



THE LOUIS DE LA PARTE FLORIDA MENTAL HEALTH INSTITUTE



Florida's Medicaid Alzheimer's Home and Community-Based Waiver Program: An Interim Report

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Florida’s Medicaid Alzheimer’s Home and Community-Based Waiver Program: An Interim Report

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Florida's Medicaid Alzheimer's Home and Community-Based Waiver Program: An Interim Report

Executive Summary

This interim report covers progress on a 1915 (b) (4) and a 1915 (c) waiver entitled the Medicaid Alzheimer's Home and Community-Based Waiver Program. The program utilizes the services of three vendors selected through a competitive bidding process. Serving the counties of Miami-Dade/Broward, Palm Beach and Pinellas, the three successful vendors for the program, herewith referred to as the Medicaid Alzheimer's Program (MAP), were each expected to develop a network of service providers to deliver direct services to community-living Medicaid recipients with a diagnosis of Alzheimer's disease who have a live-in caregiver and are aged 60 and over. The authorized services include:

- Case management
- Adult day care
- Respite care
- Wanderer alarm systems
- Wanderer identification and location programs
- Caregiver training
- Behavioral assessment and intervention
- Incontinence supplies
- Personal care assistance
- Environmental modifications
- Pharmacy review

At present, the MAP is in the middle of its second two year cycle of funding (a one year extension was granted to the first cycle due to delays in implementation). The present report deals with a program evaluation based on data collected through June 2007, at which point the MAP had completed approximately six months of the second cycle.

Methods and Findings

The mixed method multi-group design included use of both Medicaid administrative data, surveys, and site visits. Following the same criteria that established eligibility for MAP, two comparison groups were drawn. One group consisted of individuals who participated in the Medicaid Aged and Disabled Waiver (ADW). The other consisted of individuals who had not been enrolled in any waiver program for more than five months out of the evaluation year. These latter Medicaid recipients were assigned to the Non-Waiver (NW) group.

While a number of research questions were addressed in the evaluation, there were two that lie at the heart of the evaluation: (1) is the MAP budget-neutral with respect to comparable programs, and (2) is the MAP effective in delaying

admission to an nursing facility. The results are clear, and for both questions the answer is in the affirmative. The MAP currently is proving to be budget neutral, and MAP participants had averaged fewer days in the nursing home. These results of course should be considered with the caveat that to date only 53% of the proposed goal of 350 Medicaid participants has been achieved. Moreover, with respect to nursing home days, on average the differences are less than six days when the MAP group is compared to the NW group, and less than two days when MAP is compared with ADW. A longer time period will greatly enhance our understanding of the long term efficacy of MAP in delaying institutionalization. Our present analyses included only 38 Medicaid recipients who had participated in MAP for even one year, due to unavoidable lags in acquisition of administrative data.

Overall, the results to date suggest that the MAP represents a multi-dimensional intervention that targets not only problems of the Medicaid recipient with Alzheimer's disease (e.g., medication use, wandering, provision of stimulation and social contact) but also the problems and issues faced by the caregiver (need for general assistance in care provision, respite, information about the provision of care to an individual with Alzheimer's disease, etc). The results demonstrate that a specialty program like the Alzheimer's waiver can have a positive impact on the well-being and trajectories of enrollees with Alzheimer's disease and their caregivers. Indeed the results suggest that it may be efficacious to consider extending the program to enrollees with other forms of dementia. Caregiver burden and institutionalization itself are not limited to the context of a Medicaid recipient with Alzheimer's disease. In some instances the burden of care may be greater. There is, for example, evidence that caregivers of persons with frontotemporal lobe dementia and dementia with Lewy bodies, face problems similar to those encountered by caregivers to persons with Alzheimer's disease; with both types of dementia the risk of institutionalization is high.

Recommendations

Given the findings presented in this interim report, several provisional recommendations can be made. They are as follows:

- The Alzheimer's disease waiver program should be extended to cover Medicaid enrollees with any form of dementia. At the very least, Medicaid recipients with dementia of the Lewy body type should be considered for MAP eligibility. Dementia with Lewy bodies is the second most common form of dementia, after Alzheimer's disease. As is the case with Alzheimer's, Lewy body dementia is a progressive disease with similar rates of mortality and progression to institutionalization.
- The restriction of MAP to cover only Medicaid recipients who have a caregiver living with the recipient might deserve reconsideration. Although the present evaluation did not include in its comparison groups Medicaid recipients whose caregiver did not live with the recipient, we plan to expand our evaluation in the next and final report to include those without a live-in caregiver as subgroups.

- AHCA staff might wish to consider working with vendors as a means of identifying policies and procedures that could improve the flow of referrals from lead agencies. If the MAP is continued, and allowed to expand, referrals may become a critical issue in successful expansion.
- Greater flexibility in one service area, that of the hours and days during which a personal assistant can be utilized is also worth considering. In a consumer satisfaction survey conducted during the preceding year by the same evaluation team, one result was for greater flexibility in the hours during which a personal care attendant, and respite services, could become available. This result paralleled results from the literature, which also suggests that flexibility in the provision of respite-related services was seen as critical by caregivers.
- Based on the current findings of this interim report, there continue to be strong indications that the Alzheimer's waiver program is successfully meeting the needs of Medicaid recipients with Alzheimer's disease and therefore should be continued.

“In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison. If they could be obtained ... they would show subscribers how their money was being spent, what amount of good was really being done with.”

—Florence Nightingale, 1863, p. 176

Introduction

Florence Nightingale had the right idea then, and the idea is still right today: a review of medical information can facilitate an understanding of the efficacy of health care services. The work to be described in this report represents an effort to review the activities of three vendors contracting with the Florida Agency for Health Care Administration (AHCA) to implement and run a program designed to allow Medicaid recipients with Alzheimer’s disease to live in the community as long as possible.

In November 2003, a 1915 (b) (4) and a 1915 (c) waiver proposal was submitted to the Centers for Medicare and Medicaid Services (CMS). Program authority came from Senate Bill 2568 and Senate Bill 2A, Line items 195 (Agency for Health Care Administration, or AHCA) and 438A (Department of Elder Affairs, or DOEA).

As approved by CMS, the proposal called for a Medicaid Alzheimer’s Home and Community-Based Waiver Program. The program would utilize the services of three vendors to be selected through a competitive bidding process. To that end, and effective by the end of August 2004, a competitive process had selected the two vendors who would serve Miami-Dade/Broward counties, and Pinellas county. Due to a disputed contract with respect to the selection of a vendor for Palm Beach, re-bidding for that area was instituted. The successful vendor for Palm Beach was selected during the summer of 2005. However, a number of delays ensued, and enrollments did not begin in earnest until early 2006. Due to the delays, AHCA submitted to the Centers for Medicare and Medicaid Services (CMS) a request for a change in the initial effective dates for the 1915(c) waiver (to March 1, 2005 – February 28, 2008); the change was approved. A change in the initial effective dates (to March 1, 2005 – February 28, 2007) was also granted by CMS for the 1915(b)(4) waiver. AHCA is currently in its second renewal for the 1915(b)(c) waiver.

The three successful vendors for the program, herewith referred to as the Medicaid Alzheimer’s Program (MAP), were expected to:

- Develop a network of service providers to deliver direct services to recipients. The direct services consisted of those identified by each vendor as commensurate with or equal to “best practices that are effective in meeting the needs of persons with Alzheimer’s disease (AHCA, 2004).” Authorized services include:
 - » Case management
 - » Adult day care

- » Respite care
- » Wanderer alarm systems
- » Wanderer identification and location programs
- » Caregiver training
- » Behavioral assessment and intervention
- » Incontinence supplies
- » Personal care assistance
- » Environmental modifications
- » Pharmacy review
- Assist with screening, assessing, and enrolling eligible recipients.
- Plan and implement a continuing array of services for recipients as their condition declines.
- Coordinate discharge of recipients from the program to appropriate settings when necessary.
- Document successful interventions for dissemination to other practitioners.
- Assist the State in evaluating processes and outcomes in order to develop successful initiatives for further implementation.

At present, the MAP is in the middle of its second two year cycle of funding. This report deals with information collected through June 2007, at which point the MAP had completed the first six months of the second cycle.

Background

Estimates based on the 2000 Census indicate that well over four million persons in the United States have Alzheimer's disease, and that this number may quadruple by 2050 (Fillit, 2005). In Florida there are approximately 420,000 elders diagnosed with Alzheimer's disease—a substantial increase from the 370,000 estimated as recently as 2001 (e.g., OPPAGA, 2001). A significant majority (approximately 70-75%) of this population lives at home; most of those who live at home are receiving care from family or friends. For the latter, caregivers to persons with Alzheimer's disease, the burden of care increases as the dementia progresses and afflicted individual's needs become more challenging.

The fiscal challenges of providing care to elders with multiple dependencies are immense. Nationally, the cost of nursing home services alone is staggering. According to an AARP report, roughly \$600 billion was spent on long term care for elders from 1975 through 2004, and most of this money was spent to support the long term care industry. On a yearly basis, the overall cost currently approximates \$110.8 billion (Centers for Medicare & Medicaid Services, 2005). Of this amount, approximately 70% of total nursing home costs are borne by Medicaid (AARP, 2001). Another way of looking at this is that nationally over one-third (an estimated 37%) of Medicaid expenditures in 2004 were for long-term care (Salganicoff, 2006). A more recent report by the Congressional Budget Office found that only about 23% of Medicaid financing for long term care was spent on programs to help elders remain at home in 2004. In contrast, 77%, or \$36.5 billion, was spent on institutional care.

The situation in Florida reflects the national situation. Over the past few years, Florida's Medicaid costs have risen an average of 12.5%. Spending has gone from approximately \$5 billion in 1994 to over \$13 billion in 2003. The good news is that these increases have been largely enrollment-driven and the rate of increase may actually slow in the next few years (Alker & Portelli, 2004). Contrary to what might be expected, only about 10.1% of Florida's Medicaid recipients are elderly. However, this relatively small percentage actually incurs a disproportionate share of expenses: approximately 21.2% of Medicaid expenditures for Florida. Much of the latter expenditures are for long term care, and the majority of those receiving long term care suffer from some form of dementia.

Caregivers and the Cost of Caring

One of the factors underlying the origins of the Alzheimer's disease home and community-based Medicaid waiver was the importance of the caregiver in efforts to keep Medicaid recipients in place. It is generally agreed that up to 85% of caregiving is done by family members, with women being the most likely to serve as caregivers (e.g., Kane, Ouslander & Abrass, 2004). Moreover there is evidence that the well-being and attitudes/motivations of caregivers is a key determinant of nursing home placement. This is true not only in the United States but elsewhere (for an international review, see Torti, Gwyther, Reed, Friedman, & Schulman, 2004). For example, in a study of a general population of older patients and

their caregivers living in Spain, Argimon, Limon, Vila, & Cabezas (2004) found that 1.5% of the patients were placed in nursing homes over the course of one year. Those who were placed were more likely to have caregivers who had lower health-related quality of life scores of the SF 36, a standard questionnaire originally developed in the United States. One of the reasons may be the time and physical effort associated with caregiving—a factor that is particularly true when the caregiving is for individuals with Alzheimer’s disease. Feldman et al (2005) found that the time devoted to care of a patient with Alzheimer’s disease by family caregivers increased by approximately 14 hours per two week interval, on average, over the course of one year. They found that even minor changes in cognitive status had an impact on caregiver time requirements, but that declines to 16 or below on the Mini Mental State Exam (Folstein, Folstein, & McHugh, 1975) seemed to mark a transition point where most instrumental activities of daily life (IADLs: activities such as shopping or balancing the checkbook) had been significantly impacted, and activities of daily life (ADLs: activities such as bathing and toileting) were beginning to be lost as well.

