224 baseline service use transactions
81.93%=127 of 155 6 month service use transactions

[8]1.94%=52 UE "demo only" + "both" service use transactions present but TAPE zero-use transactions / 2676 baseline service transactions

1.35%=28 UE "demo only" + "both" service use transactions present but TAPE zero-use transactions / 2075 6 month service transactions

sources from the UE transaction file and retain demonstration sources for verification. If we eliminate all "nondemo only" transactions from the UE file, we lose 66.86 percent of baseline and 68.17 percent of 6 month "nondemo only" transactions that had demonstration support.[9] We cannot verify which of the remaining "nondemo only" transactions were valid nondemonstration sources or false reports of service use. Nor can we confirm which "demo only" and "both" service use transactions having TAPE zero-use transactions were valid nondemonstration sources or false reports of service use.

Separation of Reported Funding Sources

One way to provisionally reclassify reported funding sources is to ask whether each client's level of demonstration participation suggested a need for supplemental funding. We assume that clients did not pay for services unless they used up their monthly benefits. Clients who had access to demonstration funds had no economic incentive to choose nondemonstration funding. They could not "save up" unused demonstration benefits, and the project extended contracts to outside providers so that clients were not forced to either switch providers or lose coverage. To distinguish between clients who reached maximum benefit levels and those with remaining funds, UE service use transactions were crosschecked against clients' total reimbursements for all demonstration services used during the reporting period.[10] Reported funding sources were recoded in light of clients' accrued benefits.

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[9]66.86% of baseline =

$$\frac{\text{347 "nondemo only" UE service use transactions and TAPE service use transactions present}}{\text{347 "nondemo only" UE service use transactions and TAPE service use transactions present + 172 "nondemo only" UE service use transactions present but TAPE zero-use transactions}}$$

68.17% of 6 month =

$$\frac{\text{272 "nondemo only" UE service use transactions and TAPE service use transactions present}}{\text{272 "nondemo only" UE service use transactions and TAPE service use transactions present + 127 "nondemo only" UE service use transactions present but TAPE zero-use transactions}}$$

[10]Clients' dollar benefits were taken from the TAPE standard. Screening was accomplished by comparing the monthly maximum allowable / case management model / client exposure month. This method was more sensitive than summing dollars across 6 month follow-up periods and comparing, because clients who died or disenrolled from 3 to 6 months into the period would not have enough exposure months to accrue the maximum 6 month benefit regardless of use during active months.

The method used to separate service use transactions by funding source focused on UE service use transactions having TAPE zero-use transactions. "Demo only", "nondemo only" and "both" funding sources were recoded as "nondemo only" if clients used all their demonstration benefits. The corresponding service use transactions were reclassified as UE zero-use transactions having TAPE zero-use transactions. The reclassified UE service use transactions were not counted in revised estimates of source code error and service reporting error. Theoretically, the reclassified transactions were not false reports of service use funded through the demonstration, but accurate, through unverifiable, reports of service use funded outside the demonstration. "Demo only" and "both" funding sources were not recoded if clients had remaining demonstration benefits. The transactions remained as UE service use transactions having TAPE zero-use transactions. The transactions were included in revised estimates of source code error and service reporting error. "Nondemo only" funding sources were recoded as "possible nondemo" if clients had remaining demonstration benefits. The transactions remained as UE service use transactions having TAPE zero-use transactions. The transactions were not considered source code error because respondents did label the transactions as demonstration-funded, but they were counted in revised estimates of service reporting error.

It was less important to separate UE service use transactions having TAPE service use transactions by funding source: we already verified that those transactions had demonstration funding. Funding sources were recoded as "both" if clients reached the maximum allowable benefit, and as "demo only" if clients had additional funds remaining.[11] Transactions remained classified as UE service use transactions having TAPE service use transactions.

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[11]UE service use transactions having TAPE service use transactions were separated into demonstration and nondemonstration sources to verify reported units. Several methods for separating units by funding source are described in the analysis of units reporting.

The crosstabulations in Tables 10 through 12 were generated after source code reassignment. Table 10 shows the distribution of day care transactions in the source-adjusted UE file. The numbers of UE service use transactions having TAPE zero-use transactions were lower in the revised crosstabulations than in the original crosstabulations. Reporting specificity, the probability of matching any given TAPE zero-use transaction to a UE zero-use transaction, increased. UE zero-use transactions having TAPE service use transactions comprised less than 2 percent of all transactions in either reporting period. The McNemar test was performed to test the hypothesis that respondent reporting improved with practice.[12] McNemar's M indicated that the proportion of misclassified transactions reported at 6 months was significantly less than the proportion of misclassified transactions reported at baseline ($M=86.5$, $p<0.05$).

Appendix M compares UE service use transactions having TAPE service use transactions and UE service use transactions having TAPE zero-use transactions across selected variables. At baseline and 6 months, clients who used home-delivered meals, skilled nursing, transportation services, adaptive/assistive equipment, durable medical equipment, incontinence supplies, and consumable goods were more likely to have UE service use transactions having TAPE service use transactions than UE service use transactions having TAPE zero-use transactions. Other biases were not apparent.[13]

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[12] The McNemar test evaluates the hypothesis that two paired population proportions are the same by comparing frequencies of misclassified items (Shott, 1990). When N is large, the 2-sided test is calculated as $Mx^2 = (|b-c|-1)^2 / b+c$, where b and c are the frequencies of inconsistent responses shown in a crosstabulation between paired samples. M has an approximate chi-square distribution with 1 df (Hays, 1973). When $M > 3.84$ the 2-sided test is statistically significant at $p<0.05$.

[13] These differences were not statistically tested.

Table 10

Crosstabulations of Claims TAPE and UE Transaction Records for Day Care Services

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	695 (25.97) (75.63 (0.930)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	1714 (64.80) (0.889)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	52 (1.94)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	215 (8.03)

N Reporting=2676

6 Months
(12 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	500 (24.10) (76.34) (0.930)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	1400 (67.47) (0.911)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	38 (1.83)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	137 (6.60)

N Reporting=2075

Tables 11 and 12 show reporting behavior by caregiver-client living arrangement and by the caregiver's relationship to the client. Table 11 reports crosstabulations by living arrangement. Caregivers living with clients and caregivers not living with clients demonstrated similar reporting sensitivity and specificity. Each group achieved total correspondence rates of 90 percent at baseline, which increased to nearly 92 percent at 6 months. Reporting showed significant period effects ($M_{\text{live with}}=57.4$, $M_{\text{not live with}}=10.6$; $p<0.05$).

Table 12 presents reporting by caregiver relationship. All caregiver types generally improved their total match rates between the baseline and 6 month interviews. McNemar's test confirmed that differences between baseline and 6 month mismatch rates were significant for all respondent groups ($M_{\text{spouse}}=26.7$, $M_{\text{daughter}}=40.0$, $M_{\text{son}}=4.0$, $M_{\text{other}}=12.1$; $p<0.05$).

Table 11

Crosstabulations of Claims TAPE and UE Transaction Records for Day Care Services by Living Arrangement

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

		live with	not live with
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	502 (27.8) (0.937)	191 (22.5) (0.918)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	1127 (62.4) (0.887)	571 (67.2) (0.889)
UE zero-use transaction but TAPE service use transaction present	N (col %)	34 (1.9)	17 (2.0)
UE service use transaction present but TAPE zero-use transaction	N (col %)	144 (8.0)	71 (8.4)
Total N reporting		1807	850

6 months
(12 months following randomization)

		live with	not live with
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	371 (27.3) (0.937)	129 (18.4) (0.908)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	872 (64.2) (0.906)	514 (73.2) (0.919)
UE zero-use transaction but TAPE service use transaction present	N (col %)	25 (1.8)	13 (1.9)
UE service use transaction present but TAPE zero-use transaction	N (col %)	91 (6.7)	46 (6.6)
Total N reporting		1359	702

Table 12

Crosstabulations of Claims TAPE and UE Transaction Records for Day Care Services by Caregiver Relationship

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

caregiver		spouse	daughter	son	other
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	389 (29.5) (0.937)	189 (24.2) (0.922)	41 (19.7) (0.891)	76 (20.5) (0.938)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	815 (61.8) (0.816)	488 (62.6) (0.849)	144 (69.2) (0.889)	267 (72.2) (0.924)
UE zero-use transaction but TAPE service use transaction present	N (col %)	26 (2.0)	16 (2.1)	5 (2.4)	5 (1.4)
UE service use transaction present but TAPE zero-use transaction	N (col %)	88 (6.7)	87 (11.2)	18 (8.7)	22 (5.9)
total N reporting		1318	780	208	370

6 months
(12 months following randomization)

caregiver		spouse	daughter	son	other
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	280 (27.7) (0.915)	146 (23.2) (0.973)	29 (18.4) (0.906)	45 (16.2) (0.900)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	657 (65.0) (0.932)	421 (66.9) (0.879)	116 (73.4) (0.921)	206 (74.4) (0.907)
UE zero-use transaction but TAPE service use transaction present	N (col %)	26 (2.6)	4 (0.6)	3 (1.9)	5 (1.8)
UE service use transaction present but TAPE zero-use transaction	N (col %)	48 (4.7)	58 (9.2)	10 (6.3)	21 (7.6)
total N reporting		1011	629	158	277

The crosstabulations displayed in Tables 10 through 12 confirm that the source-adjusted UE file contains fewer UE service use transactions having TAPE zero-use transactions than the unadjusted UE file, but additional documentation is necessary to establish that source code reassignment effectively distinguished between funding sources. Table 13 shows the distribution of reassigned funding sources across UE service use transactions. Approximately one-fifth of UE service use transactions having TAPE zero-use transactions appear with either "demo only" or "both" source codes. By definition, these recoded funding sources represent the cleanest measure of demonstration source code error. We cannot directly verify revised estimates of demonstration source code error, but we may conclude that the revised estimates are reasonable if they correspond with rates of false positive reporting bias found in comparable validity studies.

Table 13

UE Transaction Records for Day Care Services by Funding Source Code

Source-Adjusted UE Data File

Baseline (6 months following randomization)

		all sources[1]	demo only	possible nondemo	both
UE service use transaction and TAPE service use transaction present	N row % error	695 (100.00)	616 (88.63) no error	----	79 (11.37) no error
UE service use transaction present but TAPE zero-use transaction	N row % error	215 (100.00)	44 (20.46) service & source code	168 (78.14) service ----	3 (1.39) service & source code

6 Months (12 months following randomization)

		all sources	demo only	possible nondemo	both
UE service use transaction and TAPE service use transaction present	N row % error	500 (100.00)	391 (78.20) no error	----	109 (21.80) no error
UE service use transaction present but TAPE zero-use transaction	N row % error	137 (100.00)	25 (18.25) service & source code	111 (81.02) service ----	1 (0.73) service & source code

[1]All funding source codes aggregated across individual cases.

This study compared revised estimates of false positive reporting and false negative reporting against similar validity studies to provide solid documentation that the biases reported in this study were within established parameters. The difficulty in making such comparisons is the lack of comparable reference studies. Studies of health reporting typically verified reports of functionality, health conditions, and acute care services rather than chronic care services; the length of recall periods varied from weeks to years; and most studies reported overall agreement rather than reporting biases.

Table 14 shows revised estimates of false reporting bias, total error, and net bias for reports of day care services. In the context of this study, response bias is a consistent departure from the TAPE standard over replications of the MADDE survey to the caregiver sample (Groves, 1987). False negative bias represents UE zero-use transactions having TAPE service use transactions. False positive bias represents UE service use transactions having TAPE zero-use transactions. Total error is the sum of negative and positive reporting errors. Net bias shows whether false negative or false positive reporting predominated in the sample.

Table 14 shows that false positive bias heavily affected the total error and net bias values. False positive bias is usually interpreted as false positive reporting error. In this situation we are more correct to interpret false positive bias as positive reporting variance, because a large portion of the bias is comprised of "possible nondemo" sources. The presence of service reporting error associated with "possible nondemo" funding sources comprised over 75 percent of the false positive rates. In contrast, false positive biases associated with "demo only" and "both" sources were lower than the false negative reporting rates. False negative reporting rates, our best estimate of service reporting error, were independent of funding sources.

Table 14

False Report Rates, Total Error, and Net Bias for Reports of Day Care Services

Source-Adjusted UE Data File

UE	TAPE	MATCH CATEGORY
service use	service use	A
zero-use	service use	B
service use	zero-use	C
zero-use	zero-use	D

Parameter	False Negative	False Positive	Total Error (weighted)	Net Bias (weighted)
Range	0 - 1	0 - 1	0 - 2	$^{-}0.5$ - $^{+}0.5$
Formula[1]	$\frac{B}{A+B}$	$\frac{C}{C+D}$	$\frac{B+C}{A+B+C+D}$	$\frac{A-C}{A+B+C+D}$
baseline				
all sources	0.070	0.111	0.100	0.179
possible nondemo	---	0.087	---	---
demo only & both	---	0.024	---	---
6 months				
all sources	0.071	0.089	0.084	0.175
possible nondemo	---	0.072	---	---
demo only & both	---	0.017	---	---

[1]Formulas adapted from Brown & Adams (1992), and Marquis, Cannell, & Laurent (1972).

Comparisons across validity studies demonstrate that source code reassignment distinguished between funding sources for reports of day care services. Respondents in a study of pap smear reporting had a false positive reporting rate of 0.45 (Bowman, Redman, Dickinson, Gibberd & Sanson-Fisher, 1991). Reuben and associates found a 0.002 positive bias in medical visit reporting (Reuben, Wong, Walsh & Hays, 1995). False positive reporting rates varied considerably in an evaluation of ambulatory care reporting. Patients' rates of false positive reporting ranged from 0.10 to 0.50 for reports of chest X-rays, EKGs, mammograms, occult blood tests, rectal examinations, pelvic examinations, and testicular self-examinations. Higher rates of false positive reporting were found for cholesterol tests (0.67), blood pressure testing (1.00), and breast self-examination (0.78) (Brown & Adams, 1992). Comparisons between these findings and the revised estimates of false positive reporting show that the revised estimates were within expected rates of false positive reporting error. Rates of false positive reporting due to service reporting error associated with "demo only" and "both" funding sources were

generally lower than the reported literature. We conclude that source code reassignment effectively distinguished funding sources in the UE file.

The rates of false negative reporting bias of day care services also compared favorably with recent studies. Bowman and associates found that women underreported pap smears at a rate of 0.07 (Bowman et al., 1991). Another study reported a false negative bias of 0.25 for medical visits (Reuben et al., 1995). Brown and Adams reported rates of false negative bias of 0.01 for blood pressure testing and 0.53 for testicular self-examination. False negative rates for eight other diagnostic tests and examinations ranged from 0.08 to 0.22 (Brown & Adams, 1992).

Logistic Multiple Regression Modeling of Source-Adjusted Data

Simple stratified analyses and multivariate modeling are two acceptable alternatives for further exploring whether multiple factors contributed to reporting behavior. Model selection and specification separates statistical modeling from simpler statistical techniques but both are derived from mathematical models (Greenland, 1989). A simple stratified analysis using crosstabulations would crosstabulate any number of record subsamples by any combination of variables such as living arrangement, caregiver relationship, education, income, depression, and so forth. Yet dividing the sample into multiple strata is limited by the assumptions of the test such as unbiased sampling, maintaining adequate sample sizes in each cell (at least 5 per cell), avoiding the presence of confounding variables in collapsed cell categories, and others (Greenland, 1989; Shott, 1990). Multivariate modeling may be a more effective way to evaluate data patterns than simple stratified analyses, though the possibility of bias is greater in modeling (Greenland, 1989).

Multiple regression modeling explains variation in a dependent variable (i.e., claims units) by evaluating the relationship of the dependent variable to an explicit set of independent variables (i.e., education, income, depression) (Hardy, 1993). Ideally, the model explains this relationship using the fewest variables required to achieve the best

fitting model. In logistic multiple regression, the dependent or outcome variable is binary or dichotomous (i.e., match / no match) (Hosmer & Lemeshow, 1989; Hosmer, Taber & Lemeshow, 1991). Linear logistic regression estimates the effect of each independent variable on the logarithm of the "odds", $\log_e(p / p\text{-}1)$, where p is the probability of the outcome event happening and p-1 is the probability of the outcome event not happening. The "logit", $\log_e(p / p\text{-}1)$, is linearly dependent on the independent variables. A unit change in an independent variable produces an equal change in the logit. The linear logistic model, $\log_e(p / p\text{-}1)=\beta o + \beta_1 X_1 + \beta_2 X_2 \ldots \beta_k X_k$, estimates β and each β_i using a maximum likelihood method. Each estimated β_i equals the effect that each X_i has on the logit, holding all other independent variables constant (Columbe, Juster, Salvatierra & Garovoy, 1988).

Dichotomous and continuous independent variables may be modeled using logistic regression. Consider the regression predicting the occurrence of day care record matches at baseline (Table 15). A dichotomous variable for caregiver living arrangement was coded 1 / 0 for live with / not live with. A measure of association called the odds ratio, ψ, was used to estimate how much more likely or less likely it was for UE matches to occur for records reported by caregivers living with clients (x=1) than for caregivers not living with clients (x=0). ψ was derived by taking the antilog of the logit coefficient (parameter estimate) (Hardy, 1993; Hosmer & Lemeshow, 1989). Table 15 shows that the odds of reporting a matching UE record was 1.8 times higher for caregivers living with clients than for caregivers not living with clients, holding all other factors constant. The 95% confidence interval reports the upper and lower bounds of the odds ratio. The positive sign on the parameter estimate indicated the positive direction on the odds. The p value showed that the estimated difference between caregivers living with clients and caregivers not living with clients was statistically significant.

When the independent variable is continuous and the logit is linear in the variable, the slope coefficient, β, equals the change in the log odds for a one unit rise in the

continuous independent variable. ψ was derived by taking the antilog of the logit coefficient (parameter estimate) (Hosmer & Lemeshow, 1989). Consider the variable for caregiver depression. The units on caregiver depression ascend with increasing depression. The negative parameter estimate on caregiver depression seen in Table 15 states that for every 1 unit increase in caregiver depression, the log odds of reporting a matching UE record dropped 0.0412. The odds ratio indicated that for every unit increase in depression, the odds of reporting a matching UE record was 0.960 times less likely.

Although often neglected, interpretation of logistic data should include goodness of fit (GOF). This study evaluated fit using a summary measure of error called the likelihood ratio test. SAS automatically generates the "G" test statistic, but there are several methods for assessing the statistical fit of the data. While goodness of fit is an important step in model building, it should not be the sole criterion for selecting variables (Hosmer & Lemeshow, 1989; Hosmer et al., 1991). The test of GOF was not significant for most of the logistic regressions generated in this study, and the decision to retain the independent variables reported in these models was based on theoretical reasons.

Multiple logistic regression models for day care reporting appear in Tables 15

Table 15
Logistic Regressions Predicting UE Service Use Transactions and TAPE Service Use Transactions Present, and UE Zero-Use Transactions and TAPE Zero-Use Transactions

Day Care Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.0210	0.0700	0.7636	0.979	(0.854-1.123)
cg income	-0.0217	0.0507	0.6692	0.979	(0.886-1.081)
live with client	0.6180	0.2478	0.0126 *	* 1.855	(1.141-3.015)
cg depression	-0.0412	0.0198	0.0375 *	* 0.960	(0.923-0.998)
daughter	0.0476	0.2914	0.8701	1.049	(0.592-1.857)
son	0.6085	0.4394	0.1661	1.838	(0.777-4.348)
other	0.8023	0.4309	0.0626	2.231	(0.921-5.191)
daughter*live with	-0.6458	0.3388	0.0567	0.524	(0.270-1.018)
son*live with	-1.1932	0.5528	0.0309	0.303	(0.103-0.896)
other*live with	-1.0019	0.5246	0.0562	0.367	(0.131-1.027)

N=2161
GOF for model=24.143 (p=0.0072) *
*p<0.05

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.0897	0.0863	0.2986	0.914	(0.772-1.083)
cg income	-0.0430	0.0623	0.4897	0.958	(0.848-1.082)
live with client	0.5174	0.2837	0.0682	1.678	(0.962-2.925)
cg depression	-0.0118	0.0254	0.6424	0.988	(0.940-1.039)
daughter	0.4078	0.3513	0.2457	1.504	(0.755-2.993)
son	0.1741	0.4622	0.7064	1.190	(0.481-2.945)
other	0.6784	0.5302	0.2007	1.971	(0.697-5.571)
daughter*live with	-0.9832	0.4118	0.0170	0.374	(0.167-0.838)
son*live with	-0.0270	0.7018	0.9693	0.973	(0.246-3.851)
other*live with	-1.4893	0.6085	0.0144	0.226	(0.103-0.743)

N=1707
GOF for model=16.201 (p=0.0940)

through 17.[14,15] The regressions in Table 15 predict UE service use transactions having TAPE service use transactions, and UE zero-use transactions having TAPE zero-use transactions. The baseline model shows that the interaction between caregiver relationship

[14]Reports from formal caregivers were not modeled because these caregivers did not provide demographic or depression data on themselves.

[15]Regressions were run using nested models to test whether the interaction between caregiver relationship * living arrangement was a significant predictor of reporting. A preliminary set of regression models were generated to test whether caregiver type and the interaction between caregiver relationship * living arrangement were significant predictors of reporting. Neither caregiver relationship nor the interaction term were significant at p<0.05 for any day care or personal care/housekeeping/companion model.

* living arrangement did not significantly affect the odds of reporting matching service use and zero-use transactions (GOF=7.292).[16] Only caregiver depression and living arrangement were significant predictors of reporting. The odds of reporting matching service use transactions and zero-use transactions decreased as caregiver education, income, and depression increased. Caregivers living with clients were more likely to report matching transactions than caregivers not living with clients. Daughters sons, and others were more likely to report matching transactions than spouses. The 6 month model shows no significant findings, but shows the same trends found at baseline. The interaction between caregiver relationship * living arrangement (GOF=9.677, $p<0.05$) may not be considered significant because GOF for the model is not significant. The odds of reporting matching transactions decreased with increasing education, income, and depression, and increased for caregivers living with clients. Daughters, sons, and others had higher odds of reporting matches than spouses.

[16]Calculated difference between nested and fully specified models.

Table 16 reports regressions predicting TAPE service use transactions having UE zero-use transactions. The interaction between caregiver relationship * living arrangement was not significant in the baseline model (GOF=2.014).[17] Neither model shows any significant main effects. It is probable that the model does not show any significant findings because the number of cases was very small.

Table 16
Logistic Regressions Predicting TAPE Service Use Transactions Present but UE Zero-Use Transactions

Day Care Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.1133	0.1569	0.4703	0.893	(0.657-1.214)
cg income	0.0549	0.1150	0.6330	1.056	(0.843-1.324)
live with client	-0.4592	0.5075	0.3656	0.632	(0.234-1.708)
cg depression	0.00669	0.0451	0.8822	1.007	(0.339-1.100)
daughter	-0.5551	0.6636	0.4029	0.574	(0.156-2.108)
son	0.00814	0.7718	0.9916	1.008	(0.222-4.576)
other	-1.3251	1.1103	0.2327	0.266	(0.030-2.342)
daughter*live with	0.5903	0.7768	0.4473	1.804	(0.394-8.271)
son*live with	-0.3908	1.2772	0.7596	0.677	(0.667-8.269)
other*live with	1.4098	1.2699	0.2669	4.095	(0.340-49.343)

N=46
GOF for model=3.331 (p=0.9725)

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.1891	0.1784	0.2891	1.208	(0.852-1.714)
cg income	0.0580	0.1343	0.6657	1.060	(0.814-1.379)
live with client	-0.3359	0.3804	0.3773	0.715	(0.339-1.506)
cg depression	0.0461	0.0492	0.3493	1.047	(0.951-1.153)
daughter	-1.4649	0.5667	0.0097	0.231	(0.076-0.702)
son	-0.4155	0.6655	0.5324	0.660	(0.181-2.432)
other	0.2864	0.5677	0.6139	0.751	(0.247-2.285)

N=35
GOF for model=11.476 (p=0.1192)

[17]SAS could not generate a 6 month regression model that included interaction terms. The maximum likelihood estimation method estimates coefficient variances and covariances "from the matrix of second partial derivatives of the log likelihood function." Coefficient variances and covariances are derived from the inverse of this "information matrix." (Hosmer & Lemeshow, 1989, pp.28-9). "Convergence" is not attained unless a unique solution is derived from the matrix. In this case, convergence was not attained because the number of UE zero-use transactions present having TAPE service use transactions was very small.

Table 17 shows regressions predicting UE service use transactions having TAPE zero-use transactions. The regression modeled demonstration and nondemonstration sources, to predict service reporting error rather than demonstration source reporting error. The baseline model shows that caregiver relationship * living arrangement was not a significant predictor of reporting (GOF=7.666). Only caregiver depression and living arrangement were significant predictors of reporting. The odds of reporting service use transactions having no matching service claims increased with increasing caregiver education, income, and depression. Caregivers living with clients were less likely to report nonmatching

Table 17
Logistic Regressions Predicting UE Service Use Transactions Present but TAPE Zero-Use Transactions

Day Care Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.0527	0.0767	0.4915	1.054	(0.907-1.225)
cg income	0.0135	0.0553	0.8071	1.014	(0.909-1.130)
live with client	-0.6342	0.2752	0.0212 *	* 0.530	(0.309-0.910)
cg depression	0.0475	0.0215	0.0273 *	* 1.049	(1.005-1.094)
daughter	0.0677	0.3174	0.8310	1.070	(0.574-1.993)
son	-0.8357	0.5294	0.1144	0.434	(0.154-1.224)
other	-0.6626	0.4636	0.1529	0.516	(0.208-1.279)
daughter*live with	0.6393	0.6393	0.0835	1.895	(0.919-3.901)
son*live with	1.5851	0.6359	0.0127	4.880	(1.403-16.971)
other*live with	0.8868	0.5719	0.1210	2.427	(0.791-7.446)

N=201
GOF for model=27.714 (p=0.0020) *
*p<0.05

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.0545	0.0969	0.5740	1.056	(0.873-1.277)
cg income	0.0337	0.0687	0.6241	1.034	(0.904-1.183)
live with client	-0.4519	0.3474	0.1934	0.636	(0.322-1.257)
cg depression	0.00151	0.0290	0.9584	1.002	(0.946-1.060)
daughter	0.0420	0.3983	0.9160	1.043	(0.478-2.276)
son	-0.1803	0.5675	0.7507	0.835	(0.274-2.540)
other	-0.4345	0.6028	0.4711	0.648	(0.199-1.077)
daughter*live with	0.8766	0.4644	0.0591	2.403	(0.967-5.970)
son*live with	0.4734	0.7801	0.5439	1.606	(0.348-7.407)
other*live with	1.4282	0.6894	0.0383	4.171	(1.080-16.109)

N=126
GOF for model=19.343 (p=0.0361) *
*p<0.05

transactions than caregivers not living with clients. Sons and others had lower odds of reporting mismatching transactions than spouses, but daughters were more likely to report nonmatching transactions than spouses. The interaction between caregiver relationship * living arrangement was not significant in the 6 month model (GOF=5.64). Although goodness of fit was significant for the model, there were no significant main effects within the model.

Personal Care / Housekeeping / Companion Services

Table 18 displays crosstabulations of TAPE and UE service transaction records for personal care/housekeeping/companion services. Differences between these crosstabulations and the crosstabulations of day care service transactions shown in Table 8 are readily apparent. More clients used personal care/housekeeping/companion services than day care services. As a group, respondents had a greater burden to recall service use and source of payment when they reported on personal care/housekeeping/companion services than when they reported on day care services. Yet reporting sensitivity was at least as high for in-home service transactions as for day care service transactions. The crosstabulations in Table 18 indicate that 75.52 percent of all baseline and 76.39 percent of all 6 month personal care/housekeeping/companion transactions matched across data files. At least 67 percent of matching transactions showed service use. Baseline reporting specificity was fair, but improved with practice.

The rates of nonmatching personal care/housekeeping/companion service transactions were nearly twice as high as those for day care service transactions. Less than 4 percent of either baseline or 6 month UE records reported zero-use transactions when TAPE service use transactions were present. The rates of UE service use transactions having TAPE zero-use transactions were much higher: 20.55 percent at baseline and 20.10 percent at 6 months. Analysis of Table 19 shows that nondemonstration funding sources accounted for 79.81 percent of baseline and 83.45 percent of 6 month UE service use transactions having TAPE zero-use transactions. Revised estimates of reporting error were 4.15 percent at baseline and 3.32 percent at 6 months.

Table 19 shows the distribution of UE service use transaction records by reported funding source code. Caregivers who reported services as funded either wholly or partly through the demonstration accurately assigned the demonstration funding source code to 87.20 percent of baseline and 89.13 percent of 6 month UE service use transactions.[18]

[18]87.20% reports verified on baseline TAPE=756 of 867 "demo only" and "both" service use transactions
89.13% reports verified on 6 month TAPE=566 of 645 "demo only" and "both" service use transactions

Table 18

Crosstabulations of Claims TAPE and UE Transaction Records for Personal Care/Housekeeping/Companion Services

Unadjusted UE Data File

Baseline
(6 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	1383 (51.68) (71.55) (0.929)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	638 (23.84) (0.537)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	105 (3.92)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	550 (20.55)

N Reporting=2676

6 Months
(12 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	1058 (50.99) (71.73) (0.935)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	527 (25.40) (0.558)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	73 (3.52)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	417 (20.10)

N Reporting=2075

Table 19

UE Transaction Records for Personal Care/Housekeeping/Companion Services by Funding Source Code

Unadjusted UE Data File

Baseline (6 months following randomization)

		all sources[1]	demo only	nondemo only	both
UE service use transaction and TAPE service use transaction present	N	1383 (100.00)	434 (31.38)	627 (45.34)	322 (23.28)
UE service use transaction present but TAPE zero-use transaction	N	550 (100.00)	64 (11.64)	439 (79.82)	47 (8.54)

N reporting=2676

6 Months (12 months following randomization)

		all sources	demo only	nondemo only	both
UE service use transaction and TAPE service use transaction present	N	1058 (100.00)	319 (30.15)	492 (46.50)	247 (23.35)
UE service use transaction present but TAPE zero-use transaction	N	417 (100.00)	39 (9.35)	348 (83.45)	30 (7.20)

N Reporting=2075

[1]All funding source codes aggregated across individual cases.

These rates were nearly identical to those seen for day care reporting. However, respondents failed to identify the demonstration funding source in a large proportion of UE service use transactions having corresponding TAPE service use transactions. Respondents reported that 45.34 percent of baseline services and 46.50 percent of 6 month services were funded solely through nondemonstration sources.[19] We know these "nondemo only" sources were either "demo only" or "both" because the reported transactions had matching TAPE service use transactions. OF UE service use transactions having TAPE zero-use transactions, caregivers said that funding for 79.82 percent of baseline and 83.45 percent of 6 month transactions came from nondemonstration sources only.[20] We cannot verify these "nondemo only" sources, but the absence of TAPE service

[19]45.34%=627 of 1383 baseline service use transactions
46.50%=492 of 1058 6 month service use transactions

[20]79.82%=439 of 550 baseline service use transactions

use transactions confirms that caregivers correctly did not assign demonstration funding sources to the transactions. UE "demo only" and "both" service use transactions having TAPE zero-use transactions were false reports of demonstration funding sources. These rates were 4.15 percent at baseline and 3.32 percent at 6 months.[21]

Separation of Reported Funding Sources

This check of source code reporting indicates that respondents did not distinguish between funding sources. Source codes were reclassified after crosschecking UE service use transactions against clients' total reimbursements for all demonstration services used during the period. The method used to separate service use transactions by funding source focused on UE service use transactions having TAPE zero-use transactions. "Demo only", "nondemo only" and "both" funding sources were recoded as "nondemo only" if clients used all their demonstration benefits. The corresponding service use transactions were reclassified as UE zero-use transactions having TAPE zero-use transactions. The reclassified UE service use transactions were not counted in revised estimates of source code error and service reporting error. Theoretically, the reclassified transactions were not false reports of service use funded through the demonstration, but accurate, through unverifiable, reports of service use funded outside the demonstration. "Demo only" and "both" funding sources were not recoded if clients had remaining demonstration benefits. The transactions remained as UE service use transactions having TAPE zero-use transactions. The transactions were included in revised estimates of source code error and service reporting error. "Nondemo only" funding sources were recoded as "possible nondemo" if clients had remaining demonstration benefits. The transactions remained as

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83.45%=348 of 417 6 month service use transactions

[21] 4.15%=111 UE "demo only" + "both" service use transactions present but TAPE zero-use transactions / 2676 baseline service transactions

3.32%=69 UE "demo only" + "both" service use transactions present but TAPE zero-use transactions / 2075 6 month service transactions

UE service use transactions having TAPE zero-use transactions. The transactions were not considered source code error because respondents did label the transactions as demonstration-funded, but they were counted in revised estimates of service reporting error.

We know that all UE service use transactions having TAPE service use transactions had at least partial demonstration funding. Source code reassignment was restricted to separating sources into "demo only" and "both" sources. Funding sources were recoded as "both" if clients reached the maximum allowable benefit, and as "demo only" if clients had additional funds remaining. Transactions remained classified as UE service use transactions having TAPE service use transactions.

Tables 20 through 22 report crosstabulations created from the source-adjusted UE file. Table 20 shows the distribution of service transactions in the source-adjusted file. The redistribution of funding sources reduced the number of UE service use transactions having TAPE zero-use transactions. Reporting specificity increased, but the minimal improvement over the specificity in the unadjusted file suggests that "possible nondemo" sources remain as UE service use transactions having TAPE zero-use transactions. UE zero-use transactions having TAPE service use transactions comprised less than 4 percent of all transactions in either reporting period. McNemar's test confirmed that caregivers improved their reporting over time. The proportion of nonmatching transactions reported at 6 months was significantly less than the proportion of nonmatching transactions reported at baseline ($M=234.7$; $p<0.05$).

Appendix M compares UE service use transactions having TAPE service use transactions and UE service use transactions having TAPE zero-use transactions across selected variables. At baseline and 6 months, clients who used home delivered meals, skilled nursing, adaptive/assistive equipment, incontinence supplies, and consumable goods were more likely to have UE service use transactions having TAPE service use

transactions than UE service use transactions having TAPE zero-use transactions. Other biases were not apparent.[22]

Tables 21 and 22 show reporting behavior by caregiver-client living arrangement and by the caregiver's relationship to the client. Table 21 reports crosstabulations by living arrangement. Each group achieved higher match rates over time, and the improvement was statistically significant ($M_{\text{live with}}$=156.3, $M_{\text{not live with}}$=37.0; $p<0.05$).

Table 22 reports reporting by caregiver relationship. All caregiver types generally improved their total match rates between the baseline and 6 month interviews. McNemar's test confirmed that differences between baseline and 6 month nonmatching rates were significant for all caregiver types (M_{spouse}=116.4, M_{daughter}=69.1, M_{son}=13.1, M_{other}=30.6; $p<0.05$).

[22]These differences were not statistically tested.

Table 20

Crosstabulations of Claims TAPE and UE Transaction Records for Personal Care/Housekeeping/Companion Services

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	1383 (51.68) (71.55) (0.929)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	655 (24.48) (0.551)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	105 (3.92)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	533 (19.92)

N Reporting=2676

6 Months
(12 months following randomization)

UE service use transaction and TAPE service use transaction present	N (% all transaction records) (% all UE service use transactions) (sensitivity)	1058 (50.99) (71.73) (0.935)
UE zero-use transaction and TAPE zero-use transaction present	N (% all transaction records) (specificity)	550 (26.51) (0.582)
UE zero-use transaction but TAPE service use transaction present	N (% all transaction records)	73 (3.52)
UE service use transaction present but TAPE zero-use transaction	N (% all transaction records)	394 (18.99)

N Reporting=2075

Table 21
Crosstabulations of Claims TAPE and UE Transaction Records for Personal Care/Housekeeping/Companion Services by Living Arrangement

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

		live with	not live with
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	935 (51.7) (0.939)	435 (51.2) (0.908)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	460 (25.5) (0.567)	191 (22.5) (0.515)
UE zero-use transaction but TAPE service use transaction present	N (col %)	61 (3.4)	44 (5.2)
UE service use transaction present but TAPE zero-use transaction	N (col %)	351 (19.4)	180 (21.2)
Total N reporting		1807	850

6 months
(12 months following randomization)

		live with	not live with
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	713 (52.5) (0.946)	338 (48.1) (0.916)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	343 (25.2) (0.567)	204 (29.1) (0.613)
UE zero-use transaction but TAPE service use transaction present	N (col %)	41 (3.0)	31 (4.4)
UE service use transaction present but TAPE zero-use transaction	N (col %)	262 (19.3)	129 (18.4)
Total N reporting		1359	702

Table 22
Crosstabulations of Claims TAPE and UE Transaction Records for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

caregiver		spouse	daughter	son	other
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	661 (50.2) (0.928)	427 (54.7) (0.945)	107 (51.4) (0.884)	188 (50.8) (0.926)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	357 (27.1) (0.589)	168 (21.5) (0.512)	47 (22.6) (0.540)	83 (22.4) (0.497)
UE zero-use transaction but TAPE service use transaction present	N (col %)	51 (3.9)	25 (3.2)	14 (6.7)	15 (4.1)
UE service use transaction present but TAPE zero-use transaction	N (col %)	249 (18.9)	160 (20.5)	40 (19.2)	84 (22.7)
total N reporting		1318	780	208	370

6 months
(12 months following randomization)

caregiver		spouse	daughter	son	other
UE service use transaction and TAPE service use transaction present	N (col %) (sensitivity)	509 (50.3) (0.936)	331 (52.6) (0.938)	86 (54.4) (0.925)	132 (47.7) (0.936)
UE zero-use transaction and TAPE zero-use transaction present	N (col %) (specificity)	268 (26.5) (0.574)	161 (25.6) (0.583)	41 (25.9) (0.631)	80 (28.9) (0.588)
UE zero-use transaction but TAPE service use transaction present	N (col %)	35 (3.5)	22 (3.5)	7 (4.4)	9 (3.2)
UE service use transaction present but TAPE zero-use transaction	N (col %)	199 (19.7)	115 (18.3)	24 (15.2)	56 (20.2)
total N reporting		1011	629	158	277

The crosstabulations presented in Tables 20 through 22 confirm that the source-adjusted UE file contains fewer UE service use transactions having TAPE zero-use transactions than the unadjusted UE file, but a high percentage of nonmatching UE service use transactions remain in the adjusted file. Further analysis is necessary to differentiate service reporting error from demonstration source error, and to establish whether source code reassignment effectively separated funding sources from each other. Table 23 shows the distribution of reassigned funding sources across UE service use transactions. About one-fifth of UE service use transactions having TAPE zero-use transactions have either "demo only" or "both" sources. By definition, recoded "demo only" and "both" sources represent the cleanest measure of demonstration source code error. We cannot verify

Table 23

UE Transaction Records for Personal Care/Housekeeping/Companion Services by Funding Source Code

Source-Adjusted UE Data File

Baseline
(6 months following randomization)

		all sources[1]	demo only	possible nondemo	both
UE service use transaction and TAPE service use transaction present	N row % error	1383 (100.00)	1226 (88.65) no error	----	157 (11.35) no error
UE service use transaction present but TAPE zero-use transaction	N row % error	533 (100.00)	64 (12.01) service & source code	422 (79.17) service ----	47 (8.82) service & source code

6 Months
(12 months following randomization)

		all sources	demo only	possible nondemo	both
UE service use transaction and TAPE service use transaction present	N row % error	1058 (100.00)	862 (81.47) no error	----	196 (18.53) no error
UE service use transaction present but TAPE zero-use transaction	N row % error	394 (100.00)	38 (9.64) service & source code	326 (82.74) service ----	30 (7.61) service & source code

[1]All funding source codes aggregated across individual cases.

revised estimates of source code error, but we may conclude that the revised estimates are reasonable if they correspond with rates of false positive reporting bias found in comparable validity studies.

Revised estimates of false positive reporting and false negative reporting were compared against the literature to document that the biases reported in this study were better than expected rates of reporting error. Table 24 shows revised estimates of false reporting bias, total error, and net bias for reports of personal care/housekeeping/companion services. Rates of total error and net bias were twice as high as for day care services. The table shows that false positive biases elevated the total error and net bias values. False positive bias is usually interpreted as false positive reporting error. In this situation we are

Table 24

False Report Rates, Total Error, and Net Bias for Reports of Personal Care/Housekeeping/Companion Services

Source-Adjusted UE Data File

UE	TAPE	MATCH CATEGORY
service use	service use	A
zero-use	service use	B
service use	zero-use	C
zero-use	zero-use	D

Parameter	False Negative	False Positive	Total Error (weighted)	Net Bias (weighted)
Range	0 - 1	0 - 1	0 - 2	$^{-}0.5$ - $^{+}0.5$
Formula[1]	$\frac{B}{A+B}$	$\frac{C}{C+D}$	$\frac{B+C}{A+B+C+D}$	$\frac{A-C}{A+B+C+D}$
baseline				
all sources	0.070	0.449	0.238	0.318
possible nondemo	---	0.355	---	---
demo only & both	---	0.093	---	---
6 months				
all sources	0.064	0.417	0.225	0.320
possible nondemo	---	0.345	---	---
demo only & both	---	0.072	---	---

[1]Formulas adapted from Brown & Adams (1992), and Marquis, Cannell, & Laurent (1972).

more correct to interpret false positive bias as positive reporting variance, because a large portion of the bias is comprised of "possible nondemo" sources. The presence of service reporting error associated with "possible nondemo" funding comprised at least 80 percent

of the false positive rates. The rates of false negative reporting, our best estimate of service reporting error, were the same for personal care/housekeeping/companion services as for day care services.

Comparisons across validity studies indicate that source code reassignment distinguished between funding sources for reports of personal care/housekeeping/companion services. Respondents in a study of pap smear reporting had a false positive reporting rate of 0.45 (Bowman et al., 1991). Reuben and associates found a 0.002 positive bias in medical visit reporting (Reuben et al., 1995). False positive reporting rates varied considerably in an evaluation of ambulatory care reporting. Patients' rates of false positive reporting ranged from 0.10 to 0.50 for reports of chest X-rays, EKGs, mammograms, occult blood tests, rectal examinations, pelvic examinations, and testicular self-examinations. Higher rates of false positive reporting were found for cholesterol tests (0.67), blood pressure testing (1.00), and breast self-examination (0.78) (Brown & Adams, 1992). Comparisons between these studies and the revised estimates of false positive reporting show that the revised estimates were within or slightly above expected estimates; discrepancies were largely due to service reporting error associated with "possible nondemo" sources. Revised estimates of false positive reporting associated with "demo only" and "both" sources were well within rates of false positive error reported in similar studies. We conclude that source code reassignment effectively distinguished funding sources in the UE file.

The rates of false negative reporting bias for personal care/housekeeping/companion services reported in this study compared favorably with recent studies. Bowman and associates found that women underreported pap smears at a rate of 0.07 (Bowman et al., 1991). Another study reported a false negative bias of 0.25 for medical visits (Reuben et al., 1995). Brown and Adams reported rates of false negative bias of 0.01 for blood pressure testing and 0.53 for testicular self-examination. False negative rates for eight

other diagnostic tests and examinations ranged from 0.08 to 0.22 (Brown & Adams, 1992).

Logistic Multiple Regression Modeling of Source-Adjusted Data

Multiple logistic regressions predicting personal care/housekeeping/companion reporting were generated from the source-adjusted UE file. The models appear in Tables 25 through 27. The regressions in Table 25 predict UE service use transactions having

Table 25
Logistic Regressions Predicting UE Service Use Transactions and TAPE Service Use Transactions Present, and UE Zero-Use Transactions and TAPE Zero-Use Transactions

Personal Care/Housekeeping/Companion Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.0115	0.0499	0.8171	1.012	(0.917-1.115)
cg income	-0.0821	0.0363	0.0235	0.921	(0.858-0.989)
live with client	0.3059	0.1872	0.1023	1.358	(0.941-1.960)
cg depression	-0.0103	0.0146	0.4814	0.990	(0.962-1.018)
daughter	0.3069	0.2273	0.1769	1.359	(0.871-2.122)
son	-0.00862	0.2832	0.9757	0.991	(0.569-1.727)
other	-0.1265	0.2618	0.6289	0.881	(0.528-1.472)
daughter*live with	-0.4352	0.2614	0.0960	0.647	(0.388-1.080)
son*live with	-0.0217	0.3892	0.9556	0.979	(0.470-2.098)
other*live with	0.0136	0.3311	0.9671	1.014	(0.530-1.940)

N=1827
GOF for model=14.112 (p=0.1679)

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.0263	0.0583	0.6523	0.974	(0.869-1.092)
cg income	-0.0502	0.0431	0.2443	0.951	(0.874-1.035)
live with client	0.1582	0.1937	0.4141	1.171	(0.801-1.712)
cg depression	-0.0101	0.0170	0.5518	0.990	(0.958-1.023)
daughter	0.3547	0.2433	0.1449	1.426	(0.885-2.300)
son	0.3791	0.3396	0.2644	1.461	(0.751-2.843)
other	0.2696	0.3233	0.4043	1.309	(0.695-2.468)
daughter*live with	-0.3557	0.2860	0.2137	0.701	(0.400-1.227)
son*live with	-0.1063	0.4703	0.8213	0.899	(0.358-2.260)
other*live with	-0.1648	0.4032	0.6827	0.848	(0.385-1.869)

N=1454
GOF for model=5.282 (p=0.8716)

TAPE service use transactions, and UE zero-use transactions having TAPE zero-use transactions. The interaction between caregiver relationship * living arrangement was not a significant predictor of matching reports at baseline (GOF=3.646) or 6 months (GOF=1.565). Neither model reveals any significant main effects.