Another element in the caregiver process that some researchers believe to be critical is the amount of information the caregivers possess about the problems faced by their care recipient. Early research, for example, indicated that understanding the source of aberrant behavior was associated with more tolerance and reduced distress. For this reason, researchers are looking at the amount of information possessed by caregivers. Jarvis and Worth (2005), for example, used a mail survey approach to examine both the prevalence of caregivers and their need for information among individuals with a primary care physician. Approximately 6% of the participants indicated they were caregivers, and of these 63% indicated they would like information relevant to that role.

Caregivers and Race/Ethnicity. In a recent survey of 655 caregivers to persons with Alzheimer’s disease, it was found that African Americans and Hispanics were less likely to associate symptoms of memory loss with Alzheimer’s disease (AFA, 2007). In general, however, the literature suggests that across race, ethnicity and nation of birth, caregiving exerts a profound stress and burden (Torti, Gwyther, Reed, Friedman, & Schulman, 2004).

Assisting the caregiver. Informal caregivers provide the bulk of care – some estimates go up to 80% of the care provided to the dependent elderly (Kane et al., 2004). The emotional and economic costs of care provision are often high. Caregivers to persons with Alzheimer’s disease for example are more likely than non-caregivers to give up their jobs, to be stressed, and generally are likely to be burdened by the demands of the caregiving role (Chiriboga, Yee & Weiler, 1992; Lawton, Brody, & Saperstein, 1989). The strain of caregiving can lead to undesirable consequences not only for the caregiver but for the care recipient. An increased risk of nursing home placement is one potential consequence; elder abuse is another (Cooney, Howard, & Lawlor, 2006). More sobering perhaps is that in the long run, the demographics of the United States, and other developed nations, suggests that fewer and fewer adults will be available to provide care to the growing proportions of frail elderly (Robine, Michel & Hermann, 2007).

Given its prevalence, there is growing recognition of the need to assist caregivers to persons with Alzheimer’s disease and other dependency-creating health problems. Caregivers in fact are the focus of national attention, since their often unheralded efforts translate into millions of dollars-worth of care provision – care that would otherwise have to be borne by the state (Talley & Crews, 2007).

Nursing Homes: The Cost of Care

One of the goals of the Medicaid Alzheimer’s Program (MAP) is to extend the time enrollees with a diagnosis of Alzheimer’s disease are able to remain in the community. At issue is both the quality of life of those afflicted with the disease, and the costs of caring for them in long term care facilities.

Quality of life is of course an intangible phenomenon, one that in the present case involves not only the quality of life of the caregiver but also the experiences of the enrollee with Alzheimer’s disease. With respect to the latter, it is important to recognize that there is evidence from at least one study of persons with Alzheimer’s disease that while cognitive decline tends to proceed at a relatively stable rate among the non-institutionalized, there is an increase in the rate of decline following admission to a nursing facility (Wilson, McCann, Li, Aggarwal, Gilley, & Evans, 2007).

The cost of long term care is a more easily measured phenomenon. The following table, from the National Clearinghouse for Long-Term Care Information (2007) shows the average cost of long-term care in Florida, but in addition the variation across regions within the state (Table 1). On average, the current cost is \$170 a day for a semi-private room, or \$62,050 a year. Of this cost, Medicaid pays a national average of 47% – the largest share of the overall cost. Out-of-pocket personal costs average 21% of overall costs, while Medicare pays a national average of approximately 18%, private insurance pays about 9%, and other public and private sources pay 5%. Clearly, then, the overall cost of caring for someone in a long term care facility is draining societal resources.

In contrast, the costs for home health aides and homemaker services are significantly lower. A home health aide working 40 hours a week for 52 weeks would cost an average of approximately \$39,520/year; a half-time homemaker would cost approximately \$16,640/year.

Table 1
Average Costs for Differing Forms of Health Care for Frail or Dependent Elders

	Average Daily Nursing Home Rate: Private	Average Daily Nursing Home Rate: Semi-Private	Average Monthly Cost in Assisted Living Facility	Home Health Aide Average Hourly Rate	Homemaker Services Average Hourly Rate
Jacksonville	\$175	\$161	\$2,627	\$19	\$16
Miami	\$225	\$180	\$2,470	\$15	\$14
Orlando	\$188	\$171	\$2,366	\$17	\$15
Rest of State	\$181	\$163	\$2,385	\$21	\$16
Tampa	\$210	\$174	\$2,081	\$21	\$16
State Average	\$196	\$170	\$2,386	\$19	\$16

Source: National Clearinghouse for Long-Term Care Information (2007).

Nursing Home: Factors Influencing Placement

The bulk of research on nursing home placement has considered factors associated with the person being admitted. The general finding is that persons who have functional limitations, more severe cognitive impairments and symptoms secondary to dementia, and few social supports, are more likely to be placed (e.g., Kane et al., 2004; Tun, Murman, Long, Colenda, & von Eye, 2007). Relevant to the present report is that the research literature also suggests that persons with Alzheimer's disease and depression are more likely to be placed in a nursing home, and that the majority of those with dementia and depression do not receive appropriate diagnosis and treatment (e.g., Kales, Chen, Blow, Welsh & Mellow, 2005). Such findings suggest the need for careful and thorough mental health evaluations of Medicaid recipients with Alzheimer's disease.

Characteristics of caregivers also may play a role. One study has found that nursing home placement was more likely when caregivers of dementia patients reported they themselves had lower levels of physical functioning and general health, or that their health had become worse (Argimon, Limon, Vila, & Cabezas, 2004). Higher levels of caregiver burden have also been associated with earlier placement.

Ethnic and racial minority status has also played a role in placement. Kolb (2003) notes that although minorities traditionally under-utilize nursing homes, the growing diversity of the nation's elderly and the frequently higher levels of functional impairment among minority elders should be borne in mind. Among the factors that may have kept minority families from placing a loved one in a nursing facility are distance from home, perceptions of racism and/or discrimination as practiced by nursing facilities, and even religious affiliation (Kolb, 2003). However, in recent years growing numbers of minorities have in fact become residents of facilities.

Interventions

Given the prevalence of dementia, and the costs of long term care, it is obvious that states such as Florida must develop interventions that are designed to allow persons with Alzheimer's disease and other dementias to remain in the community as long as appropriate. In this context it is important to recognize that Alzheimer's disease is progressively disabling, and what is effective at one stage may be ineffective at another, later stage. Critical to successful intervention is a two-tiered system of screening, which allows early detection, followed by more comprehensive assessment of cognitive deficit and probable diagnosis (Aupperle, 2006). Moreover, as pointed out by Torti and colleagues (2004), since the disease affects many dimensions of the victim's life, as well as many dimensions of the caregiver's life, interventions that target a single dimension are rarely effective.

Another factor critical to effective intervention is recognition that the majority of health care providers often have little information about how to successfully identify and assist ethnic minority families who have a family member experiencing the signs and symptoms of Alzheimer's disease. This lack of information is a health disparities issue that is made more compelling by evidence that there is a higher age-specific prevalence of the dementias in Hispanic and African American elders

(e.g., Gurland et al, 1999). In addition, there is evidence that Hispanic and African Americans are significantly less knowledgeable about Alzheimer's disease than non-Hispanic Whites and are generally less likely to access supporting services (e.g., Ayalan & Arean, 2004). We also know that compared to other racial/ethnic groups, some Hispanic caregivers may be at greater risk of caregiver burden and distress, and that certain groups of Asian caregivers may be at a lesser risk (e.g., Aranda & Knight, 1997). Identifying effective treatments for ethnic minority families is urgent, especially since Florida is among the most ethnically diverse states and is likely to become even more so in the near future, as ever-enlarging cohorts of ethnic populations grow older and become at risk for Alzheimer's disease.

Home and Community-Based Service Programs. In recognition of the high and increasing costs of long term care, Medicaid home and community-based service (HCBS) programs have increased dramatically in number over the past few years. The overall proportion of Medicaid dollars spent on HCBS programs increased from 15% to 31% in the years between 1992 and 2002 (Kaiser Commission on Medicaid and the Uninsured, 2005). There are three types of HCBS programs, of which one is the mandatory home health program. The remaining two are optional: 1915 (c) waivers such as the Alzheimer's program waiver that is the subject of the present report, and personal care service programs. Total cost to the Centers for Medicare and Medicaid for the overall HCBS programs in 2002 was approximately \$26 billion, and the number of participants just for 1915 (c) waivers was 920,833 (Kaiser Commission on Medicaid and the Uninsured, 2005).

Other Medicaid Programs. Recognizing the high cost of nursing facilities, as well as the importance of allowing Medicaid enrollees the benefit of choice, a number of states have implemented programs designed to keep Medicaid enrollees in the community as long as possible. A number of states and health care organizations have implemented Choices for Care programs, where the point is to ensure that individuals are provided information about their eligibility for various options for care. One such program, the Vermont Choices for Care Long-Term Care Plan (Kaiser Commission on Medicaid Facts, 2006; State of Vermont, 2006) operates on a Section 1115 waiver. Implemented in 2005, the program is estimated to serve approximately 1,500/year, and the number of individuals was 155 less in October 2006 than there were in October 2005. The program establishes three levels of need (highest need, high need, and moderate need), and provides an array of services according to need. Two innovations of the program that deserves particular attention are that (1) enrollees can contract with service providers such as personal care assistants directly, and (2) family members and friends can be reimbursed for services provided. Thus far, the results seem to suggest that the program is reducing costs while at the same time keeping enrollees out of institutional settings.

Increasing Costs with Increasing Illness. In one study that followed persons with presumed AD over a period of 4 years, the cost of care more than doubled over the years of study (Zhu, Scarmeas, Torgan, Albert, Brandt, Blacker, Sano, & Stern, 2006). Functional limitations were directly associated with greater cost,

as were the presence of co-morbidity. However, total direct costs of care were over 20% lower for individuals living in the community, as opposed to the costs associated with living in an institutional setting.

Medicaid Community-based programs. The well-being of caregivers is clearly central to issues such as their willingness to help maintain someone with Alzheimer's disease at home. Such willingness depends on many factors. A study of 72 caregivers' desire to institutionalize a family member with dementia found that greater desire to institutionalize was associated with greater caregiver burden, more knowledge about the disease, more interpersonal problems in the family, and less social support (Spitznagel, Tremont, Davis, & Foster, 2006). New York City one Medicaid program for home based care of the frail elderly reported a significant reduction in mortality rate (Albert, Simone, Brassard, Stern, & Mayeux, 2005).

Alzheimer's disease is marked by behavioral and psychological symptoms that may reflect this form of dementia, as opposed to others. Chiu, Chen, Yip, Hua, and Tang (2006), for example, found that Taiwanese patients with Alzheimer's disease were more likely to exhibit signs of anxiety and phobia than were persons with dementias of the Lewy body, vascular, or frontotemporal type. They may also be likely to display signs of agitation as well as apathy (e.g., Robert, Darcourt, Koulibaly, Clairet, Benoit, Garcia, Dechaux, & Darcourt, 2006; Buettner & Fitzsimmons, 2006). These symptoms and others common to Alzheimer's disease are particularly disruptive for caregivers.

Research Questions

In this interim report, the six questions guiding the overall effort were as follows:

1. How many persons are receiving services through the Medicaid Alzheimer's Program (MAP)?
2. What are the characteristics of service recipients, and do these characteristics differ from those of individuals with Alzheimer's disease who are not in the waiver program?
3. Is the program meeting the budget neutrality requirements of the 1915 (b) waiver, and has the program generated cost savings?
4. Is there evidence that progress towards institutionalization of MAP enrollees is being delayed?
5. What variations exist by racial/ethnic group status?
6. What factors predict the number of days spent in the community?