Table 26 reports regressions predicting TAPE service use transactions having UE zero-use transactions. The interaction between caregiver relationship * living arrangement was not a significant predictor of mismatching reports at baseline (GOF=0.861) or 6 months (GOF=2.173). No significant main effects are seen at baseline or 6 months.

Table 26
Logistic Regressions Predicting TAPE Service Use Transactions Present but UE Zero-Use Transactions

Personal Care/Housekeeping/Companion Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.0992	0.1105	0.3675	0.906	(0.729-1.125)
cg income	-0.0474	0.0829	0.5676	0.954	(0.818-1.122)
live with client	-0.3224	0.3783	0.3940	0.724	(0.345-1.520)
cg depression	0.0268	0.0311	0.3885	1.027	(0.966-1.092)
daughter	-0.00294	0.4604	0.9949	0.997	(0.404-2.458)
son	0.7628	0.5103	0.1350	2.144	(0.789-5.830)
other	-0.1917	0.5781	0.7401	0.826	(0.266-2.564)
daughter*live with	-0.4264	0.5782	0.4609	0.653	(0.210-2.028)
son*live with	-0.4006	0.7332	0.5848	0.670	(0.159-2.819)
other*live with	0.0980	0.7495	0.8960	1.103	(0.254-4.792)

N=96
GOF for model=12.003 (p=0.2848)

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	-0.0391	0.1341	0.7704	0.962	(0.739-1.251)
cg income	-0.1936	0.1057	0.0669	0.824	(0.986-1.493)
live with client	-0.1986	0.4372	0.6496	0.820	(0.348-1.931)
cg depression	0.00867	0.0387	0.8226	1.009	(0.935-1.088)
daughter	0.4886	0.5075	0.3356	1.630	(0.603-4.407)
son	0.2820	0.7280	0.6985	1.326	(0.318-5.523)
other	0.0334	0.7185	0.9629	1.034	(0.253-4.228)
daughter*live with	-0.5903	0.6380	0.3548	0.554	(0.159-1.935)
son*live with	0.1694	0.9540	0.8591	1.185	(0.183-7.684)
other*live with	-1.3732	1.2483	0.2713	0.253	(0.022-2.845)

N=63
GOF for model=10.433 (p=0.4034)

Table 27 reports regressions predicting UE service use transactions having TAPE zero-use transactions. The regression modeled demonstration and nondemonstration sources, to predict service reporting error rather than demonstration source reporting error. The interaction between caregiver relationship * living arrangement was not a significant predictor of mismatching records at baseline (GOF=5.176) or 6 months (GOF=3.405). There were no significant main effects in either model.

Table 27
Logistic Regressions Predicting UE Service Use Transactions Present but TAPE Zero-Use Transactions

Personal Care/Housekeeping/Companion Services

Baseline

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.0108	0.0532	0.8392	1.011	(0.911-1.122)
cg income	0.1029	0.0384	0.0074	1.108	(1.028-1.195)
live with client	-0.2668	0.2010	0.1844	0.766	(0.516-1.136)
cg depression	0.00524	0.0156	0.7375	1.005	(0.975-1.036)
daughter	-0.3446	0.2446	0.1589	0.709	(0.439-1.144)
son	-0.2374	0.3120	0.4467	0.789	(0.428-4.454)
other	0.1848	0.2768	0.5044	1.203	(0.699-2.069)
daughter*live with	0.5600	0.2793	0.0450	1.751	(1.103-3.026)
son*live with	0.1757	0.4269	0.6807	1.192	(0.516-2.752)
other*live with	-0.0377	0.3501	0.9143	0.963	(0.485-1.913)

N=485
GOF for model=16.996 (p=0.0745)

6 Months

Variable	Parameter Estimate (β)	Standard Error of β	P	Odds Ratio	(95% CI)
cg education	0.0376	0.0621	0.5444	1.038	(0.919-1.173)
cg income	0.0951	0.0457	0.0374	1.100	(1.006-1.203)
live with client	-0.1356	0.2056	0.5096	0.873	(0.584-1.307)
cg depression	0.00945	0.0182	0.6026	1.009	(0.974-1.046)
daughter	-0.5329	0.2639	0.0435	0.587	(0.350-0.984)
son	-0.4956	0.3664	0.1762	0.609	(0.297-1.249)
other	-0.3168	0.3460	0.3598	0.728	(0.370-1.435)
daughter*live with	0.5451	0.3073	0.0761	1.725	(0.944-3.150)
son*live with	0.0444	0.5170	0.9315	1.045	(0.380-2.880)
other*live with	0.3493	0.4245	0.4106	1.418	(0.617-3.259)

N=351
GOF for model=11.618 (p=0.3114)

Service Units Reporting

This section reports on the final main research question. Did respondents accurately report the level of demonstration utilization? The question refers to caregivers who reported UE service use transactions having corresponding TAPE service use transactions. The analysis of service use reporting determined that these respondents were more likely to be living with clients and have lower depression scale scores than respondents who either failed to report services appearing on the claims TAPE, or who reported services lacking confirmation on the claims TAPE. All the UE service use transactions sampled for this analysis had units funded through the demonstration; some had additional transaction units funded through other sources.

The units analysis attempted to minimize the effects of nondemonstration sources and verify demonstration sources using crosstabulations and ordinary least squares (OLS) multiple regressions. The following pages report the findings for day care services and personal care/housekeeping/companion services in turn. Crosstabulations between UE and TAPE units were evaluated for respondent reporting patterns, evidence of source code error, and change over time. OLS regression models were used to predict TAPE units and residual units.

Day Care Units

The analysis of day care units verified the number of days per period that clients reportedly attended day care. The sample of UE service use transactions included for analysis was smaller than the total number of UE service use transactions having TAPE service use transactions because some UE records lacked verifiable units.[1] The analysis verified nearly all matching day care transactions because caregivers reported either units or

[1]Verified records contained either nonzero units or expenditures. See Appendix A for discussion of UE data requirements and the conversion of reported expenditures into equivalent units.

expenditures for most transactions.[2] The analysis used 667 baseline transactions (95.97% of 695 service use matches) and 486-6 month transactions (97.20% of 500 service use matches).

Crosstabulations

In preparation for regression analysis, crosstabulations were evaluated for respondent reporting patterns, evidence of source code error, and change over time. Crosstabulations and interpretations appear in Appendix J. The main findings show that UE units clearly exceeded TAPE units. We would usually interpret UE units exceeding TAPE units as overreporting error. In this situation, we are more correct to define UE units exceeding TAPE units as reporting variance because nondemonstration sources are indistinguishable from overreported demonstration sources. The predominance of record matches within unit intervals (13.99 units) were in the exact match and next highest unit interval cells. Most exact matches were clustered within the four lowest intervals. The lower intervals contained the majority of demonstration-funded units. Only 2 percent of all UE records underreported TAPE units within each unit interval. Most underreporting did not exceed one interval. Exact matches increased over time, but so did UE records exceeding TAPE units. Differences between interval categories at baseline and 6 months were statistically significant (T=5.24, p=0.0001).

Crosstabulations by caregiver relationship revealed that the distribution of service use transactions across exact match and nonmatch categories varied by respondent relationship. Changes over time suggest that reporting (exact matches) improved and that the use of demonstration and nondemonstration funding sources varied by respondent

[2]Appendix L displays the distribution of UE service use transactions having TAPE service use transactions across selected variables. Between baseline and 6 months, rates of spouse reports having missing units increased and rates of daughter reports having missing units decreased. Rates of reports having missing units from caregivers reporting for institutionalized clients increased. The absolute number of cases having missing units was a very small percentage of UE service use transactions having TAPE service use transactions.

relationship. Differences between baseline and 6 months were significant for spouses and sons (T_{spouse}=4.33, p=0.0001; T_{son}=2.73, p=0.0019). Crosstabulations for daughters and others demonstrated no differences over time ($T_{daughter}$=1.74, p=0.0848; T_{other}=1.90, p=0.0654).

Crosstabulations by reported funding source indicate that respondents did not accurately distinguish between funding sources. Caregivers reported that clients funded well over half the baseline and 6 month transactions completely outside the demonstration. We know that is incorrect because the UE transactions have corresponding TAPE service use transactions. Clients used either demonstration funding or a combination of funding within and outside the demonstration. Instead, we see that respondents thought clients rarely supplemented demonstration funding with funding from other sources. As expected, most transactions reporting funding from a combination of sources exceeded TAPE units. Exact matches generally increased over time. This suggests that respondents improved reporting with practice, even if they did not know the funding source ($T_{nondemo}$=2.44, p=0.0155; T_{demo}=5.30, p=0.0001; T_{both}=2.17, p=0.0527).

Ordinary Least Squares Regression

Four key findings emerged from crosstabulations of UE and TAPE units. First, UE units exceeded TAPE units. More UE transaction records exceeded TAPE units than underreported TAPE units. The rate of UE units exceeding TAPE units was also higher than the rate of units underreporting. Second, reports showed unmistakable source code error. Respondents failed to report demonstration funding sources in over half the transactions. Third, crosstabulations changed from baseline to 6 months, and the differences were statistically significant. Lastly, the presence of significant change over time varied by respondent relationship.

The findings provided a solid beginning to the analysis, but suggested a need for continued analytical refinement. The analysis used multiple regression techniques to

examine several issues. First, crosstabulations were a useful way to examine "exact" matches and mismatches within intervals, but the results will vary with the number of units the intervals contain. Match rates are easily adjusted by contracting or expanding the interval widths. Regressions were used to compare the rate of increase in TAPE units relative to the increase in UE units. Second, crosstabulations gave clean estimates of UE transactions that failed to report demonstration funding sources, but they did not distinguish between nondemonstration sources and overreported demonstration sources. Regressions were used to minimize the effects of nondemonstration sources. Third, crosstabulations demonstrated that reporting changed significantly over time for some caregivers. Regressions were used to compare differences between caregivers. Regressions evaluated whether caregiver relationship and other variables were significant predictors of reporting variance.

The regression analysis compared three nested models. The first regression modeled unaltered UE and TAPE units, the units compared in the crosstabulations. This model was the basis for comparison. The second regression used log-transformed TAPE units to minimize the effects of nondemonstration sources. The final regression used UE units trimmed to the maximum demonstration units allowed / site / exposure month to remove nondemonstration sources. The three regressions modeled UE units collapsed across reported funding sources.

The sample of UE service use transactions was modified prior to analysis. Some caregivers reported that clients attended day care 7 days a week, usually at a residential care facility. The supervision a residential care facility provides for residents is not bona fide day care. UE transactions showing 180 days of day care / period were therefore excluded from the three regressions. Appendix N shows the mean UE and TAPE units on cases retained for analysis and excluded from analysis, by caregiver relationship.

Table 28 shows the baseline comparison model. The first equation,

$$TAPE_u = \alpha + \beta_1 UE_u + e,$$

which predicted TAPE units, was significant. The adjusted R square indicates that reported units explained 44 percent of the unexplained variance in TAPE units. The regression coefficient for the constant shows the average value of TAPE units equals 11.79 when UE units equals 0. Finally, the coefficient for UE units means that TAPE units increased 0.43 units for each 1-unit increase in UE units.

Steps 2 through 4 predicted the residuals that were generated in the first step. Residuals, e, are calculated as the difference between Y and the predicted value of Y (Edwards, 1979). That is, $e=Y-(\alpha+\beta X)$. In these regressions, Y=TAPE units and the expression $(\alpha+\beta X)$=predicted TAPE units. Residuals are prediction error. We would normally interpret the residuals as underreporting and overreporting error. In these models, we interpret residuals as reporting variance because the residuals captured reporting error and unverifiable nondemonstration sources. The presence of nondemonstration sources in the UE file affected the fit of the regression line and residual values.

The remaining steps of the regression,

$$\text{Residual}=\alpha+\beta_1 X_1+\beta_2 X_2+.\ \beta_i X_i X_i\ .\ +e,$$

did not identify any significant predictors of residual units. The second step of the baseline regression regressed caregiver income, caregiver education, living arrangement, and caregiver depression on residual units. The model was not significant. None of the variables were significant predictors of reporting variance. The third step of the regression added a variable for caregiver relationship. The nonsignificant F value indicates that the variable did not produce a significant increase in the adjusted R square. A significant increase in the adjusted R square would have meant that caregiver relationship significantly improved the fit of the model. There were no other significant variables in this step. The final step added an interaction term for caregiver relationship * living arrangement. This term allows us to test for the differential effects of caregiver relationship by living arrangement (or the effects of living arrangement by caregiver relationship). In this model,

the interaction term did not produce a significant increase in the adjusted R square. There were no significant findings in the step.

The first step of the 6 month regression was significant. UE units explained 48 percent of the unexplained variance in TAPE units, a slight improvement over the baseline model. UE units exceeded TAPE units at a slightly lower rate than at baseline. TAPE units increased 0.49 units for each 1 unit increase in UE units.

Step 2 indicates that taken together, income, education, living arrangement, and depression were significant predictors of residual units. The adjusted R square shows that the variables explained only 3 percent of the unexplained variance in residual units. Two variables were significant in the model. The regression coefficient for income shows that residual units decreased 1.3 units for every dollar increase in caregiver income. The coefficient for living arrangement shows residual units were 5.4 units higher for caregivers living with clients than for caregivers not living with clients.

Step 3 of the regression was also significant. Income, education, living arrangement, depression, and caregiver relationship explained 3 percent of the unexplained variance in residuals. The nonsignificant F value on caregiver relationship indicates that the addition of caregiver relationship to the model did not produce a significant increase in the adjusted R square. Living arrangement remained significant after the addition of caregiver relationship. Residual units were 5.2 units higher for caregivers living with clients than caregivers not living with clients.

The final step of the model was not significant. The addition of the product term for caregiver relationship * living arrangement did not produce a significant change in the adjusted R square. There were no significant findings in the step.

Table 28

Nested Multiple Regression for Prediction of Residual Day Care Units. Unadjusted UE and TAPE Units

Predictor Variables	Baseline Regression Coefficient	p	F	Adj R Sq
Step 1: DV=TAPE Units		0.0001	514.1	0.4363
constant	11.795970	0.0001		
UE units	0.428153	0.0001		
Step 2: DV=Residuals		0.4116	0.991	-0.0001
constant	-0.863985	0.7569		
income	-0.642266	0.2204		
education	0.823833	0.2701		
live with	2.123966	0.2071		
depression	-0.095117	0.6499		
Step 3: DV=Residuals		0.6645	0.709	-0.0034
constant	-0.446466	0.8768		
income	-0.605666	0.2622		
education	0.863404	0.2523		
live with	1.809019	0.2969		
depression	-0.119495	0.5741		
(daughter, son, other)		>0.05	0.3428	
daughter	0.088354	0.9598		
son	-2.099919	0.5224		
other	-2.008647	0.4407		
Step 4: DV=Residuals		0.6873	0.740	-0.0043
constant	-2.482158	0.4579		
income	-0.579826	0.2881		
education	0.911739	0.2291		
live with	3.866142	0.1382		
depression	-0.098918	0.6435		
daughter	1.497486	0.6706		
son	1.571024	0.7511		
other	2.798190	0.5149		
(dau, son, other*live with)		>0.05	0.8057	
daughter * live with	-1.592217	0.6883		
son * live with	-5.991531	0.3529		
other * live with	-7.558220	0.1643		

N=664

Table 28 (continued)

Nested Multiple Regression for Prediction of Residual Day Care Units. Unadjusted UE and TAPE Units

	6 Months			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	435.829	0.4774
constant	12.528902	0.0001		
UE units	0.488813	0.0001		
Step 2: DV=Residuals		0.0131	3.200	0.0282
constant	-2.477395	0.4984		
income	-1.258303	0.0535		
education	1.292606	0.1580		
live with	5.421090	0.0099		
depression	-0.065359	0.7966		
Step 3: DV=Residuals		0.0482	2.046	0.0317
constant	-1.919955	0.6104		
income	-1.142752	0.0859		
education	1.382231	0.1331		
live with	5.155420	0.0150		
depression	-0.114856	0.6622		
(daughter, son, other)		>0.05	0.528	
daughter	-2.298810	0.2757		
son	-2.266133	0.5798		
other	0.727657	0.8301		
Step 4: DV=Residuals		0.0588	1.798	0.0176
constant	-4.706954	0.2630		
income	-1.225901	0.0667		
education	1.514872	0.1025		
live with	8.120564	0.0079		
depression	-0.072738	0.7827		
daughter	0.638333	0.8752		
son	2.216437	0.7468		
other	11.192478	0.0882		
(dau, son, other*live with)		>0.05	1.208	
daughter * live with	-3.521658	0.4452		
son * live with	-5.923881	0.4795		
other * live with	-13.956455	0.0649		

N=479

The comparison regressions in Table 28 demonstrated that UE units exceeded TAPE units by over 50 percent at baseline and 6 months. The regressions made no allowances for nondemonstration sources in the UE data. In light of the few significant findings, we may speculate that high standard error associated with nondemonstration sources obscured some significant findings.

The next set of regressions attempted to adjust UE units for nondemonstration sources without deleting UE units from the analysis. Variables may be transformed to change a nonlinear relationship into a linear relationship (Schroeder, Sjoquist, & Stephan, 1986). Logarithmic transformation is a usual way of transforming highly skewed data distributions (Hardy, 1993). Changing the relationship between UE and TAPE units rather than deleting UE units avoids the risk of unwittingly deleting overreported demonstration sources. The disadvantage is that we retain nondemonstration sources as well as overreported demonstration sources.

Table 29 reports the regressions using log-transformed units. The models are called semilogarithmic models because only one variable was transformed: in this case, the dependent variable. The first step of the model predicted logged TAPE units from UE units. Logarithmic transformation of a dependent variable, Y, is interpreted as a change in the logarithm of Y for an absolute change in the independent variable, X; or, when the dependent variable is logged and the independent variable is continuous, the regression coefficient is the percent change in Y for a 1 unit change in X (Flanders, DerSimonian, & Freedman, 1992; Hardy, 193).

The first step of the baseline regression was significant. The adjusted R square shows that UE units explained 37 percent of the unexplained variance in logged TAPE units. The regression coefficient for the constant indicates that the average value of TAPE units equals 2.3 logged units when UE units equals 0. TAPE units increased 1.7 percent for each 1 unit increase in UE units.

The second step indicates that income, education, living arrangement, and depression were significant predictors of residual units, though the variables explained only 1 percent of the unexplained variance in residual units. Income and living arrangement were the only significant variables in the model. Residual units decreased 0.05 units for each dollar increase in caregiver income. Residual units were 0.17 units higher for caregivers living with clients than for caregivers not living with clients.

The third step shows no significant findings. The addition of the variable for caregiver relationship did not significantly improve the fit of the model.

The final step was significant, explaining 1 percent of the unexplained variance in residual units. The addition of an interaction term for caregiver relationship * living arrangement did not produce a significant increase in the adjusted R square. The only significant variables in the model were income and living arrangement. The coefficient for income shows that residual units increased 0.05 units for each dollar increase in caregiver income. In the previous step, the coefficient for living arrangement estimated the difference in residual units between caregivers living with clients and caregivers not living with clients. The addition of the interaction term changes the meaning of the coefficient. The coefficient now represents the effect of living arrangement on residuals for spouses (the reference group). The coefficient in step four shows that residual units were 0.31 units higher for spouses living with clients than for spouses not living with clients.

The first step of the 6 month regression was significant. The adjusted R square indicates that UE units explained 35 percent of the unexplained variance in TAPE units. The interpretation of the constant shows that the average value of TAPE units was 2.5 logged units when UE units equals 0. The regression coefficient for UE units shows that TAPE units increased 1.5 percent for every 1 unit increase in UE units.

The three steps predicting residual units were significant. The adjusted R square in the second step reports that variables for income, education, living arrangement, and depression explained 2 percent of the unexplained variance in residual units. Income was a

significant predictor, decreasing 0.05 residual units for each increase in caregiver income. Living arrangement was the other significant predictor of residual units. Residual units for caregivers living with clients were 0.22 units higher than for caregivers not living with clients.

The third step was significant. The adjusted R square for the step shows that the variables contained in the step explained 3 percent of the unexplained variance in residual units. The significant F value on caregiver relationship indicates that the variable for caregiver relationship produced a significant change in the adjusted R square. Only the variable for daughter was significant, however. The regression coefficient for daughter shows that daughters had 0.22 less residual units than spouses (the reference group). Living arrangement remained significant in the model. Controlling for all variables, residual units were 0.2 units higher for caregivers living with clients than for caregivers not living with client.

The last step of the 6 month regression model was significant. Variables for income, education, living arrangement, depression, caregiver relationship, and caregiver relationship * living arrangement explained 3 percent of the unexplained variance in residual units. The nonsignificant F value shows that the interaction term for caregiver relationship * living arrangement did not produce a significant increase in the adjusted R square. Living arrangement was the only variable that remained significant in the model. Spouses living with clients had 0.23 more residual units than spouses not living with clients.

Table 29

Nested Multiple Regression for Prediction of Residual Day Care Units. Log-Transformed TAPE Units

Predictor Variables	Baseline Regression Coefficient	p	F	Adj R Sq
Step 1: DV=TAPE Units		0.0001	386.157	0.3675
constant	2.321828	0.0001		
UE units	0.01660	0.0001		
Step 2: DV=Residuals		0.0218	2.888	0.0123
constant	-0.011923	0.9215		
income	-0.047829	0.0354		
education	0.026448	0.4139		
live with	0.175477	0.0164		
depression	-0.004255	0.6394		
Step 3: DV=Residuals		0.0819	1.815	0.0093
constant	0.016711	0.8935		
income	-0.045240	0.0535		
education	0.028465	0.3837		
live with	0.157828	0.0360		
depression	-0.005690	0.5369		
(daughter, son, other)		>0.05	0.3380	
daughter	-0.025179	0.7404		
son	-0.081107	0.5686		
other	-0.113882	0.3131		
Step 4: DV=Residuals		0.0522	1.833	0.0135
constant	-0.119646	0.4078		
income	-0.047068	0.0463		
education	0.031462	0.3368		
live with	0.308239	0.0064		
depression	-0.004376	0.6358		
daughter	0.111797	0.4626		
son	0.262968	0.2197		
other	0.127650	0.4919		
(dau, son, other*live with)		>0.05	1.867	
daughter * live with	-0.161464	0.3468		
son * live with	-0.576731	0.0388		
other * live with	-0.351974	0.1340		

N=664

Table 29 (continued)

Nested Multiple Regression for Prediction of Residual Day Care Units. Log-Transformed TAPE Units

	6 Months			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	254.276	0.3463
constant	2.539078	0.0001		
UE units	0.014922	0.0001		
Step 2: DV=Residuals		0.0057	3.689	0.0236
constant	-0.117436	0.4153		
income	-0.051843	0.0435		
education	0.049091	0.1734		
live with	0.224861	0.0066		
depression	0.002359	0.8133		
Step 3: DV=Residuals		0.0017	3.357	0.0358
constant	-0.048494	0.7419		
income	-0.038885	0.1347		
education	0.056568	0.1158		
live with	0.197408	0.0171		
depression	-0.003709	0.7182		
(daughter, son, other)		<0.05	2.846	
daughter	-0.220408	0.0077		
son	-0.269781	0.0922		
other	-0.034398	0.7952		
Step 4: DV=Residuals		0.0061	2.511	0.0328
constant	-0.083671	0.6113		
income	-0.039776	0.1286		
education	0.057455	0.1139		
live with	0.234932	0.0494		
depression	-0.002920	0.7774		
daughter	-0.191979	0.2284		
son	-0.309805	0.2496		
other	0.228758	0.3731		
(dau, son, other*live with)		>0.05	0.5675	
daughter * live with	-0.030430	0.8662		
son * live with	0.081515	0.8038		
other * live with	-0.358775	0.2253		

N=479

Comparison of the regressions using unaltered UE and TAPE units with the regressions using log-transformed TAPE units shows that caregiver income and living arrangement were consistently significant predictors of residual units across the two models. A final comparison model used UE units trimmed to the theoretical maximum demonstration units allowed / site / client exposure month. The theoretical unit maximum for each site was calculated from the site median cost per unit of service. Appendix O reports site median costs per unit and monthly unit maximums. The trim did not eliminate any cases, nor did it remove all reporting variance. The trim removed only the nondemonstration sources and overreported demonstration sources that exceeded the demonstration limit for the site.

Table 30 shows the 6 month regression. The first step, which predicted TAPE units, was significant. The adjusted R square indicates that reported units explained 61 percent of the unexplained variance in TAPE units. The regression coefficient for the intercept shows that the average value of TAPE units equals 2 when UE units equals 0. The coefficient for UE units demonstrates that the trim removed most of the UE units that exceeded TAPE units. TAPE units increased 0.83 units for every 1 unit increase in UE units.

The model steps predicting reporting variance explained less of the unexplained variance in residual units than the regressions using unaltered units and log-transformed units. The second step of this regression was significant. The adjusted R square demonstrates that variables for income, education, living arrangement, and depression explained 27 percent of the unexplained variance in residual units. The model contained no other significant findings. The third step of the regression was not significant. The nonsignificant F value on caregiver relationship indicates that the variable did not significantly improve the fit of the model. The model contained no significant findings. The final regression step was not significant. The F value on caregiver relationship * living

arrangement shows that the interaction term did not produce a significant increase in the adjusted R square. The model contained no significant findings.

Table 30

Nested Multiple Regression for Prediction of Residual Day Care Units. UE Units Trimmed to Maximum Allowed / Site / Eligible Month

	6 Months			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	738.044	0.6066
constant	1.996170	0.2250		
UE units	0.832070	0.0001		
Step 2: DV=Residuals		0.0115	1.278	0.2777
constant	-1.372771	0.6743		
income	-0.343644	0.5541		
education	0.478019	0.5583		
live with	3.577195	0.0562		
depression	-0.228371	0.3135		
Step 3: DV=Residuals		0.6006	0.784	-0.0034
constant	-1.002475	0.7660		
income	-0.331314	0.5770		
education	0.457468	0.5778		
live with	3.525001	0.0625		
depression	-0.248906	0.2900		
(daughter, son, other)		>0.05	0.1330	
daughter	-0.439407	0.8156		
son	0.681751	0.8522		
other	-1.682287	0.5791		
Step 4: DV=Residuals		0.6590	0.769	-0.0052
constant	-1.838164	0.6253		
income	-0.358682	0.5485		
education	0.437166	0.5983		
live with	4.576512	0.0939		
depression	-0.232616	0.3249		
daughter	0.919233	0.8007		
son	-1.680528	0.7846		
other	4.498231	0.4436		
(dau, son, other*live with)		>0.05	0.7378	
daughter * live with	-1.685361	0.6832		
son * live with	4.294639	0.5670		
other * live with	-8.396291	0.2145		

N=479

Personal Care/ Housekeeping/ Companion Units

The analysis of personal care/housekeeping/companion units verified the number of hours per period that clients reportedly received in-home services. The sample of UE transactions verified in the analysis was smaller than the total number of UE service use transactions having TAPE service use transactions because some UE records lacked verifiable units.[3] The analysis verified the majority of matching personal care/housekeeping/companion transactions because caregivers reported either units or expenditures for most transactions.[4] The analysis used 1279 baseline transactions (92.48% of 1383 service use matches) and 1006-6 month transactions (95.08% of 1058 service use matches).

Crosstabulations

Prior to regression analysis, crosstabulations were evaluated for respondent reporting patterns, evidence of source code error, and change over time. Appendix K presents the crosstabulations and analysis. The crosstabulations show that UE units overwhelmingly exceeded TAPE units. Records exceeding TAPE units were distributed across the range of possible unit values, with no clustering within unit intervals (52.99 units). As for day care units, we define UE units exceeding TAPE units as reporting variance because nondemonstration sources are indistinguishable from overreported demonstration sources. The low rate of exact matches within unit intervals indicates poor agreement between UE and TAPE units. The majority of matching records within unit intervals were in the exact match and next 2 higher interval cells. Rates of underreported

[3]Verified records contained either nonzero units or expenditures. See Appendix A for discussion of UE data requirements and the conversion of reported expenditures into equivalent units.

[4]Appendix L displays the distribution of UE service use transactions having TAPE service use transactions across selected variables. Between baseline and 6 months, rates of spouse reports having missing units increased and rates of other reports having missing units decreased. Rates of reports having missing units from caregivers living with clients and from caregivers reporting for hospitalized clients increased. The absolute number of cases having missing units was small compared to the total number of UE service use transactions having TAPE service use transactions.

units were extremely low. Exact matches improved slightly over time, but not enough to offset UE units exceeding TAPE units. Differences between interval categories at baseline and 6 months were statistically significant (T=7.65, p=0.0001).

Crosstabulations by caregiver relationship show that the distribution of service use transaction records across nonmatch and exact match categories varied by respondent relationship. The distribution of records across match categories shifted over time. Changes suggest that reporting improved, and the use of demonstration and nondemonstration funding sources differed by respondent type. Differences between baseline and 6 months were significant for spouses, daughters, and others (T_{spouse}=4.63, p=0.0001; $T_{daughter}$=5.33, p=0.0001; T_{son}=3.02, p=0.0034). Crosstabulations for others demonstrated no differences over time (T_{other}=1.69, p=0.0932).

Crosstabulations by reported funding source indicate that respondents did not accurately distinguish between funding sources. Respondents reported that clients funded 46 percent of baseline and 6 month transactions outside the demonstration. We know that clients funded the transactions with demonstration funds or a combination of funding sources because the transactions have corresponding TAPE transactions. Exact matches within intervals did improve over time. Transactions reporting multiple funding sources show lower rates of exact matches. Most transactions reporting multiple funding sources exceed TAPE units. Crosstabulations did change over time, and the differences were statistically significant ($T_{nondemo}$=2.88, p=0.0001; T_{demo}=2.88, p=0.0042; T_{both}=6.93, p=0.0001).

Ordinary Least Squares Regression

Crosstabulations of UE and TAPE personal care/housekeeping/companion units duplicated the key findings reported for day care units, with the exception that UE personal care/housekeeping/companion units exceeded TAPE units to a much greater degree. Regression modeling of personal care/housekeeping/companion units proceeded as for day

care units. The first regression modeled unaltered UE and TAPE units, the units compared in the crosstabulations. This model was the basis for comparison. The second regression used log-transformed TAPE units to minimize the effects of nondemonstration sources. The final regression used UE units trimmed to the maximum demonstration units allowed / site / exposure month to remove nondemonstration sources. The three regressions modeled UE units collapsed across reported funding sources.

The sample of UE service use transactions was modified before analysis. Some caregivers reported that clients were receiving round-the-clock care. Home care services were not evaluated for clients who needed institutional-level care. The analysis excluded UE transactions showing 4368 hours of personal care / period. Appendix N shows the mean UE and TAPE units on cases that were retained for analysis and excluded from analysis, by caregiver relationship.

Table 31 shows the baseline comparison regression. The first step was significant. The adjusted R square indicates that UE units explained 8 percent of the unexplained variance in TAPE units. The low predictive value is not surprising given the regression coefficients. The regression coefficient for the constant shows that the average value of TAPE units equals 76.3 units when UE units equals 0. The coefficient for UE units reports that TAPE units increased 0.06 units for every 1 unit increase in UE units.

The remaining steps in the regression were significant. The second step shows that income, education, living arrangement, and depression were significant predictors of residual units. Together, they explained less than 1 percent of the unexplained variance in residual units. Income and depression were significant variables in the model. Residual units increased 0.33 units for every 1 dollar increase in caregiver income. Residual units increased 1.7 units for each 1 unit increase in the depression scale score.

The third model step was significant. The adjusted R square shows that the model explained 1 percent of the unexplained variance in residual units. The insignificant F value on caregiver relationship reports that the variable did not produce a significant change in the

adjusted R square. Variables for income, living arrangement, and depression were significant predictors of residual units. For a 1 dollar increase in caregiver income, residuals increased 3.8 units. Residuals for caregivers living with clients were 14.7 units higher than for caregivers not living with clients. Residual units increased 2.0 units for each 1 unit increase in depression scale scores.

The fully specified model, shown in step 4, demonstrated the highest predictive ability. The adjusted R square shows the model explained 2 percent of the unexplained variance in residual units. The addition of the interaction term for caregiver relationship * living arrangement did not produce a significant improvement in the adjusted R square. Income, depression, and living arrangement remained significant variables in the model. Residual units increased nearly 4 units for each 1 unit increase in caregiver income. A 1 unit increase in the depression scale score produced a 2.1 unit increase in residual units. Residuals were 31.9 units higher for spouses living with clients than for spouses not living with clients.

The 6 month regression was consistent with the baseline model. The adjusted R square in the first step indicates that UE units explained about 18 percent of the unexplained variance in TAPE units. The regression coefficient for the constant means the average value of TAPE units equals 89.2 units when UE units equals 0. The regression coefficient for UE units indicates that TAPE units increased only 0.09 units for each 1 unit increase in UE units.

The remaining steps of the model did not explain much of the unexplained variance in residual units. The second step had no significant findings. The third step was significant. The adjusted R square demonstrated that income, education, living arrangement, depression, and caregiver relationship explained 1 percent of the unexplained variance in residual units. Only the variable for caregiver relationship produced a significant improvement in the adjusted R square. The only significant regression coefficient for caregiver relationship is seen for sons. The coefficient indicates that

residuals were 42.1 units higher for sons than for spouses. There were no other significant variables in the model.

The final step of the model was significant, but explained only 1 percent of the unexplained variance in residual units. The addition of the interaction term for caregiver relationship * living arrangement did not produce a significant improvement in the adjusted R square. The addition of the interaction term does change our interpretation of the regression coefficients for caregiver relationship. The variable no longer measures the effect of being a daughter, son, or other respondent instead of a spouse. The coefficients now estimate the difference in predicted residuals between each caregiver group and spouses (the reference group) among respondents who are not living with clients. This step shows significant differences were present for sons and others. Sons not living with clients had 41.1 residual units higher than spouses not living with clients. Others not living with clients had 45.2 residual units higher than spouses not living with clients.

Table 31

Nested Multiple Regression for Prediction of Residual Personal Care/Housekeeping/Companion Units. Unadjusted UE and TAPE Units

	Baseline			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	114.667	0.0815
constant	76.343208	0.0001		
UE units	0.060987	0.0001		
Step 2: DV=Residuals		0.0204	2.917	0.0066
constant	-20.568683	0.0218		
income	0.335834	0.0335		
education	-1.237945	0.6039		
live with	8.184309	0.1317		
depression	1.739031	0.0149		
Step 3: DV=Residuals		0.0010	3.505	0.0149
constant	-31.309590	0.0009		
income	3.829289	0.0361		
education	-2.785435	0.2517		
live with	14.694100	0.0101		
depression	2.021363	0.0048		
(daughter, son, other)		>0.05	0.5345	
daughter	15.161040	0.0077		
son	23.177563	0.0130		
other	20.258346	0.0090		
Step 4: DV=Residuals		0.0005	3.189	0.0185
constant	-46.360891	0.0001		
income	3.615227	0.0500		
education	-2.872927	0.2367		
live with	31.864072	0.0016		
depression	2.156675	0.0026		
daughter	36.769748	0.0017		
son	30.079895	0.0482		
other	45.187330	0.0011		
(dau, son, other*live with)		>0.05	2.407	
daughter * live with	-27.716536	0.0364		
son * live with	0.447178	0.9816		
other * live with	-34.653097	0.0402		

N=1282

Table 31 (continued)

Nested Multiple Regression for Prediction of Residual Personal Care/Housekeeping/Companion Units. Unadjusted UE and TAPE Units

Predictor Variables	Regression Coefficient	6 Months p	F	Adj R Sq
Step 1: DV=TAPE Units		0.0001	222.349	0.1805
constant	89.230906	0.0001		
UE units	0.088083	0.0001		
Step 2: DV=Residuals		0.6793	0.577	-0.0018
constant	-10.423608	0.3584		
income	3.123365	0.1630		
education	-0.403071	0.8928		
live with	3.856075	0.5580		
depression	0.422245	0.6262		
Step 3: DV=Residuals		0.0210	2.370	0.0103
constant	-21.044460	0.0782		
income	3.253747	0.1455		
education	-2.284674	0.4500		
live with	8.843143	0.1896		
depression	1.071637	0.2252		
(daughter, son, other)		<0.05	4.741	
daughter	11.379756	0.1005		
son	42.137578	0.0002		
other	12.502824	0.1942		
Step 4: DV=Residuals		0.0099	2.344	0.0144
constant	-31.178288	0.0252		
income	3.080012	0.1756		
education	-2.267820	0.4537		
live with	20.496766	0.0673		
depression	1.219396	0.1680		
daughter	23.826945	0.0716		
son	41.141450	0.0203		
other	45.169581	0.0101		
(dau, son, other*live with)		>0.05	2.271	
daughter * live with	-15.727889	0.3046		
son * live with	11.219857	0.6252		
other * live with	-47.499687	0.0230		

N=1006

Table 32 reports the regressions using log-transformed TAPE units. Step 1 of the baseline regression was significant. The adjusted R square shows that UE units explained 7 percent of the unexplained variance in TAPE units. The regression coefficient for the constant indicates that the average value of TAPE units equals 3.9 logged units when UE units equals 0. The regression coefficient for UE units shows that TAPE units increased less than 1 percent for each 1 unit increase in UE units.

Step 2 of the regression was significant, although it explained less than 1 percent of the unexplained variance in residual units. None of the variables in the model was a significant predictor of residual units.

Step 3 of the regression was significant. Taken together, income, education, living arrangement, depression, and caregiver relationship explained 1 percent of the unexplained variance in residual units. The significant F value on caregiver relationship shows that the variable produced a significant improvement in the adjusted R square. Compared with spouses, residual units were 0.24 units higher for daughters, 0.37 units higher for sons, and 0.26 units higher for others. Living arrangement and depression were also significant variables in the model. Residual units were 0.22 higher for caregivers living with clients than for caregivers not living with clients. Residual units increased 0.21 units for each 1 unit increase in the depression scale score.

The last step of the regression was significant. The adjusted R square indicates the model explained about 2 percent of the unexplained variance in residual units. Variables for depression, living arrangement, caregiver relationship, and the interaction term for caregiver relationship * living arrangement each significantly improved the fit of the model. The coefficient for depression determines that residuals increased 0.20 units for every 1 unit increase in the depression scale score. The coefficient for living arrangement confirms that spouses living with clients had 0.53 residual units higher than spouses not living with clients. The variable for caregiver relationship captures significant differences between each group and the spouse reference group for caregivers not living with clients.

Daughters not living with clients had 0.61 residual units higher than spouses not living with clients. Sons not living with clients had 0.57 residual units higher than spouses not living with clients. Others not living with clients had 0.70 residual units higher than spouses not living with clients.

The variable for caregiver relationship helps us to interpret the term for caregiver relationship * living arrangement. When the regression includes main effects and product variables for caregiver relationship, the main effects variable estimates the difference in predicted residuals between each respondent group and spouses for caregivers not living with clients. The sum of the regression coefficients for the main effects variables and the coefficients for the respective product terms estimates the difference in predicted residuals between each group and spouses for caregivers living with clients. Comparison of the coefficients for caregiver relationship with the summed coefficients shows that the differences in predicted residuals was smaller for caregivers living with clients than for caregivers not living with clients.[5] The *t* tests for the product terms (table) verify that differences between caregivers living with clients and caregivers not living with clients were statistically significant only for daughters and others. T tests were calculated for the summed coefficients to determine if caregiver relationship was a reliable predictor of residual units for caregivers living with clients.[6] The two-tailed tests were not significant at a=0.05. We conclude that caregiver relationship was a reliable predictor of baseline residuals for caregivers not living with clients, but not for caregivers living with clients.

The first step of the 6 month regression was significant. The adjusted R square shows that UE units explained nearly 10 percent of the unexplained variance in logged

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[5]Sum of coefficients for product terms and main effects variables.
daugher*lw + daughter = -0.476615 + 0.614288 = 0.137673
son*lw + son = -0.136601 + 0.566516 = 0.429915
other*lw + other = -0.613137 + 0.705793 = 0.092656

[6]T = coefficient(cg) + coefficient(cg*lw) / [var(cg) + var(cg*lw) + 2cov(cg*lw)]$^{1/2}$
$T_{daugher}$ = 0.614288 + (-0.476615) / [0.0250154 + 0.0320223 + 0.501362]$^{1/2}$ = 0.4205
T_{son} = 0.566516 + (-0.136601) / [0.0422515 + 0.0686069 + 0.0501362]$^{1/2}$ = 1.0715
T_{other} = 0.705793 + (-0.613137) / [0.034973 + 0.0519907 + 0.0501362]$^{1/2}$ = 0.2502

TAPE units. The regression coefficient for the constant indicates that the average value of TAPE units equals 4.1 logged units when UE units equals 0. The coefficient for UE units shows that TAPE units increased less than 1 percent for each 1 unit increase in UE units. The second and third steps of the model presented no significant findings. The final step was significant, but explained less than 1 percent of the unexplained variance in residual units. None of the variables in the step significantly improved the fit of the model.

Table 32

Nested Multiple Regression for Prediction of Residual Personal Care/Housekeeping/Companion Units. Log-Transformed TAPE Units

	Baseline			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	101.084	0.0725
constant	3.863064	0.0001		
UE units	0.000795	0.0001		
Step 2: DV=Residuals		0.1297	1.784	0.0027
constant	-0.216076	0.0752		
income	0.027355	0.2695		
education	-0.001557	0.9616		
live with	0.120627	0.1015		
depression	0.016898	0.0811		
Step 3: DV=Residuals		0.0021	3.230	0.0133
constant	-0.370041	0.0038		
income	0.026130	0.2907		
education	-0.026348	0.4237		
live with	0.217022	0.0051		
depression	0.021031	0.0303		
(daughter, son, other)		<0.05	5.138	
daughter	0.236282	0.0022		
son	0.368849	0.0035		
other	0.261375	0.0128		
Step 4: DV=Residuals		0.0003	3.336	0.0197
constant	-0.641832	0.0001		
income	0.021563	0.3869		
education	-0.028012	0.3939		
live with	0.530290	0.0001		
depression	0.023331	0.0162		
daughter	0.614288	0.0001		
son	0.566516	0.0059		
other	0.705793	0.0002		
(dau, son, other*live with)		<0.05	3.553	
daughter * live with	-0.476615	0.0078		
son * live with	-0.136601	0.6021		
other * live with	-0.613137	0.0073		

N=1281

Table 32 (continued)

Nested Multiple Regression for Prediction of Residual Personal Care/Housekeeping/Companion Units. Log-Transformed TAPE Units

	6 Months			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	109.683	0.0976
constant	4.083311	0.0001		
UE units	0.000750	0.0001		
Step 2: DV=Residuals		0.7959	0.418	-0.0025
constant	-0.138995	0.3150		
income	0.023827	0.3824		
education	0.013299	0.7152		
live with	0.058822	0.4635		
depression	0.003695	0.7265		
Step 3: DV=Residuals		0.1001	1.723	0.0055
constant	-0.243021	0.0958		
income	0.022683	0.4059		
education	-0.008268	0.8829		
live with	0.115236	0.1616		
depression	0.009488	0.3792		
(daughter, son, other)		>0.05	0.0034	
daughter	0.196244	0.0205		
son	0.373659	0.0069		
other	0.022490	0.8483		
Step 4: DV=Residuals		0.0550	1.809	0.0087
constant	-0.365801	0.0315		
income	0.019893	0.4739		
education	0.8359	0.8359		
live with	0.0593	0.0593		
depression	0.3006	0.3006		
daughter	0.0369	0.0369		
son	0.0626	0.0626		
other	0.0489	0.0489		
(dau, son, other*live with)		>0.05	2.01	
daughter * live with	0.3576	0.3576		
son * live with	0.8507	0.8507		
other * live with	0.0229	0.0229		

N=1006

Comparisons of the regressions using unaltered UE and TAPE units with the regressions using log-transformed TAPE units shows that caregiver depression and living arrangement were consistently significant predictors of residual units across the two baseline models. A final comparison model used UE units trimmed to the theoretical maximum demonstration units allowed / site / client exposure month. The theoretical unit maximum for each site was calculated from the site median cost per unit of service. Appendix O reports site median costs per unit and monthly unit maximums. This last model did not eliminate any cases. The trim removed reporting variance, defined as nondemonstration sources and overreported demonstration sources, that exceeded the demonstration limit for each site.

Table 33 reports the 6 month model. The adjusted R square indicates that UE units explained 48 percent of the unexplained variance in TAPE units. The regression coefficient for the constant shows that the average value of TAPE units equals 13.1 units when UE units equals 0. The regression coefficient for UE units means that TAPE units increased 0.76 units for every 1 unit increase in UE units.