Overall, it was anticipated that program efficacy would differ, depending on recipient characteristics such as gender and race/ethnicity. Given the emerging emphasis being placed at state and federal levels on health disparities (e.g., Smedley, Stith, & Nelson, 2003), we were particularly interested in examining ethnic and racial differences in the utilization of MAP (use vs. nonuse), and the degree of benefits from the program (e.g., postponing institutionalization of the beneficiaries).

Methods

Identification of Comparison Groups

In addition to the MAP recipients who were participating in the waiver, two comparison groups were identified after a review of possible waiver and non-waiver populations. In all cases, Medicaid recipients were selected who met the same basic criteria as used in determining eligibility for the MAP: age 60 and over, diagnosed with Alzheimer's disease (e.g. an ICD-9 code of 331.0 in Medicaid claims files), non-institutionalized and with a caregiver living in the same residence as the Medicaid recipient. Of the two comparison groups, the first consisted of Medicaid recipients who had participated in the Aged and Disabled Waiver Program (ADW) for at least eight of the 12 months of the study year. The second consisted of Medicaid recipients who had not participated in any waiver program for more than 5 months out of the 12 months studied.

Several steps were required in order to identify Medicaid recipients who could appropriately be included in the Aged and Disabled and the Non-Waiver (NW) comparison groups. The first step was to resolve issues related to proper identification of race/ethnicity. The second was to evaluate an apparent inconsistency in the coding of Alzheimer's disease across study years. The third step was to actually apply a decision model for group identification.

Step One. Identification of race/ethnicity. In previous work, the research team had identified a discrepancy in the coding of race/ethnicity in existing Medicaid data (Chiriboga, Brown, Cho, S., Cohen, & Dupree, et al, 2006). The discrepancy involved how the "Other" category was coded, with a systematic difference found when Hispanic enrollees entered the Medicaid system through SSI. While AHCA immediately took steps to begin correcting this problem, the correction was incremental for those enrollees who already were in the administrative database: corrections were to be made as new data was entered. For this reason the research team employed the same algorithm used in the past. Although the result was an increase in the number of enrollees coded as Hispanic, the increase was not as dramatic as the earlier recodes due to AHCA's implementation of the rolling correction.

Step Two. An apparent inconsistency in the coding for Alzheimer's disease across study years. While compiling the SFY2005-06 sample of Medicaid enrollees who were not participating in the MAP, it was discovered that the numbers were substantially higher from 2003-04 onwards. SFY2003-04 was of particular interest since for that year both old and new versions of the code could be compared. This dramatic increase in numbers led to a concern that possibly there was an error in coding, either in the past system or in the one currently being used. In order to examine this question in further detail, a series of cross tabulations were calculated. In the first analyses (Table 2) we examined the proportion of people who had a diagnosis in a given year, and had also received a diagnosis of Alzheimer's disease in the previous year. It can be seen that for both old and new systems, the proportions with an Alzheimer's diagnosis in the preceding year are roughly comparable.

Table 2
People with a Diagnosis of Alzheimer’s Disease for One Year as Well as for the Prior SFY

Base year	Had 331.0 Dx in the Previous Year N (%)	
	New System	Old System
2005-6 (comp to status 04-05)	8855 (31.4)	NA
2004-5 (comp to status 03-4)	8823 (29.7)	NA
2003-4 (comp to status 02-3)	8318 (28.5)	3157 (31.7)
2002-3 (comp to status 01-2)	NA	3144 (29.7)

We next looked at the proportions of enrollees under the old and new systems who were taking one or more of the standard psychotropic medications that typically are administered to persons with Alzheimer’s disease (melantadine was not included since this is a relatively new drug that is not often prescribed for Medicaid enrollees). The results, as shown in table 3, indicate that roughly equal proportions of enrollees with a diagnosis of AD under old and new systems are taking one or more of the psychotropic medications. The differences are significant, but the differences are still relatively minor: slightly over 2% more of those under the old system were taking the medications.

Table 3
Medication Use Among Medicaid Recipients Age 60 + and with a Diagnosis of Alzheimer’s Disease (ICD-9 Code of 331.0)

Taking Any One of the 3 Drugs	331.0 Dx - New System	331.0 Dx - Old System
Yes	1239 (20.10%)	549 (22.30%)
No	4925 (79.90%)	1913 (77.70%)

$\chi^2=5.17$, p-value = 0.02

Next we looked at the proportions of enrollees without a diagnosis of Alzheimer’s disease who were taking one or more of the drugs commonly given to treat Alzheimer’s disease (Table 4). Here the differences are even smaller, less than a quarter of one percent, but are significant due to the large numbers of people being compared.

Table 4
Age 60+ with No Diagnosis of Alzheimer’s Disease in SFY2002-03

Taking Any One of the 3 Drugs	No 331.0 Dx - New System	No 331.0 Dx - Old System
Yes	8481 (2.72%)	9313 (2.94%)
No	303742 (97.28%)	307541 (97.06%)

$\chi^2=28.42$, p-value <.0001

These results suggest that the differences in proportions of diagnosed enrollees do not reflect inaccuracies in the data. The source of the differences, at the time this report is being written, remains unknown. However, the results suggest that the newer coding system is capturing the same type of client. Operating with this assumption, the next step was to capture those Medicaid enrollees who met study criteria for inclusion within either of the two comparison samples.

Step Three. Assignment to comparison groups. The next table (Table 5) shows the step-down procedure that resulted in the identification of a pool of 2,631 enrollees who could be assigned to one or the other of the two comparison groups.

Table 5
Flow Chart Depicting the Selection Process Used to Create the Comparison Groups

Description of Group	Population 2005-06 (Not Duplicated)
Number of recipients in Medicaid Eligibility file from FY2005–06 with no HMO or PMHP enrollment.	1,674,123
Number of recipients who were 60 and over as of July 1, 2005.	396,903
Number of recipients with a diagnosis of Alzheimer’s as indicated by a diagnosis code of ‘331.0’ in the Medicaid claims (n = 2,653) or institution files (n = 6,717) in FY2004–05.	8,823
Number of recipients who were 60 and over as of July 1, 2005 AND diagnosed with Alzheimer’s as indicated by a diagnosis code of ‘331.0’ only in the Medicaid claims or institution files for FY2004.	6,181
Number of recipients in a nursing home in June or July of 2005.	53,498
Number of recipients who: were 60 and older, had a diagnosis of Alzheimer’s and were not in a nursing home. Sample meets the study criteria for ADW and Mixed Groups.	2,631
Number of recipients with FY2005-06 CARES/CIRTS information.	1,097
Number of recipients with CARES/CIRTS information with Caregiver/Living Situation data.	985
Number with CARES/CIRTS information with Caregiver/Living Situation data, with 5 or fewer total months of enrollment in any waiver program.	506
Size of Non-Waiver group with no caregiver.	342
Size of Non-Waiver group with a live-in caregiver; sample meets criteria for Non-Waiver (NW) group.	146
Size of Non-Waiver group with a caregiver but does not live with patient.	18
Number with CARES/CIRTS information with Caregiver/Living Situation data, with 9 or more months of enrollment in the Aged/Disabled Waiver program.	187
Size of Age/Disabled Waiver group with no caregiver.	21
Size of Age/Disabled Waiver group with a live-in caregiver: sample meets criteria for Aged/Disabled Waiver (ADW) comparison group.	157
Size of Age/Disabled Waiver group with a caregiver but does not live with patient.	9

Identification of the MAP Sample

The MAP sample consisted of:

1. All recipients who had participated in the Alzheimer’s disease waiver program for six months or more and who had administrative data available. The Medicaid recipients studied included those receiving services under the auspices of all three of the vendors who had contracted with AHCA to administer the MAP.

Inclusionary criteria for program participation were:

- Residence in proposed service area
- Age 60 or older

- Living with a capable caregiver in a private home or apartment
- Diagnosis of Alzheimer's disease by physician, as confirmed by a Memory Disorder Clinic, a board certified neurologist, or a licensed medical doctor with experience in neurology
- Completed assessment by the Department of Elder Affairs CARES staff and meets nursing home level of care criteria
- Meets the Medicaid financial eligibility standard (up to 300% of the SSI income level)
- Not enrolled in any other Medicaid waiver program

Exclusionary criteria include:

- Residing in a nursing facility or an intermediate care facility for individuals with mental retardation
- Eligible as medically needy
- Participation in another 1915(c) home and community-based waiver program other than the 1915(c) waiver program that accompanies the 1915(b) (4) upon which the Alzheimer's disease waiver is based

2. Informal caregivers for clients in the MAP.

Table 6 provides more detail on the selection of the MAP Medicaid enrollees who were included in the evaluation. Due to the need to use administrative data, the bulk of our analyses could not employ the most current data because the latter were not as yet available (FMHI receives quarterly updates). The table shows the number of months of data for the 127 MAP recipients, as based on all claims from FY2005-06 through the most current quarterly data (obtained 1/8/2007, and including data extending through December 2006). The table considers the number of enrollees who had participated in the waiver for various periods of time: less than three months, three months to less than six months, six months to less than one year, and one year or more. With respect to progress in full implementation of the MAP, these results indicate that through 2006, the MAP overall had enrolled only slightly more than 36% of the total number of Medicaid recipients (N=350) called for in the original application to CMS. As will be noted in the results section, recruitment problems have been, and continue to be, a major issue for the two smaller vendors participating in MAP.

Given that over the months following initial enrollment changes can be expected in rates and types of services utilized, it was decided that for the purposes of evaluation, a minimum of six months of participation should be required of participants included in the evaluation. The critical question was whether there were sufficient numbers with at least six months of participation. As illustrated below, there were 107 participants in the available data who initially appeared to have had at least six months of MAP participation.

Table 6
Initial MAP Sample Selection Procedures Using Number of Months of Data Per Recipient

Months	Frequency
Less than three months	6
Three or more than three months	121
Six or more than six months	107
12 or more than 12 months	69

The 127 Medicaid recipients who were indicated as participants in MAP were reviewed for factors such as eligibility. The data in the preceding table (Table 6) was based on the number of months of claims data submitted during SFY2005- December 2006. Subsequently it was decided to base selection on months enrolled. This selection procedure reduced the number with 6 more months of data to 107; however, two of these were dropped as Nursing home outliers. After adjusting for the two outliers and nine recipients with eligibility problems (Medicaid eligibility started after waiver start date), the usable sample size of recipients with at least six months of data was reduced to 97 (see Table 7). Of these 97, only 38 had a full year of enrollment. All of the latter came from a single vendor in the Miami-Dade area, a fact that could influence results due to the greater diversity in race/ethnicity in that area.

Table 7
Final Sample, Based on Months of Enrollment, for the MAP

Number of recipients enrolled in Alzheimer Waiver program as of 1/8/07 with at least 6 months of enrollment. Sample used to calculate costs for first 6 months of waiver enrollment.	97
Number of recipients enrolled in Alzheimer Waiver program as of 1/8/07 with at least 12 months of enrollment. Sample used to calculate costs for first 12 months of waiver enrollment.	38

Due to the fact that the Miami-Dade vendor was contracted to recruit more Medicaid recipients into the MAP program than either of the other two vendors, and was enrolling recipients at least six months before either of the other two vendors, we examined the numbers of recipients from this vendor included in our MAP sample. Of the 97 participants in the MAP that are being included in the present set of analyses, a total of 81 participants (slightly over 83%) are from the Miami-Dade vendor. Thirty-six percent of the MAP 12 month sample were from the Miami-Dade county vendor, as were 45% (N=45) of the 97 recipients with 6 months of participation.

Table 8
Number (and %) MAP Recipients that Received Services From the Miami-Dade Vendor, by Whether Recipients Had Been Enrolled for Either 6 or 12 Months

Race/Ethnicity	Group				Total
	12 Months		6 Months		
Black	5	13.89%	5	11.11%	10
Hispanic	16	44.44%	30	66.67%	46
Other	1	2.78%	1	2.22%	2
White	14	38.89%	9	20.00%	23
TOTAL	36		45		81

The Final Sample

The final sample included non-Hispanic White, African American/Black, Hispanic American/Latino and Other Medicaid recipients in the following distribution (Table 9). The overall sample consisted of 438 Medicaid recipients. The 12 month MAP group, with 38 recipients, was the smallest group; and the ADW group, with 157, was the largest.