The remaining steps in the model were all significant. The second step explained less than 1 percent of the unexplained variance in residual units. Depression was the only significant variable in the step. Residual units decreased 1.3 units for every 1 unit increase on the depression scale score. The third step of the regression explained 1 percent of unexplained variance in residual units. The addition of the variable for caregiver relationship did not improve the adjusted R square significantly. There were no significant predictor variables within the model. The remaining step also explained 1 percent of unexplained variance in residual units. The interaction variable for caregiver relationship * living arrangement did not produce a significant increase in the adjusted R square. None of the variables in the step were significant.

Table 33

Nested Multiple Regression for Prediction of Residual Personal Care Units. UE Units Trimmed to Maximum Allowed / Site / Eligible Month

	6 Months			
Predictor Variables	**Regression Coefficient**	**p**	**F**	**Adj R Sq**
Step 1: DV=TAPE Units		0.0001	941.523	0.4834
constant	13.046185	0.0011		
UE units	0.765364	0.0001		
Step 2: DV=Residuals		0.0357	2.586	0.0068
constant	6.124246	0.4897		
income	1.014888	0.5615		
education	0.889618	0.7033		
live with	-7.518881	0.1439		
depression	-1.348044	0.0467		
Step 3: DV=Residuals		0.0155	2.489	0.0112
constant	6.189914	0.5086		
income	1.395188	0.4259		
education	0.340280	0.8859		
live with	-7.241480	0.1707		
depression	-1.231665	0.0756		
(daughter, son, other)		>0.05	2.0158	
daughter	-5.836751	0.2825		
son	17.225315	0.0524		
other	-0.960702	0.8987		
Step 4: DV=Residuals		0.0142	2.236	0.0133
constant	2.931830	0.7883		
income	1.488278	0.4043		
education	0.247019	0.9172		
live with	-3.864871	0.6600		
depression	-1.160672	0.0947		
daughter	-3.929562	0.7048		
son	12.296810	0.3763		
other	18.362815	0.1822		
(dau, son, other*live with)		>0.05	1.6472	
daughter * live with	-1.603972	0.8939		
son * live with	12.768993	0.4788		
other * live with	-29.449291	0.0724		

N=1006

IV. DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS FOR FURTHER STUDY

Discussion

Summary of Findings

This study of primary caregivers of Alzheimer's patients hypothesized that caregivers' diverse caregiving experiences affects their ability to accurately recall and report clients' service use. Direct record check methods were used to compare reported data against demonstration billing data. The analysis used crosstabulations and multiple regression modeling to evaluate reports of service use, service funding source, and service units. Findings of logistic regressions indicated that caregiver living arrangement and depression score had a greater impact on service reporting than caregiver relationship to client. Caregivers were effective respondents overall, achieving 93 percent reporting sensitivity for all baseline and 6 month reports of service use. Reports had low error rates, with net positive biases. Reports of service units exceeded TAPE units. Least squares regressions found that caregiver living arrangement, depression score, and caregiver relationship were significant predictors of residual service units. The variables explained only a small percentage of the unexplained variance in residual units and did not introduce substantial bias into reports of service units.

Respondents significantly improved reports of service use and service units with practice, but they underestimated the extent of demonstration service funding. Reports failed to identify demonstration funding for about half the matching day care records and 54 percent of matching personal care/housekeeping/companion records. Respondents' reports of nondemonstration funding sources could not be verified against any standard. Attempts to minimize the effects of nondemonstration sources using demonstration cap amounts and logarithmic adjustments were modestly successful. The remaining nondemonstration effects spuriously elevated estimates of false positive bias and residual units. Verification

studies of reported utilization and funding sources have implications for studies of service substitution.

Limitations of the Study

This study of chronic care services reporting found similar trends between day care and personal care/housekeeping/companion service reporting. Although the significant findings and nonsignificant trends in the data generally reinforced each other, nonsignificant or weakly significant results predominated. The majority of independent variables within both logistic and ordinary least squares models did not attain statistical significance. The low adjusted R square values for all ordinary least squares regressions indicate that the models lacked explanatory power.

Post-hoc power analyses found that the logistic regressions had sufficient statistical power for detecting moderate effects between respondent groups (Appendix P). The analysis indicated that the study had low power due to the very small effect sizes. Several factors probably contributed to reduced power for detecting some differences. Caregiver groups were very unequally sized. Sample sizes for sons and others were not large enough to attain adequate power for detecting differences between groups. This is a problem cited by other researchers: spouses and daughters tend to be caregivers of Alzheimer's patients more often than sons, other relatives, and nonrelatives. In this study, sons comprised only 8 percent of caregivers and others comprised 14 percent. Groups were not well-matched by living arrangement, with two-thirds of caregivers living with clients. The sample sizes of these two groups were adequate to determine moderate effect sizes.

The variable for caregiver depression showed mixed results throughout the study. Findings for depression may have been inconsistent because the measure was not heterogeneous enough to capture differences between depressed and nondepressed caregivers. Other studies have reported high rates of clinical depression or depressive symptoms among Alzheimer's caregivers (Gallagher, Rose, & Rivera, 1989; Rabins,

Mace, & Lucas, 1982). Mean depression scores for the MADDE sample were below the scale cutoff score, and the standard deviation values showed little variability in caregiver scores (Table 3).

The inability to positively identify nondemonstration sources in the UE file was the major methodological limitation of the study. The presence of nonverifiable nondemonstration sources in the UE file increased the standard error and introduced systematic bias into the analysis. Table 34 shows that source code reassignment did eliminate some nondemonstration sources from UE service use transactions having TAPE zero-use transactions, but the rate of "possible nondemo" source transactions left after reassignment was much higher than rates of "demo only" and "both" source transactions. To the extent that nondemonstration sources remained in the UE file, nondemonstration utilization effects obscured demonstration reporting effects.

Table 34

Positive Bias Rates Before and After Source Code Reassignment

Service & Source	Reported Sources	Reassigned Sources
BL Day Care		
all sources	0.116	0.111
nondemo	0.089	0.087
demo/both	0.027	0.024
6M Day Care		
all sources	0.101	0.089
nondemo	0.083	0.072
demo/both	0.018	0.017
BL Pers Care		
all sources	0.463	0.449
nondemo	0.369	0.355
demo/both	0.093	0.093
6M Pers Care		
all sources	0.442	0.417
nondemo	0.369	0.345
demo/both	0.073	0.072

Findings of Hypothesis

Reports from caregivers living with clients are more likely to agree with claims records than reports from caregivers not living with clients. This study of Alzheimer's caregivers found that living arrangement is a significant predictor of service reporting and units reporting. Logistic multiple regression analysis determined that caregiver living arrangement is a significant predictor of service reporting for day care services, but not for personal care/housekeeping/companion services. Caregivers living with clients had significantly better odds of reporting matching service use and zero-use transactions for baseline day care than caregivers not living with clients. Caregivers living with clients were also significantly less likely to report service use transactions having TAPE zero-use transactions than caregivers not living with clients. The same trends were evident in the 6 month models, although the findings were not statistically significant.

McNemar's tests on simple crosstabulations indicated that both respondents living with clients and respondents not living with clients significantly reduced rates of nonmatching reports over time. With reporting practice, caregivers living with clients had a 94 percent probability of correctly reporting service use and a 91 percent probability of correctly reporting zero service use. Caregivers not living with clients attained a 91 percent probability of correctly reporting service use and a 92 percent probability of correctly reporting zero service use.

Living arrangement was not predictive of personal care/housekeeping/companion service reporting in any logistic model, although the findings mirrored the findings in the day care models. McNemar's tests on simple crosstabulations indicated that caregivers living with clients and caregivers not living with clients significantly reduced rates of nonmatching personal care/housekeeping/companion reports with practice. Over time, caregivers living with clients reached a 95 percent probability of correctly reporting service use and a 57 percent probability of correctly reporting zero service use. Caregivers not

living with clients correctly reported service use at 92 percent probability and zero service use at 61 percent probability.

Ordinary least squares modeling found that living arrangement is predictive of day care and personal care/housekeeping/companion residual units. In models using unaltered UE / TAPE units and log-transformed TAPE units, caregivers living with clients had significantly higher day care residuals at baseline and 6 months than caregivers not living with clients. Caregivers living with clients also had significantly higher residuals for baseline personal care/housekeeping/companion than caregivers not living with clients.

The findings show that caregivers living with clients were more likely to know whether clients used any chronic care services than caregivers not living with clients, although only day care reporting attained statistical significance. Caregivers living with clients would have to be highly involved in the clients' day-to-day activities. Home-bound caregivers would have to prepare clients for transport to day care, or allow in-home service workers into the home. Live-in caregivers who spent their days at work or school may not have had as much direct involvement with service delivery, but they would need to know service schedules to make arrangements for others to prepare clients or let in-home providers into the home.

Caregivers living with clients had higher residual units than caregivers not living with clients. Usually, this would mean that caregivers living with clients overreported units relative to caregivers not living with clients. It seems contradictory that caregivers living with clients would have better knowledge of utilization, but worse knowledge of service units. Regression coefficients from the log-adjusted regressions for day care and personal care/housekeeping/companion services reveal that the differences between groups were very small. The adjusted R square values for the models are also low, indicating that living arrangement and other variables in the model explained little of the unexplained variance in residual units. For applied work, living arrangement does not bias units reporting.

Reports from spouses, daughters, and sons are more likely to agree with claims records than reports from other relatives and nonrelative caregivers. Neither caregiver relationship nor the interaction between caregiver relationship and living arrangement is a significant predictor of service reporting among Alzheimer's caregivers. The two variables are predictive of day care and personal care/housekeeping/companion residual units. Logistic regression models for both services found that neither caregiver relationship nor the interaction term predicted service reporting in either period. McNemar's tests on crosstabulations confirmed that all respondent groups significantly reduced rates of nonmatching service use and zero-use transaction reports over time.

Caregiver relationship and the interaction between caregiver relationship and living arrangement are significant predictors of residual units. For day care services, caregiver relationship was a significant predictor of residual units in the 6 month log-adjusted model only. Daughters had lower residual units than the spouse reference group. There were no differences between units for spouses with sons and others. Matched pairs *t* tests on crosstabulated units indicated that spouses and sons improved reporting over time, but daughters and others did not.

Caregiver relationship and the interaction between caregiver relationship and living arrangement were significant predictors of personal care/housekeeping/companion residuals. Caregiver relationship and the interaction term were significant variables in the model predicting log-transformed TAPE units at baseline. Sons had higher residual units than spouses. Residuals for daughters and others were not significantly different from residuals for spouses. Caregiver relationship was also a reliable predictor of residual units in the model predicting unaltered TAPE units at 6 months. Residual units for daughters, sons, and others were significantly higher than for spouses. Matched pairs *t* tests found that spouses, daughters, and sons improved reporting over time; others did not.

Contrary to reports from other studies, caregiver relationship did not have an important impact on service reporting. The nonsignificant findings for the interaction term further indicates that reporting did not differ within groups living with clients or within groups not living with clients. Though caregiver relationship was a significant predictor of residual units in some of the least squares regressions, the low adjusted R squares for those models show that caregiver relationship and other variables in the models explained only a small amount of the unexplained variance in residual units. It is possible that strong differences between groups did not emerge because the group sizes were so unevenly balanced: sons comprised only 8 percent of caregivers and others comprised 14 percent of caregivers. Another possibility is that respondent groups had sufficient contact with clients to minimize their differences in service knowledge. Research has shown that reports from respondents who visited case subjects at least 5 times a month had higher correlations with MMSE and CES-D scale scores than reports from respondents who saw subjects less often (Bassett, Magaziner, & Hebel, 1990). Caretakers spent an average of 61 hours per week helping and supervising MADDE clients. Primary caregiver respondents provided 88 percent of that care. The distributions of contact hours across groups may have afforded each group ample opportunities to become aware of clients' utilization patterns.

The level of agreement between reported data and claims data increases over time. Service reporting and units reporting show greater agreement with TAPE records over time. McNemar's tests on simple crosstabulations found the proportions of nonmatching service use and zero-use transactions declined significantly for both services. Weighted total error for day care reporting dropped from 0.100 to 0.084, and from 0.238 to 0.225 for personal care/housekeeping/companion reporting. Agreement with the standard increased mainly because respondents reduced rates of UE service use transaction reports having TAPE zero-use transactions. The unweighted errors associated with UE service use transactions having TAPE zero-use transactions decreased from 0.111 to 0.089 for day care and from

0.449 to 0.345 for personal care/housekeeping/companion reporting. Decreased variance associated with UE service use transactions having TAPE zero-use transactions corresponded with increased reporting specificities. The probability that respondents correctly reported the non-use of day care increased from 89 to 91 percent. The probability that respondents correctly reported the non-use of personal care/housekeeping/companion services increased from 55 to 58 percent.

Respondent rates of UE zero-use transactions having TAPE service use transactions remained fairly stable across time and service, at 0.070. The rather low rate of false negative reporting was balanced by correspondingly high reporting sensitivity. Respondents attained a 93 percent probability of accurately reporting the use of day care and personal care/housekeeping/companion services in each period.

Crosstabulations of service units showed significant improvements over time. Day care and personal care/housekeeping/companion matches increased with reporting practice. Rates of underreported day care units were extremely low in both periods. Personal care/housekeeping/companion underreporting decreased over time.

Although the rates of UE units exceeding TAPE units were very high in both periods, regression modeling of unaltered UE / TAPE units shows that the rate of UE units exceeding TAPE units decreased from baseline to 6 months. Models predicting day care TAPE units indicate that the rate of UE units exceeding TAPE units decreased from 57 to 51 percent. The rates for personal care/housekeeping/companion units declined from 94 to 91 percent.

Several reasons may account for respondents' improved reporting accuracy. Most obviously, we anticipate some improvement with practice. With each succeeding interview, caregivers would become increasingly familiar with the interview process and the requested information. Respondents spoke with the same interviewers at each follow-up, and we assume they developed some rapport during the study. Caregivers may have had less difficulty recalling services or estimating units because clients' service schedules

had become fairly regular over time. Caregivers may have been trying new services or levels of service during the beginning months of the demonstration. We expect that clients eventually settled into a routine schedule of service use (or nonuse) unless changes in their status or in the household could not accommodate arrangements.

Caregiver depression increases the likelihood of reporting error. Caregiver depression is a significant predictor of service reporting and units reporting. Logistic multiple regression analysis determined that depression is a significant predictor of service reporting for day care services, but not for personal care/housekeeping/companion services. Increasing depression significantly lowered caregivers' odds of reporting matching service use and zero-use transactions for day care. Moreover, increasing caregiver depression significantly heightened the probability that respondents would report service use transactions having TAPE zero-use transactions. While these findings were only significant for baseline day care services, the 6 month model produced the same trends. Caregiver depression was not a reliable predictor of personal care/housekeeping/companion service reporting. Models for personal care/housekeeping/companion services showed the same trends as the day care models.

Caregiver depression is a significant predictor of personal care/housekeeping/companion residual units but not of day care residual units. Caregiver depression was nonsignificant in all least squares regressions of day care units. Depression was a significant predictor of personal care/housekeeping/companion residuals. In the regressions modeling unaltered UE / TAPE units and log-transformed TAPE units at baseline, residual units increased with increasing caregiver depression. In the regression modeling UE units trimmed to the maximum allowable units / site / eligible month, residual units at 6 months decreased with increasing depression.

Our findings confirm studies showing that depression adversely affects cognitive performance in complex tasks, such as recall and recognition (Brown, Scott, Bench, &

Dolan, 1994; Levy & Maxwell, 1968; Rabbitt, Donlan, Watson, McInness, & Bent, 1995; Tarbuck & Paykel, 1995). Although caregiver depression did not attain statistical significance in all our models, the nonsignificant findings showed the same trends as the significant results. Most likely, the sample did not include enough clinically depressed individuals to show strong effects between depressed and nondepressed groups.

Studies have shown lower depression among caregivers who obtain respite away from the patients' home. Employed caregivers have lower depression scores than home-bound caregivers having no supportive network (Morrison, Becker, & Rupert, 1990). Caregivers living with patients are also more likely to be depressed than caregivers not living with clients (Cohen & Eisdorfer, 1988). Some MADDE caregivers spent their days at work or school; 34 percent were not living with clients. There is the concern that demonstration placebo effects reduced caregiver depression scores. A comparison of treatment and comparison group depression scores indicates that this did not happen; group depression scores did not differ (Newcomer, et. al., 1993). We may assume that severely depressed caregivers probably did not participate in the study.

The level of agreement between reported and claims units is higher for day care services, which provides a standard set of services at each encounter, than for home care services, which groups interrelated or overlapping sets of services into flexible service packages. UE day care and personal care/housekeeping/companion units each exceeded claims TAPE units, but the rate was higher for personal care/housekeeping/companion units. In log-adjusted regression models, TAPE units increased nearly 2 percent for every 1 unit increase in UE day care units. UE units explained about 35 percent of the unexplained variance in logged TAPE units. TAPE units increases less than 1 percent for every 1 unit increase in UE personal care/housekeeping/companion units. UE units explained less than 10 percent of the unexplained variance in logged TAPE units.

Respondents may have had less difficulty estimating day care units than personal care/housekeeping/companion units. Day care providers delivered the same package of services at each encounter. Respondents only had to report the frequency of encounters to report day care units. Home health aides, housekeepers, and companions provided distinctive and shared services, by the hour. It is possible that confusion between in-home service providers and service task led some respondents to misdefine the event of enumeration. Given the smaller units for personal care/housekeeping/companion services, a small mistake in an estimation factor could conceivably result in greater error if respondents used rule-based estimation to determine service hours.

Reports are more accurate for service use than for source of payment. Reports of day care and personal care/housekeeping/companion service use were more accurate than reports of funding source. Crosstabulations confirmed caregiver reports of day care services on 75.6 percent of baseline service use reports and 76.3 percent of 6 month service use reports. Caregivers accurately identified demonstration funding sources on 49.9 percent of the matching baseline reports and 54.4 percent of the matching 6 month reports. Crosstabulations confirmed reported personal care/housekeeping/companion services on 71.5 percent of baseline service use reports and 71.7 percent of 6 month service use reports. Caregivers accurately identified demonstration funding sources on 54.7 percent of the matching baseline and 53.5 percent of the matching 6 month reports.

Although percent agreement was higher for service use than for source of payment, caregivers were very accurate when they did assign demonstration sources. Caregivers correctly assigned 87 percent of baseline demonstration sources and 89 percent of 6 month demonstration sources (same rates for both services). Nonmatching reports of demonstration sources appeared as UE service use transactions having TAPE zero-use transactions. Table 35 shows that demonstration source code error comprised only a small

portion of the service use reports that were not verified on the claims TAPE (unadjusted UE file).

Table 35

Positive Bias Rates by Reported Funding Source

Service & Source	Positive Bias
BL Day Care	
all sources	0.116
nondemo	0.089
demo/both	0.027
6M Day Care	
all sources	0.101
nondemo	0.083
demo/both	0.018
BL Pers Care	
all sources	0.463
nondemo	0.369
demo/both	0.093
6M Pers Care	
all sources	0.442
nondemo	0.369
demo/both	0.073

The seemingly low correspondence between agreement rates for service reporting and source code reporting is partially an artifact of coding. Coders assigned demonstration source codes only for services caregivers expressly identified as demonstration-funded. We did not assume that agencies on the demonstration provider list delivered demonstration-funded services, because the demonstration contracted services from providers who accepted demonstration and nondemonstration funding (Appendix F). Thus, funding source coding was biased towards undercounting demonstration sources. The findings nonetheless support other studies that have shown that elderly subjects have difficulty recalling sources of information.

Researchers who studied respondents' ability to classify sources of information report that younger respondents are better able to discriminate between sources of information than older respondents (Hashtroudi, Johnson, & Chrosniak, 1989;

Rabinowitz, 1989). The most common mistake respondents of all ages make is to report having watched an event that never happened. Older subjects make these errors more frequently than younger respondents. Older subjects are also more likely to be swayed by misinformation, even when they had earlier access to the correct information (Cohen & Faulkner, 1989). These factors are difficult to assess with respect to MADDE respondents. We could not verify demonstration and nondemonstration source reporting against separate standards, nor did we evaluate source code reporting across age groups.

We can speculate that caregivers had limited knowledge of funding sources. The demonstration expected case managers to finance client services with public or private funds before submitting requests to the demonstration. Caregivers would have had some difficulty separating funding sources, particularly if the case manager secured demonstration and nondemonstration funds for the same agency. It is also possible that caregivers were not aware of service funding sources because clients had to make a copayment on all services received. Perloff and Morris found that patients who reportedly had a routine health care provider frequently could not verify the source of care (Perloff & Morris, 1989). In the same way that medical patients could not reliably characterize health care providers by office setting or location, caregivers would not necessarily be able to identify funding sources by service provider.

Generalizability

The verification sample was drawn from a diversity of geographical locations across the United States, but it was not representative of all Alzheimer's caregivers or of primary caregivers of Alzheimer's patients. The verification sample was a nonprobability sample of primary informal caregivers who voluntarily enrolled in the MADDE project. On average, they were not as depressed as Alzheimer's caregivers in other studies, suggesting some self-selection among healthier caregivers. These respondents were highly involved in clients' daily activities and would have been unusually well-informed of clients' service

use. It is true that the verification's requirements for original caregivers of clients who survived at least 3 months into the reporting period diminished generalizability, but at the advantage of ensuring all clients had UE and TAPE records for verification and all respondents had the same practice effects. The first restriction eliminated replacement respondents for original caregivers who died, became too ill to continue the study, moved out of the catchment area, refused, or dropped out of the study for other reasons. The latter restriction eliminated caregivers of clients who may have been older or sicker.

Although the sample was not representative of the Alzheimer's caregiver population, the sample provided interesting insights into chronic care services reporting by informal caregivers of irreversibly demented patients who are willing to seek formal assistance and participate in a long-term study.

Implications for Policy and Applied Research

Caregivers of Alzheimer's patients often fulfill multiple roles for patients, serving as caretakers, proxy respondents, and consumer advocates. This study found that primary informal caregivers had knowledge of clients' service use and could provide reliable, accurate information to investigators. The possibility of biased reporting among caregivers was, nevertheless, a concern in the verification. Systematic biases in the data may lead to erroneous estimates of service utilization. This is a concern because of the potential impact of service utilization statistics on health care policy and practice.

Health utilization and expenditures data are direct measures of resource consumption. These data may also function as surrogate measures of disease incidence, prevalence, and severity (Fowles, 1994; Vollmer, Osborne, & Buist, 1994).[132] Policy

[132]The use of utilization data as proxy measures of disease states is a legitimate, but less than optimal use of these data. Fowles (1994) notes that proxy measures always have multiple interpretations, which become more indefinite the more removed the proxy measure is from the substituted measure. Yet utilization proxy measures are a useful way of inferring conditions that cannot be directly identified. When researchers at Fallon Community Health Plan determined the incidence of pelvic inflammatory disease among women who had a sexually transmitted disease (STD), they had to infer the diagnosis of STD from prescription and other diagnostic data. If researchers relied soley on ICD codes, they would have

makers typically compare utilization for population subgroups to determine if services are being distributed fairly and if programs should be modified to achieve equity (Andersen, Kasper, Frankel, et. al., 1979). Utilization data contribute to quality / effectiveness and clinical outcomes / cost-effectiveness research. Managed care corporations apply these studies in marketing, staffing decisions, resource allocation, cost-containment, and quality improvement. Policy makers use studies to legislate cost-containment and quality assurance. Consumers compare health plans to determine the best buy for their needs (Bernstein & Bernstein, 1996; Peterson, Shatin, & McCarthy, 1996). Lobbying groups cite utilization health statistics to fortify their positions and discredit their opponents.

Self-Selection Bias and Reporting Bias. Researchers have documented self-selection among respondents for Alzheimer's patients, and there was evidence of selection bias in this study. MADDE experienced difficulties reaching target enrollment levels during the caseload build-up phase of the demonstration. Many factors contributed to enrollment problems besides selection bias, but some caregivers self-selected out of the study because they denied clients were seriously ill, refused services, or would not pay service copayments. Descriptive data for respondents and comments from caregivers suggest that clinically depressed caregivers and those who perceived the patient's illness as highly stigmatizing chose not to participate.

If respondent self-selection contributed to reporting biases, the effect was not substantial. Logistic and least squares regression modeling demonstrated significant effects for caregiver living arrangement, caregiver relationship, and caregiver depression. The corresponding odds ratios and adjusted R square values were very low, indicating that differences between groups were only weakly significant. None of the variables was consistently significant across services or time. The findings suggest that although significant biases were present in the data, the levels were too low to compromise the

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undercounted STD diagnoses. According to the study author, physicians avoid making a diagnosis of STD because of the stigma to the patient (Lewis, 1996).

quality of reported service use or units data. This is an important consideration for Alzheimer's researchers, who must rely on nonprobability samples. Self-selection among primary caregiver respondents will not substantially affect proxy reported utilization for Alzheimer's patients.

Utilization Bias and Comparability Across Services . Past studies have found that caregiving tasks and service use patterns often vary by caregiver relationship or gender. The data in this study show that twice as many clients used demonstration-funded personal care/housekeeping/companion services as day care services. The utilization patterns for each service varied by caregiver relationship to client, and relationships between caregiver groups were fairly consistent over time (Tables 6, 12, & 22). Despite differences in service rates and utilization patterns, day care and personal care/housekeeping/companion reports had nearly identical rates of reporting sensitivity and false negative reporting. These are not comprehensive measures of reporting accuracy and error, but they are the cleanest comparison points because they were unaffected by nondemonstration sources. Baseline and 6 month sensitivities were 93 percent; false negative rates were about 7 percent.

The findings indicate that utilization biases did not result in reporting biases. This is an extremely important finding for studies of proxy reported chronic care services. Surveys often collect all service information from a single proxy. Some researchers have suggested that if several respondent types have special knowledge of a case, all ought to report on the case (Pickle, Brown, & Blot, 1983). This is a potentially expensive proposition which only increases the likelihood of introducing variance into the data. MADDE caregivers' preferences varied by caregiver relationship to client, yet utilization reports were comparable across services. If reporting quality did vary by utilization biases, then the aggregate estimates of each service would have been incorrect. More seriously, the relationships between services would be distorted. This study did not specifically

evaluate whether reports from spouses, daughters, sons, and others are interchangeable. The findings do suggest that utilization biases among primary caregiver respondents will not affect comparability across services and that reports will reliably capture the relationships between services.

Service Funding Source. Demonstration source code error was a major problem in the study. Caregivers reported service utilization with a high level of accuracy, but they apparently did not realize the extent of the demonstration's funding coverage. Caregivers failed to identify demonstration funding sources for at least half the reported service use transactions having TAPE service use transactions. These findings present cause for concern. One concern is consumer advocacy. If caregivers are not aware of the benefits the government provides to them, they will not lobby to retain those benefits when policy makers debate funding cuts. Another concern is the potential impact on program participation. MADDE interviewers asked caregivers to rate demonstration sources on a number of satisfaction measures. If caregivers could not distinguish services funded within and outside the demonstration, then their satisfaction ratings probably did not refer unequivocally to program services. Put another way, caregivers could not make unbiased judgements about services funded within the demonstration. This is a concern because caregivers' perceptions about program service quality or funding level may influence their decisions about remaining in a study or purchasing nonprogram services. Another consideration is the cost to the study. Maintaining adequate samples in longitudinal studies is not only expensive, replacement respondents introduce variability into the data.

All programs are voluntary in some way. A program's organization and presentation are likely to affect program participation (Rossi & Freeman, 1993). Consumers will not promote a program that fails their expectations, but they should have realistic expectations of the program. At minimum, beneficiaries should have a clear understanding of what the program offers. Programs can increase participants' awareness

of services or funding levels. Studies have shown that people who obtain information about an event from two accurate sources will give an accurate account of the event to someone else. Some individuals have more difficulty providing the correct information if they were given conflicting information about the event (Cohen & Faulkner, 1989). This suggests that case managers should provide adequate, consistent information about demonstration benefits to caregivers. Program changes or corrections should be brought to the caregiver's attention. Adults also recall significantly more information that they produce themselves (Rabinowitz, 1989). The case manager who developed a client's service plan would probably remember more about the plan than the caregiver who merely reviewed the plan. One way of increasing caregiver recall may be to have caregivers confirm client benefits in a way that requires them to generate the information, possibly by signing a register for received benefits or keeping a funding source diary.

Conclusions

Alzheimer's patients represent a sizable, rapidly growing segment of the elderly population whose need for chronic care is increasing. These patients often cannot participate in survey studies except through proxy respondents. This study of clients and their primary caregivers enrolled in the Medicare Alzheimer's Disease Demonstration Evaluation investigated proxy reporting of chronic care services, a neglected area of the proxy literature. It hypothesized that respondents' caregiving experiences affects their ability to recall clients' service use, and reporting accuracy varies among respondents having dissimilar experiences. The findings indicate that respondents who seek formal assistance were reliable respondents for service use and nonuse, but they were much less knowledgeable about service funding sources. Respondents significantly improved their reporting accuracy over time. Although respondent group differences exist, they were not consistent across services or time. Service utilization biases did not bias reports of either day care or personal care/housekeeping/companion services, indicating that reports

accurately captured utilization relationships between services. The study also found that self-selection among respondents did not introduce substantial bias into the data. The findings of this study have implications for public health policy and consumer issues.

Recommendations for Further Study

Two potential areas of research emerged from this study of proxy respondents. One is the need for more representative studies of proxy respondents. The other is the evaluation and reduction of funding source error. Studies on proxy respondents are conspicuously lacking, particularly studies that include non-spouse and non-daughter respondents. While this study included non-spouse and non-daughter respondents, the low proportion of these respondents relative to spouses and daughters emphasizes the need for more representative studies. Although many researchers heartily agree on the need for more representative studies, a systematic agenda for achieving that goal is daunting.

A major deterrent to achieving representative samples is nonobservation bias. Nonobservation errors arise when researchers cannot identify potential respondents and when respondents self-select out of studies. Nonsampling bias errors comprise the largest portion of total survey error (Andersen, Kasper, Frankel, et. al., 1979; Kish, 1965). Researchers find that nonsampling errors may be impossible to quantify and often do not attempt to evaluate these errors (Mathiowetz, 1989). A systematic evaluation of nonobservation errors among Alzheimer's proxies and of procedures for increasing the generalizability of future proxy studies would be a valuable contribution to applied research and survey methods research.

Future research is also needed to evaluate and minimize funding source error. This underdeveloped area of research has implications for studies of service substitution. Funding sources may be used to analyze service substitution in utilization impact studies involving multiple funding sources. Programs often deliver treatments to subjects who are using comparable services. Researchers conducting impact studies must differentiate gross

outcomes -- change resulting from treatment effects and extraneous confounding factors -- from the net effects of the treatment. Impact studies control confounding effects statistically or by comparison against a control group (Rossi & Freeman, 1993). The ability to reliably identify funding sources would enable researchers to quantify nonprogram utilization and evaluate service substitution.

Researchers must develop methods of separating service funding sources that are not dependent on verifying standards; investigators frequently do not have access to suitable standards for services delivered outside a program. This study of reporting by primary caregivers of Alzheimer's patients found that respondents did not reliably distinguish between two funding sources. The study also found that researchers cannot rely on demonstration benefit caps or log-transformations to eliminate the effects of nondemonstration sources. The majority of clients who used either demonstration day care or personal care/housekeeping/companion services did not reach their benefit limits, but they clearly used comparable services funded outside the demonstration. Future studies may examine whether people either do not want, or cannot accommodate, services beyond some threshold of perceived need, utilization, or funding level. It is also possible that people assume they will not gain substantial benefits from programs that do not exceed some level of service units or funding.

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Appendix A

Medicare Alzheimer's Disease Demonstration Services

MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION SERVICES

- ADULT DAY CARE
- SKILLED NURSING
- REHABILITATION NURSING
- THERAPY (SPEECH, OCCUPATIONAL, PHYSICAL)
- HOME HEALTH AIDE
- HOMEMAKER/PERSONAL CARE
- HOUSEKEEPING
- GENERAL CHORE (HEAVY CLEANING)
- HOME REPAIRS AND MAINTENANCE
- COMPANION (FRIENDLY VISITING, INCIDENTAL SHOPPING AND ERRANDS, TELEPHONE REASSURANCE)
- COMPANION FOR EDUCATION AND TRAINING (FREES CAREGIVER TO ATTEND EDUCATION/TRAINING CLASSES)
- HOME DELIVERED MEALS
- NON-EMERGENCY TRANSPORTATION FOR CLIENT
- ADAPTIVE AND ASSISTIVE EQUIPMENT
- MEDICAL SUPPLIES
- DURABLE MEDICAL EQUIPMENT
- CONSUMABLE CARE GOODS
- MENTAL HEALTH TREATMENT
- CAREGIVER EDUCATION AND TRAINING
- FAMILY COUNSELING
- CAREGIVER TRANSPORTATION TO SUPPORT GROUPS
- CASE MANAGEMENT
- MEDICAL ASSESSMENT

Source:
Newcomer, R., Fox, P., Yordi, C., Wilkinson, A., Ginther, S., Shoumaker, S., Donatoni, G., & Erskine, L. (1993). Medicare Alzheimer's Disease Demonstration Evaluation. Interim Report to Congress. San Francisco, CA: Institute for Health and Aging. p. v.

Services Verified in the Study

The Medicare Alzheimer's Disease Demonstration Evaluation gave participants access to over 20 community-based services. Caregivers reported on clients' service use in retrospective 6 month interviews. This study verified reported adult day care services and a package of personal care, housekeeping, and companion in-home services. The study examined these services because past studies of proxy reporting emphasized reporting of acute care services, functionality, illness, and symptomology, to the near exclusion of chronic care services. This appendix describes how caregiver reports were matched against claims data for comparison.

Day care and in-home services presented different recall tasks to caregivers. First, the two services shared some service components but not the method of service delivery, a factor that may have affected respondent recall. Adult day care was possibly more straightforward to report. Day care provided a fairly standard set of services at each encounter. Caregivers reporting this service had to recall only the encounter rather than individual service components. Clients left their homes to attend day care. This may have aided recall among caregivers who prepared clients for trips or who scheduled their own errands on day care days. In contrast, in-home services were quite flexible and less predictable from encounter to encounter. Respondents may have found the services conceptually difficult to distinguish from each other because home health aides, homemakers, and companions performed many of the same tasks, and clients often employed two or more of these workers. Some caregivers may have become so accustomed to the presence of outsiders in the home that they did not pay attention to their activities. On the other hand, some respondents may have been highly aware of services that benefited all household members. Second, units of in-home service were probably more difficult to recall or estimate than units of day care service. Caregivers had to distinguish personal care, housekeeping, and companion encounters from each other, and

report each in terms of hours. Day care was reported as days. Caregivers estimated the number of encounters to report units.

Service Descriptions

Adult day care services are designed to help ambulatory individuals who cannot live independently to maximize their existing ability to care for themselves. Clients attended day care at a supervised, licensed center, where they socialized with others in various organized activities. Organized day care programs must offer certain basic services: help with activities of daily living and personal hygiene, a meal having at least one-third of the daily nutritional requirements, social work services, planned activities, and transportation from the clients' home to the center. Some programs may offer rehabilitative therapies or nursing services such as changing dressings or handing out medications. All programs must monitor clients' health and handle medical or health emergencies (Health Care Financing Administration, unpublished).

Personal care, housekeeping, and companion services were provided to demonstration participants in their homes. In-home care services were authorized through the clients' care plan, delivered through a certified agency, and supervised by an appropriate professional such as a registered nurse. Home health aides provided personal care, therapy, and other assistance. Their tasks included changing dressings, routine catheter care, helping or supervising the client with tasks of daily living, and administering medications. Aides prepared meals, did light housekeeping, and laundry (Health Care Financing Administration, unpublished).

Homemaker/personal care providers created a healthy, safe home environment for clients and caregivers. They helped or supervised clients in tasks of daily living, did light housekeeping and laundry, prepared meals, and handled miscellaneous errands (Health Care Financing Administration, unpublished).

Housekeepers performed the same kinds of household tasks as homemaker/personal care workers: light housekeeping, planned shopping, cooked, laundry, and whatever needed to keep a safe, healthy home. Because housekeeping involved the clients' entire living environment, work housekeepers did for clients often helped others living in the same household. The demonstration allowed household members housekeeper benefits as long as housekeepers did not work extra hours to provide services directly to nonclients (Health Care Financing Administration, unpublished).

Chore workers managed tasks ranging from heavy cleaning to household repairs and maintenance. They mopped floors, washed walls and windows, and did major cleaning of bathrooms, kitchens, and appliances. Repair and maintenance jobs included installing grab bars or security locks, minor painting, and wall patching. Repair/chore workers might also fix ramps, change screens, repair weather stripping, and install storm windows (Health Care Financing Administration, unpublished).

Companions helped clients with activities of daily living, shopping, and errands. Companions called clients on the telephone and joined on social events. Companions performed many of the tasks done by housekeepers and personal care aides, but their main goal was not to provide those services as to help clients stay active and keep from feeling socially isolated (Health Care Financing Administration, unpublished).

Matching Services for Comparison

The TAPE data set was generated for billing purposes and the UE data set for tracking service utilization and information on clients and caregivers. Verification studies commonly compare data sets that were meant for other purposes; in fact, administrative records are the recommended verfying criterion for utilization data (Branch, 1992). But the researcher often needs to create the conceptual match between the data sets to allow such

comparisons (Verbrugge, 1989). Some adjustments were made to match the TAPE and UE files by service category, reporting period, and measures of units.

Services were matched across TAPE and UE files by coding services in each file from the Service Use and Transaction Codebook (Appendix G) and pairing like codes across data sets. The table below shows that all service categories are not comparable across data sets. Codes for in-home services match 6 TAPE and 3 UE categories. All in-home service categories were collapsed into a single code for personal care/housekeeping/companion services. It would have been desirable to collapse the TAPE categories into the UE categories, but this was impossible for two reasons. First, the 3 UE categories were difficult to distinguish from each other because the services had overlapping components; and second, the three services were delivered as variable service packages and respondents frequently reported utilization for the entire service package. No adjustments were needed to match day care services across data files.

Service Categories on Demonstration Claims TAPE and UE Data Files

Claims Tape File	UE Data File
Verified as Day Care Services	
adult day care	social day care/adult day care
Verified as Personal Care/Housekeeping/Companion Services	
home health aide	personal care services
homemaker/personal care	homemaker/housekeeping/chore
housekeeping	companion
general chore (heavy cleaning)	
home repairs and maintenance	
companion	

Additional adjustments were needed to allow verification of UE zero-use transactions. The UE file contains transaction reports for every service that clients did or

did not use. Coders prepared utilization code sheets regardless of whether clients used any services. The TAPE only contains transaction records for clients who claimed reimbursement for at least one demonstration service (excluding case management). These TAPE records include zero-use transactions for services that clients did not use. Clients who claimed no demonstration reimbursements do not have any TAPE transaction records. Zero-use transaction records were inserted for clients who used no demonstration services during an eligible month. Once service categories and zero-use transactions were matched across data files, the files were matched by reporting period.

Service periods on the claims TAPE were aggregated to align with service periods in the UE file. TAPE transactions show monthly service use, dated from the first to the last days of the month. UE transactions show service use over 6 months. Demonstration evaluators preferred the longer reporting period to assess the impact of the demonstration over time (Institute for Health and Aging, 1989). UE service periods were calculated in reference to clients' date of randomization into the study (periods could start on any day of the month). Two matches were tried between aggregated TAPE periods and UE periods. One aligned TAPE periods against UE periods that were backdated to the first of the month. The other aligned TAPE periods against unadjusted UE periods. The best alignment was achieved using unadjusted UE periods.

The final preverification cleaning required matching units for verification. Claims TAPE utilization data reports total units of service use and the demonstration reimbursement costs (80% of total costs). UE service use transactions do not contain complete utilization data because interviewers asked respondents for either units *or* costs. UE transactions with units data were retained as reported. UE transactions with costs were converted into equivalent units using the median cost per unit rate by site, as calculated from the TAPE "standard" (reimbursement costs were adjusted up to equal 100% of total costs prior to calculation of median cost / unit). Costs-to-units conversions were calculated by reported funding source code. UE transactions with reported units and UE

transactions with converted units were combined into a single large sample for the analysis of units reporting.

The following table shows that most UE service use transactions report utilization levels, and most of these contain usable units data. Comparatively few transactions report costs only. The far right column indicates the total number of transactions available for units verification, following costs-to-units conversions of those records containing costs data alone.

UE Service Use Records Compared with Records Showing Units, Records Showing Costs, and Records Following Costs-to-Units Conversions

Service / Period	All UE Service Use Records	UE with Units	UE with Costs	UE with Units and with Converted Costs
	N			N % of UE with service use
Baseline Day Care	919	863	18	881 (95.9)
6 month Day Care	655	637	2	639 (97.6)
Baseline Pers Care	1933	1719	64	1783 (92.2)
6 month Pers Care	1475	1364	27	1391 (94.3)

Appendix B

Case Management Models

Medicare Alzheimer's Disease Demonstration Case Management Models

Model A Low-Expenditure Cap	Model B High-Expenditure Cap
Overall "low" ($300) cap on per patient monthly expenditures	Overall "high" ($500) cap on per patient monthly expenditures
1:100 case manager: client ratio	1:30 case manager: client ratio
Provides in-home services including homemaker/chore personal care, home health, skilled nursing, companion, and other services	Same
Provides medical, social, or Alzheimer's adult day care	Same
Other community services, including nonemergency client transportation, caregiver education and training, and caregiver transportation to support groups.	Same

---

Model A sites: New York, Illinois, Tennessee, Oregon
Model B sites: Ohio, West Virginia, Minnesota, Florida

Source:
Newcomer, R., Fox, P., Yordi, C., Wilkinson, A., Ginther, S., Shoumaker, S., Donatoni, G., & Erskine, L. (1993). Medicare Alzheimer's Disease Demonstration Evaluation. Interim Report to Congress. San Francisco, CA: Institute for Health and Aging, University of California. pp. iv-v.

Appendix C

Client and Caregiver Data Contained in Application, Physician Referral, and Interview Forms

Client and Caregiver Data Contained in the Application, Physician Referral, and Interview Forms

	Family Application Form	Physician Referral Form	Intake Interview	Follow-Up Interview
Client Data				
Demographics				
Age, Birthdate	X			
Gender	X			
Marital Status	X			
Education			X	
Ethnicity			X	
Primary Language	X			
Legal Guardian	X			
Income			X	
Home Ownership			X	
Beneficiary Status				
Medicare Coverage	X		X	
Medicaid, date eligible			X	X
HMO			X	X
Other Health Insurance			X	X
Living Arrangements				
Household Composition			X	X
Type of Residence			X	X
Length of Time in Current Residence			X	X
Physical Health				
Diagnosis of Dementia		X		
Other Medical Conditions		X		
Cognitive/Functional Status				
Mini-Mental Status Exam			X	
ADL Impairment			X	X
IADL Impairment			X	X
Reasons for ADL / IADL Impairment (cognitive, physical, both)			X	X
Relationship of Informal Cg			X	X
Unmet Need with ADL /I ADL Tasks			X	X
Utilization of Services				
Hospital			X	X
Nursing Home (SNF, ICF)			X	X
Board & Care/ACFL/ Residential Care			X	X
Other Supportive Housing			X	X
Physician Visits			X	X
Medical Specialists Visits			X	X

	Family Application Form	Physician Referral Form	Intake Interview	Follow-Up Interview
Mental Health Services			X	X
Dental Services			X	X
Adult Day Care/ Social Day Care			X	X
In-Home Respite Care			X	X
Congregate meals			X	X
Home Delivered Meals			X	X
Nursing Service			X	X
Physical/Occupational/ Speech Therapy			X	X
Home Health Aide			X	X
Homemaker/Housekeeping			X	X
Live-in Caregiver			X	X
Companion Services			X	X
Client Education Training			X	X
Client Support Group			X	X
Transportation			X	X
Adaptive & Assistive Equipment			X	X
Medical Supplies/Equipment			X	X
Consumable Care Goods			X	X
Home Modifications			X	X
Medications			X	X
Adult Protective Services			X	X
Case Management Services				
Number of Contacts			X	X
Type of Assistance			X	X
Unmet Service Needs			X	X
Services Not Used Due to Co-Pay				X
Service Satisfaction				
Social Day Care/ Adult Day Care				X
Out of Home Respite Care				X
Personal Care Services				X
Homemaker/Housekeeping				X
Companion Services				X
Case Management				X
Reasons Services Not Utilized				
Social Day Care/ Adult Day Care				X
Out of Home Respite Care				X
Personal Care Services				X
Homemaker/Housekeeping				X
Companion Services				X
Case Management				X

	Family Application Form	Physician Referral Form	Intake Interview	Follow-Up Interview
Caregiver Data				
Demographics				
Age			X	
Marital Status			X	
Education			X	
Income			X	
Health Care Coverage			X	X
Physical Health				
Self-Assessment of General Health			X	X
ADL / IADL Limitations			X	X
Employment				
Current Hours Employed			X	X
Restrictions Due to Cg			X	X
Caregiving				
Length of Time Caregiver				X
Hours Spent Caregiving			X	X
Level of Supervision the Client Needs			X	X
Caregiver Assessment of Client's Dementia			X	X
Caregiver Assessment of Client's Behavioral Problems			X	X
Effects of Caregiving				
Caregiver Stress & Burden			X	X
Caregiver Depression			X	X
Use of Caregiver Support Services				
Mental Health Services			X	X
Education/Training			X	X
Support Group			X	X
Legal/Financial Counseling			X	X
Unmet Need for Services			X	X

Appendix D

Follow-Up Interview Instrument

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION AND RESEARCH PROJECT

6 Month Interview Form

Place Client ID, Client Name, & Caregiver Name. Adress, Phone and Relationship to Client Label Here

(24-38)
(39)

Ascertain whether the caregiver identified in the above label is still a caregiver. If not, terminate this interview and schedule an intake interview with the new primary caregiver.

Change of Information:

Caregiver's Name: _____

Caregiver's Address: _____

_____

Caregiver's Telephone Number: _____

	Date and Time of Interview	Reason for Non-Completion/ Time of Completion
1st Call	_____	_____
2nd Call	_____	_____
3rd Call	_____	_____
4th Call	_____	_____
5th Call	_____	_____
6th Call	_____	_____

Follow-up Interviewer ID __ __ - __ __ __ (40-44)

Circle the current caregiver code:

	6 month	12 month	
Original caregiver	01	02	(45-46)
1st new caregiver	11	12	
2nd new caregiver	21	22	
Closeout interview	31	32	

Date Completed /__ __ /__ __ /__ __/ (47-52)
Month Day Year

IF CLIENT IS DECEASED, CODE LIVING ARRANGEMENT AND RESIDENCE ONE WEEK PRIOR TO DEATH.

I. CLIENT DEMOGRAPHICS

1. What is CLIENT NAME current living arrangement?

Living alone	01	(53-54)
Living in a household with spouse only	02	
Living in a household with spouse and others	03	
Living in a household with relatives	04	
Living in a household w/ non-relatives only	05	
Living in a health-related facility (permanently)	06	
Other: Specify	66	

Don't know	98
Refused	99

2. What is CLIENT NAME current residence?

House	01	(55-56)
Condominium	02	
Apartment	03	
Room: Hotel/House	04	
Mobile home	05	
Senior residential facility	06	
Residential care facility/board & care/adult foster care	07	
Nursing home (convalescent hospital/SNF/ICF) (ASK Qs. 2A-B)	08	
Other: Specify _____	66	
Don't know	98	
Refused	99	

IF CLIENT IS DECEASED OR HAS MOVED OUT OF THE STUDY AREA, SKIP TO PAGE 16 - Q. 33. CODE DATE DECEASED OR DATE MOVED OUT OF AREA ON PAGE 40 OF INSTRUMENT.

ASK QS. 2A-2B ONLY IF CLIENT IS IN A NURSING HOME. IF CLIENT IS PERMANENTLY INSTITUTIONALIZED , THE QUESTION DOES NOT APPLY. CODE Q. 2A AS "977."

2A. How many months do you expect CLIENT NAME will be institutionalized?

Number of months __ __ __ (57-59)

2B. Is this a permanent or temporary nursing home placement?

Permanent	01	(60-61)
Temporary	02	
Does not apply	97	
Don't know	98	
Refused	99	

IF TOTAL EXPECTED NUMBER OF MONTHS THE CLIENT WILL BE INSTITUTIONALIZED IS LESS THAN 1 MONTH, RESCHEDULE INTERVIEW.

IF TOTAL NUMBER OF MONTHS IS GREATER THAN 1 MONTH, CONTINUE INTERVIEW.

3. **Does CLIENT NAME have Medicaid health care coverage?**

Yes (ASK Q. 3A-B)	01	(62-63)
No (SKIP TO Q. 4)	00	
Does not apply (SKIP TO Q. 4)	97	
Don't know (SKIP TO Q. 4)	98	
Refused (SKIP TO Q. 4)	99	

3A. IF YES, what was the month and year CLIENT NAME became eligible?

__ __ __ __ (64-67)
Month Year

ASK Q. 3B ONLY OF TREATMENT GROUP MEMBERS.(CIRCLE "DOES NOT APPLY - 97" IF CLIENT IS IN THE CONTROL GROUP.)

3B. Did the Alzheimer's demonstration case manager help you apply for the Medicaid program?

Yes	01	(68-69)
No	00	
Does not apply	97	
Don't know	98	
Refused	99	

4. **Is CLIENT NAME a member of a Health Maintenance Organization?**

Yes (ASK Q. 4A-B)	01	(70-71)
No (SKIP TO Q. 5)	00	
Does not apply (SKIP TO Q. 5)	97	
Don't know (SKIP TO Q. 5)	98	
Refused (SKIP TO Q. 5)	99	

4A. IF YES, what is CLIENT NAME health plan name:

_____ (72-86)
(CODE "DOES NOT APPLY" AS 97)
(CODE "DON'T KNOW" AS 98)

4B. What is the approximate month and year of CLIENT NAME HMO enrollment?

__ __ __ __ (87-90)
Month Year

ADL PROBES

Transportation out of Walking Distance

- When CLIENT has to travel to places out of walking distance, how does s/he usually get there? (For example, if CLIENT had to go to the doctor today how would s/he get there?)
- Does CLIENT need help in:
  - getting to and from the car/bus/taxi? (including stairs) (2)
  - getting in or out of the car/bus/taxi? (2)
  - does someone always go along with CLIENT? (2)
- If you were not available, could CLIENT go alone by bus or taxi? (1)
- Does CLIENT need special arrangements such as ambulance; specially equipped vehicle; maximum help from one or more people; travel only for medical appointments? (3)

Walking

- Can CLIENT walk indoors without anyone helping him/her? (1)
- Does CLIENT need:
  - support just now and again? (2)
  - just standby supervision? (2)
  - continuous physical support of another person or does not walk? (3)

Wheeling

- Can CLIENT propel the wheelchair indoors by him/herself? (get to the bathroom, kitchen, etc. independently) (1)
- Does CLIENT need help with:
  - locking/unlocking brakes? (2)
  - getting through doorways? (2)
  - getting up and down ramps? (2)
- Is CLIENT pushed on occasion only for longer distances or outdoors? (2)
- Does someone push CLIENT all or most of the time? (3)

Transfers (Bed/Chair)

- Can CLIENT get in/out of bed/chair by him/herself? (1)
- Does CLIENT need:
  - support just now and again (2)
  - standby supervision (2)
  - Does CLIENT have to be lifted by another person? (3)

Grooming

- Can CLIENT comb and shampoo his/her hair by him/herself? (1)
- Can CLIENT shave himself? (1)
- What about taking care of finger nails & toe nails? (1)
- Does CLIENT need help with:
  - any of these activities? (2)
  - some part of the activity? (2)
- Is CLIENT unable to do any of these? (3)

Bathing

- Can CLIENT take his/her own bath? (1)
- Does CLIENT need any help with:
  - getting in/out of tub/shower? (2)
  - turning on or bringing the water? (2)
  - washing any part of the body? (2)
  - towel drying? (2)
  - standby supervision, someone just to be there? (2)
- Does someone have to bathe CLIENT? (3)

Dressing

- Can CLIENT get dressed by him/herself? (1)
- Does CLIENT need any help with:
  - getting clothes from the drawer or closet? (2)
  - putting on pants or shirt? (2)
  - fasteners? (2)
  - shoes? (except for tying shoes) (2)
- Is CLIENT mainly dressed by a helper? (3)
- Does CLIENT often stay partly or completely undressed? (3)

Eating

- Can CLIENT feed him/herself? (1)
- Does CLIENT need help with:
  - cutting meat, buttering bread? (2)
  - opening cartons, pouring liquid? (2)
  - holding glass or cup? (2)
- Does someone feed CLIENT? (3)

Using the Toilet

- Can CLIENT go to the bathroom and use the toilet by him/herself? (1)
- Does CLIENT need help with:
  - getting there? (2)
  - cleaning him/herself? (2)
  - getting on or off the toilet seat? (2)
  - arranging his/her clothes? (2)
- IF CLIENT USES BEDPAN OR COMMODE:
- Does CLIENT need help with this at night or help in disposing of contents? (2)
- Is CLIENT unable to use the bathroom at all? (3)
- Does someone help CLIENT with a bowel or bladder program? (3)
- IF CLIENT HAS CATHETER/OSTOMY:
- Does CLIENT take full care of it? (1)
- Does CLIENT need help with cleaning, changing bag or in disposing of contents? (2)
- Is CLIENT unable to do any of this? (3)

Bowel/Bladder Accidents

- Is CLIENT able to control urination and bowel elimination all the time? (1)
- IF CLIENT HAS BOWEL OR BLADDER ACCIDENTS:
- Does CLIENT have occasional accidents (once a week or less)? (2)
- Is CLIENT incontinent frequently or most of the time (more than once a week)? (3)

II. ACTIVITIES OF DAILY LIVING

5. **Now I would like to ask about CLIENT NAME ability to do some daily activities without help. Even if somebody usually helps, I would like to know if s/he would be able to do the task if s/he had to.**

NEED FOR HELP PROBE: USE ADL PROBES ON THE OPPOSITE PAGE TO DETERMINE THE CLIENT'S NEED FOR HELP. FOR ANY ACTIVITY FOR WHICH THE "NEED FOR HELP" IS CODED "NONE," CODE "REASON FOR HELP," "HELP PROVIDERS," AND "ENOUGH HELP" AS 97 TO INDICATE DOES NOT APPLY.

REASON FOR HELP PROBE: Would you say the primary reason CLIENT NAME needs help with (INSERT EACH ADL) **is due to: mental impairment** (CODE 01), **physical impairment** (CODE 02), **or a combination of mental and physical impairment** (CODE 03)**?**

HELP PROVIDER PROBE: Who is helping CLIENT NAME with (INSERT EACH ADL)**?**

Help Provider Codes

00 = No one else	06 = Son-in-law	12 = Female friend
01 = Primary caregiver	07 = Brother	13 = Grandson
02 = Spouse/spouse equivalent	08 = Brother-in-law	14 = Granddaughter
03 = Daughter	09 = Sister	15 = Other relative
04 = Daughter-in-law	10 = Sister-in-law	16 = Volunteer
05 = Son	11 = Male friend	17 = Paid helper (agency/person)
		97 = Does not apply

ENOUGH HELP PROBE: In your opinion, is CLIENT NAME getting enough help with (INSERT EACH ADL)**?**

	Need for Help			Reason for Help	List up to 3 Help Providers- Write in Codes	Enough Help?			
	None	Some	Max			Yes	No	DNA	
a. Transportation (out of walking distance)	01	02	03	____	___/___/___	01	00	97	(91-102)
b. Walking	01	02	03	____	___/___/___	01	00	97	(103-14)
c. Wheeling (CHECK IF DNA ___)	01	02	03	____	___/___/___	01	00	97	(115-26)
d. Transfers (bed/chair)	01	02	03	____	___/___/___	01	00	97	(127-38)
e. Grooming	01	02	03	____	___/___/___	01	00	97	(139-50)
f. Bathing	01	02	03	____	___/___/___	01	00	97	(151-62)
g. Dressing	01	02	03	____	___/___/___	01	00	97	(163-74)
h. Eating	01	02	03	____	___/___/___	01	00	97	(175-86)
i. Using the toilet	01	02	03	____	___/___/___	01	00	97	(187-98)
j. Bowel/bladder accidents	01	02	03	____	___/___/___	01	00	97	(199-10)

IADL PROBES

Meal Preparation

- Can CLIENT prepare and cook a full meal? (1)
- Can CLIENT manage light snack meals by him/herself? (not a full meal - i.e., breakfast, lunch) (2)
- Can CLIENT prepare any part of the meal him/herself? (2)
- Does CLIENT need help with all/most of meal preparation tasks? (3)

Shopping

- How does CLIENT get groceries?
- Can CLIENT shop for groceries him/herself? (1)
- Does someone go along with CLIENT? (2)
- Can CLIENT order by telephone and then put groceries away when delivered? (2)
- Does CLIENT make his/her own shopping list then have someone purchase, deliver and put away the groceries? (3)
- Does CLIENT need help with all shopping activities? (3)

Routine Housework

- Can CLIENT do all routine housework such as:
  . vacuuming, mopping floors, cleaning kitchen and bathroom? (1)
- Can CLIENT do light housework such as:
  . dusting, tidying up, washing dishes? (2)
- Is CLIENT unable to do housework at all? (3)

Managing Money

- Does CLIENT need help managing his/her own money? (1)
- Does CLIENT need help writing his/her own checks? (2)
- Does CLIENT need help balancing his/her own account? (2)
- Does CLIENT need help paying his/her own bills? Can CLIENT keep track of them? (does all of the above) (2)
- Can CLIENT manage day-to-day purchases? (2)
- Is CLIENT unable to handle money at all? (3)

Doing Laundry

- Can CLIENT launder his/her own clothes? (1)
- Can CLIENT do small items by his/herself? (2)
- Does someone else do CLIENT'S laundry? (3)

Taking Medications

If CLIENT does not currently take medications, try to estimate whether or not help would be needed and code accordingly.

- Can CLIENT take his/her meds by his/herself? (1)
- Does CLIENT need reminders? (2)
- Does anyone set them up for CLIENT? (2)
- Does CLIENT need any one to give him/her his/her medications? (3)

Using the Telephone

- Can CLIENT use the telephone by his/herself? (1)
- Does CLIENT need help with dialing, looking up numbers? (2)
- Is CLIENT completely unable to use the telephone? (3)
- Does CLIENT have vision or hearing problems that prevent him/her from using the phone? (3)

Heavy Chores

- Can CLIENT do the heavy chores around the house such as window washing, gardening, mowing the lawn? (1)
- Who does general repairs?
- Can CLIENT do any of this his/herself? (2)
- Is CLIENT completely unable to do any heavy chores? (3)

III. INSTRUMENTAL ACTIVITIES OF DAILY LIVING

6. **Now I would like to ask about CLIENT NAME ability to do some other daily activities without help. Even if somebody usually helps, I would like to know if s/he would be able to do the task if s/he had to.**

NEED FOR HELP PROBE: USE IADL PROBES ON THE OPPOSITE PAGE TO DETERMINE THE CLIENT'S NEED FOR HELP. FOR ANY ACTIVITY FOR WHICH THE "NEED FOR HELP" IS CODED "NONE," CODE "REASON FOR HELP," "HELP PROVIDERS," AND "ENOUGH HELP" AS 97 TO INDICATE DOES NOT APPLY.

REASON FOR HELP PROBE: Would you say the primary reason CLIENT NAME needs help with (INSERT EACH IADL) **is due to: mental impairment** (CODE 01), **physical impairment** (CODE 02), **or a combination of mental and physical impairment** (CODE 03)**?**

HELP PROVIDER PROBE: Who is helping CLIENT NAME with (INSERT EACH IADL)**?**

Help Provider Codes

00 = No one else	06 = Son in-law	12 = Female friend
01 = Primary caregiver	07 = Brother	13 = Grandson
02 = Spouse/spouse equivalent	08 = Brother in-law	14 = Granddaughter
03 = Daughter	09 = Sister	15 = Other relative
04 = Daughter in-law	10 = Sister in-law	16 = Volunteer
05 = Son	11 = Male friend	17 = Paid helper (agency/perso
		97 = Does not apply

ENOUGH HELP PROBE: In your opinion, is CLIENT NAME getting enough help with (INSERT EACH IADL)**?**

	Need for Help			Reason for Help	List up to 3 Help Providers- Write in Codes	Enough Help?			
	None	Some	Max			Yes	No	DNA	
a. Meal preparation	01	02	03	____	__/__/__	01	00	97	(211-22)
b. Shopping	01	02	03	____	__/__/__	01	00	97	(223-34)
c. Routine housework	01	02	03	____	__/__/__	01	00	97	(235-46)
d. Manage money	01	02	03	____	__/__/__	01	00	97	(247-58)
e. Laundry	01	02	03	____	__/__/__	01	00	97	(259-70)
f. Medications	01	02	03	____	__/__/__	01	00	97	(271-82)
g. Telephone	01	02	03	____	__/__/__	01	00	97	(283-94)
h. Heavy chores/home maintenance	01	02	03	____	__/__/__	01	00	97	(295-06)

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IV. TOTAL CAREGIVING HOURS

7. **How long have you been CLIENT NAME caregiver?**

__ __ __ __ Months (307-10)

IF LESS THAN 6 MONTHS, RECHECK WHETHER THE CAREGIVER IS THE ORIGINAL INTERVIEWEE.

8. **Excluding the hours you spend sitting or visiting with CLIENT NAME, how many hours in an average week do you spend *helping and supervising* CLIENT NAME?** (IF DON'T KNOW,CODE 998; IF REFUSES TO ANSWER CODE 999).

__ __ __ Hours per week (311-13)

9. **And now I'd like to know how many hours in an average week you spend *sitting with or visiting* CLIENT NAME?** (IF DON'T KNOW,CODE 998;IF REFUSES TO ANSWER CODE 999).

__ __ __ Hours per week (314-16)

10. **Excluding the time you spend during an average week, how many hours do other family and friends spend *helping and supervising* CLIENT NAME?** (IF DON'T KNOW, CODE 998; IF REFUSES TO ANSWER CODE 999).

__ __ __ Hours per week (317-19)

11. **Excluding the actual hours other family and friends spend helping and supervising CLIENT NAME, how many hours in an average week do they spend *sitting with or visiting* CLIENT NAME?** (IF DON'T KNOW, CODE 998; IF REFUSES TO ANSWER CODE 999).

__ __ __ Hours per week (320-22)

V. CAREGIVER ASSESSMENT OF CLIENT'S DEMENTIA

12. I am now going to ask you some questions about CLIENT NAME ability to do some other activities. Please indicate whether CLIENT NAME is unable to perform the activity, has some trouble performing the activity or if s/he can perform the activity normally.

	Unable	Some Trouble	Normal	D/K	
First, I'd like to know about CLIENT NAME ability to:					
a. Find his/her way around familiar streets.....	01	.5	00	98	(323-24)
What about CLIENT NAME ability to:					
b. Perform household tasks.....	01	.5	00	98	(325-26)
c. Cope with small sums of money.....	01	.5	00	98	(327-28)
d. Remember short lists of items.....	01	.5	00	98	(329-30)
e. Find his/her way about indoors.....	01	.5	00	98	(331-32)
f. Interpret surroundings (e.g., to recognize whether in a hospital or at home,to discriminate between doctors and nurses, relatives, etc.).....	01	.5	00	98	(333-34)
g. Recall recent events (e.g., recent outings visits of relatives).....	01	.5	00	98	(335-36)

Does CLIENT NAME:	Yes	Somewhat	No	D/K	
h. Tend to dwell in the past?.....	01	.5	00	98	(337-38)

Now I would like some specific information about CLIENT NAME abilities (READ EACH RESPONSE AND CIRCLE THE BEST DESCRIPTION FOR EACH BELOW):

i. Would you say CLIENT NAME eats:

Cleanly with proper utensils.....	00	(339-40)
Messily with spoon only.....	01	
Simple solids, e.g., biscuits....	02	
Has to be fed.....	03	
Don't know.....	98	
Refuses to answer.....	99	

j. Would you say CLIENT NAME dresses:

Unaided.....	00	(341-42)
Occasionally misplaced buttons...	01	
Wrong sequence, commonly forgetting items.....	02	
Unable to dress.....	03	
Don't know.....	98	
Refuses to answer.....	99	

k. Does CLIENT NAME have:

Complete bladder control.....	00	(343-44)
Occasional wet beds.....	01	
Frequent wet beds.....	02	
No control over bowels and bladder.....	03	
Don't know.....	98	
Refuses to answer.....	99	

V. BEHAVIORAL PROBLEMS

13. I am going to read you a list of common behaviors. Please tell me if CLIENT NAME typically does any of these things.

	Yes	No	D/K	
a. Does s/he ask repetitive questions?.....	01	00	98	(345-46)
b. Is s/he suspicious or accusative?.....	01	00	98	(347-48)
Does s/he:				
c. Have trouble recognizing familiar people?.	01	00	98	(349-50)
d. Forget what day it is?.....	01	00	98	(351-52)
e. Do things that embarrass you?.....	01	00	98	(353-54)
f. Wake you up at night?.....	01	00	98	(355-56)
Is s/he:				
g. Constantly restless?.....	01	00	98	(357-58)
h. Constantly talkative?.....	01	00	98	(359-60)
Does s/he:				
i. Relive situations from the past?.....	01	00	98	(361-62)
j. See or hear things that are not there (hallucinations or illusions)?.....	01	00	98	(363-64)
k. Have episodes of unreasonable anger?.....	01	00	98	(365-66)
l. Have episodes of combativeness?.....	01	00	98	(367-68)

				IF NO, Would Occur W/Out Supervision?			
	Yes	No	D/K	Yes	No	DNA	
Does s/he:							
m. Wander or get lost?.....	01	00	98	01	00	97	(369-72)
n. Hide things (money, jewelry)?	01	00	98	01	00	97	(373-76)
o. Lose or misplace things?.....	01	00	98	01	00	97	(377-80)
p. Leave tasks uncompleted?.....	01	00	98	01	00	97	(381-84)
q. Destroy property?.....	01	00	98	01	00	97	(385-88)
r. Engage in behavior potentially dangerous to others?.....	01	00	98	01	00	97	(389-92)
s. Engage in behavior potentially dangerous to (him/her) self?	01	00	98	01	00	97	(393-96)

14. Can CLIENT NAME be safely left alone for more than an hour at a time?

Yes	01	(397-98)
No	02	
Don't know	98	
Refused	99	

15. During a typical week, would you say CLIENT NAME needs:

Minimal supervision	01	(399-00)
Daytime supervision, or	02	
Round-the-clock supervision	03	
Don't know	98	
Refused	99	

VI. PRIMARY INFORMAL CAREGIVER DEMOGRAPHICS

Now I want to ask you some questions about you and your feelings about caring for CLIENT NAME.

16. Are you a member of a Health Maintenance Organization?

Yes (ASK Q. 16A-B)	01	(401-02)
No (SKIP TO Q. 17)	00	
Does not apply	97	
Don't know	98	
Refused	99	

16A. IF YES, what is your health plan name:

_____ (403-17)

(CODE "DOES NOT APPLY" AS 97)
(CODE "DON'T KNOW" AS 98)

16B. What is the approximate month and year of your HMO enrollment?

__ __ __ __ (418-21)
Month Year

17. **How many hours per week do you usually work for pay?** (IF ANSWERED 'HOURS ARE IRREGULAR,' ASK APPROXIMATE AMOUNT. IF "DON'T KNOW," CODE 98. IF CAREGIVER DOES NOT WORK, CODE 00.)

Hours per week __ __ (422-23)

18. **In the last 6 months, because you were taking care of CLIENT NAME have you** (READ AND CIRCLE APPROPRIATE RESPONSE):

	Yes	No	Refused	
a. Had to leave a job	01	00	99	(424-25)
b. Had to turn down a job	01	00	99	(426-27)
c. Had to refuse a more responsible position	01	00	99	(428-29)
d. Been unable to look for a job	01	00	99	(430-31)
e. Had to work fewer hours than you would have liked	01	00	99	(432-33)
f. Had to retire early	01	00	99	(434-35)

IF INTERVIEWEE IS CLIENT'S SPOUSE, SKIP TO SECTION VII AND CODE Qs. 19 AND 19A AS "DOES NOT APPLY - 97," OTHERWISE ASK Qs. 19-19A.

19. **Do you or your family contribute money on a regular basis to CLIENT NAME care?**

Yes (ASK Q. 19A) 01 (436-37)
No (SKIP TO SECTION VII) 00
Does not apply (SKIP TO SECTION VII) 97
Refused (SKIP TO SECTION VII) 99

19A. **Approximately how much do you or your family contribute per month?** (ROUND TO NEAREST DOLLAR: IF "DOES NOT APPLY", CODE 9777; IF "DON'T KNOW", CODE 9888; IF REFUSED, CODE 9999.)

$ __ __ __ __ (438-41)
Per Month

VII. INFORMAL CAREGIVER RESPONSE TO CAREGIVING

A. Caregiver Stress and Burden

INSTRUCTIONS: The following list of statements reflect how people sometimes feel when taking care of another person. After each statement, indicate if you have felt that way, and if so, how often?

20. Do you feel stressed between caring for CLIENT NAME and trying to meet other responsibilities for your family? Would you say ...

Never	00	Quite frequently	03	(442-43)
Rarely	01	Nearly always	04	
Sometimes	02	Does not apply	97	
		Refused	99	

IF CAREGIVER DOES NOT WORK CODE 97 FOR Q21 AND SKIP TO Q22.

21. Do you feel stressed between caring for CLIENT NAME and trying to meet other responsibilities for work? Would you say ...

Never	00	Quite frequently	03	(444-45)
Rarely	01	Nearly always	04	
Sometimes	02	Does not apply	97	
		Refused	99	

22. Do you feel that because of the time you spend with CLIENT NAME that you don't have enough time for yourself? Would you say ...

Never	00	Quite frequently	03	(446-47)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

23. Do you feel angry when you are around CLIENT NAME? Would you say ...

Never	00	Quite frequently	03	(448-49)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

24. Do you feel tense or anxious because of your involvement with CLIENT NAME? Would you say ...

Never	00	Quite frequently	03	(450-51)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

25. Do you feel your health has suffered because of your involvement with CLIENT NAME? Would you say ...

Never	00	Quite frequently	03	(452-53)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

26. Do you feel your social life has suffered because you are caring for CLIENT NAME? Would you say ...

Never	00	Quite frequently	03	(454-55)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

27. Do you feel you have lost control of your life since CLIENT NAME illness? Would you say ...

Never	00	Quite frequently	03	(456-57)
Rarely	01	Nearly always	04	
Sometimes	02	Refused	99	

28. Overall, how burdened do you feel in caring for CLIENT NAME? Would you say....

Not at all	00	Quite a bit	03	(458-59)
A little	01	Extremely	04	
Moderately	02	Refused	99	

B. Caregiver Depression

29. Now I have some questions about how you have been feeling over the past week.

	Yes	No	Refused	
a. Are you basically satisfied with your life?	01	00	99	(460-61)
b. Have you dropped many of your activities and interests?	01	00	99	(462-63)
c. Do you feel your life is empty?	01	00	99	(464-65)
d. Do you often get bored?	01	00	99	(466-67)
e. Are you in good spirits most of the time?	01	00	99	(468-69)
f. Are you afraid that something bad is going to happen to you?	01	00	99	(470-71)
g. Do you feel happy most of the time?	01	00	99	(472-73)
h. Do you often feel helpless?	01	00	99	(474-75)
i. Do you prefer to stay at home, rather than going out and doing new things?	01	00	99	(476-77)
j. Do you feel you have more problems with memory than most people?	01	00	99	(478-79)
k. Do you think it is wonderful to be alive now?	01	00	99	(480-81)
l. Do you feel pretty worthless the way you are now?	01	00	99	(482-83)
m. Do you feel full of energy?	01	00	99	(484-85)
n. Do you feel that your situation is hopeless?	01	00	99	(486-87)
o. Do you think that most people are better off than you are?	01	00	99	(488-89)

VIII. INFORMAL CAREGIVER FUNCTIONAL IMPAIRMENT AND HEALTH STATUS

30. **Because of a health condition or a disability, do you now have any difficulty:** (CIRCLE ONE RESPONSE FOR EACH ITEM.)

	Some Difficulty	No Difficulty	Refused	
a. Preparing meals.....	01	00	99	(490-91)
b. Doing housework.....	01	00	99	(492-93)
c. Doing laundry.....	01	00	99	(494-95)
d. Doing shopping.....	01	00	99	(496-97)
e. Taking medicine.....	01	00	99	(498-99)
f. Traveling out of walking distance.....	01	00	99	(500-01)
g. Managing money.....	01	00	99	(502-03)
h. Using the telephone.....	01	00	99	(504-05)

31. **Because of a health condition or a disability, do you now have any difficulty:** (CIRCLE ONE RESPONSE FOR EACH ITEM.)

	Some Difficulty	No Difficulty	Refused	
a. Eating.....	01	00	99	(506-07)
b. Getting out of bed/chair...	01	00	99	(508-09)
c. Dressing.....	01	00	99	(510-11)
d. Bathing.....	01	00	99	(512-13)
e. Using the toilet.....	01	00	99	(514-15)

32. **Compared to other people your age, would you say that your health is:**

Excellent..... 01 (516-17)
Good..... 02
Fair..... 03
Poor..... 04
Refused..... 99

IX. CAREGIVER/CLIENT SERVICE PROVIDER CHECKLIST

33. Now I'd like to ask you whether you received services from the following types of providers in the last 6 months. (READ EACH SERVICE LISTED AND FOR EACH SERVICE USED, RECORD THE PROVIDER NAME, ADDRESS AND TELEPHONE NUMBER ON THE OPPOSITE PAGE INDICATING TYPE OF SERVICE.)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Total Cost Last 6 Months	
- Mental Health Services (IF YES, LIST NUMBER OF VISITS) (1)	01	00	98	_____	$_____	(518-19)
- Legal/financial counseling (IF YES, LIST # OF HOURS) (4)	01	00	98	_____	$_____	(520-21)
- Transportation (IF YES, LIST # OF ROUND TRIPS)	01	00	98	_____	$_____	(522-23)
- Caregiver Support Group (IF YES, LIST # OF SESSIONS)	01	00	98	_____	$_____	(524-25)

IF "YES" TO "CAREGIVER SUPPORT GROUP" ASK Qs. A1 - A2 FOR THE TREATMENT GROUP. FOR THE CONTROL GROUP SKIP TO Q. A2 AND CODE Q. A1 AS "97-DOES NOT APPLY."

IF "NO," CODE Q. A1 AS "97-DOES NOT APPLY" AND ASK Q. A2

A1. Did you attend a caregiver support group that was offered through the demonstration?

Yes	01	(526-27)
No	00	
Does not apply	97	
Don't know	98	
Refused	99	

A2. Do you currently have a need to attend a caregiver support group?

Yes	01	(528-29)
No	00	
Does not apply	97	
Don't know	98	
Refused	99	

- Education/training (IF YES, LIST # OF SESSIONS) 01 00 98 _____ $_____ (530-31)

IF "YES," TO "EDUCATION AND TRAINING" ASK Qs. B1 - B3.

IF "NO," ASK Qs. B2 - B3.

B1. In the last 6 months have you received education and/or training in any of the following topic areas?

	Yes	No	DNA	D/K		ASK ONLY OF TREATMENT GROUP: Were they provided by the Demo? Yes	No	DNA	D/K	
a. Information about Alzheimer's disease or other dementing diseases?	01	00	97	98	IF YES=>	01	00	97	98	(532-35)
b. Ways to control agressiveness or anger in persons with Alzheimer's disease or related diseases	01	00	97	98	IF YES=>	01	00	97	98	(536-39)
c. Financial and/or legal information such as information on conservatorships or powers of attorney	01	00	97	98	IF YES=>	01	00	97	98	(540-43)
d. Caregiving techniques such as ways to transfer a person from a wheelchair to a bed?	01	00	97	98	IF YES=>	01	00	97	98	(544-47)
e. Home modification such a adding shower grab bars to make it easier to care for a person with dementia?	01	00	97	98	IF YES=>	01	00	97	98	(548-51)
f. Ways to obtain services such as chore workers to help to care for a person with dementia?	01	00	97	98	IF YES=>	01	00	97	98	(552-55)
g. Any other training that I haven't asked you about?: Specify	01	00	97	98	IF YES=>	01	00	97	98	(556-59)

_____

B2. Do you currently need any education and/or training?

Yes (ASK Q. B3)	01	(560-61)
No (SKIP TO Q. 34)	00	
Does not apply (SKIP TO Q. 34)	97	
Refused (SKIP TO Q. 34)	99	

B3. IF YES, in what topic areas?

	Yes	No	DNA	D/K	
a. Information about Alzheimer's disease or other dementing diseases?	01	00	97	98	(562-63)
b. Ways to control agressiveness or anger in persons with Alzheimer's disease or related diseases	01	00	97	98	(564-65)
c. Financial and/or legal information such as information on conservatorships or powers of attorney	01	00	97	98	(566-67)
d. Caregiving techniques such as ways to transfer a person from a wheelchair to a bed?	01	00	97	98	(568-69)
e. Ways to modify a home such a adding shower grab bars to make it easier to care for a person with dementia?	01	00	97	98	(570-71)
f. Ways to obtain services such a chore workers to help you care for a person with dementia?	01	00	97	98	(572-73)
g. Other: Specify	01	00	97	98	(574-75)

_____

_____

Now I would like to ask you some questions about the types of services CLIENT NAME received within the last 6 months.

NOTE: Include all service providers, including volunteers, from which services were received, even if the client or family did not pay for them. Include services provided by family members or friends only if they were paid to provide those services.

34. **First of all, I would like to ask you whether CLIENT NAME received services from the following types of providers within the last 6 months.** (READ EACH SERVICE LISTED AND FOR EACH SERVICE USED, RECORD THE PROVIDER NAME, ADDRESS AND TELEPHONE NUMBER ON THE OPPOSITE PAGE INDICATING TYPE OF SERVICE. ROUND COSTS TO NEAREST DOLLAR.)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available → Total Cost Last 6 Months	
- Hospital Stay(s) (IF YES, LIST # OF ADMISSIONS & BED-DAYS) (A)	01	00	98	_____	$_____	(576-77)
- Nursing Home (SNF/ICF) Stay(s) (IF YES, LIST # OF ADMISSIONS & BED-DAYS) (B)	01	00	98	_____	$_____	(578-79)
- Physician Visits (Family doctor/neurologist/ internist/emergency room/urgent care center, etc.) (IF YES, LIST TYPE OF PHYSICIAN & # OF VISITS) (C)	01	00	98	_____	$_____	(580-81)
- Health Specialists (e.g. podiatrist;chiropractor optomotrist, opthomologist etc.) (IF YES, LIST TYPE of SPECIALIST & # OF VISITS) (D)	01	00	98	_____	$_____	(582-83)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available ↓ Total Cost Last 6 Months	
- Mental Health Services (Psychiatrist, psychologist, social worker, psychiatric nurse, etc.) (IF YES, LIST TYPE & # OF VISITS) (E)	01	00	98	_____	$_____	(584-85)
- Dentist Services (dentist; hygienist, oral surgeon, orthodontist, etc.) (IF YES, LIST TYPE & # OF VISITS) (F)	01	00	98	_____	$_____	(586-87)
- Congregate meals (IF YES, LIST # OF MEALS) (J)	01	00	98	_____	$_____	(588-89)
- Home delivered meals (IF YES, LIST # OF MEALS) (K)	01	00	98	_____	$_____	(590-91)
- Nursing Services (IF YES, LIST # OF VISITS) (L)	01	00	98	_____	$_____	(592-93)
- Physical Therapy (IF YES, LIST # OF VISITS) (M)	01	00	98	_____	$_____	(594-95)
- Speech/Occupational/ Respiratory Therapy (IF YES, LIST TYPE & # OF VISITS) (N)	01	00	98	_____	$_____	(596-97)
- Live-in Caregiver Services (IF YES, LIST # OF DAYS) (Q)	01	00	98	_____	$_____	(598-99)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available ↓ Total Cost Last 6 Months	
- Client Education Training Services (IF YES, LIST # OF SESSIONS)	01	00	98	_____	$_____	(600-01)
- Client Support Group (IF YES, LIST # OF SESSIONS)	01	00	98	_____	$_____	(602-03)
- Transportation Services Ambulance (IF YES, LIST # OF ROUND TRIPS)	01	00	98	_____	$_____	(604-05)
- Transport to health services (taxi, escort services, etc.) (IF YES, LIST # OF ROUND TRIPS)	01	00	98	_____	$_____	(606-07)
- Adaptive and Assistive Equipment (e.g., portable commodes, bathtub seats, window/door locks, etc.) (IF YES, LIST TYPE OF EQUIPMENT)	01	00	98	xxxxxxxxxx	$_____	(608-09)
- Medical Supplies/Equipment (Supplies furnished in conjunction with skilled care, unskilled care, home health aide visits and durable medical equipment). (IF YES, LIST TYPE OF SUPPLY)	01	00	98	xxxxxxxxxx	$_____	(610-11)
- Consumable Care Goods (e.g., catheters, supplies related to incontinence) (IF YES, LIST TYPE OF GOODS)	01	00	98	xxxxxxxxxx	$_____	(612-13)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available ↓ Total Cost Last 6 Months	
- Modifications to home (e.g., safety grabs and railings, raised toilet seats, etc.) (IF YES, LIST TYPE OF MODIFICATIONS)	01	00	98	xxxxxxxxxx	$_____	(614-15)
- Medications (DO NOT INCLUDE OVER-THE-COUNTER DRUGS)	01	00	98	xxxxxxxxxx	$_____	(616-17)
- Adult Protective Services (IF YES, RECORD EXPENDITURES ONLY)	01	00	98	xxxxxxxxxx	$_____	(618-19)
- Other services: Specify	01	00	98	_____	$_____	(620-21)

_____

_____

SERVICE USE AND SATISFACTION INSTRUCTIONS

In the following questions we are interested in knowing whether the services have been used in the last 6 months and your satisfaction with them. Your responses will in no way affect your services.

		Service Received? Yes	No	D/K	IF YES, # of Last 6 Mos.	Only Complete If # of Services is not Available → Total Cost Last 6 Months	
-	Social day care/adult day care service (IF YES, LIST TYPE & # OF DAYS) (G)	01	00	98	_____	$._____	(622-23)

IF "NO" TO "SOCIAL DAY CARE" ASK Q. C1.

IF "YES" CODE Q. C1 AS "97-DOES NOT APPLY" AND ASK QUESTIONS C2 - C8.

C1. Why didn't you use adult day care? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(624-25)
b.	The service was not needed.....	01	00	97	98	(626-27)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(628-29)
d.	The application process was too difficult.....	01	00	97	98	(630-31)
e.	The waiting list for the service was too long.	01	00	97	98	(632-33)
f.	You couldn't afford the service.....	01	00	97	98	(634-35)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(636-37)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(638-39)
i.	There was a transportation problem.....	01	00	97	98	(640-41)
j.	The quality of the service was poor.....	01	00	97	98	(642-43)
k.	Any other reason?: Specify.....	01	00	97	98	(644-45)

_____

_____

INSTRUCTIONS: Now I will read you a statement and I would like you to respond by indicating whether this never, sometimes, usually or always was the case for this service in the last 6 months.

C2. **You could depend on the adult day care staff to pick up CLIENT NAME on time** (IF TRANSPORTATION WAS NOT PROVIDED BY THE DAY CARE CENTER CODE "97-DOES NOT APPLY).

Never	01	(646-47)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C3. **The adult day care staff knew what to do and did it with little or no supervision from you.**

Never	01	(648-49)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C4. **You could communicate adequately with the adult day care staff** (PERSON WHO PROVIDED "HANDS ON" ASSISTANCE).

Never	01	(650-51)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C5. **The adult day care services were offered at times that were convienient.**

Never	01	(652-53)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C6. **The adult day care services were available for as many weeks as they were needed.**

Never	01	(654-55)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C7. **The adult day care services were available for as many hours per week as they were needed.**

Never	01	(656-57)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

C8. **Overall, how satisfied are you with the adult day care services you received? Would you say you are:**

Very satisfied	01	(658-59)
Satisfied	02	
Dissatisfied	03	
Very dissatisfied	04	
Does not apply	97	
Don't know	98	
Refused	99	

IF "Dissatisfied" OR "Very Dissatisfied" WAS THE RESPONSE FOR THE PREVIOUS QUESTION, ASK QUESTION C9, OTHERWISE CODE "97" AND SKIP TO "Out-of-home respite."

C9. **Could you please explain why you were dissatisfied with the service?**

_____ (660-61)

_____ (662-63)

_____ (664-65)

_____ (666-67)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available V Total Cost Last 6 Months	
- Out-of-home respite other than adult day care (e.g., hospital or nursing home respite beds) (IF YES, LIST # OF DAYS) (DD)	01	00	98	_____	$_____	(668-69)

IF "NO" TO "OUT-OF-HOME RESPITE" ASK Q. D1.

IF "YES" CODE D1 AS "97-DOES NOT APPLY" AND SKIP TO "Home health aide."

D1. Why didn't you use out-of-home respite? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(670-71)
b.	The service was not needed.....	01	00	97	98	(672-73)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(674-75)
d.	The application process was too difficult.....	01	00	97	98	(676-77)
e.	The waiting list for the service was too long.	01	00	97	98	(678-79)
f.	You couldn't afford the service.....	01	00	97	98	(680-81)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(682-83)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(684-85)
i.	There was a transportation problem.....	01	00	97	98	(686-87)
j.	The quality of the service was poor.....	01	00	97	98	(688-89)
k.	Any other reason?: Specify.....	01	00	97	98	(690-91)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If No Service Info. Available V Total Cost Last 6 Months	
- Personal Care Services (a person who provides help with bathing, grooming, dressing and toileting) (IF YES, LIST # OF HOURS) (O)	01	00	98	_____	$_____	(692-93)

IF "NO" TO "PERSONAL CARE SERVICES" ASK Q. E1.

IF "YES" CODE E1 AS "97-DOES NOT APPLY" AND ASK QUESTIONS E2 - E9.

E1. Why didn't you use personal care services? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(694-95)
b.	The service was not needed.....	01	00	97	98	(696-97)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(698-99)
d.	The application process was too difficult.....	01	00	97	98	(700-01)
e.	The waiting list for the service was too long.	01	00	97	98	(702-03)
f.	You couldn't afford the service.....	01	00	97	98	(704-05)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(706-07)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(708-09)
i.	There was a transportation problem.....	01	00	97	98	(710-11)
j.	The quality of the service was poor.....	01	00	97	98	(712-13)
k.	Any other reason?: Specify.....	01	00	97	98	(714-15)

INSTRUCTIONS: Now I will read you a statement and I would like you to respond by indicating whether this never, sometimes, usually or always was the case for this service in the last 6 months.

E2. You could depend on the personal care staff to arrive on time.

Never	01	(716-17)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E3. The personal care staff were polite and courteous.

Never	01	(718-19)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E4. The personal care staff knew what to do and did it with little or no supervision from you.

Never	01	(720-21)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E5. You could communicate adequately with the personal care staff

Never	01	(722-23)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E6. The personal care services were offerred at times that were convienient.

Never	01	(724-25)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E7. **The personal care services were available for as many weeks as they were needed.**

Never	01	(726-27)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E8. **The personal care services were available for as many hours per week as they were needed.**

Never	01	(728-29)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

E9. **Overall, how satisfied are you with the personal care services you received? Would you say you are:**

Very satisfied	01	(730-31)
Satisfied	02	
Dissatisfied	03	
Very dissatisfied	04	
Does not apply	97	
Don't know	98	
Refused	99	

IF "Dissatisfied" OR "Very Dissatisfied" WAS THE RESPONSE FOR THE PREVIOUS QUESTION, ASK QUESTION E10, OTHERWISE CODE "97" AND SKIP TO "Homemaker/Housekeeping Services."

E10. **Could you please explain why you were dissatisfied with the service?**

_____ (732-33)

_____ (734-35)

_____ (736-37)

_____ (738-39)

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available ↓ Total Cost Last 6 Months	
- Homemaker/Housekeeping Chore Services (IF YES, LIST # OF HOURS) (P)	01	00	98	_____	$_____	(740-41)

IF "NO" TO "HOMEMAKER/HOUSEKEEPING CHORE SERVICES" ASK Q. F1.

IF "YES" CODE Q. F1 AS "97-DOES NOT APPLY" AND ASK QUESTIONS F2 - F9.

F1. Why you didn't you use homemaker chore services? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(742-43)
b.	The service was not needed.....	01	00	97	98	(744-45)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(746-47)
d.	The application process was too difficult.....	01	00	97	98	(748-49)
e.	The waiting list for the service was too long.	01	00	97	98	(750-51)
f.	You couldn't afford the service.....	01	00	97	98	(752-53)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(754-55)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(756-57)
i.	There was a transportation problem.....	01	00	97	98	(758-59)
j.	The quality of the service was poor.....	01	00	97	98	(760-61)
k.	Any other reason?: Specify.....	01	00	97	98	(762-63)

INSTRUCTIONS: Now I will read you a statement and I would like you to respond by indicating whether this never, sometimes, usually or always was the case for this service in the last 6 months.

F2. You could depend on the homemaker/chore staff to arrive on time.

Never	01	(764-65)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F3. The homemaker/chore staff were polite and courteous.

Never	01	(766-67)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F4. The homemaker/chore staff knew what to do and did it with little or no supervision from you.

Never	01	(768-69)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F5. You could communicate adequately with the homemaker/chore staff.

Never	01	(770-71)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F6. The homemaker/chore services were offered at times that were convienient.