Table 9
Number of Medicaid Recipients in Each Group and Racial/Ethnic Category

Ethnicity	MAP Group (6 months)+	MAP Group (12 months)	ADW Group	Non-Waiver Group	Row Totals
White	27	15	46	42	130
Black	12	5	51	34	102
Hispanic	54	17	48	58	177
Other	4	1	12	12	29
TOTAL	97	38	157	146	438

+Six month MAP Group represents the first 6 months that participants were enrolled and includes the 12 month MAP group.

Measures

The evaluation team used multiple sources of data and associated measures to assess how services to Alzheimer’s disease patients are provided and the cost of these services during both the start-up and the implementation phases of the Alzheimer’s disease waiver program. Specific datasets and measures included are:

State collected data. Data from FY2005-06 were used for the comparison groups, and FY2005-06 and the first two quarters of FY2006-07 were used for the MAP group. Administrative datasets included CARES (Comprehensive Review and Evaluation Services; Department of Elder Affairs) and Medicaid.

- **CARES.** The CARES dataset includes client identifiers and nursing home pre-admission assessments and is maintained by DOEA. Ratings are made by CARES teams who work directly for DOEA. The CARES is completed to determine eligibility for Medicaid nursing home level of care. The data overlap substantially with that of the Client Information and Registration Tracking System (CIRTS) – approximately 95% overlap: both sources were checked for

data on caregiver presence or absence. For the program evaluation, CARES data was also abstracted from records of the Miami-Dade/Broward vendor. Because a CARES evaluation was part of the process of determining eligibility for participation in the Medicaid Alzheimer's Program (MAP), these data were immediately available. For MAP recipients, these data allowed for evaluations of physical health, mental health, and cognitive characteristics at entry into the ADP. For the comparison group, the data were obtained from administrative files and were limited to information on the availability of caregivers.

- **Medicaid.** As noted, for the present report claims data for FY2005-06 and the first two quarters of SFY2006-07 were used.

Provider-generated data. As noted in the presentation of CARES data, the evaluation team collected data directly from records maintained by all three vendors. The data collection, which took place throughout the project year, included not only CARES but also data from intake forms that had been administered to both recipients and caregivers during the first month following approval of the recipient into MAP. The intake forms were developed in a collaborative effort. During FY2004-05, the evaluators had drafted a battery of instruments to be administered by vendors to recipients and caregivers. All vendors gave approval for their use, with final procedural decisions being made at a meeting with all vendors on August 24, 2005. The completed batteries consisted of a Month One survey for caregivers, a Month One survey for recipients with Alzheimer's disease, a Month Two survey for caregivers, and a Client Survey to be completed by the case manager. All documents were translated into Spanish by the evaluation team. Included in this report are findings based on the first two of following measures; results based on the remainder will be provided in the more comprehensive report that will be produced during the Fall 2007:

- **Modified Mini-Mental State Exam (3MS).** The Modified Mini-Mental State Examination (3MS) is an expanded and modified version of the Mini-Mental Status Exam [MMSE] (Teng & Chui, 1987), a widely used measure for cognitive screening. The 3MS revision of the MMSE consisted of the addition of four test items (date and place of birth, word fluency, similarities, and delayed recall of words) that assess a broader range of difficulty levels and cognitive domains using an increased range of possible scores (0 – 100) and by the development of a standardized scoring system that permits partial credit on specific test items (Bravo & Hébert, 1997; Teng & Chui, 1987; Teng, Chui, & Gong, 1990). The cut point below which cognitive deficit is considered serious is between 77 and 78 on the 3MS. Studies comparing the clinical usefulness of both measures in detecting cognitive impairment have reported the reliability (test-retest, split-half, & internal consistency), validity, and sensitivity of the 3MS to be consistently higher than the MMSE in a variety of samples, including normal community-dwelling elders (Bravo & Hébert, 1997; Tombaugh, McDowell, Kristansson, & Hubley, 1996), dementia cases (Bravo & Hébert, 1997), nursing home residents (Nadler et al., 1995), and community residents with probable dementia (Correa, Perrault, & Wolfson, 2001). Follow-up studies also support results reported in the original 3MS

article (Teng & Chui, 1987) of increased sensitivity in detecting dementia in comparison to the MMSE (Tombaugh, McDowell, Kristansson & Hubley, 1996; Nadler et al., 1995; Teng, Chui, & Gong, 1990). The approximate time for completion of 3MS is 5 to 10 minutes. Data are reported in this report only for enrollees.

- **Activities of Daily Life (ADL).** The ADL scale measures psychosocial and physical functional capacity. Basic tasks of self-care, such as bathing, dressing, toileting, transfer, and continence are assessed. ADLs are measured on a dichotomous scale (independent vs. dependent), a discrete scale (three levels of dependence) and an overall score with seven possible values (“independent in all activities” to “dependent in all”). The time to complete and score the ADL is approximately five minutes. Data are reported for both enrollee and caregiver.
- **Instrumental Activities of Daily Life (IADL).** The IADL assessment is an eight-item Likert-rating scale that measures everyday activities, such as ability to housekeep, shop, answer the phone, prepare food, and manage medications, from totally dependent to self-sufficient. Spector and Fleishman (1998) reported that combining ADL and IADLs increased sensitivity to detect dysfunction, and ADLs and IADLs were not hierarchically related. Therefore, a sum of item responses can be used to derive functional disability. Validity was assessed and compared to a measure of general physical health, a mental health status questionnaire, and a behavior and adjustment rating scale. Inter-rater reliability was reported as 0.87 and 0.91 on two separate substudies. Time to complete and score is approximately five minutes. Data are reported for both enrollee and caregiver.
- **Geriatric Depression Scale Short Form (GDS-SF).** A short 15-item version of the Sheikh & Yesavage (1986) Geriatric Depression Scale (GDS) was used. The internal reliability of this instrument has been reported to be reasonable (alpha greater than .75). The short form correlates .84 with the 30-item full version of the scale (Burke, Roccaforte, & Wengel, 2001; Jang, Small, & Haley, 2001). The cutoff score for probable depression for the 15-item self-report version of the GDS is > 5. Cronbach’s alpha for beneficiary data was .84 and for caregiver data was .83. Data are reported for both enrollee and caregiver.
- **Zarit Burden Scale.** Twelve items from the Burden Scale (Zarit & Zarit, 1998) were selected for inclusion in the intake form. The full version of the Zarit Burden Scale is a 22-item scale that measures subjective burden of caregivers in caring for an older person with dementia (Zarit, Orr, & Zarit, 1985). The degree to which caregivers endorse each item is rated along five-point Likert scales (never, rarely, sometimes, quite often, frequently, or nearly always). The range of possible burden scores is 0–88, with higher totals reflecting greater burden and distress. Reported reliability coefficients range from .88 to .94 (O’Rourke & Wenaus, 1998). The Burden Scale has satisfactory internal consistency (Cronbach’s alpha = 0.91) and test-retest reliability ($r=0.71$). In addition, the full scale has adequate content validity, given that items were derived from research and clinical experience with caregivers of individuals with dementia (Vitaliano, Young, & Russo, 1991). Evidence of construct validity was demonstrated by burden scores that were reported to

correlate negatively with morale and positively with hours spent giving care (Pratt, Schmall, & Wright, 1986). The time needed to complete this scale is estimated at 25 minutes. The shorter version takes approximately 10 minutes to complete. Examples of the items included in the short form are: “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?” or “Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?” Responses were scored on the original five- point scale, ranging from “never” to “nearly always.” Cronbach’s alpha for the present 12 item scale was .86 for the caregiver data.

During May and June 2007, site visits were made by members of the evaluation team. At all three vendor sites the evaluation team members interviewed the program coordinators and other staff members working on the MAP.

Analysis plans for qualitative and quantitative data. The initial work was based on obtaining and matching CARES and Medicaid data for persons aged 60 and over with Alzheimer’s disease during 2001-2004. For each identified beneficiary who met the criteria for inclusion in one of the comparison samples, one full year of data was pulled; the year of data was allowed to cross fiscal years to provide a greater sample size. Data management formed the focus of the first six to eight months of the evaluation. Data management included matching of recipients and the examination of frequency distributions to determine central tendencies and dispersion; this phase also screened for outliers and erroneous data. Costs of the Alzheimer’s disease waiver program were calculated on the basis of units of service utilization using data provided by AHCA. Generalized linear modeling statistics were used to compare the comparison group and MAP participants in terms of overall costs. Program service provision and adequacy were examined through chart review of care plans and services.

As a final comment with respect to analyses, significance levels were calculated and included in this report, despite the fact that the Medicaid recipients included in the research could be considered to constitute the entire population of recipients that met the multiple criteria for inclusion or exclusion. The restrictions imposed on the population by the criteria, however, arguably transform the population into a sample. For this reason, measurement error is important. The way one restricts the sample (i.e., by diagnosis, age, and availability of a caregiver) is measurable with error. These considerations led the evaluators to use statistical levels to help assess comparative effect sizes, but the reader should recognize that the most important factor is whether the differences in prevalence, service use and costs help inform the nature of health disparities.

Results

Medicaid Recipients Receiving Services Through the MAP

As stipulated in the original request for proposals (RFP) that was published in 2004, a total of 350 Medicaid recipients were to be enrolled into the MAP. Due to a variety of factors, this goal has not been met. As of June 2007 the Palm Beach vendor had enrolled 24 Medicaid recipients into the MAP. This represents 30% of the 80 recipients that Palm Beach was to enroll. The Palm Beach vendor was the last to be approved as a vendor, due to a contract dispute that resulted in the need for a rebid for a contract with a Palm Beach vendor.

During the same timeframe, the Pinellas county vendor had enrolled 22 recipients. This amounts to approximately 28% of the 80 recipients called for in the contract. This vendor also experienced start up problems, which were exacerbated by several changes in the director responsible for implementation of the program. In addition, both the Palm Beach and the Pinellas vendors experienced serious problems with recruitment. As noted in interviews with staff at both sites, neither of these two vendors are the lead agency in their respective areas, and they encountered problems with referrals from the lead agencies. The problems were substantially alleviated, for both vendors, when enrollments for the Florida Medwaiver Program were frozen.

The Miami-Dade county vendor has been active for the longest period of time. At the same time last year, this vendor had successfully enrolled approximately 40 recipients. Since then, the number of recipients successfully enrolled in the Miami-Dade MAP has grown to 140. This represents 74% of the 190 Medicaid recipients designated for the Miami-Dade area.

Overall, the MAP has a total of 186 Medicaid recipients who have been enrolled. This is approximately 53% of the stated goal of 350 recipients. While substantially below target levels, interviews with directors at all three sites indicate that the pace of enrollments has picked up. The vendor at Palm Beach, for example, noted several problems that have been resolved. Staff at that site indicated that their overall outreach efforts are now more successful. Moreover, they had experienced a number of problems that while minor in themselves lead to substantial delays due to factors such as the relatively small staff responsible for the MAP at the host vendor. As an example, there were problems coordinating with the Department of Children and Families (DCF) when an internet system developed by DCF became operative. Materials sent through the internet were not being transmitted to the correct contact person until the vendor and that contact person worked out a solution.