Never	01	(772-73)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F7. **The homemaker/chore services were available for as many weeks as they were needed.**

Never	01	(774-75)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F8. **The homemaker/chore services were available for as many hours per week as they were needed.**

Never	01	(776-77)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

F9. **Overall, how satisfied are you with the homemaker/chore services you received? Would you say you are:**

Very satisfied	01	(778-79)
Satisfied	02	
Dissatisfied	03	
Very dissatisfied	04	
Does not apply	97	
Don't know	98	
Refused	99	

IF "Dissatisfied" OR "Very Dissatisfied" WAS THE RESPONSE FOR THE PREVIOUS QUESTION, ASK QUESTION F10, OTHERWISE CODE "97" AND SKIP TO "Companion services."

F10. **Could you please explain why you were dissatisfied with the service?**

_____ (780-81)

_____ (782-83)

_____ (784-85)

_____ (786-87)

Only Complete If # of Services is not Available

	Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Total Cost Last 6 Months	
- Companion Services (IF YES, LIST # OF HOURS) (R)	01	00	98	_____	$_____	(788-89)

IF "NO" TO "COMPANION SERVICES" ASK Q. G1.

IF "YES" CODE G1 AS "97-DOES NOT APPLY" AND ASK QUESTIONS G2 - G9.

G1. Why didn't you use companion services? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(790-91)
b.	The service was not needed.....	01	00	97	98	(792-93)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(794-95)
d.	The application process was too difficult.....	01	00	97	98	(796-97)
e.	The waiting list for the service was too long.	01	00	97	98	(798-99)
f.	You couldn't afford the service.....	01	00	97	98	(800-01)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(802-03)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(804-05)
i.	There was a transportation problem.....	01	00	97	98	(806-07)
j.	The quality of the service was poor.....	01	00	97	98	(808-09)
k.	Any other reason?: Specify.....	01	00	97	98	(810-11)

INSTRUCTIONS: Now I will read you a statement and I would like you to respond by indicating whether this never, sometimes, usually or always was the case for this service in the last 6 months.

G2. You could depend on the companion staff to arrive on time.

Never	01	(812-13)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G3. The companion staff were polite and courteous.

Never	01	(814-15)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G4. The companion staff knew what to do and did it with little or no supervision from you.

Never	01	(816-17)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G5. You could communicate adequately with the companion staff.

Never	01	(818-19)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G6. The companion services were offered at times that were convienient.

Never	01	(820-21)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G7. **The companion services were available for as many weeks as they were needed.**

Never	01	(822-23)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G8. **The companion services were available for as many hours per week as they were needed.**

Never	01	(824-25)
Sometimes	02	
Usually	03	
Always	04	
Does not apply	97	
Don't know	98	
Refused	99	

G9. **Overall, how satisfied are you with the companion services you received? Would you say you are:**

Very satisfied	01	(826-27)
Satisfied	02	
Dissatisfied	03	
Very dissatisfied	04	
Does not apply	97	
Don't know	98	
Refused	99	

IF "Dissatisfied" OR "Very Dissatisfied" WAS THE RESPONSE FOR THE PREVIOUS QUESTION, ASK QUESTION G10, OTHERWISE CODE "97" AND SKIP TO "Case management services."

G10. **Could you please explain why you were dissatisfied with the service?**

_____ (828-29)

_____ (830-31)

_____ (832-33)

_____ (834-35)

_____ (836-37)

		Service Received? Yes	No	D/K	IF YES, # of Services Last 6 Mos.	Only Complete If # of Services is not Available V Total Cost Last 6 Months	
-	Case management services (Service coordination and client monitoring) (IF YES, LIST # OF CONTACTS) (i)	01	00	98	_____	$_____	(838-39)

IF "NO" TO "CASE MANAGEMENT SERVICES" ASK Q. H1 THEN SKIP TO Q. 35.

IF "YES" CODE Q. H1 AS "97-DOES NOT APPLY" AND ASK Qs. H2-H5.

H1. Why didn't you use case management services? (CIRCLE ALL THAT APPLY):

		Yes	No	DNA	D/K	
a.	CLIENT NAME was too ill/disabled to use them..	01	00	97	98	(840-41)
b.	The service was not needed.....	01	00	97	98	(842-43)
c.	The service was not available/unknown to caregiver.....	01	00	97	98	(844-45)
d.	The application process was too difficult.....	01	00	97	98	(846-47)
e.	The waiting list for the service was too long.	01	00	97	98	(848-49)
f.	You couldn't afford the service.....	01	00	97	98	(850-51)
g.	You could afford the service but did not want to pay for it.....	01	00	97	98	(852-53)
h.	CLIENT NAME or caregiver didn't like the service/could not adapt.....	01	00	97	98	(854-55)
i.	There was a transportation problem.....	01	00	97	98	(856-57)
j.	The quality of the service was poor.....	01	00	97	98	(858-59)
k.	Any other reason?: Specify.....	01	00	97	98	(860-61)

_____

_____

NOTE: FOR TREATMENT GROUP MEMBERS, FOCUS THE FOLLOWING QUESTIONS ON THE DEMONSTRATION CASE MANAGEMENT SERVICES.

H2. **How often did the case manager contact you by phone in the last 6 months?** (IF NO CASE MANAGEMENT WAS RECEIVED, CODE AS 977.)

Number of contacts __ __ __ (862-64)

H3. **How often did the case manager contact you in-person in the last 6 months?** (IF NO CASE MANAGEMENT WAS RECEIVED, CODE AS 977.)

Number of contacts __ __ __ (865-67)

H4. **How often did you contact your case manager in the last 6 months?** (IF NO CASE MANAGEMENT WAS RECEIVED, CODE AS 977.)

Number of contacts __ __ __ (868-70)

H5. **How satisfied are you with the case management services you have received in the last 6 months? Would you say you are:**

Very satisfied	01	(871-72)
Satisfied	02	
Dissatisfied	03	
Very dissatisfied	04	
Does not apply	97	
Don't know	98	
Refused	99	

IF "Dissatisfied" OR "Very Dissatisfied" WAS THE RESPONSE FOR THE PREVIOUS QUESTION, ASK QUESTION H6, OTHERWISE CODE "97" AND SKIP TO Q. 35.

H6. **Could you please explain why you were dissatisfied with the service?**

_____ (873-74)

_____ (875-76)

_____ (877-78)

_____ (879-80)

ASK OF TREATMENT GROUP ONLY:

35. **Now I would like to ask you whether you or CLIENT NAME have had any of the following types of problems in the last 6 months. Did you have any problem:** (READ EACH PROBLEM TYPE):

PROBLEM	Yes	No		ASK ONLY IF CLIENT RECEIVED CASE MGMT. Did your CM help you with the problem? Yes	No	DNA	
a. Obtaining services in the community.....	01	00	IF YES=>	01	00	97	(881-84)
b. Obtaining training for how to care for CLIENT NAME physical needs.....	01	00	IF YES=>	01	00	97	(885-88)
c. With service providers not showing up when scheduled.....	01	00	IF YES=>	01	00	97	(889-92)
d. With service providers giving poor quality services.....	01	00	IF YES=>	01	00	97	(893-96)
e. Obtaining information about dementia such as Alzheimer's disease such as symptoms and the course of the disease.....	01	00	IF YES=>	01	00	97	(897-00)
f. Obtaining emotional support.....	01	00	IF YES=>	01	00	97	(901-04)
g. Getting other family members involved in CLIENT NAME care.....	01	00	IF YES=>	01	00	97	(905-08)
h. Obtaining nursing home placement or discharge for CLIENT NAME.....	01	00	IF YES=>	01	00	97	(909-12)
i. With other things?: Specify.....	01	00	IF YES=>	01	00	97	(913-16)

IF CLIENT IS IN A NURSING HOME. SKIP Qs. 36 AND 36A AND CODE "97-DOES NOT APPLY." IF CONTROL GROUP INTERVIEW, THIS IS THE END OF THE QUESTIONNAIRE.

X. SERVICE UTILIZATION

36. Are there any services that would make it easier for you to care for CLIENT NAME at home? These could be more of the services that you are currently using or services that you are not now recieving.

Yes (ASK Q. 36A)..... 01 (917-18)
No (SKIP TO Q. 37)..... 00
Does not apply (SKIP TO Q. 37)... 97
Don't know (SKIP TO Q. 37)..... 98
Refused (SKIP TO Q. 37)..... 99

ARE ANY CLARIFYING REMARKS PROVIDED ON THE BACK OF THIS PAGE? IF YES, CODE 100. IF NO, CODE 000 IF DOES NOT APPLY CODE 977.

__ __ __ (919-21)

36A. What are these services? (DO NOT READ LIST. COMPLETE SERVICE CODES DURING EDITING. FOR ANY SERVICE CATEGORIES LEFT BLANK CODE 97):

Service Codes

01	Day Care Services	02	In-home Respite Care
03	Nursing Services	04	Speech/Occupational/Voc. Ther.
05	Home Health Aide/Personal Care	06	Heavy Chore Services
07	Housekeeping/Homemaker Serv.	08	Companion for Educa. & Training
09	Companion Services	10	Transport. Serv. (non-emergency)
11	Home Delivered Meals	12	Medical Supplies
13	Adaptive and Assistive Equipment	14	Consumable Care Goods
15	Durable Medical Equipment	16	Caregiver Education & Training
17	Mental Health Services	18	Case Management
95	Other Service not provided by Demonstration	97	Does not apply
		98	Don't know

	Service Name	Service Code	
Service one	_____	__ __	(922-23)
Service two	_____	__ __	(924-25)
Service three	_____	__ __	(926-27)
Service four	_____	__ __	(928-29)
Service five	_____	__ __	(930-31)
Service six	_____	__ __	(932-33)
Service seven	_____	__ __	(934-35)

ASK THE FOLLOWING QUESTIONS OF THE TREATMENT GROUP ONLY. FOR THE CONTROL GROUP, SKIP TO QUESTION 38.

(936-37)
LEAVE BLANK

37. Are there any services the case manager recommended you use that you decided not to use because of the co-payment requirement?

Yes (ASK Q. 37A)	01	(938-39)
No	00	
Does not apply	97	
Don't know	98	
Refused	99	

37A. IF YES, what were those services?

Service Codes

01	Day Care Services	02	In-home Respite Care
03	Nursing Services	04	Speech/Occupational/Voc. Ther.
05	Home Health Aide/Personal Care	06	Heavy Chore Services
07	Housekeeping/Homemaker Serv.	08	Companion for Educa. & Training
09	Companion Services	10	Transport. Serv. (non-emergency)
11	Home Delivered Meals	12	Medical Supplies
13	Adaptive and Assistive Equipment	14	Consumable Care Goods
15	Durable Medical Equipment	16	Caregiver Education & Training
17	Mental Health Services	18	Case Management
95	Other Service not provided by Demonstration	97	Does not apply
		98	Don't know

	Service Name	Service Code	
Service one	_____	__ __	(940-41)
Service two	_____	__ __	(942-43)
Service three	_____	__ __	(944-45)
Service four	_____	__ __	(946-47)

38. If client is deceased, record date of death:

/__ __ /__ __ /__ __/ (948-53)
Month Day Year

39. If client moved out of area, record date moved:

/__ __ /__ __ /__ __/ (954-59)
Month Day Year

40. **Caregiver's Name (The person who asked the caregiver stress and burden questions):** (960-974)
(975-989)
(990)

_____/_____/_____
Last Name (First Name) (MI)

41. **Caregiver's ID Number:** __ __ - __/ __ __ __ __ - __ __ (991-999)

(IF CAREGIVER IS THE SAME AS ON LABEL, USE ID # ON LABEL. IF CAREGIVER IS DIFFERENT, PLACE A STAR ON THE FRONT PAGE AND LEAVE ID # ABOVE BLANK)

INTERVIEWER COMMENTS:

Appendix E

Record Specification for Tape Criterion

1/24/90

RECORD SPECIFICATION

FILE NAME: HISTORY FILE
RECORD NAME:

DATE: 01/16/90

SYSTEM IDENTIFICATION:
ALZHEIMER'S DEMONSTRATION

CONTACT:

FIELD NAME	PICTURE TP	SZ	US DEC	SIZE	POSITION BEG	END	CONTENTS / REMARKS
HIC-NO	X	12			1	12	Medicare Health Insurance Claim No.
STMT-COVERS-PERIOD							
FROM-DT	9	6			13	18	Bill From Date (YYMMDD)
THRU-DT	9	6			19	24	Bill Thru Date (YYMMDD)
TYPE-LAST-ACTION	X	1			25	25	Type of Last Action 1 - Original 2 - Positive Adjustment 3 - Negative Adjustment 4 - Replacement 5 - Cancel
NAME							
LAST	X	13			26	38	Patient Last Name
FIRST	X	12			39	50	Patient First Name
MI	X	1			51	51	Patient Middle Initial
STATUS-CODE	X	1			52	52	Patient Status Code A - Withdraw B - Deceased C - Still Patient D - Terminated for Non-payment of Co-insurance
SITE-ID	X	5			53	57	MODEL ALZIL - A ALZOH B ALZOR - A ALZFL B ALZNY - A ALZTN - A ALZMA B ALZMB B ALZMC B ALZNY B

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9 = Numeric

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H or C = C Comp (binary)
C3 = Comp-3 Packed Decimal

RECORD SPECIFICATION

FILE NAME: HISTORY FILE
RECORD NAME.

DATE: 01/16/90

SYSTEM IDENTIFICATION:
ALZHEIMER'S DEMONSTRATION

CONTACT:

FIELD NAME	PICTURE TP	SZ	US	DEC SIZE	POSITION BEG	END	CONTENTS / REMARKS
MED-IND	X	1			58	58	Medicare / Medicaid Indicator 1 - Medicare 2 - Medicaid
MEDICAID-NO	X	15			59	73	Medicaid Number
DOR	9	6			74	79	Date of Receipt (YYMMDD)
SERVICES							
SN-101-UNIT	9	3	V	2	80	84	Skilled Nursing Visits
SN-101-TCHRG	9	4	V	2	85	90	Skilled Nursing Total Charges
SN-101-ACHRG	9	3	V	2	91	95	Skilled Nursing Allowed Charges
RN-102-UNIT	9	3	V	2	96	100	Rehabilitation Nursing Visits
RN-102-TCHRG	9	4	V	2	101	106	Rehabilitation Nursing Total Charges
RN-102-ACHRG	9	3	V	2	107	111	Rehabilitation Nursing Allowed Charges
TS-103-UNIT	9	3	V	2	112	116	Therapy Services Visits
TS-103-TCHRG	9	4	V	2	117	122	Therapy Services Total Charges
TS-103-ACHRG	9	3	V	2	123	127	Therapy Services Allowed Charges

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FILE NAME: HISTORY FILE
RECORD NAME:

DATE: 01/16/90

SYSTEM IDENTIFICATION:
ALZHEIMER'S DEMONSTRATION

CONTACT:

FIELD NAME	PICTURE TP	SZ	US	DEC SIZE	POSITION BEG	END	CONTENTS / REMARKS
HH-104-UNIT	9	3	V	2	128	132	Home Health Aide Hours
HH-104-TCHRG	9	4	V	2	133	138	Home Health Aide Total Charges
HH-104-ACHRG	9	3	V	2	139	143	Home Health Aide Allowed Charges
HC-105-UNIT	9	3	V	2	144	148	Homemaker/Personal Care Hours
HC-105-TCHRG	9	4	V	2	149	154	Homemaker/Personal Care Total Charges
HC-105-ACHRG	9	3	V	2	155	159	Homemaker/Personal Care Allowed Charges
HK-106-UNIT	9	3	V	2	160	164	Housekeeping Hours
HK-106-TCHRG	9	4	V	2	165	170	Housekeeping Total Charges
HK-106-ACHRG	9	3	V	2	171	175	Housekeeping Allowed Charges
EP-107	9	3	V	2	176	180	Adaptive Equipment - Physical Disability - No Units
EP-107-TCHRG	9	4	V	2	181	186	Adaptive Equipment Total Charges
EP-107-ACHRG	9	3	V	2	187	191	Adaptive Equipment Allowed Charges
EC-108	9	3	V	2	192	196	Adaptive Equipment - Cognitive Disability - No Units
EC-108-TCHRG	9	4	V	2	197	202	Adaptive Equipment Total Charges
EC-108-ACHRG	9	3	V	2	203	207	Adaptive Equipment Allowed Charges

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RECORD SPECIFICATION

FILE NAME: HISTORY FILE
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SYSTEM IDENTIFICATION:
ALZHEIMER'S DEMONSTRATION

CONTACT:

FIELD NAME	PICTURE TP	SZ	US	DEC SIZE	POSITION BEG	END	CONTENTS / REMARKS
MS-109	9	3	V	2	208	212	Medical Supplies (No Units)
MS-109-TCHRG	9	4	V	2	213	218	Medical Supplies Total Charges
MS-109-ACHRG	9	3	V	2	219	223	Medical Supplies Allowed Charges
DM-110	9	3	V	2	224	228	Durable Medical Equipment (No Units)
DM-110-TCHRG	9	4	V	2	229	234	Durable Medical Equipment Total Charges
DM-110-ACHRG	9	3	V	2	235	239	Durable Medical Equipment Allowed Charges
CI-111	9	3	V	2	240	244	Consumable Care Goods (Incontinent Supplies) (No Units)
CI-111-TCHRG	9	4	V	2	245	250	Consumable Care Goods (Incontinent Supplies) Total Charges
CI-111-ACHRG	9	3	V	2	251	255	Consumable Care Goods (Incontinent Supplies) Allowed Charges
CA-112	9	3	V	2	256	260	Consumable Care Goods - All Other (No Units)
CA-112-TCHRG	9	4	V	2	261	266	Consumable Care Goods - All Other - Total Charges
CA-112-ACHRG	9	3	V	2	267	271	Consumable Care Goods - All Other - Allowed Charges
MH-113-UNIT	9	3	V	2	272	276	Mental Health Hours
MH-113-TCHRG	9	4	V	2	277	282	Mental Health Total Charges
MH-113-ACHRG	9	3	V	2	283	287	Mental Health Allowed Charges
CG-114-UNIT	9	3	V	2	288	292	Chore - General - Hours
CG-114-TCHRG	9	4	V	2	293	298	Chore - General - Total Charges

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RECORD SPECIFICATION

FILE NAME: HISTORY FILE
RECORD NAME:

DATE: 01/16/90

SYSTEM IDENTIFICATION:
ALZHEIMER'S DEMONSTRATION

CONTACT:

FIELD NAME	PICTURE TP	SZ	US	DEC SIZE	POSITION BEG	END	CONTENTS / REMARKS
CG-114-ACHRG	9	3	V	2	299	303	Chore - General Allowed Charges
CR-115-Unit	9	3	V	2	304	308	Chore - Repair & Maintenance - Hours
CR-115-TCHRG	9	4	V	2	309	314	Chore - Repair & Maintenance Total Charges
CR-115-ACHRG	9	3	V	2	315	319	Chore - Repair & Maintenance Allowed Charges
CM-116-UNIT	9	3	V	2	320	324	Companion Hours
CM-116-TCHRG	9	4	V	2	325	330	Companion Total Charges
CM-116-ACHRG	9	3	V	2	331	335	Companion Allowed Charges
TP-117-UNIT	9	3	V	2	336	340	Transportation - Participant - One Way Trips
TP-117-TCHRG	9	4	V	2	341	346	Transportation - Participant Total Charges
TP-117-ACHRG	9	3	V	2	347	351	Transportation - Participant Allowed Charges
HM-118-UNIT	9	3	V	2	352	356	Home Delivered Meals
HM-118-TCHRG	9	4	V	2	357	362	Home Delivered Meals Total Charges
HM-118-ACHRG	9	3	V	2	363	367	Home Delivered Meals Allowed Charges
FC-119-UNIT	9	3	V	2	368	372	Family Counseling Hours
FC-119-TCHRG	9	4	V	2	373	378	Family Counseling Total Charges
FC-119-ACHRG	9	3	V	2	379	383	Family Counseling Allowed Charges

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RECORD SPECIFICATION									
FILE NAME: HISTORY FILE RECORD NAME:								DATE: 01/16/90	
SYSTEM IDENTIFICATION: ALZHEIMER'S DEMONSTRATION								CONTACT:	
FIELD NAME	PICTURE					POSITION		CONTENTS / REMARKS	
	TP	SZ	US	DEC	SIZE	BEG	END		
AD-120-UNIT	9	3	V		2	384	388	Adult Day Care - Days	
AD-120-TCHRG	9	4	V		2	389	394	Adult Day Care Total Charges	
AD-120-ACHRG	9	3	V		2	395	399	Adult Day Care Allowed Charges	
CE-201-UNIT	9	3	V		2	400	404	Companion - Education & Training - Hours	
CE-201-TCHRG	9	4	V		2	405	410	Companion - Education & Training Total Charges	
CE-201-OCHRG	9	3	V		2	411	415	Companion - Education & Training Outside Cap Charges	
TC-202-UNIT	9	3	V		2	416	420	Transportation - Caregiver - One-way Trips	
TC-202-TCHRG	9	4	V		2	421	426	Transportation - Caregiver - Total Charges	
TC-202-OCHRG	9	3	V		2	427	431	Transportation - Caregiver - Outside Cap Charges	
MA-203	9	3	V		2	432	436	Medical Assessment - No Units	
MA-203-TCHRG	9	4	V		2	437	442	Medical Assessment - [redacted] Total Charges	
MA-203-OCHRG	9	3	V		2	443	447	Medical Assessment - [redacted] Outside Cap Charges	
GT-999-UNIT	9	3	V		2	448	452	Grand Total Units	
GT-999-TCHRG	9	4	V		2	453	458	Grand Total Charges	
GT-999-ACHRG	9	3	V		2	459	463	Grand Total Allowed Charges	
GT-999-OCHRG	9	3	V		2	464	468	Grand Total Outside Charges	
PROC-DATE	9	6				469	474	Process Date of Last Action (YYMMDD)	
FILLER	x	46				475	520	Spaces	

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Appendix F

Guide to the Service Use and Transaction Codebook

Guide to the Service Use and Transaction Codebook

The Service Use and Transaction Codebook identifies 34 types of medical and social health services utilized by demented clients and their caregivers. A broad service code classifies each service type such as hospital, nursing home, or physician services. The broad codes correspond to specific service use items in the interview schedule (Appendix D). Each service code includes one or more service subcodes. Subcodes supply more detailed information about the service type. Service subcodes were developed from write-in comments and other provider information that caregivers reported to interviewers. Data coders assigned subcodes whenever possible to permit finer distinctions within broad service categories. Subcodes too small to allow meaningful analysis may be collapsed into the broad category without double-counting units or expenditures.

Funding source codes were derived from caregivers' identification of service providers and of payment sources for services. These codes differentiate demonstration from nondemonstration payment sources in the UE data file. Funding source codes do not appear in the TAPE data file, which contains data only on services funded through the demonstration. Funding source codes were originally meant to identify both the type of funding source (demonstration, Medicare, Medicare hospice, volunteer, private pay, or other public programs) and data source (interview, billing records, clinical records). In practice, funding source codes identify only funding source because coders recorded all follow-up and utilization data from caregiver interviews.

Funding source codes accommodate multiple funding sources within a service code. Caregivers usually identified a single payment source for a service, but many caregivers secured a service through a variety of demonstration and nondemonstration funding channels. Coders recorded separate service transactions for each funding source. Funding source codes, like service subcodes, may be collapsed without double-counting units or expenditures.

Coding for funding source codes was biased towards undercounting the demonstration funding code. Coders assigned the demonstration funding code only to services that caregivers reported as demonstration funded. We did not assume that services obtained from a demonstration provider were necessarily funded by the demonstration, because the demonstration contracted out services from providers who accepted both demonstration and nondemonstration payments. Clients who received services from a demonstration provider would have had to purchase services out-of-pocket if they exceeded their benefit cap for the month. Case managers also related that some caregivers continued to purchase out-of-pocket services that their benefits would have covered. These individuals, mistakenly thinking they could save unused benefits, wanted to purchase services they could afford and save demonstration benefits in case of catastrophic needs.

This study did not need the range of possible funding source codes, so funding codes were collapsed within service categories to separate demonstration from nondemonstration sources from each other. Services reported as demonstration funded retained the demonstration funding source code. All other funding codes were collapsed into a single code for nondemonstration funding.

Appendix G

Service Use and Transaction Codebook

MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION

Service Use and Transaction Codes

General Medicare Information

Medicare Part A, Hospital Insurance: To enroll in Part A the applicant must be 65 years or older, a United States resident, either a citizen or legal alien admitted for permanent residence who has been in the country continuously for the 5 years immediately preceding the month of application to enrollment, and eligible for Social Security or railroad retirement benefits. Someone aged 65 or over who does not meet Social Security or railroad requirements may enroll by paying premiums. Someone under 65 is eligible if entitled to Social Security, railroad retirement disability benefits, or end-stage renal disease benefits.

Federal government employees are not eligible for Medicare (see paragraph 1116, p. 730), but they must enroll in Part B.

Medicare Part B, Physician and Other Professional Services: Someone entitled to Part A benefits may enroll in Part B if that person is 65 or older, a resident of the United States, and either a citizen or legal alien admitted for permanent residence who has been in the country continuously for the 5 years immediately preceding the month of application to enrollment. Parts A and B are distinct and independent from each other, so a person may enroll in Part B and not be eligible for Part A benefits. Part B coverage begins on the first day of the enrollment month if enrollment occurred in the first month of the person's special enrollment period, or on the first day of the following month if enrollment occurs within a month after the first month of a person's special enrollment period. Coverage ends when the person dies or is terminated (i.e., does not pay premiums).

HOSPICE BENEFITS: are for terminal patients (6 months or less survival expected). To get hospice benefits, patient must *GIVE UP MOST OTHER MEDICARE BENEFITS*. This election is revocable. Patient must choose a specific hospice program.

Medicare Secondary Payer Program (MSP): Medicare payment may not be made to the extent that payment was made/can be expected to be made promptly under worker's compensation, auto or liability insurance, or employee's health insurance. Here Medicare responsibility is secondary.

Question 41 (Intake Interview), Question 34 (Follow-up): Client Service Check List

a. Hospital Services

Code Inpatient services in **DAYS**.

In General, services rendered by non participating hospital usually not paid for unless it's emergency outpatient or inpatient services. Will then pay until it is no longer necessary from a medical standpoint to care for the patient in that institution.

Note: instrument asks for the number of hospital bed days and admissions. When an interviewer has recorded only one of these items, it may be impossible to determine if days or units have been recorded. We only code days. Therefore, if only "1" or "2" is written in the units space, DO NOT CODE -- we do not want to underestimate days if the 1 or 2 is meant to be admissions. Do code costs.

0100 Inpatient, services unspecified.

0101 Inpatient, medical.

During 1989, Part A covered an unlimited number of inpatient hospital days/year, with a once a year deductible.

0102 Inpatient, surgery. (Code inpatient surgery dates, units, and hospital cost here. Physician costs and units are coded separately under 0390).

0103 Inpatient, psych (by psychiatrists). Inpatient hospitalization limited to 190 days in patient's lifetime under Part A (see book for certain restrictions).

Part B covers for expenses accruing in one calendar year: $1,375 or 62% (which ever is less) of reasonable charges including the coinsurance and deductible amounts. This applies to Dr services, without distinguishing between psych and nonpsych doctors. Services of other providers (e.g., SNF, home health agency) are not subject to the special psych limitation.

0104 Partial hospitalization, psych.

Part B covers only if patient would have otherwise needed inpatient psych care. Covers individual and grp therapy with Drs, psychologists, or other authorized mental health professionals; occupational therapy; family counseling; drugs and biologicals if not self-administered; services of social workers, trained psych nurses, and other trained staff; patient training and education.

0105 Christian Science sanatoria.

This service can qualify as a hospital and a SNF; covered by Parts A & B. Sanatoria nursing services, bed and board, some supplies used in Chris. Sci. healing are covered. Chris. Sci. practitioner, Chris. Sci. nursing service, and Chris. Sci. nursing home not covered.

b. Nursing Home Services

Code in **DAYS**.

Note: Some interviewers identify all services provided by nursing home (e.g., personal care, 1300; nursing care, 1100, etc) and some do not. Code all services listed by interviewer.

When Nursing home and hospitalization days overlap: Hospitalized nursing home clients may have overlapping hospital and nursing home days because the client pays to keep his nursing home bed while in the hospital. Code all hospitalization and nursing home costs and units.

0200 Any skilled nursing home stay (includes rehabilitation residence).
SNF is covered under Part A. Nursing care must either be provided or supervised by an RN. In 1989, patients were covered 150 days/yr. No prehospitalization requirement. Coinsurance payment required only for the lst 8 days of coverage. Inpatient or SNF can get Part B coverage for diagnostic X-rays, radiological therapy, supplies for reduction of fractures and dislocations when payment can't be made under Part A.

0201 Any non-skilled or custodial nursing home stay. Custodial Care is institutional care that is other than skilled. It includes assistance with tasks of daily living and is usually done by nonmedical personnel.
In general, this care is not covered under Medicare. This care will be covered for SNF patients if they need daily skilled nursing or skilled rehabilitation. If a patient's stay in a hospital or SNF is custodial, SOME services may be covered under Part B (e.g., physician services, X-rays). Custodial care not covered under Medicare may be covered under Hospice benefits.

0202 Custodial care at psychiatric hospitals is covered under Medicare only if it will probably improve patient's condition; it is given only when patient is admitted, or receiving treatment or diagnostic tests.

0203 Inpatient hospice. Includes hospice unit of hospital or nursing home as well as free-standing hospices Multidisciplinary care provided in an inpatient setting emphasizing comfort, pain control, and palliation of physical symptoms for persons who no longer have a realistic hope for cure. Spiritual counseling and bereavement counseling for family members is also often provided. These services should be coded in that section.(0204).

0204 Inpatient Respite, nursing home. This is a temporarily provided, 24-hour care to enable a primary caregiver a rest for the caregiver. Inpatient respite provided by a private home should be coded as 2701.

c. Physician Services

Code using **VISIT** as the unit, except for inpatient and outpatient surgeries, and diagnostic and treatment procedures See below for code instructions. *To get Part B Coverage: patient must get services directly from doctor, intern, or resident.* ***Physician Service=diagnosis; therapy; surgery; consultation; when***

Dr reads X-rays, electrocardiograms, tissue samples, etc. *According to Part B, physician services are covered within the US and may be performed in an office, institution, the scene of an accident, or the patient's home. Patient's home is where he lives: home for aged, nursing home, relatives' home, etc. (see Medicare book for comments on care received in foreign countries.)*

0300 Location or doctor type not specified (e.g., hospice).

0310 Primary Care Office Visit.
This may include some specialists (e.g., gynecologists). Code as primary care visit if client lists as primary care doctor. An office visit listed on billing statements should be coded as 0310 if there is no other information which would identify it as a specialist visit (e.g., consults). Office visits listed nearby specialist procedures (e.g.,.cystoscopy. refraction, bronchoscopy, etc.) should be coded under the appropriate specialist office visit category.
Flu shots should be coded here.

0311 Routine Physical Exam.
All routine screening procedures & tests in connection with routine physicals are not covered under Part B, however, Pap smears are covered.

0312 Dr. to patient service over telephone. *Part B does not cover.* Code office visits and phone services separately because phone services are not Medicare reimbursable.

0318 Surgeon.

0319 Neurosurgeon.

0320 Other Specialist Office Visit (excludes Neurologists and Ophthalmologist).
Part B covers consultations. Consultation must include history, examination, and written report.

0321 Neurologist Office Visit.

0322 Ophthalmologist visit (code eye surgery here rather than 0318).
Ophthalmologists perform eye surgeries, therefore, code eye surgeons here rather than 0318.

0323 Diagnostic and Treatment procedures conducted in MD office.
Code **all same day** diagnostic and treatment procedures together as ONE ENCOUNTER and record on one transaction line (Code 0411, laboratory tests; 0412, X-rays; 0413, nuclear medicine procedures; and 0414, surgical pathology separately).

0330 Ambulatory Care Center. Visits or tests identified only as "outpatient" should also be coded as 0330.

0331 Diagnostic and Treatment procedures conducted in Clinic.
Code **all same day** diagnostic and treatment procedures together as ONE ENCOUNTER and record on one transaction line
Code kidney dialysis here.
(Code 0411, laboratory tests; 0412 & 0413, X-rays; 0414, surgical pathology; 0415, EEG; 0416, nuclear medicine procedures; and 0417, EKG separately).

0340 Emergency Medical Services (EMS).

0341 Diagnostic and Treatment procedures conducted in EMS.
Code **all same day** diagnostic and treatment procedures together as ONE ENCOUNTER and record on one transaction line (Code 0411, laboratory tests; 0412, X-rays; 0413, nuclear medicine procedures; and 0414, surgical pathology separately).

0350 Home Visit. *Dr's periodic visits covered under Part B if necessary to treatment of patient.. Hospice benefits cover physician services (e.g.,. services to alleviate symptoms, pain. NOT curative).*

0360 Nursing Home Visit. *Dr's periodic visits covered under part B if necessary to treatment of patient.*

0370 Outpatient Surgery.
Includes procedures such as cataract removal-lens implants and skin lesion removals.
Code all same day procedures into separate encounters, code each as one unit; separately code all physician fees. All other fees (e.g., supplies, laboratory, treatments) should be assigned as appropriate to inpatient and other service categories. Same day procedures will be consolidated by computer into a single unit; and into single summed amount.
Surgical services requiring a 2nd opinion will not be paid under Part B if the 2nd opinion is not obtained. Surgery for cataract removal/lens replacement is covered under Part B when provided by a hospital in connection with Dr's treatment. Coverage includes facility, services of nurses, nonphysician anesthetists, psychologists, technicians, therapists, and other aides.

0380 Inpatient Visit.
If a Dr reads an X-ray already read by another, it would be covered under Part B if a direct service to the patient; by Part A if for quality control. If an attending Dr reads an X-ray after a hospital Dr has read it (radiologist or cardiologist]), it's not covered.

0390 Inpatient Surgery. **Code all same day procedures into separate**

encounters, code each as one unit; separately code all physician fees. All other fees (e.g., supplies, laboratory, treatments) should be assigned as appropriate to inpatient and other service categories. Same day procedures will be consolidated by computer into a single unit; and into single summed amount. *Surgical services requiring a 2nd opinion will not be paid under Part B if the 2nd opinion is not obtained. Surgery for cataract removal/lens replacement is covered under Part B when provided by a hospital in connection with Dr's treatment. Coverage includes facility, services of nurses, nonphysician anesthetists, psychologists, technicians, therapists, and other aides..*

0391 Cosmetic surgery.
Not covered under Part B unless necessary for reconstructive purposes

d. Other Non-Physician Medical Specialties

0400 Specialist Not Specified.

0401 Audiologist (diagnostic testing).
This is covered by Part B when part of diagnosis (e.g., to determine if surgery or medical treatment needed). Code audiologist visits as 0401 unless specified as hearing aid testing.

0402 Hearing Aid testing by audiologist or MD.
Hearing aid testing not covered by Medicare Part B regardless of whether it is done by an audiologist or an MD. Hearing aids themselves not covered under Medicare Part B (per audiologist at UCSF audiology dept.).

0403 Chiropractor. *Manipulations are covered under Part B, but the chiropractor's X-rays are not.*

0404 Optometrist. *Routine eye exams and eye exams to fit glasses, glasses, and eye refraction are not covered under Part B unless it's done as part of a service for disease or injury. Prosthetics are covered.*

0405 Podiatrist. Routine foot care (removing corns, calluses, clipping nails, soaks). *These are not covered unless it has because patient has circulation problems (e.g., diabetic). Services that are part of covered services (e.g., care of ulcers, wounds, and infections for a diabetic) are covered under Part B Treatment of warts is also covered.*

0406 Osteopath is *covered under Part B.*

0407 Christian Scientist practitioners, naturopaths *not covered under Part B.*

Auxiliary Personnel and Services

0408 Physician Assistant/Nurse Practitioner.

0409 Certified Registered Nurse Anesthetist.

0410 Other Auxiliary Personnel covered as "incident". These covered as "incident" to physician services. Incident=direct personal supervision by physician (e.g., being in office).Examples: paramedics and EMTs. Includes specialty technicians, such as someone who takes pacemaker readings over the phone.

0411 Laboratory tests.
Laboratory work covered under Part B, but not those connected with routine physicals. **Count each laboratory test as one unit; but total all same day procedures and record them on one transaction date.** Do not count venipuntures as a unit, but include venipuncture cost and the cost for all other tests in the total cost for the transaction date. Include all laboratory work here, whether inpatient or outpatient, surgical or non-surgical.

0412 Radiology: X-rays; IVPs
Part B covers skeletal films (pelvis, extremities, vertebral column, skull, chest, abdomen) not using contrast media. Portable X-rays are generally covered., although certain procedures are ***not:*** *fluoroscopy, procedures using contrast media, routine screening procedures* **Count each X-ray as one unit** (even X-rays associated with hospitalization or surgery to be coded here).
Mammograms and angiographies are included in X-rays. **Sum and record all same day X-rays into units and expenditures on that transaction date.**

0413 Radiology not including X-rays.
Includes procedures such as MRI, NMR, CT (CAT), and PET scans.
Code **all same day** procedures together and record on one transaction line.

0414 Surgical Pathology (e.g., surgical specimen, biopsies).
Code **all same day** procedures together and record on one transaction line.

0415 EEG.

0416 Nuclear Medicine procedures.
Includes procedures such as brain scans and bone scans Some procedures may be indistinguishable from 0413 services.
Nuclear medicine procedures are provisionally coded from intake and follow-up instruments. Positive identification will be made when claims forms and data tapes are available. These will be checked for the procedure and the radioactive label used.

0417 EKG (same as ECG)

e. Mental Health Providers (Code Psychiatrists here). Code using visits as the unit. *Medical social services under home health: counseling covered only as incidental to patient's covered items. Family counseling not covered. Hospice benefits: cover counseling to patient and family. Does NOT cover bereavement counseling. Hospice: Covered up to 80 hrs/yr when provided by a home health agency. Patient must be chronically dependent, lives with caregiver, and needs help with at least 2 activities of daily living (eating, dressing, etc.).* Mental health services include evaluation and treatment of functional and organic disorders; assessment of social and emotional factors related to health status; assistance coping with disease process; supportive counseling in regard to diagnosis, prognosis, and limitations imposed by illness. Bereavement counseling should also be coded under 0500 codes.

0500 Unspecified mental health provider.

0501 Psychiatrist, drug monitoring visits. Part B will not cover psychiatrist visits that are only for drug monitoring or changes when the Dr does not provide these services directly to the patient.

0502 Psychiatrist, all other visits. Generally outpatient psychotherapy is not covered under Medicare. Code psychiatrist visits as 0502 unless specified as drug monitoring visit.

0503 Psychologist.
This can be covered under Part B as incident to Dr services (e.g., psychologist tests). Diagnostic services of an independently practicing psychologist covered as "other diagnostic tests" if a DR orders. Psychologist in risk-basis HMOs and CMPs can be covered when provided without DR supervision. Can also be covered when provided at a community mental health center. ***Psychotherapy by privately practicing psychologist not covered.*** -- Include individual counseling only.

0504 Psychiatric Nurse -- individual counseling.

0505 Social Worker (counseling) -- individual counseling.

0506 Counseling center not included in above -- but for individual counseling

0507 Group counseling not included in above. These include sessions with the patient and family members as well as other types of group counseling situations. The counseling may be provided by any of the professional noted above.

0508 Mental health service received through phone call.

*Bereavement counseling should be coded under appropriate 0500 code.

f. Dental Service

Each Visit is coded as a single episode. Code each dental procedure as a separate procedure, total all same day procedures and record as one transaction..

For combination visits (e.g., cleaning [0602] and filling [0601]), code one unit for each procedure. For example, a visit for a routine cleaning and a filling should be coded 1 unit 0602 and 1 unit 0601.

0600 Dental visit, reason unspecified

0601 Procedural visits. These include fillings, crown replacements, root canals, denture repairs etc. *Dentures are excluded* unless part of a covered prosthesis

Code oral surgeons as 0601 rather than as 0318

0602 Routine visits. These include exam, cleaning, and prophylaxis; routine X-rays; adjustments of dentures. *This work is covered under Part A only if patient must be hospitalized to do the work.*

0603 Dental work that is part of a medical procedure. *Part B-coverage is available for: (l). with respect to surgery to facial structures below eyes; (2). reduction of jaw, facial fractures; (3). services that would be covered if a regular Dr . did (e.g., treat infection).* ***Outpatient surgery is Not covered:*** *services involving teeth or their supporting structures is not covered unless it's done as part of services that are covered.*

g. Adult Day Care

Code unit by **DAYS** of care. *This is an eligible service under terms of the Alzheimer's demonstration.* Unless the service is expressly specified as Day Health Care, code as Social Day Care.

Some interviewers are recording informal socializing, such as potlucks, Church affairs, and quilting circles. These are not day care services -- do not code at all.

0700 Day health care. Adult day health care means an "organized day program of therapeutic, social, and health activities and services provided pursuant to this chapter . . . for the purpose of restoring or maintaining optimal capacity for self-care" (CA Adult Day Health Care Act Guidelines, 1977). These services are more organized and structured than senior center programs. These programs may include PT, OT, and ST. If this service component is known, code these separately.

Lambert House (OR) and Volunteers of America (OH) are two providers which provide day health care.

Baths given at a day care center should be coded as 1300.

Do not code haircuts, manicures, or pedicures.

0701 Social day care. Includes all other day care not coded above.

h. In-Home Respite Care (Individuals and Agencies)

Units: **HOURS** for follow-up questionnaires; **DAYS** for intake forms (equivalent hour units for intake forms will be determined at a later date).

0800 Any in-home respite care. Defined same as inpatient respite.

Note: Follow-up questionnaires may have in-home respite written under companion services (1600) because there is no question specifically addressing in-home respite. A 1600 service which has been identified as respite should be coded as 0800.

i. Case Management (Coordination and Monitoring)

Count the Number of Encounters for any of the following types of case management activity (e.g., such as assessment visits, care planning, consultations) during the start date/end date period. In coding list the total number of encounters during the period. When using questionnaire reported information that does not have specific start date/end date information, record the number of encounters over a six month period. If the case coordination activity is unspecified and the number of encounters is unspecified, code as one unit of unspecified case management per month of active case management during the indicated time period. *Medical social services resolves social or emotional problems that impede effective treatment or rate of recovery. Part A covers inpatient and SNF medical social services. Medical social services also covered under Hospice benefits. Some state Medicaid programs also cover case management. This is a covered benefit in the demonstration.* Case management includes individualized assessment and planning to coordinate community-based services. There are two basic types of case management. (1) Routine management of non problematic cases on a sporadic basis. Management may be intensive for periods of time, but the problems are at least resolvable within a reasonable period, e.g.,, six months or less. (2) Intensive case management includes a comprehensive assessment of social, financial, supportive, psychiatric, medical and environmental components of the patient's situation; ongoing coordination of services for the patient (e.g., applying for SSI or Medicaid, obtaining a physician, etc.); periodic reassessments -- perhaps as often as monthly; a home visit reassessment at least every 6 months.

0900 Care coordination (unspecified). *Medical social workers not covered to help with Medicaid applications.*

0901 Routine Case Management, number of encounters defined as above.

This would include Medical social services -- assessment s of social/emotional factors related to illness, assistance with financial services/resources, assistance to

obtain needed community services, assistance with long term care placement and coordination of services.

0902 Intensive Case Management, number of encounters defined as above. Demonstration services are intensive by definition. See Pam Webber for a list of the intensive case management programs in each study area.

Case management on FOLLOW-UP interviews should be coded from pg. 37. Code the SUM of questions H2 and H3.

j/k Meals

CODE AS NUMBER OF MEALS per reported start date -- end date transaction period. *Part B does not cover meals for psych patients undergoing partial hospitalization.*

1000 Congregate meals. Nutritional meals served in a centrally located social setting.

1001 Home meals. This includes preparation, packaging and delivery of one or more meals for participant who are unable to prepare or obtain nourishing meals. *This service can be covered by the demonstration program.*

1002 Special food formulas (brand name examples: Ensure, Isocal, Osmolite).

l. Nursing Services

This service refers to outpatient visits and private duty nurses for inpatients. It does not include the nursing care routinely available for inpatients and clinic users. Code each visit as one unit. Code as skilled unless otherwise specified.

A nurse family member working for free should not be coded (informal service). Do code a nurse family member who does receive pay.

1100 Skilled nursing services. *Part B covers blood drawing and EKGs done at place of residence for homebound or institutionalized patient. Just picking up sputum or urine specimens not covered. Hospice benefits cover nursing care supervised by an RN. The demonstration program also covers skilled nursing -- Medicare criteria such as the intermittent care and homebound requirements do not apply.*

1101 Any other nursing service. This can include public health nursing, i.e., services aimed at prevention, health protection, promotion and early detection or problems. It also includes health counseling, education, monitoring of health status, information and referral, support and adjustment to altered health conditions and risk reduction. Services related to case management should be coded in that category.

1102 Private duty nurse/attendants. This is excluded under Part A.
Note-private nurses are paid by the hour. We should code as number of visits (given in instrument). Conversion to hours will be made later.

m/n Physical / Speech / Occupational / Respiratory Therapy

Code each session as one unit; and therapies as "skilled" unless otherwise specified. *Skilled services for inpatient of hospital covered under Part A. Skilled services for inpatient of SNF covered under Part A post-hospitalization extended care benefits. SNF may also provide outpatient physical or speech therapy, which is covered under Part B. Inpatients of SNF may have physical therapy covered under B if their A benefits have been exhausted. Physical, occupational, speech therapy are also covered under Hospice benefits and under the Alzheimer's demonstration. All services must be performed by qualified therapists.*

1200 Skilled physical therapy. This is skilled evaluation and treatment of functioning in areas such as range of motion, strengthening, endurance, muscle tone, pain, balance, transfers, and mobility to increase level of function in daily living.

1202 Skilled speech therapy. Evaluation and instruction in communication, language, voice intelligibility, comprehension, cognitive rehabilitation (orientation, reasoning, attention, memory).

1204 Skilled occupational therapy. Evaluation and training / education in ADL, IADL function, energy conservation, muscle re-education, etc.

1205 VA and other Work Programs (Clients work for half minimum wage).
Examples: VA work program; IL Human Resources Center sheltered workshop and school; IL Shelby County mental health rehab (pay for piecework).
Code as DAYS.

1206 Skilled respiratory therapy.
(Rehabilitation Nursing Services are those services designed to assist in carrying out a physician's plan of treatment for rehabilitation. They must be performed by an RN with specialized training in rehabilitation services in order to qualify for the demonstration program payment).

1208 Speech/Occupational/Respiratory Therapy (Undifferentiated)

o Home Health Aide / Personal Care Services

The primary functions of a home health aide are to perform therapeutic, supportive and/or compensatory health and personal care tasks and activities for participant in their homes. This care must be provided by a certified home health agency and assigned and performed under the supervision of a registered professional nurse.

Services include such personal care as hygiene, self-care activities, ambulation and transfers, assistance with nutritional and dietary needs, safe and sanitary environment. Aide usually has had specialized training. CODE ONE HOUR AS ONE UNIT. *Part B home health covers an unlimited number of visits, without coinsurance or deductibles. However, if person is enrolled under Part A and B, then Part A pays. Home health agencies are covered under B but not under A. This service is also covered under the Alzheimer's Demonstration.* **Home health care services, as a general category of care, should be into the component services of skilled nursing, personal care, physical therapy, occupational therapy, and speech therapy.**

1300 Services as adjunct to skilled care. Covers activities that directly support skilled therapy. ***Covered:*** *patient or intermittent care by or supervised by an RN (e.g., trained home health aide is covered). Physical, occupational, speech therapy. Medical social services under Dr's direction. Medical supplies, durable medical equipment. Any of these services provided on an outpatient basis. Drugs and biologicals* ***NOT Covered,*** *HOWEVER, the services of a licensed nurse who gives meds may be covered if it is necessary (e.g.., IVs, injections, IV feedings, oral meds only if patient's condition and the kinds of meds require nurse). Also covered: Catheter changes, wound and ostomy care, heat treatments, rehab nursing, venipuncture to collect specimens. Nursing services not covered when administering oral meds, eye drops/ointments.* ***Conditions:*** *Dr must certify patient is homebound. Patient must be under care of physician. Physician here is an MD, osteopath, or podiatrist.*

Any other aide or personal care. *Covers personal care, simple dressing changes not requiring a licensed nurse, routine care of prosthetic/orthotic devices.*

Baths given at a day care center should be coded as 1300.
Do not code haircuts, manicures, or pedicures done at day care.

Home health services/aides are covered under Hospice benefits. Code one hour as one unit. (Also code as 1300).

p. Homemaker/Housekeeping / Chore Services

1400 Any homemaker/housekeeping/chore services. This service is intended to provide assistance with IADLs and general home maintenance. Include also attendant care/personal care and homemaking usually over a longer period than homemaker/chore services. The latter may or may not be supervised by a

professional, may or may not have specialized training. *Hospice Benefits cover: homemaker, home health aide, personal care services, nursing care by licensed professional nurse covered.* Code service by hours.

q. Live-in Caregiver Services

1500 Any live-in service. Code one day as one unit.

Note-some interviewers are reporting 1500 for clients living in a 2700 situation. Code only the 2700, NOT the 1500. 1500 is only for caregivers living with the client in the client's home.

r. Companion Services

Companion services include: friendly visiting, incidental shopping and errands, telephone reassurance and incidental assistance with activities of daily living. They also include accompanying a participant to and from medical appointments, shopping , banking and other personal errands, and various socialization activities. Other duties include providing supervisory and supportive services to maintain the health and safety of a participant when the caregiver needs a period of relief or is unable to provide care. The demonstration allows reimbursement for this service. It can be provided either by individual providers or agencies.

1600 Any companion services not coded elsewhere. CODE EACH HOUR AS ONE UNIT

1601 Companion for Education and Training. The distinction between this and the preceding, is that the service is provided when the caregiver leaves the home to receive education and training provided by the demonstration. This service is a covered benefit under the demonstration.

s. Client Education / Training

1700 Any formal education/training received. Code each session as one unit.

t. Client support group

1800 Any support group. Code each session as one unit.

Note: If a client reports purchasing books, seeing videos, etc. in lieu of attending education/training classes or support groups, DO NOT CODE. ONLY CODE ACTUAL SESSIONS ATTENDED.

u. Transportation Services Not Health Related

Code each trip as one unit (e.g., round trip = 2 units); sum all units for the transaction period. This can include taxi or van service for patients unable to use other modes of transportation due to mobility impairments, shortness of breath, weakness, pain, etc.

1900 Any such transportation service. *These are not covered under Medicare.* Transportation to day care should be coded as 1900.

v. Transportation to Health Services

Code each trip as one unit (e.g., round trip = 2 units); sum all units for the transaction period. This can include taxi or van service for patients unable to use other modes of transportation due to mobility impairments, shortness of breath, weakness, pain, etc.

2000 Ambulance service. *Medicare Part B Covers ambulances provided by ambulatory surgical centers, and emergency services (there are vehicle and crew requirements); also required that other transportation is medically contradicted and that the transportation is to a local destination/closest hosp to required services.*

2001 Any such transportation service, other than ambulance. *Transportation for psychiatric patients undergoing partial hospitalization is not covered under Part B. Nor is transportation to outpatient services.*

2002 Transportation service, type unspecified.

w. Adaptive and Assistive Equipment

Code each piece of equipment as one unit (e.g., bathtub bars=1 unit), and sum all units for the given transaction period.

2100 Total all such equipment into a single dollar amount

x. Medical Supplies / Durable Medical Equipment.

2200 Durable medical equipment=things capable of repeated use -- primarily for a medical purpose.

Durable medical equipment (DME), rented or purchased (whether inpatient or outpatient) is covered by Part B. If furnished by supplier or service provider, DME is covered by Part A. For outpatients, Podiatry: shoes and orthotics not covered unless an integral part of a leg brace. For SNF inpatient, Part B covers prosthetic devices, braces. Examples of material suitable for homebound patient (gel pads, H20 mattresses, heat lamps covered). Oxygen in home covered under Part B.

2100-2200 equipment overlap, and different interviewers are writing in the same equipment in both categories. We will standardize our coding accordingly:

2100 ADAPTIVE-ASSISTIVE

portable commode
bathtub seat
cane
bed rail
wheel chair transfer belt
special mattress
hand-held shower head
hearing aids
eyeglasses
ID bracelets
door locks

2200 DURABLE MEDICAL
hospital bed
hoyer lift/hydraulic lift
lift for wheelchair or scooter
walker
infusion machine
leg braces
oxygen equipment
whirlpool bath
wheelchair
sphygmometer
blood glucose reader (e.g., Acucheck)
nebulizer

DO NOT CODE
phone answering machine
water filters

2201 Medical Supplies. *Medicare covers supplies, appliances, equipment (e.g., splints, dressings, Posey restraints, oxygen) in hospitals and SNFs (If the SNF usually supplies these items). Equipment and supplies a SNF gives to patient to use outside the facility is not covered. Comfort items like elevators, posture chairs, radio, TV, hairdresser not covered. Wigs (even for cancer patients) not covered.*

Coverage for breast prostheses appear to be determined on a case-by-case basis; not uniformly covered.

2202 Durable Medical Equipment or Medical Supplies not separately specified.

y. Consumable Care Goods

2300 Basic personal service (shampoo, shaves, etc.) that are seen as ordinary patient care is covered when the patient cannot perform these functions and these are provided by the institution they are in. *If these services are included in the flat rate of SNF; general, psychiatric hospital, or TB hospital it is covered under Part A.* Code one box/bottle, etc. as one unit, sum all units for the transaction period. Total all such goods into a single dollar amount

2301 Incontinence supplies.

z. Modifications to the Home

2400 Total all such modifications for the transaction period into a single dollar amount

aa. Prescription Medications and Blood Products

These are covered by Part A for Hospital inpatients and under Part B for inpatients of SNF if patient receives them from a hospital or Dr. that bills Medicare. Drugs and biologicals (except pneumococcal and Hepatitis B vaccine) are not covered by Part B when a SNF supplies. Blood clotting factors, even when the patient administers them himself are covered by Part B when under a SNF care. Insulin injections are not covered. Drugs and blood products are usually not covered for outpatients. Hospice benefits only cover medications used primarily for pain and symptom control. Code, sum **all same day** products together and record on one transaction line. And total all costs into a single amount

Note on source codes :

Use the **9393** source code for all services that the interviewer identifies as being associated with the drug study. These services include drugs, hospitalizations, and medical and physical testing.

Use the **9090** source code for someone buying drugs with an IL pharmacy card (the card is not Medicaid).

Units: For drugs, use the number of Rx when given.

For hospitalizations or evaluation sessions, use the number of visits

2500 Prescription medications used at home (includes SNF).

2501 Medications received during inpatient hospitalization and inpatient surgical procedures. Saline, albumin, and other plasma expanders should be coded here. Factor VIII and IX concentrates for hemophiliacs should be coded here.

2502 Medications received during outpatient surgical procedures. Saline used in outpatient transfusions should be coded here. Factor VIII and IX concentrates should be coded here.

2503 Medications received during unspecified hospital treatment (e.g., when claims form does not differentiate between inpatient and outpatient pharmacy charges). Saline, albumin, and other plasma expanders should be coded here. Factor VIII and IX concentrates for hemophiliacs should be coded here.

2504 Biologicals. These include red blood cell products, cryoprecipitate, platelets, fresh frozen plasma, and other blood products. **Saline**, which is given with red cells, should be coded under 2501, 2502, or 2503. **Transfusion infusion sets** should be coded under 2201.

bb. Adult Protective Services (includes public guardian)

2600 Any protective service. Code as active case for the transaction period. Guardianship programs may or may not include adult protective services. Code guardianship programs as 2600.

cc. Other services

2700 Assisted care living facility (ACLF), Residential Care, Adult Foster Care (AFC), and similar housing.
Code as DAYS.

Identifying 2700 residences:
-p. 2, q.2 of questionnaire lists residence as # 07
-residence offers more services than just congregate meals

Code all services provided by the residence, as identified by interviewer:
service.....do not record units.....do not record cost.
Do not record costs for individual services because it is unlikely that the costs of these services could be completely unbundled from the rent cost.

Be sure to code 2700.....days (when possible).....cost (when possible).

If a client is identified as being in 2700 housing and the interviewer has not listed this in the questionnaire, be sure to code 2700 even if you cannot fill in units or costs. These will be determined later.

Note: sometimes interviewers are listing 1500 services instead of 2700 services for someone in 2700 housing. Do not double-code (unless the services were received at different times and therefore non-overlapping).
If 1500 services were noted for the time period the client was in 2700 housing, code as 2700. Do not code 1500.

2701 AFC respite
An 0204 respite done in a private home (rather than hospital) should be coded 2701.

2800 Any other service:. Do not code a unit value.
Some interviewers listing informal services, such as when a policeman looks for a wandering client. Do not code these informal services.
Do not code unidentified services, even if providers received compensation. We have no way of knowing whether such services are countable. For example, beauty parlor services would not be coded.
Code formal services only.
Do code services such as AAA advocate, ombudsman help, Wanderguard, and Lifeline.

Question 42 (Intake), Question 33 (Follow-Up): Caregiver Service Check List

a. Mental Health Providers (Code Psychiatrists here)

CODE USING VISITS AS THE UNIT. *Medical social services under home health: counseling covered only as incidental to patient's covered items. Family counseling not covered. Hospice benefits: cover counseling to patient and family. Does NOT cover bereavement counseling. Hospice: Covered up to 80 hrs/yr when provided by a home health agency. Patient must be chronically dependent, lives with caregiver, and needs help with at least 2 activities of daily living (eating, dressing, etc.).* Mental health services include evaluation and treatment of functional and organic disorders; assessment of social and emotional factors related to health status; assistance coping with disease process;

supportive counseling in regard to diagnosis, prognosis, and limitations imposed by illness.

3000 Unspecified mental health provider.

3001 Psychiatrist, drug monitoring visits. Part B will not cover psychiatrist visits that are only for drug monitoring or changes when the Dr does not provide these services directly to the patient.

3002 Psychiatrist, all other visits. Generally outpatient psychotherapy is not covered under Medicare. Code psychiatrist visit as 3002 unless specified as a drug monitoring visit.

3003 Psychologist. *This can be covered under Part B as incident to Dr services (e.g., psychologist tests). Diagnostic services of an independently practicing psychologist covered as "other diagnostic tests" if a DR orders. Psychologist in risk-basis HMOs and CMPs can be covered when provided without DR supervision. Can also be covered when provided at a community mental health center.* ***Psychotherapy by privately practicing psychologist not covered.***

3004 Psychiatric Nurse -- individual counseling.

3005 Social Worker (counseling) -- individual counseling.

3006 Counseling center not included in above -- individual counseling.

3007 Group counseling not included in above. These include sessions with the patient and family members as well as other types of group counseling situations. The counseling may be provided by any of the professionals noted above.

3008 Mental health service received through phone call.

b. Education/Training

3100 Any formal education/training received
Code each session as one unit.

c. Caregiver Support Group

3200 Any support group. Code each session as one unit.

Note: If a caregiver reports purchasing books, seeing videos, etc. in lieu of attending education / training classes or support groups, DO NOT CODE. ONLY CODE ACTUAL SESSIONS ATTENDED.

d. Legal / Financial Counseling

Code legal as one hour=one unit.

3300 Any such service.

Do not code any services associated with lawsuits, such as relatives suing over estate.

Do code legal services rendered by phone because this is a billed service.

e. Transportation Services

Code each trip as one unit (e.g.,. round trip = 2 units); sum all units for the transaction period. This can include taxi or van service for patients unable to use other modes of transportation due to mobility impairments, shortness of breath, weakness, pain, etc.

3400 Transportation Services Not Health Related. *These are not covered under Medicare.*

3401 Ambulance service. *Medicare Part B Covers ambulances provided by ambulatory surgical centers, and emergency services (there are vehicle and crew requirements); also required that other transportation is medically contradicted and that the transportation is to a local destination/closest hosp to required services.*

3402 Any health related transportation service, other than ambulance
Transportation for psychiatric patients undergoing partial hospitalization is not covered under Part B. Nor is transportation to outpatient services.

3403 Transportation services, type unspecified.

f. Other Services

3500 Any other services

Do not code doctor's services used by the caregiver. These will be taken from Medicare tapes later.

Misc.: Code services such as.....?

wig for cancer patient	no
microwave	no
water filter	no

TV surveillance equip	yes
$12,000 garage remodel so client can live with family	yes
$6,000 bath remodel for client	yes
custom-made mobile home for client	yes

MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION
SERVICE UTILIZATION CODE SHEET INSTRUCTIONS

The purpose of the Service Utilization Code Sheet is to record the following information from Questions 41 and 42 of the Medicare Alzheimer's Disease Demonstration Intake Form, and Questions 33 and 34 of the Follow-up Interview. This form provides instructions on how to complete the code sheet. CODE **ALL** SERVICES FOR CLIENTS BELONGING TO HMOS. For NON-HMO MEMBERS, CODE ONLY SERVICES NOT REIMBURSED BY MEDICARE.

Case Identification

A label will be placed on each code sheet to identify the name, case identification number, site number, group identification, and randomization date for each case. The key punching service will enter these data directly. *There is no need to code this information.* It may be necessary to use the randomization date in some start date or end date calculations. Use a separate sheet for each client and each client caregiver.

Service Code

The first column on the code sheet is to identify the type of service received. The specific codes for this purpose on described in the Service Use and Transaction Codebook. This codebook also identifies the units of service for each service type. Use a separate line on the Service Utilization Code Sheet for each service indicated as being received. Also use a separate line for each series of service start and end dates for the same service. And if there are multiple funding sources, use a separate line for the service use associated with each funding source.

Source Codes

Column two is used to record the source from which the service units and expenditures was obtained. Use a separate source code to refer to source of information for the units and expenditures. In other words, the source code column is a four digit number. The sources are the Intake and Follow-up Questionnaires, billing claims forms obtained from the service provider, client clinical records (including patient charts, case manager records), and billing claims tapes obtained from Medicare, the demonstration program, Medicaid and other possible public funders. The following codes ask you to indicate the source for both service units and expenditures. Record source of Units first. If there are multiple sources of funding involved, e.g., private pay and Medicaid, or private pay and the demonstration, then use a separate line for each source of funding, indicating the approximate distribution of units and expenditures for each source. If no information is given, leave **Blank**.

10 Units and Expenditures are available only from the questionnaire (e.g., code as 1010)

20 Units and Expenditures are from claims forms (e.g., code as 2020). (If Units are from the claims forms and Expenditures are from the questionnaire code as 2010.)

30 Units and Expenditures are from clinical records (code as 3030). (If Units are from clinical records and Expenditures are from claims code as 3020.)

40 Services are **paid by Medicare**. Units or Expenditures are available on claims forms. These have not been coded, questionnaire data is coded, if available.

41 **hospice.** Code if provided through hospice or hospice service. This does not refer to the Medicare hospice benefit.

50 Service are **paid by demonstration**. Units and Expenditures are available on claims forms. These have not been coded, questionnaire data is coded, if available.

60 "Yes" response in the questionnaire to a service item, but no Units and/or Expenditures information is given, nor are claims forms available; service payment source is unknown.

62 **nonpecuniary compensation**. Services given in exchange for payment or as partial payment with pecuniary compensation. If provider receives a combination of nonpecuniary compensation and payment, use this source code and code the payment as a copayment.

63 volunteer services.

70 Services are **paid by Medicaid**. Units and Expenditures are available on claims forms, these have not been coded, questionnaire data is coded, if available.

80 Services are **paid by VA / CHAMPUS**. Units and Expenditures are available on claims forms, these have not been coded, questionnaire data is coded, if available.

90 Services are **paid by Other Public Programs**. Units and Expenditures are available on claims forms, these have not been coded, questionnaire data is coded, if available.(Alternative care grant included here).

91 Services are **paid by privately funded programs or grants** (e.g., Kellogg grant) (Includes multi-funded agencies whose primary funding source is private.)

92 Services received from **Church / religious organization** (Check whether the service is provided by the Church or by some other organization -- sometimes a nonreligious support groups uses Church facilities as their meeting place).

93 Drugs or services received through **drug study** (for some 2500 answers).If client is in a VA drug study, code source as drug study.

94 Services received through **study other than drug study**.

97 Not applicable. Code 9797 when **caregiver was not required to answer** questions about themselves or about the client (e.g.,. client permanently institutionalized or has died 3 months into the reporting period). If the UE item is not asked, the service code does not appear on the code sheet. If the 9797 source code were not used, the absence of a service code would indicate zero service use, which is not necessarily true in this situation.

98 **Don't know**. Code as 98 only if no other codable information is given.

99 **Refused.** Code as 99 only if no other codable information is given.

Start Date
Each service is expected to have an identified start date. Use a separate line for each new start date for every service, and each separate episode and follow the conventions described below if an actual date is not given. Code dates in the order of **Month, Day, Year**, using two digits for each. Year is coded by last two digits only. If there is no data for day, code as 00.

Intake Questionnaire:	record date as six months prior to randomization date.
Follow-Up Questionnaires:	record actual date.
New Caregiver Intake:	record date as six months prior to the date of the caregiver change.
Client Follow-Up:	6 month follow-up start the day after randomization date 12 month: one day and 6 months after randomization date 18 month: one day and 12 months after randomization date 24 month: one day and 18 months after randomization date
Caregiver Follow-Up:	6 month follow-up start the day after the intake interview 12 month: one day and 6 months after intake interview 18 month: one day and 12 months after intake interview 24 month: one day and 18 months after intake interview
Claims Forms	Record actual date if given, otherwise record month as 0100 of the year being tracked
Clinical Record	Record actual date, if given; otherwise record month as 0100 for the year being tracked.

End Date

Each service is expected to have an identified end date. Use a separate line for each new end date for every service, and follow the conventions described below if an actual date is not given. Code dates in the order of **Month, Day, Year**, using two digits for each. Year is coded by last two digits only. If there is no data for day, code as 00.

Questionnaires	ANY INTAKE OR FOLLOW-UP QUESTIONNAIRE, record date as six months after the start date for the transaction.
Claims Forms	Record actual date if given; otherwise record month as 1200 for the year being tracked.
Clinical Record	Record actual date, if given; otherwise record month as 1200 for the year being tracked.

Units
The definition for the service units is delineated in the *Service Use and Transaction Codebook*, refer to that document. If no information is given, leave blank. If a service is paid from multiple sources, record the units associated with each source on separate lines.

Expenditures
Expenditures may be reported in several forms: the billed amount, the allowed payment (such as by a Medi-Gap insurance policy, or Medicare). It is also likely that respondents will report only that portion of the bill which they paid -- either as a co-payment or

deductible. We are interested in reporting *total expenditures*. **BE CAREFUL, DO NOT CODE OUT OF POCKET CO-PAYMENT OR DEDUCTIBLE EXPENDITURES AS THE TOTAL COST.** For each service record, if known, the billed amount and the allowed amount. This information will usually becoming from claims records. Code the questionnaire reported expenditures in all cases. If no information is given, leave blank. If a service is paid from multiple sources, record the expenditures associated with each source on separate lines. When claims information is available, it will be used to overwrite the questionnaire files. Record expenditures in whole dollars.

Appendix H

Alzheimer's Service Use and Transaction Code Sheet

MEDICARE ALZHEIMERS DISEASE DEMONSTRATION
SERVICE UTILIZATION CODE SHEET

Place label here

Instructions to Keypunch
Key the Case Identification Number, and Last Name, First Name, Middle Initial from the above label. The identification number should be inserted in front of every line keyed below.

Service	Source	Start Date	End Date	Units	Expenditures Billed	Allowed	Copayment

Appendix I

Cleaning Steps for UE Data Files

Cleaning Steps for UE Data Files

Project staff at the Institute for Health and Aging (IHA) cleaned the keypunched utilization and expenditures interview data before they matched the UE and TAPE data files for comparison. Staff reconciled errors in caregiver identifiers, utilization and expenditures data, reporting periods, and client survival times in the UE data file. The corrections made in these fields are described below.

1. Caregiver / Client Identification

The demonstration evaluation used two kinds of caregiver / client identification: demonstration evaluation numbers and Medicare Health Insurance Claims (HIC) numbers. IHA supplied all caregivers and clients with a demonstration number. The demonstration number appeared on all materials collected for the evaluation. This number identified caregivers and clients in the UE data files. Demonstration sites used clients' HIC numbers to submit monthly reimbursement claims to HCFA. The HIC number identified clients in the TAPE files.

The demonstration and HIC identification numbers served a special purpose in the verification analysis. The two numbers were used to merge UE and TAPE files so that client records on the two data files could be matched for verification. First, a key file was created containing caregiver demonstration numbers, client demonstration numbers, and client HIC numbers. Next, the TAPE data files and client HIC numbers were merged with the key file. The resulting file was merged with the UE data files and demonstration numbers.

Demonstration Number

Each client was given an alphanumeric identifier showing demonstration site, membership number, and group (treatment / comparison). The caregiver partner shared an identical site and membership number. Caregivers were given a code identifying caregiver type (informal / formal) instead of the group identifier. Client and caregiver identifiers were corrected for:

- •erroneous site fields
- •erroneous client / caregiver characters
- •missing codes for client group or caregiver type
- •correction of caregiver type codes to correspond with a new coding scheme adopted during the demonstration

Medicare Health Insurance Claims (HIC) Numbers

Reimbursement payments made to the demonstration sites were funded through Medicare. For this reason, potential demonstration clients were required to carry Medicare Parts A and B health insurance.

- •reconcile HIC numbers in IHA records against HIC numbers supplied by HCFA

2. Coded Utilization and Expenditures Data

Each service transaction was coded using the following format (refer to code sheet)

service----source----start date----end date----units----billed----expend allowed----copay

Corrections were made for:

- •erroneous service code
- •erroneous funding source code
- •shift all 9797 (does not apply), 9898 (don't know), and 9999 (refused) codes from units and billed fields into the funding source code field.
- •erroneous characters in start date
- •erroneous characters in end date
- •ending service date precedes start date
- •service dates overlap between periods
- •erroneous units number
  - -bad text

-verify values >2 standard deviations within service

•erroneous billed amount

-bad text

-verify values >2 standard deviations within service

•erroneous expenditures allowed number

-bad text

•erroneous copayment number

-bad text

•provider claims records removed from UE files (medical and dental claims coded for a verification analysis apart from the dissertation)

•ad hoc service code, source code, date corrections

•verify date of permanent placement into nursing home using combination of Paradox data base information and coded data (0200 code)

•verify placement into assisted living facility using combination of application information, lists of licensed facilities from site catchment areas, and coded data (2700 code)

•ineligibility days (for demo services) removed in the presence of coded hospital (0100), permanent and short-term nursing home (0200), and assisted living (2700) services

•personal care/housekeeping/companion services (1300/1400/1600) cannot occur in presence of nursing home (0200) services. Identify and delete 1300/1400/1600 services.

•live-in caregiver (1500) cannot occur in presence of nursing home (0200) and assisted living (2700) services. Identify and delete 1500 services.

•live-in caregivers (1500) generally provide personal aide, housekeeping, and companion services (1300/1400/1600). Delete 1300/1400/1600 services that were included in 1500 services and retain 1300/1400/1600 services that were not included in 1500 services:

•retain 1300/1400/1600 services with the demonstration funding source code

•retain 1300/1400/1600 services with the nondemonstration funding source code if units and / or expenditures reported

•delete 1300/1400/1600 services with the nondemonstration funding source code if no units or expenditures reported

3. Reporting Period

Each eligible client and caregiver had separate UE transaction records showing either service use transactions or zero-use transactions for every active reporting period. Period cleaning checked for missing service transactions and transactions assigned to incorrect periods.

- •insert zero-use transactions for caregivers who did not use any services during an eligible period
- •insert zero-use transactions for clients who did not use any services during an eligible period
- •period listing of follow-up data in the UE file
- •missing periods
- •erroneous period membership

4. Client Deaths

The demonstration kept claims records on each client for each active month in the demonstration. Caregivers reported on clients who survived over three months into a (6 month) reporting period but were not asked to provide information on clients who died within the first 3 months of a reporting period. This meant that clients who died less than months into the reporting period would have TAPE records for that portion of the period but a UE record would be missing for the entire period. Any demonstration services used during the first 3 months could not be checked against caregiver reports. Clients who died within the first 3 months of a reporting period were therefore excluded from the verification analysis for the period in which they died.

Appendix J

Crosstabulations of Claims TAPE and UE Units for Day Care Services

Appendix J reports three sets of units crosstabulations for day care services.[1] The crosstabulations compare UE and TAPE units in aggregate, by caregiver relationship, and by reported funding source. Each compares units by intervals of approximately 14 days. The first set shows crosstabulations between UE and claims TAPE units, with funding sources collapsed across UE units. Reading across the table from left to right shows the correspondence between data sources using UE intervals as the reference. Baseline row percentages indicate that the greatest proportion of UE and TAPE records matched units within one interval of the exact match category. Far fewer matches are seen to the right of the exact match category than to the left of the category. This indicates that within intervals set by UE units, TAPE units occasionally exceeded UE units, but UE units predominantly exceeded TAPE units. Reading down the table from top to bottom shows the correspondence between data sources using TAPE intervals as the criterion. The predominance of exact matches cluster within the first four intervals, the intervals that contain the majority of demonstration -funded units. Records with exact matches drop off substantially from the next interval onwards, the point where units exceed mean and median TAPE unit values.[2] The highest percentage of exact matches for each TAPE interval was within the next highest category of the exact match category. UE units exceeded TAPE units in every unit interval. Only a marginal number of records show extreme outlier units. UE units rarely underreported TAPE units. The majority of UE records showing fewer units did not underreport TAPE units by more than one interval category (e.g., 1-13.99 UE units).

The 6 month crosstabulation shows the same trends as the baseline crosstabulation. In addition, row percentages of every exact match category were higher at 6 months than at baseline. Within intervals set by TAPE units, the percentages of UE records showing

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[1]Some crosstabulations were abridged to conserve space. All crosstabulations report marginals for the full crosstabulation.

[2]Table 6 shows UE and TAPE unit distributions for all services.

fewer units than TAPE were lower at 6 months than at baseline from the fifth interval onwards. Within the same intervals, the percentages of UE records showing higher units than TAPE increased. The matched pairs *t* test demonstrates that differences between baseline and 6 month match categories were significant (T=5.24, p=0.0001).

The most reliable measure of units reporting error crosstabulations can demonstrate is the rate of units underreporting within unit intervals. The first set of crosstabulations indicate that most underreporting within unit intervals did not exceed 13.99 UE units per period. Additionally, only 2 percent of all UE records underreported TAPE units within each unit interval. Overall, UE units clearly exceeded TAPE units, but the meaning of these higher values is less readily interpretable. UE units exceeding TAPE units are best defined as reporting variance rather than reporting error, because nondemonstration sources are indistinguishable from overreported demonstration sources. Row percentages in every exact match category increased over time. It is possible that exact matches increased because fewer clients relied on supplemental nondemonstration funding over time. That would eliminate some portion of the nondemonstration source variance from the reported data. Crosstabulations confirm that fewer UE records exceeded TAPE units at 6 months than at baseline, but the rate of difference between UE and TAPE units increased by one interval category. The increase in exact matches accompanied by a steeper increase in UE units may mean that reporting improved even as service utilization was changing. A second set of crosstabulations was generated by caregiver relationship to determine whether the distribution of service use transaction records across interval categories was independent of respondent type.

Crosstabulations by caregiver relationship revealed that the distribution of service use transaction records across nonmatch and exact match categories varied by respondent type (Set 2). All groups reported fewer service use transaction records over time. Declines in the number of record reports ranged from 20.0 percent for daughters to 40.5 percent for

Set 1. **Crosstabulations of Claims TAPE and UE Units for Day Care Services**

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	89 13.34 78.76 54.94	21 3.15 18.58 14.79	1 0.15 0.88 0.84	1 0.15 0.88 0.91	1 0.15 0.88 1.64	0 0 0 0	0 0 0 0	113 16.94
14-26.99	38 5.70 37.25 23.46	47 7.05 46.08 33.10	13 1.95 12.75 10.92	2 0.30 1.96 1.82	1 0.15 0.98 1.64	1 0.15 0.98 2.00	0 0 0 0	102 15.29
27-39.99	7 1.05 10.29 4.32	24 3.60 35.29 16.90	26 3.90 38.24 21.85	9 1.35 13.24 8.18	1 0.15 1.47 1.64	0 0 0 0	0 0 0 0	68 10.19
40-52.99	13 1.95 8.72 8.02	23 3.45 15.44 16.20	50 7.50 33.56 42.02	55 8.25 36.91 50.00	6 0.90 4.03 9.84	1 0.15 0.67 2.00	1 0.15 0.67 8.33	149 22.34
53-65.99	3 0.45 9.38 1.85	3 0.45 9.38 2.11	10 1.50 31.25 8.40	7 1.05 21.88 6.36	8 1.20 25.00 13.11	1 0.15 3.13 2.00	0 0 0 0	32 4.80
66-78.99	4 0.60 4.08 2.47	10 1.50 10.20 7.04	10 1.50 10.20 8.40	17 2.55 17.35 15.45	28 4.20 28.57 45.90	27 4.05 27.55 54.00	2 0.30 2.04 16.67	98 14.69
79-91.99	2 0.30 12.50 1.23	2 0.30 12.50 1.41	2 0.30 12.50 1.68	2 0.30 12.50 1.82	5 0.75 31.25 8.20	2 0.30 12.50 4.00	0 0 0 0	16 2.40
92-104.99	0 0 0 0	3 0.45 16.67 2.11	1 0.15 5.56 0.84	5 0.75 27.78 4.55	3 0.45 16.67 4.92	3 0.45 16.67 6.00	3 0.45 16.67 25.00	18 2.70
105- 117.99	1 0.15 14.29 0.62	0 0 0 0	1 0.15 14.29 0.84	2 0.30 28.57 1.82	0 0 0 0	0 0 0 0	3 0.45 42.86 25.00	7 1.05
118- 130.99	5 0.75 9.26 3.09	7 1.05 12.96 4.93	3 0.45 5.56 2.52	7 1.05 12.96 6.36	5 0.75 9.26 8.20	15 2.25 27.78 30.00	3 0.45 5.56 25.00	54 8.10
131- 143.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0
142- 156.99	0 0 0 0	2 0.30 50.00 1.41	0 0 0 0	2 0.30 50.00 1.82	0 0 0 0	0 0 0 0	0 0 0 0	4 0.60
157- 169.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.15 100.00 1.64	0 0 0 0	0 0 0 0	1 0.15
Total	162 24.29	142 21.29	119 17.84	110 16.49	61 9.15	50 7.50	12 1.80	667

Crosstabulations of Claims TAPE and UE Units for Day Care Services

UE Units TAPE Units--> 6 Months

freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	41 8.44 82.00 51.25	7 1.44 14.00 8.33	1 0.21 2.00 1.43	1 0.21 2.00 0.99	0 0 0 0	0 0 0 0	0 0 0 0	50 10.29
14-26.99	17 3.50 27.42 21.25	34 7.00 54.84 40.48	9 1.85 14.52 12.86	2 0.41 3.23 1.98	0 0 0 0	0 0 0 0	0 0 0 0	62 12.76
27-39.99	4 0.82 12.90 5.00	10 2.06 32.26 11.90	15 3.09 48.39 21.43	2 0.41 6.45 1.98	0 0 0 0	0 0 0 0	0 0 0 0	31 6.38
40-52.99	8 1.65 6.02 10.00	18 3.70 13.53 21.43	32 6.58 24.06 45.71	63 12.96 47.37 62.38	9 1.85 6.77 18.00	2 0.41 1.50 2.86	1 0.21 0.75 9.09	133 27.37
53-65.99	0 0 0 0	1 0.21 5.56 1.19	2 0.41 11.11 2.86	5 1.03 27.78 4.98	8 1.65 44.44 16.00	1 0.21 5.56 1.43	1 0.21 5.56 9.09	18 3.70
66-78.99	3 0.62 4.11 3.75	4 0.82 5.48 4.76	3 0.62 4.11 4.29	7 1.44 9.59 6.93	22 4.53 30.14 44.00	34 7.00 46.58 48.57	0 0 0 0	73 15.02
79-91.99	1 0.21 6.67 1.25	2 0.41 13.33 2.38	2 0.41 13.33 2.86	5 1.03 33.33 4.95	1 0.21 6.67 2.00	3 0.62 20.00 4.29	1 0.21 6.67 9.09	15 3.09
92-104.99	2 0.41 6.25 2.50	2 0.41 6.25 2.38	1 0.21 3.13 1.43	5 1.03 15.63 4.95	4 0.82 12.50 8.00	12 2.47 37.50 17.14	2 0.41 6.25 18.18	32 6.58
105- 117.99	0 0 0 0	0 0 0 0	1 0.21 33.33 1.43	1 0.21 33.33 0.99	0 0 0 0	0 0 0 0	0 0 0 0	3 0.62
118- 130.99	4 0.82 6.78 5.00	3 0.62 5.08 3.57	4 0.82 6.78 5.71	6 1.23 10.17 5.94	6 1.23 10.17 12.00	15 3.09 25.42 21.43	6 1.23 10.17 54.55	59 12.14
131- 143.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.21 100.00 1.43	0 0 0 0	1 0.21
142- 156.99	0 0 0 0	2 0.41 100.00 2.38	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 0.41
Total	80 16.46	84 17.28	70 14.40	101 20.78	50 10.29	70 14.40	11 2.26	486

others.[3] We may be confident that these reductions represented a real decrease in clients using demonstration funding because all respondent groups had negligible rates of false negative service use reporting (Table 12). The distribution of records across nonmatch and match categories shifted over time. Changes suggest that reporting improved, and the use of demonstration and nondemonstration funding sources differed by respondent type.

Caregiver units were crosstabulated for spouses, daughters, sons, and others. Over time, spouses reduced exact matches within the first two interval categories and markedly increased exact matches in all others. Rates of nonmatching records increased slightly within the upper interval categories. Reporting demonstrated significant period effects (T_{spouse}=4.33, p=0.0001). In constrast, daughters reported the highest proportions of exact matches within the first two interval categories at both baseline and 6 months. Rates of records exceeding TAPE units declined across all intervals over time. Period effects were not present ($T_{daughter}$=1.74, p=0.0848). Sons rarely reported records having fewer units than TAPE. Records exceeding TAPE units declined between baseline and 6 months, particularly within upper intervals. Differences between baseline and 6 month crosstabulations were significant (T_{son}=2.73, p=0.0019). Over time, others reported lower rates of records exceeding TAPE units within lower units intervals and higher rates of records exceeding TAPE units within upper unit intervals. Exact matches did not change as much over time as records exceeding TAPE units, but differences between periods were not significant (T_{other}=1.90, p=0.0654).

Crosstabulations by caregiver relationship suggest that caregivers reported service units funded within and outside the demonstration. A final set of crosstabulations was generated by reported funding source to approximate how accurately respondents identified funding sources (Set 3). The last set of crosstabulations show day care unit

[3]Percent fewer unit records at 6 months: spouse, 27.8; daughter, 20.0; son, 28.2; other, 40.5 (percent reductions including UE records with missing units data are about the same).

crosstabulations by reported funding source. Caregivers reported units of service, and whether all units were funded

Set 2. **Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship**

Spouse

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	57 15.24 79.17 63.33	12 3.21 16.67 14.46	1 0.27 1.39 1.49	1 0.27 1.39 1.56	1 0.27 1.39 2.94	0 0 0 0	0 0 0 0	72 19.25
14-26.99	20 5.35 32.26 22.22	31 8.29 50.00 37.35	9 2.41 14.52 13.43	2 0.53 3.23 3.13	0 0 0 0	0 0 0 0	0 0 0 0	62 16.58
27-39.99	5 1.34 12.82 5.56	13 3.48 33.33 15.66	17 4.55 43.59 25.37	4 1.07 10.26 6.25	0 0 0 0	0 0 0 0	0 0 0 0	39 10.43
40-52.99	6 1.60 7.32 6.67	14 3.74 17.07 16.87	27 7.22 32.93 40.30	31 8.29 37.80 48.44	3 0.80 3.66 8.82	0 0 0 0	1 0.27 1.22 25.00	82 21.93
53-65.99	1 0.27 6.67 1.11	0 0 0 0	6 1.60 40.00 8.96	3 0.80 20.00 4.69	4 1.07 26.67 11.76	1 0.27 6.67 3.57	0 0 0 0	15 4.01
66-78.99	1 0.27 1.69 1.11	6 1.60 10.17 7.23	2 0.53 3.39 2.99	12 3.21 20.34 18.75	19 5.08 32.20 55.88	19 5.08 32.20 67.86	0 0 0 0	59 15.78
79-91.99	0 0 0 0	2 0.53 25.00 2.41	2 0.53 25.00 2.99	1 0.27 12.50 1.56	2 0.53 25.00 5.88	0 0 0 0	0 0 0 0	8 2.14
Total	90 24.06	83 22.19	67 17.91	64 17.11	34 9.09	28 7.49	4 1.07	374

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Daughter

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	15 8.33 71.43 37.50	6 3.33 28.57 15.79	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	21 11.67
14-26.99	11 6.11 44.00 27.50	10 5.56 40.00 26.32	2 1.11 8.00 6.25	0 0 0 0	1 0.56 4.00 5.26	1 0.56 4.00 7.14	0 0 0 0	25 13.89
27-39.99	2 1.11 11.76 5.00	6 3.33 35.29 15.79	6 3.33 35.29 18.75	1 0.56 5.88 4.00	1 0.56 5.88 5.26	0 0 0 0	0 0 0 0	17 9.44
40-52.99	5 2.78 13.16 12.15	5 2.78 13.16 13.16	14 7.78 36.84 73.75	14 7.78 36.84 56.00	0 0 0 0	0 0 0 0	0 0 0 0	38 21.11
53-65.99	2 1.11 16.67 5.00	2 1.11 16.67 5.26	2 1.11 16.67 6.25	2 1.11 16.67 8.00	4 2.22 33.33 21.05	0 0 0 0	0 0 0 0	12 6.67
66-78.99	1 0.56 3.85 2.50	3 1.67 11.54 7.89	6 3.33 23.08 18.75	3 1.67 11.54 12.00	8 4.44 30.77 42.11	4 2.22 15.38 28.57	1 0.56 3.85 20.00	26 14.44
79-91.99	1 0.56 16.67 2.50	0 0 0 0	0 0 0 0	1 0.56 16.67 4.00	2 1.11 33.33 10.53	3 1.11 33.33 14.29	0 0 0 0	6 3.33
Total	40 22.22	38 21.11	32 17.78	25 13.89	19 10.56	14 7.78	5 2.78	180

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Son

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	8 20.51 88.89 72.73	1 2.56 11.11 14.29	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	9 23.08
14-26.99	0 0 0 0	2 5.13 100.00 28.57	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 5.13
27-39.99	0 0 0 0	2 5.13 40.00 28.57	1 2.56 20.00 14.29	2 5.13 40.00 33.33	0 0 0 0	0 0 0 0	0 0 0 0	5 12.82
40-52.99	1 2.56 14.29 9.09	0 0 0 0	3 7.69 42.86 42.86	2 5.13 28.57 33.33	0 0 0 0	1 2.56 14.29 16.67	0 0 0 0	7 17.95
53-65.99	0 0 0 0	1 2.56 33.33 14.29	2 5.13 66.67 28.57	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	3 7.69
66-78.99	0 0 0 0	0 0 0 0	1 2.56 25.00 14.29	1 2.56 25.00 16.67	0 0 0 0	2 5.13 50.00 33.33	0 0 0 0	4 10.26
79-91.99	1 2.56 100.00 9.09	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 2.56
Total	11 28.21	7 17.95	7 17.95	6 15.38	1 2.56	6 5.38	1 2.56	39

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Other

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	9 12.16 81.82 42.86	2 2.70 18.18 14.29	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	11 14.86
14-26.99	7 9.46 53.85 33.33	4 5.41 30.77 28.57	2 2.70 15.38 15.38	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	13 17.57
27-39.99	0 0 0 0	3 4.05 42.86 21.43	2 2.70 28.57 15.38	2 2.70 28.57 13.33	0 0 0 0	0 0 0 0	0 0 0 0	7 9.46
40-52.99	1 1.35 4.55 4.76	4 5.41 18.18 28.57	6 8.11 27.27 46.15	8 10.81 36.36 53.33	3 4.05 13.64 42.86	0 0 0 0	0 0 0 0	22 29.73
53-65.99	0 0 0 0	0 0 0 0	0 0 0 0	2 2.70 100.00 13.33	0 0 0 0	0 0 0 0	0 0 0 0	2 2.70
66-78.99	2 2.70 22.22 9.52	1 1.35 11.11 7.14	1 1.35 11.11 7.69	1 1.35 11.11 6.67	1 1.35 11.11 14.29	2 2.70 22.22 100.00	1 1.35 11.11 50.00	9 12.16
79-91.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 1.35 100.00 14.29	0 0 0 0	0 0 0 0	1 1.35
Total	21 28.38	14 18.92	13 17.57	15 20.27	7 9.46	2 2.70	2 2.70	74

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Spouse

UE Units TAPE Units--> 6 Months

freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	21 7.78 72.41 47.73	6 2.22 20.69 12.50	1 0.37 3.45 2.22	1 0.37 3.45 1.79	0 0 0 0	0 0 0 0	0 0 0 0	29 10.74
14-26.99	12 4.44 32.43 27.27	18 6.67 48.65 37.50	6 2.22 16.22 13.33	1 0.37 2.70 1.79	0 0 0 0	0 0 0 0	0 0 0 0	37 13.70
27-39.99	4 1.48 20.00 9.09	4 1.48 20.00 8.33	11 4.07 55.00 24.44	1 0.37 5.00 1.79	0 0 0 0	0 0 0 0	0 0 0 0	20 7.41
40-52.99	3 1.11 3.45 6.82	16 5.93 18.39 33.33	20 7.41 22.99 44.44	42 15.56 48.28 75.00	3 1.11 3.45 12.50	2 0.74 32.30 5.00	1 0.37 1.15 16.67	87 32.22
53-65.99	0 0 0 0	1 0.37 8.33 2.08	2 0.74 16.67 4.44	1 0.37 8.33 1.79	7 2.59 58.33 29.17	1 0.37 8.33 2.50	0 0 0 0	12 4.44
66-78.99	2 0.74 35.00 4.55	0 0 0 0	2 0.74 5.00 4.44	3 1.11 7.50 5.36	10 3.70 25.00 41.67	23 8.52 57.50 57.50	0 0 0 0	40 14.81
79-91.99	0 0 0 0	1 0.37 20.00 2.08	1 0.37 20.00 2.22	0 0 0 0	0 0 0 0	2 0.74 40.00 5.00	1 0.37 20.00 16.67	5 1.85
Total	44 16.30	48 17.78	45 16.67	56 20.74	24 8.89	40 14.81	6 2.22	270

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Daughter

UE Units	TAPE Units-->			6 Months				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	14 9.72 93.33 56.00	1 0.69 6.67 4.55	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	15 10.42
14-26.99	5 3.47 29.41 20.00	9 6.25 52.94 40.91	2 1.39 11.76 11.76	1 0.69 5.88 3.03	0 0 0 0	0 0 0 0	0 0 0 0	17 11.81
27-39.99	0 0 0 0	3 2.08 50.00 13.64	3 2.08 50.00 17.65	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	6 4.17
40-52.99	1 0.69 3.45 4.00	1 0.69 3.45 4.55	7 4.86 24.14 41.18	15 10.42 51.72 45.45	5 3.47 17.24 35.71	0 0 0 0	0 0 0 0	29 20.14
53-65.99	0 0 0 0	0 0 0 0	0 0 0 0	4 2.78 100.00 12.12	0 0 0 0	0 0 0 0	0 0 0 0	4 2.78
66-78.99	1 0.69 4.55 4.00	2 1.39 9.09 9.09	1 0.69 4.55 5.88	3 2.08 13.64 9.09	6 4.17 27.27 42.86	9 6.25 40.91 45.00	0 0 0 0	22 15.28
79-91.99	0 0 0 0	1 0.69 20.00 4.55	1 0.69 20.00 5.88	3 2.08 60.00 9.09	0 0 0 0	0 0 0 0	0 0 0 0	5 3.47
Total	25 17.36	22 15.28	17 11.81	33 22.92	14 9.72	20 13.89	3 2.08	144

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Son

UE Units	TAPE Units-->			6 Months				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	3 10.71 100.00 75.00	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	3 10.71
14-26.99	0 0 0 0	3 10.71 75.00 50.00	1 3.57 25.00 25.00	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	4 14.29
27-39.99	0 0 0 0	0 0 0 0	1 3.57 100.00 25.00	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 3.57
40-52.99	1 3.57 25.00 25.00	0 0 0 0	2 7.14 50.00 50.00	1 3.57 25.00 25.00	0 0 0 0	0 0 0 0	0 0 0 0	4 14.29
53-65.99	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	0 0.00
66-78.99	0 0 0 0	2 7.14 66.67 33.33	0 0 0 0	0 0 0 0	1 3.57 33.33 100.00	0 0 0 0	0 0 0 0	3 10.71
79-91.99	0 0 0 0	0 0 0 0	0 0 0 0	1 3.57 100.00 25.00	0 0 0 0	0 0 0 0	0 0 0 0	1 3.57
Total	4 14.29	6 21.43	4 14.29	4 14.29	1 3.57	6 21.43	1 3.57	28

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Caregiver Relationship

Other

UE Units TAPE Units--> 6 Months

freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	3	0	0	0	0	0	0	3
	6.82	0	0	0	0	0	0	6.82
	100.00	0	0	0	0	0	0	
	42.86	0	0	0	0	0	0	
14-26.99	0	4	0	0	0	0	0	4
	0	9.09	0	0	0	0	0	9.09
	0	100.00	0	0	0	0	0	
	0	50.00	0	0	0	0	0	
27-39.99	0	3	0	1	0	0	0	4
	0	6.82	0	2.27	0	0	0	9.09
	0	75.00	0	25.00	0	0	0	
	0	37.50	0	12.50	0	0	0	
40-52.99	3	1	3	5	1	0	0	13
	6.82	2.27	6.82	11.36	2.27	0	0	29.55
	23.08	7.69	23.08	38.46	7.69	0	0	
	42.86	12.50	75.00	62.50	9.09	0	0	
53-65.99	0	0	0	0	1	0	1	2
	0	0	0	0	2.27	0	2.27	4.55
	0	0	0	0	50.00	0	50.00	
	0	0	0	0	9.09	0	100.00	
66-78.99	0	0	0	1	5	2	0	8
	0	0	0	2.27	11.36	4.55	0	18.18
	0	0	0	12.50	62.50	25.00	0	
	0	0	0	12.50	45.45	50.00	0	
79-91.99	1	0	0	1	1	1	0	4
	2.27	0	0	2.27	2.27	2.27	0	9.09
	25.00	0	0	25.00	25.00	25.00	0	
	14.29	0	0	12.50	9.09	25.00	0	
Total	7	8	4	8	11	4	1	44
	15.91	18.18	9.09	18.18	25.00	9.09	2.27	

within the demonstration ("demo only"), outside the demonstration ("nondemo only"), or through both sources ("both").