Characteristics of Service Recipients

The second research question addressed in this report asks “What are the characteristics of service recipients, and do these characteristics differ from those of individuals with Alzheimer’s disease who are not in the waiver program?” There were minor and non-significant differences across the three study groups

with respect to gender (Table 10). The MAP recipients were significantly younger than those in the other two groups; the ADW group had the highest average age, and had the highest proportion of recipients aged 84 and over. With respect to race/ethnicity, there was also a significant difference. Over 50% of the MAP participants were Hispanic, and slightly over 12% were African American/Black--the highest and lowest proportions, respectively, across the three groups. The ADW group was nearly equal in its distribution of the three most common ethnicities, while the NW group was second highest in the proportion of Hispanic recipients. These differences in ethnicity between the MAP recipients and those in the other two groups probably reflect the fact that the Miami-Dade vendor had recruited the majority of participants, and the Miami-Dade area has an unusually high proportion of Hispanics.

Table 10
Demographic Characteristics of Study Participants for FY2005 – 01/01/2007

Characteristics	Medicaid Alzheimer's Project (MAP) Sample N=97 N (%)	Aged/Disabled Waiver (ADW) Sample N=157 N (%)	Non-Waiver (NW) Sample N=146 N (%)
Age as of 07/01/2005**			
60-75	26 (26.80)	28 (17.83)	36 (24.66)
76-83	39 (40.21)	45 (28.66)	50 (34.25)
84+	32 (32.99)	84 (53.50)	60 (41.10)
Mean Age (sd)	80.6 (8.3)	83.6 (8.4)	81.6 (8.3)
Gender			
Female	76 (78.35)	130 (82.80)	117 (80.14)
Male	20 (20.62)	27 (17.20)	29 (19.86)
Unknown	1 (1.03)	0 (0.0)	0 (0.0)
Race (New)***			
White	27 (27.84)	46 (29.30)	42 (28.77)
Black	12 (12.37)	51 (32.48)	34 (23.29)
Hispanic	54 (55.67)	48 (30.57)	58 (39.73)
Others	4 (4.12)	12 (7.64)	12 (8.22)

(N=790); MAP Participants Include All 97 Who Were Enrolled and with Medicaid Data Available as of December, 2006

*p=.10, **p=.05, ***p=.01 (chi square)

As might be expected, the spread of MAP enrollments from one vendor in the Miami-Dade area, to include vendors in Palm Beach and Pinellas counties changed the distribution on key demographic variables. Table 11 contrasts the demographic characteristics of the 38 recipients who had participated in MAP for a full year, as opposed to the 59 who had participated for only six months. What was not expected is that there were proportionately more Hispanics who entered the program from June through December 2006, and fewer non-Hispanic Whites. Indeed, among those who had enrolled during the more recent six months, nearly 63% were Hispanic. This in part reflects the fact (documented in the Methods section, above) that the Miami-Dade vendor remained the most successful in recruitment during the time period being studied. According to

interviews with staff, their success at least in part resulted from being able to assign a full-time supervisor for the case managers.

Table 11
Differences in the Distribution by Age, Gender and Race/Ethnicity for MAP Participants Who Participated for a Full Year vs. Only Half a Year

Characteristics	Alzheimer's Disease Waiver 6 Month Group		Alzheimer's Disease Waiver 12 Month Group	
		(N%)		N(%)
Mean Age (sd) at 07/01/2005	80.6	(8.7)	80.5	(7.8)
Gender				
Female	45	(76.27)	31	(81.58)
Male	13	(22.03)	7	(18.42)
Unknown	1	(1.69)	0	(0)
Race (New)				
White	12	(20.34)	15	(39.47)
Black	7	(11.86)	5	(13.16)
Hispanic	37	(62.71)	17	(44.74)
Others	3	(5.08)	1	(2.63)
Sample Size	59		38	

To examine the characteristics of MAP recipients in more detail, their scores on the modified Mini Mental State Exam (MMSE) and ADLs were examined. As shown in table 12, the Medicaid recipients participating in MAP as a group were severely debilitated. Over a third were unable to answer even a single question on the modified MMSE, and all but two of those for whom data were available scored under the cut-off for cognitive impairment of 77/78. The majority of MAP participants were also dependent on ADLS, with 64% having two or more dependencies.

Table 12
Behavioral Characteristics of MAP Participants

Domain	Number (%)
Cognition	
No correct answers on Modified MMSE	53 (38.7)
Scored below cutoff on Modified MMSE	135 (98.5)
ADL Dependencies	
Bathing	99 (78.0)
Dressing	106 (83.5)
Toileting	98 (78.4)
Transferring	81 (64.8)
Incontinent	91 (77.8)
Feeding	91 (77.8)
Two or more ADL dependencies	109 (64.1)

Per User Per Month Costs

The third research question deals with the budget neutrality of the MAP when compared to costs associated with Medicaid recipients enrolled in the Aged and Disabled Waiver. Specifically it asks, “Is the program meeting the budget neutrality requirements of the 1915 (b) waiver, and has the program generated cost savings?” The costs of providing services per user per month (PUPM) provides a beginning way of addressing this question. In the following analyses we will first consider the PUPM costs for the six month vs. the 12 month MAP recipients in order to consider whether there is evidence of differences in cost arising from the first six months of enrollment, versus an entire year. We then consider the differences in costs between the 12 month MAP participants and those in the ADW group and those who were not participating in a waiver program. In this presentation, and in the costs analyses to follow, we consider not only the total group cost differences, but the differences in costs associated with each of the three major race/ethnicities studied, since there are substantial differences between them in costs. It should be noted, incidentally, that due to the rules for inclusion it was possible that some participants in either the MAP or ADW could have had costs generally not permitted under waiver regulations, since a key rule for inclusion was participation in the waiver for nine or more months.

Differences between the six and 12 month MAP costs. Table 13 includes two columns that show the PUPM costs for those all individuals who had six full and continuous months of services under MAP, as opposed to those who had a full year (all of whom are also included in the six month group). All cost data for the six month group was based on their six months of participation (i.e., their cost data was not based on 12 month data).

One peculiarity of the six month group is that three of the MAP participants received no reimbursable MAP claims during their first six months of participation (reimbursements began in the seventh month). These three individuals, all Hispanic, were included in analyses because they had indeed been enrolled in the program. The vendor that enrolled these three indicated that there had been start up problems during the start-up phase of MAP implementation. However, the inclusion of these Medicaid recipients does make evaluation of the six month group problematic. For this reason, no statistical analyses were conducted of the differences between the six and 12 month MAP costs.

With the above caveat in mind, a comparison of the six and 12 month PUPM costs suggests that, compared to the six month group, PUPM costs for other services, including those received by the ADW program and other waive programs, generally decreased for those who had been receiving MAP services for 12 months. The major exception was for physical health care, where costs were relatively stable. It should be noted that the nursing home costs were in fact for two MAP participants who were temporarily placed in a nursing facility. There was some debate among the investigators as to whether these two participants, one non-Hispanic White and one Hispanic, should be dropped from the analyses; it was decided that in actuality temporary nursing home placements can be expected: participation in the MAP does not preclude the need for post-hospital nursing home stays.

Overall, the results in general point out that there are some differences between the average costs for the first six months of participation, and the average monthly costs for a full year. There was some indication that the direction of these differences varied not only by service but by race. For Whites and Blacks, PUPM costs associated with the MAP waiver costs were greater for the 12 month enrollment group, but were less for Hispanics (as indicated in the table presenting penetration rates, Table 13, there were very few in the “Other” category and so results for the latter group will generally not be discussed). Such results indicate that there is a general increase in the services provided, when the entire year is considered. Why MAP costs associated with Hispanic recipients should decrease is unclear.

Table 13
Per User Per Month (PUPM) Costs Across the Three Comparison Groups, and by Race/Ethnicity+

Type of Services	Ethnicity++	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Group Size		97	38	157	146
Alzheimer Waiver Services	White	829.51	981.61	0	0
	Black	781.84	1190.69	0	0
	Hispanic	752.33	536.50	0	0
	Other	958.18	1125.73	0	0
	Total	787.03	813.79	0	0
Aged Disabled Waiver Services	White	133.31	72.07	935.34	296.07
	Black	14.75	177.60	884.75	222.29
	Hispanic	289.25	144.63	1188.84	154.82
	Other	0	0	868.61	46.83
	Total	154.28	114.94	989.35	202.03
Other Waiver Services	White	0	0	0	0
	Black	144.56	0	0	0
	Hispanic	428.41	739.68	0	331.10
	Other	0	0	0	345.09
	Total	392.93	739.68	0	335.09
Case Management	White	0	0	0	81.67
	Black	0	0	0	43.33
	Hispanic	126.67	63.33	0	0
	Other	0	0	4.17	0
	Total***	126.67	63.33	4.17***	62.50***
Mental Health	White	122.40	78.68	68.07	103.20
	Black	151.50	75.75	62.15	97.78
	Hispanic	509.43	3.72	58.88	133.41
	Other	158.17	158.17	3.88	52.16
	Total***	283.70	68.20	61.14***	109.73***
Psychotropic RX	White	124.50	70.77	116.69	110.99
	Black	120.56	39.56	81.94	83.69
	Hispanic	93.20	72.67	86.51	101.48
	Other	389.28	194.64	82.41	130.04
	Total*	114.42	74.43	93.49	101.70

Type of Services	Ethnicity++	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Physical Health	White	53.25	55.96	185.11	316.48
	Black	191.96	197.66	162.65	177.28
	Hispanic	108.09	160.02	294.79	328.58
	Other	58.83	215.09	78.48	259.49
	Total***	103.86	128.00	204.17***	284.69***
Physical RX	White	42.81	20.56	116.52	100.69
	Black	192.77	150.44	96.41	100.13
	Hispanic	60.40	41.18	118.52	128.38
	Other	190.96	98.54	101.26	90.27
	Total**	67.96	40.28	109.38***	110.96***
Nursing Home	White	733.83	511.77	366.37	1184.37
	Black	0	0	386.94	1385.83
	Hispanic	1090.10	718.91	238.00	1222.13
	Other	0	0	76.00	0
	Total***	971.34	615.34	349.33***	1265.86***
Total PUMP across all services	White	1001.93	1143.87	1363.91	635.65
	Black	967.22	1441.39	1266.32	549.86
	Hispanic	971.06	866.01	1634.28	735.66
	Other	1172.20	1792.17	1122.34	502.59
	Total***	987.47	1075.77	1397.15	646.19***

+Statistics calculated for the three 12 month groups. For Case Management, Mental Health, and Nursing Home were calculated by the ranks of service costs, while Statistics for Psychotropic RX, Physical Health, Physical RX, and Total were calculated by the square root transformations of service costs. Post-hoc comparisons compared MAP to each of the other two groups.

++Race/ethnicity differences combined across all three 12 month comparison groups. No race/group interactions found.

*p=.10 **p=.05, ***p=.01

Differences between the twelve month MAP PUPM costs and the costs associated with the two comparison groups. PUPM cost difference statistics were calculated for all of the service costs that were unrelated to waiver programs. With respect to the latter, costs for the MAP program were only found for MAP participants, and costs for the ADW were highest for the ADW participants. For other waiver services, the ADW group was the highest. The PUPM for the MAP was the highest, and this was because three recipients in the 6 month MAP group and two in the 12 month group (see Table 14 for details on the MAP penetration rates) had used waiver services other than MAP and ADW; the PUPM rate was based on the use of these two and three recipients. Overall, the penetration rate for waivers was .05 for 12 month MAP, 0 for ADW, and .03 for the NW group.

The three groups differed significantly in costs for all of the non-waiver services. The ADW group had the lowest PUPM for case management and nursing home use (but MAP had the lowest penetration rate for nursing homes), and the MAP had the lowest or tied for lowest PUPM on mental health, psychotropic medications, physical health care, and medications related to physical health care. In contrast, the non-waiver group was either highest or tied for highest PUPM on all non-waiver services. Of particular relevance to this

report are the data for nursing home use. Over one third of the NW group used a nursing home, and their PUPM was more than twice that of the MAP and three times that of the ADW group.

One trend (not shown in the table) was noted for the race/ethnicity category. African American/Black recipients were generally lower than Hispanic/Latino and non-Hispanic White recipients on PUPM costs associated with psychotropic medications. This trend was evident across all three comparison groups.

Probably the most important statistic from Table 13, however, is shown in the very last row. With respect to overall user costs per month, the costs for MAP participants were significantly lower than the costs for those in the ADW group, although higher than that of non-waiver group. The average overall PUPM for the ADW group was over \$300 more than that of the MAP.

Penetration

Penetration, or the proportion of Medicaid recipients using a particular service or program, adds an important dimension to the PUPM cost data provided in the preceding table. We have already discussed the major finding from Table 14, which presents data on penetration. That finding was that only five percent of the MAP group used nursing homes, as compared to ten percent of the ADL group, and approximately eight percent of the NW.

It was also noted that that for the 6 month MAP group, there were 3 recipients, all Hispanic, who did not receive MAP waiver services during their first 6 months of MAP waiver enrollment (they do receive services during the months 7- 12). Similarly, for the ADW group, 2 Medicaid recipients – both Hispanic – did not receive any ADW waiver services during FY2005-06, even though they were enrolled in the waiver program for 12 months and were eligible for the entire 12 months.

Table 14

Annual Unweighted Penetration Rate by Program and Service, Across the Three Comparison Groups

Type of Services	Ethnicity	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Group Size		97	38	157	146
Alzheimer Waiver Services	White	1.00	1.00	0	0
	Black	1.00	1.00	0	0
	Hispanic	0.94	1.00	0	0
	Other	1.00	1.00	0	0
	Total	0.97	1.00	0	0
Aged Disabled Waiver Services	White	0.22	0.33	1.00	0.19
	Black	0.17	0.40	1.00	0.12
	Hispanic	0.06	0.18	0.96	0.17
	Other	0	0	1.00	0.17
	Total	0.11	0.26	0.99	0.16

Type of Services	Ethnicity	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Other Waiver Services	White	0	0	0	0
	Black	0.08	0	0	0
	Hispanic	0.13	0.12	0	0.05
	Other	0	0	0	0.08
	Total	0.08	0.05	0	0.03
Case Management	White	0	0	0	0.02
	Black	0	0	0	0.03
	Hispanic	0.02	0.06	0	0
	Other	0	0	0.08	0
	Total	0.01	0.03	0.01	0.01
Mental Health	White	0.15	0.20	0.20	0.26
	Black	0.08	0.20	0.25	0.35
	Hispanic	0.07	0.12	0.17	0.28
	Other	0.25	1.00	0.08	0.25
	Total	0.10	0.18	0.20	0.29
Psychotropic RX	White	0.48	0.60	0.83	0.86
	Black	0.25	0.40	0.75	0.94
	Hispanic	0.37	0.59	0.96	0.93
	Other	0.25	1.00	0.92	0.83
	Total	0.38	0.58	0.85	0.90
Physical Health	White	0.41	0.60	0.91	0.90
	Black	0.50	0.60	0.94	0.88
	Hispanic	0.52	0.65	0.98	0.95
	Other	0.50	1.00	1.00	0.75
	Total	0.48	0.63	0.95	0.90
Physical RX	White	0.37	0.60	0.93	0.98
	Black	0.17	0.20	0.94	0.94
	Hispanic	0.30	0.59	0.92	0.93
	Other	0.25	1.00	0.92	0.92
	Total	0.30	0.55	0.93	0.95
Nursing Home	White	0.04	0.07	0.11	0.05
	Black	0	0	0.16	0.12
	Hispanic	0.04	0.06	0.02	0.10
	Other	0	0	0.08	0
	Total	0.03	0.05	0.10	0.08
Total Penetration	White	1.00	1.00	1.00	1.00
	Black	1.00	1.00	1.00	0.97
	Hispanic	1.00	1.00	1.00	0.98
	Other	1.00	1.00	1.00	0.92
	Total	1.00	1.00	1.00	0.98

Per Member Per Month Costs

Per Member Per Month costs provide information on how much recipients in a particular group can be expected to cost in terms of reimbursement for claims, regardless of what services are used.

Differences between the six and 12 month MAP costs. Overall PMPM costs increased from the six month group to the 12 month group, with much of the increase being accounted for by increases in MAP service claims (Table 15). Physical health care costs also increased from the six to 12 month groups, indicating that a possible side benefit of participation in MAP is that health professionals may become more aware of the general health needs of MAP participants. On the other hand, as will be noted in the comparisons of the 12 month MAP with the ADW and NW groups, the physical health costs of MAP were generally substantially less than those in the other groups. There was no significant difference between the racial/ethnic groups, and no interaction of race/ethnicity by group.

Table 15
Per Member Per Month (PMPM) Average Costs Across the Three Groups and by Race+

Type of Services	Ethnicity++	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Group Size		97	38	157	146
Alzheimer Waiver Services	White	829.51	981.61	0	0
	Black	781.84	1190.69	0	0
	Hispanic	710.54	536.50	0	0
	Other	958.18	1125.73	0	0
	Total	\$762.68	\$813.79	\$0	\$0
Aged Disabled Waiver Services	White	29.62	24.02	935.34	47.37
	Black	2.46	71.04	884.75	27.15
	Hispanic	16.07	25.52	1139.30	25.88
	Other	0	0	868.61	4.93
	Total	\$17.50	\$30.25	\$976.65	\$30.14
Other Waiver Services	White	0	0	0	0
	Black	12.05	0	0	0
	Hispanic	55.53	87.02	0	15.10
	Other	0	0	0	31.14
	Total	\$32.41	\$38.93	\$0	\$8.75
Case Management	White	0	0	0	2.31
	Black	0	0	0	1.32
	Hispanic	2.35	3.73	0	0
	Other	0	0	0.35	0
	Total***	\$1.31	\$1.67	\$0.03***	\$0.93***
Mental Health	White	18.13	15.74	13.46	32.05
	Black	12.63	15.15	15.67	33.09
	Hispanic	37.74	0.44	9.81	38.72
	Other	39.54	158.17	0.33	14.12
	Total***	\$29.25	\$12.56	\$12.06***	\$33.55***

Type of Services	Ethnicity++	MAP Group (6 months)	MAP Group (12 months)	ADW Group	Non-Waiver Group
Psychotropic RX	White	59.94	42.46	96.81	96.10
	Black	30.14	15.82	61.02	79.01
	Hispanic	34.52	42.75	82.90	96.23
	Other	97.32	194.64	75.45	117.33
	Total	\$43.64	\$43.09	\$79.30	\$93.73
Physical Health	White	21.69	33.58	169.86	291.91
	Black	95.98	118.60	153.00	157.43
	Hispanic	56.05	103.54	288.65	315.60
	Other	29.41	215.09	78.48	210.71
	Total***	50.33	80.84	194.03***	262.04***
Physical RX	White	15.85	12.34	108.84	99.03
	Black	32.13	30.09	90.69	94.02
	Hispanic	17.90	24.23	108.65	121.16
	Other	47.74	98.54	92.70	82.80
	Total**	20.32	22.26	101.67***	105.52**
Nursing Home	White	27.18	34.12	39.59	66.88
	Black	0	0	61.20	141.05
	Hispanic	40.37	42.29	4.96	120.73
	Other	0	0	6.42	0
	Total***	30.04	32.39	33.42***	101.49***
Average Totals	White	1001.93	1143.87	1363.91	635.65
	Black	967.22	1441.39	1266.32	533.07
	Hispanic	971.06	866.01	1634.28	733.42
	Other	1172.20	1792.17	1122.34	461.03
	Total***	987.47	1075.77	1397.15	636.15***

+Statistics calculated for the three 12 month groups. For Case Management, Mental Health, and Nursing Home were calculated by the ranks of service costs, while Statistics for Psychotropic RX, Physical Health, Physical RX, and Total were calculated by the square root transformations of service costs. Post-hoc comparisons compared MAP to each of the other two groups.

++Race/ethnicity differences combined across all three 12 month comparison groups. No race/group interactions found.

*p=.10 **p=.05, ***p=.01

Differences between the twelve month MAP PMPM costs and the costs associated with the two comparison groups. The costs associated with the two waivers of particular interest, MAP and ADW, as well as the miscellaneous category of “Other Waiver Services,” produced no surprises (Table 15). The 12 month MAP group was the only group that received MAP services, the ADW group was the only one where participants received significant ADW services, and all three groups received minimal services from other waivers.

Overall ANOVA results indicated that the three groups differed on PMPM costs for all save Psychotropic medications. Between group a posteriori comparisons indicated that the MAP group was lower than either ADW or NW groups in costs associated with psychotropic medications, physical health costs, medication costs associated with physical conditions, and in costs associated with nursing home care. Perhaps more importantly, at least from the perspective of

this evaluation of the MAP, was that the MAP group was also slightly, but not significantly, lower than the ADW group in overall costs for all services combined, including waivers. The NW group was the lowest in overall costs, just as it was for per user costs.

The MAP was not always the lowest group on PMPM costs. It was highest in case management costs external to the waiver, although the amounts involved were quite small. MAP was also slightly, and significantly, higher than the ADW group on mental health costs. The NW group was highest in costs associated with mental health services.

With respect to racial/ethnic differences in PMPM, there were no differences. There were also no interactions between race and comparison group. This indicates that all racial/ethnic groups, including non-Hispanic Whites, incurred PMPM costs in relatively equal amounts.

Per Member Per Year Costs

The PMPY costs are presented in Table 16. Since these costs are essentially the same as the PMPM costs, but simply expanded by a multiple of 12, they will not be discussed in detail here. They are provided as a convenience for those readers who may wish to have a better sense of yearly costs associated with the three groups. The most important information provided is that the average MAP cost for its participants was approximately \$12,909 per year. This average was substantially below – but due to variations in the mean not significantly different from – the \$16,650 average for the ADW group, but significantly higher than the average \$7,011 PMPY in Medicaid claims recorded for the NW group. Generally these results, and those of the preceding tables that presented data on PUPM and PMPM, demonstrate the budget neutrality of the MAP with respect to a comparable group of Medicaid waiver participants.