The first set of crosstabulations in the set shows "nondemo only" units. We know that all baseline and 6 month UE records reporting "nondemo only" funding are incorrect reports of funding source. All these UE service use transactions have corresponding TAPE service use transactions. The service units would have to have been funded through either "demo only" or "both" funding sources. Rates of underreported units, the best measure of reporting error, are extremely low in both reporting periods. Exact match categories represent accurate reports of demonstration units. Row percentages in exact match categories increased over time. This indicates that respondents did improve units reporting over time, even if they did not know the funding source. Rates of UE records exceeding TAPE units decreased over time. This might represent a real decrease in overreporting error, because exact matches increased over time. UE records exceeding TAPE units include overreported "demo only" units and (possibly accurate) "both" units. The matched pairs *t* test indicates that match categories differed significantly between baseline and 6 months ($T_{nondemo}$=2.44, p=0.0155).

Crosstabulations of "demo only" units support our suspicion that a sizable portion of UE "nondemo only" records should have reported "demo only" or "both" units. The numbers of crosstabulated records in each period is far below the total number of UE service use records having TAPE service use transactions. Rates of underreported units are extremely low in both reporting periods. Row percentages in exact match categories increased over time. It appears that row percentages in "demo only" match categories are slightly lower than in "nondemo only" match categories; these differences were not tested for statistical significance. Rates of UE records exceeding TAPE units decreased slightly over time. UE records exceeding TAPE units include overreported "demo only" units and (possibly accurate) "both" units. The matched pairs *t* test shows that match categories differed significantly between baseline and 6 months (T_{demo}=5.30, p=0.0001).

Crosstabulations of "both" units shows that respondents thought clients rarely supplemented demonstration benefits with outside funding. Units underreporting is absent. The numbers of exact matches are virtually nonexistent. Most UE records exceed TAPE units. We expect these findings because respondents reported that they supplemented funding above the demonstration. The matched pairs *t* test confirms that match categories differed significantly between baseline and 6 months (T_{both}=2.17, p=0.0527).

Set 3. **Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source**

"nondemo only"

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	53 15.68 82.81 56.38	9 2.66 14.06 14.06	1 0.30 1.56 1.75	0 0 0 0	1 0.30 1.54 2.94	0 0 0 0	0 0 0 0	64 18.93
14-26.99	22 6.61 40.00 23.40	25 7.40 45.45 39.06	5 1.48 9.09 8.77	2 0.59 3.64 4.00	0 0 0 0	1 0.30 1.82 4.00	0 0 0 0	55 16.27
27-39.99	3 0.89 9.09 3.19	9 2.66 27.27 14.06	15 4.44 45.45 26.32	5 1.48 15.15 10.00	1 0.30 3.03 2.94	0 0 0 0	0 0 0 0	33 9.76
40-52.99	7 2.07 9.59 7.45	10 2.96 13.70 15.63	27 7.99 36.99 47.37	26 7.69 35.62 52.00	1 0.30 1.37 2.94	1 0.30 1.37 4.00	1 0.30 1.37 14.29	73 21.60
53-65.99	3 0.89 16.67 3.19	1 0.30 5.56 1.56	4 1.18 22.22 7.02	3 0.89 16.67 6.00	7 2.07 38.89 20.59	0 0 0 0	0 0 0 0	18 5.33
66-78.99	1 0.30 2.08 1.06	6 1.78 12.50 9.38	3 0.89 6.25 5.26	8 2.37 16.67 16.00	15 4.44 31.25 44.12	15 4.44 31.25 60.00	0 0 0 0	48 14.20
79-91.99	1 0.30 14.29 1.06	1 0.30 14.29 1.56	0 0 0 0	1 0.30 14.29 2.00	2 0.59 28.57 5.88	1 0.30 14.29 4.00	0 0 0 0	7 2.07
92-104.99	0 0 0 0	1 0.30 9.09 1.56	0 0 0 0	3 0.89 27.27 6.00	2 0.59 18.18 5.88	3 0.89 27.27 12.00	2 0.59 18.18 28.57	11 3.25
105- 117.99	0 0 0 0	0 0 0 0	1 0.30 33.33 1.75	0 0 0 0	0 0 0 0	0 0 0 0	2 0.59 66.67 28.57	3 0.89
118- 130.99	4 1.18 18.18 4.26	1 0.30 4.55 1.56	0 0 0 0	2 0.59 9.09 4.00	3 0.89 13.64 8.82	4 1.18 18.18 16.00	2 0.59 9.09 28.57	22 6.51
Total	94 27.81	64 18.93	57 16.86	50 14.79	34 10.06	25 7.40	7 2.07	338

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source

"nondemo only"

UE Units TAPE Units--> 6 Months

freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	29 11.07 82.86 53.70	5 1.91 14.29 11.63	1 0.38 2.86 3.03	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	35 13.36
14-26.99	8 3.05 28.57 14.81	16 6.11 57.14 37.21	3 1.15 10.71 9.09	1 0.38 3.57 2.33	0 0 0 0	0 0 0 0	0 0 0 0	28 10.69
27-39.99	4 1.53 22.22 7.41	6 2.29 33.33 13.95	7 2.67 38.89 21.21	1 0.38 5.56 2.33	0 0 0 0	0 0 0 0	0 0 0 0	18 6.87
40-52.99	5 1.91 8.47 9.26	11 4.20 18.64 25.58	14 5.34 23.73 42.42	27 10.31 45.76 62.79	1 0.38 1.69 4.00	1 0.38 1.69 2.44	0 0 0 0	59 22.52
53-65.99	0 0 0 0	0 0 0 0	1 0.38 11.11 3.03	2 0.76 22.22 4.65	4 1.53 44.44 16.00	1 0.38 11.11 2.44	1 0.38 11.11 11.11	9 3.44
66-78.99	3 1.15 6.98 5.56	2 0.76 4.65 4.65	3 1.15 6.98 9.09	2 0.76 4.65 4.65	14 5.34 32.56 56.00	19 7.25 44.19 46.34	0 0 0 0	43 16.41
79-91.99	1 0.38 11.11 1.85	1 0.38 11.11 2.33	1 0.38 11.11 3.03	2 0.76 22.22 4.65	1 0.38 11.11 4.00	2 0.76 22.22 4.88	1 0.38 11.11 11.11	9 3.44
92-104.99	3 1.15 7.50 5.56	1 0.38 5.50 2.33	3 1.15 7.50 9.09	3 1.15 7.50 6.98	3 1.15 7.50 12.00	9 3.44 22.50 21.95	6 2.29 15.00 66.67	16 6.11
105- 117.99	0 0 0 0	1 0.38 100.00 2.33	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 0.76
118- 130.99	0 0 0 0	0 0 0 0	0 0 0 0	1 0.38 50.00 2.33	0 0 0 0	1 0.38 50.00 2.44	0 0 0 0	40 15.27
Total	54 20.61	43 16.41	33 12.60	43 16.41	25 9.54	41 15.65	9 3.44	262

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source

"demo only"

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	36 11.9 73.47 56.25	12 3.97 24.49 16.22	0 0 0 0	1 0.33 2.04 1.85	0 0 0 0	0 0 0 0	0 0 0 0	49 16.23
14-26.99	16 5.30 34.04 25.00	22 7.28 46.81 29.73	8 2.65 17.02 14.81	0 0 0 0	1 0.33 2.13 4.00	0 0 0 0	0 0 0 0	47 15.56
27-39.99	2 0.66 6.06 3.13	15 4.97 45.45 20.27	11 3.64 33.33 20.37	4 1.32 12.12 7.41	0 0 0 0	0 0 0 0	0 0 0 0	33 10.93
40-52.99	5 1.64 7.14 7.81	11 3.64 15.71 14.86	21 6.95 30.00 38.89	28 9.27 40.00 51.85	5 1.66 7.14 20.00	0 0 0 0	0 0 0 0	70 23.18
53-65.99	0 0 0 0	2 0.66 15.38 2.70	5 1.66 38.46 9.26	4 1.32 30.77 7.41	1 0.33 7.69 4.00	1 0.33 7.69 4.55	0 0 0 0	13 4.30
66-78.99	3 0.99 6.25 4.69	4 1.32 8.33 5.41	6 1.99 12.50 11.11	9 2.98 18.75 16.67	13 4.30 27.08 52.00	11 3.64 22.92 50.00	2 0.66 4.17 40.00	48 15.89
79-91.99	0 0 0 0	1 0.33 16.67 1.35	1 0.33 16.67 1.85	1 0.33 16.67 1.85	2 0.66 33.33 8.00	1 0.33 16.67 4.55	0 0 0 0	6 1.99
92-104.99	0 0 0 0	2 0.66 40.00 2.70	1 0.33 20.00 1.85	1 0.33 20.00 1.85	0 0 0 0	0 0 0 0	1 0.33 20.00 20.00	5 1.66
105- 117.99	1 0.33 33.33 1.56	0 0 0 0	0 0 0 0	1 0.33 33.33 1.85	0 0 0 0	0 0 0 0	1 0.33 33.33 20.00	3 0.99
118- 130.99	1 0.33 4.00 1.56	5 1.66 20.00 6.76	1 0.33 4 .00 1.85	3 0.99 12.00 5.56	2 0.66 8.00 8.00	9 2.98 36.00 40.91	1 0.33 4.00 20.00	25 8.28
Total	64 21.19	74 24.50	54 17.88	54 17.88	25 8.28	22 7.28	5 1.66	302

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source

"demo only"

UE Units	TAPE Units-->			6 Months				
freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	79-91.99	Total
1-13.99	12 5.80 80.00 52.174	2 0.97 13.33 5.26	0 0 0 0	1 0.48 6.67 1.89	0 0 0 0	0 0 0 0	0 0 0 0	15 7.25
14-26.99	9 4.35 27.27 39.13	17 8.21 51.52 44.74	6 2.90 18.18 17.14	1 0.48 3.03 1.89	0 0 0 0	0 0 0 0	0 0 0 0	33 15.94
27-39.99	0 0 0 0	4 1.93 33.33 10.53	7 3.38 58.33 20.00	1 0.48 8.33 1.89	0 0 0 0	0 0 0 0	0 0 0 0	12 5.80
40-52.99	1 0.48 1.45 4.35	7 3.38 10.14 18.42	17 8.21 24.64 48.57	35 16.91 50.72 66.04	7 3.38 10.14 29.17	1 0.48 1.45 3.85	1 0.48 1.45 50.00	69 33.33
53-65.99	0 0 0 0	1 0.48 11.11 2.63	1 0.48 11.11 2.86	3 1.45 33.33 5.66	4 1.93 44.44 16.67	0 0 0 0	0 0 0 0	9 4.35
66-78.99	0 0 0 0	2 0.97 6.67 5.26	0 0 0 0	5 2.42 16.67 9.43	8 3.86 26.67 33.33	15 7.25 50.00 57.69	0 0 0 0	30 14.49
79-91.99	0 0 0 0	1 0.48 16.67 2.63	1 0.48 16.67 2.86	3 1.45 50.00 5.66	0 0 0 0	1 0.48 16.67 3.85	0 0 0 0	6 2.90
92-104.99	1 0.48 7.69 4.35	1 0.48 7.69 2.63	1 0.48 7.69 2.86	1 0.48 7.69 1.89	2 0.97 15.38 8.33	3 1.45 23.08 11.54	1 0.48 7.69 50.00	13 6.28
105- 117.99	0 0 0 0	0 0 0 0	1 0.48 100.00 2.86	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.48
118- 130.99	0 0 0 0	2 0.97 13.33 5.26	1 0.48 6.67 2.86	2 0.97 13.33 3.77	3 1.45 20.00 12.50	4 1.93 26.67 15.38	0 0 0 0	15 7.25
Total	23 11.11	38 18.36	35 16.91	53 25.60	24 11.59	26 12.56	2.0.97	207

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source "both"

UE Units TAPE Units--> Baseline

freq % row % col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	Total
1-13.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
14-26.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
27-39.99	2	0	0	0	0	0	2
	7.41	0	0	0	0	0	7.41
	100.00	0	0	0	0	0	
	50.00	0	0	0	0	0	
40-52.99	1	2	2	1	0	0	6
	3.70	7.41	7.41	3.70	0	0	22.22
	16.67	33.33	33.33	16.67	0	0	
	25.00	50.00	25.00	16.67	0	0	
53-65.99	0	0	1	0	0	0	1
	0	0	3.70	0	0	0	3.70
	0	0	100.00	0	0	0	
	0	0	12.50	0	0	0	
66-78.99	0	0	1	0	0	1	2
	0	0	3.70	0	0	3.70	7.41
	0	0	50.00	0	0	50.00	
	0	0	12.50	0	0	33.33	
79-91.99	1	0	1	0	1	0	3
	3.70	0	3.70	0	3.70	0	11.11
	33.33	0	33.33	0	33.33	0	
	25.00	0	12.50	0	50.00	0	
92-104.99	0	0	0	1	1	0	2
	0	0	0	3.70	3.70	0	7.41
	0	0	0	50.00	50.00	0	
	0	0	0	16.67	50.00	0	
105-117.99	0	0	0	1	0	0	1
	0	0	0	3.70	0	0	3.70
	0	0	0	100.00	0	0	
	0	0	0	16.67	0	0	
118-130.99	0	1	2	2	0	2	7
	0	3.70	7.41	7.41	0	7.41	25.93
	0	14.29	28.57	28.57	0	28.57	
	0	25.00	25.00	33.33	0	66.67	
131-143.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
142-156.99	0	1	0	0	0	0	1
	0	3.70	0	0	0	0	3.70
	0	100.00	0	0	0	0	
	0	25.00	0	0	0	0	
170-182	0	0	1	1	0	0	2
	0	0	3.70	3.70	0	0	7.41
	0	0	50.00	50.00	0	0	
	0	0	12.50	16.67	0	0	
Total	4	4	8	6	2	3	27
	14.81	14.81	29.63	22.22	7.41	11.11	

Crosstabulations of Claims TAPE and UE Units for Day Care Services by Funding Source "both"

UE Units TAPE Units--> 6 Months

freq / % / row % / col %	1-13.99	14-26.99	27-39.99	40-52.99	53-65.99	66-78.99	Total
1-13.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
14-26.99	0	1	0	0	0	0	1
	0	5.88	0	0	0	0	5.88
	0	100.00	0	0	0	0	
	0	33.33	0	0	0	0	
27-39.99	0	0	1	0	0	0	1
	0	0	5.89	0	0	0	5.88
	0	0	100.00	0	0	0	
	0	0	50.00	0	0	0	
40-52.99	2	0	1	1	1	0	5
	1.76	0	5.88	5.88	5.88	0	29.41
	40.00	0	20.00	20.00	20.00	0	
	66.67	0	50.00	20.00	100.00	0	
53-65.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
66-78.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
79-91.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
92-104.99	0	1	0	1	0	1	3
	0	5.88	0	5.88	0	5.88	17.65
	0	33.33	0	33.33	0	33.33	
	0	33.33	0	20.00	0	33.33	
105-117.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
118-130.99	1	0	0	1	0	2	4
	5.88	0	0	5.88	0	11.76	23.53
	25.00	0	0	25.00	0	50.00	
	33.33	0	0	20.00	0	66.67	
131-143.99	.	.	.	.	.	.	0
	.	.	.	.	.	.	0.00
	.	.	.	.	.	.	
	.	.	.	.	.	.	
142-156.99	0	1	0	0	0	0	1
	0	5.88	0	0	0	0	5.88
	0	100.00	0	0	0	0	
	0	33.33	0	0	0	0	
170-182	0	0	0	2	0	0	2
	0	0	0	11.76	0	0	11.76
	0	0	0	100.00	0	0	
	0	0	0	40.00	0	0	
Total	3	3	2	5	1	3	17
	17.65	17.65	11.76	29.41	5.88	17.65	

Appendix K

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services

Appendix K reports three sets of units crosstabulations for personal care/housekeeping/companion services.[1] The crosstabulations compare UE and TAPE units in aggregate, by caregiver relationship, and by reported funding source. Each compares units by intervals of approximately 53 hours. The first set shows crosstabulations between UE and claims TAPE units, with funding sources collapsed across UE units. The baseline model shows that the proportion of UE records underreporting TAPE units was extremely low. The rate of UE records underreporting TAPE units decreased within ascending unit intervals, reaching negligible levels in the upper intervals. Row percentages in exact match categories show poor agreement between UE and TAPE units. The majority of matching records were within two unit interval categories higher than the exact match category. The rate of UE records across the three categories nonetheless constitute a low proportion of all UE records within each interval. The major finding of the crosstabulation shows that UE units overwhelmingly exceeded TAPE units. Records exceeding TAPE units are distributed across the range of possible unit values, with no clustering within intervals.[2]

The 6 month crosstabulation shows that the rate of records that underreported units was less than half the baseline rate. Row percentages in exact match categories improved slightly, but not enough to offset UE units exceeding TAPE units. UE units grossly exceeded TAPE units within all intervals. The match pairs *t* test finds that differences between baseline and 6 month categories were statistically significant (T=7.65, p=0.0001).

The most reliable measure of units reporting error contained in the first set of crosstabulations is the rate of units underreporting within unit intervals. The

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[1]The crosstabulations in this chapter were abridged to conserve space. All crosstabulations report marginals for the full crosstabulation.

[2]Table 6 shows the mean, median, and maximum units for personal care/housekeeping/companion services. UE and TAPE distributions are grossly dissimilar, with UE units exceeding TAPE units on all three descriptives.

crosstabulations indicate that a large proportion of records did not underreport more than 52.99 UE units per period. UE records that underreported TAPE units were unevenly distributed across intervals, with the highest proportions of underreporting records contained within the three lowest unit intervals. UE units clearly exceeded TAPE units across all intervals. UE units exceeding TAPE units are best defined as reporting variance rather than reporting error, because nondemonstration sources are indistinguishable from overreported demonstration sources. Row percentages in every exact match category increased only modestly over time. It is possible that exact matches increased because fewer clients relied on supplemental nondemonstration funding over time. That would eliminate some portion of the nondemonstration source variance from the reported data. Crosstabulations show that rates of UE records exceeding TAPE units increased over time. It seems more likely that reduced underreporting over time resulted in increased rates of exact matches. Crosstabulations were generated by caregiver relationship to determine whether the distribution of service use transaction records across interval categories was independent of respondent type.

Crosstabulations by caregiver relationship revealed that the distribution of service use transaction records across nonmatch and exact match categories varied by respondent type (Set 2). All groups reported fewer service use transaction records over time. Declines in the number of record reports ranged from 18.9 percent for sons to 24.5 for others.[3] We must assume that these reductions represented a real decrease in clients using demonstration funding; adjusting for rates of false negative service use reporting suggests that the true decrease in clients using demonstration funding over time was higher (Table 22). The distribution of records across match categories shifted over time. Changes suggest that

[3]Percent fewer unit records at 6 months: spouse, 22.6; daughter, 19.0; son, 18.9; other, 24.5 (percent reductions including UE records with missing units data are higher).

reporting improved, and the use of demonstration and nondemonstration funding sources differed by respondent type.

Crosstabulations were generated for spouses, daughters, sons, and others. Spouses increased rates of exact matches across all interval categories over time, increasing

Set 1. **Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services**

UE Units	TAPE Units-->			Bsseline				
freq % row % col %	1-52.99	53- 104.99	105- 156.99	157- 208.99	209- 260.99	261- 312.99	313- 364.99	Total
1-52.99	279 21.81 75.41 56.02	60 4.69 16.22 16.76	19 1.49 5.14 8.84	9 0.70 2.43 7.96	1 0.08 0.27 1.79	1 0.08 0.27 5.56	1 0.08 0.27 20.00	370 28.93
53-104.99	90 7.04 36.59 18.07	113 8.84 45.93 31.56	34 2.66 13.82 15.81	6 0.47 2.44 5.31	1 0.08 0.41 1.79	1 0.08 0.41 5.56	0 0 0 0	246 19.23
105- 156.99	40 3.13 21.98 8.03	74 5.79 40.66 20.67	53 4.14 29.12 24.65	11 0.86 6.04 9.73	2 0.16 1.10 3.57	1 0.08 0.55 5.56	0 0 0 0	182 14.23
157- 208.99	26 2.03 25.00 5.22	33 2.58 31.73 9.22	30 2.35 28.85 13.95	10 0.78 9.62 8.85	4 0.31 3.85 7.14	0 0 0 0	1 0.08 0.96 20.00	104 8.13
209- 260.99	15 1.17 18.75 3.01	12 0.94 15.00 3.35	25 31.95 31.25 11.63	18 1.41 22.50 15.93	10 0.78 12.50 17.86	0 0 0 0	0 0 0 0	80 6.25
261- 312.99	4 0.31 8.89 0.80	10 0.78 22.22 2.79	7 0.55 15.56 3.26	13 1.02 28.89 11.50	10 0.78 22.22 17.86	1 0.08 2.22 5.56	0 0 0 0	45 3.52
313- 364.99	8 0.63 22.86 1.61	6 0.47 17.14 1.68	5 0.39 14.29 2.33	9 0.70 25.71 7.96	3 0.23 8.57 5.36	2 0.16 5.71 11.11	2 0.16 5.71 40.00	35 2.74
365- 416.99	5 0.39 12.82 1.00	7 0.55 17.95 1.96	8 0.63 20.51 3.72	8 0.63 20.51 7.08	3 0.23 7.69 5.36	4 0.31 10.26 22.22	0 0 0 0	39 3.05
417- 468.99	2 0.16 10.00 0.40	4 0.31 20.00 1.12	5 0.39 25.00 2.33	4 0.31 20.00 3.54	1 0.08 5.00 1.79	3 0.23 15.00 16.67	0 0 0 0	20 1.56
469- 520.99	2 0.16 14.29 0.40	5 0.39 35.71 1.40	2 0.16 14.29 0.93	0 0 0 0	2 0.16 14.29 3.57	1 0.08 7.14 5.56	0 0 0 0	14 1.09
521- 572.99	4 0.31 36.36 0.80	4 0.31 36.36 1.12	1 0.08 9.09 0.47	0 0 0 0	1 0.08 9.09 1.79	0 0 0 0	0 0 0 0	11 0.86
573- 624.99	3 0.23 23.08 0.60	2 0.16 15.38 0.56	1 0.08 7.69 0.47	5 0.39 38.46 4.42	0 0 0 0	1 0.08 7.69 5.56	0 0 0 0	13 1.02
Total	498 38.94	358 27.99	215 16.81	113 8.84	56 4.38	18 1.41	5 0.39	1279

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	160 15.90 76.56 50.16	30 2.98 14.35 12.10	12 1.19 5.74 7.02	5 0.50 2.39 4.55	2 0.20 0.96 2.50	0 0 0 0	0 0 0 0	209 20.78
53-104.99	65 6.46 36.93 20.38	89 8.85 50.57 35.89	14 1.39 7.95 8.19	6 0.60 3.41 5.45	1 0.10 0.57 1.25	0 0 0 0	0 0 0 0	176 17.50
105-156.99	34 3.387 21.94 10.66	44 4.37 28.39 17.74	64 6.36 41.29 37.43	7 0.70 4.52 6.36	4 0.40 2.58 5.00	0 0 0 0	1 0.10 0.65 6.25	155 15.41
157-208.99	16 1.59 17.02 5.02	26 2.58 27.66 10.48	18 1.79 19.15 10.53	25 2.49 26.60 22.73	7 0.70 7.45 8.75	1 0.10 1.06 2.38	0 0 0 0	94 9.34
209-260.99	3 0.30 4.17 0.94	14 1.39 19.44 5.65	15 14.9 20.83 8.77	18 1.79 25.00 16.36	17 1.69 23.61 21.25	5 0.50 6.94 11.90	0 0 0 0	72 7.16
261-312.99	5 0.50 10.64 1.57	8 0.80 17.02 3.23	10 0.99 21.28 5.85	8 0.80 17.02 7.27	6 0.60 12.77 7.50	5 0.50 10.64 11.90	4 0.40 8.51 25.00	47 4.67
313-364.99	5 0.50 11.90 1.57	6 0.60 14.29 2.42	6 0.60 14.29 3.51	11 1.09 26.19 10.00	7 0.70 16.67 8.75	3 0.30 7.14 7.14	3 0.30 7.14 18.75	42 4.17
365-416.99	3 0.30 7.89 0.94	5 0.50 13.16 2.02	6 0.60 15.79 3.51	5 0.50 13.16 4.55	9 0.89 23.68 11.25	6 0.60 15.79 14.29	4 0.40 10.53 25.00	38 3.78
417-468.99	4 0.40 25.00 1.25	1 0.10 6.25 0.40	2 0.20 12.50 1.17	5 0.50 31.25 4.55	2 0.20 12.50 2.50	2 0.20 12.50 4.76	0 0 0 0	16 1.59
469-520.99	4 0.40 28.57 1.25	0 0 0 0	1 0.10 7.14 0.58	2 0.20 14.29 1.82	1 0.10 7.14 1.25	4 0.40 28.57 9.52	0 0 0 0	14 1.39
521-572.99	1 0.10 7.14 0.31	1 0.10 7.14 0.40	2 0.20 14.29 1.17	3 0.30 21.43 2.73	5 0.50 35.71 6.25	2 0.20 14.29 4.76	0 0 0 0	14 1.39
573-624.99	3 0.30 33.33 0.94	5 0.50 55.56 2.02	0 0 0 0	0 0 0 0	1 0.10 11.11 1.25	0 0 0 0	0 0 0 0	9 0.89
Total	319 31.71	248 24.65	171 17.00	110 10.93	80 7.95	42 4.17	16 1.59	1006

row percentages 9 percent or more in some exact match categories. Rates of records underreporting and exceeding TAPE units decreased from baseline to 6 months. The matched pairs *t* test confirms that differences between baseline and 6 months were statistically significant (T_{spouse}=4.63, p=0.0001). Daughters increased row percentages in exact match categories between baseline and 6 months. Rates of records that underreported and exceeded TAPE units generally decreased. Reporting by daughters demonstrated significant period effects ($T_{daughter}$=5.33, p=0.0001). Sons had low rates of units underreporting at baseline, which diminished further by 6 months. Row percentages in exact match categories increased 10 percent or more in most interval categories. UE records exceeding TAPE units increased over time, with records exceeding TAPE units within intervals shifting from the lower unit intervals into the higher intervals. Differences between baseline and 6 month match categories were statistically significant (T_{son}=3.02, p=0.0034). Reports by others did not show statistically different changes over time (T_{other}=1.69, p=0.0932). Row percentages in exact match categories did not show consistent changes over time. UE records exceeding TAPE units also demonstrated no patterns between baseline and 6 months. Rates of UE records underreporting TAPE units increased slightly.

Reporting by most caregivers showed significant differences between baseline and 6 months. Changes suggest that reporting improved and that nondemonstration funding sources were present. Crosstabulations were generated by reported funding source to approximate how accurately respondents identified funding sources (Set 3). The third set of crosstabulations shows personal care/housekeeping/companion crosstabulations by reported funding source. Caregivers reported units of service, and whether all units were funded within the demonstration ("demo only"), outside the demonstration ("nondemo only"), or through both sources ("both").

The first set of crosstabulations shows "nondemo only" units. We know that all baseline and 6 month UE records reporting "nondemo only" funding are incorrect reports

Set 2. **Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship**

Spouse

UE Units	TAPE Units--> Baseline							
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	164 26.49 78.10 60.97	31 5.01 14.76 18.45	8 1.29 3.81 7.77	6 0.97 2.86 14.29	0 0 0 0	1 0.16 0.48 16.67	0 0 0 0	210 33.93
53-104.99	46 7.43 39.32 17.10	51 8.24 43.59 30.36	16 2.58 13.68 15.53	3 0.48 2.56 7.14	0 0 0 0	1 0.16 0.85 16.67	0 0 0 0	117 18.90
105-156.99	21 3.39 23.60 7.81	34 5.49 38.20 20.24	27 4.36 30.34 26.21	5 0.81 5.62 11.90	1 0.16 1.12 3.85	1 0.16 1.12 16.67	0 0 0 0	89 14.38
157-208.99	20 3.23 32.36 7.43	19 3.07 30.65 11.31	14 2.26 22.58 13.59	5 0.81 8.06 11.90	3 0.48 4.84 11.54	0 0 0 0	1 0.16 1.61 100.00	62 10.02
209-260.99	6 0.97 19.35 2.23	4 0.65 12.90 2.38	12 1.94 38.71 11.65	5 0.81 16.13 11.90	4 0.65 12.90 15.38	0 0 0 0	0 0 0 0	31 5.01
261-312.99	2 0.32 10.00 0.74	4 0.65 20.00 2.38	4 0.65 20.00 3.88	4 0.65 20.00 9.52	6 0.97 30.00 23.08	0 0 0 0	0 0 0 0	20 3.23
313-364.99	2 0.32 14.29 0.74	4 0.65 28.57 2.38	4 0.65 28.57 3.88	3 0.48 21.43 7.14	0 0 0 0	1 0.16 7.14 16.67	0 0 0 0	14 2.26
365-416.99	2 0.32 11.76 0.74	4 0.65 25.53 2.38	3 0.48 17.65 2.91	3 0.48 17.65 7.14	3 0.48 17.65 11.54	1 0.16 5.88 16.67	0 0 0 0	17 2.75
417-468.99	0 0 0 0	1 0.16 16.67 0.60	3 0.48 50.00 2.91	1 0.16 16.67 2.38	1 0.16 16.67 3.85	0 0 0 0	0 0 0 0	6 0.97
469-520.99	1 0.16 20.00 0.37	1 0.16 20.00 0.60	1 0.16 20.00 0.97	0 0 0 0	1 0.16 20.00 3.85	0 0 0 0	0 0 0 0	5 0.81
521-572.99	2 0.32 28.57 0.74	3 0.48 48.86 1.79	1 0.16 14.29 0.97	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	7 1.13
Total	269 43.46	168 27.14	103 16.64	42 6.79	26 4.20	6 0.97	1 0.16	619

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Daughter

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	64 16.20 71.11 44.76	16 4.05 17.78 14.68	6 1.52 6.67 9.09	3 0.76 3.33 6.67	1 0.25 1.11 5.88	0 0 0 0	0 0 0 0	90 22.78
53-104.99	34 8.61 40.48 23.78	37 9.37 44.05 33.94	8 2.03 9.52 12.12	3 0.76 3.57 6.67	1 0.25 1.19 5.88	0 0 0 0	0 0 0 0	84 21.27
105-156.99	11 2.78 21.15 7.69	20 5.06 38.46 18.354	16 4.05 30.77 24.24	3 0.76 5.77 6.67	1 0.25 1.92 5.88	0 0 0 0	0 0 0 0	52 13.16
157-208.99	4 1.01 16.67 2.80	8 2.03 33.33 7.34	10 2.53 41.67 15.15	2 0.51 8.33 4.44	0 0 0 0	0 0 0 0	0 0 0 0	24 6.08
209-260.99	6 1.52 20.69 4.20	5 1.27 17.24 4.59	9 2.28 31.03 13.64	7 1.77 24.14 15.56	2 0.51 6.90 11.76	0 0 0 0	0 0 0 0	29 7.34
261-312.99	2 0.51 14.29 1.40	3 0.76 21.43 2.75	2 0.51 14.29 3.03	4 1.01 28.57 8.89	3 0.76 21.43 17.65	0 0 0 0	0 0 0 0	14 3.54
313-364.99	5 1.27 33.33 3.50	1 0.25 6.67 0.92	1 0.25 6.67 1.52	4 1.01 26.67 8.89	2 0.51 13.33 11.76	0 0 0 0	2 0.51 13.33 100.00	15 3.80
365-416.99	2 0.51 11.76 1.40	3 0.76 17.65 2.75	3 0.76 17.65 4.55	4 1.01 25.53 8.89	0 0 0 0	3 0.76 17.65 60.00	0 0 0 0	17 4.30
417-468.99	1 0.25 10.00 0.70	3 0.76 30.00 2.75	2 0.51 20.00 3.03	2 0.51 20.00 4.44	0 0 0 0	1 0.25 10.00 20.00	0 0 0 0	10 2.53
469-520.99	0 0 0 0	2 0.51 40.00 1.83	1 0.25 20.00 1.52	0 0 0 0	1 0.25 20.00 5.88	0 0 0 0	0 0 0 0	5 1.27
521-572.99	2 0.51 66.67 1.40	0 0 0 0	0 0 0 0	0 0 0 0	1 0.25 33.33 5.88	0 0 0 0	0 0 0 0	3 0.76
Total	143 36.20	109 27.59	66 16.71	45 11.39	17 4.30	5 1.27	2 0.51	395

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Son

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	19 19.39 70.37 67.86	6 6.12 22.22 17.65	1 1.02 3.70 7.14	0 0 0 0	0 0 0 0	0 0 0 0	1 1.02 3.70 50.00	27 27.55
53-104.99	3 3.06 13.64 10.71	14 14.29 63.64 41.18	5 5.10 22.73 35.71	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	22 22.45
105-156.99	1 1.02 11.11 3.57	6 6.12 66.67 17.65	1 1.02 11.11 7.14	1 1.02 11.11 9.09	0 0 0 0	0 0 0 0	0 0 0 0	9 9.18
157-208.99	1 1.02 16.67 3.57	3 3.06 50.00 8.82	1 1.02 16.67 7.14	1 1.02 16.67 9.09	0 0 0 0	0 0 0 0	0 0 0 0	6 6.12
209-260.99	0 0 0 0	1 1.02 20.00 2.94	1 1.02 20.00 7.14	1 1.02 20.00 9.09	2 2.04 40.00 40.00	0 0 0 0	0 0 0 0	5 5.10
261-312.99	0 0 0 0	0 0 0 0	0 0 0 0	4 4.08 100.00 36.36	0 0 0 0	0 0 0 0	0 0 0 0	4 4.087
313-364.99	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	0 0.00
365-416.99	0 0 0 0	0 0 0 0	1 1.02 33.33 7.14	1 1.02 33.33 9.09	0 0 0 0	0 0 0 0	0 0 0 0	3 3.06
417-468.99	1 1.02 50.00 3.57	0 0 0 0	0 0 0 0	1 1.02 50.00 9.09	0 0 0 0	0 0 0 0	0 0 0 0	2 2.04
Total	28 28.57	34 34.69	14 14.29	11 11.22	5 5.10	2 2.04	2 2.04	98

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Other

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	32 19.16 74.42 55.17	7 4.19 16.28 14.89	4 2.40 9.30 12.50	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	43 25.75
53-104.99	7 4.19 30.43 12.07	11 6.59 47.83 23.40	5 2.99 21.74 15.63	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	23 13.77
105-156.99	7 4.19 21.88 12.07	14 8.38 43.75 29.79	9 5.39 28.13 28.13	2 1.20 6.25 13.33	0 0 0 0	0 0 0 0	0 0 0 0	32 19.16
157-208.99	1 0.60 8.33 1.72	3 1.80 25.00 6.38	5 2.99 41.67 15.63	2 1.20 16.67 13.33	1 0.60 8.33 12.50	0 0 0 0	0 0 0 0	12 7.19
209-260.99	3 1.80 20.00 5.17	2 1.20 13.33 4.26	3 1.80 20.00 9.38	5 2.99 33.33 33.33	2 1.20 13.33 25.00	0 0 0 0	0 0 0 0	15 8.98
261-312.99	0 0 0 0	3 1.80 43.86 6.38	1 0.60 14.29 3.13	1 0.60 14.29 6.67	1 0.60 14.29 12.50	1 0.60 14.29 20.00	0 0 0 0	7 4.19
313-364.99	1 0.60 16.67 1.72	1 0.60 16.67 2.13	0 0 0 0	2 1.20 33.33 13.33	1 0.60 16.67 12.50	1 0.60 16.67 20.00	0 0 0 0	6 3.59
365-416.99	1 0.60 50.00 1.72	0 0 0 0	1 0.60 50.00 3.13	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 1.20
417-468.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 1.20 100.00 40.00	0 0 0 0	2 1.20
469-520.99	1 0.60 25.00 1.72	2 1.20 50.00 4.26	0 0 0 0	0 0 0 0	0 0 0 0	1 0.60 25.00 25.00	0 0 0 0	4 2.40
521-572.99	0 0 0 0	1 0.60 100.00 2.13	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.60
Total	58 34.73	47 28.14	32 19.16	15 8.98	8 4.79	5 2.99	0	167

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Spouse

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	106 22.13 80.92 58.56	14 2.92 10.69 12.17	7 1.46 5.34 9.09	4 0.84 3.05 8.70	0 0 0 0	0 0 0 0	0 0 0 0	131 27.35
53-104.99	35 7.31 39.33 19.34	41 8.56 46.07 35.65	9 1.88 10.11 11.69	3 0.63 3.37 6.52	1 0.21 1.12 3.13	0 0 0 0	0 0 0 0	89 18.58
105-156.99	18 3.76 22.50 9.94	26 5.43 32.50 22.61	31 6.47 38.75 40.26	3 0.63 3.75 6.52	1 0.21 1.25 3.13	0 0 0 0	1 0.21 1.25 16.67	80 16.70
157-208.99	6 1.25 15.00 3.31	10 2.09 25.00 8.70	7 1.46 17.50 9.09	12 2.51 30.00 26.09	4 0.84 10.00 12.50	0 0 0 0	0 0 0 0	40 8.35
209-260.99	2 0.42 6.25 1.10	8 1.67 25.00 6.96	6 1.25 18.75 7.79	8 1.67 25.00 17.39	7 1.46 21.88 21.88	1 0.21 3.13 5.88	0 0 0 0	32 6.68
261-312.99	2 0.42 12.50 1.10	3 0.63 18.75 2.61	4 0.84 25.00 5.19	2 0.42 12.50 4.35	1 0.21 6.25 3.13	2 0.42 12.50 11.76	1 0.21 6.25 16.67	16 3.34
313-364.99	1 0.21 7.69 0.55	2 0.42 15.38 1.74	0 0 0 0	4 0.84 30.77 8.70	3 0.63 23.08 9.38	2 0.42 15.38 11.76	1 0.21 7.69 16.67	13 2.71
365-416.99	1 0.21 7.14 0.55	2 0.42 14.29 1.74	2 0.42 14.29 2.60	1 0.21 7.14 2.17	4 0.84 28.57 12.50	2 0.42 14.29 11.76	2 0.42 14.29 33.33	14 2.92
417-468.99	1 0.21 16.67 0.55	1 0.21 16.67 0.87	1 0.21 16.67 1.30	1 0.21 16.67 2.17	1 0.21 16.67 3.13	1 0.21 16.67 5.88	0 0 0 0	6 1.25
469-520.99	1 0.21 20.00 0.55	0 0 0 0	1 0.21 20.00 1.30	1 0.21 20.00 2.17	0 0 0 0	1 0.21 20.00 5.88	0 0 0 0	5 1.04
521-572.99	1 0.21 20.00 0.55	0 0 0 0	0 0 0 0	1 0.21 20.00 2.17	2 0.42 40.00 6.25	1 0.21 20.00 5.88	0 0 0 0	5 1.04
Total	181 37.79	115 24.01	77 16.08	46 9.60	32 6.68	17 3.55	6 1.25	479

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Daughter

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	31 9.69 64.58 40.26	11 3.44 22.92 12.09	4 1.25 8.33 6.25	1 0.31 2.08 3.13	1 0.31 2.08 3.23	0 0 0 0	0 0 0 0	48 15.00
53-104.99	12 3.75 26.09 15.58	30 9.39 65.22 32.97	4 1.25 8.70 6.25	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	46 14.38
105-156.99	7 2.19 19.44 9.09	9 2.81 25.00 9.89	18 5.63 50.00 28.13	1 0.31 2.78 3.13	1 0.31 2.78 3.23	0 0 0 0	0 0 0 0	36 11.25
157-208.99	6 1.88 15.00 7.79	14 4.38 35.00 15.38	9 2.81 22.50 14.06	8 2.50 20.00 25.00	2 0.63 5.00 6.45	1 0.31 2.50 8.33	0 0 0 0	40 12.50
209-260.99	1 0.31 3.45 1.30	6 1.88 20.69 6.59	6 1.88 20.69 9.38	5 1.56 17.24 15.63	8 2.50 27.59 25.81	3 0.94 10.34 25.00	0 0 0 0	29 9.06
261-312.99	1 0.31 5.88 1.30	3 0.94 17.65 3.30	5 1.56 29.41 7.81	3 0.94 17.65 9.38	3 0.94 17.65 9.68	0 0 0 0	2 0.63 11.76 22.22	17 5.31
313-364.99	3 0.94 16.67 3.90	3 0.94 16.67 3.30	5 1.56 27.78 7.81	3 0.94 16.67 9.38	2 0.63 11.11 6.45	0 0 0 0	2 0.63 11.11 22.22	18 5.63
365-416.99	1 0.31 6.67 1.30	2 0.63 13.33 2.20	3 0.94 20.00 4.69	1 0.31 6.67 3.13	2 0.63 13.33 6.45	4 1.25 26.67 33.33	2 0.63 13.33 22.22	15 4.69
417-468.99	3 0.94 37.50 3.90	0 0 0 0	1 0.31 12.50 1.56	2 0.63 25.00 6.25	1 0.31 12.50 3.23	1 0.31 12.50 8.33	0 0 0 0	8 2.50
469-520.99	2 0.63 50.00 2.60	0 0 0 0	0 0 0 0	1 0.31 25.00 3.13	0 0 0 0	1 0.31 25.00 8.33	0 0 0 0	4 1.25
521-572.99	0 0 0 0	0 0 0 0	1 0.31 16.67 1.56	2 0.63 33.33 6.25	3 0.94 50.00 9.68	0 0 0 0	0 0 0 0	6 1.88
Total	77 24.06	91 28.44	64 20.00	32 10.00	31 9.69	12 3.75	9 2.81	320

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Son

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	8 9.88 80.00 38.10	2 2.47 20.00 14.29	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	10 12.35
53-104.99	8 9.88 44.44 38.10	8 9.88 44.44 57.14	1 1.23 5.56 8.33	1 1.23 5.56 10.00	0 0 0 0	0 0 0 0	0 0 0 0	18 22.22
105-156.99	2 2.47 22.22 9.52	1 1.23 11.11 7.14	4 4.94 44.44 33.33	0 0 0 0	1 1.23 11.11 10.00	0 0 0 0	0 0 0 0	9 11.11
157-208.99	1 1.23 14.29 4.76	1 1.23 14.29 7.14	2 2.47 28.57 16.67	3 3.70 42.86 30.00	0 0 0 0	0 0 0 0	0 0 0 0	7 8.64
209-260.99	0 0 0 0	0 0 0 0	1 1.23 16.67 8.33	2 2.47 33.33 20.00	2 2.47 33.33 20.00	1 1.23 16.67 12.50	0 0 0 0	6 7.41
261-312.99	1 1.23 25.00 4.76	0 0 0 0	1 1.23 25.00 8.33	0 0 0 0	0 0 0 0	1 1.23 25.00 12.50	1 1.23 25.00 100.00	4 4.94
313-364.99	0 0 0 0	0 0 0 0	1 1.23 20.00 8.33	1 1.23 20.00 10.00	2 2.47 40.00 20.00	0 0 0 0	0 0 0 0	5 6.17
365-416.99	0 0 0 0	0 0 0 0	0 0 0 0	2 2.47 66.67 20.00	1 1.23 33.33 10.00	0 0 0 0	0 0 0 0	3 3.70
417-468.99	0 0 0 0	0 0 0 0	0 0 0 0	1 1.23 100.00 10.00	0 0 0 0	0 0 0 0	0 0 0 0	1 1.23
469-520.99	1 1.23 25.00 4.76	0 0 0 0	0 0 0 0	0 0 0 0	1 1.23 25.00 10.00	2 2.47 50.00 25.00	0 0 0 0	4 4.94
521-572.99	0 0 0 0	1 1.23 50.00 7.14	0 0 0 0	0 0 0 0	0 0 0 0	1 1.23 50.00 12.50	0 0 0 0	2 2.47
Total	21 25.93	14 17.28	12 14.81	10 12.35	10 12.35	8 9.88	1 1.23	81

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Caregiver Relationship

Other

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	15 11.90 75.00 37.50	3 2.38 15.00 10.71	1 0.79 5.00 5.56	0 0 0 0	1 0.79 5.00 14.29	0 0 0 0	0 0 0 0	20 15.87
53-104.99	10 7.94 43.48 25.00	10 7.94 43.48 35.71	0 0 0 0	2 1.59 8.70 9.09	0 0 0 0	0 0 0 0	0 0 0 0	23 18.25
105-156.99	7 5.56 23.33 17.50	8 6.35 26.67 28.57	11 8.73 36.67 61.11	3 2.38 10.00 13.64	1 0.79 3.33 14.29	0 0 0 0	0 0 0 0	30 23.61
157-208.99	3 2.38 42.86 7.50	1 0.79 14.29 3.57	0 0 0 0	2 1.59 28.57 9.09	1 0.79 14.29 14.29	0 0 0 0	0 0 0 0	7 5.56
209-260.99	0 0 0 0	0 0 0 0	2 1.59 40.00 11.11	3 2.38 60.00 13.64	0 0 0 0	0 0 0 0	0 0 0 0	5 3.97
261-312.99	1 0.79 10.00 2.50	2 1.59 20.00 7.14	0 0 0 0	3 2.38 30.00 13.64	2 1.59 20.00 28.57	2 1.59 20.00 40.00	0 0 0 0	10 7.94
313-364.99	1 0.79 16.67 2.50	1 0.79 16.67 3.57	0 0 0 0	3 2.38 50.00 13.64	0 0 0 0	1 0.79 16.67 20.00	0 0 0 0	6 4.76
365-416.99	1 0.79 16.67 2.50	1 0.79 16.67 3.57	1 0.79 16.67 5.56	1 0.79 16.67 4.55	2 1.59 33.33 28.57	0 0 0 0	0 0 0 0	6 4.76
417-468.99	0 0 0 0	0 0 0 0	0 0 0 0	1 0.79 100.00 4.55	0 0 0 0	0 0 0 0	0 0 0 0	1 0.79
469-520.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.79
521-572.99	0 0 0 0	0 0 0 0	1 0.79 100.00 5.56	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.79
Total	40 31.75	28 22.22	18 14.29	22 17.46	7 5.56	5 3.97	0	126

of funding source. All these UE service use transactions have corresponding TAPE service use transactions. The service units would have to have been funded through either "demo only" or "both" funding sources. The crosstabulations of "nondemo only" units shows that rates of exact matches improved from baseline to 6 months. Matches in these categories represent accurate reports of demonstration units. Rates of records underreporting units decreased slightly over time. UE records exceeding TAPE units include overreported "demo only" units and (possibly accurate) "both" units. Rates of UE records exceeding TAPE units did not show consistent changes over time. Reporting of "nondemo units" showed significant period effects ($T_{nondemo}$=2.88, p=0.0001).