Table 16
Average Per Member Cost Per Year Across the Four Groups

Type of Services	Ethnicity++	MAP Group (6 months)+	MAP Group (12 months)	ADW Group	Non-Waiver Group
Group Size		97	38	157	146
Alzheimer Waiver Services	White	4977.04	11779.36	0.00	0.00
	Black	4691.04	14288.27	0.00	0.00
	Hispanic	4263.22	6438.03	0.00	0.00
	Other	5749.10	13508.82	0.00	0.00
	Total	6,747.31	9,765.45	0.00	0.00
Aged Disabled Waiver Services	White	177.74	288.27	11102.13	479.35
	Black	14.75	852.46	10530.23	313.82
	Hispanic	96.42	306.26	13671.65	293.62
	Other	0	0	10278.51	54.64
	Total	147.70	362.97	11,638.99	332.11

Type of Services	Ethnicity++	MAP Group (6 months)+	MAP Group (12 months)	ADW Group	Non-Waiver Group
Other Waiver Services	White	0	0	0.00	0.00
	Black	72.28	0	0.00	0.00
	Hispanic	333.20	1044.26	0.00	171.26
	Other	0	0	0.00	345.09
	Total	281.11	467.17	0.00	96.40
Case Management	White	0	0	0.00	23.33
	Black	0	0	0.00	15.29
	Hispanic	14.07	44.71	0.00	0.00
	Other	0	0	4.17	0.00
	Total***	7.84	20	0.32***	10.27***
Mental Health	White	108.80	188.83	159.82	324.34
	Black	75.75	181.80	186.46	382.49
	Hispanic	226.41	5.25	117.76	439.33
	Other	237.25	1898.00	3.88	156.47
	Total***	204.83	150.75	143.69***	369.76***
Psychotropic RX	White	359.66	509.58	1149.14	972.49
	Black	180.85	189.87	726.23	913.21
	Hispanic	207.11	512.98	994.83	1091.75
	Other	583.92	2335.68	892.77	1300.38
	Total	290.12	517.09	944.99	1,033.01
Physical Health	White	130.15	402.92	2016.11	2953.81
	Black	575.88	1423.16	1821.03	1819.75
	Hispanic	336.28	1242.51	3463.81	3580.40
	Other	176.48	2581.06	928.70	2335.37
	Total***	564.35	970.09	2,312.24***	2,887.80***
Physical RX	White	95.12	148.04	1291.87	1002.09
	Black	192.77	361.07	1079.40	1086.73
	Hispanic	107.37	290.70	1303.77	1374.58
	Other	286.44	1182.45	1096.96	917.75
	Total**	136.98	267.11	1,211.59***	1,162.84***
Nursing Home	White	163.07	409.42	469.91	676.78
	Black	0	0	728.35	1630.39
	Hispanic	242.24	507.46	59.50	1369.63
	Other	0	0	76.00	0.00
	Total***	276.90	388.64	398.28***	1,118.47***
Average Totals	White	6011.58	13726.40	16188.97	6432.19
	Black	5803.31	17296.63	15071.70	6161.68
	Hispanic	5826.33	10392.17	19611.31	8320.56
	Other	7033.19	21506.01	13280.99	5109.70
	Total***	8,657.13	12,909.26	16,650.09***	7,010.67***

+Statistics calculated for the three 12 month groups. For Case Management, Mental Health, and Nursing Home were calculated by the ranks of service costs, while Statistics for Psychotropic RX, Physical Health, Physical RX, and Total were calculated by the square root transformations of service costs. Post-hoc comparisons compared MAP to each of the other two groups.

++Race/ethnicity differences combined across all three 12 month comparison groups. No race/group interactions found.

*p=.10 **p=.05, ***p=.01

Days in Community, Nursing Homes and Hospitals

The fourth research question addressed in this report was, “Is there evidence that progress towards institutionalization of MAP enrollees is being delayed?” As shown in Table 17, MAP recipients spent significantly fewer days in nursing homes than did Medicaid recipients who were enrolled in the ADW or who were not participating in a waiver program. The actual differences, however, were quite small: MAP participants averaged fewer than two days less than ADW participants, and approximately five days less than the NW group. In actual numbers, two of the 12 month MAP participants spent time in a nursing home, as compared to 15 in the ADW and 12 in the NW. With respect to days in community, the MAP enrollees averaged more days in community than did either the ADW or NW groups. The Medicaid recipients in MAP also averaged fewer days in hospitals than either of the other groups.

Table 17
Average Number of Days (and Standard Deviations) Spent in the Community, in Nursing Homes, and in Hospitals by Each of the Three 12 Month Comparison Groups

Days	Alzheimer's Waiver (MAP) (N=38)	Aged Disabled Waiver (ADW) (N=157)	Non-Waiver (NW) (N=146)
Days in Community*** +	360.79(17.80)	357.99(20.09)	353.30(43.76)
Days in Nursing Home*** +	3.61(16.95)	4.79(19.53)	9.16(42.81)
Days in Hospital*** +	0.61(1.53)	2.22(4.07)	2.53(5.71)

*p=.10, **p=.05, ***p=.01 (ANOVA)

+a posteriori tests, ADW and NW groups significantly different from MAP (p=.01)

With respect to racial/ethnic differences, tests of fixed effects indicated there were no differences by racial/ethnic group. And, as has been the case with the cost calculations and penetration results presented earlier, there were no interactions between race/ethnicity and the three groups being compared. In other words, race alone or in the context of study group had no effect on days spent in community, in nursing homes, and in hospitals. The averages by race/ethnicity and study groups are shown in Table 18.

Table 18
Average Number of Days (and Standard Deviations) Spent in the Community, in Nursing Homes, and in Hospitals by Each of the Four Racial/Ethnic Groups

Type of Services		Alzheimer's Waiver (MAP) (N=38)	Aged Disabled Waiver (ADW) (N=157)	Non-Waiver (NW) (N=146)
Days in Community	White	362.40(10.07)	356.78(24.13)	355.86(33.62)
	Black	364.60(0.89)	355.33(24.01)	350.18(57.79)
	Hispanic	358.00(25.05)	361.94(6.59)	351.33(45.71)
	Other	365.00(0)	358.17(20.61)	362.75(4.22)
Days in Nursing Home	White	2.60(10.07)	5.63(23.64)	5.86(33.40)
	Black	0.00(0)	8.00(24.05)	12.65(57.98)
	Hispanic	5.76(23.77)	0.50(3.46)	11.41(43.31)
	Other	0.00(0)	5.08(17.61)	0.00(0)

Type of Services		Alzheimer's Waiver (MAP) (N=38)	Aged Disabled Waiver (ADW) (N=157)	Non-Waiver (NW) (N=146)
Days in Hospital	White	0.00(0)	2.59(4.41)	3.29(5.96)
	Black	0.40(0.89)	1.67(2.92)	2.18(5.68)
	Hispanic	1.24(2.11)	2.56(4.89)	2.26(5.90)
	Other	0.00(0)	1.75(3.49)	2.25(4.22)

*p=.10, **p=.05, ***p=.01

+Per a posteriori tests, ADW and NW groups significantly different from MAP

Variations by Race/Ethnicity

The fifth research question was, “What variations exist by racial/ethnic group status?” Answers to this question were embedded in the answers to the first four questions. In general, there were no significant interactions of race/ethnicity and group status. There were some differences between the racial/ethnic groups themselves, but membership in the study groups did not materially influence the costs or use of services.

The Prediction of Days Spent in Community

The last research question asked “What factors predict the number of days spent in the community?” To answer this question, a regression analysis was run on the 731 Medicaid recipients who had data on all included variables. As shown in Table 19, the actual number of Medicaid days included in the study made no contribution (this variable was included because there was a slight variation in days counted, across groups). In the second model, being female accounted for a statistically significant but actually trivial amount of variance (less than 1 percent). Women were slightly more likely to stay in the community. When two dummy variables, Black and Hispanic, were entered, the status of being Hispanic was associated with more days spent in the community but again the contribution was minimal. On the other hand, when the MAP and ADW group variables were entered, both contributed significantly and added to the variance: 6.6% of the variance in community days was accounted for by these variables. Overall, these results reflect the results presented in previous sections.

Table 19
Hierarchical Regression Results for Days Spent in Community,
with Standardized Beta Coefficients in Columns

	Model 1	Model 2	Model 3	Model 4
Days in Study	-.04	-.04	-.04	.03
Age		-.01	-.00	-.03
Female		.07*	.08**	.06*
Black			.05	.00
Hispanic			.10**	.09**
MAP				.12**
ADW				.26***
Adjusted R2	.000	.003	.008*	.071***

*p=.10, **p=.05, ***p=.01

Discussion

This interim report covers progress on the MAP from its inception. A mixed method multi-group design was followed. The evaluation required that non-MAP Medicaid recipients who met the same basic inclusionary criteria followed in the MAP be identified. The latter criteria consisted of being age 60 and over, having a diagnosis of Alzheimer's disease, not being a resident of a nursing home, and having a caregiver living with the Medicaid recipient. From this pool, two comparison groups were drawn. One group consisted of individuals who were participating in the Medicaid Aged and Disabled Waiver (ADW). The other consisted of individuals who, while they might have some exposure to a waiver program, had not been enrolled in any such program for more than five months out of the evaluation year. These latter Medicaid recipients were assigned to the Non-Waiver (NW) group.

While a number of research questions were addressed in the results section, there were two that lie at the heart of the evaluation: (1) is the MAP budget-neutral with respect to comparable programs, and (2) is the MAP effective in delaying admission to a nursing facility. The results are clear, and for both questions the answer is in the affirmative. The MAP currently is proving to be budget neutral, and MAP participants had averaged fewer days in the nursing home. These results of course should be considered with the caveat that to date only 53% of the proposed goal of 350 Medicaid participants has been achieved. Moreover, with respect to nursing home days, on average the difference are less than two months when the MAP group is compared to the NW group, and only two days when MAP is compared with ADW. A longer time period will greatly enhance our understanding of the long term efficacy of MAP in delaying institutionalization. Our present analyses included only 38 Medicaid recipients who had participated in MAP for even one year, due to unavoidable lags in acquisition of administrative data.

Overall, and in conclusion, the MAP represents a multi-dimensional intervention that targets not only problems of the Medicaid recipient with Alzheimer's disease (e.g., medication use, wandering, provision of stimulation and social contact) but also the problems and issues faced by the caregiver (need for general assistance in care provision, respite, information about the provision of care to an individual with Alzheimer's disease, etc). The results demonstrate that specialty programs such as the Alzheimer's waiver program can have a positive impact on the well-being and trajectories of enrollees with Alzheimer's disease and their caregivers. Indeed these results suggest that it may be efficacious to consider extending the program to enrollees with other forms of dementia. Caregiver burden and institutionalization itself are not limited to the context of a Medicaid recipient with Alzheimer's disease. Indeed in some instances the burden of care may be greater. Riedijk, De Vugt, Duivenvoorden, Niermeijer, Van Swieten, Verhey, and Tibben (2007) point out that caregivers of persons with frontotemporal lobe dementia – another prevalent form of dementia -- experience greater burden than caregivers to persons with Alzheimer's disease. Similarly,

dementia with Lewy bodies is similar to Alzheimer's disease in being progressive in nature and in exerting great disruption on the lives of caregivers and thus often leading to institutionalization.

Recommendations

Given the findings presented in this interim report, several provisional recommendations can be made. They are as follows:

- The Alzheimer's disease waiver program should be extended to cover Medicaid enrollees with any form of dementia. At the very least, Medicaid recipients with dementia of the Lewy body type should be considered for MAP eligibility. Dementia with Lewy bodies is the second most common form of dementia, after Alzheimer's disease (Collins, Constant, Kaba, Barclay & Mohr, 2004). As is the case with Alzheimer's, Lewy body dementia is a progressive disease with similar rates of mortality and progression to institutionalization (e.g., Williams, Xiong, Morris, & Galvin, 2006).
- The restriction of MAP to cover only Medicaid recipients who have a caregiver living with the recipient might deserve reconsideration. Although the present evaluation did not include in its comparison groups Medicaid recipients whose caregiver did not live with the recipient, we plan to expand our evaluation in the next and final report to include those without a live-in caregiver as subgroups.
- AHCA staff might wish to consider working with vendors as a means of identifying policies and procedures that could improve the flow of referrals from lead agencies. If the MAP is continued, and allowed to expand, referrals may become a critical issue in successful expansion.
- Greater flexibility in one service area, that of the hours and days during which a personal assistant can be utilized is also worth considering. In a consumer satisfaction survey conducted during the preceding year by the same evaluation team, one result was for greater flexibility in the hours during which a personal care attendant, and respite services, could become available. This result paralleled results from the literature, which also suggests that flexibility in the provision of respite-related services was seen as critical by caregivers (e.g., Jeon, Brodaty, & Chesterson, 2005).
- Based on the current findings of this interim report, there continue to be strong indications that the Alzheimer's waiver program is successfully meeting the needs of Medicaid recipients with Alzheimer's disease and therefore should be continued.

References

- AARP. *Nursing Homes*. Washington, DC: AARP; 2001. Pub. No. FS10R.
- AFA. (2007). *ICAN 2: Investigating Caregivers' Attitudes and Needs*. Alzheimer's Foundation of America. Uploaded 2-9-2007. Retrieved 3-14-2007. http://www.alzfdn.org/surveys/second_survey_full_report.doc.
- AHCA. (2004). *Alzheimer's Disease Medicaid Waiver Program*. State of Florida Request for Proposal. Tallahassee, FL: Agency for Health Care Administration.
- Albert, S.M., Simone, B., Brassard, A., Stern, Y., & Mayeux, R. (2005). Medicaid home care services and survival in New York City. *Gerontologist*, 45 (5):609-16.
- Alker, J. & Portelli, L. (2004). *Florida's Medicaid budget: Why are costs going up?* Policy Brief. Winter Park, FL: Winter Park Health Foundation.
- Aranda, M.P. & Knight, B.G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. *The Gerontologist*, 37 (3): 342-354.
- Argimon, J.M., Limon, E., Vila, J., & Cabezas, C. (2004). Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. *Alzheimer Dis Assoc Disord*, 19(1):41-4.
- Aupperle, P.M. (2006). Navigating patients and caregivers through the course of Alzheimer's disease. *J. Clin Psychiatry*, 67, Supplement 3: 8-14.
- Ayalan, L. & Areal, P.A. (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry*, 19: 51-57.
- Bravo, G. & Hébert, R. (1997). Reliability of the Modified Mini-Mental State Examination in the context of a two-phase community prevalence study. *Neuroepidemiology*, 6(3):141-8.
- Buettner, L., & Fitzsimmons, S. (2006). Mixed behaviors in dementia: the need for a paradigm shift. *J Gerontol Nurs*, 32 (7):15-22.
- Burke, W.J., Roccaforte, W.H., & Wengel, S.P. (2001). The short form of the Geriatric Depression Scale: a comparison with the 30-item form. *J Geriatr Psychiatry Neurol*, 4(3):173-8.
- Centers for Medicare & Medicaid Services. *Table 2: National health expenditures aggregate amounts and average annual percent change, by type of expenditure: selected calendar years 1980-2003*. <http://www.cms.hhs.gov/statistics/nhe/historical/t2.asp> Accessed May 31, 2005.
- Chiriboga, D.A., Brown, L.M., Cho, S., Cohen, D., Dupree, L., et al (2006). *The Florida Alzheimer's Disease Medicaid Waiver Program: An Evaluation of Alzheimer's Beneficiaries Prior to Program Initiation. Final Report*. Submitted to the Florida Agency for Health Care Administration, June, 2006. Retrieved 6-25-2007. http://www.fmhi.usf.edu/institute/pubs/pdf/ahca/AHCA2006/220-73_AlzWaiver_Chiriboga_06.pdf.
- Chiriboga, D.A., Yee, B.W.K. & Weiler, P.G. (1992). Stress in the Context of Caring. In Montada, L., Filipp, S-H., and Lerner, M. *Life Crises and Experiences of Loss in Adulthood*. New York: Plenum.
- Chiu, M.J., Chen, T.F., Yip, P.K., Hua, M.S. & Tang, L.Y. (2006). Behavioral and psychologic symptoms in different types of dementia. *J Formos Med Assoc*, 105 (7):556-62.

- Collins, B., Constant, J., Kaba, S., Barclay, C.L., & Mohr, E. (2004). Dementia with Lewy bodies: Implications for clinical trials. *Clinical Neuropharmacology*, 27 (6): 281-292.
- Company; 1863:176.
- Cooney, C., Howard, R., & Lawlor, B. (2006). Abuse of vulnerable people with dementia by their carers: can we identify those most at risk? *Int J Geriatr Psychiatry*, 21(6):564-71.
- Correa, J.A., Perrault, A. & Wolfson, C. (2001). Reliable Individual Change Scores on the 3MS in Older Persons With Dementia: Results From the Canadian Study of Health and Aging. *International Psychogeriatrics* (2001), 13: 71-78.
- DOEA. (2004). Department of Elder Affairs Medicaid Aged and Disabled Adult Waiver. <http://www.oppaga.state.fl.us/profiles/5028>.
- Feldman, H.H., Van Baelen, B., Kavanagh, S.M., & Torfs, K.E. (2005). Cognition, function, and caregiving time patterns in patients with mild-to-moderate Alzheimer disease: a 12-month analysis. *Alzheimer Dis Assoc Disord*, 19(1):29-36.
- Fillit, H. (2005). Cost consequences and cost benefits of treating patients with moderate to severe Alzheimer disease. *Neurology*, 65(6), S31-S33.
- Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 12(3), 189-98
- Gurland, B.J., Wilder, D.E., Lantigua, R. et al. (1999). Rates of dementia in three ethnic-racial groups. *International Journal of Geriatric Psychiatry*, 14: 481-493.
- Jang, Y., Small, B.J., & Haley, W.E. (2001). Cross-cultural comparability of the Geriatric Depression Scale: comparison between older Koreans and older Americans. *Aging Ment Health*, 5(1):31-7.
- Jarvis, A. & Worth, A. (2005). Meeting carers' information needs. *Community Practice*, 78 (9): 322-326.
- Jeon, Y.H., Brodaty, H., & Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: Literature review. *Journal of Advanced Nursing*, 49 (3): 297-306.
- Kaiser Commission on Medicaid and the Uninsured. (2005). *Medicaid 1915 © Home and Community-Based Service Programs: Data Update*. The Henry J. Kaiser Family Foundation. Retrieved 11-13-2006. <http://www.kff.org/medicaid/upload/7345.pdf>
- Kaiser Commission on Medicaid Facts. (2006). *The Vermont Choices for Care Long-Term Care Plan: Key Program Changes and Questions*. The Henry J. Kaiser Family Foundation. Retrieved 11-2-2006. <http://www.kff.org/medicaid/7540.cfm>.
- Kales, H.C., Chen, P., Blow, F.C., Welsh, D.E., & Mellow, A. (2005). Rates of clinical depression diagnosis, functional impairment, and nursing home placement in coexisting dementia and depression. *American Journal of Geriatric Psychiatry*, 13 (6): 441-449.
- Kane, R.L., Ouslander, J.G., & Abrass, I.B. (2004). *Essentials of Clinical Geriatrics*. Fifth Edition. , New York: McGraw-Hill.
- Kolb, P.J. (2003). *Caring for Our Elders: Multicultural Experiences with Nursing Home Placement*. New York, NY: Columbia University Press.
- Lawton, M.P., Brody, E., & Saperstein, A. (1989). Respite care for Alzheimer's families research findings and their relevance to providers. *American Journal of Alzheimer's Disease and Other Dementias*, 4(6), 31- 38.

- Nadler, J.D., Relkin, N.R., Cohen, M.S., Hodder, R.A., Reingold, J., & Plum, F. (1995). Mental status testing in the elderly nursing home population. *J Geriatr Psychiatry Neurol*, 8(3):177-83.
- National Clearinghouse for Long-Term Care Information. (2007). *Paying for LTC*. Last modified 1-8-2007. Retrieved 1-30-2007. http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx#National.
- Nightingale F. (1863). *Notes on Hospitals*. London: Longmans, Green.
- O'Rourke, N. & Wenaus, C.A. (1998). Marital aggrandizement as a mediator of burden among spouses of suspected dementia patients. *Canadian Journal on Aging*, 17: 384-400.
- OPPAGA. (2001). *OPPAGA Justification Review: Services to Elders Program*. Department of Elder Affairs. Report No. 01-66. Office of Program Analysis and Government Accountability. <http://www.oppaga.state.fl.us/reports/pdf/0166rpt.pdf>.
- Pratt, C., Schmall, V., & Wright, S. (1986). Family Caregivers and Dementia. *Social Casework*. 67(2): 119-124.
- Riedijk, S.R., De Vugt, M.E., Duivenvoorden, H.J., Niermeijer, M.F., Van Swieten, J.C., Verhey, F.R., & Tibben, A. (2007). Caregiver burden, health-related quality of life and coping in dementia caregivers: a comparison of frontotemporal dementia and Alzheimer's disease. *Dement Geriatr Cogn Disord*, 22(5-6):405-12.
- Robert, P.H., Darcourt, G., Koulibaly, M.P., Clairet, S., Benoit, M., Garcia, R., Dechaux, O., & Darcourt, J. (2006). Lack of initiative and interest in Alzheimer's disease: a single photon emission computed tomography study. *Eur J Neurol*, 13 (7):729-35.
- Robine, J.M., Michel, J.P., & Hermann, F.R. (2007). Who will care for the oldest people? *British Medical Journal*, 334: 570-571.
- Salganicoff, A. Medicaid's role for women. Presentation at the conference entitled *Medicaid and Women: Looking to the Future*. May 11, 2006. Downloaded 5-14-2006 at <http://www.kff.org/womenshealth/upload/Women-and-Medicaid-Salganicoff-Presentation.pdf>.
- Sheikh, J.I. & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontology : A Guide to Assessment and Intervention* 165-173, NY: The Haworth Press, 1986.
- Smedley, B., Stith, A.Y. & Nelson, A.R. (eds.). (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: The National Academies Press.
- Spector, W., & Fleishman, J. (1998). Combining activities of daily living (ADL) with instrumental activities of daily living (IADL) to measure functional disability. *Journal of Gerontology: Social Sciences* 53B(1):S46-S57.
- Spitznagel, M.B., Tremont, G., Davis, J.D., & Foster, S.M. (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *Journal of Geriatric Psychiatry Neurology*, 19 (1):16-20.
- State of Vermont. (2006). *1115 Waiver Information*. State of Vermont Agency of Human Services Department of Disabilities, Aging and Transportation.
- Talley, R.C., & Crews, J.E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2):224-8.
- Teng, E.L. & Chui, H.C. (1987). The Modified Mini-Mental State (3MS) examination. *Journal of Clinical Psychiatry*, 48(8):314-8.

- Teng, E.L., Chui, H.C., & Gong, A. (1990). Comparisons between the Mini-Mental State Exam (MMSE) and its modified version: the 3MS test. *International Psychogeriatric Association Psychogeriatrics: biomedical and social advance*, 59: 189–192.
- Tombaugh, T.N., McDowell, I., Kristansson, B., & Hubley, A.M. (1996). Mini-Mental State Examination (MMSE) and the Modified MMSE (3MS): A psychometric comparison and normative data. *Psychological Assessment*, 8: 48-59.
- Torti, F.M., Jr., Gwyther, L.P., Reed, S.D., Friedman, J.Y., & Schulman, J.A. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease & Associated Disorders*, 18 (2): 99-109.
- Tun, S.-M., Murman, D.L., Long, H.L., Colenda, C.C., & von Eye, A. (2007). Predictive validity of neuropsychiatric symptoms on nursing home placement and survival in patients with Alzheimer disease. *American Journal of Geriatric Psychiatry*, 15 (4): 314-327.
- Vitaliano, P., Young, H., Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist*, 31, 67-75
- Williams, M., Xiong, C., Morris, J.C., & Galvin, J.E. (2006). Survival and mortality differences between dementia with Lewy bodies vs Alzheimer disease. *Neurology*, 67 (11): 1935-1941.
- Wilson, R.S., McCann, J.J., Li, Y., Aggarwal, N.T., Gilley, D.W., & Evans, D.A.. (2007). Nursing Home Placement, Day Care Use, and Cognitive Decline in Alzheimer's Disease. *Am J Psychiatry*, 164:910-915.
- Zarit S. H., Orr N. K., Zarit J. M., (1985). *Families under stress: Caring for the patient with Alzheimer's disease and related disorders*. New York: University Press.
- Zarit, S. H., & Zarit, J. M. (1998). *Mental disorders in older adults: Fundamentals of assessment and treatment*. New York: The Guilford Press.
- Zhu, C.W., Scarmeas, N., Torgan, R., Albert, M., Brandt, J., Blacker, D., Sano, M., & Stern, Y. (2006). Longitudinal study of effects of patient characteristics on direct costs in Alzheimer disease. *Neurology*, 67(6):998-1005.