Crosstabulations of "demo only" units support our suspicion that a sizable portion of UE "nondemo only" records should have reported "demo only" or "both" units. The numbers of crosstabulated records in each period is far below the total number of UE service use records having TAPE service use transactions. Rates of records that underreported TAPE units are low in both reporting periods. Row percentages in exact match categories increased over time. Row percentages in "demo only" exact match categories are higher than in "nondemo only" exact match categories; these differences were not tested for statistical significance. Rates of UE records exceeding TAPE units generally decreased over time. UE records exceeding TAPE units include overreported "demo only" units and (possibly accurate) "both" units. The matched pairs *t* test shows that match categories differed significantly between baseline and 6 months (T_{demo}=2.88, p=0.0042).

Crosstabulations of "both" units show low rates of underreporting at baseline, diminishing to negligible levels at 6 months. Rates of exact matches appear lower than for "nondemo only" and "demo only" units, though these differences were not statistically tested. Rates of UE records exceeding TAPE units generally exceeded 70 percent of UE records within intervals, and rates of records exceeding TAPE units within intervals increased over time. We expect high rates of records exceeding TAPE units because

respondents reported that they supplemented demonstration funding. The matched pairs *t* test confirms that differences between baseline and 6 months were statistically significant (T_{both}=6.93, p=0.0001).

Set 3. **Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source**

"nondemo only"

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	136 23.82 75.56 55.06	33 5.78 18.33 18.97	8 1.40 4.44 9.76	3 0.53 1.67 9.09	0 0 0 0	0 0 0 0	0 0 0 0	180 31.52
53-104.99	39 6.83 33.91 15.97	63 11.03 54.78 36.21	11 1.93 9.57 13.41	2 0.35 1.74 6.06	0 0 0 0	0 0 0 0	0 0 0 0	115 20.14
105-156.99	18 3.15 25.35 7.29	24 4.20 33.80 13.79	20 3.50 27.17 24.39	7 1.23 9.86 21.21	2 0.35 2.82 11.11	0 0 0 0	0 0 0 0	71 12.43
157-208.99	12 2.10 28.57 4.86	13 2.28 30.95 7.47	12 2.10 28.57 14.63	2 0.35 4.76 6.06	2 0.35 4.76 11.11	0 0 0 0	1 0.18 2.38 33.33	42 7.36
209-260.99	10 1.75 34.48 4.05	3 0.53 10.34 1.72	8 1.40 27.59 9.76	6 1.05 20.69 18.18	2 0.35 6.90 11.11	0 0 0 0	0 0 0 0	29 5.08
261-312.99	3 0.53 21.43 1.21	3 0.53 21.43 1.72	3 0.53 21.43 3.66	5 0.88 35.71 15.15	0 0 0 0	0 0 0 0	0 0 0 0	14 2.45
313-364.99	6 1.05 30.00 2.43	4 0.70 20.00 2.30	3 0.53 15.00 3.66	1 0.18 5.00 3.03	2 0.35 10.00 11.11	2 0.35 10.00 33.33	2 0.35 10.00 66.67	20 3.50
365-416.99	1 0.18 6.67 0.40	4 0.70 26.67 2.30	2 0.35 13.33 2.44	0 0 0 0	2 0.35 13.33 11.11	3 0.53 20.00 50.00	0 0 0 0	15 2.63
417-468.99	0 0 0 0	3 0.53 50.00 1.72	2 0.35 33.33 2.44	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	6 1.05
469-520.99	1 0.18 16.67 0.40	3 0.53 50.00 1.72	0 0 0 0	0 0 0 0	1 0.18 16.67 5.56	0 0 0 0	0 0 0 0	6 1.05
521-572.99	1 0.18 25.00 0.40	2 0.35 50.00 1.15	0 0 0 0	0 0 0 0	1 0.18 25.00 5.56	0 0 0 0	0 0 0 0	4 0.70
Total	247 43.26	174 30.47	82 14.36	33 5.78	18 3.15	6 1.05	3 0.53	571

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source

"nondemo only"

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	90 19.19 76.92 49.45	17 3.62 14.53 14.05	6 1.28 5.13 9.09	3 0.64 2.56 7.14	1 0.21 0.85 3.57	0 0 0 0	0 0 0 0	117 24.95
53-104.99	39 8.32 38.61 21.43	49 10.45 48.51 40.50	9 1.92 8.91 13.64	3 0.64 2.97 7.14	1 0.21 0.99 3.57	0 0 0 0	0 0 0 0	101 21.54
105-156.99	12 2.56 18.75 6.59	18 3.84 28.13 14.88	31 6.61 48.44 46.97	2 0.43 3.13 4.76	0 0 0 0	0 0 0 0	1 0.21 1.56 16.67	64 13.65
157-208.99	10 2.13 28.57 5.49	8 1.71 22.86 6.61	3 0.64 8.57 4.55	9 1.92 25.71 21.43	3 0.64 8.57 10.71	1 0.21 2.86 5.56	0 0 0 0	35 7.46
209-260.99	2 0.43 6.67 1.10	7 1.49 23.33 5.79	5 1.07 16.67 7.58	6 1.28 20.00 14.29	8 1.71 26.67 28.57	2 0.43 6.67 11.11	0 0 0 0	30 6.40
261-312.99	2 0.43 14.29 1.10	4 0.85 28.57 3.31	2 0.43 14.29 3.03	2 0.43 14.29 4.76	3 0.64 21.43 10.71	1 0.21 7.14 5.56	0 0 0 0	14 2.99
313-364.99	5 1.07 31.25 2.75	2 0.43 12.50 1.65	0 0 0 0	3 0.64 18.75 7.14	2 0.43 12.50 7.14	1 0.21 6.25 5.56	2 0.43 12.50 33.33	16 3.41
365-416.99	3 0.64 25.00 1.65	3 0.64 25.00 2.48	2 0.43 16.67 3.03	1 0.21 8.33 2.38	1 0.21 8.33 3.57	1 0.21 8.33 5.56	1 0.21 8.33 16.67	12 2.56
417-468.99	2 0.43 33.33 1.10	0 0 0 0	1 0.21 16.67 1.52	2 0.43 33.33 4.76	0 0 0 0	1 0.21 16.67 5.56	0 0 0 0	6 1.28
469-520.99	2 0.43 28.57 1.10	0 0 0 0	1 0.21 14.29 1.52	1 0.21 14.29 2.38	0 0 0 0	3 0.64 42.84 16.67	0 0 0 0	7 1.49
521-572.99	1 0.21 11.11 0.55	0 0 0 0	0 0 0 0	3 0.64 33.33 7.14	3 0.64 33.33 10.71	2 0.43 22.22 11.11	0 0 0 0	9 1.92
Total	182 38.81	121 25.80	66 14.07	42 8.96	28 5.97	18 3.84	6 1.28	469

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source

"demo only"

UE Units TAPE Units--> Baseline

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	120 29.63 78.95 72.73	20 4.94 13.16 18.87	8 1.98 5.26 11.27	3 0.74 1.97 8.82	0 0 0 0	0 0 0 0	1 0.25 0.66 100.00	152 37.53
53-104.99	34 8.40 35.05 20.61	41 10.12 42.27 38.68	17 4.20 17.53 23.94	3 0.74 3.09 8.82	1 0.25 1.03 5.26	0 0 0 0	0 0 0 0	97 23.95
105-156.99	6 1.48 9.68 3.64	30 7.41 48.39 28.30	23 5.68 37.10 32.39	3 0.74 4.84 8.82	0 0 0 0	0 0 0 0	0 0 0 0	62 15.31
157-208.99	4 0.99 12.50 2.42	6 1.48 18.75 5.66	13 3.21 40.63 18.31	7 1.73 21.88 20.59	2 0.49 6.25 10.53	0 0 0 0	0 0 0 0	32 7.90
209-260.99	0 0 0 0	3 0.74 15.00 2.83	4 0.99 20.00 5.63	7 1.73 35.00 20.59	6 1.48 30.00 31.58	0 0 0 0	0 0 0 0	20 4.94
261-312.99	0 0 0 0	3 0.74 23.08 2.83	1 0.25 7.69 1.41	3 0.74 23.08 8.82	6 1.48 46.15 31.58	0 0 0 0	0 0 0 0	13 3.21
313-364.99	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	. . . .	0 0.00
365-416.99	0 0 0 0	2 0.49 22.22 1.89	1 0.25 11.11 1.41	4 0.99 44.44 11.76	1 0.25 11.11 5.26	0 0 0 0	0 0 0 0	9 2.22
417-468.99	0 0 0 0	0 0 0 0	1 0.25 50.00 1.41	0 0 0 0	0 0 0 0	1 0.25 50.00 33.33	0 0 0 0	2 0.49
469-520.99	1 0.25 33.33 0.61	0 0 0 0	0 0 0 0	0 0 0 0	1 0.25 33.33 5.26	1 0.25 33.33 33.33	0 0 0 0	3 0.74
521-572.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.25
573-624.99	0 0 0 0	0 0 0 0	0 0 0 0	2 0.49 100.00 5.88	0 0 0 0	0 0 0 0	0 0 0 0	2 0.49
Total	165 40.74	106 26.17	71 17.53	34 8.40	19 4.69	3 0.74	1 0.25	405

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source

"demo only"

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	62 20.88 81.58 66.67	8 2.69 10.53 11.43	4 1.35 5.26 7.84	1 0.34 1.32 2.70	1 0.34 1.32 4.17	0 0 0 0	0 0 0 0	76 25.59
53-104.99	18 6.06 30.51 19.35	36 12.12 61.02 51.43	2 0.67 3.39 3.92	3 1.01 5.08 8.11	0 0 0 0	0 0 0 0	0 0 0 0	59 19.87
105-156.99	9 3.03 16.07 9.68	14 4.71 25.00 20.00	25 8.42 44.64 49.02	5 1.68 8.93 13.51	2 0.67 3.57 8.33	0 0 0 0	0 0 0 0	56 18.86
157-208.99	1 0.34 2.86 1.08	7 2.36 20.00 10.00	9 3.03 25.71 17.65	14 4.71 40.00 37.84	4 1.35 11.43 16.67	0 0 0 0	0 0 0 0	35 11.78
209-260.99	0 0 0 0	0 0 0 0	2 0.67 10.53 3.92	7 2.36 36.84 18.92	8 2.69 42.11 33.33	2 0.67 10.53 22.22	0 0 0 0	19 6.40
261-312.99	2 0.67 14.29 2.15	0 0 0 0	3 1.01 21.43 5.88	2 0.67 14.29 5.41	0 0 0 0	3 1.01 21.43 33.33	3 1.01 21.43 50.00	14 4.71
313-364.99	0 0 0 0	3 1.01 27.27 4.29	3 1.01 27.27 5.88	3 1.01 27.27 8.11	2 0.67 18.18 8.33	0 0 0 0	0 0 0 0	11 3.70
365-416.99	0 0 0 0	0 0 0 0	1 0.34 14.29 1.96	1 0.34 14.29 2.70	3 1.01 42.86 12.50	0 0 0 0	2 0.67 28.57 33.33	7 2.36
417-468.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.34 100.00 11.11	0 0 0 0	1 0.34
469-520.99	1 0.34 33.33 1.08	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	1 0.34 33.33 11.11	0 0 0 0	3 1.01
521-572.99	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	2 0.67 100.00 8.33	0 0 0 0	0 0 0 0	2 0.67
Total	93 31.31	70 23.57	51 17.17	37 12.46	24 8.08	9 3.03	6 2.02	297

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source

"both"

UE Units	TAPE Units-->			Baseline				
freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	23 7.59 60.53 26.74	7 2.31 18.42 8.97	3 0.99 7.89 4.84	3 0.99 7.89 6.52	1 0.33 2.63 5.26	1 0.32 2.63 11.11	0 0 0 0	38 12.54
53-104.99	17 5.61 50.00 19.77	9 2.97 26.47 11.54	6 1.98 17.65 9.68	1 0.33 2.94 2.17	0 0 0 0	1 0.33 2.94 11.11	0 0 0 0	34 11.22
105-156.99	16 5.28 32.65 18.60	20 6.60 40.82 25.64	10 3.30 20.41 16.13	1 0.33 2.04 2.17	0 0 0 0	1 0.33 2.04 11.11	0 0 0 0	49 16.17
157-208.99	10 3.30 33.33 11.63	14 4.62 46.67 17.95	5 1.65 16.67 8.06	1 0.33 3.33 2.17	0 0 0 0	0 0 0 0	0 0 0 0	30 9.90
209-260.99	5 1.65 16.13 5.81	6 1.98 19.35 7.69	13 4.29 41.94 20.97	5 1.65 16.13 10.87	2 0.66 6.45 10.53	0 0 0 0	0 0 0 0	31 10.23
261-312.99	1 0.33 5.56 1.16	4 1.32 22.22 5.13	3 0.99 16.67 4.84	5 1.65 27.78 10.87	4 1.32 22.22 21.05	1 0.33 5.56 11.11	0 0 0 0	18 5.94
313-364.99	2 0.66 13.33 2.33	2 0.66 13.33 2.56	2 0.66 13.33 3.23	8 2.64 53.33 17.39	1 0.33 6.67 5.26	0 0 0 0	0 0 0 0	15 4.95
365-416.99	4 1.32 26.67 4.65	1 0.33 6.67 1.28	5 1.65 33.33 8.06	4 1.32 26.67 8.70	0 0 0 0	1 0.33 6.67 11.11	0 0 0 0	15 4.95
417-468.99	2 0.66 16.67 2.33	1 0.33 8.33 1.28	2 0.66 16.67 3.23	4 1.32 33.33 8.70	1 0.33 8.33 5.26	2 0.66 16.67 22.22	0 0 0 0	12 3.96
469-520.99	0 0 0 0	2 0.66 40.00 2.56	2 0.66 40.00 3.23	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	5 1.65
521-572.99	3 0.99 50.00 3.49	2 0.66 33.33 2.56	1 0.33 16.67 1.61	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	6 1.98
Total	86 28.38	78 25.74	62 20.46	46 15.18	19 6.27	9 2.97	1 0.33	303

Crosstabulations of Claims TAPE and UE Units for Personal Care/Housekeeping/Companion Services by Funding Source

"both"

UE Units TAPE Units--> 6 Months

freq % row % col %	1-52.99	53-104.99	105-156.99	157-208.99	209-260.99	261-312.99	313-364.99	Total
1-52.99	8 3.33 50.00 18.18	5 2.08 31.25 8.77	2 0.83 12.50 3.70	1 0.42 6.25 3.23	0 0 0 0	0 0 0 0	0 0 0 0	16 6.67
53-104.99	8 3.33 50.00 18.18	4 1.67 25.00 7.02	3 1.25 18.75 5.56	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	16 6.67
105-156.99	13 5.42 37.14 29.55	12 5.00 34.29 21.05	8 3.33 22.86 14.81	0 0 0 0	2 0.83 5.71 7.14	0 0 0 0	0 0 0 0	35 14.58
157-208.99	5 2.08 20.83 11.36	11 4.58 45.83 19.30	6 2.50 25.00 11.11	2 0.83 8.33 6.45	0 0 0 0	0 0 0 0	0 0 0 0	24 10.00
209-260.99	1 0.42 4.35 2.27	7 2.92 30.43 12.28	8 3.33 37.78 14.81	5 2.08 21.74 16.13	1 0.42 4.35 3.57	1 0.42 4.35 6.67	0 0 0 0	23 9.58
261-312.99	1 0.42 5.26 2.27	4 1.67 21.05 7.02	5 2.08 26.32 9.26	4 1.67 21.05 12.90	3 1.25 15.79 10.71	1 0.42 5.26 6.67	1 0.42 5.26 25.00	19 7.92
313-364.99	0 0 0 0	1 0.42 6.67 1.75	3 1.25 20.00 5.56	5 2.08 33.33 16.13	3 1.25 20.00 10.71	2 0.83 13.33 13.33	1 0.42 6.67 25.00	15 6.25
365-416.99	0 0 0 0	2 0.83 10.53 3.51	3 1.25 15.79 5.56	3 1.25 15.79 9.68	5 2.08 26.32 17.86	5 2.08 26.32 33.33	1 0.42 5.26 25.00	19 7.92
417-468.99	2 0.83 22.22 4.55	1 0.42 11.11 1.75	1 0.42 11.11 1.85	3 1.25 33.33 9.68	2 0.83 22.22 7.14	0 0 0 0	0 0 0 0	9 3.75
469-520.99	1 0.42 25.00 2.27	0 0 0 0	0 0 0 0	1 0.42 25.00 3.23	1 0.14 25.00 3.57	0 0 0 0	0 0 0 0	4 1.67
521-572.99	0 0 0 0	1 0.42 33.33 1.75	2 0.83 66.67 3.70	0 0 0 0	0 0 0 0	0 0 0 0	0 0 0 0	3 1.25
Total	44 18.33	57 23.75	54 22.50	31 12.92	28 11.67	15 6.25	4 1.67	240

Appendix L

UE Service Use Transactions and TAPE Service Use Transactions Present: Comparisons of UE Records with Units and with Missing Units Across Selected Variables

UE Service Use Transactions and TAPE Service Use Transactions Present:

Comparisons of UE Records with Units and with Missing Units Across Selected Variables

	Baseline Day Care		6 month Day Care		Baseline Personal Care		6 month Personal Care	
	UE with missing units N=26	UE with usable units N=667	UE with missing units N=14	UE with usable units N=486	UE with missing units N=96	UE with usable units N=1280	UE with missing units N=50	UE with usable units N=1006
	N %	N %	N %	N %	N %	N %	N %	N %
Spouse	15 57.7	374 56.1	10 71.4	270 55.6	39 40.6	619 48.4	30 60.0	479 47.6
Daughter	7 26.9	180 27.0	2 14.3	144 29.6	28 29.2	396 30.9	11 22.0	320 31.8
Son	2 7.7	39 5.8	1 7.1	28 5.8	9 9.4	98 7.7	3 6.0	81 8.1
Other	2 7.7	74 11.1	1 7.1	44 9.1	20 20.8	167 13.0	6 12.0	126 12.5
Caregiver lives with client	18 69.2	482 72.5	9 64.3	362 74.5	48 51.6	884 69.6	30 61.2	681 68.1
Any hospital stay during period	7 26.9	150 22.5	4 28.6	105 21.6	26 27.1	327 25.5	17 34.0	258 25.6
Any nursing home stay during period	14 15.4	102 15.3	3 21.4	59 12.1	16 16.7	150 11.7	6 12.0	140 13.9
Mean demo dollars paid for ALL services	1125	1460	1343	1783	1323	1216	1553	1490

Appendix M

UE Service Use Transactions and TAPE Service Use Transactions Present, and UE Service Use Transactions Present but TAPE Zero-Use Transactions: Comparisons Across Selected Variables. Source-Adjusted UE Data File

UE Service Use Transactions and TAPE Service Use Transactions Present, and UE Service Use Transactions Present but TAPE Zero-Use Transactions: Comparisons Across Selected Variables

Source-Adjusted UE Data File

	Used at least 1 demo service during reporting period	Mean dollars demo paid for ALL services in period	Mean months of demo services during reporting period	Any client hosp stay during reporting period	Any client nursing home stay during period	Client lived with cg
	N %	N mean SD	N SD	N %	N %	N %
BL Day Care						
UE Service Use and TAPE Service Use N=695	695 (100.0)	695 1448 (794.9)	4.8 (1.4)	158 (22.7)	106 (15.3)	502 (72.4)
UE Service Use and TAPE Zero-Use N=215	136 (63.3)	135 1090 (747.5)	4.3 (1.7)	34 (15.8)	36 (16.7)	144 (67.0)
6 month Day Care						
UE Service Use and TAPE Service Use N=500	500 (100.0)	500 1771 (862.5)	5.2 (1.3)	109 (21.8)	62 (12.4)	371 (74.2)
UE Service Use and TAPE Zero-Use N=137	88 (64.2)	87 1210 (843.9)	4.5 (1.8)	31 (22.6)	21 (15.3)	91 (66.4)
BL Pers Care						
UE Service Use and TAPE Service Use N=1383	1383 (100.0)	1383 1223 (790.1)	4.6 (1.5)	354 (25.6)	169 (12.2)	935 (68.2)
UE Service Use and TAPE Zero-Use N=533	287 (53.8)	287 855 (697.9)	4.0 (1.8)	148 (27.8)	80 (15.0)	351 (66.1)
6 month Pers Care						
UE Service Use and TAPE Service Use N=1058	1058 (100.0)	1058 1493 (898.7)	5.0 (1.5)	276 (26.1)	146 (13.8)	713 (67.8)
UE Service Use and TAPE Zero-Use N=394	204 (51.8)	201 976 (755.5)	4.3 (1.9)	101 (25.6)	46 (11.7)	262 (67.0)

UE Service Use Transactions and TAPE Service Use Transactions Present, and UE Service Use Transactions Present but TAPE Zero-Use Transactions: Frequencies of Demonstration Services from Claims TAPE

Source-Adjusted UE Data File

	Baseline Day Care		6 month Day Care		Baseline Personal Care		6 month Personal Care	
	UE & TAPE svc use	UE svc use & TAPE zero	UE & TAPE svc use	UE svc use & TAPE zero	UE & TAPE svc use	UE svc use & TAPE zero	UE & TAPE svc use	UE svc use & TAPE zero
	N=695	N=215	N=500	N=137	N=1383	N=533	N=1058	N=394
	N %	N %	N %	N %	N %	N %	N %	N %
No Demonstration Services	0 0.0	80 37.2	0 0.0	50 36.5	0 0.0	246 46.1	0 0.0	193 49.0
Mental Health Services	24 3.4	13 6.0	15 3.0	4 2.9	38 2.7	16 3.0	18 1.7	9 2.3
Day Care	695 100.0	0 0.0	500 100.0	0 0.0	282 20.4	153 28.7	189 17.9	93 23.6
Home Delivered Meals	36 5.2	5 2.3	25 5.0	5 3.6	93 6.7	21 3.9	74 6.7	20 5.1
Skilled Nursing	22 3.2	2 0.9	11 2.2	2 1.4	33 2.4	2 0.4	27 2.5	3 0.8
Skilled Physical Therapy	8 1.2	2 0.9	3 0.6	1 0.7	16 1.2	6 1.1	8 0.7	4 1.0
Transportation	124 17.8	11 5.1	106 21.2	5 3.6	95 6.9	34 6.4	71 6.7	21 5.3
Adaptive / Assistive Equipment	192 27.6	44 20.5	79 15.8	13 9.5	384 27.8	83 15.6	135 12.7	28 7.1
Durable Medical Equipment	129 18.6	21 9.8	49 9.8	6 4.4	235 17.0	46 8.6	88 8.3	41 10.4
Incontinence Supplies, Consumable Goods	189 27.2	47 21.9	173 34.6	38 27.7	500 36.1	172 32.3	428 40.4	153 38.8
Personal Care/Housekeeping/Companion	292 42.0	112 52.1	183 36.6	73 53.3	1383 100.0	0 0.0	1058 100.0	0 0.0

Appendix N

Mean UE and TAPE Units on Cases Retained for Regression Analysis and Cases Excluded from Regression Analysis

Mean UE and TAPE Units on Cases Retained for Regression Analysis and Cases Excluded from Regression Analysis, by Caregiver Relationship

Set 1

Cases Retained for Regressions Predicting Day Care Residual Units

	Spouse	Daughter	Son	Other
Baseline Day Care				
N	372	180	39	73
Mean UE Units	45.8	57.8	55.9	47.5
(SD)	33.0	39.4	41.9	35.1
Mean TAPE Units	32.1	36.5	33.1	30.1
(SD)	21.9	26.3	24.3	21.0
6 Month Day Care				
N	267	142	27	59.0
Mean UE Units	53.8	69.0	71.9	59.0
(SD)	32.0	42.1	45.8	32.4
Mean TAPE Units	40.5	43.6	45.3	41.2
(SD)	24.0	28.8	31.2	25.0

Cases Excluded from Regressions Predicting Day Care Residual Units

	Spouse	Daughter	Son	Other
Baseline Day Care				
N	2	2	0	1
Mean UE Units	180	180	--	180
(SD)	--	--	--	--
Mean TAPE Units	51.5	44.5	--	33
(SD)	2.1	13.4	--	--
6 Month Day Care				
N	3	2	1	1
Mean UE Units	181.3	182	180	180
(SD)	1.1	--	--	--
Mean TAPE Units	58.3	47.5	24	76
(SD)	15.4	0.7	--	--

Mean UE and TAPE Units on Cases Retained for Regression Analysis and Cases Excluded from Regression Analysis, by Caregiver Relationship

Set 2

Cases Retained for Regressions Predicting Personal Care Residual Units

Caregiver Relationship	Spouse	Daughter	Son	Other
Baseline Personal Care				
N	621	396	98	167
Mean UE Units	176.4	288.0	345.6	238.5
(SD)	245.7	485.1	598.6	321.2
Mean TAPE Units	81.9	97.4	106.7	96.4
(SD)	76.2	86.0	85.3	82.2
6 Month Personal Care				
N	477	320	83	126
Mean UE Units	232.5	345.7	345.9	386.5
(SD)	347.7	442.1	533.9	743.2
Mean TAPE Units	102.3	122.3	148.5	125.3
(SD)	87.2	88.2	111.4	124.3

Cases Excluded from Regressions Predicting Personal Care Residual Units

	Spouse	Daughter	Son	Other
Baseline Personal Care				
N	1	3	0	1
Mean UE Units	4368	4368	--	4368
(SD)	--	--	--	--
Mean TAPE Units	88	41	--	246.2
(SD)	--	22.5	--	--
6 Month Personal Care				
N	2	0	0	0
Mean UE Units	4368	--	--	--
(SD)	--	--	--	--
Mean TAPE Units	112	--	--	--
(SD)	135.7	--	--	--

Appendix O

Median Cost Per Unit of Service and Maximum Units Theoretically Allowed Per Client Exposure Month, by Service and Demonstration Site

Median Cost Per Unit of Service and Maximum Units Theoretically Allowed Per Eligible Month, by Service and Demonstration Site

Service and Site[1]	Median Dollars / Unit	Maximum Allowable Units / Exposure Month
Baseline Day Care		
New York	40.6	7.4
Illinois	28.7	10.4
Tennessee	18.1	16.6
Oregon	30.3	9.9
Ohio	34.2	14.6
West Virginia	19.1	26.2
Minnesota	35.0	14.3
Florida	35.5	14.1
6 Month Day Care		
New York	42.7	7.0
Illinois	29.6	10.1
Tennessee	18.8	16.0
Oregon	31.9	9.4
Ohio	33.7	14.8
West Virginia	20.3	24.6
Minnesota	44.1	11.3
Florida	35.2	14.2
Baseline Personal Care		
New York	11.0	27.3
Illinois	9.3	32.2
Tennessee	9.1	33.0
Oregon	12.5	24.0
Ohio	12.6	39.7
West Virginia	8.6	58.1
Minnesota	15.8	31.6
Florida	9.3	57.8
6 Month Personal Care		
New York	11.3	26.5
Illinois	9.3	32.2
Tennessee	9.7	30.9
Oregon	12.5	24.0
Ohio	12.0	41.7
West Virginia	7.9	63.3
Minnesota	15.8	31.6
Florida	9.8	51.0

[1]$300 monthly benefit cap on NY, IL, TN, & OR. $500 monthly benefit cap on OH, WV, MN, & FL.

Appendix P

Power Analysis

Power Analysis

Power Calculations

Post-hoc power analyses for the three logistic regression outcome variables found that the study had adequate power to detect moderate differences between respondent groups. Power relationships were derived using the method for nondirectional differences of proportions for unequal samples. The effect size index for the nondirectional test is $|f_1 - f_2|$, where f_1 and f_2 are the arcsine transformations of the proportions we are comparing (Cohen, 1988; Lipsey, 1990). The following tables show the power analyses for the living arrangement and caregiver relationship predictor variables.

The first table in Set 1 shows the proportions of outcome events and nonevents for caregivers living with clients and caregivers not living with clients. The proportional differences in events were used to evaluate power. The outcome variable for UE service use transactions having TAPE service use transactions, and UE zero-use transactions having TAPE zero-use transactions had high proportions of events. We expect sufficient power to detect differences between groups because the samples were large. The other outcome variables had extremely small proportions of events, particularly the variable predicting UE zero-use transactions having TAPE service use transactions. Given the relatively small sample sizes, we probably did not attain enough power to detect small effects.

The second table shows the results of the two-tailed test at alpha=0.05. Following Cohen's proposal, we want to attain 0.80 power (Cohen, 1988). The analysis for day care outcomes found no detectable effects between caregivers living with clients and caregivers not living with clients, regardless of power. Effect sizes for personal care/housekeeping/companion services ranged from 0.02 for 6 month UE service use transactions having TAPE service use transactions, and UE zero-use transactions having TAPE zero-use transactions, to a high of 0.10 for baseline UE zero-use transactions having TAPE service use transactions. Effect sizes of 0.05 to 0.10 are considered "small" for a

power assessment using differences of proportions (Cohen, 1988). Power values were relatively modest, owing to the small effects and sample sizes.[4]

The tables in Set 2 show the power analysis for the caregiver relationship variable. The first table in the set shows the proportions of outcome events for each caregiver group. The variable for UE service use transactions having TAPE service use transactions, and UE zero-use transactions having TAPE zero-use transactions had high proportions of events. The other outcome variables had somewhat lower proportions of events. Unless effect sizes were large, we do not expect high power because the sample sizes were quite small.

The final table shows the results of the two-tailed test at alpha=0.05. The table shows power relationships between the spouse reference group and daughters, sons, and others. .Effect sizes were small, with the exception of modest effects for the personal care/housekeeping/companion outcome variable for 6 month UE zero-use transactions having TAPE service use transactions. The exception outcome attained high statistical power. All other variables had weak power, owing to small effect sizes and sample sizes.

Recommendations for Increasing Power

The statistical power of a test is the probability that the test will reject the null hypothesis. Cohen argues that 0.80 power is sufficient to detect effects without demanding sample sizes so large as to be prohibitively expensive. By convention, we set the alpha at 0.05 to control Type I error (identifying an effect when none exists) to 5 percent. Cohen's recommendation of 0.80 power sets the beta at 0.20 to control Type II error (failing to find an effect that does exist) to 20 percent. Behavioral scientists control Type I error more stringently than Type II error because finding relationships or treatment effects that do not exist have a greater impact on areas such as theory building, program evaluations, and

[4]Tables for calculating power report values for effect sizes as smal as 0.10. These appendix tables report power values for the 0.10 effect size when smaller effects were present.

social policy than failing to identify existing relationships or effects (Cohen, 1988; Lipsey, 1990).

Some sample sizes in this study were too small to attain adequate power, which increased the probability of missing significant effects or relationships. Future replications of this study may increase statistical power by adjusting the alpha level, increasing the sample size, or increasing effect sizes (Cohen, 1988; Lipsey, 1990). Increasing the alpha from 0.05 to 0.10 would increase the probability of attaining significance, but at an increased risk of committing a Type I error. A researcher's decision to relax methodological rigor to increase power depends on the study and data, but it is the least desirable of the three alternatives. Increasing sample size would be expensive and probably inefficient. At 2,745 cases, the sample was large. Equalizing comparison group sizes would produce higher power than using the harmonic mean for unequal groups. Group sizes could be equalized by oversampling sons (8 percent of caregivers) and others (14 percent of caregivers). Focused studies of service users would require oversampling to compensate for the low overall service use. In this sample, no more than 27 percent of clients had day care TAPE claims in either period, and no more than 54 percent had personal care/housekeeping/companion TAPE claims in either period. However, increasing the sample would undoubtedly prove labor intensive and costly. MADDE demonstration sites had trouble locating and recruiting subjects for this study. The study also lost cases due to death, institutionalization, and voluntary attrition.

The most practical way of increasing power for a study of this type would be to increase effect sizes. Most of the effect sizes for this sample were so small that groups exceeding 1,000 cases did not produce adequate power. Cohen observes that power increases when variance is reduced (Cohen, 1988). We know that the presence of nondemonstration funding sources in the UE file increased variance. To the extent that nondemonstration sources remained in the UE file following source code reassignment, nondemonstration service utilization effects obscured demonstration reporting effects.

Improved separation of nondemonstration from demonstration sources would increase effect sizes and power. This study distinguished funding sources for clients who used the maximum demonstration benefit, but comparatively few clients exceeded the maximum allowable benefit. Future studies may explore other means of distinguishing funding sources. One possibility is to identify the point of service substitution as opposed to the point of service augmentation.

Set 1

Proportions of Events and Nonevents for Logistic Regression Outcome Variables.

Living Arrangement Predictor Variable

			UE & TAPE Svc Use, UE & TAPE zero-use	UE Zero-use & TAPE Svc Use	UE Svc Use & TAPE Zero-use
BL Day Care	**live with**	**event**	0.90 n=1629	0.02 n=34	0.08 n=144
		no event	0.10 n=178	0.98 n=1773	0.92 n=1663
	not live with	**event**	0.90 n=762	0.02 n=17	0.08 n=71
		no event	0.10 n=88	0.98 n=833	0.92 n=779
6 M Day Care	**live with**	**event**	0.91 n=1243	0.02 n=25	0.07 n=91
		no event	0.09 n=116	0.98 n=1334	0.93 n=1259
	not live with	**event**	0.91 n=643	0.02 n=13	0.07 n=46
		no event	0.09 n=59	0.98 n=689	0.93 n=656
BL Pers Care	**live with**	**event**	0.77 n=1395	0.03 n=61	0.19 n=351
		no event	0.23 n=412	0.97 n=1746	0.81 n=1456
	not live with	**event**	0.74 n=626	0.05 n=44	0.21 n=180
		no event	0.26 n=224	0.95 n=806	0.80 n=670
6 M Pers Care	**live with**	**event**	0.78 n=1056	0.03 n=41	0.19 n=262
		no event	0.22 n=303	0.97 n=1318	0.81 n=1097
	not live with	**event**	0.77 n=542	0.04 n=31	0.18 n=129
		no event	0.23 n=160	0.96 n=671	0.82 n=573

Power Analysis for Living Arrangement Variable

Outcome Variable	N_1 live with	N_2 not live with	harmonic mean $n' = \frac{2(n_1)(n_2)}{n_1+n_2}$	effect size $h = \lvert f_1 - f_2 \rvert$	2-tailed a=0.05 Power
BL Day Care					
UE & TAPE svc use, UE & TAPE zero-use	1807	850	1156	0.00	0
UE zero & TAPE svc	1807	850	1156	0.00	0
UE svc & TAPE zero	1807	850	1156	0.00	0
6 M Day Care					
UE & TAPE svc use, UE & TAPE zero-use	1359	702	926	0.00	0
UE zero & TAPE svc	1359	702	926	0.00	0
UE svc & TAPE zero	1359	702	926	0.00	0
BL Pers Care					
UE & TAPE svc use, UE & TAPE zero-use	1807	850	1156	0.07	0.61
UE zero & TAPE svc	1807	850	1156	0.10	0.61
UE svc & TAPE zero	1807	850	1156	0.05	0.61
6 M Pers Care					
UE & TAPE svc use, UE & TAPE zero-use	1359	702	926	0.02	0.56
UE zero & TAPE svc	1359	702	926	0.05	0.56
UE svc & TAPE zero	1359	702	926	0.03	0.56

Set 2

Proportions of Events for Logistic Regression Outcome Variables.

Caregiver Relationship Predictor Variable

	UE & TAPE Svc Use, UE & TAPE zero-use	UE Zero-use & TAPE Svc Use	UE Svc Use & TAPE Zero-use
BL Day Care			
Spouse	0.91 n=1204	0.02 n=26	0.07 n=88
Daughter	0.87 n=677	0.02 n=16	0.11 n=87
Son	0.89 n=185	0.02 n=5	0.09 n=5
Other	0.93 n=343	0.05 n=18	0.06 n=22
6 M Day Care			
Spouse	0.93 n=937	0.02 n=26	0.05 n=48
Daughter	0.90 n=567	0.01 n=4	0.09 n=58
Son	0.92 n=145	0.02 n=3	0.06 n=10
Other	0.91 n=251	0.02 n=5	0.07 n=21
BL Pers Care			
Spouse	0.77 n=1018	0.04 n=51	0.19 n=249
Daughter	0.76 n=595	0.03 n=25	0.20 n=160
Son	0.74 n=154	0.07 n=14	0.19 n=40
Other	0.73 n=271	0.04 n=15	0.23 n=84
6M Pers Care			
Spouse	0.77 n=777	0.13 n=35	0.20 n=199
Daughter	0.78 n=492	0.03 n=22	0.18 n=115
Son	0.80 n=127	0.04 n=7	0.15 n=24
Other	0.76 n=212	0.03 n=9	0.20 n=56

Power Analysis for Caregiver Relationship Variable

Outcome Variable	N_1 spouse	N_2 1. daughter 2. son 3. other	harmonic mean $n'=\frac{2(n_1)(n_2)}{n_1+n_2}$	effect size $h=\lvert f_1-f_2\rvert$	2-tailed a=0.05 Power
BL Day Care					
UE & TAPE svc use,	1318	780	980	0.13	0.56
UE & TAPE zero-use		208	359	0.07	0.26
		370	578	0.07	0.35
UE zero & TAPE svc	1318	780	980	0.00	0
		208	359	0.00	0
		370	578	0.17	0.35
UE svc & TAPE zero	1318	780	980	0.14	0.56
		208	359	0.07	0.26
		370	578	0.04	0.35
6 M Day Care					
UE & TAPE svc use,	1011	629	775	0.11	0.46
UE & TAPE zero-use		158	273	0.04	0.20
		277	435	0.07	0.29
UE zero & TAPE svc	1011	629	775	0.08	0.46
		158	273	0.00	0
		277	435	0.00	0
UE svc & TAPE zero	1011	629	775	0.16	0.46
		158	273	0.04	0.20
		277	435	0.08	0.29
BL Pers Care					
UE & TAPE svc use,	1318	780	980	0.02	0.56
UE & TAPE zero-use		208	359	0.07	0.26
		370	578	0.02	0.35
UE zero & TAPE svc	1318	780	980	0.05	0.56
		208	359	0.13	0.26
		370	578	0.00	0
UE svc & TAPE zero	1318	780	980	0.02	0.56
		208	359	0.00	0
		370	578	0.10	0.35
6 M Pers Care					
UE & TAPE svc use,	1011	629	775	0.02	0.46
UE & TAPE zero-use		158	273	0.07	0.20
		277	435	0.02	0.29
UE zero & TAPE svc	1011	629	775	0.40	>.995
		158	273	0.33	0.92
		277	435	0.40	>.995
UE svc & TAPE zero	1011	629	775	0.05	0.46
		158	273	0.13	0.20
		277	435	0.00	0